

**“Searching for an answer to make it all better”. A grounded theory study exploring parental drive for diagnosis; is it really autism, or a misinterpretation of behaviour?**

An exploratory grounded theory of the views of Educational Psychologists (EPs) investigating what underpins parental concerns about their children having autism, in cases where assessment by Educational Psychologists using the Autism Diagnostic Observation Schedule (ADOS) indicates that autism is not present.

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## Abstract

The number of children being referred for an autism assessment is increasing significantly (Ballaro & Griswold, 2019). However, many children referred for assessment are not receiving a diagnosis (Monteiro et al. 2015). This is creating an extra burden on services which are already pressured, leading to increased waiting times for all. In light of scarce research into the reasons why parents think that their child's behaviour is attributable to autism, this explanatory and exploratory study answers the research question:

*“What are Educational Psychologists’ views on the contexts and mechanisms that lead to parents thinking their child has autism, in cases when their child does not receive a diagnosis based on results of the ADOS?”*

Using qualitative methodology and a semi-structured interview design, data from interviews with six Educational Psychologists (EPs) working in a local authority was analysed, utilising critical realist grounded theory (Corbin and Strauss, 2008). The grounded theory developed from the data suggests that parents think their child's behaviour is symptomatic of autism due to an unconscious psychological response against ideas, that they may in some way be responsible for their child's challenging behaviour. This unconscious psychological response is sustained through confirmation bias, enabling the parent to regard their child's difficulties as attributable to organic rather than contextual factors. Challenges which go beyond what parents feel able to cope with combined with parental anxiety; can result in thoughts about alternative explanations to autism being intolerable and therefore avoided. This grounded theory suggests a number of environmental contextual factors which contribute to these unconscious mechanisms taking place, including: the impact of technology, effects on parenting within societal change, adverse Childhood Experiences (ACEs), and socio-economic factors. Implications for EPs are explored in the discussion.

# 1 Introduction

## 1.1 Chapter overview

This chapter will provide a background to the current study, including an outline of autism together with its prevalence. The autism diagnostic pathway will then be described before considering the role of the Educational Psychologist (EP) within the local context in which the research has taken place. Following this, the rationale and aims for the study will be provided together with the research question.

## 1.2 Background

This research involves an exploration of EP's views as to what underpins parental concerns about their children having autism in cases where EP assessment using the Autism Diagnostic Observation Schedule (ADOS) indicates that autism is not present.

The author was originally an assistant EP in the Local Authority (LA) in which the current research has taken place. Whilst in this position, the author accompanied and observed senior colleagues who carried out ADOS assessments, before collaboratively scoring the assessment and writing up the subsequent report for the paediatrician. In addition, the author also attended paediatrician led Multi-Disciplinary Team meetings (MDT), where allocation of the ADOS cases took place.

During this time, in all but one of the eleven assessments, although reports and observations often indicated behavioural difficulties, the child did not meet the ADOS criteria for an autism diagnosis. For these cases, the senior EP felt confident the child did not present as being symptomatic of autism, yet during the parental interview element of the assessment, the



parents would often appear very sure that their child did have this developmental condition. Subsequent conversations with colleagues aroused the authors' curiosity as to the contexts and mechanisms that influence parents to think this way. Moreover, during the authors' experiences within this diagnostic process, professionals were sometimes heard to talk pejoratively about parents and during discussions, some EPs mentioned that at times parents are blamed by some professionals for their child's behaviour. Therefore the author wanted to carry out a study from the parents' perspective, in an attempt to look with a compassionate non-judgemental view and create understanding.

Originally the term 'misread' was used in the study to explain how parents' view their child's behaviour as being symptomatic of autism. However it became apparent that this could be interpreted as pejorative and therefore this term was changed to 'think that'.

### **1.3 Autism Spectrum Condition**

Autism Spectrum Condition (ASC) has been historically re-conceptualised from an original distinct entity, to now being considered as multi-dimensional (Frith, 2020), something which Wing (2005) argues is considerably more appropriate. Gulati et al. (2019) describe a current conceptualisation of autism as being a neurodevelopmental condition characterised by difficulties with social communication and social interaction, in addition to behaviours which are restricted and repetitive. This can often include difficulties with maintenance of eye contact, understanding and expressing emotions, difficulties with the use of gestures, understanding social cues and the facial expressions of others. Some may also display behaviours such as hand-flapping, a desire for rigid routines, obsessional interests and heightened sensory experiences (Ballaro & Griswold 2019).

Wing published a paper in 1981 (cited in Wing, 2005) introducing Asperger's syndrome as a behavioural pattern, suggesting it should be encompassed within the autistic spectrum. Wing (2005) described how many people with the syndrome found this label to be beneficial, as it helped them and others understand the difficulties they face in the social world. Additionally, it enabled appreciation of their special skills and helped more able people accept a diagnosis which was distinct from the autism label and the associated negative connotations.

The release of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) brought significant changes to the autism criteria including the change to one broad diagnosis, encompassing autism subgroups including Asperger's syndrome (Kulage, Smaldone & Cohn 2014). The DSM-5 has been found to have excellent criteria specificity for autism (Frazier et al. 2012), yet Mazefsky, McPartland, Gastgeb & Minshew (2013) discuss concerns about changes to the criteria being too restrictive. They argue that as many as 60% of those who previously received an autism diagnosis under the DSM-IV criteria, would no longer satisfy the updated criteria. Despite this, the worldwide prevalence of autism is increasing (Kulage, Smaldone & Cohn 2014).

However, there is not a universal acceptance of the medical model utilised within the DSM-5 and the deficit-based assumptions on which it has been built has been widely critiqued (Pickersgill, 2014). Baron-Cohen (2019) describes how the social model of neurodiversity, is an alternative conceptualisation to the DSM-5's medical model and one that challenges stigmas associated with autism and the assumption that it is a disorder or disease that has to be cured or even treated. Instead of viewing neurological conditions such as autism as being a deficit, neurodiversity posits that neurological differences are due to normal natural variations within the human brain. Baron-Cohen (2019) describes how many people with

autism are advocates of this approach, arguing that although their differences may be viewed as disabilities in some environments; in other environments, they can be viewed as talents and thus brings benefits to society.

On the other hand, as many people with autism and their families can face substantial challenges in social environments, including severe learning difficulties, language and sensory needs, for some, the hope of a cure, prevention or intervention means that the medical model is far more appealing and therefore appropriate to use (Baron-Cohen, 2019).

Ballaro & Griswold (2019) discuss how autism has been described as a national public health crisis by The Centers for Disease Control and Prevention in America, with the number of children receiving a diagnosis soaring. The authors cite that in 1960, 1 in every 2500 children received a diagnosis; in 2007 this rose to 1 in every 150. By 2019 this is estimated to have risen to 1 in every 59 children. They describe potential reasons behind this surge and how this is the subject of great debate, with some hypothesising environmental factors e.g. food additives and environmental toxins, whilst others argue the dramatic rise is attributable to raised clinical and public awareness.

Results from further studies include suggestions of a link between stress in pregnancy and autism (Ballaro & Griswold 2019), maternal depression and the use of anti-depressants during pregnancy (Boukhris, Sheehy, Mottron & Berard (2016), intergenerational links between mothers who have been exposed to abuse in childhood and their children being at risk of autism (Roberts, Lyall, Rich-Edwards, Ascherio & Weisskopf 2013) and the notion of a parallel decline in intellectual disability diagnoses, in addition to diagnostic criteria being

widened and Aspergers and ‘Pervasive Developmental Disorder – not otherwise specified’ also being introduced Frith (2020).

A recent paper by Ballaro and Griswold (2019) discusses how an increase in federal funding in the United States, has led to an increase in research, including the Autism Genome Project (AGP). The aim of this is to identify genes which are associated with the heritability of autism within a person’s genotype and ultimately have a blood test to identify these (Hulme, Craig, Huentelman and Stephan, 2005) with the isolation of the genes being successfully completed in 2004 and the project now being in its second phase (Ballaro and Griswold, 2019).

Consequently, there is a recent emergence of mainstream scientific consensus, suggesting that a variable and complex set of influences result in autism, with genetics being a likely key factor. (Ballaro and Griswold, 2019) also discuss a 75% chance of an identical twin having autism if their sibling is affected and the prevalence of autism in boys being fourfold that of girls. However, Frith (2020) argues this prevalence may be due to diagnostic criteria being based on a disproportionate level of research focussing on male autism, in addition to female autism often presenting differently, with minimal research into this.

Although early intervention is necessary in order to maximise positive outcomes for children (Macari et al. 2017), there can be a considerable wait to receive a diagnosis and subsequent access to appropriate services. Monteiro et al. (2015) discuss the average age for children to receive an autism diagnosis is 5.7 years, an increase from 3-4 years of age as reported by Werner, Dawson, Osterling & Dinno (2000). Yet 40% of High Risk (HR) infants (i.e. have older siblings with autism) display symptoms by the age of one (Macari et al. 2012). This

increase over time is postulated to be a combination of an escalation in referrals, a scarcity in diagnostic resources for autism and subsequent longer waiting times (Monteiro et al. 2015).

As detailed earlier, the number of autism diagnoses has increased significantly, as has the number of referrals for assessments. Despite this, many who are assessed do not receive a diagnosis. In a study of 348 people being assessed for autism in the US, 39% did not receive a diagnosis (Monteiro et al. 2015). The authors argue this provides evidence of a considerable burden on already pressured services, suggesting this highlights the need to provide autism training for those carrying out early screening, as there can be high levels of false positive rates. They conclude that consequently, there are long waiting lists as too many children are referred for assessments, when instead they could be funnelled to an alternative support service.

## **1.4 National context**

### **1.4.1 UK national guidelines for autism assessment**

In the UK, national guidelines for autism assessment are provided by the National Institute for Health and Care Excellence (NICE, 2017). This includes guidance on the recognition of signs and symptoms, together with referral guidelines for children and young people to autism teams. The NICE guidelines also provide recommendations of what should be included in an autism assessment, this includes a:

- Detailed history including concerns from parent/carer.
- Physical examination.
- Consideration of differential/co-existing conditions.

With regards to assessment measures, under section 1.5.5 it states:

*“...assessment (through interaction with and observation of the child or young person) of social and communication skills and behaviours, focusing on features consistent with ICD-10 or DSM-5 criteria (consider using an autism-specific tool to gather this information)”*

Therefore, within the UK there are no explicit recommendations for the use of particular diagnostic tools.

#### **1.4.2 UK Autism diagnostic pathway**

In an exploration of clinical practice guidelines, Hayes, Ford, Rafeeqe and Russell (2018) discuss how there is great variation in assessing autism within the UK and how MDTs are referred to as best practice guidelines, generally consisting of a child psychiatrist or paediatrician, clinical psychologist or EP and a speech and language therapist (NAS, 2018). In line with the Children and Families Act (CFA, 2014) there is also a requirement for the participation of both the individual concerned and their parent/carer, in order that their needs are communicated. Although not explicitly stated in the NICE guidelines (2017) and guidelines around this are vague, Hayes et al. (2018) found that overall, local UK autism assessment pathways utilised an interactive focus which explores symptoms, together with social and environmental contexts.

Due to variations in symptomology and no specific biomarkers at present (Molloy, Murray, Akers, Mitchell & Manning-Courtney, 2011) diagnosing autism can be challenging. Filipek et al. (2000) described the assessment process usually involving interviews, observations and clinical judgements. In a study of 116 UK multidisciplinary professionals, Rogers, Goddard,

Hill, Henry and Crane (2016) discuss a stark difference between UK diagnostic pathways that are often clear for medical diagnoses and how this is often not the case for autism diagnostic pathways. Furthermore, socio-political factors including an increase in caseloads and austerity measures have led to depletion in resources and therefore a barrier to early help and intervention post diagnosis. They found that nationally overall, standardised diagnostic tools were consistently used and viewed as being helpful, however limitations to the use of these tools were raised including their validity in atypical ASC detection e.g. autism in females.

Within existing literature (Duvekot, Ende, Verhulst & Greaves-Lord 2015; Havdahl et al. 2017; Allen, Robins & Decker 2008), universal gold standard procedures for the diagnosis of autism are stated as including a parental standardised interview such as the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter & Lecouteur 1994), in addition to a child clinical standardised observation such as the ADOS (Lord et al. 2012). The ADI-R is a modified version of the original Autism Diagnostic Interview (ADI), taking a semi-structured format and is designed to elicit information from the parent/carer of signs and symptoms of autism in their children aged from 18 months through to adulthood (Lord, Rutter & Couteur, 1994). Scores are generated from the interview for the areas of communication and language, social interaction and restricted repetitive behaviour with the resulting score indicating if a classification of autism is appropriate.

The ADOS was originally developed by Le Couter et al. (1989, cited in Molloy Murray, Akers, Mitchell & Manning-Courtney, 2011) and was designed to complement the history obtained through by the ADI-R. The ADOS consists of four modules with their individual use based on developmental and expressive language levels, each of which can be used with children and adults. As with the ADI-R, the ADOS uses a semi-structured format with the

schedule consisting of a number of standardised structured and less structured activities, which are observed by the examiner. The participant's responses are recorded in order to ascertain social, communicative and other behavioural signs and symptoms associated with autism. A diagnostic score is obtained through an algorithm which enables the examiner to establish if the autism cutoff score has been reached (AGRE, 2019). Hus and Lord (2014) discuss a change to the diagnostic algorithms of the ADOS modules 1-4, with a division into two domains making it consistent with the DSM-5 and increasing its specificity and sensitivity.

These measurements however are both time consuming and costly to use and although the benefits of professionals being trained in their use is widely recognised, they are not always deemed feasible methods to carry out (Charman & Gotham 2013). This is particularly pertinent due to the number of autism diagnoses soaring, together with the rise in number of referrals for assessments as outlined previously (Ballaro & Griswold 2019).

### **1.4.3 Local context and role of EP**

The diagnostic approach of the ADOS has been adopted in this project, due to being the approach used in the LA in which this research took place. Furthermore, the definition of autism adopted for this research is that as outlined in the DSM-5, as this is this is the model which the context also adopts. As outlined above, these are not universally accepted or agreed upon approaches. However as this is research underpinned by a critical realist perspective, it is considered pragmatic to apply both the approach and the definition in light of the design and purpose of the study.



The current study took place in an LA, comprising of coastal towns populated predominantly by white British citizens and has pockets of socio-economic deprivation. Fourteen constituencies fall within the 10% most deprived areas in the country (LA, 2019). Since 2011, the number of children and young people with an Education, Health and Care Plan (EHCP) within the LA has risen from 1.6% to 2.2%, and stands at approximately 3250, with the primary special educational needs being 34% learning difficulty, 22% behavioural difficulties, 24% speech and language difficulties, 3% sensory impairment, 4% physical disability, 11% autism and 4% other. These are all roughly in line with national figures (cited in LA's published annual report, 2018).

The LA guidance for parents/carers who have concerns that their child may have autism states they should speak to their General Practitioner (GP), health visitor, child's school or nursery, school nurse or another professional who already may be involved (cited in LA's published guidance, 2019). If the child's school also have concerns, in line with the code of practice (DofE 2005), the school may ask for an EP assessment. Yet, as in other LAs, austerity measures can often mean that schools are unable to 'buy in' an EP assessment as part of the traded model that is used by the LA's Educational Psychology Service (EPS). Furthermore, there is pressure on the role of EPs including the rise in statutory assessments and therefore on an EP's workload, in addition to difficulties in recruiting for vacant EP posts. However more funded EP training places have been promised in an attempt to address the last point (DofE, 2019).

EPs may then conduct initial exploratory assessments, however there are no clear assessment guidelines for EPs to use when exploring for possible autism. Sadreddini (2017) discusses the shortage of knowledge on the initial screening methods that are used by EPs in the UK and

how this provided a rationale for a systematic literature review. Findings suggest that EPs conduct individualised and holistic autism assessments which are triangulated with other professional views on strengths and difficulties together with contextual factors.

Following the raising of initial concerns, if deemed appropriate, the protocol GP/health visitors should follow would then be to then make a referral to the child developmental clinic, where the first appointment is with a paediatrician (cited in LA's guidelines, 2019).

In accordance with NICE guidelines (2017), within the LA in which this study took place, discrepant cases are brought by the paediatrician to a MDT. The MDT consists of paediatricians, Speech and Language Therapists (SALT) and EPs, who meet on a monthly basis. There are three MDTs throughout the LA. Here the paediatrician discusses any cases where there are discrepancies between reported symptoms and findings in the clinic and the cases are distributed amongst the SALTs and EPs.

NICE guidelines also advise that together with the possibility of autism, professionals should consider any alternative explanations for the symptoms displayed. This aligns with the everyday systemic manner of working which underpins that of EPs, who use models such as Bronfenbrenner's Ecological Model of child development (1994). This model highlights the inextricable link between a child and their surrounding environment and systems. It considers how these impact on the child's development and learning.

Once an MDT autism assessment case is allocated to the EP, the assessments predominantly take place within the child's school. The assessments include a parental interview, observation of the Child's or Young Person's (CYP's) naturally occurring behaviour in class and/or at play-time, in addition to carrying out the ADOS. The important notion of

triangulating information in order to inform hypotheses is always held in mind by the EP, gathering information from the parent's or carers, school and the CYP. This is vital as there may be inconsistencies between different adults within a CYP's systems and where they situate the CYP's difficulties i.e. within the CYP, at home or at school (Billington, 2006). Once the assessment has been completed and the ADOS cutoff score gained, this is all included in a written report which is sent to the paediatrician to inform their final diagnostic decision, which is then relayed to parents and their children.

## **1.5 Purpose and aims**

This chapter has highlighted professional concerns about problems that arise from a high number of children being referred for an autism assessment when they are later found not to meet the diagnostic criteria for autism (Monteiro et al. 2015). Within the LA in which the research was conducted, parents often instigate the assessment process and it would be useful to understand what leads parents to think that their child has autism. If we understand more about this, further insight and guidance could be afforded to EPs when working with this population of families. The hope is that parents could then be directed away from the autism assessment route to more appropriate forms of assessment and intervention. Thus, families would be helped to receive more appropriate early intervention, in addition, those who do meet the diagnostic criteria will likely be seen quicker and thereby receive earlier intervention.

The current study has an explanatory purpose: to explore the contexts and mechanisms behind parents who think that their child has autism. It is hoped that the emergent theory from this current research, will help to expand the knowledge of EPs and provide guidance to enhance practice and inform interventions.

Existing literature in this area as outlined in the preliminary literature review chapter is scarce. Therefore the research question addressed in this thesis is:

*“What are Educational Psychologists’ views on the contexts and mechanisms that lead parents to think that their child has autism, in cases when their child does not receive a diagnosis based on results of the ADOS?”*

## **2 Preliminary literature review**

### **2.1 Chapter overview**

The original grounded theory of Glaser and Strauss (1967, cited in Dunne, 2011) explicitly argued against a literature review being carried out prior to data collection and analysis. However, in line with the alternative perspective of Strauss and Corbin (1990, cited in Lo, 2016) who advocate for a general literature review, a preliminary literature review was undertaken, to ensure the intended study would add value to the Educational Psychology profession, in addition to generating new knowledge.

Therefore, this preliminary literature review asks:

*What does the existing literature tell us about parents who think that their child to have autism, but their child does not go on to receive a diagnosis.*

A second literature review took place following data collection and analysis, once the grounded theory had emerged. This is presented in chapter five, commencing on page 122.

### **2.2 Search strategy**

EBSCO was utilised to carry out the literature review as this contains a number of databases. This was in addition to a search of The National Autistic Society's reference library with box 2.1 outlining all of the databases used in the current search.

- PsycINFO.
- The Pep archive.
- Psychology and Behavioural Sciences Collection.
- PsycArticles.
- Autism Data

*Table 2.1 EBSCO databases used in preliminary literature search*

The search terms used in this preliminary literature search are shown below in table 2.2 together with both the number of results in the combined databases and the number of those that were deemed relevant to the current study.

<b>Keywords (no limiter used with keywords) (* denotes the use of truncation to include various word endings and spellings)</b>	<b>Total of articles retrieved</b>	<b>Relevant articles</b>
Parent* OR carer OR mother OR father		
Child*		
ADOS* OR Autis* OR ASD OR ASC		
Process OR procedure OR assess*		
“No diagnosis” OR “Non diagnosis” OR Non- diagnosis OR contest* OR disput* OR challenge* OR argue* OR question* OR diagnosis OR “Not receiving”		
<b>Total number of articles when above search terms combined</b>		

*Table 2.2: Key words for preliminary literature search*

In order to determine relevance to the current study, inclusion and exclusion criteria were employed, with these being outlined in Table 2.3. Inclusion criteria included for articles to be restricted to children from ages birth through to twelve, due to the autism diagnostic process within the LA in which the current study took place. Here the MDT only assesses children up to the end of primary education and therefore 11-years-old. After this time, the diagnostic process moves to the Child and Adolescent Mental Health Services (CAMHS) team which does not encompass EPs from the LA.

Upon retrieving the total articles, these were all subjected to a search of their titles, before an abstract search was conducted to determine the total relevance of articles, in line with the inclusion and exclusion criteria employed.

### **2.3 Results of preliminary literature search**

The total articles produced by the preliminary literature search totalled 2699. As stated above, by conducting a search of all titles and abstracts and applying inclusion and exclusion criteria, 13 articles remained. A hand search was then conducted of all references within these articles, with inclusion and exclusion criteria once more being applied and this yielded an additional 2 articles, making 15 in total.

The 15 articles broadly fall into five areas which will be discussed in turn, the most common being the association between parental concerns and the diagnostic process. The other areas were: comparing parental and professional concerns, considering parents as one of the

multiple informants, the parental role within the diagnostic process, cultural differences in parental reporting of their child's difficulties and support groups for parents.

**Inclusion criteria for articles:**

- Peer reviewed publication.
- Written in English language.
- Published within the last 10 years.
- Children ages birth – 12 years old.
- Topic is relevant to autism diagnostic process.
- Includes children without autism traits.
- Considers parental involvement in assessment.
- Study conducted in a Western country.

**Exclusion criteria for articles:**

- Duplication.
- Children older than 12.
- Parental involvement not considered.
- Does not include children without autism traits.
- Relating to alternative topics e.g. ADHD, comorbid conditions etc.
- Relating to children who have already received a diagnosis of autism.
- Carried out in non-western countries.

*Table 2.3: Inclusion and exclusion criteria applied during preliminary literature search.*

In all but one of the articles included in the preliminary literature review, researchers used quantitative methods. The 'framework for critiquing quantitative research' by Holland and Rees (2010) was used in order to critique the articles. This provides a checklist to ultimately guide the researcher in understanding the relevance of research and the importance of including all information for reliability and replicability purposes. Although this framework



was designed for use with quantitative articles, it was used for all articles in this literature review. It was deemed the framework provided good depth for the critique of all methodologies, in addition to providing continuity throughout the review. The framework was used to critique the whole article, with an outline of this provided in appendix 1.

### **2.3.1 Relationship between parental concerns and diagnostic outcome**

Four papers explored the relationship between parental concerns and diagnostic outcome (Lo, Klopper, Barnes & Williams, 2017; Sacrey et al., 2015; Ozonoff et al., 2010; Turygin, Matson, Williams & Belva, 2014). The areas covered by the articles included the agreement between parental concerns and diagnostic outcomes, the levels of agreement and the main areas of first concerns and associations.

Turygin, Matson, Williams & Belva (2014) carried out a study exploring the relationship between parental First Concerns (FC) and later autism diagnosis. A considerable sample of 2905 toddlers were recruited from an early-steps referral programme in America, with carers undertaking a screening assessment battery and interviews with trained clinicians. The study found that in contrast to parents whose FC were associated with communication difficulties, when parental FC related to behaviour and cognitive delay without communication difficulties, there was a predicted decrease of a later autism diagnosis. Although at times the reader was left having to search for information to obtain a clear picture of the meaning of the results, this appeared to be an appropriately designed and ethically rigorous study, raising the importance for professionals and parents to receive education on common FC and the associated risk factors for subsequent autism diagnosis.

A study by Lo, Klopper, Barnes & Williams (2017) investigated the levels of agreement for parents who had autism concerns, utilising questionnaires in addition to parental interviews.

The study had a sample of 677 children aged 14-76 months, who were recruited from their details being on a pre-existing database due to being previously assessed for developmental concerns. Results showed that approximately 30% of children in the sample, did not meet the criteria for diagnosis, with similar patterns seen irrespective of referral source or child's age. The authors found that a sizeable minority of children referred for autism assessment did not receive a diagnosis and that this placed unnecessary pressure on services, leading to longer waiting times. This wait arguably creates a barrier to accessing services and crucial early intervention for children who could benefit from an autism diagnosis. The study had an appropriate design to address the research question, with a good sample size and details of methods and data analysis being clearly outlined for replication purposes. The study addressed a gap in the literature. However the ethical rigour of the study was unclear, perhaps due to using details on a pre-existing database.

Sacrey et al (2015), carried out a longitudinal study of 237 infants across four sites in Canada, exploring the relationship between parental concerns of High Risk (HR) siblings (i.e. their older sibling had an autism diagnosis) and diagnostic outcomes. The study found that across all groups, during the first year, parents were more likely to report motor and sleep difficulties and across second and third years, this turned to behavioural and communication difficulties. Furthermore, parents whose HR children went on to receive a diagnosis of autism, recognised their differences from very early on and total parental concerns at 12 months predicted the HR children most likely to receive a diagnosis of autism. The design of the study seemed appropriate, with participants drawn from sites across Canada, so there was geographical diversity. Details were also provided of the gender ratio, however no details were provided regarding any other characteristics of the sample, so it is unclear how generalisable the results might be.

Finally in this section, Ozonoff et al. (2010) carried out a longitudinal study exploring the relationship between parental concern during the infants first 18 months and subsequent autism diagnostic outcomes. Similarly to the previous study, HR participants were also recruited, in addition to the inclusion of a Low Risk group (i.e. typically developing siblings). Over a three-year period and across two sites, the infants were periodically assessed by a clinician blinded to the trial and parental concerns were also periodically gained within this time period, with full details of measures and validity provided.

The results suggested that when infants are six-months old, rather than being based on actual developmental difficulties, parental concern was shown to be more associated with having a second and older child with autism. It was hypothesised this may be due to parents being more anxious and hypervigilant due to their older child's difficulties. However by one-year, concerns better reflected developmental difficulties and offered better prediction of diagnostic outcome. This appeared to be a methodologically rigorous study, using a comparison group, with an appropriate longitudinal design and measures used to address the research question. A diverse sample's developmental trends was assessed over a three-year period, increasing possible generalisability of the findings.

### **2.3.2 Comparison between parental and professional concerns**

Three studies were identified in the preliminary literature review that explored parental and early years workers concerns of children's difficulties (Dereu et al., 2012; Jobs, Bolte & Falck-Ytter, 2019; Macari et al., 2018). Two of the studies compared the respondents with each other and the third compared them with the Developmental, Dimensional and Diagnostic Interview (3Di) and the ADOS.

Dereu et al., (2012) carried out a study comparing screening instruments completed by childcare workers and parents. The screening instruments utilised in the study were the Checklist for Early Signs of Developmental Disorders (CESDD) (Dereu et al. 2010), (cited in Dereu et al. 2012) developed to be completed by childcare workers and the following parent questionnaires: Early Screening of Autistic Traits (ESAT; Dietz et al. 2006; Swinkels et al. 2006), Modified Checklist for Autism in Toddlers (M-CHAT; Robins et al. 2001), Social Communication Questionnaire (SCQ; Rutter et al. 2003a) and the Short-form versions of the MacArthur Communicative Development Inventories (CDIs Short-forms; Fenson et al. 2000) (cited in Dereu et al. 2012). A sample of 357 children were taken from a larger screening study whose results from childcare screening showed them to have an elevated risk of autism. Findings from the study suggested that the new childcare screening tool and parent questionnaires were both equally able to discriminate between children with and without a later autism diagnosis. The measures used seemed appropriate to ascertain the utility of the CESDD. Limitations of the study included the use of small comparison groups, in addition to sampling bias, as parental response rates suggested parents were more likely to participate when their child's development was more apparent to be atypical. This therefore limits the generalisation of the study.

Jobs, Bolte & Falck-Ytter (2019) built upon the study by Dereu et al. (2012) and examined the diagnostic accuracy in ratings comparing those given by preschool staff and parents, by utilising the ADOS ( Lord et al. 2012b), ADI-R (Rutter et al. 2003, 2008), The Vineland Adaptive Behaviour Scales (VABS-II; Sparrow et al. 2005; McDonald 2014; Mougla 2014), The Mullen Scales of Early Learning (Mullen 1995) and the Child Behaviour Checklist (Achenbach and Rescorla 2000, 2004) (cited in Jobs, Bolte & Falck-Ytter 2019).

In contrast with the Dereu et al. (2012) study which found an equal ability to discriminate, findings from this study suggest that Early Years staff were more accurate and better able to both discriminate between children at high/low risk of autism and track symptoms of autism with children who were very young. The study appeared to have an appropriate design to address its research question and used appropriate measures, with a description and the validity of each measure being addressed. The study recognised the limitations of a smaller sample size of just 56 children taken from a pre-existing longitudinal study.

Macari et al. (2018) carried out a study examining agreement rates between parents and clinicians for ratings of autism behaviours of 12-month-old infants. They provide the rationale for their study by discussing the increasing prevalence of autism and how prior to the age of two, two separate universal screenings are recommended by the American Academy of Paediatrics (Johnson and Myers, 2007, cited in Macari et al., 2018). A sample of 137 parent participants, including both HR and LR infants, completed the First Year Inventory (FYI; Baranek et al. 2003, cited in Macari et al. 2018) when the infants were 12-months-old. The infants were also assessed by clinician's blind to their risk status utilising the Autism Diagnostic Observation Schedule 2 Toddler Module (ADOS-T) (Lord et al. 2012, cited in Macari et al. 2018). The study found that there was a difference in concordance between the two groups when parents used Likert scale measures. However, when they used standardised multiple-choice formats which were more in line with clinical tools, it was found that parent/clinicians gave similar ratings. Therefore, the implications of these findings suggest that parents may find it easier or be able to give more accurate descriptions of their child's characteristics, when using multiple choice formats rather than Likert scales. The study concluded by stressing the importance of questionnaire wording and construction during their design.

### **2.3.3 Utility of using parent's concerns as one of multiple informants**

Two studies were identified in the preliminary literature review that explored the utility of using parental concerns together with other informants (Duvekot, Ende, Verhulst & Greaves-Lord 2015; Moricke, Buitelaar & Rommelse 2016). The studies addressed screening accuracy of measurements and the utility of multiple informants.

In a study by Duvekot, Ende, Verhulst & Greaves-Lord (2015), parent screening alone, in addition to parent and teacher screening accuracy utilising the Social Responsiveness Scale (SRS; Constantino and Gruber 2012, cited in Duvekot, Ende, Verhulst & Greaves-Lord 2015), was compared with the 3Di and ADOS. Excellent screening accuracy was found with the parental reported SRS, however combining with the teacher SRS improved discrimination between children who would and wouldn't meet autism cut off scores on the ADOS. In an appropriately designed study, the author concluded that the SRS could be used as a valuable screening tool within early assessment prior to referral for comprehensive assessment, in addition to the importance of multi-informants and tools being part of the overall diagnostic process.

In relation to this, another Dutch study by Moricke, Buitelaar & Rommelse (2016) asked if multiple informants are needed when assessing for autism. With participants being both parents of pre-school children (i.e. two parents for each child), this study examined report bias when informants completed questionnaires. Findings suggested that when parents individually reported their child's autism traits, no report bias was found. In contrast with this, there was a strong influence of report bias when reporting adult autistic traits, with spouse ratings being significantly higher than self-reported ratings.

### **2.3.4 Parental role within the autism diagnostic process**

Three studies explored the role of parents within the autism diagnostic process (Havdahl et al. 2017; Ward, Sullivan & Gilmore 2017; Rowberry et al. 2015). Studies explored parenting influences, the adaptation of a screening tool for parents and the utility of parent reports within the process.

Havdahl et al. (2017) carried out a study with one of its aims being to consider the influence of parental concern on the diagnostic process, by using a sample which included parents who were concerned about autism and those who did not specify autism as being a concern. All participants were assessed using the ADOS and the Autism Diagnostic Interview-Revised (ADI-R) by clinicians who were blind to the study. Findings suggested that low sensitivity was found for ADI-R cutoffs, when parents did not express specific concerns regarding autism. Therefore, the study concluded that both instruments should be used together with clinicians holding in mind any parental non- autism concerns, alongside other factors which may have an influence on measurement performance when interpreting scores; as this can lead to misclassifications. This was a novel area of research with an appropriate design to address the research question and clinicians were blind to the study. However, generalisability of the result may be affected as the study was conducted in a single Norwegian culture.

A study by Ward, Sullivan & Gilmore (2017) sought to explore the adaptation of the Autistic Behavioural Indicators Instrument (ABII), an autism screening tool used by clinicians, to an equivalent for use with parents i.e. ABII-PQ. Findings suggested that the ABII-PQ significantly discriminated between children who were typically developing and those with autism. Sensitivity and specificity values were in excess of the .70 recommended value. The

study concluded by arguing the ABII-PQ shows potential as a parent screening tool for early detection and expert referral. However, limitations of the study included the involvement of children who were already in possession of autism diagnosis, which may have led to an over-reporting of autism traits, in addition to parent's self-identifying children as having an autism or being typically developing.

Rowberry et al. (2015) conducted a study exploring the utility of parental reports when screening 12-month olds who are at HR of developing autism. Although a relatively small sample size was used, findings suggested a significant correlation between parental reporting and clinician ratings. The study also found it was parental ratings of social/communication skills that were rated to be atypical at 12 months, rather than repetitive/sensory behaviours. The study shows potential for early screening of HR 12-month olds using parental report and highlighting early warning behaviours, which if acted upon, could lead to vital early intervention.

### **2.3.5 Culture, race and ethnicity**

Two studies related to culture, race and ethnicity (Blacher, Cohen & Azad 2014; Stronach & Wetherby 2017). The studies examined differences in parental concerns and if there was a difference in the validity of measures across race and ethnicity.

Blacher, Cohen & Azad (2014) carried out a study comparing Latino and Anglo parental reports of autism concerns utilising the ADOS and ADI-R. The study found that during the screening process, more autism concerns were raised by Anglo parents and fewer social skills concerns were raised by Latino mothers. Therefore, in the ADI-R Latino mothers did not detail specific autism concerns, with general developmental delay being raised instead. However, in contrast with this, the results from the ADOS indicated that although more



symptoms were raised by Anglo parents, more autism symptoms were demonstrated by the Latino children. Providing novel findings in this area of research, the study concluded that the cultural differences highlighted, necessitate further research into this area, with the author raising the notion of autism symptoms being affected by context and being in the “*eye of the beholder*” (p.165) i.e. observable differences in clinic and home environments, which clinicians should consider, together with cultural assumptions when considering the diagnostic outcomes.

A study by Stronach & Wetherby (2017) explored whether social communication measures differ across race and ethnicity for children with/without autism. The measures used in the study were; The Communication and Symbolic Behaviour Scales Behaviour Sample (CSBS-BS; Wetherby & Prizant, 2002, cited in Stronach & Wetherby 2017) The ESAC and the ADOS. Results suggested that less educated mothers reported higher levels of autism symptoms, however moderately consistent patterns of social communication difficulties were found in children with autism across race and ethnicity groupings. The only area that showed a difference between the groups in question was in relation to understanding, however this was relevant to children both with and without autism. The study appeared appropriately designed, however no references were provided for the ESAC measure, therefore it would be difficult to ascertain validity. The authors conclude by arguing that increasing diversity within the US, necessitates the use of screening/diagnostic assessments which are culturally sensitive and account for ethnic, cultural and racial differences that can differentiate these from communication disorders such as autism.

### **2.3.6 Support groups for parents**

The final study was the only qualitative article yielded in the search. Connolly & Gersch (2013) cite the rationale of the rise in prevalence of autism leading to longer waiting times for

assessment, in addition to clinician awareness of how the prolonged wait can cause additional distress to the families concerned. Conducted in the action research tradition, parents whose children were on a waitlist for autism assessment were invited to take part in a three-stage process which used focus groups to explore parental experiences and ascertain if a short parenting programme would be beneficial. A programme was designed and implemented before it was then evaluated using questionnaires and further focus groups. Analysis yielded nine identical themes in both focus groups, with findings suggesting that parents wanted information regarding autism as soon as the possibility was raised. Benefits of the support group reported by parents included peer and professional support, in addition to the benefits of learning strategies they could use with their children.

## **2.4 Summary of Preliminary literature review**

This chapter has outlined the methodology and findings from the preliminary literature review. In line with the revised grounded theory of Strauss and Corbin (1990, cited in Lo, 2016), contrary to the original theory of Glaser and Strauss (1967, cited in Dunne, 2011), a preliminary literature review was carried out, to ascertain that the current study is a novel area of research.

The current preliminary literature review asked:

*What does the existing literature tell us about parents who think that otheir child to have autism, but their child does not go on to receive a diagnosis.*

The findings from the 15 articles included in the review, found relationships between parents' early concerns and later autism diagnosis (Turygin, Matson, Williams & Belva 2014; Sacrey

et al. 2015; Ozonoff et al. 2010) with a contrasting study finding a sizeable minority of parents concerns conflicting with the diagnostic outcome (Lo, Klopper, Barnes & Williams 2017). In relation to the comparison between parents' and professionals' concerns, studies revealed the utility of using screening instruments by Early Years staff (Dereu et al. 2012; Jobs, Bolte & Falck-Ytter 2019), in addition to concordance in professionals' and parents' ratings when using measures with multiple choice formats as opposed to Likert scales (Macari et al. (2018)

Studies exploring the utility of using parents' concerns as one of multiple informants found discrimination for diagnostic outcome improved when combining parents' and teachers' screening of concern for children with potential autism (Duvekot, Ende, Verhulst & Greaves-Lord 2015), in addition to a lack of reporting bias found (Moricke, Buitelaar & Rommelse 2016). In addition, when considering parents within the diagnostic process, studies found the importance of using the ADOS alongside the ADI-R, particularly for parents who did not have concerns regarding autism (Havdahl et al. 2017), a successful adaptation of the ABII clinician questionnaire for the use by parents (Ward, Sullivan & Gilmore 2017) and a significant correlation between parents and clinician's ratings of 12-month-old HR infants (Rowberry et al. 2015).

Furthermore, a focus on varying aspects of autism symptomology was found when exploring differences in parental concerns of autism across culture, race and ethnicity (Blacher, Cohen & Azad 2014), in addition to the importance being raised of the use of culturally sensitive tools when assessing children for autism (Stronach & Wetherby 2017). Finally, the preliminary literature review highlighted how parents found support groups to be beneficial whilst on a waitlist for an autism assessment (Connolly & Gersch (2013).

Therefore, this preliminary literature review found a lack of research relating to the research question, in addition to a shortage of articles published in the United Kingdom. Although one paper related to children who did not go onto receiving a diagnosis (Lo, Klopper, Barnes & Williams 2017), no papers were found that addressed the reasons behind parents who think that their child to have autism, but their child does not go on to receive a diagnosis. Thus, a gap in the existing research has been found and this allowed the author to draw the conclusion that the current study is indeed a novel one to research.

# 3 Methodology

## 3.1 Chapter overview

This chapter will outline a rationale for the current research, before stating the research question and purpose for this. Researcher's worldview will be discussed in order to consider and justify the chosen methodology. The research procedure will then be described in detail including an account of the participant selection, data collection and methods used for analysis, in addition to outlining of ethical considerations pertaining to the research.

## 3.2 Rationale for research

The rationale for this grounded theory (GT) research is to investigate and develop a theory of Educational Psychologists' views on what leads parents to think that their child's behaviour is related to autism. If EPs understand more about what leads parents to seek a diagnosis in cases where a diagnosis is unlikely to be given, parents could be signposted to more appropriate assessment and intervention away from the autism assessment route.

## 3.3 Research question

The research question for the current study is set as:

*“What are Educational Psychologists' views on the contexts and mechanisms that lead to parents thinking their child has autism, in cases when their child does not receive a diagnosis based on results of the ADOS?”*

### **3.4 Purpose of research**

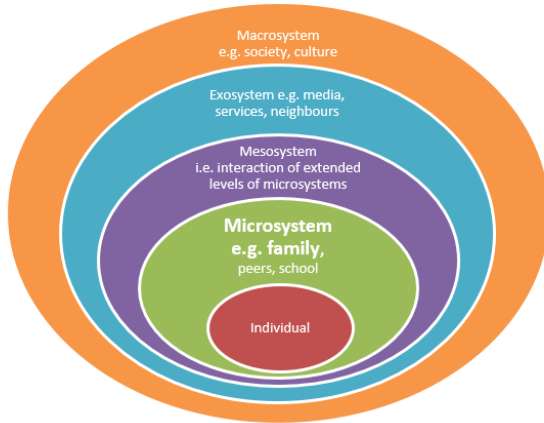
The research has an explanatory purpose, something which Robson (2011) argues is most useful for under-researched areas. In developing a theory that can subsequently be tested, understanding of the phenomenon could be furthered.

### **3.5 Researchers worldview**

Guba and Lincoln (1989, 2005) cited in Arghode (2012), discuss the notion of paradigms being adapted to the social sciences, as pertaining to worldviews of researchers. These paradigms thus reflect the researcher's assumptions and beliefs regarding reality and the accompanying methodology used to study this. Further, paradigms provide a framework for the researcher's assumptions relating to reality i.e. their ontology and the resultant valid and reliable methodology they use, i.e. their epistemology (Mertens, 2012). This is an important area of concern for the researcher in order for their selected methods to be congruent with their world view.

It was argued by Willig (2008) that questions cannot be asked without assumptions being made. Therefore, when carrying out the present research, the following assumptions were made by the researcher in relation to the research question:

- The difficulties being experienced by the child, is understood by the parent as being indicative of and attributable to autism.
- When assessing children, EPs hold onto the knowledge of autism being an external reality. Alongside this, EPs remain curious as to the consideration of contributing factors for the child's presentation and the inextricable link between a child and their environment, such as outlined in Bronfenbrenner's ecological systems theory (1994) (see figure 3.1).



*Figure 3.1: Bronfenbrenner's Ecological Model of Human Development*

### **3.6 Ontology and Epistemology**

Ontology and epistemology have their roots in the philosophy of science, they pertain to how we know something to be true and how this can be explored. Ontology is the study of reality, it refers to the nature of reality, being and existence and asks what is reality and does something actually exist.

The respective ontological position taken, then informs the epistemological position adopted, providing a framework for exploring the nature of this existence. Epistemology asks how do we actually know something; how is this knowledge created and how can this be measured and validly obtained (Robson, 2011). Epistemology therefore relates to the validity and reliability of the resultant methodology used.

The two main ontological paradigms within social science research are realism and relativism and these are used to investigate social reality concepts, each having a differing view to the other. A realist stance argues for the existence of an external reality and has its roots and epistemology within the positivist, quantitative paradigm (Arghode, 2012). Therefore, its

epistemological stance asserts that the external reality can be discovered via objective observation (Robson, 2011).

On the other hand, a relativist ontological position such as that of social constructionism argues there are multiple realities, which are all equally valid and socially constructed within their own cultural, geographical and historical contexts and it is necessary to explore these, by studying individual life experiences and the meanings which are socially constructed within.

The notion of objective observer is rejected and therefore the relativist position would have a different epistemology, arguing that the analysis of individuals cannot be truly achieved in a controlled experiment, when in reality an individual's lived experience is dynamic, fluid and context dependent. Thus, relativist epistemology would encompass a subjective observer who reflects on the impact they have on a study, in their search for multiple meanings.

With the current study seeking to understand what leads parents to think that their child's behaviour is due to autism, it is argued that the above two ontologies would be inappropriate to use. On the one hand, the current study relates to the external reality of autism, but on the other hand, the study seeks to explore the multiple realities and constructions of parents, that leads to the belief that their child's behaviour is attributable to autism. Therefore, in essence, the current study seeks an ontology that transcends the barriers of realism and relativism.

### **3.7 Critical Realism**

The above ontologies differ in their acknowledgement of reality and therefore also in the epistemological positions and methodologies they employ, which arise from their ontological



positions, making them suitable for given pieces of research. There is also an alternative position which is post-positivist and sits somewhere between the two polar opposites, that of the critical realist. A critical realist ontology argues that there are external realities, however they can never be fully known, because these are interacted with subjectively and it seeks to measure these through its epistemological stance. As the current study seeks to explore why parents came to their beliefs using the perspective of EPs, the worldview of critical realism is deemed to be appropriate to adopt.

Robson (2011) describes how this approach, which can be carried out in a flexible manner, offers a framework for scientific explanation without the constraints experienced by relativist and positivist paradigms, by recognising that human behaviour is individual and inextricably linked with the surrounding systems. Morris (2008, in Kelly, Woolfson & Boyle, Eds.) discusses the notion of subjective human experience being constrained by both the available resources, in addition to our socio-cultural discourses. Thus, critical realism argues that there is a limit to our understanding of reality and this cannot be truly objective (McEvoy & Richards 2006; Oliver, 2011).

The epistemology adopted by critical realist research, emphasises the importance of research being replicable, therefore requiring researchers to be explicit in the methodology they use (Barker et al., 2012). Furthermore, it argues that the best method should be chosen for the research question, rather than the research question guiding the method. Therefore, on the one hand, the epistemological spotlight could focus towards controlled measurable, generalisable experiments. Alternatively, richer data maybe required, for instance conducting interviews and analysing these through a method such as thematic analysis.

It is suggested that the theory constructed by critical realists is inferred in a process of retrodution, an underpinning logic of critical realism (McEvoy & Richards, 2006). Therefore, the aim of a researcher adopting a critical realist stance, is to find the most likely explanation for the phenomenon in question (Pawson & Tilley, 1997). The underlying mechanisms i.e. the interaction between a person and their environment, of a particular phenomenon are sought and theories are generated and tested. McEvoy & Richards (2006) explain that rather than seek causal relationships, lived experience (interpretivism) or generalisation (positivism), critical realists seek understanding and explanation of the phenomenon in question on a deeper level.

The notion of the environment, or context is key for critical realists and pertains to how social rules, values and norms are constructed in local and historical contexts. Further, it relates to all levels of contexts including macro i.e. socio-political and micro i.e. individual (Pawson & Tilley, 1997). In relation to what leads parents to situate the reasons for their child's behaviour to be solely within child, the contexts might include:

- Socio-cultural discourses on the nature of autism.
- The socio-economic environment in which the parents and their families live.
- Parental values.

As critical research aims to create a deeper understanding of social phenomenon, Pawson and Tilley (1997) describe how it can improve practice and policies. It is therefore argued that the position of critical realism is a suitable one to adopt in the current study, due to it seeking to investigate and explain the contexts and mechanisms that lead parents to seek a diagnosis of autism, in cases where EPs do not feel this to be present. Further, it is hoped that the findings and theory generated by the research, could go on to be used to reduce waiting times for

autism assessments, by appropriate interventions being implemented earlier for those without autism and their families.

### **3.8 Research Design**

The ontological paradigm adopted by the researcher informs the epistemological stance and therefore the research design and methodology employed. Being most akin to that of the physical sciences, historically realism has been seen as the “scientific” approach, utilising quantitative methodology to study observable external realities. Thus, it has historically been given a favoured status as the most appropriate and best research method to use in social science research (Gameson & Rhydderch, 2008). This experimental approach was also the dominant approach within the U.K. prior to a crisis in social psychology during the 1970’s when a critical qualitative social psychology emerged (Hollway, 2007).

On the other hand, rather than the testing of objective variables as in quantitative research, qualitative research is one of discovery, seeking to explore participants subjective, individual experiences of a given phenomenon and the gathering of rich data describing how meanings are made in relation to this. McEvoy and Richards (2006) describe how open-ended semi-structured interview questions can be used in qualitative methodology to explore the complexities of human behaviour, with the aim of revealing inferred mechanisms, something which would be difficult to do with standardised quantitative measures. Although there are issues regarding the generalisability of results with qualitative research, it does provide the forum for the gathering of rich data (Lyons & Coyle, 2007).

Alternative methodologies were considered for the current study, including IPA. However this was disregarded as IPA focuses on the meaning that individuals make of their lived

experience and less to do with context than Grounded Theory (Willig, 2008). Thematic analysis was also considered, however as neither influencing factors or social processes are the focus of this method, this was also deemed unsuitable. Therefore grounded theory was chosen due to its congruency with the exploratory nature of the research question. Moreover, grounded theory is highly compatible with critical realism for reasons including their shared focus on abductive reasoning (Oliver, 2011) in addition to their desire to explore the contexts and mechanisms of a given phenomenon.

### **3.9 Grounded Theory overview**

A specific methodology initially developed in the 1960's by Glaser and Strauss, grounded theory aims for the generation of a theory relating to a particular social phenomenon, which is grounded in the data, rather than based on pre-existing theories. Robson (2011) discusses how the original development of the theory arose in response to the sociological stance prevalent at the time, which held firm that research must arise from a firm theoretical knowledge base. This was also a time when quantitative research methods were gaining dominance and Glaser and Strauss sought to challenge the view that primarily, qualitative research was a precursor to more rigorous quantitative research methods (Charmaz, 1996).

The original development of grounded theory had its roots in the ontologies of *interactionism* i.e. response to action is based on meanings that are attributed to the behaviour and not the behaviour itself and *pragmatism* i.e. interest lays in the behaviour itself and the thoughts behind the behaviour (Corbin and Strauss, 2008). There has since been some diversification regarding the ontological position that researchers adopt. Although some theorists such as Corbin and Strauss (2008), adopt the original ontology, others such as Charmaz take a social constructivist ontological position, which emphasises the researcher's role within both the data interpretation and theory construction.

However, no matter the ontological position of the researcher, the epistemological stance of grounded theory remains the same, providing explicit procedures and techniques both for carrying out rigorous qualitative research and also inductive strategies for analysing the data which arises (Charmaz, 1996). It is emphasised in grounded theory that by gathering the data alongside conducting the analysis, an iterative process is created which expands the emerging categories precision (Willig, 2017). Therefore, the methodology of grounded theory provides a structured method for the organisation of data gathering and analysis. This enhances the trustworthiness of the approach and this is discussed further when considering ethical implications. Thus, the researcher is enabled to conduct their research in an effective and efficient manner. Charmaz (1996) outlines some of the distinguishing characteristics of grounded theory:

- The collection of data happens simultaneously with analysis.
- Rather than being born from preconceived hypotheses, the development of codes and categories and ultimately theory arises from the data itself.
- In order to provide an explanatory framework for behaviour and process, middle-range theories are developed.
- Grounded theory involves writing memos i.e. analytic notes for explanatory purposes and in order to “fill-out categories”, providing an essential reflective feature to use during the data gathering and coding process, in addition to the writing of initial drafts.
- Rather than using sampling based on a given populations representativeness, in order to refine the conceptual categories which emerge from the data, theoretical sampling is used.
- The literature review is delayed.

Charmaz (1996) describes the methods of grounded theory as being logically consistent, whereby the researcher begins with the rich data from individual participant experiences of the phenomenon in question. By the researcher paying close attention to the language used and meaning of the words spoken by the participants, the researcher can provide a connection between their experiences and the research question. Through studying the emerging data, the researcher can progressively develop patterns of abstract conceptual categories, by creating a hierarchy of coding in addition to an iterative process of identifying themes.

This emergence of categories from the raw data is core to grounded theory, with Glaser and Strauss' original argument being that its natural occurrence should be encouraged and any associated hypotheses should be free from existing theories. However, Dunne (2011) discusses the ongoing polemical debate regarding the use of existing literature and pre-existing theories. The original argument of Glaser and Strauss (1967) explicitly stated if using grounded theory methodology, that in contrast to both positivist research and the sociological stance prevalent at the time, a literature search should not be carried out prior to conducting data collection (cited in Dunne, 2011). Conversely, other theorists such as Morse, (2002) have argued that it is inconceivable to imagine that data can be analysed truly objectively, without it being subject to any preconceived ideas from the researcher (cited in Lo, 2016).

There are alternative perspectives to the original argument, for instance that suggested by Strauss and Corbin (1990), who advocated that in order for the researcher to provide justification for novel research, it is crucial to carry out a general literature review (cited in Lo, 2016). Whilst on the other hand a more pragmatic approach is encouraged by Charmaz (2006), who suggests that the literature review should be approached in a flexible manner.

Corbin and Strauss (2008) acknowledge the prior experience and knowledge of the researcher and they suggest within the context of the data gathering, that this may be used in the exploration of the meaning made by participants. They discuss the notion of reflexivity and how this is also at the core of grounded theory research, whereby the researcher's thoughts and perspective are held in mind and the impact that these can have on the whole research process. An essential part of grounded theory are the journal entries and memos which are implemented in order to manage any researcher bias. These tools are used in the data gathering and analytic process as a reflective tool.

Morse (2001) describes three overarching qualities of a robust and well-constructed grounded theory (cited in Lo, 2016), these are:

- For a given social phenomenon, it delivers its theoretical framework in an elegant and parsimonious manner.
- The findings although abstract in nature, are grounded in both the data and context and are therefore a true reflection of the participants words and meanings.
- The results of grounded theory research are highly relevant, providing professionals with important evidence about a particular social phenomenon.

As a novice researcher who seeks to explore the social phenomenon in the current study, the explicit framework for rigorous qualitative research and qualities that are provided by grounded theory, was felt to be a particularly good fit for this research.

### **3.10 Participants**

This section will outline details regarding the recruitment of participants.

### **3.10.1 Recruitment**

The researcher contacted all of the EPs working in the service, who carry out the ADOS assessments. This was done via email, with the information sheet and consent form attached (see appendix 5), together with an invitation for the EPs to contact the researcher with any questions that they may have. There was an aim to interview between six to ten participants. A feature of grounded theory is that data collection should continue until 'data saturation' is achieved. This refers to the point at which no new codes are being generated from new data. Experts in the field suggest this usually occurs somewhere between the sixth and tenth participant (Dey, 1999).

The invitations to participate were staggered to ensure that all those invited to participate had an opportunity to do so. Random selection was initially used to determine which EPs would be invited to participate, following this theoretical sampling was employed to support the development of the theory.

### **3.10.2 Inclusion/exclusion criteria**

The participants in the current study were EPs employed by the LA in which the researcher was on placement. All EPs working in the service who carried out the ADOS as part of the MDT were eligible for the study. This is because these EP participants will have experience of interviewing parents whose children did not meet the ADOS diagnostic criteria of autism.

Inclusion criteria included the EP carrying out the ADOS as part of a team dedicated to the assessment and diagnosis of Autism. EPs who did not carry out ADOS assessments were not eligible for participation in the study, as they are not part of the MDT and will not have had



experiences with the parents and children in question, within the context of the autism diagnostic process.

### **3.10.3 Contracting and re-contracting participant**

Initially the proposed research question sought to develop a theory based upon the views and experiences of parents who have sought a diagnosis of autism for their child, but have not received one. Therefore, the participants were going to be parents. Permission to conduct this research was received, however due to difficulties with recruiting parent participants, the focus was shifted to EP's views of this phenomenon. At this time, the researcher held discussions with the Principal EP of the LA in which the research was to take place, who deemed the new focus to be more advantageous to the profession of educational psychology. Therefore, further permission was sought and gained from the Tavistock Research Ethics Committee (see appendix 4).

### **3.10.4 Theoretical sampling**

Charmaz (2006) describes theoretical sampling as a major strength of grounded theory, due to the exploration of a particular phenomenon through participants differing experiences. Theory is developed by using the data, with emerging categories being refined and elaborated upon. Further, abductive inference is employed whereby data is checked with data, in order for explanations to be refined. With this process therefore being concept driven, theoretical sampling enables the discovery of the concepts relating to a particular phenomenon and permits there in-depth exploration (Corbin & Strauss, 2008). As this method of sampling allows for discovery, it is particularly beneficial when exploring uncharted social phenomenon, such as in the present study.

Charmaz (2006) describes how theoretical sampling enables the recruitment of additional participants, further questions being asked of previous participants and/or new settings being observed. However, theoretical sampling was restricted in the current research project, due to it being a small-scale study within the demands and constraints of a professional doctorate. Therefore, in the current study, after the first three interviews had been conducted, these were analysed and based upon the emerging theory, the interview schedule was refined (see Appendices 6 & 7) in order to explore the discovery of concepts further (see figure 3.2).

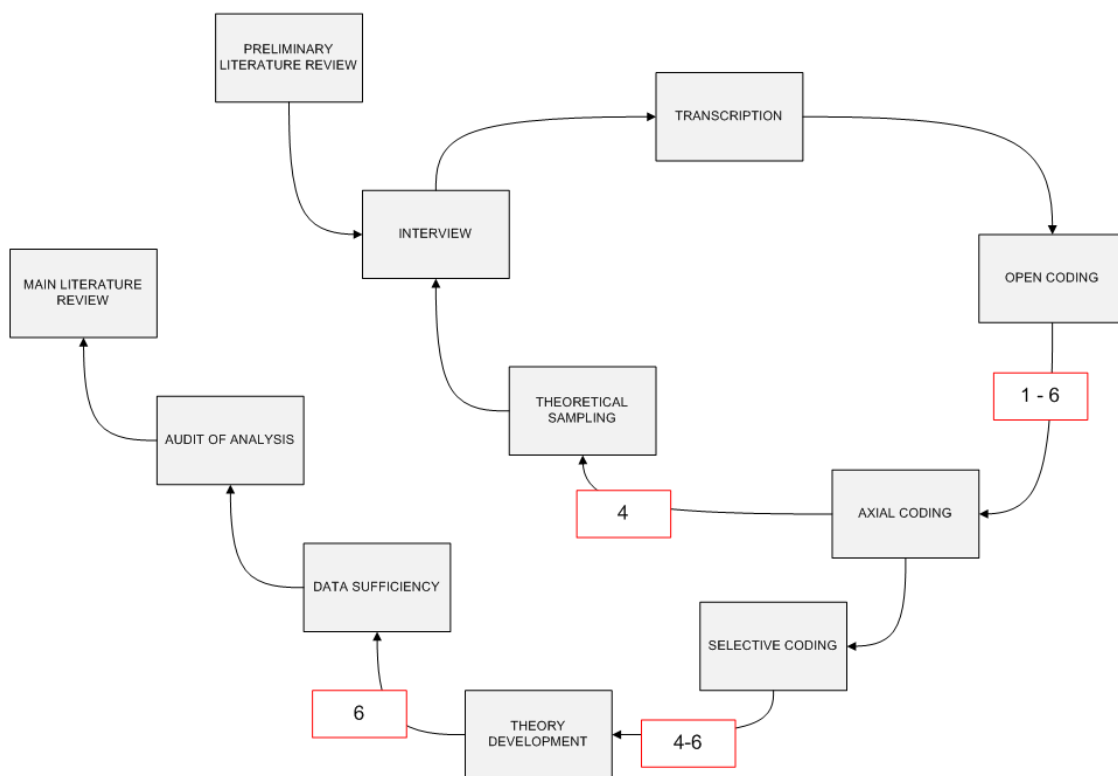


Figure 3.2: stages of data collection and analysis, with interview numbers denoted in red boxes.

## 3.11 Data Collection

### 3.11.1 Semi-structured interviews

In social sciences, interviews are the measure most commonly used in qualitative research. By utilising them in a semi-structured format, this enables the participant's to be guided by

the researcher's open-ended questions, so that their perceptions of a given phenomenon can be explored in depth (Barker, Pistrang & Elliott, 2012). The current study employed semi-structured interviews in line with Lyons and Coyle (2007) discussion on how semi-structured interviews are ideal for grounded theory. Semi-structured interviews differ to their unstructured counterparts, which merely offer guiding prompts to maintain the topic as the focus, or fully structured interviews which ask ordered and pre-set questions with a view to illicit fixed answer responses. Instead, Coolican (2009) describes how the informal but guided nature of a semi-structured interview, means that the researcher has autonomy with the order in which the interview schedule questions are asked. Moreover, they allow the researcher to ask further clarification questions and revisit earlier questions if it is deemed that further enquiry is required.

Prior to the interviews taking place, an interview schedule was prepared (see appendices 6 and 7). The researcher's ontology is that of critical realism i.e. with the assumption that there is a reality of autism which can be identified through the ADOS process, however an individual's meaning of autism is fluid and dynamic and embedded in their interactions (Corbin & Strauss, 2008). Therefore, the aim of the interview schedule was for it to contain open-ended questions covering the main points, which would be delivered with a curious and none directive stance in order to elicit the individual participants thoughts, experiences and associated meanings made (Barker, Pistrang & Elliott, 2012). In line with grounded theory and the employment of theoretical sampling, the first three participants took part in recorded interviews with their data converted to text and subsequently analysed in order to begin the process of developing hypothesis. This initial analysis involved questions being asked of the data in order to think further about particular topics and generate ideas for future questioning, thereby providing rationale for theoretical sampling (Corbin & Strauss, 2008).

Participants took part in one individual semi-structured interview. This was audio recorded, lasted no longer than one and a half hours and included a de-brief. The interviews took place at a time during the working day that was convenient to the participants, at either the offices of the educational psychology service, or at the participant's homes due to their agile working status.

### **3.11.2 Data transcription**

Due to the aforementioned time constraints, an independent transcriber was used to transcribe the interviews. Once the interviews had taken place, the anonymous audio recordings were provided to the independent transcriber who transcribed these verbatim, including pauses, hesitations and fillers in the speech e.g. umm. As the data transcription had been undertaken by an independent party, prior to conducting the analysis, the researcher listened to the individual recording whilst reading the associated transcript in order to immerse themselves in the data.

### **3.11.3 Data saturation**

Corbin & Strauss (2008) describe how within grounded theory and theoretical sampling, concepts and categories are derived from the data until data saturation is reached. Data saturation refers to the point at which no new codes are being generated from new data. Experts in the field of grounded theory suggest this usually occurs between the 6<sup>th</sup> and 10<sup>th</sup> participant. However, it is argued by Dey (1999) that data sufficiency be a more appropriate term to use due to it being very difficult to know when data saturation has been truly achieved (cited in Rees, 2015). Therefore, in accordance with Dey (1999) in addition to the time constraints associated with the research being conducted as part of a doctoral training

programme whilst the researcher was also on placement, the current study aimed for data sufficiency rather than saturation.

## 3.12 Analysis

In order to analyse the data, the grounded theory method as described by Corbin and Strauss (2008) was employed. They argue that in order to analyse the data and take it to a higher conceptual level, it is necessary to interact with the raw data and go further than merely paraphrasing it. Corbin and Strauss (2008) describe a number of analytic tools that can be used to enable deeper interaction with the data.

### 3.12.1 Analytic tools

- **Questioning:** As a fundamental part of all stages of the analysis, four different types of questions should be asked of the data by the researcher. The initial type which enables interaction with the data is *sensitising* questions, in order to find out who, what, how, why, when etc. Next there are *theoretical* questions which explore inter and intra-relationships between and within codes. There are also *practical* questions, which aid with the exploration for the development of concepts. These help to ascertain which concepts are developed and which are not and thereby providing guidance for theoretical sampling, with an aim of reaching data saturation. Finally, there are *guiding* questions which inform amendments of the interview schedule and ongoing analysis.
- **Making comparisons:** This includes both *constant* and *theoretical* comparisons. *Constant* refers to the comparison of all data incidents to ascertain similarities and differences, allowing for differentiation of aspects within categories or themes. *Theoretical* comparison refers to times when the significance or meaning of an

incident is difficult for the researcher to identify and thus requires further analysis at the property and/or dimension levels. At these times, prior knowledge and experience is drawn upon by the researcher in order to assist with their understanding and lead to rich descriptions.

- ***Various word meanings:*** This relates to the importance of the researcher not merely accepting their understanding of the meanings gathered from participants within interviews, due to the possibility of this understanding being erroneous at times. This is particularly in relation to words which enable further analysis. For these words, alternative meanings should be explored within the context of the rest of the interview data, exploring for cues in order for sense to be made.
- ***The flip-flop technique:*** Corbin and Strauss (2008) discuss how this technique can be used in order to extract the significant properties of a concept. This involves the concept being turned “inside out” or “upside down” for alternative understandings/perspectives to be made and a deeper analysis to be gained. This provides guidance for amendments to the interview schedule in order to enable further concept development.
- ***Drawing upon personal experience:*** Grounded theory requires the researcher to take a reflexive stance to minimise bias based on the researcher’s assumptions etc. However, Corbin and Strauss (2008) argue that although personal experience can be an imposition on the data, it can also be used in a positive manner to explore the possibility of alternative meanings.
- ***Waving the red flag:*** Corbin and Strauss (2008) argue that both researcher and participants bring assumptions, beliefs and biases based on culture, gender, training and time. Therefore, it is important for the researcher to hold in mind both their own biases in addition to the notion of them taking on those of the participant. For

instance, if the participant states absolutes e.g. never or always, this should be seen as *waving the red flag* and contradictions should be explored.

