An Exploration of How Professional Perspective Influences Experience of the Autism Diagnostic Process

By Michael Palmer

Volume one of a thesis submitted to the University of Birmingham for the degree of

Doctor of Applied Educational and Child Psychology

School of Education
College of Social Sciences
University of Birmingham
September 2019

Abstract

There is currently a ‘crisis’ in autism diagnosis with a high proportion of parents reportedly dissatisfied with the way that autism is being diagnosed (NAS, 2014; Crane *et al.,* 2018). Rates of autism have risen dramatically as awareness has increased and the criteria for diagnosis have changed (Taylor, Jick and MacLaughlin, 2013). Autism overlaps and intersects with many other areas of childhood additional need and can be conceptualised in a variety of different ways. The aim of this research is to explore educational psychologists’ (EPs’) and paediatricians’ professional perspectives in relation to autism and its diagnosis. This was attempted by considering the impact of the bioecological and medical perspectives on experience of multi-disciplinary autism diagnosis with implications for key stakeholders discussed. Three EPs and three paediatricians were sampled to take part in individual semi-structured interviews to explore their views. The subsequent data obtained were analysed using deductive thematic analysis (Braun and Clarke, 2006). This research found that the adoption of a bioecological perspective by the EPs and a medical model by the paediatricians significantly impacted upon their experience of autism diagnosis and participation within a multi-disciplinary team.

Acknowledgments

Thank you to the tutor team at the University of Birmingham for their ongoing support during the completion of this thesis. A special thank you to Dr Colette Soan for her patience and perseverance, Dr Huw Williams for his advice when considering the methodology for this research, and Sue Morris for her encouragement, critiques, and guidance during the three-year programme. A thank you is also in order to Dr Claire McGuiggan who gave her time and effort to support the completion of this project whilst the researcher was on placement.

Dedication

For Katie Marshall.

Contents

List of Abbreviations

3D1	Development, Dimensional, and Diagnostic Interview
ADOS	Autism Diagnostic Observation Schedule
ADHD	Attention Deficit Hyperactive Disorder
APPG	All Party Parliamentary Group
ASD	Autism Spectrum Disorder
CAT	Communication and Autism Team
DfE	Department of Education
DfH	Department of Health
EP	Educational Psychologist

MDT	Multi-Disciplinary Team
MMR	Measles, Mumps and Rubella
MHSDS	Mental Health Services Data Set
NHS	National Health Service
NICE	National Institute for Clinical Excellence
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
PMLD	Profound and Multiple Learning Difficulties
SENCO	Special Education Needs Coordinator
TA	Thematic Analysis
WHO	World Health Organisation

Chapter 1: Introduction

1.1 Introduction

The following volume presents research undertaken as part of a three-year (2016-2019) Applied Educational and Child Psychology professional training programme at the University of Birmingham. This chapter will present the current research, it’s positioning, and the broad rationale for the study.

1.2 Aims

This research aims to explore how the professional perspectives of educational psychologist (EPs) and community paediatricians have influenced their conceptualisation of autism and how these conceptualisations have affected their experience of lone and interdisciplinary working with regard to the process of diagnosing autism. This research focusses on the differences between the professionals’ bioecological and medical perspectives and how these viewpoints have affected their experience of diagnosis and multi-disciplinary working.

The research also aims to offer implications for improved collaborative working between EPs and paediatricians by examining how their differing perspectives have affected individual experiences when they are engaging with complex presentations of autism within the multi-disciplinary team.

1.3 National Context of the Research

1.3.1 Autism Diagnosis

There is currently a reported ‘crisis’ in autism diagnosis (NAS, 2014; APPG, 2016). Recent surveys have suggested that children wait an average of three and half years between their initial appointment with paediatricians and their subsequent diagnosis (NAS, 2014). This is much longer than the three months prescribed in the current National Institute for Health and Care Excellence (NICE) Guidelines (NICE, 2011; NAS, 2014). The government’s ‘Transforming Children and Young People’s Mental Health Provision’ Green Paper (2017) potentially underreports the incidence of autism given the potential number of undiagnosed children in UK schools (Baron-Cohen *et al.*, 2009; NHS and DfE, 2017). However, the paper still suggests that the heterogeneous nature and comorbidity of broader developmental needs associated with autism has put a particular strain on services designed to support those who require initial diagnosis, treatment, and interventions (NHS and DfE, 2017).

1.3.2 Autism Prevalence

The government does not currently keep a centralised record of autism diagnosis, making it difficult to accurately calculate the prevalence and incidence of autism (APPG, 2016). However, it is maintained that over the past 20 years, rates of diagnosis have increased significantly for all age groups (Waterhouse, 2013; Crane *et al.*, 2016). There has recently been a cross-party agreement to ensure that by April 2019 rates of autism diagnosis are included in the Mental Health Services Data Set (MHSDS). Local health trusts will be required to report their rates of diagnosis and associated wait times. Whilst the data are being collected, a national level of autism incidence has not yet been calculated. However, the subsequent data will eventually be available to ensure that governing bodies, parents, and professionals are able to hold health-care providers to account when becoming involved in the autism diagnostic process. Prior to these policy changes, many health care providers had not been collecting these data, meaning that prevalence and incidence of autism in the UK has been calculated using other cohort and cross-sectional methods (Best, Manktelow and Taylor, 2014).

There have been many different studies which have attempted to calculate contemporary rates of autism diagnosis. These include surveys, school screenings, and general practitioner databases (Baron-Cohen *et al.*, 2009; Taylor, Jick and MacLaughlin, 2013; Kelly *et al.*, 2017). Epidemiology data for autism are, however, notoriously variable with many studies reporting prevalence being criticised for various methodological concerns (Baron-Cohen *et al.*, 2009; Walsh and Hall, 2012; Özerk, 2016; Lyall *et al.*, 2017). There are currently few studies available which comment on autism prevalence in the UK after 2010. This could be due to the impending publication of autism diagnosis rates at a national level as a result of the inclusion of autism in the MHSDS (APPG, 2016; Özerk, 2016).

Autism first came to prominence as a condition which captured the attention of the wider public at the end of the 1980s (Waterhouse, 2013). The single biggest increase in the rate of autism diagnosis occurred between the 1991 and 2001 birth cohorts, with a 10-fold increase in the likelihood of being diagnosed with an Autistic Spectrum Disorder (ASD) during this time (Smeeth *et al.*, 2004). By 1999, around 0.3% of boys aged 2 to 5 were being diagnosed with autism, compared to just 0.06% for boys of the same age in 1988 (Smeeth *et al.*, 2004; Waterhouse, 2013). During this time period, diagnosis of broader conditions and symptoms associated with autism, conceptualised as Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) also increased from 0 to 1.06 per 10,000 people between 1988 and 2001 (Smeeth *et al.*, 2004). Even in this early stage of autism epidemiology research, large geographical differences in the rates of autism diagnosis were observed with the West Midlands having the second highest incidence rate and total number of diagnosed cases in the country (Smeeth *et al.*, 2004).

In the period between 2004 and 2010, rates of autism diagnosis ‘plateaued’ for children aged 8 years old (Best, Manktelow and Taylor, 2014). The suggested prevalence rates in 2008 for boys aged 8 is around 0.4%, with a reported annual increase of 0.12% (Taylor, Jick and MacLaughlin, 2013). However, different studies measure autism prevalence by examining different birth cohorts and age groups, making a true assessment of autism diagnosis prevalence difficult to ascertain (Waterhouse, 2013).

Prevalence of autism is now maintained to be at a rate of 100 in every 10,000 people, prompting many authors to comment that autism is no longer an ‘extremely rare’ condition (Lowe and Collins, 2017; Blaxill, 2013). However, these figures have been estimated to be even higher at a potential rate of 157 per 10,000 when taking into account potentially undiagnosed children following school-based screening studies (Baron-Cohen *et al.*, 2009). This means that autism prevalence could now be at around 1.57% for the general population compared to a rate of just 0.38% at the beginning of the 2000s (Baron-Cohen *et al.*, 2009; Taylor, Jick and MacLaughlin, 2013).

In 2018, 11.7% of the total school population in the UK held a Statement of Educational Need or Education Health Care Plan (EHCP) with 28.2% having autism recorded as their primary need (DfE, 2018). This equates to nearly 300,000 pupils in the UK with autism as a primary area of special educational need. Whilst looking at individual birth cohorts is helpful for tracking the incidence of autism over time, it is often inaccurate and does not give a true picture of the rate of autism in the current school-age population.

1.3.3 Increases in Autism Prevalence and Proposed Explanations

Alongside the current ‘crisis’ in waiting times for diagnosis, there has been a unparalleled increase in the identification of autism compared to other developmental disorders (Waterhouse, 2013). The dramatic increase in autism is now thought to be due, at least in part, to a number of changes in the conceptualisation, definition, and diagnosis of the disorder (Lyall *et al.*, 2017). If autism were an entirely genetic disorder, an idea which is increasingly being refuted, then it would be expected to remain at a stable level of incidence over time (Lyall *et al.*, 2017).

1.4 The Local Context of the Research Project

The present research project takes place in a West Midlands city, where 18 years ago, they were found to have the second lowest incidence rate of autism in the UK (Powell *et al.*, 2000). By 2004, the city was found to have the second highest incidence rate in the country, and it currently has some of the longest wait times for diagnosis in the UK (Smeeth *et al.*, 2004; APPG, 2016).

Whilst the city has a neurodevelopmental pathway, they do not fully adhere to NICE Guidelines for best practice (NICE, 2011). Recently professionals have started to set up multi-disciplinary teams (MDTs) for autism diagnosis. The teams consist of EPs and community paediatricians. The meetings have been arranged so that the two groups of professionals can discuss school-aged children who have been referred to the paediatricians due to concerns around symptoms which may be consistent with autism or could be arising from other unmet bioecological needs (Bronfenbrenner and Morris, 2007; Ravet, 2011). A list of cases to be discussed at a monthly meeting is assembled by the paediatricians and their admin teams. The cases on each list have been included following inconclusive paediatric assessment. The children raised for discussion are reported to exhibit social-communication needs in one or more different settings, are struggling to make academic progress, and have presented with needs/symptoms which could potentially be better explained by other comorbid or bioecological needs. Currently, EPs are asked to complete a feedback form which asks whether or not they have had any previous involvement with the child raised on the shared list, to share the type of work they may have completed with the child, whether the child in question presented with social-communication needs, and they are asked to provide a brief psychological formulation. The summary of involvement is collated by a nominated EP who then attends the monthly discussion meeting. At the monthly meeting, the nominated EP shares the feedback from the involvement summary sheets. The nominated EP and the paediatricians then discuss the case, presenting information from each of their professional practice activities and formulations of need based on their differing professional perspectives. These discussions are then used by the paediatricians to make decisions around diagnosis. Feedback regarding the outcomes of the discussions are then shared with parents and their children by the paediatricians at their next appointment in clinic.

This research explores the EPs’ and paediatricians’ decision-making processes, clinical judgements, and collaborative working together with schools and families around autism. This is examined with consideration of how their adoption of a medical or bioecological perspective influences their conceptualisation of autism and their experience of collaborative diagnosis.

This research adopts an interpretivist approach to help to distinguish between tacit and implicit belief systems and to help to ensure reflection around autism and its conceptualisation across the professional groups (Hollin, 2017). It is hoped that this research project will examine the way that professionals develop their positions and practice in relation to autism and interdisciplinary working, contributing to a growing knowledge base and suggesting ways of working for professionals, who hold differing perspectives, to support children and families.

1.5 Research Questions

- How do EPs and paediatricians conceptualise autism?
- How do EPs and paediatricians explain the reported rise in autism?
- How does the professional perspective of EPs and paediatricians influence their experience of casework related to autism and its diagnosis?
- How do EPs and paediatricians experience collaborative working around autism diagnosis?

1.6 Summary

The prevalence of autism has increased dramatically in the UK over the past twenty years (Taylor, Jick and Maclaughlin, 2013). There are number of explanations about why this increase has occurred, with changes in the way autism is conceptualised and defined maintained to be key influencing factors in the reported rise (O’Dell *et al.*, 2016).

Professional perspective influences how individuals conceptualise autism associated needs and experience diagnosis (Skellern, Schluter and McDowell, 2005; Evans and Trotter, 2009). This research aims to explore how EPs and paediatricians conceptualise autism and experience diagnosis by considering the influence of their bioecological and medical perspectives. This is completed with a view to gaining a deeper understanding of how EPs and paediatricians work together when attempting to diagnose autism. This research now proceeds by outlining the available literature related to autism conceptualisation and professional perspectives and experience during diagnosis.

Chapter 2: Literature Review

2.1 Introduction

This chapter presents a review of the available literature around autism conceptualisation and prevalence and professional perspectives and practice. A search of the literature using databases and Boolean logic terms was completed to identify relevant studies and papers. A snowball technique of referring to identified citations and references in order to expand the search and ensure the breadth of literature relevant to the research domain was examined.

2.2 Literature Review

2.2.1 Diagnostic Criteria for Autism

The increase in the prevalence of autism is thought to be partly linked to changes in the underlying conceptualisation and criteria required to confirm diagnosis (Waterhouse, 2013; Lyall *et al.*, 2017). It is therefore important to consider the key criteria used by professionals when they are attempting to accurately identify autism with consideration made later on about how these conceptualisations may affect their experiences.

The Diagnostic and Statistical Manual of Mental Disorders (DSM) outlines the criteria for diagnosticians and is currently in its 5th version (American Psychiatric Association, 2013). The criteria for autism changed significantly between the 4th and 5th versions of the DSM and received significant commentary and criticism when first drafted for publication (Barker and Galardi, 2015). The DSM-5 defines autism as a social communication impairment that is also characterised by restrictive activities, behaviour, or interests (APA, 2013). The DSM-5 stipulates that for autism to be confirmed, symptom presentations must not be better explained by global developmental delay, or intellectual disability, and must have been present in the individual's early developmental period (APA, 2013). The criteria also suggest that symptoms can be identified by impairment of social, occupational, or 'other' functioning (Frances and Widiger, 2012; APA, 2013). The DSM-5 alludes to environmental influences on the individual's functioning and suggests observation, assessment, and data collection from different contexts (Lobar, 2016). However, whilst there is a focus on 'environmental influences', the criteria make no explicit mention of differentiation from other bioecological needs which may present similarly (Bronfenbrenner and Morris, 2007; Teague *et al.*, 2017).

The DSM-5 criteria for autism diagnosis is notable because it subsumes Childhood Integrative Disorder and no longer includes Asperger's Syndrome or PDD-NOS (Volkmar and Reichow, 2013). Instead these diagnostic sub-labels are contained within the category of Autistic Spectrum Disorder (ASD). Alongside the reduction of subgroups the reduced or 'simplified' criteria are reported to result in fewer potential symptom combinations which can result in diagnosis (Volkmar and Reichow, 2013). While some have praised these changes, suggesting that the new criteria are easier to understand and can more accurately capture individual differences and sub-types within the autism phenotype (Grzadzinski, Huerta and Lord, 2013), others have been outspoken in their criticism (Volkmar and Reichow, 2013). Critics have suggested that the changes to the DSM have resulted in ‘taxonomical lumping’, meaning that individual groups and needs are not as well defined (Barker and Galardi, 2015). The Asperger’s community have been particularly vocal in their criticisms of the removal of the diagnostic label (Volkmar and Reichow, 2013). The previous criteria in the DSM-4 could reportedly be used in nearly 2000 different combinations of symptom presentations which would result in a diagnosis of autism, compared to a possible 12 combinations of symptoms in the DSM-5 (Volkmar and Reichow, 2013). The changes in criteria have been criticised by some authors because they can allegedly result in high functioning individuals at the ‘fringe’ of diagnosis being excluded, and potentially fail to capture early symptom presentations (Hirvikoski *et al*., 2015). These concerns are reportedly due to the new emphasis on functioning and coping in social environments within the DSM-5 criteria, and may be, in part, affected by discrepancy between the DSM-5 and the measures used in autism assessment tools (Hirvikoski *et al.*, 2015).

The International Classification of Diseases (ICD) is now in its 11th edition after being published in 2018 (WHO, 2019). The ICD-11 is also used by diagnosticians and follows the DSM-5, by conceptualising autism and its previous subgroups as ‘Autistic Spectrum Disorder’, reducing the number of potential combinations of symptoms for diagnosis, subsuming Childhood Integrative Disorders, and focussing on individual ‘functional’ impairment (Zeldovich, 2018). The ICD-11 focusses on social interactions and environmental demands, suggesting that autism is a functional social-communication impairment, where the demands of a situation can outweigh the individual's ability to cope (WHO, 2019). The ICD-11 stipulates that symptom presentation must not be better explained by intellectual disabilities or language disorders in order to confirm autism (WHO, 2019). As with the DSM-5, there is no explicit mention to ensure differentiation between autism and other bioecological needs. However, the focus on functional impairment and environmental interactions indicates some awareness of bioecological influences. There has been significant criticism and concern around the DSM-5 categorisation of autism with the APA receiving a large amount of feedback during the consultation stage for the document (Volkmar and Reichow, 2013). Despite this, the criteria for the ICD-11 has been more readily accepted than the DSM-5, with some authors suggesting that the similarity between the ICD-11 and DMS-5 conceptualisations has benefitted wider understanding and acceptance of the new autism criteria (Zeldovich, 2018).

The National Institute for Health and Care Excellence's 'Autism Spectrum Disorder in Under 19s: Recognition, Referral and Diagnosis' and 'Quality Standard: Autism' documents outline criteria and recommendations for best practice around autism diagnosis (NICE, 2011, 2014). NICE focusses on similar symptoms and needs to the DSM-5 and ICD-11. The professional group suggests that autism is a spectrum disorder identified by persistent difficulties in social interaction, social communication, stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests, and one or more of the following: problems in obtaining or sustaining employment or education, difficulties in initiating or sustaining social relationships, previous or current contact with mental health or learning disability services, or a history of a neurodevelopmental condition (including learning disabilities and Attention Deficit Hyperactivity Disorder), or mental disorder (NICE, 2011, 2014).

The NICE guidelines, like the ICD-11 and DSM-5, focus on functional impairment and the interaction of the individual with their environment. The three documents also provide conceptual space for dual diagnosis of other neurodevelopmental disorders. The NICE guidelines specifically encourage practitioners to consider the presence of other neurodevelopmental disorders, while Zeldovich (2018) suggests that the removal of criteria between the previous and current versions of the DSM and ICD allow for different symptom types to be identified and diagnosed separately (Zeldovich, 2018).

The NICE, ICD, and DSM criteria for autism have a similar focus on functional impairment, suggest the co-occurrence of other neurodevelopmental needs and encourage the consideration of the individual in context (Zeldovich, 2018). The guidelines are intentionally broad to reportedly allow professionals to take a ‘common sense’ approach to diagnosis, where the individual’s interaction with their environment is considered (Zeldovich, 2018). Whilst this focus on individual function in their environment is reported to benefit both the diagnostician and person seeking assessment, there is little evidence to suggest that these broad criteria are preferred by practitioners or that they are able to effectively consider alternative causes for similar presentations of need (Zeldovich, 2018).

2.2.2 Diagnostic Conceptualisation and the Links to a Rise in Autism Prevalence

The broadening of diagnostic criteria for autism in the DSM and ICD are maintained to have impacted upon the increase in rates of autism diagnosis (Waterhouse, 2013). This expansion of criteria has included the conceptualisation of autism as a ‘spectrum disorder’, the inclusion of diagnostic subgroups, and the removal of the requirement for severe social difficulties to be present before the age of five (Waterhouse, 2013). It has been suggested that the cumulative changes in the DSM and ICD criteria have caused a 28-fold increase in the incidence of autism since 1987 (Rosenberg *et al.*, 2009). Whilst the criteria for diagnosis may have changed and influenced incidence rates, diagnosis is still a process carried by clinicians, with many reporting that they do not ‘universally accept’ the criteria for autism outlined in either the DSM or ICD (Rosenberg *et al.*, 2009). Lord *et al*. (2012) have also reported that the diagnostic process for autism is idiosyncratic and variable, with clinicians being unable to replicate one another’s diagnosis. This suggests that the processes that diagnosticians engage in should be examined to understand how they utilise specific diagnostic criteria and guidelines to help ensure best practice.

2.2.3 Legislative and Cultural Changes and the Links to a Rise in Autism Prevalence

Research has shown that diagnosticians often give diagnoses of autism when the child may not exhibit all of the required symptoms in favour of more pejorative labels (Waterhouse, 2013). For example, in the 1980s it is maintained that as autism became more prevalent, diagnosticians would give a diagnosis of autism, even if the child's presentation was not wholly consistent with criteria, rather than diagnosing 'mental retardation' (Waterhouse, 2013). More recently autism is maintained to often be substituted for high ability children with behaviour problems, intellectual disabilities, and developmental language delays (Rosenberg *et al.*, 2009; Waterhouse, 2013).

It has also been proposed that changes in legislation have contributed to the increase in diagnoses of autism (Waterhouse, 2013). In the UK, the introduction of the NHS and Community Care Act (1990) is maintained to have been an important legislative milestone, which may have encouraged practitioners to diagnose autism to access community based care (D'Astous *et al.*, 2016). This legislative change aligns with 1993 Education Act, which stipulated that schools must provide education and support for children with special educational needs (DfE, 1993). This may mean that diagnosticians are now more supportive of giving a diagnosis of autism as it would more likely lead to inclusion and support within the wider community (Waterhouse, 2013; D'Astous *et al.*, 2016). These legislative changes coincided with emerging research which increased the understanding of autism as a spectrum condition, with practitioners becoming aware that difficulties did not need to be severe or profound for autism to be diagnosed (Waterhouse, 2013; D'Astous *et al.*, 2016).

As research into autism developed so did the availability of services and interventions, which was linked to an increase in the broader social awareness of autism as a disorder (Leonard *et al.*, 2010; Waterhouse, 2013). The understanding that early identification and support leads to improved outcomes permeated practice and likely increased the rate of diagnosis throughout the 1990s and early 2000s (Leonard *et al.*, 2010; Waterhouse, 2013). One of the most stable findings of epidemiological research into the increase of autism diagnosis in the 1990s is that the age of initial diagnosis continued to drop over time (Leonard *et al.*, 2010; Blaxill, 2013; Waterhouse, 2013; Özerk, 2016). This increased understanding of the importance of timely diagnosis and increased availably of services, interventions, and understanding of autism in the care community, may have contributed to the increase in rates of diagnosis (Waterhouse, 2013). Alongside these changes in health, care, and education communities, parents have become more aware of autism and are more likely to seek a diagnosis (Waterhouse, 2013). Research suggests that many parents are keen to seek a diagnosis of autism but are often left feeling dissatisfied by the diagnostic process and outcomes (Crane *et al.*, 2018). It is therefore important to consider parents' understanding and awareness of autism and their role in influencing professionals during diagnosis.

2.2.4 Impact of Diagnosis for Individuals and Families

Autism and its associated difficulties can have a profoundly negative impact on the lives of individuals and families affected. The National Autistic Society (NAS) completed a survey in 2013 to consider the impact of autism and the support that individuals and their families need (Bancroft *et al.*, 2012). Whilst survey data can be limited due to sampling biases and desirability and participation effects (Robson, 2011), the views of over 1000 people with autism were collected (NAS, 2013). The data they collected suggest an extreme level of need amongst the respondents with 77% reporting that they need help managing money, 73% needing help with housework, and 36% reportedly require help with washing or dressing (NAS, 2012). It is worth noting that this survey recruited adults and the needs of children and young people may be different, but the potential impact of autism is clearly demonstrated. The views of 2,938 people with autism, and 5,535 carers of people with autism, and a series of 11 interviews with people affected by autism were collected and published by the NAS (Bancroft, 2012). The data collected highlight the variable needs of people with autism with 7% of respondents saying they don’t require any additional support whilst a combined 65% suggest they need more than 30 hours of additional care per week (Bancroft, 2012). There are also associated risks of additional mental health needs, bullying, and isolation which can also affect people with autism and social communication needs (Walsh and Hall, 2012; Macmullin, Lunsky and Weiss, 2016). The NAS reports that a third of all their adult respondents have developed a mental health need over time (NAS, 2012). They go on to suggest that this highlights the need for early and prompt diagnosis (NAS, 2012). Accurate and timely diagnosis is reported to result in improved outcomes across education, mental health, and employment, partly by providing individuals with an understanding of their condition and answers about why they may have been struggling (Walsh and Hall, 2012; Moss, Mandy and Howlin, 2017). The NAS and other researchers have highlighted the toll that misunderstood social communication needs can have on individual wellbeing (NAS, 2012; Moss, Mandy and Howlin, 2017). The early language delays associated with autism can also have a long-term detrimental effect on outcomes in adulthood (Moss, Mandy and Howlin, 2017). Conversely, accurate, early diagnosis can lead to greater acceptance of the condition by the individual family, understanding in school, and result in targeted interventions and support across a range of settings (Koegel *et al.*, 2014; Moss, Mandy and Howlin, 2017). However, inaccurate diagnosis can result in the application of inappropriate interventions and support, and result in negative outcomes for the individual (Doshi-Velez, Ge and Kohane, 2014; Lobar, 2016; Murphy *et al.*, 2016). It is therefore important to consider the diagnostic process to ensure that it is as accurate and useful as it can possibly be for the individuals and families concerned. This research considers this process of diagnosis with particular emphasis of the differentiation of autism from bioecological needs.

Despite the benefits of accurate diagnosis for individuals and their families, many report high levels of stress and dissatisfaction with the current processes for diagnosis in the UK (Crane *et al.*, 2016; Crane *et al.*, 2018). Crane *et al.* completed two pieces of research to explore the experiences of adults with autism, professionals involved in diagnosis, and parents and carers of children with autism. In 2016, Crane *et al*. collected data from an online questionnaire completed by 1047 parents (Crane *et al.*, 2016). The questions included in the survey were sent to 559 autism-related services, including the NAS members' email list (Crane *et al.*, 2016). The survey data were collected between 2012 and 2013, and focussed on 6 key areas (Crane *et al.*, 2016). They were: time taken to get a diagnosis; age of child when diagnosis was received; questions to assess the quality of the intervention provided post diagnosis; the 'manner' of the professionals completing the assessments; the support offered to the family post diagnosis; and questions related to the level of stress reported by the family whilst seeking diagnosis (Crane *et al.*, 2016). Crane *et al*. found that 67% of their respondents were dissatisfied with current diagnostic procedures, compared to just 37% of parents from 15 years ago (Crane *et al.*, 2016). However, there may be some selection bias in the delivery of the survey and inherent limitations of the survey method (Cohen and Manion, 2002). It may be that parents who had a poor experience of diagnosis may have been more likely to complete the lengthy 26-minute survey compared to those who had a more neutral or positive experience (Robson, 2011; Crane *et al.*, 2016). Crane *et al*. comment on the lack of ethnic diversity in their obtained sample and the lack of representation across all regions of the UK (Crane *et al.*, 2016). This is an important consideration given the lack of a standardised approach to diagnosis across UK health trusts (NAS, 2014). This means that the data obtained and level of satisfaction of parents may vary within different regions and health-care trusts.

The results obtained by Crane *et al*. were analysed using multiple regression analysis (Crane *et al.*, 2016). They found that overall, parental satisfaction was closely related to the amount of support and information parents received post diagnosis (Crane *et al.*, 2016). They also found that the ‘manner’ of the professionals completing the diagnostic assessment was associated with increased levels of parental satisfaction (Crane *et al.*, 2016). Whilst multiple regression analysis provides information on the significance of the association between results, it is limited by the survey design and is only able to look at linear causation between the different variables and may not take into account factors which were not included in the survey question set (Cohen and Manion, 2002; Robson, 2011). For example, what other life stresses were the family experiencing at the time? What challenging behaviours did their child present with? There may also have been a recall effect influencing the data obtained with the participants generally giving answers about a diagnostic process which concluded several years before (Crane *et al.*, 2016). Crane *et al.*’s research is also limited by the change in diagnostic criteria which took place shortly after they collected their data (Crane *et al.*, 2016; Peters and Matson, 2019). The data were collected during 2012 and 2013 before the changes to the DSM-5 and ICD-11 (Lobar, 2016; WHO, 2019). In Crane *et al.*’s survey data, 40% of the children of the parents questioned had a diagnosis of autism, 37% had a diagnosis of Asperger’s Syndrome, 4% had received a diagnosis of high functioning autism, and just 13% had received a diagnosis of Autistic Spectrum Disorder (Crane *et al.*, 2016). The change in DSM and ICD criteria to encapsulate all of the diagnostic labels associated with autism under the Autistic Spectrum Disorder umbrella term, would likely influence experience of the diagnostic process (Lobar, 2016; Zeldovich, 2018). Crane *et al*. analysed the data of all of their parents in one large group (Crane *et al.*, 2016). Given the recent changes in diagnostic criteria, it may have been useful to compare the level of stress and dissatisfaction of parents whose children had been given the newer Autistic Spectrum Disorder label.

Crane *et al*. added to their survey data with a separate piece of research aiming to qualitatively explore the experiences of parents, adults, and professionals who had been through the autism diagnostic process (Crane *et al.*, 2018). They interviewed 10 parents, 10 adults diagnosed with autism, and 10 professionals involved in diagnosis (Crane *et al.*, 2018). The parents in this research were randomly sampled and recruited from the survey data set (Crane *et al.*, 2018). The interview data they collected were analysed using thematic analysis, with three themes identified (Crane *et al.*, 2018). The themes identified were, the ‘process of understanding and accepting’, ‘multiple barriers to satisfaction’, and ‘inadequate post-diagnostic support’ (Crane *et al.*, 2018). Crane *et al*. suggest that a lack of post diagnostic support is a key part of parental dissatisfaction with many having expected an autism diagnosis to unlock more support for their child than they received (Crane *et al.*, 2016; Crane *et al.*, 2018). Crane *et al*. also found that some tension existed between the professional and parents around the role of parental expertise in confirming diagnosis (Crane *et al.*, 2018). However, all the groups interviewed suggested that autism diagnosis should be child centred (Crane *et al.*, 2018). They also suggested that professionals were not always aware of the external factors influencing a child's presentation in clinic or alternative presentations of autism (Crane *et al.*, 2018).

In a similar piece of research to Crane *et al*.'s 2016 survey, Siklos and Kerns (2007) found that parents of children with more severe autism symptoms found the diagnostic process more satisfying and less stressful (Siklos and Kerns, 2007; Crane *et al.*, 2016). This may highlight the difficulty practitioners have in diagnosing and assessing 'indeterminate' autism, unconventional presentations, and bioecological needs. It will be important to explore this with the participants in this research project to consider how they reach conclusions when symptom presentations are unclear (Skellern, Schluter and McDowell, 2005; Hollin, 2017). Siklos and Kerns report that 82% of parents find the diagnostic process stressful, whereas Crane *et al*. find that 84% of parents find it 'quite' or 'very' stressful. With autism diagnosis currently in reported 'crisis' and high levels of dissatisfaction reported by adults and parents of children seeking diagnosis, the current research project is well placed to contribute to the understanding of the complexities of multi-disciplinary diagnosis for autism (NAS, 2014; Yates and Le Couteur, 2016; Crane *et al.*, 2018).

2.2.5 The Role of Schools in Autism Diagnosis

NICE guidelines suggest that information should be collected from various sources, including schools (NICE, 2011). The DSM-5 and ICD-11 both suggest that difficulties should be present in 'multiple-contexts' (NICE, 2011, 2013;

WHO, 2019). However, the role that schools should play in the diagnosis of young people is not formally defined across the UK (Baron-Cohen *et al.*, 2009). This is potentially difficult for parents and children with autism given the important role that schools play post diagnosis in providing support and intervention (Ravet, 2011). Support and intervention can often be commissioned through schools with key legislation protecting the rights of children with autism in schools (DfE, 2014). This is often achieved through the application for Education Health and Care Plans (Dunsmuir *et al.*, 2019). The structured interventions, graduated responses, and familiarity with families that schools have could hold key information in helping professionals to differentiate between autism and other types of learning, social, and bioecological needs (Bronfenbrenner and Morris, 2007; Leonard *et al.*, 2010; Doshi-Velez, Ge and Kohane, 2014). It is reported that pre-school settings often have more involvement in diagnosis compared to primary and secondary schools (Dunsmuir *et al.*, 2019). This is often through advice and signposting to parents, which may be easier in smaller more familiar pre-school settings (Dunsmuir *et al.*, 2019). Autism needs may also be more easily identified in younger children by considering the presence of language delays and sensory needs (Goodwin, Matthews and Smith, 2017; Dunsmuir *et al.*, 2019). Whilst all schools must have an awareness of autism and how to support children with a diagnosis, the lack of a universal approach may well contribute to the dissatisfaction felt by parents when first seeking an assessment to gain a diagnosis (Ravet, 2011; DfE, 2014; Crane *et al.*, 2016).

2.2.6 Autism and Comorbid Symptoms

Autism is maintained to be an innately heterogenous condition with many authors now maintaining that it is time to give up on finding a single factor causal explanation (Ravet, 2011; Hollin, 2017). There is also an increasing body of literature which outlines the significantly high rates of comorbidity of autism diagnoses with a variety of other developmental, neuropsychiatric, and bioecological needs (Ravet, 2011). Systematic reviews have found that insecure attachment occurs in 53% of cases where autism has been diagnosed, and broad mood and psychiatric conditions in 33% of cases, intellectual disabilities occur in 66% of cases, and there has also been an increasing amount of evidence published to suggest that autism can often co-occur with ADHD and schizophrenia (Doshi-Velez, Ge and Kohane, 2014; Chen, Chen and Gau, 2015; Teague *et al.*, 2017). The broad conceptualisation of autism, and the apparent comorbidity with other disorders, potentially influences professionals' experience of the 'uncertainty of autism', and their subsequent diagnostic procedures where they attempt to differentiate between the origins of symptom presentations (Skellern, Schluter and McDowell, 2005; Hollin, 2017; Hayes *et al.*, 2018).

2.2.7 Conceptualisation of Autism and Professional Perspective

There are an ever-increasing number of divergent discourses, encompassing all philosophical positions, to conceptualise autism and associated additional needs (Waterhouse, 2013; O'Dell *et al.*, 2016; Hollin, 2017). Autism is now more consistently defined as a heterogenous condition and is maintained to be inter-individually heterogenous, intra-individually heterogenous, and indeterminate (Fitzgerald and Callard, 2017; Hollin, 2017). This means that autism is now thought of by professionals from various disciplines to be variable both in terms of its causes and in presentations between individuals. This variability reportedly contributes to autism's enduring difficulty to define, construct, assess, and diagnose (Lord *et al.*, 2012; Waterhouse, 2013; APPG, 2016; Fitzgerald and Excellence, 2016; Fitzgerald and Callard, 2017; Hollin, 2017). The inherent inter and intra heterogeneity of autism, and it's indeterminant nature, is reported to have led to enduring ontological and epistemological uncertainty, resulting in tensions amongst various disciplines (Decoteau and Underman, 2015; Fitzgerald and Callard, 2017; Hollin, 2017).

Contemporary explanations for autism include positivist/realist positions, which maintain genetics and brain structure pathologies to be key determinants (Waterhouse, 2013; O'Dell *et al.*, 2016), to pragmatic/constructivist positions which maintain the importance of interacting environmental, social, and biological factors when conceptualising, defining, and diagnosing autism (O'Dell *et al.*, 2016; Hollin, 2017). There are also an increasing number of authors considering interpretivist, critical theories of autism, which embrace neurodiversity and refute the pathologising label of 'autism' altogether (Kapp, 2013; O'Dell *et al.*, 2016). Each of these philosophical positions can be associated with a different ontological, epistemological, and clinical conceptualisation of autism, and when poorly synthesised, add to the enduring 'uncertainty' of autism. Diagnosis often therefore depends on the professional perspective and conceptualisation of those involved in decision making, and is reported to be bound by the context in which the discussions and assessments take place (Ravet, 2011; Hollin, 2017).

Hollin (2017) has presented an article which provides a critical commentary on a loose thematic analysis of 20 interviews completed with researchers within the fields of cognitive psychology and social neuropsychology (Hollin and Pilnick, 2014; Hollin, 2017). Hollin aimed to examine how philosophical positions towards autism align around professional discipline and affect experience of autism research (Hollin, 2017). The thematic analysis was completed inductively with the themes being identified before the development of a semi-structured interview schedule (Hollin and Pilnick, 2014; Hollin, 2017). The subsequent analysis is then presented with a ‘critical reading’ of the literature around the five chosen thematic areas (Hollin, 2017). The theme areas chosen were: how participants came to be interested in the research topic; the nature of autism; the nature of participants’ current research; the impact of social neuroscience research; and the role that advocacy groups play (Hollin, 2017). Purposive and opportunity sampling was used to recruit the 20 participants from internet searches, colleagues within Hollin’s academic institution, and recommendations from others (Hollin and Pilnick, 2014; Hollin, 2017). The only criteria for participation were to be a current researcher with an interest in autism, neuroscience, and psychology, and be based in the UK (Hollin and Pilncik, 2014; Hollin, 2017). Hollin suggests that his critical review of the available literature and results from his thematic analysis show that practice around autism is permeated with epistemic and ontological uncertainty (Hollin, 2017). This means that professionals generally disagree on the origins of autism, and how to diagnose, assess, and treat the disorder (Hollin, 2017). Hollin suggests that the label of autism does not represent a discrete population of individuals, but a broad base of people with heterogenous needs (Hollin, 2017). He suggests that autism is also indeterminate and 'uncertain', evading description of a single core of needs by professionals from different disciplines (Hollin, 2017). Most relevant to this research, however, Hollin suggests that because autism is indeterminate and 'uncertain' in nature, it is presented and understood differently by professionals depending on their professional perspective and audience (Hollin, 2017). This suggests that EPs and paediatricians will hold different conceptualisations of autism because of their professional background, which may be changeable based on the context they are in and audience they are presenting to. The participants may therefore conceptualise autism differently when speaking within the MDT, to colleagues from the same profession, or to schools and families. Whilst Hollin's research provides an interesting critique of the available literature, with some weight given by the interviews completed with researchers from the different disciplines, his methodology and design are limited in terms the ability to generalise the subsequent findings. Hollin himself describes his interview process as having a 'great deal of flexibility' (Hollin and Pilnick, 2014 p. 281). The inductive thematic analysis and designing of a semi-structured interview based on prior reading may have limited the data obtained and subsequent findings (Cohen and Manion, 2002). Hollin does not outline the steps taken during the thematic analysis and he does not demonstrate fidelity to Braun and Clarke's (2006) model of thematic analysis (Braun and Clarke, 2006). This casts some doubt on the validity of his findings, suggesting that there may have been little objectivity during the process of analysis (Cohen and Manion, 2002; Braun and Clarke, 2006). The findings may have been more valid if the analysis were presented more broadly as a qualitative analysis of the data, or completed more rigorously through a discourse analysis of the interviews and available literature (Cohen and Manion, 2002; Braun and Clarke, 2006). The data collected were gathered between 2012 and 2013, and the changes in DSM and ICD categorisation of autism since then may have influenced the participants' research in autism (Hollin and Pilnick, 2014; Hollin, 2017). Hollin does not outline the attempts made to ensure an objective sample, and his discussion with colleagues within his institution combined with the development of an interview schedule based on his own critical reading of the literature may have resulted in some demand characteristics, where the same viewpoint is amplified between participant and researcher (Cohen and Manion, 2002). Despite this, Hollin provides an interesting critique of the available literature around conceptualisation, the ontological and epistemological claims of researchers working in the field of autism, and suggestions around practical implications for practice with consideration of external influencing factors (Hollin, 2017). As such, it is the critique he presents which is drawn upon in this research project to develop areas of exploration in the interview schedule and in consideration of the results. Many professionals have reported providing positive diagnoses for autism in the face of extreme clinical uncertainty (Skellern, Schluter and

McDowell, 2005). The multi-ontological and epistemological taxonomies and diagnostic perspectives surrounding autism suggest that a multi-philosophical and interdisciplinary approach is the most effective way to research, identify, and diagnose autism (Fitzgerald and Callard, 2017; Hollin, 2017).

The DSM and ICD conceptualisations of autism are broad with many professionals reporting that they see the DSM definition of autism as ‘unhelpful’, if not ‘dangerous’ (Frances and Widiger, 2012; Waterhouse, 2013). The DSM has been criticised for its lack of focus on patient symptoms, poor boundaries between syndromes, and inadequate use of neuroscience to inform diagnostic criteria (Waterhouse, 2013). As practitioners do not always strictly adhere to the criteria of the DSM when diagnosing autism, and given that the process of diagnosis is influenced by social factors whilst uncertainly permeates the conceptualisation, understanding, and diagnosis of autism; an examination of the processes that diagnosticians engage in is key (Rosenberg *et al.*, 2009; Waterhouse, 2013). The perspectives professionals hold are important determinants in terms of how they conceptualise, view and experience the presentations of autism and associated needs (Hollin, 2017; Ravet, 2011). Professional training and perspective will be a strong influencing factor in the formation of positions towards autism and the differences between professional groups supporting autism diagnosis should be considered.

2.2.8 Guidelines for Best Practice and Multi-Disciplinary Working in Autism Diagnosis

There are a variety of guidelines relating to ‘best practice’ for autism diagnosis, with many containing conflicting and contradictory information (Penner *et al.*, 2017). However, it is the National Institute for Health and Care Excellence (NICE) clinical guidelines, with its stipulation and focus on multi-disciplinary practice, that are the most salient for professionals in the UK (NICE, 2011; Penner *et al.*, 2017). Despite the known variability in autism and its indeterminant nature, there is currently no standardised approach to autism diagnosis across UK Health Trusts or Local Authorities encapsulated in policy or legislation (Parliament UK, 2009; Rosenberg *et al.*, 2009; NICE, 2014; Hollin, 2017).

The NICE Guidelines suggest a number of essential features of best practice for diagnosis. These include, the development of an Autism Team which consists of professionals from multiple disciplines with core membership including paediatricians, clinical/educational psychologists, and speech and language therapists; consideration of ‘complex mental health disorders’; attachment needs; collaborative working between colleagues; contextual consideration of development and symptoms; an awareness that scores on autism assessments may not mean that the child actually has autism; situational observation as a method of data gathering to inform diagnosis; psycho-educative watchful waiting as an assessment tool; and alternative explanations for symptom presentations (NICE, 2011).

The emphasis on multi-disciplinary working is clear. There is also the suggestion of bioecological exploration in the recommendations to consider alternative explanations of need and ‘watchful waiting’ (Bronfenbrenner and Morris, 2007; NICE, 2011). It is difficult to gain clarity in uncertain cases, consider bioecological needs, alternative diagnoses, or comorbid symptoms without multi-disciplinary working. However, research has shown that MDT diagnosis does not always take place (Penner *et al.*, 2017; Strunk, Leisen and Schubert, 2017). One of the main barriers to MDT working for autism is a reported lack of awareness of other disciplines (Strunk, Leisen and Schubert, 2017). Whilst this awareness of other disciplines is regularly built into academic research for autism, there have been several authors who have asserted the need for closer working relationships between professionals from medical communities and social sciences in relation to its diagnosis (Fitzgerald and Callard, 2017; Hollin, 2017; Strunk, Leisen and Schubert, 2017).

A purely positivist approach to diagnosis has been identified as a potential barrier to MDT practice, as it puts patients on a set procedure of quantitative assessments and potentially blocks more qualitative discussions between professionals who adopt different approaches to assessment and diagnosis (Strunk, Leisen and Schubert, 2017). This can potentially prevent consideration of alternative presentations of need (NICE, 2011). MDT working is reported to result in more holistic treatment and intervention plans with families reporting greater satisfaction following diagnosis from an MDT (Tobias, 2009; Strunk, Leisen and Schubert, 2017). Whilst assessment tools, such as the Autism Diagnostic Observation Schedule (ADOS), have a strong evidence base, there are enduring cultural and social factors to contend with in autism diagnosis, with diagnosis still relying heavily on clinical judgement (Hayes *et al.*, 2018). Autism is maintained to be a socially contextualised disorder, and thus requires a multi-perspective assessment of coping strategies, functioning, and bioecological need to ensure accurate diagnosis (Teague *et al.*, 2017; Hayes *et al.*, 2018).

2.2.9 Professional Perspectives and Multi-Disciplinary Teams

Autism and its multi-taxonomical nature lead to different interpretations depending upon the observer's philosophical position (Skellern, Schluter and McDowell, 2005; Fitzgerald and Callard, 2017). Those philosophical positions, often align around a professional perspective (Moore, 2005; Scotland, 2012; Scott and Briggs, 2015). Therefore an understanding of how these perspectives influence autism conceptualisation, clinical judgment, collaborative working, and the diagnostic process is important to ensure the feasibility, efficacy, and accuracy of MDTs (Fitzgerald and Callard, 2017; Hollin, 2017; Strunk, Leisen and Schubert, 2017).

There are emerging philosophical positions which conceptualise human behaviour, and specifically autism symptomatology and causes, as 'entangled', with authors suggesting that all perspectives need to be considered in both research and practice (Fitzgerald & Callard, 2015). Authors have maintained that whilst the terms 'epistemology' and 'ontology' are understood by most, what is required is a deeper understanding about the status of different claims to knowledge (Macleod, 2010). Fitzgerald and Callard suggest that emerging multidisciplinary networks, focussed on emotional and behavioural phenomena, should consider how their positions have influenced their practice in order to develop their collaborative working (Fitzgerald & Callard, 2015).

Research into personal epistemologies has found that people take implicit and explicit ontological and epistemological positions, both generally and in domain-specific areas, based on a number of influencing factors (Schraw, 2012). It is often assumed that this positioning process is rational. It has, however, been shown that this process is influenced by a number of varying factors, including emotional responses to the phenomenon in question, presence and perception of authority figures, and maturity and experience in the domain in question (Evans & Trotter, 2009; Schraw, 2012; Scotland; 2012). This is an important consideration, given the impact emotions and social dynamics can have on clinical judgement and diagnosis (Rosenberg *et al.*, 2009; Waterhouse, 2013). The emotional effect of epistemological and ontological positioning has been demonstrated in research with primary health-care workers, where it was found that when faced with uncertainty, the adoption of realist, positivist, medical approaches resulted in higher levels of stress whereas the adoption of pragmatic, biopsychosocial positions resulted in a reduction of stress, a pertinent finding given the uncertainty and multiple taxonomies of autism (Evans & Trotter, 2009; Hollin, 2017).

Evans and Trotter collected cross-sectional survey data from 78 primary care physicians, including 31 paediatricians, in the United States (Evans and Trotter, 2009). They were aiming to explore the link between the primary care physicians' epistemological position and their stress response when presented with uncertainty in a clinical setting (Evans and Trotter, 2009). They specifically looked at the difference in stress response between participants who adopted a medical epistemology or a biopsychosocial epistemology (Evans and Trotter, 2009). Evans and Trotter hypothesised that participants who adopted a biopsychosocial model would experience less stress around uncertainty because their conceptual model would encompass more of the potential problems that patients may present to them in clinical settings (Evans and Trotter, 2009). They assessed the participants' epistemological beliefs using the Physician's Belief Scale, a standardised measure of epistemology that uses Likert-type questions to assesses physicians' attitudes around hypothetical case examples and statements (Ashworth, Williamson and Montano, 1984). The Physician's Belief Scale has reportedly been standardised for modern cohorts and holds internal content and construct validity (Evans and Trotter, 2009). Evans and Trotter also used two subsets from another standardised assessment for physicians to measure their response to stress and uncertainty in clinical settings taken from the Physicians Reactions to Uncertainty Scale (Evans and Trotter, 2009). They completed a bivariate analysis to measure the relationship between epistemology and stress reactions, and a multivariate regression analysis to examine the relationship between epistemology and stress reactions while controlling for gender, specialism, and level of experience

(Evans and Trotter, 2009). They found that the adoption of a purely medical model was associated with an increased response to stress when faced with clinical uncertainty with a high level of significance (P=<0.001) (Evans and Trotter, 2009). They also found that being female was associated with a higher stress response, and that paediatricians were the only group of specialists that showed a significantly higher stress response when faced with uncertainty compared to the other groups (P=<0.001) (Evans and Trotter, 2009). The statistical power and demographic similarity of the participants in Evans and Trotter's research has significant implications for this research project and the consideration of the results (Evans and Trotter, 2009). As all of the participants are female and half of the participants are paediatricians, it may be that they are more likely to experience high levels of stress when faced with indeterminate autism compared to peers from different disciplines and specialisms (Evans and Trotter, 2009; Hollin, 2017). However, Evans and Trotter's (2009) research is potentially limited due to its small sample size and recruitment of participants from the United States, meaning that the findings might not be applicable to paediatricians from the United Kingdom who may hold different epistemological positions (Evans and Trotter, 2009). A strength of this research is its use of standardised measures which help to give weight to statistically significant findings. However, because epistemology is abstract and often conceptualised in relation to real world phenomena, it is difficult measure and the validity of assessment tools cannot always be ensured (Scott and Briggs, 2015). The survey data gathered are also limited in their transferability because of the cross-sectional design and potential for distortion in self-reported measures

(Cohen and Manion, 2002). The data obtained by Evans and Trotter were gathered from an opportunity sample and may not be applicable in other contexts (Cohen and Manion, 2002; Evans and Trotter, 2009). However, the demographic similarities of this study, and the demonstrated relationship between epistemology, professional role, and stress make Evans and Trotter's findings important to consider in the analysis of the data obtained in this research project, particularly when considering the impact of the medical and bioecological perspectives on the participants' experiences.

2.2.10 The Medical Perspective

The medical profession has been founded on, and continues to utilise, the realist, positivist paradigm (Evans and Trotter, 2009; Bunniss and Kelly, 2010; Scotland, 2012; Oppong, 2014). The aim of the positivist paradigm is predictability through correlation (Scotland, 2012). Whilst this may often illuminate trends and help for object standardisation, it can miss the true cause of a behaviour, or phenomenon, by conflating correlation with cause (Scotland, 2012). The idea of generalisation is reportedly difficult to apply to behaviour and mental attributes and is potentially flawed when not considered within the social context and individual's experience (Scotland, 2012). The measurement and predictability inherent in the positivist paradigm are also said to eliminate the need for responsiveness to patients as trends and patterns can be observed without interaction (Scotland, 2012). It could therefore be suggested that autism diagnosis from a purely medical standpoint runs counter to suggestions made in NICE Guidelines (NICE, 2012).

The medical model defines disability and illness, both physical and mental, in terms of deviation from ‘normal’ functioning (Barnes and Mercer, 2011). The medical model takes an individualist approach maintaining that the functional limitation of impairment reflects disability and illness in its totality (Barnes and Mercer, 2011; Coleman-Fontain and McLaughlin, 2013). The empirical processes implicit in the medical model have led observers to classify deviance to develop diagnostic criteria (Barnes and Mercer, 2013; Shakespeare, 2006). This has led to assumed homogeneity across constructs of additional need, which may mean that purely medical-based diagnosis for autism is inappropriate given its reportedly ‘entangled’ nature (Fitzgerald and Callard, 2017).

The medical perspective is reported to perpetuate an ‘expert’ model, with professionals who seek objective insight into the ‘problem dimension’ (Barnes & Mercer, 2013; Shakespeare, 2006). This may be challenging in an era when child-centred approaches and the views of parents are increasingly valued during the diagnostic process for autism (Russell and Norwich, 2012).

2.2.11 The Professional Perspective of Educational Psychology

The epistemological and ontological positions of educational psychologists have changed significantly in the past two decades (Greene *et al*., 2018; Moore, 2005). Previous authors have promoted a strong emphasis on interpretivist positions in educational psychology practice, whilst more recent authors have maintained the value of philosophical pragmatism (Moore, 2005; Burnham, 2013). The interpretivist or socio-constructivist philosophical positions often held by psychologists are maintained to be useful, as they allow for the consideration of multiple perspectives to uncertain problems (Moore, 2005; NICE, 2011; Fitzgerald and Callard, 2017; Hollin, 2017; Strunk, Leisen and Schubert, 2017). However, other authors have criticised the adoption of strong socio-constructivist or interpretivist positions as professionals maintaining this position can often assert that there are no common narratives across perspectives when this viewpoint is taken to the extreme (Macleod, 2010). Knowledge produced from the interpretivist perspective is also criticised for its limited transferability, as it is not integrated into a 'unified coherent body' (Scotland, 2012, p.12). Its de-constructivist nature may also be an obstacle to finding satisfactory conclusions and devising ways forward during diagnosis (Scotland, 2012). Increasingly, EPs hold a pragmatic, philosophical perspective, spanning the philosophical chasm between interpretivism and realism, which can perhaps be most accurately described as a critical realist perspective (Burnham, 2013; Scott and Briggs, 2015). This perspective allows for encapsulation of all the philosophical positions which may aid diagnosis and allow for the development of effective treatments and interventions (Scott and Briggs, 2015). EPs' consideration of psychoeducational approaches is maintained to be an important aspect of separating out and understanding co-morbid conditions associated with autistic additional needs (Lorh & Le, 2012). Educational psychologists are reported to feel a need to make their work seem 'scientific' and can feel anxious or hesitant around sharing their work and formulations if they feel that their contribution does not fit into a realist framework (Burnham, 2013).

EPs are maintained to be key professionals involved in the diagnosis of autism (NICE, 2011). The role of EPs is also reportedly valued by parents whose children do receive an autism diagnosis (Tobias, 2009). Despite this, the role of EPs in autism diagnosis is not defined in the 2015 Autism Act or the current Code of Practice (DfE, 2014; DoH, 2015).

2.2.12 The Bioecological Perspective and Educational Psychology

A key part of the EP perspective is a bioecological approach to child development (Bronfenbrenner, 1979; Kelly, Woolfson and Boyle, 2008). The bioecological approach considers the individual and their presentations as a part of their environment and is often aligned with a broader socio-constructivist perspective (Bronfenbrenner, 1979; Kelly, Woolfson and Boyle, 2008). Professionals who hold bioecological perspectives may be more likely to refuse diagnostic labels in favour of formulations and explanations focussing on the individual and their interactions within their environment and development over time (Bronfenbrenner, 1979; Kelly, Woolfson and Boyle, 2008; Algraigray and Boyle, 2017).

Whilst Bronfenbrenner's original 1979 ecological theory is reportedly preferred by EPs, it is notoriously misused across academic and professional settings (Kelly, Woolfson and Boyle, 2008; Tudge *et al.*, 2016). Bronfenbrenner made significant revisions to his original model of development and it will be important to consider how both the EPs and paediatricians apply this perspective during their autism-related casework (Rosa and Tudge, 2013). Earlier versions of Bronfenbrenner's model refer to five levels of context which operate at different systemic levels (Bronfenbrenner, 1979). **Table 1** below outlines the five levels of context included in both Bronfenbrenner's original ecological systems theory and bioecological model of human development (Bronfenbrenner and Morris, 2007).

Table 1 Bronfenbrenner's Bioecological Model of Development - Adapted from Rosa and Tudge (2013)

Level of Context	Description
Microsystem	The microsystem is the direct environment where a child lives. Their family, friends, classmates, teachers, neighbours and other people who they have direct contact with are included in their microsystem. The microsystem is the setting in which they have direct social interactions with these social agents. The theory states that children are not mere recipients of the experiences they have when participating in the microsystem environment but are contributing to the construction of the environment in a two-way process.
Mesosytem	The mesosystem involves the relationships between the microsystems in a child's life. This means that a child's family experience may be related to their school experience. For example, if a child is neglected by his parents, they may have a struggle to develop a positive attitude towards their teachers.
Exosystem	The exosystem is the link between the context where the child is actively participating and where they do not have a role. For example, the impact of parental employment on the child's development. They do not participate in the parent's employment but do interact with the parent whose employment status will affect their development.
Macrosystem	The macrosystem setting is the culture of an individual. The cultural context includes the socioeconomic status of the child's family, their ethnicity or religion and other wider cultural factors. The macrosystem is observed through activity such as praying.
Chronosystem	The chronosystem includes the transitions and shifts over a developmental lifespan and beyond. This may also include the socio-historical contexts that can influence a person. For example, divorce as a major life transition over time.

The later versions of Bronfenbrenner’s model focus on Proximal Processes, Person, Context and Time (PPCT), rather than the 5 levels of context outlined above (Rosa and Tudge, 2013). Bronfenbrenner suggested that child development was most heavily influenced by Proximal Processes, which were described as reciprocal interactions between the child and people and objects in their environment (Bronfenbrenner and Morris, 2007). Bronfenbrenner maintained that the closer the emotional bond of the people participating in these Proximal Processes, the greater the effect (Bronfenbrenner and Morris, 2007). For example, parent-child interactions would be maintained to have a greater effect on a child’s development compared to the interactions of a child with their aunt or uncle. Person, refers to the character of the persons interacting with the child (Bronfenbrenner and Morris, 2007; Rosa and Tudge, 2013). The Person can either hold disruptive or generative characteristics which impact child development (Bronfenbrenner and Morris, 2007; Rosa and Tudge, 2013). Generative characteristics tend towards delayed gratification, self-regulation, and a calm disposition, whereas disruptive characteristics tend towards, impulsiveness and aggression (Bronfenbrenner and Morris, 2007; Rosa and Tudge, 2013).

Context refers to the micro-, meso-, exo-, and macrosystems described in **Table 1** (Bronfenbrenner and Morris, 2007; Rosa and Tudge, 2013). Bronfenbrenner makes the assertion that assessment of child development should take place across multiple contexts to ensure accuracy (Bronfenbrenner and Morris, 2007; Rosa and Tudge, 2013). This suggestion echoes recommendations in ICD-11, DSM-5, and NICE criteria and recommendations for diagnosing autism (NICE, 2012; APA, 2013; WHO, 2019).

The time element in Bronfenbrenner's bioecological model is similar to the chronosystem outlined in **Table 1** (Bronfenbrenner and Morris, 2007; Rosa and Tudge, 2013). This has potentially important implications for autism diagnosis in terms of assessment in single clinic sessions and consideration of a response to intervention. This perspective on time and its influence on development may result in some tension when contrasted with the medical view of categorisation for diagnosis (Hirvikoski *et al.*, 2015). The bioecological model is perhaps most similar to the emerging 'entangled' view of autism (Bronfenbrenner and Morris, 2007; Fitzgerald and Callard, 2017). Given this perspective, its alignment with diagnostic criteria, and the reported adoption of these values by EPs, it will be important to examine how the participants draw upon this perspective, and how it is contrasted with a medical perspective, when they are discussing their casework and experiences of the diagnostic process.

2.3 Summary

The constructing process for autism is complex. Individuals' conceptualisations are influenced by their professional perspective, diagnostic criteria, legalisation, desired outcome of stakeholders and more. The literature outlined above highlights the significant changes that have taken place around diagnostic criteria, the impact of diagnosis on individuals and their families, and the complexities surrounding MDT diagnosis.

There is a need for a considered exploration of how professionals diagnosing autism construct and conceptualise autism and how these underlying assumptions affect their diagnostic practice. There are authors who advocate the explicit consideration of how professional perspective impacts the process of multi-disciplinary work, research, and autism casework in general within both the medical and educational psychology professions (Bunniss and Kelly, 2010; Hollin, 2017; Ravet, 2011).

Chapter 3: Methodology

3.1 Overview

In this chapter the theoretical underpinnings and assumptions of the current research project will be examined. This chapter will include information on participant selection and the data collection methods used. Data were obtained from semi-structured interviews and analysed using thematic analysis. This chapter will also contain a justification as to why this analytical framework was chosen for the current data set. This chapter will conclude with reflections on the ethical implications of the research and how reliability and validity were addressed within the research design.

3.2 Philosophical Position

All research is underpinned by philosophical assumptions (Cohen and Manion, 2002). These assumptions are intrinsically linked to the style of research, the data sought, the methods employed, and often the conclusions reached. The ontological and epistemological stance of the present research must therefore be considered (Thomas, 2009).

This research is conducted within an interpretivist paradigm and is therefore underpinned by constructivist philosophy. Interpretivism explores culturally and historically situated interpretations of the social world and is mindful of the context within which claims to knowledge are made (Cohen and Manion, 2002).

The present research has a phenomenological focus within its interpretivist paradigm and is concerned with how people experience and make sense of the world around them (Moran, 2004). Phenomenology promotes reflection on experience so that new understanding and insights might be obtained through the research process (Moran, 2004). This is completed with the expectation that data related to quantity and causal explanations will not be obtained (Moran, 2004). These type of data are eschewed in favour of deeper exploration of individuals' processes of understanding and developing meaning (Moran, 2004).

