School of Psychology
Ysgol Seicoleg

A Systematic Review of Autistic Adults Experiences of Healthcare in the UK, and an Empirical Study of Autistic Mothers Experiences of Statutory Services when Acting on Behalf of their Autistic Children

Thesis submitted in partial fulfilment of the requirement for

the degree of:

Doctorate of Clinical Psychology (DClinPsy)

South Wales Doctoral Programme in Clinical Psychology

Cardiff University

Sarah Radev

Supervised by: Professor Andrew Thompson & Dr Megan Freeth

22nd May 2023

Table of Contents

Paper 1 (Systematic Meta-ethnography)

Paper 2 (Empirical Paper)

Appendices

Acknowledgments

I would like to thank all the participants who gave their time to take part in interviews and for sharing their experiences without which this paper could not have been written. I would also like to give thanks to the two autistic adults who gave feedback on the materials and interview questions prior to recruitment as their input was invaluable.

Thanks to Jonathan Jones, the librarian who supported the development of search strategies for the different databases when conducting the systematic review. His enthusiasm, his time and his expertise were greatly appreciated.

Thanks to Jordan Holt for taking the time while working on her own thesis to review full texts against the inclusion and exclusion criteria and engage in discussions regarding any disagreements as part of the quality appraisal process.

I would like to thank Autistica for supporting recruitment by emailing details to potential participants on their database, and to everyone who supported recruitment on social media.

Finally, I would like to thank my supervisors Professor Andrew Thompson and Dr Megan Freeth for their continued support and guidance throughout the process of completing this work.

Preface

Autistic Spectrum Condition is a lifelong condition which impacts on social communication, restricted patterns of behaviour and differences in thinking patterns and sensory experiences, all of which are important elements to consider when seeking support from healthcare and other statutory services. To date much of the research into autistic experiences have focused on those of children, those with intellectual disabilities or those of non-autistic carers and professionals supporting autistic people. This research aims to bring the focus onto the experiences of non-autistic adults who do not have a co-occurring intellectual disability both when accessing healthcare for themselves and when advocating on behalf of their autistic children. These are issues of particular importance to the lead researcher who is herself an autistic adult without a co-occurring intellectual disability, and the parent of an autistic child.

Paper 1 presents a systematic review of qualitative research into the experiences of autistic adults without a co-occurring intellectual disability when accessing healthcare within the UK. Previous research has focused on the experiences of autistic adults from around the world, and the purpose of this research was to offer a more focused look at the experiences of autistic adults living in the UK. This is to ensure that the findings and recommendations are specific to the UK healthcare system. A meta-ethnographic approach was used with twelve papers included in the final analysis. Three superordinate themes were identified: *Professionals lack of knowledge can be damaging; Need to reduce processing demands,* and *Adaptation to improve engagement.* The impact that these experiences have on the wellbeing of autistic adults accessing healthcare in the UK, and on their ability to engage with treatment, can ultimately be damaging to the individual and this came through in the research as a key consideration. This damage may come in the form of misdiagnosis, inadequate or inappropriate treatment being delivered, overwhelming environments and inaccessible systems. The first theme regarding the lack of autism knowledge and understanding from healthcare professionals, along with autistic adults' differences in communication and sensory experiences indicate there is a need for improved training developed with autistic adults. Adaptations that are specific to the needs of autistic adults should also be considered.

Paper 2 uses interpretive phenomenological analysis to investigate the experiences of autistic parents when advocating for their autistic children. Being a parent is an important part of adult life for many people, including autistic people. Many parents of autistic children can find getting the right support for their children from healthcare and education difficult. Knowledge is currently poor about how this is experienced by parents who are also autistic themselves. Ten autistic mothers with autistic children in mainstream education were interviewed about their experiences of seeking support for their autistic children from services such as healthcare and education. Participants talked about finding the overall system being the main problem, rather than the individuals working in it, and about needing to fight to get the right support for their children. These are points that non-autistic parents have also raised before. Participants also talked about feeling judged and stigmatised for being autistic, and about struggling to manage sensory and communication difficulties, which is something that has not been talked about by non-autistic parents. Improving services to offer better support to autistic families is important and can be achieved through better training. This training should be developed and run by autistic adults and should focus on the positive aspects of autism, rather than the negative.

These papers offer a look at the autistic experience of accessing services from the perspective of autistic parents, which is not a perspective that has had a lot of focus previously, and with a focus on autistic adults' experiences specifically in the UK, allowing for recommendations that are specific to the UK healthcare system. The findings from these papers have clinical implications for the ways in which services are set up and healthcare professionals are prepared for working with autistic adults. They also provide some insight into factors which may negatively impact on wellbeing for autistic adults, and reasons why they may present in mental health services, which is directly relevant to clinical psychology.

Paper 1

How healthcare systems are experienced by autistic adults in the UK: a meta-ethnography

Sarah Radev

Supervised by Professor Andrew Thompson and Dr Megan Freeth

School of Psychology, Cardiff University

Word count for abstract: 206

Word count excluding abstract, tables, figures and references: 7611

This meta-ethnography has been prepared for the journal Autism. The submission guidelines can be found in Appendix A. For the purposes of thesis submission, the DClinPsy word limit of 8000 words has been used to ensure all relevant information could be demonstrated. This will then be reduced to 6000 for journal submission. APA format has been used throughout in line with the journal specifications.

Abstract

Autistic adults are at increased risk of both mental health and physical health difficulties, and yet can face a number of barriers to accessing healthcare. A meta-ethnographic approach was used to conduct a review of the existing literature regarding autistic adults' experiences of accessing healthcare. Four databases were systematically searched for qualitative and mixed method studies reporting on the experiences of autistic adults without a co-occurring intellectual disability accessing adult healthcare services within the UK. Twelve papers met the inclusion criteria, and seven steps were used to systematically extract the data and then generate novel themes. Three superordinate themes were identified: *Professionals lack of knowledge can be damaging; Need to reduce processing demands,* and *Adaptation to improve engagement.* This review highlights the wide-reaching damaging impact that autistic adults' experiences of accessing healthcare in the UK can have on their wellbeing and ability to engage with treatment. This damage may come in the form of misdiagnosis, inadequate or inappropriate treatment being delivered, overwhelming environments and inaccessible systems. The lack of autism knowledge and understanding experienced in interactions with healthcare professionals, along with autistic adults' own communication and sensory processing differences demonstrates the need for widely delivered training co-produced with autistic adults alongside bespoke and person-centred adaptations.

Introduction

Autism Spectrum Condition (ASC) is defined by persistent social and communication differences alongside restricted, repetitive patterns of behaviour which has a significant impact on the individual's daily life (American Psychiatric Association, 2013). Increased levels of physical health difficulties, depression, anxiety and social anxiety disorder have been identified in the autistic population compared to the non-autistic population leading to an overall poorer quality of life (Buck et al., 2014; Caamaño et al., 2013; Gilmore et al., 2022). With the prevalence of ASC currently estimated at 1.1% of the UK population (National Institute for Health and Care Excellence, 2021) and the likelihood of many more undiagnosed in the population, ensuring services are accommodating and appropriate is important. There are a number of different terms which can be used for those with an ASC diagnosis and this paper will use the identity-first term 'autistic' in keeping with the preferences of the autistic community (Crane et al., 2021; Kenny et al., 2016).

Autistic adults may require adaptations to methods of communication, and more processing time (Gilmore et al., 2022; Nicolaidis et al., 2015) as well as to the environment in which appointments take place due to sensory processing differences (Saqr et al., 2018). Reduced satisfaction with health services and higher levels of unmet needs have been reported by autistic adults when compared to the needs of non-autistic adults (Brede et al., 2022; Raymaker et al., 2017). A number of studies have investigated autistic adults experiences of healthcare, some of which have focused on mental health settings (Brede et al., 2022) and some of which have focused on physical health settings (Calleja et al., 2020; Mason et al., 2019; Walsh et al., 2020). The key themes that have most commonly arisen through existing research include difficulties with communication (Brede et al., 2022; Nicolaidis et al., 2015; Raymaker et al., 2017); sensory sensitivities (Brede et al., 2022; Brice et al., 2021; Nicolaidis et al., 2015; Raymaker et al., 2017); a lack of knowledge about autism (Brede et al., 2022; Brice et al., 2021; Jones et al., 2014; Nicolaidis et al., 2015) and difficulties with accessing services (Brede et al., 2022; Nicolaidis et al., 2015; Raymaker et al., 2017). Other themes that have come up to a lesser extent include difficulties with slower processing speeds (Nicolaidis et al., 2015; Raymaker et al., 2017); emotional regulation (Brede et al., 2022; Raymaker et al., 2017); and difficulties with the need for flexibility and certainty (Brede et al., 2022), all of which are known difficulties faced by autistic people. Some papers have focused solely on the autistic experience, while others have included perspectives from professionals and carers. Considering that one of the key recurring themes highlighted by autistic people is a feeling that professionals have a lack of knowledge about autism, the inclusion of the professionals' views when trying to understand autistic experiences of accessing healthcare may be problematic. For this reason this meta-ethnography will maintain a focus on the direct experiences of autistic adults from their own perspectives.

Previous systematic reviews focusing on autistic experiences of accessing healthcare have focused either on mental health or physical health or a mixture of the two. The systematic reviews by Mason et al. (2019), Calleja et al. (2020), and Walsh et al. (2020), focused specifically on physical healthcare experiences including both qualitative and quantitative studies published between 2003 and 2019. Bradshaw et al. (2019), conducted a systematic review on the barriers and facilitators to autistic adults accessing healthcare. Brede et al. (2022), conducted a systematic review which was focused on experiences with mental health services and included qualitative and mixed methods-studies, while Gilmore et al. (2022), looked at both mental and physical health settings only including quantitative papers with a focus on experiences of the USA healthcare system. With the exception of Gilmore et al. (2022), all of these systematic reviews have included papers from across Europe, the UK, the USA and Canada. However, the healthcare systems in these different countries are very different not only in the ways they are set up, but in the way they are accessed by the population, and so findings from systematic reviews covering a range of countries may not elicit data which is particularly applicable to informing services in any one given country. To date there have been no systematic reviews that have specifically focused on the experiences of autistic adults accessing healthcare services in the UK.

This systematic review will focus on the experiences of autistic adults, solely from their own perspective rather than including the views of carers or healthcare professionals, when accessing healthcare specifically in the UK. Since qualitative studies are a better fit when seeking to investigate experience, only qualitative and mixed-methods studies will be included in this review. Meta-ethnography is the most widely used synthesis methodology for qualitative studies on health and social care (France et al., 2019). Previous systematic reviews on the topic of autistic adults' experiences of healthcare have conducted thematic analysis or meta-synthesis rather than meta-ethnography which involves translating studies into one another in order to produce novel interpretations (Britten et al., 2002; France et al., 2019). Meta-ethnography provides an opportunity to summarise extant qualitative studies while enabling new findings, which in this case may assist in gaining a greater understanding of the experience and needs of autistic people seeking services in the UK.

Method

The protocol of this review was developed in line with the most recent PRISMA guidelines (Page et al., 2021) and is registered on PROSPERO (International Prospective Register of Systematic Reviews - Registration #: CRD42022332477, see Appendix B).

Search Strategy

The search strategy was developed in consultation with a librarian subject expert, and the full search strategy can be seen in Table 1. Four databases MedLine, PsychInfo, Scopus and PubMed were searched initially in December 2022, and run again on 10th February.

Table 1

Database specific search strategies for systematic literature search

Database	Search Strategy
MedLine / PsychInfo	(Interpretative phenomenological analysis or grounded theory or thematic analysis or content analysis or phenomenological approach or constructivist epistemological framework or semi-structured or semistructured or unstructured or informal or indepth or indepth or face-to-face or structured or guide* or interview* or discussion* or questionnaire* or focus group or qualitative or ethnograph* or field work or fieldwork or key informant) AND (autis* OR asd OR asc OR aspie OR asperger*) AND (Health Services OR health* OR practice) AND (experience* OR perspective* OR attitude* OR view* OR opinion*)
Scopus	(TITLE-ABS-KEY (“interpretative phenomenological analysis” OR “grounded theory” OR “constructivist epistemological framework” OR “semi structured” OR semistructured OR unstructured OR informal OR indepth OR “face to face” OR structured OR guide* OR interview* OR discussion* OR questionnaire* OR “focus group*” OR qualitative or ehtnograph* OR “field work” OR fieldwork OR “key informant”) AND TITLE (autis* OR asd OR aspie OR asperger*) AND TITLE-ABS-KEY (health* OR practice) AND TITLE-ABS-KEY (experience* OR attitude* OR opinion* OR view* OR perspective*))
Pubmed	((("interpretative phenomenological analysis"[Title/Abstract] OR "grounded theory"[Title/Abstract] OR "thematic analysis"[Title/Abstract] OR "content analysis"[Title/Abstract] OR "phenomenological approach"[Title/Abstract] OR "constructivist epistemological framework"[Title/Abstract] OR "semi structured"[Title/Abstract] OR semistructured[Title/Abstract] OR unstructured[Title/Abstract] OR informal[Title/Abstract] OR indepth[Title/Abstract] OR "face to face"[Title/Abstract] OR

structured[Title/Abstract] OR guide*[Title/Abstract] OR interview*[Title/Abstract] OR discussion*[Title/Abstract] OR questionnaire*[Title/Abstract] OR "focus group*"[Title/Abstract] OR qualitative[Title/Abstract] OR ethnograph*[Title/Abstract] OR "field work"[Title/Abstract] OR fieldwork[Title/Abstract] OR "key informant"[Title/Abstract]) AND (autis*[Title] OR asd[Title] OR asc[Title] OR aspie[Title] OR asperger*[Title])) AND (health*[Title/Abstract] OR practice[Title/Abstract])) AND (experience*[Title/Abstract] OR attitude*[Title/Abstract] OR opinion*[Title/Abstract] OR view*[Title/Abstract] OR perspective*[Title/Abstract])

Eligibility Criteria

Following the removal of duplicate papers, the web-tool Rayyan (Ouzzani et al., 2016) was used to conduct automated searches to eliminate studies based outside the UK, and which were not in the English Language. Titles and abstracts were then reviewed in line with inclusion and exclusion criteria (see Table 2), before full texts were examined. Studies where some participants were based outside the UK, or where there was a combination of reports from autistic adults, family members and professionals which were not presented separately, were excluded. Reports which focused on the transitional period from child services to adult services were also excluded.

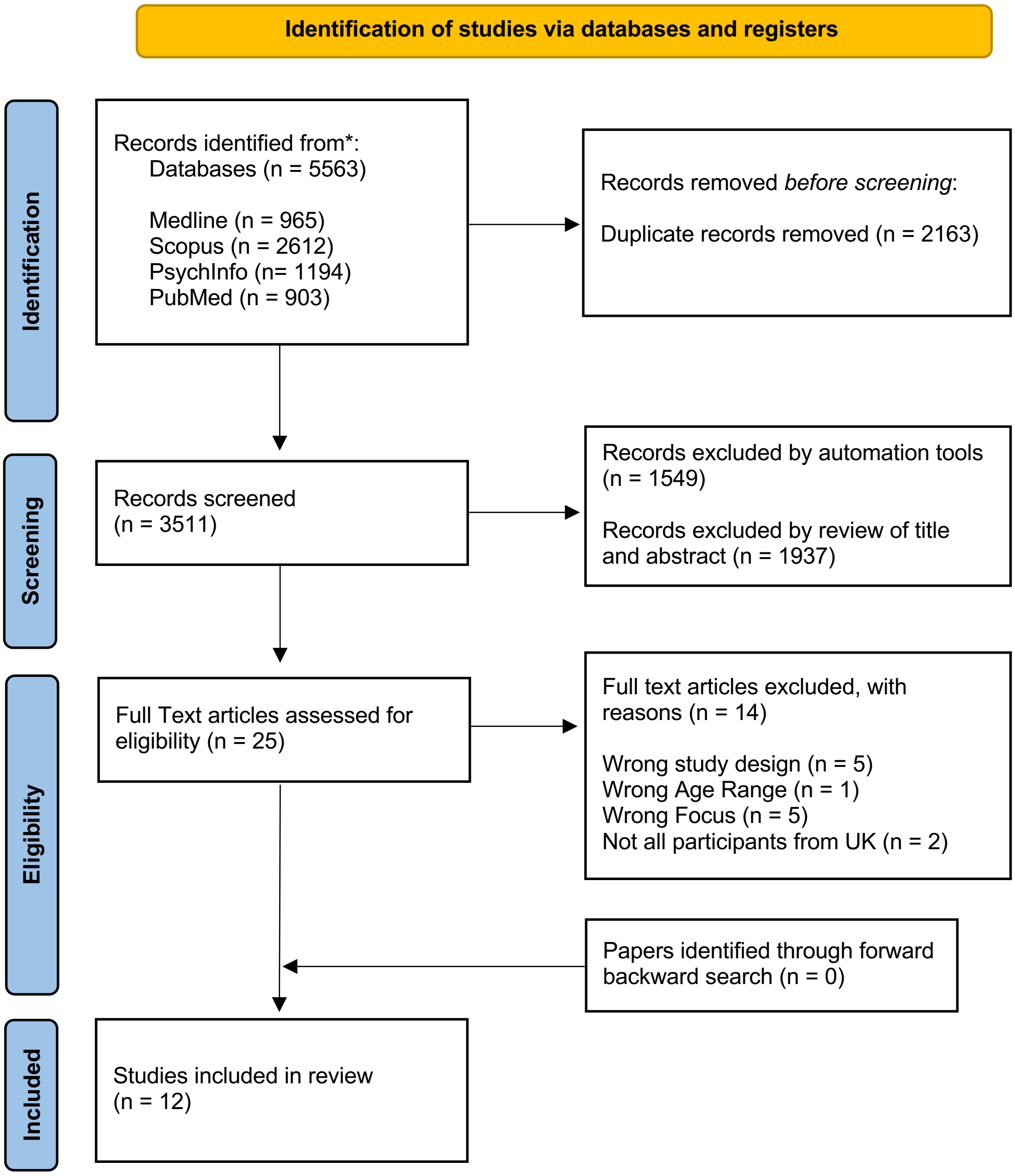
Table 2
Eligibility Criteria

Study Parameters	Inclusion Criteria	Exclusion Criteria
Language	English	Non-English
Location	Participants are based in the UK	Participants are based outside of UK
Study Population	18+ adults who are Autistic	Non-autistic adults or autistic adults who also have a learning disability
Study focus	The experiences of autistic adults accessing healthcare services	Focus is not on the experience of autistic adults, or is from the perspective of carers or professionals
Methodology	Qualitative studies and mixed-method peer reviewed studies using surveys or interviews	Purely Quantitative studies

References lists of all included papers were manually searched but no further relevant papers were found. The full process of selection can be seen in the PRISMA diagram in Figure 1 (Page et al., 2021).

Figure 1

PRISMA flow diagram for systematic literature search of autistic adults' experiences of healthcare in the UK



Full study characteristics can be found in Table 5.

Quality Appraisal Process

The methodological quality of the included papers was assessed using the Critical Appraisals Skills Programme (CASP, 2018) checklist. The CASP checklist uses nine scored questions to assess the quality of a paper, with a tenth question which is not scored, and asks how valuable the study is. Questions 1-9 were awarded a score of one if they clearly met the criteria, given a half score if the study might have met the criteria, but had not clarified how, and given a zero score where the criteria were clearly not met. Studies were then graded ‘low’, ‘medium’, or ‘high’ in relation to the risk of having significant methodological flaws. Table 3 outlines the classification system thresholds.

Table 3
Classification System for Quality Appraisal

Likelihood of Methodological Flaws	*CASP Score*
Low	8.5 or higher
Medium	5-8
High	Less than 5

Data Synthesis and theme generation

The meta-ethnography seven phase method developed by Noblit and Hare (1988), was used for synthesising data and generating new themes. An outline of the seven-phase approach and how it was followed is presented in Table 4. This process was informed by Britten et al. (2002), use of first, second and third order constructs where the first order represents opinions of the original participants, the second order represents the interpretations of the authors of the different studies, and the third order represents new interpretations of the second order constructs by this author (Schutz, 1962).

Table 4
Noblit & Hare (1988) Seven Phase Meta-ethnographic Approach

Phase	Process
Phase 1: Getting Started	The area of interest was identified through exploration of existing research and existing systematic reviews to determine where there was a need for further understandings. This meta-ethnography explores experiences of autistic adults living in the UK accessing healthcare services.
Phase 2: Deciding what is relevant to the initial interest	Inclusion and exclusion criteria were carefully developed to ensure enough of a focus to pick up studies relevant to the chosen topic, while being wide enough to ensure no relevant studies were missed. Reference lists of included papers were also checked to ensure no papers had been missed.
Phase 3: Reading the studies	Included articles were closely read several times with initial notes being made of recurring themes across the studies.
Phase 4: Determining how the studies are related	Lists of key metaphors, phrases and ideas from each study were compiled using NVivo and tabulated so that they could be compared to each other. There were no contradictions found between the papers, and they were deemed to be suitable for reciprocal translation. A line of argument that was new also began to emerge. An example of this process can be seen in Appendix D.
Phase 5: Translating the studies into one another	Studies were closely cross-referenced with the researcher considering the relationships between the studies. In line with the method suggested by Britten et al. (2002), the first order and second order constructs identified in each paper was compiled into a spreadsheet. At every step of the process the concepts from each paper were compared to those of other

	papers to determine if there was enough similarity to allow reciprocal translation. An example of this process can be seen in Appendix E.
Phase 6: Synthesizing translations	Once second order themes had been identified from each paper, and recurring themes had been translated into each other across the different papers, new third order interpretations were translated in superordinate themes and sub themes in line with the Britten et al. (2002), approach. An example of how these new third order constructs relate to the second order constructs can be seen in Table 6 and Appendix F.
Phase 7: Expressing the Synthesis	The synthesis has been expressed through the accompanying narrative.

Results

Quality Appraisal

All papers were given a quality grade for likelihood of methodological flaws of either ‘low’ (n = 4) or ‘medium’ (n = 8) on the CASP rating system indicating a low-medium likelihood of methodological flaws (see table 6). An example of this can be found in Appendix C. No studies were excluded based on their rating, and no papers received a rating indicative of having a high likelihood of having significant methodological flaws. An independent researcher separately evaluated 50% of the full-text articles with an initial 62% agreement. Following discussions regarding those papers on which agreement was not initially reached 92% agreement was achieved.

Table 5

Summary of the main characteristics of all studies included for synthesis.

Study	Authors	Title	Aim	Participants	Method of Data Collection	Method of Analysis	Key themes
1	Ali et al. (2023)	'The key to this is not so much the technology. It's the individual who is using the technology': Perspectives on telehealth delivery for autistic adults during the COVID-19 pandemic	To describe the telehealth experiences of UK-based autistic adults given the shift to widespread adoption of telehealth methods due to the COVID-19 pandemic.	UK based autistic adults aged 26-67 (n=11), family members or carers (n=7), healthcare professionals (n=6)	In-depth interviews	Thematic Analysis	1. Technology aids communication and access – except when it doesn't 2. Inflexibility
2	Au-Yeung et al. (2019)	Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults	To address the following research questions: (1) Are autistic individuals more likely to report receiving mental health diagnosis(es) and if so, what kind of diagnoses were they more likely to receive? (2) Are autistic individuals more likely to disagree with these diagnoses? and (3) What were the reasons behind any disagreement?	Three participant groups including autistic (n = 208), non-autistic and possibly autistic (n = 71).	Survey with both closed and open ended questions.	Thematic Analysis	1. 'Problems with Mental Health Diagnosis' 2. 'Clinical Barriers'
3	Babb et al. (2021)	'It's not that they don't want to access the support . . . it's the impact of the autism': The experience of eating disorder services from the perspective of autistic women, parents and healthcare professionals.	To understand the experience of the autistic women accessing eating disorder services in order to service provision for autistic women.	Three participant groups from across the UK: autistic women with experience of AN, parents of autistic women with AN and healthcare professionals. Autistic women were 18+ and there were 15.	Interviews	Thematic Analysis	1. Misunderstanding autism and autistic traits 2. One treatment does not fit all 3. Improving accessibility and engagement within services

4	Camm-Crosbie et al. (2019)	'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality	To explore autistic adults' experiences of treatment and support for mental health problems, self-injury and suicidality from their own perspective, using a participatory approach.	Autistic adults living in the UK and registered with the Cambridge Autism Research Database. N = 122 females N = 77 male N = 1 unreported	Online survey with open-ended questions	Thematic Analysis	1. 'People like me don't get support' 2. Lack of understanding and knowledge 3. Wellbeing
5	Crane et al. (2018)	Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals	To examine autism diagnostic experiences in the United Kingdom (UK) with a particular focus on accessing a diagnostic service, the diagnostic process; and post-diagnostic support.	10 diagnosed autistic adults aged 29-59 years old (42.89 mean age.) N = 6 females N = 4 males	Semi-structured interviews	Thematic analysis	1. The process of understanding and accepting autism 2. Barriers to satisfaction with the diagnostic process 3. Inadequate post-diagnostic support provision
6	Griffith et al. (2012)	I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood	To explore how individuals in middle adulthood with Asperger syndrome perceive its effects on their lives, their previous experiences of support, and their current support needs.	11 diagnosed autistic adults over 35 years old (46.45 mean age) with no ID. N = 7 males N= 4 females	Semi-structured interviews	IPA	1. 'Some days I do struggle" - living with Aspergers 2. They don't expect you to have problems with things' - employment issues 3. 'I just fall through the gaps between ' - experiences with mainstream support 4. 'Raising awareness' - Future steps towards supporting people with Asperger syndrome

7	Harmens et al. (2022)	Autistic women's diagnostic experiences: Interactions with identity and impacts on well-being	To investigate the relationships between diagnosis, well-being and identify in autistic women, by considering these issues at different stages of diagnosis.	N = 24 Autistic women aged 18+ at various stages of diagnosis in the UK	Semi-structured interviews following on from wider survey.	Thematic Analysis	1. Don't forget I'm autistic 2. What now? 3. Having to be the professional 4. No one saw me.
8	Leedham et al. (2020)	'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood	To better understand the lived experience of autistic females who receive a diagnosis in middle to late adulthood.	N = 11 women diagnosed autistic at or after the age of 40 recruited through NHS diagnostic service	Interviews	Thematic Analysis	1. A hidden condition 2. The process of acceptance 3. Post diagnostic impact of others 4. A new identity on the autism spectrum
9	Mason et al. (2021)	How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians	To design interventions to improve autistic people's access to healthcare and to simultaneously explore healthcare experiences from the perspective of both autistic people and clinicians, and investigate similarities and differences in opinions.	Self-reported diagnosed Autistic adults age range 29-65 years old N = 6 males N = 5 females	3 x focus groups	Framework Analysis	1. Cognitive factors 2. Patient characteristics 3. Healthcare professionals perceived knowledge 4. Healthcare provision 5. Adjustments to healthcare 6. Autism diagnosis
10	McMillion et al. (2021)	Dental experiences of a group of autistic adults based in the United Kingdom	To explore the dental experiences of UK-based autistic adults and whether autistic adults report more negative dental experiences (e.g., sensory discomfort, miscommunications), whether they had autism-specific challenges in accessing dental care, what worked well and what autistic adults would like to improve about their dental experiences in contrast to non-autistic individuals.	Autistic (n = 37) and non-autistic adults 18+ accessing the dentists in the UK. N = 27 female N = 9 male N = 1 other.	Survey including open ended questions.	Thematic Analysis	1. Interaction with dental practitioners 2. Preparedness 3. Challenging Sensory environment 4. Anxiety 5. Pain

11	Parmar et al. (2022)	Autism-friendly eyecare: Developing recommendations for service providers based on the experiences of autistic adults	To provide a detailed description of the barriers and facilitators to accessing optometry services for autistic adults without learning disabilities so that recommendations could be created for optometric service providers on how to provide 'autism-friendly' services	Diagnosed Autistic adults with no LD, 18+, aged 25-67 (mean age 47.1) N = 6 female N = 12 male	Focus Group	Thematic Analysis	1. Practice operation 2. Eye examination-specific considerations 3. Patient-practitioner relationship. 4. Preparing the patient for their visit
12	Punshon et al. (2019)	The 'not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood	To identify: (1) what are the experiences of adults with Asperger syndrome relating to their diagnosis; (2) whether these experiences can be accounted for using stage and/or cognitive models of adjustment to diagnosis; and (3) how services might help individuals negotiate the diagnostic process and adjust to their diagnosis.	N = 10 users of local service for adults with Aspergers, 18+	Semi-structured interviews	IPA	1. Negative life experiences 2. Experiences of services (pre-diagnosis) 3. Beliefs about symptoms of Asperger syndrome 4. Identity formation 5. Effects of diagnosis on beliefs 6. Effect of societal views of Asperger syndrome.