- ***Looking at language:*** This refers to the exploration of the nuances of participants language in order to gain rich descriptions. Also at times, participants may use conceptually expressive language, which warrants no further description by the researcher and this can be converted straight to an “*in-vivo code*”.
- ***Looking at emotions that are expressed:*** The importance of emotions as data is raised here and how they should not be overlooked by the researcher due to the potential of offering key contextual information.
- ***Looking for words that indicate time:*** The researcher should be alert to words which relate to time, as these frequently represent a perceptual shift.
- ***Thinking in terms of metaphors and similes:*** Researchers should be alert to the use of these words as they can provide meaning and create vivid pictures.
- ***Other analytic tools:*** In order to extract further meaning and develop categories, Corbin and Strauss (2008) advocate the use of asking “so what”, “why” and “what if” questions of the data. Researchers should also explore the data for how it is structured, its organisation in relation to time and ask if context is provided. Furthermore, the researcher should ask what is the participants knowledge levels, what are their cultural beliefs and assumptions and are wider societal beliefs also embedded within the data?

### **3.12.2 Coding the data**

Robson (2011) discusses grounded theory’s aim being the generation of a theory to provide an explanation for the key elements found within the data. In order to do this, a central core category is sought both at a high level of abstraction, in addition to that which originates in

the collection and analysis of the data. Once the conceptual categories are located within the data, then relationships need to be ascertained, before the relationships are conceptualised through the locating of core categories. Robson (2011) moves on to discuss how the finding of core categories is achieved by performing three different types of coding:

- **Open coding:** the creation of categories
- **Axial coding:** to establish relationships between the categories
- **Selective coding:** To identify the core category or categories.

In accordance with the assertions of Corbin and Strauss (2008), coding began soon after the first interview took place. In order for familiarisation with the data, the interviews were listened to and when independently transcribed, these were also read through. The aforementioned analytic tools as described by Corbin and Strauss (2008) were then employed whilst conducting the different levels of coding as can be seen in figure 3.3.

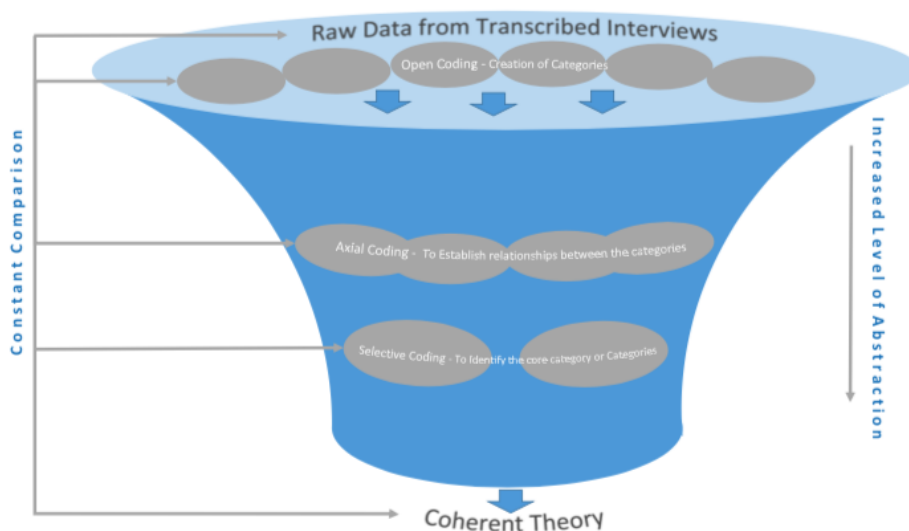


Figure 3.3: Levels of coding



## Open coding

The process of coding commenced with each interview transcript being subjected to open coding. This involved the researcher splitting the data into separate units and asking “what” questions of the data in order to look for meaning within the raw data and create codes which were explanatory in nature, leading to the formation of conceptual categories. Robson (2011) describes the importance of categorical relationships being held in mind, therefore the researcher periodically “stepped back” back from the data, in order to ascertain an overall understanding of the codes arising (see figure 3.4 for example of open coding).

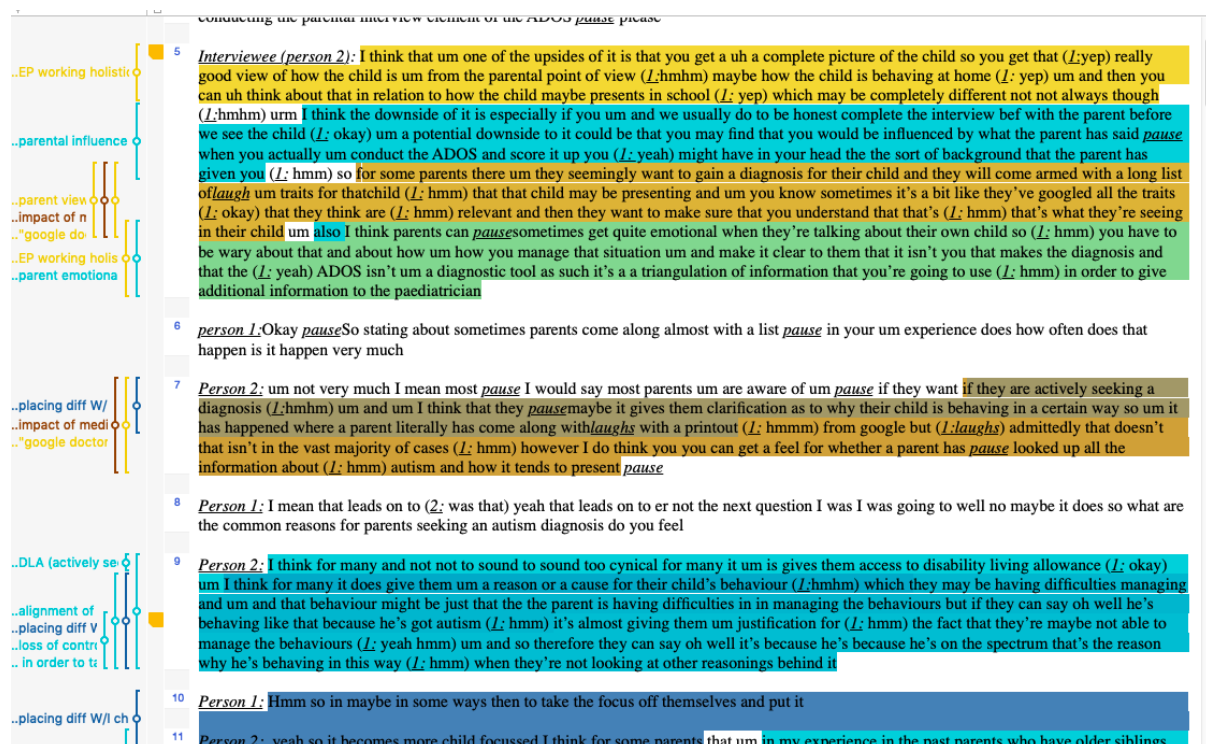


Figure 3.4: Screenshot from MaxQDA 2018 project showing open coding

## Axial coding

Robson (2011) likens axial coding to putting the data back together after the splitting process of open coding and it was here that inter-relationships of the open codes were considered and broader headings were derived. Corbin and Strauss (2008) describe how open and axial

coding are not discrete stages within the process, rather they may be developed alongside one another. In an iterative process, the researcher moved back and forth between the levels of coding in order to refine the concepts and categories (see figure 3.5 for levels of coding).

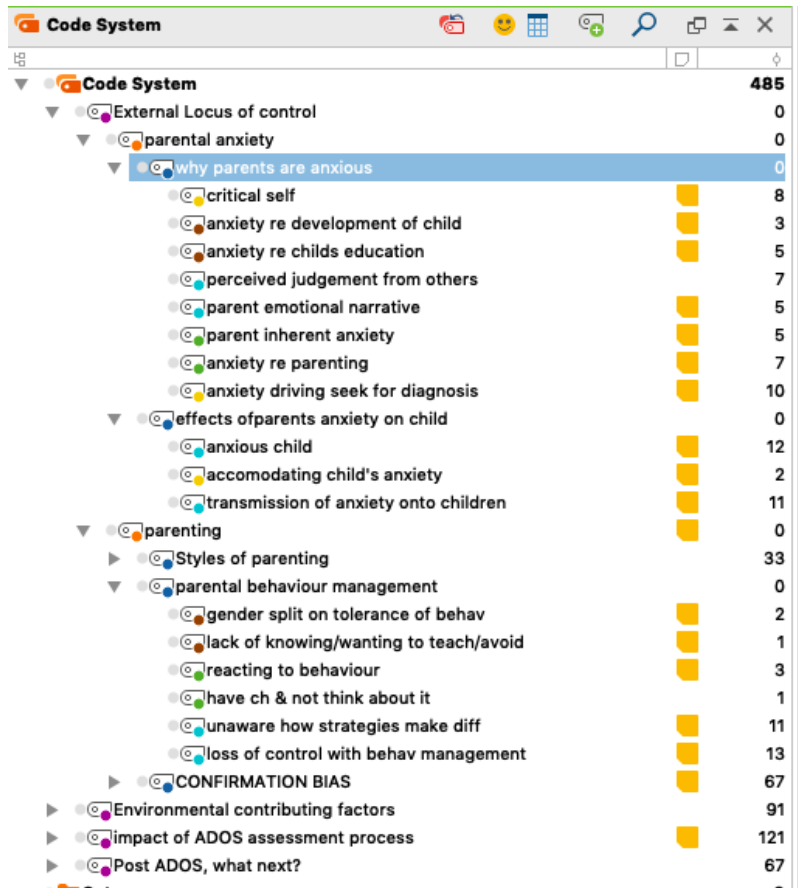


Figure 3.5: Screenshot of MaxQDA 2018 illustrating levels of coding

### Selective coding

At this stage of the analysis, the coding system was examined by the researcher and hypotheses were drawn as to the relationships between the axial codes (See figure 3.6 for example of levels of coding). Robson (2011) describes how it is at this stage of the coding process, that a central theme or core category be selected and focussed upon. This should represent the study's main theme, being the one which is suggestive of having the greatest explanatory relevance (Corbin and Strauss, 2008). Therefore, following the exploration of

relationships, a core category was established for which the criteria laid down by Corbin and Strauss (2008) was followed;

- The core category has to be abstract, whereby it is related to every major category, with them all being placed under it.
- There must be frequent appearances and indicators to the core category throughout the data.
- The core category should be fluent, consistent and logical to the data.
- There should be an appropriate level of abstractness to the core category, so that it leads to further research and formal theory development.
- Through the use of “statements of relationships” the core category should increase in its complexity and power of explanation.

Core Category	Selective Coding	Axial Coding	Open Coding	Memo	Coded Segments	Documents		
External Locus of control	parental anxiety	why parents are anxious	critical self	notion of society not encouraging reflection, but critically. int 4 p23 including feelings of guilt/shame/failure/embarrassment parent internalising blame for their child's behaviour i.e. feeling they've done something wrong notion of if have a diagnosis, will make them feel less responsible	7	4		
			anxiety re development of child	being part of society int 4 p95 notion of child not the dream child they hoped for and being a grieving process	3	2		
			anxiety re child's education	including withdrawing from school EHE int 1 p44 & p46	5	2		
			perceived judgement from others		7	3		
			parent emotional narrative	including those with/without the power to give their voice "cry for help" int 3 p43	5	3		
			parent inherent anxiety	where parent inherently struggles with anxiety/mental health difficulties e.g. int 5 p43  also notion of middle class parents struggling to understand and manage	5	3		
			anxiety re parenting	including feeling deskilled notion of sameroff transactional anxious about child's behaviour/not being able to deal with	6	3		
			anxiety driving seek for diagnosis	notion of magic wand int 3 p36 notion of seeking diagnosis to help understand int 6 p15: parents just thinking here and now, not thinking of longterm impact of label for child desperate for diagnosis looking for kind of solutions that um you know we all try to simplify things to a level that we can kind of understand	10	6		
			effects of parents anxiety on child					
			accommodating child's anxiety			2	2	
	transmission of anxiety onto children	notion of avoiding support int 6 p7  notion of helicopter parenting int 4 78-83	11	4				
	parenting	CONFIRMATION BIAS	placing diff w/ll child	int 2 p13 "so I think um often it's easier for the parent to see it as a within child issue rather than actually try to reflect and think about what they might be doing that might be sort of escalating the situation themselves"	24	6		
			parents blaming external factors	parents blaming other factors re child's behaviour also notion of teaching child to do the same int 3 p30	3	2		
			parent not looking at self/environment	not looking at the effects of their own actions	7	4		
			in order to take away the blame sibling/family member with ASC	comparing behaviour poss genetic link (however notion of learnt behaviour??) should this be under confirmatory bias???	11	6		
			alignment of behaviour with asc		5	4		
			comparing behaviour with others	notion of parent not liking things about their child int 2 p	4	2		
			parental behaviour management	transactional/transference	transactional theory of development - sameroff (systemic lens?) or transference/countertransference - psychoanalytic lens  how emotions effect child's behaviour, effect parents behaviour towards them	3	2	
					gender split on tolerance of behav	men seeing 'boyish behaviour' i.e. rough and tumble'	2	1

Figure 3.6: Excel spreadsheet showing example of levels of coding

### **3.12.3 MaxQDA**

In order to assist with the data coding process, the researcher used MaxQDA, a computer assisted qualitative data analysis software package. Saillard (2011) discusses how the interpretive style of this software is best suited for the interpretation required in grounded theory methodology. The program constructs a hierarchical coding structure where the data can be coded and stored.

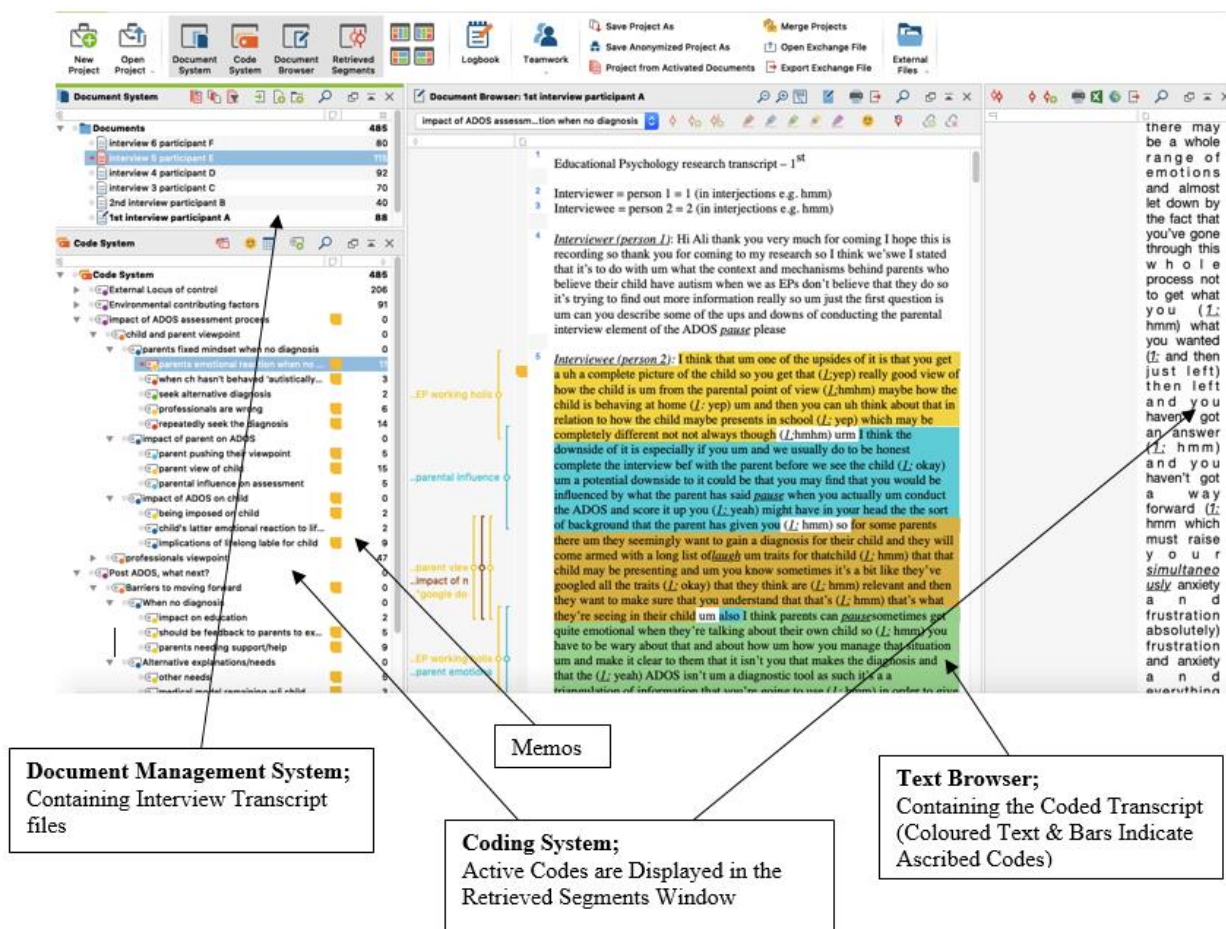
#### **Memos and diagrams**

Within MaxQDA, memos can be created and linked with data and/or codes, in addition to a comment tool being provided to enable notes. These can then be added by the researcher to individual codes.

The use of memos is an important part of grounded theory methodology and their use support the coding category development process. Corbin and Strauss (2008), describe the fluid nature of writing memos and provide a description of ways they can be used:

- “open data exploration”
- For the identification of dimensions and properties in the development of concepts and categories.
- In order to ask questions and make comparisons.
- For elaboration purposes i.e. regarding relationships between transcripts, concepts and categories.
- In order for a storyline to be developed.

In essence, memos are a record of the researchers' ideas and thoughts and are used as a reflective tool throughout the data collection and analysis process. They also facilitate the exploration of patterns within the data. As grounded theory uses theoretical sampling and therefore requires analysis to take place alongside data collection, the process of data collection and analysis can be lengthy. Memo writing therefore can be particularly beneficial for the researcher, as they allow for reflections to be made which can then be revisited, with potential researcher bias being highlighted. Further, they can be used by the researcher for comparison purposes, to ask questions of the data, create hypotheses regarding the meaning of the data and provide an indication as to the saturation of a category (Corbin and Strauss, 2008). (Please see figure 3.7 which shows memos within the features of MaxQDA).



### **3.12.4 Validity considerations**

Corbin and Strauss (2008) discuss the notion of validity being synonymous with quantitative research and how the term “credibility” is a better fit for qualitative research, a term that indicates how trustworthy the research and findings are. The author ensured that the current study was designed and robust methods were employed to ensure that the time and thought that the participants gave would be honoured.

In concordance with Corbin and Strauss (2008), the current research met their eight conditions in order for it to be quality research:

- “methodological consistency” i.e. the researcher followed the relevant procedures of grounded theory research.
- “clarity of purpose” i.e. the researcher was clear that the aim of the study was to build a theory.
- “self-awareness” also termed reflexivity i.e. during the research process, the researcher remained aware of their own biases, interests, values and assumptions. In order to control for this, verbatim transcripts of the audio recordings were produced. Furthermore, during the data collection and analysis, the researcher used memos to record their thoughts and feelings in relation to the research. This reflexive process meant these potential influencing factors were held in mind throughout the process, with the aim of encouraging greater objectivity (Bryant & Charmaz, 2007).
- “the researcher should be trained in doing qualitative research”. The researcher had undertaken both an undergraduate degree in Psychology and a master’s degree in

Foundations of Clinical Psychology and Mental Health. These both included compulsory research projects which had to be undertaken. In addition, over the three-year doctoral training programme, compulsory attendance to research seminars created further understanding of research methods, data gathering and analysis.

- “the researcher has feeling and sensitivity for the topic, participants and research” i.e. in order to capture rich data and perform good analysis, the researcher aimed to “step into the shoes of the participant” in order to develop empathy, respect, honesty and sensitivity and therefore enable an accurate representation of the participants viewpoint.
- “hard work”. The researcher had a willingness to work hard, giving the appropriate time, thought and effort to do the research study justice.
- “willingness to relax and get in touch with the creative self” i.e. the researcher embraced the importance of creativity within the research process in order to get to the heart of the meaning made by the participants.
- “methodological awareness” also termed trustworthiness i.e. throughout the research process, the researcher held in mind that all decisions needed to be credible. Checks were also in place in the form of a viva following submission of the thesis. Lincoln and Guba (1985) extend the notion of trustworthiness in relation to the findings, describing how it involves the creation of four factors. Shenton (2004) noted each factors corresponding positivist criteria and these are shown in brackets next to the headings:
  - **Credibility (as opposed to internal validity):** The researcher used a well-established research methodology and has confidence that the research findings are a true representation of the meanings made by the participants. This was gained by encouraging honest reflections from the participants and



included measures such as seeking anomalies in the data and through data reflections gathered in the form of memo entries.

- **Transferability** (*as opposed to external validity/generalisability*): The researcher endeavoured to elicit rich accounts from all of the participants with an aim of increasing their relevance to other individuals within the same population.
- **Dependability** (*as opposed to reliability/replicability*): In relation to this, the researcher endeavoured for the procedure to be clear and the findings to be consistent with the voices of the participants. This was achieved by the researcher being reflexive throughout the process and ensuring that the grounded theory methodology was followed. Furthermore, the methodological process was supported by the use of MaxQDA, a computer assisted qualitative data analysis computer software package, established for some thirty years (Saillard, 2011).
- **Confirmability** (*as opposed to objectivity*): Qualitative researchers argue that research can never be truly objective with the inevitability of researcher bias influencing the data (Shenton, 2004). With this in mind, the researcher strived to maintain a reflexive stance throughout the research process, being aware of their biases whilst aiming for an appropriate level of neutrality throughout.
- “a desire to do research for its own sake” i.e. rather than because the researcher is being pushed to do so. Although research is a necessary component of the doctoral training programme, the researcher chose a subject which was of great interest and therefore the researcher was motivated to explore this social phenomenon.



### **3.12.5 Researcher bias**

Section 1.2 outlined the reasoning behind this research, including hearing pejorative talk in addition to blame being placed on parents for their child's behaviour. Therefore, as it is anticipated that people can make judgements of parents, I took steps to guard against this, including attention and care being taken to make sure that there wasn't unconscious biases from myself. This included ongoing discussions within supervision, the use of memos as outlined in 3.12.13 and a reflexive focus being adopted during analysis as outlined in section 3.12.4. Furthermore, feedback was given from other people about how terms such as misreading were understood by some to be pejorative; therefore I changed the language to make it absolutely clear that this wasn't the case.

### **3.13 Ethical considerations**

In order to uphold the integrity and high standards of the profession of educational psychology, guidance from The British Psychological Society (BPS) code of human research ethics (2014) and BPS code of ethics and conduct (2018), was followed when conducting the research. The Tavistock and Portman NHS Trust Ethics committee approved the research (see appendix 4). Additionally, discussions were held with the Principal EP within the researcher's LA and full consent was given for the research to take place.

#### **3.13.1 Informed consent**

Participants were all emailed an information sheet (see appendix 5), this included the rationale and aim of the research, in addition to how the data would be collected. Upon receiving verbal agreement and prior to the interviews being carried out, any questions were answered and clarification given before written consent was gained (see appendix 5). The

consent forms were signed and these were stored in a secure filing system. The acting Principal Educational Psychologist (PEP) also provided written consent for the research to be carried out within the LA in which the researcher was on placement.

### **3.13.2 Confidentiality and anonymity**

Both on the information sheet and again as a reminder before the interviews took place, participants were advised that the purpose of the research was to share the thoughts of participating EPs, so in that respect, what they said would not be kept confidential. However, they were informed that the information they provided would be anonymised, so it could not be linked to them. Therefore, pseudonyms were created to use when describing their views and any identifying details were amended to in order protect the participant's anonymity.

### **3.13.3 Right to decline/withdraw**

Participants were advised and reminded of their right to decline to offer the researchers request for particular information, in addition to their right to withdraw from the research at any time. However, with respect to the challenges which would be faced given a late withdrawal of data, as per Smith, Larkin and Flowers (2009) a time limit for this was given and participants were advised that they could decide for their data to be removed up until the point that the draft thesis has been written and submitted (around June 2019).

### **3.13.4 Debrief**

Once the interviews had been completed, thirty minutes was made available for debriefing. This was a time used to discuss the information that had been shared during the interview and to 'check-in' with the participant about how they felt about the process. Participants were

asked if they would like the findings of the research to be shared with them and if so, whether they would like this to be made in person or through a summary sheet. Plans were then made to execute their wishes. Participants were reminded of the contact details for the researcher and for Tavistock and Portman NHS Trust academic quality, should they wish to discuss the research further at a later date. They were also offered a follow-up phone call and signposted to additional support where this was necessary.

### **3.13.5 Avoidance of harm**

The interviews were conducted in a safe space, with time given both during and after for reflection so that the information shared had time to be processed. Furthermore, procedures were put in place so that participants could be signposted to relevant support should they become distressed during the interviews. This included the details of the Head of Academic Governance and Quality Assurance at the Tavistock and Portman, should the participants have any concerns about the researchers conduct.

### **3.13.6 Supervision**

Regular supervision was provided throughout the research process by a Tavistock and Portman NHS Trust qualified psychologist and university tutor. As an experienced research supervisor, the research supervisor ensured that ethical considerations were a regular theme of these sessions.

## **3.14 Literature review**

As previously discussed, the original grounded theory developed by Glaser and Strauss in the 1960's, argued against a literature review prior to data collection. However vigorous debate

continues as to when the literature search should take place. This includes the argument that it is unrealistic to conduct research without any prior knowledge, whilst others offer the notion of reflexivity to transcend the barriers. Dunne (2011) moves on to discuss how after a move away from this position and work with Glaser, Strauss together with Corbin advocated an earlier literature review. Furthermore, as grounded theory is often suggested as an effective methodology to use for areas with little research and therefore a paucity of knowledge, it is argued this is difficult to ascertain without first conducting a literature review (McGhee, 2007, cited in Dunne, 2011).

Therefore, in order to ascertain that the current research was indeed novel and thus valuable to the profession of educational psychology, a brief literature review was conducted prior to commencing data collection. Moreover, this enabled the university's research committees' requirements of a research proposal to also be satisfied.

### **3.15 Chapter summary**

This research aims to explore what leads parents to seek a diagnosis of autism in cases where EPs do not think autism is present. This chapter explained the grounded theory methodology which was employed, affording a rigorous analytic process, in addition to offering congruency with the researcher's epistemological position of critical realist. Furthermore, the chapter discussed ethical considerations and presented the measures which were utilised, with the aim of conducting research which holds methodological awareness at its core.

# 4 Findings

## 4.1 Chapter overview

This chapter will outline the grounded theory emerging from the data. After previously hearing pejorative talk about parents, with blame at times being placed on them for their child's behaviour, the researcher sought to create understanding from the parents' perspective. The aim therefore was to take a compassionate, non-judgemental stance to identify the mechanisms that led to parents thinking their child had autism and the contexts in which this took place. A summary of the complete grounded theory will be followed by an exploration of individual core categories, including extracts from the interview data in order to evidence how these are grounded in the data.

The coding and full analysis completed using MaxQDA is included in a USB drive attached to the thesis.

## 4.2 The overarching theory

In this section, a colour coded system will be used in order to indicate the relationship between the selective codes and the core codes to which they are assigned. These are outlined in table 4.1 below, with the overarching theory shown in figure 3.8.

Colour		Core category
Red	→	EXTERNAL LOCUS OF CONTROL
Blue	→	ENVIRONMENTAL CONTRIBUTING FACTORS
Orange	→	IMPACT OF THE ADOS ASSESSMENT PROCESS
Green	→	POST ADOS: WHAT NEXT?

Table 4.1: Core category colour codes used in theory development

The research question of the current study as outlined in section 3.3 is:

*“What are Educational Psychologists’ views on the contexts and mechanisms that lead to parents thinking their child has autism, in cases when their child does not receive a diagnosis based on results of the ADOS?”*

- The grounded theory proposes that parents think that their child’s behaviour is symptomatic of autism because they have **an unconscious psychological response against ideas that they may, in some way, be connected with their child’s challenging behaviour**. This unconscious psychological response may be sustained through **confirmation bias**, which may enable the parent to regard their **child’s difficulties as attributable to organic factors rather than contextual factors**. Challenges which go **beyond what parents feel able to cope with** combined with **parental anxiety**, may result in thoughts about **alternative explanations to that of autism being intolerable and therefore avoided**.

- There are a number of **environmental contextual factors** which contribute both to the child's challenging behaviour in addition to the mechanisms of parenting skills and parental anxiety, these include:
  - The impact of technology
  - Effects on parenting within societal change
  - Adverse Childhood Experiences (ACE's)
  - Socio-economic factors.
- Having not received a diagnosis, parents are left still **searching for answers**, some believing that the diagnostic process is flawed. **Key barriers** to moving forward are:
  - Parents feel that not receiving an autism diagnosis is incorrect.
  - Parents requiring support.
  - Alternative need/explanation for child's behaviour.
- Linked to the above, **professions hold differing views** about diagnoses, in addition to issues relating to **power relations within the autism diagnostic process**. This gives weight to parental doubts about the accuracy of diagnosis.
- To address the above issues, **early intervention in early years, school and with parents** could support parents who think that their child's behaviour is symptomatic of autism.

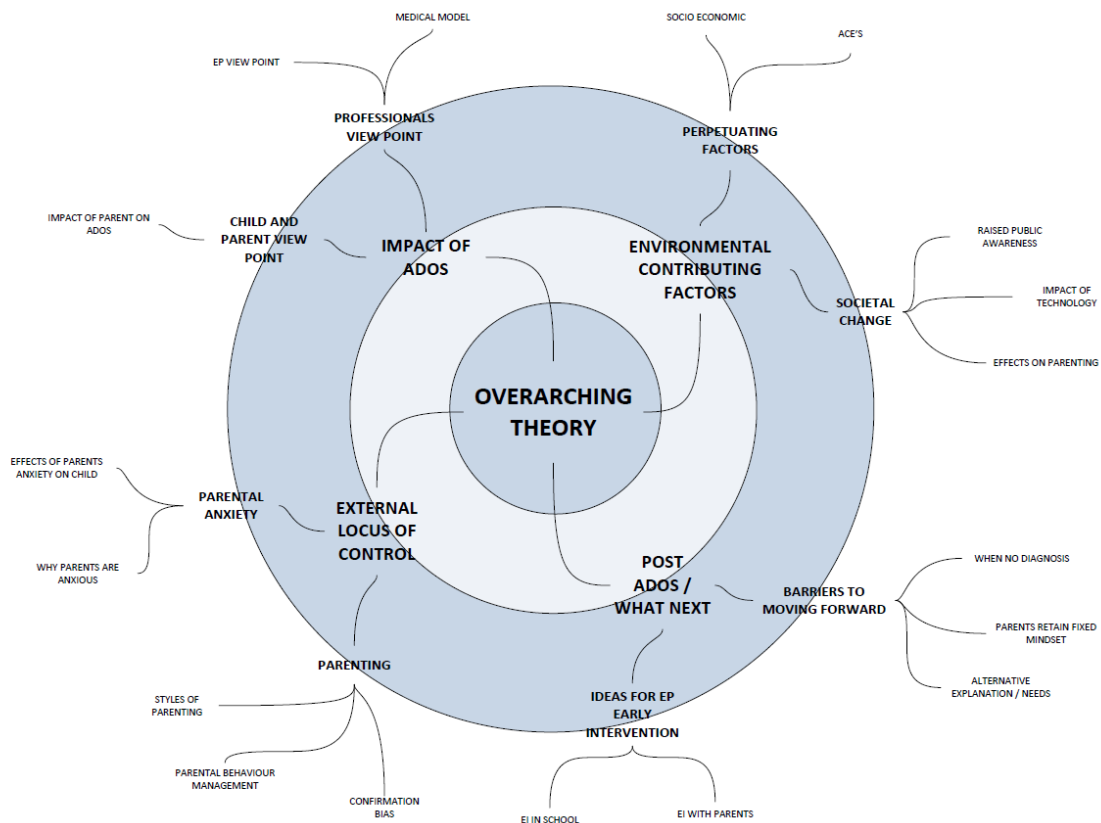


Figure 4.1: Flow diagram of overarching theory

### 4.2.1 Interacting themes

Figure 4.1 illustrates the overarching theory as outlined above. However, the categories and codes encompassed within the theory are not discrete, but in fact interact at different levels of the theory.

Figure 4.2 provides an illustration of interconnectivity and weighting within the grounded theory. As can be seen from the amount of arrows, the external locus of control selective codes of parental anxiety and parenting are the most salient elements of the theory, with it being considered that the environmental contributing factors of Adverse Childhood Experiences (ACE's) and socio-economic, in addition to effects on parenting have the greatest reciprocal effects.



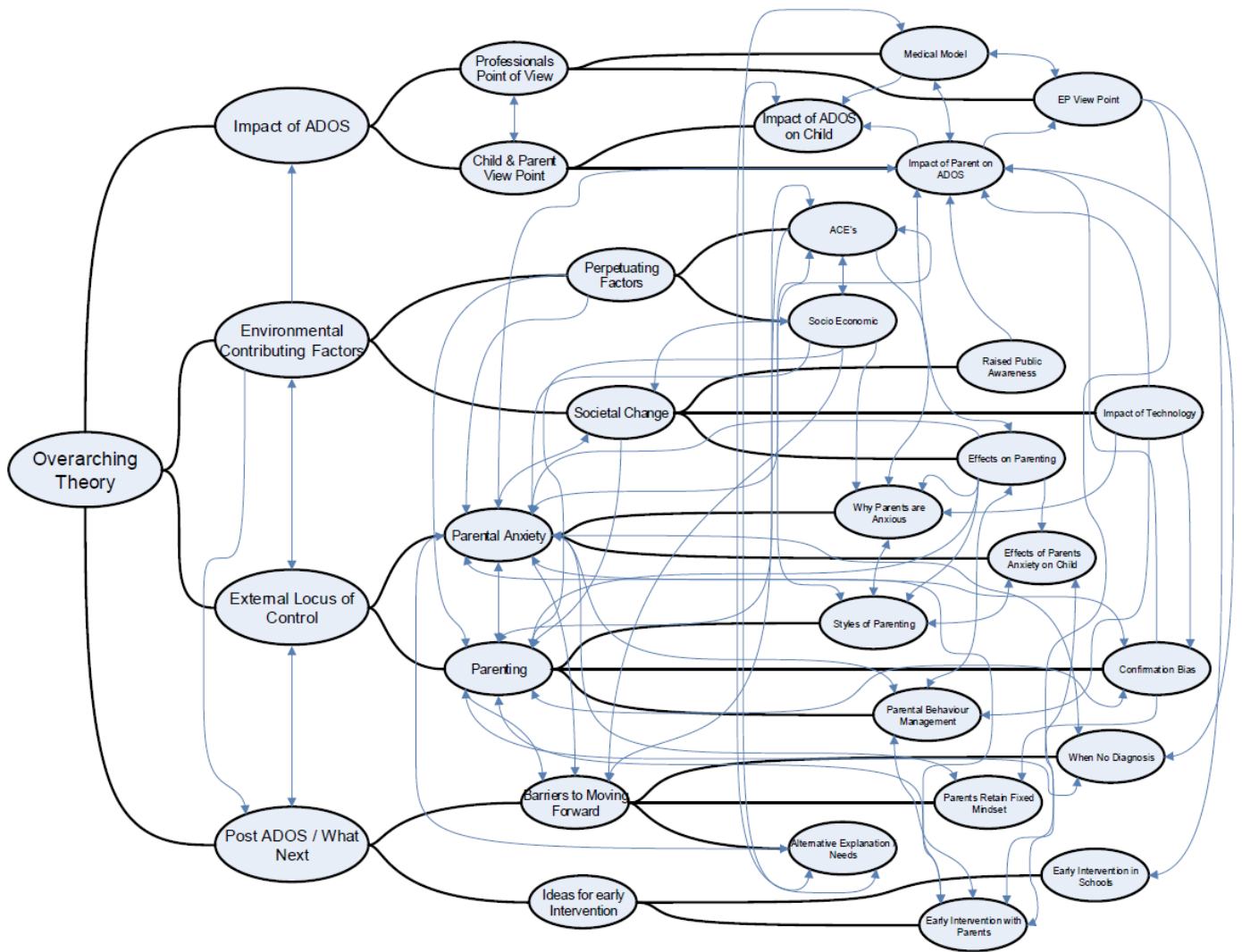


Figure 4.2 Flow diagram of overarching theory showing interconnections

### 4.3 Core categories

The nature of the interconnections show in figure 4.2 is one of complexity and as such, with an aim to explain the theory clearly, in greater depth, in addition to providing evidence on how the theory was developed from the data, the following sections will discuss each core category in turn. This will commence with an opening statement outlining the

interconnectivity, before moving on to discuss the core category using illustrations of the coding and relevant interview excerpts.

### **4.3.1 External locus of control**

As outlined in the overarching theory in section 4.2, some parents have an unconscious psychological response against the idea that they may be in some way responsible for their child's behaviour. Through analysis of the data, mechanisms were identified that underlie what drives parents to think that their child's behaviour is related to autism. This led to the emergence of the core category external locus of control and relates to parents attributing their child's behaviour as being outside of their control i.e. attributable to organic factors rather than being in relation to environmental context.

Parental anxiety and parenting skills make up the selective codes for this core code and as shown in figure 4.2 these selective codes have the biggest weighting within the theory, with a lot of interconnections with other factors. A concept map to illustrate this is shown in figure 4.3, in addition to a screenshot of the MaxQDA coding structure in figure 4.4 both of which are shown below.

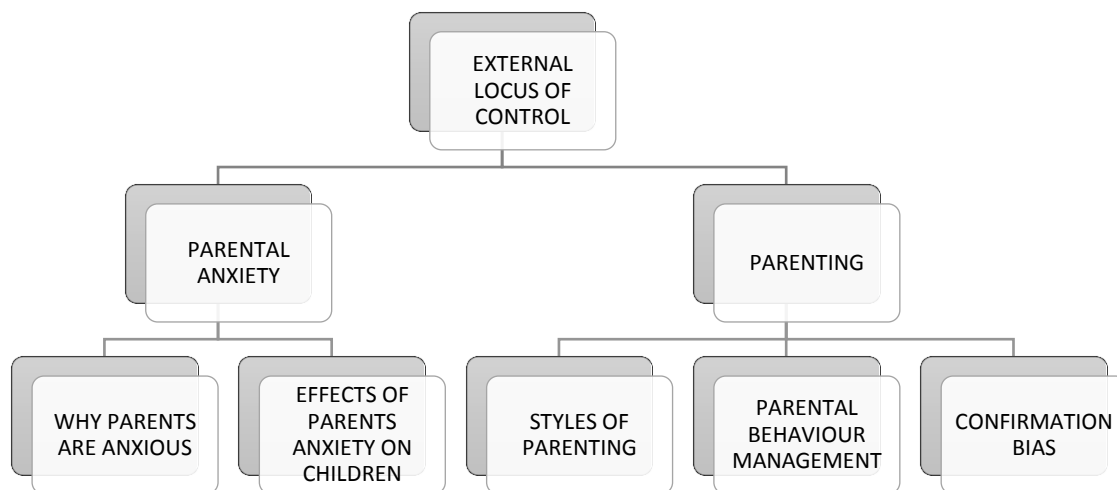


Figure 4.3: Concept map for the core category “external locus of control”



Figure 4.4: Screenshot from MaxQDA of core category “external locus of control”

#### **4.3.1.1 Parental anxiety**

A strong theme running throughout the participant's interviews related to parental anxiety. Through analysing the data, this was identified as a mechanism driving parents to think that their child's behaviour is related to autism. This was also one of the most significant themes, having reciprocal interactions with several other factors within the theory, including parenting, the other selective code within this core category. Of particular note are the interactions with ACE's, socio-economic and effects on parenting (i.e. loss of familial and cutbacks to professional support available) and how when any or sometimes all of these factors are present, parental anxiety can be exacerbated, which can unwittingly have a direct impact on their child.

These participants described evidence of anxiety being present within parents:

*"So some parents they bring their own anxiety... to it and it's their...anxiety perhaps that's driving... some of it"*

*Participant D, paragraph 5*

*"I think... parents can actually be quite anxious about what's... happening and what's going on"*

*Participant C, paragraph 11-12*

A participant discussed some of the things that parents may be anxious about:

*“I do think that they’re anxious about everything that their child does...toileting, feeding all...those aspects of...what children do that...makes parents... highly anxious and if they...don’t perform as they’re expected to... then that will drive...anxiety”*

*Participant E, paragraph 47*

Another participant spoke about the notion of parents being anxious due to their child’s behaviour:

*“then parents...being anxious every time the child comes home...because they don’t know what they’re going to be faced with”*

*Participant E, paragraph 71-72*

The notion of the high levels of anxiety the parent’s may be experiencing was discussed by some participants and the effect that this can have on children:

*“...felt their all of this child’s problems were really wrapped up in in parental anxiety”*

*Participant F, paragraph 7*

*“I think...parents are highly anxious... there’s lack of understanding of how their anxiety may well impact on... the child...lots of these parents have their own difficulties... high levels of anxiety and mental health difficulties, forming relationships...with children which will...*

*undoubtedly be having an impact...on the children*

*Participant E, paragraph 43*

*“Actually our behaviours as parents...are transgenerational so they learn you know from us they ...watch our behaviours our reactions to things they do it and they get the same emotional reaction that we get so if we’re... highly anxious or panicky... that will go in to our children”*

*Participant C, paragraph 22*

Several participants also discussed the presentation of anxious children, the lack of general understanding of this and how this can lead to anxious behaviour being thought of as due to autism:

*“Kids don’t have the language to say mum I’m anxious... I’m really worried about this or I’m angry...we sit down and... say what’s going on...why do you think you might be doing this but most parents wouldn’t they just react”*

*Participant D, paragraph 69*

*“So there’s a lot of crossover between high levels of anxiety and...ASD...and it can be linked and sometimes the behaviours are actually just anxiety and not the ASD...but those highly anxious young people and they hence at secondary school that can be very very challenging”*

*Participant C, paragraph 44*

*“I think there’s a real lack of understanding generally within the population about the emotional impact of anything on behaviour and how behaviour impacts emotionally on everybody...and by far and away the biggest of those is anxiety...but interesting...when you ask parents about their child’s behaviour and if you say is your child anxious they often don’t think that they do have an anxious child...because they don’t recognise what anxiety looks...like”*

*Participant E, paragraph 39*

The interaction between the parent’s anxiety, their child’s behaviour and how this can lead to the parent being overprotective was also raised by this participant:

*“Helicopter parenting I’ve heard it referred to... where they’re on top of everything... and there’s no...room for manoeuvre...nobody wants to see their child hurting but actually it’s the only way they learn... by having difficult experiences that they have to learn how to work through”*

*Participant D, paragraph 79*

The notion of parents not always being reflective was also discussed by several participants, for example:

*“They don’t want to look at things that they may not be doing right that they’ve done wrong... there there’s a lot of guilt in parenting isn’t there and feeling guilty... you know you’ve done it wrong or... you’ve screwed them up or you’ve done this...a lot of parents are looking for a reason...but they want it...to be the...child is the problem... not...what’s going on around that could be the problem”*

*Participant D, paragraph 9*

*“...but people aren’t encouraged to be reflective...it’s to be self-critical...what have I done wrong...not okay well this has happened how may I have done that differently”*

*Participant D, paragraph 23*

This participant linked the anxiety that parents feel with perceived judgement regarding their parenting within society:

*“I do think there is more anxiety out there now because...there’s a lot more to worry about...but...I do think there’s a lot of judgement in society against parents”*

*Participant D, paragraph 31*

In relation to the painful feelings that anxiety entails for parents, this participant discusses the notion of unconscious defence mechanisms being used to reduce anxiety:



*“I think it’s... easier...to project onto some it’s someone else’s fault it’s something about them that’s the wrong then to then to be self-critical... cos no one likes to think they’re getting it wrong do they”*

*Participant D, paragraph 21*

The parent’s anxiety can lead to an impact on their child’s education:

*“it’s a bit sad really, school have been saying that he’s fine that he’s manageable... it’s parental choice that they’ve taken him out of school he’s only on a part time timetable”*

*Participant A, paragraph 46*

And when unconscious defence mechanisms are being used by parent’s to protect against their anxiety, this can make it difficult for support to be provided:

*“(I) felt their all of this child’s problems were really wrapped up in in parental anxiety...a year later it resurfaced and the young person had been...referred into the pathway... I brought this young person up at the...meeting with paediatricians... I had a really long conversation with another ISEND (inclusion, special educational needs and disabilities) practitioner who cried on the phone...about the frustration...of working with this family and how she...felt that the parent was really avoidant”*

*Participant F, paragraph 7*

#### 4.3.1.2 Parenting skills

Together with parental anxiety, parenting was also a prominent theme within the theory. As previously noted, there are reciprocal interactions with parental anxiety which can have a direct impact particularly on confirmation bias and parental behaviour management. Furthermore, similarly with parental anxiety, the effects on parenting within societal change i.e. less familial interactions, loss of professional support and effects of social media/media can have a particular impact on parenting skills.

All of the participants shared views on the role that they felt parenting had to play for parents who think that their child's behaviour is related to autism. For instance:

*“It's not to say that these children don't have difficulties...that they don't have social communication difficulties...that they don't have difficulties with interaction with other children...have difficulties with empathy and managing emotions and all those things that make up... what looking like an autistic child might be but ...it's the way that it's...managed by a lot of families and if you're under stress... and children are picking up that level of stress then all those things...that might be present in lots of children just become overwhelming... for some children”*

*Participant E, paragraph 21*

This participant shared their views on how parenting styles are formed:

*“I think parents bring their own experiences...their own upbringing to their parenting”*

*Participant D, paragraph 7*

During the interviews, Baumrind's (1967) different styles of parenting were discussed and this participant shared their views on the effects that authoritarian parenting can have on children's behaviour:

*"I think... authoritarian... obviously...could lead to children being very...highly anxious... but...also very passive... dependent... if you think of fight or flight... you know...involved in fight all the time because they're...butting up against that"*

*Participant F, paragraph 60*

Contrasting with an authoritarian style of parenting, this participant shared views regarding the effect of indulgent parenting:

*"There are some parents who are really laid back in their parenting... children... haven't been given the... appropriate boundaries... I could even think of... a child that I've seen this week... I know...what goes on at home... he's managed in...a very nice... gentle kind of way...he becomes very hyper and...very anxious very quickly if somebody doesn't step in to define the boundaries... in nursery when he starts to do things if somebody doesn't stop that immediately...and tell him...or try and distract him... it gets beyond a position where he can be...contained... easily... there are the parents who are not giving those kind of boundaries"*

*Participant E, paragraph 25*

Still on the theme of parenting styles, this participant discussed the notion of when parenting styles are conflicting between parents:

*“It is pure behaviour...they’re not dealing with it he is very authoritarian she’s kind of oh you shouldn’t do that but come have a cookie...I think when you’ve got... parents who don’t parent together... or who have very different parenting styles...and can’t find a common ground that doesn’t help”*

*Participant D, paragraph 7*

And this participant shared views on when the conflicting parenting styles is located within the same parent and the effect of this on the child:

*“The dad he comes from quite...a difficult background boarding school military...he’s either really authoritarian... or really soft there’s no middle ground... so they never quite know what they’re gonna get”*

*Participant D, paragraph 45*

Moving on from Baumrind’s (1967) styles of parenting, the notion of how a parent’s gender can affect their parenting was discussed by this participant:

*“ It’s all often the mum... who comes in and so what you get is very often one parents’ side of the picture...and quite often...there’s a different side of the picture...from the other parent...it’s more likely to be fathers... because they interpret the behaviour particularly if it’s around boys as just being boyish...behaviour and so being quite kind of tolerant of the of*

*behaviours... almost encouraging...particularly when it's younger children... then of course if that's not addressed when when they're younger then.. it becomes more...difficult"*

*Participant E, paragraph 26-29*

This participant discussed the hypothesis of parenting, raising the notion of lack of parenting skills:

*"for some parents...I think they probably are in such a position that they can't see how their parenting might change something... therefore it's easier to say it's within child... whether or not it's to do with their parenting, I think for some parents it's easier to accept...within child because they really can't haven't got the skills...to parent differently"*

*Participant E, paragraph 33*

And the notion of taking away the blame from parenting was mentioned by several participants. For instance:

*"I think for parents... if they are concerned about...behaviour they like the diagnosis because it takes the blame off of them"*

*Participant E, paragraph 21*

*"parents are for whatever reason having some very difficult behaviour from that young person in the home and they're finding it incredibly difficult to manage and cope and actually they want a reason for that that isn't about them...they want a like... my child is autistic"*

*that's why they behave like that so therefore it kind of reneges... some parental responsibility”*

*Participant C, paragraph 14*

*“...but also take the blame away from them as parents”*

*Participant B, paragraph 38*

A strong theme arising during the interviews was the importance for children of parents giving them consistent boundaries and how some parents seem to be unaware how strategies can make a difference. For instance:

*“some they struggle with parenting issues, boundaries and having a structured household. So therefore if their child is misbehaving or having meltdowns, it sometimes isn't that it's ASD, it's that they can't discipline them in ways other parents would”*

*Participant F, paragraph 25*

And this participant raised the notion that parents appear to believe that receiving a diagnosis will wave a magic wand, providing strategies to make the behaviour all better:

*“often parents say... if I knew what it was then...that knowledge then... provide them with the strategies...clearer strategies in terms of what they would do...what the consequence or how they can cope or manage that better but actually it doesn't help does it because we all know*

*that you can apply those strategies without having that diagnosis...and apply them and support the young person with their strategies without... that diagnosis...and still be effective”*

*Participant B, paragraph 18*

A golden thread running throughout all of the interviews was that of parents placing the reason for the child’s behavioural difficulties as being within child:

*“I think by the time they get to the point they had an ADOS... sometimes they’ve had months if not years waiting...and behaviour has...deteriorated...it’s easier to see it as a within child problem”*

*Participant E, paragraph 9*

*“if it doesn’t go right well there’s a reason why and that’s within the child”*

*Participant D, paragraph 29*

In relation to confirmation bias, some participants discussed the possible reasons for parent’s believing their child’s difficulties are of an organic rather than contextual nature:

*“they’ve usually...read up or been given...or found information about autism somewhere...you often feel that they’re... presenting a picture... describing symptoms that you want to see rather than...those that may actually be there...they’ll see it as autistic rather than that it might be as a result of attachment or poor parenting or any other kind of... condition”*

*Participant E, paragraph 5*

*“often it’s easier for the parent to see it as a within child issue rather than actually try to reflect and think about what they might be doing that might be sort of escalating the situation themselves”*

*Participant B, paragraph 13*

This participant discussed how parents may have come to this opinion as their child’s behaviour difficulties may present in similar ways to autism:

*“...you see a similar kind of presentation in young people who...have got needs through their environment rather than an underlying communication need because they do look quite similar sometimes”*

*Participant B, paragraph 54*

Once again holding in mind confirmation bias, some mentioned the notion of parent’s comparing the behaviour of their child with a sibling or relative with autism and therefore believing the reason for their child’s behaviour is due to inherited/genetic links. For example:

*“a couple of times that’s happened where somebody close to them gets a diagnosis and then they see the similarities and think...that’s what it must be”*

*Participant B, paragraph 56*



*“sometimes a reason for parents wanting a diagnosis is that a relative has recently got one... and maybe similarities are seen between behaviours...people who don’t really understand what autism is often focus on the you know the sort of behaviour presentation I suppose...as a reason for autism”*

*Participant B, paragraph 54*

### **4.3.2 Environmental contributing factors**

Through analysis of the data, the core category of environmental contributing factors emerged. This relates to contextual factors which have reciprocal interactions with other factors within the theory, contributing to a child’s challenging behaviour, in addition to parental anxiety and subsequent parenting skills. The theory suggests that the interacting nature of these risk factors are fundamental in the constraints that some parents face and can lead to an unconscious psychological response whereby parents attribute their child’s behaviour to autism.

This core category encompasses the two selective codes of societal change and perpetuating factors i.e. contextual factors which can maintain a child’s challenging behaviour, in addition to parental anxiety and parenting skills. A concept map is shown in figure 4.4, together with the MaxQDA code systems for this category shown in figure 4.5.

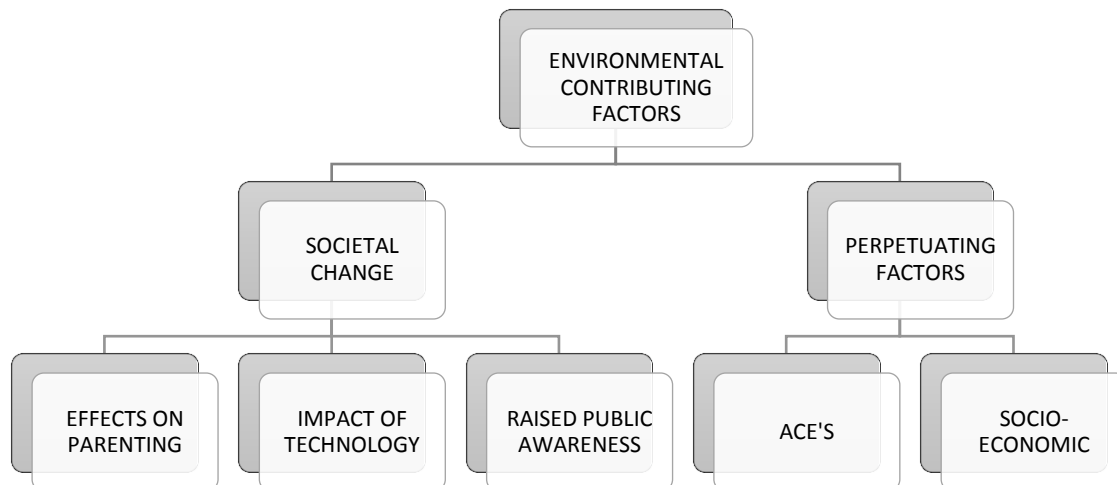


Figure 4.5: Concept map for the core category “environmental contributing factors”

Code System	Count
Code System	485
External Locus of control	206
Environmental contributing factors	0
societal change	0
effects on parenting	33
impact of technology	0
impact of tech on social communication	6
impact of media on awareness/misunderstanding	9
Raised public awareness	11
perpetuating factors	0
ACE'S	0
Child anxious due to trauma	3
impact of environment	6
domestic violence	1
bereavement and loss	1
similarities with attachment	9
Socio-economic	0
impact of socio-economic factors	6
DLA (actively seeking)	6

Figure 4.6: Screenshot from MaxQDA of core category “environmental contributing factors”

#### 4.3.2.1 Societal change

The societal change selective code relates to the historical shift in society, the effect this has on parents, their anxiety, their parenting skills and directly onto their children and the ways in which this can drive the mechanisms for parents to attribute their child's behaviour to autism.

Changes in society have, in some families, led to decreases in familial interactions which have arguably impacted on language and communication skills. This participant's vignette discusses a range of issues relating to this, including parents not understanding speech and language difficulties, having different expectations about what constitutes good communication skills, in addition to the notion of parents having poor communication skills and the effects of modelling these skills to their child:

*"I think it's a lack of understanding of language and communication difficulties I don't think parents understand...what we mean by communication... if you ask a parent what their child's language and communication skills are like they'll generally say they, oh they're quite good...so they don't really understand what we mean...it's possible that for many of these children they're not getting good communication models at home they're not learning those good...forms of communication...they don't understand about reciprocal communication"*

*Participant E, paragraph 11*

This participant discusses societal change in relation to changes to the extended family unit and how this used to provide role models for children:

*“I think there isn’t those role models perhaps now that...there were years ago and I’m not saying they were great role models then but you at least had something...to model on... you had aunts and uncles that you could look at... for a variety of reasons there isn’t a nuclear family anymore... life has changed and what families look like has changed”*

*Participant D, paragraph 39*

These two participants shared views on how the decreased extended familial interactions can impact on the parent who is trying to deal with and understand their child’s behavioural difficulties:

*“...don’t think people...ask for help as much there isn’t the older generations to ask... necessarily you know there isn’t that nuclear family always...to go back to”*

*Participant D, paragraph 37*

*“I think it’s capacity probably and it’s that safety net your family safety net...and support network that...you’ve got...about whether you feel you can cope with it...or whether actually you don’t and you need some help and you... seek to find to find that help through the state really essentially”*

*Participant C, paragraph 40*

In addition to the loss of extended family support, the loss of professional support was discussed by this participant:

*“This is the thing we don’t have a health visiting service...like we used to...yes there are parenting groups but there are few and far between now...even ten years ago there used to be a lot more... children centres and things like...that you could access”*

*Participant D, paragraph 51*

Another noted societal change discussed, was that of the impact that social media has on parenting:

*“I’m not saying that that parenting’s harder than it ever was but in some ways it is... I don’t think social media helps”*

*Participant D, paragraph 11*

Similarly, the impact of social media was discussed by another participant, this time in relation to children:

*“I think people live their lives very much more out in the open...than they used...to do and... I think that has a major impact...generally we keep hearing about mental health...and I think that does have an impact on some of...the kids”*

*Participant E, paragraph 47*

Furthermore, the notion of parents seeking help via social media was raised by this participant:

*“a lack of asking for support and...it’s looking for in the wrong places...like within... peer groups...like social media”*

*Participant D, paragraph 43*

Technology was discussed on a wider level and how this can impact on the child’s language and social communication skills:

*“With the... rise of technology life has changed...we see a lot of that don’t we with kids coming in without the language skills... because families don’t talk they’re shoved on the iPad...you know they have the iPad or the phone at dinner...there aren’t those interactions anymore, so kids are becoming much more insular”*

*Participant D, paragraph 13/15*

Remaining on the subject of technology, a different participant discussed children's motivation for social interaction:

*"...differences within young people... in terms of...how much do they want or are motivated by social interaction...don't necessarily mean they're on the spectrum it might just mean that they prefer video games or find social...interaction difficult...doesn't necessarily mean it has to be...a diagnostic criteria"*

*Participant B, paragraph 42*

In relation to perceptions of what leads parents to think that their child's behaviour is related to autism, the impact that media has on this misunderstanding was discussed by several participants. For instance:

*"I think too much information out there...parents jump to oh that's autism...google doctor is right on many levels but not so great when you're...looking for a reason so I think...technology and having information at our... fingertips... gives parents a very easy way to look for something that's wrong"*

*Participant D, paragraph 85*

*"Some parents...they seemingly want to gain a diagnosis for their child and they will come armed with a long list of... traits for that child...sometimes it's a bit like they've googled all*

*the traits...that they think are... relevant and then they want to make sure that you understand...that's what they're seeing in their child"*

*Participant A, paragraph 5*

A further contextual factor that was discussed in relation to societal change was that of raised public awareness. This included extra support at school, in addition to Education Health and Care Plans (EHCP) and extra funding:

*"...they feel that if there's a diagnosis there will be further support and further recognition of that...in school and I think often parents feel that if their child has a diagnosis of autism this will sort of open the door to...lots of different services lots of different...support mechanisms"*

*Participant B, paragraph 20*

*"maybe they'd be thinking... looking along the lines of a an education health and care plan to get more support when it you know a diagnosis doesn't mean that... necessarily...going to lead to that but I think a lot of...parents think it does"*

*Participant A, paragraph 42*

Similarly raised awareness was discussed, this time in relation to autism and how this can inadvertently lead to misunderstanding about causes. For example:



*“I heard somebody recently saying that they didn’t want their child to catch autism...they were talking about it in relation to...vaccination because there’s been quite a thing... recently about... MMR (Measles Mumps and Rubella vaccination) again... that was being looked at and people were saying I don’t want my child to catch autism... so they have this idea as well that it is something that’s out there to be caught”*

*Participant E, paragraph 13*

#### **4.3.2.2 Perpetuating factors**

##### **Adverse experiences**

This selective code outlines two factors viewed by the participants to be perpetuating children’s behavioural difficulties, in addition to parenting skills and parental anxiety, leading to attributing the child’s difficulties to be organic in nature.

The first of these was in relation to Adverse Childhood Experiences (ACEs). A variety of adverse childhood experiences were discussed including bereavement and domestic abuse. Attachment difficulties were also discussed and it was felt that although this is not explicitly listed as one of the direct and indirect experiences (BPS, 2019), the toxic stress that can be experienced by a child as a result of attachment difficulties e.g. stress responses being activated without the support of a protective relationship, warranted its inclusion here.

Some participants listed the adverse experiences, others used the terms ACE’s to discuss the issues more generically. For instance:

*“...those children that have experienced trauma...their behaviour actually again is potentially very similar to autism...but their reasons for their behaviour or their high anxiety is obviously different isn't it because...the life experiences they've had the abuse...as a young person so...that's different*

*Participant C, paragraph 54*

Similarly, this participant gave a case example of a child who had experienced adverse experiences and how upon hearing the details of the young person's background, they had challenged a paediatrician about a potential autism diagnosis:

*“This young person had a diagnosis...of autism...quite a new diagnosis ...I found out that this young person had witnessed significant domestic violence...to the point where...the mother basically used him as a shield...it went on for a long period of time ...there was another hypothesis...I did speak to her (paediatrician)... I told her a bit of the family background and she said...the mum did mention that...I think he'd also had...a significant bereavement of a...grandparent as well ...I... said...do you not think that makes the diagnosis a little bit ... it's different...explanations...and he's now gonna get a diagnosis for life”*

*Participant F, paragraph 62*

The similarities between the presentation of autism and attachment difficulties was also discussed by several participants:

*“there are many different...kind of ASC traits...both in terms of... social communication side of it but then also the...restricted and repetitive behaviours...if we think about...attachment as a broad sort of term...it’s...generally well reported now that... some children...who have experienced trauma...have not developed...attachments... can look like both you know autistic children and children with ADHD as well”*

*Participant F, paragraph 41*

*“any kind of behaviour they’ll see it as autistic rather than that it might be as a result of attachment or poor parenting or any other kind of...condition”*

*Participant E, paragraph 5*

*“children...having attachment needs can impact on the development of social and emotional...development...having any disrupted attachment early...in life can then lead to young people...having a similar kind of presentation ...they don’t know how to form secure relationships because...never been modelled and demonstrated to them...they really struggle with eye contact for those reasons...because they never really were helped to understand it from a really early age when it was...important in their developmental terms”*

*Participant B, paragraph 42*

Set within the context of their own training some twenty years ago, the expected increase in the prevalence of children with attachment difficulties was also discussed by this participant:

*“there are lots and lots of students with attachment difficulties... but then it’s misread... attachment is going to become an even bigger problem...I think... interesting when I did my training ...all the attachment theory stuff was being dissed you know ...so in twenty years that’s really...changed...it’s been a very definite swing... to attachment and ASD”*

*Participant E, paragraph 47*

### **Socio-economic status**

The second factor under the selective code of perpetuating factors was in relation to socio-economic status, the impact of this on parent’s levels of stress and anxiety and thereby the effect on their parenting skills and subsequent child’s behaviour. As outlined in the overarching theory, with the levels of stress and anxiety incurred, the parent may have an unconscious psychological response to the thought that they may in some way be responsible for their child’s behaviour, leading to them thinking that their child’s presentation is due to autism.

This participant shared views on the impact of socio-economic factors on families within the geographical area of the LA in which the children are assessed:

*“I think that there are lots of stresses on parents today... that...weren’t there...in the past ...money finances...there are families who really struggle ...to provide...for family...I think...parents...their own experiences ...that’s a big part of it...I think aspirations for families in a place like...are very...different than in other parts of...the country...poverty...mental health just generally within the community...levels of crime...there’s a big melting pot of things that are highly stressful”*

*Participant E, paragraph 47*

And this participant discussed how anxiety may be induced by a parent's socio-economic status:

*“a lot of parents have to work it's the reality like...you can't survive without it... I think that builds anxiety and feelings of guilt...which often...gets passed on to the child without you realising”*

*Participant D, paragraph 11*

Furthermore, in relation to socio-economic factors, several participants raised the issue of parents seeking Disability Living Allowance (DLA) as a by-product of their child receiving an autism diagnosis. For instance:

*“I think for many and not...to sound to sound too cynical... it...gives them access to disability living allowance”*

*Participant A, paragraph 9*

*“for some parents there definitely is financial reason...they want some kind of benefits...some parents are very aware of the...benefits...that they might get”*

*Participant E, paragraph 33*

### **4.3.3 Impact of ADOS assessment process**

This core category was constructed from participants' views surrounding the ADOS assessment process. The core category of 'impact of the ADOS assessment process' captures

when parents think that their child’s behaviour is indicative of autism and the influence this can have on the professional’s views and thereby the assessment process and resultant outcome. The interaction between parental anxiety and impact of parent on ADOS is of importance here, together with the interaction between the impact of ADOS on child and the post ADOS code of alternative explanation/needs. Moreover, this category captures the power imbalances within the roles of the different participants within this process, in addition to the significant point of the impact of the ADOS on the child.

