Major Research Project

The significance of autism assessment reports for parents within the wider diagnostic journey

Emily Hickson

Submitted to the University of Hertfordshire in partial fulfilment of the requirement of the degree of Doctor of Clinical Psychology

June 21 2024

Amended Word Count: 31,923

Acknowledgements

First I would like to thank everyone who took part in this study. In particular, I am extremely grateful to the parents who also allowed me to interview them to learn more about their personal experiences of these reports.

Thank you also to my expert by experience consultant for your contributions to this study, not just for your thoughts on the materials and themes for the project, but for the broader insight you gave me into the challenge of trying to get support for your child while juggling other roles and responsibilities.

Suzie, thank you so much for agreeing to supervise me in this project and for being the one to suggest that this would be a worthwhile area for investigation. Ben, thank you likewise for agreeing to supervise this project and for all of your guidance on turning this idea into a much more interesting study than it would have been without your input. I would also like to thank Keith for his support around statistical methods for categorical data, and all those in the course team who facilitated research methods workshops. Lizette, thank you for supporting my late change of topic and trusting me to finish this at my own pace.

Thank you to those in my cohort who have been there alongside me, for your friendship and for making the hard parts of this meaningful.

Fred – thank you for being right here with me and supporting me while I got this thing finished. Soon we can embark on new adventures.

For anyone else reading this – thank you for your interest in this topic!

List of Contents

Table of Contents

List of Appendices

List of Tables

List of Figures

Abstract

Autistic children may need a range of targeted supports, and parents of autistic children encounter various challenges. Existing research shows that the diagnostic journey is lengthy and stressful for parents. Despite an increasing body of literature into parent experiences of the diagnostic process, very little research has looked at parental perceptions of autism diagnostic reports. No research has investigated parent uses of reports. This mixed methods study investigated how parents used autism reports and how helpful and readable they found them, and explored the significance of reports for parents within the wider diagnostic journey. 34 parents of autistic children responded to an online questionnaire including both multiple choice and free text responses, and 5 questionnaire participants also took part in semi-structured interviews. The most commonly reported uses of reports related to the child's education. Reports were largely considered to be easy to understand, but factors that make them harder to read, including parent emotions, use of jargon and raw assessment scores without context, are discussed. Six themes regarding report significance in the wider diagnostic journey were generated using reflexive thematic analysis: 'The importance of proof of diagnosis for validation and understanding', 'Gap between what is promised and delivered', 'Report marks one stage in a journey', 'Grief facilitates moving forward', 'Increased awareness of difference' and 'Peer support bridges gaps'. Questionnaire findings are considered in the context of interview themes. Implications for clinical practice and research are discussed.

1. Introduction

1.1 Overview

This research investigates parental perceptions and uses of their children's autism diagnostic reports, and the value of these reports to them within the broader journey of their children's autism assessment. Adopting a mixed methods approach, descriptive statistics and content analysis are first used to illustrate parental perceptions of a range of aspects of their child's report, the ways they used these reports and how helpful they found them, collected from a questionnaire. Statistical tests of association are used to explore patterns between report variables and perceived helpfulness of recommendations and readability of reports. Interview data from a small sample of questionnaire respondents is thematically analysed to consider the value of autism reports to parents within the wider context of the journey of diagnosis. Finally, themes generated from interviews are used to discuss questionnaire findings in light of this broader significance.

This chapter starts by setting out the researcher's personal position, epistemology and relationship to the area. An introduction to the research topic and wider context follows. A systematic review of the literature on parent experiences of autism diagnostic feedback is then presented. To conclude the chapter, a rationale for the current study is provided and research aims and questions are stated.

1.2 Personal position and epistemology

1.2.1 Positioning

My own positions and context will inevitably have influenced the way this research has been carried out and presented. As a white British woman in my early thirties there are various privileges and cultural ideas I am situated within. My own experiences of disability and relationship to healthcare also influence how I interact with this topic. These impact how I make sense of and respond to knowledge, and how I see and am seen by participants. Instead of trying to remove biases which is arguably an impossible task (Braun & Clarke,

2023) I have tried instead to notice and acknowledge how my own context has shaped research decisions.

As someone who is neither a parent nor diagnosed as autistic, I am an outsider to my participants' experiences. I became interested in autism through my work with autistic young people and families awaiting autism assessment on placement, and subsequent work in an autism assessment service. Hearing from parents about the problems they were having accessing support while waiting for assessment increased my understanding of the emotional significance of this assessment for families. I also noticed the way that referrals for autistic children were often 'bounced' between services due to the complexities involved in the clinical presentations, and the perception of difficulties as being 'due to autism' or 'due to mental health' by different services, which impacted on who would be considered responsible for their care. My interest in parental views on diagnostic reports stemmed from my time spent writing parts of reports in an assessment service, and from discussions with my supervisor in which we wondered which parts of what we wrote were actually helpful to parents, and how these reports ended up being used.

It is also worth acknowledging my position as a trainee with corresponding time constraints, as this has undoubtedly shaped my research choices. Following a period of ill health and late change of research topic, my timeline for this research was particularly short with much of it being carried out alongside post training employment. Speed was therefore a priority, and methods were selected with this in mind. Despite this, care was taken to avoid compromising the quality of the project by making the most of the time available, adhering to methodological guidance and by discussing methods with my supervisors and in research methods workshops.

1.2.2. Epistemology

This current study aims to understand how parents use autism reports and how they are perceived, as well as what their value is within the broader assessment journey. As such, I am interested both in something that might be viewed as objectively factual (uses of reports) and in things that seem more subjective (parent perceptions of reports, and their value within a broader journey). I have approached this research from the position that there is a reality independent of the mind in which is it preserved, which can be meaningfully reported on, and that the way this reality is perceived is impacted by many things. Therefore the same reality can be experienced very differently by different people.

This can be described as a critical realist epistemological position (Pilgrim, 2019). A reality is acknowledged (hence ‘realist’), but is also viewed through a critical lens (‘critical realist’) which supposes that the way reality is perceived can also be explored and made sense of and is worthwhile of study. This position therefore lies somewhere between traditional realism (which only considers an objective reality as the object of knowledge (Hibberd & Petocz, 2023)) and relativism (which does not accept the legitimacy of knowledge independent of the mind or context perceiving or producing it (O’Grady, 2014)).

1.2.3. Reflexivity

Given the impact my own ideas, positions and context will have on my research decisions and interpretations, it seems important for me to reflect on these interactions and aim to understand and communicate these (Braun & Clarke, 2023). I have attempted to do this in a number of ways. I have kept a reflective research journal throughout the process of carrying out this study (see Appendix A), recording thoughts, observations and discussions with others that have impacted my research choices and interpretations. I consulted with an Expert by Experience whose child was recently diagnosed with autism at various points in the project, who influenced my thinking on certain points. I also attended research methods workshops with other trainees who encouraged me to think reflexively and offered feedback on initial coding, noting the different ways extracts could be meaningfully grouped together.

1.2.4. Language

There are ongoing debates around what language is appropriate to use when describing autism (Kenny et al., 2016). The diagnosis made within NHS services is currently ‘Autism Spectrum Disorder’ (ASD) (American Psychiatric Association (APA). 2022). Another term increasingly used and preferred by some is ‘Autism Spectrum Condition’ (ASC) (Baron-Cohen, 2023). This term reflects the idea that autism in and of itself represents a difference rather than a disorder as such, and that the ‘disorder’ affecting autistic people arises from a mismatch between the autistic condition and an environment not designed with autistic people in mind, rather than the state of disorder being located within the individual. This is in line with the social model of disability (Oliver, 2013).

While acknowledging the imperfect nature of ‘ASD’, this term will be used at times when referring to the diagnosis that is given following assessment, in keeping with the research focus on diagnostic feedback. More broadly, ‘autism’ and ‘autistic’ are used.

1.3 The wider context

1.3.1 Autism

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by differences in social communication and behaviour. Specifically, under the Diagnostic and Statistical Manual 5 (DSM–5; American Psychiatric Association, 2013) - the diagnostic manual developed in the USA - it includes ‘persistent deficits in social communication and interaction across multiple contexts’ and ‘restricted, repetitive patterns of behaviour, interests or activities’ (American Psychiatric Association, p50, 2013).

The way autism is conceptualised, and its diagnostic criteria, have changed over time. For a full review of the history of this evolution, see Rosen et al. (2021). For the purposes of this study it is simply helpful to know that since the DSM-5 was launched in 2013, Autism Spectrum Disorder has been used to refer to a single diagnosis based on multiple dimensions. This differs from previous diagnostic classification systems such as the DSM-IV-TR (DSM-IV-TR; American Psychiatric Association, 2000), in which a class of ‘pervasive developmental disorders’ was presented, including a number of disorders that might now be considered to be related to autism. For instance, previously Asperger Syndrome was a diagnosis referring to people showing differences in social communication and behaviours but without intellectual impairment or significant language delay. In the DSM-5, this diagnosis was incorporated into the broader diagnosis of Autism Spectrum Disorder. The International Classification of Diseases 11 (ICD-11) - the World Health Organisation (WHO)'s diagnostic manual which is officially recognised by the NHS - likewise adopted this broader conceptualisation in 2018 (World Health Organisation, 2022). This diagnosis therefore includes a wide range of different presentations with differing levels of need for support. Given these changes in its conceptualisation over time, public understandings of the term autism may vary.

Another shift in thinking around autism has taken place recently, with increasing use of the term neurodiversity to refer to the range of neurodevelopmental differences existing within the population (Aitken & Fletcher-Watson, 2022; Kapp et al., 2013), although this has not been without controversy (Ellis, 2023). The term 'neurotypical' refers to those who have had a typical neurodevelopmental trajectory, as opposed to those with neurodevelopmental differences seen in conditions such as autism and ADHD who might be termed 'neurodivergent'. When thinking about neurodiversity, neurodivergent behaviours and styles are viewed as part of the range of information processing styles in the population, rather than as deficient. Instead of being conceptualised as intrinsically problematic, these differences are something that might lead to difficulties due to the environment having been largely designed with the needs of neurotypical people in mind, and under the right conditions the difficulties experienced due to differences may be minimised (Aitken & Fletcher-Watson, 2022). Increasingly, clinicians are likely to be keeping this in mind and aiming to incorporate neuro-affirmative language in feedback and reports.

1.3.2 Support needed for autistic children

Autistic children may need a range of adjustments and supports for their wellbeing, including input around speech and language, specialist educational provision and/or adjustments in their education, and support for mental health. Some areas where such support might be beneficial are described below.

1.3.2.1 Occupational and speech and language therapy

Differences in communication are a key part of autism, and some autistic children struggle with speech. Some children might not speak at all, or might use speech in limited ways, for instance speaking in ways that are very repetitive or noncommunicative. It has been estimated that 30% of autistic children may remain minimally verbal (Tager-Flusberg & Kasari, 2013). Speech and language therapy can provide important support for these children, to develop language skills and arrange communication aids where appropriate (Smith & Gillon, 2022). Similarly, many autistic children have difficulties filtering sensory information. Occupational therapy can provide advice and interventions around this, and suggest adaptations to the child's environment to reduce overwhelm (Case-Smith & Arbesman, 2008).

1.3.2.2 Support in education

Many autistic children need adjustments put in place to access education. These might be changes made by the child's current school, or specialist educational provision might be required. Children can struggle with sensory overload in busy classrooms, have difficulties in interactions with other children and teachers, and changes in routine might cause a lot of stress (Horgan et al., 2023). These stressors can contribute to some children exhibiting behaviour that challenges. In turn, teachers and other children may treat the child as though they were being naughty, impacting on the way the child sees themselves, reducing confidence and contributing to anxiety at school.

Anecdotally, other difficulties might arise when school does not see difficulties, which instead may occur at home. This may happen if a child puts a lot of effort into holding in their feelings to cope with the difficult school environment and then experiences meltdowns or exhaustion at home. Schools might not agree with the need for making adaptations to the child's school environment when they are not seeing any disruption at school.

For some children, school can become such a source of anxiety that they stop attending altogether, resulting in emotionally based school avoidance (EBSA). This is more common in autistic children than neurotypical peers (Munkhaugen et al., 2017). It can then be very difficult to return, and parents may face fines from the local authority. This can result in further pressure on the child, guilt and more emotional difficulties. An Education, Health and Care Plan (EHCP) might be needed in order to assess and agree upon steps needed for the child, along with additional funding to put these provisions in place. Guidance is that this should be provided based on need, and not on diagnosis, however research suggests this is not always what parents experience (Keville et al., 2024).

1.3.2.3 Support for mental health

Mental health conditions are more common in the autistic population than in the general population, and many autistic children experience difficulties with their mental health. In particular, research suggests that anxiety is highly prevalent in autistic young people (White et al., 2009). Despite this, accessing mental health treatment can prove difficult for many autistic young people, and Hepburn et al (2014) found in their UK sample of autistic young people with complex mental health comorbidities that many received little to no intervention.

Autistic young people face specific barriers to accessing mental health treatment. Autistic children have differences in mental health presentations (Mattila et al., 2010; Pugliese et al., 2013) which commonly used clinical assessment tools might not pick up on (Glod et al., 2017). This may lead to underestimations in mental health services of the difficulties experienced by autistic children. Difficulties with interoception and awareness of one’s emotions in autism can pose barriers to young people articulating their difficulties in assessments with professionals (Crane et al., 2019; Ozsivadjian et al., 2012). It might also be that mental health professionals struggle to distinguish between autism symptoms and mental health difficulties, or perceive clinical distress as ‘normal’ for autism (O’Nions et al., 2024). One of the key concerns raised by coroners over deaths of young autistic people in recent years has been the failure by health services to treat autism and mental health problems as two separate conditions (‘Young Autistic People Still Dying despite Coroner Warnings over Care’, 2023).

1.3.3 Impact on parents

Parenting an autistic child can be a stressful experience, particularly when support services are limited (Falk et al., 2014; Papadopoulos, 2021). In the same way that autistic children can be labelled by others as ‘naughty children’, their parents can feel judged as bad parents, particularly when children are not yet diagnosed as autistic and others may not understand the child’s behaviour (Gill & Liamputtong, 2013). Stigma associated with autism can also impact on parents as well as their children (Gobrial, 2018).

Parents may need to learn lots of strategies to support their child and make changes to accommodate their needs, in addition to liaising with various professionals to try to get support for the child. These demands can be burdensome and impact on parent wellbeing. Mothers of autistic children report more difficulties across family life (Meadan et al., 2010; Nealy et al., 2012) and reduced social networks (Gobrial, 2018). Coping with mental health and behavioural comorbidities in autism can also contribute greatly to parenting stress (Miranda et al., 2019). Studies indicate that caregivers for autistic children often experience difficulties with their own mental health (Schnabel et al., 2020) and higher levels of stress than caregivers of typically developing children (Hoffman et al., 2009), and also compared to parents of children with other neurodevelopmental conditions such as Downs Syndrome and ADHD (Hayes & Watson, 2013). On top of the challenges that can come from parenting an autistic child, there is also growing evidence of increased rates of significant trauma, mood and mental health difficulties in parents of autistic children prior to the birth of the autistic child, suggesting that this population may be more vulnerable even outside of the challenges specific to parenting autistic children (Bolton et al., 1998; Jokiranta et al., 2013; Roberts et al., 2013, 2014, 2016).

Additionally, there is an economic burden associated with parenting an autistic child due to the cost of special educational provision and therapies if these are not provided by the state, with some authors estimating that it can cost twice as much to parent an autistic child then a typically developing child (Montes & Cianca, 2014).

All of these impacts on the child and their family mean that seeking an assessment is often a high priority for parents.

1.3.4 Autism assessment

Autism is not an illness and so cannot be treated, however there are nonetheless important purposes to its diagnosis. For instance, some autistic people may benefit from interventions to help with particular skills as described above. A diagnosis helps to ensure that appropriate, evidence based interventions are selected. Within healthcare, a diagnosis can help clinicians to adapt procedures and interventions to make them more accessible for autistic people. More broadly, a diagnosis facilitates statutory protections such as an Education, Health and Care Plan (EHCP) and those granted by the Equality Act 2010. Finally, many autistic people find that diagnosis can be validating and helpful in developing a positive autistic identity and connection to a wider autistic community. For parents, diagnosis can be helpful in understanding their child's behaviour and in explaining their child's needs and differences to others.

No diagnostic biomarkers have been identified for autism, meaning no biological tests can be used to determine if someone is autistic. Diagnosis is therefore based on expert clinical judgement about whether someone meets the diagnostic criteria, based on observable behaviour and another person's report about their developmental history. None of the diagnostic criteria are exclusive to autism taken individually, and there is significant overlap with features of numerous other neurodevelopmental, mental health and communication conditions. Autism also commonly co-occurs with other conditions. This means that it is essential to consider differential diagnoses as part of autism assessment.

NICE guidelines state that all assessments should include a detailed discussion about presenting concerns and background information, a developmental history, an assessment of social communication skills and behaviours, medical history and physical examination, consideration of differential diagnoses, profile of the young person's strengths and needs, and communication of assessment findings to the parent and/or young person (Montes & Cianca, 2014).

Diagnostic criteria used may vary across services. In the UK, the International Classification of Diseases (ICD) is the diagnostic manual that officially applies in the NHS in England. The newer ICD-11 is gradually replacing the ICD-10, but is not yet mandated. Additionally, many services use the DSM-5 diagnostic criteria. As DSM-5 criteria are very prominent in research they are referred to in clinical guidelines, and a number of standardised tools used in autism assessment in the UK were designed using DSM-5 criteria. Diagnostic criteria for autism are similar across the ICD-10, ICD-11 and DSM-5, but not identical.

NICE guidelines recommend that autism assessment for young people should begin within 3 months of referral (NICE, 2017). However, demand for autism assessment has skyrocketed over the past 20 years, and now exceeds capacity. The Covid-19 pandemic further impacted provision of autism assessment, as assessment capacity was profoundly reduced throughout 2020. Waiting lists have grown drastically, and NHS digital reported in 2022 that more than 125,000 people were waiting for assessment. The waiting time for a child to receive an assessment may therefore be several years in some areas.

1.3.5 Parent experiences of the diagnostic journey

Parents seek assessment in the hope that diagnosis will explain child’s difficulties and give them a greater understanding of their needs (Jacobs et al., 2020). However, studies over the years have repeatedly shown that many parents are dissatisfied with the diagnostic process (Brogan & Knussen, 2003; Chamak et al., 2011; Crane et al., 2016; Goin-Kochel et al., 2006; Howlin & Moore, 1997; Siklos & Kerns, 2007). This presents a problem, because there is evidence that parent engagement with recommended interventions can be reduced if parents were dissatisfied with the diagnostic process (Osborne & Reed, 2008).

Most parents want autism assessment to be a quicker, easier process (Osborne & Reed, 2008). Lappe et al (2018) describe the current journey to autism diagnosis as an ‘Odyssey’ due to the length and difficulty of this for parents, who experienced uncertainty and frustration around service delays and trying to navigate advice from different sources. Delays in accessing diagnosis have been linked to assessment dissatisfaction (Abbott et al., 2013; Howlin & Moore, 1997), and Goin-Kochel et al. (2006) found that parents who saw fewer professionals and received early diagnosis were more satisfied, and that parents saw 4 professionals on average prior to diagnosis. Similarly, Siklos and Kerns (2007) found that parents typically see 4 or 5 different professionals before diagnosis.

Delays are nonetheless common. Crane et al (2016) found that parents often waited a year before seeking advice after noticing differences in their child, and many reported having their concerns dismissed initially by professionals, with an average time from first professional contact to diagnosis being 3.5 years. Likewise, studies have reported parents being told their child will grow out of it, that it is too early to diagnose, or even that they as parents were neurotic (Zuckerman et al., 2015).

Factors positively correlated with assessment satisfaction include good relationships with professionals in which parent concerns are taken seriously, fewer consultations prior to diagnosis, and a good quality and amount of information provided about autism, along with this being shared in a sensitive manner (Brogan & Knussen, 2003; Hasnat & Graves, 2000; Moh & Magiati, 2012).

For an in-depth scoping review of literature on parent experiences of autism assessment internationally see Makino et al (2021), who found that publications concerning parent experiences of autism diagnosis increased sharply after 2016. The authors group papers into different stages of diagnosis and discuss findings – the journey to assessment, the assessment process, delivery of diagnosis, and post diagnostic information. Similarly, for an excellent review of parent experiences of autism assessment in the UK, see the systematic review carried out by Legg & Tickle (2019). The authors identified 11 papers and unpublished theses examining the diagnostic experiences of UK parents, again highlighting findings relating to different stages of the diagnostic journey.

1.3.6 Autism diagnostic reports

A report detailing the findings of an autism assessment should be provided by the diagnostic service. NICE guidelines say that this should include the outcome of the assessment and the reasons this conclusion was reached, should be shared within six weeks of the assessment, and a follow up appointment offered to discuss any further questions parents might have (NICE 2017). NHS operational guidance says that reports should include written recommendations to address the young person's current needs and to maximise wellbeing (NHS England 2023).

It is important that while reports need to convey a lot of information, they should also be written in a way that can be easily understood. It has been demonstrated that around 43% of adults in the UK lack the literacy skills necessary to routinely understand health information (Rowlands et al., 2015). Simple language without jargon and a clear structure are therefore likely to be important qualities of a good report.

Findings related to the role of written reports can be found within broader investigations into parental experience of autism assessment, although only one study has been published with this as its primary focus (Wilson & Gunn, 2022). These authors carried out a study looking specifically at what parents want in reports, and found that families want a lengthy and detailed report which is sensitively written and reflects the young person on their own terms. Additionally, parents wanted reports to celebrate the young person's strengths and provide meaningful recommendations. They wanted reports to have a clear and accessible structure and language, and to be direct but tactful, and accessible to the young person themselves. Parents wanted to be able to understand the process behind the conclusion from what is written. They also wanted reports to facilitate sharing of information across different settings.

Broader investigations have found that satisfaction with the assessment report strongly predicts parent satisfaction with the overall diagnostic process (Eggleston et al 2019). Mockett et al (2011) reported that most parents received a diagnostic report and 65% claimed to 'definitely understand' it and 20% to understand it to 'some extent', and that parents would have preferred less medical terminology in reports. Hennel et al (2016) recommended a tailored 'autism action plan' be included in reports with recommendations specific to the child to improve parental satisfaction with reports.

1.4 Systematic Literature Review Rationale

Overall, the literature suggests that the process of having an autism assessment is stressful and lengthy for parents. Parents face delays in getting an assessment for their child while struggling to support their children's needs (Crane et al., 2016; Zuckerman et al., 2015). When the assessment comes, many are dissatisfied with how it was conducted (Legg & Tickle, 2019). The information parents receive plays in important role in satisfaction with the assessment overall, and autism reports are key in providing this information, to the point that satisfaction with reports strongly predicts satisfaction with the assessment (Eggleston et al., 2019).

Numerous studies have explored parent experiences of autism assessment in general, which have been well reviewed (Legg & Tickle, 2019; Makino et al., 2021). Within these some have included insights into parent experiences of receiving diagnostic feedback. Fewer studies have investigated parental experiences of receiving diagnostic feedback as their primary focus, and at the time of writing only one has focused on parental experiences of written feedback specifically (Wilson & Gunn, 2022).

A novel systematic review of the literature on parental experiences of diagnostic feedback, focusing exclusively on this aspect of the diagnostic journey distinct from broader diagnostic experiences could help clarify what makes diagnostic feedback more or less helpful. Understanding this can help shed light on the role of autism diagnostic reports as a form of written feedback within this process.

Systematic Literature Review

1.5 Overview to Systematic Literature Review

The way that autism assessment observations and diagnostic decisions are shared with families is an important part of the diagnostic journey. In children's disability more broadly, Taanila et al (1998) found parents who had negative experiences of diagnostic interview were 5 times more likely to experience insecurity and helplessness than those satisfied with it, and research into the autism diagnostic journey suggests that diagnostic feedback plays a similarly important role in autism specifically (Osborne & Reed, 2008). Additionally, communicating a neurodevelopmental diagnosis to parents can be experienced as difficult and stressful by professionals (Bartolo, 2002; Brand-Gothelf et al., 2021). Understanding what factors are important in this delivery is therefore beneficial from multiple perspectives.

1.5.1 UK guidelines

Guidance exists in the UK about best practice for communicating a diagnosis of autism in children (NAPC 2003; NICE 2011; NICE 2023). This stresses several factors, including allowing enough time for discussion with families, following the lead of the parents in what they want to discuss, and giving families an opportunity to respond to the feedback given. Conclusions should be shared sensitively, in person and promptly, and should include an explanation of what ASD means and how it can affect development and functioning. The language used should be respectful and not deficit based. A detailed written report of the assessment should be provided, and a follow up appointment offered within 6 weeks to discuss further questions parents may have. Additionally, further information about autism should be provided and parents signposted to the National Autism Society as well as local autism support organisations.

1.5.2 Other frameworks

A range of strategies have been proposed for sharing a diagnosis with parents. It has been suggested that parents should be considered ‘lay’ clinicians (Arksey, 1994), and should be consulted as experts in their own right (Avdi et al., 2000). Rigazio-DiGilio (2000) proposed a relational framework of sharing a diagnosis with parents offering opportunity for meaning making. McLaughlin (2005) reviews literature on this in more depth.

1.5.3 Parent experiences of diagnostic feedback

Some studies into parental experiences of autism diagnosis more broadly include findings on parent experiences of diagnostic feedback as part of this, although few studies have this as their primary focus. The main findings are summarised below.

1.5.3.1 Dissatisfaction and stress

Some parents are dissatisfied with way autism diagnosis was communicated to them (Brogan & Knussen, 2003; Hackett et al., 2009; Mansell & Morris, 2004; Osborne & Reed, 2008). The manner of clinicians delivering feedback has been reported as impacting on this. Other parents felt the assessment process and feedback were done respectfully and professionally, but wanted more follow up support (Hackett et al., 2009).

Receiving an autism diagnosis can be stressful for families (Osborne and Reed 2008; Osborne et al 2008). Studies looking at broader disability suggest that how stressful it is may depend on the manner in which diagnosis is given (Sloper & Turner, 1993). Autism diagnosis being delivered in a direct manner with lots of information and support may decrease stress experienced by parents (Futagi & Yamamoto, 2002; Hasnat & Graves, 2000; Osborne & Reed, 2008).

1.5.3.2 Role of information

The quality and amount of information provided during diagnostic feedback was raised as an area for improvement by parents in many studies. Mockett et al (2011) found parents thought written information provided about autism and support available could be improved. Hennel et al (2016) found that parents wanted more information than could be provided in a single consultation, and also that they highly valued information about accessing allied health professionals and about the meaning of diagnosis, but that paediatricians rarely offered information about these things. Klein et al (2011) found that readiness to absorb information beyond the diagnosis itself depended on whether parents already knew much about the condition prior to diagnosis. Parents who are the most anxious about a diagnosis of autism have been found to experience a greater need for information (Anderberg & South, 2021). Parents tend to be more satisfied when given a greater amount of information about autism (Hasnat & Graves, 2000), but can also be overwhelmed by the amount of new information and therefore prefer to receive written material to process over time, rather than having to seek out potentially unverified information from lots of different sources (Osborne & Reed, 2008). Parents have found information books useful when provided following diagnosis (Mulligan et al., 2010).

In healthcare more widely, the need for information to match parents' level of understanding has been emphasised when breaking news like a diagnosis (Girgis & Sanson-Fisher, 1995). However, professionals might not notice when parents' understanding of the information they are giving is reduced (Butow et al., 1996) and so may not anticipate what parents need. In autism diagnostic feedback parents want professionals to convey information in a way that is easy to understand, avoiding jargon and technical terms (Brogan & Knussen, 2003), also valuing the possibility of follow up contact with professionals for further questions that may occur (Nissenbaum et al., 2002).

A systematic literature review was planned to develop a more comprehensive view of studies investigating parent views of autism diagnostic feedback.

1.6 Systematic review method

The current review used established methodologies for systematic reviews, as described in the Centre for Reviews and Dissemination Guide for Undertaking Reviews in Healthcare (2009). A Mixed Studies Review with a narrative synthesis was used to systematically identify, select, critically appraise and synthesise the narrative element of qualitative, quantitative and mixed methods studies. This approach was relevant to the review question, providing a better overall understanding of the findings than a single approach to research.

Initially a question around perceptions of autism diagnostic written reports specifically was considered. Initial background reading and searching on google scholar and revealed very little published on this topic, beyond Wilson and Gunn's recent study which investigated what parents want from autism diagnostic reports (2023). More findings were reported on parent views on other forms of diagnostic feedback, such as the way the diagnosis of autism was communicated and what this session involved. Written reports represent one specific form of feedback. Understanding what parents value within feedback more broadly could help in understanding what parents need in written reports and provide important context for the ways in which they use written reports. The review question was therefore set out as: What does the existing literature say about parental views on autism diagnostic feedback?

In carrying out the search the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement was followed (Moher et al, 2009). A systematic search using CINAHL, Medline, Scopus and PsycArticles was conducted on 17/08/2023. These databases were chosen as they were identified as relevant to the field concerned. A search strategy was developed in consultation with a university librarian, using the University of Hertfordshire library search planning tool. Search terms included identifiers for autism connected by OR (e.g. autism, Asperger) linked by AND to identifiers for parents (e.g. parent, mother, father), identifiers for assessment (e.g. assessment, diagnosis), identifiers for feedback (e.g. feedback, report, delivery), and identifiers for views (e.g. perception, opinion). The search terms used are presented in Table 1, and the same search terms were used in all databases. If there was an option of selecting a time period for publication, 1994 to present was selected. This is because 1994 is when the DSM-IV criteria for autism were published, and when autism was first conceptualised as a spectrum. Inclusion and exclusion criteria are presented in Table 2. The exclusion criterion 'diagnostic feedback is not primary focus' was used to exclude papers which examined broader parent experiences of their child's autism diagnosis without a particular focus on diagnostic feedback. If a paper's title and abstract indicated that diagnostic feedback might be a large part of what was being considered then the full text was screened and if diagnostic feedback was a major focus of investigation then this was included.

Table 1: Search strategy

Key concept	**Terms used**
Parental relationship	parent* OR mother* OR father* OR caregiver* OR maternal OR paternal
Autism	autism OR ASC OR ASD OR asperger* OR ‘autistic spectrum disorder’ OR ‘autistic spectrum condition’ OR ‘autism spectrum disorder’ OR ‘autism spectrum condition’
Assessment	Assessment OR diagnosis OR diagnostic OR evaluation
Feedback	report OR feedback OR delivery OR information OR letter
Experiences	Perspective* OR view* OR perception* OR satisfaction OR opinion* OR experience*

Table 2: Inclusion/exclusion criteria

Inclusion	Exclusion
• Primary focus of study concerns parental views on diagnostic feedback from their child’s autism assessment • Full text available in English • Published after 1994	• Diagnostic feedback is not primary focus • Study does not focus on parental views • Not presenting original research (e.g. review papers) • Full text not available in English • Published prior to 1994

Much of what is known about parental views of diagnostic feedback from autism assessments can be found in broader studies looking at overall experiences of the diagnostic journey, with findings related to feedback making up only a small part of what was reported overall and not always indicated in study abstracts. It was beyond the scope of this review to identify or include all studies that reported anything concerning this, although a relatively recent scoping review investigating parental experiences of diagnosis more broadly (Makino et al 2021) identifies 39 such papers and reports on key findings, broadly summarised above within the background section. For the purposes of this systematic review only papers investigating parental perceptions of diagnostic feedback as their primary focus were included. Papers which investigated parent experiences of their children’s autism diagnosis more broadly, but which did not specifically focus on experiences of diagnostic feedback, were excluded. This was determined initially by screening titles and abstracts, and then full text review of papers which seemed like they might contain a major focus on diagnostic feedback based on the abstract. A limitation of this is that noteworthy findings will have been missed if they did not make up a major focus of a study – e.g. papers on parent experiences of the diagnostic journey overall, which might have touched on this but not looked at this aspect in great depth in its own right.

Grey literature was not included due to the time constraints of this project. This meant that unpublished studies were excluded, and it is possible that significant and worthwhile findings may have been missed by this review as a result. Publication bias often means that significant findings are overrepresented in reviews excluding grey literature and non significant findings underrepresented. The papers on this topic are more descriptive than hypothesis driven so statistical significance may not be as relevant as in some topics, however it remains possible that publication bias has impacted the findings that have been published on this topic. Worthy findings might also simply have been unpublished due to constraints on the time and resources of authors.

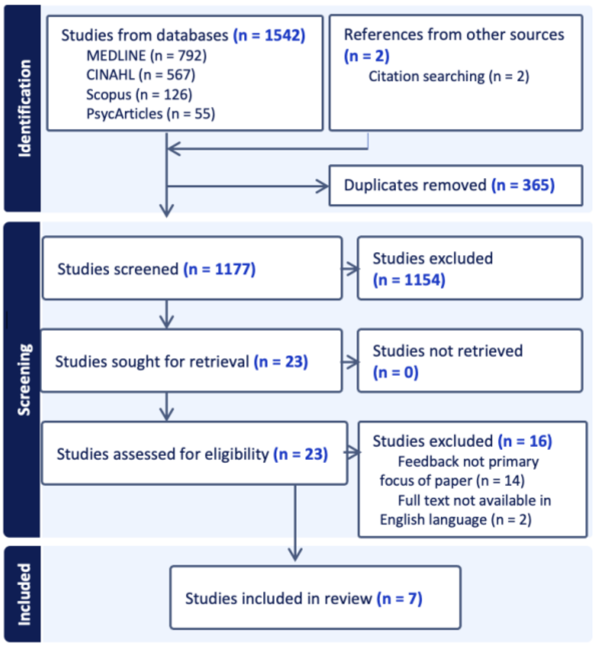
The search was not restricted to a specific methodology due to there being a range of valid methods to address the question, including qualitative approaches such as interview studies and quantitative descriptive approaches such as questionnaires. This is therefore a mixed methods review with a narrative synthesis of findings.

1.7 Search procedure

A systematic procedure was followed to arrive at the final collection of papers included. Initial search results were exported to Covidence to facilitate reviewing. Duplicate records were removed and titles and abstracts were screened for relevance. Articles of potential relevance were included for full text review. Full texts of relevant articles were assessed for eligibility by reading and judging whether they contained substantial consideration of parent experiences of diagnostic feedback. Backwards hand searching reference lists of texts included in full text review was performed to identify additional studies that may have been missed, and the paper by Nissenbaum et al (2002) was identified this way and included for full text review. Forward searching of studies that had referenced those included was also carried out, as was an informal search on Google Scholar.