Table 6

Scoring of the Critical Appraisals Skills Programme (CASP) for individual articles

CASP Criteria	Article											
	Ali et al. (2022)	Au-Yeung et al. (2019)	Babb et al. (2021)	Camm-Crosbie et al. (2019)	Crane et al. (2018)	Griffith et al. (2012)	Harmens et al. (2022)	Leedham et al. (2020)	Mason et al. (2021)	McMillion et al. (2021)	Parmar et al. (2022)	Punshon et al. (2019)
1. Was there a clear statement of the aims of the research?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
2. Is a qualitative methodology appropriate?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?	✓
3. Was the research design appropriate to address the aims of the research?	✓	✓	✓	✓	✓	✓	✓	✓	✓	?	?	✓
4. Was the recruitment strategy appropriate to the aims of the research?	✓	✓	✓	✓	?	✓	✓	✓	?	✓	✓	✓
5. Was the data collected in a way that addressed the research issue?	✗	✓	✓	?	✓	✓	✓	✓	✓	?	✓	✓
6. Has the relationship between researcher and participants been adequately considered?	✓	✗	✓	✓	✗	✗	?	✓	✗	✗	?	✗
7. Have ethical issues been taken into consideration?	?	✓	?	✓	✓	?	✓	✓	✓	✓	✓	✓

8. Was the data analysis sufficiently rigorous?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
9. Is there a clear statement of findings?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
10. a. Contributes to existing knowledge	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
b. Identifies new areas for research	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗
c. Discusses how findings can be transferred to other populations	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗
Score	7.5	8	8.5	9	7.5	7.5	8.5	9	7.5	7	7.5	8

Summary of Themes

This meta-ethnography identified three superordinate themes relating to the experiences of autistic adults in the UK when accessing healthcare: Professionals' lack of knowledge can be damaging; need to reduce processing demands; adaptations to improve engagement. Each superordinate theme contained further subthemes which are represented in Table 7.

Table 7
Summary of Third and Second Order Constructs

Super-ordinate Third Order Construct	Sub-ordinate Third Order Construct	Second Order Construct(s)	Papers Endorsing Construct
Professionals lack of Knowledge can be Damaging *Many papers talk about the experience of professionals having a lack of autism knowledge and understanding. This can be damaging due to placing additional pressure on the patient to be the expert, as well as increasing the risk of misdiagnosis and impacting the therapeutic relationship through breaking down patient trust in professionals.*	Misunderstanding leading to misdiagnosis and inadequate support	• Autism not recognised • Misdiagnosed with other conditions • Spectrum nature of Autism causes misunderstanding of needs • Failed interventions	2, 3, 4, 5, 6, 7, 8, 9, 12
	Impact on Therapeutic Relationship	• Feeling blamed for difficulties • Feeling dismissed and unsupported • Loss of trust	1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12
	Pressure to be the expert in the room	• Tension on whether the individual or the professional is 'the expert' • Lack of professional guidance can lead to self-doubt	4, 5, 6, 7, 8
Need to Reduce Processing Demands *Many papers reference communication difficulties and sensory differences as separate issues, but often these can impact on each other and ultimately there is a need to understand that*	Communication Differences	• Alexithymia makes explaining symptoms difficult • How information is presented is important • Too much verbal communication can be overwhelming • Anxiety negatively impacts ability to communicate	1, 2, 3, 4, 7, 9, 10, 11, 12

autistic people process things differently to non-autistic people.	Sensory Processing Differences	• Clinical environments should be appropriate • Sensory reactivity can cause distress	1, 3, 5, 9, 10, 11
Adaptations to improve engagement *Papers talked about autistic people disengaging from services and struggling with accessing appointments. They also stress the importance of autistic adults needing consistency and predictability. Making certain adaptations to services can help increase accessibility and engagement.*	Accessibility difficulties	• Support needs to be pitched at the right level • Difficulties accessing appointments • Diagnostic pathways are unclear	1, 3, 4, 5, 7, 9, 10, 11, 12
	Need for Consistency and Predictability	• Autistic adults need to know what to expect from an appointment • Consistency is important	3, 4, 7, 9, 10, 11

Theme 1: Professionals' lack of Knowledge can be Damaging

All papers reported that autistic adults' experienced healthcare professionals as at times not having a good understanding of autism. This was often associated with experience of distress linked to a reported sense of professional misunderstandings of misdiagnosis, which negatively impacted on the relationship.

Misunderstanding leading to misdiagnosis and inadequate support

Participants in some studies reported their difficulties were not appropriately attributed to or recognised as autistic characteristics, and were instead misunderstood as mental health symptoms (Griffith et al., 2012). An example of this misattribution of autism characteristics was found in eating disorder services, where they were seen as being driven by the eating disorder, rather than being understood as sensory sensitivities:

> When I was in hospital, I kept getting told off for walking on tip toes and for fidgeting a lot…they thought I was doing these things to burn more calories, except I'd been doing them for as long as I could remember. (Babb et al., 2021)

Similarly, communication difficulties were interpreted as a reluctance to engage in treatment and in some cases as 'rudeness.' In more severe cases a lack of eye contact was reported as being understood as an indication of psychosis rather than as their social communication style. (Au-Yeung et al., 2019). Several studies discussed this issue having arisen in the context of late diagnosis, which in itself is problematic:

> I had a formal diagnosis of bipolar (II) condition for around 17 years. I actually satisfy the DSM criteria for this, but have only [ever] been hypomanic once and that was antidepressant induced…once my autism had been diagnosed, I was able to get a consultant psychiatrist to say that she didn't think I'd ever had bipolar and it has been revoked as a current diagnosis. (Au-Yeung et al., 2019)

Such delays in receiving the correct diagnosis were reported as contributing to autistic adults sense of blame and feeling misunderstood (Leedham et al., 2020; Punshon et al., 2009). Another issue evident in the extant literature and linked to poor understanding, was a sense of professionals underestimating the level of need:

> I went to my GP, and I didn't really know what to say, but I just knew something wasn't OK, and something needed to stop, and . . . he started off saying, because I go to work every day, that means everything's fine… (Harmens et al., 2022)

Participants also reported encountering outdated and stereotyped understandings of autism which again impacted on the professionals understanding and perception of what support they needed and in some cases served as a barrier to autism diagnosis (Babb et al., 2021; Crane et al., 2018; Griffiths et al., 2019; Mason et al., 2021).

> When I went to my GP I said, 'Could you refer me to somebody, because I'd like to look into getting a diagnosis for Asperger syndrome.' He turned round, and this is really important, he said, 'Asperger's, isn't that something that kids get?' (Griffith et al., 2012)

The lack of understanding of the spectrum nature of the condition amongst healthcare professionals, is reported in the literature reviewed as either individuals being viewed as not being autistic, or being labelled as 'high functioning' and therefore requiring less or no support (Camm-Crosbie et al., 2019):

> I'm on the high-functioning end [of the autistic spectrum] and so I don't fit mental health, I don't fit learning disability. I just fall through the gaps between departments, whether it's in the health service or social services. (Griffith et al., 2012)

Such misconceptions and misattribution resulting from a lack of knowledge about autism can be damaging, not only in the impact on wellbeing and sense of self, but in the treatment that is then prescribed or/and provided. In some cases, misdiagnosis was reported as having led to inappropriate use of medication:

> I was given anti-psychotics for my behaviour … they think because [I don't] look at them and [I] am nervous of talking then [I] am 'guarded' or have 'flat affect' (Au-Yeung et al., 2019)

This was also found in the literature to be the case with regards to psychological therapy:

> The support I have received I feel isn't suitable enough. No ordinary counsellor can understand autism…If there was someone who both understood the condition and me, I feel progress would be made. (Camm-Crosbie et al., 2019)

Impact on Therapeutic Relationship

An important element of seeking support from healthcare services is the therapeutic relationship developed between patient and professional, and the experience of feeling misunderstood and even blamed can have a detrimental impact on this relationship (Punshon et al., 2009). The importance of feeling emotionally supported when discussing difficult past histories and traumas was evident in the studies, highlighting the importance of professionals understanding how to assess:

> "I found it quite traumatic…they [professionals] are dredging up old stuff, things from the past…then you're just left to work all that out for yourself." (Crane et al., 2018)

In addition to not feeling listened to, some participants talked about feelings of stress due to feeling 'criticised' and labelled as 'resistant' or 'naughty' (Babb et al., 2021) or being deemed to be ‘making excuses’ (McMillion et al., 2021). This increase in stress due to a lack of professional understanding can also result in a loss of trust in the professional and in the wider service (Ali et al., 2023; Parmar et al., 2022).

> There is a fear of doctors because doctors are trouble. . . .Because they’ll often have declared you to be bad, or you’ve got a problem or whatever…it’s not unlike the way it used to be, I think, for gay people and doctors. It was like: don’t go near doctors. Because you can’t trust them. (Ali et al., 2023)

The importance of the relationship between the autistic person and the professional was highlighted in some studies (e.g. Camm-Crosbie et al., 2019; Mason et al., 2021) from a positive stance, and there were a small number of accounts where study participants reported having had an experience of being understood, listened to, and emotionally supported:

> I went, and I sat there, and I just cried. For an hour. That’s all I did. Sob . . . He didn’t say anything, even for the hour . . . He then asked what would help me. What did I want?. . . As I was leaving he put an arm around me and said ‘we’ll do this together’. That was worth more than anything he could have given me. (Mason et al., 2021)

Pressure to be the expert in the room

Several studies contained accounts of participants feeling they had to bridge the gaps in healthcare professionals’ knowledge and be the experts in the room. It was highlighted within the extant literature that autistic adults should be considered to be the experts about their own condition, and their viewpoints which are grounded in lived experience should not be side-lined in favour of academic opinion (Griffith et al., 2012).

Given the established importance of the therapeutic relationship, this pressure to be the expert presents a nuanced tension that requires careful negotiation between the healthcare professional and the autistic person.

> it feels very much like the onus is on you as an individual to make the assessment happen, rather than a medical practitioner saying 'this is something that we should see' (Harmens et al., 2022).

This necessity to be the experts educating others about autism, was found to have a negative impact on well-being and identity, due to a lack of validation from those they turned to for support and participants felt it should not be their responsibility (Camm-Crosbie et al., 2019; Harmens et al., 2022).

> some of them have asked to borrow books from me about autism or asked me to teach them about it and I feel that shouldn't be down to me (Camm-Crosbie et al., 2019)

This patient-professional tension regarding who is the expert in the room, was also referenced as causing autistic adults to start to doubt themselves and their own understanding of their differences due to the imbalance of power:

> … got to a point where I was almost convinced that they wanted to be right and I'd actually buried some deep trauma and I had no memory of it and I started questioning the whole – like everything (Leedham et al., 2020)

This power imbalance and the harm that could be caused due to professional's lack of autism knowledge and understanding can place a great deal of stress and pressure on the autistic individual.

Theme 2: Need to Reduce Processing Demands

It was evident in the studies reviewed that many participants had experienced services as placing too many processing demands upon them, both in the form of communicative information and sensory information presented.

Communication Differences

Many of the studies identified communication differences as a key theme in the experience of autistic adults when interacting with services. Participants talked about difficulties with the way professionals interacted with them (Au-Yeung et al., 2019) which impacted on their ability to process and understand the information with one participant advising they prefer it if professionals 'don't ask rapid fire questions' (McMillion et al., 2021) and reporting that 'if they speak quickly, they might as well not bother' (Parmar et al., 2022).

> I have to say to them, slow down a bit. Or I'll say can you show me that again?…Sometimes you've just got to take control of the situation." (Parmar et al., 2022)

Participants in several studies reported particularly struggling with answering subjective or vague questions due to difficulties with tuning into the subtleties of feelings in their body (Mason et al., 2021) and with alexithymia (Camm-Crosbie et al., 2019; Punshon et al., 2009) meaning they didn’t have the language to express their emotions,

> opticians don't tell you that. They just say ‘can you see a difference’ but they don't tell you that you are supposed to be aiming for a point when there is no difference…it is very stressful for the autistic person because you are looking for a difference that isn't there…(Parmar et al., 2022).

Studies reported on the negative impact this had resulting on many feeling ‘mentally tired with all the questions’ and feeling as though they were getting it wrong and ‘giving them the wrong answer’ and thereby making things worse (Parmar et al., 2022). These difficulties did not only relate to communication with professionals, but also to communicating in treatment groups with other patients.

> I’m largely silent in any sort of group situation because I don’t know what’s expected of me. I’m worried of saying the wrong thing or I worry about misinterpreting people. (Babb et al., 2021)

In several of the studies participants expressed a need for the language used in communication with them to be concrete and explicit so that they knew what to expect and to prevent misunderstandings due to literal interpretations (Mason et al., 2021; Parmar et al., 2022; Punshon et al., 2009).

> You want to tell them things, but your mind empties, you can't find the right words…I know he [the clinician] doesn't want the literal answer…'What brings you here today?', I know he doesn't want to hear 'the bus' (Mason et al., 2021).

Many of the studies also discussed the potential use of alternative methods of communication to aid understanding such as the use of visual aids, written information or video guides provided prior to the appointment. For example, Parmar et al. (2022) reported that some of their participants expressed preferring email communication because it meant that they had communication trails they could utilise. In another study some participants described video calls as being preferable to phone calls (Harmens et al., 2022).

> Video chatting like this, I find okay, but like on the phone I really struggled with and it kind of felt like because you couldn't get, see anyone face to face, it was like I then couldn't even talk on the phone because I, that was like a barrier for me. (Harmens et al., 2022)

In addition to these communication differences, autistic adults talked about the impact anxiety could have on the ability to communicate effectively. This may be due to building anticipation of the appointment beforehand or could be triggered by sensory sensitivities in the environment, or feeling rushed in the appointment (McMillion et al., 2021).

> Well, anything that overloads my head, my brain just shuts down then … I have to take my wife everywhere and she has to tell them to go away (Parmar et al., 2022)

If too many questions are asked, or if questions are asked that are unexpected and which the individual does not have ready pre-prepared answers for, it can be too much to process and can become overwhelming (Mason et al., 2021). One participant explained that ‘if unexpected questions arise, it throws my head in a tailspin’ while another stated ‘I am less likely to complain...as I am too anxious to say’ (McMillion et al., 2021).

> I had communication issues with each therapist because they expected me to be neurotypical, so I would take things too literally and they thought it was a defence mechanism (Camm-Crosbie et al., 2019)

One of the recurring issues that participants commented on impacting their ability to effectively communicate, was experiencing sensory overload in the healthcare environments due to sensory processing differences.

Sensory Processing Differences

Negative experiences of overwhelming environments was reported to contribute to patient dissatisfaction with healthcare services (Babb et al., 2021; Crane et al., 2018; McMillion et al., 2021). For many participants this experience of sensory discomfort began from the waiting area which was often experienced as bright, noisy and busy (Mason et al., 2021; McMillion et al., 2021).

Specific sensory difficulties highlighted by participants across the studies usually included sensitivities to bright lights and too much noise. One participant shared that ‘the light, my goodness, it was too much’ (Crane et al., 2018) while another explained that ‘bright lights cause migraines’ (McMillion et al., 2021). Often these statements are made in relation to the bright lights of the hospital environment, but participants also referred to the difficulties that bright lights created during medical assessments. One participant described how a bright pen torch ‘made my eyes hurt quite a bit’ (Parmar et al., 2022) while another referred to difficulties with lights on diagnostic machines.

> I didn't like the ones where you've got bright lights in your eyes like the flash and this machine here [slit lamp]. I sort of had to tense myself to cope with it…it was at the edges of what I could tolerate. (Parmar et al., 2022)

In addition to struggling with bright lights, participants also talked about negative experiences with noise in medical settings which can be ‘intense’ and ‘upsetting’ and how it is ‘hard to block them out even with headphones or ear plugs” (McMillion et al., 2021). Often it was not a single loud noise that was problematic, but a multitude of noises.

Touch was also a particular issue for many participants, especially when examinations involved the clinician needing to get physically close. Participants expressed it is ‘beyond uncomfortable’ (Parmar et al., 2022) and ‘unpleasant being touched by a stranger’ (McMillion et al., 2021). The proximity of medical equipment was also identified as being problematic and ‘quite intrusive,’ particularly in the setting of optometry (Parmar et al., 2022).

Participants also experienced difficulties with the smell of environments including not only medical smells, but also strong perfumes worn by practitioners (Parmar et al., 2022). Others raised the issue they may not process various sensory experiences in the same way as non-autistic patients, and therefore may not have the same experience of pain.

> I told the dentist my body resists anaesthetic. I was told...go on with the procedure. I...was in terrible pain. (Mason et al., 2021).

The use of telehealth was noted in one study as a way to reduce the anxiety of the environment, although with the caveat that professionals may not get the right impression of the support needs of the individual.

> It caused less anxiety because you're in your own home and you can just relax, without all the environments being so chaotic and it being in a new place. But then, sometimes, it's hard because they don't really see the true you. (Ali et al., 2023).

Theme 3: Adaptations to Improve Engagement

The third superordinate theme 'adaptations to improve engagement' looks at how autistic adults' experiences of accessing healthcare can inform adaptations to services in order to increase accessibility and engagement.

Accessibility Difficulties

Difficulties with accessing services was a theme that came up in several studies beginning as early in the process as booking appointments. Many shared this was particularly difficult to do if a phone call was required, preferring 'other ways to make appointments than phoning' (McMillion et al., 2021) due to feeling 'really uncomfortable on the phone' (Parmar et al., 2022). Communicating on the phone was highlighted as particularly problematic for some because 'socially, I can use some visual cues, and the phone takes that away' as well as experiencing 'audio processing disorder. My memory around speech is near zero. I usually lip read' (Ali et al., 2023). For some this difficulty with talking to healthcare staff on the phone was a barrier to being able to book appointments because 'I don't phone people I don't know and I can't' (Parmar et al., 2022). These difficulties with talking to healthcare staff on the phone was not only a barrier to accessing healthcare services, but had a detrimental impact on the individuals wellbeing due to the associated anxiety (Harmens et al., 2022). For some there was a preference to book appointments in person rather than on the phone.

> I write down what days I'm available, what times I'm available, and I say, I need an eye appointment, there's the information, fit me in somewhere around that. (Parmar et al., 2022)

The stress that built up prior to attending appointments was described by many as another barrier and often resulted in appointments being cancelled, avoided until they were unavoidable or until a number of problems had accumulated (Mason et al., 2021).

> I feel very anxious about going. . . I often cancel appointments or put off going for as long as possible' (McMillion et al., 2021)

Online booking systems were highly praised as 'absolutely brilliant' and some participants found it increased their likelihood of accessing healthcare services (Ali et al., 2023; Parmar et al., 2022).

> if I can book online then I don't avoid making appointments for four months' (Parmar et al., 2022)

One study highlighted how technology can be used to aid accessibility and engagement with healthcare. Although not everyone is able to afford or access the technology to attend virtual appointments, for others having the option not only helped with the logistics of attending, but also resulted in the least disruption to the usual routine of the day.

> if I was at work and I needed an appointment, I wouldn’t have my car and then I’d have to sort out or change my routine, and, as an autistic person, it’s a huge change to my routine that I don’t like, I don’t want to deal with. It kind of removes that stress. (Ali et al., 2023)

Lack of funding in NHS pathways and services was identified as a barrier to being able to access the right support (Camm-Crosbie et al., 2019). For some there was a lack of available treatment in their local area which was attributed to a refusal ‘to fund anything’ (Crane et al., 2018) which limited access to those needing to travel further to access support, but were unable to (Camm-Crosbie et al., 2019). Suggestions were made in several studies that thinking about the accessibility of an appointment is important for autistic adults to improve engagement (Babb et al., 2021; Mason et al., 2021). However, it was commented that ‘there's never any mention of accessibility… They don't ask if you have any needs or anything’ (Parmar et al., 2022) and that accessibility could be improved by listening to the individual needs of the patient. Such adaptations to accessibility which granted autonomy were described as being empowering (Camm-Crosbie et al., 2019).

Consistency and Predictability

Another element discussed in the studies regarding adaptations that could be made to improve autistic adults engagement was to ensure consistency and predictability as changes could be ‘unsettling’ (Parmar et al., 2022). Many autistic adults talked about the importance of consistency or continuity of care to them (Mason et al., 2021; McMillion et al., 2021), particularly in relation to consistency of the professionals they saw because it allowed them to build rapport with and trust in the professional.

> Yeah, you've got to see the same person. Whether they're right or wrong, you've got to see the same person, otherwise you're just getting pushed round the system. (Mason et al., 2021)

In addition to needing consistency, studies highlighted how participants favoured predictability and being informed about both the environments they would be entering and the procedures they would be involved in ahead of their appointments. For many this was a really important factor in reducing anxiety and helping them to access services. When participants did not receive information prior to their appointment it made them feel anxious.

> now I've got the information, I'm not anxious about it anymore…And it's a tiny little adjustment from their end, but it lowers my anxiety on a day-to-day basis." (Parmar et al., 2022)

The way this information was provided was important. For some participants the preference was to ensure that 'everything is in writing' (McMillion et al., 2021) while others preferred it to be presented visually in the form of pictures or videos so that they 'didn't have to guess what the tests or equipment may be like' (Parmar et al., 2022).

> it was just like 'Oh, they really understand my needs' because they had photos and biographies of everyone you were likely to meet, they had photos of all of their

> consulting rooms, a map, a photo of the outside of the building, so it was as if they anticipated all of the things that were likely to worry me (Harmens et al., 2022)

Others praised the experience of being physically introduced to the spaces and procedures prior to their appointments.

> I was freaked about the idea of a general anaesthetic. They showed me the room in advance so I'd know where I'd be, they said other people could be there . . . [my mother] was there . . . I was shocked at how aware, she [the surgeon] was very aware. (Mason et al., 2021)

The impact that these adaptations and pre-emptive planning of supporting autistic adults to be informed of their appointments in advance was experienced as extremely important for reducing anxiety and thereby supporting engagement (Babb et al., 2021; McMillion et al., 2021; Parmar et al., 2022).

> I never would have thought, prior to finding out about my autism and everything, that this sort of stuff would be helpful for me…I'm surprised much how less anxious I feel…it just takes a little bit of the load off (Parmar et al., 2022)

Discussion

This meta-ethnography aimed to synthesise existing data regarding autistic adults' experiences of healthcare in the UK and look to generate new insights into this experience. Previous reviews have focused on global experiences, whilst the intention here is to specifically examine experience within the UK healthcare system, so as to be able to make recommendations for use in this context. The meta-ethnography revealed three superordinate themes: 'professionals' lack of knowledge can be damaging,' 'need to reduce processing demands' and 'adaptations to promote engagement.'

The first theme 'professionals' lack of knowledge can be damaging' contained three subthemes, each looking at a different way in which a lack of knowledge amongst healthcare professionals can be experienced as damaging to autistic adults. The theme of healthcare professionals lacking knowledge is one that has often been raised by autistic adults in previous research, but through this meta-ethnography what came across was the wide-reaching damage that can be done by professionals not having an adequate understanding of autism when treating autistic adults. This damage can arise through the misdiagnosis that can result from misunderstanding difficulties, the damage this can ultimately do to the therapeutic relationship, and the resulting pressure it places on the autistic adults themselves to be the expert in the room.

The data in these studies related to experiences of encountering a lack of autism knowledge from healthcare professionals resulting in autistic characteristics being misattributed or misunderstood as characteristics of alternative conditions, which ultimately led to the wrong diagnoses being given (Au-Yeung et al., 2019; Babb et al., 2021; Griffith et al., 2012) and an autism diagnosis being delayed (Griffith et al., 2012; Leedham et al., 2020; Mason et al., 2021; Punshon et al., 2009). Participants also reported encountering misconceptions regarding the spectrum nature of the condition, which meant that being classed as ‘high functioning’ and therefore able to cope resulted in inadequate support being offered (Camm-Crosbie et al., 2019; Griffith et al., 2012; Harmens et al., 2022). When treatment or support was offered, a lack of understanding of autism also resulted in what was offered being inappropriate for autistic individuals and potentially doing more damage than good (Babb et al., 2021; Camm-Crosbie et al., 2019; Crane et al., 2018; McMillion et al., 2021).

Autistic adults may find themselves being asked to engage in therapy that is not adapted for or suited to autistic people, which may not address the route issues, and which may ultimately be damaging to the individual. One example of this is that Cognitive Behavioural Therapy (CBT) is often the recommended treatment in the NICE guidelines for a variety of mental health conditions, but it’s effectiveness where there is a co-occurring autism diagnosis has been found to be significantly reduced (Murray et al., 2015). These findings are in line with previous findings that a lack of knowledge amongst healthcare professionals can lead to misdiagnosis, especially where autism and mental health was confused, delayed autism diagnosis and inappropriate treatment which can ultimately have a negative impact on the individuals wellbeing and serve as a barrier to receiving the right support (Bradshaw et al., 2019; Brede et al., 2022; R. Wilson et al., 2023; Yau et al., 2023).

