Parental Perceptions of a Pre School Diagnostic Pathway for Autism.

A thesis submitted to the University of Manchester for the degree of Doctor in Educational Psychology in the Faculty of Humanities.

2012

Madeleine Mackay Laird

School of Education
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ABSTRACT

There is a recognition that services for people with autism and their families need to improve. Although a number of good practice documents and clinical guidance have been published there is continued concern that services are still not providing optimum support. Despite many of the documents focusing upon the diagnostic procedures there is little information available on the quality of the diagnostic process from the parents’ perspective.

This qualitative study aims to explore parents’ perceptions of a diagnostic pathway for pre-school children, with autism, in a Local Authority in the North West of England. It considers the factors which, parents perceive, contribute to the success of the local pathway and aims to identify any areas of unmet need for the parents and their families. It also investigates what, if any, feelings of grief and loss are experienced by the parents when their children are diagnosed with autism. It seeks to determine whether the existing pathway supports parents through feelings of grief and loss which may accompany a diagnosis.

An interpretivist paradigm was adopted. Eight semi structured interviews were conducted with an opportunity sample of parents drawn from the Multi Agency Autism Team’s database. The interviews were recorded and transcribed and a thematic analysis was made of the data.

Two core themes, Knowledge and Loss, emerged from the data which conceptualised the parent’s perception of the diagnostic process. Both of the themes contained sub themes:

Knowledge - acquisition of knowledge: communication of knowledge: and quality of knowledge

Loss - feelings of grief and loss: being supported through loss: and loss of normal family

The results of the research are discussed within the context of the existing literature and illustrated with pertinent quotations made by the parents. The findings are supportive of previous research that the diagnosis of autism is a complex and emotionally challenging experience. The results suggest that communication with professionals, the manner in which the diagnosis is disclosed and the support available to families, are pivotal factors in the local pathway. The personal attributes of the professionals who support families, for example, ability to be flexible and have empathy, were more important to the sample than their knowledge of autism. Parents identified areas of unmet need in the existing pathway including having a clear understanding of the possible outcome of their child’s assessment, being provided with information about autism and access to post diagnostic support. The entire sample reported feelings of grief and loss when their child was diagnosed with autism. Their descriptions of these feelings suggest that they experience an ambiguous loss.

The implications of the findings for practice are discussed and areas for future research are suggested in response to the findings.
DECLARATION

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Abstracts from previous doctoral assignments

This thesis is the fourth phase of the taught doctoral programme. The abstracts from my previous three assignments are presented below.

1. Young People’s Perception of an Educational Psychology Service and the Feedback they Receive

Educational Psychologists want to improve the quality of their assessments of children. One way of doing this is to consider the views of the young people themselves. Increasing importance has been placed upon consulting with young people about their views (Todd, 2003; Roller, 1998; Gersch, 1993, 1996; Davie, 1993; Brennan, 1988). I was interested to obtain the views of young people about their access to the Educational Psychology Service and the written feedback they had received. Using a semi structured interview schedule based on the work of Woolfson and Harker (2002) I compared the experience of a small sample of children who had received personalised feedback with those who had not and investigated whether it was more effective/ useful for them. Their responses were analysed using a grounded theory technique. I identified that the key issues which influenced a young person’s perception of the Education Psychology Service were: information received prior to their appointment, awareness of referral, relationships with the Educational Psychologist and the feedback they received following my involvement. The implications for my future practice are that prior to a consultation the young person will be provided with information about the Educational Psychology Service and the role of the Educational Psychologist. The young people will then be able to make an informed choice as to whether they want to meet the Educational Psychologist. In future, feedback will be written for young people and an opportunity given to them to discuss this with a member of staff or the Educational Psychologist.
2. An Evaluation of an Anger Management Group for Young People

Improving the standards of behaviour in schools has become a major focus for the government (DfES, 2003; Ofsted, 2005) There is a general consensus that low level disruptive behaviours place the most stress on teaching staff and consequently professionals, such as Educational Psychologists, are frequently approached to work with young people who exhibit such difficulties. Group work has proved to be useful strategy to adopt when delivering anger management to young people (Faupel et al, 1998; Dwivedi, 1993; Dwivedi & Gupta, 2000; Squires, 2001).

I devised a six-session course based upon the various theories of anger which are postulated in the literature, cognitive, behavioural and psychodynamic. A pilot group was run and modifications to the programme made following a focus group discussion with the participants.

I delivered the modified course to young people in Key Stage 3 at a High School in the North West. Using a semi structured interview schedule I obtained the views of the anger management group members. Their responses were analysed using a grounded theory technique. I conclude that all of the young people felt that the course had helped them to manage their anger more effectively. The general consensus of the group members was that they had enjoyed the course. Issues about their selection for the course and the organisation of the group were highlighted. The conclusion is drawn that the allocation of EP time to deliver an anger management course is an efficient use of resources. The implications for future practice are considered.

3. An Evaluation of a ‘Circle of Friends’ Intervention

The inclusion of children with Special Educational Needs in mainstream schools is now commonplace. There is a duty on the Educational Psychologist to ensure that a child is not just educated in a mainstream school but their social and emotional needs are met. Children with Autistic Spectrum Conditions have particular difficulties with peer relationships. Educational Psychologists are
frequently approached to work with young people who exhibit such difficulties. A Circle of Friends approach has proved to be useful strategy to adopt when supporting the development of peer relationships and social skills. (Whitaker et al, 1998; Kalyva & Avramidis, 2005; Frederickson et al, 2005)

I devised a whole class session and a 5 week Circle of Friends intervention adapted from the rationale provided by Taylor (1996, 1997) and Newton & Wilson (2003). I delivered this in a Primary School in the North West of England.

Using a semi structured interview technique I obtained the views of the young people who had participated in the intervention. I made a thematic analysis of their responses and attention was paid to comments made by the Learning Support Assistant who had co-run the group and the focus child’s parents. I conclude that all the young people involved reported that the Circle of Friends group facilitated change in both themselves and the focus pupil. Issues about the young people’s motivation for volunteering for the groups, their experience of the group and the organisation of the group were highlighted. The research has provided evidence that can be shared with other schools to demonstrate that it is good use of the Educational Psychologists time to facilitate a Circle of Friends group. Implications for future practice and research are discussed.
ACKNOWLEDGEMENTS

I would like to say ‘thank you’ to the parents who gave me time from their busy lives to participate in this study – their input was invaluable and they gave me a tremendous insight into living with autism. Thanks also to my colleagues from Education, Health and the Disability Partnership who helped me with the research. I am grateful to the Psychology Service for their moral and financial support throughout my studies. A particular mention has to go to Dr Lynda Dodd who has motivated and supported me throughout this doctorate. Thank you to Rob and Debbie who have provided answers to my endless questions about formatting and drawing figures! Thanks are also given to Professor Peter Farrell for supervising my research, encouraging me and working past his retirement to ensure I completed!

Thank you to my Dad who has painstakingly proof-read this thesis and my Mum who has provided round the clock babysitting services in the last leg of my write up! Thanks to Pete for giving me the opportunity to complete my studies by being such a fantastic Dad to our boys, James and Fergus. I can’t put into words how much I appreciate the hours you have spent playing with them whilst I was working. Finally a thank you to James and Fergus – you can have your Mummy back now!
I, Madeleine Mackay Laird, am a Registered Educational Psychologist. I have a M.A (Hons) Psychology degree (University of Edinburgh 1996), a Post Graduate Certificate in Education (University of Strathclyde 1997) and a M.Sc in Educational Psychology (University of Manchester 2001). I enrolled on the Doctorate in Educational Psychology at the University of Manchester in 2003, by part time study. I interrupted my studies for two years to have my children. I now submit this thesis in part fulfilment of this degree.

I am employed by Stockport Metropolitan Borough Council as a Senior Practitioner, Child and Educational Psychologist. I have a specialist interest in autism within our Service and spend a significant proportion of my time working with the children and families who are affected by the condition. Some of my allocated time is spent working directly with children and their parents/carers in their homes and education provisions. In addition I represent the Psychology Service in the Multi Agency Autism Assessment teams for Pre School and School Aged children based at out local hospital. I am accredited to assess children using the Autism Diagnostic Observation Schedule (ADOS-G). I also work at a strategic level with colleagues from health and social care to develop effective pathways for the identification, assessment and ongoing support for children with ASD.
CHAPTER 1

INTRODUCTION

“There are over 500,000 people with autism in the UK – that’s 1 in 100. Together with their families, that’s over two million people whose lives are touched by autism every single day”

National Autistic Society (2011)

1.1 Autism

Autism is a lifelong developmental disability which affects the way a person communicates with and relates to others. In 1943 Leo Kanner described a small group of children with autism. Since this time the condition has become widely recognised and increasing numbers of people have been diagnosed.

The past three decades have witnessed a growing interest in autism and evidence has been amassed that it is more prevalent than initially thought. The National Autistic Society (NAS) estimate that there are currently over half a million people in the UK with the condition, 1 in 100 people. Research has been wide-ranging and developed our understanding of autism, it has focussed on issues such as causes, prevalence, diagnosis and assessment, approaches and interventions. At the same time films such as ‘Rain Man’ and the controversial reports in the media of the MMR vaccination ‘causing’ autism have brought the condition to the forefront of public attention. Indeed the needs of people with autism have been discussed in parliament culminating in the Autism Act, the first disability specific act of parliament. The Act was passed in 2009 and the government subsequently published ‘The Strategy for Adults with Autism in England’ in March 2010 (DH 2010).

People who have autism are not easily identifiable, they do not look different, and this has led autism to be described as a hidden disability (Rosenblatt 2008 p37). Despite the growth in our understanding and awareness of autism it “still remain[s] a baffling and distressing condition” (p4) (NIASA 2003). There is a recognition that services for people with autism and their families need to
improve. In response to this many good practice documents and clinical guidance have been commissioned and published. Of particular interest to me is their focus upon the diagnostic process. These documents set out procedures and ways to measure them. What they do not do is provide a measure of the quality of the diagnostic procedure from the perspective of the parents and clients.

In the local authority in which I work there is an established pathway for the multi agency diagnosis of autism in pre-school children. Through my work with families I am acutely aware that families and professionals have different perspectives about the diagnostic pathway. Thus, this research focuses on the experience of parents, of pre-school children, who have received a diagnosis of autism. I hope that this research will add to our understanding of parent’s perceptions of the quality of the diagnostic process.

Throughout this thesis reference will be made to autism and autistic spectrum disorders (ASD) which includes autism and Aspergers Syndrome. There are many definitions of autism but, for the purpose of this research, I will adopt the World Health Organisation (WHO) definition 1994:

“The term autistic spectrum disorders (ASD) is used to describe the group of pervasive developmental disorders characterised by qualitative abnormalities in reciprocal social interactions and in patterns of communication and by a restricted, repetitive repertoire of interests and activities”

People who are affected by autism have marked variations in the severity and nature of their needs. They may also have additional problems with cognition, behaviour, motor co-ordination and sensory perception. In order that a diagnosis of ASD can be made the triad of impairments, documented in the WHO definition, must be present and the onset be prior to the age of three. It is recognised by most parents and professionals that early diagnosis is beneficial and child and family centred interventions are most effective when they start early. (NIASA 2003)
1.2 National context
In order to improve existing services, for people with autism and their families, a number of reports have been commissioned. Several of these documents have provided good practice and clinical guidance for autism. It is helpful to briefly consider these documents in order that the current research can be placed into the national context. I have paid particular attention to points made in the documents pertaining to the identification and assessment of autism and parents perceptions of the process.

In England the National Autism Plan for Children (NAP-C) (NIASA 2003) was developed by a multi agency working party consisting of representatives from health, education, social care, the voluntary sector and parents. In the NAP-C’s foreword Bailey (2002) described the plan as “setting out a vision of what a good service for the child with suspected and proven autism / ASD would look like”. She states that:

“The intense distress associated with the diagnosis of autism / ASD cannot be taken away but at least the experience can be assisted by a system that works effectively to answer their questions and provide them with the support they need” (Bailey 2004 p4).

The NAP-C provides guidelines for parents and all professionals who work with children about the identification, assessment, diagnosis and early intervention for both pre and school age children with autism. The plan sets out detailed recommendations for each of these areas and urges that a systematic approach is taken.

A similar report was commissioned in 2001 by the Public Health Institute of Scotland (PHSI). The resultant Autistic Spectrum Disorders Needs Assessment Report reviewed current practice and made the recommendation that guidelines needed to be developed in order that assessment and management of autism could be improved in Scotland. The Scottish Intercollegiate Guidelines Network
SIGN were made available in July 2007. Its main focus was upon the assessment, diagnosis and clinical interventions for ASD. It looked at evidence about collaborating with children and adults and joint working. It also considered the effectiveness of multi agency and multi disciplinary working when meeting the needs of children with ASD.

The SIGN report devotes a chapter to ‘Information for Discussion with Children, Young People, Parents and Carers’. This is particularly pertinent in the context of this research. It refers to the need for parents and the young people to have their questions responded to. It notes that there is evidence to suggest that parents are more satisfied with the process if they have had the opportunity to ask questions and have received good quality information. The guidelines discuss how a diagnosis of autism should be shared and recognises that this is a stressful time for children, young people and their parents. It comments that strong links with local professionals can be very helpful post diagnosis. Emphasis is placed upon the importance of professionals having good communication skills when they share the news. Indeed, they observe that “a negative experience could affect parents’ satisfaction and cause added stress” (p32). Similarly it is encouraging that the report highlights the impact of the diagnosis upon families. It observes that families will react to the diagnosis and that a period of adjustment has to be supported by professionals, stressing that this may be a “prolonged and difficult” time (p32).

The Autistic Spectrum Disorder Strategic Action Plan for Wales (NHS Wales 2008) was launched in April 2008. It devotes a chapter to early identification, diagnosis and assessment. The document states that it is important that the person with ASD and their family receives “appropriate information, counselling and support” (p16). The action plan sets out service issues for commissioners and providers and identifies areas for further development, indeed, there is a section which targets ‘Family and Carer Support Services’. There is recognition of the ‘extremely’ important role that families, including siblings, and carers play in supporting people with ASD. The action plan addresses the importance of parent support groups, the co-ordination of support services and the impact upon siblings. The plan acknowledges the high levels of day-to-day stress which
family members encounter and the importance of lowering such stress for the well being of the whole family. It states that The Welsh Assembly Government is currently working to develop additional information for parents and carers to alleviate the “enormous stress placed on families simply fighting to find out what services may or, equally important, may not be appropriate to their son or daughter's needs” (p 44). The Autism Strategic Plan for Northern Ireland (2009) echoes the other documents and states that the “support, communication and information for parents and families is a key element of the Plan” and stresses the need for consistency (p4).

The National Institute for Health and Clinical Excellence (NICE) guidelines for autism were published in September 2011. The draft Scope document which preceded the guidelines observed that currently, across England, there are significant variations in all aspects of the identification, assessment and intervention for autism which can delay the process for families. The institute recognises that when the process works well “professionals and carers communicate right from the start, laying the foundation for a long-term understanding between children, carers and the professionals supporting their needs”. (p1) (NICE 2009). The draft Scope document states that one of the NICE guidelines main outcomes will be to gain “children and young people’s views and the views of their parents and carers of the process of referral, assessment and diagnosis and their support and information need” (p7).

The recently published NICE guidelines (2011) references over three hundred research papers. However, in the sections of the guidelines which are pertinent to this study, ‘Communication of Diagnosis to the Family’ and ‘Information and Support’, there are very few pieces of research quoted. Indeed, NICE rates the existing research as being of ‘very low quality’. The document expresses concern that the evidence reported gives too much weight to opinions and views, obtained from small samples, which may not be widely shared. This highlights that there is a gap in the literature and more research into parents’ perceptions of the diagnosis of autism is needed.
1.3 Local context
In the Local Authority in which I work we have responded to the national guidance. As a consequence of the proposed NAC-P a document, entitled ‘Autistic Spectrum Disorders: Position Statement and Guidance for Schools’, was written and distributed to all schools and support services in the Local Authority in 2002.

Locally there is a well established Multi Agency Autism Assessment team for pre-school children and a clear diagnostic pathway in place. The agreed referral and assessment process is illustrated in Appendix 1a and 1b. The team consists of paediatricians, from the Child Development Unit (CDU), representatives from Speech and Language Therapy Services, Occupational Therapy, the Psychology Service, the Portage Service and a Specialist Nurse Practitioner. We meet monthly to discuss the needs of children with suspected autism.

Each month a morning is set aside by the paediatrician and speech and language therapist, based at the hospital, to carry out co-ordinated autism assessments. The assessment tools used are the Autism Diagnostic Observation Schedule – General (ADOS-G) and, on occasion, the Autism Diagnostic Interview-Revised (ADI-R). These are described in Appendix 2.

Prior to the assessment morning the Educational Psychologist and Portage Home Visitor have met the family in their home and at nursery if appropriate, carried out assessment, discussed the child’s needs and provided a written report to the multi agency team. The child has also been assessed in clinic by the Paediatrician, the Speech and Language Therapist and sometimes by the Occupational Therapist.

On the assessment morning the professionals, who have administered the ADOS-G, discuss their findings and meet with the Specialist Nurse Practitioner and Portage Home Visitor to agree what should be said to parents. The news is then shared with parents and they are invited to return to the hospital for a care planning meeting the next month.
The Specialist Nurse Practitioner contacts the families in the interim period and meets them, at home, to discuss the care planning meeting and set an agenda. At the care planning meeting all professionals involved with the family are invited and parents have the opportunity to discuss the written report they have received and have any queries answered. Each professional outlines their care plan for the child and any unmet needs are addressed.

With the advent of the NICE Guidelines the local CAMHS team have placed emphasis on multi agency working and the development of an effective school age pathway. I have been working closely with colleagues from a number of disciplines to develop this. As the professional link between the two teams I want to ensure that the successful elements of the pre-school pathway are embedded in this new venture. I am aware that the views of parent’s perceptions of the existing pathway have not been sought. Through the current research I want to obtain parents views of the local pathway and determine whether they perceive that any of their own, or their family’s, needs were unmet when their child was diagnosed. This, I envisage, will facilitate practitioners to support families more effectively.

1.4 Personal interest
In a climate where targets and efficiency are paramount it is easy to forget the enormous impact upon the individual and the family following a diagnosis of autism. As a practitioner I have a clearly defined role in the pre-school diagnostic pathway and I meet parents following a well supported work up from other colleagues. Therefore, whilst I listen to and support parents around the day to day practicalities of living with autism, I do not tend to be faced with the raw emotion the parents experience as they come to terms with their child’s condition. There is always a feeling that emotional support is ‘someone else’s role’.

In partnership with a colleague from the Portage Home Visiting Team I facilitate a bi monthly support group for parents and carers of pre school children with social communication difficulties. Through my involvement with the group and the relationships I have forged with many sets of parents I have been offered a
unique insight into the experience of being a parent of a child with autism. I consider it a privilege to have worked with families throughout their diagnostic journey. I have supported families from initial concerns being raised about their child’s needs, through assessment and diagnosis, to their eventual adjustment and acceptance of their child’s condition. Each family I have worked with has told me their own unique story and shared their different perspectives of the process. Through the parents support group I am exposed to the reality of being a parent of a child with autism.

1.5 The current research
Existing good practice documents and clinical guidance have given practitioners procedures, and suggested measures, to ensure that they offer a high quality service when they make diagnosis of autism. However, they have not provided a measure of the quality of the diagnostic procedure from the parents’ perspective. The NICE Guidelines (2011) highlight the lack of research in the field and comment that existing studies are of ‘low quality’.

This thesis seeks to explore parental perceptions of a diagnostic pathway, for the diagnosis and assessment of pre school children with autism, in a Local Authority in the North West of England. To enable me to fulfil this aim I will investigate the factors that, parents perceive, contribute to the success of the local diagnostic provision. I want to determine whether they consider that any of their own or their family’s needs, have not been met by the existing pathway.

I also want to investigate what, if any, feelings of grief and loss were experienced by the parents when their children were diagnosed with autism. I hope to explore whether this cohort of parents feel their emotional needs have been met by the local pathway. Through this research I hope to make a wider contribution to knowledge as regards understanding the feelings of grief and loss experienced by families who have a child diagnosed with autism.

Following an extensive review of the literature the following research questions have been designed to enable me to fulfil the aims, documented above:
1. From the parents’ perspective what are the factors which contribute to a successful ASD pathway, in their locality, from identification, to diagnosis to intervention?

2. Do parents perceive that any of their own, or their family’s needs, were not met in the local ASD pathway?

3. What feelings of grief and loss are experienced by parents when their child is diagnosed with autism?

4. To what extent does the ASD pathway help and support parents through the feelings of grief and loss which may accompany a diagnosis?

1.6 Structure of the thesis

In this introductory chapter I have provided a rationale and purpose for the study. I have detailed the national and local context within which the research will be conducted. I have stated the aims of this thesis and presented my research questions.

In Chapter 2 I discuss why I selected the different topic areas for review. A description of how the literature review was undertaken is provided. The chapter is then divided into three discrete sections: Experience of Diagnosis, Impact on Families and Loss. At the end of the chapter I summarise the literature reviewed and indicate how it informed and led me to develop the research questions.

In Chapter 3 I provide a justification for the research paradigm which underlies my study. I give my rationale for the methodology I adopted to address the research questions. The selection of sample, the participants, and methods of data collection and analysis are detailed. A description and critique of Thematic Analysis (Braun & Clarke 2006) is made. Finally, the ethical issues related to this research are discussed. The limitations of my methodology are not referred to in this chapter, they are discussed in detail in Chapter 5.
I begin Chapter 4 with a description and my reflections upon the thematic analysis I made of my data. The findings of the research are then reported under the main themes identified in the analysis. I offer an exploratory and in-depth discussion of the results, relating them to the existing literature and illustrating them with quotations made by my sample.

In Chapter 5 I present the key findings of the study and reflect upon them in relation to my research questions. A critique of the methodology and a personal reflection of the study are also made. The unique contribution that this research makes to knowledge and theory is detailed and discussed. I then consider the implications for practice identified by the study. I conclude the chapter by suggesting areas for future research.
CHAPTER 2

LITERATURE REVIEW

2.1 Rationale for the literature review

A researcher must be mindful that the literature review is the vehicle which will refine and inform their research questions. Thus, the areas of research which are critiqued must be pertinent to the key aims of the study. There is a vast literature around autism which considers a wide range of topics, for example its historical perspective, assessment and diagnosis, prevalence, causation and different interventions. It would not be practical, or indeed appropriate, to review each of these areas of research. I therefore reflected upon the aims of this research to aide my selection of topics to review.

This research aims to explore parents’ perceptions of their local diagnostic pathway for pre-school children with autism. I seek to determine what factors, they perceive, contribute to the success of the local pathway. The first topic I have selected to critically review is the parents’ experience of the diagnosis of autism. By gaining a deeper understanding of the issues highlighted by parents in previous studies it is likely that I will be oriented to the key issues that the parents in my sample will consider to be important. I will reflect whether there are similarities across the parents’ experiences documented in the literature. When I discuss my findings I will consider whether they replicate any of the existing research in the field. This, I would postulate, may potentially enhance the external generalisability of this study.

I want to investigate whether the parents in my sample perceive that they, or their family’s, have needs which have not been met by the local ASD diagnostic pathway for pre-school children. Thus by exploring the literature around the impact of autism on families I hope to gain an understanding of the unique challenges they face. I envisage that the literature in this area will highlight the specific needs of the parents and families of children with autism. This will enable me to relate and reflect upon my own findings, within the context of the existing evidence from the literature, about the needs of families.
The current research seeks to explore what feelings of grief and loss, if any, are experienced by parents when their child is diagnosed with autism. Therefore, the third area of literature I intend to critique is **autism and loss**. An initial review of the prevalent theories of grief and loss will be conducted to provide context. I will then focus my attention upon the existing body of literature which has explored the grief and loss experienced by parents whose children have received a diagnosis of a developmental disability. My analysis of the literature will then determine whether there is research that has focussed upon the feelings of grief and loss experienced by parents when their child is diagnosed with autism.

I took a systematic approach to identifying papers to review in this chapter. In the first instance I identified the key references, which were relevant to my research, in published good practice and clinical guidance for autism (NIASA, 2003; SIGN, 2007; NHS Wales, 2008). I then made an extensive search of the literature, online via the John Ryland’s University Library, at the University of Manchester, using the databases PsychINFO and ‘Psychology: A Sage Full-Text Collection’. Some examples of the key words and phrases I used to facilitate my literature searches were: autism, autism and diagnosis, autism and loss, parents’ views of diagnosis, autism and families, impact of diagnosis. I also put the key words and phrases into the search engine ‘Google’ and made use of the NAS website to search for related articles and resources.

In the final stages of writing my thesis I wanted to ensure that I had reported the most recent research in the field. I searched the journals which I had found to be most useful to my research, for example, Autism and Focus of Autism and Other Developmental Disabilities, and trawled their most recent publications for recent, applicable, research papers.

I present this review of the literature under the three distinct headings:

- The experience of diagnosis
- The impact of autism on families
• Autism and loss

At the end of each of these sections I provide an overview which summarises the key findings of the literature and considers future areas of study and methodological issues. I conclude the chapter by summarising how the literature review has informed and helped me to refine my research questions.

2.2. The experience of diagnosis

There is a significant area of research which focuses on the experience of families who have a child who has been diagnosed with autism. Some studies have considered the whole diagnostic process from the point of initial concerns being raised to the support available to families post diagnosis (Midence & O’Neill, 1999; Waters et al, 2008). Other research has evaluated specific aspects of the diagnostic process including communication with professionals, sharing the news and support offered to families (Mansell & Morris, 2004; Osborne & Reed, 2008; Whittaker, 2002 etc).

2.2.1 Parental views on the diagnostic process

Two studies (Midence & O’Neill, 1999; Waters et al, 2008) encapsulate the essence of how parents view their overall experience of diagnosis. The small, but widely referenced, pilot study by Midence & O’Neill (1999) investigated the experience of families during a diagnosis of autism. They carried out a qualitative analysis, in North Wales, of the perceptions of parents who had a child who had been diagnosed with autism. The authors were interested to gain information about the effect that autism had on the family and how they were coping with the condition. They observed that previous studies had used standardised questionnaires to obtain the views of parents. This was one of the first studies in the field to adopt a qualitative approach. Using a semi-structured questionnaire participants were asked about their child’s developmental history, the family’s knowledge of autism and their view of the professionals they encountered and service provisions. A grounded theory analysis was made of the parents’ responses. Midence & O’Neill (1999) observed that “the period is characterized by confusion as to the cause of the behaviour, feelings of self blame and severe stress on family relationships” cited Mansell & Morris (2004) p
They identified six core categories that families used to describe their experience of the diagnosis of autism. For the purpose of the current research it is useful to consider the descriptors they provided for their core categories:

*Behaviour Development* – all of the parents in the study identified that their child did not develop in the expected way. They identified a range of difficulties experienced by their child including eye contact, language, rituals and behavioural problems.

*Confusion* - the parents reported that they could not understand why their child was behaving in particular ways. Indeed Midence & O’Neill (1999) state that “not knowing was described as the most difficult situation during pre-diagnosis” (p279). Some of the parents reported feelings of guilt about their child’s behaviour whilst others blamed themselves for the differences they were observing in their child. These feelings of blame led to difficulties within the family and in one instance isolation from family and friends.

*Incorrect diagnosis* - many parents in the sample reported that they had been given “incorrect advice or diagnosis” (p 279). The incorrect diagnoses given included Fragile X and a hearing impairment. Parents felt that they were not being understood by professionals such as their GP or ‘people from education’.

*Autism* – when parents met professionals who specialised in autism they got the help they needed. Most parents in the sample expressed relief that they knew what was wrong with their child and stressed the importance of being given a ‘label’ for their child. When there was a clear understanding of their child’s difficulties feelings of blame and guilt were resolved. The parents’ view that the condition is an ‘invisible one’ was also acknowledged.

*Support* – after the diagnosis parents felt they were receiving support. It was important to them that there was someone they could talk to who would be able to offer them practical help.
Acceptance/ adaptation – whilst the importance of diagnosis and the availability of practical help was considered to be crucial parents’ also felt that acceptance of their child’s condition was very important. Families reported that where previously life had ‘revolved’ around their child they now tried to include them in their normal family life. Many positive effects that their children had on their lives were reported and celebrated.

Midence & O’Neill’s study (1999) was illuminative and frequently referenced in the literature (Waters et al, 2008; Osborne & Reed, 2008; Fleischmann, 2004). However, I consider that some caution should be applied when considering the generalisability of their findings as it was a pilot study and a small sample, of only four families, were interviewed. References made to ‘many’ parents in the study should be interpreted in this context. The authors themselves suggest there may have been a bias in their findings due to families being self selected.

Research conducted on behalf of the North West Care Services Improvement Partnership, by Waters et al (2008), explored families and carers perceptions of their experience of a child being diagnosed with ASD. Following a 2007 audit of Primary Care Trusts in the North West it was evident that the majority had an ASD referral or care pathway in place. Waters et al (2008) observed that, whilst the audit provided measures of procedure, it gave little information about the quality of the diagnostic experience of the service users. Waters et al’s study is of particular interest to me as it was conducted in the North West and looked specifically at the families experience rather than professionals perceptions of diagnosis.

Waters et al (2008) conducted semi structured interviews with a much larger sample, 31 families, and explored the family’s experience of ASD diagnosis. Their findings endorsed many of those of Midence and O’Neill (1999). They reported that some families had to wait a long time for diagnosis and that diagnostic pathways were not transparent and coherent. The study emphasised the importance of professionals recognising the early signs of ASD and having good knowledge and understanding of the diagnostic pathway. Waters et al (2008) concluded that reluctance by professionals to label a child or a ‘wait and
see’ attitude was not considered to be helpful by the families. Indeed, in many cases it was labelled as harmful as it stopped them accessing the appropriate information, services and support. They also noted how important it was for families for a reliable diagnosis to be made before they could start the process of acceptance and adaptation as regards their child’s needs.

2.2.2 Predictors of parental satisfaction with diagnostic process

There is a body of literature which explores whether parents were satisfied with their experience of diagnosis.

Howlin and Moore (1997) conducted a survey of over 1200 parent members of autistic societies in the UK. They sought to determine the parents’ views of the diagnostic process and identify which factors facilitated parental satisfaction in the process. The questions in their survey focussed attention upon the professionals involved in the diagnosis and the length of time the diagnostic process took.

The data they collected supported their hypothesis that the less time a parent has to wait for a diagnosis the more satisfied they were with the process. One comment made by a parent in their study emphasised this finding for me:

“The whole process is far too slow and seems to depend on the parents’ persistence in pushing for a diagnosis. Months seem to go by waiting for appointment after appointment. This really prolongs the agony of what is, inevitably in any case, a painful process” Howlin & Moore (1997) p 158

Brogan & Knussen (2003) rated parents’ satisfaction around the disclosure of a diagnosis. They wanted to identify what parents thought was pivotal to a satisfactory experience. They suggested that parents were more likely to feel satisfied if their child was diagnosed at a younger age and they had had a smooth progression through the diagnostic pathway without significant delays. They were interested to determine whether a specific diagnosis, such as
‘autism’, facilitated higher levels of satisfaction than a less specific one such as ‘autistic tendencies’.

Their investigation found that compared with previous studies conducted by Sloper & Turner (1993) cited Brogan and Knussen (2003) and Howlin & Moore (1997) there were relatively high levels of parental satisfaction. Indeed, more than fifty percent of participants related their experience of disclosure as satisfactory or very satisfactory. They identified several factors which contributed to feelings of satisfaction. These were:

- The manner of the professional during the sharing of the news
- The quality of the information they were given by the professionals giving the diagnosis. This included both written documentation and the opportunity to ask questions
- The recognition of their initial concerns by professionals
- Being given a specific diagnosis. In this study a diagnosis of Asperger’s was given a higher rating of satisfaction than a less specific diagnostic label

Brogan and Knussen (2003) concluded that satisfaction was not related to the age at which the child was diagnosed or any periods of delay which may have been encountered.

An interesting study by Goin-Kochel et al (2006) surveyed the parents of children with a diagnosis of autism to determine their feelings of satisfaction with the process. The authors comment that whilst it is possible to make a diagnosis of autism before the age of two years:

“Parents are frequently faced with a slow and frustrating period of uncertainty and worry and find themselves in the position of trying to convince their children’s doctors that there is a need for a specialist assessment” Goin –Kochel (2006) p439.
In a review of the literature they concluded that many professionals suggest that parents’ concerns are premature and encourage them to give their child time to ‘grow out of’ their difficulties. (Ahern, 2000; Gray, 1995; Schall, 2000; Stephenson et al, 1991 cited Goin-Kochel et al 2006).

Goin-Kochel’s (2006) findings supported those of Howlin & Moore (1997) as regards parents’ satisfaction of the diagnostic experience. They found that 40% of their sample were ‘not satisfied’ with the process they had experienced. There were two pivotal factors for parents who reported greater levels of satisfaction. These were:

- Diagnosis at an earlier age
- Contact with fewer clinicians

In their concluding comments Goin-Kochel (2006) make the interesting point that their study only rated parents who had received a diagnosis. They did not have data available for those parents who had been advised to wait a period of time before pursuing a diagnosis. They comment that for many children this would have been the correct advice. The concerns parents raised about clinicians minimising their concerns would, for a different cohort of parents, have been strength in the system. They urge caution that the “potential harm of a wrong diagnosis must be balanced, however, against the frustration of a delayed diagnosis” (p 449).

Similarly Osborne & Reed (2008) conducted a survey of parental perceptions of the diagnosis of autism in the hope that recommendations could be made as to how to improve the process for parents. They concluded that many parents voiced the opinion that diagnosis should be a quicker and easier process.