The interpretivist paradigm maintains that reality is socially constructed and rejects the notion than an objective reality exists. This assertion is made in favour of the view that multiple constructions of the same experience can happen at the same time (Cohen and Manion, 2002). The role of the researcher within this paradigm is to be an interpreter of these individual constructions in order to gain a deeper level of understanding and knowledge from the subject (Cohen and Manion, 2002).

3.3 Methodological Position

3.3.1 Qualitative Approaches

Qualitative research aims to enrich our understanding of the phenomenon being explored by eliciting deep, descriptive data (Cohen and Manion, 2002). This aligns well with the aims of this research to explore the perspectives and experiences of the participants. Tindall (1994) has suggested that qualitative research is:

> '…theory generating, inductive, aiming to gain valid knowledge and understanding by representing and illuminating the nature and quality of people's experiences' (Tindall, 1994, p.142).

This also aligns well with the thematic analysis adopted in the present research with its inductive approach and endeavour to explore and examine the nature of the participants' experiences. A qualitative research design is deemed an appropriate choice for this study as quantitative methodology, associated with the positivist paradigm, would not have enabled the rich, meaningful and experiential views of the participants to be captured in the data.

Interpretative phenomenological analysis (IPA) was initially identified as the appropriate qualitative methodology to explore the participants experiences, and sense and meaning-making processes related to autism and MDT diagnosis. However, after further exploration it was decided that the data obtained from the semi-structured interviews did not have enough of an idiographic focus to be analysed effectively using IPA (Smith, Larkin and Flowers, 2009). Whilst the data obtained did contain some reflection from the participants on their 'lived experiences', the data also contained reflections on systemic influences and the structures which they are embedded in. It was therefore decided that thematic analysis (TA) would be a more appropriate method of analysis which would still be congruent with the aims of this research.

3.3.2 Thematic Analysis

Thematic analysis (TA) is a flexible approach to qualitative data analysis that aims to describe data by examining the connections between themes (Braun and Clarke, 2006). TA is more flexible than other approaches as it is not bound to an a priori theoretical method, like IPA or discourse analysis (Braun and Clarke, 2006). TA focusses on the context of the data obtained from the participants and the socio-cultural factors which may have influenced their perceptions (Braun and Clarke, 2006).

There are two main types of thematic analysis delineated in the literature (Braun and Clarke, 2006). Semantic analysis focusses on developing themes from the 'surface level' of the data by looking at the meaning of the words that the participants have said (Braun and Clarke, 2006). Latent analysis takes a more interpretative approach to analysis and looks at:

'…the underlying ideas, assumptions, and conceptualisations – and ideologies – that are theorized as shaping or informing the semantic content of the data.' (Braun and Clarke, 2006, p.84)

Latent analysis is chosen for this research project due to the stated aims to explore the professional perspectives of the participants, their conceptualisations of autism, and how these have influenced their experiences in relation to autism diagnosis and MDT working.

TA is inductive and places emphasis on the role that the researcher plays in interpreting and drawing out themes from the data (Braun and Clarke, 2006). Braun and Clarke discuss the role of the researcher in the development of themes and analysis of the data. They suggest that the researcher cannot be separated from this process and dismiss the idea that themes ‘emerge’ from sets of data and that the researcher’s role is to give participants a ‘voice’ (Braun and Clarke, 2006). Instead they recognise that the themes will be dependent on a number of different factors, including, the identity of the researcher, and what the research aims to explore, analyse, and discover (Braun and Clarke, 2006). They encourage the researcher to consider these choices as decisions in the research, and for the researcher to reflect on their process of analysis in the final write up (Braun and Clarke, 2006).

There has been some discussion as to whether TA is an experiential or critical approach to qualitative research. This is reflected in part in the discussion around the semantic and latent approaches within TA (Braun and Clarke, 2006; Braun and Clarke, 2014). The experiential approach to TA aims to capture the participants’ experiences and perspectives by exploring their personal accounts of phenomena (Reicher, 2000). This perspective within TA reflects the latent analytical approach, viewing language as representative of internal understanding and thought processes. Critical approaches view language as more essential in nature, and view language as a type of social action (Braun and Clarke, 2014). A latent and experiential approach to TA will be adopted in the current research to explore the participants' experiences and sense-making processes related to autism and its diagnosis.

3.3.3 Semi-structured Interviews

To collect the rich data required for TA, focussed semi-structured interviews were conducted in line with the epistemological orientation of the research protect. This enabled open-ended questions to be asked of the EPs and paediatricians to draw out, discuss, and gain deeper insight into their perspectives and experiences. There are a number of benefits to using semi-structured interviews in exploratory research. The researcher is able to build rapport with the participants, ask follow-up questions, respond reflexively to new avenues or topics of interests, and clarify points made. This data collection method fits with the view of the researcher as a dynamic influencer on the data obtained and interpretations made (Cohen and Manion, 2002).

The individual approach to the semi-structured interviews completed allowed for more personal disclosure by the participants. This is deemed an appropriate methodological choice as focus group interviews may have not yielded this kind of rich data from the participants (Smith, 2004). This is an important consideration given the two professional groups interviewed. Whether interviewed as a whole, or in separate groups, there would have been the potential for conflict, conformity, and inhibition which may have resulted in a reduction in the diversity of results obtained (Smith, 2004).

Some authors describe participants as the primary experts within research (Cohen and Manion, 2002), and semi-structured interviews provided a data collection technique that gives participants the time and opportunity to reflect in depth on their beliefs and experiences. The process of reflection in the semi-structured interview enables the exploration of multiple perspectives, the development of understanding related to experience, and fits with the interpretivist perspective of this research project (Robson, 2011).

The relative strengths and weaknesses of the semi-structured interview for the current research project are included in **Table 2** below.

Table 2: The Strengths and Weaknesses of Semi-structured Interviews, adapted from Cohen and Manion: *Research Methods in Education* (2003)

Strengths and Uses	Weaknesses and Limitations
Positive Rapport It is suggested that semi-structured interviews can be used to build positive rapport with participants to elicit rich detailed data. Given that the researcher had prior familiarity with the participants, this strength of semi-structured interviewing was limited. However, the semi-structured interview format did allow for more in-depth exploration away from the questions included in the interview schedule.	The conversational tone that can be struck when using a semi-structured interview method was, at times, limiting. The researcher's familiarity with the participants was, at times, a hinderance to data collection due to their ongoing work around multi-disciplinary diagnosis. It may have been that because of this, the participants were not able to voice their opinions as strongly as they would have if they had not known the researcher.
High Validity The participants were encouraged to reflect on their experiences of autism diagnosis in great detail. The semi-structured interview format allowed the researcher to query statements and draw out data. This helped to ensure that the data collected could be analysed effectively to answer the research questions. This likely helped to ensure that valid data were captured.	**Validity** Semi-structured interview schedules are a flexible technique for collecting qualitative data. As a result, the conversations with the participants varied significantly. This meant that some topics were not discussed with all of the participants and the depth of the discussion was not consistent across all topics. This has an impact on validity compared to more restrictive data collection methods where uniformity of data is ensured.
Complex Questions Can be Discussed and Clarified The semi-structured interview schedule allowed for exploration of complex topics and questions. This was useful in helping to achieve the research's aims of examining the participants' conceptualisations of autism and their experience of diagnosis. The semi-structured format also allowed for the researcher to probe hesitance or uncertainty to ensure that detailed data could be obtained.	**Reliability** Unfortunately, true reliability cannot be ensured in semi-structured interviews due to the unique content of each conversation. Measures were taken to ensure that the data collected were as reliable as possible. This included reflecting on each interview after it had taken place in order to help guide the researcher's interviewing technique with the next participant.

3.4 Method

3.4.1 Sampling

The participants for the research were identified through a purposive sampling technique. In purposive sampling, participants are identified for their specific interest in, or experience of, a particular phenomenon (Robson, 2011). The research required both EPs and paediatricians who had attended an MDT panel for autism diagnosis which had been set up in a major urban city. There was no limit to the amount of time the participants had to have been employed by their respective professional group. However, all participants were required to have attended at least one MDT meeting and currently be employed by either the NHS or local city council Educational Psychology Service.

Representative sampling would not have been appropriate for this research as a reflection of the general population would not have resulted in the experience-based data required for the analysis.

3.4.2 Participants

The current research required a small sample of participants to enable deep, rich data to be captured rather than large data from multiple sources.

A lead practitioner for the paediatricians was identified through the researcher's regular attendance of the MDT meetings. An email was sent to the lead practitioner with a request to contact other paediatricians who had attended the panel. An email was also sent to an identified group of EPs who had attended the discussion panels. Included in each email was an overview of the research aims, with information for participants, and details to contact the researcher to express their interest (**Appendix 2**).

Six participants were identified to take part in the research: three EPs and three paediatricians. The three paediatricians all worked within the same team. Two of the EPs worked within the same team whilst another was recruited from a different team within the same service. The recruitment of the EP from a separate team took place because they were identified as having had the most extensive experience of the autism MDT meetings. It was hoped that their more extensive experience would result in richer data that would enable a deeper level of analysis compared to less experienced potential participants.

All of the participants were female and of a similar age. At the time of obtaining consent, more specific individual and demographic information was not collected. This means that unfortunately further commentary on the identity of the participants, and how this may have impacted upon this analysis, cannot be made. No attempts were made to represent either professional group as a whole. However, the gender imbalance does reflect broad trends nationally across each professional group (Children's Workforce Development Council, 2008). The participants were of mixed ethnic heritage with two Asian paediatricians taking part, one Caucasian paediatrician, two Black educational psychologists, and one Caucasian educational psychologist. All had been qualified for a similar length of time and had been practicing within the same city for a similar period.

3.4.3 Data Collection

3.4.3.1 Semi-structured Interviews

The participants were each interviewed in a single session lasting for approximately one hour. The interviews took place either in the EPs' respective offices, or for the paediatricians, in the community paediatricians' hub. The interviews were audio recorded to be transcribed later. The recordings were numbered at the point of transcription.

Semi-structured interviewing can be a dynamic and interactive way of collecting rich qualitative data (Robson, 2011). Other authors have described semi-structured interviews as conversations with structure and purpose (Dawson, 2002). The interviews utilised a number of predetermined questions (**Appendix 4**). Each interview started with a vignette to contextualise the discussion that followed. The interview schedule was designed to help ensure that the conversation could flow and rich data, focussed on the research topic, could be collected. The use of a schedule also helped to ensure the internal validity of the interviews.

Allowing some deviation from the interview schedule helped to promote open reflection and discussion. Ordered sets of questions can potentially limit the responses participants give and can prevent deep reflection on the phenomena being discussed (Smith, Larkin and Flowers, 2009). The interview questions were open ended and designed to elicit in-depth reflections from the participants on their experiences and sense-making processes.

The questions included in the semi-structured interview schedule were directly linked to the research questions. This ensured that the data gathered were relevant and valid. The participants were read a vignette before the first research question. This helped to frame the subsequent discussion, ease the participants into questioning, and increase the internal validity of the semi-structured interviews (Cohen and Manion, 2002). The broad open-ended question first asked in the interview allowed the participants to take the discussion in a direction of their choosing and talk at length whilst giving them some structure and guidance (Smith, Larkin, and Flowers, 2009).

A degree of rapport had already been built and maintained with the participants chosen for the research project. The researcher had attended many of the MDT discussion meetings and had completed 1-1 discussions with both the EPs and paediatricians during previous working arrangements. Whilst in some ways this may have helped to facilitate the discussion, it was important to consider how this may have negatively influenced the interview and data obtained (Cohen and Manion, 2002). There were interprofessional boundaries and power dynamics to consider when completing the interviews and the researcher had to be sensitive to ongoing professional dynamics during the interviews (Robson, 2011). This further justifies the interpretivist approach adopted for this research. To help ensure appropriate discussion and rapport throughout the interview, the researcher remained aware of the participants' verbal and non-verbal behaviours. This was done with a view to ensuring that the researcher was demonstrating empathy and sensitivity to the participants. The research also ensured that they maintained their role as an active and enquiring listener (Cohen and Manion, 2002). Consideration of the impact of being a research practitioner is discussed in **Section 5.6**.

3.4.4 Data Analysis

3.4.4.1 Thematic Analysis and Thematic Networks

Thematic analysis, and subsequent thematic mapping, was used in this research project and applied to the transcription data obtained from the semi-structured interviews (Rubin and Rubin, 2005; Braun and Clarke, 2006; Robson, 2011). Thematic analysis is a model for identifying, analysing and reporting themes and subthemes from a chosen data set (Braun and Clarke, 2006). The analytical method developed by Braun and Clark contains five phases and takes an inductive, ‘bottom up’ approach (Braun and Clarke, 2006). Thematic network analysis involves the development of thematic maps to visually represent the rich data obtained from analysis (Attride-Stirling, 2001). A full worked example of the thematic analysis completed for this research project is included in **Appendices 5-11**.

Braun and Clarke clearly outline the process required to complete thematic analysis (**Table 3**). They have published several research papers considering the theoretical and methodological issues relating to thematic analysis, exploring the importance of ‘thematising meaning’ by using thematic coding (Braun and Clarke, 2006; Virginia Braun and Victoria Clarke, 2014). Braun and

Clarke assert the importance of the analyst as an active agent in the decision-making process for developing themes (Braun and Clarke, 2006). This fits with the interpretivist paradigm in which the present research takes place. Both thematic analysis and hermeneutics assert the importance of researcher reflection on their analytical process (Braun and Clarke, 2006; Finlay, 2014). Thematic analysis from a socio-constructivist perspective allows for a focus on the social and cultural influences on the participants and the data they share, rather than a purely individual psychological focus.

Thematic analysis is a widely used tool in qualitative research (Braun and Clarke, 2006). Braun and Clarke outline a step-by-step approach to completing TA and have written about its specific application to psychology research (Braun and Clarke, 2006). Their 15-point checklist for completing TA is outlined below and includes a discussion and outline of the analysis process during this research project.

Table 3: 15-point Checklist for Completing Thematic Analysis Including Discussion and Steps Completed (Braun and Clarke, 2006)

Process	**Step**	**Criteria**	**Discussion and Steps Completed**
Transcription and familiarisation with the data	1	The data have been transcribed in detail, the researcher has familiarised themselves with the data through reading and rereading of the transcripts, noting down initial ideas.	Braun and Clark suggest that the aim of this phase is to become ‘intimately familiar’ with the data collected (Braun and Clarke, 2012). Whilst there is some flexibility around the format that this can take, they suggest making notes of initial observations on both the individual data set and entire data corpus (Braun and Clarke, 2012). This was completed with brief notes being made after several read-throughs of each transcript. See Appendix 5 for an example transcript with notes. These initial notes needed to relate to the research questions being asked and formed the basis for the first codes generated (Braun and Clarke, 2012).
Generating codes and searching for themes	2 3 4	The entire data set is given equal attention in the coding process. The coding process is thorough, inclusive and comprehensive. Codes are collated into potential themes. Themes are checked against each other, and against the original data set.	This phase marks the beginning of the systematic analysis of the data. Coding is a way of describing the content present in the data (Braun and Clarke, 2012). As previously mentioned, there are two types of analysis which can be applied at this phase: semantic and latent coding (Braun and Clarke, 2006). Semantic coding is often more descriptive and observational, and focussed on the words, and their meanings, that the participants have said (Braun and Clarke, 2006). The researcher started with semantic coding during this

	5 6	Review themes to check if themes work in relation to the coded extracts, and the entire data set, generating a thematic map of analysis. Themes are internally coherent, consistent and distinctive. Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.	phase, as this seemed like a more obvious start to describing the data. They then continue with latent coding where they took a more interpretive approach to analysing the data. Latent coding looks beyond the words themselves and seeks deeper meaning from the data (Braun and Clarke, 2012). The justifications for these interpretations are shared in detail during the results and discussion section of this report.
Analysis	7 8 9 10	Data have been analysed, interpreted, made sense of – rather than just paraphrased or described. Analysis and data match each other –selection of vivid, compelling extracts, examples to support the analysis. Analysis tells a convincing and well-organised story about the data and topic. Analysis and extracts are linked to the research questions and literature to produce a scholarly report of the analysis.	Braun and Clarke maintain that the goal of thematic analysis is to tell a story about the data that you are presenting (Braun and Clarke, 2006). They suggest that this begins in phase 3 of the analysis when searching for themes. During this phase the researcher was active, choosing which codes were collated into themes (Braun and Clark, 2012). There needs to be clarity from the researcher during this phase, making explicit the inductive approach to theme generation. In this research project an inductive approach, drawing out themes from the available data, was taken (Braun and Clarke, 2006). However, this is partially informed by the pre-existing literature around contemporary debates and issues in autism and its diagnosis. There is a hermeneutic element to this phase of analysis, where the researcher is asking why they are choosing the themes that they have.

			The process of developing a theme involved clustering codes together to identify meaningful patterns within the data (Braun and Clarke, 2006). This was completed with reference to research questions being asked. During this phase the codes were considered to see which codes overlapped (Braun and Clarke, 2012). When codes overlapped significantly this suggested the development of a sub-theme (Braun and Clarke, 2006). Braun and Clarke suggested that during this phase sub-themes are not discarded and are all considered in relation to the more super-ordinate themes that may be developed later (Braun and Clarke, 2006). The process of deleting or discarding sub-themes can be completed in the next phase (Braun and Clarke, 2012). There is a back and forth process during these phases, as outlined in steps 4-6 in Table 3, where the researcher went back and forth across the data set comparing the generated sub-themes across all of the transcripts. During this phase the researcher considered which sub-themes clustered around each professional group and which sub-themes were common across all participants. Where sub-themes clustered, both within and across professional groups, they were considered for inclusion within the major themes analysed from the data. As the connections between sub-themes become more obvious during

			this phase, they can be considered and linked using ‘thematic networks’ (Attride-Stirling, 2001). This can be presented visually through the use of ‘thematic maps’ (Braun and Clarke, 2006). This visual linking of themes is a useful way to explore and demonstrate the links between the various sub-themes identified and more overarching themes developed from the data. See **Figure 1**.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over light approach.	During this phase the researcher aimed to synthesise and clarify the codes, sub-themes, and themes they have developed, ready to present their final analysis of the data (Braun and Clarke, 2012). There are two levels to this process (Braun and Clarke, 2006). Firstly, the researcher reviewed the data extracts at the level at which they were coded (Braun and Clarke, 2006). This ensures that there is coherence between the initial description of the data, codes, themes and overall analysis. Secondly, the themes were considered in relation to the entire data set (Braun and Clarke, 2006). This ensured that the themes were an accurate representation of the data that had been collected. Braun and Clarke offer a word of warning during this phase, suggesting that this process can be infinite, and the researcher will need to be disciplined to ensure that they are keeping their themes relevant and contained around their research questions (Braun and Clarke, 2012).

Written Report	12 13 14 15	The assumptions about, and specific approach to thematic analysis are clearly explicated. There is a good fit between what you claim to do, and what you show you have done – i.e. described method and reported analysis are consistent. The language and concepts used in the report are consistent with the epistemological position of the analysis. The researcher is positioned as 'active' in the research process; themes do not just 'emerge'.	Once the major themes and sub-themes have been identified and thematically networked into a thematic map, the researcher then needs to interpret and report their findings (Braun and Clarke, 2006). In this research project the questions were phenomenological in nature and related to the participants' beliefs and perspectives. This helped to focus the interpretation on the aims and research questions of the project. These interpretations are also placed within the broader social context. This fits well with the research project's aims and socio-constructionist perspective. The findings, and the discussion of them, are presented in Chapter 4. This includes an overview of the overarching themes, main themes, and sub-themes identified.

A fully worked example outlining the researchers process for completing the 5 Phases of Thematic Analysis is included in

Appendices 5-11.

3.4.4.2 Reflexivity

It is important to consider one’s own background, beliefs, and assumptions as a part of reflexivity when conducting TA (Braun and Clarke, 2019). In thematic analysis, the researcher is considered an active agent in deciding how the analysis of data progresses, including how the codes, themes, and subsequent commentary is delivered to the reader. The researcher for this project was, at the time of collecting and analysing the data, a 29-year-old male trainee educational psychologist. The researcher had been participating in multi-disciplinary discussion panels with paediatricians for around 6 months before the research project began. This involved collecting EP feedback and discussing potential diagnoses with the paediatricians when presented with ‘uncertain’ sets of symptoms. This was both a challenging and rewarding experience. There were times when there was a clear difficulty in communicating from a different professional perspective. This was often most evident when the researcher was observing other EPs and paediatricians discuss cases. There was a sense of the two professionals trying to find common ground for discussion. This experience helped to prompt the researcher to form the research project.

The researcher held the value of inclusion and the implicit assumptions of the bioecological approach discussed throughout this research project. However, it is important to consider the researcher’s family background as both of his parents were actively employed in the NHS at the time of completing this project. The researcher had an interest in the process of diagnosis with his father holding a lecturer’s position, alongside a practicing role, as a biochemist. This background of positivist science in his family led the researcher to question the strong interpretivist approach often delivered in his training as an educational psychologist. This may have meant he was more positively disposed to supporting medical diagnosis of additional needs compared to other EPs.

The researcher has a personal passion for supporting teenage boys with additional needs. He was often concerned that for this demographic their social and emotional needs could be pathologised and conceptualised as ‘within child’ disturbances, rather than a failure to meet their broader bioecological needs. This led to tension between his predisposition to support diagnosis and desire to support those with additional bioecological needs.

When the researcher began his educational psychology placement, he was intrigued by the often-conflicting approaches of medical professionals and educational psychologists around autism diagnosis. He was keen to explore how positivist science and interpretivist approaches could be synthesised to ensure accurate assessment of additional needs.

Reflecting on his underlying assumptions, the researcher concluded that he held the belief that autism was often over diagnosed. He began to ask why he thought this overdiagnosis had occurred and began a review of the literature. This assumption directly fed into the research questions for this project. The researcher, reflecting on his own personal philosophical positions, considered himself a critical realist. He held that whilst there were many individual interpretations of reality, there would also be an unchangeable objective truth (Guyon *et al.*, 2018). He hoped to explore in the research the common ground between the EPs and paediatricians to examine potential ways of synthesising the two, at times, opposing perspectives.

As a professional relatively new to the field of educational psychology, the researcher was aware of his inexperience compared to his colleagues and his gender's underrepresentation in his profession, and in paediatric medicine. This likely had an impact on the interviews which took place, all with more experienced female colleagues. The researcher was keen to ensure uniformity across the interviews but did have different levels of familiarity with the participants. This could have affected the data collection with more in-depth data potentially being collected from participants the researcher had more familiarity with. These issues were addressed with an attempt to respond sensitively to the dynamics within the semi-structured interviews and with active reflection after each interview had taken place in order to prepare for the next participant (Robson, 2011).

3.4.5 Validity and Reliability

It is important to ensure validity and reliability in all research that is conducted (Cohen and Manion, 2002). However, many authors argue that these are terms most often associated with quantitative approaches and do not apply to qualitative research (Smith, 2003). These terms require some interpretation to be applicable to qualitative and interpretivist research aims (Smith, 2003).

Yardley (2008) developed a framework of principles to evaluate the validity of qualitative research. This framework includes sensitivity to context, commitment and rigour, coherence and transparency, and impact and importance. The research is considered against these four principles in **Table 4**.

3.4.6 Ethical Considerations

In accordance with the ethical guidelines of the British Psychological Society (British Psychological Society, 2014), and the protocols of the ethics committee of the University of Birmingham, ethical considerations were attended to and followed (see **Appendix 1** for full details). **Table 5** (pg. 71) contains a summary of the ethical issues relevant to this research.

Table 4: Evaluation of the Research Project Against Yardley's Four Principles of Validity (2008)

Principle	Evaluation
Sensitivity to Context	The study has attempted to ensure sensitivity to context at several key points. The literature review considers the broad landscape related to autism diagnosis by outlining trends in prevalence, recommendations around best practice, legislation and guidance, and perhaps most importantly, how different ontological perspectives are related to subjective experience and understanding of autism. This review of the literature has helped to ensure that the subsequent interviews and analysis are grounded in understanding of context and help to inform the questions and approach taken in the semi-structured interview. During the semi-structured interviews, the researcher considered the nature of his relationship with the participants. This helped to ensure sensitivity to context by allowing the researcher to reflect on social-desirability factors and other interpersonal influences, enabling them to adapt their responses accordingly. The use of an interview schedule helped to ensure a degree of reliability. The interview schedule meant that each participant was asked questions around the same topic. The use of open-ended questions promoted sensitivity to context by ensuring that the questions were adapted to the participants' responses, helping them to feel at ease during the interview.
Commitment and Rigour	Braun and Clarke (2006) provide a detailed outline of the steps that are required to complete a thematic analysis. They also highlight potential errors that can be made by the researcher which can reduce the quality of analysis and conclusion reached. These include: shallow or descriptive analysis of the data with few conceptual links, using the questions asked as a basis for the developed 'themes', few or unclear links between themes when considered as a part of the super-ordinate themes, and a generic analysis (Braun and Clarke, 2006). Braun and Clarke (2006) also suggest using research diaries to track the process of moving from initial assumptions to theme development, extensive notations during initial coding, the extensive use of quotations, reflecting on the themes developed by considering other data sources, sharing of the analytical process with a third party to ensure quality and checking the hypothesis reached with the participants to see if they are accurate.

	Attempts were made to adhere to the above suggestions. For instance, extensive note making was kept during the coding and theme development phases of analysis. A research diary tracking the researchers thinking process and decisions made was also kept. Substantive extracts of the research were appropriately shared with tutors and peers to ensure the accuracy of analysis. The analysis is also justified in the reporting of the research through extensive use of quotations.
Coherence and Transparency	The extensive use of quotations also helped to achieve coherence and transparency. The whole data set were coded with back and forth reflection between individual interviews and the data set as a whole. This is in line with suggestions made by Braun and Clark (2006) and helped to ensure the coherence of the analysis and conclusions reached. Thematic maps from stages 1 and 2 of the thematic analysis are included in the report of the research to illustrate the identification of themes through the decision-making processes. This was again appropriately verified by a third party. The researcher ensured reflexivity, which contributed to the coherence of the analysis, by engaging with supervision. These reflections were then recorded within the research diary and made explicit in the reporting of the research.
Impact and Importance	The impact and importance of the research project are considered in the introduction and literature review chapters. There is discussion around the national trends related to autism, the subsequent impact on children and families, and consideration of the experiences of professionals who engage in diagnosis. The research aims to have some influence on the ongoing processes of Autism Discussion Panels and produce findings which may be applicable beyond the local context. The generalisation of these findings is inevitably bound to the ontological and epistemological perspectives which frame the research (Cohen and Manion, 2002). The aim of the research is to contribute to the body of knowledge surrounding conceptualisation of autism and experiences of professionals engaging in autism diagnosis. The research is also completed with the aim to contribute to the body of knowledge related to the interdisciplinary working of EPs and paediatricians. As this research is completed within an interpretivist paradigm outlining of context, the justification of the analytical decisions, and reflection of themes developed are all presented with transparency to enable the individual reader to judge the similarity to their own settings and potential application to wider settings (Smalling, 2003).

Table 5: Consideration of Ethical Issues

The Principle of Informed Consent	Volunteers were given an overview of the research, including information of the aims, time commitment required, and method of data collection prior to any expressions of interest being made. Volunteers who expressed an interest in being involved in the research were then provided with written information outlining the research topic in full. This included information regarding the context, aims, and scope of the research. In the written information, participants were informed of their right to withdraw. The participants were able to withdraw their information at any time up until their data had been transcribed and anonymised. Individual informed consent forms were signed by all of the participants. These forms detailed their understanding of the requirements for their participation, the voluntary nature of their participation, their ability to withdraw without reason at any point during the research, their ability to ask questions and discuss concerns with the research supervisor, and their understanding of how the issues of confidentiality, anonymity and data would be processed.
Confidentiality and Anonymity	Participants were assigned a code for the individual semi-structured interviews. The code was based on their professional group to prevent any identifiable names or information being attributed to the data, in order attempt to protect confidentiality. The only record of participant names appeared on the consent form. The consent forms were stored in accordance with secure data procedures. Confidentiality and anonymity are guaranteed with regard to the storage and presentation/reporting of data. Participants were informed that their data would be anonymised but may be discussed anonymously with the research supervisor. The participants were also informed that the principle of confidentiality and anonymity would have to be broken if there were any disclosures of harmful practice. Fortunately, this did not occur and the data were kept as confidential and anonymous in all instances.

	Participants were informed that the findings of the research may be shared with interested parties. This included the University of Birmingham, publication at a later date, and key service stakeholders. The participants were however assured that their data would remain anonymous, non-identifiable and confidential. Care was taken to ensure all identifying information was removed from the quotes used within the research report.
Safe and Appropriate Handling of Data	Interviews were recorded using a storage device and then transcribed (with no names or personal details included in the transcription). After an individual interview, electronically audio-recorded data were moved to a password-protected and encrypted computer file that only the researcher had access to. The audio files were then deleted from the audio-recorder. Written field notes taken during the interview in situ will be stored in a locked filing cabinet which only the researcher has access to. Transcripts were also stored in a locked cabinet to which only the researcher had access. Participant names will only be included on consent forms which will be kept in a locked filing cabinet in line with information governance procedures. Written notes were not attributed to individuals and are only identified by codes. Transcription data will be stored on a password protected laptop and backed up on a secure Local Authority Network in a password-protected folder. Only the researcher will have access to this. In line with University of Birmingham ethical guidelines, all data (electronic recordings, field notes and typed transcripts) will be kept for 10 years on a password-protected memory stick, during which time the researcher, supervisors and any university examiners may have access to it. After this time, all electronic data will be erased (and removed from any back-up drives) and printed interview transcripts securely shredded.
Dissemination of Research Findings	Participants were advised that they could request a copy of the summary of the findings from the researcher. They were advised that the research findings would be produced in the form of a report from the University of Birmingham and may be adapted for publication in a professional academic journal at a later date.

3.4.7 Pilot

A pilot was considered for this research but was not completed in full. The researcher had initially planned to include a Q-sort activity to assess the participants' professional perspectives before completing the interviews (Brown, 1996). After consultation with his academic tutor and other trainee EPs, the Q-sort methodology was abandoned (Brown, 1996). It was felt this this would be too time consuming for the participants and could not be accommodated within the word count in the final write up. The semi-structured interview schedule was discussed and shared with colleagues in the Educational Psychology Service in which the researcher was placed, who would not be participating in the research, with a sample of the key questions piloted. This helped to ensure that the questions were relevant and useful to meet the aims of the research.

3.5 Summary

Chapter Four will now continue with a discussion and presentation of the findings following the analysis described within this section. The report will present an overview of the overarching themes, main themes, and subthemes developed from analysis. These themes will be evidenced through the use of quotation and extracts from the original data set.

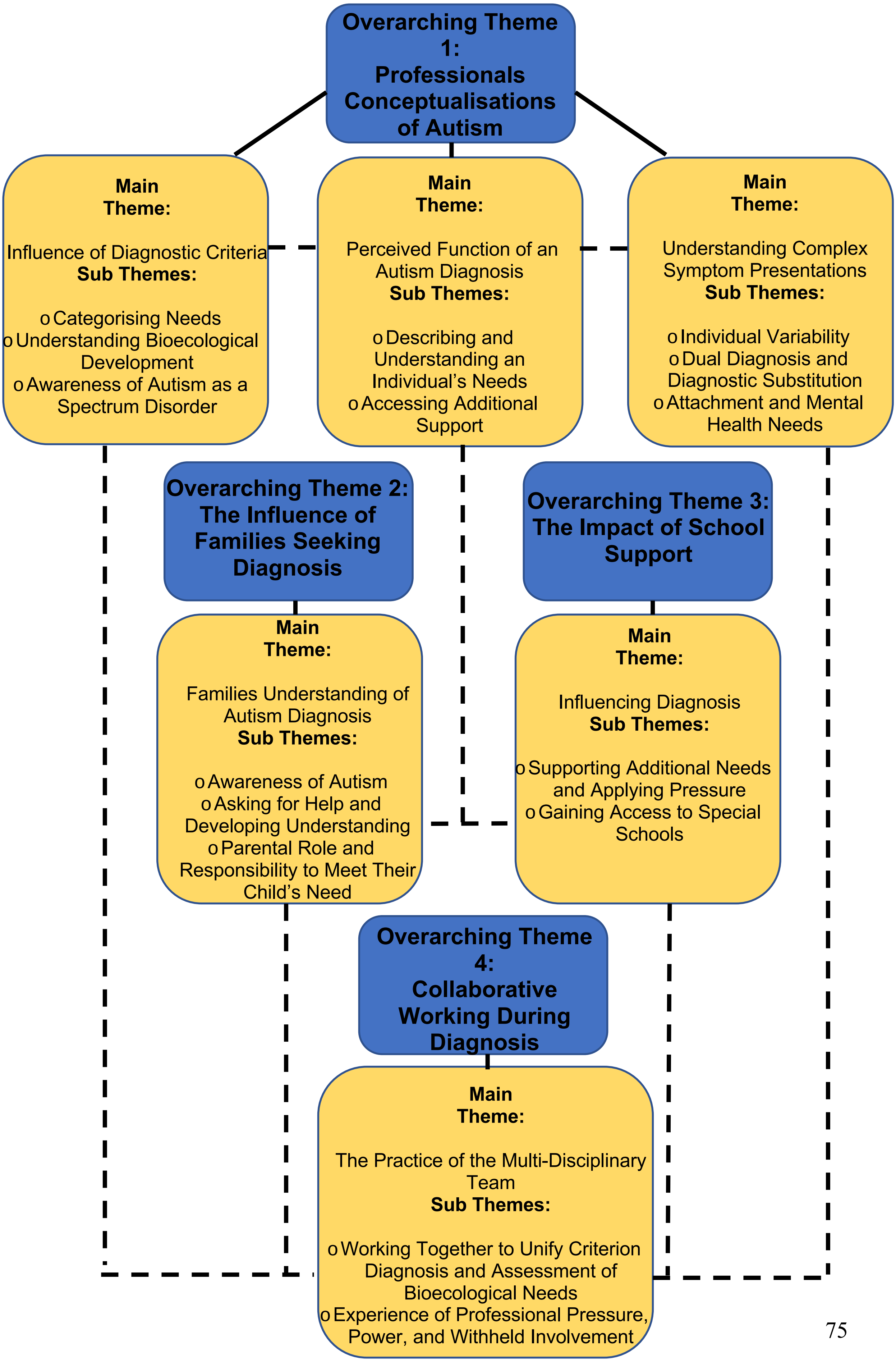
Chapter 4: Results and Discussion

4.1 Introduction

In this chapter the themes identified through the process of thematic analysis will be presented (Braun and Clarke, 2006). Four overarching themes have been identified and will be presented and examined with consideration of the main themes and sub-themes within. This has been completed with consideration of the project's research questions and the literature review that they are based upon. This chapter will also contain an ongoing analytical discussion of the main and sub themes. This will allow for the results and related discussion to be considered together, enabling a full coherent examination of the data presented. This will also help to ensure that a comprehensive analysis and discussion of the differences and similarities between the EPs' and paediatricians' perspectives have taken place. This chapter will then be followed by a consideration of how this discussion, and the results which it is based upon, relate to the research questions asked.

A thematic map representing an overview of the inductively formulated overarching themes, main themes, and subthemes is presented in **Figure 1** to provide an overview of the findings, allow for orientation of the main themes and sub-themes, and for use as reference throughout this chapter.

Figure 1. Thematic Map



4.1.1 Overview of Overarching Themes

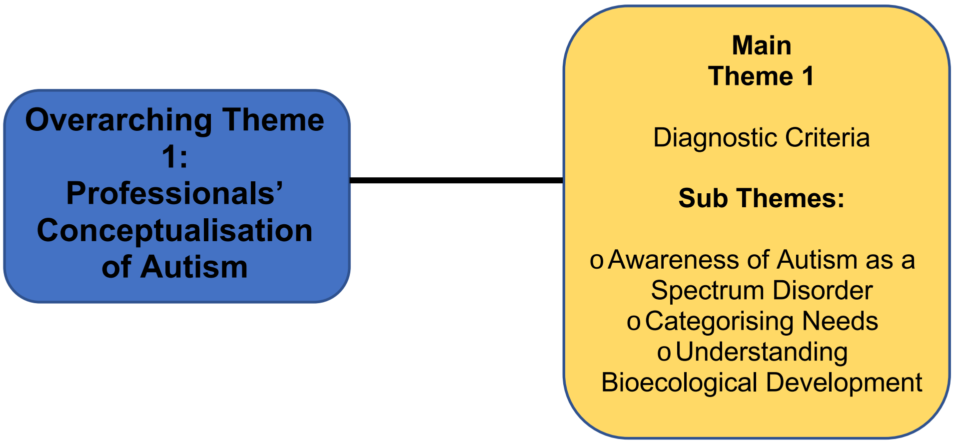
There were four overarching themes identified to encapsulate and organise the main themes developed from the data set:

- Professionals’ Conceptualisations of Autism
- The Influence of Families Seeking Diagnosis
- The Impact of School Support
- Collaborative Working During Diagnosis

The overarching themes of **‘Professionals’ Conceptualisations of Autism’** and **‘Collaborative Working During Diagnosis’** emerged from questions directly asked of the participants and were expected given the aims of the research. When organising and collating codes from the participants’ data, there were clear patterns of response around **‘The Impact of Families Seeking Diagnosis’** and **‘The Impact of School Support’**. These themes were spontaneously dividing and were not related to direct questioning around these specific areas.

4.2 Overarching Theme: Professionals' Conceptualisations of Autism

4.2.1 Main Theme 1: Diagnostic Criteria



A key aim of the research is to explore how the two professional groups conceptualise autism and how these conceptualisations cluster around their professional perspectives, affecting their experience of diagnosis. As such, the participants were asked directly about their conceptualisation of autism. From the analysis of the data, the overarching theme of **'Professionals' Conceptualisations of Autism'** was developed. In **Chapter 2** the impact of the changing diagnostic criteria contained within the DSM-5 and ICD-11 was discussed (Doshi-Velez, Ge and Kohane, 2014; Lobar, 2016). The participants rarely commented directly on the changes within the DSM-5 and ICD-11 but did frequently refer to the expanding criteria for autism as a spectrum disorder. The participants also spoke about the challenges they face categorising needs within a diagnostic framework. The participants spoke separately about bioecological needs and changes in developmental trajectory over time. They spoke specifically about the tension they had experienced between early diagnosis and bioecological intervention to promote development over time. As a result, the sub themes **‘Awareness of Autism as a Spectrum Disorder’**, **‘Categorising Needs’**, and **‘Understanding Bioecological Development’**, were developed.

4.2.1.1 Subtheme: Awareness of Autism as a Spectrum Disorder

Research suggests that the rise in rates of autism is partly due to the change in diagnostic criteria and the conceptualisation of autism as a ‘spectrum’ disorder (Skellern, Schluter and McDowell, 2005; Koegel *et al.*, 2014; Evans, 2017). The EPs and paediatricians were both aware of the change in conceptualisation of autism but did not comment on specific changes to the DSM or ICD. There is a reported lack of awareness around a ‘pure’ phenotype of autism amongst professionals and the broader conceptualisation of autism as a ‘spectrum’ disorder is thought by some to limit professionals’ understanding of individual need (Jensen and Steinhausen, 2015; Hollin, 2017).

Paediatricians’ Views

Although the participants did not comment on the specific diagnostic criteria for autism during the interviews, they did share their views around the broadening conceptualisation of autism as a spectrum disorder and the impact this had on their experience of casework and diagnosis. Only PD3 made direct reference to the ICD and DSM below. The paediatricians referred to diagnostic criteria more often than the EPs. They suggested that the broadening diagnostic criteria and development of the autistic spectrum had contributed to an increase in prevalence (Taylor, Jick and Maclaughlin, 2013).

e.g.:

PD2: ‘The criteria have now changed in the sense that they’ve included more things in the diagnostic criteria. Now you can call many people autistic because of that.’

PD2: ‘The diagnostic criteria have changed. We diagnose autism within a medical model and there are specific diagnostic criteria. Also, I think we call a lot of things that are not quite, autism, autism, because it looks to me, that this diagnosis has some kind of value or something for the families and patients [sic].’

PD3: ‘Most people now have an awareness that it’s a spectrum, and at some point, there’s a cut-off where you get diagnosis. You can be just under the, that cut-off and still have difficulties.’

PD3: ‘I’d probably be talking about ICD-10 or DSM-5 criteria for a diagnosis, but ultimately, we use the ICD-10 or DSM-5.’

PD2 suggests that they diagnose autism with a ‘medical model’. Whilst PD2 does not state which specific diagnostic criteria they refer to. Twice they mention the change in criteria and its impact on their experience of autism. This suggests that PD2 may have some familiarity with the changes in diagnostic criteria outlined in the DSM-5 and ICD-11 (APA, 2013; WHO, 2019). PD2 also suggests that the broadening of criteria has resulted in the inclusion of some additional needs which aren’t associated with classic autism. However, PD2 also reports that, in their experience, this conceptualisation of autism may not be wholly useful. They go on to say that the broader conceptualisation of need within the autistic spectrum has meant that they now ‘call a lot of things that are not quite, autism, autism’. PD2 suggests that the autistic spectrum conceptualises needs and symptoms which would not have been called ‘autism’ under previous versions of diagnostic criteria. The paediatricians’ reference to category is indicative of their adoption of the medical perspective towards diagnosis (Scotland, 2012). This indication is made explicit by PD2 who says they diagnose ‘within a medical model’. The impact of the broadening conceptualisation of autism on labelling symptom presentations is discussed in more detail in **Section 4.2.3.** PD2 suggests that the spectrum conceptualisation of autism has more ‘value’ for families compared to professionals, adopting a medical perspective and approach to considering additional need. Given the ‘functional’ focus of the DSM-5 and ICD-11, it could be that PD2 is indicating their awareness of this contextualised consideration of need (Volkmar and Reichow, 2013; WHO, 2019). The function and value of autism diagnosis for families is discussed further in **Sections 4.2.2** and **4.3.1**. PD3 discusses the challenges of categorising need within a ‘spectrum’ through empirical diagnosis, suggesting that they had experienced some tension from others when considering where the ‘cut-off’ for diagnosis lies, and that children can experience additional need without meeting diagnostic criteria. PD3 suggests there is some tension between this categorisation of need and understanding of autism as a spectrum condition. The functional and contextual focus of the DSM-5 and ICD-11 may make diagnosis from a solely medical perspective challenging (Gallo, 2010; APA, 2013; Fitzgerald and Callard, 2017; WHO, 2019). The above quotes suggest that there are specific challenges experienced by paediatricians when they approach diagnosis whilst conceptualising autism, and associated needs, from a medical perspective compared to a bioecological approach. This concern was often expressed by the paediatricians in their interviews and will form a key part of the ongoing discussion contained in this chapter.

A vague description of the need and a lack of familiarity with the pure phenotype of autism was evident across both participant groups (Doshi-Velez, Ge and Kohane, 2014). This can be seen in PD2's quote when they do not define the difficulties of an 'autistic' child, and in the hesitance displayed by PD1 when they were asked what symptoms they would be looking for when presented with a child, who potentially has autism, in their clinic.

e.g.:

PD2: 'It's useful because we do recognise what the difficulties are when you say, "this child is autistic".'

PD1: 'the main… pointers…so language delay would probably be the first one and then…all the…domains of the…interaction and the repetitive habits, so they are probably the first indicators in the younger ones [sic].'

PD3' 'Since I've been a consultant, it's always been Autism Spectrum Disorder and it's included all the different types of autism.'

As can be seen, PD2 and PD1 struggle to clearly and succinctly describe the features they would expect to see when diagnosing Autistic Spectrum Disorder. PD3 was asked if they could describe the impact of the changes of autism to a spectrum disorder. They suggested before this quote that it was 'difficult' for them to comment because they had not been a consultant since the changes had been made. The single quote was chosen from PD2 as it is representative of many similar but not as succinct quotes from the paediatricians. PD2's vague demarcation of autism appeared to be linked to quotes outlined in **Section 4.2.3** where the participants consider the broad conceptualisation of autism as a 'spectrum' disorder and its association with other comorbid difficulties. However, when compared with the below quotes from the EPs, it could be suggested that both groups of professionals do not have a clear understanding of the pure phenotype of autism (Jensen and Steinhausen, 2015; Hollin, 2017). This enduring uncertainty, and the participants' reluctance to outline specific features suggest that they are not particularly familiar with recent changes in diagnostic criteria, which could negatively impact on their ability to diagnose accurately (Strunk, Leisen and Schubert, 2017). However, it may also indicate that the participants, despite their different professional perspectives, have been caught in a unclear terrain of medical and bioecological need encapsulated within the autistic spectrum (Fitzgerald and Callard, 2017; Hollin, 2017). Many of the issues discussed throughout this chapter represent the participants' attempts to understand and overcome this tension between the contextual, functional, or bioecological needs associated with autism and the requirement to medically assess and categorise symptoms (Jensen and Steinhausen, 2015; Hollin, 2017).

EPs' Views

The EPs also reported that they had some awareness of the change of autism conceptualisation and criteria to a 'spectrum disorder'. Whilst none of the EPs referred directly to diagnostic criteria, they did discuss the impact of the changes on their experience of autism casework. The EPs were critical of the broadening ‘spectrum’ of need and suggested that the changing conceptualisation of autism had resulted in a rise in the number of children diagnosed.

e.g.:

EP3: ‘I think sometimes the spectrum seems too broad.’

EP2: ‘The conceptualisation of it has altered or didn’t exist but I think that’s *definitely* one of the reasons that we’ve seen the huge rise.’

EP3: ‘I think a psychologist, or a paediatrician, would probably agree that a classically autistic child is autistic. It’s the children who are on the broader spectrum. Where I think there’s more contention about, why do they need that diagnosis?’

In **Section 4.2.2**, the EPs report that they do not see diagnosis as an essential tool for accessing additional support and discuss how the broader conceptualisation of autism as a spectrum can limit the assessment of heterogenous needs or alternative symptom presentation in **Section 4.2.3**. In the above quotes, EP3 suggests that the spectrum conceptualisation of autism works well for children with more typical autistic needs but queries the value of diagnosis for children who display less typical traits when she says, ‘why do they need that diagnosis?’. This indicates the EPs, like the paediatricians, also experience some tension around the spectrum conceptualisation of additional need and categorisation for diagnosis (Gallo, 2010; APA, 2013; Fitzgerald and Callard, 2017; WHO, 2019). EP3’s query around the utility of diagnosis for those with less obvious medical needs reflects their adoption of the bioecological perspective where diagnostic labels are eschewed in favour of developing individual understanding and interventions (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008; Burnham, 2013).

The EPs were not often explicit about the specific needs that diagnosis refers to. They suggested that the limits of the autistic spectrum may not be well defined within their personal conceptualisations (Jensen and Steinhausen, 2015; Hollin, 2017).

e.g.:

EP1: ‘I think the label can be helpful to some, because they know that autism is this combination of…difficulties [sic].’

EP2: ‘It’s an immediate cue into, “this child has difficulties, probably in these kind of areas. Ok, I’m going to be aware of that”. If that’s all it was it would be fine, but I think it’s got caught up in a much wider fuzzy thinking, circular logic around it [sic].’

As can be seen from the above quotes, the EPs were not distinct when speaking about the specific traits that a diagnosis of autism refers to. EP1’s pause whilst speaking about a ‘combination of…difficulties’ suggests a vague conceptualisation of the needs relating to autism. EP2 is equally vague, suggesting difficulties, ‘probably in these kinds of areas’. This lack of professionals’ familiarity with the pure phenotype of autism is consistent with criticism of the conceptualisation of autism as a spectrum disorder (Jensen and Steinhausen, 2015; Hollin, 2017). It also indicates that the EPs’ bioecological perspective has meant that they do not place a high value on diagnostic labels compared to other professionals who may hold a more positivist perspective (Bronfenbrenner and Morris, 2007; Oppong, 2014).

Summary

The lack of reference by the participants to diagnostic criteria throughout their interviews meant that it was not always clear which symptoms they were referring two when they described autism. The vague descriptions are apparent despite their different professional perspectives. It could be that the participants are unfamiliar with the details of the DSM-V and ICD-11. A lack of familiarity with criteria may prove to be a barrier to effective diagnosis (Barker and Galardi, 2015). The paediatricians suggested that the spectrum conceptualisation of autism can be incongruent with a medical approach to categorising need. This is evident in their explicit commentary around poorly defined ‘cut-off’ points for the spectrum. The EPs’ bioecological perspective led them to question the utility of diagnosis altogether, in particularly for those at the ‘broader’ end of the spectrum. Both the paediatricians and the EPs suggest, in the above quotes, that autism, conceptualised as a spectrum disorder, is a less effective tool for describing individual need. This theme will be discussed further in **Section 4.2.3.1**.

4.2.1.2 Subtheme: Categorising Needs

The paediatricians and EPs often spoke about the autistic spectrum and the challenges they face when categorising needs. The participants expressed conflicting views around the role that criteria played in their diagnostic processes. As discussed above, none of the participants spoke in detail about the specifics of either the DSM-5 or the ICD-11. The only specific reference to diagnostic criteria came from the paediatricians. PD3 briefly referred to the ICD-10 and DSM-5 as their reference point for conceptualising and understanding autism during differential diagnosis. PD3 suggested that all of the paediatricians relied on these documents during diagnosis. However, both the EPs and paediatricians spoke about their requirement to categorise additional needs and the challenges they faced completing this process from within their medical and bioecological perspectives when involved in autism diagnosis.

Paediatricians' Views

It is worth noting that at the time the interviews for this research took place, the ICD-11 had not been released (WHO, 2019). This may mean that paediatricians were still conceptualising autism based on outdated criteria. The participants were not directly asked about the diagnostic criteria that they used in their clinical practice. However, the paediatricians frequently made reference to the importance of diagnostic criteria, even though PD1 and PD2 did not name the ICD or DSM directly. Despite their assertion that diagnostic criteria are an important part of their consideration of autism, they also described the criteria as a part of 'arbitrary' categorisation of need.

e.g.:

PD2: 'It needs to fulfil the criteria. I am not being pedantic, but I feel that as a medical person, I do need it to fulfil the criteria. There has to be some criteria that needs to be fulfilled.'

PD3: 'All I'm answering is whether their child's needs meet arbitrary criteria for a diagnosis. What's the point in putting them in an arbitrary group?'

PD3: 'My understanding is that the different groups were arbitrarily based on whether they had various classification. Like whether they had speech and language delay, or learning difficulty associated with their difficulties, or whether they had all three of the areas of autism, or just two, for instance. I think that there wasn't a lot of evidence that a different intervention in that group helped. So, for one group, if there's no evidence that this group need this treatment or management, and this group need this treatment and management, then what's the point in putting them in an arbitrary group?'

The above quotes highlight the paediatricians' conflicting views around criteria and categorisation of additional need for autism, despite their medical perspective. PD2 suggests that the fulfilment of diagnostic criteria is essential, indicating the paediatricians' implicit reliance on documents like the ICD and DSM when diagnosing autism (Skellern, Schluter and McDowell, 2005; WHO, 2012; APA, 2013). However, PD3 suggests that adhering to 'arbitrary' diagnostic criteria places children in 'arbitrary' diagnostic groups. PD3's quote suggests that they are pleased with the removal of sub categories between DSM-4 and 5 and feels that the conceptualisation of autism as a spectrum disorder is more appropriate as it has reduced the number of categories which do not result in different 'treatment' (Volkmar and Reichow, 2013). There is a need to ensure that all factors are taken into account when diagnosing autism to provide effective support for children and their families. This should also be completed to ensure that treatment and intervention for comorbid symptoms and needs associated with autism are accurately provided to reduce the chance of harm and negative outcomes (Doshi-Velez, Ge and Kohane, 2014; Lobar, 2016; Murphy *et al.*, 2016). Some would suggest that the designation of children into diagnostic categories is not in fact 'arbitrary' and all areas of need should be considered as a part of diagnosis even if this means inclusion in a separate diagnostic category (Volkmar and Reichow, 2013). PD3's description of diagnostic criteria and the category for autism as 'arbitrary' is surprising given the medical perspective associated with paediatric medicine (Scott and Briggs, 2015). The medical model is based on positivist science and the study of correlations to develop criteria and categories (Shakespeare, 2013; Scott and Briggs, 2015). PD3's consideration of categories and resulting interventions as 'arbitrary' may be due to the broad spectrum conceptualisation of autism and associated need and tension experienced trying to capture bioecological need within a medical framework (Bronfenbrenner and Morris, 2007; Scott and Briggs, 2015).

The challenges that medical professionals face when diagnosing autism may be an inherent difficulty with the medical approach to diagnosing developmental needs, where traditional medical testing cannot categorise symptoms as easily as physical health symptoms (Scott and Briggs, 2015). PD1 discusses the difficulties they face applying the medical model of diagnosis to the uncertainty of autism and the challenges they face categorising needs without clear biomarkers. This may contribute to PD3's view of diagnostic criteria as ‘arbitrary’. PD1 contrasted their practice around autism with more medically informed diagnoses.

e.g.:

PD1: ‘With these kinds of neurodevelopmental disorders there’s no hard and fast diagnostic test for them, unlike other medical conditions. So, if you have an immune deficiency you do the immunoglobulins, and it’s low and you say he as immune-deficiency, it’s not the same for these conditions, and that’s what the difference is, and that’s why it’s difficult for us, but we still like to think that “ok if you’ve come with a set of symptoms, we like to fit it into a box”, but we know, it doesn’t always fit into a box, and we’re very, very aware of that [sic]]. So we say ‘ok we need to know a bit more about the family, the social issues that are there to say, “Yes, he may be presenting with autism like symptoms”, but there’s so much behind that to explain why he might be behaving like that. For example, he has attachment or…it’s just poor parenting, it is sometimes [sic]!’

PD1 discusses the lack of ‘hard and fast’ ‘diagnostic tests’, demonstrating the paediatricians’ preference for biological testing and reliance on clear medical criteria (Shakespeare, 2013; Yates and Le Couteur, 2016). This quote suggests that the paediatricians may feel frustrated by the lack of traditional medical testing for autism and potentially ‘arbitrary’ criteria that cannot be empirically verified. PD1 suggests that there is some tension between the lack of clear biomarkers for autism and a pressure to account for development, that the paediatricians ‘like to fit it into a box’.

PD1 begins to discuss the tension between bioecological needs, such as ‘poor parenting’ or attachment needs, and the difficulties that can arise when trying to conceptualise these factors within diagnostic criteria (Skellern, Schluter and McDowell, 2005; Newland, 2015). PD1 comments on the difficulties they face trying to account for ‘family’ and ‘social issues’. PD1 suggests that they are ‘very aware’ of the challenges they face when considering bioecological needs. This suggests that the paediatricians can find the medical perspective and diagnostic criteria restrictive when considering broader bioecological influences on presentations of additional need. A solely medical perspective during autism diagnosis may limit the paediatricians’ ability to consider factors affecting a child’s presentation that cannot be quantified in a clinical setting. This may lead them to feel more pressure to fit the child’s symptoms ‘in a box’ (Evans and Trotter, 2009; Perron, 2018).

EPs’ Views

The EPs were critical of the medical approach to diagnosis and its reliance on diagnostic criteria. The EPs reported that they did not rely on diagnostic criteria at all. The EPs lack of engagement with diagnostic criteria, and its impact on collaborative diagnosis, is discussed in **Section 4.5.1**. The EPs suggested that a purely medical approach to diagnosis, in the local context, was not effective in assessing children with broader developmental needs as the medical model could not account for bioecological factors influencing childhood development (Bronfenbrenner and Morris, 2007). EP2 was critical of the empirical nature of diagnosis and the diagnostic criteria which it is based upon.

e.g.:

EP2: ‘It seems to me that children are identified with a sufficient number of traits that would fit with autism. If they do, then they get the identification. So, by the very nature of the process of assessment, there doesn’t seem to be a box at the bottom that says “could there be another reason for this? If so, what could it be?” [sic]’

EP2: ‘There’s not a flow diagram that asks those questions, and to be honest, that’s actually what Paediatricians have said in our discussions. They acknowledge that there are other potential hypotheses and reasons for a child’s presentation, such as attachment, but they have actually said, but we don’t have a pathway. The only pathway they have for children presenting with social communication difficulties in terms of assessment and labelling is, autism. They don’t have a pathway for [anything else].’

EP1: ‘Actually I don’t even go according to, if it’s autism, I have to know it is autism, the only thing that might change in regard to SEMH is perhaps we’re still going to work on emotional regulation [sic].’

EP3: ‘No, and meeting criteria shouldn’t override [alternative formulations of need].’

EP1 shows how little they rely on diagnostic criteria by saying ‘I don’t even go according to if it’s autism’. They suggest that whilst they can identify autism, adherence to criteria would not change their approach, and they would not attempt to categorise need. This indicates the impact of the EPs’ adoption of a bioecological perspective for their practice where labels and diagnostic criteria are not used to describe individual needs (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008). EP2 comments on the limitations of criterion-based diagnosis suggesting that there isn’t any opportunity to explore other hypotheses of formulations to understand children’s development (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008; Burnham, 2013). EP2 suggests that there are not established pathways for exploring broader types of additional need. EP2 suggests that categorisation of additional need from a medical perspective is limiting and prevents deeper understanding of individual needs. This is shown when EP2 says, ‘there doesn’t seem to be a box at the bottom that says, “Could there be another reason for this?”’. This quote highlights the EP’s consideration of factors outside diagnostic criteria and demonstrates that the EPs may be looking for an understanding of why symptoms are being presented by the child rather than relying on empiricism to categorise (Bronfenbrenner and Morris, 2007; Ravet, 2011; Scott and Briggs, 2015). This quote also indicates the tension between the medical and bioecological perspectives during diagnosis and challenge face by the EPs of considering bioecological needs within a ‘box’ (Fox, 2009).

Summary

The paediatricians and EPs both discussed the limitations of a medical approach to categorising the needs associated with autism. The paediatricians suggested that autism is challenging to diagnose because of the lack of available biomarkers and clear diagnostic testing, indicating the epistemology associated with their medical perspective. The paediatricians also suggested their medical approach to diagnosis was not able to easily account for bioecological needs. The EPs discussed at greater length the limitations of diagnostic criteria when attempting to categorise broader ecological needs (Bronfenbrenner and Morris, 2007). The EPs demonstrated a bioecologically informed anti-labelling position, suggesting that they did not often consider criteria when supporting children. Instead they report that they focus on the reasons why difficulties may be occurring and subsequent interventions. Whilst each professional group considers different limitations of the process of categorisation of needs, they both indicate that reliance on criteria alone is not effective for a holistic description of children.

4.2.1.3 Subtheme: Understanding Bioecological Development

The consideration of bioecological needs became a significant feature of the discussion with both the EPs and the paediatricians. Whilst it was apparent that the EPs adopted the bioecological perspective to a greater degree than the paediatricians, they rarely spoke using the updated terms outlined by Bronfenbrenner in his more recent revisions of his bioecological model of human behaviour (Bronfenbrenner and Morris, 2007; Tudge *et al.*, 2016). Instead the EPs often spoke about features of their practice and approach. Both the paediatricians and the EPs spoke about how they conceptualised autism needs and how these conceptualisations affect their understanding of bioecological development.

Paediatricians' Views

The paediatricians suggested that there were significant limitations with their medical conceptualisation of autism and the subsequent empirical assessment tools that they use when trying to differentiate between autism and bioecological need, or when trying to develop an understanding of why difficulties may be occurring (Bronfenbrenner and Morris, 2007; Rosa and

Tudge, 2013; Yates and Le Couteur, 2016). Below, PD3 discusses the specific limitations of their assessment tools and their inability to account for ecological need. They suggested that there can be false negative results in their assessment processes, even in children who should be diagnosed with autism.

e.g.:

PD3: ‘An ADOS could be negative, even in a child with autism. You know, it’s not 100% sensitive and specific. It’s just part of the evidence and I’ve had cases like that, if they remain unhappy, sometimes I say, “Well, I’m happy to review in a year with fresh evidence from school.” I try to encourage the school to be involved in a rereferral, rather than just the parents again. Otherwise, you just go around in the same circle [sic].’