The second subtheme relates to the therapeutic relationship between the professional and the autistic adult, and how a lack of autism knowledge and understanding on the part of the professional can be damaging to the relationship which can ultimately impact treatment. A number of studies reported participants not only experiencing a sense of being misunderstood, but of being disrespected, disbelieved and criticised (Au-Yeung et al., 2019; Babb et al., 2021; Camm-Crosbie et al., 2019; Harmens et al., 2022; McMillion et al., 2021). The impact of this lack of validation was acknowledged to impact on the individuals trust in healthcare professionals (Ali et al., 2023; Punshon et al., 2009). While some participants felt ultimately unsupported in this relationship (Crane et al., 2018; Punshon et al., 2009) the importance of the relationship was also evident in reports of positive experiences of successful encounters with healthcare professionals (Camm-Crosbie et al., 2019; Mason et al., 2021; Parmar et al., 2022). The idea that a lack of understanding amongst healthcare professionals can result is a loss of trust and motivation to engage with services has been highlighted in previous research (Brede et al., 2022; G. T. Wilson et al., 1997; Yau et al., 2023) and highlights the importance of co-production with autistic adults of appropriate training.

Such co-production would begin to address the perceived pressure on autistic adults to be the experts in the room, to educate professionals on the way systems worked, and hold the responsibility of proving themselves (Camm-Crosbie et al., 2019; Crane et al., 2018; Griffith et al., 2012; Harmens et al., 2022; Leedham et al., 2020). Participants expressed feeling it was not their place to fill in the gaps of inadequate training, and the additional stress this placed on them was damaging to both their mental health and their ability to access appropriate healthcare pathways. What this paper adds to the existing literature is that the lack of knowledge and understanding of autism amongst healthcare professionals, which has already been acknowledged as an issue, is not only resulting in poorer care, but is ultimately causing damage to the autistic adults seeking help.

The second superordinate theme ‘need to reduce processing demands’ includes the sub themes of ‘communication differences’ and ‘sensory processing differences’ which are two themes that have consistently come up in previous research. In regards to the first subtheme ‘communication differences’ participants talked about difficulties in processing information during verbal communication (Au-Yeung et al., 2019; McMillion et al., 2021; Parmar et al., 2022) which was exacerbated by feelings of anxiety (Camm-Crosbie et al., 2019; Mason et al., 2021; McMillion et al., 2021; Parmar et al., 2022). Participants reported finding it difficult to answer subjective questions and being aware that their literal interpretations could cause difficulties with communication (Camm-Crosbie et al., 2019; Mason et al., 2021; Parmar et al., 2022; Punshon et al., 2009). The use of alternative means of communication including video, phone calls, and email was beneficial for some, but not for others, emphasising the need for a bespoke approach (Ali et al., 2023; Harmens et al., 2022; Parmar et al., 2022). These findings are in line with previous papers which have identified that autistic adults can struggle with misunderstandings when communicating, have a preference for written communication and find it difficult to express emotions and answer open questions, which can be exacerbated due to feelings of stress and being overwhelmed (Bradshaw et al., 2019; Brede et al., 2022; Mason et al., 2019; Walsh et al., 2020).

Sensory processing differences were identified in several papers as one of the key ways in which participants could become overwhelmed, as is represented in the second subtheme under 'need to reduce processing demands.' These findings are in line with those found in previous papers where these sensory differences were noted to act as barriers to accessing healthcare, to impact on communication and to be misinterpreted as symptoms of mental health difficulties rather than as autistic characteristics (Bradshaw et al., 2019; Brede et al., 2022; Mason et al., 2019; Walsh et al., 2020). This paper adds to the existing literature by considering more directly the combined impact that sensory processing differences and communication differences can have on each other as each increases levels of anxiety which can then reduce ability to cope with either. Taking into consideration the number of demands placed on autistic people' to process different input throughout a healthcare visit, and keeping this to a minimum may be an important way to ensure they do not become overwhelmed.

The final superordinate theme 'adaptations to improve engagement' examined how autistic experiences can inform adaptations to improve accessibility and engagement with services. Difficulties with accessibility came up across several studies beginning with difficulties with appointment booking systems and anxiety regarding attending appointments (Ali et al., 2023; Babb et al., 2021; Harmens et al., 2022; Mason et al., 2021; McMillion et al., 2021; Parmar et al., 2022). Participants also reported assessments and treatments being aimed at children or autistic adults with intellectual disabilities (Camm-Crosbie et al., 2019; Crane et al., 2018) and difficulties negotiating healthcare pathways (Harmens et al., 2022; Punshon et al., 2009). The need for services for autistic people being 'bespoke' and 'evidence based' has been highlighted in previous articles (Brede et al., 2022) as well as the increased anxiety experienced when accessing services (Bradshaw et al., 2019).

The subtheme 'need for consistency and predictability' demonstrates how simple adaptations can be made to increase engagement through increasing consistency and predictability. The need for 'restricted, repetitive patterns of behaviour, interests or activities' is one of the diagnostic criteria for autism (American Psychiatric Association, 2013) and can result in insistence on sameness and inflexibility. Therefore it is not surprising that participants talked about the importance of consistency of staff and environments when accessing healthcare (Camm-Crosbie et al., 2019; Mason et al., 2021; Parmar et al., 2022) and of being fully informed of environments and procedures prior to appointments to increase predictability (Harmens et al., 2022; Mason et al., 2021; McMillion et al., 2021; Parmar et al., 2022). This need has not widely been reported as an overarching theme in previous papers, but Brede et al, (2022) does refer to the need for predictability.

Clinical Implications

This meta-ethnography has highlighted the wide-reaching damaging impact that a lack of autism knowledge and understanding amongst healthcare professionals can have due to the resulting misdiagnosis, damage to the therapeutic relationship and the pressure it can place on autistic adults. This is in direct opposition to the values of the UK healthcare system which values ‘improving lives’ (Department of Education & Department of Health and Social Care, 2021) and to ‘do no harm’ (Welsh Government, 2016). Therefore, in order to prevent damage being done by those in a position to offer support, it is recommended that the provision of adequate training to all healthcare professionals across the board who will come into contact with autistic patients, is prioritised.

In addition to improving healthcare professionals’ ability to understand and recognise autistic characteristics, this training should be co-produced with autistic adults with an aim to improve understandings of autism while also empowering autistic service users to reveal their specific needs. The provision of different methods of communication and alternative quiet waiting areas should also be considered. While these practical recommendations have been made in previous studies, the importance of co-produced training for healthcare professionals in how to manage and understand these as processing differences, and the need to keep overall demands on autistic people to a minimum by reducing the amount of input that needs to be processed has not.

Limitations

There is still limited research completed on UK specific experiences and the studies included covered a range of different settings with a number focused on the diagnostic pathway and mental health services, but with several standing alone as representatives in their field for optometry, dentistry and eating disorder services. Although this may mean results are less transferable to the wider healthcare system, the themes across the papers were common, suggesting the same issues tend to arise regardless of the setting.

The studies included in this meta-ethnography cover the experiences of autistic adults living across the UK, with some specifically focused on parts of England or Wales with little information collected from Northern Ireland or Scotland. It is important to note that NHS

England and NHS Wales have different ways of working and therefore although this analysis offers the first focused look at experiences specific to the UK healthcare system, results may not necessarily be generalisable from one health board to another. This meta-synthesis also cannot offer recommendations on the healthcare experiences of autistic children in the UK, or of those autistic adults' with co-occurring learning disabilities, and this is an area which may benefit from further research.

Another limitation of this study was that inter-rater reliability checking was not introduced until the search had been narrowed down to twenty-five full text articles for searching. Earlier inter-rater reliability checking following the initial searches would have been beneficial.

Recommendations for Future Research

Further research is needed into ways in which the needs of autistic people accessing healthcare could be met in a way that would not only benefit autistic people, but would benefit the non-autistic population as well, addressing the overall ways in which services are set up. It would also be beneficial for research to explore the implementation of potential adaptations to address the common issues faced by autistic adults, and then conduct further qualitative research into how the adaptations are experienced by autistic adults to assess potential benefit before implementation on a wider scale. Any additional research conducted into autistic experiences of accessing healthcare should involve autistic people, not only in the initial co-production of designing the research, but throughout the process as a key member of the research team.

Conclusion

This meta-ethnography highlights difficulties experienced by autistic adults without a co-occurring intellectual disability in the UK when accessing healthcare services. Although previous research has recognised the experience of healthcare professionals lacking knowledge and understanding of autism, along with autistic adults' processing differences impacting on communication and sensory overload, this review offers new insights into the wide-reaching damaging impact that this can have on wellbeing. Such damage occurs in the context of misdiagnosis, inadequate or inappropriate treatment being delivered, overwhelming environments and inaccessible systems. This can be addressed through more comprehensive and widely delivered training which is co-produced with autistic service users, alongside bespoke and person-centred adaptations.

References

Ali, D., O'Brien, S., Hull, L., Kenny, L., & Mandy, W. (2023). 'The key to this is not so much the technology. It's the individual who is using the technology': Perspectives on telehealth delivery for autistic adults during the COVID-19 pandemic. *Autism*, *27*(2), 552–564. https://doi.org/10.1177/13623613221108010

American Psychiatric Association (Ed.). (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed). American Psychiatric Association.

Au-Yeung, S. K., Bradley, L., Robertson, A. E., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism*, *23*(6), 1508–1518. https://doi.org/10.1177/1362361318818167

Babb, C., Brede, J., Jones, C. R. G., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Mandy, W., & Fox, J. R. E. (2021). *'It's not that they don't want to access the support . . . it's the impact of the autism'*: The experience of eating disorder services from the perspective of autistic women, parents and healthcare professionals. *Autism*, *25*(5), 1409–1421. https://doi.org/10.1177/1362361321991257

Bradshaw, P., Pellicano, E., van Driel, M., & Urbanowicz, A. (2019). How Can We Support the Healthcare Needs of Autistic Adults Without Intellectual Disability? *Current Developmental Disorders Reports*, *6*(2), 45–56. https://doi.org/10.1007/s40474-019-00159-9

Brede, J., Cage, E., Trott, J., Palmer, L., Smith, A., Serpell, L., Mandy, W., & Russell, A. (2022). "We Have to Try to Find a Way, a Clinical Bridge" - autistic adults' experience of accessing and receiving support for mental health difficulties: A systematic review and thematic meta-synthesis. *Clinical Psychology Review*, *93*, 102131. https://doi.org/10.1016/j.cpr.2022.102131

Brice, S., Rodgers, J., Ingham, B., Mason, D., Wilson, C., Freeston, M., Le Couteur, A., & Parr, J. R. (2021). The importance and availability of adjustments to improve access for autistic adults who need mental and physical healthcare: Findings from UK surveys. *BMJ Open*, *11*(3), e043336. https://doi.org/10.1136/bmjopen-2020-043336

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta ethnography to synthesise qualitative research: A worked example. *Journal of Health Services Research & Policy*, *7*(4), 209–215.

Buck, T. R., Viskochil, J., Farley, M., Coon, H., McMahon, W. M., Morgan, J., & Bilder, D. A. (2014). Psychiatric Comorbidity and Medication Use in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *44*(12), 3063–3071. https://doi.org/10.1007/s10803-014-2170-2

Caamaño, M., Boada, L., Merchán-Naranjo, J., Moreno, C., Llorente, C., Moreno, D., Arango, C., & Parellada, M. (2013). Psychopathology in Children and Adolescents with ASD Without Mental Retardation. *Journal of Autism and Developmental Disorders*, *43*(10), 2442–2449. https://doi.org/10.1007/s10803-013-1792-0

Calleja, S., Islam, F. M. A., Kingsley, J., & McDonald, R. (2020). Healthcare access for autistic adults: A systematic review. *Medicine*, *99*(29), e20899. https://doi.org/10.1097/MD.0000000000020899

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). ‘People like me don’t get support’: Autistic adults’ experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, *23*(6), 1431–1441. https://doi.org/10.1177/1362361318816053

CASP Qualitative Checklist. (2018). *Critical Appraisal Skills Programme*. https://casp-uk.net/casp-tools-checklists/

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. *Journal of Autism and Developmental Disorders*, *48*(11), 3761–3772. https://doi.org/10.1007/s10803-018-3639-1

Crane, L., Lui, L. M., Davies, J., & Pellicano, E. (2021). Autistic parents' views and experiences of talking about autism with their autistic children. *Autism*, *25*(4), 1161–1167. https://doi.org/10.1177/1362361320981317

Department of Education, & Department of Health and Social Care. (2021). *Summary of findings from the government's review of the National Autism Strategy 'Think Autism' call for evidence*. Gov.Uk. https://www.gov.uk/government/consultations/review-of-the-national-autism-strategy-think-autism-call-for-evidence/outcome/summary-of-findings-from-the-governments-review-of-the-national-autism-strategy-think-autism-call-for-evidence

France, E. F., Cunningham, M., Ring, N., Uny, I., Duncan, E. A., Jepson, R. G., Maxwell, M., Roberts, R. J., Turley, R. L., Booth, A., Britten, N., Flemming, K., Gallagher, I., Garside, R., Hannes, K., Lewin, S., Noblit, G. W., Pope, C., Thomas, J., … Noyes, J. (2019). Improving reporting of meta-ethnography: The EMERG e reporting guidance. *Journal of Advanced Nursing*, *75*(5), 1126–1139. https://doi.org/10.1111/jan.13809

Gilmore, D., Krantz, M., Weaver, L., & Hand, B. N. (2022). Healthcare service use patterns among autistic adults: A systematic review with narrative synthesis. *Autism*, *26*(2), 317–331. https://doi.org/10.1177/13623613211060906

Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). ‘I just don’t fit anywhere’: Support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, *16*(5), 532–546. https://doi.org/10.1177/1362361311405223

Griffiths, S., Allison, C., Kenny, R., Holt, R., Smith, P., & Baron-Cohen, S. (2019). The Vulnerability Experiences Quotient (VEQ): A Study of Vulnerability, Mental Health and Life Satisfaction in Autistic Adults. *Autism Research*, *12*(10), 1516–1528. https://doi.org/10.1002/aur.2162

Harmens, M., Sedgewick, F., & Hobson, H. (2022). Autistic women’s diagnostic experiences: Interactions with identity and impacts on well-being. *Women’s Health*, *18*, 174550572211374. https://doi.org/10.1177/17455057221137477

Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of Receiving a Diagnosis of Autism Spectrum Disorder: A Survey of Adults in the United Kingdom. *Journal of Autism and Developmental Disorders*, *44*(12), 3033–3044. https://doi.org/10.1007/s10803-014-2161-3

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

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). ‘I was exhausted trying to figure it out’: The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, *24*(1), 135–146. https://doi.org/10.1177/1362361319853442

Mason, D., Ingham, B., Birtles, H., Michael, C., Scarlett, C., James, I. A., Brown, T., Woodbury-Smith, M., Wilson, C., Finch, T., & Parr, J. R. (2021). How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians. *Autism*, *25*(3), 774–785. https://doi.org/10.1177/1362361321993709

Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., Brown, T., James, I., Scarlett, C., Nicolaidis, C., & Parr, J. R. (2019). A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *Journal of Autism and Developmental Disorders*, *49*(8), 3387–3400. https://doi.org/10.1007/s10803-019-04049-2

McMillion, A., Van Herwegen, J., Johnson, A., Monteiro, J., Cronin, A. J., & Remington, A. (2021). Dental experiences of a group of autistic adults based in the United Kingdom. *Special Care in Dentistry*, *41*(4), 474–488. https://doi.org/10.1111/scd.12583

Murray, K., Jassi, A., Mataix-Cols, D., Barrow, F., & Krebs, G. (2015). Outcomes of cognitive behaviour therapy for obsessive–compulsive disorder in young people with and without autism spectrum disorders: A case controlled study. *Psychiatry Research*, *228*(1), 8–13. https://doi.org/10.1016/j.psychres.2015.03.012

National Institute for Health and Care Excellence. (2021). *Prevalence | Background information | Autism in adults | CKS | NICE*. https://cks.nice.org.uk/topics/autism-in-adults/background-information/prevalence/

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., Kapp, S. K., Weiner, M., & Boisclair, W. C. (2015). “Respect the way I need to communicate with you”: Healthcare experiences of adults on the autism spectrum. *Autism*, *19*(7), 824–831. https://doi.org/10.1177/1362361315576221

Noblit, G. W., & Hare, R. D. (1988). *Meta-Ethnography: Syntehsizing Qualitative Studies*. Sage Publications Ltd.

Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—A web and mobile app for systematic reviews. *Systematic Reviews*, *5*(1), 210. https://doi.org/10.1186/s13643-016-0384-4

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*, n71. https://doi.org/10.1136/bmj.n71

Parmar, K. R., Porter, C. S., Dickinson, C. M., Baimbridge, P., Pelham, J., & Gowen, E. (2022). Autism-friendly eyecare: Developing recommendations for service providers based on the experiences of autistic adults. *Ophthalmic and Physiological Optics*, *42*(4), 675–693. https://doi.org/10.1111/opo.12975

Punshon, C., Skirrow, P., & Murphy, G. (2009). The `not guilty verdict': Psychological reactions to a diagnosis of Asperger syndrome in adulthood. *Autism*, *13*(3), 265–283. https://doi.org/10.1177/1362361309103795

Raymaker, D. M., McDonald, K. E., Ashkenazy, E., Gerrity, M., Baggs, A. M., Kripke, C., Hourston, S., & Nicolaidis, C. (2017). Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism*, *21*(8), 972–984. https://doi.org/10.1177/1362361316661261

Saqr, Y., Braun, E., Porter, K., Barnette, D., & Hanks, C. (2018). Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting. *Autism*, *22*(1), 51–61. https://doi.org/10.1177/1362361317709970

Schutz. (1962). Common-Sense and Scientific Interpretation of Human Action. *Collected Papers I*, 3–47. https://doi.org/10.1007/978-94-010-2851-6_1

Walsh, C., Lydon, S., O'Dowd, E., & O'Connor, P. (2020). Barriers to Healthcare for Persons with Autism: A Systematic Review of the Literature and Development of A Taxonomy. *Developmental Neurorehabilitation*, *23*(7), 413–430. https://doi.org/10.1080/17518423.2020.1716868

Welsh Government. (2016). *Prudent Healthcare: Securing Health and Well-being for Future Generations*.

Wilson, G. T., Fairburn, C. C., & Agras, W. S. (1997). Cognitive-Behavioural Therapy for Bulimia Nervosa. In *Handbook of Treatment for Eating Disorders* (2nd Edition). Guilford Press.

Wilson, R., Thompson, A. R., Rowse, G., & Freeth, M. (2023). The experience of seeking, receiving, and reflecting upon a diagnosis of autism in the UK: A meta-synthesis of qualitative studies conducted with autistic individuals. *Research in Autism Spectrum Disorders*, *103*, 102135. https://doi.org/10.1016/j.rasd.2023.102135

Yau, N., Anderson, S., & Smith, I. C. (2023). How is psychological wellbeing experienced by autistic women? Challenges and protective factors: A meta-synthesis. *Research in Autism Spectrum Disorders*, *102*, 102101. https://doi.org/10.1016/j.rasd.2022.102101

Paper 2

"I'm not just being difficult…I'm *finding* it difficult": Experiences of autistic mothers when interacting with statutory services regarding their autistic child.

Sarah Radev

Supervised by Professor Andrew Thompson and Dr Megan Freeth

School of Psychology, Cardiff University

Word count for abstract: 243

Word count excluding abstract, tables, figures and references: 7832

This paper has been prepared for the journal Autism. The submission guidelines can be found in Appendix A. For the purposes of thesis submission, the DClinPsy word limit of 8000 words has been used to ensure all relevant information could be demonstrated. This will then be reduced to 6000 for journal submission. APA format has been used throughout in line with the journal specifications.

Abstract

While previous studies have focused on experiences of non-autistic parents interacting with statutory services for their autistic children, this is the first study to closely investigate experiences of autistic parents seeking support for their autistic children. Interpretative Phenomenological Analysis was used as the most suitable approach for investigating experience. The lead researcher has lived experience as an autistic parent of an autistic child, which had particular value within the design and analytic processes. Ten autistic mothers with autistic children in mainstream education completed semi-structured interviews which were transcribed and analysed. Rigorous analysis led to the development of four superordinate themes: 1. *The wider system is the problem;* 2. *Feeling judged and stigmatised; 3. Need to fight for the right support;* and 4. *Feeling overwhelmed.* While Themes 1 and 3 demonstrate some similarities in the experiences of autistic parents to that of non-autistic parents in previous studies, themes 2 and 4 are unique to autistic parents whose own diagnosis can lead to differences in how they are treated, and whose autistic characteristics result in additional difficulties with sensory overload and communication. One participant commented *'I am an autistic adult trying to navigate this system to advocate for my autistic children. I'm not just being difficult…I'm finding it difficult. (Kelly).* These themes indicate adapting services is important to supporting the wellbeing of autistic families such as training co-produced with and delivered by autistic adults encouraging a more strength-based rather than deficit-based understanding of autism.

Introduction

Autism Spectrum Condition (ASC) is a lifelong neurodevelopmental condition characterised by persistent deficits in social communication and interaction alongside restricted and repetitive patterns of behaviour, interests or activities (American Psychiatric Association, 2013). Prevalence of ASC is currently estimated at 1.1% of the UK population (National Institute for Health and Care Excellence, 2021; Pohl et al., 2020).

Previous research into ASC has predominantly focused on children (Horwitz et al., 2020; van Heijst & Geurts, 2015), and on exploring the experiences of autistic adults with co-occurring intellectual disabilities (ID), rather than those without (Bishop-Fitzpatrick et al., 2017). This is particularly relevant when considering the increased prevalence of anxiety and depression amongst those with ASC and no co-occurring ID (Bishop-Fitzpatrick et al., 2017, 2018; Caamaño et al., 2013; Cage et al., 2018; Gillott & Standen, 2007; Zerbo et al., 2015). Autistic adults are particularly likely to access mental health services with approximately 70-80% having at least one co-occurring mental health diagnosis (American Psychiatric Association, 2013; 2017; Buck et al., 2014; Caamaño et al., 2013; Lever & Geurts, 2016). Previous exploration into how accessing services is experienced by autistic adults have highlighted experiences of sensory overload in the environments, communication difficulties, feeling misunderstood by General Practitioners (GPs) often found to be lacking in knowledge, and feeling as though they had fallen between the gaps of the system (Department of Health and Social Care & Department of Education, 2021; Griffith et al., 2012; Mason et al., 2019).

One important area of adult life particularly neglected in autism research is parenthood. To date the extensive research on autism and parenthood has largely focused on non-autistic parents of autistic children, rather than on autistic adults as parents themselves. Indeed, parents of autistic children are likely to experience greater levels of stress, not only when compared to parents of typically developing children, but when compared to parents of children with other disabilities (Boshoff et al., 2016; Burke & Hodapp, 2014; Chang et al., 2019; Lau & Peterson, 2011).

The act of advocating for an autistic child is something many parents find necessary during the process of seeking a diagnosis, and ongoing support in health services and educational settings (Burke & Hodapp, 2014; Sedgewick et al., 2018). Indeed in relation to parent-school relationships, levels of advocacy need to be virtually non-existent for mothers to experience lower stress levels (Burke & Hodapp, 2014). Such advocacy can be extremely emotionally charged, involve conflicts arising with professionals and requiring a certain level of agency and self-efficacy on the part of the parents (Boshoff et al., 2016). Indeed, parents of autistic children have reported professionals failing to acknowledge their concerns, often citing the problem as being with the parent and not the child, providing little information post-diagnosis and generally demonstrating poor understanding of autism (Celia et al., 2020). This form of advocating is clearly challenging and emotive, and has been described by parents as being a ‘battle’ and a ‘fight’ (Celia et al., 2020; Marriott et al., 2022; Sedgewick et al., 2018; Sproston et al., 2017).

Genetic factors play a strong factor in autism (Sandin et al., 2014; Taylor et al., 2021; Tick et al., 2016) and yet existing studies have focused more on neurotypical experiences and there has not been a focused look at how interactions with statutory services are experienced by autistic parents who may find advocating for their child more challenging than non-autistic parents. Autistic parents have also echoed the sentiment they may be more knowledgeable about autism than the professionals (Crane et al., 2021), but may not find their concerns are taken seriously or feel misunderstood (Dugdale et al., 2021). Others have raised concerns about stigma relating to their own diagnosis which leads to a reluctance to disclose to professionals for fear of judgement and being deemed unable to cope

(Bertilsdotter Rosqvist & Lövgren, 2013; Dugdale et al., 2021; Marriott et al., 2022; Pohl et al., 2020). Previous research has indicated perceived stigma from others may contribute to poorer mental health and increased sense of social isolation in autistic individuals. This may also lead to an increase in tendencies to engage in 'masking' or 'camouflaging' (Cage et al., 2018).

This study aims to investigate the lived experience of autistic parents when interacting with statutory services on behalf of their autistic children to ensure appropriate support is provided for autistic families. This is approached from an epistemology position where knowledge is formed through phenomenology, hermeneutics, and ideography. Through phenomenological inquiry we can seek to understand the meanings autistic adults' assign to their experiences depending on their own embodied placement in the world, and the understanding that experience should be examined on its own terms in the way it occurs (Smith et al., 2009). The hermeneutic theory of interpretation then allows the researcher to develop new insights, and in this case is ideographically focused on the experiences of autistic mothers interacting with statutory services for their autistic children.

Qualitative methods enable both novel concepts and nuanced aspects of autistic phenomenology to be identified (e.g. Dugdale et al., 2021; Griffith et al., 2012; Marriott et al., 2022). Interpretative Phenomenological Analysis (IPA) is a specific method by which the participants disclose their own lived experience which is then actively interpreted by the researcher (Smith & Nizza, 2022). As a consequence, IPA involves a double-hermeneutic process whereby the experiences of the participant are first interpreted and made sense of by themselves, and secondly interpreted and made sense of by the researcher (Larkin et al., 2006; Larkin & Thompson, 2012). Therefore the researchers own conceptions have an important part to play in the interpretation of the data during the analysis process and actively involving those with lived experience of the phenomenon of interest may be particularly important in this endeavour (Larkin & Thompson, 2012).

Method

Design

Ethical approval for this study was granted by the Cardiff University School of Psychology Research Ethics Committee (Appendix I). Semi-structured interviews were identified as the most appropriate means of gathering information from participants about their experiences. The lead researcher is herself an autistic parent of an autistic child and so had some insight into the primary issues when developing the semi-structured interview questions as well as how to lay out the recruitment materials. Two other autistic parents were also involved prior to recruitment to feedback on the information provided to participants and proposed semi-structured interview questions. They were able to expand on some potential prompts for interview questions and confirm suitability of the other elements.

