Exploring the experiences of pregnancy, birth and parenting of mothers with autism spectrum disorder

Tanya Burton

Thesis submitted in partial fulfilment of the requirements of Staffordshire and Keele Universities for the jointly awarded degree of Doctorate in Clinical Psychology

April 2016

Acknowledgements

I would like to acknowledge the support, knowledge and patience of Helena Priest who has guided me throughout the research process. I would also like to acknowledge Jennie Lonsdale who helped me to develop the research idea, provided valuable ideas about communication and feedback on the write up of the research.

I would like to give huge thanks and acknowledgement to the wonderful women who put me in contact with each other and shared their stories with me.

Finally, I would like to acknowledge the support of my family and friends who made it possible to get through the research process!

Contents

Paper 1: Exploring the experiences of pregnancy, birth and parenting for women with an intellectual disability: A literature review

Paper 2: Exploring the experiences of pregnancy, birth and parenting of mothers with autism spectrum disorder.

Paper 3: Navigating the research journey

List of appendices

List of abbreviations

ID........................Intellectual disability

DOH....................Department of Health

IPA......................Interpretative phenomenological analysis

CLDT..................Community Learning Disability Team

CASP..................Critical appraisal skills programme

ASD....................Autism spectrum disorder

HFA....................High functioning autism

NICE..................National Institute for Health and Care Excellence

CMHT................Community mental health team

Thesis abstract

This thesis focuses on the experiences of pregnancy, birth and parenting for women with autism spectrum disorder (ASD). Due to the limited research about mothers with ASD, a literature review was conducted exploring the experiences of pregnancy, birth and parenting for women with an intellectual disability (ID). Women with ID experience social and communication difficulties which may be similar to women with ASD, therefore their experiences may be comparable. A review of the literature highlights experiences of powerlessness for the mothers and challenges to their mother identity from professionals, family and society due to their ID. To develop further understanding about these experiences for women with ASD, a study was conducted exploring the experiences of pregnancy, birth and parenting for seven mothers with ASD. Using interpretative phenomenological analysis (IPA), four super-ordinate themes were generated: we are different, negotiating difference, the role of the mother-child relationship and navigating the parenting journey. Consideration of the mothers' experiences and how services can be tailored to meet their needs are discussed in relation to existing theory and research. Finally, the researcher reflects on how the research journey was navigated and the impact of the research findings on themselves.

Total word count: 19,485 (excluding references)

Paper 1: Literature review

Exploring the experiences of pregnancy, birth and parenting for women with an intellectual disability: A literature review

Word count: 8,168 (excluding references)

Abstract

Women with an intellectual disability (ID) have traditionally been excluded from participating in community life, particularly family life, due to assumptions and prejudices about their abilities based on their ID label. Policies state that women with ID have the same rights as women without ID but research suggests that this might not be the experience of mothers with ID. This paper aimed to understand the experiences of being a mother with an ID. A systematic search identified 13 qualitative research articles which were appraised using a quality checklist. Using thematic analysis, three themes were identified across the papers: power and the factors that impact on power differences; the mother identity and how this is seen in relation to the women's ID identity; and experience of support. Limitations of the review and clinical implications of the findings are discussed.

Key words: Intellectual disability, pregnancy, birth, parenting, women

Introduction

Background

People with intellectual disabilities (ID) have the same needs and rights as other adults including the right to be a parent (Department of Health (DoH), 2009; McGaw, 1998). With the move from deinstitutionalisation and more opportunities for independent living in the community, there are an increasing number of parents with an ID (Booth & Booth, 1993) and an increase in research about parents with ID. Most research has focused on the parenting skills of parents with ID rather than their experiences (Llewelyn & McConnell, 2002). There is often an assumption that parents with ID are not able to parent and their strengths and abilities are unrecognised, leading to views of their parenthood being not good enough (Murphy & Feldman, 2002; Reinders, 2008).

Parents with ID are at increased risk of having children removed compared to parents without ID (Booth & Booth, 1994; Tarleton, Ward & Howarth, 2006). This is seen as a consequence of parental incompetence but is often due to issues in professional practice, services and support. Studies show that ID is not a predictor of parenting competence and that social support and mental health have more of an impact on parenting ability (Aunos, Feldman & Goupil, 2008; Sterling, 1998). As with parents without ID, some parents demonstrate adequate parenting skills whilst others need support and training (Feldman, 1994; Llewellyn, McConnell, Honey, Mayes & Russco, 2003; Strike & McConnell, 2003).

Despite this, mothers with ID experience lower levels of social support than mothers without and are the most socially isolated mothers in society (Llewellyn, McConnell, Cant & Westbrook, 1999; Stenfert-Kroese, Hussein, Clifford & Ahmed 2002). Mothers with ID also experience poorer physical and mental health compared to mothers without ID (Aunos et al, 2008). Three studies investigated pregnancy and birth outcomes for women with ID across England, Sweden and America (Goldacre, Gray & Goldacre, 2015; Höglund, Lindgren & Larsson, 2015; Mitra, Parish, Clements, Cui & Diop, 2015) with the studies in Sweden and America indicating higher risks around preterm delivery, caesarean births, very low and low birth weight babies and low Apgar scores.

Goldacre et al's (2015) study found a higher rate of combined stillbirths and infant deaths for mothers with an ID. This research suggests a range of potential complex needs for mothers with ID.

Experiences of support for parents with ID are variable and can be affected by prejudice within services (Lewis & Stenfert Kroese, 2010; Höglund et al., 2013). Support has been found useful by parents with ID when it has been competence promoting rather than competence inhibiting (Booth & Booth, 1994; Tucker & Johnson, 1989) which includes practical support and training, and support at times of crisis.

Providing support to parents with ID to maintain their parenthood is vital as the parental identity is very important to parents with ID. It affirms transition into adulthood and brings pride and opportunities for social integration (Booth & Booth, 1994; Edmonds, 2000). Parenthood can bring a valued status which may previously have been lacking (Shewan & Crawley, 2012). Though there are common aspects within the parenting identity, mothers and fathers develop different identities in preparation for and becoming parents (Mayes & Sigurjónsdóttir, 2010).

Rationale for review

The stories and voices of women with ID have traditionally been excluded from public space (Johnson & Traustadóttir, 2000). Most research on parenting with ID has been conducted from a professional point of view, thus further leaving women's voices unheard. By listening to stories of women with ID, existing stereotypes can be challenged and gaps revealed in understandings of their lives (Johnson & Traustadóttir, 2000). By focusing on qualitative data this review aims to prioritise the experiences of women with ID as they share their stories about pregnancy, birth and being a parent.

To meet this aim, the review question was 'How do women with a learning disability experience the parenting journey, from pregnancy onwards?'

Structure of review

The review was conducted in a systematic manner and is described in detail to ensure replicability. The meta-search engine EBSCOhost was used to obtain literature based on the review question from the databases AMED – The Allied and Complementary Medicine Database, Medline, PsychINFO, Academic Search Complete, CINAHL Plus with Full Text and PsycARTICLES. A second search was run on the Cochrane Library but no additional articles were found. A screening process was used to identify eligibility of the articles for the review and the eligible papers were critically reviewed using a set of appraisal guidelines.

Each paper is individually reported by location of the study, with the quality appraisal of the research embedded. The findings were analysed using thematic analysis (Coughlan, Cronin & Ryan, 2013) and presented as three themes found across all papers. The strengths and limitations of the review are discussed and implications for practice and future research are suggested.

Inclusion and exclusion criteria

Inclusion criteria: Empirical study; uses a qualitative methodology that directly asks women for their views; related to women with ID; related to experiences of birth, pregnancy and parenting; articles from 1990 to present

Exclusion criteria: Quantitative studies; related to parenting including men and women, non-English language studies

This literature review only included studies that used methods to ask women directly about their experiences, as the use of predetermined scales or measures can limit women to talking about experiences within a pre-set framework (Brunton, Wiggins, & Oakley, 2011). The date limiter of 1990 was used due to the implementation of the National Health Service and Community Care Act in 1990 which prioritised the right of individuals with an ID to live more independently in the community.

Search strategy and results

A search was run in EBSCO between 28 August and 3 September 2015 containing the terms women, intellectual disability*, learning disabilit*, experience, pregnancy, birth, parent*, mother* in the combinations shown in Table 1. This elicited 446 articles. A brief hand search of articles that appeared relevant from the initial search highlighted 12 articles that had not been identified in the initial search. An additional search was run using the term 'mother* with intellectual disability* which led to a total of 545 articles including the 12 papers that had not being previously included. A later search (28 September 2015) was conducted with the terms 'mental retardation' and 'woman' to include American literature and potential single case studies. This search elicited 23 additional papers that were not eligible for review due to not meeting the inclusion criteria. A search of the Cochrane Library using the same terms highlighted 10 papers that did not meet the inclusion criteria.

Table 1. Search terms used in literature search

women intellectual disability* AND pregnancy
women Learning disabilit* AND pregnancy
women intellectual disability* AND birth
women learning disabilit* AND birth
women ID AND parent*
women ID AND experience
women LD AND experience
women ID AND mother*
women LD AND mother*
women LD AND parent*
mother*with learning disabilit*
mother*with learning disabilit* NOT of children

mother* with intellectual disabilit*

A three stage screening process (title, abstract and complete paper; Figure 1) was used to determine the eligibility of papers for review. Reasons for exclusion at screening of title and abstract included articles about children with an ID and parent or family experience, genetic and medical studies and experiences of women with ID not related to pregnancy, birth or parenting. 13 papers were considered eligible and cross validated within the research team. For a summary of these papers see Table 2.

Figure 1. Three stage screening process

Table 2. Summary of papers

Authors, publication year, location	No. of participants	Recruitment settings	Aims	Methodology	Findings
Baum & Burn (2007), England	8	Not known	To gain a better understanding of the experiences of mothers with ID when losing custody of their children and the meanings that they derive in the process	IPA	Nine super-ordinate themes - difference in perceptions of competency by mothers and professionals, powerlessness and lack of control, lack of support, emotions about losing their children, mother identity versus ID identity, coping with loss and the future.
Gould & Dodd (2012), England	9	Community team for people with learning disabilities	To explore some of the issues experienced by mothers and think how services might help these women adjust to the loss	IPA	Three superordinate themes – suitable to be a mum which explored parental ability and the mother identity versus the ID identity; responses to the removal of children including coping with the emotional impact and whether support was sought or received; the experience of powerlessness and powerful others
Sheerin, Keenan & Lawler (2013), Ireland	4	Crisis pregnancy centre and residential service	To explore experiences of mothers with ID in Ireland when interacting with	Grounded theory	Three themes – Interacting with family and child services and the women's mainly negative experiences; experiences of disempowerment; attitudes to child and family services

			community childcare services		
Wilson, McKenzie & Murray (2013), Scotland	6	Community learning disability team (CLDT)	To explore how mothers with ID experience postnatal care	IPA	Two superordinate themes – Challenges of providing support identifies the significance of practical and emotional support from family though sometimes relying on unhelpful support. Positive support provided by midwives through listening and facilitating learning. Professional support seen as intrusive when intensive; How support was delivered – Feeling told what to do impacted on mother's perception of competence and engagement with professionals, feeling judged in a negative and positive way and the importance of the care being tailored to meet the mother's intellectual abilities.
Mayes, Llewellyn & McConnell (2006), Australia	17	Antenatal clinics, professional support organisations & word of mouth	Explore the gendered experience of pregnancy for women with ID	Phenomenological approach	Three themes – experiencing feelings of joy and tenderness as the body changes; active decisions made by the mothers regarding the pregnancy; the use of people with whom they had longstanding, trusting relationships to make decisions
Mayes, Llewellyn & McConnell	17	Antenatal clinics, professional	Exploring the phenomenon of women	Phenomenological approach	Three themes – negotiating a support network prior to the baby's birth identifies how the women created new networks or

(2008), Australia		support organisations & word of mouth	negotiating a social network around themselves and baby		adapted existing networks; engaging with networks that can provide practical and financial support; including only those who recognise and support the mother's central role in baby's life
Mayes, Llewellyn & McConnell (2011), Australia	17	Antenatal clinics, professional support organisations & word of mouth	To address the question of how women with ID assume the mother identity	Phenomenological approach	Three themes – 'My baby as real' described when the women experienced their baby as real and separate; 'my place as mother' identified how a change of self occurs throughout pregnancy; 'The support of an ally' reflected the people that the mother's found supportive during the pregnancy
Mayes & Llewellyn (2012) Australia	7	Support group for parents with ID whose children had been removed	To describe the daily lives of parents with ID whose children have been removed	Narrative enquiry	Three narratives - Living as the mother I am for mothers who had come to recognise the benefits of their children being in care and who were supported to access their children; living as the mother I should be for the women who were supported in access to their children but were concerned about their wellbeing; not feeling like a mother anymore for one woman who engaged in daily activities to prove her ability as mother but had no access to her children
Höglund & Larsson (2013), Sweden	10	Compulsory schools, rehabilitation centres and	To gain a deeper understanding of the experiences of pregnancy	Content analysis	Four categories – significance of having an ID and how it impacted on understanding and the perception from others; the physical and psychological

		the Swedish National Association for Persons with ID	and childbirth in women with ID in Sweden		transition during pregnancy; thoughts, feelings and events during delivery and the child's care after delivery.
Höglund & Larsson (2014), Sweden	10	Compulsory schools, rehabilitation centres and the Swedish National Association for Persons with ID	To gain a deeper understanding of the experience of professional and social support during pregnancy and childbirth among women with ID in Sweden	Content analysis	Three categories – how the midwife contributed to the women's insight through personal characteristics and working practice; positive and negative experiences of professional support and treatment and support from others
Starke (2010), Sweden	7	Adult rehabilitation centres	To explore experiences of mothers with an ID regarding their interaction with care and support practitioners	Textual analysis	Three themes – incomprehensibility described experiences of inadequate information and improper treatment; support as empowerment identified support experienced in meaningful ways; understanding oneself as needing help and actively seeking help
Starke (2011), Sweden	7	Adult rehabilitation centres	To capture experiences and descriptions of mothers with ID regarding their	Textual analysis	Three themes – children's needs and responsibility included reflections on the practical and emotional needs of children; the mothers often sought support from their mothers and desired

			children's needs, parental responsibility and encounters with professional support		support from professionals around parenting skills; being questioned as a parent by others and themselves
Traustadóttir & Sigurjónsdóttir (2008), Iceland	18	Service system, personal contacts, self-advocacy group	To gain a better understanding of the assistance mothers with ID receive from family and formal support services and how this has changed over time.	Grounded theory approach	Two themes – Support from extended family; the 'mother's' advocacy and collaboration with service providers – the 'mother' being a non-disabled woman

Critical appraisal

Quality and trustworthiness of the studies were assessed by checking for credibility, transferability and dependability (Guba & Lincoln, 1989). This was established using a tool developed by the author based on the Critical Appraisal Skills Programme (CASP, 2013) and guidelines from Yardley (2000, see Appendix C). The quality of the papers was determined by scoring the assessment tool. Two points were given if the papers fully answered the question, one point for partially answering and no points if the question was not answered. The scores were converted to a percentage to indicate the extent that the papers met the quality criteria (Table 3). The papers cover a wide range of experiences throughout the parenting journey and a number of papers are written by the same author therefore, for ease of reading, the papers are presented by location of the study. This distinction also highlights the different contexts in which the experiences take place as each country has its own influential cultural and societal history and perspective.

Table 3. Criteria met by critical appraisal tool

Author, Publication Year,	Criteria met by critical appraisal tool (%)
Höglund & Larsson (2013)	89%
Höglund & Larsson (2014)	89%
Mayes, Llewellyn & McConnell (2011)	89%
Mayes & Llewellyn (2012)	89%
Wilson, McKenzie, Quayle & Murray (2013)	89%
Gould & Dodd (2012)	83%
Mayes, Llewellyn & McConnell (2008)	83%
Starke (2011)	83%
Mayes, Llewellyn & McConnell (2006)	78%
Starke (2010)	78%
Baum & Burns (2007)	72%
Traustadóttir & Sigurjónsdóttir	72%
Sheerin, Keenan & Lawler (2013)	67%

United Kingdom and the Republic of Ireland

Baum & Burns (2007) used Interpretive Phenomenological Analysis (IPA) to gain a better understanding of the experiences of eight mothers with ID when losing custody of their children and the meanings that they derived in the process. It is not reported where the participants were recruited which would have added context to the findings and impacts on the transparency of the process (Yardley, 2000). A strength of the study is the ethical approach to the recruitment of participants in order to support informed consent. The findings consist of nine super-ordinate themes with no sub-themes. Typically, in an IPA study, super-ordinate themes are a central organising concept containing subordinate sub-themes (Smith, Flowers & Larkin, 2009). Some of the themes could be subsumed into an overarching theme. The study highlighted the lack of support that the mothers had in order to try and keep their children and after the children were removed. The mothers did not agree with professionals about their level of competence and often felt powerless and without control over their lives or their children's. The 'mother' identity was often challenged by the 'ID' identity. The authors emphasised the need for adult ID teams to be involved when there is a concern around parenting, not just children's social care teams.

Gould & Dodd (2012) used IPA to explore the experiences of nine mothers whose children had been removed and to suggest how services could support them. This aim was not presented clearly and there were no specific research questions. The authors emphasised the ethical considerations of recruiting and interviewing women with ID. Gould also reflected on her influence on the development of the study which came from her sense of injustice when working with women who experienced prejudice from within services. The findings of the study were presented clearly, using tables to summarise information. There was a good balance between analytic narrative and data extracts, with extracts used from a range of participants. Three super-ordinate themes were presented. The first described how the ID identity and ability impacted on being 'suitable to be a mum.' The mothers spoke about how others perceived them to be incompetent and told them not to have children, which some believed was a result of prejudice against

people with ID. The second theme explored responses to removal of children, how the women felt and how they managed their emotions. The mothers also spoke about the support that they did or did not receive. The final theme was about power; the women's experience of powerlessness and the presence of powerful others. The authors provide clear recommendations to better support women in this context but do not suggest any areas for further research.

Sheerin, Keenan & Lawler (2013) aimed to explore the experiences of four mothers with ID in Ireland when interacting with community childcare services. The participant sample is small which needs to be taken into account when judging transferability to other contexts. It is not clear what the methodology of the research is because the authors do not explicitly state what method of analysis is used. The description of data analysis suggests the use of grounded theory however this would not fit with the aim of exploring experiences and the authors do not appear to attempt to generate a theory. This demonstrates a lack of coherence in the study (Yardley, 2000). Three themes were generated from the data. All the women's initial contact with the service was in the context of child protection and occurred late in the pregnancy when the women were expecting to take their children home, which was distressing for the women. The second theme highlighted the women's experiences of disempowerment and the final theme described negative attitudes to child and family services which the authors describe in the context of services using their duty of care in conflict with the mother's wishes. The data extracts were well grounded in the themes and the findings were linked to theory.

Using IPA, Wilson, McKenzie & Murray (2013) explored how six mothers with an ID experienced postnatal care. All participants had at least one child removed by child protection services which limits the transferability of the findings. Details about the data collection and analysis process allow the reader to clearly see what the authors have done which enhances the dependability of the research. A credibility check was also used to evaluate the themes. Two super-ordinate themes were identified: 'challenges of providing support' and 'how support was delivered' which contained a

number of sub-themes. The significance of practical and emotional support provided by family was emphasised but the mothers also had to rely on less helpful support. The midwives provided positive support through facilitating learning and listening. The mothers also experienced more intensive professional input as intrusive which impacted on their perception of their own competence. Support was perceived as disempowering when mothers felt they were told what to do or if they felt negatively judged. Positive judgements about care could reinforce feelings of competence. It was important for the mothers that their ID was taken into account and information and support was tailored to their individual needs. A master table of themes may have made the information more accessible to the reader.

Australia

Mayes, McConnell and Llewellyn (2006, 2008, 2011) produced three papers from a larger study aiming to understand the phenomenon of becoming a mother for seventeen women with ID. The participants were recruited through social service agencies and antenatal clinics. The use of these two settings allowed for the recruitment of participants with a range of needs and support. The range in experience and backgrounds of the participants provided evidence of the transferability of the research findings which the authors reported was "not unreasonable for an in-depth study of this nature." The process of analysis was described in depth, however, there was no reference to who the analysis was done by or whether any measures were used to enhance credibility.

The study identified three essential structures of the phenomenon of becoming a mother for women with ID which were 'recognising I am pregnant', 'understanding my importance in my baby's life' and 'negotiating a support network for me and my baby.' The three papers elaborated on these structures.

The structure of 'recognising I am pregnant' was explored in 'Misconception: the experience of pregnancy for women with intellectual disabilities (2011).' The first of three key themes identified feelings of joy and tenderness as the women experienced their bodies changing to accommodate the developing

baby. Even the women who were initially devastated by the discovery of the pregnancy later experienced these feelings. This theme was explored in the context of women with an ID previously being seen as degendered and how these findings deconstruct this idea. The second theme recognised the active decisions that the women made regarding the continuation of the pregnancy and what would happen to the baby after its birth. The authors reported that these findings challenged the stereotypes of passivity and dependence. The final theme highlighted how the women used the support of people with whom they had long standing, trusting relationships to make decisions about their babies.

Mayes et al (2008) explored how the women developed a social network around themselves and their babies. The first theme described how some of the women had to create new support networks and others adapted their current networks. The second theme 'purpose of a support network' identified the practical and financial support required. The authors commented on the lack of findings about emotional support and hypothesised that this might be because the women were describing a network for an unborn baby and practical assistance may be a priority in the final stages of pregnancy. In the third theme the women negotiate their support network around those who recognise her central importance in their baby's life. Those who question or try to supersede this position are removed or their influence is limited. Again, the authors used these findings to challenge stereotypes of passivity and dependence and note the similarities between how women with and without disabilities develop their support networks.

Mayes et al (2011) focused on how women with ID assume the mother identity. The authors identified three themes, 'my baby as real', 'my place as mother' and 'the support of an ally.' In the first theme the women described at what point the baby became real to them and how that happened. 'My place as mother' looked at the change in the women's sense of self as the pregnancy developed. 'The support of an ally' referred to those in the mothers' lives who supported the women when they found out they were pregnant. Allies were chosen based on what the mothers felt would be best

for them and their unborn child. The authors linked their findings to research on the formation of gendered identities and how the identities of women with ID are heavily influenced by their social context. The authors recognised that these findings may not be transferable to women who do not have an ally.

All three papers presented their findings clearly and provided enough raw data to put the findings in context. Only one paper considered the power difference within the relationship between the researcher and the participant and that this may be heightened by the participant having a disability. Otherwise neither the relationship between researcher and participant nor the impact of the researcher on the research process was considered. It is surprising that there is no reference to the researchers' philosophical standpoint as there was a clear emphasis on feminist and disability research throughout the papers.

Mayes & Llewellyn (2012) conducted a separate study aiming to describe the daily lives of seven parents with ID whose children were removed. Detail was provided about how the analysis was conducted and emerging narratives were discussed with colleagues, providing credibility for the findings. Three narratives were identified around how the women still engaged in a mother role on a daily basis despite the removal of their children. For the mothers 'living as the mother I am,' they recognised the benefits of their children being cared for by others and saw themselves as mothers of children in care. For those mothers 'living as the mother I should be,' though they were supported with access, their focus was on regaining custody of their children due to concern for their wellbeing. One mother lived a narrative of 'not feeling like a mother anymore.' Her daily life revolved around demonstrating her readiness and ability to care for her children although she did not have access to them. The authors acknowledged that the findings were based on a small group of mothers who volunteered to participate in a support group and that mothers who do not access this support may have different experiences.

Sweden

Höglund & Larsson (2013, 2014) produced two papers from one study focusing on different aspects of being pregnant and giving birth. The authors reported who they contacted in order to recruit participants but it is not clear where the participants actually came from which would have added context to the research. To enhance credibility, the process of data collection and analysis is described in detail and the authors reported that the findings would be transferable to women in a similar socio-demographic structure to Sweden. The 2013 paper explored the experience of pregnancy and birth and presented four categories. The first described the significance of having an ID and how this impacts on understanding and perception from others. The second category was about the physical and psychological transition through pregnancy. The third described the thoughts, feelings and events during delivery and the fourth category was about the child's care after delivery.

The second paper (2014) explored the experiences of professional and social support during pregnancy and childbirth. The women generally experienced the midwives as nice, safe and good listeners. Some of the women experienced derogative and questioning attitudes from midwives at the labour ward whilst others had their care adapted to meet their needs, which they found helpful. Continuity in care and knowing staff were helpful but sometimes the care was confusing. There was a range of support from family and friends.

Starke (2010, 2011) produced two papers from an exploratory study aiming to explore the experiences and descriptions of seven mothers living with an ID regarding children's needs, parental responsibility and encounters with professional support. Neither paper explicitly stated that it was part of the same study. There was a good description of the legislation and social support around these women in Sweden which gives context for the findings. The data extracts were used well to demonstrate how the themes had been identified, however, the presentation of the findings were not clear as there was no distinction between the themes and subthemes.

Starke (2010) concentrated on experiences with professional support and identified three themes. The theme of incomprehensibility highlighted how the women's encounters with staff did not always help to make their everyday life comprehensible. This was based on lack of information, experiences of being questioned and judged and not being believed. The second theme demonstrated how the women felt supported in an empowering way through trusting relationships and receiving useful knowledge. In the third theme the women recognised that they needed outside support and actively sought it, though it was not always received.

The second paper elaborated on the mothers' descriptions of children's needs and parental responsibility. The author described in detail the theoretical perspective used to create a deeper understanding of the women's experiences which gave a clearer idea of the author's position when analysing the data. The author did not refer to any processes used to increase credibility. Three themes were discussed which described the reflective nature of the women when describing the practical and emotional needs of their children, how support is obtained from family and professionals and the experience of being questioned as a parent by family and professionals.

Iceland

Traustadóttir & Sigurjónsdóttir (2008) conducted two studies and this paper combined the findings from 18 women across both studies. The authors conducted in-depth interviews with the women but also spent time with them in their daily lives and with their families. The group included women from three different generations which highlighted how the experiences of women with ID have changed over time. The authors emphasised developing trusting relationships with the women, however, they do not report any other considerations around ethical issues. Although there were descriptions of the women's stories, there were not enough data extracts to emphasise the women's voices and to show how the findings were related to the raw data.

The findings were presented as descriptions of the three different generations and two themes about the nature of support received by the

women. The first theme highlighted the support provided by extended family which was particularly around practical support for the two older generations. The increase in public support has called for different forms of support from family, particularly advocacy and support in dealing with professional services. The second theme referred to the role of the mother's 'mother,' a woman without a disability who plays the role of advocate and the factors that dictated whether it was a successful role or not.

All papers

An integral aspect of qualitative research is the reflection on the researcher's role or bias during the study as this aids transparency and demonstrates commitment to the philosophy behind qualitative research (Yardley, 2000). Only one paper in this review did this and in a limited way (Mayes et al, 2011).

Summary of synthesised findings

Three themes were identified across papers using thematic analysis. The findings section of each paper was examined and coded and themes were developed by grouping codes together. Similar and contradictory findings were examined and critical analyses and authors' discussions were examined to account for differences (Coughlan, Cronin & Ryan, 2013).

Power

Power was a theme in all the studies particularly the power difference between the mothers with an ID and powerful individuals without an ID. In this theme the areas of knowledge, decision making and powerful others are discussed in relation to their impact on power differences.

Knowledge.

Knowledge appeared to be a contributory factor in the experiences of power or powerlessness. Höglund & Larsson (2013) highlighted the lack of knowledge that the women in their study had about sex, pregnancy and fertility and this lack of knowledge may have led to unplanned pregnancies. A number of the women found out they were pregnant late on in the pregnancy

(Mayes et al, 2008, 2011; Sheerin et al, 2013) and this took away their decision to have the baby or not, which was highly distressing. Not understanding the labour process and being unable to communicate their needs made the deliveries more difficult (Höglund & Larsson, 2013).

A lack of knowledge played a key role in the experiences of mothers regarding threats or the actual removal of their children. Some women were able to realise that threats from family members were empty (Mayes et al, 2007) because they knew their rights. However, this was not a typical experience for the majority of the women. They did not understand the process of parenting assessments or why their competence was deemed not good enough (Gould & Dodd, 2014; Sheerin et al, 2013; Starke, 2010). The women also did not know about the court processes, did not understand what they were signing (Sheerin et al, 2013) and did not know who to go to or what to do when promises were broken regarding access to information about their children (Baum & Burns, 2007).

Decision making.

Seven papers refer to important situations where decisions were made without the women's consultation or consent. Höglund & Larsson (2013) highlighted how this decision making was done by hospital staff regarding the child's care. For another mother, the decision about how long she should stay in a hostel whilst her parenting was assessed was constantly changed without her input, with the threat of her child being taken if she left (Sheerin et al, 2013). For the rest of the women these decisions were made in the context of their children being removed without their consent. Eight out of nine mothers in Gould & Dodd's (2012) study believed it was a foregone conclusion that their children would be taken and one woman stated this was due to her ID. Baum & Burns (2007) reported that the mothers were not able to contest the case at court stage which is in contrast to most childcare proceedings and is reflective of the powerlessness felt by women with an ID. Often the mothers felt they had no say in when the children were taken, how they could say goodbye to their children (Gould & Dodd, 2007) or where the children went (Mayes & Llewellyn, 2012).

In contrast, Mayes et al's study (2006, 2008, 2011) emphasised how the women made active decisions about their lives and their children's care. These decisions were around whether they would have babies and who they would have in their support network. The authors reported that their findings challenged the stereotypes of passivity and dependence of women with an ID. However, the authors also acknowledged these women had the support of an ally and trusted relationships in which to make decisions, which may not be the same for the women in other studies.

Powerful others.

Gould & Dodd (2012) referred to the strong influential force of 'powerful others' who are not intellectually disabled and have considerably more power than the mothers with an ID. These 'others' have more of an influence on the decision making than the women and can challenge their role as mothers. Though these powerful others are not explicitly identified in the other studies, the impact of the power difference is evident. However, the 'powerful others' can also have a helpful role and can assist mothers in their attempts to keep their children by providing knowledge or support (Mayes et al, 2011; Traustadóttir & Sigurjónsdóttir, 2008).

Traustadóttir & Sigurjónsdóttir (2008) wrote about the 'mother' role fulfilled by non-disabled women who have a stronger position in relation to services than that of the mothers with an ID and are able to support and empower them. The authors reported that all but one of the mothers with an ID who kept custody of their children had a 'mother.' The impact of the 'mother' on relationships with services was dependent on how much the 'mother' agreed with services about the competency of the mother. If the disability was not regarded as a problem, then professionals concluded that the 'mother' did not understand the impact of the disability which limited the possibilities of planning with services and advocating on behalf of the mother with an ID.

The mother identity

All the women in these studies had a mother identity and an ID identity. Traustadóttir & Sigurjóndottir (2008) highlighted how historically it was

believed that women with ID had no right or competence to raise children but perceptions are changing and legislation emphasises the right for women with an ID to lead regular lives. However, this is not always the lived experience of women with an ID. This theme explores how the mother identity developed throughout pregnancy and onwards, the challenges that the ID identity can bring to the mother identity and maintaining the mother identity when children have been removed.

The women experienced a range of reactions when discovering their pregnancies including happiness, excitement, surprise, distress and worry about others' reactions (Mayes et al, 2007; Höglund & Larsson, 2013; Sheerin et al, 2013). There were mixed reactions from friends and family ranging from positive support, grief and demands that the women should have an abortion. Right from the beginning some of these women were experiencing challenges to their mother identity.

Mayes et al (2011) and Höglund & Larsson (2013) described women's experiences of their babies becoming real, seeing the ultrasounds and realising a sense of responsibility as the pregnancy developed. These are all experiences that are in keeping with women who do not have an ID and demonstrate the inaccuracy of seeing women with ID as 'degendered' beings (Mayes et al, 2011). Starke's (2011) study also showed how mothers with an ID form similar ideas about children's needs and parental responsibilities based on society's norms and values to mothers without an ID. A change that may be more pertinent to women with an ID is the change in identity and social status that being a mother can bring. Through becoming a mother, the women saw themselves as becoming more autonomous, more open and less isolated (Starke, 2011). However, this was not always recognised by family members and professionals who may have seen the ID identity more prominently than the mother identity with one mother stating, "They treat you like a child 'cause you've got special needs" (Gould & Dodd, 2012; Baum & Burns, 2007; Höglund & Larsson, 2013). Some of the women debated about sharing their diagnosis of an ID because of the impact it might have on professionals' perceptions. The mothers disclosed if they thought it would benefit the child and that they would get additional support (Gould & Dodd,

2012). However, by not disclosing they may have put themselves in an even more powerless position (Baum & Burns, 2007).

Part of the process of developing and maintaining the mother identity for the women in Mayes et al's (2008, 2011) study, was recognising their central importance in their baby's life and creating a support network that also recognised and supported that central role. The mothers disconnected from those that tried to challenge that role but this was more difficult to do with professionals.

Eleven out of thirteen papers reported mothers' worries about their children being taken away and all the studies contained at least one mother whose child had been removed. This fear of removal came from presumptions of incompetency from professionals which some mothers felt was based on stereotypes about women with an ID; already having a child removed, and family reactions to pregnancy and doubts about ability to care for their children (Traustadóttir & Sigurjóndottir, 2008; Höglund & Larsson, 2014; Gould & Dodd, 2012; Starke, 2010; Sheerin et al, 2013. Traustadóttir & Sigurjóndottir (2008) reported how the threat of child removal was used to control the mothers to the extent that a support worker used this to decide what the children would eat and wear. Six out of nine mothers in Gould & Dodd's (2012) study reported professional intervention that impacted on their attachment with their babies. The women consistently said they faced threats to their mother identity from professionals.

It was particularly difficult for the mothers to retain the mother identity when they lost custody of their children. The women experienced grief and loss and symptoms similar to PTSD (Baum & Burns, 2007; Gould & Dodd, 2012; Mayes & Llewellyn, 2012). The women were able to retain some form of a mother role either as the women who had given birth to their children (Gould & Dodd, 2012) or if they had access to their children and could be mothers of children in custody. This was more difficult when they thought their children were not benefitting from being in care (Mayes & Llewellyn, 2012) or they felt their role was threatened by the foster carer (Baum & Burns, 2007). The women who did not see their children or have access to information about

them no longer saw themselves as mothers but hoped for future contact with their children (Mayes & Llewellyn, 2012; Baum & Burns, 2007). Some mothers tried to 'fill the gap' by having more children who were then also removed (Baum & Burns, 2007).

Experience of support

Six papers specifically explored the experiences of support for mothers with an ID (2008; Sheerin et al, 2013; Starke, 2010; Traustadóttir & Sigurjónsdóttir, 2008; Wilson et al, 2013) but it was also discussed in the remaining papers. This theme explores how the women experienced informal and formal support and the lack of support during child protection processes.

      Informal support.

When in trusting relationships, the women tended to turn to family, partners and friends for practical, financial and emotional support (Gould & Dodd, 2012; Höglund & Larsson, 2014; Mayes et al, 2007, 2008, 2011; Starke, 2010; Wilson et al, 2013). Mayes et al (2008) noted that the emphasis was on practical support rather than emotional support in contrast to other findings and hypothesised that this might be due a different focus in the late stages of pregnancy. Family, partners and friends were also advocates for the mothers (Mayes et al, 2011; Traustadóttir & Sigurjónsdóttir, 2008). Some of the women relied on less helpful support which is consistent with the literature (Wilson et al, 2013) whereas the women in Mayes et al's study did not. The suggested ideas about this difference were that individuals may prove unhelpful once the baby is born and unhelpful people may affirm the women's central position in their children's lives and thus are kept in the support network. Some women did not have support from family and friends and relied on formal support (Baum & Burns, 2007; Gould & Dodd, 2012).

      Formal support.

Ten out of thirteen papers reported experiences of women being treated badly, feeling judged, not believed, accused, bullied and their parenting competency questioned by professionals. Sometimes professional involvement was seen as surveillance (Baum & Burns, 2007), with

monitoring and observations reinforcing to the mothers that they were not competent (Gould & Dodd, 2012). If the mothers felt they were being told what to do or undermined, they became confrontational with the staff (Starke, 2010; Wilson et al, 2013).

Six papers reported positive experiences with professionals (Höglund & Larsson, 2013, 2014; Starke, 2010, 2011; Traustadóttir & Sigurjónsdóttir, 2008; Wilson et al, 2013). Better relationships with staff developed when information or the environment was tailored to meet their needs and the women felt listened to (Wilson et al, 2013). Traustadóttir & Sigurjónsdóttir (2008) reported that provision of support was most successful when the mothers and families had input into the planning and delivery. Höglund & Larsson (2014) reported that the women generally had good experiences with their midwives. The factors that helped with this were knowing the midwife previously, if the midwife had been working a long time, having a range of ways to contact the midwife, continuity of care through pregnancy and labour, not assuming knowledge levels and providing enough time at appointments to talk. Parenting groups were helpful for some of the women and increased their confidence though some thought it would have been useful to have a group for parents with an ID only (Höglund & Larsson, 20113; Wilson et al, 2013).

Support during child protection processes.

Starke (2011) reported that two of the women in their study had asked for support from child protection services and were happy with the outcome. However, the majority of women whose children were removed did not have this experience. Requests for parent training by mothers were made before children were removed and not fulfilled (Baum & Burns, 2007). Often ID services were not involved with the mothers at this time and the majority of mothers did not receive any individual support for their emotional or mental health after their children were removed (Baum & Burns, 2007; Sheerin et al, 2013). The need for this support was evident as the women tried to bottle up their feelings which then had an adverse impact on mental health (Baum &

Burns, 2007), experienced PTSD symptoms and attempted suicide (Gould &
Dodd, 2012).

Conclusion

Following a systematic search and screening process, 13 articles were
reviewed in order to find out how women with an ID experience the parenting
journey. The articles were of a fairly high quality varying in levels of
credibility, transferability and dependability (Guba & Lincoln, 1989). Three
themes of power, mother identity and experience of support were identified
across all papers with some differences in experiences within the themes.
Findings about the mothers' experiences of pregnancy and descriptions
about their ideas of parenting were consistent with mothers who do not have
an ID and challenge the idea that women with ID should be seen only in light
of their ID or as 'degendered' beings (Mayes et al, 2006). The mother identity
was often overridden by the ID identity as seen by professionals, resulting in
increased judgement, control over the mothers and child removal which is
consistent with other research (Booth & Booth, 2005; International
Association for the Scientific Study of Intellectual Disabilities, 2008).

Mayes et al's (2006, 2008, 2011) study highlighted a difference in
experiences of powerlessness compared with the other studies. This may be
due to a difference in where the women were recruited from. 12 out of 17 of
the women were recruited from an antenatal clinic at the hospital whereas in
the other studies the women were recruited from CLDTs, rehabilitation
services, support groups for individuals whose children have been removed,
crisis pregnancy centres and residential services. These other services are
usually used when individuals are experiencing difficulties whereas antenatal
services are used routinely in pregnancy.

Strengths and limitations of the review

The description of the search strategy and decisions that led to the final
papers for review is sufficiently detailed to facilitate replicability. Cross
validation within the research team of the search strategy and final review
papers enhances confidence in the representation of the papers chosen for

review. However, the quality assessment was not assessed by another reviewer which could limit the credibility of the review.

The majority of the studies recruited participants from services that are accessed by individuals who experience difficulties, which reduces the extent to which the findings can be transferred. This is emphasised by the difference in findings in the one study where the mothers were recruited from antenatal services. Though the reviews are from a range of countries, valuable information may have been missed from the review due to the exclusion of non-English literature.

By choosing to focus on qualitative research that explores experiences as described by the mothers themselves, this review prioritises the voices of a marginalised group (Johnson & Traustadóttir, 2000).

Clinical implications

Despite national and international policies pronouncing that individuals with an ID have the same rights as adults without an ID, this was not always experienced by mothers with an ID within health and social care contexts. The presence of advocates was also not always enough to mediate prejudice and assumptions about parental capacity. To address this, training in understanding and recognising prejudice and bias within health and social care staff may be beneficial.

There is a clear gap in services and clinical need for support for mothers with an ID whose children have been removed. It is recommended, in line with papers in this review, that support pathways are put in place for mothers before, during and after contact with court systems and processes around child removal.

Further research based within universal parenting services is needed to identify whether mothers with an ID who do not access specific ID services experience the same challenges.

References

Aunos, M., Feldman, M., & Goupil, G. (2008). Mothering with intellectual disabilities: Relationship between social support, health and well-being, parenting and child behaviour outcomes. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 320-330. doi: 10.1111/j.1468-3148.2008.00447.x

Baum, S., & Burns, J. (2007). Mothers with learning disabilities: Experiences and means of losing custody of their children. *Tizard Learning Disability Review*, 12 (3), 3-14. doi.org/10.1108/13595474200700018

Booth, T., & Booth, W. (2005). Parents with learning difficulties in the child protection system: experiences and perspectives. *Journal of Intellectual Disabilities*, 9 (2), 109-129. doi:10.1177/1744629505053922

Booth, T., & Booth, W. (1994). *Parenting under pressure: Mothers and fathers with learning difficulties*. Buckingham: Open University Press.

Booth, W., & Booth, T. (1993). Learning the hard way: Practice issues in supporting parents with learning difficulties. *Social Work and Social Sciences Review*, 4(2), 148-162. Retrieved from http://www.supportedparenting.co.uk/practicepoints/learning.pdf

Brunton, G., Wiggins, M., & Oakley, A. (2011). *Becoming a mother: A research synthesis of women's views on the experience of first-time motherhood.* London: EPPI Centre, Social Science Research Unit, Institute of Education, University of London. Retrieved from http://eppi.ioe.ac.uk/cms/LinkClick.aspx?fileticket=hGTI6U9cFJE%3D&tabid=3295

Critical Appraisal Skills Programme (2013). *CASP checklists*. Retrieved from

http://media.wix.com/ugd/dde87_29c5b002d99342f788c6ac670e4
9f274.pdf

Department of Health (2009) *Valuing people now: a new three-year
strategy for people with learning disabilities*. London, HMSO.
Retrieved from
http://webarchive.nationalarchives.gov.uk/20130107105354/http:/
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/docume
nts/digitalasset/dh_093375.pdf

Feldman, M. A. (1994) Parenting education for parents with intellectual
disabilities: a review of outcome studies. *Research in
Developmental Disabilities*, 15(4), 299–332. doi:10.1016/0891-
4222(94)90009-4

Gould, S., & Dodd, K. (2012). 'Normal people can have a child but
disability can't: The experiences of mothers with mild learning
disabilities who have had their children removed. *British Journal of
Learning Disabilities*, 42(1), 27-37. doi: 10.1111/bld.12006

Guba, E., & Lincoln, Y. (1989). *Fourth generation evaluation.* California:
Sage Publications.

Höglund, B., & Larsson, B. (2014). Professional and social support
enhances maternal well-being in women with intellectual disability
– A Swedish interview study. *Midwifery*, 30(11), 1118-1123.
doi: 10.1016/j.midw.2014.03.018

Höglund, B., & Larsson, B. (2013). Struggling for motherhood with an
intellectual disability – A qualitative study of women's experiences
in Sweden. *Midwifery*, 29(6), 698-704.

Höglund, B., Lindgren, P., & Larsson, M. (2013). Midwives' knowledge of
attitudes towards and experiences of caring for women with
intellectual disability during pregnancy and childbirth: A cross-
sectional study in Sweden. *Midwifery*, 29(8), 950–955.
doi.org/10.1016/j.midw.2012.12.002

International Association for the Scientific Study of Intellectual Disabilities (IASSID). 2008. Parents labelled with intellectual disability: position of the IASSID SIRG on parents and patenting with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 296-307. doi: 10.1111/j.14683148.2008.00435.x

Lewis, S., & Stenfert Kroese, B. (2010). An investigation of nursing staff attitudes and emotional reactions towards patients with intellectual disability in a general hospital setting. *Journal of Applied Research in Intellectual Disabilities*, 23 (4), 355–365. doi: 10.1111/j.1468-3148.2009.00542.x

Llewellyn, G., & McConnell D. (2002) Mothers with learning difficulties and their support networks. *Journal of Intellectual Disability Research* 46(1), 17–34. doi: 10.1046/j.1365-2788.2002.00347.x

Llewellyn, G., McConnell, D., Honey, A., Mayes, R., & Russco, D. (2003). Promoting health and home safety for children of parents with intellectual disability: a randomised controlled trial. *Research in Developmental Disabilities*, 24(6), 405-431. doi:10.1016/j.ridd.2003.06.001

Mayes, R., & Llewellyn, G. (2012). Mothering differently: Narratives of mothers with intellectual disability whose children have been compulsorily removed. *Journal of Intellectual and Developmental Disability*, 37(2), 121-130. doi:10.3109/13668250.2012.673574

Mayes, R., Llewellyn, G., & McConnell, D. (2011). 'That's who I choose to be:' The mother identity for women with intellectual disabilities. *Women's Studies International Forum*, 34(2), 112-120. doi:10.1016/j.wsif.2010.11.001

Mayes, R., Llewellyn, G., & McConnell, D. (2008). Active negotiation: Mothers with intellectual disabilities creating the social support

networks. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 341-350. doi: 10.1111/j.1468-3148.2008.00448.x

Mayes, R., Llewellyn, G., & McConnell, D. (2006). Misconception: The experience of pregnancy for women with intellectual disabilities. *Scandinavian Journal of disability Research*, 8(2-3), 120-131. doi:10.1080/15017410600774178

McGaw, S. (1998). Parents who happen to have a learning disability. In: Emerson E., Hatton C., Bromley J., Caine A (Eds). *Clinical psychology and people with intellectual disabilities.* Chichester: John Wiley and Sons

Murphy G. & Feldman M.A. (2002) Parents with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(4), 281-284. doi: 10.1046/j.1468-3148.2002.00139.x

Reinders, H.S. (2008). Persons with disabilities as parents: What is the problem? *Journal of Applied Research in Intellectual Disabilities*. 21(4), 308-314. doi: 10.1111/j.1468-3148.2008.00445.x

Sheerin, F., Keenan, P., & Lawler, D. (2013). Mothers with intellectual disabilities: interactions with children and family services in Ireland. *British Journal of Learning Disabilities*, 41(3), 189-196. doi: 10.1111/bld.12034

Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* London: Sage Publications.

Starke, M. (2011). Descriptions of children's needs and parenthood among mothers with intellectual disability. *Scandinavian Journal of Disability Research*, 13(4), 283-298. doi:10.1080/15017419.2010.507374

Starke, M. (2010). Encounters with professionals: views and experiences of mothers with intellectual disability. *Journal of Intellectual Disabilities*, 14(1), 9-19.   doi: 10.1177/1744629510373052.

Stenfert Kroese B., Hussein H., Clifford C. & Ahmed, A. (2002) Social support networks and psychological well-being of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15(4), 324–340. doi: 10.1046/j.1468-3148.2002.00128.x

Sterling, J. (1998). *Determinants of parenting in women with mental retardation.* The Fielding Institute: Ann Arbour.

Strike, R., & McConnell, D. (2002). Look at Me, listen to me, I have something important to say. *Sexuality and disability*, 20(1), 53-63. doi 10.1023/A:1015234404530

Tarleton, B., Ward, L., & Howarth, J. (2006). *Finding the right support?* London: The Baring Foundation/Norah Fry.

Traustadóttir, R., & Johnson, K. (2000). *Women with intellectual disabilities: Finding a place in the world.* London: Jessica Kingsley Publishers.

Traustadottir, R., & Traustadottir, H. (2008). The 'mother' behind the mother: Three generations of mothers with intellectual disabilities and their family support networks. *Journal of Applied Research in Intellectual Disabilities*, 21(4), 331-340. doi: 10.1111/j.1468-3148.2008.00450.x

Tucker M., & Johnson, O. (1989). Competence promoting vs. competence inhibiting social support for mentally retarded mothers. *Human Organization*, 48(2), 95–107. doi.org/10.17730/humo.48.2.d64q452755008t54

Wilson, S., McKenzie, K., Quayle, E., & Murray, G. (2013). The postnatal support needs of mothers with an intellectual disability. *Midwifery*, 29(6), 592-598. doi: 10.1016/j.midw.2012.05.002

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15(2), 215-228. doi:10.1080/08870440008400302

Paper 2: Empirical study

Exploring the experiences of pregnancy, birth and parenting of mothers with autism spectrum disorder

Word count: 8,812 (excluding references)

Abstract

The lack of research about women with Autism Spectrum Disorder (ASD) may have led to an increasing population of women with ASD who are having children and engaging with services that do not understand their needs. Research about the experiences of pregnancy, birth and parenting for women with an intellectual disability (ID) highlights challenges that mothers with ASD may also experience regarding their mother identity and receiving support. In order to develop further understanding of these needs, the experiences of pregnancy, birth and parenting for seven women with ASD were explored using interpretative phenomenological analysis (IPA). Four superordinate themes were developed: we are different, negotiating difference, the role of the mother-child relationship and navigating the parenting journey. Consideration of the mothers' experiences and how services can be tailored to meet their needs are discussed in relation to existing theory and research.

Key words: Autism, mother, pregnancy, birth, parent, qualitative research

Introduction

There is a lack of research about women with ASD particularly around their experiences of pregnancy, birth and parenting. Women are increasingly being diagnosed with ASD despite previous research suggesting that ASD primarily affects males (Gould & Ashton-Smith, 2011). Therefore, there is an increasing population of women with ASD who are having children and engaging with services and environments that are not tailored to their needs. Research highlighting the experiences of women with an intellectual disability (ID) may provide a useful comparison as they often experience difficulties with communication and social understanding which may be similar to women with ASD. Women with ID are also a population of individuals whose voices have been supressed and who have not been afforded their rights to parenthood (Booth & Booth, 1994; Johnson &Traustadóttir, 2000) which may also be applicable to women with ASD.

This study aims to explore experiences of pregnancy, birth and parenting with women with ASD, the challenges experienced and their strengths as mothers.

ASD

Primarily, ASD is characterised by difficulties with social interaction and communication, and repetitive and rigid routine behaviours (Wing & Gould, 1979; Charman, 2002). Difficulties in processing and understanding emotional stimuli for self and others can make emotional expression and self-regulation challenging (Bird, Press & Richardson, 2011; Bölte, Feineis-Matthews & Poustka, 2008; Samson, Huber, & Gross, 2012). Individuals with ASD can experience difficulties with language skills which impact on their expressive and receptive speech and understanding of inference from others (Lewis, Woodyatt& Murdoch, 2008). Reduced theory of mind skills can also affect the understanding of shared beliefs, intentions and motivations of others for individuals with ASD (Baron-Cohen, Leslie & Frith, 1985; Philip et al, 2012). Executive function difficulties can create issues with planning, flexibility and inhibition for individuals with ASD (Hill, 2004). A significant feature of ASD is atypical sensory experiences such as oversensitivity to

touch or experiencing a painful response to certain noises (Baranek, 2002). People with ASD may also seek sensory stimulation which can lead to repetitive behaviours such as spinning. These heightened senses can be fascinating but also fearful and avoidance is often used to manage sensory overload (Smith & Sharp, 2013). These communication, social and sensory difficulties make the world feel uncertain and unpredictable and individuals with ASD often use routine and repetition as a way of managing uncertainty and lack of control (Davidson, 2007; Simone, 2010).

The medical model emphasises the 'deficits' associated with ASD whereas there is a growing response from individuals with ASD who dismiss the presumption of disability and prefer to be known as part of a distinct culture (Bowker &Tuffin, 2002). It is a culture that consists of individuals with a different cognitive style rather than cognitive deficits (Baron-Cohen, 2000) where 'symptoms' are linked to atypical mind/body communication (Nikopoulous& Keenan, 2004) and are often necessary for emotional and environmental protection (Davidson, 2007).

ASD and women

It is being increasingly recognised that there is an under diagnosis of girls and women with ASD (Kopp &Gillberg, 1992; Lai et al, 2011). Narrow definitions of ASD based on a male presentation can lead to the exclusion of women's different experiences and behaviours (Dworzynsky, Ronald, Bolton & Happe, 2012; Kirkovski, Enticott& Fitzgerald, 2013). Women who have high functioning ASD (HFA) are thought to be able to mask or compensate for their difficulties more than males (Attwood, 2007; Gould & Ashton-Smith, 2011; Head, McGillivray & Stokes, 2014). Women have been historically disadvantaged by this lack of recognition, leading to a lack of support and internal confusion and distress caused by not understanding why they are different (Baldwin & Costley, 2015).

Several systematic reviews have suggested that females with ASD have a greater interest in socialisation, fewer stereotypical and repetitive behaviours, interests that are more in line with social norms and higher levels of mental and emotional health difficulties than males (Kirkovski et al, 2013; Van

Wijngaarden-Cremers et al, 2014). Women with ASD still experience difficulties with social communication, information processing and atypical sensory experiences but these difficulties are expressed in subtler ways than by males with ASD. Women with ASD may have an increased interest in socialising but their difficulties with social communication and understanding of typical and implicit social rules make it difficult to make and maintain the social connections they desire (Davidson, 2007; Simone, 2010). Baldwin and Costley's (2015) study identified a sense of ongoing struggle in coping with everyday life for women with HFA. High levels of stress and worry impacted on their daily functioning, which was exacerbated by a lack of support. The women's struggles affected relationships, work and education and due to the subtlety of the social communication and processing difficulties, they were not recognised until the women experienced significant levels of emotional and mental health difficulties.

ASD and experience of healthcare

Individuals with ASD often experience additional challenges within a healthcare setting linked to social, emotional, communication, sensory and behavioural differences (Aylott, 2010). These challenges include experiences of an overstimulating environment, lack of information and detail about what will happen in appointments and anxiety about having to communicate with unfamiliar people. Poor understanding of ASD in general medicine adds to these challenges (Venkat, Jauch, Russell, Crist & Farrell, 2012). Despite research and text books suggesting practical strategies to adapt environments and communication towards individuals, particularly women, with ASD (Aylott, 2010, Giarelli & Gardner, 2012) this is not always implemented. Women with HFA experience significantly more anxiety than women without ASD during appointments and in waiting rooms which reduces expressive communication abilities (Lum, Garnett & O'Connor, 2014). Women with ASD also find it more difficult to communicate their pain, concerns and needs during childbirth than women without ASD (Lum et al, 2014).

Experiences of pregnancy, birth and parenting for women with ASD

As highlighted, there is limited research about women with ASD and even more so around their experiences of pregnancy, birth and parenting. A search of the literature identified two studies about women with ASD and pregnancy, birth and parenting (Gardner, Suplee, Bloch & Lecks, 2016; Taylor, 2014).

Taylor (2014) described her experiences as a student midwife supporting Ann, a woman with ASD, during early labour. Ann's anxiety about new environments and high levels of pain impacted on her communication with staff. Her hypersensitivities to pain, bright lights, smells and unexpected noises also increased her discomfort during labour. Developing a tailored environment which emphasised privacy, the use of adapted communication, ensuring Ann's advocate could stay with her and a non-judgemental attitude from staff reduced Ann's anxiety.

Gardner et al. (2016) analysed qualitative data provided by eight women with Asperger Syndrome who had given birth. The study highlighted difficulties processing sensations associated with pregnancy and enhanced sensitivities to touch, light, sounds, smell and interaction. This increased sensitivity to noise, smells, touch and lights made it difficult to tolerate the hospital environment and some aspects of the prenatal check-ups such as gel on their stomachs or physical contact. High levels of noise also made it difficult to process information during appointments. Some women found breastfeeding difficult in terms of tolerating the sensations, however, they were all determined to breastfeed and one woman reported that it increased her emotional sensitivity to her baby.

The women experienced a lack of control over their actions and their environment and it was thought that a birth plan could have been used more effectively to support self-advocacy and choice. Childbirth was described as dehumanising and demeaning with one women experiencing post-traumatic stress disorder. When adapting to motherhood, some women identified concerns about connecting emotionally with their babies and understanding their needs. Some reported that understanding their baby's facial cues was

difficult but they were more sensitive to their baby's sounds. The women reported difficulties when trying to develop their own ways of being mothers amidst expectations of how motherhood should be experienced and that their parenting skills and decisions were being judged.

In addition to these published studies, Kim (2014) wrote a series of blogs describing her own and others' experiences of being mothers with ASD. The women in this series noted the lack of information for them about being a parent and the assumption that mothers with ASD do not exist. They often compared themselves unfavourably to other mums, leading to feelings of guilt, depression and loneliness. They also highlighted their strengths as mothers with routine bringing consistency for their children and a shared understanding (Kim, 2014; Simone, 2010).

Experiences of pregnancy, birth and parenting for women with ID – A literature review

Women with ID may have similar experiences during their parenting journey as women with ASD due to their communication and social difficulties and their experiences of society's perceptions about their ability to parent based on their diagnosis. Women with ID faced challenges to their mother identity from professionals and family due to their ID. Their individual abilities were not recognised despite aspects of the women's descriptions of their parenting lives being consistent with mothers who do not have an ID (Burton & Priest, 2016). Support from healthcare professionals was experienced as helpful when the women had good relationships with staff and when information and the environment were tailored to meet their needs. However, the majority of studies reported experiences of the women feeling judged and being treated badly with their individual needs not being met.

Rationale for study

This limited understanding about women with ASD may have led to a population of women whose needs are ignored and neglected despite experiencing high levels of emotional and mental health difficulties. The limited literature around pregnancy, birth and parenting for women with ASD

identifies the challenges and experiences that may be specific to women with ASD, however, more research is needed to understand this further.

This study aims to address this gap by exploring the experiences of pregnancy, birth and parenting for women with ASD. Exploring these experiences could improve awareness and understanding of those working with women with ASD and contribute to a more tailored health approach during pregnancy, birth and parenting. It may also increase awareness for women with ASD of other women who may have similar experiences and reduce the experience of alienation

Research Question

How do women with ASD experience pregnancy, birth and parenting?

Method

Design

As the study aimed to explore participants' lived experiences of being a mother with ASD, IPA was chosen as the method of analysis. IPA is concerned with exploring detailed experiences and how people make sense of them (Smith, Flowers & Larkin, 2009). IPA recognises the role of the researcher in making sense of how participants make sense of their experiences, thereby creating a double hermeneutic. Therefore, it is important to identify the researcher's epistemological stance as a critical realist which will guide the interpretation. This reflects an assumption that there is an 'authentic' knowable reality but it can only be partially accessed as knowledge is subjective and socially influenced (Braun & Clarke, 2013). The researcher's interest in feminist research and issues of power may also influence the interpretation of the data.

Ethics

Ethical approval was granted by the Staffordshire University (Appendix D). Due to the nature of the topics, participants might have found the interviews distressing therefore plans for managing potential distress were agreed before the interview started. It was important due to potential vulnerabilities

of participants and communication difficulties that the issue of informed consent was fully explored and participants were given several opportunities to understand the research process and think about consenting.

Recruitment

The study was advertised on a number of online forums, through social media and via a number of Autism charities (see Appendix E for list of recruitment venues). One participant contacted the author in response to an advert online and the remaining participants were recruited through a local Autism self-help and social group for adults which had been recommended by the local learning disability service. The head of the organisation, who knew the participants well, sought consent for the researcher to contact them and passed their contact details following their consent. The researcher spoke with the participants by phone or email to discuss the research and obtain consent to send the information sheet and consent form (Appendices F and G) before meeting. All participants had copies of the forms at least 24 hours before meeting to give them an opportunity to go through the information and to make an informed decision about participation.

Table 1. Participant information

Pseudonym	Age	No. of children	Age of children	Additional MH diagnosis given	Children with ASD
Anne	43	1	17	Yes	1
Mary	28	2	2,6	No	1
Lucy	48	2	10,14	Yes	2
Penny	38	3	10,15,18	Yes	3
Wendy	22	1	3	Yes	0
Polly	31	1	4	Yes	0
Melissa	36	3	4,13,14	No	0

Seven mothers with a diagnosis of ASD or Asperger's Syndrome participated in the study (Table 1). They all received their ASD diagnosis after having children. Six of the seven women were from a rural county in the Midlands

and one woman was from a coastal town. All seven women were white British. One mother was single, one had a partner who lived elsewhere, three mothers were living with their partners or husbands and one mother was divorced. One women had two children adopted and another had her child temporarily fostered as a baby. Five of the seven women had psychiatric diagnoses as well as an ASD diagnosis including dissociative identity disorder, postnatal depression, bipolar disorder, obsessive compulsive disorder, anxiety and paranoid personality disorder.

Semi-structured interviews

The semi-structured interviews were conducted using a schedule based on an interview with a mother with ASD and the current literature. The researcher consulted with the mother and a psychologist that worked within a specialist autism service to ensure the type of questions and the language used were sensitive to the population (Appendix H). The questions were initially open to encourage in-depth responses (Smith et al, 2009), however, they were then adapted to any comprehension difficulties that arose. Six interviews took place at the participants' homes by their choice and one interview was conducted via Skype. The initial part of the meeting consisted of answering questions and completing the consent form. Four participants had partners or carers present for all or part of the interviews for support. Any data provided by the partners or carers was disregarded due to the emphasis on the participants' voices and experiences.

Data analysis

Audio recordings of the interviews were transcribed and analysed following Smith et al's (2009) guidelines. To gain a greater understanding of the participants' experiences the researcher listened to the audio files whilst reading the transcript and recorded initial notes. Line by line coding was conducted identifying descriptive, linguistic and conceptual codes (Appendix I). For each transcript, initial themes were identified from the codes and then clustered into emergent themes based on connections and patterns between initial themes (Appendix J). The emergent themes and corresponding line numbers were cut out on paper and moved around to determine connections

and patterns across participants' data (Appendix K). Synthesis and reorganisation of the themes led to superordinate themes (Appendix L).

Rigour

Notes were recorded throughout analysis to identify the researcher's preconceptions and biases that might influence analysis (Braun & Clarke, 2013). Credibility checks were conducted through an IPA peer group.

Findings

Four superordinate themes were generated containing 14 sub-themes (Table 2).

Table 2. Superordinate and subthemes.

Superordinate theme	Subtheme
We are different	Being different because of ASD
	Discrimination and powerful others
	Internalised stigma
	Celebrating difference
Negotiating difference	Power of diagnosis and understanding
	Fighting systems
	Universal parenting experiences
Role of mother-child relationship	Unique relationship with child
	Child gives meaning and focus
	Relationship as agent of change
Navigating the parenting journey	The medical system
	Importance of trust and humanity in relationships with professionals
	Lack of control and uncertainty
	Significance of family

We are different

This superordinate theme describes the mothers' experiences of being different to others around them due to their ASD, mental health difficulties or a sense of not being 'normal.' In the subordinate theme of 'Being different because of ASD' the women describe the experiences they felt were due to their ASD which created particular challenges throughout their parenting journey. The theme of 'Discrimination and powerful others' highlights how professionals' negative perceptions of the women's difference impacted on the women's rights to be a parent. The theme 'Internalised stigma' identifies how the women internalised their experiences of being different as a sense of not being good enough or having something wrong with them which affected their sense of identity and confidence as parents. In the theme 'Celebrating difference' the women identified strengths in their difference such as their shared understanding with their children.

Being different because of ASD.

Anne and Lucy referred to 'us and them' when talking about how they communicated differently to those without a diagnosis of ASD. This referred to the difficulties in talking face to face and processing issues as well as understanding social communication differently.

> *"if someone with autism does the same things a neurotypical person it often isn't for the same reason…it is literally a complete like being on a different planet like a different language even though it's the same language the meaning and inference can be so you know different (Lucy)."*

Lucy spoke about this as a general experience but also in the context of communicating with educational professionals.

Four women spoke about how their sensory experiences impacted on pregnancy, birth and parenting. Mary did not like to be touched which meant she did not hug her eldest son often. She found that breastfeeding helped to overcome the discomfort with her youngest son and was making a concerted effort to hug her eldest son more. For Polly, the dislike of touch made her particularly tense during medical examinations. Penny found the hospital experiences difficult due to her sensory needs:

> *"just having a stranger putting their hands on you erm or standing too close to you or really brightly lit rooms or you know people rushing in and out and you don't know what's happening it's it really is erm its it's not a nice experience at all."*

Several women found their sensory experiences were heightened during pregnancy particularly around smell, hearing and touch.

Mary, Lucy and Penny spoke about the clash of sensory needs with their children who also had ASD:

> *"it's been hard having sensory issues erm when there's been meltdowns from them that's very very hard for me because its makes me feel really overwhelmed (Lucy)."*

Lucy and Melissa also found that their executive dysfunction difficulties made it hard to co-ordinate managing the house and looking after children.

Penny spoke about having to find her own ways to be part of the mainstream world:

> *"I've had to interact with the world erm and whether or not I liked it it was there and I had to face it."*

By the nature of their sensory or social experiences with others, these women felt different to the majority and had to adapt to find a way of surviving in a world that they felt did not appreciate diversity. Having children increased this contact with the mainstream world, which may have increased this sense of difference when comparing themselves to other parents.

Discrimination and powerful others.

Becoming a parent brought the women into contact with powerful others who, due to their professional status, had the power to judge their parenting rights and capacity but also exposed them to society's judgements about parenting. Due to their experiences of mental health and ways of surviving difficult experiences and diagnoses, the women in this study found themselves part of marginalised groups facing discrimination regardless of individual capacity or rights.

Anne unexpectedly had her parental rights removed when expecting to take her baby home and due to her trust that the system knew best did not question this,

> *"I thought they were the people who knew best and they were putting Chloe's best interests at heart and things like that but as time came on I thought well I've done nothing wrong you've got no evidence so why take her?"*

Lack of resources and opportunities to demonstrate parental capacity resulted in Anne and Melissa having their children removed and they felt powerless to challenge this:

> *"they'd already kind of made up their minds they were going to be adopted that I was going to have no chance of getting them back (Melissa)."*

Prejudice also appeared to lead to a different threshold for demonstrating parenting. The mothers had to demonstrate that they needed no help at all or their parental capacity would be questioned; if they needed help then this questioned their parental capacity. This led to some of the mothers feeling unable to ask for help leaving them in an even more powerless position. Anne explained why she did not get any support after getting her daughter back:

> *"they said you want your child back get on with it."*

Internalised stigma.

The majority of women in this study had a psychiatric diagnosis and had experienced trauma and mental health difficulties before and during their parenting journey. They consistently received messages from society and others around them that their difference was seen in a negative way or they were 'naughty or bad' or 'a horrible person' as described by Polly and Mary. Experiences of social discrimination can lead to internalised stigma, internal feelings of shame, inadequacy and differentness (Goffman, 1963). Four women in this study shared beliefs about themselves that can be seen as a result of internalising these messages. They questioned their competency and even their right to be a parent.

> *"I just thought how could you be a mother when you've got issues (Wendy)."*

Though Wendy was able to challenge this at times when she had the baby:

> *"and I thought I cou I can do this I know I can do it"*

It was difficult for her to hold on to this idea and Wendy lived in fear of her child being taken away despite not being involved in services. This was reinforced by seeing stories on the news about children being removed because of their parents' diagnosis of ASD.

Celebrating difference.

Five of the women highlighted how their ASD and their difference gave them strengths. This was particularly around having a shared understanding with their children, the majority of who had ASD and how they could understand their needs in a way that parent without ASD might not be able to. Two mothers whose children did not have ASD also spoke about being connected to and understanding their children's needs.

> *"I don't know if I would be able to do that if I was I was just mainstream so it is a strength in a lot of ways it's like a super parent power (Penny)."*

This contrasts with the narrative about individuals with ASD lacking empathy due to difficulties with theory of mind which was highlighted by Lucy:

> *"I think there's certain elements of empathy that can be affected but I think actually a lot of us are very very empathetic and in tune with our children."*

All the women emphasised their ability to understand their children and be close to them.

The majority of the mothers also felt that their routines and black and white thinking provided good consistency for their children.

Negotiating difference

This superordinate theme highlights how the women made sense of their differences and the strategies used to negotiate the mainstream world. The

theme 'Power of diagnosis and understanding' reflects the different experiences of the women regarding their diagnosis of ASD and its impact on themselves and others. In the theme 'Fighting systems' the women explain how they had to fight for their rights and their children's rights regarding education and healthcare. The theme 'Universal parenting experiences' indicates that despite feeling different to others the women also experienced the same challenges that parents without ASD face, though this maybe of a higher intensity when combined with ASD specific difficulties.

Power of diagnosis and understanding.

For Polly, the diagnosis helped her to understand herself, her difficulties and to be more accepting of herself. This understanding allowed her to have a different experience of her second pregnancy and to connect with her' bump.' Polly thought that her experiences of depression during her last pregnancy and difficulties bonding with her baby were in part due to not having the diagnosis and this understanding of herself:

> *"and I just felt like why can't I bond with her why am I like this there was so many question marks why am I like this and then til meeting Susan it was just like this preg this pregnancy is completely different I've bonded with the bump."*

For Penny, the progress that came following the diagnosis allowed her to have her children living back with her:

> *"we met Susan and it was just amazing Susan spoke my own language it was like wow we're from the same planet and the diagnosis came really quickly after that so and then I'm you know from that it's just been a constant progress onwards (Penny)."*

For some of the women the diagnosis also brought more understanding from professionals and they felt listened to. However, others thought that the diagnosis did not make a difference to some professionals' attitude, whether this was due to lack of awareness about ASD or lack of care:

> *"even if you were to explain to them I have Asperger's it wouldn't be enough for them… I don't think there's enough knowledge or care out there (Penny)."*

Fighting systems.

Four of the women spoke about having to fight persistently for their rights and their childrens'. Mary felt that that this persistence was misunderstood by professionals when she was fighting for support for her son:

> *"if I didn't fight the way I was I wouldn't have got anywhere near where I am today with David and they think I'm erm I'm aggressive or I'm nasty and I'm not I'm just trying to get my point across without with someone listening (Mary)."*

Knowledge was very important for Anne and Lucy because it enabled them to challenge professional systems and put forward their rights. They obtained this knowledge either by doing research themselves or accessing support to do this.

The constant fighting for support and rights had a significant impact on some of the women:

"you lose your energy your emotions go your energy goes you feel flat in yourself coz you're just arguing all the time (Anne)."

All the women spoke about wanting to raise understanding about ASD and particularly about women with ASD. Lucy stated that they were a big enough of a minority to justify understanding.

Universal parenting experiences.

All of the women shared examples of universal parenting experiences such as managing children's behaviour and boundaries, the challenge of managing children and housework and establishing parental roles:

> *"it's just like what I ask her to do sometimes it's like go get your school clothes no dad asks her and she gets them like that so frustrating (Melissa)."*

Six of the women spoke about the conflict between parents' and children's needs and how the women often put their children's needs first, sometimes, to the detriment of their own:

> *"it's really stressful erm so yeah I mean I I always have to squash my needs down…. you do you get a kind of burn out and you can cope with much less (Lucy)."*

Though putting children's needs before parent's needs is a universal parental experience it may occur more consistently for mothers with ASD due to extra challenges around managing sensory difficulties and communication. Previously the mothers may have avoided situations where these challenges arose in order to cope but when they have children they are less able to do this. For example, having to attend mother baby groups or meetings.

Due to the internal stigma and awareness of others' judgement the women appeared to feel the need to always put their children's needs first and found it difficult to prioritise their own needs, leading to burnout. This might have been further exacerbated by feeling unable to ask for help.

Role of mother–child relationship

This superordinate theme highlights the importance of the mother-child relationship for five of the mothers, which they did not get anywhere else in their lives. In the theme 'Unique relationship with the child' the women describe relationships that bring a sense of being known, lasting connections and being needed, which contrasts with the lack of connection and being understood in other relationships. The theme 'Child gives life meaning and focus' describes the central role that the mother-child relationship has in creating a daily, but also something to live for. In the theme 'Relationship as agent of change' the women describe the impact of the change that having children brought but also their love for their children as a motivator for change.

Though some aspects of these themes are universal, the meaning of the experiences described in the themes may be particular to some mothers with ASD. Their experiences of being different and having social communication difficulties have excluded them from meaningful experiences in other relationships or areas of their lives.

Unique relationship with child.

Four of the women commented on the uniqueness of their relationship with their child, particularly the joy of being able to grow life inside them and knowing and being known by this baby as it had come from them. This sense of really knowing someone may be very important when the world and other people are difficult to understand:

> *"I know her so well and you know sort of erm she's mine (Polly)."*

The kind of love they felt for their children was different to other relationships they had and it was also the most stable relationship for some:

> *"I know that she's never going to go sort of thing I'm always her mum and she's always my daughter (Wendy)."*

The pregnancy and early childhood were important to the mothers in terms of the child just being theirs and totally dependent on them which reinforced the uniqueness of the relationship:

> *"I missed feeling the baby moving around inside and having that close bond with someone that no one else can (Wendy)."*

Child gives life meaning and focus.

Four of the mothers spoke about how their child gave their life purpose and kept them functioning:

> *"so I've always focused around her so when she's not in the house I tend to fall apart a bit she doesn't but I do (Anne)."*

For Wendy, her child brought meaning to her life but it also created a lot of anxiety at the thought of the loss of this meaning:

> *"I live for her that's all I live for."*

The mothers do not seem to experience this level of meaning in other relationships or areas of their lives, so the mother-child relationship is even more important.

Relationship as agent of change.

Four of the mothers spoke about the life changing impact their children had on their lives. This could be a shocking change which they needed time to adjust to or it brought about a change in their lifestyle that saved their lives. For individuals with ASD, managing change can be very difficult, therefore the adjustment to this change may be harder than for parents without ASD:

> *"that is really hard because erm you suddenly realise that your life is never ever going to be the same you know you kind of like have routines about you know like favourite programmes you might sit down to watch at certain times and different stuff and you just realise it's all gone (Lucy)."*

Motherhood brought a new sense of identity and confidence that the women had not experienced before:

> *"it's like is that really my daughter and she's so confident you know she gives me a bit of confidence now and then (Polly)."*

The children were seen as motivators for change, giving the mothers a reason to put themselves in situations that they might not usually enter and to try new things. The love and joy in these relationships also allowed them to tolerate the discomfort of being in those situations:

> *"when I'm having days that are very difficult…I don't want to do things I have to keep reminding myself that I'm doing this for these three people that are responsible you know that I'm responsible for(Wendy)."*

One mother emphasised that she had not changed though this may have been as a defence against possible judgement of her parenting:

> *"no what you got is what you saw I wasn't going to change for nothing you know none of my ways changed I haven't changed as a person over the years (Anne)."*

Navigating the parenting journey with others

This superordinate theme describes the obstacles that the mothers faced within their parenting journey with others and how they managed them. The theme 'The medical system' describes how the women were not treated as individuals and that hospital policies or processes were prioritised over

individual needs. This may be a universal experience but has a more significant impact on mothers with ASD due to their additional needs. The themes of 'Importance of trust and humanity in relationships with professionals' and 'Significance of family' highlight how relationships with professionals and families played a pivotal role in creating or managing challenges. In the theme 'Lack of control and uncertainty' the women identified their ways of coping when experiencing change and a sense of being out of control.

The medical system.

All the women experienced being treated as a medical object rather than a human individual within the hospital system. This led to professionals assuming that it was ok to touch or examine the mothers without asking or explaining why. This was particularly difficult due to heightened sensory experiences and needing explanations in order to manage the anxiety that the mothers were already feeling being in a different environment. One mother described the dehumanising process:

> *"you're all treated exactly the same it's like a conveyor belt of pregnant women that they just go through one after the other you know and you get stamped and branded and come out of the other end (Penny)."*

Hospital policies were prioritised over individual needs, leaving some mothers feeling isolated and neglected:

> *"they sent Belinda (Polly's partner) home so I was completely on my own and I hated it I didn't want her to leave but because they said she's got to go home she couldn't stay (Polly).*

Medical staff are often seen as powerful authority figures and it was difficult for the women to assert their needs, which was also exacerbated by their communication difficulties:

> *"and they decided they kind of not bullied me into an epidural but I felt like I didn't have any choice (Lucy)."*

Most of the mothers assumed that this is what they had to go through in order to have a child:

> *"I don't like people touching me erm but I suppose we basically got to you got to let them haven't you (Polly)."*

However, Mary and Melissa managed the lack of control and lack of explanation by resisting the interventions from staff. For Mary this meant crossing her legs during labour in protest as a result of the staff trying to give her pethidine when she did not want it, which delayed the birth process. Melissa refused to stay in the hospital overnight for a diabetes check because the staff had not let her know in advance, which delayed her assessment.

Importance of trust and humanity in relationships with professionals.

Five of the women reported good experiences with professional staff that were characterised by empathy, being listened to, time taken to understand the mothers' needs and a focus on the relationship. When this relationship worked it could have a significant impact on the woman:

> *"it made a massive difference a massive difference it had an impact on the way I saw things, the way I saw her (Anne)."*

Trust was important and two women spoke about broken promises of support. Melissa had been told that someone from social care would meet her at a mother and baby group but they did not come. This was already difficult for Melissa because she felt it set her apart from the group having to let them know this person would be attending and then they did not arrive:

> *"bits like the break of a promise and things like that those were the things that really rattled my cage (Melissa)."*

Lack of control and uncertainty.

All of the women spoke about their struggles with change, uncertainty and feeling out of control throughout the parenting journey and the strategies they used to manage this. Some of the women used psychological strategies such as cutting off from overwhelming environments. For others, it was the use of medication for themselves or their children. Experience and knowing what was coming played an integral role:

> *"I listened I had the injections I had the gas and air I sort of knew what I was expecting this time round (Mary)."*

For five women, routine was the main strategy that allowed them to cope. Routine was used as a way of creating predictability, making sure things were done right and knowing what to do. When routine was lost there was a sense of a loss of self and panic that something was wrong. For Wendy this occurred even if her child played with a different toy than usual:

> *"I know how it's going to go already like…when she doesn't ask for the pad and stuff I think is she ill is she going to die is she poorly and then I'm just constantly worrying why she hasn't asked for it (Wendy)."*

The home environment was the safest place for five of the women where they felt most comfortable and confident. Due to the hospital environment being so difficult or traumatic for some of the mothers, due to sensory overload, dealing with new people and lack of individual care, there was an emphasis from the mothers on trying to have home births or getting home from hospital as soon as possible.

Significance of family.

Five women spoke about the importance of having family support and working as a team with their partners or carers. They gave examples of validation and reassurance from a partner, the presence of a partner in hospital and partners acting as advocates or supporting communication:

> *"you're like my mouthpiece sometimes because I go mute sometimes (Polly)."*

Two of the women had limited family support which left them feeling isolated:

> *"it was really difficult I had no one else to you know get a break (Lucy)."*

Discussion

This study explored the experiences of pregnancy, birth and parenting for women with ASD. Four superordinate themes were identified; 'we are different', 'negotiating difference', 'the role of the mother-child relationship' and 'navigating the parent journey.' It highlights how differently the mothers

perceived themselves compared to others and the impact this had on their experiences throughout their parenting journey.

The participants described distinct differences between themselves and others regarding their sensory experiences and challenges around communication related to ASD. Their sensory experiences had a significant impact on several of the women's experiences of hospital appointments which is consistent with current research (Aylott, 2010; Baranek, 2002; Gardner et al., 2016). These sensory experiences led to feelings of anxiety and discomfort which can affect an individual's ability to think clearly and engage with others (Simone, 2010). This makes it difficult for women to process necessary information and impedes opportunities to develop good relationships with healthcare staff. Tailoring the environment to support sensory needs could have a significant impact on women's experiences.

This study highlighted the challenges around clashing sensory needs between the mothers and their children with ASD, which has not been described in the literature previously. This clash could leave the mothers feeling overwhelmed by their sensory needs or guilty if they had to prioritise their own needs over their children's. The majority of mothers spoke about suppressing their own needs in order to meet their children's which could lead to burn out. This, in turn with the masking of autistic behaviours whilst in a social context, can be mentally and emotionally exhausting which can also lead to increased mental health difficulties (Gould & Ashton-Smith, 2011).

One mother drew a parallel between her sense of difference and 'being on a different planet' which is common terminology used consistently by individuals with ASD describing their experiences (Davidson, 2007). Their experiences of being different led to an internalised stigma which affected their confidence and identities as mothers. Feelings of inadequacy were reinforced by the prejudices and stereotyping of powerful professionals and cultural stories. Some of the mothers believed this contributed to their children being taken away, worries about child removal and/or additional unwelcome involvement from services. This is consistent with experiences of some individuals from other marginalised groups such as women with ID,

physical disabilities and mental health difficulties (Burton & Priest, 2016; Diaz-Caneja & Johnson, 2004; Wołowicz-Ruszkowska, 2015).

All of the mothers had experienced mental health difficulties particularly around anxiety and depression, which is consistent with the literature (Baldwin & Costley, 2015; Van Wijngaarden-Cremers et al., 2014). These mental health difficulties are often described as psychiatric co-morbidities but can also be seen as understandable responses to the impact of being different within a society that does not appreciate diversity and the challenges of managing the sensory overload that some of the women described (Davidson, 2008; Simone, 2010).

In order to challenge the perceptions of others and themselves the women relied on several strategies. Receiving a diagnosis of ASD had an incredible impact for some women on their sense of self, which then improved their mental and emotional health and their relationships with their children. The diagnosis had less effect on their interactions with professionals due to the lack of awareness and understanding about ASD, which often led to feelings of frustration and distress. Previous research shows a lack of awareness in services (Venkat et al., 2012) despite national policies emphasising the need for increased understanding of ASD (Autism Act, 2009; Department of Health, 2010). All the women received an ASD diagnosis after having the majority of their children therefore the medical services may not have been aware of their specific needs. However, when the women did express their concerns or needs during their pregnancies and birth experiences they were not always taken into account. It may be that the validity of a diagnosis was needed to justify adjustment. The women emphasised fighting for advocacy and to increase understanding and awareness in schools, within the general public and with professionals. It was hoped this awareness could challenge existing prejudices and stereotypes.

Despite the difficulties described, there was also a celebration of being different and having ASD. The mothers identified strengths such as a shared understanding with their children and consistency brought by their routines. They also emphasised how close they were to their children and their

abilities to connect with them and understand their needs. This is in contrast to previous literature which highlights difficulties with mothers' understanding children's cues and theory of mind skills (Baron-Cohen et al., 1985; Gardner et al., 2016). The mothers may be trying to emphasise their connection and understanding with their children in response to the dominant narrative about the lack of empathy present in individuals with ASD. Or, the mothers are able to sensitively attune to their children because they are in their own supportive environments that allow them to develop secure relationships with their children (Billington, 2006). Further research is needed in this area in to understand how other women with ASD connect with their children and understand their needs and the factors that may impede or support them.

The women also shared some universal experiences and challenges of parenting. Due to the isolation of mothers with ASD, cultural stories about difference and social norms around parenting, there may be a lack of awareness that mothers without ASD also experience similar difficulties, which could reinforce their isolation. The assumption that mothers should instinctively understand and know their children's needs without help is a cultural myth that impacts many mothers (Choi, Henshaw, Baker & Tree, 2005).

The mother-child relationship was transformative for the majority of mothers in this study. It gave them a connection to another that they had not experienced before, a focus and meaning to their lives, and a new sense of identity and confidence. These are factors that being a mother can bring that can mediate the feeling of being an outsider or different (Burton & Priest, 2016). At times this could be challenging as it brought a fear of losing these things and also challenged the mothers to do things that were uncomfortable or difficult. However, the love and joy in these relationships allowed the mothers to tolerate the discomfort and engage in enjoyable activities that they might not have previously tried before.

This transformation also brought with it uncertainty and lack of control which was difficult for all the mothers at different times. This was particularly evident within the medical system where women's bodies were treated as

objects rather than humans. There was a lack of information and an assumption that the women would do as they were told. This led to resistance for some who tried to regain control by refusing to take part, ultimately impacting on the support they received. Research indicates that clear information and expectations can reduce anxiety which is particularly important for individuals who already find the world an unpredictable place (Aylott, 2010; Davidson, 2007). The medical system can often be experienced in this way by individuals without ASD but it is even more challenging for those who experience powerlessness consistently and have communication and sensory differences that should be accommodated (Brunton, Wiggins, & Oakley, 2011; National Institute for Health and Care Excellence, 2008; 2015).

When the mothers were treated with humanity and care they had good experiences with professional staff which had a positive impact on their wellbeing and tolerance in uncomfortable situations. These experiences included consistency in staff, time taken to build relationships and working collaboratively. Family support was also a significant factor in the mothers' experiences. This was provided as advocacy, support in communication and validation from partners. When that support was not available the mothers felt isolated and overwhelmed. Mothers preferred partners to stay with them at the hospital which, at times, conflicted with hospital policy. However, the NICE guidelines (2015) state that women should have an advocate with them if needed.

The use of routine featured heavily for the women in managing change and uncertainty which is consistent with previous research (Davidson, 2007; Simone, 2010), though this study highlights its role within a parenting context. Routines created predictability, an understanding of what to do and making sure things were done right. Losing routines had a significant impact on the mothers' emotional wellbeing and sense of self which is not surprising when routine is one of the few ways of having a sense of control over the world (Simone, 2010). Not all the mothers understood why routine was so important or how to manage when routines were changed or lost. Developing

an understanding around the function of routine and coping strategies when routines are lost may be useful.

Comparisons of mothers with 'high functioning' ASD and ID

Burton & Priest (2016) identified challenges in parenting for women with ID in areas of power, the mother identity and experiences of support. Due to potential communication difficulties, social challenges and social perceptions about parenting ability based on diagnosis, it was posited that mothers with ASD may have similar experiences.

This study highlighted experiences of powerlessness and judgement from others for the mothers with ASD, however, this may not have been to the same extent as mothers with ID. The participants appeared to have more access to information and more power over decision making compared to mothers with ID. Though there was a fear of their children being taken away, this was not a reality for the majority of mothers in this study. Their 'mother identity' was challenged more by an internalised stigma rather than from family members or professionals as experienced by mothers with ID (Burton & Priest, 2016). The mothers in this study may be considered to have 'high functioning' ASD whereas mothers with 'lower functioning' ASD may have experiences that are more in line with mothers with ID.

Limitations

There are a number of limitations to this study. There are only seven participants and though this is an appropriate sample for the method of analysis it does limit the transferability of the findings (Smith et al., 2010). Particular aspects of the women's experiences that may limit transferability include experiences of mental health difficulties and having children with ASD. However, given that current research highlights that women with ASD often have mental health difficulties and that there is a hereditability component to ASD, it is certainly possible that other mothers with ASD will have these experiences, in keeping with the participants in this study.

Several of the women had partners supporting them during the interview and though only the women's responses were analysed, they will have been

influenced by their partners' responses. This may have led to different information being shared compared to the interviews without partners. The women had most of their children before they received an ASD diagnosis which may have impacted on the women's experiences of the medical system during pregnancy.

Respondent validation from all participants would have enhanced the credibility of the findings but this was not pursued due to time limitations. One participant fed back that the findings supported her experiences of being a mother with ASD.

Clinical implications

All the women described experiences of emotional and mental health difficulties and had contact with mental health services before their ASD diagnosis. It is important for health professionals to be aware of how women with ASD may present and how this might be related to ASD rather than other psychiatric diagnoses which could lead to inappropriate labels and medication. It is particularly important to be aware of the impact of managing overwhelming sensory experiences and masking behaviours on the mothers' emotional and mental health. Being a parent can increase the sensory overload and bring mothers into more contexts where they feel they need to suppress their differences, for example, school meetings or hospitals.

By creating spaces and services that are flexible and meet individual needs, professionals can support mothers with ASD to have better experiences. Increasing awareness and understanding of women with ASD in a way that emphasises difference rather than deficit can reduce prejudice and create opportunities for questions about individual needs and for people to express their needs reducing the fear of negative judgement. Clinical psychologists can influence this through more research focused on the experiences of mothers with ASD, development of services and through training to other professionals such as midwives and health visitors.

One mother in the study suggested the development of a questionnaire to be used at early stages of pregnancy to inform an individual care plan that focused on sensory and communication needs. Providing information in clear

written form, using visual aids and explaining why particular examinations are important or what decisions need to be made will help ease women's anxiety and increase feelings of control. Consistency in professional staff and collaborative working enhanced the women's relationships with professionals and provided supportive experiences. All services aspire to this way of working so more research is needed as to why this is not happening consistently and whether this is due to lack of understanding, staff prejudice or lack of resources.

A significant feature within descriptions of ASD is around difficulties with theory of mind and lack of empathy. The women in this study emphasised their connections with their children and their ability to understand them. Therefore, it is important that assumptions are not made about mothers' abilities to meet their children's needs due to a diagnosis of ASD. Further research is needed to understand what difficulties with theory of mind may mean within a parenting context for mothers with ASD and to explore the ways that they connect with and understand their children.

Another area of research would be to explore the experiences of women who would be considered to have 'low functioning' ASD. The research so far, including this study, highlights the experiences of mothers who would be described as 'high functioning' within their ASD diagnosis.

The women often felt isolated and different to others around them and a number of women spoke about wanting to meet other women with ASD. Traditional ways of bringing people together may not be appropriate so alternative spaces or ways of meeting need to be developed such as an online forum. It may also be helpful for mothers with ASD to meet or hear about mothers without ASD who experience similar parenting challenges or feelings of inadequacy in order to challenge their internalised stigma.

Conclusion

The experiences of pregnancy, birth and parenting for women with ASD were explored using IPA. Four superordinate themes were developed highlighting how the women experienced themselves as different from others and how this impacted on them throughout their parenting journey. Two unique

findings from this study were the sense of connection that the women emphasised with their children which challenges current understanding and the impact of managing sensory needs within a parenting context. Other findings were consistent with existing research including the experiences of mental health difficulties and communication and sensory difficulties within healthcare settings. Professionals working within a range of settings including health and social care and education can use these findings to enhance their understanding of mothers with ASD and to develop individualised care.

References

Attwood, T. (2007). *The complete guide to asperger's syndrome*. London: Jessica Kingsley Publishers.

Baldwin, S. & Costley, D. (2015). The experiences and needs of female adults with high-functioning autism spectrum disorder. *Autism*, 1-13. doi: 10.1177/1362361315590805

Baranek, G.T. (2002). Efficacy of sensory and motor interventions for children with autism. *Journal of Autism and Developmental Disorders*, 32(5), 297-422. doi 10.1023/A:1020541906063

Baron-Cohen, S. (2000. Is asperger syndrome / high functioning autism necessarily a disability? *Development and Psychopathology*, 12, 489-500. Retrieved from http://www.larry-arnold.net/Neurodiversity/Mission/disability.htm

Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a "theory of mind"? *Cognition*, 21(1), 37–46. doi:10.1037/1089-2680.12.4.329

Billington, T. (2006) Working with autistic children and young people: sense, experience and the challenges for services, policies and practices. *Disability & Society*, 21(1), 1-13, doi: 10.1080/09687590500373627

Bird, G., Press, C., & Richardson, D. C. (2011). The role of alexithymia in reduced eye-fixation in autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 41(11), 1556–1564. doi 10.1007/s10803-011-1183-3

Bölte, S., Feineis-Matthews, S. & Poustka, F. (2008). Brief report: Emotional processing in high-functioning autism – Physiological reactivity and affective report. *Journal of Autism and Developmental Disorders*, 38(4), 776–781. doi 10.1007/s10803-007-0443-8

Bowker, N. & Tuffin, K. (2002). Disability discourses for online identities. *Disability and Society*, 17(3), 327-344. doi:10.1080/09687590220139883

Brunton, G., Wiggins, M., & Oakley, A. (2011). *Becoming a mother: A research synthesis of women's views on the experience of first-time motherhood.* London: EPPI Centre, Social Science Research Unit, Institute of Education, University of London. Retrieved from http://eppi.ioe.ac.uk/cms/LinkClick.aspx?fileticket=hGTI6U9cFJE%3D&tabid=3295

Burton, T & Priest, H. (2016). Exploring the experiences of pregnancy, birth and parenting for women with an intellectual disability: A literature review. Paper 1.

Charman, T. (2002). The prevalence of autism spectrum disorders: Recent evidence and future challenges. *European Child and Adolescent Psychiatry*, 11(6), 249-256. doi 10.1007/s00787-002-0297-8

Choi, P., Henshaw, C., Baker, S., & Tree, J. (2005) Supermum, superwife, supereverything: Performing femininity in the transition to motherhood. *Journal of Reproductive and Infant Psychology*, 23(2), 167-180. doi :10.1080/02646830500129487

Davidson, J. (2007). 'In a world of her own…': Re-presenting alienation and emotion in the lives and writings of women with autism. *Gender, Place & Culture: A Journal of Feminist Geography*, 14(6), 659-677. doi :10.1080/09663690701659135

Diaz-Caneja, A., & Johnson, S. (2004). The views and experiences of severely mentally ill mothers. *Social Psychiatry & Psychiatric Epidemiology*, 39(6), 472-482. doi 10.1007/s00127-004-0772-2

Department of Health. (2010). *Fulfilling and rewarding lives: the strategy for adults with autism in England.* London, UK. Retrieved from http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.

dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf

Dworzynsky, K., Ronald, A., Bolton, P., & Happe, F. (2012). How different are girls and boys above and below the diagnostic threshold for autism spectrum disorders? *Journal of the American Academy of Child and Adolescent Psychiatry, 51(8)*, 788-797. doi:10.1016/j.jaac.2012.05.018

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. doi.org/10.1016/j.nwh.2015.12.001

Gould, J., & Ashton-Smith, J. (2011). Missed diagnosis or misdiagnosis? Girls and women on the autism spectrum. *Good Autism Practice, 12(1)*, 34-41. Retrieved from http://www.ingentaconnect.com/content/bild/gap/2011/00000012/00000001/art00005?token=004a17cf120eddf405847447b495b2f2a31426f2c20655d363375686f232b8d32f2790e7ce

Hill, E.L. (2004). Executive dysfunction in autism. *Trends in Cognitive Sciences*, 8(1), 26-32. doi:10.1016/j.tics.2003.11.003

Kirkovski, M., Enticott, P.G., & Fitzgerald, P.B. (2013). A review of the role of female gender in autism spectrum disorder. *Journal of Autism & Developmental Disorders*, 43(11), 2584-2603. doi 10.1007/s10803-013-1811-1

Lai, M.C., Lombardo, M., Pasco, G., Ruigrok, A.N.V., Wheelwright, S.J., Sadek, S.A., Chakrabarti, B., MRC AIMS Consortium. & Baron-Cohen, S. (2011). A behavioural comparison of male and female adults with high functioning autism spectrum conditions. *PLoS ONE*, 6(6). doi:10.1371/journal.pone.0020835

Lewis, F. M., Woodyatt, G. C., & Murdoch, B. E. (2008). Linguistic and pragmatic language skills in adults with autism spectrum disorder: A pilot study. *Research in Autism Spectrum Disorders*, 2(1), 176–187. doi:10.1016/j.rasd.2007.05.002

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. doi:10.1016/j.rasd.2014.09.009

Mattila, M.L., Kielinen, M., Linna, S.L., Jussila, L., Ebeling, H., Bloigu, R., Joseph, R.M., & Moilanen, I. (2011). Autism spectrum disorders according to SDM-IV-TR and comparison with DSM-V draft criteria: An epidemiological study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 50(6), 583-592. doi: 10.1016/j.jaac.2011.04.001

Nikopoulos, C.K., & Keenan, M. (2004). Effects of video modelling of social initiations by children with autism. *Journal of Applied Behaviour Analysis*, 37(1), 93-96. doi: 10.1901/jaba.2004.37-93

Philip, R. C., Dauvermann, M. R., Whalley, H. C., Baynham, K., Lawrie, S. M., & Stanfield, A. C. (2012). A systematic review and meta-analysis of the fMRI investigation of autism spectrum disorders. *Neuroscience and Biobehavioral Reviews,* 36(2), 901–942. doi:10.1016/j.neubiorev.2011.10.008

Samson, A., Huber, O., & Gross, J. J. (2012). Emotion regulation in asperger's syndrome and high-functioning autism. *Emotion*, 12(4), 659–665. doi: 10.1037/a0027975

Simone, R. (2010). *Aspergirls; Empowering females with Asperger Syndrome*. Jessica Kingsley Publishers, London.

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

Smith, R.S. & Sharp, J. (2013). Fascination and isolation: A grounded theory exploration of unusual sensory experiences in adults with asperger syndrome. *Journal of Autism and Developmental Disorders*, 43 (4), 891-910. doi: 10.1007/s10803-012-1633-6.

Traustadóttir, R., & Johnson, K. (2000). *Women with intellectual disabilities: Finding a place in the world*. London: Jessica Kingsley Publishers.

Venkat, A., Jauch, E., Russell, W.S., Crist, C.R., & Farrell, R. (2012). Care of the patient with an autism spectrum disorder by the general physician. *Postgraduate Medical Journal*, 88(1042), 472-481. doi:10.1136/postgradmedj-2011-130727

Wing, L., & Gould, J. (1979) Severe impairments of social interaction and associated abnormalities in children Epidemiology and classification. *Journal of Autism and Developmental Disorders*, 9(1), 11- 29. doi 10.1007/BF01531288

Wolowicz-Ruszkowska, A. (2015). How Polish women with disabilities challenge the meaning of motherhood. Psychology of *Women Quarterly*, 1-16. doi: 10.1177/0361684315600390

Paper 3: Commentary and reflective review

Navigating the research journey

Word count: 2,308 (excluding references)

Submission details

This paper is a reflective account to allow the reader to understand the author's research process based on papers one and two. For ease of reading and to express the researcher's reflexivity, the paper has been written in the first person and has not been written with publication in mind.

Abstract

I provide a reflective commentary on the research process described in papers one and two and discuss the impact of the findings on my understanding of the importance of diagnostic labels.

Introduction

The research topic came from a culmination of experiences and ideas that occurred at a similar time. I was working in a community mental health team (CMHT) and observed a gap in services for individuals with ASD as their needs did not meet the criteria for a CMHT or a learning disability service. There was also a lack of understanding about how individuals with ASD presented, with their behaviour being attributed to psychiatric labels rather than a different way of understanding and seeing the world. This experience led me to think about how individuals with ASD might experience services that are not tailored to their needs and how they get appropriate support. In my personal life a number of my friends were pregnant and spoke about their encounters with health services that were often depersonalised and lacked sensitivity. I wondered what this might be like for women with ASD who have communication difficulties and extra sensory needs. I was aware that current research indicated that women were often underdiagnosed with ASD which further meant that their needs are not understood nor met. A literature search indicated a lack of research in this area particularly from the perspective of women with ASD. However, a search of the internet highlighted a number of blogs about being a mother with ASD. This suggested a gap between an academic and professional understanding of the experiences of women with ASD and that of the individuals themselves.

Literature review

As highlighted above there was limited research about women with ASD and pregnancy, birth and parenting especially from women's perspectives, therefore, I wanted to find an area that might have parallels. Women with an intellectual disability (ID) often experience difficulties with communication and social understanding which may be similar to women with ASD. Women with ID are also a population of individuals whose voices have been supressed and who have not been afforded their rights to parenthood (Booth & Booth, 1994; Johnson & Traustadóttir, 2000) which may also be applicable to women with ASD.

Ethical issues

I was aware of the potential power dynamics between myself and individuals participating in the study and that communication difficulties may enhance the power difference. Ensuring consent was as informed as possible was one way of managing the power difference. Participants were given information about the study at a number of points including when they were first introduced to the study by a person known to them, at initial contact with myself via phone or email, having copies of the information sheet and consent form before the interview and talking through the process when meeting before starting the interview. The participants decided where the meetings took place and they reported that they felt more confident and safe at home. Participants were encouraged to have someone they felt comfortable with in the interview with them if they wanted to. I was aware that individuals with ASD may express or not express emotions differently to individuals without ASD therefore I made sure that we spoke about what each person wanted me to do if they felt distressed or how they might let me know if they were feeling overwhelmed. This was particularly important for one person who explained that they might dissociate during the interview. This did occur and we followed the plan agreed at the start of the interview.

Development of interview schedule

Due to the limited information about experiences of pregnancy, birth and parenting for women with ASD, I sought consultancy from a mother with ASD, Sarah, to explore the different areas that it might be useful to ask questions about. We highlighted areas around sensory experiences, managing the change in bodies through pregnancy and relationships with professionals. Sarah also reinforced the need to ask specific questions about how and why the participant did things. Differences in social communication and understanding are one of the main challenges for individuals with ASD therefore it was important to ensure that the interview questions were accessible. However, the nature of the research question and the method of analysis, Interpretative Phenomenological Analysis (IPA), requires questions to be open and expansive (Smith, Flowers & Larkin, 2009) which is in contrast to the direct and specific style of questioning being recommended by evidence and Sarah. To manage this, I developed a schedule that began with open questions but then included flexibility in the follow up questions that allowed them to be more direct or specific if needed. The interview schedule was checked by Sarah and my clinical supervisor who worked in a specialist ASD service to ensure the style of questions and language were appropriate. During each interview I told the participants about the style of questions and asked them to let me know if the questions were difficult. The participants reported that they found the style of questions appropriate though for some at the beginning of the interviews their anxiety made the first open question difficult to answer initially.

Challenges around recruiting

The original research idea was to interview women who identified with a diagnosis of ASD at two time points in order to explore their experiences more fully. The interviews were to take place towards the end of pregnancy and a few months after birth. I also wanted to recruit participants from maternity services within hospitals rather than specific ASD services or charities. I thought this may create opportunities for a wider range of experiences as all pregnant women access these services whereas it is a

more specific population who access ASD services. However, I contacted two hospital trusts who advised that they were not able to identify any women with ASD. This was due to the nature of recording information in the system and the professionals in the services did not think they had any women with ASD who used their services. It is more likely that there will have been a number of women who accessed the services but who did not have a diagnosis of ASD or did not disclose it.

To keep the range of experiences as wide as possible I advertised the research on social media such as Twitter and through national and local ASD charities. After several months I received one response from a mother with ASD who had already had her children offering to take part in the research if the inclusion criteria were revised. Due to time constraints it was agreed with my research supervisors that we would change the focus on the timing of the experiences and interview women who had already had their children. Following this change, recruitment was fairly quick. All the women who were recruited for the study had their diagnoses after they had their children which may have been a factor in the initial recruitment problems. Also, the majority of the mothers were recruited from the same ASD charity and reported that they only felt able to meet with me because it had been arranged through a trusted person. Therefore, another possible difficulty with recruitment may have been a wariness or worry about meeting with someone who was unknown. For other organisations, I had offered to come to their base to introduce myself with no obligation on people to take part in the study but this was not taken up. For future research it may be important to build in time and opportunities for researchers to build relationships with individuals in order to meet with them or to create ways of communicating that do not rely on face to face meetings.

Data analysis

I used IPA to analyse the transcriptions of the interviews which involved a close line by line analysis of each interview, exploring meaning at different levels of interpretation and the development of emergent themes for each participant. This involved immersing myself in the data in a very time

consuming manner and needed a balance of ensuring an authentic analysis of the participants' experiences whilst being mindful that the research was a time limited project. It was important to keep the question of 'what might this have meant to the participant when they had this experience' in order to encourage the interpretative aspect of the analysis. The interpretative aspect felt contentious to me at times due to comments that one of the participants had made about individuals without ASD making assumptions about the meaning behind the actions and understanding of individuals with ASD that were usually incorrect. I was aware that I was a person without ASD making sense of how a person with ASD was making sense of their experiences. To keep this awareness of our possible differences in mind I made notes of thoughts or biases that I was consciously aware of when analysing the data. I noticed that some of my earlier interpretations were in line with a diagnostic understanding of ASD and I had used words that might be found in the DSM-V. This became less frequent the more interviews I analysed and I wonder if this was because my understanding or preconceptions were being changed by the women I met and it was about their lived experiences rather than the academic understanding that had informed my ideas previously.

To analyse the data across participants I used a hands on visual method as there was a large volume of data. At this point I included all the themes from each participant even if they did not appear to be part of a larger emergent theme as I was aware some of them occurred in other interviews. I used physical space to illustrate and search for connections across the emergent themes by physically cutting out themes on paper and corresponding line numbers and placing them together or near each other if they appeared connected. I found the movement from analysis of participant data to connections across data particularly challenging as it felt like I was losing the voices of the individual participants. To help with this I repeatedly returned to the raw data to ensure that the themes were directly related to participant experience.

Gradually as I moved themes across, re-read participant accounts and used processes of abstraction and polarisation (Smith, Flowers & Larkin, 2009) to

highlight relationships between themes that were based on likeness or opposition, I developed four super-ordinate themes. I attended an IPA peer group which helped verify or challenge links between data and themes and brought credibility to the findings. The analysis continued as I further interpreted the findings whilst writing them up and reflected on my interpretations. Initial feedback on my analysis highlighted a lack of emphasis on what was different for mothers with ASD compared to mothers without ASD, despite the data showing clear differences. Reflecting upon this, I realised that I had responded to the mothers' difficult experiences of being seen as different as shown in the theme of 'Being different' by trying to minimise their differences and put them more in line with mothers without ASD. The mothers had also emphasised that having their differences understood by others rather than dismissed was helpful. By keeping this in mind I was able to bring this part of the analysis back in line with the data. Due to the difficulties in recruiting and the time pressures of this research I was not able to build in an opportunity for validation from the participants in time for submission. However, I have planned to send the participants the findings of the study and will be meeting some of the participants at a women's group run by one of the organisations involved in recruitment for feedback and to think about how to use the findings.

Impact of findings

One of the key findings was the importance of being understood and having individual needs recognised and supported. One of the main ways of doing this in our society, where the medical model is prioritised, is by having a diagnosis or a label that gives this difference credence. This may be particularly important for individuals whose difference is not obviously visible but can lead to difficulties in communication or differences in behaviour. Within my clinical practice and reading I have found the process of labelling, particularly in mental health services with psychiatric labels, as stigmatising and often leading to traumatic and restrictive practices such as forced medication or hospitalisation. As such I have been actively avoidant of diagnostic labels. However, in contrast, when undertaking this research, I realised how reliant both myself and the women in this study were of using a

label of ASD to facilitate understanding from others and for themselves and as a way of legitimising their difference in order to access support or resources. This seemed as though it was the only way for the women's experiences to be understood. This has challenged my ideas around the use of diagnoses and labels and how to work within a society that needs labels to organise understanding and resources. I recognise that actively avoiding a label is not necessarily helpful, as this can minimise the needs of women with ASD as I had done within my analysis. But perhaps it is through developing understanding of difference, rather than deficit, and promoting flexible practices that are based on individual need rather than labels that can help move away from the reliance on labels to ensure understanding and acceptance.

References

Booth, T., & Booth, W. (1994). *Parenting under pressure: Mothers and fathers with learning difficulties*. Buckingham: Open University Press.

Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, method and research.* Sage, London.

Traustadóttir, R., & Johnson, K. (2000). *Women with intellectual disabilities: Finding a place in the world*. London: Jessica Kingsley Publishers.

Appendix A – Relevant journal submission guidelines for Paper 1 to Disability & Society

Disclaimer

Paper 1 has been written for publication in Disability & Society. General submission guidelines for the target journal have been followed, however, for the purposes of thesis submission Ariel font size 12 and APA referencing has been used to adhere to University submission guidelines.

Additional content included for the purposes of thesis review will be removed prior to manuscript submission to the target journal.

- A typical manuscript will not exceed 8000 words. Authors should include a word count with their manuscript
- Taylor & Francis standard reference style: Chicago author-date
- Abstracts of 100-150 words are required
- Each manuscript should have 2 to 6 keywords
- All authors should be named with full contact details
- Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research
- Please supply all details required by any funding and grant-awarding bodies as an acknowledgement in a separate funding paragraph

Appendix B – Relevant journal submission guidelines for paper 2 to Autism

Disclaimer

Paper 1 has been written for publication in Autism. General submission guidelines for the target journal have been followed, however, for the purposes of thesis submission APA referencing has been used to adhere to University submission guidelines.

Additional content included for the purposes of thesis review will be removed prior to manuscript submission to the target journal.

- Research reports are generally restricted to a maximum of 6000 words. Authors should include a word count with their manuscript
- Sage Harvard reference style
- Follow journal guidance on terms for Autism
- The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point
- Participant information should be anonymised and if informed consent is obtained it should be indicated in the submitted articles.
- All authors should be named with full contact details and academic affiliations
- Please supply all details required by any funding and grant-awarding bodies as an acknowledgement in a separate funding paragraph

Appendix C – Critical appraisal tool

1. What were the aims of the research?

   What were the research questions? Were they presented clearly? Was the relevance of the aims stated?

2. Was the choice of qualitative methodology appropriate?

   Was the design appropriate for the aims? Did they explain the philosophical underpinnings of their choice?

3. Were ethical issues considered?

   Has approval been sought from the ethics committee? Were there sufficient details of how the research was explained? Is there discussion about issues of consent, confidentiality or the impact of the study on participants?

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

   Has the researcher examined their own role, bias or influence during the development of the study or in data collection?

5. Was the recruitment strategy appropriate to the aims?

   Did the recruiter explain how participants were selected? Was there enough information about the participants for reader to make judgements about transferability? Were the participants who were selected the most appropriate to provide access to the type of knowledge sought?

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

   Was it clear how data was collected? Has the researcher justified the methods chosen? Is there indication of how interviews were conducted? Has the researcher discussed saturation of data if appropriate?

7. Was the data analysis sufficiently rigorous?

   Is there an in-depth description of the analysis process? Is it clear how results have been derived from the data? Was the data analysis credible (triangulation, participant review of findings, following guidelines)?

8. Is there a clear statement of findings?

   Are findings explicit? Is sufficient data provided to support the findings? Has contradictory evidence been sought out and accounted for? Are the findings

discussed in relation to the research questions? Is there evidence of linking data to theory?

9. How valuable is the research?

Has the researcher discussed the contribution of the study to existing knowledge or understanding? Are new areas of research identified? Is there discussion of transferability?

Appendix D – Ethical approval letter from Staffordshire University

STAFFORDSHIRE UNIVERSITY

ETHICAL APPROVAL FEEDBACK

Faculty of Health Sciences

Researcher name:	Tanya Burton
Title of Study:	Exploring the experiences of birth, pregnancy and parenting of women who identify with a diagnosis of autism
Award Pathway:	Clin Psyc Doctorate
Status of approval:	Approved

Dear Tanya,

Thank-you for your email, and revised protocol requesting an amendment to the inclusion/exclusion criteria of your participants. I do hope it has the desired effect of enabling you to answer your research question, whilst increasing the number of participants.

I am happy to approve this amendment, and confirm receipt of an email from your supervisor, Dr Priest, in which she states her support for this amendment.

We wish you well with your study.

Action now needed:

Your project proposal has been approved by the Faculty's Ethics Panel and you may commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

You should arrange to meet with your supervisor for support during the process of completing your study and writing your dissertation.

When your study is complete, please send the ethics committee an end of study report. A template can be found on the ethics BlackBoard site.

Signed: Professor Karen Rodham
Chair of the Faculty of Health Sciences Ethics Panel

Date: 14th August 2015

Appendix E – List of recruitment venues contacted

National Autistic Society (Charity, advertise study online)

Autism West Midlands (Charity, advertise study online)

Autonomy Shropshire (Charity)

Staffordshire Adults Autistic Society (Charity)

North Staffs Autism/Asperger Society (Charity)

Shropshire & Telford Asperger Carers Support

Lifeworks

Netmums (Advertise study online)

The Autism Directory (Charity, advertise study online)

Aspergers and ASD UK Online Forum

Appendix F – Research information sheet

Exploring the Experiences Pregnancy, Birth and Early Parenting of Women with Autism
INFORMATION LEAFLET 1

I would like to invite you to take part in my research study. I am a Trainee Clinical Psychologist studying at Staffordshire University and working in Shropshire and South Staffordshire NHS Trust. This research study is part of my doctoral qualification.

Before you decide I would like you to understand why the research is being done and what it would involve for you. If you wish, talk to others about the study and ask if there is anything that is not clear.

What is the purpose of the study?
Girls and women are being increasingly referred for Autism assessments however there is little information about the experiences of being a woman with Autism, especially around pregnancy, birth and parenting. This study aims to explore experiences of pregnancy, birth and parenting to improve awareness and understanding for those working with women with Autism and to contribute to a more tailored health approach.

Why have I been invited?
I am asking women who identify with a diagnosis of Autism and who have given birth and parented a child to participate in the study. You have been given this information sheet because you identify with a diagnosis of Autism and have given birth and parented a child.

Do I have to take part?
It is up to you to decide to join the study. I will describe the study and go through this information sheet. If you agree to take part, I will ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This will not affect any support you receive.

What will happen to me if I take part?
I will speak with you by telephone and arrange the interview. In this interview we will discuss the study and if you are happy to continue I will ask you to sign a consent form. I will ask you questions about your experiences of pregnancy, birth and parenting. The interview can be held at a venue of your choosing. The interview will last 60-90 minutes and will be audio recorded.

What do I have to do?
You will be asked to sign and date the consent form before you can participate in the study. You will be asked to take part in an interview at a suitable venue that is convenient for you.

What are the possible disadvantages and risks of taking part?
We may talk about some sensitive topics or difficult experiences that you may have had and this may cause some distress. We can take regular

breaks during the interviews and you will be directed to appropriate sources of further support if needed.

What are the possible benefits of taking part?
You may not experience any direct benefit from taking part in this study. In the future, it may lead to more awareness and understanding of the experiences of pregnancy, birth and parenting for women with autism.

What is there is a problem?
If you have a concern or questions about any aspect of this study, you can speak to me or my supervisor using the contact details below.

What if I want to withdraw from the study?
You can withdraw from the study at any time and you do not have to give me a reason for your withdrawal if you do not wish. The information from your interviews can also be withdrawn up until two weeks after the interview. Once the information has been analysed it is combined with other interview data therefore it is difficult to withdraw.

Will my taking part in this study be kept confidential?
Yes. We will have confidentiality and security agreements in place to ensure your details are dealt with in the strictest confidence. However, as a researcher I have a duty to break confidentiality if I believe you or someone you know is at risk. I will discuss this with you if we need to share this information. If you have any questions about this we can talk about it further. We will follow ethical and legal practice such as the Data Protection Act 2003 and all information about you will be handled in confidence.

All information which is collected about you during the course of the study will be kept strictly confidential, and any study information about you will have your name and address removed so that you cannot be recognised.

The research team, which includes myself and my supervisors, will have access to your information. This process is sometimes audited to make sure we are following appropriate guidelines therefore regulatory bodies may also need to access the data collected.

What will happen to the results of the research study?
We plan to publish the results of this study in a scientific journal. However, you will not be identified in any publication. I also hope to publish the results in a manner that is more widely accessible for example on relevant websites or in newsletters.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by the Health Sciences Faculty Ethics Committee, Staffordshire University.

Further information and contact details
Please contact Tanya Burton (Researcher)   Helena Priest (Supervisor)

Telephone Number   (07709 811491)   (01782) 295785
Email b030770c@student.staffs.ac.uk   H.M.Priest@staffs.ac.uk

Signposting for further support
Autism West Midlands **www.autismwestmidlands.org.uk** 0303 03 00 111
National Autistic Society **– www.autism.org.uk 0808 800 4104**
Samaritans Helpline - 08457 90 90 90

Thank you for reading this information sheet

Appendix G – Consent form

Participant Identification:

CONSENT FORM

Title of Project:

Name of Researcher:

Please initial box

1. I confirm that I have read the information sheet
dated....................
(version............) for the above study. I have had the
opportunity to consider the information, ask questions
and have had these answered satisfactorily.

2. I understand that my participation is voluntary and
that I am free to withdraw at any time without my
medical care or legal rights being affected. The
information from my interviews can be withdrawn until
two weeks after the interview.

3. I understand that the interviews will be audio
recorded and then transcribed. My information will be
kept confidential and identifiable information such as
names, addresses will be removed.

4. I agree to take part in the study.

Name of Participant   Date   Signature

Name of Person   Date   Signature
taking consent

Appendix H – Interview schedule

Being a parent

- To start with I'd like to know more about being a parent as someone who identifies with / has a diagnosis of autism – can you tell me what it is like for you?

- How do you find being a parent?

- Can you tell me about your strengths as a parent? Is that related to the (your?) Autism? How does that help you with parenting?

- Can you tell me about any challenges / issues you have faced as a parent? *Prompt questions -* How did you resolve them? Did you have any support? If so what was that support? How did you find the support?

- How would you describe your relationships with your children?

- (For those with partners who share parenting) How have you found sharing the parenting?

- What do you think is important for others to know about you as a parent with ASD?

Pregnancy

- Can you tell me about your experiences of being pregnant? How did you find the pregnancy?

- What were your ideas / thoughts about becoming a parent?

How did you find the experiences of your body changing throughout the pregnancy?

-

Birth

- Can you tell me about your experience of having the baby /babies? Where did you have the baby? What was that like? Who was with you?

- Was there anything that was particularly helpful / unhelpful for you at this time?

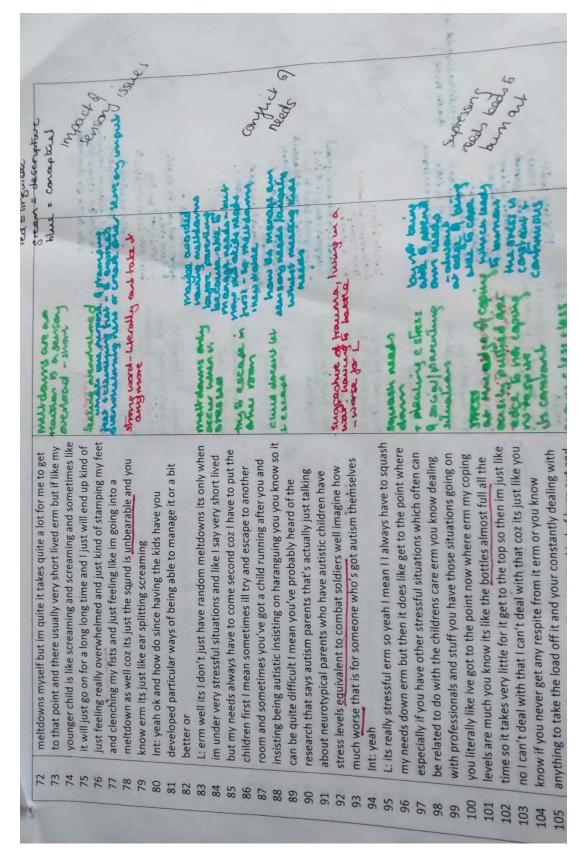- How did you find the experiences of your body changing after pregnancy and birth?

Questions that can apply to pregnancy, birth and parenting

Some individuals with ASD have spoken about difficulties managing change, did you experience any issues with this? For example, the change in routine, being off work?

-

- Was there anything particularly helpful that healthcare staff have done? What was the communication like?

Appendix I – Example of line by line coding

Line	Transcript
72	meltdowns myself but im quite it takes quite a lot for me to get
73	to that point and there usually very short lived erm but if like my
74	younger child is like screaming and screaming and sometimes like
75	it will just go on for a long long time and I just will end up kind of
76	just feeling really overwhelmed and just kind of stamping my feet
77	and clenching my fists and just feeling like im going into a
78	meltdown as well coz its just the sound is unbearable and you
79	know erm its just like ear splitting screaming
80	Int: yeah ok and how do since having the kids have you
81	developed particular ways of being able to manage it or a bit
82	better or
83	L: erm well its I don't just have random meltdowns its only when
84	im under very stressful situations and like I say very short lived
85	but my needs always have to come second coz I have to put the
86	children first I mean sometimes ill try and escape to another
87	room and sometimes you've got a child running after you and
88	insisting being autistic insisting on haranguing you you know so it
89	can be quite difficult I mean you've probably heard of the
90	research that says autism parents that's actually just talking
91	about neurotypical parents who have autistic children have
92	stress levels equivalent to combat soldiers well imagine how
93	much worse that is for someone who's got autism themselves
94	Int: yeah
95	L: its really stressful erm so yeah I mean I I always have to squash
96	my needs down erm but then it does like get to the point where
97	especially if you have other stressful situations which often can
98	be related to do with the childrens care erm you know dealing
99	with professionals and stuff you have those situations going on
100	you literally like ive got to the point now where erm my coping
101	levels are much you know its like the bottles almost full all the
102	time so it takes very little for it get to the top so then im just like
103	no I can't deal with that I can't deal with that coz its just like you
104	know if you never get any respite from it erm or you know
105	anything to take the load off it and your constantly dealing with

Appendix J – Example of development of emergent themes

Participant 4 – Emergent themes

Clash of autisms (6)	Keeping the baby 'just mine' (425)
Carer support (19)	Increase tolerance by focusing on baby (435)
Managing conflicting needs of children x2 (29, 80)	Putting baby's needs first (above own) (441)
Constant role of a parent (37)	Joy of growing life (456)
Supressing own needs for children x2 (45, 116)	Missing the unique connection of baby inside (462)
Lack of support (46)	Special 'mine only' relationship (470)
Raising children to fit in mainstream world (56)	Hard making transition from bump to baby (477)
Children as motivators (62)	Impact of breastfeeding on transition from bump to baby (481)
Medication as coping strategy (70)	
Understanding children's needs (72)	Challenge of developing new routine (486)
Parenting as a constant challenge / battle (87)	Easy to adapt routine once in place (495)
Difficult interacting with people don't know (100)	Impact of own experiences of being parented (509)
Building relationships over time (105)	Questioning right to be a parent (521)
Familiar environment (106)	Pride and joy in children (525)
Impact of change (112)	Appreciating their difference (529)
Managing sensory issues (135)	Unprepared for levels of pain during birth (536)
Finding balance of protecting and exposing children to experiences (149)	Managing dealing with new people (544)
	Wanting to get home ASAP (552)
Impact of life experiences making a good parent (166)	Hospital stay worst part of process (557)
	No control in hospital (562)
Learning to adapt to (NT) world (185)	Better in own space (569)
Empathy with children (194)	Focus of birth plan to get home 571)
Autism way of thinking provides consistency (201)	Hospital stay traumatic (578)
	Home birth preferred (583)
Close and tactile relationships with children (225)	Putting baby's needs before own (602)
	Systems needs prioritised over individual needs (621)
My routine is the only routine (240)	
Diagnosis helps others' understanding (248)	No individual care (642)
Professionals making assumptions that are not ok (265)	Help to have personal care plan (651)
	Cant understand lack of effort in care (676)
Impact of sensory needs x3 (272, 282, 542)	Support from carer to access places (793)
Lack of communication x3 (280, 291, 632)	Impact of MH on family life (799)
Not knowing (290)	Impact of ASD diagnosis x3 (820, 908, 921)

Knowing the diagnosis would not be enough to change attitudes (profs) (297)	Good communication between parents (829)
Lack of care (304)	Conflicting sensory needs (892)
Being judged (320)	Children's diagnoses (926)
Have to fit in with the system (327)	Super parent power – ASD brings shared understanding with children (982)
Not listened to x2 (400, 611)	
Dehumanised (405)	
Sensory experiences (414)	

Experience of hospital process / system

Managing conflicting needs

Good support from carer

Unique mother-child relationship

My job as a parent

Impact of ASD diagnosis

Factors that help with managing difficult situations

Difficulties with change

Factors that make me a good parent

Being different to others

Sensory issues

Appendix K – Analysis across participant data

Appendix L – Examples of reorganisation and synthesis of themes