PD3 describes the need for qualitative evidence from schools, suggesting that this type of evidence can hold more weight during differential diagnosis than standardised assessment tools like the ADOS. The preference for qualitative evidence from schools and other contexts reflects the need for multi-disciplinary diagnosis in autism and the paediatricians’ implicit consideration of bioecological need when diagnosing autism (Waite and Woods, 1999; NICE, 2011). PD3’s quote suggests that the paediatricians may recognise the value of multi-disciplinary working between EPs and paediatricians during autism diagnosis to accurately consider diagnostic criteria and bioecological needs (Bronfenbrenner and Morris, 2007; Walsh and Hall, 2012; Fitzgerald and Callard, 2017).

The paediatricians’ conceptualisation of autism and professional perspectives related to bioecological needs and development were often expressed during their discussions around provision of diagnosis for young children. The paediatricians often suggested that to ensure improved outcomes for children and young people, children should be diagnosed as soon as possible.

e.g.:

PD2: ‘Typical [autistic children] who come to your clinic and you know they’re autistic, but it’s a bit difficult to give that diagnosis of autism the day you see them.’

PD2: ‘See, there is classic autism. They are diagnosed within the year. By three, three-and-a-half. That’s CDC. And then they go into special schools, or they go into special units or you know, whatever [sic].’

PD1: ‘They will get seen if they are referred because new patients have to be seen, so we’ve got a time scale about seeing the new ones. In the past if they had a CDC assessment, and they’ve had a diagnosis, so we’re talking for pre-schoolers, if they had a diagnosis of autism then they would be discharged unless there were other medical needs. We aim to try and discharge them after we’ve seen them, after we’ve given then diagnosis. We don’t always succeed because they have problems often relating to sleep. Sleep is one of the biggest reasons why we see children for follow up [sic].’

Development over time is an important feature of the bioecological perspective. In more recent versions of his model, Bronfenbrenner highlighted the importance of time and change within contexts when considering childhood additional needs (Bronfenbrenner and Morris, 2007). PD2 speaks about the felt pressure to give out diagnosis on the same day that they see a child. PD1 discussed the time constraints they have experienced during pre-school diagnosis and suggests they try and discharge the child as soon as possible. PD1 suggests that they ‘don’t always succeed’ in discharging pre-school age children promptly. They suggest that parents often return with ‘problems often relating to sleep’. They report that this is ‘one of the biggest reasons’ why children return to their caseload. This discussion from PD1 and PD2 suggests that the paediatricians are under pressure to provide diagnosis promptly to young children. This view could reflect the impact of their adoption of the medical perspective and implicit view that intervention and support should be provided, as a result of diagnosis, as promptly as possible (Taylor, Jick and MacLaughlin, 2013; Koegel *et al.*, 2014). PD2 discussed the function of providing diagnoses to pre-school children saying that ‘by three, three-and-a-half. Then they go into special schools or they go into special units or – you know, whatever’. This may indicate that the paediatricians are disconnected from the process of providing intervention and support for children with autism and assume that a diagnosis will unlock additional support. This is in contrast with the interventionist approach adopted by the EPs as a part of a broader understanding of bioecological needs (Bronfenbrenner and Morris, 2007). The paediatricians’ preference to diagnose need as early as possible appears to be related to their medical perspective and approach to autism diagnosis (Scott and Briggs, 2015). Within the medical perspective, efficient ‘treatment’ or intervention may be associated with prompt and early categorisation of need. This professional perspective adopted in the context of a ‘crisis’ in autism diagnosis waiting times may have influenced the paediatricians to diagnose as early and as quickly as possible (APPG, 2016). This approach may also have been guided by the debated assumption that early diagnosis leads to effective ‘treatment’ and improved outcomes for all children with autism (Koegel *et al.*, 2014; Crane *et al.*, 2016).

The above quotes highlight the specific issues that paediatricians may have separating out autism from bioecological needs, such as parenting issues, within the context of their current clinical practice. They also suggest that they are under pressure to diagnose young children as promptly as possible, a view which contrasted with the EPs’ bioecological approach to development and diagnosis.

EPs’ Views

The EPs were much keener to delay diagnosis and take a ‘wait and see’ approach to assess bioecological needs compared to the paediatricians. The EPs suggested that children required support and intervention before a diagnosis of autism can be confirmed.

e.g.:

EP1: ‘I think we should just let, you know with the right support, let children develop. With the right support, the right type of interventions based on, on their presentations and lets you know wait and see [sic].’

EP3: ‘We are giving diagnosis that is possibly going to stay with that child for their life. Their whole life. It’s got to be given very, very carefully and if you’re not sure, what I would like to see, and I think there’s a bit of resistance to this, is delaying a diagnosis.’

EP1 and EP3 discuss their approach to bioecological development during autism diagnosis. EP1 suggests that professionals should ‘let children develop’ with the ‘right support’ and EP3 discusses their awareness that a diagnosis stays with a child ‘for their whole life’. This consideration of developmental trajectory and appropriate support shows the influence of the conceptualisation of time, intervention, and variable development within the bioecological model (Bronfenbrenner and Morris, 2007). EP3 suggests that this perspective is in contrast with the paediatricians’ approach to diagnosis and reports that there can be ‘some resistance to delaying diagnosis’.

The EPs often spoke about their preference to separate out ecological needs before confirming autism. They outlined a clear position on autism, recognising that correlation, or adherence to criteria, does not equal cause (Waite and Woods, 1999; Scotland, 2012). They suggest that social communication needs can often be explained by bioecological factors which may be impacting upon a child’s development and presenting symptoms.

EP1 and EP2 comment directly on historical childhood development and interactions between key adults and children, demonstrating the EPs’ bioecological perspective when considering development over time (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008).

e.g.:

EP2: ‘Autism is social communication difficulties, where there are no interactive type factors, or experiences that the child may have had that could explain that, therefore it might be because we can’t identify that. Then we would have to assume that it must be, environmental, possibly broader, types of needs [sic].’

EP2: ‘It’s about what are their needs and that’s where you’d go back to looking at them as an individual. Where are they? What do they need in all areas of development? In a child like that, social communication would just be one area you’d be looking to support them in.’

EP1: ‘What’s happened to this child historically? Has there been any clinical history? What were they like at birth? Were there any factors that could have interrupted the child’s development. such as, bereavement in the family, post-natal depression, whether they’ve been taken into care, are there, or neglect abuse, are there any other factors, that could have caused an interruption in the child’s social emotional development?’

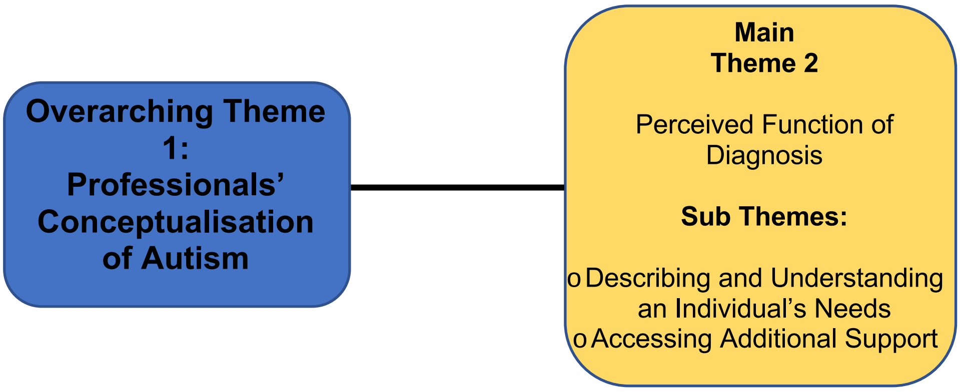
EP2 makes the clear distinction between ‘biological’ autism and ecological need (Bronfenbrenner and Morris, 2007; Hollin, 2017). EP1 suggests there should be a consideration of ‘clinical history’. Both EP1 and EP2 suggest excluding all interactive and environmental factors before confirming a diagnosis of autism (Skellern, Schluter and McDowell, 2005). This suggests a fundamentally different approach to conceptualising and understanding autistic need compared to the medical approach of the paediatricians (Evans and Trotter, 2009; Scott and Briggs, 2015).

The differences between the participants’ views appeared to be linked to the extent that they adopted a bioecological perspective (Bronfenbrenner and Morris, 2007). The more universal adoption of the bioecological perspective of the EPs may mean that they are more mindful of development and changes which can occur when support is provided compared to the paediatricians, and as a result, are keener to delay diagnosis (Bronfenbrenner, 1979; Skellern, Schluter and McDowell, 2005; Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008; Scotland, 2012).

Summary

In the above quotes, the EPs allude to the tensions they have experienced when considering bioecological needs and development, particularly around early diagnosis. The EPs suggest some resistance to delaying diagnosis, and a preference to provide intervention and support first. The paediatricians comment on the pressure they have experienced to provide diagnosis as quickly as possible. This suggests that participants' professional perspectives and underlying conceptualisations of additional need is having an impact on their experience of autism diagnosis. The challenges of integrating the bioecological and medical perspectives, and the impact of these conceptualisations on collaborative working in multi-agency practice are explored further in **Section 4.5.1.**

4.2.2 Main Theme 2: Perceived Function of Diagnosis



The EPs and paediatricians, and individuals within each group, had differing views around how autism should be conceptualised and the purpose of giving a child a diagnosis. The participants involved in the research spoke about the function of diagnosis as a key aspect of how they conceptualised autism and experienced diagnosis. This led the researcher to develop the main theme, **'Perceived Function of an Autism Diagnosis'**. The participants identified a number of interrelating expressed functions of diagnosis, which were formed into subthemes. These were: **'Describing and Understanding an Individual's Needs'**, and **'Accessing Additional Support'**. The participants often simultaneously spoke about the function of a diagnosis to describe and understand additional need. As a result, these two distinct functions were combined into one subtheme. Whilst the participants spoke about the function of diagnosis as a part of their overarching conceptualisation of autism, they often spoke about the role that schools and parents have in supporting children. As a result, there are significant links between this main theme and **Sections 4.2.2** and **4.4.1**.

4.2.2.1 Subtheme: Describing and Understanding an Individual's Needs

All of the participants from both the EP and paediatrician groups identified description as a key function of diagnosis. They often spoke about the difference between autism diagnosis as a tool for 'describing' the presenting symptoms of a child, and as a way of 'understanding' where those symptoms had come from, although these two functions were often combined in the discussions.

All of the participants suggested that diagnosis served as an aid to ensure a deeper understanding of autism-associated needs for parents and schools. This aligns with the findings in recent research which suggests that individuals and parents of children with autism are seeking a greater level of understanding into the difficulties they have been experiencing when seeking a diagnosis (Crane *et al.*, 2018).

Paediatricians' Views

The paediatricians suggested more frequently than the EPs that children and families needed a diagnostic label to gain an understanding of the individual needs associated with autism. However, they also suggested that the diagnostic label of autistic spectrum disorder is too broad and does not describe individual need well.

e.g.:

PD2: ‘We still call it autism because there isn’t any specific name, or the names aren’t good enough.’

PD2: ‘We are not good in actually pointing out the difficulties within autism that the individual child has. Autism is so broad now, so we don’t tell you, for example, about a child who has got anxiety disorder. Which would be within the autistic spectrum as well, he’ll be called autistic. And there’ll be another child, who is non-verbal and having lots of stereotypical behaviour. He’ll be autistic too. So, one word can mean so different things. That is too broad.’

PD3: ‘Many of the children that now have a diagnosis of ASD, who would have previously had a diagnosis of sematic-pragmatic, but no one would have really understood what that meant.’

PD3: ‘Some families want a diagnostic label to feel that they understand their child. But I try to point out to them that they already understand their child’s needs.’

In the above quotes, PD2 speaks about not having a ‘specific name’ for some of the additional needs that children can present with, highlighting their medical preference for labelling and categorisation through diagnosis compared to the EPs. PD2 reports that ‘the names aren’t good enough’, suggesting they can feel limited by the medical model of criteria and categorisation during diagnosis (Scotland, 2012). They suggest that some of the labels are ‘good enough’ for professionals but do not give parents a more in-depth understanding. They go on to say that a diagnosis of autism does not describe individual needs well. PD2 highlights the difficulty of accounting for bioecological states such as ‘anxiety’ within the single label of autism. The NICE guidelines suggest that there should be a focus on individual needs and strengths (NICE, 2014). However, there appears to be a conflating of this focus on individual presentation and a need for diagnosis in the paediatricians' above quotes. This is shown when PD2 says, 'We still call it autism because there isn't any specific name, or the names aren't good enough.' This is also expressed again by PD3 who suggests that families are seeking diagnosis to gain a deeper understanding of their child, whilst having a good level of understanding of their individual need without the diagnostic label. Parents are reportedly highly dissatisfied with current diagnostic procedures in the UK (Crane *et al.*, 2016). They reported feeling ill-informed and directionless even after having received their diagnosis (Crane *et al.,* 2018). This may suggest that the label of autism is not able to effectively describe individual need or take into account the bioecological context of parents and families (Bronfenbrenner and Morris, 2007). PD3 continues discussing the conceptualisation of autism as a spectrum disorder and its limitations in describing individual need and promoting understanding.

> e.g.:
>
> PD3: 'It's not a specific disease anyway. It's just a collection of difficulties. So, what's the point in putting them in a group if you can't then target them with a specific therapy. So, I think my understanding is that it was felt to be more helpful to just say, "They have these difficulties," and then you target the therapy depending on that individual person. Rather than putting them in a group when you can't then target any therapy at that particular group.'

Whilst PD3 discusses the utility of diagnosis in terms of providing effective interventions and support, she also discusses the potential benefits of focussing on individual need without a diagnosis. She suggests that for key stakeholders, it is 'more helpful to just say, "they have these difficulties"' and to focus on intervention for the ‘individual person’. This suggest that PD3 can see the benefit in taking an individually focussed bioecological approach during diagnosis to aid both understanding and effective intervention (Bronfenbrenner and Morris, 2007). In **Section 4.5.1**, the paediatricians compliment the EPs’ focus on individual need through the application of a bioecological approach. Here PD3 suggests this focus on need without a specific diagnostic label is useful to parents and schools too.

The above quotes suggest that the paediatricians recognise the limitations of the medical model and conceptualisation of autism as a spectrum disorder in their ability to categorise and describe individual need (Skellern, Schluter and McDowell, 2005; Kelly, Woolfson and Boyle, 2008). There is a lack of direct quotation from PD1 in this section due to an interruption in the interview just as questioning around this area began. They, however, began to share similar views around how parents can find it difficult to understand the specifics of an autism spectrum diagnosis.

EPs’ Views

The EPs from the study sample suggested that they would prefer to focus on individual child need, suggesting that an autism diagnosis limited their ability to think holistically about children and their development. They were universally critical of the ability of a diagnosis to ensure an understanding and description of individual need.

e.g.:

EP2: ‘It’s about what are their needs? And that’s where you go back to looking at them as an individual, where are they? What do they need in *all* areas of their development?’

EP2: ‘You’ve got a whole group of children within that who have ended up with a diagnosis that’s not necessarily reflective of their complete needs or an understanding of their needs, getting interventions that aren’t necessarily very relevant [sic].’

EP2: ‘we don’t want to know about labels we’re looking at the Diagnosis whole child, as an individual.’

EP3: ‘The understanding around the individual child’s needs is there anyway. So, you know, you can understand the child’s presenting needs whether or not they’ve got a diagnosis.’

EP1: ‘The use of the diagnosis of autism helps people out there understand what it is, and I suppose it does reduce in them some anxieties. But for me, as a practitioner supporting schools to meet needs, it’s neither here nor there because I’m looking at what the presenting difficulties are and I’m giving advice on how you do this. So, how do you address social emotional difficulties with this child, how do you address communication difficulties with this child.’

The EPs’ anti-labelling perspective and preference for focussing on individuals within their environment is emblematic of their adoption of the bioecological perspective (Bronfenbrenner, 1979; Kelly, Woolfson and Boyle, 2008). EP2 speaks about ‘all areas’ of child development, suggesting a broad systemic focus on additional need. EP2 suggests that there is a link between a focus on the individual and provision of effective interventions. They go on to suggest that the EP profession as a whole does not want to focus on ‘the diagnosis’ and prefers to focus on ‘the individual’. The above quotes from EP2 and EP3 further demonstrate their adoption of bioecological approaches and feeling that diagnosis is not an effective tool to promote understanding at the individual level (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008). EP3 reports that they ‘can understand the child’s presenting needs whether or not they’ve got a diagnosis’. This suggests that both EP2 and EP3 do not reflect on the label of autism to same degree as the paediatricians when considering individual needs. EP3 suggests that for families and schools, understanding is ‘there anyway’, and that a diagnosis does not leave them with a better description of the child’s needs or understanding of their difficulties. EP1 recognises that a diagnosis can reduce ‘some anxieties’ for people seeking diagnosis. They, however, suggest that as an EP, a diagnosis is irrelevant and ‘neither here nor there’ in their thinking when planning to support schools and children. Instead, their focus is on providing support for the underlying needs in context. The suggestion from the EPs is that diagnosis is not required in order to understand and support individuals and when it is provided can only partially describe child development. This reflects the EPs implicit focus on Proximal Process, Person, Context, and Time, and intervention within the bioecological framework (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008).

Summary

The EPs and paediatricians both suggest that increasing parental understanding is a key aim of providing an autism diagnosis. Yet there is acknowledgement by both that the current conceptualisation of autism may limit the depth of individual understanding that can be achieved (Volkmar and

Reichow, 2013) .They suggest that this is partly due to the broad nature of autism as a spectrum condition and its limited ability account for individual bioecological need. This is shown with both the paediatricians' and EPs' focus on targeted or individualised 'intervention' as a result of diagnosis. Whilst both were critical of an autism diagnostic label's ability to promote understanding and depth, the EPs expressed a stronger, bioecologically informed, anti-labelling perspective. Compared to the paediatricians, the EPs were keen to focus solely on underlying needs where the paediatricians suggest that more effective 'names' for conditions may be more useful. In the above quotes, there is the suggestion that there is an increased awareness of autism amongst parents and carers, and that many are actively seeking a diagnosis of autism. The aims, perspectives, and role of parents in autism diagnosis are discussed in greater depth in **Section 4.3**.

4.2.2.2 Subtheme: Accessing Additional Support

The second subtheme developed from the data, within the main theme of **'Perceived Function of Diagnosis'**, is **'Accessing Additional Support'**. The participants from both groups spoke frequently about how they conceptualised autism diagnosis as a mechanism for gaining access to additional support. The participants did not speak frequently about the role of broad community-based interventions; instead, they focussed more specifically on intervention and support provided by schools (McLeroy *et al.*, 2003). As such there are major links between this subtheme and the overarching theme of **'The Impact of Support in Schools'** in **Section 4.4**.

Paediatricians' Views

The introduction of the NHS Community Care Act (1990) is maintained to have been a key driver in the rising rate of autism diagnosis in the UK (D'Astous *et al.*, 2016). The Act is one of the first legislative steps taken in the UK making the NHS an 'enabler' of support, rather than a provider (Department of Health, 1990). The Act outlines the role that diagnosis should play in prompting local authorities to provide social and health care for people with additional needs. The creation of the Act is maintained to be linked to a push to broader community-based interventions for people with a diagnosis of autism (D'Astous *et al.*, 2016). The role of education and schools is poorly defined within the term 'community-based intervention' (McLeroy *et al.*, 2003; D'Astous *et al.*, 2016). However, the legislative assertion that schools must provide support for children with additional needs has continued into the more recent Children and Families Act (2014), which may suggest that schools are often implied within the legislative reference to 'community-based interventions' (McLeroy *et al.,* 2003; DfE, 2014). This may have led to an NHS impetus to diagnose to prompt schools to put support in place (Paget and Emond, 2016). However, as a result of the Children and Families Act (2014), schools have come under less direct control of local authorities, operating more independently (DfE, 2014). It could therefore be considered that autism diagnosis is given as a way of ensuring that schools provide support for children with additional needs in the absence of an empowered local authority that can hold schools to a greater level of accountability. This is explored by the paediatricians when they discuss the function of diagnosis in terms of accessing additional support.

e.g.:

PD3: 'I think it's a shame that children have to have a diagnosis in order to access additional support. I think there are…a certain amount of support should, be, be, able to be put in, if a child has a difficulty without a diagnosis, but I think, in reality, they need- most, most people, because of resources being limited, want a child to have a diagnosis before they'll give them a certain amount of support.'

PD3: 'So, some support needs a diagnosis, because you have to have a lid on who can access it because it isn't an unlimited resource. So, they have to priorities that resource. So, say, for instance, the Communication and Autism Team, they have to limit their resource because they're only funded to do a certain number of hours, and they're limiting that to those in most need. And you could argue that generally across the city, those in most need are the ones with the m-more difficulties. They're more likely to be the ones with the diagnosis. But I wish there was enough resource that if somebody had difficulty in one area, they could just have help for that one area.'

PD1: 'The reason that most of them give us is they say that schools will not help them unless they have a diagnosis. That is what we are told more or less by every single person, by every single parent.'

PD2: 'For me, it describes their need and for anybody else who's using it, that should mean what support they should have. That's why I'm describing their need. It's all about understanding and the support, and then having somebody there to, sort of, answer their question.'

The Communication and Autism Team is a support service within the city, mainly working with schools, but which can only be accessed once a child has received a diagnosis of autism. PD3, in the above quotes, is suggesting that diagnosis acts as a resource allocation tool. Research into parental and professional views around diagnosis suggest that diagnosis is often perceived as tool to unlock intervention and treatment (Crane *et al.*, 2016). However, many parents, and professionals, are often dissatisfied by the lack of support available post diagnosis (Crane *et al.,* 2018). PD3 describes diagnosis as a tool for managing ‘finite’ resources, a practically grounded consideration of support which is in contrast to the bioecological focus on changing interactions (Bronfenbrenner and Morris, 2007). PD1 and PD2 discuss with more subtlety the link between diagnosis, community interventions, and description and understanding. PD1 suggests that there is a common pattern amongst the parents they see who ask for a diagnosis so their child can access support in school. This highlights the potential confusion that can exist around school inclusion and community-based interventions. PD2 discusses the more bioecological role that diagnosis can play in helping parents to access additional support. PD2 conceptualises diagnosis as a tool to communicate to other agencies and professionals ‘what support [a child with autism] should have’. PD2 suggests that alongside this practical enabling of intervention from other support services, that diagnosis also facilitates supportive discussion with parents. PD2 says that diagnosis is ‘all about understanding and support’ and suggests that parents benefit from having somebody there to ‘answer the questions’. This quote gives us the suggestion that the function of diagnosis is partly to address the contextualised bioecological need of parent and child interactions (Bronfenbrenner and Morris, 2007). PD2 describes a consultation approach usually more frequently associated with educational psychology (Kelly, Woolfson and Boyle, 2008). The above quotes from the paediatricians suggest that their adoption of the medical model leads them to consider diagnosis as tool to practically manage access to limited resources. However, they also suggest that this is only partly sufficient for families and bioecological issues need to be addressed to help support children with additional needs effectively.

EPs' Views

The EPs and paediatricians were all keen to ensure that children with identified needs were able to access additional support, resources and, interventions. The paediatricians spoke about currently limited resources and the necessity of diagnosis for children and families to access support primarily through schools. The EPs took a more critical approach, suggesting access to intervention does not require a diagnosis of autism.

e.g.:

EP1: 'That was what the disagreement was. "But they need support! How are they going to get support?" I said, "well they do go to school have a notional SEN budget of up to six thousand".'

EP1: 'I think people find autism quite complex concept to get their heads around, so complex that is a belief that it's not easily dealt with or addressed or supported in school.'

EP3: 'There's sort of this huge pressure. You know, for a diagnosis. Because the children do enter school with significant needs and as school support, I think has become less available it throws up those needs even more.'

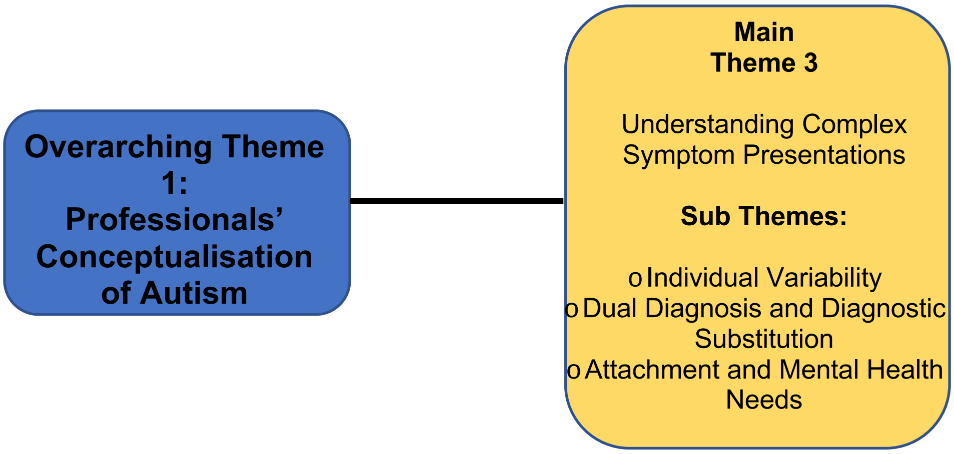
EP2: 'That's where you'd go back to looking at them as an individual, where are they, what do they need in all areas of development, and in a child like that, social communication would just be one area you'd be looking at to support them in.'

EP1 highlights the practical support strategies available to children in school. EP1 reports that children are entitled to ‘six thousand’ pounds of additional support without a diagnosis. They go on to say that that people can find ‘autism quite a complex concept’, suggesting that there is a false belief that it is not ‘easily addressed’ in school. This focus on intervention rather than the ‘complex concept’ of autism indicates EP1’s bioecological approach to supporting additional need. Whilst EP1 suggests there is almost no requirement to have a diagnosis to access additional support, EP3 reports an awareness of the limited resources available to children and families and the ‘huge pressure’ this creates to seek a diagnosis. They, however, also describe the link between unsupported needs and requirement for diagnosis. This further highlights the contextualised and interactive perspective of the EPs’ bioecological approach, where conceptualisation of childhood need is entangled with the support that they are provided with from the adults and systems around them (Bronfenbrenner and Morris, 2007). EP2 expands on this position by describing the need to focus on the individual ‘where are they, what do they need in all areas of development’ to provide intervention and support rather than diagnosis of single needs.

Summary

The EPs and paediatricians both recognised that limited school and community resources have resulted in an increased demand for autism diagnosis. The paediatricians often saw diagnosis as a tool to enable intervention in other settings but recognised the limitations of diagnosis to support more immediate bioecological needs. The EPs, adopting the bioecological approach to a greater degree, suggested that diagnostic labels aren’t needed at all, and that intervention should be focussed on the holistic needs of the individual rather than their diagnosis. Alongside the difference in perspective between the EPs and paediatricians, they are also likely influenced by the context of their practice. EPs are heavily influenced by the Children and Families Act and may have a much greater awareness of the funding streams available to schools (DfE, 2014; Fox, 2015). EPs more often work directly with schools and have a greater awareness of the notional budget that schools can access to support students. Their bioecological focus may also steer their practice towards localised interventions within school settings focussing on interactions between adults and children (Waite and Woods, 1999; Bronfenbrenner and Morris, 2007). Paediatricians, on the other hand, may be more likely to be influenced by the Equality Act, Community Care, and the Autism Act (DoH, 1990; Parliament UK, 2009; DoE, 2010). These differences in role and legislative focus for the paediatricians might be associated with a more medical and biological perspective around diagnostic labels where diagnosis leads to ‘treatment’ and becomes a protected characteristic that must be supported (Frances and Widiger, 2012). However, autism is not a medical condition with clear identifiable biomarkers and ‘treatment’ is often based on social and interactive support provided for children in schools (Skellern, Schluter and McDowell, 2005; Ravet, 2011). This may mean that there is some tension and contradiction when medical diagnosis is used to arrange additional support which requires a bioecological focus. This is alluded to when the paediatricians discuss a need for parents to understand the impact of their child’s autism diagnosis to feel supported. It could therefore be suggested that part of the enduring dissatisfaction that parents report around not having access to additional support following diagnosis arises from the disconnect from the medical profession and sources of additional support and a lack of bioecological support (Crane *et al.,* 2018).

4.2.3 Main Theme 3: Symptom Presentations



The participants frequently spoke about how they developed an understanding of the varied symptom presentations that they encountered in their practice. They spoke about how they developed and applied their professional perspective and conceptualisations of autism to diagnose and understand heterogenous and variable individual needs. As such, the main theme of **‘Understanding Complex Symptom Presentations’** was developed. Through the analysis of the data, the subthemes **‘Individual Variability**, **‘Dual Diagnosis and Diagnostic Substitution’**, and **‘Attachment and Mental Health Needs’** were developed. The participants spoke about the challenges they faced when trying to account for individual differences during diagnosis, the phenomena of dual diagnosis and diagnostic substitution, and they placed particular emphasis on their experiences of having to consider attachment and mental health needs. These discussions were often related to, but were distinct from, the participants’ discussion of diagnostic criteria. This main theme represents the participants’ attempts to understand their experience of symptoms and behaviours within the conceptualisations they have developed from their experiences and professional perspectives.

4.2.3.1 Sub-Theme: Individual Variability

Autism is maintained to be a disorder high in inter and intra heterogeneity (Fitzgerald and Excellence, 2016; Fitzgerald and Callard, 2017). This often means that professionals have to account for a high degree of variability and uncertainty when engaging in autism diagnosis to differentiate autism from other comorbid needs (Fitzgerald and Excellence, 2016).This research explores how paediatricians’ and EPs’ medical and bioecological perspectives influenced their experience of ‘indeterminate’ autism and associated presentations (Fitzgerald and Callard, 2017; Hollin, 2017). The paediatricians and EPs discussed how they differentiated autism from other similar conditions when presented with a high level of individual variability (Doshi-Velez, Ge, and Kohane, 2014).

Paediatricians’ Views

The paediatricians often spoke about the limitations of their medical perspective when trying to consider individual variability whilst differentiating autism from bioecological needs. They highlighted the restrictive nature of diagnostic categories and difficulty assessing complex or ‘uncertain’ presentations (Hollin, 2017).

e.g.:

PD1: ‘It’s about untangling is it autism or is it something else. Which could just be, maybe that’s learning difficulties, maybe it’s another neurodevelopmental disorder, maybe it’s a medical condition. Maybe it’s just behaviour because of issues in the family, and that’s one of the things we find difficult because we don’t know very much about the social background of the family.’

PD2: ‘There are lots of things allied [with autism and] and newer development of things. But it’s not quite autism. It doesn’t fit the category or criteria that we go by. We still call it autism because there isn’t any specific name, or the names are not good enough. For example, learning difficulties is a good name for me, but it’s not a good diagnostic name.’

PD3: ‘Then you have to ask, “What’s the benefit in having a more niche diagnosis if you can’t target them with a particular therapy or management?” So, if there’s no point to that, then what’s the point in doing it? I personally find it better to say, “They, they meet the threshold for this diagnosis. This is this child’s individual needs.”

PD2 suggested that despite the fact that the criteria for autism has expanded in an attempt to include a wider range of individual heterogeneity and additional need, it is still limited in its ability to encapsulate bioecological wellbeing (Skellern, Schluter and McDowell, 2005; Hollin, 2017). This is demonstrated when PD2 says autism is ‘not a good diagnostic name’, describes needs which don’t ‘quite fit the category’ and needs being diagnosed as autism, which are ‘not quite autism’. The application of an autism diagnosis where other needs are present may be due to several factors, including how the medical perspective influences how the paediatricians conceptualise and experience individual variability in presentations of autism (Evans and Trotter, 2009; Hollin, 2017). The paediatricians’ medical perspective may provide them with a mandate to categorise and diagnose needs. When faced with uncertainty in individual presentations they may be forced to accommodate needs which ‘are not quite autism’ within the diagnosis. PD1 speaks about the difficulty they have ‘untangling’ bioecological need from autism. They suggest that their medical perspective and approach is not well equipped to consider the ‘social background of the family’. PD1 may be describing a particular limitation of the medical conceptualisation of additional need and subsequent approach, where finite criteria cannot account for variable, contextualised, and systemic needs of an individual (Bronfenbrenner and Morris, 2007; Scotland, 2012). PD3 recognises this limitation of diagnostic criteria when considering individual variability and suggests that to overcome this, they have said to parents, ‘They meet the threshold for this diagnosis. This is this child’s individual needs.’ It is clear that PD3 recognises the limitations of diagnostic criteria and its inability to accommodate for biogeological need. As a result, PD3 has chosen to speak separately about fulfilment of diagnostic criteria and individual need. The ICD-10 and DSM-5 outline the diagnostic criteria used by the paediatricians when assessing for autism (World Health Organisation, 2012; APA, 2013).

e.g.:

PD3: ‘Ultimately, we use the ICD-10 or DSM-5.’

In Section F84.12, the ICD-10 outlines the features of atypical autism (World Health Organisation, 2012). In this section, the ICD-10 suggests that a diagnosis of autism can be given if there are atypical symptoms that are not congruent with ‘childhood autism’ (WHO, 2012). It suggests that for atypical autism to be diagnosed, the child does not have to have symptoms present before the age of 3 or show the same, or all, of the symptoms for a diagnosis of ‘childhood autism’ (WHO, 2012). This means that an extremely broad set of symptoms can be included within a diagnosis of autism (Kapp, 2013). This may partly explain the reported rise in autism and why the paediatricians feel able to diagnose things that are ‘not quite’ autism, as autism. A suggested solution for this is a great focus on sensory abnormalities within the autism diagnostic criteria (Kapp, 2013). The inclusion of broader symptom types in autism diagnosis reported by the paediatricians may also be linked to changes in DSM criteria where autism as a spectrum disorder has subsumed diagnostic categories like Pervasive Developmental Disorder Not Otherwise Specified (Smeeth *et al.*, 2004; Rosenberg *et al.*, 2009). This is considered by PD3 when she questions the purpose of having a more ‘niche’ diagnosis if it does not lead to more effective targeted treatment. This echoes some of the concerns from both groups of participants about the broadening, medically based, conceptualisation of autism where they have suggested that it has become a less effective label to describe individual need (Frances and Widiger, 2012; Waterhouse, 2013).

EPs’ Views

The EPs reported feeling more comfortable when presented with heterogenous individual symptom presentations (Bronfenbrenner and Morris, 2007; Evans and Trotter, 2009; Burnham, 2013). The adoption of a bioecological and socio-constructivist approached, under an interpretivist paradigm, may relieve EPs of the need to stick to criteria and categorise a child's difficulties within a diagnostic label (Bronfenbrenner, 1979; Kelly, Woolfson and Boyle, 2008). This may help them to approach needs that arise from outside a medical or biological framework, resulting in a low level of felt pressure to provide a diagnosis (Evans and Trotter, 2009). In the below quotes, EP1 gives a clear response when asked if they thought their philosophical perspective enabled them to respond to 'uncertain' presentations more effectively.

e.g.:

EP1: 'Yeah absolutely, and I like that uncertainty [sic]! Because, it gives you more sort of scope for when you're giving advice, support, and recommendations. Well actually I don't even go according to, if it's autism, I have to know it is autism, the only thing that might change in regards to [social, emotional, mental health] is perhaps we're still going to work on emotional regulation, we're still going to work on developing social interaction or social communication skills, but maybe the way it's going to be done is slightly different.'

EP2: 'You might have to try a lot of different things an explore a lot of different avenues until you actually decide yes this is the best way to conceptualise this child's difficulties.'

EP3: 'You know, if someone has this diagnosis, yes, we know they're probably going to have some problems with communication and social skills. But what that actually looks like for the individual is so varied, isn't it?'

EP2 discusses the many 'avenues' they can travel down to decide 'the best way to conceptualise' a child's needs. The ability to 'explore' lots of different avenues indicates the multi-systemic focus of their bioecological perspective.

The active tone of exploring avenues of need also suggests an involved interventionist approach to the 'conceptualisation' of additional need (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008). This quote suggests that the EP feels confident applying the bioecological perspective to heterogenous individual needs. EP3 suggests that there is a high level of variability in the needs of individuals. They suggest that diagnosis does not help them to understand individual child variability. It has been suggested by several authors that EPs adopt more pragmatic, predominantly socio-constructivist and bioecological approaches in their practice (Bronfenbrenner, 1979; Kelly, Woolfson and Boyle, 2008; Burnham, 2013). Research has demonstrated that professionals who adopt these approaches are less likely to feel stress or give affirmative diagnoses when faced with uncertain presentations of 'autism' (Skellern, Schluter and McDowell, 2005; Evans and Trotter, 2009). The bioecological framework allows professionals to consider the biological reality of symptom presentation and many contextual and systemic factors that can determine an individual child's development (Bronfenbrenner and Morris, 2007). This broad perspective may help to give the EPs epistemological 'space' to account for individuality and uncertainty, resulting in a greater level of confidence and optimism in the absence of diagnosis (Evans and Trotter, 2009).

Summary

The paediatricians report experiencing challenges when trying to apply the label of autism to an inherently variable and heterogenous set of individual and bioecological needs (Skellern, Schluter and McDowell, 2005; Bronfenbrenner and Morris, 2007; Hollin, 2017). In contrast to the paediatricians, the EPs reported that they enjoy the 'uncertainty' of autism diagnosis. They suggest that the bioecological perspective gives them freedom and flexibility to explore different areas of need with confidence. They have suggested that they do not feel bound to diagnostic criteria and that this allows them to feel more comfortable when faced with individual presentations of need. In line with best practice, there should be multi-disciplinary working taking place around autism diagnosis and consideration of various professionals' perspectives (Skellern, Schluter and McDowell, 2005; NICE, 2011; Fitzgerald and Callard, 2017; Hollin, 2017). This is done to ensure that differential diagnosis can take place effectively, separating out bioecological and medical needs (Skellern, Schluter and McDowell, 2005; Waterhouse, 2013; Hollin, 2017). The positive approach of EPs to individual presentations of autism is valued by the paediatricians and discussed further in **Section 4.5**.

4.2.3.2 Subtheme: Dual Diagnosis and Diagnostic Substitution

The participants also spoke about their experiences of dual diagnosis and diagnostic substitution. Dual diagnosis refers to the phenomenon where children who, under previous conceptualisations of autism, would have only received one diagnosis, now receive two. For example, under the broader conceptualisation of autism, children with Downs Syndrome often have their social communication needs identified separately. Individuals are then given a separate, additional diagnosis of autism (Bishop *et al.*, 2008; Crane, Batty, Adeyinka, Goddard, *et al.*, 2018). Diagnostic substitution refers to the application of one diagnosis at the expense of another (Bishop *et al.*, 2008). For example, a learning or language delay may be diagnosed as autism if the child meets diagnostic criteria, giving them an autism diagnosis rather than a label identifying their learning need (Bishop *et al.*, 2008; Leonard *et al.*, 2010; Jensen and Steinhausen, 2015). Diagnostic substitution has reportedly contributed to the rising rates of autism diagnosis (Bishop *et al.*, 2008; Leonard *et al.*, 2010). Autism epidemiology research also suggests that dual diagnosis has partially contributed to the rise in rates of autism (Bishop *et al.*, 2008; Doshi-Velez, Ge and Kohane, 2014). This trend has also been noticed by the participants in this study, with the paediatricians providing some of the most significant commentary during their interviews.

Paediatricians' Views

The paediatricians reported experiencing diagnostic substitution and dual diagnosis more frequently than the EPs. They suggested that these phenomena of diagnosis had contributed to a significant rise in autism in their casework.

e.g.:

PD1: ‘A lot of children who in the past would have had that diagnosis of intellectual disability now will have additional diagnosis of autism and intellectual disability, which is perhaps a good thing, that that there is that identification, it’s not just a global identification of disability they do have factors that are more specific as well that are related to autism.’

PD2: ‘Everything is called autism. For example, a child with Down’s Syndrome has got learning difficulties, which is a known factor because of chromosomal problems, that’s how the child is made. Now, learning difficulties will have a lot of features which will be autistic or within the autism spectrum, which we knew for ages, for years, hundreds of years. But now, those features, which are autistic features, are separately identified as autism, which we never used to do in the past. We would just say, “this child’s got Down’s Syndrome,” and that would include learning difficulties, autism, hearing problems and lots of other things, which is the syndromes symptoms. But now, it has to be Down’s Syndrome, autism, and short stature. What I’m saying is, lots of things are broken down now, and that autism bit, which is a part of many conditions is taken out and named autism.’

PD3: ‘I suspect that many of the children that now have a diagnosis of ASD would’ve previously had a diagnosis of semantic pragmatic, but no one would really understand what that means. They would’ve had a more specific diagnosis before, whereas now they’re just ASD and I do think that that’s probably the best way is to make it more general.’

PD3: ‘My understanding is that the different groups were arbitrary based on whether they had various classifications. Like whether they had speech and language delay, or learning difficulty associated with their difficulties, whether they had all three of the areas of autism or just two, for instance. I think that there wasn’t a lot of evidence that a different intervention in that group helped. So, if there’s no evidence that this group needs different treatment or management then what’s the point in putting them in an arbitrary group?’

PD2 speaks with hyperbole saying, ‘everything is called autism’. This is reminiscent of the language used in the previous PD1’s quote in **Section 4.2** where they say, ‘autism has taken over’. There is the suggestion in the above quote that instead of a focussing on individual need within a diagnostic label, autism is now identified separately. PD1 seems to suggest that this additional identification is a good thing for children. However, they do not say why this may be so. They suggest that autism is a more ‘specific’ diagnosis for identifying need. This is in contradiction to the earlier claims by most participants in **Section 4.2** who suggest that autism as a spectrum disorder is too broad to accurately describe individual need. It may be that the paediatricians are assuming that an autism diagnosis is beneficial for families as a result of the influence of their medical perspective. However, this cannot be assumed given the current high rates of dissatisfaction that parents report both during and after a diagnosis of autism has been given (Crane *et al.*, 2016; Crane *et al.*, 2018). Qualitative interviews and survey data suggest that parents and patients are critical of the autism diagnosis procedures, saying that they receive more information, support, and guidance when being assessed for other medical conditions, such as cancer (Crane *et al.*, 2016; Crane *et al.*, 2018). This may therefore highlight the limitations of the medical model in diagnosing autism where a bioecological model may be more useful to parents if there is a separately identified social communication need (Skellern, Schluter and McDowell, 2005; Newland, 2015; Crane *et al.*, 2018). It is therefore important to explore the utility of additional diagnoses for parents and children where dual diagnosis has taken place. PD3 discusses diagnostic substitution and autism. She suggests that previous, more specific diagnoses, such as ‘sematic pragmatic disorder’, were just indicators of a different configuration of traits within the autistic spectrum.

EPs' Views

The EPs also reported experiencing dual diagnosis and diagnostic substitution in their casework. They reported concerns that when this occurs autism can become the primary focus, distracting from other mental health, developmental, and bioecological needs that the child may be experiencing.

e.g.:

EP2: 'Even in the children where the diagnosis is right, I think it's becomes the only thing that's become focussed on for that's child's difficulties. It's become kind of the predominant and dominating view of that child. So even in some cases, well loads of cases, where I feel that it's not where I think the diagnosis is wrong. Now everything is being perceived through the lens of autism and actually there are other things going on for this child and the interventions are all being [delayed].'

EP2: 'I think we are missing, kids with general learning difficulties. I had one in a school the other day where parents were pushing for an autism diagnosis, fits lots of boxes for and autism diagnosis, when talking to the SENCO, mum describing all the social difficulties that he had, and talking to the SENCO actually his social development is in line with his general development.'

EP2 suggests that the criterion assessment methods for autism are unhelpful as they mask other types of additional need. The above quotes highlight the EPs' relative ambivalence to diagnostic criteria compared to the paediatricians. They suggest that by focussing on criteria, professionals are not taking into account the circumstance or context of additional needs. EP2's experience of dual diagnosis and diagnostic substitution appears to be focussed around learning needs. EP2 describes how an autism diagnosis can become the 'predominant and dominating' view of a child. They suggest that whilst they may not disagree with the diagnosis of autism, they do feel that it can limit their ability to consider the child holistically. EP2 suggests that diagnostic substitution is a particular issue when considering learning needs. This highlights the EPs' bioecological perspective and preference for focussing on individual need and systemic context (Bronfenbrenner, 1979; Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008). This is contrasted with the medical model of autism, adopted by the paediatricians, where correlation equals cause, and autism is diagnosed through criterion-based assessment (Bishop *et al.*, 2008; Scotland, 2012) .

Participants from both groups suggested that diagnostic substitution is a key driver in the reported rise of autism rates, reflecting findings from epidemiology research (Bishop *et al.*, 2008; Leonard *et al.*, 2010). EP2's quote below reflects the confusion around diagnostic substitution suggesting that the EPs may be concerned by the narrowing focus of the referrals that they receive.

EP1 suggests that diagnostic substitution has occurred in a large portion of their casework over time. They express that earlier in their career, they encountered a wider range of learning needs. They compare this experience to their current casework, which they suggest is predominantly autism focussed. EP1 goes on to suggest that autism can subsume a wide range of developmental needs reflecting their commentary on the breadth of the autistic spectrum and its limitations in **Section 4.2**.

e.g.:

EP2: ‘So you partly wonder yeah where have all the autistic children come from but also where have all the others gone [sic]?’

EP1 ‘I can’t even remember the prevalence when I started out, but there were more PMLD, severe learning, there was a range of features, speech and language, in terms of pre-school allocations, whereas now it’s like, 1 in 5 isn’t an autism diagnosis.’

EP1: ‘If they’ve got social emotional difficulties, it’s autism, if it’s speech and language, it’s autism, if it’s emotional difficulties it’s autism, so the only way autism isn’t there is if it’s PMLD or even severe learning difficulties it’s autism.’

EP3: ‘The wrong diagnosis may lead to, erm, you know, an absence of the right factors, like a key adult support to the family. You know, can some of those attachment issues be addressed within the family?’

EP3: ‘You know, you should be looking for those, those examples where, “Well, actually, is that the right diagnosis?”’

EP3: ‘What are we looking for that would say to us, “Actually, you know, no. This child does have difficulties, but it may not be autism.”’

EP1 reports that dual diagnosis and diagnostic substitution can occur for a range of issues including ‘emotional difficulties’ and ‘severe learning needs.’ Their repetition of ‘it’s autism’ suggests that they are frustrated by the replacement of these needs and conditions with a diagnosis of autism. EP3 comments on the ‘wrong diagnosis’ and its impact on intervention. They suggest that for the EPs, just because diagnostic criteria can be met by an autism diagnosis, it should not always be confirmed. Both EP2 and EP3 suggest that diagnostic substitution and dual diagnosis of autism can be problematic because it can limit the perspective of others when considering additional needs. Their bioecological perspective is apparent when they suggest that this is an issue because it can lead to ‘an absence of the right factors’ or delayed ‘interventions’.

Summary

Both the paediatricians and EPs reported a high rate of diagnostic substitution and dual diagnosis in their casework. The EPs queried diagnostic substitution around learning difficulties, expressing some frustration. They suggested that where dual diagnosis and diagnostic substitution had occurred, they limited professionals’ ability to apply bioecological interventions. The paediatricians also queried the utility of dual diagnosis and diagnostic substitution, suggesting that autism had ‘taken over’ and did not necessarily led to more effective treatments and interventions. The paediatricians and EPs were both in agreement that diagnostic labels should be applied to ensure accurate support and interventions for children with additional needs. The paediatricians’ commentary on dual diagnosis and diagnostic substitution was influenced by their medical perspective. In contrast to the EPs, they suggest that dual diagnosis and diagnostic substitution could be helpful to parents.

4.2.3.3 Subtheme: Attachment and Mental Health Needs

Attachment and mental health needs can present similarly to autism and many of the interventions provided to address the underlying needs are the same (Rutgers *et al.*, 2007; Teague *et al.*, 2017). The bioecological sources of attachment and mental health needs may however be very different from the causes of autism (Rutgers *et al.*, 2007; Teague *et al.*, 2017). Below, the participants discuss their experiences of casework in this area, with some consideration of the implications and processes of discerning between autism and other bioecological needs.

Paediatricians' Views

The paediatricians reported concerns about the limitations of their approach to autism assessment, and their lack of training around mental health and social, emotional need. They strongly suggested that they were not well equipped to differentiate between autism and bioecological needs in this area.

e.g.:

PD1: 'Attachment's a difficult one. If there is a history of reasons for having an attachment disorder then yes, we definitely would be considering that, and thinking about how strong is the attachment and how much is it autism [sic]. There's so much overlap. We're not the best people to make the distinction because we're not psychol-clinical psychologists [sic]. We don't have access to clinical psychologists to do this, so we have to do the best that we can, with the tools we have.'

PD2: 'No. Mental health? No. I'm not trying to do that at all. Attachment [sic]? Because I do looked after children for many years as well, so that is very at the top of my thought process [sic]. I don't think everybody has that, because they don't do that work. I do always look at that, and I look at mum's alcohol consumption, mum's drug consumption, or pre-natal problems. Those are the things doctors need to look at, because I know psychologists are not going to look at that. I do look at all of that, because that's what I've been trained to do for a long time, but I often don't know what to do with it. And, you know, it's more a can of worms than anything else.'

PD3: 'Sometimes you do need to go back to the families and say, "You know, I don't think its autism, but, you know, here's some support to help you manage their behaviours."'

PD1 suggests that paediatricians are not ‘the best people to make the distinction’ between mental health, bioecological needs, and autism (Rutgers *et al.*, 2007; Doshi-Velez, Ge, and Kohane, 2014; Jensen and Steinhausen, 2015). They describe the challenges they face differentiating between autism and attachment needs because ‘there’s so much overlap’ between the symptom presentations. PD1 suggests that as medical professionals, they are not as prepared as psychologists to differentiate between two. PD1’s hesitation around naming psychology services and then saying they don’t have access to ‘clinical psychologists’ may suggest that the paediatricians feel that EPs are reluctant to become involved in multi-disciplinary diagnosis. The inclusion of clinical psychologists, rather than educational psychologists may indicate the paediatricians feel that clinical psychologists aid with diagnosis, where EPs do not (Skellern, Schluter, and McDowell, 2005). This may arise from the EPs’ historic traditional adoption of socio-constructivist and anti-labelling perspectives within their bioecological position (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008). Clinical psychologists may take a more positivist and empirical approach to diagnosis, supporting mental health needs more frequently, and spanning the gap between bioecological need and medical diagnosis more effectively from the point of view of the paediatricians (Skellern, Schluter and McDowell, 2005; Rutgers *et al.*, 2007). PD1’s commentary on ‘overlap’ between autism and attachment needs may also suggest that criterion assessment and a medical approach is limited in its ability to consider underlying causes of childhood additional need. PD2 asserts that they ‘not trying to do that at all’ when it comes to assessing mental health and bioecological need. They suggest that due to their experiences working with looked-after children that they are more aware of bioecological factors, such as maternal health and wellbeing, compared to other medical professionals. Despite this relative bioecological focus, PD2 does not feel that they are able to effectively differentiate between autism, mental health, and attachments needs. This may indicate their awareness of the limitations of the medical perspective during autism diagnosis. This is highlighted with their particularly emotive 'can of worms' phrasing, suggesting that the experience of encountering bioecological needs for paediatricians can be stressful and overwhelming. It may be that the paediatricians do not feel that they have the training, or professional perspective, to decipher between bioecological and psychological needs from autism, and as such, may be more likely to provide a diagnosis of autism when a child meets the criteria (Evans and Trotter, 2009). PD3 briefly comments on the difficulty they have differentiating between autism and parenting needs. They suggest that they can sometime assume autism is present but 'have to go back to families' to say, 'I don't think it's autism'. This indicates the complex back and forth of differentiating between bioecological and medical needs and the requirement for paediatricians to 'go back' and reconsider their initial assumptions.

EPs' Views

Although the EPs expressed some concern about autism diagnosis subsuming learning needs, they were much more critical of diagnostic substitution in instances of comorbid/overlapping mental health and broader bioecological needs (Doshi-Velez, Ge and Kohane, 2014; Lyall *et al.*, 2017). A key area of concern for both groups was the presentation of children with attachment needs and how they would be considered during an assessment for autism.

> e.g.:
>
> EP1: ‘I am saying we should be confident in saying “we think this child’s got attachment difficulties”, we believe that they presenting in ways that are indicative of early life trauma, we believe there are learning difficulties, take that information and decide whether you want to give them an autism diagnosis.’
>
> EP2: ‘I don’t know if everybody seems to know, everybody talks about the fact that attachment and autism present so similarly and it’s very hard to tell them apart, and yet we see, time and time again, children with traumatic backgrounds, attachment difficulties, that’s been noted. So that’s why I say it’s not like it’s being missed, it’s not like nobody knew that information, it’s being noted but it’s almost disregarded because the sufficient box is ticked that fits with the label. So that’s one of the big ones I think we are not missing it, we’re aware of but carrying on regardless.’
>
> EP2: ‘I think things are definitely being missed or maybe not missed, missed is probably the wrong word, but they’re being noted but they’re not being given sufficient weight in considering, the complete needs of that child, and I think that those things would include, well the big one is the attachment. Well broader than attachment, you know, the trauma and the emotional needs and all those sorts of things, and it’s incredible.’
>
> EP3: ‘I think there are those children with real attachment difficulties, because their presentation can be similar, can’t it? You know, there can be an absence of wanting to, kind of, interact as sort of a closed presentation.’

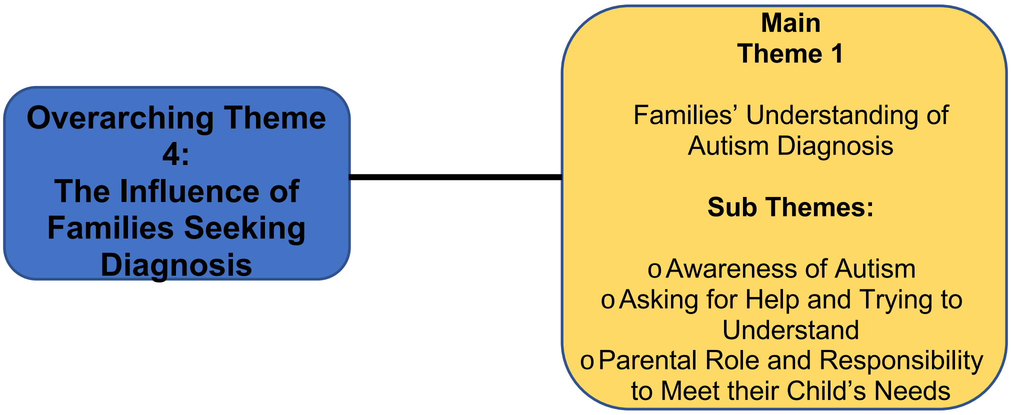
The EPs in the above quotes highlight what they perceive as a limitation of the medical perspective’s criterion assessment of autism (Skellern, Schluter and McDowell, 2005; Doshi-Velez, Ge and Kohane, 2014). EP2 speaks about ‘sufficient boxes’ being ticked and not taking into account ‘broader’ social emotional needs. The comorbidity of autism and attachment needs are well known (Rutgers *et al.*, 2007; Teague *et al.*, 2017). EP2 however suggests that some social, emotional needs are broader than the diagnostic category of autism (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008). They suggest that ignoring these needs in favour of needs which can be encapsulated under medical criteria is 'terrible'. EP3 comments briefly on attachment needs recognising that autism and attachment needs 'can be similar'. EP2 reports that 'everybody knows' that attachment and trauma needs can present similarly to autism. They suggest that attachment needs aren't 'being missed' by other professionals but that a diagnosis of autism is often provided because 'the sufficient box is ticked that fits the label'. EP2 suggests that is it a challenge to formulate and differentiate between autistic and bioecological needs, such as attachment and trauma difficulties. They suggest that the paediatricians are limited by the adoption of a purely medical perspective when considering attachment needs and can be bound to providing a positive diagnosis. EP1 suggests that their role is not to confirm autism but instead to outline alternative formulations of attachment needs to help the paediatricians to diagnose. This suggests that EP1 is much more comfortable identifying attachment needs compared to autism as a result of their bioecological perspective.

Summary

The above quotes highlight the paediatricians' view that they are extremely limited and 'doing the best' they can to assess mental health and bioecological need that may present similarly to autism (Rutgers *et al.*, 2007; Doshi-Velez, Ge, and Kohane, 2014; Teague *et al.*, 2017). Research suggests that a purely medical approach to diagnosis limits multi-disciplinary practice and the consideration of other approaches and perspectives (Strunk, Leisen and Schubert, 2017). We can see from the above quotes that the paediatricians recognise this limitation. Attachment, mental health, and other bioecological needs can present similarly to autism (Rutgers *et al.*, 2007; Hollin, 2017; Teague *et al.*, 2017). The above quotes clearly highlight the paediatricians' view that they are not well equipped to deal with, assess, or support these needs. The EPs in contrast feel much more confident in identifying attachment needs as a result of their professional perspective. They expressed some frustration that attachment and historical developmental needs are often known by professionals but not considered during diagnosis or are inaccurately labelled as autism when the 'sufficient box' is ticked. The EPs' bioecological approach became apparent when they discussed their views around supporting the paediatricians to diagnose. EP1 reported that they felt their role was not to diagnose autism but to provide an alternative formulation of need.

4.3 Overarching Theme: The Influence of Families Seeking Diagnosis

4.3.1 Main Theme 1: Families’ Understanding of Autism Diagnosis



This research project focusses on the views and experiences of professionals. The discussions which took place held a significant focus on the role that parents play in the diagnostic process. There was one question included in the semi-structured interview schedule which asked participants **‘What involvement do you have with parents when trying to decide if their child presents as having autism?’**. This was the only question included related to the role of parents and autism diagnosis. However, families became a dominant theme throughout the interviews conducted, with professionals holding different views on the role that families can and should play. The participants almost exclusively spoke about their experience of families who wanted a diagnosis for their child and how this affected their practice. This led to the development of the overarching theme of **‘The Influence of Families Seeking Diagnosis’**. The participants spoke about a wide range of interrelating and connected topics in regard to the influence of families. This included family understanding of autism, parents' role in supporting their child with additional needs, and parents' attempts to get help and support prompted by diagnosis. As a result, the subthemes **'Awareness of Autism'**, **'Asking for Help and Developing Understanding'**, and, **'Parental Role and Responsibility to Meet their Child's Needs'**, were developed.

4.3.1.1 Subtheme: Awareness of Autism

Research suggests that the reported rise in autism is partly due to increased awareness amongst both professionals and the general population (Taylor, Jick and MacLaughlin, 2013; Yates and Le Couteur, 2016). Both EPs and paediatricians felt that awareness of autism amongst the parents was a key factor in the increased rates of autism they had experienced.

Paediatricians' Views

The paediatricians spoke directly about the link between autism awareness and referral rate.

e.g.:

PD1: 'There is a lot more recognition of these difficulties at a much younger age, from everyone, parents, professionals.'

PD2: 'I think there's more awareness of autism by GPs, by other health professionals, and by parents.'

PD3: I don't think they necessarily always came with that question. They came with the problems. Now, they kind of come with a, "I think my child's got autism." So, they're more aware.'

The paediatricians all suggested that increased awareness amongst parents had led to an increase in the number of referrals they had received. PD3 suggests that this increased awareness of autism amongst parents has prompted them to seek a diagnosis of autism rather than a general solution to undefined ‘problems’. This may suggest that the paediatricians feel like that while the general awareness of autism in the general population has increased, families do not always understand the specifics of the condition (Bishop *et al.*, 2008; D’Astous *et al.*, 2016). The paediatricians provided limited commentary on families’ awareness of autism. They spoke functionally about the broad increase in awareness on the rates of referrals they experienced. This is in contrast to the EPs who, from within their bioecological perspective, considered the cultural factors fuelling this rise and how this rise in awareness has affected diagnosis.

EPs’ Views

The EPs also suggested that awareness of autism had increased amongst parents and families but spoke more frequently about the role that media played in promoting this awareness. This included the changing representation from singular cultural examples like ‘rain man’, to parental ability to search the internet to consider their child’s symptoms.

All three EPs comment on the role of media in increasing families’ awareness of autism. Television is mentioned as a potential driver behind the rising awareness of autism by EP1 and EP3, with EP3 also discussing the role that the internet plays in helping families to understand autism. The consideration of cultural factors by the EPs may also indicate their bioecological perspective and preference to consider the macro-systemic level, cultural influences on the phenomenon of autism (Bronfenbrenner and Morris, 2007).

e.g.:

EP1: ‘Autism is no longer “oh what’s that?”’

EP2 ‘it was kind of something I’d vaguely heard about from rain man, have you heard of rain man?’

EP3: ‘I think parents can look on the internet. They can Google it. They can find information.’

