CORA Cork Open Research Archive
Cartlann Taighde Oscailte Chorcaí

Title	The experiences of autistic adults accessing healthcare services
Authors	Moore, Laura
Publication date	2023
Original Citation	Moore, L. 2023. The experiences of autistic adults accessing healthcare services. DClinPsych Thesis, University College Cork.
Type of publication	Doctoral thesis
Rights	© 2023, Laura Moore. - https://creativecommons.org/licenses/by-nc-nd/4.0/
Download date	2026-10-30 02:00:12
Item downloaded from	https://hdl.handle.net/10468/15046

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

The Experiences of Autistic Adults Accessing Healthcare Services

Systematic Review: Mental Health Professionals' Experiences of Adapting Mental Health Interventions for Autistic Adults: A Systematic Review and Thematic Synthesis

Major Research Project: Understanding the Experiences of Receiving and Providing Maternity Care for Autistic Adults

Thesis presented by Laura Moore

In partial fulfilment of the requirements for the Degree of Doctor of Clinical Psychology

School of Applied Psychology

University College Cork

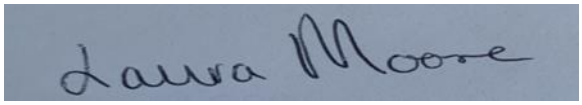
May 2023

Supervisors: Dr Fionnuala Larkin and Dr Sarah Foley

Field Supervisor: Dr Freda Wynne

Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism."

Signed: 

Date: 01/05/23

Acknowledgements

I would like to thank my supervisors Dr Fionnuala Larkin and Dr Sarah Foley for their commitment, support, and enthusiasm throughout the research process. Thanks to Dr Freda Wynne for her support with recruitment and insight on perinatal mental health.

I am very grateful to the participants who were so generous in sharing their experiences and giving up their time to contribute to this research.

I am beyond grateful for the support I've received from so many people along the way. Thanks to Gary for his unending patience and support at every step of this doctorate journey. Thanks to all my family, especially Noreen and Denis, for believing in me and encouraging me. To the girls, thanks for the laughs and good times that offered a much-needed break from thesis life. To my fellow trainees, I appreciate the laughs, tears, and beers that made the last three years easier.

Table of Contents

Declaration **2**

Acknowledgements **3**

Table of Contents **4**

List of Tables **10**

List of Figures **11**

Abbreviations **12**

Chapter One: Thesis Introduction **13**

Overview and Context 13

Thesis Aims 16

Outline of Chapters 16

References **18**

Chapter Two: Systematic Review **22**

Abstract 23

Mental Health Professionals' Experiences of Adapting Mental Health Interventions for Autistic Adults – A Systematic Review and Thematic Synthesis 24

The Present Study 29

Methodology 29

Research Question 30

Inclusion and Exclusion Criteria....30
Search Strategy....30
Screening Process....31
Data Extraction....31
Data Synthesis....32
Results....32
Study Selection....32
Quality Appraisal....33
Results of Thematic Synthesis....33
Unique Experience of Delivering Adapted Interventions....38
Factors which Facilitate Successful Adaptations of Interventions....42
Challenges in Successfully Adapting Interventions....44
Discussion....47
Implications for Clinical Practice....50
Strengths and Limitations....52
Suggestions for Future Research....52
Conclusion....53
References....55
Chapter Three: Systematic Review Extended Methodology....64
Development of the Research Question....64
Rationale for Thematic Synthesis....65

Identifying Studies for Inclusion 67

Search Strategy 68

Quality Appraisal 69

Data Extraction 69

Thematic Synthesis 70

Transparency in Reporting 71

References 72

Chapter Four: Major Research Project 77

Abstract 78

Introduction 79

Autism and the Perinatal Period 79

Challenges in the Perinatal Period for Autistic Mothers 80

Maternity Care Professionals' and Autism 81

The Present Study 83

Method 83

Study Design 83

Participants 84

Procedure 85

Data Analysis 86

Results 87

The Challenge of Autism within Maternity Care 88

Relational Care within the Maternity Context for Autistic Mothers 93
Competing Demands and Priorities within Maternity Care 97
Discussion 101
The Challenge of Autism within Maternity Care 101
Relational Care within the Maternity Context for Autistic Mothers 103
Competing Demands and Priorities within Maternity Care 104
Clinical Implications 105
Limitations 107
Future Directions 108
Conclusion 109
References 110
Chapter Five: Major Research Project Extended Methodology 119
Research Design 119
Interpretative Phenomenological Analysis 119
Multiperspectival Interpretative Phenomenological Analysis 120
Rationale for Methodology 122
Public and Patient Involvement 123
Sampling and Recruitment 125
Recruitment of Autistic Mothers 125
Recruitment of Maternity Care Professionals 126
Data Collection 127

Data Analysis 127

Ethical Considerations 130

Reflexivity 132

References 135

Chapter Six: Discussion and Conclusion 139

Summary of Findings 139

Mental Health Professionals' Experiences of Adapting Mental Health Interventions for Autistic Adults 139

The Experience of Receiving and Providing Maternity Care for Autistic Mothers 141

Clinical Implications 144

Conclusion 146

References 148

Appendices 152

Appendix A: Publishing Guidelines for the Journal of Autism and Developmental Disorders 152

Appendix B: Guidelines for Review of Electronic Search Strategies 157

Appendix C: CASP Quality Appraisal 158

Appendix D: PRISMA Statement 159

Appendix E: Search Terms for Additional Databases 162

Appendix F: Systematic Review Data Extraction Tool 163

Appendix G: Example of Coding for Thematic Synthesis 164

Appendix H: Example of Descriptive Theme in Thematic Synthesis 165

Appendix I: ENTREQ Statement **166**

Appendix J: Publishing Guidelines for Autism Journal **168**

Appendix K: Letter of Ethical Approval **179**

Appendix L: Social Media Recruitment **180**

Appendix M: Information Sheets **181**

Information Sheet for Autistic Mothers 181

Information Sheet for Maternity Care Professionals 184

Appendix N: Informed Consent **187**

Appendix O: Interview Schedules **188**

Semi-structured Interview Schedule for Mothers on the Autism Spectrum who have Experienced Maternity Care 188

Semi-structured Interview Schedule for Maternity Care Professionals 189

Appendix P: Sample Interview Transcript with Exploratory Notes and Experiential Statements **191**

Appendix Q: Subset of Experiential Statements and Example of Clustering Experiential Statements **194**

Appendix R: Section of Table of Personal Experiential Themes for Rebecca **195**

Appendix S: Example of Group Experiential Theme for Autistic Mothers **196**

Appendix T: Tables of Group Experiential Themes **198**

Appendix U: Multiperspectival Between Group Themes **199**

List of Tables

Table 2.1 Example Search Strategy for Web of Science…….p.31

Table 2.2 Demographic and Methodological Information for Included Studies…….p.35

Table 4.1 Autistic Mothers Demographic Information……p.85

Table 4.2 Midwives Demographic Information……..…..p.85

List of Figures

Figure 2.1 PRISMA flow diagram……..p.34

Figure 4.1 MRP Themes and Subthemes…….p.88

Abbreviations

MHI Mental Health Interventions

MCP Maternity Care Professional

IPA Interpretative Phenomenological Analysis

PPI Public Patient Involvement

Chapter One: Thesis Introduction

Overview and Context

Until relatively recently, autism was considered a childhood disorder and the majority of autism research focused on this developmental period (Howlin, 2021). As a result, the experiences and needs of autistic adults[1] are comparatively less understood. Increasingly, adults are accessing assessments and receiving autism diagnoses for the first time (Pellicano, 2022). Simultaneously, generations of children diagnosed with autism, since improved understanding and access to assessments, are moving through adulthood (Howlin, 2021). A review by Howlin and Magiati (2017), identified that only 3.5% of autism research focused specifically on adults which underlines the need for additional research with this population. Therefore, further research into the experience of autistic adults is warranted. This thesis aims to explore healthcare experiences of autistic adults in two domains: mental health services and maternity care. In this chapter, I will provide an overview of key literature for both areas addressed in this thesis and provide further detail on the content of the thesis.

Autism in Adulthood

Adults on the autism spectrum face challenges and experience, generally, poorer outcomes across a range of domains including education, employment, relationships, quality of life, community involvement, and health (Lai et al., 2020; Lai & Baron-Cohen, 2015; Pellicano et al., 2022). There is some evidence that diagnosis in adulthood is associated with worse quality of life, particularly in relation to mental health (Atherton et al., 2022). Research has consistently demonstrated that autistic adults are significantly more likely to experience

[1] The terminology used to describe people on the autism spectrum is subject to continued discussion (Botha et al., 2020; Vivanti, 2019). Recent empirical research suggests that autistic individuals tend to prefer identity first language (IFL), "autistic person", or the term "person on the autism spectrum" over person first language, "person with autism" (PFL) (Bottema-Beutel et al., 2021; Bury et al., 2020; Kenny et al., 2016). Therefore, IFL is used throughout this thesis, in keeping with the preferences expressed by the MRP study participants, though it is acknowledged that this does not represent the preferences of all individuals on the autism spectrum.

premature mortality compared to non-autistic people, and this risk is even greater for autistic women (Woolfenden et al., 2012). This increased incidence of premature mortality can partly be attributed to an elevated risk of suicide amongst autistic adults (Cassidy et al., 2018), as well as the prevalence of a range of co-occurring physical and mental health conditions (Rydzewska et al., 2021; Weir et al., 2021). Therefore, research exploring autistic adults' experiences of healthcare is essential to improving services and outcomes for autistic adults.

Healthcare and Autistic Adults

Autistic adults report greater use of most healthcare services (Zerbo et al., 2019), however, they also report significantly greater unmet healthcare needs (Bradshaw et al., 2019; Nicolaidis et al., 2013). Autistic adults have reported significant barriers in accessing healthcare. Research has identified patient level factors that impact access to and experiences of healthcare such as communication difficulties, sensory sensitivities, processing speed, difficulty with organisation, and anxiety (Bradshaw et al., 2019; Nicolaidis et al., 2015). Importantly, these patient level factors interact with healthcare provider factors to further impact on autistic people's experiences of accessing healthcare services (Nicolaidis et al., 2015). Healthcare professionals' knowledge about autism in adults, the perception of professionals' biases, and professionals' unwillingness to appropriately alter services have been identified as provider level factors which act as barriers. (Bradshaw et al., 2019; Nicolaidis et al., 2015). System level factors such as the complexity of healthcare services and lack of referral pathways have also been identified as barriers to autistic adults accessing healthcare service (Bradshaw et al., 2019; Nicolaidis et al., 2015).

Mental Health and Autistic Adults

Increasingly, there is a move towards reasonable adjustments in healthcare to ensure equality of access for those with disability or neurodiversity (Department of Health, 2010; Haydon et al., 2021). Some guidelines exist for clinicians regarding adaptations for mental health interventions, specifically NICE guidelines (NICE, 2021). However, research with autistic adults has highlighted that, in practice, adaptations are frequently not available (Adams & Young, 2021; Brice et al., 2021). These findings, the prevalence of mental health conditions amongst autistic adults (Hollocks et al., 2019; Lai et al., 2019), and the increased risk of suicidality (Cassidy et al., 2018) indicate a need for improved mental health services for autistic adults. Therefore, the aim of the systematic review component of this thesis is to understand clinicians' experiences of adapting mental health interventions (MHI) for autistic adults.

Healthcare Experiences of Autistic Women

The healthcare experiences of adult women on the autism spectrum are particularly under researched (Kassee et al., 2020). In particular, limited research exists exploring autistic women's reproductive health and experiences of pregnancy and childbirth (McDonnell & DeLucia, 2021). A recent systematic review identified seven studies related to the perinatal period (pregnancy and up to one month post birth) (McDonnell & DeLucia, 2021). Quantitative and qualitative findings from this review suggest that autistic mothers are more likely to experience pre-natal and post-natal depression. Autistic mothers were also found to be at greater risk of specific pregnancy complications such as preterm births, caesarean delivery, and preeclampsia (McDonnell & De Lucia, 2021). A comparative, quantitative study by Pohl et al. (2020) found that autistic women experience greater dissatisfaction in their interactions with healthcare providers during pregnancy, compared to non-autistic women. Currently, there is a lack of research exploring healthcare providers experiences of

delivering maternity care to autistic women and no specific guidelines pertaining to reasonable adjustments within a maternity context.

Thesis Aims

Overall, the objective of this study is to contribute to the understanding of autistic adults' experiences of accessing healthcare, particularly mental health and maternity care and to make recommendations for improving the provision of services in these important healthcare domains.

Aims of the Systematic Review

The aim of the systematic review is to synthesise findings from qualitative studies regarding mental health professionals' experiences of adapting mental health interventions (MHI) for autistic adults.

Aims of the Major Research Project

The aim of the major research project component of the current thesis is to explore the experiences of autistic women and maternity care professionals (MCPs) in receiving and providing maternity care for autistic mothers.

Outline of Chapters

Chapter Two: Systematic Review

This chapter will present a systematic review of qualitative studies regarding mental health professionals' experiences of adapting mental health interventions for autistic adults. This is presented in the form of a journal article which has been accepted for publication and is currently in press with the *Journal of Autism and Developmental Disorders.*

Chapter Three: Systematic Review Extended Methodology

This chapter expands on methodological considerations of the systematic review which could not be included in the systematic review paper which was prepared for a peer reviewed journal. This chapter also provides additional context and rationale for decision making that occurred as part of the design and implementation of the systematic review process.

Chapter Four: Major Research Project

This chapter presents the major research project, which explores the experiences of autistic mothers and maternity care professionals' experiences of receiving and providing maternity care for autistic mothers. The project is presented as a paper written for the journal *Autism.*

Chapter Five: Major Research Project Extended Methodology

This chapter expands on methodological considerations of the major research project and provides additional context and rationale for decision making. This includes the rational for the use of interpretative phenomenological analysis (IPA), details of the public patient involvement (PPI) process, ethical considerations, reflexivity, and further detail regarding sampling and data analysis.

Chapter Six: Thesis Discussion and Conclusion

The final chapter summarizes the findings of this thesis and discusses the clinical implications of the systematic review and major research project.

References

Adams, D., & Young, K. (2021). A Systematic Review of the Perceived Barriers and Facilitators to Accessing Psychological Treatment for Mental Health Problems in Individuals on the Autism Spectrum. *Review Journal of Autism and Developmental Disorders*, *8*(4), 436–453. https://doi.org/10.1007/s40489-020-00226-7

Atherton, G., Edisbury, E., Piovesan, A., & Cross, L. (2022). Autism Through the Ages: A Mixed Methods Approach to Understanding How Age and Age of Diagnosis Affect Quality of Life. *Journal of Autism and Developmental Disorders*, *52*(8), 3639–3654. https://doi.org/10.1007/s10803-021-05235-x

Botha, M., Hanlon, J., & Williams, G. L. (2021). Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti. *Journal of Autism and Developmental Disorders.* https://doi.org/10.1007/s10803-020-04858-w

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood*, *3*(1), 18–29. https://doi.org/10.1089/aut.2020.0014

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

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

Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2023). "It Defines Who I Am" or "It's Something I Have": What Language Do [Autistic] Australian Adults [on the Autism Spectrum] Prefer? *Journal of Autism and Developmental Disorders, 53*(2), 677–687. https://doi.org/10.1007/s10803-020-04425-3

Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, *9*(1), 42. https://doi.org/10.1186/s13229-018-0226-4

Department of Health. (2010, March 3). Fulfilling and rewarding lives: the strategy for adults with autism in England. www.webarchive.nationalarchives.gov.uk. Retrieved December 20, 2021 https://webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

Haydon, C., Doherty, M., & Davidson, I. A. (2021). Autism: Making reasonable adjustments in healthcare. *British Journal of Hospital Medicine*, *82*(12), 1–11. https://doi.org/10.12968/hmed.2021.0314

Howlin, P. (2021). Adults with Autism: Changes in Understanding Since DSM-111. *Journal of Autism and Developmental Disorders, 51*(12), 4291–4308. https://doi.org/10.1007/s10803-020-04847-z

Kassee, C., Babinski, S., Tint, A., Lunsky, Y., Brown, H. K., Ameis, S. H., Szatmari, P., Lai, M.-C., & Einstein, G. (2020). Physical health of autistic girls and women: A scoping review. *Molecular Autism, 11*(1), 84. https://doi.org/10.1186/s13229-020-00380-z

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

Lai, M.-C., Anagnostou, E., Wiznitzer, M., Allison, C., & Baron-Cohen, S. (2020). Evidence-based support for autistic people across the lifespan: Maximising potential, minimising barriers, and optimising the person–environment fit. *The Lancet Neurology*, *19*(5), 434–451. https://doi.org/10.1016/S1474-4422(20)30034-X

Lai, M.-C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, *2*(11), 1013–1027. https://doi.org/10.1016/S2215-0366(15)00277-1

McDonnell, C. G., & DeLucia, E. A. (2021). Pregnancy and Parenthood Among Autistic Adults: Implications for Advancing Maternal Health and Parental Well-Being. *Autism in Adulthood*, *3*(1), 100–115. https://doi.org/10.1089/aut.2020.0046

National Institute for Health and Care Excellence (NICE). (2021). *Autism spectrum disorder in adults: Diagnosis and management*. https://www.nice.org.uk/guidance/cg142

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

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013). Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership. *Journal of General Internal Medicine*, *28*(6), 761–769. https://doi.org/10.1007/s11606-012-2262-7

Pellicano, E., Fatima, U., Hall, G., Heyworth, M., Lawson, W., Lilley, R., Mahony, J., & Stears, M. (2022). A capabilities approach to understanding and supporting autistic adulthood. *Nature Reviews Psychology*, 1–16. https://doi.org/10.1038/s44159-022-00099-z

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

Rydzewska, E., Dunn, K., & Cooper, S.-A. (2021). Umbrella systematic review of systematic reviews and meta-analyses on comorbid physical conditions in people with autism spectrum disorder. *The British Journal of Psychiatry*, *218*(1), 10–19. https://doi.org/10.1192/bjp.2020.167

Vivanti, G. (2019). Ask the Editor: What is the Most Appropriate Way to Talk About Individuals with a Diagnosis of Autism? *Journal of Autism and Developmental Disorders*, *50*, 691–693. https://doi.org/10.1007/s10803-019-04280-x

Weir, E., Allison, C., Warrier, V., & Baron-Cohen, S. (2021). Increased prevalence of non-communicable physical health conditions among autistic adults. *Autism*, *25*(3), 681–694. https://doi.org/10.1177/1362361320953652

Woolfenden, S., Sarkozy, V., Ridley, G., Coory, M., & Williams, K. (2012). A systematic review of two outcomes in autism spectrum disorder - epilepsy and mortality: Review. *Developmental Medicine & Child Neurology*, *54*(4), 306–312. https://doi.org/10.1111/j.1469-8749.2012.04223.x

Zerbo, O., Qian, Y., Ray, T., Sidney, S., Rich, S., Massolo, M., & Croen, L. A. (2019). Health Care Service Utilization and Cost Among Adults with Autism Spectrum Disorders in a U.S. Integrated Health Care System. *Autism in Adulthood*, *1*(1), 27–36. https://doi.org/10.1089/aut.2018.0004

Chapter Two: Systematic Review

Mental Health Professionals' Experiences of Adapting Mental Health Interventions for Autistic Adults – A Systematic Review and Thematic Synthesis

Authors:

Laura Moore, University College Cork, Psychology Department, Cork, Ireland

(corresponding author e-mail: 120224736@umail.ucc.ie)

Dr Fionnuala Larkin, University College Cork, Psychology Department, Cork, Ireland

Dr Sarah Foley, University College Cork, Psychology Department, Cork, Ireland

Manuscript is currently in press with the *Journal of Autism and Developmental Disorders (JADD)*. Author guidelines for *JADD* are presented in Appendix A.

This work was supported by the Health Services Executive as the sponsor of a doctoral training post to Laura Moore. The research was conducted independently of the sponsoring agency and the sponsoring agency had no role in the conception, design, analysis, or write-up of this study.

Abstract

Background: Autistic adults experience high rates of metal health difficulties and face significant barriers to accessing appropriate mental health care. Empirical research and recent professional guidelines emphasise the importance of modifying standard mental health interventions to best meet the needs of autistic adults. *Aim:* This systematic review explored mental health professionals' experiences of adapting mental health interventions for autistic adults. *Method:* A systematic search was conducted on CINAHL, PsycINFO, PubMed, Scopus, and Web of Science in July 2022. The findings from 13 identified studies were synthesised using thematic synthesis. *Results:* Three major analytical themes were generated, the unique experience of adapting interventions for autistic clients, factors which facilitate successful adaptations, and challenges to adapting interventions. Each theme contained a number of subsequent sub-themes. *Conclusion:* Professionals view the process of adapting interventions to be a highly individualised process. A range of personal traits, professional experiences, and systemic, service-based issues were identified in facilitating or challenging this individualised process. Further research regarding adaptations with different intervention models and increased supportive resources are required to enable professionals to successfully adapt interventions for autistic adult clients.

Keywords: Adaptations; Mental Health Interventions, Autistic Adults; Thematic Synthesis; Autism

Mental Health Professionals' Experiences of Adapting Mental Health Interventions for Autistic Adults – A Systematic Review and Thematic Synthesis

Autism is a neurodevelopmental condition which is characterized by difficulties in social interaction and social communication, as well as restricted or repetitive patterns in behaviour, interests, and activities (American Psychiatric Association, 2013). Until the last decade, autism research has focused primarily on improving outcomes for autistic children and their families (Howlin, 2021). Increasingly, however, adults are accessing and receiving autism diagnoses (Pellicano et al., 2022). Later diagnosis in adulthood is associated with poorer mental health and an overall reduced quality of life (Atherton et al., 2022). A significant proportion of autistic people[2] will experience mental health difficulties at some point throughout their lives (Hollocks et al., 2019; Lai et al., 2019; Lever & Geurts, 2016). A recent umbrella review of systematic reviews and meta-analyses found a prevalence rate of 54.8% for at least one psychiatric disorder amongst autistic adults, with anxiety and mood disorders being the most common mental health presentations (Hossain et al., 2020).

The same umbrella review by Hossain et al. (2020) found that autistic adults experienced elevated levels of suicidality. Cassidy et al. (2018) examined risk markers associated with the increased risk of suicidality and found that risk markers shared with the general population, such as non-suicidal self-injury, employment, and mental health, were significantly more prevalent for autistic adults. This study also found that an autism diagnosis

[2] The terminology used to describe people on the autism spectrum is subject to continued discussion (Botha et al., 2020; Vivanti, 2019). Recent empirical research suggests that autistic individuals tend to prefer identity first language (IFL), "autistic person", or the term "person on the autism spectrum" over person first language, "person with autism" (PFL) (Bottema-Beutel et al., 2021; Bury et al., 2020; Kenny et al., 2016). Therefore, IFL is used throughout this paper though it is acknowledged that this does not represent the preferences of all individuals on the autism spectrum.

was, in itself, an independent risk factor for suicidality, and also identified unique risk markers specifically related to autism, such as the harmful impact of camouflaging autistic traits and having unmet support needs across a number of areas including mental health care, employment, housing, and education (Cassidy et al., 2018). Evidently, there are unique factors related to autism which need to be considered in the assessment and treatment of comorbid mental health difficulties experienced by autistic adults.

The high prevalence rates of mental health difficulties and the associated significant consequences highlight a need for specific intervention or services to improve outcomes for autistic adults. However, autistic adults regularly report barriers to accessing appropriate mental health care (Brede et al., 2022; Camm-Crosbie et al., 2019; Crane et al., 2019; Petty et al., 2021). There are a number of factors which likely contribute to this difficulty. Research from the UK by Crane et al. (2016) found that young autistic adults reported poor management of transitions between youth and adult services and lengthy waiting times for mental health intervention. Autistic adults with comorbid mental health difficulties, without intellectual disability, also regularly fall between the gap of mental health services and specialist autism services (Camm-Crosbie et al., 2019). This lack of specialist care often means autistic adults are treated in generic mental health services. Young adult participants in Crane et al.'s (2016) study highlighted that they did not benefit from accessing treatment designed for a neurotypical population. This may be due to uncertainty around referral routes, difficulties with phone-based communication, sensory sensitivities in new environments, as well as the organisational demands of arranging appointments and completing homework tasks (Brede et al., 2022; Camm-Crosbie et al., 2019; Crane et al., 2019; Petty et al., 2021). One systematic review of 12 studies found that a lack of therapist knowledge of autism or therapists' unwillingness to tailor their approaches to intervention were the most commonly reported barriers to accessing psychological treatments for autistic individuals (Adams &

Young, 2021). There may even be negative consequences for autistic people in accessing and receiving mental health support which is not specifically targeted to their individual needs. A systematic review by Brede et al (2022) highlighted that the mental health support currently available can result in autistic adults feeling misunderstood or dismissed, due to their use of camouflaging, which can have a negative impact on wellbeing, relationships, and the likelihood of them engaging in future mental health supports.

These system level and clinician level barriers could be further compounded by client level factors associated with autism. For example, the social communication challenges associated with autism may make it difficult for an autistic client to accurately communicate the extent of their distress within a mental health setting (Cooper et al., 2018). The prevalence of alexithymia amongst autistic individuals (Kinnaird et al., 2019) may impact on an individuals' ability to access standard emotion focused therapies. NICE guidelines highlight that staff delivering interventions for autistic adults should have "an understanding of the core features of autism and their possible impact on the treatment of coexisting mental disorders" (National Institute for Health and Care Excellence (NICE), 2021). However, quantitative research with mental health practitioners and medical professionals highlights limited confidence, training, and comfort in providing adapted care for autistic individuals (Brookman-Frazee et al., 2012; Cooper et al., 2018).

Although there is a lack of appropriate service provision and a number of barriers to accessing services, there is a growing body of evidence that common mental health interventions (MHI) can be used effectively for autistic adults. Research demonstrates modest effect sizes for the efficacy of CBT and mindfulness in the treatment of anxiety and depression (Howlin & Magiati, 2017; Sizoo & Kuiper, 2017; White et al., 2018). A recent systematic review by Linden et al. (2022) of over 71 RCTs found that mindfulness-based interventions had a small effect on anxiety for autistic adults and a medium effect on

depression. Adaptations to standard MHI are frequently used in practice and are viewed as important by autistic people (Brice et al., 2021). There is limited research specifically focused on the impact of adaptations on MHI for autistic people. However, the same systematic review as above found that compared to non-adapted, self-directed CBT, self-directed CBT which had been adapted was more effective in reducing depression and anxiety symptoms for autistic adults (Linden et al., 2022).

In line with these findings, professional guidelines for treatment and intervention for mental health difficulties with autistic adults recommend adaptations and the individual tailoring of therapeutic support (NICE, 2021). These guidelines outline that adaptations should include:

- "a more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and 'tool boxes')
- placing greater emphasis on changing behaviour, rather than cognitions, and using the behaviour as the starting point for intervention
- making rules explicit and explaining their context
- using plain English and avoiding excessive use of metaphor, ambiguity and hypothetical situations
- involving a family member, partner, carer or professional (if the autistic person agrees) to support the implementation of an intervention
- maintaining the person's attention by offering regular breaks and incorporating their special interests into therapy if possible (such as using computers to present information)" (NICE, 2021, p.32).

There have been some efforts at characterizing adaptations for interventions used with young people on the autism spectrum. A review of 83 articles by Dickson et al. (2021) found

the most common adaptations used when tailoring CBT interventions for autistic youth with mental health difficulties were increased involvement of parents and autism specific strategies to increase engagement such as use of visuals or special interests. Changes to the content and structure were also frequently reported in order to introduce less material and reducing the length of intervention. Research which examined the use of psychosocial treatments targeting depression and anxiety symptoms in autistic adolescents and adults identified that adaptations to mindfulness interventions included eliminating poetry or metaphors and changing the length of meditations (White et al., 2018). Adaptations to CBT interventions for the same population included increased parent involvement, increased use of structure and visuals, concrete examples and language, and increased psychoeducation on emotions (White et al., 2018). Such adaptations appear appropriate and important, yet it is unclear how clinicians make decisions about how to adapt MHI for autistic adults or what impact these adaptations have on their clinical practice.

From the perspective of the autistic community, a survey of 537 autistic adults identified a number of adjustments that were deemed to be important in improving the accessibility and acceptability of mental health services (Brice et al., 2021). The adjustments identified were: adjustments to the sensory environment, such as noise and light levels, adjustments to the service context, such as length of appointments or additional information prior to appointments, and adjustments to clinician communication, such as formality of approach or clinicians understanding of autism. These are somewhat different to the adaptations recommended by NICE (2021), but reinforce the importance of modifications in improving, not just the efficacy of MHI, but also the accessibility and acceptability of interventions for autistic adults. Notably, although deemed important, autistic mental health service users reported that these adjustments were often not available in their experience of mental health care (Brice et al., 2021). Therefore, the current study aims to understand how

clinicians apply the available guidelines to their practice and what factors facilitate or impede clinicians in adapting MHI for autistic adults.

The Present Study

Based on the available research and guidelines there appears to be a consensus that adaptations are important in improving the accessibility, acceptability, and efficacy of MHI for autistic adults. However, previous research with autistic mental health service users highlights that, in practice, adaptations are frequently not available, and this is viewed as a barrier to accessing mental health support (Adams & Young, 2021; Brice et al., 2021). Given that the onus is on professionals to appropriately identify, incorporate, and develop such adaptations it is important to understand professionals' perspectives on this matter. Therefore, the current systematic review will synthesise qualitative research regarding how mental health professionals experience adapting MHI for use with autistic adults. The aim of the current review is to understand clinicians' experiences of adapting MHI for autistic adults and to specifically respond to the following research questions:

- How do clinicians experience adapting MHI for autistic adults?
- What factors facilitate professionals in adapting MHI for autistic adults?
- What challenges do professionals experience adapting MHI for autistic adults?

Methodology

This systematic review was conducted and reported with reference to PRISMA guidelines (Page et al., 2021) and in line with the ENTREQ guidelines (Tong et al., 2012). ENTREQ consists of 21 items which cover the five main areas of a qualitative systematic review: introduction, methodology, results, literature search and selection, appraisal, and data synthesis. The systematic review protocol was registered on PROSPERO on 15/06/22, registration number: CRD42022340037.

Research Question

The 'PICo' framework (Lockwood et al., 2015) for developing qualitative research questions for systematic reviews was used to formulate the research question and search strategy. In line with this framework, the *population* referred to mental health professionals including psychologists, counsellors, psychotherapists, mental health nurses, occupational therapists, social workers, and psychiatrists, the *interest* referred to the experience of adapting MHI, and the *context* was for autistic people.

Inclusion and Exclusion Criteria

Studies were included if they were qualitative and focused on the experiences of mental health professionals adapting MHI for autistic adults. Qualitative components of mixed method studies were included if qualitative results were presented as distinct from the quantitative findings. Mental health professionals could include, but was not limited to, psychologists, psychiatrists, social workers, occupational therapists, and mental health nurses.