Chamak et al (2011) made a study of parental perceptions of the diagnosis of autism in France. They observed that, until recently, French psychiatrists had been reluctant to make a diagnosis of autism. Chamak et al (2010) said that this was partly attributable to French families being able to access services without a
formal label for their child’s condition. Although the study was made in a different country, with a different diagnostic ethos, their findings concurred with much of the existing literature. Many parents reported that their initial concerns were dismissed by professionals or attributed to their parenting technique. They reported that a significant number of the parents, 93%, expressed feelings of dissatisfaction about the process because of “long delays in obtaining the diagnosis and a blunt announcement without care or consideration sometimes enhancing feelings of guilt” (p91). The parents in Chamak et al’s (2011) study described feelings of disbelief, shock and anger when they received the diagnosis. It was found that parents were more likely to report that they felt relief if their child had waited longer for a diagnosis.

The literature which has been discussed above has considered families overall experience of the diagnostic process and suggested predictors for satisfaction. It is useful to look at some of these areas to enable us to identify ways we can improve parents’ experiences of diagnosis.

**Specific versus Vague Diagnosis**

Howlin & Moore (1997) predicted that parents who got a specific diagnosis would be more positive about the process. Indeed, when they compared parents who received a clear diagnosis, such as ‘autism’ or ‘Aspergers Syndrome’, with those who were given a less clear one, such as ‘autistic traits’, they reported higher levels of satisfaction. This led Howlin & Moore to suggest that where possible “labels such as ‘autistic tendencies’ or ‘features’ should be avoided unless absolutely necessary” (p 161). One of the parents in Mansell and Morris’s (2004) study reported that her child had been diagnosed with a pervasive developmental disorder. She observed “no one, apart from experts, has ever heard of pervasive developmental disorder, so I had to explain it, even to school!” (p404). Despite concerns about the label given Howlin & Moore (1997) acknowledged that receiving any diagnosis was, for many parents, a relief:

“He diagnosed my son within an hour. I could have kissed the man for ending our despair and putting the word ‘autism’ to
Parents in Whittaker’s (2002) sample placed similar emphasis upon the importance of the diagnosis being given in “clear and unambiguous terms”. They commented that a lack of false hope helped them to resolve themselves with the diagnosis. Where parents had not received a clear diagnosis, or had experienced some delay in receiving one, they were more likely to report dissatisfaction.

**Time of diagnosis**

Whilst early diagnosis of autism is regarded as a positive in the literature I feel that the reasons why early diagnosis can be of benefit need to be considered.

Goin & Myers (2004) stress the importance of early detection of autism, they suggest that early diagnosis benefits the family as well as the child. A diagnosis means that children can access intervention services at the earliest opportunity. Secondly when an early diagnosis is made Goin & Myers (2004) suggest that family stress is reduced in the long term. When parents know what their child’s diagnosis is they can make decisions about their care based upon fact and identify interventions which are appropriate for them. Indeed they state that “significant delays in detection have adverse effects on both children’s developmental outcomes and their family’s ability to cope with autistic disorders” (p 11).

The conditions in which the diagnosis takes place are also pivotal. Indeed, Goin & Myers (2004) reference several studies which describe the difficulties parents encounter when seeking a diagnosis. They report Schall (2000) who found that some parents have encountered professionals who dismiss their concerns about their child. They also quote work by Godhard et al (2000) who state that:

“Parents described a system that compartmentalised, that regularised, and that fostered fear, confusion and frustration.”
Within this overriding system problems of coping with disability emerged” (Goin & Myers p6).

Goin & Myers (2004) discuss the need to provide parents with accurate information about their child’s difficulties as this will help them adopt the best ways to care for them and manage their behaviours. They stress the importance of having a team of professionals around the child and parents who are knowledgeable, sensitive to their needs and will address their concerns.

Boyd et al (2010) discuss the implications for early identification and diagnosis of autism. They report a study by Zwaigenbaum et al (2009) which reported that the mean age for diagnosis of autism in the US was around 4 years old. Boyd et al (2010) suggest that as researchers have now developed and validated sensitive diagnostic tools for younger children we may now see the age of diagnosis fall. They make the pertinent observation that the availability of a diagnostic tool does not necessarily mean there will be early diagnosis. They argue that professionals who work with children need to be aware of the ‘early warning signs’ of the condition and act on them. They propose that screening tools should be introduced on training programmes for teachers, speech and language therapists and occupational therapists amongst others. This, they consider, will promote early identification of the condition.

Boyd et al (2010) also urge caution, suggesting that:

“All emphasis on early screening and diagnosis is necessary but not sufficient for high quality service provision and must be combined with subsequent evidence based services for infants, toddlers and pre-schoolers with ASD and their families” (p 84).

They stress the importance of all families having access to a responsive delivery service whereby they can access the appropriate intervention for their child. This should be regardless of socioeconomic or ethnic backgrounds. Boyd et al (2010) make a strong claim in their conclusion that with early identification, assessment and intervention for children with autism:
“The possibility exists for the prevention of autism (Dawson 2008) or at least, a reduction in the severity of children’s symptoms over the lifespan, because of the malleability of the brain during this critical period of development” (p 93).

They emphasise the importance of provider’s co-ordinating and integrating services for families if the outcomes for infants and toddlers are to be optimal.

Whittaker (2002) urges caution when considering early diagnosis. He observes that sometimes the drive for “speedy and definitive diagnosis for very young children creates a real risk of reaching premature and incorrect conclusions” (p 415). This is especially true when the children may also have significant learning difficulties and further monitoring and assessment is needed. In such instances parents in Whittaker’s (2002) study said that providing this is explained and they are informed of the plan for future assessments, they were able to cope with the uncertainty.

2.2.3 Communication with professionals during diagnosis

The SIGN Guidelines (2007) emphasise the importance of the quality of the communication skills a professional has when making diagnosis. This is an area which is frequently reported as being a particular stressor for parents. However there is an observation in the literature that there is a limited amount of research which has focussed on parental communication with professionals when autism is diagnosed and during the follow up period. (Osborne & Reid 2008).

Graungaard & Skov (2006) carried out a longitudinal study of 16 sets of parents who had a severely disabled child. Whilst their cohort did not have children with autism I think their findings provide a comprehensive view of their dealings with professionals. It is useful to consider their research in this review of the literature. Graungaard & Skov (2006) worked with the parents in their sample to determine what their needs were when communicating with professionals during the diagnostic period. They reported them to be:

- “Equality in co-operation between parents and physicians”
Research has found that the family’s initial experiences of health professionals have a direct correlation with their ability to cope with their child’s condition (Davies et al 2008). It is therefore of paramount importance for professionals to facilitate positive relationships with parents. A number of studies discuss the implications if these relationships are not fostered. For example, parents who contributed to Osborne & Reed’s (2008) study made reference to the need for some professionals to receive interpersonal skills training. Osborne & Reed (2008) identify this to be a major factor which contributes to the stress experienced by the parents. Indeed, Osborne et al (2007) found that if parents had had a stressful or aversive contact with professionals this may have a negative impact upon the success of future interventions.

‘Sharing the News’ with parents

Good quality communication with professionals is important at all stages of the diagnostic period. Research has suggested that the way in which the diagnosis is shared with parents is paramount. Brogan and Knussen (2003) assessed whether the manner of the professional who shared the news and the quality of information they were given would impact upon parental satisfaction. Brogan and Knussen concluded that professionals play a very important role in a parents’ perception of the quality of their experience. Indeed they observed that “they can ensure that parents feel supported, respected and informed or, conversely, they can leave parents feeling confused, angry, distressed and humiliated”. (p 45)

Nissenbaum (2002) observes that despite a rise in the number of children diagnosed with autism there is a restricted literature on how to share a diagnosis with parents of children with this condition. He reports that the ‘good
practice’ literature available tends to be aimed at professionals who work collaboratively with the family over a long period of time. In reality, assessment of autism and the subsequent interpretative conference tends to happen in a short time scale and “in these cases, professionals do not have the luxury of frequent and repeated visits with the family” (p 30). Nissenbaum (2002) notes that most of the literature around interpretative conferencing is for conditions, such as Down’s syndrome, which are identifiable from birth.

Nissenbaum et al (2002) conducted a study of parents and professionals which looked closely at their perceptions of the definition of autism and the perceived outcomes of autism. The study stressed the importance of professionals having a good knowledge of the diagnosis, the prognosis and the interventions available. They compiled nine recommendations for good practice when sharing a diagnosis of autism. These are documented in the table below:

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<td>1.</td>
<td>Become knowledgeable about autism</td>
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<td>2.</td>
<td>Establish family friendly setting</td>
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<td>3.</td>
<td>Understand the families needs</td>
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<td>4.</td>
<td>Use good communication skills</td>
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<td>5.</td>
<td>Provide a list of resources and interventions</td>
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<td>6.</td>
<td>Provide follow up</td>
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<td>7.</td>
<td>Discuss prognosis</td>
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<td>8.</td>
<td>Provide hope</td>
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<tr>
<td>9.</td>
<td>Recognise that it is not unusual for professionals to react to giving the diagnosis of autism.</td>
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**Table 1 Nissenbaum et al (2002) Recommendations for Good Practice**

As the study is central to my research I will consider the above recommendations in more detail.

Despite increasing awareness of the condition the professional participants in Nissenbaum et al’s (2002) study frequently referred to autism as a ‘controversial disability’. Nissenbaum et al emphasise that it is important that practitioners are
knowledgeable about autism and are confident in giving the diagnosis. They suggest that this will reduce the risk of parents challenging the diagnosis and parents will be more likely to accept their recommendations for interventions.

The study recognises that simple considerations such as the physical layout of the room the diagnosis is given in can facilitate a successful contact between parents and professionals. Comfortable chairs, toys for children and prior thought about the positioning of all members of the meeting are important. Indeed, Nissenbaum et al draw attention to the placement of tissues within easy reach should a parent become upset in order that the meeting can continue to ‘flow’.

When a family learns that their child has autism there will be a significant impact upon them. By understanding the needs of the individual family and considering what their perceptions of autism are, or may be, the professional can ensure that the interpretative conference will be ‘tailored’ to the individual family. Professionals need to think, prior to the meeting, what information needs to be shared with the family and how the diagnosis should be presented to them. In the current pre-school pathway I am involved in the sharing the news session takes place on the same morning as the diagnostic assessment of the child. Whilst I do feel that this is a strength of the pathway it does lead me to question whether there is time for an in depth consideration of the needs of the families prior to the diagnosis being shared. I hope to gain more insight into parents’ views of the appropriateness of the meeting for their individual family.

On a practical level Nissenbaum et al (2002) urge the professionals to consider a list of resources and interventions which will be useful to the family. These should pay attention to ease of access to services, up to date contact numbers and even the names of individuals. Regardless of the tendency for professionals to urge caution about engaging with specific treatments, parents will want to pursue interventions for their child. By considering the information available from the assessment the professionals can signpost those that are most applicable for the family during the interpretative conference.
Nissenbaum et al (2002) emphasise how important it is to provide families with the opportunity to access follow up appointments. They offer the opportunity to revisit points they have missed in the sharing the news meeting and ask questions they have thought about since the diagnosis. The parents I intend to interview will have had the opportunity to attend a planning meeting a month after the original diagnosis. This allows them time to assimilate the news they have been given, formulate questions and have the chance to have their queries answered. In this study I am interested to seek the parents’ views of the planning meeting and determine whether it was useful for them.

Nissenbaum et al (2002) highlighted how important it was for parents to receive information about their child’s future. The majority of the parents in Nissenbaum et al’s (2002) study did not believe that the professionals sharing the diagnosis had considered the outcomes for their child. A quote from one of the participants in the study is illuminative:

“The people that we went to, I think are very good at diagnosing, but I don’t think that they really thought about the outcomes. They were thinking about the diagnosis right now and what this child had….they mentioned absolutely nothing about what we could look for down the road with him and I don’t even think this was on their mind at this point” (Nissenbaum, 2002: p 34).

It was recognised that due to the nature of autism professionals could not predict outcomes. However, Nissenbaum et al (2002) did suggest that some sharing of thoughts about the prognosis for children with the condition may be useful. They suggest that a future area of study would be how to ensure that parents leave the interpretative conference with feelings of hope. As a regular participant in the sharing the news conference I recognise the importance to families of showing empathy and celebrating their child’s areas of strength. However I would caution against inadvertently providing families with ‘false hope’.
An older study by Shea (1993) focussed upon sharing a diagnosis of autism with parents. She identified several elements which need to be considered when facilitating a ‘sharing the news’ conference with parents. These are:

- Setting goals for the conference
- Stating the diagnosis
- Allowing families to react emotionally to the diagnosis
- An appropriate physical setting
- The use of language
- The opportunity to discuss the child’s future

Shea suggested that an area of her study which perhaps needed further investigation was the parents and professionals views of the interpretative conference. This is an area I would like to address in the present research in relation to parents.

**Sharing the news – perspective of the professional**

The feelings of the professionals giving the diagnosis were also considered to be very important. Nissenbaum et al (2002) urged that professionals recognise how difficult it is to share the news with parents. As part of their research Nissenbaum et al (2002) interviewed professionals to gain a deeper understanding of the reactions they had when giving and receiving a diagnosis of autism. Many reported negative emotions including “feeling sad, wanting to cry, feeling empathy for the families and having doubts about the diagnosis of autism” (p 36). In the majority of cases professionals reported feeling nervous, these feelings were exacerbated when they were unsure how parents may react. Many professionals in Nissenbaum et al’s (2002) study reported that they ‘dreaded’ interpretative conferences and these feelings were intensified when they did not think that parents suspected the diagnosis. The research suggested that the obvious emotional impact upon the professional can evoke different reactions from parents. Positive consequences were reported to be that parents felt they were more empathetic and sensitive towards them. Conversely, the
negative effects were “rushing, failing to give relevant information, jumbling words, presenting an unclear diagnosis and using poor eye contact” (p 36).

Nissenbaum et al (2002) identified that, whereas parents often had a positive outlook about the condition, the professionals' view of outcomes tended to be more negative. Indeed “many professionals indicated they would be devastated if their child was diagnosed with autism” (p 33). However, they stress that if the professional shows a negative reaction it can have a marked impact upon the parents’ ability to accept the diagnosis.

Bartolo (2002) conducted a study which investigated how professionals communicated a diagnosis of a developmental disability to parents. He observes that whilst it is difficult for parents to receive a diagnosis of ASD it is also hard for a professional to deliver bad news about a child’s needs. This supports Nissenbaum’s findings. Bartolo (2002) suggests that when the news of a diagnosis is shared in a sensitive and skilful manner it can be described as a “therapeutic turning point for parents” as they are helped to understand their child’s needs and are able to access the appropriate provisions to help their child (p65).

Bartolo (2002) reports an ever growing awareness of the rights of clients to be given clear information post diagnosis. He states that there has been a shift of perception from ‘whether’ to report a diagnosis to ‘how’ to report the diagnosis to families. He made an analysis of two multidisciplinary teams, operating in the London area, and identified 3 different frameworks which professionals utilised to share the news. These were:

- A parent-friendly framework- the parents were invited to express their views and professionals empathised and made attempts to align the parents to their judgements
- Defocusing the bad news – professionals focus on the progress the child has made and what educational provisions were relevant for the child
• Hopeful formulation – there was a focus on the positive traits and focussing on progress before identifying delayed functioning

Bartolo (2002) concludes that his work illuminated the difficulties professionals have sharing the news. He stresses the importance of further developing skills and auditing parents’ experiences.

2.2.4 Parents’ reactions to the diagnosis

A body of literature has investigated how parents react to and feel about a diagnosis of ASD (Grungaard & Skov, 2006; Mansell & Morris, 2004; Waters et al, 2008). Whilst acknowledging there are wide variations in parents reactions the research has identified that receiving a diagnosis of autism can be traumatic for the family.

Many studies have made use of retrospective interviews to determine parental reaction to diagnosis. Grungaard & Skov (2006) conducted a longitudinal study to investigate the experiences of parents. They worked with the parents of severely disabled new born children during the process of the diagnosis. They identified the significant importance that the diagnostic process had on the parents experience and potential coping abilities post diagnosis. They found there to be five main themes which parents identified when reporting their experiences (p300). These are documented in the table on the next page:
<table>
<thead>
<tr>
<th>Main Theme</th>
<th>Content (properties)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Creating future images</td>
<td>Shattered dreams, uncertain prognosis, creating new future images, emotional strain of uncertainty, general views of future horizons, next child</td>
</tr>
<tr>
<td>Identifying possibilities of action</td>
<td>Powerlessness, collecting information, doing everything possible, alternative medicine, regaining control, retaining hope, training and stimulation</td>
</tr>
<tr>
<td>Perceiving the child</td>
<td>Deficits versus potentials, case or child, diagnosis credibility, recovery possibilities</td>
</tr>
<tr>
<td>Communicating with health professionals</td>
<td>Satisfaction, setting, timing, level of information, communication style, co-operation, gender, hope conflicting with information</td>
</tr>
<tr>
<td>Implicit expectations of the health care system</td>
<td>Diagnosis and cure, fight for the child, physical and structural conditions, human errors</td>
</tr>
</tbody>
</table>

**Table II Graunegaard & Skov (2006) Main Themes and Content**

The theme they identified, which is most pertinent to the present research, is that around communicating with the professional. They reported the need for empathy and co-operation. They expected *“the health professionals engaged in their situation [had] the ability to feel the impact their words were having on the family’s life and to let it show”* (p 303). Many parents reported the importance of the health professionals acknowledging that they, as parents, were the ‘expert’ on their child and working co-operatively with them. Graunegaard & Skov (2006) observed that whilst health professionals needed to give clear and realistic information to parents it was important to parents that they still had ‘hope’. There is sometimes therefore a discrepancy between the need for factual information and affording the parents’ time to have a process of realisation.

Watchel & Carter (2008) note the diversity of feelings that parents may experience when they receive a diagnosis of autism for their child: *“from relief that their suspicions have finally been validated to grief over the loss of the life...”*
they envisioned for themselves and their child”. (p575) They acknowledge the significant impact that a diagnosis has on the family at a practical level, for example, the financial implications many families face of giving up work to meet their child’s needs.

Mansell & Morris (2004) conducted a questionnaire based study and collected quantitative and qualitative data, to assess parents’ reactions to the diagnosis of an autistic spectrum disorder, in the local authority in which they worked. Mansell & Morris (2004) comment upon the variety of emotions that families experience when their child receives a diagnosis of autism. Three quarters of their respondents expressed feelings of relief that professionals had confirmed a diagnosis that they may have considered themselves. They felt that being able to label the condition provided them with the means to explain and accept their child’s behaviour. In addition receiving a diagnosis enabled families to access specific resources and avenues of support which were previously unavailable.

Alongside the positive outcomes of receiving a diagnosis Mansell and Morris (2004) consider less welcome consequences. They reported that the majority of families reported negative consequences of receiving a diagnosis. For many families this is a very upsetting time and they “experience shock and disbelief when the diagnosis is received” (p 388). They have to come to terms with the long term impact that the diagnosis will have upon their family life. Some of the families reported that they had not understood the diagnosis and it was difficult to determine whether the problem behaviours their child exhibited were due to the condition or not.

The parents in Mansell and Morris’s (2004) study had mixed feelings about diagnostic process. Some expressed concern that had their child received an earlier diagnosis they may have accessed help sooner. Other parents questioned the reliability of the diagnosis and questioned if it was correct. This was especially true of parents who had observed good progress in their child. Issues about the lack of resources available to help their child, how they would support their child and explain the nature of their needs to them in the future were identified. Many of the parents reported that they had found it easier to
accept the diagnosis over time and, with hindsight, found the label of ‘autism’ to be a useful one. Mansell & Morris (2004) recommend that more research is needed to confirm their finding.

An interesting observation is made by Osborne and Reed (2009) who asked parents what they had found helpful and what could be improved during the diagnostic process. They conducted focus groups with parents of pre-school, primary and secondary school aged children who had recently received an ASD diagnosis. Half of the responses made by parents of pre-school children indicated that they had found nothing helpful about the diagnosis whereas between 10-25% of the other parents in the sample reported the same. They suggest that this may be due to the pre-schoolers receiving their diagnosis closer in time to the focus group. However, they also hypothesised that when parents had reported a positive about the diagnosis it was due to feelings of relief they felt that their concerns about their child had been confirmed.

The reactions of parents to the diagnosis were also probed in Nissenbaum et al’s (2002) study. Professionals reported that parents tended to show relief. Nevertheless they did note the variations in reactions and identified three broad groups of parents and the typical responses they had to the diagnosis:

- Parents who suspect autism – they tended to have a positive reaction and display feelings of relief, acceptance and receptiveness
- Parents who suspect delays but not autism - they present with both positive and negative emotions including relief, receptiveness, denial, anger, devastation and feelings of being overwhelmed
- Parents who do not recognise any problem – they tend to have the most negative reactions

Nissenbaum et al’s (2002) study suggested that when parents reacted to the diagnosis some expressed dislike for the person who gave the diagnosis or became angry with them. An occupational therapist who was interviewed observed that they “often hate the messenger’ because he or she is telling the
family something they do not want to hear” (p 36). The responses of parents who were interviewed for the study mirrored those of the professionals to a large extent. Some stated that they had not believed the diagnosis, others expressed their feelings of concern about how their family and friends would react to the diagnosis. Both parents and professionals reported that the families went through a period of grief following the diagnosis.

Waters et al (2008) describe receiving a diagnosis as “heartbreak and relief”. They acknowledge that whilst many parents experience a sense of relief that their child’s difficulty has been acknowledged and clearly defined this is “also accompanied by feelings of shock, disbelief, despair and grief” (p 25). In Waters et al’s study the parents emphasised the importance of professionals giving them straightforward and realistic information but also said that it was important to be told positive things about their child.

2.2.5 What makes parents feel supported during the diagnosis of ASD?

The literature provides a critique of several different types of support that families may access. These include:

- Access to a key worker
- Support groups
- Information provided about ASD

Luther et al (2005) looked at the coping strategies employed by parents of children with autism. They promote the view that by working with parents, assessing their stress levels, coping issues and the social support they have, professionals can be enabled to “facilitate more effective interventions” (p 46).

Key workers

As the prevalence of autism rises and children are frequently diagnosed at a younger age Gupta & Singhal (2005) stress the importance of appropriate parent support services. Their interest was in setting up services in India where the research was just emerging. They therefore looked further afield to
determine what good practice was. Gupta & Singhal (1995) stress the importance of a key worker for families. By providing such a service parental morale is higher, they receive a higher level of practical help, more respite and experience less feelings of isolation.

Osborne & Reed (2008) highlight the importance of effective multi agency work. The parents they worked with said how important liaison between professionals was in order that they could access support and help. Some parents drew attention to the disparity between the medical and educational systems they had to work with. The study suggested that the allocation of a ‘key worker’ would alleviate many of the difficulties families encountered and facilitate a more successful outcome for families.

In Whittaker’s (2002) survey all of the parents found the role that the support worker played to be invaluable. Parents placed particular value upon the role that the support worker plays in helping them to ‘mediate’ the vast amount of information about autism and signpost them towards the most pertinent for their specific child. In the authority that Whittaker (2002) undertook his research there was not a formalised multi disciplinary assessment pathway. He emphasised the potentially important psychological support that multi disciplinary assessment teams provide to families and suggested that they can help to manage anxiety. Whilst we have a clear multi disciplinary pathway in the authority in which I practice the psychological support given to parents is not explicitly stated. It will be illuminative to gain the views of parents as to whether this is being provided for them.

**Support groups**

In Osborne & Reed’s (2008) study parents expressed the view that a support group, access to counselling, or the provision of a key worker to coordinate the work of different agencies may enhance the process. Interestingly the participants in their study, who had pre-school children, indicated that they had more opportunities to meet parents in a similar situation and access support groups. Some of the parents suggested that a professional should attend a support group but this was not considered imperative by the whole cohort. A
similar conclusion was made by Whittaker (2002) who observed that parents found it useful to have access to other parents who had been in the same situation together with the opportunity to have further discussions with professionals.

The Mansell & Morris (2004) study, into the reaction of parents to diagnostic services, highlighted the importance of the information provided by support workers. Indeed, 89% of the families had received input. The research emphasised the importance of local parents support groups. Parents gave high ratings when they evaluated the usefulness of courses and workshops that they facilitated.

Luther at al’s (2005) research identified that parent support groups were a way of providing social support to the families of children diagnosed with autism. They suggest that “support groups benefit parents by giving them a place to discuss their difficulties, to share coping strategies and accomplishments, and to meet other parents in a similar situation” (p45).

Mandell & Salzer (2007) studied the reasons why parents of children with autism may join support groups. Previous literature had identified the importance of support groups for the parents of children with developmental disorders. (Salzer et al, 2002; Solomon et al, 2001; Kerr & McIntosh, 2000; Law et al, 2001; all cited Mandell & Salzer, 2007). Mandell & Salzer (2007) reviewed the evidence base and reported that that these parents:

“Are highly satisfied with the sense of agency and belonging they achieve from participating in groups and report that their parenting skills improve as a result of participation, their sense of isolation is reduced, they obtain important information about services and they feel a greater sense of emotional support” (p 112).

Despite extensive literature on the value of such groups Mandell & Salzer found there was a dearth of research into which parents accessed the groups and how
certain factors, such as the characteristics of their child, may help us predict which families would be more likely to access the group.

**Virtual support groups**

As the availability of the internet has increased it is inevitable that parents have sought virtual support. Fleischmann (2004) stresses how the internet has become an important vehicle for families to communicate with others in similar situations and create ‘virtual support groups’. He acknowledges previous research which suggests that:

“*The primary source of anxiety and emotional distress often experienced by parents of children with autism is the challenge they face in helping their children to adjust and function in the world around them*” (Lainhart, 1999; cited Fleischmann, 2004 p 41).

For the parents in his study, the internet has facilitated them to express these feelings, make contact with others and reduce their feelings of isolation.

Fleischmann (2004) collated narratives written by parents of children who had been diagnosed with pervasive developmental disorders and then published on the internet. Whilst acknowledging that the narratives he found on the internet are not conventionally written Fleischmann considers them a primary source of information about how parents cope with the distress of the diagnostic process. He made a qualitative analysis of their content and identified that they all, to some extent, showed a degree of similarity in the core story that they told.

Many of the narratives reported that parents had initially used the internet to find information about the condition. They wanted to use their experiences to help others who may find themselves in similar situations hence the reason they posted their story. Fleischmann suggests that, for parents of recently diagnosed children in particular, making a website may not be entirely altruistic it can also be therapeutic. Indeed Pennebaker & Seagal 1999 (cited Fleischmann 2004) promote the health benefits of producing a narrative about your experiences.
They provide a vehicle for the individual to consider and work through periods of emotional stress. Narrative theory suggests that the story we tell “holds the realities of our lives and our ability to cope are influenced by the stories we tell about ourselves” Gergen 1988 (cited Fleischmann p42).

Fleischmann (2004) documented that the point of diagnosis marked a shift in the feelings of the parents. In his study he observed that delays in diagnosis resulted in many of the sample reporting feelings of distress. Conversely parents reported that having received a diagnosis they could look forwards and become more proactive in helping their child. He concludes that the internet narratives provide parents with a means of telling their story and therefore changing their perceptions and attitudes. He argues the importance of practitioners helping parents to tell their story in order that their coping mechanisms are enhanced.

Huws et al (2001) made a grounded theory study of mails produced by parents of children with autism who accessed an e-mail group. They highlighted the way the coping process is enhanced by exchanging narratives and correspondence. His study found that by constructing a new story for themselves parents are able to approach their child’s needs in a more positive way.

**Information about autism**

There is some debate as to how much information families should be given at the point of diagnosis. Whittaker (2002) found that there are times when interventions can be presented to parents too quickly following diagnosis. In these instances parents have not fully assimilated the diagnosis and may not be emotionally ready to take on board new information. Whittaker refers to the Early Bird intervention in the authority in which the research was conducted. He observes that in many cases parents attended workshops but were not able to apply the approaches until a later time.

Whittaker (2002) makes the interesting observation that following diagnosis some families display a strong desire to seek information. They amass huge amounts of information about the condition and become ‘experts’ in the field.
Indeed, I have worked with parents who constantly search the internet for information about autism and often focus upon unsubstantiated research. Whittaker postulates that the quest for information “may well be a short term strategy for managing overwhelming emotional needs” and is more acceptable than asking for the emotional support they need (p419).

Mansell & Morris (2004) looked at the different types of information that were available post diagnosis and compared the rating of usefulness awarded by parents. In general, sources such as the internet, books and academic journals received high ratings. The research found that the information provided by professional’s e.g. educational psychologists, consultant paediatricians, occupational therapists etc was not rated as highly. The authors suggest this may be due to the limited time available to give information. They also query whether professionals may “have more fixed ideas on the appropriate information to provide, whereas written information can be accessed freely” (p 398).

Howlin and Moore (1997) highlighted the lack of basic information about autism and practical advice that was available to parents. The NAS plan (2003) made recommendations about resources and interventions which should be available to families. This is an element I want to explore with the families I interview to determine what they have received, what has helped them and identify ‘gaps’ in our provision.

Whilst there is consensus that parents need to be given information about autism the point at which it is offered to parents is open to debate. The parents in Osborne and Reed’s (2008) study gave two different responses to their focus group question about the stage at which information about professional help they could access should be given. The parents of pre school and primary aged children tended to want information to be given to them at the time of diagnosis. Many of the cohort acknowledged that they may not be able to assimilate the information but felt ‘having it at hand’ would be very useful to them. A different perspective was offered by the parents of secondary aged children who
suggested that information should be given slowly, in different phases, after their child had been diagnosed.

2.2.6 Overview of experience of diagnosis
The literature pertaining to parents’ experience of the diagnosis of autism indicates that there is a limited amount of existing research in this area. The research I reviewed suggested that the majority of families find the diagnostic process to be complex, lengthy and frustrating (Midence & O'Neill, 1999; Waters et al, 2008). Waters et al (2008) call for additional research to be conducted which elicits parental views of their child’s diagnosis of autism.

The review has explored factors which enhance parents’ satisfaction ratings for the diagnostic process (Howlin & Moore 1997). There is evidence to suggest that parents’ communication with professionals is pivotal at all points of the diagnostic process (Brogan & Knussen 2003). However Osborne & Reid (2008) observed that there is a restricted body of research which has focused on parents’ communication with professionals in the period during and after a diagnosis of autism.

Research has indicated that the way in which the disclosure of autism is made can have a profound effect on a family’s ability to cope with the condition (Graungaard & Skov 2006). The literature suggests protocols for sharing the news and acknowledges the emotional impact that disclosing a diagnosis has on professionals (Nissenbaum, 2002; Bartolo, 2002). Nissenbaum (2002) highlights that there is a dearth of literature which addresses the disclosure of a diagnosis of autism. Although his study was made in 2002 my review suggests there remains a gap in the literature. Nissenbaum observes that most literature on sharing a diagnosis concerns other condition such as Down’s, Cerebral Palsy and other syndromes which are identifiable from birth. Similarly the ‘good practice’ guidelines for ‘sharing the news’ are aimed at professionals who work with families over a long period of time. Autism tends to be diagnosed over a short time scale, thus there is a need for increased insight into parental views of the disclosure of autism.
My review of the literature indicated that there are other predictors of parental satisfaction with the diagnostic process, for example, the clarity of diagnosis, and the age at which it is given (Howlin & Moore, 1997; Goin & Myers, 2004; Chamak et al 2011). The role of key workers and the type and amount of information that is given to parents after diagnosis is subject to scrutiny in the literature (Gupta & Singhal, 2005; Osborne & Reed, 2008). The families who have taken part in research report that they value the support they receive from parents in similar situations (Mandell & Salzer, 2007; Fleischmann, 2004). Many of the studies reviewed were conducted in different countries, for example in France, the USA, and Canada. (Chamak, 2011; Woodgate et al, 2008; Mandell & Salzer, 2007). Whilst these provide an insight into the experience of the parents they worked with it can be argued that their findings can not be applied to the UK, far less the locality in which I work.

Midence & O'Neil (1999) observed that older studies of parents’ experiences of the diagnosis of autism had made use of quantitative measures. They noted there was ‘very little’ research which had been carried out using qualitative methods. Their pilot study was one of the first to use semi-structured interviews to elicit the parents’ experience. My review of the literature identified that there continues to be a paucity of qualitative research in the field.

Many of the studies I reviewed were conducted with small samples. For example, one of the most frequently cited studies, Midence & O'Neil (1999), reported upon a pilot study of only 4 families. Indeed, several authors acknowledge this weakness in their methodology (Osborne & Reed, 2008; Mansell & Morris, 2004; Brogan & Knussen, 2003). The consequence of such small sample sizes is a lack of generalisability: their findings can only be applied to the locality in which they were conducted. This reinforces that there is a need to conduct research, in the locality in which one works, to ensure that pertinent data is obtained to inform future practice.

2.3 The impact of autism on families

Increasing numbers of children are being diagnosed with autism, the most recent data on prevalence suggesting it to be as high as 1:100. Despite this
significant population, there is a limited body of literature which has directly explored parents’ experiences of the impact raising a child with autism has on the family. The current research seeks to determine whether the parents in the sample perceive that they, or their families, have needs which have not been met in the existing ASD pathway for pre-school children. By reviewing the literature which explores the difficulties families encounter when a child has autism it is envisaged the potential needs of the family will be highlighted.

Some of the studies cited in this review of the literature were conducted in different countries such as France, America and Australia. The effect of the different cultures should be considered when interpreting their findings. Attention will be paid as to whether the parents, in the different studies reviewed, reported similar experiences regardless of local context.

2.3.1 Challenges faced by parents

LeCavalier et al (2006) state that the caregivers of children with developmental disabilities are faced with unique challenges. They report that compared with the caregivers of typically developing children they experience more negative psychological outcomes such as “additional financial burdens, more restrictions on social activities and heightened parental stress” (p172). The literature suggests that higher levels of stress and depression are displayed in families of children with autism when compared with those who have other developmental disabilities or are physically ill (Dunn et al, 2001; Eisenhower, et al 2005; Osborne et al, 2007).

The foreword of the National Autism Plan for Children (NIASA 2003) acknowledges that whilst any diagnosis of a serious condition is devastating for a parent:

“Autism is a particularly cruel condition from the parents’ perspective. Usually the child looks physically normal and to the outside world there is no apparent explanation for his/ her strange and often disturbing behaviour” (NIASA, 2003, p4).
Indeed, Randall & Parker (1999) observe that there are “few developmental disorders of childhood that create such complex stressors for families as autism” (p1). Similarly Gupta & Singhal (2005) suggest that autism “has been considered one of the most complex and intractable developmental disorders with which families may have to cope” (p 63).