EP1: I’ve seen a TV show, that has shown some quite severe autism, and I mean they’re people who look very difficult and challenging, and sometimes the behaviours that they present with are quite incomprehensible, you know you can’t understand them, you can’t make sense of them, so I think people find autism quite a complex concept to get their heads around.

EP1 suggests that the conceptualisation of autism as a spectrum disorder can be confusing for parents. She suggests that more severe levels of needs can be conflated with children who sit on the ‘lower end’ of the spectrum, leading to the assumption that difficulties are ‘not easily dealt with or addressed’. The EPs suggest that autism and associated need is represented as a fixed state that is not changeable over time. EP1 alludes to the lack of bioecological representation of additional need in terms of how autism is represented in the media. This view of fixed, determined, and severe autism is reflected in EP2’s reference to ‘rain main’.

The EPs differ from the paediatricians, discussing the causes of the increased awareness amongst parents and questioning whether this was beneficial to children, families, and the systems that support them. They suggested that this increase in awareness had led to excessive labelling of additional need as a fixed determined state and the pathologising of traits which may have, in the past, been considered part of normal human variation.

e.g.:

EP1: 'If someone is a bit quirky, "oh it's autism", but if you're quirky for no other reason you're odd!'

EP3: 'It's absolute madness. As I say, it, it just is then another variant, isn't it? It's another variant of human development and maybe that's a point we need to get to, where there's no point in diagnosing it. It's so normal, it's just there.'

EP1 suggests that diagnosing additional social communication needs as autism may relieve the stigma for children and families around behaviour that seems 'odd'. Both EP1 and EP3 suggested that in their experience, there has been a move away from the pathologising connotations which may have been associated with an autism diagnosis in the past (Russell and Norwich, 2012). EP3 goes on to suggest that the tendency to diagnose 'odd' behaviour as autistic has increased to such a point that autistic behaviour has become the new norm and is almost as acceptable as the 'quirky' behaviour, described by EP1, was in the past. This discussion again highlights the EPs' bioecological perspective and their preference for considering additional need within the

PPCT described in Bronfenbrenner's updated model (Bronfenbrenner and Morris, 2007). They suggest that perception of additional need is dependent on the current cultural climate, interactions, and perception of the people involved with the child's behaviour. This is highlighted further when EP3 discusses families who are resistant to receiving an autism diagnosis for their child.

> e.g.:
>
> EP3: 'Some of the parents I meet are not seeking the diagnosis. They're not pushing for it initially. In fact, in many ways they don't particularly want it. Sometimes seen as a bit of a stigma within the community that they're in.'
>
> EP3: 'What does this mean for my child going forwards and what does it mean for my child within this community? How will other people see it? How will I be judged as a parent? There are all of those factors going on.'

The above quotes highlight EP3's awareness of culture, community and context when families are considering a diagnosis of autism for their child. They suggest that community factors can play a big role in influencing a family's perception and acceptance of autism. They suggest that some families can be resistant to diagnosis. This is in contrast to the paediatricians who, operating from a medical perspective, did not discuss the bioecological contextual factors of family awareness to the same degree as the EPs.

Summary

Both the EPs and paediatricians had noticed an increase in the level of awareness of autism amongst parents. The paediatricians noticed that this had resulted in a general increase in the number of referrals they had experienced for autism diagnosis. However, they did not consider the underlying causes of this increase in awareness. The EPs considered family awareness of autism in much more depth as a result of their adoption of the bioecological perspective. The EPs considered the role that the media and the internet played in increasing the awareness of autism amongst families. They suggested that autism is often displayed as a fixed-state condition and that this view of autism can be encapsulated within the autistic spectrum. They were concerned that as a result, normal variations in childhood behaviour can be pathologised under the label of 'autism' and conceptualised as fixed and unchangeable. The EPs also suggest that cultural background played an important role in developing families' understanding of autism and how they interacted with professionals during the diagnostic process.

4.3.1.2 Subtheme: Asking for Help and Developing Understanding

The paediatricians and EPs also discussed what they thought families were seeking when pursuing a diagnosis of autism. Their views were often linked to their professional perspective and subsequent considerations of parental role and requirement to take responsibility for their child's additional needs. Parents often report being dismayed at the lack of available treatment following diagnosis and are not always clear about what they are seeking from a diagnosis of autism (Crane *et al*., 2018). It is therefore important to consider the participants' experience of parents asking for help to consider how parents can be supported effectively.

Paediatricians' Views

The paediatricians reported that they often thought parents were looking for support when seeking an autism diagnosis for their child. In the below quotes, the paediatricians suggest that parents are seeking a diagnosis to access practical support from schools. They also suggest that parents are looking to achieve broader ill-defined 'goals' as a result of obtaining a diagnosis of autism.

e.g.:

PD1: 'I would say that parents are keen on a diagnosis. What are the reasons for that? The reason that most of them give us is that schools will not help them without a diagnosis.'

PD2: 'It looks to me like this diagnosis has some kind of value or something for the families and patient, to achieve some of their goals. You know, sometimes, they would seek a diagnosis of this kind, whereas that wouldn't be our first diagnosis, and I don't know the reason. The reason is something completely beyond us. But it is something that they are after, for reasons which are not medical.'

PD3: 'I think some parents feel that the diagnosis helps them to understand why their child's difficult. Without necessarily feeling the blame of it being due to something they've done.'

PD2, in the above quote, suggests that an autism diagnosis has 'some kind of value' for parents. PD2 suggests that this value is 'not medical', suggesting they are seeking diagnosis to 'achieve some of their goals'. PD2 suggests that this may be to gain a deeper understanding of their child's needs in a way that is 'beyond' the ability of the medical perspective to provide. PD3 however suggests that parents are seeking a diagnosis of autism to absolve them of the 'blame' discussed further in **Section 4.3**. PD3 also suggests that parents are seeking a diagnosis to gain a deeper level of understanding about their child's needs without a focus on bioecological factors. Qualitative interviews and large questionnaire data sets suggest that parents are looking to gain a deeper understanding of their child's needs and are seeking additional support (Crane *et al.*, 2016; Crane *et al.*, 2018). However, parents are reportedly often disappointed by the lack of available support post-diagnosis and want quicker and earlier access to more comprehensive support (Crane *et al.*, 2018). The same research also highlights parents' dissatisfaction and unwillingness to receive alternative diagnoses or formulations if they already 'know' that their child has autism (Crane *et al.*, 2018). This may indicate that parents are looking to gain a number of things, that they cannot often define, from an autism diagnosis for their child. PD2 suggests that parents are not always looking to gain a diagnosis for 'medical' reasons, which could indicate a need for bioecological assessments when undertaking an autism diagnosis. This would help professionals to consider the child's wellbeing within their family system and the role that a diagnosis would serve for the family (Bronfenbrenner and Morris, 2007; Leonard *et al.*, 2010). However, the ill-defined 'goal' that paediatricians discuss and the consideration by PD3 that parents may be seeking to absolve themselves of blame does not fit well with the interventionist dimension of the bioecological approach (Bronfenbrenner and Morris, 2007).

EPs' Views

The EPs also reported that they felt that parents are often seeking some additional undefined goal from diagnosis but thought that parents are not always clear about what they hoping to change. EP2 discusses parental dissatisfaction post-diagnosis.

e.g.:

EP2: ‘I think lots of parents seek the diagnosis because they think it will be something that it’s not. You hear that quite a lot from parents, particularly after they’ve got the diagnosis and then been discharged, and it doesn't result in treatment. It raised the question to me about why it’s seen as a medical diagnosis at all. Why go down processes of being diagnosed by medics and then be discharged because there is no treatment for your diagnosis?’

EP2 queries the utility of the medical diagnosis of autism for parents, suggesting it does not provide the understanding, insight, or support that they were hoping for. Parental dissatisfaction during autism diagnosis is reportedly at an all-time high (Crane *et al.*, 2016; APPG, 2016; Crane, *et al.,* 2018). Throughout this discussion, commentary has been made on the EP view that the bioecological perspectives should be applied to focus on individual child need to help support parental understanding and access to intervention. Parents in the UK report high levels of dissatisfaction with the diagnostic process, often not feeling supported by professionals, feeling disappointed with the conceptualisation of their child’s needs, or feeling directionless (Crane *et al*., 2018). In the above quotes, EP2 suggests that adoption of the medical model and its approach to autism and related needs has directly contributed to these outcomes for parents, asking the question ‘why go down the process of diagnosis’? EP3 also suggests that many parents aren’t able to cope and are seeking additional bioecological support to manage their child's additional needs.

e.g.:

EP3: 'There is the issue of it unlocking resources, for schools and children. Well it also looks like it unlocks resources for parents, like [training and support].'

EP3: 'So often parents really don't know how to manage these needs. You know they're doing the best they can.'

EP3 discusses the functional unlocking of resources that can be achieved by gaining a diagnosis of autism but goes on to discuss the need for parent training and support groups. In the original transcript, EP3 named a programme of support for parents where they are given information about autism, practical strategies on managing behaviour, and are able to join a community of parents with autistic children. EP3 suggests that this bioecological support and intervention maybe what parents are seeking as a result of diagnosis. EP3 recognises the difficulties parents can face, suggesting that parents on the whole 'are doing the best they can'. EP1, however, took a more critical approach suggesting that parents are not accepting of bioecological support and are instead seeking a diagnosis to be absolved of 'blame' and responsibility for their child.

e.g.:

EP1: 'Parents don't want to hear that because the diagnosis, it kind of means that they're not culpable, it's not their fault [sic]. A diagnosis means that this is in my child and it wasn't anything to do with me. So, to say that you know actually it's something that's more environmental that doesn't always go down well.'

Whilst EP2 and EP3 suggest that parents are seeking bioecological support, rather than medical support as a result of diagnosis, EP1 suggests that parents may be seeking a diagnosis so that they don't have to take responsibility for their child's needs. EP1 suggests that parents don't want their child's additional needs to be 'their fault' and that suggesting that disruptions in their environment have caused their additional needs doesn't 'go down well' with them. These quotes highlight the potential controversy of bioecological formulations of need.

Summary

The EPs and paediatricians both recognise that parents want access to additional support as a result of diagnosis. Both paediatricians and EPs also recognised that parents are not always clear about what they want as a result of diagnosis. Within both the EPs and paediatrician professional groups, individuals varied in their extension of empathy towards parents. Some suggested that parents are doing the best that they can and just require support and reassurance. Others suggested that parents are looking to absolve themselves of blame by obtaining a diagnosis for their child. The EPs predominantly view the bioecological approach to assessment as empowering and the correct approach to encourage families to take responsibility for their child's development. They also commented on their perception of the failings of the medical model in supporting families with children with additional needs. The paediatricians suggested diagnosis helped parents to not feel 'blame' and understand their child's symptoms.

4.3.1.3 Parental Role and Responsibility to Meet Additional Needs

Below the participants discuss families’ understanding of autism, their approach to parental role, and how responsibility to meet their child’s needs affects how they participate in diagnosis. Their view around parental responsibility often aligned around their professional perspective and the extent to which they adopted a bioecological model of practice.

Paediatricians’ Views

Families often report experiencing strong emotions throughout the diagnostic process and say that they don’t want to feel ‘blamed’ for their child’s condition (Crane *et al.*, 2018). The paediatricians spoke about the importance of an autism diagnosis in helping parents to accept their child’s difficulties without experiencing stigma. This often aligned around their medical perspective and preference to conceptualise needs ‘within child’.

PD3: ‘I think there’s probably less stigma attached to having a disability, or having a diagnosis, and that probably helps. I think nobody wants to feel like a bad parent. So, when their child’s playing up or pushing children and things, nobody wants to be labelled as a bad parent. So, I think some parents feel that the diagnosis helps them to understand why their child is difficult. Without necessarily feeling the blame of it being due to something they’ve done.’

PD3, in the above quote, speaks with empathy towards parents of children who display challenging behaviour, saying ‘nobody wants to feel like a bad parent’. They however focus on helping the parent to avoid ‘feeling the blame’. This language is in contrast to the EPs’ discussions later in this section around taking ‘responsibility’. PD3’s quote suggests that as a result of their medical perspective, they hold a conceptualisation of child difficulty as arising from within the child rather than from the interactive environment that the child and their parents participate in. This is shown when PD3 says that parents do not want to feel that their child is ‘difficult’ because of ‘something they’ve done’. This highlights the ‘within child’ perspective built into the medical perspective which narratively reduces the impact of parental and ecological factors on the child (Bronfenbrenner, 1979; Scotland, 2012; Oppong, 2014; Algraigray and Boyle, 2017). Given the intense emotions experienced by parents, their reported refusal to accept an alternative diagnosis, and pressure felt by medical professionals during diagnosis, it is understandable that professionals may seek to avoid a conceptualisation of need which focuses on parental role (Skellern, Schluter and McDowell, 2005; Evans and Trotter, 2009; Crane, *et al.*, 2018).

The paediatricians spoke with generally more empathy and understanding of the challenges parents face in supporting children with additional needs. PD1 discusses how parent role can affect their decision as to whether or not to provide a diagnosis of autism. They suggest when parents aren’t ‘able to cope’ they will seek a diagnosis of autism.

PD1: ‘There have been at least one or two occasions where families have been very keen on a diagnosis and the school questionnaires have come back completely negative. Then speaking to the school, they tell us a lot more about the mental health issues of the parents themselves, how they are not able to cope with that particular child, how they are not able to engage with other services that have tried to support them.’

PD1: ‘It’s just poor parenting, it is sometimes!’

PD2: ‘Just letting the parent know that this is what is fine, normal, you know, this is okay for the child to do. That kind of thing calms a parent down, and they can cope with it better. Parenting is not easy, and the knowledge that parenting is not easy, even that is important.

PD2: ‘I feel really sorry for them, lots of these parents, because all they need is reassurance. You know, all they need is just somebody to say, “It’s okay, don’t worry.”’

PD1 reports that they then have to clarify with schools how well that parent engages with other agencies. There is the suggestion in PD1’s quote that parents can abdicate responsibility for their child’s needs, if they are not able to ‘cope’, by seeking a diagnosis of autism. PD1 emphasises this point by suggesting that sometimes additional needs are due to ‘poor parenting’. PD2 takes a much more empathic position towards parental need and bioecological support. She says that parenting ‘is not easy’ and comments on the expectations parents can have of their child. She suggests that many parents just need external support and ‘reassurance’ to cope with the demands of parenting. The above quotes from the paediatricians indicated an awareness of bioecological factors and their influence on parent and child need. However, in contrast to the EPs, they are much more supportive of parents who may be seeking diagnosis because they are struggling.

EPs' Views

The EPs take a more challenging and critical view of the role of parents in supporting their children and seeking a diagnosis compared to the paediatricians. This links to the EP view outlined in **Section 4.2.3.3** where they strongly disagreed with diagnostic substitution and dual diagnosis when mental health, attachment, and other bioecological needs were present. The EPs suggested that when dual diagnosis or diagnostic substitution occurred alongside the above needs, stakeholders would only focus on the diagnosis of autism. As a result of this, the child's needs became conceptualised within the medical model at the expense of the broader bioecological perspective. The EPs generally held the view that autism diagnosis where other bioecological needs are present absolves families of responsibility and prevents progress.

The EPs were overall more sceptical about parents seeking a diagnosis of autism. EP1 suggests that she can have a 'strong suspicion' that presentations of additional need can often be due to interruptions in the bioecological systems of the child. EP1 suggests that 'parents don't want to hear' bioecological formulations of additional need, and that the within-child conceptualisation of needs from the medical perspective, means that parents aren't 'culpable'. This contrasts with the paediatricians' view about reducing 'stigma' and 'blame' for parents seeking diagnosis.

e.g.:

EP1: ‘Particularly in cases where I don’t feel that it’s autism, where I have a strong suspicion that the presentation that I’m observing or I’m hearing about could be down to interruptions in development or caused by early childhood experiences, trauma, attachment. Parents don’t want to hear that because the autism diagnosis means that they’re not culpable, it’s not their fault. A diagnosis means that this is in my child and it wasn’t anything to do with me. So, to say that you know actually it’s something that’s more environmental that doesn’t always go down well.’

EP2: ‘Just being the individual and looking at your needs is actually a really uncomfortable position for individuals, maybe for an adult. But for a parent of a child with special educational needs? That’s not where they want to be. I think as psychologists we kind of overlook that really powerful impact that that has, because we’ve taken this kind of ethical position, “no we have this ethical position where we’re looking at the whole child, so we’re not going to let you have that psychological thing that helps you.”’

EP3: ‘It’s almost seen as if that that lack of attachment and interaction in key relationships is just part of autism. You may not be able to put your efforts around developing those, which is actually exactly what a child with attachment difficulties would need.’

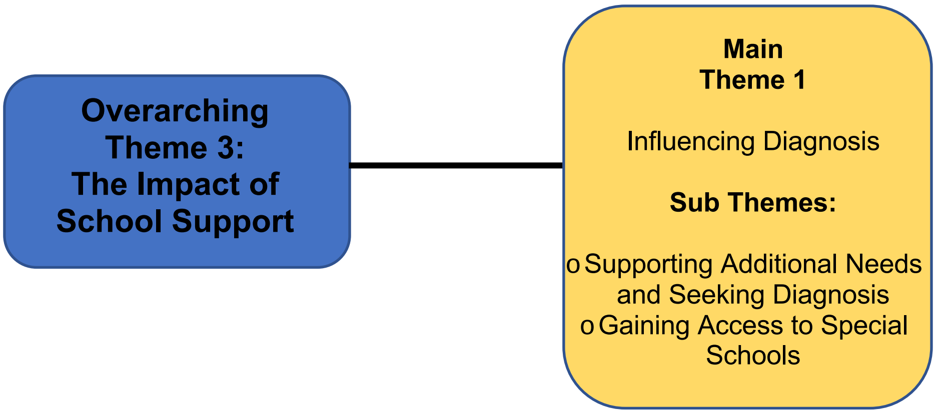
EP3 suggests that a diagnosis of autism can often mean that professionals and key stakeholders become permissive of poor attachments and a ‘lack of’ effective interaction, demonstrating the EPs’ strong preference for considering bioecological factors over within-child needs. EP2 recognises the bioecological approach can be distressing for parents. She suggests that taking responsibility for a child’s additional needs is not where parents ‘want to be’. EP2 goes on to suggest that the EPs’ bioecological formulations, and a refusal to engage in diagnostic labelling, can be difficult for parents. She suggests that EPs have taken an ‘ethical position’ which can result in parents feeling excessive blame and responsibility for their child’s wellbeing.

Summary

The paediatricians and EPs both suggest that parents don’t want to feel ‘blame’ for their child’s difficulties, a finding reflected in other research (Crane *et al*., 2018). The EPs spoke about their desire to focus on ecological factors and individual child need, an approach praised by the paediatricians in **Section 4.5**. In contrast, the paediatricians prefer to ascribe need to ‘within-child’ factors through the provision of an autism diagnosis. The EPs were much more critical of parents and their role in supporting their child with additional needs. This was often linked to their ecological focus and preference for direct intervention. The paediatricians were much more accepting of the pressure faced by parents and the challenges they experience supporting their children. The above quotes from the paediatricians and EPs highlight the views from both professional groups that parents do have a role in the presentation of their children, but diagnosis can reduce the stigma, blame, or responsibility around that role by ascribing child need to the medical and unchangeable label of autism (Algraigray and Boyle, 2017). Research suggests that parents are often shocked when they receive a diagnosis of autism and learn that it is a lifelong condition which cannot be ‘cured’ (Crane *et al.,* 2018). There may be several benefits to the inclusion of the bioecological perspective alongside a medical conceptualisation of autism and additional needs. Research suggests that families are looking for in-depth understanding of their child when seeking a diagnosis (Crane *et al.,* 2018). In **Section 4.2**, the limitations of the diagnostic label in promoting understanding are discussed. The EPs, employing a bioecological perspective, have said that they want to focus on the child and the systems that they live in; this may, however, be controversial with parents (Bronfenbrenner and Morris, 2007).

4.4 Overarching Theme 3: The Impact of School Support

4.4.1 Main Theme 5: Influencing Diagnosis



The EPs and paediatricians held differing views, and shared different experiences, around how schools have been, and should be, involved in autism diagnosis. NICE Guidelines, the ICD-11, and DSM-5, all stipulate that for autism to be confirmed, the child must present with difficulties in more than one context. The documents suggest that difficulties and functional impairment arising from autism can be assessed by examining performance in school (NICE, 2011; WHO, 2012; APA, 2013). It was therefore expected that the interviews with the participants would illicit data around the role that schools play in autism diagnosis.

The participants spoke frequently about the role that schools played in supporting children and their families, and how the level of support provided can affect child functioning and subsequent likelihood of diagnosis. The participants also spoke about the positive and negative influence schools can have on families and professionals both before and during the diagnostic process. There was also some commentary on the role that schools play in promoting inclusion, providing evidence for assessments, and supporting parents to gain access to specialist settings for their child. During the interviews, the participants discussed the role that schools play in either supporting children in schools or in pushing for a diagnosis to seek additional support. The participants' views aligned around their professional perspectives and were synthesised within the overarching analysis of this research. There were notable differences between the EPs' and paediatricians' experiences of school involvement in diagnosis. The data analysed were organised in this overarching theme under the main theme of **'The Impact of School Support'** and the subthemes of **'Supporting Additional Needs and Applying Pressure'**, and **'Gaining Access to Special Schools'**.

4.4.1.1 Subtheme: Supporting Additional Needs and Seeking Diagnosis

There is little information defining what type of information schools should be providing and a dearth of research into the role that schools play during autism diagnosis (Goodwin, Matthews and Smith, 2017). NICE Guidelines suggest that schools play an important role in autism diagnosis by providing reports where appropriate and by allowing professionals to observe children in their setting when consented for by parents (NICE, 2011). Schools, however, are reportedly more likely to support a diagnosis of autism if they are struggling to meet a child's additional needs (Ravet, 2011; Ravet and Williams, 2017). Difficulty managing challenging behaviour in schools is often a key driver behind stakeholders seeking a diagnosis of autism and parents report feeling high levels of distress when their child is struggling to cope in school (Crane *et al.*, 2016; Paget and Emond, 2016). Challenging behaviour can lead to an urge to relocate a child into 'specialist' provision rather than focussing on changes to the person, process, context, and timing of their additional needs (Bronfenbrenner and Morris, 2007; Scotland, 2012; Shakespeare, 2013; Algraigray and Boyle, 2017). This conceptualisation of behavioural difficulties represents a shift to a 'within child' medical conceptualisation of their challenging behaviour, rather than a bioecological perspective, where the child is a product of their environment (Bronfenbrenner, 1979; Maskey *et al.*, 2013).

A child's performance in school, which may be indicative of the quality of support provided, may be conceptualised as a measure of autistic-type needs under the newer versions of diagnostic criteria (Bronfenbrenner and Morris, 2007; Volkmar and Reichow, 2013). Children may therefore meet the criteria for an autism diagnosis, not because their needs are especially high, but because their school has failed to support them effectively.

Paediatricians' Views

Research suggests that paediatricians are under pressure to prevent exclusions as a result of challenging behaviour in school by engaging in effective assessment and subsequent diagnosis for autism (Paget and Emond, 2016; Algraigray and Boyle, 2017). This may mean that paediatricians are receiving pressure from schools and families to assess and diagnose in place of schools being challenged to meet a child's additional needs (Paget and Emond, 2016). The paediatricians discussed the pressure they can receive from parents when their child is struggling to cope in school.

e.g.:

PD2: 'They get the push from somewhere else. I guess from school. I mean, they want the children to get the help they think they need, and the only way, that's what they tell us, the only way they feel they get the help they need is if they have this diagnosis.'

PD3: '[We have a lot of children] that are potentially excluded from schools, or parents have withdrawn them from schools because they're not happy with the support.'

PD1: 'The reason that most of them give us is they say that schools will not help them unless they have a diagnosis. That is what we are told more or less by every single parent. So that's where we start to explain "no we've spoken directly" this is not the case. I don't know if there's something in the middle there where the schools are not giving them the information, or the right message isn't getting across to parents. There's some break down there, between you and us.'

The paediatricians reported that they felt that parents receive lots of pressure from schools to seek a diagnosis. All of the paediatricians said that they thought that parents were pressured by schools to seek diagnosis so that their child could access more support. The paediatricians have said that they have limited influence in terms of the support that schools can provide and are often only able to support children in schools by providing diagnoses as a result of the restrictions of their medical perspective and role. PD2 suggests that schools may 'push' parents to seek a diagnosis. PD1 suggests that 'more or less every single parent' who comes in for diagnosis for their child reports that they need a diagnosis to access more support in school. PD3 comments on the relationship between school support and exclusion. PD3 links parents' withdrawal of their child from school with their dissatisfaction with the support provided whilst discussing exclusion in the context of diagnosis. PD2 explicitly states that parents see diagnosis as a tool for accessing support when their school has not effectively catered for their child's additional needs. This point is made clear when PD2 says, 'the only way they feel they get the help they need is if they have this diagnosis'. This is perhaps emblematic of the parents' implicit adoption of a medical conceptualisation of autism and associated need where a diagnosis is the only tool to get 'treatment'. It also highlights how a lack of school support can increase the need for diagnosis. PD1 recognises, however, that a diagnosis is not needed to access school support. She also indicated that there has been a breakdown in the relationship between paediatricians and schools. She suggests that EPs are the ideal professional to facilitate this relationship during diagnosis. Although not clear in the quote, when PD1 says she has spoken 'directly', she is referencing conversations with the EPs where they have discussed the need to for schools to provide bioecological support with or without diagnosis.

The role that diagnosis plays in unlocking additional support has been discussed in **Section 4.2.** In this section, the EPs commented on schools' access to a notional budget of six thousand pounds to cater for the special needs of individual children, suggesting that diagnosis is not needed to access additional support (DfE, 2014). The role of the EP is central to this issue, as they can be a key mediator between parents, schools, and paediatricians, applying the bioecological perspective (Fox, 2015). EPs could play an important role in prompting schools to provide support and in outlining support and intervention options available to children for parents and paediatricians. However, the participants suggest that there are lots of children being raised for diagnosis who are not coming to the attention of EPs before being raised for the discussion panel.

e.g.:

PD3: ‘I think we’ve learnt over the last year that we don’t see the same- We often don’t see the same children, we think that we should be seeing the same children, but we’re not [sic].”

PD1: ‘They’re not know to yourselves. In the majority of cases. I mean that’s very disappointing for us, that we can’t have that other professional opinion on a child.’

The above quotes highlight how the paediatricians in particular think that EPs are not involved frequently enough with children who may require a diagnosis and how they find this lack of EP involvement challenging when operating within the restrictions of their role. This is demonstrated when PD1 describes the lack of EP involvement as ‘disappointing’ and when PD3 says ‘we think that we should be seeing the same children, but we’re not’. The paediatricians suggest that a high volume of the children they see are not known to the Educational Psychology Service. This may be indicative of a lack of support in school which may exacerbate additional need and increase the need for diagnosis to be sought. A lack of EP involvement may also indicate that the bioecological perspective has not been applied when considering the child’s functioning. It could be suggested that if the EPs had been involved and the child's bioecological needs had been met, then they would not have needed to seek diagnosis. The above quotes also highlight the value that the paediatricians place in the EP involvement in supporting them to complete diagnosis.

EPs' Views

The EPs suggest that many children do not receive support in school which may help them to manage their additional needs and as a result, this increases the pressure schools put on parents to seek a diagnosis of autism. The EPs also suggested that schools weren't as likely to support a diagnosis of autism if they were able to meet the child's needs easily and effectively. EP3 suggested that when children, and as a result their families, were supported effectively by schools, then they were less in need of a diagnosis.

e.g.:

EP3: 'So, it may just be that, that for many of these children that their needs can be met. They don't need to come to the attention of an EP, do they? But someone somewhere has raised them as needing a diagnosis. My reading would be that it is the schools.'

EP3: 'Children do enter school with significant needs and as school support I think has become less, less available, it throws up those needs even more.'

EP3 suggests that if children's 'needs can be met' then they do not come to the attention of the Educational Psychology Service. They suggest that when schools do not access EP support and children have additional needs then they are raised for diagnosis. She goes on to say that when children enter school with ‘significant needs’, and ‘less support available’, then their additional needs become more apparent, which may prompt schools to pressure parents to seek diagnosis. The availability of support as a result of diagnosis is discussed in **Section 4.2**. EP2 suggests that there is potentially a complex relationship between school support, EP services, and pressure to diagnose children.

e.g.:

EP2: We only seem to get involved in the identifying part and then the intervention part, and certainly within the educational sphere, I don’t think the conversations are really happening around the why [sic].

EP2 suggests that EPs are not involved in the mediating process of managing additional needs to prevent diagnosis. She says that EPs are only involved in the ‘identifying’ and ‘intervening’ part of diagnosis and could be more concerned with asking from a bioecological perspective, why children are being brought forward for diagnosis and why their additional needs are not being met in school.

In their interviews, the EPs often were critical of schools providing evidence, suggesting that they may be biased towards supporting diagnosis to move the child on to specialist provision. EP1 was critical of schools, suggesting that they sometimes seek diagnosis to move children into special schools rather than providing inclusive support for their additional needs.

e.g.:

EP1: ‘Sometimes they just want the child out and if I’m saying actually there are things you can do, but they haven’t got the resources, they just want the diagnosis to just move them on.’

EP1 reports that when they have tried to work with schools to support additional needs without seeking diagnosis they can be concerned because they ‘haven’t got the resources’ and just want to ‘move them on’. The above quote highlights the interaction between the availability of resources, school support, and a need for diagnosis. This is partly linked to the EP view that a diagnosis of autism can be an abdication of responsibility for key stakeholders. It may also indicate that at a time of reduced capacity in school, many feel like they are not able to commit to potentially resource-heavy bioecological interventions to meet needs. Instead, they opt for diagnosis so that children can access support in special schools. EP1’s use of the phrase ‘move them on’ suggests that they are critical of this approach. In the following subtheme, the EPs discuss in more detail their views on specialist provision.

Summary

The above quotes illustrate the importance of the relationship between school support for additional needs, parental involvement, and professionals in autism diagnosis. Schools are not only key in supporting children and their families but are also powerful influencers in providing information and opinions on a child’s bioecological needs (Bronfenbrenner and Morris, 2007). The paediatricians suggested that most of the families they see are seeking a diagnosis because they feel under pressure from their child’s school. The paediatricians were also concerned that many of the children who have been raised with them for a potential diagnosis have not been seen by an EP. The EPs reported similar concerns suggesting that when schools have not involved EPs in applying bioecological interventions to meet their additional need, they are more likely to pressure parents to seek a diagnosis. The EPs were critical of this approach, suggesting that schools do not always engage with EP support due to limited resources and an urge to move children out into special schools.

4.4.1.2 Subtheme: Inclusive Practice and Gaining Access to Special Schools

The participants spoke frequently about the role that diagnosis played in gaining access to special schools. Their views were closely related to their professional perspective and conceptualisation of the function of an autism diagnosis. As such, there are key links between this subtheme and **Section 4.2.2**.

The issue of inclusion in autism diagnosis has been hotly debated (Ravet, 2011). Much of the available research supports the inclusive utility of children gaining diagnosis through improved outcomes across education, employment, and social skills (Ravet, 2011; Lobar, 2016). However, there are other authors who suggest that labelling children through diagnosis can be exclusive and harmful (Lauchlan and Boyle, 2007; Ravet, 2011). They suggest that the label of autism can malign children in terms of their peers, separate them in terms of their education, and result in negative outcomes, including decreased social opportunity and low self-esteem (Ravet, 2011; Shakespeare, 2013; Algraigray and Boyle, 2017). This is often reflected in the discussion around the utility of specialist provision. Some argue that children with autism benefit from being educated with diagnosed peers away from mainstream settings (Ravet, 2011). Positions in the debate around the inclusive utility of specialist provision often align around the bioecological and medical perspectives towards autism discussed so far (Ravet, 2011).

Paediatricians' Views

Compared to the EPs, the paediatricians spoke less frequently about specialist autism provision. This is not surprising given their adoption of the medical perspective and difference in role. The paediatricians did however mention both schools and specialist settings as key sources of support for children with a diagnosis.

e.g.

PD1: 'The reason that most of them give us is they say that schools will not help them unless they have a diagnosis. That is what we are told more or less by every single parent. So that's where we start to explain "no we've spoken directly" this is not the case.

PD2: 'See, there is classic autism. They are diagnosed within the year three, three, three years, yeah. By three, three- and-a-half. That's CDC. And then they, they go into special schools or they go into special units or- you know, whatever [sic].'

PD2: 'They do [support children with autism]. Some schools do, and special schools certainly do.'

PD3: 'I encourage families to share the reports with the school. So, I write a brief letter to the school saying they've got a diagnosis, but the full report, which has a lot of that detail'

Whilst PD1 spoke at length about mainstream school support, she did not provide any quotable discussion in relation to special schools. PD1 suggests that mainstream school should support children regardless of whether or not they have a diagnosis of autism. This may demonstrate an inclusive element of their professional perspective. PD3 mentioned specifically how a diagnosis can inform school settings. She suggests that once a diagnosis of autism has been confirmed, she ‘encouraged families to share reports with the school’ to help inform the support for their additional needs. PD3 did not discuss any particular benefit to inclusion within mainstream settings or location in special schools. PD2, however, speaks with certainty about the path that children can follow into special school post diagnosis. There is a lack of familiarity with the process of school allocation, compared to the EPs, when she says, ‘then they go into special schools, or they go into special units, or you know, whatever’. PD2 recognises the association of diagnosis with access to specialist provision. There is however a lack of commentary on the specifics of EHCP application and the dismissive tone of ‘whatever’ suggests that this process of school allocation is not a concern for her in her practice. This could be problematic given the close association of need for diagnosis and access to a specialist setting (Ravet, 2011). It also suggests that PD2 may not have considered the value of inclusion within mainstream settings to the same degree as the EPs as a result of their role limitations and adoption of a medical perspective. PD2’s quote perhaps also highlights the need for EP involvement in autism diagnosis where they can contribute their knowledge of school support, EHCP assessments, and allocations to specialist school.

EPs' Views

Educational psychologists play a key role in arranging access to special schools by supporting statutory assessment for Educational Health and Care Plans (Tobias, 2009; DfE, 2014). The EPs spoke about the need for children to be diagnosed to attend autism focussed settings and the pressure families felt to obtain a diagnosis so that their child would be able to attend their school of choice. The EPs, whilst recognising the need for specialist schools, generally held an inclusive perspective, believing that children should be educated within a mainstream setting wherever possible.

EP1 spoke about mainstreams schools abdicating responsibility when they pressure parents to seek a diagnosis in order to send a child to a specialist provision.

> EP1: "If this isn't autism, we've got to take responsibility. First of all, we've got accept there are things that we might not have done, correctly and for school staff that means we should be doing that, which could require quite heavy resource allocation and time. Whereas autism this is never going to be fixed there's special schools for children like these let's get rid."

EP1 suggests that 'if this isn't autism then we've got to take responsibility' and 'accept there are things that we might have done wrong'. This indicates that the EPs feel that bioecological interventions for additional needs are an alternative to a 'within-child' diagnosis of autism and subsequent placement in special schools (Fitzgerald and Callard, 2017). EP1 also suggests that a bioecological formulation of need is harder for schools to accept because it will require 'heavy resource allocation', whereas sending a child to an autism special school will 'get rid' of the child. It is clear in the above quote that EP1 feels a medical 'within child' conceptualisation of need can be seen as anti-inclusive practice.

e.g.

EP3: 'If the child is going to move on from mainstream to access certain types of provision, they need a diagnosis for certain. If you want them to have an autism specific setting, then obviously they will need the diagnosis. That's one of the factors, I think.'

EP3: 'There's sort of this huge pressure for a diagnosis because the children do enter school with significant needs and as school support I think has become less available, it throws up those needs even more.'

EP3 speaks about the 'huge pressure' to ensure children obtain a diagnosis of autism to gain access to a specialist setting. She suggests that if children are to access autism-specific settings they will 'for certain', 'need the diagnosis'. Whilst the role of supporting children to access specialist provision is a key part of EP practice, there seemed to be some conflict between this aspect of their role and the bioecological and inclusive perspectives which the EPs held (Bronfenbrenner and Morris, 2007; Ravet, 2011; Fox, 2015; Algraigray and Boyle, 2017). This was demonstrated in the EP discussion around the role that EHCPs played in arranging specialist provision, promoting a within-child view of additional need, and 'stopping progress'.

e.g.

EP2: ‘Give us the power and then we’ll stop doing it. You can almost see how that’s happened generally with labels.’

EP1: ‘It stops progress then once they’ve been diagnosed with autism, it’s “let’s get an EHCP’ an EHCP, let’s get them into [an autism specialist school], let’s get them into [an autism specialist school], let’s get them into an autism specific school, which is geared to treat, to support children with autism”.’

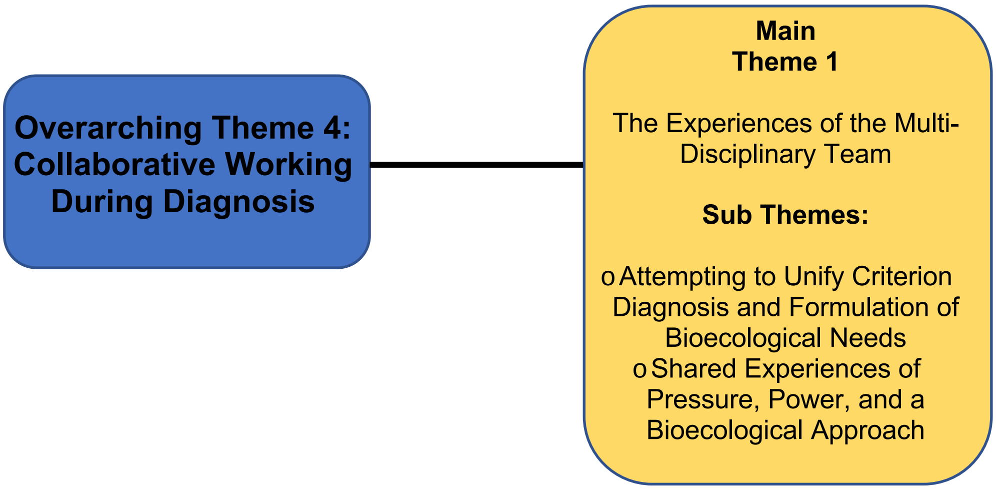
EP2 did not comment on specialist schools directly. They did however speak at length about anti-labelling and inclusive practice. EP2 suggested that there was no need to label children and that they should be educated in mainstream settings, indicating a strong bioecological focus. EP1 comments on how a diagnosis of autism can ‘stop progress’ even when resulting in an assumed ‘EHCP’ to ‘get them into’ an autism specialist setting. There is clear tension in the quote from EP1 between the EPs’ bioecological perspective and the need in their role to arrange specialist provision for children. The use of quotation by EP1 suggests that this pressure comes from outside agencies, perhaps parents and schools. The repetitions also suggest that the EP does not agree with the view that children should be educated in autism-specific settings, reflecting the ongoing debate around autism and inclusion (Ravet, 2011; Goodwin, Matthews and Smith, 2017).

Summary

Both the EPs and paediatricians recognised that many children are referred for an assessment of autism to seek a placement in a specialist school. The paediatricians, whilst unfamiliar with the detail of the EHCP application process, suggested that special schools play a key role in supporting children with additional needs. They took a generally neutral approach to inclusion which may be a result of their different area of practice compare to the EPs and their adoption of the medical perspective. The EPs, in comparison, shared more complex views. They suggested that their preference would be to provide bioecological interventions to support children in mainstream schools. They also however noticed that there is a lot of pressure around diagnosis to ensure that children can access specialist settings when appropriate. The EPs began to discuss their bioecologically informed anti-labelling and inclusion-focussed perspective. This tension between this perspective and the EPs' requirement to facilitate access to special school and support diagnosis had a significant impact on the collaborative working which takes place within the multi-disciplinary team.

4.5 Overarching Theme: Collaborative Working During Diagnosis

4.5.1 Main Theme: The Practice of the Multi-Disciplinary Team



A key aim of the research projects is to explore how professional perspective has influenced the experience of paediatricians and EPs during multi-disciplinary diagnosis. As such, there were direct questions asked of the participants around how they felt their own and their colleague's professional perspectives influenced their collaborative working during diagnosis. This elicited data which when analysed resulted in the development of the overarching theme **'Collaborative Working During Diagnosis'**. The participants often spoke about their own, and their perception of their colleagues', professional perspective, and the practice within the context of the Multi-Disciplinary Team. This led to the development of the main theme of **'The Experiences of the Multi-Disciplinary Team'**. During the interviews, the participants spoke frequently about the challenges they faced trying to work collaboratively with their colleagues and fit their practice within different epistemological frameworks. The participants' reflected on the challenges they faced in trying to accommodate both medical criterion assessment and bioecological formulation when engaging in differential diagnosis for autism. Both the EPs and paediatricians discussed their perception of what they regarded as EPs' reluctance to participate in autism diagnoses within the Multi-Disciplinary Team. They spoke about the pressure they felt, their perception of their colleagues' expectations, and their ability to influence the diagnostic process to varying degrees. As a result, the subthemes **'Attempting to Unify Criterion Diagnosis and Formulation of Bioecological Needs'** and **'Shared Experiences of Pressure, Power, and a Bioecological Approach'** were developed to structure and organise the data from the interviews.

4.5.1.1 Subtheme: Working Together to Unify Criterion Diagnosis and Assessment of Bioecological Needs

The EPs and paediatricians discussed at length the challenges they had faced when working together. A key issue for the participants was in their attempts to unify their different professional perspectives. The paediatricians rely mainly on criterion assessment to diagnose autism. The EPs suggested they would much prefer to provide bioecological formulations of need and potential hypotheses as to why difficulties may have occurred. The discussion that follows examines their attempts to unify these two sometimes opposing approaches. This subtheme has strong thematic links to **Sections 4.2.1**, **4.2.3**, and **4.3** where discussion takes places around the paediatricians' struggles to gather and assess bioecological information related to psychological wellbeing, school performance, and family functioning.

Paediatricians' Views

The paediatricians suggested that they feel limited in their ability to collect bioecological data on the children they assess for a potential diagnosis of autism. The paediatricians often spoke about their own limitations in this area when considering the role of EPs during MDT diagnosis.

> e.g.
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> PD2: 'I'm inadequate to give a diagnosis, because I don't know the child's functioning as much at all. But I have to give a diagnosis, just because I'm called the doctor, but I'm not in a position to do that, because I don't know enough. So, a psychologist has that power to find out if the child has got some problems at home, if it's a temporary thing, it's got a new sibling or twins are born to a single mum, and this is the five-year-old, or things like that. And then, inform the teacher. You know, "No, this is not because the child is bad or deviant. It's because of this and do this about it." You know, after a period of time. Because we want instant things. They come here to my clinic and they want a diagnosis when they're going out, but it's a developmental problem. It's a time thing, you need time, and I explain to people, and they think I'm fobbing them off.'

The difference between the paediatricians' medical perspective and the EPs' bioecological perspective is demonstrated when PD2 discusses the EPs' ability to assess over time. PD2 reports that they are 'inadequate to give a diagnosis' giving a sense of how limiting it can be to diagnose from a purely medical perspective. PD2 says that parents and families come into their clinic wanting 'a diagnosis when they're going out, but it's a developmental problem. It's a time thing, you need time'. PD2 recognises the pressure this results in and the expectation among families of diagnosis by the end of their appointment. PD2 praises the EPs' ability to consider contextual, time-bound factors, such as the birth of a new sibling, harkening to the PPCT elements of the bioecological framework (Bronfenbrenner and Morris, 2007). PD2 discusses their perception of the EPs' ability to work across settings and over time applying the bioecological perspective. They suggest that EPs have the 'power' to find out if a child's got problems at home, or if it's a 'temporary thing'.

e.g.

PD3: 'When we got really good information saw, you know, descriptions of peer interaction or lack of peer interaction during school observations. And, or lack of, you know, facial expression and gesture during lessons, and things like that. And the schools, especially for schools that have said that they can't see any difficulties, that's really useful. Observational experience from an experienced professional. So that's really helpful. And I think sometimes when someone says, "Actually, there's loads more going on than you know. Like in the school, in the family," just having another professional that's seen that family and that child from a different angle that we wouldn't. Like, we've had people saying, "Actually, the school's one of the issues," and they're all like that at the moment, because there's so much upheaval in the school. And actually, just knowing that background information's really, really helpful, but you wouldn't normally get that.'

PD3 directly praises the value of the bioecological information they can get from EPs. They describe 'really good information' focussing on 'observational experience from an experienced professional'. There is a clear show of respect towards the EPs' contribution in the description of 'experienced professionals'. PD3 considers the qualitative information provided EPs, focussing on school performance, and ‘the family’, as ‘really, really, helpful’ and something that they ‘wouldn’t normally get’. The discussion of observation of interactions alludes to an approach to assessment that is significantly different from the standardised assessment tools completed within the medical perspective. The value placed on qualitative information that would not fit within a medical model is also highlighted when PD3 praises EPs’ commentary on ‘facial expression’, suggesting it is something they ‘wouldn’t normally get’.

Both PD2 and PD3 speak highly of the EPs’ ability to interact with and mediate between clinical and school settings during assessment to contribute towards an autism diagnosis. PD3 suggests that EPs are able to consider context within their perspective and account for school settings where entire groups may be in ‘upheaval’. They suggest that school information can contradict their findings during assessment in clinic and EP involvement can help to unpick this discrepancy.

PD2 and PD3 speak highly of the EP perspective and the information they have received during multi-disciplinary diagnosis. They are also aware of their own limitations when applying the medical perspective during diagnosis, with PD2 suggesting they are ‘inadequate’ when giving a diagnosis of their own, and PD3 saying that when they receive bioecological information from EPs they become aware that ‘there’s loads more going on than you know’. These quotes highlight the unique contribution that EPs can make during diagnosis and the value placed on the bioecological perspective by the paediatricians.

The paediatricians indicated that they were aware of the ‘entangled’ nature of autism and felt that diagnosis should not take place only using the medical perspective (Fitzgerald and Callard, 2017). They suggested that the medical model perspective does not account for broader bioecological need and a multi-disciplinary approach needed to be implemented to differentiate autism from broader neurodevelopmental needs.

e.g.:

PD1: ‘I don’t think paediatricians [should be at the centre of diagnosis] and that may be different for different children, because some children have lots of medical needs. So yes, the paediatrician needs to be the centre but, equally you need information from other professional about that child because even if he’s got multiple medical issues, he might still have autism or ADHD, so you still need everybody else.’

PD2: ‘I think it should be a multidisciplinary decision. It’s not any person’s decision because there’s so many facets to this condition that you cannot just say. I can tell the medical bit. You can tell the psychological bit, or somebody else can tell the other bit, because that child is made up of all that [sic].’

PD1 suggests that children may present with different types of needs and suggests that the focus on the key professionals involved should change depending on the child’s presentation. They say that even when a child has ‘lots of medical needs’ the paediatricians should not necessarily be at the centre of the diagnostic process. If alternative information is needed from ‘other professionals’, PD1 is happy to differ. PD1 indicates their awareness of the limitations of the medical model to account for broader bioecological need, suggesting that other professionals hold perspectives which can accommodate information that does not fall within the ‘medical’ perspective. PD1 goes on to say that even if a child has ‘multiple medical issues, he might still have autism’. This indicates that PD1 may consider autism a non-medical condition, or a condition where bioecological need can present so similarly that it may be difficult to differentiate the two (Fitzgerald and Callard, 2017). This distinction between ‘medical issues’ and autism may arise from the adoption of the medical perspective and the distinct categorisation of need. PD1 may be aligning bioecological need with autism because they do not possess the language to describe the difference between medical, biological autism and broader development needs arising from disruptions in bioecological functioning (Skellern, Schluter and McDowell, 2005; Bronfenbrenner and Morris, 2007). PD2 also discusses this point, suggesting that ‘there’s so many facets to this condition’. They recognise that autism is both ‘medical’ and ‘psychological’. Their categorisation of needs highlights their adoption of the medical perspective. EPs adopting a bioecological perspective may see additional need as existing on a continuum where there is less of a distinction between the ‘medical’ and ‘psychological’ (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008).

e.g.:

PD3: ‘Without funding for MDT, you’re left doing it on your own. So, I think given the situation that we were in, which was that we were left doing it on our own, we’ve trained ourselves to do the most reliable assessment as possible. So, we use 3Dis and ADOSs. Some children will get both if needed. So, we are using the best assessments out there. Well, you know, the most reasonable assessments for the time and constraints [sic].’

The paediatricians all suggested that the challenge of accounting for medical and bioecological need during diagnosis is best met by utilising a multi-disciplinary approach. PD3 suggests that when, in the past, this has not taken place they have, as a team, tried to overcome this limitation by ‘using the most reasonable’ assessments given the constraints they have experienced. PD3 suggests several standardised assessments for autism that the paediatricians have been trained to use. This quote highlights the limitations of lone diagnosis from one professional perspective. The response to lone working by the paediatricians has been to increase their use of standardised assessment. The use of standardised assessments is a key epistemological tool of the medical perspective. The quote from PD3 shows how professionals are limited by their professional perspective and are only able to use more of the tools available to them from within the perspective they adopt. PD3 does not, for instance, suggest that to overcome the limitations of lone diagnosis they have increased their use of observation, consultation, and formulation which may be used more routinely by the EPs (Kelly, Woolfson and Boyle, 2008).

The paediatricians recognise the importance of standardised assessments and value of the input of EPs. They do however suggest that there are specific difficulties that they have encountered when working with the EPs and when trying to consider their findings in relation to diagnostic criteria. Whilst the paediatricians spoke positively about wanting to have EP involvement in the multi-disciplinary team meetings, they suggested that the EPs are reluctant to give a firm stance on diagnosis or comment directly on diagnostic criteria for autism.

e.g.:

PD1: ‘If the Educational Psychologists don’t want to commit to that, I don’t mind. But what I do want is, very clear information, about what they observed. Obviously if they have some opinion that’s very useful, but not everybody likes to give an opinion, that’s fine if they don’t want to, but their observations, their assessments are really important.’

PD3: ‘Whereas we’ll come at things as, “Do they meet the threshold for a diagnosis?” kind of point of view, and that’s different. And that’s okay. Whilst the information is really helpful, I think sometimes it’s difficult. I guess it’s difficult if, [Educational Psychologists] on the whole don’t necessarily want there to be a diagnosis, because then they might be reluctant to tell us information that’s on the criteria’

PD3: ‘If the purpose of it is to assess for ASD, you need to have [Educational Psychologists] that are willing to comment on things that are part of the criteria for autism.’

PD3: ‘There definitely seems to be tension between [Educational Psychologists] and Paediatricians about a diagnosis or not, and I know that like you all come at things from a hypothesis point of view.’

The above quote suggests some confusion as to why EPs may be reluctant to comment directly on diagnostic criteria and fit their findings within a medical framework. PD3 does however suggest that they feel like ‘educational psychologists on the whole don’t necessarily want there to be a diagnosis’. The EPs’ stance towards diagnosis and its impact on the MDT will be discussed in more detail in the next subtheme. However, this position taken by the EPs may be in part due to their adoption of the bioecological perspective which moves away from empirical criteria and closer to a more interpretivist co-construction, with labels subsequently being denied or not considered as important

(Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008; Burnham, 2013). PD3 reports that the paediatricians approach diagnosis by considering if children ‘meet the threshold for diagnosis’. They go on to say that they feel that EPs may be ‘reluctant to tell us information that’s on the criteria’. This suggests that the EPs are providing more descriptive, and potentially uncertain, information about the children they have worked with. PD3 goes on to suggest that the EPs like to ‘come at things from a hypothesis point of view’. It may be assumed that by adopting the medical perspective with its foundation on empirical science, that the paediatricians would be more intent on hypothesis testing (Scotland, 2012). However, the paediatricians suggest that the EPs are more likely to donate a ‘hypothesis’ when contributing to the diagnostic process. As diagnosticians, the paediatricians rely more rigidly on criterion assessment for autism. This preference and reliance on criterion assessment are also demonstrated above in PD3’s discussion around their extensive use of standardised assessment. EP practice may be contrary to this processes of standardised assessment where they rely on observation and consultation to produce descriptive, hypothetical, formulations of need that are contextualised and subject to change over time when considered through a bioecological perspective (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008). PD1 also recognises that EPs are reluctant to comment directly on criteria or the presence of autism. They suggest that they do however need ‘very clear information about what they have observed’. There is a clear tension between the criterion and standardised assessments used by the paediatricians and the qualitative data obtained by the EPs, often through observation. The paediatricians recognise that EPs would prefer to give formulations or hypotheses, rather than diagnosis, and would be happy to accept that information as long as it was evidence-based and presented as a clear recommendation. There is however a challenge faced by the EPs to ensure their information is useful and can be considered within the realist framework of the medical perspective.

EPs' Views

The EPs recognise that the information they can contribute to the MDT is valuable. However, some of the EPs took a more critical approach to framing their opinions and perspectives within a medical framework (Burnham, 2013).

e.g.:

EP1: 'I'm not saying that's definitely autism, although that's what they want from us. They want us to say whether we think it's autism or not, but I am saying, we should be confident if saying "we think this child's got attachment difficulties, we believe that they are presenting in ways that are indicative of early life trauma, we believe there are learning difficulties", take that information and decide whether you want to give them an autism diagnosis.'

EP1: 'With this information do you still think it's autism? They're the clinicians that make the diagnosis. I'm not saying you can't. I'm saying please do consider that these are the formulations that we've come up with.'

The tone of EP1's statement, saying, 'that's what they want from us', suggests a more critical approach to multi-disciplinary working than in the above paediatricians quotes where they speak about 'highly valuable' EP information. This relative criticism could arise from the anxiety that EPs reportedly feel providing opinions and formulations within a realist medical framework (Burnham, 2013). EP1 does however suggest that they are much more confident in saying ‘we think’ or ‘we believe’ when presenting their opinions or formulations of additional need. This may indicate the comfort and preference for uncertainty afforded to the EPs by their adoption of bioecological perspectives (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008; Evans and Trotter, 2009; Burnham, 2013). There is a clear view that EPs want to submit formulations and hypotheses rather than clear commentary on diagnostic criteria and the presence of autism. This seems to be acceptable to the paediatricians. In the above quotes, EP1 suggests that when they are providing formulations to the paediatricians, they are asking them ‘do you still think it’s autism?’. EP1 suggests that the paediatricians are looking for autism and finding it because of their criterion approach to diagnosis. However, diagnosis is based on criteria and the paediatricians do suggest they need some commentary on criteria to refuse a diagnosis or accept an alternative formulation.

The other EPs often spoke about their concerns around diagnosis being deterministic. They suggested that standardised assessment and criterion diagnosis could lead to children being given an autism diagnosis without exploration of broader bioecological needs. They suggested that their role, and preference for sharing formulations, was fuelled by a desire to consider broader conceptualisations of need, including the attachment and trauma needs discussed by EP1 above.

e.g.:

EP3: ‘One of our roles is to make sure that everything has been considered, including what we know of the child’s background. We have arrived with a much broader view. A broader perspective and making sure we’re looking at that child across those different settings.’

EP3: ‘If there is an alternative view, we should be giving it. We should be making sure that the evidence is broad.’

EP2: ‘There doesn’t seem to be a box at the bottom that says “could there be another reason for this? If so what could it be?” That’s actually what paediatricians have said in our discussion and they acknowledge that there are other potential hypothesis and reasons for a child’s presentation, such as attachment, but they have actually said, but we don’t have a pathway. The only pathway they have for children presenting with social communication difficulties in terms of assessment and labelling is, autism.’

EP3 suggests that their role is to accommodate a ‘broader perspective’, considering a child across ‘different settings’. They say that the EP role during diagnosis is to give an ‘alternative view’. This echoes EP1’s suggestion that the EPs’ role is to query diagnosis and provide alternative explanations of need. The EPs’ approach to diagnosis, and labelling more broadly, is discussed in the next subtheme. There is however a theme of EP reluctance to provide diagnosis, which had been noticed and discussed by the paediatricians. The EPs’ preference to provide an ‘alternative’ explanation reflects the interpretivist dictum that correlation does not equal cause (Cohen and Manion, 2002). This interpretivist preference to consider alternative explanations contrasts with the paediatricians’ medical approach to considering realist phenomena through standardised assessment and criteria. EP2 seems to recognise this difference between the EP and paediatric perspective when they discuss their concerns with current diagnostic procedures. They suggest that by the nature of ‘identification’, autism is more likely to be found present, and laments that there isn’t a ‘box at the bottom that says, “Could there be another reason for this?”’. EP2 suggest that the paediatricians recognise the limitations of this correlation approach to diagnosis of additional need. The above quotations show that the EPs are aware of the limitations of criterion assessment but appear to be much more critical of the paediatricians’ approach to assessment compared to the paediatricians’ views of the EPs. This criticism from the EPs could be fuelled by the pressure they feel having to accommodate their formulations within a realist framework and could be a driver behind the EPs’ withdrawal from diagnosis as commented on by each professional group (Burnham, 2013).

The ‘broader’ perspective the EPs suggest that they adopt was considered further when they discussed their information-gathering processes and how this was then shared during the MDT discussions. They linked this consideration of broader types of information with the formulations they provide and their attempts to refute diagnosis.

e.g.:

EP3: ‘I’m happy for that to be collated across a range of environments and from different people. In fact, I think that’s how it should be done. You should be looking for those, those examples where, “Well, actually, is that the right diagnosis?” Because that’s how important it is. But how often do we actually test that out with children, do we test out the hypothesis? What are we looking for that would say to us, “Actually, you know, no. This child does have difficulties, but it may not be autism.” [sic]’

EP3: ‘The child should be presenting with needs across different environments. That’s part of the diagnosis. Not just in the family home, for example.’

EP2: ‘I’m saying autism is possibly, social communication difficulties where we cannot identify any other environmental reasons for having those social communication difficulties. But it seems to me that children are identified with a sufficient number of traits that would fit with autism.’

EP1: ‘That’s what I thought we were doing when we did these groups. We were giving them contra-indications. With this information do you still think it’s autism?’

EP3 suggests that their preference is to collect information ‘across a range of environments’, highlighting the multi-systemic perspective of their bioecological approach. They suggest this consideration of different environments leads them to hypothesis testing in an attempt to discount autism diagnosis. This hypothesis testing approach to diagnosis indicates that whilst traditionally the EPs may be working using a interpretivist framework, they are also applying scientific principles in their casework (Burnham, 2013). This point is echoed by both EP2 and EP3. EP2 suggests that they define autism as a condition of social communication need that cannot be explained by ‘other environmental reasons’. EP3 suggests the EP role is to provide paediatricians with ‘contra-indications’ to aid diagnosis. The language in the above quote is contrasted with many of the EPs’ statements about preference for qualitative data and aversion to standardised testing. This language of ‘contra-indications’ and hypotheses suggests that the EPs can be philosophically pragmatic holding both interpretivist and realist positions towards autism (Burnham, 2013). It is not clear from the interview data that this rigorous approach to diagnosis is communicated effectively to the paediatricians who are often unsure of why the EPs are reluctant to comment on the presence of autism. This preference for hypothesis testing suggests there is some attempt from EPs to fit their knowledge within a realist framework. Their consideration of ‘environmental reasons’, and ‘broader presentations’, ‘not just in the family home’ suggests that the EPs’ adoption of the bioecological framework allows them to consider and hold a number of hypotheses and a greater level of uncertainty around diagnosis compared to the paediatricians (Bronfenbrenner and Morris, 2007; Evans and Trotter, 2009). This ability to hold a greater level of uncertainty may mean that the EPs are less likely to provide a positive diagnosis of autism (Evans and Trotter, 2009). The paediatricians outline their approach to diagnosis by discussing observation schedules, criteria, and standardised assessments. The EPs are critical of this approach to diagnosis suggesting that it can result in confirmation bias.

e.g.:

EP1: ‘I think it’s about formulation as well. I don’t think there’s much formulation with observation. You know they look at certain behaviours, “yes definitely autism.” That’s what I think anyway. But now they’re tapping into us, so we’re giving them other narratives.’

EP2: ‘It seems to me that children are identified with a sufficient number of traits that would fit with autism.’

EP3: ‘You can almost mould a child into a certain diagnosis if you’re not cognisant to the fact that if you’re not looking for any other behaviours and developing behaviours as well. I think once a child’s given a diagnosis of anything, what we all do is look for? It’s confirmation bias, isn’t it? We’re looking for the evidence to support that diagnosis. So, we will ignore any evidence that refutes it.’