Papers were excluded if they were primarily opinion articles, not empirical research. Studies were excluded if they explored only professionals' experiences of adapting MHI for autistic children. At the exploratory search stage, it became clear that adaptations used with adults varied sufficiently from those used with children and merited a focused qualitative synthesis. Quantitative studies were excluded as the research question is focused on clinicians' subjective experiences. Studies not available in English were also excluded.

Search Strategy

Electronic pre-planned searches were conducted across five databases: CINAHL, PsycINFO, PubMed, Scopus, and Web of Science in July 2022. The first five pages of Google Scholar and the reference lists of included articles were screened to identify any further relevant articles. An additional database search was conducted in December 2022 to identify any more recent publications. Search terms were adapted to individual databases

(Table 2.1). The search strategy was assessed by the primary researcher (Appendix B) using the Peer Review of Electronic Search Strategies (PRESS) checklist and was found to be in keeping with these guidelines (McGowan et al., 2016).

Screening Process

Once database searches were complete and all duplicates were removed using Rayyan, the primary author screened all titles and abstracts. The second author screened 20% of the titles and abstracts and any conflicts (n = 11) were resolved through discussion. The primary author then screened all remaining full texts for relevance and a third author screened 20% of these full texts. Again, conflict (n = 1) was resolved through discussion, until it was agreed that 13 papers met the criteria for inclusion in this review (Figure 2.1).

Table 2.1

Example Search Strategy for Web of Science

Search Number	Search String
#1	autism spectrum disorder OR autism OR ASD OR Asperger*
#2	Psychological therap* OR psychological intervention* OR therapy OR CBT OR DBT OR EMDR OR anxiet* or depress* OR mental health OR self harm OR suicid* OR mental health treatment* OR mental health intervention
#3	adapt* OR modif* OR adjust* OR alter*
#4	Mental health profess* OR psychologist* OR counsellor* OR psychotherapist* OR nurse* OR occupational therapist* OR psychiatrist* OR social worker
#5	#1 AND #2 AND #3 AND #4

Data Extraction

Demographic and methodological information was extracted from each study using a pre-planned data extraction table. The results section of each of the primary studies was extracted into N-Vivo to facilitate data analysis.

Data Synthesis

An inductive approach was used to develop themes and subthemes from the results sections of included studies. The extracted data was synthesised using thematic synthesis. It has been suggested that thematic synthesis can be particularly appropriate for descriptive syntheses targeted at informing policy and clinical practice (Thomas & Harden, 2008). Thematic synthesis involves three steps: line by line coding of the extracted data, developing descriptive themes, and generating analytical themes (Thomas & Harden, 2008). The results section of each included study was extracted to NVivo. In NVivo, a code was created for each line of text, with subsequent data either being assigned to a pre-existing code or given a new code where necessary. This process developed a set of 113 codes which enabled ideas within studies to be translated and synthesised across articles.

These codes were then examined for similarities and differences and grouped into descriptive themes. Groups of codes were given new codes in order to capture their meaning related to the review question. This enabled "going beyond" the content of the primary studies and the development of analytical themes which introduced new concepts and ideas, specific to the research question of the current systematic review, that had not been visible in the primary studies alone.

Results

Study Selection

A total of 791 unique studies were identified. After the screening of abstracts, 119 papers remained, and these were assessed for eligibility against the inclusion criteria. This resulted in a further 106 papers being excluded for the reasons outlined in Figure 2.1. Thirteen papers were included in the review. The demographic and methodological characteristics of these studies are outlined in Table 2.2. In total, there were 197 participants included across the 13 studies. The most frequently sampled profession was psychology,

however, counsellors (Hume, 2022; Mitran, 2022), mental health nurses (Cooper et al., 2018; Kinnaird et al., 2017; Spain et al., 2017), social workers (Cooper et al., 2018), occupational therapists (Cooper et al., 2018; Kinnaird et al., 2017; Petty et al., 2021, 2022) and psychiatrists (Heijnen-Kohl et al., 2022; Spain et al., 2017) were also represented. The majority of the studies occurred in the UK (Ainsworth et al., 2020; Cooper et al., 2018; Kinnaird et al., 2017; Petty et al., 2021, 2022; Russell et al., 2019; Siddell, 2022; Spain et al., 2017), two studies were from the USA (Maddox et al., 2020; Mitran, 2022), and there was one study each from New Zealand (Hume, 2022) and the Netherlands (Heijnen-Kohl et al., 2022).

Quality Appraisal

All studies that met the inclusion criteria were subject to quality appraisal using the Critical Skills Appraisal Programme (CASP) qualitative checklist (CASP, 2018). The CASP is a widely used 10-item checklist. Nine of the items relate to the validity and presentation of results and these items are examined in Appendix C. The studies included in this review appeared to be of a relatively high standard. However, there are limitations in the studies related to the use of convenience sampling, limited sample sizes, and the varying levels of autism specific experience held by study participants. These limitations suggest that some caution should be applied when considering the generalizability of results within the included studies. The final question of the CASP considers how valuable the research is. The majority of articles included in the current review attempt to add value to the field by making recommendations for practice or future research. No studies were excluded on the basis of quality assessment.

Results of Thematic Synthesis

Three overarching categories, consisting of 10 analytical themes, were established as a result of thematic synthesis:

- **The Unique Experience of Adapting Interventions for Autistic Adults**, which included different expectations, individual nature of adaptations, differences in communication, and attitudes towards the work.
- **Factors which Facilitate Successful Adaptations of Interventions**, which included flexibility in practice, prior experience with autism, and positive impact of other relationships.
- **Challenges in Successfully Adapting Interventions**, which included complexity of autism, limited resources, and an inflexible system.

Figure 2.1

PRISMA flow diagram

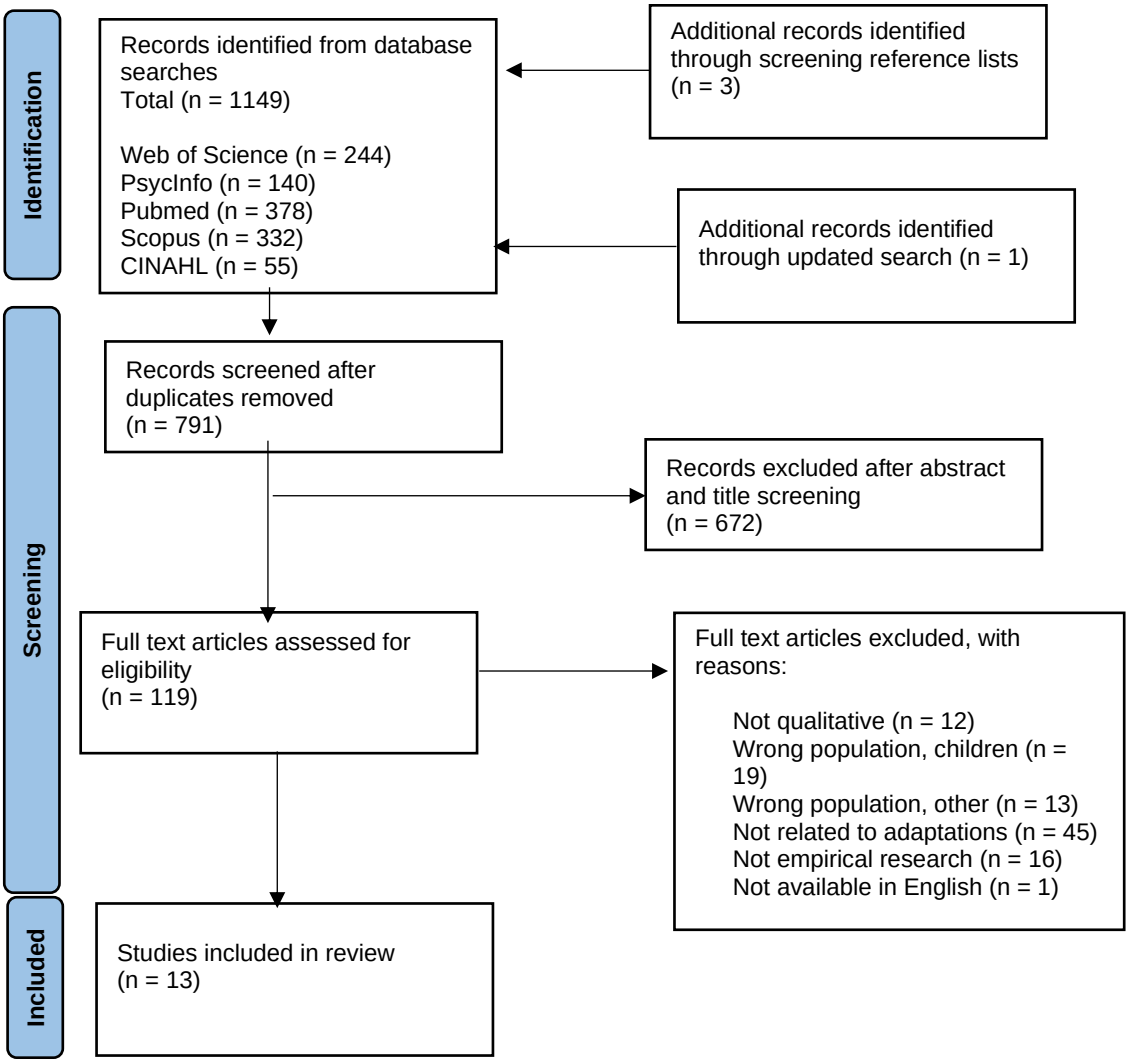


Table 2.2

Demographic and Methodological Information for Included Studies

Reference (Year), Location	Study Aims	Qualitative Data Collection Method	Data Analysis	Participants Professions (N)	Intervention	Characteristics of Intervention Recipients
Siddell (2022), UK	To explore the views of clinical psychologists working therapeutically with people with both ASD and ID, particularly in relation to accessibility and effectiveness of psychological interventions.	Semi-structured interviews	Thematic analysis	Clinical psychologists (7)	Various models of therapy including - psychodynamic, cognitive analytic therapy, person-centred, CBT and systemic	Adults with ID across South and West Yorkshire in the UK
Ainsworth et al. (2020), UK	To explore practitioners' experience of anxiety in autistic adults.	Semi-structured interviews	Thematic analysis	Clinical psychologists (6) Consultant clinical psychologist (1) Nurse practitioner (1)	Psychological therapy	Adults with ASD using an NHS adult mental health service
Mitran (2022), USA	To explore the experiences of mental health providers when working with neurodiverse clients.	Semi-structured interviews	Discourse analysis	Licensed counsellors (5)	Interventions in either a group or private practice setting with neurodiverse clients including a narrative model, EMDR, social thinking approach, human development model, curiosity, role reversal, DBT, goal oriented, proper screening, de-escalation techniques, and script responses	Neurodiverse adult counselling clients

Heijnen-Kohl et al. (2022), Netherlands	To describe what professional experts in clinical practice currently consider specific diagnostic and/or therapeutic aspects of autistic older adults.	Delphi method	Consensus analysis	Geriatric psychiatrists (2) Clinical psychologists (2) Clinical neuropsychologists (2) Mental health care psychologists (5)	Not specified	Autistic older adults
Russell et al. (2019), UK	To understand guided self-help coaches' views of a trial on the use of guided self-help for depression in autistic adults.	Semi-structured interviews	Thematic analysis	Assistant psychologists (4) Trainee clinical psychologist (1)	10 sessions of guided self-help which was based on the principles of CBT and included behavioural activation	Autistic adults with depression
Spain et al. (2017), UK	To ascertain professional perspectives about social anxiety (SA) in ASD, and to establish how, if at all, clinicians and researchers adapt their practice when working with this clinical population.	Focus groups	Thematic analysis	Adult consultant psychiatrists (5) Child and adolescent psychiatrists (2) Speciality doctors (2) Clinical psychologists (2) Trainee clinical psychologists (3) CBT therapist (1) Nurse specialist (1) Researchers (6)	Not specified	Autistic adults with social anxiety
Hume (2022), New Zealand	To take a first step toward providing more robust guidelines for relationship building between autistic adults and their healthcare professionals.	Semi-structured interviews	Creative analytic practice	Mental health counsellors (2) Clinical psychologist (1)	Counselling and psychotherapy	Autistic adults attending support services
Cooper et al. (2018), UK	To survey a sample of UK based psychological therapists, to investigate their current knowledge and past experience of working within a cognitive behavioural framework with autistic people.	Open ended questions with free text box	Quantitative content analysis	CBT therapists (50) Nursing (46%) Other core training (30%) Clinical psychologists (18%) Occupational therapy (2%) Social work (2%) No response (2%)	CBT	Autistic adults attending CBT for anxiety, depression, anger, and/or substance abuse

Maddox et al., (2020), USA	To identify barriers and facilitators to providing quality mental health care for autistic adults.	Focus groups and individual interviews	Thematic analysis	Community mental health clinicians (44)	Outpatient psychotherapy	Autistic adults
Babb et al. (2021), UK	To triangulate a more rounded understanding of autistic women's experiences of eating disorder services.	Individual interviews	Thematic analysis	Clinical psychologists (6) Psychiatrists (4) Counselling psychologist (1)	Clinical work in eating disorder services	Autistic adult women with eating disorders
Kinnaird et al. (2017), UK	To understand how clinicians approach treating comorbid anorexia and ASD, and how they adapt their typical therapeutic techniques for these patients.	Semi-structured interviews	Thematic analysis	9 clinicians including nurse therapists, CBT therapists, cognitive analytical therapist, psychotherapist, dietitian, occupational therapist	Not specified	Autistic adults with an ED attending outpatient eating disorder team
Petty et al. (2021), UK	This study sought the agreed and prioritised recommendations for adapting therapy services for autistic clients by utilising the knowledge of a specialist autism service in the UK	Freelisting – qualitative ethnographic interviewing	Freelisting analysis	Clinical psychologists (5), assistant psychologists (2), speech and language therapists (2), occupational therapist (1), senior psychotherapist (1), medical secretary (1), senior administrator (1), chief officer of clinical services (1) customer relations manager (1)	All worked in a specialist service which provided diagnostic, post-diagnostic and therapeutic services for children, young people and adults.	Not specified
Petty et al. (2022), UK	The aim of this study was to ask specialist clinicians about their individual and service-level adaptations to practice for autistic adults.	Semi-structured interviews	Thematic analysis	Clinical psychologists (4) Assistant psychologists (2) Occupational therapist (1)	All clinicians delivering therapeutic interventions for autistic adults within a specialist autism services.	Autistic adults attending specialist autism service.

Unique Experience of Delivering Adapted Interventions

Different Expectations

Within the reviewed studies, professionals described adjusting their expectations towards MHI for autistic clients (Petty et al., 2021; Russell et al., 2019; Siddell, 2022; Spain et al., 2017); "I think that this kind of, sit down 1:1 in a room, that's a classic notion of therapy and sometimes I think that's very hard…" (Siddell, 2022, p. 6). Therefore, professionals described adjusting MHI by incorporating preparatory work which often focused on emotions (Ainsworth et al., 2020; Petty et al., 2021; Spain et al., 2017). This was captured by one professional: "I think there's pre-therapeutic work to do just getting people to trust, and emotional recognition, labelling thoughts, understanding how it all links together." (Spain et al., 2017). Interventions often moved at a slower pace to allow clients to gradually build familiarity with thinking in this way (Cooper et al., 2018; Petty et al., 2021; Petty et al., 2022; Russell et al., 2019; Siddell, 2022; Spain et al., 2017).

Many of the studies also described how expectations around outcomes are different when adapting MHI for autistic clients. For example, clients may report increased symptoms, but the intervention may have been successful in enabling the client to better describe or identify symptoms (Ainsworth et al., 2020; Mitran, 2022; Siddell, 2022; Spain et al., 2017). Some participants also highlighted how difficulty generalizing outside of session and rigidity, associated with autism, can also contribute to this difficulty with measuring progress and how this changes the professionals' role (Ainsworth et al., 2020; Babb et al., 2021; Russell et al., 2019; Spain et al., 2017). For example, Spain et al (2017) detailed differences in expectations from clients: "What a change looks like in their mind, it might be 'I have to be 100% better and nothing's better until I've reached that point' but actually our whole job is pointing out the shades of grey ….." (Spain et al., 2017, p. 16). Delivering adapted MHI requires professionals to adjust their own outlook regarding the therapeutic process and the

evaluation. This finding in relation to expectations, outcomes, and evaluation of MHI for autistic adults is not considered within the available guidelines and recommendations for practice.

Individual Nature of Adaptations

There was a clear sense that appropriate adaptations are viewed as a key component of effective MHI for this client group. Adaptations were associated with more positive outcomes, more meaningful work, and improved client engagement (Ainsworth et al., 2020; Heijnen-Kohl et al., 2022; Kinnaird et al., 2017; Russell et al., 2019; Siddell, 2022). Clinicians' personal skills and experiences contributed to the particular modifications they make (Babb et al., 2021; Siddell, 2022). Some viewed a cognitive focus to adaptations as effective and appropriate (Russell et al., 2019; Spain et al., 2017), whereas others modified a CBT approach by focusing more heavily on behavioural components of intervention (Ainsworth et al., 2020; Heijnen-Kohl et al., 2022; Petty et al., 2022). Professionals describe a focus on making adaptations on an ad hoc basis dependent on the particular client in front of them, therefore adaptations can be viewed as "catered interventions to the client rather than any particular defined diagnosis of neurodiversity" (Mitran, 2022, p. 6).

An area which a number of reviewed studies highlighted was the use of special interests in order to tailor interventions and approaches to meet the individual needs of autistic clients (Ainsworth et al., 2020; Kinnaird et al., 2017; Siddell, 2022). One participant described having a "tool kit of interventions that can be customised to a particular patient" (Spain et al., 2017, p. 18). There was an overall consensus across studies that the adaptations professionals make to MHI do not take a standard format and instead are highly individualised based on the unique needs of individual clients, which is in line with NICE guidance and research with autistic mental health service users (Brice et al., 2021).

Differences in Communication

The majority of studies described how professionals adapt their own language use and communication style as part of adaptations to MHI for autistic adults. One participant reported; “it’s all about putting an autistic lens on and saying, how could I explain this differently?” (Babb et al., 2021, p. 1416). The majority of studies specifically noted adapting language by using clear, concrete, literal language and avoiding metaphors (Ainsworth et al., 2020; Cooper et al., 2018; Heijnen-Kohl et al., 2022; Kinnaird et al., 2017; Mitran, 2022; Petty et al., 2021; Siddell, 2022; Spain et al., 2017). Other communication adaptations included written diaries, communicating by phone or video and increased use of visual aids (Ainsworth et al., 2020; Cooper et al., 2018; Kinnaird et al., 2017; Spain et al., 2017).

Clients’ difficulties communicating their own distress was sometimes described as uniquely challenging (Ainsworth et al., 2020; Cooper et al., 2018; Kinnaird et al., 2017; Siddell, 2022; Spain et al., 2017). Many studies described the process of building a therapeutic relationship and facilitating the clients’ engagement as being difficult (Ainsworth et al., 2020; Babb et al., 2021; Cooper et al., 2018; Kinnaird et al., 2017). A number of studies described how facilitating relationship-building became a core component of working with autistic clients as highlighted by this quote; “This is who I am, and I’m really interested in who you are. It’s okay for you to come here and be you” (Hume, 2022, p. 157). This process required ongoing attention from professionals. Two studies noted how autistic adults’ communication styles could negatively impact professionals’ experience of the therapeutic relationship and could contribute to a wider view of the individual client as difficult or rude (Kinnaird et al., 2017; Russell et al., 2019). This finding reinforces the importance of adaptations to communication as is well documented within the available research. Here, it also highlights the impact of communication-based misunderstandings, in either direction, on the therapeutic relationship.

Attitudes towards Work

Studies reported various attitudes towards the work of adapting MHI for use with autistic clients. Three studies, in particular, highlighted how professionals experience this work as rewarding (Hume, 2022; Mitran, 2022; Siddell, 2022). These professionals described a joy and passion for their work; Hume (2022, p.157) reports: “They all expressed love for working with their autistic clients...”. There was also an acknowledgement that providing intervention for autistic clients can be emotionally affecting, sometimes due to an awareness of client’s previous negative interactions with mental health professionals (Hume, 2022).

Other studies highlighted ambivalent attitudes towards adaptations to MHI for autistic adults. Many professionals did not consciously decide to work with autistic clients and highlighted that professional interest in mental health did not necessarily include autism (Babb et al., 2021; Mitran, 2022). Professionals frequently described feeling uncertain and uninformed regarding approaches to adapting interventions for use with autistic clients which often led to fear around this work (Ainsworth et al., 2020; Kinnaird et al., 2017; Maddox et al., 2020). One participant described it as “and that could be because of unfamiliarity. That could be because of fear that you wouldn’t be able to know what to do” (Maddox et al., 2020, p. 9). This theme highlights the uncertainty experienced by professionals regarding the work of adapting MHI. It seems likely that professionals with passion for the area would be more motivated to focus on unique adaptations required by each client. This theme provides novel insights that enhance our understanding of how clinicians, in practice, experience their work adapting MHI for autistic adults.

Factors which Facilitate Successful Adaptations of Interventions

Flexibility in Practice

Most of the studies highlighted a need for flexibility from professionals when adapting interventions for autistic adult clients. Professionals placed a strong emphasis on thinking outside the box, using creative approaches to intervention work, being open minded about individual clients' experiences of specific interventions, and being willing to change practicalities around appointments such as length, time, and format (Ainsworth et al., 2020; Kinnaird et al., 2017; Mitran, 2022; Petty et al., 2021; Petty et al., 2022; Russell et al., 2019; Siddell, 2022; Spain et al., 2017). One psychologist noted "As I am talking about this I realise, oh I did that with one person and that other thing with one other person. I think it's all about thinking ultra-flexibly" (Siddell, 2022, p. 6). Many participants described the importance of taking a trial-and-error approach as there is "no hard and fast rule about which techniques work best" for this client group (Spain et al., 2017, p. 18). Professionals appeared to rely on their clinical intuition when it came to knowing when and which adaptations to use (Ainsworth et al., 2020; Siddell, 2022; Spain et al., 2017). Others emphasised the importance of creativity, resourcefulness, and using initiative in most effectively seeking information and adapting resources and techniques for the individual needs of clients (Ainsworth et al., 2020; Kinnaird et al., 2017; Mitran, 2022). Therefore, a clinician level capacity and willingness to be flexible in their practice appears to be an important facilitator to the appropriate adaptation of MHI for autistic adults, as recommended in available guidelines.

Prior Experience with Autism

The extent of professionals' previous experience and knowledge of working with autistic clients varied across the studies in this review. However, it was frequently noted that the extent of experience held by professionals contributed significantly to their comfort and

confidence with making adaptations to suit their autistic clients (Ainsworth et al., 2020; Babb et al., 2021; Kinnaird et al., 2017; Maddox et al., 2020; Mitran, 2022; Siddell, 2022). It was also acknowledged that because this is so individual to each professional, there can be significant discrepancies with the interventions offered within and between services (Ainsworth et al., 2020; Babb et al., 2021). As well as prior experience of working with autistic clients, a number of studies also highlighted the role of formal training or personal experience of autism in facilitating the successful adaptation of interventions (Maddox et al., 2020; Mitran, 2022; Petty et al., 2021; Russell et al., 2019). One study noted "All coaches described how, after receiving the training, they felt knowledgeable, confident and well prepared to deliver the intervention" (Russell et al., 2019, p. 56). This finding highlights the ability to adapt MHI for autistic adults as a skill which can develop with time and experience.

Positive Impact of Other Relationships

The majority of studies noted the importance of including important people in the client's life in interventions. This could assist clients with communication difficulties, support clients in generalizing outside of intervention sessions, and provide valuable collateral information (Ainsworth et al., 2020; Heijnen-Kohl et al., 2022; Kinnaird et al., 2017; Mitran, 2022; Petty et al., 2021; Siddell, 2022; Spain et al., 2017). Two studies highlighted almost a reliance on the involvement of others as a critical component of successful interventions with autistic clients (Ainsworth et al., 2020; Cooper et al., 2018).

A number of studies also highlighted the importance of relationships with other professionals in facilitating adapted MHI. The ability to work collaboratively and to offer and receive support was valued by professionals (Heijnen-Kohl et al., 2022; Kinnaird et al., 2017; Petty et al., 2021; Petty et al., 2022; Siddell, 2022). It was clear from a number of studies that professionals felt a strong need for support in the form of training, supervision, and

collaborative working in order to alleviate some of the burden of uncertainty and complexity that appears to be a significant component of this work (Ainsworth et al., 2020; Hume, 2022; Kinnaird et al., 2017; Maddox et al., 2020; Mitran, 2022; Russell et al., 2019; Siddell, 2022). "You might speak about some work you've done and then a colleague might say ''oh yes I did something similar'' and that makes you feel less like your off doing things on your own." (Siddell, 2022, p. 7). From a number of the studies reviewed it was clear that professionals would like collaborative working to be more common (Ainsworth et al., 2020; Kinnaird et al., 2017; Maddox et al., 2020). As noted in one study "It may be the case that increased peer support or knowledge exchange could alleviate some of the difficulties associated with having to rely on resourcefulness in this particular area of practice" (Ainsworth et al., 2020, p. 6). In some ways, the involvement of family members or supportive working relationships with colleagues appeared to alleviate some of the burden on the professional in adapting MHI. This theme reinforces the NICE guidance recommendation of involving others in interventions and draws attention to the importance of support from other professionals in facilitating clinicians to adapt MHI for autistic adults.

Challenges in Successfully Adapting Interventions

Complexity of Autism

Many studies described some difficulty with adapting MHI due to the complexity of distinguishing characteristics of autism from symptoms of mental illness. This concern about diagnostic overshadowing was a particularly prominent feature of studies which focused on interventions with autistic people with comorbid anxiety or eating disorders (Ainsworth et al., 2020; Babb et al., 2021; Kinnaird et al., 2017; Spain et al., 2017). One participant described difficulty "differentiating between anxiety relating to ASD that the client does not want to address and anxiety getting in the way of them living their life in the way they want" (Cooper

et al., 2018, p. 48). Professionals experienced this difficulty as "murky and a grey area" (Babb et al., 2021, p. 1413) which complicated their work of appropriately offering adapted interventions. Some professionals viewed clients' cognitive limitations, such as trouble concentrating, poor retention, or limited understanding, as an aspect of autism which may increase the challenges of adapting and delivering interventions (Cooper et al., 2018; Maddox et al., 2020). Only one study described the specific challenge of the impact of comorbid intellectual disability (Siddell, 2022).

Some studies described how the rigidity, black and white thinking, and focus on routine associated with autism could be challenging (Cooper et al., 2018; Kinnaird et al., 2017; Russell et al., 2019). The following quote illustrates how this can lead clinicians to worry about how the MHI will be perceived "...change makes them anxious, so I thought, 'Gosh, this whole thing is building up to this point where they have to change something'." (Russell et al., 2019, p. 62). Other studies noted how clients' sensory sensitivities could add a layer of complexity to interventions, as greater attention needs to be paid to sensory aspects of the environment (Babb et al., 2021; Cooper et al., 2018; Kinnaird et al., 2017; Maddox et al., 2020; Petty et al., 2021; Petty et al., 2022). Although many professionals were enthusiastic about involving other people in the client's life in interventions, this can also be uniquely challenging, particularly if there were discrepancies between the client's goals and the goals of the family member (Ainsworth et al., 2020; Cooper et al., 2018). This finding offers one rationale for why, in practice, clinicians may find it difficult to appropriately adapt MHI.

Limited Resources

The majority of studies indicated that professionals' ability to effectively adapt MHI was limited by a lack of external resources. A lack of training was frequently noted as a

limiting factor (Ainsworth et al., 2020; Maddox et al., 2020; Mitran, 2022; Siddell, 2022). One participant described “I don’t see myself helping that person because of my training. It would be a disservice...” (Maddox et al., 2020, p. 8), highlighting the importance of autism specific training in improving clinicians’ abilities and confidence. These studies described how mental health training often does not include a focus on adapting MHI; “… we all recognised that we really don’t have an awful lot of training, and not a lot of training in adaptation for CBT working with this group” (Ainsworth et al., 2020, p. 5). It was also noted that additional training for MDT teams and services would be helpful in facilitating colleagues, with less autism experience, to see the value of professionals approaches to adapting interventions (Kinnaird et al., 2017; Maddox et al., 2020; Siddell, 2022). Two studies identified training delivered by autistic people could be important to increase understanding (Maddox et al., 2020; Siddell, 2022).

A number of studies also emphasised how the limited evidence base regarding adapted MHI impacts professionals’ experiences of carrying out this work (Ainsworth et al., 2020; Heijnen-Kohl et al., 2022; Maddox et al., 2020; Mitran, 2022; Siddell, 2022). One participant described “a lack of research resources to draw upon, despite feeling these would be very helpful" (Ainsworth et al., 2020, p. 6). This lack of evidence-base meant professionals often needed to be more flexible, creative, and put greater time and effort into making adaptations. However, professionals often described that they had limited resources, such as time, materials, and autonomy, which made this challenging (Ainsworth et al., 2020; Cooper et al., 2018; Petty et al., 2021). This theme highlights how a lack of available resources acts as a barrier to clinicians adapting MHI for autistic adults.

An Inflexible System

Although professionals value and recognise the importance of a flexible approach, as described within the 'flexibility in practice' theme, there was evidence that this was not always valued within the services and systems in which they work. Professionals felt limited by the challenges of "working flexibly in an inflexible system" (Siddell, 2022, p. 6). This was experienced in relation to freedom to make decisions regarding appointment times, session lengths, locations, duration of intervention (Ainsworth et al., 2020; Cooper et al., 2018; Petty et al., 2021). Professionals also experienced inflexibility regarding environmental adaptations which could be useful for their autistic clients (Babb et al., 2021; Petty et al., 2021; Siddell, 2022; Spain et al., 2017). Typical mental health settings were often viewed as inappropriate: "For somewhere as busy as our clinic, having so many people, so many visitors, something like that isn't designed in a way that's friendly for ID or ASD really" (Siddell, 2022, p. 4).

Some studies highlighted how professionals experienced the rigidity of service models and policies; "But what's difficult is when there's a service model that says work in this way……and you don't know whether the person's going to fit in that or not…." (Spain et al., 2017, p. 15). Some studies highlighted how professionals questioned the suitability of services to meet the needs of their autistic clients and how this lack of flexibility contributes to significant variations in the quality of interventions (Maddox et al., 2020; Siddell, 2022; Spain et al., 2017). Some studies also emphasised that this inflexibility led to frustration for professionals (Siddell, 2022; Spain et al., 2017). These findings highlight how wider systemic factors can act as a barrier to clinicians, in practice, adapting MHI for autistic adults by limiting their capacity to provide adjustments and alterations for their clients.