Marshall and Long (2010) listed a number of these stresses which they had identified in their critique of the literature including:

- Child’s behaviour
- Parents difficulty obtaining diagnosis and treatment
- Ignorance and insensitivity of the public vis a vis the behaviours displayed by this cohort of children
- The child’s language and cognitive deficits
- The nature of intensive treatment programmes

Marshall & Long (2010) propose that rather than autism being an “isolated” stressor for families it should be “considered the centre of a cluster of stressors which accumulate and interact over time” (p 107). They analysed the stories told by five mothers, of children who had autism, and sought to examine the ways they coped with the stressors presented to them. I was interested in their methodology, as they had a small sample and made a narrative analysis, so feel it appropriate to describe it in more depth. Marshall & Long (2010) collected the data in three different phases:

- Phase 1 – a life story interview was audio taped and transcribed verbatim. This was considered to be the primary collection phase.
- Phase 2 – participants were asked to choose three to five stories which illustrated stressful situations they had experienced in the past two weeks. These situations were to reflect “ordinary stressful circumstances rather than situations that were extraordinarily stressful” p 107. The participants were asked to generate a metaphor to describe their role in coping with the stressful situation and give a title to the story. They were
asked to determine what their story illustrated about parenting a child with autism

- Phase 3 – with the permission of participants all the stories were shared with all of the participants. They were asked to reflect on points of similarity and difference.

Marshall & Long (2010) analysed the narratives and identified several common themes for coping across the stories that the parents told. These themes were:

- Comparison as coping – comparing your own situation with that of others.
- Resets as coping – changing your circumstances such as moving school, area etc.
- Negotiating understandings of autism – there are a wide range of theories and opinions about autism. The mothers frequently reported competing understanding between family members, school staff and professionals.
- Negotiating engagement and separation – there is a desire to integrate your child into ‘normal’ activities but have significant difficulties achieving this goal.
- Creating communities – often social support came from inside the ‘autism’ communities.
- Anticipatory coping – the mothers anticipated difficulties in advance and acted upon them. For example use of social stories before a trip.

Marshall & Long (2010) concluded that they had identified many stressors experienced by mothers who had children with autism. They argue that the life stories told by the mothers in their sample revealed that, as they came to terms with their child’s diagnosis, they were “meaning-making” over time (p115). They observe that there is a lack of qualitative research into the way parents cope with autism. Marshall and Long (2010) state that narrative approaches have been used in a limited number of studies and feel that our “understanding of mothers’ coping will be enhanced by further narrative research in this area” (p115).
2.3.2 Impact upon mental health

The literature provides evidence to suggest that having a child who has been diagnosed with autism can place parents at increased risk of mental health problems.

Benson (2006) looked at the impact that the severity of autism and parenting stress had upon the psychological adjustment of a cohort of parents whose children had autism. He found strong evidence to suggest that parenting stress and the severity of children’s symptoms were predictors of paternal depression. These findings were replicated in research by Tomanik et al (2004) and Hastings et al 2005 (cited Lee et al 2009). Both studies found that parents, of children with autism, experience mental health problems which may be linked to the demands they face caring for their children.

A similar review of the literature is provided by Gupta & Singhal (2005). They observed that parents of disabled children have a propensity to stress and quote research by Slope & Turner (1993) that high levels of distress are found in up to 70% of mothers and 40% of fathers of severely disabled children. Gupta & Singhal (2005) note several factors which makes the impact of autism unique from other developmental disorders:

- There is no definitive biological marker
- Diagnosis and prognosis can be ambiguous
- The difficulties children have with social interaction can impact upon attachments with their parents and ability to show affection. Indeed they observe that "parents of children with autism are often denied some of the fundamental rewards of parenthood" (p 63).

From their review of the literature Gupta & Singhal (2005) summarise that some parents “go through periods of disbelief, deep sadness a depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt” (p63). They stress that it is not just parents
alone who feel the impact of autism, it is the whole family unit. Nevertheless, Sander & Morgan (1997) (cited Gupta & Singhal, 2005) note that it tends to be the mothers of children with autism who experience the greatest levels of stress in the family.

Estes et al (2009) emphasise the solid evidence base that the mothers of children with developmental and psychiatric difficulties are at greater risk of experiencing distress than their counterparts with typically developing children. Further, they note that some studies suggest that the mothers of children with autism may experience higher levels of distress than those who have children with other disabilities (Gallacher & Bristol, 1989; Dumas et al, 1991; cited Estes et al 2009). They query whether this can be attributed to the characteristics that this cohort of children exhibit. For example, these children find it hard to relate socially which can be emotionally painful for mothers. They also suggest that the unusual behaviours and communication that their children display can be misunderstood and misinterpreted by uninformed members of the public. Conversely, they suggest that whilst these characteristics are common in all children with developmental disabilities they tend to be more marked in children with autism.

Estes et al (2009) conducted a study to investigate how child characteristics can influence maternal parenting stress and psychological distress. They assessed parenting stress in a matched group of mothers of pre school children who had developmental delay without autism and those who had autism. They found that the mothers of children who had autism reported higher levels of parenting stress and psychological distress than those with children who had developmental delay. The parents’ responses provided evidence that higher levels of child problem behaviours significantly increased maternal stress. They conclude that when considering what support clinical services can give to families there should be a focus upon reducing the problem behaviours that children with developmental disabilities exhibit. Estes et al (2009) identify a potential limitation of their study. They hypothesise that their sample, families who had the time and energy to participate in the research, may not have particularly high stress levels. Thus the findings may not generalise to a larger

Goin and Myers (2004) highlight the frustrations experienced by parents of children with a disability, in particular autism. They acknowledge how difficult it is to parent a child with difficulties with social interaction, communication and impairment of imagination. This frustration is often compounded by the obstacles parents have to overcome in order to get a diagnosis and access services to help their child.

2.3.3 Impact on family life
Werner (2001) (cited Luther et al, 2005) conducted interviews with parents and identified themes which demonstrated how their families lives changed when their child was diagnosed with autism. Some of these themes were:

- Family life revolves around coping with and addressing their child’s autism and unusual behaviours.
- Parents experience loss because their child can not lead a ‘normal’ life.
- The family experiences only ‘fleeting moments’ of feeling like a family.

Werner (2001) (cited Luther et al 2005) stresses how important it is that families have strong coping skills and access to both formal and informal support.

Dillinburger et al (2010) sought the views of parents and professionals about living with children who are diagnosed with autism. They comment that there is limited information in the literature as to the impact, upon the whole family, of living with a child diagnosed as ASD. They had a large sample, of ninety five parents and care givers and sixty seven professionals, who completed a written questionnaire. The questionnaire explored the needs of families with autism including current provision, future need, experiences and views. For the purpose of this thesis I feel it is more useful to consider the parents’ reports about living with autism rather than comment upon the comparisons made between parental and professional’s views and views on current education provision.
The majority of parents reported that the most difficult child behaviours they encountered were associated with their lack of social communication skills, self help skills and sleep pattern. Most of the parents said that autism restricted their recreation and social interests. The impact upon families going on holiday was frequently mentioned. Parental responses indicated that families isolate themselves from friends and family who do not understand their children’s needs. Most of the cohort said that having a child on the autistic spectrum placed restrictions upon the time they could spend with significant people in particular other children and their partners. Indeed, Dillenburger et al (2010) cite evidence from previous research that divorce rates among families of children with autism have been estimated at 82%. They report that one in three families, with a child diagnosed with ASD, are headed by lone parents.

A Canadian study by Woodgate et al (2008) sought the views of 16 families about their experience of parenting a child with autism. Prior to designing their study they identified that research into the experience of being a parent of an autistic child is in its infancy. The purpose of their study was to describe the ‘lived’ experience of parents with children who were autistic. A strong theme that emerged from their qualitative interviews was that parents were “living in a world of our own” (p 1078). The analysis identified four main reasons, mainly the result of external sources, that parents felt isolated:

- Societies lack of understanding.
- Missing a normal way of life.
- Feeling disconnected from the family.
- The unsupportive system

Woodgate et al (2008) probed the parents coping mechanisms and found them to use a variety of strategies. They reported that parents placed value on their children’s accomplishments and tried to change systems that they were unhappy with by voicing their discontent. Woodgate et al (2008) suggest that they have helped to confirm what it is like to be a parent of a child with a
‘chronic condition’ such as autism. This, they argue, will help professionals to “provide more comprehensive and sensitive care” (p1083). Furthermore Woodgate et al (2008) suggest that, in the future, parental expertise could be utilised to teach professionals how best to respond to the parents of children with disabilities.

An older study by Gray (1993) talks of the impact that autism has on family members. He observed that mothers tended to be most affected by the diagnosis and it impacted upon all aspects of their lives. For example, mother’s careers were affected as they tended to be the parents who looked after their child during the day. When mothers did work the number of hours and type of job they did was affected. In general mothers tended to be held responsible for their child’s behaviours by both family members and outsiders. Gray (1993) also found that fathers felt a personal impact of their child’s autism but this was usually related to the difficulties it presented to the family and the stress under which the child’s mother was placed.

Gray (1993) found that parents would isolate their families from social contact due to their child’s condition. They tended to opt to be in environments which were accepting such as being with close friends or families. Many of the families in the study described difficult social situations and often reported that “the most unpleasant aspect of difficult public encounters was the way in which their abilities as parents were seemingly doubted” (p 110).

In Gray’s (1993) study many of the respondents spoke of the impact on the siblings of children with autism. Whilst some noted the positive effects, such as having a greater understanding of people with disabilities, there were many disadvantages reported. These included a loss of a ‘normal’ family life and the lack of holidays and outings that typical families enjoyed.

An anonymous article, reported by Gupta & Singhal (2005), gives an account of being the sibling of an autistic child. Whilst recognising that they feel love for their sibling many reported that their parents gave more time and attention to their autistic sibling. They “felt that their parents perceived their needs as
secondary” (p 65). This can produce feelings of resentment that their parents do not spend as much time with them, or, that they are not being treated fairly. Anger, embarrassment and guilt are also feelings that siblings report as normal.

Randall & Parker (1999) draw an interesting parallel between Maslow’s (1954) hierarchy of needs and the stresses experienced by families of autism. In the first instance it is useful to consider Maslow’s hierarchy of needs:

- Physiological needs – food, water, oxygen
- Safety needs – comfort, security, freedom from fear
- Belongingness and love needs – affiliation, acceptance, belongingness
- Esteem needs – competence, approval, recognition
- Cognitive needs – knowledge, understanding, novelty
- Aesthetic needs – symmetry, order, beauty
- Self actualisation – realise potential, fulfil potential and become what one can

Randall & Parker (1999) frequently refer to a survey they had conducted, this was unfinished at the time of publication, to identify the met and unmet needs of people with autism and their immediate family members. They discuss their outcomes in relation to the model above.

**Physiological and safety needs**

Regardless of the severity of the autism it was likely that families had the potential for a greater financial burden than for a child who did not have a disability. The responses suggested that if the child displayed very challenging behaviours there was more likelihood that the child would physically harm themselves or other family members. Families of children with autism were met with constant uncertainly about their future and hence had a lack of security and a heightened sense of fear.

**Belongingness and love needs**
The families experienced reduced social interaction, intimacy and recreation both within the family and in their wider environment. Families reported that there was variable acceptance of their child and the family by people in society. Parents’ responses drew attention to their acceptance of each other, in many cases they blamed each other for their child’s condition.

**Esteem and achievement needs**
The survey suggested that the opportunities that parents and siblings had for career success were reduced.

Parents also identified that they had less experience of parenting competence.

**Cognitive needs**
Families in the survey reported that they did not understand their child as well as they would a typically developing child. This was attributed to both a lack of knowledge and information from the professionals they were involved with.

**Aesthetic needs**
Families reported that their roles were rigidly defined. Mothers in particular reported an unequal balance of role demands as they tended to be the caregiver.

The autistic child’s complex needs and behavioural difficulties resulted in families experiencing disorganisation. There was also interference with the way the family operated from outsiders.

**Need for self actualisation/ self fulfilment**
Family members had fewer opportunities to engage in activities that they were interested in. The respondents reported that there were obstacles preventing them fulfilling their ambitions.

**2.3.4 Parents making sense of the diagnosis**
Dale et al (2006) conducted a study of mother’s attributions following the diagnosis of their child as autistic. They felt it important that professionals
gained an understanding of the way mothers search for meaning, following diagnosis, in order that they can be properly supported. Dale et al recognised the value of research into the stresses experienced by families but identified that there was limited research into the impact of the diagnosis itself.

Dale et al (2006) observe that one of the ways we make sense of our world and things that happen to us is, especially in relation to stressful events, is to make attributions about the cause. They cite research by Weiner (1985) who proposes three different dimensions to attribution:

- **Locus of cause** – whether it is due to internal or external factors.
- **Stability** – extent to which the event is chronic or has the potential to change in the future.
- **Controllability** – whether the ability to change the event lies with internal or external forces.

Dale et al (2006) reviewed the literature around the impact of attributions in the field of childhood disability and found only a small number of studies. Those they found suggested that the causal beliefs that parents have about their child’s disability helps us to predict outcomes. For example, Morrissey-Kane & Prinz (1999) found that the attributions parents made about childhood disability can be predictors of whether they engage with treatment for their child in mental health settings and their perception of how well they will be able to manage their child’s needs. Dale et al highlighted the absence of research around the role of attributions following a diagnosis of autism. Indeed they stated that:

“It is clear that we currently know little about the processes they engage in while coming to terms with a diagnosis and still less about the contribution that their beliefs and attributions make to their well being” (Dale et al, (2006) p 465).

Dale et al (2006) investigated the attributions of parents following a diagnosis of autism through a semi-structured interview and taking formal measures of their
emotional well being, beliefs and sense of efficacy. The qualitative and quantitative analysis of the data they collected suggested that mothers in the study made attributions that were consistent with Weiner’s (documented above). All the mothers made an attribution about the locus of cause, however, these were diverse in nature. In general they did not allocate blame for their child’s condition but tended to focus on their futures. However, Dale et al (2006) noted that where mothers did have a particular belief about the cause of the autism it had a significant impact upon their other views about the condition. For example, if a parent felt that the MMR vaccination had caused the autism they believed that a biomedical cure could be found.

There were strong links between the mother’s theories about the cause and the stability of the condition and consequently who was best placed to help their child. Dale et al (2006) expressed some concern about the number of mothers in their sample, approximately a third, who believed that their child would overcome autism. They suggested these parents were more likely to believe there was a ‘cure’ and advocated that they needed to be provided with support to consider their choices around interventions. They said that if parents thought their child could change they would be more likely to engage with interventions.

Attributions of controllability were also identified in the study. A theme they identified was that “mothers experienced a sense of isolation and burden and that they were struggling with the responsibility of helping their child, feeling they held too much of the responsibility by themselves” (p476). Dale et al (2006) therefore argue that families need to be supported to ‘make sense’ of their child’s development. This, they propose, will reduce stress in the family.

Dale et al (2006) conclude that research has informed good practice as regards disclosing a diagnosis and providing appropriate information and allowing questions to be asked. However one area, which has been paid little attention, is the need to acknowledge the beliefs that parents have about autism and how this will influence the way they make sense of the information that we provide them. They suggest that “understanding attributions may enable greater
understanding of the decision making process parents engage in with regard to education and other interventions” (p 477).

2.3.5 Overview of impact of autism on families

A critique of the literature into the experience of raising a child with autism and the impact upon the family has been made. The evidence from previous research would suggest that autism has a profound effect upon families and presents them with unique challenges (Le Cavalier et al, 2006). It is proposed that autism should not be considered an isolated stress for the families. Instead it should be considered as pivotal within a cluster of stresses that accumulate and interact over time. (Marshall & Long, 2010). Autism is often described as a ‘hidden condition’ and parents perceive themselves to ‘live in a world of their own’ (Woodgate et al 2008). The literature reviewed stresses the importance of understanding the experience of raising a child with autism from the parents’ perspective.

A common theme reported in the literature is that there is a paucity of research which has directly explored the experience of parents, and the impact upon the family, when raising a child with autism. Family lives change when a child is diagnosed with autism (Gray, 1993; Werner, 2001; cited Luther et al 2005). Research has identified that families have a tendency to isolate themselves and avoid or are restricted from participating in normal everyday activities such as shopping, socialising and going on holidays (Randall & Parker, 1999; Dillenburger et al, 2010). The significant impact upon siblings of children with autism is widely accepted. However, Dillinger et al (2010) identify that there is a lack of information about the impact upon the whole family when a child has autism. Woodgate et al (2008) argue that research which aids our understanding of the parents experience will, in turn, facilitate professionals to “provide more comprehensive and sensitive care” (p1082)

The literature reported that family members, particularly mothers, experience high levels of stress which can impact significantly upon their mental health (Benson, 2006; Gupta & Singhal, 2005; Estes et al, 2009). Estes et al (2009)
argue that it is important to identify problem behaviours exhibited by their children in order that clinical support services can targeted at reducing them.

Previous studies have considered how parents make sense of their child’s diagnosis over time. There is a suggestion that the impact of attribution needs to be explored in future research (Dale et al 2006). Dale et al (2006) has identified that there is a lack of research into the impact of diagnosis upon parents, especially mothers. They conclude that professionals need to understand the process parents engage with when they are coming to terms with their child’s diagnosis. They hypothesise that this will facilitate better support for families.

2.4 Autism and Loss
There is a body of literature which explores the loss experienced by families following a disclosure of childhood disability (Ellis, 1989). Osborne and Reed (2006) suggested that an analysis of the literature, around the process of adjustment and adaptation, following the diagnosis, would promote our understanding of the needs of parents.

2.4.1 Models of grief and loss
There are different theories which exist to describe the grief process. They attempt to give an explanation of the way that people experience loss and bereavement. For the purpose of this research I am not going to make a comprehensive exploration of the different models of loss and bereavement. Nevertheless, I consider it useful to provide a brief overview of models of loss which are frequently referenced in the literature.

The Stage Model of Loss (Kubler-Ross 1969) is widely accepted and was initially developed to help terminally ill patients cope with death and bereavement. It suggests that when a person is bereaved they pass through five discrete stages: grief, denial and isolation, anger, bargaining, depression and acceptance. Kubler-Ross theorises that these stages provide a framework in which people learn to face their own death or cope with a loss. It is not proposed that everyone goes through all of these stages or does so in a linear way.
Worden (1994) suggests that when you experience loss you work through the Tasks of Mourning, these are described as:

- To accept the reality of the loss
- To work through the pain of the grief
- To adjust to an environment in which the deceased is missing
- To emotionally relocate the deceased and move on with life

Bowlby (1980) considers loss in the context of attachment. He suggests an alternative grief process and postulates that there are four phases to grief:

- Shock and numbness
- Searching and yearning
- Disorganisation
- Reorientation

Silverman and Klass’s (1996) ‘Continuing Bonds Model’ suggests that the “bereaved maintains links with the deceased, these bonds are not severed, but flow on into time” (Holland, 2001 p31). They do not think that loss and bereavement can ever be fully resolved. Instead the pivotal idea of the theory is that people still maintain a relationship with those they have lost.

Whilst these models are robust and well researched they have been developed through work with specific populations or individuals who have experienced a finite bereavement, the death of a loved one. When a child is diagnosed with a disability the family have not physically lost their child. Therefore theories of non-finite and ambiguous grief are more pertinent models of grief and loss to consider during this research.

2.4.2 Non-finite and ambiguous grief

Bruce and Schultz (2002a) define non-finite loss as an “enduring loss precipitated by a negative life event or episode that usually retains a physical presence, a psychological presence or both” (p 9). Ambiguous loss is described
by Boss (1999 cited Boss 2007) as “a loss that remains unclear”. Underlying her ambiguous loss theory is the notion that “uncertainty or a lack of information about the whereabouts or status of a loved one as absent or present, as dead or alive, is traumatising for most individuals, couples and families” (p 105). She theorises that the ambiguity prevents them going through a typical grieving process which ultimately results in closure. Families are unable to access the common rituals which would support them during their loss. Boss has found that when there is an ambiguous loss the support network for families, such as friends and neighbours, will distance themselves as they do not know what to say or how to help them. Instead, the individual or family have “no other option but to live with the paradox of absence and presence” cited Boss 2007 (p105). Indeed Gergen (2006) states that “the ambiguity ruptures the meaning of loss, so people are frozen in both coping and grieving” (cited Boss 2007 p106).

Research has been undertaken which explores the experiences of non finite loss for parents who care for children with disabilities. Boss et al (2000) and Bruce and Schultz (2001, 2002a, 2002b) have worked with families and developed our understanding of the grief and loss they experience.

Boss and her colleagues (Boss & Couden, 2002; Caron, Boss & Mortimer, 1999) studied the impact of chronic illness on families. They determined which specific elements of ambiguous loss contribute to distress in families. These are documented below:

- A lack of clarity in diagnosis.
- Difficulty in predicting outcomes
- Day-to-day changes in functioning of the ill person that affect family relationships.
- The fact that the ill individual may give an outward appearance of health thus raising expectations for his or her behaviour and functioning within the family.
- Fear that important emotional relationships will be affected by the illness.
Bruce & Schultz (2001), (2002a), (2002b) provide a rationale for the model of non finite grief through their work with parents of children who had been diagnosed with an intellectual or developmental disability. They explore the difference between coping with a finite loss, such as death, and a non-finite loss, such as disability and chronic illness. Bruce & Schultz observe that when the individual experiences a non finite loss they “endure painful and constant clashes between aspirations and reality”. They explain non finite loss to be “a grief that persists and changes as aspects of life continually fall short of expectations”. They suggest that the term “‘non-finite loss’ is the most apt we could find to describe the lifespan of grief of many of the families who entrusted their story to us” (2002 a p9).

Bruce & Schultz (2002a) discuss what they consider to be ‘crucial knowledge’ for those professionals who are working with parents whose child has received a diagnosis of a disability. Primarily they found that grieving is an ‘ongoing feature’ which never disappears when parents raise a child who has a disability. They note that there are certain triggers which will reignite the grief at certain times and they observe that the intensity of the grief feelings is inconsistent and can be more marked at certain junctures. Bruce and Shultz make the interesting comparison of the way mothers and fathers face the period after diagnosis. They observe that mothers are more likely to stay at home and experience almost constant exposure to their child’s needs. This is compounded by “being forced to compare and contrast her child’s development against normal environmental settings” (p10). Conversely, Bruce and Shultz argue that fathers tend to be in the workplace and are distracted. They hypothesise that whilst mothers become desensitised to their child’s disability fathers often feel grief at different times, for example, fathers often experience heightened grief when their sons reach puberty.

Bruce and Shultz (2002a) make recommendations for professionals communication with parents based upon their understanding of non finite grief following diagnosis of childhood disability. They stress the importance of
professionals working in partnership with parents and respecting their opinion and knowledge of their child.

2.4.3 Non-finite grief and autism
O’Brien (2007) draws direct parallels with the above elements and those experienced by the families of children diagnosed with autism. I feel that these are particularly pertinent to the current research. I consider it useful to provide an overview of her description of ambiguous loss for these families:

_Lack of clarity of diagnosis_
A diagnosis of autism is not straightforward. Despite an acceptance by professionals that there is a neurological and genetic component to the condition there is not a definitive assessment available. Instead the diagnosis is dependent upon behavioural assessment which identifies the presence of the triad of impairments in social interaction, communication and flexibility of thought (imagination) with onset before the age of three years. Diagnosis therefore requires that assessment takes place over a prolonged period in order that the child can be observed in different environments and situations.

Following the diagnosis parents often theorise as to the aetiology of their child’s autism. Many of the parents I work with categorically believe that certain environmental factors such as interventions at birth, exposure to immunisations or certain food types have contributed to their child’s condition. This often compounds the uncertainty and lack of clarity around the diagnosis for families. Waters et al (2008) reported that several interviewees in their sample reported that they “struggled with feeling responsible, that somehow, they have passed on autism to their child” (p 36). They give the example of one father who left the family home due to his strong feelings of responsibility.

_Difficulty in predicting outcomes_
A diagnosis of autism does not provide parents and families with an understanding as to the way in which the condition will affect their child. It is not possible for practitioners to predict how their client will present in adulthood or determine how the triad of impairments will impact upon them. As a practitioner
who has spent several years working with children with ASD I have accepted that each child needs to be viewed as an individual and the way they are affected by autism is unique, this is a difficult concept for families.

For many families the belief that there is a ‘cure’ compounds the ambiguity which surrounds the diagnosis. A simple internet search can identify several interventions and therapies which can ‘cure’ a child. Indeed, O’Brien observed:

“The challenge for parents whose children have ASD’s is to accept the reality of the permanent nature of their child’s condition whilst maintaining optimism about potential gains that can be made through effective intervention” (p 136).

A diagnosis of autism does not provide a family with assurances about their child’s future development. Practitioners can not predict how their child will cope with certain situations or be able to provide them with accurate predictions for long term outcomes.

**Day-to-day variability in functioning**

The nature of the condition means that the child will not present with a consistent pattern of behaviours. A challenge that can be easily overcome on one day can be insurmountable the next. The unpredictability of the child’s presentation impacts upon the family’s ability to plan for events. Similarly, an effective behaviour management strategy which can be applied on one day will not necessarily work on the next occasion.

Often children with an ASD have particular skills whilst experiencing more marked impairment in other areas. Such uneven profiles once again exacerbate the feelings of ambiguity experienced by families.

**Appearance of health**

Children with ASD do not look different to their peers. O’Brien & Daggert (2006) describe the difficulty that parents can have adjusting to a diagnosis of ASD when they have regarded their child as ‘typically’ developing in their formative
years. They note how a parents’ constructs of their child and their relationship with them alters. O’Brien & Daggert observe that a child’s apparently ‘normal’ appearance can, on occasion, lead the extended family to question the diagnosis. This may well reinforce the ambiguity that the parents are experiencing.

Loss of Relationship
The triad of impairments found in ASD impacts upon the relationship between the family and the child. Their response to situations and the level of care and attention they need alters the relationships within the family.

In order to test the validity of her theory O’Brien (2007) used a semi structured interview technique to explore whether families of children with ASD experienced ambiguous loss. She made a deductive qualitative analysis of the data and concluded that this was indeed the case. O’Brien (2007) argues that as a consequence of the ambiguous nature of the loss that parents experience it can never be resolved. She suggests that practitioners will not be able to facilitate the parents to ‘come to terms’ with their loss. Thus she concludes that applying simple grief models are not helpful when working with parents whose children have been diagnosed with autism.

In the second part of her study she considered the issue of ‘identity ambiguity’ in families of children with ASD’s. O’Brien (2007) defined identity ambiguity as occurring when the parents “are so preoccupied with their child’s autism that they are unable to view their own lives as independent from the difficulties their child experiences” (p 137). It was suggested that these parents will find it hard to decision-make about the appropriate interventions for their child and consider life choices for themselves. O’Brien (2007) found quantitative evidence to support her hypothesis that “higher levels of identity ambiguity in mothers are linked to higher levels of depressive symptoms and perceived stress independent of the severity of the child’s diagnosis” (p135).

Rogers (2007) made a qualitative study of the emotional dilemmas experienced by parents following their child’s diagnosis with a disability at an early age.
There were examples of parents of children with autism in her cohort. Following her analysis of the parents narratives she identifies that when told that their child has a disability parents experience an “emotional rollercoaster” that is driven by their perceived expectations for their ‘normal child’. She describes such expectations as “giving birth to a ‘normal child: the expected celebrations: the imagined future of the child: and the internalised norms of parenting” (p142). Rogers discussed in detail the emotions of loss, denial, shock and disappointment experienced by parents in her sample. She emphasised that such emotions are not experienced in a timely way indeed “these feelings can happen sporadically and occur in a messy unpredictable way which are repeated time and time again” (p142) Rogers made the observation that the unpredictable way in which these emotions reoccur presents a challenge to professionals when supporting the family through their grief. I found Rogers study to be very applicable to the current research and was interested in her findings. When reading it I was also aware that she had introduced herself as a parent of a child who had been diagnosed with a disability. Her unique insight into the topic was referred to in the article and undoubtedly added depth to her study but I would question whether it in any way influenced her findings?

Boushey (2001) gives an account of her experience of the grief cycle following her ten year old son’s diagnosis of high-functioning autism. Whilst I recognise that her comments have no statistical significance, and one can not generalise from her experience, I consider it useful to comment upon the grief cycle that she reports. Boushey documents her experience of an initial sense of loss for their typically developing child, to her eventual acceptance of being a parent of a child with autism. She describes her feelings of shock, when his difficulties were diagnosed, and then a period of denial that he was autistic. Boushey then groups the next phases of her grief cycle - guilt, shame and, isolation - explaining they were all feelings she experienced whilst going through depression. Boushey observed that she felt panic that she did not know enough about autism and she involved herself in a ‘quest’ for knowledge. She subsequently moved through the stages of anger and then bargaining before reaching a stage of acceptance and hope. Boushey explained that by studying the grief cycle and mapping her own experience onto it she realised that she
was “a normal parent who had normal reaction when told that my child had a disability” (p 30) She recognises that there are times when she still experiences different stages of the grief cycle. This supports an observation by Moses & Van-Hecke-Wulatin (1981) cited Ellis (1989) that parents of children with disabilities do not proceed through stages of grief in a specific order.

Swanepoel (2003) interviewed parents of children with autism and replicated Boushey’s findings. She observed that:

“Participants expressed varying emotions that are associated with stages in the grief cycle, namely: initial shock and denial, anger and resentment, depression and eventual acceptance” (p 41).

I hope to use this research to further develop this theoretical model of the grief and loss experienced by parents of children with autism.

I have already discussed Mansell & Morris (2004) research which assessed whether parents attitudes to the diagnosis of autism had changed over time. It is useful to revisit their findings as their sample also document the feelings of grief and loss reported by Boushey (2001) and Swanepoel (2003). Feelings of “shock, anger hopelessness, denial and confusion” were some of the initial reactions reported by respondents (p 402). A number of parents in their sample reported that their initial difficulty accepting the diagnosis did not change with time. The authors concluded that:

“The process of coming to terms with the diagnosis appears to involve accepting a child’s often serious limitations while also keeping in mind that improvement can occur under the right circumstances” (Mansell & Morris, 2004; p405).

The literature also investigates how the stress experienced by parents’ can impact upon their ability to engage with their child, parent them and effectively use the intervention strategies suggested to them.
A study by Wachtel & Carter (2008) cites work by Marvin & Pianta (1996) who observed that parents, who have not come to terms with the grief that accompanies the diagnosis of their child, can “find it harder to be attuned and responsive to their child’s cues” (cited p 578). They suggest that parents who have resolved their feelings have a more sensitive parenting style with a child with autism. Consequently, they predict that there is a better outcome for parent focussed interventions.

An older, but still relevant study, by Ellis (1989) examined the process that parents go through when they are grieving the loss of the perfect child. He favours a grief model put forward by Schneider (1983) which takes a holistic view of the process of grief and focuses on the motivation for growth and resolution of grief. Ellis (1989) gave examples of clinical cases of disclosure of disability, including autism, and used these to illustrate each of the stages proposed by Schneider. He concludes that professionals need to do more than simply acknowledge the feelings of grieving parents. He urges that they need to help the individual understand the grief process and help them through it.

Ellis offers guidelines for professionals to facilitate parents through the grief process. Amongst others, he stresses the importance of parents having the opportunity to tell their story and talk about the feelings they are experiencing. Professionals need to prepare families for the range of emotions which are expected and encourage them to be dealt with openly. Ellis recognises the importance of support for families and comments that successful grieving “appears to be dependent upon significant human interactions” (p 268). He suggests that professionals encourage people to ask for help or attend groups. Ellis asks parents to include their children in the grieving process and acknowledge that they too are experiencing a range of emotions.

2.4.4 Overview of autism and loss
Several different theories are offered in the literature to describe the way people experience the process of grief and loss (Kubler Ross, 1969; Worden, 1994; Bowlby, 1980; Silverman and Klass, 1996). Whilst recognising the value of
these models, I consider that theories of non-finite loss and ambiguous loss are more relevant when considering the grief of parents following a disclosure of childhood disability.

Ambiguous and non finite grief occurs when a loss is unclear and people are unable to go through a typical grieving process (Boss, 2007; Bruce & Schultz, 2001, 2002). Parallels have been drawn that families of children who are diagnosed with autism experience an ambiguous loss (O'Brien 2007). Evidence from personal narratives and qualitative studies of parents' feelings, in the period after diagnosis, has supported this view (Boushey, 2001; Rogers, 2007). O'Brien (2007) advocates that helping parents to understand the concept of ambiguous loss can be beneficial as this will help them to live with such a loss. Similarly if professionals understand ambiguous loss they can be more supportive and empathetic towards parents. The literature reports that parents experience a myriad of reactions to their child’s diagnosis of autism including shock, denial and confusion. My reading has identified a restricted literature which discussed the ambiguous loss experienced by parents when their child is diagnosed with autism.

When I conducted my review of the literature I observed that authors, such as Boushey (2001) and Rogers (2007), were also are parents of children with disabilities. This may have impacted upon their findings. This field of research may be enhanced by further evaluation of the emotional experience of diagnosis by a researcher who does not have personal experience of being the parent of a child with a disability.

2.5 Conclusion
This review of the literature has focused on three main areas:

- The experience of diagnosis
- The impact of autism on families
- Autism and loss
Through my analysis I have identified gaps in the existing body of research and considered methodological issues encountered in previous studies. In this final section of the literature review I will consider how this has guided the formulation of my research questions.

The experience of diagnosis

My review of the literature identified that there are a limited number of studies which have explored parents’ experience of their child’s diagnosis of autism. Authors such as Waters et al (2008) have called for further, similar research, to be conducted. I found that much of the existing research had explored the experience of small samples of parents. This led authors of previous studies to acknowledge that their research findings lack generalisability (Midence & O’Neill, 1999; Brogan & Knussen, 2003; Mansell & Morris, 2004; Osborne & Reed, 2008). Similarly, a number of the articles I reviewed reported research that was conducted in different countries (e.g. Woodgate et al, 2008; Chamak et al 2011) and this meant that their findings may not be relevant to the population in the UK.

