

Autistic mothers and the perinatal period: maternal experiences and infant development



Sarah Caroline Hampton
Corpus Christi College

Department of Psychiatry
University of Cambridge

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Preface

This thesis is the result of my own work and includes nothing which is the outcome of work done in collaboration except as declared in the Preface and specified in the text. It is not substantially the same as any that I have submitted, or, is being concurrently submitted for a degree or diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text. I further state that no substantial part of my thesis has already been submitted, or, is being concurrently submitted for any such degree, diploma or other qualification at the University of Cambridge or any other University or similar institution except as declared in the Preface and specified in the text.

It does not exceed the prescribed word limit set by the School of Clinical Medicine and Clinical Veterinary Medicine Degree Committee.

Data collection for the CHILD study (Chapters 2, 4, 5 and 6) was conducted by myself with assistance from other members of the study team: Rosemary Holt, Ezra Aydin, Kate Maxwell and Alex Tsompanidis. Some participants in the CHILD study were recruited through the Cambridge Ultrasound Siblings and Parents study, led by Ezra Aydin.

Chapter 5 reports on parent-infant interaction data from the CHILD study. These data are also reported on in an undergraduate dissertation submitted by Kate Maxwell to the University of Bath. This dissertation reports unadjusted models of the 2-3 month data and their associations with factors such as gestational age. The findings are therefore not substantially the same as those presented in this thesis.

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Sarah Hampton

Abstract

Maternal wellbeing during the perinatal period is an important public health concern due to its impact on both mother and child. For autistic women, who experience sensory and communication differences and can face barriers to healthcare, the perinatal period may pose unique challenges. Despite this, research into the parenthood experiences of autistic women is scarce. This thesis explores the perinatal experiences and wellbeing of autistic mothers, their parenting behaviours, and the development of their infants.

Chapter 1 reviews the literature, and Chapter 2 reports on qualitative interviews with both autistic (n = 24) and non-autistic women (n = 25). Compared with non-autistic women, autistic women reported greater challenges with the physical burden of pregnancy; including heightened sensory experiences, pain, and morning sickness. Autistic women reported a lack of autism understanding among healthcare professionals and a reluctance to disclose their diagnosis. Continuity of care, as well as clear communication surrounding their care, were highlighted as important support needs.

Chapter 3, an online survey study of autistic and non-autistic people's perinatal experiences, explored whether the themes of Chapter 2 generalise to a larger sample using quantitative methods. Autistic women (n = 429) were more likely than non-autistic women (n = 551) to find the sensory and physical aspects of pregnancy and birth overwhelming and were more likely to experience perinatal depression and anxiety. They were also less satisfied with prenatal, birth-related and postnatal healthcare across a number of domains. They tended not to disclose their autism diagnosis to professionals and felt that professionals did not have a good understanding of autism.

Chapter 4 explores wellbeing at three time-points in autistic (n = 27) and non-autistic (n = 29) women: during the third trimester of pregnancy, 2-3 months after birth and 6 months after birth. Autistic women experienced greater self-reported stress, depression, and anxiety compared with non-autistic women. Explorations of self-reported parenting styles and parenting confidence revealed no significant group differences.

Chapter 5 finds no differences between autistic and non-autistic parents on parenting behaviours such as sensitive responsiveness, scaffolding, and affect during observations of play with their 2-3 month old and 6 month old infants. No group differences were found in infant social behaviour. This may reflect the coding method employed, or it may reflect that at this early stage in development no differences exist.

Chapter 6 explores associations between mothers' perinatal wellbeing (stress, depression and anxiety) and structural MRI measures of their child's brain development during the third trimester of pregnancy and 8-12 weeks after birth. For infants of both autistic and non-autistic mothers, associations were found between maternal wellbeing and the growth of brain regions implicated in mood disorders. This novel finding has important implications for perinatal care practice.

Overall, these studies show that the perinatal period can bring a number of challenges for autistic women, including navigating physical experiences and accessing adequate healthcare, and can leave them vulnerable to reduced wellbeing. The thesis provides evidence that autistic parents are not less likely to engage in positive parenting behaviours with their infants. Infants of autistic mothers show similar social interaction to infants of non-autistic mothers during the first 6 months of life, although the brain development of infants of both autistic and non-autistic mothers is influenced by their mothers' wellbeing. Overall, the thesis highlights that access to adequate perinatal support is essential for both maternal wellbeing and infant development and illustrates the need for more research into autistic women entering parenthood as they have been neglected in research. Discussion centres on the need to translate this research into guidelines for perinatal care practice.