Discussion

This thematic synthesis explored mental health professionals' experiences of adapting MHI for use with autistic adults. In keeping with professional guidelines, which recommend

"individual tailoring of therapeutic support" (NICE, 2021, p.32), clinicians described the process of adapting MHI as uniquely tailored to each client's needs. In line with NICE guidance, professionals highlighted their use of adaptations such as communication style, involving others, incorporation of special interests, focus on behaviour, adjustments to intervention pace, length, or duration, as well as environmental adaptations. These findings, regarding the 'individual nature of adaptations', 'differences in communication', and 'flexibility in practice', reinforces the necessity of professional guidelines and offer evidence of how these are applied. Further, the adaptations most frequently noted by professionals within the current systematic review are in keeping with research exploring autistic adults' views on factors which improve the acceptability of MHI (Brice et al., 2021; Camm-Crosbie et al., 2019; Crane et al., 2019; Horwood et al., 2021; Maddox et al., 2020). This consensus between clinicians and autistic adults offers further support for the central role of appropriate, individualised adaptations to MHI for autistic adults.

NICE guidelines also recommend involving another person to support intervention, where appropriate. Similarly, findings from the current thematic synthesis emphasize the importance of involving supportive others. Results from the current study offer a more nuanced understanding that involvement of others appears to serve a dual purpose. First, it improves accessibility for autistic clients who may struggle within a novel therapeutic setting. Second, this appears to alleviate some of the fear and uncertainty professionals experience in adapting MHI for autistic adults as a result of the complexity of autism and the limited resources available to them. Therefore, supportive input from others facilitates clinicians' abilities to adapt MHI in practice. Professionals also highlighted how their own capacity and willingness to be flexible in their approach was essential to successfully adapting interventions for their autistic clients. A systematic review by Adams and Young (2021) highlighted that therapists' unwillingness to adapt and tailor their approach to intervention

was viewed as a significant barrier by autistic adults. Given the significance of this barrier, it is encouraging that many professionals within the reviewed studies described how their training, prior experience of autism, willingness to seek feedback, and ability to adapt practical aspects of appointments enabled the appropriate adaptations required for individual clients' needs. Again, this highlights the consensus among mental health clinicians and autistic mental health service users regarding the significance of therapist flexibility and willingness to adapt their approach to MHI for autistic adults.

The novel findings from the current thematic synthesis in relation to the challenges to adapting MHI which exist in practice are particularly important. Notably, professionals within the reviewed studies varied in their attitudes towards work adapting MHI for autistic adults. Some professionals felt passionate and emotionally invested in the work. There was evidence of many professionals engaging in creative, resourceful, and reflective practice to provide individually tailored adaptations. Other professionals described feeling more ambivalent, disinterested, unsure, or even fearful of the work. (Ainsworth et al., 2020; Babb et al., 2021; Mitran, 2022). Ambivalence and limited experience likely contribute to a sense of uncertainty and fear in approaching adaptations which could, feasibly, impact the development of a therapeutic alliance, a central component of all MHI (Norcross, 2010). In Hume's (2022) study, 17 autistic adults were interviewed and emphasized the importance that autistic adult counselling clients place on the therapeutic relationship. The existence of the double empathy problem (Milton, 2012), alongside the communication differences described in the relevant subtheme, explains some of the challenge which exists in forming a therapeutic alliance. This can lead to autistic people being misperceived within mental health services which can maintain mental health difficulties despite treatment (Mitchell et al., 2021). Therefore, it is important that clinicians have a keen understanding of the challenges

and adaptations which are required to build therapeutic relationships with autistic adults to facilitate the delivery of MHI.

Professionals' feelings of fear and uncertainty are further compounded by the limited evidence base and professional guidance. Though there are emerging efforts to introduce professional guidelines on working with mental health and autism (BPS, 2021; PSI, 2022). Such guidelines are likely too recent to have had a significant impact on professionals sampled in the studies reviewed here. Many professionals also felt constrained in their approach to adapting MHI by the limited resources available to them, and a lack of autonomy to alter aspects of their professional practice while working in inflexible systems or services, which are not designed to facilitate the flexibility required by autistic adults. Some of this inflexibility may be informed by the prevalence of the medical model within many mental health services and a tendency towards attempting to fit autistic people into a neurotypical model, rather than a more neurodiverse informed approach (Mitchell et al., 2021).

Implications for Clinical Practice

Findings from the current systematic review highlight that there is an ongoing need for training for professionals working with autistic people in mental health settings. Importantly, the finding that, in practice, clinicians feel constrained when attempting to work flexibly within 'an inflexible system' reinforces the need for ongoing training and education for all involved in the delivery of MHI including the wider multidisciplinary team, management, and policy makers. This would enhance understanding regarding the level of flexibility required in the successful delivery of MHI for autistic adults. Clinicians could then be facilitated and empowered to implement the adaptations deemed important by the findings described here, in available guidelines (NICE, 2021), and by autistic people (Brice et al., 2021; Camm-Crosbie et al., 2019). It is crucial that any such training for professionals ensures that autistic people are central to the development, delivery, and evaluation processes

given their unique and critical role as autism experts (Fletcher-Watson et al., 2019; Gillespie-Lynch et al., 2017).

Given the unique challenges of the complexity of autism, the limited resources, and the inflexible systems which exist it is understandable that clinicians particularly appreciate collaborative, supportive working with other professionals. Thus, space and time for such reflective and functional working should be prioritised for clinicians whose work routinely involves the adaptation of MHI for autistic adults. This could be facilitated within particular services or across geographic areas. Such emphasis on collaborative sharing would serve to buffer against the fear, uncertainty, and ambivalence described by professionals within the reviewed studies. Consequently, this would facilitate an enhanced understanding and awareness of the unique needs of autistic clients and, ultimately, improve the efficacy of adapted MHI.

With consideration of the highly individual tailoring required, the double empathy problem, and the primary importance of autistic clients feeling understood in adapted MHI (Brice et al., 2021; Mitchell et al., 2021) clinicians, in practice, should routinely seek open discussion and feedback regarding the suitability of any adaptations. At the outset, with each client clinicians should discuss what communication, practical, sensory, or environmental adaptations might be required. During intervention, clinicians should seek feedback from their clients regarding any additional adaptations which might be appropriate. Feedback could be sought through informal discussion or through the use of an evaluative outcome measure. Given the finding from Adam & Young (2021) that therapists' unwillingness to adapt was the most significant barrier to accessing mental health support for autistic people, this open, collaborative style of working would likely be well received by autistic clients.

Strengths and Limitations

This systematic review is the first to synthesise qualitative research exploring how clinicians experience adapting MHI for autistic adults. The thematic synthesis extends research with autistic adults by Brice et al. (2021) and illustrates the factors which facilitate and challenge the application of adaptations in practice. The search strategy utilised was robust and quality checked against the PRESS guidelines (McGowan et al., 2016) which provided an additional layer of quality control. All studies, except the study by Heijnen-Kohl et al. (2022), occurred in English speaking countries and all studies have utilised a Western sample of clinicians. Therefore, it is unclear if these findings are relevant cross-culturally. The studies included in this review were heterogeneous, had different aims, utilised different analytical methods, and sampled a broad range of mental health professionals, though psychologists were over-represented. A risk that is present in all qualitative synthesis is that in merging the overall findings from qualitative studies some of the meaning of individual studies is lost (Duden, 2021). It is also important to consider the heterogenous nature of autism, which encapsulates individuals with a broad spectrum of intellectual and communicative capabilities. Only one of the included studies samples autistic people with intellectual disability and none of the studies include or reference non-verbal autistic people. Therefore, results should be interpreted with this limitation in mind.

Suggestions for Future Research

There is a limited, but growing, evidence base regarding the efficacy of MHI for autistic adults and the impact of adaptations to MHI. The majority of the evidence base regarding efficacy is focused on CBT for anxiety and depression (Linden et al., 2022). Frequently, the adaptations are described in vague terms which acts as a barrier to clinicians applying such adaptations in practice. Future studies concerned with the efficacy of MHI for autistic adults would benefit from a defined case study approach of naming and describing the specific

adaptations incorporated. As is clear from the papers included in this review, clinicians in practice are utilising a variety of approaches, such as psychodynamic, systemic, and narrative, to their intervention work with autistic people. However, CBT continues to be the main focus of efficacy research. This contributes to clinicians' uncertainty and frustration with a limited evidence base. Future research in this area should consider a wider variety of treatment models, this would ensure autistic adults are offered a selection of appropriate interventions. Research exploring adaptations to MHI for conditions apart from anxiety and depression, such as obsessive-compulsive disorder or eating disorders, which are also common amongst autistic adults (Hossain et al., 2020), would be important. The studies included in this review sampled a wide variety of mental health providers, such as psychologists, social workers, and occupational therapists, and, frequently, collated the qualitative findings across groups. Future research may benefit from a consideration of the unique perspectives and challenges within each professional discipline. This could highlight particular strengths, areas of weakness, and identify particular roles for different professions in MHI for autistic adults, particularly within multidisciplinary service contexts.

Conclusion

This systematic review synthesised the findings from 13 qualitative studies exploring mental health professionals' experiences of adapting MHI for autistic adults. Professionals viewed adaptations which were individualised and based on each clients' unique needs as central to the successful delivery of adapted MHI. Professionals viewed this work as a unique experience due to the significant need for individual tailoring, an adjustment of their expectation, differences in communication, and the complexity of autism. Although professionals agree with the views of autistic people and professional guidelines regarding the need for a tailored approach to MHI for autistic adults, in practice they felt constrained by the limited availability of resources and the challenges of inflexible systems. Many

professionals described uncertainty and fear in their attitudes towards adapting MHI, whereas others described high levels of motivation and creativity. A capacity for flexibility in practice, prior experience with autism, and supportive relationships facilitated professionals in appropriately adapting MHI. Professionals highlighted that increased guidance, evidence, and resources would facilitate their work to appropriately adapt MHI for autistic adults.

References

*Ainsworth, K., Robertson, A. E., Welsh, H., Day, M., Watt, J., Barry, F., Stanfield, A., & Melville, C. (2020). Anxiety in adults with autism: Perspectives from practitioners. *Research in Autism Spectrum Disorders*, *69*. https://doi.org/10.1016/j.rasd.2019.101457

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

Atherton, G., Edisbury, E., Piovesan, A., & Cross, L. (2022). Autism Through the Ages: A Mixed Methods Approach to Understanding How Age and Age of Diagnosis Affect Quality of Life. Journal of Autism and Developmental Disorders, 52(8), 3639–3654. https://doi.org/10.1007/s10803-021-05235-x

Adams, D., & Young, K. (2021). A Systematic Review of the Perceived Barriers and Facilitators to Accessing Psychological Treatment for Mental Health Problems in Individuals on the Autism Spectrum. *Review Journal of Autism and Developmental Disorders, 8*(4), 436–453. https://doi.org/10.1007/s40489-020-00226-7

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

Barthélémy C., Fuentes, J., Howlin, P. & Van der Gaag, R. (2019). *People with Autism Spectrum Disorders: Identification, Understanding, Intervention.* Policy Document Autism Europe. https://www.autismeurope.org

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood*, *3*(1), 18–29. https://doi.org/10.1089/aut.2020.0014

Brede, J., Cage, E., Trott, J., Palmer, L., Smith, A., Serpell, L., Mandy, W., & Russell, A. (2022). "We Have to Try to Find a Way, a Clinical Bridge" -Autistic Adults' Experience of Accessing and Receiving Support for Mental Health Difficulties: A Systematic Review and Thematic Meta-Synthesis. *Clinical Psychology Review*, *93*. https://doi.org/10.1016/j.cpr.2022.102131

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

Brookman-Frazee, L., Drahota, A., Stadnick, N., & Palinkas, L. A. (2012). Therapist Perspectives on Community Mental Health Services for Children with Autism Spectrum Disorders. *Administration and Policy in Mental Health and Mental Health Services Research*, *39*(5), 365–373. https://doi.org/10.1007/s10488-011-0355-y

Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). "It Defines Who I Am" or "It's Something I Have": What Language Do [Autistic] Australian Adults [on the Autism Spectrum] Prefer? *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04425-3

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

CASP. (2018). Qualitative Checklist. https://casp-uk.net/casp-tools-checklists/

Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, *9*(1), 42. https://doi.org/10.1186/s13229-018-02264

*Cooper, K., Loades, M. E., & Russell, A. J. (2018). Adapting Psychological Therapies for Autism – Therapist Experience, Skills and Confidence. *Research in Autism Spectrum Disorders*, *45*, 43–50. https://doi.org/10.1016/j.rasd.2017.11.002

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

Duden, G. S. (2021). Challenges to qualitative evidence synthesis – Aiming for diversity and abstracting without losing meaning. *Methods in Psychology*, *5*, 100070. https://doi.org/10.1016/j.metip.2021.100070

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, *23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts. *Frontiers in Psychology*, *8*. https://doi.org/10.3389/fpsyg.2017.00438

*Heijnen-Kohl, S. M. J., Hitzert, B., Schmidt, R., Geurts, H. M., & van Alphen, S. P. J. (2022). Features and Needs of Autistic Older Adults: A Delphi Study of Clinical Experiences. *Clinical Gerontologist*, 1–11. https://doi.org/10.1080/07317115.2022.2060157

Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: A systematic review

and meta-analysis. *Psychological Medicine*, *49*(4), 559–572. https://doi.org/10.1017/S0033291718002283

Horwood, J., Cooper, K., Harvey, H., Davies, L., & Russell, A. (2021). The experience of autistic adults accessing adapted cognitive behaviour therapy: ADEPT (Autism Depression Trial) qualitative evaluation. *Research in Autism Spectrum Disorders*, *86*, 101802. https://doi.org/10.1016/j.rasd.2021.101802

Hossain, M. M., Khan, N., Sultana, A., Ma, P., McKyer, E. L. J., Ahmed, H. U., & Purohit, N. (2020). Prevalence of comorbid psychiatric disorders among people with autism spectrum disorder: An umbrella review of systematic reviews and meta-analyses. *Psychiatry Research*, *287*, 112922. https://doi.org/10.1016/j.psychres.2020.112922

Howlin, P. (2021). Adults with Autism: Changes in Understanding Since DSM-111. *Journal of Autism and Developmental Disorders*, *51*(12), 4291–4308. https://doi.org/10.1007/s10803-020-04847-z

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: Outcomes in adulthood. *Current Opinion in Psychiatry*, *30*(2), 69–76. https://doi.org/10.1097/YCO.0000000000000308

*Hume, R. (2022). Show Me the Real You: Enhanced Expression of Rogerian Conditions in Therapeutic Relationship Building with Autistic Adults. *Autism in Adulthood*, *4*(2), 151–163.

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

*Kinnaird, E., Norton, C., & Tchanturia, K. (2017). Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: A qualitative study. *BMC Psychiatry*, *17*(1), 292. https://doi.org/10.1186/s12888-017-1455-3

Kinnaird, E., Stewart, C., & Tchanturia, K. (2019). Investigating alexithymia in autism: A systematic review and meta-analysis. *European Psychiatry*, *55*, 80–89. https://doi.org/10.1016/j.eurpsy.2018.09.004

Lai, M.-C., Kassee, C., Besney, R., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry*, *6*(10), 819-829. https://doi.org/10.1016/S2215-0366(19)30289-5

Lever, A. G., & Geurts, H. M. (2016). Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *46*(6), 1916–1930. https://doi.org/10.1007/s10803-016-2722-8

Linden, A., Best, L., Elise, F., Roberts, D., Branagan, A., Tay, Y. B. E., Crane, L., Cusack, J., Davidson, B., Davidson, I., Hearst, C., Mandy, W., Rai, D., Smith, E., & Gurusamy, K. (2022). Benefits and harms of interventions to improve anxiety, depression, and other mental health outcomes for autistic people: A systematic review and network meta-analysis of randomised controlled trials. *Autism: The International Journal of Research and Practice*. https://doi.org/10.1177/13623613221117931

Lockwood, C., Munn, Z., & Porritt, K. (2015). Qualitative research synthesis: Methodological guidance for systematic reviewers utilizing meta-aggregation. *International Journal of Evidence-Based Healthcare*, *13*(3), 179–187. https://doi.org/10.1097/XEB.0000000000000062

*Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., Nicolaidis, C., & Mandell, D. S. (2020). "I Wouldn't Know Where to Start": Perspectives from Clinicians, Agency Leaders, and Autistic Adults on Improving Community Mental Health Services for Autistic Adults. *Autism: The International Journal of Research and Practice*, *24*(4), 919–930. https://doi.org/10.1177/1362361319882227

McGowan, J., Sampson, M., Salzwedel, D. M., Cogo, E., Foerster, V., & Lefebvre, C. (2016). PRESS Peer Review of Electronic Search Strategies: 2015 Guideline Statement. *Journal of Clinical Epidemiology*, *75*, 40–46. https://doi.org/10.1016/j.jclinepi.2016.01.021

Milton, D. E. M. (2012). On the ontological status of autism: The 'double empathy problem.' *Disability & Society*, *27*(6), 883–887. https://doi.org/10.1080/09687599.2012.710008

Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. *British Journal of Developmental Psychology*, *39*(1), 1–18. https://doi.org/10.1111/bjdp.12350

*Mitran, C. (2022). Experiences of Licensed Counselors and Other Licensed Mental Health Providers Working with Neurodiverse Adults: An Instrumental Case Study. *The Family Journal.* https://doi.org/10.1177/10664807221104138

Moss, P., Howlin, P., Savage, S., Bolton, P., & Rutter, M. (2015). Self and informant reports of mental health difficulties among adults with autism findings from a long-term follow-up study. *Autism*, *19*(7), 832–841. https://doi.org/10.1177/1362361315585916

National Institute for Health and Care Excellence (NICE). (2021). *Autism spectrum disorder in adults: Diagnosis and management*. https://www.nice.org.uk/guidance/cg142

Norcross, J. C. (2010). The therapeutic relationship. In B. L. Duncan, S. D. Miller, B. E. Wampold, & M. A. Hubble (Eds.), *The heart and soul of change: Delivering what*

works in therapy (pp. 113–141). American Psychological Association. https://doi.org/10.1037/12075-004

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *Systematic Reviews*, *10*(1), 89. https://doi.org/10.1186/s13643-021-01626-4

Pellicano, E., Fatima, U., Hall, G., Heyworth, M., Lawson, W., Lilley, R., Mahony, J., & Stears, M. (2022). A capabilities approach to understanding and supporting autistic adulthood. *Nature Reviews Psychology*, 1–16. https://doi.org/10.1038/s44159-022-00099-z

*Petty, S., Bergenheim, M.-L., Mahoney, G., & Chamberlain, L. (2021). Adapting services for autism: Recommendations from a specialist multidisciplinary perspective using freelisting. *Current Psychology*. https://doi.org/10.1007/s12144-021-02061-3

*Petty, S., Donaldson, C., Whetton, J., & Baxter, N. (2022). Recommended adaptations to therapy services for autistic adults from specialist clinicians. *Current Psychology*. https://doi.org/10.1007/s12144-022-04034-6

*Russell, A., Gaunt, D., Cooper, K., Horwood, J., Barton, S., Ensum, I., Ingham, B., Parr, J., Metcalfe, C., Rai, D., Kessler, D., & Wiles, N. (2019). Guided self-help for depression in autistic adults: The ADEPT feasibility RCT. *Health Technology Assessment*, *23*(68), 1–94.

*Siddell, P. (2022). Psychologists' views on the accessibility and effectiveness of psychological therapies for people with intellectual disabilities and autism. *Advances*

in Mental Health and Intellectual Disabilities, *16*(3), 147-156. https://doi.org/10.1108/AMHID-11-2021-0041

Sizoo, B. B., & Kuiper, E. (2017). Cognitive behavioural therapy and mindfulness based stress reduction may be equally effective in reducing anxiety and depression in adults with autism spectrum disorders. *Research in Developmental Disabilities*, *64*, 47–55. https://doi.org/10.1016/j.ridd.2017.03.004

* Spain, D., Rumball, F., O'Neill, L., Sin, J., Prunty, J., & Happé, F. (2017). Conceptualizing and Treating Social Anxiety in Autism Spectrum Disorder: A Focus Group Study with Multidisciplinary Professionals. *Journal of Applied Research in Intellectual Disabilities*, *30*(S1), 10–21. https://doi.org/10.1111/jar.12320

The British Psychological Society. (2021). *Working with autism: Best practice guidelines for psychologists*. The British Psychological Society. https://www.bps.org.uk/psychologist/working-autism

The Psychological Society of Ireland (2022). *Professional Practice Guidelines for the Assessment, Formulation, and Diagnosis of Autism in Children and Adolescents. The Psychological Society of Ireland.* https://www.psychologicalsociety.ie/source/PSI%20Autism%20Guidelines%202022%20(Interactive%20Version).pdf

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(1), 45. https://doi.org/10.1186/1471-2288-8-45

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, *12*(1), 181. https://doi.org/10.1186/1471-2288-12-181

White, S. W., Simmons, G. L., Gotham, K. O., Conner, C. M., Smith, I. C., Beck, K. B., & Mazefsky, C. A. (2018). Psychosocial treatments targeting anxiety and depression in adolescents and adults with autism spectrum disorder: Review of the latest research and recommended future directions. *Current Psychiatry Reports, 20*(10), 82. https://doi.org/10.1007/s11920-018-0949-0

Chapter Three: Systematic Review Extended Methodology

This chapter expands on methodological considerations of the systematic review which could not be included in the systematic review paper which was prepared for a peer reviewed journal. This chapter also provides additional context and rationale for decision making that occurred as part of the design and implementation of the systematic review process.

Development of the Research Question

A number of scoping searches were conducted in order to develop a general oversight of the available literature regarding autism in adults, healthcare, maternity care specifically, and the female experience of autism. Initially, given the topic of my major research project, I was primarily interested in maternity care specifically. However, as will be described in greater detail in Chapter Four, there is a paucity of research exploring autistic adults' experiences of pregnancy and parenthood and a comprehensive, recent systematic review exists which details findings in this area (McDonnell & DeLucia, 2021).

Therefore, I needed to widen my search terms in order to consider alternative, related concepts. A number of avenues of inquiry were considered including: adult females experiences of accessing and receiving diagnoses, autistic adults' or autistic women's experiences of accessing healthcare services, autistic adults' or autistic women's experiences of accessing mental health services, and interventions to improve healthcare access for autistic people. By conducting these scoping searches and reviewing the relevant literature I discovered a number of recent reviews covering these topics that had been completed or were prospectively registered on PROSPERO (Adams & Young, 2021; Dickson et al., 2021; Gellini & Marczak, 2023; Walsh et al., 2020; Walsh et al., 2021). This proliferation of systematic reviews related to autistic adults is indicative of the increasing emphasis on the

need for additional understanding of the experiences of autistic adults (Howlin, 2021; Pellicano, 2022).

In the process of conducting these searches and reviewing relevant literature I became increasingly aware of the challenges faced by autistic people in accessing appropriate, adapted mental health interventions (MHI). A gap within the available research was identified in relation to mental health professionals' experiences of providing adapted MHI for autistic adults. Considerable evidence demonstrates the efficacy of appropriate adaptations in improving the accessibility and acceptability of MHI for autistic people (Adams & Young, 2021; Dickson et al., 2021) and guidelines exist to aid professionals in making adaptations to their practice (NICE, 2021). However, research with autistic people has found that, in practice, adaptations are not widely available, and this acts as a barrier to accessing mental health services (Adams & Young, 2021; Brice et al, 2021). Therefore, it is important to understand mental health professionals' experiences of adapting and delivering MHI for autistic adults and this was the question that was formulated for the current systematic review.

As I was interested in exploring mental health professionals' first-hand experiences of adapting MHI for autistic adults the review was designed as an experiential, qualitative review and the question was formulated according to the 'PICo' format (Lockwood et al., 2015) as described in Chapter Two.

Rationale for Thematic Synthesis

Systematic reviews follow a structured approach to the search, collation, and critical analysis of the best available research regarding a specific clinical question (Munn et al., 2018). In this way, systematic reviews are seen as the most valid and reliable evidence base to inform clinical practice and decision making (Aromataris & Pearson, 2014). Originally, the

primary focus of systematic reviews was examining the efficacy of interventions by comparing and summarizing the results of randomized controlled trials using meta-analysis as the means of quantitative data synthesis (Munn et al., 2018). Over time, the methods and range of questions appropriate for systematic reviews has expanded to include qualitative research synthesis (Armoataris & Pearson, 2014; Lockwood et al., 2015).

Qualitative reviews tend to focus on the perspectives of individuals interacting with interventions (Munn et al., 2018) and, therefore, a qualitative focus appeared most appropriate in understanding mental health professionals' experiences of adapting MHI for autistic adults. Further, it has been suggested that qualitative reviews are an important tool in exploring and understanding why specific interventions are not practice or adopted in spite of the available evidence (Pearson, 2004). This appeared particularly relevant to the research question that was developed, considering the availability of NICE guidelines on adaptations to MHI and the findings that, in practice, autistic people report adaptations are often unavailable (Adams & Young 2021, Brice et al., 2021).

Qualitative systematic reviews collate the findings from primary qualitative research studies in order to provide rich interpretations and understandings of individuals' and groups' experiences, views, and priorities for healthcare (Flemming & Noyes, 2021). Qualitative healthcare research has a significant impact on policy design and implementation (Newman, 2006), which was deemed particularly relevant to the topic and question of the current systematic review. In comparison to the methods which exist for quantitative data synthesis, namely meta-analysis or narrative synthesis, a wide range of approaches for the synthesis of qualitative research has developed over time (Barnett-Page & Thomas, 2009).

Thematic synthesis (Thomas & Harden, 2008) was the chosen method for the current qualitative systematic review for several reasons. Thematic synthesis combines elements of

meta-ethnography and grounded theory and was developed specifically to address questions relating to healthcare interventions (Barnett-Page & Thomas, 2009). In comparison to the objective idealism epistemology shared by meta-ethnography and grounded theory, thematic synthesis appears to have more grounding in critical realism (Barnett-Page & Thomas, 2009).

Although both grounded theory and meta-ethnography are interpretative, it is more readily apparent in thematic synthesis that interpretation mediates our knowledge of reality, and this contributes to the ease with which findings from thematic synthesis can be applied in practice. For example, findings reported in Chapter Two highlight that clinicians' perceptions of inflexible systems impact their ability to appropriately adapt MHI for autistic adults. Furthermore, although third order interpretations in meta-ethnography and analytical themes in thematic synthesis both allow the researcher to "go beyond" the results of original studies, the analytical themes of thematic synthesis are more appropriate in addressing specific review questions to inform policy or practice (Thomas & Harden, 2008). Whereas meta-ethnography is deemed to be more appropriate in the development of a theory (Thomas & Harden, 2008) and requires studies with "rich, thick" data (Noyes et al., 2018). An initial exploratory review of the relevant literature suggested the presence of a mixture of "thick" and "thin" studies, which is another reason why thematic synthesis was selected in line with recommendations from Noyes et al. (2018).

Identifying Studies for Inclusion

The search strategy and study selection process for this systematic review was designed in line with PRISMA guidelines (Appendix D) and this process is outlined in Figure 2.1, Chapter Two.

Search Strategy

As described above, the process of developing a search strategy began with a number of scoping searches. Search terms were decided on following these initial scoping searches and in consultation with research supervisors and a university subject librarian. CINAHL, PsycINFO, PubMed, Scopus, and Web of Science were selected as databases to ensure studies contained across a number of databases could be identified. The first five pages of Google Scholar were also reviewed in order to identify grey literature. Although it is acknowledged that Google Scholar alone is not sufficient in the identification of grey literature for systematic reviews (Haddaway et al., 2015), this limit was decided on in the context of time and resource constraints. Final studies for inclusion were identified in July 2022 by searching the relevant databases and screening the reference lists of included studies.

Further, McGowan et al. (2016) developed an evidence-based guideline for peer review of electronic search strategies (PRESS) for systematic reviews. Peer review was not possible, owing to time and resource constraints. However, I reviewed my search strategy against the PRESS guidelines (Appendix B) in order to enhance the quality and comprehensiveness of the search. Through this process, and in consultation with supervisors, I identified that my keywords related to ‘psychological therapy’, ‘psychological intervention’, ‘therapy’, ‘mental health treatment’, and ‘mental health intervention’ were too broad. Therefore, searches were not identifying studies with a more specific focus such as ‘CBT’ or ‘anxiety’. Search terms were updated to reflect this. An example of the search strategy for Web of Science is presented in Chapter Two. Additional database searches are presented in Appendix E. No limits or filters were placed on searches within databases to ensure all potentially relevant studies were identified.

Quality Appraisal

A key aspect of both quantitative and qualitative systematic reviews is the quality appraisal of the available evidence to be included for review (Noyes et al., 2018). However, the value of appraising qualitative research is debated and the methods for quality appraisal are less developed and standardized compared to appraisal methods for quantitative research (Long et al., 2020). Quality appraisal is warranted given the role of qualitative research in informing policy and practice (Long et al., 2020). As described in Chapter Two and evidenced in Appendix C, the decision was made to use the CASP checklist (CASP, 2018) for quality appraisal of studies included in this systematic review. CASP is the most recommended and used method for the appraisal of qualitative research in published systematic reviews (Noyes et al., 2018). In line with Cochrane guidance, a scoring system was not used to determine inclusion or exclusion based on quality appraisal. Instead, the quality appraisal was discussed with research supervisors and consideration was given to how any methodological limits might impact overall findings (Noyes et al., 2018).

Data Extraction

Following guidance from Noyes et al. (2011), I developed a data extraction tool (Appendix F), to extract the key demographic and methodological information from relevant studies. This initial process of data extraction involved extracting information regarding study design, sample characteristics, types of interventions used, as well as the key themes and results from qualitative papers in order to begin to develop an overview of findings across papers. As described in Chapter Two, the full results sections from each paper were also extracted into N-Vivo. This inclusive, comprehensive process of data extraction is recommended by Thomas and Harden (2008) and represents the first stage in thematic synthesis.

Thematic Synthesis

Following the process of thematic synthesis described by Thomas and Harden (2008), each line of the results sections of each study was coded according to meaning and content by the primary researcher (LM). This was an iterative process where, initially, codes were created based on the line-by-line coding of the first text and translated across subsequent texts. However, where new codes were identified, previously coded texts were reviewed in order to ensure identification of all relevant codes across texts. Coding was conducted using N-Vivo and an example of the coding process is presented in Appendix G. A section of coding was reviewed by a second researcher (FL) in order to ensure transparency and comprehensiveness.

This process of coding resulted in the production of 113 codes. These codes were collated by the primary researcher and similarities and differences between codes were considered. This resulted in an initial grouping of codes into 'descriptive themes'. These descriptive themes were then reviewed and discussed by all three researchers (LM, FL, SF). This process resulted in 13 descriptive themes. An example of a descriptive theme and the relevant codes are presented in Appendix H.

The third and final step in thematic synthesis is the development of 'analytical themes' which "go beyond" the findings of the original studies (Thomas & Harden, 2008). Analytical themes were identified by considering the descriptive themes, identified in step two, in the context of the question regarding mental health professionals' experiences of delivering adapted mental health interventions for autistic adults and considering the implications for clinical practice. This involved iterative interpretation of the descriptive themes and conversations with the research team in order to refine themes. This process resulted in three overall analytical themes with a number of subthemes, as described within the systematic review chapter.