Figure 1 presents a flow chart of search results and Prisma screening process (Page et al., 2021).

Figure 1: PRISMA flow diagram



1.8 Systematic literature review results

The search strategy identified 1177 articles after 365 duplicates were removed, and 1154 of these were excluded at the title screening stage. 23 were retrieved and full texts screened for eligibility. Two of these was identified from hand searching reference lists of other included studies. Of these 23 papers 16 were excluded, 14 due to diagnostic feedback not being the primary focus of the paper (e.g. the focus was broader, or exclusively on another aspect of diagnosis) and 2 due to not being available in English language.

The type of data to be extracted was determined by the nature of the studies and guided by the Centre for Review and Dissemination guidance. The data extraction checklist included the following headings: Authors, title, year of publication and location; study aim; methodology; sample characteristics; key findings and strengths and limitations. This information was recorded in excel and is summarised in Table 3.

1.9 Findings summary

Table 3: Summary and evaluation of Studies in the Systematic Literature Review

Table 3: Study characteristics of all included articles

Title, date, location	Study aim	Methodology	Sample	Key findings	Strengths and limitations
Abbot, Bernard and Forge (2013) Communicating a diagnosis of ASD - a qualitative study of parents' experiences. UK	To investigate the experiences of parents receiving a diagnosis of ASD for their child in a CAMHS service in the UK.	Qualitative semi-structured interview approach. Analysed using a general inductive thematic analysis.	Nine sets of parents of children diagnosed with ASD within the previous 6 months. Mean age of children at diagnosis 11.2 years, range 8-15, all white British, 89 % male, 89% lived in two parent families, range of socioeconomic backgrounds.	Four key themes identified: Parents' emotional state and reactions to diagnosis, amount and clarify of information, structure of session and consultation style and relationships with clinicians.	Strength and limitation: older age of children at diagnosis due to CAMHS setting means experiences likely to be different to those of parents of children diagnosed at younger age. Interview based approach gives richer depth of individual experiences than quant methods, though less possible to generalise findings
Brogan & Knussen (2003) The disclosure of a diagnosis of an autistic spectrum disorder: Determinants of satisfaction in a sample of Scottish parents. Scotland, UK	To investigate determinants of parental satisfaction with disclosure interview of ASD diagnosis	Quantitative, cross sectional questionnaire study. Relationships between range of variables and parent satisfaction with diagnosis disclosure examined using Chi square and ANOVA.	126 parents (73%mothers, 27% fathers) of 96 children (85% male) diagnosed with autistic spectrum disorders including Asperger syndrome (mean age at diagnosis 55 months ranging from 14 to 180 months. 77% diagnosed with autism, 16% Asperger syndrome, remainder given diagnosis including autistic features or tendencies.	55% satisfied or v satisfied with disclosure. More likely to be satisfied if positively rated manner of professional and quality of info provided, if had been given written info and chance to ask questions, and if early suspicions were accepted by professionals. Higher satisfaction also linked to diagnosis of Asperger syndrome, a definite diagnosis, and children not currently in an educational placement.	Strengths - Relatively large sample size, includes several factors related to satisfaction. Limitations - Response rate low, findings might not generalise to target population. Higher socioeconomic status overrepresented in sample. Large proportion of variance remained unexplained in multiple regression analysis.

Chiu, Chou, Lee, Wong, Chou, Wu, Chien and Gau (2014) Determinants of maternal satisfaction with diagnosis disclosure of autism. Taiwan, China	To: 1) describe current practice of autism diagnostic counseling in Taiwan. 2) evaluate maternal satisfaction with diagnosis-informed counseling 3) identify factors related to maternal satisfaction 4) present ideal diagnosis-informed counseling guidelines	Quantitative, cross sectional questionnaire study. Stepwise linear regression used to identify significant predictors of maternal satisfaction with diagnostic feedback.	151 mothers of 151 children (87.4% male) with diagnosis of DSM-IV autistic disorder, receiving a treatment program prior to 6 years of age, and living with both parents. Parents of children with Asperger syndrome or other pervasive developmental disorders excluded. Mean child age at diagnosis not reported, range 3 – 12.	Satisfaction with diagnostic feedback was related to attitude of professionals and timing and duration of feedback, more than to its content. Parents' 'social desirability', educational level and employment status were negatively associated with satisfaction with feedback. Majority of mothers preferred to be informed of the diagnosis only after it had been confirmed, rather than when first suspected.	Strengths - First study to look at Chinese population. Relatively large sample size, includes several factors related to satisfaction. Limitations - subject to potential recall bias as data not collected immediately following diagnostic feedback, sample restricted to those diagnosed with one autistic presentation under DSM-4.
Jurin, Simlesa and Cepanec (2022) Parental perception of the process of communicating a diagnosis of autism spectrum disorder in the Republic of Croatia. Croatia	To examine the experiences of parents in Croatia regarding the process of communicating a diagnosis of ASD, and to determine the level of satisfaction with various characteristics of this.	Quantitative, cross sectional questionnaire study. Correlations were examined between satisfaction with feedback and range of variables.	52 parents (96% mothers) of children suspected to have or diagnosed with ASD aged 0-7 within the last 18 months. Mean age of child at diagnosis not reported, range not reported.	82.6% parents satisfied with feedback. Positive correlation found between parental satisfaction and positive characteristics in variables related to experts' communication, space and time characteristics and the information given.	Limitations – not all children included had actually been assessed for autism, some only suspected of being autistic. Sample recruited through organisations providing support, so participants might be more satisfied than those not accessing these organisations and findings may not generalise. Self-selecting sample, those who chose to participate

					might have had more positive experiences.
Mulligan, MacCulloch, Good and Nicholas (2012) Transparency, Hope and Empowerment: A Model for Partnering With Parents of a Child With Autism Spectrum Disorder at Diagnosis and Beyond. Canada	To examine the experiences of parents receiving a diagnosis of ASD for their child.	Qualitative semi-structured interview approach. Content analysis used to generate themes.	10 parents (8 mothers 2 fathers) of children diagnosed with ASD (all boys, mean age 4.8 years, range not reported)	Themes generated related to experiences of diagnostic feedback: Preference for diagnostic information in a hopeful tenor, and feeling overwhelmed with information and emotion at diagnosis Recommendations for feedback provided by authors.	Strengths: Purposive sampling used to get variety of demographics. Good researcher awareness of own positions and methods used to note bias. Member checking and peer debriefing used to explore findings.
Nissenbaum, Tollefson and Reese (2002) The Interpretative Conference: Sharing a Diagnosis of Autism with Families. USA	To examine professionals' and parents' perceptions of giving and receiving a diagnosis of autism.	Qualitative unstructured interview approach. Transcripts analysed using naturalistic inquiry to generate categories of findings which then informed recommendations.	17 parents (15 mothers 2 fathers, majority white ethnicities, majority affluent) of 15 children diagnosed with DSM 4 autism, Asperger syndrome or PDD NOS within the past year, and 11 nonmedical professionals. Mean age at diagnosis 4 years, range 3-7 years.	7 categories generated: Perceptions of the definition and outcomes of autism, how the diagnosis of autism is presented to families, a comprehensive view of important issues, reactions to giving and receiving a diagnosis of autism, recommendations regarding how to improve the interpretative conference, families' stories and miscellaneous. 9 recommendations given by authors.	Methodological log, member check.
Wilson and Gunn (202). What parents want in an autism diagnostic report: An interview-	To assess how well a service's autism assessment reports met	Mixed methods. Structured telephone interviews or written	30 parents of children who had recently been diagnosed with autism. Mean	Parents want detailed, balanced and sensitively written reports. Reports should be	The only paper found on parent experience of autism diagnostic reports.

based study of parents accessing a neurodevelopmental assessment service. UK	principles set out in NICE guidelines according to parents, and to explore more generally how parents found reports.	questionnaire - closed questions with option to add comments. Descriptive statistics generated for quantitative data, and qualitative comments thematically analysed.	child's age at diagnosis 10 years, range 6 – 17 years.	accessible and clearly structured. Parents valued practical personalised recommendations based on individual strengths and difficulties. Ten recommendations for reports provided by authors.	Quant and qual elements used well. 100% response rate from those invited to participate.

1.10 Study quality appraisal

The included studies were critically appraised for methodological quality using 3 method specific appraisal tools.

The 3 quantitative cross sectional studies were evaluated with the AXIS appraisal tool designed for Cross Sectional Studies (Downes et al., 2016).

The 3 qualitative interview studies were evaluated using the ‘Big Tent’ Criteria for Excellent Qualitative Research (Tracy, 2010). This tool allows for different qualitative paradigms to be evaluated within one framework. This is helpful for the current review as the 3 qualitative studies take differing approaches to data analysis.

The single mixed methods study was evaluated using the Mixed Method Appraisal Tool (MMAT) and scoring system (Bartlett et al., 2018). Although this tool has less comprehensive criteria than method specific tools, it allows for each arm of the study to be evaluated and then combined in one overall evaluation, which includes an evaluation of the integration of different methodologies used.

None of the papers appeared to be of poor quality to suggest that they needed to be viewed with caution. All quantitative papers were rated ‘not specified’ at least once where relevant details were not described. Some qualitative papers met certain criteria in part, which was defended by the researcher when necessary. For details of ratings on appraisal tools please see relevant tables in Appendices B, C and D.

1.10.1 Aims

All studies aimed to investigate parent perceptions of, experiences of, or satisfaction with receiving diagnostic feedback of ASD for their child in some way. Abbot et al. (2013), Mulligan et al. (2012) and Jurin et al. (2022) aimed to investigate parents’ experiences of receiving an ASD diagnosis. Nissenbaum et al. (2002) aimed to examine both parents’ perceptions while receiving an autism diagnosis for their child and also professionals’ perceptions of giving a diagnosis of autism. Chiu et al. (2014), Brogan et al (2003) and Jurin et al. all (2022) aimed to investigate parental satisfaction with this experience and to identify determinants of or characteristics associated with this. Chiu et al. (2014) also aimed to describe current practice around diagnostic counselling for autism in Taiwan and to present guidelines for this. Wilson et al.'s (2022) aims differed from the studies above in focusing specifically on written diagnostic feedback in the form of diagnostic reports, rather than the initial feedback session or diagnostic feedback more broadly. The authors aimed to assess how well one service's autism assessment reports met NICE guidelines as well as to explore more generally how parents had found reports.

1.10.2 Location

Most studies took place within Western regions. Three studies were carried out in the UK, 2 in England (Abbot et al., 2013; Wilson et al., 2022) and 1 in Scotland (Brogan & Knussen, 2013). One study took place in Croatia (Jurin et al., 2022), 1 in Canada (Mulligan et al., 2012) and 1 in the USA (Nissenbaum et al., 2002).

Chiu et al. (2014) carried out their study in Taiwan, within a very different cultural context to that of the other studies. The authors discuss the impact of the Confucian tradition and consider how news of having an 'abnormal' child may be particularly troublesome to families in a context in which family is prioritised over the individual, and children's academic achievement is highly valued. This different context may account for the lower parental satisfaction with diagnostic feedback found in this study compared to satisfaction rates found in other studies, most of which have been carried out in the Western world.

1.10.3 Sample characteristics

There were differences across samples in the diagnostic criteria and conceptions of autism used, due to diagnostic criteria changing with the introduction of the DSM-V in 2014. The 2 most recent studies (Jurin et al., 2022; Wilson et al., 2022) use samples diagnosed with DSM-V or ICD 10 criteria for ASD, which is inclusive of a range of presentations within the broader umbrella of newer diagnostic criteria, while the other 4 samples were comprised of children diagnosed when DSM-IV criteria were in use. Of the studies using samples assessed using DSM-IV, there are differences in which diagnostic classifications were included in samples; Brogan & Knussen (2003) and Nissenbaum et al. (2002) include diagnoses of autism, Asperger syndrome and diagnoses including autistic features or tendencies, while Chiu et al. (2014) exclude those diagnosed with Asperger syndrome or other pervasive developmental disorders. Mulligan et al. (2012) do not give specific details of diagnostic categories included in the sample but state they included parents of children diagnosed with autism spectrum disorders. Although the majority of children included in studies where diagnostic subtype is reported were given a diagnosis of autism (as opposed to Asperger syndrome or PDD-NOS), this is an important difference in samples and may impact on findings as a diagnosis of Asperger syndrome has been linked to greater parental satisfaction with feedback (Brogan & Knussen,2003).

Where sex of child was reported children of all samples were mostly male (Abbot et al., 2013, 89% male; Brogan & Knussen, 2003, 85% male; Chiu et al ,2014, 87.4% male; Mulligan et al, 2012, 100% male; Wilson et al., 2022, 63% male). All samples were comprised overwhelmingly of mothers, while Chiu et al. (2014) looked at mothers only. Chiu et al (2014) also excluded children not living with both biological parents.

The age at diagnosis of children of parents differed across studies, from a mean age at diagnosis of 4 (Mulligan et al., 2012; Brogan & Knussen, 2003) to a mean age of 11 in Abbot et al. (2013), whose sample had children older than in other studies due to its context in a CAMHS setting. In Abbot et al., 2013, the mean age was 11 and the range was 8 – 15. In Brogan & Knussen, 2003, the mean age was 4 and the range was 1 – 15. In Chiu et al., 2014, the mean age was not reported and the range was 3 – 12. In Jurin et al., 2022, the mean age was not reported and the inclusion range was 0-7 but exact ages were not reported. In Mulligan et al., 2012, the mean age at diagnosis was 4 and the range was not reported. In Nissenbaum et al., 2002, the mean age was 4 and the range was 3 – 7. In Wilson & Gunn, 2022, the mean age was 10 and the range was 6 – 17.

Sample sizes in quantitative studies were reasonably large, at 126 parents of 96 children (Brogan & Knussen, 2003), 151 mothers of 151 children (Chiu et al., 2014) and 52 parents, number of children not reported (Jurin et al., 2022). In the qualitative studies, Mulligan et al. (2012) interviewed 10 parents, Nissenbaum et al. (2002) interviewed 17, and Abbot et al. (2013) 9 sets of parents. Wilson et al. (2022) for their mixed method study had a sample of 30 parents, a good number to generate themes from qualitative data and to see trends in the frequencies reported from the quantitative data. The mean sample size across all studies included was 56.42, ranging from 9 – 151 participants. The mean sample across quantitative studies was 109, ranging from 52 – 151. The mean sample across qualitative studies was 12, ranging from 9 – 17.

1.10.4 Data collection

Most studies recruited participants through clinics, inviting parents whose child had recently been assessed to participate. Response rates varied, from all parents contacted agreeing to participate in Wilson et al.'s study (2022), to only 38% of parents contacted by Brogan & Knussen (2003) responding – Wilson et al. contacted participants by telephone and administered the questionnaire following a more general check in, whereas Brogan & Knussen sent invitations out postally which may account for this difference, as well as Brogan & Knussen's choice to send separate questionnaire to both mothers and fathers. Brogan & Knussen (2003) clearly present information on who was contacted and who among these took part. Jurin (2022) et al. do not provide much detail on how participants were recruited except that participants volunteered and accessed the questionnaire online.

Four studies used self-report questionnaires to collect data, 3 of which were designed specifically for the study (Jurin et al., 2022; Wilson & Gunn, 2022; Brogan & Knussen, 2003) with one of these being based on a questionnaire previously used to investigate parental reactions to disclosure of disability more broadly (Brogan & Knussen, 2003). Chiu et al. (2014) used a measure previously developed for use in Downs Syndrome along with personality and symptom rating measure. The three qualitative studies used semi-structured (Abbot et al., 2013; Mulligan et al., 2012) or unstructured (Nissenbaum et al., 2002) interviews to collect data.

1.10.5 Analysis and findings

Of the studies examining satisfaction ratings, Jurin et al. (2022) found 82.6% of parents were satisfied, Brogan & Knussen (2003) 55% satisfied, and Chiu et al. (2014) 43.2% satisfied. Jurin et al. (2022) found significant positive correlations between overall parental satisfaction and specific characteristics within communication, space and time and information, and calculated correlation coefficients. Likewise, Brogan & Knussen (2003) found satisfaction to be related to manner of professional and quality of information provided, being given written information and the chance to ask questions, and early suspicions being accepted by professionals, as well as diagnosis of Asperger syndrome, definite diagnosis and children not currently being in an educational placement. They compared differences in responses between satisfaction groupings with ANOVA and used chi square test to assess relationships between a range of variables with satisfaction. Chiu et al. (2014) found significant predictors of satisfaction were information about treatment, parental college degree (negatively predicted), timing of when they were informed, duration of feedback (wanted longer duration), and professional's attitude. Chiu et al. (2014) also found that mothers preferred information to be given face to face, to be accompanied by their spouse, and to be told of diagnosis only after it was confirmed.

The 3 studies using qualitative methodologies used different methods of analysing transcripts: Naturalistic enquiry (Nissenbaum et al., 2002), general inductive thematic analysis (Abbot et al., 2013), and content analysis (Mulligan et al., 2012). Various methods were used to increase rigour and sincerity, such as methodological logs or 'memoing' to bracket researcher bias, consensus processes to resolve differences in coding, member checking and peer debriefing to explore findings and consider alternate explanations. Findings included themes related to emotions experienced by parents, information received, clinician matter and space and time factors, supporting and adding depth to the findings of the questionnaire based studies. Findings were illustrated by quotations in all 3 papers, and contextualised within comprehensive discussion sections. No papers explicitly mentioned epistemological or ontological position.

1.11 Synthesis method

A narrative synthesis was selected as an appropriate way to bring the data together due to the range of study designs included in results, yielding quantitative, qualitative and mixed methods findings. This method uses a textual approach to explain and bring together a range of findings, effectively ‘qualitizing’ the data from quantitative studies to facilitate synthesis with qualitative findings. This was informed by the European and Social Research Council Methods Programme (ESRC) (Tracy, 2010) and by Siddaway et al (2019). This ‘qualitizing’ of the quantitative findings was relatively straightforward to do, as the quantitative and qualitative studies reviewed were examining very similar things using different methods – for instance, a quantitative study reporting a correlation between professionals highlighting reasons for hope with a trusting relationship between parent and clinician is easy to relate to an interview based qualitative study’s finding that a hopeful tone when giving feedback is important to parents. Both of these findings could be meaningfully discussed together using narrative synthesis under the theme of ‘Importance of hope and attention to the individuality of the young person’.

Preliminary synthesis involved tabulation of study characteristics and generating a written description of the findings. This helped to identify differences in data collection, samples and analysis methods, and to compare results. Textual descriptions helped to explore relationships within and between studies and identify key concerns indicated by parents.

After familiarisation with the papers, recurring and prominent themes were noted to generate patterns of meaning relevant to the experiences of parents receiving diagnostic feedback following autism assessment. These concepts categorised under the following headings:

- Interpersonal manner of clinicians giving feedback
- Importance of hope and attention to the individuality of the young person
- Emotional impact of receiving diagnosis
- Wanting information but struggling to process it
- Time and space factors

1.12 Narrative synthesis of findings

1.12.1 The interpersonal manner of clinicians giving feedback

The manner of the professionals giving feedback comes up in all studies. Abbot et al. (2013) talk about the consultation style and parent-clinician relationship as a theme, with finding the professionals supportive and being listened to being very important to parents. Brogan & Knussen (2003) talk about the manner of the professional, and the importance of having had early suspicions accepted and taken seriously by professionals. Chiu et al. (2014) find the attitude of professionals to be an important determinant of satisfaction with diagnostic feedback. Jurin et al. (2022) cite expert communication style as a key factor, and cite specific behaviours such as spending too much time looking at files during the session, not showing understanding of parent concerns, not being prepared to answer questions as negatively impacting on satisfaction. Mulligan et al. (2012) stress the importance of an ‘honest, yet hopeful’ delivery of the diagnosis. Nissenbaum et al. (2002) likewise found that how diagnosis is presented to families was mentioned as important, particularly the sense of being listened to. They also found that some parents’ found delivery of diagnosis to be ‘too blunt’, while others found it ‘too indirect’. Wilson & Gunn (2022) reported less on overall manner due to their focus on written reports rather than the in person encounter, but the importance of the language used (written manner) is emphasised in terms of being sensitive to the feelings of the parents reading the report.

1.12.2 The importance of hope and attention to the individuality of the young person

The importance of hope within diagnostic feedback comes up in a number of the papers and is often linked to mentioning the young person’s strengths and to professionals’ knowledge of the young person as an individual, and keeping them and their life in mind. Sense of hope is named as an important foundation of being able to face the challenges of supporting young person, and a ‘hopeful tenor’ is presented as a key theme as something important to parents (Mulligan et al., 2012). Abbot et al. (2013) highlight the importance of a positive attitude to the child and their strengths, and the value of an optimistic tone. Nissenbaum et al. (2002) found that parents felt professionals conveyed less hope in feedback than they would like, and that optimism around outcomes was something important to parents. Wilson & Gunn (2022) found parents valued written reports that celebrate the young person's strengths and reflect the young person as an individual. Experts highlighting the child's strengths and reasons for optimism were found to contribute to a trusting relationship between parents and professionals (Jurin et al., 2022).

1.12.3 Emotional impact of receiving the diagnosis

All qualitative papers find the emotional impact of receiving the diagnosis to be important for parents in feedback sessions, with strong emotional reactions the norm even when the outcome was expected. Abbot et al. (2013) report 'parents' emotional state and reactions' as a key theme, with common reactions including anxiety, anticipation, concern about receiving incorrect diagnosis, and emotional impact persisting beyond the session. Mulligan et al. (2012) made being 'overwhelmed by emotional reaction' a key theme. Nissenbaum et al. (2002) describe 'reactions to receiving a diagnosis' a key theme with reactions including tears, relief, surprise, helplessness, devastation.

1.12.4 Wanting information but struggling to absorb it

Findings around information were present in most papers, with parents wanting a lot of information, but also finding it difficult to absorb the information presented. Brogan & Knussen (2003) found that quality of information provided impacted on parents, and written information was valued. Jurin et al. (2022) found that information provided was an important determinant of satisfaction.

Difficulty absorbing information came up in several papers (Abbot et al., 2013; Mulligan et al., 2012; Nissenbaum et al., 2002). Factors contributing to this included to the sheer amount of information being provided, being emotionally overwhelmed, and the timing of this information which could be presented at the end of a lengthy assessment session. Sometimes technical language or the complexity of what was being described contributed to this. Numerous authors recommended providing written information for parents to look at after the initial feedback session, to allow for this to be processed over time.

1.12.5 Environmental factors

Factors related to the environmental conditions of the disclosure session also came up within some papers. Some parents reported being given uncomfortable chairs or an insufficient number of chairs for both partners. Some reported not having enough time to talk to professionals, or that the session was disrupted by other people entering the room or by a ringing telephone. Tissues were not usually available in the feedback room (Jurin et al., 2022)

The child was usually present when diagnosis was communicated, and some parents experienced this as disruptive and would have preferred them not to be present, while others preferred the child to be present (Jurin et al., 2022; Nissenbaum et al., 2002). Jurin et al. (2022) recommend that for young children, either toys and activities should be given to keep children entertained during this session or professionals should arrange a later time to meet with the parent without the child present to communicate the diagnosis.

1.13 Conclusions of SLR

This systematic review on parental views on diagnostic feedback following autism assessment identified 7 research studies. It is limited to peer reviewed studies published in English in specific databases. Additional studies might be available in other databases, published in other languages, or in the unpublished literature, and other relevant findings can be found within broader investigations into the experiences of parents of autistic children but were beyond the scope of this review.

Overall, the studies showed that the manner in which professionals deliver diagnostic feedback is highly important to parents. A direct and honest but tactful approach was preferred, and attention being given to the child’s strengths and reasons to be hopeful was important. Parents experience a range of strong emotions during the feedback session, which can be overwhelming and last for some time after the session. This, along with the volume and sometimes technical nature of information being presented make it hard for parents to absorb information during the session, despite this information being much desired. Written information (such as reports) was valued by parents as a way to absorb information at their own pace. Finally, while most parents found the feedback environment suitable, some reported disruptive influences such as not enough chairs for everyone in the room, not being given enough time, or being interrupted by other people entering the room or a ringing telephone.

This systematic literature review offers a novel contribution by bringing together findings from studies focusing primarily on parent views of autism diagnostic feedback. While other literature reviews exist which provide an overview of parent experiences of diagnosis more broadly, this review focuses specifically on experiences of diagnostic feedback as a distinct point in the diagnostic journey and examines these in depth. The limitations of the search strategy in only including papers with this as their primary focus as indicated in the abstract mean that it is very possible that other papers with findings on this were excluded, and papers that may have explored this in some depth as one aspect of the diagnostic journey without mentioning this in the abstract were not considered. The decision not to include grey literature also means that unpublished findings were not covered by this review.

1.14 Current study rationale

The current study aims to identify what parents use autism assessments for, and how helpful they find them. There is a lack of research investigating parental views of autism reports in general, with only one study published on this topic to the author’s knowledge (Wilson & Gunn, 2022).

Understanding this is important for a number of reasons.

Firstly, how autism is presented to parents and what information they are given influences what they do and how hopeful they feel after diagnosis, and the report is a written, lasting record of this. It is therefore a key way to ensure important messages are remembered and communicated. Parents have been on a long journey to reach this point and the report can be an important key to unlock supports for their child, so it matters that the report is something useful they can take away from the diagnostic process.

Secondly, the report serves multiple purposes and may be seen by numerous different people such as family members, the young person themselves, educational and health professionals, and may inform support for the child. The parent is the one sharing this with all those people, and will often be advocating for their child and driving any change that might come about as a result of recommendations contained within the report. We need to know how parents are sharing these, and whether parents are finding the report useful in bringing these changes about.

Thirdly, parents struggle with information overload and the report is a potential anchor to return to so parents can absorb information in their own time. It is important to know if reports are readable and make information digestible. We also know that health literacy can be poor and a lot of the information might be hard for parents to understand.

Lastly, services are hugely under resourced and writing reports is resource intensive. It is important to know how reports are actually being used and what is helpful to parents to ensure that professionals’ time is being used efficiently and what they are putting in is actually delivering benefits. If they are not being read by parents because the language is not accessible, or not being shared because the format they are in is too unwieldy, it is important to understand this and improve on these things so that the effort that went into them is not wasted.

1.15 Current study aims

Given the factors impacting on parental experiences of diagnostic feedback identified in the systematic literature review, and the problems and potential benefits of diagnostic reports listed above, gaining a better understanding of how parents experience these reports and what they use them for seems like a worthwhile research endeavour. Understanding the practical uses and perceived helpfulness of reports could help clinicians to tailor reports to better fit with what parents need. Additionally, understanding the broader significance of autism reports to families within the overall diagnostic journey could identify additional factors that influence the way parents experience diagnostic reports, and contribute to the existing literature around parental experiences of autism diagnosis. Therefore, the aims and research questions for the current study are as follows:

Aims

A) Identify what parents are using autism assessment reports for
B) Find out how helpful parents find them
C) Build a picture of how autism reports fit into the broader journey of childrens' autism assessment for families

Research Questions

1) How are parents using autism assessment reports?
2) How helpful are parents finding autism assessment reports for these uses?
3) What is the value of autism reports to parents within the broader journey of their child's autism diagnosis?

2. Methodology

2.1 Overview

This chapter describes the mixed methods used in the study. First it outlines the quantitative and qualitative methods used to investigate parent questionnaire responses to multiple choice questions and free text items. Secondly it describes the qualitative methods used to analyse interviews held with parents. A rationale for using a mixed methods approach with reflexive TA is given, along with details on questionnaire construction, recruitment, and the interview procedure. Details are given on ethical issues and quality assessment of methods.

2.2 Design

The study used both concurrent and sequential mixed methods design, with cross sectional quantitative and qualitative data collected together in an initial questionnaire. Data obtained from the questionnaire informed the topics discussed in subsequent interviews. The richer qualitative data collected in interviews was then used to contextualise questionnaire findings within the bigger pictures of parents' experiences of seeking support for their child and the value of the report within this.

2.2.1 Epistemological considerations

As discussed in the introductory chapter, this study was carried out from a critical realist epistemological standpoint, taking the position that ontologically there is a reality beyond the person perceiving it, but that the way people experience and come to know the world is necessarily subjective and influenced by their social context, personal values and experiences. I have aimed to understand what is important to parents rather than simply describe this. Parent views are shaped by their wider contexts impacting on what they need and find helpful at that point in time. The questionnaire includes items intended to capture aspects of identity and context in order to examine potential relationships between these and what parents found helpful, while also inviting parents to give free text responses to expand on their answers and give additional context to these.

A more in-depth qualitative approach was adopted in the form of reflexive TA of interviews to allow for deeper exploration of the meanings and broader journeys behind responses. It seemed important to capture the participants' own language to best explore these, and a qualitative approach that makes use of researcher subjectivity was judged to be most appropriate. Reflexive TA was therefore used to analyse interview transcripts. This method uses subjectivity as asset rather than considering it something to be neutralised, with the research actively considering their own position and values.

Within my critical realist position I can consider how the lens through which I view the comments participants make influences how I interpret these. I might also be viewed as an outsider, or as an NHS professional in a position of power by participants. Keeping this in mind encouraged me to be reflexive and take note of my own assumptions (for example, see Appendix A for reflective journal entry on how my experience assessing adolescents meant that parents of older children were at the forefront of my mind, whereas most research focuses on younger children, whose parents are likely to have different concerns and experiences).

2.2.2 Rationale for use of Mixed Methods

The research question could be meaningfully addressed in multiple ways. A mixed methods approach was chosen to address both the more descriptive aspects of the research question, and to build upon that with qualitative methods to better understand the context behind responses and the deeper value of autism reports to parents within that context. Data from the questionnaire part of the study was to be used in the development of the interview schedule for the interview part of the study, so that interesting findings could be explored further in interviews. The questionnaire also facilitated recruitment for the second part of the study by identifying potential interview participants, as respondents were invited to leave contact details if they would like to take part in an interview about their experiences of reports. Themes generated from interviews were then to be used to further consider the meaning of questionnaire responses. In this way the combination of different methods formed part of the analysis, with this integration creating something greater than the sum of its parts which could go beyond what either part of the study could do independently.

Quantitative

Quantitatively, multiple choice questions could quickly capture an overview of the different ways parents used autism reports, and how helpful they found various aspects of these, and allowed more parents to respond than would be possible than using more personalised qualitative methods such as interviews. This method also demanded less time of participants, which was an important consideration as the population faced many other demands on their time, and many viewpoints might be missed by only using a more time intensive mode of participation. This also allowed for the capture of categorical and interval data that could be used to statistically examine correlations between variables and particular outcomes – the perceived helpfulness of recommendations and perceived readability of reports.

Qualitative

Qualitatively, there were two methods of collecting and analysing data. Firstly, participants were invited to expand on their responses in their own words to go beyond the limited multiple choice options on the questionnaire, and these free text responses were content analysed to present themes and frequencies. These free text responses were an important way to understand answers to multiple choice questions and also to allow for participants to raise points about reports that it might not have occurred to the researcher to ask about, and to provide ideas for prompts to ask about in later interviews.

Secondly, questionnaire participants who expressed an interest in saying more about their experiences were interviewed in order to better understand how autism reports connected to broader experiences around the journey to diagnosis. Free text responses from the questionnaire informed the content of the interview schedule. For instance, responses to a question about the impact of language used in reports overwhelmingly had little to say about this, so this felt like an important area to cover in interviews to ensure that this question could be properly articulated by the researcher and respondents given sufficient time and prompts to address this topic. Some free text questionnaire responses had indicated that hopeful or respectful language had felt helpful, or that the language used had felt unhelpful, so prompts around language feeling respectful/hopeful were used to explore whether this was important to participants. Similarly, many questionnaire participants referred in free text responses to proof of diagnosis being the most important aspects of reports for them, as opposed to report content, so a specific prompt around this was incorporated into the interview schedule. Reflexive TA was then used to generate themes from interview transcripts that told a story about the significance of autism reports for parents. These themes were then used to go back to questionnaire findings in the discussion, to consider them in light of these.

2.2.3 Expert by experience consultation

A colleague with recent experience of their child's autism diagnosis offered to act as an expert by experience consultant for the project. They provided thoughts on questionnaire items and initial codes and themes generated in the analysis of interview transcripts. Additionally, one of the supervisory team is an expert by experience in this topic, and brought this lens to supervisory meetings in addition to their professional knowledge. Further expert by experience consultation was impacted in part by time limitations – see reflective journal extracts in Appendix A for more thoughts on this, and how with more time and foresight I might have been able to work with the National Autism Society to involve a panel of Experts by Experience.

Quantitative methodology

2.3 Questionnaire

A cross sectional questionnaire design was used to gather quantitative data and brief free text responses.

2.4 Participants

2.4.1 Inclusion criteria

Inclusion criteria for participation were to be a parent of a child assessed for autism within the past 10 years in the UK, who had received a report or letter detailing this assessment.

2.4.2 Recruitment

Participants were recruited by reaching out to local organisations providing support to parents of autistic children and asking if they could post a study advertisement on their websites (see Appendix E for advertisement). A link to the study advertisement was also posted on a Facebook group known to one of the research supervisors for parents of autistic children. The advertisement contained a link to the questionnaire, where participants could read an information sheet before deciding whether to take part.

2.4.3 Sample characteristics

34 participants completed the questionnaire fully and were included in analysis. 56 initially responded to the questionnaire, however a large number did not finish it. In keeping with participant information, this was taken as possible withdrawal of consent, and so these were not included in the analysis. This may have been due to a technological failure with the Qualtrics software, because a large number of responses sequentially were only recorded up to the same questionnaire item with no further responses recorded.

The sample was made up overwhelmingly of mothers, mostly of white ethnicities with English as their first language. Just over half the sample were aged 7-12 at assessment, just over a quarter 0-6 and the remainder 13-16 at time of assessment. The sample was highly educated, many to a postgraduate level. Just over half of assessments had been carried out privately and the remainder on the NHS, all in England. All children had been diagnosed with autism. For the majority of parents this was their first experience of autism assessment, but just over a quarter had some prior experience of this (e.g. through another child already having gone through this process).

For further details of demographic information about participants, see Table 4 in Results chapter.