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Chapter 1: Introduction

1.1 The importance of exploring autistic¹ parenthood

The experiences of autistic parents is a topic almost entirely neglected by research. However, as will be outlined throughout this chapter, exploration of this topic is both important and timely. Pregnancy, childbirth and the postnatal period are times of great physical change, with issues such as sensory changes during pregnancy and the physical challenges of breastfeeding impacting upon quality of life (Hankel et al., 2019; Swallow et al., 2005). For autistic people, who experience differences in sensory processing (Tavassoli et al., 2014), these changes may be even more challenging. Difficulties surrounding mental health are common during the perinatal period (Vesga-Lopez et al., 2008). Given increased prevalence of mental health conditions among autistic people (Lai et al., 2019) and evidence that a prior history of mental health conditions is a risk factor for poorer perinatal mental wellbeing (Lancaster et al., 2010), autistic people's perinatal mental health is an important topic of research. Furthermore, autistic people can face barriers to accessing healthcare appropriate to their needs (Raymaker et al., 2017), though there is little research assessing autistic people's healthcare experiences and needs within a maternity care context. Finally, while it is known that infants with an autistic sibling can follow a different developmental trajectory to infants without an autistic relative, there is no research focusing on infants with an autistic parent. Research addressing this issue is necessary in order to identify how infants of autistic parents may be best supported to flourish.

1.2 Autism among women and girls

Autism spectrum disorder (hereafter 'autism') is a lifelong neurodevelopmental condition, with a prevalence of around 1% (Brugha et al., 2011). Autism is clinically characterised by difficulties in social interaction and communication, restricted and repetitive behaviours, intense interests and sensory processing differences (American Psychiatric Association (APA), 2013). Autistic social difficulties have long been documented, including difficulties understanding social cues such as complex facial expressions (Baron-Cohen et al., 1997) and faux-pas (Baron-Cohen et al., 1999). However, while social difficulties in autism have

¹ Identity-first ('autistic person') rather than person-first ('person with autism') language is used in line with the preferences of the autistic community (Kenny et al., 2016).

traditionally been conceptualised as an autistic impairment, there is increasingly recognition that these difficulties may in part arise from a bidirectional mismatch of communication styles between autistic and non-autistic people (known as the 'double empathy problem'; Milton, 2012). Just as autistic people have difficulties understanding the mental states of non-autistic people, non-autistic people demonstrate difficulties understanding the mental states of autistic people (Edey et al., 2016). Furthermore, communication occurs more effectively within pairs where both members are autistic than within mixed autistic/non-autistic pairs (Crompton et al., 2020).

While not part of the diagnostic criteria for autism, differences between autistic and non-autistic people also arise in a number of non-social domains such as difficulty with executive function (processes involved in goal-oriented behaviour such as planning and organising; Wallace et al., 2016), superior attention to detail (O'Riordan et al., 2001) and enhanced perceptual capacities (Brinkert & Remington, 2020).

Autism is diagnosed more commonly among males than females, with a male to female ratio among clinical samples of around 4:1 (Fombonne, 2009). While this difference may in part be due to biological factors, such as a genetic female protective effect (Gilman et al., 2011) and hormonal influences (Auyeung et al., 2013), it is now also thought that autistic females have an elevated risk of going undiagnosed or being misdiagnosed with another condition (Lai & Baron-Cohen, 2015). Indeed, in samples not referred to the clinic the male to female ratio drops to around 3:1 (Loomes et al., 2017; Sun et al., 2014), suggesting that many females who meet the criteria for autism do not come to clinical attention. There is evidence that, compared with males with similar levels of autistic characteristics, females need to exhibit greater intellectual or behavioural problems in order to meet diagnostic criteria (Dworzynski et al., 2012). Furthermore, those females who do gain a diagnosis tend to receive this diagnosis later in life than males (Begeer et al., 2013).

