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“I Want to Have a Path”: An Exploratory Study of
Parent Experience of Early Autism Diagnosis in
Massachusetts and Central Scotland

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Doctorate in Education

The University of Edinburgh

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Declaration

This is to certify that that the work contained within has been composed by me and is entirely my own work. No part of this thesis has been submitted for any other degree or professional qualification.

Ruth Glynne-Owen

May 2015

Contents

Acknowledgements.....	8
Abstract.....	10
Chapter 1: Introduction	12
1.1 Introduction to the Study.....	12
1.1.1 Research Aims.....	12
1.2 Introduction to Autism.....	13
1.2.1 The Diagnosis	14
1.2.2 Definition of Terms	15
1.2.3 Prevalence.....	17
1.3 Introduction to Research on Parents of Children with Autism	18
1.3.1 Experiences of Diagnosis.....	19
1.3.2 Limitations of the Current Research Paradigms	20
1.4 Introduction to Locations: The United States and Scotland	21
1.4.1 Differences in Policy and Practice	21
1.4.2 Massachusetts and Central Scotland	22
1.5 Introduction to the Researcher.....	23
1.5.1 Background to Researcher and Research Interests	24
1.5.2 Critical Incidents.....	25
1.5.3 Reflection on Researcher Position	26
1.6 Structure of this Thesis	28
Chapter 2: Review of the Literature.....	30
2.1 Introduction	30
2.1.1 Parameters and literature review process.....	31
2.2 Models of Disability.....	32
2.2.1 Structure of this Section.....	32
2.2.2 Defining Disability through Stigma and Difference.....	33
2.2.3 The Medical Model	35
2.2.4 The Social Model of Disability	38
2.2.5 The Minority Model of Disability	42
2.2.6 Summary and Implications for the Thesis.....	44
2.3 Conceptualising Autism	45

2.3.1 US and UK Research Focus.....	46
2.3.2 Autism and Media Conceptions.....	49
2.3.3 Summary of this Section	52
2.4 Experiences of parents of young children with autism.....	53
2.4.1 Family Research on Parents of Children with Disabilities.....	53
2.4.2 Research on Parents' Experience of the Diagnostic Process	60
2.4.3 The Literature on Parent Perceptions of Autism	71
2.5 Summary and Reflections on my Review of the Literature	73
2.5.1 Implications for this Thesis.....	74
Chapter 3 Policy Comparisons: US and UK.....	77
3 .1 Introduction	77
3.1.1 Structure	77
3.1.2 Parameters and Definition of Terms.....	78
3.1.3 Relevance of Policy: Considerations for This Study	79
3.2 Setting the Context	80
3.2.1 Economic Context	81
3.2.2 Policy Context	81
3.3 Policy Content	86
3.3.1 The Conceptualisation of Autism in Policy.....	86
3.3.2 'Parents as Partners' Discourse within Policy	94
3.4 Discussion.....	96
3.5 Research Questions	96
Chapter 4: Methodology and Methods	98
4.1 Introduction	98
4.1.1 Benefits of a Qualitative Paradigm	98
4.1.2 Ontological and Epistemological Position.....	100
4.1.3 Qualitative Methodologies	101
4.2 Symbolic Interactionism.....	104
4.2.1 Implications for this Study	104
4.2.2 Theoretical Origins.....	106
4.2.3 Action and Meaning.....	107
4.2.4 Social Interaction	107
4.2.5 Self.....	109

4.2.6 Criticisms and Limitations of the Approach	110
4.2.7 An Extended Interactionism.....	111
4.2.8 Implications for This Study.....	114
4.2.9 Symbolic Interactionism in Autism Research.....	115
4.3 Research Design and Methods.....	116
4.3.1 The Research Design	117
4.4 Research Method: Interviewing.....	120
4.4.1 The Interview	120
4.4.2 Limitations.....	122
4.5 Reflection: Validity and Reliability in Interview Research	123
4.5.1 Reflection on Dual Role of the Researcher	124
4.5.2 Reflections on Co Construction.....	126
4.6 Research Context : Locations	127
4.6.1 Western Boston	128
4.6.2 Central Scotland	129
4.6.3 Selecting the Sample Group.....	131
4.6.4 Participants	134
4.6.5 Arranging the Interviews.....	139
4.7 Ethics	140
4.7.1 Procedural Ethics	141
4.7.2 Ethics in Practice	143
4.8 Data Analysis	146
4.8.1 Transcription	147
4.8.2 Codes and Categories.....	148
4.8.3 Themes.....	148
Chapter 5: Findings, Analysis and Discussion: Part 1.....	151
5.1 Research Question 1	152
5.1.1 Theme 1: Identifying Difference	153
5.1.2 Theme 2: Feelings of Discomfort or Reassurance.....	157
5.1.3 Theme 3: Shock.....	162
5.1.4 Summary of Research Questions	166
5.2 Research Question 2	166
5.2.1 Theme 1: Professional Perspectives of Autism	168

5.2.2 Theme 2: Sense of Urgency.....	174
5.2.3 Theme 3: Finding a Pathway	180
5.2.4 Theme 4: Empowerment through Choice.....	182
5.2.5 Summary: Research Question 2.....	189
Chapter 6: Finding, Analysis and Discussion Part 2.....	191
6.1 Research Question 3	192
6.1.1 Theme 1: Autism Stereotypes and Stigma.....	193
6.1.2 Theme 3: Change through Interaction.....	199
6.1.3 Summary of Research Question 3.....	205
6.2 Research Question 4	206
6.2.1 Theme 1: Changing Perspectives	207
6.2.2 Theme 2: Adjustments in Aspirations.....	212
6.2.3 Theme 3: Hope.....	217
6.2.4 Summary of Research Question 4.....	218
Chapter 7 Conclusions	220
7.1 Introduction	220
7.1.1 Shared Conceptualisations of Autism	220
7.1.2 Impact of Policy on Parent Experience	224
7.1.3 Interactions with Others	227
7.1.4 The Impact of Choice and Control	230
7.2 Limitations of this Study.....	232
7.3 Implications of Results on Policy and Practice.....	235
7.4 Implications for Future Research.....	237
7.5 Conclusion.....	240
References	242
Appendix 1.1 Interview Schedule	300
Appendix 1.2 Information for Participants and Consent	302
Table 1.1 Differences in Diagnostic Terms (DSM IV and ICD 10)	16
Table 4.6 Participants.....	136
Fig 5.1 Codes to Themes... ..	152
Fig 5.2 Codes to Themes... ..	168
Fig 6.1 Codes to Themes... ..	192

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Abstract

Parents of children with autism have been identified across research as having unique experiences in comparison to parents of children with other disabilities. The focus to date has been on identifying factors impacting on parental well-being post-diagnosis, with some more recent studies looking more specifically at parent experience of the diagnostic process.

However, there is less literature that explores the impact that this diagnosis may have on parental perspectives of, and aspirations for, their child. In addition, within this current research, little is known about how parents of toddlers make meaning of their situation pre and post-diagnosis, with limited literature so far that looks at the influence that geographical location may have on this.

As an exploratory, qualitative study of parent experience of early autism diagnosis in Massachusetts and central Scotland, this thesis aimed to bridge this gap by investigating parents' experience in these early years, in two similar, yet contrasting settings with significant differences in policy and practice. Utilising Blumer's (1969) principles of symbolic interactionism, this thesis examined the factors that had an effect on participants' meaning making, drawing on extended premises of SI (Snow, 2001; Stryker, 2008) to explore the extent to which structural and social influences in each country may have impacted on this. It looked at the similarities and differences between parents' experiences of: the autism diagnostic process; access to, and engagement with, post-diagnosis services; changes in perceptions of autism over time; and whether perspectives of, and aspirations for, their child altered since diagnosis. All 18 participants (14 mothers and 4 fathers) had a child (13 boys and 5 girls) under 5 years old with a diagnosis of autism. Data were generated through semi-structured interviews, using open coding to group initial categories, before moving into interpretive, inductive analysis to identify wider themes. Findings highlighted key differences between policy and practice, which influenced parent experience in a number

of ways. In particular, the differences between the services and support available to young children with autism and their families in each location appeared to have a significant impact on participants.

However, this study also concluded that, in spite of differences in policy and practice, there were also a number of similarities in the ways in which parents made meaning and sense of their child's diagnosis. Interaction with other parents (both face to face and online) had a strong influence on this, alongside parents' exposure to media portrayals of autism, which were similar in both locations. Conversely, in spite of their experiences with a wide range of professionals, these interactions had a more limited effect overall on the perspectives that parents developed of their child. In addition, in spite of recognising previously held beliefs regarding stigma and stereotype in autism, all parents in this study actively rejected these perceptions after receiving a diagnosis for their child. Overall, data reflected a shared understanding of autism that crossed geographical and structural boundaries, with parents from both countries experiencing the same hopes, aspirations and fears for their child's future. These findings may have implications for policy considerations and for services in both locations delivering pre and post-diagnostic support, with potential for more positive outcomes overall for those receiving an early diagnosis for their child.

Chapter 1: Introduction

1.1 Introduction to the Study

This thesis is an exploratory, qualitative study that looks at parent experience of preschool autism diagnosis in two locations: central Scotland and Massachusetts. Using semi-structured interviews from 18 participants; this research considers similarities and differences in the experiences of the autism diagnostic process and post-diagnostic support services. It also looks at the ways in which parents make sense of these experiences and the factors that may impact on any changing perceptions of autism, alongside perspectives of, and aspirations for, their child.

In this chapter I present my research aims, followed by a brief introduction to autism and an explanation of the terms used in this study. I then look at some of the distinct challenges that this diagnosis may present to parents with young children, together with an overview of some of the issues that research on this topic has presented to date. Additionally, I discuss my choice of settings, highlighting some of the dynamics that make this comparison potentially meaningful in the field of autism and parent experience. Finally, I introduce myself as researcher, discussing the background to this study and the research questions, reflecting on my role as a professional in this field and the strengths and limitations this may present for this thesis.

1.1.1 Research Aims

The aim of this study is to explore the similarities and differences in the experiences of parents of children who have been diagnosed with autism before the age of 5 years, in Massachusetts and central Scotland. In considering the ways in which parents understand and make sense of their child's diagnosis and the factors which

influence this in both locations, this thesis seeks to make an original contribution to the literature on parenting children with autism. It also aims to bridge a clear gap in knowledge regarding the impact that geographical location and age of child may have on these experiences. In addition, as a qualitative study, I hope it can add to a small but growing body of research that uses interpretative methods and methodologies to explore rich descriptions of parents' understanding of autism, alongside their perspectives of, and aspirations for, their child. The results of this research will also potentially provide a critical insight into the lives and experiences of participants who have young children with this diagnosis and further extend current understanding in this area. Through a secondary focus on comparing policy context within each location, this study aims to highlight the possible impact that differences at this level may have on parent experiences overall, leading to a number of implications for further research and practice in this field.

1.2 Introduction to Autism

As Bilken *et al.* (2005) recognised in their ethnographic writing on autism: “It is inherently challenging to do qualitative enquiry in a field as highly medicalised as autism, for most of the language of the field assumes a shared, normative perspective of an observable reality.” (2005:11). However, when considering parents' experiences and perceptions, it is also necessary to have a thorough understanding of the medical aspects of the diagnosis and define these terms appropriately. Furthermore, when exploring the similarities and differences which may arise in parents' understanding of autism in this study, it is essential to look at the variations between diagnostic assessments across locations. In this section I look specifically at the diagnostic criteria and the potential challenges presented by the distinctions between the assessments used in each location, alongside a clarification of the terms I will be using.

I then briefly consider the current prevalence of autism across both countries before looking at some of the challenges that this diagnosis may present for parents with a young child.

1.2.1 The Diagnosis

Autism is defined in diagnostic terms as a life-long ‘pervasive developmental disorder’. It is characterised by delays and differences in an individual’s social, communication and language development (Wing, Gould and Gillberg, 2011) paired with difficulties with flexible thought processes (Jordan, 2001), and often issues with sensory processing (Tomchek and Dunn, 2007). Originally identified by Kanner in the early 1940s, it was initially regarded as a type of childhood schizophrenia. On assessing 11 children with shared psychological ‘disturbances’, Kanner developed a diagnostic profile for autism, claiming that:

All of the children’s activities and utterances are governed rigidly and consistently by the powerful desire for aloneness and sameness. Their world must seem to them to be made up of elements that, once they have been experienced in a certain setting or sequence, cannot be tolerated in any other setting or sequence; nor can the setting or sequence be tolerated without all the original ingredients in the identical spatial or chronologic order. (1944:249)

With the marked variations in the cognitive and language abilities of individuals with an autism diagnosis, it is also referred to as a ‘spectrum’ condition (Wing, 1996) and formal assessments use the categories of Pervasive Developmental Disorders or Autism Spectrum Disorders (ASDs) interchangeably to classify a number of different diagnoses that fit within this category. There are currently two diagnostic manuals used by paediatricians and psychologists worldwide to formally assess those presenting with the symptoms of autism; the *International Classification of Diseases 10* (ICD10)

(WHO, 1992) and the *Diagnostic and Statistical Manual V* (DSM V) (APA, 2013). For an individual to receive a diagnosis of an ASD they need to meet a number of specific criteria set out in one of these assessments. However, categories to define autism differ between the documents and, most notably for this study; there is variability in their use between Scotland and the United States. Although there are exceptions, currently Scottish diagnosticians are most likely to use the ICD 10, whereas practitioners in the US would use the DSM V (APA, 2013). In addition, it is important to observe that the DSM IV (APA, 1994) was still in use throughout the US when participants received their child's diagnosis.

1.2.2 Definition of Terms

With the distinction in the categories and language that these diagnostic documents use, it is important to briefly consider the impact this could have had on my research and explain my reasons for choosing to use 'autism' as the inclusive term to describe the diagnosis of all the children whose parents make up this study. As is clear from Table 1.1, there are a number of differences between the ICD 10 and DSM IV in terms of potential diagnoses for individuals with an autism spectrum disorder. In undertaking a study that looks at experiences of parents across these two locations, it is essential to be sensitive to the issues that this could present. This is particularly apparent when looking at the distinction between Pervasive Developmental Disorder (Not Otherwise Specified) (PDD-NOS) within the DSM IV and Atypical Autism versus Pervasive Developmental Disorder (unspecified) in the ICD 10. It appears that PDD-NOS was used within the DSM IV as an alternative to Autistic Disorder, where symptoms or onset may be atypical. This is in contrast to the ICD 10 classification, where PDD is still regarded as an alternative to Atypical Autism. Although there have been some differences in presentation recognised between children diagnosed with

Autistic Disorder and PDD-NOS (Hassan and Perry, 2011) it has also been argued that professionals within the US often use PDD NOS as an alternative when they are hesitant to use the term ‘autism’ (Filipek *et al.*, 1999) or where there is no alternative clinical definition (Walker *et al.*, 2004).

Table 1.2 Differences in Diagnostic Terms (DSM IV and ICD 10)

DSM IV	ICD 10
299.00 Autistic Disorder	F84.0 Childhood autism
299.80 Pervasive Developmental Disorder, Not Otherwise Specified	F84.1 Atypical autism .10 Atypicality in age of onset .11 Atypicality in symptomatology .12 Atypicality in both age of onset and symptomatology
299.80 Rett's Disorder	F84.2 Rett's syndrome
299.10 Childhood Disintegrative Disorder	F84.3 Other childhood disintegrative disorder F84.4 Overactive disorder associated with mental retardation and stereotyped movements
299.80 Asperger's Disorder	F84.5 Asperger's syndrome F84.8 Other pervasive developmental disorders F84.9 Pervasive developmental disorder, unspecified

As will be discussed in section 4.6.1, when selecting participants whose child had an early autism diagnosis, I included a number of children in the Massachusetts sample with a diagnosis of PDD-NOS as well as children who had an Autistic

Disorder diagnosis. Therefore, in order to maintain clarity within this thesis, I chose to use 'autism' as the inclusive term to describe the diagnosis of all the children whose parents make up this study and to describe the condition throughout¹. However, this does not mean that I did not recognise the potential differences within the range of clinical categories that make up the autism spectrum and the comparisons that these may have presented within the data. I remained sensitive to these potential variations across my data collection and analysis. In addition, it is useful to note that according to a recent study looking at the change in diagnostic terms between the DSM IV and DSM V, 91 percent of children who had previously received a PDD-NOS diagnosis would have been given an Autism Spectrum Diagnosis under the new criteria (Huerta *et al.*, 2014).

1.2.3 Prevalence

Since being classified by Kanner in the 1940s, autism has become the most widely researched of all childhood disorders (Wolff, 2004) and has undergone a growth in prevalence, particularly over the past 20 years (Matson and Kozlowski, 2011; Eyal *et al.*, 2010). In 2010 it was estimated that there were 52 million cases of autism worldwide (Baxter *et al.*, 2014) which would equate to a prevalence of 1 in 132. With this perceived increase in diagnosis there have been some claims that there is now an autism epidemic (Gillberg *et al.*, 2006; Eyal *et al.*, 2010; Leonard *et al.*, 2010). A number of researchers attributed this rise to environmental factors (Rimland, 2000; Kirby, 2005; Good, 2009) whilst others accredited the increase to an ever widening diagnostic profile (e.g. Wing, 1996; Fombonne, 2003) or an 'epidemic of discovery' (Grinker, 2007) as professionals have become more accomplished at recognising signs and symptoms.

¹ Where appropriate within my review of the literature I have adopted the terminology used by authors in their studies.

It is also important to note that it is the recording of autism diagnoses that has increased through better recognition and monitoring, which may not mean a significant rise in actual prevalence of the condition (Taylor, 2006). However, diagnostic statistics within the US appear to show a significant rise in incidence from 1 in 150 in 2000 to 1 in 68 in 2010 (Baoi, 2014). This is in direct contrast to Taylor, Jick and Maclaughlin's 2013 study which looked at autism prevalence in the UK between 2004 and 2010 and found no notable increase. In addition, diagnosis rates between Massachusetts and Scotland vary considerably for early year's children (see section 2.4.2), a point discussed in further detail within Chapters 3 and 4.

1.3 Introduction to Research on Parents of Children with Autism

Parents of children with autism have been positioned within a wide range of research as a distinct group who have somewhat unique experiences in comparison to parents of children with other conditions. This is particularly true of studies that have looked at the emotional impact autism can have on parent stress levels (Estes *et al.*, 2009; Rivard *et al.*, 2014) and coping strategies (Hastings and Brown, 2002; Hall and Graff, 2011). Although this literature will be reviewed in detail in Chapter 2, I will now briefly consider the main issues that parents might experience when pursuing and receiving an early autism diagnosis for their child, before looking more specifically at the literature on parents of children with autism and the space that this thesis aims to fill.

1.3.1 Experiences of Diagnosis

Autism diagnosis is often a long process (Mansell and Morris, 2004) and can involve a number of different professionals (Siklos and Kerns, 2007) with the

potential for mixed feelings of satisfaction and dissatisfaction for parents (Howlin and Asgharian, 1999; Brogan and Knussen, 2003). Follow up support and services can also be a contentious issue depending on a number of factors, including access to therapy and relationships with professionals (Sansosti, Lavik, and Sansosti 2012; Hutton and Caron, 2005). In addition, in spite of the medical aspects of diagnosis, there are as yet no specific bio markers. Instead, evaluation relies on clinical assessment alone (Mercati and Chaste, 2015) with standardised diagnostic tools based on the measurability of observable behaviours (Kim, 2013). In common with many other behaviourally based disorders, this observation in itself can never be wholly objective, and will always be affected by an individual's reaction to the environment, to the diagnostician and to the various stimuli that is being presented (Duchan, 1998). This aspect of the diagnostic process also presents distinct challenges to parents, who may feel that their child's assessment is based on an observation of a difficult day rather than a true reflection of their child (e.g. Avdi, Brough and Griffin, 2000). In addition, whilst there is clearly a biological element to the condition (e.g. Hacking, 1999) there is also a social component. Nadesan argues that:

“...the social factors involved in its identification, representation, interpretation, remediation and performance are the most important factors in the determination of what it means to be autistic, for individuals, for families and for society.” (2005:2)

As a professional working in this field I recognise and respect the efficacy of many of the standardised assessment tools and the level of training required to use them. However, the medical diagnosis alone cannot always reflect the reality of what autism means to families who have a young child diagnosed with the condition and this is something that this thesis aims to explore.

1.3.2 Limitations of the Current Research Paradigms

Although there is a large body of research on parents within the autism field, the main focus to date has been on quantitative studies relating to stress and coping, alongside ongoing analysis of parent/ child interactions, and more recently parent input into autism intervention. Parent stress levels in these studies have often been linked with the severity of a child's condition (Bebko, Konstantareas, & Springer, 1987; Freeman, Perry, & Factor, 1991; Kasari and Sigman, 1997), particularly with regard to challenging behaviours (Hastings, 2002; Hastings and Brown, 2002). However, recently there has been more of a focus emerging on the bidirectional relationship between parent distress and child problem behaviour (e.g. Zaidman-Zait *et al.*, 2014) and a study by Falk, Norris and Quinn (2014) argued that parent cognitions and socio economic support may actually be greater predictors of parent mental health than child specific variables.

In addition, there is a growing body of research exploring the benefits and challenges of parental involvement in early intervention therapies for parent and child. In recent studies, the role of parents in their child's therapy is being regarded as critical in supporting child progress (Steiner *et al.*, 2012; Dawson and Rogers, 2009; Rogers and Dawson, 2010), and parent input has been identified as a fundamental factor in alleviating possible symptoms in babies under 12 months old (Rogers *et al.*, 2014).

However, there have been fewer studies in this field which are based on qualitative methods and methodologies. Although research has identified that typically there are higher levels of stress in parents of children with autism, that coping strategies for this group are often distinct and that they are encouraged to be involved in their child's intervention early on, there is more limited detail within current literature that focuses

on the ways in which these factors may contribute to parents' understanding of autism and the diagnostic process. In addition, there are only a small number of studies that use interview data to explore parents' experiences of the diagnostic journey, particularly in the early years. Finally, and most crucially for this thesis, as yet there are no qualitative comparative studies on how parents in different locations may experience this early diagnosis of autism and the factors which may influence this.

1.4 Introduction to Locations: The United States and Scotland

Economically and culturally the United States and Scotland have many similarities. For example, both have a shared language and are developed countries with good health and education services for children under 5 years. In addition, each location has specific policies regarding disability and special educational needs.

However, there are also some key variations between the two countries in terms of autism diagnosis and autism intervention, and it is the impact of these differences that this thesis aims to explore.

1.4.1 Differences in Policy and Practice

In spite of similarities in context, the focus and content of policy on special education and autism varies greatly between the two countries. With over \$2 billion in funding for the early screening, diagnosis and treatment of autism in the early years, the *Combating Autism Act* (2006) has created a unique climate within the United States for parents with young children with autism. With no similar legislation in the United Kingdom, this has resulted in significant differences in policy aims and application between the two locations, which have in turn impacted on mainstream and specialist service levels and provisions in each setting.

Although this will be considered in greater detail within Chapter 3, it is important to acknowledge from the outset that, alongside a marked contrast in prevalence rates for the condition between the two countries, the levels of support and intervention available to children with this diagnosis are also considerably different. Services provided to families who have children with an early diagnosis of autism (before 5 years of age) vary in their intensity and methodology. In the United States, children under 3 are given access to early post-diagnosis therapy services which are government funded in many areas, including Massachusetts. With Applied Behaviour Analysis being the only specialist therapy advised by the American Medical Council (National Research Council, 2001) the majority of families receive an intensive, behavioural approach derived from Lovaas (1987). At 3 years old the state provides children with placements in mainstream or ‘inclusive’ preschool settings. Similarly, the Scottish Government mainly provides inclusive mainstream provision for children aged 3 and over. However, specialist services are more limited in intensity and use a holistic approach to therapy, with early intensive behavioural interventions regarded as having a limited evidence base overall (SIGN, 2007).

1.4.2 Massachusetts and Central Scotland

As a small scale study, this thesis cannot present findings from parental experiences across the whole of the United States and Scotland. Instead I chose to focus on a single location within each country. Although I would agree that “social science should rely on imaginative comparison rather than replication”, it is still important to exercise some elements of control within qualitative research (Bechhofer and Patterson, 2000:9), which is why I have chosen two locations that are similar in many ways.

The area of North West Massachusetts (western Boston) was selected for a number of reasons. Firstly, it is an area with mixed demographics which will be discussed in more detail in section 4.6. Secondly, Massachusetts is regarded as a particularly well resourced State for early autism diagnosis, family support and intensive specialist services (MacFarlane and Kanaya, 2009; Berman *et al.*, 2001). It also has a wide range of government funded and private early intervention services available (Massachusetts Autism Commission, 2013), alongside inclusive mainstream preschool provision. Lastly, I have worked directly with families with young children with autism in this area and in doing so have firsthand experience of the levels of support and services available to parents. This knowledge, alongside professional connections across the State, meant that I had access to a large and varied group of parents who were linked with a range of practitioners and services.

Central Scotland was selected as a location for similar reasons. It is also an area of mixed demographics, which will be explored in more detail in Chapter 4 and as a professional based there I had access to a wide range of possible interviewees. I was also running a service that supported families across Scotland who had a young child diagnosed with autism, and the central Scotland Health Boards were some of the only locations across the country where early diagnosis was being offered. Families within this area were also being provided with NHS and Education services for their child, so the element of comparison between provision could be considered between the groups.

1.5 Introduction to the Researcher

It is important when writing on a topic that I am personally invested in to reflect on and acknowledge my position, interests, allegiances and beliefs (Griffiths, 1998). As both a researcher and professional working in the field of autism and early

intervention, this thesis has drawn on elements of practitioner research and it is essential to acknowledge the role of self within this study. It is also crucial to the validity of this research that I recognise that the journey to my research questions, the choice of analytical framework and the overall analysis of my data involved value judgements and some element of partiality, particularly because I am personally invested in the field I am researching. Although I will look at reflection in greater detail in section 4.8, I will now briefly consider the background to this research and my research questions, through focusing on my previous experiences and the critical incidents that led to my interest in this study.

1.5.1 Background to Researcher and Research Interests

Having worked as an early year's teacher in a number of mainstream and special schools, I left education in 2007 to set up an independent service providing home based support to families who had young children diagnosed with autism. I had recently completed a Masters in Autism and Education and, through my studies and research, had become more aware of a growing body of research in early therapeutic intervention for young children with autism. I decided to explore this further and extend my knowledge in this area. As much of this research was based in the United States, I went there to undertake training in two specialist approaches that I felt would be most beneficial to my continuing professional development.

I travelled to California in 2010, and then Massachusetts in 2011, to complete intensive training in both the Early Start Denver Model (ESDM: Vismara and Rogers, 2008; Rogers and Dawson, 2010) and Floortime (DIR: Greenspan and Weilder, 2006) respectively. A critical element of training in both these methods was spending time with families of preschool children who had an autism diagnosis. It was the experiences I had with these parents of young children, alongside the direct comparison I had gained from working similar situations in Scotland that led to an

increased interest in parent experience of the diagnosis process and how their understanding of autism might be influenced by a number of similar or different factors in each location.

1.5.2 Critical Incidents

Employing a more critically reflective paradigm, I would refer to the experiences that I had as ‘critical incidents’ in my journey both as a professional and a researcher.

According to Tripp (1993) critical incidents are:

... produced by the way that we look at a situation: a critical incident is an interpretation of the significance of an event. To take something as a critical incident is a value judgement we make. (1993:8)

Using both reflection-in-action and reflection-on-action (Schon, 1983; 1987) I was particularly drawn to two incidents that occurred during my visits. I spent time both during and after these encounters considering them in detail and feel that my reflections on these have had a key impact on the development of my research focus. Both involved the responses of parents to their child’s situation post-diagnosis, and directly related to their perspectives of, and aspirations for, their child. These appeared to be markedly different to the experiences I had had with parents in similar situations in Scotland.

The first occurred in California in 2010. As part of my ESDM training we worked with a 2 year old who was significantly challenged by his difficulties. However, his mother remained incredibly positive and confident about his future potential. In a discussion after a therapy session, she spoke of her ambition for him to be in mainstream school, and her conviction and belief was remarkable. Her aspirations and response to her child’s diagnosis was noticeably different from parents I had

encountered in Scotland, who had often been more inclined to talk about their perceived limitations of their child and worries regarding their future. Having followed this child's progress after the course, I learned that he did successfully transition into a mainstream preschool programme later that year and had age appropriate speech and development. I returned to the UK with a new interest in parental perspective and the factors which might impact on individual perceptions of autism, alongside their aspirations for and perspectives of their diagnosed child.

In Massachusetts in 2011 I had a similar experience with a parent whose 3 year old daughter had a recent diagnosis of autism and had just started to speak. On observing their session, the mother spoke confidently about her child going to college and her aspirations for a successful future in graduate employment. This secure optimism was again distinctly different from the interactions I had with families in similar situations in Scotland. In contrast to the US, the majority of exchanges with parents I had worked with across the UK had been less positive. These attitudes appeared to have developed in response to the information that parents had received from their paediatrician at diagnosis or through post-diagnosis interactions with other professionals, which seemed to influence their perspectives of and aspirations for their child overall. Reflecting on these experiences and the potential difference in parent reactions to their child's autism, I was drawn to consider the factors that may have impacted on parental experience, perspectives and aspirations across these locations.

1.5.3 Reflection on Researcher Position

Having considered the experiences that led me to this study, it is clear that my role as practitioner in this field has directly influenced my research interests. However, as will be discussed in more detail in section 4.8.2, the fact that I am acknowledging potential issues presented by the dual role of practitioner and

researcher from the outset means that I am acutely aware of the challenges that this may present and the need for continual reflection on this throughout the research process. Griffiths (2011) argued that this dual identity is not necessarily a limitation to a research study that explores human experiences. On the contrary:

We all learn to make judgements, including academic ones, within human relationships. Indeed, only if we understand the meanings and nuances of a human situation, can we be in a position to assess it at all (p.185).

As a professional working within the field of autism I regularly advocate for early identification and early intervention for children presenting with this diagnosis. In addition, I am also a researcher who believes in social justice with regard to disability and disability rights. Within this paradigm of equality, I would place myself at a distance from the medical model of disability, where classification can be synonymous with the labelling and ‘othering’ of young children. However, I am also aware that through my work in early intervention, I am situating myself within a discourse which I am not comfortable with. Margaret Minow (1985) in her writing on bilingualism and special education, refers to this type of professional tension as a ‘dilemma of difference’ (p.160). She does not offer a solution to this dilemma, but instead talks of how professionals within this predicament should learn to live with the conflicts that this presents, through reflection rather than attempting a conceptual escape: “Thinking about such tensions differently, however, can help us learn to live with them.” (p.202).

The way in which we classify or identify young children will always create discourses of difference and the way in which I view autism as a condition that can benefit from specialist early support will remain a dilemma throughout this study. However, this does not mean that I disregard the value of inclusive, mainstream services and this needs to be clarified from the outset. On the contrary, whilst I believe

that young children with autism need some level of specialist intervention in order to reach their full potential, I also believe that this can be delivered effectively within a mainstream environment.

In addition, it should be acknowledged that as a practitioner it has been challenging at times not to see the benefits of one approach or one country as more advantageous to young children with autism and their families, particularly with regard to policy and practice differences. However, as a researcher I have attempted to remain balanced throughout, so that the conclusions made reflect a true and valid overview of my data. This was a key focus throughout this thesis, and something that I returned to repeatedly during the research process, in order that this study might be considered a valid contribution to knowledge in a field to which I am so dedicated.

1.6 Structure of this Thesis

In attempting to reflect and make sense of the experiences of individual families who have a child diagnosed with autism, I felt that it was important to acknowledge the dilemmas and tensions as a researcher/ practitioner in this first chapter, before setting out to answer my research questions. Through an overview of the literature in Chapter 2 I consider the ways in which autism is conceptualised both as a disability and as a distinct diagnosis, before looking at the body of literature on parents' experiences and using this to explore the ways in which such a diagnosis may have impacted on the experiences and perceptions of parents across my locations.

In Chapter 3 this overview of literature is extended through a specific focus on policy context and content. Initially I explore disability and autism policies in the US and the UK more generally before I look at Scotland and Massachusetts in greater detail. Throughout this chapter I look at the similarities and differences between policy contexts and focus, before examining the content and themes of some key documents.

This is a valuable addition to understanding the wider perspectives on autism in both locations and sets the scene for this study, before I introduce the research questions that I intend to answer.

In Chapter 4 I describe my research design and methods, including a discussion of the benefits and limitations of these, and approaches to data collection and analysis. This chapter also includes a section on my methodology and my analytical framework. Chapters 5 and 6 consist of my findings for each of my research questions and my analysis of the data, alongside a discussion section for each research question. Finally, in Chapter 7, I discuss my conclusions and bring together the critical findings from my data and discuss any potential implications for future research and practice in each location.

Chapter 2: Review of the Literature

2.1 Introduction

In this chapter I set the scene for my research questions through an evaluation of what is already known within this field, alongside an acknowledgement of the gaps in the existing literature that this study aims to fill. This review is divided into three sections: Models of Disability, Conceptualisations of Autism, and Autism Parent Research. Firstly, as this thesis is primarily concerned with the experiences and meaning making of parents going through the diagnostic process for their child in two separate locations, it is useful to examine the wider literature on conceptualisations, or models, of disability that are most prevalent across both settings. In doing so, this sets the scene for any potential similarities or differences in policy and practice that will be explored further in Chapter 3, alongside providing a background to some of the factors which may influence the ways in which participants may make sense of their child's diagnosis. Secondly, in order to begin to explore the ways in which parents' may perceive autism, it is useful for this thesis to have a broad overview of the ways in which this diagnosis is understood across a range of research and media genres. Finally, I look at the literature concerning parent experience of autism and the ways in which this group has been represented in research to date. This section briefly explores family research on parents with children with other disabilities, before looking at research that focuses directly on parent experience of autism pre and post-diagnosis. As this thesis uses qualitative interview data, I am particularly interested in the presence of parent perspectives within current studies relating to the experiences of their experiences of having a child diagnosed with autism and this will be a final focus in this chapter. Reviewing the literature across these three key areas will not

only help frame my research questions and analysis, but show that there is a real space for this study in terms of adding to and augmenting the literature on parent experience in this field.

2.1.1 Parameters and literature review process

When writing anything that touches on the subject of autism, it is essential to acknowledge that there is an incredibly wide range of research topics and genres covered within this field. It is a subject that crosses many disciplines including genetics, biology, psychology, neurology and education. As discussed in the introduction to this thesis, it has become the most widely researched of all childhood disorders (Wolff, 2004), with a significant amount of research within this field focusing on evaluating treatment programmes (Odom *et al.*, 2010), mainly through the utilisation of quantitative methods (Glynne-Owen, 2010; Rocque, 2010). Research in this field has been largely focused on quantitative methods to assess and evaluate parent mental health, with a particular emphasis on stress and coping and it can be harder to find information that reflects lived experience of parents of children with autism (Hastings, 2002).

In order to undertake a detailed review of the literature in this field and keep it relevant to this thesis, I attempted to set boundaries in terms of the type and content of the studies that I searched for and that I read. However, it was difficult within an area as broad as autism, and an issue as extensive as parent experience, to disregard any one discipline, as I often found something of consequence to this thesis contained within a domain I may have thought previously to disregard. Although this is a qualitative study, I included a high number of references to quantitative literature because they have been of significance to this thesis, particularly with regard to family research in autism and early autism intervention approaches.

2.2 Models of Disability

When attempting to understand the many challenges that an autism diagnosis may present for parents, it is important to consider the potential impact of wider perceptions of disability, which have developed over time and across locations.

Although there are various opinions regarding the status of autism as either disability or difference (Baron-Cohen, 2000; Kapp, *et al.*, 2013) it is defined within policy and practice across both the US and the UK as a disability. Therefore, when beginning to unpack the issues around the conceptualisations of autism that may be relevant to parents in this study, I believe it is critical to situate this exploration within the literature on perspectives and models of disability that exist across research disciplines and cultures in each location.

It is important to recognise from the outset that individuals, and in this case parents of children with an autism diagnosis, will make sense of their experiences drawing on a wide variety of interactions (Bogdan and Biklen, 2003). It is not expected that participants in this study were necessarily aware of, or chose to situate their perception of their child's autism within, one specific model of disability. However, one model may have had more influence over another within policy and practice in a particular location, which may in turn have impacted directly or indirectly on parents, and this is something I will develop further in Chapter 3 when I explore policy context and content across the two settings.

2.2.1 Structure of this Section

Firstly, I focus primarily on the wider interpretation of what disability has come to mean within developed countries such as the US and the UK, looking at the notions of stigma and difference and normality and abnormality that have come to be

synonymous with this category across the Western world (Barnes, Oliver and Barton, 2002). I then look more closely at three key models of disability; the medical, social and minority models. The distinctions between the medical and social model in particular have been the main thrust of disability discussion in the social sciences over the past century (Barnes, Mercer and Shakespeare, 1999) and this was prevalent across my literature search from the two locations. Therefore, these perspectives of disability may be an important element in understanding some of the potential similarities and variations in perception and experience that occurred for parents in my two settings.

As the focus of this thesis is on parents who have a preschool child diagnosed with autism, I selected the models of disability that I felt may have had the biggest potential impact on parent experiences, as well as on policy and practice across my two locations. I chose to concentrate on the medical, the social and the minority models in particular because they were the most prevalent across my search of disability research in the US and the UK. This choice does not mean that I disregard other models. On the contrary, there are elements of these that will also be relevant to this thesis, such as the economic and charity models, and these will be referenced and discussed when and if there are connections to be made.

In my discussions between these three models, I will be concentrating on the principal features of each and how they compare to or oppose one another before looking at their potential impact on parental perceptions of autism.

2.2.2 Defining Disability through Stigma and Difference

It is important to note that the term ‘disability’ can mean many things to many people, with a multitude of classifications, designations and implications making it difficult to define (Oliver, 1996; Grech, 2009). For some it is seen as being “remediable and social” (Hull, 1998:199) for others it is something more clearly

defined in terms of impairment (Hughes and Patterson, 1997). It is not a fixed and absolute category (Lang, 2001) and has been viewed through many lenses across cultures and history (Barnes, Oliver and Barton, 2002; Lang, 2001; Oliver, 1990a). However, it is nearly always value- laden and “charged with emotion” (Brown, 2002:34) which makes it a difficult concept to attempt to describe and a complex issue for parents to make meaning of with regards to their child.

Throughout history, disability has been viewed in terms of deviance and difference (Goffman, 1986, Susman, 1994; Trammell, 2009). Persons with impairments have existed “from the dawn of time” (Barnes, Oliver and Barton, 2002:

9) and have been present worldwide. In his writing on stigma, Goffman (1986) described various forms of difference and how these may be stigmatised by those he calls the ‘normals’. He referred to ‘abnormalities of the body’ as being one category for stigma, and how those with physical impairments may be negatively categorised by this ‘undesired difference’:

By definition, of course, we believe the person with the stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. (1986:4)

In this discussion of stigma, he explored the various ways in which society classifies individuals by the attributes they feel are ‘ordinary and natural’ for members of constructed categories. He observed that the unconscious assumptions and categories we make are based on the outward appearance of others, building a ‘virtual social identity’ before their ‘actual social identity’ is confirmed. He also highlighted the impact that the possession, or lack, of an attribute can have in placing someone ‘outside’ of the category available to them. Stigma, according to Goffman, reduces someone in our minds “...from a whole and usual person to a tainted, discounted one.”