The concept map for this core category is shown in figure 4.6 and the MaxQDA code system is shown in figure 4.7.

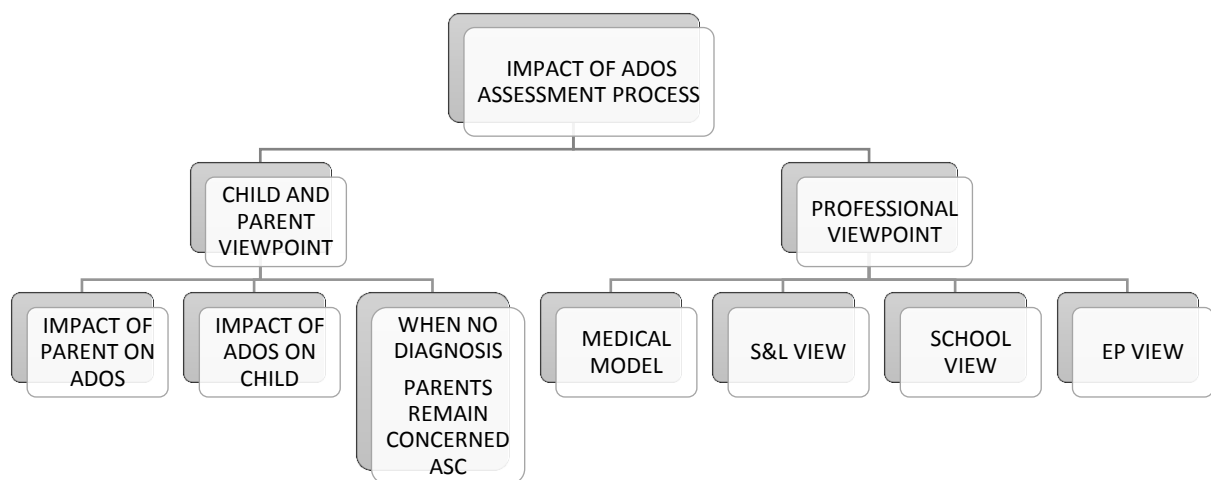


Figure 4.7: Concept map for the core category “impact of ADOS assessment process”

Code System	Count
External Locus of control	206
Environmental contributing factors	91
impact of ADOS assessment process	0
child and parent viewpoint	0
impact of parent on ADOS	0
parent pushing their viewpoint	5
parent view of child	15
parental influence on assessment	5
impact of ADOS on child	0
being imposed on child	2
child's latter emotional reaction to lifelong lable	2
implications of lifelong lable for child	9
professionals viewpoint	0
medical model	0
diff view/focus of medical model	6
paediatricians being reliant on parent voice	3
EP challenging Paediatrician	2
S&L view	3
school view	7
EP view	0
EP working holistically	19
ADOS - clinical vs EP assessment	7

Figure 4.8: Screenshot from MaxQDA of core category “impact of ADOS assessment process”

#### 4.3.3.1 Child and parent viewpoint

The first selective code to be outlined in this core category represents participant’s views regarding the role that parents have to play in the ADOS assessment process, in addition to the impact of the assessment process on the child.

This participant sets the context as to EP involvement within the autism assessment process and the role of giving parents a voice:

*“A lot of cases that we deal with when we do our ADOS’s are the ones where the paediatrician’s really not sure...sometimes the parents haven’t felt heard or...they’re unsure about their views so...that voice is just a really important part of the process”*

*Participant C, paragraph 6*

When considering parents attributing autism due to an unconscious defence mechanism sustained through confirmation bias, these participants' views move on to discuss the ways in which the parents can influence the assessment process, by relaying the symptoms that support their belief. This was also taking place within a relationship where there is a power imbalance, with the power weighted towards the expert who has the ability to make the diagnosis:

*“I think the parents that come when they're... seeking a diagnosis those are the ones that are very keen to tell you absolutely every trait...that they're seeing at home”*

*Participant A, paragraph 21*

*“I think by the time they get to...an ADOS they've had a very long wait...sometimes they've had months if not years waiting...and behaviour has...deteriorated and... it's easier to see it as a within child problem so I think very often...any kind of behaviour that they've seen over time they will have clocked that and...put it in the store cupboard as that's an example of...that kind of...behaviour and they want to prove it”*

*Participant E, paragraph 9*

And finally, in relation to parent's views, this participant discusses an apparent expectation by some parents within the context of the ADOS, referred here as the pathway:



*“A lot of parents are ...inducted onto that pathway there is an expectation around a diagnosis... I’m not...saying it’s something that happens...either...singularly by school by parent...maybe it’s...the world wide web and information being available...I do think sometimes when you’re meeting parents there is a... sense of they’re trying to persuade you ...they’ve already decided their child is autistic and they’re trying to kind of justify... their behaviours”*

*Participant F, paragraph 9*

Turning once again to power imbalances and that of the child within the diagnostic process, this participant raises the notion of consent and the child being constrained by lack of autonomy:

*“I don’t know whether parents think this...if you go for an...autism diagnosis your child...isn’t really giving informed consent for that”*

*Participant C, paragraph 40*

And this participant spoke about the implications of a child’s anxiety on the ADOS assessment process:

*“there are lots of children that... will misbehave or be freaked by being in a...clinic setting...because of...the high levels of anxiety ...have a huge impact...on the level of diagnosis...in a clinic setting is it any wonder that a child doesn’t want to engage in conversation... when...you’re highly anxious and that emotional blocking happens...”*

*Participant E, paragraph 23*

Participants also shared views on the impact of the child's behaviour being thought of as autism and the possibility of a resultant diagnosis. For example:

*"I've also known children that have got the diagnosis and don't want it...and it's... an inappropriate diagnosis as well...and once you've got it it's quite difficult to...get rid of it"*

*Participant E, paragraph 57*

*"...this is what you just sometimes think...why are you giving this child this...parents don't realise that's for life...and actually that...can impact them further down the line...you know...that label is there...I think parents...only think about it in the here...and (not) the long term impact for that young person"*

*Participant D, paragraph 105*

#### **4.3.3.2 Professionals' viewpoints**

Participants discussed the viewpoints of the different professionals involved in the assessment process and the interaction between these. The first of these to be outlined is that of the paediatrician and how the EP participants viewed the focus of the medical model, as being different to that of the way in which they work. This participant speaks about pathologising within the medical model:

*"You know there is a kind of over pathologising...around...young people... maybe having you know anxiety disorders or having anxiety...which is sort of you know more elevated than it than it should be"*

*Participant F, paragraph 35*

The interaction between the parents and the paediatricians within the assessment process was also discussed:

*“I think the really difficult thing for the paediatricians...they are very reliant on what they hear...from parents...EPs at least have an opportunity to talk to school staff...and various other...professionals who might be involved...paediatricians have less opportunity for that...so their diagnosis is...often based on...what the parents tell them in a clinic...setting”*

*Participant E, paragraph 23*

*“The parental interview is a big part of it...and the problem is...they (Paediatricians) would have the... history of what’s happened...they very definitely listen to the parents and they’re not seeing the child in their school environment...it’s...purely a clinical setting...I think we have to be quite wary of assessments that are conducted purely in that clinical setting”*

*Participant A, paragraph 57*

When one participant was asked to consider reasons for parent’s attributing their child’s behaviour to autism rather than external factors, they cited a case study in their reply to highlight their views on the importance of EPs being involved in the diagnostic process. This also relates to the power imbalance which could be seen to be present between the medical

profession and EPs, in that it is the medical profession who makes the final decision and holds the power to diagnose. Firstly the medical model and the notion of pathologisation was discussed in relation to the case study:

*“I think the medical profession could collude a bit...I was at a multiagency meeting about a young person who was severely traumatised...she was in year three...and...presented as a cat...she thought she was a cat and these were her...presenting behaviours...because of the traumatic experiences she’d had so obviously psychologically she was really quite damaged...the doctor that was there on the multiagency meeting wanted to do an ADOS to eliminate...that it could be autism”*

*Participant C, paragraph 56*

Continuing to discuss the same case study, the participant moves onto discuss the different way in which EPs formulate a child’s difficulties:

*“ whereas I would professionally challenge that because actually the behaviours are presented in a severely traumatised individual...would be probably very similar...and she probably would pass I could tell them now she’d probably pass the ADOS but it doesn’t necessarily mean she’s got it uh autism...which in itself would present with severe autism potentially”*

*Participant C, paragraph 56-58*

And finally, this participant contrasted the viewpoints of the medical and EP model of formulation:

*“ so I think the way we see the world and the way the medical profession see the world is quite different so I think it’s a really positive thing that we actually get involved in the ADOS’s...medical still very much diagnose...we’ll give an ADOS...whereas actually many more factors that need to be kind of taken into account and considered”*

*Participant C, paragraph 58*

Views were shared by participants of the benefits of carrying out the ADOS within the child’s natural environment, rather than a clinical setting:

*“I’ve always had concerns around ADOS’s being done in hospital because the whole point around the ADOS is try create an.... environment...where the child feels...relaxed enough to be...themselves...hospital is going to be the last place...kids feel quite safe and secure in school...obviously home...it really is...their...natural environment”*

*Participant F, paragraph 9*

*“It’s not so much the completion of the ADOS in... those two different environments it’s the ability to be able to see the child within their...school environment...that’s the additional...piece of the puzzle...because you get to... see them at playtime...in the classroom...how they’re able to function and whether they are initiating any interaction...when they’re out on the playground whether they’re actually by themselves...so it gives you an additional wealth of information that you don’t get when they’re just sitting in a clinical setting”*

*Participant A, paragraph 61*

Similarly, this participant discussed how an EPs systemic focus can bring added value to the assessment process:

*“if you are only just seeing the parental side...you need to find out more about what’s going on in the school...that’s really important to be able to...triangulate that information to give you...a holistic picture of the young person...obviously as EPs we believe that the young person is at the centre...of...systems...and how...those views and thoughts and everything can kind of impact that young person”*

*Participant C, paragraph 6*

This participant takes this a step further and thinks of the systemic focus in relation to potential autism diagnoses:

*“it would be really easy with many of the parents descriptions of behaviour to give a diagnosis that would fit with... autism immediately without seeing the child and then very often seeing the child is...really quite...different...parents aren’t seeing the child socially in the same way that we have the...opportunity to... particularly when we do the ADOS in schools...they’re seeing...the child’s behaviour in terms of what they see at home which...comes with all the baggage...and the difficulties from home”*

*Participant E, paragraph 9*

### 4.3.4 Post ADOS, what next?

This core category captures participant's views and ideas about what happens when the children of parents who think that their child's behaviour is due to autism, do not receive a diagnosis. Parental anxiety interacts with barriers to moving forward, particularly in relation to the code 'parents retain fixed mindset'. The next steps for both children and their parents are also incorporated within this core category.

The category captures participant's alternative explanations for the child's difficulties alongside their ideas about early intervention with the population in question. The concept map for this category is shown in figure 4.8 and the MaxQDA code systems in figure 4.9.

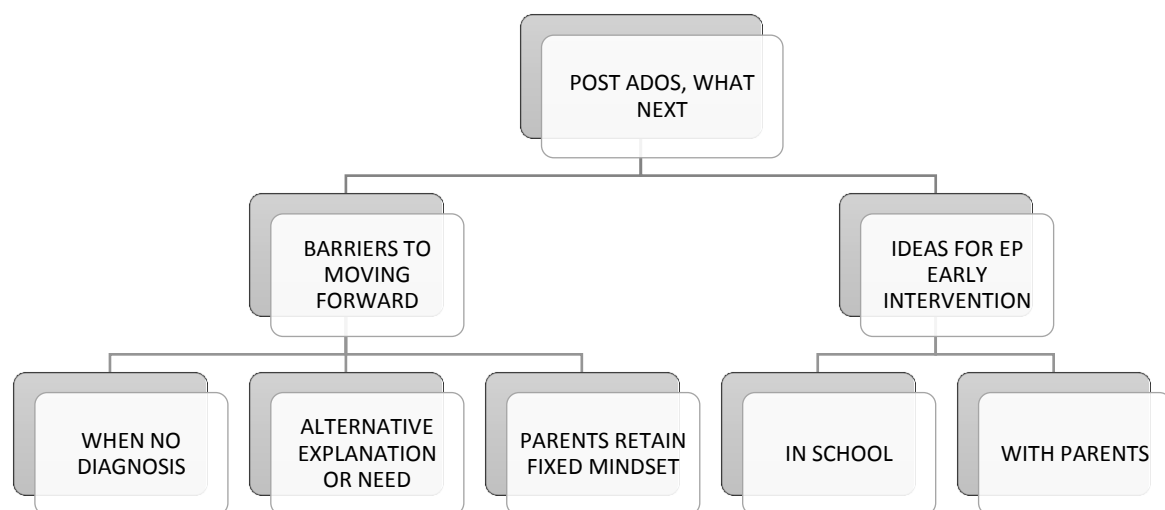


Figure 4.9: Concept map for the core category "post ADOS, what next"

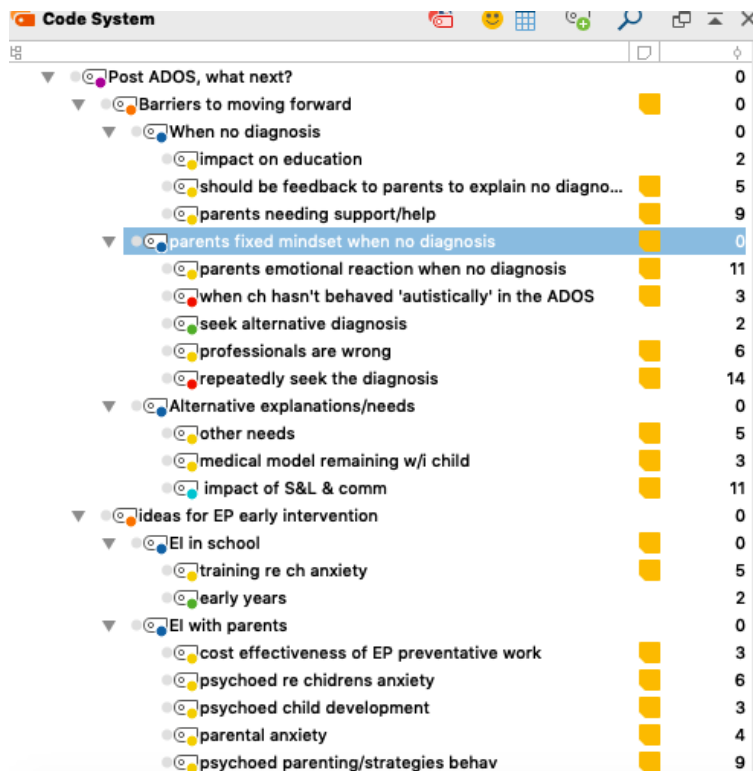


Figure 4.10: Screenshot from MaxQDA of core category “Post ADOS, what next”

#### 4.3.4.1 Barriers to moving forward

The first selective code in this core category to be outlined is constructed from participants’ views, discussing the factors which create barriers for the parents in order for them to move forward after being informed that their child does not have autism. At these times parent’s may not be given any alternative explanation for their child’s continuing difficulties, so they may be left wondering and this participant discussed parental reactions to this:

*“I think for some... they’re perhaps disappointed that...they haven’t been given some reasoning for the child’s behaviour”*

*Participant A, paragraph 50*



This participant extended the view of parents' emotional reactions to thinking about how the family may benefit from help in the home:

*“They really feel that something isn't right they're really struggling to cope and they're feeling that the system isn't supporting them...the way they would like the system to support them is... to get a label to help them understand...give them some...support in the home...for them to be able to cope...it's normally about some very difficult behaviours in the home ...that the parents are struggling to cope with”*

*Participant C, paragraph 12*

There is also the notion that despite not having a diagnosis, their child's behavioural difficulties will continue which may necessitate help at school. However, with scarce resources, this can be hard to come by without a diagnosed need:

*“How's that impacting on the school if it's an undiagnosed need...not necessarily autism but another undiagnosed need what's the behaviour like in school is that young person missing out in school is it going to lead to school refusal...so the impacts could be huge”*

*Participant C, paragraph 44*

This participant raised the notion of parents left wondering who can help and the contextual barriers of available resources:

*“There are no community services are there? So I mean what... are paediatricians...going to you know...they’re not ... saying well I’ll see you in six weeks’ time”*

*Participant F, paragraph 80-82*

Participants considered how some parents feel that not receiving an autism diagnosis is incorrect. This participant discussed the hypothesis of parents misunderstanding autism and also in relation to this, misunderstanding what the ADOS actually measures:

*“The parent had felt that the ... diagnostic situations hadn’t been reflective of the young person... so there’s a feeling that they hadn’t been successful in recognising...the...set of symptoms that she was seeing”*

*Participant B, paragraph 26-28*

Various participants discussed how some parents can question the professional’s judgement. For example:

*“I suppose if they don’t receive (a) diagnosis...if they feel like they should...there’s just a view that the professionals are wrong”*

*Participant B, paragraph 22*

The importance of cultural factors, relationships and building trust within the assessment process and how this can effect some parent's acceptance of their child not being given a diagnosis, was discussed by this participant:

*"I think they're often disappointed...they're often angry...depending on who the paediatrician (is who has) been involved they may not believe that paediatrician...quite often they ask for a second opinion...because...there will be certain paediatricians... that they don't trust because of...cultural differences... or just generally...how parents have that relationship with the...paediatrician"*

*Participant E, paragraph 74-75*

The notion of some parents not accepting a lack of autism diagnosis for their child and repeatedly trying to seek a diagnosis was discussed:

*"They'll go look for second opinion...unfortunately there are people out there that will then give it"*

*Participant D, paragraph 99*

*"I recently carried out a statutory assessment for a young person who'd had four ADOS's...carried out over the period of their lifetime ...the parent had been continually seeking for that diagnosis and every time it hadn't been recognised by the professionals"*

*Participant B, paragraph 24*

This participant shared the view of parents buying a diagnosis and how those who have/are experiencing ACEs are not in a position to do so:

*“The ACEs... um you know...they’re not the people that are going...buying diagnosis are they...they haven’t got the money”*

*Participant F, paragraph 24*

Another barrier to moving forward, was described as when the child’s behaviour was actually due to an alternative undiagnosed need:

*“I suppose also not really understanding that other things can cause things like difficulties engaging socially can be caused by so many other reasons...sometimes parents don’t really understand that children can develop at different speeds...so discrepancies can develop between them and their peers without it needing to be a diagnosis”*

*Participant B, paragraph 40*

This participant discussed speech and language needs and how this can impact on their social communication and interaction:

*“The conclusion I came to wasn’t that he (the child the EP was assessing) didn’t want to interact with his peers but he didn’t have the language skills...to enable him to do that”*

*Participant A, paragraph 52-55*

#### 4.3.4.2 Ideas for EP early intervention

The second and final selective code to be discussed in this core category contains practical ideas generated from the participant's discussions, when being asked to think about what could be done as a profession to help and support the population in question.

The role that EPs could take in providing feedback to parents when their child does not receive a diagnosis and the necessity for this feedback was discussed by this participant:

*"I think as educational psychologists we are best place(d) to be able to talk that through with the parent...follow up on the...reasoning why the diagnosis wasn't given...and then...make suggestions about things that we can put in place because you can still put those strategies in place...just giving them the clear boundaries...letting them know what's going to be happening...just makes the child feel a bit more supported and...I worry that we don't have much follow up...in school...and support for those parents"*

*Participant A, paragraph 69*

The notion was raised of what support could be provided and the implications of vulnerable families receiving early intervention, thereby preventing children without autism from entering the autism diagnostic pathway:

*"if there was some kind of support or service that could help them look...at what's happening at home...and systems...it could and save several pupils from having...wrong diagnoses"*

*Participant D, paragraph 101-103*

Two participants discussed the use of a particular Cognitive Behavioural Therapy (CBT) programme, aimed at parents who can be overprotective of their children due to both their own and their child's anxiety. This participant provides the rationale for early intervention by outlining overprotective parenting and the implications of this:

*“So if a child is anxious about something the parents will take steps so they don't have to experience it...which obviously as parents who want the best for our children we feel like we are doing the right thing...but children actually need to be sad they need to experience anxiety in safe kind of contained way...need to have experiences which will provoke anxiety and we need to help them manage that to build resilience...especially in some of the schools I work in that isn't always happening...as parents we probably need some understanding about emotions”*

*Participant C, paragraph 48*

The same participant moves on to discuss the CBT programme designed to provide psychoeducation for parents regarding overprotective parenting:

*“There's an interesting piece of work that Ben (pseudonym) has done ... I don't know if you've read it...Space trial...basically there's a theory that...parents in modern society often can make what we call accommodations for their children who are anxious... where we might view accommodations as a positive thing...it's more about colluding so basically...enabling”*

A second participant also discussed the same CBT programme, giving a little more detail on what the programme entails and why this is of importance:

*“there are some...interventions coming out now that have got better success...rates...CBT...where...the practitioners are working solely with parents and not with...the young person at all ...working with parental anxiety...to allow their child to experience anxiety and...not ...avoid it...what stops those parents wanting their young...person to...go through that is...their own anxiety...maybe because of their own experience or just because actually it’s really distressing to see your child...really distressed”*

*Participant F, paragraph 29*

Other ideas for early intervention targeting anxiety were also discussed, with this participant raising the notion of early years settings and supporting vulnerable families to prevent the escalation of children’s behavioural difficulties:

*“I would say an early identification perhaps in nursery settings...of parents EP training set up around parental anxiety as well parental anxiety child development social emotional behavioural side...would be probably fantastic I think”*

*Participant C, paragraph 22*

The notion of the benefits of relaxation in helping children with anxiety and behavioural difficulties was also discussed:

*“I think there needs to be more around things like mindfulness...mindfulness is quite powerful...and there’s not enough of it”*

*Participant D, paragraph 61*

Other ideas were also shared of working with parents offering psychoeducation regarding parenting and the use of strategies. This participant discussed the importance of doing this whilst children were young:

*“We need to provide training and support for parents’...it’s about imparting knowledge...with knowledge comes understanding...with that they’ll feel supported they’ll have an understanding of their behaviours maybe strategies that they might be able to implement and the younger you do that...the less severe those behaviours will be”*

*Participant C, paragraph 22*

The benefits and constraints of EPs being involved in the community was also discussed:

*It would be great if we could have more of a role in say parenting groups...and children’s centres but...that’s all kind of been eroded and I think that’s part of the problem...we don’t always get in there as early as we would like...often the point we’re in is crisis...or the looking at diagnosis...it would be great as we’ve talked about for many years more in the*



*way of preventative stuff...and EPs I think are really well placed for that...but it's having the time to be able to deliver that"*

*Participant D, paragraph 59*

Finally, participants shared views regarding the need for psychoeducation within education settings. This participant discussed the necessity of building awareness and understanding of autism, anxiety and other behaviour which may also mimic the symptoms of ASC and how to differentiate between these:

*"It does help to understand what are the behaviours that look like autism and what can we do in schools to address that...that's a really important bit rather than...the label...because if we've got lots of highly anxious children...who...aren't managing social communication...interaction what can we do to...support that...I still don't think that anxiety is fully understood and yet if you look at you know all the students that (local pupil referral unit) are working with...they're all out of school with high levels of anxiety and ASD... if you looked at the children that are being excluded from school...if it's not ASD all of those ASD kind of behaviours will be present...high anxiety lack of communication skills lack of empathy...inability to read and understand emotions all of those things will be missing*

*Participant E, paragraph 51-53*

This participant discussed targeting parental anxiety as an early intervention at early years settings:

*“We’ve been talking about...running parental anxiety...training and support for early years...but also supporting the practitioners who are often anxious themselves...then meeting with anxious parents...running a group...for anxious parents they won’t come...but if we go to other things and drip feed...into the early years advisors who are going in and doing that role or the support...workers they’re in a better place to support parents”*

*Participant D, paragraph 59*

This participant discussed how it would be beneficial to provide psychoeducation at school level on calming strategies and elements of CBT to provide support for children with anxiety.

*“I know teachers have shedloads to do and they’re not experts but why not have mindfulness in school...on a...regular basis...or using some of the... elements of CBT...those type of approaches that we know can be embedded into schools...and that’s...why I think we have a big role that we could play...things like the ELSA (Emotional Literacy Support Advisor) you know...it’s that kind of stuff”*

*Participant D, paragraph 65*

#### **4.4 Chapter summary**

This chapter has provided a summary of the current study’s findings, an outline of the grounded theory developed from the data and used vignettes to demonstrate the theory’s grounding within the data.

# 5 Main literature review

## 5.1 Chapter overview

The results of the main literature review, which was conducted after data collection and analysis will be outlined in this chapter. After an outline has been provided regarding the approach taken to conduct the literature reviews, the chapter will continue to describe the search strategies employed. The findings will then be discussed in order to establish what the existing literature tells us in relation to the grounded theory of the current study.

## 5.2 Grounded theory and literature reviews.

In line with the methodology of grounded theory as outlined by Corbin and Strauss (2008), following data collection and analysis, a main literature review was conducted in order to explore what the current literature tells us about the core categories from the emergent theory.

This necessitated eleven different literature searches to be conducted, as each pertained to a different element of the grounded theory. Each individual literature search asked a question specific to the different elements of the current grounded theory. The first eight literature searches in this main literature review asked:

*“How do the findings from this research align, support, challenge or extend existing understanding of parents, who think that their child’s behaviour is attributable to autism, when it is in relation to”:*

- *parental external locus of control* (Search one)
- *Parental anxiety* (Search two)

- *Parenting* (Search three)
- *Environmental contextual factors* (Search four)
- *Changes to family context* (Search five)
- *Impact of technology* (Search six)
- *Adverse Childhood Experiences (ACEs)* (Search seven)
- *Socio-economic factors* (Search eight)

A further three literature searches were conducted which respectively asked the following questions:

- “*What is known about parents who disagree with not receiving a diagnosis?*” (Search nine)
- “*What is known about power imbalances within the diagnostic process?*” (Search ten)
- “*What is known about the effectiveness of early intervention for children who have not received a diagnosis of autism/are displaying behavioural symptoms similar to autism?*” (Search eleven)

### **5.3 Search strategy**

The aim of the literature review was to explore any existing literature which is in line with the emergent grounded theory of the current study. EBSCO was utilised to carry out the searches due to the number of databases it encompasses (see table 5.1). As outlined above, eleven searches were conducted in relation to the core categories within the developing theory. Table 5.2 shows the combination of keywords which were further combined with the individual search terms shown in table 5.3. A field was not specified within the search in order to yield the greatest number of articles. Keywords originally included “misread\*,”

however this was then omitted from the search terms as zero articles were retrieved with its inclusion. Table 5.1 outlines the databases used.

- |   |
|---|
| <ul style="list-style-type: none"> <li>• PsycINFO.</li> <li>• The Pep archive.</li> <li>• Psychology and Behavioural Sciences Collection.</li> <li>• PsycArticles.</li> </ul> |
|---|

*Table 5.1: EBSCO databases used for main literature review*

Upon retrieving the total articles as per table 5.3 in order to exclude papers, inclusion and exclusion criteria were employed and these are shown in table 5.4. Inclusion criteria included publication within the last ten years and for children’s ages to be from birth to twelve, as in the LA in which the study took place, after children leave primary education, the autism diagnostic process moves to a different team which does not encompass EPs from the LA.

<b>Search terms (keywords)</b> <b>(* denotes the use of truncation to include various word endings and spellings)</b>
Parent* OR carer OR mother OR father
Misread* ( <i>originally included however then omitted as when combined, zero articles were retrieved from all databases</i> )
Child*
Behav*
Autis* OR ASD OR ASC

*Table 5.2 Keywords combined and used with individual searches 1-8 as shown in table 5.3*

Limiters on the databases were used to encompass some of the inclusion criteria e.g. publication in the last ten years and children's ages. The remaining inclusion and exclusion criteria were then applied as each of the titles and abstracts were searched in order to deem their relevance to the current study. It became apparent that none of the retrieved articles related to parents thinking that their child's behaviour is attributable to autism. Therefore, the titles and abstracts of retrieved articles were searched to ascertain relevance to the grounded theory topic and children's behaviour e.g. relating to external locus of control and children's behaviour. Consequently, none of the articles from the preliminary literature review were included, as these all related to parents and children within the autism diagnostic process.

As the articles titles and abstracts were searched, the author was surprised to find so few were relevant. However, the relevant research questions were held in mind during this process and this therefore satisfied the requirements of the main literature review and a total of fourteen articles were identified (see Appendix 2 for list and critique of included papers).

## **5.4 Results of literature search**

When the inclusion and exclusion criteria were applied, none of the relevant articles pertained to parents thinking their child's behaviour was attributable to autism when this is in relation to an external locus of control, environmental contextual factors, family, impact of technology, Adverse Childhood Experiences (ACEs), socio-economic factors, mis-diagnosis or power relations within the diagnostic process. Therefore the fourteen articles fell into the three selective coding areas of parental anxiety, parenting skills and early intervention.

<b>Search terms (Keywords)</b> (* denotes the use of truncation to include various word endings and spellings)		<b>Total of articles retrieved</b>	<b>Included articles</b>
Search 1	(combined words from table 5.2) AND “External locus of control” Or “locus of control”	44	0
Search 2	combined words from table 5.2) AND “Parental anxiety” OR “parent anxiety” OR “anxiety parent” OR “maternal anxiety” OR “paternal anxiety”	47	5
Search 3	(combined words from table 5.2) AND parenting	1721	6
Search 4	(combined words from table 5.2) AND Environment*	384	0
Search 5	(combined words from table 5.2) AND Famil*	1462	0
Search 6	combined words from table 5.2) AND technology	285	0
Search 7	(combined words from table 5.2) AND “adverse childhood experiences” OR ACE*	36	0
Search 8	(combined words from table 5.2) AND Socio-econom* OR socioeconom* OR socio econom*	306	0
Search 9	Parent* OR carer OR mother OR father AND “disagree diagnosis” OR “missed diagnosis” OR “incorrect diagnosis” OR “failure to diagnose” OR “wrong diagnosis”	11	0
Search 10	“power imbalance” OR “power relations” OR power AND “diagnostic process” OR “clinical assessment” OR diagnosis	314	0
Search 11	“early intervention” AND behave* OR SEMH OR SEBD or BESD <i>(“no autism diagnosis” OR “non-diagnosis” OR Autism OR ASC OR ASD OR “behaviour similar to autism” was originally included, however this only provided early intervention for autism. Therefore, these keywords were omitted)</i>	195	3
	<b>Total number of articles when above search terms combined</b>	4805	14

Table 5.3: Key words for literature searches 1-8 used together with combined key words from table 5.2 and literature searches 9-11 as stand-alone searches.

In all but one of the articles retrieved from the literature search, the researcher used a quantitative methodology. Therefore, similar to the preliminary literature review, these were evaluated utilising the framework for critiquing research articles by Holland and Rees (2010) as outlined in section 2.3 (see Table one and two in appendix 2 for details). The other article's researcher used a meta-analysis methodology and with secondary sources being used, a different critiquing approach was warranted, therefore the Critical Appraisal Skills Programme (CASP) was used for the critique of this paper (see table three in appendix 2 for details).

#### **5.4.1 Parental anxieties and children's behavioural difficulties**

Five papers explored children's behaviour in relation to parental anxiety (Gross, Shaw & Moilanen 2008; Neece, Green & Baker 2012; Pesonen et al. 2008; Van Batenburg-Eddes et al. 2013 & Voigt et al. 2014). Areas covered by the articles included reciprocal associations between the two variables, the effects of parental stress on the behaviour of pre-term toddlers, effects of both maternal and paternal depression and anxiety during pregnancy and the transactional relationship between child's temperamental development and self-regulation skills.

Gross, Shaw & Moilanen (2008) carried out a study employing a longitudinal design over a five-year period, to investigate the reciprocal associations between the variables of boys externalising difficulties and maternal depressive symptoms. Participants' were periodically asked to complete the Beck Depression Inventory (Beck et al., 1961), the child behaviour checklist (Achenbach, 1991) (cited in Gross, Shaw & Moilanen, 2008), in addition to a self-reported delinquency measure, with details pertaining to validity of instruments being provided.



**Inclusion criteria for articles:**

- Peer reviewed publication.
- Written in English language.
- Published in last 10 years.
- Children ages birth – 12 years old.
- Considers parent/carer and child.
- Article is relevant to topic of interest e.g. parents who think that their child's behaviour is attributable to autism in relation to parenting.
- Study conducted in a Western Country.
- Full article is accessible to the reader.

**Exclusion criteria for articles:**

- Duplication.
- Sample only features children older than 12 of age.
- Relating purely to alternative topics e.g. developmental delay, intellectual disability, ADHD, comorbid conditions etc.
- Relating to children who have already received a diagnosis of autism.
- Non-western countries.

*Table 5.4: Inclusion and exclusion criteria applied during preliminary literature search.*

Analysis of the data suggested that associations between the variables are prolific at times of transition e.g. significant reciprocal effects were found for maternal depression and boys' behavioural difficulties at ages five to six and therefore transition to school. Consistent

effects across participants were also found from maternal depression to youth reported Anti-Social Behaviour (ASB), significantly so when aged eleven to twelve, with some evidence found for the effects of ASB and later levels of maternal depression. The study concluded by also noting that for this cohort of children, their areas of risk for early adverse school experiences will increase. These may include difficulties with both peer and adult relationships and academic work, particularly if in an area of socio-economic deprivation. The design employed and measures used appeared appropriate for the study and findings seemed to offer evidence for the necessity of early intervention for vulnerable mothers and children, particularly at first transition to school, with a focus being on maternal mood and affect.

Another study by Voigt et al. (2014) explored the effects of parental mental health, this time with a focus on parental stress as a moderator for effortful control in pre-term born toddlers and the association between this and neonatal distress. Although this was a correlational study (therefore no causal conclusion can be made), findings suggest that poorer capacities for effortful control were found in preterm born toddlers who had experienced a greater degree of distress whilst in a Neonatal Intensive care unit. Furthermore, in early childhood poor capacity of effortful control was not offset by low parent stress. However low parenting stress facilitated the development of effortful control, therefore deeming this a protective factor. The authors concluded by arguing for the necessity of early intervention to increase effortful control with this at-risk population.

Van Batenburg-Eddes et al. (2013) carried out a study investigating the relationship between both maternal and paternal symptoms of depression and anxiety during pregnancy and children's later attentional difficulties. Employing a survey design across two cohorts in order to investigate consistency, 5722 pregnant women and their partners recruited from two larger

Dutch population studies, completed questionnaires regarding depression and anxiety in addition to children's attentional difficulties measured at 3 years of age. The study's findings across both cohorts suggest there is an association between problems with children's attention and maternal antenatal anxiety and depressive symptoms, with paternal symptoms showing a weaker association. However, the association between child attention and maternal pregnancy symptoms weakened when postnatal symptoms were accounted for at the time of the child's behaviour assessment. This therefore suggests that it is the persistence of maternal symptoms rather than intrauterine (i.e. within the uterus) effects which is an important factor of the association. With a large sample size and the design of the study being across two cohorts, there are implications for generalisation of the findings.

In two articles, researchers utilised the transactional model of child development as a framework for their studies. This model views child development as being a product of the bidirectional effects of the continuous interactions the child experiences within their environmental contexts (Sameroff & Mackenzie, 2003). Employing a longitudinal design, Pesonen et al. (2008) used a transactional framework to investigate the relationship between maternal stress and a child's temperamental development. With a focus from infancy over a five-year duration, 231 mothers completed measures to record their stress levels, in addition to their infant/child's temperament. Findings suggest that in relation to emotional reactivity and emotional self-regulation, an infant's temperamental development is likely to be affected by the reciprocal effects of maternal stress. With a strength in its longitudinal design, findings provide evidence for the provision of early maternal support for mental health in addition to providing interventions for children's self-regulation skills in this at-risk population

Neece, Green & Baker (2012) also used a longitudinal design and the transactional model of child development in order to empirically test the relationship between parental stress and

child behaviour in a sample of Typically Developing (TD) and Developmentally Delayed (DD) children from early to middle childhood. Also utilising questionnaires, findings from the study suggest that there is a transactional relationship between both the variables of parenting stress and child behaviour problems i.e. both variables are an antecedent and consequence of the other and over time, they appear to have reciprocal escalation/de-escalation effects. The findings were similar for both TD and DD children. The study concluded by providing clear suggestions of the implications for the bidirectional relationship of findings i.e. interventions for both parental stress and child behaviour problems.

#### **5.4.2 Parenting skills and children's behavioural difficulties**

Six papers explored the relationship between parenting skills and children's behavioural difficulties (Bailey, Hill, Oesterle & Hawkins, 2009; Combs-Ronto, Olson, Lunkenheimer & Sameroff, 2009; Flanders, Leo, Paquette, Pihl & Seguin, 2009; Hove et al., 2009; Marquis & Baker, 2014; Rinaldi & Howe 2012). The areas covered in the studies included the association between parenting styles and behaviour in toddlers, intergenerational transmission of behaviour and the links with harsh discipline, in addition to disruptive behaviour and negative maternal parenting. Further studies included the exploration of father and child rough and tumble play, cultural differences in parenting practices and the relationship between parenting and delinquency.

Maternal parenting has been the overwhelming focus of previous parent and child research with paternal contributions to parenting having not been adequately investigated (Cabrera, Tamis-LeMonda, Bradley & Hofferth, 2000). This informed the rationale for a study by Rinaldi & Howe (2012). Employing a survey design, Rinaldi and Howe (2012) explored associations between the parenting styles of mothers and fathers and the externalising, internalising and adaptive behaviours of toddlers. Overall, the study found the self-rating

authoritative parenting styles of mothers and fathers to be congruent i.e. self-reporting authoritative mothers and fathers tended to be partnered together, with correlations being lower yet still significant for authoritarian and permissive parenting couples. When parents rated themselves as highly authoritarian, permissive or authoritative, partners were also likely to rate themselves highly too. This was the case except when mothers rated fathers as permissive, suggesting variations in the interpretations of this parenting style. Correlations between parent's self-reports were low, therefore providing support for previous studies on the avoidance of sole reporting.

With respect to fathers, there was an association in the study of Rinaldi and Howe (2012) between authoritarian parenting and children's internalising and externalising behaviour, with children's adaptive behaviour being significantly correlated with paternal authoritative parenting. Contrary to expectations, correlations were not found between permissive parenting and child outcome behaviours, yet the study highlighted limitations of potential lack of sensitivity in the permissive scale used. Finally, when exploring the combination of parenting, consistent with Baumrind's theory of parenting styles (1991, cited in Rinaldi & Howe, 2012), there was found to be a unique prediction between father's authoritarian parenting styles together with mothers permissive parenting for the externalising behaviour of children. Although the study's sample size was small at 59 cohabiting families and the results should be regarded with some caution due to self-reporting, the findings provide useful evidence for future research and interventions and the need to clarify individual parenting styles in order to inform these.

An article by Flanders, Leo, Paquette, Pihl & Seguin (2009) was the only one of the articles which focussed purely on father's parenting. The study employed a correlational design and its strengths included the use of observational methods in addition to researcher

questionnaires to explore the association between father-child Rough and Tumble Play (RTP) and children's regulation of aggression. Findings suggested that the relationship between children's physical aggression and RTP was moderated by the dominance of the father i.e. if the father was more dominant, the child was less aggressive and if the father was less dominant, this led the child to have more aggressive tendencies. The authors concluded by stating the findings support previous research that activities which include RTP can be associated with children's behavioural difficulties, however this is more likely when boundaries and limits are not put into place by the father.

Employing a longitudinal study design, Bailey, Hill, Oesterle & Hawkins (2009) investigated the intergenerational transmission of children's externalising behaviour, across three generations i.e. grandparents, parents and their children. The study used teacher, parent and grandparent reports to exploring the parenting factors of harsh discipline and parental monitoring, with drug use being a mechanism within this. Results of the study suggested an overall significant indirect effect of the harsh parenting of grandparents on the externalising behaviour of children in both generations. Therefore, the grandparent parenting was associated with the parents externalising behaviour in adolescence. This in turn was associated with later substance abuse, in addition to being predictive of their own child's externalising behaviour. Finally, the parent participants substance misuse in adulthood appeared to explain externalising behaviour continuity across the generations. The study concluded with the author stating that as the magnitude for intergenerational transmission was small, there was also clear discontinuity in parenting practices, the mechanisms of which should be the focus of future research. The study had an appropriate design, with triangulation of reporting, to address the research question and ideas for future research to inform parenting interventions were given.

With similarity to the previous section on parental anxiety, a further two articles were retrieved, where researchers used the transactional model of development (Sameroff & Mackenzie, 2003) as a framework for their studies, this time in relation to parenting.

Combs-Ronto, Olson, Lunkenheimer & Sameroff (2009) conducted an informative longitudinal study of 235 sets of parent, children and teachers in order to investigate the association between children's disruptive behaviour and negative maternal parenting, with a main aim being to establish the direction of association. Using self-report in addition to observational methods, the study found that over the pre-school period (approximately 2-4 years of age), negative maternal parenting was associated with children's externalising behaviour. Maternal parenting was also associated with boys and girl's non-compliance, although there was a decrease in average levels of externalising behaviour, with self-regulation skills normatively increasing. During the kindergarten period (approximately 5-7 years of age) negative maternal parenting was associated with externalising behaviour, but no longer with children's non-compliance.

Findings from this study suggest that negative maternal parenting was a predictor of alterations in children's externalising behaviour and conversely a change in children's externalising behaviour was a predictor of a change in maternal negative parenting. Furthermore, children's externalising behaviour in pre-school was a predictor of negative maternal parenting during the kindergarten years. Interactions were found between negative maternal parenting in the pre-school period and children's early externalising behaviour, with this establishing a coercive negative cycle and therefore leading to predictions of externalising behaviour during the kindergarten period.

The study concluded that findings provided evidence for how young children change and contribute to the quality of the parenting they receive, making them active agents within their environment. Moreover, the authors discuss a further contributing factor during the period of school entry which should be held in mind. At this time, children's externalising behaviour can be distressing for parents due to the consequences and feedback from school and other parents. With perceived feelings of blame and judgement, this can therefore make it difficult for negative parenting modifications to take place, thus necessitating the provision of early intervention support for this at-risk population.

The second article also utilising the transactional model as a framework, had a cultural focus to its study. Marquis & Baker (2014) conducted a multi-method study using observation and questionnaires to examine differences in parenting practices between Anglo and Latino parents for children with behavioural problems. Findings suggested that higher reports of behavioural difficulties were reported by Latino mothers at age three, however this was marginal for externalising behavioural reports when socio-economic status was accounted for. Furthermore, in relation to sensitivity and scaffolding, there was a difference between ethnicity and status groups, with greater sensitivity being exhibited to children age three by Anglo mothers. However, the authors stated that this was once again likely to be as a result of socio-economic disadvantages and related stress. No significant effect was found in relation to the child's developmental status i.e. TD or DD. The authors concluded by stating the study's findings provide support for previous findings that socio-economic status accounts for the relationship between child behaviour difficulties and ethnic minority status.

The final article relating to parenting and child behavioural difficulties yielded was one with a large number of citations in the PsycINFO database and is a series of meta-analyses of the association between delinquency and parenting conducted by Hoeve et al. (2009). Meta-



analysis results from 161 studies, found significant links confirming the relationship between parenting and delinquency. On parenting dimensions, the strongest links were for psychological control and the weakest links were for authoritarian and authoritative control. The study also found a negative association between parental monitoring and delinquency, however some indicators of this parenting style including active monitoring, child disclosure and parental knowledge had strong links with delinquency. The strongest links to delinquency were with respect to the negative parental aspects of support including hostility, neglect or rejection.

Certain characteristics of the study were found to be significant moderators, such as age and sex of participants, delinquency type and informant of parenting, suggesting that certain parenting dimensions are more crucial for certain subsamples in certain situations e.g. there was a relatively strong association between delinquency and parental lack of support, if the parent and child were of the same gender. Furthermore, there was a stronger association between parenting and delinquency for school children and early adolescents than older adolescents and overt delinquency was more strongly associated with parental monitoring. Lastly, there were larger effects found when parenting was based on child reports rather than self-reports.

### **5.4.3 Early intervention (EI)**

Three papers explored the effectiveness of EI for children who had not received a diagnosis of autism/were displaying behavioural symptoms similar to autism (Kaminski et al., 2013; Rapee, 2013; Walker et al., 2009). These all covered evaluations on the efficacy of parent and child early intervention programmes.

In the United States, Walker et al. (2009) conducted a Randomised Controlled Trial (RCT) of an EI for grades one to three i.e. ages six to nine. The study employed a cohort study design over a four-year period with two-hundred children who were exhibiting externalising behaviour being randomly assigned to the “First Step to Success” intervention group, or the usual care comparison group. A manualised intervention programme was followed and results showed moderate to strong effects for all the outcome measures. The outcome measures were drawn across three domains: observations, teacher and parent questionnaire and the collation of academic data. Parents gave high level of satisfaction and reported at least moderate levels of gains in the externalising behaviour of their children. Moreover, authors argued that as 70% of the participants were of an ethnic minority status, the results show good generalisation to the general population. This was a robust and well-designed study and at the time of writing the article, follow up assessments were being completed with these to be reported at later date.

Rapee (2013) also conducted an evaluative study, this time for the long-term effects of a brief EI for pre-school children in Australia, who were at risk of internalising behaviour. A sample of 146 pre-school children took part in the original intervention, all of whom displayed high levels of withdrawal and inhibited behaviour which was deemed to be at risk for anxiety and mood disorders, with half being randomly assigned to the intervention group. Due to their age and research showing the efficacy of the involvement of parents, the intervention was delivered to parents in a group format over six sessions. The evaluative study used quantitative methodology and employed a survey design, in addition to clinical assessment, with 70% of the original sample being assessed eleven years later.

Outcome measures included a clinical psychologist evaluating the adolescents and giving current diagnoses if applicable. The evaluative data was gained through interviews, in addition to parent and child questionnaires which assessed their symptoms, negative thinking and the extent of the interference to their life. Results showed large effect sizes for girls with benefits through to middle adolescence. The effect was not as clearly shown in boys, with the authors concluding that this may be because EI for internalising behaviour is not as effective for boys, or on the other hand the small effect size may have been due to the small sample size. This was a well-designed study with the author concluding that as it was a very low-cost intervention and could have major benefits to public health even with small effect sizes for boys being shown.

The final article was an evaluation by Kaminski et al. (2013), of a United States public health strategy, aimed at improving the developmental outcomes of children who had been born into poverty. Recruited either prenatally or at the birth of their children, 574 mother-child dyads took part in cohort study of the original “Legacy for Children” intervention, with randomised trials, taking place across two sites. Parent reported outcome measures were gathered post intervention with results showing that children in the intervention group were less likely to meet criteria for both behavioural and socioemotional concerns at 24 and 48 months respectively. Marginal effects were shown after the first year, however after the second year, the effects were significant, with children also being significantly less likely to reach the criteria for hyperactivity. This was a well-designed evaluative study with one site showing a higher number of significant effects, this was hypothesised to be due to the group being at a demographically higher risk (e.g. less educated and younger, more likely to be unemployed and single). However, upon closer inspection, the intervention was not delivered in the same

way at both sites i.e. number and duration of sessions, which may account for some of the effect differences.

## **5.5 Summary of main literature review**

This chapter has detailed the results of the second and main literature review, after the preliminary literature review outlined in chapter two deemed the current study to be novel. In line with grounded theory methodology, the main literature review took place after the data had been gathered, analysed and the resultant grounded theory was generated from the data. The current literature review then focused on the emergent core categories, with eleven separate literature reviews taking place (see table 5.3 and appendix 2) with a total of fourteen articles considered to be relevant.

For literature searches one-to-eight, when searching for articles pertaining to parents who think that their child's behaviour is attributable to autism, the author was surprised to find a scarcity of articles directly pertaining to external locus of control, environmental contextual factors, impact of technology, adverse childhood experiences, or socio-economic factors. Therefore, the current study extends on the existing literature by finding that these contextual factors contribute both to the child's challenging behaviour in addition to the mechanisms of parenting skills and parental anxiety.

For literature searches one-to-eight, parental anxiety and parenting were the only relevant articles retrieved. This could be seen to have similarities with the findings from the current study, where the greatest percentage of codings were for issues relating to parenting and the second largest in relation to parental anxiety. The current study supports existing research with associations found between parental anxiety (including stress and depressive symptoms)

and the externalising behaviour of children (Gross, Shaw & Moilanen 2008; Van Batenburg-Eddes et al. 2013; Neece, Green & Baker 2012; Voigt et al. 2014; Pesonen et al. 2008).

The existing literature looked directly at the link between parental stress and anxiety and children's behavioural difficulties. It is argued that the current study extends on the existing research by also suggesting an indirect link be

tween the two variables, with parents attributing their child's behaviour to external factors, due in part to their anxiety and to being in denial that their child's behaviour may in some way be connected with themselves.

The current study found a transgenerational effect of anxiety with children learning from their parent's anxious behaviour. This supports existing research of an intergenerational association between the two variables of parental anxiety and children's behavioural difficulties (Bailey, Hill, Oesterle & Hawkins 2009). Finally, findings from a study into the cultural differences in parenting practices, found that the relationship between child behaviour difficulties and ethnic minority status, was accounted for by socio-economic rather than ethnic status (Marquis & Baker 2014). The current study supported these results by finding that socio-economic factors impact on many levels, including the child's behavioural difficulties, the parent's anxiety and their parenting skills, contributing to parents thinking that their child's behaviour is attributable to autism.

Similarly, findings from the current grounded theory also support existing literature of associations between parenting and children's externalising behaviour (Combs-Ronto, Olson,

Lunkenheimer & Sameroff 2009; Flanders, Leo, Paquette, Pihl & Seguin 2009; Hoeve et al. 2009; Rinaldi & Howe 2012), particularly in relation to the study by Rinaldi and Howe (2012) which also found associations between the combination of father's authoritarian and mother's permissive parenting styles and children's externalising behaviour.

Literature searches 9-11 did not yield relevant articles relating to misdiagnosis or power relations within the diagnostic process. Therefore, it is argued that the current study goes beyond the existing literature by suggesting that when parents hear their child has not received an autism diagnosis, in addition to issues relating to power imbalances in the diagnostic process, they remain with the belief that their child has autism and this may then drive them to continue to seek a diagnosis. The current grounded theory highlighted EPs ideas for early intervention. This and literature search number eleven yielded three articles (Kaminski et al., 2013; Rapee, 2013; Walker et al., 2009) which all found the early interventions to be efficacious.

In the following chapter, the grounded theory from the current study will be discussed in relation to the existing literature base.

# 6 Discussion

## 6.1 Chapter overview

As outlined in section 1.4.3, this research has adopted the approach of the ADOS and the definition of autism as per the DSM-5. Although these are not universally accepted, as this is a critical realist piece of research conducted in a context which implements their use, this was deemed to be the best approach to take and will inform the content within this chapter.

A summary of the overarching theory will be outlined here before consideration of the current study's grounded theory will be given, in light of existing research and theoretical links within this area. The implications for the study will be outlined, before a description of how the research findings will be disseminated, in addition to suggestions for future research being provided. Finally, the author will give concluding comments and reflections.

## 6.2 Summary of findings

The research question was set as:

*What are Educational Psychologists' views on the contexts and mechanisms that lead to parents thinking their child has autism, in cases when their child does not receive a diagnosis based on results of the ADOS?*

After hearing pejorative talk about parents whilst previously working as an assistant EP, the aim for this study was to explore parents' perspectives in a non-judgemental and compassionate way. Therefore, the grounded theory developed from the data and subsequent analysis has provided the following answer:

- The grounded theory proposes that parents think that their child's behaviour is symptomatic of autism because they have an unconscious psychological response against ideas that they may, in some way, be connected with their child's challenging behaviour. This unconscious psychological response may be sustained through confirmation bias, which may enable the parent to regard their child's difficulties as attributable to organic factors rather than contextual factors. Challenges which go beyond what parents feel able to cope with combined with parental anxiety, may result in thoughts about alternative explanations to that of autism being intolerable and therefore avoided.
  
- The grounded theory suggests that there a number of environmental contextual factors which contribute to both the children's unmanageable behavioural difficulties:
  - The impact of technology
  - Effects on parenting within societal change
  - Adverse Childhood Experiences (ACE's)
  - Socio-economic factors
  
- Having not received a diagnosis, parents are left still searching for answers, with some believing that the diagnostic process is flawed. Key barriers to moving forward are:
  - Parents feel that not receiving an autism diagnosis is incorrect
  - Parents requiring support.
  - Alternative need/explanation for child's behaviour.



- Linked to the above, professions hold differing views about diagnoses, in addition to issues relating to power relations within the autism diagnostic process. This gives weight to parental doubts about the accuracy of diagnosis.
- To address the above issues, early intervention in early years, school and with parents could support parents who think that their child's behaviour is symptomatic of autism.

Figure 4.2 in section 4.2.1 provided an illustration of the interconnectivity and weighting within the grounded theory. As previously outlined, the external locus of control selective codes of parental anxiety and parenting are the most salient elements of the theory, with the researcher deeming the environmental contributing factors of socio-economic and ACE's, in addition to effects on parenting having the greatest reciprocal effects.

### **6.3 Critical realism and research question**

A critical realism ontology was adopted for the current study. This ontology posits that there are external realities, however these can never be fully known because individuals interact with reality in a subjective manner.

The author believes autism externally exists and this is assessed using a diagnostic pathway. Within the context of the LA in which this study took place, the diagnostic pathway has a multi-disciplinary team which includes paediatricians and EPs and utilises the ADOS. However, diagnosing autism can be challenging, as there are variations in symptomology, with no specific biomarkers at present (Molloy, Murray, Akers, Mitchell & Manning-Courtney, 2011), in addition to the commonalities and overlap in symptoms with other conditions such as attachment difficulties (Moran, 2015).

EPs often work with a systemic focus and consider a child's difficulties in light of their inextricable link with their environment e.g. through the application of Bronfenbrenner's Ecological Systems Theory (1994). What became apparent during the data gathering and analysis phase of this current research was that EPs do not always prescribe to the critical realism view of autism and will at times flip between critical realism and a constructivist/systemic view of the child and their presentation. This will be explored through the use of the participant voices and their relation to each mechanism during this chapter.

## **6.4 Grounded theory, existing literature and theory**

The grounded theory developed from the data and analysis of the current study will now be broken down, with the individual elements considered in relation to existing literature and theory.

### **6.4.1 External Locus of Control**

When analysing the data for the contexts and mechanisms that lead parents to seek a diagnosis of autism in cases where their child's ADOS profile does not meet the criteria for a diagnosis of autism, a key core category that emerged from the data was external locus of control. This core category captured what were seen to be parents' unconscious psychological responses against the idea that there may be a link between them and their child's challenging behaviour. Curtis (2015) describes how denial is a defence mechanism which can occur due to the determination of the unconscious mind to alter a truth and assert a different cause to a situation, in order to protect against emotional pain. The current theory maintains that confirmation bias sustains this unconscious defence mechanism which can overvalue a parent's interpretation of their child's behaviour to support the belief of organic factors i.e.

autism, to account for the behaviour, rather than contextual factors such as parenting skills and parental anxiety.

Originally developed as a construct within the social learning theory of personality (Rotter, 1954) external and internal locus of control refers to the events that happen in peoples' lives and the extent to which they believe they are in control of these events (cited in Hiroto, 1974.) People who have a strong internal locus of control believe their own abilities and actions are primarily responsible for the events. Those with a strong external locus of control would attribute outcomes to be outside of their control such as attributing their child's behaviour to autism rather than being related to their parenting skills.

None of the relevant articles in the main literature review pertained to parents thinking that their children's behaviour is due to autism, when it is in relation to their own external locus of control. There appears to be a gap in the research and therefore suggests the current study provides novel research in this area.

Although the current study's main literature review did not yield any papers directly in connection with external locus of control, articles relating to parental anxiety and parenting were provided and these areas will now be discussed in turn.

#### **6.4.1.1 Parental anxiety**

The theme of parental anxiety led to theorising that attributing their child's behaviour to external factors may be due in part, to parents having an unconscious psychological response of being in denial that their child's behaviour may in some way be connected with themselves. Moreover, parental anxiety also provides a contextual factor within which the child's behaviour is borne and maintained and has reciprocal interactions with other elements

of the theory, in particular parenting skills, ACE's, socio-economic factors in addition to effects on parenting.

These findings are consistent with previous research outlining the effects on children of parental anxiety. For instance, findings from a study by Brei, Schwarz & Klein-Tasman, 2015 suggested parents display similar high-levels of stress when their children are experiencing behavioural difficulties or displaying symptoms associated with autism. A family systems approach also suggests a relationship between the well-being of a single family member having an impact on that of the others (Griffiths, Hastings & Petalas, 2014). In fact, parenting stress is a variable which is one of the most consistently associated with child aggressive behaviour and poor child outcomes (Moreland, Felton, Hanson, Jackson & Dumas, 2016). Moreland et al's study found associations between an increase in parental stress, a decrease in parental internal locus of control and an increase of children's behavioural difficulties.

Consistent with previous research, the grounded theory highlights the contextual effect that parental anxiety can have on children. Leijdesdorff, Van Doesum, Popma, Klaassen and Van Amelsvoort (2017) outline the issues of parental mental health on a global level, discussing how 15–23% of children have a parent with mental health difficulties and how this then in turn increases the children's chances of developing mental health difficulties e.g. anxiety, by up to 50%. The notion of anxiety triggering behavioural difficulties in children oriented towards parent/carer's, has been recognised in psychology for a number of decades (Bowlby, 1969, cited in Lebowitz et al., 2014).

Participants in the current study discussed the effects of parental anxiety on children and how this can lead to children also becoming anxious, which can impact on their behaviour and

how this can then be thought of as being attributable to autism by parents. Therefore, the notion is raised that children's behaviour may be borne from anxiety rather than autism.

The worldwide prevalence of children's emotional, mental health and behavioural difficulties is estimated to be between 14 and 20% (Sumargi, Sofronoff, & Morawska, 2015). One of the most common reasons for young children to be referred to mental health services is for disruptive behaviour (Zisser & Eyberg, 2010). Furthermore, Parent et al. (2011) discuss how research shows that without treatment, children's disruptive behaviours persist across periods of development. In classrooms, there appears to be an increasing number of children and young people with social, emotional and mental health problems, who are showing their distress in different ways (Bomber, 2007). However, there is evidence to suggest that this transmission may be due environmental factors rather than being hereditary in nature. By providing support to parents who are experiencing mental health difficulties, this risk can be ameliorated (Cartwright-Hatton et al., 2019).

The rising awareness of potential mental health difficulties in school populations is the topic of discussion on a national level, with The Department for Education (2016) issuing non-statutory advice for schools, raising the notion of difficulties in Children and Young People's behaviour as being a symptom of an unmet mental health need. The Prime Minister delivered a speech advising that one in ten children have a diagnosable mental health condition and/or behavioural disorder (May, 2017). In relation to personal costs, if left untreated, this raises the risk of long-term effects including poor social and developmental outcomes, persistent mental health difficulties, anti-social behaviour drug dependency, risk of ending up in prison and a reduced life expectancy (Saavedra, Silverman, Morgan-Lopez & Kurtines, 2010).

Cobham (2012) discusses how children's unmet mental health needs can impact on academic,

personal and social day to day living, causing significant emotional distress and this also has the potential to lead to further mental health problems and substance misuse. However, despite this, more than 80% of children with an anxiety disorder do not receive any treatment. This may be due to a number of factors including the costs in both time and financial terms, in addition to a perceived stigma of requiring psychological help. In relation to the current study, another factor may be due to society's general understanding of anxiety as being synonymous with internalising behaviours.

Internalising is characterised by behaviours which are focussed inwards e.g. withdrawn, fearful etc., whereas externalising behaviour is characterised by behaviours which are focussed towards the external environment e.g. physical aggression, bullying etc. Therefore when a child is displaying externalising behaviour, this may then be attributed to autism, rather than anxiety. Due to the rise in prevalence of mental health problems, in addition to a focus on mental health in schools, it is also imperative that the issue of stigma is addressed. Despite the lack of mentioning their role in government policies (O'Hare, 2017), it is argued that EPs are ideally situated in aiding this.

Further findings from the grounded theory, were in relation to participants' discussing the circular familial effects of children's difficulties. This is consistent with the transactional model of child development (Sameroff & Mackenzie, 2003) whereby child development is viewed as being a product of the child in relation to their environment and the continuous bi-directional and dynamic interactions that happen within. For instance, extensive research has provided evidence for parental stress affecting a child's temperament which in turn affects the parent's behaviour, which affects the child's development (Pesonen et al., 2008). However, not all studies find evidence for a bi-directional relationship, for instance the relationship between maternal mental health and child behaviour difficulties was explored by

Totsika, Hastings, Emerson, Lancaster, Berridge and Vagenas (2013). This study found this relationship was not bi-directional and that it was specifically maternal mental health which was a risk factor for subsequent child behaviour difficulties.

The grounded theory found how defence mechanisms can result in parents projecting the reasons for their child's behaviour onto the child, a finding which supports evidence in existing studies. Lewis-Morton, Dallos, McClelland & Clempson (2014), discuss how parents have a concern regarding accountability, leading to a desire for the parents to demonstrate themselves as being competent, rather than acknowledging a more systemic explanation. Together with constraints of societal discourse, this leads the parents to think that the observed difficulties must lie within the child, a phenomenon termed an "illness model" and the current study adds support to this theory.

Also revealed in the findings was the notion of parents' anxiety being in part due to perceived blame and judgement within society. This finding builds upon existing research into the moral stigma of mothers who have children with disabilities and how mothers experience "mothers blame" (Blum 2015, cited in Davis & Manago, 2016, p. 72) and these experiences are central to their interactions in society including within schools and hospitals. The findings from the current study suggests that the "mothers blame" also extends to judgement regarding their child's behavioural difficulties. This leads to parents having an unconscious psychological response to protect themselves against these feelings and subsequently viewing their child's behavioural difficulties as being organic and symptomatic of autism.

Parental anxiety as a contextual factor for the maintenance of children's behavioural difficulties was discussed by participants in relation to overprotective parenting, with parents

seeking to prevent their child from having negative experiences which inadvertently exacerbate their difficulties. Also termed helicopter parenting, this has been theorised to be as a result of family projection in order to diffuse anxiety within the parental system due to reasons such as difficulties within the parental relationship or family transitions (Dumont 2019).

This finding supports research into family accommodation, which was initially investigated in relation to obsessive compulsive disorder (Calvocoressi et al. 1995, cited in Lebowitz, Omer, Hermes & Scahill, 2014), before also incorporating anxiety disorders (Lebowitz, 2013). In relation to OCD, family accommodation refers to participation and modification of the parents' behaviour so that their child avoids particular situations which may trigger their symptoms. Lebowitz (2013) further elaborates that the child may also forcefully impose accommodation behaviours in the parent, through disruptive and coercive behaviours in a reaction to attempts by parents to reduce accommodation.

It is argued that the current study extends these findings by suggesting that family accommodation is also used by parents when their child has behavioural difficulties as a symptom of an unmet mental health need, something which the DofE (2016) describes all difficult behaviour as being attributed to. For instance, a modification in parental behaviour may include avoiding taking the child shopping as this can result in negative behaviour being displayed by the child. As previously outlined, this could lead to feelings of shame, blame and judgement by society on their skills as a parent, leading to intolerable thoughts which produce an unconscious psychological response, leading to the parent attributing the child's difficulties to organic reasons i.e. autism, rather than contextual factors.



#### **6.4.1.2 Parenting skills**

The grounded theory also identified that parenting skills and different parenting styles, in particular authoritarian and indulgent/permissive parenting, can contribute to children's behavioural difficulties and how parental anxiety and effects on parenting can interact with these skills. In turn, parents' thoughts that they may in some way be connected to or responsible for their child's behaviour produces an unconscious psychological response, leading to the parent to seek alternative explanations and therefore think their child has autism.

Authoritative, authoritarian and permissive parenting styles were initially identified as styles of parenting in a study by Baumrind (1967), with a dimension of parental control or demandingness being used to describe these within the study. A second dimension of responsiveness, in addition to a fourth parenting style, was later created by MacCoby and Martin (1983, cited in Garcia & Gracia, 2009). At this time, permissive parenting was also theoretically differentiated and split into the two styles of indulgent and uninvolved/neglectful, each being dependent upon the parents' level of responsiveness or warmth. These theories laid out a position on the effect of each parenting style on a child's development, particularly their emotional self-regulation and therefore effects upon their behaviour.