2.5 Ethics

Ethical approval for the study was given by The University of Hertfordshire Health, Science, Engineering & Technology Ethics Committee with delegated authority, protocol number LMS/PGR/UH05470. Full ethics application can be seen in Appendix F. Risk assessments were carried out for both parts of the study and actions taken to minimise potential harm (see Appendix G for details). Information about the study was provided to participants prior to the questionnaire. Participants were free to leave the questionnaire part way through and this would be taken as withdrawal of consent. Participants were required to select ‘yes’ to confirm that they had read this information and consented to take part before they could continue to the rest of the questionnaire. Information about local and national support organisations was provided at the end. Participants were given the researcher’s email address with an invitation to get in touch if they had any concerns they wanted to talk through, or if they would like to receive a copy of the paper once this had been written up.

2.6 Data collection

Data was collected using the Qualtrics platform between September and November 2023, through of a mixture of multiple choice questions and free text responses. Questions included demographic information about participants and their child, questions about the assessment, the content of the report, the readability, format and language of the report, parent uses of the report and perceived usefulness of the report. For full questionnaire see Appendix H.

2.7 Data analysis

2.7.1 Questionnaire multiple choice responses

Descriptive data was presented to show the range of responses to questions.

Chi square tests were initially run to test for statistical associations between a range of report and parent variables and two target variables: Firstly, perceived helpfulness of recommendations and secondly, how easy reports were to read. These target variables were selected as simple measures of 2 important report qualities that were measured by interval data on a 5 point scale and therefore were compatible with statistical examination of association (as opposed to qualitative free text response data that could not be examined in this way). Neither of these were reverse scored and no data transformation was required. The variables selected to examine associations against these were: Sections included in the report (e.g., whether or not the report included an explanation of what autism is, recommendations etc), professional involvement in the report (which professionals were involved in writing the report), who the report was shared with (e.g. school), parent level of education and whether the assessment was carried out privately or in the NHS. These were measured as categorical data (yes/no for each category of response). These variables were selected as factors that could conceivably impact on perceived helpfulness of report recommendations and perceived readability of reports. Analysis was exploratory rather than hypothesis driven. There is therefore an increased risk of type one errors (false positive relationships).

The chi square test is only an approximation, and can be inaccurate with smaller sample sizes. In particular, if expected cross tabulation cell values are below 5 it is likely to be unreliable. Due in part to the small sample size, in the cross tabulations examined in this study a high number of cells contained an expected count of less than 5. A non-parametric test, the Fisher-Freeman-Halton Exact Test, yields an exact p value even with small samples. Therefore p values from this test were ultimately reported. No data transformation was required to run this analysis.

SPSS version 29 was used to analyse the data.

2.7.2 Questionnaire free text responses

A content analysis was carried out on free text responses to facilitate presentation of open ended comments. This was a loose analysis, not following a strict, established procedure, but was broadly based on the process discussed by White et al (2006). Themes were generated inductively from the text for each open-ended question to represent each new idea in responses. Where appropriate, these were further categorised by topic summary (e.g., ideas relating to a question about what made a report helpful or unhelpful were grouped by 'helpful' and 'unhelpful'.) Due to the large number of different questions being coded individually, and due to them being coded only by one author rather than multiple researchers, no codebooks were created. Identified themes were counted and presented in tables alongside multiple choice answers to expand on these. The purpose was to provide a loose illustration of what participants were expressing, rather than to provide either an in-depth qualitative analysis or a tight numerical analysis of specific concepts. This was also intended to capture ideas on parental concerns that could be further explored in interviews later on.

2.8 Quantitative methods quality

The quantitative aspects of the study are mainly descriptive, making use of categorical data to show what parents reported finding more or less helpful about their reports and how they had used them. Pre-existing measures were not used, rather questions were constructed that seemed likely to provide information relevant to the questions of how parents used reports and what made them more or less helpful.

Relationships between variables were explored statistically with tests of association, however this was small part of study and not its main purpose. Given the relatively small sample size, statistically significant associations are treated with caution. For the same reason of relatively small sample size, near significant findings were also looked for and discussed, as these might meet significance if further investigated in future research with larger samples.

For qualitative appraisal of quantitative aspects of the study, see discussion section.

Interview data

2.9 Rationale for Thematic Analysis

TA was selected as the approach that best fit the research question, aims and theoretical assumptions. Generating themes which tell a story about patterns in the data across participants matched the study aims. TA's flexibility in allowing for a continuum of inductive and deductive theme development was appealing, accommodating my chosen primarily inductive position while acknowledging that a pure inductive approach is not possible. Similarly it allowed for data to be coded both on manifest and latent levels. This seemed suitable in the context of autism assessment, when some language was best taken at face value, while I still aimed to interpret latent meaning in participants' language to an extent. My focus leaned more towards an experiential analysis than critical, perhaps due to my relatively small sample, and reflexive TA accommodated this.

2.10 Participants

2.10.1 Criteria and recruitment

Participants were recruited via the questionnaire part of the study and met the criteria for this outlined above. In the questionnaire participants had been asked if they would be interested in taking part in a focus group or interview to say more about their experiences around their child's autism report, and if so were invited to leave contact details. 17 left details, all of whom were contacted. 8 initially responded confirming their interest, 3 of whom later had to cancel interviews due to personal/family difficulties. 5 participants ultimately took part in interviews.

This is a small sample size for TA. If this had been a purely qualitative study, a number closer to 15 participants would have been sought. However, as one part of a wider mixed methods study this would have been beyond the project's scope. For the purposes of addressing the question of value of reports within a wider diagnostic journey to contextualise questionnaire findings, this number proved sufficient.

One of the justifications traditionally given for larger sample sizes in TA has been to reach ‘data saturation’ – the point in data collection at which no additional insights are identified and new data simply repeats ideas previously generated, so that further data collection is redundant. However, this idea has been challenged in recent years on the basis that it is not compatible with the values and assumptions of reflexive TA. This is in part because meaning is always generated through interpreting the data, rather than passively existing within it to be mined by a researcher, and so judgements about when this process is finished this will always be subjective and impossible to determine prior to the analysis (Braun & Clarke, 2021; Nelson, 2017). The phrase ‘conceptual density’ has been suggested as an alternative by Nelson (2017), which seems like a better fit for this study. While it is impossible to know if further meanings would have been generated by using a larger sample size, it seems reasonable to claim that the sample used in this study reached sufficient conceptual density, by allowing for generation of meaningful themes patterned across the data. Furthermore, while I probably lost out on an increased range of meanings or iterations of existing meanings, I arguably gained a deeper understanding of the experiences and stories of my individual participants due to the smaller number. This may have inclined me to analyse the transcripts in a more experiential way, remaining closer to the meanings expressed by the individuals participating in my study, compared to a more critical, removed analysis that might have resulted from a greater number of participants.

2.10.2 Participant demographics

See Table 5 in Results chapter for interview participant demographics.

2.11 Interview methods

Initially a focus group was planned. This was both to allow participants to build on one another’s views and experiences, and for maximum efficiency given significant time restraints. However, it proved difficult to find a time when all participants could attend.

Additionally, some participants voiced a preference for individual interviews over a group format, therefore interviews were used.

Interviews followed a semi-structured format, allowing participants to talk about their experiences in some depth and follow lines of thought that were important to them, while granting the interviewer flexibility to probe and follow up on avenues opened up by participants. This allowed for a greater familiarity and rapport with individual participants than a focus group might have. However, other opportunities were lost through this choice. For instance, a focus group might have allowed participants to spark ideas in one another that wouldn't have otherwise occurred to them in an individual interview, and may have led to interesting discussions around differences in perspective.

All interviews were carried out via video call using Microsoft Teams or Zoom depending on participant preference. Many participants said they could only meet virtually, due to their busy schedules, and several years after the onset of the Covid-19 pandemic all participants were familiar with videoconferencing software and comfortable with this mode of communication. All participants were in a private space when they took part, and no significant disruption occurred. Interviews ranged in length between 25 and 50 minutes, averaging around 40 minutes. Interviews followed a semi structured interview schedule (see Appendix J). Interviews were recorded and transcribed verbatim using a professional transcription service.

2.12 Ethics

Ethical approval was given by The University of Hertfordshire Health, Science, Engineering & Technology Ethics Committee. Interview participants received an information sheet by email along with a consent form, which participants signed and emailed back prior to taking part. Participants had an opportunity to ask questions before the interview commenced, and were free to stop or pause the interview at any point if needed. When a transcription service was used, a confidentiality contract was signed. All transcripts were anonymised, with names of people and places redacted. Transcripts were saved separately to potentially identifying data including consent forms and participant contact details. In the write up pseudonyms were used.

2.13 Data collection

2.13.1 Resources

Interviews were carried out online using Microsoft Teams or Zoom software depending on participant preference. A confidential transcription service was used to transcribe recordings. Microsoft Word was used to edit transcriptions and code data. Microsoft Excel was used to keep track of codes and supporting data extracts, and a macro was used to export codes and extracts from Word into Excel (Babbage & Terry, 2023).

2.13.2 Interview schedule

The interview schedule was developed to build on questions asked in the questionnaire (see Appendix J). The supervisory team then offered additional prompts for some questions to help elicit richer responses, and the EbE consultant also offered feedback. The interview schedule covered initial impressions on reading the report, perceived readability, uses of the report and the report's helpfulness for this, impact of the report on relationships, and things they might have wanted to be different about the report. Each question included possible prompts intended to elicit information to expand on initial answers.

2.13.3 Interview process

The interviewer introduced herself and outlined some practicalities such the expected duration of interview, the option to pause the recording if a break was needed, and what to do in the event of internet connection difficulties. Participants were reminded that the interviewer was interested in their thoughts and experiences, and encouraged to feel free to talk about things not directly asked about if they felt relevant.

A fluid approach was taken to approximate a natural flow of conversation. The order of questions changed in each interview to stay close to what participants were bringing up.

Before each interviewed ended the schedule was checked to confirm that all areas had been covered.

After the interview was finished and recording stopped, the researcher checked in with how the participant had found the interview, reiterated what would happen next with their data and provided space for any further questions. The researcher also checked that participants were happy for the researcher to send them initial themes once these had been generated and invite comments from them.

2.14 Data analysis

This followed 6 phases to explore patterns across interviews (Braun & Clarke, 2022). Initial familiarisation with the data was undertaken by re-listening to interviews and repeated reading of the transcripts while writing down my initial thoughts. I was aware of passages resonating with things I had heard from parents on clinical placements, and by writing these down aimed to keep my own position and identities in mind when I turned to the next phase of initial coding, and stay open to different ways of seeing things as far as possible. Codes were generated by noting statements that seemed to capture something about the text that was relevant to the research question, initially by hand on printed transcripts. I coded transcripts first in one order, and then repeated coding in the reverse order, noticing that I was wording codes slightly differently stressing different elements of related concepts when I started with different transcripts at the beginning. The data was then re-coded to further develop them, partly by reducing a large number of meaningfully similar but differently worded codes down to a more concise set. This re-coding was carried out on Microsoft Word using notes under the review tab. These were then exported into Microsoft Excel using a macro designed for this purpose (Babbage & Terry, 2023).

A list of codes was printed and cut up. This allowed codes to be physically moved around and grouped into clusters. Six themes were initially generated in this way. These were revised and some codes moved around. Ultimately six themes were presented in the analysis, which linked with one another to tell a story about the data.

2.15 Quality and reflexivity

2.15.1 Assessing quality of methods

To facilitate rigour in the analysis, selected codes and excerpts were shared in research methods workshop with fellow trainees to support reflection on the process of coding. Themes and example codes were shared with supervisors and the EbE consultant. Member checking was also attempted by inviting participants to comment on whether themes resonated with their experiences, although a limited response was received with only one participant responding (who said they did resonate). Member checking has been criticised for implying that there is one reality that participants have direct access to, when actually reality might look different across members (Braune and Clarke, 2021). Please see reflective journal in Appendix A for further thoughts on the use of member checking in this study. To appraise quality and validity of this part of the study Big Tent criteria were used (Tracy, 2010). See discussion chapter for full details of this.

2.15.2 Reflexivity

Participants knew I was a professional in training with an interest in how autism reports get used by parents and what the value of these is. I may have been viewed as an ‘outsider’, as someone who was not a parent to an autistic child. I was not asked by anyone whether I had this experience and did not state that that I had not, but had positioned myself as a researcher with a professional interest, so an outsider position was likely assumed. As someone entering into the systems experienced as at times unhelpful or frustrating, I might also have been viewed as someone potentially able to help change those systems, or at least to feed something back to those systems about the difficulties participants had faced.

My relationship to the topic was informed by my experiences on placement in an autism assessment service, and on other placements in which I had spoken to parents waiting for their children’s autism assessment. The participants’ stories resonated with what I had seen and heard from other parents in those settings. My perspective and approach was also inevitably influenced by my personal health and career context over the course of the research. I kept a reflective journal while doing research tasks to try to be aware of the impact of my own feelings, assumptions and personal context, which helped me to remember that other contexts open up different ways of doing things – for example, it was useful to look back at those reflections after discussions with my expert by experience and notice how my thinking shifted after spending time considering their perspective (e.g. at one point from ‘how can parents use reports?’ to ‘should the onus to use reports actually be primarily on parents?’).

3. Results

3.1 Overview

This chapter begins by presenting the main questionnaire data and findings. This includes an overview of descriptive data, themes identified in free text responses, and statistical results on relationships between report variables and perceived helpfulness of report recommendations and readability of reports. A qualitative analysis of 5 semi-structured interviews is then presented. 6 themes were generated through reflexive TA, summarised in Table 6. These are discussed in depth with reference to quotations from transcripts. Quotations were selected carefully to best illustrate the spirit of each theme. Parts of some excerpts had to be omitted in order to be concise. Where words other than repetitions and filler words such as ‘erm’ have been removed, this is indicated by […]. All names included are pseudonyms.

3.2 Questionnaire data

For the sake of concision, only the data most relevant to research questions is presented here. For additional questionnaire data collected, please see appendix K.

3.2.1 Descriptive information about participants and assessments

For further information about participant demographics, see Table 4.

Table 4: Participant demographics

	Number	Percentage of sample
	Relationship to child	
Mothers	32	94.1
Fathers	2	5.9
	Broad ethnic category	
White	31	91.2

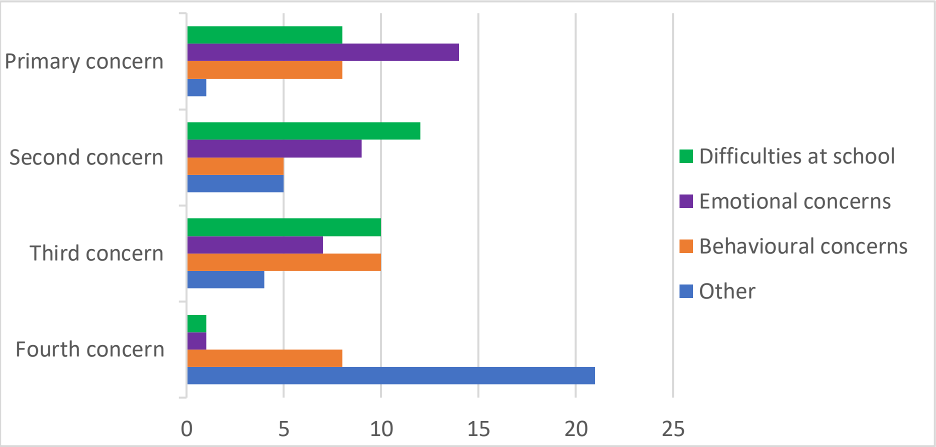
Black, Black British, Caribbean or African	2	5.9
Other	1	2.9
English as first language		
Yes	32	94.1
No	2	5.9
Level of parent education		
Primary school	2	5.9
GCSEs	5	14.7
A levels	6	17.6
Bachelor's degree	9	26.5
Postgraduate master's	7	20.6
Postgraduate doctorate	5	14.7
Recency of assessment		
Within last year	13	38.2
Within last 5 years	18	52.9
More than 5 years ago	3	8.8
Age of child at assessment		
0-6	10	29.4
7-12	18	52.9
13-16	6	17.6
Private or NHS		
NHS	15	44.1
Private	19	55.9
Country		
England	34	100
Region		
East of England	17	50
South East	10	29.4
Greater London	5	14.7
North East	1	2.9

North West	1	2.9
Diagnostic outcome		
Diagnosed with ASD	34	100
Parent experience of other autism assessments		
This was only experience	25	73.5
Had had other experience	9	26.5

3.2.2. Parent concerns leading to assessment

See Figure 2 for parent concerns leading to assessment for their child, ranked in order of importance to parents, and Table 8 for details of other concerns specified by parents. Emotional concerns were most commonly cited as the primary concern leading to assessment, but concerns around school and behaviour were also frequently reported as prompting assessment. Concerns around the child's social relationships were also reported as a pressing concern.

Figure 2: Main concerns leading to assessment



Other main concerns described in the free text responses predominantly concerned the child's social relationships. For full list of themes see Table 8 in Appendices.

3.2.3 Descriptive and free text information about reports

100% of parents said they read the entire report fully.

See Figure 3 for the number of reports that included each feature asked about, and Table 9 for themes in parent comments about which sections were helpful and why. Responses about what was helpful were varied, naming a range of things. Responses about what was less helpful were more unified, with many responses agreeing that overly generic recommendations made the report less helpful.

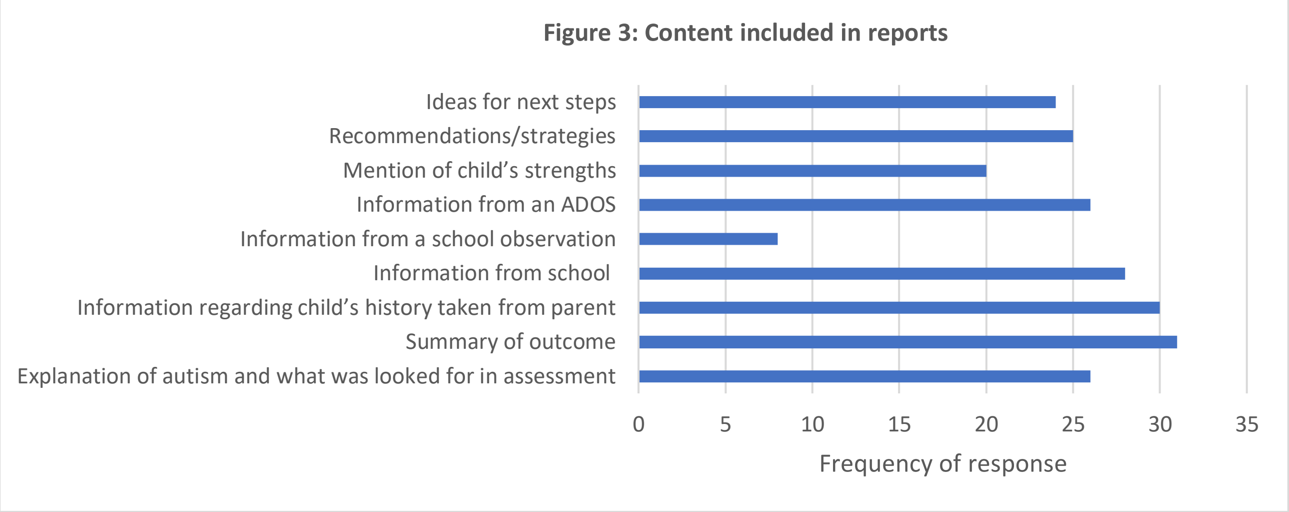
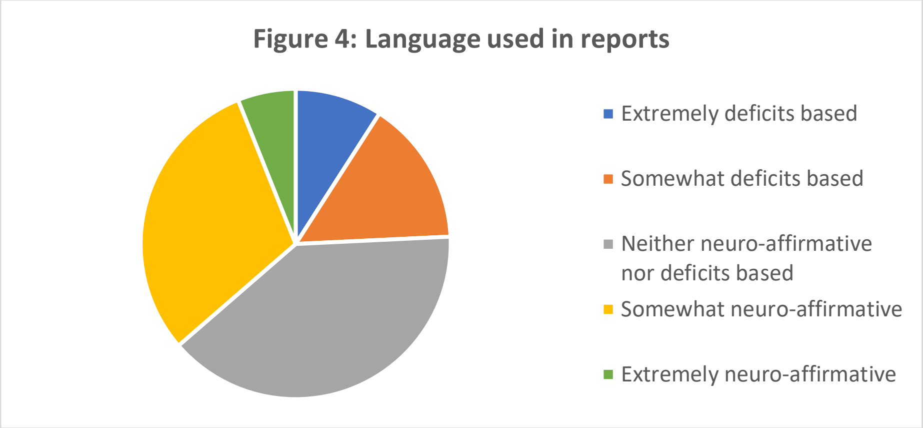


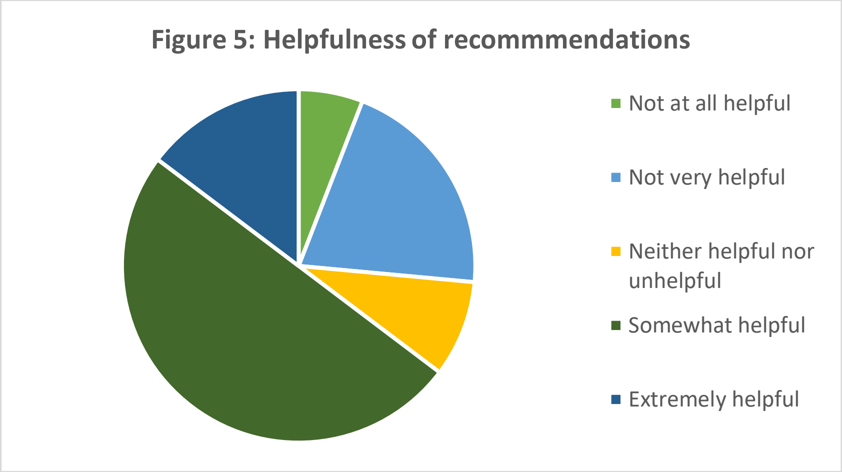
Figure 3: Content included in reports

In free text responses parents reported a broad range of views on the sections of the report that were most helpful and why. Recommendations were most frequently named as the most helpful part of the report, with a summary section, details of observations from others (other than the parent themselves), highlighting of difficulties the child experienced which were not obvious to others, and clearly showing how the child met diagnostic criteria and how their differences were linked to autism also came up in multiple responses. Generic or unsuitable recommendations was most frequently named as a section making reports less helpful, along with an overwhelming level of detail in reports. For full list of themes see Table 9 in Appendices.

See Figure 4 for proportions of ratings of neuro-affirmative language in reports from 33 respondents. In free text responses following this up, most respondents indicated that they didn’t have particular thoughts on neuro-affirmative language or did not think it mattered, but some reported that this language had a positive impact, or that medicalised language had a negative impact. For full list of themes generated see Table 10 in appendices.



For helpfulness of recommendations see Figure 5. More participants found recommendations helpful than unhelpful, but more than a quarter still rated them as either ‘not very’ or ‘not at all’ helpful. From the free text responses, it was apparent that factors making recommendations more or less helpful mainly involved their practical utility. Where these were not personalised enough to be useful this was unhelpful, as was others not being prepared to act on these. Not all reports contained recommendations at all, and a lack of these was reported as being unhelpful. For a full list of themes generated from responses see Table 11 in Appendices.



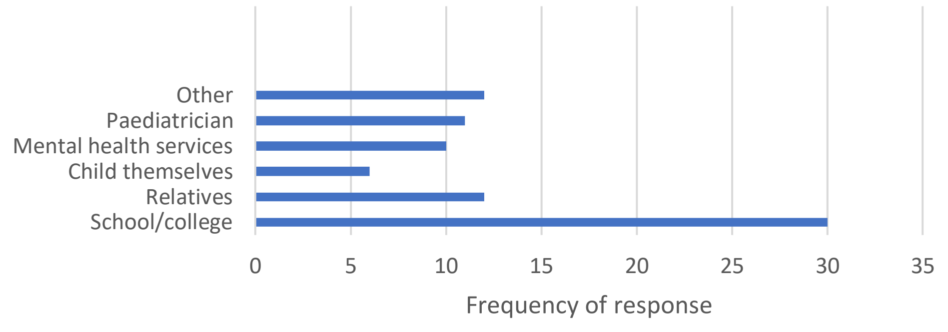
3.2.4 Use of reports

61.8% of parents reported having a use for their child’s autism report in mind prior to assessment. Only 38.2% of parents reported being given ideas for how to use the report during the assessment process.

32.4% of parents responded ‘yes’ to the question about whether they thought information in the report was used by others to support their child, while 41.2% responded ‘somewhat’. 26% reported ‘no’ to this. Free text responses from those answering ‘somewhat’ indicated that their child’s school or college had used reports, although a number said that this only happened after they fought for this to happen. For full list of themes from responses to this item see Table 12 in Appendices.

See Figure 6 for who parents shared reports with, illustrating that they were mainly shared with school or college. Free text responses following up ‘other’ responses showed this was often still related to education, e.g. the local authority for supporting an EHCP or to arrange wraparound care around school. See Table 22 for full list of themes from this item.

Figure 6: Who did you share the report with?



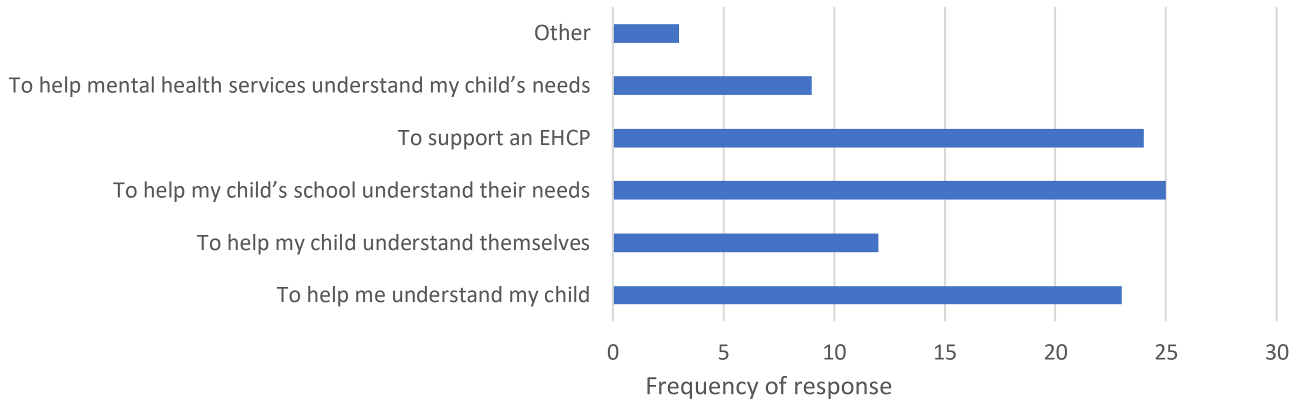
Parents were also asked about whether the assessment report changed their understanding of their child, or their relationship with them, as well as whether this impacted on how other people understood their child. Many parents said that the report did not change their relationship with their child, but a number also said that it helped them to better understand their child’s needs, or changed how others such as school professionals or relatives understood the child. Some said that the report did not do any of these things, but that post diagnostic support they received did. 3 participants said that the report likely would have changed their understanding of their child if they had got the diagnosis sooner. Unfortunately, 2 participants had had negative experiences where the report changed professionals' understandings of the child for the worse, for instance by lowering their expectations for the child inappropriately rather than working to support the child to achieve their potential. See Table 13 in appendices for full list of themes in parent responses about this.

See Figure 7 below for the ways parents used reports. In line with answers from previous questions, educational purposes were most frequently reported, either to help the child's school understand them, to support an EHCP or both. Helping the parent to understand their child was also very frequently reported. Some used the report to help their child understand themselves – this might depend on the child's age at assessment. A smaller number reported using the reports to help mental health services better understand their child. Some 'other' responses were followed up with free text responses, showing that they had also been used by parents to help family members understand the child, to get Disability Living Allowance, or for one parent, not used for anything. See Table 14 in appendices for list of themes in 'other' responses specified by parents.

Parents were also invited to share more about their uses of reports in a free text response. The majority of these responses mentioned that the main use of the report had been proof of diagnosis. A smaller number mentioned trying to use the report as proof of diagnosis to unlock support for their child but support had been refused, and a few comments expressed that their child had been badly let down by not being given any support until they were able to present the report for proof of diagnosis. See Table 15 in appendices for full list of themes from this item.

Parents were then invited to comment on how helpful they found the reports for the uses they described in the previous item. Many of these comments said that the report had been helpful, but numerous comments also said that the report had been helpful only insofar as it had functioned as proof of diagnosis (as opposed to the report content being helpful in and of itself). A number commented that the report would be more helpful if it highlighted specific, personalised strategies and adjustments that would be likely to help their child, and a few said that although the report contained helpful information, this did not help them because others did not act on that information. For full list of themes from this item see Table 16 in appendices.

Figure 7: What did you use the report for?



3.2.5 Accessibility and format

47.1% of parents found the report ‘very easy to understand’, 32.4% found it ‘fairly easy to understand’, 11.8% found it ‘neither hard nor easy to understand’, 5.9% found it ‘somewhat hard to understand’ and 2.9% found it ‘very hard to understand.’

Parents were invited to write responses on what made reports easier or harder to read. Use of clear language and clearly structured information were named as qualities that made reports easier to read. The things that made them harder to read were more varied, but included the use of jargon, inclusion of raw test scores, lengthy reports, grammatical errors and parent emotion. For full list of themes from this item see Table 17. In the next item, parents were invited to comment on whether any parts of the report seemed unnecessary, hard to understand or too detailed. Many reported that no parts fit this description, but some reported that the parent interview contained too much detail, impacting on their willingness to share this with other people, and some found the suggestions included in the report overwhelming. For full list of themes from this item see Table 18 in appendices.

3.4.6 Other parent comments on reports

Finally, parents were invited to comment on any other reflections on their reports outside of what had been asked about in the questionnaire. The themes from these responses are varied and a number refer to parental experiences of the wider diagnostic journey, for instance the lengthy waiting time for an assessment, and the diagnostic process being overwhelming. Themes related to the reports themselves included that more practical guidance on what parents could do next and on specific adjustments that could be made for their child would be helpful. For full list of themes in other parent reflections on the reports outside of what was asked about in the questionnaire, please see Table 19 in appendices.

3.4.7 Statistical analysis

Chi square tests were initially run to test for statistical associations between a range of report and parent variables and two outcome variables: Firstly, perceived helpfulness of recommendations and secondly, how easy reports were to read. For full details of rationale for this and limitations of this, please refer to method section.

Due to the small sample and infrequency of some responses, expectations of the Chi Square Test were not met. Results from a non-parametric test of association, the Fisher-Freeman-Halton Exact Test (hereafter Exact Test), were therefore reported instead. No data transformation was required for this.

Associations with perceived helpfulness of recommendations

The inclusion of recommendations in reports was, unsurprisingly, significantly associated with helpfulness of recommendations, Exact Test =10.92, p = .009. Inclusion of a section detailing developmental history taken from a parent was also significantly associated with this, Exact Test = 8.66, p = .03.

None of the parent factors analysed were associated with perceived helpfulness of report recommendations. No particular professional involvement in writing the report was associated with helpfulness of recommendations. No specific sharing recipients were associated with helpfulness of recommendations. Sharing a report with school almost reached significance (Exact Test – 6.79, p = .087), so it is possible that future studies with a larger sample might find a significant relationship.

Associations with perceived readability of reports

No parent factors, professional involvement in the reports, specific report content, or parties reports were shared with were statistically associated with readability.

3.3 Interview data

3.3.1 Participant demographics

See table 5 for interview participant demographics.

Table 5: Interview participant demographics

Participant number	Relationship	Broad Ethnic category	English first language	Recency of assessment	Age of child at assessment	NHS or private
“Rose”	Mother	White	Yes	Within last 5 years	0-6	NHS
“Lily”	Mother	White	Yes	Within last year	7-12	Private
“Holly”	Mother	White	Yes	Within last 5 years	7-12	NHS
“Marie”	Mother	White	Yes	Within last year	7-12	Private
“Emma”	Mother	White	No	Within last year	0-6	NHS

3.3.2 Interview data thematic analysis

A summary of six themes generated in relation to the value of and limitations of autism assessment reports for parents is presented in Table X.

Table 6: Theme summary table

Theme	Characteristics
Importance of proof of diagnosis for validation and understanding *Summarising quotation: 'It's not your parenting... they have to change their strategies'*	Proof of diagnosis validated parents' experiences, proving the child's difficulties were not due to bad parenting or the child being bad and leading to changes in how others perceived the child and increasing willingness to make accommodations to support the child.
Gap between what is promised and delivered *Summarising quotation: 'The very agencies that are there to help you don't help you'*	Parents encountered a huge difference between the support that was supposed to be available and what was actually available, both before and after diagnosis. This meant parents had to engage in a brutal, exhausting fight for support, which left them depleted and overwhelmed by the new tasks ahead of them opened up by the report.
Report marks one stage in a journey *Summarising quotation: 'It was just the first stepping stone on a journey'*	The report marked an ending on the long journey to diagnosis, but also a beginning to a new task. The report captured one moment in time, and preserved the overwhelming information and recommendations from assessment in place for gradual digestion.
Grief facilitates moving forward *Summarising quotation: 'you have to get over perhaps a grieving process when you get the report before you're*	Parents experienced grief on reading their child's report, which gave way to hope and a renewed focus on nurturing their child's individual strengths.

able to then decide your child's life isn't ruined and actually, life is still good'	
Increased awareness of difference *Summarising quotation: 'everyone in our family's like this anyway so let's just move on'*	Reading the report made parents more aware of their child's differences, and also of neurodivergence within the wider family. This awareness increased optimism about the child's future, and boosted practical support within the family.
Peer support bridges gaps *Summarising quotation: 'What is more valuable than anything is being connected into a peer group who are able to offer you support and practical advice and practical tips'*	Peer support gave help beyond what reports could provide, by allowing parents to relationally exchange ideas and solutions and see what strategies looked like in practice, and to better understand the local support context.