(1986:3). In categorising people by conventional expectations, society differentiates between what is 'normal' and what is 'deviant', classifying those that do not possess stigma as 'the normals', expanding Durkheim's (1982) understanding of normal through the 'abnormal'.

People who are classified as disabled, through physical or sensory impairments in particular, have consistently experienced a range of negative social attitudes (Livneh, 1982; Hirschberger, Florian and Mikulincer, 2005), including "horror, fear, anxiety, hostility, distrust, pity, over protection and patronizing behaviour." (Barton, 1996:8). Although the term 'normal' was not added to the English Dictionary until 1840 (Davis, 2006), disabled persons have long been viewed as abnormal and often seen as a burden on society (Barnes, 1992). It has been claimed that traditionally "...responses to the needs of persons with disabilities have oscillated between charity on the one hand and welfarism on the other." (Pothier and Devlin, 2006:1) and those categorised as disabled need help from those who are able. As stated by Hughes and Paterson, 1997: "The response to impairment in modernity has been essentially anthropoemic: disabled people have been cast in the role of the other and cast out." (p.325) which has led to those classified as disabled becoming a largely marginalised and disenfranchised group.

2.2.3 The Medical Model

Although medical thinking is regarded as being the main lens through which disability has been viewed through the centuries in both the United Kingdom (Oliver, 1990b) and the United States (Hahn, 1985), a more specific 'medical model' view first emerged in the 1960s, when disability became something to be classified for welfare and social benefits (Nagi, 1965; Harris, 1971). This medical, or individual model viewed disability as a problem within the individual, equating it with limitations or

defects, where medical knowledge and practice determined treatment (Barnes, Mercer and Shakespeare, 1999). Although it has now been rejected by many disability researchers in favour of more socio political conceptualisations of disablement, it is still prominent within many aspects of life (Sullivan, 2011) including policy (Hwang and Brandon, 2012) and media perceptions (Areheart, 2008). It also remains of particular relevance to those with intellectual disabilities or behavioural conditions and their families, as it is regarded by many as still being the prevalent focus when identifying and supporting individuals with these diagnoses (McKenzie, 2013).

Before 1980, the majority of policy frameworks, as well as sociological writing and research, were rooted in a Parsonian paradigm, which defined disability primarily through medical symptoms and impairments (Oliver and Barnes, 1993). Parsons believed that illness impeded psychological as well as physical abilities, and sick people needed to be relieved of their normal responsibilities and treated (Gerhardt, 1979). Disability was regarded as ‘sickness’ from which people needed to be cured (Kaplan 2000; Rovner, 2003). With the individual’s psychological and physical impairments being portrayed as the cause of disability, disability was considered as being out with what is normal (Oliver and Barnes, 1993) and as an individual burden and tragedy (Linton, 2006). This view of disability as a medical need emphasised the limitations of individuals’ physical and mental functioning and regarded these issues as being situated purely within the person.

Most notably perhaps for parents experiencing the autism diagnosis process for a young child, medical model thinking viewed, and still views, disability as a problem requiring medical intervention, which can in turn give doctors and other professionals control and responsibility to ‘fix’ these issues (Ralston and Ho, 2010).

2.2.3.1 Autism and the Continued Impact of Medical Thinking

In spite of a move toward a more socio-political paradigm in the majority of disability literature, it is apparent from my literature search that autism research still remains focused on a largely medical interpretation of disability. As a relatively new diagnosis, the main focus of the majority of research from the 1940s until the 1980s was to establish “...the distinctness of this category, developing internally consistent criteria for diagnosis and differentiating it from other categories...” (Jordan, 2009:128). As behaviourally defined conditions do not fit with the traditional view of disability as an observable difference, it is argued that autism is an invisible disability (Ong Dean, 2005) which appears to have been left behind in the push for a more social model view of physical or sensory impairments. Osteen (2008) maintained that this is perhaps due to the disregard that researchers seem to show for those with cognitive impairments:

Though the brain is, of course, an organ, the effects of neurological disabilities are both systemic and subtle. In many cases (aside from conditions such as Down syndrome or fragile X syndrome) there are no obvious physical abnormalities. Thus, theories that address visual enfreakment, pictorial representation, and so forth, don't fit well. (2008:5)

In addition, an emphasis on accountability and higher standards in areas such as education and health has contributed to a more concerted focus on classifying young children in terms of their diagnosis (Florian *et al.*, 2006) and this is particularly true of autism in the United States (see section 3.2), where diagnosis is often linked directly to intervention (MacFarlane and Kanaya, 2009).

Although it is a model that is now rejected by many researchers, policy makers and individuals with disabilities, it could be argued that for many parents of young

children with autism there is an element of acceptance of the medical conceptualisation of autism through their pursuit of diagnosis, alongside their focus on finding and securing treatment and intervention for their child (Landsman, 2005). This might at times be seen as being at odds with the social model thinking from a neuro diversity perspective of autism (Barry, 2012). However, in spite of the negative connotations associated with a medical view, it can also have a positive impact on some aspects of parent experience, particularly in the early stages of their child's diagnosis. A number of studies have concluded that utilising a medical model framework to understand the diagnosis in the early years can in actual fact be empowering for parents in many ways, such as helping them to legitimise their child's behaviour and unusual development and to seek out an explanation for their child's problems and secure appropriate services (Florian *et al.*, 2006; Farrugia, 2009; Russell and Norwich, 2012; Ong Dean, 2005). However, there is room for parents to negotiate between both a medical and social concept of disability when attempting to make sense of their child's diagnosis and this is something I will discuss in more depth after introducing the background to the social model.

2.2.4 The Social Model of Disability

The social model was first developed in the United Kingdom in the 1970s by disability activists, as a response to the perceived oppressive nature of the medical view (Lang, 2001). In contrast to these previous interpretations, they rejected the idea that disability was a medical condition. Instead it was argued that individuals were disabled by the restrictions placed on them by the society in which they lived (Oliver, 1996). Advocated strongly by UK-based disability researchers, this model became the "ideological litmus test of disability politics in Britain." (Shakespeare and Watson, 2002:3), and policies and organisations were viewed as either progressive, or not,

dependent on their promotion of social model principles (ibid). It is a model that still remains prevalent today within research, policy and practice across the UK and it is viewed as the dominant UK-specific reaction to disability rights (Barnes, 2012).

The term ‘Social Model’ came to the forefront of disability research in 1983 when Oliver first made a definite distinction between a medical or ‘individual model’ and a ‘social model’ (Oliver, 1990b, 2013). Advocates of this newly defined social perspective regarded medicalization of any form of disability to be fundamentally wrong (Oliver, 1990b, 1995) because disability was distinct from impairment and “...disability has nothing to do with the body” (Oliver, 1995:4). Instead, the social model regarded disability as being caused when society failed to provide adequate services and meet individual needs (Oliver, 1983; 1990b; 1995) and through disabling attitudes within culture (Barnes and Mercer, 2010).

With pressure from disability organisations, this social model was adopted by health and social policy makers and government organisations across the UK (Crow, 1996; Lang, 2001; Shakespeare and Watson, 2002; Barnes and Mercer, 2010).

2.2.4.1 Autism and the Social Model

As the social model relies heavily on the voice of disabled researchers repositioning themselves as experts in their own condition (Shakespeare, 1999) it is subsequently more difficult for individuals with autism and behavioural or cognitive impairments to make their voice heard within this debate (Brownlow and O’Dell, 2006; Biklen *et al.*, 2005). Furthermore, within much of the medical and psychological research to date, there appears to be more of a focus on the identification, diagnosis and aetiology of autism rather than the social barriers that this diagnosis may present (Nadesan, 2005; Eyal *et al.*, 2010). However, there is also growing body of research within the Critical Disability Studies field that is emerging as a reaction to the

perceived medicalization of autism as a condition. For example, there is a range of popular literature authored by individuals with an autism diagnosis (e.g. Grandin, 2006; Williams, 1999; Jackson, 2002) that has contributed greatly to this field. But, these are most often written by those who would be regarded as high functioning.

This emphasis on the perceptions of higher functioning individuals on the autistic spectrum is also true of researchers writing within the neurodiversity model, which is a framework developed by and with adults who have autism diagnoses. This approach has developed as a direct response to the medical view of autism, reflecting a counter reaction against traditional autism metaphors and deficit thinking (Pellicano and Stears, 2011). Instead it views individuals with this diagnosis as having a number of key strengths, and argues that autism is a natural neurological variation (Jaarsma and Welin, 2012). For example, in their 2008 study, Broderick and Ne'eman referred to the perspectives present in academic and popular culture of people with an autism diagnosis as including 'alien', 'locked in a shell', and 'autism as a disease', which the neurodiversity movement rejects. Ne'eman, himself a researcher with autism, spoke of a growing and strong self-advocacy movement within the autism community, which he hoped would start to position autism within a more socially- based model.

As autism is a spectrum disorder there is wide range in the cognitive and communicative abilities for individuals with this diagnosis. Consequently these social model approaches to redefining autism cannot always speak effectively for those who are regarded as less high functioning. One of the key advocates for those with autism and communication/cognitive impairments has been Douglas Biklen, a Critical Disability Studies researcher, whose book *Autism and the Myth of the Person Alone* (Biklen *et al.*, 2005) set out to challenge and critically reflect on many of the key conceptualisations of autism as disability. This included what he viewed as a prominent myth that people classified as autistic are abnormal and avoidant of social

interaction. In a series of interviews and reflections, he incorporated contributions by writers who have been diagnosed with autism and sought to challenge the perception of autism as tragedy which he argued have been developed by proponents of traditional medical classification.

In terms of the impact that social model perceptions of disability may have on the experiences of parents going through an early autism diagnosis for their child, and their developing perceptions and aspirations, there appears to be a lack of research, analysis and evaluation relating to social theories of disability and the implications for children and their families (Brett, 2002). However, as discussed, parents often seek a diagnosis for their child in order to rationalise unusual behaviour or development, and to secure support and services (Avdi, Griffin and Brough, 2000; Florian *et al.*, 2006). Although this could be seen as an acceptance of a medical model view regarding their child's differences, it does not mean that parents who pursue diagnosis then reject a social model view of disability or of their child's impairment. On the contrary, as argued by Ong Dean (2005) in his study on disability in parent literature, seeking a diagnosis is often a means through which parents can begin to advocate for their child against the social barriers that they have faced regarding their developmental differences:

Until this classifying practice tells us that we have a disabled child, it is not a question of whether the problems of the child will be viewed through the lens of the medical or the social model of disability, but whether the child will be seen as disabled at all. (p.142)

Parents who actively pursue a diagnosis for their child can also be perceived through a social model focus in that they are actively seeking ways to break down social obstacles for their child. As argued by Ryan and Runswick-Cole (2008):

The search for a diagnosis, rather than being seen as evidence of parents embracing a medical model of disability, can also be seen as a political act of pragmatism by parents who advocate barrier removal. (p.200)

Mothers of children with autism in particular have also been recognised within research as needing to advocate more frequently and at a more complex level than other parents (Ryan and Runswick- Cole, 2009), which is a consideration I will take forward in the next section of this chapter when looking at parent experience more specifically. However, with these points in mind, it is more realistic to presume that parents who experience an early autism diagnosis for their child will be situated somewhere in between both the medical and social models (Hornstein, 2011), particularly when developing their perceptions of autism and in pursuing the best course of action for support.

2.2.5 The Minority Model of Disability

The minority model has many similarities with the UK social model in that it reflects a social approach to classifying disability. However, there are also some key differences. Most significantly, it does not go as far as to view disability solely in terms of social oppression (Shakespeare and Watson, 2002). Instead, proponents of this model have advocated that individuals with disability should be viewed as a minority group (Hahn, 1988, 1996). Although this model was first developed in the 1960s, it remains relevant to the experiences of parents within this thesis as it is still advocated widely across policy and practice in the United States (Donaghue, 2003). In common with their UK counterparts, this model was created by individuals classified as disabled in the United States, who also began to develop a more socio-political conception of their disability. Although there was equal rejection of the over

medicalization of the past (Hahn, 1996) this US response was situated more within a framework of civil rights (McClaughlin *et al.*, 2008), where individuals with disabilities were viewed as a minority and the focus was on encouraging social change for those who fell within this category (Hahn, 1988, 1996; Gabel, 2006).

Furthermore, US disability researchers and activists did not make the same distinction between biological impairment and the social nature of disability (Barnes, 1999), and did not reject the impact that physical impairment can have (Shakespeare and Watson, 2002). Instead, individuals who were classified as disabled were viewed as an oppressed minority (Hahn, 1985, 1988, 1996; Grue, 2011) who should be brought into the American political system as an “additional interest group” (Liggett, 1988). Although US researchers embraced social model thinking (Lang, 2001), they continued to focus on impairments of the physical body rather than conceptualising disability as being caused solely by social barriers (Albrecht, 1992; 2002; Rioux and Bach, 1994; Davis, 1995, 2002).

2.2.5.1 Autism and the Minority Model

The implications that these subtle differences in UK and US social type model concepts of disability may have on policy and practice in the two locations will be discussed further in Chapter 3. However, with regard to the potential impact on experiences of parents of young children with an autism diagnosis in the US context, the focus on a minority model appears fit more comfortably with the emerging neurodiversity approach where individuals with autism are positioning themselves as a minority group (Langan, 2011). It also seems to provide a slightly clearer focus for parents to view their child’s diagnosis within a rights-based paradigm, where seeking intervention for a child’s impairment is not necessarily an acceptance of a solely medical model framework, but a means by which to advocate a child’s right to support

(Ong Dean, 2005). Whether the difference between these two models of disability will have an impact on parent experience across both locations remains to be seen, however the discussion around these issues is something I will take forward in my overview of policy as well as my analysis of the data.

2.2.6 Summary and Implications for the Thesis

With some potential differences overall in perceptions of disability across these two locations, it would be logical to presume that there could be a direct impact on parental experiences and meaning making, including perceptions of and aspirations for a young child with diagnosed with autism, even if parents themselves are not directly aware of specific ‘models’. For example, in the United Kingdom there has been a strong advancement in a social model of disability across research, policy and practice which rejects any link between disability and the body (Shakespeare and Watson, 2002). This has in many ways distanced those with a cognitive impairment or behavioural condition such as autism from accessing the emancipatory potential of this approach to the same extent as those with physical impairments (Osteen, 2008). Subsequently, views of autism and other behaviourally defined conditions have remained largely within a medical model framework (Mckenzie, 2013). However, whilst there has been a clear shift in thinking around disability from a medically dominated discipline to more socially based models in both countries, there has not been a total rejection of one model over another, which will be seen more clearly in the policy documents reviewed in Chapter 3.

Although there has been contention between the medical and social models of disability across my locations, with the medical model being regarded by social model advocates in an essentially negative light, it is clear that concepts such as diagnosis

and intervention can at times be potentially useful and empowering for parents of young children with autism (e.g. Ong Dean, 2005). Through seeking diagnosis and intervention, parents can advocate for their child's rights to better mainstream integration (Florian *et al.*, 2006) and better life opportunities. It is also clear from reviewing the literature on these three models of disability that parents will most likely not perceive their child through any one lens. Instead, they will utilise the elements of each that are most relevant at different stages of the process and, where relevant, for strategic purposes (Ryan and Runswick Cole, 2009)

Nevertheless, it is not clear from current research and writing within this field how much impact these models of disability may have on parent experience in each location, or on understandings of autism more generally. With some potentially significant variations in how disability is viewed across each country, it will be interesting to return to these sections in my findings and analysis, to assess the influence, if any, that these issues may have had on the experiences of the participants in this study.

2.3 Conceptualising Autism

Although autism is classified as a medical category, it has ever changing diagnostic criteria (Matson and Kozlowski, 2011) and the meaning and concepts surrounding autism have been socially created through human interaction and interpretation (Hacking, 2009a). Within this, various historical and cultural contexts have impacted on the way in which individuals ascribe meaning and behave towards the concept of autism (Nadesan, 2005). Therefore, rather than situating my exploration of parents' developing perceptions of autism solely within a focus on the different models of disability, it is perhaps best understood through a wider framework that highlights the

importance of their interaction with research, media and policy, alongside their ongoing social interaction and self-reflection (Blumer, 1969).

From the early stages of my data collection it became clear that there were two main issues that parents were particularly focused on when trying to make sense of their child's diagnosis. These were: the availability and efficacy of support services or intervention approaches, and their own changing perceptions of autism. In order to explore these in more detail in the context of both locations, I will firstly discuss the research focus of each country with regards to autism and early year's children, before looking at how autism has been and still is conceptualised within the media.

2.3.1 US and UK Research Focus

In terms of research on autism in the early years, there is a clear distinction between priorities in the United States and the United Kingdom. With \$2 billion funding allocated to early identification and early intervention in the *Combating Autism Act* (2006), the United States has an extensive focus on exploring the efficacy of therapy approaches for young children with autism. In comparison, the UK appears to place less weight on evaluating early therapeutic approaches and more on identifying early signs in toddlers and babies who are classed as 'at risk'.

This is particularly true of research into, and use of, behavioural approaches which are considered as best practice in the US (e.g. Volkmar *et al.*, 2014; Rosenwasser and Axelrod, 2001) but mostly disregarded across the UK (Keenan *et al.*, 2014),

However, this potential difference between the US and the UK does not limit parents' access to a range of studies, regardless of geographical location. With parents of children with autism identified as particularly prolific users of the internet (Jordan, 2010) they may potentially be interacting with a range of information from diverse

sources, directly through open access publications or indirectly through stories in the media. Nonetheless, the difference in research interests between the two locations is important to this thesis as it could have both a direct and indirect impact on the experiences of participants in a number of ways; not least through the influence that these variations may have on policy and practice.

2.3.1.1 Autism Intervention Research- US and UK Contexts

Since Lovaas first published research into behavioural teaching as a treatment for young children with autism (Lovaas, 1981), Applied Behaviour Analysis (ABA) has taken root as the leading treatment across the United States for young children with autism (Rosenwasser and Axelrod, 2001). It is recommended by the American Medical Council (National Research Council, 2001) and the US Surgeon General, alongside being accepted by almost all insurance providers, particularly since the Act Relative to Insurance Cover for Autism (ARICA) was passed in 2010. Subsequently, the largest body of literature that exists in the field of autism in early childhood within the United States is focused on intervention and treatment studies with a clear focus on evidence based practice at the heart of all early intervention models and approaches across the country (Levine and Chedd, 2013).

The majority of US based research studies looking at autism and early intervention centre on a range of ABA approaches (Shea, 2004; Odom *et al.*, 2010). With a wide variety of behavioural interventions researched, these approaches are prevalent within services for preschool children with autism throughout the US. Two of the most well used for preschool children currently are Pivotal Response Training (PRT) (Koegel *et al.*, 1999) and the Early Start Denver Model (ESDM) (Rogers and Dawson, 2010). Both models have similar foundations to Lovaas' ABA approach, although they focus more on child-choice and shared control (Koegel, 1988), alongside the development of shared experiences, joint attention and reciprocal communication (Rogers *et al.*,

2014).

In contrast to this US based research, there appears to have been more of a focus in the UK on identifying, classifying and attempting to better understand the deficits associated with an autism diagnosis, rather than developing and evaluating models of intervention and treatment. In terms of this early year's research, the majority of UK-based studies have looked at early indicators of autism in toddlers (e.g. Baron-Cohen, Allan and Gillberg, 1992; Charman and Baird, 2002), including identifying deficits in joint attention (e.g. Baron- Cohen *et al.*, 1996; Charman *et al.*, 2000) and eye gaze (e.g. Phillips, Baron- Cohen and Rutter, 1992, Wass *et al.*, 2015).

From my literature search I only identified three intervention studies relating to pre 5s that had been based in the UK in the past 15 years. Both the Scottish Centre for Autism early intervention study (Sellars *et al.*, 2002) and the Preschool Autism Communication Trial (Green *et al.*, 2010) advocated for a holistic approach to therapy which was largely parent-led, with neither study promoting any behaviourally based intervention or more than 8 hours per week of therapy for a child. The third study was the Southampton Childhood Autism Project (Remington *et al.*, 2007) which is the only study within the UK to date which has investigated the efficacy of intensive Applied Behavioural Analysis in preschool children.

This disparity between research focus, and subsequently between intervention approaches, across the US and the UK is significant. It is a potential indicator parents will not have access to the same type of support or therapy in the two locations.

Whilst there are a range of reasons for these differences, there appears to be a fundamental difference in ideology between the two countries, and an explanation for this is outside the boundaries of this thesis. However, it is useful to note that Keenan *et al.* (2014), in their study on the differences in autism intervention between

Europe and North America, concluded that misconceptions regarding the ethics and efficacy of behavioural approaches in particular are more prevalent in Europe than the US, and that this has impacted extensively on the autism intervention methods used across both continents.

2.3.2 Autism and Media Conceptions

Although it would be impossible to fully analyse the influence of all media interaction on participants' perceptions of autism, looking briefly at the ways in which the condition is conceptualised within the popular media of each country is useful to developing understanding of the experiences of parents in this study.

According to Draaisma (2009) in his writing on autism stereotypes, much of what we have learned about autism has been produced by representations on television, movies, novels and autobiographies. The ways in which autism is characterized within these is critical to understanding how individuals may build their own perceptions of this diagnosis. For example, autism is generally represented in popular media as "stereotypes exhibiting bizarre behaviour" (Leong, 2013:2) where individuals are mostly portrayed as exaggerated examples of the diagnostic criteria (Safran, 1998). This often leads to a distorted view, particularly for those with a limited knowledge outside of their media exposure:

For many citizens with limited exposure to individuals with specific impairments, film, regardless of its accuracy, serves as a major source of information on the very nature of disabilities (Safran, 1998:227)

According to Connor and Bejoian (2006), individuals interact more with visual media than written, and film in particular has a substantial impact on influencing people's perceptions of disability. The most significant portrayal of autism in film was through the character of *Rain Man* (1998) (Draaisma, 2009). Although some have

viewed this as a positive example of autism being explored within popular media (Wing, 1992) the representation has been criticised by many as creating an unrealistic stereotype (Murray, 2008; Burks-Abbott, 2008, Hannam, 2014). Similarly, the film *Mercury Rising* (1998) also promoted a perception that autism is expressed through savant skills (Draaisma, 2009), reinforcing an idealistic interpretation of the condition that individuals with autism cannot live up to in reality (Young, 2012).

The representation of autism in novels and autobiographies has also been a key element in developing public perceptions of autism (Bates, 2010; Hacking, 2009b), and there has been a growing body of literature in this field. Novels such as *The Curious Incident of the Dog in the Night-time* (Haddon, 2006) are regarded by some as presenting “a form of domesticised autism” making it “commensurate and graspable” (Kuppers, 2008:195), which could be viewed as a positive way in which to develop popular understanding of the condition. However, this novel has also been perceived more negatively by some individuals with an autism diagnosis, who have viewed it as reinforcing stereotypes similar to those presented in *Rain Man* (Burks-Abbott, 2008).

2.3.2.1 US and UK Media Contexts

Although the condition has become “highly visible” worldwide (Eyal *et al.*, 2010) in comparing these two locations, media interest appears to be more prevalent in the US where there have been more awareness campaigns from large, media- focused organisations such as Autism Speaks (AS). Set up by Bob and Suzanne Wright in 2005 after their grandson’s diagnosis, AS has been a key contributor in raising public awareness of autism across America over the past decade. As chair of NBC and head of General Electric, Wright has been able to exercise a significant influence on the US media (Broderick, 2011) and Autism Speaks is currently the

largest autism advocacy and research organisation in the world (Paula *et al.*, 2011).

A number of popular sitcoms (e.g. *Parenthood*) and TV dramas (e.g. *All My Children* and *The Bridge*) have also focused on autism in the States, with less equivalent focus in the UK. Although these representations in popular culture can be seen in a positive light in terms of raising awareness of autism within the public conscience, they are often based on a portrayal of a family or individual story where the diagnosis has impacted negatively on the lives of those concerned (Murray, 2008) or are linked with the autism stereotype of savant skills (Draaisma, 2009). As Broderick and Ne'eman (2008) asserted in their writing on autism and metaphor, these kinds of media depictions can have a detrimental effect on the perspectives and meaning making of parents who have a child diagnosed with the condition.

In his book 'Representing Autism', UK-based researcher Murray (2008) described how he set up a daily Google alert for the term 'autism', and how this information helped him to frame the representation of autism within the popular media at the time. He stated: "More than anything else, autism emerges from these multiple daily stories as a worry, an unknown fear and threat that needs to be addressed as soon as possible." (2008:3). This was an issue that was also recognised by Huws and Jones (2010) in their study of British newspaper representations of autism over a 9 year period (1999-2008). They identified three key themes across the articles analysed. Firstly, they saw that the voices of individuals with autism were almost always absent from any reports written on the subject. Secondly, there was a view that the condition was a burden that made individuals suffer and reports referred to them as 'victims' throughout. Lastly, they recognised that the label was largely misused and sensationalised due to fundamental misconceptions of the diagnosis. From a US perspective, writing on autism metaphor within popular media, Broderick (2010) also maintained that autism spectrum conditions have often been portrayed in the media as

negative, with little regard for personal narratives or positive focus.

2.3.3 Summary of this Section

Although UK parents may access US media, and vice versa, the similarities and differences in media portrayal between these two locations may nonetheless be indicative of variations in autism awareness and perspectives of the condition across both countries. With the prevalence of negativity surrounding these media portrayals and perceptions, parents of children with this diagnosis in both the US and the UK may be presented with a different set of challenges compared to those who have children with better understood or less stereotyped disabilities. Combined with the largely unknown aetiology and prognosis which is considered unique to autism, parents have a range of potential issues which can impact on their experience in a variety of ways. How these are presented, and how parents have been positioned within this research is the next focus for this review.

2.4 Experiences of parents of young children with autism

In this final section of my literature review I will look at the research relating to the experiences of parents who have a young child diagnosed with autism. Starting with a broader focus on research on families of children with disabilities, I will consider the ways in which autism has been identified as having an exceptional impact on parent wellbeing compared to other diagnoses. Initially, I will examine the wider literature that exists on stress and coping and how parents of children with autism are often uniquely positioned within this. I will then go on to explore the research on parents' experience of the autism diagnosis process, including their involvement in early identification, interaction with professionals and post-diagnosis

services, investigating how parents of young children in particular are represented within this literature and what the key findings have been. In the final section of this review, I will look at the literature that exists on parental perceptions of autism in the early years and the current limitations within this field. Throughout this section I will actively explore whether there are any key similarities and differences in these research findings between my two locations, before restating the case for this thesis to make a new and original contribution to this field.

2.4.1 Family Research on Parents of Children with Disabilities

Research focusing on families of children with disabilities has traditionally employed a medical model, particularly with regard to the experiences of mothers (Ryan and Runswick-Cole, 2008). Studies in this field have mostly been situated within a 'loss' or 'stress reaction' paradigm where disability diagnosis is seen as a tragedy for the family (Avery, 1999; Fisher and Godley, 2007), and where parents are expected to go through a grieving process (Bruce and Shulz, 2002). It has been argued that there is less emphasis within this research on the positive adjustments parents can make to having a child with a disability (Hastings 2002; Hartshorne, 2002; Kausur, Jevney and Sobsey, 2003) because of the largely negative perceptions of disability overall. Across this literature, there is a prominence placed on the ways in which parents of children with disabilities experience and react to stress. Notably, there is a further emphasis on the perceived higher levels of stress experienced by parents of children with autism, which not only separates this group within research, but may unintentionally reinforce some of the notions of stigma and fear that can be attached to this diagnosis in particular.

As discussed, from my initial review of the literature on parent experiences of autism, it became clear that many of the research themes within this field involved

parental well-being, with a particular focus on stress. The strongest emphasis to date appeared to be on quantitative research which attempted to identify stress levels and factors (e.g. Koegel *et al.*, 1992; Seymour *et al.*, 2013) as well as comparative studies which looked at the differences between parents of children with autism and those with other disabilities (e.g. Pisula, 2007; Abbeduto *et al.*, 2004). Although there were some studies within this literature that looked specifically at parents of preschool children, the majority of research in this field has been on parents of children from a wider age range. Although this thesis is not looking at parental stress per se, this body of research remains relevant to developing a clearer understanding of parent experience of autism, not least because it constitutes such a significant focus in this field.

In this section I will firstly look briefly at the literature on stress within the wider disability parenting field, before focusing on the research relating specifically to parents of children with autism, and the ways in which this diagnosis is viewed as a uniquely challenging, emotional experience for this group.

2.4.1.1 Disability Parenting and Stress

Parenting stress can be perceived in many different ways within disability research (Woodman, 2014), but it is generally linked directly to child behaviour, ability to manage parenting tasks, or to atypical interaction between child and parent (Abidin, 1995). Over the past 20 years, researchers in this field have maintained that parents of children with disabilities experience higher levels of stress than parents of typical children (e.g. Scorgie, Wilgosh and McDonald, 1998; Hartshorne, 2002) which can have a negative impact on parental mental health (e.g. Cramm and Neiboer, 2011). It is widely accepted across this research that there are raised levels of stress in parents of children with developmental delays compared to parents of typically developing children (e.g. Hodapp *et al.*, 2003), with language and behaviour problems impacting

heavily on parent stress and emotional well-being (e.g. Bakér-Ericzen *et al.*, 2005).

2.4.1.2 Autism and Parenting Stress

A number of comparative research studies within this literature have looked at parents of children with autism more specifically and claim that the stress levels experienced by this group appear to be higher than those who have children with other disabilities. This is a growing theme in this field, with a number of other comparative studies claiming that this group of parents have higher stress levels than parents of children with Down's syndrome, (Pisula, 2007; Dabrowska and Pisula, 2010; Hayes and Watson, 2013) fragile X syndrome (e.g. Abbeduto *et al.*, 2004) and cerebral palsy (Mugno *et al.*, 2007). For example, in a questionnaire based study of 162 parents (mothers and fathers) of preschool children (2-6 years old) with autism and children with Down's Syndrome, Dabrowska and Pisula (2010), found that participants with children with autism had higher stress levels than those who had children diagnosed with Down's syndrome, with mothers experiencing a greater degree of stress than fathers. Weiss (2002) also used data from questionnaires in a comparative study of 120 mothers of preschool children with autism, intellectual disability, or typical development. They concluded that those who had children with autism experienced higher levels of stress than parents of children with intellectual disability and were more likely to experience depression. This was due to increased levels of anxiety in the mothers of children with autism and the lower perceived availability of social support. Such studies have contributed to a growing body of literature in this field that identifies the experiences of parents of young children with autism as unique within disability parenting. This claim was prevalent across this research and was highlighted further by Estes *et al.*, (2009). In their study of parenting stress and psychological functioning of 76 mothers of preschool children with either

autism or general developmental delay, they stated that of the comparative studies they looked at: "...no study to date has found a group of mothers with higher distress levels than mothers of children with ASDs." (p.377).

The findings across this body of literature are not remarkable. It is reasonable to presume that the difficulties presented by parenting a child with a disability are going to be different to raising a typical child, and will clearly lead to a higher degree of stress for parents in these situations. However, it is relevant to this thesis that a growing number of studies have claimed that parenting a child with autism can lead to greater levels of stress than parenting a child with other disabilities. The higher levels of stress and mental health issues described within this literature appeared to be influenced by a number of factors that are seen as being specific to autism, and there seemed to be some distinct challenges identified for parents of children with this diagnosis. There are a number of possible reasons for this, and it is useful when attempting to develop a clearer understanding of parent experience across my two locations to briefly consider the literature relating to the unique challenges that autism can present.

2.4.1.3 Autism as a Unique Challenge for Parenting

In his Australian study of 21 mothers and fathers of children and young adults with autism, aged between 5 and 26 years, Gray (2002a) identified three distinct stress factors that he claimed were specific to 'autism parenting'. Firstly, child characteristics (or behavioural symptoms) can be difficult to manage. Secondly, lack of adequate support from professionals in terms of pre and post-diagnosis support and access to services can leave parents feeling frustrated and lost. Thirdly, society's attitudes toward individuals with autism can often reflect a lack of understanding. These issues would link clearly with Abidin's definition of parenting stress (1995)

which, as discussed, emphasised the impact that child behaviour, ability to manage parenting commitments and dysfunctional interaction between parent and child could have on parental well-being overall.

As part of the diagnostic profile, children with autism often display more negative emotional responses than are seen in typically developing children, or those with intellectual disabilities (Capps *et al.*, 1993). These are mostly described as ‘challenging behaviours’ and can lead to parents feeling isolated within the community (Dunlap, Robbins and Darrow 1994). They may also feel helpless when trying to manage their child’s behaviours (Hastings, 2002) which can have a significant impact on parent mental health as their child gets older. For example, Weiss *et al.* (2012), in their survey study of 228 families with children with autism aged between 6 and 21 years, found that as child problem behaviour increased, parent psychological acceptance of their child decreased. This resulted in a direct impact on parent mental health.

Alongside potential problem behaviour, individuals with autism are reported to display difficulties with social interaction (Baker, Koegel and Koegel, 1998) and Estes *et al.* (2009) attributed the exceptional levels of stress experienced by parents of children with autism in their study to the emotional pain that mothers may experience with the social unrelatedness that is unique to this diagnosis (2009). In addition, young children with autism often have limited or no communication skills and this is generally the first recognisable sign of difference in the early years and the primary reason that parents seek professional support (Charman and Baird, 2002; Goin-Kochel and Myers, 2005). These communication issues in particular can have a detrimental effect on parent/ child interaction, and subsequently on parent stress levels (Konstantareas and Papageorgiu, 2006).

Parent- child interaction can also be affected by delayed or absent play skills (Kasari *et al.*, 2008) as children with autism are often described as being ‘object focused’ rather than ‘person focused’ within their play activities (Freeman and Kasari, 2013), and it is reported that this ‘object focus’, along with communication difficulties (Dawson and Rogers, 2009) can make it harder for parents to engage their child in interactive play activities without professional intervention (Kasari *et al.*, 2010).

However, against the backdrop of the deficit focused, stress/ loss paradigm within more general disability and parent research in this field, a move toward a positive outlook on parenting children with disabilities has been present within this research. For example, Kausur *et al.* (2003) also undertook a small scale case study looking at the concept of ‘hope’ for parents who had children with developmental disabilities including, but not exclusively, autism. They found that although initially the experience of discovering a child’s disability was “frustrating, shocking and challenging...” with a clear threat to parent’s aspirations of hope for their child, positive elements did arise. They concluded that “...each family's experience of having a child with a disability is unique in light of their specific circumstances, the nature of the child's disability, and available resources and support for the family.” (p.38).

In a study on factors related to mother’s positive perceptions of their child, Hastings *et al.* (2002) found that personal growth and maturity, happiness and fulfilment and children as a source of family strength and closeness were all factors contributing to positive feelings for their sample group. Other researchers have also found that parents can find positives in autism (Gray, 2006; Green, 2007; King *et al.*, 2006).

2.4.1.4 Summary of Parental Stress Research and its Implications for this Thesis

Although this thesis does not focus on, or measure, parents' stress reactions to diagnosis, this vast body of literature relating to parent mental health in autism is relevant in developing a clearer understanding of the ways in which individuals may process and react to their child's diagnosis. It is also useful to use this review to highlight the gaps in the current knowledge of parent experience in this field, and it is evident from the research I have looked at in this section that there is a space that this study can fill.

It is also clear, from the range of literature on parent stress and coping in autism, that it is perceived by researchers as a condition that can cause a unique emotional reaction for parents compared to other disabilities. However, with such a quantitative focus across the majority of studies to date, it is noticeable that there is less known about how parents themselves may perceive their child's diagnosis, particularly in the early years. In addition, there are no studies to date that look at these experiences across locations or cultures.

When considering what is already known in this field, it has been useful to consider some of the autism specific factors which have been regarded as having a direct link to stress and anxiety for parents, in order to continue to build the foundations for my research questions and analysis. Although some aspects of this experience could be regarded as measurable through stress assessments and questionnaires, there are other influences and processes which can only be understood through a qualitative framework. For example, as this thesis is concerned primarily with the ways in which parents make sense of their child's diagnosis and the factors which impact on this, a qualitative approach to exploring the ways in which these meanings are conceptualised is best fit for this study. I will now look more specifically at the

literature relating to the diagnostic journey. This will include research on pre-diagnostic experiences, parental satisfaction, and access to, and experiences with, post-diagnostic services for those who have young children specifically.

2.4.2 Research on Parents' Experience of the Diagnostic Process

It is widely accepted across the research looking at parent experiences of autism assessment that positive or negative aspects of this process can impact on reactions to the diagnosis itself (e.g. Gray, 1993; Midence and O'Neil, 1999; Siklos and Kearn, 2007). Therefore, in attempting to understand how participants in this study processed and made sense of their child's diagnosis, it is important to consider the various factors which have been recognised within this literature as having the greatest impact on parent experience overall.

In line with studies that consider the impact that autism can have on parental stress, research within this field has also identified difficulties for parents experiencing this diagnostic process. According to Siegel (1997), an autism diagnosis is part of a long adaptive process which is made more difficult due to the absence of any physical representations of disability and there are particular challenges when dealing with an 'invisible disability' (Midence and O'Neill, 1999). In addition, there are complicated pressures faced by parents needing to redefine their child years after birth (Norton and Drew, 1994).

With autism symptoms being most frequently evident through atypical behaviour and development, rather than by aetiology (Young, Brewer and Pattison, 2003), this group of parents are often more heavily involved in this diagnostic process than those who have children with other disabilities (Reiner-Hess and Landa, 2012). For parents with young toddlers, the recognition of early autism symptoms usually occurs in the

1st or 2nd year of a child's life (Gray and Tonge, 2001; Young, Brewer and Pattison, 2003). This early identification of autism for children under 3 years of age is generally made by parents rather than professionals (DeGiacomo and Fombonne, 1998) with 18 months being the average age that parents first become concerned about autism (Howlin and Asgharian, 1999). However, in spite of early parental concerns, studies have shown that diagnosis is more likely after a child has turned 3 years old in the United States (Mandell *et al.*, 2007) or 7.5 years old in the UK (Crane *et al.*, 2015). Therefore, it is important to recognise that for parents experiencing early concerns for their child, the diagnostic process can potentially be highly frustrating.

Parents can also have a difficult time convincing others around them, including professionals, of their child's differences (Avdi, Griffin and Brough, 2000) and this issue appeared to be similar in studies looking at these experiences in the US (e.g. Hutton and Carron, 2005; Harrington *et al.*, 2006 Sansosti, Lavik and Sansosti, 2012) and the UK (e.g. Howlin and Ashgarian, 1999; Avdi, Griffin and Brough, 2000; Crane *et al.*, 2015). In addition, parents' satisfaction at diagnosis can be influenced by more practical issues, such as waiting times, and their child's age at diagnosis (Howlin and Moore, 1997; Howlin and Ashgarian, 1999). As these may vary between and within countries (e.g. MacFarlane and Kanaya, 2009; Bowen, 2014; Autism Achieve Alliance, 2014) there is potential that parents' experiences in each of my locations may be influenced by these factors in different ways. In order to attempt to understand parents' experiences of the autism diagnostic process in more depth, I will firstly look at three studies that have focused on parental satisfaction before considering more specific research on age at diagnosis and waiting times in each country.