Participants

Ten participants were recruited via purposive sampling on social media sites (6 participants), and through the Autistica research database (4 participants). This number is commensurate with the IPA approach and was deliberately chosen to ensure that each participants experience remains present in the final results (Reid et al., 2005; Thompson et al., 2011).

Participants were identified as either meeting or not meeting inclusion criteria, outlined in Table 1, via completing a survey (Appendix J). Participants were then emailed with further information (Appendix K) and an invitation to take part if they met the criteria.

Of the twenty-seven who completed the survey and met the criteria, ten took up the offer of participating, all of whom were women.

Table 1

Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Aged 18+	Below age 18
Fluent in English	Not resident in the UK
Formal Diagnosis of Autism	Co-occurring ID
Parent of an autistic child currently attending mainstream school	Parent of an autistic child, but child was not in mainstream school

Data collection

Semi-structured interviews were used, and an outline of the question areas can be found in Table 3 (see Appendix L for the full schedule). Participants were offered the choice of conducting interviews via telephone (2 participants), video consultation (8 participants) or in person (no participants). Informed consent was obtained (Appendix M) prior to the interviews commencing. Demographic data (Table 2) was obtained prior to the interview starting.

Table 2

Demographic Information of Participants

Category	*No. of participants*
Age range at time of interview	(mean 46.6)
35-40	2
40-45	1
45-50	3
50-55	4
Time since diagnosis	(mean 2.9)
<1 year	4
1-2 years	2
4-5 years	3
>5 years	1
Ages of Autistic child/children	
3-5 years	1

5-10 years	1
11-17 years	7
Ethnicity	
White British	8
Mixed Race	2
Further Education	
NVQ	1
Undergraduate Degrees	4
Masters	1
PhD	3
Employment Status	
Student	1
Unemployed	3
In employment	6
Marital Status	
Married / Co-habiting with child’s father	8
Co-parenting with child’s father	1
Single Parent	1

Audio recordings of interviews were stored on an encrypted device and then transcribed. Interviews ranged in length from 48 minutes to 92 minutes (mean 63.4 minutes). At the end of each interview participants were briefed on what would happen with the data and given the opportunity to talk about anything they may have found difficult. None of the participants felt this was something they needed.

Table 3

Primary questions asked within the semi-structured interview

	Questions
1.	What healthcare professionals have been involved in supporting your child?
2.	Does your child receive any support from Social Services?
3.	Can you tell me about how things have been with your child’s school?
4.	What have you shared or talk about in relation to your own diagnosis to professionals when talking to them about your child?
5.	How have your experiences of interacting with professionals regarding your autistic child impacted on your experience of being a parent?
6.	What are your greatest sources of support in this area of your life?
7.	Is there anything else that you have not had the chance to tell me about today that you feel would be important for me to know about your experience of being an autistic parent seeking support for an autistic child?

Analysis

Prior to formal analysis, transcripts were read closely while relistening to the audio to ensure that the full context of the responses were considered. The IPA analysis process outlined by Smith and Nizza (2022) was adopted and began with careful analysis of each interview transcript to identify meanings and experiential themes. Exploratory notes were made on descriptive, linguistic, and conceptual elements of the transcript. Following this, experiential themes were noted and linked to supporting quotes (Appendix N). This process was then repeated with each transcript on an individual basis before a cross-case interpretative analysis was conducted and a table of themes compiled reflecting themes relevant to the studies aims (Smith, 2004).

A reflective log (Appendix O) was kept throughout the process of conducting interviews and the process of analysis to ensure that the lead researcher could reflect and utilise personal and theoretical knowledge without this biasing the interpretations. This was particularly important considering the personal lived experience of the lead researcher.

Quality Control

The process of data collection and analysis conducted by the lead researcher was audited through the use of a checklist (Appendix P) to verify and evidence each step during supervision (Spencer & Ritchie, 2012). Excerpts from the reflective log were also discussed within the research team.

Results

During the cross-case analysis four superordinate themes came through as particularly important in understanding the experiences of these parents, each of which had further subthemes. These themes are outlined in Table 4. Pseudonyms have been used to protect the anonymity of participants.

Table 4

Themes

Superordinate Theme	Subtheme	Number of contributing participants
1. The wider system is the problem	Feeling dismissed and unsupported	9
	The system is unjust	6
2. Feeling judged and stigmatised	Use of negative language offensive and misleading	7
	Training is not good enough	7
	Usefulness of disclosing diagnosis	8
3. Need to fight for the right support	Fighting has an impact on mental health	7
	Knowledge is a powerful tool	5
4. Feeling overwhelmed	Experiencing sensory overload	6
	Communication can be impacted	6

Number of contributing participants is included as additional contextual information only.

Theme 1 – The wider system is the problem

All participants felt the wider system is a greater problem than the professionals working in it, whether they were talking about healthcare, education or social services. Most talked about experiences of feeling dismissed, unsupported and passed back and forth due to the way systems operate. Many also talked about the system being unjust and how particularly difficult this is to understand and manage as an autistic person.

Feeling dismissed and unsupported

Participants experienced a lack of support from statutory services and even that they ‘don’t get a lot of support from anywhere really’ (Rachel). They used words like ‘fobbed off’ (Kayleigh, Tara), ‘rejected’ (Kim) and ‘dismissive/dismissed’ (Susan, Kim, Elaine, Dawn) and felt they needed to rely on themselves rather than professionals and services due to the lack of support received:

> that made me take it on myself to do my own research and do it myself because I found the school and the SENCO quite useless (Tara).

Some talked about lack of consistency and communication between services who ‘don’t share information’ (Chloe) which results in being passed back and forth between services instead of being offered support from the beginning:

> So we end up in this situation where we can try and get support from places like Social Services, and they just pass us back and forth between teams, blaming the other entity…saying, “Well, they need to deal with it.” (Kim).

There was frustration expressed with the way systems are set up which allows children to fail before any support is given due to a reluctance to provide support earlier.

> Another definition of stepped care is - See how many times somebody fails until you give them something that's vaguely appropriate. Rather than give them something that you think is actually appropriate to their level of need (Elaine)

There was an acknowledgement from most participants that the individual professionals they encountered had the best intentions and argued it's 'not [their] fault' (Chloe) and they are 'doing the best they can' (Claire) but the problem lies in the way the system is set up:

> I think I am frustrated with the systems and processes more than with the people…And I can understand that people are forced to work within systems that they haven't designed. (Claire)

Some participants talked about feeling as though services have been 'lying' (Elaine) to them and there had been a 'breakdown' (Kelly) in that professionals 'promise you all these things…that never actually come to fruition' (Dawn). This lack of support and the need for self-reliance has an impact on their own mental health and sense of trust not only in the systems, but in themselves as well.

> Actually, they were very dismissive and made me feel very stupid and as if I was just an anxious person making some stuff up…it *really* has impacted on me and made me feel…inadequate…and foolish. (Susan)

For some participants this had a direct impact on their experience of parenting causing them to feel like a 'bad parent' who '[hasn't] done stuff' (Rachel) because there is 'much less space for creativity and spontaneity and just joyous stuff' (Elaine) with the focus being on getting support, rather than on family life:

> I have a really big failure complex. I feel like I've failed at a lot of things, and I do often feel like a rubbish mum because I feel like we didn't have as much fun. (Kim)

The impact the experience of feeling unsupported has had on the experience of being a parent for some of these participants, resulting in feelings of failure and as though they are letting their children down, is another element impacting negatively on their mental health.

The system is unjust.

Another subtheme which was particularly relevant to being an autistic parent, was the sense of injustice at not getting the support they were promised and entitled to. This is in keeping with cognitive processes in autistic individuals and was felt particularly keenly when the specific rules laid down in legislation were not being followed:

> I found that process really distressing, as any mum would, wanting the best for your child, but also as a quite pedantic autistic person with this massive sense of injustice, because I was like, "They're not doing this by the rules. They are breaking them. I'm just pointing out the rules, that I didn't write, that government have written, that they are breaking." (Kim)

The systems were also described as being 'non-accessible to an autistic person' (Elaine) and 'extremely ableist' (Chloe). The need for equality, justice and things being done a certain way being a particularly autistic trait was brought up by several participants.

> as an autistic person justice is really important, and it was like my child deserves this, they need this, you should provide it and they were like, well no actually we don't. (Kayleigh)

Participants talked about how it is particularly difficult to understand things not being done the way they expect, and in particular, why they need to fight for what they are entitled to.

> I think an Autistic persons' understanding of what your entitlements are was like, "Well I'm entitled to that I shouldn't have to fight for it." (Elaine)

The result of this is an awareness of being viewed as a pain by professionals, because they know what they are entitled to and will push to get it.

> they just see me being a pain. Demanding reasonable adjustments, which actually are within the law that they need to do, and I have said that to them. I said "this *is* a legal requirement that you make these adjustments. (Kelly).

There was also a frustration expressed regarding the unjust inequality of the system which does not provide support equally to all children, but only to those able or willing to fight, or to invest money.

> the parents who shout the loudest or have some bit of money to spend, they often get the more support, but that's actually not very fair for people who haven't. (Tara).

This experienced inequality in the system is another way the overarching system has been experienced as the problem, rather than the individuals within the system, and even when participants were able to benefit from this inequality, there was still a level of frustration and anger expressed when thinking about others who were not as fortunate.

Theme 2 – Feeling judged and stigmatised

Participants talked about feeling judged and stigmatised through the language used by professionals to describe autism which indicated outdated and stereotyped understandings. This judgement was felt to be in part the result of poor autism training which failed to give professionals adequate understanding. This also meant parents spend a lot of time in their interactions educating professionals, on top of advocating for their children. There were mixed views on the usefulness of disclosing their own diagnosis with some feeling it gave them more credibility and others having concerns it would result in them being judged.

Use of negative language offensive and misleading.

One key way participants felt they were being judged and stigmatised was through the use of ‘negative language’ (Chloe) and outdated terminology such as ‘high’ or ‘low functioning’, to describe autism:

> it’s the classic sort of thing why we don’t use the functioning language anymore. “Oh he’s high functioning” and then *totally* disrespect his needs. (Elaine).

Functioning language was thought to be problematic because describing a person as either high or low functioning comes with the implication a person can be more or less autistic, which undermines the needs and experiences of those classed as ‘high functioning’

(Rachel) and leads to the view from professionals that ‘well you know, they’re functioning’ (Chloe) and ‘ingrained expectations’ (Elaine) on what support needs the child does or does not have:

> the doctor that we were trying to see was explaining about how…he basically drew a line and was talking about how you can be more or less autistic, and I knew immediately that wasn’t right. (Kelly).

Some participants talked about how ‘ridiculously deficit based’ (Susan) and personally offensive the language used is and the importance of being ‘disability positive [and] neurodiversity positive’ (Kim) in the language used:

> I registered a complaint, and the manager of the service phoned me up, and began talking about autistic spectrum disorder to me. Oh my God! I really think that that’s quite an offensive term now, because I’m not disordered, and Jack isn’t disordered. (Claire).

One participant had the experience of being asked by a professional if her son was a ‘bad autistic?’ (Rachel) and the point was raised by another that with the negative connotations of the language used, comes a reluctance from professionals to even raise the possibility of autism with parents because it is seen as something negative:

> the way it is at the moment, they’re just so reluctant to use that label. You know because it’s almost as if autism is this stain on people’s record…you know if it’s even raised you know, it’s like putting a black mark on them or something, it’s a dirty

> word. They don't want to use it…it's just a type of person, it's not anything to be scared of…But they're making people scared with the negative language. (Chloe).

The negative language many participants encountered in their interactions with professionals can be seen to not only be taken as offensive, but to impact on perceptions of support needs of the children, and ultimately led to wrong, or inadequate support being provided.

Training is not good enough.

Training provided to professionals in general, across both healthcare and education settings was described as 'absolutely awful' (Chloe), 'out of date' (Elaine, Susan) and often the lack of understanding demonstrated through the language being used was attributed to professionals not having adequate training in autism:

> If staff knew enough about these conditions themselves, they were the type of people…that had been trained properly and knew what these things *really* were rather than…the very vague idea, or that somebody who hasn't been trained properly might have (Chloe).

One of the impacts of professionals not having adequate training was the pressure it placed on parents to then take on the responsibility of 'doing that advocacy and that educating alongside' (Kelly) and to 'upskill and train' (Susan) the professionals themselves:

> If the teachers had a lot more training and understanding of all the different additional needs, they would be able to pick them up quicker and…the parents wouldn't have to. (Tara).

Many participants had the experience it was those professionals who had personal experience of autism that demonstrated the best understanding:

> They do not have the training or support. Unless they've got that personal experience…it'll either be total confusion or they'll have out of date stereotypical attitudes and have no idea what to do with information. (Elaine).

It was also felt the training was too much based on outdated and medicalised models of autism, which results in 'quite a rigid view' (Kim) of what autism is:

> if the medical professional can just think of the social model a little bit more, within training, then they would be advantaged at being able to support and work alongside people. (Claire).

Usefulness of disclosing diagnosis.

Participants had mixed views on the usefulness of disclosing their own diagnosis due to the mixed responses from professionals with some feeling it was an important part of spreading awareness and being listened to while others were fearful of being judged as people would 'use it against me' (Tara):

> there is a worry as an autistic parent, because there is a lot of stigma there, that if you say that you're struggling, that can be a lot more detrimental than it can be for other parents (Kim).

Some who had disclosed experienced a reaction indicating professionals had changed their view of them, and were somehow viewing them as less capable because of the diagnosis:

> I've disclosed to some people in situations that I am also autistic. And then you almost get that sort of patronising when they start to speak more slowly (Kelly).

In contrast, many felt disclosing gave them a lot more credibility and helped them feel 'empowered' (Chloe) because it indicated to professionals they had a real understanding of their children, and placed them in a position where they could help educate about autism.

> I think being an autistic parent with an autistic child has made me much more credible…and I think it's been harder for people to fob us off (Kayleigh)

Another experience that came up for several participants was the awareness professionals were assuming they were not themselves autistic and expected they would be able to manage and process things in the same way as non-autistic parents:

> I also think there is a massive assumption that the parents aren't autistic…autistic people don't have children, therefore any of these parents of autistic children and otherwise disabled children we're speaking to, are going to 100% have the ability to

> communicate in the way that we want them to, to do all the admin in the way that we want them to, and to be functioning at 100% all of the time. (Kim).

The understanding that ‘autistic children have autistic parents is not taken seriously’ (Claire) by professionals and that the same level of communication was expected from autistic parents as non-autistic parents was a source of frustration. It was felt that ‘working on the assumption that one or other of the parents is likely to be on the spectrum is probably a reasonable place to start’ (Elaine) since this lack of understanding meant their own needs were not considered.

> I think that schools forget…that autistic children come from autistic parents generally on the whole. And they put stuff in place for the kids, but then don’t think about how that’s going to affect their parents. (Kelly)

The inconsistency in the experiences and views on disclosure suggests variability in levels of training, and demonstrates how dissatisfactory the experience can feel to autistic parents.

Theme 3 - Need to fight for the right support.

The need to fight for the right support was an important theme running through all the accounts. Participants used language such as calling the process of advocating ‘a minefield to navigate’ (Dawn) and needing to ‘fight and scream and shout every step of the way’ (Elaine). They talked about the wider impact this fight can have on their mental health, and how they turned to arming themselves with knowledge as a powerful weapon in the fight.

Fighting has an impact on mental health.

Participants talked about the need to ‘save my own sanity’ (Dawn) and feeling a sense of ‘desperation’ (Kelly). The emotional impact was wide reaching and for some had impacted on all areas of their life:

> I think that the combination of the battles with the SEN system and school, getting older…just meant there was just a total breakdown in my mental health. (Elaine)

There was a real sense of this battle being a never-ending tiring experience, described as ‘exhausting’ (Dawn), ‘like you’re running on the treadmill and it will never stop’ (Kayleigh) and resulting in ‘limited energy’ (Susan). This feeling of being worn out by the battle had a detrimental impact on their wellbeing and was particularly evident in those who had been to tribunal and engaged in legal procedures (Kayleigh, Kim):

> I’m still paying the price emotionally now, over a year later and it’s all sorted…it took a toll on my wellbeing, on my sleep, on my everything…so yeah, mentally quite damaged as a result of what went on there. (Kayleigh)

This level of exhaustion was also linked to a reduced ability to advocate effectively for their children and a sense it was important to prioritise certain battles over others and rebalance the importance of the relationships with services with the need to get support:

> I have limited energy to try and pick the battles that are the most important so that I don’t burn all the bridges and damage all the relationships with the very people that are in the position of supporting my children (Susan).

Participants also talked about how the struggle they experience with managing this battle can be misunderstood by professionals as them being difficult:

> I *am* an autistic adult trying to navigate this system to advocate for my autistic children. I'm not just being difficult…I'm *finding* it difficult. (Kelly)

Knowledge is a powerful tool.

The main weapon many participants felt they had in this battle was knowledge. Participants placed the acquirement and appropriate use of knowledge in high esteem, and many talked about doing a lot of their own research to achieve this:

> Forewarned is forearmed, so to speak isn't it…it's knowledge that breaks down all the barriers for everything. (Chloe).

Participants talked about the importance, not only of knowledge, but of supporting evidence, which is in keeping with the Autistic presentation of everything needing a reason and a purpose to be valued.

> the local authority finally gave in after we battled them for ten months; we provided huge quantities of high-quality evidence and they knew they would lose at tribunal, so didn't take us to tribunal over placement, only over speech and language provision (Kayleigh).

In some cases having knowledge also gave participants the confidence to challenge professionals:

> I think he was basically ready to dismiss us out of hand and say…“Because your child is functioning in school and doing well academically” and all of those things…and it was only because I had that knowledge myself that that wasn’t right and that I kind of…pushed for what was gonna happen next (Kelly).

Autistic individuals often become absorbed in specific interest and can apply themselves to researching in a way that achieves results of a high standard. Several participants had a positive narrative as to how being autistic enabled them to use knowledge, describing themselves as ‘focused’ (Tara); using ‘determination and my autistic features’ (Kayleigh); and being a ‘typical autistic person [who] did lots of research’ (Kelly).

> I was like typical, you know, autistic spectrum person…with the big piles of information…“I’ve read about this…” (Chloe)

Sometimes it was the arming themselves with knowledge that was identified not just as a weapon but as something that might exacerbate the combative responses of professionals who expect to have the upper hand when it comes to knowing the system:

> I think there is this presumption that parents don’t know the systems, they don’t know the policies, they don’t know all of these things…They don’t think parents sit there and read the…Additional Learning Needs Bill cover to cover making notes. And they

> get a little bit combative, they get combative then in meetings when parents are more educated (Kim).

Participants also compared themselves to other parents who perhaps do not arm themselves with knowledge, and as a result their children don't get the same level of support:

> this other autistic child who was in the same class as my son, you know…because his mother…didn't have as much time as I did, her child didn't get as much support as mine because I was able to fight for it, and that's not fair because he probably needed it more than my son (Tara)

In this respect participants demonstrated how in some ways they perceived themselves to be at an advantage being autistic, because they were able to apply themselves to the fight.

Theme 4 – Feeling Overwhelmed

Most participants talked about the impact feeling overwhelmed can have on their ability to effectively advocate for their children. This can be the result of experiencing sensory overload due to the environments in medical settings and busy crowds at school events and feeling overwhelmed by social interactions and anxiety which can impact communication.

Experiencing sensory overload.

Participants talked about difficulties they experienced with 'sensory overload' (Kim, Claire). A common sensory issue participants talked about was being 'noise [sensitive]'

(Rachel, Kim) and things being ‘too loud’ (Kayleigh) which leads to an increase in anxiety and reduced ability to focus:

> I can’t hear, it’s too loud…I can’t hear, can’t focus. So yeah, that is a struggle, definitely (Kayleigh).

Most participants talked about the difficulties with noise being something they particularly noticed in the school setting, especially at face-to-face parent’s evenings, at concerts, or in the school playground:

> I need to speak to you ideally somewhere quiet because on the playground, with 300 parents…I am not going to be able to process what you’re saying or respond effectively. (Kelly)

For some being ‘light sensitive’ (Kim) or finding that ‘lighting is often challenging’ (Kelly) was a problem, in particular the bright lights in medical settings, especially when combined with the noise:

> the environment’s very unpleasant the waiting rooms are difficult, it’s very bright, it’s noisy, particularly in areas for children because there’s lots of other children there. (Susan)

The impact this sensory overload had on them was a reduced ability to be there for their children who may also have been experiencing sensory overload:

> because I was overwhelmed from a sensory perspective, I didn't have anything in reserve to calm my son down (Kim)

This was another way in which autistic parents may experience stress because they have too much to manage with their own needs in the environments they find themselves in, to be able to support their children with the same needs.

Communication can be impacted.

Participants talked about the impact feeling overwhelmed can have on their ability to communicate. They talked about needing to 'muddle through' (Rachel) and the effort required for communication being 'draining' (Kelly). Ultimately this then impacts on advocacy:

> Because your communication might be impacted, your anxiety might be really high, all the skills and the tools that you need to advocate…can be impacted (Susan)

For some, it was so overwhelming and difficult to manage, that ultimately they had to withdraw from the situation and find alternative means to support their children:

> I got to the point where I couldn't, I just could not interact with the people in school. I was just dipping. And so they agreed that my partner would be the lead contact. (Elaine)

However, it was not just sensory overload or the anxiety of the situation, or needing to fight for everything that caused participants to become overwhelmed to the point their communication was impacted. For some, the act of communicating itself was overwhelming:

> if you're often faced with a panel of three or four complete strangers who are, you know, obviously very experienced in special needs and they're quite, you know, knowledgeable about the laws and things and it's quite intimidating to have to, you know, argue against them (Tara).

Participants talked about how it is not only their ability to communicate effectively that may be impacted, but their ability to process and understand the information given to them:

> I was obviously being autistic. When you put me in a room where I've got to communicate with four or five people at a time…I *don't* catch everything that's being said. And I might just say yes to something that I'm not really understanding. (Dawn).

Communication is one of the key criteria for an autism diagnosis, and so it is not surprising this would come up as a theme, and yet it is a crucial element of interacting with services and advocating for the needs of the children.

Discussion

This is the first study to look specifically at the experiences of autistic parents regarding interacting with statutory services on behalf of their autistic children. While some themes were in keeping with themes that have arisen with non-autistic parents, some are experienced differently by autistic parents, while others are unique to autistic parents.

The first superordinate theme ‘the wider system is the problem’ presented in the ways participants felt generally dismissed and unsupported by services. This theme has come up in previous research in relation to feeling educational providers do not listen (Sproston et al., 2017), healthcare professionals failed to recognise the child’s differences and were unempathetic (Celia et al., 2020), and a failure to recognise or provide validation for the increased complexity of being an autistic parent of an autistic child (Marriott et al., 2022) which were all themes featured in the experiences of the participants.

In contrast to previous findings, participants in this study were very conscious about clarifying it was not the individual professionals that were unhelpful, so much as it was the wider system in which they were working, and demonstrated empathy for how difficult working in these systems might be. Nevertheless, the ultimate lack of support experienced was an important factor in reduced wellbeing and parental stress.

One particular frustration raised in relation to the systems was a sense of injustice. Characteristics of autism such as ‘inflexible adherence to routines’ and ‘rigid thinking patterns’ (American Psychiatric Association, 2013) may contribute to an increased need for fairness and authenticity amongst autistic people (Kirchner et al., 2016), and these character traits might contribute to autistic parents particularly struggling when professionals and services are unable to act consistently or to adhere with legislation. Participants also talked about an imbalance in the system in terms of certain families being at an advantage due to having more resources such as time, money and education. This is in keeping with previous research were the issue of lower socioeconomic status and lower educational status were found to be barriers to successful advocacy (Boshoff et al., 2016).

The second superordinate theme ‘feeling judged and stigmatised’ is one particularly relevant to autistic parents of autistic children, and has not come up in previous research into the experiences of non-autistic parents although it has come up in research examining experiences of autistic adults (Cage et al., 2018; Perry et al., 2022).

One primary issue raised by participants was the use of negative language by professionals. Terminology has an important part to play in shaping perceptions, and while previous research has demonstrated identity-first language is the preference of the autistic community, most professionals still prefer to use person-first language (Bury et al., 2022; Kenny et al., 2016). All participants indicated a preference for using the term ‘autistic’ and expressed frustration over professionals using terms such as ‘Autistic Spectrum Disorder’ which feels stigmatising and ‘high functioning’ which implies a linear understanding of autism. Such terms can either strengthen negative perceptions of autism, or be misleading in terms of the individual’s needs. Previous studies have highlighted the importance of seeing autism not as a neurological disorder, but as a difference, with a focus on changing the environments around an individual rather than the individual themself (Monk et al., 2022), and this is echoed in the current study.

Many participants felt one solution was improved training, judging existing training as generally outdated and focused on the medical model of autism, leaving parents in the position of having to educate professionals, whilst also advocating for their children. It is not uncommon for individuals to feel more knowledgeable than the professionals (Griffith et al., 2012; Mason et al., 2021). The need for additional training for healthcare providers in providing adequate support for autistic patients has also been highlighted in previous research, especially in the ability to recognise that adult patients may be autistic (Zerbo et al., 2015).

This lack of understanding was experienced by many participants as feeling stigmatised and judged and for some resulted in a reluctance to disclose their own diagnosis for fear of being ‘othered’ and deemed as being unable to be good parents due to having a ‘disability’ (Bertilsdotter Rosqvist & Lövgren, 2013). Camouflaging or masking one’s autistic identity is not an uncommon strategy to gain acceptance (Cage et al., 2018), and many participants felt safer in their interactions with professionals by avoiding disclosing their own diagnosis. Perry et al. (2022) reported a direct link between higher perceived autism stigma and increased reporting of camouflaging. This was supported by many participants reporting a general assumption from professionals that parents would not be autistic like their child, which for some allowed them to mask, while for others resulted in frustration due to not feeling understood. Conversely, some of the participants reported disclosure was empowering. Indeed previous research has indicated where professionals have a good understanding of autism, autistic parents were more likely to receive increased respect (Dugdale et al., 2021). This split in how comfortable participants felt to disclose their own diagnosis, appeared linked to previous experience, and this indicates that there is likely to be variability in the understanding of autism amongst professionals.

Smart Richman and Leary (2009) propose experiences of being stigmatised, and feeling rejected can be experienced as a threat to acceptance and can illicit three potential motivations: seeking acceptance; harming others; and withdrawal. The first two are particularly relevant to the experiences of participants in this study. Those who reported preferring not to disclose and to mask or camouflage when interacting with professionals, could be said to be motivated by ‘seeking acceptance.’ However, with the sense of threat potentially activated, it is also not surprising that many participants talked about fighting back, which is in keeping with the second motivation regarding defending oneself against the source of rejection.