Table 7: Code clusters by theme

Theme	Examples of codes
Importance of proof of diagnosis for validation and understanding	Proof of diagnosis most important aspect Child not bad Not bad parents Report validates parents' experiences Report changes views of others Report key to unlocking support
Gap between what is promised and delivered	Gap between support promised and delivered Services are lacking Many layers of barriers to support Parents must fight Report helps parents fight back Fight leaves parents depleted Abandoned to the work of parenting an autistic child Parent becomes expert
Report marks one stage in a journey	Report marks a beginning Report marks an ending Report marks a stage in a journey Report illuminated next steps Can only take in so much info at once

	Report helps remind parent of details
Grief facilitates moving forward	Grieving process
	Grief facilitates moving forward
	Diagnosis has big emotional impact
	Conflicting emotions about diagnosis
	Diagnosis both creates and contains worry
Increased awareness of difference	Increased awareness of child’s disability
	Increased awareness of neurodivergence within family
	Autism not entirely disabling
	Autism one of many aspects of child’s identity
	Language of differences supports hope
	Language of deficits made report hard to read
Peer support bridges gaps	Value of peer support
	Value of local organisations
	Report recommendations hard for layperson to implement
	Peer support bridges gaps
	Lived experience contextualises ideas
	Duty to pass on peer support to others
	You don’t know what you don’t know

3.3.2.1 Theme 1: Importance of proof of diagnosis for validation and understanding

Proof of diagnosis was often mentioned as the main or among the most important aspects of the assessment report. This proof validated parents’ experiences and proved to others and themselves that difficulties were not the result of bad parenting or of the child being bad. The idea of being a bad parent or of the child being bad was explicitly brought up by participants. For example, in the quotation below Rose spoke about having proof of not being a bad parent and not having a bad child being the only useful thing offered by the report.

You don't have a naughty child, it’s not your parenting, they can get .. good things out of him but they have to change their strategies. So that’s the sort of .. good- you know, that’s what the report’s for really, it doesn't help you in any way, it just provides proof that you're not a bad parent. (Rose)

This sense of not being bad had important impacts, as being perceived as a bad parent or a bad child had influenced treatment by others, leading them to respond inappropriately and causing bigger problems than those initially presented with in the case of Marie who describes this below.

They labelled him as naughty, they restrained him, they did all sorts of things they shouldn't have done and the consequence of that was he had a mental health crisis, he just couldn't do anything… (Marie)

Being labelled as a 'naughty child' had led others to respond inappropriately to her child and impacted on his mental health, causing bigger problems than those he initially presented with. Marie also names the continuous self-doubt she experienced as a parent prior to diagnosis, wondering if they were exaggerating typical parenting difficulties and imagining problems:

It was always in the back of our heads, you know, I - are we making a bigger deal of what things are? You know, is it just that he's being badly behaved and we're letting him get away with stuff? You know, is he just not eating because he's, you know, he just doesn't want that, he just wants his McDonalds? Erm, it, it does cross your mind [laughs], erm and it, so it was nice, it was reassurance that you know, all his little traits that we'd picked up over the years that you know, it, it has been recognised that you know, he, he does have difficulties and it is because he has autism." (Marie)

The report carried a professional weight that a parent's voice lacked, and participants spoke of the power of the report in getting their views listened to, which had previously been ignored, as described by Lily in the quotation below.

So again, it was quite helpful to pull out elements of it, you know, from a professional because you're just a parent, you know, your opinion isn't given much weight but obviously there's a lot of weight given to professionals so yeah, it was just about sort of strategically pulling the bits out and, and using them as you sort of needed to. (Lily)

Much like the difficulties caused by being perceived as a bad parent/bad child by professionals, some participants referred to similar struggles with family members. In the below excerpt Holly describes the value of the report in helping family members understand her child's behaviour, which in turn led them to adapt their own behaviour and responses to the child.

For very close family members, I let them read it so they could have an insight to how and why he behaves and acts like he does and it has helped because I, you know, being on holiday with family was a nightmare, erm and all the comments and you know, I would get up and just leave with [child], erm, because I didn't want him subjected to these negative comments […] they were treating him like a toddler back and obviously now he's a teenager and you know .. they ask him and they ask permission whereas before it was forced on him. (Holly)

There was also a practical reality of diagnosis being necessary to unlock institutional support. The report functioned as a pre-requisite for accessing support that was otherwise unavailable. As stated by Lily in the quotation below, this function was named by parents as the main or only value of the report.

The report itself wasn't that important to me, what was important was the diagnosis. […] To me it was just the key to unlock the next .. sort of level if that makes sense. (Lily)

Lily's talk of unlocking the 'next level' also speaks to this proof being necessary to move onto a new stage on a journey, a theme explored in more detail further below.

Parents also reported knowing that in theory schools were supposed to provide support for children in response to need, rather than diagnosis, but that getting the diagnosis made a noticeable difference in the willingness of schools to provide this support, articulated in the quotation by Rose below.

And it, you know, the school was a lot easier. I mean they were being quite supportive but they were really supportive, once you'd got the diagnosis and it's not supposed to matter but it does. (Rose)

This ties into the theme of the gap between what is promised and delivered, explored below.

3.3.2.2 Theme 2: Gap between what is promised and delivered

Linked to proof of diagnosis being necessary to unlock support, there was a strong pattern across interviewees of there being a gap between what support is said to be available for their children and the support actually forthcoming. This was true both prior to diagnosis, when some support was supposed to be based on need rather than diagnosis, and afterwards, when there had been a belief that getting the report would finally unlock the awaited support and this failed to materialise. For instance, Lily reported local institutions being unable to offer her son services he needed in the quotation below:

…what I did find very difficult, very difficult erm, was that you end up in crisis and the sort of very agencies that are there to help you don't help you so when the NHS won't work with you and you know, the local authority don't provide a suitable education, that, that was difficult. (Lily)

Similarly, Marie spoke of how much she had to fight to get an EHCP for her child. She described the illusion of this being needs-led as 'rubbish', and confronting the council with the illegality of their failure to uphold this was required to get this support:

…we had had to have so many reports for [child] in order to get this EHCP. And it was obviously very tricky, very expensive, very emotionally draining and we fought, despite the fact that an EHCP is supposedly needs led, not diagnosis led, that's all rubbish and the only reason we got the EHCP was because we threatened judicial review of the council. (Marie)

Likewise, Rose described the difference between how long her child's EHCP was supposed to take in theory and how long it had taken in practice:

I mean his EHCP, we're 18 months into a process that should take 26 weeks. (Rose)

The above excerpts all convey the gulf between what parents knew 'should' have happened when their child was experiencing difficulties related to autism and what actually did happen. Getting support was described as an obstacle ridden process, and getting through one stage did not mean that support would be available, as a new obstacle would then present itself. Lily and Rose articulate how painstaking this process is in their quotations below:

So yeah, it's .. yeah, it, it's kind of an iterative process of unlocking stage by stage but yeah, abs-absolute yeah, you wouldn't, unless you'd been through it, you wouldn't believe how hard it is. (Lily)

Getting a diagnosis doesn't mean that they'll help in the school. You then have to have evidence that whilst the school has done everything that they can, he still needs extra help. (Rose)

Parents experienced attempting to get support for their children as a fight against these constant barriers and obstacles. The report represented a tool in this fight, giving parents 'a chance' to push back against relentless barriers. Lily alludes to this below:

It was just absolute hell, like I've never had to fight so hard for anything, just another level of fight, so obviously yeah without that [report], I don't think anyone stands a chance … other professionals probably found it a bit of a thorn in their side ultimately because you've got some evidence from which to, to push back. (Lily)

By the time of assessment, parents had been engaged in this fight for a long time and felt depleted. There was little energy left for reading the report and taking in new information.

While the report was an important tool in this fight it was also perceived as adding to the parent’s burden by giving them reading to do and strategies for them out into practice.

I think that’s the other side of it, is that possibly when you get a report like this, you've had to fight so hard, you might not actually have any strength left to want to read about it at that moment […] I don't want to read anymore reports, I’ve had enough, I just want my son to be a little boy, I don't want to medicalise him anymore. (Marie)

The child was also viewed as being under assault by this process, and in the extract above this is linked to his being ‘medicalised’ and his personhood bound to the nature of his difficulties by systematic failures to provide support for these.

Some parents referred to becoming an expert out of necessity, while waiting for ‘support that never comes’ due to the many barriers that needed to be got through. Parents undertook a process of training themselves as access to expertise from services was lacking, as described by Lily below:

… you can then go and upskill yourself and educate yourself so how do I best support my child while you wait for the support that never comes? But you know it’s then about okay, well I know he’s got generalised anxiety, I’ll do a parenting course around that. (Lily)

Following receiving the assessment report, parents felt abandoned to the difficult task of parenting an autistic child, and on their own in trying to find appropriate support. There was a sense of unmet expectation for further support, and even when recommendations were provided these were experienced as a task to be undertaken alone and unsupported, as Emma and Rose describe:

After you get this autism assessment .. no-one, there is no further actual communication with other professionals so you need to fight for this and you need to think about it by yourself, where you need to refer your child, who else can help you. (Emma)

The most difficult thing about the report was just basically they say, "Right, your child has autism, that's it, we're done." […] That was most difficult, I think because it's not an easy thing to live with, you have to completely change your style of parenting. I mean he's my third child but we had to change everything… To just be abandoned with an autism diagnosis, "there you go" is quite, quite hard. (Rose)

In many ways, it seemed that participants had carried a hope that assessment would mark the end point to the fight they had been engaged in, and that the burden of finding help might at this point be handed over to, or shared with, professionals. Receiving a report saying that the service's involvement had now ended and with a list of new suggestions for the parent to try instead represented a further challenge ahead.

3.3.2.3 Theme 3: Report marks one stage in a journey

Receiving the report marked a stage in a wider journey around understanding and supporting the child. It was perceived as an ending to the long journey to diagnosis. However, it also marked a beginning, with an awareness of how much more work there was still to do to get support for the child. Holly and Lily refer to this seeming ending actually being a beginning of sorts in the quotations below. For Holly there was also a sentimental value to the report as a reminder of how far the family had come.

…at first I thought, "oh, that's very final" but then I knew I had so much to do! […] …having the report, it was sort of a nice closure to that part of our lives. […] It come after a long hard time! So you know, it was a good ending really. […] …having the report, it just closes one door and another door opens. …It's nice to look back and read it and realise how our journey has completely changed and it, you know .. what we're doing now, we could have never dreamed of doing a few years ago when we got the report. (Holly)

I think it was just the first stepping stone on a journey that unlocked the resources that then enabled you to really understand what your child needs. (Lily)

The report illuminated new directions for parents, but also marked ‘closure’ to ‘a long hard time’, a reminder of what had been fought for and won. Connected to this was the sense of the report capturing one point in time and representing one temporary presentation of the child, which might feel out of date quite quickly, so its utility for helping others understand the child’s current needs was somewhat limited, as Lily articulated below.

The report doesn't answer for all of your questions because the autistic child, he keeps changing all the time, the things that he was doing last year, now he is different. (Lily)

Preserving information in time helped parents to take it in. Parents expressed being overwhelmed with the volume of information in the report, and finding it hard to take in all the recommendations and resources at once, which Holly and Marie comment on in the quotations below. Having the information recorded in one place allowed parents to come back and gradually digest this information in their own time.

It’s also good to sometimes read over it because you don't remember everything and all his difficulties. (Holly)

It’s very hard to learn everything at once, it’s just not possible is it? (Marie)

This felt particularly important in light of the timing of initial feedback following assessment, which typically came at the end of a lengthy and emotionally draining process. Participants described finding it very difficult to take this information in at that point in time, which Rose spoke about below:

…they rattle off when you're talking to them, they rattle off a whole list of places you can go and the charities that help, particularly the local ones but .. that’s at the end of a two hour play thing, plus a half an hour talk with the .. clinician, erm, you don't take it all in. (Rose)

There is a sense in what Rose said of the clinicians casually ‘rattling off’ information that is routine to them, in contrast to the novelty and significance this information has to the participant, who is reeling from a diagnosis and the emotional impact of this. It is hard for parents to take in the information about future support in this major moment of ending to the diagnostic journey. The report preserves that valuable information until parents are ready to start the next journey this information represents.

3.3.2.4 Theme 4: Grief facilitates moving forward

Parents spoke of a grieving process on reading their child's autism report, even when they had been sure already that their child was autistic. Conflicting emotions were expressed, with sadness and worry mixing with relief and often giving way to hope and a renewed focus on the child's individual strengths. This is evident in the following quotation from Marie:

We clearly knew he was autistic before the report. So I felt .. very upset in the sense that I knew it was the case but I still felt very upset […] but my husband actually felt.. he said, "This is brilliant, now we know," [laughs] and you know, he said, "This is so good because it can now mean that we can give the support we need to our son." […] You get sad because I thought, "Gosh, this is .. quite a big thing" but relieved and actually, very pleased that we were able, once I'd kind of come to it and now I actually think .. I'm really changing my mindset anyway because I'm thinking, "Well, he's a brilliant boy. Yes, he has some social communication differences but he's a fantastic mathematician, he's fantastically full of energy" and not to think about sort of, it's not all about the negatives, it's about the positives […] I think you have to get over perhaps a grieving process when you get the report before you're able to then decide your child's life isn't ruined and actually, life is still good…. (Marie)

Going through the grief seemed to be connected to reaching a more hopeful state where parents could look forward and focus on nurturing their child as they are. In Marie's quotation above, sadness conflicts with relief as the realisation of disability sinks in. Although Marie was already sure her son was autistic, this had to be professionally confirmed before acceptance was possible. Once acceptance was reached, attention turned to the support they could offer their son, and so the diagnosis was 'brilliant'. The participant's focus then shifted to her son being a fantastic mathematician with lots of energy. Similarly, Holly initially hoped for her child not to be autistic, preferring that he be 'just' badly behaved, which seems perhaps less permanent and something they might more easily influence:

I was hoping that they'd say "No, he doesn't have autism" and you know, "he's just being badly behaved" and er .. but then you just think, well actually, it doesn't change anything and .. you know, just for other people outside the family it will change, and it's a stepping stone for us to understand him and for him to understand himself as he gets older. (Holly)

Holly's husband went through a similar shift in mindset described below, first struggling with the loss of the future and activities he expected to bond with his child through, before accepting that the child will have his own different strengths:

It, at first for my husband, I think it was really hard because he was I think grieving for this child that he thought was gonna be really sporty, really able, erm .. and then he realised you know, [child] .. will thrive in his own way and we've just got to let him .. pick and choose what he wants to do and not force him […] he found it hardest out of everybody to accept that you know, there's something quite different with [child]. But also having the report, I think helped him move on from it… (Holly)

Reading the report helped Holly's husband shift to a place of enabling his son's strengths by learning possible strategies and responses to challenging situations. In addition to grief about the loss of one possible future, the diagnosis could create new worries.

Finding out a diagnosis, you've now got the worry of the future. You've got the worry of .. "well, he can do this now, is he going to be able to do it next year or the year after?" because you are warned that children can go backwards, not just forwards, you know? […] If I didn't have the diagnosis, I'd be really worried about that [toilet training] but I'm just like, "Okay, he'll get there." (Rose)

Interestingly for Rose the diagnosis also served to help contain this anxiety as well as creating it. Diagnosis is associated with new worries about loss of skills in the extract above, but it is also named as helping the parent accept worries and take a hopeful attitude of 'he'll get there'.

Grief involved accepting the differences in their child before being able to move on to embracing these and focusing on strengths and possibilities.

3.3.2.5 Theme 5: Increased awareness of difference

A topic of parents becoming more aware both of their child's differences and differences in themselves or within the family came up in many interviews. This awareness echoed the theme of grief facilitating hope above, as there was a re-framing of traits as neurodivergent that might not have been seen this way previously. Reading reports made some parents aware of things they had not noticed in their child, which were described as a difference in the report. For instance, Rose described realising for the first time that her child used eye contact differently when she read the report.

…before, I would have thought his, his eye contact was normal but obviously not. (Rose)

This could lead to an increased sense of loss and awareness of disability, as described by Marie:

I think I felt a moment of great sadness, thinking "my son is disabled" (Marie)

However, parents also connected these differences to neurodivergent traits in themselves or within the family, which meant that these things did not always show up as differences in the family context, as described by Marie, Holly and Rose in the quotations below.

…my sister's autistic, her three children are, my dad is […]. So actually, as a family, things like, the social niceties of saying hello, saying goodbye aren't always observed, people don't always look each other in the eye, people might give up in the middle of the meal and go and play the piano to take a break. […] So I think that's what's hard about the whole diagnosis thing is it's, for example, how did I play with my toys when I was little? I liked to organise

them in nice little rows, so I think that is the tricky thing is that … you may have not seen a lot of this behaviour as necessarily different or problematic but it was. (Marie)

…my older brothers have had a look, […] my oldest brother actually thinks that he's autistic… (Holly)

…the majority of scientists that I worked with are probably on the autistic spectrum somewhere, I'm sure I am, I've learned a lot about myself, going to all of these .. courses, 'cause you're like, "ooh, I do that – and I do that and I do that. (Rose)

Increased awareness of neurodivergence within the family and peers seemed to facilitate hopefulness, with a realisation that this diagnosis did not represent something completely new, but a formally acknowledged version of something already familiar which they could recognise aspects of in themselves, other family members or skilled and competent peers like the scientists described above. Along with the broader grief described in the theme above, this connection of differences in the child to differences in the family could help parents feel more able to move forward into the future, as articulated by Marie below.

…realising my grandmother, who used to have a huge amount of non-verbal communication and spoke almost entirely with kind of set phrases, once you realise that then it changes how you look at everything anyway? […] You may well feel a bit of a grieving process and then you think, "Well, it was the same before, it'll be the same after, everyone in our family's like this anyway so let's just move on. (Marie)

Autism became positioned as one of many aspects of the child's identity, not negative in and of itself, and not entirely disabling given the right context. Increased family awareness of neurodivergence also led to mutual peer support within the family, as illustrated in the following excerpt:

Especially now because that we have more members of the family who are autistic, at different levels, it means that they can relate to all the children, "oh yeah, oh", you know, "[other child in family]'s having problems", "Oh that's what [child] has as well", you know?

"How did you ..?", so they're trying to get information from some other members of the family, how we deal with things, what support groups we're with, erm, which is really good." (Holly)

When language of difference was used in reports this seemed to support hope, while language of deficits made reports feel harder to read. Marie below spoke about the report contributing to an understanding that the differences being described were not necessarily negative.

I think that the use of the language, "strengths and differences" is obviously .. quite good because "differences" doesn't necessarily mean negatives, […] And so I think perhaps that does come from the report in the sense that you realise people are different, as opposed to wrong. (Marie)

With this shift, parents were also aware of how others viewed their child, and the importance of the autism diagnosis not being something that caused others to view them through a lens of inability, but the importance of neurodivergent children having expectations like other children and pushed to reach their potential. In the following quotation, Rose describes the impact teachers' attitudes could have on their child at school:

So last year, [child] had the most fabulous teacher who was, basically his position was you can and not you can't. [Child] made a lot of progress that year because it was all about enabling [child] and this year the teacher's the same. … So, "Oh he can't do this, he can't do that, he can't .." whatever and I know he's getting older and more able to sit down and things as he's getting older but .. if you start with you can't, then they end up doing nothing because they're not pushed to do anything. And not many children push themselves. So you know, we just want him to be the best he can be. (Rose)

Related to this increased awareness of difference was the value of peer support, explored below.

3.3.2.6 Theme 6: Peer support bridges the gaps

Peer support came up in many interviews as something that had helped parents navigate the gaps between the overwhelming and sometimes abstract information on their reports and what good support could look like in practice. Connecting with other parents locally helped in exchanging ideas and finding out what had worked for other people. Local organisations were particularly valued for navigating services and hearing about how others had got through obstacles to support. Lily described a sense of duty to pass on this peer support to others, having been helped through this ‘assault course’ of a journey – this also links to the earlier theme of the gap between what is promised and delivered.

I see SEND as a bit of an assault course so you know, you’ve kind of got this massive A frame that you’ve got to figure out to get up the top of. But once you're at the top of it, you know, and actually other parents have helped you up it as well, it’s your duty to sit on the top and help other parents up so yeah, I think largely other parents helping you out. (Lily)

Recommendations listed on reports were not always easy for a layperson to make sense of or implement, as Marie and Rose both comment on below:

The real issue with the report is they say a lot of things like, “Your son would benefit from social stories,” but you actually have no idea what that actually means or how that would benefit them. (Marie)

I mean just saying that “your child needs autism friendly strategies” isn't the most helpful sentence in the world … I mean what are the autism friendly strategies? (Rose)

Peer support served a function of helping translate ideas from the report into something meaningful by showing what strategies could look like, and what kinds of support might be worth pursuing. Marie voiced this in the quotation below:

What is more valuable than anything is being connected into a peer group who are able to offer you support and practical advice and practical tips, […] you might see in reality how *these types of things could work and that will probably be more valuable just seeing the practical application? (Marie)*

Until they were spoke to others, parents did not know what they did not know – it could be hard to know what they should be looking for, and what the information on their reports meant for them concretely. For instance, Rose quoted below was advised on the report that an occupational therapist might be helpful, but not why.

"You may want to see an occupational therapist", it was the EHCP person who said "oh, you know, oh his handwriting, his fine motor's not that great, oh, let's check with the occupational therapist," I didn't realise occupational therapists did that. (Rose)

It was only when another professional linked this recommendation to a more concrete task that it made sense and became meaningful to the parent. Similarly, outside of professional support, peers could offer ideas for day to day difficulties that might not always be considered by professionals. For instance, in the excerpt below Rose described avoiding certain activities as they did not know there was support available. This was not something they would have thought to ask for, and it was only through that informal contact with peers that this solution spontaneously came about.

I think you find out by word of mouth, you're like, we, we were sort of avoiding places like Legoland because of the queues and somebody said, "Oh, by the way if you get one of these cards then you can queue virtually, so you don't have to physically stand in the queue." And you're like, "oh, oh that's good, how do you get one?" (Rose)

Learning from lived experience also offered parents something broader than professional advice, alluded to in the extract below:

I read this book, also Scatterbrain which is not a self-help book, it's more of an autobiography and also The Reason Why I Jump and actually reading things like that for me was, I found more interesting because I felt a greater sense of… it was less about sort of, "You could do this, you could do that," it was just someone's lived experience." (Marie)

Although not explicitly stated, reading about these lived experience accounts seems to have contextualised ideas for Marie in a way that a list of recommendations could not. Exposure to the lived experience of others seemed to bridge gaps between the child's difficulties and the wider experiences of others, helping parents understand a bigger picture of living as, or parenting, an autistic person in the world.

4. Discussion

4.1 Overview

In this chapter findings from the questionnaire are first discussed in relation to the existing literature. Themes from the thematic analysis of interview data are then discussed in relation to questionnaire findings, and in relation to other research in this area. This is followed by a critical appraisal of the study. Finally, clinical and research implications are discussed, along with concluding remarks.

4.2 Summary of questionnaire findings

The following section summarises the findings of the questionnaire part of the study in relation to the research questions, ‘how do parents use autism assessment reports?’ and ‘how helpful do they find them?’

4.2.1 Uses of reports

The most commonly reported use of autism assessment reports was to help the child’s school understand their needs, closely followed by the related item of using the report to support an ECHP. Free text responses expanding on report usage highlighted the importance of reports as the key to unlocking support for the child via proof of diagnosis. Helping others to understand the child was also commonly mentioned here, and helping parents to understand the child was also mentioned by numerous participants.

The importance of reports for helping schools understand the child’s needs was further supported by schools or colleges being the most commonly reported recipient of shared reports, and by concerns around school being among the most commonly reported reasons for parents seeking assessment.

4.2.2 Helpfulness of reports

Free text responses regarding the helpfulness of reports for the uses parents reported were mixed. Many responses indicated that parents had found the reports helpful, but many also said that the report was only helpful as proof of diagnosis (as opposed to the content being helpful in and of itself). A number of participants said that the reports would have been more helpful if they had included more specific strategies and adjustments personalised to their child.

Most parents reported finding report recommendations helpful, and the helpfulness of recommendations was statistically associated with the inclusion of a section for recommendations in the report.

The inclusion of developmental history taken from a parent was also statistically associated with parents reporting that the recommendations were helpful. This finding might simply reflect the overall quality of reports. A report omitting details of the neurodevelopmental history might be likely to also omit other areas, and is perhaps less likely to feature clear or detailed recommendations.

4.2.3 Readability of reports

If reports are difficult to understand then it seems probable that they will be less useful to parents. The majority of parents in this study found reports either very easy or easy to understand, but a minority found them somewhat or very hard to understand. Given the unusually high level of education in the sample, this is likely to be an underestimation of the difficulty faced by the overall population of parents receiving autism reports.

Free text responses expanding on this item did not provide any consensus on factors making reports harder to understand, but some comments named lengthy reports, use of jargon, grammatical errors, the inclusion of raw test scores and parental emotions while reading the report as making this harder. When asked about particular parts of the report being hard to understand, unnecessary or overly detailed, numerous parents mentioned the parent interview being presented in excessive detail, and suggestions being overwhelming.

Readability of reports was not statistically associated with any particular variables measured. Parent level of education reached near significance, as did inclusion of developmental history from a parent and the inclusion of a summary of the assessment outcome.

4.3 Relationship between questionnaire findings and wider research

4.3.1 Uses of reports

The finding that helping the child's school understand the child's needs was the most commonly reported use of reports fits in with what is known about the difficulties experienced by autistic children in educational settings. Autistic children appear to be more likely to underachieve academically in a classroom setting than typically developing peers, while simultaneously exhibiting more behavioural and emotional difficulties (Ashburner et al., 2008, 2010). A range of barriers exist for autistic children which can worsen at the secondary level, when inconsistencies in routine and social complexities tend to increase (Hedges et al., 2014).

If a child has been identified as autistic, schools may be able to implement specific supports and accommodations which can help them manage better at school (Adreon & Stella, 2001). For some children, alternative educational provision might be a better setting to meet their needs (Goodall, 2019). In the UK, parents can request an assessment for an ECHP from the local authority. This is a legally binding document giving a child support needed to meet their educational and care needs, and can facilitate additional funding and resources beyond that which the child's school could otherwise provide. However, accessing this support can be a struggle for parents in practice (Keville et al., 2024). Sharing the report with the school and using it to support an EHCP assessment and/or education professionals' understandings of the child's behaviour may be an important step towards this access.

Reports were also commonly used to help others to understand the child. Helping others to better understand autism has been shown to increase acceptance and community inclusion of autistic children (Anthony et al., 2020), so it makes sense that parents would use reports to facilitate better understanding. Many parents also reported using the report to better understand their child. The literature suggests that parent training on autism can have helpful effects (Booth et al., 2018). Parent coaching interventions have been shown to reduce parenting stress in the months following autism diagnosis (Estes et al., 2014).

4.3.2 Helpfulness of reports

Most parents who commented on helpfulness of reports found them helpful, which corresponds with wider literature suggesting the majority of parents found autism diagnostic feedback satisfactory (Brogan & Knussen, 2003). In particular, Eggleston et al (2019) found that 75% of their sample found diagnostic reports satisfactory. However, a number of respondents commented that more specific and personalised strategies would make them more helpful. This matches with findings from Wilson & Gunn (2023) that parents value personalised recommendations in reports based on the child's strengths and difficulties.

A number of parents said that the report had been helpful purely through its function as proof of diagnosis, as opposed to the content being helpful in its own right. Given how lengthy and arduous the process of obtaining a diagnosis can be for parents, it might be that some parents have already done a lot of learning around autism, their child's strengths and difficulties and local resources prior to assessment. The reports might not therefore contain much new information for them. In line with this possibility, more than one participant commented that the report came too late to be helpful for their child, and that it would have been more helpful earlier on.

4.3.3. Readability

The majority of the sample found their reports easy to read, but some found them difficult to understand. The length of reports, use of jargon, raw test scores being included without context, and parent emotion were named as some factors contributing to reports being difficult to read. Existing research suggests that most parents prefer autism reports to be longer (Wilson & Gunn, 2023), but this is likely to vary from person to person. The use of jargon has been criticised by parents in previous findings on autism feedback (Brogan et al, 2003) so it is unsurprising that this is also the case in reports. Parent emotion has similarly been named in previous research as a factor that can make it harder to take in post-diagnostic information (Abbott et al., 2013; Mulligan et al., 2012; Nissenbaum et al., 2002).

As mentioned earlier, the sample in the current study is more highly educated than the general population and this might be impacting how many found the reports easy to read. Given that 43% of adults in the UK struggle to understand health information, keeping reports clear and simple should be an important aim for clinicians (Rowlands et al., 2015).

4.4 Summary of qualitative analysis

The following section summarises the findings of the qualitative part of the study in relation to the research question, ‘what is the value of autism reports to parents in the context of the wider journey of autism diagnosis?’

The qualitative analysis suggested that the report was linked to a number of parent experiences within the journey to getting support for their children. Reports providing tangible proof of diagnosis was valued by parents. This proof granted validation by others that their child had differences and needed adaptations, which materially facilitated access to resources and psychologically relieved parents of fears that they were, or would be viewed as, a ‘bad parent’ or that their child was a ‘bad child’. This seems to reflect a lack of conceptual space within wider societal discourses around parenting; a medicalised explanation of disorder is presented as the alternative narrative to that of being ‘bad’. This seemingly binary choice opens up a question of whether reports might be able to facilitate a more nuanced understanding of the difficulties faced by autistic children. Reports also reminded parents of a gap between the support they had been told should be available and what they actually found to be forthcoming. This happened both by reports finally allowing parents to access support which should have been made available based on need rather than depending on diagnosis, and in revealing that less support was available post diagnosis than they had been hoping for. Reports represented one stage in a larger journey for parents, who reflected on having to fight both before assessment and afterwards to get support for their child. For some parents, the report held sentimental value by revealing how much had changed since the time of assessment. Reports also froze information in time, providing a volume of information that could be overwhelming in one place, so that this could be returned to at the parent's own pace. This came with downsides, in that the presentation captured in reports was quickly out of date.

Reports could bring up feelings of grief for parents, reinforcing concretely that their child was different and summarising the difficulties the child had experienced. Again, it seems possible that this might in part be connected to the limited discourses that parents are presented with around autism – either accepting a 'bad parent/bad child' narrative or a narrative of medical disorder and deficit, neither of which might seem satisfactory choices. Grief was described as an initial reaction, which passed and gave way to acceptance and a more optimistic focus on the future. This initial grief could make reports difficult to read. Reports made parents more aware of areas of difference in their child, some of which they may not have realised were not considered typical. Reports also made parents consider difference within the wider family, with interviewees reflecting on other family members and/or themselves in relation to neurodivergence. This could be connected to greater support and understanding within the family for the child's differences. Finally, while reports recommendations could be difficult for parents to translate into concrete ideas, peer support came up in interviews as a resource that helped to make these recommendations easier to understand by providing examples, in addition to giving parents other ideas for what support was available locally.

4.5 Themes in relation to questionnaire findings and wider literature

This section examines how the themes from the interview data can help to make sense of questionnaire findings, and how they relate to the wider literature.

4.5.1 Theme 1: Importance of proof of diagnosis for validation and understanding

Interview participants spoke of the importance of diagnostic proof, for a range of reasons including validation that their child's difficulties did not make them bad parents or their child a bad child, allowing them and others to better understand their child, and facilitating access to support not otherwise forthcoming.

This importance provides context to questionnaire findings that the main uses of reports indicated by parents were helping the child's school to understand their child and to support an EHCP. School can be the site of many challenges for autistic young people, and the way education professionals make sense of these challenges can have a big impact on young people's ability to access education (Horgan et al., 2023). If children's behaviour is misunderstood they may be excluded, either directly by the school or by school avoidance, which can further impact of the mental health of young people and parents (L. Gray et al., 2023; Martin-Denham, 2022).

This theme also gives context to the finding that after school and EHCP, the next most commonly reported parental use of reports was to help others understand their child. Interviewees said that sharing the report with family members helped them to better understand the child, and reduced the sense that the child was bad or that they were a bad mother. Using the report to help others understand their child's behaviour might help to reduce stigma in others around the child. Parents of autistic children can experience both perceived and enacted stigma from others, and report encountering behaviours such as rude comments and hostile staring (Kinnear et al., 2016), and there is evidence that the impact of stigma tends to decrease over time as parents form connections with others who accept their child's diagnosis (Gray, 2002). The perception of oneself as a 'bad mother' has been found in the wider literature (Gill & Liamputtong, 2013), and parents report being blamed by professionals for their child's behaviour when they seek help (Hollingsworth et al., 2024). Other qualitative studies have also generated themes around the validation parents can feel after their child is diagnosed as autistic after diagnosis provides an explanation for their child's difficulties which is not their fault as parents (Jacobs et al., 2020; Nissenbaum et al., 2002). It seems that a discourse of blame or a discourse of disorder can be experienced as the only two options for making sense of these difficulties. A societal shift towards a more nuanced understanding of how difficulties develop in families, such as that suggested by Dallos (2019), might help to relieve the pressure on parents of autistic children who face this dilemma.

4.5.2 Theme 2: Gap between what is promised and delivered

There was a large difference between the support interview participants expected to receive or should have received based on NICE guidelines and the support actually available to them, both before and after diagnosis. Reports provided recommendations and resources, but the burden of following these up, requesting referrals and understanding what these meant fell on parents.

This theme may provide some context for questionnaire responses suggesting parents had hoped for more personalised recommendations for their child – a finding that echoes the existing literature (Crane et al., 2016; de Verdier et al., 2020; Hennel et al., 2016; H. S. Ho et al., 2014; Nissenbaum et al., 2002; Renty & Roeyers, 2006; Sansosti et al., 2012). One free text response did explicitly express surprise that nobody was going to take on the burden of finding their child support following assessment, and that they were still responsible for coordinating this, reflecting a gap in the support they expected to get following diagnosis and the reality of still needing to seek additional help.

This sense of disappointment is reflected by findings in the wider literature that the support currently provided to parents following autism diagnosis does not meet parents' needs (Galpin et al., 2018). Existing studies have found that parents feel more professional support is needed to co-ordinate their child's care, which currently all falls on the parents (de Verdier et al., 2020; Legg & Tickle, 2019; Rabba et al., 2019; Tait et al., 2016). Interviewees spoke of feeling abandoned and alone after receiving their report, which is also a theme in the existing literature (Carlsson et al., 2016; H. S. Ho et al., 2014; Jegatheesan et al., 2010; Raymond-Barker et al., 2018; Tait et al., 2016).

The idea that support should be provided based on need and not diagnosis was mentioned by participants as one example of something that should be true but is not. Again, this can be connected to the choice parents must make of accepting a medicalised understanding of their child's difficulties in order to obtain help and support. Parents trying to access an EHCP for their child often face difficulties and delays in this (Keville et al., 2024), and while having a diagnosis of autism should not matter it is easy to see how the absence of diagnosis might make this harder.

4.5.3 Theme 3: Report marks one stage in a journey

This theme captured the way parents found the report useful to come back to for gradual digestion. Some questionnaire free text responses referred to finding the amount of information in reports overwhelming, and this interview theme presents another side to this, with the report providing a way to keep all this overwhelming information together, allowing for its gradual understanding and implementation.