Baumrind (1967) originally theorised authoritative parenting to be the optimum parenting style and this remains the most prominent view within theories of parenting styles, with it described as being high in both demandingness and responsiveness, blending nurture and discipline where necessary (Simons & Conger, 2007). Authoritative parenting offers children support, guidance and teaching, encouraging exploration, whilst building problem-solving skills by parents helping children talk through their frustrations and thereby learn to

emotionally regulate (Piotrowski, Lapierre & Linebarger, 2013). Without this support, children can experience difficulties in both understanding and regulating feelings which may be intense or difficult and this could make them more likely to engage in behaviour that would be more difficult for parents to manage (Marvin, 2009, cited in Lewis-Morton & Dallos, 2014).

Conversely, authoritarian parenting emphasises strict standards of behaviour and obedience and is therefore high on the demandingness dimension, but low on responsiveness and is described as being emotionally unresponsive (Simons & Conger, 2007). The intergenerational transfer of this parenting style in addition to the effects on the externalisation of children's behaviour was found in a study by Bailey, Hill, Oesterle & Hawkins (2009). Furthermore, some studies have shown harsher parenting practices by low-income urban parents as opposed to middle-class parents (Kelly et al., 1992; Steinberg et al., 1991, cited in Shumow, Vandell & Posner, 1998).

On the other hand, an indulgent parenting style avoids punishment and instead is accepting of children's impulses, with parenting described as being high on the responsive dimension, but low on demandingness. This was a parenting style discussed by some participants in the current study, particularly in relation to the lack of application by parents of consistent boundaries, suggesting parental lack of skills and/or understanding that by implementing these it will go some way to addressing children's difficult behaviour. In the original theory, Baumrind (1967) hypothesised that permissively parented children would have poor control of their impulses, would frequently encounter difficulties associated with their learning and were at higher risk of anti-social behaviours. Studies have provided support for this in finding lower levels of delinquency being related to parental monitoring and consistent discipline

(Fischer, 1983; Coughlin and Vuchinich, 1996, cited in Hovee et al., 2009). Similarly, significant correlations have been found between children's adaptive behaviour and paternal authoritative parenting (Rinaldi & Howe, 2012).

The findings from the current study provide further support to existing extensive research into parenting styles and the effects of this on children's emotional regulation and behaviour. Parent et al. (2011) used Baumrind's (1967) theoretical framework of authoritarian and permissive parenting styles, to explore the relationship between these and children's disruptive behaviour. They found that more extreme disruptive behaviour in both genders was related to harsher discipline. Moreover, greater levels of permissive parenting were related to more extreme disruptive behaviour, however interestingly, this was only in relation to boys. If these findings are linked back to the current study, particularly in relation to the provision of harsher discipline, it is suggested that the parent may feel that they are putting down the rules and boundaries and therefore seeing their child's behaviour as being external to their own locus of control i.e. it's attributable to autism.

The effects on children of permissive or indulgent parenting was discussed in the current theory, for instance how this can lead young children to becoming hyper and anxious in nursery when boundaries are not defined. Studies have identified how this parenting style is a significant predictor of emotional regulation difficulties in children (Jabeen et al., 2013; Houlberg et al., 2016; Hovee et al., 2009). However the results of a meta-analysis into the links between parenting and delinquency found the strongest significant links were regarding negative aspects of support as opposed to lack of warmth and support (Hovee et al., 2009). Similarly bi-directional interactions were found between children's externalising behaviour and maternal negative parenting (Combs-Ronto, Olson, Lunkenheimer & Sameroff, 2009).

As discussed previously, Lewis-Morton, Dallos, McClelland & Clempson (2014) suggest that parents have difficulty understanding their children's behavioural difficulties in relational and psychosocial terms and consequently, they are unsure as to the appropriate balance of affection and discipline to give. This balance can be complex for many parents to manage, however for parents whose child is displaying behavioural difficulties, this can lead to them feeling "frozen" in their parenting skills and therefore the "illness model" can be seductive not only with the hope of the waving of a magic wand, as discussed by participants in the current study, also in resolving conflicts in relation to both school and within family dynamics.

The findings from the current study can be used to build upon existing research by theorising how the effects of the parenting styles i.e. authoritarian and permissive parenting are a contextual factor for both the trigger and maintenance of children's' behavioural difficulties. When this is combined with parental anxiety and thoughts that as parents they may be in some way responsible for their child's difficulties, this produces an unconscious psychological response which can result in the belief that their child's behaviour results from organic rather than environmental factors i.e. adopting the illness model and attributing the behaviour to autism.

#### **6.4.2 Environmental contributing factors**

The grounded theory identified environmental factors the interactions of which it was considered had the greatest effect on the levels of anxiety being experienced by parents. It also identified that these environmental may factors also contribute to the knowledge base

and available resources of the parent, influencing their parenting skills and the resultant behaviour of the child.

#### **6.4.2.1 Societal change**

Participants suggested that changes to society have had an impact on parenting skills and parental anxiety. The changes identified focussed on changes to the familial system and the impact of technology i.e. media and social media on parenting.

Participants discussed issues relating to changes to family structure and how for parents with children who are displaying challenging behaviour, there often isn't the much needed support and parenting role models from extended families there used to be, which can contribute to parents feeling frozen in their parenting skills. Moreover, funding cuts as part of the government's austerity measures have also exacerbated a lack of crucial support being available, mostly for those that are some of the most vulnerable in areas of socio-economic deprivation. For instance, a study by the Sutton Trust, an education and social mobility foundation, found that the early years support programme of Sure Start Children's centres, which offered support for economically and socially disadvantaged children, have been cut by as many as 1000 since 2010 (cited in The Guardian, 2018).

As evidenced in the main literature review, there is a dearth of existing literature regarding changes to the nuclear family and extended family support. This is a point recognised in a study of Turkish families using the Bronfenbrenner's Ecological Systems Theory (1994) as a framework, by Akcinar & Baydar (2016). The study was not included in the literature review due to the exclusion criteria of non-Western studies, however the findings are pertinent to the current study and therefore are included in the discussion.

Akcinar & Baydar (2016) employed a longitudinal design using interview, observation and questionnaire methods to collect the data. The findings suggest that an increase in support from fathers, extended family and neighbours was associated with a decline in children's externalising behaviours. Furthermore, reciprocally, when child's externalising behaviour was high when coupled alongside physically harsh maternal parenting, this was associated with a decline in support from these areas.

Further research has also found a positive association for the quality of relationships between parent and child together with social support, due to a buffer being provided for maternal stress due to its negative effects on parenting (Baydar et al. 2014; Kotchick et al. 2005, cited in Akcinar & Baydar 2016). Furthermore, a meta-analytic review conducted by authors in Israel found that support from providers within the mesosystem (i.e. the interaction of the different microsystems that the child finds themselves in e.g. home, school etc.) may be discouraged due to the negative effects from a mother child relationship, as this can create a "spillover" i.e. the stress and tension may be transferred onto others (Erel and Burman 1995, cited in Akcinar & Baydar 2016). The current grounded theory builds on these studies in Turkey and Israel respectively. If as previously hypothesised, there is maternal harsher discipline in an attempt to deal with their child's challenging behaviour, this may lead to a further decline in support from family and the community due to the possible spillover of stress, leading to attribution of behaviour to organic factors.

An article by Bengtson (2004) discusses the debate within sociology of changes within the family context. The article outlines the "family decline" hypothesis of Popenoe (1993, cited in Bengtson, 2004) regarding the modern nuclear family within American society, which

focuses on the changes within family structures, due to single parenting and divorce, positing this as having negative consequences for the overall well-being of children. This is contrasted with the hypothesis that for many in America, there is increasing importance placed on multi-generational bonds for support and well-being, over and above that of nuclear family relationships. The study suggests this is due, in part, to increased life-expectancy, changes in societal structures and an increase in marital instability. It is argued that the findings from the current study add to the paucity of knowledge in this area, suggesting the changes to family structure and support on child-rearing can lead to an effect on the emotional well-being of children and their families.

Participants also discussed views on the effects to a change in family mealtimes, with less discussion and interaction taking place, with both the participants and the author hypothesising that this has led to an increased number of children experiencing difficulties with language and communication skills. Moreover, participants discussed how parents may not understand the nuances of language and communication and perhaps have different expectations of their children's speech, language and communication difficulties and the impact this can have on children's well-being. In a report presenting information pending social policy reform in America, societal changes including eating in front of the television, are claimed to have led to a decline in family's sharing meal-times around the table (Fiese & Schwartz, 2008). The report discusses how studies have shown an association between family mealtimes and language development, academic achievement, physical health, in addition to a reduction in the risk for substance abuse.

Family mealtimes represent a time when social relationships are formed and role modelling can be provided, in addition to the provision of time for the development of structure,

connection and family unity, in order to build a feeling of safety and security for children (Fulkerson & Neumark-Sztainer, 2006). On the other hand, cultural and class differences lead to different family behaviours and therefore it is imperative that EPs retain a curious stance when triangulating information and building formulations of children's behavioural difficulties.

Analysis of the current study's data raised views regarding the impact of technology, including media and social media and how this may have negative effects on parenting skills, parental anxiety and subsequently effecting children's behavioural difficulties. Based on the main literature review questions and keywords used, no articles were retrieved in this area. However, the findings of the research may provide some support to a study carried out by Radesky et al. (2018) which found that the maternal use of mobile phones during parent-child mealtimes, was significantly associated with maternal mental representations of their child i.e. the mother's ability to reflect on the characteristics and emotional state of their child in addition to their parenting. It is important for researchers and professionals to bear in mind counter-arguments such as how technology is a powerful tool, which can provide support and access to parents who are maybe feeling frozen, isolated and at a loss, with researchers arguing against Neo-Luddism i.e. the demonization and scaremongering of modern technology (Bowman, 2019).

For parents who may not have the support networks as discussed in the grounded theory, particularly as first time parents it is important for them to receive support from the outset in order to help with transition to parenthood, build parenting skills and feelings of self-efficacy as a parent. A study of new mothers of six-week-old infants carried out by Leahy-Warren, McCarthy & Corcoran (2012) found significant relationships between both functional and



social support and postnatal depression and maternal parental self-efficacy. Yet as previously discussed, there can be a lack of support and role models due in part to changes in family structure. The grounded theory suggests this can lead parents to seek help from social media and how the help received may not always be the most helpful.

As previously discussed, a rise in the number of referrals for an autism assessment has been linked to greater public awareness of autism (Lo, Klopper, Barnes & Williams 2017). This may be due in part to the ease of gaining information on the internet, in addition to the emphasis in society of impaired social skills (Russell, Collishaw, Golding, Kelly, & Ford 2015). In support of this hypothesis, several participants in the current study described having discussions with parents regarding their child's difficulties and at times it seeming as though parents have consulted "google doctor". Escarrabill, Martí & Torrente (2011), likened the use of the internet as akin to a "Google swiss army knife", having the capacity for clinicians and the general public to browse, diagnose and share information.

The grounded theory identified how parents may repeatedly seek a diagnosis and sometimes have repeated ADOS assessments, providing support for a study by Bianco, Zucco, Nobile, Pileggi, & Pavia, M (2013), which found that out of 1039 parents, 84.7% conducted internet searches for medical conditions for themselves or family members, with some doing so as they were dissatisfied with information received from health professionals. Similarly, another study found that low-income families, who have children with special health care needs, may be particularly vulnerable due to not having the skills to be able to differentiate between high and low quality advice and information (Knapp, Madden, Wang, Sloyer, & Shenkman 2011). The findings of Knapp, Madden, Wang, Sloyer, & Shenkman (2011) may have relevance to

the current grounded theory which took place in an area with pockets of socio-economic deprivation.

A well-known example of the effects of media publicity is that pertaining to the Measles, Mumps and Rubella (MMR) vaccine and the supposed links between this and autism. Clements & Ratzan (2003) conducted a study which found that exposure to the public of a range of conflicting views, resulted in feelings of being misled, together with confusion regarding the safety of the vaccine. This led to a decline in parents vaccinating their children for fear that their child would get autism as a result, something one of the participants voiced discussing how she had heard a parent saying they didn't want their child catching autism. This controversy has ultimately resulted in the United Kingdom being one of four European countries to lose its measles eradication status (BBC, 2019) and puts the safety of children at risk.

Therefore, it is argued that the findings from the current study compliments existing literature to give an account of changes to society regarding familial systems and technology and how these can have an impact on parenting skills and parental anxiety. A resultant implication of this is children experiencing behavioural difficulties, with parents having an unconscious psychological response against the idea they may be in some way to blame, leads them to thinking that their child's behaviour is due to autism. As previously discussed, parents may be drawn into the seductive power of the "illness model" and then, as the outlined studies suggest, some parents may lack the skills in differentiating between high and low quality information, leading to them believing their child to have autism.

#### **6.4.2.2 Perpetuating factors**

The grounded theory identified two perpetuating factors which interacts with parental anxiety and parenting skills, maintaining the difficulties that are being experienced by families and thereby being a further factor that leads parents to attribute organic causes to their child's behavioural difficulties.

#### **Socio-economic environment**

There is a wealth of research regarding the importance of socio-economic risk factors and the interconnections with parental anxiety and parenting skills. The current grounded theory adds support to the existing literature on the socio-economic environment being a perpetuating factor for children's challenging behaviour and therefore providing a context that leads to parents thinking their child has autism. The current theory particularly closely aligns with a combined grounded theory and discourse analysis study by Dallos and Hamilton-Brown (2000), which drew upon social constructionist and systemic perspectives when exploring the meanings constructed by families including explanations and attributions for children's difficulties.

Findings from semi-structured interviews (Dallos and Hamilton-Brown, 2000), revealed that participating families appeared to be stuck in a cycle of negative constructions of incidences whereby they pathologised their children's behaviour, felt incompetent as parents and experienced feelings of isolation in dealing with their children's behavioural difficulties. The emotional atmosphere added a further contextual factor in the maintenance of this cycle, with parenting often being polarised and conflicting. This conflicting manner of parenting then triggered acting out from the child i.e. externalisation of behaviour, due to them being confused, which in turn triggered parental anxiety and lead to a strengthening in the polarity

of the parenting positions.

The study found that when families were living with simultaneous stressors e.g. socio-economic factors, divorce, bereavement etc., this could lead parents to magnify the child's difficulties and interpret them as being organic rather than contextual. Due to lack of emotional resources, parents were not able to reflect on the impact of the family's dynamic interaction with of these stressors and this led to their children's behavioural difficulties to be pathologised. The current grounded theory therefore complements this research as it also identifies the effect on children's behaviour of conflicting parenting styles in addition to perpetuating environmental contextual factors and the pathologisation of their children's behaviour.

With further reference to the interaction between contexts of socio-economy and parenting, Baumrind (1967) suggested that a more authoritarian approach is an adaptive parenting style when living in environments which are considered to be unsafe or dangerous (1991, cited in Shumow, Vandell & Posner 1998). Furthermore, permissive parenting has been found to significantly increase risk for young adolescents from disadvantaged areas by being indirectly and directly associated with antisocial behaviour by way of anger reactivity (Houltberg et al. 2016).

Further risk factors for children associated with the socio-economic context, include young adolescents from low income backgrounds who also face the risk of early-onset puberty and exhibiting antisocial behaviour (Houltberg, Morris, Cui, Henry and Criss 2016). This is in addition to them receiving less resources and opportunities to practice behavioural and emotional regulation (Piotrowski et al., 2013). There is also an expectation of boys in low

income environments to engage in rough play and to be more extroverted (Entwisle 2007) and when the father is less dominant in rough and tumble play, this is associated with increased physical aggression in children (Flanders, Leo, Paquette, Pihl & Seguin 2009). Furthermore, research by Kishiyama, Boyce, Jimenez, Perry & Knight (2009), provides evidence of changes to pre-frontal cortex functioning and cognitive processes associated with regulation, in children from impoverished backgrounds.

### **Adverse Childhood Experiences (ACEs)**

The developed theory suggests that adverse experiences, for instance experiencing bereavement or witnessing domestic violence, can be a further important perpetuating factor for children's behavioural difficulties, with behaviour being explained as a response to trauma. However, due to challenges which go beyond what parents feel able to cope with, in addition to the interactions with parental anxiety, the behaviour can lead parents to thinking that this is due to autism. Exposure to ACEs is common universally with prevalence being similar across countries despite their income levels (38 – 39% of children worldwide with experiences of ACEs) in addition to being prevalent in families from both rich and poor backgrounds (Kessler et al. 2010, cited in Haliburn, 2018).

The grounded theory provides support for existing literature within this field, particularly exemplified by one participant who discussed challenging a paediatrician's diagnosis of autism, upon hearing the child had experienced both a significant bereavement and witnessed significant domestic violence. Hiscock (2018) describes how 60% of a paediatrician's caseload consists of children with developmental and behavioural difficulties, with many of the children having experienced adverse experiences, exposure to which can aggravate both physical and mental health conditions.

Hiscock (2018) discusses constraints at the systems, practitioner and intervention levels in responding to these cases, including a lack of coordination across services. Most services only treat at an individual level meaning if only the child is being treated, the contributing adverse parenting practices and/or parental anxiety are not addressed and therefore the problems may persist. At a practitioner level, the constraints include a lack of training in how to raise and respond to concerns regarding adverse experiences, therefore there is a risk they go undetected as practitioners will often not ask about them. Furthermore, at an intervention level, there is a scarcity of programmes which are tailored for ACEs, with long-term outcome measures and costings, leading to programmes which are not properly implemented or sustainable with little evidence to support their efficacy or cost.

Existing literature in this field highlights the necessity of providing early intervention when children experience bereavement, particularly the death or loss of a parent as this would constitute a major stressful event and without early support, can lead to children experiencing serious behavioural and emotional difficulties (Kirwin & Hamrin 2005). Moreover, it is recommended that a relational model is utilised by professionals when considering the impact of domestic violence on children (Vetere & Cooper, 2005, cited in Lewis-Morton, Dallos, McClelland & Clempson 2014). It is suggested that at times when parents are frightening or are frightened, they are less likely to be able to hold their children in mind and their caring responses may be inconsistent or volatile. It may be difficult for the parent to recognise any distress which is then shown by the child, with the child being left in a contradictory position as the parent is one to whom they seek security and comfort, yet they are not able to trust the response they may receive from the parent.

The current grounded theory complements these findings as in situations such as domestic violence, children will be unlikely to learn the skills to emotionally self-regulate and thereby often display behavioural difficulties. Due to frightening experiences, the parent may have increased anxiety and may be more likely to unconsciously defend against any notion that they may in some way be to blame for their child's behaviour, instead attributing the causes to organic factors for which no blame to themselves is attributable.

### **6.4.3 Impact of the ADOS assessment process.**

As outlined in section 4.3.3, it is considered that the interaction between parental anxiety and impact of parent on ADOS is of importance here for the professional involved, in addition to the interaction between the impact of ADOS on child and the post ADOS code of alternative explanation/needs. The study identified power imbalances to be of importance in relation to the diagnostic process.

The developed theory suggests this is particularly pertinent to the parent who takes on a lay-person role, with the doctor being the expert and holding all of the diagnostic power. (Wilhelmsen & Nilsen, 2015). However the grounded theory also highlighted power imbalances in relation to the child within the diagnostic process, with one participant raising the notion of the process being done to the child without their consent and others discussing the notion of a child being given a diagnostic label they may not want and will have for the rest of their lives.

The grounded theory adds support to existing literature regarding power within the relationship between the professional and the parent/carer and child. Schein (2009) argues that issues of power pervade the diagnostic process and maintains that there can be one of

three roles adopted by the “helper”. These are the expert resource role, the doctor role and the process consultant role. Schein suggests that both the expert resource role and the doctor role place the professional as the expert who diagnoses, prescribes and if appropriate, administers a cure.

This creates a power imbalance with all the power being cited within the “expert”, leading to disempowerment for the parent. In at least two of the ADOS cases which were observed by the author when employed as an assistant EP, once all of the evidence had been assimilated, the paediatrician, or “expert” went onto suggest the problem was to do with parenting. This imbalance of power can then lead to the parent/carer feeling subordinated, defensive and silenced (Hjorne and Saljo 2004; Hodge and Runswick-Cole 2008; Lundeby and Tøssebro 2008; Rogers 2011, cited in Wilhelmsen & Nilsen, 2015) in addition to defensive and hostile (Cottman and Espie 2014). Perhaps this may go some way to explain why some parents may remain convinced that their child having autism and repeatedly seek a diagnosis, as described by some participants in the current study

This once more raises the notion of autism being an external reality, with diagnostic criteria being used to determine this. However as previously discussed, with no bio-markers and a varying symptomology, this can place constraints on any potential diagnosis. Within the LA in which the study takes place, this leads the MDT autism diagnostic pathway to ask for the involvement of EPs to triangulate information and carry out the ADOS within the child’s natural context of school. Does this therefore open a debate that autism is not a medical condition but is a socially constructed one? On the other hand, several participants discussed “google doctor” with parents’ searching for and overvaluing data that supports their pre-existing belief of autism i.e. confirmation bias. Therefore, could it be that the professionals



and parents are referring to different diagnostic criteria, with parents perhaps receiving inaccurate information on the internet, or as the grounded theory highlighted, from the “wrong places” such as social media?

The current grounded theory goes beyond the existing literature whereby differences in the setting for the autism assessment were seen as significant. Here, if the child’s behavioural difficulties are due to them experiencing anxiety, a clinical environment may well increase this anxiety and possibly have a bearing on their ability to self-regulate and interact with the ADOS assessment. This could once again have implications for issues relating to power, with the “expert” being housed within the institution of a clinical environment where diagnoses are provided. On the other hand, as identified in the grounded theory, a more familiar school setting may limit levels of stress for the child, resulting in better self-regulation and therefore providing a clearer view for the professional of the child’s natural presentation.

Furthermore, when an EP carries out assessments within the school setting, they will triangulate evidence from observation and assessment with the child, in addition to holding a consultation with parents/carers and the school, in order to consider the impact of the child’s surrounding systems with which the child is inextricably linked. Within the National Institute for Health and Care Excellence (NICE) guidelines (2017) for the autism diagnostic assessment process, section 1.5.9 only recommends to triangulate information if there are discrepancies between the autism assessment and signs or symptoms in the clinical setting. Yet, it is argued that if the child is indeed suffering from anxiety as stated above, this discrepancy model wouldn’t account for this. An issue once again relating to power imbalances, as the child does not have any power or autonomy within the diagnostic process.

#### **6.4.4 Post ADOS, what next?**

When considering what happens once the families in question are informed their child will not be receiving a diagnosis of autism, the study identified barriers or constraints to the families moving forward and possible alternative explanations for the child's behavioural difficulties, in addition to ideas for early intervention with this population.

This core category captures participant's views and ideas about what happens when the children of parents who think that their child's behaviour is due to autism, do not receive a diagnosis. Parental anxiety interacts with barriers to moving forward, particularly in relation to the code 'parents retain fixed mindset'. The next steps for both children and their parents are also incorporated within this core category.

##### **6.4.4.1 Barriers to moving forward**

It was considered that the interaction of parental anxiety, particularly in relation to the code 'parents retain fixed mindset' provided a particular barrier to moving forward and could be instrumental in professional's parental views the researcher heard as outlined in sections 1.2 and 6.2. The study identified that a negative reaction from parents at hearing their child will not receive a diagnosis of autism, may be driven by lack of explanation of what is causing their child's behavioural difficulties and with no alternative reason given, the confirmation bias driving the belief of autism remains. Furthermore, parents remain in need of help, as despite a diagnosis not being received; the difficulties experienced with the child's behaviour remain.

The grounded theory generated in this study aligns with Morton's publication (2017) that explored an increase in parent's apparent pursuit to receive a diagnosis for their children.

Their survey revealed that in order for parents to access help for the difficulties their children face, some seek a diagnosis from a second, often private professional, when a first assessment concludes that autism diagnostic criteria has not been met. This, the study found, was due to parents being desperate to seek help and gain understanding of their child's difficulties, which are often behaviourally based.

Also identified in the grounded theory as a barrier to moving forward, were issues relating to trust and relationships within the assessment process. In the current study, a participant spoke about the importance of the relationship between the parent and paediatrician and depending on the quality of this, this relationship can contribute to the parent not accepting the decision when told that their child does not have autism. This together with the notion of parents perhaps feeling silenced and subordinated provides support for a study by Moh (2012) who found parental satisfaction with the diagnostic process was higher and less stress was experienced when the relationship with the professional was of a more collaborative nature.

The possibility of parents thinking that their child's behaviour is attributable to autism due to actually being an undiagnosed need was also identified in the grounded theory as a barrier to moving forward, a finding that supports existing literature. For instance, participants discussed the overlap in symptomology between autism and attachment disorder, a phenomenon found in a study of Romanian orphans who had received minimal human interaction (Rutter et al., 2001, cited in Flackhill, James, Soppitt & Milton, 2017). Symptomology overlap includes a preference for predictability, difficulties with social interaction and difficulty appreciating other peoples' views and thoughts (Moran, 2015). With no bio-marker for the diagnosis of autism and interpretations of autism and attachment disorder having to be considered by clinicians, this can create difficulty and contributes to

misdiagnosis (McKenzie & Dallos, 2017). In order to aid with differentiation, the Coventry Grid was originally created by Child and Adolescent Mental Health Services (CAMHS) clinicians in Coventry (Moran, 2010, cited in cited in Flackhill, James, Soppitt & Milton, 2017).

Some language difficulties such as Specific Language Impairment (SLI) can also present in similar ways to autism, including difficulties in both areas of social communication and language. Leyfer, Tager-Flusberg, Dowd, Tomblin and Folstein (2008), carried out a study using the ADOS and ADI to explore the overlapping clinical features seen with autism and SLI. Results suggested that 41% of children with SLI met autism criteria on the social or communication domains. This once more highlights the need to look at the overall clinical picture, as due to the overlapping symptomology this can lead to misdiagnosis (Botting & Conti-Ramsden, 2003).

#### **6.4.4.2 Ideas for early intervention**

As outlined in section 6.4.2.1, the effect of the government's austerity measures have also exacerbated a lack of crucial support being available, particularly for vulnerable populations in areas of socio-economic deprivation. As discussed previously, this then interacts with parental anxiety, leading to a possible reason why parents think their child's behaviour is indicative of autism. The grounded theory identified ways in which EPs could provide early intervention, so that early support can be provided for parents away from the autism assessment route.

Providing support for existing literature, participants shared views on working with parents to provide Cognitive Behavioural Therapy (CBT), targeting the anxiety of both parents' and

their children, in addition to overprotection and family accommodation, due to their child's anxiety. Although treating anxiety in children with CBT has strong theoretical underpinnings (Albano & Kendall, 2002), it can be problematic due to the necessity of active participation of the child (Lebowitz, Omer, Hermes & Scahill, 2014). In a trial of a parent-based intervention for children with anxiety disorders (Lebowitz, Omer, Hermes & Scahill, 2014), results found significant improvement for child anxiety and family accommodation.

Mindfulness was also raised as an early intervention idea by participants for use with children. Rather than seeking to adapt thoughts as used in CBT methods, one of the aims of mindfulness is the acceptance of thoughts. Although this has been found to be efficacious in reducing anxiety in adults (Semple, Reid & Miller, 2005), there is little empirical research regarding its efficacy with children (Greenberg and Harris, 2012). However, in a review of current research on mindfulness by Greenberg and Harris (2012), they concluded that there is enthusiasm for this practice and beneficial outcomes were found for children in previous research on yoga and meditation, which has its roots in mindfulness.

Early intervention by way of the provision of strategies was also identified in the theory, providing support for existing literature within this area. Used within the LA in which the research took place, the Triple P Positive Parenting programme has sound theoretical and empirical underpinnings and is one of the most widely universally used parenting programmes. Designed to enhance the confidence, knowledge and skills of parents in order to prevent and treat emotional, the programme has been found to improve children's behavioural difficulties and that these improvements are sustained over time (De Graaf, Speetjens, Smit, De Wolff & Tavecchio, 2008).

When considering the need for early intervention, the provision of strategies and the manner in which this is raised to parents, the current grounded theory goes beyond the existing literature due to raising the notion of power relations. As previously outlined, if a parent is thinking their child's behaviour is symptomatic of autism due to having an unconscious psychological response against the possibility that they may be in some way to blame, professionals need to be mindful of the manner in which parenting skills are raised. This needs to be done in a sensitive, non-judgemental and collaborative manner, as due to the aforementioned power imbalances, if left feeling judged and to blame, parents can come to feel defensive and hostile (Cottman and Espie 2014), thereby effecting motivation and engagement.

## **6.5 Implications for Educational Psychologists**

The rationale for the study outlined that if more understanding was provided as to the reasons why parents may seek a diagnosis in cases where autism is not present, the provision of, or signposting to more appropriate intervention and assessment could be provided away from the autism assessment route.

The current study presents a theory that due to parents experiencing challenges which go beyond what parents feel able to cope with combined with their own anxiety, the idea that they may in some way be connected with their child's challenging behaviour creates an unconscious psychological response<sup>7</sup>, leading to them attributing this to autism. Furthermore, there are a number of environmental contributing factors which may be contributing to both the parenting skills and parental anxiety in addition to the child's behavioural difficulties.

These findings can inform the practice of EPs and their fellow professionals, through exploring whether the findings relate to individual cases and consider adapting practice to explore more widely and test hypotheses. It is proposed that EPs and their colleagues hold in mind that parents may think that their child's behaviour is organic in nature rather than being caused by contextual factors. Curious sensitive questioning may then be used to explore the existence of any adverse childhood experiences and/or socio-economic deprivation in addition to exploring family support networks etc. This may then provide the necessary information to inform signposting to relevant services and/or early intervention.

The findings from this grounded theory have yet to be tested, despite this there are actions EPs can consider, these may include:

- Provision of training to early years and school settings to support with the early identification of parental anxiety. This could include psychoeducation of the impact of parental anxiety on children, details on the chances of their children also developing mental health difficulties, in addition to strategies for ameliorating this.
- Many EPs have received training in Cognitive Behaviour Therapy (CBT) and are ideally placed being in schools to work at an early intervention level with parents to support their children with anxiety. Perhaps EPs could develop a programme together with health colleagues that could then be delivered to small groups of parents. Alternatively, an existing manualised programme could be used such as Timid to Tiger (Cartwright-Hatton, 2010), a book designed for clinicians to work with parents of anxious children aged three to nine and was reviewed as being an excellent guide (Callaghan, 2012).

- Provision of training to early years and school settings regarding how to raise and respond to concerns regarding adverse experiences and the effect of these on a child's social and emotional development.
- Parent workshops to discuss effects of anxiety on children, including the behavioural manifestations.
- Parent workshops to discuss parenting skills and strategies. A workshop is suggested with a view to this being run collaboratively with parents and therefore in a non-judgemental manner.
- Training in schools and early years settings regarding child anxiety, how this can manifest in symptoms which may appear similar to autism and how to differentiate between the two.
- Training in school on the benefits to emotional well-being and learning of relaxation strategies e.g. mindfulness.

## **6.6 Dissemination**

The findings from the current grounded theory study will be disseminated to all participants. Furthermore, the findings will be presented to the Educational Psychology Service whole team meeting within the LA in which the study took place.

Finally, there is an aim for the study to be disseminated through writing papers to be published within relevant journals.

## **6.7 Limitations**

This theory comes from EPs, is based on their perspectives and is yet to be tested with parents and individual cases.



All six of the EPs were recruited from the LA in which the study took place. Participants included only one male, with five of the participants being white British and the other white American. Therefore, there may have been a lack of cultural and ethnic diversity in the views expressed.

Although the LA has economic diversity with pockets of socio-economic depravity, the population is predominantly white British. Also, different authorities have different diagnostic processes. Therefore, this should also be explored further in order to test the findings from theory.

There were only six EPs in the LA who carried out the ADOS autism assessments and they were all interviewed. Whilst this was a limited number and the aim was for data sufficiency, it is felt that theoretical saturation was achieved at interview six.

EPs came to the interviews with their own preconceived ideas both about autism and about the ADOS and the diagnostic process, which may have introduced bias. Furthermore, whilst all efforts were made by the researcher to take a reflexive stance throughout the research process, by using verbatim transcripts of the audio recordings and memos to record thoughts and feelings, it is not possible to be truly objective. Therefore the findings should be treated with caution and tested due to possible researcher bias.

## **6.8 Future studies**

Further research could include the findings from this study being tested by exploring the issues arising with parents, in order to explore whether the EP perspective reflects reality.

In order to test the generalisability of the findings, further research could include the exploration of EPs' views in an authority which has cultural and ethnic diversity from both a population and EP perspective.

It would also be beneficial to test the findings in an authority which uses an alternative autism assessment to the ADOS. Furthermore, a parenting programme could be run, with pre and post outcome measures to explore the impact on parental perceptions of their child's behaviour.

## **6.9 Concluding comments and researcher reflections**

The aim of the current study was to provide EPs with an understanding on the contexts and mechanisms that lead parents to think that their children's behaviour is related to autism and thereby inform their practice and early interventions with the population in question. Seeking and then not receiving a diagnosis can be a very distressing time for parents. Many have had a long-wait to get to the final stage of the autism diagnostic process before being told their child does not have autism. With no alternative explanation and their child still displaying behavioural difficulties, the parents belief that their child has autism may remain and this may lead to repeatedly seeking the diagnosis.

A hypothesis that some parents think that their child's behaviour is caused by organic rather than contextual factors, can guide professionals towards this possibility and inform early interventions accordingly. This, it is hoped, could lead to parenting support being provided at an earlier stage, thereby reducing stress for the families and children and reducing the burden on resources and therefore waitlists too. However, as further research is needed to

substantiate the theory, at this stage appropriate caution in relation to the findings needs to be applied. Nonetheless, hypothesis generation in this area would be appropriate.

The experience of conducting this research has been a challenging yet rewarding one. It has been fascinating to hear EPs' views of working with this population.

It has at times been challenging to remain true to the critical realism paradigm adopted for this study, as this was not the dominant paradigm amongst participants; several participants' discussed how they worked in a systemic fashion and took a constructivist stance. At this present time, with no biomarker for autism as yet identified, there will continue to be the possibility of false positives and false negatives, raising the question of whether we can ever definitively say who is and who isn't autistic. However, it is hoped that the first step that has been taken with this study, which has provided a "first look" understanding that could lead to ameliorating the difficulties experienced by the population in question.

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# Appendix 1 : Preliminary Literature Review Summary

## Table

Table 1 Adopting the research critique of Holland & Rees, this table addresses the research articles focus, background, aim, methodology, method of data collection, method of data analysis and details of sample.

Table 2 Continuing with the adopted critique tool of Holland and Rees, this table addresses the research articles ethical considerations, main findings, conclusions and recommendations, overall strengths and limitations and application to practice.

**Table 1**

STUDY	FOCUS	BACKGROUND	AIM	METHODOLOGY	DATA COLLECTION	DATA ANALYSIS	SAMPLE
Turygin, Matson, Williams & Belva (2014)	Study exploring the relationship between parental first concerns and later ASC diagnosis.	Discusses emergence of ASC symptoms early in development, with various studies citing areas of First Concern (FC).  Discusses previous studies including: relationship between FC and level of child's difficulties, the later diagnostic predictive outcome when FC was in relation to communication. Therefore establishes	Clear statement of aim exploring relationship between FC, effect of other areas of concern and later diagnostic outcome.	Quantitative methodology using a survey design.	Measures used are clearly described and include a screening assessment battery and interviews with carers by trained clinicians.	There is no clear mention of the statistical process used e.g. SPSS, however statistical tests employed are detailed.	Toddlers and carers recruited through an early steps programme, where they had been referred due to potential developmental delay. Number not explicitly stated in body of article, leaving the reader having to work this out/go to abstract.  Discusses how some sample eliminated from data set and reasons for

		self as novel piece of research.					this.
Lo, Kloppner, Barnes & Williams (2017)	Explores relationship between referrers concern regarding ASC at point of referral (including parents) and diagnostic outcome.	Paper discusses the rise in public awareness and referrals for those seeking diagnosis of ASC. However states that 39% children referred in USA did not go onto receive a diagnosis and how this contributes to greater waiting times for all.	Not a clear statement of aim in body of article.  Study reviews data of children referred to an assessment team in Sydney over a 3 year period, looking at referrals from all sources including parents, medical professionals and school staff. This data was examined to look for agreement between referral concern and outcome of assessment.	Within a quantitative methodology, data was extracted from a database and put into 1 of 2 categories i.e. ASC concern, without ASC concern with questionnaire completed regarding their cognitive and developmental levels.	Data was extracted from a pre-existing database, in addition to the use of questionnaires and parent interviews.	Clear statement provided advising that data analysed using SAS version 9.3 and the statistical tests applied therein.	677 children aged between 14-76 months who had been referred during 2008-2010, with details being on an existing database.
Sacrey et al. (2015)	Relationship between parental concerns of High Risk (HR) siblings and diagnostic outcome.  Variables clear from the title.	Discusses how ASC often diagnosed at approx. 4 yrs of age, yet parents often report retrospective concerns from much earlier even at less than 1 year of age.  Also discusses how parents perceptions maybe influenced by more commonly known traits of ASC and not early signs e.g. sensory or motor difficulties, as growing	Clear aim stating examining parental concerns of children age 6-24 months, across multiple domains and in association with their risk for ASC.  Primary objective to differentiate between parental concerns of HR children diagnosed with ASC at 36 months and LR/other HR infants.	Quantitative methodology, with longitudinal design.	Several measures administered to ascertain cognition, ASC traits and adaptive behaviour over time.  ADOS and ADI-R used to measure ASC symptoms.  Semi-structured interview exploring parental concerns during first 2 years. Data was then blindly coded.	Clear statement of use of SPSS and statistical tests applied.	Part of longitudinal study across 4 sites in Canada. Additional LR infants recruited from community in surrounding areas.  It was not clearly stated number of participants, with the reader being left to work this out.

		literature suggests.					
Ozono ff et al. (2009)	Topic of concern regarding the relationship between parental concern during the first 18 months and subsequent ASC diagnostic outcomes.	Discusses importance of parental voice when collating developmental history within the autism assessment process. Due to media attention, general public knowledge is increasing leading to a rise in parents reporting concerns.  Discusses earlier signs of autism far before diagnosis with a 1/3 parents stating concerns raised by 12 months. However assessing the accuracy of these concerns can be complicated e.g. symptoms emerge over time and parental concern can be influenced by the status of the child's health	There is no clear statement of aim. However at end of introduction states that the study is novel in exploring the correlation between longitudinal parent report and diagnostic outcome of later autism assessment.	Quantitative methodology employing a longitudinal design.	4 questionnaires were utilised together with completion of ADOS. Footnotes were also present addressing validity of measures employed.	There is no clear mention of the statistical process used e.g. SPSS, nor the statistical tests employed and it is left for the reader to interpret this.  However the statistical test results appear to be well laid out and supplemented by graphs and tables	After the withdrawal of 31 participants, total number remaining was 243 infants recruited over 2 sites. The study gives a clear outline of the sample details.
Dereu et al (2012)	A comparison between screening	Various screening tools are in use in order	Clear statement of aim being to compare new screening	Quantitative methodology, survey design.	Measures used for both childcare	Article does not explicitly state	Clear sample information stated.

	instruments completed by childcare workers and parents.	to aid early detection of ASC. Discusses new screening instrument to be completed by childcare workers.	instrument with commonly used questionnaires for parents.		workers and parents are clearly described. Study mentions return rates for parental questionnaires was low.	the statistical process used e.g. SPSS, however individual statistical tests employed are detailed.	Taken from a larger screening study of 7092 children, 357 children took part whose results from childcare screening showed them to have an elevated risk of ASC.
Jobs, Bolte & Falck-Ytter (2019)	Diagnostic accuracy compared in ratings given by preschool staff and parents. Variables clear in the title.	Discusses emergence of ASC symptoms often in 2 <sup>nd</sup> year, the recommendation that ASC assessment should include both the ADOS and ADI-R and citing Dereu et al (2012), how previous studies have highlighted the valuable information received from early years workers.	Clear aim of study stating <i>“The purpose of this study was to compare parents’ and preschool staff’s ratings of autistic symptoms in young children in relation both to diagnostic assessments and to a gold-standard diagnostic instrument (the ADOS-2).”</i> Further advising what they hypothesis results to be.	Quantitative methodology using a survey design.	Measures used for both childcare workers and parents are clearly described, with mention of them being empirically based and therefore noting their validity.	Clear statement of use of SPSS and statistical tests applied.	Sample of 56 children taken from pre-existing longitudinal study. Clear statement of numbers of high/low risk of ASD within sample.
Duvekot, Ende, Verhulst & Greaves-Lord (2015)	Teacher and parent screening accuracy when using the Social Responsiveness Scale (SRS)	Discusses complexity of diagnosing ASC, particularly highlighting overlap of alternative disorders and how	Two study aims clearly stated, both comparing with the 3Di and ADOS. The first being to examine and compare parental screening accuracy of	Quantitative methodology using a survey design.	All measures used are clearly described, in addition to the validity of each being discussed.	Article does not explicitly state the statistical process used e.g. SPSS, however individual	Part of a multi-centre “social spectrum study”, with clinically referred high risk children,

	<p>compared with the 3Di and ADOS. Variables clear in the title.</p>	<p>there is a gold standard of the 3Di or ADI-R and the ADOS. Discusses the economic and time costs associated with their use. Contrasts these implications with the use of the SRS, stating although the tool has been validated for general population use, usually only used as a high-risk screening tool.</p>	<p>SRS.</p> <p>The second was examining SRS completed by teachers in addition to the parents.</p>			<p>al statistical tests employed are detailed.</p>	<p>where interrelationships between ASC are examined together with family factors and characteristics of behaviour.</p> <p>Sampling design clearly stated, detailing response rates and how screened to final sample of n=186 children.</p>
<p>Moricke, Buitelaar &amp; Rommelse (2016)</p>	<p>Study examines report bias when both parents are asked to complete ASC screening tools. Variables are clear in the title.</p>	<p>Discusses commonplace use of questionnaires and how the cost effectiveness of this. However usually this just involves one respondent i.e. the mother and how teachers and fathers interpretations may differ.</p> <p>Moves on to discuss how there is little research about validity and utility of</p>	<p>Clear statement of aims, being for the level of report bias in parental reports being systematically investigated. This was in relation to their child, in addition to their spouse and within themselves.</p> <p>Moreover, correlational differences between individual parent reports of parent and child ASC traits was also investigated</p>	<p>Quantitative methodology using a survey design.</p>	<p>Clear outline of measures used and how previous cited studies were utilised with regards to analysing scores.</p>	<p>Article does not explicitly state the statistical process used e.g. SPSS, however individual statistical tests employed are detailed.</p>	<p>A subsample of n=188 from general population with study stating that the selection had an equal division of low to high risk for ASC.</p>



		multiple informants in ASC assessments, before outlining how report bias is examined within research.					
Macari et al. (2018)	Examines the agreement between parent and clinicians behaviour ratings of 12 month old children at high/low risk of ASC.	provide the rationale by discussing the increasing prevalence of ASC and how prior to the age of two, two separate universal screenings are recommended by American Academy of Paediatrics and therefore how early intervention is key for maximising outcomes. Moreover, universal early screenings could reduce delays in the diagnostic process and in their design, parent/clinician concordance is of great importance.	Clear statement of aims being to explore the difference in parental/clinicians concordant and discrepant judgement of ASC behaviours.	Quantitative methodology using a survey design.	All measures used are clearly described, in addition to the validity of each being discussed.	Clear statement of use of SPSS and statistical tests applied.	Sample n=137 of high/low risk infants, with details including ethnicity, parental education and tools for assessing stated.
Havdahl et al.	Study explores validity of	Discusses gold standard use	Clear primary aim in last paragraph of	Quantitative methodology using a	All measures and their	Clear statement of use	Detailed account of how

(2017)	ADI-R & ADOS in Norwegian cohort and if parental concern influences the ASC diagnostic process/outcome.	and therefore heavy worldwide reliance of ADI-R and ADOS, however sparse studies exploring validity outside of specialist centres in the U.S. Additionally discusses the possibility of parents who have ASC concerns having increased awareness and/or inclination to report ASC behaviours, thereby having potential to bias parent reporting tools e.g. ADI-R.	introduction seeking to ascertain diagnostic agreement of ADOS & ADI-R in Norwegian population based sample. A second aim considered influence of parental concern on diagnostic instruments by using sample which included parents who were concerned about ASC and those who did not specify ASC.	survey design in the form of the ADI-R and ADOS.	use is clearly described.	of SPSS and statistical tests applied.	sample were recruited from Norwegian mother and child cohort study.
Ward, Sullivan & Gilmore (2017)	To adapt an ASC screening tool used by clinicians, to an equivalent for parents. Variables clear from the title.	Brief screening tools which require less training are needed by primary health providers, so that children who have ASC concerns can be detected early.  The Autistic Behavioural	Clear aim of study is to adapt ABII so that it can be used as a parent questionnaire.	Quantitative methodology with an observational cross-sectional study design.	ABII clearly outlined and adaptation to parental questionnaire (ABII-PQ).	Article does not explicitly state the statistical process used e.g. SPSS, however individual statistical tests employed are detailed.	Clear paragraph details sample of n=102 made up of typically developing children and those with ASC.

		Indicators Instrument (ABII) is named is outlined as a screening tool used by clinicians which requires minimal training and studies are provided as to its validity.					
Rowberry et al. (2015)	Explores utility of parental reports when screening 12 month olds who are at High Risk (HR) of developing ASC. Clear from the title.	Discusses how ASC has strong genetic basis i.e. siblings of children with ASC, in addition to difficulties with early detection e.g. differences in symptoms and onset. Cites previous studies suggesting upto 40% HR infants show traits by 12 months and lack of studies on parental report of this population.	Three clear aims of study set out. <ol style="list-style-type: none"> <li>1. Compare parental ratings of repetitive and social-communication behaviours for HR siblings who go on to receive ASC diagnosis and those with alternative outcomes.</li> <li>2. Comparison between parent reporting and clinician ratings.</li> <li>3. Investigating</li> </ol>	Quantitative methodology using a survey design.	Measures used clearly laid out citing studies re validity.	Article does not explicitly state the statistical process used e.g. SPSS, however individual statistical tests employed are detailed.	Clear paragraph details sample of n=96 made up of HR, LR and typically developing infants, taking part in longitudinal research study in addition to exclusion criteria stated.

			specific traits which constitute early signs of ASC at 12 months .				
Blacher, Cohen & Azad (2014)	Study compares Latino and Anglo parental reports of ASC concerns	Discusses and cites multiple previous research studies into racial and ethnic incongruencies in diagnosis/treatment of physical and mental health conditions yet studies exploring ASC socio-culturally are inconclusive with few differences shown with regards to prevalence amongst different ethnic and social groups.  Also cites consistent findings that Latino children are less likely to be diagnosed with ASC in comparison with white children.	Separate headed section provided detailing two research questions being: <ul style="list-style-type: none"> <li>- Do Latino and Anglo parents differ in terms of ASC concerns.</li> <li>- How do clinician ratings compare with these.</li> </ul>	Quantitative methodology using a survey design.	Measures clearly outlined and consists of a screening intake form with hyperlink provided, ADOS and ADI-R.	Article does not explicitly state the statistical process used e.g. SPSS, however individual statistical tests employed are detailed.	Sample of n=83 mothers (Anglo = 28 and Latino = 55) whose children had been referred to ASC screening clinic.

		<p>Hypotheses raised that this may be under-diagnosis, or protective factors within this population.</p> <p>Separate section given discussing cultural beliefs regarding child development and disabilities.</p>					
Stronach & Wetherby (2017)	Study exploring if social communication measures differ across race and ethnicity for children with/without ASC	<p>Discusses early emergence of ASC symptoms and ethnic/cultural disparities in ASC diagnoses including prevalence and age at diagnosis.</p> <p>Sections considering social learning theory and social communication through a cultural lens.</p>	Clear purpose of study being to investigate and compare profiles of social communication between typically developing toddlers, developmental delay and those with ASC across 3 racial/ethnic groups in the US (Hispanic, white non-Hispanic and black non-Hispanic).	Quantitative methodology using a survey design	Measures used were ADOS, ESAC (parent reporting tool) and Communication and Symbolic Behaviour Scales Behaviour Sample (CSBS-BS). Details regarding its validity and procedure given.	Data analysis details placed under results section. Article does not explicitly state the statistical process used e.g. SPSS, however some information regarding individual statistical tests employed is outlined.	Participants n=364 toddlers age 18-36 months recruited as part of a longitudinal study. Clear details given as to ethnic/racial make-up of sample
Connelly & Gersch (2013)	Clearly identify the focus from the title of assessing the utility of support group for parents	Discusses rise in prevalence of ASC leading to longer waiting times for assessment.	<p>Six clear objectives were outlined under a separate heading:</p> <ul style="list-style-type: none"> <li>- Exploring parental experie</li> </ul>	Qualitative design in the action research tradition	Study employed a focus group discussion design and reasonably discussed how this was	Thematic content analysis with the six step approach clearly outlined.	Purposive sampling was utilised for all stages of the study and criteria used is clearly

	<p>whose children are on waitlist for ASC assessment .</p> <p>Involves 3 stages: research, intervention and evaluation.</p>	<p>Provides explicit rationale for study by outlining clinician awareness of distress caused to parents of prolonged wait and this has been cited as being the worst part of the diagnostic process.</p>	<ul style="list-style-type: none"> <li>- nces</li> <li>- Ascertaining if short parenting programme would be beneficial.</li> <li>- Design and implement programme.</li> <li>- Evaluate programme.</li> <li>- Add to literature</li> <li>- Inform service delivery</li> </ul>		<p>appropriate to address aims of research.</p>		<p>detailed.</p>
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**Table 2**

STUDY	ETHICAL CONSIDERATIONS	MAIN FINDINGS	CONCLUSION AND RECOMMENDATIONS	OVERALL STRENGTHS AND WEAKNESSES
Turygin, Matson, Williams & Belva (2014)	Clear statement of ethical approval received, in addition to the gaining of informed consent.	<p>When parental FC related to behaviour and cognitive delay, without communication difficulties there was a predicted decrease of an ASC diagnosis in comparison with parents whose concerns were associated with communication.</p> <p>A significant</p>	<p>Raises importance for professionals and parents to receive education on common FC and the associated risk factors for subsequent ASC diagnosis.</p> <p>Ends conclusion saying that social and environmental factors should also be taken into account when ascertaining risk of diagnosis.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Ethical rigour.</li> <li>• Clearly outlined rationale for research and identified gap in current literature.</li> <li>• Concludes with argument for holistic evaluation of parental concerns.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• At times, the reader was left</li> </ul>

		<p>difference was also found between parents who reported only one FC and those who reported more. Later towards the end of the discussion, the authors elaborated on this explaining those with multiple FC's have an increasing risk of ASC diagnosis.</p>		<p>having to search for information to obtain a clear picture of the meaning of the results.</p>
<p>Lo, Klopper, Barnes &amp; Williams (2017)</p>	<p>Clear statement of ethical approval received and reference number provided. However no ethical issues were discussed, it is therefore unclear as to how ethically rigorous the study was.</p>	<p>Across the 3 year period, of the 677 sample, 35% was due to ASC concerns. Ratio for male/female diagnosis was 4:1. In 87% of cases, there was an agreement between referral reason and diagnosis. The Referral reason for 79% of the remaining 85 children was ASC concerns, but no diagnosis was given.</p> <p>Agreement levels across all referrers was at least 80%.</p> <p>Therefore approximately only 30% of children for ASC assessment did not meet the criteria for diagnosis, with similar patterns</p>	<p>Provides evidence that sizeable minority of children referred for ASC assessment did not receive a diagnosis. This creates a pressure on services – particularly for , leading to longer waiting times and therefore a barrier to accessing services where a diagnosis is required.</p> <p>Discusses if these were have been to an assessment team which was ASC specific, this would have led to them being over-burdened, once again providing barriers for children who do go on to get an ASC diagnosis.</p> <p><u>Recommendations</u> Children should be referred for comprehensive assessment taking into account function and/or behavioural concerns</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>Fairly large sample</li> <li>Good practical recommendations</li> <li>Addressed gap in literature.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>lack of ethical considerations.</li> <li>Finding relate to children 6 years and under, therefore not possible to generalise across other ages.</li> <li>Data was gathered from one source.</li> <li>Only information at time of initial referral and assessment was available, therefore didn't</li> </ul>

		seen irrespective of referral source or child's age.	rather than all for ASC specific assessments. This will reduce not only waiting time, but also avoidable anxiety for families.	take into account any changes over time.
Sacrety et al. (2015)	There was no mention of any ethical considerations.	<p>Parents whose HR children go on to receive a diagnosis of ASC, recognise their differences from very early on.</p> <p>Across all groups, during the first year parents were more likely to report motor and sleep difficulties and across 2<sup>nd</sup> and 3<sup>rd</sup> years behavioural and communication difficulties. These reports were individually predictors of receiving a diagnosis of ASC.</p> <p>Total parental concerns at 12 months predicted the HR children most likely to receive a diagnosis of ASC.</p>	<p>Study states that findings are the most detailed for this population of parental concerns.</p> <p>Findings suggest utility for the use of sensitive ASC screening tools and are in line with current practice guidelines. The removal of barriers to this uptake could include referral systems which are streamlined with staff who are trained to deal with referrals in a timely manner.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Addressed gap in literature for in-depth study for this population.</li> <li>• End of report gives clear clinical guidance.</li> <li>• States implications for practice.</li> <li>• Longitudinal design.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Sample not clearly stated, with the reader having to work this out from a table.</li> <li>• Due to lack of information regarding ethics, it is difficult to state if this study was ethically rigorous.</li> </ul>
Ozonoff et al. (2009)	Clear statement of overall ethical approval received. However no explicit mention of any ethical procedures e.g. informed consent and confidentiality etc.	<p>For parents with older child with ASC, by 1 year of age significant concerns were significantly related to measures and ASC symptoms and a good predictor for later diagnostic outcome.</p> <p>However, it was not possible to predict the</p>	<p>Results suggest that when infants are 6 months old, rather than being based on actual developmental difficulties, parental concerns more associated with older child with ASC. It was hypothesised this may be due to parents being more anxious and hypervigilant due to older child.</p> <p>However by 1 year,</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Addressed gap in literature.</li> <li>• Longitudinal design.</li> <li>• Validity of tools of measurement addressed.</li> <li>• Findings at 12 months consistent with other studies.</li> <li>• Supports view that high risk should be</li> </ul>



		<p>diagnostic outcome for the same group when infants were 6 month old.</p>	<p>concerns better reflect developmental difficulties and offer better prediction of diagnostic outcome.</p> <p><u>Recommendations</u> Due to self-sampling and therefore selection biases, recommends future studies should use community based epidemiologic samples.</p>	<p>monitored so that key early intervention can be offered.</p> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>Ethical rigour unclear as ethical procedures omitted from article.</li> <li>Lack of clarity regarding statistical measures used, therefore making any replication of this study difficult to carry out.</li> <li>Study recognises selection biases with the sample as was self-selection</li> </ul>
Dereu et al (2012)	<p>There was no mention of ethical considerations. However readers were signposted to the larger screening study from which the sample was taken</p>	<p>Parental response rates suggest parents more likely to participate when their child's development was more apparent to be atypical.</p> <p>Findings suggests that both the new childcare screening tool and parent questionnaires are able to discriminate between children with and without a later ASC diagnosis. All instruments appeared to perform equally well.</p>	<p>Study suggests a very useful tool in order to enhance early detection of ASC. Furthermore when using the care worker tool for screening children with suspected ASC, the false negatives was half that of the parent questionnaire.</p> <p>However, out of the instruments used if taking the children who scored positively on any of these, this would have led to 82.49% in ASC false positive cases.</p> <p><u>Recommendations</u> The care worker tool should be considered as a level one early years population screening tool, with parents being asked to complete questionnaires only for children highlighted with potential developmental difficulties.</p> <p>This has the potential to</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>Explores useful tool in ASC screening, training childcare workers who have good knowledge of the children.</li> <li>Provides practical ideas for practice for use in early years and therefore early intervention.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>Ethical rigour unclear as ethical procedures omitted from article.</li> <li>Comparison based on small sample sizes.</li> <li>The article felt at times confusing to read e.g. flipping between stating participants screened to be at</li> </ul>

			alleviate both overburdened assessment clinics in addition to taking into consideration the distress caused for parents and children upon entering the assessment process.	<p>risk of ASC and then stating as if they were already in receipt of diagnosis.</p> <ul style="list-style-type: none"> <li>• Study recognised limitations of sample being largely made up of children screening positive on the childcare screening tool and therefore at high-risk. Therefore difficult to generalise results.</li> </ul>
Jobs, Bolte & Falck-Ytter (2019)	Clear statement of overall ethical approval received. However no explicit mention of any ethical procedures e.g. informed consent and confidentiality etc. However sample taken from existing longitudinal early autism study in Sweden.	<p>Clear statement of findings in first paragraph of discussion of comparison between parents and early years workers. Findings suggest that early years staff are more accurate and better able to both discriminate between children at high/low risk of ASC and track symptoms of ASC with children who are very young.</p> <p>Also discusses how finding support other studies, with details noted.</p>	Discusses how results showing early years staff are significantly better able to discriminate for ASC symptoms, may be in part due to assessing with children's peers who they are able to compare against and more in line with clinical observation. Discusses how results can be generalised to other countries with early years staff trained to the same level i.e. the present studies early years workers included teachers with bachelor's degree and care staff with upper secondary level qualifications.	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Well written article that was very easy for the reader to access.</li> <li>• Use of empirically tested tools of data collection.</li> <li>• Clear and informative abstract.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Study notes limitation of small sample size</li> </ul>
Duvekot, Ende, Verhulst & Greaves-Lord (2015)	Clear statement of ethical approval received and reference number provided. However no ethical issues were discussed, it is therefore unclear as to how ethically rigorous the study was.	Excellent screening accuracy was found with parental SRS, however combining with the teacher SRS improved discrimination between children who would/wouldn't	Argues how results suggests SRS could be used as a valuable screening tool within early assessment prior to referral for comprehensive assessment, in addition to the importance of multi-informants and tools being part of the overall diagnostic	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Novel research.</li> <li>• Sample details clearly stated.</li> <li>• Use of empirically tested tools of data collection.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Ethical rigour unclear as ethical procedures</li> </ul>

		meet ASC cut off scores on the ADOS.	process.	<p>omitted from article.</p> <ul style="list-style-type: none"> <li>• Discussion about results was not clear to the reader.</li> </ul>
Moricke, Buitelaar & Rommelse (2016)	Clear statement of overall ethical approval received. However no explicit mention of any ethical procedures e.g. informed consent and confidentiality etc.	<p>For individual parental reports regarding child ASC traits, no report bias was found, with results suggesting acceptable agreement and fair interrater reliability between them.</p> <p>However in contrast there was a strong influence of report bias when reporting adult autistic traits, with ratings for spouse being significantly higher than reporting regarding self.</p>	Parental report bias affected ratings for spouse and self, but not child. The study concluded with outlining how this provides evidence for some studies, yet is in contrast with others and recommends further studies be carried out. If further studies provide the same findings, recommends procedures/statistics be employed to ameliorate this	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Good background which clearly led to gap in literature and rationale for research.</li> <li>• Clear ideas and recommendations for further research.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Ethical rigour unclear as ethical procedures omitted from article.</li> <li>• Relatively small sample size weighted with boys.</li> <li>• Questionnaires were self-report and completed independently</li> </ul>
Macari et al. (2018)	Clear statement of ethical approval received and that parental permission was gained.	Study found that there was a difference in concordance when parents used Likert scale measures. However when they used multiple choice formats which was more in line with clinicians tools and the measures were standardised, it was found that parent/clinicians gave similar ratings.	Study concludes by arguing findings highlight the potential of parental and clinicians reports to be aligned and discrepancies minimised if similar questioning formats are used and therefore stresses the importance of questionnaire wording and construction.	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Clear rationale for study.</li> <li>• Novel area of research.</li> <li>• Practical guidelines for questionnaire design.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• The results section was at times difficult to understand with the reader left trying to make sense of the findings.</li> </ul>

<p>Havdahl et al. (2017)</p>	<p>Clear statement of ethical approval received and that informed consent was gained from participants</p>	<p>When addressing the primary aim – results suggested ADOS had similar cutoff rates with 85-100% sensitivity i.e. correctly identifying those with ASC and 71-87% specificity i.e. correctly identifying those without ASC. However the ADI-R showed decreased sensitivity at 57-80% with an increase in specificity 79-94%. Additionally non ASC behavioural difficulties e.g. anxiety and hyperactivity tended to be more abundant in false positive diagnoses, this was in relation to informant specific associations between behaviour and ratings of ASC behaviour and appeared to affect both the ADOS and ADI-R</p> <p>When addressing the second aim, finding were similar to the primary aim i.e. for parents with ASC concerns, cutoffs for ADOS were consistently high for both sensitivity and specificity and ADI-R showed decreased sensitivity and increased specificity among those without ASC</p>	<p>Studies conclude that measurement cutoffs have varying sensitivity and specificity. Additionally, for those without ASC concerns, clinicians should hold this in mind alongside other factors which may have an influence on measurement performance when interpreting scores, as this can lead to misclassifications. This will also have a knock on effect regarding interventions etc.</p> <p>Furthermore albeit ADOS cutoffs performed well as stand alone measurement, when used together with ADI-R contributions offered were over and above . Therefore parental views remain valuable source of information. However these should be taken together with alternative sources of information e.g. observation, childcare settings etc.</p> <p>Study concludes that measurements should have modifications to allow for parents who do not have ASC specific concerns. Therefore recommends replication studies should be carried out to determine how this may be done.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Some clear ethical procedures stated e.g. informed consent.</li> <li>• Novel area of research highlighting limitations to ASC diagnostic instruments.</li> <li>• Clinicians administering ADOS/ADI-R were blind to information relating to study.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• generalisability of results may be affected by: <ul style="list-style-type: none"> <li>- selection bias.</li> <li>- study conducted in a single Norwegian culture.</li> </ul> </li> </ul>
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		<p>specific concerns. Findings suggest ADI-R is affected by parental reports and those with ASC concerns provide more examples and display more awareness of features of ASC. Therefore study suggests the ADOS/ADI-R cutoffs which are based on US specialist centres may misclassify those without parental ASC concerns.</p>		
<p>Ward, Sullivan &amp; Gilmore (2017)</p>	<p>Clear statement of ethical approval received and consent was inferred upon completion of questionnaires.</p>	<p>Study found that the ABII-PQ significantly discriminated between children who were typically developing and those with ASC. Sensitivity and specificity values were in excess of the .70 recommended value.</p>	<p>The ABII-PQ shows potential as a parent screening tool for early detection and expert referral.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Novel area of research.</li> <li>• Raises potential of an early screening instrument which can be administered with minimal training.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• As study involved children who were already in possession of ASC diagnosis, there may have been an over-reporting of ASC traits.</li> <li>• Parent's self-identified children as ASC or typically developing.</li> </ul>
<p>Rowberry et al. (2015)</p>	<p>Clear statement of ethical approval received and that informed consent</p>	<p>Study found parental ratings of social functioning for HR infants</p>	<p>Study shows potential for early screening of HR 12month olds using parental report and early</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Ethical rigour.</li> <li>• Clear rationale.</li> </ul>

	was gained.	<p>more abnormal compared with other groups.</p> <p>A significant correlation was found between parental reporting and clinician ratings.</p> <p>Findings suggest social/communication skills rated to be atypical at 12 months, rather than repetitive/sensory behaviours.</p>	warning behaviours, which if acted upon, could lead to vital early intervention.	<ul style="list-style-type: none"> <li>• Easily accessible article.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Relatively small sample size.</li> <li>• Study notes lack of ethnic diversity so difficult to generalise results.</li> <li>• Participants had high levels of education.</li> </ul>
Blacher, Cohen & Azad (2014)	Clear statement of ethical approval received and that informed consent was gained from participants	<p>In the screening, more ASC concerns were raised by Anglo and fewer social skills concerns raised by Latino mothers. Therefore in the ADI-R, Latino mothers did not detail specific ASC concerns, general developmental delay was raised instead.</p> <p>However, in contrast with this the results from the ADOS indicated that although more symptoms were raised by Anglo parents, more ASC symptoms were demonstrated by the Latino children.</p>	Study concluded that the cultural differences highlighted necessitate further research into this area. Author also raises the notion of ASC symptoms being affected by context and in the “ <i>eye of the beholder</i> ” i.e. observable differences in clinic and home environments, which clinicians should take into account, together with cultural assumptions.	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Novel area of research.</li> <li>• Findings provide strong rationale for further research</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• All sample received screening and ADOS, however only subsample of 40 mothers completed the ADI-R due to it being included after the study commenced.</li> <li>• Only mother’s ethnicity was used to explore group differences.</li> </ul>
Stronach & Wetherby (2017)	The study does not mention any ethical considerations nor confirmation that ethical approval was gained.	Results suggest moderately consistent patterns of social communication difficulties in	Increasing diversity within the US, necessitates the use of screening/diagnostic assessments which are culturally sensitive.	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Raises necessity for the use of ASC diagnostic measures that are</li> </ul>

		<p>children with ASC across race and ethnicity.</p> <p>The only area that showed a difference was in relation to understanding, however this was relevant to children with and without ASC.</p> <p>Results also suggested that less educated mothers reported higher levels of ASC symptoms</p>	<p>Also an ethnic/cultural disparity in health services. Assessment tools need to account for ethnic, cultural and racial differences that can differentiate these from communication disorders such as ASC.</p>	<p>culturally/ethnically and racially sensitive, such as CSBS-BS</p> <ul style="list-style-type: none"> <li>• Relatively large diverse sample.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Ethical rigour questionable as no details given.</li> <li>• Study recognises that measures translated into Spanish, but haven't been separately tested for Hispanic population.</li> <li>• Translators were available if requested, however participants may have been reluctant to do so. Therefore there may have been assessment inconsistencies due to language barriers.</li> <li>• Groups were separated using US census categories, however these do not take cultural differences/specific ethnicity into account e.g. immigrant status, home language etc.</li> </ul>
<p>Connolly &amp; Gersch (2013)</p>	<p>There is no mention of ethical approval being received. The only ethical details noted is in a sentence regarding stage one:  <i>“Invitation letters explaining the nature of the study and the rationale for</i></p>	<p>Themes derived from both discussion groups data are clearly outlined. Outlines how detailed analysis yielded 9 identical themes in each, details of which are provided in table format in</p>	<p>Authors state the study's objectives were generally met and some of the parental needs addressed. Parental insight was gained, a programme was designed for parents and implemented whilst on the waitlist and parents evaluated this to be a</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Well written, well-structured and easily accessible paper.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Ethical rigour questionable as no details given.</li> <li>• Small number of</li> </ul>

	<i>the focus group were sent"</i>	addition to written prose.	<p>useful source of information, support and empowerment.</p> <p>The researchers consider ways in which the research can be used by making a number of recommendations at the end of the article.</p>	<p>participants.</p> <ul style="list-style-type: none"> <li>• Study notes possibility of researcher bias as participants were known to one of the authors</li> <li>• No mention was made as to the credibility of the study e.g. respondent validation</li> </ul>
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## Appendix 2 : Main Literature Review Summary Table

Table 1 Adopting the research critique of Holland & Rees, this table addresses the research articles focus, background, aim, methodology, method of data collection, method of data analysis and details of sample.