In order to improve services and inform practice in the LA in which I work I need to gain an understanding of parents perceptions of the existing local pathway. I am interested to see whether my sample will comment upon factors which have been regarded as predictors of parental satisfaction in previous studies. For example, their communications with professionals and opportunities for follow up appointments to discuss the assessment (Nissenbaum et al 2002), the age at which their child is diagnosed (Goin-Kochel, 2006), the information they are given (Mansell & Morris 2004), and the support they have received (Osborne & Reed 2008). To this end my first research question is:

From the parents perspective what are the factors which contribute to a successful ASD pathway, in their locality, from identification, to diagnosis to intervention?
The impact of autism upon the family

The literature pertaining to the impact of autism on families highlighted the unique challenges they face (Randall & Parker, 1999; Le Cavalier et al, 2006; Marshall & Long, 2010). There is recognition that professionals are often unaware of the needs of the wider family, hence, more research is needed in this area. If professionals have an understanding of the needs of the family when a child is diagnosed with autism I would suggest they will be in a better position to support them. Thus, I consider it important to identify areas of unmet needs of parents, and their families, within the locality in which I work. I envisage that this will facilitate the identification of ways to improve the existing pathway. This has led to the formulation of my second research question:

Do parents perceive that any of their own, or their family's needs, were not met in the local ASD pathway?

Autism and Loss

The literature review identified a small number of studies that discussed the ambiguous nature of the loss experienced by parents when a diagnosis of childhood disability is disclosed (Boss et al, 2000; Bruce & Schultz, 2001, 2002). My third research question was formulated in response to the restricted literature about the feelings of grief and loss experienced by parents when their child is diagnosed with autism (Boushey, 2001; Swanepoel, 2003; Rogers, 2007). I particularly wanted to extend our understanding of ambiguous loss and autism (O’Brien 2007).

This led me to ask:

What feelings of grief and loss are experienced by parents when their child is diagnosed with autism?

Rogers (2007) recognised that parents of children with autism experience grief feelings “sporadically” and observed that they “can occur in a messy and unpredictable way, which are sometimes repeated time and again” (p142). Rogers (2007) acknowledged that the findings of her research were not
generalisable to a wider population but suggests that they can be used to give professionals an insight into the experience of parenting a child with a disability. She argues that a lack of support and understanding can ‘disable’ a whole family. Thus I would suggest that more research, which enhances our understanding of the emotional experience of parents when their child is diagnosed with autism, is required. This will facilitate professionals to support the emotional needs of parents and identify ways to improve the local pre-school diagnostic pathway. This has led to the development of my final research question:

To what extent does the ASD pathway help and support parents through the feelings of grief and loss which may accompany a diagnosis?
CHAPTER 3

METHODOLOGY

3.1 Introduction
In this chapter I restate the aims of my research and provide a justification for my methodology. I discuss the selection of my sample, the participants, my method of data collection and instrument design and describe my procedure. I provide a rationale for my method of data analysis and a critique of thematic analysis is made. I then consider ethical issues which I encountered when designing the research. I do not comment upon the limitations of the methodology in this chapter, these are discussed in detail in Chapter 5.

This research aims to explore parental perceptions of a diagnostic pathway, for the diagnosis and assessment of pre-school children with autism, in a Local Authority in the North West of England. An overview of the existing ASD pathway is described in detail in the Introductory Chapter. I want to investigate which factors, parents perceive, contribute to the success of the local diagnostic provision. I hope to determine whether the parents consider that any of their own, or their family’s needs, have not been met by the existing pathway.

I seek to investigate the feelings of grief and loss that parents may experience following a diagnosis of ASD. I want to find out whether the parents in my sample perceive that the current pre-school pathway provided them with emotional support their child was diagnosed with autism. Through this research I hope to make a wider contribution to understanding the feelings of grief and loss experienced by families who have a child diagnosed with autism.

3.2 Justification for Methodology
I recognised that when conducting my research I needed to ensure that the theoretical framework and methods I adopted would enable me to answer my research questions. I considered the different paradigms in the social sciences and their epistemological differences and adopted an interpretivist stance.
A paradigm is defined by Ritzer (1975) who states that:

“A paradigm …serves to define what should be studied, what questions should be asked, and what rules should be followed in interpreting the answers obtained. The paradigm is the broadest unit of consensus within a science and serves to differentiate one scientific community (or sub community) from another” (p7).

Robson (2002) describes the ‘paradigm wars’ which have been ‘endemic’ in social sciences in recent decades between positivists, who take a scientific, quantitative approach, and constructionalists, who are phenomenologists and qualitative researchers. I recognise that the debate about the advantages and disadvantages of different paradigms is beyond the scope of this thesis. However I consider it to be important to consider the difference between interpretivism and positivism.

Interpretivist paradigms study individuals and their varied characteristics, behaviours, opinions and attitudes (Cohen et al 2000). The underlying assumption of interpretivism is that in order to understand phenomena you need to examine the whole. Hence interpretivism proposes that there are multiple realities which can differ across time and place. By adopting an interpretivist paradigm a researcher endeavours to understand the situation as it has been construed by the participant.

Conversely the positivist paradigm places importance upon the precise measurement of phenomena. The researcher seeks to collect and analyse data from parts of a phenomena. Healy & Perry (2000) explain that in positivist research a quantitative measure is made of independent facts, hence there is a ‘single apprehensible reality’. They describe the researcher as looking at the world through a ‘one way mirror’ (cited Krauss 2005 p 760).

An aim of this research was to facilitate an exploration of the in-depth, personal views and experiences of the parents who had accessed the local pre-school
diagnostic pathway. Maykut and Morehouse (1994) comment that “it is human experiences and situations that are the subjects of qualitative research” (p3), similarity Bell (1993) observes that opting to use a qualitative perspective results in researchers being concerned with seeking insight and comprehending individual perceptions of the world. Qualitative research allows you to focus upon the detail and quality of an experience and enables you to understand an experience as it is constructed by the participants. If I had adopted a positivist paradigm I do not consider that I would have been able to gain a deep understanding of the parents experience and their feelings throughout the diagnostic process. I therefore concluded that the epistemological approach I had to adhere to was the interpretivist paradigm.

I looked to the literature for guidance on conducting interpretivist research. Angen (2000) provided useful criteria for evaluating research which has an interpretivist perspective. I have endeavoured to adhere to his suggestions that:

- When formulating and articulating the research questions there needs to be careful consideration
- The inquiry should be conducted in a respectful manner
- The researcher must be aware of and articulate the choices and interpretations they make during the study. They should evidence that they have taken responsibility for these choices.

Angen (2000) argues strongly that the interpretivist researcher must have regard for ethical and substantive validity. Ethical validity can be achieved through the researcher considering whether the research is helpful to the target population, seeking out alternative explanations to those they construct and questioning whether they have really learned something from their work. Angen (2000) suggests that in order to have substantive validity there needs to be evidence of the interpretative choices the researcher has made. There also needs to be an assessment of the biases which are inherent at each stage of the research. Angen calls upon the researcher to be self reflective and seek to understand their own transformation in the research process.
I want to obtain the parents perceptions of the effectiveness of the local pre-school ASD diagnostic pathway. The research can be described as a formative evaluation as I have the intention that my findings will be used to develop and improve the service offered to families. Robson (2002) notes that “evaluation intrinsically is a very sensitive activity where there may be a risk or duty of revealing inadequacy or worse” (p 202). He stresses that researchers conducting evaluations must carefully consider what they are doing and why. He states that “the contentious issues are who does this, for whom, in what way and for what purpose” (p202). I considered this and concluded that as I have not been commissioned to undertake this evaluation I can have confidence that the interests of families who receive the service are being promoted. I envisage that the research may highlight areas for change in the existing system. Therefore it will be important that I communicate my findings to commissioners within the Local Authority and the multi agency team as well as fulfilling the requirements of the university.

I will be conducting research within the setting I normally work therefore I will be regarded as an ‘insider’. I recognise the advantages of such research, namely I will have:

- Prior knowledge of the context both now and historically.
- A knowledge base obtained through working in the system.
- An understanding of the ‘politics’ of the system in which I work.
- Access to those people who will facilitate my research.
- “Street credibility” through being known in the organisation.

(cited Braun and Clarke (2006) p382)

However it is important to consider the disadvantages of being the ‘insider’ when conducting research. For example:

- I had to consider the impact being both a researcher and a colleague can have during the research.
If I obtained confidential information about colleagues’ practice during the research this must not impact upon working relationships.

Should mistakes be made during the research they will be known in my workplace.

Issues around maintaining objectivity.

Grady and Wallston (1988) cited Robson (2002) discuss these issues and suggest the following principles to adhere to when conducting insider research:

- Try to foresee likely conflicts.
- Make a plan and deal with them.
- Record your responses.
- Where possible get the collaboration of researcher colleagues from outside the situation

I felt it to be important to discuss my proposed research with colleagues as I would be an ‘insider researcher’. I recognised that there were potential conflicts to being both a researcher and practitioner in the local authority in which I work therefore I needed to minimise these. I discussed my research with a group of EP colleagues prior to finalising my methodology.

I met the group at our office base. With their consent I made handwritten notes which documented the salient points of the discussion. I outlined my research, discussed my proposed methodology and addressed ethical considerations. I shared the draft questions I intended to ask the parents and used the discussion as a vehicle to obtain their views as regards their appropriateness.

I was particularly mindful that the sample of parents I selected would have children who were currently on my colleagues’ caseloads. In partnership with colleagues I formulated a contingency plan which could be followed should any issues be identified. A protocol was agreed should the parents express concerns about the service they had received from our team or unmet needs be identified during the interviews.
The discussion generated with the group of EP colleagues has helped to shape my final methodology for this research project.

3.3 **Selection of Methods and Instrument Design**
My research questions require me to gain rich, detailed data to enable me to understand the participants’ experience of their child’s diagnosis of autism. Thus I selected semi-structured interviews as the most appropriate method of data collection to answer all of the research questions.

**Semi structured interviews**
Potter and Hopeburn (2005) describe semi structured interviews (also called conversational, active, qualitative or open ended interviews) as one where you are:

> “Guided by a schedule of topics or questions, although their order in the interview may vary and interviewers are likely to depart from the schedule and use a variety of follow up questions (or comments, responses or some other contributions)” (p 283).

Potter and Hepburn (2005) make a critique of semi structured interviews and observe that they have become the ‘technique of choice’ for the qualitative researcher in psychology. They suggest that researchers have taken their use for granted and do not tend to justify their appropriateness for the study. In this case the semi structured interview schedule was designed to act as a guide whilst giving me the scope to vary the wording of my questions dependant upon the participant’s responses. It was envisaged that the semi structured format would encourage the participants to structure their responses rather than give a ‘yes’ or ‘no’ answer to my questions.

I looked to the literature for guidance as to how to compose the interview format. Robson (2000) urges the researcher to pay careful thought and preparation to the semi structured interview schedule in order that you utilise the time allocated
to the interview to maximum effect. He suggests that the schedule is used as an ‘aide memoir’.

Robson (2000) considers the importance of considering how to word open ended questions such as those which I hoped to use in my semi structured interview. He states that the wording of the questions should:

- “Allow the interviewee to respond in their own terms. It should not seek to pre-specify the dimension on which response is made.”
- “Be clearly understandable to interviewees”.
- “Be sensitive to the possible effects of questions. It is clearly impossible to predict all possible reactions to a question. However forethought and knowledge, both of the situation and those you are interviewing can help you to avoid many pitfalls.”

Robson (2000) page 92

When devising the questions the researcher must be sensitive to the possible effects of the questions on the interviewee. This will be particularly true in this research as the topic may be very emotive for the families.

Randal (1996) cited Randall & Parker (1999) produced a ‘Survey of Met and Unmet Needs in Respect of Families and Autism’ to seek information, from families in Hull, about their experience of the diagnosis of their child. His questionnaire was subdivided into eight different areas. It required parents to answer open ended questions and complete simple rating scales to provide information their met and unmet needs. Randall (1996) sought parents’ views about their early experience of seeking a diagnosis and also of finding resources and information. Questions were compiled to determine the child’s present clinical profile and these were related to current stressors for the family.

The questionnaire Randall (1996) compiled is lengthy and was designed to be administered, by interview, over 2 to 3 hours. Many items in the survey were not applicable to my research, for example the clinical presentation of the child
and access to adult services. However the subsections on ‘Diagnosis of Autism or Related Disorder’ and ‘Family Service’ were relevant to my research as they explored the parents’ perceptions of their experience of diagnosis, the support they had received and their feelings when they received a diagnosis. I adopted many of Randall’s (1996) original questions and formulated additional ones, namely around the assessment day and impact on the family. I used these to design a semi-structured interview schedule which could be used as an aide memoir when I interviewed the parents in my sample (see appendix 5).

3.4 Selection of the sample

I used opportunity sampling from the database held by the Multi Agency Autism Team to identify parents who would be willing to participate in the research. An opportunity sample consists of identifying people who are available at the time of the study who meet the criteria I am looking for. Therefore, in this case I wanted to identify parents, in the local authority I work in, who had a preschool child who had been diagnosed with autism or ASD during the past two years.

Opportunity sampling is popular due to its ease and economic benefits. However, there are potential difficulties which must be recognised. It can produce a biased sample as the researcher can approach people they know well or are from their own social and cultural group, there is a risk that it is not representative of the target population. Similarly, people may opt not to participate therefore one must consider whether the sample is biased as those who have chosen to participate are particular types of people. To this end when I consider my findings I must recognise that themes can only be applied to this small group.

Approximately 24 pre-school children have a multi agency autism assessment via the pathway during a typical year. To minimise any bias I removed the names of parents who had children that I had directly assessed in my role as Educational Psychologist. As I wanted to explore the feelings of grief and loss that families experience when their child is diagnosed with autism I also removed the names of children who had not received a diagnosis. I therefore
had a relatively small number of families, approximately 20, from which to select parents to participate in the research.

When considering the size of my sample for this research I was mindful that I would amass a large amount of rich, detailed, qualitative data from each parental interview. To enable me to familiarise myself with the data prior to my analysis I intended to transcribe each interview myself. I recognised, from previous research that I had conducted in my doctoral studies, that transcription is a long and time consuming process. This guided my decision to opt for a small sample. Similarly my review of the literature had identified that similar, qualitative studies had tended to have small sample sizes. Indeed one of the most referenced studies, Midence & O’Neill (1999), had a sample of four parents. Thus, in discussion with my research supervisor it was agreed that I would invite 10 parents to participate in my study.

Gaining consent for participation

I initially sent the parents a letter which outlined my research project and explained that I would be contacting them to request their involvement in the study (see appendix 3a). I then followed up with a phone call to discuss the research further and obtain their informed consent to participate. A letter confirming our appointment was then sent (see appendix 3b).

3.5 Participants

Eight parents agreed to participate in the study. The sample consisted of 6 mothers and 2 fathers from different families. Their children had all received a diagnosis of autism or ASD in the past two years and accessed the local preschool diagnostic pathway for autism.

The local CDU have strict guidelines about the age at which children can be seen in their clinics. Thus, the Pre-School Multi Agency Team can only work with children up to the age of 4 years and 11 months old. To this end, the mean age that the children of the participants in the study were diagnosed with autism was 3 years 3 months old and the range was 22 months. Consequently my
research will be focusing upon the experience of parents who have received a relatively early diagnosis for their child.

To provide the reader with contextual information about the participants I have provided a pen picture of each of their families. These can be found in Appendix 4.

3.6 Procedure
I made appointments to meet the parents, in their own homes, and conduct the semi structured interviews. Prior to the interview commencing I gave the parents an information sheet about the research and obtained permission to tape record their interviews.

I used the interview schedule detailed in Appendix 5 as an aide memoir during my discussions with the parents. This allowed me to be flexible and I did not have to ask the questions in a prescribed order. The literature emphasises the importance of forging a good relationship with your interviewees as it can enhance the quality of the data you obtain. The parents were all very willing to talk to me and I was able to develop a good rapport with them. I endeavoured to ensure that I was “empathetic and committed”, showed interest and was non judgemental during the interview (O’Connell et al 1994).

Each interview I conducted was audio taped and I took detailed handwritten notes. The duration of the interview was approximately 60 minutes, although in one case I spent over two hours with the family.

As all of the appointments took place in the homes of the participants there were some interruptions such as phone calls and visitors calling. The interviews were conducted during the day time so, in some instances, there were young children playing and TV noise. This resulted in background noise on the recordings. The detailed notes which I took to accompany the tape recordings were therefore invaluable during the transcription of the interviews.
At the end of the interview I spent some time with the parents and debriefed. I agreed to follow up any issues which had arisen during my interviews. For example, in one instance I referred a sibling to our local Young Carers organisation for support.

### 3.7 Data Analysis

Having taped and made notes during the eight interviews I had amassed a significant amount of qualitative data.

Qualitative data is described by Miles (1979) as an “attractive nuisance” cited Robson (2002) p455. It is regarded as attractive as the data, which usually consists of words, is viewed as rich and detailed when compared with that obtained by quantitative means. It is said to be a ‘nuisance’ as collection and analysis can leave the researcher open to unforeseen difficulties. Robson (2002) draws a comparison between qualitative data and ‘codified common sense’. He accepts however that as humans we have inbuilt biases and deficiencies and therefore must adhere to a ‘systematic approach’ when we analyze qualitative data. As a researcher using qualitative research methods one must be aware of the potential problems inherent in the approach. Robson (2002) provides a helpful summary of the work of Sadler (1981) as to the nature of such deficiencies. These include the possibility of data overload, the effect of your first impression, internal inconsistency, uneven reliability and confidence in judgment. See Appendix 6 for full text.

Tesch (1990) investigated the different ways that qualitative researchers describe their analytic approach. She obtained a list of forty six different labels from which she suggests four groupings:

- “The characteristics of language”
- “The discovery of regularities.”
- “The comprehension of the meaning of text or action.”
- “Reflection”

(cited Robson, 2002 p457)
Miles and Huberman (1994) cited Robson 2002 document several common features of qualitative data analysis. These can be identified as follows:

- Coding your original materials e.g. observations, interviews etc.
- Producing a memo in the form of adding a comment or reflection.
- Identification of common themes, relationships, phrases etc.
- Using the above commonalities to enable you to make further data collections.
- Drawing together generalizations to explain the consistencies you identify in the data.
- Formalising these to become constructs and theories.

I paid careful attention to which qualitative approach to adopt when addressing each research question. My research questions were exploratory in nature and related to each other. Each question necessitated me to seek the views of parents about their perceptions of their child’s diagnosis of autism. Thus I considered it to be sensible to use one qualitative approach to analyse my whole data set, rather than use different methods for each research question.

I considered the use of different approaches – content analysis, grounded theory, and Interpretative Phenomenological Analysis (IPA) – before I concluded that a thematic analysis was best suited to this research. I present a brief overview of each approach below and consider their appropriateness for this research.

A widely used qualitative research technique is content analysis. It is a flexible approach with researchers tending to adopt a conventional, directed or summative approach to their analysis (Hsieh & Shannon 2005). The key difference between each approach is how the initial coding of the data is made. For example, in a conventional content analysis, codes are derived from the data as opposed to a directed content analysis where the coding of the data is guided by pre-existing theory. A summative content analysis looks for keywords
in the data which have been guided by the existing literature, or the interest of the researcher. If I had adopted this approach I felt that a conventional content analysis would be the most appropriate of the three for this study. My codes would be defined during the analysis, rather than led by existing theory or my knowledge of the literature.

Grounded theory is another extensively used approach for qualitative data analysis. It endeavours to develop a theory that emerges from the researcher’s observations and interviews in real life situations, as opposed to those which are formulated in formal hypothesis testing in the laboratory. It begins with a research situation in which the researcher tries to understand what is happening. The researcher is required to conduct their data collection and analysis concurrently to enable them to develop their theory until they reach the point of saturation. In previous research I had opted to use a grounded theory approach to make an analysis of the data I had obtained. Although I had adhered to the prescribed method for making the analysis I would support the observation of Holloway and Todres (2003) that:

“Such analyses do not appear to fully subscribe to the theoretical commitments of a ‘full-fat’ grounded theory which requires analysis to be directed towards theory development”. (cited Braun & Clarke, 2006, p81)

Interpretative Phenomenological Analysis (IPA) takes an idiographic focus, it aims to describe the personal experience, in a specific context, of a particular phenomena. Studies which adopt IPA usually have a small number of participants who have been selected to give the researcher insight into a specific topic. Typically the data to be analysed in IPA studies is rich and detailed, often a transcript, and has been collected via techniques such as interviews, focus groups or diaries. The researcher generates codes from the data rather than using the existing theory and applying it to the data. I concluded that whilst IPA would be an appropriate and useful method to adopt when
analysing my data I wanted to use an approach that I was already familiar with. Thus I opted to analyse the data by making a thematic analysis, a method I had used in previous research as part of my doctoral studies.

3.7.1 Thematic Analysis – an overview

Daly, Kellehear & Gilksman (1997) describe thematic analysis as “a search for themes that emerge as being important to the description of the phenomenon” cited Fereday & Muir-Cochrane (2006, p3). Floeresch (2010) states that:

“Thematic analysis is a commonly used qualitative method to identify, report and analyze data for the meanings produced in and by people, situations and events” (p 3).

They refer to Boyatzis (1998) who, amongst other things, said that thematic analysis functions as:

- “A way of seeing.”
- “A way of making sense of seemingly unrelated material.”
- “Away of analysing qualitative information.”
- “A way of systematically observing a person, an interaction, a group, a situation, an organisation or a culture.”

cited pg 2 Floersch et al (2010)

Willig (1999) (cited Braun and Clarke 2006 p 81) states that there are three different types of Thematic Analysis:

1. Essentialist or Realist Method – this reports what has happened to the individual and their reality of the situation and what it means to them. It documents the experience.
2. Constructionist Method – looks at the way our understanding of society impacts upon events, our understanding of reality and our meaning of the world.

3. Contextualized Method – this acknowledges the way the individual makes sense of their experiences whilst recognizing that our understanding of society and its contexts impacts upon this.

In this research I have taken an essentialist or realist method as I want to report the parent’s perception of their experience of their local ASD diagnostic pathway.

The Process of Thematic Analysis

Braun and Clarke (2006) are frequently referenced in studies that employ thematic analysis. Floersch et al (2010) note that until recently, with the exception of Braun and Clarke (2006), there has been little in the literature “that specifically delineated the steps for conducting thematic analysis” (p 3). I therefore looked to the literature to find other examples.

Fereday & Muir-Cochrane (2006) discussed the methodological approach of thematic analysis by describing how it can be used to interpret raw data. Fereday & Muir-Cochrane (2006) describe the process of thematic analysis in detail using the example of ‘Feedback of a Self Assessment of Nursing Practice’. They provided a step by step description of the procedure, presented in the figure below, to represent each stage of the coding in thematic analysis.
They provided a comprehensive exemplar of the process and concluded that they had “provided an illumination of the steps involved in the process of thematic analysis and described an approach that demonstrates rigor within a qualitative research study” (p9). Another, very simple and readable, description of the process of thematic analysis is provided by Brikci & Green (2007) in a handbook of qualitative research produced for Medecins Sans Frontieres.

I found Braun and Clarke’s (2006) descriptors of the six distinct phases in data analysis to be most suitable for the current research. They describe them as:

1. **Familiarizing yourself with the data** – this involves the transcription of your data and repeatedly re-reading it to ensure you are very familiar with
its contents. During this phase the researcher may make some initial notes about the data or the way they may wish to code.

2. **Generalizing initial codes** – during this phase you read through all of the data and make initial codes. Coding is executed by writing with different coloured pens or post it notes to highlight particular pieces of data. Ensure that all of the data has been coded. You begin to organize the data in a meaningful way looking for repeated patterns in the data – this will lead to your themes.

3. **Searching for themes** – once you have coded and collated all of the data you then try to sort them into possible themes. It is recommended that you use visual means to record this, such as mind maps or tables, which allow you to consider the relationship between codes and themes.

4. **Reviewing themes** – this has two levels:
   - Level one – you re-read all of the coded extracts and determine whether they form a coherent pattern.
   - Level two – consider whether your themes are valid in relation to the whole data set and produce a ‘thematic map’. It may be necessary to revisit your data and review your coding to accommodate any additional data.

5. **Defining and naming themes** – for each theme you collate extracts from your data and present them in a consistent way with a narrative. It is then necessary to discuss why the theme is of interest and explain why. You will produce a name for each theme and identify any sub themes that have emerged from the coding.

6. **Producing the report** – this commences when you have a full set of themes. You present interesting data extracts to illustrate the themes and provide a narrative that relates the themes to your research question.
Issues with Thematic Analysis

Despite its apparent simplicity when using the method of thematic analysis one needs to be aware of the potential limitations of the technique. Braun and Clarke (2006) draw the researcher’s attention to a number of ‘potential pitfalls’.

Primarily, there is a risk that the researcher fails to actually analyse the data and merely presents extracts from the data without using them to illustrate their findings, or fails to make any analysis beyond their immediate content. When analysing my data I recognised the importance of providing a narrative which would illustrate that I had made a critical analysis of the data and considered my findings within the context of the research in the area.

When conducting a thematic analysis it is imperative that the researcher does not simply rename the interview questions as themes. You need to illustrate how you have analysed the responses you have been given to formulate the themes. Similarly, one must ensure that you have robust evidence from the data to illustrate your themes. You therefore have to demonstrate that you have considered all of the data and not small pieces which ‘fit’ your theme. If you do not consider the above the end result will be a “weak or unconvincing analysis” Braun and Clarke (2006) p 94.

The researcher who makes a thematic analysis must ensure that the data extracts are consistent with their interpretation. That is not to say that the data should totally support all of the themes. An analysis which does not illustrate any exceptions should be viewed with a degree of suspicion.

Finally it is important that the analysis clearly sets out its theoretical assumptions and provides a clear description of how it has been carried out and for what purpose. Without this crucial information even a thorough and interesting analysis will be lacking.
Brikci & Green (2007) give some helpful guidelines for good practice when making a thematic analysis. They emphasise the need for transparency by urging the researcher to state their methods clearly and consider whether others could replicate the work. They propose that the researcher needs to provide a clear account and justification of the procedure and ensure that there is an ‘audit trail’ that others can follow. Brikci & Green (2007) suggest that notes and transcripts should be made available for independent inspection to ensure transparency. An example of a transcript from this research can be found in Appendix 7.

Brikci & Green (2007) propose that one way to maximise the reliability of the thematic analysis is to use more than one analyst or coder. I have adapted this suggestion and following my initial coding and collation of the themes I asked a colleague to independently collate the initial codes. I would hypothesise that such triangulation will enhance the reliability of my interpretation of the data. Conclusions that are made from a thematic analysis must be based on supporting evidence. Bricki & Green (2007) remind researchers that inclusion of evidence which contradicts their themes will also maximise validity.

It could be argued that a weakness of a thematic analysis methodology is the absence of measurable quantitative date. Floersch et al (2010) acknowledges that thematic techniques do not test for statistical significance. Hence they observe that the significance of themes must come from “(1) skilful identification of new themes and confirmation of themes identified in the extant literature and (2) confidence in the systematic nature of the coding procedure” (p3). I therefore am mindful that in my analysis I need to be systematic and draw comparisons to previous findings in the literature wherever possible.

At the beginning of the Results and Discussion Chapter I have included a step by step description of the thematic analysis I executed when I analysed my data. I offer a personal reflection of the different phases of thematic analysis described by Braun and Clarke (2006).
3.8 Ethical considerations

When undertaking this piece of research there will be significant ethical implications. As an EP undertaking research I need to be committed to the British Psychological Societies (BPS) ‘Code of Ethics and Conduct’ (2006). The code is based upon the Ethical Principles of respect, competence, responsibility and integrity. Similarly I have regard for the University guidelines.

Fox & Rendall (2002) observe that one’s ethical position is socially constructed and only meaningful when you look at the context in which you are working. They state that “participants views of what an educational psychologist does, and their values and their attitudes inherently affect the research and at the same time affect the ethics of the process” cited p 63. Interestingly, they discuss the case of parents of children with ASD and the way in which they respond when asked to participate in a research project about their views on the EP. It is imperative that I clarify the professional role I will assume as researcher and ensure there is no conflict of interest in my role as the Educational Psychologist.

A criticism of EP research could be that we focus on groups of people who are not in positions of power such as parents or children with SEN. Fox and Rendall (2002) argue that the reason we do not conduct research with those people who hold high-powered positions is that they recognise they can not control the study therefore will not participate. The parents who are the focus of my research may be viewed as a ‘disempowered’ group and it is therefore very important to me that high ethical standards are maintained.

It is essential they understand that their comments will be used to illustrate points and I will interpret what they say for a wider audience. I must have their informed consent and ensure that they understand my neutrality, even if I have already worked with the families in my capacity as their early years EP. Participants will be assured that should they wish to withdraw their participation at any time they have a right to do so and/or decline to answer particular questions. This would in no way influence their future relationship with the Psychology Service.
I was concerned that all of the participants in this evaluation would know that they were involved in a research project and that they had given voluntary informed consent to take part. I was mindful that by informing the participants of the way I will use their input I may have inadvertently promoted anxiety and biased the information that they gave me. Similarly, I considered how I would respond to any unmet needs or significant areas of concern raised by parents as I did not want to raise their anxieties and not be able to provide a follow up. The BPS (2006) stress the importance of debriefing research participants, this is particularly pertinent for this cohort as the subject of the discussion may arouse feelings of distress about a difficult time in their lives.

Sieber (1998 cited Robson 2000 p 31) observes that:

“An individual’s understanding of the consent statement and acceptance of his or her status as an autonomous decision maker will be most powerfully influenced not by what the individual is told but by how he or she is engaged in the communication”.

To this end I asked the families whether they would be willing to participate in my research. All of the families agreed to be included in the sample. They were given assurance about issues surrounding confidentiality and anonymity. I also considered it to be important to obtain informed consent from my colleagues. I discussed my research with EP colleagues and ensured that members of the Multi Agency Autism Team were fully informed of my proposed research.

I was aware of the inherent power relationship between researchers and the sample. In order to minimise the ethical problems of imbalanced power relationships when I was collecting my data I tried to use methods which were non-invasive and non-confrontational and recognised the potential vulnerability of my sample. I considered the location and time of the data collection and the power relationship between the researcher and the parents.
When conducting my research I ensured that effects of age, gender, disability, ethnicity, language, education, marital or family status or sexual orientation were considered and did not cause a power imbalance.
CHAPTER 4

RESULTS AND DISCUSSION

4.1 Introduction

I begin this chapter with a description and critique of the thematic analysis I made of the data. The results are then reported under the main themes identified in the analysis of all the data. An exploratory and in depth discussion of the results is made in relation to the existing body of literature. I then present the key findings in the Summary and Conclusion Chapter (Chapter 5) and reflect upon them, with reference to the original research questions.

Eight parents were interviewed to determine their views of the current diagnostic pathway, for pre-school children with Autism, in a local authority in the North West of England. The research aimed to explore parental perceptions of the diagnostic pathway and investigate which elements of the existing pathway the parents’ value. It sought to determine whether they feel that any of their own, or their family’s needs, have not been met by the pathway.

The study aimed to explore whether the parents in my sample experienced feelings of grief and loss when their children were diagnosed with autism. The study also investigated whether this cohort of parents’ perceived that the existing ASD pathway supported them through the feelings of grief and loss which may accompany a diagnosis of autism. The interviews were tape recorded, transcribed and a thematic analysis (Braun & Clarke 2006) was made.

4.2 My Thematic Analysis

As discussed in the methodology there is a dearth of literature around thematic analysis, indeed Braun and Clarke (2006) is one of the few papers which gives a step by step guide to the process. Braun and Clarke also discuss a number of decisions that the researcher takes when making a thematic analysis, they argue that these need to be made explicit in the methods section of research papers. To give the reader an insight into my thought processes at each stage
of my analysis I have provided a description of my thematic analysis and a personal reflection. This is documented below under the six phases of thematic analysis described by Braun and Clarke (2006).

**Phase 1**

Braun and Clarke (2006) had stressed the importance of familiarising yourself with the data and cautioned against the temptation to “skip over this phase or be selective” (p87). I took the decision to transcribe all of the data obtained at interview myself. I would agree with Bird (2005) that transcription is “a key phase of data analysis within interpretative methodology” (p227). The transcription was, at times, a laborious task, but one which helped me to immerse myself in the data. I was concerned that my sample was too small, however I would now question whether a larger amount of data would have allowed me to have the level of familiarly I had with the data throughout the analysis.

I was reassured by Braun and Clarke (2006) that when transcribing interviews for a thematic analysis the researcher does not have to adopt a specific way of recording such as the ‘Jefferson’ system. I endeavoured to make an accurate account of the spoken word and ensured that I recorded punctuation correctly so I did not lose the meaning of what had been said. I showed pauses and noted any interesting non verbal occurrences which I had recorded when note taking during the interviews, for example, crying or laughing. Once I had transcribed an interview I listened to the tape recording and refined and checked my written transcription for accuracy. I have enclosed an example of a transcribed interview in Appendix 5.

**Phase 2**

I made an inductive analysis of the data and endeavoured to code the data without any preconceived ideas about the themes that would emerge. This was a challenge as I had immersed myself in the literature and had thought about
possible themes as I transcribed the interviews. After my initial transcription and note taking I left a period of time, approximately five weeks, before returning to code the transcripts. I consider that this enabled me to take a ‘fresh look’ at the data.

I opted to make a data driven analysis of the entire data set rather than focussing upon a theory driven one which would have given a ‘detailed and nuanced’ account of one particular theme or themes which emerged from the interviews. I re-read all of the transcripts and referred back to the initial notes I had made when transcribing. I then manually coded each transcript and wrote on the original transcripts. There were instances where I coded the same extract several times as it could have different meanings.