Previous studies have also found that the amount of information received in autism assessment can be overwhelming for parents, partly due to the timing of this, with parents often being told things straight after a lengthy assessment. For this reason, many authors have recommended that written information be provided to parents (Abbot et al; Mulligan et al; Nissenbaum et al).

This theme also captured something the questionnaire did not, around the sentimental value of reports. This was not a practical ‘use’ or something parents sought assessments for, but was a hidden value, possibly noticed only as a consequence of participation in this study and the re-reading of old reports this prompted. Other research has found that it can be motivating more broadly for parents to look back and consider how far they had come with their autistic child (Ho et al., 2018). Perhaps reports could play a role in narrative therapeutic interventions for families with autistic children as tool for reflecting on changes and growth. The potential of reports to shape the narratives families develop is worth noting, as report writers can influence this through the way autism is explained and the way the child’s differences are presented in the report.

4.5.4 Theme 4: Grief facilitates moving forward

This theme highlights the grief reactions parents can have to confirmation of their child's autism diagnosis, and the way that there can be a process of experiencing this as a loss before being able to re-orient to hope and a stronger focus on the future.

This context might help to understand the questionnaire's free text data around parents finding the information in reports overwhelming. At least one questionnaire participant named emotion as being a factor making the report difficult to read, in line with existing research findings (Abbott et al., 2013).

Existing literature has found that grief is a common initial parental reaction to autism diagnosis (Alimohamadi et al., 2024; Bravo-Benítez et al., 2019; Makino et al., 2021). In particular, it has been linked to the idea of ambiguous loss which lacks a clear resolution (Boss, 2004). Relief is an even more commonly cited reaction to autism diagnosis (Makino et al., 2021). As some time has usually passed since the assessment when parents receive their written report, it perhaps makes sense that this may have faded by the time they read these, which might account for why this emotion did not come up in the current study.

For the interviewees in this study, grief was a transient stage that was apparent before giving way to acceptance of differences and a shift towards thinking about the future.

4.5.5 Theme 5: Increased awareness of difference

Although only one interview participant in the current study had a diagnosed neurodevelopmental condition and none had an autism diagnosis, some spoke about recognising potential autistic traits in themselves and their families as a result of learning more about the condition, including one participant who said she was "sure" that she herself was autistic. Only a minority of questionnaire participants reported having a neurodevelopmental condition, but this theme provides a context of parents becoming more aware of their own and/or other family members' differences and possible neurodivergence after their child has been diagnosed. This perhaps suggests that the number in the questionnaire may not capture the true proportion of neurodivergent respondents, and indeed one participant commented in the free text response for this question that they suspected they had undiagnosed ADHD.

This theme also captured that parents might not be aware that some of their child’s behaviours are not considered atypical prior to reading the report, particularly when these fit with family norms. While questionnaire responses did not generally address this, free text responses about what made reports helpful suggested that reports could show parents behaviours or responses their child demonstrated during the assessment context that they had not seen, which perhaps is related to this. It seems possible that in addition to helping parents understand their child, reports could help some undiagnosed neurodivergent parents better understand themselves. This theme gives more context to questionnaire responses about reports helping family members to understand the child – family members of some interviewees recognised aspects of themselves in report descriptions of autistic traits. This theme also ties in to questionnaire responses about language used in reports. While the majority of questionnaire participants did not report having any thoughts on language, or reported this not making a difference to them, a minority did report the language having an important impact, either naming neuro-affirmative language as a helpful thing, or deficit focused language as making reports difficult to read. There is a lack of research on the impact of neuro-affirmative language on autistic people to compare this to. This might be an area in need of further investigation.

Conceptualising autism as a difference, rather than as a primarily medical disorder, may be important in a number of ways. There is evidence that a dominant ‘autism discourse’ focused on neurobiological deficits in the child can create challenges for relationships between parent and child, diminishing the perceived interpersonal meaning of child actions and causing parents to view conflict as fixed and unchangeable (Dallos et al., 2023). This discourse may situate problems within the child and encourage parents to view the child as separate and disconnected (Grey et al., 2021). While the diagnosis might validate the parent’s experience of their child as difficult, there is a risk that this leaves the child themselves being blamed (Oprea & Andreea, 2012).

There is increasing evidence that developing a positive autistic identity may be a protective factor against poor mental health in autistic people (Camus et al., 2024; K. Cooper et al., 2017, 2023; R. Cooper et al., 2021; Maitland et al., 2021). The way parents conceptualise and speak about autism impacts on how autistic young people perceive their autistic identity (Riccio et al., 2021). Using language that emphasises autism as a difference rather than a deficit may therefore support the wellbeing of both autistic young people and their families.

4.5.6 Theme 6: Peer support bridges gaps

The qualitative finding about the value of peer support, and the way this helps parents to bridge the gap between the somewhat abstract information written in the report the concrete reality of putting this information into practice, was not captured at all by the questionnaire. It was not something considered in the design of the study, and is not directly relevant to the original research questions. However, it came up unprompted in every interview in some form in powerful ways. This might be in part due to the recruitment for this study, which took place through local groups supporting parents of autistic children, meaning that all participants had some experience of this kind of peer support. Interviewees described peer support as being incredibly valuable in understanding how to implement recommendations described in reports, as well as showing them new sources of local support and sharing information in a relational way. This represents one possible antidote against parents getting 'lost' or feeling abandoned by services, which did come up in the questionnaire free text responses.

The wider literature suggests that parents of autistic children would like to be connected with peer support from families who have also been through this experience (de Verdier et al., 2020; Osborne & Reed, 2008; Stahmer et al., 2019). Parent to parent peer support can have good outcomes for parents and help promote a sense of belonging and alleviate social isolation (Lee et al., 2024). It seems likely that there are things that can be learned through relationship to others that cannot be learned in the same way didactically – a network for sharing information about autism in an NHS healthcare trust found that professionals found the informal relationships more valuable for their learning than the lectures provided (Kirby

& Payne, 2023). In the same way, peer support networks might allow parents to exchange ideas in a relational way that goes beyond what can be learned from paper or electronic information sources or even taught courses on autism.

One interviewee mentioned that autobiographical books written by autistic people were more useful than factual resources about autism, helping to give a broader context and perspective for understanding what it is actually like to be autistic in the world. These lived experience accounts might counteract the 'anti-mentalising' effect that autism can have (Grey et al, 2021) by helping readers understand the minds of autistic individuals. Previous studies have found that psychologists perceive reading autobiographical books about mental health to be helpful for their clients, and that this may be helpful in a number of ways including education, inspiration, empowerment and social engagement, among others (Clifford et al., 1999). The value of autobiographical resources for autistic people and parents of autistic children might be an area worthy of future study.

Neurodiversity and decolonising

Some of the findings indicate that the way autism is written about in reports can have an important impact on parents, for instance by facilitating hope

Considering neurodiversity can represent a form of decolonising (add reference). From this perspective, a deficit based medical understanding of autism as a disorder located within the diagnosed individual has dominated or colonised the narrative around autism, and therefore also the systems and relationships around autistic people. By exploring different understandings of autism in thinking about neurodiversity and viewing autism as a difference rather than a deficit, this dominant narrative is challenged.

It is important to note that autistic people will have a range of different positions on this. While for many autistic people thinking about neurodiversity can contribute to the development of a positive autistic identity and sense of hope, other autistic people might criticise some discourses around neurodiversity for potentially downplaying the severity of disability they experience. Expanding the ways people can make sense of autism and challenging the dominant discourse around this represents is important, but individual preferences around language and identity are also important to respect.

4.6 Clinical and research implications

4.6.1 Clinical

Keep educational needs in mind

Given that parents' main reported use of reports involved their child's schooling, clinicians writing reports should keep this in mind. Where possible, consider highlighting possible adjustments school could make that might benefit the child.

Consider signposting for peer support

The unexpected theme arising from interviews on the value of peer support for parents suggests that it could be valuable to include details of local peer support organisations in reports, and to include some resources involving lived experience accounts, both from autistic people themselves and parents of autistic children. If diagnostic services have the resources for peer support workers to work with parents while waiting for assessment and post-assessment to help them manage difficult emotions and for practical support translating reports into next steps, this might be valued by parents. Some NHS services already employ peer support workers to support patients and carers across a range of settings, and the current study suggests that autism diagnostic services might be an area where these positions could be of benefit.

Consider the emotional and narrative impact of reports

It might be worth acknowledging parent emotional reactions to diagnosis in reports to normalise these, and potentially to stress the importance of parents looking after themselves. Signposting to local wellbeing services for both children and adults in reports may be beneficial.

More broadly, it is worth clinicians considering the impact reports will have on the narrative that families, the child and others will adopt to make sense of their differences. The report both stories the family's journey and becomes a part of this story and framework for how others see the child. Simple choices like using neuro-affirmative language, considering the child's strengths and emphasising differences rather than deficits throughout the report can contribute to a more hopeful and nuanced understanding of difficulties.

Make reports and recommendations clear, concrete and concise

Language used in reports should be easy for a layperson to understand, and the use of jargon should ideally be avoided, or if necessary, explained to the reader. It might be worth omitting raw scores on assessment tools, which are likely to be meaningless to parents and anybody not trained in autism assessment, and focusing on qualitative information about what these assessments indicate in a way that is understandable to parents. While some parents prefer longer reports, others may find long reports overwhelming. To make them less overwhelming while retaining important information, it might be worth summarising the assessment outcome and important next steps briefly at the beginning of the report and including more detailed information in appendices.

Parents can find it difficult to understand how to implement recommendations, especially if these involve specialised language. Some of these recommendations might be aimed more at other professionals who report might be shared with. When this is the case, it could be helpful to clarify this to parents. It might also be helpful to provide examples to help parents understand when a particular recommendation might be useful (e.g. examples of when it might be worth trying to access speech and language therapy for the child, and how parents might be able to access this).

4.6.2 Research implications and further directions

Professional uses of reports

Autism diagnostic reports have various uses and meanings for parents of autistic children, however they serve multiple functions and clinicians may be writing reports with other professionals in mind just as much as parents. Reports might hold different purposes and meanings depending on context. With that in mind, it could be useful to know how professionals make use of autism diagnostic reports, and what they value in them. In particular, given this study's finding that the most common uses parents made of reports involved their child's education it could be helpful to better understand how professionals working in school settings and those involved in EHCP processes make use of reports. This could be a worthwhile direction for future research.

Peer support

Further research into the role of peer support for parents of autistic children along stages of the diagnostic journey is another possible direction highlighted by the findings of this study. Our findings suggested that peer support played a powerful role in helping parents to understand what report recommendations could look like in reality, and in helping parents to learn things they could not have known about without learning from others who had been in a similar position to themselves. Some NHS trusts may already employ peer support workers to help parents in this way as part of neurodevelopmental teams. An evaluation of the impact of this could confirm whether parents are indeed benefitting from this support and whether this has a similar or different value to more informal kinds of peer support. It might also be worth exploring the impact this has on parent relationships to services and whether this reduces the sense of abandonment parents have expressed both while waiting for assessment and later following diagnosis.

Adult uses of own autism reports

Finally, the present study looks at autism reports written about children. Adults who are diagnosed with autism are at a different stage of life and may be facing different challenges when they receive their report. It would be interesting to explore how adults use their own autism diagnostic reports, and what value and meanings they hold at this different developmental stage.

4.7 Critical appraisal of study

As a mixed methods study with a significant qualitative component, two critical appraisal tools were used to evaluate study quality. Firstly, relevant criteria from the Mixed Methods Critical Appraisal Tool to consider overall quality of the mixed methods approach (Bartlett et al., 2018). As this tool lacks some important qualitative appraisal considerations, the Big Tent Criteria for qualitative quality are also used to evaluate the qualitative component of the study in greater depth (Tracy, 2010). See Tables 20 and 21 further below for detailed appraisals of Mixed Methods and Qualitative components respectively, using established appraisal tools. The main points are discussed narratively below.

The quantitative and qualitative strands of the study are each appropriate to address the research questions and meet the methodological standards of their respective traditions. Reflexive TA was used to provide context to the descriptive questionnaire data and illustrate the stories behind those figures. The strength of this study lies in its used of mixed methods to reach a deeper understanding than would have been possible through a single method. This mixed methods approach aligns with the critical realist epistemological stance behind the research question, neglecting neither a quantifiable reality nor the subjective realities making up people's experience.

There are strengths in the ways each methodological approach was taken, with methodologies adhering to their traditions. The questionnaire used a suitable sampling strategy, with appropriate presentation and analysis of data. Interview data informed a worthy and timely topic as diagnostic services seek to find ways to meet the needs of autistic children and their families in the face of increased referral rates and waiting lists. Rich sources of data were used and analysed with sufficient rigour to generate meaningful stories about this. This was conducted in a sincere way, with multiple steps taken to maintain reflexivity. Quotations were provided across participants and different viewpoints were taken into account to support robust credibility of findings. Resonance of findings was checked through discussion with experts by experience, participants where possible, and consideration of relation of findings to existing literature. The study generated a significant contribution to the limited existing literature on the value of reports to parents. These methods were used to strengthen and expand one another meaningfully, with the questionnaire data informing the interview schedule, and interview themes being used to contextualise questionnaire data in the discussion.

There are nonetheless limitations to the study that are important to acknowledge. Using a mixed methods approach where the focus was on something greater than the sum of its parts meant that less time could be spent on each individual part of the study, which means that the strength of each aspect taken in isolation is less than if this had been the only method used. While sufficient overall for the study's aims, the sample size for the questionnaire is relatively small, limiting the statistical power of the study to detect associations between factors and the generalisability of questionnaire findings. The sample size for interviews was also unusually small for reflexive TA, which brings issues of data saturation and generalisability into question. As discussed earlier, the notion of data saturation itself has limitations. Still, the small sample means that findings are generated from a small group of individuals recruited in a specific context and this does impact generalisability. The sample were mainly recruited from the local area and limited to parents already accessing support networks, were more highly educated than average and fathers were very underrepresented. There is also likely to be a response bias in this study's findings, as participation required time and effort and only those able and willing to give this are represented.

With a larger sample, different themes might have been generated reflecting a greater diversity of experiences. This might even have allowed for different forms of analysis, such as dividing interviewees into 2 groups based on different characteristics if distinct themes were emerging based on a particular characteristic (e.g., age of child at the time of assessment).

There are also limitations in the methods of analysis used. The content analysis used was only intended as a loose way of summarising themes within questionnaire free text responses at a surface level, rather than generating anything deeper or new. The statistical tests of association were also conducted in an exploratory way rather than being hypothesis driven, which does increase the risk of false positive errors.

Despite these limitations, the study provides a meaningful contribution to an under-researched area and generated clinical recommendations and research implications.

Table 8: Mixed Methods Critical Appraisal Tool criteria (Hong, 2018)

Criteria	Strengths	Limitations
Qualitative methodology		
Is the qualitative approach appropriate to answer the research question?	- Yes, appropriate for understanding role of reports in wider parental journey	
Are the qualitative data collection methods adequate to address the research question?	- Yes, interviews were an appropriate way to gather data to answer this question	
Are the findings adequately derived from the data?	- Yes, reflexive TA used to show how findings were derived	
Is the interpretation of results sufficiently substantiated by data?	- Yes, quotations from across the sample are used to illustrate how the data supports the findings	
Is there coherence between qualitative data sources, collection, analysis and interpretation?	- Yes, attention is paid to coherence between the target population, data collection, analytic method and	

	interpretation, and between study findings and recommendations and the wider literature.	
Quantitative descriptive methodology		
Is the sampling strategy relevant to address the research question?	• Yes, sample taken from target population who were able to give data addressing the research question	
Are the measurements appropriate?		• Questionnaire does not use existing measures.
Is the risk of nonresponse bias low?		• Nonresponse bias is likely present as participation took time and was voluntary.
Is the statistical analysis appropriate to answer the research question?	• Yes, chi square statistical analysis used to explore relationships between categorical variables to consider what impacts on perceived helpfulness and readability of reports	

Is the sample representative of the target population?	• Sample is drawn from the target population	• Relatively small sample recruited mostly from one region means that sample may not represent the entire target population
Mixed methods		
Is there an adequate rationale for using a mixed methods design to address the research question?	• Yes, methods approach different questions with qualitative findings providing context for descriptive quantitative findings.	
Are the different components of the study effectively integrated to answer the research question?	• Yes, findings are integrated in the discussion	
Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	• Integration is interpreted with reference to existing literature to support interpretation	

Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	- Quantitative and qualitative results addressed different aspects of the question and capture different things. Where findings were not captured by both methodologies this is discussed.
Do the different components of the study adhere to the qualitative criteria of each tradition of the methods involved?	- Yes.

Table 9: Critical Evaluation of Study Using "Big Tent" Criteria for Qualitative Quality (Tracy, 2010)

	Description of criteria	**Strengths**	**Limitations**
Worthy Topic	Research topic is interesting, relevant, significant and timely	- Increasing demand for autism assessment and stretched capacity of NHS services combined with resource intensive nature of report writing makes topic timely and relevant	

		• Research is significant as autism reports are an under-researched topic	
Rich Rigour	Study uses sufficiently rich and abundant data sources. Data analysis rigorous and complex and deep enough to describe the phenomena being studied.	• While analysis is informed by researcher's own position and interests, this research attempts to capture the perspectives of parents of autistic children • Number of participants was sufficient to generate meaningful themes present across participants • Appropriate and complex analysis (reflexive TA) used and reported transparently within the study	• Sample size limited by time constraints and mixed methodology • Recruitment took place through a small number of organisations in one area, and the diversity of participants was limited
Sincerity	Reflexivity of researcher about subjective positions and biases, and transparency about methods and challenges.	• Researcher's voice is evident in use of first person in appropriate sections • Extracts from reflexive research diary included in Appendix A to	

		provide more context and transparency about method and challenges - Researcher's personal and professional context reported transparently, along with details of epistemological position	
Credibility	Plausibility and trustworthiness of findings	- Quotations from multiple transcripts included to provide rich narratives - Analysis reviewed by Expert by Experience consultant and research supervisory team to consider different perspectives - Participants were given the opportunity to comment on themes generated	- Time and resource constraints meant that analysis was carried out by one researcher, and while analysis was reviewed by others to check credibility, input from others with different perspectives was necessarily limited.
Resonance	Research influences or moves reader through clear and	- Findings resonated with Expert by Experience consultant, interview	- Sample were mostly recruited from

	evocative representation of data. Resonance is transferable for different audiences and contexts.	participant who looked at these and supervisory team • Many quotations are used to help readers connect with participant accounts • Within discussion, resonance of findings is explored through links to existing literature	organisations in the local area and were more highly educated than the general population, so it is possible that not all findings would resonate with parents from different areas or different backgrounds.
Significant Contribution	Research provides a significant contribution by extending knowledge, theoretical or methodological understanding or clinical practice.	• This study contributes to a very limited literature on autism reports and is to the author’s knowledge the first to investigate parent use of reports. The discussion makes recommendations for clinicians based on findings.	• Findings largely match what might be expected based on existing literature

Ethical	Considers ethical issues, adherence to ethical guidelines and responding ethically to situations arising in research process.	• Ethical approval was granted by the University of Hertfordshire's Health, Science, Engineering and Technology Ethics Committee. • Ethical considerations are kept in mind throughout research processes • Interview participants were given the opportunity to comment on qualitative findings • Findings will be disseminated in a range of ways via academic journals, local parent support services, local NHS autism diagnostic teams and in accessible format for parents of autistic children.	• One expert by experience consultant was recruited, rather than a panel who might have expressed different views
Meaningful Coherence	Whether study achieves its aims and coherence between different aspects of research.	• Critical realist epistemological position has been considered, and thought given to the coherent use	

	of quantitative and qualitative methodologies within this. • Study findings and interpretations are meaningfully connected to existing literature and recommendations for clinical practice and future research.	

4.8 Proposed dissemination of findings

The author is planning to offer a presentation of this project's findings to her current NHS team which carries out autism assessments for children, and to the service she carried out a training placement in when this project was first begun. These sessions will be offered in continuous professional development (CPD) slots for these teams, and it has been proposed that these can cover both the findings of the systematic literature review on how parents experience diagnostic feedback and the findings of the current study on the uses and significance of written diagnostic reports, as well as the clinical implications from this. It is hoped that this will be of value to clinicians in these teams who are writing reports and delivering feedback, and might inform practices in these services. Findings may also be summarised in simple language in a brief poster format and sent to the local organisations who facilitated recruitment.

A paper will also be written based on the current study and submitted to a journal prior to the author qualifying from training.

5. Conclusion

This thesis has provided a critical review of the current literature around parental perceptions of autism diagnostic feedback and has contributed an understanding of the ways in which parents use their children's autism diagnostic reports, along with how helpful they find the reports and how their experiences of reports fits into the wider journey of autism diagnosis. This study has provided insight into the different ways parents use autism assessment reports, in particular highlighting the importance to parents of using these to help their child's school understand their behaviour and needs. It has also shown that parents mostly find their reports helpful, but they could be more helpful with some changes, most notably by including more personalised recommendations. The study has also explored the significance of autism reports for parents within the wider journey of autism diagnosis. This study has also generated several clinical and research implications: Clinically, professionals writing autism reports should keep schools in mind and aim to include information that will be helpful for education professionals, keep recommendations as concrete as possible, acknowledge the emotional reactions of parents to diagnosis and consider signposting parents to peer support services. Future research directions might include exploring the uses and significance of autism reports to people diagnosed in adulthood, how various professionals use autism reports, and the impact of peer support on parents of autistic children. This work demonstrates the capability to plan, design and carry out a study to produce new knowledge with the potential to influence clinical practice in NHS autism diagnostic services across the UK.

References

Abbott, M., Bernard, P., & Forge, J. (2013). Communicating a diagnosis of Autism Spectrum Disorder—A qualitative study of parents' experiences. *Clinical Child Psychology and Psychiatry*, *18*(3), 370–382. https://doi.org/10.1177/1359104512455813

Adreon, D., & Stella, J. (2001). Transition to Middle and High School: Increasing the Success of Students with Asperger Syndrome. *Intervention in School and Clinic*, *36*(5), 266–271. https://doi.org/10.1177/105345120103600502

Aitken, D., & Fletcher-Watson, S. (2022, December 15). Neurodiversity-affirmative education: Why and how? *BPS*. https://www.bps.org.uk/psychologist/neurodiversity-affirmative-education-why-and-how

Alimohamadi, A., Ghasemzadeh, M., Fooladi, F., Abdolmohamadi, K., Killikelly, C., & Janghorbanian, Z. (2024). Living-loss: A narrative synthesis review of the grief process in parents of children with autism spectrum disorder. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, *0*(0). https://doi.org/10.1016/j.pedn.2024.03.036

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders: DSM-IV-TR. Washington, DC: American Psychiatric Association

Anderberg, E., & South, M. (2021). Predicting Parent Reactions at Diagnostic Disclosure Sessions for Autism. *Journal of Autism and Developmental Disorders*, *51*(10), 3533–3546. https://doi.org/10.1007/s10803-020-04817-5

Anthony, B. J., Robertson, H. A., Verbalis, A., Myrick, Y., Troxel, M., Seese, S., & Anthony, L. G. (2020). Increasing autism acceptance: The impact of the Sesame Street "See

Amazing in All Children” initiative. *Autism*, *24*(1), 95–108. https://doi.org/10.1177/1362361319847927

Arksey, H. (1994). Expert and lay participation in the construction of medical knowledge. *Sociology of Health & Illness*, *16*(4), 448–468. https://doi.org/10.1111/1467-9566.ep11347516

Ashburner, J., Ziviani, J., & Rodger, S. (2008). Sensory processing and classroom emotional, behavioral, and educational outcomes in children with autism spectrum disorder. *AJOT: American Journal of Occupational Therapy*, *62*(5), 564–574.

Ashburner, J., Ziviani, J., & Rodger, S. (2010). Surviving in the mainstream: Capacity of children with autism spectrum disorders to perform academically and regulate their emotions and behavior at school. *Research in Autism Spectrum Disorders*, *4*(1), 18–27. https://doi.org/10.1016/j.rasd.2009.07.002

Avdi, E., Griffin, C., & Brough, S. (2000). Parents’ constructions of professional knowledge, expertise and authority during assessment and diagnosis of their child for an autistic spectrum disorder. *British Journal of Medical Psychology*, *73*(3), 327–338. https://doi.org/10.1348/000711200160543

Babbage, D. R., & Terry, G. (2023). *Thematic analysis coding management macro v2.0* [Computer software]. https://doi.org/10.17605/OSF.IO/D32HG

Baron-Cohen, S. (2023, May 14). *ASD vs. ASC: Is One Small Letter Important?* 2015 International Meeting for Autism Research, Salt Lake City, UT, United States. https://insar.confex.com/insar/2015/videogateway.cgi/id/693?recordingid=693

Bartlett, G., Vedel, I., Hong, Q. N., Pluye, P., Rousseau, M.-C., Fàbregues, S., Boardman, F., Griffiths, F., Cargo, M., Dagenais, P., Gagnon, M.-P., Nicolau, B., & O’Cathain, A. (2018). The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for Information*, *34*(4), 285–291. https://doi.org/10.3233/EFI-180221

Bartolo, P. a. (2002). Communicating a diagnosis of developmental disability to parents: Multiprofessional negotiation frameworks. *Child: Care, Health and Development*, *28*(1), 65–71. https://doi.org/10.1046/j.1365-2214.2002.00243.x

Bolton, P. F., Pickles, A., Murphy, M., & Rutter, M. (1998). Autism, affective and other psychiatric disorders: Patterns of familial aggregation. *Psychological Medicine*, *28*(2), 385–395. https://doi.org/10.1017/s0033291797006004

Booth, N., Gallagher, S., & Keenan, M. (2018). Autism, interventions and parent training. *Psichologija*, *57*, 74–94. https://doi.org/10.15388/Psichol.2018.0.11904

Boss, P. (2004). Ambiguous Loss Research, Theory, and Practice: Reflections After 9/11. *Journal of Marriage and Family*, *66*, 551–566. https://doi.org/10.1111/j.0022-2445.2004.00037.x

Brand-Gothelf, A., Hasson-Ohayon, I., Hertz-Palmor, N., Basel, D., Gothelf, D., & Karnieli-Miller, O. (2021). The Delivery of Diagnosis by Child Psychiatrists: Process Characteristics and Correlates of Distress. *Frontiers in Psychiatry*, *12*, 632207. https://doi.org/10.3389/fpsyt.2021.632207

Braun, V., & Clarke, V. (2021). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, *13*(2), 201–216. https://doi.org/10.1080/2159676X.2019.1704846

Braun, V., & Clarke, V. (2022). *Thematic Analysis: A practical guide*. SAGE Publications ltd.

Braun, V., & Clarke, V. (2023). Toward good practice in thematic analysis: Avoiding common problems and be(com)ing a knowing researcher. *Taylor & Francis*. https://www.tandfonline.com/doi/abs/10.1080/26895269.2022.2129597

Bravo-Benítez, J., Pérez-Marfil, M. N., Román-Alegre, B., & Cruz-Quintana, F. (2019). Grief Experiences in Family Caregivers of Children with Autism Spectrum Disorder (ASD). *International Journal of Environmental Research and Public Health*, *16*(23), 4821. https://doi.org/10.3390/ijerph16234821

Brogan, C. A., & Knussen, C. (2003). The disclosure of a diagnosis of an autistic spectrum disorder: Determinants of satisfaction in a sample of Scottish parents. *Autism : The International Journal of Research and Practice*, *7*(1), 31–46. https://doi.org/10.1177/1362361303007001004

Butow, P. N., Kazemi, J. N., Beeney, L. J., Griffin, A.-M., Dunn, S. M., & Tattersall, M. H. N. (1996). When the diagnosis is cancer: Patient communication experiences and preferences. *Cancer*, *77*(12), 2630–2637. https://doi.org/10.1002/(SICI)1097-0142(19960615)77:12<2630::AID-CNCR29>3.0.CO;2-S

Camus, L., Rajendran, G., & Stewart, M. E. (2024). Social self-efficacy and mental well-being in autistic adults: Exploring the role of social identity. *Autism*, *28*(5), 1258–1267. https://doi.org/10.1177/13623613231195799

Carlsson, E., Miniscalco, C., Kadesjö, B., & Laakso, K. (2016). Negotiating knowledge: Parents' experience of the neuropsychiatric diagnostic process for children with autism. *International Journal of Language & Communication Disorders*, *51*(3), 328–338. https://doi.org/10.1111/1460-6984.12210

Case-Smith, J., & Arbesman, M. (n.d.). *Evidence-based review of interventions for autism used in or of relevance to occupational therapy—Document—Gale Academic OneFile*.

Retrieved 17 August 2024, from https://go.gale.com/ps/i.do?p=AONE&u=uniherts&id=GALE|A208275732&v=2.1&it=r&sid=summon

Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism: The International Journal of Research & Practice*, *15*(1), 83–97. https://doi.org/10.1177/1362361309354756

Chiu, Y.-N., Chou, M.-C., Lee, J.-C., Wong, C.-C., Chou, W.-J., Wu, Y.-Y., Chien, Y.-L., & Gau, S. S. F. (2014). Determinants of maternal satisfaction with diagnosis disclosure of autism. *Journal of the Formosan Medical Association*, *113*(8), 540–548. https://doi.org/10.1016/j.jfma.2012.07.040

Clifford, J. S., Norcross, J. C., & Sommer, R. (1999). Autobiographies of mental health clients: Psychologists' uses and recommendations. *Professional Psychology: Research and Practice*, *30*(1), 56–59. https://doi.org/10.1037/0735-7028.30.1.56

Cooper, K., Russell, A. J., Lei, J., & Smith, L. G. (2023). The impact of a positive autism identity and autistic community solidarity on social anxiety and mental health in autistic young people. *Autism*, *27*(3), 848–857. https://doi.org/10.1177/13623613221118351

Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*, *47*(7), 844–854. https://doi.org/10.1002/ejsp.2297

Cooper, R., Cooper, K., Russell, A. J., & Smith, L. G. E. (2021). "I'm Proud to be a Little Bit Different": The Effects of Autistic Individuals' Perceptions of Autism and Autism Social Identity on Their Collective Self-esteem. *Journal of Autism and Developmental Disorders*, *51*(2), 704–714. https://doi.org/10.1007/s10803-020-04575-4

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). ‘Something needs to change’: Mental health experiences of young autistic adults in England. *Autism: The International Journal of Research and Practice*, *23*(2), 477–493. https://doi.org/10.1177/1362361318757048

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism : The International Journal of Research and Practice*, *20*(2), 153–162. https://doi.org/10.1177/1362361315573636

Dallos, R. (2019). *Don’t Blame the Parents: Corrective Scripts and the Development of Problems in Families*. McGraw-Hill Education (UK).

Dallos, R., Grey, B., & Stancer, R. (2023). Anger without a voice, anger without a solution: Parent–child triadic processes and the experience of caring for a child with a diagnosis of autism. *Human Systems*, *3*(1), 51–71. https://doi.org/10.1177/26344041221115255

de Verdier, K., Fernell, E., & Ek, U. (2020). Blindness and Autism: Parents’ Perspectives on Diagnostic Challenges, Support Needs and Support Provision. *Journal of Autism and Developmental Disorders*, *50*(6), 1921–1930. https://doi.org/10.1007/s10803-019-03944-y

Downes, M. J., Brennan, M. L., Williams, H. C., & Dean, R. S. (2016). Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open*, *6*(12), e011458. https://doi.org/10.1136/bmjopen-2016-011458

Eggleston, M. J. F., Thabrew, H., Frampton, C. M. A., Eggleston, K. H. F., & Hennig, S. C. (2019). Obtaining an autism spectrum disorder diagnosis and supports: New Zealand parents' experiences. *Research in Autism Spectrum Disorders*, *62*, 18–25. https://doi.org/10.1016/j.rasd.2019.02.004

Ellis, J. M. (2023). Imagining Neurodivergent Futures from the Belly of the Identity Machine: Neurodiversity, Biosociality, and Strategic Essentialism. *Autism in Adulthood: Challenges and Management*, *5*(3), 225–235. https://doi.org/10.1089/aut.2021.0075

Estes, A., Vismara, L., Mercado, C., Fitzpatrick, A., Elder, L., Greenson, J., Lord, C., Munson, J., Winter, J., Young, G., Dawson, G., & Rogers, S. (2014). The impact of parent-delivered intervention on parents of very young children with autism. *Journal of Autism and Developmental Disorders*, *44*(2), 353–365. https://doi.org/10.1007/s10803-013-1874-z

Falk, N. H., Norris, K., & Quinn, M. G. (2014). The Factors Predicting Stress, Anxiety and Depression in the Parents of Children with Autism. *Journal of Autism and Developmental Disorders*, *44*(12), 3185–3203. https://doi.org/10.1007/s10803-014-2189-4

Futagi, Y., & Yamamoto, Y. (2002). [Disclosure of a diagnosis of childhood autism and parents' acceptance of the disability]. *No to Hattatsu = Brain and Development*, *34*(4), 336–342.

Galpin, J., Barratt, P., Ashcroft, E., Greathead, S., Kenny, L., & Pellicano, E. (2018). 'The dots just don't join up': Understanding the support needs of families of children on the autism spectrum. *Autism: The International Journal of Research and Practice*, *22*(5), 571–584. https://doi.org/10.1177/1362361316687989

Gill, J., & Liamputtong, P. (2013). Walk a mile in my shoes: Life as a mother of a child with Asperger's Syndrome. *Qualitative Social Work*, *12*(1), 41–56. https://doi.org/10.1177/1473325011415565

Girgis, A., & Sanson-Fisher, R. W. (1995). Breaking bad news: Consensus guidelines for medical practitioners. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology*, *13*(9), 2449–2456. https://doi.org/10.1200/JCO.1995.13.9.2449

Glod, M., Creswell, C., Waite, P., Jamieson, R., McConachie, H., Don South, M., & Rodgers, J. (2017). Comparisons of the Factor Structure and Measurement Invariance of the Spence Children's Anxiety Scale—Parent Version in Children with Autism Spectrum Disorder and Typically Developing Anxious Children. *Journal of Autism and Developmental Disorders*, *47*(12), 3834–3846. https://doi.org/10.1007/s10803-017-3118-0

Gobrial, E. (2018). The Lived Experiences of Mothers of Children with the Autism Spectrum Disorders in Egypt. *Social Sciences*, *7*(8), 1–11.