The third superordinate theme ‘need to fight for the right support’ has been noted in previous studies as an important element of the experiences of non-autistic parents (Celia et al., 2020; Marriott et al., 2022; Sedgewick et al., 2018; Sproston et al., 2017) and so it is no surprise it would also arise as an important theme for autistic parents. It has also previously been noted as a sub-theme in other papers with a wider focus on the overall experience of being an autistic parent (Dugdale et al., 2021). Participants talked about the impact engaging in this fight had on their mental health, which is in keeping with previous reports from autistic parents (Marriott et al., 2022).

For some participants this fight for support involved healthcare services, while for others it involved education. Previous studies exploring the experiences of non-autistic parents have found the quality of the relationship between parents and school has a direct impact on levels of stress where positive relationships resulted in parents experiencing significantly less stress (Burke & Hodapp, 2014). For these participants the increased levels of stress they experienced for having to fight for the right support had a wide-reaching impact on their mental health, and for some even on their ability to work.

One of the key resources participants talked about using in this battle for support, was arming themselves with knowledge, which several participants attributed to being a specifically autistic strength and skill. One of the diagnostic criteria for autism is ‘highly restricted, fixated interests that are abnormal in intensity’ (American Psychiatric Association, 2013) and special interests have long been recognised as common to autistic people and viewed as a great strength as well as a way to manage anxiety (Grove et al., 2016). Kirchner et al. (2016) cites a ‘love of learning’ as one of the most frequent signature strengths of being autistic with an ability to acquire an astonishing body of knowledge and Baron-Cohen (2009) talks about how the autistic brain is able to achieve excellent attention to detail. Participants talked with pride about their ability to gather the information needed about their child's differences, the legislation relating to what they were entitled to and the therapies best suited to support their child. This was very much viewed by participants as a strength of being autistic.

The ability to acquire and effectively use knowledge as evidence was not only a beneficial weapon in the fight, but a way of managing the stress involved and mitigate its impact. Autistic people struggle with uncertainty and a perceived lack of information, which many participants cited experiencing and which can result in an increased sense of threat (Conner et al., 2022). Therefore, the pursuit of knowledge may be an important coping mechanism of autistic parents as a way to increase certainty and feelings of agency.

The fourth and final superordinate theme 'feeling overwhelmed' referred to participants experiencing sensory overload and increased difficulties in communication. Hyper- or hypoactivity to sensory input is one of the diagnostic criteria for autism (American Psychiatric Association, 2013), and sensory stimuli has been found to correlate with high anxiety levels in autistic people (Cage et al., 2018; Gillott & Standen, 2007) which might involve noise, strong lights or smells and busy environments being experienced as overwhelming (Griffith et al., 2012; Mason et al., 2021). Sensory sensitivities have been highlighted as particular barriers to autistic people accessing healthcare in previous research (Mason et al., 2019), and so may be expected to be an issue for autistic parents.

Participants reflected on how feeling overwhelmed due to sensory overload impacted on their ability to support and comfort their children, and on their ability to communicate with professionals and be effective advocates. One of the key criteria for an autism diagnosis is 'persistent deficits in social communication' (American Psychiatric Association, 2013) and feeling overwhelmed may impact on the ability to process information, pick up on the subtleties of communication, and have the energy to modulate eye contact. The difficulties of social communication in Autism and the need for explicit communication is well documented (Müller et al., 2008). Interactions with professionals may be impacted by slower processing speed, increased difficulties with memory and difficulty with completing necessary paper work (Mason et al., 2019). Participants experienced these difficulties as feeling overwhelming and exhausting, resulting in information being missed and increased anxiety over feelings of uncertainty about what was to happen next.

While some of the themes in this study reflect similarities between the experiences of non-autistic parents and autistic parents, such as the need to fight for support, concern over level of training provided to professionals and generally feeling unsupported, other themes such as the drive for knowledge, feeling judged and stigmatised and overwhelmed by sensory stimuli and communication difficulties are particular to the autistic experience.

Reflections

The keeping of a reflective log throughout the process of conducting interviews and analysing transcripts, ensured that this author’s personal experience did not bias the ways in which the information was collected and interpreted. Although most of the experiences covered by participants felt very familiar and easy to relate to, there were some elements that were different to this author’s experience, primarily in relation to disclosing one’s own diagnosis. That half of the participants had experienced increased credibility and felt empowered by disclosing their own diagnosis was familiar, and in keeping with personal experience. However, it was both surprising and disappointing to hear that for many disclosure had not been a positive experience, and that they had learnt to mask and avoid disclosure for fear of judgement.

Future Directions

The findings from this study indicate a number of considerations to be taken into account when supporting autistic parents seeking support for their autistic children. Due to the experiences of participants feeling stigmatised and misunderstood it is recommended that when supporting autistic children professionals consider the possibility parents may also be autistic, and ask families what terminology they prefer to use. In response to difficulties faced with sensory overload it is recommended autistic families are offered private rooms while waiting for appointments, and the earliest slots to limit waiting times. To ensure training provided to professionals is up-to-date and relevant, it is recommended all training be co-developed with autistic adults and provided to all professionals who may encounter autistic families. To aid understanding and processing of information and reduce uncertainty, written details of discussions with professionals should be provided to parents. The development of autism friendly clinics and meetings with limited sensory stimulation, pre-prepared documentation and increased time for appointments is also recommended. Considering the impact of additional difficulties that autistic parents face, the provision of support groups is recommended to help lessen the negative impact on the wellbeing of these parents.

Limitations

The sample used in this study consisted only of women with a mean age of 46, who were largely White British and well educated, and may not be transferable to the wider autistic population. There was no representation of autistic fathers, and no representation of younger parents, which would be beneficial to explore in future research. It is also important to note this study only included individuals who had received an autism diagnosis, which may have excluded autistic parents struggling to get a diagnosis for various reasons. All participants had also received their diagnosis in adulthood and so may not be representative of the experiences and views of autistic parents diagnosed as children.

Conclusion

The findings in this study highlight some very specific difficulties faced by autistic parents when advocating for their autistic children and improvements that would be beneficial in both healthcare and educational settings. Autistic parents have experienced feeling stigmatised, judged, dismissed and misunderstood, and there is a strong need for the development of improved autism training for all professionals working with autistic families not only to support a better understanding of autism, but of the terminology preferred by the autistic community. We suggest this training is co-produced with autistic adults who have lived experience, and even that it is delivered by autistic adults themselves. It is hoped this would also encourage a more strength-based understanding of autism, using positive language, rather than a deficit-based understanding. It will also be important for services to understand the impact of sensory overload and differences in communication with autistic parents, which may require information being offered in written format and provided at the earliest opportunity to limit experiences of uncertainty.

References

American Psychiatric Association (Ed.). (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (5th ed). American Psychiatric Association.

Baron-Cohen, S., Ashwin, E., Ashwin, C., Tavassoli, T., & Chakrabarti, B. (2009). Talent in autism: Hyper-systemizing, hyper-attention to detail and sensory hypersensitivity. *Philosophical Transactions of the Royal Society B: Biological Sciences*, *364*(1522), 1377–1383. https://doi.org/10.1098/rstb.2008.0337

Bejerot, S. (2007). An autistic dimension: A proposed subtype of obsessive-compulsive disorder. *Autism*, *11*(2), 101–110. https://doi.org/10.1177/1362361307075699

Bertilsdotter Rosqvist, H., & Lövgren, V. (2013). Doing adulthood through parenthood: Notions of parenthood among people with cognitive disabilities. *Alter*, *7*(1), 56–68. https://doi.org/10.1016/j.alter.2012.11.002

Bishop-Fitzpatrick, L., Mazefsky, C. A., & Eack, S. M. (2018). The combined impact of social support and perceived stress on quality of life in adults with autism spectrum disorder and without intellectual disability. *Autism*, *22*(6), 703–711. https://doi.org/10.1177/1362361317703090

Bishop-Fitzpatrick, L., Minshew, N. J., Mazefsky, C. A., & Eack, S. M. (2017). Perception of Life as Stressful, Not Biological Response to Stress, is Associated with Greater Social Disability in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *47*(1), 1–16. https://doi.org/10.1007/s10803-016-2910-6

Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents' voices: 'Why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder: A meta-synthesis of parents' experiences of advocating for their child with autism. *Child: Care, Health and Development*, *42*(6), 784–797. https://doi.org/10.1111/cch.12383

Buck, T. R., Viskochil, J., Farley, M., Coon, H., McMahon, W. M., Morgan, J., & Bilder, D. A. (2014). Psychiatric Comorbidity and Medication Use in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *44*(12), 3063–3071. https://doi.org/10.1007/s10803-014-2170-2

Burke, M. M., & Hodapp, R. M. (2014). Relating Stress of Mothers of Children With Developmental Disabilities to Family–School Partnerships. *Intellectual and Developmental Disabilities*, *52*(1), 13–23. https://doi.org/10.1352/1934-9556-52.1.13

Bury, S. M., Jellett, R., Haschek, A., Wenzel, M., Hedley, D., & Spoor, J. R. (2022). Understanding language preference: Autism knowledge, experience of stigma and autism identity. *Autism*, 136236132211423. https://doi.org/10.1177/13623613221142383

Caamaño, M., Boada, L., Merchán-Naranjo, J., Moreno, C., Llorente, C., Moreno, D., Arango, C., & Parellada, M. (2013). Psychopathology in Children and Adolescents with ASD Without Mental Retardation. *Journal of Autism and Developmental Disorders*, *43*(10), 2442–2449. https://doi.org/10.1007/s10803-013-1792-0

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of Autism Acceptance and Mental Health in Autistic Adults. *Journal of Autism and Developmental Disorders*, *48*(2), 473–484. https://doi.org/10.1007/s10803-017-3342-7

Celia, T., Freysteinson, W., Fredland, N., & Bowyer, P. (2020). Battle weary/battle ready: A phenomenological study of parents' lived experiences caring for children with autism and their safety concerns. *Journal of Advanced Nursing*, *76*(1), 221–233. https://doi.org/10.1111/jan.14213

Chang, J. P.-C., Lai, M.-C., Chou, M.-C., Shang, C.-Y., Chiu, Y.-N., Tsai, W.-C., Wu, Y.-Y., & Gau, S. S.-F. (2019). Maternal and Family Processes in Different Subgroups of Youth with Autism Spectrum Disorder. *Journal of Abnormal Child Psychology*, *47*(1), 177–194. https://doi.org/10.1007/s10802-018-0404-z

Conner, C. M., Kim, P. S., White, S. W., & Mazefsky, C. A. (2022). The role of emotion dysregulation and intolerance of uncertainty in autism: Transdiagnostic factors influencing co-occurring conditions. *Research in Developmental Disabilities*, *130*, 104332. https://doi.org/10.1016/j.ridd.2022.104332

Crane, L., Lui, L. M., Davies, J., & Pellicano, E. (2021). Autistic parents’ views and experiences of talking about autism with their autistic children. *Autism*, *25*(4), 1161–1167. https://doi.org/10.1177/1362361320981317

Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, *19*(7), 814–823. https://doi.org/10.1177/1362361315577517

Department of Health and Social Care, & Department of Education. (2021). *Summary of findings from the government’s review of the National Autism Strategy ‘Think Autism’: Call for evidence—GOV.UK*. Summary of Findings from the Government’s Review of the National Autism Strategy ‘Think Autism’: Call for Evidence. https://www.gov.uk/government/consultations/review-of-the-national-autism-strategy-think-autism-call-for-evidence/outcome/summary-of-findings-from-the-governments-review-of-the-national-autism-strategy-think-autism-call-for-evidence

Dugdale, A.-S., Thompson, A. R., Leedham, A., Beail, N., & Freeth, M. (2021). Intense connection and love: The experiences of autistic mothers. *Autism*, 136236132110059. https://doi.org/10.1177/13623613211005987

Gillott, A., & Standen, P. J. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of Intellectual Disabilities*, *11*(4), 359–370. https://doi.org/10.1177/1744629507083585

Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). 'I just don't fit anywhere': Support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, *16*(5), 532–546. https://doi.org/10.1177/1362361311405223

Grove, R., Roth, I., & Hoekstra, R. A. (2016). The motivation for special interests in individuals with autism and controls: Development and validation of the special interest motivation scale: Special interests, motivation, and autism. *Autism Research*, *9*(6), 677–688. https://doi.org/10.1002/aur.1560

Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., Herbrecht, E., Stopin, A., Anckarsäter, H., Gillberg, C., Råstam, M., & Leboyer, M. (2009). Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC Psychiatry*, *9*(1), 35. https://doi.org/10.1186/1471-244X-9-35

Horwitz, E. H., Schoevers, R. A., Greaves-Lord, K., de Bildt, A., & Hartman, C. A. (2020). Adult Manifestation of Milder Forms of Autism Spectrum Disorder; Autistic and Non-autistic Psychopathology. *Journal of Autism and Developmental Disorders*, *50*(8), 2973–2986. https://doi.org/10.1007/s10803-020-04403-9

Joshi, G., Wozniak, J., Petty, C., Martelon, M. K., Fried, R., Bolfek, A., Kotte, A., Stevens, J., Furtak, S. L., Bourgeois, M., Caruso, J., Caron, A., & Biederman, J. (2013). Psychiatric

Comorbidity and Functioning in a Clinically Referred Population of Adults with Autism Spectrum Disorders: A Comparative Study. *Journal of Autism and Developmental Disorders*, *43*(6), 1314–1325. https://doi.org/10.1007/s10803-012-1679-5

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

Kirchner, J., Ruch, W., & Dziobek, I. (2016). Brief Report: Character Strengths in Adults with Autism Spectrum Disorder Without Intellectual Impairment. *Journal of Autism and Developmental Disorders*, *46*(10), 3330–3337. https://doi.org/10.1007/s10803-016-2865-7

Larkin, M., & Thompson, A. R. (2012). Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research. In *Qualitative Research Methods in Mental Health and Psychotherapy A Guide for Students and Practitioners*. Wiley-Blackwell.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102–120. https://doi.org/10.1191/1478088706qp062oa

Lau, W., & Peterson, C. C. (2011). Adults and children with Asperger syndrome: Exploring adult attachment style, marital satisfaction and satisfaction with parenthood. *Research in Autism Spectrum Disorders*, *5*(1), 392–399. https://doi.org/10.1016/j.rasd.2010.06.001

Lever, A. G., & Geurts, H. M. (2016). Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. *Journal of*

Autism and Developmental Disorders, *46*(6), 1916–1930. https://doi.org/10.1007/s10803-016-2722-8

Marriott, E., Stacey, J., Hewitt, O. M., & Verkuijl, N. E. (2022). Parenting an Autistic Child: Experiences of Parents with Significant Autistic Traits. *Journal of Autism and Developmental Disorders*, *52*(7), 3182–3193. https://doi.org/10.1007/s10803-021-05182-7

Mason, D., Ingham, B., Birtles, H., Michael, C., Scarlett, C., James, I. A., Brown, T., Woodbury-Smith, M., Wilson, C., Finch, T., & Parr, J. R. (2021). How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians. *Autism*, *25*(3), 774–785. https://doi.org/10.1177/1362361321993709

Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., Brown, T., James, I., Scarlett, C., Nicolaidis, C., & Parr, J. R. (2019). A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *Journal of Autism and Developmental Disorders*, *49*(8), 3387–3400. https://doi.org/10.1007/s10803-019-04049-2

Monk, R., Whitehouse, A. J. O., & Waddington, H. (2022). The use of language in autism research. *Trends in Neurosciences*, *45*(11), 791–793. https://doi.org/10.1016/j.tins.2022.08.009

Müller, E., Schuler, A., & Yates, G. B. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism*, *12*(2), 173–190. https://doi.org/10.1177/1362361307086664

National Institute for Health and Care Excellence. (2021). *Prevalence | Background information | Autism in adults | CKS | NICE*. https://cks.nice.org.uk/topics/autism-in-adults/background-information/prevalence/

Perry, E., Mandy, W., Hull, L., & Cage, E. (2022). Understanding Camouflaging as a Response to Autism-Related Stigma: A Social Identity Theory Approach. *Journal of Autism and Developmental Disorders*, *52*(2), 800–810. https://doi.org/10.1007/s10803-021-04987-w

Pohl, A. L., Crockford, S. K., Blakemore, M., Allison, C., & Baron-Cohen, S. (2020). A comparative study of autistic and non-autistic women's experience of motherhood. *Molecular Autism*, *11*(1), 3. https://doi.org/10.1186/s13229-019-0304-2

Reid, K., Flowers, P., & Larkin, M. (2005). Give an introduction to interpretative phenomenological analysis. *The Psychologist*, *18*(1), 4.

Sandin, S., Lichtenstein, P., Kuja-Halkola, R., Larsson, H., Hultman, C. M., & Reichenberg, A. (2014). The Familial Risk of Autism. *JAMA*, *311*(17), 1770. https://doi.org/10.1001/jama.2014.4144

Sedgewick, F., Hill, V., & Pellicano, E. (2018). Parent perspectives on autistic girls' friendships and futures. *Autism & Developmental Language Impairments*, *3*, 239694151879449. https://doi.org/10.1177/2396941518794497

Smart Richman, L., & Leary, M. R. (2009). Reactions to discrimination, stigmatization, ostracism, and other forms of interpersonal rejection: A multimotive model. *Psychological Review*, *116*(2), 365–383. https://doi.org/10.1037/a0015250

Smith, J. A. (2004). *Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology*. 18.

Smith, J. A., & Nizza, I. E. (2022). *Essentials of Interpretative Phenomenological Analysis*. American Psychological Association.

Spencer, L., & Ritchie, J. (2012). In Pursuit of Quality. In *Qualitative Research Methods in Mental Health and Psychotherapy A Guide for Students and Practitioners*. Wiley-Blackwell.

Sproston, K., Sedgewick, F., & Crane, L. (2017). Autistic girls and school exclusion: Perspectives of students and their parents. *Autism & Developmental Language Impairments*, *2*, 239694151770617. https://doi.org/10.1177/2396941517706172

Taylor, S. C., Steeman, S., Gehringer, B. N., Dow, H. C., Langer, A., Rawot, E., Perez, L., Goodman, M., Smernoff, Z., Grewal, M., Eshraghi, O., Pallathra, A. A., Oksas, C., Mendez, M., Gur, R. C., Rader, D. J., Bucan, M., Almasy, L., & Brodkin, E. S. (2021). Heritability of quantitative autism spectrum traits in adults: A FAMILY-BASED study. *Autism Research*, *14*(8), 1543–1553. https://doi.org/10.1002/aur.2571

Thompson, A. R., Larkin, M., & Smith, J. A. (2011). *Interpretative phenomenological analysis and clinical psychology training: Results from a survey of the Group of Trainers in Clinical Psychology*. 5.

Tick, B., Bolton, P., Happé, F., Rutter, M., & Rijsdijk, F. (2016). Heritability of autism spectrum disorders: A meta-analysis of twin studies. *Journal of Child Psychology and Psychiatry*, *57*(5), 585–595. https://doi.org/10.1111/jcpp.12499

van Heijst, B. F., & Geurts, H. M. (2015). Quality of life in autism across the lifespan: A meta-analysis. *Autism*, *19*(2), 158–167. https://doi.org/10.1177/1362361313517053

Vannucchi, G., Masi, G., Toni, C., Dell’Osso, L., Marazziti, D., & Perugi, G. (2014). Clinical features, developmental course, and psychiatric comorbidity of adult autism spectrum disorders. *CNS Spectrums*, *19*(2), 157–164. https://doi.org/10.1017/S1092852913000941

Zerbo, O., Massolo, M. L., Qian, Y., & Croen, L. A. (2015). A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System. *Journal of Autism and Developmental Disorders*, *45*(12), 4002–4014. https://doi.org/10.1007/s10803-015-2579-2

Appendix A – Submission Guidelines for ‘Autism’ Journal with SAGE Publications

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to Autism, please ensure you have read the Aims & Scope.

There is no need to submit a pre-submission enquiry to the journal, and in fact we discourage this as our scope is clearly stated at the link above.

It is journal policy for all submitted manuscripts to be screened by an Editor who will decide whether to send the manuscript for review. In this screening process, Editors will focus on:

- fit with the journal aims and scope, and listed Article Types (see below)
- relevance to autistic people’s quality of life
- justification of the research question
- relevance and quality of the methods and analysis methods for the topic under study
- validity of the conclusions in relation to the methods and findings
- quality of the writing
- potential for practical impact

1.2 Article Types

The Journal considers the following kinds of article for publication:

Research Reports. Full papers describing new empirical findings. These papers may present quantitative and/or qualitative data. In each case, the methods should be carefully selected to address the research question being posed, with due justification being given for: needfulness of the research; relevance to autistic people’s quality of life; appropriateness of the sample size and diversity; quality of the methods; robustness of the analysis methods; validity of the conclusions.

Fundamental or basic scientific discoveries can be considered for publication but need to make a convincing case for relevance to autistic people’s lives, especially if future implementation of the discovery is still far off.

Research Reports are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [200 words maximum], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review

Before submitting a Research Report, please make sure to review the author guidelines, and especially section 2.8 for our reporting expectations.

Review Articles. General reviews that provide a synthesis of an area of autism research. These will normally be systematic but narrative and/or focused reviews can be considered if the authors make a convincing case for their ability to address a gap in knowledge.

Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract [200 words maximum], notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.

Before submitting a Review, please make sure to review the author guidelines and especially section 2.8 for our reporting expectations.

Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. The title should begin with 'Short Report'. Short reports also report empirical findings from quantitative and / or qualitative data, but these may be preliminary, low-impact, or otherwise less substantial than a Research Report. Another reason to submit a Short Report is if your rationale, methods and findings are simple and neat. If your paper can be reported within the 2000 word limit we would encourage you to do so.

Letters to the Editors. Readers' letters should address issues raised by articles published in our journal, or issues in the field of autism research more generally. The issues should be contextualised within the literature to permit readers to draw general conclusions. Letters might cover: discussions of existing debates in the literature, articulations of new or controversial ideas, comments on work published in our journal, theoretical perspectives, methodological or conceptual critiques, The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 1000 words, with no tables and a maximum of 5 references.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: How to Help Readers Find Your Article Online.

2. Editorial policies

2.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published, consulting with other Editors if and when they feel it is necessary. Our Editors strive to make this initial review within two weeks after submission, so that authors do not have to wait long for a rejection. In some cases, feedback may also be provided on how to improve the manuscript, or what other journal would be more suitable. The criteria used by the Editors when determining what to reject or send for review as described here [https://journals.sagepub.com/author-instructions/aut#Aims-Scope]. Each manuscript which passes this initial screening, is sent out for peer review by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Autism requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity, you should withhold this information until you submit your final accepted manuscript.

2.4.1 National Institutes of Health (NIH) funded articles

If you have received NIH funding for your research, please state this in your submission and if your paper is accepted by *Autism* an electronic version of the paper will automatically be sent to be indexed with the National Library of Medicine's PubMed Central as stipulated in the NIH policy.

2.5 Declaration of conflicting interests

Autism encourages authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the SAGE Journal Author Gateway. In particular, for working reporting on the development or evaluation of interventions the ICJME Conflict of Interest form provides an excellent template for considering a range of potential sources of conflict, and this can be uploaded and submitted with your manuscript if relevant.

Where an Editor of Autism is a lead or contributing author to a paper submitted to publication, the paper is always handled through the peer review process by another member of the Editor team and three reviews are obtained in each case. A statement is also published on each article where this occurs.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.7 Clinical trials

Autism conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

2.8.1 Transparent reporting of trials

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

The What Works Clearinghouse (WWC) guidelines should be followed when submitting in single-case design (SCD) and meet the standards outlined for internal validity of the SCD.

Other resources can be found at NLM’s Research Reporting Guidelines and Initiatives

2.8.2 Sample selection and demographic characteristics

Autism now requires authors to report the following information for all Research Reports (including systematic reviews):

i. procedures for sample selection and recruitment; and
ii. major demographic characteristics, including age, gender, race/ethnicity and socioeconomic status.

Including this information will provide greater clarity regarding sample characteristics and generalisability of the findings, even when such characteristics are not used in the analysis (although we encourage investigation of subgroup differences, where possible). It should also encourage researchers to consider the way in which context and culture contribute to their findings.

If authors are unable to report some or all of this information, its absence must be acknowledged with a clear statement of explanation (e.g., “specific data on socioeconomic status and educational attainment levels were not recorded”). Manuscripts that contain neither the required information nor an appropriate statement will be returned prior to consideration by the editors.

2.8.3 Community involvement

Autism encourages research that is actively carried out ‘with’ or ‘by’ members of the Autistic and autism communities (rather than ‘to’, ‘about’, or ‘for’ them), often referred to as ‘co-production’, ‘participatory research’, ‘patient and public involvement’ or ‘integrated knowledge translation’.

We therefore now require authors to include a community involvement statement at the end of the Methods section for Research Reports, outlining whether autistic people or family members, community providers, policy makers, agency leaders or other community stakeholders were involved in developing the research question, study design, measures, implementation, or interpretation and dissemination of the findings. Community members should be duly acknowledged – as authors or in the acknowledgements section – depending on the extent and nature of their contribution. We recommend that authors follow the BMJ's editorial guidelinesfor documenting how community stakeholders were involved in their research.

If community members were not involved in the study, authors should state this.

For more details about the reasoning behind this journal requirement, and editorial expectations of authors, please download this FAQs document.

.

2.9 Data Policy Statement

Autism supports open research practices and FAIR principles. As such encourages authors to share their data wherever possible and submit their data (or a link to it) and where applicable, their syntax/command files for the analyses presented in the contribution. Authors can make data available through a third party data repository or on the journal website as a supplementary data file.

If cited data is restricted (e.g. classified, require confidentiality protections, were obtained under a non-disclosure agreement, or have inherent logistical constraints), authors should notify the editor at the time of submission. The editor shall have full discretion to follow their journal's policy on restricted data, including declining to review the manuscript or granting an exemption with or without conditions. The editor shall inform the author of this decision prior to review.

Where data is sensitive and cannot be shared in an open forum, authors are encouraged to share metadata and provide a contact for requesting access if the raw data itself cannot be made available.

Data can be submitted with your article and hosted on the SAGE *Autism* website where we work with Figshare to host data content. Authors can use a recognised third party data repository service to host their data such as Open Science framework. Authors may use their institution's data sharing repository.

Autism also encourages authors to delineate clearly the analytic procedures upon which their published claims rely, and where possible provide access to all relevant analytic materials. If such materials are not published with the article, we encourage authors to share to the greatest extent possible through a digital repository (above).