2.4.2.1 Parental Satisfaction

There were three key studies that I located in my literature search that explored parent satisfaction relating to the diagnostic experience. Of these, two were UK-based, with one looking at experiences of parents countrywide (Howlin and Moore, 1997) and the other looking more specifically at Scotland (Brogan and Knussen, 2003). Notably, although it used quantitative methods, this was the only study to date that has looked at any aspect of parent experience of autism diagnosis in Scotland. The third was based in Ohio, US (Sansosti, Lavik and Sansosti, 2012) and used mixed methods to assess the experiences of a small sample of parents at the early stages of diagnosis.

In their survey of 1200 families across the UK, Howlin and Moore (1997) looked at the diagnostic experiences of parents of children and adults aged between 2 and 49 years old. Over half of the sample group had a child under the age of 11 years. They covered a wide range of geographical locations in the United Kingdom, with 8.6 percent of respondents coming from Scotland. It found that factors such as long waiting times between referral and diagnosis, along with perceptions of help received after diagnosis had a significant impact on parental feelings of satisfaction overall.

Notably for this thesis, there were a higher number of Scottish parents (54.9 percent) who were not satisfied with the diagnostic process, compared to some other areas of the UK. Conversely though, this group of parents had one of the highest levels of satisfaction with help received after diagnosis, with 51.4 percent reporting high satisfaction. However, these data were obtained from parents in one area of Scotland only and therefore does not necessarily reflect parental experiences of diagnosis Scotland-wide.

A Scottish based questionnaire study (Brogan and Knussen, 2003) looked more

specifically at parent satisfaction relating to the diagnostic ‘disclosure’ for their child. Using a self-report questionnaire with 126 families, participants were asked to rate their levels of satisfaction regarding how professionals delivered their child’s diagnosis. Participants were recruited using the records from three hospitals and one voluntary organisation. It is not clear from the study whether this reflected a wide area of the country or one smaller locality. Children of the participants were aged between 3 years 3 months and 17 years old. Just over half of the children had been diagnosed by 4 years old and the mean age at diagnosis within this sample group was 4.5. Just over 90 percent of participants had received a diagnosis for their child within the previous 5 years. This study found that 55% of parents were either ‘satisfied’ or ‘very satisfied’ at the ways in which their child’s diagnosis had been communicated to them, which related directly to the manner in which the professional had communicated the diagnosis. Parents’ satisfaction was also found to be linked to the quality of information provided by the professionals and the opportunity to ask questions. Although the authors claimed that they found no direct relation between child age at diagnosis and parental satisfaction, it was notable that participants whose child was not yet in educational provision (and therefore younger) were more satisfied than other parents.

In 2012 Sansosti, Sansosti and Lavik interviewed 16 families in Ohio. They used mixed quantitative and qualitative approaches to data collection and analysis, and found similar results in factors relating to parent satisfaction around the diagnostic process. Although this was a smaller scale study, parental feelings of satisfaction related specifically to the quality of information they felt that they had received from specialist professionals, once they were able to meet with them. However, they also found that parents in their sample group were less satisfied with the process if their child was diagnosed later. They concluded that participants

became increasingly frustrated or dissatisfied with the process as they became more educated about the various evidence-based approaches advocated within US policy on early intervention. This was attributed to their increased realisation of the mismatch between advice and provision.

In all three studies, findings reflected the impact that age at diagnosis and waiting time can have on parent experiences of the diagnostic process, alongside the influence that positive or negative interactions with professionals can have on this process overall. However, only one study used any type of qualitative approach to data collection (Sansosti, Lavik and Sansosti, 2012) and therefore it could be argued that relying on questionnaire responses only (Howlin and Moore, 1997; Brogan and Knussen, 2003) may not have identified the subtler factors influencing parents' satisfaction at diagnosis. In addition, self-report quantitative questionnaires in particular have been recognised as having significant limitations within research (Spector, 1994) as they give participants such limited response options.

Having considered the issue of parental satisfaction more generally, I will now focus on the literature on child age at diagnosis, which has been acknowledged in a number of studies as having a specific impact on parent satisfaction overall.

2.4.2.2 Age at Diagnosis

In their recent critical review of differences in age at diagnosis worldwide, Daniels and Mandell (2014) looked at the various factors that have influenced this, summarising 42 studies published over 20 years, including 19 from the US and 9 from the UK. They concluded that, across this literature, diagnosis was often delayed between parents' initial identification of their child's differences to professionals delivering an official assessment. Although the mean age of diagnosis for autism spectrum disorders ranged from 38 to 120 months across all 42 studies, they also

concluded that this had decreased over time worldwide. Whilst they did not give a direct comparison of age at diagnosis between the locations covered within these studies, a brief calculation of this across the studies that were UK-based gave an average age of 66 months, compared to 48 months across all 19 US studies. In addition, they recognised that there were some key differences in diagnostic ages which related to specific areas of each country, identifying a particular trend within certain areas of the US to identify and diagnose children much earlier than the rest of the country.

One study included in this overview was Rosenberg *et al.*, (2011) who undertook a national survey across the United States of children's age when receiving an autism diagnosis, with 6124 participants. They found that the mean age at diagnosis was 3 years and 9 months for boys and 4 years for girls. They also observed that children in the north eastern states were diagnosed earlier, with a mean age at diagnosis of 3 years and 7 months. This perhaps links with MacFarlane and Kanaya's 2009 findings of an increased prevalence of autism diagnosis across Massachusetts in comparison to other States. These studies are of critical relevance to this thesis, as they indicate potential atypicality for the experiences of my Massachusetts sample group, compared to other US families.

A recent similar study in the UK looked at parent experiences of the autism diagnosis and considered the potential influence of age at diagnosis. Crane *et al.* (2015) surveyed 1047 parents of children with autism across the United Kingdom and found that the mean age at diagnosis was 7.5 years old. This sample included children aged from 3 to 18 with a range of diagnoses across the autism spectrum, and it is useful to note that the mean age varied between these. For children who were considered to fit an autism diagnosis, the mean age was 5.6 years old.

Although this data is a useful comparison to Rosenberg *et al.* (2011) it is also important to observe that only 6 percent of respondents within this study were from Scotland. Whilst Scottish data is included in UK-wide research on autism, there are no Scotland-wide studies to date that look at the factors impacting on parent experience of diagnosis in a similar way, despite differences in policy from the rest of the UK. However, a recently published Executive Summary on waiting times for autism diagnoses in Scotland (Autism Achieve Alliance, 2014) estimated that, although the average age of referral for diagnosis is 3.6 years in preschoolers, the mean age at diagnosis in Scotland for boys was 8.4 years, and girls 10.8 years.

Although these figures were significantly different from those within the US report, these were more in line with Crane *et al.* (2015), which may reflect some differences between the US and the UK more generally regarding diagnosis. This point will be discussed in more detail in Chapter 3 when considering policy and practice. It is also important to note that the Scottish study used proportionate stratified sampling and figures used are taken from eight child health teams across Scotland, rather than the whole country.

In a Scotland specific study looking at autism diagnosis, Campbell *et al.* (2013) focused specifically on children aged 0-6 years in Glasgow. Although this research only considered data from one area of the country, it provided some useful information for this thesis. In their analysis of the database of referrals to the Glasgow Community Autism Team between 2004 and 2007, they found that of 546 cases, there had been 246 diagnoses for children in this age group. Of these, 72 percent had been referred before their 4th birthday, but only 34 percent were diagnosed by the age of 4 years. The mean age at diagnosis for this sample was 4.5 years, which was much lower than that found by Crane *et al.* (2015). However, this was a much smaller sample, set within one area of the country and limited by age to

those under 6 years old.

2.4.2.3 Parent Interaction with Professionals

As discussed, Howlin and Moore (1997) identified that the difficulties parents experienced with professionals and services when attempting to obtain a diagnosis for their child were a significant contributor to elevated stress levels in this population. Similarly, in their 2011 cross-sectional, descriptive study of 75 US parents of children with autism, Hall and Graff found that parents within their sample group expected professionals to have up-to-date knowledge of autism, in order to be able to give direction and support to families. This was also a factor identified in Hutton and Carron's 2005 interview study of 21 parents of early year's children in New England. Concerns with the extent of professional knowledge and training in autism led to frustration for participants when trying to secure services for their child. In addition, this study found that nearly half of those interviewed did not feel respected by the professionals involved in their child's diagnosis. This theme was also echoed in two UK-based studies which identified parents' disappointment with medical and educational professionals' understanding of the field, leading to frustration and disillusionment concerning the professionals' knowledge of autism (Mansell and Morris, 2004; Osborne and Reed, 2008).

For many parents, the lack of professional support for, or action taken to address, their early concerns impacts negatively on their experiences of diagnosis in a number of ways. In their interview study of 24 parents of children with autism aged between 3 and 11 years from across the UK, Ryan and Salisbury (2012) found that parents who were actively seeking information regarding their child's unusual development were left feeling distressed, angry, humiliated and frustrated by a lack of professional engagement with their concerns. These findings were also in line with Hutton and

Carron in the US (2005) who concluded that professionals' disregard for parental initial concerns had a significant impact on their emotional well-being.

There were two other studies within this literature on parent/ professional interaction that further highlighted the impact that parents' negative perceptions of professional expertise can have on experiences of diagnosis in both locations. Avdi, Griffin and Brough (2000), interviewed three families in the West Midlands who had children aged between 2.5 and 3 years old. From their discourse analysis of 11 semi-structured interviews, they reported that their participants often considered professionals to be judgemental and controlling, and suspected them of withholding information. Although this was relatively small scale study, it was one of the few that used a qualitative, interview-based approach to exploring the experiences of parents of young children with autism based in the UK.

In a similarly small scale study, Stoner *et al.* (2005) used interviews to explore parents' perceptions of their interaction with professionals. All four participants were recruited from the same small town in the Midwest United States but children were older, ranging in age from 6 to 8 years old. Although they were looking at the experiences of parents with school aged children, they did question parents about their initial experiences. They found that when parents had struggled to obtain diagnosis for their child, this initiated a pattern of persistent behaviour and a sense of distrust in medical practitioners. However, although there were feelings of dissatisfaction with school-based services, parents in this study had positive perceptions of early intervention services because they supported their need to self- educate about autism in their child's early years.

2.4.2.4 Parent access to Intervention and Services

Having explored the literature on diagnosis and the potential implications for parents in this study, I will now go on to look at the more limited research that exists on post-diagnosis experiences, including factors that might impact on parents' meaning making of their child's autism, such as access to support, intervention and services.

In spite of the importance of professional support and post-diagnosis information, studies from a number of locations have reported that parents have struggled to access appropriate support and services at this crucial stage (e.g. Howlin and Moore, 1997; Smith, Chung and Vostanis., 1994; Valentine, 2010), with the task of arranging support being left mainly with the parent (Weiss, 2002). Overall parent experience across this research reflected clear variations in access to, and levels of, support after diagnosis, and this was equally true for studies based in the UK (Avdi *et al.*, 2000; Midence and O'Neil, 1999; Mansell and Morris, 2004; Crane *et al.*, 2015) and those based in the US (Hutton and Caron, 2005; Sansosti, Lavik and Sansosti, 2012).

Whilst Midence and O'Neil (1999) reported that all four of the families in their Welsh-based interview study felt that they received appropriate practical help and the support that they needed, Crane *et al.* (2015) found that only 21 percent of parents in their large scale UK wide study were offered any direct help or support after diagnosis. 38 percent were signposted to other services for help; another 35 percent reported that they were offered no post-diagnosis follow-up services for themselves or their child.

In their study of parents accessing a single diagnostic assessment service in Greater London, Mansell and Morris (2004) found that parents answering their survey had mixed levels of satisfaction and dissatisfaction with their post-diagnosis services.

Some were extremely grateful to the service for the support that they had received, whilst others were dismayed at the lack of follow-up intervention for their child. These mixed responses from parents accessing a similar service clearly show that perceptions of support post-diagnosis may be dependent on the individual and their family circumstances rather than on the support offered.

Within the literature that considered parent post-diagnosis experiences in the US, there were similar findings. Although as discussed, Stoner *et al.* (2005) concluded that their participants reflected on previous interactions with early intervention services as largely positive due to the opportunities that these provided for learning about their child's diagnosis, Hutton and Carron (2005) asserted that early services often involved an extensive amount of paperwork and planning for parents of young children with autism. However, they also found that parents in their study were satisfied overall with the services that they received, but that the majority of interviewees felt that therapy could be made more intense and speech therapists in particular could be better trained.

Conversely, Sansosti, Lavik and Sansosti (2012) found that participants in their study experienced a range of barriers to accessing early intervention services post-diagnosis. They attributed this to the lack of appropriate information and guidance given to these families by professionals, particularly with regards to the efficacy of specific therapy programmes. However, this was a relatively small scale study of 16 parents in Ohio and may reflect more specific issues relating to this location rather than implications for experience of parents countrywide.

In spite of the mixed reports within this research relating to parents' experience of post-diagnosis support and services, access to effective and appropriate assistance in these early stages were considered to be crucial for all families who had a young child

diagnosed with autism. This is a key area for this thesis to consider when looking at the similarities and differences in parent experience of diagnosis in Massachusetts and central Scotland and will be an issue that I will consider at length in my findings and analysis in Chapter 5. In particular I will build on this previous research through focusing on the impact that interaction with professionals and access to support and intervention can have on parent experiences across these two locations.

2.4.3 The Literature on Parent Perceptions of Autism

In order to review the literature on parent perceptions of autism across the two countries, I searched for studies from each location that were qualitative, focused on parents of preschool children and included at least some data on parent perspectives of autism. In this search I was able to identify only three studies that fitted these criteria, each with a qualitative interview design, and a focus, at least in part, on the exploration of parental perceptions of autism and of their child.

In Hutton and Carron's 2005 study of 21 parents in the New England area of the US, they found that almost all parents had recognised their child's early difficulties through their behaviours, which they had viewed as being typical of autism. Although this study did not focus on parental perspectives of autism specifically, it was evident from the interview data that the parents in this group shared common perceptions of autism and 'autism behaviours'. All participants spoke about their initial feelings that there was 'something wrong' and directly referenced lack of eye contact, self-stimulatory behaviour and lack of speech as being amongst their first concerns about their child. It was also clear that they viewed their child's autism through the frame of normal child development. Nearly all parents reported a sense of relief when they received their child's diagnosis because they could reframe these atypical behaviours through the lens of autism. In addition, this study looked at data

from mothers and fathers, which is unusual given the focus on the experiences of mothers in much of the research to date (Hastings, 2003, Flippin, 2011). However, they did not report any differences in responses, with both mothers and fathers sharing similar perceptions of autism overall.

Vacca's 2013 study of US fathers' experiences of autism focused on perspectives surrounding autism pre and post-diagnosis, in an attempt to begin to contribute to the much neglected area of fathers' perspectives in autism research. Although he initially targeted 30 fathers across two separate early intervention projects in Maryland and Philadelphia, response was poor and the final number of participants was eight. Vacca used semi-structured interviewing to ask fathers about their experiences of the autism diagnosis and their perceptions of their child. This study did not find marked differences between the responses of fathers versus the previous research focusing on mothers' experiences of and perspectives of autism. However, it was interesting to observe that fathers in this study saw their primary role post-diagnosis as one of supporter and advocate. The majority of participants also spoke about their initial fear of autism pre diagnosis, which was related to their own anxieties regarding their perceptions of the condition. Notably, nearly all the participants stated that when they heard the term 'autism' they knew that their child's needs would be life-long. However, they had also felt that therapy would 'normalise' their child, but as time went on they realised this was not the aim or focus of intervention.

In a mixed methods study of 16 UK mothers with children with autism aged between 3 and 9 years, Dale, Jahoda and Knott (2006) used semi-structured interviewing to look specifically at parent attributions following their child's autism diagnosis. Within this they looked at perceptions concerning cause, stability of diagnosis and the control they felt with regards to helping their children. These results were varied, and participants had a wide range of perceptions regarding autism

overall. For example, two mothers blamed themselves for their child's diagnosis and three felt that the cause was external. The remaining 11 participants attributed either no or mixed causes to their child's autism. With regards to stability of diagnosis, two mothers interpreted autism as meaning their child could not make progress and regarded the diagnosis as unchangeable. However, more mothers believed that their child's autism was not life-long and there was potential for them to outgrow some of the challenges associated with their diagnosis. Unusually, five mothers regarded autism as being something that their child could outgrow completely, seeing the diagnosis as temporary and unstable.

Although there were only three studies that met my criteria, it was clear from the evidence presented that there were shared themes across the data from both locations regarding parental perspectives. These included the sense of fear and uncertainty that surrounded autism, the recognition of behaviours that parents regarded as typically autistic in their child and the confusion as to whether the diagnosis was long term or potentially curable. However, this literature on parent perspective was limited and there are no studies to date that look at the similarities and differences across these two locations. In addition, most previous studies looked at a wider age range and therefore missed the opportunity to focus on parents' earliest perspectives of autism and their child. Therefore, there remains a clear gap in current knowledge in this field which I hope that this thesis will fill.

2.5 Summary and Reflections on my Review of the Literature

Having reviewed a wide range of literature on conceptual models of disability, research and media perceptions of autism and family research relating specifically to parents of children with an autism diagnosis, I have highlighted a number of issues that are relevant to this thesis. Although there are similarities between the United

States and the United Kingdom in the ways in which disability research has changed focus over the past 40 years, there are some differences between the two countries in terms of perspectives of disability overall. Whilst researchers in both countries have pushed for a redefinition of disability by viewing it in terms of social barriers, a medical view of autism still remains across these locations. In addition, there are some significant differences in the conceptualisation and treatment of autism between the US and the UK. These potential differences in policy and practice may have a considerable impact on the experiences of parents in both settings and this will be explored further in my discussion in Chapter 3.

With regards to the literature on family research and parent experience, it is clear that there has been a long history of exploring mental health issues in parents of children with an autism diagnosis. There was evidence across this literature that parenting a child with this condition is unique in terms of the emotional impact it can have, which appears to be due to a wide range of factors. However, within this research there is a considerable focus on the negative impact that an autism diagnosis can have on a family, with far less qualitative research on this or on parent experience of autism more generally, particularly within the early years. In addition, there is evidence to show that interaction with professionals and access to services can have a potentially significant impact on parents in the early stages of processing their child's diagnosis and this is a key focus for this thesis. With differences in perspectives on disability and understanding of and treatment for autism, it is reasonable to presume that parent experiences may differ in some ways between the two locations.

2.5.1 Implications for this Thesis

In focusing on parent experience of the diagnostic process for young children with

autism, I hope to make a meaningful contribution to the body of existing literature in this area. As discussed, although there are a number of qualitative studies in this field, the current nature of knowledge relating to parents experiencing an autism diagnosis for their child in the preschool years has been mostly developed through a quantitative, or positivist, epistemology. In this thesis, by choosing to use a qualitative framework, I am looking at developing this knowledge in a different and more interpretive way. Since statistical generalisation is not a goal of this type of research (Merriam, 2009) qualitative researchers are more focused on interpreting and gaining insights into a phenomenon in order to better understand it. This type of research is focused on the exploration and understanding of how people "... interpret their experiences and construct their worlds" (Merriam, 2009:5).

In addition, in looking at the similarities and contrasts between the practices in two countries that have never been compared in this way, and considering in detail the ways in which parents' interactions with professionals and services can impact on their sense making of their child's diagnosis, I hope that my findings will have a positive impact on practice in these two locations, particularly with regard to improving the support experiences of parents of young children diagnosed with autism. Finally, in looking at the aspirations parents may have for their diagnosed child I aim to contribute to an area that few studies have explored to date. In doing so, I will explore some of the factors that may contribute to understanding the positive and negative perceptions of what autism means to parents of early year's children across two locations. This issue is of particular interest to me as a researcher given the critical incidents that led me to this study in the first instance (see section 1.5).

In order to look more closely at the context of both locations, I will now focus on exploring the similarities and differences in policy context and content across the

United States and the United Kingdom, with specific reference to this thesis and the research questions it intends to answer.

Chapter 3

Policy Comparisons: US and UK

3.1 Introduction

In the previous chapter I explored the academic literature on the constructs of disability and autism, alongside the experience of parents of early year's children pre and post- diagnosis. This revealed that there was a clear focus in the literature of conceptualising autism as a disability with unique challenges, whilst positioning parents of children with autism as a distinct group, particularly in relation to stress and coping. In this chapter I shift my focus to the discussion of policy and practice guidelines relating to autism and the role of parents in the two locations, in order to explore how similarities and differences in context, focus and content may have been factors in influencing the experiences of both groups of parents. In doing so, I hope to set the background for my research questions, which I present at the end of this chapter.

3.1.1 Structure

This chapter is made up of three sections. Firstly, I examine the overall policy context relating to disability and autism in each location, highlighting some of the economic and historical background to the current policy on autism specifically. Within this section I consider the similarities and differences that exist between these contexts and begin to explore the ways in which parents' and children's rights are represented in each country. Secondly, I consider more specifically the content of a number of key policy documents, looking at two areas of interest for this thesis: how autism is described or viewed and how parents are positioned. Finally, I discuss these

findings in relation to this study, setting the scene for the introduction of my research questions.

3.1.2 Parameters and Definition of Terms

During the initial planning of this thesis, through my critical incidents in particular, I began to consider the impact that policy could have on the experiences of parents on their diagnostic journey. Policy can mean many things, but in the context of this thesis I have chosen this term to refer to all public legislation and guidance documentation at both a substantive and administrative level. As asserted by Ozga (1999), policy can be regarded as any ‘vehicle or medium for carrying and transmitting a policy message’ (p.33). It can also be defined as “...a projected programme of goals, values and practicesthe exercise of authority to achieve collective purposes” (Colebatch, 1998)

Substantive policy relates to the legislative aspects of governance and is generally concerned with national level issues. Administrative policy is more locally focused and often concentrates on how national priorities can be implemented on a smaller scale. It is useful to look at examples of both in this thesis, as one will inform the other and this will provide a fuller understanding of the background to parent experience in each location. However, in terms of comparison between two countries, it is also important to note that policies will not exist in isolation from one another. There will be a degree of policy learning taking place across these locations, leading to some degree of policy transfer (Wolman, 2005). With factors such as performance data now shaping policy and practice worldwide (Desrosieres, 1998; Novoa and Lawn, 2002; Lawn, 2006), knowledge acquisition and knowledge transfer has become increasingly important in a progressively mobile world (Ozga and Jones, 2006). The effects of globalisation and ‘travelling’ policy have started to shape national and

international agendas and a new emphasis on social capital has changed the way in which countries respond to many areas of policy making. Education and health are key examples of policy areas where data and performativity now have much greater influence in the developed world. (Ozga, 2005) and this is equally true of the United States context as it is Scotland.

3.1.3 Relevance of Policy: Considerations for This Study

Whilst I cannot claim that economic and policy considerations had a direct influence on the ways in which parents in this study developed their understanding of autism, it can be argued that these issues may have impacted on individuals' experiences in a number of ways. Although participation in, and influence of, policy is difficult to measure, it was clear from the literature in Chapter 2 that parents of children with autism in both locations have had a long history of acting as advocates for their children (Silverman, 2013; Murray, 2012, Nadesan, 2005; Ryan and Runswick Cole, 2009), having often been directly involved in the policy making process through advocacy groups and campaigns (Feinstein, 2010).

From the research reviewed in section 2.4 it was also clear that concerns with practice, such as access to, and levels of, services can impact on parents' reactions pre and post-diagnosis in a number of ways (e.g. Howlin and Moore, 1997; Hutton and Carron; Siklos and Kerns, 2007). These experiences may also be shaped through interaction with professionals who have first-hand knowledge of policy discourse and policies often directly influence the way that professionals are advised to interact with families (Adams, Snyder and Stanport, 2002; Brooker *et al.*, 2010). However, policy implementation, if undertaken effectively, can strengthen some areas of family life for parents who have a child with a disability, including access to community support and engagement (Dokecki and Heflinger, 1989). Conversely, it can also have a negative

impact when funding or services are cut (Gray, 2002a). In addition, policy language itself can both empower and disempower specific groups in society (Fairclough, 2001).

As Hahn (1985) stated in his discussion of disability definitions and the impact on policy in the United States, "...the environment is molded by public policy and that policy is a reflection of prevalent social attitudes and values" (p.295). From a symbolic interactionist perspective, Blumer (1969) argued that society and individual are closely interlinked, reflecting the idea that structural considerations, such as policy, can be shaped through interaction, but can also shape interaction and subsequent meaning making. Through interaction with others, the provision of written information and advice, and the media and popular culture of each country, parents' experiences and perspectives of autism could be directly or indirectly affected and influenced by policy discourse. As policy content and practice vary between the US and the UK, looking at the contexts and subject matter in more detail across locations is an important focus when attempting to understand the factors which influenced the ways in which parents made sense of their child's diagnosis in this study.

3.2 Setting the Context

Another key theme identified in the literature reviewed in Chapter 2 was that autism is a condition that has experienced a substantial level of research, particularly around aetiology, treatment and intervention. With an estimated 52.6 % of children having co-occurring intellectual disabilities (Emerson and Baines, 2005) it is a diagnosis that can require high levels of lifelong support. Due to the complexity of autism and the differences in clinical and functional presentation, costs for treatment, care and support can vary from individual to individual and across countries. As policy is often driven by economic factors, it is useful to briefly consider research

that has focused on autism expenditure at a wider national level in both settings.

3.2.1 Economic Context

In 2007, Ganz used prevalence based data to estimate that supporting an individual with autism in the United States across their lifespan would cost \$3.2 million (equivalent at that time to almost £2 million). In 2009 Knapp, Romeo and Beecham used a similar approach to obtain estimates on national prevalence, individual characteristics (including intellectual ability), place of residence and costs per individual with autism. From this data they concluded that the long term costing of supporting an individual with autism and intellectual disability in the UK was £1.23 million pounds over a lifetime, almost half that of the States.

Buescher *et al.*, (2014) recently completed a comparative study between the US and the UK that looked at the total cost of supporting individuals with autism across a range of domains. Most significantly for this study, they differentiated costs across age groups, with substantial differences in expenditure between the two countries for the 0-5 year age group. In the UK it was estimated that approximately £15,000 was spent per year on an individual child aged 0-4 years with an autism diagnosis and learning difficulties, whilst in the United States it was £107,000 up to the age of 5 years. Although there will be a number of location-specific factors impacting on these costs, this considerable difference in amounts leads to some interesting questions regarding policy and practice for children with autism across the two locations.

3.2.2 Policy Context

There has been a significant increase in Education and Health legislation focusing on young children with disabilities in both the United States and the United

Kingdom over the past four decades (Turnbull *et al.*, 2008). With a greater focus on disability as an equal rights (Barnes, 2007), and human rights, issue (Mallory, 1995), there have been significant advancements in medical knowledge and considerable changes in theories that inform policy, research and services in this field (Brett, 2004). However, although they may have similar aims, policies from contrasting locations appear to vary in their “approach and tactics”, resulting from basic cultural, administrative or political differences (Cyr, 1975).

3.2.2.1 The United States

As is the case in most countries, policy legislation is a precursor to policy guidance, and in the United States this is implemented at three distinct levels: Federal (national), State and local. With both Federal and State government sharing the responsibility for making and enforcing legislation, this can result in variation between states and between local governments. However, all states must implement Federal legislation, and disability policy in particular has a long history of federal involvement (Wegner, 1983; Winter, 2003.)

There have been a growing number of national policies over the past decade that provide guidance for the treatment and diagnosis of young children with autism and promote access to quality-assured, regulated early childhood intervention services as a basic right. Provision for preschool children with autism is detailed in the *Individuals with Disabilities in Education Act* (IDEA, 2004) and the *Combating Autism Act* of 2006 which sanctioned almost one billion dollars for early screening, intervention, treatment and research relating to autism across all States. In 2008, the US government’s *No Child Left Behind* policy (2001) required all practitioners to adopt scientifically validated intervention models (Stansberry-Brusnahan and Collet-Klingenberg, 2010). This was also supported by the National Research Council

(2001), who advocated six key areas that effective interventions must focus on for children with autism: functional spontaneous communication, social skills, play skills, cognitive development, proactive approaches to behaviour problems, and functional academic skills.

3.2.2.2 Scotland

In Scotland, policy responsibility is shared between national and local governments alongside the United Kingdom government. Although Scotland has long had its own education system, since Devolution in 1999 it now also has responsibility for policy within health. However, control of wider equal opportunities legislation alongside welfare, benefits and housing lie with the UK government in Westminster. National (Scottish) policy is implemented at local level within councils, referred to as Local Authorities. Although these have the independence to decide how they meet Scottish Government objectives, in 2007 a Concordat was signed by local and national government to begin to move toward Single Outcome Agreements (SOAs) for all 32 Scottish Councils in all areas of policy (Midwinter, 2009).

However, there is currently no autism-specific policy or legislation for treatment and intervention for preschool children, comparable to that in the US. Individuals with an autism diagnosis come under the broader category of ‘Additional Support for Learning’ (see section 3.3.1), and support is only offered by statutory services from 3 years of age. In contrast to the US, there appears to be more limited specialist support provided by local authorities to children under school age. Instead, 15 hours per week of free nursery education is offered to all children aged 3 and over (Bradshaw, Lewis and Hughes, 2014). This is provided in either mainstream or special education settings, and in some cases children can access early nursery placements from 2 years old, depending on local resources and policies. Children with additional support needs are

also given access to NHS services for speech, occupational and physiotherapy (SIGN, 2007) and these services will be discussed in further detail in Chapter 4. However, with this emphasis on more inclusive services, a number of UK-based studies have identified a gap between diagnosis and access to specialist educational intervention at a national level across the country (Jordan and Jones, 1996; Shields, 2001; Mansell and Morris, 2004; Crane *et al.*, 2015).

Guidelines do exist advising on best practice for the diagnosis process within the health sector (SIGN, 2007) and the *Children in Scotland Act* of 1995 clearly highlighted the need for comprehensive assessments for those that may have an additional support need. Most recently, during the writing of this study, the Scottish Government started to work toward a national autism strategy to review, consolidate and improve practice in autism services and support across the country (2011). In addition, there has been a *Menu of Interventions* published (The Scottish Government, 2013), which details autism strategies and support. However, compared to similar guidance in the United States, it is less concerned with the efficacy of specific approaches. Instead the recommendations centre around the individual challenges that autism might present.

3.2.2.3 Disability Classification in Policy

It is clear that there is a distinction between policy context and focus across these two locations and one of the key differences appears to be the identification (or non identification) of children by their diagnosis. Florian and McLaughlin (2008) argued that the question of classifying children with disabilities has long caused concern and controversy internationally. Apprehension has surrounded the ways in which labelling children can influence stereotype and stigma and how errors in classification may result in inappropriate support. These issues, along with concerns regarding the overrepresentation of specific groups in ‘special education’ categories,

the potential that classification can have on lowering standards and expectations, and the implication that diagnosis can have on resources has led to some very different responses across UK and US educational policies.

In the United States, the identification of children who have specific disabilities has become a prominent feature of education legislation (e.g. IDEA, 2004). However, it is useful to note that this shift in policy occurred after a long history of failure in the education of disabled children (Burke and Ruedel, 2008) where high percentages of individuals with educational needs were previously excluded from mainstream settings (Turnbull, 2008). Therefore, this emphasis on classification has become regarded as a crucial component of a rights based framework as a "...useful tool for program planning and allocation of services." (Burke and Ruedel, 2008:69). In addition, it should also be acknowledged that there remains a strong debate in US education policy and practice against the grouping of children by their diagnosis, as it can lead to stigmatisation, inappropriate or over generalised support and there is often poor correlation between the label and the treatments available. (Reschly, 1996)

In contrast, the Scottish education system has been more focused on a managerial and professional policy framework (Riddell, 2008). Within this there has been an argument that specific classifications not only create stigma but also add pressure on resources and on professionals' performance. Instead, the more general term of 'Additional Support Needs' has been adopted into legislation in Scotland to define any individual who may experience barriers to learning (ASL Act, 2004). The aim of this is to provide support for a wider range of children, where needs are recognised and supported irrespective of diagnosis. However, although local authorities have a duty to identify children with additional support needs, there is no specific guidance on models of assessment or intervention.

This debate on classification is a notable difference in ethos between the two countries, with strong arguments for and against it on both sides. With particular relevance to this thesis, it will be important to keep these differences in mind when considering policy context and content in each location, and again further on in later chapters when I explore parent experience in more depth. However, in order to explore this in greater detail, I will now look more closely at the content of a number of relevant policy documents relating to disability education, health and autism.

3.3 Policy Content

Although there are clear similarities in context and aims across both locations, there are also differences in how autism is viewed and treated and how parents and children are positioned within a number of key documents. In considering the US perspective, it could be argued that policy is set within a more rights-driven paradigm focused on classification, outcome, attainment and treatment. In contrast, Scottish policy appears to be set within a more inclusive, needs-led system that considers the individual and looks at more tailored input rather than diagnostic specific therapy models. These ideas appear to fit with the themes identified in the literature around disability models in each location (see section 2.2). Therefore, it is useful to explore the impact that the potential differences in disability models may have on policy and how this may impact on the experiences of parents who have a young child with autism in each setting.

3.3.1 The Conceptualisation of Autism in Policy

Although the policies referenced in this section do not reflect an exhaustive list of all documents available for comparison between the two locations, I attempted to select examples which were comparable in background and aims, in order to balance similarities with differences. I chose firstly to compare two substantive educational

policy documents which focus specifically on the rights and entitlements of children with a disability in each country. Both the *ASL Act* (Scotland) and the *IDEA* (US) are the most recent national-level legislative policies in each location and were both written as a response to issues identified with previous disability discrimination legislation and policy (Riddell, 2009; Turnbull, 2008). Aimed at policy makers, professionals and parents, both these documents could be regarded to have had some influence over the wider socio-cultural attitudes toward disability, and more specifically treatment of autism, for young children in each location. With particular reference to this thesis, in terms of support for early years' children, The *IDEA* includes a section on supporting children from birth to 2 years old (Part C, 2004) whereas the *ASL Act* makes provision for children 3 years and over, unless there are special circumstances.

3.3.1.1 *IDEA and ASL*

Whilst both documents have a similar focus, the way in which they regard disability appears to be quite different. The *IDEA* states that disability is “a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society” (2004: 3). It views disability in terms of specific diagnoses and makes clear that the criteria for support is linked to identification of particular medical or psychological needs. It also refers to the specific rights of children with identified disabilities throughout the document, which appears to reflect the minority model thinking that could be seen as typical of a US concept of disability more generally (e.g. Hahn, 1988, 1996; Gabel, 2006).

In contrast, the *ASL Act* introduces the concept of ‘Additional Support Needs’ (ASN) which are not related to specific diagnosis or disability:

A child or young person has additional support needs for the purposes

of this Act where, for whatever reason, the child or young person is, or is likely to be, unable without the provision of additional support to benefit from school education provided or to be provided for the child or young person (2004:1)

Instead of being linked with diagnosis, the concept of disability within this policy is set within a more social model framework, describing issues that may limit a child's access to education. This concept of 'Additional Support Needs' appears to be more in line with the UK social model discourse on disability (e.g. Oliver, 1995; 2013) and reflects a different view than its American equivalent; where children need a specific diagnosis in order to obtain support. These differences reflect the contrast in emphasis on classification of children with disabilities, as discussed in section 3.2, and highlight a clear distinction in the ways in which educational needs are defined in each location.

Both documents are similar in their promotion of achievement for children with disabilities, and refer to the impact that an appropriate education can have on a child's potential. As stated in the *IDEA*:

(A)) having high expectations for such children and ensuring their access to the general education curriculum in the regular classroom, to the maximum extent possible, in order to--
(i) meet developmental goals and, to the maximum extent possible, the challenging expectations that have been established for all children. (2004:118)

And the ASL Act:

...the reference to school education includes, in particular, such education directed to the development of the personality, talents and mental and physical abilities of the child or young person to their fullest potential. (2004:1)

Looking at the perspectives on autism in both these documents, neither the original *ASL Act* (2004) nor its amendments in 2009 make any direct reference to autism or autism spectrum disorders, reflecting the idea that diagnosis does not define a child's need for support. In contrast, the *IDEA* makes several references to autism, listing it as a distinct disability, and highlighting it as a priority training need for specialist teachers. It also classifies individuals with this diagnosis as a group that requires 'specialist services'.

3.3.1.2 AACAP and SIGN Guidelines

In contrast to the substantive education policies, when comparing national diagnosis guidelines between the two locations, there were many similarities in their perspectives on autism. Both the American Academy of Child and Adolescent Psychiatry (AACAP) (Volkmar *et al.*, 2014) and the Scottish Intercollegiate Guidelines Network (SIGN, 2007) view autism through a medical model perspective; as an issue that benefits from correct diagnosis and treatment. Whilst this is not unusual for a health-based document, it is notable that the medical focus of the *SIGN* guidelines is in contrast to the more social model discourse within the *ASL Act*. In both the *SIGN* and *AACAP* documents, autism is defined through deficit, with direct reference to the specific criteria of the *DSM V* or *ICD 10*. However, there are some significant variations between these guidelines when recommending early screening of or treatment and intervention for young children with autism. In the *SIGN* Guidelines, population screening is not recommended due to the possibility of false negatives or positives (p.5). In addition, whilst it recommends behavioural interventions that deal with specific behaviours (such as self-injury or aggression), *SIGN* does not recommend any type of early intensive behavioural therapy, stating that these approaches lack a strong evidence base (p.18). Instead, there appears to be stronger

perceived proof for a number of pharmacological interventions, such as risperidone, methylphenidate and melatonin to ameliorate autism symptoms.

Whilst the AACAP guidelines (Volkmar *et al.*, 2014) also recommend similar pharmacological interventions for specific symptoms or co-morbid conditions, in contrast to *SIGN*, they actively promote the early screening of all young children for ASDs (p.243). They also strongly recommend the use of intensive behavioural and educational therapy approaches for young children with autism. In Recommendation 4, AACAP states: “The clinician should help the family obtain appropriate, evidence-based, and structured educational and behavioral interventions for children with ASD.” (p.244). As discussed in section 2.4.2, a variation in access to services could have a subsequent influence on parent experience overall (e.g. Howlin and Moore, 1997; Hutton and Carron, 2005; Gray, 2002a). Therefore, this clear difference in advice on treatment approaches has the potential to have a significant impact on parent engagement with early services for their child in each location.

3.3.1.3 Educating Children with Autism and the Autism Toolbox

One of the key documents relating to autism support and intervention in the United States is called *Educating Children with Autism (ECA)* (NRC, 2001). Aimed at education and health professionals, this document states that the education of children and teachers is currently the “primary form of treatment for autistic spectrum disorders.” and details a range of diagnostic issues and intervention approaches with particular regard to autism in the early years. It describes ‘autistic disorders’ as:

...unique in their pattern of deficits and areas of relative strengths.

They generally have lifelong effects on how children learn to be social beings, to take care of themselves, and to participate in the community
(p.1)

This statement clearly reflects a medical view of autism through identification and

treatment, which is found in other policy documents in this location. However, although this medical perspective could be seen as a negative assessment of the condition in some ways, this focus on treatment and therapy also offers a clear focus on supporting young children with this diagnosis to make progress.