Table 2 Continuing with the adopted critique tool of Holland and Rees, this table addresses the research articles ethical considerations, main findings, conclusions and recommendations, overall strengths and limitations and application to practice.

Table 3 Adopting the research critique of the Critical Appraisal Skills Programme (CASP) this table addresses the research articles focus, search technique, addition and review of relevant studies, overall results and precision of these.

**Table 1**

STUDY	FOCUS	BACKGROUN	AIM	METHODOLOGY	DATA COLLECTION	DATA ANALYSIS	SAMPLE
Gross, Shaw & Moilane n (2008)	Investigates the reciprocal associations between boys externalising difficulties and maternal depressive symptoms .	Outlines evidence of maternal depression and child psychopathology with substantial evidence of a link between this and negative outcomes for the child including internalising and externalising behaviour.  Also details research on reciprocal associations between parental behaviour and child characteristics, however this is mainly focussed on parenting with little	Study is two-fold exploring reciprocal associations between aggressive behaviour in boys in middle childhood (age 5 to 10) and also for the time of transition for boys between adolescence and middle adolescence (age 10 to 15) relating to antisocial behaviour.	Quantitative methodology using a longitudinal design.	All measures for both mothers and children are clearly outlined including details pertaining to validity.	Article clearly states that M-Plus version 4.0 and details the analysis used.	Details given of where sample recruited from n=310 at first assessment, n=284 at second assessment.  Details are provided as to age, details of ethnic backgrounds etc.

		regarding parental mental health.					
Voigt et al. (2014)	Explored skills of effortful control in toddlers born pre-term, exploring the links between this, neonatal distress and the moderating influence of parenting stress.	Commences introduction providing a clear rationale for the study, by outlining research into early childhood adversity which is believed to have a long-term effect on neurobehavioral brain development.  Moves onto discuss the link between disruptions in cognitive and emotional development, early adverse experiences and the mediating role of self-regulation.  Therefore it is of high importance to understand self-regulatory development in high-risk populations experiencing a high amount of distress early in life.	2 aims clearly stated for the reader:  -Exploring if cumulative exposure to distress related to neo-natal intensive care units affects the capacity for effortful control in preterm born toddlers.  -exploring moderator of parental stress.	Quantitative methodology utilising a cross-sectional study design.	Measures used clearly stated including multiple tasks and questionnaires.	Article does not explicitly state the statistical process used e.g. SPSS, however statistical tests employed are detailed.	N=119 children born preterm without major neurological difficulties, drawn from larger longitudinal study

Van Batenburg-Eddes et al. (2013)	To investigate the relationship between maternal and paternal symptoms of depression and anxiety during pregnancy and children's attention problems	<p>Outlines previous studies regarding consequences on child's behaviour, development and physical health of adverse emotional well-being during pregnancy. Discusses how this can potentially influence both the foetal environment and placenta functioning.</p> <p>Discusses notion of how this may also be in relation to other factors e.g. socio-economic, genetic predisposition to mental health difficulties and if these persist postnatally etc.</p>	<p>Clear aim in last paragraph of introduction stating seeking to explore if evidence of effect of maternal depression/anxiety on child's later problems with attention when this occurs intrauterine.</p> <p>Secondly also investigated this association postnatally i.e. when child is 3 years old.</p>	Quantitative methodology using a survey design across two cohorts.	All measures used are clearly stated.	Article does not explicitly state the statistical process used e.g. SPSS, however statistical tests employed are detailed.	<p>Study and therefore sample taken from 2 larger population based studies: n = 2,280 and n = 3,442.</p> <p>Full details of data collection including dates and geographical location is provided.</p>
Pesonen et al. (2008)	Using a transactional model, investigating relationship between child temperamental development from infancy	<p>Article discusses social adaptability outlining bidirectional influences from both child and parent.</p> <p>Outlines and cites</p>	Aims are interwoven over 7 paragraphs between citing previous research.	Quantitative methodology using a longitudinal study design.	Measures used are clearly stated.	Article does not explicitly state the statistical process used e.g. SPSS, however statistical tests employed	N=231 mother/infant dyads, details were provided as to age/gender etc. of sample.

	and maternal stress over 5 years duration.	theoretical models of transactional change in temperamental development and the influences on parenting, in addition to the effects of parental stress on parenting. Furthermore describes how existing literature is largely of a cross-sectional design, thereby providing rationale for their longitudinal study.				d are detailed.	
Neece, Green & Baker (2012)	Study empirically tests the relationship between parent stress and child behaviour over time using the transactional model of development.	Outlines transactional model of development discussing the utility of this model when understanding the associations between parent/child inter-relationships and child development.	Clear aim of study to extend previous research by examining the interaction of parent stress and child development over early to middle childhood i.e. 3 to 9 years of age.	Quantitative methodology using a longitudinal research design.	Questionnaires used are clearly outlined with background information and references cited.	Article does not explicitly state the statistical process used e.g. SPSS, however models and analyses used are clearly detailed under data analytic plan section.	N=237 families as part of longitudinal study, consisting of Typically Developing (TD) and developmentally delayed (DD) children in early to middle childhood. further 19 recruited at 5 yrs later. Details of geographical location and ages provided.

<p>Combs-Ronto, Olson, Lunkenheimer &amp; Sameroff (2009)</p>	<p>Longitudinal study exploring the association between children's disruptive behaviour and negative maternal parenting.</p>	<p>Discusses the risks of children displaying disruptive and aggressive behaviours, including poor mental health and academic performance, family conflicts and peer rejection.</p> <p>Moves on to discuss importance of identifying the factors which place children at risk for persistent and chronic behaviour difficulties.</p> <p>Also discusses research into toddlers and times of transition due to the acquirement of self-regulation skills and the risks of aggression and disruptive behaviours if the skills are not established, detailing risk factors that can increase this likelihood, including parenting and child characteristics.</p>	<p>Aim clearly stated under rationale and research question section. Outlines the use of a transactional model of child development to investigate the association between children's disruptive behaviour and negative maternal parenting with the main aim to establish the direction of association.</p> <p>Outlines gaps in literature study wishes to address.</p>	<p>Quantitative methodology, adopting a prospective cohort study design.</p>	<p>Measures clearly stated including questionnaires, tasks &amp; assessment of socioeconomic status.</p>	<p>Article does not explicitly state the statistical process used e.g. SPSS, however statistical tests employed are detailed.</p>	<p>N=235 children, parents and teachers, part of existing longitudinal research.</p> <p>Details of recruitment and screening methods provided.</p>
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Marquis & Baker (2014)	Looks at differences in parenting practices between Anglo and Latino parents for children with behavioural problems.	<p>Outlines transactional model of development . Moves on to discuss previous research into the developmental status of infants born pre and full term, how no difference was found between the groups for social and cognitive skills, however there was a significant variance when family factors including the attitude of mothers were investigated.</p> <p>Then moves onto discuss the differences between parenting children with and without developmental difficulties, between Latino and Anglo parents and a combination between these two groups.</p>	<p>Aims of study clearly laid out being to investigate differences in parenting styles i.e. sensitivity and scaffolding for children with behavioural difficulties, between Latino and Anglo parents in relation to the developmental status of their child i.e. Typically Developing (TD) and Developmentally Delayed (DD).</p>	Quantitative methodology using a longitudinal study design.	Questionnaires were used in addition to the recording of observed play sessions which were then coded with details provided of the coding measure used, which was referenced together with issues of validity discussed.	Article does not explicitly state the statistical process used e.g. SPSS, however statistical tests employed are detailed.	N=191 families with a description provided regarding the demographic characteristics of the sample.

Rinaldi & Howe (2012)	Title clearly details and exploration of the associations between the parenting styles of mothers and fathers and the externalising, internalising and adaptive behaviours of toddlers.	Discusses children's earliest exposure to socialisation is within the home environment and how most studies in this area focus on the contribution of one parent. Clearly provides rationale for study detailing how previous research mainly focusses on the role of the mother.	Clear statement of aim – to explore the individual and joint parenting of mothers and fathers and how this can predict behavioural difficulties in toddlers.	Quantitative methodology using a survey design	Questionnaires used for parenting styles and child behaviour clearly outlined, with references provided.	Article does not explicitly state the statistical process used e.g. SPSS, however statistical tests employed are detailed.	N= 59 cohabiting families. Details provided of diversity, ages, household income etc.
Flanders, Leo, Paquette, Pihl & Seguin (2009)	Study exploring father-child rough and tumble play and children's regulation of aggression.	Discusses how children's physically aggressive behaviours observable from approximately 18 months old, with a decrease in this commencing around age 2-3. For those with persisting aggressive behaviour, at higher risk of latter psychosocial difficulties including drug use, crime and unemployment.  Discusses	This is clearly stated - to test hypothesis that in RTP when the father is more dominant, there should be an association between the frequency of this and children's less aggressive behaviour. Conversely, when the father is less dominant there should be an association	Quantitative methodology using a correlational study design.	Questionnaires were used in addition to the recording of observed play sessions which were then coded with details provided of the coding measure used, which was referenced together with issues of validity discussed.	Article does not explicitly state the statistical process used e.g. SPSS, some information was provided re analyses, however it was difficult to ascertain how thorough the description was therefore	N=85 father-child dyads. Table provided with characteristics of sample.

		<p>for child's social development of physical play, how both girls and boys enjoy this, however Rough and Tumble Play is engaged with by more boys than girls. Goes on to describe RTP, including dominance within this.</p> <p>Providing a clear rationale for the study, introduction moves on to outline suggestions that RTP can be a contributing factor in a child's ability to self-regulate their aggression.</p>	<p>between frequency of RTP and more aggressive behaviour.</p>				
<p>Bailey, Hill, Oesterle &amp; Hawkins (2009)</p>	<p>Title gives clear idea of study being "parenting practices and problem behaviour across three generations: Monitoring, Harsh Discipline, and Drug Use in the Intergenerational</p>	<p>Discusses later risk factors for externalising behaviour, in addition to inter-generational transfer of this.</p> <p>Cites studies investigating links between children's externalising behaviour, parental monitoring and harsh</p>	<p>Clearly stated under a separate heading of "the present study". In relation to the intergenerational transmission of children's externalising behaviour, the study seeks to explore the</p>	<p>Quantitative methodology employing a longitudinal study design.</p>	<p>Measures used clearly outlined in addition to issues regarding validity discussed.</p>	<p>Article stated the use of Mplus Version 3.0 and details of the statistical tests employed are provided.</p>	<p>Including grandparents, parents and their school age children n = 136. Samples taken from two existing longitudinal studies. Details outlined as to the recruitment and</p>



	ational Transmission of Externalizing Behavior”	discipline. This leads into clear rationale for study of the hypothesis of continuity and the need to investigate this in order to bring about a reduction in the transmission of these behaviours. Finally outlines social developmental model which provides the framework for the current study and provides references for this.	parenting factors of harsh discipline and parental monitoring across two longitudinal studies, with drug use being a mechanism within this.  A verbal argument in addition to a conceptual model is also included in this section in order to outline how the present study addresses gaps in the current literature				characteristics of the sample.
Walker et.al., (2009)	Exploring efficacy of first step to success EI programme.	Outlines increase in children who at risk of behaviour challenges and impact of this on education, family and community. Raises importance of stopping trajectory to get best outcomes. Discusses EBP and how impacts on interventions	Clear statement of aim in final paragraph of intro, RCT of first steps to success programme with children who experiencing externalising behaviour difficulties.	Quantitative methodology employing an RCT cohort study design.	Manualised programme followed with full details included and baseline/postintervention data collected. Outcome measures across 3 domains: observations, teacher and parent questionnaires (full details including references given), in addition to the collation of	Article does not explicitly state the statistical process used e.g. SPSS, however statistical tests employed are detailed.	Cohort 1 n=99 and cohort 2 n=101 children, all randomly assigned to either intervention group or usual care comparison group.

		<p>which are selected by schools &amp; how insufficient evidence on efficacy of these.</p> <p>Outlines first steps to success which is a manualised intervention, consisting of 3 modules: screening, school intervention and targeting of home setting with parent training.</p>			academic data (full details given of types of academic data collected)		
Kaminski et al., (2013)	An evaluation of “legacy for children” a US public health strategy aimed at improving children’s developmental outcomes from families in poverty.	<p>Statistics on number of children born into poverty given and risks associated with this, including parenting &amp; cognitive &amp; developmental outcomes. Outlines the rationale and design of legacy for children public strategy</p>	Clear aim of article evaluating the first results of socioemotional and behavioural outcomes for children.	Quantitative methodology employing cohort study design.	<p>Outlined details of Legacy for children intervention (some details of philosophy, theory and activities provided.</p> <p>Outcome measures – questionnaires and assessment details provided with details of validity outlined.</p>	Article does not explicitly state the statistical process used e.g. SPSS, however statistical tests employed are detailed.	N=574 mother/child dyads across 2 sites who participated in trial 2001-2009
Rapee (2013).	Study evaluating preventative efficacy of brief EI for parents of pre-school children who are at risk of internalising behaviour	<p>Outlines growing evidence base of EI for internalising behaviour disorders, many aimed at school age children. Although reviews show promising</p>	Clear aim is 11 year follow up to study outlined in introduction. Therefore sample now adolescents age approx. 15.	Quantitative methodology using a survey design, in addition to clinical assessment.	<p>Brief outline of original intervention given .</p> <p>Outcome measures = clinical psychologist giving current diagnoses, gained through interview and parent and child report</p>	Article does not explicitly state the statistical process used e.g. SPSS, however statistical tests employed are detailed.	N=103 adolescents who took part in study 11 years previously.

		<p>outcomes, effect size is small and lack of follow up data. Increased effects over time mainly shown for EI for externalising behaviour, whereas for internalising – some show maintenance whilst others show decrease. However, like externalising there is very little data re follow-up over longer term.</p> <p>Outlines previous study by same author re preventing internalising in pre-school children. Intervention brief 6 x 90mins group sessions, with results showing significantly less anxiety at 12 months and cost effective to age 7</p>			<p>which included Questionnaires details to assess symptoms, negative thinking, life interference,</p>		
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**Table 2**

STUDY	ETHICAL CONSIDERATIONS	MAIN FINDINGS	CONCLUSION AND RECOMMENDATIONS	OVERALL STRENGTHS AND WEAKNESSES
Gross, Shaw & Moilanen (2008)	No details regarding ethical approval nor ethical procedures applied are included in the article.	Findings suggest significant reciprocal effects for boys age 5 to 6. There was also consistent effects found from maternal depression to youth reported Anti-Social Behaviour and some evidence found for the effects of ASB and later levels of maternal depression.	<p>Findings support hypotheses that child and parent effects would be most prolific at times of transition. E.g. maternal depression was most strongly associated with boys behavioural difficulties at age 5 to 6 (middle childhood) i.e. when starting school and again at periods of transition in adolescence, significantly so when aged 11 to 12.</p> <p>Study concludes by also noting that for this cohort of children, their areas of risk for early adverse school experiences will increase. These may include difficulties with both peer and adult relationships and academic work, particularly if in an area of socio-economic depravity.</p> <p>Recommendations of further research using moment by moment observations to identify specific mechanisms for the reciprocal effect.</p> <p>Findings indicate need for early intervention, particularly at first transition to school, with a focus being on maternal mood and affect.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Clear rationale for study.</li> <li>• Different informants used to report on maternal depression and child behavioural difficulties.</li> <li>• Provides evidence for early intervention</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Difficult to ascertain ethical rigour as no ethical details included.</li> <li>• Study notes participants primarily from low-income background.</li> </ul>
Voigt et al. (2014)	Study does not mention ethical procedures. However is part of a larger referenced longitudinal design.	<p>2 major results were found in study:</p> <p>-poorer capacities for effortful control were found in preterm born</p>	Author states due to the importance of self-regulation for both cognitive and emotional functioning, the study's findings provide evidence for early intervention in the form of self-regulation skills	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Clear rationale provided for research.</li> <li>• Identified novel area of research.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Ethical rigour</li> </ul>

		<p>toddlers who had experienced a greater degree of distress whilst in NICU.</p> <p>-in early childhood, poor capacity of effortful control was not offset by low parent stress, however this did facilitate the development of effortful control, therefore deeming this a protective factor.</p>	<p>for this at risk population.</p>	<p>unclear.</p> <ul style="list-style-type: none"> <li>• As correlational study, causal conclusions cannot be made.</li> <li>• Neonatal distress included procedures, didn't allow for subjective individual reactions to the environment.</li> </ul>
<p>Van Batenburg-Eddes et al. (2013)</p>	<p>Clear statement of ethical approval received in addition to informed consent gained.</p>	<p>Study's findings across both cohorts suggest that there is an association between problem's with children's attention and maternal antenatal anxiety and depressive symptoms.</p> <p>There was some statistical evidence in one of the cohorts, that paternal symptoms showed a weaker association than maternal ones, with the association of maternal symptoms largely shown with children at 3 years of age.</p> <p>However, the association between child</p>	<p>The study concludes by stating that the findings offer little evidence for the association between foetal programming and child's attention problems.</p> <p>Moreover the authors also state that the findings might also suggest association can at least partly be explained by environmental factors e.g. genetic, socioeconomic and lifestyle factors.</p> <p>Study recommends further research into other intrauterine contributing factors e.g. genetics, susceptibility of infections gained in postnatal period, in addition to the postnatal environment.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Ethical rigour.</li> <li>• Large sample size, with two cohorts being used to study consistency cross-cohorts.</li> <li>• Comparison of effects of both maternal and paternal depressive and anxiety symptoms.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Analyses focussed on foetal programming and did not take into account interaction effects e.g. children's vulnerability to maternal symptoms.</li> <li>• Study acknowledges that there may have been an influence of non-random</li> </ul>

		attention and maternal pregnancy symptoms weakened when postnatal symptoms were accounted for at the time of the child's behaviour assessment. This therefore suggests that it is the persistence of maternal symptoms rather than intrauterine factors which is an important factor of the association.		attrition – with details outlining the effects of this.
Pesonen et al. (2008)	Clear statement of ethical approval received and informed consent gained.	<p>Study found support for hypotheses based on previous studies:</p> <ul style="list-style-type: none"> <li>An increase in mothers stress would be predictive of increase in maladjustment of infants temperament over time.</li> <li>Infants temperament traits would be predictive of changes to maternal</li> </ul>	<p>Findings suggest in relation to emotional reactivity and emotional self-regulation, an infant's temperamental development is likely to be affected by the reciprocal effects of maternal stress.</p> <p>Study adds to knowledge base of maternal stress being a key contextual factor in infant temperamental development.</p> <p><u>Recommendations</u> Further research conducted which includes micro level observation of relational interactions.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>Good introduction and clear rationale for study.</li> <li>Study adds novel findings to literature base.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>Statement of aims not clearly defined as interwoven over 7 paragraphs.</li> <li>Reliance in study of parental assessment</li> <li>Study outlines limitation of lack of micro level observation of patterns of interaction.</li> </ul>

		<p>l stress.</p> <p>However these changes were not found at the same time/using the same model. Study gives details of the different models used and findings gained from each of these is outlined.</p> <p>Findings suggest that changes to the child's temperamental development were more prominent when these originated during infancy in relation to maternal stress e.g. an increase in relation to anger and a decrease in soothability and the ability to focus attention.</p>		
Neece, Green & Baker (2012)	Clear statement of ethical approval, discusses information sheet sent, however does not discuss informed consent etc.	Findings from the study suggest that there is a transactional relationship between both the variables of parenting stress and child behaviour problems i.e. both variables are an antecedent and consequence of the other and over time, they appear to have reciprocal escalation/de-escalation effect. Findings were similar for both TD and DD	<p>Study outlines ideas for future research to build on findings.</p> <p>Gives clear suggestions of implication for bidirectional relationship of findings i.e. interventions for both parent stress and child behaviour problems with references cited as to evidence of their utility.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>Clearly laid out article, accessible for the reader.</li> <li>Ethical rigour.</li> <li>Novel area of research with clear implications given for theory into practice i.e. interventions.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>Self-report measures due to stress being a subjective construct.</li> </ul>

		children.		
Combs-Ronto, Olson, Lunkenheimer & Sameroff (2009)	Clear statement of annual ethical approval of longitudinal study received. No further information outlined regarding ethical procedures carried out.	<p>The study found that across time:</p> <ul style="list-style-type: none"> <li>-over pre-school period there was a decrease in average levels of externalising behaviour, with self-regulation skills normatively increasing. Also negative maternal parenting over this period associated with externalising behaviour and boys and girls non-compliance.</li> <li>-in kindergarten period (approx. 5-7) negative maternal parenting associated with externalising behaviour, but no longer non-compliance.</li> <li>-negative maternal parenting was predictor of alterations in children's externalising behaviour and conversely a change in children's behaviour was a predictor of a change in maternal negative parenting.</li> <li>-interactions were found between negative</li> </ul>	<p>Young children change and contribute to the quality of parenting received, making them active agents within their environment.</p> <p>Authors discuss how during period of school entry, children's externalising behaviour can be distressing for parents due to the consequences and feedback from school and other parents and can therefore make it difficult for negative parenting modifications to take place.</p> <p>Furthermore associations between children's externalising behaviour and negative maternal parenting were similar between boys and girls.</p> <p><u>Recommendations</u></p> <p>For future research:</p> <ul style="list-style-type: none"> <li>-children's non-compliance should encompass multiple measures and include father.</li> <li>-more than the 2 time points used in present study,</li> </ul>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Provides clear rationale outlining gap in literature for this novel research.</li> <li>• Well laid out article and accessible to reader.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Single measures were used for non-compliance tasks.</li> <li>• Most children from 2 parent middle class backgrounds, therefore difficult to generalise.</li> </ul>



		<p>maternal parenting in pre-school period and children's early externalising behaviour, establishing a coercive negative cycle and therefore leading to predictions of externalising behaviour during kindergarten period.</p> <p>-children's externalising behaviour in pre-school was a predictor of negative maternal parenting during kindergarten.</p>		
Marquis & Baker (2014)	Clear statement of ethical approval of received. However, no further information outlined regarding ethical procedures carried out.	<p>Findings suggested that in relation to sensitivity and scaffolding, there was a difference between ethnicity and status groups, with greater sensitivity being exhibited to children age 3 by Anglo mothers, however this is likely to be as a result of socio-economic disadvantages and relating stress.</p> <p>Higher reports of behavioural difficulties was</p>	<p>Authors cite study provides support for previous findings that socio-economic status accounts for the relationship between child behaviour difficulties and ethnic minority status.</p> <p>Findings also suggest different trajectories predicted by scaffolding and sensitivity with a significant decrease in externalising difficulties for Latino children associated with higher sensitivity and scaffolding, however there was no associated found between scaffolding and behavioural difficulties in Anglo children.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Multi-method approach.</li> <li>• Longitudinal design.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Rationale for study did not appear to be very robust.</li> <li>• Unknown ethical rigour.</li> <li>• Article was not very reader friendly e.g. lots of abbreviations were used throughout the article making it time consuming for the reader to ascertain their meaning, with</li> </ul>

		<p>reported by Latino mothers at age 3, however this was marginal for externalising behavioural reports when socio-economic status was accounted for,</p> <p>No significant effect was found relating to the child developmental status i.e. TD or DD.</p>	<p><u>Recommendations</u></p> <p>Development of culturally sensitive interventions.</p>	<p>some not being able to be found within the article.</p> <ul style="list-style-type: none"> <li>• Study noted immigrations status and acculturation details not gathered from sample.</li> </ul>
<p>Rinaldi &amp; Howe (2012)</p>	<p>Outlined that information letter sent and consent had to be received by both parents. However there is no mention of ethical approval received.</p>	<p>Overall the study found the self-rating parenting styles of mothers and fathers to be congruent i.e. authoritative mothers and fathers tending to be with each other, with correlations being lower yet still significant for authoritarian and permissive parenting.</p> <p>Modest yet significant correlations were found between the self-reported parenting styles of mothers and fathers.</p> <p>When parents rated themselves as highly authoritarian, permissive or authoritative,</p>	<p>Authors state that overall the study found similarities in parenting between mothers and fathers.</p> <p>Permissive parenting scale may not have been sensitive enough as no correlations found between this and children's behavioural difficulties</p> <p>Findings add support to previous research that father's authoritative parenting is associated with children's adaptive behaviours.</p> <p><u>Recommendations</u></p> <p>Early behaviour in young children is better understood when both parenting styles are taken into account.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Provided novel findings by including association of fathers parenting and children's behaviour.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Lack of details re ethical rigour.</li> <li>• Permissive parenting scale may not have been sensitive enough.</li> </ul>

		<p>partners were also likely to rate themselves highly too, except for when mothers rated fathers as permissive suggesting variations in the interpretations of this parenting style.</p> <p>With respect to fathers, there was an association between authoritarian parenting and children's internalising and externalising behaviour. However children's adaptive behaviour was significantly correlated with paternal authoritative parenting.</p> <p>Contrary to expectations, correlations were not found between permissive parenting and child outcome behaviours</p> <p>For combined parenting styles there was found to be a unique prediction between father's authoritarian parenting styles together with mothers permissive parenting with the externalising behaviour of</p>		
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		children		
Flanders, Leo, Paquette, Pihl & Seguin (2009)	Article states APA ethical guidelines followed and informed consent received, but no ethical approval discussed.	Study found that the relationship between children's physical aggression and RTP was moderated by the dominance of the father i.e. if father more dominant, child less aggressive and vice versa.	<p>Authors stated finding support previous research that activities which include RTP can be associated with children's behavioural difficulties, however this is more likely when boundaries and limits are not put into place by the father.</p> <p><u>Recommendations</u></p> <p>Future research could adopt a longitudinal design with RTP observed in preschool years with psychosocial skills being assessed at a later point in time.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Outlined validity of measurements used.</li> <li>• Identified gap in literature for novel research.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Ethical approval not discussed.</li> <li>• Lack of clarity re statistical analysis.</li> <li>• Is a correlational study, therefore causal factors cannot be asserted.</li> <li>• Limitations to generalisability due to possible self-selection bias in sampling.</li> </ul>
Bailey, Hill, Oesterle & Hawkins (2009)	The article does not mention any ethical clearance nor ethical procedures taken. It does note that the sample were taken from existing longitudinal studies and gave the name for these, however no references of further details were supplied.	<p>Results suggest:</p> <p>An overall significant indirect effect of the harsh parenting of grandparents on the externalising behaviour of children.</p> <p>Grandparent parenting was associated with the parents externalising behaviour in adolescence. Only parents harsh parenting was associated with children's</p>	<p>Study concludes with the author stating results suggest intergenerational transmission of parenting across generations, however the magnitude was small, therefore there was also discontinuity in parenting practices.</p> <p><u>Recommendations</u></p> <p>Future research should include a focus on the mechanisms of discontinuity in the transmission of intergenerational parenting practices, in order to inform parenting interventions.</p>	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• Provides clear rationale for study.</li> <li>• Easily accessible article for the reader.</li> <li>• With each finding from the study, recommendations for future research were provided.</li> </ul> <p><u>Weaknesses</u></p> <ul style="list-style-type: none"> <li>• Difficult to ascertain ethical rigour due to lack of information in study.</li> <li>• Design was not genetically informed.</li> </ul>

		<p>externalising.</p> <p>The externalising behaviour of the parents during adolescence was associated with later substance abuse and was also predictive of their children's externalising behaviour.</p> <p>A significant yet weak indirect association between grandparent harsh parenting and externalising behaviour in children via increased levels of parents harsh parenting.</p> <p>An association between child externalising behaviour in both generations and harsh discipline.</p> <p>Parents substance misuse in adulthood appeared to explain externalising behaviour continuity across the generations</p>		<ul style="list-style-type: none"> <li>• Age range of children participants was wide (from age 10 to 27years) study notes that developmental differences may have influenced the results.</li> <li>• As measures collected at the same time (parenting and externalising behaviour) not possible to establish direction of causality.</li> </ul>
Walker et.al., (2009)	Discusses how approval and consent was sought from school staff & parents, however no other ethical	Moderate to strong effects across 3 outcome assessment	Follow up assessments were still being completed with authors stating these will be reported at later date.	<p><u>Strengths</u></p> <ul style="list-style-type: none"> <li>• RCT</li> <li>• Clearly written article with full details re programme</li> </ul>

	considerations discussed nor details regarding ethical approval given.	domains.  Parents gave high level of satisfaction and reported at least moderate levels of gains in symptoms of children. This was all relative to the comparison group of usual care.	Authors argued as 70% of participants of ethnic minority, good test of applicability to this population	and measures used  <u>Weaknesses</u> <ul style="list-style-type: none"> <li>No details given re ethical clearance</li> <li>No details given re sustainability of outcome.</li> </ul>
Kaminski et al., (2013)	No details regarding ethical considerations given, however evaluation of intervention already taken place	Gave demographic statistics across 2 sites.  Children in intervention group less likely to meet criteria for both behavioural and socioemotional concerns at 24 & 48 months respectively, also significantly less likely to reach criteria for hyperactivity. 1 site higher number of significant effects	Marginal effects after first year, however after second year, significant effects. Longer term effects still being assessed.  Site which showed higher significant effects hypothesised to be due to group being a demographically higher risk.	<u>Strengths</u> <ul style="list-style-type: none"> <li>Measures valid</li> <li>Randomisation of participants.</li> </ul> <u>Weaknesses</u> <ul style="list-style-type: none"> <li>No details given re ethical clearance</li> <li>Reliance on parent report.</li> <li>Analysis did not account for participant dropout.</li> <li>Results in discussion not clear.</li> </ul>
Rapee (2013).	Details given re ethical clearance and participant info/consent	Larger effect shown for girls with benefits through to middle adolescence. Effect not as clearly shown in boys, authors conclude this may be because EI for internalising not as effective for boys, or larger sample needed as effect sizes are small.	Author concludes that as very low cost intervention, major benefits to public health even with small effect sizes.	<u>Strengths</u> <ul style="list-style-type: none"> <li>Novel research for long-term effects 11 years after pre-school</li> </ul> <u>Weaknesses</u> <ul style="list-style-type: none"> <li>Possibility that sample of boys not larger enough to detect effect size.</li> </ul>

**Table 3 CASP meta-analysis critique**

STUDY	CRITIQUE QUESTION	ANSWERS TO CRITIQUE
Hoeve et al. (2009)	Did review address clearly focused question?	Yes
	Did the authors look for the right type of papers?	Yes
	Do you think all the important, relevant studies were included?	Yes
	Did the reviews authors do enough to assess the quality of the studies included?	Yes
	If the results of the review have been combined, was it reasonable to do so?	
	What are the overall results of the review?	<p>Meta-analysis results found significant links confirming the relationship between parenting and delinquency. On parenting dimensions, strongest links were for psychological control and weakest links for authoritarian and authoritative control. Also found a negative association between parental monitoring and delinquency, however some indicators of this parenting style including active monitoring, child disclosure and parental knowledge had strong links with delinquency. The strongest links to delinquency were with respect to the negative parental aspects of support including hostility, neglect or rejection.</p> <p>Certain characteristics of the study were found to be significant moderators such as age and sex of participants, delinquency type and informant of parenting, suggesting that certain parenting dimensions are more crucial for certain subsamples of certain situations e.g. there was a relatively strong association between delinquency and parental lack of support if the parent and child were of the same gender.</p> <p>Furthmore, there was a stronger association between parenting and delinquency for school children and early adolescents than older adolescents and overt delinquency was more strongly associated with parental monitoring. Lastly, there were larger effects found when parenting was based on children reports rather than self-reports.</p>
	How precise are the results?	<p>Study outlined date of publication for the 161 studies and also included in-depth details of : central tendency, effect sizes across the studies for 40 different discrete characteristics of parenting behaviour.</p> <p>Results offered very detailed information for each category of focus e.g. short-term vs long term associations, sex differences etc., suggesting precision of results, however it was not possible to locate information regarding confidence intervals.</p>
	Can results be applied to local population?	Yes
	Were all important outcomes considered?	Yes
	Are the benefits worth the harms and costs?	Yes

## Appendix 3 : Initial Ethics Approval

The Tavistock and Portman   
NHS Foundation Trust

Quality Assurance & Enhancement  
Directorate of Education & Training  
Tavistock Centre  
120 Belsize Lane  
London  
NW3 5BA

Tel: 020 8938 2548  
Fax: 020 7447 3837  
[www.tavi-port.org](http://www.tavi-port.org)

Lara Weaver

By Email

05 June 2018

**Re: Research Ethics Application**

*Title:* In cases where parents seek a diagnostic assessment of autism for their child and a diagnosis is not given, what contexts and mechanisms influence the request for an assessment.

Dear Ms Weaver,

I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely,

Best regards,




**Paru Jeram**  
Secretary to the Trust Research Degrees Subcommittee  
T: 020 938 2699  
E: [pjeram@tavi-Port.nhs.uk](mailto:pjeram@tavi-Port.nhs.uk)

cc. Course Lead, Research Lead, Supervisor, Course Administrator, Academic Quality



## Appendix 4 : Final TREC Approval

The Tavistock and Portman 

NHS Foundation Trust

Quality Assurance & Enhancement  
Directorate of Education & Training  
Tavistock Centre  
120 Belsize Lane  
London  
NW3 5BA

Tel: 020 8938 2699

<https://tavistockandportman.nhs.uk/>

Lara Weaver

By Email

11/2/2019

Dear Ms Weaver

**Re: Trust Research Ethics Application**

*Title:* In cases where parents seek a diagnostic assessment of autism for their child and a diagnosis is not given, what contexts and mechanisms influence the request for an assessment.

Thank you for submitting your updated Research Ethics documentation. I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely,



**Paru Jeram**

Secretary to the Trust Research Degrees Subcommittee

T: 020 938 2699

E: [pjeram@tavi-Port.nhs.uk](mailto:pjeram@tavi-Port.nhs.uk)

cc. **Course/Research Lead, Supervisor, Course Administrator**

# Appendix 5 : Information and Consent Sheet

## Participant Information Sheet

**Title:** What are the contexts and mechanisms that influence parents to believe their child may have Autism and no diagnosis is given following a subsequent diagnostic assessment.

### Who is doing the research?

My name is Lara Weaver and I am studying a course in Child, Community and Educational Psychology. I am doing this piece of research as a part of my course.

### Would you like to take part in research?

I would like to invite you to take part in my research study. Before you decide whether you would like to take part, you need to understand why the research is being carried out, why you are being invited to participate and what it would involve for you. Please take time to read the information carefully and decide whether or not you wish to take part.

### What is the aim of the research?

I am undertaking this research because I am interested in the factors that lead to parents connecting the concerns they have about their child with a diagnosis of autism, when a subsequent autism assessment indicates they do not have autism. Not being given a diagnosis of autism does not mean a child does not have difficulties, it means the difficulties they experience do not fit the pattern of needs and behaviors that lead to a diagnosis of autism.

I hope that in undertaking this research, educational psychologists will find out more about the help that would be most useful for families who have children whose needs may be being misread as relating to autism.

### Why am I being invited to participate?

You have been asked to participate in this research because:

- Your child has recently undergone an assessment for autism, but did not receive a diagnosis.
- You have indicated that your child does experience difficulties and their autism assessment profile supports this.
- I would like to understand more about your experience of seeking support for your child.

### Do I have to take part?

You do not have to take part, and it is up to you to decide whether you wish to or not. Even if you do decide to participate, you are free to withdraw (stop taking part in the research) at any time, without giving a reason. This will not affect any of your entitlement to help and support from any of the local authority's services or provision.

**What will happen if I take part?**

You will be asked to take part in an interview that will last for approximately one hour. The interview will involve you being invited to answer a few questions which will guide you to talk freely about your experiences as a parent with a child who is experiencing difficulties.

Additional time will be made available once the interview has finished, in order to provide an opportunity to discuss the information that has been shared and answer any questions or concerns that you may have.

In addition to this, a phone-call the following day will be offered, to ensure that no adverse effects have been experienced due to talking about the difficulties that have been experienced by you and your family.

I would like to make audio recordings of the interview to help me remember what you said. The recordings will be stored anonymously using password-protected software. You can ask for the recordings to be stopped or deleted at any time. The recordings will be deleted once I have typed them up.

The interviews will take place at either the X or X Educational Psychology Service, located at: X and X. Or, if you preferred, I could come and interview you in your home.

**What are the possible benefits of taking part?**

There is not much available research that looks at parents' experiences of when a child is assessed for autism and a diagnosis isn't given. If we can understand more about what leads parents to have concerns about autism, what they hope or fear will come from a diagnosis and what happens when a diagnosis isn't given, we can think about the support that can be offered.

In taking part in the study, you have the opportunity to help educational psychologists better understand what would be helpful to other families in a similar situation to you. You may find it helpful to know that your views matter and may be used to help shape future provision.

**What will happen to the findings?**

The findings will be typed up and recorded in a thesis, which will be part of my Educational Psychology qualification. I will share some of the findings with the Educational Psychology Service and Paediatricians so they can review how best to support families. I would also like to tell you about the findings of the research if you would like me to share this. We can talk about the ways in which you would like to know about the findings such as me explaining them to you in person or me sending them to you.

If you would like to know more about the findings but do not want to participate in the research, please contact me and I will make sure that you are sent a summary of the findings.

**What will happen if I don't want to carry on participating in the research?**

You can change your mind at any time. You can also decide for your data (what you said during the interviews) to be removed up until the point that the draft thesis has been written and submitted (around January 2018).

**Will my taking part be kept confidential?**

Confidential usually means keeping something secret or not sharing information. The purpose of this research is to share what parents have said about their experiences, so in that respect what you say will not be kept confidential. However, the information you provide will be anonymised, so that it cannot be linked to you. This means using a pseudonym when describing your views and changing any details that could identify that what was being said came from you.

Once the recording from your interview has been transcribed, the recording will be deleted and all of the data stored will be recorded as belonging to the pseudonym. All data collected during the study will be stored and used in compliance with the UK Data Protection Act (1998).

**Are there times when my data cannot be kept confidential or anonymous?**

If you tell me something that makes me concerned about your safety or the safety of someone else, then I might have to share that information with others in order to keep you or someone else safe. However, I would always aim to discuss this with you first when possible.

**Further Information:**

This research has been formally approved by the Tavistock Research Ethics Committee.

If you have any questions about the research or if you would like to know more about it you can contact me using the following information:

Lara Weaver, Trainee Child and Educational Psychologist  
Educational psychology Service

[Redacted contact information]

Telephone: [Redacted contact information]

### Research participant consent form

**Research Title:** What are the contexts and mechanisms that influence parents who seek a diagnostic assessment for Autism and no diagnosis is given?

**Please initial the statements below if you agree with them:**

**Initial here:**

I have read and understood the information sheet and have had the chance to ask questions.

I understand that my participation in this research is voluntary and I am free to withdraw at any time without giving a reason.

I agree for my interviews to be recorded.

I understand that my data will be anonymised to reduce the chance of people linking the data to me.

I understand that if I share information that leads the research to fear for my safety or that of others, she may share this information in order to try and keep everybody safe.

I understand that my interviews will be used for this research and cannot be accessed for any other purposes.

I understand that the findings from this research will be published and available for the public to read.

I am willing to participate in this research.

Participant's Name: .....

Participant's Signature:

Date:

Investigator's Name: LARA WEAVER

Investigator's Signature:



## Appendix 6 :Interview Questions A From Participant 1 - 3

*What are the contexts and mechanisms that drive parents to believe that their child has Autism in cases where EP's do not believe this to be the case?*

- Can you describe some of the ups and downs of conducting the parental interview element of the ADOS?
- From the perspective of this study, what are the common reasons for parents seeking an autism diagnosis?
- What hopes and fears do parents typically have in relation to their child receiving a diagnosis of autism?
- Have you noticed any differences between parents who seek a diagnosis when their child does not have obvious traits (as per the ADOS) and those that do have obvious traits?
- What thoughts do you have about these differences/the reasons behind these differences?
- What do you think the implications are for parents seeking a diagnosis and then their child not receiving one?

Seek clarifying questions. E.g.:

Could you tell me more about this

Could you give me an example of this..

## Appendix 7 : Interview Questions B from Participant 4

*What are the contexts and mechanisms that drive parents to thinking that their child's behaviour is related to Autism?*

- Can you describe some of the ups and downs of conducting the parental interview element of the ADOS?
- What do you think leads some parent's to place difficulties as being within child and have a blindness to external reasons for their child's behaviour?
- What hopes and fears do you think parents typically have in relation to their child receiving a diagnosis of autism?
- Have you noticed any differences between parents who seek a diagnosis when their child does not have obvious traits (as per the ADOS) and those that do have obvious traits?
- Some people have talked about parental anxiety being a contributing factor of parents thinking their child's behaviour is related to autism, what are your thoughts on this?
- Where do you think this anxiety comes from i.e. internal or externally driven?
- What sorts of things do you think they are anxious about and why?
- Another theme that has arisen, is in relation to parenting, what are your thoughts on this?
- What sort of parenting styles or behaviour is leading children to behave in this way?
- Is there anything else that you think may be a contributing factor?
- What do you think the implications are for parents who believe their child's behaviour to be Autism driven and then they do not receive a diagnosis?

Seek clarifying questions. E.g.: Could you tell me more about this; Could you give me an example of this..

# Appendix 8: MaxQDA Final coding system

A1

The screenshot shows the MAXQDA 2018 software interface. The top menu bar includes: Home, Import, Codes, Variables, Analysis, Mixed Methods, Visual Tools, Reports, and MAXDICTIO. The address bar shows the file path: /Users/laraweaver/Documents/Thesis/310819.mx18 - MAXQDA Plus 2018 (Release 18.2.0). The main toolbar contains icons for MAXMaps, Code Matrix Browser, Code Relations Browser, Code Map, Document Comparison Chart, Document Portrait, Codeline, and Word Cloud. The 'Code System' window is open, displaying a hierarchical tree of codes. The 'critical self' code is highlighted in blue. The counts for each code are as follows:

Code System	Count
Code System	485
External Locus of control	0
parental anxiety	0
why parents are anxious	0
critical self	8
anxiety re development of child	3
anxiety re childs education	5
perceived judgement from others	7
parent emotional narrative	5
parent inherent anxiety	5
anxiety re parenting	7
anxiety driving seek for diagnosis	10
effects of parents anxiety on child	0
anxious child	12
accommodating child's anxiety	2
transmission of anxiety onto children	11
parenting	0
Styles of parenting	0
doing 'their' best	6
parenting influenced by own experiences	7
conflicting parenting styles	3
impact of diff types of parenting styles	3
neglectful parenting	2
indulgent parenting	6
authoritarian parenting	6
parental behaviour management	0
gender split on tolerance of behav	2
lack of knowing/wanting to teach/avoid	1
reacting to behaviour	3
have ch & not think about it	1
unaware how strategies make diff	11
loss of control with behav management	13
CONFIRMATION BIAS	0



A2

The screenshot displays the MAXQDA 2018 software interface. The top menu bar includes options like Home, Import, Codes, Variables, Analysis, Mixed Methods, Visual Tools, Reports, and MAXDictio. The main workspace shows a 'Code System' tree with the following structure and associated counts:

- CONFIRMATION BIAS (0)
  - "google doctor" (8)
  - placing diff W/l child (24)
  - parents blaming external factors (3)
  - parent not looking at self/environment (7)
  - in order to take away the blame (11)
  - sibling/family member with ASC (5)
  - alignment of behaviour with asc (5)
  - comparing behaviour with others (4)
- Environmental contributing factors (0)
  - societal change (0)
    - effects on parenting (0)
      - less familial interactions (11)
      - loss of professional support (5)
      - affects of social media/media (10)
      - materialism (3)
      - separation (2)
      - IVF (2)
    - impact of technology (0)
      - impact of tech on social communication (6)
      - impact of media on awareness/misunderstanding (9)
    - Raised public awareness (0)
      - surrounding EHCP/special school (6)
      - raised profile of ASC (2)
      - MH more in public focus (3)
  - perpetuating factors (0)
    - ACE'S (0)
      - Child anxious due to trauma (3)
      - impact of environment (6)
      - domestic violence (1)
      - bereavement and loss (1)
      - similarities with attachment (9)
    - Socio-economic (0)

MAXQDA2018 Home Import Codes variables Analysis mixed methods visual tools Reports MAXQDA

/Users/laraweaver/Documents/Thesis/310819.mx18 - MAXQDA Plus 2018 (Release 18.2.0)

Home Import Codes Variables Analysis Mixed Methods Visual Tools Reports MAXDictio

MAXMaps Code Matrix Browser Code Relations Browser Code Map Document Comparison Chart Document Portrait Codeline Word Cloud

**Code System**

Code System	Count
▼ Socio-economic	0
◦ impact of socio-economic factors	6
◦ DLA (actively seeking)	6
▼ impact of ADOS assessment process	0
▼ child and parent viewpoint	0
▼ impact of parent on ADOS	0
◦ parent pushing their viewpoint	5
◦ parent view of child	15
◦ parental influence on assessment	5
▼ impact of ADOS on child	0
◦ being imposed on child	2
◦ child's latter emotional reaction to lifelong lable	2
◦ implications of lifelong lable for child	9
▼ professionals viewpoint	0
▼ medical model	0
◦ diff view/focus of medical model	6
◦ paediatricians being reliant on parent voice	3
◦ EP challenging Paediatrician	2
▼ S&L view	0
◦ scoring differently	1
◦ questioning other professionals scoring	2
▼ school view	0
◦ schools role in why Parents go for ADOS	1
◦ school view of child	6
▼ EP view	0
◦ EP working holistically	19
◦ ADOS - clinical vs EP assessment	7
▼ Post ADOS, what next?	0
▼ Barriers to moving forward	0
▼ When no diagnosis	0
◦ impact on education	2
◦ should be feedback to parents to explain no diagnosis	5
◦ parents needing support/help	9
▼ parents fixed mindset when no diagnosis	0

The screenshot displays the MAXQDA 2018 software interface. The top menu bar includes: Home, Import, Codes, Variables, Analysis, Mixed Methods, Visual Tools, Reports, and MAXQDA. The current window is titled 'Code System' and shows a hierarchical tree of codes. The tree is organized into several main categories, each with a dropdown arrow. The counts for each node are listed on the right side of the tree.

Code System Node	Count
questioning other professionals scoring	2
school view	0
schools role in why Parents go for ADOS	1
school view of child	6
EP view	0
EP working holistically	19
ADOS - clinical vs EP assessment	7
Post ADOS, what next?	0
Barriers to moving forward	0
When no diagnosis	0
impact on education	2
should be feedback to parents to explain no diagnosis	5
parents needing support/help	9
parents fixed mindset when no diagnosis	0
parents emotional reaction when no diagnosis	11
when ch hasn't behaved 'autistically' in the ADOS	3
seek alternative diagnosis	2
professionals are wrong	6
repeatedly seek the diagnosis	14
Alternative explanations/needs	0
other needs	5
medical model remaining w/i child	3
impact of S&L & comm	11
ideas for EP early intervention	0
EI in school	0
training re ch anxiety	5
early years	2
EI with parents	0
cost effectiveness of EP preventative work	3
psychoed re childrens anxiety	6
psychoed child development	3
parental anxiety	4
psychoed parenting/strategies behav	9
Sets	0

## Appendix 9 : Final Coding System

Core Category	Selective Coding	Axial Coding	Open Coding	Coded Segments	Documents
External Locus of control					
	parental anxiety				
		why parents are anxious			
			critical self	8	4
			anxiety re development of child	3	2
			anxiety re child's education	5	2
			perceived judgement from others	7	3
			parent emotional narrative	5	3
			parent inherent anxiety	5	3
			anxiety re parenting	7	3
			anxiety driving seek for diagnosis	10	6
		effects of parents anxiety on child			
			anxious child	12	5
			accommodating child's anxiety	2	2
			transmission of anxiety onto children	11	4
	parenting				
		Styles of parenting			
			doing 'their' best	6	2
			parenting influenced by own experiences	7	4
			conflicting parenting styles	3	2
			impact of diff types of parenting styles	3	3
			neglectful parenting	2	1
			indulgent parenting	6	3
			authoritarian parenting	6	3
		parental behaviour management			
			gender split on tolerance of behave	2	1
			lack of knowing/wanting to teach/avoid	1	1
			reacting to behaviour	3	2
			have ch & not think about it	1	1
			unaware how strategies make diff	11	5
			loss of control with behave management	13	5
		CONFIRMATION BIAS			
			"google doctor"	8	5
			placing diff W/I child	24	6
			parents blaming external factors	3	2
			parent not looking at self/environment	7	4
			in order to take away the blame	11	6
			sibling/family member with ASC	5	3

Environmental contributing factors		alignment of behaviour with ASC	5	4
		comparing behaviour with others	4	2
	societal change			
	effects on parenting			
		less familial interactions	11	3
		loss of professional support	5	2
		effects of social media/media	10	2
		materialism	3	2
		separation	2	2
		IVF	2	2
	impact of technology			
		impact of tech on social communication	6	3
		impact of media on awareness/misunderstanding	9	5
	Raised public awareness			
		surrounding EHCP/special school	6	4
		raised profile of ASC	2	1
		MH more in public focus	3	2
	perpetuating factors			
	ACE'S			
		Child anxious due to trauma	3	1
		impact of environment	6	2
		domestic violence	1	1
		bereavement and loss	1	1
		similarities with attachment	9	3
	Socio-economic			
		impact of socio-economic factors	6	3
		DLA (actively seeking)	6	4
impact of ADOS assessment process	child and parent viewpoint			
	impact of parent on ADOS			
		parent pushing their viewpoint	5	3
		parent view of child	15	4
		parental influence on assessment	5	3
	impact of ADOS on child			
		being imposed on child	2	2
		child's latter emotional reaction to lifelong label	2	2
		implications of lifelong label for child	9	4

Post ADOS, what next?	professionals viewpoint				
		medical model			
			diff view/focus of medical model	6	3
			paediatricians being reliant on parent voice	3	2
			EP challenging Paediatrician	2	1
		S&L view			
			scoring differently	1	1
			questioning other professionals scoring	2	1
		school view			
			schools role in why Parents go for ADOS	1	1
			school view of child	6	2
		EP view			
			EP working holistically	19	6
			ADOS - clinical vs EP assessment	7	4
		Barriers to moving forward			
		When no diagnosis			
			impact on education	2	2
			should be feedback to parents to explain no diagnosis	5	3
			parents needing support/help	9	4
		parents fixed mind- set when no diagnosis			
			parents emotional reaction when no diagnosis	11	5
			when ch hasn't behaved 'autistically' in the ADOS	3	1
			seek alternative diagnosis	2	2
			professionals are wrong	6	3
			repeatedly seek the diagnosis	14	5
		Alternative explanations/needs			
			other needs	5	4
			medical model remaining w/i child	3	1
			impact of S&L & comm	11	2
	ideas for EP early intervention				
		EI in school			
			training re ch anxiety	5	3
			early years	2	2
		EI with parents			
			cost effectiveness of EP preventative work	3	3
			Psycho-ed re children's anxiety	6	3
			Psycho-ed child development	3	2
			parental anxiety	4	3
			Psycho-ed parenting/strategies behave	9	4

## Appendix 10 : Transcript Interview 1

Educational Psychology research transcript – 1<sup>st</sup>

Interviewer = person 1 = 1 (in interjections e.g. hmm)

Interviewee = person 2 = 2 (in interjections e.g. hmm)

*Interviewer (person 1):* Hi Ali thank you very much for coming I hope this is recording so thank you for coming to my research so I think we's we I stated that it's to do with um what the context and mechanisms behind parents who believe their child have autism when we as EPs don't believe that they do so it's trying to find out more information really so um just the first question is um can you describe some of the ups and downs of conducting the parental interview element of the ADOS pause please

*Interviewee (person 2):* I think that um one of the upsides of it is that you get a uh a complete picture of the child so you get that (I: yep) really good view of how the child is um from the parental point of view (I: hm hm) maybe how the child is behaving at home (I: yep) um and then you can uh think about that in relation to how the child maybe presents in school (I: yep) which may be completely different not not always though (I: hm hm) urm I think the downside of it is especially if you um and we usually do to be honest complete the interview bef with the parent before we see the child (I: okay) um a potential downside to it could be that you may find that you would be influenced by what the parent has said pause when you actually um conduct the ADOS and score it up you (I: yeah) might have in your head the the sort of background that the parent has given you (I: hmm) so for some parents there um they seemingly want to gain a diagnosis for their child and they will come armed with a long list of laugh um traits for that child (I: hmm) that that child may be presenting and um you know sometimes it's a bit like they've googled all the traits (I: okay) that they think are (I: hmm) relevant and then they want to make sure that you understand that that's (I: hmm) that's what they're seeing in their child um also I think parents can pause sometimes get quite emotional when they're talking about their own child so (I: hmm) you have to be wary about that and about how um how you manage that situation um and make it clear to them that it isn't you that makes the diagnosis and that the (I: yeah) ADOS isn't um a diagnostic tool as such it's a triangulation of information that you're going to use (I: hmm) in order to give additional information to the paediatrician

*person 1:* Okay pause So stating about sometimes parents come along almost with a list pause in your um experience does how often does that happen is it happen very much

*Person 2:* um not very much I mean most pause I would say most parents um are aware of um pause if they want if they are actively seeking a diagnosis (I: hm hm) um and um I think that they pause maybe it gives them clarification as to why their child is behaving in a certain way so um it has happened where a parent literally has come along with laughs with a printout (I: hmmm) from google but (I: laughs) admittedly that doesn't that isn't in the vast majority of cases (I: hmm) however I do think you you can get a feel for whether a parent has pause looked up all the information about (I: hmm) autism and how it tends to present pause

*Person 1:* I mean that leads on to (2: was that) yeah that leads on to er not the next question I was I was going to well no maybe it does so what are the common reasons for parents seeking an autism diagnosis do you feel

*Person 2:* I think for many and not not to sound too cynical for many it um is gives them access to disability living allowance (1: okay) um I think for many it does give them um a reason or a cause for their child's behaviour (1: hm hm) which they may be having difficulties managing and um and that behaviour might be just that the the parent is having difficulties in in managing the behaviours but if they can say oh well he's behaving like that because he's got autism (1: hmm) it's almost giving them um justification for (1: hmm) the fact that they're maybe not able to manage the behaviours (1: yeah hmm) um and so therefore they can say oh well it's because he's because he's on the spectrum that's the reason why he's behaving in this way (1: hmm) when they're not looking at other reasonings behind it

*Person 1:* Hmm so in maybe in some ways then to take the focus off themselves and put it

*Person 2:* yeah so it becomes more child focussed I think for some parents that um in my experience in the past parents who have older siblings who've already got a diagnosis (1: hm hm) um the negative aspect of coming and um they're almost actively seeking a diagnosis for the younger child because um because they they want sor confirmation that that they've got a diagnosis and I sometimes feel that maybe they're looking *pause* trying to actively look for those particular traits (1: hmm) in the child because it's happened in a um an older child (1: okay) an older sibling whereas if that child was their first child (1: hmm) and they hadn't got had a diagnosis they may not be necessarily aware or (1: hmm) be looking out for it specifically

*Person 1:* what do you think that might be the reason then that they're specifically looking for *pause* those traits

*Person 2:* I think I think largely it's because my my two main reasons would be like I said because they're looking for a reason for the child's behaviours (1: hmm) and that they're um not able to manage those behaviours (1: hmm) very successfully or they're feeling out of control and therefore it's easier to project a reason for the behaviour is (1: hmm) because they have a condition rather than looking to maybe the reason for their behaviour is because I'm not able to manage (1: hmm) them um in the in you know my parenting style is such that it's not managing that behaviour (1: yeah) um and then again access to disability living allowance (1: hmm) and I and I that probably isn't many of the cases that we see but it definitely is some (1: okay) for some families

*Person 1:* it is a factor there for some (2: yeah) thank you so what hopes and fears do parents typically have in relation to their child receiving a diagnosis of autism do you think

*Person 2:* I think there are some parents who are very fearful of receiving that diagnosis (1: hm hm) because they um they are maybe *pause* uh potentially in denial that there might be any difficulties with that you know with their child (1: hmm) and they um obviously any parents child is very precious to them and they don't want to maybe acknowledge that there might not be something (1: yeah) um untoward and that and that those difficulties would need to be addressed I think they can be fearful about the the implications of having a diagnosis as well because (1: hmm) um because of the knock on effects as they go through



school and (*I*: hmm) later on in life maybe and then equally I think like I said some parents are hopeful of a diagnosis because um it then gives them a better understanding of the reasons behind their child's (*I*: hmm) behaviours and um and then you know it can allay their fears about their um their parenting and you know whether it's an issue with their parenting (*I*: hm hm) and because they may have felt it when their child is showing some extreme behaviours (*I*: hmm) um and having a complete meltdown they have may have felt as a parent like they're um out of control they're not able to manage that situation (*I*: yeah) and that it's all because they can't manage the situation that the child the reason their child is like that (*I*: hmm) when actually if they then get a diagnosis it can be a positive thing for them (*I*: hmm) in that it helps to maybe explain (*I*: hmm) the reasoning behind the child's difficulties and that it's not due to their parental management style (*I*: yeah) it's due to them having an actual diagnosed condition which um we can then put strategies in place (*I*: hmm) to help support them

*Person 1*: So in respect to that then do you think part of it is the feelings of maybe judgement that they're feeling

*Person 2*: I think so for some parents (*I*: hmm) I think it can be that you know that they take their child out say for example to the supermarket the child isn't able to manage that environment (*I*: hmm) because its noisy and busy and then they have a complete meltdown outside (*I*: hmm) you know I think some parents are very fearful of being put in that situation they wouldn't have the um ability or capacity to be able to stand up to a bystander who would (*I*: hmm) make some comment about you shouldn't let them do (*I*: hmm) behave that way (*I*: yeah) um so I think it's um it is very difficult for them to to (*I*: hmm) take their children be seen to in public in that respect (*I*: hmm) can't remember I'm sorry I can't remember what the (*I*: no no) question was now

*Person 1*: I was no its absolutely fine no I I was saying about um do you feel from what you said it makes me wonder about um they're thinking about judgement from other people (*2*: yeah I think) whether that could be a driving force

*Person 2*: I think so because like I said then if you can actually say turn round and say to somebody who's being critical of what's going on with your child in a in a public situation if you can actually turn round and say well actually the reason (*I*: hmm) is I mean I know a lot of parents don't feel that they have to give any justification (*I*: no) as to why a meltdown is occurring but (*I*: hmm) for some it might give them some peace of mind to know that actually you know my child is this way because he has this condition and (*I*: hmm) there are times when this is what the outcome is because he is not able to cope with the environmental stimulus that's (*I*: yeah) going on around him (*I*: yeah) or her um so I think it does give them like I said clarification I think the main hope is clarification of of um what's been happening with their child and what you know the reasoning behind all the (*I*: hmm) diagnosis and maybe the slightly bizarre behaviours or um maybe they's they view their child in terms of if they've taken their child to play with other children or parties or and they haven't behaved in the way that other peers around (*I*: hmm) them are behaving you know it gives them some understanding of why

*Person 1*: yeah yeah okay thank you so I mean that also ah I suppose the questions link anyway but um thinking that I was just thinking about with regards to the judgement and you said about parents um some parents will be able to accept that maybe better than others and and just the different types of parents or different types of people um what's going on behind that

so my next uh my next question is have you noticed any differences between parents who seek a diagnosis when their child does not have obvious traits as per the ADOS and those that do have obvious traits

*Person 2: pause* I think so because um I think the parents that come when they're when they're seeking a diagnosis those are the ones that are very keen to tell you absolutely every trait (*1: hmm*) that they're seeing at home um and then like I said they will they perhaps are the parents that have got a pre prepared list of (*1: yeah*) *laughs* of all the traits that they think you know and it may not be that that child is exhibiting all of those traits (*1: hmm*) that we're seeing um so so if they're actively seeking a diagnosis I think they're very keen to to let you know absolutely everything (*1: hmm*) um and often some you know in some instances it can appear that a parent has like using phrases that have been put on the internet to so obviously (*1: hmm*) phrases that they googled that they perhaps wouldn't have (*1: yeah*) necessarily used in in normal conversation (*1: hmm*) and then the ones that um are not actively seeking a diagnosis maybe a little bit reticent about telling you (*1: okay*) telling you certain things (*1: hmm*) um so they might want to to cover up certain things (*1: okay*) and sometimes I think it's it's those parents where the child is is sh obviously showing traits of autism um it's very difficult as a professional because technically we're not allowed to elude to the fact that they are showing these autistic type traits (*1: hm hm*) unless a parent raises the issue (*1: okay*) themselves so if they don't really want to um acknowledge that there are some um traits being shown by the child (*1: hmm*) then they're they're less likely to be open with you about (*1: okay*) what exactly is happening at home or at school or um it's a bit slightly in denial of (*1: hmm*) of what the true sit picture is really

*Person 1:* Even though they are going down the ADOS pathway there's still that sometimes you feel that denial

*Person 2:* I think so (*1: hmm*) because even though I mean they will have been asked to to go to to attend a an an initial appointment with the paediatricians and then the paediatricians would have asked for the ADOS to be (*1: hmm*) um either do it themselves or they will ask for an ADOS to be completed um and I think it's um it is quite difficult with those parents because they almost don't want to acknowledge that there is (*1: hmm*) anything (*1: yeah*) the matter equally the ones whose children are not necessarily showing the traits (*1: hmm*) when when the when the parent receives the outcome from the ADOS assessment they will often come back and question sometimes exactly they want to know exactly what the score was so they want to know um so I think we have to be very careful with reporting it back um

*Person 1:* sorry which which parents are they that often will question it the parents that the ones (*2 simultaneous:* the parents who whose children) that wanted to seek or not

*Person 2:* Whose children um they feel are not not showing the traits of autism uh no the parents of the children who um who may not be showing many traits of autism (*1: yeah*) but they're going down the ADOS route because they want to get a diagnosis

*Person 1:* okay so the (*2:* so they) ones that you say are typically coming and also almost with the list prepared (*2:* yeahh) okay