Transparency in Reporting

As noted in Chapter Two, the systematic review was conducted and reported according to the PRISMA checklist (Moher et al., 2009). The PRISMA statement for this systematic review is presented in Appendix D. The review was also reported in line with Enhancing Transparency in Reporting the Synthesis of Qualitative Research Guidelines (ENTREQ). These guidelines aim to improve the explicit and comprehensive reporting of qualitative systematic reviews (Tong et al., 2012). The ENTREQ statement for the systematic review is presented in Appendix I.

References

Adams, D., & Young, K. (2021). A Systematic Review of the Perceived Barriers and Facilitators to Accessing Psychological Treatment for Mental Health Problems in Individuals on the Autism Spectrum. *Review Journal of Autism and Developmental Disorders*, *8*(4), 436–453. https://doi.org/10.1007/s40489-020-00226-7

Aromataris, E., & Pearson, A. (2014). The Systematic Review: An Overview. *AJN, American Journal of Nursing*, *114*(3), 53–58. https://doi.org/10.1097/01.NAJ.0000444496.24228.2c

Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: A critical review. *BMC Medical Research Methodology*, *9*(1), 59. https://doi.org/10.1186/1471-2288-9-59

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

CASP. (2018). Qualitative Checklist. https://casp-uk.net/casp-tools-checklists/

Dickson, K. S., Lind, T., Jobin, A., Kinnear, M., Lok, H., & Brookman-Frazee, L. (2021). Correction to: A Systematic Review of Mental Health Interventions for ASD: Characterizing Interventions, Intervention Adaptations, and Implementation Outcomes. *Administration and Policy in Mental Health and Mental Health Services Research*, *48*(5), 884–908. https://doi.org/10.1007/s10488-021-01144-4

Flemming, K., & Noyes, J. (2021). Qualitative Evidence Synthesis: Where Are We at? *International Journal of Qualitative Methods*, *20*, 160940692199327. https://doi.org/10.1177/1609406921993276

Gellini, H., & Marczak, M. (2023). "I Always Knew I Was Different": Experiences of Receiving a Diagnosis of Autistic Spectrum Disorder in Adulthood—a Meta-Ethnographic Systematic Review. *Review Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s40489-023-00356-8

Haddaway, N. R., Collins, A. M., Coughlin, D., & Kirk, S. (2015). The Role of Google Scholar in Evidence Reviews and Its Applicability to Grey Literature Searching. *PLOS ONE*, *10*(9), e0138237. https://doi.org/10.1371/journal.pone.0138237

Howlin, P. (2021). Adults with Autism: Changes in Understanding Since DSM-111. *Journal of Autism and Developmental Disorders*, *51*(12), 4291–4308. https://doi.org/10.1007/s10803-020-04847-z

Lockwood, C., Munn, Z., & Porritt, K. (2015). Qualitative research synthesis: Methodological guidance for systematic reviewers utilizing meta-aggregation. *International Journal of Evidence-Based Healthcare*, *13*(3), 179–187. https://doi.org/10.1097/XEB.0000000000000062

Long, H. A., French, D. P., & Brooks, J. M. (2020). Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences*, *1*(1), 31–42. https://doi.org/10.1177/2632084320947559

McDonnell, C. G., & DeLucia, E. A. (2021). Pregnancy and Parenthood Among Autistic Adults: Implications for Advancing Maternal Health and Parental Well-Being. *Autism in Adulthood*, *3*(1), 100–115. https://doi.org/10.1089/aut.2020.0046

McGowan, J., Sampson, M., Salzwedel, D. M., Cogo, E., Foerster, V., & Lefebvre, C. (2016). PRESS Peer Review of Electronic Search Strategies: 2015 Guideline Statement. *Journal of Clinical Epidemiology*, *75*, 40–46. https://doi.org/10.1016/j.jclinepi.2016.01.021

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & for the PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *BMJ*, *339 21*(1), b2535–b2535. https://doi.org/10.1136/bmj.b2535

Munn, Z., Stern, C., Aromataris, E., Lockwood, C., & Jordan, Z. (2018). What kind of systematic review should I conduct? A proposed typology and guidance for systematic reviewers in the medical and health sciences. *BMC Medical Research Methodology*, *18*(1), 5. https://doi.org/10.1186/s12874-017-0468-4

Newman, M. (2006). Helping practitioners understand the contribution of qualitative research to evidence-based practice. *Evidence-Based Nursing*, *9*(1), 4–7. https://doi.org/10.1136/ebn.9.1.4

National Institute for Health and Care Excellence (NICE). (2021). *Autism spectrum disorder in adults: Diagnosis and management*. https://www.nice.org.uk/guidance/cg142

Noyes, J., Booth, A., Cargo, M., Flemming, K., Garside, R., Hannes, K., Harden, A., Harris, J., Lewin, S., Pantoja, T., & Thomas, J. (2018). Cochrane Qualitative and Implementation Methods Group guidance series—paper 1: Introduction. *Journal of Clinical Epidemiology*, *97*, 35–38. https://doi.org/10.1016/j.jclinepi.2017.09.025

Noyes, J., Booth, A., Flemming, K., Garside, R., Harden, A., Lewin, S., Pantoja, T., Hannes, K., Cargo, M., & Thomas, J. (2018). Cochrane Qualitative and Implementation Methods Group guidance series—paper 3: Methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *Journal of Clinical Epidemiology*, *97*, 49–58. https://doi.org/10.1016/j.jclinepi.2017.06.020

Noyes J & Lewin S. Chapter 5: Extracting qualitative evidence. In: Noyes J, Booth A, Hannes K, Harden A, Harris J, Lewin S, Lockwood C (editors), *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions*. Version 1 (updated August 2011). Cochrane Collaboration Qualitative Methods Group, 2011. Available from URL http://cqrmg.cochrane.org/supplemental-handbook-guidance

Pearson, A. (2004). Balancing the evidence: Incorporating the synthesis of qualitative data into systematic reviews. *JBI Reports*, *2*(2), 45–64. https://doi.org/10.1111/j.1479-6988.2004.00008.x

Pellicano, E., Fatima, U., Hall, G., Heyworth, M., Lawson, W., Lilley, R., Mahony, J., & Stears, M. (2022). A capabilities approach to understanding and supporting autistic adulthood. *Nature Reviews Psychology*, *1*(11), 624–639. https://doi.org/10.1038/s44159-022-00099-z

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, *8*(1), 45. https://doi.org/10.1186/1471-2288-8-45

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, *12*(1), 181. https://doi.org/10.1186/1471-2288-12-181

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

Walsh, C., O'Connor, P., Walsh, E., & Lydon, S. (2021). A Systematic Review of Interventions to Improve Healthcare Experiences and Access in Autism. *Review Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s40489-021-00279-2

Chapter Four: Major Research Project

Understanding the Experiences of Receiving and Providing Maternity Care for Autistic Mothers.

Authors:

Laura Moore, University College Cork, Psychology Department, Cork, Ireland

(corresponding author e-mail: 120224736@umail.ucc.ie)

Dr Sarah Foley, University College Cork, Psychology Department, Cork, Ireland

Dr Fionnuala Larkin, University College Cork, Psychology Department, Cork, Ireland

Manuscript has been prepared in accordance with author guidelines for the journal *Autism* (Appendix J).

Abstract

Background: Available research suggests autistic mothers experience greater dissatisfaction with maternity care compared to non-autistic mothers. Limited research exists exploring autistic mothers' experiences of maternity care and no research to date has considered maternity care professionals' experiences of delivering care to autistic mothers. *Aim:* This qualitative study aims to explore the experiences of receiving and providing maternity care for autistic mothers. *Method:* Data was collected using semi-structured interviews with four autistic mothers and four midwives. Data was analysed using Multiperspectival Interpretative Phenomenological Analysis. *Results:* Three overarching themes emerged: 'the challenge of autism within maternity care', 'the importance of the caring relationship', and 'the challenge of navigating competing demands and priorities'. *Conclusion:* Findings highlight the unique challenges experienced by autistic mothers during labour and birth, the need for increased autism awareness in midwifery, and further suggest universal changes to the delivery of maternity care for all, which would likely have additional benefit for autistic women.

Introduction

Becoming a parent is a significant developmental stage in the life course and is associated with a range of physical, psychological, social, and spiritual changes (Athan & Reel, 2015). As well as being a source of purpose, meaning, and positive emotion, parenthood is also associated with emotional and psychosocial stress and strain (Nelson et al., 2014). The perinatal period (beginning in pregnancy and lasting up to 1 month post birth), in particular, has been identified as a critical stage for a range of maternal and infant health, functional, and wellbeing outcomes (Misra et al., 2003). Yet, despite calls for the prioritisation of research on women and girls by the autism community (Pellicano et al., 2014), and the increase in women being diagnosed with autism (Loomes et al., 2017), there remains a limited body of research exploring the experience of the perinatal period for women on the autism spectrum.

Autism and the Perinatal Period

A recent systematic review identified thirteen studies which examined the concepts of parenthood and/or pregnancy with autistic samples (McDonnell & DeLucia, 2021). Seven of these studies pertained to the perinatal period in particular. One epidemiological study found evidence that autistic mothers are at greater risk of preterm births and caesarean delivery and indicated a need for individualised care for this group (Sundelin et al., 2018). A quantitative study by Pohl et al. (2020) compared the perinatal experiences of autistic mothers and non-autistic mothers and found that autistic mothers reported greater incidence of antenatal and postnatal depression. They also reported increased levels of anxiety and isolation, and difficulty seeking support. In a comparative study conducted in the UK, Hampton et al. (2022) found that a sample of 27 autistic women scored higher than a similar sample of non-autistic women on measures of stress, anxiety, and depression across three time points of the

perinatal period. As such, the research to date indicates that autistic people may have unique experiences and challenges around parenting and pregnancy which warrant further research.

Challenges in the Perinatal Period for Autistic Mothers

Despite the limited nature of the available research, two clear themes have emerged regarding the specific challenges of the perinatal period for autistic people. A number of studies have found that the sensory aspects of pregnancy and childbirth can be challenging (Donovan et al., 2020; Gardner et al., 2016; Hampton et al., 202; Rogers et al., 2016). Most of these studies noted that autistic people felt as though their pre-existing sensory processing issues, a characteristic of autism (Crane et al., 2009), were heightened during pregnancy and that this could lead to sensory overload (Hampton et al., 2021).

Difficulties with communication and interactions with professionals is the second major theme emerging from research with autistic people during the perinatal period. Quantitative findings from Pohl et al. (2020) highlight that in comparison to non-autistic mothers, autistic mothers reported greater dissatisfaction with their communication with healthcare professionals during pregnancy. In a wider study of health communication with autistic women, Lum et al. (2014) included five items in relation to maternal healthcare communication. This study found that autistic adults reported dissatisfaction with information and support services provided in pregnancy and greater difficulty with communicating around pain, concerns, or needs during childbirth (Lum et al., 2014). This implies that there are specific communication difficulties within the relationship between autistic mothers and maternity care professionals (MCPs), which warrant further exploration.

To date, the qualitative research regarding the perinatal period for autistic women has been limited to individual case study approaches (Rogers et al., 2017), a qualitative analysis of pre-existing blogs (Litchman et al., 2019), secondary analysis of online Aspergers support

groups (Gardner et al., 2016), an interpretative descriptive account of autistic mothers' childbirth experiences in an acute setting (Donovan, 2017), and a thematic analysis of 21 autistic mothers' experiences of pregnancy, postnatal support, and parenting (Hampton et al., 2021). These studies substantiate findings from quantitative research and go some way to highlighting the importance of communication and relationships with healthcare professionals in a maternity care context. For example, the mother interviewed for Rogers et al. (2017) case study described the experience of not being listened to; "No matter how many times I tried to explain that what they were doing was aggravating the Asperger's Syndrome because the hospital was stressing me out, they would not listen" (p.92). Findings from these studies also highlight the importance autistic mothers place on being able to build a relationship with MCPs (Donovan, 2017; Gardner et al., 2016; Hampton et al., 2021).

However, none of the currently available research explores how this caring relationship and interactions with MCPs are subjectively experienced by people on the autism spectrum or focuses on the lived experience of maternity care as an autistic mother. Given the finding, within a neurotypical population, that women who felt 'very well' looked after in the perinatal period are likely to experience improved postnatal functioning (Michels et al., 2013), it is imperative that this experience of maternity care is understood for autistic women, specifically.

Maternity Care Professionals' and Autism

Furthermore, there is a significant lack of research focusing on MCPs knowledge, awareness, or ability in providing maternity care for autistic people (Hampton et al., 2021). Evidence from the intellectual disability literature highlights that MCPs report lacking the awareness or training to be able to provide suitable maternity care for people with intellectual disabilities (Castell & Stenfert Kroese, 2016; Homeyard et al., 2016). Within the autism field,

research with other groups of healthcare professionals, including GPs, nurses, and allied health professionals, has identified that professionals report lacking the necessary training, skills, or tools to effectively provide care for autistic people (Morris et al., 2019; Urbanowicz et al., 2020; Zerbo et al., 2015). One systematic review analysed 35 studies from different countries with healthcare workers from different professional backgrounds and found that professionals reported only low to moderate knowledge of autism (Corden et al., 2021). Another study with GPs in the UK identified that although GPs had good knowledge of autism, they had limited confidence in their ability to identify and appropriately manage autistic patients (Unigwe et al., 2017).

This lack of confidence and self-efficacy likely contributes to the interaction difficulties which have been noted as a barrier for autistic people accessing healthcare services (Dern & Sappok, 2016). One study found that autistic people perceive a lack of autism knowledge among healthcare professionals and that it is a healthcare professional's knowledge, attitudes, and skills which determine the success of interactions (Nicolaidis et al., 2015). These findings are supported within a maternity context. For example, one mother from Hampton et al. (2021) study expressed her concern that, in her experience, professionals' autism awareness was developed through informal avenues; "I just thought that was the most awful thing, that reality TV is educating people who have the power to possibly take my child away from me." (Hampton et al., 2021, p.7). Furthermore, masking, which is a well-documented characteristic of autism, particularly in females, may lead to service providers or professionals underestimating the healthcare needs of this group (Tint & Weiss, 2018). A survey of 355 autistic mothers found that 80% worried about disclosing an autism diagnosis to healthcare professionals and 40% rarely or never disclosed due to the perception of stigma and fear of judgment (Pohl et al., 2020). The prevalence of masking, as well as the perception of stigma, may exacerbate the interaction and communication

difficulties experienced by autistic people in encounters with maternity care professionals. Recognised need and policy are informing a move towards ‘reasonable adjustments’ in healthcare services for autistic people (Department of Health, 2010; National Disability Authority, 2014). However, at present there is no specific consideration of maternity care for autistic people highlighting the need for further research in this domain.

The Present Study

Therefore, the current study aims to deepen the understanding of the lived experience of maternity care as an autistic mother, with a particular focus on understanding how autistic mothers make sense of their interactions with MCPs. As, to the best of our knowledge, no available research exists exploring MCPs experiences of delivering care to autistic women, the study also aims to understand how MCPs make sense of their experiences delivering maternity care to this group of patients. This multiperspectival approach thus explores the meanings both groups attach to the experience of the relationship, challenges experienced within these interactions, and considerations of the context of maternity care for autistic mothers.

Method

Study Design

The study design was informed by a project advisory panel of autistic people, utilising a consultation approach to Public Patient Involvement (PPI) research (INVOLVE, 2012). The PPI panel gave feedback and advice on the design of interview schedules, information sheets, and on data collection procedures.

A Multiperspectival Interpretative Phenomenological Analysis (IPA) design was utilised in the current study to explore the experience of maternity care for autistic mothers and midwives. IPA is a qualitative method designed to understand people’s lived experience

and how they make sense of it within the context of their personal world view (Smith et al., 2009). The double hermeneutic and commitment to reflexivity within IPA have marked it as a particularly appropriate qualitative methodology within participatory autism research (MacLeod, 2019). A multiperspectival design was selected due to the relational and systemic nature of the phenomenon of maternity care, in particular, the central role of the caring relationship between autistic mother and maternity care professional. Multiperspectival IPA maintains an idiographic approach to data collection and analysis but extends this by synthesizing analyses within and between samples (Larkin et al., 2019). Multiperspectival designs offer particular advantage in exploring relationships between patients and healthcare providers (Borg Xuereb et al., 2015; Larkin et al., 2019).

Participants

Purposive sampling was used in order to recruit two relatively homogenous groups (Smith et al., 2009) of four autistic mothers (Table 4.1) and four MCPs (Table 4.2). Autistic mothers met the inclusion criteria if they (a) had an autism diagnosis, (b) had given birth, (c) were over 18, and (d) were not experiencing acute mental health symptoms at the time of interview. Professionals met the inclusion criteria if they (a) had experience of working within maternity care, (b) had provided maternity care to people on the autism spectrum. All participants within the professional sample worked as midwives. Importantly, two of the midwives had a diagnosis of autism. The other two midwives had strong personal connections with autism with one having a daughter on the autism spectrum and the other having an autistic brother. This sample of midwives had a clear personal interest in autism and the delivery of maternity care to autistic people and may not be representative of the views and experiences of midwifery as a whole. The sample of autistic mothers varied with regards to the time since their autism diagnosis and the time since their maternity care experience.

Table 4.1

Autistic Mothers Demographic Information

Pseudonym	Location	Age	Age of Children	Time of Autism Diagnosis
Ellen	UK	45	20	Later in life
Rebecca	UK	38	8 & 4	Perinatal period
Jennifer	UK	37	4	Pre-pregnancy
Alice	Ireland	38	7	Later in life

Table 4.2

Midwives Demographic Information

Pseudonym	Location	Age	Mother	Autism Status
Katie	UK	25	No	Autistic
Ann	UK	48	Yes	Not autistic
Maggie	UK	34	Yes	Autistic
Sue	UK	29	No	Not autistic

Procedure

Institutional ethical approval was obtained for the study (Appendix K). Participants were recruited via posts on social media (Appendix L). Potential participants contacted the lead researcher and were then sent an information sheet (Appendix M) at which point informed consent was obtained (Appendix N)

Semi-structured interviews are noted to be the exemplary data collection method within IPA methodology (Smith et al., 2009). Therefore, a semi-structured interview schedule for autistic mothers (Appendix O) was designed in collaboration with the PPI panel. A

separate semi-structured interview schedule was designed in order to access the experiences of MCPs (Appendix O). In line with guidelines for inclusivity within autism research (Nicolaidis et al., 2019), participants were offered a selection of interview formats including online, by phone, written interviews via e-mail, and an in person option if practical. All participants in the current study opted for online interviews on MS Teams and varied in their preference for having their cameras on or off. Interviews lasted between 35 and 75 minutes. Interviews were recorded and transcribed verbatim before being anonymised to disguise participants' identities.

Data Analysis

The multiperspectival IPA analysis was informed by the inductive and iterative approach outlined by Smith & Nizza (2022) and key multiperspectival papers by Rostill-Brookes et al. (2011) and Larkin et al. (2019). Each individual transcript was read and re-read, and exploratory descriptive, linguistic, and conceptual notes were made. Then, experiential statements were formulated to capture the idiographic meaning of participants' experiences within each portion of individual interviews. Next, experiential statements were clustered for each individual interview in order to find patterns of connection within experiential statements. A table of personal experiential statements was then compiled for each individual participants' interview. The next step was cross-case analysis within the group of autistic mothers and within the group of midwives, this involved the production of a table of experiential themes for each group. The final step in the multiperspectival analysis was looking for relationships, convergence, and divergence between the two groups. This step included relabelling some of the themes in order to consider the relationship between groups and resulted in the production of a final table of themes.

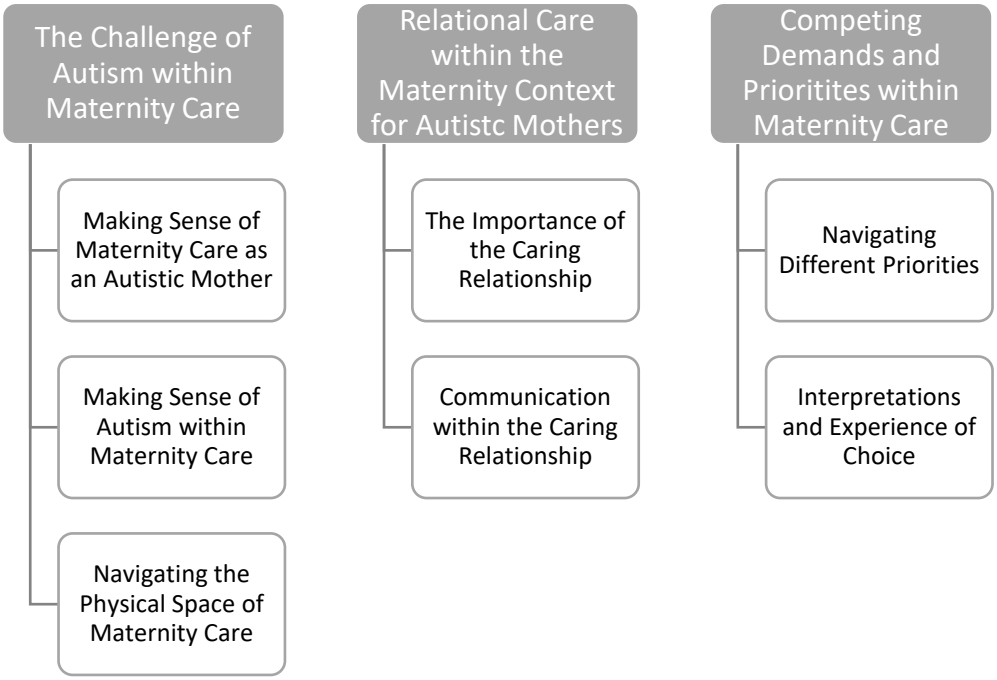
Quality and Reflexivity

The approach to study design, data collection, data analysis, and study write up were informed by two papers aimed at ensuring quality and validity within qualitative research (Levitt et al., 2018; Yardley, 2017). Reflexivity was practiced throughout the data collection and analysis process in the form of a reflexive diary kept by the first author and through reflexive discussions among authors. This process ensured sensitivity to context by paying close attention to participants' meaning making accounts and the researcher's interpretation of these accounts, with consideration to the researcher's preconceptions, context, and own world view. A selection of the exploratory notes, personal, and group level themes constructed by the first author were reviewed by the second author to enhance validity.

Results

Multiperspectival analysis resulted in three major themes, each with subthemes (Figure 4.1). The first theme demonstrates how autistic mothers and midwives make sense of how autism fits within current maternity care services. The second theme explores the experiences of the caring relationship within the maternity care context. The third theme examines the subjective challenges of competing demands that exist within maternity care.

Figure 4.1
Themes and Subthemes



The Challenge of Autism within Maternity Care

Both mothers and midwives experienced challenges when making sense of how autistic people 'fit' within a maternity care system. Due to the level of divergence and subjectivity held by each group, this is divided into two separate subthemes for autistic mothers and midwives. Both groups also described the challenge of the sensory aspects of maternity care for autistic mothers.

Making Sense of Maternity Care as an Autistic Mother

For mothers on the autism spectrum the experience of maternity care was often confusing and overwhelming. The mothers felt that there was an assumption from MCPs that they would know what to expect from labour, which was at odds with their lived experience:

> I felt very frightened almost and just confused and like I had no clue what was going on…..It was just…a given that this is what happened, but I was just bewildered by the whole process. (Ellen, mother)

Autistic mothers struggled to make sense of their experience when their own expectations of pregnancy, motherhood, and maternity care were not met. Jennifer describes how her understanding of a mother's ability to comfort her new baby was based on TV depictions of motherhood and says:

> 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. Nothing has logically caused him pain and the midwife checked him over, therefore he must hate me. So, it was a very rigid...that's the only possible thing. (Jennifer, mother)

Jennifer then goes on to describe how responsive care helped her come to a new understanding of this experience: "It took a lot of support to understand that actually it's normal for new-borns to cry." This indicates that new challenges arise in response to ambiguity regarding children's needs and MCPs can play a role in mitigating this challenge.

As autistic mothers were trying to make sense of the new, often overwhelming, experience of maternity care, they were also trying to make sense of and communicate their own individual support needs. In response to a question regarding what would have improved her maternity care experience, Alice responded "Easier?....knowing myself better." This sense was shared by Rebecca, who had two children, and felt better able to understand, and thus, express her needs in her second maternity care experience: "Yeah, second time around there's very small specifics, whereas first time around was a mixture of naivete and not really knowing and thinking that's what they do."

This subtheme highlights the challenging role that expectations play within maternity care for autistic women and draws attention to the burden autistic women feel in making

sense of how their autism specific needs are impacting their perception of what is an already challenging experience for most mothers.

Making Sense of Autism within Maternity Care as a Midwife

The midwives sensed that autism is an overlooked experience within maternity care, as explained by Maggie: “There's nothing at all. There's no policies in the hospital. There's just nothing in place whatsoever for the women we look after…. just nothing there like at all…..that I think shocked me more than anything.” This lack of consideration to autism was understood to have negative implications for patients:

> It's not fair that they get….I don’t want to say the word discriminated, but sometimes I think they probably are because they're not being looked after in the best way possible, and that is impacting their outcomes. (Sue, midwife)

Although Sue was reluctant to use the word “discrimination”, this was a shared understanding by all of the midwives and lack of awareness was seen as contributing to misconceptions regarding autism within the profession. Here, Katie is making sense of judgemental comments she had heard from other midwives regarding autistic mothers: “It's from a place of ignorance rather than malice, but the course doesn't really give any information on it, so it isn't kind of supported in a learning environment.”

All midwives had a strong personal understanding of autism, which they described as helpful in delivering care to autistic women:

> I guess, it's for me...it's easier to care for them because I know that they can really identify with a lot of what I'm going through, so I feel like I can...I don't have to mask around them... (Katie, midwife)

Their personal understanding of autism meant the midwives in the current study positioned themselves outside of the dominant understanding of autism within maternity care. This led to challenges navigating the prevailing attitudes and misperceptions that exist. Here, Ann makes sense of how midwives perceive 'out of the ordinary' care choices by autistic mothers: "Because…they've made an informed decision. Whereas that might, maybe sometimes get seen as not advocating for themselves or the baby and then it becomes a moral judgment..."

A particular challenge for midwives within the current study was making sense of the perception, from colleagues, that autistic mothers are challenging to care for:

> The first thing that normally I noticed is they're labelled as being difficult and it's normally spread then through the unit. This lady is really difficult.....good luck basically. And then I just think sometimes like there's just no need for it and that really annoys me. (Maggie, midwife)

This subtheme highlights the challenge of how autistic mothers' needs fit within a system in which autism is overlooked and misperceptions exist. It also highlights the challenges and opportunities that exist for midwives that have a special interest in autism within maternity care.

Navigating the Physical Space of Maternity Care

Autistic mothers highlighted the challenges they face in navigating the physical and sensory space of maternity care environments. The sensory sensitivities of autism exacerbated these autistic mothers' sense of overwhelm and powerlessness within the maternity care context:

> [the physical space had] a very profound effect that you know everything, 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, it would be like that you know, almost an out of body experience, but my body was just completely spiralling in all, all my senses, all the way through. (Ellen, mother)

This highlights the experience of feeling out of control as a result of the intense sensory experiences of being in hospital. In particular, mothers found shared wards challenging due to sensory overwhelm and the social pressure of shared spaces at a vulnerable time:

> I said no, 'cause I will not get out of bed, I will not ring that buzzer if I need help because I'm very conscious of people I don't know being around me and stuff….I physically could not bring myself to do it. (Rebecca, mother)

By chance, Alice spent some time in a private room and then a room shared with one other person, she described: “But that was a great transition, that was easy. And I was lucky in that I was in a room with just one other person so it was quiet and easy.”

Alice makes sense of this positive experience as it aligned with her sensory needs as an autistic woman. Similarly, midwives described their understanding that the unsuitability of the environment can impact on how autistic women present, which feasibly then impacts how they are perceived and treated by MCPs:

> If you're on a busy ward and there's a lot of noise and things like that it can be really overwhelming for certain people and then they can't quite control their emotions as well, where they often are going into some sort of meltdown, and sometimes they may not even speak at all. (Maggie, midwife)

Here, Maggie demonstrates an awareness of the emotional distress that can be experienced as a result of sensory overwhelm and is empathic towards this experience for autistic patients. Importantly, midwives highlighted that the physical space of maternity care presents challenges for all mothers, not just those on the autism spectrum:

> Before I knew about autism, I would go into a room and I would say things like 'oh babies don't like bright lights'……. so it's all very calm and that's the way I understand birth works best and now I can see that I was facilitating that because that's better for everybody, for an autistic as well. (Ann, midwife)

Therefore, although the maternity care environment may be experienced as inappropriate for all mothers, the negative impact may be heightened for those on the autism spectrum due to sensory sensitivities. This awareness of sensory overwhelm as a result of environmental factors was shared by mothers and midwives.

Relational Care within the Maternity Context for Autistic Mothers

This theme focuses on the central role of the caring relationship within maternity care. Both the autistic mothers and the midwives in this study valued this relationship highly. However, both groups experienced challenges in establishing a caring relationship.

The Importance of the Caring Relationship

The autistic mothers in this study experienced a strong desire to build relationships with MCPs and found it challenging to deal with different MCPs at each appointment:

> But because I didn't have that bond to someone, 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... (Rebecca, mother)

Speaking about the impact of "face blindness" on her ability to build interpersonal relationships with multiple MCPs, Alice describes: "I can't build a relationship or feel a bit safer with someone if I didn't recognize them."

Similarly, midwives identified that ongoing relationships were important to identifying mothers that are struggling, this was particularly important for autistic mothers, where masking may impact the identification of difficulties. Midwife, Sue, described "But you also knew and you could pick up and say, actually.....you're very different to how you were the last time I saw you is everything OK? You could pick it up a lot better then." Both groups believed that continuity of care allowed the professional to identify a mothers' needs and also facilitated mothers' disclosure of needs.

When mothers perceived a person-centred relationship, this had a positive impact on their overall experience:

> And my health visitor was a gift from God. She was just a beautiful human being and that was the first time I'd had anybody who I felt was interested in me as a person, not just you know, a medical specimen…… it was incredible and I went to every clinic and I practically lived at the doctors, I just wanted to see her. (Ellen, mother)

For the midwives, this ability to build relationships was experienced as a valued and rewarding aspect of their professional identity, Katie noted "I feel very protective over the women that are autistic that I'm looking after because I will go in and have a lovely chat and bond with her."

In describing how she experienced supportive interactions with professionals as distinct from challenging interactions, Jennifer described "The ones that were really good listened to me specifically, understood my issues that were autism related and those that were

trauma related and were able to differentiate between the two." Notably, Jennifer also identified personality as a factor that impacted on her experience of supportive relationships within maternity care, "She was just someone who cared...for everyone, every patient, she's kind of the type of midwife where you go like that's the type of person you want in that kind of field..."