All of the EPs suggest that identification of traits without a consideration of alternative explanations results in a ‘confirmation bias’ towards a positive diagnosis of autism. The paediatricians have suggested that they are ‘inadequate’ to diagnose on their own and do not have the training or experience to consider attachment, trauma, mental health or other bioecological needs. The EPs suggest that what they perceive as the narrow medical perspective during diagnosis means that as long as a ‘sufficient number of traits’ can be identified, autism is confirmed. EP3 suggests that this is a specific limitation of the medical perspective more broadly. Their commentary of ‘developing behaviours’ highlights their view that symptom presentations are changeable and bound within time and context (Bronfenbrenner and Morris, 2007). EP1 suggests that the paediatricians ‘look for certain behaviours’ to confirm autism. This quote is taken from a discussion where EP1 considers the paediatricians' use of observational assessments. They suggest that the role of formulations they provide is to refute the findings of these observational assessments and provide 'alternative narratives', around childhood additional need. We can here see the EPs' awareness of the difference between their own, bioecologically grounded, socio-constructivist perspective where they attempt to provide qualitative data and consideration by understanding and describing 'narratives', and criterion assessment (Kelly, Woolfson and Boyle, 2008; Burnham, 2013). This contrasts with the EPs' discussion of hypothesis testing in the above quotations. The EPs are often aware of the challenges they face adopting their more interpretivist/constructivist, or bioecological perspective, within the paediatricians' medical model. Below, a single quote from EP3 is included; she speaks succinctly about the differences between the medical and EP perspective.

e.g.:

EP3: 'I think there's a bit of resistance to delaying a diagnosis. Well, wait, let's see what this child looks like in a year. Now, I think there's a problem with that. Because I'm just picking up that then keeps them on the caseload for a whole other year, and at some point you've got to make a decision. I personally don't think it sits well with medics to not be decisive. It doesn't sit well with them to say, "Come back in a year. Come back in a year." So, I would like to see a bit more of that for borderline cases.'

EP3 discusses the difficulty of combining the bioecological and medical perspectives by talking about the pressure they feel from the paediatricians to contribute to a prompt diagnosis. They notice that it 'sits well with the medics to be decisive', alluding to their quick categorisation of needs compared to EPs' more uncertain and lengthy formulations. EP3's adoption of the bioecological perspective is clear when they suggest that they would like to wait and 'see what this child looks like in a year'. They suggest that this approach doesn't 'sit well' with the paediatricians, highlighting their understanding of the challenges of fitting the bioecological perspective with the medical approach during diagnosis.

Summary

There are clear differences between the EPs' and paediatricians' perspectives. These differences influence their practice and afford them different facilitators and limitations in terms of their ability to collect information (Skellern, Schluter and McDowell, 2005; Scotland, 2012). For EPs, they are able to span various contexts and systems, applying the bioecological perspective. In the above quotes, the EPs comment on their preference to consider 'broader' types of information, perspectives, and formulations of need. The paediatricians' perception of EPs' ambiguous responses during diagnosis seemed to be driven by the EPs' adoption of the bioecological perspective, where need is changeable based on process, person, context, and time (Bronfenbrenner and Morris, 2007). As a result, they are often unhappy to present certain claims to knowledge around child wellbeing. The EPs suggest their role is to challenge medical diagnosis and consider alternative explanations, preferring to present their opinions as formulations and hypotheses. The paediatricians suggested that they can feel limited by their methods and practice in accounting for bioecological causes of additional need. They praised the quality of EP information in terms of its ability to consider discrete phenomena and span different environments and contexts. The paediatricians suggest that the information they receive is extremely valuable but would be more useful if the EPs were to provide more direct commentary on the presence of autism or diagnostic criteria. Both groups have noticed a reluctance on the part of the EPs to comment directly on diagnostic criteria and provide definitive answers as to whether autism is present or not.

4.5.1.2 Subtheme: Shared Experiences of Pressure, Power, and a Bioecological Approach

The EPs and paediatricians hold medical and bioecological perspectives respectively which influence their practice in the MDT and approach towards diagnosis. The paediatricians require the EPs to provide clear commentary on needs and would prefer EPs to consider diagnostic criteria in the information they provide. The EPs have been reluctant to do so and prefer to provide less certain formulations of need. Both the EPs and paediatricians notice an EP reluctance to be fully engaged in the diagnostic process. They often discussed this ‘anti-labelling’ approach and how this can interact with the pressure and sense of power they can perceive as professionals within the MDT.

Paediatricians’ Views

In the above section, the paediatricians discuss what they perceived as EPs’ reluctance to comment directly on diagnostic criteria. The paediatricians and EPs both discussed this feature of their shared practice and also noted a lack of

EP engagement with the MDT panel more broadly. Whilst the paediatricians had noticed that the EPs had withdrawn, they were often unsure about why this had happened.

e.g.:

PD3: ‘I don’t know if there’s been a change in culture or something over the past couple of years, but it seems that we’ve had less clear information. We seem to get information when it’s, “Oh, we think it’s predominantly a learning difficulty.” And that’s helpful. That’s still helpful information. But we get less of the evidence. So, we’ve kind of stopped. I’ve kind of stopped bringing a lot of my ASD cases to the discussion now.’

PD3: ‘I think the EP information is highly valuable. But it’s difficult to get that. Even with the means that we’ve had it’s been difficult, and it started off as just getting more information and over the years it’s got less. I don’t know whether that’s because EPs have just got less time and are more stretched, or whether they’re not seeing the benefit to them as to the information and time that they’re putting in.’

PD2: ‘Whether the psychologists have gone away from it on purpose or not, I don’t know. But what I know is that because it has been left with the doctors to do it for whatever reason, that it is not a good. It is not a wholesome assessment.’

PD1: ‘We’re forced to understand [psychology] more from that perspective because that’s not our training. Everything we’ve learned about autism has been on the hoof really!’

It’s clear from PD3’s quote that they have noticed a clear withdrawal and ‘change in culture’ within the EP profession. Whilst PD3 is passingly aware of a ‘cultural’ shift that may have impacted on EPs’ approach to diagnosis, they also consider whether EPs are ‘not seeing the benefit’ of being involved in the MDT. PD3 considers whether this is due to time restrictions or because of limited capacity. However, there is a sense of disappointment from PD3 and a resignation to an unchangeable EP position. PD3 suggests that the EPs' reluctance to provide clear information in the MDT meetings has meant that they have 'stopped bringing a lot of their cases to the discussion'. PD2 has also noticed the same withdrawal of EPs. PD2 wonders whether EPs have withdrawn 'on purpose'. There is clear confusion and a lack of explanation available to the paediatricians to explain this perceived withdrawal and they suggest that the EPs' absence has negatively impacted the MDT. PD2 suggests that when EPs have provided information, they have commented more directly on learning difficulties, rather than autism. However, PD3 also comments on the declining quality of the information provided by the EPs, suggesting they get 'less of the evidence'. The paediatricians often make the point that the EPs' information is 'highly valuable'. PD1 suggests that the withdrawal of the EPs and their increasingly unclear information has meant that they're forced to consider bioecological needs that fall outside their training. They make it clear that they have been 'forced to understand' these broader bioecological needs relating to autism and go on to say that in the absence of other professionals to provide this 'perspective', they have had to learn 'everything' about autism 'on the hoof'. This use of language conveys the pressure and limitations the paediatricians feel having to consider psychological and bioecological need without the support of EPs. PD3 alludes to an absence of psychological and bioecological formulation from EPs by suggesting that they still receive commentary on 'learning difficulty', which is 'still helpful information'. Although not articulated, this is in contrast to some of the paediatricians' commentary on the 'highly valuable' information provided by EPs around bioecological need.

PD2 continues this discussion, suggesting that EP withdrawal has resulted in a low quality, ‘less wholesome’ assessment of individual need during autism diagnosis.

Throughout this chapter, the paediatricians expressed the view that they were limited in their ability to differentiate between autism and broader bioecological needs. The paediatricians spoke further about their experiences of having to manage diagnosis, as they perceived, on their own.

e.g.:

PD3: ‘So, I think we do the best we can, given that we’re doing it on our own, but I don’t think that we should be doing it on our own.’

PD3: ‘I mean, without funding for MDT, you’re left doing it on your own. So I think given the situation that we were in, which was that we were left doing it on our own, we’ve trained ourselves to do the most reliable assessment as possible. So, we use 3Dis and ADOSs. Some children will get both if needed. So, we are using the best assessments out there. Well, you know, the, the most reasonable assessments for the time and constraints.’

PD2: ‘I’m inadequate to give a diagnosis, because I don’t know the child’s functioning as much at all. But I have to give a diagnosis, just because I’m called the doctor, but I’m not in a position to do that, because I don’t know enough. So, a psychologist has that power to find out if the child has got some problems at home.’

PD1: No, I’m not [satisfied with the way we diagnose autism] because autism diagnosis should be multidisciplinary. It used to be a diagnosis of exclusion. And it needs to be. It needs to fulfil the criteria. I am not being pedantic, but I feel that as a medical person I do need that. There has to be some criteria that needs to be fulfilled.’

The above quotes contain the emotive language of being ‘left to do it on our own’, suggesting a sense of isolation and limitation. The use of the phrases, ‘I don’t think we should be doing it on our own’, and ‘I think we do the best we can’, give an idea of the pressure felt by the paediatricians when they diagnose away from the support of EPs within the multi-disciplinary team. PD2 suggests they are ‘inadequate to give a diagnosis’ because they ‘don’t know the child’s functioning at all’. This is contrasted with their description when they say that a psychologist has ‘the power to find out if the child has got problems at home’. This highlights the value of the EPs’ perspective applying the bioecological model during diagnosis and the sense of limitation the paediatricians can feel diagnosing from a solely medical perspective. PD1 suggests that they are ‘not at all’ satisfied diagnosing without multi-disciplinary support. They suggest that effective differential diagnosis of exclusion cannot take place without the involvement of other professionals. In the above quotes, PD3 suggests that the way they have attempted to overcome these limitations has been to use more metric assessment tools to increase reliability. However, professionals need access to, and to consider, multiple perspectives to accurately assess behavioural-related needs, including autism (Skellern, Schluter and McDowell, 2005; Macleod, 2010; O’Dell *et al.*, 2016; Fitzgerald and Callard, 2017; Ravet and Williams, 2017).

PD2 spoke most succinctly about the pressure they felt trying to provide a diagnosis as a lone practitioner and their perceptions of safety around their application of standardised assessments from within their medical perspective.

e.g.:

PD2: ‘Because the ADOS has been standardised, you feel it’s sort of safer. Safer for yourself and for the parents’ sake. That you’ve done something which is a standardised assessment, and they feel that, “Oh, yes, that has been done,” and so, you know, this is yes or no. It’s like a test, kind of thing [sic].’

PD2’s repetition of ‘safe’ and ‘safer’, particularly in reference to parents, highlights the pressure the Paediatricians may face when engaging in lone diagnosis. They suggest that standardised assessment offers some ability to communicate information effectively to parents and patients. The influence of the restricted, categorised, medical perspective is demonstrated in their commentary on the benefits of a ‘yes or no’ test. Throughout this chapter, commentary has been made on EPs’ comfort with uncertainty compared to the paediatricians. The adoption of the medical model and restrictive ‘yes or no’ tests may result in the paediatricians feeling more pressure when bioecological needs aren’t easily categorised (Evans and Trotter, 2009; Fitzgerald and Callard, 2017).

The paediatricians spoke frequently about wanting more multi-disciplinary involvement. They said that they would ideally have a number of professionals involved but often mentioned psychology services specifically.

e.g.:

PD1: ‘Ideally, we should have and MDT for an autism assessment, not just a doctor, a Paediatrician, we should have an Educational Psychologist, we should have a Clinical Psychologist, and a Speech and Language Therapist, this is really the key people who would be able to give the best assessment results.’

PD3: ‘I like the observational evidence, where it’s there, it has been really helpful. Sometimes an Educational Psychologist will notice something that we wouldn’t necessarily notice if we were doing the same observation.’

PD2: ‘I think it should be a multidisciplinary decision. It’s not any person’s decision because there’s so many facets to this condition that you cannot just say. I can tell the medical bit. You can tell the psychological bit, or somebody else can tell the other bit, because that child’s made up of all that. I’m inadequate to give a diagnosis, because I don’t know the child’s functioning as much at all. But, I have to give a diagnosis, just because I’m called the doctor, but I’m not in a position to do that, because I don’t know enough.”

PD2: ‘I would love anybody else, Nurse, Psychologist, or Psychiatrist, or Neurologist, I don’t know anybody who knows the child, to have a say in the child’s diagnosis or assessment. But whether the Psychologists have gone away from it on purpose or not, I don’t know. But what I know is that because it has been left with the doctors to do it for whatever reason, that it is not a good. It is not a wholesome assessment.’

The paediatricians, in the above quotes, speak clearly about feeling limited and sometimes unable to give a diagnosis without multi-disciplinary involvement. PD1 recognises the importance of having EPs involved to provide ‘the best assessment results.’ PD3 suggests that EPs notice things they ‘wouldn’t necessarily notice’ ‘during observation’. These two quotes highlight the power often ascribed to EPs and their adoption of the bioecological perspective during the interviews. PD2 builds on this point when discussing EP involvement in diagnosis saying, ‘I have to give a diagnosis, just because I’m called the doctor, but I’m not in a position to do that, because I don’t know enough’. This highlights the value paediatricians place in EP involvement and their application of the bioecological perspective to consider ‘functioning, and broader interactive needs’ to help inform diagnosis. The pressure and isolation experienced by the paediatricians as a result of withheld EP involvement is shown when PD2 says that they would, ‘love anybody else’ to be involved in diagnosis. The paediatricians speak enthusiastically about wanting other professionals involved in diagnosis. The paediatricians recognise the limitations of the medical perspective and their ability to gather information, speaking about the need for information from different contexts. They suggest that both the ‘medical’ and ‘psychological’ perspectives are needed to accurately diagnose autism and speak positively about EPs being involved in multi-disciplinary diagnosis. This demonstrates the limitations experienced by the paediatricians in terms of how they carry out their role without the support of EPs to integrate bioecological information into assessment data.

EPs’ Views

The EPs also spoke about their perception of EP reluctance to be fully engaged with diagnosis and the multi-disciplinary meetings. The EPs spoke directly about why they felt their profession had withdrawn. The content of their discussion is considered below.

The EPs were aware of the pressure that they and their paediatric colleagues face during multi-disciplinary autism diagnosis. The EPs recognised that the paediatricians experience pressure around diagnosis and felt that a large part of this pressure came from parents.

e.g.:

EP2: ‘In fact really quickly from the panel was set up, we quickly found that there was lots of common ground in the middle and they were asking lots of the same questions we were, and struggling with, a lot of the same things that we were, and we talked, initially it felt like “oh what a relief, we all think the same thing” but that same thing was, “goodness, what are we going to do about all these autism diagnoses and pressure from parents?” we were all on board with that.’

EP1: ‘Those regular meetings with panel have stopped that. They very much stick with what they know and what they do best which is diagnosis, but also alerting them to that inaccurate diagnosis just because parents are pushing for it, it might help get them off your back, but it doesn’t help our cause.’

EP3: ‘I think there’s so much pressure for children to be diagnosed at a very, very early stage.’

Whilst the EPs spoke positively about the panel and multi-disciplinary working, they were more critical of the paediatricians’ approach to autism diagnosis. They often suggested that the paediatricians gave out positive diagnoses too readily. The EPs suggest that they understand that there is a lot of pressure on the paediatricians from parents around diagnosis in the above quotes. This is commented on more directly by EP1 and EP2. EP3 doesn’t name parents directly in the above quote but does consider the pressure for children ‘to be diagnosed’ at a ‘very, very, early stage’. This perception of paediatric practice may have arisen as a result of a lack of effective EP, or multi-disciplinary involvement, in diagnosis in the local context. As a result of this lack of multi-disciplinary working, the paediatricians may have felt more pressure during diagnosis when they have been unsupported by the EPs to consider bioecological formulations which could be used to delay diagnosis. This may be combined with the paediatricians' limited ability to collect more detailed information from different contexts and result in an increase in the pressure felt to provide positive diagnosis (Evans and Trotter, 2009). EP2 suggests that pressure from parents is a common struggle and something the paediatricians and EPs are 'all on board with'. EP1 discusses the role of paediatricians, suggesting that they 'stick with' diagnosis, with the EPs alerting them to 'inaccurate diagnosis' that may arise because 'parents are pushing for it'. EP1 goes on to say that this can 'help to get them off your back, but it doesn't help our cause', recognising the pressure and emotions at stake during diagnosis (Crane *et al.*, 2016). Here we can see the potential controversy that EPs can become entangled in when providing the bioecological 'contra-indications' and 'alternative perspectives' discussed in the previous subtheme. In **Section 4.2.3**, the EPs discuss their concerns around mental health and bioecological need being misdiagnosed in uncertain presentations of autism (Rutgers *et al.*, 2007; Doshi-Velez, Ge, and Kohane, 2014; Hollin, 2017). It may be that when EPs are providing formulations that focus on bioecological need and refute autism, parents can become upset. This resulting conflict and pressure EPs may face could in part explain why the paediatricians perceive the EPs to have gradually withdrawn from providing clear information in the MDT discussion, commenting less frequently on the presence of autism and more frequently on 'learning difficulties'. The EPs may have therefore withdrawn from direct commentary on bioecological needs because they would be suggesting a negative diagnosis and do not want to engage in confrontation with parents who may be expecting a diagnosis to be confirmed quickly (Waite and Woods, 1999; Skellern, Schluter and McDowell, 2005; Crane *et al.,* 2018).

The EPs continued to discuss the pressure and power of providing bioecological formulations during diagnosis. They suggested that their formulations can often be controversial and not universally well received by parents and schools. Parts of this discussion are considered through **Sections 4.3** and **4.4** where the EPs discussed the role and responsibility of parents and schools during diagnosis.

The EPs discussed at length their concerns around providing bioecological formulation during the diagnostic process for autism. EP1 suggests that providing bioecological formulations that refute autism means that schools and families have to 'take responsibility'. They report that they feel parents 'aren't always truthful' and will conceal ecological disturbances including 'dysfunctional' family dynamics and 'mixed up lives'.

e.g.:

EP1: If this isn't autism, we've got to take responsibility. First of all, we've got accept there are things that we might not have done correctly. And for school staff that means we should be doing that which could require, quite heavy resource allocation and time. Whereas autism, this is never going to be fixed, "there's special schools for children like these let's get rid".'

EP1: 'Parents aren't always truthful. They won't always talk about things that are going on at home, mixed up lives, or dysfunctional families. They won't talk about that to the paediatricians, so I think it's helpful when we can give them a bit of context and background to help them to make the right decisions.'

EP1: 'The shame is focussed on environmental factors that weren't [sic] or conditions, or key teaching and learning that should have been given, that wasn't provided. Things that parents could perhaps have done to help their children, but didn't want to accept that they're responsible, or they could have contributed towards the presentation of the child.'

EP3: 'I do think when you take a child into clinic, you may not be seeing a good representation of what that child can do if you're listening to a very strong parental voice. "Well, we must listen to the parental voice." There can again be bias there. Are you looking for evidence against, that doesn't support [autism]? If you think a child is autistic, you should be looking for evidence that doesn't support it. Looking at what can a child do that might contravene that bias of thinking "autistic" immediately. What are we looking for that would say to us, "Actually, you know, no. This child does have difficulties, but it may not be autism".'

EP3: Whereas actually what I felt we needed to be doing very much with this child is looking for evidence that refuted a diagnosis of ASD.

EP1 suggests it is the EPs' role to share information around this bioecological dysfunction with paediatricians. EP3 also suggests there is 'bias' in parents presenting their child's needs in clinic and that parents are prone to looking for autism. They suggest that the EP role for some children is to look 'for evidence that refuted a diagnosis of ASD' and suggests that EPs should be looking for ‘evidence that doesn’t support’ autism. EP3 goes on to suggest that instead, EPs should be to provide an alternative formulation to autism diagnosis, saying ‘actually, you know, no. This child does have difficulties, but it may not be autism’. In these quotes from EP1 and EP3, we can see the EPs’ preference for bioecological formulation and their somewhat critical response to autism diagnosis. EP3 seems to suggest that the EPs’ default position is to ‘refute’ an autism diagnosis, a perception echoed earlier in this section by the paediatricians. EP1 comments on the difficulty schools and families can face when being offered these challenging formulations by EPs. EP1 says schools are keen for diagnosis because an autism diagnosis abdicates responsibility. By accepting alternative bioecological formulations of need, schools have to ‘accept things that have not been done correctly’. They go on to say that for schools this could require quite heavy resource allocation and time’. Here we see the power of bioecological formulations and the pressure that this can put on key stakeholders for autism, and as a result, the EPs providing them. When discussing family’s responses to bioecological formulations, EP1 discusses the ‘shame’ that families can feel when an alternative formulation is given to an autism diagnosis.

e.g.:

EP1: ‘The shame is focussed on environmental factors that weren’t [sic] - or conditions, or key teaching and learning that should have been given, that wasn’t provided. Things that parents could perhaps have done to help their children, but didn’t want to accept that they’re responsible, or they could have contributed towards the presentation of the child.’

The above quote gives a sense of the weight of these formulations for the EP. The use of the word ‘shame’ indicates a strong emotional response. If EPs are aware that their formulations can result in ‘heavy resource allocation’, large demands on time, and ‘shame’ for families, it is perhaps not surprising that the paediatricians have noticed a withdrawal from the MDT as a whole and direct commentary to symptoms of autism in favour of more neutral commentary on learning needs.

e.g.:

EP2: ‘So you can see the huge resistance to not using the labels and in the power that we have. So, can you imagine if we were the ones identifying autism, and ADHD, and we went down a similar route to dyslexia. The profession’s taken dyslexia down a route saying, “actually it’s not helpful, what we need to do is talk about interventions for children who present with those difficulties”, which is what we’re trying to do with dyslexia, we would be putting ourselves right at the front of a huge, huge battle. So what we’ve done is step away from the battle saying “we don’t want anything to do with it”, but all sorts of other forces are coming to play, and unfortunately we are still in it and we kind of find ourselves on the periphery of but involved in it saying “we’re not really comfortable with this, we don’t really know why this happened, this isn’t necessarily the way we want to work” but that’s the way the system has gone without us.’

EP2 has recognised the weight of the EPs’ bioecological approach and suggests that it has resulted in experiences of conflict and pressure for the profession as a whole. They compare the EP approach to autism diagnosis to the developments in the identification of dyslexia. EP2 suggests that EPs would prefer to consider ‘interventions’ rather than labels (Bronfenbrenner and Morris, 2007). They say that providing bioecological formulations would be akin to ‘putting ourselves right at the front of a huge, huge battle’. The sense of pressure felt in this quote is clear. The commentary of ‘huge, huge battle’, when taken in context with EP1’s quotes around ‘shame’ and ‘responsibility’, gives a sense of the power and pressure felt by EPs when they try to provide bioecological formulations that contra-indicate autism. EP2 recognises that this pressure has contributed towards the paediatricians’ perception of EP withdrawal from diagnosis. EP2 says that the EP profession has chosen to ‘step away from the battle, saying “We don’t want anything to do with it”’. EP2 suggests that this has not been an effective strategy and discusses the changes that have happened in the systems around autism diagnosis without EP involvement.

e.g.:

EP2: ‘unfortunately we [EPs] are still in it [the system of autism diagnosis] and we kind of find ourselves on the periphery of it, but involved in it, saying “We’re not really comfortable with this, we don’t really know why this happened, this isn’t necessarily the way we want to work” but that’s the way the system has gone without us.’

Here EP2 clearly articulates some of the central issues around diagnosis and collaborative working for the local MDT. EP2 suggests that EPs have wilfully withdrawn from a pressure-filled ‘battle’, where powerful bioecological formulations have the potential to disrupt the lives of others. EP2’s description of being engaged with autism diagnosis but on the ‘periphery’ of any meaningful input resonates with the paediatricians’ description of EP reluctance and withheld involvement. This is further outlined by EP2 when they comment on the EPs being ‘not really comfortable’ with the way the system has progressed without them. The hesitation and confusion that follows suggests a disempowerment and perhaps indicates how EPs' withholding information or not engaging effectively with MDT has negatively affected the diagnostic process and their experience of their own practice.

The EPs expressed some ambivalent views around their involvement and power to influence the process of diagnosis within the MDT. Some suggested that the information they shared was almost universally accepted by other professionals. Others suggest that they had little to no power to influence diagnosis and questioned the value of their involvement. These views were often contrasted with the paediatricians who universally spoke positively about EP involvement in the MDT.

e.g.:

EP1: 'We can only give our views. We don't make the diagnosis. In terms of interventions. I think they should have no influence there. We're supposed to have more influence, but we don't always have influence.

EP1: 'You know, to date no one has disagreed with me. I'm so forceful in my views!'

EP1: 'The paediatricians have the power with regards to the diagnosis. We can only give our views. We don't make the diagnosis. I think we've been helpful in nun terms of looking at other factors which could explain their presentations, hence their referral forms have changed. I think we've been helpful in giving them the nm more confidence to say "no".'

EP3: 'So, I would say that it's probably very useful for them. More useful for them than for us really. felt, erm, I felt it was useful to them, because I thought they were using it to, erm, enquire about cases.'

EP3: 'What I don't know is how often our perspective changes anything.'

The above quotes highlight some of the conflicting statements the EPs made about their involvement in the MDT diagnostic process. EP1 suggests they have a passive role in the MDT saying they ‘can only give their views’ and suggesting that they ‘don’t always have influence’. The language they use in this quote suggests a passive, resigned role within the MDT and desire for more power to influence diagnosis. However, earlier in the transcript, EP1 discusses what it is like when they share bioecological formulations with other professionals and says that ‘no one has ever disagreed with me’, commenting on how ‘forceful’ they can be when expressing their views. EP1 explicitly discusses their view of the EP role during diagnosis. They suggest they have ‘no power in regard to diagnosis’, suggesting that the power and ownership of diagnosis lies with the paediatricians. They go on to say that the they see the EPs’ role as providing information to give paediatricians ‘the confidence to say “no”’ to a positive diagnosis of autism. There is some ambivalence around the role, involvement, and power of EPs in this quote. Do the EPs have no ‘power’ in diagnosis; are they only able to ‘provide their views’? Or are they more subtle influencers giving paediatricians the ‘confidence’ to carry out diagnosis? Throughout this section the view expressed by the EPs that it is their role to ‘refute’ diagnosis by providing bioecological formulations has been discussed. This may be the source of the EPs’ ambivalence. If their bioecological formulations are accepted, they feel ‘forceful’, and if they are not, they feel like they have ‘no influence’. It could be suggested that by holding a contrary position to diagnosis, they are limiting their ability to engage effectively in diagnosis and may experience more pressure, resulting in more ambivalence (Evans and

Trotter, 2009). EP3 also spoke with some ambivalence about the power they have in the MDT group. They suggested that EP involvement is ‘probably very useful’ for the paediatricians. They then go on to say that they don’t know how often the EP perspective ‘changes anything’. This further suggests that EP ambivalence towards the MDT is related to their role refuting diagnosis by providing bioecological formulations. When the formulations are accepted, they are perhaps viewed by EP3 as ‘very useful’. When diagnosis is confirmed the EPs may question how often their ‘perspective changes anything’.

The EPs may feel under pressure engaging with the medical perspective. Research suggests that EPs feel a need to make their work seem more ‘scientific’ and can feel anxious or hesitant around sharing their work and formulations if they feel that their contribution does not fit into a realist framework (Burnham, 2013). This may partly be fuelling their hesitation to make clear recommendations around bioecological formulations and could be contributing to their ambivalence towards the panel processes. This adds to tension between EPs and paediatricians around diagnosis that has not gone unnoticed by the paediatricians. The EPs are also perhaps partially withdrawn from the pressure that may be put upon them by parents whilst reporting to want more influence in the diagnostic process. EP reluctance during diagnosis leaves the paediatricians with more pressure and responsibility, and more uncertainty, which may lead to increased rates of diagnosis (Skellern, Schluter and McDowell, 2005; Evans and Trotter, 2009). There is clear weight to the suggestion that discussion needs to take place across disciplines to consider the professional philosophical perspective to help overcome these issues and to ensure reliable diagnosis whilst considering the role that outside forces may play (Fitzgerald and Callard, 2017).

EPs’ experience of ambivalence, pressure, and reluctance to diagnose was discussed at length by EP2. EP2 shared a number of quotes which have been presented in isolation below because they so clearly describe the experience alluded to by the other EPs. EP2 suggests that the EP profession has an ‘anti-labelling’ legacy, where the efficacy and utility of labelling children has been criticised in terms of impact on individual child wellbeing (Lauchlan and Boyle, 2007; Algraigray and Boyle, 2017).

e.g.:

EP2: ‘I don’t understand how we as a profession, 20 years ago, were in this position of “we’re anti-labelling, we’re not going to label children” to 20 years later that’s all that seems to go on. I mean we’re not directly doing it but within our work, you know we turn up at a meeting and the first thing they do within the referrals is table the labels the kids have. So, I think we’ve come so far from where we were saying we wanted to be 20 years ago why has that happened? And this is talking about all labels now…and part of that as I would say is that we, as EPs, aren’t very powerful in that because we aren’t the ones giving the labels.’

EP2: ‘I think the way we used to work years ago and this was really, sort of strongly promoted in EP training when I trained and it was this kind of anti-labelling position. Essentially, we don’t want to know about labels we’re looking at the whole child, as an individual, and there was a real kind of anti-labelling movement and I still have that kind of, you know, within me, because that was that was so important in the training, but I feel like we’ve come so far from that and I honestly…I’m trying to think of a different word for baffles because it does baffle me, how we… because I guess it’s just because we as a profession aren’t very powerful in this.”

EP2: ‘Give us the power and then we’ll stop doing it. And you can almost see how that’s happened generally with labels because we were kind of, as a profession, are anti the labelling so we stood right back from it. So, the whole medicalised profession came to kind of take it over, and obviously really medics are in this business of identifying and diagnosing! They’re quite comfortable with it, or that’s what they do. So yeah, maybe it’s because we stood back.’

The extended quotations from EP2 highlights the issues experienced discussed by the EPs throughout this research paper. EP2 speaks about the impact of EP training on the development of their professional perspective. They suggest that the EP profession adopts a bioecologically informed ‘anti-labelling’ perspective, which was imparted to them through their training 20 years ago. EP2 suggests that historically, as a profession, EPs were ‘not going to label children’ and would instead focus on ‘the whole child, as an individual’. Whilst EP2 does not describe Bronfenbrenner’s work directly, we can consider this as a description of EP2’s perceptions of the EPs’ adoption of the bioecological framework and how this was shared with them through training (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008). It is clear that EP2 feels passionately about the change in position from an anti-labelling position to becoming involved in diagnosis. EP2 articulates the tension between the EPs’ strong bioecological perspective and medical diagnosis. They suggest that EPs who initially held a strong anti-labelling perspective have stepped away, and ‘stood right back’ from diagnosis. EP2 suggests that as a result of this withdrawal from EPs, the medical perspective has ‘taken over’ and now EPs prioritise ‘the labels the kids have’. The EPs in this research project have suggested that they view their role in MDT as providing evidence to refute diagnosis and give contra-indications of need. It could be suggested that over time, the EPs’ anti-labelling perspective has shifted from actively applying the bioecological perspective through formulation, viewing their role as refuting diagnosis, to ambivalence and withdrawal from diagnosis altogether. In the above section, the EPs discuss their perception of power in the MDT diagnosis group. The EPs often report feeling empowered when their bioecological formulations are accepted but feel like ‘nothing changes’ when diagnosis is confirmed. EP2 suggests that the shifts over the last 20 years of EP practice has left EPs ‘not very powerful’. It could be suggested that EPs have often felt disempowered when autism diagnosis has been confirmed. Confirmation of any diagnosis may be in conflict with the bioecological and ‘anti-labelling’ perspective which may be more universally adopted by the EPs (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008; Burnham, 2013). This conflict of values within the professional perspective may have resulted in some of the ambivalence the EPs have expressed towards the panel. EP2 confirms this, to some extent, by saying that EPs ‘aren’t very powerful because we aren’t the one’s giving labels’. It could therefore be suggested that EPs’ experience of power during the MDT discussion comes from their ability to provide alternative explanations and refuse diagnosis. This is a position which may arise from their anti-labelling perspective. This is demonstrated further when EP2 says, ‘give us the power and we’ll stop doing it’, when discussing EPs’ ability to diagnose autism.

e.g.:

EP2: ‘I guess the one comparison that we can give to that is dyslexia. Because that is the one where we kept the power to identify and I think dyslexia is quite a good comparison because we EPs can look over 20 years and see how we’ve oddly been given a power we’re very uncomfortable with in identifying dyslexia, and you can see everything that’s going on with dyslexia at the moment where the profession is trying to thwart, or certain authorities within the profession, are trying to step away from using the term dyslexia, so they’re trying to not use the label. So, you can see the huge resistance to not using the labels in the power that we have. So, can you imagine if we were the ones identifying autism and ADHD.’

EP2: ‘We went down a similar route to dyslexia, the profession taken dyslexia down a route saying, “actually it’s not helpful, what we need to do is talk about interventions for children who present with those difficulties”, which is what we’re trying to do with dyslexia. If we did that for autism diagnosis we would be putting ourselves right at the front of a huge, huge battle. So what we’ve done is step away from the battle saying “we don’t want anything to do with it”…but all sorts of other…forces are coming to play, and unfortunately we are still in it and we kind of find ourselves on the periphery of but involved in it saying “we’re not really comfortable with this, we don’t really know why this happened, this isn’t necessarily the way we want to work” but that’s the way the system has gone without us.

The above quotes from EP2 describe a potential source of the EPs’ reluctance to comment directly on diagnostic criteria. However, EP2 suggests that the EPs’ anti-labelling position is not the only reason why EPs would be reluctant to engage in multi-disciplinary diagnosis. EP2 suggests that EPs have ‘stood back’ from diagnosis and as a result, the medical profession has ‘taken over’. EP2 recognises the role the EPs play in refusing diagnosis, suggesting that part of the rise in diagnosis that they have experienced may be because EPs have withdrawn from engaging in multi-disciplinary diagnosis and subsequently providing alternative formulations of need. They compare their experience on autism diagnosis to EP practice around dyslexia. EP2 comments on the shift in EP practice from consideration of the label to a more bioecological focus on ‘interventions for children who present with those difficulties’. EP2 suggests that EPs were ‘very uncomfortable’ with being ‘given the power’ to identify dyslexia, drawing parallels between the EPs’ withdrawal from dyslexia identification and autism diagnosis. EP2 goes on to suggest that as the profession removed themselves from dyslexia diagnosis, they faced ‘huge resistance’. They go on to say that if EPs were to voice the same criticism for autism and apply a perspective more focussed on ecological factors and intervention, then they would be putting themselves at the front of a ‘huge, huge, battle’. EP2 suggests that if EPs were more central to the process of diagnosis then they would often refuse diagnosis compared to medical professionals. They suggest that this would potentially draw EPs into conflict and to avoid this conflict, EPs have tried to step away from diagnosis altogether. This complex dynamic of anti-labelling approaches, enthusiasm for alternative formulations, and disappointment when diagnosis is confirmed has combined with resistance and pressure from parents for many of the EPs interviewed in this research. It is no wonder they have often discussed complex and ambivalent views about their role in multi-disciplinary teams, how their formulations influence other professionals, and their perspective towards autism more broadly. EP2 describes this process succinctly suggesting that EPs, on the one hand, ‘don’t want anything to do’ with autism diagnosis but have now found themselves on the ‘periphery of being involved’ in a diagnosis system which has evolved without their active participation. EP2 describes the cost of this lack of involvement to the EP profession. They say, '"We're not really comfortable with this, we don't really know why this happened, this isn't necessarily the way we want to work" but that's the way the system has gone without us.'

Summary

The paediatricians often discussed their limitations and experiences of lack of power when presented with bioecological needs during diagnosing outside the MDT. They often felt limited by their adoption of the medical model within the realist framework and described their attempts to overcome their lack of available information from their professionals by increasing their use of standardised tests. The paediatricians spoke positively about EP involvement but were often confused by what was often described as EP reluctance to be involved in the MDT or comment directly on the presence of autism. The paediatricians described the pressure they can feel when having to provide a diagnosis from their limited perspective. They recognised that the EPs could also experience this pressure and preferred to provide formulations and hypotheses of need. This EP preference for formulations and hypotheses appeared to be related to their adoption of the bioecological perspective. However, the paediatricians suggested that for the MDT to be effective they needed EPs to provide a clear position on whether or not they thought autism was present and a commentary on how their formulations related to diagnostic criteria. They did not specify which diagnostic criteria they would like EPs to comment on.

The EPs described a much more ambivalent relationship with their involvement with their colleagues in the MDT, their own sources of power, and position towards diagnosis more broadly. The EPs suggested that their role in the MDT is to provide alternative bioecological formulations of additional need. They reported feeling comfortable when presented with uncertain presentations of need but felt more pressure when being asked to present their observations within the medical framework (Burnham, 2013). This was often expressed by the EPs in their aversion to early life diagnosis and preference for intervention over time. The EPs' adoption of the bioecological framework is clear. Their professional perspective and view that it was their role to refute diagnosis often resulted in an expressed ambivalence towards the process of diagnosis and work with their colleagues. The source of this ambivalence was explored through the EPs' discussions around their relationship to diagnosis. They often felt powerful when they expressed their views and diagnosis was refused. They suggested that their colleagues regularly listened to them and accepted, and valued, their formulations. This was contrasted with their discussion around their experiences of positive diagnosis. The EPs suggested that they felt disempowered and they experienced their involvement as ineffective when diagnosis was confirmed, highlighting the contradictions within the EPs' perspective. The EPs are keen to be involved in MDT diagnosis but have the aim of refusing diagnosis as often as is appropriately possible. The underpinning of the EPs' bioecological perspective was discussed by EP2 who outlined the EPs' 'anti-labelling' position. EP2 outlined the EP professions' approach to dyslexia diagnosis where EPs have been uncomfortable with the power given to them to diagnose. EP2 discussed the conflict and pressure that that exposed EPs to and suggested that a similar dynamic is at play during autism diagnosis. The EPs expressed a desire to be involved in diagnosis to share alternative formulations and refuse confirmations of autism. They are also potentially motivated by avoiding conflict and pressure from parents by providing formulations which encourage parents and school to ‘take responsibility’. As a result, the EPs described being involved in a system which has evolved without them.

4.6 Chapter Summary

The findings from this research have been rich, highlighting many important aspects of EPs’ and paediatricians’ views around autism and its diagnosis. These have been presented within this chapter as a broad picture in order to reflect the broad data set and its analysis. They have also been discussed in relation to the findings in the wider literature. **Chapter Five** will contain a summary of these findings and discussion in relation to the four research questions. From this, links will be made to implications in the area of EP and paediatric practice, and the assessment and diagnosis of autism. This chapter will also consider the methodological limitations of the research, areas for future research and the generalisability of the findings.

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Chapter 5: Conclusion

5.1 Introduction

This chapter presents a conclusion to the research study. Within this chapter, the key findings of the research will be summarised and considered in relation to the four research questions. The implications for practice, service delivery and multi-disciplinary working will be considered in light of the key findings with specific reflection on autism assessment and diagnosis. Questions arising from the findings will be raised and posed as discussion points which may indicate areas of further research or discussion. Methodological reflections and limitations of the research will also be discussed

The conclusion continues below with a presentation of the key findings for each research question. The views of the EPs and paediatricians are summarised in tabular form and are followed by an analysis and conclusions for each question.

5.2 Key Findings

5.2.1 Research Question 1: How do EPs and paediatricians conceptualise autism?

5.2.1.1 Summary of Views

Table 6: Conceptualisation of Autism Summary Table

	EPs' Views	**Paediatricians' Views**
Conceptualisation of autism	◊EPs consider childhood development through a bioecological perspective. They see childhood need as arising from disruptions in system and interactions. They hold an anti-labelling perspective and prefer to focus on interventions. ◊ ◊EPs think that bioecological disruption gets diagnosed as autism. ◊EPs think that true autism is primarily biological in origin and cannot be easily treated/intervened with. They conceptualise autism as a life-long disorder. They define autism as a set of social-communication needs that cannot be explained by other environmental or interactive factors.	◊Paediatricians view autism as a set of symptoms that match criteria. They report struggling with the lack of biomarkers and traditional diagnostics tests for autism. ◊Paediatricians conceptualise autism as a spectrum disorder which may have become too broad to accurately describe individual need. ◊Paediatricians think that the criteria for autism can hide comorbid and bioecological needs. This often occurs through dual diagnosis and diagnostic substitution.

Conceptualisation of autism	◊EPs do not consider diagnostic criteria when assessing for autism. ◊EPs see autism as a spectrum disorder which may have become too broad to accurately describe individual need. ◊EPs think that the current conceptualisation of autism is too broad and encompasses too many areas of comorbid need. ◊EPs think that the criteria for autism can hide comorbid needs. This often occurs through dual diagnosis and diagnostic substitution. ◊EPs will only confirm a diagnosis of autism when all bioecological needs have been ruled out. ◊EPs think that autism diagnosis does not effectively help children and families to gain access to additional support. ◊EPs think that the medical conceptualisation of autism stops progress being made. They think this because need is ascribed to biological/medical causes rather than eco-systemic needs that can be changed over time. ◊EPs think that function of diagnosis is to enable children to access specialist provisions.	◊Paediatricians view autism diagnosis as a tool for unlocking additional support, mainly in schools. ◊Paediatricians use the ICD-10 and DSM-5 to define and conceptualise autism. However, they rarely refer to the specific criteria or how they use them to inform diagnosis. Instead, they discuss their use of standardised assessment. ◊Paediatricians describe the diagnostic criteria as ‘arbitrary’ and think that the label of autism does not promote in-depth understanding or individually targeted intervention. ◊Paediatricians conceptualise autism through a medical model. They rely on empirical observation, questionnaires and standardised assessments to confirm a diagnosis.

5.2.1.2 Analysis and Conclusions

The participants discussed the major distinctions between the medical and bioecological perspectives towards additional need and how this related to their conceptualisations of autism (Bronfenbrenner and Morris, 2007; Scotland, 2012; O’Dell *et al.*, 2016). The EPs adopt a bioecological perspective but do recognise that there is a biological basis to autism (Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008). As a result, the EPs prefer to focus on environmental and interactive factors and identify autism much less frequently than the paediatricians. EPs place priority on ruling out bioecological needs before confirming autism. The EPs define autism as a deficit in social-communication that cannot be explained by bioecological factors. They suggest that autism is resistant to intervention and should be confirmed over time after the provision of additional support.

The paediatricians almost exclusively conceptualise additional need through the medical model. There was some variation amongst the paediatricians with PD3, in particular, discussing the need to consider bioecological factors which may influence the process of diagnosis. The paediatricians all recognise that there is a bioecological component to additional need but report having limited knowledge and experience in this area. The paediatricians’ comment on the importance of diagnostic criteria but also describe the criteria as ‘arbitrary’ and did not describe the specific details of key diagnostic documents. They suggested that the only way they can confirm or refuse a diagnosis of autism is by matching symptom presentations to criteria or through the use of standardised assessments.

Both EPs and paediatricians think that the criteria for autism are too broad and as result, have made the diagnostic label of autism a less effective descriptor of additional need. They also suggest that the broadening criteria have made differential diagnosis more challenging. Both the EPs and paediatricians agree that a key aim for differential diagnosis for autism is to separate out bioecological, mental health, and developmental needs which may present similarly to autism (Skellern, Schluter and McDowell, 2005; Bronfenbrenner and Morris, 2007; Doshi-Velez, Ge and Kohane, 2014; Hollin, 2017).

Both EPs and paediatricians conceptualise autism diagnosis as a functional tool. They suggested that autism diagnosis performs two key roles. The first is to act as a descriptor to facilitate understanding of additional need. They also suggested that an autism diagnosis is used for accessing additional support. The paediatricians assumed more frequently that autism diagnosis unlocked additional support in schools. This view appeared to originate from a misunderstanding held by parents and from the paediatricians' lack of knowledge of school support structures and funding streams available to children with additional needs. The EPs did not view autism diagnosis as an effective tool for accessing additional support in mainstream schools and suggested that support should be provided regardless of whether or not a child received a diagnosis. They also suggested that if bioecological support were provided early on, many children’s families would not feel the need to seek diagnosis. The EPs did however recognise that autism diagnosis was necessary in some instances to access specialist educational settings and support services. The EPs and paediatricians linked this functional use of diagnosis to the reported rise in autism incidence, suggesting a lack of resources in schools had contributed to more parents and schools seeking autism diagnosis.

5.2.2 Research Question 2: How do EPs and paediatricians explain the reported rise in autism?

5.2.2.1 Summary of Views

Table 7: Views on Reported Rise of Autism Summary Table

	EPs' Views	**Paediatricians' Views**
Views on reported rise of autism	◊EPs think that the reported rise in autism is due to many interrelated and often unclear factors. ◊EPs think that the expanding diagnostic criteria have contributed to the reported rise in autism. ◊EPs think that reduced budgets in schools and access to additional support have contributed to the reported rise in autism. They suggest that parents and schools will now more readily seek out a diagnosis to access additional support services. ◊EPs suggest that dual diagnosis and diagnostic substitution have contributed to the reported rise in autism. ◊EPs think that there is a greater awareness of autism amongst parents and schools, contributing to the reported rise in autism. The EPs discuss the cultural	◊Paediatricians think that the reported rise in autism is due to many interrelated and often unclear factors. ◊Paediatricians think that the expanding diagnostic criteria have contributed to the reported rise in autism. ◊Paediatricians think that reduced budgets in schools and access to additional support have contributed to the reported rise in autism. They suggest that parents and schools will now more readily seek out a diagnosis to access additional support services. This is often due to increased pressure from schools. ◊Paediatricians suggest that dual diagnosis and diagnostic substitution have contributed to the reported rise in autism.

Views on reported rise of autism	influences on this increased awareness and how it has affected the process of autism diagnosis. ◊EPs think that a purely medical approach to diagnosis has contributed to the reported rise in autism. They suggest that the medical approach to differential diagnosis stops other causes of additional need being explored. ◊EPs suggested a lack of early intervention prior to diagnosis may have contributed to the reported rise in autism.	◊Paediatricians think that there is a greater awareness of autism amongst parents and schools, contributing to the reported rise in autism.

5.2.2.2 Analysis and Conclusions

EPs and paediatricians both identified with the reported rise in autism (Taylor, Jick and MacLaughlin, 2013; Lyall *et al.*, 2017). They suggested the rise they experienced in their casework had been dramatic, increasing significantly over time. Both EPs and paediatricians suggested that the reported rise was due to a number of interrelated factors. The EPs and paediatricians suggested the same factors contributed to this reported increase. These include, a greater awareness amongst schools, parents and the general public, broader diagnostic criteria, diagnostic substitution, and dual diagnosis. These suggestions broadly reflect findings from autism epidemiology research (Leonard *et al.*, 2010; Lyall *et al.*, 2017). The EPs, considering bioecological influences, discussed the role that media played in increasing parents' understanding of autism. They suggest that autism is presented as a fixed-state condition on television and parents can often conflate bioecological needs with autism. As a result, the EPs suggest that parents can assume that their child's additional needs cannot be intervened with or supported to change.

The EPs and paediatricians spoke at length about dual diagnosis and diagnostic substitution. They suggested that dual diagnosis may be beneficial to the individual because the social communication needs associated with autism were now being identified separately. However, EPs were concerned that when dual diagnosis has occurred, autism becomes the primary focus of key stakeholders at the expense of other bioecological needs. The EPs and paediatricians differed in their views around diagnostic substitution and how this contributed to their experience of the reported rise in autism (Lyall *et al.*, 2017). Both EPs and paediatricians suggested that autism had often replaced a variety of other learning, mental health, and bioecological needs (Bishop *et al.*, 2008; Leonard *et al.*, 2010). The paediatricians were mildly critical of this substitution suggesting that autism has ‘taken over’. The EPs were outspoken in their criticism of diagnostic substitution in cases where bioecological or mental health needs many be present. They suggest that diagnostic substitution for these needs was damaging to the individual and could represent an abdication of responsibility on the part of parents and schools. These viewpoints arise from the tension between the bioecological and medical conceptualisations of additional need held by the two professional groups (Bishop *et al.*, 2008; Leonard *et al.*, 2010). The medical conceptualisation of additional need maintains that symptoms arise from innate, potentially unchangeable, biological forces (Skellern, Schluter, and McDowell, 2005; Algraigray and Boyle, 2017). The EPs suggested that the reported rise in autism, partially due to diagnostic substitution and ascription of need to biological forces, means that potentially more malleable and ‘treatable’ bioecological needs are being diagnosed as autism (Skellern, Schluter and McDowell, 2005; Bronfenbrenner and Morris, 2007; Doshi-Velez, Ge and Kohane, 2014). They suggested that this medical conceptualisation of additional need through the application of a diagnosis of autism means that environmental, interactive, and systemic factors were often ignored. They suggested that this could mean that potential intervention and support options were not explored and resulted in descriptions of need which did not take into account the holistic wellbeing of the individual child.

5.2.3 Research Question 3: How does the professional perspective of EPs and paediatricians influence their experience of casework related to autism and its diagnosis?

5.2.3.1 Summary of Views

Table 8: Professional Perspective Summary Table

	EPs' Views	**Paediatricians' Views**
Professional Perspective: Casework and Diagnosis	◊EPs adopt a bioecological perspective. They suggest that they feel much more comfortable with uncertain presentations of need. They suggest they are able to focus on the individual need without having to label it. They do not comment on diagnostic criteria regularly. ◊The EPs' bioecological perspective allows them to adopt a 'wait and see' approach more readily. This means that they are hesitant to support diagnosis and prefer to observe response to intervention over time. ◊EPs suggest that they are better able to think systemically about families due to the bioecological perspective they hold. They suggest they take into account parental and child wellbeing, family functioning and historic development when considering a diagnosis.	◊Paediatricians reported feeling limited by their role and the medical model. They suggested that they have to adhere to diagnostic criteria and rely on standardised assessments. They suggested that the tools they use and the way that they practice limits their ability to collect information. They also suggest that diagnosis is one of the only tools they have to support children and families who are in need. ◊Paediatricians, working from a medical and criteria-based view of additional need, are keen to diagnose as soon as possible so

Professional Perspective: Casework and Diagnosis	◊EPs suggested they had a good awareness of learning, mental-health, and developmental needs which may present similarly to autism. They felt that their role and bioecological approach enabled them to engage in differential formulations of need effectively. ◊EPs consider the PPCT of additional needs, contextualising their assessments during autism diagnosis. ◊EPs take an anti-labelling stance. This is often based around their views on inclusion and influenced by their bioecological perspective. As a result, they generally disagree with giving a diagnosis, except in very clear cases. ◊The EPs anti-labelling and bioecological perspective has led them to take a contrary position to autism diagnosis. They feel that it is their role to give contra-indications to autism when working with the paediatricians. ◊The EPs' contrary position has led them to feel ambivalent towards MDT diagnosis. If a diagnosis of autism if confirmed they feel powerless. If an autism diagnosis is refused, they feel influential and powerful. ◊The EPs' bioecological perspective can be controversial. They recognise the recommendations they give can place blame on schools and families and require heavy resource and time allocation.	that a child may access additional support quickly. ◊Paediatricians feel that their role does not allow them the access to school and families that they would like. They suggest there is not enough time for them to use qualitative tools to explore issues with families. They suggested this limited their ability to consider other explanations of need. ◊The paediatricians report that they are not trained or experienced enough to consider bioecological needs and the role that they could play in presentations in clinic. They suggested that this lack of training and experience limited their ability to engage in effective differential diagnosis for autism. ◊Paediatricians are not aware of the funding streams available to children for them to access additional support in school. ◊Paediatricians want to support parents. They suggest that a

Professional Perspective: Casework and Diagnosis	◊As a result of the controversy and ambivalence the EPs experience and the underpinning of their bioecological and anti-labelling approach, they have been hesitant in MDT diagnosis providing less clear commentary on autism. ◊EPs have more of an awareness and familiarity of schools, statutory assessments, and funding streams to access additional support. They suggested that this enables them to think about the support that children are entitled to without having to receive a diagnosis. ◊The EPs' role allows them access to children across multiple settings, including their school and home. ◊EPs engage regularly in statutory assessment for children to access specialist provisions. They recognised the need for some children to have an autism diagnosis to access these settings.	diagnosis of autism helps to reduce the stigma for parents, assuring them that their child's need isn't because of something they have 'done'. ◊Paediatricians report feeling under pressure when involved in lone diagnosis because they are unable to effectively query parents, explore other bioecological factors, or collect information in order to aid assessment for autism. ◊The limitation the paediatricians perceive themselves as having has led them to more actively seek multi-disciplinary involvement compared to the EPs.

5.2.3.2 Analysis and Conclusions

The EPs in this research made it clear that they hold a bioecological perspective (Bronfenbrenner and Morris, 2007). They suggested that they do not often take into account diagnostic criteria when considering whether or not a child has autism. As a result of their perspective, the EPs felt less pressure to present their findings in relation to diagnostic categories and criteria (Evans and Trotter, 2009; Fitzgerald and Callard, 2017). The EPs and paediatricians suggested that this has enabled the EPs to focus on individual need and systemic child wellbeing by not having to consider diagnostic criteria to the same degree. The EPs reported that they benefitted from their approach, feeling more comfortable with ‘uncertain’ presentations of need during diagnosis (Evans and Trotter, 2009; Fitzgerald and Callard, 2017). They suggested that their professional perspective enabled them to collect a variety of information from different sources and contexts to consider holistic child wellbeing. This helped them to consider function assessments of child wellbeing. The EPs were also more comfortable taking a ‘wait and see’ approach to diagnosis. This appeared to be related to their developmental perspective of children and the role that time plays in bioecological formulations (Waite and Woods, 1999; Bronfenbrenner and Morris, 2007; Fox, 2017). The EPs presented an ‘anti-labelling’ approach to additional need (Algraigray and Boyle, 2017). This view was grounded in their values around inclusion and their preference for bioecological thinking (Bronfenbrenner, 1979; Bronfenbrenner and Morris, 2007; Kelly, Woolfson and Boyle, 2008; Fox, 2015; Algraigray and Boyle, 2017).

They suggested that diagnostic labels were often used to move children from mainstream schools to specialist provisions. A core aspect of EP practice is statutory assessment to contribute towards EHCPs (Fox, 2015). This familiarity with statutory assessment, specialist provision, and mainstream schools gave the EPs an enhanced perspective on funding streams for children with additional needs and the types of interventions which can be applied within mainstream schools. The EPs contrasted the bioecological approach to assessment of additional need with the medical conceptualisation of autism. They suggested that an autism diagnosis defined additional need ‘within’ the child. They felt that an autism diagnosis often became the sole focus of key stakeholders at the expense of broader bioecological needs. The EPs suggested that this was an abdication of responsibility by schools and parents and theorised that this conceptualisation was often shared to reduce a sense of ‘blame’ felt by parents. The EPs also suggested that bioecological interventions are more challenging and costly to implement meaning they were not as readily accepted as models of treatment. The EPs suggested that they generally saw their role as to provide alternative formulations of need to the paediatricians to help them to refuse a diagnosis of autism. They preferred to provide formulations and hypotheses rather than clear commentary on diagnostic criteria. The paediatricians were not always sure why the EPs would refuse to comment on diagnostic criteria. However, they generally spoke highly of the EPs’ approach and involvement in the MDT. The EPs, however, expressed more ambivalent views. By contra-indicating autism as a default position and being reluctant to comment on diagnostic criteria as result of their anti-labelling perspective, they developed a contradictory relationship with the MDT discussion group. The EPs felt influential when a diagnosis was refused and like their involvement did not matter when autism had been confirmed. The EPs also reported that their bioecological formulations of additional need were controversial and resulted in pressure from external stakeholders because of the responsibility they placed on parents and schools. As a result, the EPs had become increasingly reluctant to provide clear commentary on diagnostic criteria and had partially withdrawn from the MDT.

In contrast to the EPs, the paediatricians reported wanting to identify and diagnose autism as quickly as possible. This was related to their medical perspective towards diagnosis and their consideration of symptom presentations and criteria, rather than development over time. The paediatricians believed early identification would result in prompt provision of treatment and support. However, research suggests many parents are frustrated by the lack of support they receive following diagnosis (Crane *et al.,* 2018).

The paediatricians had noticed the withdrawal of the EPs from the MDT discussion and a lack of clarity in the information they provided. However, they were not sure why this had occurred. The paediatricians suggested that their purely medical approach to autism diagnosis had several limitations. They reported that they did not have the knowledge or experience around bioecological need, mental health, or learning needs to engage in effective differential diagnosis on their own. They reported struggling with the lack of traditional diagnostic tests for autism and felt a need to define symptoms within a category of diagnosis. This resulted in the paediatricians feeling more pressure from parents and schools when engaging in lone diagnosis (Evans and Trotter, 2009). The paediatricians reported wanting to help families in turmoil and felt that diagnosis was one of their only options to facilitate support (D'Astous *et al.*, 2016). They reported feeling limited by their role and unable to collect valuable information from schools and families. In an attempt to overcome these limitations, they had tried to rely on more tools from within their professional perspective. This took the form of increased standardised testing. The paediatricians suggested that they felt pressured to diagnose autism if symptom presentations matched diagnostic criteria and they did not have access to other formulations of need (Fitzgerald and Callard, 2017). They suggested that having access to qualitative bioecological information gave them the opportunity to consider other formulations and hypotheses during diagnosis, valuing the EPs' contrary position to diagnosis.

5.2.4 Research Question 4: How do EPs and paediatricians experience collaborative working around autism diagnosis?

5.2.4.1 Summary of Views

Table 9: Multi-Disciplinary Working Summary Table

	EPs' Views	Paediatricians' Views
Collaborative Working and Autism Diagnosis	◊EPs report feeling frustrated by diagnostic criteria. They suggest that correlation does not equal cause and that professionals should be asking 'Why are these symptoms occurring?' rather than matching symptoms to criteria to diagnose. This has contributed toward their lack of commentary on diagnostic criteria during MDT assessment. ◊EPs report that they have been reluctant to engage with MDT diagnosis. They suggest that this is because they do not have much 'power' or influence over diagnosis. They suggest that when they provide bioecological formulations that refuse diagnosis, they face increased pressure from families and schools.	◊Paediatricians report often feeling frustrated by EPs' lack of commentary on diagnostic criteria during multi-agency assessment. They are not always sure why EPs don't give clear opinions on whether or not autism is present or why difficulties may be occurring. ◊Paediatricians feel like EPs have withdrawn from MDT diagnosis. As a result, they are raising cases for discussion less frequently. ◊Paediatricians do not think the current system of MDT diagnosis is particularly effective. They view a lack of prior EP involvement and unclear information from EPs as clear barriers to more effective practice.

Collaborative Working and Autism Diagnosis	◊EPs are critical of the labelling approach to additional need, diagnostic substitution, dual diagnosis, and a lack of focus on bioecological need. ◊EPs are critical of the medical conceptualisation of autism and additional need. They suggest that paediatricians give diagnoses too readily and do not questions the reasons behind symptom presentations. ◊EPs are critical of the medical conceptualisation of autism. They are reluctant to fit their views and opinions within a medical framework. ◊EPs suggest that bioecological formulations of need result in more expensive and intensive interventions. They are critical of the interventions and support associated with the medical conceptualisation of autism as they feel that they are not inclusive or particularly effective. ◊EPs suggest that schools pressure families into seeking diagnosis when they are not meeting the child's needs effectively. ◊EPs recognise the value of diagnosis to parents and suggest that they can be forceful when seeking a diagnosis of autism.	◊Paediatricians value the time to make links with EPs and to discuss and share their perspective on additional need. They feel that this has helped them to understand the other profession's perspectives. ◊Paediatricians recognise that EPs prefer to provide formulations and hypotheses related to additional need. They are happy to accept these and understand that EPs do not want to give a 'yes/no' decision around the presence of autism. They do however say that these formulations and hypotheses need to focus on the needs that are present and be related to diagnostic criteria to be useful. ◊Paediatricians value the EP perspective and speak positively about their skills and the position that they take. They specifically comment on the EPs' focus on individual need, intervention over time, and highlight their familiarity with schools and families as a strength of their practice. ◊Paediatricians suggest that they have been left 'on their own' during diagnosis. They speak passionately about wanting more involvement from other agencies. They make specific commentary on the need for increased psychological input, recognising

	◊The EPs recognised that paediatricians would like them to comment directly on diagnostic criteria but they are generally unwilling to do so.	the limitations of the medical model and their role in autism assessment. ◊Paediatricians value the EPs' bioecological perspective. ◊Paediatricians value the EPs' ability to collect a wide range of information and data.