The under-diagnosis of autistic females may in part be due to a dominant conceptualisation of autism that is biased towards a male presentation. There is evidence of sex/gender differences in the presentation of autism. For example, females may have greater social motivation (Sedgewick et al., 2016), fewer externalising behaviours (Mandy et al., 2012) and fewer restricted and repetitive behaviours (Van Wijngaarden-Cremers et al., 2014). Females may also be more likely than males to camouflage or mask their autistic characteristics in

social situations (Lai et al., 2017). Camouflaging is common among autistic people (Cage & Troxell-Whitman, 2019) and may involve conscious or unconscious attempts to suppress less socially acceptable autistic behaviours (such as repetitive behaviours) or engage in more socially acceptable behaviours (such as forcing oneself to make eye contact or imitating non-autistic people's facial expressions; Hull et al., 2017). Camouflaging is often motivated by a desire to avoid judgement and discrimination, and while it can facilitate assimilation with non-autistic people, it can also have a negative impact on the individual (Hull et al., 2017). Camouflaging has been associated with adverse mental health outcomes such as depression and anxiety (Cage & Troxell-Whitman, 2019) as well as suicidality (Cassidy et al., 2018). This may in part be due to the considerable effort that camouflaging requires, leading to feelings of exhaustion (Livingston et al., 2019), as well as due to the negative impact on identity that pretending not to be autistic can cause (Hull et al., 2017). Camouflaging can also lead to an individual's difficulties being hidden and their needs therefore going unmet. It can, for example, be a barrier to receiving an autism diagnosis due to the individual's autistic characteristics being underestimated by clinicians (Bargiela et al., 2016).

Given conceptualisations of autism as a predominately male condition, autistic women have been underrepresented in research, with most studies having focused upon males (Watkins et al., 2014) and child samples (Edwards et al., 2012). While pregnancy, childbirth and the postnatal period represent significant aspects of adult life for many individuals who are assigned female at birth², autistic people's experiences of these events has received little attention among researchers. It is unknown what proportion of autistic people become parents. However, people with disabilities commonly become parents, with one study estimating that approximately 10% of women who had recently given birth had a longstanding limiting illness (such as a musculoskeletal, respiratory or mental health disorder; Šumilo et al., 2012). Furthermore, autistic people participate fully in other aspects of adult life, such as romantic relationships (Sedgewick et al., 2019), indicating the need for research to explore related adult life events including parenthood. Pregnancy, childbirth and the postnatal period can present difficulties for any parent. For autistic people, who experience

² It is acknowledged that not all people who experience pregnancy and childbirth are women as transmen and non-binary people can become pregnant.

differences in communication and sensory experiences, these events may pose additional challenges.

1.3 Experiences of pregnancy, childbirth and the postnatal period among non-autistic people

While having a child can be a positive and welcome event, the perinatal³ period can be physically and psychologically demanding. Up to 80% of people experience nausea or vomiting during pregnancy (Gadsby et al., 1993) and a minority (around 0.5% to 2%) experience hyperemesis gravidarum (severe vomiting that can lead to dehydration and weight loss; Eliakim et al., 2000). Furthermore, the hormonal changes of pregnancy often cause alternations to the senses, such as smell and taste (Cameron, 2014; Faas et al., 2010) and this can aggravate issues with nausea and vomiting (Swallow et al., 2005). Nausea and vomiting during pregnancy can lead to lower quality of life and impact upon daily life functioning (Heitmann et al., 2017). Other physical demands such as pelvic girdle pain and lower back pain are common during pregnancy (Gutke et al., 2018) and can take an emotional toll in addition to impacting upon daily life (Close et al., 2016). The physical symptoms of pregnancy, in addition to poor sleep quality and concerns surrounding body image also impact upon emotional wellbeing and self-esteem (Kamysheva et al., 2008). Adding to the emotional impact, pregnancy also brings a number of worries, including concerns about the unborn child's health, fears relating to childbirth and concerns about parenthood (Borghei et al., 2016).

Childbirth can be a difficult and even traumatic experience (Soet et al., 2003), with an estimated 3.1% of people developing post-traumatic stress disorder following birth (Grekin & O'Hara, 2014). A number of factors influence how childbirth is experienced, including quality of communication with medical staff, feeling listened to by medical staff, and feeling a sense of control over the birth experience (Hallam et al., 2016; Henderson & Redshaw, 2013a). Birth-related and neonatal medical complications also impact upon the experience. Those undergoing forceps-assisted vaginal birth or unplanned caesarean section report worse

³ The term perinatal can have widely varying definitions and is used here to denote pregnancy and up to 6 months after birth.

health and wellbeing compared with those undergoing unassisted vaginal births or planned caesarean delivery (Rowlands & Redshaw, 2012). Unexpected neonatal outcomes such as infant transfer to neonatal care also contribute towards experiencing childbirth as traumatic (Simpson & Catling, 2016).