Once all of the transcripts were coded manually I then made a list of initial codes (see Appendix 8) and went back to the electronic transcripts and cut and pasted each extract under the appropriate code. I ensured that I preserved the context of the coded item by keeping some of the surrounding text when I was collating them. This was undoubtedly a long and very frustrating procedure but one which I felt was invaluable as it helped me to become even more familiar with my data set.

**Phase 3**

Braun and Clarke (2006) define a theme as *capturing “something important about the data in relation to the research question, and represent some level of patterned response of meaning within the data set”* (p 82). They reassure the researcher that there is not a prerequisite for the amount of data you need to have to count it as a theme. You therefore have to use your judgement as a researcher and ensure that you employ consistency when making an analysis

Having coded and collated all of the transcripts I then started to look for themes in the data. I did this by writing all my codes on separate pieces of coloured
paper and set them out on the floor. I then made a first attempt at putting them into theme piles. From this sorting emerged an initial thematic map which is documented in the figure below:

![Initial Thematic Map](image)

**Figure 2. Initial Thematic Map**

Braun and Clarke (2006) criticise thematic analyses which have identified themes which simply reflect the questions they asked their sample. I spent several hours considering potential candidate and sub themes and manually moving them around on the floor as I thought of the relationships between them. I have taken photographs of the different stages of this organisation to illustrate how I did this (see Appendix 9). During this process I refined and developed my thematic map. See Figure 3 below:
Figure 3. Refined Thematic Map

Phase 4

I identified an initial set of candidate themes, ‘support’, ‘communication’ and ‘feelings’ and a number of sub themes related to each category. I then began to refine these themes by looking back at the coded extracts and seeing whether they fitted together and were coherent. I found myself unable to reach a stage where I was satisfied that my thematic map was a true reflection of the coded data. Braun and Clarke (2006) warn against the pitfall of involving oneself in ‘endless re-coding’ and observe that the researcher needs to recognise when further ‘fine tuning’ does not add to the analysis. Indeed at one point I felt that I had made my map too simplistic and had lost the essence of my data set.

My colleague had agreed to independently collate the initial codes. We met after she had done so and I was encouraged that her sorting of the initial codes was
not dissimilar to mine. I then reviewed the themes one more time before moving onto defining and naming themes.

**Phase 5**

I returned to the computer and moved the coded data under each theme. I looked individually at each coded extract and decided whether it captured the essence of the theme and started to organise them into a coherent storyline. As I began to refine that data, I changed the names of some of the sub themes to help me structure the candidate theme. I analysed the coded extracts as I worked, moving them around and discussing why they were of interest to me. I was aware that the final report could not contain all of the coded extracts but opted to keep them all in the body of the text at this point as I wanted to identify the most striking examples when I produced the final report.

During this phase I started to think about the names I would give to my final themes. Braun and Clarke (2006) suggest that these need to be “concise, punchy, and immediately give the reader a sense of what the theme is about” (p93). These are documented in the final thematic map below.

![Figure 4. Final Thematic Map](image-url)
Phase 6

Braun and Clarke (2006) distinguish between the researcher identifying themes at a semantic/ explicit or a latent/ interpretative level. I had looked at the words that my interviewees had said, coded and organised them into themes and then, in the final phase of the analysis I attempted to relate them back to the previous literature. I did not try to examine the underlying meanings of what they had said therefore I would argue that my themes were identified at the semantic level. I have provided lots of data extracts to illustrate these themes but have been careful to produce a narrative which is not merely descriptive. Wherever possible I have provided contradictions which I found in the data.

When completing the final write up I was aware that there had been instances where I had ‘double coded’ extracts, I was mindful that there should be no replication. I have tried to make use of the powerful words the parents used to describe their experience of their child being diagnosed with autism. I had expressed concern to my supervisor, prior to my analysis, that a lot of the data I had obtained was very emotive and I was mindful that this was an academic paper I was writing and not a magazine article. I therefore had to give careful consideration as to how to capture the essence of what the parents said without producing a report which was overly sentimental.

Concluding comment on Thematic Analysis
The six phases of thematic analysis documented by Braun and Clarke (2006) gave me a protocol to adhere to when I analysed my data. The detail they gave in their descriptors of each stage has enabled me to say, with confidence, that I have made a ‘true’ thematic analysis. This critique clarifies the process I used and has given me the opportunity to raise some of the challenges I encountered in the analysis.

4.3 Presentation and discussion of findings
To give the reader an understanding of the context in which the parents comments were made I have detailed the current diagnostic pathway in the Introduction Chapter. In Appendix 4 I have provided a brief pen picture of each
of the interviewees’ family and the agencies that were working with around the time of diagnosis.

The key findings are reported under the two candidate themes, Knowledge and Loss, and the sub themes which emerged from the analysis of the qualitative data. These are illustrated in Figure 4 above, however, for convenience I have presented them again below.

![Final Thematic Map](image)

**Figure 4. Final Thematic Map**

### 4.4 Knowledge
This section of the results and discussion is presented in three subsections which reflect the sub themes identified in the analysis. These are:

- Acquisition of knowledge
- Communication of knowledge
- Quality of knowledge

These are represented in the figure on the next page:
4.4.1 Acquisition of knowledge

Parents reported a growing awareness of an initial concern
Seven of the eight parents reported that prior to involvement from professionals they had an awareness that that their child’s development was not typical. This supported the findings of Midence and O’Neill’s (1999) pilot study where all of the parents had reported that their child’s early development was ‘different’ to what they expected. Similarly, Waters et al (2008) had reported that in 63% of cases in their study the first concerns were raised by parents.

The nature of the early concerns, such as rituals, lack of eye contact, language acquisition and behaviour, reported by parents are widely discussed in the literature (Goin & Myers, 2004; Howlin & Moore, 1997; Osborne & Reed, 2008). The parents in this study made similar observations:

I started to notice the little things, like Ollie loves cars and started lining them up together, if one was moved out of place he would get really upset about it, nobody else could touch them (Katie)

He would only have his bottle a certain way he wanted to have the numbers so he could see it while he was drinking it. (Ravi)
Going to the group over at the school he wouldn’t join in the songs. If I sang he would put his hand over my mouth and try to shut me up. He would scream at everybody, like…” don’t sing, I don’t want to hear it’. I used to have to come out of the room: I had to stop going. (Sylvia)

Two of the parents reported changes in their child’s behaviour and intoned that their skills were regressing:

He was slowly but surely going into his own little world. That was the worrying thing because he used to say things to communicate, then it was that slow regression, it was quite a while before you noticed. (Debbie)

The first things we became aware of was the fingers, looking at her fingers and she slowly stopped finger feeding, paying attention to you and smiling.. things like that. She went from a bubbly, happy, little girl to a little girl who literally would sit in the corner and wouldn’t get out of it. She spent all day in the corner .. facing that way … (Scott)

Prior to any professional input two of the parents, Lisa and Scott, had suspected that their children were autistic, reflecting Nissenbaum’s (2002) observation that, whilst many parents had identified something unusual about their child prior to the diagnosis, only a few suspected they had autism.

Amber and Jane reported that they had realised, with hindsight, that there were indications that their children were not developing typically. However they explained that they, and others, had normalised the initial indications that their child was experiencing difficulties. Both had been told not to compare their child’s development with other children. This added weight to a finding made by Waters et al (2008) that many of the parents in their sample were advised, by professionals, not to compare their child to others. They question such a philosophy and voice a parent’s observation that a developmental check is all about comparison and the identification of norms.

Amber explained that she had some low level concerns about her son’s speech and toileting but this was the ‘beginning and the end’ of her concern. She
described how shocked she was when presented with paperwork to sign giving permission to access support for her son:

She asked me to sign one of them, no mention of autism at this point, I said well if I am going to sign it, can I read it. She looked at me, she warned me, she said I have been quite strong here, if I don't he is not going to get any help. I was absolutely flabbergasted .. it said he just lies on the floor, he gives nothing, he only responds to babble, he is in a world of his own and it was just really, really painful to read. It wasn't the Noah that I would see at home, but in a different environment, that is where he struggled.

Concerns voiced about the time taken to acquire knowledge.
Having identified that their child was not developing in the expected way many of the parents in the sample reported a sense of urgency around getting a diagnosis:

If it's going to help the child .. you just want them to get the help straight away .. just get on with it. (Amber)

The period between the identification of the initial concern and the diagnosis of their child was criticised by the parents in the sample. Many parents reported that, after they had raised their concerns, they had to wait a long time before they had an initial contact with a member of the multi agency team:

I don't know that I have met any parents who didn't want it [the diagnostic journey] to be faster. Everyone that I have spoken to has said 'oh it just takes so long' that is their main complaint. (Scott)

This was a common theme identified in previous studies (Water’s et al 2008). Howlin & Moore (1997) found that satisfaction with the diagnostic process has a strong correlation with the length of time you have to wait to receive a diagnosis. The parents I interviewed stated different reasons for their frustration about the length of time it took. For some it meant delayed access to resources:

It's just the whole process takes too long .. really .. there is so much time in-between where you are thinking…What's
happening here… when is he going to get his ADOS test .. why is it taking so long for his statement to come through.. that was a long time to wait.. we were missing deadlines cos we wanted to get him into school in the new year to start with. When it started to go into February we knew we would have to wait until the new academic year. (Amber)

Jane simply wanted to know what was wrong with her child:

Em I thought it was too long because I would have liked to have known sooner, it was just the not knowing what was wrong .. I would just like to have known sooner.

Ravi was an exception, he felt that the time taken to diagnose his son was acceptable. He valued having the time to prepare himself for his son’s eventual diagnosis:

It was alright for us, we took it gradually, as I told you before we didn’t really expect that he would have some problems anyway…it was ok .. gradually it happened… it was not all of a sudden we got the news.

Scott and three other parents found it frustrating that families were asked to repeat their stories several times and aired the view that this made the process much longer than it needed to be:

If you have five people to talk to… you go to the first person and you say my child is autistic and she does this, she does that and they say ‘ok, alright then you need to see such and such a person’ and they say ‘can you tell me a bit about your child’.. and it just drags like.. it’s like groundhog day… it really is groundhog day .. honestly because you have so many people to see and you have to say the same story over and over again.

This reflected the views of parents interviewed by Waters et al (2008). Parents in their study reported a negative view of the assessment process because it was, amongst other things, characterised by “long waits, repetition of basic information” (p20). Scott offered a simple solution to the problem:
You could do with some sort of report being written down so it saves a whole day of your wasted time to try to get them up to speed with what has been going on. That would be a really good help that, you know, some sort of intervention thing on the computer, a report so people who are involved in the process could access and dip into that report could look at it and add to it and keep it up to date. I mean it is not difficult.. anyone with half a brain could setup that kind of system.

There are existing government strategies such as Early Support and the Common Assessment Framework in place to ameliorate these problems but I know, from my own practice, that professionals still insist upon making their own, initial assessment. The detrimental effect upon the family of repeating their concerns several times needs to be addressed.

A recommendation was made by Waters et al (2008) that parents would benefit from being given a written diagnostic pathway so they gained a sense of where they are in the process. Whilst I can see the benefit of this I would argue that for some of the parents we work with, pre-school, much of the pathway has already been navigated before they are aware that we are assessing for autism, this needs to be considered by the multi agency team.

The diagnostic assessment

The diagnostic assessment is undertaken after professionals, following a multi agency work up, determine that it is appropriate to consider a formal diagnosis of autism. The current diagnostic pathway involves the child attending the CDU at the local hospital and having an ADOS assessment that is administered by a paediatrician and a speech and language therapist. Following a short professionals’ meeting the diagnosis is shared with the family on the same morning. All of the parents I interviewed spoke about the assessment morning.

The act of having the assessment was perceived by the majority of the families as being very important:

It was that definitive thing that meant you could launch yourself in the right direction at last and we all knew what was
wrong, we keep being told ‘we do think that this is it’ but we won’t know for definite until the ADOS. (Katie)

The ADOS was like freedom wasn’t it? It was like putting a stamp on it, it’s definite he has got that and that is it. (Sylvia)

The emphasis placed by professionals on making a diagnostic assessment was criticised by Scott and Sylvia:

That’s where the problem lies and it’s too much focus on one particular event. Everything is like a spider’s web, everything hinges on that one event and it shouldn’t be like that. Things could get done sooner if you let them (Scott)

The usefulness of receiving a diagnosis
Knowing that there was a reason for their child’s difficulties helped many of the families for a variety of reasons. Four of the parents in my sample reported that the diagnosis was important because they were able to access resources:

One thing is that we got all of the organisational support once we got the diagnosis and we understand that this organisation will work with us and will help him when he grows up. He will get better educational support (Ravi)

The only advantage of getting the diagnosis was getting a nursery placement and some more intervention from the speech and language therapist. (Lisa)

These comments are in line with Waters et al (2008) who reported that their interviewees had said that the most useful thing about getting a diagnosis was being able to access services and support, often via a Statement of Special Educational Need. Similarly, Howlin & Moore (1997) said that 30% of the families they surveyed considered help with education was the main benefit to them. My research focussed on pre-school children who, in the local authority I work in, do not need a Statement to access additional support in their nursery year. I would suggest that this meant that the educational support that parents accessed as a result of diagnosis was less clearly defined for them.
Many of the parents commented that a diagnostic label helped them to understand their child’s needs:

*It’s helped to have a diagnosis, before…. not knowing…. I couldn’t help Tom because I didn’t know or understand what was wrong. Now that I do it’s a lot better, a lot easier.* (Sylvia)

*I can understand a lot more and I can help her and it’s not like before when I thought maybe she is just a little bit lazy.* (Jane)

*It was a good thing because I could finally say .. put something to it .. say he is not a bit behind there is something wrong. It’s not terrible twos. Now I could say he was autistic.* (Katie)

The realisation that their child was autistic increased their confidence in their parenting skills. Amber commented that she had felt responsible for her son’s behaviour but receiving the diagnosis gave her a reason for the way he behaved and reassured her:

*It certainly helped me. .. I feel less of a failure really .. cos em when he was younger and repetitively doing things that are slightly irritating in other peoples houses… like opening and shutting doors and you would say ‘Noah now that’s enough’ and he wasn’t listening to me. I kind of felt like perhaps I was doing something wrong .. I am a bad parent .. you know what I mean. Now I feel reassured that actually he is quite a good kid considering all these problems that he faces on a day to day basis.*

Amber also said that getting a diagnosis of autism meant she could explain her son’s difficulties to people. Half of the parents in my sample reported this to be the case:

*Just being able to tell people now when we are out. … he is doing this because he is autistic, he is not being naughty, he is autistic, then if people want to look and stare then that is their problem. We know that he isn’t being naughty so it is fine. It is that kind of confidence which takes time to build up. But I am at that place now.*
The comments made support previous findings in the literature. Waters et al (2008) had reported that prior to diagnosis parents frequently questioned and criticised their parenting and felt they were to blame for their child’s behaviour. Similarly, Midence and O’Neill (1999) had observed that the period prior to diagnosis was a distressing and confusing one; parents felt guilt and blamed themselves for their child’s behaviour.

A more cynical view was put forward by Scott, to him, receiving a diagnosis merely reinforced what he already knew:

> It’s like stamp, stamp, stamp stamp stamp, there you go sir, you have an autistic child .. we believe you! Look…proof she is not just a naughty kid.. give me the t-shirt.

Osborne and Reed (2006) found that half of the parents of pre-school children they spoke to did not find anything helpful about the process of receiving a diagnosis. A similar percentage of the parents in my sample echoed this finding. Lisa articulated that receiving a diagnosis was not helpful:

> All it did was give me the name of what I thought was up with him ..autism.. It wasn’t helpful because I didn’t know what to do once they had told me.

She had expected to be given advice about living with autism from the professionals:

> They tell you nothing. You are not told to do this. You are not told to do that, you are not told about the sleeping, about the smearing, you are just told it is autism.

Sylvia and Katie voiced similar opinions to Lisa, knowing that her child had autism did not necessarily change things:

> It’s still the same, nothing has changed really. (Sylvia)

> They explained what autism was but not what to do next. I was thinking of the next step .. ok he’s autistic .. where do we go from here? (Katie)
One of the parents, Ravi, said that the family had not really wanted a diagnosis but he acknowledged that it helped him to access support:

No it was really hard, we didn’t want any label.. because it is helping him to get his support it is good but otherwise personally we don’t want a label.

Parents in Midence and O’Neill’s (1999) study highlighted the importance of a label. They reported that it helped them to know what their child’s difficulty was and what to do. The parents in my sample put forward a different view. Parents questioned the usefulness of professionals giving a label of autism due to the diversity of the condition:

That’s the only downfall of giving someone a label, especially something like autism, it is diverse, you won’t find two autistic children the same, so I don’t like have confidence in anyone. How can anyone be that knowledgeable about autism. it’s so diverse. (Debbie)

I think it’s one of those conditions that no one understands. (Sylvia)

Stop labelling people… it’s such an umbrella spectrum that it is not understood by anybody. (Scott)

I think because autism is not very clear cut, it is such a massive spectrum it takes a long time to get to know your child’s needs, doesn’t it? (Amber)

### 4.4.2 Communication of Knowledge

**The effect of initial communication with professionals**

The effects of communication of knowledge emerged as a sub theme from my analysis of the transcripts. The parents in the sample reported that their initial communication with professionals had a significant impact upon their overall impression of the diagnostic process.
Some of the parents found it difficult to get professionals to listen to their concerns. This theme is well documented in the literature. Midence and O’Neill (1999) reported that many parents were initially given incorrect diagnosis, or advice, when they sought help. They gave an example of a parent being labelled ‘neurotic’. This happened to Lisa:

> When they said I was making it up, it was awful, it made me feel horrible, it made me think I was a bad mum and that I was trying to make excuses but I knew that I wasn’t. In my own way I did have good parenting.

Goin & Myers (2004) noted a similar trend in the literature and reported the frustration that some parents had experienced as professionals had dismissed their concerns and opinions about their child. Waters et al (2008) reported that many of the parents in their study described getting professionals to take them seriously was ‘a battle’. Three of the parents raised their initial concerns with professionals and were told that there was nothing wrong with their child. They felt that their concerns were dismissed by the health visitors and they were not being listened too:

> I wasn’t being listened too,….that got to me….I kept saying ‘there is something wrong’. (Debbie)

> I think they put it down to my age, with being quite young …. I was hitting a brick wall every time and I knew that something wasn’t right.(Lisa)

> It was just the process of getting somebody to listen which was an absolute joke. (Sylvia)

Sylvia and Debbie emphasised that parents need to have their concerns taken seriously, even if professionals do not share the opinion of the parents. Debbie referred to ‘battling’ for a diagnosis, she challenged the health visitor and threatened to complain about her. This supported one of the findings made by Graunegaard & Skov (2006) who observed that parents who have encountered a difficult diagnostic process consider that they have ‘fought’ for the child.
Lisa did not feel able to challenge professionals. Waters et al (2008) reported that receiving a diagnosis made parents, who had not been believed, feel vindicated. This was true for Lisa, she told me that she would now have the confidence to go back to speak to those professionals who disregarded her initial concerns:

Now he has been diagnosed I feel like turning round to everyone that did push me away and say ‘look I was right and you were wrong’ you can’t do that though, but yet they still think they were right because they don’t know.

The other parents in the sample did feel that their initial concerns had been listened to. Ravi spoke positively about his initial communication with the health visitor explaining she shared his concerns and was supportive. Scott and Katie told me that whilst professionals listened to their concerns and agreed with them the manner in which they dealt with them was abrupt:

She was quite abrupt and she said “I think there is something wrong here. Do you think she might have autism, have you ever thought about that?” .. it just .. it was wrong at the time. (Katie)

Preparing parents for a diagnosis of autism
The multi agency assessment team work with families in the months prior to their ADOS assessment. There is an expectation that prior to the assessment day families have a clear understanding of what will happen on the day and that likely outcome of the assessment will be a diagnosis of autism. This is not explicitly written into the pre school diagnostic pathway but prior to the family being offered an assessment the professionals discuss whether the family is ‘ready’ for diagnosis.

Most of the parents reported that they had a clear understanding of what would happen during the assessment. Conversely Lisa told me that she had not understood the purpose of the ADOS. She told me that she had tried to help her son during the assessment and had intervened in the activity, she observed:
If I had known what to expect during the ADOS they wouldn’t have had to tell me to shut up half way through the assessment. They said ‘be quiet and don’t intervene’. If I had been told in the letter I would have known to sit back and watch.

Despite receiving a detailed description of what would happen on the assessment day many of the parents reported that it had not been made explicit by professionals that their child could receive a diagnosis of autism. This replicates the finding of Bruce & Schultz (2002) who stated that in their experience parents tend to have “little or no conception of what they are about to be told” (p 12).

Katie and Sylvia said that although they had not been explicitly told that their child would be assessed for autism they knew that this was the case:

No one, before he was assessed, said he was going to be assessed for autism. It wasn’t really said. I knew, I knew fine well. I had a good idea he was on the autistic spectrum because I had done a lot of research myself. You know looking at the tick boxes…I knew he was on the autistic spectrum just about but none, not one person said he is being assessed for autism. (Katie)

No, no, not at all. Like I say, they never said he was being assessed for autism. If I was someone else it might not have crossed my mind, it would have been devastating. (Sylvia)

Osborne & Reed (2008) found that parents in their sample spoke of hearing words, such as autism and Asperger’s syndrome, being ‘bandied about’ prior to the actual diagnosis. Indeed Amber acknowledged that the possibility of autism had been discussed but she had dismissed it:

It was three months prior to the ADOS test that the word autism had been used. It was just ruling out autism. I think it was the Doctor, he said he just had this ADOS test and it was to just rule out, you know autism, to pick up on it. It was only mentioned briefly the once. We needed to know that but I suppose I was in denial. I thought Noah needed speech therapy and that was it ....
Amber and Katie did not feel that they had been psychologically prepared to receive a diagnosis:

> It just felt to me .. it just felt like we weren’t prepared. If someone had offered us some counselling prior to receiving the diagnosis I think I would have coped better.

> I wasn’t prepared before I went for the feedback .. we just had to come home and just deal with it like we did do.

These comments reinforce the findings of Mansell & Morris (2004) who reported that some of the parents they surveyed felt strongly that they had not been prepared for the diagnosis. Consequently, in their local area, changes have been made in the way that they prepare parents for diagnosis. Professionals engage in a one to one session with the parents prior to the assessment and ‘venture’ the opinion that the child may receive a diagnosis of autism. They hypothesis that this preparation will help facilitate parents ability to resolve and adapt to the eventual diagnosis.

**The way in which professionals ‘shared the news’**

All of the parents in the sample commented upon their communications with professionals on the day their child was diagnosed with autism.

The literature emphasises how important the experience of sharing the news is for parents and discusses the crucial role that professionals have at this time (Waters et al 2008, Brogan & Knussen 2003). Bruce & Schultz (2002) found that the words used when making a diagnosis “mark the beginning of their [parents] trauma” they comment that “in retelling their trauma individuals return to these words again and again” (p 11). The entire sample I interviewed recalled, with clarity, the actual disclosure that their child had autism.

The importance of the manner in which professionals shared the news was identified by Champak et al (2011). They reported that the delivery of the diagnosis affected parent’s ability to cope. Brogan & Knussen (2003) concluded that parents gave a higher satisfaction rating of their experience of diagnosis if they felt positive about the manner of the professional who made the disclosure.
of autism. Debbie’s comment encapsulates the responsibility that is placed upon the professional to get this right:

*It was just the attitude of one professional but he had the most important job at the time.*

The manner in which information was communicated to families during the sharing the news session was referred to by seven of the parents. Six of the parents in my sample gave negative examples of the way the news was shared:

*It was just unbelievable how so…so detached this man was surely that’s not the first time he has told parents that.* (Katie)

*Just the way it was said .. very, very casual, very abrupt.* (Sylvia)

*It wasn’t something we didn’t know it was the way it was delivered. It was artificial .. it felt that it was done because we had to do the paperwork. He wrote it down, it was quite insulting really, he wrote AUTISM in big capital letters and said that is what he has got” … it was like he was thinking “and you would never have known!”* (Debbie)

The views I obtained from the parents in my study reiterated Nissenbaum et al (2002) finding that the language professionals used when giving a diagnosis was important. Some of their cohort also said that it was stated too bluntly. Similarly Chamak et al (2011) found that “some parents are still feeling the impact, remembering every word in detail, the expressions, the manner and the style of delivery” (p94).

I would also suggest that the comments made by many of the parents in my sample could be interpreted differently in the light of Bruce & Shultz’s (2002) observation that:

*“Professionals are so familiar with the breadth, depth and content of their knowledge-base that they themselves will sometimes underestimate the emotional impact of the information that they deliver to parents”* (p 11).
I agree that professionals routinely give diagnosis and have observed, first hand, the devastating effect it can have on the parents, even those who are well prepared for a diagnosis.

The professional’s ability to show empathy to the parents was something all the sample commented upon, regardless of whether they had done so successfully or not. This replicated Graungaard & Skov’s (2006) findings that empathy was a dominant parental expectation when communicating with professionals. Jane and Ravi felt the assessment day and disclosure of autism was made easier by the manner of the professional:

“They were just nice, understanding and said it was ok to cry and stuff. (Jane)

It was a long day… they were very supportive in the way they were…we found most of the things were positive. Everyone was very helpful and understanding. (Ravi)

Graungaard & Skov (2006) said that “parents expected the health professionals engaged in their situation [to have] the ability to feel the impact their words were having on the family’s life, and to let it show” (p303). Debbie did not report a positive experience:

And then, when he said right .. this is autism.. I got , you know a bit upset and the stupid man, turned round and said ‘why are you upset’. I said ‘I beg your pardon’. ‘why are you upset?’.
You have got someone who is making you feel as though you are a freak because you are upset. To me I can’t understand why anyone would question why you are upset in that situation. Especially, someone in his position, he must have done....seen parents upset. Because I am not as upset, I can say what I was thinking now…. [starts crying].

I would suggest that the negative comments made by parents were due to the nature of the information that was being communicated to them. A neutral observer may interpret the disclosure in a different way. This supports Nissenbaum et al’s (2002) view that when parents react to the diagnosis they express dislike or anger towards the person who shared the news. It could be
hypothesised that other people present at the sharing of the news, for example the Portage worker or Specialist Nurse Practitioner, would give a more neutral response when asked to describe the manner of the professionals making the disclosure.

**The effect of the language used by professionals**

Professionals must ensure that the information they are conveying is accessible to parents when they are communicating with them. Nissenbaum et al (2002) emphasises that it is vital to use clear language that parents understand. Four of the parents in the sample expressed the view there were certain things they did not understand. Jargon and acronyms were used by professionals and they were not explained to them. Debbie commented that:

> I think they could have worded things better for me. Instead of using normal words they used words they would when talking to other professionals.

Lisa told me that she had wanted to ask questions but didn’t want to appear ignorant:

> You look like you don’t know very much if you ask questions. You are expected to know it but I didn’t really know what autism was.

Lisa explained that she did not have the confidence to say that she did not understand the terms that professionals were using when they spoke to her:

> They just assume you know what they are talking about. I was going along with it saying ‘yeah’ and when they said they were going to try PECS it was only then I said ‘what actually is it’. I am not stupid but they always use these long words and I agree and say ‘yes’ but I don’t always know what they mean. I just wish they would take longer to explain things, to tell you what they actually mean.

Sylvia shared this view:

> PECS, ADOS – I didn’t know what the hell it was…When they first said I was going to get an ADOS assessment everyone
Jane and Sylvia both commented that the paediatrician who diagnosed their children used medical language:

I didn’t understand anything that he was saying...he was talking in Dr speak, it was out of a medical book, it could have been more parent friendly. (Jane)

At the feedback meeting it would be better if they would talk normal, not like talking to another doctor. (Sylvia)

The views obtained by my sample support Chamak et al (2011) who emphasised the importance of information being explained in straightforward language and found that it helped parents accept the diagnosis.

**Seeking and receiving knowledge about autism**

Osborne and Reed (2006) had found that the parents of pre-school and primary aged children had a strong desire to be given information about autism at the time of diagnosis. Indeed Graungaard & Skov (2006) report that information seeking is widely used as a problem solving strategy and has been shown to have a positive effect. All of the parents I interviewed spoke about the importance of having access to information about autism when their child was diagnosed.

The literature discussed what type of information should be available to parents after diagnosis and considers when it should be given. The NAS suggests that a limited amount of information is given to parents at the point of diagnosis.

Debbie’s comment supports the prevalent view held that information should be made available at the parents own pace. She recognised that different families have different needs:

*Information should be there ready for the parents in case they do want it straight away. I think lot of parents would find it useful.*
Seven of the parents reported that following the diagnosis they were given some initial written information by the multi agency team. Some of the parents felt overwhelmed by the information. Amber and Ravi did not feel able to take in all of the information:

*It was such a heavy read.. you are just not in the state of mind .. my mind was swirling. I couldn’t even put one foot in front of the other, you know all these questions were coming into my mind ….all of these ridiculous things rather than concentrating upon the here and now and all the practical things which are going to help Noah (Amber)*

*We couldn’t get it all into us because..we are in a different situation .. we are not in an emotional state to hold information. It was hard for them to explain to us .. they tried to explain everything to us but we were not in a mood to hear. (Ravi)*

These comments reinforce Bruce & Schultz’s (2002) assertion that professionals should not underestimate the emotional impact of receiving a diagnosis. They state that “we are aware that even a careful choice of words is liable to wreak havoc, because the emotional intensity of the experience places severe limitations on an individual’s ability effectively to process what is being said” (p 11).

Sylvia also commented upon the myriad of information that was available and said that it made her feel stressed. She would have liked the information to be given to her in ‘bite size pieces’.

Five out of eight parents expressed dissatisfaction with the information that they had been provided with since the initial information at diagnosis. This supports Osborne & Reed (2006) who reported that a high proportion of parents in their sample did not feel they had received help, support or advice about autism. In Whittaker’s (2002) research he noted that a lack of information was the most frequently expressed unmet need for his cohort.

Lisa still feels that she has not been given information about autism:
It’s like if I had had someone to speak to and things to read, now, two years down the line I wouldn’t feel as I do now, wouldn’t feel so down, and so lost in this little bubble as I am. I think it would have been really good if I had had a better understanding of autism. I only understand it by watching Jayden growing up every day that is my understanding of it.

She felt strongly that the professionals had a responsibility to share their knowledge of autism with parents.

The parents I interviewed gave examples of the type of information that they wanted. Many said they wanted information about what to do having received a diagnosis of autism. Debbie’s comment encapsulated the feelings of the sample:

You need a bit more information about what you are going to do when you get back home. Once you get off the bus or out of the car. It’s like you sit down and say ‘right, do we do anything different?’

Lisa wanted strategies from professionals but these are not forthcoming:

The paediatrician… I tell him about the things that are hard, he just sits there, sits back and observes him and every time I go to him I ask for help or suggestions he just says to me ‘carry on doing what you are doing, you are doing all that you can do’. That’s not what I want. I want some help and advice, I want to hear that I can get help with this or here are some strategies not ‘carry on with what you are doing’.

Ravi wanted to know about other ways to help his child:

If there were any private programmes that can help us or how good they are we would like to know …they are very expensive… we can’t afford it ..if it is good for him could we get it from the government…we wanted more info about it.

Jane said that:

I just wanted to find out what it is and why she has got it, was it genetic?
The parents gave suggestions as to the type of information that should be made available to parents in the future:

A book of guides! They should have told me to expect temper tantrums, to expect smearing: I was never told that it was to do with autism. I just thought he was disgusting. I think they should have given me a step by step guide maybe to expect this, it might not happen, but it might. (Lisa)

Just a couple of phrases about how other parents had felt might have been useful. (Amber)

All of the parents told me that increasing their knowledge base was very important to them. Many parents gave examples of them searching for information:

I can’t resist every time I turn my lap top on. (Debbie)

My partner is on the internet a lot of the time, my friend gave me a book to read about autism. (Jane)

My husband spent a lot of time [on the internet]. yeah, most evenings he would be looking up the subject and trying to differentiate between autism and Aspergers and trying to find out where Noah fits and what the score meant and .. what possibilities there are for him really. (Amber)

I wanted to find out about autism myself. (Sylvia).

I would suggest that the parents in my sample collected information about autism for two reasons. As well as being a means of finding out about autism it was also a coping strategy. This conclusion is well supported by previous research. Graungaard & Skov (2006) identified various different coping strategies that the parents in their sample used. One of these was the problem-focused one of collecting information. Marshall & Long (2010) suggest this strategy has many practical purposes including lessening feelings of powerlessness. Whittaker (2002) commented upon “the very conspicuous thirst for information about autism” in the parents he interviewed (p419). He also postulates that information gathering is a parent’s way of dealing with their
significant emotional needs. Whittaker suggests that parents consider this to be more acceptable than expressing the need for emotional support.

Osborne & Reed (2008) cautioned against parents seeking their own information. They found that when the parents in their study had sourced their own information it was often ‘negative in nature’ and there was a tendency for it to provoke negative reactions and make them worry. The parents in my sample wanted information therefore I would argue that professionals need to consider how to meet this need.

4.4.3 Quality of Knowledge

The effect of the professional’s knowledge of autism

Some of the parents in the sample questioned the professional’s knowledge of autism. A lack of professional knowledge about the ‘Red Flags for autism’ emerged from the information that the parent’s gave in their interviews. An example of the Red Flags for Pre School Children can be found in Appendix 10.

Goin-Kochel et al (2006) consider why clinicians hesitate before acting upon initial concerns raised by parents. They hypothesise that one explanation was a lack of knowledge and quoted research by Shah (2001) that had found fourth year medical students scored less than five out of ten on a questionnaire about autism. More recently, Boyd (2010) has called for professionals working with children to be made more aware of early warning signs of autism and know what to do if there are concerns. The comments made by parents in this study give weight to such a theory:

I went to the doctors with him and told him that I thought there was something wrong because he never used to look at you as a baby or react to anything with certain toys. ..I got told he had an ear infection, I got told he was teething and I got told by the doctor that I was an overprotective mother. (Lisa)

She came round a few times and had a look at him, she said he was frustrated. (Debbie)
I think I took him to the doctor at least five times and they kept on giving him antibiotics and he didn’t need them. Saying he was teething although he had every tooth in his mouth, nothing made sense. (Sylvia)

Debbie questioned the knowledge of the health visitor who first made contact with her and emphasised that they need to be able to identify concerns:

It has to start off with the health visitor they are the ones really that need some serious training on picking up on this. If I had been a different sort of person, who…. you know thought the health visitors word was god…. he wouldn’t have been diagnosed until 5/6 so I think that is paramount. That is where it all starts from.