Interpretation of personality also played a role in how midwives made sense of the experience of establishing relationships with autistic mothers. Here, Maggie is describing her perception of colleagues' difficulties in establishing such relationships: "Honestly.....the worst thing is they don't really give the women the time, and because they're more difficult, they seem to give them even less time because that's how they perceive them as being."

Therefore, although there is significant value and meaning attached to the caring relationship, there are challenges in establishing this relationship within a maternity care context for autistic mothers.

Communication within the Caring Relationship

Both mothers and midwives experienced challenges making sense of communication difficulties within interactions. Mothers described experiencing challenges in making their needs known to MCPs, as described by Ellen: "I felt very internalized in the whole thing….and I kind of did shut down in terms of communicating to other people."

This challenge was also evident for the midwives in the sample. Maggie stated, "You can find that they don't really know what to say…or they're not just taking anything in, 'cause they are just shutting down completely."

Some of this challenge was attributed to the prevalence of masking amongst autistic women.

> And I found all of that really difficult because I was used to minimizing things when I described them, but I needed to accurately describe it, 'cause I really needed advice but conveying how things actually were..... I found really difficult. (Alice, mother)

According to the midwives' experience, autistic mothers often asked more questions and needed more detail in order to understand 'routine' procedures, which negatively impacted how they were perceived by MCPs. Katie describes observing an interaction between an obstetrician and autistic patient, "he talked to her as if she was stupid and just was like being inconvenient and being grumpy for the sake of it..." (Katie, midwife).

A significant lived experience of feeling unheard as an autistic mother in maternity care was evident for the mothers in this sample. This is described by Rebecca, "They were so dismissive….I didn't even tell them that I thought I might be autistic because….some people you can just tell that they will not, not even entertain it in the slightest." and Jennifer "And then I use extreme examples because nobody tends to listen to me or they talk over me or speak to my husband...". This implies that MCPs hold some stigma and biases in relation to the capabilities of autistic mothers.

Communication from professionals was interpreted as overly casual considering the emotional impact of the information being shared. In making sense of her experience of an internal examination, Rebecca said "Yeah, especially as I was not told that was going to happen at all. She just said she was *just* having a look and she did it without me even....."

There was a strong view that language and communication from MCPs held significance for mothers and had a lasting impact on their view of themselves, "And that is something, that is a phrasing that has followed me ever since, 'she's autistic, so she doesn't understand what she's doing is wrong'." (Jennifer, mother)

Mothers viewed attempts at empathy or understanding from MCPs as patronising. This quote from Ellen suggests an overly literal interpretation of such communication from an obstetrician:

> He said, 'I know this is a bit uncomfortable' and I went, 'No, you don't'. I said how dare you, I said don't you dare patronize me I said you've got absolutely no idea what it's like… (Ellen, mother)

The midwives within this study felt an important part of their role was bridging the gap between other MCPs and autistic mothers, according to Sue "I do sort of give people a bit of fair warning and like the doctors gonna come in speaking a lot of medical terms….I'll translate for you as best I can in human speak."

The communication challenges which are a central feature of autism impact on autistic mothers' ability to express their own needs and to interpret communication from MCPs. This also impacts on how autistic mothers are perceived by MCPs which can further threaten the development of a caring relationship.

Competing Demands and Priorities within Maternity Care

This theme explores the competing priorities that exist for autistic mothers compared to midwives, the system demands experienced by midwives, and how choice is experienced and interpreted within the health service.

Navigating Different Priorities within Maternity Care for Autistic Mothers

The mothers within this study experienced significant negative and long-lasting reactions as a result of the overwhelming sensory experiences of medical interactions:

> She was like measuring and pushing my bump….I would never imagine anybody in any circumstance would go pushing like I mean it was sore and I didn't know that

> was.....it really upset me for days afterwards.....sorry like it's still upsetting when I think about it. (Alice, mother)

There was a shared understanding of these physical interactions as traumatic and upsetting. Here, Ellen explains how she interpreted the experience of a midwife checking how dilated she was in labour:

> It was just monstrous, and she was really brutal and I was trying to kick her off and swearing at her and I had to be pinned down so that which was deeply traumatic. I mean, it borders on sexual assault in my mind. It feels like you know, a really deep violation. (Ellen, mother)

Although these interactions were interpreted as upsetting, there was an understanding of the requirement for such procedures on the part of MCPs. Autistic mother, Rebecca, noted "I don't like people touching me anyway, but like at the appointments it made it quite uncomfortable 'cause obviously they have to be quite hands on."

Interestingly, only the midwives who were on the autism spectrum considered the sensory experience of medical procedures within interviews:

> For example with vaginal examinations..…it's terrifying to me, but we do it to women all the time and it's kind of one of those things where if a woman doesn't want a vaginal examination, we're like, why? (Katie, midwife)

Autistic mothers expressed a strong desire for emotional care within the maternity setting. They viewed themselves as vulnerable and felt there was no space for emotional expression within maternity care. "Nobody really asked me about anything very much about how I was feeling…It was really quite unsettling, to be honest, the whole thing all the way through." (Ellen, mother)

Mothers believed that emotional expression on their part could be misinterpreted by MCPs or ‘used against them’:

> I actively begged people for help, so that while I was struggling with the sensory overload and adjusting that I wouldn't shout and I wouldn't have breakdowns so that my child wouldn't be exposed to that, but the sheer fact I thought it was a possibility for them meant, OK, she's a danger. (Jennifer, mother)

This lack of attention to emotions and the sensory experience of medical interactions from the perspective of midwives can be attributed to midwives’ priority of ensuring the physical health of mother and child. It can also be explained by the competing demands midwives experience within the maternity context. Ann explains that midwives are busy and this means:

> There's very little room to have any outside thinking of oh right.....OK, she's needing this or she's needing that..... it would have to be that the midwife has extra time in the day to have those thoughts... (Ann, midwife)

Similarly, although midwives demonstrated a keen awareness of autistic mothers need for additional support, they felt constrained by the demands within the system to provide such support:

> It could be deemed as.....you're spending too much time, you've got to...start working through discharges to get people home but.....you want to …the ultimate goal is to make sure you've got people who can look after themselves and their baby. (Sue, midwife)

This highlights the difficulty in meeting the individual needs of autistic mothers within an imperfect maternity care system.

Interpretations and Experiences of Choice

The different priorities that exist also had an impact on how autistic mothers viewed their position as an autistic patient within maternity care. Mothers experienced limited choice, power, and autonomy in decision making: “And I didn't feel like they saw me as a human being, I was just a subject and one that wasn't performing as she was supposed to.” (Ellen, mother)

Autistic mothers felt their opinions about their own births were not considered or valued and there was a strong sense of having to get in line with professionals’ opinions on maternity care. Summarizing some of these interactions with MCPs, Jennifer said: “I think they were all.....they were all approaching it from a holier than thou approach, the I am the XYZ.....and kind of talking down to me.” This approach of MCP knows best was also perceived as a barrier to providing adapted care by the midwives: “I know a lot of colleagues are very much like OK, I'm going to tell you what to do and you're going to do it.” (Sue, midwife)

This perception of limited choice was corroborated by midwives, who believed that any decisions by mothers, that could be considered out of the ordinary, were grounds for judgement from professionals. Ann described, “Some women might not consent to like some things that are very routine for everybody else……. you know it would become a moral judgment.....like oh, why is she doing that?”

Notably, midwives also experienced some limitations in terms of their power and autonomy to provide adaptations to maternity care for autistic women. Describing how her attempts to adapt the environment are not valued by other MCPs, Sue said “You've got doctors that will still come in and they will whack up the lights to full brightness.....and like no, come on, it's not nice.”

Both midwives and mothers shared a perception that midwifery led care is more amenable to adapting for individual differences. Rebecca experienced a consultant led model for the birth of her first baby and a midwifery led model for her second birth experience:

> Like even in the hospital, it's like you're a number in the queue, aren't you? It's get in, have your baby, get out. With the midwife it's so much more calmer, and it is about you and how you want to do it, rather than how a hospital expects you to have a baby. It's quite empowering, really. (Rebecca, mother)

> Some hospitals have midwifery led which is kind of less intervention, a smaller room.....where you might have the autonomy to have the lights down low and things like that. (Ann, midwife)

For both mothers and midwives, there is a sense that midwifery led care is more person centred and offers greater choice, which empowers mothers to take control of their own birth experience. Whereas limited choice and interpretation of limited ability to share their own maternity experience contributes to a sense of feeling out of control. The perception of limited autonomy by midwives may have meaning within the wider maternity and healthcare context.

Discussion

This study aimed to explore autistic mothers and MCPs lived experiences of maternity care for autistic women. Multiperspectival analysis resulted in three overarching themes which deepen the understanding of the experience of receiving and providing maternity care for autistic mothers.

The Challenge of Autism within Maternity Care

Autistic mothers in the current study outlined the difficulty they experience in navigating maternity care services. This difficulty was particularly apparent when the lived

experience of maternity care did not meet mothers' expectations. This is consistent with research with neurotypical populations, which suggests that disparity between experience and expectations is a significant factor in patient satisfaction with care during the perinatal period (Britton, 2012). This discrepancy may be particularly impactful for women on the autism spectrum due to the cognitive rigidity and intolerance of uncertainty which are associated with autism (South & Rodgers, 2017) and contribute to the experience of anxiety (Stark et al., 2021).

The difficulties that autistic mothers experience within maternity care are compounded by the lack of awareness of autism from MCPs, as observed by midwives in the current study. This perceived lack of autism awareness is in keeping with findings for other groups of healthcare professionals (Morris et al., 2019). Within the current study, this lack of awareness from MCPs meant that autistic mothers experienced an additional challenge of having to identify and communicate their specific needs, at an already overwhelming time. This lack of understanding can further contribute to the misperceptions, judgements, and stigma that exist regarding autism within maternity care, which have been identified here and in previous research with autistic mothers (Pohl et al., 2020). Notably, although aware of the necessity of medical intervention, autistic mothers in the current study experienced medical interactions requiring physical touch in a way that suggests significant trauma (Beck, 2009). This was a neglected phenomenon on behalf of the non-autistic midwives within the study and suggests lack of awareness can do harm to autistic mothers within maternity care.

The finding that autistic mothers struggle to navigate the physical space of the maternity care environment was expected given previous research in relation to sensory sensitivity during the perinatal period for autistic women (Samuel et al., 2022). Research exploring patients' experience of and satisfaction with maternity care does not appear to

consider the impact of the environment (Britton, 2012; Redshaw & Heikkila, 2010). Midwives within the current study viewed the maternity care environment as less than ideal for all mothers and infants, as evidenced by Ann's quote "babies don't like bright lights". This suggests that universal design principles may be appropriate in improving this aspect of maternity care for all, with particular benefits for those on the autism spectrum (Milton et al., 2016).

Relational Care within the Maternity Context for Autistic Mothers

The caring relationship was experienced as a salient feature of maternity care for both autistic mothers and midwives. A consistent research finding for all populations is that the quality of relational support has a significant impact on mothers' perceptions of perinatal care, and has implications for postnatal functioning and the experience of postnatal depression (Britton, 2012; Michels et al., 2013; Tinkler & Quinney, 1998). The establishment of a supportive relationship may have additional challenges for autistic mothers due to autism specific challenges such as difficulty recognizing faces (Griffin et al., 2021), camouflaging (Cook et al., 2021), and the social and communication deficits that are criterion for autism diagnosis (American Psychiatric Association, 2022). Research by Lum et al. (2014) supports the view that autistic women experience greater challenges within healthcare communication, compared to non-autistic women. Although such challenges exist, it is clear from the current findings that when this supportive relationship is available, it has a profound positive affect on mothers and is experienced as rewarding by midwives.

Autistic mothers and midwives within the current study believed continuity of care plays an important role in building this relationship and identifying or communicating specific challenges faced by autistic mothers. Notably, midwifery continuity of care models have been shown to be associated with a range of improved clinical outcomes for mothers

and babies (Bradford et al., 2022), as well as greater satisfaction with maternity care for mothers (Perriman et al., 2018). A recent review of maternity care practices globally by Bradford et al. (2022) highlighted the need for system level reform to enable this model of care to become the standard nationally and internationally.

Competing Demands and Priorities within Maternity Care

Consistent with primarily quantitative research undertaken with neurotypical mothers (Britton, 2012), autistic mothers within the current study experienced limited choice, control, and participation in decision making which impacted how they felt about themselves and how they made sense of their experience of maternity care. Research by O'Brien et al. (2021) highlights how trusting relationships with MCPs have a significant impact on mothers' capacity to participate in shared decision making, offering support for the significance of relational care in a maternity context. This perception of limited choice appears to be a common phenomenon for women in maternity care (Bohren et al., 2015). However, current findings highlight that autistic women may be more likely to attribute this to a problem within themselves, perhaps due to long held experiences of being different (Milner et al., 2019), rather than a problem within the system. Findings from midwives within the current study indicate that MCPs do experience negative perceptions and judgements of women who make choices that are 'out of the ordinary'.

Similarly, midwives feel constrained in their ability to adapt maternity care for autistic mothers by the competing demands that exist within the system. Midwives in the current study felt overworked and had limited autonomy in their approach to care. The majority of midwives in the current study worked within the NHS. However, research in an Irish context by Doherty and O'Brien (2022) highlights that midwives experience comparatively high levels of burnout which has implications for care provision.

Recommendations from this study included creating time and space for debriefing and reflection, as well as the practical need to address staff shortages. Organizational factors such as absence of care pathways, lack of time, heavy workload, and an absence of continuity of care have been identified as barriers to midwives addressing mental health concerns in the perinatal period (Higgins et al., 2018). Such factors offer some explanation as to why midwives are not seen to prioritise the needs identified by autistic mothers within the current study.

Both the midwives and autistic mothers in the current study identified that midwifery led maternity care appeared more suitable in meeting the needs of autistic women. Available research highlights that, for low risk women, midwifery led care improves a number of health outcomes, reduces the amount of intervention in labour, and increases patient satisfaction with care (Sutcliffe et al., 2012). Future research could explore how specific, less medical aspects of midwifery led care could be applied across maternity care settings or the feasibility of incorporating midwifery led care across contexts.

Clinical Implications

Findings from the current study represent a deeper understanding of the specific challenges autistic mothers experience within maternity care. Although autistic mothers experience challenges in the environment, with sensory aspects of care, and with communication, the presence of a supportive caring relationship appears to be a protective and valued experience. This is in line with findings from a neurotypical population (Britton, 2012) and suggests that midwives, and other MCPs, need to explicitly consider the relationship and work towards strengthening and developing this relationship with autistic mothers.

The lack of awareness of autism within maternity care is a challenge to the development of understanding relationships between autistic mothers and maternity care professionals. This is particularly apparent in relation to the traumatic meaning autistic women attribute to physical interventions and the lack of consideration to this aspect of care by midwives. The experience of trauma in the birth environment is associated with long term trauma symptoms, relationship difficulties, fear of childbirth, and difficulties in the mother-infant relationship (Beck, 2009). Therefore, there is a need for increased awareness and training on autism within maternity care. Increasingly, there is an understanding of the importance of research and training that is led or co-created by autistic people (Pellicano et al., 2014) and evidence to support the importance of peer support for autistic adults in different contexts (Crane et al., 2021). The experiences, views, and unique position of the autistic midwives within the current study represent an opportunity to build on their practices of advocating for autistic mothers within maternity care. Autistic midwives, or midwives with a special interest in autism, could act as leaders and advocates for autism in maternity care by encouraging colleagues to consider the sensory and communication needs of autistic mothers. They could also contribute to wider organisational and system level adjustments to maternity care for autistic women.

Notably, autistic mothers' preferences in relation to the environment, increased availability of choice, continuity of care, and midwifery led care are shared by many recipients of maternity care (Bohren et al., 2015; Britton, 2012). Such care is not yet widely available but has been linked with improved maternal and infant outcomes (Bradford et al., 2022; O' Brien et al., 2021; Sutcliffe et al., 2012). Therefore, ongoing efforts to improve the experience of maternity care for all are warranted and are likely to hold additional benefit for mothers on the autism spectrum.

Limitations

It appears that this study was the first to explore MCPs experiences of delivering maternity care to autistic mothers. Although recruitment was open to MCPs from any professional background, the study sample was made up solely of midwives and so may not represent the experiences of other MCPs. Further, the midwives who participated in the current study were self-selected and had a clear personal interest in autism. Two of the midwives had autism diagnoses and two had close relatives with autism diagnoses. Therefore, this sample of midwives have a unique 'insider' perspective on the experience of autism which influence their professional experience of delivering maternity care to autistic women. The midwife participants spoke to their experiences of colleagues' understanding of autism, this was a subjective interpretative account which may differ from the experiences of those who did not participate in the research. The current research does not fully address the subjective, interpretative experiences of neurotypical midwives delivering maternity to autistic women.

The interviews with autistic mothers and midwives were predominantly retrospective recollections of their experiences. Therefore, their interpretations of these experiences may have changed over time. This is particularly relevant for the sample of autistic mothers, which varied in relation to when they first received an autism diagnosis, as described in Table 4.1. Only one of the mothers was aware of her autism diagnosis at the time of pregnancy and labour, while another mother was diagnosed in the post-natal period. Two of the mothers received an autism diagnosis many years after their maternity care experiences. Therefore, these women are looking back at their experiences with an updated understanding of themselves as autistic which will likely have re-shaped their subjective interpretations over time.

It is also important to note that all of the autistic mothers sampled within the current study did not have intellectual disability and were able to communicate verbally. Therefore, their experiences are not representative of the full spectrum of autism and may differ from the experiences of non-verbal autistic women or those with intellectual disabilities.

Finally, seven of the eight participants were based in the UK and had experienced a UK model of maternity care. All participants were white European women. Therefore, findings should be interpreted within this context.

Future Directions

Future research into the experience of maternity care and the caring relationship should occur at the time of care, or shortly after, to capture the initial meaning making process as it occurs. As described, three of four autistic mothers sampled within the current study were unaware of their autism diagnosis at the time of receiving maternity care. Future research with women with a confirmed autism diagnosis at the time of pregnancy and birth would enable a greater understanding of issues such as the experience of disclosing an autism diagnosis to MCPs, the efficacy of autism centred care planning, and the availability of supports or adaptations for autistic mothers.

The midwives sampled within the current study held a unique position, within their profession, in terms of their experience of autism. The current sample of midwifes was not sufficient to speak to the experiences of neurotypical midwives without a personal experience of autism. Therefore, future research should consider the views of neurotypical midwives. A quantitative, survey measure could be useful in ascertaining the autism specific knowledge and experience held by a greater number of midwives. It would also be helpful to consider the views and experiences of MCPs from different backgrounds such as obstetricians, gynaecologists, and public health nurses.

Conclusion

This study has drawn together the perspectives of autistic mothers and midwives to deepen the understanding of the experience of receiving and providing maternity care for mothers on the autism spectrum. Findings highlight the unique challenges autistic mothers experience in navigating the maternity care system and the preferences they hold for maternity care which seem to align with overall preferences for maternity care. This study appears to be the first to explore midwives' experiences of providing maternity care for autistic mothers. Autism appears to be an overlooked experience in the delivery of maternity care which leads to misperceptions, difficulty forming the essential caring relationship, and creates the potential for harm to mothers on the autism spectrum. The unique perspectives of autistic midwives within the current study represent an opportunity for changes to the maternity care experience for autistic mothers.

References

American Psychiatric Association. (2022). Diagnostic and statistical manual of mental disorders (5th ed.). https://doi.org/10.1176/appi.books.9780890425787

Athan, A., & Reel, H. L. (2015). Maternal psychology: Reflections on the 20th anniversary of *Deconstructing Developmental Psychology*. *Feminism & Psychology*, *25*(3), 311–325. https://doi.org/10.1177/0959353514562804

Beck, C. T. (2009). Birth Trauma and Its Sequelae. *Journal of Trauma & Dissociation*, *10*(2), 189–203. https://doi.org/10.1080/15299730802624528

Bohren, M. A., Vogel, J. P., Hunter, E. C., Lutsiv, O., Makh, S. K., Souza, J. P., Aguiar, C., Saraiva Coneglian, F., Diniz, A. L. A., Tunçalp, Ö., Javadi, D., Oladapo, O. T., Khosla, R., Hindin, M. J., & Gülmezoglu, A. M. (2015). The Mistreatment of Women during Childbirth in Health Facilities Globally: A Mixed-Methods Systematic Review. *PLOS Medicine*, *12*(6), e1001847. https://doi.org/10.1371/journal.pmed.1001847

Borg Xuereb, C, Shaw, RL & Lane, D. (2015). Patients' and physicians' experiences of atrial fibrillation consultations and anticoagulation decision-making: a multi-perspective IPA design. *Psychology & Health, 31*(4). https://doi.org/10.1080/08870446.2015.1116534

Bradford, B. F., Wilson, A. N., Portela, A., McConville, F., Fernandez Turienzo, C., & Homer, C. S. E. (2022). Midwifery continuity of care: A scoping review of where, how, by whom and for whom? *PLOS Global Public Health*, *2*(10), e0000935. https://doi.org/10.1371/journal.pgph.0000935

Britton, J. R. (2012). The assessment of satisfaction with care in the perinatal period. *Journal of Psychosomatic Obstetrics & Gynecology, 33*(2), 37–44. https://doi.org/10.3109/0167482X.2012.658464

Castell, E., & Stenfert Kroese, B. (2016). Midwives' experiences of caring for women with learning disabilities – A qualitative study. *Midwifery*, 36, 35–42. https://doi.org/10.1016/j.midw.2016.02.001

Cook, J., Hull, L., Crane, L., & Mandy, W. (2021). Camouflaging in autism: A systematic review. *Clinical Psychology Review*, *89*, 102080. https://doi.org/10.1016/j.cpr.2021.102080

Corden, K., Brewer, R., & Cage, E. (2021). A Systematic Review of Healthcare Professionals' Knowledge, Self-Efficacy and Attitudes Towards Working with Autistic People. *Review Journal of Autism and Developmental Disorders, 1*(14). https://doi.org/10.1007/s40489-021-00263-w

Crane, L., Goddard, L., & Pring, L. (2009). Sensory processing in adults with autism spectrum disorders. *Autism, 13*(3), 215-228. https://doi.org/10.1177%2F1362361309103794

Crane, L., Hearst, C., Ashworth, M., Davies, J., & Hill, E. L. (2021). Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme. *Journal of Autism and Developmental Disorders*, *51*(3), 892–905. https://doi.org/10.1007/s10803-020-04486-4

Department of Health. (2010, March 3). Fulfilling and rewarding lives: the strategy for adults with autism in England. www.webarchive.nationalarchives.gov.uk. Retrieved December 20, 2021 https://webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369

Dern, S., & Sappok, T. (2016). Barriers to healthcare for people on the autism spectrum. *Advances in Autism, 2*(1), 2-11. https://doi.org/10.1108/AIA-10-2015-0020

Doherty, J., & O'Brien, D. (2022). Reducing midwife burnout at organisational level—Midwives need time, space and a positive work-place culture. *Women and Birth*, *35*(6), e563–e572. https://doi.org/10.1016/j.wombi.2022.02.003

Donovan, J. (2020). Childbirth experiences of women with autism spectrum disorder in an acute care setting. *Nursing for Women's Health*, 24(3), 165-174. https://doi.org/10.1016/j.nwh.2020.04.001

Gardner, M., Suplee, P. D., Bloch, J., & Lecks, K. (2016). Exploratory study of childbearing experiences of women with Asperger syndrome. *Nursing for Women's Health*, 20(1), 28-37. https://doi.org/10.1016/j.nwh.2015.12.001

Griffin, J. W., Bauer, R., & Scherf, K. S. (2021). A quantitative meta-analysis of face recognition deficits in autism: 40 years of research. *Psychological Bulletin*, *147*(3), 268–292. https://doi.org/10.1037/bul0000310

Hampton, S., Allison, C., Aydin, E., Baron-Cohen, S., & Holt, R. (2022). Autistic mothers' perinatal well-being and parenting styles. *Autism*, *26*(7), 1805–1820. https://doi.org/10.1177/13623613211065544

Higgins, A., Downes, C., Monahan, M., Gill, A., Lamb, S. A., & Carroll, M. (2018). Barriers to midwives and nurses addressing mental health issues with women during the perinatal period: The Mind Mothers study. *Journal of Clinical Nursing*, *27*(9–10), 1872–1883. https://doi.org/10.1111/jocn.14252

Homeyard, C., Montgomery, E., Chinn, D., & Patelarou, E. (2016). Current evidence on antenatal care provision for women with intellectual disabilities: A systematic review. Midwifery, 32, 45–57. https://doi.org/10.1016/j.midw.2015.10.002

INVOLVE. (2012). *Briefing notes for researchers: Involving the public in NHS, public health and social care research.* INVOLVE.

https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371

Larkin, M., Clifton, E., & de Visser, R. (2009). Making sense of 'consent' in a constrained environment. *International Journal of Law and Psychiatry*, *32*(3), 176–183. https://doi.org/10.1016/j.ijlp.2009.02.003

Larkin, M., Shaw, R., & Flowers, P. (2019). Multiperspectival designs and processes in interpretative phenomenological analysis research. *Qualitative Research in Psychology*, *16*(2), 182–198. https://doi.org/10.1080/14780887.2018.1540655

Levitt, H. M., Bamberg, M., Creswell, J. W., Frost, D. M., Josselson, R., & Suárez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *American Psychologist*, *73*(1), 26–46. https://doi.org/10.1037/amp0000151

Litchman, M. L., Tran, M. J., Dearden, S. E., Guo, J. W., Simonsen, S. E., & Clark, L. (2019). What women with disabilities write in personal blogs about pregnancy and early motherhood: qualitative analysis of blogs. *JMIR Pediatrics and Parenting, 2*(1), e12355. https://doi.org/10.2196/12355

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, *56*(6), 466–474. https://doi.org/10.1016/j.jaac.2017.03.013

Lum, M., Garnett, M., & O'Connor, E. (2014). Health communication: A pilot study comparing perceptions of women with and without high functioning autism spectrum disorder. *Research in Autism Spectrum Disorders*, *8*(12), 1713–1721. https://doi.org/10.1016/j.rasd.2014.09.009

MacLeod, A. (2019). Interpretative Phenomenological Analysis (IPA) as a tool for participatory research within Critical Autism Studies: A systematic review. *Research in Autism Spectrum Disorders, 64*, 49–62. https://doi.org/10.1016/j.rasd.2019.04.005

McDonnell, C. G., & DeLucia, E. A. (2021). Pregnancy and Parenthood Among Autistic Adults: Implications for Advancing Maternal Health and Parental Well-Being. *Autism in Adulthood, 3*(1), 100–115. https://doi.org/10.1089/aut.2020.0046

Michels, A., Kruske, S., & Thompson, R. (2013). Women's postnatal psychological functioning: The role of satisfaction with intrapartum care and the birth experience. *Journal of Reproductive and Infant Psychology, 31*(2), 172–182. https://doi.org/10.1080/02646838.2013.791921

Milner, V., McIntosh, H., Colvert, E., & Happé, F. (2019). A Qualitative Exploration of the Female Experience of Autism Spectrum Disorder (ASD). *Journal of Autism and Developmental Disorders, 49*(6), 2389–2402. https://doi.org/10.1007/s10803-019-03906-4

Milton, D., Martin, N., & Melham, P. (2016). Beyond reasonable adjustment: autistic-friendly spaces and Universal Design. Pavilion Publishing and Media.

Misra, D. P., Guyer, B., & Allston, A. (2003). Integrated perinatal health framework. *American Journal of Preventive Medicine, 25*(1), 65–75. https://doi.org/10.1016/S0749-3797(03)00090-4

Morris, R., Greenblatt, A., & Saini, M. (2019). Healthcare Providers' Experiences with Autism: A Scoping Review. *Journal of Autism and Developmental Disorders, 49*(6), 2374–2388. https://doi.org/10.1007/s10803-019-03912-6

National Disability Authority. (2014). Annual report. National Disability Authority. Dublin. Retrieved December 20, 2021 http://nda.ie/Publications/Others/National-Disability-Authority-Annual-Reports/Annual-Report-2014.htm

Nelson, S. K., Kushlev, K., & Lyubomirsky, S. (2014). The pains and pleasures of parenting: When, why, and how is parenthood associated with more or less well-being? *Psychological Bulletin, 140*(3), 846–895. https://doi.org/10.1037/a0035444

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

Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism, 23*(8), 2007–2019. https://doi.org/10.1177/1362361319830523

O'Brien, D., Butler, M. M., & Casey, M. (2021). The importance of nurturing trusting relationships to embed shared decision-making during pregnancy and childbirth. *Midwifery, 98*, 102987. https://doi.org/10.1016/j.midw.2021.102987

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism, 18*(7), 756–770. https://doi.org/10.1177/1362361314529627

Perriman, N., Davis, D. L., & Ferguson, S. (2018). What women value in the midwifery continuity of care model: A systematic review with meta-synthesis. *Midwifery, 62*, 220–229. https://doi.org/10.1016/j.midw.2018.04.011

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

Redshaw, M. & Heikkila, K. (2010). *Delivered with Care: A national survey of women's experience of maternity care 2010.* National Perinatal Epidemiological Unit. https://www.npeu.ox.ac.uk/research/projects/99-nms-2010

Rogers, C., Lepherd, L., Ganguly, R., & Jacob-Rogers, S. (2017). Perinatal issues for women with high functioning autism spectrum disorder. *Women and Birth, 30*(2), e89-e95. https://doi.org/10.1016/j.wombi.2016.09.009

Rostill-Brookes, H., Larkin, M., Toms, A., & Churchman, C. (2011). A shared experience of fragmentation: Making sense of foster placement breakdown. *Clinical Child Psychology and Psychiatry, 16*(1), 103–127. https://doi.org/10.1177/1359104509352894

Samuel, P., Yew, R. Y., Hooley, M., Hickey, M., & Stokes, M. A. (2022). Sensory challenges experienced by autistic women during pregnancy and childbirth: A systematic review. *Archives of Gynecology and Obstetrics*, *305*(2), 299–311. https://doi.org/10.1007/s00404-021-06109-4

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research.* SAGE.

Smith, J. A., & Nizza, I. E. (2022). *Essentials of interpretative phenomenological analysis.* American Psychological Association.