In looking for equivalent documents in Scotland, I identified the *Autism Toolbox* (2009), which was written as guidance to support the understanding of best practice in autism education across Scotland's nurseries and schools. In contrast with the *ECA*, the *Toolbox* uses a more 'person first' approach to defining autism and subsequently reflects less emphasis on classification of individuals by their diagnosis:

Autism Spectrum Disorder (ASD) is part of the story of who the child is as a person with a unique profile that includes their personality, strengths, challenges, likes and dislikes. (p.29)

Although the *Toolbox* makes some reference to interventions, it is more focused on how professionals can adapt their teaching and the environment to support the child. This lack of focus on therapy approaches and 'treatment' would also fit with a social model premise that appears to be more prevalent across Scottish autism policy and guidance. Most recently, an additional guidance document for professionals has been published called the '*Menu of Interventions*' (The Scottish Government, 2013) which claims to provide an overview of relevant interventions for children with autism in Scotland. However, in contrast to documents such as *ECA*, it does not advocate for specific research based approaches. Instead it draws:

...from a wide range of professionals, individuals and families of people on the spectrum, regarding the challenges faced by people with ASD across the lifespan and ability range and how these might be best addressed... It is not however, a comprehensive list of all

possible interventions and supports nor can it provide information regarding the efficacy of specific interventions. (p.2)

Although similar in aims, the differences between the medical versus social model views of autism within these ‘professional guidance’ documents in each country are significant to this thesis. These themes at national level also appear to impact at a local level and I will now look briefly at local autism policy and guidance as it relates to my specific locations.

3.3.1.4 Local Autism Policy

Although the Scottish government published an autism strategy in 2011, the responses from Local Authorities are not yet finalised and at the time of writing this thesis, no Local Authority in the central Scotland area had a published autism specific policy. Instead, young children with this diagnosis fall under the current *Additional Support for Learning* policies in each area, reinforcing the overall view that children do not need a diagnosis in order to receive support. Although two Local Councils from the area covered in this study now offer a brief guidance document for parents that details the support available for children with an autism diagnosis (Clackmannanshire and Stirling), there is no information within these documents that refers to autism as a distinct condition which may benefit from specialist treatment. Instead, there is more emphasis on children accessing mainstream services, but having the option of multi professional assessments and input through health, education and social work as required.

In contrast, Massachusetts has a number of policy and guidance documents relating specifically to autism and early intervention, where autism is described throughout as a disability that requires intensive support. For example, the ‘*Massachusetts Early Intervention Speciality Services for Children with Autism-*

Operational Procedures states:

Intervention sessions frequently last several hours and may be provided a number of times per week as children on the autism spectrum may require a number of hours of engagement to promote learning and minimize the development of challenging behaviours. (2011:2)

Therefore, there appears to be a clear distinction between the two locations with regard to support and services offered, alongside the differences in the ways that autism seems to be conceptualised in public policy. As discussed, this may have had a direct and indirect impact on study participants in a number of ways and these will be critical factors that I take forward in my analysis of the data.

3.3.1.5 Summary

With regard to the variations in the content of policy documents relating to children with autism in the early years, it is clear that there is a fundamental difference between the two locations in the ways in which autism is perceived and supported through services. This focus on a need for intensive specialist treatment in Massachusetts versus a more individualised, inclusive and less diagnostic-specific view of autism in central Scotland, is a factor that could contribute to significant diversity in parent experiences across these two locations. However, it is important to note that within a symbolic interactionist framework there could be a number of other influences that shape the ways in which parents make sense of their child's diagnosis. Direct and indirect interaction with policy discourse may only be a small part of this. In addition, there are also some similarities in policy content across both settings with regard to the positioning of parents as partners with professionals and services. To explore these further I will now return to the two key substantive policy documents reviewed earlier

in the chapter, alongside ECA and the Autism Toolbox.

3.3.2 'Parents as Partners' Discourse within Policy

Both the *IDEA* and the *ASL* position parents at the centre of their child's education planning. For example, *IDEA* states that one of its key aims is:

...strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home.
(2004:118: STAT 2649)

It also talks about its focus on the protection of children's and parents' rights throughout their educational experiences. Although the *ASL Act* does not contain any comparable quotations relating to parents' rights and role as partner, one of the fundamental aims for the *Act* was to secure parental rights to make requests for assessments, coordinated support plans and placements. It also placed a duty on Local Authorities to share greater information with parents regarding their rights (Riddell, 2009)

The theme of parent rights and parents as equal partners is also evident throughout the autism specific policy documents considered earlier. Both the *ECA* and the *Autism Toolbox* make reference to parents as key collaborators in their child's education and intervention. *ECA* states that: "We recognize that parents are partners in an educational process that requires close collaboration between home and school."(p.34) and also that:

...parents typically are active partners in their child's education to ensure that skills learned in the educational program transfer to the home setting and to teach their child the many behaviors that are best mastered in the home and community. (p.32)

This emphasis on developing parents' skills as active partners in their child's education is also advocated by the Scottish *Autism Toolbox*:

It is important to acknowledge that parents are also on a journey of discovery with their children and may not have benefited from good information in order to help them understand their children in terms of the impact of ASD. (p.62)

In addition, the *Toolbox* has a section on 'Partnership with Families' and discusses various ways to include knowledgeable parents in decision making and target setting.

Although the assessment of a child's additional needs still remains largely in the hands of professionals in Scotland (Riddell, 2009), the ASL Act has given parents greater rights overall. With greater access to a range of redress mechanisms, parents now have clearer options to seek independent mediation or to use the tribunal process. With increased rights to choose to make placement requests for preferred schools, parents can now take their local authority to tribunal if they are unhappy with a school placement choice, if they want to contest a refusal to award a CSP or if they wish to challenge the contents of a CSP (Riddell and Weedon, 2009).

With parents being positioned as partners within educational policies and guidance in both countries, it would be reasonable to assume that this will have a positive and empowering influence on their experiences with professionals and services during and post-diagnosis. It will be interesting to observe within the analysis of the data in subsequent chapters, whether this focus has had a positive impact on parent experience overall.

3.4 Discussion

Although I cannot provide an exhaustive discussion of policy context and content across my locations within the scope of this thesis, I have endeavoured to select the themes, topics and documents that related most directly to my research focus. In giving this brief overview, alongside a review of the research literature in Chapter 2, I have attempted to set the scene for the research questions that have emerged from my exploration of these areas. In considering the wealth of literature that surrounds autism, autism parenting, and early intervention in particular, it is evident that there is a considerable gap in the knowledge that we already hold. This is particularly apparent when looking at how parents experience their child's diagnosis and make sense of this situation at an early age and across different locations. It is also clear from an overview of policy context, focus and content that there are some fundamental differences between the United States and Scotland in terms of the ways in which autism is conceptualised and treated. Although there are similarities in the ways in which parents are positioned within specific policy documents, parental rights and roles in their child's education or intervention may in fact be enacted differently across both settings.

Having established strong foundations for the motivation behind this research, I will now introduce the research questions that I aim to address, and set the agenda for this study more specifically.

3.5 Research Questions

The main aim of this thesis is to explore the experiences of parents who have a child with autism, under the age of 5 years, in Massachusetts and central Scotland. In order to develop an understanding of these experiences and the ways in which these parents attach meanings to their situation, I will explore the following questions

through my findings and analysis:

What are the similarities in, and differences between, Massachusetts (US) and Central Scotland (UK) in terms of:

- 1. Parents' experiences of the autism diagnostic process?*
- 2. The impact of post-diagnosis services and support on how parents experience and make sense of their child's diagnosis?*
- 3. The ways, if any, in which parents feel that their perceptions of autism have changed over time and to what they attribute any changes?*
- 4. The ways, if any, that parents feel that their perspectives of, and aspirations for, their child have changed over time and to what they attribute any changes?*

In order to answer these research questions, it is essential that I firstly set out the methods and methodology of this thesis, before reporting on my findings and analysis of my data, and finally drawing my conclusions. Having reviewed the literature and policy contexts in both locations, I will now introduce my research design, methods and analytical framework.

Chapter 4: Methodology and Methods

4.1 Introduction

In the previous chapters I reviewed the literature on disability models, conceptualisations of autism and parent experience, alongside a brief overview of the similarities and differences in policy context and content across both countries.

Divided into two parts, this chapter opens with a discussion of the theoretical underpinnings of this study looking specifically at the benefits and limitations that a qualitative paradigm can bring to the exploration of parent experience in this field. I then move on to explore ontological and epistemological considerations in more detail before concluding this section with an overview of the methodological framework I have selected. In the second half of this chapter I present my research design and a summary of my data collection and analysis methods, including a discussion on researcher reflexivity and the ethical challenges that this study has raised.

4.1.1 *Benefits of a Qualitative Paradigm*

Through my review of the literature in Chapter 2, it became clear that much of the research to date focusing on parent experience of autism diagnosis has been undertaken using a quantitative approach. These research methods have been utilised effectively in a range of studies in this field to investigate parent reaction to diagnosis and the impact this has had on their mental health (e.g. Estes *et al.*, 2009). However, there was more limited literature that employs a solely qualitative approach to explore parents' understanding of autism and the ways in which they have made meaning of their child's diagnosis, particularly in the preschool years.

As argued by Hastings and Taunt (2002) a wholly quantitative paradigm in this field is limiting in many ways and research using such methods has also focused primarily on the negative aspects of having a child diagnosed with autism. Therefore, it is clear that there is a growing space within the literature for studies that look more qualitatively at parent experience of autism alongside positive aspects of the diagnosis and parents' perceptions of and aspirations for their child. There is also a more specific need for studies that look primarily at parents' experiences in the earliest stages of their child's diagnosis, and the ways in which these experiences may be influenced by factors such as geographical location.

As this study is specifically concerned with the ways in which parents make sense of their child's diagnosis and the impact that this understanding has on their perspectives of, and aspirations for, their child, I have decided that a qualitative, rather than quantitative, methodology is best fit to answer my research questions. In contrast to quantitative research, where there is often a distance between researcher and participant (Bryman, 1984), qualitative inquiry goes "beyond a report of surface phenomena to their interpretations, uncovering feelings and the meanings of their actions." (Holloway and Wheeler, 2002:13). When exploring the lived experiences of parents and "naturally occurring ordinary events in natural settings" (Miles and Huberman, 1994:10) qualitative methods can provide us with "thick descriptions" (ibid) and can better reveal the complexities of the ways in which people develop their perceptions, assumptions and understanding of the social world.

However, this choice of paradigm is also a reflection of my own ontological position as a researcher and it is important to recognise the impact that this position may have, not only the analysis of my data, but on the choices I make relating to my methodological framework and research design. As asserted by Miles and Huberman:

“It is good medicine, we think, for researchers to make their position clear.” (1994:5) so those engaging with their research can know better where they are situated. In selecting a wholly qualitative approach to this study, I am making plain that my primary interest as a researcher is not in the use of numerical data to attempt to explain or to test predetermined hypotheses. Instead, it is in the exploration of the meaning of human action (Carter and Little, 2007) and the ‘how’ and ‘why’ questions related to the lived experiences of the parents in my study. With this in mind it is important to acknowledge my own beliefs regarding the nature of reality and briefly discuss this with regards to this study.

4.1.2 Ontological and Epistemological Position

From an ontological perspective, I would align myself with a critical realism similar to that which is described by Miles and Huberman (1994). They state that “social phenomena exist not only in the mind, but also in the objective world” (p.4) and that there are lawful and stable relationships between the two. Whilst I recognise that there are a number of different forms of critical realism, the extent of which is beyond the boundaries of this study, in establishing my position as researcher I would agree with the view that there is a reality that exists outside of our understanding, perceptions and constructions. However, I would also argue that individuals create and construct their meanings of this world in order to understand it (Maxwell, 2012). In addition, although I would disagree with a wholly social constructionist viewpoint that there are “multiple realities” (Berger and Luckmann, 1991) I would still acknowledge that individuals can hold different perspectives of reality which are influenced and created through personal experience.

Alongside clarity regarding a researcher's ontological perspectives, qualitative research studies benefit significantly from having a clear framework that considers epistemology, methodology, methods and their interrelationships (Carter and Little, 2007). Epistemology can be defined simply as theory of or justification of knowledge (2007:1317) and provides researchers "philosophical grounding for deciding what kinds of knowledge are possible." (James and Busher, 2009:8).

4.1.3 Qualitative Methodologies

Alongside a wealth of epistemological positions in qualitative research, there are also numerous methodologies or "strategies of inquiry" (Denzin and Lincoln, 2000) that researchers can use to attempt to understand meaning making processes. In view of my research questions and the focus of this study, I was drawn to investigate approaches that could help me explore how parent experience could be better understood across the two locations, particularly with regard to the ways in which meanings of autism can be made and constructed. I initially considered three potential methodologies; Critical Discourse Analysis (CDA), social constructionism, and symbolic interactionism, which I will now briefly outline, before stating my reasons for my final choice.

CDA, as advocated by Fairclough (2001), is a trans-disciplinary approach to exploring discourse, either through written or spoken text (Fairclough, 2001). The approach draws upon the field of critical linguistics but combines this with social theory. It has many strengths and can be used in a range of ways, both to highlight and disrupt inequalities within society and as an emancipatory device with which to redress the power/knowledge balance. However, as this study aims to explore the ways in which parents act toward their child's diagnosis through the meanings that autism has

for them, it is important to highlight that discourse theory does not make the individual part of the analysis (Cruikshank, 2012:45). Although CDA can be used to analyse interview data, it appears to be an approach best suited to social justice research which centres on documentary, or policy, analysis. In addition, although there have been attempts to combine CDA with an interpretive epistemology (Dirks, 2006), it is an approach best suited to a more critical theoretical framework that advocates emancipation and change.

In attempting to further explore the view that meaning can be constructed through language, and through reflection on the ways in which the conceptualisations of autism have developed over time, I was drawn to the idea that perceptions of autism could be regarded as being constructed socially.

Although the principles of a social constructionist methodology may have been in conflict with my ontological position, I began to consider the work of Hacking on the construction of classification and autism (1999, 2007, 2009).

Taking a more critical realist approach to constructionist principles, Hacking has written widely on what he views as the social construction of autism (1999; 2009a, 2009b; 2010). In particular, as discussed in chapter 2, the way in which autism has been classified and re-classified over the years can and will impact on the way in which families of individuals with this diagnosis view autism. Hacking discussed this within his concept of an 'autism narrative' and the 'looping effect'. For example, he argued that the growing genre of autistic narrative (life writing by individuals with autism and autism fiction) is both informing and transforming the ways in which autism is understood and conceptualised (2009a, 2009b). This in turn has a 'looping effect' where diagnostic classifications start to affect the overall understanding of autism and the way in which individuals make sense of it.

In his writing on how autism is talked about (2009a), Hacking made an interesting distinction between the medical diagnosis and the more socially constructed understanding of autism. He argued that whilst there is A) a yet unknown shared neuropathology that 'is' autism, which exists as a real entity, there is also B) an element of autism that has been developed through a kind of social construction, which exists outside of this medical definition. With regards to this study, these ideas appeared to be potentially useful to frame my discussion and analysis, as autism has come to mean different things to different people (Draaisma, 2009; Murray, 2012), in spite of a common diagnostic criteria.

However, as I explored these theories further within the development of my methodology, I came to realise that Hacking's work did not have a set framework for modelling or analysis (Kuorikoski and Pöyhönen, 2012). I also felt that his social constructionist theories and Fairclough's approach to CDA lacked an acknowledgement of the fundamental role that human agency and interaction with others can have in the process of meaning making. As I believed that this could be a central aspect of my data analysis, I began to look for a methodological approach that could combine elements of CDA alongside Hacking's work on the social construction of autism, whilst still reflecting elements of critical realist and interpretive approaches to understanding how meanings are created through interaction. Agreeing with Seidman, who stated: "At the very heart of what it means to be human is the ability of people to symbolize their experience through language." (2006:8) and Griffin who argued that "Most human and humanizing activity that people engage in is talking to each other" (2012:54), I chose to investigate the principles of a Symbolic Interactionist methodological framework to help me understand more fully the experiences of parents across my two locations.

4.2 Symbolic Interactionism

The Symbolic Interactionist framework (Blumer, 1969), defined in further detail below, appeared to best fit for the theoretical focus of this study and its research questions for a number of reasons. It is concerned primarily with meaning, language and thought (Griffin, 2012) where human beings are understood as social people who create and are created by interaction with self and others (Blumer, 1969; Charon, 2010). Most significantly symbolic interactionism advocates that humans are not simply a product of society but are active agents in creating its meanings (Charon, 2010; Stryker and Vryan, 2006; Stryker, 2008; Snow, 2001). Notably it differs from a traditional social constructionist methodological framework in this aspect as it goes beyond being a theory about what is 'known' to a theory about why individuals act in the ways that they do.

4.2.1 Implications for this Study

For parents in the early stages of understanding and accepting their child's diagnosis, the ways in which they make sense of this situation can be influenced by a range of factors. As can be seen from the literature reviewed in Chapter 2, parent experience can be greatly influenced by their dealings with others, either through the range of professionals involved in their case (Siklos and Kerns, 2007; Hutton and Carron, 2005) or the networks of support they build with other parents in similar situations (Huws, Jones and Ingledeu, 2001; Jordan, 2010). It can also be influenced by the meanings that individuals have already attributed to certain concepts through past experiences, for example the development of autism stereotypes (Broderick and Ne'eman, 2008). Throughout these processes, it appears that interaction with self and others is fundamental.

Although it has roots in a constructionist epistemology, symbolic interactionism is an interpretivist methodological approach that "...builds on the social formation of symbols, common or shared meanings." (Barbalet, 2009:185). It recognises that reality is constructed on an individual basis, with meanings being attached to objects and experiences through the use of language and symbol. It also offers a framework for understanding the ways in which these meanings have been made through interaction with others (Blumer, 1969), and how meanings are 'embedded' in a social context (Charon, 2010). In addition, it has a strong focus on the 'self' and how this is constructed through interaction with others (Blumer, 1969; Charon, 2010; Griffin, 2012), and advocates the premise that the ways in which we make sense of the world dictate how we act towards it (Denzin, 1992; Snow, 2001).

In using symbolic interaction as a methodological framework for this study, I will attempt to identify the significant factors that may influence parents' meaning making processes of their child's diagnosis and also look more closely at how and why perceptions of autism and their child may have changed over time. It will also provide a way to explore how these meanings were made through interactions with the media, professionals and other parents before and after diagnosis, alongside looking at the impact that structural concerns such as policy might have had on the experiences of parents in each location. Through utilising these principles, parents' experiences of making and ascribing meaning to their child's diagnosis will be understood within a context of interpretation and subjectivity (Denzin, 1992). This approach will also enable a better understanding of the origin of some of the contrasts in meaning and perceptions of autism that emerge from the data and help to explore some of the shared themes that developed. Having established this methodology as the framework for this study, I will now discuss the theoretical origins, key premises, strengths and limitations

in more detail.

4.2.2 Theoretical Origins

When developing the roots of symbolic interactionism, Blumer drew on the work of Mead (1934) and his exploration of the social self in particular. Although Mead's work was based on behaviourism, he "...redefined human behaviour as a response to individual interpretations of the world rather than to the world itself." (Oliver, 2012:410). Blumer, in his initial description of symbolic interaction as an approach, asserted three main premises to the theory:

- "1: That human beings act towards things on the basis of the meanings things have for them.
2. The meanings of such things are derived from or arise out of social interaction with others.
3. These meanings are handled in, and modified through, an interpretive process used by the person in dealing with what he encounters." (1969:5)

Although it is a complex approach with many interpretations and schools of thought (Pascale, 2011), for the purpose of establishing the methodological implications of symbolic interaction to this study specifically, I will now look at these three initial premises of Blumer in more detail and discuss their relevance for my research questions.

4.2.3 Action and Meaning

The premise that human beings act toward things on the basis of the meaning that it has for them is crucial in attempting to understand how parents act towards and think about autism, and subsequently how they act toward their diagnosed child. In symbolic interaction, a person's actions are directly related to the ways in which they understand certain concepts. This understanding and subsequent action is based on the meanings that situations have for him or her, rather than in direct response to the event or situation itself (Burbank and Martins, 2009).

When exploring parents' conceptualisations of autism pre and post-diagnosis, and what it could mean for their perceptions of and aspirations for their child, it is important to acknowledge that they will have ascribed meaning to autism through a variety of interpretations. This will have occurred through a combination of self-reflection and reflection on past experiences (Charon, 2010), as well as through interactions with others (Blumer, 1969). There may also be a number of factors which contributed to this process, some of which will be shared across both geographical locations as common themes and others may be culturally dependent or wholly individual.

4.2.4 Social Interaction

According to Pascale (2011) there are a "limitless number of layers to the meaning making process" (p.93). However, the principal of social interaction within symbolic interactionism is critical. Mead (1934) understood social interaction as an interpretive process by which symbols (gesture, language or objects) are symbolically decoded through the meaning that this interaction has, and then acted upon according to that meaning. With a specific focus on parent/ professional interaction within my

interviews and my research questions I feel that this principle within Blumer's description is crucial for understanding the impact that direct interaction with others might have on the meaning making of parents in this study.

Social interaction and the interconnections between self and society mean that human group life is regarded as a constantly developing process, not simply a product of fixed psychological or sociological structures. Blumer also asserted that through interaction with others, "patterns of group life" are established, and that their continued existence relies on the continued use of specific schemes of interpretation. However, once something changes within this interpretation by others, these established patterns can collapse and become redefined.

Redefinition imparts a formative character to human interaction, giving rise at this or that point to new objects, new conceptions, new relations, and new types of behaviour." (Charon, 2010:67).

This idea of an ever changing, interpretive pattern of understanding can be seen as paramount when looking at the shifting definitions and perspectives in autism. Redefinition can also happen over time, as parents experiencing diagnosis have considerable and sometimes prolonged interaction with professionals who are involved with their child (e.g. Koegel *et al.*, 1992; Goin-Kotchel, Macintosh and Myers, 2006) and therefore may have extensive opportunities for their meaning making to be shaped and changed by the views of others over weeks, months and years.

4.2.5 Self

In addition to interaction with others, interaction with self is a key principle of this approach, with the two being intrinsically linked. Blumer considered the ‘self’ a social rather than psychological concept and that self and society exist within a reciprocal relationship (Blumer, 1969; Stryker, 1988). It could be argued that through interaction with self, parents may begin to define what the various concepts of disability and autism mean to them. In addition, interaction with others is crucial to an individual’s concept of self, and their self-image within their society.

One key contributor to this field was Goffman (1959), who wrote extensively about social interaction and the social construction of self. Within his ‘dramaturgical analysis’ Goffman regarded human beings as actors whose ‘selves’ are a social product, “...in the sense that it depends upon validation awarded and withheld in accordance with the norms of a stratified society.” (Lemert and Branaman, 1997:66). Agreeing with Cooley’s definition of the ‘looking glass self’ Goffman also argued that “...the degree to which the individual is able to sustain a respectable self-image in the eyes of others depends on access to structural resources and possession of traits and attributes deemed desirable by the dominant culture.” (ibid).

As discussed in section 2.4, parents of children with autism may feel isolated and uncomfortable when facing the reactions of others, and they may also question their own parenting skills or experience courtesy stigma (Gray, 2002b). In addition, autism is a condition that has been conceptualised through stereotype and stigma (Broderick and Ne’eman, 2008), particularly within the media (Draaisma, 2009). Therefore, the concept of stigma and looking glass self are of particular relevance to this study and will be an important consideration within my analysis in Chapters 5 and 6.

4.2.6 Criticisms and Limitations of the Approach

As with any theory or theoretical framework, there are limitations to the scope and the use of symbolic interactionism in research, and criticism of this approach has been almost constant (Denzin, 1992). This was most prevalent in the 1970s when it came under attack both from ‘in-house’ and non-interactionist critics (Meltzer, Petras and Reynolds, 1975). Some of the limitations that have been recognised are that symbolic interactionists have failed to clearly express a “...systematic theory” (Benzies and Allen, 2001:545), and that it has neglected the more emotional aspects of meaning making (Denzin, 1992). However, one of the fundamental perceived limitations of this approach is that it neglects structural considerations in society and the larger symbolic picture (Stryker, 1988; Meltzer, Petras and Reynolds, 1975; Stryker and Vryan, 2006). For example, Litchman (1970) argued that the approach ignored how the interpreted meanings of individuals “are shaped and channeled by society’s dominant institutions” (p.75). In focusing solely on the small scale, neglecting large scale structures it is argued that interactionists are left open to “structural blindness” (Denzin, 1992).

However, Dennis and Martin (2005) considered these criticisms to be misrepresentative of the field. Cooley, one of the original interactionists, regarded self and society to be opposite sides of the same coin and since the 1980s there has been a movement in the symbolic interactionist discipline to begin to recognise the social aspects of power and constraint (Musolf, 1992). In his study on the new directions taken by symbolic interactionists since 1975, Musolf asserts that through “Making the link between microsociological communication processes and macrosociological community structures, interactionists have also expanded their definition and exploration of power. “ (p.172).

4.2.7 An Extended Interactionism

Since Blumer's initial definition of the approach, it has undergone a number of "movements of thought" (Pascale, 2011:84). Although this has meant that it has not developed into a "homogenous intellectual presence" (Ibid) these movements have attempted to address these various limitations of symbolic interaction, primarily the perceived lack of focus on structural considerations.

In attempting to answer the criticisms, two advocates emerged to clarify what they regarded as an extended symbolic interactionist position. Both Stryker (1988, 2008) and Snow (2001) chose to acknowledge and expand the three key premises that Blumer had advocated, in order to try to attend to some of the issues that these perceived limitations had presented. Both of these are relevant to this study in a number of ways.

Stryker, building on Blumer's premise of developing meaning through social interaction, argued that a true account of human behaviour needs to include the perspective of the actor, rather than relying solely on the perspective of the observer. He also argued, like Blumer, that social interaction is fundamental, but that both self and social organisation can emerge from this "social process" (1988: 35). Social processes shape society, self and social interaction, with each feeding back on the others (2008:18). Thirdly, he asserted the additional premise that an individual's reflexive responses to self link "larger societal processes to the social interactions of those persons."(1988:35). Moving into a 'Structural Symbolic Interactionist' frame (2008), Stryker extended these principles further, reconceptualising notions of self through identity theory and re framing social structures as "patterned interactions and relationships." (p.19). However, although his reframing of the approach is useful to this study in that it provides a broader theory which emphasises the importance of

structural considerations, the most relevant extension of symbolic interaction with regards to parent experience in this thesis is that of Snow (2001).

Although he regarded Blumer's initial premises as a "principal introduction to the perspective", Snow (2011) argued that these linked symbolic interaction too tightly and narrowly to the issues of meaning and interpretation. Like Stryker, Snow proposed additional and wider definitions to the original principles, incorporating more of an emphasis on social structure and collective meaning making. His focus on interactive determinism, symbolization, emergence and human agency added much needed layers to Blumer's original theories and I will now discuss these in further detail before clarifying the approach to symbolic interaction that I will be taking in this thesis.

4.2.7.1 Snow's Approach to Symbolic Interactionism

Firstly, with his focus on interactive determinism, Snow, like Stryker (1988, 2008), extended the premise that individual and society are linked. He advocated that, in order to fully understand objects of analysis, one cannot only attend to the qualities that are presumed intrinsic to them. Instead, he argued that interactive determinism within this extended symbolic interaction framework meant that "neither individual or society nor self or other are ontologically prior but exist only in relation to each other" (p.369) and can only be understood through their interaction. This idea is of significance to this thesis in that I am interested in exploring the impact that structural considerations and policy in particular may have had on parents across my two locations.

Secondly, in an extension of Blumer's focus on the importance of symbolisation, Snow argued that instead of being engaged in a continuous attempt to make sense of

the social world through interpretation of symbols, the meanings that we have for them are: “often, perhaps routinely, embedded in and reflective of existing cultural and organizational contexts and systems of meaning.” (2011:371). Although this premise did not disregard the constructionist dimension to symbolization, he clearly acknowledged that a structural element also exists within meaning and interpretation. This is an important element to any study that explores the ways in which parents have attributed meaning to a concept such as autism, which, as discussed, may have been conceptualised within long standing stereotypes across research, policy and the media in both locations (Nadesan, 2005; Draaisma, 2009; Broderick and Ne’eman, 2008; Murray, 2008).

Thirdly, Snow discussed the principle of emergence with regard to a symbolic interaction approach. In contrast to the structural element he acknowledged as a key part of symbolization, this premise highlights the dynamic character of social life, where perspectives and conceptualisations can change through interaction. This can be collective change through social movements or individual through “epiphanic moments” (Denzin, 1992). As parents of children with autism have been recognised within research as having unique experiences relating to advocacy for their child (e.g. Ryan and Runswick- Cole, 2009), the principle of emergence will be a useful framework through which to analyse parent interactions with professionals in particular and this will be something that I take forward within my analysis.

Finally, Snow’s fourth premise was that of human agency. Although Blumer (1969) focused on human agency as a key part of meaning making and action, Snow extended this by focusing on the impact that structural and cultural constraints can have on this action. He argued that through taking for granted, or ‘routinizing’, the behaviours that these constraints prescribe, the issue of human agency can often fade

into the background of social life. However, when there is a perceived threat to this routine through injustice for a particular group or individual, “the issue of agency likely springs to the foreground as individuals attend to some kind of corrective or remedial action” (2001:374). Snow regarded agency as an “orienting principle” in a symbolic interaction approach due largely to the fact that “work within the interactionist tradition has tended to accent and focus on those niches and crevices of social life in which matters of intentions and actions are at play.” (p. 376). In terms of the participants in this study, the principle of human agency is a potentially important factor to consider with regards to reactions to access to support and services for their child pre and post-diagnosis.

4.2.8 Implications for This Study

Whilst I have chosen to use a symbolic interaction approach to explore the meaning making of parents’ experiences of their child’s autism diagnosis, I am not neglecting the structural aspects that may contribute to this experience. Although this thesis utilises the three premises of symbolic interactionism first established by Blumer (1969), it is within Snow’s (2001) extended methodological framework that I will situate my analysis. Through the contextual examination of a range of policy, legislative and guidance documents in each location, alongside interview data reflecting the lived experiences of parents who have a young child diagnosed with autism, I will be actively looking for links between the macro and the micro (Fine, 1992).

In addition, Snow’s extended principles of symbolization and emergence focused on the ways in which meaning can be embedded in, and reflective of, existing systems, but can also emerge and change through collective and individual interactional

responses. These ideas have particular relevance to this study as perceptions and understandings of autism can be situated within wider conceptualisations located in a structural or cultural context, but can also be influenced by individual experience and interaction with others. Understanding of autism has also changed over time and will continue to do so, both collectively and individually.

Finally, both Blumer's original premises and Snow's extended principles of symbolic interaction acknowledged the impact that human agency has on meaning making. Individuals are not simply passive recipients, but are active and willful actors, constantly engaged in the processes of understanding their world through interaction, reflection and thought.

4.2.9 Symbolic Interactionism in Autism Research

As a methodological approach, symbolic interactionism has been used in a small number of studies relating to more general disability parenting and parent perception of childhood diagnosis (e.g. LaRossa and Reitzes, 1993). It has also been utilised in studies looking at the relationships that non-disabled people have with those that are disabled (Bogdan and Taylor, 1989) and has been employed to explore the decisions that parents make regarding how and whether they communicate information regarding their child's disability (Todd and Shearn, 1997). With regard to autism specifically, it has been applied within a small study specific to autism parenting and family life (e.g. Huws, Jones and Ingeldew, 2001). However, there has only been one study to date that used Symbolic interactionism to explore parents' experience of an autism diagnosis and perspectives on their child (Al Kandari, 2006- unpublished PhD thesis) which was undertaken in Kuwait. This study looked at the experiences of 11 mothers of children and young adults aged between 9 and 22 with an autism diagnosis.

It found that initially parents had a deficit focused perspective of autism, with largely stereotyped views and were therefore shocked at their child's diagnosis as it was unexpected given their interpretation of their child's behaviours. In addition, it found that many parents viewed autism as curable, which was a perspective developed over time through their religious beliefs and interactions with others. Although it is clearly a useful methodology for studies looking at parent experiences and perceptions of autism, as yet symbolic interactionism has not yet been applied as an analytical framework for studies looking at this experience at the time of diagnosis or within a cross cultural study on perspectives or conceptualisations of autism.

Having explored the methodological considerations for this thesis in detail, I will now present an overview of my research design and methods.

4.3 Research Design and Methods

In this section I present the research design used in this study, followed by an overview of the research methods. Beginning with a discussion of my research design and methods, I look at the ways in which using elements from case study research has been relevant to this thesis, alongside a discussion on interviewing and its strengths and limitations for this study. I then focus on the process of selecting my sample group, looking specifically at the reasons for choosing my study locations and the participants themselves, before moving on to an exploration of the ethical issues that this study may present, alongside my reflections as a researcher.

Finally, I discuss my data collection and analysis methods before presenting my findings, analysis and discussion in chapters 5 and 6.

4.3.1 The Research Design

As considered in the previous section, I chose to situate this study within a qualitative interpretivist framework. Drawing on a critical realist ontological perspective and an extended symbolic interactionist methodological approach, I have explored the experiences of parents across two settings that have marked differences within policy and practice relating to early autism diagnosis and intervention.

Alongside numerous methodologies, there are also many research designs that could be and have been used to explore parent experience of an autism diagnosis. These include large scale statistical analysis of survey data (e.g. Siklos and Kerns, 2007; Ogston, Mackintosh and Myers, 2011; Howlin & Moore, 1997) as well as randomised control studies relating to the impact of parent training on child outcomes pre and post-diagnosis (Gengoux *et al.*, 2015). However, as a qualitative researcher, I have chosen to use an interpretative approach which reflects my deep interest in other people's stories and the language that they use to symbolise their experiences. More specifically, I was drawn to consider the benefits of case study research and I have chosen to use elements of this to support the design of this study.

4.3.1.1 Case Study Research

The majority of description and explanation of conventional case study research asserts that multiple perspectives (Simons, 2009) and multiple methods of data collection (Stake, 1995; Yin 1994) are crucial for triangulation of data and results. As I am using a single method of data collection rather than several different approaches, this study cannot meet the criteria for a more traditional definition of case study research (Thomas, 2011). Nevertheless, there are key elements of this

design that can be used in this thesis and I will now discuss the components of this approach that I considered most relevant to my research, stating my rationale for this choice.

In designing this study, I initially used Yin's (2003) and Stake's (1995) work on types of case alongside Thomas' (2011) structure of subject, purpose and approach as an initial framework. In collecting and analysing data from participants across two locations, I found these concepts useful. According to Thomas' definition of case subject, this thesis is could be regarded as an example of a 'local knowledge case' as I have come to this study due to my personal experience in the field. In addition, when considering the purpose of this study it can be viewed as both instrumental (Stake, 1995) and explanatory (Yin, 2003). The primary aim of an instrumental study is to use a case to illuminate the understanding of a wider phenomenon or issue (Stake, 1995). Although, as discussed, I am not proposing to generalise from these findings, in looking specifically at parents who have a diagnosed child in either Massachusetts or central Scotland, I aim to situate these experiences within the wider conceptualisations of autism, autism parenting and policy, whilst focusing on the individual as well as collective experiences of my participants.

This study also has an explanatory purpose (Yin, 2003) in that I am looking for ways to understand and explain the experiences of parents in both locations, through the identification of similarities and differences across a number of areas. A key focus of explanatory case study design is "...to determine how events occur and which ones may influence particular outcomes." (Hancock and Algozzine, 2006:33). This explanatory element is also useful in trying to understand why things might be different and attempting to make sense of the differences that might exist between

two different locations and their response to a similar phenomenon (Hantrais and Mangen, 1996).

4.3.1.2 Using Elements from Case Study Design: Implications for this Thesis

I chose to use these elements in the early stages of my study design for a number of reasons. By defining my research focus as a potential ‘case’ I set clear limits as to what I included and excluded from this study and my analysis. This is an important element of any study, but particularly with regards to research within a field as extensive as autism, this approach offered a ‘rich picture with boundaries’ (Thomas, 2011: 21). Secondly, a case study approach enables the writer to “analyse a ‘naturally occurring phenomenon” (Yin, 1993) rather than something that has been created for the purpose of research. It is also most useful for answering ‘how’ and ‘why’ questions (Yin, 2003; Baxter and Jack, 2008), and can illuminate more detail than other research designs (Stake, 1995), leading to a richer exploration of the data and ultimately the “thick description” (Miles and Huberman, 1994) that I have aimed to reflect within this thesis.

Finally, case study design can be used both to build on theory propositions (Yin, 2003) and to develop context- dependant knowledge (Flyvbjerg, 2006). It can also be used when the researcher wishes to cover the contextual conditions of the case that are relevant to the phenomenon under study. Although my analytical focus is on interview data, my consideration of policy context is a crucial aspect in developing a clear understanding of parent experience of diagnosis across the two locations. Therefore, in drawing upon some key strategies and elements from case study methodology I have shaped the background, bound the context and framed the analysis of my data. Having used this structure to describe the design for this study, I will now discuss the data collection methods used before moving on to describing the two locations that provide settings for this thesis.

4.4 Research Method: Interviewing

To investigate the main focus of this study, parental experience, I chose to conduct a number of semi-structured interviews with parents of young children diagnosed with autism. I selected interviewing as my method of data collection because it appeared to be best fit for the aims, framework and research questions of this study. In fitting with a symbolic interaction methodological focus, interviewing is the method of enquiry "...most consistent with people's ability to make meaning through language." In addition, it "...affirms the importance of the individual without denigrating the possibility of community and collaboration." (Seidman, 2006:14)

Through interviews, the researcher can access a participant's perceptions, meanings and constructions of reality (Punch, 2013). In fitting with an symbolic interaction approach to understanding the ways in which individuals construct meaning, interviewing allows a researcher to enter into another's perspective, beginning with the assumption that other peoples' perspectives are "...meaningful, knowable and able to be made explicit." (Patton, 2002:341).

4.4.1 The Interview

In structuring my interviews I used a combination of an Interview Guide and Standardized Open Ended approach (Patton, 2002). The combination of these allowed for some standardisation within the questions asked, which I felt was important to enable a clearer analysis across participants and locations. However, unlike a traditional structured interview, a semi-structured approach offered a degree of flexibility which was crucial when I was offered an opportunity to explore a specific issue or experience in more depth. This provided me with the opportunity to ask

‘predetermined but flexibly worded questions’ which in turn contribute directly to answering the research questions (Hancock and Algozzine, 2006: 40).

I interviewed a total of 18 parents across two locations and focused my interviews on key areas of parental experience relating to my research questions: experience of the diagnostic process, post-diagnosis services and support, perceptions of autism over time and parental perspectives of and aspirations for their child.

Interviews typically lasted between 60 and 90 minutes, depending on the participant and the level of detail that they entered into. For some individuals parts of the interview were more detailed than others. This was particularly true of participants when describing their journey to diagnosis, which was often a detailed and largely uninterrupted narrative of their early experiences that acted as a way in to the interview for many parents. I attempted to keep the atmosphere informal and relaxed so that it was more of a “conversation with a purpose.” (Dexter, 1970:136). This focus on creating a relaxed interview setting was important to enable parents to share their stories openly.

Although I chose to let participants respond in a narrative way to describe their experiences, at times I did need to use cues or prompts to encourage parents to expand an overly short answer (Mathers, Fox and Hunn, 2002) or to redirect them where necessary (Patton, 2002). Notably, I found that I tended to use more prompts, or probes, to encourage fathers to expand on their answers than mothers. This was because often the fathers’ initial answers were shorter and less detailed than the responses of mothers. However, in doing so I was aware of the potential issues that too much probing could have on the participant, making them feel interrogated or uncomfortable (Reed and Stimson, 2005).