*Person 2:* but they will often question the outcome of the diagnosis of the ADOS assessment (*1: really*) so in the past I actually had a parent ring up and ask me what the score was on (*1: hmm*) the ADOS um which is the reason why I don't think we should be uh we don't actually put the score at the end of any (*1: okay*) correspondence with the parent (*1: yeah*) and they

wouldn't be told what the score was on the (1: hmm) ADOS assessment they don't normally have access to that however recently there are some um speech and language therapists who've completed ADOS assessments (1: hmm) not necessarily with the child that we're talking about (1: hm hm) um who've rung up as well and asked for what the score was (1: okay) and wanting to see all the notes that have been taken (1: hmm) we've taken during the ADOS assessments (1: hmm) and and I don't think that's right either because the ADOS assessment is a snapshot in time on the day (1: hm hm) and you literally are reporting what you see on the day (1: hmm) so whether that child is exhibiting um completely different traits if they were to complete *laugh* (1: hmm) um a uh an ADOS assessment with a with a different person it well first of all it wouldn't be valid if you did it so so close together anyway (1: hmm) would it and um and secondly I don't think I don't think it's right that another professional questions another professional about what they

Person 1: and (2: have done) does that sometimes happen then

Person 2: yeah that has happened

Person 1: can you tell me more about that

Person 2: yeah like well like like I said it's um it was from um a speech and language therapist who was um assigned to a particular school (1: hmm) um who has completed ADOS assessments (1: okay) so she is aware o um has trained to complete ADOS assessments as well um so she's aware of what the ADOS assessment is all about but we were asked as educational psychologists we were asked to go in and complete the ADOS assessment with a child in her school (1: hm hm) and then she um she uh emailed in and um got the parent to ring in to ask what the score was and whether they could have a copy of the notes that we'd taken for the

Person 1: the speech and language therapist got the parent to do it

Person 2: yeah

Person 1: blimey

Person 2: Of whether they could have a copy of the of the booklet and the um algorithm as well and we don't as a matter of course send those out to parents (1: no) they go direct to the paediatrician so actually we've also I've also had *laugh* a parent whose approached the GP once she'd got the result of the ADOS assessment (1: hmm) she took it to the GP to ask the GP her her GP what the the what the results meant because she hadn't got an appointment with the paediatrician for quite a while afterwards (1: hmm) and she she didn't know what it meant we don't (1: okay) put scores in or anything but um I think *pause* I think I think somehow she'd asked the no we we'd we'd just said that he'd reached the in the in the letter that we sent out he had reached the um above the threshold for um the cutoff threshold (1: hmm) for autistic spectrum disorder but she didn't know what that meant so she took it to the GP and then he said oh he means he's scored above whatever it was (1: hmm) but it's I think we just have to be very careful how it's reported back (1: yeah) and when the parents we have been talking recently about whether we should send the letter out to the parent which is what has happened in the past before they go for their follow up (1: okay) appointment (1: yeah for that very reason) yeah and um when we've discussed with the paediatricians they said actually we maybe should be treating it like it's a clinical appointment the ADOS

assessment is (*L: hmm*) a clinical appointment and you wouldn't normally get the results of that (*L simultaneously: until everything was gathered*) until you hear back (*L: yeah*) yeah and I think that's a better way of doing it (*L: hmm*) because I think it can alarm some parents and equally it can um anger some parents if it isn't what they want to um see (*L: hmm*) and then they've got to wait a couple of months or more before they go back and (*L: hmm*) have follow up appointment (*L: yeah*) by which time they're armed and ready to *laugh* (*L: yeahh*) go in all guns blazing and (*L: hmm*) um put their point across that they don't don't agree with the outcome

*Person 1:* hmm and do you find the from the two sets of parents we were talking about those that are in denial and those that are seeking it do you um with regards to that are you finding its one more one than the other

*Person 2:* I think it's more parents who are actively seeking it than than parents who are in denial (*L: hmm*) it's it's not very often because usually a parent does have an inkling that there might be something (*L: yeah*) not quite right (*L: yeah*) maybe first time parents it's different because they don't have any (*L: hmm*) any uh for the want of a better word um any typical um child development to compare it with (*L: of course yeah*) so so for them it's understandable that they might think oh there's mu there's nothing the matter with my child this (*L: hmm*) you know maybe they're just a bit delayed (*L: yeah*) you can understand that if they've not got um any any comparison really (*L: yeah yeah*) but if for ones that have um older siblings that have been you know typically developing older siblings and then their their child is um not developing along the same pathway I think (*L: hmm*) um I think for them sometimes they might be a little bit in denial or want to be in denial that there's not anything wrong um (*L: yeah*) because they don't want it to happen again or you get a parent who's actively looking for those traits (*L: hmm*) very early on in that child because they've already got a child who's got (*L: right okay*) a diagnosis (*L: hmm*) so it's quite a complex *laugh* (*L: yeah*) area really they don't really fall in to distinct (*L: two neat*) camps (*L: yeah exactly*) theres a bit of overlap I think (*L: yeah*)

*Person 1:* I was just thinking about when you said earlier the the the parents that are more seeking the diagnosis that you said about giving you giving you a list um when you go to see the child um and I'm presu well ah how often does their presentation match the list um but also I'm wonderi with regards to that but I'm also wondering if their presentation clearly doesn't match the list what do you think is driving the parent to do that when it will maybe so obviously not be seen how what what do you think's you know I don't know if I'm saying that rightly

*Person 2:* I I don't know I think some parents just it I think often is just um maybe a justification for the child's behaviour (*L: hmm*) I think some parents just do actually want to have a diagnosis because they they want their child to have that label because it's a reason to (*L: hmm*) uh a reason for their behaviour technically (*L: yeah*) or it does give them which is really I sou I sound really cynical and awful but it does give them access to disability living allowance (*L: hmm*) it does give them parents think it gives them access to more support at school but (*L: yeah*) a diagnosis doesn't necessarily lead to that but I think in the parents head they think it (*L: yeah*) will

*Person 1:* one of maybe one of their hopes is is that then

*Both:* yeah

*Person 2:* so um maybe they'd be thinking looking along the lines of a an education health and care plan to get more support when it you know a diagnosis doesn't mean that that's necessarily (*1:* hmm) going to lead to that but I think a lot of (*1:* hmm) parents think it does

*Person 1:* so do you ever get anything come back about that then (*2:* what tha) from any of the parents

*Person 2:* what that they don't get a um given an education and health (*1 simultaneously:* yeah possibly yeah) and care plan yeah sometimes (*1:* hmm) they think it's it's quite difficult I mean I've got a case at the moment actually of a little boy whose parents are convinced that he's um on the spectrum he hasn't got a diagnosis of as yet (*1:* hmm) um they've actually withdrawn him from school (*1:* hm hm) and they're looking they've are actively seeking an education health and care plan (*1:* okay) um and yes he is showing some traits of it (*1:* hm) but when I observed him in class he's he's manageable you know (*1:* hmm) he's not um I think the difficulties arise you know when their when their child is showing really extreme signs of anxiety and behavioural issues (*1:* hmm) um then you might potentially be looking at something but but these parents *laugh* were very adamant we want him to have one to one support we want him (*1:* okay) to have an education health and care plan (*1:* hmmm) because he's like this but he hasn't actually got a diagnosis yet anyway (*1:* yeah) and he certainly is not he wouldn't fall into the camp of h needing that i uhm intense support to be able to cope in a classroom (*1:* hmm) he's a he he would be easily managed with (*1:* hmm) just some good strategies in place you know knowing what he's doing next some boundaries (*1:* yeah) in terms of don't ask him whether he wants to do his writing *laughs* (*1:* okay) it's making a statement we are doing writing now and then (*1:* yeah) you can you know but they have made it quite clear that they will take it further if he doesn't get

*Person 1:* okay so using that as a case example *pause* I'm won just wondering what the reasons are that they're pushing for that how how have school been have school been saying no he's fine here or are they saying yeah he is difficult I'm just (*2 simultaneously:* yeah no school school have been) wo what's driving the parents to

*Person 2:* I mean it's a bit sad really school have been saying that he's fine that he's manageable (*1:* okay) it's parental choice that they've taken him out of school he's only on a part time timetable (*1:* okay) um and yes he does have some some traits of it but he's got a lot of other things (*1:* hmm) um tha uh a lot of other history (*1:* hmm) which may think you know may lead you to a a different conclusion (*1:* okay) or it may be that yes he would be found to be on the the spectrum but he's manageable (*1:* yeah) so I'm not quite sure I mean I have explained to them that it is a lifelong label (*1:* yeah) if they were to if he were to get that diagnosis and therefore you know sometimes things can be managed by putting (*1:* hmm) the same strategies in place but not necessarily having that label (*1:* hmm) but they've made up their mind *laugh* (*1:* hmm) that he is they told me he was but uh i he hasn't had a diagnosis (*1:* right okay)

*Person 1:* it's interesting isn't it just to the extreme and he hasn't got a diagnosis and the school are also saying actually he's he's doing he's you know he is managing here that they've that it goes to such a extreme you just wonder what's behind that

*Person 2:* I don't know I mean I don't know what their thinking is (*1:* hmm) other than they maybe want him to go to some sort of specialist placement they you know he didn't strike me



as a little boy that needed that level of (*L:* hmm) intervention (*L:* yeah) so it's a bit *pause* a bit sad for him really (*L:* hmm) if he does get a diagnosis I mean he may very well get a diagnosis (*L:* yeah yeah) like I said he was exhibiting lots of traits of it he was a little quirky *laugh* (*L:* hmm) I wouldn't be surprised if he got the diagnosis but I it's that is going to take him down a route (*L:* hmm) that professionally I wouldn't have *laughs* (*L:* yeah) I wouldn't have sent him down (*L:* okay) um because the parents are quite adamant that (*L:* hmm) this is what they want and this is what they this is the support they want for him (*L:* yeah) *pause* um *pause* so (*L:* hmm tricky) yeah

*Person 1:* okay thank you um so sorry just picking back up again so we tal spoke about the differences between parents who seek a diagnosis when the child has obvious and those that don't so in relation to that what thoughts do you have about these differences and the reasons behind those differences I think we've pretty much covered that actually haven't we (*2:* yeah) even as I'm saying it sorry okay so it's the last one on my list then is what do you think the implications are for parents seeking a diagnosis and then their child not receiving one

*Person 2:* *pause* I think *pause* I think for some they're they're perhaps disappointed that um that it hasn't um they haven't been given some reasoning for the child's behaviour (*L:* hmm) um I think there are some parents who will take it further and keep pushing so (*L:* okay) they will go back you know again and again (*L:* okay) until they get a diagnosis

*Person 1:* and does that id has that happened

*Person 2:* sometimes it has (*L:* okay) you know in the past I've had parents who well we've completed the ADOS assessment with them and the child hasn't come out as being on the (*L:* hm hm) spectrum and we fed that information back to the paediatrician who's then put together all the information that they've got and they have not made a diagnosis (*L:* okay) um and then parents have gone back subsequently (*L:* okay) two two or three times after and the child and I think I the end the the paediatrician has thought well we'll send them for another opinion (*L:* okay) so they get sent up to the Evelina (*L:* hm hm) hospital for an out of county assessment (*L:* okay) and then because the um the paediatrician's take a lot of that um developmental and parental history (*L:* hm hm) you sometimes feel like actually they're listening more to the *laughs* to the parent then (*L:* oh really) so sometimes they do then go ahead and get given a diagnosis (*L:* oh I see okay) but then equally I've had just recently I've had a case of a um a young boy that I saw quite a long time ago he di had the ADOS assessment done (*L:* hmm) not by me um it had come back as borderline (*L:* hm hm) so he was near to the threshold but he had significant speech and ling um language

*Man speaking in background*

*Person 1:* sorry just one moment *PAUSED* okay sorry to pause that there can I ask you to carry on

*Person 2:* okay so the the young lad had um quite significant speech and language difficulties (*L:* okay) and um I was then asked to do a follow up observation of him in class and that was the conclusion I came to wasn't that he didn't want to interact with his peers but he didn't have the language skills (*L:* oh I see okay) to enable him to do that um there was quite a difficult parental history parents were separated um he had an older sibling who did have a diagnosis and um the the children lived with mum but she wa wr was finding it difficult to cope with them (*L:* yeah) and um dad didn't think that the *laugh* um young child had um was

was on the spectrum (I: okay) um but he he hung around in the system for quite a time because I saw him quite a long time ago (I: hmm) and um yesterday I got a letter through saying that he's been up to the Evelina hospital (I: okay) and they had actually decided that he didn't meet the threshold either (I: ahh) and actually professionally it made me think yeah you know (I: *laughs*) I should have the courage of my convictions because when I heard that he'd been referred up there I was thinking (I: hmm) it just looks like I'm you know I don't know what I'm talking about in terms of (I: hmm) maybe I just um didn't look hard enough or didn't spot something when he was (I: yeah) at school but actually I I think that's perfectly the right um diagnosis for him cos he's speech and language difficulties were such that he it impacted on his ability to socially interact but it wasn't because (I: hm of course) the intention wasn't there (I: yeah) so

Person 1: yeah absolutely I was just thinking about um when you said about going up to Evelina so Evelina by the sounds of it does things differently to East Sussex um and it's it's mainly around the parental interview what's your thoughts (2: there are it's uh) to

Person 2: uh the parental interview is a big part of it (I: okay) and the problem is because the I mean they I I guess they would have the the history of what's happened (I: hmm) down here but I think um because they very definitely listen to the parents and they're not seeing the child in their school environment (I: hmm) it's uh purely a clinical setting (I: hmm) uh I think it is I think we have to be quite wary of assessments that are conducted purely in that clinical setting (I: okay) but that's the advantage of being an educational psychologist that we (I: hmm) can go out and see them in a school environment cos that gives you a wealth of information that you don't get in a clinical setting (I: hmm) so in a clinical setting you're just purely observing what happens with the ADOS assessment (I: hm hm) and reporting that back and you've got the parental interview to report back and (I: hmm) give that information for as well

Person 1: So when you do the ADOS do you generally do it in the school

Person 2: Yes

Person 1: So what would you see as the differences then of an ADOS being completed in school and one that's completed in a clinical environment

Person 2: It's not so much the completion of the ADOS in in those two different environments it's the um ability to be able to see the child within their (I: okay) school environment (I: yeah) so that's the additional um piece of the puzzle as it were (I: hmm) because you get to go out and see them at playtime (I: yeah) um you get to (I: in their natural) yeah and see them in the classroom for a little bit (I: hm hm) sometimes (I: hmm) to see how they're able to function and whether they are initiating any interaction or whether they're (I: hmm) just sitting there and keeping themselves to themselves (I: yeah) when they're out on the playground whether they're actually by themselves (I: hmm) so it gives you an additional wealth of information that you don't get when they're just sitting in a clinical setting (I: yeah yeah absolutely) in an unfamiliar environment as well (I: hmm) hm

Person 1: yeah absolutely so we thes the question was about thinking about the implications for those that seek a diagnosis and don't receive one so one of the things you said was they some parents can um re seek for want of a better word they keep wanting to keep (2 *simultaneously*: yeah some) doing that

*Person 2:* some parents will keep pursuing a diagnosis

*Person 1:* okay there any other implications that you feel that there may be so what do you think so the question was what do you think the implications are for parents seeking a diagnosis and then their child not receiving one *pause* so other than

*Person 2:* well I think you know for some it can be quite upsetting if if they felt that their child clearly (*I:* hmm) warranted a diagnosis and hasn't been given one (*I:* yeah) and so it might make them question whether they whether they were correct um (*I:* hmm) and whether they should keep keep pursuing it because sometimes it does happen that the child isn't isn't picked up early on (*I:* hmm) um so I think it's difficult because if the the usually the parents that will keep actively pursuing a diagnosis are the ones that are able to have that they've got a voice and they're able to express how they feel about about the situation (*I:* hmm) and and wanting to pursue it and for some parents they don't get a diagnosis um for them it can be quite quite a disappointment (*I:* hmm) for them I think an and they may not know where to turn then (*I:* yeah) if they were pinning all their hopes on that (*I:* absolutely) diagnosis they they've got no other potential avenue to explore (*I:* yeah)

*Person 1:* and what happens then type thing for them

*Person 2:* I think then they get lost in the system unless they come back again and say (*I:* hmm) well actually this is still going on (*I:* hmm) um and I do think something needs to be looked at again (*I:* hmm) um you know I do worry about those parents who don't have the ability to maybe speak for their child or speak for their child's needs as such (*I:* hmm)

*Person 1:* that just seeking that diagnosis again (*2:* hm) so in your view what what could be done at that stage do you think

*Person 2:* I think there maybe needs to be some follow up support for those parents who um where the diagnosis hasn't turned out the way they maybe (*I:* hmm) wanted so maybe give an explana I mean I'm sure when they go to the follow up appointment with the paediatrician give some sort of ex that they would give some explanation (*I:* hmm) as to why they they didn't meet the threshold for (*I:* hmm) the diagnosis I think as educational psychologists we are best place to be able to talk that through with the parent (*I:* hmm) and you know follow up on the the reasoning why the diagnosis wasn't given (*I:* hmm) and then maybe you know make suggestions about things that we can put in place because you can still put those strategies in place that are suitable for a child on the (*I:* hmm) spectrum can still be used with other children (*I:* yeah) you know just giving them the clear boundaries yeah letting them know what's going to be happening you know so just makes the child feel a bit more supported and I (*I:* hmm) I worry that we don't have much follow up in (*I:* hmm) in school um and support for those parents

*Person 1:* yeah cos when the child does have a diagnosis there's obviously all sorts of things that that kick in then (*2:* yeah) isn't there (*2:* yeah) and it just makes me think back again to what you were saying about the whole issue of judgement I wonder where that might fall come into it for those parents as one of the implications (*2:* hmm) viously you know when their child hasn't received the diagnosis



*Person 2:* yeah I don't I don't know if they necessarily feel judged I mean maybe when they go back to to school they might (*I:* hmm) feel that the school maybe you know pre judged the situation but then (*I:* hmm) um I don't know really I don't (*I:* no no) I don't know if they'd necessarily feel judged as such (*I:* hmm) *pause* I think *pause* I think parents who are really actively pursuing a diagnosis and then don't get it maybe they would feel *pause* judged because they wouldn't they wouldn't have found the justification for their (*I:* hmm) thoughts (*I:* hmm) and they might feel that people have made the wrong decision (*I:* yeah) which then forces them down down a route like I said of of that quite persistence (*I:* hmm) in trying to get a diagnosis (*I:* yeah yeah) but equally you know there are children who things don't come to light until a bit later (*I:* hmm) and you know maybe it wasn't as apparent when they had a first ADOS assessment (*I:* yeah) to maybe the next time they go it might be a couple more years down down the line (*I:* hmm) and maybe they are then showing much more (*I:* hmm) obvious signs) yeah (*I:* yeah) but um but yeah I do question sometimes the ADOS assessment as such as a tool because I think a lot of it is very verbal (*I:* okay) and I think a child that has speech and language difficulties (*I:* hmm) would struggle with some aspects of the ADOS assessment even if they didn't have any difficulties if you see what I mean (*I simultaneously:* autistic difficulties yeah) but that's yeah if they didn't have any autistic difficulties um because speech and language impacts across (*I:* hm) a lot of those areas (*I:* yeah) and some of the things that we're asking them to do if they've not got very good speech and language skills (*I:* hm) I think is bound to have an effect on on how they react within the (*I:* hmm) ADOS assessment (*I:* absolutely) although I it's technically supposed to have been factored in (*I:* okay) I still question that (*I:* hmm) in that you've got to have quite good skills to be able articulate to be able to articulate your feelings (*I:* yeah) and and emotions (*I:* which is part of the ADOS) hm (*I:* yeah) and although they're not directly scored on on those answers (*I:* hm hm) for those questions it does come into you know whether they can uh are able to recognise those feelings and (*I:* hmm) talk about those emotions and if you've not got very good speech and language skills (*I simultaneously:* yeah makes it difficult) you're not going to be able even as an adult you'd find it difficult to explain why you what well you might fi be able to answer what makes you happy (*I:* hmm) to answer how you feel when you're happy is a different ball game isn't it really (*I simultaneously:* it is I know its quite a big concept) *laughs* quite a big concept (*I:* yeah) to explain (*I:* yeah) if you've not got good verbal skills (*I:* hmm) even if you have got good verbal skills *both laugh* you might struggle might you

*Person 1:* yeah no that's that's interesting stuff for another study I think that one is (*2:* yeah) *both laugh*

*Person 2:* sorry (*I simultaneously:* no no no not at all) gone off on a tangent there

*Person 1:* no it's really interesting well that's the yeah that's the end of my my questions so thank you very much

## Appendix 11 : Transcript Interview 2

Educational Psychology research transcript – 2<sup>nd</sup>

Interviewer = person 1 = 1 (in interjections e.g. hmm)

Interviewee = person 2 = 2 (in interjections e.g. hmm)

*Person 1:* okay so thank you very much for (2: that's alright) doing this for me so um yeah my title at the moment is what are the context and mechanisms that drive parents to believe that their child has autism in cases where EPs do not believe this to be the case (2: okay) so my first question is can you describe some of the ups and downs of conducting the parental interview element of the ADOS please

*Person 2:* um so when you say parental interview (1: hmm) we don't actually do that in East Sussex or do you mean just (1: just meeting the parents) okay (1: do you meet the parents as part yeah yeah) so (1: so that part of it yeah) no I was a little bit confused because I think there is a specific parental interview for the ADOS isn't there

*Person 1:* Right okay in which case I need to change my the wording of not na that then so it's yeah just about meeting the parents (2 *simultaneously*: meeting the parents) as part of the ADOS

*Person 2:* okay sorry can you repeat the question *laughs*

*Person 1:* yeah of course so can you describe some of the ups and downs of of meeting the parents (2: yeah) as part of the ADOS

*Person 2:* um *pause* so oh god that's a tricky one ups *pause* the parents um I spose often have their own views (1: hm hm) about their child um just tryna think about situations *pause* so *pause* one parent I met it felt like they were describing certain symptoms that they'd read or researched in terms of (1: yeah) um so that can be a down I spose cos you feel like um it's very negative (1: hm hm) in terms of how they are talking about their young person or how they're perceiving what the young person is ah or how they are presenting if that makes sense (1: yeah) um so it feels like they've sort of read a list of things that they might be seeing if the young person has autism and then (1: yeah) they're finding ways or reasons in which the young person kind of fits into that (1: yeah) um so often what they see then isn't necessarily um a kind of true reflection because it feels like it's sort of biased by what they would like to think (1: okay) does that make sense (1: yeah yeah absolutely absolutely) uh I don't know whether I'm being very clear so um *pause* I mean othe other than that um *pause* one of the advan w so one of the nicer things about um uh I dunno really I don't know whether what the ups would be it's a difficult question

*Person 1:* hmm just going back to what you were saying then (2: yeah) about um the parents seeing what they would like to see (2: hmm) what're your feelings with regards to what do you think's behind that

*Person 2:* um *pause* so the young lad I was talking about the parents um I think there was quite significant behavioural issues (1: hm hm) around the young person um and I don't

know whether sometimes for the parent it's a clearer explanation or an easier explanation for them to feel like there's something wrong with the child (1: hm hm) um and rather than that actually sometimes it's about things that are going on in the home um and sort of issues within the family um or sort of complexities around the relationships between (1: yeah) parent and young person um so pause yeah what was the question again sorry

Person 1: so I was (2: why) when you said about yeah they that they were wanting it to wanting that um their child to almost fit that what might be the reasons behind that

Person 2: okay yeah so I think um often it's easier for the parent to see it as a within child issue rather than actually try to reflect and think about what they might be doing that might be sort of escalating the situation themselves (1: yeah yeah)

Person 1: what what do you this might tap in to some of the other questions but (2: yeah) what do you think the parent will is hoping to get out of that then what are their hopes then do you think or hopes and fears for doing that Cough

Person 2: um pause (1: cough) I don't know is it because they want an answer and they feel like having a diagnosis might provide them with a kind of easy strategy or easy solution (cough) are you okay laugh (cough) then with autism that's (cough) never the case is it it's not like they're gonna receive laugh you alright do you want a drink of water (1: try not to cough easily) laugh

PAUSE

Person 1: go thank you so yeah hopes and fears

Person 2: um so in terms of hopes yeah I was just saying how maybe they feel that it will provide kind of an easy often parents say don't they that um if I knew what it was then at least you know having having that knowledge then gives them kind of is it better does that then provide them with the strategies m clearer strategies in terms of what they would do (1: hmm) and what the consequence or how they can cope or manage that better but actually it doesn't help does it because we all know that you can apply those strategies without having that diagnosis (1: yeah absolutely) and apply them and support the young person with their strategies without that without that diagnosis (1: hmm) and still be effective um when you said what was the question again sorry (1 simultaneously: so it was um) hopes and

Person 1: yeah hopes and fears I mean that does link in to one of my questi one of my questions was what hopes and fears do parents typli typically have in relation to their child receiving a diagnosis of autism

Person 2: yes so the hope is to ha get an explanation I spose and (1: hm hm) you know to try to help if they feel that if there's more understanding of it then they can put in sort of the correct strategies which will then um kind of significantly change things for they for the child I think hopes also they feel that if there's a diagnosis there will be further support and further recognition of that of that (1: hmm) in school and I think often parents feel that if their child has a diagnosis of autism this will sort of open the door to um lots of different services lots of different um support mechanisms fears pause I think ah I dunno whether some parents are scared of the labelling in itself aren't they (1: hmm) and they don't actually like their child to have a label or for that label to be known so I have known parents who have tried to avoid

that even once they have had a diagnosis of autism will then (1: hmm) um try not to try to make as few people as need to know that that's what it is (1: hmm) um so I don't know if their fear sometimes that that diagnosis might or the label might lead to them to the young person sort of being fitted in certain boxes or or not making the progress or the expectations being lowered or (1: hmm) I don't know yeah

Person 1: I suppose with regards to hopes and fears then um it's so I said about hopes and fears in relation to the child receiving a diagnosis but flip that around (2: yeah) what do you think the hopes and fears of parents when they were seeking a diagnosis of them not receiving that diagnosis

Person 2: so when they don't (1: hmm) um *pause* I don't know really I suppose if they don't receive diagnosis I often feel that if they feel like they should and they don't actually there's a need there's just a view that the professionals are wrong (1: hmm) and that they've they haven't recognised what they are seeing or (1: hmm) have experienced um so I suppose the fear is that they just often gonna have to continue along how else do I get this or what else can I do in order for this to be from what for the for my child's autism to be recognised

Person 1: hmm so ye have you come across that

Person 2: um yes yes but not in terms of the ADOS in terms of other um I recently carried out a statutory assessment for a young person who'd had four ADOSes (1: really) carried out over the period of their lifetime so sort of reached the age of sixteen um I think no not four ADOSes but four um diagnostic kind of (1: hmm) situations basically (1: hmm) throughout their life where um the parent had been continually seeking for that diagnosis and every time it hadn't been recognised by the professionals

Person 1: and what your in relation to that what were your thoughts behind why the parent was doing that

Person 2: um I think because the parent had felt that the um situations that o the diagnostic situations hadn't been reflective of the young person (1: hmm) so there's a feeling that they hadn't been successful in recognising (1: hmm) um the kind of set of symptoms that she was seeing so (1: hmm) that's how she perceived it I think you know (1: hmm) she was seeing these issues or these difficulties and that um every time she's been to that interview or to that um assessment her understanding of the assessment I don't think had been really full in terms of she'd seen that the assessment had been carried out for example on a day when the young person had been in a good mood and (1: right) therefore it can't possibly have been reflective of the issues (1: hmm) or the or what she was seeing for the young person

Person 1: so do you think in her that person's respect sometimes they don't feel their point of view is held strong enough

Person 2: um yeah yeah in that case specifically um and I suppose also also misunderstanding of the actual assessment (1: hmm) in itself because actually ADOS looks at sort of the underlying (1: hmm) behaviours in terms of sort of things like eye contact or (1: hmm) and actually that's not not based on mood and whether the day has been good it's just about (1: hmm) whether they can demonstrate those (1: yeah) social skills so I think an un a misunderstanding of what it actually measures or what the assessment does

Person 1: okay so that maybe that would be a good thing to try and (2: yeah) and do that then

Person 2: yeah I don't think there's much understanding of parents actually of what the ADOS looks like or how it (1: hmm) you know the reports that we write don't necessarily um provide huge amounts of information of of how it's done I sponse (1: no no they don't do they) interesting (1: it is an interesting point actually) yeah and the ADOS when they carry out the ADOS for younger pupils the parent's always involved I wonder actually w whether that would be helpful although obviously you'd see that would change it for the young persons (1: yeah) perspective if they were if their parent was in the room (1: yeah) but I have been trying to video record them actually so maybe that's something that could be shared I mean but m w you know if we're talking about paren parents having more understanding of what we're doing and what we're looking for then (1: hmm) that might be something that you could help them to understand you know if they if there's confusion about the procedure or what it was or what or why you've come to that decision (1: hmm) maybe providing them with sort of video clips to demonstrate (1 simultaneously: yeah absolutely I mean) what you've seen or

Person 1: that so um I mean that fits in with the last question that I have on there about about the implications for parents seeking a diagnosis when the child doesn't receive one um (2: yeah) I suppose there I mean what you're talking about is part of that isn't it (2: yeah)

Person 2: yeah cos I suppose if you walk away from the ADOS situation you've um write them a report to say actually I've seen these behaviours (1: hm) and that would suggest you know that the marks more what happens with the ADOS is then you get a lesser mark (1: hmm) which at the end then when you score it up they don't come past that criteria or (1: yeah) that line um that yeah so then if the parent were to walk away and say oh well you know I don't think that's reflective um then yeah you could provide them with (1: hmm) more information about how you reached that decision and what that looks like um and why (1: hmm) yeah cos I sponse actually a lot you know our pare the parents think about autism in such a negative way pause that that kind of im impacts really are they seeing you know sometimes I wonder for parents who um think that they a child has autism are they just looking at the negative aspects (1: hmm) of it and the and the things that they are seeing on a daily on a day to day basis that they don't really like about their young person (1: that's really interesting) when actually that's not really autism (1: hmm) and they haven't really understood sort of the underlying difficulties that young people with autism have and actually the strengths that they can show as well (1: hmm) so there's so much focus on the negatives around autism when you look at it diagnosis as well which is

Person 1: there is isn't there yeah (2: definitely) real deficit (2: yeah) model of looking at it (2: what aren't they doing what can't they show) yeah so with that in mind then (2: yeah) for those for the parents that don't get a diagnosis thinking about tht the child doesn't get the diagnosis (2: yeah) um what do you think could help then so we said about doing the the video but you also mentioned um the fact that that perhaps they've been focussing on the negatives so (2: yeah) what could you see what would you feel would be a good next move then to help

Person 2: what to help young people (1 simultaneously: and their parents) parents who don't have (1: hmm) who haven't had um and walk away without the (1: hmm) from the ADOS without having (1: yep) a diagnosis um well I sponse maybe more understanding of what autism is tha actually that's not really well what they need is some some further support to



identify how they can address what they are seeing (1: yeah) um in terms of you know the issues that they are bringing up um and the concerns they have is what support could be put in place in order to sort of see progress and um change in those areas (1: hmm) maybe some focus on on the positives as well and what is going well and what is (1: yeah) good (1: hmm) rather than just what isn't (1: hmm) yeah

Person 1: no absolutely thank you um we might have I think we have touched on this but the the another question is what are the common reasons for parents seeking an autism diagnosis

Person 2: um I spose if you look at it from a general perspective its kind of an an observed difference between them and their peers a sort of different way of interacting um (1: hmm) and socialising um sometimes I spose parents you know its such a general question isn't it because theres so many so many reasons

Person 1: hmm I spose I'm I'm I'm (2: yeah) I'm doing it from from the perspective of the title so for (2: yep) those children that you in your professional opinion aren't (2 simultaneously: diagnosed) aren't diagnosed (2: okay) are't um autistic what do you see are the common reasons for their parents seeking that diagnosis

Person 2: um so from that perspective its often um to try to get some understanding of negative thing negative occurrences and difficulties that they experience on a daily basis that they so they feel the diagnosis would give them some explanation or some strategies that would therefore kind of make significant amounts of change (1: hm) but also take the blame away from them as parents (1: hmm) often

Person 1: and what do you think those reasons are I'm sorry I know I keep like (2 simultaneously: or or a misunderstanding) diving deeply

Person 2: of autism itself I suppose and (1: yeah) and not and sort of seeing the negatives of what autism means without really understanding the needs behind it (1: hmm) and I spose also not really understanding that other things can cause things like difficulties engaging socially can be caused by so many other reasons other than just um (1: hmm) it being a core difficulty (1: hmm) um and sometimes parents don't really understand that children can develop at different speeds I spose and the there so discrepancies can develop between them and their peers without it needing to be a diagnostic (1: yeah) thing (1: yeah something wrong with the child) yeah (1: yeah) actually some you know people are different aren't they people that's so (1: yeah) you know so one um well no because that doesn't really apply I was going to say one young person who had been um sent to do the ADOS with me but then his par so his parent didn't think that he was autistic it was just the paediatricians who thought that (1 simultaneously: right okay) but um he was just shy really I think (1: hmm) so didn't so wasn't very forthcoming so the you know in the um paediatrician kind of interview or whatever it is they'd identified there might be social communication needs (1: right okay) um but the parent just thought sort of was very aware that the young person was just not very not very outgoing (1: yeah) but yeah that doesn't really apply to what you were saying so *laughs* (1: that's fine)

Person 1: so you said before about um so common reasons for parents seeking a diagnosis seeking that you said to to take the focus away from them as parents (2: yep) what do you feel then thinking of it you know so taking it from within child to within environment what

do you think might be the reasons for um the reasons for that the child having those (2: demonstrative) yeah (2: representing those sort of needs) yeah

*Person 2:* um well sometimes we know don't we that attachment and can sort of um produce children on having attachment needs can impact on the development of social and emotional (1: hmm) um development so sort of having any disrupted attachment early (1: hmm) in life can then lead to young people um having a similar kind of presentation in terms of you know having difficulties forming relationships maybe they have that kind of push and pull with people (1: hmm) who um who they're close to and they don't know how to form secure relationships because that's never been modelled and demonstrated to them (1: hmm) sort of their internal working model of that (1: hm hm) um also things like so you know we know how important that early attachment figure is for the development of social and emotional skills therefore if you take that away or that young person hasn't had much experience of that for whatever reason (1: hmm) then um you know maybe that they really struggle with eye contact for those reasons (1: yeah) because they never really were helped to understand it from a really early age when it was really (1: hmm) important in their developmental terms um yeah or I spose sort of differences within young people um in terms of you know how much do they want or are motivated by social interaction (1: hmm) don't necessarily mean they're on the spectrum it might just mean that they prefer video games or find social (1: that's a really good point yeah) yeah interaction difficult um (1: hmm) yeah doesn't necessarily mean it has to be a yeah a diagnostic criteria

*Person 1:* hmmm that's a really interesting point thing you know the (2: yeah) the fact that more and more it's you know on social media and it's not face to face anyway is it and the impact of that (2: yeah)

*Person 2:* I mean yes how much is communication nowadays done through (1: hmm) kind of means of la electronic means rather than rather than (1: yeah) face to face or phone calls (1: yeah) um (1: absolutely) so it's a change in in com in how we how we engage (1: hmm) yeah

*Person 1:* hm that's very thought provoking (2: laughs) um so we've just done that so have you noticed any differences between parents who seek a diagnosis when the child doesn't have obvious traits and those that do have obvious traits so have you noticed a difference between the parents

*Person 2:* um do or don't in terms of actually if they have been then diagnosed or

*Person 1:* so yes so thinking about tho the the children that go on to get a diagnosis and those that don't so the parents when you um and I know you haven't done (2: yeah) you still at the beginning but I don't know if you've so the parents that like you say almost go in with a list (2: yeah) and their child doesn't are you noticing in the difference between (2: between the parents) yeah

*Person 2:* um I spose it's very difficult to tell because uh so yes only having had the three (1: yeah) or no four I've observed now um I no I can't say I from that it's very (1: yeah) difficult to know patterns (1: yeah no I understand that) um I'm just tryna remember parents *pause* um who's the last one *pause* cant actually remember *pause* ohh no no I can't

*Person 1:* no no that's fine thank you um so what thoughts do you have uh I was gonna it's linking into the last one thoughts (2: yeah) so ah just about the differences the reason behind

the differences but not really had um (2: yeah) those differences so um yeah so that's pretty much all my questions (2: okay) so yeah thank you very much (2: that's alright) thank you

**End of recording**

**Start of second recording**

Person 2: um

Person 1: so yeah you did a you did a another (2: yeah) you did another observed on with somebody else

Person 2: well yeah sometimes a reason for parents wanting a diagnosis is that a relative has recently got one (1: okay) got a diagnosis for their child (1: right okay) and maybe similarities are seen between behaviours (1: yeah) but because I think li as I was saying before with the negatives der in terms of people who don't really understand what autism is often focus on the you know the sort of behaviour presentation I spose (1: yeah) as a reason for autism but I think actually that's just for some children with autism that can be a by-product of the autism you know because they can't express themselves or they (1: hmm) can't communicate effectively so um you know often you will see them turning to behaviour to get their need needs met rather than um rather than communicating that effectively (1: hmm) so because you see a similar kind of presentation in young people who um perhaps have got needs through their environment rather than an underlying communication need because they do look quite similar sometimes (1: yeah) I can see why some parents would then think oh but there my nephew's just got it (1: yeah) a diagnosis (1: yeah) and actually when you see them together they look really similar in terms of you know they're both presenting with similar types of behaviours (1: yeah) so oh yeah well then mine must have autism as well

Person 1: rather than recognising the impact of the environment

Person 2: yes rather than thinking about what what has gone on or in the family or you know all the changes that they've been had in their lives yeah (1: hmm) yeah so that's been a couple I think a couple of times that's happened where somebody close to them gets a diagnosis and then they see the similarities and think I mu that's what it must be (1: right okay) yeah

Person 1: yeah that's interesting thank you

Person 2 laughs



## Appendix 12 : Transcript Interview 3

Educational Psychology research transcript – 3<sup>rd</sup>

Interviewer = person 1 = 1 (in interjections e.g. hmm)

Interviewee = person 2 = 2 (in interjections e.g. hmm)

*Person 2:* nervous now *laughs*

*Person 1:* oh no don't be no thank you ever so much for agreeing to take part in please don't feel nervous I feel really nervous and there's yeah no it's fine yeah thank you ever so much so um yeah just to remind you so the it's my title at the moment is what are the context and mechanisms that drive parents to believe that their child has autism in cases where EPs don't believe this to be the case (*2:* okay) so it's just a semi-structured interview it's just to find your views really (*2:* hm hm) so yeah please don't be nervous so my first um my first question is can you describe some of the ups and downs of conducting the parental interview element of the ADOS (*2:* hm hm) um yeah so um yeah parental interview gives it a bit of a grand title but yeah just the bit where you meet the parents beforehand (*2:* yeah) so yeah (*2:* yeah) just what your ups and downs of (*2 simultaneously:* okay) that are

*Person 2:* okay so um up sort of side of it is it gives it context (*1:* yep) what you're doing basically (*1:* hm hm) so um because um otherwise you I often feel if you go into a school and hear school's view you are sort of almost blinded to I uh a big (*1:* yep) huge part of that person's young person's life and similarly if you are only just seeing the parental side again you know you ha you sort of need to find out more about what's going on in the school cos (*1:* yep) that's really important to be able to kind of triangulate that information to give you a kind of a holistic picture of the young person (*1:* hm hm) and I think obviously as EPs we believe that the young person is at the centre o of of systems isn't it and how (*1:* hmm) those those views and thoughts and everything can kind of impact that young person um the *sigh* that's the biggest upside I think and you get some really lovely pieces of insight from parents as well (*1:* hmm) and you get to listen to them and to hear they're often quite anxious themselves parents (*1:* hmm) so I think another positive is that they get to meet you (*1:* hmm) often before you do the ADOS and they know that you you know you're a nice human being I suppose (*1 simultaneously:* yeah no you're real hmm) kind of you know you're real and you're not a scary psychologists and (*1:* hmm) and what that term might mean to people (*1:* hmm) and also they by bei by being heard you know they feel better about things as well because a lot of cases that we deal with when we do our ADOSes are the ones where the paediatrician's really not sure (*1:* okay) so sometimes the parents haven't felt heard or um they're unsure about their views so (*1:* hmm) and I think for them to have that voice is just a really important part of the process

*Person 1:* unsure about their views in what way

*Person 2:* so I think I think it's really quite complex and multifaceted (*1:* hmm) how parent's get to the point when they agree or decide or whatever word you might want to use to go for (*1:* hmm) an assessment (*1:* hmm) um and I think you've almost if you agree to go to an assessment so whether school's persuaded you or you've come to that conclusion yourself I think you've had to go through a journey and you've had to come to terms with the potential that your child to whatever degree may not be as you expected them to be (*1:* hmm) and all

those hopes and dreams you know when you're pregnant and when they're growing up (1: absolutely yeah) and again I mean there's lots of high functioning autistic people and then there isn't you know so the this does have other sort of levels (1: hmm) and degrees in it as well (1: hmm) but so some parents coming back to the original point some parents may feel unsure about their views because they may not even want them to be true (1: hmm) if that makes sense (1: yeah) I think (1: yeah) or they may feel that professionals have had a different view (1: hmm) and that theirs isn't as powerful or as right (1: hmm) or you get other parents who actually feel very strongly that their views are right and they've been told differently by the people and they feel quite angry about that (1: yeah) so there is there's lots that goes on I think in that process of diagnosis

Person 1: definitely and and just saying that about being angry so just going down see so have you noticed differences then between parents so just a reminder of the actual the title so it's it's what's driving parents to believe that their children have autism in cases that we don't as EPs don't actually that think that they are autism with regards to that and as you said just then about parents being ang some parents being angry have you noticed any differences between parents who seek a diagnosis when their child doesn't have obvious traits as per the ADOS to those that do have so does that make sense

Person 2: yeah I see what you mean so do I notice a difference in the parents sort of levels of anger (1 simultaneously: a just all of it) or or or

Person 1: so you've mentioned anxiety (2: yep) anger (2: yep) just the whole the way just the way that they are I suppose their approach so those that that their child does come out as being (2: hmm quite strongly autistic) or eh well just being on the on the spectrum (2: yeah yeah) or those that which is what my research is (2: hmm) going for those that the the children (2: aren't) when we see them we're like they they're not (2: they're not) so do you have you noticed a difference with those types of parents

Person 2: yeah so I suppose I I suppose not oh sorry not (1: that's alright) necessarily with anxiety I think both sets of parents can actually be quite anxious about what's (1: hmm) happening and what's going on but I think the ones whose children you know we may think actually they're not on the autistic spectrum (1: hmm) those parents can be angry they can feel the system's failed them and it may not be they think they fai that the system's failed them because they haven't got a diagnosis of autism (1: hm) it may be that that actually they really feel that something isn't right they're really struggling to cope and they're feeling that the system isn't supporting them (1: hmm) um and the way they would like the system to support them is is to get a label to help them understand (1: hmm) um and give them some some sort of support in the home (1: hmm) you know for them to be able to cope and manage because often the behaviours in the home that's what's driving it (1: hmm) it's normally about some very difficult behaviours in the home (1: yeah) they that the parents are struggling to cope with (1: hmm) that's probably does that answer your question

Person 1: yeah no (2: yeah) absolutely absolutely so with regards to that what do you ah what are you f what do you feel about the parents so if it's something you just said about it's it's things in the home feeling angry and not heard (2: yeah) which must be really difficult for them what do you feel what do you think are the reasons that the parents believe that their child is demonstrating these traits and therefore they're putting it within child so I'm really trying to explore our beliefs (2 simultaneously: my beliefs) of why that yeah yeah (2: okay that's really interesting)

*Person 2:* um I mean my belief as to why parents are doing that I would say and I it it it it is a belief that I have but I'm always willing to be challenged on it is that parents are for whatever reason having some very difficult behaviour from that young person in the home and they're finding it incredibly difficult to manage and cope and actually they want a reason for that that isn't about them (*1:* hmm) they want a like this chi my child is autistic that's why they behave like that so therefore it kind of reneges responsibility (*1:* hmm) some parental responsibility (*1:* hmm) that's quite harsh view I know it is but I know it's not always the case (*1:* no) but I think that there is a wide range of parenting styles out there that are very very good for a wide range of young people but if you get a parenting style for some young people they don't match and that's perhaps (*1:* hmm) why you'll get some of those behaviours for example a lack of routine um a lack of sort of um if some young people they may not be autistic but they may have sensory difficulties they may f (*1:* yeah) still find pressures just hard maybe that actually that isn't present in them it's quite chaotic home life (*1:* hmm) and actually that's giving those behaviours that they just want to label they just want (*1:* hmm) yeah potentially

*Parent 1:* so it's more to do you think it's more to do with then how they can then cope if a label's given or how they're perceived what do you so do you think it's an in or an outward uh that's not even making sense (*2 simultaneously:* no it is making sense) do you know what I mean yeah (*2:* yeah definitely um *sigh* do you know what I d) so you know whether it's whether that will help them (*2:* yeah) to cope or whether it is for perceptions

*Person 2:* yeah so whether it's actually helping them cope or or it is (*1:* hmm) their how they see the world to perceive them I mean I think it's probably a bit of both (*1:* okay) but I think if the reality for them would be that nothing changed with a label I don't think they understand that (*1:* hmm) so

*Person 1:* so maybe they don't have as much insight in to what they th th the am I right in thinking that you're saying if they get a label they think everything's going to be okay type thing so maybe they have some lack of insight into what it actually means to get a label

*Person 2:* yeah (*1:* hmm) I think that's it

*Person 1:* so in your f in your view then if if that could be w what would you see that would be of help then to (*2:* to the parents) to the parents yeah (*2:* yeah)

*Person 2:* so to have a label I think they think that with a label they they'll be able to manage that behaviour better (*1:* hm hm) they'll get more resources more support but I think what they don't realise is that actually just getting a label doesn't bring all the support (*1:* hmm) getting a label yes it brings understanding but it means you've got to do more work (*1:* hmm) if that makes sense (*1:* hmm) and you've got to put in place the environmental strategies there's no magic cure or (*1:* yeah) you know it's not like (*1:* yeah) you can go to the doctors and get a blood test and then get some pills (*1:* hmm) you know it's actually quite quite a complex social environment where changes need to be made that are potentially really quite hard (*1:* yeah) and an initially would be a lot of hard work (*1:* hmm) short term pain for long term gain sort of thing

*Person 1:* so with that in mind of of like helping the home then I suppose is what maybe drives your I think right in that a lot of parents feel that it's that to get that help (*2:* yes) so is

there you know to go through cos it must be er difficult going through the ADOS process (2: yes) is so there anything that you you think of in a professional capacity we could do to help earlier or

Person 2: I think one of my passions is about um parental understanding and giving parents knowledge and (1: hmm) understanding of childhood development (1: hmm) um and sort of psychoeducational side of things (1: yeah) um and how you know the whole thing how emotions develop um cognitively we develop socially do we develop that (1: hmm) whole thing and um where and what might potentially go wrong essentially (1: hmm) or not be you know developmentally atypical you know (1: hmm) that sort of thing and I think that we need to provide training and support for parents I'll be honest (1: yeah) I really do it's about imparting knowledge (1: yeah) and with knowledge comes understanding (1: hmm) um and with that they'll feel supported they'll have an understanding of their behaviours maybe strategies that they might be able to implement and the younger you do that (1: hm) the less severe those behaviours will be (1: absolutely) um so I would say an early identification perhaps in nursery settings (1: yeah) of parents EP training set up around parental anxiety as well parental anxiety child development social emotional behavioural side (1: hmm) would be probably fantastic I think (1: I think it would yeah) yeah (1: so cost effective as well simultaneously: when you think about it) it would be so cost effective and EP drop in sessions for parents in nurseries and pre-schools (1: yeah) you know just to have a chance to talk and to problem solve you know it's basic simple strategies that are our bread and butter (1: hm) the parents can use in the home or try to use in the home (1: yeah) um actually will you know alleviate some of these behaviours from becoming kind of entrenched (1: hmm) and habitual um because cos I also think on reflection you know that actually our behaviours as parents um are transgenerational so they learn you know from us they they watch our behaviours our reactions to things they do it and they get the same emotional reaction that we get so if we're (1: hmm) highly anxious or panicky or deh deh deh (1: hmm) that will go in to our children so it's about helping parents reflect on how they behave and what's being (1: yeah) you know just (1: yeah) become more aware of that side of things

Person 1: and I suppose in that way being done in a non-judgemental way (2 simultaneously: yeah just imparting of knowledge you know) so they can clearly see yeah

Person 2: it's things we know and you may or may not know it if you know it you probably do something about it but (1: hmm) rather than no that's wrong that's o that's the way I like to see things (1: yeah I would definitely I like the sound of that) laughs (1: keep hold of that as well) one day we'll do that (1: laugh yeah one day)

Person 1: so you've mentioned quite a few times about anxiety parental anxiety where do you think that comes from the anxiety

Person 2: um feelings of guilt failure like I would say (1: hmm) um i it's a fundamental having a child is a fundamental part of who you are isn't it I think um (1: definitely) yeah and when you feel you aren't parenting as well or you've done something wrong or you've you might feel I'm using these words may not be you know my view but you may think there's something wrong with my child gasps what is going (1: yeah yeah) you know all those kind of fro cognitive kind of things flying through your mind (1: hmm) will evoke those sort of reactions of guilt (1: hmm) shame anxiety and then will lead (1: hmm) to perhaps anger at the system blaming you know (1: yeah) it's quite difficult isn't it it's quite complex I think (1: yeah)

Person 1: and and going back to then thinking it's easy to place it in their child rather than (2: external that's it yeah) hmm rather (2: rather) rather than (2: I thin) this is my fault (2: yeah)

Person 2: and I think you'll get varying des I kinda differences with that won't you with different parents and I think that will that will show up in the parents I mean some parents probably would just completely internalise and think this is awful I've done something terribly wrong (1: hmmm) it's all about you know me and what can I be doing better (1: hmm) and then others will push against the system (1: hmm) look for answers outside of the the home and yeah (1: hmm)

Person 1: I wonder what the differences in the par the two types of parents that would do that and where that comes from those that blame themselves and those that (2: externalise) externalise it

Person 2: um that would probably be family dynamics that's that would be a learnt (1: hmm) kind of think it's like an external locus of control isn't it (1: hmm) um and we teach that to our children I think (1: hmm) as well as (1: yeah) parents and how we again you know if you're driving and some oh that person over there blame them for your mistake you know (1: yeah) or if you're ac if you go oh god I did that wrong you know it's (1: yeah) it's all about us isn't it (1: family dynamics yeah) yeah definitely

Person 1: said that and intergenerational transmission of that (2: definitely) that's really interesting thank you um so um thin so going back to thinking about um so for those parents who believe their child to do be autistic and that we don't think the or they don't appear to be autistic and by the ADOS is shows that they don't meet the criteria what do you think are the common reasons for parents seeking that I think we've pretty much co we've covered that anyway though haven't we

Person 2: ask me it if I might have some

Person 1: so what are the common reasons for parents seeking an autism diagnosis

Person 2: yeah I think I think yeah we have covered it (1: hmm) I think it's (1: there's nothing else that) that I might think of to eliminate it (1: hmm) potentially (1: okay) that might be one as well (1: hmm) an extra one so school have you know have said you know I think your child's autistic parents will be like no no no you know they're not at all and then they go for the ADOS just (1: hmm) to say look they haven't got it (1: right okay) I reckon that (1 simultaneously: that's interesting) could potentially be one (1: yeah) cos I have had situations where school have been quite adamant and parents have been like no (1: okay) you know and they (1: hmm) the parents have refused to go for the ADOS and refused and refused and refused (1: hmm) and then gone ahead (1: right and then it is so like so the) yeah (1: they're not) they're not (1: hmm) or you know you may have several hypotheses with about your child you may think (1: hmm) is it ADHD or is it (1: hm) ASD or you know you may have gone to the paediatrician um just and the paediatricians use process of elimination as well don't they (1: hmm) it's a medical model isn't it (1: definitely) so (1 simultaneously: yeah) yeah potentially (1: yeah thank you)



*Person 1:* so um for those parents who believe that their to their children do have ASD what do you think their hopes and fears are typically in relation to their child receiving a diagnosis I know we've covered (2: hmm) we have covered some of it by getting help and strategies do you is there anything else that you

*Person 2:* for parent the parents (1: hmm) thoughts about (1 simultaneously: what their hopes and fears are) hopes and fears obviously hopes is a magic wand (1: hmm) I think an answer (1: hmm) to make it all better I think fundamentally that underlies everything (1: hmm) um fears public perception (1: hmm) I think I have a child that's autistic (1: hmm) you know um how putting that label on the child mean's that child's gonna be perceived by school (1: hmm) by peers by people in the workplace (1: hmm) um kind of later on in their life what that means that they have had a child that's autistic what does that mean about you (1: about them hmm) if I have given birth to created a child that's autistic (1: hmm) and I mean it depends on the parents views like do they just think about it as neurodiversity and they look at the strengths of the young person or do think of it as a deficit (1: hmm) or a difficulty or you know how that goes and also cultural so (1: hmm) in um my one of my best friends is Greek is Cypriot (1: hmm) and in the Greek culture also worked with another family actually in my job in the Greek culture it's really looked down upon and the Indian I think for to have a child with special needs (1: hmm) so you're almost ostracised by your (1: hmm) kind of family and community groups so it depends how your culture views it as well (1: yeah) that would be very difficult about whether you went for the diagnosis to get it in the first place or if you did get it how you would tell family and friends

*Person 1:* so for those that do seeking to get it what do you think that their hopes and fears then are

*Person 2:* with um severely in from cultures that find (1: yeah I mean that's a really in cos that hasn't been brought up yet) I know (1: yeah the cultural) yeah (1: aspect of it) um I I cant I mean I can only mind read and project (1: hmm) you know I mean I have worked with a family a an Indian family who whose son was severely autistic he was non-verbal (1: hmm) so they had to kind of go for that diagnosis they had to get it investigated is that it (1: it is tough isn't it) yeah (1: yeah) it took quite a long time for them to kind of go for that process and they don't live anywhere near their family now (1: hmm) um I would ho I would imagine that their hopes might be understanding from their family if they (1: yeah) get the the label (1: yeah) and share that (1: hmm) you know and say this is what he's got you know and try and educate that (1: hmm) kind of cultural view and if they live within an English culture which is is more accepting (1: yeah) mostly you know I can't generalise can I (1: hmm) but it's yeah so

*Person 1:* that is a really impo interesting point I well worked with somebody the same from an Indian they just really struggling and just the shame and everything (2: hm) that comes from is so sad and then the suppor the lack of support they're then getting because they're not going out to (2: no) tell anybody (2: yeah) it's really sad um okay so have you noticed any differences I think we did we did speak about that didn't we earlier sorry I'm going back and forth okay so um thinking about we spoke about differences between parents who seek a diagnosis when their child doesn't have obvious traits as per the ADOS and those that do so what thoughts do you have about these differences the reasons behind these differences these the questions are really sort of like yeah

*Person 2:* what why parents some parents do seek it and (*I:* yeah) some parents don't (*I:* yeah) why do I think of the diff the reasons ah I think it's capacity probably and it's that safety net your family safety net um and support network that you you've got (*I:* hmm) about whether you feel you can cope with it (*I:* hmm) or whether actually you don't and you need some help and you you seek to find to find that help through the state really essentially (*I:* hmm) and through a medical model (*I:* yeah) um po potentially also when there's been other incidents genetic in the family so oh my you often hear my um my father's autistic or (*I:* hmm) his uncle's autistic or you know so and they're noticing characteristics and kind of wanting to go cos it cos it there is a genetic link isn't there it's been (*I:* hmm) proven so I think perhaps things like that could influence them as well (*I:* yeah) um (*I:* and help to explain the behaviours) yeah (*I:* that they're seeing to then thinking oh well that's the same) that happened with so and that worked (*I:* yeah) I also think parents have a lack of understanding that actually you can change environmental factors without getting a diagnosis and actually they can do all those changes can really implement change (*I:* hmm) and you don't necessarily need that (*I:* the diagnosis) yeah I think (*I:* and that goes again back to that early intervention doesn't it and and just *simultaneously* cycle education) an understanding (*I:* yeah) yeah I think I don't know whether parents think this I would think this I so I imagine some parents will if you go for an autistic diag autism diagnosis your child doesn't isn't really giving informed consent for that (*I:* hmm) but yet they're gonna get a lifelong label (*I:* hmm) so I'm sure some parents probably do think that so you it's quite a big decision for you because can you take that back (*I simultaneously:* hmm) you know when they get older and they display less symptoms would they want that labelled would they be angry (*I:* hmm) they've been had that label so you know you're making quite a an important decision for a young person's life (*I:* definitely yeah) um and where do they have to show that on medical forms life insurance holiday insur you know *clears throat* so I think there's there's quite a lot to think about isn't there I (*I simultaneously:* there is) spouse

*Person 1:* isn't there and how society treats them (*2:* hm) knowing that that person has that diagnosis how society treats them (*2:* job applications) yeah just everything school (*2:* yep) everything um so do you think that come do you think that that comes into it with parents at all do you think they do think about that

*Person 2:* I'd hope so (*I:* yeah) I think some probably do (*I:* hmm) I think some are probably so caught up in reactive and trying to cope that they (*I:* hmm) are just desperately looking for some help from somewhere (*I:* hmm) um they're probably not thinking they're living in the moment (*I:* hmm) but I think some for some parents yeah I'm sure they do (*I:* hmm) think kind of long term think it think it through

*Person 1:* hmm must be tough mustn't it (*2:* yeah) um okay so yeah my last um question so what do you think the implications are for parents seeking a diagnosis and then their child not receiving one

*Person 2:* ooh the implications uh well initially I think there'd be an emotional reaction wouldn't there from parents some parents be relieved (*I:* hmm) that's great some parents be angry or feel let down by the system (*I:* hmm) um not heard um and then potentially there'll be an impact in that family what other support do they get (*I:* hmm) cos they clearly need some support some families that go through this (*I:* hmm) that's why it's a cry for help isn't it (*I:* yeah) so they're not getting the support then there's a need in the family isn't there and the behaviours that are being shown is that impacting on family life siblings parents wider family how's that impacting on the school if it's an undiagnosed need (*I:* hmm) not necessarily autism but another undiagnosed need what's the behaviour like in school is that

young person missing out in school is it going to lead to school refusal (1: hmm) so the impacts could be huge (1: hmm) or not very much (1: yeah) it really depends doesn't it (1: hmm) on on the presenting behaviours really I think (1: yeah) and whether they escalate especially when you got that transition to secondary (1: yeah yeah absolutely) yeah that can really blow up can't it (1: hmm) so there's a lot of crossover between high levels of anxiety and and ASD (1: yeah) and it can be linked and sometimes the behaviours are actually just anxiety and not the ASD and then (1: hmm) but those highly anxious young people and they hence at secondary school that can be very very challenging (1: yeah) and what support can they ha get and how can you support the parents (1: hmm) so yes does that answer the question

Person 1: um yeah I mean I could that comes to anxiety doesn't it and the children's high anxiety I mean what's your perceptions of the reasons behind those children shar sha having such high anxiety that it's being misread as (2 *simultaneously*: as ASD) autism yeah (2: um) by paediatricians as well cos as you say (2: oh yea yea yea) like the fact (2: yeah) um the ones that the ADOS you do where the paediatrician's not quite sure so yeah what are your what are your views on

Person 2: um I think um it's probably learnt within a fam family behaviours (1: hmm) high levels of anxiety um so it could be learned as from having high highly anxious parents or it could be due to traumatic events (1: hmm) wouldn't it and things like that so because anxiety comes from many different causes (1: hmm) and um sometimes there's there's a there's an interesting piece of work that Warren has done on an Warren from CAMHS (1: okay) um I don't know if you've read it Space (1: no) Space trial and um basically there's a theory that um parents in modern society often can make what we call accommodations for their children who are anxious (1: hmm) and or where we might view accommodations as a positive thing it's not viewed it's more about colluding so basically or um enabling (1: hmm) so if a child is anxious about something the parents will take steps so they don't have to experience it (1: hmm) so um which obviously as parents who want the best for our children we feel like we are doing the right thing (1: hmm) but children actually need to be sad they need to experience anxiety in safe kind of contained way (1: hmm) and they need to have experiences which will provoke anxiety and we need to help them manage that to build resilience (1: hmm) and then to build healthy you know individuals um and actually that isn't they're ah that's especially in some of the schools I work in that isn't always happening (1: hmm) and then what then happens is they then don't wanna go to school or they don't wanna go to that lesson or they don't want to do this (1: hmm) and the parents don't want to see them des what they see as distressed or anxious (1: hmm) so again they kind of allow that to happen (1: hmm) whereas actually I think as parents we probably need some understanding about emotions and you know it's health we're all going to be sad or we're going to get anxious we're going to be frightened we're gonna be (1: hmm) angry and they're all okay (1: hmm) it's how we kind of help children work through that really we can't (1: yeah) take them away cos they're gonna be adults one day and they need to experience that and have the resilience to (1: hmm) to deal with it so I think coming from a an interesting what did you say cultural (1: hmm) something societal (1: yeah) change in parenting potentially

Person 1: yeah I have a friend of mine who works at a school and they ca call it snow ploughing (2: okay) parents doing the snow ploughing (2: yeah) yeah so they just like pushing away any worries (2: yeah) or any you know any adverse experiences (2: yeah)



*Person 2:* and what does the young person learn about that well I can't cope with anything like that that's bad (*I:* yeah) mum'll take it away

*Person 1:* yeah (*I:* but yeah) and then perhaps the rather than so am I right in thin rather than the parents then realising what they're doing and their child's showing these behaviours they're then then saying well it must be autism or something like that rather than (*I:* potentially) hmm

*Person 2:* yeah rather than perhaps challenging with some of the you know som just life's normal anxiety (*I:* yeah) so Warren's got an intervention where he uhh challenges that belief and (*I:* okay) he will sort of coach parents to say you know things like I believe you can do this you know you're gonna go to school today and you can phone me once at lunchtime and text me in the afternoon and that's all you're gonna do (*I:* hm hm) no that's all I'll accept and the children respond from that and he's had more success in reducing anxiety than with CBT (*I:* really) hm hm (*I:* blimey) and I wanna find out more *laughs*

*Person 1:* I've just written down (*2:* I know) to ask you about it afterwards (*2:* I know) I wanna know more (*2:* yeah)

*Person 2:* I'm gonna ask Andrew about it because I think he so it's new to the CAMHS service but I think it's something that we need to know as EPs (*1 simultaneously:* oh my goodness yeah) in all secondary schools I bet you could think about parents (*I:* oh god yeah name several of them) hm hm (*I:* just yeah wow)

*Person 1:* but anyway that's really interesting (*2:* yeah)

*Person 2:* so yeah that's my views at the moment about anxiety apart from those children that have experienced trauma um and their behaviour actually again is potentially very similar to autism (*I:* hmm) but their reasons for their behaviour or their high anxiety is obviously different isn't it because (*I:* hmm) the life experiences they've had the abuse (*I:* hmm) as a young person so (*I:* yeah) and that's different

*Person 1:* and so in that respect is I mean the parents wanting it to be autism again rather than to externalise it rather than yeah

*Person 2:* g have an answer I think the medical profession could collude a bit you know because um I was at a multiagency meeting about a young person who was severely traumatised (*I:* hmm) she was in year three um and um she presented as a cat so she would be she thought she was a cat and these were her sort of presenting behaviours (*I:* hmm) because of the traumatic experiences she'd had so obviously psychologically she was really quite damaged (*I:* hmm) and um the doctor that was there on the multiagency meeting wanted to do an ADOS to eliminate um the fact that it could be autism whereas I would professionally challenge that because actually the behaviours are presented in a severely traumatised individual (*I:* hmm) would be probably very similar (*I:* hmm) and she probably would pass I could tell them now she'd probably pass the ADOS but it doesn't necessarily mean she's got it uh autism

*Person 1:* yeah yeah and actually how fit for purpose would the ADOS be in that situation cos that child's not gonna be able to really engage with it are they (*I:* no)

Person 2: but which in itself would present with severe autism potentially so I think the way we see the world and the way the medical profession see the world is quite different so I think it's a really positive thing that we actually get involved in the ADOSes (1: usually yeah hugely) yeah so got medical still very much diagnosis you know much like how you know we'll take a blood test we could diagnose that you know we'll give an ADOS we could diagnose that whereas actually many more factors that need to be kind of taken into account and considered (1: hmm) I think (1: hmm)

Person 1: okay and that's a whole other research project (2: is it okay) *both laugh*

Person 2: you're doing another one *both laugh*

Person 1: well thank you very much very (2: no its that okay) helpful that's lovely thank you (2: good I hope you've got enough)

## Appendix 13 : Transcript Interview 4

Educational Psychology research transcript – 4<sup>th</sup>

Interviewer = person 1 = 1 (in interjections e.g. hmm)

Interviewee = person 2 = 2 (in interjections e.g. hmm)

*Person 1:* okay well thank you for taking the time to do this hopefully it won't the the m it's been taking about 45 minutes something like that (*2:* that's fine yeah) okay so it's just a reminder so my title for it keeps changing a little bit and it's it's it's getting more condensed it was really long title but at the moment its um what are the context and mechanisms that drive parents to misread their child's behaviour as being related to autism (*2:* okay) so that's what we're going with at the moment so my first question is can you describe some of the up's and downs of conducting the par parental interview element of the ADOS so when you meet with the parents and

*Person 2:* um *pause* the ups and downs um so some parents they bring their own anxiety (*1:* hm hm) to it and it's their their anxiety perhaps that's driving (*1:* yep) some of it um I had a case of that the uh ADOS I did last week where I would say it's about parenting and parents parental anxiety feeding this young girl's very significant anxiety (*1:* yeah) um I think um the upside of doing it in school is that you're not in the clinic setting and sometimes (*1:* yeah) you get more information out of it (*1:* hmm) um I always do more I always take the whole go back and ask what happened before um some parents are really informed some aren't (*1:* hmm) sometimes the more informed ones it's not helpful (*1:* hmm) um yeah I think it it I think sometimes parents are just looking for a label and they will come with a list of all the stuff that's gone wrong (*1:* yeah) I also think sometimes they want someone just to listen because things at home aren't good (*1:* hmm) and it isn't necessarily around autism but there's no one else listening to give them support at home

*Person 1:* yeah and feeling isolated and yeah the needing to be heard yeah it's interesting the the first two things that you're saying about so my interviews my my questions have changed cos I'm doing a grounded theory so looking at what's what's coming out and my next question well one of the questions was some other people that I've interviewed have mentioned about parental anxiety being a contributing factor for parent's misreading the child's behaviour so what are your thoughts on this what do you think might be behind that

*Person 2:* I think there's a lot of anxiety about getting it right and children being a certain way (*1:* hmm) um I think parents bring their own experiences to their own upbringing to (*1:* hmm) their parenting I think they want a reason why a child might not be behaving (*1:* hmm) um and als they want a quick fix they don't you know when you say to them well have you tried these things oh well we tried it and it didn't work (*1:* yeah) and and that's often what you get oh we tried it and it didn't work it's got to be (*1:* try it maybe once and) yeah or they've tried it for a couple of days and got bored with it (*1:* yeah) um yeah (*1:* not getting the quick fix) yeah (*1:* that you're talking about but yeah) or they've tried they've been doing it for a while it worked and the child's got bored with it and they've not (*1:* yeah) thought to change it up (*1:* yeah yeah) um I think some parents feel quite deskilled and don't (*1:* hmm) because of their own anxiety (*1:* hmm) don't feel they have the skills to parent but also it's about very different parenting styles I have it within a friend a very good friend of mine her two children have issues (*1:* hmm) one could possibly be spectrum the other one is it is pure

behaviour and (*L*: yeah) they're not dealing with it he is very authoritarian she's kind of oh you shouldn't do that but come have a cookie (*L*: *laugh* very indulgent) yeah (*L*: yeah) so I I I think I think when you've got p parents who don't parent together (*L*: hmm) and who or who have very different parenting styles (*L*: hmm) and can't find a common ground that doesn't help (*L*: yeah) I also think parents just want to label because then it's not them (*L*: yep yeah) um and it's not their fault (*L*: yeah) um yeah

*Person 1*: absolutely that that leads into my next one saying what do you think leads parents to place difficulties as being within child and seem to have a blindness to external reasons (*2*: they're not wanna) with children

*Person 2*: they're not wanna look at themselves (*L*: hmm) they don't want to look at things that they may not be doing right that they've done wrong you know what you there there's a lot of guilt in parenting isn't there and feeling guilty (*L*: hugely) you know you've done it wrong or (*L*: yeah) you've screwed them up or you've done this (*L*: yeah) um and you know a lot of parents are looking for a reason (*L*: hmm) for why um but they want it that to be the child uh the child is the problem (*L*: yeah) not well what's going on around that could be the problem

*Person 1*: what do you thi what do you think that I there is that anxiety comes from then do you think that anxiety is a within the parent or is it anxiety about being a parent but the that does that make sense

*Person 2*: I think it's both (*L*: yeah) I think some of it is you have very anxious parents who are clearly (*L*: hmm) anxious within themselves (*L*: yeah) and so yeah really struggle with anxiety (*L*: hmm) and but then on the flipside uh and I'm not saying that that parenting's harder than it ever was but in some ways it is (*L*: hmm) I don't think social media helps (*L*: yeah) and there's this expectation of what a parent should be (*L*: hm hm) the the news and information that's out there raises parental anxiety (*L*: yeah) things like you know we were talking about this at uh with some friends at the weekend there were always kids that were taken kidnapped whatever (*L*: hm hm) but you didn't (*L*: you're more aware of it) you're more aware of it because it's it's sensationalised and you have 24 hour news (*L*: hmm) so you can't get away from it you know where even from when I was a kid you know you had you had the 6 o'clock news and the 10 o'clock news now it's (*L*: yeah) you know whereas now you've got rolling news all day every day (*L*: flashes coming up on) yeah (*L*: your phone and things) yeah I've just had four alerts of different things that have happened today (*L*: hmm) if I hear one more thing about Brexit (*L*: *laughing simultaneously to talking*) I may just delete every app there is about news but whatever um but I I think I do think I think some of it is in inbuilt parental anxiety (*L*: hmm) but I do think there's a lot of pressure on parenting you know there is the gossip at the school gates which (*L*: hmm) can have a real impact um the social media and there's media (*L*: hmm) presentation of what a parent should look like (*L*: hmm) and what a parent should do and you know a lot of parents have to work it's the reality like (*L*: yep) you can't survive without it (*L*: hmm) and I think that builds anxiety and feelings of guilt and all of that which often I think gets passed on to the child without you realising

*Person 1*: hmm and the link between parental anxiety a then going on into the child as well but I suppose the guilt that would come from that (*2*: yeah) if they were aware of that of it actually being (*2*: and also I think) passed on to the child

*Person 2:* children spend eh the it has changed to with the the rise of technology life has changed (*1:* hmm) and you know we see a lot of that don't we with kids coming in without the language skills (*1:* yep) because families don't talk they're shoved on the iPad (*1:* hmm) you know they have the iPad or the phone at dinner ah (*1:* hmm) you know you'll go out to a restaurant now won't you we were out in a restaurant at Chr Christmas Eve with friends with family and on the other table there was a massive group of them and all the kids had headphones and iPads

*Person 1:* probably to keep them quiet just to

*Person 2:* but like (*1:* yeah) what's the point why go you know whereas our kids were drawing colouring yeah okay they were playing on the floor a little bit with cars but still (*1:* hmm) they and thy were interacting with us (*1:* yep) we we wouldn't they weren't allowed to have any technology at the table (*1:* yeah) because (*1:* yeah) there isn't those interactions anymore so kids are becoming much more insular (*1:* hmm) but that's just my my thoughts on it

*Person 1:* no definitely it's really interesting isn't it so they're not having that interaction so they're not (*2 simultaneously:* not open to developing the social skills and they're not building those social skills and) being the parenting's not going on either are they yeah

*Person 2:* not seeing those social interactions (*1:* hmm) and how they negotiate that you know they're watching a screen and what happens is the screen doesn't emulate what's in real life (*1:* yep) I think that that's particularly true of older um children you know (*1:* hmm *simultaneously* games and things) seven eight nine (*1:* yeah) young but younger but younger ones as well parents aren't there there isn't that interaction as much

*Person 1:* no so I suppose then they take that off and then (*2:* yeah) and parents try to parent and the parents doesn't want any of (*2:* yeah) it and yeah cos they're not used to those interactions

*Person 2:* and there is that there is that link isn't there between screen time and behaviour (*1:* hmm) um yeah and I certainly have seen it with friends' kids where you know they take the iPad off them and they go nuts (*1:* hmm um and then what's the easiest thing to do) give them the iPad back

*Person 1:* give it back yeah exactly and then (*2:* yeah) not see that as anything (*2:* yeah) other than something wrong with the child (*2:* yeah) yeah (*2:* yeah)

*Person 2:* I think it's it's easier isn't it it's easier to project onto some it's someone else's fault it's something about them that's the wrong then to then to be self-critical (*1:* yeah) cos no one likes to think they're getting it wrong do they

*Person 1:* no no and to see it as a negative other than (*2:* yeah) being able to be reflective and to and to take it on the chin and think okay what m what can I do about that

*Person 2:* but people aren't encouraged to be reflective it's (*1:* no) it's to be self-critical (*1:* yeah) what have I done wrong (*1:* yeah) not okay well this has happened how may I have done that differently it's that (*1:* yeah) reframing and most people don't do that

Person 1: they don't but society doesn't doesn't (2: no) that (2: no no)

Person 2: we're not encouraged (1: encouraged) to do it no we're encouraged to you know beat ourselves up because we're getting it wrong (1: yeah) not

Person 1: so the basically the best thing is to do is to defend against that (2: yep) and to put it out onto

Person 2: well your best defence and offence is someone else has done that wrong

Person 1: yeah that's really interesting is that is that that whole reflection that we're not encouraged to do it at all (2: no we're not) hmm yeah thank you so um I I've already asked the next one then so (2: okay) um what sort of uh sorry I think I've asked this one as well really what sorts of things do you think they're anxious about and why

Person 2: their kids achieving having friends being li being part of society them being seen as being a good parent (1: hmm) t then having the right things the right look the right (1: hmm) you know being part of (1: hmm) um and you know there's gotta if it doesn't go right well there's a reason why and that's within the child (1: hmm)

Person 1: hmm um and what do you think so to think of the reasons say there's got to be a reason why so do you think that comes internally driven or do you think that's because of perceived judgement from others both

Person 2: I think perceived judgement sometimes from others (1: hmm) um and and people do people judge you know as much as they say they don't people do people judge all the time (1: yeah) um (1: we all do don't we) yeah we all do it (1: even I find myself doing it and I think) yeah (1: yeah) and you know that whole thing about you know be kind you don't you you know you don't know what's going on in someone else's life be kind always (1: hmm) because you don't you have no idea what that parent's going through (1: yeah) you know the people who come up and you know say well your child shouldn't be in the supermarket because they're having a paddy in the middle of the (1: hmm) the sweet aisle (1: hmm) who you know who hasn't been there (1: yeah absolutely we just spoke about if you got other things going on in your life as well) yep yeah (1: yeah) so I think I do think there is more anxiety out there now because (1: hmm) there's a lot more to worry about um but al I do think there's a lot of judgement in society against parents (1: hmm) and

Person 1: do you think that comes more from older generations or (2: yeah) or for everybody

Person 2: um I think a lot comes from older generations but I do think our own generations are quite critical of the (1: hmm) of our peers (1: hmm) ugh why are they letting them do that (1: yeah yeah) yeah so I I think I do think the older generation because it was you know children weren't seen or heard you know they weren't (1: it was different back then wasn't it) yeah you just (1: hmm) you got a slap on the side of your head and you just sat down (1: laugh yeah) um

Person 1: but there wasn't the social media (2: no) and the technology

Person 2: no and kids were out and they had to socialise and (1: hmm) they had to learn how to socialise (1: hmm) and children and young people and adults with autism didn't weren't



shown they didn't you didn't see them (1: hmm) you know if I think back now to we had a special needs class in every year group in our school (1: hm hm) so it was a class of eight or nine students that were taught in the school that (1: hmm) that were the es were the special needs class (1: hmm) and if I think now I say probably half of them were autistic (1: hmm) and if I even if I think about ones in my year group I can identify people that I think now who probably were on the spectrum (1: hmm) um but it just wasn't talked about and it just they were the (1: hm) quirky ones that they were the ones who didn't really have friends didn't (1: yeah) you know they were kind of on the fringes or they hung out with the geek group or they were in the you know the that class (1: hmm) you know it would have been the handicap class back then (1: yeah yeah yeah) so

Person 1: um okay so another thing that's arisen which obviously you've mentioned is in relation to parenting so what are your thoughts on this being reasons to misread child's behaviour as autism

Person 2: I don't think people ask questi ask for help as much there isn't the older generations to ask (1: yeah) necessarily you know there isn't that nuclear family always (1: hmm) to go back to (1: hmm) to ask questions a lot again social media you know they ask in the wrong places for information (1: hmm) um and some of these groups online are just you just think oh my god you know I follow I I follow it from when the girls were little u um a baby group (1: yeah) that people ask questions and some of the comments you get you just think whoa why are you asking this on social media (1: really) yeah (1: like can you give an example) um well this one was saying about she wanted to move from exclusively breastfeeding moving towards formula feeding (1: hmm) and some of the why would you do that you know this whole the whole beating up breast is best and then others saying I think formula's the best thing ever and you know and you get really really conflicting information

Person 1: and that whole thing of being on in um not actually face to face (2: yeah) people would say things that they they (2: yeah *simultaneously* wouldn't even dream of) wouldn't normally do yeah

Person 2: you know there's stuff online you you just wouldn't dream of saying to (1: hmm) someone's face um I so I think there isn't those role models perhaps now that (1: yeah) there were years ago and I'm not saying they were great role models then but you at least had something (1: yeah) to model on (1: yeah) or you had aunts and uncles that you could look at you know there isn't so much (1: hmm) that anymore (1: hmm) and you know for a variety of reasons there isn't a nuclear family anymore family (1: hm hm) life has changed and what families look like has changed (1: yeah) so there's different there's all that that brings to it um and and I don't think I think people just think oh have children and there isn't the consequence there isn't thinking about the consequences or (1: hmm) think about what might happen what could happen what you know planning for it (1: yeah) um you know I think it's just this expectation you you get married or you're in a relationship and you have a kid

Person 1: you'll just know what to do (2: yeah) yeah

Person 2: and you don't like I didn't have a freaking clue *both laugh*

Person 1: I remember saying to my kids and my husband at the time going this doesn't come with a handbook (2: no) I wish it came with a handbook

*Person 2:* nope doesn't come with a manual I you know I don't have a clue half the time (*L:* yeah) I'm winging it (*L:* yeah) a lot of the time (*L:* yeah but I spose we it's what comes instinctively you're parenting in an instinctive way) you do in an and some people don't have don't have those inbuilt instincts or those their inbuilt instincts are coloured by their own experiences (*L:* yeah) which ness aren't necessarily you know positive as we see with looked after children (*L:* yeah) who then go on to be parents themselves (*L:* hmm) and I think if I'm right the research shows that a high proportion of those who've been in care who go on to be parents their own children end up with social services involvement or in (*L:* really) care (*L:* yeah) um you know it's much higher than the the general population (*L:* hmm) because they haven't had the role models to (*L:* no) parent from so I think there is a loss of role models I think there's a lack of asking for help a lask (*L:* hmm) a lack of a lack of asking for support and it's a la it's looking for in the wrong places (*L:* like within um *simultaneously* peer groups) like social media

*Person 1:* and social media and things like that yeah and you also mentioned I spose it's a lack of knowledge in the about the different parenting styles as well isn't it because like you say if you get one that's an authoritarian (*2:* yep) parent and the other that's an indulgent parenting (*2:* yep) um (*2:* and the two don't mix) yeah

*Person 2:* um so through in the example of my friends son the younger one *pause* um he's a nightmare (*L:* yeah) his behaviour is really challenging (*L:* hmm) but when she's challenged on it oh yeah it's really difficult but they shouldn't have done that you know that group of children shouldn't have talked to him like that (*L:* right okay yeah) so we get yeah (*L:* *simultaneously:* it's that than external factors again) the whole yep yeah (*L:* yeah) but yeah the the dad he comes from quite a uh a a difficult background boarding school military *shooting noise* (*L:* so authoritarian background) yeah or he's either way he's either really authoritarian (*L:* hmm) or really soft there's no middle ground (*L:* okay) so they never quite know what they're gonna get (*L:* yeah so it's always worth pushing it then isn't it) yeah

*Person 1:* because you might get the non-authoritarian (*2:* yeah) dad (*2:* yeah) yeah

*Person 2:* so I think that there's I I don't think we have the same links that we had before that helped with parenting (*L:* hmm) um yeah and also I think you know with the rise in IVF and things (*L:* hm hm) you get parents who then are incredibly precious because that's a gift they didn't think they'd have (*L:* hmm) so you you get that with parents too where there's been a and I've had that numerous times where y you're trying to work it out and then someone says oh well they were IVF and you're like (*both:* ahhh) (*L:* yeah) that that's why (*L:* yeah) so I think th but I do think there's the lack of parenting role models

*Person 1:* you think that's a big thing part (*2:* yeah) of it but yeah

*Person 2:* and asking for the the ri information in the wrong place and (*L:* yeah)

*Person 1:* but where could they where could they ask for that information

*Person 2:* but this is the thing we don't have a health visiting service (*L:* yeah) like we used to (*L:* yeah yeah) we don't have um you know yes there are parenting groups but there are few and far between now you know that even ten years ago there used to be a lot more than the children centres and things like (*L:* hmm) that you could access (*L:* hmm) there were



more parenting groups when I had Chloe and there were only four years between the girls (1: hmm) then there was by the time I'd had Holly (1: yeah) um yeah so

Person 1: and I suppose if a parenting group is mentioned it's always because and it's always (2: something's wrong) exactly (1: yeah) so it's seen as like um a consequence to (2: yeah) you know and then people's defences come up and (2: yeah) and it just doesn't work does it so what are your thoughts on that where um and whe what could be done about that then (2: I think) from an EP's point of view

Person 2: I think it's making it a positive experience (1: hmm) I mean I I got sent to one because of breastfeeding issues (1: hm hm) and actually it was a real lifeline because I'd go every Thursday there were other parents there there (1: hmm) were babies of all different ages (1: hmm) and it was actually quite pos (1: hm hm) you know they made toast for you and you'd have tea and (1: get some nurturing) yeah and there were two nursery nurses there who you know older women who were really supportive (1: hmm) and would offer advice if if you asked for it (1: hmm) never pushed it you didn't feel judged so I think it's all that you know I think groups it needs to be more of a positive (1: hmm) spin on this is a parenting group for just somewhere for you to go and meet other parents and have a chat bit of toast a bit of hanging out (1: yeah a bit of advice talk) a bit of grown up time for a couple of hours

Person 1: rather than it be something that felt done to them (2: yeah) you got to go on this because you're a bad parent and that's also what is often the way that it's said isn't it (2: yeah) I know there's a um a paediatrician um in Hastings that he has you know maybe a cultural thing as well but he says to has said to parents no they're not autistic it's your parenting so when it's said like that (2: yeah) defences are gonna come up (2: oh yeah) aren't they

Person 2: and he's probably right

Person 1: he probably is but there's ways and means of saying it *laughs*

Person 2: but but there are ways to go about it (1: yeah) I mean I can be quite blunt but there are times when (1 *laughs*) there are times and spaces for that (1: yeah) and that's not one of them

Person 1: it isn't so we in our role what could you see that we could we could do and well I'm I'm really passionate about this and thinking (2: hm) you know a preventative starts both at parenting and parental anxiety

Person 2: I think uh we were we've been talking about um as part one of the PIP activities (1: hmm) paren running parental anxiety (1: hmm) training and support for early years (1: yeah) but also supporting the practitioners who are often anxious themselves (1: yep) then meeting with anxious parents (1: yeah) cos it running a group to for anxious parents they won't come (1: hmm) but if we go to other things and drip feed in and if we feed (1: hmm) into the early years advisors who are going in and doing that role or the support (1: hmm) workers they're in a better place to support parents (1: yeah and get it early and yeah) I think I do think early is is good I think (1: hmm) I I it would be great if we could have more of a role in say parenting groups (1: hmm) and children's centres but that you know that's all kind of been eroded and I think that's part of the problem (1: get out in the community psychology) yeah cos we don't always get in there as early as we would like (1: yeah) cos often the point we're in is crisis (1: yeah) or the looking at diagnosis (1: yeah) or you know

so much has happened already (1: hmm) it would be great as we've talked about for many years more in the way of preventative stuff (1: hmm) and EPs I think are really well placed for that (1: massively) but it's having the time to be able to deliver that

Person 1: yeah definitely definitely I mean it's um I so it fits into my masters that I did as well I worked with uh um a professor over at Sussex who's she's a professor in child psychopathology I think (2: oh okay) it is and um and her her babies all about parental anxiety and (2: yeah) the transfer of it onto her onto her to children (2: yeah) and my masters was to do with that as well (2: oh okay) and I did speak to her about this only a couple of weeks ago um discussions with Natalie cos she said that um Andrew was gonna speak to um Warren about the Space programme (2: oh yeah) that he's been doing and that it's been found to be as efficacious as CBT (2: ookay) um so I spoke to it's Samantha Cartwright Hatton over in um at Sussex uni she's written (2: oh okay) she's written books Timid to Tiger she wrote (2: oh okay) which is a a parental um it's a guide book of how to parent (2: yeah) an an anxious children and she said you know she's certainly gave advice you know if she could and although she couldn't be directly involved she certainly give advice or anything like that because she's loads and loads of research around it and she just

Person 2: I think there's a lot to be said and I think you know uh um there is I think parents are more anxious now (1: hmm) and I think that does then transfer onto children (1: yeah) um and then they don't know what to do with it and we're telling them well you c don't be anxious but (1: hmm) we don't we don't give them the tools to not be anxious (1: yeah) you know and I think there needs to be more around things like mindfulness I think (1: hm) mindfulness is quite powerful (1: yep) um and there's not enough of it (1: hmm) um I think there's there a a um mindfulness club running in Saltdean today in the park (1: hmm) for kids from seven to twelve who may have levels of anxiety and they're doing all kinds of activities there should be more stuff like that

Person 1: y uh making it normal (2: yeah) cos people would and a lot of I suppose um a lot of narrative in in um cultural (2: hm) in in you know (2: in us) yeah oh god I don't want to be doing that (2: yeah you're crazy) yeah (2 simultaneously: saying there's something wrong with you) exactly yeah

Person 2: instead of the fact that you know for many many years I mean our gener our parent's generation they had ank they had anxiety and things (1: hmm) they just hid it in different ways (1: hmm) you know they used alcohol or they (1: yeah) self-medicated in some ways or they were (1: yeah) very angry or you know (1: yeah) they had their own issues (1: hmm) it just wasn't talked about (1: hmm) whereas now you know we're being more open about mental health (1: hmm) um but yet there is still this stigma (1: yeah) well there's something wrong you're nuts (1: yeah) but you you wouldn't think that about someone in a wheelchair or you wouldn't think that (1: hmm) about someone with a broken leg (1: hmm) but our first thing is oh it's mental health ugh (1: yeah) that again that old (1: yeah) chestnut

Person 1: yeah so we're breaking down barriers but it's still (2 simultaneously: a long way to go) mountains to go yeah

Person 2: yeah there's a long way to but you know I thought that this mindfulness day was brilliant (1: yeah) that you know and that why isn't that the norm why don't they you know and I know teachers have shedloads to do and they're not experts but why not have

mindfulness in school (1: definitely) you know on a date (1: yeah) on a a regular basis or or (1: hugely) or using some of the the elements of CBT (1: yep) you know those type of approaches that we know can be embedded into schools (1: definitely) and that's (1: yeah) why I think we have a big role that we could play (1: yeah) things like the Elsa you know (1: oh that's gonna be amazing absolutely) it's that kind of stuff (1: yeah)

Person 1: yeah and when I did um the worry bus when I was back here (2: yeah) as an assistant I did it in one school in Hastings and then I went and met the teachers and um and encouraged them to all do mindfulness and a few of the teachers did pick up on it and they did it when the ki children came back in from (2: yeah) play um playtime it was brilliant I also gave them the CBT hot cross bun (2: oh yeah) which they then put into it was (2: yeah) a year six teacher (2 simultaneously: and like zones of regulation and) that brought back together hmm

Person 2: and helping kids where are what zone are you in today (1: yeah) what does that mean and how what kind of things can you put in place to help you (1: yeah just get it being simultaneously talked about) to to get out of (1: yeah) the red and into green or yellow or whatever (1: yeah) it is (1: yeah) um I think more conversations about it (1: hmm) part of it is they're drawn they're driven by the national curriculum and we know (1: hmm) that doesn't suit purpose (1: hmm) you know the national curriculum no longer suits purpose (1: hmm) it's for a generation long ago (1: hmm) you know and it really needs updating and changing and it needs things around how to deal with technology (1: hmm) how to deal with the fallout from technology how to deal with mental health how to deal with mindfulness (1: hmm) you know to how do you use technology to support literacy and numeracy (1: hmm) it it we've evolved so much in the last even the last twenty years and education hasn't po hasn't kept up with that

Person 1: so I suppose if you then add that into what we're talking about about parents misreading (2: yep) and and children's anxiety tha the curriculum together with (2: yeah) parents being anxious and

Person 2: and kids don't have the language to say mum I'm anxious (1: hmm) mum I'm worried it's lashing out or getting you know and Chloe will do it she'll you can she's worrying about something but she's being a real little cow (1: hmm) and it's because she she doesn't know how to say to us (1: hmm) I'm really worried about this or I'm angry about so you know we use a treasure ducks with her and things and we you know we sit down and and say what's going on why why do you think (1: hmm) you mi why do you think you might be doing this but most parents wouldn't they react

Person 1: yeah they just yeah cos (2 simultaneously: yeah to be fair I react) they don't have that knowledge and those skills do they

Person 2: when I'm tired and I'm stressed I react (1: hmm) every parent does (1: hmm) so then it's all about well what's what's wrong with the child (1: yeah and it's just) just back to that whole thing of (1: yeah) um but I think we're place into doing the interventions and you know the mind you know bringing mindfulness in bringing CBT type approaches helping schools to set up mindfulness days (1: hmm) you know we're in a really good position to do that and we're also in a good position to support around parental anxiety in the early years (1: hmm) that's where it's starting

*Person 1:* yeah yeah definitely that sounds really exciting um okay so *pause* we sort of we have touched on this so uh uh talking about parenting again so what sort of parenting styles or behaviour is leading children to behave in this way then

*Person 2:* no boundaries (*1:* hmm) that's that's a big thing (*1:* hmm) a lot of kids don't have boundaries you know and and if they do have boundaries they're moveable boundaries so (*1:* yeah) yeah we all know you know they're gonna push and push and push and push and push and as hard as it is you've gotta stand fast to it (*1:* hmm) because the minute you cave they will do it again (*1:* yeah) and and I think that's a big thing I think there are no boundaries (*1:* hmm) and paren you know parents are all we like to give them freedom kids need boundaries they need to know where the expectations are they need to know to like you said to feel safe (*1:* hmm) so I I do think that a big big thing is (*1:* hmm) just just no boundaries or boundaries that aren't stuck to

*Person 1:* so more of like with indulgent parenting then or or like you say maybe it's flitting from being authoritarian (*2:* yeah) so shouting to them flipping to be to be indulgent (*2:* yeah) so them se so the boundaries are (*2:* yeah) *simultaneously* moveable

*Person 2:* and you know and giving in to those sim you know where you said no ice cream I want ice cream no ice cream we're (*1:* hmm) on and on and by the fifth time you're like oh have it then (*1:* hmm) yeah so they know that the next time they'll push it again and it (*1:* yeah) starts with ice cream and it moves up to the iPad do to two o'clock in the morning an (*1:* hmm) and all the rest of the things that come after (*1:* hmm) so I I do think yeah I think it I'm not so much sure it's I mean style clearly has something to do with it I do think it's about boundaries how those boundaries are presented (*1:* hmm) do the children know where the boundaries are do the boundaries stay the same do they are they changeable are they in existence (*1:* hmm) I think I do think that's a big part of it (*1:* hmm)

*Person 1:* I suppose that's psychoeducation about authoritative parenting isn't it (*2:* hm) and how it's about res mutual respect (*2:* yeah) and having those firm boundaries (*2:* yeah) and explaining why I'm not just shouting or

*Person 2:* and there's boundaries the other way where they're ridiculously (*1:* hmm) too tight (*1:* yeah) and and you are gonna get kids that are gonna go either they're gonna be very frightened of them or (*1:* hmm) they're gonna go hell for leather try and break them (*1:* yeah)

*Person 1:* well with parents I know that sometimes I I've put in boundaries and I've said to my Holly you know there might be sometimes you don't agree with something and I'm always willing to listen and if I then think oh actually maybe that is a bit too much (*2:* yeah) then we can maybe negotiate something (*2:* hmm) so as parents we don't always we try and put them in in the right way don't (*2:* yeah) we but yeah some people may put in just ones that are just ridiculous (*2:* yeah) but sometimes again that handbook thing isn't it we don't come with a (*2:* no) handbook (*2:* we don't) you think you're doing the right thing (*2:* yeah) something else that's been brought up I can't remember the name that other people have used it but I know a friend of mine that works in a school they call it snowplough parenting where they put where so the (*2:* yeah) child doesn't have any adverse experiences (*2:* yeah)

*Person 2:* yes or the helicopter parenting I've heard it referred to as (*1:* okay) where they're on top of everything (*1:* okay) and there's no room for we there's no wiggle room and room for manoeuvre (*1:* hmm) where you know they're just on top of hovering on top of it all the

time and like you said you know nobody wants to see their child hurting but actually it's the only way they learn (1: yeah yeah) by having difficult experiences that they have to learn how to work through (1: hmm) and that's hard as a parent to step back and watch that happen (1: yeah) but you know they need to (1: yeah)

Person 1: so do you think that's maybe a contributing factor then to it all as well

Person 2: yeah I think w we don't let kids get hurt enough (1: hmm) and I don't mean y and I don't mean that in a you know they should we should (1: hmm) let children get hurt but you know these parents who when their child falls over oh my god are you okay you know checking them over coddling them giving them ice cream whereas you know I'm like yeah alright off you go and off chop you off today you'll be fine (1: yeah laughs) you know it it's that whole making little things a huge issue so that (1 simultaneously: yeah) everything is then a huge drama

Person 1: do you think do you think that's getting worse as well I know my friend said you know they eh I the one who works in a school she they've even got parents that they had one parent that the girl was going to do a violin exam and they knew that she uh she failed it but the little girl didn't know so the mum went home and made her her certificate that she'd passed it and didn't even tell her that she'd (2: no) she'd failed so it feels as though maybe the it's almost a different style of parenting that's coming over

Person 2: yeah and it might be (1: hmm) um I don't know if there's more of it I think we're more aware of it (1: yeah yeah) um yeah and and yeah I think we're more a more I don't know if there's more of it but (1: hmm) certainly the ones who do it are spectacular at it (1 laughs yeah absolutely it's another extreme of it) yeah

Person 1: um so we've mentioned parenting and anxiety as uh one of the the main contributing factors we think towards it but is there anything else that you think might be a contributing factor to parents misreading

Person 2: I think too much information out there you know and parents jump to oh that's autism (1: hmm) you know google doctor is right on many levels but not so great when you're (1: yeah) looking for a reason so I think (1: hmm) technology a and having information at our fin fingertips literally is (1: hmm) great on many levels (1: hmm) not so great on others so it gives parents a very easy way to look for something that's wrong (1: yeah)

Person 1: yeah and again placing that the difficulty

Person 2: and finding a label (1: yeah) it's much easier to find a label now then it (1: hmm) would've been

Person 1: what do you think parents hopes are then of finding of getting that label

Person 2: it's not them (1: hmm) it's not their fault

Person 1: and you think that is that is (2 simultaneously: I I do) a main



Person 2: think that is the big part of it it's not their fault they can blame it on something else (1: hmm) they can have a go at the school for not doing the right support they can have a go at others they can get and for some of them it's about getting funding you know not all but there are some parents that we've come across

Person 1: so funding

Person 2: DLA yep (1: hmm) um but I I do think a big thing is it's that it's that it's not them it's not their fault (1: hmm) my child's autistic I it can't be helped they just are that way

Person 1: and then w so do you think that would be more about then them being able to accept it as well then not having to fight searching for that

Person 2: um I think it's m then they have something to hang it on (1: yeah) I don't know if they ever acc and even for the parents where they don't want a label and the child clearly is (1: hmm) um ye I've always said it it's it's a grieving process you're grieving for the child you didn't get (1: hmm) and you're trying to learn how to do to manage and support the child you've been given (1: hmm) so pause I think for some it's somewhere to hang it and then they don't have to deal with the m the fact that it might be them and for others I think it's a very long journey (1: hmm pause yeah)

Person 1: um so I don't know if we've answered this one I'm reading it as I'm saying it as I'm reading it what do you think the implications this is my last one what do you think the implications are for parents who believe their child's behaviour to be autism driven then they don't receive a diagnosis

Person 2: I think then they look for the next thing sometimes

Person 1: what so look as it is it something alternative to autism or (2: yeah) okay

Person 2: look for some kind of other diagnosis (1: hmm) um or you know they they they'll go look for second opinion (1: hmm) um and unfortunately there are people out there that will then give it (1: hmm) and you know in and I've done the job a long time and I've seen both I've seen some where they accept it and they move on and maybe then they start to get support around their parenting and things I've also seen the ones who've gone up to the who've gone to London and then they've been given a diagnosis and we're like did you talk to any of us down here to get any information no (1: hm) um so I I think it some parents will carry on fighting and looking for (1: hmm) a a label of some description some will accept it and may work with schools and other agencies to (1: hmm) manage it and yeah pause and some I think their kids they're the ones then end up in our SCMH special schools

Person 1: yeah but it's saying about the the the former ones so the ones um that may keep keep looking for it even those that then don't accept it more I suppose it's about again the they're not offered something something else are they if if there was (2: no) something that um done in not a um critical way (2: yeah) it's your parenting (2: yeah) but being if there was sort of offered

Person 2: if there was some kind of support or service that could help them look (1 simultaneously: understand yeah) at what's happening at home (1 simultaneously: and being reflective) and systems yeah

Person 1: rather than critical (2: yeah) yeah it may yeah god it would save the whole country a fortune as well (2: could) wouldn't it laughs

Person 2: it could and save several pupils from having uh you know wrong diagnoses (1: yeah)

Person 1: god I know yeah absolutely

Person 2: yeah I I mean this is what you just sometimes think what why why are you giving this child this like and I I also think parents don't realise that's for life that's it and actually that can that can impact them further down the line (1: hmm) when they go for the army or the m or (1: yeah) the armed forces or the police (1: yeah) or fire service or (1: hmm) you know any kind of government job (1: hmm) you know that that label is there and okay we have the DDA but (1 simultaneously: DDA) but there are disability discrimination act (1: okay) but that doesn't mean pause people will find reasons not to employ (1: hmm) or they're not you know there are certain ones that are you know you wouldn't they aren't gonna want someone who's autistic (1: hmm) working in certain fields (1: hmm) because it's it's people driven (1: hmm) so I I think parents also only think about it in the here and now not what the long term impact is (1: yep that it will take away that) and the long term impact for that young person (1: hmm hmm)

Person 1: yeah cos they just I suppose in crisis and just trying to find that reason to take away the blame or whatever

Person 2: but that's a lifetime diagnosis (1: yeah absolutely) and that's what they don't realise (1: hmm) you know it's not a well here's a label that'll go away in a while (1: hmm) that that's for life (1: hmm) and it's very difficult to get a label removed (1: hmm) once it's given (1: yeah yeah absolutely)

Person 1: absolutely um that's all my questions so thank you ever so much (2: that's alright) thank you

Pause

Person 1: sorry yeah carry on

Person 2: my godson I would bet my bottom dollars on the on the autistic spectrum (1: hmm) he ticks every box um but parents aren't aren't able to hear that (1: hmm) and they're not but you know so they move schools because that would be better and they've done this because that'll make him better and oh he's doing karate you know and but the they didn't seem to I mean they were angry but we were visiting he used a takedown move on Chloe and you know he's ten she's she's eight (1: hmm) um it you know and it was like oh she e e there must have been something we didn't know about he must of wound him you know he must of just of got wound up in the wrong way

Person 1: so it's almost like a flip isn't (2: yeah) it for parents that that their child has got those (2: yeah) traits and then they're blaming external factors

Person 2: and then you've got the flipside of the ones who they clear uh if they're autistic I'd eat my hat (1: yeah) who are oh they're autistic they can't do that (1: yeah and it's them

blaming internal factors) yeah (1: isn't it) and oh they're autistic you you can't talk to them about that or (1: yeah) they they uh the uh all those kinds of things (1: hmm) so yeah

Person 1: and the knock-on effect of those those children (2: it's huge) for their life it's massive isn't it

Person 2: and that that follows them through (1: hmm) for the rest of their lives (1: yeah) so

Person 1: I know scary

Person 2: love it

Person 1: yeah thank you ever so much



## Appendix 14 : Transcript Interview 5

Educational Psychology research transcript – 5<sup>th</sup>

Interviewer = person 1 = 1 (in interjections e.g. hmm)

Interviewee = person 2 = 2 (in interjections e.g. hmm)

*Person 1:* okay thank you very much um yeah I've said about my my title at the minute so it's yeah what are the context and mechanisms that um lead parents to mislead ah misread their child's behaviour as being autistic in nature um so I've just got a few questions to go through then (*2:* hm hm) um so the first one is can you describe some of the ups and downs of conducting the parental interview element of the ADOS please

*Person 2:* some of the ups and downs um so the positives are first parents are always very keen to give you all the information (*1:* hm hm) um they can give some really good um examples of children's behaviour um usually able to give a good developmental history (*1:* hm hm) um but alongside that they often have come from a position where they've got they've been waiting a long time for an appointment so they're often angry (*1:* okay) frustrated they often want an answer immediately they've usually um read up or been given in or found information about autism somewhere so that (*1:* okay) they you often feel that they're presenting a picture um and describing symptoms that you want to see rather than ma those that may actually be there um and anything that they might describe very often has a slant towards um you know any kind of behaviour they'll see it as autistic rather than that it might be as a result of attachment or poor parenting or any other kind of condition

*Person 1:* what do you think what do you think are the driving elements then of them presenting some of the of what you want to see do you feel that it's a conscious act doing that I know you can't say for all of them but

*Person 2:* um I think that sorry that that I want to see or that

*Person 1:* yea yeah the fact that they're they're they're so like adamant and you said that they can they can come and there's angry that they they they the presenting some things that there do you think they believe it to be true what they're presenting or that they they are consciously elevating it and why do you think that might be

*Person 2:* I think it's a mixture of both I think by the time they get to the point they had an ADOS they've had a very long wait (*1:* hmm) sometimes they've had months if not years waiting (*1:* hmm) and behaviour has um deteriorated and the it's easier to see it as a within child problem so I think very often any th any kind of behaviour that they've seen over time they will have clocked that and you know put it in the store cupboard as that's an example of (*1:* okay) that kind of beh behaviour and they want to prove it um you know it would be very and it would be really easy with many of the parents descriptions of behaviour to give a diagnosis that would fit with (*1:* hmm) with autism immediately without seeing the child and then very often seeing the child is is really quite quite different and I think also um parents aren't seeing the child socially in the same way that we have the (*1:* hmm) opportunity to do particularly when we do the ADOS in schools and so they're seeing um often the child's behaviour in terms of what they see at home which is you know comes with all the baggage

of home (1: hmm) and the difficulties from home and they can't then um separate that from what might be being seen um you know in the school setting

*Person 1*: this is probably gonna link in with a lot of my further questions (2: yeah) coming down but I need to pick on you said you mentioned about proving it and also within child what do you think are the reasons behind that that parents are wanting to do that

*Person 2*: takes the blame away from from um them for poor parenting I think very often parents really don't know what to do to manage (1: hmm) behaviour and I think there are some really difficult behaviours and they don't don't know um how to manage it I think it's a lack of understanding of language and communication difficulties I don't think parents understand um what we mean by communication (1: hmm) I think that's a really big thing um in any kind of assessment that we do you you know if you ask a parent what their child's language and communication skills are like they'll generally say they oh they're quite good (1: hmm) so they don't really understand what we mean by you know (1: hmm) um communication and probably for you know or it's possible that for many of these children they're not getting good communication models at home they're not learning those good (1: hmm) you know forms of communication they don't you know they don't understand about reciprocal communication (1: hmm) um their voice isn't maybe heard and and you know parents don't want to hear their voice at home I think parents are spending a long time on computers (1: hmm) iphones and ipads and whatever and so they don't develop those skills and then you know they're going to school and they don't have those skills and then teachers might comment on it and parents jump on a bandwagon (1: okay) and then you know it it kind of steamrollers a bit (1: hmm) so I think a lot of it is parents lack of understanding of the difficulties that children have um and I think there are too many professionals friends all sorts talking about autism and raising (1: hmm) profile of and it's um yeah it's become a bit of a buzzword (1: yeah that's it at the moment) it is to me yeah how come how come there's all these children with autism (1: hmm hmm) and it's it's phenomenal the numbers now that there has to be something within what's going on in society and something that explains quite a lot of that

*Person 1*: I was just about to say so sort of delving a bit deeper you know the about not understanding communication (2: yep) as well but yeah what do you think the reasons are then um like you said you just said about society so (2: yeah) what about society or the home life

*Person 2*: well I think I think it is very different there's you know very different there's not sitting round a table communicating (1: hmm) that doesn't happen there isn't um you know you very often speak to the parents of the children that we work with and they don't go out as a family they don't do things as a family they tend you know many times did they say we don't type take our child to the supermarket um because he can't behave well (1: hmm) and sometimes you've got to learn those sorts of things (1: yeah) um and I think it's very easy for parents then to you know to to not do the things that they find find difficult but I heard somebody recently saying that they didn't want their child to catch autism (1: really) so yeah and they were talking about it in relation to um vaccination because there's been quite a thing ab recently about (1: it's coming out again isn't it) DLR again (1: yeah) and that was being you know that was being looked at and people were saying I don't want my child to catch autism (1: oh my goodness) so they have this idea as well that it is something that's out there to be caught

*Person 1:* so there's a (2 *simultaneously unintelligible to "misunderstanding about autism"*) misunderstanding on both sides isn't it a misunderstanding about autism but misunderstanding about their own (2: yeah) child's behaviour and why they feel that (2: yeah) to be (2: yeah yeah yeah) crikey

*Person 2:* so you know I think it's uh and I think it's spiralling definitely (1: hmm) and I don't know what the numbers are like at the moment but (1: hmm) every child I'm seeing is coming up as (1: crikey) yeah as social communication difficulties and then you know with with traits where are all these social communication difficulties coming from (1: hmm so rapidly increasing) yeah (1: problem) because I don't have within my circle of friends um you know I can't think of any children with a diagnosis (1: no no nor mine either) and you know that's quite a wide circle of friends (1: hmm) I can think of them with other difficulties (1: hmm) but not with autism so is that because you know there's more of the kind of of you know group of friends you know or is it about the fact that you know we've got different parenting styles or is it you know I I don't know but it you know you would think if you looked at the spread of autism across the (1: hmm) continuum that you would know you know you would find it

*Person 1:* and it would be interesting then to look at cos you said the the circles that you move in so (2: yeah) socioeconomic where the what the impact I mean the I don't know how long you've been doing the ADOS and doing a bit is it are you seeing it's more of a particular population of people as in those that (2: I've) are misreading them (2: we yeah) yeah

*Person 2:* yeah I think I think that is true I think it is you know whether or not that's because the patch is Hastings patch of course (1: yeah of course yeah) I'd say that be that comes with it's own socioeconomic territory um you find you know and I if I think of some of the children who I can really think of with diag diagnoses where where I think it's the right diagnosis then then you know I can see a spread of that across different a across socioeconomic groups (1: hmm) you know I pick out now you know a dozen names where I could think that's a that's a crikey ASD (1: hmm) child in a you know (1: yeah) nice middle class family but also you know that's a child with a an ASD diagnosis that's absolutely right in a you know (1: hmm) in a family that's really struggling and (1: hmm) where there's lots of poverty and deprivation but I do think that a lot of it is probably being seen you know across lower socioeconomic (1: the people that *both* misreading the symptoms) I do think so and I think a lot of that is due to you know home circumstances um communication within the home but also I think um you know some of the family relationships and difficulty difficult home environments that families are (1: hmm) you know are experiencing and kids are experiencing (1: hmm) and they're not learning those sorts of you know models of behaviour

*Person 1:* and and like you say I mean the generational thing (2: hmm) so if their parents themselves have maybe not (2: yeah) learnt

*Person 2:* that they ex yeah exactly (1: yeah) so *both* hmm

*Person 1:* I mean I'm going back down but just picking up on what you said um about parenting so that is everything ma that has arisen (2: hmm) with with other people in relation to parenting so I mean you just mentioned it there but what are your thoughts on parenting

*Person 2: sigh* I think for parents parents if they are concerned about about behaviour they like the diagnosis because it takes the blame off off them and I do think that um some of it definitely some of the diagnosis you know are could be changed if you looked at differ different parenting models or I mean it's not to say that these children don't have difficulties (*L: hmm*) and that they don't have social communication difficulties (*L: hmm*) and that they don't have difficulties with interaction with other children and they you know have difficulties with empathy and managing emotions and all those things that make up you know what looking like an autistic child might be but I think you know it's a little bit of that in everybody (*L: hmm*) and so it's the way that it's it's managed by a lot of families and if you're under stress and (*L: hmm*) and children are picking up that level of stress then all those things that you know that might be present in lots of children just become overwhelming for (*L: hmm*) for some children (*L: yeah*) um so is it poor parenting I mean I you know I think parents probably think they're doing a good job (*L: yeah* and doing the best they can with) yeah but it's the lack of understanding maybe of how you might support you know support that (*L: hmm*) um and I suppose you know in an ideal world if we were looking at how you might do those um assessments that around children with autism it would be really good to go and do some of that in the home (*L: wouldn't it*) in the home (*L: yeah* well) because that's not we do it I mean we do it in school because that's a social situation and (*L: hmm*) that is good and it's good to look at you know how a child is in the playground (*L: definitely*) but I also think you know um it would be really interesting (*L simultaneously*): it would be great to have a bit of extra time wouldn't it) to see these children at home yeah yeah to (*L: so that you're able to do both of them not*) yeah (*L: just one of them*) yeah

*Person 1:* cos you're right it's so important to see them in the natural environment (*2: yeah*) and without the parents being there as well (*2: yeah hmm*) but then to also to be able to do so you can give a real holistic (*2: picture of it*) I wonder if I wonder if that would then make a difference to there we were talking before about possibly um paediatricians having a different view of us as EPs (*2: hmm*) if that would make a difference to the way that they then went on to give a diagnosis or not

*Person 2:* paediatricians I think the really difficult thing for the paediatricians is um they are very reliant on what they hear (*L: hmm*) from parents (*L: hmm*) um and we as EPs at least have an opportunity to talk to school staff (*L: hmm*) and teaching assistants and (*L: hmm*) and various other you know um professionals who might be involved and the paediatricians have less opportunity for that (*L: hmm*) so their diagnosis is really um is often based on um you know what the parents tell them and a clinic sit setting (*L: hmm*) and there are lots of children that are you know will misbehave or be freaked by being in a in a clinic setting (*L: because of anxiety or*) because of (*L: yeah*) the high levels of anxiety um so I think those two things are you know have a huge impact on (*L: hmm*) on the level of diagnosis (*L: hmm*) um and you know I mean the ADOS is good but it's only part of you know (*L: hmm*) the triangulation of all of that in information (*L: hmm*) and I think sometimes um you know there's there can be a tendency just to look at what that what that can provide (*L: yeah*) and and you know in a clinic setting is it any wonder that a child doesn't want to engage in conversation or (*L: no or play with*) or how much um how much of that is around language and communication difficulties (*L: yeah*) in particular language and understanding in you know when (*L: hmm*) when you're highly anxious and that emotional blocking happens (*L simultaneously*: absolutely) and captures your language it doesn't work yeah (*L simultaneously*: yeah and the anxiety that arise if you know that you're gonna be asked questions and) questions yeah yeah (*L: yeah*) and questions that you know if I'm perfectly honest you know what do you want to do when you're older and where do you want to live and who do you want to marry and (*L:*

hmm) so on are really difficult for a seven or eight year old and (1: yeah) if you haven't got the language (1 *simultaneously*: language on top of it) and schemas around that (1: yeah) then how can you answer those questions (1: absolutely) um and there has to be if I was to look at anything around the ADOS as well it would be how do you get that picture of what a child understanding and empathy and (1: hmm) what is the understanding of emotions and (1: hmm) their sort of social understanding is like there would be a different way than asking those questions (1: yeah yeah) cos they aren't really relevant to

Person 1: but no it feels quite dated I thought in some ways (2: hm) yeah but that's a whole other research topic isn't it *laughs* linking into parenting you mentioned about styles as well parenting styles I mean I I have thought about the different Baumrind styles (2: hm hm) and behavioural pro yeah and just what are your thoughts on what sort of parenting styles and behaviour do you think is leading children to behave in the way that then behaviour is being misread as autism

Person 2: what kind of behavioural styles what from the children (1: from the parents) from the parents um I don't know that I've really thought about that to be perfectly honest um because I do think that that it could be anything so there are some parents who are really laid back in their parenting (1: hmm) and um (1 *simultaneously*: so more the indulgent parenting) where I think yes yeah yeah where I think actually children haven't be therefore haven't been given the right kind of you know appropriate boundaries (1: hm hm) um and I suppose you know you quite often see that then when children come into school and I could even think of you know a child that I've seen this week where you know a behaviour and I know what goes on what goes on at home and you know he's managed in you know I a very nice kind of gentle kind of way because (1: hmm) that's the the way the parents are um and that's fine but what happens for him is that he becomes very hyper and uh very anxious very quickly if somebody doesn't step in to define the boundaries and (1: hmm) you know give him di directions so in nursery when he starts to do things if somebody doesn't stop that immediately um and tell him you know or try and distract him or whatever (1: hmm) then actually it gets beyond a position where he can be (1: hmm) um contained e easily um so I think there is you know there are the parents who are not giving those kind of boundaries um but also um *pause* is it parents who are being too too demanding not really sure

Person 1: would you say that would be more like (both authoritarian) parenting yeah and also the the wondering as well about when you mix those two (2: hmm hmm) together so one parent is

Person 2: so one parent is giving mixed messages I think that's um yeah um and how many if I look at the background as well you know when we look at parents who come in for we with children you know its of it's all often the mum (1: hmm) come who comes in and so what you get is very often one parents' side of the picture as well (1: yep yeah) and quite often um there's a different side of the picture from the from the other parent and I suppose that becomes more obvious when you've got situations where there's been a family break up (1: yeah) and so you know you might have a conversation with one parent and then when you speak to the other parent which you're more likely to do in the case where the ch you know where parents are separated but actually you get a very different picture uh the other partner doesn't want a diagnosis doesn't believe in the diagnosis won't accept the diagnosis cos that's the other thing that's interesting is where where one parent in the partnership won't accept the diagnosis



*Person 1:* so do you find not wanting to be gender specific or anything like that but are you finding that I I it's mainly the the the mum or the dad that is would be saying no I don't want that I don't agree with it (*2 simultaneously:* I think it's more typically the father) okay

*Person 2:* I well that would be a general impression (*1:* yeah) is that it's more likely to be fathers who um don't particularly if it's around behaviours (*1:* hmm) because they interpret the behaviour particularly if it's around boys as just being boyish laddish (*1:* hmm) behaviour and so being quite kind of tolerant of the of behaviours and you know (*1:* okay) almost encouraging quite you know (*1:* right yeah) um particularly when it's younger children (*1:* hmm) and then of course if that's not addressed when when they're younger then you know um and it it becomes more more difficult then they won't you know they're less likely to accept that (*1:* hmm) a diagnosis (*1:* yeah) so I do think it happens b it tends to happen more with men

*Person 1:* so from what you're saying it sounds as though the the the men are almost being more indulgent parenting (*2:* hm hm) so I wondered if it would be the other way round with the men being the more authoritarian the mum being but maybe it is (*2 simultaneously:* I think) yeah

*Person 2:* it's more yeah I think it's more seeing it as boyish behaviour (*1:* hmm) and being more tolerant of it because (*1:* hmm) you know that's how boys are (*1:* hmm) um (*1 simultaneously:* mum may be struggling with it more) so mum may be struggling with it yeah yeah and um probably man trying to manage it more in you know playground and (*1:* hmm) you know in and out of school and so on

*Person 1:* that's very interesting (*2:* hmm) um okay so um going back up to the top of my my questions but what do you think leads some parents to place difficulties as being within child and therefore have a blindness to external reasons for their child's behaviour I know you (*2:* hmm) we sort of hinted at that and saying like take away the blame is there anything

*Person 2:* um I think there is for some parents there definitely is financial reason (*1:* okay) cos they want some kind of benefits (*1:* hm hm) um and there you know some parents are very aware of the the benefits (*1:* hm hm) that they might get um I mean you know for some parents it's *sigh* I think they probably are in such a position that they can't see how their parenting might change something and (*1:* hmm) therefore it's easier to say it's within child and it's (*1:* what so they can't they can't see) that they (*1:* because they're ins they can) yeah (*1:* they know it's to do with their parenting do you think) yeah (*1:* oh okay) but actually or but it isn't but f whether or not it's to do with their parenting I think for some parents it's easier to accept or to want to accept that it's (*1:* hmm) within child because they really can't haven't got the skills (*1:* yeah) to parent differently

*Person 1:* so maybe with the recognition (*2 simultaneously:* gnition yeah) that it is that do you think then (*2:* yeah) but it it's just easier

*Person 2:* I don't know that they think it's I think most parents who are looking for a diagnosis really believe there's a problem (*1:* hmm) for the child (*1:* hmm) I do I do but you know whether or not they want to hear that it might be something else that's that's (*1:* hmm) always difficult and I know that all the time that I'm involved in any kind of assessment I will say to parents if you don't get a diagnosis then be grateful that you haven't got a dae diagnosis (*1:* ooh yeah yeah) don't see that as something negative because you know (*1:*

yeah) if it is autism it's a lifelong condition and (1: hmm) that your child has got to live with that (1: hmm) if we can say that we think it's something different (1: hmm) or it doesn't merit that diagnosis (1: don't see it as not a good thing) then that might be something (1: hmm) really positive that we can go at changing that you know (1: that's a really good thing to say though isn't it) and I always (1: just to give) done that with parents (1: yeah cos it's so important) they're desperate so desperate for a diagnosis

Person 1: yeah and like you say they've been down through such a (2: yeah) a long journey to even get to to having the ADOS that they're pinning maybe pinning everything on that and seeing that as the holy grail (2: yeah) where and yeah

Person 2: and and I think they definitely do with the ADOS because you know there are a number of occasions where actually they've been in and out of clinics over a number of years and they've been told no it's not a diagnosis it's not you know they've asked for a second or a third opinion and when ADOS is mentioned as a test that somebody might be able to give them a definitive answer (1: hmm) then they are desperate for that to come out (1: hmm) and it's um it's very rarely that you speak to a parent who would rather not have a diagnosis for ASD (1: really crikey what that just what) that's what they want (1: so they've just been through) that's (1 *simultaneously*: a journey and) that's that's yeah yeah for whatever reason whatever has brought them to that (1: hmm) position um and you know I think there's so much spoken about behaviour um but I think there's quite a lack of understanding about behaviour and I think there's a real lack of understanding generally within the population about the emotional impact of anything on behaviour and how behaviour impacts emotionally on everybody (1: yep absolutely so the transference of) yeah (1: that countertransference and everything) yeah so I think that's a really big thing because it's very very emotive (1: hmm) without a recognition that you know emotions are a really big part of that (1: hmm) and and by far and away the biggest of those is anxiety (1: hmm) yeah but interesting when you say to parents when you ask parents about their child's behaviour and if you say is your child anxious they often don't think that they do have an anxious child (1: because they're) because they don't recognise what anxiety looks (1: no) like

Person 1: so it's misunderstanding that as well isn't it and seeing anxiety as somebody trembling maybe in the corner yeah

Person 2: rather than seeing that the behaviour is a symptom of high levels of anxiety (1: yeah) and what can I do to address that an (1: hmm) anxiety so you know do coming back to that question of do parents see you know is it within child um there it is even more within child in that you're s you know you've got a child who's doing something but actually I can't understand what it is that you know (1: hmm) what is making that child present in in that way and what parent's aren't able to do is recognise that you know it's an emotional syate that's often resulting (1: hmm) in those behaviours and usually it's anxiety (1: hmm) and even less understanding of what might ma be making them anxious (1: hmm) or what they can do about it (1: yeah) so when you've got children who you know can't don't cope with change or can't make transitions or whatever (1: hmm) but you know think of chi parents parenting at home where we know that children can't accept transition when parents wh what do parents know about transitions (1: hmm absolutely)

Person 1: and when they know cos it's clearly stated children with ASD can't cope with transitions you can see why (2: yeah yeah) they would make those (2: yeah but what does that) jees (2: mean to you know)

Person 2: a parent can't manage a transition (1: hmm) and often (1 simultaneously: doesn't like going to the shop) what's next hm and often of course the parents themselves have got difficulties

Person 1: well yeah and that that does lead on to another one down here and that's um so um some people that are other people that I've interviewed have spe spoken about parental anxiety um being a contributing factor for them re misreading their child's behaviour as being autistic so yeah what were your thoughts on that

Person 2: hmm well I think par parents are highly anxious highly anxious and highly embarrassed often um if you ask parents what they're worried about they're often worried about their child being excluded from school (1: hm hm) so they're worried about being contacted by the school they're worried about how they're gonna manage if they can't you know get on with the things they want to be doing so that makes them highly anxious there's lack of understanding of how their anxiety may well impact on on the child um but also um you know lots of these parents have their own difficulties so (1: hmm) they have difficulties with communication with (1: hmm) high levels of anxiety and mental health difficulties forming relationships with with children which will you know undoubtedly be having an impact on (1: hmm) you know on uh on the children (1: yeah)

Person 1: absolutely so with regards to that so with regards to the parents anxiety do you think that is is well it's it's not and or it's it's not and it's it's both of them is it about internally and externally driven what would you see as being some of the contributing factors to for the parents to be anxious other than what you've said about (2: yeah) being anxious about the child being excluded but their own anxiety where do you see

Person 2: in relation to the child

Person 1: huh it that that makes them then misread their (2: yeah hmm) child's (2: hm hm) ah but but but as we said about the transmission of (2: hmm) anxiety onto the children so for the parents to be anxious in the first place (2: hm hm) I mean uh I don't know for instance to do with um maybe um oh postnatal depression (2: hm hm) you know that same where that anxiety comes (2 simultaneously: comes from yeah yeah ) from in themselves

Person 2: and I d well I do think that they're anxious about everything that their child does and you look at the you know toileting feeding all fo those aspects of of what children do that (1: hmm) makes parents high highly anxious and if they don't perform as you know as they're expected as children don't perform as they're epected to (1: hmm) then that will drive um anxiety I think that there are lots of stresses on parents today um that weren't weren't there um you know in the past um (1 simultaneously: what for instance) and I think I think um social media's a big thing (1: hm hm) prov I I think um money finances um although I often struggle to understand why because it does look as if modern day society has more than you know previous generations but even so I think there are families who really struggle to (1: hmm what because they have a visual) because they have (1: like phones and) yeah yeah (1: things) yeah they have all the the sort of trappings but that's at the expense of you know years and years ago you know we used to laugh and say that um you could drive up some of the streets and you know it was the houses where you knew there was the least money that had the Skyboxes outside (1: hmm) and you know that sort of thing so that it's that inability to uh to manage to budget and you know (1: hmm) to to to provide for for family um I think



um parents you know their own experiences um (*L*: so they're ran they're the parenting that they received and everything as well) and I think in somewhere like Hastings you know um that's a big part of it you know (*L*: hmm) that I think aspirations for families in a place like Hastings are very (*L*: okay) different than in other parts of the you know the country um poverty um I think um the mental health just generally within the community (*L*: hmm) um is you know is difficult I think levels of crime in in I just think there's a big melting pot of things that are highly stressful (*L*: hmm) whe if you think of within a community like Hastings but I think if you looked at any community there are high levels of stresses that I don't think (*L*: hmm) were there um years ago (*L*: yeah) and I'm just really interested when I hear the generation of kind of 30 year olds like my kids you know talking about the number of their um friends who are on antidepressants and (*L simultaneously*: really) not managing not coping with the demands of work and so on now you know that's that may not be something because the you know there's high levels of unemployment and and (*L*: hmm) benefits and everything in in Hastings but if you looked at populations elsewhere I think that I think generally people tend to be more stressed and that's shared and (*L*: hmm) maybe spoken about more than it used to be but there's less family support around probably um and less and more demands more you know um need to be seen to be to have all the latest of everything (*L*: hmm) and to I think people live their lives very much more out in the open than they than they used (*L simultaneously*: yeah absolutely) to do and and I think that has a major impact on you know just generally we keep hearing about mental health (*L*: hmm) and I think that does have an impact on some of the (*L*: hmm) some of the kids um and you know I think there are lots and lots of students with attachment difficulties whatever that might wherever that attachment might difficulty (*L*: hmm) might come from (*L*: hmm) but then it's misread or some of the behaviours around that are are (*L*: hmm) misread um and I think you know attachment is going to become an even bigger problem (*L*: yeah I heard that yesterday) um (*L simultaneously*: or the other day) and I think um you know that's the next thing to be looked at and interesting when I did my training um back in the nineties that I did my psychology training the all the attachment theory stuff was being dissed you know (*L*: really) Frederick Bowlby was you know and that's come completely full circle when I stared as an EP you know we were really talking then about whether there was you know home how important attachment was (*L*: oh my goodness) so in twenty years that's really really changed (*L*: that's really interesting isn't it) though it's been a very definite swing (*L*: hmm) across from you know from what we might have been looking at which was lots of dyslexia *unintelligible* (*L*: hmm) and difficulties and so on to um to attachment and ASD and I think the other thing that's really interesting is the number of children who ha are born y you know so early (*L*: hmm) IVF children I mean (*L*: yeah) you get IVF children do you (*L*: hmm) know that have diagnosis have with ASD um or children who have are born you know with some kind of condition and ASD (*L*: hmm) well why does the and ASD bit have to go alongside (*L*: hmm) the diagnosis of you know global developmental delay because you know some and ASD (*L*: hmm) but ASD is tagged onto everything now

*Person 1*: why do you think that is who knows it just helps to (*L simultaneously*: we don't know) explain

*Person 2*: it yeah because you know because there's difficulties around communication and some you know lots of people have got difficulties with co (*L*: hmm) communication lots of people have got difficulties with their emotional state lots children lots of people have got difficulties with the need for repetitive behaviours and (*L*: hmm) I don't know (*L*: because it makes them feel safer) it doesn't make them (*L*: anxiety) yeah that's right (*L*: hmm) so what is it that we should should be looking at (*L*: you could just see it going like that couldn't you)

but but it is (1: yeah) really so is a diagnosis for ASD helpful (1: you're asking me now) that's the thing oh that's what I mean isn't it yeah it is for some but is it helpful (1: hmm) for all of these children

Person 1: and then like you say it's gonna be a lifelong (2: yeah hmm) lifelong label (2: hm hm) um cos it is is like you see it almost helps everybody to to (2: hmm) understand oh well that's what it is (2: hmm)

Person 2: but it does help to understand what are the behaviours that look like autism and what can we do in schools to address that (1: hmm) cos that's a really important bit rather than than the label isn't it you know (1: hmm) because if we've got lots of highly anxious children then what can we do to make school a better (1: yeah) place (1: absolutely) for them to manage if we've got children who are coping ah who aren't managing social communication in interaction what can we do to support that (1: hmm) and (1: *unintelligible*) those that are yeah um but you know is putting lots of them in a school together the right way society's not like that although the rate we're going *both laugh* (1: yeah) you know

Person 1: so maybe as you said going into school and raising awareness and training and

Person 2: and looking at what it is that is driving some of those behaviours I still don't think that anxiety is fully understood and yet if you look at you know all the students that teaching and learning provision are working with ah you know they're they're all out of school with high levels of anxiety and ASD (1: really) pretty well all are (1: crikey) ASD underpins you know most of the exclusions from school (1: I wasn't aware of that) hmm no it's nothing (1: blimey um) if you looked at you know just as an aside if you looked at the children that are being excluded from school *pause* no or if it's not ASD all of those ASD kind of behaviours will be present they may not so some of those older boys won't have that diagnosis of ASD (1: no) but all of those behaviours of high anxiety lack of communication skills lack of empathy an inability to read and understand emotions all of those things will be missing

Person 1: so that would be worth when I'm writing up this and in the discussion to maybe go to schools and do a questionnaire or something about that um yeah try and find out more information

Person 2: you know if you went to ESBAS for example and asked who whoever does the exclusions now (1: hmm *simultaneously* of course yeah) um if you could look at who the list of students who've been excluded (1: hmm) you know you may well find some some parallels there (1: hmm) cos I certainly know if you looked at um places like New Horizons you know most of the students there um and most of the prison population will have identify as speech and language and communication difficulties so it's only one step from that to looking at what does (1: and a ASD diagnosis) what those other things that make up (1: hmm) what might be an ASD diagnosis (1: hmm) we could diagnose lots of the school of the population (1: hmm wrongly) wrongly (1: yeah) if you don't believe your diagnosis of ASD but there's definitely a you know a set of behaviours that what ah (1: hmm) what's the point at which you know (1: yeah) there's a little bit of that in all of us (1: oh) that's the trouble isn't it you know (1: definitely) yeah well (1: definitely) there is (1: yeah definitely) can see it in bits of it in everybody (1: hmm) more in men than women *1 laughs* (1: no *laughs* have to scrub that bit off)