South, M., & Rodgers, J. (2017). Sensory, Emotional and Cognitive Contributions to Anxiety in Autism Spectrum Disorders. *Frontiers in Human Neuroscience*, *11*. https://doi.org/10.3389/fnhum.2017.00020

Stark, E., Stacey, J., Mandy, W., Kringelbach, M. L., & Happé, F. (2021). Autistic Cognition: Charting Routes to Anxiety. *Trends in Cognitive Sciences*, *25*(7), 571–581. https://doi.org/10.1016/j.tics.2021.03.014

Sundelin, H. E., Stephansson, O., Hultman, C. M., & Ludvigsson, J. F. (2018). Pregnancy outcomes in women with autism: A nationwide population-based cohort study. *Clinical Epidemiology, Volume 10*, 1817–1826. https://doi.org/10.2147/CLEP.S176910

Sutcliffe, K., Caird, J., Kavanagh, J., Rees, R., Oliver, K., Dickson, K., Woodman, J., Barnett-Paige, E., & Thomas, J. (2012). Comparing midwife-led and doctor-led maternity care: A systematic review of reviews. *Journal of Advanced Nursing*, *68*(11), 2376–2386. https://doi.org/10.1111/j.1365-2648.2012.05998.x

Tinkler, A., & Quinney, D. (1998). Team midwifery: The influence of the midwife-woman relationship on women's experiences and perceptions of maternity care. *Journal of Advanced Nursing*, *28*(1), 30–35. https://doi.org/10.1046/j.1365-2648.1998.00769.x

Tint, A., & Weiss, J. A. (2018). A qualitative study of the service experiences of women with autism spectrum disorder. *Autism, 22*(8), 928–937. https://doi.org/10.1177/1362361317702561

Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. (2017). GPs' confidence in caring for their patients on the autism spectrum: an online self-report study. *British Journal of General Practice, 67*(659), e445-e452. https://doi.org/10.3399/bjgp17X690449

Urbanowicz, A., Parkin, T., Dooren, K., van Girdler, S., Ciccarelli, M., & Lennox, N. (2020). The experiences, views, and needs of health professionals who provide care to adults on the autism spectrum. *Research and Practice in Intellectual and Developmental Disabilities, 7,* 179–192. https://doi.org/10.1080/23297018.2020.1735943

Yardley, L. (2017). Demonstrating the validity of qualitative research. *The Journal of Positive Psychology*, *12*(3), 295–296. https://doi.org/10.1080/17439760.2016.1262624

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

Chapter Five: Major Research Project Extended Methodology

This chapter expands on methodological considerations of the major research project and provides additional context and rationale for decision making. This includes the rational for the use of interpretative phenomenological analysis (IPA), details of the public patient involvement (PPI) process, ethical considerations, reflexivity, and further detail regarding sampling and data analysis.

Research Design

Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) is an approach to qualitative analysis which is informed by the philosophies of phenomenology, hermeneutics, and idiography (Smith et al., 2009). Phenomenology is a philosophical approach to the study of human experience. A key principle of phenomenology, according to Husserl, is that human experience should be examined in the way that it occurs, on its own terms. Therefore, in carrying out phenomenological research, the researcher should endeavour to put aside any pre-existing ideas, theories, or scientific constructs in order to understand the subjective lived experience of the phenomenon under investigation (Smith & Nizza, 2022).

IPA is further informed by hermeneutics, the theory of interpretation (Smith et al., 2009). Heidegger's work contributed to the theoretical foundations of IPA with the view that phenomenology is an explicitly interpretative endeavour. Heidegger believed that the meaning of experiences is not always readily apparent and that getting at the meaning required going beyond the surface description of experiences. The hermeneutic circle means that how we understand parts of the whole is influenced by our understanding of the whole, but also acknowledges that we can only understand the whole if we understand individual parts (Willig, 2013). The hermeneutic circle underlines the iterative nature of IPA analysis.

Furthermore, IPA research involves a double hermeneutic (Smith & Osborn, 2003), in which the participant is trying to make sense of their own experiences, while the researcher is trying to make sense of the participant's sense making (Smith & Nizza, 2022).

IPA is also idiographic in its approach. Idiography is defined as a 'focus on the particular,' therefore, idiographic research focuses closely on understanding one case study. By considering a single case study, it is possible to examine an individuals' experience in detail, within context in its own terms (Smith & Nizza, 2022). IPA research is therefore interested in understanding the particular experiences of individuals before making comparisons and generalized statements across cases. General statements within IPA research are always linked to specific instances within the data (Smith et al., 2009).

Therefore, IPA draws on phenomenological, hermeneutic, and idiographic philosophies in order to understand the subjective lived experience of participants, to make sense of how participants make sense of their experience, and to analyse each individual's experience on its own terms before engaging in cross-case analysis.

Multiperspectival Interpretative Phenomenological Analysis

Multiperspectival IPA is a variation on standard IPA which was designed to capture more complex, systemic phenomena by recruiting participants from different but related groups in order to understand different perspectives on certain experiences (Smith & Nizza, 2022). The typical focus within IPA is on personal meaning making within a reasonably homogenous group who share contextual experience of a particular phenomenon. Therefore, this approach has limitations when the phenomenon being explored has a strong relational or systemic element, such as understanding a caring relationship. Multiperspectival IPA maintains a commitment to depth and idiography in data collection and analysis, but the

combination of two or more perspectives enables a wider understanding of the relational, intersubjective, and systemic dimensions of phenomena (Larkin et al., 2019).

Multiperspectival IPA retains strong links to phenomenology, hermeneutics, and idiography, while also being connected to concepts from systemic psychology. The key theoretical underpinning of including multiple perspectives within IPA, is the view that important meanings are often located "in between" people and groups (Larkin et al., 2019). Although more concerned with the "inner world" of individuals, Husserl did describe how perceptions of the "outer world" of things and events are influenced by our spatial and relational place in the world. This concept was further developed by Heidegger and Merlau - Ponty who emphasised the mutuality of the person and the world. Therefore, our sense of experience is a result of our position and perspective in relation to the experience or object we observe (Larkin et al., 2019).

Frequently, psychological research is focused on the experiences of individuals, viewed as held in the mind of individuals (Bradley, 2005). Hermeneutics offer a different perspective as it is concerned with intersubjective aspects of experience. Multiperspectival IPA approaches view experiences as complex, dynamic, and subject to processes of mutual meaning making (Larkin et al., 2019). Similarly, systemic theories view that events are best understood by considering what happens between individuals in terms of interactions, stories, and language (Anderson, 1987). Therefore, multiperspectival IPA is related to systemic theories in that there is a view that varying perspectives on particular experiences can be understood by a third party by exploring meaning making and ensuring an understanding that each perspective offers greater understanding of aspects of shared experiences (Larkin et al., 2019).

Rationale for Methodology

My epistemological position in relation to psychological research is a constructivist, interpretivist approach. This position relates to the belief that reality and meaning are constructed through complex processes of social interactions and that to understand this meaning a process of interpretation is required (Schwandt, 1998; Willig, 2013). The research question was formulated in line with this epistemological stance.

The aim of the major research project was to understand the lived experience of receiving and providing maternity care for autistic mothers. Therefore, a multiperspectival IPA approach was selected. IPA enables the researcher to explore the personal lived experiences of individuals and how they respond to and interpret these experiences (Smith et al, 2009). IPA is also interpretative and recognizes the role of the researcher engaging in a 'double hermeneutic' of making sense of how individuals make sense of their experience (Smith et al., 2009). In this way, IPA gives voice to the concerns of participants while also contextualising and making sense of these concerns (Larkin et al., 2006).

Increasingly, qualitative research is exploring the lived experience of being autistic (DePape & Lindsay, 2016), however, there is limited research exploring the lived experience of the perinatal period for autistic women (McDonnell & De Lucia, 2021). Therefore, an IPA approach was warranted in order to give voice and make sense of the experience of maternity care for this population. Further, the 'double empathy problem' highlights the mutual misunderstandings that can occur between autistic participants and non-autistic researchers (Milton, 2012) and is often seen as a limitation to autism research (Howard et al., 2019). It has been suggested that IPA's recognition of the 'double hermeneutic' and focus on reflexivity may be particularly suitable in autism research as these concepts lessen the impact of the 'double empathy problem' by actively considering the context of participant's meaning

making and the researcher's interpretation (Howard et al., 2019). Similarly, IPA's foregrounding of individual experiences and focus on researcher reflexivity means research which utilises IPA methodology has been found to align well with participatory approaches to autism research (MacLeod, 2019).

Specifically, a multiperspectival IPA approach was chosen due to the apparent relational focus of the concept of 'maternity care' which necessarily includes a care giver and care recipient. Therefore, it was deemed important to consider the intersubjective, relational aspects of maternity care with an exploration of the meaning that is constructed "in between" (Larkin et al., 2019) autistic mothers and maternity care professionals. Multiperspectival designs appear to be increasingly common in understanding relationships between healthcare providers and patients (Borg Xuereb et al., 2015; Larkin et al., 2009). An advantage of multiperspectival designs is the capacity for greater inferential range when combining the viewpoints of two related groups regarding a specific phenomenon (Larkin et al., 2019). Idiography remains important within multiperspectival designs and, thus, careful consideration of how multiple perspectives relate to and impact one another is required, in order to avoid artificially implying consensus across perspectives (Larkin et al., 2019).

Public and Patient Involvement

This major research project was also designed with consideration of guidelines for public and patient involvement (PPI) and participatory autism research. For some time, PPI has been an important and expected component of health-related research activity (Mockford et al., 2012). Public involvement in research has been defined as "research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" (INVOLVE, 2012, p.6). A PPI model increases the value of studies for both researchers and the group

being studied and is associated with greater impact on healthcare services (Mockford et al., 2012).

Traditionally, autism research was primarily carried out ‘on’ or ‘for’ autistic people without considering the important insider perspective of being an autistic person (Pellicano et al, 2014). However, in recent years there has been a significant shift towards autism research being codesigned and coproduced by the autism community (Fletcher-Watson et al., 2019; Nicolaidis et al., 2019; Pellicano & den Houting, 2021). Meaningful input from autistic people in autism research ensures the research produced is meeting the specific needs of this group and that any interventions developed as a result of research have greater clinical efficacy (Fletcher-Watson et al., 2019).

The current research was informed by a project advisory panel of autistic people, utilising a ‘consultation’ approach to PPI research (INVOLVE, 2012). A consultation model within PPI is “when you ask members of the public for their views and use these views to inform your decision making’ (INVOLVE, 2012, p.21). This usually takes the form of one-off meetings around specific elements of a proposed project. The advisory panel of autistic people had previously contributed to research conducted by my research supervisor. This panel of people were approached and asked if they would be willing to contribute to the current project for which they would receive financial compensation. The panel consisted of five autistic women, all based in the UK, aged between 25 and 45. A brief online meeting was held in which I introduced myself and my research topic to the panel. At this stage, some participants commented on their experiences of motherhood and suggested topics that appeared important to include within an interview.

In Spring 2022, Google Forms was utilised to enable the advisory panel to provide feedback and comments on an initial draft of a semi-structured interview schedule. Members

of the panel highlighted difficulties with ambiguous wording of some questions and suggested that many autistic people would feel more comfortable if there were some prompts included, if it was made clear that there was no 'right' answer, and if questions were phrased as clearly and directly as possible. Importantly, in setting up this aspect of the PPI feedback, participants generally agreed that they would prefer to contribute by writing feedback rather than participating in an online, verbal meeting. This experience also informed the design of data collection methods within the current study, which were adapted to include the option to participate in a written interview. This provision was also informed by guidelines on inclusivity in autism research, which highlight that the provision of various modes of research participation maximises accessibility and the inclusion of autistic people with various strengths and needs (Nicolaidis et al., 2019).

Sampling and Recruitment

Purposive sampling was utilised within the current study in order to ensure that participants all had experiences of receiving or providing maternity care for autistic mothers. Purposive sampling is in line with IPA's objective to ensure a detailed examination of the lived experience of participants (Smith & Nizza, 2022). In recruiting both groups of participants, efforts were made to ensure two relatively homogenous samples of autistic mothers and maternity care professionals in order to ensure the research question and findings were as meaningful as possible. The primary criteria for assessing homogeneity was as follows; for autistic mothers, that they had an autism diagnosis and had experienced giving birth and, for maternity care professionals, that they had experience of delivering maternity care to autistic women.

Recruitment of Autistic Mothers

No specialist services exist for autistic parents or autistic women in Ireland and there are significant challenges associated with accessing an autism assessment or diagnosis as an

adult (Huang et al., 2020). Therefore, the decision was made to utilise social media in order to ensure access to a wider geographical population. A post (Appendix L) was shared by members of the research team on Twitter and on Facebook groups related to autistic women, autistic parents, and parents of children on the autism spectrum. Initially, seven individuals contacted the primary researcher. Six agreed to participate in online interviews, however two eventually dropped out due to scheduling difficulties. Another participant agreed to participate in a written interview and was sent the interview questions, however declined to respond to follow up e-mails. Therefore, four autistic mothers participated in the study.

Recruitment of Maternity Care Professionals

Approval was granted by the Local Information Governance Group of Cork University Maternity Hospital (CUMH) to recruit maternity care professionals through the maternity hospital. This process was supported by a field supervisor who worked as a clinical psychologist within the maternity hospital. A recruitment e-mail and information sheet (Appendix M) was sent to all staff at the hospital, encouraging interested maternity care professionals to contact the lead researcher. No staff from CUMH contacted the primary researcher. The challenges associated with accessing an autism assessment as an adult in Ireland mean it may be less likely that women in Ireland identify themselves as autistic within maternity services. There is limited data available regarding adult rates of autism, but one report has estimated that 1.5% of Irish school going children have an autism diagnosis (NCSE, 2016). Plausibly, the rates of diagnosis in adult females would be significantly lower, reducing the likelihood that MCPs in Ireland have provided care for autistic women.

Therefore, social media was again utilised to recruit maternity care professionals. A post (Appendix L) was shared on Twitter and on Facebook groups related to midwifery,

nursing, and obstetrics. This resulted in six midwives contacting the primary researcher. Four midwives returned signed informed consent forms and participated in individual interviews.

Data Collection

In depth semi-structured interviews are the most common means of collecting the rich, detailed first-person accounts of experiences required for IPA (Smith & Nizza, 2022). Therefore, separate interview schedules were designed for autistic mothers and maternity care professionals (Appendix O). As noted above, feedback from the PPI panel was incorporated which resulted in the inclusion of prompts and an introductory paragraph designed to increase comfort for autistic participants. The schedule was also designed so that it could be utilised in a written interview via e-mail, with consideration of principles of inclusivity in autism research (Nicolaidis et al., 2019), ultimately this option was not chosen by any of the participants. The interview schedules were used as a guide in interviews, however, flexibility was important throughout interviews in responding to topics that were important for each individual participant and dealing with unexpected information that arose (Smith & Nizza, 2022). All interviews were conducted online via Microsoft Teams. Participants varied in their preferences for having their cameras on or off, which did not appear to impact on the development of rapport or the quality of the information that was shared.

Data Analysis

IPA analysis is an inductive, iterative process. Although the process of IPA analysis is flexible, the steps outlined by Smith and Nizza (2022) informed the analysis in the current study. The process of analysis was further informed by key papers on multiperspectival IPA by Larkin et al. (2019) and Rostill-Brookes et al. (2011). Steps one to four, outlined below, were completed eight times for each individual interview transcript. Step five, cross-case analysis was completed twice, once for the group of autistic mothers, and once for the group

of midwives. Step six was completed once in order to draw together the multiple perspectives of both groups.

Step One: Reading and Exploratory Notes

The first step involved reading and re-reading each individual transcript while recording initial reactions to the text in one margin. I followed guidance from Smith et al. (2009) and differentiated between descriptive, linguistic, and conceptual notes. Descriptive notes summarized the elements of the transcript which structured the participant's thoughts and experiences (Smith & Nizza, 2022). Linguistic notes pertained to the participants' use of language and how this may relate to the participants' meaning making. Therefore, long pauses, repetitions, laughter, and tone were commented on where relevant. Conceptual notes shift away from the explicit claims of participants and are more interpretative, often taking the form of questions. This process of note making is illustrated for a portion of one participant's transcript in Appendix P.

Step Two: Formulating Experiential Statements

This step involved capturing what was learned about the meaning of the experience to each participant in each portion of text and was developed from the exploratory notes that were taken in step one. Experiential statements are usually connected to a specific place within the transcript and combine the important aspects of participants' experiences with the analyst's understanding of that experience (Smith & Nizza, 2022). This is a reflective and time-consuming process, which is reviewed at various time points due to the iterative nature of the IPA process. A selection of experiential statements connected to the relevant segment of transcript is also contained in Appendix P.

Step Three: Finding Connections and Clustering Statements

Step two results in a long list of experiential statements for each interview transcript. Therefore, the next step is to refine and review these statements finding connections and patterns amongst them. To this end, I printed the experiential statements for each interview in order to visually group clusters of statements and to easily position and reposition individual statements. A subset of experiential statements and the resulting clusters is presented in Appendix Q.

Step Four: Compiling the Table of Personal Experiential Statements

Once the clustering felt meaningful, I then converted the clusters into a table of personal experiential themes, where I named each cluster and included the identifying information for all the experiential statements. This process is illustrated in Appendix R in relation to the clusters presented in Appendix Q.

Step Five: Cross-Case Analysis

This step involved looking at patterns and differences within groups and resulted in a new table of group experiential themes. This process involved examining together the table of personal experiential themes for each group member and identifying connections, patterns, and differences. An example of a group experiential theme is presented in Appendix S. Tables containing theme names are also presented for each group in Appendix T.

Step Six: Between Group Analysis

The final step was multiperspectival analysis. This final step involved comparing and contrasting the two tables of group level experiential themes in order to identify patterns, divergences, and relationships across groups. This also involved reconsidering and renaming

themes in order to reflect the relationship between groups. The final multiperspectival table, which references group experiential themes, is presented in Appendix U.

Finally, it is important to note that although these steps were followed, the iterative nature of IPA meant there was a constant shifting between steps in order to best understand and illuminate the lived experiences of participants. Even in writing up the results, new understandings emerged, and gaps were identified. The process of IPA analysis also involved a continuous process of referring back to original transcripts to check that participants' subjective, idiographic experiences were being reflected.

Ethical Considerations

This research was designed and conducted with consideration of the Code of Professional Ethics established by the Psychological Society of Ireland (PSI, 2019). In designing my major project, I endeavoured to ensure it was in keeping with the ethical principles of respect for the rights and dignity of the person, competence, responsibility, and integrity (PSI, 2019).

Informed Consent

Potential participants contacted the researcher following posts on social media (Appendix L) At this stage, participants were provided with an information sheet (Appendix M) detailing what participation would entail, the likely risks and benefits, the right to withdraw consent, the time limit for withdrawal of consent, and the procedures for audio recording, and data storage. Participants were given the opportunity to ask any questions prior to consenting to take part in the study. At the beginning of interviews participants were briefly reminded of this information and given a second opportunity to ask any questions.

Anonymity

Interview transcripts were anonymised to protect the identities of participants in the study. This involved omitting the names of people and places. Once transcripts had been transcribed and anonymised the original recordings were deleted. Each participant was assigned a pseudonym which was used during analysis, in discussion with supervisors, and in writing up the results of the study.

Potential for Harm

Due to the potentially upsetting nature of the topic being explored, consideration was given to the possibility of participants experiencing emotional distress during interviews. Therefore, it was made clear to participants that they could choose not to answer particular questions, take breaks if they needed to, and could choose to end the interview at any time. Due to my role as a trainee clinical psychologist, I felt equipped to recognize and respond to emotional distress in participants. I remained attuned to participants' emotional states throughout interviews. At the end of each interview, I checked in with participants regarding their emotional state and thanked them for their participation. A list of available supports and services was prepared for participants in case they required additional support following interviews. No participants experienced emotional distress during interviews and there was no requirement to provide this list to participants.

Ethical Approval

Ethical approval was granted by the UCC Clinical Psychology Research Ethics Committee (Appendix K). Approval was also granted by the Local Information Governance Group of Cork University Maternity Hospital to recruit maternity care professionals through the maternity hospital.

Reflexivity

Reflexivity requires an awareness of the researcher's own impact on the production of meaning within qualitative research (Willig, 2013). This process of acknowledging the intersubjective, interpretative nature of qualitative research and the impact of these factors on all stages of research design, data collection, and analysis enhances the trustworthiness and transparency of qualitative findings (Finlay, 2002).

Given the hermeneutic underpinnings of IPA research, researcher reflexivity is central to ensuring that the researcher's interpretation is derived from participants' subjective interpretations rather than being overtly influenced by the researcher's prior knowledge and beliefs (Smith et al., 2009). Reflexivity is required within and throughout each stage of analysis within IPA (Engward & Goldspink, 2020). Therefore, in this section I acknowledge my subjective position in relation to participants and how this has been informed by my roles, values, and beliefs. I also describe the measures I employed to ensure reflexivity throughout the research process.

Reflexive Statement

I am a white, Irish, female in her 30s. These demographic characteristics were shared by the majority of participants within the current study which may have influenced participants willingness to share their experiences with me and also influenced my interpretation of some of those experiences. I am currently in the final year of a Doctoral training programme in Clinical Psychology and have worked within the field of mental health for the past eight years. These experiences have shaped my values and beliefs and influenced the way in which I interact with individuals sharing their life experiences. Predominantly, this was an advantage in the research process as I felt I could attune to participants emotional states and use appropriate questioning to get at deeper interpretative meanings. At times, I

found it difficult to switch off my clinical thinking and reasoning as the format of individual one-to-one interviews was strikingly similar to the one-to-one therapeutic work which makes up a large part of my role as a trainee clinical psychologist. Therefore, it was necessary to consider how clinical concepts such as reflecting and paraphrasing could impact and shape participants responses.

I am not a mother and have not experienced pregnancy or childbirth, therefore, I did not have a personal experience of maternity care to draw on. I do hope to be a parent in the future, and I did recognise emotions such as worry and disappointment at the provision of maternity care which arose from this subjective position. After the research design and data collection phase of this project I began a clinical placement in the specialist perinatal mental health service within Cork University Maternity Hospital. This experience did give me additional insight into both the experiences of women in the perinatal period and the profession of midwifery. Therefore, when analysing interview transcripts I was more likely to connect participants experiences with the experiences of clinical clients and midwifery colleagues. Therefore, as much as possible, I attempted to be explicit about these connections in supervision and in my reflexive journal.

It is also important to acknowledge my position as a non-autistic researcher. A primary motivation for carrying out this research was my experience of working with mothers and fathers who began to recognise their own autism traits as a result of their childrens' diagnoses. I have also worked clinically with autistic young people and adults. Although I have clinical experience of working with people on the autism spectrum, I was careful to consider the preconceived knowledge and ideas this work had resulted in before undergoing this research. I also attempted to bring conscious awareness to the presence of the

'double empathy problem' (Milton, 2012) and acknowledge how my position as a non-autistic researcher could influence my interpretations of autistic peoples' experiences.

Reflexive Process

Considering my epistemological position and writing a reflexive statement ensured that I developed and made explicit my awareness of how my own views, values, and beliefs could impact the interpretative process of IPA.

In order to ensure rigour throughout the research process reflexive journals are recommended as a central component of reflexivity in qualitative research (Bradbury-Jones, 2007). Therefore, I used a reflexive journal at all stages of the research process. This process was helpful in bracketing and acknowledging my biases and expectations regarding autism, motherhood, pregnancy, maternity care and midwifery both before and in between individual interviews. My use of a reflexive journal also facilitated my awareness of when I was becoming overly clinical regarding participants' experiences in a way which was more in line with formulation within clinical psychology rather than interpretation in qualitative research. Discussions with my research supervisors complemented my use of reflexive journalling and enabled me to test out my concerns regarding being overly clinical in my approach to analysis.

Alongside this process of reflexive journalling, I also made sure to carefully document my decision-making regarding research design and data analysis. I also asked my research supervisor to review a selection of my initial noting of transcripts and my descriptions of themes to ensure this process was not unduly impacted by my own beliefs, while still being interpretative.

References

Andersen, T. (1987). The reflecting team: dialogue and meta-dialogue in clinical work. *Family Process*, *26*(4), 415–28. https://doi.org/10.1111/j.1545-5300.1987.00415.x

Borg Xuereb, C, Shaw, RL & Lane, D. (2015). Patients' and physicians' experiences of atrial fibrillation consultations and anticoagulation decision-making: a multi-perspective IPA design. *Psychology & Health, 31*(4). https://doi.org/10.1080/08870446.2015.1116534

Bradbury-Jones, C. (2007). Enhancing rigour in qualitative health research: Exploring subjectivity through Peshkin's I's. *Journal of Advanced Nursing*, *59*(3), 290–298. https://doi.org/10.1111/j.1365-2648.2007.04306.x

Bradley, B. (2005). *Psychology and Experience.* Cambridge University Press.

DePape, A.-M., & Lindsay, S. (2016). Lived Experiences from the Perspective of Individuals with Autism Spectrum Disorder: A Qualitative Meta-Synthesis. *Focus on Autism and Other Developmental Disabilities*, *31*(1), 60–71. https://doi.org/10.1177/1088357615587504

Engward, H., & Goldspink, S. (2020). Lodgers in the house: Living with the data in interpretive phenomenological analysis research. *Reflective Practice*, *21*(1), 41–53. https://doi.org/10.1080/14623943.2019.1708305

Finlay, L. (2002). Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research*, *2*(2), 209–230. https://doi.org/10.1177/146879410200200205

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism, 23*(4), 943–953. https://doi.org/10.1177/1362361318786721

Howard, K., Katsos, N., & Gibson, J. (2019). Using interpretative phenomenological analysis in autism research. *Autism, 23*(7), 1871–1876. https://doi.org/10.1177/1362361318823902

Huang, Y., Arnold, S. R., Foley, K.-R., & Trollor, J. N. (2020). Diagnosis of autism in adulthood: A scoping review. *Autism, 24*(6), 1311–1327. https://doi.org/10.1177/1362361320903128

INVOLVE. (2012). *Briefing notes for researchers: involving the public in NHS, public health and social care research.* INVOLVE, Eastleigh. Retrieved December 20, 2021 https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371

Larkin, M., Clifton, E., & de Visser, R. (2009). Making sense of 'consent' in a constrained environment. *International Journal of Law and Psychiatry, 32*(3), 176–183. https://doi.org/10.1016/j.ijlp.2009.02.003

Larkin, M., Shaw, R., & Flowers, P. (2019). Multiperspectival designs and processes in interpretative phenomenological analysis research. *Qualitative Research in Psychology, 16*(2), 182–198. https://doi.org/10.1080/14780887.2018.1540655

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

MacLeod, A. (2019). Interpretative Phenomenological Analysis (IPA) as a tool for participatory research within Critical Autism Studies: A systematic review. *Research in Autism Spectrum Disorders, 64*, 49–62. https://doi.org/10.1016/j.rasd.2019.04.005

McDonnell, C. G., & DeLucia, E. A. (2021). Pregnancy and Parenthood Among Autistic Adults: Implications for Advancing Maternal Health and Parental Well-Being. *Autism in Adulthood, 3*(1), 100–115. https://doi.org/10.1089/aut.2020.0046

Milton, D. E. M. (2012). On the ontological status of autism: The 'double empathy problem.' *Disability & Society, 27*(6), 883–887. https://doi.org/10.1080/09687599.2012.710008

Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. (2012). The impact of patient and public involvement on UK NHS health care: a systematic review. *International Journal for Quality in Health Care, 24*(1), 28-38. https://doi.org/10.1093/intqhc/mzr066

National Council for Special Education (NCSE) (2016). Policy Advice on Supporting Students with Autism Spectrum Disorder in School. NCSE. https://ncse.ie/policy-advice-on-supporting-students-with-autism-spectrum-disorder-in-schools

Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism, 23*(8), 2007–2019. https://doi.org/10.1177/1362361319830523

Pellicano, E., & Houting, J. (2022). Annual Research Review: Shifting from 'normal science' to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry, 63*(4), 381–396. https://doi.org/10.1111/jcpp.13534

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, *18*(7), 756–770. https://doi.org/10.1177/1362361314529627

Psychological Society of Ireland. (2019). *Code of Professional Ethics.* https://www.psychologicalsociety.ie/footer/Code-of-Ethics-1

Rostill-Brookes, H., Larkin, M., Toms, A., & Churchman, C. (2011). A shared experience of fragmentation: Making sense of foster placement breakdown. *Clinical Child Psychology and Psychiatry*, *16*(1), 103–127. https://doi.org/10.1177/1359104509352894

Schwandt, T. A. (1994). Constructivist, interpretivist approaches to human inquiry. *Handbook of qualitative research*, *1*(1994), 118-137.

Smith, J. A., & Nizza, I. E. (2022). *Essentials of interpretative phenomenological analysis.* American Psychological Association.

Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods (*pp. 51–80). Sage Publications.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. SAGE.

Willig, C. (2013). *Introducing Qualitative Research in Clinical Psychology.* Open University Press.

Chapter Six: Discussion and Conclusion

This chapter summarises the findings of the two studies described in this thesis and discusses the clinical implications of the research. The aim of this thesis was to explore the experiences of autistic adults accessing healthcare services, specifically mental health, and maternity services.

Summary of Findings

Mental Health Professionals' Experiences of Adapting Mental Health Interventions for Autistic Adults

The systematic review in Chapter Two synthesised evidence from 13 qualitative studies on mental health professionals' experiences of adapting mental health interventions (MHI) for autistic adults. Thematic synthesis highlighted that professionals view adapting MHI for autistic adults as a unique aspect of their work. Professionals described a strong awareness of the necessity for individual adaptations, based on the unique needs of individual autistic clients. This was in line with the preferences that have been identified by autistic adult mental health users and is reflected in NICE guidance (Brice et al., 2021; NICE, 2021).

Similarly, the most frequently mentioned adaptations, which included: communication style, involving others, incorporation of special interests, focus on behaviour, adjustments to intervention pace, length, or duration, as well as environmental adaptations, were in line with adaptations which have been suggested by autistic people and professional guidance (Brice et al., 2021; Crane et al., 2019; NICE, 2021). As well as these findings which support previous research in the area, the thematic synthesis in this thesis contributed several novel findings. Professionals identified that they hold different expectations regarding the outcomes and evaluation of adapted MHI for autistic adults. Professionals highlighted that

standard methods of evaluating treatment outcomes may not be sufficient in identifying the impact of adapted MHI for autistic adults.

Findings from the systematic review also highlighted some unique challenges and facilitators experienced by professionals in adapting MHI for adults on the autism spectrum. Professionals' attitudes to adapting MHI varied. Some professionals enjoyed adapting MHI and experienced this as a rewarding aspect of their work. Other professionals felt ambivalent or fearful regarding the work of adapting MHI for autistic adults. Therefore, attitudes held by professionals could act as either a barrier or facilitator to adapting MHI. This offers further explanation to the finding that autistic adults perceive therapists' unwillingness to tailor MHI to be a significant barrier in accessing mental health treatment (Adams & Young, 2021). Findings here suggest that mental health professionals may be fearful or uncertain rather than 'unwilling'.

In relation to challenges identified by the thematic synthesis, professionals described how the complexity of autism, particularly the difficulty of discerning symptoms of mental health difficulties from autism characteristics, challenged their ability to appropriately adapt MHI for autistic clients. Professionals also described how limited resources such as a lack of autism training, the limited evidence base, and time and resource constraints, impacted their ability to use adapted MHI with autistic adults. Professionals also reported that their ability to flexibly adapt MHI for autistic adults was constrained by working within inflexible systems. Factors which facilitated professionals in using adapted MHI for autistic adults included a personal capacity to work flexibly, prior experience and understanding of autism, and the presence of supportive relationships, both with important others in their autistic clients lives and with other professionals. These factors, identified by mental health professionals, are in line with the model proposed by Nicolaidis et al. (2015) as a result of research exploring

autistic adults' experiences with healthcare. This model proposed that a variety of patient, healthcare provider, and system level factors interact to determine the success of healthcare interactions (Nicolaidis et al., 2015).