I would fully support the view of Goin-Kochel et al (2006) that as the incidence of autism is rising, professionals, particularly doctors, need to be well informed about autism both during initial and ongoing training. Similarly Osborne & Reed (2006) urged greater professional training. The challenge is ensuring that this happens.

Parents views of the quality of information obtained in the diagnostic assessment

Some of the parents reported that they had been worried that professionals would not gain an accurate picture of their child on the assessment day:

What happens if she doesn’t act like she does, what happens if she has an extremely good day .. god .. we have never seen an extremely good day .. but the worry is still there cos you are thinking…. This might be when she does something so people won’t see what we are living with everyday. (Scott)

Brogan & Knussen (2003) said that it was important that parents “feel that their opinions, observations and fears are taken seriously by professionals, and they feel that their knowledge and understanding of their child is respected” (p44). Similarly, Graungaard & Skov (2006) emphasised the importance of professionals acknowledging that the parent was the ‘expert’ on their own child. The views of the families I spoke to support this finding.
Lisa did not feel that the professionals had a true understanding of the extent of her sons needs:

I wouldn’t say they understood my little boy after the assessment. He wasn’t having a bad day. It wasn’t as bad as what I see at home with him. Even though they gave him a score of 24 which is quite high I thought you could have given him more if you had seen him at his worst.

Conversely, Jane said that her daughter did not give a true reflection of her skills during the assessment:

It feels very frustrating, you want to get down on your knees and show them what she can do. I did have a chance to say what she could do but that’s not the same.

In one instance the decision was made to conduct the assessment in the nursery environment. Debbie valued that professionals had used their knowledge of her child and were flexible in order that an accurate picture of his needs could be obtained. Her view reinforced Graungaard & Skov’s (2006) finding that parents prefer a proactive and individualised service provision for their child.

Ravi was aware that culturally the ADOS assessment put his son at a disadvantage:

Em … the only thing that we felt was that some of the tasks were not associated with our culture, some items like the birthday cake he had never seen… so he wasn’t familiar so ..you know..there were no chances to tell people that. We don’t have birthday party..ours is a different kind of celebration.

Similarly he explained that:

English is not spoken in our home, so he wasn’t responding to the questions, he doesn’t understand because he is not aware of English as much. Most of the things were toy based so it was alright, but if we could have got it in our language it would have been better.
Ravi intonated that the families needs were overlooked and said that an interpreter would have helped them to express themselves more clearly. These comments need to be considered in the future assessments when working with families who do not have English as their first language.

**Lack of knowledge about autism in the community**

A particular challenge faced by the families was the way their child’s condition and behaviours were perceived by others. Put simply Katie said:

> They haven’t got a clue.

Scott told me how difficult it was to get people to understand the impact that autism had on his life:

> I have got to go down to the social later and I have to try to explain to them what autistic means because they haven’t a clue. They think.. hang on.. you can’t go to work because you have a child who will not listen in class.

Lisa explained that people she expected to have an understanding of the condition did not:

> Now when I go to my local GP he is trying to speak to him and I say ‘no he can’t speak, he has autism’ and then Jayden will be smashing on the table and banging on the computer and things and I notice that he moves things away but doesn’t seem to understand that he does have autism and he can’t help it. He asks me ‘can you get him to sit down so I can have a look at him’ it’s like maybe some autistic children can sit down and do what they are told but he can’t.

Many of the parents commented that autism is a hidden condition and people do not know their child’s needs just by looking at them. This brings with it its own challenges:

> They don’t understand.. to look at him he is perfect but they expect to see he has a bent arm or his face is twisted.. something in that respect. (Sylvia)
If she looked different, had a condition that people recognised, they would understand. You can have somebody that has Downs or you have a club foot for instance and you think ‘oh’ what a shame because you can see something, you can associate something, you can say, oh it must be awful she can’t walk properly. Then you have a little girl who seems normal, who looks normal, everything to the other person is normal and then they say ‘oh what a terrible little girl, oh, nightmare.. it’s the parents fault why don’t the parent, why don’t the parents give her a slap. (Scott)

Amber spoke about her sons unusual behaviour explaining:

*It makes perfect sense to us, knowing where he is coming from as an autistic person, it caused quite a lot of problems in public, we had to relax with that.*

These comments corroborate those made in the literature. Woodgate, Ateah & Secca (2008) spoke about the publics’ ignorance and their lack of sensitivity towards parents with autism. Gray (1993) also reported that parents of autistic children “frequently encounter hostile or insensitive reaction from the public when their children behave inappropriately” (p 103). They consider that this is exacerbated by the ‘normal’ physical appearance of their children. Gray makes the interesting observation that parents often make inferences about people’s opinion in these situations rather than the criticism being expressed verbally to them.

### 4.5 Loss

This section of the results and discussion is also presented as three subsections which reflect the sub themes identified in the analysis of the interview transcripts.

- Feelings of grief and loss
- Being supported through loss
- Loss of normal family life

These are represented in the figure below:
4.5.1 **Feelings of grief and loss**

There are numerous theories which describe the grief process. In the literature review I provided an overview of the most referenced models of grief and loss, the Stage Model of Loss (Kubler-Ross 1969), Tasks of Mourning (Worden 1984), Bowlby’s Attachment Theory and the Continuing Bonds Model (Silverman and Klass 1996). All of the descriptions given by parents I interviewed about their feelings, following a diagnosis of autism, indicate that they have experienced a significant loss. Many equated the experience to bereavement.

Analysis of the transcripts of the interview produced strong evidence that all of the interviewees were going through a process of resolution and adaptation to their new situation. Whilst I would acknowledge that the parents responses could be reported under each of the aforementioned models of grief and loss, I found that the Stage Model leant itself most readily to the information the parents gave me. This was similar to Boushey (2001) who made reference to feelings of shock and denial, anger, depression and eventual acceptance in her paper.

All of the parents made direct or indirect reference to the ambiguity of their loss. It was apparent from the transcripts that they were not experiencing the different
stages of grief and loss in a uniformed way. Instead they reported re-experiencing these feelings at different times as new situations arose.

**Shock**
The initial shock that parents experience when their child is diagnosed was validated by the cohort:

> The assessment day was shocking .. I mean.. I was still optimistic and I was thinking that it can’t be that [autism]…yes the diagnosis was shocking for us. (Ravi)

> I knew that he was going to be autistic, I had an idea..still we hoped that he is not..it was still shocking. (Sylvia)

> Nothing prepared me for the shock. (Katie)

> It’s a strange feeling, yes , it’s like when you know someone is terminally ill, you know they are dying but when they die it still hits you like a ton of bricks, it’s still a shock. It’s the same thing. I was expecting .. you know.. but it was still a shock and still upsetting. (Debbie)

> You just think it’s so bizarre, it’s like a bolt out of the blue. (Amber)

Parents intonated that the diagnosis of autism was life changing:

> You basically are telling something to someone which just changes everything. (Debbie)

> It changes things so much, it is absolutely ridiculous. (Sylvia)

Even Scott, who had felt very frustrated that his daughter took so long to be given a diagnosis and had told me that he knew she was autistic before the assessment commented:

> It really did bring it home .. even though we thought it .. it brought it home BANG (slaps his knee) and then….it was upsetting cos it was put like… we had concerns.. I had made the decision to give her a chance to live her life and see how she gets on and it was just like a big brick over the head basically.. boom she is autistic.
Ninety three percent of the parents in Waters et al (2008) research described feelings of relief when they were given the diagnosis. I had expected some of the parents in my sample to also report this, however, none did. I would hypothesise that as children in my sample were diagnosed at a much younger age than those in Waters et al's research the parents I interviewed had not experienced such a significant period of concern.

**Upset**
Three of the parents reported that they had displayed intense emotional reactions to the diagnosis and wanted to remove themselves from the situation:

*I remember sitting in that room and wanting to scream and shout and just cry and run out of the hospital but somehow I just held it together until I could go the toilet and cry in the toilet.* (Amber)

*His Dad wasn't happy, he started crying actually which was a big shock to be because he isn't like that.* (Debbie)

*When they said that one word I actually ran out crying.* (Jane)

Others reported the upset they felt when they got home:

*I just em .. fell apart for about forty eight hours. I just couldn't stop crying.* (Sylvia)

*I did get really upset when I got home, but obviously not there, in front of them.* (Lisa)

*I cried for an entire weekend after that I just got on with it.* (Katie)

Most parents continue to experience feelings of upset at certain times:

*Even now I have the days when I burst into tears and Ian says, what are you crying for..I just cry sometimes because I don't know what to do with him.* (Lisa)
Denial

None of the parents explicitly stated that they were in a period of denial however all of the cohort made statements which were coded as such in the thematic analysis.

A common theme that the parents reported was, that despite evidence to the contrary, they had convinced themselves that their child did not have autism:

Mmmm ...I don’t know really. emm it is hard to explain, even though I sort of knew it was like you convince yourself that he doesn’t display this, he doesn’t display that. (Debbie)

I think he was upset, gutted, he really thought there was nothing wrong with Gemma at all, he thought she was just behind with her speaking. (Jane)

I knew that he was going to be autistic, I had an idea, .still we hoped that he is not..it was still shocking. (Ravi)

I thought they were going to say well actually there is nothing wrong with him he is just a bit behind. He was just having some difficulties in some areas. That’s what I thought they were going to say ..His Dad still didn’t believe it. (Katie)

Three of the parents made comments that suggested that they continue to be experiencing denial about their child’s condition, a significant period of time after the diagnosis. Two example of this were:

Obviously they gave their opinion that they thought it was autism but they still never actually know..., we decided to say he had learning difficulties. We still say that now, you know if someone asks me I don’t really like saying ‘he is autistic’. (Katie)

Most of our friends don’t know about autism..we need to explain everything to them..so we are just telling him that he is not at the level of speaking..that’s what we are saying. (Ravi)

Some of the parents reported that despite their families knowing what the child’s diagnosis was they did not accept this to be the case:
My family still think that, even though we told them he was autistic...they think there is nothing wrong with him. (Debbie)

This is not an unusual reaction from family and friends. Indeed, O'Brien (2007) made a similar observation that often the normal appearance of the child leads family and friends to 'discount' the diagnosis.

**Anger**

Feelings of anger and frustration were commonly expressed by the parents. Some parents expressed anger at the assessment that was made of their child:

They have been with your child for half an hour and say ‘oh they have autism’ and we have been with them a lot longer than half an hour .. surely we have a better judgement that you? There was nothing said on the day that hadn’t been said numerous times before. (Debbie)

A source of frustration and anger that two of the parents voiced was that the diagnosis had not changed things or helped them:

It hardly changed for us at all .. it was just so frustrating .. knowing that he was autistic but there was nothing really available for him to help him and we just had to wait for the school and that was that. (Amber)

It’s not being told what to do and where to go for help next that is frustrating …you need to be told that. (Lisa)

Some expressed annoyance that people who said they would help had let them down:

I would rather not have interference from people who don’t do what they say they will. (Sylvia)

If you can’t do it .. I am not bothered if you can’t do it , tell me you can’t do it, don’t tell me you can do it. It was them that made all of the offers. I was like .. I don’t want charity, I’m not even asking for it and they are telling me just hang on .. then twelve months later .. nothing .. when I could have been doing a couple of hours every day and getting it done. (Scott)
Depression and Guilt
Many of the parents reported feeling very isolated after they had received their diagnosis. Reports of feelings of isolation are well documented in the literature (Dale et al 2006).

*I just felt during that period of time we were just on our own. So if you had any questions or any doubt there was nobody, there was nobody.* (Debbie)

*Alone …very isolated because I did feel I was the only one.* (Katie)

A similar theme emerged from the interviews conducted with parents in Woodgate et al (2008). Parents reported that they were “living in a world of our own” (p1076). They felt that in all aspects of their daily lives they were isolated. Comments made by Lisa reflected this:

*It’s just me and him against the world! I am like his second hand… I do everything for him…I have nobody to say ‘I am upset today, or, he has done this to me.’*

*Some days I sit here now and look at parents going to school, I look at other parents and I think ..what they have got…a perfect child…I do feel so alone. I have a disabled child.*

Some of the parents reported that they felt guilt. They offered different reasons for this. Scott felt guilty because he was unable to give his son the attention he needed due to the severity of his sisters autism:

*But at the time when it was really bad he didn’t get enough attention. He wasn’t put at risk, don’t get me wrong, not in any way shape or form… I mean Dad’s half dead all of the time and Mum is half dead all of the time and he wants to play and do things like normal children want to do and he is living in an entirely different world. She didn’t want to know him, she would push him away, so I felt, you know.. very sorry for him.*

Swanepoel (2003) reported that she obtained similar views from the parents in her cohort. They commented on having a pre-occupation with their autistic child’s needs and showed a “tendency to devote less parental attention to
normal developing siblings due to the extreme demands that their autistic child made on their time and energy”. (p 38)

Two of the parents, Lisa and Jane, explained that they feel a strong sense of guilt that they have caused their children’s autism:

*I always do feel responsible for the autism, cos I know its’ in my family. It’s missed Olivia and it’s come out in Jayden..it is genetic so I feel it is my fault that he has autism. I do feel sorry for Jayden and I do blame myself a lot of the time.* (Lisa)

*If it’s a genetic thing I wonder if everyone feels as guilty as I do.* (Jane)

Dale et al (2006) investigated mother’s attributions following diagnosis of autism and identified that themes of personal responsibility were a common thing reported by their cohort. Gray (1993) reported that mothers often hypothesised what had caused the autism and often placed blame on themselves. He cautioned this finding as there were only a small number of fathers in his sample. Although limited evidence has been amassed in the current study it could be argued that it adds weight to Gray’s theory as neither of the fathers I interviewed mentioned personal blame, instead Scott blamed the external factor of the MMR vaccination.

**Resolution**

Waters et al (2008) and Midence & O’Neil (1999) identified acceptance and adaptation as a common theme raised by parents when they discussed the period of time after diagnosis. Indeed, Waters et al (2008) observe that “many of our families felt that the process of acceptance couldn’t really begin until they had a confirmed and official diagnosis”. They suggested that diagnosis provides more than a label but an explanation of “who and how the child is” (p 34).

Osborne & Reed (2006) called for more research into parents coming to terms with the diagnosis of autism. The comments made by the parents in the current research reinforce the view that they go through a period of adjustment and adaptation.
Some of the parents spoke about readjusting and being able to move forward:

*Once you feel sorted you feel like you can take on the challenge.* (Sylvia)

Lisa and Amber referred to finding the strength to do so:

*I needed something to push me forward as a mother and to help me deal with it.* (Lisa)

*I felt very negative for about forty eight hours .. then something kicks in like parental responsibility and you have just got to get on with it. You realise he is still your little boy and he hasn’t changed.* (Amber)

Fleischmann (2004) comments on such strength in his study of web based narratives of parents with autism. He observed that “parents, it seems, redirect the anxieties for their child’s welfare that paralysed their action in the past into a positive force that energises them to work to help their child cope and grow” (p 39).

Many reported a realisation that their child may have received a diagnosis of autism but they had not changed:

*You realise he is still your little boy and he hasn’t changed.* (Amber)

*It doesn’t change my little girl, she is still the same. That’s what people kept saying.* (Jane)

My findings add weight to the observation made by Bruce & Schultz (2002) that parents regard grieving for the loss of their ‘normal child’ as an ongoing process. Comments made by my sample provide powerful illustrations of this. Some of the parents referred to their attitude to the diagnosis changing over time but recognise that they have not fully come to terms with the diagnosis:

*It changed over the months, well, cos I have got used to the idea now. Then I was worried about my little girl and how it*
would affect her but now I know I don’t have to worry as much. (Jane)

We are coming to terms now but it will take…I think..a very long time. (Ravi)

Other parents said that they could not see a time when they would be able to accept the diagnosis:

I don’t think you ever get your head round it… I won’t. (Katie)

It’s still hard now, all this time later, I don’t know how to move forward still…I am still where I was two years ago really. (Lisa)

Many of the parents now see autism as bringing something positive to their lives. This suggested to me that they had started to adapt to the diagnosis even if, as in Lisa’s case, she said she would never be able do so:

It’s hard but I just love him if someone ever said you have a million pounds and I will change him tomorrow ..I would just say I would no I want to keep him, I want him to have these strops.. but I would just say I just wish he could talk, tell me how he feels. Some days he will cry all day and I cuddle him and he hits me away..I just want him to be able to say “I am upset because of this…I have a headache’ or something like that. I would love to hear him say that. (Lisa)

I would give anything to be just a normal, average family but then in ways I would never, ever change it. (Katie)

I wouldn’t take autism away from him because it is him. (Sylvia)

You have that close …really unwavable bond.. it’s a spooky thing because she gives you this attention that a normal kid wouldn’t. That’s where it comes from, the attention that you get off the child, like I say at first it’s hard, it’s always there, it’s difficult but once you get over that you are so close. (Scott)

Parent’s positive reflections about autism are a common theme which has been identified in previous research. Midence & O’Neill (1999) found that as families accepted the diagnosis of autism they had an “ability to perceive and value their child’s personality and the effects the child had on their lives” (p281). Similarly, Mansell & Morris (2004) reported that parents in their sample expressed the
view that they had been ‘lucky in one way or another’ despite their child’s difficulties.

**Loss of certainty about the future**

Underpinning the parents descriptions of the feelings they experienced during the diagnosis were frequent references to losing the life they thought they were going to have. All of the parents spoke of the loss of the future that they had anticipated for their child:

*It’s hard when you see what he could have been like…you just think.* (Sylvia)

*It’s like losing the child you thought you had…you know what I mean. You worry about the future and things …it’s like a sense of grief.* (Katie)

*You are losing the life you think you are going to have, your normality has gone.* (Scott)

Many of the parents said they were worried about their child’s future:

*So many questions pop into your mind straight away about how, what sort of future we are going to have, are they ever going to be independent or are they always going to need round the clock care.* (Amber)

*We were worried about his future and we are still worried.* (Ravi)

*Well absolutely. I am worried about him if anything happened to me, you know, that is my main, main concern.* (Debbie)

The uncertainty that accompanied the diagnosis of autism impacted upon parents in the cohort:

*I still don’t know what’s gong to happen in the future, you can’t. I suppose thats the thing … if I am being blunt, if I had a little girl who couldn’t walk and was in a wheelchair .. I would structure my life in a certain way… I would be able to say .. ‘look, she is in a wheel chair, she can still do this, we can still go shopping and yeah, alright. There are certain bits that she can’t do .. there is always something you can do’. Now you haven’t got any sort of certainty and I think that that is what makes it so horrid.* (Scott)
Graungaard & Skov (2006) and Bruce & Schultz (2002a) suggest that fathers have a stronger need to know what the future may bring than mothers, who tend to concentrate upon the present time. The response from the parents in my sample appeared to support this finding. Four of the parents reported that the male member of the household gave more thought to the future.

4.5.2 Being supported through loss
A significant theme which emerged in the analysis of the parents’ interview transcripts was the support that was offered to them after they received their child’s diagnosis.

The effect of support given to parents in the post diagnostic period
Parents are asked to attend a planning meeting one month after their diagnosis. The purpose of the meeting is for parents to have the opportunity to discuss the diagnosis with professionals, have any questions answered, and identify any unmet needs that the family have. The interviewees spoke favourably about this meeting:

We could ask questions, we had time to prepare from the notes so we could ask things during the meeting. (Ravi)

That was a crucial meeting that. It gave me more clarification because until then you didn’t know what was going to happen, it was probably one of the most useful meetings that there was! (Debbie)

Nissenbaum et al (2002) had stressed the importance of follow up meetings after diagnosis and the parents in my sample agreed with this view.

Although she understood why, Amber felt strongly that the time between the diagnosis and planning meeting may have been too long:

A month later, it just feels a long time .. it feels just too long. I suppose they do that so that you can get back to normal life, try to digest.. this news that you have received .. just for me if felt like you should get the option whether you want to see
someone in a months time or, you know have contact in-between.

Debbie had a very different view:

No. it was an alright gap to be honest, I mean... even then I was still then I was still shaken badly...if it had been any sooner I would have been sitting there like a zombie, unable to absorb anything ....so for me personally it was ok. Any sooner it would have been in one ear and out the other.

No support post diagnosis

Waters et al (2008) reported post diagnosis support to be ‘patchy’ and ‘disjointed’. They observed that many parents felt ‘dropped’ by the professionals. These findings were replicated in this research. All of the parents without exception made reference to the lack of support they received post diagnosis. Waters et al had suggested that the perceived lack of support in their study could be attributed to the closing of cases by health professionals after school-aged children were diagnosed in hospitals or clinics. However all of the children in my sample were diagnosed pre-school by a multi agency team and parents still reported being abandoned:

It kind of upset me a bit because we had all that support before we found out then the day we found out people didn’t want to know then. (Jane)

No nothing, just the diagnosis, ‘toodle ooh.’ I hardly got any information. (Debbie)

This was discrepant to the findings of Midence and O’Neill (1999) who reported that all of the parents in their sample were now getting the support they needed. Their cohort had emphasised their need for practical help and having someone to talk too.

It would have been useful to determine what the parents in my sample would define support as. Indeed four of the parents in my sample reported that diagnosis meant that their child’s educational needs were now being met and
two reported that they could access funding and disability allowance however they did not classify this as ‘support post diagnosis’.

Ways to improve post diagnosis
The parents voiced several suggestions that they felt would improve their experience of diagnosis. These included more frequent visit from the Portage Service, increased access to Speech and Language Therapy and a book detailing the A-Z of autism! Other parents wanted a more specific intervention for their child:

*We really just wanted .. like .. I really just wanted to get him on some sort off programme, you know, straight away .. where we could give him some real practical help. Maybe if there was some sort of a course, somewhere where children and parents could just be helped … it’s reading a book .. it’s just not enough.*

Ravi felt that the Psychology team had something unique to offer parents:

*I think the autistic kids are different in attitude, so the child psychologist can understand the individual child and they can give proper training based on his own needs. They are people who give us more information about our child rather than autism.*

The important role that a key worker could play in supporting parents was mentioned in four of the interviews. A number of families in Waters et al (2008) study had said they would have valued a key person to co-ordinate the process and who could offer both practical and emotional support to them:

*You aren’t given a key worker now .. that has all stopped now. That would be brilliant to have someone like that. (Lisa)*

*Having one person to do it for you .. oh that would be amazing. That would be such a positive thing .. it’s almost like having .. I don’t know em .. a family member if you like, someone that would know Noah but would also know how to advise you. Do you know what I mean .. someone you could build a bit of a relationship with and with the child .. that would be perfect .. rather than just meeting that person once, someone from the DLA once, someone from Parents*
Partnership once. They are all well intentioned people but you don’t really see them again after that because they are so busy. (Amber)

Even a weekly or a fortnightly call to say how are you doing, is there anything that you need to know or .. for them to provide that information. If that’s someone’s specialised subject they can weed out all the crap and give you the right information …bang there it is on the table … it would take me six months! (Sylvia)

Whittaker (2002) conducted research in a local authority which provided a support worker to families as part of an ongoing home visiting service. Parents in his sample rated this as very useful.

**Need for emotional support post diagnosis**

The parents frequently referred to the need to be provided with emotional support. Two of the parents commented that at no point had they been asked how they were feeling after they got the diagnosis:

Nobody asks you how you feel about it at the time, about the process … to be quite honest I don’t think they bloody want to know ..do they! [laughs] (Debbie)

You are given the diagnosis and your head is everywhere, I was an emotional wreck em, you know, I think a lot of parents would find it useful if they knew they had access to some sort of help and support. Just for dealing with their own emotions… ah … but obviously nothing was offered. (Sylvia)

There was a general acknowledgement that although professionals had endeavoured to provide families with emotional support this should be available in a formal rather than ad hoc manner as it is now:

People try to give you support but the people that try to give it to you are not necessarily the people that should be trying to give it to you but they are doing it because they are trying to help you and that’s not their job to do that you know.. they don’t quite fit but they try, everybody tries but at the time it doesn’t quite fit because you need that one person .. a psychologist I suppose… they know what you are going
Indeed seven out of eight of parents identified that this was a gap in the current pathway and said that emotional support should be formalised in the pathway.

Debbie and Lisa felt the support should be offered by people who had had a child diagnosed with autism:

*It needs to be someone who has had their own personal experience, obviously a parent, because .. support is completely different from a medical diagnosis. You need to speak to someone who has gone through what you have. They can talk to other parents and explain how it works.* (Debbie)

Several parents suggested that a counsellor or simply somebody to sit and talk to in the period immediately after diagnosis should have been made available to them:

*People, they should be offered some counselling because there will be a lot of people that find it hard to deal with. Jesus Christ I did and I am not the weakest of people, but I still struggle with it.* (Sylvia)

*I just em .. fell apart for about forty eight hours. I just couldn’t stop crying . if there had been a counselling service that we could have gone to straight away when we came out of that meeting and received the diagnosis . it would have been brilliant. Or someone to come to the house and visit us .. someone to sit and listen with a cup of tea. Just someone there that could make you think you are not alone .. you will be fine .. it takes time but you will be fine.* (Amber)

Parents in Waters et al’s (2008) sample also commented that counselling, post diagnosis, would help them to cope with their feelings of despair and depression.

Surprisingly, Katie said that she had found being involved in the research to be a source of emotional support:
I think what your doing now, just what you’re doing, asking questions about it. Sometimes I don’t know what is going to come out. Everyone should get that chance just to sit and think and talk about what has happened. Things come into your head that you don’t realise you have even been thinking about. I don’t realise I was thinking about it. This is the first time I have sat and talked about what has happened, I have never had to normally I don’t speak to anyone really about it. It’s just like Ollie is just like any other normal child I just go through my day as I am going through it I don’t sit with anyone professionally and speak about it.

This replicates the finding of Bruce & Schultz (2002) who said that parents needed the opportunity to retell their story. They reported that parents are rarely debriefed after the diagnosis and advocate its importance.

The effect of support from significant people

A general trend was that the parents in the study felt supported by the professionals in the diagnostic pathway. In each of the interviews I conducted the parents named specific people who had been pivotal in supporting them through the diagnosis of their child. The literature states that the “expertise of those providing support is an important factor in the alleviation of parental stress, in particular in relation to self efficacy, behaviour management and provision of home based care”. (Dillinburger, 2010; p14)

Many of the parents reported that they valued professionals who made time for them:

*She came round immediately and was just supportive. Now, she is the head nurse there, she could have palmed it off onto anybody but she didn’t, she heard how distressed I was.. I was eternally grateful for that. It was a point where I didn’t know what I was doing. (Sylvia)*

For Scott the Occupational Therapist was the person who stood out as the most supportive and he compared her favourably to another professional who he perceived to be very unhelpful:

*She was sort of the one person… she seemed to hit the nail on the head about every single thing. Things moved very*
quickly with her .. and then you go from her who is the best .. right over to the other end of the scale...they were just useless, absolutely useless.

Several of the parents, Debbie, Katie, Lisa, Scott and Ravi commented that staff at the nursery their child had attended after their diagnosis had been a source of great support. The Educational Psychologist, Speech and Language Therapist and Parent Partnership Service were also commended by the parents.

The parents in my study who did not feel supported had wanted specific strategies to help their child in the period after diagnosis:

\[ I \text{ didn’t really feel supported by the professionals, they gave me a diagnosis but did not tell me how to go on from there.} \quad (Sylvia) \]

What was unique in my study was the importance parents placed on personal attributes of the key people who supported them. This was mentioned by all of the cohort. Their responses indicated that regardless of experience or status the personal qualities of the professionals were most important to them.

The service most frequently mentioned by the parents was the Portage Home visiting service. Six out of the eight families had received fortnightly support from this service in the months leading up to their diagnosis and they all spoke highly of them. It became clear that the relationship they had forged with the family was a very supportive one, parents valued their expertise but also the personal support they gave:

\[ \text{The portage team were very good at the social intervention types, just giving you a tap on the back and saying you are not on your own, they were people that really helped you with your mental state if you like, nobody else seemed to.} \quad (Scott) \]

\[ \text{The portage team are really brilliant .. they are very friendly...especially because with our family, there is no one here... they were like a family member.} \quad (Ravi) \]
Parents in this study reported that they valued the professionals who knew their child well, related well to them and understood their idiosyncrasies.

**Usefulness of support groups**

All parents of pre-school children who are known to have social communication skill difficulties or have had a diagnosis of ASD are invited to attend a parent support group which is facilitated bi monthly in the evenings. There are also other groups which are run for parents, with their children, via the hospital and resourced nurseries.

Many of the parents reported that they valued the support they accessed by meeting other parents who had children with similar needs. This is in line with previous research which has documented the importance of meeting families in similar situations and discussed the support they have received from each other (Waters et al, 2008; Osborne & Reed, 2006; Mansell & Morris, 2004). Whitaker (2002) reported that having the opportunity to have contact with other parents in a similar situation was highly valued by his cohort. This finding is replicated in the current study.

The parents I interviewed gave different reasons why it was a positive thing to access support groups. Amber explained that meeting parents of children with autism helped her to navigate the information she had been given:

*You don’t know who to contact, there is the help out there but you have to go and search and look for them … It is only through meeting other people that you get to know what you can access .. then you think ‘oh gosh yes .. I did read something .. that name rings a bell .. it doesn’t actually make sense until someone says that their child had been through it and that is what it is about.*

Sylvia said that hearing about the experiences of others made her feel more confident in her ability to parent her child:

*Sharing your experiences and talking to other people, certainly at the TOPS groups, that really helps, cos sometimes you do feel like you know nothing and you will be talking about a*
Another benefit cited was that parents could give advice to others based on their own experience. This made them feel empowered.

Some parents reported that meeting people in similar situations, not necessarily at a group, had made them feel less isolated:

*You don’t feel like you are on your own ... and if you’re having a bad day you know there is someone at the end of the phone, you can go for coffee and advice and vice versa.*

*(Katie)*

*There are people out there with similar experiences which you can talk to. You just don’t feel like you are on your own and that is so important.*

*(Debbie)*

Jane felt that she would have benefited from attending a support group but explained why she decided not to access one:

*It would have been useful to go to TOPS but I am not good with other people. It’s just the way I am, I am very quiet ... it’s just me ... I don’t like it, I am not someone who asks for help.*

Mandell & Slazer (2007) make the interesting observation that support groups are under utilized by certain populations. They found that they generally appealed to families with certain characteristics such as being educated, married and from middle and upper income groups. They suggest that these parents have more confidence to discuss their private feelings with others and have greater resources and time to access these groups. It may be appropriate for us to look more closely at the demographic of the participants of the support group run locally and consider alternative ways of rolling out support to families who have not accessed the resource.

Scott reported that he had attended one session but had been pre-occupied and did not feel it was the right thing to do to leave his daughter:
I could have done with it but it then meant being away from my little girl ....It tears you apart when you are not with them but on top of that she is going to be a nightmare for her mum. ....I was the person who needed the support because I am the carer and I am up all night but I am in this room, just sat there, waiting to go because I know how much she is going to be kicking off. I am feeling almost guilty that she is going through any sort of upset because I am not there so it defeats the object of going. That’s the reason that I really stopped going so much. It wasn't because I didn’t appreciate it, it was because of what I felt I was putting my daughter through by going.

Other parents spoke about practical issues which prevented them from attending the groups such as their timing. Debbie observed:

*I don’t have the bloody time!*

**Support received from families and friends**

Many of the parents discussed the role that their extended family had in supporting them. Some of the interviewees spoke positively about the support they had received from their family:

*Oh yeah...god...definitely...em of course .like we are a close family, I have two brothers and a sister and they help me, they understand him. But Sam is just Sam so everyone accepts him.* (Debbie)

*You know, speaking to friends and family really helped and you know twelve months on we are in a completely different place now. It’s still upsetting, especially when I talk about it, but twelve months on we are so much better.* (Amber)

Five out of eight interviewees reported that although their families were supportive they did not really know how to help them:

*My mum, she knew something was wrong but not ASD. She does come round and speaks about it ... what else can she do?* (Jane)
Woodgate et al (2008) found that parents in their sample were isolated from family members as they appeared to lack a true understanding of their situation and or did not offer practical support and help:

They really take a bit of a back seat.. they don’t interfere. (Amber)

I told my mum he had autism, she wouldn’t have him there, she doesn’t understand him, she won’t have him at her house, it’s too much for her. Sometimes she says ‘I don’t know how you do it, I don’t know how you cope’ and I look at her and she’s got 3 normal kids and I think what I would do not to have a disabled child. (Lisa)

Your grandparents are well meaning as they are .. you can never ask them for help with that sort of stress cos they can’t do it. (Scott)

Gray (1993) reported that grandparents appear to be reluctant to accept the seriousness of the difficulties encountered. This was reflected in the comment made by Debbie:

They are quite oblivious to his diagnosis. I think if they are going to be ignorant about it we can’t change it, it doesn’t matter. (Debbie)

Ravi’s description of the support he was offered by his family shows how different cultures respond to disability:

My mother told me to send him over [to India] and they would look after him ..he is still here!

He also commented upon the way his daughter offers support:

His elder sister she is hoping that he will be alright. She doesn’t know that he has autism ..she is only 8 so in her daily prayers she is praying for him to make progress.

This comment struck me as unusual however, on closer inspection of the literature, Ghupta & Singal (2005) commented that in India one of the most commonly used coping strategies in times of distress was religion.
4.5.3 Loss of normal family life

A sub theme identified in the analysis of the transcripts was the impact that autism had on the family. The responses from the parents in the study adds to the growing evidence in the literature that the presence of a child with autism places a number of stresses on the family (Marshall & Long, 2010; Le Cavalier, 2006).