5.2.4.2 Analysis and Conclusions

The paediatricians and EPs have noticed that the EPs have been reluctant to be involved with MDT diagnosis and often provide unclear information in regard to autism. The paediatricians have suggested that the information they have received from EPs does not comment directly on diagnostic criteria and less frequently provides a clear opinion as to whether or not autism is present. Commentary on diagnostic criteria is an essential part of the paediatricians' diagnostic process when assessing for autism (NICE, 2011; Penner *et al.*, 2017). The paediatricians have reported feeling left 'on their own'. As a result they have experienced an increased amount of pressure when engaging in lone diagnosis (Evans and Trotter, 2009; Fitzgerald and Callard, 2017). However, the paediatricians did not suggest which diagnostic criteria they would like the EPs to comment on more routinely. The paediatricians suggest that without EP involvement they do not have access to a bioecological perspective. The paediatricians hold the EP perspective, and the quality information they receive from EPs, in high regard. They value EP information that provides a clear commentary on autism and related need by considering bioecological factors. The paediatricians also reportedly feel that their own medical perspective does not equip them to effectively assess for psychological, developmental, and bioecological needs on their own. This suggests that they are lacking the 'distinctive' contribution that EPs can make by providing explanatory models of human behaviour through the application of psychology and systemic thinking (Cameron, 2006). The paediatricians suggest that their ability to differentially diagnose autism is impaired when they are not able to have access to an effective EP contribution.

The paediatricians recognise that they sometimes, 'call things that are not quite autism, autism'. The increased pressure that the paediatricians experience during lone diagnosis, as a result of EP non-involvement, may mean that they are more likely to provide affirmative diagnoses of autism where symptom presentations could be better explained by alternative bioecological formulations (Evans and Trotter, 2009; Fitzgerald and Callard, 2017). This is further suggested by the paediatricians reporting that they have limited options to support families in need, other than diagnosis.

The paediatricians want EP involvement and are accepting of their preference to provide formulations and hypotheses rather than more direct commentary and diagnosis. They suggest that they often value the EP perspective over their own, especially when bioecological needs play a factor in the child's presentation.

The respect and high regard that paediatricians show when speaking about EP involvement is in contrast with the EPs' view of their own involvement in MDT diagnosis. The EPs suggest that they do not hold much power in the diagnostic process as they do not have ownership over the final say about whether or not a diagnosis is applied. Their ambivalence is often fuelled by their experience of diagnosis more broadly. The EPs' bioecological anti-labelling perspective also contributes to their reluctance to be fully involved in diagnosis (Algraigray and Boyle, 2017). Both EPs and paediatricians have recognised the EPs' tendency to disagree with autism diagnosis in favour of formulations and hypotheses based on bioecological need. The paediatricians suggested they would accept these alternative explanations, recognising the EPs' bioecological expertise which can help them to differentiate between autism and broader developmental needs (Bronfenbrenner, 1979; Waite and Woods, 1999; Cameron, 2006; Bronfenbrenner and Morris, 2007). The paediatricians also suggested that EPs were better equipped to collect and synthesise qualitative information from schools and families which contributed to differential diagnosis for autism by exploring the presentation of need within different contexts (NICE, 2011; World Health Organisation, 2012).

The EPs held strong views around false positive diagnoses of autism. They suggest that diagnoses of autism, that could be better explained by bioecological formulations, were an abdication of schools' and parents' responsibility. They were critical of schools, parents, and paediatricians ascribing ecological need to within-child forces through autism diagnosis. They suggested that parents and schools are resistant to the bioecological formulations that they would ideally contribute. The EPs maintained that this resistance was because these formulations of need would suggest that parents and schools played a role in the child's current presentation.

The EPs' strong stance towards conceptualisation of need, and insistence that within-child autism diagnoses are an abdication of responsibility had left the EPs feeling that their contributions could be controversial. They suggested that the resource- and time-heavy recommendations they provided as a result of their bioecological perspective were easily accepted by parents and school. This partially explained the resistance experienced by the EPs when sharing alternative bioecological formulations of need. This pressure, the EPs' anti-labelling stance, and inaccurate assessment of the power dynamic within the MDT likely all contribute to the EPs' reluctance to provide clear commentary on diagnostic criteria (Skellern, Schluter and McDowell, 2005; Burnham, 2013; Algraigray and Boyle, 2017).

As a result of the MDT discussion the EPs and paediatricians have reported an increased level of understanding into each other's professional perspectives. However, lack of clear commentary from the EPs when providing information has been felt by the paediatricians to have negatively impacted the MDTs' ability to effectively complete differential diagnosis for autism. The EPs have a responsibility to share their alternative formulations to ensure effective diagnosis, MDT working, and to support children with additional needs (NAS, 2014; Fitzgerald and Excellence, 2016; Penner *et al.*, 2017). EP reluctance and withdrawal contradicts EPs' core values and aims to ensure child beneficence and systemic working (Fox, 2015; Algraigray and Boyle, 2017). A lack of effective EP involvement in diagnosis means that the paediatricians can only collect information using tools from their own epistemological framework (Hollin, 2017). This could significantly limit the accuracy of differential diagnosis for autism and make defining indeterminate autism challenging (Skellern, Schluter and McDowell, 2005; Fitzgerald and Excellence, 2016; Hollin, 2017). Assessment from different philosophical perspectives is maintained to be a key feature of best practice for autism diagnosis and is currently lacking in the local context when EPs are not involved or do not provide clear information when working with the paediatricians (Skellern, Schluter and McDowell, 2005; NICE, 2011; Fitzgerald and Excellence, 2016; Hollin, 2017).

Increased EP involvement in diagnosis could also ensure that schools are held accountable and are supported to ensure that they are meeting the needs of children who could potentially be referred for autism diagnosis (Paget and Emond, 2016; Algraigray and Boyle, 2017; Boyle *et al.*, 2017). The application of EPs' consultation skills alongside the sharing of bioecological formulations at an early stage in the diagnostic process may help schools and parents to feel empowered to support children with additional needs more effectively. This may help parents and schools to access and manage the resources and additional support available to them (Boyle *et al.*, 2017).

EP hesitation to comment directly on diagnostic criteria and provide clear formulations around bioecological need could potentially have resulted in inaccurate diagnosis and the application of inappropriate interventions which may result in a number of detrimental negative outcomes for children (Doshi-Velez, Ge and Kohane, 2014; Koegel *et al.*, 2014; Hollin, 2017). Whilst EPs may face criticism and resistance to sharing their formulations, they have a responsibility to share their perspective clearly and to work with the paediatricians to synthesise their claims across professional perspectives (Waite and Woods, 1999; NICE, 2011; Fitzgerald and Callard, 2017). Their ability to adopt a pragmatic approach to philosophical conceptualisations further suggests they should play a more integral role in MDT autism diagnosis (Burnham, 2013).

5.3 Methodological Reflections and Research Limitations

This research focuses on the professional perspective and experiences of EPs and paediatricians. The research adopted a social constructionist approach within an interpretivist paradigm to consider their perceptions and experiences through semi-structured interviews and a thematic analysis. As such, whilst the findings are rich and partially illuminate the experiences of the participants, they are not generalisable beyond the local context (Cohen and Manion, 2002).

The researcher's identity as a trainee educational psychologist, working within the local authority where this research took place provided a strong practitioner orientation to this study which provided both strengths and limitations to the design and consideration of the findings. The researcher's knowledge, understanding and experience of EP practice, autism diagnosis, and collaborative working with paediatricians assisted in ensuring that sensitivity to context, and consideration of impact and importance were maintained (Cohen and Manion, 2002; Yardley, 2017). However, as a trainee EP, the researcher also holds their own constructs, perceptions, and understanding of the EP role in relation to autism diagnosis. This could have influenced the approach to the research design, and application of the methodology and analysis. The researcher was aware of this potential influence from the early stages of conceptualising the research project. This was explicitly discussed within tutorials at the time of the research proposal and continued to be actively discussed and reflected upon throughout the research process. Specific reflections are included in the application for ethical approval for this research (**Appendix 1**), and a full consideration of these reflections is included in **Section 3.4**. Steps were taken to ensure that the influence of the researcher's experiences and perceptions were limited within the design, and explicitly reflected upon at each stage of the process. This was achieved through establishing open questions which allowed a full exploration of each individual's personal experience and conceptualisations. In between each interview, reflection took place to ensure that unnecessary influence or guidance had not occurred. Careful checking and rechecking of emerging themes against the transcripts' codes took place to ensure that there was sufficient evidence for the themes. Quotes were used extensively within the results and discussion section to provide evidence of the themes identified and discussed.

The researcher, in their role as trainee EP, had worked with all of the EPs and paediatricians interviewed. This could be considered as a potential threat to the reliability and validity of data. The EPs and paediatricians may have felt judged when sharing their own practice. Researcher familiarity may have resulted in accord and discord around the various discussion points (Cohen and Manion, 2002). To minimise this, no questions were asked about specific cases, the researcher did not ask about any of the specific interactions they had been involved in, the participants were provided with information on the study area and research questions before the interviews, and participants were given explicit information on how their data would be anonymised, stored and used.

This research focused on a deliberately broad area. It was important to allow participants to define for themselves the scope of their experiences and for their conceptualisations of autism to emerge within the findings. The impact, however, of broad research questions, was some limitation in terms of the depth and complexity of the themes and the analysis. In hindsight, there were discussion points which could have been pursued further in individual interviews to elicit richer more in-depth data, particularly around meaning and sense-making processes.

This research studies the perceptions of three paediatricians and three EPs. All of the participants work within the same local authority and within the same model of MDT autism diagnosis. As a result of this, and in line with the interpretivist paradigm, this research does not make strong claims to be applicable outside this context. Through providing rich accounts from the data, the applicability of the findings is discussed and presented. The use of semi-structured interviews may have limited the validity of the claims made as a result of this research. The lack of standardisation across interviews or inclusion of statistically significant data makes any claims hard to generalise.

Thematic analysis was an appropriate methodology for this research due to its theoretical flexibility and ability to accommodate detailed, rich, and complex data (Nowell *et al.*, 2017). This was useful for the present research project due to its focus on a wide range of topics from conceptualisation of autism to experience of multi-disciplinary diagnosis. Braun and Clarke maintain that thematic analysis is a useful tool for examining the views of different research participants, making this method of analysis an ideal tool for the current research (Braun and Clarke, 2006). It is maintained that the flexibility of thematic analysis can be a limitation which can result in inconsistency across themes (Nowell *et al.*, 2017). Attempts have been made to overcome the limitation by revisiting the analysis and providing methodological transparency throughout this report.

The use of Bronfenbrenner's bioecological model of human development as a theoretical driver brought greater depth and clarity to the analysis (Bronfenbrenner and Morris, 2007). The bioecological model enabled consideration of many of the unarticulated assumptions of the EPs, paediatricians, and interaction from MDTs with outside stakeholders. The adoption of the model as theoretical driver ensured a consistent approach to the analysis which was able to permeate all sections of this research. It also enabled comparisons to be made between the EPs' implicit approach and the medical perspective of the paediatricians. There were however several limitations of using this approach as a theoretical base. Firstly, it potentially limited the analysis of the participant experiences of MDT diagnosis. When this research project was first conceived, the researcher wanted to understand what it was like to diagnose in an MDT. The bioecological approach meant that a greater focus was given to the perspectives of the professionals and how this affected their practice. As such there was less of a focus on the meaning and sense-making processes that the researcher had originally hoped to explore (Smith, Larkin and Flowers, 2009). The bioecological model as a theoretical underpinning may have also been limited due to its lack of detailed internal mechanisms (Christensen, 2016). It may have been that other theoretical approaches could have considered the interactions of the participants with each other, their conceptualisations, and their perspectives around autism diagnosis in more detail. Other approaches could have been used to more rigorously examine the group dynamics of the MDT. The use of Communities of Practice as a theoretical underpinning may have shed more light on the group dynamics of the MDT by considering their identities as professionals and social interactions as a group (Wenger, 2009). By examining these areas and the aims of the MDT Communities of Practice as a theoretical driver, it may have potentially resulted in more specific recommendations to improve the MDTs' practice in the local context (Wenger, 2009).

5.4 Suggested Implications for EPs and Key Stakeholders

As a result of the small sample size in the present study, this and the interpretivist paradigm in which this research is situated, it is difficult to generate generalisable findings outside the immediate local context. The following should therefore be considered as potential suggestions to improve practice rather than bold claims around recommendations.

In the overarching theme 'Professional Conceptualisations of Autism', both the EPs and paediatricians suggested that criteria for autistic spectrum disorder were too broad. They reported that this broad conceptualisation of need made it difficult to differentiate between bioecological needs and the symptoms of autism. All of the participants suggested that the expanding diagnostic criteria made differential diagnosis more challenging, made autism a less effective descriptor of need, and potentially ascribed ecological needs inaccurately to biological forces (Bishop *et al.*, 2008). In the main theme 'Perceived Function of Diagnosis', the participants suggested that parents are looking to gain a deeper understanding of their child and access additional support, mainly in schools. The participants suggested that the broad nature of the current conceptualisation of autism limited parents' understanding of individual need. It may therefore be worth exploring the utility of the broadening criteria of autism for families to make sure it is still useful for those who could benefit from it most. This should be considered in light of the merging and removal of separate categories of autism (Volkmar and Reichow, 2013). The removal of these diagnostics sub-categories within the DSM-5 proved to be controversial, as many people felt like they were a better descriptor of their individual needs (Volkmar and Reichow, 2013; Lobar, 2016). The findings of this research suggest that these issues with the broader conceptualisation of autism could be overcome with routine commentary on individual and bioecological needs from

EPs and paediatricians when a diagnosis of autism is provided. This could include a description of how the child's needs may manifest in context and could give parents and schools practical strategies to facilitate support. This may help to promote parents' understanding of autism and their child's needs whilst ensuring greater satisfaction as a result of diagnosis (Crane *et al.*, 2018). It may also help to synthesise bioecological and medical information around additional needs, providing children with a more holistic set of potential support strategies.

In the overarching themes 'The Impact of School Support' and 'The Influence of Families Seeking Diagnosis', the EPs and paediatricians both suggested that school performance and family wellbeing were key drivers in children being referred for a potential autism diagnosis. The findings of this research also suggested that for many children, if they were provided with timely bioecological intervention and support in their home and school then they may not have needed to seek diagnosis at all. With challenging behaviour in schools being a key driver behind referrals for diagnosis, it could be suggested that EPs need to be involved much earlier on for children with potentially progressive additional needs (Ravet, 2011). This involvement would allow EPs to develop bioecological formulations over time completing contextualised assessment by considering response to intervention in both home and school settings (Bronfenbrenner and Morris, 2007). This could potentially require an extension of the intervention and data-collecting process which would feed into eventual diagnosis. This may result in more time from the initial raising of concerns to diagnosis, and could prove controversial with parents (The National Autistic Society, 2014). However, this may enable schools and families to access the support they need to promote inclusive practice effectively. Early EP involvement may also help to reduce a number of negative childhood outcomes including disruption to emotional development and exclusion from school (NICE, 2012; Moss, Mandy and Howlin, 2017). Bioecological formulation and interventions can be costly in terms of both resources and time (Kelly, Woolfson and Boyle, 2008). The limitations within EP services could be overcome by the involvement of assistant EPs who could gain experience implementing and recording bioecological intervention with schools and families under the supervision of main grade and senior EPs. When bioecological needs had then been ruled out, the information gathered could be collated to be passed on to paediatricians. This would help families feel as though they were receiving active support, increase the capacity of SENCOS and teachers in schools, and help to aid contextualised assessment for diagnosis. The time this process could take may also alleviate some of the pressure around waiting times for diagnosis and help to increase parents' satisfaction with the diagnostic process (NAS, 2014; Crane, *et al.*, 2018). However, this strategy may also have the opposite affect increasing wait times and parents' frustration by denying them prompt access to EPs and paediatricians, and subsequent diagnosis (Crane, *et al.*, 2018). This early access to EPs and extension of intervention time may also help professionals to differentiate between autism and development needs such as language delays and attachment needs, which could be more changeable over time (Bishop *et al.*, 2008; Teague *et al.*, 2017). A caveat to this may be for children who are presenting with additional sensory needs (Kapp, 2013). The paediatricians and EPs made a distinction between uncertain presentations of autism and more clear presentations aligned with what may be considered 'classic autism' (Rosenberg *et al.*, 2009). They suggested that children presenting with needs in this area exhibited a higher degree of idiosyncratic sensory processing, impairment, and developmental delay. They also suggested that children with these needs were in need of early and effective intervention as a result of diagnosis. These findings lend support to the suggestion that there should be a separate identification for autism where more extreme sensory needs are present (Kapp, 2013). Practically, it could be suggested that there should be a separate identification and diagnostic pathway for children with these needs where they are 'fast-tracked' through diagnosis and statutory assessment to access the early intervention and specialist support that they need to improve later life outcomes (Kapp, 2013; Koegel *et al.*, 2014). This reflection on the needs of children with sensory idiosyncrasies could be considered within academic research around the utility of the ASD diagnostic label. This work could explore whether there is practical utility in having a sperate diagnostic label for children with autism and high sensory needs (Kapp, 2013).

Throughout the research, the participants suggested that collecting and sharing information around bioecological development has been a challenge to ensuring effective diagnosis. In the overarching theme 'The Practice of the Multi-Disciplinary Team', it was highlighted that many of the children raised for referral for diagnosis had not received any support from the EPs. It could be suggested that to address this issue in the local context, schools should be trained in the use of assessment tools to differentiate between autism and bioecological need (Moran, 2010; Flackhill *et al.*, 2017). The Coventry Grid is a research-backed tool to help differentiate between autism and additional need arising from disruptions to attachments (Moran, 2010; Flackhill *et al.*, 2017). If schools were to routinely use this assessment tool it would potentially help them to manage their referrals to EP services more effectively so EPs could become involved in ‘uncertain’ cases, applying the bioecological perspective. In the overarching theme ‘The Practice of the Multi-Disciplinary Team’, the paediatricians discussed how they had tried to overcome the limitations of their professional perspective by increasing their use of standardised assessments. By getting schools to complete The Coventry Grid, the paediatricians may have broadened their evidence base to inform diagnosis, whilst having a clear paper trail to keep in the child’s records (Moran, 2010; Flackhill *et al.*, 2017). This could help to improve the accuracy of diagnosis, synthesise clinical and contextual assessment of needs, and ensure appropriate allocation of resources and support for children and their families (Teague *et al.*, 2017). This research also suggests that there is a role for schools more broadly in diagnosis. School could perhaps be invited to the MDT meetings for children where it proved to be challenging to differentiate between their bioecological and medical needs. If a school representative were able to attend a panel meeting, the EPs and paediatricians could work with them to consider the best plan of support. This would help to ensure that schools had implemented appropriate interventions before children were raised for diagnosis and would allow EPs to consult with school staff where they had not had any previous involvement with the child.

In the overarching theme ‘The Influence of Families Seeking Diagnosis’ and main theme ‘Perceived Function of Diagnosis’, the participants suggested that families weren’t always clear about what they were hoping to gain as a result of diagnosis. The participants suggested that parents’ aims ranged from increasing their level of understanding of their child’s needs, to access to specialist support, and broader undefined goals. It could be suggested that as a part of the referral and consultation process for diagnosis, parents should be asked why they are seeking a diagnosis of autism. This would help the professionals to differentiate between bioecological needs and autism and help to ensure parents were able to access the effective support that they needed. This would also help to ensure that parents had an accurate understanding of the nature of autism, making sure they understand that it is a lifelong condition with no ‘cure’ (Crane, *et al.*, 2018). The enduring theme of this research is the difficulty professionals have differentiating between bioecological needs and autism. As such, it could be suggested that the process of diagnosis would benefit from an increased level of family support available to those seeking a diagnosis. This could take the form of autism training classes for parents whose child gains a diagnosis. This may help them to feel supported, included, and able to implement practical strategies for their children at home (Crane, *et al., 2018)*. These training sessions could be attended by EPs and paediatricians to help contextualise individual needs to ensure a greater level of satisfaction for families of a child who holds a diagnosis (Crane, *et al.*, 2018). The EPs would have a particular role to play in this by applying the bioecological perspective. This increase of family support could also be developed within the MDT discussions. In the overarching theme 'The Influence of Families Seeking Diagnosis', the professionals suggested that many parents sought diagnosis because they could not 'cope' with their child's additional bioecological needs. The EPs also suggested that parents were not always transparent about why they were seeking a diagnosis and would attempt to hide issues around family dysfunction, trauma, and mental health need. It could be suggested that children, families, and professionals would benefit from having a social care representative, or family support worker attend the discussion meetings. Having family support workers or social care representatives on the panel may help the professionals to see through any subterfuge and diagnose accurately. This would also help the MDT to facilitate any community-based intervention to help address the child and family's bioecological needs (McLeroy *et al.*, 2003). Increasing the number of professionals involved in the MDT may also help to reduce wait times, increase individual professional capacity, and share financial and physical resources across organisations and departments (Parliament UK, 2014; Yates and Le Couteur, 2016).

5.5 Suggested Implications for Multi-disciplinary Working

To overcome the challenges of diagnosing a multi-taxonomical disorder such as autism, there needs be a synthesis between categorisation and interpretation and bioecological and medical needs (Skellern, Schluter, and McDowell, 2005; Fitzgerald and Callard, 2017). This is one of the key challenges for MDT working using different professional perspectives (Skellern, Schluter and McDowell, 2005; Fitzgerald and Callard, 2017). One of the key ways to aid this process of synthesis is for professionals who hold differing perspectives to discuss their ontological and epistemological assumptions and how this affects their practice (Fitzgerald and Excellence, 2016; Fitzgerald and Callard, 2017). As a result of this research, the EPs and paediatricians should be encouraged to continue to discuss in more explicit terms their professional perspective and how this has influenced their experience of MDT diagnosis and practice related to autism. In the current research project, this current deficit of practice became clear around the EPs' bioecological and anti-labelling perspectives (Algraigray and Boyle, 2017). In the overarching theme 'The Practice of the Multi-Disciplinary Team', the paediatricians reported that they had felt that the EPs generally did not want a diagnosis of autism to be provided but were often unsure why. The EPs then went on to discuss at length their views around inclusion and anti-labelling practice. However, this key aspect of the EPs' training and approach was not shared or understood by the paediatricians (Algraigray and Boyle, 2017). The paediatricians at times perceived this anti-labelling approach as a lack of commitment to the MDT, leaving them confused as to why they felt EPs had withdrawn. The paediatricians in the local context recognised that the EPs preferred to provide formulations and bioecological hypotheses of additional need. However, whilst the paediatricians were happy to accept the EPs' approach, the EPs could have been more flexible in meeting the requirements the paediatricians had to complete diagnosis effectively. The paediatricians, and the EPs in the current study, reported that in their experience, EPs rarely, if ever, directly commented on diagnostic criteria. Direct reference to diagnostic criteria helps to ensure accuracy during autism diagnosis (Barker and Galardi, 2015). EPs should therefore be encouraged to comment on the criteria when providing information to the MDT. If they believe that children do meet the criteria for autism but that their needs arise from bioecological factors then they should say so and give their reason why (Ravet, 2011; Fitzgerald and Callard, 2017). However, EPs may be reluctant to provide bioecological formulations because of the potential impact on families and schools discussed in this research. EPs should be encouraged within the MDT to see their formulations as hypotheses which can be considered, critiqued, and confirmed through a supportive multi-disciplinary approach (Yates and Le Couteur, 2016). This would help to ensure a more thorough examination of potential sources of need and supportive ways forward for children and families. In this research project, none of the participants commented directly on the content of up-to-date diagnostic criteria from the DSM-5 of ICD-11 (APA, 2013; WHO, 2019). Whilst the paediatricians reported that they would like more consistent commentary on diagnostic criteria from the EPs, they did not say which criteria they would prefer them to refer to. The paediatricians should be explicit in telling the EPs which criteria they would like them to comment on and which aspects of ‘functional’ impairment they would like them to explore through their access to school and families while applying a bioecological perspective (NICE, 2011). Both EPs and paediatricians should ensure that they have an up-to-date understanding of diagnostic criteria to ensure that they are able to diagnose accurately and ensure consistency across professional groups (NICE, 2011; Barker and Galardi, 2015). An accurate understanding of up-to-date criteria may help to speed up professional decision-making processes, resulting in better outcomes for children and their families (Barker and Galardi, 2015; Peters and Matson, 2019).

The experiences professionals have of uncertainty and pressure during diagnosis can impact on their decision making (Evans and Trotter, 2009). These experiences and subsequent decisions are often aligned with their professional perspective (Evans and Trotter, 2009). MDT working may therefore benefit from time outside diagnosis to discuss together their experiences of uncertainty and pressure. This may help professionals to rely on each other's professional perspectives to account for a wider range of phenomena outside their epistemological framework (Evans and Trotter, 2009; Fitzgerald and Callard, 2017). This reflection on challenging casework diagnosis and the dynamic of pressure may help the paediatricians and the EPs to more successfully navigate the emotional challenges of working together as a team. This may help them to more readily accept each other's perspectives and achieve a synthesis between bioecological assessment and medical diagnosis, whilst more practically helping the professionals to manage their interactions with outside stakeholders, including schools and families. This has particular relevance for the paediatricians who suggested that they often faced pressure from families and schools and are limited in their ability to explore issues which may be impacting on child needs that fall outside their medical perspective and clinical setting. In an attempt to overcome this limitation, the paediatricians have tried to increase the use of standardised assessments, drawing on more techniques from within their limited professional perspective. The EPs could support paediatricians to consider the potential bias of standardised assessment (Skellern, Schluter and McDowell, 2005). This would help the professionals to consider and integrate formulations of bioecological needs into their assessment (Skellern, Schluter and McDowell, 2005; Bronfenbrenner and Morris, 2007). EPs conversely could, where possible, consider the value of criterion assessment as this may be a more accessible tool for paediatricians and other key stakeholders to access. These approaches would help to synthesise contextual and clinical assessments of autism (NICE, 2011).

Both EPs and paediatricians agreed that EPs need to play a more central role in autism diagnosis in the MDT. Currently the MDT diagnosis process in the local context falls short of NICE Guidelines (NICE, 2011). A key concern from the participants was around the number of children referred for diagnosis who had no EP involvement. The inclusion of other professionals from speech and language therapy, or occupational therapy, would make this process truly multi-disciplinary and more effective, and be more congruent with guidelines for best practice (NICE, 2011; Fitzgerald and Excellence, 2016). Referral pathways could be designed where schools were prompted to refer for extended EP involvement to help ensure that effective ‘response to intervention’ had been completed (Taylor, Jick and MacLaughlin, 2013). This would help to satisfy the

EPs' preference for bioecological assessment and help to support effective differential diagnosis for autism. This may also help to ensure that parents and children are able to access the effective support they may need and help to support schools manage additional needs effectively. The inclusion of other professionals in the MDT may help to spread the financial and time-based costs of practice. Having a variety of professionals involved may also mean that families are better able to access support to meet their individual needs. There are a number of best practice guidelines and established pathways for multi-disciplinary working. The EPs and paediatricians should be encouraged to follow them more closely to ensure effective diagnosis for autism.

EPs could lead the MDT by refocussing the discussion to consider bioecological needs. It may be that by having EPs and paediatricians working together with a primary focus on excluding bioecological needs that they are more effectively able to identify autism (Flackhill *et al.*, 2017; Teague *et al.*, 2017). Whilst the EPs and paediatricians would need to consider diagnostic criteria whilst examining why the difficulties are arising, rather than if the difficulties are present. This may help to inform more effective differential diagnosis for autism by separating correlation from cause (Fitzgerald and Excellence, 2016; Fitzgerald and Callard, 2017). If EPs are able to mediate their anti-labelling stance and consider criteria whilst applying the bioecological perspective, it could be suggested that they are the most suitably placed professionals to lead on differential autism diagnosis (Fitzgerald and Excellence, 2016; Fitzgerald and Callard, 2017).

The suggested implications outlined above recommend that EPs take a more active role in MDT diagnosis and work with parents and schools to support their understanding of bioecological needs. This may require a level of EP support for diagnosis which could be difficult to provide in the current financial climate of local authorities and with enduring issues around EP recruitment and training (DfE, 2019). The inclusion of speech and language and occupational therapy professionals in the MDT would also potentially incur a consider time and financial cost. EP services, schools and the encompassing local authorities and NHS Trusts that support those involved in diagnosis should consider the ‘crisis’ in autism diagnosis and its implications for children and families (NAS, 2014). The development of service-level agreements to include EPs more routinely in diagnosis may help to address this ‘crisis’ and more broadly help support children experiencing additional bioecological needs.

5.6 Reflections as a Research Practitioner

It is important to reflect on the process of conducting research in any field of study. Ongoing reflection throughout the research process helps to ensure the reliability and validity of the data collected and rigorous application of the methods used (Cohen and Manion, 2002). The researcher also included a commentary on reflexivity in **Section 3.4** in an attempt to ensure that the underlying assumptions of the researcher would not impact the project in a negative way (Braun and Clarke, 2019). There are however particular challenges to being a research practitioner when situated and familiar with the participants recruited (Robson, 2011). As a research practitioner, it was important to consider the purpose of the research and how it impacts upon the participants.

Being a research practitioner helped to facilitated the access needed to complete this project (Robson, 2011). The researcher’s participation in the MDT discussion meant that requesting access to the clinical lead to facilitate recruitment could be achieved with relatively few challenges. This was also the case for the recruitment of the EPs where the researcher was able to contact colleagues to help ensure that the EPs required could participate.

Although being a research practitioner aided recruitment, it was a potential hinderance during data collection. The familiarity of a researcher with the participants can impact on the reliability and validity of the data obtained (Robson, 2011). It was a challenge for the researcher to break out of the familiar pattern of conversation with the participants where, in all cases, he was the junior colleague. Leading the interview required sensitivity to the dynamics of the conversation and an awareness of the prior interactions that had taken place (Robson, 2011). In some of the interviews, participants alluded to prior events which the researcher would not have been aware of if not actively working with the participants outside the research. Whilst this had the benefit of helping to facilitate some discussion, and explore some points further, it may have also negatively impacted the data collection. More neutral researchers may have been able to obtain more objective data (Cohen and Manion, 2002).

During the analysis phase of the research project, it was important to consider the researcher role as a situated practitioner. The process of thematic analysis completed included consideration of the underlying constructs, emotions, and dynamics of the researcher and his relationship with the participants during the description phase of analysis (Braun and Clarke, 2006; Robson, 2011). When it came to code and theme generation, the researcher kept in mind the principle of reflexivity with particular emphasis on how their working patterns and relationship may affect theme generation (Braun and Clarke, 2006; Robson, 2011). This was completed with a view to considering how the participants' own professional perspective may influence the subsequent findings.

It was important to ensure that the findings presented were not overly critical of any one group or viewpoint but remained impartial, valid, and reliable (Robson, 2011). To achieve this, the researcher attempted to present the data in a neutral tone whilst being transparent about the choices made during thematic analysis (Braun and Clarke, 2019). A presentation of the research findings was planned to ensure that participants were aware of how their data had been analysed and the findings that had been developed. This was important to ensure that trust permeated the research process, helping to maintain the relationships the researcher needed to continue with the colleagues who participated (Robson, 2011).

5.7 Areas for Future Research

The current research project is limited in its ability to make generalisable claims due to its small sample size. In order to make the claims of this exploratory research more generalisable, future research should recruit a larger number of participants. This should include EPs and paediatricians who may hold different views to those interviewed in this project, with a wider range of gender and age groups included. For example, it could include interviewing participants who had been qualified for different lengths of time. This would help to examine if there were any differences between professionals who had recently completed their training and those who had been practicing for some time. This could also be extended to professionals from different disciplines who may have different views on autism and its diagnosis. This would help to examine to what degree the bioecological perspective permeated each profession, impacting upon their conceptualisation of autism and experience of diagnosis (Bronfenbrenner and Morris, 2007; Fitzgerald and Callard, 2017). Completing future research in this area would help to strengthen the claims made about the impact of the bioecological perspective on experience of autism diagnosis and practice within an MDT.

The role of schools was developing into a significant theme in this research, highlighting the variable and impactful role schools can have on the process of diagnosis. The design of this research could be completed with school staff to gain their insight into their professional perspective and autism. This would help to examine how they perceive their role in supporting children with additional needs and in identifying autism for potential diagnosis. This may help to further develop an understanding of school staff's conceptualisation of autism and how this influences professionals' experiences. This may also lead to improved recommendations for schools working with MDTs during diagnosis.

Given the regional variations in rates of diagnosis and performance of MDTs, it would be useful to complete this research in other areas of the UK (NAS, 2014; Crane *et al.*, 2016). This would help to highlight the commonalities and differences between the EPs' and paediatricians' perspectives and demonstrate the strengths and weaknesses of different models of diagnosis (Fitzgerald and Excellence, 2016; Fitzgerald and Callard, 2017).

This research may also benefit from being extended to include idiographic data from the participants. If the interviews were conducted again, perhaps over several sessions, then in-depth data on the participants' meaning and sense-making processes may have been obtained (Smith, Larkin and Flowers, 2009). This would have permitted the use of interpretive phenomenological analysis and more considered exploration of each individual's experienced (Smith, Larkin and Flowers, 2009). A research project using this analytical method may help to illuminate, in more detail, the pressures experience by professionals and their decision-making processes in relation to MDT diagnosis (Smith, Larkin and Flowers, 2009).

Alternatively, future research could utilise more structured interviews to help ensure consistency of data across the participants (Cohen and Manion, 2002). This could then be used to complete a deductive analysis retaining the codes from this research project to help compare the views of the EPs and paediatricians across regions and potentially with other stakeholders (Braun and Clarke, 2006). Perhaps most significantly, the above future research considerations could be completed with parents and children with autism. This would help to explore their perspectives and understanding of autism and how this affects their experience of diagnosis. This may highlight important considerations for MDT working and ways to improve diagnosis for children and families.

5.8 Concluding Comments

This research has demonstrated that EPs in the local context define autism as a biological condition that cannot be explained by other environmental or interactive factors. The paediatricians define autism by matching symptom presentations with criteria. These conceptualisations of autism are influenced by the professionals' different perspectives. This research has added weight to findings that suggest that professional perspective affects experience and decision making during diagnosis (Skellern, Schluter and McDowell, 2005; Evans and Trotter, 2009). In the current study, it has been suggested that holding a bioecological perspective significantly impacts on the professionals' experience of autism diagnosis and MDT working (Bronfenbrenner and Morris, 2007). The paediatricians' medical perspective was associated with an increased sense of limitation and pressure felt when presented with uncertainty during diagnosis (Evans and Trotter, 2009). It has also demonstrated that EPs and paediatricians can feel under pressure from schools and families to provide positive diagnoses.

Autism diagnosis is maintained to be ‘the key diagnostic issue of the 21st century’, mainly affecting children and families (Hollin, 2017). EPs in the local context have, however, been reluctant to fully engage with multi-disciplinary diagnosis. Whilst bioecological formulations of need may sometimes be difficult for schools and families to accept, they are an essential feature of effective differential diagnosis (NICE, 2011). The is a clear need for EPs to be actively engaged with their medical colleagues to engage in effective differential diagnosis to help support the children and families who need it most.

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Appendix 1: Application for Ethical Review

UNIVERSITY OF BIRMINGHAM
APPLICATION FOR ETHICAL REVIEW

Who should use this form:

This form is to be completed by PIs or supervisors (for PGR student research) who have completed the University of Birmingham's Ethical Review of Research Self Assessment Form (SAF) and have decided that further ethical review and approval is required before the commencement of a given Research Project.

Please be aware that all new research projects undertaken by postgraduate research (PGR) students first registered as from 1st September 2008 will be subject to the University's Ethical Review Process. PGR students first registered before 1st September 2008 should refer to their Department/School/College for further advice.

Researchers in the following categories are to use this form:

1. The project is to be conducted by:
- staff of the University of Birmingham; or
- a research postgraduate student enrolled at the University of Birmingham (to be completed by the student's supervisor);

2. The project is to be conducted at the University of Birmingham by visiting researchers.

Students undertaking undergraduate projects and taught postgraduates should refer to their Department/School for advice.

NOTES:

- Answers to questions must be entered in the space provided.
- An electronic version of the completed form should be submitted to the Research Ethics Officer, at the following email address: aer-ethics@contacts.bham.ac.uk. Please **do not** submit paper copies.
- If, in any section, you find that you have insufficient space, or you wish to supply additional material not specifically requested by the form, please it in a separate file, clearly marked and attached to the submission email.
- If you have any queries about the form, please address them to the Research Ethics Team.

X☐ **Before submitting, please tick this box to confirm that you have consulted and understood the following information and guidance and**

that you have taken it into account when completing your application:

- **The information and guidance provided on the University's ethics webpages (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-of-Research.aspx)**

- **The University's Code of Practice for Research (http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf)**

UNIVERSITY OF BIRMINGHAM **APPLICATION FOR ETHICAL REVIEW**	*OFFICE USE ONLY:* Application No: Date Received:

1. TITLE OF PROJECT

The Uncertainty of Autism: How do the ontological and epistemological positions of Educational Psychologists and Paediatricians affect their experience of complex ASD Cases and Interdisciplinary Working

2. THIS PROJECT IS:

University of Birmingham Staff Research project ☐
University of Birmingham Postgraduate Research (PGR) Student project ☒
Other ☐ (Please specify):

3. INVESTIGATORS

a) PLEASE GIVE DETAILS OF THE PRINCIPAL INVESTIGATORS OR SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first	Dr Colette Soan
Highest qualification & position held:	EdPsychD / Academic and professional tutor
School/Department	School of Education (Disability, Inclusion and Special Needs Department)
Telephone:	[redacted]
Email address:	[redacted]

Name: Title / first name / family name	Mrs Sue Morris
Highest qualification & position held:	M. Ed. (Ed Psych) / Programme Director of Professional Training
School/Department	School of Education (Disability, Inclusion and Special Needs
Telephone:	[redacted]
Email address:	[redacted]

b) PLEASE GIVE DETAILS OF ANY CO-INVESTIGATORS OR CO-SUPERVISORS (FOR PGR STUDENT PROJECTS)

Name: Title / first name / family name	
Highest qualification & position held:	
School/Department	
Telephone:	
Email address:	

c) In the case of PGR student projects, please give details of the student

Name of	Michael Palmer	Student	[redacted]
Course of study:	Applied Educational and	Email address:	[redacted]
Principal	Dr Colette Soan		

4. ESTIMATED START Date: June 2018 **OF PROJECT**

ESTIMATED END OF Date: August **PROJECT**

5. FUNDING

List the funding sources (including internal sources) and give the status of each source.

Funding Body	*Approved/Pending /To be submitted*
N/A.	

If applicable, please identify date within which the funding body requires acceptance of award:

Date: ☐

If the funding body requires ethical review of the research proposal at application for funding please provide date of deadline for funding application:

Date: ☐

6. SUMMARY OF PROJECT

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon. Please explain any technical terms or discipline-specific phrases.

There are also an increasing number of authors writing about relativist/interpretivist, critical theories of Autism, which embrace neurodiversity and refute the pathologising label of Autism all together (O’dell et al., 2016). Each of these philosophical positions can be associated with a different ontology, epistemology and clinical response; with varying outcomes, interventions, treatments and provision provided depending on the position of the professionals involved and experiencing the phenomena (Ravet, 2011). Autism is however maintained to be a variable, heterogenous and often ‘indeterminate’ syndrome (Hollin, 2017); with professional groups often disagreeing on the causes, diagnostic profiles/formulations and outcomes for the same cases and presentations of symptoms/behaviours. This area is presented as ripe for exploration to further understand how professionals construct their knowledge in relation to Autism (Hollin, 2017; Ravet, 2011). The ontological and epistemological positions that professionals hold are said to be key determinants in how they conceptualise, view and experience the presentation of Autism Spectrum Disorders and associated symptoms (Hollin, 2017; Ravet, 2011). However, there are also suggestions made that this process is influenced in interagency working by power relationships, emotional responses and other socio-cultural, interactive affects (O’dell et al., 2016; Ravet, 2011).

Alongside this, there is also an increasing body of literature which outlines the significantly high rates of comorbidity of Autism diagnoses with attachment difficulties, ADHD and a variety of other developmental and neuropsychiatric conditions (Perlov & Sawyer, 2017; Stadnick et al, 2017; Teaguae et al., 2017), adding greatly to differing opinions and professional uncertainty related to ASD. There is evidence to suggest that the interventions for these various comorbid diagnoses can have a multitude of harmful effects if misdiagnosed and if incorrectly prescribed (Murphy et al., 2016). Inappropriate interventions are said to cause distress to both the individual child, and their parents, and can impact on future life outcomes, including: employability, mental wellbeing and satisfaction in relationships (Murphy et al., 2016). There has been research conducted which suggests that efficacy of Autism diagnosis must be ensured, not only for the beneficence of the child and their family, but to help ensure efficiency of intervention and resource delivery; an important consideration in a climate of financial cuts in public health settings (Stadnick et al., 2017).

There are a variety of guidelines relating to ‘best practice’ for Autism diagnosis (Clin et al., 2005; Penner et al., 2017). EPs are maintained to be key professionals involved in the diagnosis of Autism (NICE Guidance, 2011), and consideration of psychoeducational approaches are maintained to be important when separating out and understanding co-morbid conditions associated with Autism (Lorh & Le, 2012). The role of EPs is also reportedly valued by parents whose children do receive ASD diagnoses (Tobias, 2009). Despite this, the role of EPs in Autism diagnosis is not defined in the 2015 Autism Act or the current Code of Practice (DfE, 2014; DoH,2015). This often means that only professionals who adopt a realist/positivist philosophical position are involved in the diagnosis of Autism and have limited opportunity to consult with professional who hold viewpoints. There is currently no standardised approach to Autism diagnosis across UK Health Trusts or Local Authorities (DfH, 2015).

Purpose

The aim of this research is to explore how the philosphical positions, of Educational Psychologist (EPs) and Community Paediatricians have influenced their experience of lone purpose and interdisciplinary working in relation to the construction and diagnostic procedures for Autism Spectrum Disorders (ASD). The research aims to offer implications for improved collaborative working between EPs and Paediatricians by examining how differing philosophical positions affect individuals' experience from each professional group when they are engaging with complex presentations of Autism (and associated comorbid difficulties), interdisciplinary working to develop collaborative formulations or diagnoses and when deciding on interventions, treatments and provision.

The research will utilise Thematic Analysis to examine the professionals' experience of interdisciplinary Autism diagnosis and formulation with the context of 'Autism Spectrum Disorder (ASD) Discussion Panels; which have been set up in the north area of a major city. Children who present with ambiguous ASD symptoms and associated needs are referred and raised for discussion at the ASD Panel meetings which are attended by both EPs and Paediatricians.

The participating professionals will be asked to take part in a semi-structured interview which will focus on their experiences of coming to firm conclusions, and the interdisciplinary working processes that they engage with. The semi-structured interview questions will be devised to focus on the ontological and epistemological issues related to the concept of Autism and the professional experiences in relation to formulation/diagnosis and associated casework (Hollin, 2017). The questions will focus on the participants' 'lived experiences' of this process with particular focus on their embodied emotional sensations, cognitions and attempts to construct meaning from the phenomenological experience.

The themes identified will then be presented in relation to each professional group and their ontological and epistemological positions.

Background rationale

Autism has been said to be the 'key diagnostic issue of the 20th and 21st century' (Hollin, 2017). Rates of Autism diagnosis have increased significantly for all age groups over the past 20 years (Russell et al., 2015), while at the same time an increasing number of authors have reported that 'it's time to give up on a single explanation for Autism' (Happé et al, 2006). There is also an ever increasing amount of divergent discourses, encompassing all philosophical positions, when conceptualising Autism Spectrum Disorders (ASD) (Hollin, 2017; O'dell et al., 2016). Explanations for Autism include realist/positivist positions, which maintain genetics and brain structure pathologies to be key determinants (O'dell et al., 2016), to pragmatic/constructivist positions which maintain that an interaction of environmental, social and biological factors are important to consider when conceptualising, defining and completing casework related to Autism (Hollin, 2017; O'dell et al., 2016).

The epistemological and ontological positions of Educational Psychologist have changed in the past two decades (Greene et al., 2018; Moore, 2005). Previous authors have promoted a strong emphasis on interpretivist positions (Moore, 2005), whilst more recent authors have maintained the value of philosophical pragmatism (Bunham, 2013; Scotland, 2012). A similar trend has been taking place in both medical research and health care communities (Bunniss & Kelly, 2010). There is also an increasing amount of discussion around the inclusive utility of realist, interpretivist and pragmatic philosophical positions; with authors arguing that examination of professional ontological and epistemological positions must take place to ensure inclusive outcomes; particularly when faced with 'uncertain' neurodevelopmental conditions (Hollin, 2017; Ravet, 2011). There are authors who advocate the explicit consideration of how philosophical positions impact on the process of interdisciplinary work and research, within both the medical and educational psychology professions; and in relation to Autism casework in general (Bunniss & Kelly, 2010; Hollin, 2017; Ravet, 2011). However, at present there has been no available research found which examines how ontological and epistemological positions influence the experiences of EPs and Paediatricians when working together in relation to Autism.

Research into personal epistemologies has found that people take implicit and explicit ontological and epistemological positions, both generally and in domain specific areas, based on a number of influences (Schraw, 2012). It is often assumed that this positioning process is rational, it has however been shown that this process is influenced by a number of varying factors including emotional responses to the phenomena in question, presence and perception of authority figures and maturity and experience in the domain in questions (Evans & Trotter, 2009; Schraw, 2012; Scotland; 2012). It has also been shown that epistemological and ontological position towards a phenomena develops over time (Schraw, 2012). The emotional effect of epistemological and ontological positioning has been shown in research with primary health care workers where it was found that when faced with uncertainty the adoption of realist, positivist, medical approaches, resulted in higher levels of stress, whereas the adoption of pragmatic biopsychosocial philosophical positions resulted in a reduction of stress (Evans & Trotter, 209). Research with Educational Psychologists has also shown that EPs feel a need to make their work seem 'scientific' and can feel anxious or hesitant around sharing their work and formulations if they feel that their contribution does not fit into a realist framework (Burnham, 2013). It is partly for these reasons that a phenomenological approach is proposed, to explore how professional's philosophical position has affected their experience of individual and interdisciplinary casework in relation to complex presentations of Autism and associated needs.

There are emerging philosophical positions which conceptualise human behaviour as ‘entangled’, with authors suggesting that all philosophical positions need to be considered in both research and practice (Fitzgerald & Calard, 2015). However, other researchers have suggested that ‘ strong ontological and epistemological boundaries must be maintained’ when different disciplines are working together in relation to Autism (Hollin, 2017). Other authors have maintained that “whilst the terms ‘epistemology’ and ‘ontology’ are understood by most, what is required is a deeper understanding about the status of different claims to knowledge.” (Macleod, 2010, p.105). Fitzgerald and Calard also suggest that emerging multidisciplinary networks focussed on emotional and behavioural phenomena should consider how their philosophical positions have influenced their practice to aid their collaborative working (2015).

The interpretivist approach will help to distinguish between tacit and implicit belief systems and help to ensure that the philosophical reflection that is maintained to be needed around Autism and it’s conceptualisation across professional groups is present in the current research context (Hollin, 2017). It is hoped that this project will shed light on the way that professionals develop their philosophical positions in relation to Autism and interdisciplinary working, contributing to a growing knowledge base and suggesting ways for professionals who hold differing philosophical positions to work together effectively to support children and families.

The and interpretivist positions of this research, holds that the individuals included in the research project are representative of perspective, rather than populations. This will mean that the experience of the professionals can be somewhat ascribed to professionals of disciplines who may have perspectives different to the professional body to which they belong (Malhotra, 2015).

Research Questions

- How do the Educational Psychologists and Paediatricians conceptualise Autism?
- How do EPs and Paediatricians explain the reported rise in Autism?
- What do the does the philosophical position of EPs and Paediatricians influence their experience of casework related to Autism?
- How do Educational Psychologists' and Paediatricians' professional identities affect their ability to engage in interdisciplinary work related to Autism?

Expected Outcomes

The proposed project will result in an increased understanding of how ontological and epistemological positions influence professionals who engage in the ASD Discussion Panels. The project will increase local understanding of current dynamics of working practices of EPs and Paediatricians within the context of the procedures outlined for the ASD panels. This will then result in recommendations to develop more effective interdisciplinary diagnostic procedures across the city, with consideration of the best practice and procedures outlined in various literature sources (Penner et al., 2017). Beyond this local impact, the project will suggest how EPs and Paediatricians can work together more effectively by understanding how ontological and epistemological positions affect interdisciplinary working and conceptualisation of Autism and associated difficulties.

Autism Spectrum Disorder (ASD) Discussion Panel

ASD Discussion Panel refers to: a series of ongoing meetings which take place between Educational Psychologists (EPs) and Community based Paediatricians. The meetings have been arranged so that the two groups of professionals can discuss school aged children who have initially been referred to the Paediatricians due to concerns around developmental delay symptoms which are often consistent with Autism Spectrum Disorders. A list of cases to be discussed at the monthly meetings is put together by the Paediatricians and their admin team. The cases on each list have been put there as a result of paediatric assessment in clinic where there has been difficulty for the Paediatricians in giving a clear decision relating to the diagnosis or discharge of children who: are currently reported to exhibit ASD symptoms in one or more different settings, are thought to be struggling to make progress academically and whose set of needs/symptoms could potentially better fit to a phenotype of a comorbid disorder or differing eco-systemic explanation. At present EPs are asked to complete a feedback form which asks; whether or not they have had any previous involvement with a child raised on the shared list and asked to share the type of work they completed with the children, whether they felt the child in question presented with social-communication difficulties and are asked to provide a brief formulation of psychoeducational need. The summary of involvement is then collected by a nominated EP who then attends the monthly discussion meeting. Consent is sought by the EPs to complete EP casework separately, and consent for the child's case to be discussed at the planning meeting with the EPs sought in clinic by the Paediatricians. At the monthly meeting the nominated EP shares the feedback from the EP involvement summary sheets. The nominated EPs and Paediatricians discuss the case; presenting information from each of their professional practices' activities and formulations of need based on their differing professional perspectives. These discussions are then used by the paediatrician to make decisions during the panel as to what will happen next. This can include whether or not give a diagnosis of Autism or may result in more in-depth assessment by the Paediatricians or a period of waiting. The panel discussion outcomes do not allocated tasks outside of the reporting of information to EPS. Feedback regarding the outcomes of the discussions is then given to parents and children by the Paediatricians in their next appointment in clinic.

7. CONDUCT OF PROJECT

Please give a description of the research methodology that will be used

The current research will take a interpretivist approach. This is deemed to be appropriate as the task at hand is not to place a value judgement on the perspectives and positions of the participants but to understand how those positions affect their experience in relation to the ASD interdisciplinary working. The interpretivist approach holds that there is no absolute truth which can be revealed through its associated methods. The approach maintains that its methods will produce knowledge rather than reveal what is already there.

A request for the voluntary participation in semi-structures interview will be sought for all of the EPs and Paediatricians who have attended the North area ASD discussion panels. It is hoped that there will be 3 EPs and 3 Paediatricians who will participate in the research. This small purposive sample will be reflective of the majority of professionals who have attended the ASD Discussion Panels so far. Participation letters and consent forms will be sent out to all prospective participants prior to any research being conducted.

The semi-structured interview schedule will be piloted with individual EPs and Paediatricians to ensure that it's design is effective before being used in the research. The role of the researcher in the semi-structured interviews is to facilitate the sharing of the participants' experiences of the phenomena outlined above, encouraging them to reflect on their philosophical and ontological positions. The semi-structured interview schedule will outline key issues to be explored but will give the participants the freedom to share and explore their own personal perspective and experience in rich detail. At the start of each semi-structured interview, in the pilot and main body of research, a short vignette will be read out to facilitate conversation and dialogue during the interview. The semi-structured interviews for the main body of the research will have their audio recording and will then be transcribed. The data from these records and transcripts will be thematically analysed. Audio recording and transcription will not place for the pilot interview.

8. DOES THE PROJECT INVOLVE PARTICIPATION OF PEOPLE OTHER THAN THE RESEARCHERS AND SUPERVISORS?

Yes ☒ No ☐

Note: ”Participation” includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

If you have answered NO please go to Section 18 . If you have answered YES to this question please complete all the following sections.

9. PARTICIPANTS AS THE SUBJECTS OF THE RESEARCH

Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

The informed, voluntary consent of the 3 Educational Psychologists, who will be employed by the Local Authority, will be sought through team directed emails. The Community Paediatricians, employed by the NHS, will be recruited specifically due to their involvement with the Local Authority ASD Discussion panels, and will have their informed voluntary consent sought by contact through an identified lead practitioner. A participation letter will be sent out attached to a summative email.

Age and gender are not significant factors for the participants in the current study. The participants involved in the study will likely vary in their age. Due to the repetition of both genders in Educational Psychology and Community Paediatrics the sample may well be all female if the limited number of males in each professional group choose not to participate.

The study requires at least 3 Paediatricians and 3 EPs to take place. This will provide a representative sample of the professionals taking part in the ASD Discussion Panels.

All of the participants will be asked if they would offer their time for voluntary participation in an individual semi-structured interview. The participants will be told that the semi-structured interview is expected to last for no longer than 1 hour and 30 minutes.

Inclusion Criteria

- Community Paediatricians who have attended the Local Authority ASD Discussion Panels with Educational Psychologists.
- Educational Psychologists who are currently employed by the City's Local Authority and have attended the ASD Discussion Panels with Community Paediatricians.

Exclusion Criteria

- Community Paediatricians who have not attended the ASD Discussion Panels with Educational Psychologists.
- Educational Psychologists who have not attended the ASD Discussion Panels with Community Paediatricians.

10. RECRUITMENT

Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student).

Note: Attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.

The researcher will approach EPs in the Local Authority in which the researcher, as a Trainee Educational Psychologist, is based to recruit the participants needed for the present research. As a purposive sample is required for the current research an email will be sent out to EPs and Paediatricians who have attended the ASD panels, outlining the purpose of the research, what participation would entail and the selection criteria. The participation letter will be attached to the email.

The paediatric lead for the ASD Discussion Panels has already been identified and contacted through the researcher's attendance of the panel meetings. The paediatric lead has also offered to arrange the recruitment of Paediatricians who have not yet attended the diagnosis panel. The paediatric lead will be given the participation letter to pass on to other Paediatricians for recruitment. The participation letter will explain the research purposes and make a request for volunteers (British Psychological Society ethical guidelines 1.3, 2009; BERA ethical guidelines 11, 2011). The paediatric lead will approach Paediatricians who have attended the ASD Discuss Panel and offer them the opportunity to participate by sharing the participation letter and by offering them a potential interview date. The Paediatricians will then be able to accept or decline the offer. All of the prospective participants work in the same office so will likely be approached in person by the paediatric lead. The participation letter will also detail procedures for maintaining the participants confidentiality and their right to withdraw up to one week after the interview has taken place (BPS Code of ethical conduct 1.3, 1.4, 2009; BERA ethical guidelines 10, 11, 15, 2011).

11. CONSENT

a) Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why. If the participants are minors or for other reasons are not competent to consent, describe the proposed alternate source of consent, including any permission / information letter to be provided to the person(s) providing the consent.

Note: Attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.

b) Will the participants be deceived in any way about the purpose of the study?**Yes** ☐ **No** ☒

If yes, please describe the nature and extent of the deception involved. Include how and when the deception will be revealed, and who will administer this feedback.

Not applicable.

12. PARTICIPANT FEEDBACK

Explain what feedback/ information will be provided to the participants after participation in the research. (For example, a more complete description of the purpose of the research, or access to the results of the research).

Following the analysis of data from the semi-structured interviews and Q sorts, I intend to present the findings to the Principal Educational Psychologist (Manager of the EPs) and Lead Paediatricians for the ASD Discussion Panel (Representative for the Paediatricians). A summary report of the findings will also be provided for all EPs and Paediatricians, as well as access to the public domain briefing and the research paper which will be included in the written-up thesis. The summary report for all participants will inform them of the outcomes and nature of the research. The summary report will ensure that the findings are communicated and the practical significance of the research, in a clear, straightforward fashion and in language judged appropriate to the intended audience (BERA Ethical Guidelines for Educational Research, 2011).

Individuals will be asked at the beginning of their semi-structured interview if they would like individual feedback. If they decide that they would, they will be sent a summary of the findings.

13. PARTICIPANT WITHDRAWAL

a) Describe how the participants will be informed of their right to withdraw from the project.

Verbal and written information will be given to participants prior to the interviews taking place, informing them of their right to withdraw (British Psychological Society, ethical guidelines 1.4, 2009; BERA ethical guidelines 15, 2011). This will occur when the participants are contacted via email and the information sheets and again before each interview commences. This will also be stated explicitly on consent forms given to participants. Participants will be free to withdraw at any time prior to, during or after the interview. Withdrawal time after the interview takes place will be limited to a maximum of one week after the interview has taken place (BPS, ethical guidelines, 1.4, 2009; BERA ethical guidelines, 15, 2011) as after this time data analysis will have commenced and it will be difficult to remove participants' data from the analysis process. Participants will be informed of this time limit in the participation letter and consent forms.

b) Explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

There will be no consequences for participants if they wish to withdraw from the research study.

If participants wish to withdraw during or up to one week after the interview, their data will be identified, the transcript will be destroyed, and audio-recording erased from storage devices. Any written field notes taken during the interview will also be shredded. This data will not be included in the data analysis. In the event of this a new participant may have to be identified and interviewed for the purposes of the research.

14. COMPENSATION

Will participants receive compensation for participation?

i) Financial **Yes** ☐ **No** ☒

ii) Non-financial **Yes** ☐ **No** ☒

If **Yes** to **either** i) or ii) above, please provide details.

Not applicable.

If participants choose to withdraw, how will you deal with compensation?

Not applicable.

15. CONFIDENTIALITY

a) Will all participants be anonymous?
Yes ☐ **No** ☒
b) Will all data be treated as confidential? **Yes** ☒ **No** ☐

Note: Participants' identity/data will be confidential if an assigned ID code or number is used, but it will not be anonymous. Anonymous data cannot be traced back to an individual participant.

Describe the procedures to be used to ensure anonymity of participants and/or confidentiality of data both during the conduct of the research and in the release of its findings.

Participants will be assigned a code for the individual semi-structured interview. The code will be based on their professional group and will prevent any identifiable name being attributed to data, in an attempt to protect confidentiality. The only record of participant names will be on the consent form, the consent forms will be stored in accordance with the secure data procedures. Confidentiality and anonymity is guaranteed with regards to the storage and presentation/reporting of data.

The semi-structure interviews will be conducted in a room that is not accessible to any other persons.

Participants will be reminded at the beginning of the interview that individual cases are not to be discussed, and that names or identifying features of individuals whom they have worked with should not be shared during the interview. If the participant does disclosure any names of identifying features of cases they will be reminded not to do so and the identifying information will be redacted from the audio recording prior to transcription. The participant will also be reminded that if they persist in sharing identifying information of the cases that they are discussing then the interview will be terminated the audio recording destroyed.

If participant anonymity or confidentiality is not appropriate to this research project, explain, providing details of how all participants will be advised of the fact that data will not be anonymous or confidential.

Anonymity cannot be offered within this study as it involves the conducting of face-to-face interviews. However, anonymity outside of the researcher role and the project in general will be ensured by allocating each participant a number, rather than using their name. Participants will be informed of this in the emails sent out and in the participation letter.

16. STORAGE, ACCESS AND DISPOSAL OF DATA

Describe what research data will be stored, where, for what period of time, the measures that will be put in place to ensure security of the data, who will have access to the data, and the method and timing of disposal of the data.

All data will be kept and stored in accordance with the Data Protection Act (1998, modified 2003).

Interviews will be recorded using a storage device and then transcribed (with no names/personal details included in the transcription). After an individual interview, electronically audio-recorded data will be moved to a password-protected and encrypted computer file that only the researcher has access to. The audio files will then be deleted from the audio-recorder. Written field notes taken during the interview in situ will be stored in a locked filing cabinet which only the researcher has access to in the Educational Psychology Service at which the researcher is on placement as a Trainee Educational Psychologist. Any printed transcripts will also be stored in a locked cabinet which only the researcher has access to. Participant names will only be included on consent forms which will be kept in a locked filing cabinet in line with Local Authority information governance procedures.