*Person 1:* um okay so going back to so what hopes and fears I think we we have touched on this definitely do you think parents typical typically have in relation to their child receiving a diagnosis of autism

*Person 2:* what hopes do they have they hope that um people understand better they hope that they might get ah have an EHC plan (*L:* hm hm) you know that's often why parents cos they want additional support so it might not be a plan but they've are hoping that that will be you know the gate the gateway to um more support in school better understanding (*L:* hmm) um and that you know there may be some additional funding additional support services (*L:* hmm) that that go in um I don't know what they fear other than you know that that things won't change (*L:* okay) um what else might they fear in getting a diagnosis I mean I you know I think parents by the time they get that diagnosis that's really what they want (*L:* hmm) um if I was a parent getting it I'd that's not fair to say I'd be sad about it because you know you speak to parents who will s who when they've got very autistic children and where that's clearly the appropriate diagnosis and parents will say but that diagnosis I wouldn't change it because that child is the first thing (*L:* hmm) I now I know if they didn't have autism they wouldn't be (*L:* yeah) them you know so um so what you hope is that if if they get a diagnosis it's an appropriate diagnosis it helps them to understand (*L:* hmm) but also that they help the child to understand (*L:* yeah yeah absolutely) you know that's the bigger thing (*L:* hmm) having a child that cos I've also known children that have got the diagnosis and don't want it (*L simultaneously:* okay and and it's it's a innapropriate diagnosis as well) *unintelligible* yeah um not always no (*L:* hmm) you know not hasn't always been but you know some students don't want that kind of label (*L:* no no) and once you've got it it's quite difficult to to get rid of it (*L:* hmm absolutely) um yeah so I think parents you know by the time they get it they're struggling and they just want it to end that's (*L:* hmm) and they hope that you know partic and it's usually around school (*L:* okay) so they hope that things will be better in in school (*L:* hmm) sure but I don't know whether they see any disadvantages to it at all do you

*Person 1:* um *pause* no I think like you say for them going and and they they've gone to such a long (*L simultaneously:* pathway) pathway isn't it (*L:* yeah hmm) that the that the there's a fear that they won't because then they'll be just left high and dry um

*Person 2:* and if you don't get that diagnosis then what is the cause of the problem (*L:* yeah because) that's *simultaneously unintelligible* (*L:* there's still not that support to to look) yeah yeah

*Person 1:* possible contributing factors (*L:* yeah) to it (*L:* hmm) so yeah (*L:* yeah) um thank you um so have you noticed I'm saying this but we might have already answered it have you noticed any differences between parents who seek a diagnosis when their child doesn't have obvious traits as per the ADOS and those that do have obvious traits so we spoken already about socioeconomic (*L:* hmm) backgrounds and there could well be a difference there any other differences

*Person 2:* um the only other group sometimes I see children um parents who have um adopted or fostered quite often they're quite keen for a diagnosis which I (*L:* hm hm) also find quite difficult (*L:* hmm) cos they're clearly a group that are likely to have attachment difficulties (*L:* hmm) um and so that's a group of parents that I think when when faced with you know particular difficulties they will look for a diagnosis (*L:* hmm) that's not the question you asked though

Person 1: well no maybe it it says (2: uh um) it's it's that's talking about but I spose populations isn't it (2: yeah) yeah no notice any differences between parents who seek a diagnosis and their child does have the traits and those that are seeking a diagnosis that don't that aren't autistic

Person 2: pause no cos I think most of them will have traits of something or (1: hmm) they wouldn't you know say (1: yeah) unless the children are presenting with with some kind of behaviours

Person 1: yeah so I'm I'm saying that wrong really about so between the parents that are misreading their child (2: children yeah) should be autistic rather than those that are clearly (2 simultaneously: autistic) autistic

Person 2: um no not really I think I think socioeconomic and I think um pause I I do think that if parents are really struggling so parents with mental health difficulties (1: hmm) and I suppose sometimes that is maybe more middle class as well (1: okay) where um where parents are really struggling to understand and to um to manage that

Person 1: so with their own anxiety or with anxiety about their child (2: yeah no) there both

Person 2: their own anxiety (1: okay) yeah (1: hmm) and I think that can have quite a big impact as as well if I think of the kind of parents struggling a little to think of to think of any at the moment but if I think at kind of the wider patch there's some yeah I can think of parents who've already got their own mental health difficulties (1: hmm) um and um often then they're really desperate for some kind of diagnosis

Person 1: hmm hmm well yeah I mean we've spoken about anxiety isn't it (2: hm hm) well so you just wanna someone in place don't you um okay so I've read that one I said about that parenting so is there anything else that you think might be a contributing factor we've spoken a lot about socioeconomic parenting and anxiety is there anything else that you think

Person 2: communication I do think (1: yeah so we said that) is a big yeah no that that I don't think that's a big one (1: misunderstanding about) both unintelligible misunderstanding of behaviour and misunderstanding of communication are definitely jm (1: hmm) you know driving factors there um pause and I think if children are failing in education for whatever reason you know I think sometimes parents feel that they need a diagnosis as a way of getting out and so (1: a way of getting out for them or for simultaneously their children) for no for the children (1: okay) you know when it bec when it really becomes too because you can see the parents who you know get a diagnosis and then want to know what happens next (1: hmm) you know cos they expect with a diagnosis there to be an outcome from that um (1: what as in resources and things simultaneously and) as in resources and so on (1: yeah) um and you know schools don't work like that (1: no) no no um diagnosis does not mean you know doesn't equal um something different (1: hmm) something different should have happened hopefully before that but (1: hmm) parents have an expectation that um you know something different will (1: hmm) will happen um pause I think parents are often angry at sch at education you know particularly those children who are whol and I think probably for those children that hold it together in school cos there are lots of children who do manage quite (1: hmm) successfully in school and don't present you know major major difficulties but leave school and the it they're a different persona going home (1: hmm) and um you

know they they completely change (I: hmm) and I think those are often the children th where the paediatricians hear a lot of um (I: yeah) very negative stuff coming in from from parents (I: hmm) um because yeah schools schools can hold o hold it and usually of course that's around kind of structure and routine (I: yeah) and anything else (I: and the boundaries) exactly the boundaries that (I: hmm) schools are able to put in um but sometimes I do believe that you know there are children who can hold it all together in school because all of that's in place but actually they need the emotional release when they (I: hmm) when they go (I: yeah) um and whatever the parent might do um you know may not be successful in managing that (I: hmm) because the you know they need to release that somewhere and somehow (I: hmm) um but you know again there is no very limited support around that (I: hmm) and so that's really hard for parents that are trying to to manage that and some really quite violent behaviours at times as well

Person 1: wait that goes back again to anxiety doesn't it and and holding that all together all the time and then going home and then misreading of that anxiety (2: exactly yeah yeah) because of seeing aggressive behaviour

Person 2: and then parents be being anxious every time the child comes home (I: hmm) because they don't know what they're going to be faced with (I: hmm)

Person 1: which then changes their behaviour so then that is just it's just a vicious circle isn't it

Person 2: but it's a you know the whole autism thing is interesting because I saw one a boy this week who I mean you know he yeah he had difficulties and I think he has got a diagnosis but you really would hardly have known in school (I: hmm) because in because the school were doing things to support to support him (I: hmm) and he was clearly felt com comfortable (I: hmm) the mum wants a special school (I: really) hmm (I: oh my goodness) because if you ask her why she's worried and he can be violent and she's worried he'll get excluded from school (I: hmm but he's coping in school) but he is coping but so what happens is there's constantly that um you know that tension (I: yeah) of what might happen next what might happen when (I simultaneously: well that's purely driven by mum's anxiety isn't it) or has unintelligible yeah probably (I: it's tough isn't it) so I think there's you know a lot of that (I: hmm) and it's tough for parents it's tough you know I mean none of them are coming in with children who aren't presenting with some kind of difficulty (I: hmm) absolutely and that's why the paediatrician sent them in the first place isn't it because he recognises that) hm hm but there is or there may well be the case that there's something else under underlying (I: yeah) and that difficulty um and you know I know the pae paediatricians would always like there to be a cognitive assessment and that doesn't always happen (I: hmm) but there should probably always be a language assessment (I: yeah) but I'm not sure that that always happens either (I: hmm) cos even when speech and language are involved what they're doing is the ADOS rather other than doing the (I: yeah) language assessment and you know I think language is um big part of that (I: hmm) *pause*

Person 1: yeah okay so um my final question is what do you think the implications are for parents who believe their child's behaviour to be autism driven and then they don't receive a diagnosis

Person 2: um I think they're often disappointed (I: hm hm) I think they're often angry they depending on who the paediatricians been involved they may not believe that paediatrician so



quite often they ask for a second opinion (*L:* why eh do why depending on the paediatrician that they) because they there will be certain paediatricians then I know there are certain paediatricians that they don't trust because of you know culturally different (*L:* okay) cultural differences (*L:* right yeah okay) so you know we do know that you know so the consultant paediatrician locally if she makes a diagnosis you know that tends to be or not make a diagnosis *coughing* in many ways they're probably more likely to accept that than if it was one of the other registrars or (*L:* really) something yeah (*L:* because of the cultural) because and that that maybe cultural or you know yeah some language barrier bits there and and so on (*L:* hmm) as well um or just generally um how parents have that relationship with the the paediatrician (*L:* hmm) so um very often um there may well be collusion between um school and the parent (*L:* oh right okay) and so I have known um schools kind uh you know agreeing with the parent and you know trying to push them back to to the consultants and then do that before (*L:* so to get a *simultaneously* second opinion) second guess a second opinion yeah um oh so what (*L simultaneously:* no I said do d uh what do you) what do

*Person 1:* think the implications (*2 simultaneously:* implications) are for parents who believe their child's behaviour to be autistic um and then they don't receive a diagnosis

*Person 2:* um I don't think it changes anything in terms of the way they parent I'm sure it doesn't um I don't and and the difficulty then is that if there's no other diagnosis given if all they're given is a no it's not autism (*L:* hmm) then they go away not knowing anything different (*L:* absolutely) and how to (*L:* yeah) how to manage so it doesn't doesn't actually change the problem (*L:* hmm) in terms of the child (*L simultaneously:* cos they're not being) um because they (*L:* given any) haven't been given any strategies to support that (*L:* hmm) or any advice or any anythi anything else um and you know that's the biggest part is about what can change for the child what is it (*L:* hmm) what is that so you know that yeah that's the biggest thing is that there may be a whole range of emotions and almost let down by the fact that you've gone through this whole process not to get what you (*L:* hmm) what you wanted (*L:* and then just left) then left and you haven't got an answer (*L:* hmm) and you haven't got a way forward (*L:* hmm which must raise your *simultaneously* anxiety and frustration absolutely) frustration and anxiety and everything else

*Person 1:* and we mentioned before we actually started the recorded interview about if they're if they're told that it is their parenting (*2:* uh huh) um it can it can feel (*2 unintelligible*) quite quite judgemental (*2:* yeah)

*Person 2:* and can actually raise all sorts of negative (*L:* hmm) connotations there as well because you know again um a they're being criticised and b they don't really know what to do about it (*L:* hmm) and usually by the time it's got to that stage behaviours can be quite can be quite difficult as well (*L:* yeah) that is if the ASD diagnosis is around behaviour (*L:* hmm) what you know and and around kind what we might say is challenging behaviour cos sometimes it's not you know (*L:* hmm) lots of children that we see actually they're not certainly when they come in to work with us they're not they're not presenting as challenging (*L:* hmm) I mean I'm always surprised at the children who will come in and work with us to do an ADOS comply (*L:* hmm) engage with (*L:* hmm) um go through all the activities and generally seem to quite enjoy what what they're doing (*L:* hmm) um and I think sometimes you'd quite like to share that with other people as well because um you know we see a side that I suppose parents often you know almost don't believe that we would see (*L:* yeah)

Person 1: and maybe then they're misunderstanding of the process of the ADOS as well (2: hm hm hmm) pause (2: hmm) that's it thank you very much yep

Person 2: I'm not sure how helpful any of that is

Person 1: really helpful thank you

## Appendix 15 : Transcript Interview 6

Educational Psychology research transcript – 6<sup>th</sup>

Interviewer = person 1 = 1 (in interjections e.g. hmm)

Interviewee = person 2 = 2 (in interjections e.g. hmm)

*Person 1:* so thank you very much for coming along so um (2: okay) so first oh um first thing I need to do get you to do ... *pause* ... very much so um yes my working title uh at the moment so it could change a little bit it wasn't very it was massive so I'm working along the lines of what are the context and mechanisms that drive parents to misread their child's behaviour as being related to autism so my first question is can you describe some of the ups and downs of conducting the par parental interview element of the ADOS please

*Person 2:* oh the ups and downs (1: hmm) um *pause* do you do you mean that in terms of like the sort of positives and nega negatives

*Person 1:* yeah I sa yeah from so from your view as an EP conducting that what can you se yeah the positives and negatives (2: okay) to the child to the parent to you just the whole thing really

*Person 2:* oh of of having the parental interview (1: yeah) okay so not specifically things that have happened in that interview but what are the positives about having the the interview (1: both) okay um so I suppose the let's I'm going to be very unsocial focussed and start on the negatives (1: yep) um I spose the negatives sometimes are the um *pause* no I'm not I'm going to do the other way round I'm going to start on the on the positives actually I think the positives are that y'know that's kind of good practice (1: hm hm) in in that obviously you're getting parental um you know a parent and carers views around (1: yep) their young person and you know one of the problems of you know doing any any assessment you know even if you're you know whether it's standardised unstandardized you know whatever (1: hmm) it's it's a snapshot in time (1: yep) you know of of that time that you're observing so the parent as expert in my in my my view is you know their their view is really important around their their young person's uh needs (1: yep) um *pause* and I would say you know most of the time you know they they're very um skilled in being able to sort of describe (1: hm hm) you know there's sort of nuances and the contexts around their children's behaviour um I suppose the negatives around it um and actually is it's quite interesting someti I don't want to say I do this as a as a sort of uh style of sort of assessing but someti sometimes I have read all the sort of supporting information (1: hmm) really thoroughly um it's quite interesting I think uh um um I'll just finish and sometimes I don't (1: hmm) very very occasionally if there hasn't been a great deal of of of information you know I have very very very limited information (1: hmm) uh but I'm always quite intren intrested in and I have got an answer to this but how that affects my sort of engagement (1: yeah) both with the parent and the young person and how much that influences (1: hmm) you know as one obviously I I I'm trained so in terms of scoring an an ADOS you know you'd you score it on on how that young person (1: hm hm) has presented but I do think it's interesting sometimes when you you know don't have any any information (1: yeah) to pre to pre judge you know you d so you don't come there with any preconceptions of how (1: hmm) um you know cos I have had situations where um I've had information I mean I did a an an ADOS at home with with the paediatrician quite recently (1: oh right) and I had a lot of information from cos I knew the family or I'd known



of the family I'd spoken to the mum on the phone probably a year earlier (*L:* hmm) um where she was having problems at school and she wanted an EP assessment and of course you know being a traded service (*L:* hmm) couldn't do that but liaised um with school school didn't really want to have a support consultation meeting uh or didn't want to have use any of support consultation time to have a consultation for (*L:* hmm) felt their all of this child's problems were really wrapped up in in parental anxiety (*L:* yeah) and a year later it resurfaced and the young person had been sort of referred into the pathway and in fact I brought this young person up at the at at um um a meeting with paediatricians (*L:* hmm) and anyway uh I had a really long conversation with another ISEND practitioner who cried on the phone (*L:* really) about the frustration (*L:* crikey) of working with this family and how she um felt that the parent was really avoidant and (*L:* hmm) anyway so I ha I and I had spoken to mum on the phone but but a a few times but quite briefly I hadn't done a big long con phone conversation (*L:* hmm) anyway so I had a very strong view in my mind of what this (*L:* yeah) parent was going to be g going to be like and when we did the home visit I it really I was really quite sort of shocked because I felt I felt the parent was really totally plausible (*L:* hmm) in what she was saying and I and I really sort of of you know well trying to be sort of um objective you know I really I really could buy into what (*L:* hmm) into where she was coming from (*L:* hmm) and I really I kind of thought wow you know that's not how I expected (*L:* and with the best *simultaneously* word in the world) the the context to be you know um so sorry I I digress slightly but going back to um negatives not really a set of negatives but I spose the difficulties sometimes you know par parents are um you know can be very distressed (*L:* hm hm) um you know often they've been through a very long long journey (*L:* hmm) to get to this point um so they can also be quite sort of frustrated (*L:* hmm) and angry you know it's not as you say it's not a uh a not not a negative in the sense they you know but obviously in terms of um you know managing that that that (*L:* hmm) requires um some skill from from from our perspective um I've sort of gone around the houses a little bit I'm just trying just think *pause* there's probably others but I can't think of any off the top of my head (*L:* might come up in a minute) yep

*Person 1:* that's really interesting you said about um working with the paediatrician cos obviously usually as EPs we do it in the natural environment of the school (*L:* yes) and we do it without an obv and the paediatricians do it within a clinical environment so there's also that's a whole other thing isn't it but how was what was the difference in working with a paediatrician did you notice any

*Person 2:* um well I I think it's it's I don't know about working with the paediatrician there's a paediatrician I know well (*L:* hmm) and I feel that I you know have a reasonable sort of relationship with (*L:* hm hm) and I have done other ADOSes one or two other ADOSes with her (*L:* okay) and I did the ADO you know well the way we work (*L:* hmm) is that I do the ADOS and she observes and scores (*L:* okay) we s and we score it together in fact actually we scored it separately but but then sort of (*L:* hmm) you know discussed um but I have done other ADOSes where they've been sort of co scored (*L:* hmm) where I've had EPs either observing (*L:* hmm) or sort or sort of EPs like at the moment where you know we've got EPs who are trained and are doing the ADOSes (*L:* yeah) but are you know kind of apprentice apprentices (*L:* yeah) at the moment so I guess it it I you know I think that there are um reliability meetings and I I I'm I'm aware that there is a bit of a view that possibly in health particularly by the speech and language therapists that they might be slightly more um stricter in terms of (*L:* hmm) their scoring as in (*L:* hmm) strict is perhaps the right wrong word but (*L:* but yeah maybe but scoring higher than) scoring higher (*L:* yep I've heard that) as in higher in a more observing sort of more autistic sort of features (*L:* hm hm) than sort of

educational psychologists um I would say my experience of scoring with Rachel would be that probably I you know if there were borderline things with I feel is the is what we're told to do (I: hmm) I veer more towards (I: on the side of caution rather than) yeah rather than sort of ramping it up (I: hmm) yeah so um but of course you know they the home I you know going back to what you were saying (I: in a natural environment) well I've always I've always had concerns around ADOSes being done in hospital because the whole point around the ADOS is try create an (I: yeah) environment (I simultaneously: natural yeah) where the child feels (I: hmm) relaxed enough to be (I: hmm) themselves (I: hmm) and you know hospital is going to be the last place you know (I: yeah yeah simultaneously true) so I think I think most you know often kids feel quite safe and secure in school (I: yep) so that's fine but (I: hmm) obviously home (I: obviously home yeah absolutely) is either is either better you know (I: yeah) because uh it really is the their sort of natural environment um you know and interestingly again back to that one where I did with the paediatrician um again I was quite surprised given you know comments from the school and and everything um that actually he scored quite high you know both of us scored him relatively highly (I: right okay) you know I'm pretty sure he's gone on and got a diagnosis (I: yeah) well he will have done I know (I: yeah) because I have spoken to her to the paediatrician (I: yeah) um so it's interesting you know I think uh you know you really do ha you know pause you know I guess our role is is to score the ADOS on the basis of what happens in that room (I: hmm) with those materials um but you know it's that importance of of triangulation and (I simultaneously: absolutely looking at it holistically isn't it absolutely) and and contextualise contextualising you know (I: yeah) you know another see with with this particular lad that is the advantage of school is that you can see a child in in a variety (I: hmm) of different social (I: hmm) contexts um and uh the problem in in home and um hospital for different reasons you know is you don't see them in a sort of social context (I: hmm) other than you know with their parent (I: yeah) um yeah going back to the because I thought of some more I think also the p I think sometimes I think that um pause you know pare I think uh I it's not a you know because I wouldn't ever say you shouldn't get parental views (I: hmm) or meet parents and and talk about what's happening at at home because we have no other than unless we're doing that that assessment at home we don't have impact on that but I do think um there's something about the pause ah I'm not quite sure how to put this but something about the pathway that does you know when parents kind of but are are a lot of parents are sort of you know inducted onto that pathway there is an expectation around a diagnosis and (I: what by the parents) I I don't know I'm not I'm not sort of saying it's something that happens you know either by s singularly by school by parent you know maybe it's you know also about you know the world wide web and information being available you know that and it's not true of every parent cos I think lots of parents you know probably also really feeling like I really don't I really hope this doesn't (I: hmm) you know turn into a a diagnosis (I: hmm) but I do think sometimes when you're meeting parents there is a sort of sense of they're trying to persuade you (I: hmm) you know they they've already decided their child is autistic and they're trying to kind of justify (I: hmm) their their behaviours (I: yeah) and that's not always the case but I have sometimes (I: aware of that) aware of that you know (I: yeah)

Person 1: I mean that is it's that cohort of parents that I'm obviously interested in (2: yeah) and cos it like I came across them when I was with a across many parents like that when I was with Dav which was where it all came from it made me interested (2: yeah) didn't it um and that so without um it leads on to so many questions but (2: yeah) um with regards to that cohort of parents then what do you think leads to some parents to place difficulties as being within child and therefore having a blindness to external reasons for their behaviour

*Person 2:* oh yes that's a difficult question isn't it um so I would like to just you know I shouldn't answer a question by asking a question but I would like just to clarify (*L:* hm hm) what is that cohort of parents

*Person 1:* what that I'm talking about (*2:* yeah) I suppose it's from (*2:* yeah) when so when I went I um as the appren uh like an apprentice I was going along with Dav (*2:* yeah) and also Ali and at the time in moment in time I was an assistant and the very first one that I did with Dav we met with the parents and then she said right what do you think and I said oh I'm sure the you know the child's gonna be really autistic and bla bla bla and she went oh you're gonna get so cynical (*2:* right) and every single one that we saw in that time was the parent type of parent that you were saying that comes along almost with a google list of traits (*2:* yeah) trying to justify you know very sure that um their child is going to get (*2:* yeah) get the diagnosis and yet then we when we went on to do the observations in within the school and do the the ADOS (*2:* yeah *simultaneously* they weren't unnecessarily) they weren't showing the characteristics and they weren't scoring so when I talk of that cohort it (*2:* yeah) it is meaning parents (*2:* okay) that yeah

*Person 2:* so I guess that um (*L:* but not but maybe not consciously so) no

*Person 1:* they are just they're mis you know they're seeing the child's behaviour and then linking that with autism

*Person 2:* yeah yeah and I I think that um you know I'm sure that there are many reasons that it's and you know and they're kind of complex (*L:* hm) and kind of multifaceted and interrelated and everything so trying to sort of un unpick that you know I guess you know one is um parents looking for solutions (*L:* hm hm) that they well looking for solutions full stop (*L:* hmm) but also maybe looking for kind of solutions that um you know we all try to simplify things to a level that we can kind of understand don't we (*L:* hm hm) you know but maybe we don't but I I I kind of fear I do that (*L:* yeah) um (*L:* I think we do as humans) *laughs* (*L:* and as parents as well I spose) yeah and um you know a single unifying diagnosis (*L:* hmm) of anything while upsetting you know is is quite clear cut you know as (*L:* hmm) as to you know and I don't think parents really at that stage fully un understand you know that that no two autistic children necessarily look the same and (*L:* hmm) that that's going to kind of you know just fix and explain everything that's kind of going on but I suppose the idea of a single unifying diagnosis of autism you know explains gives them an an answer (*L:* hm hm) and you know and the sort of cynical view and I and I'm sure I I um necessarily really agree with a sort of cynical view that it it that some people express you know that it kind of lets parents off the hook and that actually you know they don't have to take responsibility (*L:* hm hm) it's actually a condition (*L:* hmm) and it's not you know their fault and (*L:* hmm) I'm not attributing kind of blame and (*L:* yeah) and I don't and I think my my experience and again maybe I'm being just a little bit too you know um rose tinted glasses is you know that that you know most parents if not all in some way you know they want the best for their (*L:* hmm) for their young person you know they might do not necessarily have the skills to be able to kind of to be able to provide that but you know they (*L:* they're trying their best) they're trying their they're tying they they do really want that (*L:* hmm) um but I suppose on an unconscious level I I'm sure that does sort of actually go on the fact that um you know because I think for a lot of parents you know there is a there is a lot of guilt (*L:* hmm) there is a lot of distress and um you know if uh if um a diagnosis can explain their children children's difficulty you know that is going to sort of make them feel less less responsible I suppose really (*L:* hmm) um *pause* yeah I mean I I I don't know I guess um there's a lot of *pause* you

know it's become just so much more part of the mainstream uh our sort of awareness of autism you know through you know films plays (L: hmm) a a acs you know access now for everybody to you know to kind of the the internet um pause like you said I say you know a parent can just google that and and actually because you know again you don't people have varying views about this but you could you know lay claim to for an argument that you know we are all somewhere on that that spectrum or we certainly all have at different times (L: hmm) those um you know kind of manifestations (L: oh definitely) you know if we're in an interview or something you know we are highly sort of stressed about that (L: hmm) you know we are going to be you know slightly sort of tongue tied and you know (L: yeah absolutely) you know so it it's easy to sort of look you know oh for a a lot of children and I and look at sort of ASC kind of um trends and and I think god yeah I think actually my child might be on the spectrum you know (L: yeah absolutely) pause yeah (L: hmm) end of answer

Person 1: yeah thank you (*both laugh*) um so I suppose we we've spoken about this really but um just in case it triggers anything else but what hopes and fears do you think that parent's typically have then in relation so they're going through that process and they believe their child to have autism what do you think of their hopes and tru and fears are of them actually receiving the diagnosis clears throat

Person 2: uh um pause I think there's a fear of the unknown I guess um I I don't real I don't really sort of know because I spose I not a question I've I've sort of you know it's interesting isn't it you know in terms of a lot of our work you know we're talking aro asking parents around their aspirations (L: hmm) for six months you know a year (L: hmm) three to five years (L: yeah not) you know (L: what their fears are) don't re yeah (L: hmm) but also actually I don't know in in terms of a parental kind of consultation around a a an ASC assessment that I ask that question around what are their aspirations (L: no no no) for the for the short term for the long term um but I'm guessing you know the aspirations are that that their child is gonna get the help they need (L: hmm) I don't think they really know what that help is (L: hmm) and I think there probably is a a kind of misnomer that it's going to sort of unlock the doors to some some support and resources that they think is out there (L: hmm) um I'm sure there is a bit of a fear that pause you know that um the child is going to be labelled (L: hm hm) you know I think certainly parents have expressed that fear sometimes in you know you know what what will happen long term is this going to affect my child's you know life chances in terms of (L: hmm) employment housing

Person 1: with pe with regards to that is that more people that children are are displaying characteristics as per the ADOS or those that aren't or a bit of both

Person 2: I don't know whether (L simultaneously: explain what the difference is) I don't know whether it is really whether it's really related to you know how likelyhoo how likely the child to you know I'm not sure that parents whose kids are you know pretty clearly you know got sort of social communication difficulties (L: hmm) I think I think it's more around you know the something ending up in writing (L: hmm) on my child's record (L: hmm) so before I even anybody's even looked at or met my child (L: hmm) they've already (L simultaneously: labelled them with that hmm) kind of made a decision around their suitability for something (L: hmm) so I think in a way it doesn't really it's not really related to you know where they might be on the that spectrum or how severe their their sort of characteristics are

*Person 1:* or whether the parents are seeking it for um for what we see as as recognisable traits or those that are misreading the signals as that is across is across board (2: yeah) for parents then

*Person 2:* I think so I (1: hmm) you know I get some of these things I haven't really thought about (1: no) so I don't you know I'm kind of answering it on the hoof sort of now (1: hmm) um but I think um yeah I I and I'm kind of answering a little bit as a as a parent myself I suppose thinking of what I'd be like in that (1: hm hm) situation but I you know I think genuinely the hopes for parents I think there are some hopes they'll get a diagnosis (1: hmm) and I think there is that universal sort of hope that things will things will improve because (1: yeah) I think for for all of those parents you know life is pretty shitty (1: hmm) um *pause* and *pause* you know as we you know that's your reason that you're doing this you know you know that's not always is not always as simple because of the child may have a you know a kind of developmental disorder you know (1: hm hm) there are other sort of systemic things kind of going on (1: hmm) um but again as I said I don't you know I'm not sure I can think of any particular situations where you know I felt a parent was really looking for a diagnosis just so that they they could have a free reign (1: hmm) and not have to worry at all about what their you know (1: hmm) what kind of environment they were providing you know (1: hmm)

*Person 1:* that's good to hear um something that has has come up in other interviews (2:hmm) is the influence of socio-economic factors on on parents misreading their child's behaviour as autistic, what are your thoughts on this.

*Person 2:* think it's true to be honest (1: hmm), lots of parents have difficulties with parenting skills (1: hmm), and they and look for another reason why their child's behaviour is extreme really. For instance if they're having tantrums, they they can almost look for diagnoses so it doesn't look like their parenting skills (1: hmm). Then if you also think about attachment and economic status, some of these parents haven't got the ability to form strong bonds with their child and this of course leads into the Coventry grid. (1: hmm). And also, I don't mean, don't mean to be cynical, but they also want to get DLA.

*Person 1:* to do with their socio-economic status?

*Person 2:* yes (1: hmm), for them it's, I know it sounds horrible, but it's another source of income. Not all parents do this, just some (1: hmm), some, some they struggle with parenting issues, boundaries and having a structured household. So therefore if their child is misbehaving or having meltdowns, it sometimes isn't that it's ASD, it's that they can't discipline them in ways other parent's would (1: hmm). I'm being cynical though, not everyone in this bracket is like this, just some.

*Person 1:* okay, that's interesting thank you. so um my next one is so some people um that I've already interviewed have talked about parental anxiety being a contributing factor I know that you mentioned that earlier so what are your thoughts on that so the parental anxiety being a contributing factor of the child's behaviour being as it is

*Person 2:* um um parental anxiety I in relation to the to to the process or just (1: no) in general



Person 1: in in general so the the reasons that the child's behaviour um

Person 2: may be mana may be (1 *simultaneously*: manifesting) looking like autism (1: yeah like well like the the the parents) yeah (1: misreading them) I would say as a psychologist you know the work I've done you know and you've partaken in some of this work you know around sort of an anxiety with young people (1: hmm) you know it's not it's not a great surprise you know that not all the time you know but there there are at time you know very anxious parents (1: hmm) nearly said autistic then (1 *laughs*) bit of a Freudian slip (1 *laughs*) there are anxious parents (1: hmm) um you know behind those those sort of young people and I think that *pause* you know any kind of behaviour you know it's it's sort of easy to project that onto the onto the sort of young person (1: hmm) um you know and there may even be you know kind of genetic sort of markers and (1: hm hm) predisposes that that are accounting for that as well um you know and I think it's int interesting that um you know some of the you know this is a bit of a side side track but I think this intervention is is being used with young young people potentially with who are potentially autistic as well you know I think some of the as I understand it some of the more you know there are some event interventions coming out now that have got better success um you know rates things like sort of CBT (1: yeah) um you know where the where the you know the practitioners are working solely with parents and not with (1: hmm) the young person at all (1: absolutely) um and part of that is not really working with parental anxiety well it is actually um it's really about sort of working with parents to allow their child to experience anxiety and (1: hmm) and not you know kind of avoid it (1: hmm) um but I guess it is kind of working with parental anxiety because I think what stops those parents wanting their young peop person to get go through that is their own (1: their own anxiety) their own anxiety (1: yeah) you know which maybe because of their own experience or just because actually it's really distressing to see your child (1: hmm) you know really distressed you know (1: hmm) um so yeah I think you know I think it it's a big sort of you know it plays a big sort of part I think (1: hmm)

Person 1: yeah I find it fascinating although it links in with my masters that project that I did and the um the supervisor I had at um at Sussex who she's now (2: right) working purely with with parents uh (2: right okay) with anxiety yeah and I and it's Warren somebody (2 *simultaneously*: yeah yeah yeah yeah yeah) somebody isn't it who's doing that yeah and I've spoken to Natalie

Person 2: so she's okay so she's a clinical psychologist then

Person 1: she's a professor yeah of uh of clinical child (2: yeah) and I have (2: but it's Warren) spoken to her about this and she said she's because the a I'm so (2 *simultaneously*: it's called the space programme) interested yeah it is I spoke I interviewed Natalie (2: oh yes because you said that yeah) yeah and we sp (2 *simultaneously*: because it's Warren moved over to) spoke he's West Sussex isn't he (2 *simultaneously*: West Sussex now) yeah

Person 2: but also there is and I have to you know I'm going to discuss it next when I meet with Natalie um there is some sort of m kind of discussions going on at the moment possibly with Warren about maybe even um Warren is got some concerns around it from a I think from a kind of clinical point of view but around East Sussex developing (1: oh that would be so fantastic) um something that they but there's talk about maybe an online thing (1: yeah) or um anyway there is stuff there is stuff afoot but (1: an aside from this I'd really love to be involved in that) yeah

*Person 1:* I did speak to Samantha Cartwright Hatton who's the (2: yeah) lady that I spoke to about I said that was my in supervisor and she's she's written worldly world wide acclaimed books on it (2: yeah) all and she said although she wouldn't be able to be directly involved she'd certainly be willing to have a chat (2: yeah yeah) and see if there's any guidance or (2: yeah) anything she but to do something like the Worry Busters that we did that was in collaboration (2: yeah) with Tamms wasn't it (2: yeah) I mean how fantastic would that be (2: yeah) anyway that is a side issue but yeah very exciting um right so *pause* I said my the next one where do you think this anxiety from the parents comes from i.e. is it internally driven or externally driven but I think we've sort of covered that haven't we because you saying about (2: yeah well I think it you know probably both I guess) bit of both yeah

*Person 2:* I mean I think that *pause* yeah I I mean I think that you know I I definitely you know there are we have psychologists here who have very strong feelings around that and I and I and I agree that you know there is a kind of over pathologising for pathology pathologisation you know the word whatever the word should be around um young people maybe having you know anxiety disorders or having anxiety which is (1: hm hm) which is sort of you know more elevated than it than it should be (1: hmm) um and *pause* without and I just think I'm just stopping now because actually I've been someone you know Judy Peryton you know (1: hmm) that mental health coordinator uh emailed me about I think the sort of early help t team you know wanting to use a sort of anxiety measure as a kind of baseline measure (1: hm hm) right across their their team and they were looking at the Spence and the Arcas and and she wanted she was asking me whether she thought that was appropriate and everything and I'm not sure I really feel qualified to to to (1: hmm) but one of my concerns about that would be which is what I've linked to what I was going to say was that actually you know sometimes for young people yeah they're like you know they are you know living in very difficult circumstances (1: very context dependent) um yeah you know and they're the whole you know that big bit of research done in um in America but it's also getting sort of replicated here about you know children living in adverse um childhood experiences that ace work (1: hmm) so my concern would be for a child who is living in adverse childhood experiences (1: hmm) and you know you did a Spence with them or something (1: because it then internalises it to them) you scored real they scored really highly an you'd be thinking about we need to refer this child to CAMHS (1: hmm) you know it's actually their their response to their environment (1: hm) it's entirely appropriate (1: it's adaptive isn't it yeah) it's highly appropriate (1: yeah) they're not they haven't got an anxiety disorder (1: hmm) and that's where I think that um you know there are clearly young people who do have um problems with managing an anxiety (1: hmm) whether that's identifying it or or self-regulating or or having kind of you know problems with uh perception around their experience and CBT dia you know (1: hmm) uh needing sort of you know would benefit from CBT so ou without a doubt I'm not saying everything is environmental (1: hmm) but that would be my concern around (1: hmm) so anyway in answer to your question it's both (1: bit of both yeah) yeah (1: yeah) and they and they interact off each other don't they you know (1: definitely) it's nature and nurture (1: hmm definitely) you know that whole I never really got that until I um I spose until I started doing psychology (1: hmm) I just you know why do we have to why does it we have to have this nature or nurture (1: yeah that dual isn't it) I mean surely it's gonna be both

*Person 1:* and I think that's the that's so much for the different perspective we as psychologists bring though isn't it cos we I believe could use the Arcas and the Spence as baseline measures but we would use it in a holistic by taking into effect okay we wouldn't just (2 *simultaneously*: yeah you've got to triangulate it haven't you) medicalise it exactly

you'd look at all the other factors but I suppose the concern is when other professionals who don't maybe have that that knowledge and experience would just use it and think oh right okay well they (2: yeah) they got a anxiety disorder this is what yeah that is the concern

*Person 2:* yeah also I've started using a little bit well I've stopped because I again I've just thought some of the questions are quite hard difficult to ask the young people but things like the Bex (1: hmm) um you know which I think I think is like an anxiety subscale and (1: hm hm) depression and but you know some of the kids that I was using it on were scoring really really highly (1: hmm) and I don't know I just and again you know they were of this was for statutory work and they were all all of these were generally in in sort of um living in quite tough (1: hmm) situations and I just didn't feel I felt a little bit uncomfortable that I have this data (1: hmm) and I wasn't I was reporting on it but (1: hmm) I wasn't kind of necessarily acting upon it in terms of referring onto (1: right okay yeah) CAMHS or anything but I didn't really feel (1: that that was appropriate) it was appropriate (1: yeah)

*Person 1:* but in but also in your in your um your report though (2: yeah) you can sort of say you know in all likelihood this is because of what's (2: yeah) I mean yeah but I suppose there's but the other thing is people that read the reports will they read everything or just read (2: yeah) that bit that's a worry isn't it

*Person 2:* no and I did feel a bit uncomfortable cos I kind of felt like well you know I I've made a professional judgement (1: hmm) but you know I I kind of I made a professional judgement but I'm also really sort of leaving myself a bit open (1: hmm) because you know there is there it is in black and white terms of (1: hmm) in terms of how they scored on this assessment (1: hmm) I'm typically you know if they'd scored that high you know certainly if any any primary mental health worker or anybody was (1: hmm) doing that they'd definitely be (1: going down that avenue) they'd be going down that avenue (1: yeah) and that's kind of uh I think I probably did put a like maybe I did put a bit of a marker in there in that (1: hmm) this if if these difficulties persist you know (1: yeah yeah so) might just consider a CAMHS referral but so I yeah I think you have to be really (1: difficult isn't it) there's ofso often the information you're getting from those tools those checklist di the up passes perception tools you know you kind of know anyway (1: hmm)

*Person 1:* yeah absolutely so I suppose that's of us feeling sometimes that we need to give that that evidence somewhere (2: yeah) rather than the evidence being in being in our opinion (2: yeah) hmm um so um so another thing that's arisen in my discussions with other people has been in relation to parenting being the reasons for um the children behaviour manifesting itself as the way that it is so what are your thoughts on on that

*Person 2:* um yeah I'm just sort of taking I'm just taking my time there because I suppose I'm you know there are many different sort of uh kind of ASC traits aren't there (1: hm hm) so both in terms of the sort of social communication side of it but then also the sort of restricted and repetitive behaviours (1: hmm) um and I guess firstly the thing first thing to say is yes there certainly um you know if we think about sort of attachment as a broad sort of term (1: hm hm) um you know I think it's kind of uh generally well reported now that I some children you know who have experienced trauma (1: hm hm) and maybe you know have not developed um well adapted sort of attachments um can look like both you know autistic children and children with ADHD as well (1: hmm hmm) you know kind of hypervigilance impulsivity (1: hm hm) um you know they kind of mania so I think *pause* uh you know parenting styles or uh you know maybe not parenting styles but you know the way



that the sort of templates that are laid down for that young person (1: hmm) it in terms of what they learn about (1: hmm) communication and reciprocal social interaction and they learn about around how the sort of manage um their own feelings of anxiety and stress (1: hmm) um are really sort of key but I spose I was just thinking about sometimes those uh sort of restrictive and repetitive and obsessive behaviours pause just what I which act which actually I think in terms of the work we do around ASC diagnosis with the ADOS often doesn't pick up (1: hmm) because it's you know in a in a room you know they're not you know there are toys and they're playing with toys but you know it you know I don't I've never particularly ever in all the ADOSes I've done ever done even with kids who are quite autistic you know they've not sort of sat there and nicely lined all the toys (1: hmm) up (1: hmm) you know or you know got down and put their head on the on the thing and looked at (1: yeah) you know they're not they haven't been like those you know (1: yeah) classic things that you you hear about um but that's the yeah so um the c there is more obsessive I mean sometimes in terms of what they're talking about you see t you know those kind of uh obsessive and sometimes stereotyped speech but actually not not very much I would say (1: hmm) um so I don't know I've slightly gone off off piece but I'm I'm not I'm not sure that paren parenting styles and capacity to sort of parent in a really sort of healthy way is going to account for all of all of the sort of the autistic behaviours you might observe

Person 1: what about for for the I know maybe that I'm not really I'm misre misinterpreting what you're saying as well so what about for so we're thinking about the cohort of parents that um placing difficulties as within child and that because of their behaviour they're saying well that's autistic it is because due to autism um is some people have said well it might be to do with parenting styles so like the the (2: oh yeah no yeah) so what are your thoughts with regards to that to the children that wouldn't come out as being autistic as per the ADOS what would you what do you think uh um about the possibility that it could be that the child's presenting like that because of parenting styles and the different types of parenting styles

Person 2: yeah I mean I think that uh I mean I've had a I've had sort of ADOSes or assessments you know I've met parents where they've got their phone out (1: hmm) and they've shown me video you know (1: hmm) kind of video footage on their phone of their of the young person who you know basically most of the time it's when the young person's having a sort of melt (1: yeah) meltdown (1: hmm) um you know then the parent's gone on to day you know I b I basically am you know um when I've sort of talked to them about that you know that's sort of transpired you know that they basically sort of lo just locked them in the room and (1: hmm) went downstairs or something and they didn't they just carried on you know (1: yeah) yeah (1: yeah) so yeah I I guess yeah I I and it kind of links I spose I'm a sort of linking that to you know attachment (1: hm hm) and um you know I think there there you know there clearly is a a link between how parents parent and (1: hmm) how children children sort of behave um pause but I spose I'm just kind of mindful as well that you know there's that's also sometimes an easy easy path for us to take to kind of think (1: yeah) you know just becau you know just because there are some issues around around sort of parenting you know there may be other things going on as well (1: hmm)

Person 1: it certainly is none of it is none of this is meant to be in any way a judgement it d (2: no) judge it's it's it's meant to be to really try and to really dig deep and find out what we believe with with the view of hopefully some way back here (2: yeah) we could provide interventions and support and psychoeducation (2: yeah) and work with parents to to stop them getting into the I mean the they all seem very difficult situations having difficult you know (2: yeah) real difficulties with their child to even go down this this route so (2: yeah)

Person 3: sorry to disturb I think we're due in here at the moment

Person 2: oh okay

Person 1: okay thank you

PAUSED

Person 1: okay so I I think we we were talking about this anyway but so what sort of parenting styles or behaviours do you think are leading children to behave in this way we were talking about that anyway weren't we (2: yeah) yeah

Person 2: uh what pa type of parenting styles

Person 1: I mean I spose I'm thinking about the Baumrind's four main ones you know (2: yeah) like authoritative authoritative (2: right okay) indulgent or negligent I think was the other one something like that

Person 2: uh what what are the four again

Person 1: so there's authoritative authoritative um indulgent parenting or neglectful parenting I think was the fourth one

Person 2: yeah pause okay I'm just thinking about that pause so when should so you're wondering which type of which types of parenting style might sort of develop might sort of um lead a young person to pr present autistically

Person 1: well their t their behaviour in a way that (2: yeah) that creates the parent to misread it as autism so creates this behaviour (2: okay) which (2: okay) which then the parent is thinking not thinking it's anything to do with their parenting styles or any other (2: yeah) contributing factors they must be behaving in this way because they're autistic

Person 2: okay pause quite I don't I'm kind of thinking it could be an any of them but I suppose I suppose um certainly sort of authoritative (1: hm hm) neglectful but probably indulgent (1: hmm) as well um (1: authoritarian was the other one) authoritarian (1: authoritarian not authoritative yeah) authoritarian (1: yeah) rather um (1: that was me that said it wrong laughs) pause

Person 1: yeah so sorry either authoritarian or indulgent you were saying

Person 2: I'd say yeah I'm just kind of a bit pause you know it's that nature nurture thing again isn't it you know where you know I think that it's there is that interplay upon how you know we're you know I am I am a kind of believer intuitive believer in you know in terms of you know personality being quite sort of laid down (1: hmm) and then tha our environment (1: interacting with you) I sup you know and I guess that's why pause you know you take two kids living in the same same sort of you know like don't even have to be twins but (1: hmm) I guess twins obviously helps because (1: hmm) they have the same kind of genes um but there's that you know that difference kind of interaction with with the environment (1: hmm) so you take two kids and just one kid is just more in terms of their

own characteristics just more kind of resilient (*L:* hmm) so yeah I dunno I mean *pause* I think that as you say we've kind of discussed all that you know I think that there are styles of parenting or I'm not even sure that some of them are styles of parenting you know there are um *pause* interactions you know or lack of interactions between sort of the parents and children that are going to be going to kind of impact on upon the way that child (*L:* hmm) but I haven't really thought about the about it in the context of particular styles of parenting *pause* but I would definitely say neglect (*L:* hmm) and that I probably I guess I I guess I'm thinking more around how that might affect a child's attachment (*L:* hmm) um

*Person 1:* so I suppose that one was more linked into attachment what about the other three then so authoritarian authoritative or indulgent

*Person 2:* well I think indulgent is is very linked in with attachment as well because I (*L:* hmm) see that as quite there you know quite sort of ambivalent and (*L:* hmm) um quite sort of you know where there's quite a lot of collusion going on (*L:* hmm) between parents and and children and (*L:* hm hm) um you know cos good attachment you know parenting is is supporting your you know helping your child develop a secure base (*L:* hm hm) from which to explore but being able to you know it's not about not not having boundaries it it (*L:* hmm) it's about sort of um you know just not allowing them to do whatever they want to do (*L:* hmm) uh and I think sort of *pause* yeah I think sort of an authoritarian just trying to think now you know how that you know I suppose obviously that that could lead to children being very uh quite sort of highly anxious (*L:* hmm) but also very also very passive (*L:* hmm) um or again dependent on the on the young person you know it you know if you think of fight or flight (*L:* hm hm) you know involved in fight all the time because they're (*L:* hmm) butting up against that (*L:* hmm) yeah I don't know I suppose that's quote an it I suppose that's quite an interesting sort of you know thinking about *pause* sort of young people in the pathway or young people who are presenting (*L:* hm hm) you know whether you actually can determine I say I suppose my my I suppose my issue is whether whether sort of is that that clear that you can kind of attribute a single parenting style (*L:* hmm) to to a sort of parent

*Person 1:* oh it's it's all yeah it's all contributing factors isn't it (*2:* yeah) it's not a single thing and I suppose the other thing is no two parents is with the best will in the world parent in exactly the same way (*2:* no exactly) whereas some people have got very different in different parenting

*Person 2:* yeah so (*L:* styles) if you've got a two-parent family you know you're going well that's often the case (*L:* hmm) isn't it you know that's where you know the issue often is isn't it you know um you know which then causes lots of problems with relationships between (*L:* hmm) between parents um (*L:* hmm) yeah I don't know I kind of feel like I'm not answering that one very well (*L laughs*) I feel slightly like I'm in an interview (*L laughs*) and I've not given (*L:* fight my own parenting styles) I'm not giving a very good answer (*L laughs*) um (*L:* no it's fine) no no no but I don't I yeah I'm I'm not I'm not sure *pause* yeah I suppose I'm kinda just maybe I've not really as I said you know I mean obviously with all the time you're conscious of um what in terms of that young person what has been their their experience they've had (*L:* hmm) um *pause* you know and those k those times where you know for example you know I was doing an ADOS it was a statutory assessment as well actually but I'd also done an ADOS for this young person and this young person no that's right it was a statutory assessment and I this young person had a diagnosis of aut of autism (*L:* hmm) but quite a new diagnosis and I I hadn't done the the ADO been involved in it but through doing the statutory assessment you know I probably spent longer with the parent than the

paediatrician had (1: hmm) and I I found out that this young person had witnessed significant domestic violence (1: okay) um to the point where he was you know the mother basically used him as a shield (1: hmm) um and you know he wasn't when he was you know it went on for a long period of time so it was from when he was quite young until (1: hmm) you know he was re wa you know reasonably sort of old as well um and you know I'm not saying I'm not sort of really sort of making I wasn't really making a judgement around whether he was or wasn't because he did display a lot of autistic characteristics (1: hmm) but there was a there was another hypothesis as to why and I did speak to cos Melanie Lietburg actually I did speak to her and I said did you know that you know and I told her a bit of the family background and she kind of said oh yes well the mum did mention that you know I think he'd also had like a a significant bereavement of a uh grandparent as well (1: hmm) and she said oh I did know that he had a a bereavement and there were some problems at home you know and I you know I said do you he you know witnessed significant (1: hmm) and I and I I don't know if I at that point um you know probably in my head I said to her you can't go round diagnosing children you know probably in reality you know I probably sort of said something about you know I I you know do you not think that makes the diagnosis a little bit (1: hmm) cos I kind of just think (1: yeah it's different expl *simultaneously* explanations) I'm not sure yeah (1 *simultaneously*: and he's now gonna get a diagnosis for life) yeah I'm not sure yeah I'm not sure in those situations you you can really g you know confidently give that diagnosis (1: hmm) you know I mean if over time that that sort of per persists then (1: yeah) then maybe but (1: what was her reaction to that) no so what I'm saying is I'm be kind of not entirely remembering cos her reaction basically was um uh you know yes she didn't mention something but (1: hmm) it was sort of I was telling her that (1: nothing) kind of expecting her so say ooh good need to revisit that one you know but it was actually phh it's not you know I I took some of that history but you know but mum hadn't shared any of that stuff with her you know (1: no) um you know possibly because mum was you know possibly because mum thought you know that might stop him getting a diagnosis

Person 1: yeah possibly and the shame and everything (2: yeah) not maybe consciously but if shame (2: yeah) she her part not part you know what I mean (2: yeah) she did you you know the part that she had to play in that (2: yeah) and her child

Person 2: so I spose essentially so I spose perhaps I tend to think more about the kind of environment a young person has has grown up in in terms of you know them being able to d to you know innately develop th all of those good sem emotional communication skills (1: hmm) we have (1: hmm) you know rather than thinking what is the parent what is the parenting style this parent is is using (1: hmm) um (1 *simultaneously*: well that always is it feels like it's judgemental doesn't it) cos that makes it somehow that makes it more and also it makes it sound like a little bit more like it's it's very conscious (1: which yeah then this is yeah and this absolutely and I should make a should *simultaneously* make a) I don't think I don't mean you're what you're doing (1: no) I just when I mean a parent is thinking (1: yeah yeah yeah) this is the kind of parenting style (1: absolutely) that I'm gonna use and I don't you know (1: no) well we're parents did you ever think of what parenting style should I use with my children

Person 1: no well though at times when I thought well read about authoritative parenting and thought thank goodness for that because that's what that is mainly what I do (2: yeah) but um but no not at the beginning I didn't I (2: no) thought oh my goodness why doesn't this come with a handbook *laughs*

*Person 2:* no well because you you know you sort of um like you say there's no handbook is there (*L:* hmm) and you kind of take the bits from your own experience of (*L:* hm hm) of a parent (*L:* hmm) from being a child (*L:* hmm) you know and and trying to replicate those maybe and and also avoid you know the ones that you just thought well that didn't work (*L:* yeah yeah) um and als but even then I kind of just think oh that goes out the window and it's a sort of it's a fluid thing isn't it (*L:* hmm) and I guess you know my kids were quite young when I when I was first starting be you know being doing this but I think you know if I did be if I did everything ten years later I think I would have been more self-aware (*L:* hmm) because I think it's quite difficult you know all of the the emotion coaching stuff all that stuff about just you know taking a step back and just you know being aware of how much is your (*L:* hmm) emotion (*L:* hmm) you know and how much is the child's emotion you know (*L:* hmm) *pause* yeah I mean I think it's it it's interesting and it's a really it's a real kind of grey grey (*L:* hmm) muddy area isn't it (*L:* yeah) I think

*Person 1:* I spose that's I mean why I'm just try and get people's sort of ideas (*2:* yeah) about it but um yeah so I mean we've mentioned parental anxiety and parenting and the are are there any other contributing factors that you can think of we mentioned attachment as well didn't we that could lead to a child presenting in a way that their the parents are misreading that as being due to autism

*Person 2:* well I suppose you know and they're all linked to all of those things you know they are they are kind of coping strategies aren't they you know those children those those children the behaviour children are exhibiting are generally str well you can either call them coping strategies or strategies to somehow you know get their their needs met (*L:* hmm) or you know whether you know their needs may be about avoiding the parent you know (*L:* hmm) because they're gonna get hit or whatever (*L:* hmm) um what was your question are there ah are there other things which (*L:* do you say yeah have you do you think there is there anything else that you think might be a contributing factor) to them behaving the way (*L:* hmm) that that they may be (*L:* and it not being autism related) uh *pause* uh I suppose I mean this kind of goes you know we've mentioned this as well I suppose children that you know experience sort of bereavement and loss (*L:* hmm) um *pause* uhh I think sometimes you know children can have I mean is going to more within child (*L:* hmm) things but I think sometimes children can you know genuinely have um you know have sort of developmental delay in terms of say their emotional development (*L:* hmm) um and you know that can kind of impact upon their um you know social skills social interaction (*L:* hmm) skills I think another one o another thing as well I think is that which I always thought was quite interesting was the sort of links between sort of social communication disorders and dyspraxia (*L:* hmm) and that children who are quite often dyspraxic um you know have a bit of pres an an autism presentation (*L:* hmm) about them particularly and often you know we're talking about boys (*L:* hmm) in that um and it's and I'm being very generalistic about this but I it's my it my kind of experience you know that quite often children who are you know boys who are dyspraxic you know aren't very good at football don't (*L:* hmm) don't really play football at at playtimes (*L:* hmm) and you know sometimes (*L:* can't communication) uh yeah (*L:* hmm) so they they're sort of on the outside on the periphery of that those social groups (*L:* hmm) and they they do have some some s kind of social communication difficulties you know (*L:* hmm that's interesting) *pause* but as I say I think um some of those more idiosyncratic behaviours *pause* I'm not sure I'm not sure what else what what else is causing those (*L:* hmm) is contributing to those *pause*



*Person 1:* okay thank you my very last one is and you'll be free to go um what do you think the implications are for parents who believe their child's behaviour to be autism driven and then they don't receive a diagnosis

*Person 2:* okay what are the implications (*1:* implications for the parents and for the children as well you know what next for them) uh well I think it's I think it's kind of a g ah a kind of question for of whether they do get a diagnosis or or don't get a diagnosis you know (*1:* hmm) cause I think that well let's take uh f the implications for

*Person 1:* yeah so the I mean so it is for for the for the parents when when the child doesn't receive so (*2:* yeah) so it's talking about those parents that believe their child to be autistic and they're going down the ADOS path and as you said it's (*2 simultaneously:* uh I know) on the assumption that they're going to get it

*Person 2:* yeah well they're kind of left a bit high and dry aren't they (*1:* hmm) and I think that I'm being slightly um you know my my my sense my blue sky thinking and I often say this to parents when I'm meeting parents and I'm explaining the process to them (*1:* hmm) and the fact that you know they after the ADOS and I've written a report they'll get a you know there'll be another clinic appointment (*1:* hmm) and the paediatrician will make a diagnostic decision (*1:* hmm) around you know um but I think the way that I kind of phrase that cos I I don't str I kind of hild it back a bit there because I think I don't generally I'm not obviously trying to pre-judge it but I also I'm what I'm really trying to say to them is the whole point of this you know is not around securing a diagnosis you know (*1:* hmm) it's around um you know trying to kind of explore ways forward (*1:* hmm) and that actually whether you whether you get a d you know whether little Johnny gets a diagnosis or not (*1:* hmm) the paediatrician will will help you th you know think about and signpost path pa onward pathways (*1:* hmm) and obviously we know you know CLASS+ and and you know (*1:* hmm) post diagnostic you know (*1:* hmm) visit um (*1:* but for those parents that) but (*1:* don't get) but that's (*1:* it do they get a say) well that's what I'm saying I you know we don't really have um any data around that (*1:* hmm) what happens (*1:* hmm) you know (*1:* hmm) um I think quite often you know there may be a referral to CAMHS because I think that you know in their in their quite sort of discreet ways you know talking to Danya about this you know they um that's like okay they haven't got autism (*1:* hmm) it must be mental health you know (*1:* hmm) um and so there may be a or it may be ADHD (*1:* hmm) so there'll be a refer referral to CAMHS (*1:* hmm) but I think (*1:* which again or placing it within child aren't they so it is is anything) yeah (*1:* think about okay what can we help on a bi environmental what can we explore in the environmental) yeah (*1:* there isn't that doesn't happen does it) well no well well I mean it uh I don't know um *pause* I don't you know I don't know what paediatricians have the capacity to to do (*1:* hmm) in terms of um you know there may be some linking in with schools and thinking about triple P and you know (*1:* hmm) parenting and stuff (*1:* hmm) and stuff like that but I don't I'm not sure that really (*1:* no)

*Person 1:* I suppose it it just makes of you know in that situation and also like Triple P I've heard from a lot of people it's again it's being done to the pa you're a bad parent (*2:* yeah) and it's not going to wh we we need to in a wes we said said several times if this isn't a conscious thing but e I believe that every parent well mostly they are you maybe that's my blue sky thinking as well they are trying the best that they can (*2:* yeah) with the information that they have with the knowledge they have so being able to be supported and work with to to help them to to create a better understanding and better future for I spose yeah that's where it all comes from in the (*2:* yeah) in the hope that to try and find some that would lead to

further research that could maybe mean interventions are put in earlier in place (2: yeah) um yeah

*Person 2:* yeah well I suppose also um you know I suppose sometimes and it'll be interesting I mean I have occasionally done not for a long time but more in the early days did use to do you know the odd ADOS in clinic (*L:* hmm) and then was you know involved in um with the paediatrician (*L:* hmm) when the paediatrician is giving the diagnosis (*L:* hmm) or sort of not but I kind of think I think the on the odd occasion and probably there is literally two or three times I've done that and not for probably ten years or something and you know I think generally they were all getting a getting a diagnosis (*L:* hmm) um (*L simultaneously:* it would be interesting to) oh well actually there was one cos there was one where um there was a kind of attachment issue and it was not a paediatrician who is there now (*L:* hmm) but the paediatrician you know didn't get a diagnosis but really clumsily made the parent feel like it was her fault she just really (*L:* really) it was blegh so and I like (*L:* you must have been *simultaneously:* cringing) I was sat there and I was I did I think I did sort of interject at one point because you know in a it was like her bedside manner she didn't mean she wasn't at all saying this is your fault (*L:* hmm) but she did she didn't she wasn't careful in (*L:* hmm) you know cos for us we'd be so and we are when I'm talking about that I'm so treading on eggshells that I don't want a parent to feel that (*L:* yeah judged or anything) that that they're being judged yeah and there's poor poor parent was absolutely in floods of tears and I think I did sort of go out and and sort of (*L:* hmm) speak to her a bit in the corridor and kind of say you know the paediatrician's not saying because it was just it was kind of but at least the paediatrician did not feel able to give a a (*L:* yeah) diagnosis but I generally don't know you know what happened you know maybe that I think cos I guess sometimes um you know and again sometimes I might say this to parents when I'm doing my initial you know thing about um you know that's that that idea around you know all children that are you know pretty much all children that are re referred certainly I'd say now I mean a when we first started we were getting lots where I think the paediatrician didn't think they were at all autistic (*L:* hmm) and they were really quite difficult parents (*L:* hmm) and they wanted more ammunition to be able to sort of I really genuinely believe that you know to be able to say to parents look they didn't score very high in the ADOS and the psychologist doesn't think they're they're autistic (*L:* hmm) you know not that we would say that but I would say now they're much more they're always quite close (*L:* hmm) you know they're not very they're not ver always very clear cut it's quite you know um so I think you know most of those children that are being referred into the pathway do present with social communication difficulties (*L:* hmm) now before you you know for I yo saying I'm jeopardising your research you know its wha you you know it's the whole point isn't it is actually you know is that autism why are they presenting with those (*L:* hmm) those behaviours (*L:* yeah) um but I suppose in the context of a di of a diagnosis you know I wonder whether paediatricians are saying you know this doesn't mean your child doesn't have social communication difficulties (*L:* hmm) they just you know they don't (*L:* other reasons behind it) they d well or they're just not at a level (*L:* hmm) that we would give a diagnosis (*L:* hmm) so sometimes I think parents are are going away from those those thinking their children do have not autism but they do have traits of autism (*L:* hmm) but I'm not you know it's not they just can't kind of call it autistic (*L:* hmm) which of course is not maybe exploring other (*L:* hmm) reasons why (*L:* yeah) why these why their children might be presenting in (*L:* hmm) that way um but of course that's you that's really incredibly complex anyway isn't it (*L:* hmm yeah absolutely) but I don't know I don't know like I don't know maybe um are are you gonna talk to paediatricians at all or

Person 1: no that's not that (2: no) not (2: not part of your design) no it would be (2 simultaneously: cos that would be interesting wouldn't it) I I would I wanted to um I mean that's yeah I wanted to and I wanted to do that as but my research supervisor went no you're not doing that (2: no okay) it's because I was wanting to explore you know th things like that and (2: yeah) things like cos it's it's come up with other people about um there being a bit of a discrepancy sometimes between a medical model so more (2: yeah) within child and and us looking you know what's the differences there but she was just like no it's too contentious (2: yeah) I was like oh okay

Person 2: yeah exactly it's sort of what are what are the different you know (1: hmm) could be a f what's the differences in professionals' perceptions (1: yeah) around (1: absolutely) around that (1: yeah) but I also I just would be quite interested in maybe I a question I can ask next time I have a you know we have our uh kind of um PLF meetings you know what do w and it will vary from child to child but what do pa you know are there times when the paediatrician literally just sends the parent off (1: hmm) you know kind of with nothing (1: and what do they do) you know (1 simultaneously: yeah) where do they (1 simultaneously: and then sometimes you get them subsequently trying to do) cause I said again cause I'm kind of feel a bit like am I setting parents up cause I will say you know you will have that clinic (1: hmm) and I do t t generally tell tend to say this you know that you know if you know little Johnny does not um (1: hmm) is not given a da a diagnosis the paediatrician will help to think about (1: hmm) appropriate you know either signpost or to kind of think about other possible (1: hmm) um explanations as to why you know little Johnny's having (1: hmm) having these sort of difficulties

Person 1: but you're saying maybe that's not the case

Person 2: maybe that doesn't happen

Person 1: it could be worth

Person 2: I think that kind of does happen but I'm not sure (1: I'd I'd be interested) I (1: to know laughs) I won you know I wonder what purchase they have over (1: yeah) I mean you know there are no community services are there so I mean what what are paediatricians (1: what is simultaneously on offer yeah) going to you know they can't they're not keeping those o you know they're not sort of saying well I'll see you in six weeks' time (1: hmm) and then um

Person 1: it's all down to money as well isn't it

Person 2: yeah

Person 1: that's it then (2: okay) thank you ever so much (

Person 2: well yeah uh I think it'll be very interesting looking forward to)

STOP

Start second audio



*Person 2:* the Aces um you know but they're not the people that are going going to star jumps and and buying diagnosis are they (*I:* yeah cos like they haven't got the money *simultaneously* to it yeah yeah absolutely) they haven't got the kind of mo they can't afford it so there is a completely different cohort you know that perhaps um you know that may you know and I I'm now hypothesising you know but maybe their their children children have just not worked out the way that they they thought they would (*I:* hmm) and you know through not really wanting to um take responsibility for that you know (*I:* hm hm) go and buy a diagnosis (*I:* hmm) to be able to totally you know not (*I:* exonerate themselves from *simultaneously* that hmm) yeah to to totally separate themselves (*I:* hmm) um but you know I still think they're quite kind of simplistic simplistic ideas (*I:* hmm) and I think it's more complex than that (*I:* hmm yeah absolutely) but hey ho

*Person 1:* thank you

*Person 2:* yep

*Person 1:* thank you