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism: The International Journal of Research and Practice*, *10*(5), 439–451. https://doi.org/10.1177/1362361306066601

Goodall, C. (2019). 'There is more flexibility to meet my needs': Educational experiences of autistic young people in Mainstream and Alternative Education Provision. *Support for Learning*, *34*(1), 4–33. https://doi.org/10.1111/1467-9604.12236

Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, *24*(6), 734–749. https://doi.org/10.1111/1467-9566.00316

Gray, L., Hill, V., & Pellicano, E. (2023). "He's shouting so loud but nobody's hearing him": A multi-informant study of autistic pupils' experiences of school non-attendance and exclusion. *Autism & Developmental Language Impairments*, *8*, 23969415231207816. https://doi.org/10.1177/23969415231207816

Grey, B., Dallos, R., & Stancer, R. (2021). Feeling ‘like you’re on … a prison ship’ – Understanding the caregiving and attachment narratives of parents of autistic children. *Human Systems*, *1*(1), 96–114. https://doi.org/10.1177/26344041211000202

Hackett, L., Shaikh, S., & Theodosiou, L. (2009). Parental Perceptions of the Assessment of Autistic Spectrum Disorders in a Tier Three Service. *Child and Adolescent Mental Health*, *14*(3), 127–132. https://doi.org/10.1111/j.1475-3588.2008.00508.x

Hasnat, M., & Graves, P. (2000). Disclosure of developmental disability: A study of parent satisfaction and the determinants of satisfaction. *Journal of Paediatrics and Child Health*, *36*(1), 32–35. https://doi.org/10.1046/j.1440-1754.2000.00463.x

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*(3), 629–642. https://doi.org/10.1007/s10803-012-1604-y

Hedges, S. H., Kirby, A. V., Sreckovic, M. A., Kucharczyk, S., Hume, K., & Pace, S. (2014). “Falling through the Cracks”: Challenges for High School Students with Autism Spectrum Disorder. *The High School Journal*, *98*(1), 64–82.

Hennel, S., Coates, C., Symeonides, C., Gulenc, A., Smith, L., Price, A. M., & Hiscock, H. (2016). Diagnosing autism: Contemporaneous surveys of parent needs and paediatric practice. *Journal of Paediatrics and Child Health*, *52*(5), 506–511. https://doi.org/10.1111/jpc.13157

Hepburn, S. L., Stern, J. A., Blakeley-Smith, A., Kimel, L. K., & Reaven, J. A. (2014). Complex Psychiatric Comorbidity of Treatment-Seeking Youth With Autism Spectrum Disorder and Anxiety Symptoms. *Journal of Mental Health Research in Intellectual Disabilities*, *7*(4), 359–378. https://doi.org/10.1080/19315864.2014.932476

Hibberd, F. J., & Petocz, A. (2023). Philosophy, realism and psychology's disciplinary fragmentation. *Philosophical Psychology*, *36*(3), 621–649. https://doi.org/10.1080/09515089.2022.2081542

Ho, H., Fergus, K., & Perry, A. (2018). Looking back and moving forward: The experiences of canadian parents raising an adolescent with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *52*, 12–22. https://doi.org/10.1016/j.rasd.2018.05.004

Ho, H. S., Yi, H., Griffiths, S., Chan, D. F., & Murray, S. (2014). 'Do It Yourself' in the parent-professional partnership for the assessment and diagnosis of children with autism spectrum conditions in Hong Kong: A qualitative study. *Autism: The International Journal of Research and Practice*, *18*(7), 832–844. https://doi.org/10.1177/1362361313508230

Hoffman, C. D., Sweeney, D. P., Hodge, D., Lopez-Wagner, M. C., & Looney, L. (2009). Parenting Stress and Closeness: Mothers of Typically Developing Children and Mothers of Children With Autism. *Focus on Autism and Other Developmental Disabilities*, *24*(3), 178–187. https://doi.org/10.1177/1088357609338715

Hollingsworth, D., Ferguson, L., Schaub, J., & Kempson-Byrne, S. (n.d.). *Autism and Parental Blame: A Systematic Literature Review*.

Horgan, F., Kenny, N., & Flynn, P. (2023). A systematic review of the experiences of autistic young people enrolled in mainstream second-level (post-primary) schools. *Autism:*

The International Journal of Research and Practice, *27*(2), 526–538. https://doi.org/10.1177/13623613221105089

Howlin, P., & Moore, A. (1997). Diagnosis in Autism: A Survey of Over 1200 Patients in the UK. *Autism*, *1*(2), 135–162. https://doi.org/10.1177/1362361397012003

Jacobs, D., Steyaert, J., Dierickx, K., & Hens, K. (2020). Parents' views and experiences of the autism spectrum disorder diagnosis of their young child: A longitudinal interview study. *European Child & Adolescent Psychiatry*, *29*(8), 1143–1154. https://doi.org/10.1007/s00787-019-01431-4

Jegatheesan, B., Fowler, S., & Miller, P. J. (2010). From symptom recognition to services: How South Asian Muslim immigrant families navigate autism. *Disability & Society*, *25*(7), 797–811. https://doi.org/10.1080/09687599.2010.520894

Jokiranta, E., Brown, A. S., Heinimaa, M., Cheslack-Postava, K., Suominen, A., & Sourander, A. (2013). Parental psychiatric disorders and autism spectrum disorders. *Psychiatry Research*, *207*(3), 203–211. https://doi.org/10.1016/j.psychres.2013.01.005

Jurin, A., Šimleša, S., & Cepanec, M. (2022). Parental perception of the process of communicating a diagnosis of autism spectrum disorder in the Republic of Croatia. *Clinical Child Psychology and Psychiatry*, *27*(4), 1006–1018. https://doi.org/10.1177/13591045221105191

Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, *49*(1), 59–71. https://doi.org/10.1037/a0028353

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442–462. https://doi.org/10.1177/1362361315588200

Keville, S., Mills, M., & Ludlow, A. K. (2024). Exploring mothers' experiences of accessing an Education Health and Care Plan (EHCP) for an autistic child attending mainstream school in the United Kingdom. *International Journal of Developmental Disabilities*, *0*(0), 1–12. https://doi.org/10.1080/20473869.2023.2298606

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives. *Journal of Autism and Developmental Disorders*, *46*(3), 942–953. https://doi.org/10.1007/s10803-015-2637-9

Kirby, L., & Payne, K.-L. (2023). Knowledge of Autism gained by learning from people through a local UK Autism Champion Network – a health and social care professional perspective. *Autism*.

Klein, S., Wynn, K., Ray, L., Demeriez, L., LaBerge, P., Pei, J., & Pierre, C. St. (2011). Information Sharing During Diagnostic Assessments: What Is Relevant for Parents? *Physical & Occupational Therapy In Pediatrics*, *31*(2), 120–132. https://doi.org/10.3109/01942638.2010.523450

Lappé, M., Lau, L., Dudovitz, R. N., Nelson, B. B., Karp, E. A., & Kuo, A. A. (2018). The Diagnostic Odyssey of Autism Spectrum Disorder. *Pediatrics*, *141*(Suppl 4), S272–S279. https://doi.org/10.1542/peds.2016-4300C

Lee, J. D., Terol, A. K., Yoon, C. D., & Meadan, H. (2024). Parent-to-parent support among parents of children with autism: A review of the literature. *Autism*, *28*(2), 263–275. https://doi.org/10.1177/13623613221146444

Legg, H., & Tickle, A. (2019). UK parents' experiences of their child receiving a diagnosis of autism spectrum disorder: A systematic review of the qualitative evidence. *Autism*, *23*(8), 1897–1910. https://doi.org/10.1177/1362361319841488

Maitland, C. A., Rhodes, S., O'Hare, A., & Stewart, M. E. (2021). Social identities and mental well-being in autistic adults. *Autism*, *25*(6), 1771–1783. https://doi.org/10.1177/13623613211004328

Makino, A., Hartman, L., King, G., Wong, P. Y., & Penner, M. (2021). Parent Experiences of Autism Spectrum Disorder Diagnosis: A Scoping Review. *Review Journal of Autism and Developmental Disorders*, *8*(3), 267–284. https://doi.org/10.1007/s40489-021-00237-y

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism: The International Journal of Research and Practice*, *8*(4), 387–407. https://doi.org/10.1177/1362361304045213

Martin-Denham, S. (2022). Marginalisation, autism and school exclusion: Caregivers' perspectives. *Support for Learning*, *37*(1), 108–143. https://doi.org/10.1111/1467-9604.12398

Mattila, M.-L., Hurtig, T., Haapsamo, H., Jussila, K., Kuusikko-Gauffin, S., Kielinen, M., Linna, S.-L., Ebeling, H., Bloigu, R., Joskitt, L., Pauls, D. L., & Moilanen, I. (2010). Comorbid Psychiatric Disorders Associated with Asperger Syndrome/High-functioning Autism: A Community- and Clinic-based Study: Journal of Autism & Developmental Disorders. *Journal of Autism & Developmental Disorders*, *40*(9), 1080–1093. https://doi.org/10.1007/s10803-010-0958-2

McLaughlin, J. (2005). Exploring diagnostic processes: Social science perspectives. *Archives of Disease in Childhood*, *90*(3), 284–287. https://doi.org/10.1136/adc.2004.052118

Meadan, H., Halle, J., & Ebata, A. (2010). Families With Children Who Have Autism Spectrum Disorders: Stress and Support. *Exceptional Children*, *77*, 7–36. https://doi.org/10.1177/001440291007700101

Miranda, A., Mira, A., Berenguer, C., Rosello, B., & Baixauli, I. (2019). Parenting Stress in Mothers of Children With Autism Without Intellectual Disability. Mediation of Behavioral Problems and Coping Strategies. *Frontiers in Psychology*, *10*, 464. https://doi.org/10.3389/fpsyg.2019.00464

Mockett, M., Khan, J., & Theodosiou, L. (2011). Parental Perceptions of a Manchester Service for Autistic Spectrum Disorders. *International Journal of Family Medicine*, *2011*, e601979. https://doi.org/10.1155/2011/601979

Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, *6*(1), 293–303. https://doi.org/10.1016/j.rasd.2011.05.011

Montes, G., & Cianca, M. (2014). Family Burden of Raising a Child with ASD. *Comprehensive Guide to Autism*, *1*, 167–184. http://dx.doi.org/10.1007/978-1-4614-4788-7_4

Mulligan, J., MacCulloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, Hope, and Empowerment: A Model for Partnering With Parents of a Child With Autism Spectrum Disorder at Diagnosis and Beyond. *Social Work in Mental Health*, *10*(4), 311–330. https://doi.org/10.1080/15332985.2012.664487

Mulligan, J., Steel, L., MacCulloch, R., & Nicholas, D. (2010). Evaluation of an Information Resource for Parents of Children with Autism Spectrum Disorder. *Autism*, *14*(2), 113–126. https://doi.org/10.1177/1362361309342570

Munkhaugen, E., Gjevik, E., Pripp, A. H., Sponheim, E., & Diseth, T. (2017). School refusal behaviour: Are children and adolescents with autism spectrum disorder at a higher risk? *Research in Autism Spectrum Disorders*, *41–42*, 31–38. https://doi.org/10.1016/j.rasd.2017.07.001

Nealy, C. E., O’Hare, L., Powers, J. D., & Swick, D. C. (2012). The Impact of Autism Spectrum Disorders on the Family: A Qualitative Study of Mothers’ Perspectives. *Journal of Family Social Work*, *15*(3), 187–201. https://doi.org/10.1080/10522158.2012.675624

Nelson, J. (2017). Using conceptual depth criteria: Addressing the challenge of reaching saturation in qualitative research. *Qualitative Research*, *17*(5), 554–570. https://doi.org/10.1177/1468794116679873

Nissenbaum, M. S., Tollefson, N., & Reese, R. M. (2002). The Interpretative Conference: Sharing a Diagnosis of Autism with Families. *Focus on Autism and Other Developmental Disabilities*, *17*(1), 30–43. Scopus. https://doi.org/10.1177/108835760201700103

O’Grady, P. (2014). *Relativism*. Routledge. https://doi.org/10.4324/9781315710730

Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, *28*(7), 1024–1026. https://doi.org/10.1080/09687599.2013.818773

O’Nions, E., Brown, J., Buckman, J. E. J., Charlton, R., Cooper, C., Baou, C. E., Happé, F., Hoare, S., Lewer, D., Manthorpe, J., McKechnie, D. G. J., Richards, M., Saunders, R., Mandy, W., & Stott, J. (2024). Diagnosis of common health conditions among autistic adults in the UK: Evidence from a matched cohort study. *The Lancet Regional Health – Europe*, *41*. https://doi.org/10.1016/j.lanepe.2024.100907

Oprea, C., & Andreea, S. (2012). Mothers of Autistic Children. How do They Feel? *Procedia - Social and Behavioral Sciences*, *46*, 4191–4194. https://doi.org/10.1016/j.sbspro.2012.06.224

Osborne, L. A., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism : The International Journal of Research and Practice*, *12*(3), 309–324. https://doi.org/10.1177/1362361307089517

Overview | Autism spectrum disorder in under 19s: Recognition, referral and diagnosis | Guidance | NICE. (2011, September 28). NICE. https://www.nice.org.uk/guidance/cg128

Ozsivadjian, A., Knott, F., & Magiati, I. (2012). Parent and child perspectives on the nature of anxiety in children and young people with autism spectrum disorders: A focus group study. *Autism: The International Journal of Research and Practice*, *16*(2), 107–121. https://doi.org/10.1177/1362361311431703

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ (Clinical Research Ed.)*, *372*, n71. https://doi.org/10.1136/bmj.n71

Papadopoulos, D. (2021). Mothers' Experiences and Challenges Raising a Child with Autism Spectrum Disorder: A Qualitative Study. *Brain Sciences*, *11*(3), 309. https://doi.org/10.3390/brainsci11030309

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., & Britten, N. (n.d.). *Guidance on the Conduct of Narrative Synthesis in Systematic Reviews*.

Pugliese, C. E., White, B. A., White, S. W., & Ollendick, T. H. (2013). Social Anxiety Predicts Aggression in Children with ASD: Clinical Comparisons with Socially Anxious and Oppositional Youth. *Journal of Autism and Developmental Disorders*, *43*(5), 1205–1213. https://doi.org/10.1007/s10803-012-1666-x

Rabba, A. S., Dissanayake, C., & Barbaro, J. (2019). Parents' experiences of an early autism diagnosis: Insights into their needs. *Research in Autism Spectrum Disorders*, *66*, 101415. https://doi.org/10.1016/j.rasd.2019.101415

Raymond-Barker, P., Griffith, G. M., & Hastings, R. P. (2018). Biographical disruption: Experiences of mothers of adults assessed for autism spectrum disorder. *Journal of Intellectual & Developmental Disability*. https://www.tandfonline.com/doi/full/10.3109/13668250.2016.1262011

Renty, J., & Roeyers, H. (2006). Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents. *Child: Care, Health and Development*, *32*(3), 371–385. https://doi.org/10.1111/j.1365-2214.2006.00584.x

Riccio, A., Kapp, S. K., Jordan, A., Dorelien, A. M., & Gillespie-Lynch, K. (2021). How is autistic identity in adolescence influenced by parental disclosure decisions and perceptions of autism? *Autism*, *25*(2), 374–388. https://doi.org/10.1177/1362361320958214

Rigazio-DiGilio, S. A. (2000). Relational diagnosis: A coconstructive–developmental perspective on assessment and treatment. *Journal of Clinical Psychology*, *56*(8), 1017–1036. https://doi.org/10.1002/1097-4679(200008)56:8<1017::AID-JCLP3>3.0.CO;2-D

Roberts, A. L., Koenen, K. C., Lyall, K., Ascherio, A., & Weisskopf, M. G. (2014). Women's posttraumatic stress symptoms and autism spectrum disorder in their children.

Research in Autism Spectrum Disorders, *8*(6), 608. https://doi.org/10.1016/j.rasd.2014.02.004

Roberts, A. L., Lyall, K., Rich-Edwards, J. W., Ascherio, A., & Weisskopf, M. G. (2013). Association of maternal exposure to childhood abuse with elevated risk for autism in offspring. *JAMA Psychiatry*, *70*(5), 508–515. https://doi.org/10.1001/jamapsychiatry.2013.447

Roberts, A. L., Lyall, K., Rich-Edwards, J. W., Ascherio, A., & Weisskopf, M. G. (2016). Maternal exposure to intimate partner abuse before birth is associated with autism spectrum disorder in offspring. *Autism: The International Journal of Research and Practice*, *20*(1), 26–36. https://doi.org/10.1177/1362361314566049

Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The Diagnosis of Autism: From Kanner to DSM-III to DSM-5 and Beyond. *Journal of Autism and Developmental Disorders*, *51*(12), 4253–4270. https://doi.org/10.1007/s10803-021-04904-1

Rowlands, G., Protheroe, J., Winkley, J., Richardson, M., Seed, P. T., & Rudd, R. (2015). A mismatch between population health literacy and the complexity of health information: An observational study. *British Journal of General Practice*, *65*(635), e379–e386. https://doi.org/10.3399/bjgp15X685285

Sansosti, F. J., Lavik, K. B., & Sansosti, J. M. (2012). Family Experiences Through the Autism Diagnostic Process. *Focus on Autism and Other Developmental Disabilities*, *27*(2), 81–92. https://doi.org/10.1177/1088357612446860

Schnabel, A., Youssef, G. J., Hallford, D. J., Hartley, E. J., McGillivray, J. A., Stewart, M., Forbes, D., & Austin, D. W. (2020). Psychopathology in parents of children with autism spectrum disorder: A systematic review and meta-analysis of prevalence. *Autism*, *24*(1), 26–40. https://doi.org/10.1177/1362361319844636

Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities*, *28*(1), 9–22. https://doi.org/10.1016/j.ridd.2005.09.003

Sloper, P., & Turner, S. (1993). Determinants of parental satisfaction with disclosure of disability. *Developmental Medicine and Child Neurology*, *35*(9), 816–825. https://doi.org/10.1111/j.1469-8749.1993.tb11733.x

Smith, D., & Gillon, G. (2022). *Autism Spectrum Disorder: Caseload characteristics, and interventions implemented by speech-language therapists. | Kairaranga*. https://www.kairaranga.ac.nz/index.php/k/article/view/271

Stahmer, A. C., Vejnoska, S., Iadarola, S., Straiton, D., Segovia, F. R., Luelmo, P., Morgan, E. H., Lee, H. S., Javed, A., Bronstein, B., Hochheimer, S., Cho, E., Aranbarri, A., Mandell, D., Hassrick, E. M., Smith, T., & Kasari, C. (2019). Caregiver Voices: Cross-Cultural Input on Improving Access to Autism Services. *Journal of Racial and Ethnic Health Disparities*, *6*(4), 752–773. https://doi.org/10.1007/s40615-019-00575-y

Taanila, A., JÄrvelin, M.-R., & Kokkonen, J. (1998). Parental guidance and counselling by doctors and nursing staff: Parents’ views of initial information and advice for families with disabled children. *Journal of Clinical Nursing*, *7*(6), 505–511. https://doi.org/10.1046/j.1365-2702.1998.00190.x

Tager-Flusberg, H., & Kasari, C. (2013). Minimally Verbal School-Aged Children with Autism Spectrum Disorder: The Neglected End of the Spectrum. *Autism Research*, *6*(6), 468–478. https://doi.org/10.1002/aur.1329

Tait, K., Fung, F., Hu, A., Sweller, N., & Wang, W. (2016). Understanding Hong Kong Chinese Families’ Experiences of an Autism/ASD Diagnosis. *Journal of Autism and*

Developmental Disorders, *46*(4), 1164–1183. https://doi.org/10.1007/s10803-015-2650-z

Tracy, S. J. (2010). Qualitative Quality: Eight “Big-Tent” Criteria for Excellent Qualitative Research. *Qualitative Inquiry*, *16*(10), 837–851. https://doi.org/10.1177/1077800410383121

White, M. D., & Marsh, E. E. (2006). Content Analysis: A Flexible Methodology. *Library Trends*, *55*(1), 22–45.

White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in Children and Adolescents with Autism Spectrum Disorders. *Clinical Psychology Review*, *29*(3), 216–229. https://doi.org/10.1016/j.cpr.2009.01.003

Wilson, A. C., & Gunn, S. (2022). What parents want in an autism diagnostic report: An interview-based study of parents accessing a neurodevelopmental assessment service. *Clinical Child Psychology and Psychiatry*, 13591045221138703. https://doi.org/10.1177/13591045221138703

Wilson, A. C., & Gunn, S. (2023). What parents want in an autism diagnostic report: An interview-based study of parents accessing a neurodevelopmental assessment service. *Clinical Child Psychology and Psychiatry*, *28*(3), 937–951. https://doi.org/10.1177/13591045221138703

World Health Organisation. (2022). *ICD-11: International classification of diseases* (11th Revision). https://icd.who.int/

Young autistic people still dying despite coroner warnings over care. (2023, September 7). *BBC News*. https://www.bbc.com/news/uk-66731265

Zuckerman, K. E., Lindly, O. J., & Sinche, B. K. (2015). Parental concerns, provider response, and timeliness of autism spectrum disorder diagnosis. *The Journal of Pediatrics*, *166*(6), 1431-1439.e1. https://doi.org/10.1016/j.jpeds.2015.03.007

Appendices

Appendix A: Reflective journal entries

Systematic Literature Search – August 2023

Many papers are likely to contain little bits of information about how parents experienced feedback of autism diagnosis, but it would be very difficult to review all of this. This would probably require a scoping review on a larger scale than is feasible for this MRP. I decided to only include papers that have a significant focus on parent experiences of assessment feedback – enough for this to be mentioned in the abstract.

On the ways autism is perceived – August 2023

I noticed in the title screening stage that lots of papers do refer to autism as a 'disease' reflecting the heterogeneity in how autism is understood and written about. Having worked in services where as part of the diagnostic feedback we tend to explicitly say that autism is not a disease, it surprised me to see how common it was for it to be described this way.

As I read the literature I'm also increasingly aware that my own experience is limited mainly to high masking adolescents and not younger children, and that experience around diagnosis for parents of young children is likely to be quite different to this. Understandings of autism where day to day difficulties have not been as obvious also likely to be different to when parents have been very aware of differences from an early age. For the people I have worked with the most, it has seemed fairly typical for parents to make sense of autism as a difference which may not always represent a disability, or viewing the disability that arises as stemming from mismatch between individual and environment designed for neurotypical needs as opposed to being located within the individual. Where disability is more obvious parents might arrive at different understandings.

On the literature search question – August 2023

A different direction could have been taken and literature around health literacy reviewed, or parent or patient views on health reports or health information outside of autism. This could help to contextualise findings about uses of autism written reports and aid in understanding how written health information specifically is perceived. There are likely to be differences between what people find important in spoken feedback sessions and in written reports, which are a lasting document that might inform a number of other decisions and facilitate access to specific kinds of support. However, to lose the focus on autism would miss the nuances of what parents experience when their child receives this particular diagnosis. As discussed above, autism differs significantly from many other conditions that might be diagnosed in healthcare settings due to the lack of specific biological markers associated with it and the heterogeneity of its presentation and impact, and in how it is conceptualised in wider societal discourses. By keeping the review question focused on autism specifically, these nuances are retained and enable the wider study findings to be discussed in the context of this. The wider literature around health literacy and diagnostic written information are discussed more broadly and considered in relation to the overall research question to develop the main study and make sense of findings in the discussion chapter.

The question I regret not asking – November 2023
Due to the time limitations on this project (which were tighter than usual due to my personal circumstances following time off for illness, and a subsequent late change of research topic) I created my questionnaire to attach to my ethics proposal prior to carrying out my systematic literature review. It was only after data collection had commenced that I realised that nowhere in the questionnaire had I asked for a simple quantitative measure of overall satisfaction with the report, instead asking about a variety of different uses and perceived helpfulnesses, and much of this in a qualitative manner. While this gathered useful information that addressed my research question, it would have been very helpful to have one overall measure of satisfaction because this is what the previous quantitative studies of parent experiences of autism assessment feedback I found in my literature review have done. Not having this outcome measure limits the comparisons I can draw with those studies, with the closest measure I have being perceived helpfulness of report recommendations.

In hindsight, I think that I was in a hurry to get my data collection underway as I knew that the time available to me would soon be reduced when I started a new clinical role. If I had taken more time to review my questionnaire items following my SLR, or had the order I had done things happened in a different way, I might have noticed this omission and been able to make an amendment.

Questionnaire participant numbers and recruitment – December 2023

Initially I was aiming for 35 – 45 participants for the questionnaire. This would provide enough data to look for meaningful quantitative trends while also being small enough for the qualitative questionnaire free text response data to be manageable.

The plan was to recruit initially through some local organisations supporting parents of autistic children known to researchers. If needed, additional organisations such as similar organisations in other counties, or national organisations such as the National Autism Society (NAS) would be contacted. Upon contacting the NAS I learned that for them to advertise the study they would need to have been involved from the outset of the study, including the initial proposal stage, and the study would need to have used their own EbE panel. Unfortunately given my timeline this was not possible. However, from the initial organisations contacted, I saw that I already had over 50 questionnaire respondents. This was higher than the number we had been aiming for, and to recruit more participants risked making the qualitative data analysis too large for the scope of this study, so I did not try to recruit beyond this.

After I had downloaded the data I discovered that a large number of responses between certain dates all stopped abruptly at a certain point in the questionnaire. As such, in keeping with the participant information I had to assume that these participants had chosen to stop responding part way through and withdrawn their consent, and discard this data. This was a blow, as it left me with only 34 participants. If I had known this sooner I would probably have reached out to some more organisations to boost that number. Unfortunately at the point I discovered this it was too late to do this without significantly delaying my overall timeline, so I proceeded with the data I had. If my personal context had been different (if I had not started this project very late due to illness, or not been working in a role that requires me to be qualified before I can carry out an important part of this role) I may have chosen to extend this stage of the project to gather more data.

Interview participant numbers – February 2024

Of 8 people who initially agreed to take part in interviews, 3 needed to cancel. This seemed like a high proportion, but might simply reflect the emotional and time pressures this population are operating under. 2 people cited family crises as the reasons for cancelling interviews, and 1 had forgotten a conflicting appointment and was not able to find another time.

I had 5 interviewees in the end. This is a small number for a thematic analysis. The usual number for an MRP would be closer to 15. However, this is a mixed methods project which the thematic analysis was only one part of, so a very large number of interviewees would never have been within the scope of this. The original plan was to carry out a focus group with a small number of questionnaire participants to add context to those findings, rather than to carry out interviews at all. While 8 might have made for a stronger study, the data my 5 participants provided was enough for me to generate meaningful themes with good consistency between participants, and achieved its purpose of providing context to help understand questionnaire responses.

Thoughts on member checking (22/03/24)
I always planned to carry out member checking after generating themes. This was partly to try to increase rigour, but also because it felt important ethically to give participants the opportunity to comment on what I had done with their data. All interviewees consented to me contacting them again following the initial thematic analysis, and after creating a table of themes I sent this along with some key codes for each theme to each interview participant. I felt very conscious that my participants had a lot of time commitments and demands on their resources, and that they had already given a lot to my project. It felt important that not to demand too much from them, or exploit them for the sake of this study. Therefore I was careful to stress that while any reflections they might have on whether these themes resonated with them was valuable, this was completely optional and dependent on whether they wanted to do this or not at this point in time. I subsequently only heard back from one of my five participants, who said all the themes resonated with her experiences. I was unsure what to make of the lack of response from the other four. It may have been that they did not think the themes resonated but did not want to say so, or it may simply have been that they were busy or did not want to spend further time responding when they had already given me so much time and energy on what could be quite an emotive topic. In discussion with my supervisor, he brought up the limitations of member checking and the risk of viewing this checking as confirming something as right or wrong when it is more subjective than this. He also pointed out that while I may not have learned much for the research itself, I had still offered participants an opportunity to respond if they wanted

to. This felt important ethically, even if it did not add to the analytic rigour of the study.

Evolving research question – March 2024

While I was doing my initial coding of interview transcripts I realised that there was lots of data that I was coding which did not directly address my research questions, as it did was not about parent uses or perceived helpfulness of diagnostic reports. However it still felt meaningful, and relevant in some way to what I was trying to understand. This made me realise that maybe I had different research questions in my head on some level, besides those stated in my proposal. I ended up amending my research questions to include a question around how autism reports fit into the broader diagnostic journey for parents, as this is what these extracts which felt important were addressing. This allowed me to capture important themes such as 'the gap between what is promised and delivered', which related more to how parents experienced reports within a broader journey than how they used the reports pragmatically.

Appendix B: Quality Appraisal Scoring for Quantitative Cross Sectional Studies

Quantitative Cross-Sectional Studies Critical Appraisal Table
Abbreviations: NA – not applicable NS – not stated

Authors & Year	Brogan & Knussen (2003)	Chiu et al (2014)	Jurin et al (2022)
1. Were the aims/objectives of the study clear?	Yes	Yes	Yes
2. Was the study design appropriate for the stated aims?	Yes	Yes	Yes
3. Was the sample size justified?	NS	NS	NS
4. Was the target/reference population clearly defined?	Yes	Yes	Yes
5. Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?	Yes	To an extent – excluded Asperger and PDDNOS diagnoses, children not in treatment prior to age 6 and children not living with both biological parents	Yes
6. Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?	Yes	Yes to extent but also likely to exclude some	NS
7. Were measures undertaken to address and categorise non-responders?	Yes (to a limited extent)	NS	NA
8. Were the risk factor and outcome variables measured appropriate to the aims of the study?	Yes	Yes	Yes
9. Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?	Yes	Yes	No – new questionnaire constructed for study
10. Is it clear what was used to determine statistical significance and/or precision estimates (e.g. p-values, confidence intervals)	Yes	Yes	Yes
11. Were the methods (including statistical methods) sufficiently described to enable them to be repeated?	Yes	Yes	Yes
12. Were the basic data adequately described?	Yes	Yes	Yes
13. Does the response rate raise concerns about non-response bias?	Yes	No	NA
14. If appropriate, was information about non-responders described?	Yes (to a limited extent)	No	NA
15. Were the results internally consistent?	NS	NS	NS
16. Were the results presented for all the analyses described in the methods?	Yes	Yes	Yes
17. Were the authors' discussions and conclusions justified by the results?	Yes	Yes	Yes
18. Were the limitations of the study discussed?	Yes	Yes	Yes
19. Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?	No	No	No
20. Was ethical approval or consent of participants attained?	NS	Yes	Yes

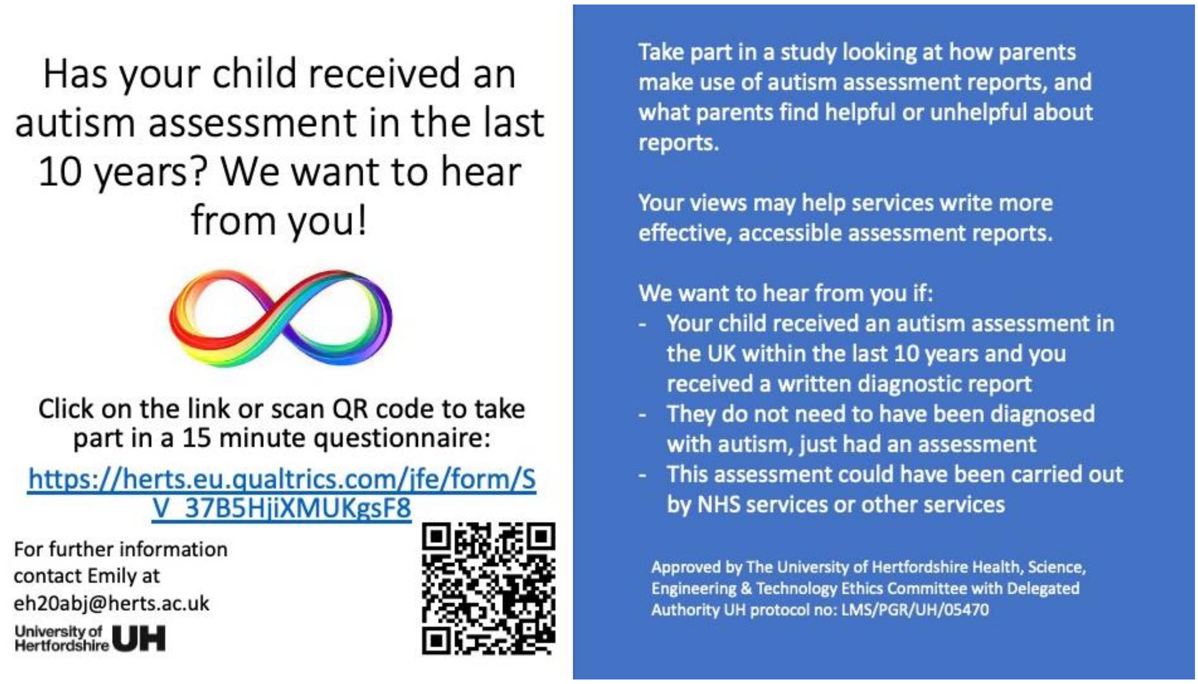
Appendix C: Quality Appraisal for Qualitative Studies

Appendix X: Qualitative Studies Assessed Using "Big-Tent" Criteria for Qualitative Quality (Tracy, 2010)			
Authors & Year	Abbot et al (2012)	Mulligan et al (2012)	Nissenbaum et al (2002)
Worthy Topic	Yes	Yes	Yes
Rich Rigour	Yes	Yes	Yes
Sincerity	Some – awareness of possible impact of researcher's position as psychiatrist. Lacks more in depth situating of researchers. Transparent about methods and challenges.	Yes	Yes
Credibility	Yes	Yes	Yes
Resonance	Yes	Yes	Yes
Significant Contribution	Yes	Yes	Yes
Ethical	Yes	Yes	Yes
Meaningful Coherence	Yes	Yes	Yes

Appendix D: Quality Appraisal for Mixed Methods Study

Appendix X: Quality Assessment of Mixed Methods Study Appraisal Tool (MMAT) version 2018. Hong et al					
Wilson et al (2023)					
Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?	x			
	S2. Do the collected data allow to address the research questions?	x			
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1 Is the qualitative approach appropriate to answer the research question?	x			
	1.2 Are the qualitative data collection methods adequate to address the research question?	x			
	1.3 Are the findings adequately derived from the data?	x			
	1.4 Is the interpretation of results sufficiently substantiated by data?	x			
	1.5 Is there coherence between qualitative data sources, collection, analysis and interpretation?	x			
2. Quantitative randomised controlled trials	2.1 Is randomization appropriately performed?				n/a
	2.2 Are the groups comparable at baseline?				n/a
	2.3 Are there complete outcome data?				n/a
	2.4 Are outcome assessors blinded to the intervention provided?				n/a
	2.5 Did the participants adhere to the assigned intervention?				n/a
3. Quantitative non-randomised	3.1 Are the participants representative of the target population?				n/a
	3.2 Are measurements appropriate regarding both the outcome and intervention (or exposure)?				n/a
	3.3 Are there complete outcome data?				n/a
	3.4 Are the confounders accounted for in the design and analysis?				n/a
	3.5 During the study period, is the intervention administered (or exposure occurred) as intended?				n/a
4. Quantitative descriptive	4.1 Is the sampling strategy relevant to address the research question?	x			
	4.2 Is the sample representative of the target population?	x			
	4.3 Are the measurements appropriate?	x			
	4.4 Is the risk of nonresponse bias low?	x			
	4.5 Is the statistical analysis appropriate to answer the research question?	x			Descriptives only
5. Mixed methods	5.1 Is there an adequate rationale for using a mixed methods design to address the research question?	X			
	5.2 Are the different components of the study effectively integrated to answer the research question?	X			
	5.3 Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	x			
	5.4 Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	x			
	5.5 Do the different components of the study adhere to the qualitative criteria of each tradition of the methods involved?	x			

Appendix E: Study advertisement



Has your child received an autism assessment in the last 10 years? We want to hear from you!