During the postnatal period, the responsibility of parenthood can be overwhelming. Having limited time to oneself, experiencing isolation and feeling drained of energy contribute towards feeling overwhelmed (Nyström & Öhring, 2004). Breastfeeding can be a particular challenge, with studies emphasising the need for good quality, person-centered support in order to succeed (Rayfield et al., 2015; Schmied et al., 2011). Loss of confidence and self-esteem can be common during the postnatal period and successful breastfeeding experiences are important for increasing mothers' sense of self-efficacy (Hankel et al., 2019). The challenges of the postnatal period can also put strain on relationships, including partner relationships, and adequate support from others during the postnatal period is crucial for wellbeing (Leahy-Warren et al., 2012; Lupton, 2000). For first-time parents, adjusting to the transition to parenthood and their changing role can be challenging and parents can feel a loss of identity and autonomy (Forster et al., 2008). Worries can arise about the health of their baby and their ability to care for their baby, with first-time parents sometimes feeling underprepared and lacking adequate information and support about the practical aspects of parenthood (Khan & McIntyre, 2016).

The challenges detailed above can contribute towards poorer mental health. In particular, loss of identity, isolation, feeling overwhelmed, lack of confidence, breastfeeding issues and lack of social support have been associated with postnatal depression and anxiety (Haga et al., 2012; Nicolson, 1999; Wardrop & Popadiuk, 2013). Psychiatric conditions are common during the perinatal period, with an estimated prevalence of around 25% (Vesga-Lopez et al., 2008). Though it is important to note that psychiatric disorders do not appear to be any more common during the perinatal period than among those who have not been pregnant or given birth during the same time frame (Van Bussel et al., 2006). However, risk of poor perinatal mental health increases with the presence of risk factors such as lower socio-economic status, postnatal physical complications (Gaillard et al., 2014), low birth weight (Helle et al., 2015), single parenthood, younger age, unplanned pregnancy, partner violence and a previous history of psychiatric disorders (Lancaster et al., 2010; Robertson et al., 2004).

Hormonal factors such as progesterone and oestrogen levels are also a risk factor for poorer mental health (Ingram et al., 2003; Mehta et al., 2019).

For autistic people the challenges of the perinatal period may be heightened. Autistic people often have atypical sensory experiences and can experience sensory overload (becoming overstimulated by sensory input, for example bright lights, loud sounds, touch and strong smells; Robertson & Simmons, 2015; Tavassoli et al., 2014). These sensory processing differences can impact upon daily life. For example, sensory sensitivities are associated with school-based difficulties such as attentiveness (Pastor-Cerezuela et al., 2020), emotional distress (Robertson & Simmons, 2015) and anxiety (Uljarević et al., 2016). The sensory aspects of the perinatal period, such as changes in smell and taste, and the sensory demands of breastfeeding may therefore be particularly challenging for autistic people. Furthermore, there is evidence of differences in interoception (awareness of one's internal bodily sensations) between autistic and non-autistic people, such that some autistic people can have difficulties recognizing bodily states such as pain (Elwin et al., 2012) and thirst (Fiene & Brownlow, 2015). Conversely, other studies have found increased subjective perception of bodily signals among autistic people (Garfinkel et al., 2016). There is also evidence for differences in proprioception (awareness of the position and movement of the body), such as balance, among some autistic people (Blanche et al., 2012; Weimer et al., 2001). Differences in interoception and proprioception may make the bodily sensations associated with pregnancy such as fetal movements, nausea, pain and changes in body size especially challenging for autistic people.

Autistic people may also be at increased risk for perinatal mental health conditions. Autism and mental health conditions often co-occur, with estimates suggesting that around 20% of autistic people experience an anxiety disorder, 11% a depressive disorder, 9% obsessive-compulsive disorder, 5% bipolar disorder and 4% a schizophrenia spectrum disorder (Lai et al., 2019). Given this high prevalence, together with the fact that a prior history of mental health conditions is a risk factor for poorer perinatal mental health (Lancaster et al., 2010), autistic people may face increased vulnerability for perinatal mental health conditions. Further, communication differences may impact upon autistic experiences of maternity healthcare.