Autism encourages authors to use data citation practices that identify a dataset's author(s), title, date, version, and a persistent identifier. In sum, data should be referenced and cited, where possible, as an intellectual product of value.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Autism and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

3.3 Open access and author archiving

Autism offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelinesand Publishing Policies.

4. Preparing your manuscript for submission

4.1 Formatting

Autism asks that authors use the APA style for formatting. The APA Guide for New Authors can be found on the APA website, as can more general advice for authors.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.4 Terminology

4.4.1 Terminology about autism and autistic people

Autism has researched and produced its own guidance on terminology and language used in autism research. Please consult the guide here: autism terminology guidelines.

4.4.2 Language used to discuss race and ethnicity

Likewise, *Autism* has also produced the following guidance to be considered when writing about race and ethnicity. Please consult the guide here: race and ethnicity language guidelines.

4.5 Reference style

Autism adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

Autism is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit http://mc.manuscriptcentral.com/autism to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Lay Abstracts

As part of your submission you will be asked to provide a lay abstract of your article. Lay abstracts are a brief (max 250 words) description of the paper that is easily understandable. These abstracts will be made widely available (to the general public, and particularly to autistic people and their families). As such, lay abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

Authors may consider the following questions when composing their lay abstract.
a. What is already known about the topic?
b. What this paper adds?
c. Implications for practice, research or policy

Authors may also find the following resources helpful on this topic:

- How to write a summary paragraph
- Self Advocacy Resource and Technical Assistance Center (SARTAC): Plain Language
- Center for Plain Langauage: Five steps to Plain Language

5.4 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway

Back to top

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

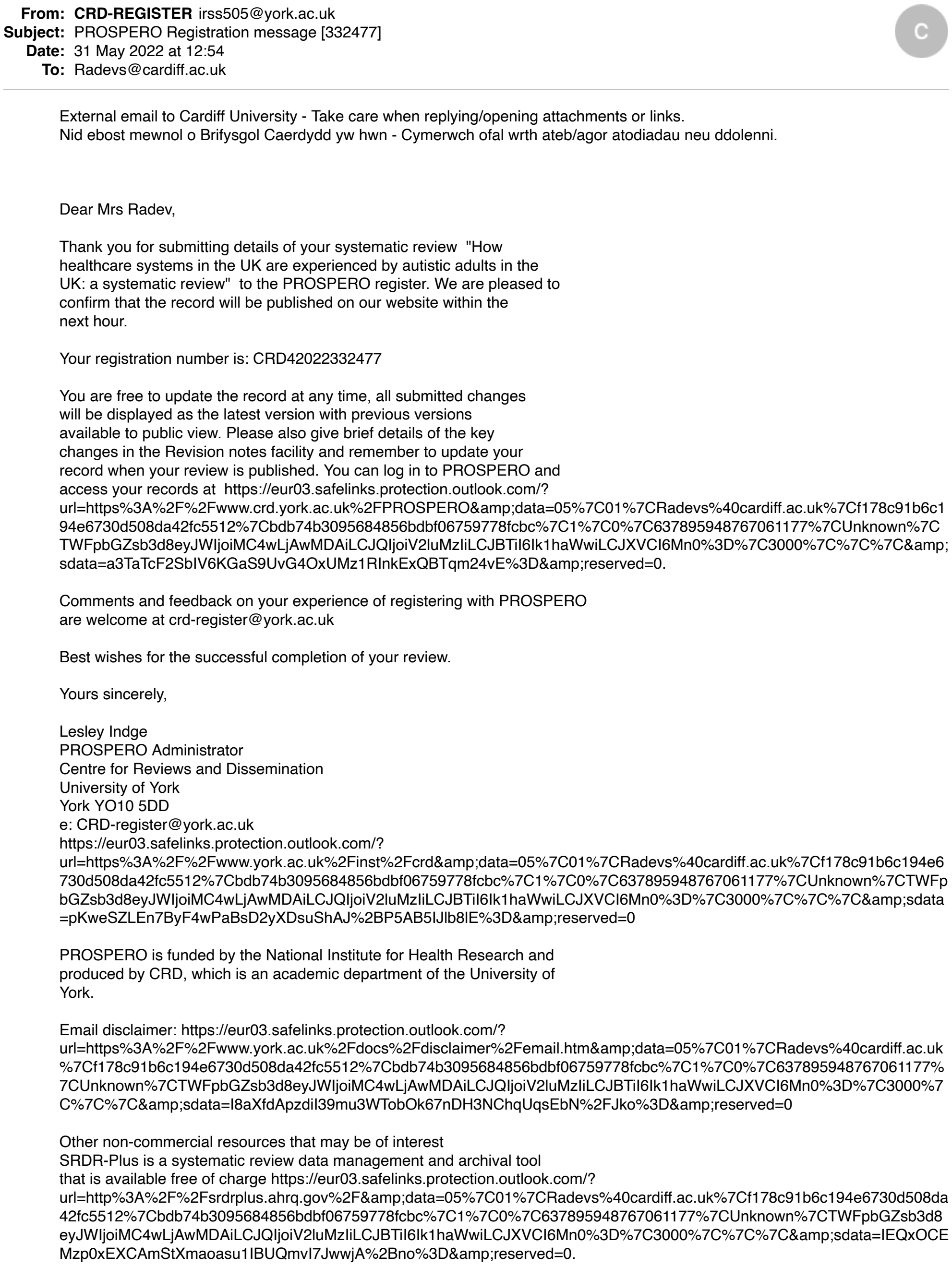
6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Articlepage on the Gateway for tips and advice.

Appendix B - PROSPERO Confirmation email



From: **CRD-REGISTER** irss505@york.ac.uk
Subject: PROSPERO Registration message [332477]
Date: 31 May 2022 at 12:54
To: Radevs@cardiff.ac.uk

External email to Cardiff University - Take care when replying/opening attachments or links.
Nid ebost mewnol o Brifysgol Caerdydd yw hwn - Cymerwch ofal wrth ateb/agor atodiadau neu ddolenni.

Dear Mrs Radev,

Thank you for submitting details of your systematic review "How healthcare systems in the UK are experienced by autistic adults in the UK: a systematic review" to the PROSPERO register. We are pleased to confirm that the record will be published on our website within the next hour.

Your registration number is: CRD42022332477

You are free to update the record at any time, all submitted changes will be displayed as the latest version with previous versions available to public view. Please also give brief details of the key changes in the Revision notes facility and remember to update your record when your review is published. You can log in to PROSPERO and access your records at https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.crd.york.ac.uk%2FPROSPERO&data=05%7C01%7CRadevs%40cardiff.ac.uk%7Cf178c91b6c194e6730d508da42fc5512%7Cbdb74b3095684856bdbf06759778fcbc%7C1%7C0%7C637895948767061177%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=a3TaTcF2SbIV6KGaS9UvG4OxUMz1RInkExQBTqm24vE%3D&reserved=0.

Comments and feedback on your experience of registering with PROSPERO are welcome at crd-register@york.ac.uk

Best wishes for the successful completion of your review.

Yours sincerely,

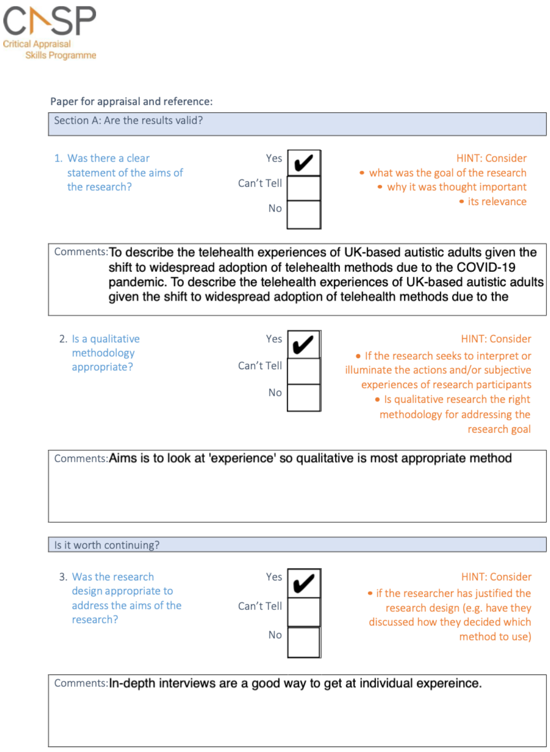
Lesley Indge
PROSPERO Administrator
Centre for Reviews and Dissemination
University of York
York YO10 5DD
e: CRD-register@york.ac.uk
https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.york.ac.uk%2Finst%2Fcrd&data=05%7C01%7CRadevs%40cardiff.ac.uk%7Cf178c91b6c194e6730d508da42fc5512%7Cbdb74b3095684856bdbf06759778fcbc%7C1%7C0%7C637895948767061177%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=pKweSZLEn7ByF4wPaBsD2yXDsuShAJ%2BP5AB5IJlb8lE%3D&reserved=0

PROSPERO is funded by the National Institute for Health Research and produced by CRD, which is an academic department of the University of York.

Email disclaimer: https://eur03.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.york.ac.uk%2Fdocs%2Fdisclaimer%2Femail.htm&data=05%7C01%7CRadevs%40cardiff.ac.uk%7Cf178c91b6c194e6730d508da42fc5512%7Cbdb74b3095684856bdbf06759778fcbc%7C1%7C0%7C637895948767061177%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=I8aXfdApzdiI39mu3WTobOk67nDH3NChqUqsEbN%2FJko%3D&reserved=0

Other non-commercial resources that may be of interest
SRDR-Plus is a systematic review data management and archival tool that is available free of charge https://eur03.safelinks.protection.outlook.com/?url=http%3A%2F%2Fsrdrplus.ahrq.gov%2F&data=05%7C01%7CRadevs%40cardiff.ac.uk%7Cf178c91b6c194e6730d508da42fc5512%7Cbdb74b3095684856bdbf06759778fcbc%7C1%7C0%7C637895948767061177%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=IEQxOCEMzp0xEXCAmStXmaoasu1IBUQmvI7JwwjA%2Bno%3D&reserved=0.

Appendix C – Example CASP checklist



CASP
Critical Appraisal Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments: To describe the telehealth experiences of UK-based autistic adults given the shift to widespread adoption of telehealth methods due to the COVID-19 pandemic. To describe the telehealth experiences of UK-based autistic adults given the shift to widespread adoption of telehealth methods due to the

2. Is a qualitative methodology appropriate?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments: Aims is to look at 'experience' so qualitative is most appropriate method

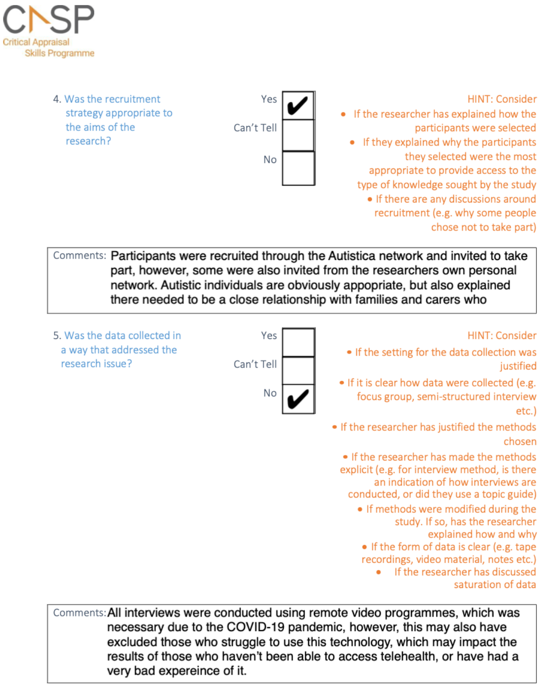
Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments: In-depth interviews are a good way to get at individual expereince.



CASP
Critical Appraisal Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

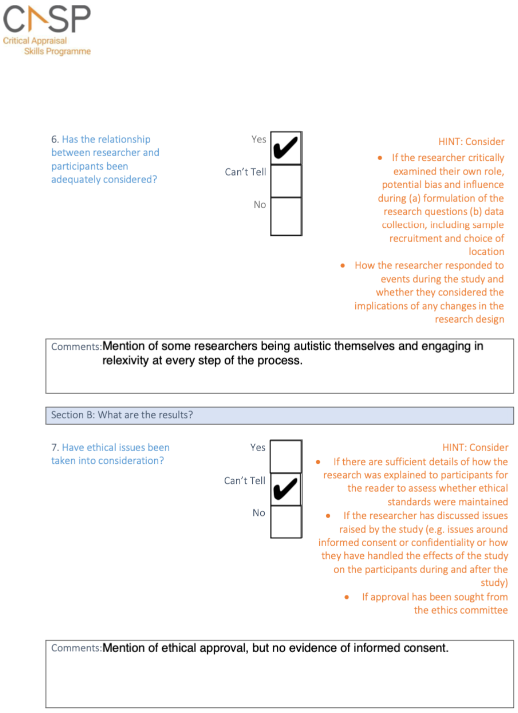
Comments: Participants were recruited through the Autistica network and invited to take part, however, some were also invited from the researchers own personal network. Autistic individuals are obviously appropriate, but also explained there needed to be a close relationship with families and carers who

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☑

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments: All interviews were conducted using remote video programmes, which was necessary due to the COVID-19 pandemic, however, this may also have excluded those who struggle to use this technology, which may impact the results of those who haven't been able to access telehealth, or have had a very bad expereince of it.



CASP
Critical Appraisal Skills Programme

6. Has the relationship between researcher and participants been adequately considered?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments: Mention of some researchers being autistic themselves and engaging in relexivity at every step of the process.

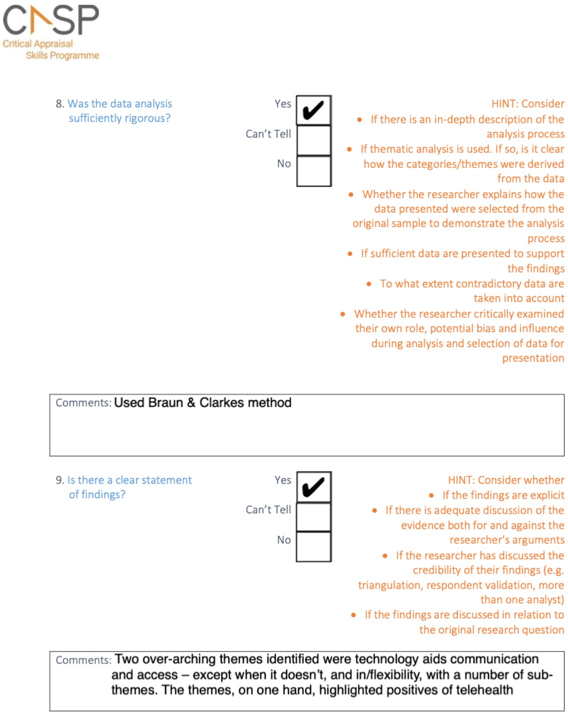
Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☑
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments: Mention of ethical approval, but no evidence of informed consent.



CASP
Critical Appraisal Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments: Used Braun & Clarkes method

9. Is there a clear statement of findings?

Yes ☑
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments: Two over-arching themes identified were technology aids communication and access – except when it doesn't, and in/flexibility, with a number of sub-themes. The themes, on one hand, highlighted positives of telehealth

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments: Acknowledges that generalisability was limited by only those with the ability to access technology being able to take part. Recomends several avenues for future research including increased participant numbers and specialist Autism services.

Appendix D – Phase 4 of meta-ethnography: Determining how the studies are related

Ali et al. (2022)	Au-Yeung et al. (2019)	Babb et al. (2021)	Camm-Crosbie et al. (2019)	Crane et al. (2018)	Griffith et al. (2012)
Telehealth could make attending appointments more affordable and accessible. Not attending clinics in person was less anxiety provoking. Harder to communicate distress over a remote call. Potential for strong emotions to be misperceived as aggression. Overall sense of mistrust in the healthcare service. Mixed views on whether telehealth improved communication or not. Support for online booking systems.	ASC characteristics confused with symptoms of a mental health condition and mental health difficulties perceived to be resultant of ASC . Importance of autism awareness training. Priority is given to treating mental health conditions and thus leaving autism unaddressed. Healthcare professionals' lack of awareness and understanding of autism. Poor communication between autistic adults and healthcare professionals. Treatment not being suited to their needs.	Mental health diagnoses as a barrier to autism diagnosis. Autistic traits often attributed as ED-fuelled. Communication difficulties or a lack of flexibility, were often misinterpreted as disengagement from treatment. Typical therapeutic approaches not beneficial Importance of feeling heard and validated within services. Adapting service environments, particularly relating to sensory sensitives is important. Routine and structure resonated as an important factor for many autistic women in their ability to engage with treatment.	Improved autism training needed, so it's not down to autistic people to educate professionals. Lack of understanding contributes to barriers to accessing support. Need for support dismissed due to (mis)perceptions of 'high-functioning' ASC. It took much longer to establish a rapport. Communication difficulties exacerbated further when 'in crisis' and in an unfamiliar and noisy environment. Alexithymia, communication problems and camouflaging leads to challenges in recognising they needed help. Therapy is effective but takes longer. Consistency is important.	Tension over whether the individual or the professional is 'the expert' Lack of autism awareness amongst professionals. Tendency to focus on negatives not positives. Spectrum nature of the condition was highlighted as a key barrier. Clinical environments are important, waiting areas should be appropriate so as not to contribute to fears and anxieties. Autism diagnostic pathways are not clear or supportive. More transparency is needed concerning the whole process, including the role of the professionals involved.	Participants opinions and viewpoints often side-lined in favour of academic opinion. Services should be individualised and tailored to each person. Support services are often tailored for those with intellectual or physical disabilities. Accurate information about Asperger syndrome is important to help challenge stereotypes and misunderstandings. A mainstream approach to helping people with anxiety or depression is cognitive behavioural therapy (CBT), but this may not be helpful for autistic people.

Harmens et al. (2022)	Leedham et al. (2020)	Mason et al. (2021)	McMillion et al. (2021)	Parmar et al. (2022)	Punshon et al. (2019)
Feeling unseen and needing to be the professionals themselves. Autism training on women and girls is needed Focus on difficulties, rather than strengths. Impact of masking on recognition, diagnosis and validation. No clear diagnostic pathway. Professionals lacked knowledge of autism and how to support an autistic person. Feeling disbelieved and dismissed. Accessibility and well-being impacted by anxieties and communication difficulties	Experience was not understood by professionals. Mental health difficulties were present across the data, with many still specifically experiencing anxiety and low mood post-diagnosis. Frequently mislabelled and misdiagnosed. Widespread limited understandings of ASC in females, which influenced late diagnosis Negative consequences of power imbalances.	Professionals have poor knowledge about autism, stereotyped and incorrect views resulting in negative impact on the quality of care provided as well as physical symptoms being potentially overlooked. Alexithymia can impact on ability to describe symptoms. Cognitive strategies such as rehearsing conversations may be used, which will cause problems if unexpected questions are asked. Literal understandings may also cause problems. Waiting rooms can be aversive due to sensory sensitivities, being too busy, bright, noisy or smells. Continuity of care is also important. Adaptations will improve healthcare access and result in improved healthcare outcomes.	Autistic people felt dismissed by general medical professionals. Concerns not acknowledged and not treated with dignity and respect. Lack of feeling understood, as well as lack of understanding. Adequate time to process communication and provision of adapted information is important. Sensory sensitivity to the environment included bright lights and upsetting noises and adapting environments can help reduce anxiety. Increased anxiety beginning before appointments and inhibiting communication. Lack of consistency, familiarity is important.	Eye care providers lack a basic understanding of Autism. Importance of continuity with who is seen as well as limiting how many different people are seen. Time is needed to become comfortable with someone. Clear and explicit communication is very important, subjective questions are difficult to answer and too many questions can be overwhelming. Written communication is preferable to verbal Altered sensory reactivity can cause distress and anxiety. Provision of 'what to expect' information in advance is beneficial There should be a range of ways to book appointments to increase control.	Lots of contact with mental health services Being misdiagnosed with other mental health problems. Failed interventions. Clinicians not trained to diagnose ASD. Early ASD diagnosis is associated with positive psychological outcomes Failures led to feeling misunderstood and blamed for difficulties. Alexithymia, difficulties with social and communication skills, and ‘camouflaging’ led to challenges in recognising they needed help and successfully requesting help. A lack of support led to loss of trust in services and anxiety over their diagnosis

Appendix E – Phase 5 of meta-ethnography: Translating the Studies into one another.

Common Concept from Phase 4	Ali et al. (2022)	Au-Yeung et al. (2019)	Babb et al. (2021)	Camm-Crosbie et al. (2019)	Crane et al. (2018)	Griffith et al. (2012)
Professionals lack of knowledge and understanding	Overall sense of mistrust in the healthcare service. *'There is a fear of doctors because doctors are trouble. . . .Because they'll often have declared you to be bad, or you've got a problem or whatever. It's not unlike – I mean, I am gay – it's not unlike the way it used to be, I think, for gay people and doctors. It was like: don't go near doctors. Because you can't trust them'*	ASC characteristics confused with symptoms of a mental health condition *'I had a formal diagnosis of bipolar (II) condition for around 17 years. I actually satisfy the DSM criteria for this, but have only [ever] been hypomanic once and that was antidepressant induced. I don't benefit from mood stabilisers, antipsychotics or most antidepressants, and things like stress, working long days and staying up late don't induce mania. …Hence, once my autism had been diagnosed, I was able to get a consultant psychiatrist to say that she didn't think I'd ever had bipolar and it has been revoked as a current diagnosis.'* Healthcare professionals' lack of awareness and understanding of autism. Treatment not being suited to their needs.	Autistic traits often attributed as ED-fuelled. *'When I was in hospital, I kept getting told off for walking on tip toes and for fidgeting a lot . . . they thought I was doing these things to burn more calories, except I'd been doing them for as long as I could remember.'* Typical therapeutic approaches not beneficial *'With the CBT, maybe the problem is that they assume you have a lot of these skills already . . . Therefore, I couldn't even begin to make changes, because I don't have any of those foundational skills.'*	Improved autism training needed, so it's not down to autistic people to educate professionals. *'some of them have asked to borrow books from me about autism or asked me to teach them about it and I feel that shouldn't be down to me'* Lack of understanding contributes to barriers to accessing support. Need for support dismissed due to (mis)perceptions of 'high-functioning' ASC. *'I think some of the issues with understanding is that some people don't think you can be really struggling if you are managing to go to work/uni etc. Of course in hindsight with the Asperger's diagnosis that is just partly because dropping the routine would be even worse.'*	Tension over whether the individual or the professional is 'the expert' *'The [professionals] said I didn't have [autism] and I knew that they'd got it wrong…although they were meant to be like the experts, I really didn't feel like they were…'* Lack of autism awareness amongst professionals. *'it seems that GPs aren't trained in awareness of Asperger's syndrome.'* Spectrum nature of the condition was highlighted as a key barrier. *'There's just not a lot of help unless you're very visibly autistic.'*	Accurate information about Asperger syndrome is important to help challenge stereotypes and misunderstandings. *'When I went to my GP I said, 'Could you refer me to somebody, because I'd like to look into getting a diagnosis for Asperger syndrome.' He turned round, and this is really important, he said, 'Asperger's, isn't that something that kids get?' Which really, really shocked me, I stood up, and said 'What happens to those children, do they not grow into adults?'* A mainstream approach to helping people with anxiety or depression is cognitive behavioural therapy (CBT), but this may not be helpful for autistic people.