Click on the link or scan QR code to take part in a 15 minute questionnaire:

https://herts.eu.qualtrics.com/jfe/form/SV_37B5HjiXMUKgsF8

For further information contact Emily at eh20abj@herts.ac.uk

University of Hertfordshire UH

Take part in a study looking at how parents make use of autism assessment reports, and what parents find helpful or unhelpful about reports.

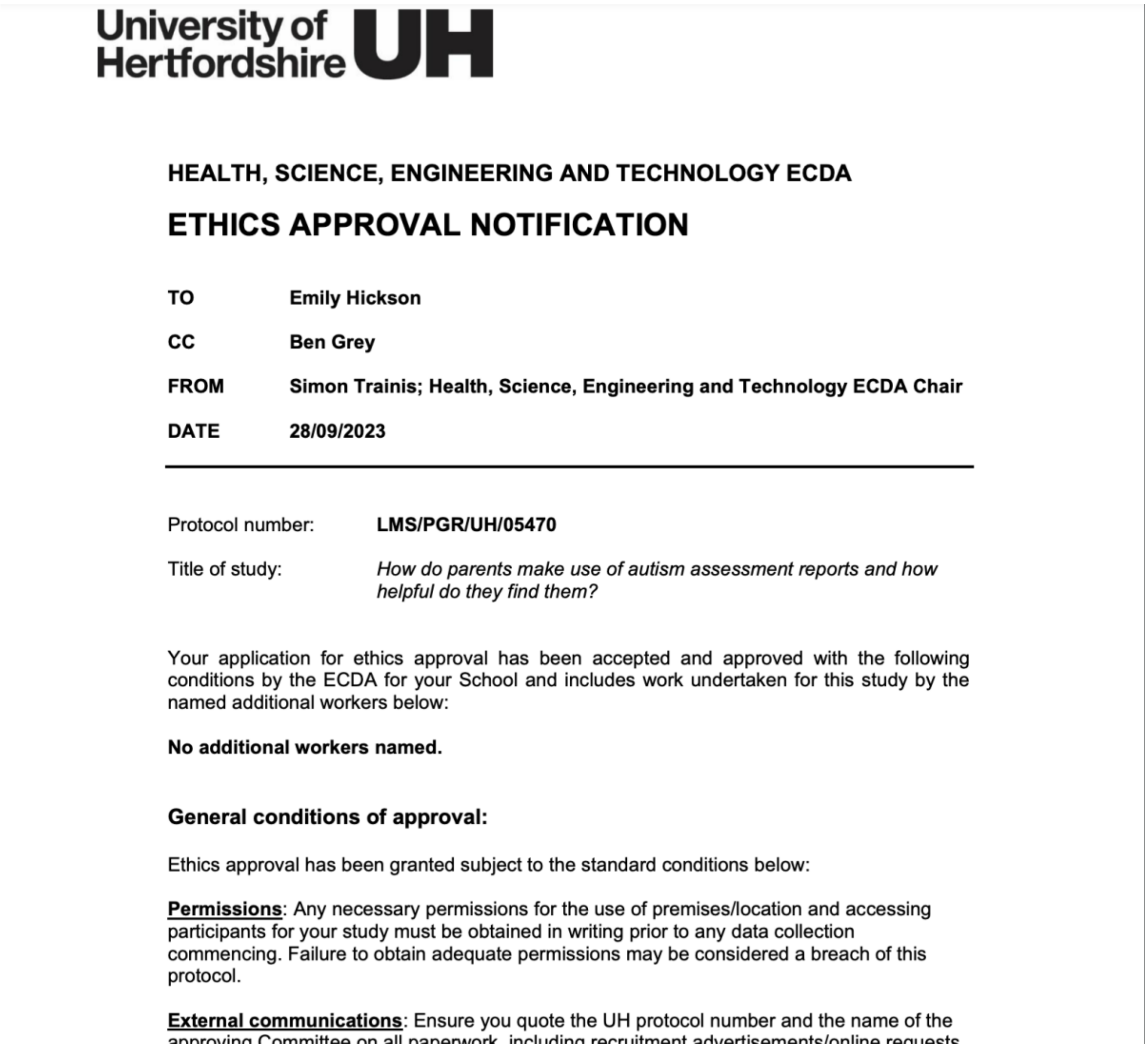
Your views may help services write more effective, accessible assessment reports.

We want to hear from you if:

- Your child received an autism assessment in the UK within the last 10 years and you received a written diagnostic report
- They do not need to have been diagnosed with autism, just had an assessment
- This assessment could have been carried out by NHS services or other services

Approved by The University of Hertfordshire Health, Science, Engineering & Technology Ethics Committee with Delegated Authority UH protocol no: LMS/PGR/UH/05470

Appendix F: Confirmation of ethical approval with later amendment



University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO **Emily Hickson**

CC **Ben Grey**

FROM **Simon Trainis; Health, Science, Engineering and Technology ECDA Chair**

DATE **28/09/2023**

Protocol number: **LMS/PGR/UH/05470**

Title of study: *How do parents make use of autism assessment reports and how helpful do they find them?*

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

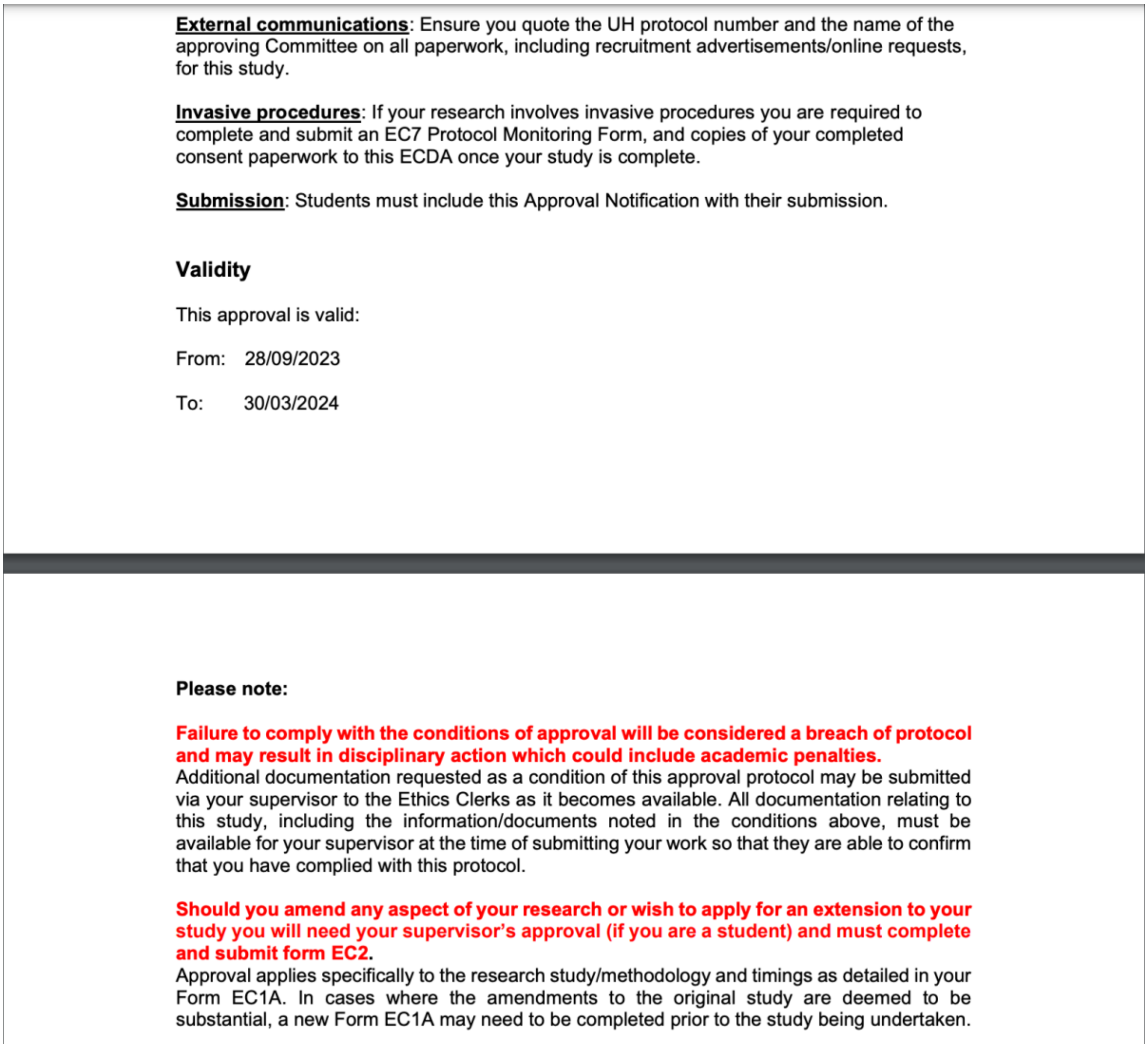
No additional workers named.

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests



External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity

This approval is valid:

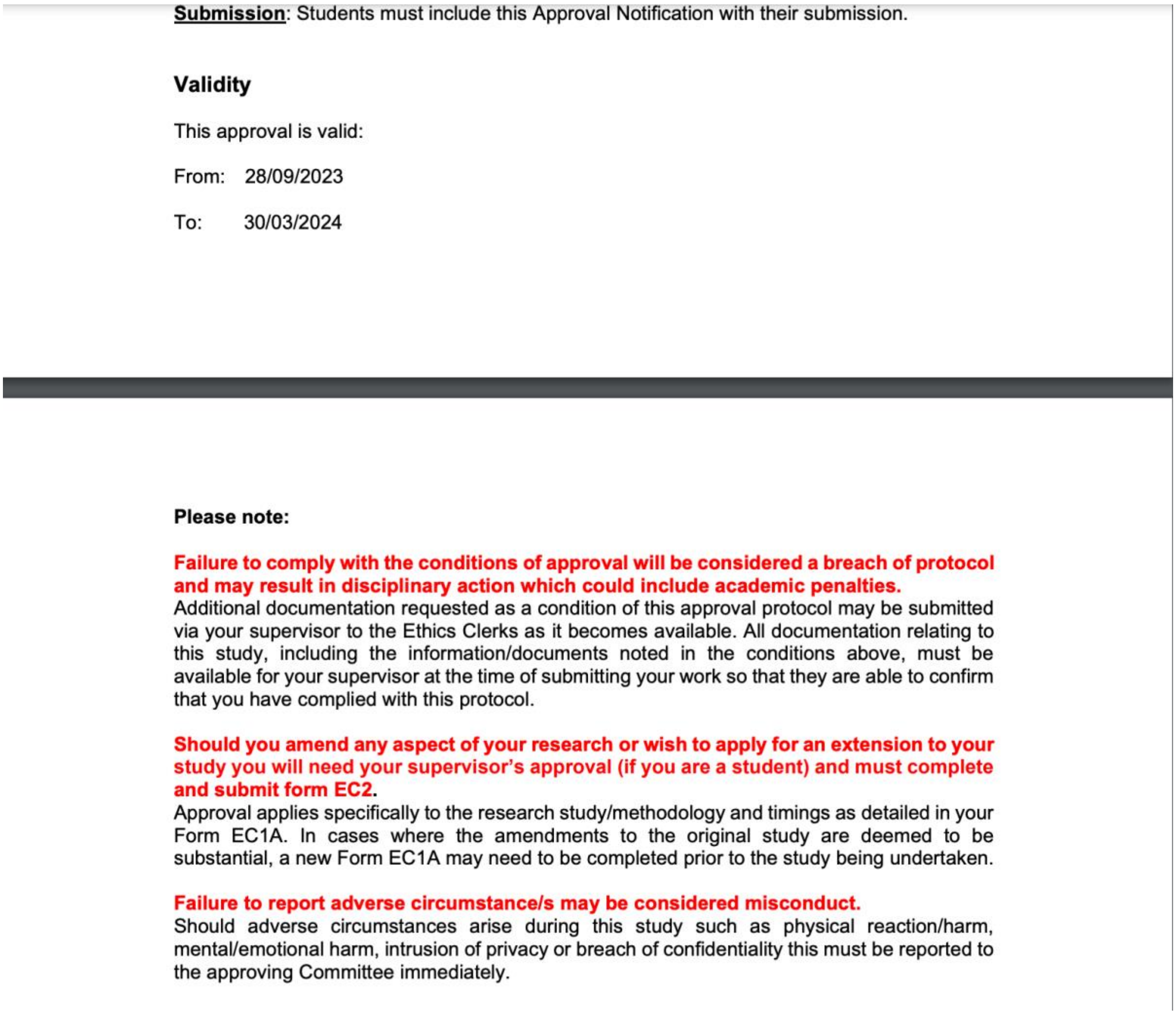
From: 28/09/2023

To: 30/03/2024

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.



Submission: Students must include this Approval Notification with their submission.

Validity

This approval is valid:

From: 28/09/2023

To: 30/03/2024

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Emily Hickson
CC	Dr Ben Grey
FROM	Dr Rebecca Knight, Health, Science, Engineering and Technology ECDA Vice-Chair
DATE	21/12/2023

Protocol number:	**aLMS/PGR/UH/05470(1)**
Title of study:	How do parents use autism assessment reports, and how helpful do they find them?

Your application to modify and extend the existing protocol as detailed below has been accepted and approved by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

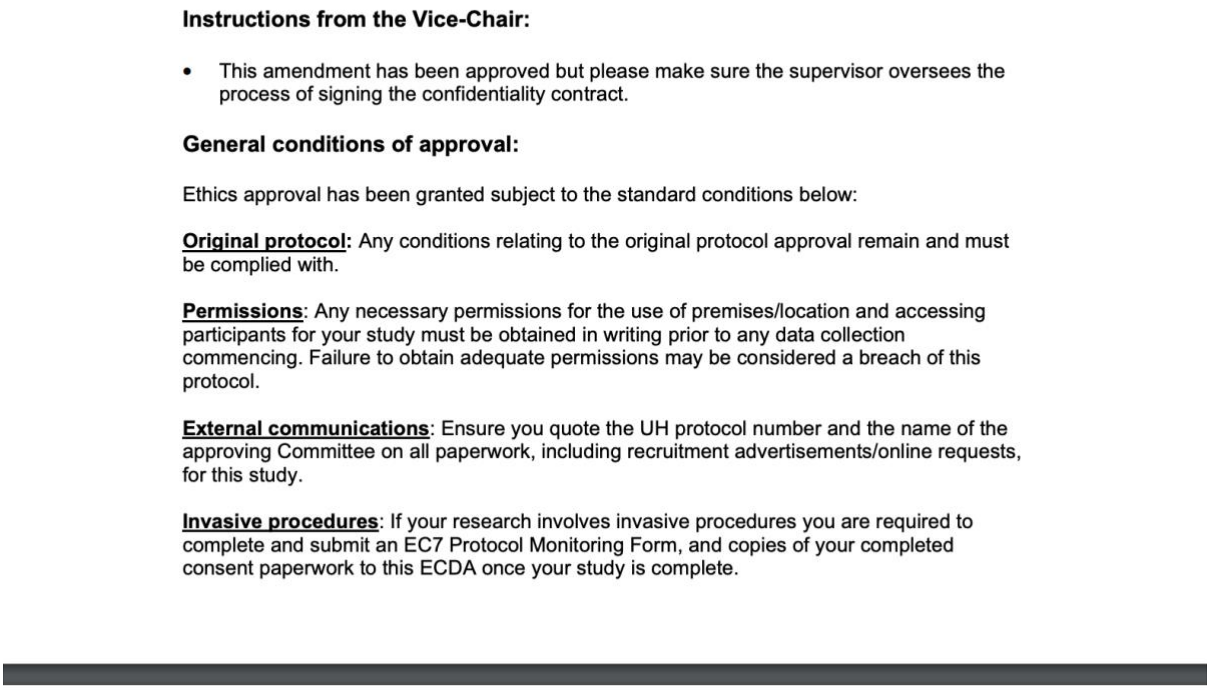
No additional workers named

Modification:

Use of a professional transcription service as detailed in the approved EC2 application.

Instructions from the Vice-Chair:

From:



Instructions from the Vice-Chair:

- This amendment has been approved but please make sure the supervisor oversees the process of signing the confidentiality contract.

General conditions of approval:

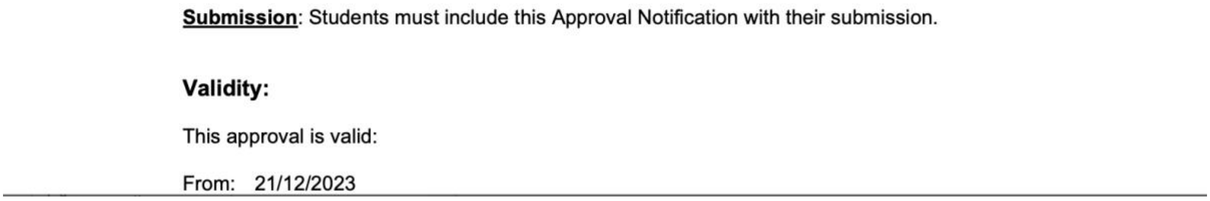
Ethics approval has been granted subject to the standard conditions below:

Original protocol: Any conditions relating to the original protocol approval remain and must be complied with.

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

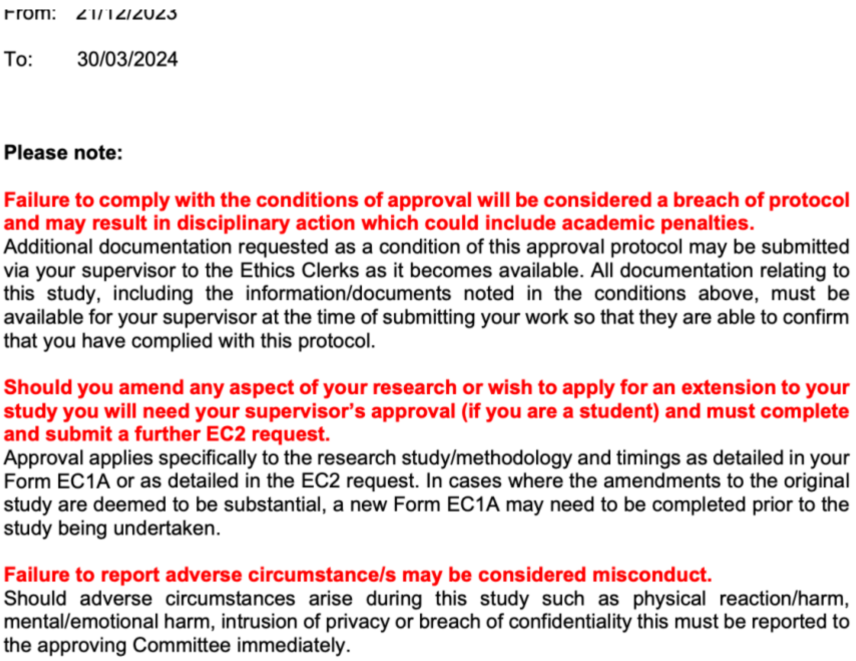


Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 21/12/2023



From: 21/12/2023

To: 30/03/2024

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit a further EC2 request.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A or as detailed in the EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix G: Risk assessments

Ref No.	
Date	
Review Date	
	OFFICE USE ONLY

SCHOOL OF LIFE AND MEDICAL SCIENCES
UNIVERSITY OF HERTFORDSHIRE

Appendix E: Life and Medical Sciences Risk Assessment

The completion of this is an integral part of the preparation for your work, it is not just a form to be completed, but is designed to alert you to potential hazards so you can identify the measures you will need to put into place to control them. You will need a copy on you when you carry out your work

General Information					
Name	Emily Hickson	Email address	Eh20abj@herts.ac.uk	Contact number	07415 771841
Supervisor's name (if student)	Dr Ben Grey	Supervisor's e-mail address	b.grey@herts.ac.uk	Supervisor's contact number	

Activity	
Title of activity	How do parents make use of autism assessment reports, and how helpful do they find them?
Brief description of activity	1) Online questionnaire which will take approximately 10 minutes to complete, consisting of mainly multiple choice questions with some free text responses. Participants will be recruited via social media, word of mouth and potentially advertised via organisations supporting parents of autistic children. Participants will be self selecting and will follow a link to access the online questionnaire, and asked if they would be interested in.participating in a focus group or interview in the questionnaire. If so they can leave contact details in the questionnaire. Data and any recordings made will be stored on UH OneDrive. 2) Those who have indicated in the questionnaire that they would be interested in this might take part in a focus group or interview. This is likely to take place virtually, but if participants live locally and many express a preference to do it in person it might take place on campus.
Location of activity	1) The questionnaire will be online so participants can complete it wherever they want to on their own devices. 2) Focus groups (and/or interviews) will most likely take place virtually on MS Teams, but if participants live locally and express a preference to meet in person this would take place on campus within the school of Psychology, in a room booked by me.
Who will be taking part in this activity	1) Participants will be parents whose children have received an autism assessment within the last 10 years, anywhere in the UK. 2) The same as above, who have also expressed an interest in taking part in a focus group or interview. For a focus group only researcher and the participants will be present.

Types of Hazards likely to be encountered				
X Computers and other display screen	☐ Falling objects	☐ Farm machinery	☐ Fire	☐ Cuts
☐ Falls from heights	☐ Manual handling	☐ Hot or cold extremes	☐ Repetitive handling	☐ Severe weather
☐ Slips/trips/falls	☐ Stress	☐ Travel	☐ Vehicles	☐ Workshop machinery
X Psychological distress (to interviewer or interviewee)	☐ Aggressive response, physical or verbal	☐	☐	☐
Other hazards not listed above	COVID-19			

Risk Control Measures

List the activities in the order in which they occur, indicating your perception of the risks associated with each one and the probability of occurrence, together with the relevant safety measures.
Describe the activities involved.
Consider the risks to participants, research team, security, maintenance, members of the public – is there anyone else who could be harmed?
In respect of any equipment to be used read manufacturer's instructions and note any hazards that arise, particularly from incorrect use.

Identify hazards	**Who could be harmed?** *e.g. participants, research team, security, maintenance, members of the public, other people at the location, the owner / manager / workers at the location etc.*	**How could they be harmed?**	**Control Measures – what precautions are currently in place?** *Are there standard operating procedures or rules for the premises. Are there any other local codes of practice/local rules which you are following, eg Local Rules for the SHE labs? Have there been agreed levels of supervision of the study? Will trained medical staff be present? Etc*	**What is the residual level of risk after the control measures have been put into place?** *Low Medium or High*	**Are there any risks that are not controlled or not adequately controlled?**	**Is more action needed to reduce/manage the risk?** *for example, provision of support/aftercare, precautions to be put in place to avoid or minimise risk or adverse effects*
Computers and other display screen	Participants, principal researcher	Eye strain from looking at screen during online questionnaire. Eyes could feel tired from looking at screen while completing questionnaire (for participants) or	Questionnaire will be designed to minimise eye strain as far as possible by using appropriate font size and spacing. Questionnaire will not take too long to complete so any strain should be minimal.	Low	No	No

		looking at results (researcher).				
Psychological distress (to interviewer or interviewee)	Participants	Emotional distress for participants, during online questionnaire or focus group/interview. Completing the questionnaire and discussing experiences in a focus group or interview might bring up memories of the assessment process for their child – for some parents this might have been a challenging time.	Debrief page following questionnaire includes information on organisations that may be able to provide emotional support for parents. Participants will have my contact details in case they would like to arrange a telephone debrief to talk through anything that came up for them. Signposting information will made available again following focus groups or interviews.	Low	No	No
COVID-19	Participants, principal researcher		Researcher will ensure rooms used for in-person interviews / focus groups are well-ventilated. If the researcher or participants are showing symptoms of COVID-19 or have recently tested positive for COVID-19, they should not attend the in-person interviews / focus groups.	Low	No	No

List any other documents relevant to this application	Life and Medical Sciences Health and Safety documents

Signatures					
Assessor name	Emily Hickson	Assessor signature		Date	18/08/2023

Supervisor, if Assessor is a student	Dr Ben Grey	Supervisor signature	Benedict	Date	24/08/2023
Local Health and Safety Advisor/ Lab Manager	Alex Eckford	Local Health and Safety Advisor/ Lab Manager signature	Alex Eckford	Date	31st August 2023

Appendix H: Questionnaire

How do parents use autism assessment reports and how helpful do they find them?

Start of Block: Default Question Block

Q1
Participant information

How do parents use autism assessment reports, and how helpful do they find them?
This is an invitation to take part in a study about parent experiences of autism assessment reports. The study is conducted by Emily Hickson at the University of Hertfordshire as part of a doctoral thesis, supervised by Dr Ben Grey and Dr Suzie Gratton.

What is the purpose of this study?
The purpose of this study is to better understand how parents make use of autism assessment reports, and how helpful they find the reports for these purposes, as well as looking at what factors impact on the helpfulness of reports for parents. It is hoped that better understanding of this might contribute to improving the quality and efficiency of the reports written by autism assessment services.

Do I have to take part?
It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be asked to indicate your consent to take part by clicking some boxes at the beginning of the questionnaire. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage while completing the questionnaire.

Are there any restrictions that may prevent me from participating?
o You must have a child who had an autism assessment within the last 10 years within the UK.
o They do not need to have received a diagnosis of autism as a result of this assessment
o You must have access to the internet and a computer, tablet, smartphone or other device that allows you to access the online questionnaire

How long will my part in the study take?
Completing the questionnaire will take approximately 10-20 minutes.

What will happen to me if I take part?
If you take part, you will be directed to an online questionnaire which will ask you questions

about your child's autism assessment, about the written report you received following this, and how you used this report. Some of these questions will involve choosing from a list of answers, and others will be more open ended with space for you to type responses. You need to consent to take part before starting the questionnaire. There is a section below where you say you agree to take part if you go ahead.

What are the possible disadvantages, risks or side effects of taking part?

There should not be any significant risks or downsides to taking part. If your child's autism assessment process was a difficult time for you and your family, completing this questionnaire may bring up some upsetting memories and experiences. You will be directed to some organisations at the end of the questionnaire that can provide support in case you would like to access these. If at the end of the questionnaire you would like to have a debriefing conversation with one of the researchers, you are welcome to contact the principal investigator, Emily Hickson, at eh20abj@herts.ac.uk to arrange a telephone call or video chat.

What are the possible benefits of taking part?

You might find it rewarding to participate in the study. By taking part, you will be contributing to a greater understanding of how parents tend to use autism assessment reports, and what makes reports helpful or less helpful. This understanding may ultimately lead to reports that are better suited to parents' needs and the needs of their children.

How will my taking part in this study be kept confidential?

You will not need to provide your name or other personally identifying information to take part in the study, so your data will remain confidential. If you choose to leave contact details in order to take part in a focus group or interview, these will be stored separately to the rest of your responses and your data will be given a code linking it to your contact details so that we can identify you.

What will happen to the data collected within this study?

Data collected in this study will be stored digitally and analysed in order to determine how participants made use of their children's autism assessment reports, and what was found to be helpful or unhelpful. These findings will be written up and presented as part of a doctoral thesis, and may be disseminated more widely through submission to an academic journal and presentations made at conferences or to local services. Anonymised data will be kept for 7 years. If you would like to hear about the findings, please contact Emily at eh20abj@herts.ac.uk.

Who has reviewed this study?

This study has been reviewed by: • The University of Hertfordshire Health, Science, Engineering & Technology Ethics Committee with Delegated Authority The UH protocol number is …

Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with Emily Hickson at eh20abj@herts.ac.uk, or Dr Ben Grey at b.grey@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University’s Secretary and Registrar at the following address: Secretary and Registrar University of Hertfordshire College Lane Hatfield Herts AL10 9AB.

Thank you very much for reading this information and giving consideration to taking part in this study.

Consent
If you are happy to go ahead with the survey, please click on the 'yes' boxes for each of the statements below to say you consent to taking part in this research. You will not be able to start the survey unless you click on all the 'yes' boxes.

I confirm that I have read the participant information for the above study. I have had the opportunity to consider the information and have any questions I have had answered.

○ Yes (1)

○ No (2)

✱

Q2 I understand that my participation is voluntary, that I can stop the survey at any time and my answers will not be used if I do.

○ Yes (1)

○ No (2)

✱

Q3 I agree to take part in this study.

○ Yes (1)

○ No (2)

End of Block: Default Question Block

Start of Block: Demographics

Q39 We would like to know a bit about your background, so that we can better understand how peoples experiences may differ across demographics. You do not have to answer any questions you do not want to, but if you do it could help us understand these differences.

What is your relationship to the child who was assessed?

○ Mother (1)

○ Father (2)

○ Other (please describe in the text box below) (3)

____

Q40 Which of the below categories based on UK national census categories best describes your ethnicity?

○ White (1)

○ Asian/Asian British (2)

○ Black, Black British, Caribbean or African (3)

○ Mixed or multiple ethnic groups (4)

○ Other ethnic group (5)

Q42 Is English your first language?

○ Yes (1)

○ No (2)

Q43 Did you have any disabilities, neurodevelopmental or long term health conditions at the time of your child's assessment?

☐ Yes neurodevelopmental (1)

☐ Yes long term physical health (2)

☐ Yes mental health (3)

☐ Yes other (please say more in box below) (4) ____

☐ No (5)

Q48 Which of the following best describes the highest level of education you had completed at the time of your child's assessment?

○ Primary school education (1)

○ GCSEs or equivalent (2)

○ A levels or eqivalent (3)

○ Bachelors degree (4)

○ Postgraduate Masters degree (5)

○ Postgraduate Doctorate (6)

End of Block: Demographics

Start of Block: Block 1 - Information about your child's assessment

Q4 How recently did your child receive an autism assessment?

○ Within the last year (1)

○ Within the last 5 years (2)

○ More than 5 years ago (3)

Q5 How old was your child when they had their autism assessment?

○ 0-6 (1)

○ 7-12 (2)

○ 13-16 (3)

○ 17-18 (4)

Q6 Was your child's autism assessment carried out in the NHS or privately?

○ NHS service (1)

○ Private service (2)

Q44 What country did your child's autism assessment take place in?

○ England (1)

○ Wales (2)

○ Scotland (3)

○ Northern Ireland (4)

Display This Question:

If What country did your child's autism assessment take place in? = England

Q45 If in England, what region did the assessment take place in?

○ South East (1)

○ North West (2)

○ East of England (3)

○ North East (4)

○ East Midlands (5)

○ South West England (6)

○ Yorkshire and the Humber (7)

○ West Midlands (8)

○ Greater London (9)

Q7 Was your child given a diagnosis of autism?

○ Yes (1)

○ No (2)

Q28 How confident are you in the outcome of the assessment?

○ Fully confident (1)

○ Mostly confident (2)

○ Neither confident nor not confident (3)

○ Not very confident (4)

○ Not confident at all (5)

Q27 Is this the only autism assessment you have experienced, or have you been through this process more than once (e.g. for another child, yourself or another family member)?

○ This is the only autism assessment I have been involved in (1)

○ I have been involved in multiple autism assessments (2)

Q29 Does your child have any other neurodevelopmental, mental health or physical health diagnoses?

☐ No (1)

☐ Yes other neurodevelopmental (2)

☐ Yes mental health (3)

☐ Yes physical health (4)

Q34 What was your main concern for your child that led to them having an assessment? (Please rank in order, as far as possible - click and drag to position)

______ Difficulties at school (1)
______ Emotional difficulties (2)
______ Behaviour that challenges (3)
______ Other main concern (please describe in text box) (4)

Q35 To what extent do you think there was a cultural match between yourself and the professionals carrying out your child's autism assessment? (E.g., to what extent do you think you share a similar background to those doing the assessment, thinking about things like socioeconomic, ethnic, religious and language factors?)

○ Close cultural match between me and the assessors (1)

○ Some cultural match between me and the assessors (2)

○ Neither cultural match nor very different cultures between me and the assessors(please comment on impact of this in text box) (3)

○ Quite different cultural backgrounds between me and the assessors (4)

○ Extremely different cultural backgrounds between me and the assessors (5)

Q36 Do you think the level of cultural match/mismatch between yourself and those carrying out the assessment had an impact on how you or your child were understood by those doing the assessment? In what way did it have an impact?

____

____

____

____

____

End of Block: Block 1 - Information about your child's assessment

---

Start of Block: Information about your child's assessment report

Q9 What kinds of professionals contributed to your child's autism assessment report? Please select all that apply.

- ☐ Speech and Language Therapist (1)
- ☐ Clinical Psychologist (2)
- ☐ Educational Psychologist (3)
- ☐ Paediatrician (4)
- ☐ Occupational Therapist (5)
- ☐ Child and adolescent psychiatrist (6)
- ☐ Other (please specify in text box) (7) ____
- ☐ I am unsure or cannot locate this information (8)

Q30 Have you read the entire report, or did you only read certain sections?

- ○ I read the entire report fully (1)
- ○ I skim read the whole report but focused on specific sections (2)
- ○ I did not read the report (3)

Display This Question:

If Have you read the entire report, or did you only read certain sections? = I skim read the whole report but focused on specific sections

Q46 Which sections did you focus on? (Please type your response)

____

Q11 Which sections of the report did you find the most helpful? Was anything less helpful? (Please type your response)

____

____

____

____

____

Q10 What was included in your report? (Please select all that apply)

☐ An explanation of what autism is and what was being looked for in your child's assessment (1)

☐ A summary of whether your child does/does not meet current criteria for Autism Spectrum Disorder (2)

☐ Information about your child's history taken from an interview with a parent or caregiver (3)

☐ Information provided by your child's school (e.g. a school questionnaire) (4)

☐ Information from a school observation (5)

☐ Information from an Autism Diagnostic Observation Schedule (ADOS) carried out with your child (6)

☐ Mention of your child's strengths (7)

☐ Recommendations, strategies and resources that could help your child (8)

☐ Ideas for next steps/other services that could help your child (9)

Q12 If your child was secondary school age or older when they were assessed, was the report written to them, or to you?

○ N/A - My child was younger than secondary school age (1)

○ My child was secondary school age or older and it was written to them (2)

○ My child was secondary school age or older and it was written to me as a parent (3)

Q13 To what extent do you think neuro-affirmative language was used in your child's autism report? (This means the language talks about autism as a difference rather than as a deficit - neuro-affirmative language avoids negatively labelling autistic traits, e.g. instead of 'poor eye contact' a neuro-affirmative report might say 'reduced eye contact')

	Extremely deficits based (1)	Somewhat deficits based (2)	Neither neuro-affirmative nor deficits based (3)	Somewhat neuro-affirmative (4)	Extremely neuro-affirmative (5)
Language used in report (1)	○	○	○	○	○

Q14 Do you have any thoughts on how the language used in your report impacted on you or on your child? (Please type your response)

____

Q15 How helpful did you find the recommendations included in your report?

	Not at all helpful (1)	Not very helpful (2)	Neither helpful nor unhelpful (3)	Somewhat helpful (4)	Extremely helpful (5)
Helpfulness of recommendations (1)	○	○	○	○	○

Q16 What made the recommendations helpful or unhelpful?

____

____

____

____

____

End of Block: Information about your child's assessment report

---

Start of Block: Block 3 - Uses of your child's assessment report

Q18 Who did you share your child's autism assessment report with, if anyone?

☐ Child's school or college (1)

☐ Relatives (2)

☐ My child themselves (3)

☐ Mental health services (4)

☐ Paediatrician (5)

☐ Other (please describe in the text box) (6) ____

Q17 What did you use your child’s autism assessment report for after you got it? Please select all that apply.

☐ To help me understand my child (1)

☐ To help my child understand themselves (2)

☐ To help my child’s school better understand their support needs (3)

☐ To support an EHCP (4)

☐ To help mental health professionals better support my child (5)

☐ Other - please specify: (6)

____

Q19 Could you say a bit more about the ways in which you used your child’s autism assessment report? (Please go into as much detail as you feel comfortable with. We are interested in hearing about your individual experience, thoughts and feelings around this.)

____

____

____

____

____

Q20 How helpful did you find the report for the purposes you described above?
What about the report made it useful for this? Was there anything that could have made the report more helpful for this?

____

____

____

____

____

Q25 Did your report change how you understood your child? Did this have an impact on your relationship with your child?

____

____

____

____

____

Q21 On a scale of 1-5, how readable and easy to understand did you find your child's autism assessment report?

	1 - Not at all unerstandable (1)	2 - Somewhat hard to understand (2)	3 - Neither hard to understand nor easy to understand (3)	4 - Fairly easy to understand (4)	5 - Very easy to understand (5)
How easy to understand was it? (1)	○	○	○	○	○

Q47 Could you say a bit about what made it easier or harder to understand and read? Please type your response

____

____

____

____

____

Q23 Were there any parts of the report that seemed unnecessary, hard to understand or too detailed? Please type your response

____

____

____

____

____

Q24 Do you have any other reflections on your child's autism assessment report that you would like to share? Please type your response

____

____

____

____

____

Q32 Would a one page summary of the conclusion of the assessment plus recommendations have been sufficient? Why, or why not?

○ Yes (please say why in text box) (1) ____

○ No (please say why not in text box) (2) ____

End of Block: Block 3 - Uses of your child's assessment report

Start of Block: Block 4

Q37 We would really like to carry out a focus group with parents of children who have had an autism assessment in order to get a deeper understanding of some of the things we have asked about in this questionnaire, or to learn about things that might be important to parents that we have not asked about here. This would involve a small group (around 6-8) of parents meeting with a researcher and talking together for about 60 - 90 minutes about what is important to you about autism reports, and how you have used them.

Would you be willing to take part in such a focus group? If so, please write your contact details below (email address and/or phone number) so that a researcher can get in touch to tell you more about this. Alternatively feel free to send an email to Emily at eh20abj@herts.ac.uk to learn more about this.

If you would not feel comfortable talking in a group but might be interested in speaking to a researcher individually in an interview, please leave your contact details and mention this to the researcher.

○ I would be interested in taking part in a focus group or interview to say more about my experiences (please type your contact details in the text box) (1)
____

○ No thank you, I would prefer not to take part in a focus group or interview (2)

End of Block: Block 4

Appendix I: Post questionnaire signposting information

Thank you for your time and thoughts, they are very much appreciated.

We hope that your answers today will contribute to improving the way autism assessment reports are written, to make them as helpful as possible for the things parents use them for.

If responding to this survey has brought up any difficult feelings, there are some sources of support listed below which may be available to you.

If you are living in Hertfordshire:

ADD-vance is a Hertfordshire based charity that supports families affected by ADHD, Autism or a related condition and the professionals who support them.

SPACE is a Hertfordshire based charity supporting families of children and young people who are neurodivergent (Autism, ADHD, Dyslexia, Dyspraxia, Dyscalculia, Tourette's and other neurodiverse conditions.)

If you or your child are in need of support for your emotional wellbeing and you live in Hertfordshire, you can contact Single Point of Access (SPA) on 0800 6444 101 for referral to mental health services and helplines.

Outside of Hertfordshire:

The National Autistic Society is the UKs leading charity for autistic people and their families. https://www.autism.org.uk/ and contains a directory of support services you can use to search for services local to you.

If you or your child are in need of support for your emotional wellbeing and you live outside of Hertfordshire, the number for your local Single Point of Access will vary, but if you google 'Single Point of Access' and your location this will bring up the number you can call for referral to local mental health services and helplines.

If you have any questions about this study, would like to hear about the findings, please feel free to contact Emily Hickson on eh20abj@herts.ac.uk

Appendix J: Interview information sheet and consent form

PARTICIPANT INFORMATION SHEET – FOCUS GROUP OR INTERVIEW

1 Title of study

How do parents make use of autism assessment reports and how helpful do they find them?

2 Introduction

You are being invited to take part in a study. The study is conducted by Emily Hickson at the University of Hertfordshire as part of a doctoral thesis, supervised by Dr Ben Grey and Dr Suzannah Gratton.

3 What is the purpose of this study?

The purpose of this study is to find out how parents of children who have had autism assessments use the assessment reports, and what makes reports helpful or unhelpful to them. We would also like to learn more about what is important to parents more generally in autism assessment reports.

4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage prior to data being analysed without giving a reason.

5 Are there any age or other restrictions that may prevent me from participating?

You must be over 18 to take part.

You will need to be a parent of a child who has had an autism assessment (although they do not need to have been diagnosed with autism – just assessed for it).

You will need to have received a report or letter detailing the conclusion of this assessment.

It is important that you feel able to talk about this experience, and that doing so will not feel too distressing for you at this time.

6 How long will my part in the study take?

Focus groups and interviews will last approximately 90-120 minutes.

7 What will happen to me if I take part?

You will be invited to a focus group or interview, which may take place via videoconference or in person depending on participant preferences, locations and individual needs. If you attend a focus group, you will be part of a small (4-8 people) group and will be asked to discuss your views on and experiences of your child's autism assessment report. If you attend an individual interview you will be asked about the same things individually.

Focus groups and interviews will be video and audio recorded to allow researchers to transcribe discussions.

8 What are the possible disadvantages, risks or side effects of taking part?

If your experiences of your child's autism assessment involved difficult emotions, taking part might bring these up for you. In a focus group hearing about the experiences of other parents might also bring up difficult feelings. It is important to decide whether this feels manageable to you at this point in time.

9 What are the possible benefits of taking part?

You might find it rewarding to participate in the study. By taking part, you will be contributing to a greater understanding of how parents tend to use autism assessment reports, and what makes reports helpful or less helpful. This understanding may ultimately lead to reports that are better suited to parents' needs and the needs of their children.

10 How will my taking part in this study be kept confidential?

Your consent form will be stored separately from transcript information so that your identity cannot be linked to what you have said. No identifying information such as your name or specific locations or services will be included in the transcript of the focus group or interview. Any recordings made of focus groups or interviews will be deleted after the research has been completed and the researcher's doctoral research has been examined. All study information will be kept digitally and securely on a password protected account.

12 What will happen to the data collected within this study?

The anonymized transcripts of focus groups and/or interviews will be stored electronically in a password protected computers of the researcher and her supervisors and they will not be viewed by anyone outside the research team. We will examine the themes brought up within the focus group and interview data. These findings will be written up and presented as part of a doctoral thesis, and may be disseminated more widely through submission to an academic journal and presentations made at conferences or to local services. Recordings made of focus groups or interviews will be deleted after doctoral examination of the research is complete. If you would like to hear about the findings, please contact Emily at eh20abj@herts.ac.uk.

14 Who has reviewed this study?

This study has been reviewed by:

- The University of Hertfordshire Health, Science, Engineering & Technology Ethics Committee with Delegated Authority

The UH protocol number is LMS/PGR/UH/05470

15 Factors that might put others at risk

Please note that if, during the study, any circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

16 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me or my primary supervisor, in writing or by email:

Emily Hickson	Dr Ben Grey
eh20abj@herts.ac.uk	b.grey@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

CONSENT FORM

(UH Protocol number LMS/PGR/UH/0547)

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study.

2 I have been assured that I may withdraw from the study at any time up to the point of data being analysed without disadvantage or having to give a reason.

3 In giving my consent to participate in this study, I understand that voice, video or photo-recording will take place and I have been informed of how/whether this recording will be transmitted/displayed.

4 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

5 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

6 I have been told that I may at some time in the future be contacted again in connection with this or another study.

Name of participant:

Signature of participant…………………………………..….Date…………………………

Signature of (principal)
investigator……………………………………………………Date…………………………

Name of (principal) investigator *[in BLOCK CAPITALS please]*

…………………………………………………………………………………………………

Appendix K: Interview schedule

Semi-structured interview schedule

(Loose – will be guided by what participants feel is important to them about the reports)

Could you start by telling me a bit about the report you received after your child's assessment?
Possible prompts: Do you remember what your initials impressions were, or what it was like to read it?

How readable was the report?
Possible prompts: Was it structured in a way that made sense? Were things worded in a way that was easy to understand?

What did you use the report for?
Possible prompts:
For instance, did you use it to inform your own understanding of your child's needs?
Did you share it with other people? Did you use it to help get your child accommodations they needed, e.g. at school or anywhere else? Simply to have proof of diagnosis?
What was the main importance of the report for you?
Can you give me an example/tell me about what that was like?

How useful was the report for that?
Possible prompts:
What was it that made it useful?
Was there anything that could have made it more useful for this?

Have you ended up using the report for anything you didn't expect to?
Possible prompts: Or did you already know that you needed the report for something specific prior to their assessment?

Is the report something you have come back to over time?
Possible prompts: E.g. have you used it for different things at different times, like for something particular right after diagnosis, and then something else later on?

Did the information in the report change your relationship with your child?
Can you think of any examples?

Did you have any thoughts about the language used in the report, the tone of it, the way your child was written about?
Possible prompts: For instance, did you feel it was written in a way that was respectful towards your child?

Did you learn anything new from the report?
Possible prompts: For instance, strategies to help your child? Information about autism? Ideas for sources of support?

Is there anything else you would have wanted to be done differently, about the report specifically?
Possible prompts: Or anything you think that professionals should know about your experience of the report?

Appendix L: Questionnaire findings less relevant to research questions, and full tables of content analysis themes from free text responses

Figure 8: Parent disability at time of assessment

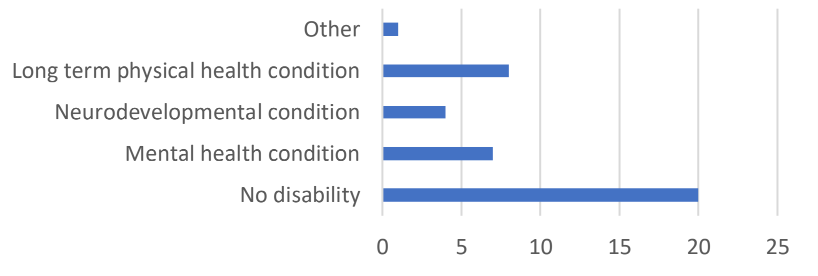


Table 20: Parental disability, other (total responses 1)

Theme	*Frequency*
Suspected ADHD	1

Figure 9: Child's other diagnoses at time of assessment

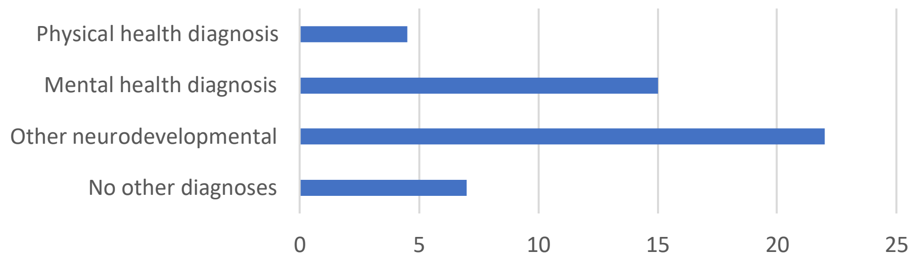


Figure 10: Perceived cultural match between family and professionals

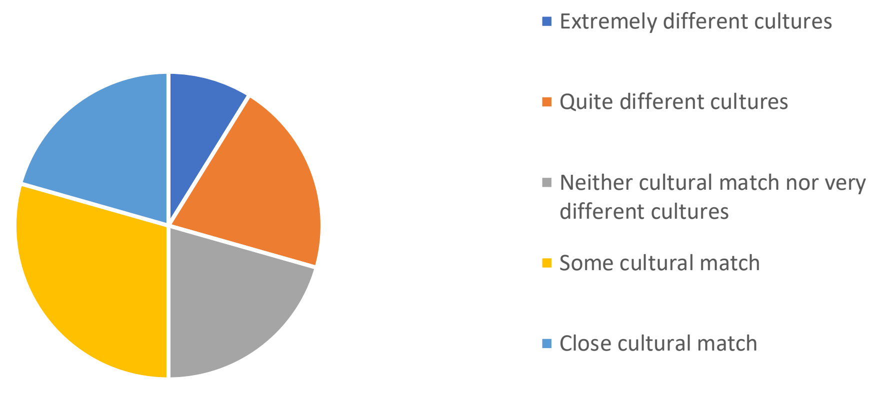


Table 21: Impact of cultural match between parent and assessors (total responses 28)

Theme	*Frequency*
No impact	19
Positive impact	3
Negative impact	3
Not sure/ambiguous response	3

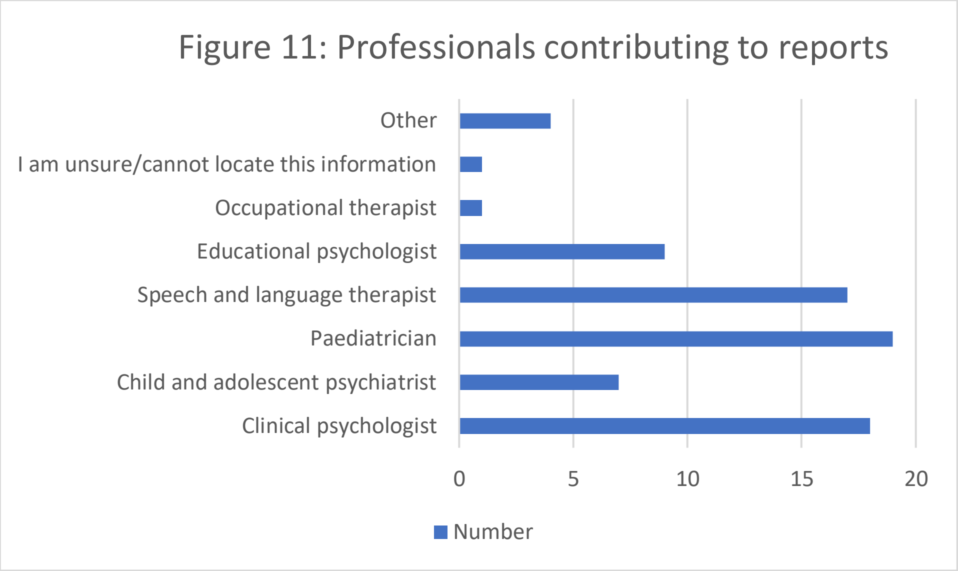


Figure 11: Professionals contributing to reports

Table 22: What professionals contributed to report, other (total responses 4)

Theme	*Frequency*
School or nursery staff	2
Health visitor	1
Child psychologist	1

Out of the 29 who responded to the question about whether a one page summary would have been sufficient, 22 said no, 7 said yes. See themes in responses to why or why not in Tables 23 and 24.

Table 23: Would a one page summary have been sufficient, why or why not? Yes, say why in text box (5 responses)

Theme	*Frequency*
Would be useful to give to others	2
No we needed detail of full report	2
Yes would make it easier to understand	1
Not coded due to ambiguous/uninformative response	1

Table 24: Would a one page summary have been sufficient, why or why not? No, say why in text box (22 responses)

Theme	*Frequency*
Detail of full report was needed	21

Report already contained summary section at beginning	1

Of 33 responding, 19 reported receiving their report in a digital format, 10 paper and 4 both.

Of 29 responding, 22 reported being happy with the format they received the report in and 7 reported being unhappy. 5 did not respond – perhaps reflecting the lack of a neutral option here. For themes in responses saying more about why they were happy with the format, see Table 25 and for themes in responses saying more about why they would have preferred a different format see Table 26.

Table 25: I was happy with the format, say more in text box (10 responses)

Theme	*Frequency*
Easy to share	1
Always available	1
Not coded due to ambiguous or uninformative response (e.g. just 'yes' with no further info)	8

Table 26: I would have preferred it in a different format, say more in text box (6 responses)

Theme	*Frequency*
Would have preferred both digital and paper	3
Would have preferred digital	2
Didn't have printed so was hard to highlight specific parts for school	1
Digital report got lost in email folders	1
Lost device report was digitally stored on	1

82% of parents were fully confident in the outcome, 14.7% were mostly confident and 2.9% were not confident at all.

Table 8: Main concerns leading to assessment, other (total responses 10)

Theme	*Frequency*
Social relationships	5
Specific behavioural concerns	2
Wanting to understand differences	2

Sensory processing concern	1

Table 9: What sections were most helpful? Was anything less helpful? (total responses 21)

Theme	*Frequency*
Helpful	
Whole report was helpful	4
Recommendations/strategies helpful	3
Summary helpful	2
Showing how child met diagnostic criteria helpful	2
Information about difficulties noticed by others (e.g. school) helpful	2
Linking difficulties to autism helpful	2
Highlighting difficulties less visible to others helpful	2
Information about autism helpful	1
Information about common parental emotional reactions to diagnosis helpful	1
Information about child’s strengths helpful	1
Background info about what led to assessment helpful	1
Unhelpful	
Less helpful: Suggestions generic/unsuitable	6
Level of detail overwhelming, unhelpful	3
Inaccuracies in report unhelpful	2

Absence of link to local offer website unhelpful	1
Not coded due to ambiguous or uninformative response	1

100% of parents of secondary school aged children at time of assessment who responded reported that the report was written to them as parents, rather than to their child.

Table 10: Thoughts on how language used in report impacted on parent or child (17 total responses)

Theme	*Frequency*
Language used did not matter/no thoughts on this	10
Language had positive impact	2
Language had negative impact	1
Not coded due to ambiguous or uninformative response	3

Table 11: What made recommendations helpful or unhelpful? (24 responses)

Theme	*Frequency*
Helpful	
Practical ideas or signposting were helpful	5
Backs up what parent has been saying, helpful	3
Information about child’s development helpful	1
Unhelpful	
Not personalised enough	5
Content of recommendations helpful, but rendered unhelpful by others not acting on them	3
No recommendations included in report	3

Recommendations contain nothing new to parents	2
Recommendations were overwhelming	2
Not enough practical guidance given on recommendations	2
Report missing important recommendations	1
Recommendations not accessible to parents	1
Could not be coded due to ambiguous response	1

Table 12: Do you think others made use of information in report to support child? Somewhat, say more in text (12 responses)

Theme	*Frequency*
Yes school or college used info	5
Yes but only after fight by parent	4
No, services did not make use of info	2
Diagnosis came too late for others to make use of info	1
Diagnosis itself was used but not information in report itself	1

Table 22: Who did you share the report with? Other (12 responses)

Theme	*Frequency*
Local authority/professionals involved in EHCP	5
GP	4
School/wraparound care	3
Professionals involved in disability living allowance application	2
Occupational therapist	1

Table 13: Did the report change your understanding of your child, relationship with child, or how others understood your child? (28 responses)

Theme	*Frequency*
Yes	
Helped parent understand child's needs	7
Changed how school understood child positively	4
Did change understanding/relationship	4
Changed family members' understanding of child positively	2
Changed how some professionals understood child in a negative way (e.g. lowered expectations)	2
No	
Did not change understanding/relationship	18
Would have if received earlier	3
Report didn't, but diagnosis or post diagnostic support did	2

Table 14: What did you use report for after you got it. Other, please specify (3 responses)

Theme	*Frequency*
To help family understand child	1
DLA or disabled badge	1
Hasn't been used	1

Table 15: Say more about ways you used report (27 responses)

Theme	*Frequency*
Report as key to unlocking support via proof of diagnosis	16

Helping others understand child	11
Helping parents understand child	7
Tried to use report as key to unlock support, but support refused	3
Sense of child being failed until proof of diagnosis obtained	3
Identifying next steps	2
Surprise that diagnosis did not automatically trigger relevant support and responsibility for coordinating this fell on parents	1

Table 16: How helpful did you find the report for purposes they described above? (26 responses)

Theme	*Frequency*
Helpful	
Report was helpful	8
Report helpful only as proof of diagnosis	5
Moderately helpful	1
Helpful because validated what parent had already been saying	1
Unhelpful	
Would be more helpful if specific strategies and adjustments child needs were highlighted	7
Not helpful because others did not act on information in report	3
Would be more helpful if included age appropriate letter explaining diagnosis to child	1
Would be more helpful if shorter	1

Unhelpful because it came too late	1
Not coded due to ambiguous or uninformative response	1

Table 17: Say what made report easier/harder to read (20 responses)

Theme	*Frequency*
Easier: Language used was clear	7
Easier: Information was clearly structured	6
Harder: Parent emotions made it hard to read	1
Harder: Length might make it hard to read	1
Harder: Jargon made it harder to read	1
Harder: Spelling/grammatical errors made harder to read	1
Harder: Raw test scores with no interpretation made it harder to read	1
Easier: Being present for assessment and understanding process made it easier to read	1
Not coded due to ambiguous/uninformative response	4

Table 18: Did any parts of report seem unnecessary, hard to understand or too detailed? (16 responses)

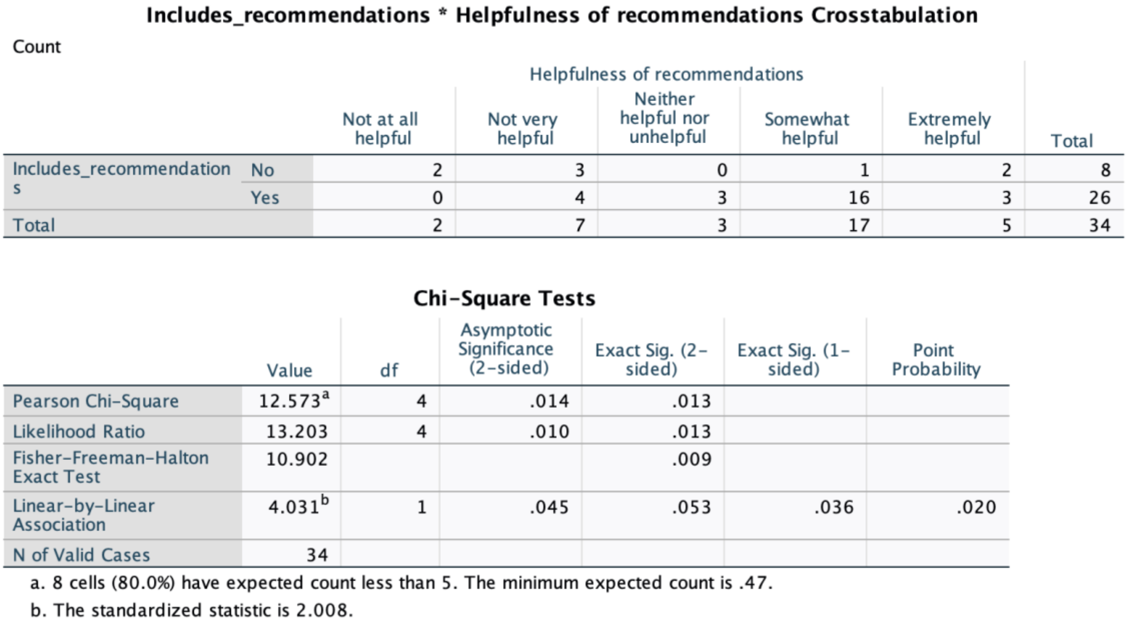
Theme	*Frequency*
No	12
Parent interview presented in excessive detail, would prefer not to share this with others	3
Suggestions overwhelming	3
ADOS report was poor	1

Not coded due to ambiguous/uninformative response	1

Table 19: Other reflections on child's autism assessment report to share (17 responses)

Theme	*Frequency*
Wait for diagnosis took too long	2
More practical guidance would be helpful	2
Diagnostic process was overwhelming/ should be better explained beforehand	2
Sadness about having to pay for private diagnosis due to NHS waiting lists	1
Report detailed all key concerns parent had which was helpful	1
Ideas for specific adjustments child needs would be helpful in report	1
Mention of child's strengths would be helpful in the report	1
Would be helpful if once diagnosis children automatically received more in depth assessments e.g. from OT, SLT, Ed Psych	1
A follow up appointment would have been helpful	1
Report contained lots of inaccuracies which was unhelpful	1
Diagnosis provided comfort to the child	1
Would have liked 'proper assessment and report' including parental interview	1
Not coded to ambiguous or uninformative response (e.g. 'no' with no further info)	5

Appendix M: SPSS output



Includes_recommendations * Helpfulness of recommendations Crosstabulation

Count

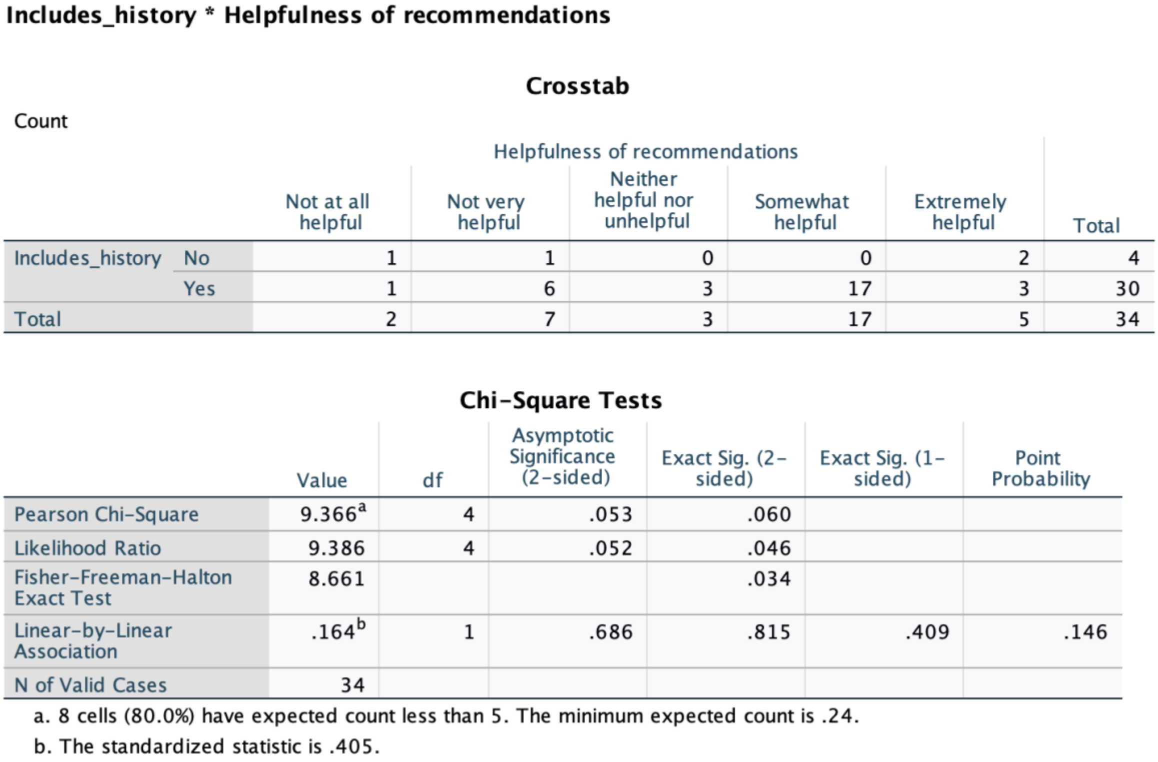
		Helpfulness of recommendations					
		Not at all helpful	Not very helpful	Neither helpful nor unhelpful	Somewhat helpful	Extremely helpful	Total
Includes_recommendations	No	2	3	0	1	2	8
	Yes	0	4	3	16	3	26
Total		2	7	3	17	5	34

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)	Point Probability
Pearson Chi-Square	12.573[a]	4	.014	.013		
Likelihood Ratio	13.203	4	.010	.013		
Fisher-Freeman-Halton Exact Test	10.902			.009		
Linear-by-Linear Association	4.031[b]	1	.045	.053	.036	.020
N of Valid Cases	34					

a. 8 cells (80.0%) have expected count less than 5. The minimum expected count is .47.

b. The standardized statistic is 2.008.



Includes_history * Helpfulness of recommendations

Crosstab

Count

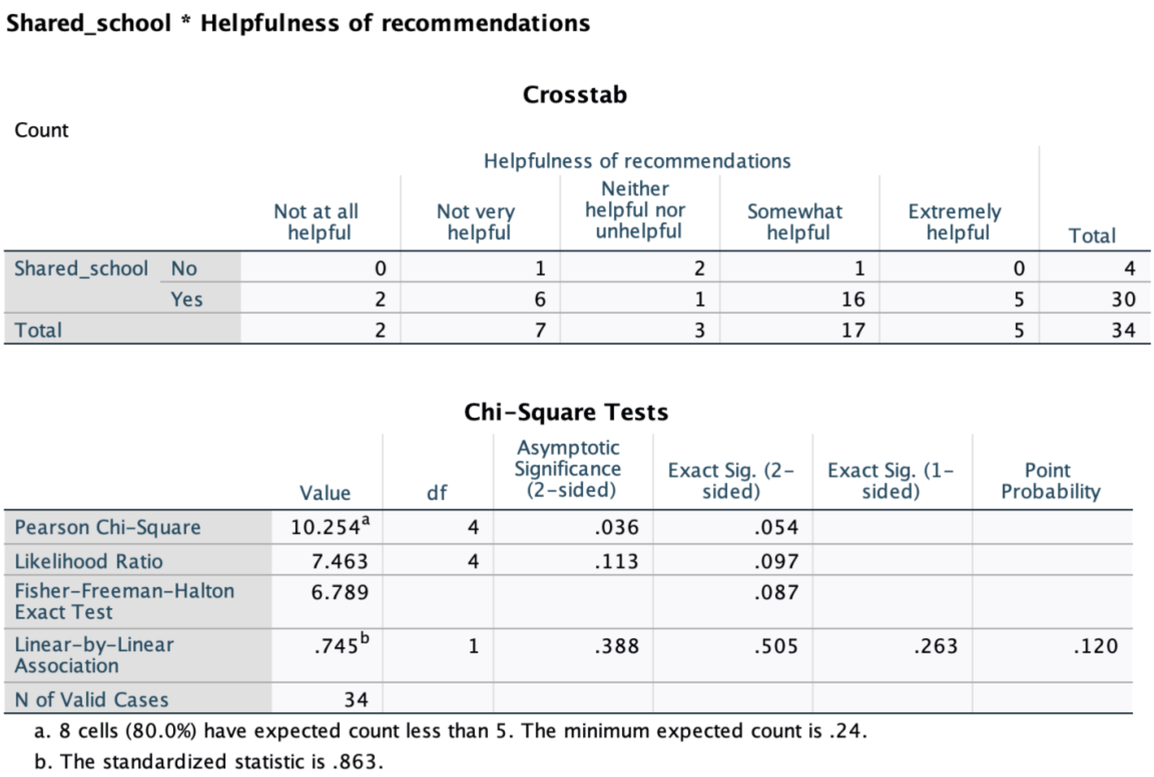
		Helpfulness of recommendations					
		Not at all helpful	Not very helpful	Neither helpful nor unhelpful	Somewhat helpful	Extremely helpful	Total
Includes_history	No	1	1	0	0	2	4
	Yes	1	6	3	17	3	30
Total		2	7	3	17	5	34

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)	Point Probability
Pearson Chi-Square	9.366[a]	4	.053	.060		
Likelihood Ratio	9.386	4	.052	.046		
Fisher-Freeman-Halton Exact Test	8.661			.034		
Linear-by-Linear Association	.164[b]	1	.686	.815	.409	.146
N of Valid Cases	34					

a. 8 cells (80.0%) have expected count less than 5. The minimum expected count is .24.

b. The standardized statistic is .405.



Shared_school * Helpfulness of recommendations

Crosstab

Count

		Helpfulness of recommendations					
		Not at all helpful	Not very helpful	Neither helpful nor unhelpful	Somewhat helpful	Extremely helpful	Total
Shared_school	No	0	1	2	1	0	4
	Yes	2	6	1	16	5	30
Total		2	7	3	17	5	34

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)	Point Probability
Pearson Chi-Square	10.254[a]	4	.036	.054		
Likelihood Ratio	7.463	4	.113	.097		
Fisher-Freeman-Halton Exact Test	6.789			.087		
Linear-by-Linear Association	.745[b]	1	.388	.505	.263	.120
N of Valid Cases	34					

a. 8 cells (80.0%) have expected count less than 5. The minimum expected count is .24.

b. The standardized statistic is .863.