Some of the sample commented on the exhaustion that accompanied having a child with autism:

_I mean . he is screaming ... you have this little boy who will not even look at you.. he is your son you want to cuddle him but every time you are cuddling him he is screaming at the top of his voice and you are not getting any sleep, at night time the temperatures change, he is screaming again, you never get any, any rest whatsoever..no respite, no help with anything. (Sylvia)_

_You can't get any respite. (Jane)_

_It was the worst time in the world and I was literally walking around for three or four days with zero sleep. Not an hour not two hours .. having bit of a rest .. nothing... nothing whatsoever I am like this...I am bloodshot and she is there and every time she was there going ‘aargh’ down your ear hole. She was scratching, she was itching.. it was before people became involved.. it was horrid.. didn’t know what to do and I literally passed out. It got to the point .. it was on the fourth day... I didn’t know what to do, I didn’t know how to carry on. (Scott)_

Participants in Swanepoel’s (2003) case study of four families gave similar reports of “extreme demands on time and energy” (p37).

Two of the parents reported the impact that autism had on their own social life:

_Everyone I used to know before I had Jayden, they are out every weekend, their mum and dad’s have their kids..they haven’t got the responsibility that I have got..my child is a different matter all together. (Lisa)_
When she wanted to go on a night out I wanted to tell her I have been up for three days and nights with no sleep, if I pass out and Summer does something dangerous what happens then? (Scott)

These views replicated one of themes that Werner (2001) identified in a phenomenological study that parents feel losses because they can't lead a normal life.

Parents frequently commented that there were specific situations they avoided due to their child’s needs and gave reasons for this:

It is really hard to keep him under control, he gets so excited and people ask us so many questions so we avoid some places. For the sake of his sister we used to go to places but it is hard so I take him to my friend’s home and my wife and his sister play. (Ravi)

You can't go to a hotel, she will scream, you can't go to a standard caravan site she will still keep everyone awake. What the hell do you do to go somewhere to have a little bit of a break? (Scott)

I refuse to take Sam to a lot of things. I just get scared when we go out, he won't listen to me. he will run out in the roads. I can’t even take him to the shops. (Debbie)

We stopped going to town because it was a big problem. (Jane)

Conversely Amber did not feel that autism had impacted upon her family:

Everything is still the same, everything that we do is the same….we try to keep it as normal as possible.

This view supports the findings from previous research. Dillenburger et al (2010) found evidence that autism prevented families pursuing their normal social and leisure activities such as holidays and family outings. Swanepoel (2003) noted that participants in her study said that they were restricted from participating in specific activities such as going out for meals or on holidays due to their child's autism. She said that all of the participants in her study had “felt that the presence of an autistic family member makes it very difficult and challenging to
Swanepoel reported that as shops and restaurants were often venues for confrontation and embarrassment families often opted not to go to these places, this increased their isolation. The findings also support an older, but still relevant, study by Gray (1993) who found that many parents of children with autism endeavour to isolate themselves and their families from contact with the outside world.

**Normal models of parenting and autism**

Five of the interviewees commented that acknowledging that normal models of parenting do not work for them had helped:

> You don’t understand your child, you treat them like normal kids and they are not.. you shouldn’t. (Sylvia)

They felt it important that families were told this when professionals had concerns about their child’s social communication skills:

> You have to tell people that they need to throw all of the standard parenting out of the window. Right at the beginning you should be told that, way before the ADOS, you need someone to sit down and say we think she might be autistic so we are going to give you a little bit of advice. When people tell you she is a naughty kid and tell you to smack her.. don’t do it. The worst thing you can is undermine the little trust they have got in you anyway. When you start approaching them in a different way that’s when things start changing, you do get that bond, I can honestly say I don’t think you get that if you parent an autistic child in a ‘typical’ way. (Scott)

Conversely Amber said that she uses the same strategies with all of her children but referred to it being a challenge:

> Sometimes it’s not like we forget that he is autistic but it is still flippin’ annoying when he is doing something!! I treat him like how I treat Jacob and I will treat Erin … I won’t let him take advantage, he has to know the difference between right and wrong .. I just have to show him a bit more patience, that’s all it is. Instead of telling him something once I might have to tell him hundred times before he will understand.
Impact of autism on siblings

Seven of the families discussed the impact that autism had on siblings. For many of the families having a child with autism meant there were restrictions placed upon their other children participating in everyday activities:

We are limited to what we can do and where we can go with them. We can’t have people round. (Ravi)

Olivia can’t have friends round because Jayden smears, she is good and tries tidying it up. (Lisa)

Gray (1993) reported that he identified a similar theme in the interviews he conducted. The parents in his sample had reported particular concern for their other children. He noted that parents were concerned that autism placed a stigma on siblings and prevented them enjoying normal activities.

Many of the parents commented how difficult having a sibling with autism is:

She thinks he gets away with things or says that he screams all of the time: she has found it harder than any of us. (Ravi)

It must be horrible for him because as much as I am getting no sleep he is getting hardly any sleep because she kept him awake. He had no routine whatsoever to work too, he was a little baby getting woke up at all sorts of hours and times and pushed to the side sort of things. He didn’t get any attention at all, everything was focussed on the other one. (Sylvia)

She says it’s not fair. We explain all the time that here is something wrong within Sam and he needs more help with things. She isn’t old enough to understand what is going on. She feels it’s not fair, he always gets his own way. (Debbie)

Amber said that there was not an impact on her other children:

They don’t know any different .. he is just noisy and that is the way he is.

There were benefits for the siblings:

I think it makes you a better parent in the end, because you are far more understanding, you are more patient. (Scott)
The impact of autism upon relationships
The majority of the parents commented upon the support they gave to and received from their partners. There was an acknowledgement that autism put a strain upon their relationship. Swanepoel cites older research by Takatomi et al (1974) and Sharpley & Bitsika (1997) which concur that having an autistic child places detrimental effects on marital relationships.

Scott spoke very frankly about his experience. He explained how the pressure of parenting his daughter had had an enormous impact upon his relationship. I felt it important to document his comment in its entirety:

You don’t give emotional support to your partner, you don’t want to be cold and calculating, you are just too tired and broken. A wedge is forced between you. You don’t sleep together, you don’t sleep at the same time, you don’t talk, you are like zombies.

It must be fucking horrible for Nat, I am sorry for using that word but I can’t think of another one which is strong enough. I am fucked, you are absolutely in every sense of the word fucked .. there is no word but that one.

To be honest I don’t know how families stay together.

Lisa reported that her partner does not understand autism and this has impacted upon family life:

We can’t have a normal life, a lot of it is arguments between me and Ian because we are tired cos we have been up all night. He hasn’t changed his bum for two years now cos he says he is too old and should do it himself, he should be on the toilet by now..he doesn’t understand..it’s just me on my own.

Sylvia also commented upon the way she viewed autism differently from her husband and she felt she was disconnected from him. Other parents also spoke of such difficulties:
The other parent gets ignored, you have to accept it .. cos I am so focussed [on Megan] that I got to that point so much quicker than Rick.

There are different perspective taken by different parents. If you are the closest you find it easier to accept. You are a completely broken person, you either carry on or you accept that your friends have gone by the wayside, you won’t go out for the next ten years, you won’t have nights out .. you accept and you move on with your life”. (Katie)

A similar finding was made Woodgate et al (2008) who stated that “parents on occasion also felt disconnected from their spouses when both experience different feelings that resulted in their not ‘always being on the same wave length’ or stage of the autism trajectory” (p1079).

Surviving being a parent of a child with autism
Several of the parents told me how difficult it was being the parent of a child with autism. They reported that it was an isolating experience:

It’s nearly five years now of being up all night trying to get food down him, he’s only just got out of nappies. Sometimes I think I can’t go on, I can’t get up for another night. He won’t go into his own room, he is straight into my bed. He wakes or just walks around and sits and screams. I don’t tell anyone. Sometimes I just think please just lie down and go to sleep. (Debbie)

Most of the time I am just one of those people who just gets on. I don’t speak about it . I just do what I am doing and if there is ever a problem I will sit and think about it but I won’t sit and go on about it, about how depressed I am .. if I have a bad day I have a bad day .. that’s about it. (Lisa)

Scott and Katie explained that although they still faced significant challenges things were better for them than when they were at the beginning of the diagnostic journey:

If you’re lucky enough to get out the other end intact, and when you look at the figures there is not many people that manage that .. you get out the other side of the tunnel. (Scott)
It was more difficult when he was smaller, like a toddler when he first started crawling. I didn’t want to be round him at all, he was so difficult …It’s not so bad now, it’s gone on so long, I just get on with it. Sometimes I think I don’t need any support, I didn’t need it then. I feel like I survived that, the baby part, I got through it. (Debbie)

The views that the parents put forward highlighted the lack of support that was available to the whole family following diagnosis. They identified this as an area of unmet need:

If the family falls apart what does the child do?, It completely destroys any chance that the child has got to try to live a normal life. (Scott)

If the parents aren’t strong how can you help your child? (Lisa)

Taken in the context of the statistics that Dillinger et al (2008) cite that there is an estimated 82% divorce rate in families of autistic children and 1:3 families of children with autism are headed by lone parents these are poignant words.

There was a tacit agreement made by the focus group that there was a need to create capacity for family support in the authority It was proposed that a family worker for ASD would be best placed to fulfil this role and a working party should be convened to facilitate this.

4.6 Overview

The findings from this research indicate that parents perceive the diagnosis of autism to be a complex and emotionally challenging experience. They value the support of professionals and place great importance upon receiving information about the diagnostic process and autism. The impact of autism upon the family is wide ranging and, in most cases, affects all of the family members. Parents described the feelings of grief and loss they encountered, and continue to experience, when their child was diagnosed with autism. In the next Chapter I relate my findings to the original research questions and reflect upon them.
CHAPTER 5

SUMMARY AND CONCLUSIONS

In this Chapter the key findings are summarised and reflected upon under four main headings that represent the research questions asked. The limitations of the research are discussed and a personal reflection of the research is given. I then consider the contribution that this thesis makes to knowledge and theory. Finally implications for practice are explored and I propose future areas of study.

5.1 Summary of the key findings and concluding comments

Research Question 1.
From the parents’ perspective, what are the factors which contribute to a successful ASD pathway, in their locality, from identification, to diagnosis to intervention?

Many positive aspects of the pathway were identified by the parents I interviewed:

- *Parents valued professionals taking their initial concerns about their child’s development seriously and acting upon them.* Most of the parents in my sample reported that, prior to any professional involvement, they were aware that their child’s development was not typical. Three of the parents did not feel that their initial concerns were taken seriously when they sought help from professionals. They spoke at length about this early part of their diagnostic journey. Their reports echo research, by Waters et al (2008) and Schall (2000) cited in Goin & Myers (2004), which described the difficulties parents encounter when raising their initial concerns with professionals. Interestingly, in the current research, the parents who perceived that professionals had listened to their concerns made little reference to this part of the diagnostic process. This suggested to me that the parent's initial communications with
professionals were a pivotal factor as regards their overall impression of the diagnostic process.

- The ADOS assessment was valued by all of the parents, most observed that receiving a diagnostic label had helped them to understand their child’s needs and access educational resources. I had not fully appreciated the value that families place upon this part of their child’s assessment. My findings strongly suggest that parents consider it to be at the centre of the diagnostic process, they reported that it told them whether or not their child was autistic. This supports Midence & O’Neil (1999) who identified that parents stressed the importance of being given a ‘label’ for their child’s needs. I was interested to hear Scott and Sylvia’s frustrations that they considered professionals to place too much emphasis upon the diagnostic assessment. As a professional I perceive the ADOS assessment to be ‘another part of the jigsaw’ which helps us to understand the child’s needs. I would suggest that we need to emphasise to parents that the ADOS alone does not ‘diagnose’ their child. All of the other contacts their child has with professionals, assessments and observations contribute to our assessment.

- The majority of the sample reported that they were satisfied that they knew what would happen on the assessment day and considered this to be a strength in the pathway. Nevertheless Lisa reported that she had not fully understood what her role was during the ADOS assessment. She explained that she had tried to help her child and intervened. Lisa continues to feel upset that she was told by professionals to sit down and ‘be quiet’ whilst they administered the ADOS. This reinforced to me the importance of preparing parents well for the assessment day.

- It was important that professionals recognised parent’s opinions and concerns about their child and worked collaboratively with them. Several parents reported that they had been concerned that professionals would not gain an accurate picture of their child on the day of the assessment.
Such concerns have been acknowledged in the existing literature. Brogan & Knussen (2003) emphasised that it was vital for parents to feel that their concerns are listened to. Similarly, Graunegaard & Skov, (2006) stressed the importance of professionals acknowledging to parents that they are the ‘expert’ on their child. I would suggest that professionals must ensure that they listen to parents and take on board their concerns, even if they do not share their opinion. As a professional I always stress to parents that they know their child better than anybody, this research has reinforced to me that this is good practice.

- **The planning meeting that was convened one month after diagnosis was a useful meeting for parents.** The parents valued having the opportunity to ask questions and clarify issues. The responses I obtained from the parents in my sample corroborate Nissenbaum et al’s (2002) observation that follow up meetings after a diagnosis are desirable. One of the parents I interviewed suggested that a month was too long to wait for this meeting. I would argue that it is an appropriate time gap, it gives parents an opportunity to begin to assimilate that their child has received a diagnosis and prepare themselves to receive information. Debbie’s comment personified this for me “any sooner I would have been sitting there like a zombie…..any sooner it would have been in one ear and out the other”.

The sample identified areas of the pathway that could be improved upon:

- **The parents in the sample criticised the length of time it took from the identification of initial concerns to diagnosis.** Many felt that they had to wait a long time until they were able to meet with a member of the multi agency team. Indeed, only one felt the diagnosis happened in a timely way. These findings support the existing literature that the diagnostic period is too long (Howlin & Moore, 1997; Waters et al, 2008). I had empathy for the parents when they described what it had felt like to wait for the diagnosis. As a parent myself I can appreciate their desire to get
‘answers’ very quickly. This research had made me reflect upon the different perspective that professionals have of timescales. I work with several families each week, I have to provide them all with an equitable service and therefore a child can not be ‘fast tracked’ through the systems which are in place. Nevertheless, I acknowledge that for the majority of families a shorter time scale would be welcomed.

- **Many of the participants expressed frustration at having to repeat their ‘stories’ to different professionals. It was suggested that a more streamlined process of information gathering would contribute to a more successful pathway.** Scott likened the process to ‘groundhog day’, and spoke negatively about the number of times he had to tell his story to different professionals This supports the views of the parents interviewed by Waters et al (2008) who complained that they had to repeat basic information during the assessment process. As a professional I am very conscious of this problem. I would suggest that existing frameworks such as Early Support and the Common Assessment Framework could be utilised more effectively to prevent this repetition of information. However this would require a more cohesive multi agency approach. We would need to obtain the correct information to fulfil the needs of the different professionals and ensure that this information would be shared.

**Research question 2**
Do parents perceive that any of their own, or their family’s needs, were not met in the local ASD pathway?

- **Several of the respondents reported that professionals did not listen to their initial concerns and perceived that they had not been taken seriously.** It is well documented in the literature that parents can find it difficult to get professionals to listen to them (Midence & O’Neill 1999; Goin & Myers, 2004; Waters et al, 2008). However, I was surprised that so many of the sample echoed these findings. The children we work with are all of pre-school age and, consequently, receive an ‘early’ diagnosis.
I had not considered that almost half of the parents I interviewed would report that their initial concerns had been dismissed. It highlighted to me that many professionals lack a basic awareness of autism and there is a significant training need. Indeed, the parents in this sample want more professional awareness of the ‘red flags’ for autism.

- **Despite receiving a detailed description of what would happen on the assessment morning some parents reported that it had not been made explicit that their child may receive a diagnosis of autism.** This corroborates the finding of Bruce & Schultz (2002) that parents often have “little or no conception of what they are about to be told” p12. Similarly, Osborne & Reed (2008) observed that although terms such as autism and Asperger’s were mentioned, in passing, to parents in the period prior to diagnosis, the potential outcome of the assessment was not made explicit. The comments made by my sample emphasised to me the importance of practitioners stating clearly, prior to the assessment morning, that there is a possibility that a diagnosis of autism will be made. Undoubtedly this will be a difficult conversation for both the parent and professional to have, however, I would suggest that it will help parents to prepare themselves for a possible diagnosis. The existing pathway needs to be adapted to ensure that all families routinely receive this information prior to their child’s ADOS assessment.

- **Issues about the appropriateness of using the ADOS for children who have different cultural backgrounds were raised.** One parent reported that they had English as an additional language. Whilst they were able to converse in English they felt that they would have benefited from an interpreting service. I consider myself to be an ethical practitioner and was taken aback that I had not considered these issues. Ravi explained that he had not had the chance to raise his concerns about the suitability of some of the ADOS items with professionals. This is an issue that must be addressed at the earliest opportunity.
Many of the parents reported a lack of satisfaction with the manner of the professional and the language used when their child’s diagnosis was disclosed to them. The literature emphasises the importance of communicating a diagnosis in a sensitive way (Nissenbaum et al, 2002; Chamak et al, 2011). When I interviewed the parents I was struck by the clarity with which they recounted, almost verbatim, the way the diagnosis was shared with them. Many expressed the view that the disclosure had been ‘casual’ or ‘abrupt’. I was disconcerted that six of the parents reported a negative experience during their sharing the news meeting. This led me to agree with the findings of Bruce and Schultz (2002 a) that “the trauma embedded in bad news is complicated by the ‘delivery’ process itself” p11. I would urge professionals to give careful consideration to the way they ‘share the news’ with parents when giving a diagnosis. I feel that the comments made by my sample about the disclosure of autism gives me strong evidence to make a case for the multi agency team to re-visit our ‘Sharing the News Protocol’.

There is recognition in the literature (Bartolo 2002) that professionals often find it hard to make the disclosure of disability to parents. I would hypothesis that the professionals feelings of, for example, nervousness or sadness may have contributed to the style of disclosure. Nevertheless the emotion that the parents in this study conveyed when they recalled the manner and words used by the professionals demonstrated the huge responsibility we have to do this correctly. When interpreting the data I was also mindful of Nissenbaum et al’s (2002) observation that parents often react to a diagnosis by expressing dislike or anger towards the person who shared the news.

In the period after diagnosis parents felt that they were not given enough information about autism or said that the information they got was not easily accessible to them. This is not a surprising finding as it is in accord with my own experience of the views of parents I have met whilst facilitating the TOPS parents support group. Similarly, the issue of the
amount of information to give parents, post diagnosis, has been discussed in the existing literature (Osborne & Reed, 2008; Whittaker, 2002). One of the parents, Debbie, encapsulated the views of most of the cohort that information needs to be available for parents so they can access it in their own time. Thus I would suggest that in our locality we need to review the type and amount of information we give to parents, and ensure that we can be flexible to meet the needs of the family. It is also imperative that we consult the parents to determine whether the information we provide is the type of information that they actually want. I liked Lisa’s suggestion that a ‘book of guides!’ be compiled by parents of children with autism. This would document potential areas of difficulty and suggest helpful strategies. As a practitioner working with families I learn a huge amount from their personal experience of having a child with autism. I think it would be very appropriate to utilise the vast experience of parents to help others in the same situation.

- Many of the sample reported that they felt that they were ‘abandoned’ by professionals after their child was diagnosed. They expressed the view that there was a significant gap in post diagnostic support and interventions for themselves and their child. This reinforced the view of Waters et al (2008) who said that post diagnostic support tended to be ‘patchy’ and ‘disjointed’. I reflected that it would have been useful to determine how the parents in my sample defined support. Many had commented that their child’s educational needs were now being met or that they had been able to access funding and disability allowance, however they did not class this to be ‘support’ per se. I would suggest that the parents wanted face to face support from professionals.

- Parents highlighted the absence of a key worker or ASD family worker to be an unmet need in the current pathway. Four of the parents identified ways that a key worker may be able to support them and their families. For example, helping them to navigate information or building a relationship with the family and autistic child. I would fully support and
emphasise Luther et al’s (2005) view that “autism affects the family so intensely that families require strong coping skills and formal and informal support” (p41). The challenge to the professional is how this can be delivered. I would argue that we need to listen to what families actually want rather than project what they want. This research therefore goes someway to shaping a model of support that parents would value. Post diagnostic counselling and the provision of a key worker were the two main support systems suggested by parents. Whilst acknowledging this was a small sample I would argue that this ‘wish list’ is commensurate with those identified in previous research (Waters et al, 2008; Midence & O’Neill, 1999; Whittaker, 2002).

• Parents made comments pertaining to the lack of social and emotional support for the families of preschool children post diagnosis. It was apparent to me, as I interviewed the parents, that the current pathway did not provide social and emotional support. Although the parents suggested several different ways to improve and develop the existing services I was struck by comments made by Debbie and Sylvia. They simply observed that nobody had asked them how they felt when their child received a diagnosis of autism. They and five other parents felt that emotional support needs to be formalised in the pathway. Carpenter (2005) encapsulates this when he stresses the importance of professionals supporting families in the appropriate way:

“At the point of diagnosis of a child’s disability, a parent’s first question is hardly likely to be about the local intervention services. These families are frightened, disturbed, upset, grieving and constantly vulnerable. The role of the professionals involved with them is to catch them when they fall, listen to their sorrow, dry their tears of pain and anguish, and, when the time is right, plan the pathway forward” (Carpenter (2005) p181).
When planning post diagnostic services it may, in some instances, be helpful to consider Debbie and Lisa’s suggestion. They postulated that parents who have had a child diagnosed with autism may be better placed to support families than professionals.

Research Question 3
What feelings of grief and loss are experienced by parents when their child is diagnosed with autism?

- The sample described feelings of shock, upset, denial, anger, depression and guilt and resolution. The parents did not experience these feelings in a uniform way and they described different events that evoked an array of feelings. A very high percentage of the parents in Waters et al’s (2008) study had reported feelings of relief, this led me to expect my sample’s responses to be similar. However, I was interested to observe that none of the cohort I interviewed reported feeling relieved when they received the diagnosis. This may be a consequence of the relatively early age that their children were diagnosed as the current study focussed on a pre-school pathway.

Bruce and Schultz’s (2002) description of what happened when a parent receives a diagnosis of autism encapsulated what the parents in my study reported to me. They described that “a personal, quiet tragedy for a parent and child has transpired but, in the absence of a physical death to mourn, it has no prescribed rituals for parents or others” (p12). My research has helped me to gain a better understanding of the different emotions that parents experience when their child is diagnosed with autism. I would argue that professionals have a very important role in helping parents recognise and manage their grief. Too often a diagnosis is regarded as the end of the professional’s involvement however I would argue the diagnosis is the starting point.
All of the parents made direct or indirect reference to the ambiguous nature of their loss. The current research supports O'Brien's (2007) findings that theories of ambiguous loss can be applied to describe the experience of parents who have a child diagnosed with autism. My results indicated that all of the parents in the cohort were experiencing an ambiguous loss. They all described feelings and gave examples that mirrored those factors identified by O'Brien (2007). These included difficulty predicting outcomes, day to day variability in functioning, and appearance of health and loss of relationships.

The feelings of grief and loss reported by my sample further validated Bruce & Schultz's (2002) finding that parents regard the loss of their 'normal child' as an ongoing process. Although most of the interviewees said that their attitude towards the diagnosis had begun to change over time they each had their own unique perspective. Jane reported that she was beginning to accept the diagnosis whereas Katie said "I don't think you ever get your head round it ...I won't". I consider that this adds weight to O'Brien's conclusion that simple models of grief and loss are not helpful when working with the parents. O'Brien (2007) argued that due to the ambiguity of the parent's loss it can never be resolved. My findings have led me to concur with her view that practitioners may not be able to ever help parents 'come to terms' with their loss. The ambiguous nature of the cycle of grief and loss that parents experience needs to be made explicit to professionals.

In the previous chapter I made a decision to report feelings of grief and loss as a discrete sub theme. I would postulate that the parents of children with autism begin to experience ambiguous loss from the point at which they start to be aware that their child is in some way different from their peers. Professionals need be mindful of this during the pre-diagnostic period.

Pianta and Marvin (1993) (cited Watchel & Carter, 2008; p576) investigated the degree to which parents resolved their feelings
associated with diagnosis. They propose that a successful resolution “involves accepting the diagnosis, incorporating the diagnosis into ones reality and resisting self blame”. They suggest that parents who have not resolved their grief find it more of a challenge to be sensitive and respond to their child’s cues. I would hypothesise that if we have a greater understanding of where parents are ‘up to’ as regards their resolution and adaptation we can support and facilitate this process. This, I envisage, will facilitate professionals to work more effectively with families and help them to recognise the impact the parent’s feelings of loss may have upon their behaviours.

I consider that by providing appropriate emotional support we may be able to enhance the outcomes of interventions for children. Indeed, Watchel & Carter (2008) found that mothers who were more emotionally resolved to their child’s diagnosis of autism showed greater use of verbal and non verbal scaffolding to enhance their children’s play and consequently were more reciprocal and there was greater mutual enjoyment in the interaction.

- All of the parents commented upon the loss of the future they had anticipated for their child. Sylvia, Katie and Scott all made direct reference to the loss of the life they thought they were going to have. This reflects Rogers (2007) finding that parents lose their ‘imagined future’ of their child and their perceived expectations for their ‘normal child’ are challenged. I consider it essential that professionals recognise that parents are not only adapting to their child’s diagnosis but also the impact the diagnosis will have in the future. I would suggest that this significant loss is rarely acknowledged by professionals.

Research Question 4
To what extent does the ASD pathway help and support parents through the feelings of grief and loss which may accompany a diagnosis?
The majority of parents did not feel that the pathway provided emotional support in the period after their child was diagnosed with autism. As I conducted my review of the literature, and gained a deeper understanding of the emotional impact upon parents of a diagnosis of autism, I suspected that the sample would report a lack of emotional support. Nevertheless I was humbled by the frank descriptions the sample made of their unmet needs. Their views supported those of the parents in Waters et al’s (2008) study that there is a need for counselling, post diagnosis, to help them to cope with their feelings of despair and depression.

The sample reported that significant people had helped and supported them emotionally during their child’s diagnosis. They observed that this support tended to be given on an ‘ad hoc’ basis. Each parent was able to name a person who had been particularly important to them on their diagnostic journey. The sample valued the personal attributes of the practitioner more that their knowledge of autism. The Portage Home Visiting Service was praised by all of the families they had supported. Although these practitioners undoubtedly had expertise in the field of autism it was the relationship they had forged with the families which they were commended for. The importance of the personal attributes of the professionals who provide support has not, to my knowledge, been documented in the existing literature.

The parents support group, TOPS, was highly valued by parents as were other opportunities to meet people in similar situations. This is supportive of the literature which emphasises that it is important to meet other parents who have children with similar needs (Waters et al, 2008; Osborne & Reed, 2006; Mansell & Morris, 2004). My sample reported that sharing experiences was beneficial. Sylvia felt more confident in her ability to parent a child with autism, whilst another parent reported that she felt empowered that she could give advice based upon her own experience. When I have facilitated parent support groups I have
considered there to be great value in parents sharing information and experiences. The findings of this research have confirmed this for me. Nevertheless some of the parents gave reasons as to why support groups were not helpful, such as not wanting the leave their child, and the timing of the meetings. These are factors which need to be taken into account when planning future groups.

- All of the respondents reported that a diagnosis of autism had placed great stress on the family and had impacted upon their normal family life. My analysis identified that a diagnosis of autism results, in most cases, in a loss of normal family life. All but one of the parents reported that there were specific situations they avoided, for example, going on holiday, taking their children to play at friend’s houses and going into town. These views support the findings of Dillenburger et al (2010) and Swanepoel (2003). Scott and Lisa both commented upon the way in which autism had placed a significant strain upon their relationship with their partners. When I interviewed them both I was struck by the honestly of their anecdotes. They reinforced to me that it is imperative that we gain an understanding of the impact of autism upon the whole family if we want to provide the correct support to them. Although family support was not explicitly mentioned by the sample the data would suggest that the current ASD pre school pathway does not provide family support following a diagnosis.

5.2 Limitations of the research
I have considered various issues pertaining to the limitations of the research and a critique of the methodology. These are discussed below.

My research questions meant that I would be exploring the thoughts, feelings and emotions of the parents in my sample thus, the implication for the methods I used was to adopt an interpretivist paradigm. When designing my study I debated whether to obtain additional quantitative measures. The two additional sources of data collection I considered were:
• Collating a rating scale around levels of satisfaction which could be distributed via a questionnaire to a wider sample of parents.

• Obtaining information about parent’s current level of stress using the Parental Stress Index.

I decided to continue with my original design as I felt that obtaining such quantitative measures may have detracted from the rich, detailed data I hoped to obtain by interviewing them. With hindsight I do feel that a rating scale may have enhanced my study. If I was starting over I would consider adopting a post positivist paradigm. In addition to interviewing the sample of eight parents I would have devised a simple satisfaction scale, and distributed a paper questionnaire to all of the families who had gone through the pre school diagnostic pathway. I feel that such a quantitative measure may have allowed me to draw more measurable conclusions.

My sample size was modest and this could be viewed as a limitation of the research. I was reassured that other, well cited studies, in the literature also had small sample sizes (Midence & O’Neill, 1999; Boushey, 2001). I amassed a significant amount of data in this research and spent several days transcribing all the taped interviews. I would question whether it would have been practical to have a larger sample size due to the time limitations placed upon me due to work and family commitments and the university deadlines. It is also important to document that I considered that I had begun to reach a ‘saturation point’ in the data obtained from the parents after the first five interviews. Strauss & Corbin (1998) suggest that saturation is a “matter of degree” and should be concerned with reaching the point where the acquisition of new data “becomes counter productive” and that “the new” discovered does not add anything to the overall story, model, theory or framework (p 136). Although the parents reported their own personal anecdotes the essence of the story they told me about their child’s diagnosis of autism, and their experience of the pathway, was reasonably consistent. This reassured me that a larger sample size may not have enhanced my findings.
I had hoped to meet with parents after my initial analysis of their interview transcripts to ‘check out’ my findings. Due to time limitations I was unable to return to the parents I interviewed and seek their view as to whether I had captured the essence of their experience of the diagnostic pathway. I consider such a ‘member check’ would have improved the reliability of my findings.

I conducted ‘insider’ research and I discussed the difficulties this could cause in the Methodology Chapter. I did not feel that my position as an insider researcher led me, consciously or unconsciously, to look for certain findings and ignore others. Nevertheless, I am mindful that the research findings could be open to criticism by the wider audience due to this methodological decision. The most significant issue that being an ‘insider researcher’ has presented to me is in my considerations of how to feedback my findings to colleagues within the multi agency teams. I have arranged to feedback to the team on completion of my thesis. It is imperative that the positive and negative aspects are fed back to colleagues but I need to ensure that this is done in a sensitive way.

I have reported upon the parent’s feelings of grief and loss in a discrete subsection of my results. When I was analysing the data I spent a considerable length of time debating whether to present my findings as five main themes which depicted the staged model of grief and loss. It could be argued that all of the coded data could have been sorted in this way. For example some of the parents’ initial beliefs that their child did not have difficulties despite evidence to the contrary could be coded as denial and the quest for information after the diagnosis could have been coded as seeking resolution. I decided against this interpretation of the data as I was concerned that it would oversimplify the parents’ experience.

Qualitative research allows one to focus upon the detail and quality of an experience, and understand it as it is constructed by the participants. Thus, it does not regularly aim to produce results which can be generalised. When considering whether my findings are generalisable I found it useful to consider Marshall (1992, 1996) cited Robson (2002) who makes a distinction between
internal and external generalisability. Internal generalisability relates to whether findings can be generalised within the specific setting that the research has been conducted. External generalisability occurs when one’s findings are generalisable to other settings and populations.

This research sought the views of a small sample, of eight parents, on their local ASD pathway for the diagnosis and identification of autism in pre-school children. I obtained rich and detailed data which gave an insight into the experience of this specific sample of parents before, during, and after their children were diagnosed with autism. Hence I acknowledge that my findings can only be said to have internal generalisability. They are specific to the research setting and are not generalisable to other people, settings or times than the ones studied.

I also recognise that caution must be taken when claiming that my findings have internal generalisability. I had a very small sample of eight parents all of whom agreed to participate in the research. Would other parents who did not want to participate in the study, or had not been asked to do so, have a very different perception of the pathway? This study did not seek the views of parents who did not receive a diagnosis of autism for their child. They too may have had a very different perception of the diagnostic pathway.

Although my research aimed to obtain the views of parents on their local ASD diagnostic pathway I would suggest that by relating my findings to the existing literature I can, to some extent, make them more generalisable to the wider population. There is much discussion about generalisability in the literature around case study methodology. Pettigrew (1985) postulates that “case studies are useful in developing and refining generalisable concepts and that multiple case studies can lead to generalisations in terms of propositions” (cited p87). Similarity Yin (1984) addresses the commonly asked questions of case study research “how can you generalise from a single case?” (p 21). Yin (1994) argues that “when a previously developed theory is used as a template with which to compare the empirical results of the case study. If two or more case studies are shown to support the same theory, replication can be claimed”
Many of my findings supported those of previous researchers, who had sought the views of parents diagnosis of autism (Waters et al, 2008; Mansell & Morris, 2004; Nissenbaum et al, 2002; Graungaard & Skov, 2006 etc). I would therefore argue that my findings have, to some degree, external generalisability.

The value of generalisability of studies is also discussed by Holstein and Gubrium (1995), who suggested that the importance of this is superseded by the ability to be able to replicate a study. Lewis and Lindsay (2000) argue that if a study can be replicated and similar findings made, they can be generalized to an extended population over time. I feel confident that my study could be replicated by others. By including a step by step guide of the thematic analysis I undertook future researchers will be able to adhere closely to the process I followed. However, as I adopted an interpretivist paradigm, and I worked alone to interpret the data, I recognise that a different individual may have drawn alternative conclusions from the data. By asking a colleague to independently collate the initial codes I had identified from the data I endeavoured to minimise bias in my findings.

5.3 Personal reflections
This has been an emotive and interesting piece of research to conduct and write up. It has given me a unique insight into the reality of having a child with autism. I consider myself to be very privileged that the parents I interviewed were willing to share their experience of the journey from initial concern, to coping with the diagnosis of autism. Each parent told me their own unique story: I was struck that despite their experiences being so different, common themes ran through each. I was humbled by the emotional trauma that was reported to me and the strength that the families displayed coping with the diagnosis.

I think it was very important that I was able to immerse myself in the relevant literature prior to conducting my research and this gave me a preliminary insight into the issues that parents encountered during the diagnostic period. However, I would suggest that reading the literature does not allow the researcher to truly appreciate the huge impact a diagnosis has on individuals.
Whilst I enjoyed meeting the parents and interviewing them, it was, at times, a harrowing experience. When writing up my research I re-read Bruce and Schultz’s (2002) paper and realised that the act of conducting this research had provided the parents an opportunity to debrief about their diagnosis. This was personified by Debbie who told me that this was the first time she had spoken to any other person about her feelings around her son’s diagnosis. Her appreciation that I listened was very important to me and made me feel that, regardless of the research I was conducting, my time had been well spent.

I was aware that the effect of interviewing the parents at home may have biased the responses that they gave me. I would hypothesise that they felt relaxed and comfortable in familiar surroundings and this was reflected in the frankness of their interview responses. Had I conducted the interviews in a clinic based setting I may have obtained a different, less forthright, view of the diagnostic pathway.

I found the process of writing the Results and Discussion Chapter to be a particularly challenging one. All of the comments made by the parents were very powerful and I had to be selective as to which quotations best illustrated my findings. Each time I chose not to report what a parent had said I felt regret and guilt that a part of their story was not being told.

I have spent the past ten years working with many children and families who have autism. This research has made me reflect on my practice and I consider that I am more cognisant of the grief process that parents are navigating themselves through. When I work with parents who have just received a diagnosis of autism I am more sensitive to their needs.

When I am involved in planning meetings at the CDU I am aware that I have gained a much better understanding of the grief process that parents go through. In the past I have regarded the planning meeting to be a rather mechanical process where professionals outline their care plans. I now view it to have a different purpose. For many families it is their first opportunity to explore
their initial feelings of grief and loss with a professional. What I have recognised is that, for many families, having the opportunity to talk and explore how they are feeling is more important than professionals offering them solutions to problems.

At the planning meeting parents frequently seek the professionals opinion on the long-term out comes for the child. This is an impossible question to answer and parents are told that no two individuals with autism present in the same way so it is not possible to speculate. As a professional I have been of the opinion that this is a truthful response. Since I have conducted this research I now view this question in a different way. Perhaps the parents need to be able to have hope to project themselves to the future?

As a practitioner I work with parents who appear to be engaged in a constant battle with the LA. It could be postulated that some of these parents have not resolved their feelings about their child’s diagnosis and continue to feel angry. I would hypothesise, that by furthering our understanding of the feelings of grief and loss that parents experience when their child is diagnosed with a disability, we may be able to work more effectively with some of these parents. Could the significant amount of professional time taken up with re-assessments and appeals against LA decisions have been directed in a more positive way for the child? In many instances having empathy and affording them time to discuss their angry feelings may be much more beneficial to them than providing them with resources for their child.

For several years I have facilitated a support group for preschool parents who have a child with autism or suspected social communication difficulties. I have found this to be one of the most rewarding elements of my work and the discussions I had with parents during this research emphasised to me the importance of such groups. It was with great sadness that, following my data collection, we were told that due to budget cuts it can no longer be funded. Whilst writing up this thesis I have strengthened my resolve to challenge this decision as I consider it to be a crucial resource for many of the families I work with.
5. 4 Contribution to knowledge and theory
This research has made a unique contribution to our knowledge about parent’s perceptions of the pre school ASD diagnostic pathway at a local level. The study identified factors which the parents in the sample valued in the local pathway. These included having their initial concerns about their child listened to, the assessment day and the subsequent planning meeting. By identifying areas of unmet need in the existing pathway I have been able to gain knowledge about ways to make the pathway more effective for parents in the future. For example by ensuring a better professional awareness of the ‘red flags’ for autism, provision of written information about the diagnostic process, and access to emotional and social support post diagnosis.

The study has also reinforced that it is imperative that the disclosure of a diagnosis of autism is sensitively handled by professionals. This knowledge has been cascaded to colleagues to ensure that this is facilitated. The research has extended knowledge of the impact a diagnosis of autism has upon the family: it places great stress on the family and impacts upon family life.

Previous research has identified the crucial role that professionals have in supporting families when, during and after a child is diagnosed with autism. A finding of this research was that parents placed more importance upon the personal characteristics of a professional than their knowledge of autism. As far as the researcher is aware, this is the first study to have stated this explicitly. This is a unique contribution to our knowledge of parental perceptions of diagnosis.

In general, the findings of this research support the existing body of literature around parent’s experiences of diagnosis of autism. However, the majority of the studies discussed in the literature review have small sample sizes and provide a ‘snapshot’ of the experiences and feelings of a small cohort of parents in a specific area. Lewis and Lindsay (2000) have suggested that studies which have similar findings can be generalized to a population over time. The themes I identified in this research are supportive of the previous research and replicate
many of their findings. It could therefore be argued that my findings contribute to our emerging knowledge base, of parents’ experience of diagnosis of autism, at a national level.

There is a small but important body of literature which has considered the feelings of grief and loss experienced by parents of children who receive a diagnosis of autism. This research furthers our understanding of the grief and loss that parents experience when their child is diagnosed with autism. I was able to use the Stage Model of Loss (Kubler-Ross 1969) to structure my report of the parents' emotional experiences in the post diagnostic period. However the parents in my sample did not describe that they had experienced the feelings associated with these stages in a uniformed way. I would conclude that this study builds on previous research by O'Brien (2007) and that it contributes to the theory that parents experience an ambiguous loss when their child is diagnosed with autism.

The research found that parents do not only experience feelings of grief and loss in the post diagnostic period. Indeed parents in this study reported feelings of shock, denial, upset and adjustment prior to their child being given a diagnosis. This knowledge can be applied: both at a local and wider level, to further develop services and resources to support parents and their families when their child is diagnosed with autism.

5.5 Implications for practice
The participants in this study were willing to share their experience with me to improve the diagnostic pathway for other families. It is therefore important that the findings are used to improve the existing practice. I have identified different ways to realise this.

- I intend to write a short paper describing the current research, documenting its findings and make the following recommendations for changes to the existing pre-school pathway. This will be fed back to commissioners, the Multi Agency Autism Team and the parents I interviewed.
• The information that is provided to parents about the autism pathway both pre and post diagnosis needs to be revised and improved. This research has indicated that parents would value a clear description of the ADOS assessment and approximate times scales for each part of the diagnostic process. We need to collate an accessible, parent friendly pack of information that can be provided immediately after the diagnosis. It would be beneficial if parent’s views of the proposed resources were obtained.

• Consideration needs to be given to the way in which parents are prepared for a possible diagnosis of autism. There is currently an agreed work up and the professionals involved in the multi agency team have a tacit agreement that no family will be considered for a formal diagnostic assessment until they are considered to be ‘ready’. However whilst the majority of the sample indicated that they understood what would happen on the assessment day, many did not expect a diagnosis of autism to be the final outcome. A recommendation will therefore be made to the multi agency team that a ‘preparation’ meeting needs to be made explicit in the pathway and an agreed protocol in place.

• The period after diagnosis was one where parents search for information. I would agree with Whittaker’s (2002) view that this is a way of coping with their child’s diagnosis. I conclude that professionals play a crucial role at this time as they can guide parents to good quality information. I would argue that consideration needs to be given to rolling out a scheme, such as the Earlybird programme, which all parents are given the opportunity to access. I hope that this research provides strong evidence to support such timely interventions. To this end I intend to present a paper to the commissioners in the LA in which I work arguing the case for a more formalised scheme to be put into place.
It is interesting and useful to explore the grief cycle that parents go through, following diagnosis, for a number of reasons. All of the parents I interviewed described their immediate reactions to the diagnosis and feelings of shock, isolation and upset were mentioned by the whole cohort. Several parents suggested that they would have benefited from the opportunity to discuss their feelings with professionals in the period immediately after diagnosis. In response to this I have had discussions with the Psychology Service manager and negotiated that I will run a pilot project over the coming months and offer a debrief to parents following the diagnosis.

As these findings have been obtained from a modest sample of 8 parents I accept that their generalisability is limited. However, I intend to make use of the main themes I identified to devise a simple satisfaction scale, which can be given to parents in the period after diagnosis, in order that quantitative data can be amassed about parent’s experience of diagnosis. The practical issues raised by the parents about diagnosis can be measured by such a scale.

5.6 Future areas of study
As I wrote my thesis and considered my findings within the context of the existing literature I identified some areas of future study.

My analysis of the parent’s interview transcripts has indicated that parents go through a process of adapting to their child’s autism. However, this does not occur in a linear way and different events prompt parents to describe different emotions which are akin to those identified in models of grief and loss.

Having affirmed to myself that parents do go through a grief process following the diagnosis of autism I feel that it would be appropriate to investigate these feelings in much more depth. I feel that the logical next step for this research will be to focus in on the stages of grief and parental adjustment. We need to determine whether parents are able to move forward or can not get past their
grief. I would suggest that mothers and fathers grieve very differently and this is borne out in the literature. Professionals need to consider how we can support both parents and meet their unique set of needs.

All of the parents were able to tell me, verbatim, how the professionals had delivered the news that their child was autistic. The majority of the interviewees reported this to be a negative experience and told me that professionals were blunt or lacked empathy. The literature suggests that parents perceptions of disclosure of disability is negative and they ‘often hate the messenger’ (Nissenbaum, 2002). A future area of study may be to obtain footage of the sharing the news meeting and seek the views of the family and the professionals who attended the meeting.

In my discussion with parents I became aware that many were using coping mechanisms, such as searching for information and sharing narratives with others at support groups. A future area of study would be to investigate the coping mechanisms of parents of children with autism. This information would enhance the design of post diagnostic support packages.

“Nobody asks how you feel about it at the time, about the process….to be quite honest I don’t think they bloody want to know…. do they! “ Debbie
REFERENCES


Gupta, A. & Singhal, N (2005) Psychosocial support for families of children with autism Asia Pacific Disability Rehabilitation Journal 16 (2) 62-83


Ritzer, G. (1975) Sociology a Multiple Paradigm Science, Boston, Allyn & Bacon


Woodgate, R, L., Ateah, C. & Secco, L (2008) Living in a world of our own: The experience of parents who have a child with autism *Qualitative Health Research*, 18 (8), 1075-1083


Appendix 1a

What will happen next?

Reports from the inter-disciplinary assessment morning will be sent to you. The care plan will detail the services which are to be involved.

The Speech and Language Therapist will provide information about the therapy programme(s) which will be put into effect for your child.

If your child is not yet attending nursery/school, the Portage Home Visitor will continue to visit regularly and will work closely with the Speech and Language Therapist.

The Specialist Health Visitor will arrange a review of the care plan, or if your child is attending nursery/school (or is about to start), the review may take place there.

The Education Psychologist will discuss with you arrangements for your child’s education, and refer your child for additional support if necessary.

Contact Numbers

Children with Communication and Social Interaction Difficulties in Early Childhood

Information for Parents and Carers on Diagnosis and Assessment

Social Interaction Difficulties in Early Childhood

Information on Diagnosis and Assessment

Your child’s paediatrician has recommended an inter-disciplinary assessment to find out what your child’s needs are and to provide a diagnosis if appropriate.

Professionals from a number of disciplines are involved in this so that a complete picture of strengths and needs can be obtained, and so that effective plans can be made for you and your child. You will be invited to the Tree House for an assessment morning, at the end of which we will meet to discuss our findings with you.

The professionals who may be involved are:

- **Consultant Paediatrician**
  A doctor who specialises in the medical care of children and has an interest in the development of children.

- **Educational Psychologist**
  A psychologist who works in the education services. He/she assesses a child at home and/or nursery to provide a profile of a child’s strengths and weaknesses, which can assist in programme planning and the identification of suitable educational provision.

- **Speech and Language Therapist**
  He/she assesses and treats children who have difficulties in the development of language and communication.

- **Specialist Health Visitor**
  A member of the Child Development Team who co-ordinates the inter-disciplinary assessment process and visits parents to discuss care planning needs.

- **Portage Home Visitor**
  A member of the Portage home-visiting team who has received additional training and experience in autistic spectrum disorders. She may well already visit you at home to work with you and your child and to provide advice and support.

Prior to the assessment morning, the Specialist Health Visitor will visit you at home to explain the programme for the morning and answer any questions you may have. The Educational Psychologist and Portage Home Visitor, if appropriate, will also have visited you to assess your child in a familiar setting, such as home or nursery.

You are welcome to bring a relative or friend to the assessment morning.

On the assessment morning:

- The programme for the morning will be discussed with you, any questions answered and you will be asked what you wish to achieve from the assessment morning.

- You and the Consultant Paediatrician will meet to discuss any medical issues and the child and family history.

- Your child will be assessed by a Speech and Language Therapist and the Consultant Paediatrician using the Autism Diagnostic Observation Schedule. Videotaping will be used to provide you and the team with a record of the assessment and one of the team will observe and record the session. Your child may spend some time alone with the team members, or may stay with you if this is more appropriate.

- The team will meet to discuss their findings. Usually, this meeting is also attended by the Educational Psychologist and the Portage Home Visitor.

- The team will meet to discuss their findings and arrange a planning meeting.

Planning Meeting:

- The following month, you will be invited back for a care planning meeting attended by the team, any other professionals involved with your child and yourselves. You will be invited to suggest other professionals you would like to attend.
Appendix 6: Referral and Assessment Pathway for Under-Fives with Suspected ASDs

NB. Health Visitors should refer to Community SALT if concerned about autism/social communication, only if CDT criteria for referral are not met (i.e. positive SOGS, positive CHAT would be referred to CDT). A child with just a positive CHAT should be referred for community SALT screening (within 12 weeks). There may be a subsequent referral to CDT.

Agreed by inter-Disciplinary Assessment Team 04 12 02
Appendix 2

ADOS-G

The Autism Diagnostic Observation Schedule (ADOS) is recommended in several Best Practice Guideline as an appropriate standardised diagnostic observation tool. It includes a standardised administration of interactive activities introduced by the examiner, designed to elicit social interaction, communication and repetitive behaviours for the purpose of diagnosing ASD. The measure takes 30 – 60 minutes to administer and consists of four different modules for use with individuals of different developmental and language levels. Activities vary based on the language level and chronological age of the child. For example, Modules 1 and 2, which are designed for use with children with a language level of less than 48 months, include playing with bubbles, the release of an inflated balloon, and a pretend birthday party. Modules 3 and 4, which are designed for older children, adolescents, and adults who have the ability to use complex sentences and talk about things that are not immediately present, include questions about emotions and relationships as well as retelling a story from a book and demonstrating a routine activity. For each task, a hierarchy of ‘presses’ or social structures is provided. During the administration of a task a child is able to take as much initiative as possible. If this does not occur, the examiner gradually makes the tasks more specific and increasingly structures the situation to observe the child’s response. The ADOS is standardised in terms of the materials used, the activities presented, the examiner introduction of activities, the hierarchical sequence of social presses provided by the examiner and the way behaviours are coded or scored. Following the administration of the ADOS, behaviours are coded using a 0 to 3 point coding system, with a 0 indicating that the behaviour is not abnormal in the way specified in the coding description and a 3 indicating that a behaviour is abnormal and interferes in some way with the child’s functioning.

ADOS classifications are based on specific coded behaviours that are included in a scoring algorithm using the DSM-IV diagnostic criteria, resulting in a Communication score, a Reciprocal Social Interaction score and a Total score
(Sum of the Communication and Reciprocal Social Interaction scores) Scores are compared with an algorithm cut-off score for autism or the more broadly defined ASD in each of these areas. If the child’s score meets or exceeds cut-offs in all three areas, they are considered to meet criteria for that classification on the measure.

**ADI-R**

The Autism Diagnostic Interview-Revised (ADI-R) is a semi structured interview that is conducted with the parents or primary caregiver and is designed to elicit the full range of information needed to verify a diagnosis of autistic disorder to ASD diagnosis. Diagnostic decisions are based on algorithm items.

Appendix 3a

Parental Views of the Pre-School Diagnostic Pathway for autism

An Invitation to take part in a Study

The aim of my study is to evaluate parents' perceptions of the diagnosis of autism and investigate met and unmet needs in families. The study will involve asking parents who have had a pre-school child diagnosed with autism about their experience. The purpose of getting a better understanding of parents' views about the diagnosis of autism is to ensure that we are supporting children and families in the best possible way in the future.

Taking part will involve talking to me (Madeleine Laird, Educational Psychologist) about your family’s experience of the diagnostic pathway. I am interested in your views about your child's assessment and your feelings throughout the diagnostic journey. I plan to take notes and tape record our conversations, I will then study them in order to pick out the important themes. You can say as much or as little as you want to. Your comments will be treated confidentially and at the end of the study the notes and tape recordings will be destroyed. When I write up the study it will include some of your views but you will remain anonymous. I can be contacted on                    if you would like to obtain more information about the study.

Your participation in this study is voluntary but I am very grateful for your contributions. I will contact you by telephone in the next few weeks to find out whether you are willing to take part and, if so, make a convenient appointment to meet you.

Thank You

Madeleine Laird

Child and Educational Psychologist
August 2010
Dear Lisa,

As we discussed on the telephone I am currently undertaking an evaluation of parent’s perceptions of the diagnosis of autism and investigating met and unmet needs in families. This is part of my doctoral research at the University of Manchester.

Thank you for agreeing to meet with me to discuss your experience. I am looking forward to visiting you at home on Monday 27th September at 10.30am. I expect the interview to take about an hour.

The main topics included in the interview are as follows

- Your experience about the time before you received the diagnosis
- Your views about the assessment, the feedback and planning meeting
- What support you received, or felt that you needed, during and post diagnosis
- The impact upon your family

Many thanks for your help and time.

Yours sincerely

Madeleine Laird

Child and Educational Psychologist
Appendix 4

Pen pictures

Scott
Scott lives with his wife and two children. His eldest child, Summer, was diagnosed with autism when she was 3 years and 1 month old. The family noted a regression in Summers’ skills when she was 13 months old. They sought support from their Health Visitor when Summer was 2 years old. The family received support from the Portage Service, Speech and Language Therapist, Occupational Therapist, Paediatrician and the Educational Psychology Service before and during diagnosis. Following her diagnosis Summer accessed a resourced nursery provision and then transferred to a specialist school provision for children with severe learning difficulties.

Ravi
Ravi lives with his wife and two children. His eldest child, Noor was diagnosed with autism when he was 3 years 2 months old. The family raised initial concerns about his development when he turned two and his speech was not developing. The family received support from the Portage Service and Speech and Language Therapy Service prior to his diagnosis. He was also under the care of the Paediatrician and Educational Psychologist. Since his diagnosis Noor has accessed a resourced nursery provision. He then transferred to a mainstream school with a resourced unit for children with moderate learning difficulties. The family have English as an additional language.

Amber
Amber lives with her husband and three children. Her oldest child Noah was diagnosed with autism when he was 3 years and 9 months old. When Noah entered his local mainstream nursery Amber and her husband were aware that he had delayed speech development and was not toilet trained. Staff at the nursery raised concerns about his social communication skills and pursued a referral to the Paediatrician. The Paediatrician then referred Noah to the Educational Psychologist and the Speech and Language Therapy Service.
Noah spent an additional year in the mainstream nursery with support following his diagnosis of autism. He then transferred to a mainstream school with a resourced unit for children with moderate learning difficulties.

**Jane**
Jane lives with her partner and their only child. Gemma was diagnosed with autism when she was 3 years and 4 months old. Concern was raised about Gemma’s development by staff at a playgroup she attended, they made a referral to the Health Visitor. Prior to her diagnosis Gemma received input from the Portage Service, Speech and Language Therapy and Occupational Therapy Service. She was also under the care of the Paediatrician and Educational Psychologist. Following her diagnosis Gemma accessed a resourced nursery provision and transferred to a specialist school provision for children with complex needs.

**Debbie**
Debbie lives with her partner and five children. Sam is her third child: he has regular contact with his Dad. Sam received a diagnosis of autism when he was 4 years 5 months old. Debbie first became concerned about his development when he was 18 months old and reported that she raised this several times with her Health Visitor. When Sam was 3 years 4 months old the Health Visitor referred him to Portage. They then requested involvement from a Paediatrician, Speech and Language Therapist and the Educational Psychologist. Sam attended a resourced nursery provision throughout the diagnostic period and subsequently accessed a specialist school provision for children with severe learning difficulties.

**Lisa**
Lisa lives with her partner and her three children. Jayden is her middle child. Jayden received a diagnosis of autism when he was 2 years and 6 months. Lisa first became concerned about his development when he was 8 months old and raised concern with the Health Visitor. The Health Visitor referred him to the Paediatrician when he was 22 months. Prior to his diagnosis Jayden was supported by the Portage Service, Speech and Language Therapy Service and
known to Educational Psychology. Following his diagnosis he accessed a resourced nursery provision and then transferred to a specialist school provision for children with severe learning difficulties.

**Katie**
Katie lives at home with her husband and three children. Her middle child, Ollie, received a diagnosis of autism when he was 3 years and 5 months old. He was referred to the CDU by his health visitor when a developmental assessment at 2 years of age showed him to have a significant delay in his acquisition of skills. Prior to diagnosis Ollie accessed support from the Portage Service, Speech and Language Therapy Service and was known to the Educational Psychology Service. Following his diagnosis he was allocated a resourced nursery provision and then transferred to a specialist school provision for children with complex needs.

**Sylvia**
Sylvia lives at home with her partner and their two children. Her son Tom was diagnosed with an autistic Spectrum Disorder when he was 2 years 9 months old. Sylvia raised concerns about his language development when he was 18 months old and sought a referral to Speech and Language Therapy. They then made referrals to the Paediatrician, and Educational Psychologist. Tom was supported by these agencies prior to diagnosis. Following diagnosis he continued to access a private day nursery with additional support and then transferred to a resourced nursery provision. He then allocated a placement at a specialist school provision for children with complex learning difficulties.
Appendix 5

Semi Structured Interview Aide Memoir

Pre Diagnosis
Which factors led them to make the diagnosis?

What were the timescales for your child’s diagnosis from initial concern to the assessment?

How did you feel the assessment day went for you?

Sharing the news
Had you expected them to make a diagnosis?

How clear was the information you received?

What did you find helpful about the process of getting a diagnosis?
  ● Practically
  ● Personally

Could it have been improved?

Communication with professionals
Which professionals did you see around the time of the diagnosis?

Did you feel supported by professionals?

Was there anything or person in particular which stands out for you?

Have you any comments about your communications with professionals?
Information given
Around the time of the diagnosis did you receive much information about autism?

What information did you as parents want at this time?

Feelings
Have you any comments to make about the time before you received the diagnosis and the difficulties that you experienced?

Please could you try to put into words how you felt when you received the diagnosis?

How do you feel some time after the diagnosis?

Do you feel that you were supported emotionally during the process? If so by whom?

Have you any suggestions how we could help to support other people through the process having experienced it yourselves?

Impact on the family
Have you any comments to make about the impact of autism upon your family at a personal or practical level?

How do your other children accept living with autism?

What thoughts do you have about the future?

Support
Have you been offered access to support services?

Have you any comments to make about these services?
On a personal level who supports you - family/ friends etc?

Do you have links with other parents of children with autism- if so how did this come about?

How much advice and support from professionals do you receive at this stage of you son/ daughters life

**Conclusion**
Overall do you have any comments about the diagnostic procedures and your experience of this?
Appendix 6

Deficiencies of Human Analyst cited Robson (2002) p460

Deficiencies of the human as analyst

1. Data overload  Limitations on the amount of data that can be dealt with (too much to receive, process and remember).

2. First impressions  Early input makes a large impression so that subsequent revision is resisted.

3. Information availability  Information which is difficult to get hold of gets less attention than that which is easier to obtain.

4. Positive instances  There is a tendency to ignore information conflicting with hypotheses already held, and to emphasise information that confirms them.

5. Internal consistency  There is a tendency to discount the novel and unusual.

6. Uneven reliability  The fact that some sources are more reliable than others tends to be ignored.

7. Missing information  Something for which information is incomplete tends to be devalued.

8. Revision of hypothesis  There is a tendency either to over or to under-react to new information.

9. Fictional base  The tendency to compare with a base or average when no base is available.

10. Confidence in judgement  Excessive confidence is rested on one’s judgement once it is made.

11. Co-occurrence  Co-occurrence tends to be interrupted as strong evidence for correlation.

12. Inconsistency  Repeated evaluation of the same data tend to differ.

(Adapted and abridged from Sadler 1981, pp 27-30.)
Appendix 7

Example of transcript- extract from Debbie’s interview

When did you initially become concerned about Sam’s needs?

Well I became concerned about his when he was about two years old

Uh huh

Emmm …and my…em, my health visitor [cough].. had just emigrated to Australia so I got a different one. and eh .. to be quite frank she was a bloody half wit. I kept saying ‘there is something wrong’….this woman didn’t even have kids.. she was only young. She was like ‘oh you know, boys are slower blah de blah’ and I said ‘are you not listening to me’. ..‘it’s not he’s slower … he could speak, he was communicating and it’s like he’s regressed’

Yeah

‘oh no well give it a bit longer, give it a bit longer’ she said. An them em .. it must have been getting on for a year, I just ended up… well…[cough]. being quite blunt and saying ‘listen if you do not have my son referred to somebody, then I will be sticking a complaint in about you’ …‘I am telling you, you can’t tell me what my son is like’…it was like a slow regression kind of thing

Yeah

And I said it’s not necessarily what he doesn’t say…umm…, it’s like he doesn’t understand and isn’t tuning into anything, he was slowly but surely going into his own little world….That was the worrying thing because he used to say things to communicate then it was that slow regression, it was quite a while before you noticed.

Sort of happened quite slowly?

That was it… try saying this to the stupid woman [taps head] . So…, eventually in the end she did refer us but then that was something like five months before he got an appointment …eh ..I think it was speech and language first of all

Uh huh

And then like months after that before, you know the paediatrician got involved so it was …ummm…quite a while. I think he was four before he got his diagnosis

So did you feel that was a really long time?

Yeah

Did you find once you had been referred to the right people did they share the same concerns with you very quickly?
Eh .. well ..obviously they knew that something wasn’t quite right and . but ….they wasn’t too convinced it was autism at first because .em…. Sam.. Sam displays certain behaviour which is quite opposite to certain autistic children, he is always had good eye contact, that has never been an issue. He isn’t disconnected or anything like that so .. he has empathy to other children, like if they were sick…so there are certain things where…

He doesn’t tick the boxes ..... 

Yeah, so they weren’t quite sure. When he was in nursery they did an assessment on him .because that was like the best place to sort of see him …

So he wasn’t seen at the hospital?

No, they couldn’t get him into the hospital. They tried to get him to the speech and language appointment …flipping heck [laughs] ... we had to leave, he was freaking out….different building he can’t cope

Is he always like that when you go out somewhere different?

You see he has got a bit better….but then he was absolutely horrendous. They did his assessment at nursery and me and his Dad we watched, he didn’t see us.

Oh yes it’s got the one way mirror..

Then the doctor and the speech and language therapist they came in and spoke to us and the consultant who did the assessment….Dr L…my god...I think…I am not saying he isn’t good ..I mean he is a doctor.. but in that situation, the man was .. just [shakes head] .. I couldn’t believe he did this to a parent. He was sat there, even the teacher, the speech and language therapist….. .when he came in he was asking questions

Uh huh

He as asking ... he kept turning round and asking his dad. I was saying he doesn’t live with his Dad he lives with me. He kept saying Debbie will know .. and it was like I wasn’t there. And then, when he said right .. this is autism.. I got , you know a bit upset and the stupid man, turned round and said ‘why are you upset’. I said ‘I beg your pardon’. ‘why are you upset?’ . I thought I don’t believe this…so subsequently I have had no other dealings with him, I got another Doctor. Because... obviously I complained. Even the nursery teacher complained cos it was just unbelievable how so…so detached this man was surely that’s not the first time he has told parents that?

Uh huh

He must have an idea....

Some empathy
Well the thing is, he must … you know, god… even if he doesn’t have children himself which I think he has it stands to reason that you would be upset. Luckily for him I was that upset otherwise I would have given him a piece of mind that’s for sure. So I found… eh…. that day, it was really difficult, especially the attitude, it was so sort of.. making me feel like there was something wrong with me for being upset. It’s a natural reaction for a parent, you’re not going to sit there and go ..[claps her hands]… lovely. Of course, even then when you do know yourself…your expecting that result ..still….it’s still a shock

*So you didn’t feel as if he really included you …?*

Yeah it was like I wasn’t really there and his manner.. it was unbelievable

*Up until that assessment day, had you felt it went ok?*

Yeah Portage got involved, Eileen explained, you know what different professionals were going to do and obviously Nursery came along. Luckily the staff at nursery were absolutely brilliant. I couldn’t fault them.
Appendix 8

Initial Codes

Professional’s reaction to initial concern (personal)
Professional's reaction to initial concern (practical)
Parents knowing there is an initial problem
Noticing changes in their child
Denial about initial problem
Unaware of a problem
Parents/ profs want different things
Diagnosis takes time
Length of time before initial contact
Manner of professional
Parents challenging professionals
Feelings about length of time for diagnosis
Reactions/ feelings to diagnosis
Being ignored re concerns
Parent's perception of assessment day
Lack of help prior to diagnosis
Professional’s attitude at assessment day
Significant people positive and negative
Planning meeting
Hope not a problem
Relationships suffer
Way of dealing with diagnosis
Future is ambiguous
Loss of control
Information given
Ambiguity around why assessing
Denial of autism
Ways to improve pre diagnosis
Ways to improve post diagnosis
Surviving being a parent of a child with autism
Stopping doing things
Frustration
Blame
Impact on siblings
Feelings of stress
Feel lucky
Child doesn’t look different – hidden condition
Parents opinion of how treated by prof
Loss of normality
Lack of understanding of terms
Anger
Feeling let down
Being prepared for a diagnosis
No support post diagnosis
Grief
Issues around ADOS
Too much emphasis on ADOS
Seeing a lot of professionals
How professionals shared the news
How parents feel they have been treated by professionals
Flexibility
Searching/ seeking information
Confidence in professionals
Feelings about the future
Telling others about the diagnosis
Needs to be personal to your child
Meeting people in similar situations
Hope
Info/ support parents want
Need for emotional support
Usefulness of support groups
Isolation
Shock
Ignorance about autism in the community
Holding it together
Upset
Need to plan for the future
Parents feel ready to pursue diagnosis
Worry
Listening to parents
Practical difficulties currently faced
Helpfulness of professional
Empathy is important
Normal models of parenting don’t work
Understanding
Being listened to
Label means support
Change
Coming to terms with diagnosis
Feeling supported
Impact on family life
Benefit of diagnosis
Knowledge of professional
Guilt
Support received
Impact on family life
Feelings around labels
Feeling in limbo
Parents are experts
Need time to get your head around
Optimism v’s worry
Appendix 9

Photo 1 Initial sort of codes

Photo 2 Sorting codes into initial themes
Photo 3 Refining themes

Photo 4 Identifying sub themes
Photo 5 Matching the coded extracts to the sub themes
**Appendix 10**

**DRAFT FOR CONSULTATION – NICE (2009)**

**Table 1.1 Preschool children (or equivalent mental age)**

<table>
<thead>
<tr>
<th>Social interaction and communication behaviours</th>
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<tbody>
<tr>
<td>• Delay in language development (babble or words)</td>
<td></td>
</tr>
<tr>
<td>• Lack of meeting eye gaze</td>
<td></td>
</tr>
<tr>
<td>• Lack of response to name despite normal hearing</td>
<td></td>
</tr>
<tr>
<td>• Relative lack of responsive social smiling</td>
<td></td>
</tr>
<tr>
<td>• Limited responsiveness to other people’s facial expression or feelings</td>
<td></td>
</tr>
<tr>
<td>• Rejection of cuddles</td>
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<tr>
<td>• Relative lack of social interest in others</td>
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<tr>
<td>• Lack of joint attention shown by lack of:</td>
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<tr>
<td>- gaze switching</td>
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<tr>
<td>- following a point</td>
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<tr>
<td>- using pointing at or showing objects to share interest</td>
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<tr>
<td>• Lack of gestures and facial expression to communicate (although may place adult’s hand on objects)</td>
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<tr>
<td>• Relative lack of sharing enjoyment</td>
<td></td>
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<tr>
<td>• Lack of imagination of others’ actions</td>
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<tr>
<td>• Lack of imagination and variety of pretend play</td>
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<tr>
<td>• Lack of initiation of social play with others</td>
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<tr>
<td>• Abnormal-sounding vocalisations</td>
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<tr>
<td>• Language present:</td>
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<tr>
<td>- odd or flat intonation</td>
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<tr>
<td>- frequent repetition of set words and phrases (‘echolalia’)</td>
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<tr>
<td>- reference to self as ‘you’ or ‘she/he’ beyond 3 years</td>
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<tr>
<td>• Limited and/or infrequent use of language for communication, for example use of single words although can speak in sentences</td>
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<table>
<thead>
<tr>
<th>Unusual and/or rigid/repetitive behaviours</th>
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<tbody>
<tr>
<td>• Unusual repetitive hand, finger and body mannerisms</td>
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<tr>
<td>• Highly repetitive and/or stereotyped play, for example opening and closing doors, spinning</td>
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<tr>
<td>• Over or under reactivity to sensory stimuli, for example textures, sounds, smells</td>
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<tr>
<td>• Extremes of emotional reactivity to change and/or new situations, insistence on things being ‘the same’</td>
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<tr>
<td>• Over-focused and/or unusual interests</td>
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<tr>
<td>• Excessive reaction to certain properties of food and/or extreme food fads</td>
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<tr>
<td>• Unusually negative response to the requests of others (demand avoidant behaviour)</td>
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</tbody>
</table>