	Harmens et al. (2022)	Leedham et al. (2020)	Mason et al. (2021)	McMillion et al. (2021)	Parmar et al. (2022)	Punshon et al. (2019)
Professionals lack of knowledge and understanding	Needing to be the professionals themselves. *'it feels very much like the onus is on you as an individual to make the assessment happen'* Focus on difficulties, rather than strengths. *'When I got my report back from my diagnostic process and that was like literally 15 pages of deficits, and I felt really low for a couple of days after that, and I had to kind of really consciously kind of re-find the positivity.'* Professionals lacked knowledge of autism Feeling disbelieved and dismissed. *'I went to my GP, and I didn't really know what say, but I just knew something wasn't OK, and something needed to stop, and . . . he started off saying, because I go to work every day, that means everything's fine and to me that wasn't really true'*	Experience was not understood by professionals. Frequently mislabelled and misdiagnosed. *[Clinician] would say 'oh, you've got borderline personality disorder' ... I explained to him exactly why I wasn't BPD ... I wasn't getting any answers, I just stopped going. I just stopped asking for help, I just stopped, you know, looking for answers.'* Widespread limited understandings of ASC in females, which influenced late diagnosis Negative consequences of power imbalances. *'got to a point where I was almost convinced that they wanted to be right and I'd actually buried some deep trauma and I had no memory of it and I started questioning the whole – like everything.'*	Professionals have poor knowledge about autism, stereotyped and incorrect views resulting in negative impact on the quality of care provided as well as physical symptoms being potentially overlooked. *'Or they say you don't have it because they met someone once with autism and you don't fit into their image of what an autistic person is.'*	Autistic people felt dismissed by general medical professionals. *'when I've previously told dentists I'm autistic, it appears to have largely been ignored'* Concerns not acknowledged and not treated with dignity and respect. *'dentists act like I'm making excuses'* Lack of feeling understood, as well as lack of understanding.	Eye care providers lack a basic understanding of Autism. Time is needed to become comfortable with someone. *'if the optician straight away has been quite friendly to start with, I feel more comfortable. So, they can come into my space more…'*	Being misdiagnosed with other mental health problems. *'I wasn't surprised that I had Asperger syndrome but I was surprised that I was being told . . . that I had Asperger syndrome because I got so used to people being so rubbish at diagnosis, like all of these doctors and psychiatrists and psychologists . . . who had just failed completely to get to the bottom of what was wrong with me.'* Failed interventions. *'My social worker thought, you know, if you just put a bit of pressure on him you can get him to go outside and socialize with people.'* Failures led to feeling misunderstood and blamed for difficulties. *'I was seeing a psychiatrist at the time . . . I was having a lot of difficulty communicating with him. The first time I saw him erm . . . he was very angry with me because he said 'How can I help you if you don't tell me what is wrong?'*

Appendix F – Example of Superordinate Theme Development

Concepts identified in Phase 4 across all papers	Second Order Construct(s)	Sub-ordinate Third Order Construct	Super-ordinate Third Order Construct
• ASC characteristics confused with symptoms of a mental health condition • Autistic traits often attributed as ED-fuelled. • Frequently mislabelled and misdiagnosed. • misdiagnosed with other mental health problems. • Healthcare professionals' lack of awareness and understanding of autism. • lack a basic understanding • Professionals have poor knowledge about autism, • Lack of autism awareness amongst professionals. • Professionals lacked knowledge of autism • Lack of understanding • Not understood by professionals. • challenge stereotypes and misunderstandings. • Focus on difficulties, rather than strengths. • (mis)perceptions of 'high-functioning' ASC. • Spectrum nature of the condition • Treatment not being suited to their needs. • Typical therapeutic approaches not beneficial • CBT may not be helpful for autistic people. • Failed interventions.	• Autism is often not recognised by professionals • Autistic people are often misdiagnosed with other conditions • The spectrum nature of Autism causes misunderstandings of ability to cope and support needs • Therapies offered based on misdiagnosis or which are not adapted for autism results in failed interventions	Misunderstanding leading to misdiagnosis and inadequate support	**Professionals lack of Knowledge is Damaging** *Lots of papers talk about the experience of professionals having a lack of autism knowledge and understanding. This can be damaging due to placing additional pressure on the patient to be the expert, as well as increasing the risk of misdiagnosis and impacting the therapeutic relationship through breaking down patient trust in professionals*
• Overall sense of mistrust • Feeling disbelieved and dismissed. • Negative consequences of power imbalances. • dismissed by general medical professionals. • Feeling misunderstood and blamed for difficulties.	• Feeling blamed by professionals for difficulties due to a lack of understanding • Feeling dismissed and unsupported by professionals	Impact on Therapeutic Relationship	

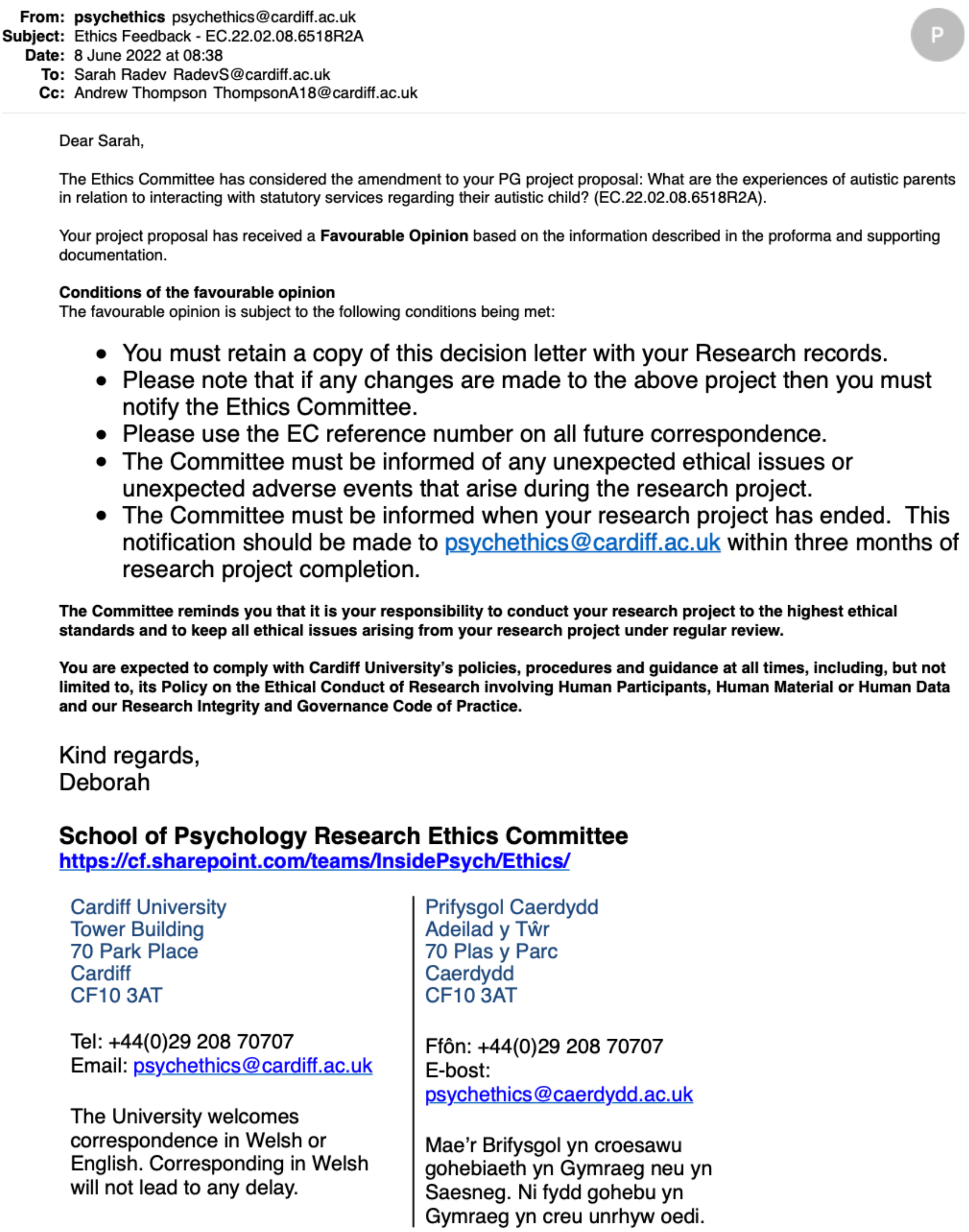
• Concerns not acknowledged • Lack of feeling understood, • Time is needed to become comfortable with someone.	• Leads to a loss of trust in professionals and in services in general		
• Tension over whether the individual or the professional is 'the expert' • Needing to be the professionals themselves.	• Tension on whether the individual or the professional is ‘the expert’ • Lack of professional guidance can lead to self-doubt	Pressure to be the expert in the room	

Appendix G – Additional Quotes

Theme 1: Professionals' lack of Knowledge can be Damaging	
Misunderstanding leading to misdiagnosis and inadequate support	I wasn't surprised that I had Asperger syndrome but I was surprised that I was being told . . . that I had Asperger syndrome because I got so used to people being so rubbish at diagnosis, like all of these doctors and psychiatrists and psychologists . . . who had just failed completely to get to the bottom of what was wrong with me. (Punshon et al., 2009) I think some of the issues with understanding is that some people don't think you can be really struggling if you are managing to go to work/uni etc. Of course in hindsight with the Asperger's diagnosis that is just partly because dropping the routine would be even worse. (Camm-Crosbie et al., 2019) The [professionals] said I didn't have [autism] and I knew that they'd got it wrong…although they were meant to be like the experts, I really didn't feel like they were (Crane et al., 2018) [Clinician] would say 'oh, you've got borderline personality disorder' … I explained to him exactly why I wasn't BPD … I wasn't getting any answers, I just stopped going. I just stopped asking for help, I just stopped, you know, looking for answers (Leedham et al., 2020)
Impact on Therapeutic Relationship	I was seeing a psychiatrist at the time . . . I was having a lot of difficulty communicating with him. The first time I saw him erm . . . he was very angry with me because he said 'How can I help you if you don't tell me what is wrong?' (Punshon et al., 2009) She basically didn't believe me when I said this is not about [body image] . . . she wanted to do body image therapies with me and I . . . found it humiliating, and also irritating and condescending that I was being not listened to. (Babb et al., 2021) This created anxiety at an already stressful time: "I'd never brought anything up like this with the GP before…I felt completely at the mercy of whether they believed me or not…whether they agreed with my assessment of myself…I was really very worried. (Crane et al., 2018)

Theme 2: Need to Reduce Processing Demands	
Communication Differences	I felt like I was having a breakdown inside but I didn’t know how to make the inside feelings show to other people. (Camm-Crosbie et al., 2019) People think if you’re really sensitive you must be really in tune with the slightest twinge, you know where it is . . . but I don’t know what’s wrong. Or how to articulate it (Mason et al., 2021). I don't want to anticipate, but I wish the language was more concrete.…don't ask me what's better, ask me is it supposed to be sharper or brighter or something. (Parmar et al., 2022) I can’t always communicate if I’m in crisis. Ward rounds in the hospital would always be awfully stressful for me, having to talk in front of a room of people. So are meetings with my Psychiatrist. (Camm-Crosbie et al., 2019)
Sensory Processing Differences	When you do get the appointment you’re in a waiting room and you can’t always get space to yourself, kids are screaming and it’s too noisy. (Mason et al., 2021) it would be nice to have some constant [white] background noise, whether it was sort of waves of a sea…just something to amalgamate all the sounds together.” (Parmar et al., 2022)
Theme 3: Adaptations to Improve Engagement	
Accessibility Difficulties	to even approach the building, the stress of that, 110% outweighs the stress of where I have to go, what I have to do (Parmar et al., 2022)
Consistency and Predictability	going back to the same person was good because it takes me ages to form a good rapport (Camm-Crosbie et al., 2019) You talk to someone and then you talk to someone else, and then you go and have like the pre-exam… And then you go and see the optician who's someone else. And then you speak to the salesperson. So yeah, I find that very difficult. And I knew it was going to be like that, so I did put it off as long as I could (Parmar et al., 2022)

Appendix H – Ethics Approval



From: **psychethics** psychethics@cardiff.ac.uk
Subject: Ethics Feedback - EC.22.02.08.6518R2A
Date: 8 June 2022 at 08:38
To: Sarah Radev RadevS@cardiff.ac.uk
Cc: Andrew Thompson ThompsonA18@cardiff.ac.uk

Dear Sarah,

The Ethics Committee has considered the amendment to your PG project proposal: What are the experiences of autistic parents in relation to interacting with statutory services regarding their autistic child? (EC.22.02.08.6518R2A).

Your project proposal has received a **Favourable Opinion** based on the information described in the proforma and supporting documentation.

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met:

- You must retain a copy of this decision letter with your Research records.
- Please note that if any changes are made to the above project then you must notify the Ethics Committee.
- Please use the EC reference number on all future correspondence.
- The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.
- The Committee must be informed when your research project has ended. This notification should be made to psychethics@cardiff.ac.uk within three months of research project completion.

The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.

You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.

Kind regards,
Deborah

School of Psychology Research Ethics Committee
https://cf.sharepoint.com/teams/InsidePsych/Ethics/

Cardiff University
Tower Building
70 Park Place
Cardiff
CF10 3AT

Tel: +44(0)29 208 70707
Email: psychethics@cardiff.ac.uk

The University welcomes correspondence in Welsh or English. Corresponding in Welsh will not lead to any delay.

Prifysgol Caerdydd
Adeilad y Tŵr
70 Plas y Parc
Caerdydd
CF10 3AT

Ffôn: +44(0)29 208 70707
E-bost:
psychethics@caerdydd.ac.uk

Mae'r Brifysgol yn croesawu gohebiaeth yn Gymraeg neu yn Saesneg. Ni fydd gohebu yn Gymraeg yn creu unrhyw oedi.

Appendix I – Recruitment Advert

Are you the parent of an Autistic child and have an Autistic spectrum diagnosis yourself? I am looking for participants for a research study aimed at better understanding the experiences of autistic parents when interacting with services to support the needs of their autistic child. This will involve taking part in an hour-long interview about your experience of interacting with services for your autistic child how being autistic yourself may impact this experience. We hope that the research will be helpful for informing appropriate support for autistic parents when seeking support for their child.

I am a Trainee Clinical Psychologist and this project will form part of my final dissertation. You will be eligible to take part if you:

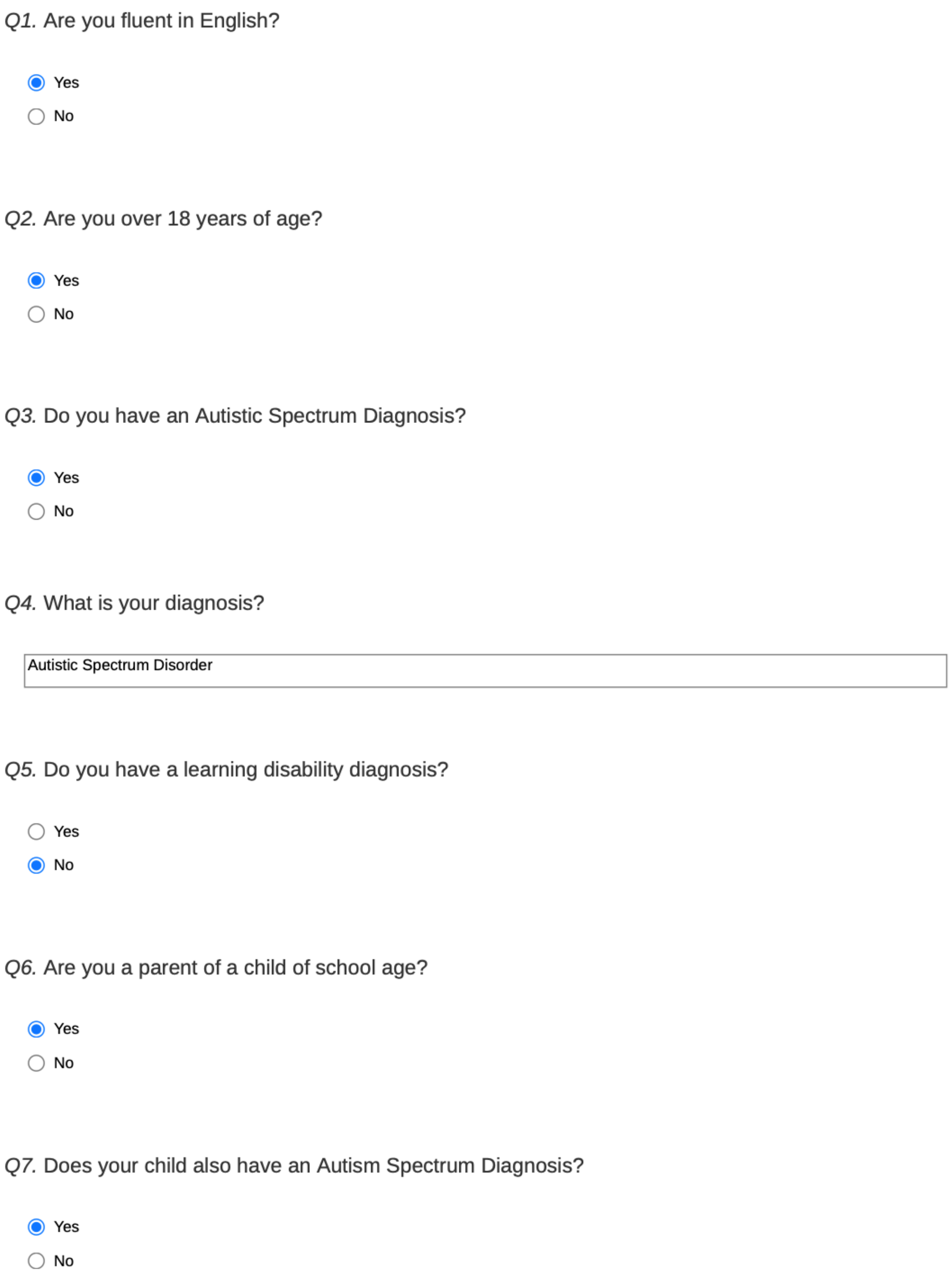
- Have a formal diagnosis on the autism spectrum (e.g. autism; Asperger Syndrome; High-functioning autism; autism spectrum condition/disorder)
- Are a parent of an Autistic child who attends mainstream school
- Do not also have a diagnosis of a learning disability
- Are fluent in English
- Are over 18 years of age

If you are interested in taking part please access the following survey which will log your interest and assess whether or not you meet the necessary eligibility criteria.

Please do get in touch if you have any questions and further information will be provided.

Sarah Radev: radevs@cardiff.ac.uk

Appendix J – Qualtrics Inclusion Criteria Survey



Q1. Are you fluent in English?

● Yes
○ No

Q2. Are you over 18 years of age?

● Yes
○ No

Q3. Do you have an Autistic Spectrum Diagnosis?

● Yes
○ No

Q4. What is your diagnosis?

Autistic Spectrum Disorder

Q5. Do you have a learning disability diagnosis?

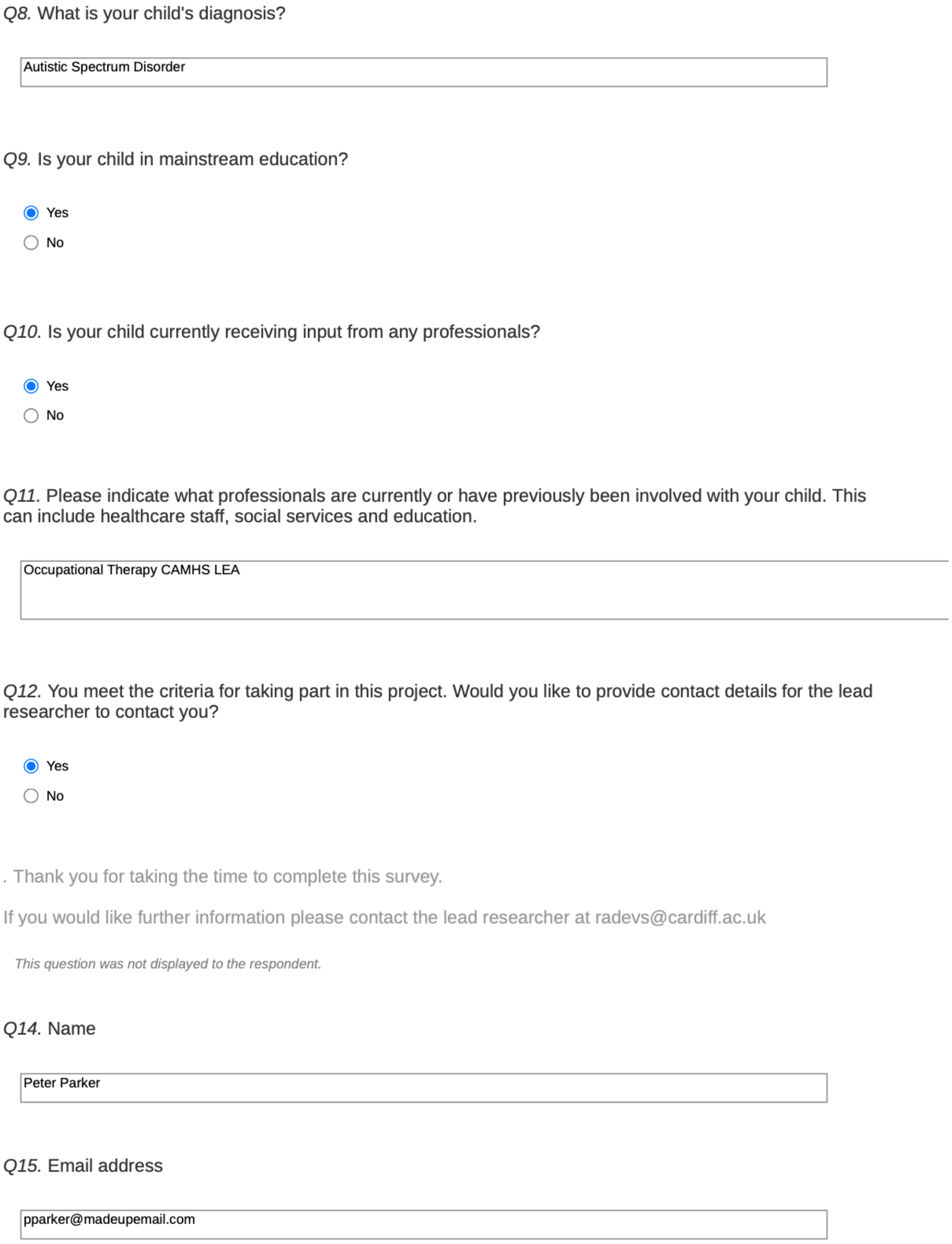
○ Yes
● No

Q6. Are you a parent of a child of school age?

● Yes
○ No

Q7. Does your child also have an Autism Spectrum Diagnosis?

● Yes
○ No



Q8. What is your child's diagnosis?

Autistic Spectrum Disorder

Q9. Is your child in mainstream education?

● Yes
○ No

Q10. Is your child currently receiving input from any professionals?

● Yes
○ No

Q11. Please indicate what professionals are currently or have previously been involved with your child. This can include healthcare staff, social services and education.

Occupational Therapy CAMHS LEA

Q12. You meet the criteria for taking part in this project. Would you like to provide contact details for the lead researcher to contact you?

● Yes
○ No

. Thank you for taking the time to complete this survey.

If you would like further information please contact the lead researcher at radevs@cardiff.ac.uk

This question was not displayed to the respondent.

Q14. Name

Peter Parker

Q15. Email address

pparker@madeupemail.com

Q16. Phone Number

07973 659993

Q17. Preferred method of contact

● Email

○ Phone

Appendix K – Information Sheet

Sarah Radev
Trainee Clinical Psychologist
Doctoral Programme in Clinical Psychology
Cardiff University
11th Floor, Tower Building
70 Park Place
Cardiff CF10 3AT
Email: radevs@cardiff.ac.uk

You have been invited to take part in a research study. Before you make the decision whether or not to participate, please ensure that you have read all of the following information which will outline what will be involved.

Why have I been invited?

You have been invited to take part because you have indicated that you are an adult with an autism spectrum diagnosis who is also the parent to a child with an autistic spectrum diagnosis.

Do I have to take part?

No. It is entirely your decision whether or not you take part and what you feel comfortable to disclose. This remains the case throughout the process and if at any time you decide that you no longer want to participate or for any information gathered to be used in this project, you are free to withdraw without any explanation. Any information already collected from you will at that time be destroyed.

You also retain the right to decline to answer any questions you do not wish to at any point in the interview.

What will participating involve?

You will contacted either by telephone or email, depending on your preference, by the lead researcher and asked to take part in a one hour long interview. The interview will take place either in person on university premises, via video or on the telephone, depending on what you would be most comfortable with. The interview will involve asking you some questions about your experience of interacting with services on behalf of your autistic child.

The interview will be recorded on a secure password encrypted device and then transcribed by a university approved transcriber. It will then be analysed using Interpretative Phenomenological Analysis.

Will information I give be confidential?

Yes. All information will be kept on password protected secure devices, and you will not be identifiable in any reports or publication.

What benefits are there to me taking part?

You will have the opportunity to share your own experiences which it is hoped will be helpful in informing services of the best ways to support autistic parents when advocating on behalf of their autistic children.

Will I be reimbursed for taking part?

There will be a reimbursement of any relevant travel expenses incurred through your participation in this project where receipts of travel are provided.

How will my information be used?

This project is funded and organised by Cardiff University. The results collected in this project will be analysed and submitted as part of the lead researcher's doctoral dissertation in May 2023, as well as being prepared for publication. A copy of the study can be made available to you on request.

Contact Information

The lead researcher on this project is **Sarah Radev**, Trainee Clinical Psychologist. If you have any questions about the research, either before participation or at any time during the course of participating, she can be contacted at radevs@cardiff.ac.uk.

Appendix L – Semi-structured Interview Schedule

Introduction

Thank you for taking part in this research. As you will know I'm interested in exploring the experience of autistic adults when interacting with services on behalf of their autistic children. This may be healthcare services, social services or education services. I myself am an autistic parent of an autistic child, so I do have some first hand experience myself, but I am really interested in hearing what *your* experience has been. I will be asking you some questions about what services you have been involved with for your child, and what your experiences of this have been. First though, do you have any questions you would like to ask me?

[Complete consent form together]

If at any time you have any questions that you would like to ask, or you would like to take a break or stop the interview please let me know and we can do so.

Everything we talk about today is confidential and all of your information you have provided and that will be contained in the recording from today will be anonymised in the final report so it will not be possible to identify you.

However, the exception to this would be if you were to talk about something that caused concerns either for your own safety or for the safety of anyone else, in which case I would need to discuss with a healthcare professional to ensure you had the necessary support in place. In this instance, I would discuss this with you first.

First of all we're just going to collect some simple information about you and your family.

Demographic Information

What is your relationship to the child you are a parent of? *Ie. Mother, father, carer etc…*
How old were you when you were diagnosed?
How old are you now?
What name, or terminology do you prefer to use to refer to your diagnosis?
What age was your child when they were diagnosed?
How old is your child now?
Do you have any other children?
Do any of your other children have a diagnosis?
Does your child live with you?
How would you describe your ethnicity? *(Prompts: for example, British)*
What is your marital or relationship status?
Do you have any formal qualifications?
What is your employment status?
Have you received any other diagnosis from other healthcare professionals?

Main Interview Schedule

1. What healthcare professionals have been involved in supporting your child?
    a. Can you tell me about what the experience of interacting with these professionals has been like for you?

Prompt: What emotions have these experiences brought up for you? What impact have these experiences had on your family life? How do you feel communication with these professionals is? Do you find it easy to talk to them?

   b. How do you experience the environments where you see these professionals?

Prompt: How comfortable and accessible do you find waiting rooms? How do you negotiate any sensory difficulties you may have in these environments?

2. Does your child receive any support form **from** Social Services? If so can you tell me a bit about your experience of this?

   Prompt: What emotions have these experiences brought up for you? What impact have these experiences had on your family life? How do you feel communication is? Do you find it easy to talk to them?

   a. Where do these interactions take place?

   Prompt: How do you feel about where these interactions take place? How does it feel inviting people into your home for home visits?

3. Can you tell me about how things have been with your child's school?

   Prompt: What is your experience of communicating with the school? Does your child have a statement of educational needs? Do you have a regular contact at the school you can talk to, such as a SENCO? Do you have regular meetings with the school about your child's education? Do you feel being autistic has given you a different experience than other parents?

   a. What has been your experience of liaising with the LEA?
   b. What has been your experience of educational psychologists?
   c. What has been your experience of parent's evenings?

   Prompt: Have you found parent's ***parents'*** *evenings accessible to you? Have you found it easy to talk to your child's teachers about their progress? What have parent's* ***parents'*** *evenings been like from a sensory perspective?*

4. What **if anything** have you shared or talked about in relation to your own diagnosis to professionals when talking to them about your child?

   Prompt: Do you choose to disclose at all? Do you think that it is helpful to disclose? What reactions have you experienced from professionals when you have disclosed?

5. How have your experiences of interacting with professionals regarding your autistic child impacted on your experience of being a parent?

   Prompt: Do you think being autistic has helped you advocate for you child differently? Has the experience impacted on your own mental health in any way?

6. What are your greatest sources of support in this area of your life?

   Prompt: Are you part of any support groups? Do you have friends with similar experiences? How do you manage this area of your lives as a family? Are there any professionals that have been particularly supportive?

7. Is there anything else that you have not had the chance to tell me about today that you feel would be important for me to know about your experience of being an autistic parent seeking support for an autistic child?

End of Interview

Thank you for taking part in this research today. Your interview will now be transcribed and analysed alongside other interviews to find similarities in experiences and areas where recommendations to professionals may be beneficial. The hope is that this research will help to inform services in supporting autistic parents when seeking support for their autistic children to make it a positive experience for them.

I am aware this could be a difficult topic to talk about. Is there anything you feel you would like to talk about further?