Written notes will not be attributed to individuals but will be identified by codes. Transcription data will be stored on a password protected Educational Psychology Service laptop and backed up on a secure Local Authority network in a password protected folder. Only the researcher will have access to this. In line with university ethical guidelines, all data (electronic recordings, field notes and typed transcripts) will be kept for 10 years on a password-protected memory stick, during which time the researcher, supervisors and any university examiners may have access to it. After this time, all electronic data will be erased (and removed from any back-up drives) and printed interview transcripts securely shredded.

17. OTHER APPROVALS REQUIRED? e.g. Criminal Records Bureau (CRB) checks

☒ YES ☐ NO ☐ NOT APPLICABLE

If yes, please specify.

In date Enhance Disclosure and Barring Service Certificate held by the researcher.

18. SIGNIFICANCE/BENEFITS

Outline the potential significance and/or benefits of the research

The research will aim to provide insight into how the ontological/epistemological positions and associated professional identities of Educational Psychologist and Paediatricians shape their experiences of Autism diagnosis/formulations, interdisciplinary working and associated casework.

The research will seek to highlight the barriers and facilitators to accurate, inclusive and satisfactory practice around ASD diagnosis/formulation and associated needs. This will hopefully lead to recommendations to enhance the practice of paediatric and educational psychology interagency working in relation to ASD and associated need.

19. RISKS

a) Outline any potential risks to **INDIVIDUALS**, including research staff, research participants, other individuals not involved in the research and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.

There is a potential that some of the interview questions may lead to upsetting experience being recalled in relation to professional conflict or emotionally charged cases where ASD has been considered as a possible diagnostic label. Participants will be interviewed in a manner which bears this in mind and respects the individual's differences and experiences of the participants.

Participants will be debriefed after the interviews in order to give participants the opportunity to ask any questions regarding the research and to help identify any concerns. Participants will be appropriately signposted to information and services as required in the unlikely event that they may wish to seek further support.

A quiet place will be required to carry out the interviews where participants will not be overheard. Interviews will be carried out in quiet rooms booked in the paediatric centre and educational psychology office. Participants will be informed in advance of the location of the interviews.

Participants will be reminded that at the beginning of the interview that they are not to discuss any individual cases and should not be referring to colleagues who are not present by name. If any of the Paediatricians report any harmful misconduct the interview will be terminated and written details of the disclosure passed on to the paediatric lead via email. If any Educational Psychologist share any reports of harmful misconduct, then again the interview will be terminated and a written summary of the disclosure will be passed on to an identified Senior Educational Psychologist and the service's Principal Educational Psychologist via email.

b) Outline any potential risks to **THE ENVIRONMENT and/or SOCIETY** and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.

It is not anticipated that there will be any risks to the environment and/or society as a result of this research.

20. ARE THERE ANY OTHER ETHICAL ISSUES RAISED BY THE RESEARCH?

Yes ☐ **No** ☒

If yes, please specify

Not applicable.

CHECKLIST

Please mark if the study involves any of the following:

- Vulnerable groups, such as children and young people aged under 18 years, those with learning disability, or cognitive impairments ☐
- Research that induces or results in or causes anxiety, stress, pain or physical discomfort, or poses a risk of harm to participants (which is more than is expected from everyday life) ☐
- Risk to the personal safety of the researcher ☐
- Deception or research that is conducted without full and informed consent of the participants at time study is carried out ☐
- Administration of a chemical agent or vaccines or other substances (including vitamins or food substances) to human participants. ☐
- Production and/or use of genetically modified plants or microbes ☐
- Results that may have an adverse impact on the environment or food safety ☐
- Results that may be used to develop chemical or biological weapons ☐

Please check that the following documents are attached to your application.

	ATTACHED	**NOT APPLICABLE**
Recruitment advertisement	☐	☒

Participant information sheet	☒	☐
Consent form	☒	☐
Questionnaire	☐	☒
Interview Schedule	X	

21. DECLARATION BY APPLICANTS

I submit this application on the basis that the information it contains is confidential and will be used by the University of Birmingham for the purposes of ethical review and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent.

I declare that:

- The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it.
- I undertake to abide by University Code of Practice for Research (http://www.as.bham.ac.uk/legislation/docs/COP_Research.pdf) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines.
- I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer.
- I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Birmingham Research Ethics Officer.

Name of Principal investigator/project	Dr. Colette Soan
Date:	7.6.18

Please now save your completed form, print a copy for your records, and then email a copy to the Research Ethics Officer, at aer-ethics@contacts.bham.ac.uk. As noted above, please do not submit a paper copy.

Appendix 2: Participant Information Letter

Dear (Ed. Psych/Comm. Paediatrician name),

RE: The Uncertainty of Autism: How do the ontological and epistemological positions of Educational Psychologists and Paediatricians affect their experience of complex ASD Cases and Interdisciplinary Working

Please see this letter as an invite to voluntarily take part in a research project to explore, and hopefully contribute towards, the service delivery of Educational Psychologists (EPs) and Community Paediatricians individual and collaborative practice around Autism Spectrum Disorders (ASD).

This research project aims to explore how the differing philosophical positions of EPs and Paediatricians have affected their experiences of diagnosing/formulating, both independently and collaboratively, when working with complex presentations of Autism Spectrum Disorder (ASD). The project aims to explore how professionals from each group have experienced their case work in this area and offer implications to improve practice and collaborative working between the two groups.

The research project will utilise semi-structured interviews, lasting no longer than one hour and thirty minutes, to collect data from participants to achieve its aims. The interviews will take place at each professional's convenience, in a quite setting of their choice, in August 2018.

The outcomes of this project will inform the continued development of the processes and procedures for the 'Autism Spectrum Disorder Discussion Panels' taking place across the City, and offer insight into how Paediatricians and Educational Psychologists work together.

The primary researcher for the project is Michael Palmer, a Trainee Educational Psychologist working on placement for Birmingham City Council's Educational Psychology Service.

Rationale

Autism has been said to be the 'key diagnostic issue of the 20th and 21st century' (Hollin, 2017). Rates of Autism diagnosis have increased significantly for all age groups over the past 20 years (Russell et al., 2015), while at the same time an increasing number of authors have reported that 'it's time to give up on a single explanation for Autism' (Happé et al, 2006). Explanations for Autism include realist/positivist positions, which maintain genetics and brain structure pathologies to be key determinants (O'dell et al., 2016), to pragmatic/constructivist positions which maintain that an interaction of environmental, social and biological factors are important to consider when conceptualising, defining and completing casework related to Autism (Hollin, 2017; O'dell et al., 2016) Each of these philosophical positions can be associated with a different ontology, epistemology and clinical response; with varying outcomes, interventions, treatments and provision depending on the position of the professionals involved and experiencing the phenomena (Ravet, 2011). This area is presented as ripe for exploration to further understand how professionals construct their knowledge in relation to Autism (Hollin, 2017; Ravet, 2011). The ontological and epistemological positions that professional hold are said to be key determinants in how they conceptualise, view and experience the presentation of Autism Spectrum Disorders and associated symptoms (Hollin, 2017; Ravet, 2011).

There is also an increasing body of literature which outlines the significantly high rates of comorbidity of Autism diagnoses with attachment difficulties, learning needs, ADHD and a variety of other developmental and neuropsychiatric conditions (Perlov & Sawyer, 2017; Stadnick et atl, 2017; Teaguae et al., 2017). There is evidence to suggest that the interventions for these various comorbid diagnoses can have harmful effects on the child if misdiagnosed and if incorrectly prescribed (Murphy et al., 2016). Inappropriate interventions are said to cause distress to both the individual child and their parents and can impact on future life outcomes; including employability, mental wellbeing and satisfaction in relationships (Murphy et al., 2016). There has been research conducted which suggests that efficacy of Autism diagnosis must be ensured, not only for the benefit of the child and their family, but to help ensure efficiency of intervention and resource delivery(Stadnick et al., 2017). Developing an increased understanding of the way that professional experience complex presentations of Autism and associated comorbid symptoms is key aim of this research project and will hopefully help to inform future collaborative working between Educational Psychologist and Paediatricians.

This project will written up as a Volume 1 Thesis for the primary researchers Doctorate in Applied Educational and Child Psychology currently being undertaken at the University of Birmingham.

Data

An audio-recording of each interview will take place and the data then transcribed. This data will then be analysed using thematic analysis. All audio and transcription files will be password protected and stored on a single encrypted laptop.

Confidentiality

The research project outlined above will involve professionals talking about their current and historic working practices specifically focussing on their experiences engaging with ASD in individual and collaborative casework. The following measures will be in place to ensure that individual's views are not identifiable to others whilst the research is being conducted or once it has been recorded and reported.

- Individual's names will not be ascribed to them in either audio recordings or written transcripts of either the semi-structured interviews. However, anonymity cannot be guaranteed due to the 1-1 nature of the interviews.
- All raw data collected, including audio recordings and paper copies, will be kept either securely in a locked filing cabinet or on a University endorsed encrypted cloud based filing system. These data are only accessible to the primary researcher and University of Birmingham supervisors. The raw data will be kept on file for 10 years and then destroyed.
- All participants will be able to withdraw and have all associated data from the semi-structured interviews destroyed until the one week after they have completed their semi-structured interview.

- Participants will be able to withdraw without having to provide a specific explanation. To do this participants will need to inform the primary researcher (Michael Palmer), by contacting them in person or via telephone/letter/email. Participants data can be destroyed at any time up until one week after their semi-structured interview has taken place.
- Any and all concerns regarding confidentiality should be raised with primary researcher and will be addressed immediately.
- Confidentiality would however need to be broken in instances where a participant reports harmful misconduct. In these instances the participant will be informed of the infraction and the intention for the disclosed information to be reported to either the identified Lead Paediatrician or Principal Educational Psychologist, dependent on the professional group to which they belong.

Thank you for considering this request for your participation in the above research. To take part in the project please complete and return the enclosed consent form either in post or via email by no later than **Friday 21st December 2018.** If there are any queries that you have before giving your consent to participate, please don't hesitate to get in touch.

Yours Sincerely

Michael Palmer
Trainee Educational Psychologist
Tel: 07**********
Email: [redacted]

University Supervisor: Dr Colette Soan

Appendix 3: Consent Form

Title of Project: **The Uncertainty of Autism: How do the ontological and epistemological positions of Educational Psychologists and Paediatricians affect their experience of complex ASD Cases and Interdisciplinary Working**

Researcher: Michael Palmer
[redacted]
07************

This research is part of my Doctoral Studies at The University of Birmingham

Purpose of the study

- The aim of this research is to explore how the philosophical positions, of Educational Psychologist (EPs) and Community Paediatricians have influenced their experience of lone practice and interdisciplinary working in relation to construction and diagnostic procedures for Autism Spectrum Disorders (ASD). The research aims to offer implications for improved collaborative working between EPs and Paediatricians by examining how differing philosophical positions affect individuals experience from each professional group when they are engaging with complex presentations of Autism (and associated comorbid difficulties), transdisciplinary working to develop collaborative formulations or diagnoses and when deciding on interventions, treatments and provision.

1. I have had the opportunity to ask questions about the research and have received satisfactory answers to the questions I have asked. ☐

2. I understand that my participation in the research is voluntary and that I may withdraw my participation or data from the semi-structured interview at any time up until one week after the completion of the interview, without explanation, by advising the researcher in person/telephone/letter/email. ☐

3. I understand that only the researcher will have access to the personal data provided, that data will be stored and used only for research purposes. ☐

4. I agree to take part in the study. ☐

5. I agree to audio recording of the semi-structured interview. I give my permission for the recording to be used for transcription and analysis as a part of the researcher's studies at the University of Birmingham. ☐

Name………………………………………………………………………………

Signed……………………………………………………………………………..

Job Title……………………………………………………………………………

Date………………………………………………………………………………..

Appendix 4: Semi-Structured Interview Schedule

Research Questions

- How do EPs and Paediatricians conceptualise autism?
- How do EPs and Paediatricians explain the reported rise in autism?
- How does the professional perspective of EPs and Paediatricians influence their experience of casework related to autism and it's diagnosis?
- How do EPs and Paediatricians experience collaborative working around autism diagnosis?

Introduction

- Researcher introduces self and reasons for doing this research.

  'Since taking part in the ASD Discussion Panels I have become more and more interested in the multidimensional nature of the construct of Autism. I am particularly interested in how Autism can be constructed in many different ways, depending on who you are speaking to; especially when this is considered across professional groups. I am interested in how the philosophical positions of professionals affect their experiences of constructing, formulating or diagnosing Autism, both independently and when working with professionals from a different discipline.

  I will aim to ask you questions which will explore your experiences of your independent and collaborative casework with [educational psychologists/Paediatricians]. These questions will aim to explore your thoughts, feelings and processes of developing meaning when you are attempting to diagnose, formulate or construct Autism. The questions will focus on your experiences of being presented with complex cases which may present with symptoms of other co-morbid neurodevelopmental disorders and where a diagnosis of ASD is not clear-cut. There will be questions which will ask you to reflect on your individual practice, but there will be particular emphasis on how you have engaged with other professional groups during this process. It is important to note that when the word Autism, or the Acronym ASD, when mentioned means I am referring to Autism Spectrum Disorder and its associated conditions.'

- Give the participants the opportunity to ask any questions that they may have.
    - Inform the participants that there are not right or wrong answers and that I am interested in their views and experiences.
    - Confirm that it is still ok to audio record the interview, letting them know that I may make notes during the interview.
    - Inform the participants that they can have a break at any time that they wish.

Plan for the Interview

The general plan for the interview: to be presented to the participants as a guide.

You have been asked to participate in this interview because you are part of a group of professionals who have attended the 'Autism Discussion Panels'. The interview partly aims to explore your experiences engaging in the collaborative process of formulation and discussion in the panel meetings and what have been the barriers or facilitators to the successful coordination of the panel meetings.

'I am going to start by reading to you a vignette. I will then ask you some questions. There will be some questions outlined in this interview guide, other questions will be asked in order to gain a deeper understanding of your answers or to explore them more fully. If required another vignette will be read out later on in the interview'

Vignette 1 – *'Autism has been said to be the 'key diagnostic issue of the 20th and 21st century' (Hollin, 2017). Rates of Autism diagnosis have increased significantly for all age groups over the past 20 years (Russell et al., 2015), while at the same time an increasing number of authors have reported that 'it's time to give up on a single explanation for Autism' (Happé et al, 2006).'*

1. **Why do you think that rates of Autism Spectrum Disorder (ASD) have increased over the last 20 years? What do you put this down to?**
   Do you think that this is a good or a bad thing? Do you think that this trend will continue?

2. **In the second part of the vignette it says that 'it's time to give up on single explanation for Autism'. What do you think of this statement?**

How do you define/describe Autism? How does this differ from the professionals you work with?

3. **Thinking back to you individual casework. How do you know or go about deciding, that the child you are working with presents as having 'Autism'?**
   Are you satisfied with this process? What would you like to do differently? What do you think is good about it? How has this process changed over time? How would you like it to change?

4. **How has your training influenced how you engage with potential cases of Autism?**
   What were you told during your training? How do you rely on your training in your practice?

5. **How would you describe you ontological and epistemological position in relation to ASD formulation and diagnosis?**
   Give definition of ontology and epistemology. Outline realist, pragmatic and interpretivist positions in relation to ASD.

6. **What involvement do you have with parents when trying to decide to decide if their child presents as having Autism?**
   How do you feel during this process? What do you have to consider when working with parents in this area? What happens if your disagree with a parent?

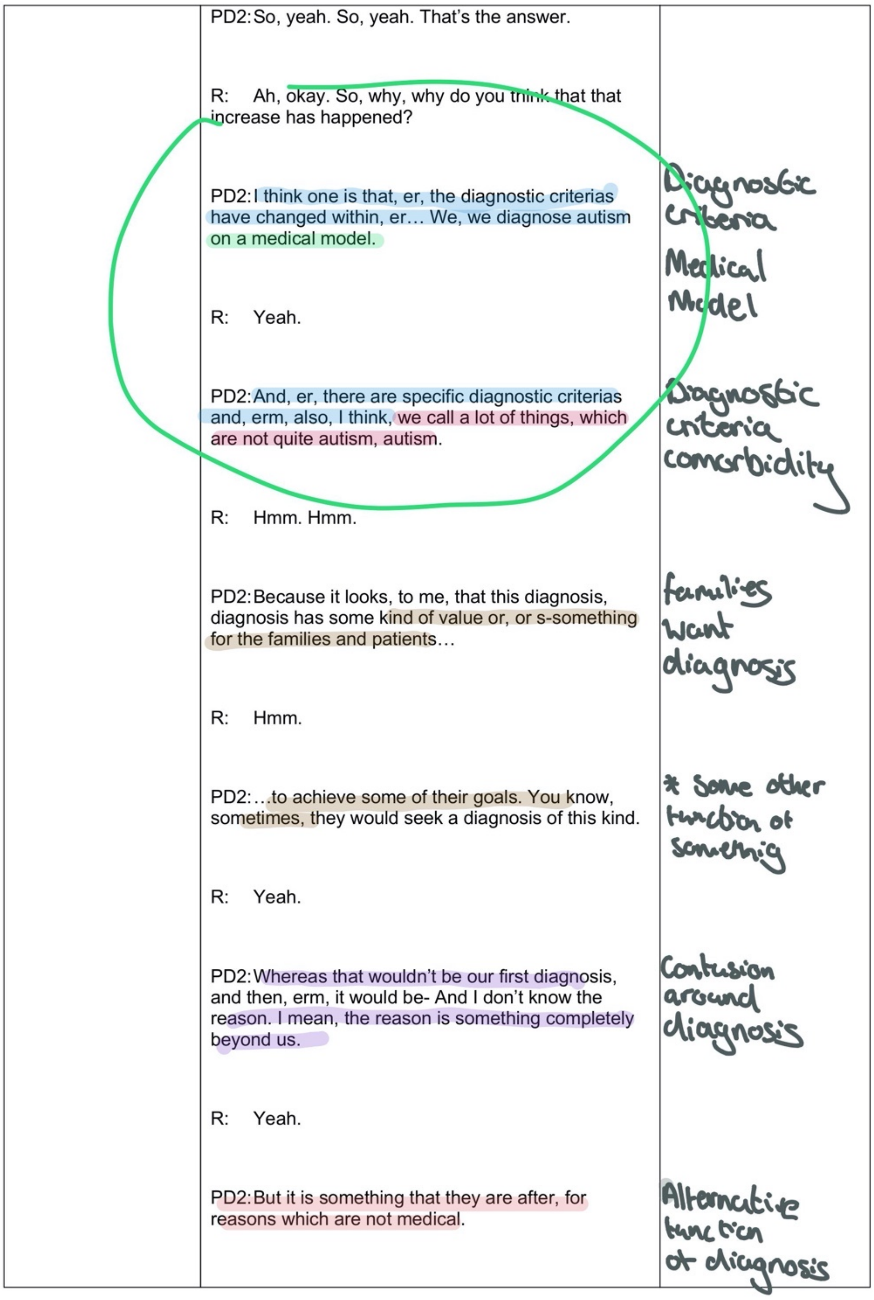
7. **Could you reflect on a case where it has not been clear whether or not a child has Autism, ADHD, Attachment needs or other associated learning and development delays… what's the experience of engaging with these sorts of cases like as an [educational psychologist/paediatrician]?**
   What helps you to [make a/produce a] clearer [decision/formulation]? Who else helps you gain clarity in these instances? How do you feel and what do you think if the person you seek advice from has a different opinion to you?

8. **Why do you engage with the ASD discussion panel process?**
   Can you describe what happens at the panel? What is the process of engaging with the other professionals like? How has this helped you, if at all, in your practice around Autism? How would you describe the practice of the other professionals in the panel?

9. **What has been your experience of the panel discussion so far?**
   Are there things that are good about the panel? Are there things that could be improved? How would like the panel to develop? What is it like when there are disagreements between the two professional groups? How has your perspective changed since taking part in the panel discussions?

10. **What perspective do professionals from the other group offer when focussing on complex Autism presentations?**
How does this help you to come to conclusions in your own work? What would like them to offer?

Appendix 5: Thematic Analysis Process - Example Transcript (Phase 1)



	PD2: So, yeah. So, yeah. That's the answer.	
	R: Ah, okay. So, why, why do you think that that increase has happened?	
	PD2: I think one is that, er, the diagnostic criterias have changed within, er… We, we diagnose autism on a medical model.	Diagnostic criteria Medical Model
	R: Yeah.	
	PD2: And, er, there are specific diagnostic criterias and, erm, also, I think, we call a lot of things, which are not quite autism, autism.	Diagnostic criteria comorbidity
	R: Hmm. Hmm.	
	PD2: Because it looks, to me, that this diagnosis, diagnosis has some kind of value or, or s-something for the families and patients…	families want diagnosis
	R: Hmm.	
	PD2: …to achieve some of their goals. You know, sometimes, they would seek a diagnosis of this kind.	* Some other function of something
	R: Yeah.	
	PD2: Whereas that wouldn't be our first diagnosis, and then, erm, it would be- And I don't know the reason. I mean, the reason is something completely beyond us.	Confusion around diagnosis
	R: Yeah.	
	PD2: But it is something that they are after, for reasons which are not medical.	Alternative function of diagnosis

	R: Okay.	
	PD2: And they would like a diagnosis. So, this is one of the things why there's lots of au- Everything is called autism…	Broader conceptualisation Parents want diagnosis
	R: Hmm.	
	PD2: …whatever the, er, medical problem is. It's called autism. For example, a child with Down's Syndrome has got learning difficulties which is a known factor because of chromosomal problems. You know, that's how the child is made. Now, learning difficulties will have a lot of features which will be autistic…	Medical perspective Autism taking over
	R: Hmm.	
	PD2: …or within the autism spectrum, which we knew for ages, for years, hundreds of years. But now, those features, which are autistic features, are separately identified as autism, which we never used to do in the past.	Broader conceptualisation
	R: Okay.	
	PD2: We would just say, "This child's got Down's Syndrome," and that would include learning difficulties, autism, hearing problems and lots of other things, which is the Syndrome's, you know, things.	Autism overlap Learning Difficulties
	R: Yeah.	
	PD2: But now, it has to be Down's Syndrome, autism and short stature, or something, which is, like, Do- It's a part of Down's Syndrome, that is, you know.	
	R: Hmm.	
	PD2: So, so what I'm saying is, lots of things, erm, are, sort of, erm, erm, broken down now, and that	Autism overlap

	PD2: I have to say- This is exactly why, because the parents have come today, after Christmas (Laughter) for a- you know, to discuss this with me.	Parents want diagnosis
	R: Right.	
	PD2: To- I've done an ADOS.	
	R: Yeah.	
	PD2: And it was negative. I've done everything I could for this child to- so that I, I was sure that the child was not, ___[00:07:13] parents thought he was.	Diagnostic Criteria
	R: Yeah.	
	PD2: And, and now there's- They are ___[00:07:19] disappointed but they are, sort of, desperately needing help, wanting help.	family wellbeing Access to intervention
	R: Okay.	
	* PD2: And, er, they feel- And I said, look, "He will get help because he does need help, but it's not because he's autistic. It's because he needs help. He will get help." So, there's ___[00:07:36] they're, they're not given, er, the diagnosis, whatever, but, you know, it's, it's just, erm- And they desperate parents. They, they don't- They want the best for their ch- kids.	Access to intervention Learning difficulties family wellbeing
	R: Hmm.	
	PD2: It's just, erm, the way the structure is, er, of, erm , I don't know, our, our diagnos- diagnosis, our education, our funding, our- or whatever.	
	R: Hmm.	

	PD2: And if they have this diagnosis, they perceive that lots of help will be given to the child.	
	R: Okay. So, what do you think's fuelling the increase in diagnosis most? The- That change in, in con- in diagnostic criteria, the overlap and, perhaps-	
	PD2: Hmm. Overlap with other, other conditions, comorbidities, comorbid conditions. Erm…	Overlap and comorbidity
	R: Yeah. Or the push from parents?	
	PD2: Er, it's a combination, honestly. I cannot- I, I cannot s-singly say this or that or that. Diagnos- A change in diagnostic criteria is very important for us, because our basis of diagnosis- I mean, I wouldn't diagnose if my- most of my criteria were not met. I would not give the diagnosis, although a lot of people - Like, today, I've not given a diagnosis for your kid, although this kid has got global learning difficulties and has got lots of- flaps their hands, and- etc.	Diagnostic criteria Refusing Diagnosis
	R: Hmm. Yeah.	
	PD2: But does not meet my criteria of diagnosis, so I said, "Sorry. He doesn't have autism but has got lots of problems, and should-," this is why I was asking you about your colleague, so that that child can get help.	Refusing Diagnosis
	R: Yeah.	
	PD2: He doesn't have autism.	
	R: So, you said, "Sorry, this child doesn't have autism."	
	PD2: Yeah.	
	R: Why do you think you have to say sorry?	

	autism bit, which is a part of many conditions…	
	R: Hmm.	
	PD2:…er, is taken out, and therefore they're named autism.	
	R: Okay.	
	PD2: You know what I'm saying?	
	R: Yes, definitely. So, you've said there that, kind of, the- There's been a change in the diagnostic category for autism.	
	PD2: Criteria, yeah.	
	R: Yeah. There, there's then this, this push from parents.	Change in Criteria Push from Parents
	PD2: Push from parents, yeah.	
	R: And that, kind of-	
	PD2: Pu-, push from parents, and it's not them, them. They get the push from somewhere else.	Parents want diagnosis Parents dont want diagnosis
	R: Okay. Where do you think they get that push from?	
	PD2: I guess from school. I mean, they don't want their children- They want, they want the children to get the help they think they need, and the only way – that's what they tell us – the only way they feel they get the help they need is if they have this diagnosis.	Role of Schools Access to intervention
	R: Okay.	

	PD2: I think it's a mixture of everything which makes, er, this, erm, this so much more common than before.	
	R: Yeah, okay.	
	PD2: I, I know if, ten years ago, er, our EHCs, I, I cannot remember at all, er, when I started here, to give these levels of autism, er, in my EHC plan. And now, I can't, can't, er, I do not know when I did not give the diagnosis of autism in my EHC medical, you know.	EHCPs Increase in diagnosis
	R: So, do you think that that's… Do you think that that's because autism has just become the catch-all category for all [Crosstalk 00:08:41], lots of them?	
	PD2: Lots of things. I do think that is, to some extent, is the- is true. There are lots of things which are, erm, which are probably allied, sort of, a newer development of things.	Autism Overlap
	R: Yeah.	
*	* PD2: But not quite autism. That doesn't fit the category- criteria that we go by. We still call it autism because there isn't any specific name, or the names are not good enough. For example, learning difficulties is a good name for me, but it's not a good name – I mean, good in inverted commas – name for, er, the parents.	awareness/ recognition Diagnostic Criteria Child individuality learning difficulties Parents understanding
	R: Okay.	
	PD2: Why? (Laughter)	
	R: Why? Yeah.	
	PD2: Why? Because I think it's a- the way it has been , if you like, advertised. (Laughter)	Awareness / recognition
	R: Yeah, right. So, you think there's this big thing	

	around understanding there?	
*	PD2: (Laughter) Absolutely. Very big thing about understanding, yeah. I mean, it's, er, I think it's our fault, a lot, medical profession, because we don't make it clear…	Awareness/ understanding Medical Perspective
	R: Right.	
	PD2: …er, maybe, when they're little. For example, a child who's got global learning difficulties, we just say , "Oh, he's got global learning difficulties. My. Look after him." (Laughter)	Learning Difficulties
	R: Okay.	
	PD2: And we need to explain what that means when they are 16 or 18, you know, and that kind of thing. So, they expect, "Oh, yeah, global learning difficulties at three. I don't know why he can't learn today." (Laughter) This is the kind of thing we hear.	Parental understanding Learning difficulties
	R: Okay. So, are you satisfied with the way that you diagnose autism?	
	PD2: No, I'm not because autism diagnosis should be multidisciplinary, should be, er- It used to be a diagnosis of excluse- exclusion.	
	R: Yeah.	
	PD2: And it needs to be- And also, it needs to fulfil the criteria. I am, I am not being pedantic, but I feel that in- as a medical person, erm, I, I do need that there has to be some criteria that needs to be fulfilled .	Diagnostic criteria Medical Perspective
	R: So, would that mean your ADOS and your 3Di?	
	PD2: No, no. It means- No, no. No, no, no, no. Not at all. What mea- No, it means that the child should	Medical Perspective

	have, erm, difficulties in the old three, three or four areas.	
	R: Yeah, okay.	
	PD2:…which we- which you look at – repetitive behaviour, or in- inflexibility, or, you know, those, those things that are correct diagnostic criteria, which is autism.	Observation Diagnostic Criteria
	R: Yeah, yeah. And where would you get that information from around whether they're meeting that criteria or not?	
	PD2: Where would I get it from?	
	R: Yeah.	
	PD2: By, by talking to the parent, looking at the child. (Laughter)	Role of Parents & observation
	R: Okay. So, I, I assumed that you just always did the, either ADOS or 3Di.	
	PD2: No, no.	
	R: Okay. Erm, are there times when you give a diagnosis and, and just done it from, kind of, consultation and observation?	
	PD2: Yes, yes. I have. Very rarely, now. Very rarely now, because- only because people like proof, a lot of them, and, and, and, and, and you always doubt yourself. You haven't done- I mean, I don't always. You can. There's, there's a, you know, chance that you say, "Oh, was I right?" and also, ADOS is not always right.	Observation Evidence
	R: Yeah, yeah.	

	PD2: So, erm, but because ADOS has been standardised, you feel it's, sort of, safer, safer for yourself and for the parents' sake, patient's sake, sorry, er, that, that you've done something which is a standardised assessment, and they feel that, "Oh, yes, that has been done," and so, you know, this is yes or no. Er, there is a- it's like a test, kind of thing. They, they like, erm, because it's such a, er, inaccurate or un- things that you can't see. That's why they like some kind of test.	
	R: Yes, bit of value to it.	
	PD2: Yeah, yeah. I think.	
	R: Are, are there every any times where maybe they scored really highly on ADOS or 3Di and, and you- but you've still felt it's- that, that's not autism?	
	PD2: Many times.	
	R: Right.	
	PD2: Yeah, many times. You mean, when the school has, sort of, pushed us to do it.	Conflict Role of schools
	R: Yeah.	
	PD2: And I don't feel that it is…	
	R: Yeah.	
	PD2: Yeah, it happens, yeah. It happens.	
	R: Okay.	
	PD2: I can't name the things or I can't even- yeah. Yeah, it has happened to all of us.	

	R: Yeah.	
	PD2: Yeah.	
	R: Okay. So, that's, kind of, a bit of, like, a contradiction, isn't it? You've got doubt around- from observation and consultation…	
	PD2: Yeah.	
	R: …but then, there are times when the assessments might not be accurate.	
	PD2: The- No. You have- That is- All- Everything is in, erm- It's not all or none. So, your- A child comes to you. You're the only person seeing them, so you- your, your job is to take a good history and good examination, and, er, neurological examination, etc. and, and not miss out important things in that, which may influence the child's development.	Observation Developmental history Medical perspective
	R: Hmm.	
	PD2: That's – as a medical person – that's what your job is. But then, diagnosis or assessment of autism has many things – observation of behaviour, taking, er, specific history, or obser- of them, and then, you know, questionnaires completed by people which are screening questionnaires, people who know them on a daily basis.	Observation Developmental history Medical perspective Questionnaires and Standardisation
	R: Yeah.	
	PD2: From different- In different settings. That's a third thing. Then the fourth thing is, if he- After this, if you still have doubt that it's autism, then you do the, er, ADOS or, you know, some other thing.	
	R: Yeah, okay.	
	PD2: So- But now, it has become almost as if these	Limitations of tool and role

	are stages of the [prompt 00:14:40] procedure, but actually, there are children you- ___ typical autisms who come to your clinic and you know they're autistic . But it's, it's a bit, bit difficult to give that diagnosis on the day you see them.	Classical Autism
	R: Yeah, of course.	
	PD2: You can't, and so you do a few other things and, because you always have learned that autism is a diagnostic exclusion, so in your mind you need to exclude other things, and make sure it is autism, because you do give a diagnosis for life. You cannot just say, "Oh, well, he's not talking today, he's got autism." You can't do that, so you have to…	Diagnostic criteria limitations of tools
	R: So, what are you looking to exclude with those , kind of broader presentations?	
	PD2: So, so you're looking to exclude medical problems like neurofibromatosis or, or other (Laughter) other things which present with global development and delay, like speech delay or hearing problems.	Comorbid medical conditions
	R: Do you ever look to exclude things like attachment needs and mental health difficulties?	
	PD2: No. Mental health? No. I'm not trying to do that at all. Attachment? Because I do, or, looked-after children for many years as well, so that is very, very top of my thought process. Not- I don't think everybody has that, because they don't do that work.	Alternative psychological explanations
	R: Okay. * confusion around purpose	
	PD2: So, bec- And I do always look at that, and I look at Mum's alcohol consumption, Mum's drug consumption, or whatever, you know, pre, pre, pre-natal problems. Those are the things doctors need to look at, because I know psychologists are not, not, not going to look at that. Well, I don't know whether they do, but-	Environmental factors Alternative medical Developmental history
	R: Yeah, I mean, we, we would, really.	

	PD2: Would you?	
	R: And we do a lot of, kind of, questioning around , like, very early life experiences, and we're maybe looking for attachment and pre-natal stuff, especially more now than ten years ago.	
	PD2: I mean, what then, what then, what if you do look at-? I mean, the thing is, I (Laughter), I do look at all of that, because that's what I've been trained to do for a long time, but I often don't know what to do with it.	* Developmental history Role limitations Access to intervention
	R: Yeah.	
	PD2: (Laughter) I look at it. So? And, you know, it's more a can of worms than anything else. You know, I , I look at it. So? I mean, that's the problem with going into it more than you can, erm, help with.	Role limitations Developmental history Professional expertise Availability of info
	R: Right.	
	PD2: You know? (Laughter)	
	R: So, it's about, kind- It's, like, that pragmatic approach, isn't it? What's gonna be useful for that family, the child?	
	PD2: Yeah, yeah. It's, it's- You know, it's not- it's not the diagnosis. It's not the name. It's how the child can be helped.	
	R: Okay. Okay. Do you think that's part of the problem, there?	
	PD2: I think so. I think so. I mean, many times, these kids, er, go out of school and they're all fine.	
	R: Hmm.	

	PD2: Fine, absolutely fine.	
	R: So, what in- what influence has influenced your practice more, do you think? Do you think it's your, your… the, kind of, criteria and the assessment tools you're, you're meant to follow, or your experience as a clinician?	
	PD2: Oh, experience, definitely. Criteria does. I mean, criteria- Tomorrow they might say, "Oh, you can diagnose autism if they have blue eyes." I mean, it's, it's- you know, that can change.	
	R: Yeah, yeah.	
	PD2: But it's your experience. How is it going to- Is the child finding it difficult? Is the child unhappy? Is the- You know, why?	Observation
	R: Yeah.	
	PD2: Erm, the criterias have changed in the sense that they've included many more things in the diagnostic criteria. Now, you can call many people autistic because of that. That's okay. Even with those , they have probably rightly done that, because people with those difficulties are unhappy, are not coping.	Broadening criteria Family wellbeing
	R: Yeah, yeah.	
	PD2: And that's why they've done it. That's fine. I'm happy with that. But it's my experience, it's because I've seen it so, so many times.	
	R: Okay.	
	PD2: I think. I don't know. Maybe, maybe it's not so for everybody. (Laughter) I just think that. I've been here too long, probably.	

	R: So, I mean, the difference between, kind of, EPs and paediatricians is, you get the final say on whether a diagnosis is given or not.	* Want EP involvement
	PD2: I don't know why. (Laughter)	
	R: Is that- Do you like having that position, or, or not, then, really?	
	PD2: My colleagues would totally disagree with- I don't mind who gives the diagnosis. (Laughter)	
	R: Hmm. Okay.	
	PD2: Because I think- I think it should be a multidisciplinary decision. It's not any person's decision because there's so many facets to this condition that you cannot just say- And I can tell the medical bit. You can tell the psychological bit, or somebody else can tell the other bit, because that child's made up of all that.	Multi-disciplinary Profession expertise interagency
	R: Yeah, yeah.	Want EP involvement
* Role limitations self-criticises	PD2: And so, I don't think just I giving the- I, I don't- sometimes, I'm totally not- I'm inadequate to give a diagnosis, because I don't ~~know the child's~~ functioning as much at all.	
	R: Hmm.	
	PD2: But here, you know, like I say, I have to give a diagnosis, just because I'm called the doctor and-, you know, but I'm not in a position to do that, because I don't know enough.	Role limitations expectations
	R: Okay.	
	PD2: But on a- on the other hand, in some cases, I do know the child much more, because I have seen	

	the child for ma-many, many years and pe- (Laughter) and others have changed. They don't know the child , and then I'm in a position to give that or assess the child better. So… yeah.	
	R: Yeah, okay. So, what's it like when you've got parents who want a diagnosis and you have to say no?	
	PD2: What's it like?	
	R: Yeah.	
	PD2: I mean, it's like any, anywhere else. Any, anything else. It's unhappy.	
	R: Hmm.	
	PD2: I mean, it's not just about the diagnosis. If you want anything else, and I'm not giving it to you, you're unhappy. (Laughter)	Conflict with Parents
	R: Well, I guess- Do you think the psychologists have, kind of… it's been a bit of a cop-out, maybe, that the psychologists haven't been as involved in that process as they, they could have been?	
	PD2: Er, in, in the assessment process?	
	R: Yeah. I, I mean, maybe I, I think that the- that psychology as a profession has really tried to distance itself from diagnosis, and because of that, we're not in a pos- we're now, kind of, completely hands-off.	
	PD2: Hmm. Er, I can't comment on that, because I, I do not know. I mean, I would love anybody else – nurse, psychologist, or psychiatrist, or neurologist, I don't know, er, anybody who knows the child – to have a say in the child's, erm, you know, diagnosis or assessment. But whether the psychologists have gone a- gone away from it on purpose or not, I don't know. But what I know is that because it has been left	Multi-disciplinary want EP involvement

	with the doctors to do it for whatever reason, that it is not a good as- it is not a wholesome assessment.	
	R: Okay.	
	PD2: That's what I think.	
	R: Yeah, yeah. Okay. What information are you looking for from, from psychologists when involved in, kind of, multidisciplinary assessment?	
	PD2: (Sigh) Okay. Erm, I don't know, er, how much psychologists can, erm, can let us know. But, for example, in the middle, when I just- I was struggling so much about the child…	Personal experience
	R: Hmm.	
	PD2: …and I didn't know what was going on, even with questionnaires and everything, so I, I used to make a point of going and visiting the school, to watch them in class and, more, more importantly, talk to the teachers.	role of schools
	R: Hmm.	
	PD2: Talk to the teachers, actually, one-to-one, and I have a, sort of, questionnaire about how they are, you know, which helped me, so I would go through that with, with the, the teacher, the class teacher, and most- mostly the teaching assistant who knows the child. So, basically, I want to know the child's behaviour.	
	R: Yeah, yeah.	
	PD2: Not only on one day, but generally, how the behaviour is, and the change in behaviour.	
	R: So, is that, kind of, social functioning?	

	PD2: Yes, yes, social functioning.	Interactions
	R: Okay.	
	PD2: I, I- Also, I want to know- I wanted to know academically is the behaviour due to his global learning delay or is it because of deviant behaviour? Or is it because there is a problem at home? Is it because Mum's just died? Or is it because, because there's a sibling who's born? Those are the things which matter to children, which make their behaviours different. I know that and that's why I want to find out. Erm, they can present as autism because they may temporarily, you, you know, fulfil the criteria of autism, but not for a long term.	Developmental history
	R: Yeah. So, if you think that that's, kind of- that's where the process is [Crosstalk 00:24:09].	
	PD2: Yeah, that's where I would like.	
	R: So, it's about that response to- response to stimuli, isn't it? Whether it's, like, a bereavement or intervention, or the interactions they have. Is that what you're looking for from psychologists? How have they responded to what's going on in their environment?	
	PD2: What you- I would like is, what should- in my view, what it should be, that a teacher has a- has an issue, they have access to a psychologist.	Role of schools Want EP involved Access to intervention
	R: Hmm.	
*	PD2: And they say, "Can you tell me how to help this child because this child has got a problem, I think ?" So, a psychologist has that power to find out if the child- if the child is- has got some problems at home, or it's a- it's a- it's a temporary thing, it's got a new sibling or twins are born to a single mum, and this is the five-year-old or- you know, things like that. And then, inform the teacher. You know, "No, this is not because the child is bad or deviant. It's because of this and do this about it."	Want EP involved compliment expertise context access to intervention family wellbeing

	R: Yeah.	
	PD2: Tell- you know, a period of time. Because we want instant things. They come here to my clinic and they want a diagnosis when they're going out.	Parents want diagnosis
	R: Yeah.	
	PD2: It's a developmental problem. It's a time- you need time and I, I explain to people and they think I'm fobbing off- I don't know what they think, but anyway, they- and, so I feel that there- if there was this- that time and the psychologist was there to support, and then the psychologist may say, "Oh no," you know, "I have observed this child. There's no other problem. Yes, this is actually a thing that needs to be assessed by somebody else as well." And that's when the child should be referred to somebody who knows a little differently about the conditions. You know, that, that's- or, maybe the nurse- there's- there can be a nurse who is more informed or can give, give, er- or the psychologist can perhaps say, "Oh, the child is depressed or-," you know. I don't know what [Crosstalk 00:26:12].	Time
	R: Yeah.	
	PD2: Those- that- that's where I think there's a- that's what I feel the psychology- psychologist's function should be. I'm not saying you should be doing that, but I'm saying ideally, you know.	
	R: Yeah, yeah, of course.	
	PD2: What, what would be nice is that.	
	R: So, that's, kind of, like, intervention and assessment at the same time, isn't it?	
	PD2: Yes, intervention and assessment. Assessment and intervention, er, time-limited.	Time

	R: Yeah, yeah.	
	PD2: And then you reassess and say, “Oh, this is not working. This child’s not, not so good, so go to the doctor now.” Then, then there is a process. Then, also, I know everything has happened.	
	R: Yeah.	
	PD2: And I can assess it. I know everything’s been ruled out.	
	R: And if you think about what you were saying about the parents want it because they think it’s going to open up all those avenues for support…	Parents want diagnosis's Access to intervention
	PD2: Yes.	
	R: …that’s the missing link, then, isn’t it? That, that response to intervention, because that’s part of your, kind of, exclusionary assessment, then, isn’t it? So, if you’ve done work with parents around parenting interactions [Crosstalk 00:27:16].	
	PD2: Exactly. I mean, the thing I really feel is that a parenting- not- it’s not psychologists who have to do it, but general parenting information, er, course. Not course. Er, I don’t know how to call it. Something, but to know how- what children- what can be expected from children, and how to, you know, have a happy parenting or what- you know, a normal parenting, because I think we- there are expectations from children which are really unreal in many families and, er, and, and they, er, you know, and, er, you know, there’s lots of things like that, I suppose. I mean, so that can be- nurse can do that, definitely, or parents can opt for parenting classes. In many- er, we, we went to one of the conferences, er, in that. They wouldn’t accept anybody unless they had been to a parenting class for six weeks.	Role of Parents Parent expectation
	R: Okay. That’s impressive.	

	PD2: They wouldn't accept as a referral at all, whatever. R: Right. PD2: If you have been referred by a beha- for a behaviour, to a doctor, there's no acceptance unless you go back to a parenting class for six weeks. So… R: How, how recent was this conference? PD2: How recent? Last year. This year, yeah. R: Okay. So, that's, kind of- where I used to work, erm, they had parent support advisors, but they were all, kind of, removed in the 2008 round of budget cuts. PD2: Yeah. You know, also, had- we had lovely- we- didn't we have here, 2008. We had- 2008 and 2009, we had, er, fantastic parent, er, parenting courses, like, parent, parenting courses, I think they were called. At least you could learn how is positive reinforcement, how is- you know, what is appropriate, appropriate punishment. What is, you know- how to, how to punish people. They think- I mean, most parents think sending a nine-year-old to his bedroom is punishment. R: Hmm. PD2: You know. It, er, is not punishment, nine-year-old, he does- he wants to be in his bedroom. He doesn't want to be with the family, or- you know, and, and- so, it's, it, it's just- I think, it's just telling- letting them know how best to interact with their children, I guess. R: Yeah. PD2: I don't know. I mean, the, the- lots of psychologists can do lots.	

	R: Yeah. I mean, I guess the thing is, then, we've almost said- we've talked about this missing point being, like, response to intervention. But is that even broader than that, then? It, it- That, really, what parents are looking for when they come for an autism diagnosis is, is information and understanding, and if they had more of that on the front end, we'd maybe get less, or fewer, parents looking for diagnosis.	
	PD2: Ab- yes. I, I- yes. Information and understanding is key.	Information
	R: Hmm.	
	PD2: Er, to most things, you know, erm, of these behaviour things. I mean, even when there's a phone call and I explain, you know, I can see the parents really becoming calmer, I mean, I have done, done nothing. I haven't even looked at the child.	Parents
	R: Yeah.	
	PD2: But just letting the parent know that this is what is fine, normal, you know, this is okay for the child to do.	
	R: Okay.	
	PD2: That kind of thing calms a parent down, and they can cope with it better.	
	R: Yeah, definitely.	
	PD2: And so, it's, it's, it's- parenting is not easy and the knowledge that parenting is not easy, even that is important.	
	R: Yeah, yeah.	
	PD2: You know. I feel that nobody has told them	

	R: Yeah.	
	PD2: I mean, at the moment, schools are, are saying, “We don’t care if you’ve got autism, and we’re not doing anything about it.”	
	R: (Laughter)	
	PD2: (“Let’s stop,” 00:32:45], I think. (Laughter)	
	R: Do you think, do you think, do you think that’s gonna happen, though?	
	PD2: No. The school- I think they- if they don’t- they might say, “I would- we would like a diagnosis of , erm, neurodevelopmental disorder category one,” for example.	Schools Medical Conditions
	R: Right, okay. So, I think that autism, as it’s, kind of, getting broader and broader…	
	PD2: Yeah. (Laughter)	
	R: …it’s becoming, maybe, less meaningless. More meaningless, sorry.	
	PD2: Yeah. Yeah.	
	R: And if you think back to how it- perhaps ten, fifteen, twenty years ago…	
	PD2: There’s much more, yeah.	
	R: It would be more around individual need. So , do you think that autism- a diagnosis of autism is, is useful?	

	PD2: I think it does have usefulness, yes, because we, erm- I know what I mean when I give a diagnosis of autism.	awareness/ understanding
	R: Hmm.	
	PD2: So- and I expect most doctors mean that, er, you know, and so, of course, that is a very important set of difficulties in a person, in a child, so it is useful. But your questions were that has the diagnosis of autism become meaningless? Has it become too broad? And things like that. But those are also true, but that doesn't mean that the diagnosis of autism is mean- it doesn't have any usefulness for the child who's got autism.	
	R: Yeah.	
	PD2: It is useful because we do recognise what the difficulties are when you say, "This child is autistic ."	awarenes understanding
	R: Right. But do you think that- as it gets broader, do you think it's missing any of that individual need?	
	PD2: Yeah, yeah, it does. It gets- it's diluted. Yeah , it gets diluted, which is not good, but we do need to be- you know, we are very, er, I mean, it's because of , maybe, time or whatever. We are not good in actually pointing out the, the difficulties within autism that the individual child has. Autism is so broad now, so we don't tell you- For example, a child who has got anxiety disorder. Anxiety and, say, sensory needs .	Child individuality comorbidity Alternative psych explanation
	R: Yeah.	
	PD2: And nothing else.	
	R: Yeah.	
	PD2: Yeah, which would be within the autistic	

	that, sometimes, you know (Laughter) and, er, it's, erm, lots of things. I think they need support, I think, parents. So, when children have behaviour issues, if the teachers had access to, not you guys, not you. Probably you guys are very expensive, but some psychological support to say, "What, what can we…? " You know, family support, but not go and tell them, you know, dictate what to do because that's really hard, then. But, erm, just the communications. What's going on in the family and why is child behaving like this and what steps they can take. And if nothing's improving and then go onto the next step. That, I think, would be…	Awareness Information Communication
	R: So, it's that, kind of, collaboration across everyone, isn't it?	
	PD2: Yeah. I think so. I think it's a- it's a multidisciplinary team, that's what, er, is, is very important.	
	R: Okay. And if you think, then, you know, it's not really autism that's multidimensional, it's just children are multidimensional, but we've got an- but maybe that's why autism is so sought-after, because it does-	
	PD2: I think that is a temporary thing.	
	R: Really?	
	PD2: I think so.	
	R: Why?	
	PD2: It's one of those- I mean, because, because, like I said, we, sort of, call lots of things autism. (Laughter)	Comorbidity
	R: [Crosstalk 00:32:32].	
	PD2: So, it'll move to something else, maybe.	

	R: Whereas if autism is, you know, from anxiety and sensory experience to language and social communication, that seems quite, kind of, disparate.	
	PD2: Yeah, absolutely. I mean, there's- it's, it's- I know I, I- this- that's why I made the comparison because we diagnose autism from a medical- it's a medical model, our diagnosis, and I'm saying- what I'm saying is, that's what we have learned to do. And I agree that there- like I keep saying, that has to be multidisciplinary and we should, sort of, go off that model. But that doesn't take away the importance of the medical model, also, because it is important to recognise the difficulties.	Medical Perspective
	R: No.	
	PD2: Me, I think autism has become so broad that it has become meaningless, because of that.	
	R: Okay.	
	PD2: But if we could- what we should so is actually go more into – as medical people – go more into it and, for individual children, tell their difficulties, what they are, more than just say autism.	Individual chil Needs focussed assessment
	R: So, I think that's what psychologists have tried to do.	
	PD2: Is it?	
	R: So, we would- you've maybe seen this in some of the feedback we've had, where we've said things like, er, social communication difficulties and a delay in language.	
	PD2: Yes, yes.	
	R: But- when we could say, "Consistent with autism," they very, very rarely would do that. Erm, I think that's a little bit of a missed trick, really, because we've now just removed ourselves from that	

	process when really, if you gave that diagnosis of autism and we gave the information in all of the- around that quite specific individual need, that's hopefully the best of both.	
	PD2: Yes, yes, I think- I, I think- there is one thing that- er, because, like you say, social communication difficulty, er, and sensory difficulties might, might happen in children who also, for example, I've taken neurofibromatosis very often because I have seen children like that.	Interactions Alternative medical condition
	R: Hmm.	
	PD2: It's, it's a, erm, dominant inherited condition and it, er, gives autistic features. So, you may pick that up…	Alternative medical conditions
	R: Hmm.	
	PD2: …but I need to pick up, also, er, the underlying condition.	
	R: Right.	
	PD2: So, it's important that that is picked up too. That's why the medical thing is important.	Medical Perspective
	R: And that's it, then, isn't it? If you think that, from what we've said about that, like, response to intervention and environment, that's, kind of, medical model and social model.	
	PD2: What do you mean? Which?	
	R: So, you're doing, kind of- If we're looking at interactions, yeah?	
	PD2: Yeah.	

	R: Whether that's the way the child interacts with their environment as an individual or the way the people in, in that environment interact with that child, that's, like, a social construction of autism.	
	PD2: Yeah.	
	R: Erm, whereas for yourselves, if you're excluding other medical conditions, that's, like, the scientific method. That's, that's medical.	
	PD2: Yeah, but they're not exclusive of each other.	
	R: No, that's what I'm saying.	
	PD2: Yeah.	
	R: That, that those two- That again, it's that ques-	
	PD2: They have to be together.	
	R: Yeah, exactly, exactly. Yeah.	
	PD2: Yeah, I agree. I totally agree to that because this is one way of diagnosing- This is- I mean, this is to say that, yes, you have basically- even in the medical model, the difficulties of autism is the social difficulties, even if you diagnose a medical- by a medical method or whatever.	Medical model/ societal interactions
	R: Yeah, yeah.	
	PD2: It's, it's the social difficulties. So, the help which the child needs, the interventions the child needs, is the social model.	Social difficulties access to intervention
	R: Yeah.	

	PD2: Always.	
	R: Okay. Do you think schools provide enough support for children with additional needs?	
	PD2: Some schools do. Yeah.	
	R: Okay.	
	PD2: They do. Some schools do, and special schools certainly do.	Schools specialist intervention
	R: Okay. That's very diplomatic. (Laughter) I guess the reason I asked that question is, 'cause I wonder then if, erm, if schools were maybe better at, kind of, supporting those additional needs, would we have fewer children coming into clinic, looking- with parents looking for that diagnosis to get more of that support?	
	PD2: To be fair to schools, they are actually very good, and parents increasingly come to us in Year 4 and 5 and 6, 5 and 6, because they're afraid that the, the support that the child has is going to fall.	
	R: Yeah.	
	PD2: And that's why they come to us.	
	R: And it- and it does.	
	PD2: And it does, and so who can blame them?	
	R: And all of the research around how every type of need just .increases massively in that transition [Crosstalk 00:42:09].	
	PD2: So, what we need to do is pro- is continue to provide the same support that primary school has in the secondary school.	

	R: Yeah.	
	PD2: Then, we won't be talking about all this now, because that's it. (Laughter)	
	R: Okay. So, do you feel like you, you see more children in Year, you know, 4, 5 and 6?	
	PD2: I would say- See, there is classic autism. ___[00:42:31] autism. They are diagnosed within the year three, three, three years, yeah. By three, three-and-a-half.	Classic autism Early diagnosis
	R: The pre-schoolers, yeah.	
	PD2: That's CDC. And then they, they go into special schools or they go into special units or- you know, whatever.	Specialist provision
	R: Yeah.	
	PD2: And then there are- there's this category which are they grey area, who are neurodevelopmental problem, who have got the frontal lobe, you know, problem.	Neurodevelopment
	R: Yeah.	
	PD2: Who has got co- comorbidities together, erm, patchy, patchy difficulties.	Comorbidity
	R: Hmm.	
	PD2: So, those- they str- they thrive in primary school 'til Year 3. They do very well. There's a blip when they go Year 3 and then they again survive, but Year 5, the world becomes difficult and things start falling apart and parents start worrying about secondary school and that's very often when they come.	

	R: Right, okay.	
	PD2: Nine and ten years of age, they come.	
	R: Sure.	
	PD2: And they come because there's lots of difficulties, and a lot of it is learning difficulties.	learning difficulties
	R: Yeah, okay. I think we've kinda talked- we're back to that support going through again. If that's there, that-	
*	PD2: Yeah. I mean, it's all about- it's all about understanding and the support, and then having somebody there to, sort of, answer their questions. I mean, I feel really sorry for them, lots of these parents, because all they need is reassurance. You know, all they need is just somebody to say, "It's okay. Okay, don't worry," or, you know, give a person a hug or whatever, I don't know. (Laughter) You know , and they are, erm, they're- Even today, I just said to them, I said, "You know, your child has got learning difficulties. It's not the end of the world. We just need to support him," and I said, "Learning difficulties doesn't mean that's only at school. It's also at home." You know, he'll- he doesn't learn things quickly, even when he's going for a movie or going to a restaurant, er, or standing in a queue. He said, "Really? I thought it was in school." I said, "No, no. It means, er…" So, they don't understand. They're- and they're really well-researched, these, er, parents. I said, "Learning difficulties means learning difficulties to learn everything, not just Maths and English, but everything." And that's the message they never got.	Awareness understanding learning difficulties
	R: So, I think that makes me feel a bit guilty, 'cause I, I think, like, as a profession, we've really tried to move away from this idea of, like, expert model of practice.	
	PD2: Yeah.	

	R: And I think that's, you know fine. In some ways, you're empowering parents to do that, but if you're missing information, that's pretty dangerous, really.	
	PD2: Yeah. I think, you know, giving parents the- yeah, you know, that, like you say, empowerment, letting them know that, first of all, that everybody doesn't need to confirm to the same.	
	R: Yeah.	
	PD2: That all children will have different learning capacity, and I, I was telling them all very basic things. They said, "Yeah, I see what you mean." I s- I mean, only then did the dad, dad say that he, he had a statement all his life in school. (Laughter) Yeah. I said, "Okay, I understand lots now."	
	R: Yeah.	
	PD2: But you know, erm, so it, it is the expectation. It's expectation as well, I think. Erm, usual things. But in the scheme of things, I think they do get help, children, from school.	
	R: Yeah. So, you've said, erm, you've talked about the, sort of, preschool group and where they're diagnosed in the first three years. Do you think the rate- I mean, in your experience, do you think we're diagnosing more children with classic autism?	Developmental Delay
	PD2: Er… I think we do give autism diagnoses more easily now, even in them. In the- in the past, I think we'd just leave them and say, "Delay," and I think, nowadays- Please don't quote me on this because I don't do that, that big of diag- I don't, I don't do that, at the moment. Er, but I think generally, erm, yeah, we give that diagnosis more easily. Er, in the past, we would say, "Delay," which, which would mean we'd review the situation.	
	R: Hmm.	

	PD2: And that's what we did, and actually, because of that, lots of children just stayed in our- on our lists for life. (Laughter) You know, they never got discharged because they didn't have a diagnosis. R: Okay. PD2: So, that was [Crosstalk 00:47:18]. R: So, it's going, like, kind of, back to that pragmatic use of the diag- diagnosis, isn't it? PD2: Yeah, so diagnosis does make a difference then. R: Yeah. PD2: You know. It has to be a balance. R: Yeah. PD2: It has to be a balance. R: So, if you think to, like, the discussion panels we've had over the last 12 months, what's been-? If you could change one thing about that process, what would you change? PD2: In our discussion panel, the ones you and I- we have? R: Hmm. PD2: I mean, what we would- I	

	would like, er, is, erm, you know, erm… Like we said before, the children that we get, erm, we see and who- and we do the, erm… They come, er, come to us because of behaviour difficulties, usually.	
	R: Hmm.	
	PD2: And we are assessing for neurodevelopmental problems, and they, for example , screen negative for it.	Neurodevelopmental
	R: Yeah.	
	PD2: But they're still having- struggling in school. So, we would like information or support from yourselves to those children in school, because we can't do much about them.	Schools
	R: No.	
	PD2: That's, that's, I think, will be really helpful for us. If I want to change one thing, that would be it. (Laughter)	
	R: Yeah. I think the worry for, for me is how many on those lists aren't known to psychologists.	
	PD2: That's right, and this is what the practice, I think, needs to change in psych- When they tell the parents to go to the doctor, they should also tell the parents- or they themselves should refer to psychologists because they easily say, er, "Go to the doctor." That's because the mother has to do it. Someone [Crosstalk 00:49:27].	
	R: I wonder if there'd be a way of, kind- 'Cause we- The thing we- Because the school- schools pay for our, our service…	
	PD2: That was another things.	

	spectrum as well. And he'll be called autistic and there'll be another child who is non-verbal, erm, and, erm, you know, with- and, and, and having lots of stereotypy. He'll be autistic too. So, one word can mean so different things that that, that it is too broad, and- But then, if I specify it, the autism with this, this, this, that would be more meaningful, and I guess that's what we should do, really. I don't know.	Broader conceptualisation
	R: Do you think it's useful, then, because it- you know, you take those two cases, anxiety and a non-verbal pre-schooler, is it useful because it describes their need, or because it informs the support that they should have?	
	PD2: For me, it describes their need.	description
	R: Okay.	
	PD2: Er, and for anybody else who's using it, that should mean what support they should have. That's why I'm describing their need.	awarss
	R: Okay.	
	PD2: I should- that's my j-job, isn't it? I should tell what is your difficulty or your problem.	Description role
	R: Hmm.	
	PD2: Like, for example, to a diabetic, I should say that you, you, you've got blood- high blood sugar, and this is how much insulin you would take- you should take. And at home, he or his wife or whoever, or the nurse, the district- needs to come and give it, so that his blood sugar goes down and he's fine.	
	R: But then, that's quite discrete difficulty, isn't it ?	
	PD2: Yes. Hmm.	

Appendix 6: Thematic Analysis Process – Generating Initial Codes (Phase 2)

1. Increase in identification	2. Increase in rate of diagnosis	3. Neurodevelopmental Conditions
4. Multi-variate autism	5. Increase in Referral	6. Increased Awareness
7. More recognition	8. Comorbidity of Symptoms	9. Confusion around Increase
10. Parental Understanding	11. Confusion or misunderstanding	12. Early Identification
13. Early Life Diagnosis	14. Pre-school Casework	15. Learning Difficulties
16. Social Interactions	17. Broader Conceptualisation	18. Autism Spectrum Disorder
19. More Symptoms Included	20. Developmental History	21. Diagnostic Criteria
22. Schools Pushing for Diagnosis	23. Schools Providing Info	24. School Perspective
25. School Support	26. Inclusion in Schools	27. Schools Awareness
28. School Challenges	29. Schools Meeting Needs	30. Conflict with Families
31. Parental Involvement	32. Parents Pushing for Diagnosis	33. Parents are Worried
34. Parents Confused	35. Parents Awareness of Autism	36. Taking Responsibility
37. Supporting Needs	38. Families don’t want Diagnosis	39. Seeking Support
40. School Intervention	41. Reduced Support	42. Comorbid Medical Conditions
43. Alternative Formulations	44. Attachment Needs	45. Mental Health Needs
46. Parenting Needs	47. Development over Time	48. Role Limitations
49. Time Limitations	50. Questionnaires	51. Standardised Assessments
52. Professional Power	53. Questioning Diagnosis	54. Diagnostic Substitution
55. Dual Diagnosis	56. Autism Subsuming	57. Needs Focussed Assessment
58. Child Individuality	59. Want EPs Involved	60. Medical Model
61. Empiricism	62. Diagnosis of Exclusion	63. Diagnostic Criteria
64. Hypothesis Testing	65. Formulations	66. Treatment
67. Opinion	68. Observation	69. Involvement
70. Information	71. Assessment	72. Familiarity
73. Best practice Guidelines	74. Blame	75. Agreement

76. EHCP	77. Specialist Provision	78. Deceit
79. Trust	80. Disagreement	81. Personal Experience
82. Teaching	83. Criticism	84. Challenging Behaviour
85. Taking Responsibility	86. Collaborative Work	87. School Familiar
88. Blocks to Progress	89. Expectation	90. Confirmation Bias
91. Describing Needs	92. EP Hesitance	93. Family Functioning
94. Heterogeneity	95. Language	96. Lifelong Condition
97. Children Pathologized	98. Family Intervention	99. Communication
100. Power	101. Anti-labelling	102. Optimism about panel
103. Hoping for more Involvement	104. Professional Influence	105. Anxiety and Worry
106. Families Want Diagnosis	107. Media Representation	108. EP Absence
109. Understanding		

Appendix 7: Thematic Analysis Process: Searching for Themes - Version 1 (Phase 3)

Potential Theme A: Trends in Diagnosis	**Potential Theme B: Collaborative Working During Diagnosis**	**Potential Theme C: Concepts of Autism**
1. Increase in identification 2. Increase in rate of diagnosis 5. Increase in Referral 6. Increased Awareness 7. More recognition 9. Confusion around Increase 22. Schools Pushing for Diagnosis 31. Parental Involvement 32. Parents Pushing for Diagnosis 33. Parents are Worried 34. Parents Confused 10. Parental Understanding 12. Early Identification of needs 13. Early Life Diagnosis 14. Pre-school Casework 17. Broader Conceptualisation 18. Autism Spectrum Disorder 19 More Symptoms Included 28. School Challenges 22. Schools Pushing for Diagnosis 35. Parents awareness of autism 54. Diagnostic Substitution 55. Dual Diagnosis 56. Autism Subsuming 81. Personal Experience 90. Confirmation Bias 97. Children Pathologised 109. Understanding	11. Confusion or misunderstanding 15. Learning Difficulties 16. Social Interactions 20. Developmental History 30. Conflict with Families 43. Alternative Formulations 47. Development over Time 48. Role Limitations 49. Time Limitations 50. Questionnaires 51. Standardised Assessments 52. Professional Power 53. Questioning Diagnosis 57. Needs Focussed Assessment 59. Want EP Involvement 60. Medical Model 64. Hypothesis Testing 65. Formulations 67. Opinion 72. Familiarity 74. Blame 75. Agreement 85. Taking Responsibility 86. Collaborative Work 88. Blocks to Progress 92. EP Hesitance 96. Lifelong Condition 99. Communication 100. Power 101. Anti-labelling 102. Optimism about panel 103. Hoping for more involvement	1. Increase in identification 2. Increase in rate of diagnosis 3. Neurodevelopmental Conditions 4. Multi-variate autism 5. Increase in Referral 6. Increased Awareness 17. Broader Conceptualisation 18. Autism Spectrum Disorder 19. More Symptoms 60. Medical Model 8. Comorbidity of Symptoms 11. Confusion or misunderstanding 12. Early Identification of needs 13. Early Life Diagnosis 16. Social Interactions 19. More Symptoms Included 20. Developmental History 42. Comorbid Medical Conditions 44. Attachment Needs 45. Mental Health Needs 47. Development over Time 67. Diagnosis of Exclusion 94. Heterogeneity 95. Language 96. Lifelong Condition 109. Understanding

	78. Deceit 79. Trust 80. Disagreement 81. Personal Experience 83. Criticism 86. Collaborative Work 89. Expectation 90. Confirmation Bias 106. EP Absence 100. Power 8. Comorbidity of Symptoms 9. Confusion around Increase 10. Parental Understanding 11. Confusion or misunderstanding 12. Early Identification of Needs 13. Early Life Diagnosis 14. Pre-school Casework 18. Autism Spectrum Disorder 20. Developmental History 28. School Challenges 22. Schools Pushing for Diagnosis 23. Schools Providing Info 42. Comorbid Medical Conditions 43. Alternative Formulations 44. Attachment Needs 45. Mental Health Needs 46. Parenting Needs 47. Development over Time 52. Professional Power 62. Diagnosis of Exclusion 73. Best practice Guidelines	

	74. Blame 75. Agreement 80. Disagreement 81. Personal Experience 89. Expectation 90. Confirmation Bias 97. Children Pathologized 99. Communication 109. Understanding	
Potential Theme D: Schools 23. Schools Providing Info 24. School Perspective 25. School Support 26. Inclusion in Schools 27. Schools Awareness 28. School Challenges 29. Schools Meeting Needs 40. School Intervention 41. Reduced Support 15. Learning Difficulties 30. Conflict with Families 16. Social Interactions 72. Familiarity 67. Opinion 85. Taking Responsibility 99. Communication 16. Social Interactions 20. Developmental History 7. More recognition 11. Confusion or misunderstanding 12. Early Identification of needs 13. Early Life Diagnosis 14. Pre-school Casework 20. Developmental History	**Potential Theme E: Families and Parents** 30. Conflict with Families 31. Parental Involvements 32. Parents Pushing for Diagnosis 33. Parents are Worried 34. Parents Confused 35. Parents Awareness of Autism 85. Taking Responsibility 37. Supporting Needs 106. Families want diagnosis 38. Families don’t want diagnosis 39. Seeking Support 10. Parental Understanding 30. Conflict with Families 16. Social Interactions 72. Familiarity 67. Opinion 85. Responsibility 99. Communication 16. Social Interactions 20. Developmental History 7. More recognition 11. Confusion or misunderstanding	**Potential Theme F: Public Profile** 6. Increased Awareness 7. More recognition 107. Media Representation 1. Increase in identification 2. Increase in rate of diagnosis 10. Parental Understanding 11. Confusion or misunderstanding 12. Early Identification of needs 13. Early Life Diagnosis 17. Broader Conceptualisation 18. Autism Spectrum Disorder 28. School Challenges 33. Parents are worried 35. Parents awareness of autism 45. Mental Health Needs 76. EHCP 77. Specialist Provision 81. Personal Experience 89. Expectation 91. Describing Needs 97. Children Pathologized 99. Communication

22. Schools Pushing for Diagnosis 23. Schools Providing Info 37. Supporting Needs 39. Seeking Support 45. Mental Health Needs 46. Parenting Needs 47. Development over Time 77. Specialist Provision 76. EHCP 74. Blame 75. Agreement 78. Deceit 80. Disagreement 81. Personal Experience 82. Teaching 91. Describing Needs 95. Language 97. Children Pathologized 99. Communication 109. Understanding	12. Early Identification of needs 13. Early Life Diagnosis 14. Pre-school Casework 28. School Challenges 22. Schools Pushing for Diagnosis 29. Schools Meeting Needs 41. Reduced Support 44. Attachment Needs 45. Mental Health Needs 46. Parenting Needs 47. Development over Time 76. EHCP 74. Blame 75. Agreement 78. Deceit 80. Disagreement 81. Personal Experience 91. Describing Needs 93. Family Functioning 97. Children Pathologized 99. Communication 109. Understanding	109. Understanding
Potential Theme G: Professional Practice 48. Role Limitations 49. Time Limitations 50. Questionnaires 51. Standardised Assessments 52. Professional Power 53. Questioning Diagnosis 64. Hypothesis Testing 65. Formulations 66. Treatment 67. Opinion 68. Observation 69. Involvement 70. Information	**Potential Theme H: Criteria of Autism** 1. Increase in identification 2. Increase in rate of diagnosis 21. Diagnostic Criteria 5. Increase in Referral 6. Increased Awareness 7. More recognition 9. Confusion around Increase 73. Best practice Guidelines Learning Difficulties 16. Social Interactions	**Potential Theme I: Process of Diagnosis** 61. Empiricism 62. Diagnosis of Exclusion 63. Diagnostic Criteria 68. Observation 69. Involvement 70. Information 71. Assessment 73. Best practice Guidelines 90. Confirmation Bias 91. Describing Needs 94. Heterogeneity 43. Alternative Formulations

71. Assessment 72. Familiarity 60. Medical Model 51. Standardised Assessments 52. Professional Power 53. Questioning Diagnosis 57. Needs Focussed Assessment 59. Want EP Involvement 60. Medical Model 64. Hypothesis Testing 65. Formulations 67. Opinion 72. Familiarity 74. Blame 75. Agreement 85. Taking Responsibility 108. EP Absence 100. Power 101. Anti-labelling 103. Hoping for more involvement 11. Confusion or misunderstanding 12. Early Identification of needs 13. Early Life Diagnosis 14. Pre-school Casework 23. Schools Providing Info 27. Supporting Needs 43. Alternative Formulations 45. Mental Health Needs 46. Parenting Needs 67. Diagnosis of Exclusion 66. Treatment 81. Personal Experience 82. Teaching 90. Confirmation Bias	20. Developmental History 3. Neurodevelopmental Conditions 4. Multi-variate autism 8. Comorbidity of Symptoms 10. Parental Understanding 11. Confusion or misunderstanding 12. Early Identification of needs 13. Early Life Diagnosis 16. Social Interactions 17. Broader Conceptualisation 18. Autism Spectrum Disorder 19. More Symptoms Included 20. Developmental History 42. Comorbid Medical Conditions 44. Attachment Needs 45. Mental Health Needs 47. Development over Time 56. Autism Subsuming 90. Confirmation Bias 91. Describing Needs 94. Heterogeneity 96. Lifelong Condition 109. Understanding	47. Development over Time 88. Blocks to Progress 13. Early Life Diagnosis 15. Learning Difficulties 57. Needs Focussed Assessment 16. Social Interactions 20. Developmental History 3. Neurodevelopmental Conditions 4. Multi-variate autism 7. More recognition 8. Comorbidity of Symptoms 10. Parental Understanding 11. Confusion or misunderstanding 12. Early Identification of needs 13. Early Life Diagnosis 14. Pre-school Casework 15. Learning Difficulties 16. Social Interactions 17. Broader Conceptualisation 18. Autism Spectrum Disorder 19. More Symptoms Included 20. Developmental History 22. Schools Pushing for Diagnosis 23. Schools Providing Info 37. Supporting Needs 41. Reduced Support 42. Comorbid Medical Conditions 43. Alternative Formulations 44. Attachment Needs 45. Mental Health Needs

91. Describing Needs 98. Family Intervention 99.. Communication 109. Understanding		46. Parenting Needs 47. Development over Time 54. Diagnostic Substitution 55. Dual Diagnosis 52. Professional Power 67. Diagnosis of Exclusion 66. Treatment 73. Best practice Guidelines 81. Personal Experience 90. Confirmation Bias 91. Describing Needs 99. Communication 109. Understanding
Time 13. Early Life Diagnosis 47. Development over Time 88. Blocks to Progress 15. Learning Difficulties 71. Assessment 73. Best practice Guidelines 53. Questioning Diagnosis 64. Hypothesis Testing 65. Formulations 68. Observation 3. Neurodevelopmental Conditions 12. Early Identification of needs 14. Pre-school Casework 20. Developmental History 44. Attachment Needs 45. Mental Health Needs 89. Expectation 95. Language 96. Lifelong Condition 97. Children Pathologized		

Appendix 8: Thematic Analysis Process – Reviewing Themes (Phase 4)

Theme 1: Influence of Diagnostic Criteria

Sub Theme:

Categorising Needs

Codes:
Multi-variate autism, Confusion around Increase, Early Identification, Learning Difficulties, Broader, Conceptualisation, Autism Spectrum Disorder, More Symptoms Included, Developmental History, Diagnostic Criteria, Comorbid Medical Conditions Alternative Formulations, Questionnaires, Standardised, Assessments, Medical Model, Empiricism
Formulations, Observation, Assessment, Best practice Guidelines, Describing Needs, Understanding

Sub Theme:

Understanding Bioecological Development

Codes:
Early Life Diagnosis, Development over Time, Blocks to Progress, Learning Difficulties, Questioning Diagnosis, Hypothesis Testing, Formulations, Observation, Neurodevelopmental Conditions, Early Identification of needs, Pre-school Casework, Developmental History, Expectation, Language, Lifelong Condition, Understanding, Time Limitations

Sub Theme:

Awareness of Autism as a Spectrum Disorder

Codes:
Increase in identification, Increase in rate of diagnosis, Neurodevelopmental Conditions, Multi-variate autism, Increase in Referral, Increased Awareness, More recognition, Comorbidity of Symptoms, Confusion around Increase, Confusion or misunderstanding, Early Life Diagnosis, Learning Difficulties, Broader Conceptualisation, Autism Spectrum Disorder, More Symptoms Included, Developmental History
Diagnostic Criteria, Alternative Formulations, Autism Subsuming, Needs Focussed Assessment, Medical Model, Empiricism, Formulations, Observation
Assessment

Theme 1: Perceived Function of an Autism Diagnosis

Sub Theme:

Describing and Understanding and Individual's Needs

Codes:
Neurodevelopmental Conditions, Increased Awareness
More recognition, Confusion around Increase, Parental Understanding, Confusion or misunderstanding, Early Identification, Social Interactions, Broader Conceptualisation, Autism Spectrum Disorder, More Symptoms Included, Developmental History, Diagnostic Criteria, Parents Pushing for Diagnosis, Autism Subsuming, Medical Model, Hypothesis Testing
Opinion, Personal Experience, Criticism, Language, Understanding

Sub Theme:

Accessing Additional Support

Codes:
Increase in identification, Neurodevelopmental, Conditions, Increased Awareness, More recognition, Parental Understanding, Schools Pushing for Diagnosis
School Support, Inclusion in Schools, Parents Pushing for Diagnosis, Parents are Worried, Supporting Needs
Seeking Support, Reduced Support, Parenting Needs
Needs Focussed Assessment, Child Individuality, Treatment, Best practice Guidelines, Family Functioning
Language, Hoping for more Involvement

Sub Theme:

Individual Variability

Codes:
Social Interactions, More Symptoms Included, Developmental History, School Support, Parental Involvement, Parents Confused, Supporting Needs, Seeking Support, Alternative Formulations, Attachment Needs, Mental Health Needs, Parenting Needs
Time Limitations, Standardised Assessments, Child Individuality, Want EPs Involved, Involvement, Familiarity, Best practice Guidelines, Personal Experience, Challenging Behaviour, Describing Needs
Family Functioning, Heterogeneity, Lifelong Condition
Communication, Anti-labelling, Understanding

Theme 3: Understanding Complex Symptom Presentations

Codes:
Increase in identification, Increase in rate of diagnosis, Neurodevelopmental Conditions, Multi-variate autism
Increase in Referral, Increased Awareness, More recognition, Comorbidity of Symptoms, Confusion around Increase, Early Life Diagnosis, Pre-school Casework, Learning Difficulties
Social Interactions, Broader Conceptualisation
Autism Spectrum Disorder, More Symptoms Included
Developmental History, Diagnostic Criteria, Schools Pushing for Diagnosis, School Support, School Challenges, Schools Meeting Needs, Parents Pushing for Diagnosis, Parents Awareness of Autism Comorbid Medical Conditions, Alternative Formulations
Attachment Needs, Mental Health Needs
Development over Time, Diagnostic Substitution
Dual Diagnosis, Child Individuality, Medical Model
Empiricism, Diagnosis of Exclusion, Hypothesis Testing

Sub Theme:

Dual Diagnosis and Diagnostic Substitution

Codes:
Increase in identification, Increase in rate of diagnosis, Neurodevelopmental Conditions, Multi-variate autism
Increase in Referral, Increased Awareness, More recognition, Comorbidity of Symptoms, Confusion around Increase, Early Life Diagnosis, Pre-school Casework, Learning Difficulties
Social Interactions, Broader Conceptualisation
Autism Spectrum Disorder, More Symptoms Included
Developmental History, Diagnostic Criteria, Schools Pushing for Diagnosis, School Support, School Challenges, Schools Meeting Needs, Parents Pushing for Diagnosis, Parents Awareness of Autism Comorbid Medical Conditions, Alternative Formulations
Attachment Needs, Mental Health Needs
Development over Time, Diagnostic Substitution
Dual Diagnosis, Child Individuality, Medical Model
Empiricism, Diagnosis of Exclusion, Hypothesis Testing

Sub Theme:

Attachment and Mental Health Needs

Codes:
Increase in identification, Increase in rate of diagnosis, Neurodevelopmental Conditions, Multi-variate autism
Increase in Referral, Increased Awareness, More recognition, Comorbidity of Symptoms, Confusion around Increase, Early Life Diagnosis, Pre-school Casework, Learning Difficulties Social Interactions, Broader Conceptualisation Autism Spectrum Disorder, More Symptoms Included Developmental History, Diagnostic Criteria, Schools Pushing for Diagnosis, School Support, School Challenges, Schools Meeting Needs, Parents Pushing for Diagnosis, Parents Awareness of Autism Comorbid Medical Conditions, Alternative Formulations
Attachment Needs, Mental Health Needs
Development over Time, Diagnostic Substitution
Dual Diagnosis, Child Individuality, Medical Model
Empiricism, Diagnosis of Exclusion, Hypothesis Testing

Theme 4: Families Understanding of Autism

Sub Theme:

Awareness of Autism

Codes:
Neurodevelopmental Conditions, Confusion or misunderstanding, Broader Conceptualisation
Parental Involvement, Parents Pushing for Diagnosis, Parents are Worried, Parents Confused, Parents Awareness of Autism, Taking Responsibility, Families don't want Diagnosis, Attachment Needs, Parenting Needs, Development over Time, Autism Subsuming, Child Individuality, Opinion, Blame
Personal Experience, Challenging Behaviour, Expectation, Confirmation Bias, Family Functioning
Lifelong Condition, Communication, Professional Influence, Families Want Diagnosis, Media Representation, Understanding

Sub Theme:

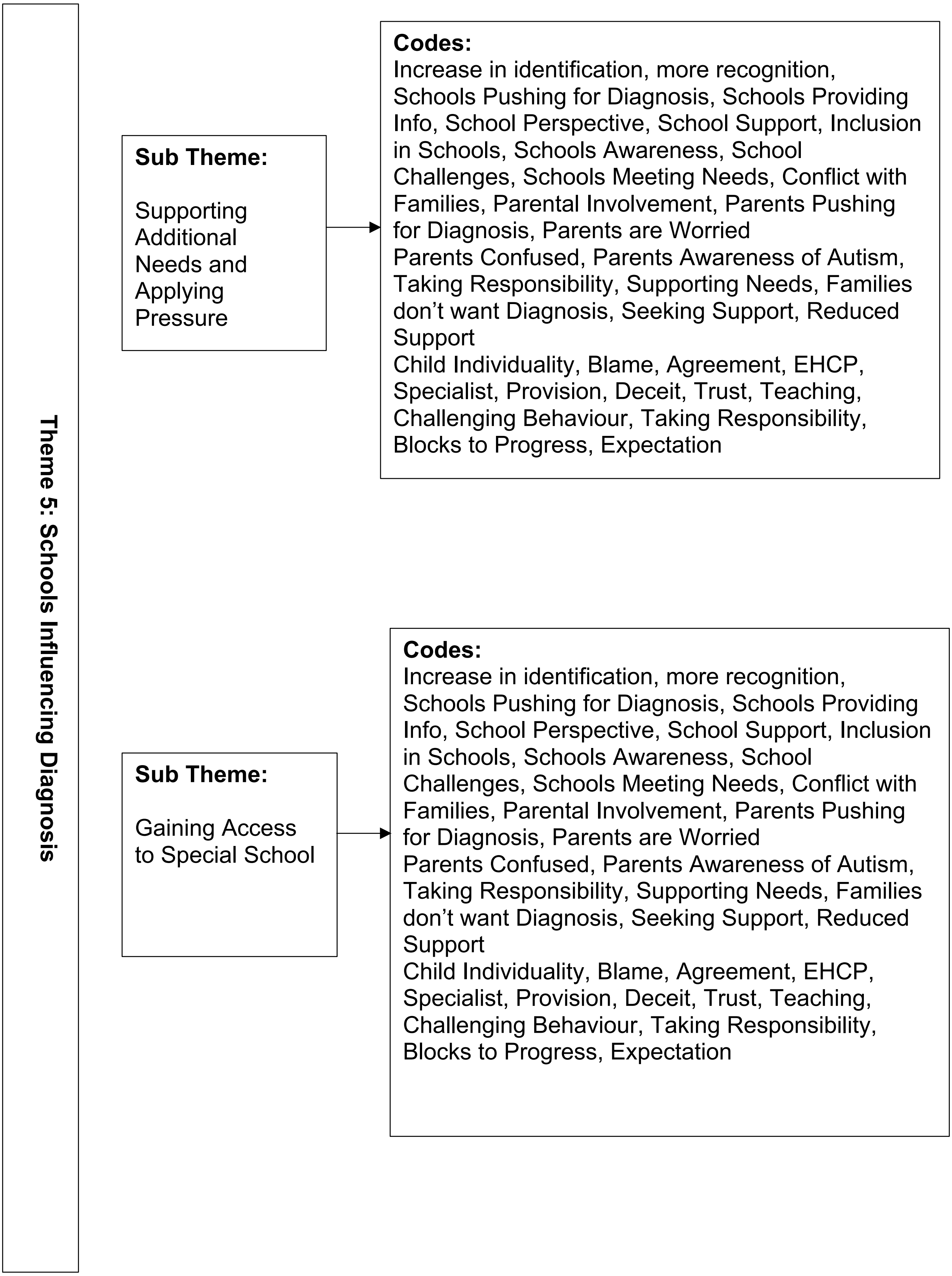
Parental Responsibility to Meet their Child's Needs

Codes:
Neurodevelopmental Conditions, Confusion or misunderstanding, Broader Conceptualisation
Parental Involvement, Parents Pushing for Diagnosis, Parents are Worried, Parents Confused, Parents Awareness of Autism, Taking Responsibility, Families don't want Diagnosis, Attachment Needs, Parenting Needs, Development over Time, Autism Subsuming, Child Individuality, Opinion, Blame
Personal Experience, Challenging Behaviour, Expectation, Confirmation Bias, Family Functioning
Lifelong Condition, Communication, Professional Influence, Families Want Diagnosis, Media Representation, Understanding

Sub Theme:

Seeking Diagnosis to Ask for Help

Codes:
Increase in identification, Neurodevelopmental, Conditions, Increased Awareness, more recognition, Parental Understanding, Schools Pushing for Diagnosis
School Support, Inclusion in Schools, Parents Pushing for Diagnosis, Parents are Worried, Supporting Needs
Seeking Support, Reduced Support, Parenting Needs
Needs Focussed Assessment, Child Individuality, Treatment, Best practice Guidelines, Family Functioning
Language, Hoping for more Involvement



Theme 5: Schools Influencing Diagnosis

Sub Theme:

Supporting Additional Needs and Applying Pressure

Codes:
Increase in identification, more recognition, Schools Pushing for Diagnosis, Schools Providing Info, School Perspective, School Support, Inclusion in Schools, Schools Awareness, School Challenges, Schools Meeting Needs, Conflict with Families, Parental Involvement, Parents Pushing for Diagnosis, Parents are Worried
Parents Confused, Parents Awareness of Autism, Taking Responsibility, Supporting Needs, Families don’t want Diagnosis, Seeking Support, Reduced Support
Child Individuality, Blame, Agreement, EHCP, Specialist, Provision, Deceit, Trust, Teaching, Challenging Behaviour, Taking Responsibility, Blocks to Progress, Expectation

Sub Theme:

Gaining Access to Special School

Codes:
Increase in identification, more recognition, Schools Pushing for Diagnosis, Schools Providing Info, School Perspective, School Support, Inclusion in Schools, Schools Awareness, School Challenges, Schools Meeting Needs, Conflict with Families, Parental Involvement, Parents Pushing for Diagnosis, Parents are Worried
Parents Confused, Parents Awareness of Autism, Taking Responsibility, Supporting Needs, Families don’t want Diagnosis, Seeking Support, Reduced Support
Child Individuality, Blame, Agreement, EHCP, Specialist, Provision, Deceit, Trust, Teaching, Challenging Behaviour, Taking Responsibility, Blocks to Progress, Expectation

Theme 6: The Practice of the Multi-Disciplinary Team

Sub Theme:

Working Together to Unify Criterion Diagnosis and Assessment of Bioecological Needs

Codes:
Neurodevelopmental Conditions, Autism Subsuming, Child Individuality, Want EPs Involved, Medical Model, Empiricism, Diagnosis of Exclusion, Diagnostic Criteria, Hypothesis Testing, Formulations, Opinion, Observation, involvement, Assessment, Familiarity, Best practice Guidelines, Blame, Agreement, Trust, Disagreement, Criticism, Collaborative Work, Expectation, Confirmation Bias, Describing Needs, Power, Anti-labelling, Hoping for more Involvement, EP Absence

Sub Theme:

Experience of Pressure, Power, and a Bioecological Approach

Codes:
Child Individuality, Want EPs Involved, Medical Model, Empiricism, Diagnosis of Exclusion, Diagnostic Criteria, Hypothesis Testing, Formulations, Opinion, Observation, involvement, Assessment, Familiarity, Best practice Guidelines, Blame, Agreement, Trust, Disagreement, Criticism, Collaborative Work, Expectation, Confirmation Bias, Describing Needs, Power, Anti-labelling, Hoping for more Involvement, EP Absence, Broader Conceptualisation, Autism Spectrum Disorder, Developmental History, Diagnostic Criteria
Parents Pushing for Diagnosis, Reduced Support, Development over Time, Role Limitations
Standardised Assessments, Want EPs Involved

Appendix 9: Thematic Analysis Process - Name of Each Theme (Phase 5) and Extracts (Phase 6)

Name of Theme	Select Quotations
1. Influence of Diagnostic Criteria 1.1 Categorising Needs	Paediatricians Views PD2: ‘And also, it needs to fulfil the criteria. I am, I am not being pedantic, but I feel that in- as a medical person, erm, I, I do need that there has to be some criteria that needs to be fulfilled.’ PD3: ‘All I’m answering is whether their child’s needs meet an arbitrary criteria for a diagnosis. What’s the point in putting them in an arbitrary group?’ PD3: ‘Well, my understanding is that the different groups were arbitrarily based on whether they had various classification. Like whether they had speech and language delay, or learning difficulty associated with their, erm, er, difficulties. But actually- Erm, or whether they had all three of the areas of autism or just two, for instance. And I think that there wasn’t a lot of evidence that a different intervention in that group helped. So, for, for one group- If there’s no evidence that this group need this treatment or management, and this group need this treatment and management, then what’s the point in putting them in an arbitrary group?’ EP Views EP2: ‘But it seems to me that, you, children are identified with a sufficient number of traits that would fit with autism. And that if they’re-and if they do then they get the identification, so that - by its very nature of the process of assessment, there doesn’t seem to be a box at the bottom that says “could there be another reason for this? If so what could it be?”’ EP2: ‘There’s not a like a flow diagram that kind of asks those questions as it does along a kind of funnel- and to be honest that’s actually what Paediatricians have said in our discussion, and they acknowledge that there are other potential hypothesis and reasons for a child’s presentation, such as attachment, but they have actually said, but we don’t have a pathway-you know, the only pathway they have for children presenting with social communication difficulties…urrm in terms of assessment and labelling is, autism. They don’t have a pathway for [anything else]…’

1.2 Understanding Bioecological Development	Paediatricians Views PD2: 'Typical [autistic children] who come to your clinic and you know they're autistic . But it's, it's a bit, bit difficult to give that diagnosis of autism the day you see them.' PD2: 'I would say- See, there is classic autism. autism. They are diagnosed within the year three, three, three years, yeah. By three, three- and-a-half. That's CDC. And then they, they go into special schools or they go into special units or- you know, whatever.' PD1: 'I think a little bit, in our clinics at least because… errm they will get seen if they are referred because new patients have to be seen, so we've got a time scale about seeing the new ones… in the past if they had a CDC assessment, and they've had a diagnosis, so we're talking for pre-schoolers, if they had a diagnosis of autism…ermm then they would be discharged unless there were other medical needs… we aim to try and discharge them after we've seen them, after we've given the diagnosis…we don't always succeed because they have…problems often relating to sleep, sleep is one of the biggest reasons why we see children for follow up.' EP Views EP1: 'I…don't agree with that. I think we should just let, you know with the right support, let children develop, with the right support, the right type of…interventions based on, on their presentations…lets you know…wait and see." EP3: 'You know, we are giving diagnosis that is possibly going to stay with that child for their life. Their whole life. And, you know, it, it's got to be given very, very carefully and if you're not sure, what I would like to see, and I think there's a bit of resistance to this, is delaying a diagnosis.' EP2: 'Whereas I'm, so then I'm thinking autism, so I guess what I'm saying is autism is social communication difficulties, where there are no interactive type factors or experiences that the child may have had that could explain that, therefore it might be, because we can't identify that, then we would have to assume that it must be.. environmental, possibly broader, type needs.'

1.3 Awareness of Autism as Spectrum Disorder	<u>Paediatricians Views</u> PD2: ‘Erm, the criteria have now changed in the sense that they’ve included more things in the diagnostic criteria. Now you can call many people autistic because of that.’ PD2: ‘I think one is that, er, the diagnostic criteria have changed, within, er, we-we diagnose autism within a medical model. And, er, there are specific diagnostic criteria, and ,erm, also, I think we call a lot of things that are not quite, autism, autism. Because it looks to me, that this diagnosis has some kind of value or something for the families and patients.’ PD3: ‘Most people I think now have an awareness that it’s a spectrum, and at some point there’s a cut-off where you get diagnosis. And you can be just under the, that cut-off and still have difficulties.’ <u>EP Views</u> EP3: ‘I think sometimes the spectrum seems too broad.’ EP2: ‘the conceptualisation of it has altered, or didn’t exist. But I think that’s *definitely* one of the reasons that we’ve seen the huge rise.’ EP3: ‘You know, I think if a psychologist, or a paediatrician, you know, they would probably all agree that a classically autistic child is autistic. It’s the children who are on the broader spectrum. Where I think there’s more contention about, is it, isn’t it, and why do we need that diagnosis? EP1: ‘I think the label can be helpful to some, because they know that autism is this combination of…difficulties.’ EP2: ‘So it’s an immediate cue into, “this child has difficulties, probably in these kind of areas. Ok, I’m going to be aware of that”. If that’s all it was it would be fine, but I think it’s got caught up in a much wider *fuzzy* thinking, circular logic around it.’

2. Perceived Function of an Autism Diagnosis 2.1 Describing and Understanding an Individual's Needs	<u>Paediatricians Views</u> PD2: 'We still call it autism because there isn't any specific name, or the names aren't good enough. For example, learning difficulties. It's good enough for me but it's not good enough – I mean good enough in inverted commas, for the parents.' PD2: 'We are not good in actually pointing out the, the difficulties within autism that the individual child has. Autism is so broad now, so we don't tell you- For example, a child who has got anxiety disorder. Anxiety and, say, sensory need .Yeah, which would be within the autistic spectrum as well. And he'll be called autistic, and there'll be another child who is non-verbal, erm, and, erm, you know, with- and, and, and having lots of stereotypical behaviour. He'll be autistic too. So, one word can mean so different things that that, that it is too broad, and- But then, if I specify it, the autism with this, this, this - that would be more meaningful, and I guess that's what we should do, really. I don't know.' PD3: 'Many of the children that now have a diagnosis of ASD, who would have previously had a diagnosis of sematic-pragmatic, but no one would have really understood what that meant.' PD3: 'Some families want a diagnostic label to feel that they understand their child. But I try to point out to them that they already understand their child's needs.' <u>EP Views</u> EP2: 'So I suppose yeah, it's about what are their needs? And that's where you go back to looking at them as an individual, where are they? What do they need in *all* areas of their development?' EP2: 'You've got a whole group of children within that who have ended up with a diagnosis that's not necessarily reflective of their complete need or an understanding of their needs, getting interventions that aren't necessarily very relevant.' EP2: 'we don't want to know about labels we're looking at the Diagnosis whole child, as an individual.'

	EP3: 'I think it often is. Because the understanding around the individual child's needs is there anyway. So, you know, you can understand the child's presenting needs whether or not they've got a diagnosis.'
2.2 Accessing Additional Support	Paediatricians Views PD3: 'I think it's a shame that children have to have a diagnosis in order to access additional support. I think there are…a certain amount of support should, be, be, able to be put in, if a child has a difficulty without a diagnosis, but I think, in reality, they need- most, most people, because of resources being limited, want a child to have a diagnosis before they'll give them a certain amount of support.' PD3: 'But, you know, so some support needs a diagnosis, because you have to have a lid on who can access it because it isn't an unlimited resource. So, they have to priorities that resource. So, say, for instance, the Communication and Autism Team, they have to limit their resource because they're only funded to do a certain number of hours, and they're limiting that to those in most need. And you could argue that generally across the city, those in most need are the ones with the m-more difficulties. They're more likely to be the ones with the diagnosis. But I wish there was enough resource that if somebody had difficulty in one area, they could just have help for that one area.' EP Views EP1: 'That was what the disagreement was. "But, but they need support! How are they going to get support?" I said, "well they do go to a ummm school have a notional SEN budget of up to six thousand"-and, and having to explain that over and over.' EP3: 'There's sort of this huge pressure. You know, for a diagnosis. Because the children do enter school with significant needs and as school support I think has

	become less, less available, it throws up those needs even more.’
3. Understanding Complex Symptom Presentations 3.1 Individual Variability	<u>Paediatricians Views</u> PD2: ‘Lots of things. I do think that is, to some extent, is the- is true. There are lots of things which are, erm, autism which are probably allied, sort of, a newer development of things. But not quite autism. That doesn’t fit the category- criteria that we go by. We still call it autism because there isn’t any specific name, or the names are not good enough. For example, learning difficulties is a good name for me, but it’s not a good mmm diagnostic name.’ PD2: ‘there are- there’s this category which are they grey area, who are neurodevelopmental problem, who have got the frontal lobe, you know, problem. Who has got co-comorbidities together, erm, patchy, patchy difficulties.’ PD3: ‘No. Erm, I’d probably be talking about ICD-10 or DSM-5 criteria for a diagnosis, yeah… But ultimately, we use the ICD-10 or DSM-5.’ <u>EP Views</u> EP1: ‘Yeah, yeah. Absolutely, and I like that uncertainty! Because, it gives you more sort of scope for…when you’re sorting giving advice and support and recommendations…well actually I don’t even go according to, if it’s autism, yeah I have to know it is autism, the only thing that might change in regards to SEMH is…is perhaps we’re still going to work on emotional regulation, we’re still going to work on developing social interaction or social communication skills…urm but maybe the way it’s going to be done is slightly different. Maybe.’

3.2 Dual Diagnosis and Diagnostic Substitution	Paediatrician Views PD2: learning difficulties which is a known factor because of chromosomal problems. You know, that’s how the child is made. Now, learning difficulties will have a lot of features which will be autistic or within the autism spectrum, which we knew for ages, for years, hundreds of years. But now, those features, which are autistic features, are separately identified as autism, which we never used to do in the past. We would just say, “This child’s got Down’s Syndrome,” and that would include learning difficulties, autism, hearing problems and lots of other things, which is the Syndrome’s, you know, things. But now, it has to be Down’s Syndrome, autism, and short stature, or something, which is, like, Do- It’s a part of Down’s Syndrome, that is, you know. So, so what I’m saying is, lots of things, erm, are, sort of, erm, erm, broken down now, and that autism bit, which is a part of many conditions er, is taken out, and therefore they’re named autism.’ PD1: ‘ummmm, because nobody….a lot of children who in the past would have had that diagnosis of intellectual disability, now will have additional diagnosis of autism and intellectual disability, which is perhaps a good thing, that that there is that identification, it’s not just a global identification of disability they do have…errm factors that are more specific as well that are related to autism.’ EP Views EP2: ‘And even in the children where the diagnosis is right, I think it’s becomes the only thing that’s become focussed on for that’s child’s difficulties, it’s become kind of the predominant and dominating view of that child. So even in some cases-well loads of cases where I feel that’s the case, not where I think the diagnosis is wrong. Now everything is being perceived through the lens of autism urrm and actually there are other things going on for this child and the interventions are all being-so we go back to that idea of interventions and it’s a shortcut for interventions but then I think some of the interventions are really blunt instruments.’ EP2: ‘I think we are missing, kids with general learning difficulties, urrm, I had one in a school the other day where parents were pushing for an autism diagnosis, fits lots of boxes for and autism diagnosis, when talking to

	the SENCO, mum describing all the social difficulties that he had, and talking to the SENCO actually his social development is in line with his general development.' EP1: 'If they've got social emotional difficulties, it's autism, if it's speech and language, it's autism, if it's urrm emotional difficulties it's autism, so the only way autism isn't there is if it's PMLD or – even severe learning difficulties it's autism.'
3.3 Attachment and Mental Health Needs	<u>Paediatricians Views</u> PD1: 'Yes…yes we do, do have…situations there…attachment's a difficult one if there is a history of reasons for having an attachment disorder then…Then yes, we definitely would be considering that, and thinking about how strong is the attachment and how much is it autism, umm there's so much overlap, so I'm probably, not probably, we're not the best people to make distinction because we're not psychol-clinical psychologists. umm…but we don't have access to clinical psychologists to do this so we have to do the best that we can with the tools we have.' PD2: 'No. Mental health? No. I'm not trying to do that at all. Attachment? Because I do, er, looked-after children for many years as well, so that is very, very top of my thought process. Not- I don't think everybody has that, because they don't do that work. I do always look at that, and I look at Mum's alcohol consumption, Mum's drug consumption, or whatever, you know, pre, pre, pre-natal problems. Those are the things doctors need to look at, because I know psychologists are not, not, not going to look at that. I do look at all of that, because that's what I've been trained to do for a long time, but I often don't know what to do.' <u>EP Views</u> EP2: 'I don't know if everybody seems to know, everybody talks about the fact that attachment and autism present so similarly and it's very hard to tell, tell them apart and yet we see, time and time again, children with traumatic backgrounds, attachment difficulties, that's been noted, so that's why I say it's not like it's being missed, it's not like nobody knew that information, it's being noted but it's almost disregarded because the- the sufficient box is ticked that fits with the label, so

	that's one of the big ones I think we are, are not missing, we're aware of but carrying on regardless.' EP2: 'I think things are definitely being missed-or maybe not missed, missed is probably the wrong word, but they're being noted but they're not being given sufficient weight in considering, the…complete needs of that child, urrm, and I think that those things would include, well the big one is the attachment-I would-well broader than attachment, you know, the trauma and the emotional needs and all those sorts of things, and it's incredible.' EP3: 'Yes, definitely. I think, I think there are those children with real attachment difficulties. Erm, because their presentation can be similar, can't it? You know, there can be an absence of wanting to, kind of, interact as sort of a closed presentation.'
4. Families Understanding of Autism Diagnosis 4.1 Awareness of Autism	<u>Paediatricians Views</u> PD1: 'There is a lot more urrm …recognition of these difficulties at a much younger age, from everyone, parents, professionals.' PD2: 'Yeah, I think so. I think more, erm- I think there's more awareness of autism in, in-By GPs, by other health professionals and by parents.' PD3: 'I don't think they necessarily always came with that question. They came with the problems Rather than now, they kind of come with a, "I think my child's got autism." So, they're more aware.' <u>EP Views</u> EP1: 'Autism is no longer "oh what's that?"' EP2 'it was kind of something I'd vaguely heard about from rain man, have you heard of rain man?' EP3: 'I think parents can look on the internet. They can Google it. They can find information.' EP1: I've seen a TV show, that shown some, quite, you know autistic people, quite severe autism, and I mean they're people who look very difficult and challenging, and sometimes the behaviours that they present with are quite

	incomprehensible, you know you can't understand them, you can't make sense of them, so I think people find autism quite complex concept to get their heads around , so complex that…I think there is a belief that it's not, it's not easily, dealt with or addressed or supported in school.
4.2 Parental Role and Responsibility to Meet their Child's Needs	<ins>Paediatricians Views</ins> PD3: 'I think there's probably less stigma attached to having a disability, or having a, err, a diagnosis, and- So, that probably helps. I think nobody wants to feel like a bad parent. So, when their child's playing up or pushing children and things, that nobody wants to be labelled as a bad parent. So, for parents, I think some parents feel that the diagnosis helps them to understand why their child's difficult. Without necessarily feeling the blame of it mmmm being due to something they've done.' PD3: 'Some of them- Some families want a diagnostic label for them, for them to feel that they understand their child. But I try to point out to them that they already understand their child's needs. All I'm answering is whether their child's needs meet an arbitrary criteria for a diagnosis.' <ins>EP Views</ins> EP1: 'It's, because, particularly in cases where I don't feel that it's autism…where I have a strong suspicion that the presentation that I'm observing or I'm hearing about could be down to urmm, interruptions in development, cause by early childhood experiences trauma attachment…urmm, because, parents don't want to hear that because the diagnosis urmm, it' kind of means that they're not culpable it's not their fault, a diagnosis means that this is in my child and it wasn't anything to do with me, so to say that you know actually it's something that's more environmental that doesn't, doesn't always go down well.'
4.3 Seeking Diagnosis to Ask for Help	<ins>Paediatricians Views</ins>

	PD1: ‘Definitely urrm one of the reasons for ri-rise is because there is a lot more urrm …recognition of these difficulties at a much younger age, from everyone, parents, professionals…urrrm…. that’s definitely lead a to an increase in the referral rate.’ PD2: ‘Because it looks, to me, that this diagnosis, diagnosis has some kind of value or, or s-something for the families and patient …to achieve some of their goals. You know, sometimes, they would seek a diagnosis of this kind, whereas that wouldn’t be our first diagnosis, and then, erm, it would be- And I don’t know the reason. I mean, the reason is something completely beyond us. But it is something that they are after, for reasons which are not medical.’ PD2: ‘I guess from school. I mean, they don’t want their children- They want, they want the children to get the help they think they need, and the only way – that’s what they tell us – the only way they feel they get the help they need is if they have this diagnosis. And if they have this diagnosis, they perceive that lots of help will be given to the child.’ PD2: ‘And, er, they feel- And I said, look, “He will get help because he does need help, but it’s not because he’s autistic. It’s because he needs help. He will get help.” So, there’s… they’re, they’re not given, er, the diagnosis, whatever, but, you know, it’s, it’s just, erm- And they’re desperate parents. They, they don’t- They want the best for their ch- kids. It’s just, erm, the way the structure is, er, of, erm , I don’t know, our, our diagnos- diagnosis, our education, our funding, our- or whatever.’ <u>EP Views</u> EP2: ‘I think that happens as well when parents get the diagnosis , I think lots of parent seek the diagnosis because they think it will be something that it’s not, well, and you hear that quite a lot from parents, particularly after they’ve got the diagnosis and that they’re then, discharged. or doesn't mean treatment. It’s not, you know, it raised the question to me about why it’s seen as a medical diagnosis at all, why-what-you go down processes of being diagnosed by medics and then being discharged because there is no treatment for your diagnosis.’

5. Schools Influencing Diagnosis 5.1 Supporting Additional Needs and Applying Pressure	Paediatricians Views PD2: ‘They get the push from somewhere else. I guess from school. I mean, they don’t want their children- They want, they want the children to get the help they think they need, and the only way – that’s what they tell us – the only way they feel they get the help they need is if they have this diagnosis.’ PD3: Yeah, and ones that are potentially excluded from schools, or parents have withdrawn them from schools because they’re not happy with the support. PD1: ‘The reason that most of them give us is they say that schools will not help them unless they have a diagnosis. That is what we are told more or less by every single person laughing by every single parent. So that’s where we start to explain “no we’ve spoken diretly” this is not the case but, I don’t know if there’s something in the middle there where the schools are not giving them the information or the right message isn’t getting across to parent’s, there’s something-some break down there, between you and us. EP Views EP1: ‘Because sometimes they just want the child out and if I’m saying actually there are things you can do, but we haven’t got the resources and they just want the diagnosis and just move them on.’ EP3: **‘**So, it may just be that, that for many of these children that their needs can be met. They don’t need to come to the attention of an EP, do they, if their needs are being met in school but someone obviously somewhere has raised them as needing the diagnosis.’
5.2 Gaining Access to Special School	Paediatricians Views PD2: ‘See, there is classic autism. They are diagnosed within the year three, three, three years, yeah. By three, three- and-a-half. That’s CDC. And then they, they go into special schools or they go into special units or- you know, whatever.’ PD2: ‘They do [support children with autism]. Some schools do, and special schools certainly do.’

	<u>EP Views</u> EP3: ‘Well, so one of the points is, if you- If the child is going to move on from mainstream to access certain types of provision, they need a, the diagnosis for certain- You know, if you want them to have an autism-specific setting then obviously they will need the diagnosis. And that, that’s one of the factors I think. Erm, I, I think it, it- In a lot- Now- At the moment, now, not so much in the past, it will unlock resources of the communication and autism team.’ EP3: ‘There’s sort of this huge pressure. You know, for a diagnosis. Because the children do enter school with significant needs and as school support I think has become less, less available, it throws up those needs even more. EP1: “I think it is, yeah. If there is-if this isn’t autism we’ve got to take responsibility, first of all we’ve got accept there are things that we might not have done, correctly. And for school staff that means we should be doing that, which could require, you know, quite heavy resource allocation…urrrm…and time. Whereas autism this is never going to be fixed there’s special schools for children like these let’s get rid.” EP1: ‘Yeah there are some quirky kids here, but do you know what, to me, apart from the quirkiness, they’re just like any other child, that you know, that I see mainstream school, they have the same range of emotions, I see them crying, I see them laughing, I see them having a bit of a joke with the teacher. I don’t see any specialist approaches being used…I don’t see what’s specialist about the provision.’

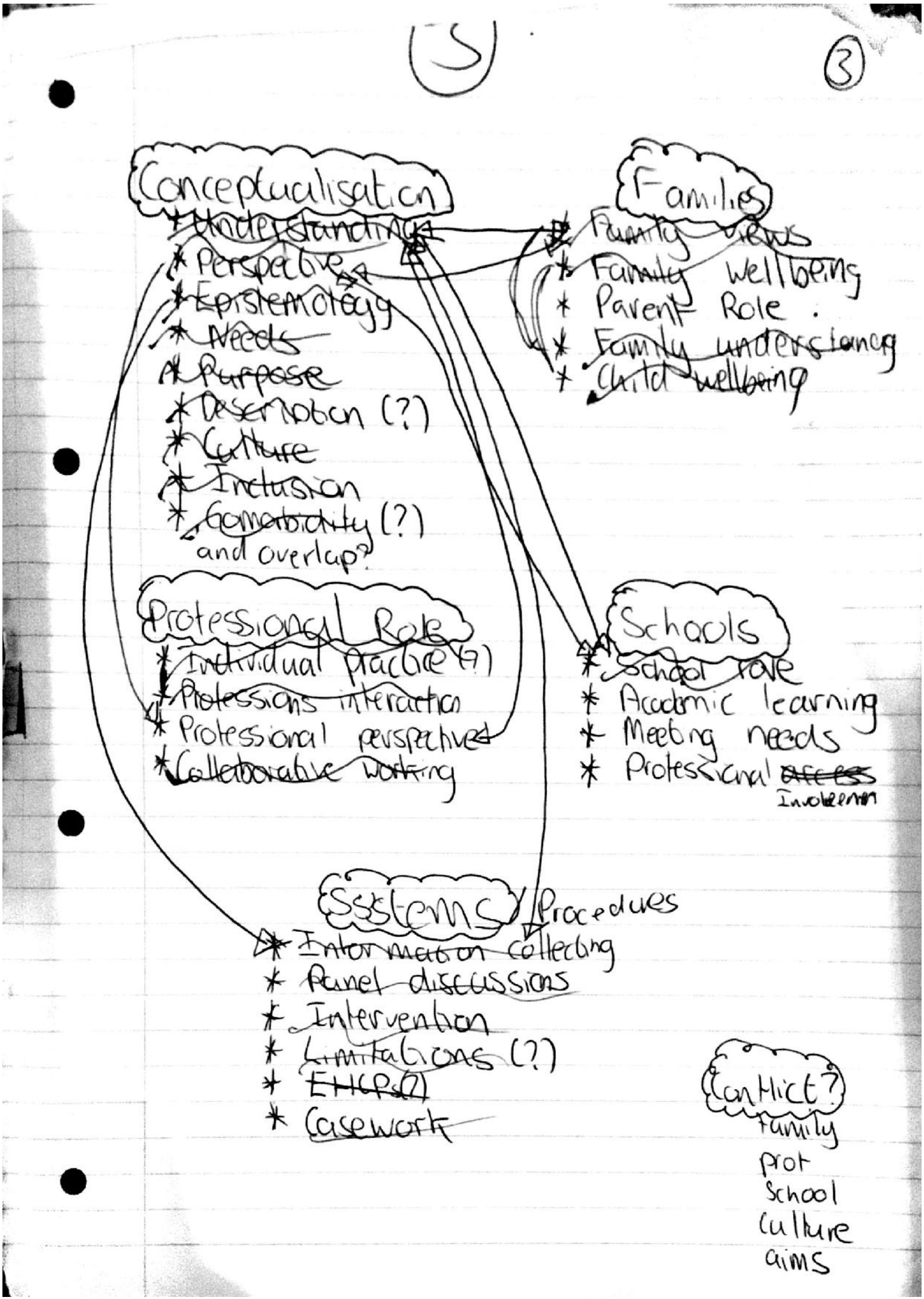
6. The Practice of the Multi-Disciplinary Team 6.1 Working Together to Unify Criterion Diagnosis and Assessment of Bioecological Needs	Paediatricians Views PD2: 'I'm inadequate to give a diagnosis, because I don't know the child's functioning as much at all. But I have to give a diagnosis, just because I'm called the doctor, but I'm not in a position to do that, because I don't know enough. So, a psychologist has that power to find out if the child has got some problems at home, if it's a temporary thing, it's got a new sibling or twins are born to a single mum, and this is the five-year-old, or things like that. And then, inform the teacher. You know, "No, this is not because the child is bad or deviant. It's because of this and do this about it." You know, after a period of time. Because we want instant things. They come here to my clinic and they want a diagnosis when they're going out, but it's a developmental problem. It's a time thing, you need time, and I explain to people, and they think I'm fobbing them off.' PD3: 'When we got really good information saw, you know, descriptions of peer interaction or lack of peer interaction during school observations. And, or lack of, you know, facial expression and gesture during lessons, and things like that. And the schools, especially for schools that have said that they can't see any difficulties, that's really useful. Observational experience from an experienced professional. So that's really helpful. And I think sometimes when someone says, "Actually, there's loads more going on than you know. Like in the school, in the family," just having another professional that's seen that family and that child from a different angle that we wouldn't. Like, we've had people saying, "Actually, the school's one of the issues," and they're all like that at the moment, because there's so much upheaval in the school. And actually, just knowing that background information's really, really helpful, but you wouldn't normally get that.' EP View EP3: One of our roles is to make sure that everything has been considered, including what we know of the child's background. we have arrived with this type of much more broader view. A broader perspective and making sure we're looking at that child across those different-

	EP3: Yeah, if there is an alternative view, we should be giving it. We should be making sure that the evidence is broad. EP2: And that if they'yre-and if they do then they get the identification, so that by it's very nature of the process of assessment, there doesn't seem to be a box at the bottom that says "could there be another reason for this? If so what could it be?" that's actually what paediatricians have said in our discussion and they acknowledge that there are other potential hypothesis and reasons for a childs presentation , such as attachment, but they have actually said, but we don't have a pathyway-you know, the only pathway they have for children presenting with social communication difficultites…urrm interms of assessment and labelling is, autism. EP3: 'I'm happy for that to be collated across a range of environments and from different people. In fact, I think that's how it should be done.you should be looking for those, those examples where, "Well, actually, is that the right diagnosis?" Because that's how important it is. But how often do we actually test that out with children, do we test out the hypothesis? What are we looking for that would say to us, "Actually, you know, no. This child does have difficulties, but it may not be autism."' EP3: really, the child should be presenting with needs across different environments. That's part of the diagnosis, isn't it? Not just in the family home, for example. EP2: I'm saying autism is, is possibly, social communication diffilcities-where there- where we cannot identify any other environmental reasons for having those social communication diffilcites. But it seems to me that, you, children are identified with a sufficient number of traits that would fit with autism. EP1: That what I would, that's what I thought we were doing when we did these groups, we were ginving them contra- indications…Well another perspective then. Yeah, itcould be another perspective. Urrm with this information do you still think it's autism?

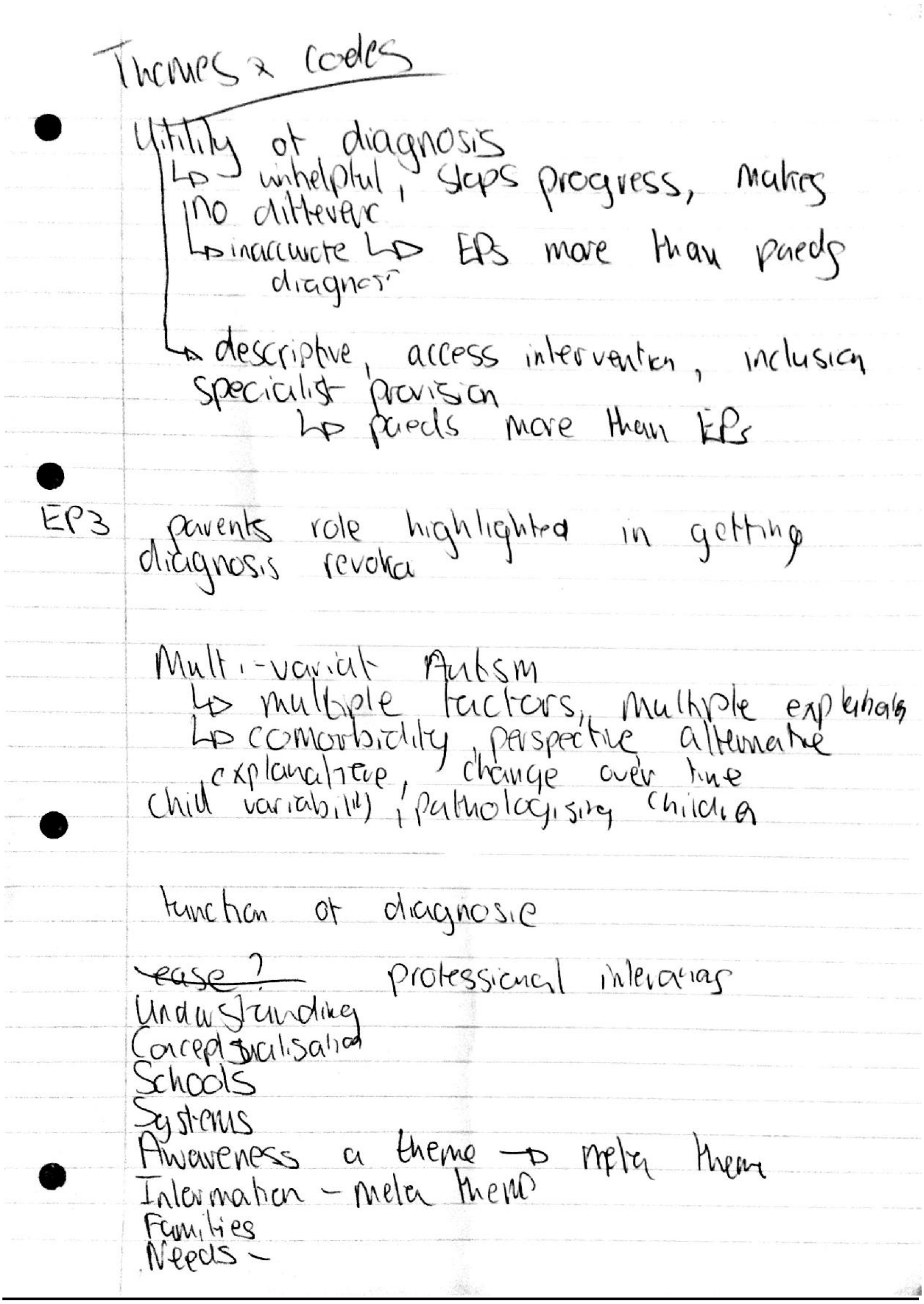
6.2 Experience of Professional Pressure, Power, and Withheld Invovlement	Paediatricians Views PD3: ‘So, I think we do the best we can, given that we’re doing it on our own, but I don’t think that we should be doing it on our own.’ PD3: ‘I mean, without funding for MDT, you’re left doing it on your own. So I think given the situation that we were in, which was that we were left doing it on our own, we’ve trained ourselves to do the most reliable assessment as possible in that we- So, we use 3Dis and ADOSs. Some children will get both if needed. So, we, we are using the best assessments out there. Well, you know, the, the most reasonable assessments for the time and constraints.’ PD2: ‘I’m inadequate to give a diagnosis, because I don’t know the child’s functioning as much at all. But I have to give a diagnosis, just because I’m called the doctor, but I’m not in a position to do that, because I don’t know enough. So, a psychologist has that power to find out if the child has got some problems at home. PD1: No, I’m not [satisfied with the way we diagnose autism] because autism diagnosis should be multidisciplinary, should be, er- It used to be a diagnosis of excluse- exclusion. And it needs to be- And also, it needs to fulfil the criteria. I am, I am not being pedantic, but I feel that in- as a medical person, erm, I, I do need

	that there has to be some criteria that needs to be fulfilled <u>EP Views</u> EP2: ‘and just in fact really quickly from the panel was set up, we-we quickly found that there was lots of common ground in the middle and they-they were asking lots of the same questions we were, and struggling with, a lot of the same things that we were, and we talked-initially it felt like “oh what a relief, we all think the same thing, we’re all”- but that same thing was, “goodness, what are we going to do about all these autism diagnoses and pressure from parents?” we were all on board with that.’ EP1: ‘Those regular meetings with panel have stopped that. They very much stick with what they know and what they do best which is diagnosis, but also alerting them to that that urrm our urrm inaccurate diagnosis just because parents are pushing for it… might help get them of you back , but it doesn’t help our cause.’ EP3: I think there’s so much pressure for children to be diagnosed at a very, very early stage.

Appendix 10: Thematic Analysis Process - Draft Thematic Map



Appendix 11: Example of Research Diary Notes



Themes & codes

Utility of diagnosis
↳ unhelpful, stops progress, makes no difference
↳ inaccurate ↳ EPs more than paeds
diagnosis
↳ descriptive, access intervention, inclusion
specialist provision
↳ paeds more than EPs

EP3 parents role highlighted in getting
diagnosis revoked

Multi-variant Autism
↳ multiple factors, multiple explanations
↳ comorbidity, perspective alternative
explanations, change over time
child variability, pathologising children

function of diagnosis

~~ease?~~ professional interactions
Understanding
Conceptualisation
Schools
Systems
Awareness a theme → meta theme
Information – meta theme
Families
Needs –