The Experience of Receiving and Providing Maternity Care for Autistic Mothers

In the major research project, both autistic mothers and midwives experienced challenges in making sense of how autistic people 'fit' within maternity services. Autistic mothers found the experience of maternity care overwhelming and struggled when their experiences did not match their expectations. Mothers and midwives both identified particular challenges for autistic women in navigating the physical space of maternity care. For example, autistic mothers felt environmental factors such as shared wards, bright lights, unfamiliar environments, and sounds, contributed to a sense of feeling powerless and out of control. This finding supports previous research on the sensory challenges experienced by autistic mothers during the perinatal period (Donovan, 2017; Gardner et al., 2016; Rogers et al., 2016; Hampton et al., 2021). Therefore, the environmental aspect of maternity care services can be seen as a key contributor to autistic mothers' distress within maternity care.

A novel feature of the current thesis was the exploration of midwives' experiences of delivering maternity care for autistic mothers. From the midwives' perspective, the physical environment was deemed to be unsatisfactory for all mothers. However, they recognised a particular emotional impact of environmental factors on autistic patients in their care. All midwives in this study had significant personal experience of autism and two had an autism diagnosis. However, they believed autism was an overlooked experience within maternity care and midwifery training. Due to their personal experiences, midwives advocated for their autistic patients and found this to be a rewarding aspect of their work. They also struggled with making sense of misperceptions and biases they observed from colleagues and felt these

biases had an impact on how autistic mothers are perceived and treated within maternity services.

The caring relationship between mother and midwife was experienced as a valued component of maternity care by both autistic mothers and midwives. Autistic mothers described significant, positive impacts of person-centred caring relationships that developed during their maternity experiences. Similarly, midwives regarded ongoing relationships with autistic mothers as being significant in allowing them to identify specific challenges faced by mothers in their care. This supports findings from neurotypical mothers that the quality of relational support has a significant impact on mothers' perceptions of perinatal care (Britton, 2012). Therefore, this caring relationship is similarly important for autistic mothers, however, both groups identified specific challenges in establishing this relationship. Midwives in the current study identified that, from their perspective, some colleagues' misperceptions of autistic mothers impacted on their ability to develop strong relationships with these women. Autistic mothers struggled to develop relationships when there was multiple MCPs involved in their care and had a strong preference for continuity of care with a small number of professionals. Importantly, a continuity of care model of maternity care is associated with improved outcomes and greater satisfaction with care for all mothers (Bradford et al., 2022; Perriman et al., 2018). Findings here suggest that this model of service would have additional, specific benefits for mothers on the autism spectrum.

Further, both groups identified specific communication challenges that could contribute to difficulty building relationships within maternity care. Previous research has identified that, compared to non-autistic mothers, autistic mothers experience greater dissatisfaction in their communication with MCPs (Pohl et al., 2020). The findings from the current study offers further explanation as to how these communication challenges are

experienced by both autistic mothers and midwives. Autistic mothers described difficulty in making their needs known to MCPs, they described a sense of feeling unheard by professionals and perceived communication from MCPs as being overly casual and dismissive. Similarly, midwives identified a sense that autistic mothers sometimes 'shut down' which contributed to difficulty in identifying their needs and forming relationships. Midwives within the current study felt, due to their personal understanding of autism, part of their role was to bridge the communication gap between autistic mothers and other MCPs.

Findings from the major research project also identified the challenge of competing priorities for autistic mothers and midwives. Autistic mothers experienced significant and long-lasting impacts from the physical interventions of maternity care. Medical interactions were experienced as upsetting and traumatic by autistic mothers. This experience was recognised by both autistic midwives sampled, however, was not considered by the non-autistic midwives in the sample. This lack of awareness could inadvertently contribute to the experience of trauma for autistic mothers within maternity care services (Watson et al., 2021). Autistic mothers also expressed a desire for emotional care to form part of their maternity care and identified that there was little space for emotional expression within maternity services. Midwives felt constrained by competing demands within the system which impacted their ability to offer the additional time and care that was required for autistic mothers. This is in line with research exploring barriers to midwives addressing mental health concerns in the perinatal period (Higgins et al., 2018).

Mothers experienced limited power, autonomy, and choice in their maternity care. Research by O' Brien et al. (2021) highlighted that trusting relationships between mothers and midwives have a significant influence on shared decision making. However, midwives here identified that autistic mothers who expressed a desire for altered care were often viewed

as ‘difficult’ by MCPs. This suggests that difficulties within the relationship contribute to a sense of limited choice and power for autistic mothers. Midwives within the current study also experienced limited power and choice in being able to adapt care for their autistic patients due to the dominant model of maternity care and perceptions from their maternity care colleagues. Both groups identified that midwifery led care may be a model of maternity care that is particularly suitable for autistic mothers. This is in line with research which found that midwifery-led models increase patient satisfaction with care (Sutcliffe et al., 2012). Although medical complications may exclude women from accessing a midwifery led model of maternity care, the philosophical and relational aspects of this model (Sutcliffe et al., 2012) could be applied across contexts to benefit autistic mothers.

Clinical Implications

Findings from both studies highlight limited autism awareness within generic healthcare services. This lack of awareness has the potential to cause harm by contributing to trauma in a maternity context (Beck, 2009) and by acting as a barrier to accessing mental health services (Adams & Young, 2021). Therefore, there is a need for additional awareness and training for healthcare professionals working with autistic adults. Additional training has been found to change non-autistic people’s perception of behaviours displayed by people on the autism spectrum, to reduce stigma, and increase positive attitudes towards autistic people (Gillespie-Lynch et al., 2015). Autistic people should be central in the provision of any such training, as this is associated with enhanced understanding of autism and a further reduction in stigma (Gillespie-Lynch et al., 2017).

Results from the major research project, in particular, suggest that there is an important role for autistic healthcare professionals in contributing to colleague’s understanding of autism and in improving care for autistic patients. The autistic midwives sampled within the major research project, acted as advocates for their autistic patients and

described bridging the gap between colleagues and mothers on the autism spectrum. Autistic led peer support has been found to be particularly supportive in post-diagnostic support services (Crane et al., 2021). Findings, from this thesis imply that peer led support would also be beneficial in the context of maternity and, feasibly, mental health services. Little research exists exploring the rates of autism among healthcare professionals, however in one study of 304 UK based GPs, 1% identified as autistic (Unigwe et al., 2017). As described elsewhere, greater support and understanding is required to enable autistic healthcare professionals to continue to offer benefit within healthcare services (Moore et al., 2020). Importantly, non-autistic professionals in both studies did also advocate for their autistic clients and were attuned to their unique needs. Therefore, autism advocate or peer support roles should be formalised within maternity and mental health services.

Findings from both papers also highlight the necessity of flexibility from healthcare professionals and within healthcare services for autistic people. Much of how this need is described within the current thesis is in keeping with the concept of patient centred care, which was initially described as "understanding the patient as a unique human being" (Balint, 1969). Seemingly, this need for flexibility is not specific to autistic healthcare service users, however, increased patient centred practice may offer particular advantage for autistic adults. As outlined throughout this thesis, autistic adults are more likely to struggle within healthcare services and so, healthcare which is patient centred, communicative, compassionate, and accommodating (Santana et al., 2017), is more likely to meet the needs of autistic adults. Therefore, clinicians should endeavour to adapt their practices based on the unique needs of individual autistic clients. An online healthcare toolkit has been developed to assist autistic adults in identifying the accommodations they require for accessing primary healthcare (Nicolaidis et al., 2016). This has been found to improve the self-efficacy of autistic adults in identifying and communicating their needs. Healthcare providers also found it helpful in

better understanding their autistic clients (Nicolaidis et al., 2016). Aspects of this toolkit could be utilised for maternity services or mental health services to facilitate open discussions regarding the unique needs of autistic adults in accessing these healthcare services.

Notably, a systematic review of interventions to improve healthcare experiences in autism found that only 6.5% of 31 studies were organisation focused interventions (Walsh et al., 2021). However, findings from the current thesis suggests that systemic issues are a significant limiting factor in health care professionals' ability to offer adapted care for autistic adults. A framework for patient centred care highlights the role of organisation level factors in creating a culture, workforce, and environment which facilitates the provision of patient centred care (Santana et al., 2017). Within both studies, professionals and autistic adults made a number of suggestions regarding environmental adaptations and flexible systems which would enhance services for autistic adults. Therefore, the views of autistic adults should inform service design and provision at an organisational level. Many of the adaptations suggested could be considered through the lens of 'universal design' (Milton et al., 2016). Such adaptations, including sensory considerations and relational support, would likely improve the healthcare experiences of all health service users, while offering specific additional benefit for autistic adults due to the specific sensory and communication challenges that have been identified throughout this thesis.

Conclusion

The aim of this thesis was to explore the experiences of autistic adults accessing healthcare services, specifically mental health, and maternity care. Both the systematic review and the major research project also considered the experience of healthcare professionals in providing care for autistic adults. A number of unique challenges and facilitators were identified in the provision of healthcare for adults on the autism spectrum.

This thesis contributes to research aimed at improving the healthcare experiences of autistic adults by highlighting the clinical implications of findings.

References

Adams, D., & Young, K. (2021). A Systematic Review of the Perceived Barriers and Facilitators to Accessing Psychological Treatment for Mental Health Problems in Individuals on the Autism Spectrum. *Review Journal of Autism and Developmental Disorders*, *8*(4), 436–453. https://doi.org/10.1007/s40489-020-00226-7

Balint, E. (1969). The possibilities of patient-centered medicine. *The Journal of the Royal College of General Practitioners*, *17*(82), 269.

Beck, C. T. (2009). Birth Trauma and Its Sequelae. *Journal of Trauma & Dissociation*, *10*(2), 189–203. https://doi.org/10.1080/15299730802624528

Bradford, B. F., Wilson, A. N., Portela, A., McConville, F., Fernandez Turienzo, C., & Homer, C. S. E. (2022). Midwifery continuity of care: A scoping review of where, how, by whom and for whom? *PLOS Global Public Health*, *2*(10), e0000935. https://doi.org/10.1371/journal.pgph.0000935

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

Britton, J. R. (2012). The assessment of satisfaction with care in the perinatal period. *Journal of Psychosomatic Obstetrics & Gynecology*, *33*(2), 37–44. https://doi.org/10.3109/0167482X.2012.658464

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

Crane, L., Hearst, C., Ashworth, M., Davies, J., & Hill, E. L. (2021). Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme. *Journal of Autism and Developmental Disorders*, *51*(3), 892–905. https://doi.org/10.1007/s10803-020-04486-4

Donovan, J. (2020). Childbirth experiences of women with autism spectrum disorder in an acute care setting. *Nursing for Women's Health*, 24(3), 165-174. https://doi.org/10.1016/j.nwh.2020.04.001

Gardner, M., Suplee, P. D., Bloch, J., & Lecks, K. (2016). Exploratory study of childbearing experiences of women with Asperger syndrome. *Nursing for Women's Health*, 20(1), 28-37. https://doi.org/10.1016/j.nwh.2015.12.001

Gillespie-Lynch, K., Brooks, P. J., Someki, F., Obeid, R., Shane-Simpson, C., Kapp, S. K., Daou, N., & Smith, D. S. (2015). Changing College Students' Conceptions of Autism: An Online Training to Increase Knowledge and Decrease Stigma. *Journal of Autism and Developmental Disorders*, *45*(8), 2553–2566. https://doi.org/10.1007/s10803-015-2422-9

Hampton, S., Allison, C., Aydin, E., Baron-Cohen, S., & Holt, R. (2022). Autistic mothers' perinatal well-being and parenting styles. *Autism, 26*(7), 1805–1820. https://doi.org/10.1177/13623613211065544

Higgins, A., Downes, C., Monahan, M., Gill, A., Lamb, S. A., & Carroll, M. (2018). Barriers to midwives and nurses addressing mental health issues with women during the perinatal period: The Mind Mothers study. *Journal of Clinical Nursing*, *27*(9–10), 1872–1883. https://doi.org/10.1111/jocn.14252

Milton, D., Martin, N., & Melham, P. (2016). *Beyond reasonable adjustment: autistic-friendly spaces and Universal Design.* Pavilion Publishing and Media.

Moore, S., Kinnear, M., & Freeman, L. (2020). Autistic doctors: Overlooked assets to medicine. *The Lancet Psychiatry*, *7*(4), 306–307. https://doi.org/10.1016/S2215-0366(20)30087-0

National Institute for Health and Care Excellence (NICE). (2021). *Autism spectrum disorder in adults: Diagnosis and management*. https://www.nice.org.uk/guidance/cg142

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

Nicolaidis, C., Raymaker, D., McDonald, K., Kapp, S., Weiner, M., Ashkenazy, E., Gerrity, M., Kripke, C., Platt, L., & Baggs, A. (2016). The Development and Evaluation of an Online Healthcare Toolkit for Autistic Adults and their Primary Care Providers. *Journal of General Internal Medicine*, *31*(10), 1180–1189. https://doi.org/10.1007/s11606-016-3763-6

O'Brien, D., Butler, M. M., & Casey, M. (2021). The importance of nurturing trusting relationships to embed shared decision-making during pregnancy and childbirth. *Midwifery*, *98*, 102987. https://doi.org/10.1016/j.midw.2021.102987

Perriman, N., Davis, D. L., & Ferguson, S. (2018). What women value in the midwifery continuity of care model: A systematic review with meta-synthesis. *Midwifery*, *62*, 220–229. https://doi.org/10.1016/j.midw.2018.04.011

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

Rogers, C., Lepherd, L., Ganguly, R., & Jacob-Rogers, S. (2017). Perinatal issues for women with high functioning autism spectrum disorder. Women and Birth, 30(2), e89-e95. https://doi.org/10.1016/j.wombi.2016.09.009

Santana, M. J., Manalili, K., Jolley, R. J., Zelinsky, S., Quan, H., & Lu, M. (2018). How to practice person-centred care: A conceptual framework. *Health Expectations*, *21*(2), 429–440. https://doi.org/10.1111/hex.12640

Sutcliffe, K., Caird, J., Kavanagh, J., Rees, R., Oliver, K., Dickson, K., Woodman, J., Barnett-Paige, E., & Thomas, J. (2012). Comparing midwife-led and doctor-led maternity care: A systematic review of reviews: *Comparing midwife-led and doctor-led maternity care*. *Journal of Advanced Nursing*, *68*(11), 2376–2386. https://doi.org/10.1111/j.1365-2648.2012.05998.x

Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. (2017). GPs' confidence in caring for their patients on the autism spectrum: An online self-report study. *British Journal of General Practice*, *67*(659), e445–e452. https://doi.org/10.3399/bjgp17X690449

Walsh, C., O'Connor, P., Walsh, E., & Lydon, S. (2021). A Systematic Review of Interventions to Improve Healthcare Experiences and Access in Autism. *Review Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s40489-021-00279-2

Watson, K., White, C., Hall, H., & Hewitt, A. (2021). Women's experiences of birth trauma: A scoping review. *Women and Birth*, *34*(5), 417–424. https://doi.org/10.1016/j.wombi.2020.09.016

Appendices

Appendix A: Publishing Guidelines for the Journal of Autism and Developmental Disorders

Full list of author guidelines can be viewed here:

https://www.springer.com/journal/10803/submission-guidelines

Instructions for Authors

Editorial procedure

Double-Anonymous Peer Review

MANUSCRIPT FORMAT
All JADD manuscripts should be submitted to Editorial Manager in 12-point Times New Roman with standard 1-inch borders around the margins. Please disregard the suggestion of 10-point font in the Text section below.
APA Style
APA Publication Manual standards must be followed.
As of January 20, 2011, the Journal has moved to a double-anonymous review process. Therefore, when submitting a new manuscript, DO NOT include any of your personal information (e.g., name, affiliation) anywhere within the manuscript. When you are ready to submit a manuscript to JADD, please be sure to upload these 3 separate files to the Editorial Manager site to ensure timely processing and review of your paper:

- A title page with the running head, manuscript title, and complete author information. Followed by (page break) the Abstract page with keywords and the corresponding author e-mail information.
- The anonymized manuscripts containing no author information (no name, no affiliation, and so forth).

Types of papers

Articles, Commentaries Brief Reports, Letters to the Editor
*JADD is no longer accepting manuscripts with only one participant or group studies without an appropriate comparison group.

- The preferred article length is 20-23 double-spaced manuscript pages long (not including title page, abstract, tables, figures, addendums, etc.) Manuscripts of 40 double-spaced pages (references, tables and figures counted as pages) have been published. The reviewers or the editor for your review will advise you if a longer submission must be shortened.
- Special Issue Article: The Guest Editor may dictate the article length; maximum pages allowed will be based on the issue's page allotment.

- A Brief Report: A Brief Report: About 8 double-spaced pages with shorter references and fewer tables/figures. Must meet the demands of scientific rigor required of a JADD article but can be preliminary findings.
- A Letter to the Editor/Commentary is 6 or less double spaced pages with shorter references, tables and figures.
  Style sheet for Letter to the Editor:
- A title page with the running head, manuscript title, and complete author information including corresponding author e-mail information
- The anonymized manuscripts containing no author information (no name, no affiliation, and so forth):-
  - 6 or less double spaced pages with shorter references, tables and figures
  - Line 1: “Letter to the Editor”
  - Line 6: Text begins; references and tables, figure caption sheet, and figures may follow (page break between each and see format rules)

Review your manuscript for these elements

1. Order of manuscript pages
Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.
Anonymized Abstract, manuscripts and References without contact information
Appendix
Figure Caption Sheet
Figures
Tables
Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

Permissions

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

Online Submission

Please follow the hyperlink “Submit manuscript” and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

Title Page

Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.

Abstract

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

- Purpose (stating the main purposes and research question)
- Methods
- Results
- Conclusion

For life science journals only (when applicable)

- Trial registration number and date of registration for prospectively registered trials
- Trial registration number and date of registration followed by “retrospectively registered”, for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- **Competing Interests:** Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

Body

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
- Introduction (The introduction has no label.)
- Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
- Results (Center the heading.)
- Discussion (Center the heading.

Headings

Please use no more than three levels of displayed headings.
Level 1: Centered
Level 2: Centered Italicized
Level 3: Flush left, Italicized

Footnotes

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.
Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.
Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

Appendix B: Guidelines for Review of Electronic Search Strategies

Table 1. PRESS 2015 Guideline Evidence-Based Checklist

Translation of the research question	• Does the search strategy match the research question/PICO? • Are the search concepts clear? • Are there too many or too few PICO elements included? • Are the search concepts too narrow or too broad? • Does the search retrieve too many or too few records? (Please show number of hits per line.) • Are unconventional or complex strategies explained?
Boolean and proximity operators (these vary based on search service)	• Are Boolean or proximity operators used correctly? • Is the use of nesting with brackets appropriate and effective for the search? • If NOT is used, is this likely to result in any unintended exclusions? • Could precision be improved by using proximity operators (eg, adjacent, near, within) or phrase searching instead of AND? • Is the width of proximity operators suitable (eg, might adj5 pick up more variants than adj2)?
Subject headings (database specific)	• Are the subject headings relevant? • Are any relevant subject headings missing; for example, previous index terms? • Are any subject headings too broad or too narrow? • Are subject headings exploded where necessary and vice versa? • Are major headings (“starring” or restrict to focus) used? If so, is there adequate justification? • Are subheadings missing? • Are subheadings attached to subject headings? (Floating subheadings may be preferred.) • Are floating subheadings relevant and used appropriately? • Are both subject headings and terms in free text (see the following) used for each concept?
Text word searching (free text)	• Does the search include all spelling variants in free text (eg, UK vs. US spelling)? • Does the search include all synonyms or antonyms (eg, opposites)? • Does the search capture relevant truncation (ie, is truncation at the correct place)? • Is the truncation too broad or too narrow? • Are acronyms or abbreviations used appropriately? Do they capture irrelevant material? Are the full terms also included? • Are the keywords specific enough or too broad? Are too many or too few keywords used? Are stop words used? • Have the appropriate fields been searched; for example, is the choice of the text word fields (.tw.) or all fields (.af.) appropriate? Are there any other fields to be included or excluded (database specific)? • Should any long strings be broken into several shorter search statements?
Spelling, syntax, and line numbers	• Are there any spelling errors? • Are there any errors in system syntax; for example, the use of a truncation symbol from a different search interface? • Are there incorrect line combinations or orphan lines (ie, lines that are not referred to in the final summation that could indicate an error in an AND or OR statement)?
Limits and filters	• Are all limits and filters used appropriately and are they relevant given the research question? • Are all limits and filters used appropriately and are they relevant for the database? • Are any potentially helpful limits or filters missing? Are the limits or filters too broad or too narrow? Can any limits or filters be added or taken away? • Are sources cited for the filters used?

Abbreviation: PICO, population/problem, intervention/exposure, comparison, outcome

Appendix C: CASP Quality Appraisal

CASP Quality Assessment Table

Study	Siddell (2022)	Ainsworth et al. (2020)	Mitran (2022)	Heijnen-Kohl et al. (2022)	Russell et al. (2019)	Spain et al. (2017)	Hume (2022)	Cooper et al. (2018)	Maddox et al., (2020)	Babb et al. (2021)	Kinnaird et al. (2017)	Petty et al. (2021)	Petty et al. (2022)
Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the research design appropriate to address the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y
Was the data collected in a way that addressed the research issue?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Has the relationship between researcher and participants been adequately considered?	Y	Y	Y	N	Y	Y	N	CT	N	N	Y	N	N
Have ethical issues been taken into consideration?	CT	Y	Y	CT	Y	Y	CT	Y	CT	Y	Y	Y	Y
Was the data analysis sufficiently rigorous?	Y	Y	Y	Y	Y	Y	CT	Y	Y	Y	CT	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
How valuable is the research?	V	V	V	V	V	V	V	V	V	V	V	V	V

Appendix D: PRISMA Statement

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	p.24
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	p.24-28
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	p.29
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	p.30
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.30
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix E
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.31
Data collection process	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 study investigators, and if applicable, details of automation tools used in the process.	p.31 & Chapter 3
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.35-37 & Chapter 3
	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.35 -37 & Chapter 3
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.33 & Chapter 3
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)).	n/a
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Chapter 3

Section and Topic	Item #	Checklist item	Location where item is reported
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	n/a
	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.34
	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.	n/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	p.33
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.34
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	
Study characteristics	17	Cite each included study and present its characteristics.	p.35-37
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Appendix C
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.	n/a
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	n/a
	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.	n/a
	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.	n/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	n/a
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.47 - 49
	23b	Discuss any limitations of the evidence included in the review.	p.54

Section and Topic	Item #	Checklist item	Location where item is reported
	23c	Discuss any limitations of the review processes used.	p.54
	23d	Discuss implications of the results for practice, policy, and future research.	p.52 - 53
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.29
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	p.29
	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.23
Competing interests	26	Declare any competing interests of review authors.	p.23
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.	Chapter 2 & 3

Appendix E: Search Terms for Additional Databases

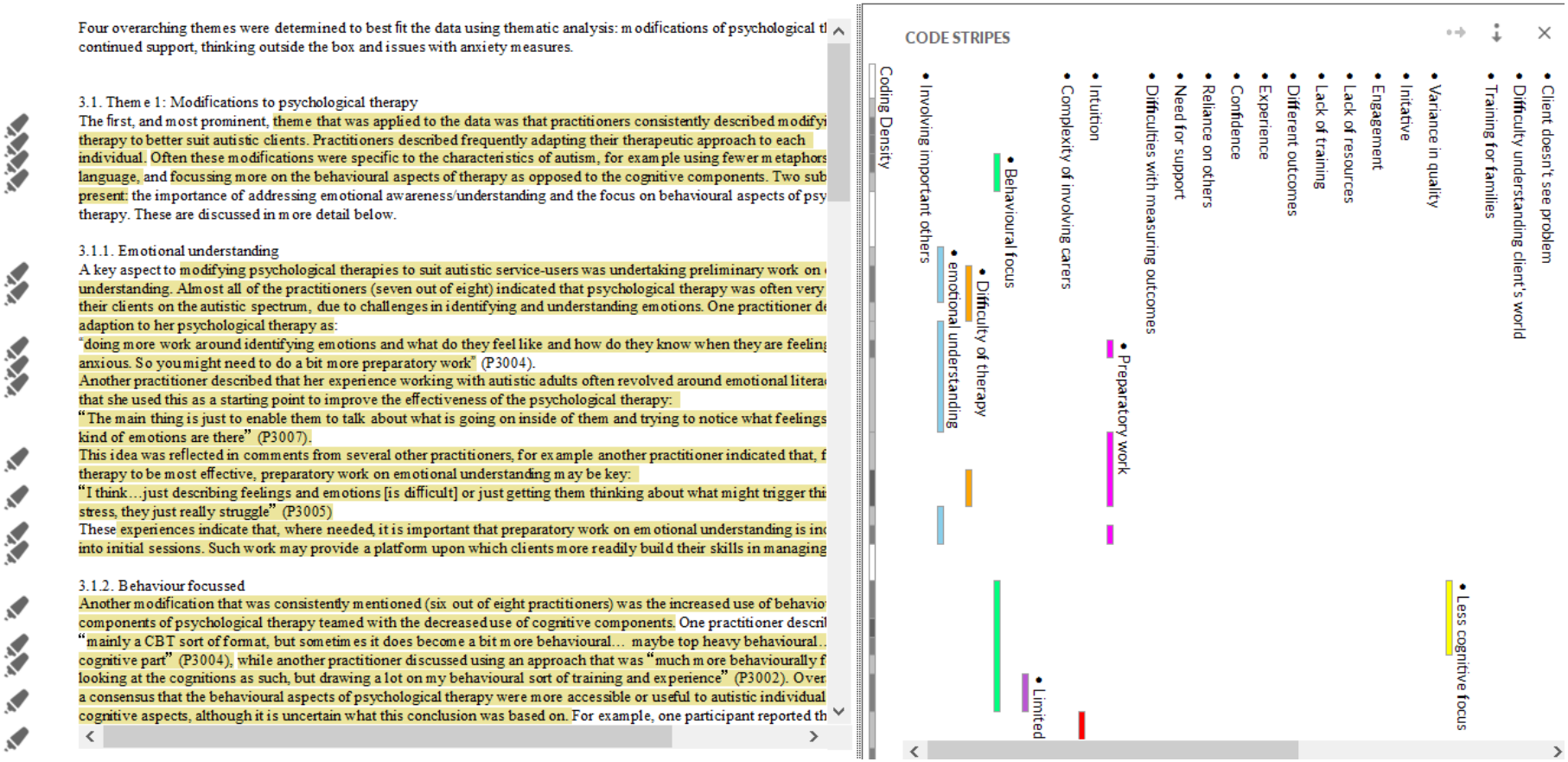
Table. Search Terms for Databases excluding Web of Science

Database	Search Terms
CINAHL	((MH "Autistic Disorder") OR (MH "Asperger Syndrome") OR ASD) AND (Psychological therap* or psychological intervention* or therapy or CBT or DBT or EMDR or anxiet* or depress* OR mental health OR self harm OR suicide) AND (Mental health profess* OR psychologist* OR counsellor* OR psychotherapist* OR nurse* OR occupational therapist* OR psychiatrist* OR social worker)
PsycINFO	AB ((DE "Autism Spectrum Disorders" OR DE "Autistic Traits")) AND AB (Mental health profess* OR psychologist* OR counsellor* OR psychotherapist* OR nurse* OR occupational therapist* OR psychiatrist* OR social worker) AND AB (Psychological therap* or psychological intervention* or therapy or CBT or DBT or EMDR or anxiet* or depress* OR mental health OR self harm OR suicide)
PubMed	(Mental health profess* OR psychologist* OR counsellor* OR psychotherapist* OR nurse* OR occupational therapist* OR psychiatrist* OR social worker) AND (Psychological therap* or psychological intervention* or therapy or CBT or DBT or EMDR or anxiet* or depress* OR mental health OR self harm OR suicid*)) AND (Autism or autism spectrum disorder or ASD or Asperger or pervasive developmental disorder)
Scopus	(TITLE-ABS-KEY ("psychological therap*" OR "psychological intervention*" OR therapy OR cbt OR dbt OR emdr OR anxiet* OR depress* OR "mental health" OR "self harm" OR "suicid* " OR "mental health service*" OR "mental health treatment*" OR "mental health intervention*") AND TITLE-ABS-KEY ("autism spectrum disorder" OR " autism" OR "asperger*") AND TITLE-ABS-KEY ("Mental health profess*" OR psychologist* OR counsellor* OR psychotherapist* OR nurse* OR "occupational therapist*" OR psychiatrist* OR "social worker"))

Appendix F: Systematic Review Data Extraction Tool

Data Categories	**Data Extracted**
Bibliographic Information: Title, author, year, location	
Study Aims	
Study Design and Theoretical Background	
Data Collection Method	
Data Analysis Method	
Sample: Size, profession, years of experience, reported demographic information, recruitment strategy	
Intervention(s) Used in Study	
Characteristics of Intervention Recipients	
Key Themes	

Appendix G: Example of Coding for Thematic Synthesis



Appendix H: Example of Descriptive Theme in Thematic Synthesis

Descriptive Theme: Flexibility in Practice

Quotes from Text	Codes
"I would say I have been more inclined to be quite inventive with people." (P3008) (Ainsworth et al., 2020, p.5)	Creativity in approaches
"And working at level of flexibility which is going to give them some movement in their life without asking too much of them." (Participant 5) (Kinnaird et al., 2017, p.4)	Flexibility in approach
"Most clinicians described using a flexible therapeutic approach with awareness of recommended content and delivery" (Petty et al., 2021, p.5)	Flexibility in approach
"The flexibility in what could be used for the scale for the feelings chart was appreciated by coaches and allowed them to individualise the intervention based on the participant's preference." (Russell et al., 2019, p.59).	Flexibility with materials
"As I am talking about this I realise, oh I did that with one person and that other thing with one other person. I think it's all about thinking ultra-flexibly." (P4) (Siddell, 2022, p.6)	Flexibility in approach Individual tailoring
"Participant #2 identified listening with an open mind, spontaneity, and openness as essential supportive behaviors to achieve success. Open-mindedness was also emphasized by four participants" (Mitran, 2022, p.6)	Open mindedness Creativity in approaches
"it is important that clinicians are open-minded and flexible, that is being aware that there is a need to potentially adapt the structure, (Spain et al., 2017, p.17)	Open mindedness Flexibility in approach

Appendix I: ENTREQ Statement

No.	Item	Guide and Description	Evidenced
1	Aim	State the research question the synthesis addresses	p.30
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis)	p.33
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	p.31
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	p.31
5	Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	p.31
6	Electronic search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	p.31
7	Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	p.32
8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	p.36 - 38
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).	p.35
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	p.34
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting	p.34
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	p.34

13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	App A
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).	p.32
15	Software	State the computer software used, if any.	p.32
16	Number of reviewers	Identify who was involved in coding and analysis.	p.32
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	p.33
18	Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	p.33
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	p.33
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation.	Results
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct)	Results

Appendix J: Publishing Guidelines for Autism Journal

1. What do we publish?

1.1 Aims & Scope

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

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

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

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

1.2 Article Types

The Journal considers the following kinds of article for publication:

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

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

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

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

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

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

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

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

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

1.3 Writing your paper

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

1.3.1 Make your article discoverable

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

Back to top

2. Editorial policies

2.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard practice

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

2.2 Authorship

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

2.3 Acknowledgements

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

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

2.3.1 Third party submissions

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

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

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

2.4 Funding

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

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

2.4.1 National Institutes of Health (NIH) funded articles

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

2.5 Declaration of conflicting interests

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

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

2.6 Research ethics and patient consent

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

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

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

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent

for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

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

2.7 Clinical trials

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

2.8 Reporting guidelines

2.8.1 Transparent reporting of trials

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

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

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

2.8.2 Sample selection and demographic characteristics

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

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

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

If authors are unable to report some or all of this information, its absence must be acknowledged with a clear statement of explanation (e.g., "specific data on socioeconomic status and educational attainment levels were not recorded"). Manuscripts that contain neither

the required information nor an appropriate statement will be returned prior to consideration by the editors.

2.8.3 Community involvement

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

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

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

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

.

2.9 Data Policy Statement

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

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

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

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

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

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

Back to top

3. Publishing Policies

3.1 Publication ethics

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

3.1.1 Plagiarism

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

3.1.2 Prior publication

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

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is

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

3.3 Open access and author archiving

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

Back to top

4. Preparing your manuscript for submission

4.1 Formatting

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

4.2 Artwork, figures and other graphics

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

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

4.3 Supplementary material

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

4.4 Terminology

4.4.1 Terminology about autism and autistic people

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

4.4.2 Language used to discuss race and ethnicity

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

4.5 Reference style

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

4.6 English language editing services

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

Back to top

5. Submitting your manuscript

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

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

5.1 ORCID

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

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD

will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

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

5.2 Information required for completing your submission

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

5.3 Lay Abstracts

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

Authors may consider the following questions when composing their lay abstract.

a. What is already known about the topic?
b. What this paper adds?
c. Implications for practice, research or policy

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

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

5.4 Permissions

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

6. On acceptance and publication

6.1 SAGE Production

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

6.2 Online First publication

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

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

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

Back to top

7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Autism editorial office as follows:

Katie Maras

Department of Psychology

University of Bath, UK

Email: katiemaras.autism@gmail.com

Appendix K: Letter of Ethical Approval

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Coláiste na nEalaíon, an Léinn Cheiltigh agus na nEolaíochtaí Sóisialta
College of Arts, Celtic Studies and Social Sciences

Scoil an Síceolaíochta Feidhmí
School of Applied Psychology

University College Cork,
Cork, Ireland.

T +353 (0)21 490 4551 / 4552
E infoapsych@ucc.ie
http://www.ucc.ie/en/apsych/

9th February 2022

Dear Laura,

Understanding the Experiences of Receiving and Providing Maternity Care for Autistic People.

Laura Moore

Thank you for presenting the above research proposal to the clinical psychology research and ethics panel on the 19th November 2021. Your resubmission was received on the 5th January and this was approved in full by the clinical psychology research and ethics panel on 1st February 2022.

Yours sincerely,

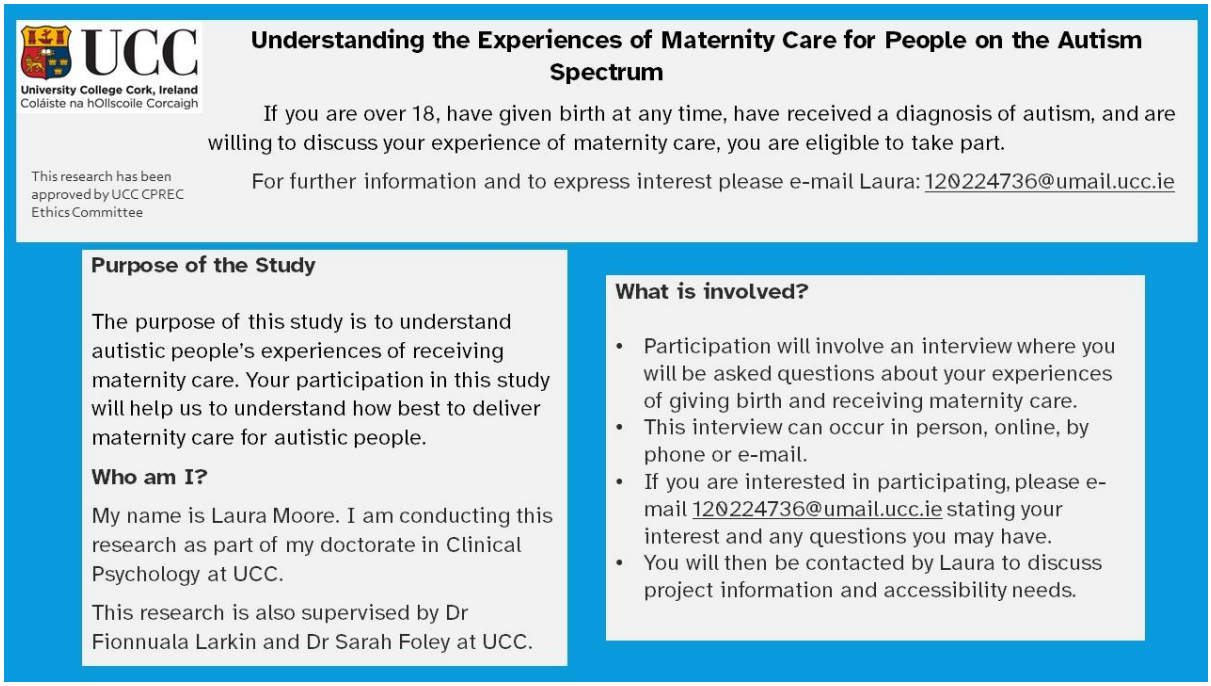
Dr Mike Murphy
Chair Clinical Psychology Research and Ethics Panel

Prof Carol Linehan
Head of School of Applied Psychology

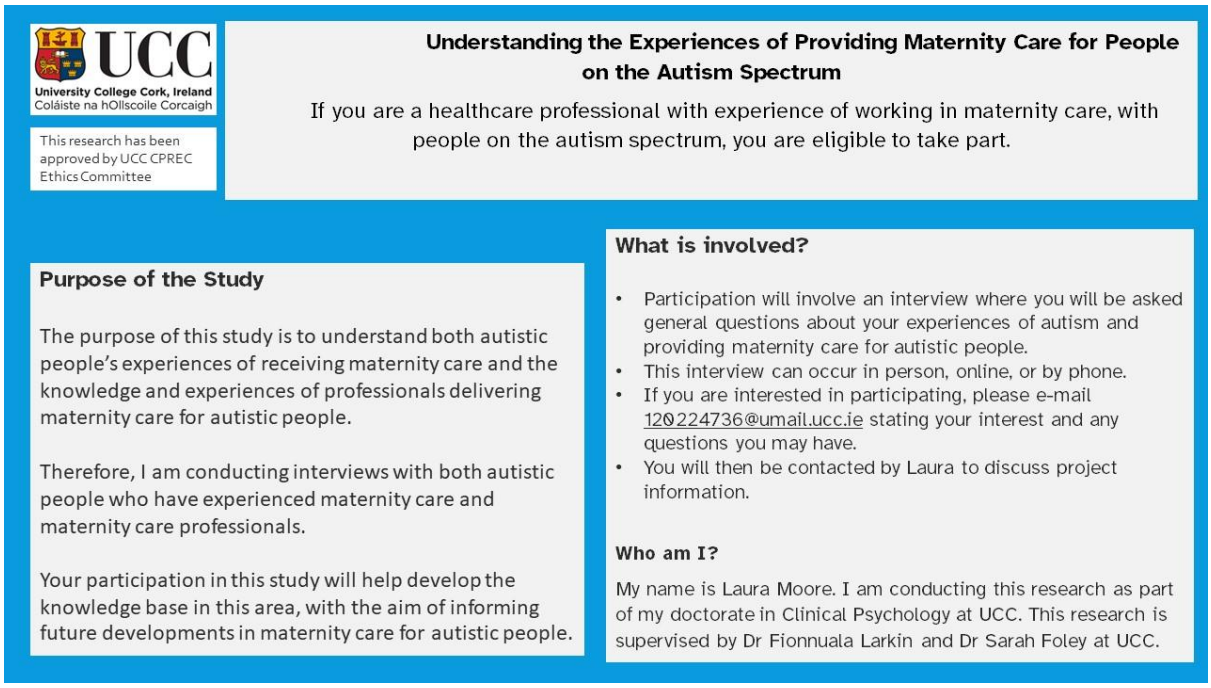
Coláiste na hOllscoile Corcaigh
University College Cork

Appendix L: Social Media Recruitment

Social Media Recruitment Post for Autistic Mothers



Social Media Post for Maternity Care Professionals



Appendix M: Information Sheets

Information Sheet for Autistic Mothers

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Information Sheet

Understanding the Experiences of Maternity Care for People on the Autism Spectrum

Thank you for considering participating in this research project. The purpose of this document is to explain to you what the work is about and what your participation would involve, so you can make an informed choice whether or not to take part. If after reading this document you are interested in being in the project, please email me at 120224736@umail.ucc.ie.

Purpose of the Study

The purpose of this study is to understand autistic people's experiences of receiving maternity care. Therefore, I am interviewing autistic people who have experienced maternity care to find out what it was like. Your participation in this study will help us to understand how best to deliver maternity care for autistic people.

Who can take part?

If you have been diagnosed with autism, have given birth at any time, and are willing to discuss your experience of maternity care you can take part.

When should I not take part?

If you are currently experiencing serious mental health difficulties requiring inpatient care, now may not be a good time to take part.

What Participation Involves

Participation will involve a one-to-one interview with the researcher, Laura Moore. This interview will explore topics related to your experiences of maternity care - you can see the questions in advance of the interview. The interview can take place in person or online, using voice, video, or text. Every effort will be made to ensure this is a comfortable experience for you. If we meet online, you will have the option to have your camera on or off, or to use text or email responses to my questions if preferred. What we discuss will be recorded. The interview will usually take 1 hour to complete.

Do I have to take part?

Participation in this study is completely voluntary. There is no obligation to participate, and you can refuse to answer specific questions or decide to withdraw from the interview at any time without giving a reason. Once the interview is finished, you can choose to withdraw your data at any time in the following two weeks by emailing me.

What happens my information?

The information you provide will be kept confidential and anonymous and will be available only to the researcher and the research supervisors. The only exception is where information is disclosed which indicates that there is a serious risk to you or to others, when I may need to share information with others to keep you or others safe. If that were the case, I would discuss this with you before I shared information.

Once the interview is completed, the recording will immediately be transferred to a secure laptop and deleted from the recording device. Everything we discussed will be typed out by the researcher into a transcript, and all information that could identify a person (e.g. names, places) will be removed. Once this is done, the audio-recording will also be deleted and only the anonymized transcript will be saved. This will be stored on the University College Cork

OneDrive system and on the UCC computer storage system. This information will be stored for ten years. The consent form which you must sign will be stored separately from interview transcripts.

The anonymized information you provide will form part of my Major Research Project for a Doctorate in Clinical Psychology, as well as possible research publications and/or conference presentations. Publications and presentations will use extracts from interviews but will never identify a particular individual.

What are the possible risks of taking part?

There is no intention to cause any distress to participants. However, some of the topics broached in the interview are of a sensitive and personal nature and could lead to emotional distress if you had a difficult time using maternity services. Should you wish to do so, you can choose not to answer questions, and you can withdraw from the interview at any time. You should only choose to take part if you feel you would like to discuss your experiences, and to do so would not be too upsetting for you.

At the end of the interview, I will discuss with you how you found the experience and how you are feeling. Should you feel distressed by the interview, the contact details for support services that may be of assistance will be provided.

Who can I contact for more information or if I have concerns about the study?

If you have any queries about this research, you can contact me, Laura Moore, at 120224736@umail.ucc.ie, or you can contact my supervisors, Dr Fionnuala Larkin: flarkin@ucc.ie and Dr Sarah Foley: sarah.foley@ucc.ie

If you have a concern about how we have handled your personal data, you are entitled to raise this with the Data Protection Commission. https://www.dataprotection.ie/

Ethical Approval

This study has obtained ethical approval from the UCC School of Applied Psychology Ethics Committee.

If you have a complaint about how this research was conducted please contact in writing:

The Ethics Committee,

School of Applied Psychology,

University College Cork.

Information Sheet for Maternity Care Professionals

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Information Sheet

Understanding the Experiences of Receiving and Providing Maternity Care for People on the Autism Spectrum

Thank you for considering participating in this research project. The purpose of this document is to explain to you what the work is about and what your participation would involve, to enable you to make an informed choice. If after reading this document you are interested in participating in this research you can contact me, Laura Moore, at 120224736@umail.ucc.ie.

Purpose of the Study

The purpose of this study is to understand autistic people's experiences of receiving maternity care and to explore the experiences of professionals delivering maternity care for autistic people. Therefore, I am conducting interviews with autistic people who have experienced maternity care and with maternity care professionals. Your participation in this study would help develop the knowledge base in this area which may inform future developments in maternity care for autistic people.

What Participation Involves

Participation would involve a one-to-one interview with the researcher, Laura Moore. This interview will explore topics related to your experiences as a maternity care professional.

This interview can take place in person or online. The audio from the interview will be recorded. The interview will take 1 hour to complete.

Do I have to take part?

Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions or decide to withdraw from the interview at any time. Once the interview has been concluded, you can choose to withdraw your data at any time in the subsequent two weeks.

What happens my data?

The information you provide will be kept confidential and anonymous and will be available only to the researcher and the research supervisor. The only exception is where information is disclosed which indicates that there is a serious risk to you or to others.

Once the interview is completed, the recording will immediately be transferred to an encrypted laptop and wiped from the recording device. The interview will then be transcribed by the researcher, and all identifying information will be removed. Once this is done, the audio-recording will also be deleted and only the anonymized transcript will remain. This will be stored on the University College Cork OneDrive system and subsequently on the UCC server. The data will be stored for ten years.

The anonymized information you provide will form part of my Major Research Project for a Doctorate in Clinical Psychology, as well as possible research publications and/or conference presentations.

What are the possible risks of taking part?

There is no intention to cause any distress to participants. However, some of the topics broached in the interview may be of a sensitive and personal nature and could lead to distress. Should you wish to do so, you can choose not to answer questions or to withdraw from the interview at any time.

At the end of the interview, I will discuss with you how you found the experience and how you are feeling. Should you experience distress arising from the interview, the contact details for support services that may be of assistance will be provided.

Who can I contact for more information or if I have concerns about the study?

If you have any queries about this research, you can contact me, Laura Moore, at 120224736@umail.ucc.ie.
Or you can contact my supervisors, Dr Fionnuala Larkin: flarkin@ucc.ie and Dr Sarah Foley: sarah.foley@ucc.ie
If you have a concern about how we have handled your personal data, you are entitled to raise this with the Data Protection Commission.
https://www.dataprotection.ie/

Ethical Approval

This study has obtained ethical approval from the UCC School of Applied Psychology Ethics Committee.

If you have a complaint about how this research was conducted please contact in writing:
The Ethics Committee,
School of Applied Psychology,
University College Cork,
Cork

Appendix N: Informed Consent

Consent

I agree to participate in this study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview to be audio-recorded.

I understand that I can withdraw from the interview, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications.

Signed:

Date:

Appendix O: Interview Schedules

Semi-structured Interview Schedule for Mothers on the Autism Spectrum who have Experienced Maternity Care

Introduction: Throughout this interview I am interested in understanding your personal, subjective experiences of being autistic, giving birth, and interactions with maternity care services. Questions are designed to be open ended as I am interested in hearing about what feels important to you. There are no right or wrong answers to these questions. Sometimes I will give additional prompts but this does not mean your answer needs to touch on every aspect I mention, only those which feel important or relevant to you.

Demographic Information

• Do you prefer identity first or person first language? [incorporate answer into wording of questions below]
• Can you tell me how many children you have?
• What ages are they?
• What system of maternity care did you experience?
Prompts: In which country, hospital/home birth….

Autism

• Did you know you were autistic before giving birth?
• Can you tell me how you learned you were autistic?
• In what ways did discovering you are autistic impact you?
• What factors influenced your decision to become a parent?
• Did you consider autism in relation to becoming a parent?
Possible prompts: societal views regarding autism, worries about challenges, perception of strengths
• Did you feel it was important to disclose your autism diagnosis / possible diagnosis to any professionals during pregnancy/labour/post-natal period?
• Were you able to disclose?
Possible prompts: Opportunities to disclose? Comfort with disclosing? Concerns about disclosing? How was it received? Did it have any impact?
• How did it feel to disclose/not disclose?

Pregnancy and Labour

• What did you think about becoming pregnant? What did it mean to you?
• How did you feel emotionally?
• Can you tell me about how you experienced pregnancy?
Possible prompts: How did you feel? Access to information? Informal support? Formal support from healthcare staff/etc? Challenges? Are there any memories that are particularly strong when you think back to that time?
• Do you think autism impacted or shaped your pregnancy in anyway?
Possible prompts: Care received, midwife/obstetrician appointments.
• Can you tell me about your experience of labour? Looking back, are there any stand out memories? How did you feel at the time, and is it different now?
Possible prompts: How did you feel? Positives? Challenges? Were there any complications? Access to information/support?
• Do you think that autism influenced your experience of labour? If so, how?

Post-Natal

• Can you tell me about your experiences in the immediate post-natal period, e.g. first two

weeks?
Possible prompts: How did you feel? What was challenging? What went well? Do you feel you had access to supports/advice/information?
• Can you tell me about your experiences in the post-natal period, after those first two weeks?
Possible prompts: How did you feel? What was challenging? What went well? Access to supports/advice/information?

Interactions with Professionals
• At any stage, do you remember any noteworthy positive interactions with maternity care professionals?
- Or individual professionals who stand out as having a positive impact?

• How did you experience these positive interactions?
- What did it mean? How did it feel?

• At any stage, do you remember any noteworthy negative interactions with maternity care professionals?
- Or individual professionals who stand out as having an unhelpful impact?

• How did you experience these negative interactions?
- What did it mean? How did it feel?

• How did you find the experience of communicating your needs or your baby's needs to professionals?
• Did you require any mental health support during pregnancy or the postnatal period?
- If so, did you receive this? Were you satisfied with it?

Maternity Care
• Were there elements of maternity care that felt unsuitable/unhelpful to you as an autistic person?
• Do you have any thoughts on any adaptions to maternity care that would be helpful for autistic people? If maternity care was designed specifically for you, what would it look like?
• Do you have anything else you feel is important to share in relation to your experience of maternity care as an autistic person?

Semi-structured Interview Schedule for Maternity Care Professionals

Profession
- What is your professional background? For how long have you worked in that profession?
- For how long have you worked in maternity care specifically? What does working in this field mean to you?
- What is your favourite part of your job? What does this mean for you?
- What is your least favourite/most challenging part of the job? How do you experience this part?

Autism
- How much knowledge/experience do you have with autism?
  Possible prompts: Education, professional training, professional experiences, personal experience
- What does autism mean to you in relation to your work? Any thoughts or feelings that arise?
- Do you have experience of autism in a maternity care setting specifically?
  Possible prompts: Specific experiences, training
- Do any thoughts or feelings arise for you when considering delivering maternity care to autistic people?

Interactions

- Have you/Would you feel comfortable asking patients if they have an autism diagnosis? How did you experience this?
  Possible prompts: Why? Why not? When would this typically happen?
- Can you tell me about your experience of delivering care to people on the autism spectrum? Any differences compared to non-autistic patients? Challenges? Rewards? Adaptions to delivery of care?
- Were there any communication differences or challenges? How did you experience this?
- What was this experience like for you? How did it feel?
- In general, how confident do you feel about delivering care to autistic people?
  Possible prompts: Confidence? Concerns?

Maternity Care

- Are there aspects of maternity care you believe to be helpful/positive for autistic people? Are there aspects that are unhelpful/negative?
- Is there anything you feel would be necessary/helpful in improving your ability or confidence in providing maternity care for autistic people?
- Is there anything else you feel is important to share in relation to this topic?

Appendix P: Sample Interview Transcript with Exploratory Notes and Experiential Statements

Experiential Statements	Interview	Exploratory Notes
Making sense of births by comparing two experiences Felt continuity of care contributed to more positive second experience. Felt supported and sense of belonging from midwives. Felt able to name and ask for her needs to be met in second pregnancy. Traumatic impact of first birth shaped second experience.	**Interviewer:** And was that with both with both your pregnancies? **Mother:** No, my second couldn't have been further from that. No problem. He was a very easy baby. I had two midwives and I only saw those two midwives the entire time. Uhm, I did develop diabetes in pregnancy and the local hospital were adamant I couldn't have midwifery care, but my midwives fought for my case and said no she belongs with us. She needs like from the right ……from the get go, I told them exactly what I needed out of my care and said look, I can't settle for anything less because I can't go back through what I did before. Uhm, and they they listened to everything and yeah they would like even come in, they came to my house to do the	Couldn't have been further, *emphasises difference between births* Continuity of care in second pregnancy, *impact of this?* Diabetes in second pregnancy Midwifery care in second pregnancy, *contribution to better expereience* 'my midwives', *sense of closeness?* Fought, *midwives in her corner* *Sense of security/belonging from midwives* Informed them of her needs, *impact of first experience on second.* Can't settle, *determined to shape care* *Highlights negative impact of first experience* Felt listened to *Impact of home care?*

Care felt personal and she could build relationship with midwives Second labour experience was better than first. Positive impact of feeling looked out for. Self-advocated for care to meet own needs. Fear informed by first experience.	appointment and it was a bit like what it used to be with midwifery care, it was very personal and they got to know you and everything about you and amm.. Even with the diabetes, that was really easy, it was only diet based. But even his labor was amazing compared to my eldest. So it it made a world of difference knowing I had someone sort of looking out for me as much as what I did….the other thing was I set myself up for that care in case I slipped back into postnatal depression. So I put in place the perinatal in like interviews and things like that with them just in case. And and because I was afraid so, to skip back, my first was also a very difficult labor. She was 38 hours and at the time I didn't know they put the epidural into the wrong spot on my nerves so it went down my leg…	*personal care, could develop relationship* Diabetes was easily managed Compares labour experiences. World of difference, *the extent of the positive impact of feeling cared for* *Self advocacy/self awareness contribution to care planning* To skip back: *fear in second pregnancy informed by first labour. Trauma?*

	Interviewer: Oh, ok. And what impact did that have on your second pregnancy? **Mother:** I was very worried of that happening again, so it was either natural birth or section and I was like I'm not having any epidural, never no drip or nothing in between. And then again, the midwives fought for me to have that and which is really nice, 'cause the the obstetrician basically said I was being a wimp and needed to go and get checked out by the mental health team for being afraid of having a baby. I was like...I'm not afraid of having a baby anymore, I was like, I'm afraid of damaging my back even further. Yeah, it's I was……I was quite a bit more aware of my needs second time around, and I suppose that typical you've been through it once, therefore, you kind of expect, know what to deal with.	Very worried Never/nothing in between. *Adamant to have choice in experience.* 'midwives fought for me', *felt supported by midwives* Basically said…*her interpretation that she was perceived as a wimp* *Mental health check advice perceived as judgement, could have been supportive?* *Miscommunication or misunderstanding between obstetrician & mother?* *Increased awareness and knowing what to expect helped.*
Worried about repeating first labour experience. Determined to have say in her own birth experience. Felt her care choices were supported by midwives. Felt judged as weak and mentally ill by obstetrician. Highlights potential for misunderstandings when communicating needs. Awareness and experience empowered her coping in second pregnancy.		

Note. Underlined exploratory notes are linguistic comments, italicized notes are conceptual comments, and regular text comments are descriptive notes.

Appendix Q: Subset of Experiential Statements and Example of Clustering Experiential Statements

Subset of Experiential Statements from Transcript
Felt supported and sense of belonging from midwives.
Care felt personal and she could build relationship.
Communication from MCPs perceived as overly casual.
Positive impact of feeling looked out for.
Determined to have say in her own birth experience.
Appreciation for choice being facilitated during labour.
Emotional impact of being denied choice.
Lack of communication from professionals led to emotional distress.

Example Clustering of Experiential Statements
A
Felt supported and sense of belonging from midwives.
Care felt personal and she could build relationship.
Positive impact of feeling looked out for.
B
Communication from MCPs perceived as overly casual.
Lack of communication from professionals led to emotional distress.
C
Determined to have say in her own birth experience.
Appreciation for choice being facilitated during labour.
Emotional impact of being denied choice.

Appendix R: Section of Table of Personal Experiential Themes for Rebecca

Themes	Page	Quotes
Theme 1. Perception of person-centred care		
Felt supported and sense of belonging	13	*the local hospital were adamant I couldn't have midwifery care, but my midwives fought for my case and said no she belongs with us.*
Care felt personal and contributed to relationship	13	*it was very personal and they got to know you and everything about you*
Positive impact of feeling looked out for.	14	*it made a world of difference knowing I had someone sort of looking out for me as much as what I did.*
Theme 2. The impact of communication from professionals		
Communication from MCPs perceived as overly casual.	17	*it turned out it was a mistake, but they literally went, Oh, we'll come back in a minute to talk about having her early and went again and I was just like what was going on.*
Lack of communication from professionals led to emotional distress.	21	*they did a sweep as well without consent and that kind of sent me through the roof.*
Theme 3. Choice in own maternity care		
Determined to have say in her own birth experience.	15	*so it was either natural birth or section and I was like I'm not having any epidural, never no drip or nothing in between.*
Appreciation for choice being facilitated during labour.	47	*there was a pool in there, there was a bed there was like fabrics hanging down so you could hang on to the fabrics, they had the balls like everything was there. If you wanted to use it, you didn't have to wait for someone to come round or bring a buzzer and say Oh emmm could I try doing this instead*
Emotional impact of being denied choice.	35	*And he was outright telling me no to my face, and I remember leaving there in tears despite the fact that I'd argued really well against it.*

Appendix S: Example of Group Experiential Theme for Autistic Mothers

Group Experiential Theme 1: The Sensory Aspects of Maternity Care for Autistic Mothers

1a. Navigating the Physical Space of Maternity Care		
Ellen	*a very profound effect that you know everything that 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 with would be like that you know, almost an out of body experience, but my body was just completely spiralling in all my senses all the way through*	p.20
Rebecca	*I said no, 'cause I will not get out of bed, I will not ring that buzzer if I need help I said because I'm very conscious of people I don't know being around me and stuff….but I physically could not bring myself to do it.*	p.19
Jennifer	*if they can make adjustments for a person who's lost their legs then they should be able to make adjustment for a person who struggles with certain sounds and actively experiences physical pain for them.*	p.50
Alice	*But that was a great transition, that was easy. And I was lucky in that I was in a room with just one other person.....so it was quiet and easy.....*	p.14

1b. The Overwhelming Sensory Experience of Physical Interactions

Ellen	*So he performed this the this smear and it's one of the most traumatic experiences of my life. The pain was excruciating and I had a really, really severe trauma response and I lay on the bed afterwards completely inconsolable for half an hour afterwards*	p.12
Rebecca	*And then I do remember in labor they were stroking my feet like I cannot abide feet being looked at or touched and I ended up kicking the midwife out of pure instinct and they did a sweep as well without consent and that kind of sent me through the roof.*	p.17
Jennifer	*I warned them I said like look I will flinch, it's nothing to do with you, I just don't like people near me, so ideally I would want the induction- you in a different room and just throwing stuff at me. But I know that doesn't work*	p.25
Alice	*I was quite pregnant at that point and she was like measuring and pushing my bump and it was, it was really……not aggressive.....but like really, I would never imagine anybody in any circumstance would go pushing like I mean it was sore and I didn't know that was.....it really upset me for days afterwards*	p.12

Appendix T: Tables of Group Experiential Themes

Group Experiential Themes for Autistic Mothers
Theme 1. The challenge of maternity care for autistic mothers
1a. Experience of care not matching expectations
1b. Experiencing heightened emotions with no space for emotional expression
1c. Navigating the physical space of maternity care
Theme 2. Relational care within the maternity context
2a. Overwhelming sensory experience of physical interactions
2b. The importance of the caring relationship
2c. Limited power and choice as a patient
Theme 3. Communication within the caring relationship
3a. Feeling unheard as an autistic mother within maternity care
3b. The impact of communication from professionals

Group Experiential Themes for Midwives
Theme 1. Understanding autism within maternity care
1a. Autism as an overlooked experience within maternity care
1b. Navigating misperceptions within the profession
1c. Impact of personal experience on understanding of autistic mothers
Theme 2. Towards Person Centred Care
2a. Establishing a caring relationship
2b. Understanding communication challenges
2c. Considering the sensory experience for autistic mothers
Theme 3. The challenge of autism within maternity care
3a. Competing demands on midwives within the health system
3b. Concern over adapting care to meet needs of autistic mothers

Appendix U: Multiperspectival Between Group Themes

Theme 1. The Challenge of Autism within Maternity Care	Theme 2. Relational Care within the Maternity Context	Theme 3. Competing Demands and Priorities within Maternity Care
1a. Navigating the Physical Space of Maternity Care MO: Navigating the Physical Space of Maternity Care MW: Considering the Sensory Experience for Autistic Mothers **1b(i). Making Sense of Autism within Maternity Care** MW: Autism as an Overlooked Experience within Midwifery MW: Navigating Misperceptions within the Profession MW: Midwives Personal Experience of Autism Influencing Care **1b(ii). Making Sense of Maternity Care as an Autistic Mother** MO: Experience not Matching Expectations MO: The Challenge of Understanding and Expressing own Care Needs	**2a. The Importance of the Caring Relationship** MO: Experiencing the Caring Relationship as Supportive MW: The Experience of Establishing a Caring Relationship **2b. Communication within the Caring Relationship** MO: Autistic Mothers Experience of Feeling Unheard MO: The Impact of Communication from Professionals on Autistic Mothers MW: Midwives Understanding of Communication Challenges	**3a. How Choice is Experienced and Interpreted** MO: Limited Power and Choice as a Patient MW: Concern over Adapting Care to Meet Needs of Autistic Mothers MW: Respecting Individual Differences (Navigating Misperceptions within the Profession) **3b. Navigating Different Priorities** MO: Experiencing Heightened Emotions with No Space for Expression MW: Competing Demands on Midwives within the Health System MO: Overwhelming Sensory Experience of Medical Interactions