Appendix M– Consent Form

Sarah Radev
Trainee Clinical Psychologist
Doctoral Programme in Clinical Psychology
Cardiff University
11th Floor, Tower Building
70 Park Place
Cardiff CF10 3AT
Email: radevs@cardiff.ac.uk

Title of Research Project:

Name of Researcher: Sarah Radev

Participant Identification Number for this project:
Yes No

1. I have read and understood the information sheet provided explaining the outline of the project. ☐ ☐
2. I consent to take part in the project. ☐ ☐
3. I consent to the audio recording of my interview and understand this will remain on a secure encrypted device for confidentiality for no longer than the duration of completing the project. ☐ ☐
4. I understand that my participation is voluntary and that I am free to withdraw at any time in the process without given a reason and to decline to answer any questions I do not wish to answer during the interview process. ☐ ☐
5. I understand that all information I volunteer will remain confidential, meaning that in the final report I will not be identifiable. ☐ ☐
6. I consent to the use and publications of quotes of my words in publications, reports, web pages and other research outputs, which I understand will equally remain confidential with no inclusion of information that make me identifiable. ☐ ☐
7. I agree for the data collected from me during the course of this project to be stores anonymously and potentiality used in future research. ☐ ☐

Name of Participant ____________________ Date ____________ Signature ____________________

Lead Researcher ____________________ Date ____________ Signature ____________________

To be signed and dated in presence of the participant

Appendix N – Samples of Analysis Process

Step 1 – Original Transcript was read through while listening to audio

Step 2 – The transcript was read through line by line and Exploratory Notes made in the right hand column with the use of descriptive notes to summarise explicit meaning, linguistic notes to comment on the specific language used and *conceptual notes* where questions arose regarding wider understanding.

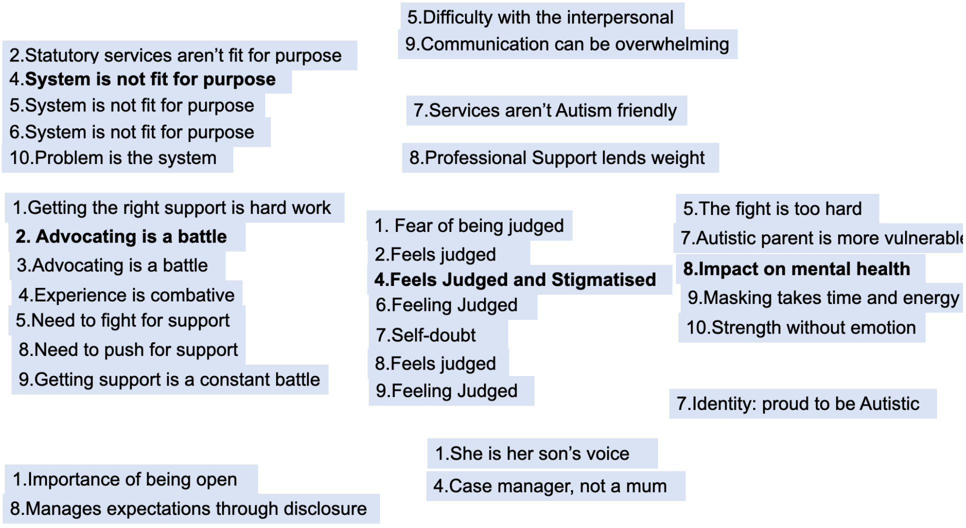
Step 3 – The transcript was read through again and experiential statements made in the left hand column

Experiential Statement	Original Transcript	Exploratory Notes
EHCP uses ableist language Expectation is to look and function 'normally'	Chloe: It's worded in very kind of, once again, ableist type language. You know it's almost as if they're trying to get, the child's targets are to try to make them look more normal, do you know what I mean?	The language used in EHCPs is ableist because the focus is on the expectation that the child will be working towards being 'normal'
	SR: I do.	
	Chloe: And function more normally.	
	SR: Yeah.	
Not the professional that's the problem, it's the process Focus on being normal, rather than being themselves	Chloe: I don't think that's a Psychologist who's…has…it's not her fault. She's probably got to follow a particular format hasn't she…I mean I know, I was a psychiatric nurse. I had really ridiculous tools to fill out, that were all based on targets and, you know, they were trying to make something measurable that wasn't really measurable. And you know the EHCP's kind of written in those kind of terms, so it's kind of not…I mean rather than trying…the language isn't...is much more about your child learning to *look* like normal people, function like normal people, non-autistic people you know, rather than becoming the best version of themselves.	*It's not the professionals fault, it's the system she has to work in* High expectation to be 'normal' and conform for her children, rather than focusing on the positives and their existing strengths

Step 4 – Experiential Statements were compiled in a new table and clustered to form experiential themes with supporting quotes. Exploratory notes were used to add additional information under each theme title.

Themes	Page	Quote
System not fit for purpose *The system is more complicated than it needs to be which makes it hard work. The job they are doing badly is easy and shouldn't be done badly. There are problems with communication between services but with her as well. Appointments aren't always a good use of the time, or the resources available and additional appointments are required which makes the service inefficient. It's not the professional's fault, it's the system they have to work in. Often private services run better because they have better funding.*		
• Frustrated at lack of inter service communication	1	"I think the most frustrating thing is that they don't share information with each other and a lot of it's duplicated."
• Things are overcomplicated	2	"There's a whole process that's just made too complicated."
• Process is disjointed and inconsistent	7	"it's frustrating form the point of view of it's very inefficient…and it's very disjointed…but each individual that you *do* see, does seem to be quite pleasant. But you'll quite often not see the same person again…*ever*."
• Process is inefficient	6	"And the other frustrating thing CAMHS is that they've got allocated appointment times, and quite often it goes beyond that time, but they'll just wrap it up, and then not finish. And then it's "oh yeah well we'll need to do the rest of this another time," and then you'll wait for months again…. and it's like, in the appointment time, when they should have just given you a longer appointment to begin with."
• Part of problem is lack of NHS funding	7	"quite often private companies will actually get it done quite quickly, presumably because they've got the money to do it… But I'm pretty sure that the NHS could have…you know…could do that as well, if it was better funded…"
• Not the professional that's the problem, it's the process	14	"I don't think that's a Psychologist who's…has…it's not her fault. She's probably got to follow a particular format hasn't she…"
• She's doing most of the work for the professionals	17	"I think that they didn't follow the right procedure. And I think that that was…because, when they described what they'd done, they hadn't filled out the right referral form. And *I* ended up referring them myself."
Feeling Judged *Being seen and understood and appropriately supported without any judgement has been important to her. Blaming and judging has a negative impact on her mental health. Her experience as a parent has been impacted because it has made her feel different to the other parents which may be triggering after a lifetime of being othered*		
• Feels judged as a bad mum	9	"there's one head teacher in particular that seemed to be very judgemental, but I'm one of those families, you know, a single parent, not working, living on benefits, you know. And he would take digs at it regularly"

Step 5 – Key themes from each transcript were placed into a powerpoint presentation where they were grouped together to form overarching themes.



2.Statutory services aren't fit for purpose
4.**System is not fit for purpose**
5.System is not fit for purpose
6.System is not fit for purpose
10.Problem is the system

5.Difficulty with the interpersonal
9.Communication can be overwhelming

7.Services aren't Autism friendly

8.Professional Support lends weight

1.Getting the right support is hard work
2. Advocating is a battle
3.Advocating is a battle
4.Experience is combative
5.Need to fight for support
8.Need to push for support
9.Getting support is a constant battle

1. Fear of being judged
2.Feels judged
4.Feels Judged and Stigmatised
6.Feeling Judged
7.Self-doubt
8.Feels judged
9.Feeling Judged

5.The fight is too hard
7.Autistic parent is more vulnerabl
8.Impact on mental health
9.Masking takes time and energy
10.Strength without emotion

7.Identity: proud to be Autistic

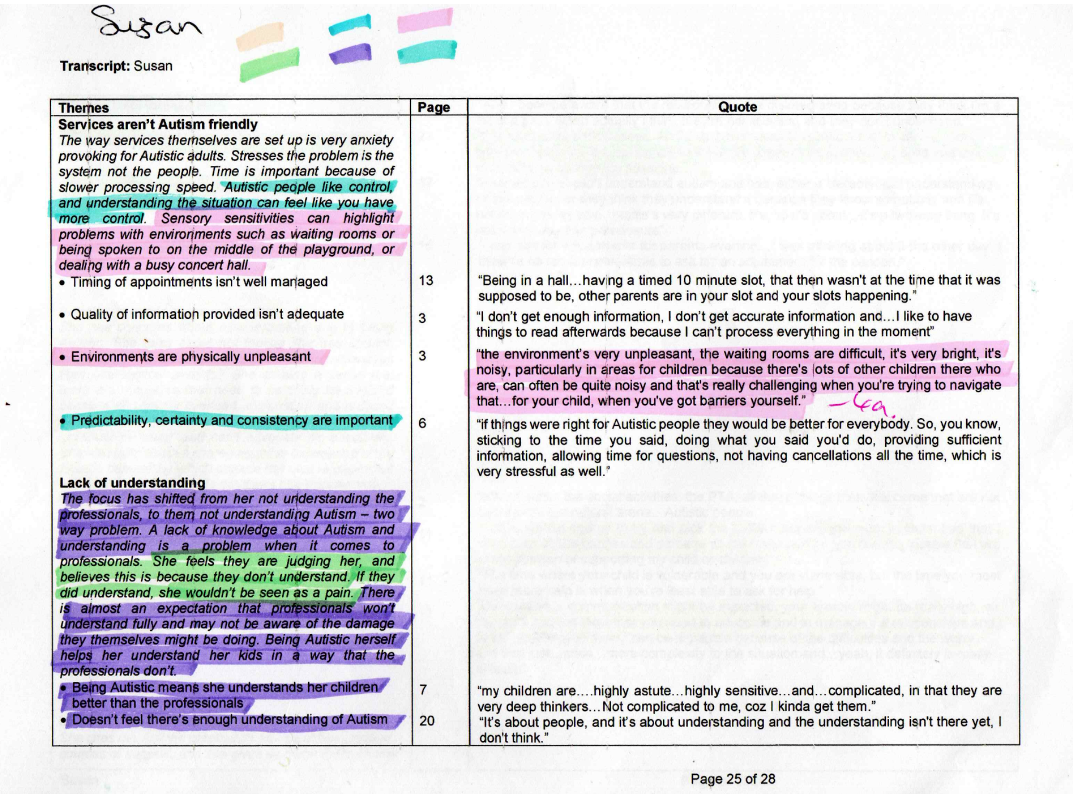
1.She is her son's voice
4.Case manager, not a mum

1.Importance of being open
8.Manages expectations through disclosure

Step 6 – Initial themes were identified along with potential sub themes and identifying which transcripts contributed to the theme. Each theme was colour coded.

1. Advocating is a battle – (impact on mental health), (knowledge is power)
   Contributing transcripts 1, 2, 3, 4, 5, 6, 7, 8, 9,10
2. Feels judged and stigmatised – (disclosure helps), (negative language used)
   Contributing transcripts 1, 2, 3, 4, 5, 6, 7, 8, 9, 10
3. Feels dismissed and unsupported
   Contributing transcripts 1, 2, 3, 4, 5, 7, 8, 9
4. Lack of understanding – (training not good enough), (mother has better understanding), (assumption parents won't be autistic)
   Contributing transcripts 1, 3, 4, 5, 6, 7, 8, 10
5. Sensory Difficulties – (feeling overwhelmed), (communication)
   Contributing transcripts 1, 3, 4, 7, 8
6. System not fit for purpose (unjust)
   Contributing transcripts 2, 3, 4, 5, 6, 7, 8, 10

Step 7 - Once this process was completed for each transcript the themes tables were printed off and highlighters used in a cross-case analysis to pick out experiential themes for the group.

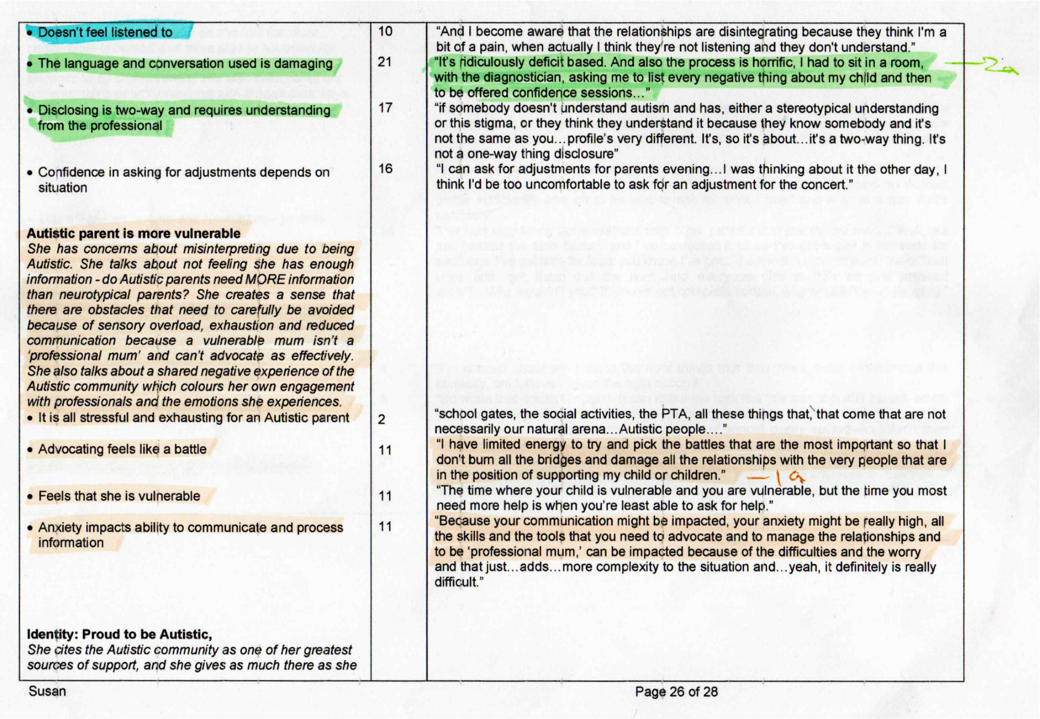


Susan

Transcript: Susan

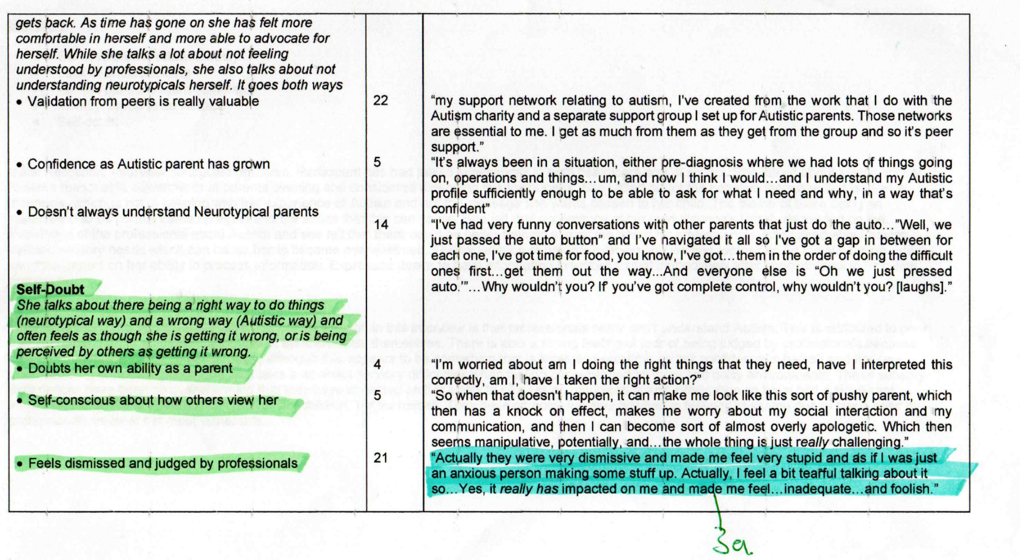
Themes	Page	Quote
Services aren't Autism friendly *The way services themselves are set up is very anxiety provoking for Autistic adults. Stresses the problem is the system not the people. Time is important because of slower processing speed. Autistic people like control, and understanding the situation can feel like you have more control. Sensory sensitivities can highlight problems with environments such as waiting rooms or being spoken to on the middle of the playground, or dealing with a busy concert hall.*		
• Timing of appointments isn't well managed	13	"Being in a hall…having a timed 10 minute slot, that then wasn't at the time that it was supposed to be, other parents are in your slot and your slots happening."
• Quality of information provided isn't adequate	3	"I don't get enough information, I don't get accurate information and…I like to have things to read afterwards because I can't process everything in the moment"
• Environments are physically unpleasant	3	"the environment's very unpleasant, the waiting rooms are difficult, it's very bright, it's noisy, particularly in areas for children because there's lots of other children there who are, can often be quite noisy and that's really challenging when you're trying to navigate that…for your child, when you've got barriers yourself." – 5a.
• Predictability, certainty and consistency are important	6	"if things were right for Autistic people they would be better for everybody. So, you know, sticking to the time you said, doing what you said you'd do, providing sufficient information, allowing time for questions, not having cancellations all the time, which is very stressful as well."
Lack of understanding *The focus has shifted from her not understanding the professionals, to them not understanding Autism – two way problem. A lack of knowledge about Autism and understanding is a problem when it comes to professionals. She feels they are judging her, and believes this is because they don't understand. If they did understand, she wouldn't be seen as a pain. There is almost an expectation that professionals won't understand fully and may not be aware of the damage they themselves might be doing. Being Autistic herself helps her understand her kids in a way that the professionals don't.*		
• Being Autistic means she understands her children better than the professionals	7	"my children are….highly astute…highly sensitive…and…complicated, in that they are very deep thinkers…Not complicated to me, coz I kinda get them."
• Doesn't feel there's enough understanding of Autism	20	"It's about people, and it's about understanding and the understanding isn't there yet, I don't think."

Page 25 of 28



- Doesn't feel listened to	10	"And I become aware that the relationships are disintegrating because they think I'm a bit of a pain, when actually I think they're not listening and they don't understand."
- The language and conversation used is damaging	21	"It's ridiculously deficit based. And also the process is horrific, I had to sit in a room, with the diagnostician, asking me to list every negative thing about my child and then to be offered confidence sessions…" 2a
- Disclosing is two-way and requires understanding from the professional	17	"if somebody doesn't understand autism and has, either a stereotypical understanding or this stigma, or they think they understand it because they know somebody and it's not the same as you…profile's very different. It's, so it's about…it's a two-way thing. It's not a one-way thing disclosure"
- Confidence in asking for adjustments depends on situation	16	"I can ask for adjustments for parents evening…I was thinking about it the other day, I think I'd be too uncomfortable to ask for an adjustment for the concert."
Autistic parent is more vulnerable *She has concerns about misinterpreting due to being Autistic. She talks about not feeling she has enough information - do Autistic parents need MORE information than neurotypical parents? She creates a sense that there are obstacles that need to carefully be avoided because of sensory overload, exhaustion and reduced communication because a vulnerable mum isn't a 'professional mum' and can't advocate as effectively. She also talks about a shared negative experience of the Autistic community which colours her own engagement with professionals and the emotions she experiences.*		
- It is all stressful and exhausting for an Autistic parent	2	"school gates, the social activities, the PTA, all these things that, that come that are not necessarily our natural arena…Autistic people…."
- Advocating feels like a battle	11	"I have limited energy to try and pick the battles that are the most important so that I don't burn all the bridges and damage all the relationships with the very people that are in the position of supporting my child or children." 1a
- Feels that she is vulnerable	11	"The time where your child is vulnerable and you are vulnerable, but the time you most need more help is when you're least able to ask for help."
- Anxiety impacts ability to communicate and process information	11	"Because your communication might be impacted, your anxiety might be really high, all the skills and the tools that you need to advocate and to manage the relationships and to be 'professional mum,' can be impacted because of the difficulties and the worry and that just…adds…more complexity to the situation and…yeah, it definitely is really difficult."
Identity: Proud to be Autistic, *She cites the Autistic community as one of her greatest sources of support, and she gives as much there as she*		

Susan Page 26 of 28



gets back. As time has gone on she has felt more comfortable in herself and more able to advocate for herself. While she talks a lot about not feeling understood by professionals, she also talks about not understanding neurotypicals herself. It goes both ways		
- Validation from peers is really valuable	22	"my support network relating to autism, I've created from the work that I do with the Autism charity and a separate support group I set up for Autistic parents. Those networks are essential to me. I get as much from them as they get from the group and so it's peer support."
- Confidence as Autistic parent has grown	5	"It's always been in a situation, either pre-diagnosis where we had lots of things going on, operations and things…um, and now I think I would…and I understand my Autistic profile sufficiently enough to be able to ask for what I need and why, in a way that's confident"
- Doesn't always understand Neurotypical parents	14	"I've had very funny conversations with other parents that just do the auto…"Well, we just passed the auto button" and I've navigated it all so I've got a gap in between for each one, I've got time for food, you know, I've got…them in the order of doing the difficult ones first…get them out the way...And everyone else is "Oh we just pressed auto.'"…Why wouldn't you? If you've got complete control, why wouldn't you? [laughs]."
Self-Doubt *She talks about there being a right way to do things (neurotypical way) and a wrong way (Autistic way) and often feels as though she is getting it wrong, or is being perceived by others as getting it wrong.*		
- Doubts her own ability as a parent	4	"I'm worried about am I doing the right things that they need, have I interpreted this correctly, am I, have I taken the right action?"
- Self-conscious about how others view her	5	"So when that doesn't happen, it can make me look like this sort of pushy parent, which then has a knock on effect, makes me worry about my social interaction and my communication, and then I can become sort of almost overly apologetic. Which then seems manipulative, potentially, and…the whole thing is just *really* challenging."
- Feels dismissed and judged by professionals	21	"Actually they were very dismissive and made me feel very stupid and as if I was just an anxious person making some stuff up. Actually, I feel a bit tearful talking about it so…Yes, it *really has* impacted on me and made me feel…inadequate…and foolish." 3a

Step 8 – Initial themes were revisited, merged and renamed. A group experiential themes table was compiled with relevant quotes and page numbers of where to find them in original transcripts.

Group Experiential Theme 2: Feeling judged and stigmatised (All 10) *All of the parents talked about feeling judged and stigmatised in their dealings with statutory services. This came up in the* ***use of negative language*** *to describe autism which indicated outdated and stereotyped understandings of Autism which sometimes felt judgemental. A lot of the parents felt that* ***training is not good enough*** *to give professionals an adequate understanding of Autism which meant that parents spend a lot of the time in their interactions educating them. There were mixed views on the* ***usefulness of disclosing their own diagnosis*** *with some feeling to gave them more credibility and others having concerns that they would be judged as incompetent if they disclose.*	
2a: Use of negative language (7)	
Elaine: it's the classic sort of thing why we don't use the functioning language anymore. "Oh he's high functioning" and then *totally* disrespect his needs.	14
Chloe: the way it is at the moment, they're just so reluctant to use that label. You know because it's almost as if Autism is this stain on people's record…you know if it's even raised you know, it's like putting a black mark on them or something, it's a dirty word. They don't want to use it…it's just a type of person, it's not anything to be scared of…But they're making people scared with the negative language.	34
Susan: it's ridiculously deficit based. And also the process is horrific, I had to sit in a room with the diagnostician, asking me to list every negative thing about my child.	21
Kelly: the doctor that we were trying to see was explaining about how…he basically drew a line and was talking about how you can be more or less autistic, and I knew immediately that that wasn't right.	1
Claire: I registered a complaint, and the manager of the service phoned me up, and began talking about autistic spectrum disorder to me. Oh my God! I really think that that's quite an offensive term now, because I'm not disordered, and Jack isn't disordered.	16
2b: Training is not good enough (7)	
Tara: I mean the teachers need more training basically. If the teachers had a lot more training and understanding of all the different additional needs, they would be able to pick them up quicker and we wouldn't…the parents wouldn't have to point it out so much.	5
Elaine: They do not have the training or support. Unless they've got that personal experience, it'll just be all of the…it'll either be total confusion or they'll have out of date stereotypical attitudes and have no idea what to do with information.	18
Chloe: If staff knew enough about these conditions themselves, they were the type of people…that had been trained properly and knew what these things *really* were rather than just what they…the very vague idea, or that somebody who hasn't been trained properly might have	20
Kelly: So I'm still doing that advocacy and that educating alongside that	21
Claire: if the medical professional can just think of the social model a little bit more, within training, then, then they would be advantaged at being able to support and work alongside people.	14

Appendix O – Reflective Log

All interviews were conducted by a neurodiverse researcher and so the keeping of the reflexive log was a crucial part of maintaining an awareness of the way the researcher's personal experiences as an autistic parent of an autistic child impacted on the ways the data was understood. Issues of having to fight against the system for the right support, and feeling stigmatised by the negative language used were issues that were particularly related to.

Table 4

Reflexive Log

Extracts
'I noticed some similarities between this woman and my own experience…this might have coloured my reaction to this in a defensive way as I viewed with through the lens of a parent who also didn't like being referred to social services.'
'This is also another example of a parent who is also a healthcare professional and how this makes communication with healthcare staff easier to do than it perhaps might otherwise be. This is an element that I can relate to.'
'There was a strong sense of frustration other people's lack of understanding that I personally related to.'
'She talked about a lot of things that were from her perspective as a professional rather than as a parent, but I did connect with a lot of what she was saying, and so I let her go off on tangents. This does means that there will be some unusable stuff in this interview.'
'There was a strong sense of "I don't want them to go through what I went through" which resonated with me on a personal level as this was my own response when my son was first diagnosed.'

Appendix P – Audit Checklist

Audit Checklist

Process	**Yes**	**Partially**	**No**
Data Collection			
1. Is there evidence that raw data was collected and is appropriate for the research aims?	X		
2. Has relevant demographic and background information been collected to contextualise the sample?	X		
3. Have reflections been noted through the data collection process?	X		
Data Analysis			
4. Has the researcher engaged appropriately in supervision as part of the research process?	X		
5. Has the data been analysed systematically in a way appropriate to answer the research question?	X		
6. Is it clear that the researcher has engaged in a process of refining and redefining the themes and subthemes and are these processes justified?	X		
Cross-checks			
7. Crosschecking randomly selected excerpts from the interviews against the corresponding exploratory notes, experiential statements and themes. Are these consistent?	X		
8. Vice-versa cross checking randomly selected themes and subthemes against the corresponding data. Are these consistent?	X		
Study write-up results			
9. Are quotes sufficient to provide evidence of the themes and subthemes.	X		
10. Does the results / write-up sufficiently address the aims of the study?	X		

Signature of researcher:

Signature of auditor: