Autistic Mothers' and Birthing Peoples' Experiences of Being a Parent

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Submitted in partial fulfilment of the requirements for the award of Doctorate in Clinical Psychology at the University of Sheffield

Declaration

This work has been submitted in partial fulfilment of the requirements for the award for Doctorate in Clinical Psychology at the University of Sheffield. The work has not been submitted to any other institution, or to obtain any other qualification.

Structure and Word Counts

Section One: Literature Review

Word count excluding references, figures and tables	7989
Word count including references, figures and tables	15355

Section Two: Research Report

Word count excluding references, figures and tables	7998
Word count including references, figures and tables	10185

Total Word Count

Excluding references, figures and tables	15987
Including references, figures and tables	25540

Lay Summary

Recent research has identified specific challenges in the experiences of parenthood for autistic mothers. A qualitative review and thematic synthesis was conducted to further understand the experience of parenthood for autistic mothers and birthing people. Four databases were searched, and 29 studies met the criteria for inclusion. Results highlighted that being an autistic mother/parent is overwhelming, specifically due to the sensory, communication and emotional demands of parenthood. Results also showed that parents experienced challenges with navigating systems and services, including facing stigma and discrimination, and there was value in finding a trusted person. Finally, results highlighted that through connection with their children, participants developed their maternal and neurodiverse identity, which facilitated a process of acceptance.

The perinatal period is defined from preconception to two years after birth. Autistic people are more likely to face challenges during this time, placing this population at increased risk of mental ill health. A study was conducted to understand the experiences of autistic women and birthing people who have a perinatal mental health condition, focused on their experiences of care. Five autistic women were interviewed using Interpretative Phenomenological Analysis. Results showed that participants' experiences resulted in them feeling different and disconnected. Results also amplified participants' experiences of losing trust in help. Finally, results highlighted the value participants found in understanding their experiences, both through an autism diagnosis, therapy and peer support in bringing connection, compassion and acceptance.

Findings across both studies highlight the importance of systemic change to ensure accessible support for autistic mothers and birthing people. One way to ensure that this is achieved is through widening conversations about ‘difference’ in motherhood and ensuring that women and birthing people are directed to appropriate diagnostic pathways to facilitate earlier diagnosis and prevent the challenges of misdiagnosis and misunderstanding.

Acknowledgements

I would like to thank my research supervisors, Professor Megan Freeth and Dr Alexandra Leedham. Your expertise and experience in this field of research, alongside your focused and supportive approach, have supported me considerably across the journey of this project. I would also like to thank Dr Vyv Huddy and Professor Andrew Thompson, who have supported this project through their advice and expertise.

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This research would not be possible without the commitment from the participants and volunteers who shared their experiences and insights to support this research. Across our meetings, I have valued the openness and willingness you each showed to share your experiences to support autistic women and birthing people in the future, and I hope that I have done your experiences justice.

Finally, I would not be able to be where I am without the continued support of my placement supervisors, my friends and colleagues Katie, Katherine and Kate, and my friends and family, particularly my parents, sister, Ben, Tilly and my partner Jordan. I would not be where I am today without your emotional and, at times, practical support keeping me on track.

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Section One: Literature Review

Section Two: Research Report

Autistic Mothers' and Birthing Peoples' Experiences of Parenting: A Systematic Review of Qualitative Evidence and Thematic Synthesis

Word Count: 7989

Emma Armstrong (Trainee Clinical Psychologist)

Submitted as part of the Doctoral in Clinical Psychology (University of Sheffield)

Abstract

Objectives

Parenthood is considered transformative and encompasses physiological, social and relational changes. Qualitative research highlights unique strengths and challenges in this experience for autistic parents. The review aimed to collate, critically appraise and thematically synthesise qualitative literature to further understand the lived experience of parenthood for autistic mothers and birthing people.

Design and Method

Four electronic databases were systematically searched using specified search terms. 29 studies between 2016-2025 with 713 participants were included, and data extracted and analysed using thematic synthesis. The quality of included papers was assessed using the Critical Appraisal Skills Programme qualitative research checklist, and a sensitivity analysis was conducted to assess the possible impact on the review findings.

Results

Synthesis revealed three themes and nine subthemes. The three themes were: ‘Being an Autistic Mother/Parent is Overwhelming’, ‘Navigating an Inaccessible System’, and ‘Discovering Identity and Values as an Autistic Parent’.

Conclusions

Findings highlighted both individual and systemic challenges faced during mother/parenthood. Despite this, for many participants, connecting with their children facilitated the discovery of their identity and values as an autistic parent, through which participants identified advocating to support change for themselves and their children.

Practitioner Points:

- Findings highlight the value of personalised, non-judgemental, consistent support for autistic women and birthing people during parenthood.
- A whole family approach to care, liaising between organisations, may have positive implications for how supported autistic mothers and birthing people feel during parenthood.
- Professionals in healthcare and education environments may benefit from additional training to reduce stigma and facilitate earlier diagnosis for autistic mothers and birthing people.

Keywords: Autism, ASD, Parenting, Systematic Review, Thematic Synthesis, Qualitative

Introduction

Faced with physiological, social and relational changes (Bleidorn et al., 2016; Delicate et al., 2018; Grant & Erickson, 2022), the transition to parenthood is considered transformative, both for adoptive and birth parents (Saxbe et al., 2018). Through developments in research, we recognise that social, economic, physical and individual factors during family planning through to experiences after having a child, can have significant implications on the health and wellbeing of parents and children (Misra et al., 2003; Saxbe et al., 2018). In the United Kingdom [UK], resources have been placed into supporting parents during this time, specifically in early parenthood, to reduce poor health outcomes across the family (Leadsom et al., 2014). In line with maternity and parenting literature, the current paper uses the language of mothers and birthing people to promote inclusivity for those who identify with a broad range of gender identities who may enter mother/parenthood (Barcelona et al., 2023).

According to diagnostic criteria, Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by social communication differences and restricted and repetitive patterns of behaviour or activity (American Psychiatric Association [APA], 2022). In the mid-90s, the ‘neurodiversity movement’, a social justice movement, was coined, advocating for neurodivergent people. One of the main focuses has included challenging the widely understood view of autism as a ‘disorder’, and rather understanding experiences as ‘difference’ (Kapp, 2020). It is in this approach that the author positions themselves, and in line with the available literature reporting preference of language, identity-first language (autistic person) is used (Taboas et al., 2023).

The social model of disability is a political framework arguing that people are disabled by the barriers faced by society, and not by an impairment or condition (Oliver, 1981). Applying this understanding to parents' experiences has brought attention to the influence that the socialisation of individuals with disabilities has upon social attitudes and experiences of parenting (Parchomiuk, 2014). For many years, there has been a gap in understanding the experiences of autistic parents. Given our understanding of the social challenges faced by individuals who have been defined as disabled in the context of parenting (Parchomiuk, 2014), and the health implications of this time both for parents and children (Misra et al., 2003; Saxbe et al., 2018), understanding the lived experience of autistic parents is important to ensure that this is not a voice that remains unheard or unsupported.

In the past 5 years, there has been an increase in qualitative research providing a starting point to understanding this experience for autistic parents. In 2021, a review of qualitative and quantitative research focused on the experiences of pregnancy and parenthood for autistic adults (McDonnell & DeLucia, 2021). Although parenting was recognised as a rewarding experience, findings highlighted sensory and communication challenges, and that autistic parents were more likely to feel incompetent, isolated and fear judgement and were at higher risk of physical and mental health challenges, in comparison to neurotypical parents (McDonnell & DeLucia, 2021). This was the first comprehensive review exploring autistic parents' experiences and drew attention to the unique strengths and challenges faced by autistic parents, specifically within early parenthood.

With growing literature in the field, a further review was completed in 2024, focusing on experiences from conception into parenthood (Thom-Jones et al., 2024a). In line with the previous review, both unique strengths and challenges were identified. However, with greater literature reporting autistic parents' experiences beyond parenting infants, findings highlighted that sensory and communication challenges continued into parenthood, including during interactions with service providers for themselves and their children. Consistent across both reviews was the argument for systemic change to support autistic parents.

Although both reviews (McDonnell & DeLucia, 2021; Thom-Jones et al., 2024a) provide a helpful overview of the current literature. At present, we do not understand the meanings or relationships between these experiences beyond a narrative review, and as such, findings should be interpreted in this way. Analysing and interpreting points of similarity and difference across the journey of parenthood would provide a greater understanding of this lived experience to ensure that services do not remain a disabling experience for autistic parents.

The wider parenting literature argues that parenting is influenced by the social and cultural context of the parent (Gopfert et al., 2004). For cis women from Western, educated, industrialised, rich and democratic (WEIRD) countries, this context faces societal narratives to be attentive, maintain employment, control, ensure successful child development, and be happy (Schmidt et al., 2023). Such narratives place significant pressure upon mothers and have been argued to impact emotional wellbeing and perpetuate inequalities of motherhood (Schmidt et al., 2023), including for nonbinary birthing people (Bower-Brown, 2022). For autistic women and birthing people, this experience is placed in a context of an understanding of autism that is traditionally understood through the lens of cis males (e.g. 'extreme male brain' theory; Baron-Cohen, 2002), which may result in a late diagnosis, influencing autistic women's sense of themselves, experiences of relationships, and service provisions (Gosling et al., 2024; Wilson et al., 2023; Leedham et al., 2020).

To help us understand the nuance of this experience for autistic women and birthing people, a recent mixed-methods review and synthesis of the literature has been conducted, exploring autistic cis women's experiences of the perinatal period, defined in the study from pregnancy, up to one year postpartum (Westgate et al., 2024). Findings provided a similar narrative overview of previous reviews (McDonnell & DeLucia, 2021; Thom-Jones et al., 2024a), providing support that these experiences were consistent from the perspective of autistic cis women in the perinatal period. Whilst also providing further in-depth interpretation into this lived experience, drawing conceptual links between the sensory demands faced both internally and externally, challenges in healthcare communications and feeling overwhelmed, alongside emphasising rewards through parenting. However, at present, little can confidently be said about whether these experiences remain consistent across the journey of parenthood.

In answering this question, there has been one study with the primary aim of understanding autistic cis women's experiences of parenting. Using qualitative data, this study provided an in-depth understanding of both the challenges and strengths (Dugdale et al., 2021). Unique to the previous reviews, findings highlighted the journey of development and acceptance, shaped through participants' experiences of being a parent and receiving an autism diagnosis, and the value of services and systems taking a holistic approach to care (Dugdale et al., 2021). This study has implications for how services understand and support autistic mothers. With growing literature, a review and synthesis of the literature, encompassing the experiences of parenthood from family planning and beyond, would increase confidence in these findings to guide clinical decision-making, alongside addressing any gaps in the literature to prompt further research.

Aims

The current review aimed to collate, critically appraise and thematically synthesise literature with qualitative data to support our understanding of the lived experience of parenthood, from family planning, giving birth, and into experiences of parenting, for autistic mothers and birthing people.

Method

Design

Due to the specific focus on autistic women and birthing people's experiences of parenthood, a systematic review of qualitative data was conducted and analysed using thematic synthesis. Thematic synthesis was chosen as this provides a flexible approach to gather the findings from multiple qualitative studies underpinned by various epistemological positions (Thomas & Harden, 2008). The review has been reported using PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) guidelines (Page et al., 2021; Appendix A) alongside specific guidance for reporting and conducting qualitative evidence synthesis (Noyes et al., 2023).

The review protocol was registered with the National Institute for Health and Care Research [NIHR], PROSPERO (reference: CRD42024543051) (Appendix B).

Eligibility Criteria

The review included qualitative studies reporting primary data on autistic women and birthing people's experiences of parenting. The definition of parenting was not limited to traditional family structures, and in line with the wider maternity and perinatal policy and literature (Barcelona et al., 2023; National Health Service [NHS], 2019), alongside definitions of parenting used in previous study (Thom-Jones et al., 2024a), mothers and birthing people were defined as those who have experienced family planning, pregnancy, birth, no matter what intervention or pathology may be involved, and/or were involved in the raising of a child as a mother (this may include step-parent, adoption or fostering) or birthing person. Studies may have reported on any aspect of this journey. Where it was not possible to ascertain whether the participant was a birthing person, for example, participants who were non-binary and reported experiences of parenting, these participants were removed. An example of the decision-making regarding participant inclusion is available below (Appendix C). Women and birthing people were then included who, at the time of the original data collection, identified as autistic. Both formal and self-identification were included due to the challenges autistic women may face in receiving a diagnosis (Wilson et al. 2023). The review was not limited to a specific time frame, location or setting. Although reviews or syntheses were used to direct to further papers, they were excluded from the articles included.

The benefits of including grey literature were balanced with a lack of reproducibility in methods alongside the aims and scope of the review (Mahood et al., 2014), and the present review excluded grey literature on this basis. Table 1 reports study inclusion and exclusion criteria.

Table 1.

Study inclusion and exclusion criteria

Inclusion	Exclusion
Women and birthing people who either have a diagnosis or self-identify to be autistic at the time of the original data collection	Women and birthing people who do not have a diagnosis or self-identify to be autistic at the time of the original data collection
Have experienced mother/parenthood, defined from family planning (preconception), birth and/or involved in raising a child	Fathers or other partners who are not identified to be birthing people
Are reporting on their personal experiences of the journey of mother/parenthood	Studies that do not contain qualitative data focusing on the preferences, attitudes or experiences of autistic women and birthing people during mother/parenthood
Peer reviewed	Studies where it is not possible to ascertain quotes from autistic women and birthing people separately from others (such as partners or healthcare professionals)
	Systematic, literature or synthesis reviews
	Studies where the full text is not accessible

	Studies that are not available in English

Search Strategy

Four electronic databases (Medline, Scopus, CINAHL, and PsycINFO) were searched due to their focus on both health and social research. At registration, an additional database was proposed to be accessed (BNI). However, access was not possible.

One search was carried out in August 2024, and an additional search in April 2025, to include any recently published articles. The search strategy searched the article title, abstract or keywords on each database using the search terms below (Table 2). The search strategy was developed following the SPIDER framework (Cooke et al., 2012) and adapted to ensure this was suited to the databases chosen. This framework was chosen over alternatives as it is specifically adapted for qualitative and mixed-methods research (Cooke et al., 2021). CINAHL produced a significant volume of medical literature, which was not relevant (7489 papers). Where relevant papers were produced, these were often duplicated across Scopus. Key papers relevant to the aims were identified on Scopus, and a search re-run on CINAHL in October 2024 with titles only, and the search produced these papers. As such, the decision was made to conduct a title-only search on CINAHL.

Table 2.

Search strategy following the SPIDER framework (Cooke et al., 2012) and adapted to ensure suitability to the databases chosen

Construct	Search Term
Sample**:** Autistic mothers or birthing people	“Autis*” OR “Asperger's” OR “ASD” OR “ASC”

Sample/**P**henomenon of **I**nterest: Experience of being a mother/parent	“Mother*” OR “Parent*” OR “*Natal” OR “Birth*” OR “Pregnancy” OR “Maternity” OR “Preconception” OR “Family” OR “Postpartum” OR “Feeding”
Design/**E**valuation/**R**esearch type: Studies encompassing a qualitative design illuminating lived experience	“Experience” OR “perspective” OR “attitudes” OR “preferences” OR “Interview” OR “group” OR “qualitative” “interpretative phenomenological” OR “template” OR “narrative” OR “content” OR “discourse” OR “thematic” OR “stories” OR “survey”

Note. Boolean operators, including *, allow for results to be shown that contain variations. Each construct was bracketed and followed by ‘AND’.

Study Selection

Studies were imported into EndNote 21 (Endnote Team, 2013) for reference management, before moving to Rayyan, an online platform to aid systematic reviews (Ouzzani et al., 2016), where duplicates were identified, and confirmed and removed by hand by the author. Through reviewing the titles and abstracts against the eligibility criteria, the first 10% of studies were screened independently by two reviewers (the author and a peer researcher), and 100% inter-rater reliability was achieved. If there had been discrepancies, these would have been discussed and an outcome agreed upon, which would inform further screening processes. The remaining titles and abstracts were then screened by the author applying the eligibility criteria. Where articles were deemed eligible through initial screening, or where it was not possible to determine eligibility in initial screening, full-text screening took place. At this stage, if articles were excluded, reasons were recorded. Although systematic reviews were not included, lateral searches from these reviews were conducted. From included articles, forward citation searches were conducted in April 2025 using Google Scholar, and eligibility criteria were applied to these studies.

An example of decision-making regarding study inclusion is available below (Appendix D).

Data Collection

For each study, data on the following were extracted independently by the author and populated into a table on Excel: author, country, year of publication and data collection, aim, available sample characteristics including for participant's children, qualitative methodology and findings. In acknowledging the importance of collaboration in research (Hoekstra et al., 2018), data was also collected to determine any adaptations made by the authors to facilitate the involvement of autistic people. Any limitations identified by the author, or other factors that may affect the results were noted separately.

Quality Appraisal

For each paper, quality was assessed using the Critical Appraisal Skills Programme qualitative research checklist (CASP, 2024; Appendix E). The CASP checklist was chosen as it allows an assessment of validity across both qualitative and mixed methods designs. Mixed methods studies were appraised on the qualitative aspect of the study only. The checklist includes ten questions, each with prompts, to allow the researcher to reflect on the validity of the results, the presentation of results and wider implications. Approximately 10% of articles (n = 3) were randomly chosen and appraised by an independent peer researcher. There were minimal discrepancies, and discrepancies were resolved through discussion. Although quality appraisal was not used to remove articles from inclusion, appraisal was used to determine the relative contribution of studies to the final analytic themes (Franzel et al., 2013).

Data Synthesis

Data from the ‘results’ section of each study were extracted onto NVivo 15 (Lumivero, 2025). This included the initial authors’ commentary about the data, to ensure that data was considered within the context it was initially placed within. In line with the stages of thematic synthesis (Thomas & Harden, 2008), data was firstly reviewed line-by-line and coded, and inductive descriptive themes were developed (Appendix F). Codes were then collated into analytical themes (Appendix G), which addressed the research question. Data was coded and analysed by the author.

Quality and Rigour

Although in the initial proposed steps of conducting a thematic synthesis (Thomas & Harden, 2008), researcher reflexivity was not a key component. It has been increasingly recognised that qualitative research is contextual, occurring at a specific time between two or more people, namely the researcher and the data, and naming this increases the quality of the findings (Dodgson, 2019). To ensure transparency, the author has documented and reflected on their personal and professional positionality throughout to ensure this is actively considered within the findings (Appendix H). This was further supported through seeking supervision, alongside the rigour of the review and synthesis process.

Results

Identified Studies and Characteristics

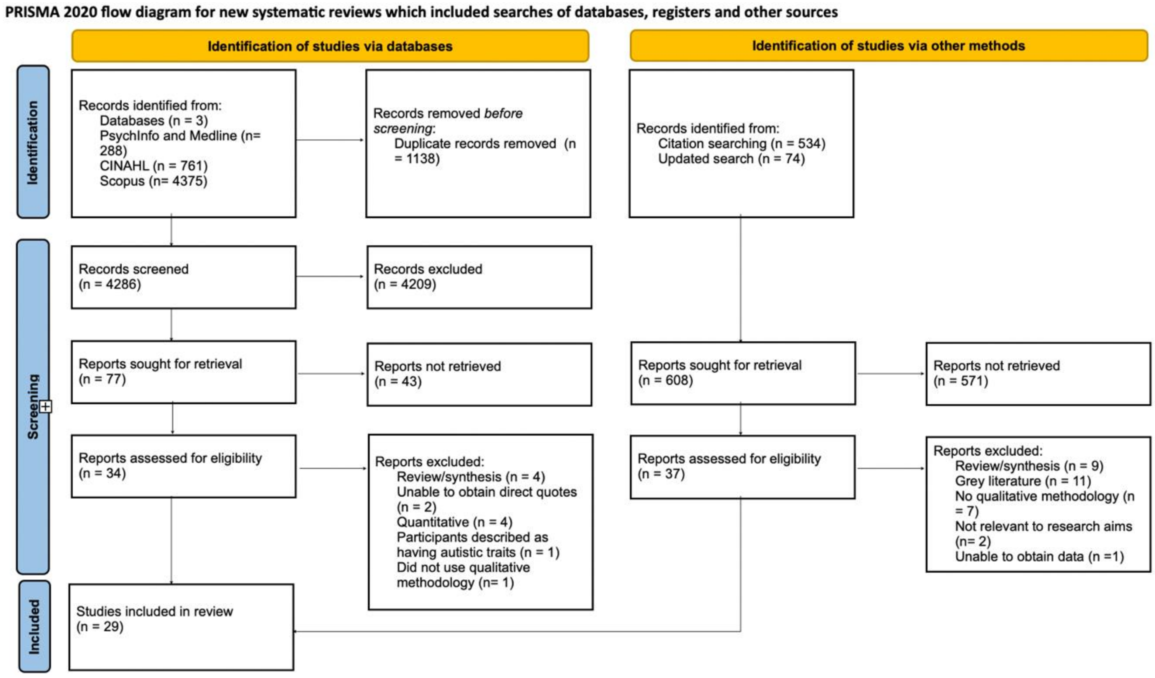
As illustrated through a PRISMA diagram (Figure 1; Page et al., 2021), 5,424 records were identified in total. Following the removal of duplicates (*n* = 1138), *n* = 4286 articles completed initial screening through title and abstract and *n* = 77 remained. Following full text screening, and *n* = 43 articles were excluded as there was no reference to autistic women or birthing people's experiences of parenting, and *n* = 34 articles remained. *n* = 12 articles were removed for the following reasons: *n* = 4 articles were a review/synthesis, *n* = 4 quantitative design, *n* = 2 unable to determine participant demographics or direct quotes, *n* = 1 participants described as having autistic traits and *n* = 1 did not apply qualitative methodology. As such, *n* = 22 articles remained.

Forward citation searches were conducted on these articles and from identified systematic reviews, and a further 534 records were identified. After removing duplicates and articles where the title and abstract did not align with the research aims, an additional *n* = 31 articles were retrieved to complete a full-text screen. From these articles, *n* = 25 articles were removed for the following reasons: *n* = 11 grey literature, *n* = 8 review or synthesis, *n* = 6 no qualitative methodology. As such, *n* = 6 articles remained.

An updated search retrieved a further 74 records. After removing duplicates and articles where the title and abstract did not align with the research aims, an additional and *n* = 6 articles were retrieved. From these articles, *n* = 5 articles were removed for the following reasons: *n* = 2 not relevant to research aims (focus on autistic infant and family support and perinatal loss), *n* = 1 review, *n* = 1 unable to obtain data, and *n* = 1 quantitative. As such, *n* = 1 articles remained.

Figure 1.

PRISMA Diagram



Studies were carried out between 2016-2025 and collected data via blogs, social media, surveys, focus groups and interviews. Data was analysed using different methodologies. Within the included articles, where this data was available, [1]there were 713 autistic women and birthing people, and participants in the study ranged from 1 (Rogers et al., 2017) to 144 (Grant et al., 2025a). Participants in the studies were aged between 19-64yrs, and predominantly identified as White American, Canadian, British or New Zealand/Australian cis birth mothers with an autism diagnosis, who were married, had pursued further education and were employed. Where this was discussed, most participants identified as autistic within their experiences of parenting, parented more than one child aged between 0 (pregnant) and 37 years, some of whom were also autistic. Six participants were not

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[1] Authors were contacted to obtain further information

parents. Key information is reported in Table 3. A comparison of studies included in the current review and qualitative studies included in previous reviews in the field has been collated into a table below (Appendix I).

Across some studies, it was not possible to ascertain where information reported the demographics of autistic mothers and birthing people or autistic parents in general. As such, it was not possible to account for this in the demographics summarised above.

Table 3.

Characteristics of Included Studies

Author (Year)	Country	Aim	Sample and characteristics	Sampling strategy	Data Collection and Methodology	Community Involvement	Key findings
Gardner et al., (2016)	N/A	Childbearing experiences of autistic women	N = 8 women aged 27-52yrs (*M* = 39yrs). Majority (62.5%) married and diagnosed autistic after giving birth (50.0%)	N/A	Qualitative design, using a secondary analysis of data derived through the development of a questionnaire. Open methods of coding before deriving major themes, no specified analysis approach	No reference	Four main themes were identified across pregnancy, birth and postnatally, referring to difficulties managing sensations and control, feeling unsupported and expectations about motherhood, judgement and lack of choice
Litchman et al., (2019)	Nationwide	Experiences of pregnancy, birth, postpartum and early motherhood amongst women with a disability	N = 125 blogs, 96% written by 12 women with TBI and SCI, and 4.0% by 3 autistic women. N = 1 woman diagnosed following pregnancy; no information provided about further two.	Search on one search engine. 12,600 records identified, 215 of which were personal blogs. Reviewed by two reviewers, and agreement	Qualitative design, analysing data from written blogs using inductive approach to thematic analysis by two researchers	No reference	Four main themes were identified across pregnancy, birth and postpartum experiences reflecting the barriers and challenges faced by women with disabilities, alongside feeling unsupported, similarities in experiences to women without a disability, and misconception, judgement and misunderstanding. All

				required for inclusion			themes were present for autistic mothers within family planning and early motherhood.
Crane et al., (2021)	UK	Autistic parent's perspective and experience of talking with their autistic children about autism	N = 34, *N* = 30 autistic women (inclusive of transgender female) Demographics of the whole sample: Aged 27-55yrs (*M* 42yrs). Majority (79.4%) diagnosed autistic, White British (94.1%), Irish or other. Number of children *M* = 2.3, majority male (61.8%) diagnosed autistic (88.2%).	Opportunity sampling via social media, targeting organisations and parent support groups	Mixed methods design using an online survey. Qualitative data analysed using essentialist inductive approach to thematic analysis in collaboration with two researchers	No reference	Four main themes were identified reflecting the value of open and honest discussions with their children, developing a shared understanding through using their own experiences, including supporting conversations about being autistic as a 'difference' and shaping conversations to ensure they are relevant to their child.
Dugdale et al., (2021)	UK	Autistic women's experiences of motherhood	N = 9 women, married, aged 27-44yrs (*M* = 39.5yrs). Majority (88.8%) identified as White British or Welsh, employed (77.7%), diagnosed autistic (88.8%) all in the last 6 years (*M* = 2.6yrs), with additional physical, mental or neurodevelopmental diagnosis (66.7%). Number of children *M*= 2.2,	Purposeful through a research database, social media and local charities	Qualitative design, using semi-structured interviews analysed using IPA	Interview schedule designed in collaboration with autistic parents. Outcomes disseminated to participants who took part in the study,	Four main themes were identified reflecting that being autistic gave rise to strengths and challenges when parenting, mothers faced a battle to receive support, parenting involved a process of adjustment, development and acceptance and there

			majority aged 5-15yrs diagnosed with or have previously or due to undergo an autism assessment (80.0%), birth parents (77.8%).			alongside relevant services.	were positive and challenging experiences of parenting.
Fletcher-Randle (2022)	Nationwide	Autistic parents' experiences and discourses about parenting	N = 15 data sets, n = 8 by autistic parents, discussing between one and 13 autistic families. Experiences of N = 30 autistic mothers/birthing people discussed.	Search on two search engines alongside through social media.	Data analysed using thematic content analysis, however no detail of analysis process described	Researcher's lived experiences as autistic	Three main themes were identified reflecting experiences stereotypes, the challenges of parenting and acting as an advocate for their own experiences
Hampton et al., (2022b)	Nationwide (UK, US, Ireland)	Comparison of childbirth and postnatal experiences for autistic and neurotypical women	N = 21 autistic women, N = 25 neurotypical women. Autistic sample: Aged 24-36yrs (*M* = 31.1), in relationships. 100.0% identified as White and majority from the UK (71.0%) and had pursued further education (55.0%). 65.0% diagnosed with a mental health condition. Mean age of children 10.76 weeks, majority this was their first child	Hospital database, support groups, and social media or magazine adverts	Part of larger projects exploring child development and perinatal experiences in autistic women. Qualitative comparison study using semi-structured interviews via either face-to-face or online, 2-3 months after birth, analysed using an inductive approach to thematic analysis	Interview schedule developed with autistic mothers and feedback provided on the results and write up	Three main themes were identified across both groups reflecting both positive and negative experiences of birth, rewards and demands of motherhood alongside experiences of formal and informal support. Findings showed that autistic parents experienced unique challenges across each of these themes in comparison to the neurotypical group.

Saeed et al., (2022)	Canada	Women with an IDD and/or sensory disabilities experiences of communicating in the context of perinatal care in Ontario, Canada	N = 17 women, 94.1% diagnosed with an IDD and/or sensory disability, and n =1 diagnosed autistic in additional to a physical disability. Details of autistic sample: birth parent to one child. Demographics of whole sample: Aged between under 20-35yrs, majority married or in a relationship (64.7%), heterosexual (82.4%), White (70.6%).	Convenience and purposeful through flyers sent via mailing lists, newsletters and websites supporting people with disabilities or parents in Ontario	Part of a larger project exploring perinatal care for people with physical, sensory and intellectual disabilities in Ontario. Qualitative design using semi-structured interviews and analysed using deductive and inductive approaches to thematic analysis	Interview schedule developed in collaboration with advisory committee comprising people with disabilities. Not clear if this included autistic people.	Two main themes were identified across the sample, reflecting the barriers of communication, including lack of policies, experience, effort and assumptions, alongside the facilitators of communication, including knowledge, access, empathy, adaptation and communication between services. A breakdown of the contribution to themes was not provided, however evidence provided to support the value of empathy in communication for autistic women and birthing people.
Wilson & Andrassy (2022)	Nationwide (US, UK, New Zealand and Canada)	Experiences of breastfeeding for autistic women	N = 23 autistic women, majority White (87.0%) married (73.9%), at least two children (78.3%) and pursued further education (69.6%). Majority from the US (60.8%)	Purposeful using support groups on social media	Qualitative design using semi structured interviews conducted via telephone (43.5%), video (13.0%), email	No reference	Three main themes were identified which reflected heightened sensory experiences, women's determination or interest, and feeling misunderstood and

					or text (43.5%). Qualitative analysis process unclear		unsupported by the current model of care.
Winnard et al., (2021)	UK	Autistic women's experiences, or how they perceive they will experience parenthood	N= 8 women aged 28-63yrs (*M* = 41.5). All had a partner, had received autism diagnosis between 9-50yrs (*M* = 28.9), majority in adulthood (87.5%). 50% were parents with children aged 8-40yrs (*M* = 23yrs), of these 75.0% had autistic children. 50.0% were not parents, and of this 25.0% wished to be a parent.	Purposeful snowball approach using autism support groups, and parenting groups on social media	Qualitative design using semi structured interview face-to-face or via telephone, analysed using IPA	No reference	Six main themes were identified across groups reflecting the love and enjoyment of parenting, giving and receiving in the context of support, embedding routine and structure, sensory differences, challenges with social interactions alongside having a unique insight and understanding of themselves and their children.
Hampton et al., (2022a)	Nationwide (UK, US, Ireland)	Comparison of the pregnancy experiences for autistic and neurotypical women.	N= 24 autistic women, n = 21 neurotypical women. Autistic sample: Aged 21-35yrs (*M* = 31.1), majority (95.8%) in relationships, White (100.0%) from the UK (79.0%), pursued further education (58.0%), diagnosed with a mental health condition (66.0%). 25.0% of women had additional children (not including current pregnancy)	Hospital database, support groups, and social media or magazine adverts	Part of larger projects exploring child development and perinatal experiences in autistic women. Qualitative comparison study using semi-structured interviews either via video call or telephone, during the third trimester.	Interview schedule developed with an autistic mother and feedback provided on the results and interpretation	Three main themes were identified across groups reflecting the physical impact of pregnancy, experiences of support and concerns and hopes for motherhood. Findings showed that autistic women experienced unique challenges across each of these themes in comparison to the neurotypical group.

					Analysed using an inductive approach to thematic analysis		
Heyworth et al., (2023)	Nationwide (Australia, UK)	Autistic parents' experiences of parenting during the COVID-19 pandemic	N = 35 autistic parents of autistic children, majority women (94.0%) (inclusive of transgender female), diagnosed autistic in adulthood (74.3%) (*M* age = 42.9yrs). Demographics of the whole sample: Majority from Australia (97.0%) White (91.0%), living with a partner (74.0%), pursued further education (71.0%), employed (51.0%), diagnosed with an additional mental health condition (66.0%), had two or more children (76.0%), who were autistic (100.0%), majority were male (54.0%) Children aged from 4-25yrs, and majority (67.0%) accessed mainstream education	Purposeful through social media.	Part of a larger study exploring autistic experiences of the COVID-19 pandemic. Qualitative design using an online survey and semi-structured interviews either online (63.0%), telephone (14.0%) or email (23.0%). Reflexive thematic analysis using an essentialist inductive framework used to analyse the data with three researchers.	Research design coproduced with autistic researchers and advocates including autistic parents.	Four main themes were identified reflecting the challenges of day-to-day life, additional pressures of the COVID-19 lockdown, the influence on parent's mental health and unique insights which support family life
Hwang & Heslop (2023)	Not clear	Autistic parents' experiences of parenthood	N = 7 autistic parents, majority (71.4%) women. Of the female sample: Aged 36-53yrs all	Purposeful sampling through	Qualitative design using online focus groups structured around six	No reference	Three main themes were identified reflecting the enjoyments and challenges of

		and social care support	diagnosed autistic after or at the 30 years old, married (60.0%), White (100.0%) additional learning disability (60.0%). Number of children ranged from 1-3, with all participants having 1 autistic child. Children's ages ranged from 4-25yrs.	national charity	questions, with an inductive framework applied to analysing the data through thematic analysis from two researchers		parenthood, feeling misunderstood and judged and battling for help
Smit & Hooper (2023)	UK	Explore factors that influence autistic parents' mental health and wellbeing	N = 9 autistic parents, majority (88.9%) women and of this sample: Aged 34-50, (50.0%) diagnosed autistic, majority (87.5%) White. Number of children 1-3, with at least 1 child diagnosed autistic or observable traits. 62.5% cohabiting or married	Purposeful sampling via social media, national charities and via student research database	Qualitative design, using semi structured interviews either via video (77.8%) or messaging (22.2%), analysed using IPA	Researcher's lived experiences as autistic	Three main themes identified reflecting participants identity and purpose as a parent, approaching parenting through the lens of trauma and the influence of external factors including interactions with systems and pressures
Talcer et al., (2023)	UK	Autistic mothers' sensory experiences	N = 7 autistic mothers', aged 30-55, majority (85.7%) White. Number of children 1-3 aged between 2-22yrs, 71.4% children diagnosed autistic.	Volunteer sampling through social media and research database	Qualitative design, using semi structured interview conducted face-to-face, data analysed using deductive approach to thematic analysis	Interview schedule developed in consultation with patient and public involvement. Researchers lived experiences as an autistic	Five main themes were identified reflecting participants antenatal sensory experiences, sensory experiences in motherhood, the overall impact of these experiences, approaches to managing and

						mother. Participants offered to comment on themes.	experiences of receiving a diagnosis
Garcia-Molina & Cortés-Calvo (2024)	Spain	Spanish autistic women's maternity experiences and their family relationships	N= 9 autistic women, aged 29-58yrs (*M* = 42.3), majority (88.8%) received formal autism diagnosis, between 27-55yrs (*M* = 39.3). 77.8% women were mothers, 22.2% wanted to be mothers. 85.7% birth mothers. Majority (77.8%) had a partner. Number of children 1-3, aged 1-37yrs. Majority children (57.1%) diagnosed autistic.	Five autism charities in Spain	Qualitative design, using structured interviews conducted online (77.8%), via video (11.1%) or email (11.1%), and analysed using inductive approach to thematic analysis	No reference	Four main themes were identified reflecting autistic mothers' experiences of diagnosis, experience of understanding and support from their family, sensory processing and anxiety
Gore et al., (2024)	Australia	Experiences of Australian autistic working mothers	N = 10 autistic women (assigned female at birth or nonbinary), aged 34-50yrs (*M* = 42.7), 100.0% had pursued further education, and majority were employed (77.8%), married or cohabiting (60.0%) and Australian (80.0%). 90.0% women diagnosed as autistic in adulthood (*M* = 38.4yrs), and majority identified with co-occurring mental health	Purposeful sampling through social media	Qualitative design, using semi structured interview conducted online, analysed using inductive approach to thematic analysis adopting a relativist ontological perspective	Interview schedule developed in collaboration with five autistic adults with relevant lived experience	Three main themes were identified reflecting the importance of work in providing purpose and supporting wellbeing, challenges of being an autistic working mother and challenges associated with the invisibility of being autistic

			or neurodevelopmental conditions. All participants had two or more children under 18yrs, and 90.0% had one or more children who were neurodivergent.				
Grant et al., (2023)	UK	Experiences of maternity and associated healthcare for autistic people	N = 152 participants, n= 141 provided qualitative data. Demographics of the whole sample: Ranged 19-54yrs, *M*= 36.39yrs, majority (57.9%) diagnosed autistic, cis woman (82.9%), White (92.1%), pursued further education (63.1%), with a diagnosed disability in addition to being autistic (76.3%). Participants had between 1-7 children they had given birth to (*M*= 2.1), and children's ages ranged from 0-28yrs (*M*= 9.5).	Purposeful sampling through social media	Mixed methods design, using an online survey. Qualitative data analysed using inducive approach to thematic analysis	Researchers lived experience as autistic	Three main themes were identified reflecting participants' motivation to breastfeed, experiences of using formula, and feeding support
Libster et al., (2024)	Nationwide (US, England, Canada)	Autistic mother's relationships with their neurotypical daughters	N= 7 autistic mothers aged between 40-64 (*M* = 50yrs), all diagnosed autistic or self-identified as autistic between 34-52yrs (*M* = 40.7). Majority pursued further education (85.7%), all were employed. Majority lived in	Flyer through organisations and online communities for targeted sample	Qualitative design using semi structured interviews conducted online, data analysed using IPA	Autistic mothers involved in the design of the research including interview schedule	Four main themes were identified reflecting the love and connection mothers felt with their daughters, strengths in parenting, challenges in social interactions and developing daughters' social skills

			the US (57.1%). All were White cis women, and biological parents. Majority were married or coparenting (85.8%). Participants had 1-3 children, 57.1% of participants had autistic children. Children ranged from 10-37yrs (*M*= 18yrs)				
Radev et al., (2024b)	UK	Autistic parents' experiences of interacting with statutory services for their autistic children	N= 10, all women aged between 35-55yrs (*M* = 46.6), majority recently diagnosed autistic (*M* = 2.9yrs). Majority (80.0%) White British, pursued further education (90.0%), employed (60.0%) and married (80.0%). Children aged between 5-17yrs (80.0% between 11-17yrs)	Purposeful sampling through social media and research database	Qualitative design using semi structured interviews conducted via video (80.0%) and telephone (20.0%), analysed using IPA	Researcher's lived experiences and involvement of autistic parents in interview schedule	Two main themes were identified reflecting challenges of wider systems and feeling judged and stigmatised
Lewis et al., (2021)	Nationwide (US, UK, New Zealand)	Autistic women's experiences of childbirth	N=16 self-identified autistic women aged 21-57yrs (*M*= 37.6yrs), majority (87.5%) White, and from the US and UK (75.0%). Majority (68.8%) became aware they were autistic after giving birth.	Convenience sample through online autism forums and social media	Qualitative design using online survey, narrative analysis used to analyse the data	No reference	Findings identified that participants felt uncared for and ignored in healthcare and experienced challenges related to their sensory experiences in birth
Donovan et al., (2023)	Nationwide	Autistic women's childbirth,	N = 24 autistic women, aged between 20-50yrs, majority White (83.3%), in	Purposive sampling	Part of a larger study exploring autistic women's	Researcher's lived	Three main themes were identified overall, and one theme was

		specifically focussed on their early postpartum experiences	the US (70.8%), married (66.6%) and pursued further education (50.0%)	using social media	experiences of childbirth. Qualitative design, using semi-structured interview conducted face-to-face, video or via messenger. Data analysed using interpretative descriptive approach	experiences as autistic	identified in the context of participant's early postpartum experiences and reflected autistic mother's experiences of breastfeeding, bonding and healthcare experiences
Thom-Jones et al., (2024b)	Not clear	Autistic mothers' experience of motherhood and the support they offer each other	N = 23 posts, n = 131 comments. 23 unique users (posts) 65 unique users known (comments). Where information available, most posts (65.2%) referred to children aged 5 and under, majority had 1 child (69.6%), who was male (56.5%).	Retrieval from autistic parents' blogs from specified dates in line with specified inclusion criteria	Qualitative design, data analysed using inductive approach to thematic analysis by two researchers	Researcher's lived experiences as autistic and additional consultation with autistic people at each research stage	Four main themes were identified referring to the unique challenges and strengths faced by autistic mothers, stigma experiences and learning through the COVID-19 lockdown
Rogers et al., (2017)	Australia	Exploring the challenges for autistic women during the perinatal period	N=1, autistic woman 26 years old, diagnosed autistic at 17yrs, pursued further education.	Autism support organisations , University	Qualitative case study design, data gathered through emails and an interview and analysed using thematic analysis	No reference	Three main themes were identified referred to communication and service challenges experienced with maternity care, overwhelming sensory differences and

							judgement and stigma as a parent
Grahame et al., (2024)	Nationwide	Autistic women's experience of pregnancy and birth	N= 8 autistic women, aged between 33-52yrs (*M* = 39.6yrs). All participants identified as White, and majority diagnosed autistic post-pregnancy and with additional diagnoses including ADHD, and/or mental health diagnoses (87.5%)	Research database and social media	Qualitative design using semi-structured interview over video, data analysed using IPA	Autistic women consulted in design of interview schedule and documentation	Three main themes were identified reflecting participants' making sense of their perinatal experiences following their autism diagnosis, challenges and enjoyments of connecting with their maternal identity and experiences of seeking support
Khan et al., (2021)	Canada	Factors that shape perinatal care experiences for people with an IDD	N = 10, n = 1 autistic and physical disability. Demographics of whole sample: Majority 26-34yrs and White (70.0%), women (90.0%), heterosexual (80.0%), married (50.0%), high school education (50.0%)	Convenience and purposeful sampling across organisations supporting people with disabilities and networks of research team	Qualitative design using semi-structured interviews face-to-face (60.0%) and telephone/online (40.0%), analysed using deductive approach to content analysis, using socioecological model to guide analysis	Interview schedule developed in collaboration with advisory committee comprising people with disabilities. Not clear if this included autistic people.	Barriers and facilitators to perinatal care for people with an IDD were identified on a societal, institutional and interpersonal level. breakdown of the contribution to themes was not provided, however evidence provided to support barriers to care on a societal level through societal norms of motherhood and an interpersonal level through inadequate

							support through family and friends, alongside facilitators to support through positive interactions with healthcare professionals
Moore et al., (2025)	UK	Experience of maternity care for autistic mothers	N = 4 autistic mothers, n = 4 midwifes. Autistic mothers aged between 37-45yrs (*M* = 39.5yrs), children aged between 4-20yrs (*M*= 8.6yrs). Most women diagnosed autistic during or after perinatal period (75.0%)	Purposeful sampling, no further details	Qualitative design, using multi-perspectival IPA. Data gathered using semi-structured interviews (online)	Interview schedule developed in collaboration with panel of autistic people	Three main themes were identified across participants' experiences reflecting the challenges faced for autistic mothers' in maternity care, the importance of caring relationships and challenges associated with navigating competing priorities and demands for staff and service users.
Rabba et al., (2025)	Australia	Experience of autistic parent's interacting with schools about their autistic children	N = 31 autistic mothers, 34-59yrs (*M* = 44.6yrs). All diagnosed or self-identified as autistic later in life (*M* = 41yrs). Majority pursued further education (64.0%) and employed (68.0%) and identified as White (93.5%). Most reported additional physical and mental health diagnoses	Purposeful sampling through social media and connections in the community	Qualitative design, using semi-structured interviews online, analysed using reflexive thematic analysis within essentialist framework	Researcher's lived experiences as autistic. Community advisory group of autistic parents to support each research stage	Four main themes were identified reflecting the challenges of feeling blamed, the battle against schools, the importance of respect and advocacy

Sutcliffe-Khan et al., (2024)	UK	Autistic women's experiences of motherhood	N = 9 autistic mothers, majority diagnosed autistic after having children (77.8%) with additional mental health diagnoses (77.8%). Most participants had more than one child who were either diagnosed or querying a diagnosis of autistic (88.9%), aged between 2 months – 24 years.	Purposeful sampling through social media	Qualitative design using semi-structured interviews either over email (44.4%) in person (11.1%) or video (44.4%), data analysed using inductive approach to reflexive thematic analysis	No reference	Two main themes were identified reflecting the strengths and challenges of parenting for autistic mothers
Grant et al., (2025a)	UK	Autistic people's experiences of antenatal and birth care in the UK	N = 193, n = 144 provided qualitative data. Demographics of the whole sample: Aged 19-63yrs (*M*= 36.5yrs), majority (47.8%) diagnosed autistic, cisgender woman (85.1%), white (91.0%), pursued further education (58.1%), with additional physical or mental health diagnoses (74.6%)	Purposeful sampling through Facebook support groups and social media	Mixed methods design using a survey, qualitative data analysed using reflexive thematic analysis with three researchers	Researcher's lived experiences as autistic. Consultation with autistic people who were pregnant to support survey design	Three main themes identified reflecting healthcare professionals understanding of autism, systemic challenges in care, and the impact of inaccessible care

Note. Where an autism diagnosis is discussed, this refers to a diagnosis or self-diagnosis of Autism Spectrum Disorder (ASD), associated conditions, using historic terminology such as Asperger's, or preferred terminology. Where sample characteristics are not discussed, this was because this was not provided either in the write-up or following contact with the authors, or it was not relevant to the current review (for example, quantitative methodology and findings)

UK [United Kingdom], PDA [pathological demand avoidance], IDD [Intellectual and Developmental Disabilities], IPA [Interpretative Phenomenological Analysis], COVID-19 [Coronavirus Disease], ADHD [Attention Deficit Hyperactivity Disorder]

Quality Appraisal and Individual Contribution

For the most part, the included studies provided valid results that were clear and contributed to the literature. Across a minority, research aims, design, findings and ethical considerations were not transparent. In some instances, this was due to changes in the research methodology. Consistently, there were noted gaps in researcher self-reflexivity. 18 studies reported the inclusion of autistic people in some aspect of the research.

Where there were studies with methodological limitations, these were considered in the context of the derived themes, to consider if removal of these studies influenced the themes. Methodologically limited studies did not derive any new themes or remove any existing themes. A summary of the quality appraisal is provided below (Table 4).

Table 4.

Quality appraisal of included studies summary

Article Reference	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
Gardner et al., (2016)	Yes	Yes	Yes	Can’t Tell	Can’t Tell	Can’t Tell	Can’t Tell	Can’t Tell	Yes	Yes
Litchman et al., (2019)	Yes	Yes	Yes	No	Can’t Tell	Can’t Tell	Yes	Can’t Tell	No	Yes
Crane et al., (2021)	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Yes	Can’t Tell	Yes
Dugdale et al., (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Fletcher-Randle (2022)	Yes	Yes	Can’t Tell	Yes	Yes	Can’t Tell	Can’t Tell	Can’t Tell	No	Can’t Tell
Hampton et al, (2022a)	Yes	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Yes	Yes
Saaed et al., (2022)	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Yes	Yes	Yes
Wilson & Andrassy (2022)	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Can’t Tell	Can’t Tell	Can’t Tell
Winnard et al., (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hampton et al., (2022b)	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Can’t Tell	Yes	Yes	Yes
Heyworth et al., (2023)	Can’t Tell	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Yes	Yes
Hwang & Heslop (2023)	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Yes	Yes	Yes
Smit & Hooper (2023)	Yes	Yes	Can’t Tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Talcer et al., (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Garcia-Molina & Cortés-Calvo (2024)	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Yes	Yes	Yes
Gore et al., (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Grant et al., (2023)	Can’t Tell	Can’t Tell	Yes	Can’t Tell	Can’t Tell	Can’t Tell	Can’t Tell	Can’t Tell	Can’t Tell	Yes

Libster et al., (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Radev et al., (2024b)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lewis et al., (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Yes	Yes
Donovan et al., (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes
Thom-Jones et al., (2024b)	Yes	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Yes	Yes
Rogers et al., (2017)	Yes	Yes	Yes	Can’t Tell	Can’t Tell	Can’t Tell	Yes	Can’t Tell	Yes	Yes
Grahame et al., (2024)	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Yes	Yes	Yes	Yes
Khan et al., (2021)	Yes	Yes	Yes	Yes	Yes	Can’t Tell	Yes	Yes	Yes	Yes
Moore et al., (2025)	Yes	Yes	Yes	Yes	Can’t Tell	Can’t Tell	Yes	Can’t Tell	Yes	Yes
Rabba et al., (2025)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sutcliffe-Khan et al., (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Grant et al., (2025a)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Thematic Synthesis

Analysis of the data resulted in three themes and nine subthemes (Table 5). Although there were differences in participants' experiences, themes reflect prevalent experiences across the data. There are some aspects of participants' experiences which were represented across multiple themes.

Table 5.

Themes and Subthemes

Theme	Subtheme
Being an Autistic Mother/Parent is Overwhelming (26 articles)	Multiple Demands of Mother/Parenthood (22 articles) Unable to Cope in the Same Way and Finding Alternatives (19 articles) Expectations and "Good Enough" (20 articles)
Navigating an Inaccessible System (28 articles)	Inaccessible to "Difference" (23 articles) Stigma and Judgement (24 articles) Value to Trusting Relationships (20 articles)
Discovering Identity and Values as an Autistic Parent (26 articles)	Getting to Know Each Other and Connection (17 articles) Journey Towards Self-Acceptance (19 articles) Providing a Different Experience (20 articles)

Being an Autistic Mother/Parent is Overwhelming

This theme captures participants' experiences of managing the demands associated with parenthood. Although individual differences, themes were noted in experiences of managing the sensory, social and emotional demands of parenthood, alongside noticing that parenthood brought changes to previous coping methods and as such required finding alternatives.

Multiple Demands of Mother/Parenthood. Across most studies, participants identified challenges associated with parenting, which influenced both decisions of becoming a parent as well as experiences of parenting. This included discussions about the sensory demands of parenting, reflected in participants narratives of the experience of pregnancy, and into experiences of being a parent, with specific challenges noted during birth, breastfeeding, play, noise and touch with their children, and with preparing food (Dugdale et al., 2021; Garcia-Molina & Cortés-Calvo, 2024; Gardner et al., 2016; Grahame et al., 2024; Grant et al., 2023; Gore et al., 2024; Hampton et al., 2022a; 2022b; Heyworth et al., 2023; Lewis et al., 2021; Rogers et al., 2017; Smit & Hooper, 2023; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Thom-Jones et al., 2024b; Wilson & Andrassy, 2022; Winnard et al., 2021):

"I hated expressing milk – it made me very angry instantly, I hated the noise and I hated how it felt" (Grant et al., 2023, p.8).

For most, where sensory experiences were discussed, these were identified as heightened experiences, which felt challenging. Where participants had autistic children, in some instances, conflict was identified between their own and their children's sensory needs, which exacerbated this experience. However, for the minority, parenthood reduced sensory sensitivity, which brought relief.

Participants also described the social demands of parenting, and challenges were identified in navigating these interactions. This experience was reflected through the increased attention and expectation participants felt to interact with others during parenthood, alongside supporting their children through these same experiences (Dugdale et al., 2021; Fletcher-Randle, 2022; Hampton et al., 2022a; 2022b; Heyworth et al., 2023; Libster et al., 2024; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Winnard et al., 2021):

"Children make people avoidance impossible. I need to interact with schools and their friendships. Also interactions with other parents. These types of interactions can

rob me of my energies throughout the day and can then make me struggle for the rest of the day or even days following” (Sutcliffe-Khan et al., 2024, p. 21797)

Alongside the above, participants also described the day-to-day challenges of parenting from managing the physical and emotional demands associated with pregnancy, birth, breastfeeding in early parenthood, through to managing multiple demands from daily household chores, their children and balancing employment (Donovan et al., 2023; Dugdale et al., 2021; Gore et al., 2024; Grahame et al., 2024; Grant et al., 2023; Hampton et al., 2022a; 2022b; Hwang & Heslop, 2023; Litchman et al., 2019; Rabba et al., 2025; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Wilson & Andrassy, 2022; Winnard et al., 2021):

“I am the family ringmaster and juggler” (Heyworth et al., 2023 p.29)

For many, the accumulation of these demands resulted in feeling overwhelmed, exhausted and burnout, and in some instances unable to meet all demands:

“I ended up pulling them out of school, just for the last three days of term, because I was like, I’m exhausted, they were exhausted” (Rabba et al., 2025, p. 1038).

Unable to Cope in the Same Way and Finding Alternatives. Across multiple studies, participants identified that parenting brought change, which resulted in previously helpful coping strategies being ineffective. For many, making time for themselves was important to maintaining their mental wellbeing. However, through parenthood, many participants identified putting the needs of their children before their own, resulting in forgetting or being unable to make time for themselves. For some, this was reflected through decisions to stop or reduce their hours at work, despite work having a positive influence on their wellbeing (Dugdale et al., 2021; Gore et al., 2024; Grant et al., 2023; Hampton et al., 2022a; 2022b; Heyworth at al., 2023; Litchman et al., 2019; Rabba et al., 2025; Smit & Hooper, 2023; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Winnard et al., 2021):

"The biggest change for me was losing all my self-soothing methods." (Smit & Hooper, 2023, p. 71)

Many described the importance of maintaining a routine to feeling in control. However, parenting brought changes to routine, and worries about the impact this could have, or experiences of this, shaped participants' sense of control in parenthood (Dugdale et al., 2021; Hampton et al., 2022b; Heyworth et al., 2023; Hwang & Heslop, 2023; Libster et al., 2024; Litchman et al., 2019; Sutcliffe-Khan et al., 2024; Winnard et al., 2021):

"I found it very hard to accept the lack of rigid routine, especially when she was newborn, she could wake up any minute, so I was on edge the whole time" (Hampton et al., 2022b, p. 1170)

Despite change to routine and coping patterns, many participants showed resource in navigating these changes, and for many this was prioritised in knowing that maintaining their wellbeing was important to their role as a parent. This was shown through implementing structure and routine where possible, including through birth plans and with breastfeeding, finding alternative sensory strategy or distraction, seeking additional information and support, putting in boundaries to find time for themselves and perseverance (Dugdale et al., 2021; Donovan et al., 2023; Gore et al., 2024; Grahame et al., 2024; Grant et al., 2023; Hampton et al., 2022a; Heyworth et al., 2023; Lewis et al., 2021; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Thom-Jones et al., 2024b; Wilson & Andrassy, 2022). For some, making time for these strategies became easier as the children grew older:

"You get on with it because you are caring for your kids" (Sutcliffe-Khan et al., 2024, p. 21796)

Expectations and "Good Enough". Present within multiple studies were discussions about the expectation associated with mother/parenthood. Expectations were formed through information, their own experiences, alongside messages received through by others and society. These were experiences of what parenthood *"should"* look like, including in the context of birth, breastfeeding and bonding, through to expectations in the context of their family role as *"Mum",* including that they were the *"main carer",* in a relationship, made time for work and housework, were social, engaged in *"motherly duties"* and were *"fun"*. For some, expectation was also present through the internal pressure placed upon themselves that their children's experiences would be different from their own (Gardner et al., 2016; Gore et al., 2024; Grahame et al., 2024; Grant et al., 2023; Hampton et al., 2022a; Heyworth et al., 2023; Hwang & Heslop, 2023; Khan et al., 2021; Libster et al., 2024; Moore et al., 2025; Rabba et al., 2025; Radev et al., 2024b; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Wilson & Andrassy, 2022):

"There's always that juggle between. You're expected to be a full-time mother and a full-time worker" (Gore et al., 2024, Theme 2, Subtheme 1)

Where participants' experiences did not align with expectation, many internalised "*difference",* including beliefs of not being a *"good enough"* parent. These beliefs had an impact on participants' mental health, experiences of seeking help and support, and, in some instances, shaped decisions about becoming a parent (Dugdale et al., 2021; Fletcher-Randle, 2022; Gore et al., 2024; Grahame et al., 2024; Grant et al., 2023; Heyworth et al., 2023; Hwang & Helsop, 2021; Litchman et al., 2019; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Thom-Jones et al., 2024b):

"I am a constant bag of nerves, since being a Mum requires me to try to do all those things [social tasks of parenting]. Not doing them... makes me feel like a failure, a 'bad mum'" (Fletcher-Randle, 2022, p. 400)

Navigating an Inaccessible System

This theme captures participants' experiences of navigating services and systems in the context of mother/parenthood including healthcare, employment, social support, alongside services and support for their children.

Inaccessible to "Difference". Across multiple studies, participants were faced with experiences where services and systems were not accessible. For many, these experiences encompassed sensory and communication differences (Donovan et al., 2023; Gardner et al., 2016; Grahame et al., 2024; Grant et al., 2023; 2025a; Hampton et al., 2022a; 2022b; Khan et al., 2021; Lewis et al., 2021; Moore et al., 2025; Radev et al., 2024b; Rogers et al., 2017; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Wilson & Andrassy, 2022; Winnard et al., 2021):

"The hospital was a sensory hell" (Grant et al., 2025a, p. 20)

"I needed 100% clear information at all times and no fluffy language" (Hampton et al., 2022b, p. 1170)

Identified *"difference"* from services and systems where participants felt their experiences required to *"fit into a box",* left many participants feeling *"overwhelmed", "misunderstood"* and *"dismissed",* and ultimately on their own following receiving inadequate care and support. Interactions with services in some instances resulted in harm caused, described by some as *"traumatic"* and *"frighten[ing]"* (Dugdale et al., 2021; Hampton et al., 2022a; 2022b; Hwang & Heslop, 2023; Gardner et al., 2016;

Grahame et al., 2024; Grant et al., 2023; 2025a; Gore et al., 2024; Lewis et al., 2021; Smit & Hooper, 2023; Sutcliffe-Khan et al., 2024; Rabba et al., 2025; Radev et al., 2024b Rogers et al., 2017; Talcer et al., 2023; Thom-Jones et al., 2024b; Moore et al., 2025; Wilson & Andrassy, 2022).

Stigma and Judgement. Across multiple studies and settings, participants described feeling stigmatised and judged in interactions with others. This included perceived judgment or feared judgment about their abilities to parent. This experience was present throughout participants parenting journey from professionals, family, employers and social circles (Dugdale et al., 2021; Fletcher-Randle, 2022; Garcia-Molina & Cortés-Calvo, 2024; Gore et al., 2024; Hampton et al., 2022a; Heyworth et al., 2023; Hwang & Heslop, 2023; Gardner et al., 2016; Grahame et al., 2024; Grant et al., 2023, 2025a; Lewis et al., 2021; Litchman et al., 2019; Khan et al., 2021; Radev et al., 2024b; Rogers et al., 2017; Saeed et al., 2022; Smit & Hooper, 2023):

"I've been asked by a couple of the midwives how I think I can be a mum if I'm autistic" (Hampton et al., 2022a, p. 1276).

For participants who identified with other marginalised characteristics, intersections with aspects of their identity exacerbated this experience, including in the context of living with a mental health condition, being a single parent, a working Mum or where their children were also autistic:

"I was completely infantilised as a person throughout the entire experience and having known sensory issues and known mental illness only made this worse" (Grant et al., 2025a, p. 20)

Across multiple contexts, driven by a fear of judgement, participants felt unable to share their experiences or aspects of their identity, and actively avoided interactions with services, and where participants did share their experiences, some participants faced further judgement including being labelled as *“emotional”, “exaggerating”,* or a *“problem”* parent or patient (Dugdale et al., 2021; Garcia-Molina & Cortés-Calvo, 2024; Gore et al., 2024; Grahame et al., 2024; Grant et al., 2025a; Hampton et al., 2022a; 2022b; Heyworth et al., 2023; Hwang & Heslop, 2023; Lewis et al., 2021; Litchman et al., 2019; Moore et al., 2025; Rabba et al., 20225; Radev et al., 2024b; Rogers et al., 2017; Smit & Hooper, 2023; Sutcliffe-Khan et al., 2024; Talcer et al., 2023):

“It is difficult to find people to say these things to because you fear that if you speak... they’re immediately going to go, “postnatal depression” [and a] risk for this family or child or whatever” (Talcer et al., 2023, p. 841).

Value to Trusting Relationships. Although rare, there were instances where participants described positive interactions with services. Through these experiences, participants identified value in personalised, accommodating, consistent, non-judgemental care both in the context of support for themselves and their children. These experiences brought trust and connection in what otherwise was perceived as an untrustworthy, uncaring system. In some instances these professionals shared similarity in participant’s experiences through also being autistic (Donovan et al., 2023; Dugdale et al., 2021; Gardner et al., 2016; Grahame et al., 2024; Grant et al., 2023; 2025a; Gore et al., 2024; Lewis et al., 2021; Hampton et al., 2022a; 2022b; Hwang & Heslop, 2023; Khan et al., 2021; Radev et al., 2024b; Rabba et al., 2025; Rogers et al., 2017; Saeed et al., 2022; Smit & Hooper, 2023; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Moore et al., 2025):

“He was just really funny. He just made me feel positive” (Grahame et al., 2024, p.18)

Where this was not accessible through services, participants identified seeking connection with others through online forums and blogs, peer support with both neurotypical and autistic parents, family, advocacy and a doula (Dugdale et al., 2021; Gardner et al., 2016; Grant et al., 2023; Hampton et al., 2022a; 2022b; Heyworth et al., 2023; Khan et al., 2021; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Thom-Jones et al., 2024b).

Discovering Identity and Values as an Autistic Parent

This theme reflects participants' experiences of discovering their identity and values as a parent. For most, this was shaped through getting to know their children, which facilitated connection to their maternal and neurodiverse identity, and an ambition for things to be different.

Getting to Know Each Other and Connection. Across multiple studies, participants discussed their experience of bonding with their children, which facilitated connection to their maternal identity. For some, this bond was present in pregnancy. However, for others they experienced, or were concerned about, delayed bonding with their baby (Donovan et al., 2023; Dugdale et al., 2021; Garcia-Molina & Cortés-Calvo, 2024; Gardner et al., 2016; Grahame et al., 2024; Hampton et al., 2022a; Hwang & Heslop, 2023; Lewis et al., 2021; Litchman et al., 2019; Talcer et al., 2023):

"I didn't bond with him right away. It took about three months. He didn't seem like a person to me" (Gardner et al., 2016, p. 33)

When the baby arrived, most participants identified an unconditional love which strengthened through getting to know each other. Where this was not present, this was often shaped through the method of becoming a parent, time to get to know their child, alongside contextual experiences, including a traumatic birth, and battles with their mental and physical health (Donovan et al., 2023; Dugdale et al., 2021; Gardner et al., 2016; Grahame et al., 2024; Grant et al. 2023; Libster et al., 2024; Smit & Hooper, 2023; Winnard et al., 2021).:

"I mean I did love them, of course, don't get me wrong, but the love deepened after I got to know them" (Donovan et al., 2023, p. 8)

Through getting to know their children, in some instances, similarity was identified, specifically in the context of neurodiversity. For many, neurodiversity provided a shared understanding between themselves and their children, and where this was talked about, many participants identified as autistic following their children receiving a diagnosis (Crane et al., 2021; Dugdale et al., 2021; Fletcher-Randle, 2022; Garcia-Molina & Cortés-Calvo, 2024; Gardner et al., 2016; Grahame et al., 2024; Hwang & Heslop, 2023; Libster et al., 2024; Sutcliffe-Khan et al., 2024; Smit & Hooper, 2023; Talcer et al., 2023):

"until I had my son, I did not realise that these characteristics could be due to autism...I felt identified" (Garcia-Molina & Cortés-Calvo, 2024, p. 5)

For some, this strong bond and connection brought uncertainty about whether they would share the same experience with their neurotypical children, but this was not consistent:

"She's probably the most challenging for me as a parent because yes, we're not wired the same. I just don't understand her at all" (Heyworth et al., 2023, Theme 4)

Journey Towards Self-Acceptance. For most, receiving a diagnosis or identifying as autistic, brought understanding and acceptance both internally and, in some instances, externally (Dugdale et al., 2021; Crane et al., 2021; Fletcher-Randle, 2022; Garcia-Molina & Cortés-Calvo, 2024; Grahame et al., 2024; Hampton et al., 2022b; Khan et al., 2021; Rabba et al., 2025; Radev et al., 2024b; Smit &

Hooper, 2023; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Thom-Jones et al., 2024b):

"Being autistic... this is part of me" (Grahame et al., 2024, p. 9).

Before identifying as autistic, participants' narratives often reflected feeling of being misunderstood and judged. Since receiving clarity and understanding, several participants reflected on how being autistic was interwoven with strengths associated with their approaches to parenting. For example, absorbing information, researching, communication, focussed attention, routines, problem solving and patience (Dugdale et al., 2021; Fletcher-Randle, 2022; Gardner et al., 2016; Hampton et al., 2022b; Lewis et al., 2021; Libster et al., 2024; Litchman et al., 2019; Grant et al., 2023; Radev et al., 2024b; Sutcliffe-Khan et al., 2024; Thom-Jones et al., 2024b; Wilson & Andrassy, 2022; Winnard et al., 2021).

However, this was not the same for all, and some identified grieving the loss of the life they could have had if they had received this diagnosis earlier (Grahame et al., 2024; Litchman et al., 2019; Talcer et al., 2023).

Providing a Different Experience. For many, watching their children's development was an aspect of parenting which they enjoyed. Due to the experiences faced by participants, most identified a strong desire to protect their children and for their experiences to be different to their own. Some participants showed this through their parenting style, whereby a strengths-based, open, respectful, accepting and flexible parenting environment was endorsed (Donovan et al., 2023; Dugdale et al., 2021; Crane et al., 2021; Fletcher-Randle, 2022; Hampton et al., 2022a; Heyworth et al., 2023; Hwang & Heslop, 2023; Libster et al., 2024; Sutcliffe-Khan et al., 2024; Thom-Jones et al., 2024b):

"I am always open and honest about her neurology, she is wonderful and there is no need to hide that" (Crane et al., 2021, p. 1165)

Participants also described advocating for systemic change, including advocating for earlier diagnosis, support for the whole family, and challenging *"neurotypical"* 'norms' (Dugdale et al., 2021; Gardner et al., 2016; Gore et al., 2024; Hwang & Heslop, 2023; Rabba et al., 2025; Radev et al., 2024b; Sutcliffe-Khan et al., 2024; Talcer et al., 2023; Wilson & Andrassy, 2022; Winnard et al., 2021).:

"I think that schools forgot... the 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" (Radev et al., 2024b p. 1401)

However, maintaining this role required a strong sense of self-identity as participants were often on their own in this position, *"batt[ling]"* services. Where participants did not have this security, such interactions had a significant impact on the family's wellbeing:

"I'm having full-blow heart palpitations at the thought of having to deal with teaching staff and school and the whole system" (Rabba et al., 2025, p. 1039)

Discussion

The review aimed to collate, critically appraise and thematically synthesise literature with qualitative data to support our understanding of the lived experience of parenthood for autistic mothers and birthing people. Synthesis generated three themes and nine subthemes across 713 mothers and birthing peoples' experiences of parenting. The main themes were: 'Being an Autistic Mother/Parent is Overwhelming', 'Navigating an Inaccessible System' and 'Discovering Identity and Values as an Autistic Parent'.

Being an Autistic Mother/Parent is Overwhelming

Participants described the overwhelming demands of mother/parenthood. This is a theme consistent across the wider parenting literature, specifically for working mothers, where the *"juggling act",* and inequitable standards based on gender are discussed (Forbes et al., 2021). However, the current review suggests that autistic mothers and birthing people faced additional challenges in managing sensory, social and emotional demands. Sensory differences are recognised as a key aspect of being autistic, reflected in the diagnostic criteria (APA, 2022), and research has highlighted that such differences, specifically hypersensitivity, which most participants described, contribute to feeling overwhelmed (Taels et al., 2023). The social differences described also align with theory and understanding underpinning autism, specifically the 'double empathy problem', whereby it is argued that differences in the way that autistic people experience the world can make communications with neurotypical people challenging (Milton, 2012).

The current review suggests that participants' experiences contributed to feeling *"different"* from expected ideals, implicating views of themselves as *"good enough".* This supports the notion that experiences of parenting are socially constructed, and that different cultural norms and values, expected roles and contexts shape experiences (Gopfert et al., 2004; Schmidt et al., 2023). This is not a unique experience faced by autistic adults and may also reflect the challenges of living within the constraints of neurotypical ‘norms’ (Han et al., 2022).

Despite the challenges faced, autistic parents showed resource through adaptation. This is in line with existing research reporting autistic adults’ experiences through navigating a ‘neurotypical world’ (Ghanouni & Quirke, 2023).

Navigating an Inaccessible System

Participants identified consistent challenges navigating systems and services both for themselves and their children, who were in some instances also autistic. This is consistent with the literature, where inaccessibility of services for autistic people is highlighted within educational settings (Boshoff et al., 2024), mental health care (Brede et al., 2022) and healthcare (Radev et al.., 2024a). For some participants, rather than acknowledging systemic failings, blame or judgment was attributed to participants or their children. These findings align with the person-system fallacy (Ross & Nsxbett, 1991), referring to the idea that ‘problems’ are often located in a person rather than acknowledging systemic failings.

Participants described facing stigma and discrimination, including having to prove competence as a parent. These challenges are consistent across the literature reporting experiences of parenting an autistic child (Swaab et al., 2021) and parents who have a disability (Dunne & Ryan, 2024), and findings from the current review provide evidence for this experience for autistic mothers and birthing people. In line with the intersectionality framework (Crenshaw, 1989), this experience was amplified in the context of intersections of identity deviating away from Westernised ‘norms’ of mother/parenthood (Schmidt et al., 2023).

Discovering Identity and Values as an Autistic Parent

For many, getting to know their children facilitated identification as an autistic parent, which contributed towards acceptance. Findings align with the literature reporting autistic women's experiences of receiving an autism diagnosis (Leedham et al., 2020). However, the current review provides a lens to this experience in the context of parenthood, specifically how similarities in the parent-child relationship facilitated this process. This aligns with the understanding underpinning social identity theory, which has been used to understand identity in autistic adults (Davies et al., 2024), whereby self-identity, acceptance and belonging is developed through similarity and group membership (Tajfel & Turner, 1979).

In the context of the challenges faced, participants identified a strong desire for experiences to be different. This is consistent with the literature on adversity, whereby positive change can be shown (Tedeschi & Calhoun, 1995). However, this literature has been criticised for ignoring epistemology and, as such, ignoring the embedded contexts, which are particularly relevant for marginalised communities (Adler & Schwaba, 2024). Findings from the current review emphasise the importance of accounting for such contexts when considering positive change for autistic parents.

Collectively, there are similarities in findings to previous reviews in this field, specifically in the context of communication and sensory challenges, alongside strengths and commitment in their role as a parent (McDonnell & DeLucia, 2021; Thom-Jones et al., 2024a; Westgate et al., 2024). However, findings generate new insights into these experiences for autistic women and birthing people, notably within the context of how these experiences contributed to feeling overwhelmed, unsupported, alongside facilitating their developing identity and values. There are similarities in these findings to individual studies included in this review (Dugdale et al., 2021; Smit & Hooper, 2023; Winnard et al., 2022). These studies addressed a similar research question and approached analysis using constructivist methodological approaches, and findings from the current review provide supportive evidence of these constructs.

Quality Appraisal and Individual Contribution of Studies

Through completing a critical appraisal of the individual studies, studies varied in quality according to the criteria they were assessed. For the most part, included studies provided valid and clear results, with community involvement. Within a minority of studies, there was not always clarity and transparency in the aims, design, findings, self-reflexivity or ethical considerations which influenced the quality of the paper.

After the thematic synthesis was completed, relative contributions to themes were reviewed, and poorer quality studies contributed comparatively little, and did not contain unique themes, and higher quality studies contributed more. This is in line with conclusions drawn in previous qualitative reviews whereby higher quality data provided “thicker” experiential data, whereas lower quality data provided “thinner”, descriptive data, which often provided limited insight into the participants’ world (Noyes & Popay, 2007; Thomas & Harden, 2008).

Limitations and Areas for Future Study

The present review contains limitations. Firstly, a broad definition of parenthood was used to encompass diversity of experiences and reflect the available literature. Over the past year the available literature has grown, and the broad scope of the review may have lost nuance of participants experiences. Future research may benefit from exploring specific aspects of this experience, for example, parent-professional interactions or parent-child interactions, to narrow the scope. Due to time constraints, the present review was also not supported through community involvement. Future review may benefit from this inclusion to ensure relevance to the autistic community.

Additionally, most of the included papers reflected early parenting experience focusing on interactions with services, from predominantly White American, British or Australian cis women, undertaken by researchers from disciplines in Psychology and Psychiatry. Studies were included that reflected experiences of mother/parenthood across different countries. However, articles were limited to those published in English. Although a minority were excluded on this basis, findings are a product of these papers and, therefore, may reflect only specific experiences and approaches to understanding parenting. Many of the studies' inclusion criteria also required participants to identify as female. As such, the findings do not reflect a representative voice from autistic birthing people. Further research illuminating the diversity of experiences of autistic mothers and birthing people across the journey of parenthood would add to the current literature.

Although the present review has reported some interesting findings which may relate to experiences of their gender, caution should be taken when generalising this, as in some studies, questions were not focused specifically on gender.

Clinical Implications

Findings have various clinical implications. Firstly, participants identified the inaccessibility of support both for themselves and their autistic children. Participants emphasised the importance of recognising systemic failings to facilitate the process of acceptance, flexibility and openness to support the whole family. Systemic approaches are supported through the National Institute for Health and Care Excellence [NICE] guidance (NICE, 2021) for autistic adults and endorsed on a wider scale by the World Health Organisation (De Savigny & Adam, 2009). Considerations should be made as to how organisations can work together, facilitating holistic care for autistic mothers and birthing people.

Despite the challenges faced, where there was a key person, this had a positive influence on rebuilding their relationship with support. This was often centred around support being consistent, non-judgemental and personalised. Although the NICE guidance (NICE, 2021) recommends that professionals work from this basis. As highlighted, this was not always the case, and in some instances, disclosure of their autism diagnosis resulted in stigma and judgement. Professionals across health and education settings may benefit from additional training to reduce stigma and judgement and facilitate non-judgemental approaches to care. Such training may also facilitate earlier diagnosis for autistic mothers and birthing people, something that was noted as particularly important within internal and external processes of acceptance.

Conclusion

The present review aimed to collate, critically appraise and thematically synthesise qualitative data to support our understanding of the lived experience of parenthood for autistic mothers and birthing people. Findings highlight both individual and systemic challenges faced. Despite challenge, participants identified that becoming a parent brought connection with their children, which facilitated an understanding of themselves and their values as a parent. Participants identified advocating in the context of these values to support change. Findings support the importance of systemic changes to ensure that autistic women and birthing people and their families feel supported across their experiences of parenthood.

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Appendices

Appendix A

PRISMA checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	p.8
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Journal Guidance Followed
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	p.11-15
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	p.15
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	p.16-17
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	p.18
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	p.18-19
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	p.19
Data collection	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from	p.19-20

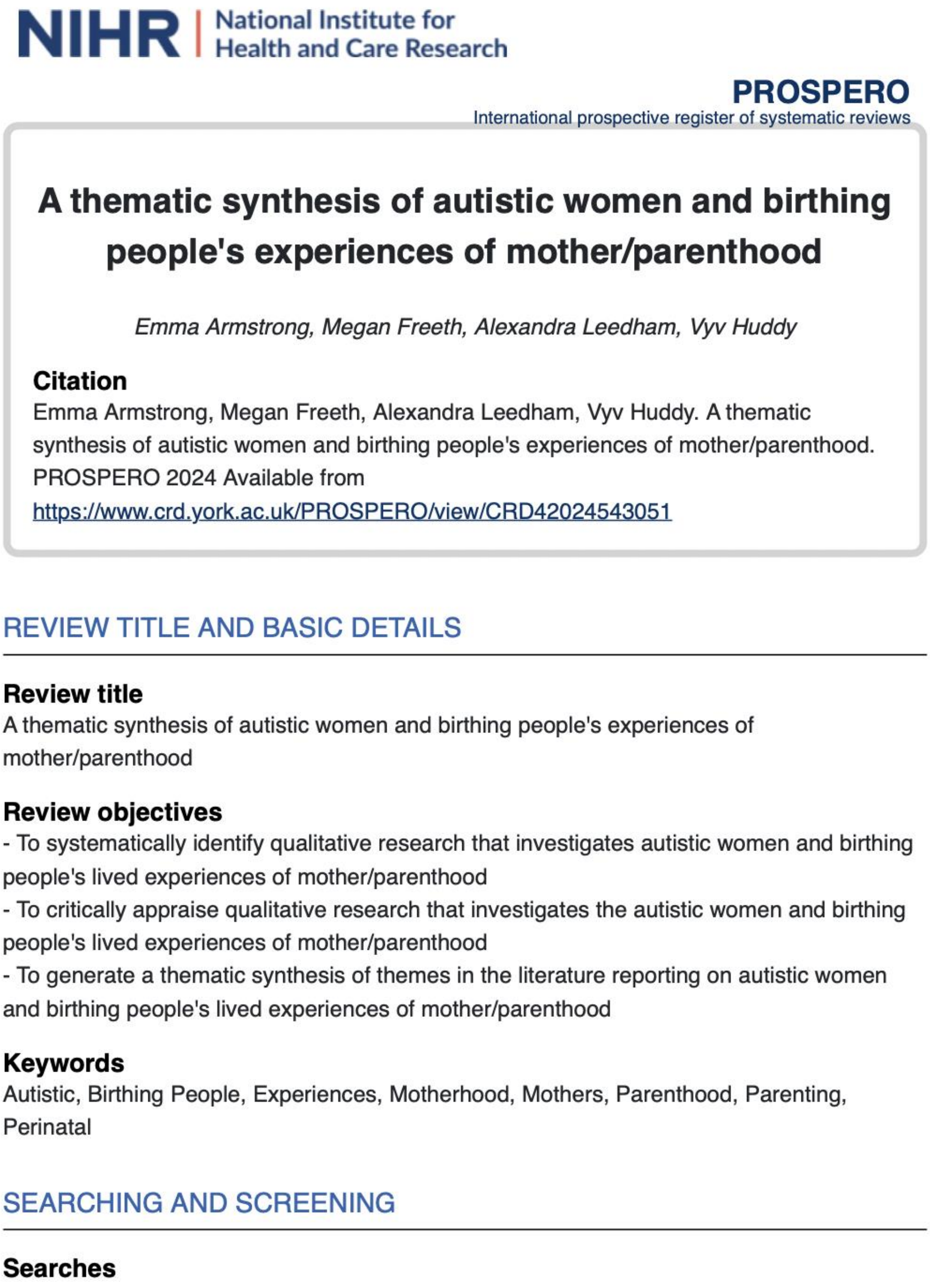
Section and Topic	Item #	Checklist item	Location where item is reported
process		study investigators, and if applicable, details of automation tools used in the process.	
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	p.19-20
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	p.19-20
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	p.19
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	p.19
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	p.20
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	p.20
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	p.16
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	p.20
Reporting	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
bias assessment		reporting biases).	
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	p.22-23
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	p.22-23
Study characteristics	17	Cite each included study and present its characteristics.	p.23-39
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	p.40-42
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	p.23-39
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	p.23-42
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	p.43-54
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	p.40-42
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A

Section and Topic	Item #	Checklist item	Location where item is reported
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	p.55-58
	23b	Discuss any limitations of the evidence included in the review.	p.58-59
	23c	Discuss any limitations of the review processes used.	p.58-59
	23d	Discuss implications of the results for practice, policy, and future research.	p.59-60
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	p.16
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	p.16
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	p.1
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Appendix A-I

Appendix B

PROSPERO registration



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PROSPERO
International prospective register of systematic reviews

A thematic synthesis of autistic women and birthing people's experiences of mother/parenthood

Emma Armstrong, Megan Freeth, Alexandra Leedham, Vyv Huddy

Citation
Emma Armstrong, Megan Freeth, Alexandra Leedham, Vyv Huddy. A thematic synthesis of autistic women and birthing people's experiences of mother/parenthood. PROSPERO 2024 Available from https://www.crd.york.ac.uk/PROSPERO/view/CRD42024543051

REVIEW TITLE AND BASIC DETAILS

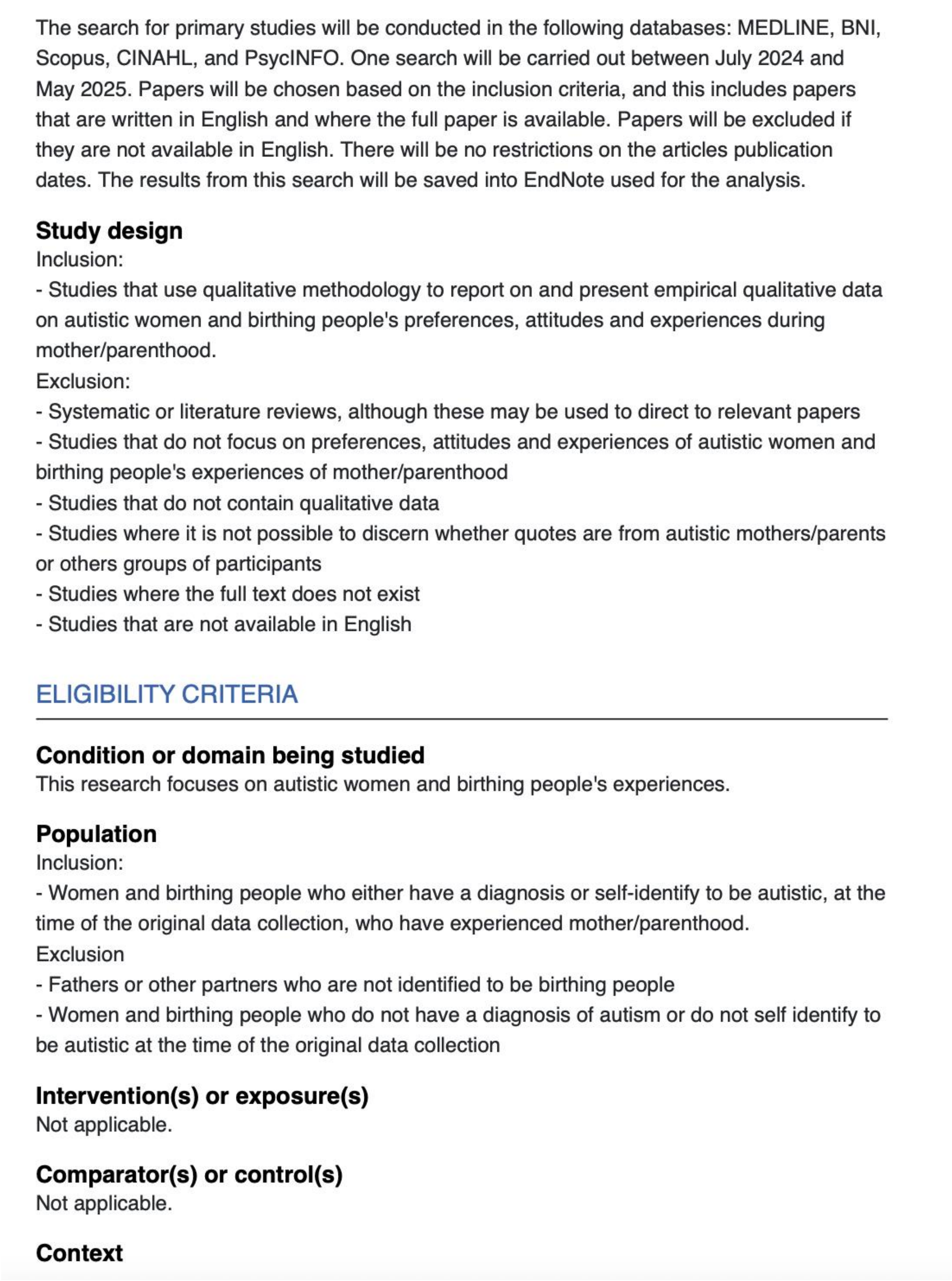
Review title
A thematic synthesis of autistic women and birthing people's experiences of mother/parenthood

Review objectives
- To systematically identify qualitative research that investigates autistic women and birthing people's lived experiences of mother/parenthood
- To critically appraise qualitative research that investigates the autistic women and birthing people's lived experiences of mother/parenthood
- To generate a thematic synthesis of themes in the literature reporting on autistic women and birthing people's lived experiences of mother/parenthood

Keywords
Autistic, Birthing People, Experiences, Motherhood, Mothers, Parenthood, Parenting, Perinatal

SEARCHING AND SCREENING

Searches



The search for primary studies will be conducted in the following databases: MEDLINE, BNI, Scopus, CINAHL, and PsycINFO. One search will be carried out between July 2024 and May 2025. Papers will be chosen based on the inclusion criteria, and this includes papers that are written in English and where the full paper is available. Papers will be excluded if they are not available in English. There will be no restrictions on the articles publication dates. The results from this search will be saved into EndNote used for the analysis.

Study design

Inclusion:

- Studies that use qualitative methodology to report on and present empirical qualitative data on autistic women and birthing people's preferences, attitudes and experiences during mother/parenthood.

Exclusion:

- Systematic or literature reviews, although these may be used to direct to relevant papers
- Studies that do not focus on preferences, attitudes and experiences of autistic women and birthing people's experiences of mother/parenthood
- Studies that do not contain qualitative data
- Studies where it is not possible to discern whether quotes are from autistic mothers/parents or others groups of participants
- Studies where the full text does not exist
- Studies that are not available in English

ELIGIBILITY CRITERIA

Condition or domain being studied

This research focuses on autistic women and birthing people's experiences.

Population

Inclusion:

- Women and birthing people who either have a diagnosis or self-identify to be autistic, at the time of the original data collection, who have experienced mother/parenthood.

Exclusion

- Fathers or other partners who are not identified to be birthing people
- Women and birthing people who do not have a diagnosis of autism or do not self identify to be autistic at the time of the original data collection

Intervention(s) or exposure(s)

Not applicable.

Comparator(s) or control(s)

Not applicable.

Context

Women and birthing people who have a diagnosis of autism or self-identify to be autistic who have experiences of mother/parenthood (defined from preconception (family planning), antenatal (pregnancy), birth, postnatal, and into their child's life).

OUTCOMES TO BE ANALYSED

Main outcomes

The aims of the review are:
- To systematically identify qualitative research that investigates autistic women and birthing people's lived experiences of mother/parenthood. This will be carried out through the researchers applying the studies inclusion criteria to the papers generated from the search strategy and reporting on the research identified.
- To critically appraise qualitative research that investigates the autistic women and birthing people's lived experiences of mother/parenthood. This will be carried out through the researchers gathering information and reporting on: the authors, title and journal, study setting, study design, any adaptations made to facilitate the involvement of autistic people in the study and any limitations (identified by the author) or other factors that may affect the results. This will also be supported through the use of the Critical Appraisal Skills Program (CASP) checklist.
- To generate themes in the literature reporting on autistic women and birthing people's lived experiences of mother/parenthood. This will be carried out through thematic synthesis methods.

Additional outcomes

Not applicable.

DATA COLLECTION PROCESS

Data extraction (selection and coding)

Study selection:
Articles will be initially screened through reviewing the abstracts, however where needed, full paper searches will be completed. Two reviewers will independently apply the eligibility criteria and select the studies for inclusion for the first 10% of studies. Inter-rater reliability will be assessed and discussions will take place to consider any discrepancies in studies selected. Discrepancies will then aim to be resolved by consensus between two authors and, if necessary, the wider research team. Any decisions made regarding regarding discrepancies will be recorded on the software system Rayyan. These discussions will then inform how studies are then screened which will be completed by one reviewer. Data screening will also be supported by using the software Endnote to remove any duplications.
Data extraction:
For each study, the following data will be extracted by one reviewer:

Primary data:
- Direct quotes from autistic mothers and birthing people who are sharing their experiences of mother/parenthood

Secondary data:
- Authors, title and journal
- Study setting: country, date and year of data collection
- Study design: aim, inclusion and exclusion criteria, sample size and sampling strategy and methodology
- Any adaptations made to facilitate the involvement of autistic people in the study
- Any limitations (identified by the author) or other factors that may affect the results, supported through the use of the Critical Appraisal Skills Program (CASP) checklist.

If there is data missing from reports, the first author will be contacted to see if this data can be obtained to be included in the analysis. If data cannot be obtained, this will be detailed in the write up.

An Excel spreadsheet will be used to collect the data.

Risk of bias (quality) assessment

The Critical Appraisal Skills Program (CASP) qualitative tool will be used to assess quality of each individual article. One reviewer will assess the quality of studies and decisions will be reported into the report in a quality assessment table. Independent review of 10% of the articles will be reviewed and inter-rater reliability will be assessed and discussions will take place to consider any discrepancies. Discrepancies will then aim to be resolved by consensus between two authors and, if necessary, the wider research team. Any decisions made regarding regarding discrepancies will be recorded. These discussions will then inform how the quality of articles are reviewed moving forwards, which will be completed by one reviewer.

The review will be reported using the PRISMA 2020 Checklist.

PLANNED DATA SYNTHESIS

Strategy for data synthesis

Once the primary data has been extracted a thematic synthesis (Thomas and Harden, 2008) will be used to synthesise findings using three stages. Firstly the data will be entered into the database. One reviewer will then independently code each line of the text according to its meaning and content. Free codes will be created inductively to capture the meaning and content of each sentence. The use of line-by-line coding will enable the translation of concepts between studies. Following this step is the development of descriptive themes which involves translating the concepts from one study to another and a hierarchical structure will be created by grouping the codes based on similarities and differences between the codes. Finally, analytical themes will be generated that go beyond the content of the original articles. Themes will be reviewed independently by one researcher to consider

implications and then discussed with the research team to to allow for the emergence of more abstract messages and themes that go beyond the content in the original materials. Analysis will be supported using the software NVivo.
Secondary data will be used to support quality assessment and the write up of the review.

Analysis of subgroups or subsets
Not applicable.

REVIEW AFFILIATION, FUNDING AND PEER REVIEW

Review team members

- Miss Emma Armstrong, Sheffield Health and Social Care NHS Foundation Trust
- Professor Megan Freeth, University of Sheffield
- Dr Alexandra Leedham, Sheffield Health and Social Care NHS Foundation Trust
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Review affiliation
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TIMELINE OF THE REVIEW

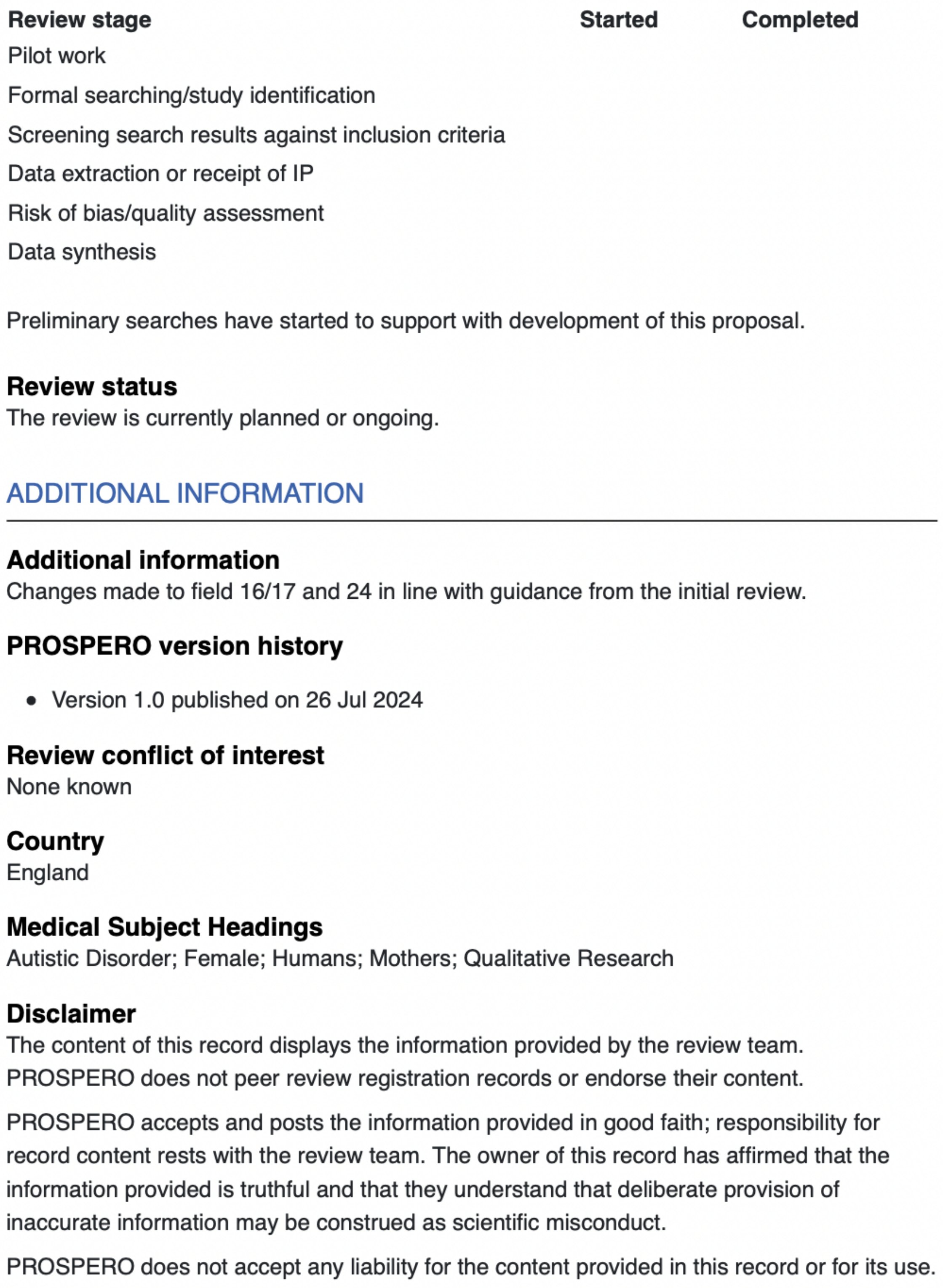
Review timeline
Start date: 29 July 2024. End date: 30 May 2025

Date of first submission to PROSPERO
12 July 2024

Date of registration in PROSPERO
26 July 2024

CURRENT REVIEW STAGE

Publication of review results
The intention is to publish the review once completed.The review will be published in English



Review stage	Started	Completed
Pilot work		
Formal searching/study identification		
Screening search results against inclusion criteria		
Data extraction or receipt of IP		
Risk of bias/quality assessment		
Data synthesis		

Preliminary searches have started to support with development of this proposal.

Review status

The review is currently planned or ongoing.

ADDITIONAL INFORMATION

Additional information

Changes made to field 16/17 and 24 in line with guidance from the initial review.

PROSPERO version history

- Version 1.0 published on 26 Jul 2024

Review conflict of interest

None known

Country

England

Medical Subject Headings

Autistic Disorder; Female; Humans; Mothers; Qualitative Research

Disclaimer

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Appendix C

Example of participants not included and reasons

Author (Year)	Data Source/Participant Detail	Decision to Exclude
Fletcher-Randle (2022)	Deweert (2017)	Data source no longer exists
	Pacton (2016)	Data source no longer exists
	O'Donnell (2019)	Written from the perspective of an autistic father
	Farmer (2020)	Written from the perspective of an autistic father
	Rudy (2020	Not written from the perspective of an autistic parent

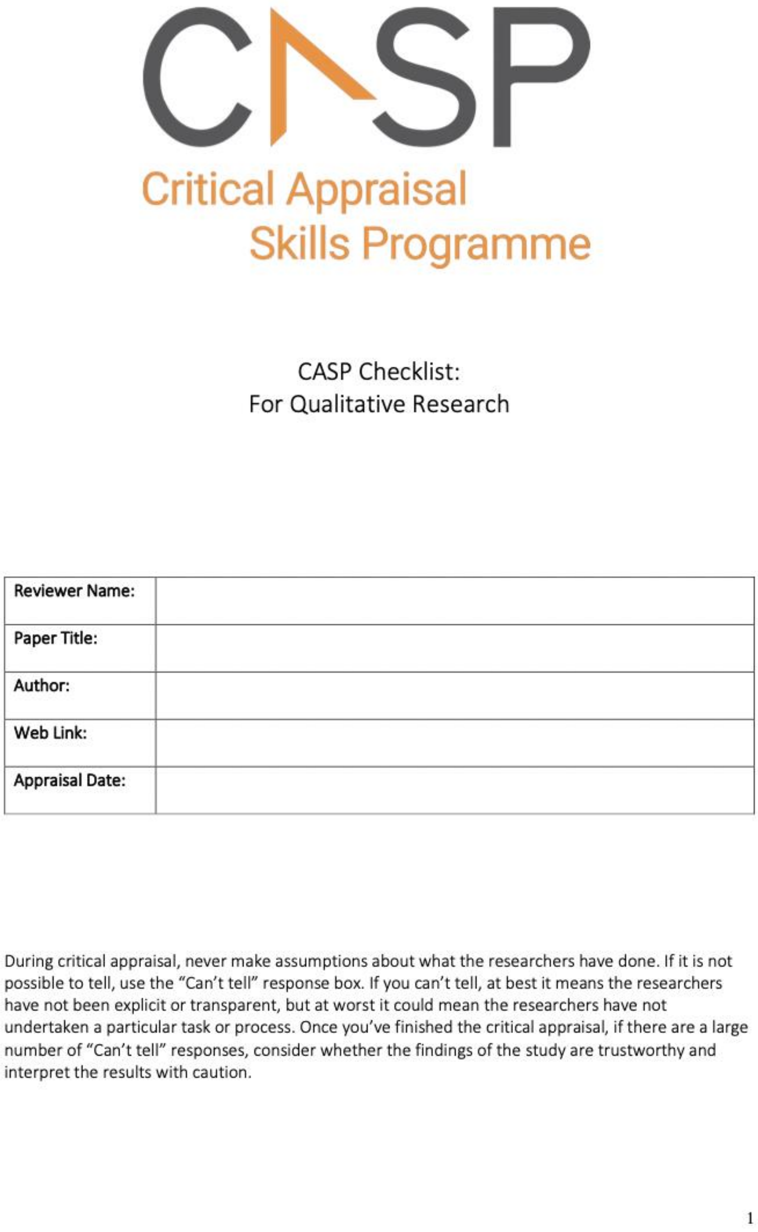
Appendix D

Examples of studies not included and reasons

Author (Year)	Decision to Exclude
Prince (2010)	Ethnographic article and not a research study
Rosqvist & Lövgren (2013)	Cannot distinguish participant details, unable to ascertain if the participant is an autistic mother or birthing person and raw data providing this information is unavailable
Burton (2016)	Not a peer reviewed article
Ghanouni & Trottier-Chi (2025)	Unable to obtain participant details, including through contact with the author
Grant (2025b)	Paper is exploring experiences of perinatal loss rather than experiences of parenting

Appendix E

Critical Appraisal Skills Programme qualitative research checklist (CASP, 2024)



CASP
Critical Appraisal
Skills Programme

CASP Checklist:
For Qualitative Research

Reviewer Name:	
Paper Title:	
Author:	
Web Link:	
Appraisal Date:	

During critical appraisal, never make assumptions about what the researchers have done. If it is not possible to tell, use the "Can't tell" response box. If you can't tell, at best it means the researchers have not been explicit or transparent, but at worst it could mean the researchers have not undertaken a particular task or process. Once you've finished the critical appraisal, if there are a large number of "Can't tell" responses, consider whether the findings of the study are trustworthy and interpret the results with caution.

Section A Are the results valid?	
1. Was there a clear statement of the aims of the research?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	
2. Is a qualitative methodology appropriate?	☐Yes ☐ No ☐ Can't Tell
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?*	
3. Was the research design appropriate to address the aims of the research?	☐Yes ☐ No ☐ Can't Tell
CONSIDER: • *if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	
4. Was the recruitment strategy appropriate to the aims of the research?	☐Yes ☐ No ☐ Can't Tell
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)*	

5. Was the data collected in a way that addressed the research issue?	☐Yes ☐ No ☐ Can't Tell
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*	
6. Has the relationship between researcher and participants been adequately considered?	☐Yes ☐ No ☐ Can't Tell
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*	
Section B: What are the results?	
7. Have ethical issues been taken into consideration?	☐Yes ☐ No ☐ Can't Tell
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*	

8. Was the data analysis sufficiently rigorous?	☐ Yes ☐ No ☐ Can't Tell

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*

9. Is there a clear statement of findings?	☐ Yes ☐ No ☐ Can't Tell

CONSIDER:

- *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*

Section C: Will the results help locally?

10. How valuable is the research?	☐ Yes ☐ No ☐ Can't Tell

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*

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*		
Positive/Methodologically sound	**Negative/Relatively poor methodology**	**Unknowns**

Appendix F

Descriptive Codes

Descriptive Code	Number of references (studies)	Example Quotes
Connection with others through neurodiversity	38 (16)	“If I go down the route for diagnosis as well, it’s going to be a constant fight. So from an autistic perspective, having the knowledge and having gone through it before” (Sutcliffe-Khan et al., 2024) “I think my diagnosis is fabulous modelling for them about autistic positive living” (Rabba et al., 2025)
Diagnosis including self-identification provides understanding and acceptance	43 (12)	“A lot more accepting about being autistic... this is a part of me” (Grahame et al., 2024) “I didn’t know I was autistic, I just thought I was like a crazy person” (Talcer et al., 2023)
Individual strengths in parenting	45 (17)	“I feel like I can read and communicate with my kids more seeking how verbal communication isn’t my primary method of communication” (Thom-Jones et al., 2024b) “I kept with it because that’s how my brain is wired” (Wilson & Andrassy, 2022)
Expectations, Judgement and Difference	101 (21)	“I’m supposed to act a certain way, give certain answers when people ask me, ‘Isn’t being pregnant great’”(Hampton et al., 2022a) “I had the expectation of myself that I should know everything and so, therefore wouldn’t ask questions” (Gardner et al., 2016)
Information and preparation	18 (8)	“Advice is so conflicting and I still don’t understand what temperature you should give a baby milk” (Grant et al., 2023) “just like the room I’m going to be in or the ward, that sort of thing would make a huge different to me” (Talcer et al.,2023)
Sensory challenges in parenthood	68 (15)	“I didn’t have a problem with the contractions and all the other pains, but just having someone touch me while doing all those things would set me over my limits” (Hampton et al., 2022b)

		“Crying babies are a sensory nightmare. My whole-body shivers and cringes and my skin crawls” (Wilson & Andrassy, 2022)
Communication differences	15 (9)	“I can’t look people in the eye, so I come over as being shifty” (Fletcher-Randle, 2022) “The school thing was a nightmare because that made me make contact with other parents” (Winnard et al., 2021)
Stigma and Discrimination	52 (18)	“He [family physician] seemed a little judgey about the whole no there being a dad”(Khan et al., 2021) “She thought I couldn’t do parenting, I couldn’t manage my son” (Hwang & Heslop, 2023)
Openness in parenting style	20 (9)	“I am very open about my own difficulties and spend a lot of time modelling that it’s ok to not cope with some things” (Crane et al., 2021) “Being open to ideas about parenting rather than following methods because of family, friends or traditions” (Sutcliffe-Khan et al., 2024)
Bonding and Connection	36 (13)	“I found breastfeeding comforting... I felt the oxytocin from it”(Grant et al., 2023) “You’re the best mum in the world” (Dugdale et al., 2021)
Resilience and resource	48 (16)	“I just kept distracting myself” (Grahame et al., 2024) “I was dogged though and never gave up” (Grant et al., 2023)
Time for self is important	27 (10)	“Being close to nature and outdoors in my garden gives me much needed headspace. Lots and lots of alone and downtime” (Sutcliffe-Khan et al., 2024) “time by myself to reenergise” (Heyworth et al., 2023)
Parenting is overwhelming	41 (16)	“It’s like I’m already overflowing and sometimes I’m afraid of myself. I switch off” (Garcia-Molina & Cortés-Calvo, 2024) “It’s kind of a combination of a whole lot of you know, medical things, mental health things, and autism. I get very, very exhausted and I’ve been exhausted for years, but it’s gotten to a whole new level” (Gore et al., 2024)
Lack of help and support	87 (24)	“I do have a couple of like parents that I know who are also autistic and have kids, so we meet every now and then. But again, we’re not too social” (Khan et al., 2021)

		“I just feel there is not enough support services for people like me and I’m not sure where to go” (Rogers et al., 2017)
Sensory differences in service experiences	34 (13)	“I needed utter silence and low light to labour. Any sensory onslaught and it set off an adrenaline rush which slows things down” (Grant et al., 2025a) “The bright lights and the noises, and it was, I mean... I don’t take drugs, but I imagine when people talk about like having a really out of control trip experience” (Moore et al., 2025)
Communication differences in service experiences	28 (10)	“I wasn’t able to convey how much discomfort I was in” (Gardner et al., 2016) “I need to know what’s going on” (Hampton et al., 2022b)
Power and advocacy	57 (14)	“It seems like school’s set us up to be a really aggressive kind of power struggle, and we don’t have the power” (Rabba et al., 2025) “I have limited energy to try and pick the battles that are the most important” (Radev et al., 2024b)
Past experiences impacting on parenting now	19 (5)	“I knew I didn’t want to bring up a child in that type of environment” (Libster et al., 2024) “I also had abusive parents and bad experiences with the medical profession all throughout my childhood” (Rogers et al., 2017)
Personalised support	54 (15)	“Very lucky we found this school and this school is supporting us” (Rabba et al., 2025) “She understands me so it’s helpful having her” (Hampton et al., 2022a)
Mental health	29 (9)	“I think 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” (Radev et al., 2024b)
Not feeling understood	28 (11)	“The medical profession doesn’t seem to understand or care about how pregnancy and Asperger’s syndrome interact” (Rogers et al., 2017) “... they [professionals] don’t believe you if you just say it, they want you to perform it” (Dugdale et al., 2021)
Not opening up	32 (16)	“I would be worried to speak out about certain things that I might have struggled with in case people said “oh well, if you’re struggling now what are you gonna be like when the baby’s here””(Grahame et al., 2024)

		“I’m afraid that if I brought up other concerns maybe they would treat me differently” (Hampton et al., 2022a)
Power and Advocacy	57 (14)	“I would have said no but I didn’t feel I could” (Grahame et al., 2024) “We stopped giving him the formula and they got real pushy” (Rogers et al., 2017)
Changes in Routine	17 (9)	“I found it very hard to accept the lack of a rigid routine” (Hampton et al., 2022b) “I think being autistic made me delay motherhood until I was confident, I had the ‘learned scripts’” (Hwang & Heslop, 2023)

Appendix G

Analytical Themes

Theme	Subtheme	Example quotes
Being an Autistic Mother/Parent is Overwhelming (26 articles)	Multiple Demands of Mother/Parenthood (22 articles)	“I didn’t know what was wrong with me but those sort of being oversensitive to everything (Grahame et al., 2024) “I ended up pulling them out of school, just for the last three days of term, because I was like, I’m exhausted, they were exhausted” (Rabba et al., 2025) “My kids are sensory-seekers and I am sensory avoidant, so that’s hard” (Sutcliffe-Khan et al., 2024) “When he (baby) started moving inside me it was unbearable” (Talcer et al., 2023) “Light, touching and smells and sounds and all of that is magnified and amplified” (Hampton et al., 2022a) “Participants acknowledged they may struggle with executive function... which has made it difficult to meet some of the logistical demands of raising children” (Hwang & Heslop, 2023) “Turns out, most of the time I’m just in sensory overload” (Thom-Jones et al., 2024b) “My whole body shivers and cringes and my skin crawls” (Wilson & Andrassy, 2022) “It was a complete sensory overload” (Lewis et al., 2021) “Mothers reported that social interactions required effort and were “hard work”” (Libster et al., 2024) “I was a stay at home parent and didn’t have much time for anything other than caring for my family” (Heyworth et al., 2023) “He drives me nuts with his sensory needs” (Dugdale et al., 2021) “I had a feel of dread with every let down” (Grant et al., 2023) “Near constant sensory overload and processing overwhelm” (Smit & Hooper, 2023) “I have to finish work at 2.30[pm] so that I’m there to pick up my daughter” (Gore et al., 2024) “I just couldn’t multi-task and have a work head and a parent head” (Winnard et al., 2021) “I’m more prone to sensory issues” (Rogers et al., 2017)

		“I’m terrified of becoming a mother due to hypersensitivity” (Garcia-Molina & Cortés-Calvo, 2024) “Babies have demanding round-the-clock needs” (Litchman et al., 2019) “I am a constant bag of nerves, since being a mum requires me to try to do all those things” (Fletcher-Randle, 2022) “The demands of frequent feedings could also be challenging for some women” (Donovan et al., 2023) “Movement inside felt like an invasion of privacy” (Gardner et al., 2016)
	Unable to Cope in the Same Way and Finding Alternatives (19 articles)	“I just kept distracting myself with telling [..] to talk to her sister” (Grahame et al., 2024) “I’d given up my job” (Rabba et al., 2025) “I loved the Gina Ford one because it said do this, this, this, and it gave me a routine and said obviously you change it if you need to. But it gave me the structure I needed” (Sutcliffe-Khan et al., 2024) “I can’t work because I’m full of kids, of parenting, I can’t do anything else unfortunately” (Talcer et al., 2023) “Some things that I would be able to cope with normally, I wouldn’t be able to cope with” (Hampton et al., 2022a) “I think being autistic, trying to cope with this change is difficult” Hwang & Heslop, 2023) “I escape for a few minutes to ground myself” (Thom-Jones et al., 2024b) “I needed a quiet dark room with no distractions or bright lights to stay calm” (Wilson & Andrassy, 2022) “I spent a lot of time in the heating birthing bath” (Lewis et al., 2021) “I think this is part of why I get irritated when there’s this plan and then you change it” (Libster et al., 2024) “All that sort of personal organisation – that’s probably one of the support things I’m missing most” (Heyworth et al., 2023) “I had to stop work at six weeks because my body was just in sensory overload” (Dugdale et al., 2021)

		“Breastfeeding helped me overcome the feelings of being overwhelmed it stopped me from completely shutting down” (Grant et al., 2023) “The biggest change for me was losing all my self-soothing methods” (Smit & Hooper, 2023) “I love that sense of satisfaction and fulfilment [at work], that I’m doing something that is important, something that, you know, I’m not just someone’s mum” (Gore et al., 2024) “I like my routine... I don’t like things suddenly changing” (Winnard et al., 2021) “Time alone and carefully crafted routines no longer existed” (Litchman et al., 2019) “A few women in the study included information about their sensory needs on their birth plan and used strategies... to combat offending sensory stimuli” (Donovan et al., 2023) “I did not enjoy breastfeeding, but I did it” (Gardner et al., 2016)
	Expectations and “Good Enough” (20 articles)	“The one [obstetrician] here in [my hometown] wasn’t necessarily great regarding the whole single thing” (Khan et al., 2021) “Being a new mum, you are made to feel like ‘crack on’” (Grahame et al., 2024) “I thought if I could do a better job, and again, I took that on as guilt, that I wasn’t doing a better job with the kids” (Rabba et al., 2025) “When I look back I feel like I was awkward and I was weird with people” (Sutcliffe-Khan et al., 2024) “But in that moment, I think I was the most rigid black and white I’ve ever been. I’ve been very much, child cries he’s fed, he doesn’t have a wet diaper, he must either be in pain or hate me” (Moore et al., 2025) “My kids then have to not have me go to their parents evening because of how I am, so I feel bad” (Talcer et al., 2023) “It’s a big things babies, very important, and I want to make sure I do it right” (Hampton et al., 2022a)

		“I think being autistic made me delay motherhood until I was confident” (Hwang & Heslop, 2023) “I am very aware of my shortcomings regarding my ability to guide my sons in the outside world” (Thom-Jones et al., 2024b) “I felt so knowledgeable, but breastfeeding was different” (Wilson & Andrassy, 2022) “I wasn’t a good model for her” (Libster et al., 2024) “Rubbish Mum because I feel like we didn’t have enough fun” (Radev et al., 2024b) “Holding everything together for everyone else” (Heyworth et al., 2023) “I feel bad that she feels so anxious a lot of the time” (Dugdale et al., 2021) “I had very little milk for my felt child yet felt so pressured to breastfeed (by myself, not just by others)” (Grant et al., 2023) “For a long time I just constantly felt like I was failing as a parent” (Smit & Hooper, 2023) “I definitely feel [guilt]. My husband doesn’t feel any guilt about dropping our kids off at childcare early and picking them up at quart to six” (Gore et al., 2024) “When you’re undiagnosed and going into parenthood, many issues can arise. However, becoming a parent when you know your disability can hinder your parenting abilities; this creates an entirely different dilemma” (Litchman et al., 2019) “Not doing them, or asking my parents or husband to do those things, makes me feel like a failure, a ‘bad mum’” (Fletcher-Randle, 2022) “I felt I had failed after getting Demerol, and the doctor was disappointment with me” (Gardner et al., 2016)
Navigating an Inaccessible System (28 articles)	Inaccessible to “Difference” (23 articles)	“I haven’t necessarily liked people touching me” (Khan et al., 2021) “I felt like a very small cog in a very big machine that really wasn’t very interested” (Grahame et al., 2024) “I often had to explain autism to [health care professionals]” (Grant et al., 2025a)

	“Everyone needs to fit into a box” (Rabba et al., 2025) “If I go down the route for diagnosis as well, it’s going to be a constant fight” (Sutcliffe-Khan et al., 2024) “I felt very frightened almost and just confused” (Moore et al., 2025) “It could have been made so much simpler and easier for me if they (medical professionals) could have made little changes” (Talcer et al., 2023) “I mentioned it [being autistic] at the first appointment and she was a bit like, ‘oh, what does that mean?” (Hampton et al., 2022a) “The people running the services are poorly educated and lack the knowledge or understanding of what autism even is” Hwang & Heslop, 2023) “Most adults do not understand autism and will make negative assumptions because they don’t understand” (Thom-Jones et al., 2024b) “I didn’t like the nurses touching me” (Wilson & Andrassy, 2022) “As soon as I could walk, I booked myself out because I didn’t feel safe since no one listened to me” (Lewis et al., 2021) “Don’t get a lot of support from anywhere really” (Radev et al., 2024b) “I just don’t quite fit in” (Libster et al., 2024) “As an autistic in a non-autistic world, it just can be so exhausting and draining” (Heyworth et al., 2023) “unwritten social hierarchy” (Dugdale et al., 2021) “I’m not sure if they didn’t listen to me because of poor communication or whether they treat everyone like that” (Grant et al., 2023) “They don’t have the expertise, because they’ve got nobody who’s got experience with autism” (Smit & Hooper, 2023) “When we say we’re autistic, people are like, no you’re not, and then we try to tell them that we’re struggling, and they just don’t get it” (Gore et al., 2024) “it might be difficult for the parent to understand what the teacher is saying” (Winnard et al., 2021) “The hospital was stressing me out” (Rogers et al., 2017) “Winne found it difficult to express to the nurse how badly she felt when anyone touched her” (Donovan et al., 2023)

		“Some felt that the providers did not understand their needs” (Gardner at al., 2016)
	Stigma and Judgement (24 articles)	“Corey explained how their doctors “was not concerned about me being autistic at all” (Khan et al., 2021) “You’re going to be a bad mother... because you’ve got an eating disorder” (Grahame et al., 2024) “I was generally ignored and one point told I was lying and needed to stop making it up” (Grant et al., 2025a) “The problem... even though we were so polite and so gentle and so proactive” (Rabba et al., 2025) “could be misunderstood by professionals as them being difficult, “you got to be on the ball all the time to get the right support” (Sutcliffe-Khan et al., 2024) “I was just a subject and one that wasn’t performing as she was supposed to” (Moore et al., 2025) “It is difficult to find people to say these things to because you fear that if you speak to the GP or whoever, or the midwife, they’re immediately going to go “postnatal depression”, [and think you are a] risk for this family” (Talcer et al., 2023) “Some medical professionals think that Asperger’s is a kind of hypochondriac fake excuse disorder” (Hampton et al., 2022a) “Which has led to autistic parents’ behaviours being categorised as “bizarre” “wrong” or “strange”” (Hwang & Heslop, 2023) “Instead of treating me more like a child. Because that’s something I find a lot in general with medical professionals” Saeed et al., 2022) “They seemed to think I was making a fuss over nothing” (Lewis et al., 2021) “Made me feel stupid and as if I was just an anxious person making some stuff up” (Radev et al., 2024b) “Not having to perform neurotypical parenting so that they don’t think I’m a terrible mother” (Heyworth et al., 2023) “they assumed participants were “aggressive””(Dugdale et al., 2021)

		“Kept commenting how difficult it was coz I was so obese” (Grant et al., 2023) “Outside the curtains they kept talking about me being “someone with autism” (Smit & Hooper, 2023) “I didn’t get the promotion. I didn’t get an upgrade” (Gore et al., 2024) “They mistook by obsession as a sign I was unstable” (Fletcher-Randle, 2022) “It seemed to Melanie that her mother took every opportunity to discourage her from ever becoming a parent... Melanie experienced her mother’s voice “running through my head” (Rogers et al., 2017) “She said our education about parenting class had to be repeated” (Rogers et al., 2017) “My friends did not believe me” (Garcia-Molina & Cortés-Calvo, 2024) “Autistic people are people with their own wants and needs and goals, and we can make our decisions about what is and is not in our best interest” (Litchman et al., 2019) “Autism is much misunderstood. Stereotypes abound, and many would assume that autism and motherhood don’t make comfortable bedfellows” (Fletcher-Randle, 2022) “One women said that she “brought my own blanket – nurse was irritated – rolled her eyes” (Gardner et al., 2016)
	Value to Trusting Relationships (20 articles)	“A lot of people who are just a little different happen to be autistic” (Khan et al., 2021) “I was really lucky in that their techniques really really suited my sensory needs and, what I didn’t get when I did transfer to the hospital” (Grahame et al., 2024) “I was under the perinatal mental health team at my hospital for my second and third births. That made a real difference... these midwives were adept at empathic care and ensuring continuity of care” (Grant et al., 2025a) “even when there’s a bump in the road, you know that everything’s going to be okay” (Rabba et al., 2025)

	"If you got one good professional then half the battle is done" (Sutcliffe-Khan et al., 2024) "I didn't feel like I could have that close enough relationship for someone to see that actually I might have needed a little bit extra" (Moore et al., 2025) "I found a lot of online solidarity"(Talcer et al., 2023) "She listens to what I have to say about my experiences and then adapts it" (Hampton et al., 2022a) "Do other autistic parents feel this way by the end of the day?" (Thom-Jones et al., 2024b) "The most positive support I got was from people who would actually listen" (Saeed et al., 2022) "One recalled how the clinicians were "kind and nonjudgmental"" (Lewis et al., 2021) "She made a point of going over to me and explaining what everyone was doing" (Radev et al., 2024b) "very close dear [autistic] friends... who get me more than anyone else" (Heyworth et al., 2023) "Shared experiences often improved understanding in social support, leading participants to feel as though they had an "ally"" (Dugdale et al., 2021) "I would not have been able to breastfeed without this support" (Grant et al., 2023) "He was really good with me and I felt supported" (Smit & Hooper, 2023) "I'm very blessed to have a manager who's also out and autistic" (Gore et al., 2024) "The midwife who delivered [baby] was great. She seemed to respect my wishes" (Rogers et al., 2017) "The nurse assisting her was caring and had a gentle approach that was comforting" (Donovan et al., 2023) "My mother would say, "now you know those books are second to human nature... and this is what you need to do" and she'd walk me through it" (Gardner et al., 2016)

Discovering Identity and Values as an Autistic Parent (26 articles)	Getting to Know Each Other and Connection (17 articles)	“I’d just tell him about things” (Grahame et al., 2024) “He knows things that you wouldn’t even dream of knowing. I just find... he is funny and dead interesting” (Sutcliffe-Khan et al., 2024) “Hang on a minute that was me. If this is my normal, then I’m autistic” (Talcer et al., 2023) “I really, really can’t express how excited I am about being able to meet and cuddle her” (Hampton et al., 2022a) “I think it helps me to understand him [her autistic son]” (Hwang & Heslop, 2023) “We can talk about stuff neurotypicals just don’t get or understand” (Crane et al., 2021) “I distinctly remember not wanting to touch, hold, or even look at my baby” (Lewis et al., 2021) “Mothers described their daughters as “exuberant, funny, extremely silly, super bright and so emotionally intelligent” (Libster et al., 2024) “Learning with him and finding ways to make it easier for him” (Heyworth et al., 2023) “peas in a pod” (Dugdale et al., 2021) “Since having them I have had a lot more emotions that I had before... a complete love for them” (Smit & Hooper, 2023) “Well good things about being a parent is the absolute love you get from your children” (Winnard et al., 2021) “My son received his diagnosis at 18 months, once we went to his therapy and they suggested that I could be on the spectrum” (Garcia-Molina & Cortés-Calvo, 2024) “Concerns about their ability to connect emotionally with their baby were described” (Litchman et al., 2019) “Potential for understanding and support based on shared neurology” (Fletcher-Randle, 2022) “While expressing love for their baby and caring for them, these women spoke of a need to get to know their babies before fully bonding with them” (Donovan et al., 2023)

		“I didn’t bond with him right away. It took about three months. He didn’t seem like a person to me” (Gardner et al., 2016)
	Journey Towards Self-Acceptance (19 articles)	“A lot of people who are just a little different happen to be autistic” (Khan et al., 2021) “Now you know your autistic because so many things that made sense now” (Grahame et al., 2024) “Their diagnosis helped them to develop “a confidence that comes with self-acceptance” (Rabba et al., 2025) “You can become quite knowledgeable, especially with... parenting styles and what’s good psychologically for children (Sutcliffe-Khan et al., 2024) “I sat in the library and I bawled my eyes out because suddenly somebody got it” (Sutcliffe-Khan et al., 2024) “I didn’t know I was autistic, I just thought I was like a crazy person” (Talcer et al., 2023) “We are all autistic and probably know more about how to live and deal with it than the professionals doing the diagnosis” (Crane et al., 2021) “I feel like I can read and communicate with my kids more seeing how verbal communication isn’t my primary method of communication” (Thom-Jones et al., 2024b) “I prepare well in advance by joining breastfeeding support group... it became by hyperfocus” (Wilson & Andrassy, 2022) “I think that’s also strength because I don’t get emotionally overwhelmed with stuff” (Libster et al., 2024) “using “determination and my autistic features” (Radev et al., 2024b) “Participants linked such behaviour to a “special interest”... resulting in a desire to be “all in” and “the best parent I [they] could” (Dugdale et al., 2021) “Breastfeeding was a special interest” (Grant et al., 2023) “The speech and language therapist was fantastic when I mentioned that I was autistic as well” (Smit & Hooper, 2023)

		“For me I suppose one of my biggest traits is that I need structure and I need routine and obviously that helps kids” (Winnard et al., 2021) “I felt identified by my repetitive routines” (Garcia-Molina & Cortés-Calvo, 2024) “One theory I like is that we actually make great mothers because we research, research, research” (Litchman et al., 2019) “I also know my autism helps me be a good mother” (Fletcher-Randle, 2022) “I am very sensitive to sounds so I knew their [baby’s] sounds... I was more in tune with grunts and coos” (Gardner et al., 2016)
	Providing a Different Experience (20 articles)	“Wanted their life to be very different to how mine had been” (Grahame et al., 2024) “I went to a very academic school that was very, very, very square peg, round hole, and there’s probably a layer of my worry... I feel like I can see it happening already” (Rabba et al., 2025) “I want them to have much better than my upbringing and don’t want them to experience the struggles, confusion and distress that my memories are filled with” (Sutcliffe-Khan et al., 2024) ““Knowing myself better” would have improved her experience of maternity care” (Moore et al., 2025) “Participants stopped trying to fit into the “neurotypical” mould”” (Talcer et al., 2023) “I want to understand... I don’t know whether that’s because I’ve felt misunderstood so much” (Hampton et al., 2022a) “I should respect their choices and beliefs” (Hwang & Heslop, 2023) “I am always open and honest about her neurology, she is wonderful and there is no need to hide that” (Crane et al., 2021)

	“I could use my weaknesses to explain and teach them about myself and the world around me” (Thom-Jones et al., 2024b) “Don’t view us as broken and less but different” (Wilson & Andrassy, 2022) “I knew I didn’t want to bring up a child in that type of environment” (Libster et al., 2024) “I am an autistic adult trying to navigate this system to advocate for my autistic children” (Radev et al., 2024b) “Being very upfront about what each other needs” (Heyworth et al., 2023) “Seeing his progression and celebrating the wins and the small things that other parents would take for granted... for us is a huge celebration (Dugdale et al., 2021) “I enjoy the feeling of pride as I watch them grown and lean” (Smit & Hooper, 2023) “I’m fighting to get him [her son] changed to a class with kids he knows, being an advocate” (Gore et al., 2024) “When you are growing your own kids and seeing all these things it feeds into you are well and makes you want to be , makes you want to do better” (Winnard et al., 2021) “I’m doing everything I can to give my children everything” (Fletcher-Randle, 2022) “Fiercely protective” of them” (Donovan et al., 2023) “I had frequent conflicts with staff who did not want to inform me, did not want to adhere to my choices, and did not respect my authority” (Gardner et al., 2016)

Appendix H

Researcher Positionality Statement and Reflexive Diary Extract

Positionality Statement

The author is a neurotypical White heterosexual cis woman who does not have children herself. During the time of this research, the author became an Auntie, and some of her close friends have become parents, and as such has been immersed in discussions of motherhood, including from both a personal and professional perspective. The author is also a mental healthcare professional working in the National Health Service (NHS) in the United Kingdom [UK] who has experience working with autistic clients across the lifespan, including autistic women and birthing people who are parents.

Reflexive Diary Extracts

Study Design

Having worked alongside autistic mothers within my role and experiencing motherhood through the lens of my friends and family, this is an important topic area to me. As a neurotypical cisgender female who does not have children herself, I am cautious in entering this topic area to ensure that I am able to provide a voice to the experiences of autistic mothers and birthing people. Although I recognise that my lens and experiences will influence the design, interpretation and reporting of data, I hope that my chosen design will provide a starting point to illuminating these experiences.

Data Collection and Analysis

Within data collection I was struck by the narratives and positioning present across some of the historic literature on autism, specifically in the context of medicalised narratives, and “treating” autism. I wonder what it was like for participant’s facing these experiences within their lives, and is this experience any different for them now? If this isn’t, what does that mean for them?

During data collection, I noticed strong personal reactions to the experiences faced by autistic women, and in some instances how this had been depicted by the authors in some of the historic literature, about ‘rights to parent’, which was not ultimately included in the study due to not meeting inclusion criteria. Freedom, independence, and autonomy are important values to me; however this is not an experience I have faced. It is difficult to imagine what this must be like for participants, I wonder if there are experiences within participants narratives which may help me with understanding this experience?

Write Up

Whilst developing themes, I was struck by the continued stigma and discrimination participants faced in their experiences of contact with services. It is important that I emphasise this in my write up to advocate change for these participants. However, I am a neurotypical healthcare professional, and I mustn’t be blind to my own lens and bias in this area. I will keep returning to participant’s voices and experiences, alongside the wider literature, where these voices are eliminated, to ensure an advocacy position for change is maintained.

Appendix I

Table comparing qualitative studies included in the present review in comparison to qualitative studies included in previous reviews in the field

Article	McDonnell & DeLucia (2021) [pregnancy and early parenthood]	Thom-Jones et al., (2024a) [motherhood]	Westgate et al., (2024) [perinatal]	Current Review
Burton (2016)	-	X	X	-[a]
Gardner et al., (2016)	X	X	X	X
Kanfiszer (2017)	X	-	-	-[b]
Rogers et al., (2017)	X	X	X	X
Cribb (2019)	X	-	-	-[c]
Litchman et al., 2019)	X	X	X	X
Donovan et al., (2023)	-	X	-	X
Dugdale et al., (2021)	-	X	-	X
Lewis et al., (2021)	-	X	X	X
Hampton et al., (2022a)	-	X	X	X

Note. Reasons for not including papers in the current review are detailed as a footnote below.

[a] Grey literature

[b] Not primary experiences of parenthood from autistic mothers' and birthing people

[c] Not primary experiences of parenthood from autistic mothers' and birthing people

Hampton et al., (2022b)	-	X	X	X
Wilson & Andrassy (2022)	-	X	X	X
Prince (2010)	-	X	-	-[d]
Donovan (2020)	X	X	X	-[e]
Heyworth et al., (2021)	-	X	-	-[f]
Murphy (2021)	-	X	-	-[g]
Lilley et al., (2023)	-	X	-	-[h]
Crane et al., (2021)	-	-	-	X
Fletcher-Randle (2022)	-	X	-	X
Saeed et al., (2022)	-	-	-	X
Winnard et al., (2021)	-	-	-	X
Heyworth et al., (2023)	-	X	-	X
Hwang & Heslop (2023)	-	X	-	X
Smit & Hooper (2023)	-	X	-	X
Talcer et al., (2023)	-	X	X	X

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[d] Not a research study

[e] Not primary experiences of parenthood from autistic mothers’ and birthing people

[f] Not primary experiences of parenthood from autistic mothers’ and birthing people

[g] Not identified during searches

[h] Not primary experiences of parenthood from autistic mothers’ and birthing people

Garcia-Molina & Cortés-Calvo (2024)	-		-	X
Gore et al., (2024)	-	-	-	X
Grant et al., (2023)	-	-	-	X
Libster et al., (2024)	-	X	-	X
Radev et al., (2024b)	-	X	-	X
Thom-Jones et al., (2024b)	-	-	-	X
Grahame et al., (2024)	-	-	-	X
Khan et al., (2021)	-	-	-	X
Moore et al., (2025)	-	-	-	X
Rabba et al., (2025)	-	-	-	X
Sutcliffe-Khan et al., (2024)	-	-	-	X
Grant et al., (2025a)	-	-	-	X

“There’s no real place that’s just for us”: Autistic Mothers’ and Birthing Peoples’ Experiences of Perinatal Mental Healthcare an Interpretative Phenomenological Analysis (IPA)

Word Count: 7998

Emma Armstrong (Trainee Clinical Psychologist, University of Sheffield)

Running title: Autistic Mothers’ and Birthing Peoples’ Experiences of Perinatal Mental Healthcare

Abstract

Objectives

The perinatal period is defined from preconception to two years after birth. Autistic people are more likely to face challenges in navigating sensory, physical and social experiences. This can result in motherhood feeling isolating, placing this population at increased risk of mental illness. The current study sought to understand the experiences of autistic women and birthing people who have a perinatal mental health condition, specifically focusing on their experiences of mental health care.

Design and Method

Five autistic women who experienced challenges with their mental health in the perinatal period completed semi-structured interviews. Interpretative Phenomenological Analysis (IPA) was used to provide an in-depth understanding of this lived experience.

Results

Three group experiential themes (GETs) emerged through the data, each with subthemes: ‘Amplification of Feeling ‘Different’ and Disconnected’, ‘Losing Trust that I will Get Help’ and ‘The Value of Understanding and Connection’.

Conclusions

Findings highlight the individual, systems and societal barriers to receiving perinatal mental health support. Receiving an autism diagnosis, therapeutic and peer support brought understanding, acceptance and facilitated self-compassion. However, there was concern about how much resource participants had left to sustain this journey on their own. Systemic changes are considered to support autistic mothers and birthing people.

Practitioner Points:

- Organisations should consider approaches to support the accessibility of care for autistic mothers and birthing people, including considerations about diagnostic pathways.

- Considerations should be made about the offer of peer support on a local and national level for autistic mothers, including for those who are experiencing perinatal mental health difficulties.
- On a societal level, it is hoped that through increased conversations about ‘difference’ in motherhood, this may have positive implications on the mental health of autistic mothers and birthing people.

Keywords: Autism, ASD, Parenting, Perinatal, Mental Health, Mental Health Care, Qualitative, Interpretative Phenomenological Analysis

Introduction

According to diagnostic criteria, Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterised by early-onset differences in social communication and interaction alongside repetitive behaviours, which may include hyper- or hypo-reactivity to sensory input, across multiple contexts (American Psychiatric Association [APA], 2022). In recent years, increased input from the neurodivergent community has reframed autism from an entirely deficit-based model to understanding being autistic as a neurodevelopmental difference which brings both strength and social disadvantage in the context of current society (Kapp, 2020). It is from the latter approach that the researcher positions themselves. In line with many autistic people's preference, identity first (autistic people) language is used throughout the paper (Taboas et al., 2023).

Systematic review and meta-analytic evidence highlight that co-occurring mental health conditions are more prevalent in autistic people than in the general population (Lai et al., 2019). However, recent evidence has shown that, concerningly, the current offer of mental health support is not accessible to autistic adults and rather poses the risk of additional harm (Brede et al., 2022). Findings from this paper have been replicated across the field, including for autistic adults who experience suicidality (Wilson et al., 2025). Authors recommend a collaborative approach to care, understanding how being autistic affects an individual's experiences of mental health and the support offered (Brede et al., 2022). One way of developing this understanding is by illuminating underrepresented autistic adults' experiences of living with a mental health condition through research.

Early theory into understanding autistic people's experiences was primarily driven through an understanding of autism from the perspective of cis males, including the 'extreme male brain' theory (Baron-Cohen, 2002). Although an approach that is not typically applied now, such theories have shaped societal attitudes and approaches to care. Research has shown that this has had implications on autistic cis women's self-identity, experiences of relationships, service provisions and diagnosis (Gosling et al., 2024), and for autistic cis women, diagnosis typically occurs later in comparison to cis men (Wilson et al., 2023). Receiving a late diagnosis brings challenges, specifically in the context of living within what has been described as a "hidden identity", and individual and societal acceptance when a diagnosis is received (Leedham et al., 2020). These experiences can have a significant influence on autistic cis women's mental wellbeing (O'Connor et al., 2024). Although there has not been extensive research into autistic cis women's experiences of mental health care, early literature has shown that care was inaccessible and autistic cis women often report feeling misunderstood and criticised (Babb et al., 2021). Qualitative evidence has been key in shining a light on the challenges faced by autistic cis women. However, at present, this remains a growing area of research, and further information on the nuances of experiences faced by autistic cis women is important to ensuring accessible and person-centred approaches to care.

Cross-culturally, the transition to motherhood, including decisions about becoming a mother (Barnett, 2016) and experiences of being a mother (Hwang et al., 2022; Prinds et al., 2014) brings challenges through adjusting to physical, psychological, social, and spiritual changes. For some, this can have a significant influence on emotional and psychological wellbeing (Al-Abri et al., 2023). In the United Kingdom [UK], the postnatal period has been identified high-risk for new and recurrent experiences of mental illness, and suicide remains the leading cause of direct maternal deaths (Mothers and Babies: Reducing Risk through Audits and

Confidential Enquires across the UK [MBRRACE-UK], 2023). The effect of mental illness not only has a significant impact on the mother, but also on the child, through the maternal-infant bond (O’Dea et al., 2023), and child development (Martucci et al., 2021).

Responding to this literature, perinatal mental health care pathways were developed to ensure timely mental health support for women and birthing people from conception to 12 months following the birth of a baby (National Health Service [NHS] England, 2018). With additional research on the importance of the first 1001 days as a critical time for providing a platform for children’s development (Leach, 2017), the NHS has placed additional funding in supporting specialist mental health care for women and birthing people from preconception to 24 months following the birth of their baby (NHS, 2019). As recognised by the Royal College of Midwives [RCM] (2022), language reflects accessibility. In line with maternity and perinatal literature (National Maternity and Perinatal Audit [NMPA], 2022), throughout this paper, the language of women and birthing people is used to promote inclusivity. Despite this, research may be cited that uses alternative language.

Over the past 4 years, there has been growing literature reporting on autistic women and birthing people’s experiences of the perinatal period. A review of this literature suggests that autistic cis women face unique challenges (McDonnell & DeLucia, 2021; Westgate et al., 2024). These challenges reflect the sensory demands in both pregnancy and into early parenthood, alongside challenges with healthcare interactions, reporting feeling misunderstood and that maternity services are not tailored or accepting of their experiences (McDonnell & DeLucia, 2021; Westgate et al., 2024). As a result, autistic cis women are often hesitant to disclose they are autistic these settings (Hampton et al., 2022c; 2002d; Pohl et al., 2020), resulting in parenthood feeling isolating. Quantitative reports have highlighted that autistic cis mothers are at greater risk of experiencing mental illness than neurotypical mothers (Hampton et al., 2022a; 2022b; Pohl et al., 2020).

Although there is evidence to suggest that autistic cis mothers are at greater risk of experiencing mental illness. To date, we have limited understanding of the experiences of autistic mothers and birthing people who have experienced a perinatal mental health condition. Given the literature reporting challenges with healthcare communications in maternity care (Westgate et al., 2024), alongside the wider literature reporting on the challenges experienced in mental health care for autistic adults and women (Babb et al., 2021; Brede et al., 2022; Wilson et al., 2025). It is important that autistic women and birthing people who have experienced a perinatal mental health condition are provided with a platform to voice their experiences. Within the available literature, there has been one study exploring autistic cis women's experiences of accessing an NHS Specialist Perinatal Mental Health Service in Brighton and Hove, and participants reported mixed experiences of the service (Pentz et al., 2023). Although beneficial in starting discussions within this area, the study used a mixed methods design to provide a broad overview of experiences to guide service development within this locality. Given the extensive expansion of specialist perinatal mental health services in the UK (NHS, 2019), further rigorous study is required to ensure that mental health care is adequate and accessible to autistic mothers and birthing people.

Research Aims

The current study aimed to better understand the experiences of autistic women and birthing people who have experienced a perinatal mental health condition, specifically focusing on their experiences of perinatal mental health care.

Method

Design

The study used Interpretative Phenomenological Analysis (IPA) (Smith et al., 2022), a qualitative design that aligns with the epistemology of social constructivism. Other qualitative research methodologies were considered, including narrative (Andrews et al., 2000), grounded theory (Glaser et al., 1967) and reflexive thematic analysis (Braun & Clarke, 2022). However, IPA was chosen due to the focus of understanding autistic mothers and birthing people's experiences, within the context of their wider perinatal experiences and social environment.

The researcher is a neurotypical mental healthcare professional. Understanding may be shaped through communication between neurotypical and autistic people ('the double empathy problem') (Milton, 2012), alongside through the researchers' personal and professional experiences. Whilst acknowledging that direct access to a participant's world is not possible, IPA allows the researcher to actively consider the impact of their own experiences on the interpretation of the results (Howard et al., 2019; MacLeod, 2019). Due to this, IPA is being increasingly used as an effective tool to illuminate autistic people's experiences within the literature (MacLeod, 2019), including autistic parents (Dugdale et al., 2021).

Ethical approval was obtained via the Integrated Research Application System (IRAS: 337360) and from Tees Esk and Wear Valleys NHS Foundation Trust and South West Yorkshire NHS Foundation Trust for governance (Appendix A).

Participants and Recruitment

Five cis autistic women were recruited. Inclusion and exclusion criteria to participate are summarised in Table 1. In line with methodological guidance, decisions to close recruitment were balanced with the quality and richness of data (Pietkiewicz & Smith, 2014).

Table 1.

Inclusion and exclusion criteria

Inclusion Criteria	Exclusion criteria
1. Adults (aged 18 years or older)	1. Cannot self-verify a formal diagnosis of Autism Spectrum Disorder (ASD) from a UK healthcare professional, including variants such as Asperger's
2. Received a diagnosis of Autism Spectrum Disorder (ASD), including previous diagnostic terminology such as Asperger's from a UK healthcare professional	
3. Experienced a perinatal mental health condition in the past 5 years	2. Diagnosis of a global learning disability
4. Have capacity to consent and participate in research	3. Not fluent in English

In line with current definitions, a perinatal mental health condition was defined as a mental health difficulty onset or exacerbated during preconception to 24 months following the birth of a child (NHS, 2019). During recruitment, both current and historic autism diagnostic terminology were used to ensure clarity, however following recruitment, participants' preferred terminology was used.

Previous research into autistic people's perinatal experiences has noted limitations through including retrospective accounts, due to concerns about reliability and relevance to the current societal context (Hampton et al., 2022b). Barriers to receiving timely assessment for cis women may mean that it is not until access to adult services that diagnostic assessment is pursued (Kanfiszer et al., 2017; Wilson et al., 2023). To account for this, a cut-off of 5 years from the onset of experiences was decided, as at the time of design, this encompassed waiting times for NHS autism diagnostic assessment in the local area.

The process of obtaining and accepting an autism diagnosis brings about significance for cis women (Leedham et al., 2020). As such, to limit sample heterogeneity, those who could not self-verify receiving an autism diagnosis from a UK healthcare professional were excluded. In October 2024, this criterion was amended from a diagnosis from an NHS healthcare professional due to challenges faced nationally with access to autism diagnostic assessments, and adults ‘Right to Choose’ diagnostic services (Psychiatry UK, 2025). To limit sample heterogeneity, participants were excluded if they had a comorbid diagnosis of a global learning disability or were not fluent in English. Participants were also required to indicate that they could consent and participate in research.

Participants were aged between 29-37 years (*M*= 34.4yrs). All participants were diagnosed as autistic within 1.5 years of the interview and described experiences of anxiety and depressive disorders in the perinatal period, which, for the most part, was defined both by participants and healthcare professionals as ‘moderate’. Further participant demographic information is provided in Table 2. Pseudonyms have been used to protect participant confidentiality.

Table 2.

Participant Demographics

Participant	Age	Gender	Ethnicity	Country	Relationship Status	Employment	Details of autism diagnosis	Additional diagnoses	Details of mental health and support	Children	Recruited through
Danielle	36	Female	White British	England	Married	Employed	Private, 3 months prior to the interview preferred terminology autistic.	No	Depression, self-identify as autistic overwhelm. Perinatal mental health midwife, NHS community perinatal mental health team, private doula, private psychologist (autism diagnosis and counselling).	22 weeks pregnant	NHS community perinatal mental health team
Holly	37	Female	White British	UK	Single	Employed	Private, 2 months prior to the interview, preferred terminology autistic.	ADHD, diagnosed at the same time as Autism	Postnatal depression, PTSD. NHS GP, Bupa GP, private psychologist (autism diagnosis and therapy), private doula.	Boy, 2 years old	Social media – National Charity advert
Karolina	35	Female	White Other (Lithuanian)	England	Married	Employed	Private (right to choose), 1 year 1 month prior to the interview, preferred terminology autistic.	No, queries dyslexia	Depression and anxiety (self-described). Talking therapy (private), medication.	Trying to conceive	Social media – Autism Support Group
Jamie	29	Female	White British	England	Engaged to Married	Employed	Private (right to choose), 4 months prior to the interview, preferred terminology autistic.	Waiting list ADHD assessment	Depression and anxiety, self-querying complex PTSD. NHS mental health services (talking therapies), baby massage (NHS), six-week bonding course (third sector), medication.	Boy, 18 months	Social media – Autism Support Group

Lucy	35	Female	White British	England	Cohabiting	Employed	Private (right to choose), 10 months prior to the interview, preferred terminology autistic.	Waiting list ADHD assessment	Depressive anxiety disorder, self-identity with anxiety with moderate depressive symptoms. Perinatal mental health midwife, peer support (NHS), art therapy (third sector), baby massage (third sector/NHS), medication	Female, 6 months	Social media – Autistic Women's Support Group

Note. Information is relevant to participants at the time of the interview. UK [United Kingdom], NHS [National Health Service], ADHD [Attention Deficit Hyperactivity Disorder], PTSD [Post Traumatic Stress Disorder], GP [General Practitioner]

Procedure

Previous study exploring autistic women’s experiences of the perinatal period noted challenges with recruitment (Hampton et al., 2022a), as such the current study approached recruitment using a purposeful snowball approach, across multiple pathways. The research advert (Appendix B), was shared to women and birthing people accessing three local NHS specialist community perinatal mental health services, in South West Yorkshire NHS Foundation Trust and Tees Esk and Wear Valleys NHS Foundation Trust (*n* = 1), with autism support groups and pages on social media including X (formally Twitter), LinkedIn and Facebook (*n*= 3) and through national and local charities (Appendix C) (*n*= 1). Homogeneity in the experience of a perinatal mental health condition was ensured by maintaining clear eligibility criteria. To allow time for research and governance across multiple NHS Trusts, recruitment was staggered from July 2024 to January 2025. Recruitment closed in March 2025.

Interested participants contacted the researcher using preferred contact methods and received an information sheet in an accessible format (Appendix D) before confirming consent to participate (Appendix E). Participants were interviewed using a semi-structured interview approach. The main schedule (Table 3) was informed by relevant literature, as well as methodological guidance (Smith et al., 2022) and given to participants before the interview. A collaborative-dialogic approach informed the researchers interview approach, due to the underpinning of hermeneutic philosophies and social construction theories (Anderson, 2014). As such the interview schedule was used as a framework and data derived through conversation based on individual participants’ experiences. There were some questions which were not relevant to participants’ experiences and therefore not asked. Guiding prompts and exploratory questions were asked to gain a greater understanding in line with the research aims. This was made clear prior to the interview. An extract of an anonymised participant transcript (Appendix F) is provided to support transparency and replicability. Interviews took place either face-to-face at the local NHS base in which the participant was accessing support from (*n*=1), or through a video call using approved video technology (Google Meet) with the researcher (*n*=4). Interviews lasted between 50-113 minutes and participants were debriefed at the end (Appendix G). Interviews were recorded using an audio recording device or using recording and transcribing functions on Google Meet and transcriptions were completed by the researcher.

Table 3.
Main Interview Schedule

Question number	Question wording
1	Can you please tell me about your experiences of becoming pregnant?
2	Can you please tell me about your experiences of being pregnant?
3	Can you please tell me about your experiences of giving birth?
4	Can you please tell me about your experiences after you had given birth?
5	How did you first identify that you were struggling with your mental health?
6	Can you please tell me about your experiences of support?
7	Is there any other support that you received/are receiving?
8	Is there anything that you would have liked to have been different in how you were/are supported?

The interview schedule and participant-facing documentation were designed alongside two autistic adults, who volunteered to contribute to the design of the research following advertisement shared with the Sheffield Autism Research Lab (ShARL) research database (Appendix H). Volunteers were provided with a £25 voucher in line with patient and public involvement (PPI) guidelines (National Institute for Health and Care Research [NIHR], 2022), alongside appropriate recognition. Based on these discussions, the main changes made were to the wording and structure to ensure clarity (Appendix I). This process also allowed the researcher to reflect on and justify decisions made throughout the design process. Participants were also encouraged throughout the interview to share their experiences and using this information, the researchers' approach was adapted to ensure that participants were placed at the centre of the research (Hoekstra et al., 2018).

Data Analysis

Smith et al., (2022) provides a general framework to IPA analysis. This guidance has been applied with appropriate flexibility to ensure relevance to the current dataset. Firstly, the researcher immersed themselves in each data set by listening to the audio recording and transcribing each interview. Initial annotations (exploratory notes) were added line-by-line, and these annotations focussed on the specific language used (linguistic), and how it is employed as a tool to convey their lived experience (descriptive), alongside initial ideas on interpretative meaning for the participant, made by the researcher, which took into account the researchers positionality, alongside relevant perinatal and autism literature and theory (conceptual). Following this, tentative exploratory statements grounded in the participants' experiences were added alongside the transcript (Appendix J). These statements were then grouped through clustering and conceptual mapping (Appendix K) to develop personal experiential themes (PETs) and subthemes (Appendix L). This process was repeated for each participant, before PETs were looked at together to develop Group Experiential Themes (GETs) and subthemes (Appendix M).

IPA focuses on understanding individual experiences through interpretation (Smith et al., 2022) using double hermeneutics (Giddens & Giddens, 1982; Heidegger, 1962). Subsequently, undergoing a process of self-reflexivity is vital to providing a credible account of participants' experiences (Engward & Goldspink, 2020). After each interview, the researcher took reflective notes on initial reactions, accounting for non-verbal interactions alongside personal thoughts and emotions present from the interview. These notes were maintained throughout data analysis and used as part of the iterative process of analysis, to raise awareness and ensure transparency of the researchers' values, beliefs and experiences in the context of emerging themes (Appendix N). To further support self-reflexivity, the researcher met with an autistic adult who volunteered to discuss the researcher's initial themes to prompt additional thought and consideration about the researcher's positionality during analysis and write-up (Appendix O).

Close considerations were made during the analysis process, to ensure the themes aligned closely with the aims and did not lose individual participant's voices and experiences. To support with this, supervisor guidance was sought, alongside an independent audit of each stage of the analysis process on randomly selected data (Appendix P).

Results

Analysis gave rise to three GETs and eight subthemes. Each theme is discussed below, grounded in participants' experiences. To ensure clarity, missing information is represented by '…' and additional information as '[ ]'. Themes do not represent all information shared but rather an interpretation of aspects of participants' experiences in the context of the research question. Certain aspects of participants' experiences apply across themes. Participants' contributions to each theme are illustrated below (Table 4).

Table 4.

Participant contributions to Group Experiential Themes (GETs) and sub-themes

Group Experiential Themes	Subthemes	Danielle	Holly	Karolina	Jamie	Lucy
Amplification of feeling 'different' and disconnected	The challenges with not fitting a predefined path	✓	✓	✓	✓	✓
	Judgement results in internalised difference	✓	✓	✓	✓	✓
Losing trust that I will get help	Information and support are gatekept	✓	✓	✓	✓	✓
	Not thinking about me	✓	✓	✓	✓	✓
	Power influences choice	✓	✓	✓	✓	✓
	Failed and let down	✓	✓	✓	✓	✓
The value of understanding and connection	Understanding brings acceptance	✓	✓	✓	✓	✓
	Similarity brings compassion	✓	✓	✓	✓	✓

Theme 1 – Amplification of Feeling 'Different' and Disconnected

This GET encompasses experiences of predefined paths, in the context of motherhood, mental health, and mental health support. For participants, such pathways amplified a feeling of 'difference' and disconnection, both in the context of themselves and others.

The Challenges with Not Fitting a Predefined Path – From the start of participants' experiences, predefined expectations and assumptions about motherhood and mental health were faced, which shaped participants' understanding of their experiences and where they could seek support. For example, for Karolina, Lucy and Danielle, societal expectations about motherhood resulted in challenging social interactions both in pregnancy and whilst trying to conceive, which resulted in the identification of 'difference' in their experiences in comparison to others:

"People want to ask you how the pregnancy is going, and like expect you to be glowing and just all loved up with this baby, and because I'm like the opposite of that, I'm finding that very difficult" (Danielle).

For others, this was reflected through messages received during healthcare communications. For example, for Jamie, communications about *"positivity"* in pregnancy and *"closeted"* attitudes towards termination highlighted early on that her experiences did not fit these pathways. For Holly, the environment of maternity care brough assumption about family relationships, which were not welcoming to her experiences as a single mother:

"I was in like this chair, which was already like, because all the other chairs were just normal chairs, and they were all like in twos... I was just in this one chair alone in the corner that was for some reason bigger than the other chairs and had like massive arm things... I was sticking out like a sore thumb" (Holly).

These experiences continued into participants' experiences of mental health support. For example, for Karolina, Jamie and Lucy, narratives about mental health and how they *"should"* feel were reflected in the lack of support and guidance offered, which shaped their perceptions of their experiences. For Jamie, this was reflected through a lack of support following her birth, which shaped her perception of whether her experiences were something that was *“traumatic”* and something she could access support for:

“On paper, it’s a textbook birth. What could possibly go wrong? What have you got to complain about?” (Jamie).

And for participants’ where therapeutic support was offered, this was not deemed helpful or accessible, which further amplified the separation they felt (Karolina, Jamie and Lucy):

“They always say, ‘this is going to be helpful, and you know the stats are up here with who and how much we’re gonna help”... I just felt very separate from it all” (Jamie).

For Lucy, Danielle and Karolina, their perinatal experiences not only amplified ‘difference’ from others but also within themselves. For example, methods which they used to support their wellbeing, such as *“masking”* and “*rehearsal”* (Danielle), were no longer accessible or helpful to them. For Lucy, this was exemplified through losing coping through reading:

“One of my big hobbies was reading. I cannot read. My brain won’t stay there... So yeah, it’s not working at the moment” (Lucy).

For most, *“sticking out”* and feeling *“different”* was not a unique position, and participants consistently faced experiences of being misunderstood (Lucy) and misdiagnosed with a plethora of mental and physical health diagnoses (Danielle, Holly, Karolina) across their life. However, participants’ perinatal experiences amplified this experience, which for most had a significant impact on their mental health and experiences of receiving support:

“Being autistic is isolated already and then it just goes on another level… you are not just on your own you also cannot share your feelings and thoughts with anyone” (Karolina).

Judgement Results in Internalised Difference. For most, where ‘difference’ was identified, interactions were compounded with stigma, judgement and discrimination. For example, after Holly shared that she was a single mother in a maternity setting, she was asked *“are you worried that your parents are going to be ashamed of you?”.* And for Lucy, although she hoped that sharing that she was autistic would have a positive implication on her maternity care, maternity staff’s infantilising response resulted in Lucy feeling *“condescend[ed]”:*

“She just took it upon herself to bring a projector into the room and project some image of space onto the ceiling. And she said, “I thought you might like this”... Erm like you’re autistic. This is what autistic people like isn’t it?” (Lucy).

For most participants, perceived judgement only continued into conversations with their support networks. For Danielle and Holly, this was exemplified through narratives within their family about mental health and autism, which shaped how comfortable they felt to speak openly with them:

“I haven’t told my Mum how I’ve been feeling mental healthwise. She knows I’ve struggled a bit, but she was quite against me trying for a baby anyway because of “how I am”, in her word. (Danielle).

“I don’t think they really believe in autism, or my dad was quite angry… he was going normal, normal, normal. Almost like it would be offensive if I was autistic” (Holly).

Consistent narratives about how things *“should”* be also resulted in participants making comparative judgements towards themselves:

“Why can’t I do what they do” (Lucy).

In fear of the consequences of judgement, both in terms of the social threat, including not *"fit[ting] in"* (Holly), as well as against themselves and their baby, most participants faced experience of not voicing their experiences or "*allow[ing]"* (Karolina) themselves to feel a certain way. For Karolina, she felt that it was safer to *"mask"* her experiences through a language barrier than to disclose she was autistic, and for Holly fears of judgement resulted in feeling too scared to speak*:*

"I really thought that if I told them not told them I was struggling, if I told them I was having these feelings, that basically they would take [her baby] away from me" (Holly).

In the absence of help and understanding, most participants internalised 'difference', and they were left feeling *"broken"* (Lucy), and that they had "*done something wrong"* and were the *"worst mother in the world"* (Holly). This was a familiar position, and had a significant influence on participants' mental health and relationship with themselves:

"I mean I've always disliked myself because I've been, I am so different" (Danielle).

Theme 2 – Losing Trust That I Will Get Help

This GET reflects a shared experience of the barriers faced to receiving accessible mental health support, which resulted in participants feeling overlooked, both by professionals, services and society, and ultimately losing trust that help will be offered. All participants identified a reliance on alternative pathways, including privately funded support and self-management. However, for most, uncertainty within the context of this support contributed further to a loss of trust in help.

Information and Support are Gatekept – All participants described a journey faced with barriers to receiving mental health support. For some, this was shaped through previous experiences of accessing mental health support through the NHS, which was then paralleled through their perinatal experiences. For example, for Holly in accessing help she was aware of the *"mountain"* of *"getting help"*, yet went ahead with this and was faced with continued barriers:

"You call exactly as the clock turns to 8[am] and it's like you are number 137 in the queue" (Holly).

For most, this experience was layered with similar experiences in the context of seeking a neurodevelopmental assessment:

"the doctor just was like, pff, it's a two-year waiting list, you'd, there's no point, sort of thing, who on earth would you want, why do you need a diagnosis" (Danielle).

Barriers were not only faced through waiting lists, but also through jargon, and certain professionals:

"the doctor will make you speak to her before they'll approve it" (Danielle).

And even the timeframe which has been defined as 'motherhood':

"*You're not allowed into the club, into the exclusive conversations until you're there"* (Lucy).

This resulted in participants not knowing *"who to speak to about this"* (Karolina), and for Danielle, she felt that she was required to be at her *"worst"* before she could access help and support due to the narratives from the perinatal mental health team about access to support based on the perinatal timeframe:

"Oh well, you're only, you know we've got ages yet... but that doesn't help in that moment, it's not about getting you feeling right at 40 weeks. It's feeling right during pregnancy" (Danielle).

In the face of significant barriers and hurdles, most participants did not receive support through the NHS, and where participants did receive helpful mental health support either through the NHS or alternative pathways, they often attributed this to negotiation, *"luck"* (Danielle; Lucy), a *"miracle"* and *"chance"* (Holly):

"I feel like I had to kind of weave my way in through the back door, and sneak on in, because otherwise how would you find out about it?" (Lucy).

However, for one participant, barriers consisted in the context of accessing private services:

"I don't know if I need a counsellor, a psychologist, a psychiatrist. I don't know what level of help, I don't know what level of person I need" (Jamie).

Not Thinking About Me – Across multiple contexts, participants described the perceived "*bus[iness]"* (Danielle*,* Holly, Lucy) of others, which resulted in participants feeling overlooked and uncared for. For Holly, this was reflected at the start of her perinatal experiences through maternity care:

"People are busily walking past you and nobody's like are you alright? Or you know nobody ask you if you're okay or if you need anything" (Holly).

For Danielle, through her experiences of feeling dismissed by perinatal mental health services:

"I was at a low really, then I remembered I was on the phone with the receptionist, I were on the phone and she just said, well I'm sorry, but we've got to cancel it and I, I was a bit like desperate in my voice and she said, you do know that you can just ring up at any time don't you, and she was just quite snappy with me" (Danielle).

And for Lucy, through formulaic mental health screening questions from the health visitor:

"I'm here to do this certain job. I can tick that box. I've done that" (Lucy).

Consistent across these experiences was the feeling that others were more focused on their agenda rather than thinking about the participants. As such there was limited room for participants to share how they were feeling, which had implications for how supported they felt with their mental health. This was reflected in Holly's experiences of sharing her birth plan with maternity staff, an important part of feeling supported in her mental health during birth, however healthcare professionals did not share the same priority:

"I was holding this birth plan in my hand…. And so I was waiting for somebody to come and say. Can I take your birth plan… But like nobody ever did that" (Holly).

All participants described experiences where healthcare professionals had been available, supportive and friendly. These experiences were reflected across interactions with maternity and mental healthcare professionals from private and public health services. Such experiences brought trust and allowed space for some participants to open up. However, these experiences were minimal or required an active approach to seeking out this help for themselves:

"You know when you're completely starved of kindness and then a kind person comes to you, it's almost like you're so relieved to see them" (Holly).

Power Influences Choice – Consistent across participants' experiences was the recognition of power within healthcare. For some, this started in their experiences of maternity care, where power influenced choice over care. For Holly, this mirrored previous traumatic experiences and had a significant influence on her mental health:

"I didn't want him to do it… and I said is there no female doctor available and sort of like, they just sort of made me feel so… like it was a silly question and I was putting my baby in danger if I didn't just let him do it… so I just let him do it" (Holly).

For others, this was reflected in the lack of power and choice felt in the context of healthcare resources. This was a consistent experience for both participants and healthcare professionals. For Lucy, her GP acknowledging this shared position was validating:

“I basically went and spoke to the GP about it and she said...Basically there’s nothing we can do for you...I felt really actually heard and seen by this doctor, but I felt her powerlessness” (Lucy)

In the context of a lack of power and choice in public healthcare, majority sought alternative support. Three participants sought advocation to support healthcare communications, including through family (Karolina), and privately funding a doula (Danielle, Holly), three participants sought private therapy (Danielle, Holly, Karolina), and Lucy received art therapy through a third-sector organisation, a therapeutic offer which endorses freedom of choice. However, participants discussed the inequality in access to support based on the resources they had which left participants feeling *“fortunate”* (Holly) and that this did not feel fair to others:

“If I didn’t have the money to see X [doula] and they’ll be women out there who don’t have that I know, like God knows how I would have been” (Danielle).

For Jamie and Lucy, uncertainty within their mental health care remained, either due to being unable to access support, or through uncertainty within the funding of support, which resulted left Jamie and Lucy powerless in decisions about their mental health care:

“I am considering much against my will, I am considering me, medication again, which I really don’t want, I view that as an absolute last resort” (Jamie).

For Lucy, she tried to obtain some power over these decisions through telling others about the art therapy group to ensure that outcomes can be provided, to *“prove”* that the support is helpful.

However, it was questioned why such approaches to ensuring accessible support were considered the ‘norm’:

“What if you shouldn’t have to be the kind of person who can scream and shout in order to get the kind of healthcare you need” (Holly).

Failed and Let Down - Consistent experiences of inaccessible and uncaring systems both currently and historically, resulted in participants feeling let down and losing trust. For Karolina, this was the only experience of mental health support she had received from the UK and had a lasting influence:

“They failed me... I no longer can trust GPs and doctors because I know they’re professionals and I know I should be trusting them, but from my experience when I was reaching out for help for so many years and they still did not” (Karolina)

For all participants, a lack of support in the context of neurodiversity amplified this experience and many participants received minimal support following their diagnosis:

“They go okay, here’s your new information about your brain and who you are. Goodbye” (Jamie).

For some participants, they also reflected on what their experiences would have been like without that ‘one person’ thinking about neurodivergence. For Jamie this resulted in questioning current assessment approaches applied in mental health settings:

“The way that people are taught it doesn’t, it doesn’t lend itself to a comprehensive holistic view of anything” (Jamie).

Faced with a lack of trust in others, participants identified that they were facing this journey on their own, reflected in Holly’s experiences where she faced *“the realisation for the first time being like I’m really doing this alone”* (Holly). For some, they resorted to ways they had coped previously, including gathering information on themselves and becoming an 'expert' of their own care. However, through participants' efforts they soon realised that there is *"not a lot [of information or support] out there"* (Danielle). This resulted in participants not only feeling failed through services, but also on a wider societal level (Holly, Lucy, Karolina), and Karolina and Holly spoke about the challenges of being part of *"a group that all the people do not care about"* (Karolina), which left Holly with the lasting view that:

"There's no real place that just for us" (Holly).

Although supporting oneself was a familiar position, participants referred ahead to the known journey of motherhood and voiced concern about how much resource they had left to sustain this approach and whether they would also let themselves down:

*"I've managed to bring myself out of the darkest time but apprehensive about what's to come as well" (*Danielle).

Theme 3 – The Value of Understanding and Connection

This GET encompasses participants experiences of seeking understanding of their experiences. This was achieved in different ways, including through an autism diagnosis and therapeutic support. For participants, understanding themselves facilitated acceptance and connection with others, which, for most, in turn facilitated a process towards discovering self-compassion.

Understanding Brings Acceptance - At the start of participants' perinatal experiences, for all participants', seeking understanding was important to bringing control to what they were experiencing and opening up pathways of support:

"I need someone to tell me that it's normal or that I'm okay" (Danielle).

“You enter all of these new phases without a support system, but without the knowledge or the words to be able to understand or express what your struggle is to get help for that struggle” (Jamie).

Understanding was sought in different ways including through information from podcasts (Jamie; Danielle), Google (Danielle, Holly), social media including Reddit (Jamie; Karolina), chat GPT [an artificial intelligence program], therapy (Holly, Karolina), and encompassed a multifaceted approach to understanding their experiences of being an autistic mother who is experiencing mental health difficulties:

“I’d been trying to learn how to autism almost, how to parent... I’ve been trying to learn from scratch because it’s all happened... at the same time” (Jamie)

For all participants, receiving an autism diagnosis was a key part of their journey towards understanding, and this understanding facilitated acceptance both within themselves and others:

“I’ve been wrongly diagnosed with different things in the past, erm which now makes sense that you know I was struggling with being overwhelmed due to my autism and things like that” (Danielle).

“When I said I’m autistic, she was like, oh okay that makes a lot of sense… so that was nice to be understood” (Lucy).

Similarity Brings Compassion - For some, receiving an autism diagnosis facilitated connection. This included connection with the wider neurodivergent community, including through peer support, such as through podcasts (Danielle, Jamie), online communities (Karolina) and for Holly a *“neurodiversity support network at work”*. Shared experiences offered an extension to acceptance and understanding through providing common humanity. For Danielle, this was exemplified through shared experiences of neurodivergence with her doula which left Danielle feeling that she did not need to "*ask her to do anything different"* (Danielle). This contrasted to experiences with other healthcare professionals, where, for Danielle, disclosure of her diagnosis brought fears of judgement.

Connection was also facilitated through identifying other women and birthing people who had shared similarity in their experience of motherhood. This was achieved through interactions with healthcare professionals as well as through formal and informal peer support:

"It's just so helpful to speak to another human being who goes through exactly the same experience. It just means so much more. You understand that there is… another person who understands". (Karolina)

"She was also pregnant, which I wonder if that had something to do with it for me, like oh she gets it" (Lucy).

For some, connecting with others who shared similarity facilitated self-compassion:

"If I'm so empathetic with this other person and I fully understand what she goes through, should I be so nice to myself as well and should I wish myself as well as those things because I'm going through the exactly the same" (Karolina).

And opened space for self-recognition of their own strengths and accomplishments, shown through Danielle and Karolina's reflections at the end of the interview:

"I'm autistic and I'm proud of this because it's actually amazing" (Karolina).

"I'm kind of a bit proud of myself that I'm, I've come through it, and I haven't succumbed to it" Danielle).

Discussion

The present study aimed to explore the experiences of autistic women and birthing people who have a perinatal mental health condition, specifically focusing on their experiences of mental health support. Participants' experiences, analysed and understood through IPA, revealed three GETs: 'Amplification of Feeling 'Different' and Disconnected', 'Losing Trust that I Will Get Help' and 'The Value of Understanding and Connection', each with subthemes. Themes are discussed below, considering how the findings from the current study relate to and extend existing theory and literature.

'Amplification of Feeling 'Different' and Disconnected'

Participants referred to expectations and pathways in the context of motherhood and mental health, which shaped their mental health and experiences of care in the context of perceived 'difference' from these expectations. This finding is consistent with the social construction approach (Vygotsky & Cole, 1978), which argues that cultural norms, expectations and history shape experiences. Where this approach has been applied to understanding motherhood, various social 'norms' have been brought to light. However, it has been argued that such 'norms' perpetuate health inequalities, as for some, it may be more challenging to meet such standards and expectations (Schmidt et al., 2023). This is consistent with participants' experiences, as identified 'difference' in the context of predefined pathways and expectations of motherhood resulted in participants internalising this experience and feeling disconnected. In line with the intersectionality framework (Crenshaw, 1989), this experience was amplified in the context of intersections of their identity, including participants' ethnicity, neurodiversity, being a single mother and experiencing mental health challenges. This experience was also reflected in participants' experiences of mental health support through services. The literature shows that this is not a unique experience faced by autistic adults, as the support offered is often based around neurotypical ‘norms’ (Brede et al., 2022).

For participants, these experiences were amplified through judgement and discrimination associated with aspects of their identity, which were often then internalised through views of being the *“worst mother”.* Although this is the first study in this area, findings are consistent with literature reporting neurotypical mothers’ experiences of living with a perinatal mental health condition (Adlington et al., 2023), alongside research into autistic mothers’ perinatal experiences where judgement and dismissal from healthcare professionals were a consistent theme (Westgate et al., 2024). Additionally, all participants were recently diagnosed as autistic, and this finding aligns with themes which arose for autistic cis women who were diagnosed later in life, specifically in the context of attempts to *“fit in”* and misdiagnosis, which resulted in internalised negative beliefs about themselves (Leedham et al., 2020).

‘Losing Trust That I Will Get Help’

For all participants, mental health support was not readily available, and they identified feeling powerless in decisions over their care. These experiences were consistent within current and historic care experiences across multiple settings and shaped participants’ relationship to help. Within the wider perinatal mental health literature, it has been identified that cis women’s experiences of perinatal mental health care reflects a complex intersection of individual, professional, organisational and societal factors, which shape each level of care, from deciding to access, to assessment and provision of care (Webb et al., 2023). Using this as a frame to contextualise the current research, findings suggest that at each level autistic women and birthing people faced barriers, including on an individual level through losing trust in the system, on a healthcare professional level through experiences of professionals appearing too busy to care, on a system and organisational level through long waiting lists, and a societal level through feeling uncared for. This is a consistent experience reported across the literature reflecting autistic adults' experiences of seeking mental health support (Brede et al., 2022).

'The Value of Understanding and Connection'

Participants referred to the importance of understanding their experiences. For each participant, this was achieved in different ways, including an autism diagnosis, accessing information, or through therapy. Understanding facilitated connection with others through similarity, which, for most, facilitated a journey towards self-compassion. Presenting findings are consistent with the literature reporting the benefits of receiving a diagnosis for autistic cis women in facilitating social connectedness and self-compassion (Bargiela et al., 2016; Leedham et al., 2020), alongside the benefits of understanding through psychological therapy for neurotypical women in the perinatal period (O'Brien et al., 2024). Findings align with theory underpinning compassion-focused therapy (CFT), which suggests that psychological wellbeing is centred in connectedness both to oneself and others (Gilbert, 2014). It has been argued that connectedness is particularly important in the perinatal period (Seppälä et al., 2022), due to the significant changes which may bring disruption to belonging, control and social support (Haslam et al., 2021).

Clinical Implications

Firstly, findings highlighted the barriers faced in receiving perinatal mental health support. Participants' experiences reflected the lasting influence that interactions with healthcare professionals and services can have on trust. As such, professionals across a variety of settings including general practice, health visiting, and maternity settings, should consider accessibility of their services for autistic mothers and birthing people. The SPACE framework is a framework derived to help services consider the accessibility of support for autistic people (Doherty et al., 2023). For participants, personalised approaches on the grounding of similarity were favoured and, in these instances, participants did not feel the need for approaches to be adapted. Looking towards the therapeutic literature, this follows the view that the client is the expert and, as such, professionals take a ‘not-knowing’ approach to understanding the experiences as spoken about by the client (Anderson & Goolishian, 1992). Limits in resources and competing organisational demands can influence professionals applying such approaches (Moore et al., 2025), as such, where individuals feel comfortable disclosing, listing diagnoses on clinical record systems shared across systems may provide healthcare professionals with a platform to consider adjustments to their practice to ensure this is centred in the clients’ experiences.

Participants faced experiences of stigma and discrimination in the context of their perinatal experiences, as well as through being autistic. Within the literature, it has been suggested that with growing heterogeneity in what is constructed as ‘good’ mothering, there is a potential for social change (Schmidt et al., 2023). As such, it is hoped that with increased conversation about ‘difference’, this has the potential for social change to support autistic mothers and birthing people’s experiences. This may be facilitated through organisations supporting participation from the neurodiverse community in policy and research.

Participants placed value in understanding, which for some was facilitated through an autism diagnosis. Many participants reported barriers to receiving a diagnosis and described feeling a *“miracle”* that this had been obtained. It is important that clinicians across healthcare settings, understand autism, particularly what this may look like in adult cis women, to ensure that women are provided with the platform for a timely assessment to minimise the challenges of being misdiagnosed. This may be achieved through specialist training.

Participants referred to the value of similarity in facilitating compassion. However, there were limited pathways to accessing this peer support. Maternity and mental health services should consider on both local and national level, peer support networks for autistic mothers and birthing people.

Strengths, Limitations and Areas for Future Study

Participants' experiences were rich and detailed, and participants required minimal prompting or guidance during interviews. This allowed the researcher to access the participants' world through what was important for them to share. Participants reported that they felt comfortable in the interview process, and receiving the questions in advance, alongside the flexible and open approach taken by the researcher, supported this. Through applying IPA methodology, first-order concepts as described by the participants were easily identified. In considering second-order concepts, derived through the researchers' understanding of these experiences and third-order concepts, relating insight to theory, literature and construct, the researchers' position as a neurotypical healthcare professional who has not experienced motherhood will influence this understanding. Methodological decisions, including choosing IPA, and engaging in self-reflexivity, aimed to address some of these challenges, however it is recognised that there are limits to how much any research methodology allows us to truly understand participants' experiences.

The majority of the current sample consisted of employed autistic women who were White British and who were experiencing anxiety and depressive disorders, self-described and diagnosed within the 'moderate' range. The purpose of the study was not to produce generalisable results. Rather, it is hoped that findings provide an understanding of some autistic women and birthing people’s experiences, providing a platform for services to consider their approach. Further research would be required to examine the extent to which these themes might be generalisable across autistic women, who may be experiencing a wide spectrum of experiences, including mental health conditions defined as ‘severe’, which were not reflected in the current study. One approach to this may be completing a survey, in line with previous research into autistic women’s experiences of the perinatal period (Hampton et al., 2022b), combining quantitative and qualitative data to understand a larger sample’s experiences. Due to the present study’s recruitment of a homogeneous sample, those who self-identified as autistic were excluded. However, if an alternative research methodology were applied, it would be encouraged that these participants are not excluded, due to the barriers experienced by many women in receiving an autism diagnosis (Wilson et al., 2023).

The present study did not ask about academic experiences or socioeconomic status. Previous study highlights these factors as important in access to perinatal mental healthcare (Webb et al., 2023). Future research may benefit from reporting these demographic factors.

Conclusion

Findings highlight the individual, system and societal barriers faced to receiving perinatal mental health support for autistic mothers and birthing people. Receiving an autism diagnosis, therapeutic and peer support brought understanding and supported acceptance and compassion. However, participants reported concern as to how much resource they had left to sustain this journey on their own. Findings reflect the importance of systemic changes to supporting autistic mothers and birthing people, aligning with previous research for neurotypical women. However, additional considerations should be made to ensure accessibility for autistic parents, for example, through focused training, clear documentation of diagnosis and person-centred care, alongside societal interventions to support stigma and culture of ‘difference’ in motherhood. Future research would be supportive in understanding the generalisability of the findings.

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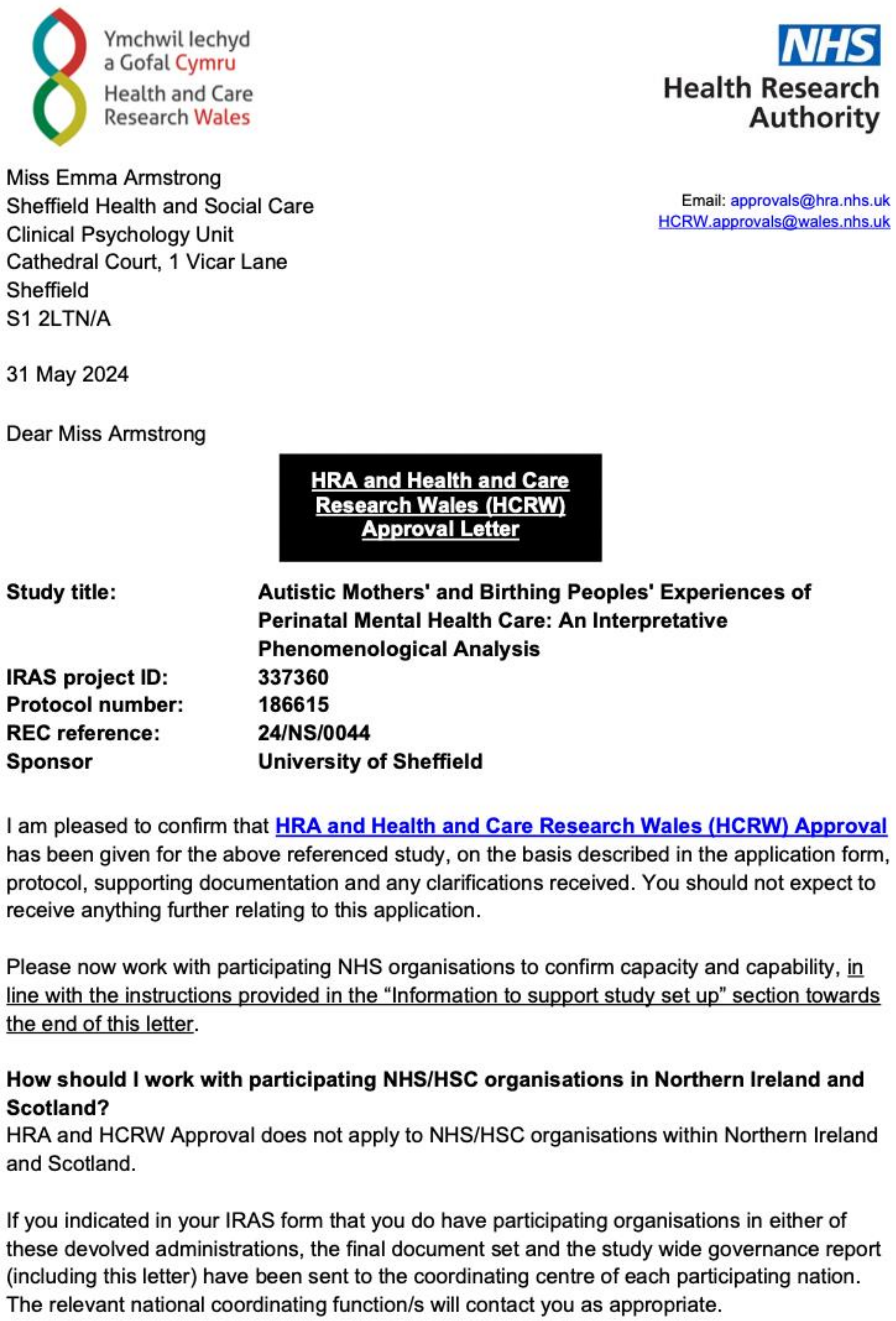
Appendices

Appendix A

Letter of Ethical Approval, including amendments



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

Miss Emma Armstrong
Sheffield Health and Social Care
Clinical Psychology Unit
Cathedral Court, 1 Vicar Lane
Sheffield
S1 2LTN/A

31 May 2024

Dear Miss Armstrong

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Autistic Mothers' and Birthing Peoples' Experiences of Perinatal Mental Health Care: An Interpretative Phenomenological Analysis**
IRAS project ID:	**337360**
Protocol number:	**186615**
REC reference:	**24/NS/0044**
Sponsor	**University of Sheffield**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

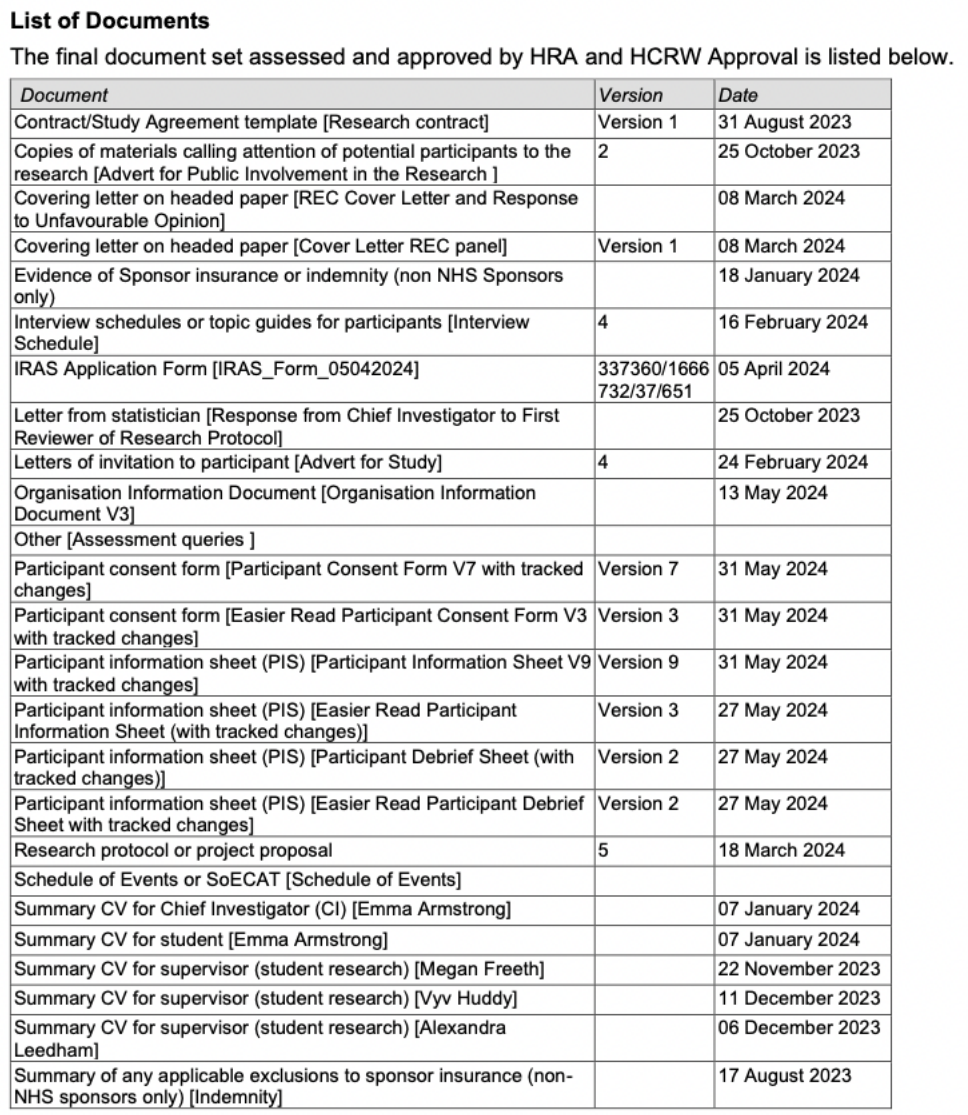
- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **337360**. Please quote this on all correspondence.

[redacted]



List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Contract/Study Agreement template [Research contract]	Version 1	31 August 2023
Copies of materials calling attention of potential participants to the research [Advert for Public Involvement in the Research]	2	25 October 2023
Covering letter on headed paper [REC Cover Letter and Response to Unfavourable Opinion]		08 March 2024
Covering letter on headed paper [Cover Letter REC panel]	Version 1	08 March 2024
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		18 January 2024
Interview schedules or topic guides for participants [Interview Schedule]	4	16 February 2024
IRAS Application Form [IRAS_Form_05042024]	337360/1666732/37/651	05 April 2024
Letter from statistician [Response from Chief Investigator to First Reviewer of Research Protocol]		25 October 2023
Letters of invitation to participant [Advert for Study]	4	24 February 2024
Organisation Information Document [Organisation Information Document V3]		13 May 2024
Other [Assessment queries]		
Participant consent form [Participant Consent Form V7 with tracked changes]	Version 7	31 May 2024
Participant consent form [Easier Read Participant Consent Form V3 with tracked changes]	Version 3	31 May 2024
Participant information sheet (PIS) [Participant Information Sheet V9 with tracked changes]	Version 9	31 May 2024
Participant information sheet (PIS) [Easier Read Participant Information Sheet (with tracked changes)]	Version 3	27 May 2024
Participant information sheet (PIS) [Participant Debrief Sheet (with tracked changes)]	Version 2	27 May 2024
Participant information sheet (PIS) [Easier Read Participant Debrief Sheet with tracked changes]	Version 2	27 May 2024
Research protocol or project proposal	5	18 March 2024
Schedule of Events or SoECAT [Schedule of Events]		
Summary CV for Chief Investigator (CI) [Emma Armstrong]		07 January 2024
Summary CV for student [Emma Armstrong]		07 January 2024
Summary CV for supervisor (student research) [Megan Freeth]		22 November 2023
Summary CV for supervisor (student research) [Vyv Huddy]		11 December 2023
Summary CV for supervisor (student research) [Alexandra Leedham]		06 December 2023
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Indemnity]		17 August 2023

Document	*Version*	*Date*
Interview schedules or topic guides for participants: Interview Schedule	5	15 October 2024
Participant Consent Form	8	15 October 2024
Participant Consent Form: Easier Read	4	15 October 2024
Research protocol or project proposal	6	15 October 2024

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities – see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 337360: **Please quote this number on all correspondence**

Yours sincerely

[redacted]

Enclosures: List of names and professions of members who took part in the review

North of Scotland Research Ethics Service
Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558458
Email: gram.nosres@nhs.scot

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

23 October 2024

Miss Emma Armstrong
Clinical Psychology Unit
University of Sheffield
Cathedral Court Sheffield
1 Vicar Lane
SHEFFIELD
S1 2LT

Dear Miss Armstrong

Study title:	**Autistic Mothers' and Birthing Peoples' Experiences of Perinatal Mental Health Care: An Interpretative Phenomenological Analysis**
REC reference:	**24/NS/0044**
Protocol number:	**186615**
Amendment number:	**186615**
Amendment date:	**14 October 2024**
IRAS project ID:	**337360**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool: Amendment Tool	1	14 October 2024
Copies of materials calling attention of potential participants to the research: Advert for Study	5	15 October 2024

Document	*Version*	*Date*
Interview schedules or topic guides for participants: Interview Schedule	5	15 October 2024
Participant Consent Form	8	15 October 2024
Participant Consent Form: Easier Read	4	15 October 2024
Research protocol or project proposal	6	15 October 2024

Membership of the Committee

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IRAS Project ID - 337360:	**Please quote this number on all correspondence**

Yours sincerely

[redacted]

Enclosures:	List of names and professions of members who took part in the review

Appendix B

Participant Recruitment Advert

IRAS Project ID: **337360**
Version number: 5
Date: 15/10/24

The University Of Sheffield.

Are you autistic and have experienced a co-occurring mental health condition during pregnancy, birth and/or following the birth of your child?

Researchers at the University of Sheffield are looking for participants to help us better understand **autistic people's experiences of mental health support during pregnancy, birth and following the birth of a child.**

Who can participate?

- Have a diagnosis of Autism Spectrum Disorder (ASD) from a UK healthcare professional, including variants such as Asperger's
- Are over 18 years of age
- Are currently or have previously experienced (in the past 5 years) mental health difficulties that developed for the first time or worsened during pregnancy, birth or two years following the birth of your child.
- Do not also have a diagnosis of a global learning disability
- Are fluent in English

What will I do?

The study will involve a single, one-off interview (lasting no longer than 90 minutes) to discuss your experiences of mental health support pre and post birth. The time and location of the interview will be considered with you to best suit your needs.

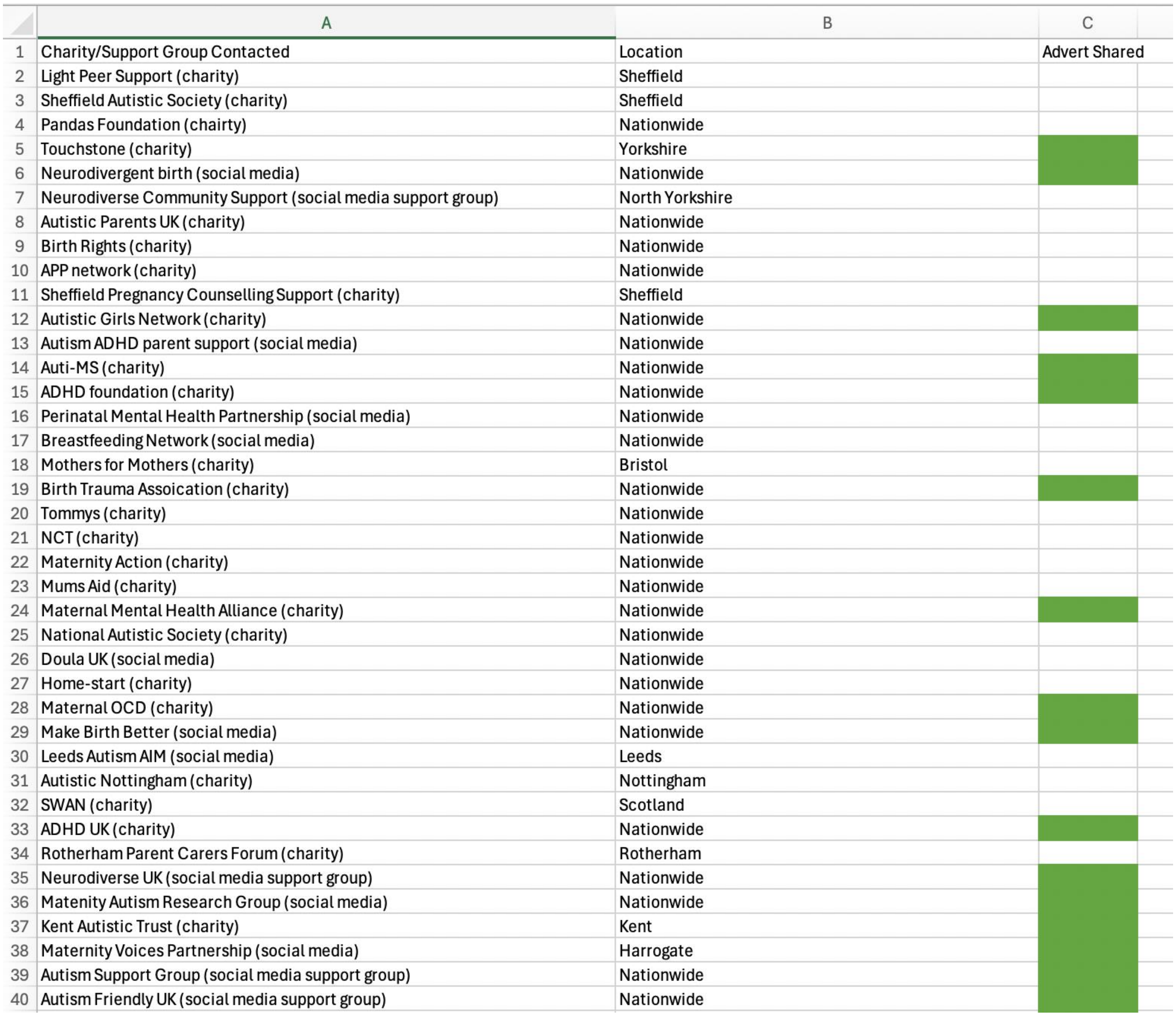
What are the benefits?

It is hoped that your experiences will be used to support mental health services better meet the needs and priorities of autistic individuals.

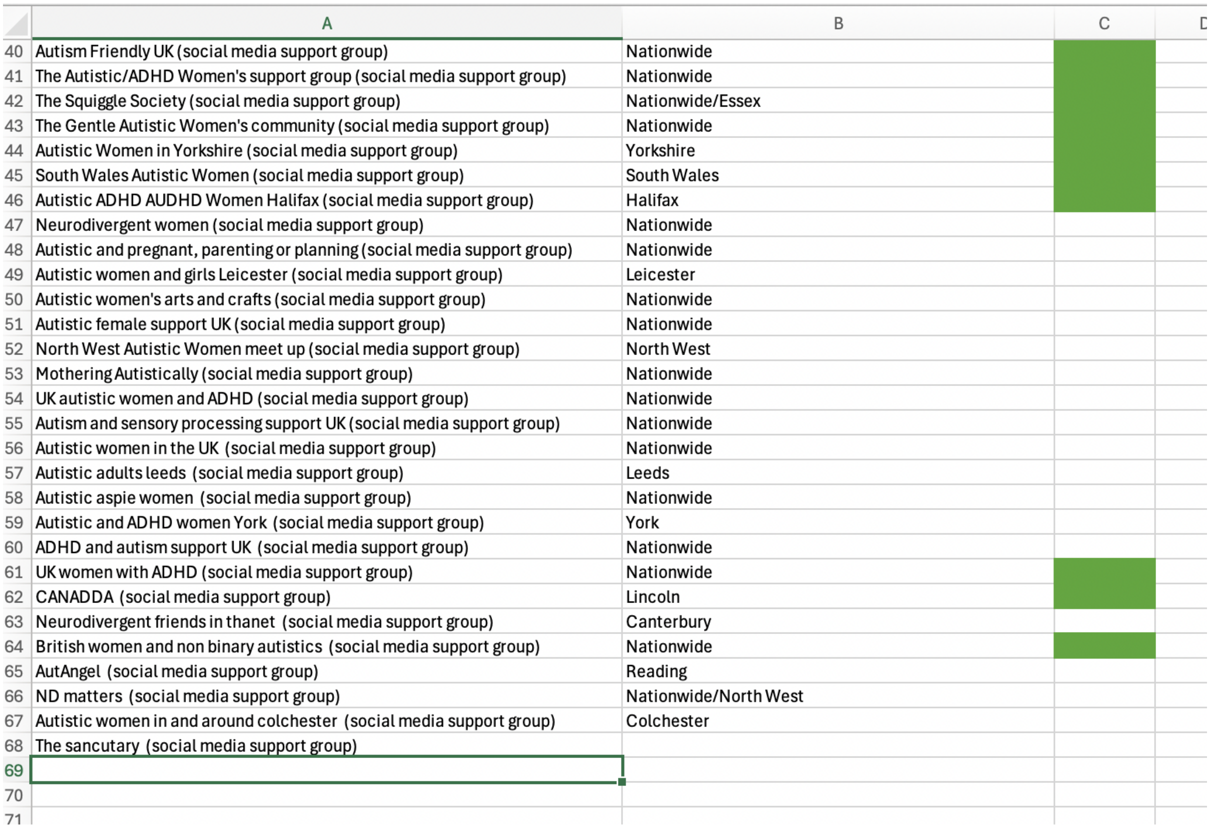
If you are interested and/or have additional questions, contact: Emma Armstrong (Trainee Clinical Psychologist) by emailing earmstrong6@sheffield.ac.uk or you can leave a message by contacting the University of Sheffield Research Support Officer on: 0114 222 6650.

Appendix C

Recruitment Networking Spreadsheet



	A	B	C
1	Charity/Support Group Contacted	Location	Advert Shared
2	Light Peer Support (charity)	Sheffield	
3	Sheffield Autistic Society (charity)	Sheffield	
4	Pandas Foundation (chairty)	Nationwide	
5	Touchstone (charity)	Yorkshire	🟩
6	Neurodivergent birth (social media)	Nationwide	🟩
7	Neurodiverse Community Support (social media support group)	North Yorkshire	
8	Autistic Parents UK (charity)	Nationwide	
9	Birth Rights (charity)	Nationwide	
10	APP network (charity)	Nationwide	
11	Sheffield Pregnancy Counselling Support (charity)	Sheffield	
12	Autistic Girls Network (charity)	Nationwide	🟩
13	Autism ADHD parent support (social media)	Nationwide	
14	Auti-MS (charity)	Nationwide	🟩
15	ADHD foundation (charity)	Nationwide	🟩
16	Perinatal Mental Health Partnership (social media)	Nationwide	
17	Breastfeeding Network (social media)	Nationwide	
18	Mothers for Mothers (charity)	Bristol	
19	Birth Trauma Assoication (charity)	Nationwide	🟩
20	Tommys (charity)	Nationwide	
21	NCT (charity)	Nationwide	
22	Maternity Action (charity)	Nationwide	
23	Mums Aid (charity)	Nationwide	
24	Maternal Mental Health Alliance (charity)	Nationwide	🟩
25	National Autistic Society (charity)	Nationwide	
26	Doula UK (social media)	Nationwide	
27	Home-start (charity)	Nationwide	
28	Maternal OCD (charity)	Nationwide	🟩
29	Make Birth Better (social media)	Nationwide	🟩
30	Leeds Autism AIM (social media)	Leeds	
31	Autistic Nottingham (charity)	Nottingham	
32	SWAN (charity)	Scotland	
33	ADHD UK (charity)	Nationwide	🟩
34	Rotherham Parent Carers Forum (charity)	Rotherham	
35	Neurodiverse UK (social media support group)	Nationwide	🟩
36	Matenity Autism Research Group (social media)	Nationwide	🟩
37	Kent Autistic Trust (charity)	Kent	🟩
38	Maternity Voices Partnership (social media)	Harrogate	🟩
39	Autism Support Group (social media support group)	Nationwide	🟩
40	Autism Friendly UK (social media support group)	Nationwide	🟩



	A	B	C	D
40	Autism Friendly UK (social media support group)	Nationwide	🟩	
41	The Autistic/ADHD Women's support group (social media support group)	Nationwide	🟩	
42	The Squiggle Society (social media support group)	Nationwide/Essex	🟩	
43	The Gentle Autistic Women's community (social media support group)	Nationwide	🟩	
44	Autistic Women in Yorkshire (social media support group)	Yorkshire	🟩	
45	South Wales Autistic Women (social media support group)	South Wales	🟩	
46	Autistic ADHD AUDHD Women Halifax (social media support group)	Halifax	🟩	
47	Neurodivergent women (social media support group)	Nationwide		
48	Autistic and pregnant, parenting or planning (social media support group)	Nationwide		
49	Autistic women and girls Leicester (social media support group)	Leicester		
50	Autistic women's arts and crafts (social media support group)	Nationwide		
51	Autistic female support UK (social media support group)	Nationwide		
52	North West Autistic Women meet up (social media support group)	North West		
53	Mothering Autistically (social media support group)	Nationwide		
54	UK autistic women and ADHD (social media support group)	Nationwide		
55	Autism and sensory processing support UK (social media support group)	Nationwide		
56	Autistic women in the UK (social media support group)	Nationwide		
57	Autistic adults leeds (social media support group)	Leeds		
58	Autistic aspie women (social media support group)	Nationwide		
59	Autistic and ADHD women York (social media support group)	York		
60	ADHD and autism support UK (social media support group)	Nationwide		
61	UK women with ADHD (social media support group)	Nationwide	🟩	
62	CANADDA (social media support group)	Lincoln	🟩	
63	Neurodivergent friends in thanet (social media support group)	Canterbury		
64	British women and non binary autistics (social media support group)	Nationwide	🟩	
65	AutAngel (social media support group)	Reading		
66	ND matters (social media support group)	Nationwide/North West		
67	Autistic women in and around colchester (social media support group)	Colchester		
68	The sancutary (social media support group)			
69				
70				

Appendix D

Participant Information Sheet, using wording approved by the University of Sheffield Research Ethics Committee (2018a) and edited in line recommendation through IRAS ethical review. An easy read format was available written in line with guidance (UK Association for Accessible Formats [UKAAF])

Participant Information Sheet

Emma Armstrong (Trainee Clinical Psychologist)
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield
S1 2LT

Email:earmstrong6@sheffield.ac.uk
Date: 31/05/24
Version 9
IRAS Project ID: 337360

PARTICIPANT INFORMATION SHEET

Autistic Mothers' and Birthing Peoples' Experiences of Perinatal Mental Health Care: An Interpretative Phenomenological Analysis

Before you decide whether to take part, it is important to understand why the research is being done and what it will involve. Please read the following information carefully and discuss with others including the Lead Researcher (Emma Armstrong) professionals involved in your care, a friend, family member or carer if this would be helpful.

What are the aims of the project?

There is not very much information available about autistic women and birthing people's experiences of pregnancy, and the time after birth. This research project aims to better understand the experiences of autistic women and birthing people who have experienced mental health difficulties that started or worsened during pregnancy, birth, or two years after birth, specifically their experiences of mental health support.

This research is being conducted by **Emma Armstrong** (Trainee Clinical Psychologist) and will be used to write a thesis which fulfils part of her doctoral training. Emma is a non-autistic healthcare professional, and it is recognised that this may influence how much she can understand your experiences. To help with this, Emma has worked alongside autistic people who have volunteered to support the design of the study.

Why have I been invited?

You have been invited to take part because you are over the age of 18 years, have indicated that you are autistic and are currently experiencing or have previously experienced mental health difficulties that developed or worsened during pregnancy, birth or in the first two years following the birth of a child.

Do I have to take part?

No, it is up to you to decide whether you would like to take part. Participation in this study is entirely voluntary. If you decide not to take part in the study, this will not affect your current care within services if you are accessing these.

What will happen if I take part?

Taking part in the study will involve completing a one-off interview with Emma Armstrong. Before completing the interview, Emma will talk with you and considerations will be made to support the interview feeling as comfortable as possible. For example, the interview may take place either via telephone, online, using Google Meet (recognised by The University of Sheffield as a secure platform), with the camera on or off, or face-to-face at the perinatal mental health service you are accessing or the University of Sheffield if this is not possible.

The interview will last approximately 30-90 minutes where you will be asked some information about yourself, including your gender, ethnicity, age, details of your autism diagnosis, as well as questions related to your experiences of mental health during pregnancy, birth and following the birth of your child. You are welcome to bring with you a supportive individual if this would help, however they are unable to participate during the interview. Any information to support the interview will be sent to you before the interview, this may include a map of the location of the interview, alongside the interview questions.

The interview will be audio recorded using an encrypted audio recording device, or through functions on Google Meet. Each interview will then be transcribed either by Emma, using the transcribing functions on Google Meet and checked by Emma, or using an approved University of Sheffield transcriber, to allow for analysis. All audio recordings will be destroyed following completion of the research.

What will happen with the information I share?

Only the research team will be able to see your name and contact details (personal information) and this information will be kept safe and secure. Other people may look at information we have collected from you, but they will not know it is about you, it is confidential. When writing up the report a different name from your own will be used to ensure that you could not be identified in any reports or publications unless you indicate that you would like to be identifiable in the write up.

The only exception to this would be if during the interview Emma became concerned about a risk of harm to yourself (e.g., suicidal risk), or someone (e.g., a child or another adult) you talk about (e.g., risk of neglect or physical/emotional harm). In such a situation Emma would discuss the need to breach confidentiality with you; the aim of this would always be to support yourself and those you mention to ensure safety. For example, it may involve letting relevant services or professionals know about the situation, to allow for further assessment and support to be put into place to support you or the person you mention, including a child. If this occurs, the interview may need to be stopped.

You can withdraw from the study at any stage before and during the interview, and up to 2 weeks following the interview, without giving a reason. This can be done by contacting

Emma Armstrong using the contact details below. You are also free to decline to answer any questions without giving a reason.

For further information about how your data is used please refer to the section 'Further information about how my data is used'.

What will happen to the results of the study?

The results will be submitted as part of Emma Armstrong's doctoral thesis in May 2025. You can let Emma know at the start of the study if you would like a copy of this and this can be sent to you. The results will also be shared with local services and submitted for hopeful publication.

What are the risks involved in taking part in the study?

It is hoped there are no significant risks involved in taking part in the study. However, as part of the interview, we may talk about some topics which may be distressing to you, including talking about experiences of pregnancy, birth and the years after birth, as well as experiences of mental health support. To minimise this risk, a copy of the interview questions will be sent to you before the interview, and you can say if you do not want to answer any of the questions at any stage before or during the interview without giving a reason.

If during the interview you felt there was a problem, you can let Emma know. This may be because we discussed a topic that was difficult to talk about or felt distressing to you. If this occurs, we can consider together someone who may be able to help you. This may include a mental health service if you are under their care, your General Practitioner (GP) or Crisis support. In this situation, confidentiality may be broken to support safety.

What are the benefits of taking part?

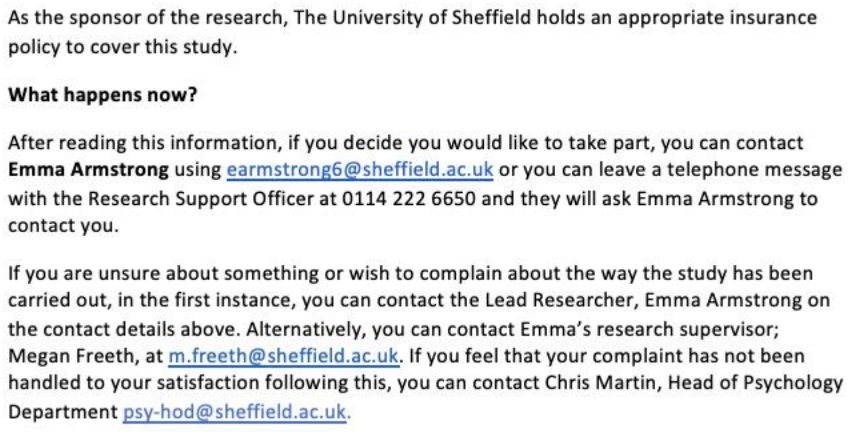
Although there are no direct benefits to taking part, sometimes people find that talking about their experiences with someone who is listening and understanding can be helpful for them. Through sharing your experiences, we may also be able to help people who need support in the future.

Will I receive any reimbursement of expenses for taking part in this research?

If interviews were conducted face-to-face at the University of Sheffield, there would be reimbursement of relevant travel expenses incurred by participating in the research at this location (subject to providing receipts of travel).

Who has reviewed the study?

The University of Sheffield has reviewed this study as the organiser and funder for the research. This project has also been reviewed by the North of Scotland (2) Research Ethics Committee and by the collaborating National Health Service (NHS) trusts for governance who are there to make sure you are treated well.



As the sponsor of the research, The University of Sheffield holds an appropriate insurance policy to cover this study.

What happens now?

After reading this information, if you decide you would like to take part, you can contact **Emma Armstrong** using earmstrong6@sheffield.ac.uk or you can leave a telephone message with the Research Support Officer at 0114 222 6650 and they will ask Emma Armstrong to contact you.

If you are unsure about something or wish to complain about the way the study has been carried out, in the first instance, you can contact the Lead Researcher, Emma Armstrong on the contact details above. Alternatively, you can contact Emma's research supervisor; Megan Freeth, at m.freeth@sheffield.ac.uk. If you feel that your complaint has not been handled to your satisfaction following this, you can contact Chris Martin, Head of Psychology Department psy-hod@sheffield.ac.uk.

Further information about how my data is used

Data protection legislation came into effect across the European Union (EU), including the United Kingdom (UK) on 25 May 2018; this means that we need to provide you with some further information relating to how your personal information will be used and managed within this research project.

To collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'. As we will be collecting some data that is defined in the legislation as more sensitive (e.g. information about your health), we also need to let you know that we are applying an additional condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your name, your preferred contact details, and information about yourself that is relevant to the project, including details of your autism diagnosis and experiences of mental health difficulties and support received during pregnancy, birth and following the birth of your child. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data to check the results. We will write our reports in a way that no-one can work out that you took part in the study. If you would like to be identified within the write up of the study, please let Emma Armstrong know using the contact details below, and she can consider with you how you would best like for this to happen.

In line with the University of Sheffield policy, your anonymous data will be retained in a locked storage cabinet for 5 years before being destroyed confidentially.

What are my choices about how information is used?

- You can stop being part of the study at any time before and during the interview, and up to 2 weeks following the interview, without giving a reason and your data will be withdrawn. This can be done through either speaking with the Emma Armstrong during the interview, or following the interview on earmstrong6@sheffield.ac.uk or you can leave a telephone message with the Research Support Officer on: 0114 222 6650 and they will ask Emma Armstrong to contact you.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you change the data we hold about you.

Where can I find out more about how my information is used?

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/
- The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. For further information on how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), please access the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general
- By contacting Emma Armstrong on the earmstrong6@sheffield.ac.uk or you can leave a telephone message with the Research Support Officer on: 0114 222 6650 and they will ask Emma Armstrong to contact you.
- Alternatively, if you have any queries or concerns regarding your data protection, please contact the University of Sheffield's Data Protection Officer Magda Schulz on 0114 222 21058 or m.k.schulz@sheffield.ac.uk.

Easier Read Participant Information Sheet

Emma Armstrong (Trainee Clinical Psychologist)
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield
S1 2LT

Email:earmstrong6@sheffield.ac.uk

Date: 27/05/24
Version 3
IRAS project ID: 337360

Easier Read Information Sheet

A study about autistic people's experiences of mental health support during pregnancy, birth and following the birth of a child.

This information can be discussed with others including the Lead Researcher (Emma Armstrong), professionals involved in your care, or a friend, family member or carer if this would be helpful.

What is the study about?

Emma Armstrong would like to invite you to take part in our research study where we are trying to find out more about autistic peoples' experiences of mental health support during pregnancy, birth and following the birth of a child. This can sometimes be called the perinatal period.

Why me?

You are invited to take part because you are an autistic adult who has experienced difficulties with their mental health during pregnancy, birth and/or following the birth of your child.

Do I have to take part?

No, you do not have to take part. It is your choice, if you change your mind, that is okay. If you say no, it will not change your care in anyway.

What will happen if I take part?

If you say it is okay, we will ask you some questions about your experiences of pregnancy, birth and following the birth of your child, including your experiences of mental health support.

The questions will be asked either through using the telephone, video call or meeting together face-to-face.

What happens after I take part?

Your answers to the questions will be audio recorded and written up. Only the research team will be able to see your name and contact details (personal information). Other people may look at the information we have collected but they will not know it is about you, it is **confidential.**

This would only be different if Emma became concerned about your safety or someone you talked about. In such a situation, Emma would talk with you about how we could support you or the person you mentioned to keep them safe.

For further information about how your data is used please refer to the section ‘further information about how my data is used’ in the participant information sheet. This information can also be discussed with others including Emma as well as professionals involved in your care, or a friend, family member or carer if this would be helpful.

The results will then be written up into a report and shared with local services to support the care that they offer. If you would like you can attend these events. If this is the case, you would need to let Emma know.

Are there any negatives to taking part?

It is hoped there is no harm caused through taking part, but we may talk about some difficult topics.

A copy of the interview questions will be sent to you before the interview, and you can say if you do not want to answer any of the questions.

If you feel there is a problem at any time, you can let Emma know and she will help you with thinking about who may be able to help you. In this situation we might need to share information about you with others to help keep you and/or others safe.

Are there any positives of taking part?

Sometimes people find that talking about their experiences with someone can be helpful for them.

Through sharing your experiences we may also help people who need support in the future.

Will I receive any money for taking part in the research?

You will not be paid for taking part in the research, however if you meet Emma at the University of Sheffield, we will pay for your travel to get there, please share your receipts with us so that we can pay for this.

What happens now?

After reading this information, if you decide you would like to take part, you can contact **Emma Armstrong** using earmstrong6@sheffield.ac.uk or you can leave a telephone message with the Research Support Officer at 0114 222 6650 and they will ask Emma Armstrong to contact you.

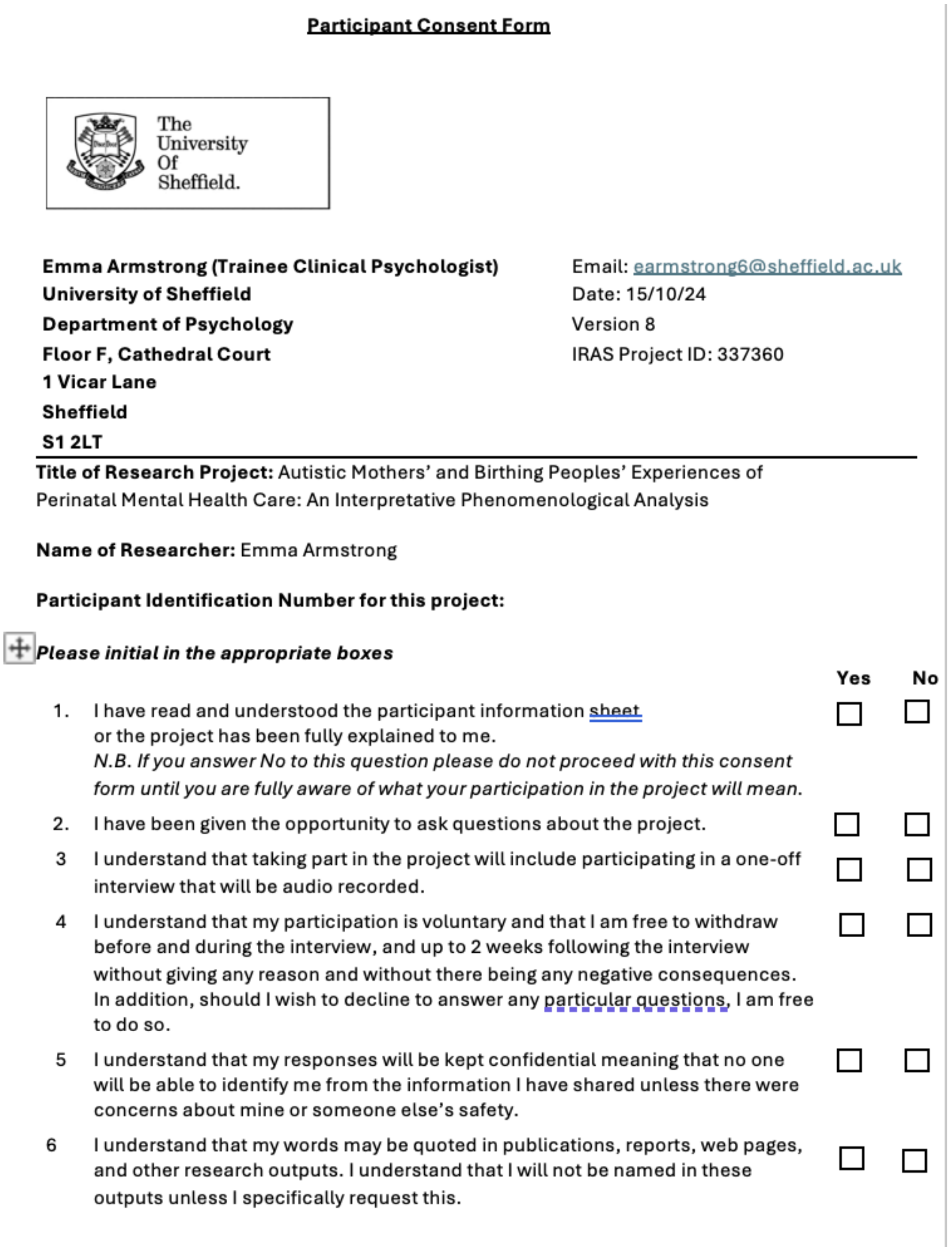
If you are unsure about something, please ask Emma Armstrong using the details above, and further information can be provided. This information can also be discussed with others including Emma as well as professionals involved in your care, or a friend, family member or carer if this would be helpful.

If you are unhappy about something, or you are worried about someone's safety from the project, you can speak with Emma Armstrong on the details above or Chris Martin, Head of Psychology Department psy-hod@sheffield.ac.uk.

This research project has been reviewed by the University of Sheffield as well as The North of Scotland (2) Research Ethics Committee and National Health Trust Services (NHS) who are there to make sure you are treated well.

Appendix E

Participant Consent Form using wording approved by the University of Sheffield Research Ethics Committee (2018b) and edited in line with guidance and recommendation through IRAS ethical review. An easy read format was available written in line with guidance (UK Association for Accessible Formats [UKAAF])



Participant Consent Form

The University Of Sheffield.

Emma Armstrong (Trainee Clinical Psychologist)
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield
S1 2LT

Email: earmstrong6@sheffield.ac.uk
Date: 15/10/24
Version 8
IRAS Project ID: 337360

Title of Research Project: Autistic Mothers' and Birthing Peoples' Experiences of Perinatal Mental Health Care: An Interpretative Phenomenological Analysis

Name of Researcher: Emma Armstrong

Participant Identification Number for this project:

Please initial in the appropriate boxes

		Yes	No
1.	I have read and understood the participant information sheet or the project has been fully explained to me. *N.B. If you answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.*	☐	☐
2.	I have been given the opportunity to ask questions about the project.	☐	☐
3	I understand that taking part in the project will include participating in a one-off interview that will be audio recorded.	☐	☐
4	I understand that my participation is voluntary and that I am free to withdraw before and during the interview, and up to 2 weeks following the interview without giving any reason and without there being any negative consequences. In addition, should I wish to decline to answer any particular questions, I am free to do so.	☐	☐
5	I understand that my responses will be kept confidential meaning that no one will be able to identify me from the information I have shared unless there were concerns about mine or someone else's safety.	☐	☐
6	I understand that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	☐	☐

7 I understand that research data collected during the study, may be looked at by individuals from regulatory authorities or from the (National Health Service) NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐ ☐

8 I confirm that I am 18 years or older. ☐ ☐

9 I confirm that I have a diagnosis of Autism Spectrum Disorder, or previous similar diagnosis including Asperger's Syndrome, from a UK healthcare professional. ☐ ☐

10 I confirm that I am currently experiencing or have previously experienced (in the past 5 years) mental health difficulties that developed for the first time or worsened during pregnancy, birth or up to 2 years following the birth of a child. ☐ ☐

11 I confirm that I am able to consent to participating in research. ☐ ☐

12 I agree to take part in the above research project. ☐ ☐

13 I understand that I can view the data collected from me if I request this, however, for the research to be reliable, I understand that I can't change this data. ☐ ☐

14 Optional: After I have participated in the study, I consent to being contacted using my preferred contact details, to receive a summary of the results. ☐ ☐

______________________ _______________ ___________________

Name of Participant Date Signature

_______________________ _______________ ___________________

Lead Researcher Date Signature

Copies:

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form and the information sheet. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Easier Read Participant Consent Form

Emma Armstrong (Trainee Clinical Psychologist)
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield
S1 2LT

Email:earmstrong6@sheffield.ac.uk

Date: 15/10/24
Version 4
IRAS Project ID: 337360

Easier Read Consent Form

A study about autistic people's experiences of mental health support during pregnancy, birth and following the birth of a child.

This information can be discussed with others including the Lead Researcher (Emma Armstrong), professionals involved in your care, or a friend, family member or carer if this would be helpful.

Instead of using your name on this form we will use this code instead:

Please initial in the appropriate boxes:

1) **I have read and understood the participant information sheet or the project has been fully explained to me. (If the answer is no, please do not continue until you know more information)**

Yes ☐ ✓ **No** ☐ ✗

2) **I have been given the opportunity to ask any questions I have about the project**

Yes ☐ ✓ **No** ☐ ✗

3) **I understand that taking part in the project includes a one-off interview that will be audio recorded.**

Yes ☐ ✓ **No** ☐ ✗

4) I understand that it is my choice if I take part and that I am free to change my mind before and during the interview and up to 2 weeks following the interview without giving a reason and there will be no consequences. I can also decide not to answer some questions.

Yes ☐ ✓ **No** ☐ ✗

5) I understand that anything I share will be kept confidential meaning that no one will be able to know that I shared this information, unless there were concerns about mine or someone else's safety

Yes ☐ ✓ **No** ☐ ✗

6) I understand and agree that my words may be quoted in the write up of the work. I understand that I will not be named unless I ask for this.

Yes ☐ ✓

No ☐ ✗

7) I understand that the data collected may be looked at by the National Health Service (NHS) Trust. I give permission for these people to access information about me.

Yes ☐ ✓

No ☐ ✗

8) I confirm that I am 18 years old or older.

Yes ☐ ✓

No ☐ ✗

9) I confirm that I have a diagnosis of Autism Spectrum Disorder, or a similar diagnosis such as Asperger's Syndrome, from a UK healthcare professional.

Yes ☐ ✓ **No** ☐ ✗

10) I confirm that I am experiencing or have previously experienced (in the past 5 years) mental health difficulties that developed for the first time or worsened during pregnancy, birth or up to 2 years following the birth of a child.

Yes ☐ ✓ **No** ☐ ✗

11) I confirm that I am able to consent to participating in research

Yes ☐ ✓ **No** ☐ ✗

12) I agree to taking part in this study

Yes ☐ ✓ **No** ☐ ✗

13) I understand that I can view the data collected from me if I ask for this. However, I understand that I cannot change this data.

Yes ☐ ✓ **No** ☐ ✗

14) Optional: After I have taken part in the study, I would like to be contacted using the contact details I have provided, to hear more about the results of the study.

Yes ☐ ✓ **No** ☐ ✗

__________________ __________ _______________
Name of Participant Date Signature

____________ ___________ _______________
Lead Researcher Date Signature

Appendix F

Example of an Extract of an Anonymised Participant Transcript

probably because I'm ADHD as well as autistic. So you know lying in the bed is not really something I'm very good at. So I was kind of like up and walking around before they expected and trying to do things for myself, you know rying to look after, my son. And so I just really really wanted to go home, and I was not very happy, I think partly because of just the lack of sleep and the fact that I couldn't care for him or I hadn't been able to care for him. The fact that, feeding was a lot harder than I expected. You know, I tried breastfeeding, and I think the element of not knowing as well, you know I think breastfeeding is a bit like you don't really know how much milk they're getting, you know, there's not a number you can write down, do you know what I mean. So, I was sort of combination feeding him and I didn't really know, like how much he needs that, am I giving him too much? Not enough? And my parents have met him by that point as well. And it's almost like, I slightly just was like, felt so overwhelmed suddenly by all the responsibility that almost, I just let them take over, and so it was almost like they were the parents and I was like a big sister or something. And yeah, I was really really finding it very difficult. I wasn't sleeping obviously. Now I know, you know babies cry, more often at night, but I didn't know that at the time. and then eventually I was told that I was being transferred to the maternity ward and I think I don't know if it was me reading into it or if they just explained it wrong, but I thought that that was just a formality, like go to maternity ward and then you get sent home. So I was really, really excited to go to maternity ward. It's just really, and obviously, HDU is quite small, so you're only sharing with like maybe six, eight other people. But then you go to maternity ward and, there's like hundreds and hundreds of people there. So I got transferred to maternity ward, kind of, it would have been on, tomorrow actually [redacted] And I got transferred to Maternity Ward. Kind of quite late at night, I think. And, and my expectation was they're probably gonna send me home, you know in the morning. So I got kind of put on maternity ward and I just had the worst night ever. Because the maternity ward, obviously there's loads and loads of rooms with babies in and in your little room that's usually four beds. So I'm in one bed and I started out by myself and then was quickly joined by three other mums and babies and dads as well. So, first off, maybe I don't know if this is rational or not, but it was just, I felt a little bit anxious, having the dads there because obviously, maternity ward, not maternity ward, induction ward, that was like women only, there were really strict covid rules. It was basically just the mums, and the staff who was 99% women. And up until that, and HDU there was some like some dads and obviously my dad came as well but that was like visiting hours. But then maternity ward, they can just be there basically all the time, there's no real, there are visiting hours but if you're already there, you can basically stay as long as you want. And so that was already a little bit anxiety inducing for me all. Also it's very, it's a lot more cramped than the others room, so you're very close together. You're basically just separated by this paper thin curtain, and by that point. And again, I didn't really know this at the time but by that point, my son X was likea few days old, you know, so he was full newborn mode, crying all night and whereas all the other babies and had literally just been born, you know they were fresh out, they were like brand new babies and, babies, are obviously quite tired after being born. So they're like all fast asleep. Pretty much constantly all these babies and mine is the only one crying. And I can just hear people, like, like, not saying it, but being really disapproving like why is that baby crying all the time? Why is that baby keeping me, awake all the time. Why is that Mum not stopping them crying and I presume like these people later found out that, you know babies cry (*laughing*).

Researcher: Yeah, that's normal (*laughing*).

Participant 2: But I just felt, at the time I just felt so rubbish. Like I've made this terrible mistake. I thought I could cope with it and it turns out like I'm the worst mother in the world and I've basically brought my son into the world and he's gonna have to grow up with this rubbish mother and I don't know how to make him happy. I don't know how to make him stop crying. I don't know what he wants. I don't know what all the crying, different types of crying means. I don't know if he's hungry, I don't know if he's cold, I don't know if this I don't know if that and like, it was such a horrible night that I just felt like we're not thriving at this hospital. So basically about nine am the next morning the erm midwife came round and again it just took so much bravery to like get up the courage to say something that I wanted without being asked for it. And I said that I would like to discharge myself and go home and she basically, she sort of treated me a bit like I was silly silly little girl, erm but she was like oh fine, but we're busy, and it was just I was a big inconvenience. I was causing a big trouble which, I think I try to go through life without bothering anybody else like people-pleasing, trying to be of like as minimal burden as possible. So it's quite a strong feeling for me to be like the idea that I've created them paperwork, which actually, logically, they would have had to discharge me at some point (*laughing*).

Researcher: Yeah, they can't keep you there forever! (*laughing*)

Participant 2: No they can't keep me there forever (*laughs*). So that was at like 9:00 am that I asked to be discharged and the hours were going by, the hours were going by, and at some point early afternoon, maybe two three pm, a nurse came around. And I was like, I'd asked about being discharged. Erm and she just went off on one at me. She was like, you may be able to discharge yourself but you cannot discharge your baby so you will just have to wait your turn for a doctor and it was really a telling off and I was just asking, you know I was just asking for an update because obviously I'd been quite t a few hours since I'd ask to go home. And then I didn't get discharged until I think, maybe like 10 11pm at night. Erm and because it wasn't me, obviously, I could leave at any point, it's not like a prison, but the issue is that they weren't discharging my son. And if felt a bit like, you know he was being held hostage, basically, to keep me there. Which, you know in hindsight. What would they have done if I'd been like, okay, I'll come and pick him up later tonight. I mean, they sort of assume you're not gonna do that and it's. But I think that contributed to it, because, or at least it contributed to why I didn't get help sooner. Or why I didn't express how I was feeling sooner mentally, because I felt like, I did feel a bit like my son was being held hostage and like I thought, I really thought that if I told them I was struggling. If I told them I was having these feelings that basically, they would take him away and I was so convinced that they were gonna take him away. That it took me like probably longer than it might have done to ask somebody for help erm with the feelings that I was having. But I did eventually get discharged. And we went home and I had that feeling of just suddenly like being alone in my house with a newborn baby and being like oh my gosh, like this is it now, you know, this is it and I think I sort of had expected things to suddenly get better, now that I was at home. But unfortunately it didn't because while I was in a comfortable place and there wasn't all this sensory stuff, I did really really struggle at first with the newborn phase. And he was physically very small. He was I think five pounds three, something like that. And, he just looked so fragile like he could break and he had a lot of feeding issues, he was very colicky, he would get a lot of trapped wind and It would be very painful for him. And he didn't really sleep, at all, I literally couldn't put him down. Every time I put him down, he would wake up and cry. And I would think I was getting maybe 45 minutes, sleep, maximum every single day. And there would be days where literally I would be like I'm not gonna sleep. Am I? And I would get like really like frustrated with him and I'd get frustrated with myself. And like I just felt I made this terrible mistake like and I was an awful mother and I should have been able to predict that I would be such a bad mother and you know, that I basically made my son suffer by bringing him into the world with me as a mother. And I felt so bad and they talk about baby blues and your hormones going crazy. But in the moment, it felt like these were real feelings, do you know what I mean, and you know like, and I really felt like... I was Googling things like how to get your son adopted not because I didn't love him but because I genuinely at that time thought he would be happier with somebody else. I was even Googling things silly in hindsight, but like can babies be depressed? Because I thought that my sadness was giving him bad vibes or something and that he was like... and obviously with a bit of space in that period. I know that he was crying because he's a baby and that's what babies do like, you know they've basically got one word for all discomfort. You know, it could mean, I'm in serious pain and I need help or it could mean, I'm ever so slightly cold, there's a bit of a breeze in here. Erm so they've basically got like, everything is a 10 because they've never experienced discomfort before. Erm and my parents were kind of coming to help me, after work every day and I was getting even frustrated with them because it was like I felt like and I would cry whenever they left.

I would just be like, you know, whenever they left, I would just be in like floods of tears. Like I'm so inadequate. I'm so ill-equipped. And I even like, I briefly moved back in with them but the problem is their house, they've got three dogs that are all not very friendly, let's say they've got my brother and sister still live with them and, and so, every time I would get him to sleep, the dogs would bark or my brother would kind of thunder up and down stairs. And so he was getting even less sleep and I had to share a bed with my mum, and my dad was like not happy because he was sleeping on the sofa and to stay away from the dogs I basically just had to stay in their bedroom all the time. So I was like confined to one room. So even though I was occasionally getting a break and being able to hand him over to somebody else, it was still like, it was almost worse than just being at home. So eventually we kind of, after Christmas, we kind of just came home. But yeah, really, really early on he was days old and that was probably the worst point in my mental health. It was just so bad. I was having these feelings of like hurting myself of like of suicide. And I genuinely in the moment thought that I would be doing him a favor, do you know what I mean, because now he's gonna get like a good mummy who knows what she's doing. And because I've had like depression in the past, that was resolved before the pregnancy. I had already kind of been over the mountain of like getting help and things like that. So I basically just fortunately. I have insurance with my work. Which I've never, I've never really used it before but they had like online GP's. Because I tried to call my own GP. And it's like you know it's like you kind of call at 8am and you call exactly as the clock turns to eight and it's like you are number 137 in the queue. So I'd tried to get help and I'd not managed. But luckily, I just remembered that I had this insurance through work and I managed to get like an appointment with a GP, and she kind of reassured me that, you know a lot of women feel the way that I do and she referred me to a psychologist. And because in the past, I sort of found that therapy had not really helped me. And that could possibly be that I was like undiagnosed autistic and so it makes sense, right, that you can't cure quote, unquote, autism.

Researcher: Yeah, absolutely. Yeah.

Participant 2: Yeah, so I've sort of been misdiagnosed with other things before. I've been misdiagnosed with like OCD and generalised anxiety, things like that and also depression as well. But I managed to get an appointment with erm, you know, basically because it's through insurance, I managed to get basically a free choice of who I went to and I found this lady who like specialised in women's trauma in, like postpartum depression. Things like that. And I started having regular appointments with her and she also, by complete chance ran an Autism Diagnostic Service as well, her other specialty was autism and neurodiversity. So we did like, we didn't even talk about autism for, until really late, and I basically did therapy with her and it was just like so helpful. Because, it was like, it wasn't just talking about, the pregnancy. It was talking about, everything that had happened in my life, like my childhood and past relationships, that had contributed to my feelings of being basically like how I found it so easy to believe that I wasn't a very good mother. And I think through this therapy, which I think I did once a week, erm from probably for like over a year. And it was like, being listened to and feeling like I was in control, and like understanding a bit and going a bit easier on myself and I also think, just naturally babies get a bit easier as they get older as well. You know, when he was like sleeping through the night, when it was, like, I could actually put him down. And, because at the beginning, I literally wasn't doing any kind of self-care. I wasn't eating, I wasn't cooking. I wasn't like having showers. I wasn't like sleeping. I wasn't basically doing anything. And that was just for me, everything was for him. And just the fact that you could like put him down just for a few seconds and go and have a sandwich or go to the toilet or go and have a shower and he's not gonna cry and that was just part of I think what helped as well as the therapy just naturally him sort of getting older. And yeah it was really really, I found that therapy really really positive. I think it's probably the best therapy I've had probably my whole life. Erm and yeah, I think gradually and she would help me like with certain trigger points like Christmas and birthdays and things that are leaving him alone for the first time and all of those kind of events. Erm so it was really, really kind of helpful to like work through all of that with a therapist. And then I'd been doing therapy for like a year and a half. And I started to feel like a bit more myself, again, you know what I mean, like confident like I've got this and I'm doing a good job. And I think also when my son started going, because I had to go back to work quite early. But when my son started going to nursery as well, just having that like a bit of a break because with autism obviously you get overloaded quite easily. And I do still find that I really struggle with extended periods of time, like holidays and things. And I do still struggle with that. You you know when it's just constant 24/7 for several days in a row. And so it was really helpful to kind of work through that with her. And erm yeah, and then it was probably a year in and I had thoughts for a long time about erm Autism and ADHD as well because I really struggle with my attention span. And it was probably over a year when I raised the subject of that there were certain things that no matter how much therapy, I did were not getting better social awkwardness, erm attention and things like that. Like erm there were just little things that were happening, where I felt like, it wasn't like other people didn't have the same challenges that I had. I just remember, there was this one time I went to a party. With my son, he was probably like, I don't know, one at the time and it was like I've been doing quite well in my recovery from postnatal depression. And I got to the party and I was doing my absolute best to be sociable and have small talk and things like that, which I always struggled with, but I never had the right word for it. You know people called me shy and things like that. But I just never had, the right word to explain, why is it that I find it so difficult to just chat with people that I've known all my life you know, like my family and they've my family, I've literally known them, well they knew me since before I was even born and yet I find it really hard to keep a conversation going with them and know what I'm supposed to say next. And there was just like this erm, this moment, where a, basically, it was, my whole family was there and also my great uncle was there with his daughter, and his daughter it's a bit older than me. She's probably closer to the age of my parents. Obviously I know of her and I know for sure that I've met her in the past, But I just don't remember it. I don't because I see her hardly ever. But I know that I've met her when I was a child and I just don't remember meeting her. And we got chatting and it turned out we work in the same industry. So it was easier to carry a conversation because we had something to talk about, we could talk about work. We could talk about our kids. And then, and we were leaving and I had X in my arms and I was saying goodbye. and then I was about to say, it's been nice meeting you, but then in my brain I thought that I can't say it's been nice meeting you because, I've already met you and then I was like, should I say it's been nice seeing you? But I was like I can't say that because I don't see her all the time. It implies, I see her all the time? And I'm going through these different options in my head. And then, what I realised I'd done in real life was just go, goodbye, it's been and then paused and then just been silent for like several minutes (*laughs*). And I feel like that's when it really slotted into place, oh I could be, this could be something that's not just shyness. And then, I talked to my therapist about it and she's like, have you ever thought about getting a diagnosis of or going for an assessment? And I sort of said like that, I thought about it but I never actually done it before and I'd think I tried to, go through my GP but it's quite hard to persuade them and like I said, I don't really argue with people. I don't advocate for myself, I'm non-confrontational to quite an extreme degree. So, he just said that he didn't think it was necessary and I went like, oh okay then. Then I just went home and felt a bit sad, but then by some miracle, I think there's a bit of a loophole in my insurance. I managed to get an assessment through my work insurance. And that's when I got my diagnosis, which is why it's so recent because it was kind of triggered by all of the difficulties that I'd had had during the pregnancy. And obviously, before that as well. But it's nice having an actual, it's almost like a neutral word, do you know what I mean, autism. It's like words like shy and awkward. Are quite negative but autism is just neutral. So that's like, birth till now.

Researcher: Yes, yeah. No. Thank you X. That's really, really helpful and really helpful to hear that kind of just that richness of your experiences as well. I really do appreciate talking about that and you talked about the support that you had from the therapist. And this was prior to you erm knowing that were autistic or that you had ADHD. Was there anything that she did differently to help to support you, was there anything that worked really well or anything that didn't work so well? Just in terms of that support that they offered.

Appendix G

Debrief Form using wording approved by the University of Sheffield Research Ethics Committee (2018a) and edited in line recommendation through IRAS ethical review. An easy read format was available written in line with guidance (UK Association for Accessible Formats [UKAAF])

Participant Debrief Sheet

Emma Armstrong (Trainee Clinical Psychologist)
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield
S1 2LT

Email:earmstrong6@sheffield.ac.uk

Date: 27/05/24
Version 2

PARTICIPANT DEBRIEF SHEET

Autistic Mothers' and Birthing Peoples' Experiences of Perinatal Mental Health Care: An Interpretative Phenomenological Analysis

Thank you for taking part in the above research project, your time in supporting this project is valued.

There is not very much information available about autistic women and birthing peoples' experiences of pregnancy, and the time after birth. This research project aims to better understand the experiences of autistic women and birthing people who have experienced mental health difficulties during this time, specifically their experiences of mental health care.

This research is being conducted by **Emma Armstrong** (Trainee Clinical Psychologist) and will be used to write a thesis which fulfils part of their doctoral training.

What if there is a problem and I need further support?

It is hoped there are no significant risks involved in taking part in the study, however, as part of the interview, we may have talked about some difficult topics.

If you felt there was a problem after you finished the interview you may wish to speak with Emma Armstrong using the contact details below. This method of communication does not provide access to emergency or crisis mental health support. If you have found any of the questions distressing and feel you would benefit from additional support, you can contact your General Practitioner (GP) or Lead Professional from a mental health service if you are currently under their care. You can also contact the following services 24/7 for mental health support in a crisis: Samaritans 116 123 or text "SHOUT" to 85258 to contact the Shout Crisis Text Line.

I have also listed below some charitable organisations that can provide support specifically related to perinatal experiences and experiences of care. This list is by no way exhaustive:

- PANDAS is a community offering peer-to-peer support for people who have experienced perinatal mental health difficulties. They offer free helpline calls on 0808 1961 776, alongside email support (info@pandasfoundation.org.uk) and support groups. For more information visit https://pandasfoundation.org.uk
- The Maternal Mental Health Alliance, is a great resource to explore pathways of support, including localised support near you. For more information visit their website https://maternalmentalhealthalliance.org
- Autistic parents UK is an autistic-led charity and is committed to supporting autistic parents in a number of ways, including online peer support groups, monthly webinars and Q&A sessions. For more information visit their website https://www.autisticparentsuk.org/#:~:text=Autistic%20Parents%20UK%20is%20an, monthly%20book%20giveaways
- AIMS supports all maternity service users to navigate the system as it exists, and campaigns for a system which meets the needs of all. Helpline volunteers are experienced in providing advice, and can provide a listening ear and practical support for women who are unhappy with their experiences https://www.aims.org.uk/
- The Patient Advice and Liaison Service (PALS) offers confidential advice, support and information on health-related matters including concerns or problems when using the NHS. You can find PALS officers in your local hospital or GP surgery, or through following this link https://www.nhs.uk/service-search/other-health-services/patient-advice-and-liaison-services-pals

What will happen to the information I shared?

Only the research team will be able to see your name and contact details (personal information) and this information about you will be kept safe and secure. Other people may look at other information we have collected from you, but they will not know it is about you, it is confidential. When writing up the report a different name from your own will be used to ensure that you could not be identified in any reports or publications. If you would like to be named in the report, you can let Emma Armstrong know using the contact details below.

The only exception to this would be if during the interview Emma was concerned about a risk of harm to yourself (e.g., suicidal risk), or someone (e.g., a child or another adult) you talk about (e.g., risk of neglect or physical/emotional harm). In such a situation Emma would have discussed the need to breach confidentiality with you and considered with you how to provide those involved with support.

You can withdraw from the study up to 2 weeks following the interview, without giving a reason. This can be done by contacting Emma Armstrong using the contact details below.

For further information about how your data is used please refer to the section 'Further information about how my data is used' in the participant information sheet.

What if I would like to provide further information that I did not share at the time of the interview?

If you would like to provide further information that you did not share at the time of the interview, or speak with the research team about your interview, you can speak with Emma Armstrong using the contact details below.

What will happen to the results of the study?

The results will be submitted as part of Emma Armstrong's doctoral thesis in May 2025. The results will also be shared with local services and submitted for hopeful publication. You can let the researcher know at the start of the study if you would like a copy of the report or to attend these events.

Will I receive any reimbursement of expenses for taking part in this research?

If interviews were conducted face to face at the University of Sheffield, there would be reimbursement of relevant travel expenses incurred by participating in this research at this location (subject to providing receipts of travel).

What if I have any questions or wish to complain about the way the study has been carried out?

In the first instance, you can contact the Lead Researcher, Emma Armstrong (Trainee Clinical Psychologist) at earmstrong6@sheffield.ac.uk or you can leave a telephone message with the Research Support Officer on: 0114 222 6650 and they will ask Emma Armstrong to contact you. Alternatively, you can contact Emma's research supervisor; Megan Freeth, at m.freeth@sheffield.ac.uk.

If you feel that your complaint has not been handled to your satisfaction or you have concerns regarding someone's safety from the project, you can contact Chris Martin, Head of Psychology Department psy-hod@sheffield.ac.uk.

Easier Read Participant Debrief Sheet

The
University
Of
Sheffield.

Emma Armstrong (Trainee Clinical Psychologist)
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield
S1 2LT

Email:earmstrong6@sheffield.ac.uk

Date: 27/05/24
Version 2

Easier Read Debrief Sheet

A study about autistic people's experiences of mental health support during pregnancy, birth and following the birth of a child.

This information can be discussed with others including the Lead Researcher (Emma Armstrong), professionals involved in your care, or a friend, family member or carer if this would be helpful.

What was the study about?

Thank you for taking part in the above study, your time is appreciated.

There is not very much information about autistic people's experiences of pregnancy, and the time after birth. This project aims to better understand the experiences of autistic people who have experienced mental health difficulties during this time.

What happens now I have taken part?

Your answers to the questions will be recorded and written up. Only the research team will be able to see your name and contact details (personal information). Other people may look at the information we have collected but they will not know it is about you, it is **confidential.**

This would only be different if Emma was concerned about your safety or someone you talked about at the interview, including a child. In such a situation, Emma would have talked with you about how we could support you or the person you mentioned to keep them safe.

The results will be written up into a report and shared with local services to support the care that they offer. If you would like to be named in this report, you can let Emma Armstrong know using the contact details below.

If you would like to withdraw from the study, you can do so up to 2 weeks following the interview without giving a reason, by contacting Emma Armstrong using the details below.

For further information about how your data is used please refer to the section ‘Further information about how my data is used’ in the participant information sheet. This information can also be discussed with others including Emma as well as professionals involved in your care, or a friend, family member of carer if this would be helpful.

What is there was a problem and I needed support?

It is hoped there was no harm caused through taking part, but we may have talk about some difficult topics.

If there was a problem after you have finished the interview you can speak with Emma Armstrong about this using the contact details below.

If you would benefit from more support, you or someone who knows you well can help you to contact your General Practitioner (GP), or Lead Professional from a mental health service if you are under their care.

You could also contact the following services 24/7 for mental health support in a crisis:

- Samaritans 116 123
- Text “SHOUT” to 85258

Will I receive any money for taking part in the research?

You will not be paid for taking part in the researcher, however if you met with the researcher at the University of Sheffield, we will pay for your travel to get there, please share your receipts with us so that we can pay for this.

What if I have questions or wish to complain?

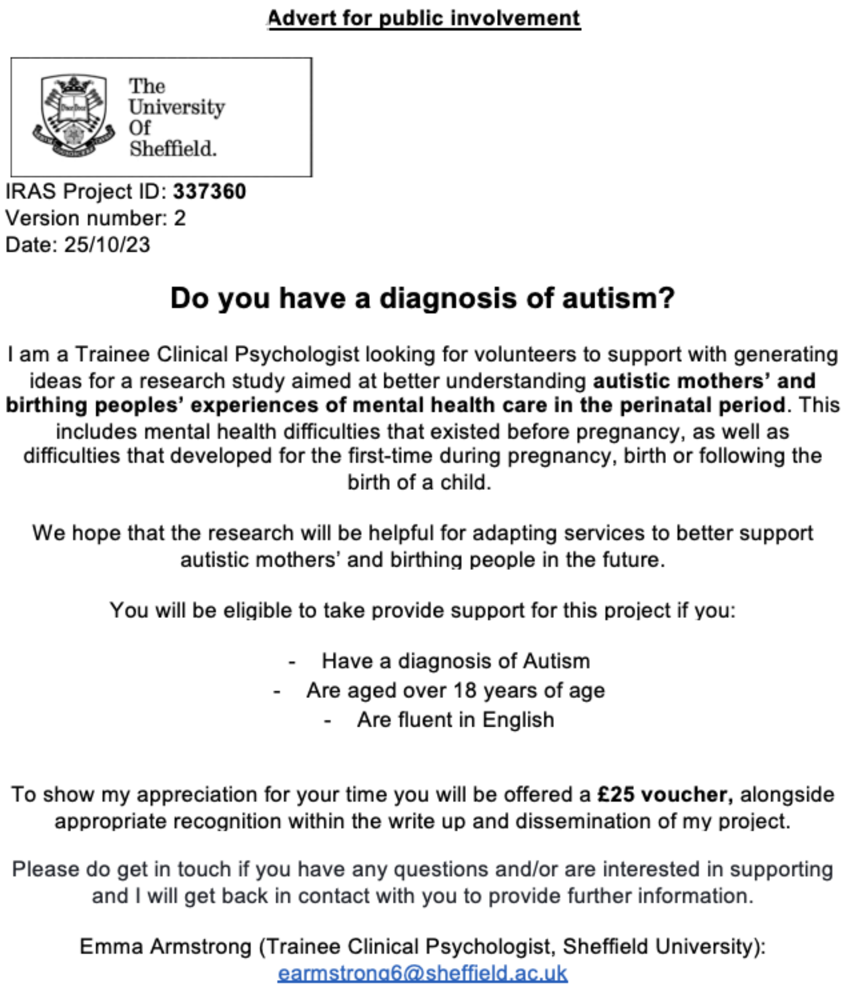
If you are unsure about something, please ask Emma Armstrong using the details above, and further information can be provided. This information can also be discussed with others including Emma as well as professionals involved in your care, or a friend, family member or carer if this would be helpful.

If you feel that your complaint has not been handled to your satisfaction or you have concerns regarding someone's safety from the project, you can contact Chris Martin, Head of Psychology Department psy-hod@sheffield.ac.uk.

This research project has been reviewed by the University of Sheffield as well as The North of Scotland Research Ethics Committee and National Health Trust Services (NHS) who are there to make sure you are treated well.

Appendix H

Recruitment Advert for Autistic Volunteer shared across Sheffield Autism Research Lab (SHARL)



Advert for public involvement

The University Of Sheffield.

IRAS Project ID: **337360**
Version number: 2
Date: 25/10/23

Do you have a diagnosis of autism?

I am a Trainee Clinical Psychologist looking for volunteers to support with generating ideas for a research study aimed at better understanding **autistic mothers' and birthing peoples' experiences of mental health care in the perinatal period**. This includes mental health difficulties that existed before pregnancy, as well as difficulties that developed for the first-time during pregnancy, birth or following the birth of a child.

We hope that the research will be helpful for adapting services to better support autistic mothers' and birthing people in the future.

You will be eligible to take provide support for this project if you:

- Have a diagnosis of Autism
- Are aged over 18 years of age
- Are fluent in English

To show my appreciation for your time you will be offered a **£25 voucher,** alongside appropriate recognition within the write up and dissemination of my project.

Please do get in touch if you have any questions and/or are interested in supporting and I will get back in contact with you to provide further information.

Emma Armstrong (Trainee Clinical Psychologist, Sheffield University):
earmstrong6@sheffield.ac.uk

Appendix I

Amendments made following community consultation

1. Volunteer 1

Advert

Suggested changes/reflection points	**Changes considered or made**
Limiting recruitment to those who can only access email	Contact telephone number added to advert.
The advert is quite wordy, but I understand why you'd need that information on it. I would focus on creating an engaging poster that has that information in a condensed manner.	Advert reviewed and changes made to support engagement.

Participant information sheet

Suggested changes/reflection points	**Changes considered or made**
Very long – condense, make clearer, some sections repeating itself	Reviewed and condensed, repeating sections removed
Can participants contact services they are involved in after the study?	Yes – directed to discuss with professionals involved in their care on participant information sheet and debrief sheet
Is there a safeguarding lead for the project?	Information for head of department who acts as safeguarding lead in participant information sheet and debrief sheet
Participant information sheet missing title	Title added in
Recommendation to include debrief form, may cut down some of the information in the participant information sheet	Debrief created

Participant consent form

Suggested changes/reflection points	**Changes considered or made**
Participant ID number – is this linked to email? e.g. if they withdraw need to know	Participant ID number will be linked with preferred contact details to ensure that if participants wish to withdraw their data this can be done.

Remove details of diagnosis – not needed to have this information in consent form, concerns about personal information being present on this document.	Added into interview schedule.
Formatting changes	Checked and changes made in line with errors highlighted.

Interview schedule

Suggested changes/reflection points	**Changes considered or made**
Discussed benefit in using IPA questions as a framework, and that follow-up questions can be asked if needed	Positive feedback - no changes to be made based on this discussion point
Volunteer liked that I will be referring to participants own terminology for their diagnosis throughout	Positive feedback - no changes to be made based on this discussion point
Recommended wording changes Q5 demographic information – do you have any other difficulties such as neurodevelopmental difficulties or physical health difficulties	Wording changed in line with recommendations
Possibility child taken out of their care – consider in Q6 demographic information	Wording changed in line with recommendations
Recommendation to reword prompts in Q1-4 of main interview schedule to be more casual	Wording changed across prompts Q1-4
Liked prompts at the end for the participant to say more if they wish	Positive feedback - no changes needed to be made
Clarity on debrief process at end with inclusion of debrief sheet	Wording changed in line with recommendations
Also, in terms of interview location being either face-to-face or online, I think this is great and makes it accessible to a lot of individuals! I have found some people (i.e., neurodivergent) prefer face-to-face when it comes to interviews and others like the online versions for comfort reasons. Also, you aren't limiting it to individuals who 'have to travel' (i.e., might not be physically able to or lack the initial funds, though they would later be compensated) or	Positive feedback – no changes to be made

have 'access to the internet and an electronic device'.	
If attending face-to-face, you will need a document with clear instructions (with pictures) on how to access the site. Any information about the interview should be sent days ahead so that they are able to familiarise themselves with it and ask questions if needed.	Created map which will be sent prior to the interview if required, alongside interview schedule

General

Suggested changes/reflection points	**Changes considered or made**
Strengths – really positive project lots of clinical utility	No changes to be made
Considerations regarding dissemination and discussion – services do not readily record autism diagnosis, possible recommendation? My outcomes of the research may then further inform supporting person with this diagnosis	No changes to be made will prompt thoughts at dissemination phase of project

2. **Volunteer 2**

Advert

Suggested changes/reflection points	**Changes considered or made**
Please consider the following variation for your headline Instead of "do you have a diagnosis of autism?" **Are you Autistic with a cooccuring Mental Health Condition?** **Would you like better perinatal mental health care?** I think this could be more attention grabbing and emphasises exactly what the study is about and how it may help so as to entice the reader to read further.	Headline revised and wording changed. However, decision to not include second suggested heading due to concerns this may lead the participants responses ahead of the interview.

Please consider <u>condensing and tweaking a couple of your paragraphs</u> 1st Paragraph I am looking for research participants to help us better understand **autistic mothers' and birthing peoples' experiences of mental health care in the perinatal period (from pregnancy till age 2).** ~~This includes mental health difficulties that existed before pregnancy, as well as difficulties that developed for the first time during pregnancy, birth or following the birth of a child.~~ I have crossed out the rest of the paragraph because this is covered in the eligibility criteria. I've also spelt out what the perinatal period was as some members of the public may not be familiar with this medical term.	Wording changed in line with recommendations.
Instead of: I am a Trainee Clinical Psychologist, and this project will form part of my training, please consider mentioning your background in both autism and perinatal services and that you are passionate about improving the support available to autistic people with a mental health condition - during what may in fact be a very vulnerable point in their lives	Wording changed in line with recommendations, however decision to not add too much detail in order to not lead participants responses.
What you have put: Participating in this research will involve a **one-off interview** (approximately 30-90 minutes) about your experiences of mental health care in the perinatal period. We hope that the research will be helpful for adapting services to better support autistic mothers' and birthing people in the future. Proposed alternative to the first sentence which I hope sounds less formal and	Wording changed in line with recommendations, however decision to still use the terminology 'interview' as concerns informal conversation does not provide possible participants with enough information about the interview to provide informed consent.

more friendly. I think it seems a little negative to bold one-off interview *As a participant, the study will involve a single, one-off informal conversation (lasting no longer than 90 minutes) to discuss your experiences of mental health support - both pre and post birth.*	
Proposed alternative second sentence: *It is hoped that your opinion and that of other participants, will be used to rethink mental health services so as to better meet the needs and priorities of autistic individuals who are either expecting or have recently given birth.*	Wording changed in line with recommendations.
Please also consider putting something about being willing to meet with mothers at a time and place to suit them (due to childcare commitments/family responsibilities) if that is something you are prepared to offer.	Wording changed in line with recommendations to highlight that individual considerations will be made to support the participant as much as possible. However there are limits to the place of interview due to constraints of the study (timing, funding, confidentiality) which would limit arrangements for interview to pre-determined locations. This Is clear in participant information sheet.
Cut down information, suggestion made: If you are interested and/or have additional questions, please contact: Emma Armstrong (Trainee Clinical Psychologist, Sheffield University), by emailing earmstrong6@sheffield.ac.uk or you can leave a message by contacting the University of Sheffield Research Support Officer on: 0114 222 6650	Wording changed in line with recommendations.
Mental Health Difficulties- do you mean mental health conditions such as bipolar, schizophrenia or serious post partum	Recruitment through services will allow for this to be clearly defined however as I may be opening out recruitment this will be subjective

depression as opposed to minor depression, the baby blues or mild anxiety. Is it only about mental health conditions requiring medication, specialist input and/or hospitalisation or is it about all mental health issues.	to the participant based on the defining criteria I have provided.
Learning Disability- many autistic people have specific learning impairments SLIs such as dyslexia, dyspraxia, slowed processing, non verbal learning disorder, dysgraphia etc which makes it more difficult to learn. Does learning disability for the purposes of your study include these conditions, or are you referring only to autism with cooccurring significant intellectual impairment (ie. An IQ below 70). Maybe use the term learning impaired as that doesn't have the stigma of learning disability.	Considered and terminology changed to global learning disability as in the literature this has been indicated as current preferred terminology.
Discussions about the challenges associated with limiting the study to only those who have a formal NHS diagnosis of Autism Spectrum Disorder. Considerations about using AQ screening questionnaire for all participants instead.	Understanding of concerns raised, however concerns that broadening the study in line with recommendations would not be in line with research aims and methodology. This will be however noted as a possible limitation to the current study and possible recommendation for future research.
Please consider using some more attention grabbing formatting and graphics	Considered and changes made to support accessibility of documents.

Participant information sheet

Suggested changes/reflection points	**Changes considered or made**
Is there any way the document can be condensed - perhaps having all the nitty gritty stuff on confidentiality and data protection separately in an	Document condensed to support accessibility.

appendix or separate leaflet available upon request or a website set up especially for your project that participants can access. Suggestions: removing information about signposting, moving to debrief	
Plain English standards	Reviewed and changes made to the document to ensure they are in line with standards.
Easy read version/pictures	Easy read documents for participant information sheet, debrief sheet and consent forms created and will be accessible to participants if indicated or felt to be helpful.
About me section? - further detail of benefits of study	Documentation reviewed and added in some information about myself and benefits to the study as in agreement that this may help participants in making a decision as to whether to participate or not. However I did not want to add too much due to concerns of lengthy document/leading the participant prior to interview.
Can you consider putting in option to turn the video off with google meet, option for them to use the chat function on google meet as and when they want, along with the option for just a phone call for those that are not able to access fancy phones, wifi or are not confident with technology.	Documentation reviewed and added in further information to ensure emphases is placed on individual considerations being made to support the participant in participant information sheet.
Supplementary information to support autism friendly	Map created and easy read format now available to support accessibility to information if required.

Participant consent form

Suggested changes/reflection points	**Changes considered or made**
Formatting changes	Checked and changes made in line with errors indicated.
Discussion about consent for data to be used for future research and if this is required to be discussed, possibility of an alternative consent form to ensure meaningful	Considered and this aspect has been removed as on consideration does not feel that this is required for the current project.

Discussion about copyright and concerns that participants cannot see, hold or change their data.	Considered and wording changed to allow for participant to see their data. However, unfortunately it is not possible to assign copyright to the person as there is also information about the researcher which will be present in the interview and the data is being collected as part of the research.
Moreover is participation in the study contingent on the person agreeing to all of the questions in the form?	Yes – this will be reviewed with the participant and made clear prior to commencing the interview
With regards to making it easier for people to participate from a distance - with regards to the paperwork aspects - can you please consider getting the consent form digitised on a website so that the person can fill it out online (ideally on a smartphone compatible site) as opposed to the participant having to print out hard copies themselves (many people do not have an office set up) before then having to post the signed forms back (which may not be a straightforward as it would seem, if you are a sleep deprived new mother overwhelmed with children and household responsibilities). For those participants who wish to do things in a less tecchy way please consider providing a free post envelope for easier return of the forms - as going to a post office and queuing could be an insurmountable task to a new mother with serious depression or other mental health issue.	Consent form will only be completed by participants online if interviews are not completed face-to-face. If this is the case, I will ensure formatting to ensure completion is as easy as possible without impacting on data management plan. Freepost envelopes have not been considered within the costings therefore this would not be possible to add in due to the funding constraints of the study.

Interview schedule

Suggested changes/reflection points	**Changes considered or made**
Location considerations – e.g. negotiation – coffee shop? Telephone? (socioeconomic considerations)	Participants will be provided with the choice of pre-determined locations (e.g. online, face-to-face at the University of Sheffield or local

	perinatal mental health service if this is possible and they are under their care). However, unfortunately it will not be possible to complete interviews at any preferred location due to confidentiality and safety. Telephone as an option for interview has been added in.
Practicalities of managing babies – activities for children?	Researcher or participant can bring things to interview if felt to be helpful to support with feeling comfortable and this will be discussed prior to the interview.
Some more familiar with zoom	Unfortunately, this is not possible with university security, but recognised as a possible limitation
Process after interview – how to contact if they have any more thoughts – encourage this	Added prompts into debrief for how the participant can get into contact if they have any more thoughts.
Talk about ways appropriate for appropriate identification in right up if this is wanted	Added option into information sheet.
Hand written thank you note?	May be appropriate for some participants however may not be for all. Due to standardisation of process, it was not felt this would be possible as part of the research process however it is hoped that this gratitude is expressed in debrief sheet.
Spelling errors and formatting	Reviewed and corrected.
With regards to your question about becoming pregnant (which has the potential to be taken not as you intend particularly if the autistic person has a tendency to be very literal) could the question be reworded to something like: *How were you mental health-wise and what was your life generally like in the lead up to and around the time you became pregnant?*	This has been considered within the context of methodological guidance and it was considered that further information may be too leading in participants responses. If the participant is unclear on the question asked, prompt questions added to prompt for considerations about mental health and wellbeing.
Possibility for an autistic person to support with analysis.	Due to methodological approach chosen this may limit the validity of the analysis due to the ‘interpretative’

	component. Possibility for reflective discussions to support analysis process between researcher and autistic volunteer – currently being explored.
With regards to having to break confidentiality if you suspect the participant could harm either themselves or others. May I suggest you state that you will where possible seek to broach the matter with the participant directly yourself in the first instance before going on to involve other professionals / organisations were this to occur.	This would be the case, and I have ensured that this information is clear in both the participant information and debrief sheet.
My final thought is the last part of your script regarding if the person is distressed or needs further support could be condensed. Much of this could be further explained on a debrief sheet as the person may be by that point of the interview oversaturated both mentally and emotionally.	I have considered this point and it is felt important to remind at the end of the interview verbally as well as putting into debrief sheet.
Given these issues with how the NHS treats autistic people with a cooccuring mental health disorder, I personally think that you as the person conducting the study has a duty of care to do whatever it takes to make sure that any seriously distressed participant does in fact get the support they need before you disengage with them - even if that may entail your spending hours on the phone or someone suitably qualified from the university psychology department providing such support themselves.	The project is going through an ethical approval process to ensure the study is not distressing to participants. In addition to this, participants are also sent the interview schedule before and can opt in/out of questions/consent to take part in the study.

General

Suggested changes/reflection points	**Changes considered or made**
Debrief sheet really good idea, considerations about pathways of	Added additional pathways of support into debrief sheet.

support on this e.g. peer support, charitable, youtube	
Discussed challenges with recruitment e.g. not able to verify ASD diagnosis, logistics from autism diagnostic services	Unfortunately, this is not possible due to constraints of the study, but recognised as limitation.
Dissemination – health visitors, midwives, gps – how is it applied and. Going to help the community Option for participants to join dissemination meeting.	Will consider in dissemination plan and added into information sheet that participants are welcomed to join if they wish.
Website with all information accessible?	I have been unable to obtain this for my project however individual approaches will be taken to ensure information is accessible to all participants.
if some participants agree - you could cross reference the narratives of the mothers with what health professionals have written in the notes / letters / reports. This will enable a richer and much more nuanced picture of what happened. In particular discrepancies between the autistic mother's experience (from her perspective) verses that of her health care professionals could be very telling. This could help with your analysis.	This sounds like a really great idea, however this would not be in line with the current research aims of my project. Could be something that could be recommended for future study.

Appendix J

Example of Initial Exploratory Coding and Experiential Statements for Participant Transcript

Transcript	Exploratory Analysis	Experiential Statements
Experiences of Pregnancy *Interviewer:* Erm so can you please tell me about your experiences of becoming pregnant? *Participant 1:* Erm like how I felt after being pregnant, do you mean? *Interviewer:* Yeah, yeah.	Did not talk about experiences of becoming pregnant – however was this led by my response to this initial question? Or was this not important to participants experiences. – does talk about later on.	
Participant 1: I mean it's been very difficult for me, erm the first trimester was extremely hard erm I guess just all the changes erm extremely difficult. It threw me just into a complete breakdown, really, I can only describe it. I felt like someone else just took over my head erm I was very suicidal. Not thinking to do it, but I just every day just didn't want to be here, just waking up thinking I can't do this. Erm I felt very sick which was very difficult for me because erm I struggle with knowing like fe… like am I a hungry, do I feel sick? Do I… Or is it a different feeling? I struggle to know what the feelings are. So I was like feeling very sick but trying to eat all the time to get rid of it because to me it was like, is this hunger. So that was very hard, I've piled a lot of weight on erm which is hard for me. I'm like highly masking. So I spend my life, well masking, as I'm doing now, and it's all to do with me appearance which I've probably	Initial changes were challenging. Was this physiological changes as this is often first changes you notice? Out of control, not self, unable to cope or continue. Physiological changes difficult to identify and rectify. Masking related to appearance, and changes to appearance impacting upon how able she feels to mask. Masking during interview – does this impact upon seeing true thoughts, feelings?	Visibility of pregnancy impacted on control (self-identity, ability to cope) Normally hide true identity from others but this is now not possible
spent my life building up a certain appearance and now I've put like 30 pounds in you know 22 weeks and that appearance is out of the window now, so I found that very hard. Erm the baby's moving now and I'm finding that extremely difficult. Erm, I don't have a bond, people keep asking me if I've got this bond with the baby, but I find it hard to bond with any human who's here, and alive in front of me. So let alone something that isn't here. So that's been very hard and then I feel extreme guilt about that. Erm literally when I first felt the baby move was like having a panic attack about it, cause I've got no control over the movements. Erm so that's been very hard as well. So yeah, it's been difficult.	Normally in control over how others view her Panicked about movements, uncontrollable Not connected/bonded, not unusual, but now expectations from others around brings guilt. Ability to cope hindered by lack of connection with the baby.	Not feeling connected to self, baby or society Societal expectation of motherhood influences feelings towards self and ability to cope
Interviewer: you spoke about specifically the movements being difficult for you. Erm would you be okay to just tell me a little bit more about that? *Participant 1:* Yeah, erm I mean, from about 16 weeks you start with they call them flutters, don't those little poppy feelings, butterfly wings. That at first was okay, because to be honest, it just feels like you've got wind or something, it's just that feeling of popping in your stomach, but it took me a while, it just takes me a bit longer to get used to things. So I got used to that, but then I think I remember the first time they're	Societal/medical description of flutters - "they call them" but her experiences feel different – "poppy feelings" in comparison to feelings like an "illness, tumor"	Detached from others as personal experiences feel very different.

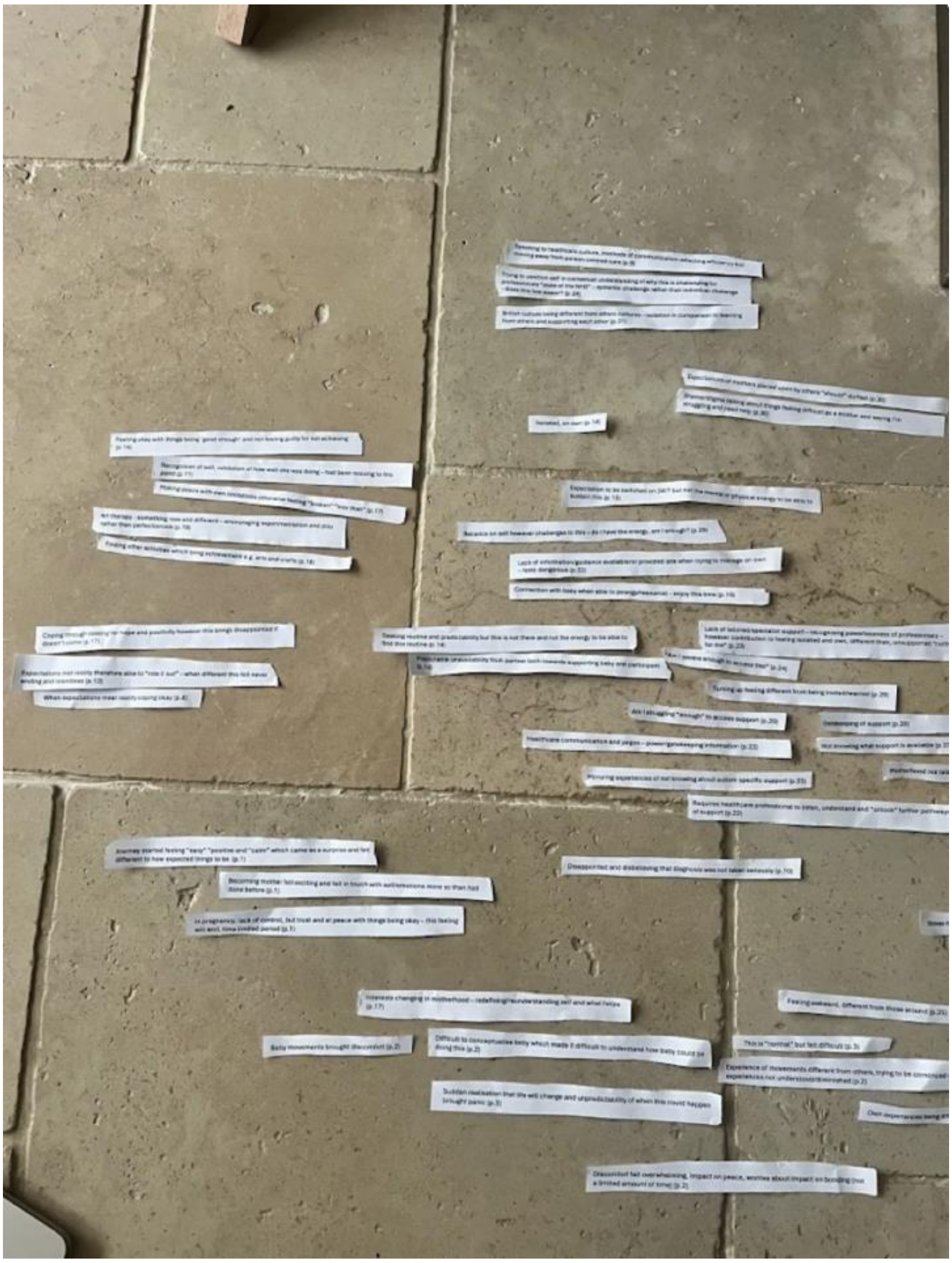
like, it was like an actual kick, I was laid in bed and I felt two, it must have been its feet, like kick me and it was just well it just sent me into I went haw, I couldn't breathe, because I can't control it, can't stop it or, I don't know when it's going to happen and to be honest, it's like a feeling of squeamishness mixed with like being repulsed, which sounds absolutely horrendous and I'm well aware of that, but that's how it felt. I'm getting used to it erm and I'm not panicking as much. I use meditation a lot. In my life it's just helps me and I've been doing a lot of meditation erm and it's helping me get used to it. But it's still, I'm very worried how I'm gonna feel. It's almost like the pregnancy so far has been like an illness, a tumor, that's making me poorly. Or an alien that's making me poorly, that's how I feel. So then to feel it moving has been very difficult. *Interviewer:* Is there any further information you want to share about your mental health during pregnancy? *Participant 1:* Erm, well no, not really. I mean, I, I struggle with life on a day-to-day basis because obviously now, I know, it's because I'm autistic and erm I've always thought something wasn't right with me, I'm not normal, you know mental health problems in some capacity, but I've been wrongly	Trying to make sense of movements – "it must have been its feet, like kick me". "it" – disconnect. "haw" – reliving experience Movements uncontrollable and unable to understand/get used to brought "squeamishness" and "repuls[ion]" Supporting self through ways she has coped in the past (meditation) Will this be enough? Movement as a reminder of disconnection Pregnancy in context of struggles with day-to-day life Internalised difference "Normal" – in comparison to what? Misunderstood and wrongly diagnosed	Attempts to get use to and regain control through using techniques that have been helpful in the past. Reliant on self for support – is this enough? Layered experience to struggle Not a new position, always felt different to others and misunderstood Differences understood as mental health "problems"
diagnosed with different things in the past, erm which now makes sense, that, you know I was struggling with being overwhelmed due to my autism and things like that. So it's all, it's come at the same time because I got pregnant in May, and then got me diagnosis in July. So I'm like trying to learn about me autism, and while combating all these pregnancy symptoms as well. So I think that's probably what's just like put me on this massive breakdown with me mental health. but yeah, just trying to learn and trying to research autism in pregnant people and there's not a lot out there, is there. So, hence, why I agreed to do this. Because obviously how I'm feeling you like, I'm just like a terrible person, and why do I feel like this? There's a few podcasts that I've listened to, and I've heard such similar things to what I've said. It's really like comforting to know I'm not the only one who feels like it. So, but yeah. It's erm, I'm feeling a lot of guilt for how I'm feeling, so that's probably affecting my mental health as well. *Interviewer:* So you've spoken there about your experiences of being pregnant as well. Is there any more experiences that you want to share about that that you, we've not covered from what you've shared?	Being autistic brings understanding Trying to understand and make sense of experiences but as there is not much information feeling different from others and alone "Trying" – not achieving "combating" – fighting, battling Trying to understand and help others through process of interview – reflects lack of this from others/information currently available Online community and podcasts have allowed to hear others with similar experiences – feeling less on my own. Guilt – social emotion, experienced in comparison to others	Looking back with different understanding of myself Exploring self-identity whilst battling challenges of pregnancy Due to limited information left feeling like a "terrible person". Seeking understanding and validation through process of interview, reflective of lack of support elsewhere. Validation, understanding and comfort from hearing similarities in others experiences Not feeling understood and feeling different brings "guilt"

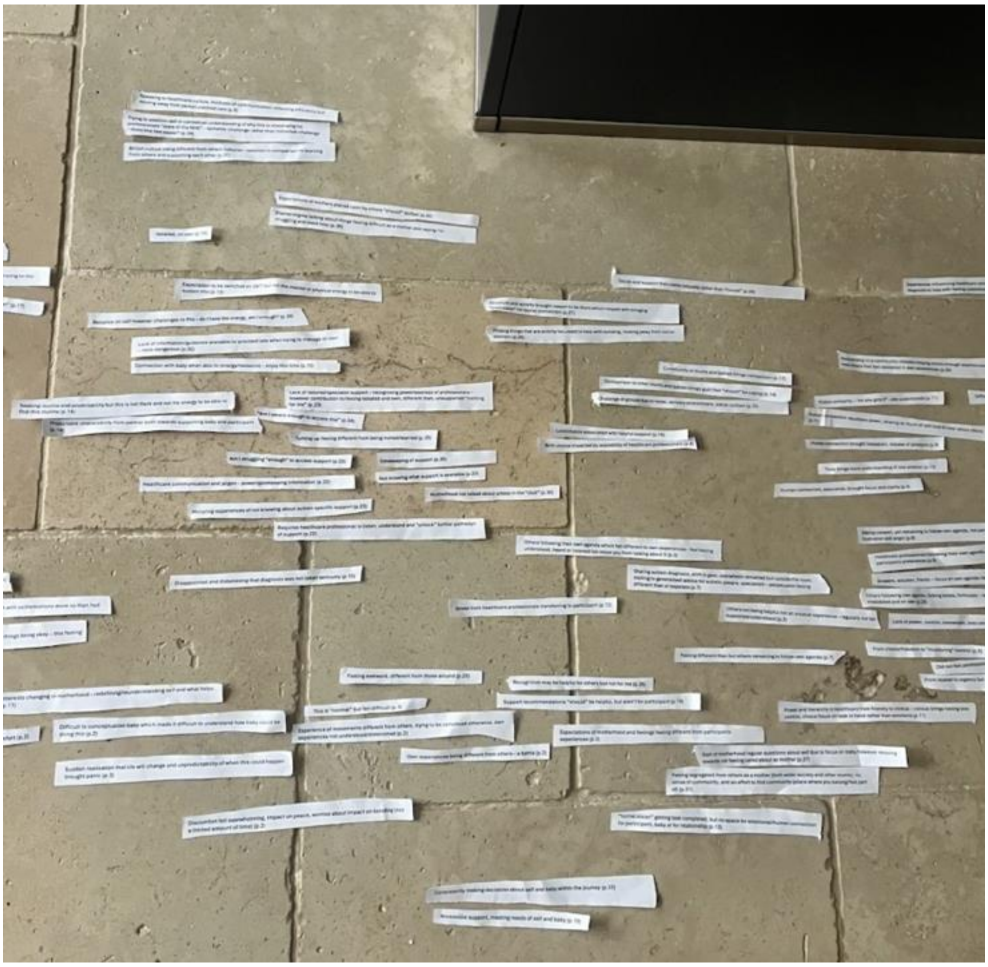
Participant 1: Erm well, I suppose it's just like that, normal, for people who are normally pregnant and they're just you get attention, don't you? And people want to ask you how the pregnancy is going, and like expect you to be glowing and just all loved up with this baby, and because I'm like the opposite of that, I'm finding that very difficult. Plus, I just don't like attention on me anyway or anyone really asking me questions about stuff, I find that real difficult. Just the being pregnant and people knowing that is very difficult as well to be the centre of attention sort of thing. *Interviewer:* Could I ask you a bit more about how does that make you feel? You referred to people coming over and giving you attention. How does that make you feel? *Participant 1:* Erm, well I just, I, panicked. I don't li, I don't like attention at all. I don't like talking to people really in general. So yeah, just overwhelmed and panicked. And if I haven't prepared, so I prepare for things, I practice conversations, practice questions people will ask me and answers erm if I haven't prepared for it, it just completely throws me off.	Repetition of "normal" – highlighting difference Societal expectations of motherhood (glowing and all loved up) brings attention and feeling opposite is very difficult Pregnancy brings attention and visibility to difference Feeling out of control in pregnancy and bringing unplanned conversation	Expectations to be "glowing" and "loved up" but this feeling different Pregnancy has brought visibility to difference Pregnancy brought unplanned conversation and enquiry from others
Experiences of Accessing Support *Interviewer: H*ow did you first identify that you were struggling with your mental health?		

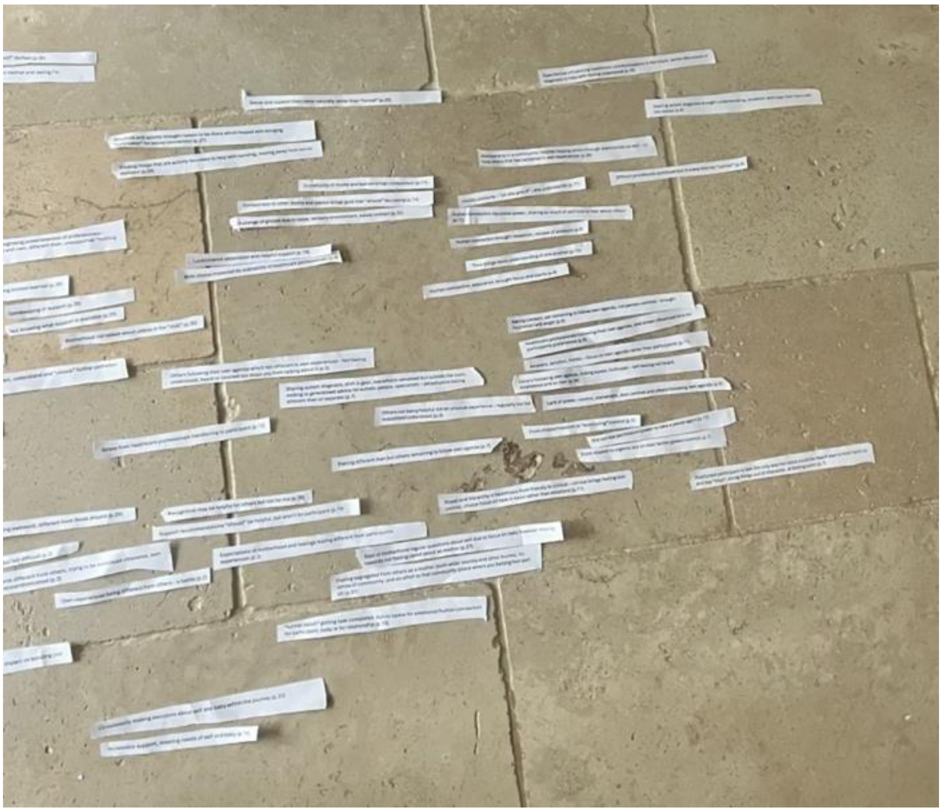
Coding:
Descriptive
Linguistic
Conceptual

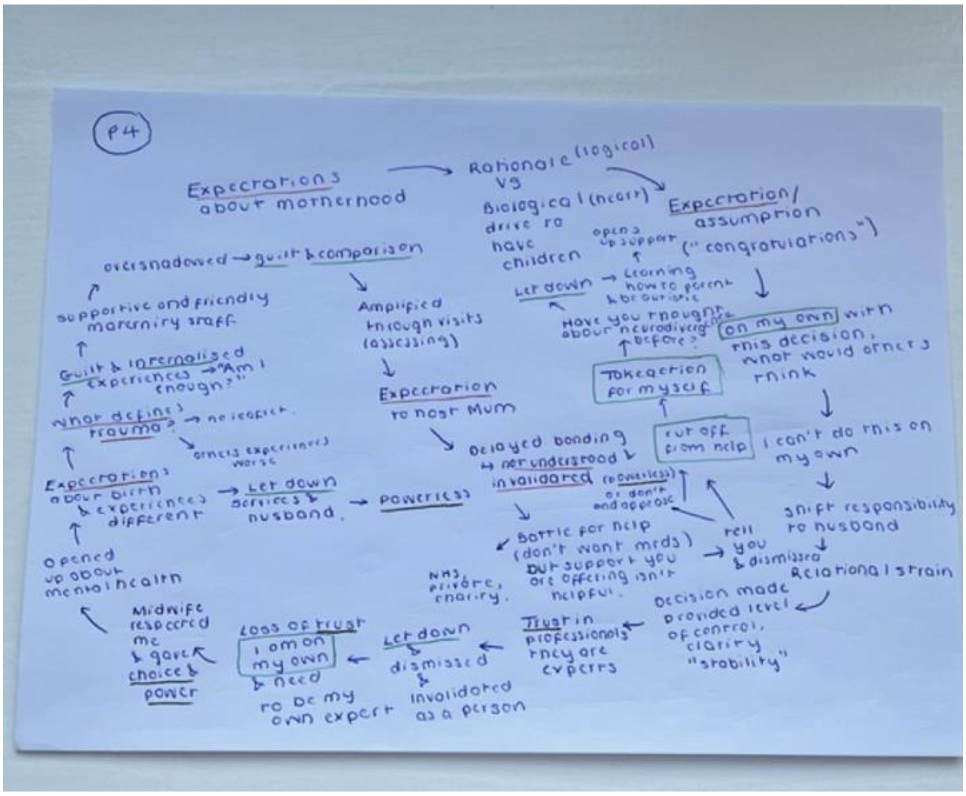
Appendix K

Example of Process to Develop Experiential Themes



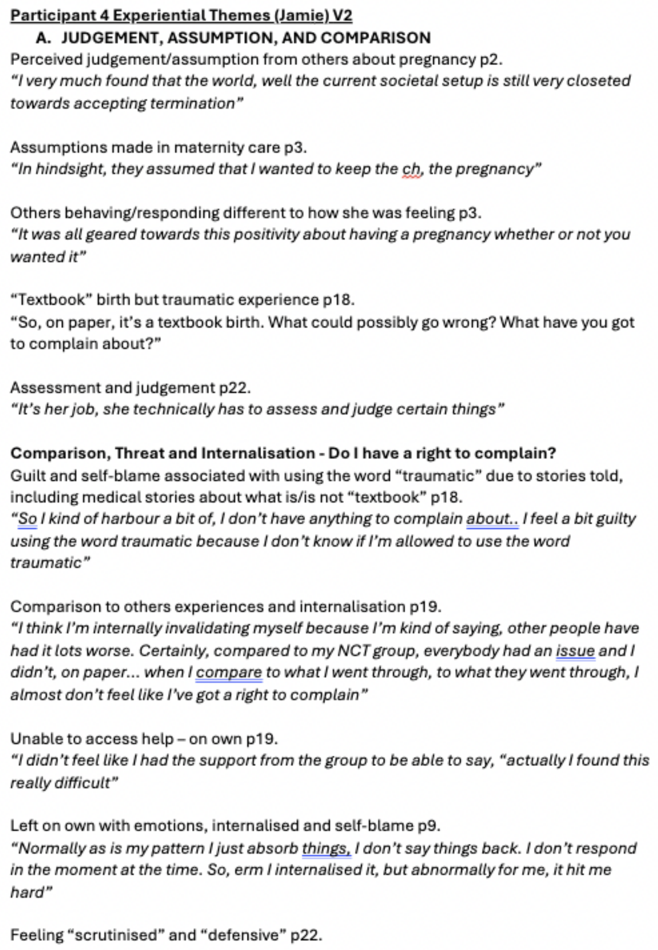





P4
Expectations about motherhood
Rationale (logical) vs Biological (heart) drive to have children
Expectation/ assumption ("congratulations")
overshadowed → guilt & comparison
supportive and friendly maternity staff
Amplified through visits (assessing)
Guilt & internalised experiences → "Am I enough?"
Expectation to host Mum
What defines trauma? → no leaflet.
others experiences worse
Expectations about birth & experiences different
→ Let down services & husband. → Powerless
delayed bonding → not understood & invalidated
(powerless) or don't and appease
Battle for help (don't want meds) but support you are offering isn't helpful.
NHS, private, charity.
tell you & dismissed
Let down → Learning how to parent & be autistic
opens up support
Have you thought about neurodivergence before?
Take action for myself
cut off from help
on my own with this decision, what would others think
I can't do this on my own
shift responsibility to husband
Relational strain
Decision made provided level of control, clarity "stability"
Trust in professionals they are experts
Let down & dismissed & invalidated as a person
Loss of trust
I am on my own & need to be my own expert
Midwife respected me & gave choice & power
opened up about mental health

Appendix L

Example of Personal Experiential Themes



Participant 4 Experiential Themes (Jamie) V2

A. **JUDGEMENT, ASSUMPTION, AND COMPARISON**

Perceived judgement/assumption from others about pregnancy p2.
"I very much found that the world, well the current societal setup is still very closeted towards accepting termination"

Assumptions made in maternity care p3.
"In hindsight, they assumed that I wanted to keep the ch, the pregnancy"

Others behaving/responding different to how she was feeling p3.
"It was all geared towards this positivity about having a pregnancy whether or not you wanted it"

"Textbook" birth but traumatic experience p18.
"So, on paper, it's a textbook birth. What could possibly go wrong? What have you got to complain about?"

Assessment and judgement p22.
"It's her job, she technically has to assess and judge certain things"

Comparison, Threat and Internalisation - Do I have a right to complain?
Guilt and self-blame associated with using the word "traumatic" due to stories told, including medical stories about what is/is not "textbook" p18.
"So I kind of harbour a bit of, I don't have anything to complain about.. I feel a bit guilty using the word traumatic because I don't know if I'm allowed to use the word traumatic"

Comparison to others experiences and internalisation p19.
"I think I'm internally invalidating myself because I'm kind of saying, other people have had it lots worse. Certainly, compared to my NCT group, everybody had an issue and I didn't, on paper… when I compare to what I went through, to what they went through, I almost don't feel like I've got a right to complain"

Unable to access help – on own p19.
"I didn't feel like I had the support from the group to be able to say, "actually I found this really difficult"

Left on own with emotions, internalised and self-blame p9.
"Normally as is my pattern I just absorb things, I don't say things back. I don't respond in the moment at the time. So, erm I internalised it, but abnormally for me, it hit me hard"

Feeling "scrutinised" and "defensive" p22.

"I amplify that internally. And so I, I make myself feel really heavily judged and sort of hyper scrutinised… I was very sort of hackles up, defensive, took things personally"

B. MISUNDERSTOOD AND NOT TAKEN SERIOUSLY

Unable to voice, concerns won't get taken seriously p19.
"I feel unable to voice them or I feel like I won't get taken seriously with how much they've affected me"

Experiences were not taken seriously or validated as traumatic p20.
"I didn't feel validated in requesting one because they didn't send me one to start with"

Difficulty bonding with son – invalidated, not understood by others p23.
"I definitely experienced delayed bonding with my son… and if I ever tried to voice that, it was "no, you do love him. You just haven't learned to recognise that yet"… I felt a bit misunderstood"

Experiences of medical care as invalidating and dismissive p9.
"She sat across from me and said no the only issues that people have with PCOS is getting pregnant and clearly that's not an issue for you"

Narratives about it being helpful – feeling separate from this p25.
"They always say, "this is going to be really helpful, and you know the stats are up here with who and how much we're gonna help" and I felt like it was more, not invalidating, but I just felt very separate from it all"

Feeling seen and understood brought trust and I opened up
Feeling valued, heard and understood brought trust p12.
"I think because she'd managed to build that level of trust that I then trusted her and her team enough to do what they felt was best in whatever situation I landed in"

Asking my views helps me to hope up about how I am feeling p11.
"She was really supportive in every sense from, from general approachability and friendliness all the way through to explaining little details, giving me lots of time to think about things and ask questions… She really took the time with me.. It made me feel a lot more seen, validated, valued"

Healthcare staff respectful, giving space to develop dynamics as a family p21.
"They were respectful. They let us do what we needed to do to learn our new setup, dynamic. But without being pushy, without sort of you need to do it this way, you need to do it that way. We're here if you need us"

Feeling seen and understood through neurodiversity p26.
"Can I just ask if you have got any neurodivergency?" And I went, well you're the first person that's ever said this to me"

Feeling valued, heard and understood brought trust p12.
"I think because she'd managed to built that level of trust that I then trusted her and her team enough to do what they felt was best in whatever situation I landed in"

C. **LET DOWN AND NOT TRUSTWORTHY**

Let down when husband did not advocate for p17.
"Even to this day, what really upset me is that he didn't advocate for me at all"

Let down by society p33.
"Society makes it a disability because it doesn't support you to be able, despite the difference"

Information, expertise, guidance and trust

Let down by systems through not taking wider holistic assessment p33.
"Not one person bar the assessor on the phone went actually let's think about neurodivergency"
"The way that people are taught it doesn't, it doesn't lend itself to a comprehensive holistic view of anything... if people actually went, do you know what, we don't know, so let's start asking, but we do know these things, so let's start including"
"It's not necessarily the individual problem because you only know what you're taught. But if you're not taught a holistic approach, then you're not, then the patient isn't going to receive that care and we're going to suffer as a result of it"

Unjust and let down that information was withheld and practitioner did not follow guidance p9.
"Knowing that a medical professional who is supposed to be there to do everything that the medical professionals are there to do, to go completely against the NHS website that they're supposed to, they're supposed to sing form that hymn sheet and she didn't tell me about the risk associated between the condition and pregnancy"

Not warned of how painful this could be p15.
"Not to be told that actually yes, this could hurt. It's not just discomfort. It could actually hurt and it could really hurt. Erm I, that really upset me because I do feel like I should have been warned of the potential that, that could have added to my pain"

Dismissing experiences of mental health care, lack of consent and information about what it would entail p26.
"All of the stuff that they're supposed to start with in telling you the process of what to expect for your course, she missed it all off. Opened a whole load of can of worms on what I was experiencing... and then kicked me out with no, this is the end of the session"

Anger, let down, blame p18.

"I associate blame to the team for increasing the risk of that happening"

Lasting impact of interactions with medical professionals, lack of trust p11.
"I've had very little trust in the GP practice ever since"

Help is not accessible or available
Let down by the offer of support p24.
"I went from 1-1 counselling which was going to be adaptive and responsive to my needs and erm sort of more of an integrated approach... it was a supportive setup and environment for me to have been in. And then I got changed onto this postnatal course, which was an online group CBT course... It wasn't an environment that I felt at all supported in"

Barriers and gatekeeping of support p29.
"I don't know what level of person I need, but nobody's gotten back to me"

Investment of time and emotion to be held back from support p30.
"You fill all the forms out and they go "no we're not going to see you"

Barriers to support p30.
"Everything is so difficult to access"

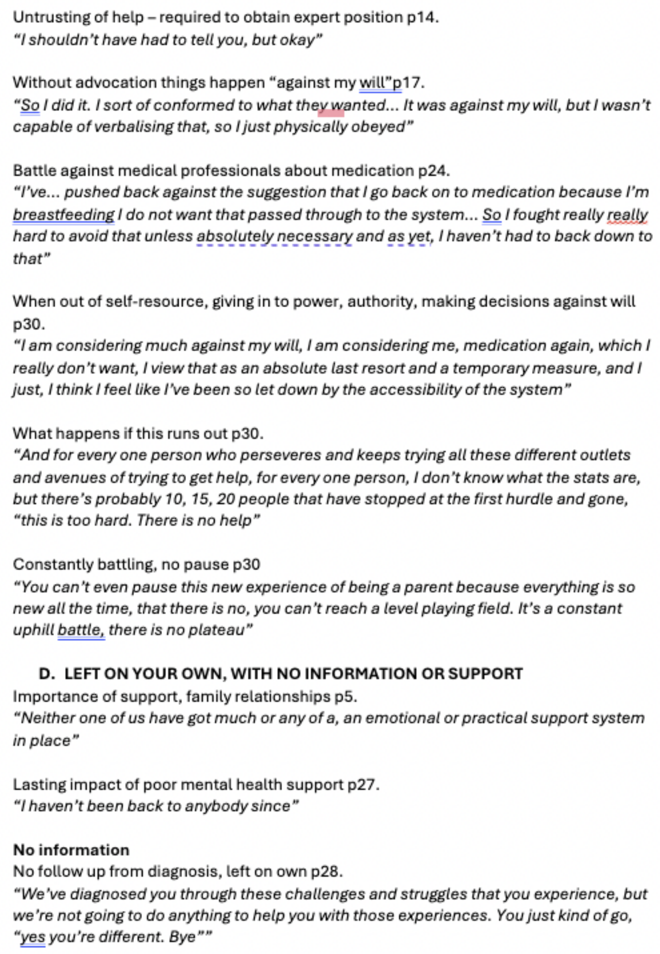
Cut off from any help p24.
"I felt completely dissociated from any actual help"

Unsupported, forgotten about p25.
"Again, I felt completely unsupported and unvalidated and forgotten and like I'd sort of slipped through the net"

No choice over care
Value of choice and autonomy in own support p27.
"I no longer feel the NHS can provide me the support that I need because we don't get to choose what that support is"

Assumptions of what she would like based on what is taught rather than preference p17.
"I knew that they were doing that because that's what they'd been taught, not because that's what was best for me in the moment"

Pushing back, power and resource
Taking expert position due to concerns about not being taken seriously p11.
"It's not my job to know because I go in there, but I feel like I have to, before I go in because I've not got this ingrained sort of, I just don't feel like I've been taken seriously sort of attitude"



Untrusting of help – required to obtain expert position p14.
"I shouldn't have had to tell you, but okay"

Without advocation things happen "against my will"p17.
"So I did it. I sort of conformed to what they wanted... It was against my will, but I wasn't capable of verbalising that, so I just physically obeyed"

Battle against medical professionals about medication p24.
"I've... pushed back against the suggestion that I go back on to medication because I'm breastfeeding I do not want that passed through to the system... So I fought really really hard to avoid that unless absolutely necessary and as yet, I haven't had to back down to that"

When out of self-resource, giving in to power, authority, making decisions against will p30.
"I am considering much against my will, I am considering me, medication again, which I really don't want, I view that as an absolute last resort and a temporary measure, and I just, I think I feel like I've been so let down by the accessibility of the system"

What happens if this runs out p30.
"And for every one person who perseveres and keeps trying all these different outlets and avenues of trying to get help, for every one person, I don't know what the stats are, but there's probably 10, 15, 20 people that have stopped at the first hurdle and gone, "this is too hard. There is no help"

Constantly battling, no pause p30
"You can't even pause this new experience of being a parent because everything is so new all the time, that there is no, you can't reach a level playing field. It's a constant uphill battle, there is no plateau"

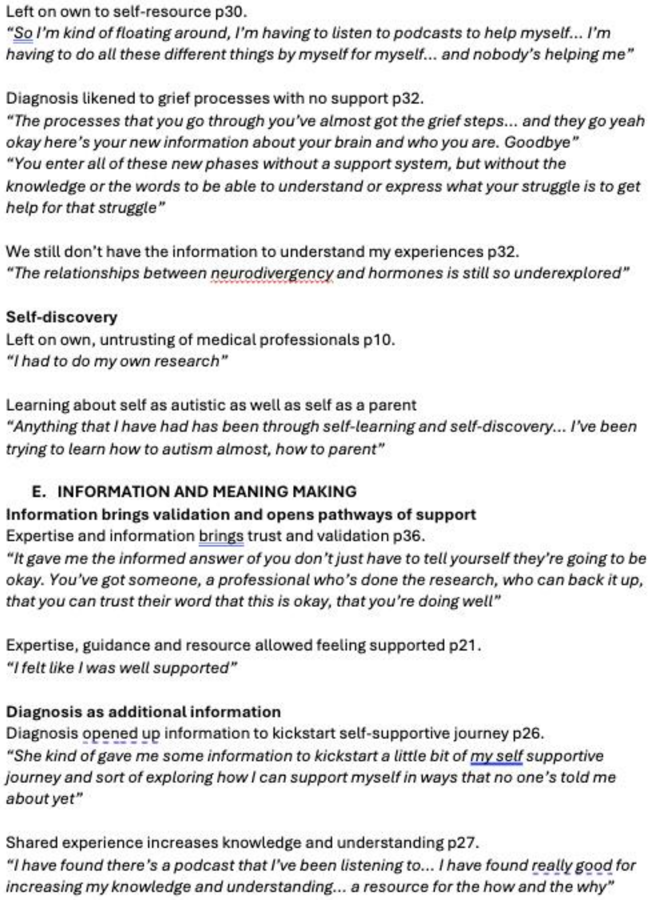
D. LEFT ON YOUR OWN, WITH NO INFORMATION OR SUPPORT

Importance of support, family relationships p5.
"Neither one of us have got much or any of a, an emotional or practical support system in place"

Lasting impact of poor mental health support p27.
"I haven't been back to anybody since"

No information

No follow up from diagnosis, left on own p28.
"We've diagnosed you through these challenges and struggles that you experience, but we're not going to do anything to help you with those experiences. You just kind of go, "yes you're different. Bye""



Left on own to self-resource p30.
"So I'm kind of floating around, I'm having to listen to podcasts to help myself... I'm having to do all these different things by myself for myself... and nobody's helping me"

Diagnosis likened to grief processes with no support p32.
"The processes that you go through you've almost got the grief steps... and they go yeah okay here's your new information about your brain and who you are. Goodbye"
"You enter all of these new phases without a support system, but without the knowledge or the words to be able to understand or express what your struggle is to get help for that struggle"

We still don't have the information to understand my experiences p32.
"The relationships between neurodivergency and hormones is still so underexplored"

Self-discovery
Left on own, untrusting of medical professionals p10.
"I had to do my own research"

Learning about self as autistic as well as self as a parent
"Anything that I have had has been through self-learning and self-discovery... I've been trying to learn how to autism almost, how to parent"

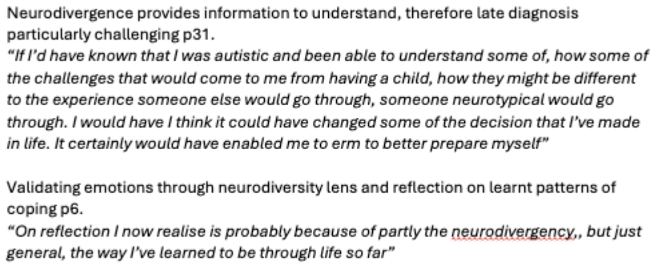
E. INFORMATION AND MEANING MAKING

Information brings validation and opens pathways of support
Expertise and information brings trust and validation p36.
"It gave me the informed answer of you don't just have to tell yourself they're going to be okay. You've got someone, a professional who's done the research, who can back it up, that you can trust their word that this is okay, that you're doing well"

Expertise, guidance and resource allowed feeling supported p21.
"I felt like I was well supported"

Diagnosis as additional information
Diagnosis opened up information to kickstart self-supportive journey p26.
"She kind of gave me some information to kickstart a little bit of my self supportive journey and sort of exploring how I can support myself in ways that no one's told me about yet"

Shared experience increases knowledge and understanding p27.
"I have found there's a podcast that I've been listening to... I have found really good for increasing my knowledge and understanding... a resource for the how and the why"



Neurodivergence provides information to understand, therefore late diagnosis particularly challenging p31.
"If I'd have known that I was autistic and been able to understand some of, how some of the challenges that would come to me from having a child, how they might be different to the experience someone else would go through, someone neurotypical would go through. I would have I think it could have changed some of the decision that I've made in life. It certainly would have enabled me to erm to better prepare myself"

Validating emotions through neurodiversity lens and reflection on learnt patterns of coping p6.
"On reflection I now realise is probably because of partly the neurodivergency,, but just general, the way I've learned to be through life so far"

Appendix M

Group Experiential Themes

Group Experiential Theme	Subtheme	Example Quote
Amplification of feeling ‘different’ and disconnected	The challenges with not fitting a predefined path	“People keep asking me if I’ve got this bond, but I find it hard to bond with any human who’s here and alive in front of me, so let alone something that isn’t here” (Danielle) “Just the being pregnant and people knowing that is very difficult as well to be the centre of attention sort of thing” (Danielle) “I’ve just got such a well-rehearsed life, or I did, you know because everything, it’s very hard to describe, but everything’s an act and fake... but all that was thrown off” (Danielle) “But in my family, it’s erm mostly boys that are diagnosed and I think in boys it’s sort of, autism looks a bit different... that kinds of leaves you with quite a negative feeling like I’m just weird or I’m just like what’s wrong with me” (Holly) “I felt like everybody was looking at me and feeling sorry for me even though I didn’t want a birth partner” (Holly) “But it was more the feeling of being different, that was really blown up like every kind of proportion” (Holly) “If there was some kind of prenatal, pre-birth support for people who are single people who are autistic or just anybody that’s not in a conventional neurotypical heterosexual relationship, and it’s not like promoting a certain way of seeing a birth and a certain way of what that family should look like” (Holly) “The assumption with one size fits all is really difficult” (Holly) “It’s very difficult for me in general not to have control over something. But here I have absolutely no control” (Karolina) “People just start asking me questions. So when are you getting a baby” (Karolina)

		“I very much found that the world, well the current societal setup is still very closeted towards accepting termination” (Jamie) “It was all geared towards this positivity about having a pregnancy whether or not you wanted it” (Jamie) “I definitely experienced delayed bonding with my son... and if I ever tried to voice that it was “no you do love him. You just haven’t learned to recognise that yet”... I felt a bit misunderstood” (Jamie) “I spoke to other pregnant people and they were like really surprised that I didn’t like it and they tried to sort of convince me that well you know it’s a good thing.. but no I never liked it” (Lucy) “You should do this, you shouldn’t do that” (Lucy) “All we have is CBT which I know doesn’t work for me, doesn’t work for. A lot of autistic people” (Lucy)
	Judgement results in internalised difference	“I tend to internalise anyway, I don’t like to tell people how I’m feeling (Danielle) “I’ve always thought something wasn’t right with me, I’m not normal, you know mental health problems in some capacity” (Danielle) “Because no one knows about me diagnosis” (Danielle) “My parents weren’t ashamed of me. But like it did plant the seed and as a result I didn’t tell anybody until I think I was about 20 weeks” (Holly) “I did basically over half the pregnancy by myself, erm without kind of that family support, just because of this seed that kind of planted in there that I’ve done something wrong” (Holly) “I thought, I really thought that if I told them I was struggling. If I told them I was having these feelings that basically they would take him away from me” (Holly)

“When you’ve been undiagnosed for such a long time, you have a tendency for like anything that goes wrong is just internalised and you sort of blame yourself” (Holly)
“I’m easily masking it under the language barrier” (Karolina)
“Going through infertility and even trying to conceive without being infertile is still quite an isolated experience... yeah it eases up the closedness that I’m as autistic experiencing in general” (Karolina)
“When it’s something now as sensitive as this subject, but when it goes to that part, erm I get lost completely” (Karolina)
“I think I’m internally invalidating myself because I’m kind of saying, other people have had it lots wore. Certainly compared to my NCT group” (Jamie)
"I probably did that to myself because of my sort of internalised ableism invalidation whatever you want to call it, issues” (Jamie)
“Normally as is my pattern, I just absorb things. I don’t say things back. I don’t respond in the moment at the time. So erm I internalised it, but abnormally for me, it hit me hard” (Jamie)
“I can feel really defeated sometimes because sometimes I can maybe get into the bad habit of comparing myself to other people and thinking why can’t I do what they can do?” (Lucy)
“Sometimes I feel like a little bit of a fraud, like oh, well, I’m not struggling as much as those people” (Lucy)

Losing trust that I will get help	Information and support are gatekept	“is this not enough to go to somebody about” (Danielle) “the doctor just was like, pff, it’s a two-year waiting list, you’d, there’s no point, sort of thing, who on earth would you want, why do you need a diagnosis” (Danielle) “I had already kind of been over the mountain of like getting help” (Holly) “I tried to go through my GP but it’s quite hard to persuade them... so he just said that he didn’t think it was necessary” (Holly) “Either it was like we don’t take pregnant women or it was like you’re not pregnant enough” (Holly) “They are asking me is really that what you need? Have you tried this? Have you tried that?” (Karolina) “I don’t know what level of person I need, but nobody’s gotten back to me” (Jamie) “You fill out all the forms and they go “no we’re not going to see you” (Jamie) “Everything is so difficult to access” (Jamie) “For somebody who struggles but not “enough”, I don’t really know what there is out there” (Lucy)
	Power influences choice	“It was hard because I, I literally put all my eggs in that basket of right they’ll help me feel better and tell me if I’m absolutely cracking up or not” (Danielle) “She was the only mental health perinatal erm midwife in X... so she were like so if I’d have not gone with her then what would I have done?” (Danielle) “I got my notes back from that like a week later, and she wrote erm X is an unsupported mother, erm who’s hoping that her parents will support her and it was totally not what I said” (Holly) “He really really tried to help me but he just couldn’t” (Holly) “When you’re not being given any options, you’re not being given the space to kind of explain what you want, this kind of a bit of a waste of time... it gives you an unrealistic expectations of how

	much you’re gonna be listened to and how much control you have” (Holly) “I didn’t feel like I had any control over what was happening. It felt like it was totally out of my hands” (Holly) “The GP explained what I’m going through... she literally grabbed me by my hand, got me out the surgery and showed me a path and said, “you see that path? This is a very nice walkable path” (Karolina) “I realised that obviously I cannot communicate properly my experience and feelings. So I’d rather just agree with what she was proposing rather tan try to explain” (Karolina) “I sort of conformed to what they wanted... It was against my will, but I wasn’t capable of verbalising that, so I just physically obeyed” (Jamie) “I had to hold my hand basically to say “stop”” (Lucy) “I basically went and spoke to the GP about it and she said, “yeah all those things that Psychiatry UK are suggesting, we don’t have”. Basically there’s nothing we can do for you” (Lucy)
Not thinking about me	“She said we’re really really busy so it’s going to be a lot longer than normal” (Danielle) “A lot of the time, you know, they’re so busy, that they can’t you know, really give you that personal care” (Holly) “I was just sitting in this chair waiting for the consultant and they were really, really busy” (Holly) “I think they had just like forgotten I was there” (Holly) “I don’t think anybody asked me even like once how I wanted to give birth. Erm so I never really offered up the information” (Holly) “I just found all the bravery that I had, and I asked... she was just kind of, was a bit dismissive” (Holly)

	“I’m sitting there and not understanding. I’m not afraid of anything. And she continues to push me like, like “no but this is how your brain works”” (Karolina) “I know that they were doing that because that’s what they’d been taught, not because that’s what was best for me in the moment” (Jamie) “I didn’t feel understood, or heard, or listened to properly because people had their own idea” (Lucy) “Because they’re so caught up in just doing a job at the end of the day, they, they make everything feel really urgent and you know we’ve got to do this now.. I think they maybe just get used to communicating in that way for efficiency” (Lucy) “I didn’t actually feel like they were very interested in me” (Lucy)
Failed and let down	“Just trying to learn and trying to research autism in pregnant people and there’s not a lot out there, is there?” (Danielle) “What I have done in the meantime is erm, because I was just desperate and I was like, I cannot go on like this, I, I got a doula” (Danielle) “Literally no one would take me” (Holly) “You’re just kind of sitting there feeling a bit scared by yourself” (Holly) “It was just the feeling of like nobody’s like, you know are you all right, I think, you know as socially awkward as I am, if somebody was like in tears in the middle of the hospital, I think even I would be like, are you okay. But nobody, nobody really like cares” (Holly) “I don’t believe there is enough information and support form NHS for anyone going through that and even more for autistic individuals” (Karolina) “No one even assumes that if a person goes through that they might be experiencing a lot of mental health issues” (Karolina)

		“I wish the NHS would be that place where I would go for all support, not just being referred but also for maybe some literature” (Karolina) “Even to this day, what really upset me, is that he didn’t advocate for me at all” (Jamie) “Society makes it a disability because it doesn’t support you to be able, despite the difference” (Jamie) “All of the stuff that they’re supposed to start with in telling you the process of what to expect... she missed it all off. Opened a whole load of can of worms on what I was experiencing... and then kicked me out” (Jamie) “I associate blame to the team for increasing the risk of that happening” (Jamie) “What nobody had told me was that... coming off it cold turkey can sometimes produce this awful side effect. And I think that’s a little bit dangerous that we still don’t know what we’re doing” (Lucy) “That means I’ve been on my own” (Lucy) “It transpired that it [diagnosis] hadn’t made its way onto my notes” (Lucy) “You’ve got an autism diagnosis, and what” (Lucy)
The value of understanding and connection	Understanding brings acceptance	“I need someone to tell me that it’s normal or that I’m okay” (Danielle) “So I’m trying to learn about me autism, and while combating all these pregnancy symptoms as well” (Danielle) “having the diagnosis has explained why I’m like that and give me a little bit of acceptance of why am I like that” (Danielle) “She was like... don’t worry, I’ll be there with you. And I’ll make sure that they know this” (Holly)

“It felt like you can finally be transparent with somebody and finally talked about and like yourself in a way, that’s not trying to be like whatever other people want to hear” (Holly)
“It’s nice having an actual, it’s almost like a neutral word, do you know what I mean, autism” (Holly)
“To have someone who would listen and say that all my feelings are valid and that I’m actually going through a really really difficult time, it helped me to reflect on it” (Karolina)
“She was really supportive in every sense from, from general approachability and friendliness all the way through to explaining little details, giving me lots of time to thnk about things and ask questions... She really took the time with me... It made me feel a lot more seen, validated, valued” (Jamie)
“It gave me the informed answer of you don’t just have to tell yourself they’re going to be okay. You’ve got someone, a professional who’s done the research who can back it up, that you can trust their word that this is okay, that you’re doing well” (Jamie)
“When I said I’m autistic, she was like, oh okay that makes a lot of sense.. so that was nice to be understood” (Lucy)
“I just needed that reassurance.. everything’s going all right” (Lucy)
“I would kind of go in there telling everybody I met, “Oh I’m autistic”. If I was to do it again, just as a reminder, I’m autistic” (Lucy)

	Similarity brings compassion	"I didn't feel like I need to ask her to do anything different. She just saw me and got me" (Danielle) "There's a few podcasts that I've listened to, and I've heard such similar things to what I've said. It's really like comforting to know I'm not the only one who feels like it" (Danielle) "I can imagine for any autistic pregnant woman, that would be a massive thing" (Danielle) "Actually like a lot of women are a bit like me, like they don't know, a lot of women don't get diagnosed" (Holly) "I remember her name because it's quite similar to my name" (Holly) "I feel like I'm really glad that I'm able to contribute because... I thought my experience was really unusual... so I thought if I share it for this research. Maybe like, you know even if nothing changes, at least maybe some other people won't feel so isolated and alone" (Holly) "I just felt that I've never been so seen" (Karolina) "I'm autistic and I'm proud of this because it's actually amazing" (Karolina) "Just because you are supporting someone else it really helps" (Karolina) "It's just so helpful to speak to another human being who goes through exactly the same experience" (Karolina) "On reflection I now realise is probably because of partly the neurodivergency... but just in general, the way I've learned to be through life so far" (Jamie) "One sort of extra mum contact who I feel like we have a sort of shared experience because she also experiences anxiety" (Jamie) "It feels like an effort to find the community" (Lucy)

"She was also pregnant, which I wonder if that had something to do with it for me, like oh she gets it" (Lucy)
"It's made for mums who have had mental health struggles" (Lucy)

Appendix N

Extract from Reflexive Diary and Positionality Statement

Positionality Statement

The researcher is a neurotypical White heterosexual female mental healthcare professional who works in the NHS and has had experience working with autistic clients across the lifespan, including in perinatal mental healthcare settings. Within her experiences, she has been struck by gaps in understanding of autistic adults and how this is reflected in mental healthcare settings. During the time of this research, the researcher also became an Auntie, and as such has both a personal and professional understandings of experiences of motherhood. The research started in 2023 and is contextually placed during a time of growing literature in the field.

Extracts from Reflexive Diary

Data Collection

- This interview felt a little disjointed. I found myself taking the participant back to the experiences she had talked about before to obtain further information. In the context of this interview I am not sure if this felt appropriate. I wondered if the participant may have prepared her answers prior to the interview and as such this approach may to questioning may have thrown her off in the context of her responses. Following this, I tended to stick to the questions to try to alleviate anxiety as much as possible, and the participant appeared more comfortable. This might be something helpful to consider in future interviews, and to discuss in supervision.
- I am finding my position working in the services that have let participants down very difficult to own. I wonder how this influences the way that I am

questioning participants and ultimately how I analyse the data. It is important that I am not stepping into a therapeutic role and maintain my position in the project as a researcher.

- In this interview I found myself saying very little and letting the participant share their experiences. I wonder what helped them to open up in this way, and if there was something about my style that I could take forward into future interviews?
- In this interview, I noticed that the participant did not share much about their experiences of mental health. I found myself drawn to understanding this more, e.g. what does anxiety/depression look like for you, but I questioned if this was because of my role. I made the decision to hold back from exploring this, as it is important that I am guided by the research question and the experiences participants wish or do not wish to share.
- This interview made me very aware of the limitations of the NHS and services and at the end of the interview I noticed myself feeling pulling to wanting to explore different support options with this participant. Again, it was important that I reflected on my role as a researcher rather than a clinician. It is hoped that the signposting that is available in the debrief sheet was helpful to this participant.

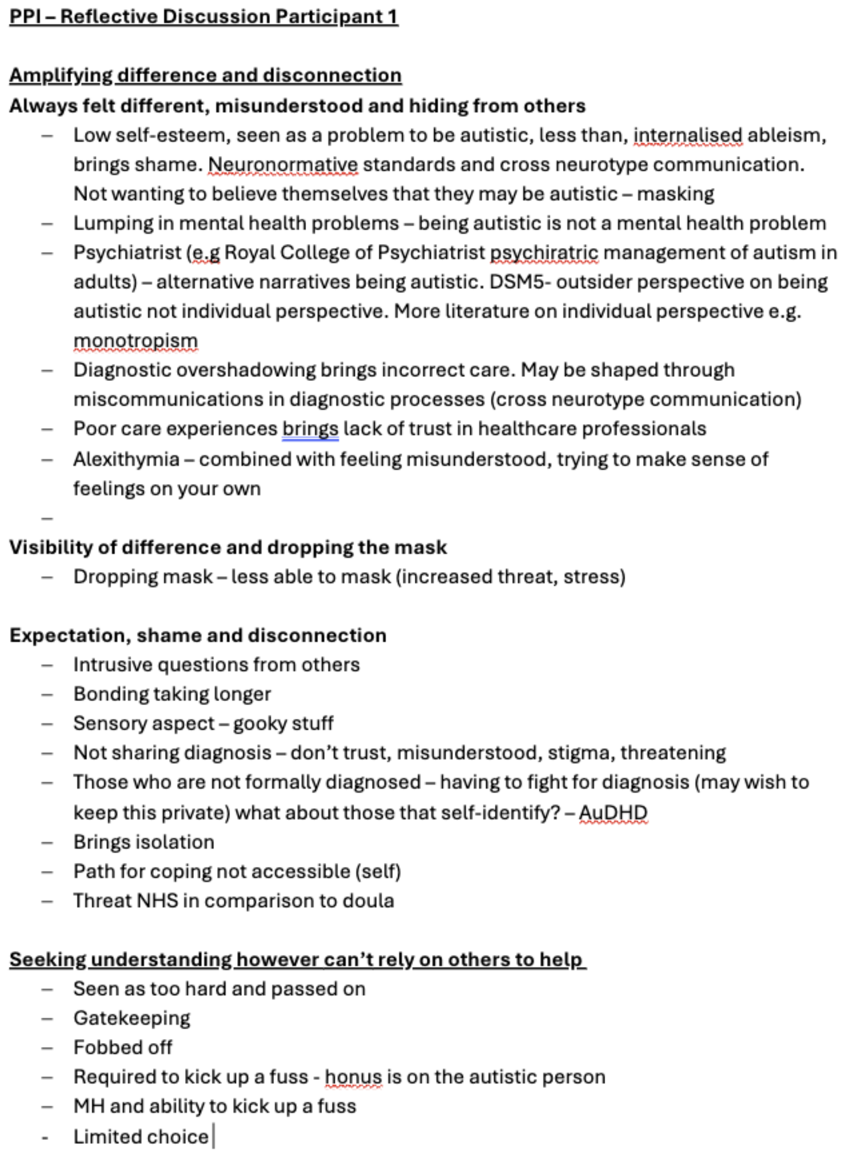
Data Analysis

- Through my personal experiences, I am aware of the role of a doula, and it is interesting that in the case of this participant, the doula has provided what they described as their main support, despite this role typically being considered as a temporary part-time position. I wonder if the doula holds the same perspective as the participant?

- This participant has eloquently described their experiences in rich detail. I am finding it challenging to not provide descriptive themes in this instance, as I do not want to lose the participant’s experiences through my interpretation.
- Through my personal experiences, I am aware that there are different approaches taken in hospitals to parenthood, birth and feeding, and that in some instances these can be quite polarised. I wonder what this was like for the participants to navigate? Are there experiences which amplify how this felt for each participant?
- One participant spoke about the experiences of noticing that once you are ‘in it’ (motherhood), you see it more. This is an experience that I personally resonate with, as through my previous professional roles as well as my personal experiences I have found myself immersed in conversations about motherhood. This has opened my eyes to an understanding that I had not previously considered. For this participant, it sounded like this was a helpful experience, and they wished they had been welcomed into this ‘club’ sooner.

Appendix O

Extract From a Reflective Discussion with Autistic Volunteer



PPI – Reflective Discussion Participant 1

Amplifying difference and disconnection

Always felt different, misunderstood and hiding from others

- Low self-esteem, seen as a problem to be autistic, less than, internalised ableism, brings shame. Neuronormative standards and cross neurotype communication. Not wanting to believe themselves that they may be autistic – masking
- Lumping in mental health problems – being autistic is not a mental health problem
- Psychiatrist (e.g Royal College of Psychiatrist psychiratric management of autism in adults) – alternative narratives being autistic. DSM5- outsider perspective on being autistic not individual perspective. More literature on individual perspective e.g. monotropism
- Diagnostic overshadowing brings incorrect care. May be shaped through miscommunications in diagnostic processes (cross neurotype communication)
- Poor care experiences brings lack of trust in healthcare professionals
- Alexithymia – combined with feeling misunderstood, trying to make sense of feelings on your own
-

Visibility of difference and dropping the mask

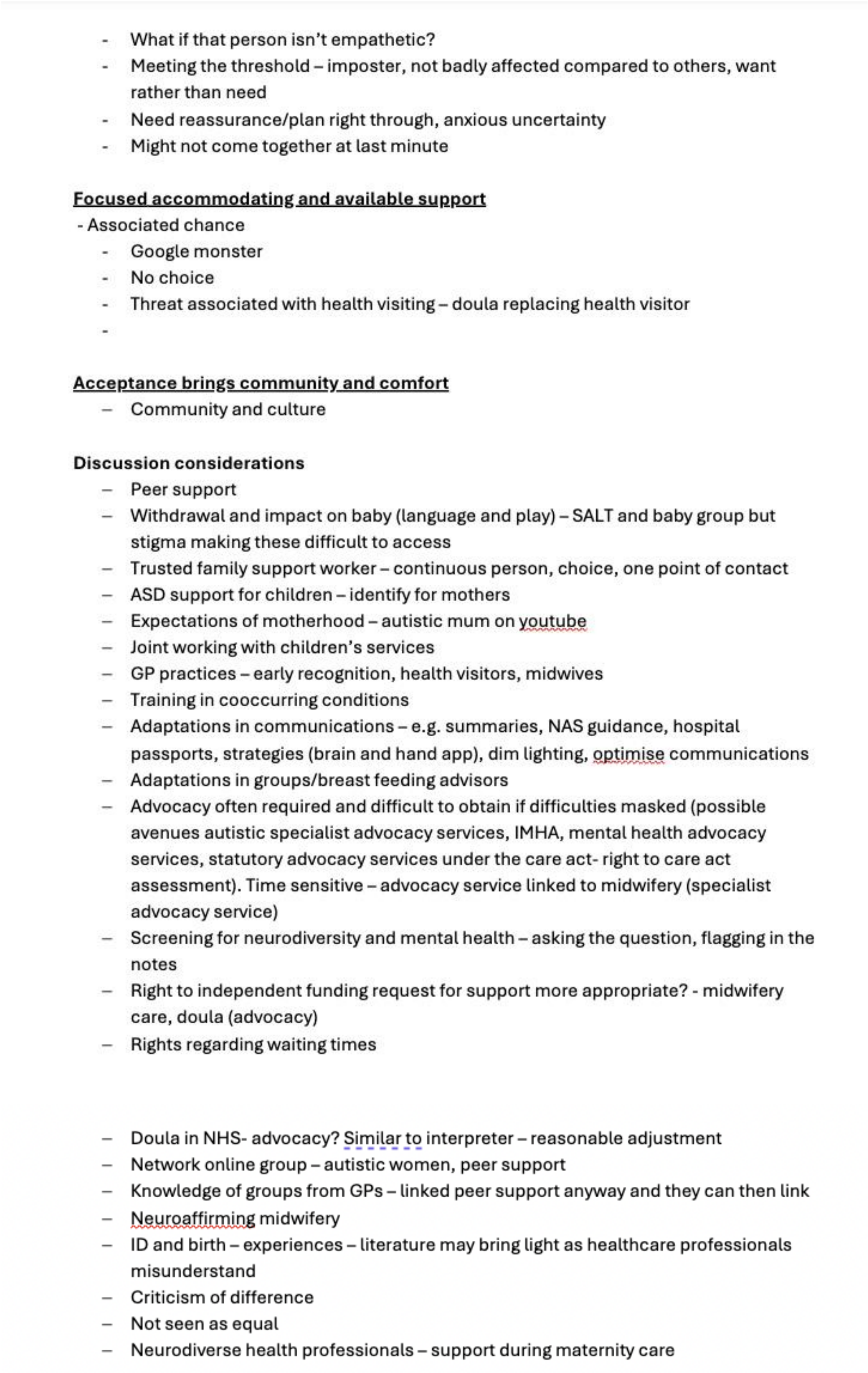
- Dropping mask – less able to mask (increased threat, stress)

Expectation, shame and disconnection

- Intrusive questions from others
- Bonding taking longer
- Sensory aspect – gooky stuff
- Not sharing diagnosis – don't trust, misunderstood, stigma, threatening
- Those who are not formally diagnosed – having to fight for diagnosis (may wish to keep this private) what about those that self-identify? – AuDHD
- Brings isolation
- Path for coping not accessible (self)
- Threat NHS in comparison to doula

Seeking understanding however can't rely on others to help

- Seen as too hard and passed on
- Gatekeeping
- Fobbed off
- Required to kick up a fuss - honus is on the autistic person
- MH and ability to kick up a fuss
- Limited choice



- What if that person isn't empathetic?
- Meeting the threshold – imposter, not badly affected compared to others, want rather than need
- Need reassurance/plan right through, anxious uncertainty
- Might not come together at last minute

Focused accommodating and available support

- Associated chance
  - Google monster
  - No choice
  - Threat associated with health visiting – doula replacing health visitor
  -

Acceptance brings community and comfort

- Community and culture

Discussion considerations

- Peer support
- Withdrawal and impact on baby (language and play) – SALT and baby group but stigma making these difficult to access
- Trusted family support worker – continuous person, choice, one point of contact
- ASD support for children – identify for mothers
- Expectations of motherhood – autistic mum on youtube
- Joint working with children's services
- GP practices – early recognition, health visitors, midwives
- Training in cooccurring conditions
- Adaptations in communications – e.g. summaries, NAS guidance, hospital passports, strategies (brain and hand app), dim lighting, optimise communications
- Adaptations in groups/breast feeding advisors
- Advocacy often required and difficult to obtain if difficulties masked (possible avenues autistic specialist advocacy services, IMHA, mental health advocacy services, statutory advocacy services under the care act- right to care act assessment). Time sensitive – advocacy service linked to midwifery (specialist advocacy service)
- Screening for neurodiversity and mental health – asking the question, flagging in the notes
- Right to independent funding request for support more appropriate? - midwifery care, doula (advocacy)
- Rights regarding waiting times

- Doula in NHS- advocacy? Similar to interpreter – reasonable adjustment
- Network online group – autistic women, peer support
- Knowledge of groups from GPs – linked peer support anyway and they can then link
- Neuroaffirming midwifery
- ID and birth – experiences – literature may bring light as healthcare professionals misunderstand
- Criticism of difference
- Not seen as equal
- Neurodiverse health professionals – support during maternity care

Appendix P

Independent Audit of Analysis Using Template Created for Auditing Interpretative Phenomenological Analysis

Audit Checklist

Data collection
1. Is there evidence that raw data was collected and is appropriate for the research aims?
Yes (As evidenced by anonymised transcripts)

I saw the interview transcript for a participant that I requested to see. There was evidence of questions being asked by the researcher in line with the semi-structured interview protocol and high quality data being collected.

2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age, interview location/time)?
Yes

I saw the demographic data that was collected for Participant 2.

3. Are there reflections/notes/summaries on the data collection process?
Yes

Emma read sections of her reflexivity diary.

Research/analysis process
4. Has the researcher engaged appropriately in supervision as part of the research process?
Yes

Emma regularly attended supervision meetings and set the agenda for these.

5. Has the data been sufficiently coded? (e.g., is all the relevant data coded?)
Yes

Emma showed me data from a participant that I requested to see. She showed me examples of descriptive, linguistic and conceptual codes.

6. Has the data been systematically coded?
Yes

I have seen the coding on the transcripts.

7. Is it clear that the researcher has engaged in a process of refining and redefining the themes and subthemes and are these processes justified?

(This may be evidenced by looking at different versions of documents and notes, and changes to coding/themes should be justified).
Yes

Emma showed me photographs of how she initially arranged the experiential statements. In supervision we had initial discussions and reflections that outlined that initial reviewing was quite descriptive. This moved on in subsequent supervision sessions.

Cross-checks

8. Crosschecking randomly selected excerpts from the interviews and photo-elicitation items against the corresponding coding and themes recorded.

Are these consistent?
Yes

9. Vice-versa crosschecking randomly selected themes and subthemes against the corresponding data.
Are these consistent?
Yes

Study write-up/results
10.Are quotes sufficient to provide evidence of the themes and subthemes?
Yes

Quotes were illustrative of themes

11.Does the results/write-up sufficiently address the aims of the study?
Yes

The write-up addresses the aims of the study

Signed

[redacted]

Prof Megan Freeth

DClinPsy thesis supervisor