Utilising a similar approach to that of Ryan and Runswick-Cole (2008) parents were asked questions in two parts. The first section of the interview consisted of two or three open ended questions relating to parents' early concerns about their child's development and their pathway to diagnosis. The second part of the interview consisted of eight additional questions relating specifically to the ways in which the diagnosis was communicated, follow up information and support, access to services, parent feelings regarding their involvement in their child's services, their perceptions of autism pre diagnosis and their perceptions and aspirations for their child post-diagnosis (see appendix 1: Interview Schedule).

4.4.2 Limitations

Due to the time frame involved with one to one, face to face interviewing and subsequent transcription (Adams and Cox, 2008), alongside the work involved analysing each interview, it is a method that is best suited to smaller scale research studies. This means that sample sizes can be limited as it does not allow for the larger scale data collection seen in questionnaires or surveys.

Although questionnaires have clear benefits over interview data in larger scale research studies (Bryman, 2012), taking my research focus and research questions into account, they were not regarded as best fit for the interpretive framework of this study. Hollway and Jefferson (2000) argued that survey research, whilst suited for questions of measurable or quantifiable factors, is not best placed for answering why or how questions relating to people's experiences. In addition, Phellas, Bloch and Seale (2012) claimed that interviews have certain advantages over questionnaires in that they provide face to face opportunities for clarification of questions and elaboration of replies. They can also be more rewarding for participants than

responding to anonymous questionnaires as they provide the interviewee with a “sympathetic listener.” (p.182).

4.5 Reflection: Validity and Reliability in Interview Research

It is argued that interviews cannot tell us directly about a person’s experience, offering instead representations of those experiences (Silverman, 2006) where knowledge is constructed through “...the interaction of interviewer and interviewee roles.” (Kvale, 1996:128). It is important, therefore, to acknowledge that the interview is not a neutral tool but an active process (Fontana and Frey, 1994) and produces “...situated understandings grounded in specific interactional episodes.” (Denzin and Lincoln, 1994: 643). As a co-constructer of knowledge the interviewer must recognise the impact that his or her role can have on the data (Kvale, 2006).

Therefore, as a professional actively involved in the field that I am researching, it was important to reflect throughout my data collection and analysis on the impact that a potentially knowledgeable interviewer might have on this co-construction of knowledge during the interview process.

As this study uses a symbolic interactionist methodology, it was also important to acknowledge that through the interactional nature of meaning making, I may have directly and indirectly contributed to participants’ reflections on their experiences. However, although I recognise that my role as a practitioner in this field may have led to a different interpretation of the data to that of a researcher who has another background, I do not believe that this has impacted negatively on the validity or reliability of my findings overall.

4.5.1 Reflection on Dual Role of the Researcher

As practitioner–researcher I was continuously aware throughout this study of the duality of my role and the impact this could have on the data through experiences of participants within the interview. Although all families in both sample groups were aware of my professional background before they agreed to participate in the study, I was also involved with four of the final sample of UK-based families on a professional basis. However, I did not work directly with their children and therefore did not have a therapeutic relationship with those concerned. Although this situation could have presented potential ‘ethical dilemmas’, I have been careful throughout this study to use reflexivity not only to scrutinise my data, but also to scrutinise and ‘take stock of’ my actions and my role within this situation (Mason, 2002).

Reflexivity has a clear link to ethical practice (Guillemin and Gillam, 2004; Etherington, 2007) and consideration of it within this study was critical in ensuring a transparent and ethical relationship with all participants.

During all interviews I was constantly responsive to the researcher- participant relationship and the issues presented by the potential balance of power that my dual role could cause. I was also extremely aware of the potential issue of researcher dominance that could occur within the interview situation. My use of a schedule rather than set questions reflected the importance I placed on the interview being a two-way conversation. Without this clear focus on reflective ethics (Kvale, 2003) there could have been significant issues with an asymmetrical power relationship within the interview, where interviewees felt that the agenda was solely set by the researcher who dominated the conversation (Brinkmann and Kvale, 2008). However, with careful critical and reflection of my role as practitioner-researcher throughout, I was vigilant to ensure that all participants understood that there would be no value

judgement of their responses and their knowledge of autism and their child was not being called into account.

I was also sensitive to the potential impact that the location of the interview could have on the data. Eight of the ten interviews in Massachusetts were conducted within a local psychologist's office that families had attended on at least one previous occasion for assessment or therapy. Five of the interviews in central Scotland were conducted within the family room at my charity, with four of these five families having attended this centre on at least one occasion previously. All other interviews were conducted in the parents' homes. Although location was always parental choice, this was something I reflected on carefully when conducting my analysis and any differences in the data would have been acknowledged and discussed. However, as the study progressed there did not appear to be any variations between the responses of parents who were interviewed in their home setting versus those that were interviewed in professional premises in either location. In addition, as will be made clear in my analysis, there were no clear differences in the data from Scottish parents involved with the charity, compared to those who were not, in terms of their responses and reactions overall.

Throughout all my interviews I was careful to explain that whilst I would be able to discuss any potential questions that parents may put forward regarding their child, this would not form part of the interview situation. Anything that participants wanted to discuss or ask could be brought up after the interview had ended. In addition, on some occasions during an interview, I felt an ethical duty to make note of anything that I felt I could potentially help with on a professional basis and was careful to discuss this after the interview ended.

4.5.2 Reflections on Co Construction

Although "...the words we attach to fieldwork experiences are inevitably framed by our implicit concepts" (Miles and Huberman, 1994:9), through acknowledging the function that this interaction might have on meanings being made, researchers can minimise any potential distortion of data (Seidman, 2006). In utilising a symbolic interaction perspective within this study, I was cautious to ensure that, as a practitioner, my conceptualisations of autism and my opinions on the efficacy of intervention approaches in particular did not influence my participants. This was achieved through careful reflection before making any comments or asking additional questions within the interview situation. However, it is important to acknowledge that the interviewer, no matter how diligent they might be in attempting to minimise the effect that they might have on the participant's reflection, is an integral part of the shaping of this reconstruction (Seidman, 2006).

Nevertheless, participants involved in these interviews did not appear to be negatively affected by this interactive, meaning making process. Instead, as argued by Mishler (1991), interview participants can gain a greater insight into their own worlds through the process of research. By creating a space for the voices of participants in the analysis and interpretation of the data, the researcher is acting not only as a reciprocal partner in the construction of this knowledge, but an advocate for participants overall. Through focused and thorough rigour, the researcher can challenge questions of validity and reliability by

...replacing the sense making, meaning construction, and voice of the researched person with that of the researcher, by representing the text as an authoritative re-presentation of the experiences of others by using a system of researcher-determined and dominated coding and

analytical tools. (Denzin and Lincoln, 2000: 10).

Although I cannot claim to uncover universal truths about the experience of all parents with a preschool child diagnosed with autism in my two locations, I can confirm the experiences of my participants through quality research craftsmanship, having taken care to continually check, question and interpret my data from the outset of this study. Through careful use of “externalised rules” (Denzin and Lincoln, 2000) qualitative research becomes a “...continuous iterative process”, well documented through a process of data collection, reduction and analysis (Miles and Huberman, 1994:10). It is the rigour of any study that is critical to its trustworthiness and taking a careful and thorough approach to data collection grounded in sensitive reflection, alongside ethical guidelines and considerations, I hope that this thesis will make a credible and dependable contribution to knowledge in the field of parent experience in autism.

Having discussed my research design and data collection methods in detail, I will now move on to talk about my research contexts and participants before discussing my ethical considerations. I end this section with a discussion of my data analysis, setting the scene for my next chapter on my findings, analysis and discussion.

4.6 Research Context: Locations

To bind the context of this study, I originally chose to compare two areas with similar demographics, but some differences in early autism policy and practice. Lexington is a small town within Massachusetts with a population of 32,780 and an average annual household income of \$122,000 (approximately £65,000) (United States Census, 2010). It is a university town with Harvard less than 9 miles away. Stirling, although it has

City status, is similar to Lexington in a number of ways. It is also a university town and has a population of just over 33,000. However, it has one of the widest ranges of income in the UK, with average household income ranging from £13,000 to £73,000 and a median of just under £50,000 (Clackmannanshire Council, 2013).

As I began recruiting participants, I quickly became aware of the ethical considerations regarding confidentiality when researching such a small area of Scotland. It became clear early on that there was only one diagnostic team within this area and as one of my research focuses relates to experiences with professionals, I decided to widen my research area to cover the central belt of Scotland alongside an equivalent area West of Boston. Again, both these areas have similarities in demographics, and present a broad range of social circumstances in each location which I will now discuss in more detail.

4.6.1 Massachusetts

The area covered by this study comprises of a number of towns in western Boston including Lexington, Concord, Acton, Worcester, Shrewsbury, Dover, Newton and Billerica in the further North West. This area of Massachusetts is often referred to as ‘metrowest’ and reflects mixed demographics, with towns such as Dover having a combined median household income of \$185,000 (approximately £120,000), contrasting with Billerica at \$95,128 (approximately £60,000) (United States Census, 2010). For the purpose of this study, when describing this area or participants from this sample, it will be referred to as Massachusetts or MA.

As discussed in Chapter 3, Massachusetts is regarded as one of the leading states in providing services to individuals with disabilities (Massachusetts Autism Commission, 2013). It was one of the first States to pass the Autism Insurance Bill,

or ARICA, (2010) which requires all health insurers to provide cover for the diagnosis and treatment of autism. In addition, for those with lower incomes, there is an Autism Waiver Programme which covers intensive home based services for up to 3 years for children under 9. It also has a wide range of government funded services for young children with disabilities. All early intervention programmes for eligible children aged birth to 3 years who have delays or disabilities are funded through public health, and all children aged 3-5 years old are entitled to receive special education through inclusive preschool placements in their local school systems (Massachusetts Autism Commission, 2013; Bowen, 2014). These services are accessible to all, regardless of social economic status.

All children in this group were accessing a range of mainstream and specialist services. Specialist services included government funded intensive autism programmes as well as independent specialists.

4.6.2 Central Scotland

The central Scotland area I focused on covered Stirlingshire, Clackmannanshire, South Edinburgh and Southern Fife and consultation of national statistics confirmed the mixed demographics of this area. For example, a 2011 study by the Office of National Statistics estimated that Edinburgh South had one of the highest average annual incomes in Scotland of £27,319 per capita, with Ochil and South Perthshire (Clackmannanshire area) having the lowest at £19,276 (Office of National Statistics, 2011). This contrast was also reflected in the 2012 data from the Scottish Index of Multiple Deprivation. The SIMD divides the country by postcode into 6505 datazones and provides a relative measure of deprivation for comparison of areas.

Using a number of indicators, including education, income and employment, these datazones are divided into levels of multiple deprivation, which are then represented as quintiles or deciles. For example, most datazones in Clackmannanshire were found to be in the mid and more deprived deciles in the SIMD, whereas Edinburgh City and Stirling datazones were within the least deprived. Fife datazones were distributed evenly across the less, middle and more deprived deciles. Although the SIMD does not represent a measure of individual deprivation, it is a useful tool to highlight the mixed demographics of this area.

This area also comes under three health boards, NHS Forth Valley, NHS Fife and NHS Lothian. At the time of writing this study, no board had a location-specific diagnosis policy or autism guidelines. Instead all health and education boards in Scotland come under the guidance of national policy and legislation (see Chapter 3). Whilst NHS Scotland has specific autism diagnosis guidelines (SIGN, 2007) it does not advocate for specialist early intervention or special education at the same level as Massachusetts. As discussed in section 3.2, the Additional Support for Learning legislation does not promote diagnostic specific specialist services for children. Instead it looks at identifying and supporting individual barriers to learning. However, in spite of this broader view of Additional Support Needs, local authorities across Scotland are required to provide information on children with specific difficulties, who fall within particular categories. These categories are ever expanding and with the increasing influence of voluntary sector organisations representing those with specific diagnoses such as Autism, there is a pressure growing to adapt and change mainstream services to meet particular educational needs (Ibid).

In addition to education and health support, families in Scotland can access a range of services through social work. With new legislation recently introduced for self-

directed support (Manthorpe *et al.*, 2015) parents of children with disabilities can request a Section 23 assessment. If they meet certain criteria, parents are given financial support to utilise services within the voluntary sector that can provide them with short breaks away from their child or support within the home.

In the sample group, 6 children were accessing mainstream nursery settings for 15 hours per week. This was without any additional support. 1 child was attending a specialist nursery provision for 15 hours per week and the remaining child accessed a child development centre for 3 hours per week because they did not yet qualify for a full time nursery placement. All children in this group accessed national health service input for speech and language at varying levels. Two children had been assessed by occupational therapy and one had been assessed by physiotherapy, but none were receiving ongoing support from these services. One family had started the Section 23 process to access self-directed support.

4.6.3 Selecting the Sample Group

Originally I aimed to set boundaries for participants in this study in terms of diagnosis, age of child, place in family and time since diagnosis. I also aimed to interview parents who had an only child under the age of 3, between 6 and 12 months after an autism diagnosis. I chose to focus on interviewing both mothers and fathers. As fathers are often neglected within autism research (Hastings, 2003, Flippin and Crais, 2011) I felt that interviewing a mix of mothers and fathers as individuals, not couples, would provide an opportunity to bridge a gap in existing research, alongside offering an additional comparison for analysis. In addition, I looked for a balance of girls and boys, as the majority of previous studies on autism and parent experience appear to focus on mothers of boys. Again this mix of participants would provide an

additional aspect for comparison in my data.

I chose these initial boundaries because I wanted to focus on first-time parents who had no previous experience of child development in order to explore how autism might be conceptualised without the background of comparison with another child in the family. I also wanted to look specifically at parents with children under 3 years old, because although early autism diagnosis has received significant attention in recent years, there is limited research to date on the impact that early recognition may present for parents. I wanted to focus on interviewing parents between 6 and 12 months after diagnosis as this gave parents time to reflect on their situation, yet it was still recent enough to be fresh in their memory.

Although these controls relating to age and place in family were possible in Massachusetts, diagnosis was not happening regularly with children under 3 in the central belt of Scotland at the time of the study, and particularly not with first children. As I could not find enough families who fitted these original criteria in Scotland, I extended these measures to include children under 5 years and allowed for parents of larger families, with the child occupying any position in the birth order.

Initially, the selection of participants was purposive, or “criterion- based” (LeCompte, Preissle and Tesch 1993:69). However, as discussed by Maykut and Morehouse (1994), qualitative researchers cannot always specify who will make up the final sample, since it takes time to discover “...what is most important to know about the phenomenon we are studying, or who are the best people to inform our understanding.” (p.61). As my initial data collection visit to Boston drew to a close I began to look at using a more ‘purposeful’ method to begin to develop sub groups and

facilitate better comparisons (Miles and Huberman, 1994). I started to look at the pairings of mother with son or daughter versus father with son or daughter in the Massachusetts group and begin to look for matches for these examples within central Scotland. Patton (2002) described this method as creating “samples within samples”.

Although my initial aims were to reflect a typical sample of parents experiencing early diagnosis in both locations, using Patton’s “typical case” method (2002), I recognise that there were some atypical features within both participant groups. I also acknowledge that my final sample could be seen to suggest more of a ‘convenience’ method in my selection of participants. However, in spite of the limitations of convenience sampling (Marshall, 1996; Patton, 2002), I would argue that my selection was purposive in intent. I was clear in my aims from the outset and had well-defined boundaries for selecting participants. As the research began, there were a number of constraints including participant response, travel and time limitations, which impacted on my original objectives. In Massachusetts I would argue that my participants were typical in many ways, as a sample of parents who accessed a range of services for their child, which, in line with policy and procedures in this location, reflected standard practices. Although this group had slightly higher education levels than the national average, this was reasonably typical of Massachusetts. According to the 2014 US census over 89% of individuals aged over 25 in Massachusetts are high school graduates and over 40% have a bachelor’s degree or higher (US Census, 2014). However, although I had actively targeted services that were public health funded and served a wide demographic, it is fair to say that this sample group did not reflect a broader range of social economic status.

In central Scotland there were similar issues with initial response levels and my sample group in this location could be considered atypical in a number of ways.

Although participants reflected a fair representation in terms of ethnicity, with over 95% of individuals in central Scotland identifying as ‘white’ (National Records of Scotland, 2011), 6 out of the 8 parents interviewed had some level of post-secondary education. This was in contrast to the most recent Scottish census data which showed that only 26% of the country have university degrees or equivalent, and just over 30% of adults in central Scotland have any kind of post-secondary qualification (ibid.). Participants in this group had also obtained early diagnosis for their child which, from looking at national statistics on age of diagnosis (Autism Achieve Alliance, 2014), is not typical of most parents’ experiences in this location. In addition, four participants were at the early stages of beginning to access an independent voluntary service whose approaches to intervention are unique in Scotland. This service was part funded at the time with parents paying a small fee to access the provision.

4.6.4 Participants

The sample group was made up of ten families from Massachusetts (MA) and eight families from central Scotland (CS). Although ten families were originally recruited in central Scotland, one interview failed to record and one other family withdrew their consent before interview. Due to the fact that these issues arose near the end of my data collection, along with the difficulties I had experienced in finding participants in Scotland, I could not recruit further families.

Table 4.6 shows the variety of parents interviewed (mothers and fathers) and the sex, diagnosis and age at diagnosis of each child. It also includes an overview of services accessed by each family. As discussed in Chapter 2, there are differences reported in the literature regarding the experiences of mothers versus fathers (Vacca, 2013) and to allow some exploration of this in this study, I have the same number of

fathers in both my sample groups. One in each location is a father with a son and one in each location is a father with a daughter.

Table 4.6: Characteristics of Participants

Parent's 'name'	Parent's Highest Qualification	Parent's Ethnicity	Child Age at Dx	Child Age at Int	P/C relation	Child Place in Family	Other ASD in family	Hrs/wk specialist Therapy	Hours per week mainstream education	Diagnosis
Maria	PG	C	19M	28M	M/S	1/2	Y	30	15	PDD-NOS
Marnie	PG	C	24M	32M	M/S	1/2	N	30	20	PDD
Martina	PHD	C	23M	29M	M/S	Only	N	30	15	PDD-NOS
Mona	G	AA	20M	26M	M/S	Only	N	30	12.5	Autism
Melissa	G	AF	25M	32M	M/S	2/2	N	25	15	Autism
Maya	PG	C	23M	31M	M/D	2/2	Y	25	15	PDD
Monica	PG	C	42M	54M	M/S	1/2	Y	30	20	Asperger's
Melvin	S	C	24M	35M	F/S	1/2	N	30	25	PDD-NOS
Maggie	FE	C	27M	39M	M/S	3/3	N	30	15	Autism
Michael	S	IN	24M	34m	F/D	Only	N	35	20	PDD-NOS
Carrie *	FE	C	30M	39M	M/S	3/3	N	1	15	Autism
Colin *	FE	C	44M	49M	F/S	Only	N	1	15	ASD
Connie	G	C	42M	48M	M/S	2/2	N	1.5	15	ASD
Carmen *	S	C	45M	52M	M/S	4/4	N	0	10	Autism
Caitlin	PG	C	42M	49M	M/D	3/4	Y	0	10	Autism
Cara *	G	C	30M	38M	M/D	1/2	N	0	15	Regressive Autism
Claire	S	C	45M	53M	M/S	2/3	N	1	10	Childhood Autism
Cameron	G	C	26M	39M	F/D	Twin	N	1	3	Classic Autism

Key:

Educational Background: S: School/ FE: Some Further Education/G: Graduate/ PG: Post Graduate

Ethnicity- C: Caucasian/ AA: American Asian/ AF: African American/ IN: Indian

Parent/ child relation: M/S- Mother with Son F/S- Father with son F/D- Father with daughter M/D- Mother with daughter

*Participant accessed charity services

As can be seen clearly in Table 4.6, there were two significant differences between the sample groups: age at diagnosis and levels of specialist services.

Firstly, with many children in the MA sample diagnosed on or before their second birthday, the mean age at diagnosis for children in MA was 25 months, but for children in CS it was 38 months. With the use of different assessment criteria between the two countries, the variations in diagnostic terms would also be typical for children in both areas. In the MA group the professional diagnoses of eight of the children in the MA group was either Pervasive Developmental Disorder (PDD) or PDD (not otherwise specified) (PDD-NOS). The remaining two were diagnosed with autism. However, these terms were used interchangeably by parents during the interviews. As discussed in section 1.2, it is typical in the US for preschool children to be given an initial diagnosis of PDD/ PDD-NOS to gain access to autism services at an early age and then reassessed yearly, where the diagnosis may change (MacFarlane and Kanaya, 2009). All children in the MA group had undergone an ADOS assessment and had been diagnosed using DSM-IV, although since 2013 the DSM-V (APA, 2013) is now used across the United States.

Parents in the central Scotland group also used a range of diagnostic terms including autism, childhood autism, ASD and autism spectrum. Professionals delivering diagnoses in this group commonly used the ICD-10 criteria, which is used more typically in European settings. However, according to parent report, no child in this group was diagnosed using a standardised assessment such as the ADOS which was used so widely by professionals in Massachusetts. In spite of professional diagnosis reports for each child, no parents appeared to be aware of the ICD-10 or the criteria and assessments used with their child for diagnoses. This was in clear contrast to parents in Massachusetts who were able to refer to the DSM-IV and the ADOS, and terms used within both, to explain their child's diagnosis.

Table 4.6 also shows the level of services (per hour) that each child received. I divided these into specialist versus mainstream services to highlight the potential difference in focus between each location. Although the level of non specialist mainstream education the children received were similar across both groups, the number of hours of specialist support varied considerably between the two locations. As discussed previously, in considering policy and practice differences between each, these support levels would be a largely typical reflection of families accessing services in each setting.

All ten families in Massachusetts attended mainstream provisions alongside a variety of early specialist therapeutic services for their child. They also had a range of professionals involved with them. This experience is characteristic of most Massachusetts families with a diagnosed child who access services through a mix of government funded programmes and insurance (Liptak *et al.*, 2008). In addition, it is important to note that whilst there may not have been a wide range of socio economic backgrounds within this sample group, early intervention services for children with autism are not restricted to high income families. All families in Massachusetts are entitled to up to 30 hours per week of government funded autism specialist services, regardless of their socio economic status. These are offered as soon as a child is diagnosed, up until the age of 3. As well as the provision with the ARICA legislation and the Autism Waiver Programme discussed in 4.6.1, the Autism Omnibus Bill (2014) now requires Massachusetts Health Department to cover all medically necessary treatment for individuals under 21 with an autism diagnosis. This included therapies such as ABA and speech and language support.

The central Scotland sample group had similar access to mainstream nursery settings and two children attended specialist nursery provisions part time. Although all participants used National Health Services, including speech therapy, the level of

specialist support that their child received was more limited. However, as discussed, four of the families were in the process of starting to access a small independent charity that was run by the researcher which provides a similar, but limited, version of the support that was available in MA. The remaining four families did not access this service. This difference within the CS group provided an opportunity for some additional analysis of data from this location to explore whether access to specialist early therapeutic intervention appeared to impact on parent experiences overall.

Although there were some clear atypicality within my sample groups, I do not feel that this impacted on the rigour or validity of this research. As a qualitative, exploratory study, generalisation was not a focus for this thesis. Instead, the aim of this research was to provide a rich, detailed account of the similarities and differences of parents in two locations who were experiencing an early autism diagnosis for their child. It is also important to acknowledge that qualitative enquiry can produce transferable results (Lincoln and Guba, 1985) particularly with regard to the provision of “thick description.” (Holloway, 1997). With regards to my data, I feel that the in depth interviewing of participants will have produced sufficient detail with which to potentially transfer any conclusions to other settings or situations and this is something that I will discuss in more detail in chapter 7.

4.6.5 *Arranging the Interviews*

Parents were initially contacted through linking with a variety of government funded and independent services in MA, and through a similar network in Scotland. In MA I also contacted a number of local service providers specialising in early intervention for preschool children with autism and explained my study. I then asked these organisations to share details of my study online and through email with parents who may be interested in participating. I did the same in Scotland and contacted a

range of family support services, advocacy groups and professionals who worked with families of young children with autism. They also shared details of my study through social media, emails and their websites. Parents who contacted me expressing interest were then sent letters or emails explaining the purpose and nature of the study along with a consent form (Appendix 2). Further details were then explained by phone and a date was arranged to meet at the family home, a local psychologist's office (in MA) or at my charity's premises (central Scotland) depending on the preference of the parent. Interviews were recorded on an iPad for later transcription. On meeting, parents were reminded about the aims and purpose of the study, what their participation would involve and were asked for consent to record their responses. The iPad used to record the interviews was pointing at the ceiling and not directly at any participant, allowing for greater anonymity alongside a more relaxed interview experience. Parents were reminded that they were free to withdraw from the study at any point, even if this was during the interview. All parents signed a consent form at this stage and the interview began.

4.7 Ethics

With the active role that the interviewer can play in potentially shaping the participants' stories and overall experience of the interview, alongside the vulnerability the interviewee may experience in sharing personal experiences, ethical considerations are crucial when utilising this method of data collection. Guillemin and Gillam (2004) highlight the importance of considering two different dimensions to ethics in research; procedural ethics and 'ethics in practice'. Procedural ethics are defined as the formal measures of establishing ethical protocols in research studies. However, they argue that whilst these are essential within all social research, they are limited and cannot provide "all that is needed for dealing with ethically important moments..." (p.262). Therefore, in addition to these practical considerations, 'ethics in practice', or the day-

to-day ethical issues that arise in research, must also be considered.

In this section I will firstly look at the elements of procedural ethics that were pertinent to this study, looking at the ethical considerations of interview methods in particular. I then use the concept of ‘ethics in practice’ to critically reflect further on my dual role as interviewer and professional, focusing particularly on the aspects of the feminist principles of the ‘ethics of care’ that became relevant to my data collection.

4.7.1 Procedural Ethics

Ethical approval for this study was sought and agreed by the University of Edinburgh. As an educational researcher I followed the ethical guidelines of the British Educational Research Association (BERA, 2011), operating at all times within an ‘ethic of respect’. Participants were treated fairly, sensitively and with dignity, and voluntary informed consent was sought from the outset. All participants were given the opportunity to discuss the study in detail with me before their interview and were given a study information sheet to take away with them and read before being asked for written consent.

4.7.1.1 Confidentiality and Anonymity

According to the BERA guidelines (2011) researchers must “...recognize the participants’ entitlement to privacy and must accord them their rights to confidentiality and anonymity...” (p.7). Confidentiality is crucial to maintaining the relationship of trust between researcher and participant, and Israel and Hay (2006) assert that all research participants “...should be able to maintain secrets, deciding who knows what about them.” (p.78). However, as Seidman (2006) notes, researchers cannot absolutely guarantee anonymity for interviewees because of the

detail that they may go into regarding their life experiences. It could be that someone who knew the participant may be able to identify them from certain information included in the data.

In spite of the challenges that total anonymity may present, researchers still have an ethical obligation to protect their interviewees' right to confidentiality and privacy at all times (Israel and Hay, 2006) and meet the expectations that participants may have of researchers throughout the process and beyond. With this in mind, I worked at all times to ensure confidentiality and to protect the privacy of the parents interviewed. I also took necessary steps to protect individual identities wherever possible for all participants in this study. This included the omission of small sections of data that could potentially identify a participant, alongside changing the names of all participants and children referred to within each interview. For each participant group I assigned aliases to participants and their children that reflect their location. All Massachusetts parents were given a name beginning with 'M' and all central Scotland participants were given a name beginning with 'C'. I was also careful to select names that none of the participant had already in either of the locations.

4.7.1.2 Rights of the Participant

When agreeing to share in depth details about a personal and emotional experience such as the diagnosis of a child, it was crucial that the rights of all participants in this study were recognised and acknowledged. The most fundamental right of a research participant is not to participate (Seidman, 2006) and voluntary participation is essential. As a professional running a service that four of the Scottish participants were accessing, the assurance that all involvement was voluntary was communicated clearly from the outset and throughout. Interviewees were advised that the research was being undertaken as part of my doctoral degree through the University of Edinburgh and not

on behalf of the service. They were also assured that withdrawal from the study would have no penalty or impact on the continuation of their services with us.

The right to withdraw is of paramount importance to all interviewees in any study and is particularly important for participants who are disclosing personal information around their child, their family and their own emotions. It may be that the interviewee later regrets something that was disclosed in the interview (Kirsch, 1999) and is no longer happy for parts of, or the entire interview to be used in the study. Therefore, the right to view and review their interview transcripts was key in this thesis and all participants were offered the opportunity to do so post-interview.

Notably, for those that chose to review their transcripts, no participant chose to withdraw consent or ask for anything to be removed from the data.

4.7.2 Ethics in Practice

Procedural, or ‘dutiful ethics’ are not always sufficient when addressing the many issues that research into other people’s lives can present. Gabb (2010) argued that working with formalised codes of practice in the field of family studies can be extremely difficult. Those involved in empirical enquiry into ‘family life’ inevitably become “...embedded in the personal worlds of those being researched.” (p.2). This can also lead to researchers feeling a commitment to participants, or a vested interest, that can conflict with the need to have a critical and analytical view of the research. She also asserted that the study of families and personal relationships have been largely set within a feminist standpoint through a focus on ‘ethics of care’. Morris (2001) defined this as being:

...based on a recognition of interdependence, relationships and responsibilities, and criticises notions of autonomy, independence and individual rights as being too much based on a masculine view of people as separate from each other. (p.25)

Although I am not setting this study within a feminist methodological framework, I was drawn to the relevance of elements of feminist ethics with regard to the reality of researching parent experiences. In acknowledging these principles as part of my ethical considerations, this has helped to address some of the issues that a study of personal, lived experiences and other peoples' stories may present.

In their discussion of Christians' feminist communitarian model, Denzin and Lincoln described it as a "...collaborative social science research model..." which "...makes the researcher responsible not to a removed discipline (or institution) but rather to those studied "(2000:37). Similarly, Etherington (2007) argued for the importance of a feminist approach to ethics in narrative research because its principles "...challenge researchers to make transparent the values and beliefs that lie behind their interpretations and to let slip the cloak of authority." (p.600).

Whilst I recognise and acknowledge the importance of impartiality and neutrality in research, it is also important to concede that research into people's lived experiences does create a level of responsibility and involvement that cannot always be dealt with through formal rules and rights based ethics. Ethical decisions sometimes need to be made in the moment and as a researcher interviewing parents in potentially emotional and vulnerable situations I was drawn to the principles of Sevenhuijsen's 'ethics of care' (1998) in particular. Building on the work of Young (1997), Sevenhuijsen advocated the importance of dependence and vulnerability alongside asymmetrical reciprocity and trust.

These principles of trust and asymmetrical reciprocity drawn from Sevenhuijsen's model were a key aim for me as a researcher building my relationships with participants within the interview situation. Although it is argued that you can never truly see the world through someone else's eyes (Miles and Huberman, 1994; Seidman, 2006), reciprocity in research starts with: "the willingness to be open to

everyone's unique, embodied subjectivity: the idea that everyone is positioned differently and leads an existence which cannot be reduced to that of other." (Sevenhuijsen, 2003: 187).

The element of trust was also critical to this study as parents entrusted me with their stories, making my role "interwoven with power and responsibility." (p.185). Although some element of power imbalance is somewhat inevitable within interview situations (Holloway and Jefferson, 2000), it is also important to recognise that it can be understood in more "...relational, dynamic and positive ways..." (p.85). The fact that participants might view a researcher in a dual role of professional and interviewer can actually lead to positive emotional outcomes for the interviewee when a researcher-expert can "...sympathise and recognise their dilemmas." (ibid).

It is important to note however that participants are not powerless within the interview situation. They can choose what to disclose, when to redirect and what to steer away from (Gabb, 2010). It is also useful to recognise that emotions are a normal part of talking about parent or family experience (Daly, 2007). In addition, Holloway and Jefferson (2000) acknowledged that talking about emotional experiences can be distressing for some participants, but that this does not necessarily cause them harm. Huthchinson, Wilson and Wilson (1994) went much further with this idea and wrote about the potential cathartic benefits of engaging in qualitative interviews, alongside increased self-awareness, sense of purpose, healing and providing a voice to the disenfranchised. With regard to this study, participants were always offered the opportunity to pause or stop an interview if they felt they needed to. However, none of the parents that were interviewed presented as feeling overly emotional regarding their situation or the diagnosis of their child, and spoke with authority and passion regarding their experiences.

In spite of the potential ethical issues and dilemmas that were present within

this and all other studies that involve the collection and interpretation of the experiences of others, and whilst there may be ethical limitations in being actively involved in my research in a dual role, I recognise the benefits that this potential co-construction of knowledge may present overall and agree with Etherington's description of:

The researcher, as audience, may become actively involved in co-constructing previously untold stories by asking curious questions that help thicken and deepen existing stories and invite the teller into territory beyond what is already known to him or her. (2007: 600)

4.8 Data Analysis

From the outset of any discussion on data analysis it is important to acknowledge that analysis is a continuous process and that it "...does not occur in a vacuum" (Erlandson, 1993:113). In my attempt to structure the analysis of a large amount of interview data, I began with the premises of Miles and Huberman (1994) who distinguished three key processes within the analysis of qualitative data. Firstly, they focused on data reduction. Occurring "throughout the life of a qualitatively orientated project" (p.10), reduction refers to the selection, abstraction and transformation of the data into codes and themes. Secondly, Miles and Huberman referred to the 'display' of data as "...an organised, compressed assembly of information that permits conclusion drawing and action."(p.11). Lastly, they described the verification and 'conclusion drawing' aspect of analysis, where researchers use their final data collection to draw conclusions and look for confirmation of these assumptions across their data set.

4.8.1 Transcription

In his discussion of process of data analysis, Kvale (2006) argued that it is the “quality of the craftsmanship” in research that continually checks, questions, and theoretically interprets the findings (p.3). This takes place from start to finish, throughout the ‘production’ of the data, not just at the end of the study through analysis. By transcribing each interview, I was immersed in the production and analysis of my data from the outset of this study. I ensured that I transcribed each interview before conducting another, so that the experience was still fresh in my mind. Although working in this way did not cause me to change the focus of my questions or interview schedule, I acknowledge that it may have had an impact on some aspects of my technique and style. As I listened to the interviews, I recognised ways in which I could improve certain elements of my questioning. In addition, I also began to identify potential codes, categories and themes as I transcribed.

I also understand that the order that I undertook the interviews may have also impacted on the data collection process. Due to work and travel commitments, alongside the constraints of sourcing suitable applicants, I conducted interviews from each location in two parts. This meant that I visited Massachusetts on two occasions over a 6-month period to collect my data. On my initial visit I interviewed parents in three families (Maria, Marnie and Martina) and on my return to Scotland I interviewed my first three CS families (Carrie, Colin and Connie). On my second visit to Massachusetts I interviewed my seven remaining MA families, before interviewing parents in a further five families on my return to Scotland. Although I am conscious that my technique and interview style developed throughout the course of these interviews, I did not see a marked difference in the content or quality of the data generated between the beginning and end of the process. In addition, by conducting two separate data collections in each location, this potential refinement of

interview style did not impact on one sample group over the other.

4.8.2 Codes and Categories

Although there are many ways to define and name the various levels and stages of data analysis, in this study I undertook a three part process. I initially coded my data line by line through ‘open coding’ (Strauss and Corbin, 1990), utilising Saldana’s definition of a code as a “... word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data.” (2008:4)

As I transcribed my first three MA interviews I developed a bank of around 25 initial codes which increased as I began to work comparatively across interviews from the two locations. Through active reading and rereading of the transcripts, I added more codes to my list and began to group my codes into ‘higher-order headings’ (Burnard, 1991) or categories. In utilising a symbolic interaction methodological framework, I was actively aware of codes and categories that reflected interaction with others alongside those reflecting structural factors, such as policy and media influences, and focussed my analysis on these aspects of my data.

When I returned to Massachusetts to undertake my final seven interviews, I had already coded three Scotland and three Massachusetts interviews and organised these data into several key categories. My final Massachusetts interviews were transcribed and coded during my second visit and my final five Scotland interviews were completed and coded shortly afterwards.

4.8.3 Themes

When all interviews were completed, the third step in my analysis was to then look beyond the categories I had established. When compared to a theme, a category can be regarded as a more simplistic way of classifying data. According to Morse (2008), a

category is “a collection of similar data sorted into the same place” and a theme “a meaningful “essence” that runs through the data” (2008:727). In contrast to the classification of codes into categories where I simply looked for similar data and sorted it into one place, I used interpretive analysis to think about what the data were actually about in order to develop themes. Ryan and Bernard (2003) argued that themes are “abstract (and often fuzzy) constructs” (p.87) making them hard to define. However, they attempted to define eight techniques to help researchers identify them within data. Although these were not all relevant to this study, I focussed on three of these ideas when looking at my data: repetition; metaphor and analogy; and similarities and differences.

Identifying themes within interview data can either be inductive or a priori, and most studies will reflect some degree of both. Although I used an inductive approach to my analysis (Maykut and Morehouse, 1994), I need to acknowledge that both my work on my literature review, my focus on my methodological framework and the development and content of my interview schedule will have resulted in some a priori themes emerging within the data (Coffey and Atkinson, 1996; Dey, 2003).

Moving toward a thematic analysis, I began to ‘unitize’ the data into meaningful wholes (Lincoln and Guba, 1985), looking for more abstract themes present within the defined categories. The data were re-read several times to look for shared and contrasting themes and sub-themes across the two interview groups.

Initially I identified around 15 themes for each research question, but through further reading and analysis, I was able to combine a number of these initial ideas into larger overall themes, with sub themes where necessary. There were some occasions where autonomous smaller themes emerged from the data from one location and not the other. However, most themes were present in the data from both groups with sub themes used to highlight similarities and differences between the two as and when

they occurred.

Having presented an overview of my methodology, methods and data analysis for this study, I will now move on to presenting my findings and discussion related to my four Research Questions.

Chapter 5: Findings, Analysis and Discussion

Part 1

In this chapter I will discuss the analysis of data from my interviews with 18 parents from Massachusetts and Central Scotland. Sections are structured by research questions; looking at parents' experience pre and post-diagnosis, their interaction with professionals and access to services. Within each section I present the findings through the analysis of themes and sub themes (see Fig 5.1 and 5.2). I also provide a detailed discussion of each theme before presenting a summary at the end of each section, where I will review the main points that will be explored further in my conclusions. Although a number of themes are prevalent throughout more than one research question, I have selected what I believe to be the most relevant themes within each, highlighting the connections between them wherever they arise.

5.1 Research Question 1:

What are the similarities and differences between MA and Central Scotland in terms of parents' experiences of the autism diagnostic process?

Fig 5.1 Codes to Themes

Codes	Categories	Themes	Sub Themes
Something is Wrong No Speech No Interaction Child Changing Reframing Child Realisation it's Autism Denial Fear Stigma	<i>Pre Diagnosis</i>	Identification of Difference	
Diagnosis Appointment Negative experience Physical discomfort Child behavior unusual	<i>Diagnostic Moment</i>	Comfort	<i>Reassurance</i> <i>Discomfort</i>
Shock Relief Unexpected Prepared but shocked	<i>Reaction to Diagnosis</i>	Shock	<i>Prepared</i> <i>Not Prepared</i>

Key: **Massachusetts Sub Theme**/ *central Scotland Sub Theme*/ *Shared Sub Theme*

Having reviewed literature and policy documentation across both countries, it is apparent that there are some differences in approach and focus when diagnosing young children with autism. However, in spite of this there were a number of shared

themes that emerged during the analysis of this data, with parents from both locations presenting similar understandings of their journey to diagnosis. I will now discuss my findings from this research question in more detail.

5.1.1 Theme 1: Identifying Difference

When asked to reflect on their journey to diagnosis, parents across both sample groups spoke about the ways in which they had realised that there was something different about their child's development early on. This overall sense of 'identifying difference' was present in all interviews and was a similar experience for parents in central Scotland and Massachusetts. Initial concerns occurred most frequently when the child was aged between 12 and 18 months. This was when parents reported that they had become anxious about their child's behaviour, which they regarded as unusual in a number of ways. For example, Carrie, whose son was one of the youngest to be diagnosed in the central Scotland sample, first recognised these differences in her son when he was a year old:

When I first noticed I was taken aback. I was like 'oh....something's wrong'. It was round about when he first turned one

She also talked about how he started to ignore her and focus on the television, which then reinforced her concerns regarding his social development:

He totally kept looking at the telly and I was like that was about the third time he'd done that and it was sort of clicking in my brain ...and I was like 'hmmm?'

Other parents also identified their child's unusual behaviour as being repetitive or inflexible. For example, Melvin realised that his son had some restrictive play routines when engaging with blocks:

He would want to build things with blocks and they were just inherently the structures just by the laws of physics would not work the way he wanted them to. And he would get so upset and he could not see any other way that we could possibly build it.

It was interesting to note that throughout this data, parents across both locations appeared to have a shared sense of ‘normality’ through their awareness of typical child development. This also appeared to suggest a shared view that autism in these early stages reflected something potentially abnormal about their child. Typical children were used as their main frame of reference and this was true of first time parents and those with other children, and parents from both groups discussed feeling that there was ‘something wrong’ when they compared their child’s early progress to that of their peers or siblings. For example, Colin, a first time father of a 4 year old boy diagnosed with autism at 44 months, described his initial concerns when he saw that his son was not developing in the same way as his cousins:

When we were at parties and stuff with other kids and maybe his cousins’ and things...em...you know we’d seen them growing up and I think it was when we were at his little cousin’s birthday party that he was just different.

There was also a clear sense from parents that the behaviours their child was displaying, alongside the skills they were not yet showing, meant that they would need assessment or support of some type. This belief was prevalent across the data from fathers as well as mothers in each sample.

5.1.1.1 Discussion: Normality and Difference

It was evident from the analysis of these data that participants’ early experiences of recognition of autism in their child were similar between settings. As discussed in section 1.2, autism is a condition that is identified through behavioural and

developmental differences (Rellini *et al.*, 2004) with parents being more involved in the early stages of identification than professionals (Reiner-Hess and Landa, 2012; DeGiacomo and Fombonne, 1998; Howlin and Asgharian, 1999). Studies which looked at data from single locations worldwide have already found that parents recognised these initial signs of autism in a similar way and this is equally true of studies from the US (e.g. Hutton and Carron, 2005; Sansosti, Lavik and Sansosti, 2012) and the UK (e.g. Midence and O'Neill, 1999; Crane *et al.*, 2015). For example, Crane *et al.* (2015) found that the parents in their UK-wide survey most commonly identified issues with socialisation, flexibility and behaviour in the early years. They also found that 96 percent of their participants identified these atypicalities before professionals. In addition, Avdi, Brough and Griffin (2000), in their UK-based study of three families at the early stages after diagnosis, asserted that parent recognition of the early indications of autism were often reflective of shared meanings of normality and abnormality. Therefore, the ways in which parents in this study identified early signs of autism in their child were not unusual in comparison with previous studies in this field.

However, previous research has not yet compared a similar sample across these locations and it was interesting to note that despite the differences that I identified in policy, practice and media coverage between both countries, participants in central Scotland identified issues with their child's development in the same ways and at the same stage as those in MA. With the variation in focus on early identification and screening between the two settings (e.g. Volkmar *et al.*, 2014 and SIGN, 2007), it might have been expected that parents in the MA sample would have been more likely to be aware of the first signs of autism than parents in the UK. Therefore, it was potentially significant for this study to observe that this group of Scottish parents were also identifying this difference at the same early stage and this reflected a number of

shared conceptions of autism across these locations.

The similar ways in which participants acknowledged their child as ‘different’ appeared to demonstrate a shared sense of typical child development, alongside perceptions of normality across both locations. This linked with Goffman’s extension of Durkheim’s premise that normality is largely understood through abnormality (Drew and Wootton, 1988), and in reflecting on their child’s atypical development, parents in both locations defined normality through the contrasts between their child’s behaviour and that of their peers or siblings.

As asserted by Blumer (1969), individuals develop meaning through interaction with others and it seemed that participants in this study had developed their understanding of their child’s behaviour through interaction with typical children and perhaps with other parents. It was also apparent that interviewees were involved in a continual interpretive process where meanings were modified and adapted within this. However, there also appeared to be some pre-conceptions of autism and normality that existed outside of this interaction, whereby some meaning may have already been attached to previous experiences or wider cultural perspectives which were similar in both locations (see section 6.1). This concurred with Snow’s (2001) premise of symbolization and the idea that there are some aspects of meaning making that will be embedded in, and reflective of organizational or cultural contexts rather than being constructed solely through individual interaction. Although the locations in this study had many differences relating to policy and practice, they also appeared to have many similarities from a cultural perspective relating to normality and child development overall.

5.1.2 Theme 2: Feelings of Discomfort or Reassurance

This theme was related directly to the diagnostic appointment and, in contrast to section 5.1.1, analysis of these data reflected some noticeable differences between the two locations. Parents seemed to feel either a sense of emotional comfort (through reassurance) or actual physical discomfort caused by a number of external factors. Notably these differences did not relate to other variables such as parent gender or place of child in family, but appeared to be directly linked to location.

Seven of the eight interviewees within the central Scotland group referred to their experiences of this appointment as being physically unpleasant. It seemed that this was due largely to two factors: their perceptions of the apparently disorganized environment and the way in which the professionals behaved toward the parent and child. For example, Colin described the physical discomfort he experienced during this appointment, which he attributed to the surroundings:

They kind of locked us in a room with all the heating on. It was really warm and got us all uptight...and it was a horrible old room in an old building and they seemed to almost attack us and make us feel on edge.

Interviewees also expressed the discomfort experienced by their child, which they believed then caused unusual behaviour. For example, Cara described how her daughter reacted to the paediatrician's attempts to engage her with the assessment tools:

The Doctor pursued this with this big book which she was kicking and saying things like 'I don't like it' and 'yeuch' which is one of her phrases that she says a lot....and she was really starting to do a lot of flapping...I just really thought it was bizarre actually.

This was reported in a similar way by Caitlin, who described how the paediatrician found her daughter hard to engage and attempted tasks that were not developmentally appropriate. This then caused her to feel distressed.

...and the paediatrician was showing her a book and asking her to point out the person that was sad...and I did say to the paediatrician, three times, that I don't think many 3 and a half year olds could answer that....and the paediatrician said 'oh I just wanted to see if she would engage' and I said 'maybe if we did it with toys'?

In contrast, there was only one similar example in the MA group. Mona, the mother of a 3 year old boy diagnosed with PDD-NOS, referred to her anxiety relating to the number of professionals involved in the appointment and again focused on what she perceived as unusual behaviour for her child:

There were actually more people there when we got there and it was actually quite chaotic. He had a fever the previous night so was a little fussy...

The responses from the remainder of parents in MA appeared to reflect more of a feeling of emotional comfort and reassurance relating to their experiences at diagnosis. One of the factors that seemed to impact on this for parents in this location was their ability to choose between providers and select an individual or assessment team that they felt had the best reputation. This meant that they had confidence in the expert knowledge of a particular professional or team before their diagnostic appointment. This was discussed in detail by Monica, whose 4 year old son had been diagnosed with Asperger's. She spoke about how they were able to go with their first choice of professional team for their son's diagnostic appointment and that it was an extremely thorough assessment, which reassured her:

He was looking at the physicality of how does he walk? How does he move? Then she kind of...then the people who saw him...the next three appointments were split up between the ADOS test that was done... I felt it was very comprehensive.

Parents in this location also spoke about the reassurance that they felt due to their freedom to make choices and access additional opinions if necessary. For example, Melissa, the mother of a 3 year old boy who had been diagnosed with autism, reinforced this idea further in her discussion about pursuing a second opinion about her son, who had been almost 2 at the time:

I don't know in the UK if you have you know a right to see more than one, just to be sure...even if we knew...it's good to have more than one neurologist. So we went to see another neurologist.

In contrast, the majority of parents in the central Scotland group seemed to feel a lack of confidence in the professionals involved with their child's diagnosis. This was due to a number of factors, including the amount of time they felt that the diagnostician had spent with their child. For example, Claire was particularly angry with the lack of time that the diagnostic team spent with her son (who was almost 4 years old at the time) which she regarded as an "insult". She had waited the longest time (18 months) in this sample between referral and diagnosis:

Do you really need somebody who's seen him for 40 minutes to tell you that he has autism? It's a joke, it's an insult actually...it's really insulting. Don't sit there and preach to me about my son when you've seen him for half an hour. I could take him to a bus stop and wait longer for a bus.

This frustration and lack of confidence in professional opinion was also reflected by Carrie:

We saw Dr T which was a useless process...we went into his office and my son fell asleep...and he basically told us when he was asleep that he had autism ...and I was like 'well we know that' kind of thing...and I don't know what I was looking for but I was just looking for more kind of input-like how do I help him?

5.1.2.1 Discussion: Comfort, Reassurance and Choice

These apparent differences between the experiences of the two sample groups may have been related to a number of factors. Firstly, as discussed, the ability to select the professionals you want to be involved in your child's assessment was both comforting and reassuring for participants in MA. Furthermore, the variation in resources available to professionals across both locations may have influenced these diagnostic experiences in a variety of ways. For example, National Health Service premises and resources were potentially quite different to those of well-funded, private medical services in Massachusetts and this may have impacted on feelings around comfort or discomfort in a number of ways, particularly with regard to the physical environment.

As interaction with others is a critical component in the meaning making process (Blumer, 1969), it is important to acknowledge the role that professionals may have played in influencing parents' perceptions of and aspirations for their child in these early stages. Whilst I will discuss this in more detail in sections 5.3 and 6.2, it is clear from the analysis of data in this theme that participants in each location had a mixed reaction to their interactions with professional during their child's diagnostic appointment. It was evident that there were positive and negative views relating to the role and expertise of the diagnosticians and diagnostic teams within these data. The differences between these perceptions were linked directly to participants' location,

reflecting what appeared to be a variation in practice between the two settings. It will be interesting to explore this in further detail in later sections, and explore the impact that these interactions with professionals had or did not have on parents' conceptualisations of autism overall.

As discussed, participants in MA were paying for their diagnosis either privately or through insurance and the critical differences between a system of publically funded medicine in the UK with a "market-driven non system" (Ham, 2005:192) in the US seemed to have an influence over participants' involvement in this process. In this case it appeared that the opportunity to access private services had a positive impact on parents' experiences of diagnosis in MA. Conversely, participants using government funded provisions in central Scotland seemed to have a more negative perception of their diagnostic appointment overall. Notably, this appeared to be a novel finding for this thesis as previous research set within each location had reflected the opposite picture of parent reactions to the diagnostic appointment or diagnostic disclosure in each case.

In their study of parents across a small area of Scotland, Brogan and Knussen (2003) concluded that the majority of participants were either satisfied or very satisfied at the way in which professionals had delivered their child's diagnosis, which would seem to be in direct contrast to the participants in this study. Remarkably, previous US studies found that participants often felt that they had been given limited information at diagnosis (Sansosti, Lavik and Sansosti, 2012) or the professionals involved lacked training in or knowledge of autism (Hutton and Carron, 2005). Findings from both these studies appear to contrast directly with my analysis of these data.

However, it is useful to note the differences in research methods between these

studies. As discussed in section 2.4, Brogan and Knussen used a self-report questionnaire, which would present a number of limitations when attempting to understand the real, lived experiences of parents going through an early autism diagnosis with their child. It was also set within one specific area of Scotland rather than country-wide. In contrast, both US studies were small-scale, and used interview methods to collect a detailed overview of parents' reactions to diagnosis.

Again these studies were set within specific areas of the US, and so findings may have been reflective of the practices in those areas. Whilst this is also true of the findings in this thesis, it is useful to note the influence that systemic issues, such as choice, can have on parent experience in each location and this will be a point that I will take forward in my discussions in subsequent research questions.

5.1.3 Theme 3: Shock

A third theme that emerged from my analysis of these data related directly to the initial reaction to diagnosis which was shared between both groups. However, although this was a shared theme, there appeared to be significant differences between locations in the ways in which participants experienced these feelings of shock.

The majority of parents in the central Scotland group stated that their child's diagnosis was delivered unexpectedly, during what they had believed to be a routine appointment. For example, Connie, the mother of a 4-year-old boy, spoke about how she had been invited to attend a meeting, which she had believed to be a discussion regarding her son's nursery placement. Instead, the paediatrician gave her his diagnosis:

That was a bolt from the blue that I just did not expect at that meeting. I just burst into tears. Although at the back of my mind I

always knew or suspected that was always going to be the diagnosis I didn't expect it there and then. I was like 'Oh my God I didn't think he was going to come out with it straight away' and I was really upset, although I wanted a diagnosis.

This sense of shock that the professional concerned was going to take the opportunity to diagnose their child in an unexpected way was also discussed by Carmen who described a similar incident:

I was like 'Oh my God I didn't think he was going to come out with it straight away...and I was really upset ...although I wanted a diagnosis.

In contrast, all ten parents from the MA group had actively sought the input of a professional or a team of professionals to undertake a diagnostic assessment for their child. As I will discuss in section 5.2, diagnosis was also viewed as choice for many parents in this location. Therefore, it would be reasonable to presume that participants in MA felt prepared in many ways. However, mothers as well as fathers in this setting discussed the idea that, although the diagnosis was mostly expected, it still surprised them and there was a strong sense of shock. Melvin was the father of a 3 year old boy who had been diagnosed with PDD NOS. Although he viewed his son's challenges as 'mild', he was still surprised and saddened by his diagnosis:

I was surprised when he got the diagnosis...I was kind of crushed but I was surprised too. But they did tell us that the symptoms are mild...to which now I have more experience ...you know, mild can still be tough.

Whilst there may have been differences in the ways in which parents in each location felt prepared or unprepared, this overall theme of 'shock' in response to the diagnosis was evident across almost all interviews in both locations. However, one exception to this was a mother in the MA group who had a diagnosis of Asperger's Syndrome

herself. Instead of feeling shocked at daughters' diagnosis, she felt it was a normal part of her family's identity:

So for a long time my attitude has been that this is something that is very characteristic of my whole family...my siblings, my parents, my extended family ... To me this is really...this is normal to me.

5.1.3.1 Discussion: Comparing Shock Reactions

Shock reactions have been identified in a number of studies regarding parent experience of autism diagnosis in both countries (e.g. Hutton and Carron, 2005; Midence and O'Neil, 1999; Crane et al., 2015; Sansosti, Lavik and Sansosti, 2012; Hutton and Carron, 2005). However, to date there has been no research comparing this across locations. Although these feelings were shared by both groups, there were some differences in the ways in which parents felt prepared or unprepared and this appeared to be directly related to their interaction with professionals involved.

Parents in the central Scotland group related their sense of shock directly to the way in which they had felt unprepared for their diagnosis, or that a professional had chosen an unexpected time to deliver it. In contrast, parents in the MA group had felt largely prepared for the diagnosis overall, but connected their sense of shock directly to their perceptions of their child and the ways in which they felt their child's behaviour did not fit with their views of autism (see section 6.1).

These differences again reflected a disparity between healthcare systems in the UK and the US. As asserted by Ham (2005) in his comparative study of practices between the NHS and a private health provider in California, US healthcare is a competitive market and services must satisfy customers in order to ensure loyalty. In contrast, there is less competition for clients amongst practitioners in the NHS and patients may have little choice of who they see for medical or assessment appointments. This difference in focus may have impacted on the ways in which

professionals interacted with parents experiencing diagnosis in both locations.

In addition, for participants in both groups, this shock reaction appeared to be linked to a fear of autism and what it could mean for their child or for themselves. This was discussed in more detail further on in the interview when parents spoke about their previously held perceptions of autism (see section 6.1). Although this was equally evident in the responses of mothers as well as fathers, this was a similar reaction to that of the fathers interviewed in Vacca's (2013) US based study, where participants talked about their fear of autism in the early stages of their child's atypical development and diagnosis. It also potentially reflected a further development of the idea that there may be some shared conceptualisations of autism between both locations, with this sense of shock perhaps being linked to preconceived negative meanings that participants had attached to this diagnosis. These notions of fear regarding autism will be discussed further in section 6.3, but it is interesting to observe the potential impact that these perspectives may have had early in the diagnostic process.

Finally, this theme also highlighted the initial stages of the interpretative process which parents went through when attempting to make sense of their child's diagnosis. As asserted by Blumer (1969), meanings are made through interactions with others and modified through interpretation. At diagnosis, parents may have experienced a significant change in their perspectives of their child; therefore, their meaning making processes may have been drawing on previous knowledge (of autism) to make sense of their present situation (e.g. Charon, 2010). Depending on prior experiences or perspectives of autism, this may have impacted negatively on their reactions to diagnosis and feelings of shock overall.

5.1.4 Summary of Research Questions

Surprisingly, in spite of the clear differences at a structural level between locations, there were some findings which reflected similarities in the experiences of parents early on in their journey to diagnosis. The ways in which participants made sense of their child's early differences in development appeared to reflect similar perceptions of autism that were shared across locations. However, a fundamental difference between participants in these early stages was in their recollection of their diagnostic appointment. This highlighted the impact that practical factors such as the environment and access to services can have on parent experience.

Overall, the findings from this research question may have a number of implications for developing the understanding of parent experience of diagnosis across both locations, which will be taken further in subsequent research questions. In addition, many of the points raised have potential implications for practice across settings and these are considerations which I will explore further in section 7.4.

5.2 Research Question 2

What are the similarities in, and differences between, Massachusetts (US) and Central Scotland (UK) in terms of: parents' experiences of early post-diagnosis services?

With the variation in the policies and practices relating to early autism services between both locations, it was likely that there could be some fundamental differences in the ways in which parents discussed these. As highlighted in Chapter 3, Scotland's *Additional Support for Learning Act* (2004) focuses on a social model approach to identifying support needs and the *SIGN Guidelines* (2007:18) claim that there is limited evidence for intensive specialist behavioural interventions, which are standard

practice in the US. Therefore, the type of services offered to parents in the two locations were likely to be reflective of these policy considerations in some way. During this part of the interview participants were asked to comment on the range of services that their child received, both mainstream and specialist. However, as will become clear in the analysis sections below, although participants discussed the mainstream educational provisions that their child attended, the majority of parents in both locations chose to focus more on the impact of or access to specialist services for their child.

Fig 5.2 Codes to Themes

Codes	Categories	Themes	Sub Themes
Professional attitude to autism Professional Negative Professional Positive Prognosis	Interaction with Professionals	Professional Perspectives of Autism	Optimism Negativity
Do something Time passing Push for Diagnosis Support Service provision Number of hours Therapy approaches Way forward Autism as barrier Feeling lost Feeling hope Anger	Access to Services	Sense of Urgency Finding a Pathway	Time running out Need to do Something
Satisfaction Choice Involvement in education Inclusion by professionals Feeling listened to Respect Empowerment Control Disempowerment No control	Parent Involvement in Ed and Therapy	Empowerment through Choice	Empowerment Disempowerment

Key: **Massachusetts Sub Theme**/ central Scotland Sub Theme/ **Shared Sub Theme**

5.2.1 Theme 1: Parents Accounts of Professional Perspectives of Autism

Linking with the themes from the first research question, the ways in which parents made sense of autism and experienced it from a wider perspective appeared to be largely shaped by their interaction with others. Initially, within my analysis of these data it appeared that parents' perceptions of their interactions with professionals had a significant impact on this experience, both pre and post-diagnosis. Although there

were some overlaps with the themes reported in 5.1, here I looked specifically at the data that was related to the wide range of post-diagnosis support and services that participants received. In spite of some exceptions, these data are where there started to be some much clearer differences in the experiences and responses of parents from each location.

When discussing their interactions with professionals, the majority of parents in the MA sample highlighted the importance that they placed on positive professional attitudes regarding autism and the impact that they felt these had on their perspectives of their child. Melissa, a second time mother whose son was diagnosed with autism at 2 years, spoke at length about her contact with his neurologist. In particular, she focused on the impact that this individual's optimism had on her perceptions post-diagnosis. Notably, this neurologist also had a child with autism and in sharing her positive experiences, gave Melissa a great deal of hope for her son's future:

I think she was trying to give us the hope and keep us positive. I think the best thing for us as parents and for people that are involved, and for my son is to just be positive.

The importance of the positivity of professionals was also discussed by Marnie, whose son had been diagnosed with PDD aged 2 years:

I haven't had a negative experience with anyone... and as a parent you want to ...you really want to hear the positives ...a little positive cos it's hard.

This theme of positive professional perspectives was consistent in all except one interview in the MA group. In contrast to other Massachusetts participants, Michael had initially struggled to access a diagnosis for his daughter and felt he had not had the opportunity to choose a team of professionals that he was comfortable with. He stated that, although he felt more positivity from professionals regarding his

daughter's autism post-diagnosis, this was a reflection on individual practitioners rather than something that he felt was universal or systematic within Massachusetts:

Later on we worked with professionals who were more understanding, more supportive. Again they were not...they were more individuals being good as opposed to a systemic ... you need to help parents through this. It wasn't there systemically.

In common with the majority of participants in MA, interviewees in central Scotland also focused on the importance that they placed on professionals' perspectives of autism, in order to help them process their experiences. However, these responses reflected some different experiences in this group, which in turn appeared to impact on parents' reactions to their child's diagnosis. Remarkably, a number of participants felt that an autism diagnosis presented a barrier to obtaining support, as they felt that it was viewed in a largely negative light by professionals. Carrie in particular reflected on her feelings regarding professional perspectives after her son's diagnosis. She had been told that there were no appropriate services and there was nothing that could be done, because he would never make progress:

don't expect him to talk...really don't expect him to talk...because he won't. He'll probably be in nappies forever...and this was them saying this to me...he's going to be in nappies 'til he...he could be 15...don't expect him to talk because he might be non-verbal for all his life...em...just things like that...you realise that autism...that autism is brain damage...it's ...things like that.

Some parents in this group expressed feelings of anger with regards to lack of positive feedback when professionals discussed autism and the prognosis for their child. This was largely linked to the frustration that they felt when they were told that although their child had autism, there was nothing that could be done. Carmen, who had experienced the second longest waiting time within this group from initial referral

to diagnosis, felt outraged about the fact that no one had offered her anything for her son:

That's just something that's sickening...that's really, really sickening, that we have all these doctors that can make a diagnosis but then not offer treatment...because I can't think of anything else where you're offered diagnosis and not treatment. Whether it be asthma...vision problems you are offered glasses.

Claire also reflected a real sense of anger at the way in which she perceived professionals as having disregarded her son:

He's nobody's priority...and it just makes me so angry. I really feel like screaming and I'm sorry for swearing but I feel like asking 'why does nobody give a shit about my son?' this is his life, time is ticking away

Colin was the only parent in the CS group to discuss any sense of positivity with regards to his post-diagnosis interactions with a professional. Although it was a brief reference, it reflected a similar experience to Michael in that it highlighted the difference between systemic and individual issues in parental interaction with professionals. In this part of the interview he spoke about how his family had a positive experience with an Occupational Therapist, and that their Health Visitor had been supportive, but the impact of waiting lists and the system as a whole had a negative influence on this:

We had an OT once I think about 7 or 8 months ago who seemed really nice...sort of assessed him over...she seemed to be really quite good, but then again that was about 8 months ago and we've never had any contact whatsoever from her. None. Not a phone call, not a letter, nothing.

5.2.1.1 Discussion: The Impact of Positivity

It was apparent from my analysis of these data that parents in the MA sample were influenced by their interactions with professionals and this in turn appeared to impact on the ways in which they reacted to their child's diagnosis. Through largely positive accounts of professionals' perspectives in MA, parents in this location appeared to develop perceptions of autism as a condition that could be improved and treated. As discussed, from a symbolic interaction perspective, individual meaning is developed through interaction with others (Blumer, 1969). Therefore, positive interaction with professionals who can provide advice and support regarding ways to help their child make progress appeared to have a significant impact on the way in which parents in this location processed and made sense of their child's future potential.

Notably, the findings from both groups concurred with those of Nissenbaum, Tollefson, and Reece (2002) and Hutton and Carron (2005) who asserted that parents in their US studies were influenced by professionals' positive or negative responses toward autism. For example, Nissenbaum, Tollefson, and Reece (2002), in their interview study of 17 parents and 11 professionals, found that the majority of their parent group felt that a sense of hope was essential when making sense of their child's diagnosis. They stressed that being given positive feedback regarding a child's potential provided them with a sense of optimism for the future.

Conversely, in the central Scotland sample, parental reports of professional responses toward their child after diagnosis reflected more of a negative perspective of autism than those in MA. This in turn seemed to cause frustration for many of the interviewees. However, in spite of the negative feedback they received, parents in this location appeared to act against this and developed a more positive view of their

child's diagnosis overall. It was interesting to observe that these parents also appeared to share similar perceptions of autism with the MA participants and viewed it as something that could be improved through support and specialist therapy. In addition, they attempted to act toward it in the same way, with the same expectations regarding intervention and treatment. This seemed to be in spite of their interaction with professionals, rather than because of it.

This aspect of the data potentially reflected a strong focus on human agency in developing parental understanding of autism in this location. This would relate to Snow's extended framework of symbolic interactionism whereby individuals are seen as "active and willful..." rather than passive social actors. In line with Snow's premise on agency, parents in the CS sample became more aware of the constraints presented by societal and cultural barriers and could be argued to have actively sought ways to challenge these. As Snow stated: "The issue of agency likely springs to the foreground as individuals attend to some kind of corrective or remedial action." (2001:374).

With the apparent differences between parents' interactions with professionals in each location, it is clear that this issue of agency was more in the foreground for those in the central Scotland group than it was for participants in Massachusetts. However, this does not mean that I considered parents in MA to be more passive in the ways in which they experienced their child's diagnosis. Instead, due to a more positive experience overall for individuals in this location, there appeared to be less reason for these participants to be involved in any corrective action regarding their perceptions of or intervention for their child.

However, this focus on agency alone did not necessarily explain the shared meaning making processes relating to autism that emerged across these findings, particularly the emphasis that seemed to be placed on autism as a medical construct that could be

treated and improved. Therefore, there may have been a number of other factors that impacted on parents' developing conceptualisations of autism, aside from their interaction with professionals, and this will be an issue I will take forward in Research Question 3 in more detail.

5.2.2 Theme 2: Sense of Urgency

In reflecting on the early stages of the diagnostic process, a second theme that was evident across both locations was participants' 'sense of urgency' to do something to support their child's development. This was expressed by all parents in this study and was shared between mothers and fathers in both groups. However, although participants had a similar aim; to secure early support for their child, there appeared to be some subtle differences between locations regarding the focus of this sense of urgency. Subsequently two sub themes - 'time running out' and 'need to do something', were identified to reflect this.

5.2.2.1 Sub Theme: Time Running Out

In the Massachusetts group, parents spoke about this sense of urgency in terms of securing specialist services for their child as soon as possible. This belief that time was 'running out' for their child appeared to be strongly linked to the fact that specialist home-based services finish after a child turns three. For example, Mona spoke about the overwhelming sense of urgency she felt to get her son's formal letter in order to access services straight away:

I know this may only take a week to turn around but I cannot afford to wait anymore, he hasn't made any progress, we were on this waiting list and I need this diagnosis letter today.

This focus on time frames showed that all parents interviewed in this location were

aware of the legislation regarding specialist services for young children with autism and many discussed it in detail. Although no participant named specific policy documentation, this is the first clear example of how policy content may have impacted on parent experience in MA and therefore how structural factors influenced parents' understanding of and actions towards their child's diagnosis.

In spite of a large body of evidence relating to parent stress and coping in autism, as discussed in section 2.3, there have been no studies to date that have looked specifically at the impact that policy-related issues can have on parents' experience of autism diagnosis in the early years. However, a number of US studies have found that access to services can have a significant influence on parents' positive and negative perceptions of the diagnosis process and, as service provision is directly influenced by policy, it is useful to look again at some of this literature in light of these findings.

Hutton and Carron (2005) in their study of 21 parents of children with autism in New England found that over half of their participants had difficulties accessing early services. They had also experienced long waiting lists and problems finding appropriate professionals. Even those with services stated that they were not adequate in their intensity. This focus on intensity reflected a similar perspective to the Massachusetts participants in this thesis and could imply a country wide outlook on expectations surrounding services more generally. In Sansosti, Lavik and Sansosti's 2012 study of 16 families in Ohio, the majority of parents interviewed were dissatisfied with the level of services received for similar reasons, including lack of intensity.

However, most notably for this thesis, no data from either study reflected a similar sense of urgency to access early services. This may have been due to the age of the children involved, as both included a wider range. In addition, this concept of time

running out could have been influenced by location. As discussed in section 3.4, Massachusetts had better government funded early intervention services for pre 3s than some other states (MacFarlane and Kanaya, 2009). Subsequently parents may have been more aware of this and therefore more focused on accessing these for their child as early as possible.

Sub Theme: Need to do ‘Something’

In the Central Scotland sample there was also a shared ‘sense of urgency’ from parents regarding their child’s diagnosis and access to specialist support. However, these findings did not reflect the same focus on time running out. Instead, parents’ responses reflected a ‘need to do *something*’, without a clear understanding of what ‘something’ was. In comparison to participants in MA, there appeared to be less clarity of pathway with regard to intervention choices and services for parents in this location. Although all children in this location were accessing nursery provision, there was a view from many participants that this was perhaps not fully meeting their child’s needs. For the majority of parents, their child was accessing a mainstream setting without any additional support and they felt that they needed more specialist input. Carrie, who had identified her son’s challenges when he was 12 months old, reflected that she felt she needed to do something more to help him early on.

...then I sat and thought about it when he was in his bed and I was like ‘no I need to start getting help for him...because I just cannae keep going from day to day because he’s no learning anything so that was when I sort of thought ‘right ok...start trying to find something.

Carmen, the mother of a 4 year old boy who was attending a mainstream nursery provision without any additional help, discussed that she needed to find additional ways to support her son. However, she felt that she was receiving limited support

from her local council services and subsequently decided to do her own research. Having no clear pathway resulted in her spending a great deal of time on Google, which she perceived as a “kind of whirlpool”:

At some point I remember saying to my Mum ‘I’m sorry I know I’m a bit obsessed, but I have to be. I have to learn so much in such a short time. I don’t have five years to read up on this. I need to know everything and I need to know now!’

In contrast to the more focused responses of parents in Massachusetts, the comments from all parents in this sample appeared to reflect an element of uncertainty within this overall sense of urgency. Although children were accessing education and health services, participants felt that this input was not enough. However, parents in this group were largely unaware of the variety of specialist therapies available and this is shown through a lack of reference made to specific approaches, which is likely due to the difference in the services available in the two locations.

5.2.2.2 Discussion: Differences in Sense of Urgency

Although this aspect of choice will be discussed in further themes within this research question, it is useful to note that two specialist autism therapies, Floortime (Greenspan and Weilder 2006) and ABA (Lovaas, 1981), were referred to in the majority of the Massachusetts interviews. As discussed, in Massachusetts there were a range of approaches used in both independent and government services, which reflected the national focus on evidence based practice in this field (e.g. Volkmar *et al.*, 2014; Levine and Chedd, 2013). Parents in this sample appeared to be better informed as consumers who had often undertaken thorough research to make an informed choice regarding which service or setting might be best for their child. In addition, they had received detailed information from professionals before making

their choice. This appeared to be in contrast to evidence from previous studies in other parts of the US that found that parents felt poorly informed with regards to the efficacy of specific early intervention approaches (e.g. Sansosti, Lavik and Sansosti, 2012).

It was notable that despite parents' discussions about their ongoing engagement with the internet in this location, no participant in central Scotland made reference to any specialist approaches such as ABA, Floortime or other therapy models in any interview. This indicated a potential disparity in awareness between participants regarding the existence of specific researched interventions, alongside an indication of a difference in experience relating to choice of services for their child. This lack of awareness of specific intervention approaches within the findings from the central Scotland sample appeared to be reflective of the advice given in the *SIGN* Guidelines (2007), which were described in more detail section 3.4. However, this does not necessarily indicate an acceptance of the *SIGN* recommendations by this group of parents. Instead it could be argued to reflect a lack of wider information provided at diagnosis relating to intervention approaches, alongside an absence of choice for parents in this location overall.

It is also important to note that these differences between the sub themes within this section may not have been recognised by a researcher with less direct experience in the autism and early intervention field. Parents in both locations spoke in detail about the sense of urgency that they felt regarding securing support for their child, and any differences were extremely subtle, relating directly to the ways in which parents discussed specific intervention approaches. Therefore, within this part of my analysis, I acknowledged the impact that my previous experience as practitioner may have had on my interpretation of this data (Kvale, 1996; 1999). This was also a clear example of the ways in which I may have acted toward the data on the basis of the meanings

that they had for me (Blumer, 1969). However, I did not feel that this had a negative impact on the analysis of this particular theme, as my interpretation was a useful way to tease out a subtler difference between participants' experiences between my two locations.

In spite of these differences, parents across both samples appeared to share a similar sense of urgency relating to their need to do something to support their child. This joint focus on intervention again reflected a common understanding of autism across participants through the concept that specialist therapy can support progress. This was in line with the medical model view of autism that emerged from other themes within this analysis. This medical perspective was also identified within previous literature which looked at parent conceptualisations of and reactions to diagnosis (Ong Dean, 2005).

However, these findings did not necessarily reflect a rejection of a social model outlook which, as discussed in section 2.2.5, often co-occurs with parents' medical perceptions in these early years (Hornstein, 2011). In addition, as argued by Ryan and Runswick Cole (2008): "...embracing a medical model of disability, can also be seen as a political act of pragmatism by parents who advocate barrier removal." (p.200).

For parents in MA there was the additional possibility that their views were being influenced by the minority model approach, which was prevalent in policy and media within this location. Situated within a right's based paradigm (Hahn, 1985), policy in the US actively promotes parents to advocate for their child against a background of rehabilitation. Therefore, parents within this location may have developed their understanding of autism within a disability framework that views disability in a positive sense, promoting treatment and intervention as amelioration and not cure. However, despite diversity between the locations regarding policy and practice for children obtaining an autism diagnosis in the early years these perceptions seemed to

exist in a similar way across locations.

5.2.3 Theme 3: Finding a Pathway

The majority of parents in both countries spoke about the impact that access to services had on their aspirations for their child's future, through their perceptions of a clear, or not so clear, way forward. This reflected an overall focus on the importance of a sense of direction for parents post-diagnosis, with a theme of 'finding a pathway' emerging from the data analysis across locations. Within the MA sample, a number of parents referred to the clarity of thinking that having access to specialist services in particular gave them and the optimism they felt when they could move forward with their child's intervention programme. For example, Melissa commented that having what she perceived as appropriate support helped her to see progress in her child, which then impacted significantly on her hopes for his future:

But now I am seeing things coming...oh my goodness...I am brushing so many things aside. Now we have services... now I am very hopeful, because he is looking, he wasn't looking. Everything is just changing when I think of that time. Yeah, I have to push forward.

Michael, the father of a 3 year old girl, expanded on this concept of services as pathways and discussed the impact that they had had on his experiences of his daughters diagnosis overall. Even though he had found the experience extremely difficult, having a way forward in the confusion had had a significant impact:

There's days when we will still worry. Some days are more hopeful...some days are great, you worry less.

You definitely went into that trough and you know...now I think it's more balanced. We are able to cope with it to a large extent. And just time helps, just seeing that these services are there.

Conversely, in central Scotland participants reflected on a perceived lack of direction from the services offered and their frustrations associated with this. In contrast to Melissa, Carmen spoke about a lack of services and support from professionals, who told parents to just ‘wait and see’. This then made her feel as though she had no direction:

It was just wait and see...wait and see...anytime I asked would he be able to do this, would he be able to do that it was just ‘you’ll have to wait and see’. We don’t know...we don’t know. So you’re very much left in limbo.

This was echoed by Cameron, a father of a 4 year old girl who felt that he had been given no direction from the limited services that she was accessing:

I don’t think there’s any clear idea that this is what we’ve got planned moving forward now. It was ‘yes you can keep coming to the centre one morning a week and we’ll try and aim to support her’ and so forth... but there wasn’t any plan, there was no clear direction from it.

These feelings were shared by all participants in this sample and appeared to have a significant impact both on their post-diagnostic experiences overall.

5.2.3.1 Discussion: The Impact of a Pathway

The impact that access to services can have on parent satisfaction of the diagnostic process was recognised within a number of previous studies across both locations. Howlin and Moore (1997) found that 35 percent of their 1200 participants in their UK wide study were dissatisfied with post-diagnosis information and support. This has also been found in more recent studies, and Crane *et al.* (2015) reported an increase in dissatisfaction levels within their participant group as compared to the data presented by Howlin and Moore. Notably 40 percent of Crane’s group reported receiving no post-diagnosis support. Hutton and Carron’s 2005 US study found that there was a

direct link between levels of services and parent stress. Where parents felt that they were receiving appropriate services, their stress levels were reduced. This was also reflected in the findings from Sansosti, Lavik and Sansosti (2012), where participants spoke about a lack of direction or “roadmap” which had a negative effect on their experiences overall.

However, none of the findings within these previous studies reflected the impact that access to or levels of services had on parents’ aspirations and hopes for their child’s future. Although I will discuss parental aspirations in more detail in section 6.4, this theme of ‘pathways’ was a significant finding for this study as it highlighted the differences that practical implementation of policy and guidance can have on parental feelings post-diagnosis. With less focus on the importance and efficacy of intensive early intervention in Scottish policy (e.g. *SIGN* 2007; *ASL Act*, 2004, 2009) there was a direct impact on the levels of support that parents in this location could access for their child. Conversely, for parents within Massachusetts, national and state-specific policy and guidance had (and still has) a clear focus on intensive early support services, which was reflected clearly through parents’ experience in this setting. This aspect of the data potentially reflected the premise within symbolic interaction methodology; that society and individual are interlinked (Blumer, 1969; Vryan and Stryker, 2006; Snow 2001), and that social structures can shape experiences (Stryker, 2008) and ultimately parents’ definition of their situation (Charon, 2010).

5.2.4 Theme 4: Empowerment through Choice

Within both groups there was a sense that the choices that parents felt they had in their child’s intervention or education programme directly related to their feelings of empowerment or disempowerment. A number of parents in the MA sample spoke about the element of choice that professionals gave them from early on in their

journey and how this impacted on their experiences of post-diagnosis services overall. For example, Maggie, who had moved from another State just before her son's autism diagnosis, reflected that she had been offered a wide range of services but she felt no pressure from any professional involved.

Notably, and in common with a number of other parents in this sample, she spoke about the choice she was given by professionals whether to pursue diagnosis:

She didn't want to say 'we really need to get him into...' she was like 'here in Massachusetts we have...' and she laid it all out for us...if you decide to go for diagnosis you can get these services for him...but like we don't have to, we can still work on them without it. You just need to go home and think about it.

This is an interesting point as it showed that parents within this location not only felt that they had a choice in services for their child but also felt that they could select whether to pursue the diagnosis, which is not something that parents within central Scotland made any reference to in their interviews. Although diagnosis was clearly not compulsory in Scotland, it is not obvious from the data whether parents in this location felt that pursuing their child's diagnosis was a choice. Again, this highlights a variation at structural level between the two countries, where access to private, self-chosen services created a different parental experience from that of statutory provision.

In addition, all participants within Massachusetts talked about the sense of control and empowerment that they felt in their interactions with their child's therapists. They largely viewed this relationship as a partnership where they felt treated as equals. For example, Monica spoke at length about the positive and equal relationship she felt she had with those involved in her son's therapy:

I don't think I would work with someone or seek someone out who was just dictating to me...and I also wouldn't want to work with someone who was just saying to me 'what should we do? As I just don't feel I know enough. So I like to have it be a partnership...with every relationship.

In contrast, only one parent in the central Scotland group spoke about how she felt she had involvement in her son's nursery education. Connie, who was one of the four parents in this sample who had not chosen to access private services for her 3 year old son, reflected on the positive experience of having her views heard through being involved in his nursery targets:

I am absolutely totally involved in it. I go to all the meetings I get reports on the meetings...I am involved when they set him education targets.

The remaining participants in central Scotland made reference to the ways in which they felt they had been offered no choice in the services that their child accessed and that they had no involvement in their education or therapy. This was reflected clearly by Colin, who had become increasingly frustrated with the level of input his son was receiving. He talked about the lack of options he had experienced since the diagnosis:

They don't give you any options. They tell you this is it. That's what's available. This is what you're going to do, this is what we're going to do and that's it.

Cara also expanded on this, saying how she felt that choice was not an option for parents because she felt they were not allowed to question the systems in place:

You can see how the system would totally shut you down as they don't want you to question anything; just accept.

Participants in this location directly related their lack of control to feeling disempowered. They felt that this absence of control and choice was largely due to

the lack of information or guidance they felt they had been given by professionals after diagnosis. For example, Carrie compared her post-diagnosis experiences to being thrown into the sea:

No...you just feel as though you're swimming in a big sea just no getting anywhere...as I said you get to the point that there's just diagnosis...and then all of a sudden it's just...it's like you've just been flung off a big boat...like there you go...and you're like 'oh'.

Caitlin went further with this and highlighted the discrepancies she saw between the policy guidance that advocates for parent choice and empowerment in Scotland and how things have been for her in practice:

There's just...there's no choice... and that was one of our things to the council in referencing all the Getting it Right for Every Child and all the legislation that's there. It talks all this talk but you think actually in reality there's nothing that's meeting this policy ...there's nothing that's being offered that's reflecting what they are suggesting children should be offered.

Notably Caitlin's was the only reference made to any specific policy guidance or legislation within the data from central Scotland, which appeared to reflect a lack of awareness from parents in this location regarding policy more generally. As discussed, although they did not name specific policies, a number of participants in MA made reference to legislation relating to early intervention, which reflected more of a sense of being informed overall.

However, not all parents within the MA sample saw their choice of services in a positive light. This was due to the pressure that some experienced regarding the intensity of therapy on offer within this location. This led some parents to think that they had little control over their child's programme and constant professional input

made them feel disempowered as parents. This contrasted clearly with the sense of choice over intervention approaches and diagnosis discussed previously. For example, Maria talked about how she felt that professionals were at times taking away from some of the interaction she should be having as her child's mother:

I also think that one of the real difficulties of having a child diagnosed here in the states is just the intervention models that are in place is that you have a lot of professionals coming in and doing what I used to do with him... you know playing with him, teaching him things...and um in a way you feel a little disempowered like a little bit like 'can't I take care of him?' ...he's like my son you know.

Maya also reflected this in her discussion of what she perceived as a culture of intensive services within Massachusetts. The pressure of which left parents like herself with little choice but to access them:

There's almost a cult idea here that if you don't do intensive services you've completely lost and if you do do intensive services you completely change the kid and I think both sides of that are flawed. I think intensive services can genuinely help but I think actually what really needs to happen is that you need to provide some scaffolding to make sure the family is functioning.

This was an unexpected finding in this thesis and one which I will discuss in more detail further on.

5.2.4.1 Discussion: Parental Choice and Control

In spite of the common themes across policy in both countries regarding parents as partners and parents as equals (*IDEA*, 2004; *ASL Act*, 2004, 2009; *Educating Children with Autism*, 2001 and *The Autism Toolbox*, 2009), there appeared to be a disparity between locations regarding the ways in which these policies or guidelines were enacted. Parents' perceptions of empowerment in each location were directly affected by the level of choice they were given when selecting the best support for their child.

It was clear that many participants in central Scotland felt that this was limited through a lack of control and involvement in their child's education and therapy and a perceived lack of specialist services for their child. Conversely, the findings from the Massachusetts sample reflected a clearer sense of partnership and choice with regards to interaction with services and professionals. This would perhaps appear to exemplify a different commitment to policy enactment within this location in terms of parental rights. However, it is also important to note that parental rights in the US are protected through Due Process (*IDEA*, 2004), which has been passed as legislation. Although the *ASL* Act and subsequent guidance promotes parental rights, these are not protected by law in the same way.

The diagnostic process and its follow up have long been recognised as a highly stressful experience for parents of young children with autism (Banach *et al.*, 2010) and feelings of control and empowerment relating to access to services can have a significant impact on parental well-being short and long term (Gray, 2002a; Kausur Jevney and Sobsey, 2003; Graungaard *et al.*, 2011). However, there is less written about the importance of parental involvement in these services and the impact this could have on their experiences. In their study looking at developing "helping relationships" in health education, van Ryn and Heaney (1997) concluded that when parent-professional relationships were empowering they had a positive effect on service delivery overall. Nachschen and Minnes (2005) also found that feelings of empowerment in parents of children with developmental disabilities reduced stress in this population. In addition, more recent research has focused on parental feelings of empowerment through their direct involvement in training in specific approaches. For example, Minjarez *et al.* (2012) found that through increasing their knowledge of Pivotal Response Therapy (Koegel, 1988) parents felt more empowered and this had a direct impact on their well-being overall.

Another notable finding within this analysis was the feeling of disempowerment reflected by some participants in Massachusetts. With regard to the intensity of services being offered to young children with autism in MA, it could be assumed that this level of support would be positive for parents because they were seeing their child supported and often making significant progress. Although the majority of parents in this location found access to intensive services to be immensely beneficial for them and their child, some felt disempowered due to their perceived lack of control and choice. They also felt that having a large number of practitioners interacting with their child negatively affected their role as parent.

These findings appear to be unique within the US based research to date. However, a Canadian study by Mulligan *et al.* (2012) found that all 12 parents interviewed had experienced an “alarming and disempowering journey from diagnosis to treatment” (p.322), whereby they were being forced into intensive services with little or no choice. Another study, of Australian families (Valentine *et al.*, 2010), concluded that when parents were being offered no alternative to intensive ABA services, they felt largely disempowered by the process. This study also argued that: “Whatever the explicit expectation placed on them, parents of newly diagnosed children are inevitably placed into this enormously dense, contested field of information and interpretation.” (p.956).

The pressure that was described by some parents within the Massachusetts sample is also an example of the way in which participants developed their understanding through interaction with others (Blumer, 1969). Through dealings with other parents accessing this type of intensive specialist intervention in this location, these mothers developed the idea that such services were necessary, even though they did not feel completely at ease with this level of support. This perceived culture of intensive services is also an illustration of Blumer’s premise that established “patterns of group life” seemed to exist in each location, and that their existence relied on the continued

use of specific shared schemes of interpretation. In this case these schemes of interpretation were directly related to the ways in which parents had conceptualised autism as a condition that could be treated through intensive services.

5.2.5 Summary: Research Question 2

It is clear from the analysis of these data and the themes that developed within this research question, that there were a number of differences in parent experiences of early, post- diagnosis services across the two locations. Interactions with professionals were perceived as either negative or positive, depending on parent location and this appeared to be directly related to policy and practice contexts. Although access to mainstream provision was similar in both locations, service levels and access to specialist input also varied significantly between the two countries. This in turn appeared to impact on parent feelings of hope and clarity of thinking for their child's future. Notably, in spite of the policy focus on inclusion and non-diagnostic specific input for children with autism in Scotland, participants in this location still felt strongly that their child needed access to specialist therapy approaches. The ability to choose services and take the role of consumer appeared to have a considerable influence on parents' feelings of control and empowerment, although a number of parents in Massachusetts had a potentially unique experience of feeling pressured by what they perceived as a culture of intensive services that they felt had developed in relation to autism within this state.

Although these findings showed some differences between locations with regard to parent experience of post-diagnosis processes and services, there were also shared themes which reinforced the findings from research question 1. As discussed in section 5.1, there appeared to be an emerging shared perspective of autism across both countries, based on a medical view of the diagnosis, particularly with regard to

the importance and perceived benefits of autism specific intervention or therapy. This then led to comparable parental expectations of services in both locations, although it was only in MA that these expectations were met. Notably, these similarities seemed to exist in spite of clear differences in parental perceptions of, and experience with, professionals' attitudes toward autism, alongside disparity in policy and practice overall.

Having looked at the data relating to my first two research questions which were more directed at the practical aspects of having a young child diagnosed with autism across both locations, I will now discuss the findings from my final two research questions which focused on parental perspectives of autism pre and post-diagnosis and participants' changing perspectives of and aspirations for their child.

Chapter 6: Finding, Analysis and Discussion

Part 2

In the second section of each interview, I asked participants a number of questions relating to their earliest perceptions of autism and whether these had changed post-diagnosis. I also asked about their perceptions of and aspirations for their child and how or why these may have altered after their autism diagnosis. In the data relating to these last two research questions there was a clear convergence between locations regarding conceptualisations of autism pre and post-diagnosis as well as many shared themes relating to parents' perceptions of and aspirations for their child.

Research Question 3

What are the similarities in, and differences between, Massachusetts (US) and Central Scotland (UK) in terms of: the ways, if any, in which parents feel that their perceptions of autism have changed over time and to what they attribute any changes?

Fig 6.1 Research Question 3: Codes to Themes

Codes	Categories	Themes	Sub Themes
Rain Man Media Perspectives Film roles Book characters Fear Past experience Learning difficulty Disability	Perspectives before Diagnosis	Stereotype and Stigma	
Not my child Not autism Dissonance Change in perspectives Positive perceptions Hope	Perspectives post-diagnosis	Changing through interaction	Interaction with Others Interaction with Child

Key: **Massachusetts Sub Theme**/ **central Scotland Sub Theme**/ **Shared Sub Theme**

In spite of some fundamental differences in post-diagnosis experiences between the two locations, when parents were asked to talk about their perceptions of autism before and after their child’s diagnosis, shared themes emerged across the data from both sample groups. The factors which influenced these conceptualisations were similar across locations. Notably the issues which influenced parents’ perceptions post-diagnosis did not appear to be directly related to the positive or negative experiences they may have had, either in their interaction with professionals, or in accessing services. Instead, the most significant elements of interactive meaning making that

participants reflected on was through their relationship with their child and contact with other parents. This was a key finding and will be discussed in further detail below.

6.1.1 Theme 1: Autism Stereotypes and Stigma

The majority of parents in both locations spoke of their pre diagnosis and pre parenting perceptions of autism as being shaped largely by previous experiences, with the concept of autism stereotypes emerging as a key theme. The majority of parents believed that these opinions had either been influenced by personal interactions or media influences prior to having their child and they reflected on these stereotypes as being largely negative. There were similar responses across both groups when discussing their impressions of autism at this stage. Within their discussions on autism stereotypes, a number of parents in both groups linked this to previous interactions with individuals with autism. They spoke about how specific encounters developed and reinforced their negative stereotypes around the diagnosis. For example, Mona reflected on the images of autism she had before her child's diagnosis, which she stated had been largely developed through observation of individuals in public settings:

I think that before, whenever we hear autism we think about a child sitting at a corner of a room not interacting with anybody and just looking at the wheels of a car, or lining up cars, or doing some repetitive stuff.

Caitlin in central Scotland, whose background had been in mental health, also reflected on her negative and stereotyped perceptions of autism prior to her daughter's diagnosis. These had been largely developed through her experiences in adult nursing:

I suppose I probably was someone who did think of it in the stereotyped ways of people who couldn't speak, or struggled to speak and people who could be quite aggressive, I suppose if I am honest. That probably would have been my view on autism until someone told me otherwise

Four parents in the CS group and two in MA referred to their early, and sometimes only, perceptions of autism as being shaped by the film 'Rain Man'. This is clearly exemplified in Carmen's discussion of the film:

I think I have to say.... with a lot of people...I have to put my hands up. I was completely ignorant and all I knew was Rain Man...really all I knew was Rain Man. So I really didn't know anything...I always...I assumed that everyone with autism had a learning disability.

A number of parents in both groups also referred to other mainstream media examples shaping their early perceptions. They felt that in retrospect they did not teach them a great deal about autism and served only to reinforce negative stereotypes. In addition, they spoke of the limited attention they had given to references to autism that they observed in the media. Melvin talked about how, although he was aware of autism featuring in the news or in documentaries, he paid little notice to it before his son's diagnosis because it was not a part of his life:

I was aware you know that it had to do with...I don't know... and those perspectives were probably based on mass...you know...either media or movies, magazines, whatever...and I probably didn't think about it much at all...why would you, right? If it's not part of your life, you wouldn't.

6.1.1.1 Stigma

A number of parents in both groups also reflected on the stigma that they had attached to autism as part of these early beliefs. The discussions around this theme were linked either to the negative perceptions that parents felt they had before their child's diagnosis, or reflections on the stigmatizing views of others. Cara reflected on her feelings before her daughter's regression, when a close friend had told her that her son had autism:

I remember her telling me he had this diagnosis of communication delay but that they believed it was autism...and I remember saying 'god that must be the worst thing ever'. I remember saying that at the time and thinking 'how would you cope with that?'

Colin also reflected on his experiences of viewing autism as stigma through his interaction with his neighbours when he was younger. His discussion touched on the idea of courtesy stigma (Goffman, 1986) whereby his neighbours appeared to want to keep their child hidden:

So at the time when I was growing up as a teenager he was just odd...the boy...and you never really seen him...I think his mum and dad kept him quite sheltered from the other kids.

Maggie in Massachusetts spoke about the stigma that she felt was promoted within the media regarding autism, through lack of understanding and negativity. She referred specifically to parenting magazines that she often read before her son's diagnosis:

They always just made everything seem so gloomy so I don't even want to read that article....there's always that kind of stigma that gets attached to it...and not explained too that there is such a wide spectrum.

Michael also linked this lack of understanding and negativity in the media and across

society with his concerns about stigma and acceptance of individuals with autism:

For somebody who is not a parent of a child on the spectrum - how much they are exposed to, how much acceptance there is? That's still a big societal problem...perceptions, acceptance you know of children with different challenges.

This reference to the importance of acceptance at a societal level was an interesting contrast with the medical model view that parents in both locations had reflected when discussing therapy and intervention for their child. Michael's concerns appeared to indicate a more social model perspective of autism as a poorly misunderstood condition within society and it will be interesting to observe whether this became more prevalent for parents when discussing their later perceptions of autism after diagnosis, alongside their perspectives and aspirations for their child.

6.1.1.2 Discussion: Stereotypes and Stigma

It was notable that in spite of differences in conceptualisations of disability and autism as reflected in the policy and practices between the two locations, when considering their pre-diagnostic views of autism, parents' perceptions were similar across both Massachusetts and central Scotland. It was also interesting to observe that although there were some differences in the content and focus of media and culture in the two locations (see section 2.2), parents in both groups had similar reflections on its influence on their pre-diagnostic stereotypes of autism.

The majority of parents in each setting discussed the impact that they felt the media had on their initial ideas of autism and what it meant to be autistic. Specific films and television shows were referenced as having had a significant influence on participants' opinions initially and these experiences led to the proliferation of largely negative autism stereotypes in both countries. This would fit with the assertion that perspectives

of autism developed through the media are often negative (Murray, 2008) and stereotypes at either extreme are common amongst those with no direct experience of the disorder (Draaisma, 2009). The emphasis on Rain Man within parents' reflections was in agreement with much of the literature that exists regarding this film (e.g. Burks-Abbott, 2008) whereby it is seen as negatively reinforcing autism stereotypes worldwide.

In addition, this theme highlighted the overall influence that media had on participants across both countries. As discussed by Barnes (2002), media can have a significant impact on developing belief systems and culture. She asserted that micro systems such as interpersonal communication supported the larger macro systems of culture and society, stating that "both interpersonal and cultural communication depend upon the sharing of symbolic messages over time and space." (p.3). With an increasingly shared space for interpersonal and cultural communication worldwide through the internet and social media (Robinson, 2007), it is clear that the process of meaning making is expanding from a focus on face to face social interaction through wider access to extended 'communication channels' (Shibutani, 1955). Therefore, in spite of the differences between the two locations in terms of media focus and policy context, these extended boundaries meant that experiences could have been influenced by factors outside of geographical limitations.

Draaisma (2009) in his writing on the proliferation of autism stereotypes argued that there is a general perception of autism which has become a "set of stereotypes" and "is graphically brought out by what movies need or need not show to explain the autistic condition." (p.1476). This set of stereotypes is largely negative and, as argued by Hacking (1999, 2007) in his writing on the 'looping effect', (see section 4.1.5) is acting to constantly reinforce these general perceptions of autism.

The emergence of this theme on ‘stigma’ was interesting due to the ways in which parents’ reflections on this were again similar in both locations. As discussed in section 2.2.2, this would be consistent with previous literature which focused on perceptions of stigma in disability (Goffman, 1986; Huws, Inglewood and Jones, 2001, Bogdan and Taylor, 1998). Stigma has long been associated with perceptions of abnormality and deviance, and according to Goffman, it reduces someone in our minds (1986:3). Although the concept of stigma has generally been attached to visible “abnormalities of the body” (ibid, p.4), parents of children with autism can experience stigma due to their child’s unusual behaviours (Gray, 1993; 2002a; 2002b). They can also experience stigma through a lack of understanding from the general public (Martin, 2013) which is directly related to the concepts of autism stereotype, as discussed in the previous section.

The perceptions of the same stereotypes and stigma attached to autism in both locations would again link with Blumer’s premise that established patterns of group life exist, where meanings are continuously reinforced by specific schemes of interpretation. However, the ways in which parents subsequently discarded these original concepts of stigma in autism were a clear example of how established patterns of meaning making can collapse and become redefined through individual and collective changes in this interpretation (Blumer, 1969). As argued by Charon (2010), redefinition “...imparts a formative character to human interaction, giving rise at this or that point to new objects, new conceptions, new relations, and new types of behaviour.” (p.67). The redefinition here appeared to be largely due to the ways in which parents’ perspectives of autism changed through their ongoing interactions with their child, which I will now discuss in more detail.

6.1.2 Theme 3: Change through Interaction

Although there were a number of factors discussed across both groups as influencing their changing perceptions of autism, all participants agreed that their perceptions of autism changed over time. The overall theme that emerged within the analysis of these data was ‘change through interaction’. Within this there were two sub themes that I identified: ‘interaction with their child’ and ‘interaction with others’.

6.1.2.1 Interaction with their Child

Of these two sub themes, the biggest impact on parents’ changing perspectives appeared to be through their continued interactions with their child. Initially many parents spoke about the confusion that they had felt regarding their child’s behaviours due to the stereotyped views they had of autism and because felt that their child did not fit within these. Interviewees across both locations discussed the surprise and confusion that they felt initially when they began to realise that their child may be showing red flags for this diagnosis. However, for many, their daily interactions with their child began to challenge their earlier views of autism in a number of different ways. Martina talked about her feelings of surprise when she realised that autism did not necessarily represent the negative stereotypes she had previously held:

...and the fact that a child could be engaged at times you know but still qualify for somewhere on the autism spectrum surprised me...as I thought of autism as like the head banging, you know very anti...anti-social kids who didn't like to be touched and who didn't really like any of that. That was kind of surprising.

The realisation that autism could be something different than what they had believed was a theme shared by parents in both samples. Cara spoke about how, even after diagnosis, her daughter did not appear to have what she and other family members perceived as ‘typical’ autism:

People in my family will still say 'but she's not typical;' there's still that perception that Cara is different from a normal...from an autistic person...and that's with us doing quite a lot of reading.

Monica talked about how initially she had felt her son could not have autism as he did not fit in with her stereotyped views of the diagnosis. She then went on to discuss how her perceptions of autism changed after her son's diagnosis and she began to view it more positively:

It's nice to be able to know ...you know...what your child's issues are...and also know 'my child is so good at this and this...and let's not overlook that' I think... you're able to say 'well you know he has these things...so he falls in that...but he also has these things which make him a candidate to hopefully outgrow certain aspects of that.

For some parents, like Monica this change in perspective was gradual. However, for others, such as Maggie, there was more of a sudden realisation where they recognized that their perceptions of autism had been incorrect because their child did fit the diagnostic criteria:

It just feels like a light bulb went off in my head...like it's a delay but more than I ever thought of before...like he would rather be playing with things than people.

This sudden realization was also experienced in a similar way by Marnie, who also had a 'lightbulb' moment when some of her son's repetitive behaviours were pointed out by his preschool staff:

They had noticed he was doing strange movements with his hands which I had never noticed before but after they pointed it out to me I started to observe the same phenomena obviously...and that really scared me because then I realised what they were talking about.

6.1.2.2 Interaction with Others

The second sub-theme that emerged across all interviews was the importance of ‘interaction with others’. Participants in both locations felt that their interactions with other people influenced them significantly. Notably, very few parents spoke about their exchanges with professionals within these data. Instead they focused on their interactions with other parents of children with autism, which were either face to face or online. For example, Cara spoke about how her perceptions of autism had been altered by spending time with other parents and children in a support group for children with the diagnosis. She had attended this prior to and post-diagnosis and found that over time it changed her views of what autism meant and gave her hope:

Seeing all the kids I have seen and meeting all the parents that I have met...just that it's not... the ability to learn is still there and the ability to progress is still there and that it's not a shut book case....there is still a lot that can be done.

A large number of parents, particularly in the CS group, also referred to their experiences of researching on the internet as being a critical influence in changing their perspectives on autism. Within this, many interviewees discussed their interactions in forums or through emails with other parents. Carrie, who talked about the significant changes she perceived in her son before diagnosis, reported how she spent time each evening looking for an explanation for her son’s loss of skills. Although she initially had negative stereotypes in mind, she found that her perspectives of autism were changed through reading and watching videos made by other parents:

But my ...thing with autism...it was definitely through the internet. It's been a very big learning curve... but definitely the internet. I didn't have a clue about autism so it's been ...but it's a good thing actually...it's kind of opened my eyes...it's amazing how intelligent

some of them are...looking at different cases and different children and stuff ...so it's been good.

Mona, in common with Carrie, spoke about a defining moment that changed her perspectives of autism coming from her experience on a parent forum:

But then while I was waiting for the diagnosis...I went on this forum and I saw like all these parents talking about their kids and I was like 'no way these kids have autism' because they all sounded like real babies, like regular babies with some delays.... like some not even so obvious.

6.1.2.3 Discussion: The Importance of Interaction with Others and Child

As argued by Blumer (1969), the meanings of things are produced over time through interaction. In addition, these meanings are modified within this interaction through interpretive processes (Pascale, 2011). It appeared that for parents in both locations the ongoing interaction with their child impacted significantly on their interpretation of autism longer term. As they realized that their child had autism, but did not fit into their previous concepts of stereotype or stigma, their perceptions of autism changed to a more positive outlook on the diagnosis. This was particularly true when observing the rejection of stigma which seemed to occur for the majority of participants. As their perceptions changed through their interaction with their child, no parent in either group discussed their prior perceptions of stigma affecting their post-diagnosis perspectives of autism.

This finding was an interesting contrast with a number of studies that have looked at parent experience of autism (e.g. Gray 1993, 2002b). For some parents in these studies, the stigma associated with their child's diagnosis caused them to feel that they were also a potentially stigmatised group. Goffman (1986) referred to this as 'courtesy stigma', meaning that through association with their child's disability parents became

stigmatized themselves.

However, one other study also highlighted a similar rejection of stigma for parents post-diagnosis. In their study of parental reaction to diagnosis, Russell and Norwich (2012) explored the dilemmas that parents of children with autism experienced regarding whether to attempt to retain their child's 'normal' status, or whether to attempt to 'normalise' their child's potentially stigmatising behaviours through diagnosis. They concluded that where parents chose to diagnose their child, they became active advocates to try and de stigmatise and reframe autism, attempting to change society itself.

Linking in with Goffman's premise on the relation between stigma and looking glass self, Lemert and Branaman (1997) argued that stigma is directly related to being able to maintain positive self-image within society and "...the degree to which the individual is able to sustain a respectable self-image in the eyes of others depends on access to structural resources and possession of traits and attributes deemed desirable by the dominant culture." (p.66). The fact that participants in this study did not view autism as stigma after their child's diagnosis could be due to a number of factors. This may have been due to the age of their child, as atypical or unusual behaviours in younger children would be easier to manage within public settings than those of older children. Therefore, it would be interesting to observe whether these feelings of stigma changed over time as a child became older.

Interaction with others outside of the parent child relationship also appeared to have had a significant impact on a number of parents in both countries. Remarkably, although it appeared that participants in MA had been positively influenced by their interactions with professionals, the majority of parents did not reference these as being a significant part of their interpretation and meaning making processes regarding autism, particularly with regard to their redefinition of stereotypes and stigma.

Although this lack of professional influence was evident in both settings, it was particularly relevant to those in the central Scotland sample. As discussed in section 5.2, parents within this location reported largely negative encounters with a range of practitioners both during and post-diagnosis. For a number of these participants, they actively rejected the negative prognosis they had been given, choosing instead to undertake their own research and make their own choices. Through seeking out alternative interactional experiences, both face to face with other parents and online, it is clear that parents within the central Scotland group took ‘corrective action’ (Snow, 2001) and developed perspectives of autism that were similar to those held by their Massachusetts counterparts.

Although this finding could be considered as unusual in the perceived lack of impact that interaction with professionals had on participants’ perceptions of autism, it was in agreement with a number of studies that have looked specifically at the ways in which parents seek support and information about autism post-diagnosis.

Mackintosh, Myers and Goin Kochel’s (2005) international study of sources of information and support used by parents of children with autism found that just over 72 percent of parents worldwide reported that their largest source of information was from other parents of children with autism. This was in comparison to only half of their participants viewing educators and other professionals as sources of support.

There have been a number of other studies that have looked specifically at the ways in which parents of children with autism interact (e.g. Huws, Jones and Ingledew 2001) and seek support (e.g. Mickelson, 1997) online. As these studies have recognised, parents of children with autism often rely heavily on online information and interactions such as forums to gain support and information. For example, Huws Jones and Ingledew (2001) reported that, alongside providing social support for parents, interaction within email groups also influenced the ways in which participants

developed their representations of autism. This again highlights the ever widening communication channels available to parents in this study, which clearly existed outside cultural and geographical boundaries.

6.1.3 Summary of Research Question 3

In spite of the structural differences between Massachusetts and central Scotland there was appeared to be an overall sense that there were shared meanings within the analysis of these data regarding perceptions of autism pre and post-diagnosis. The ways in which perspectives changed may have varied between individuals, but the factors influencing these changes seemed to be shared across both groups. The biggest impact on this for all participants was their continued interaction with their child as they became more aware that he or she had autism. This interaction and observation challenged parents' original negative stereotypes and ideas of stigma, and resulted in a more positive view of autism through their experiences of their child.

The findings relating to this research question were significant for this thesis, as they showed some clear differences compared to previous literature on parent reports on experience of stigma relating to autism. They also highlighted the importance of reflection and re interpretation for parents after diagnosis. Redefinition through ongoing interaction and modification of meanings of autism were important factors in developing parents' positive perceptions. The shared experiences of participants in both locations were again surprising; in view of the differences in the positive versus negative prognosis they had been given. However, they reflected the critical influence that ongoing positive interactions with their child, alongside optimistic communication with other parents, could have on perspectives of autism overall.

6.2 Research Question 4

What are the similarities in, and differences between, Massachusetts (US) and Central Scotland (UK) in terms of the ways, if any, that parents feel that their perspectives of, and aspirations for, their child have changed over time and to what they attribute any changes?

Although the ways in which parents responded to questions relating to their perspectives of and aspirations for their child reflected many individual experiences, there were shared examples across both locations where an autism diagnosis changed the way in which participants perceived their child in the short term. Aspirations and hopes for the future adjusted for many parents post-diagnosis and there are a number of shared themes here across both countries regarding both elements of this question.

Fig 6.2 Codes to Themes

Codes	Categories	Themes	Sub Themes
Stereotype Rain man Everything is autism Negativity Futility of diagnosis Nothing has changed Same person Question diagnosis Progress Hope	Perspectives of Child	Changing Perspectives	Through the Lens of Autism The Same Child Change through Progress
Equal treatment Mainstream Speaking Independence Limits One day at a time Fear Potential Happiness Job	Aspirations	Adjustments in Aspirations Hope	Normality Uncertainty

Key: **Massachusetts Sub Theme**/ **central Scotland Sub Theme**/ **Shared Sub Theme**

6.2.1 Theme 1: Changing Perspectives

Although there was a widely held view across participants from both countries that their child's diagnosis had changed their perceptions of autism, when reflecting on whether this had changed their perspectives of their own child, there was a mixed response overall. The main theme within this data was 'Changing Perspectives' with three sub themes reflecting similarities and differences across both groups.

6.2.1.1 Sub Theme 1: Through the Lens of Autism

A total of six parents from both locations spoke about the way in which their perspectives of their child changed when they started to view them 'through the lens of autism'. These interviewees reflected that, post diagnosis, they began to regard almost all of their child's behaviours or interactions as being associated with autism. However, this was perceived as a short term change which did not affect their perspectives overall. For example, Mona spoke in depth about how initially she analysed her son's behaviour almost constantly, as she regarded everything as being related to autism:

Whenever I look at him I am trying to see something I need to fix or is it something I need to redirect him from...or why is he asking me for letters again...most parents would be thrilled that their child loves alphabet...but when he comes to me with letters I'm like 'what's wrong with you, why do you want letters again?'

Connie echoed this and spoke about the way in which some of her son's behaviours started to reinforce her previously held stereotypes:

But I do see myself sometimes thinking ...like the Mickey Mouse thing...he's memorised some of this...and I think back to the Rain Man and he memorised the phone book.

Although the majority of parents had discussed their changing perspectives of

autism as being largely positive after diagnosis, it is interesting to note that for some interviewees their views on autism stereotypes still remained. This was particularly evident when these parents spoke about their observation of their child's atypical behaviours, viewing these through a lens of autism that was clearly linked to stereotypical perceptions of the diagnosis. For example, Maria discussed the ways in which even subtle behaviours could affect her perspectives of her son as she would view them as being related to his diagnosis:

...but having the label- it's not fun sometimes. ... And I tend to overanalyse everything he is doing. Like if he has a bad day, kids have bad days, but when he has bad days we tend to be really hard on ourselves. He even looks at a light 3 times a day for 30 seconds. Before I was like 'ok' but now your heart tightens when you see any kind of behaviour that's autism related.

This theme appeared to be a clear example of Blumer's (1969) premise that individual action toward an object, in this case an autism diagnosis, is specifically related to the meanings that the object has for them. In the case of parents reflecting on their perceptions of their child in this theme, it was clear that these meanings were directly related to past experiences (Charon, 2010).

However, participants reported that these feelings were short lived. In addition, it was significant that parents across both groups largely rejected the idea of stigma relating to autism stereotypes post-diagnosis and this will now be discussed in further detail in the second sub theme in these findings.

6.2.1.2 Sub Theme 2: The Same Child

Other parents spoke of their belief that their perspectives had not changed after diagnosis and that their child was still the 'same child'. This was most prevalent in the CS group, although there was one example in the MA group. Many of the central

Scotland parents felt that they had already accepted their child's autism before their diagnosis due to the time frame involved between initial recognition of differences and the final diagnosis. For example, Cara spoke about her acceptance of her daughter's autism occurring long before diagnosis:

I think I knew for the more than 6 months before that that she was going to have that diagnosis...so I think I had done my crying and had my upsets at that point.

Two parents in the CS group expanded on this theme, stating that their perceptions had not changed post-diagnosis, because they felt that diagnosis meant nothing to them in terms of changing the way they viewed their child. Claire, who also had a negative experience of diagnosis and had waited the longest time out of the CS group for her appointment, echoed the sentiments that her child's diagnosis was not important to her, because her perspectives of him had not changed:

Autism to me is just something else like he's got blonde hair, he's got blue eyes, he's got autism....he's got flat feet. You know it makes absolutely no difference. He's the same person as he's always been and he'll always be, and there's no point me grieving for a child that's never existed or a child that I thought he should be you know because that's not who he is.

Carrie also echoed this sentiment and felt that the time taken to diagnose her son meant that she had already come to terms with his autism, and her perspectives of him had not changed:

I didn't see him in a different light cos I knew fairly early on...but when they said it was autism I was like 'uh huh, I know that...this is a pointless meeting'...but I think they've got to go through that for paperwork...but I definitely didn't see him any different...by then, to me it had been such a long process...he'd built his own wee personality...his new wee personality up.....but it was just like the same wee boy.

As discussed, overall parents in the MA group shared feelings of changes in perspectives regarding their child post-diagnosis; only one parent in MA reflected that her perceptions of her son had not changed at all. Martina reflected that she still saw her son as the same child:

I actually still see him as the same child...I think my attitudes toward him haven't changed at all...he continues to be a very loving child... he's a very affectionate child...I think he is actually very related.

These responses implied some differences between the experiences of both groups overall. Whilst parents in each location talked about the idea that their perceptions did not change considerably after diagnosis, this theme of 'the same child' seemed far more prevalent in the CS group. Parents in Scotland felt that they had already accepted their child's differences before their diagnosis, which appeared to be linked with the longer waiting times experienced in this location. It was also interesting to note that this perspective could also link clearly with a social model view (e.g. Oliver, 1996) of autism, which was not reflected in the same way in the data from the Massachusetts participants. Conversely, as will be discussed in sub theme 3, the majority of participants in Massachusetts related their changing perspectives of their child to the progress that they were making through specialist therapeutic input.

In addition, the focus on the irrelevance of diagnosis that some CS parents made reference to could be seen as a result of a longer waiting time between initial referral and diagnosis, but could also be viewed as a reaction to the lack of services offered. For parents experiencing limited support and intervention post-diagnosis it was understandable that they may have perceived it as being largely meaningless. As discussed in section 5.2.1, some parents in this location also viewed the diagnosis of autism as being a barrier to help and support.

6.2.1.3 Sub Theme 3: Changing Perspectives through Progress

One theme that emerged strongly in the MA group, with only one example in the CS group, was a change in parental perspective of their child. This directly related to their progress. This was also connected to their child's access to specialist services and response to therapy input. For example, Michael, who had already described the access to services as providing a 'pathway', went on to explain that the progress that he observed helped him to facilitate changes in his perspective of his daughter every day:

Your perception of your child changes along the way. I think it evolves every day, with every interaction.

Melissa also spoke about a similar sense that her changing perceptions of her child were related specifically to the progress that he was making with his therapy. Notably, she began to feel as though he had much milder problems than she had originally thought:

To tell the truth now sometimes I feel he doesn't have any problems because of the help they have done...it's so intense

Only one parent in the CS group reflected similar changes in perspective attached to progress. Carmen talked about how, after seeing the improvements that her son made with his speech, she had changed her ideas that he would always be child-like:

I genuinely assumed that he would always be child-like...and I don't know....but now that I do know that this isn't necessarily the case.

This theme appeared to be an extension of the earlier theme of 'finding a pathway' as it highlighted more directly the impact that access to services had on parents' meaning making through impacting positively on their perspectives of their child. Although there has been limited research that focuses on the positive aspects of

parenting a child with an autism diagnosis (Hastings and Taut, 2002), these findings were in line with other studies that have looked at the impact that child progress can have on parental well-being (e.g. Gray, 2002a; Green *et al.* 2010, 2007; King *et al.*, 2006). As discussed in section 2.4, Gray's 2002 longitudinal study of parents of children with autism in Australia found that parental perceptions changed over time and were linked to progress (positive versus negative). This was echoed by King *et al.* (2006) in their comparative study of parents of children with autism versus parents of children with Down's syndrome in Canada, who identified the importance of parental feelings of hope for participants in both groups.

6.2.2 Theme 2: Adjustments in Aspirations

Although the analysis of data from this interview question reflected many individual responses to the ways in which their aspirations changed or didn't change, the overall consensus from participants across locations was that they had adjusted their expectations for their child after diagnosis. There was a mix of positive and negative alterations in aspirations and both groups of participants reflected similar levels of uncertainty mixed with hope for their child's future.

6.2.2.1 Sub Theme 1: Aspirations for Normality

A central theme that occurred across the analysis of data from both locations reflected what parents' perceived as an adjustment to their aspirations, through their hopes for what they regarded as 'normal experiences' for their child. A key aspect of this for many participants was their desire for their child to be treated equally by others. Connie, although she had reported that she felt positive about her involvement in her son's education programme, spoke about her short term aspiration for him to be treated equally or 'normally' within his mainstream nursery:

I don't want him to be different and this is the thing that I've tried to say in nursery at every meeting. I want him to be included in the group; I want him to be involved in the reading time even if it is only for 2 seconds, 5 seconds. I want him to be included in the group I don't want him to always be pulled out.

Marnie also reflected on her aspirations for equal treatment for her son through her desire for him to go to a mainstream setting for his preschool:

Like I want him to go to a normal kindergarten and I don't know if that's a real goal now...so I...that's sort of still my goal.

The majority of other parents also focused on the short term aims that they had for their child in terms of equal opportunities and access to mainstream education. This was evident across both locations and reflected a shared sense that having a 'normal' life was equated with equal treatment and typical experiences, including inclusion within mainstream nurseries and schools. This finding would again link in with Goffman's (1986) premise on normality being understood and conceptualised through responses to abnormality (Misztal, 2001).

For some parents they linked their aspirations for their child to have a normal life with their child's ability to learn to speak. Colin was particularly focused on speech and talking as being a key aspiration for his son and an indicator of 'normality':

At the moment he can't talk...he doesn't speak and that's what I want of him ...in his education plan I want him to be able to talk at the end of the next 12 months...that's what I want of him.

This was reflected by a number of parents whose children had limited verbal skills across both locations. For example, Marnie's son had just started to use single words at the time of her interview. When discussing her hopes for his future, she spoke about her aspirations for him to be able to talk like other children his age:

I think like 'oh he said towel today' and I'll see this other 3.5 year old who said to me 'I don't like to play with kids that are taller than me' and I'm like 'oh my god...that's such a complex thought...I can't even imagine...if my son said 2 words together we'd be thrilled.

As communication difficulties or delays are often the first and most pertinent red flag that parents observe when identifying early signs of autism in their child (Charman *et al.*, 2000; Charman and Baird, 2002) it is not unusual that parents within this study were focusing on speech as an aspiration. However, notably parents' desire for their child to develop ability to speak and communicate within this analysis was closely related to aspirations for a normal life and was a desire shared by participants in both locations.

Although there was less focus on longer term aspirations within this theme, one mother in the MA sample spoke about her long term hopes for her child to have what could be regarded as 'normal' experiences as she grew older. Maya also had a son with autism but saw her daughter's potential as being different than his:

So I believe that my daughter will do well in life. She will have relationships...she fundamentally likes being around people...and that helps. She might have weird relationships but those are good.

This was echoed by Cameron who talked about the ways in which he wanted his daughter to have normal life experiences as she grew up:

You say it's silly but you want to have those sorts of teenage rebellion type thing... You know 'argue with me!' All parents think they don't want that. I kind of want that. Cos then I know that it's normal.

These responses were interesting in terms of what participants regarded as reflecting 'normality'. Parents in both locations held similar aspirations for their child and viewed normality as being linked to equal treatment by others, typical childhood

experiences and being able to communicate. This again reflected a shared process of meaning making across both locations relating to this concept, which could be argued to reflect Snow's premise of symbolization, whereby meanings can be "often, perhaps routinely embedded in and reflective of existing cultural and organizational contexts and systems of meaning." (Snow, 2011: 371).

6.2.2.2 Sub Theme 2: Uncertainty

Although parents' responses revealed many positive aspects relating to the aspirations they had for their child, a large number of parents in both groups also spoke about the uncertainty that they felt regarding their child's future. In the MA sample, most participants spoke about their focus on taking things one day at a time rather than thinking about the bigger picture, which they found uncertain and overwhelming at times. For example, Maggie talked about how mostly she just needed to focus on the day in hand and make it as positive as possible:

At a certain level I have to do it one day at a time as I can't think out there ...and I want to positive about where we're going but there's certain days that we're just 'let's just focus on today, and have today be as good as it can be'.

This theme was reflected across both locations, with Cameron in the CS sample describing the ambiguity that he felt regarding his daughter's future, using the metaphor of a cloud to reflect his feelings of uncertainty:

I don't know what she's capable of? She's so young it's hard to tell how far is she capable of going? But I just want her to go as far as possible, as high as she can. But it's so difficult to ...it's almost like a cloud there, thinking 'well how far can she go?' and is that ever going to clear? You just don't know.

Two parents reflected on their aspirations directly after diagnosis and the despair that this uncertainty caused at that time. Michael in the MA group likened his experience to tearing down your hopes in order to build them up again:

We all project into the future, for our children...and pretty much you crash...you need to sort of destroy the whole thing, and then rebuild it. So essentially you have every parent with a child who has a sort of projection, knowing they ...for the future...even that you are going to do the basic things, like being able to playing with your child, doing certain things with your child, going out with your child...so you start to question for a while if all of that or none of that is going to happen.

This was echoed by Connie who also discussed the ways in which her initial aspirations were broken down and rebuilt after diagnosis:

all the things you expect the minute you are handed a baby...you plan their whole life in the first 10 minutes of seeing them, you assume this is what's going to happen and you take it for granted. You start to realise 'this wont happen...and that wont happen' so whenever you addressed subjects 'will he be able to go to school' we don't know... 'will he talk' we don't know... 'how do I do this?'. Well he's your son and you'll eventually work it out. And I suppose I did.

These feelings of uncertainty were similar for participants across MA and central Scotland and appeared to show a shared sense that autism can be unpredictable with regard to outcomes and prognosis. This would link in with much of the literature relating to autism and its largely unknown or uncertain prognosis (e.g. Howlin, Magiati and Charman, 2009) which has also been identified as having a potential impact on parental stress and well-being (Eyal *et al.* 2010). Notably for this study, this shared meaning seemed to exist in spite of a range of positive aspects discussed by parents in both locations, particularly the MA parents with the many positive interactions they had with professionals during and after diagnosis.

It could be argued that there would be an element of uncertainty for all parents of typically developing preschool children when asked directly about their aspirations for their child's future. However, with conflicting ideas on the aetiology of autism (Eyal *et al.*, 2010) and a large number of competing therapeutic options for young children with this diagnosis (e.g. Odom *et al.*, 2010; Boyd *et al.*, 2010), there is not often a clear pathway for parents to take.

However, in spite of the focus on intervention and support in US policy and practice, the responses from parents in Massachusetts still reflected a similar level of uncertainty. This would appear to reflect similarities in the ways in which parents in both locations understood the potential implications of their child's diagnosis and again suggested more of a shared perspective of autism overall.

6.2.3 Theme 3: Hope

A final theme that I identified in my analysis of these data was that of hope, through parents' desires for their children to achieve their full potential. Although the same participants had spoken about their uncertainty and fears for the future, it was also apparent that for parents in both locations, in spite of their adjustments to their aspirations, they believed that their child would reach their full potential. Within this theme, a number of parents discussed their acknowledgement of their child's capabilities. There was also the idea of that this might change over time or be limited in certain ways, but this would not impact on their child's happiness or the way in which they supported them as parents. For example, Colin talked about the promise he could see in his son, but to him as a father, it didn't matter how far he progressed long term:

But you can see that he will do something important because he's certainly got a background intelligence there in a lot of things...mathematics as well is one of them...no I think it's just reaching their potential is the aspiration... but it doesn't matter how far he goes cos he's still your son and you will look after him regardless.

Monica spoke about how her aspirations in terms of her son's potential had adjusted since diagnosis, but that she still believed he would reach it overall:

So for example I always thought he'd go to college, and I still think he will go to college... maybe he'll go to college and it will take him 5 years instead of 4 years. College might take a little longer, he'll have to find a very specific type of woman or man to love him, and he probably won't be president of the United States but he might be some CEO of some computer company.

In spite of the potential limitations of their child's diagnosis and the constraints imposed by policy and practice, throughout this theme, the overwhelming sense was that even though there were uncertainties, parents in both locations had hope and a strong belief that their child would achieve in whatever way was appropriate and possible for them to do so.

6.2.4 Summary of Research Question 4

This analysis of data in this research question presented some interesting themes, showing overall that in spite of some important differences in the experiences and journeys of the parents across locations, their perspectives of and aspirations for their children developed in similar ways. Some parents spoke about the ways in which these perspectives had changed after diagnosis and how they saw their child differently, either through the lens of autism or with a sense of relief that they experienced when they saw their child make progress. Other parents talked about

how they felt their perspectives had not changed, as they had had time to accept their child's autism months before their actual diagnosis. Parents' aspirations for the future were similar across both locations and the majority acknowledged that a diagnosis of autism caused these hopes to change, sometimes significantly or for others more subtly. The shared hopes of for normality, happiness and achievement, alongside the shared uncertainties that they felt showed that in spite of some marked differences in the experiences leading up to this point, the aspirations that parents had for their child with autism were largely similar across locations.

Most notably, the differences in experiences at a systemic level did not appear to have had a significant impact on parents' individual meaning making processes regarding their child. In spite of considerable variations in policy and practice across the two locations, there was a shared perspective of autism by participants before diagnosis, with shared experiences of redefinition afterwards. Therefore, Blumer's (1969) concept of meaning being made through interaction with self and others appeared to be paramount. I will now further discuss my conclusions from these findings in Chapter 7, drawing together the critical points from each research question in these two chapters and considering the implications that these may have on practices in both locations.

Chapter 7

Conclusions

7.1 Introduction

The aim of this chapter is to draw some final conclusions regarding these research findings, alongside a discussion of the methodological limitations of this study and the implications for future research and practice in this field. A number of findings were particularly significant, not least because some appeared to have been influenced greatly by the variation in policy context and content in the two countries, which has directly affected practice, whilst others appeared to be largely unaffected by these constraints. Contrary to what might have been expected, the ways in which parents made sense of this diagnosis was markedly similar in both locations. Conceptualisations of autism, and the ways in which parents' perspective of and aspirations for their child changed after diagnosis, were consistent across both sample groups and it is useful to now consider the possible reasons for this in the light of previous studies and current literature.

7.1.1 Shared Conceptualisations of Autism

With regard to participants' overall experiences of the diagnostic process in Massachusetts and central Scotland, a key finding within the analysis of these data was a sense of a shared understanding of what autism meant to parents in these early stages. This was a significant finding for this study as it indicated that participants' meaning making processes were similar across settings and appeared to exist out with structural constraints, particularly in the central Scotland sample. For example,

parents identified red flags for the condition in similar ways and at comparable ages in both locations. Although this early recognition of autism through differences in development has been identified throughout previous studies in national contexts (e.g. Charman *et al.*, 2000; Goin-Kotchel and Myers, 2005) it has not yet been explored in other international contexts. In addition, it was notable that this experience was so alike in spite of considerable differences at policy level.

Although it is not unusual for parents to identify behavioural differences in their child as the first signs of autism (Reiner-Hess and Landa, 2012; DeGiacomo and Fombonne, 1998; Howlin and Asgharian, 1999), it was interesting that participants from both locations reflected a similar understanding regarding how autism could present in these early years. In the central Scotland sample, this knowledge appeared to exist outside the boundaries of policy and practice and was an indication that interviewees may have been using a wide range of processes in order to make sense of their child's differences. These included internet research and talking to other parents, which not only reflected Blumer's premise of meaning making through interaction with others (1969) but also the impact that an ever growing shared space for interaction over a wide range of communication channels can have on the ways in which people make sense of their situations (Barnes, 1992; Robinson, 2007).

This finding also appeared to highlight a shared understanding between parents in both locations whereby autism was defined as something that was unusual or different about their child. This related to previous literature regarding concepts of disability as deviance from the norm (Goffman, 1986; Susman, 1994; Trammell, 2009). Through the use of typically developing children as frames of reference, parents drew on their own perceptions of normality to define abnormality. This process reflected Goffman's premise that normality is understood through abnormality (Drew and Wootton, 1988) and suggested that participants perceived autism through a medical view of there being

‘something wrong’ (e.g. Barnes and Oliver, 1993) with their child in these early stages. This medical view of autism as something that needed ameliorated was also reflected in the data in section 5.2 where parents in both locations spoke at length about the sense of urgency that they felt in finding support or therapy services to help their child make progress. This perspective; that their child’s symptoms could be improved through specialist intervention, suggested a medical model outlook, where disability was something that needed intervention (Ralston and Ho, 2010) and something which benefited from the input of professionals (Hahn, 1985).

However, there were also examples where the same parents also appeared to conceptualise their child’s diagnosis through a social, or minority, model view. This was most evident when participants discussed their changing understandings of autism from pre to post-diagnosis. Although they initially regarded the condition through stereotype and stigma, they changed their perspectives as they began to realise that their child did not fit with the negative meanings they had attached to this diagnosis. This tension was a clear example of Blumer’s premise of ‘redefinition’ (1969), whereby established patterns of meanings can be broken down and re-established through changes in perceptions (Charon, 2010). After holding some deep rooted views of autism as stigma within a largely medical model perspective, participants appeared to actively reject these once it became clear that their child had this diagnosis.

This conflict between opposing views of autism (medical versus social model and stigma versus non stigma) was also an example of cognitive dissonance (Festinger, 1957) which was identified in similar ways in Russell and Norwich’s 2012 study of parental perspective of diagnosis. This study found that participants who accepted their child’s diagnosis also took steps to actively reject stigma that they had previously associated with autism. However, in contrast with Russell and Norwich’s findings, no parent in either Massachusetts or central Scotland made any attempts to avoid their

child's diagnosis and protect their 'normal status'. Instead, all parents in this thesis actively sought assessment, diagnosis and intervention for their child, in spite of any of the previously held negative perceptions of autism they may have had. Although some parents spoke about their initial changes in perspectives being linked to seeing them through the 'lens of autism', this was mostly short lived and appeared to form a part of their wider meaning making process. Significantly, none of the participants from either location chose to redefine their child longer-term through their diagnosis and decided instead to adjust their meanings of autism through interactions with their child.

Evidence of social model perspectives of autism were also seen in the analysis of these data when participants from Massachusetts and central Scotland talked about their aspiration for their child's future. Notably, although access to intervention, and their child's responses to this, influenced their ongoing changing perspectives of their child, the need for treatment through a medical model view did not feature in their discussion on aspirations overall. Instead, parents from both locations spoke about their hopes being linked to the ability of their child to reach their full potential. Any uncertainties or adjustments to these aspirations appeared to be related to the barriers that society presented to their child, rather than from their child themselves. This would reflect similar views to the majority of social, or minority model advocates in both countries (e.g. Oliver, 1983; Shakespeare and Watson, 2002; Hahn, 1985).

Parents of children with autism have been well documented throughout research as being able to adopt characteristics of both the social and medical models of disability in strategic ways (Russell and Norwich, 2012; Ryan and Runswick Cole, 2009). However, this has never been looked at from an international, comparative aspect. Although there are clear limitations on the impact that can be attributed to policy or media considerations with regards to individual meaning making (as

discussed below), it was still significant for this study of parents in two locations that such similar processes of conceptualising autism were identifiable in the analysis of these data, despite the fundamental differences in policy context and content overall.

As policy in the US is largely focused on identifying and treating young children with autism, parents' focus on the importance of diagnosis and specialist intervention within this setting was mostly expected. However, data from parents in the central Scotland sample showed a surprising emphasis on what could be regarded as a largely medical model view of autism, particularly with regard to accessing autism specific therapy services. This existed in spite of a more social model focus of national legislation and policy guidance. These similarities between parents in both locations regarding their adoption of both models of disability, in order to better understand and advocate for their child, were a clear example of the ways in which individual meaning making at this level was perhaps not directly influenced by policy considerations in either setting.

However, an equally significant finding for this thesis was that policy appeared to have a fundamental impact on the differences in practical experiences of the diagnostic process and follow up services for parents in each location, and I will now discuss this in further detail.

7.1.2 Impact of Policy on Parent Experience

Although there were similarities in the ways in which parents understood autism in both settings, there was some significant variation in the ways that participants experienced more practical aspects of the pre and post-diagnosis process. These differences appeared to be influenced by the policy contexts and policy enactment in each country and, whilst these issues did not appear to have an impact on parents' perspectives of or aspirations for their child overall, it was possible that they had some

implications for aspects of parental well-being.

As has been widely recognised across the literature, access to and provision of services can have an effect on parents' levels of stress and coping (e.g. Hutton and Carron, 2005; Midence and O' Neil 1999). For participants in this study it was apparent that levels of services and support appeared to have a directly positive or negative influence on their emotions. For example, parents in Massachusetts who perceived their support as adequate and effective reflected a strong sense of happiness and hope for the future. This sense of hope was largely linked to their child's progress. Conversely, participants in central Scotland felt that specialist services and support were more limited, which made it difficult for them to see a clear way forward. Although their children were accessing a range of services, they felt that these were insufficient overall.

The focus of all participants on the importance of having 'a pathway' was an important finding in this study, as it highlighted the consequence that effective or ineffective provision can have on parental experience at this early stage. Whilst there have been a number of studies looking at parent experiences of post-diagnosis services (e.g. Valentine et al, 2010; Bromley *et al.*, 2004; Renty and Roeyers, 2006) no study to date has looked at these early stages of diagnosis and support across two countries in a similar way. Therefore, the findings in this thesis are largely novel as they reflect the impact that differences in support systems and practice can have on a range of aspects of the diagnostic journey for the participants in these locations.

Although there did not appear to be any differences in the ways in which parents accepted their child's diagnosis in either location, there seemed to be a clearer sense of a 'way forward' from parents within the Massachusetts sample. For those in central Scotland there were many examples of parents feeling lost and confused due to lack

of appropriate information and an absence of support. Some even regarded an autism diagnosis as a barrier to effective services. This led to the majority of parents in this group feeling frustrated and angry with professionals. Although they were not asked directly about their own well-being, it appeared that these experiences may have had a negative impact on parents' emotional health overall.

One of the most notable findings with regard to the differences in parent experience was related to participants' recollection of their diagnostic appointment. In Massachusetts, reports appeared to be largely unremarkable and interviewees commented on the comprehensive nature of the assessment or the positive interactions with professionals. In contrast to this, almost all parents in the central Scotland group reflected on feelings of discomfort. These were either physical and specifically related to the environment, or emotional due to the way in which professionals interacted with them or their child. This difference between the two locations highlighted the impact that systemic influences may have had on parents from two locations with diverse health care services. As recognised by Ham (2005) and Levine (1988), the US and the UK have very different practices which can result in a distinct experience between 'consumers' and 'patients'. It was evident that accessing self-chosen services had more positive implications for participants in this study than accessing statutory services that were often under resourced and oversubscribed. In addition, the impact that policy differences had on the interactions between parents and professionals were also a key factor in understanding the ways in which participants processed their child's diagnosis in the early stages and I will now discuss the influences of 'interaction with others' on parental experiences in greater detail.

7.1.3 Interactions with Others

As interaction with others is a critical part of the way that individuals attach meaning to things within a symbolic interactionist framework, it is important to look at the impact that these interactions had on parents in this study, in order to draw some conclusions about the influences that various ‘others’ had on their understanding of autism and of their child. Another significant finding in this thesis was that parents in Massachusetts had more positive perceptions of their interaction with professionals during the diagnostic process than participants in central Scotland. Due to the limitations on services within this location, many parents reflected a sense of anger and frustration relating directly or indirectly to professionals that they were interacting with. They viewed these exchanges as negative, due to the perspectives that professionals in this location appeared to hold regarding autism. Notably however, these interactions did not appear to influence parent views of their child longer-term. Instead, the negativity they encountered presented as an important catalyst for parents in this location to move toward ‘corrective action’ (Snow, 2001), through recognition of the constraints that they perceived in current policy and practice in Scotland. Parents in this setting appeared to be motivated to challenge standard practices in order to ameliorate their situation through actively seeking specialist services. This finding would concur with Ryan and Runswick Cole (2009) in their writing on mother’s roles as activists in autism, where they recognised that ongoing negative interactions with professionals can act as an incentive for some individuals to stand up and fight against the system for the sake of their child.

Overall, similar studies based in single locations in either the UK (Avdi, Griffin and Brough, 2000) or the US (Hutton and Carron, 2005) found that parent perceptions of their interactions with professionals were often fraught with mistrust and

misunderstanding, due to negative feedback or poor information about autism. Although this was true of the experiences of parents in the central Scotland sample, it was not the case for the majority of participants in Massachusetts. In contrast, parents in this location perceived professionals' perspectives of autism as being largely optimistic and constructive. These positive interactions had an impact on their sense of hope for their child overall. In addition, it appeared that participants in the Massachusetts sample had a more positive experience with professionals than has been the case in previous studies that have looked either at US-wide data (Goin-Kochel, Mackintosh and Myers, 2005) or at individual states such as Ohio (Sansosti, Sansosti and Lavik, 2012). This was a potential example of how Massachusetts may be different from other states in the US with regard to services. Previous US studies also looked at data from parents who may not have been accessing self-chosen professionals or services in the same way, and this aspect of choice may have been a critical factor in understanding the differences between this thesis and other US studies (see section 7.1.4).

However, most significantly for this study, these interactions with professionals at the early stages post-diagnosis, whether negative or positive, did not appear to have a significant impact on parents' perspectives of and aspirations for their child longer-term. As discussed in section 7.2.1, parents in both locations had a shared understanding of autism and this appeared to have been developed through self-reflection, alongside interaction with others outside of professional services. These interactions, as well as ongoing exchanges with their child, seemed to have a bigger impact on parents' meaning making overall. Therefore, another somewhat unexpected finding within this thesis was the influence that interaction with others who were not professionals had on parents' changing perspective of autism.

When asked to reflect on their perspectives of autism and of their child post-diagnosis, participants spoke about the influence that exchanges with other parents of children with autism had on their understanding of the condition. These interactions, which were either face to face or online, supported them to redefine previously held beliefs on stigma and stereotype. Often they also offered hope through positive anecdotes from others or the realisation that other children with the same diagnosis had made significant progress. This finding corresponded with Huws, Inglewood and Jones 2001 study on parents' engagement in online forums, where they concluded that participants' perspectives of autism were being directly influenced by their exposure to the views of other parents through ongoing interaction. However, there have been no other studies to date that have looked at the differences in influence that interaction with professionals versus interaction with other parents may have on parents meaning making of their child's diagnosis in the early years. This finding; that parents in this study appeared to be more influenced by their interactions with other parents than with professionals, was novel to this thesis and is an important consideration when trying to better understand the factors that impact on individual experiences in this field.

Another critical influence for parents in the early stages of making sense of their child's diagnosis was their ongoing interaction with their child. As discussed, the cognitive dissonance between their previous views of autism through stereotype or stigma and their views of their child post-diagnosis resulted in parents redefining their meanings of autism in light of their change in perspective. In addition, parents spoke about the ways in which interaction with their child supported them to make sense of the diagnosis in a positive way. The ways in which parents attributed these interactions as positive in supporting their meaning making processes is in contrast to other literature looking at the impact of parent- child interaction in autism. In other studies, parental interaction with their child has been regarded as a factor in

increasing stress (e.g. Seskin *et al.*, 2010) specifically with regards to limited social reciprocity and affect (Hoppes and Harris, 1990; Estes *et al.*, 2009). It was not clear from the analysis of these data whether participants in either sample also found their interaction with their child stressful in some ways, as this was not addressed directly. However, participants across both locations made direct reference to the ways in which their ongoing interactions with their child led to positive changes in their perspectives of autism and their perspectives of their child overall (see section 7.4.2).

7.1.4 The Impact of Choice and Control

As discussed in section 3.2, parents are positioned throughout US policy as being joint experts in their child and have a wide range of legal rights (Hunt and Marshall, 1999). In their interactions with the numerous private services available across the States, they are clearly in a role of consumer or customer (Ham, 2005). Therefore, participants in MA appeared to have more choice and control than parents in Scotland, where specialist services in particular are more limited. The ways in which these differences across locations impacted on parental feelings of empowerment and disempowerment were another important finding in this thesis as this again highlighted the impact that policy may have had on parental experience in the two locations and presented a number of implications for practice (see section 7.4).

The importance of having, or perceiving to have, control over your child's education or therapy programme is an important consideration for any parent after a diagnosis which is as confusing as autism. For all parents in this thesis, their sense of empowerment was directly linked to the choices they felt they had or did not have regarding their child's education and support. The issue of choice for parents of children with autism has been recognised as an important factor influencing parental feelings of empowerment in a number of other studies in locations worldwide (e.g.

Mulligan et al., 2012; Valentine et al., 2010; Avdi, Griffin and Brough, 2000, Stoner *et al.*, 2005). For example, Mulligan *et al.* (2012) found that parents in their Canadian study felt powerless when they felt that they had no choice in treatment options for their child. In their small scale UK study, Avdi, Griffin and Brough (2000) found that some of their participants felt controlled by professionals, rather than guided by them and this had an effect on their perceptions of empowerment as parents. However, no study to date has looked at the impact that choice and control in child therapy and education programmes can have on parents' sense of empowerment across two locations, therefore this finding again appears novel to this thesis.

However, the findings relating to choice and control also highlighted some unusual reactions from parents in Massachusetts with regards to being provided with intensive autism specialist therapies. Although parents in the MA sample focused mainly on the positive aspects of having services and the clarity that they provided, a number discussed their perceived lack of choice with regards to accessing these services. This was reported as pressure that they felt to have their child scheduled for numerous hours of therapy per week. While this was not a requirement at policy level, recommendations from national legislation advise that young children with autism should have between 20 and 25 hours per week of intervention (Volkmar *et al.*, 2014). In addition, parents who discussed this theme felt that there was a culture of intensive therapy that had developed for families of children with autism that was perhaps specific to Massachusetts. To reject this option for their child would have been to go against their perceived expectations of culture in this location.

This finding also highlighted an interesting perspective on Goffman's premise of Cooley's 'looking glass self' (Lemert and Branaman, 1997:66), where parents in this location were aware of the need to be seen by others as 'good autism parents' through engaging in the practices that had become acceptable and normal in their social

world. It was apparent that the parents who discussed this issue felt that there would be a kind of stigma attached to any choices they made to reject this approach for their child. This was also a unique finding for this thesis. Although there are a number of studies that have looked at parents' experiences of stigma in autism (e.g. Gray 2002b, Russell and Norwich, 2012) there are none to date that have found a similar link between choice of therapy options and the potential impact on parents' own feelings of stigma. Conversely, Russell and Norwich (2012) in their study of UK parents of children with autism across a wider age range (3-11 years) concluded that parents choosing not to access services or diagnosis for their child felt that they were doing so to protect their 'normal status'.

7.2 Limitations of this Study

In concluding this thesis, it is also essential to consider any limitations and recognise areas that could have strengthened this research overall. Firstly, with a relatively small sample of participants this limits any claims that can be made from these findings. However, as considered in detail in Chapter 4, this study was set within an exploratory, qualitative paradigm where generalisation was not a consideration. Instead, the aim of this research was to provide a rich, detailed account of the similarities and differences of parents in two locations who were experiencing an early autism diagnosis for their child. As highlighted in section 4.6, qualitative enquiry can produce transferable results, as long as there is adequate contextual information provided (Lincoln and Guba, 1985). As argued by Stake (1994) and Denscombe (1998), although a qualitative case may be unique, it is an example that exists within a broader group and its transferability should not be discounted. As I will discuss in section 7.3, in order to reinforce the transferability and validity of these findings, it would be beneficial to

pursue similar research questions with a larger sample size across a wider location, particularly with regards to any implications for policy and practice in either country.

In addition, it is useful to briefly consider the participant group. Although I would stress that neither sample was completely typical or atypical of their location, it could be argued that their motivation to participate in this study was due to the fact that they were keen to share their experiences. This could be seen from two extremes. Through active recruitment of participants in both countries I was perhaps unknowingly targeting parents who may have had less of a typical experience. Parents in the Massachusetts sample overall may have had particularly positive experiences that they wanted to communicate. Conversely, parents in the central Scotland sample reflected more negative interactions with services and professionals and a number of the parents in this group had actively sought out additional services for their child. However, it would be more difficult to locate individuals who felt they had less of a story to share, which is a well-recognised challenge for research recruitment (Patton, 1990). Through acknowledging these potential differences from the outset of this study I do not feel that these have impacted on the validity of the claims that this study can make.

Lastly, when considering the limitations of this study it is also essential to reflect again on the possible issues presented by my dual role as researcher and practitioner. As discussed in sections 1.5, 4.6 and at various points in my analysis, there are a number of challenges presented with a dual role, particularly with regards to co-construction of data (Kvale, 2006). With this in mind it is clear that there may have been some findings or differences between data that may not have been identified in the same way by a researcher without in depth knowledge of this field. However, this was also strength for this study as this made me constantly reflective in my analysis which I feel has contributed to the validity of my methods (Miles and Huberman, 1994; Denzin and Lincoln, 2000). In addition, it is also important to note that I was

native to one country (Scotland) and not the other (US), which may have impacted on the detail and type of information that participants disclosed to me during their interviews. Lastly, as discussed in section 1.5, whilst I am a professional who advocates for early specialist support for young children on the autism spectrum I also actively seek to distance myself from the medical view of this diagnosis. In recognizing my 'dilemma of difference' (Minow, 1985) I have constantly reflected on the impact that my perspectives may have had on my analysis and conclusions within this study. However, having been clear regarding my ontology from the outset and been mindful of this throughout my data collection and analysis I do not feel that this had a negative impact on the validity or transferability of these findings overall.

This study also had a number of strengths. For example, through a mixed data collection schedule between both locations I was able to constantly compare experiences of parents in each country from the outset, rather than collecting all my data from one setting before I went to another. I also transcribed all interviews immediately as each was completed, which helped me to become truly immersed in the data and develop codes, categories and then themes through continual reflection across interviews.

In looking specifically at the experiences of participants from two locations that had many cultural similarities, but marked differences in policy and practice, this study has made an original and valuable contribution to the literature on parent experience of autism. Through using an extended symbolic interactionist framework (Snow, 2001) that considered the ways in which individuals create meaning through interaction with others, whilst acknowledging the influences of structural constraints, I have provided a rich and detailed account of the ways in which parents make sense and meaning from a potentially confusing and difficult situation. As discussed throughout this thesis, nobody had previously explored parent experiences of autism

diagnoses at such an early stage as a comparison between these locations, and the impact that these structural differences in particular had on participants presents a number of significant implications for practice and future research. Most importantly, although this study has shown that parents in contrasting locations experienced autism diagnosis for their child in similar ways, with the same fears and hopes for their child's future, having a clear way forward through access to appropriate services in these early years appeared to make a considerable difference overall.

7.3 Implications of Results on Policy and Practice

Although this study identified marked differences between these two locations in terms of policy and practice for parents of young children with autism, it was clear that alongside the challenges of the pre and post-diagnosis process that parents in this situation can experience, there were also many positive aspects for families in both settings. With regards to the Scottish context, it was apparent that parents in this location benefited from a system that provided diagnosis and support without charge. However, the limitations that free statutory services can present were identified as impacting directly and indirectly on parents' well-being through increased frustration and a perceived lack of support overall. This conclusion is similar to those of other recent UK-based studies (e.g. Crane et al., 2015) and numerous other previous, large scale UK-based studies (e.g. Howlin and Moore, 1997; Howlin and Asgharian, 1999), and highlights the need for a reassessment of current practice in this field.

It is also clear that a difference in the emphasis placed on the importance of early diagnosis and intervention for young children with autism seemed to impact negatively on parent perceptions of support within the central Scotland sample. Due to an ever widening range of information sources available through the internet and other media (Barnes, 1992), there was a feeling reflected by some participants in this study that

current Scottish policy and practice is falling behind other countries like the US, because it is not providing the same levels of specialist therapy services that parents might regard as potentially beneficial to their child. These results, although taken from a small sample, do have potential implications for practice within this location. As I will discuss further within the following section, these findings would indicate that there is a need for more support for parents in this location experiencing an early diagnosis of autism for their child. It would also imply that there needs to be a reassessment of the levels and types of services and therapeutic approaches available to young children at this stage. This study showed a clear link between child progress and parents' feelings of hope within the Massachusetts sample, therefore it could be beneficial for Scotland to reconsider the advice and information contained within documents such as the *SIGN* Guidelines (2007) in relation to early intervention approaches in particular. However, in order to assess the need for this reassessment in greater detail, there are also implications for future research directions in order to gain sufficient evidence to justify these claims.

Therefore, it would be constructive to consider undertaking a larger scale in-depth study on parent experience of diagnosis and post-diagnosis services within Scotland specifically, similar to the recent UK wide study by Crane *et al* (2015) where the impact of limited support and services on parent well-being is considered in more detail. This in turn could indicate the level of need for a reassessment of current policy relating to early identification, early diagnosis and early intervention for young children with autism in this location.

In addition, it is useful to highlight the current discrepancy between Scottish guidelines on intervention and specialist services for young children with autism and those of National (UK- wide) recommendations. In the National Autism Plan for Children (Le Couteur *et al.*, 2003), the minimum recommendation for preschool

children with an autism diagnosis is 15 hours of “appropriate ASD specific programmes.” (p.12). However, 15 hours per week is much lower than the recommendations from other countries such as Australia (20 hours per week: Valentine *et al.*, 2010) and the United States (25 hours, Volkmar *et al.*, 2014).

With regard to the US participants in this study, it was interesting and unexpected to find that a number of parents felt pressurised by the intensity of services offered to them within their current system. Again, as these findings were from a small sample it would be essential to take this forward through a larger scale analysis before concluding that this was an issue that was more prevalent across Massachusetts. However, in contrast to other studies that have considered parent experience of diagnosis (e.g. Goin-Kotchel, Mackintosh and Myers, 2005) and interaction with professionals (e.g. Hutton and Carron, 2005), the findings from this sample overall reflected particularly positive feedback regarding their satisfaction with the diagnostic process and the professionals they encountered. Therefore, it would be useful to further investigate their models of practice to see if this was state wide, in order to replicate these on a wider scale.

7.4 Implications for Future Research

As discussed in Chapter 2, there is limited qualitative literature that examines parent experience of autism diagnosis and there is even less that looks at this experience at such an early stage. In addition, in spite of the research implications for looking at the differences between the US and the UK in terms of policy and practice in early autism identification and intervention, this is currently the only study of its kind to compare parent experiences in these two locations. The findings from this thesis also highlighted some potential areas for future research that will further expand and consolidate this contribution to knowledge.

Firstly, as discussed it would be useful to explore the validity of these findings in greater detail through an additional study that includes a wider and larger sample group across both locations. This could still be undertaken using interview methods with a larger sample group, but with the addition of focus groups to generate more data from a wider participant group. Other future research areas include:

1. An in-depth assessment of parental experiences of early autism diagnostic services
Scotland wide

As discussed in my previous section on implications for practice, it would be beneficial in the first instance to undertake a qualitative study of parent experience of early autism diagnosis across Scotland, with a particular focus on the ways in which parents perceive support and service levels and whether this does in fact impact on their meaning making processes relating to their child's diagnosis and their sense of hope. In doing so it would be interesting to explore whether the experiences of my sample group are shared by larger numbers of parents country-wide who have potentially experienced the same level of services and support.

2. An exploration of the ways in which professionals from each location conceptualise autism and autism prognosis in early year's children and whether this impacts on parents directly or indirectly.

Another research direction that would be beneficial to gain a wider understanding of the effects of differences at policy level between the two locations would be an interview study with a number of relevant professionals in each location, looking specifically at their perceptions of autism to see whether there is a clear divergence between positive and negative conceptualisations between these two locations.

Interviewing professionals would also provide greater potential for exploring potential

links between policy and practice across both countries. In addition, as the findings in this thesis have shown that interaction with professionals can have a more limited impact on the ways in which parents themselves conceptualise autism, this would be an interesting point to consider in greater detail within a study that focuses on the views of professionals.

3. The potential changes in parents' perceptions of stigma and stereotype in autism as their child grows older

As discussed, a novel finding in this thesis was that parents actively rejected their previously held views of stigma and stereotype regarding autism after their child was diagnosed. There was also limited evidence that parents felt any sense of stigma attached to their child. This is in direct contrast with a number of other studies looking at the issue of stigma for parents with children with autism (e.g. Gray 2002b). This issue would merit further exploration to look at the implications that the age group of children in this thesis had on parental feelings of stigma, and whether these changed over time, or whether these perceptions stay the same for some individuals. In addition, it would also be useful to explore whether there are potential differences between parents receiving an early diagnosis for their child compared to those who perhaps receive a later diagnosis.

4. Whether differences in service levels and support impact on parent well-being and child outcomes longer term. (Massachusetts and central Scotland)

Finally, with the potential implications for parent well-being that arose within these findings relating directly to access to services and feelings of support, it would be highly constructive to look in more depth at the impact that the systemic differences in service levels and approaches to early intervention has on both parent experiences and child outcomes longer term in both locations. As a number of

current research studies have shown, parental information and training can have a direct impact on child outcomes (Gengoux *et al.*, 2015) and child outcomes can have a direct impact on parental wellbeing (Estes *et al.*, 2014) and this would be a key area to explore further.

7.5 Conclusion

In spite of the many similarities in the ways in which parents made sense of their child's diagnosis and conceptualised autism, the differences in support and services available across locations appeared to have the biggest impact on participants' experiences overall. The influence that access to appropriate and effective services can have on parents experiencing an early autism diagnosis for their child was a critical finding for this thesis and one which I would like to highlight in order to conclude this study. It is clear that when presented with a diagnosis as confusing and uncertain as autism, parents need to be given the right support in order to feel that they have direction and a way forward for themselves and their child. In reflecting on my dual role as practitioner and researcher, I feel that this finding is crucial in developing a fuller understanding of how to best support families in this situation and how to improve current policies and practice worldwide. As a fundamental aim of this research was to provide an in depth description of parental experiences across these locations, I feel it is only right to end this study with a quote from one of my participants that reflects this. As described by Michael, the father of a 3 year old girl in Massachusetts, being given access to support and services for his daughter impacted on all aspects of his diagnostic journey, because they gave him a pathway and this pathway offered him hope:

So when you get diagnosis you go to the other extreme...you go to the other extreme of thinking nothing is like...this huge depression, this negative thing I guess...and then you ...and that's the period when your perception of the child, all your sort of thoughts about, you know, the child's future...a lot of worry, fear, expectations...it like feeds on itself, the negativity...then when the services start and things like that, we start to see some positive improvements and then over time that sort of...I don't know if it's acceptance, it's partly acceptance but it's also seeing 'yeah there is a path that you can walk towards, it's not a dead end.' It's a different path, it's a harder path but there is a path that you can push along. And for me it's like ok, any little opening that you can get we'll go through that. I want to have a path.

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Appendix 1.1 Interview Schedule

Background to diagnosis- when did you start to notice differences?	
Chain of events to diagnosis- who, when?	
Who was involved in diagnosis? How was it communicated to you?	
How was the diagnosis described? What did they say about 'autism'?	
Input for your child since dx- services/therapies?	
Involvement in this programme of therapy/services?	
Perceptions of autism before dx? Where did they come from?	
Did perceptions of your child change after dx?	
Aspirations- what are they and have they changed since dx?	

Appendix 1.2 Information for Participants and Consent

Dear Parents,

I am a Doctoral Student at Edinburgh University in Scotland. I am also an early intervention professional. For my thesis I am writing a comparative case study exploring the experiences of parents with preschool children diagnosed with Autism U.S. vs. U.K

The thesis has full ethical approval from the University of Edinburgh.

As part of my data collection I need between 4 and 6 families to volunteer to contribute their experiences to my study and undertake a semi-structured interview with me (lasting between 1 and 2 hours). The data from these interviews will be used to contrast the experiences of parents across the two countries.

The main focus of the interviews will be to look at your experiences of the diagnostic process, the ease of access to services, experiences with professionals, perceptions of autism and the ways in which an autism diagnosis may affect perceptions of your child (yours and other peoples').

Interviews will be recorded by video for purposes of transcription later on. All video will be held on a secure computer that only the researcher will have access to. It will also be password protected. Video footage will be destroyed within 2 months of publication of the thesis. Parents may have a copy of the interviews if they so wish.

When written, all interview data will be anonymized and I will ensure that parents remain anonymous contributors. Names will be changed and any details that could identify you as individuals will be omitted. You will also be given the opportunity to see any material that will be included in the thesis before publication, in order to give your approval. You are always free to change your mind and withdraw from the study at any time and your data will not be used

The thesis will be published sometime around December 2014 and all families involved will be given an executive summary of the findings, and an electronic copy of the thesis if they so wish.

This study is aiming to be an original contribution to knowledge of parental experience in this field and an opportunity to highlight the need for change in one or both of the cases under study.

For further details and to express your interest in the project, please contact me on
ruthglynneowen@googlemail.com

Interviews can be held either at your home or at the offices of Helping Children with
Challenges/ Massachusetts ARC.

I will be looking for volunteers for the first round of interviews for the week of 11th June.

Looking forward to meeting you.

Best wishes

Ruth Glynne-Owen

MA (Autism and Education); PGCE; BA hons

I _____ give Ruth Glynne-Owen permission to record my interview using video.

I give permission for video to be used for transcription purposes and shared solely with the
researcher and thesis supervisor.

I give permission for my interview data to be used within Ruth Glynne-Owen's doctoral
thesis.

I understand that this data will be anonymized and pseudonyms will be used at all times to
protect my identity.

I understand that I can withdraw from this process at any time and my interview data will
then be destroyed and will not be used within the thesis.

Signed: _____

Date _____

Researcher signature: _____