1.4 Autism and access to healthcare

For non-autistic people, the quality of maternity care received impacts upon the experience of the perinatal period. Women in the UK tend to report high satisfaction with maternity care (Henderson & Redshaw, 2017). A number of aspects of care influence level of satisfaction; women value continuity of care (Hodnett, 2000), good communication and respectful relationships with healthcare providers (Rowe et al., 2002) and having the opportunity to make informed choices about their care (Jomeen & Martin, 2008). For autistic people, who may experience additional barriers to communication with healthcare professionals, accessing adequate perinatal care may be more challenging.

Indeed, autistic people face a number of communication-related barriers to adequate healthcare. These include difficulties processing verbal information during appointments (Raymaker et al., 2017), insufficient time to respond to questions in appointments (Dern & Sappok, 2016) and a lack of accessible communication formats such as written information (Nicolaidis et al., 2015). In addition, sensory processing issues can be a barrier to healthcare for autistic people, including difficulties with the sensory environment of healthcare facilities (such as bright lights and loud, crowded waiting rooms; Raymaker et al., 2017), difficulties identifying and reporting on inner experiences such as pain, and discomfort with unannounced touch during appointments (Dern & Sappok, 2016). Autistic people also report a lack of autism knowledge among healthcare professionals. Professionals can make incorrect assumptions about autistic people's abilities and needs, such as assuming low support needs due to high intellectual ability, and autistic adults can be reluctant to disclose their autism to professionals due to fear of discrimination (Nicolaidis et al., 2015). Echoing reports by autistic people, professionals across a variety of areas of healthcare report that they lack adequate knowledge and training about autism in adults (Morris et al., 2019; Urbanowicz et al., 2020; Zerbo et al., 2015) and can lack confidence providing care to autistic people (Unigwe et al., 2017).

It is possible that autistic females may face additional barriers to healthcare compared with autistic males. For example, professionals' conceptualisation of autism as a male condition can be a barrier to obtaining an autism diagnostic assessment for women (Bargiela et al., 2016). Further, autistic women report that their ability to mask their autistic characteristics is a barrier to accessing services as healthcare providers underestimate their needs (Tint &

Weiss, 2018). Autistic people may therefore experience barriers to accessing adequate maternity healthcare and this may adversely affect both their wellbeing and outcomes for their child.

1.5 Maternal influences on child outcomes

1.5.1 Maternal prenatal wellbeing and child outcomes

Maternal wellbeing during the perinatal period is an important public health concern due to its impact not only on the mother but also on child development. Maternal prenatal stress, depression and anxiety have independent links with child developmental outcomes. These include adverse birth outcomes such as preterm birth and low birth weight (Accortt et al., 2015; Beydoun & Saftlas, 2008; Ding et al., 2014; Kurki et al., 2000), in addition to child behavioural and emotional outcomes across development. For example, prenatal maternal stress, depression and anxiety are associated with infant temperament (such as greater infant distress; Erickson et al., 2017), lower outcomes on cognitive assessments (Bergman et al., 2007), poorer executive functioning (Buss et al., 2011), greater behavioral and emotional difficulties across childhood and adolescence (Leis et al., 2014; Robinson et al., 2011; Van den Bergh et al., 2008) and greater symptomology of ADHD (Van den Bergh & Marcoen, 2004). These associations tend to persist after accounting for postnatal maternal mental health, suggesting that effects of prenatal maternal mental health are not simply attributable to postnatal factors. Environmental factors such as socio-economic status, maternal marital status, birth outcomes and prenatal substance use may partially mediate the relationship between maternal prenatal mental health and child outcomes. However, studies accounting for these factors tend to find that associations between prenatal maternal mental health and child outcomes persist. It is also important to note that many studies do not establish the direction of causality between maternal mental health and child outcomes, and maternal and child factors likely have bidirectional influences upon each other (explored in greater detail in the following section).

The *fetal programming hypothesis* suggests that the maternal uterine environment, including prenatal maternal psychological distress, can influence the fetus, causing long-lasting alterations in offspring development (Gluckman et al., 2007). One potential mechanism for these effects is that maternal psychological distress increases the release of maternal stress hormones such as cortisol, which cross the placenta and affect the developing HPA axis of the

fetus leading to alterations in subsequent development (Sandman et al., 2012). Epigenetic mechanisms may play a role, with maternal prenatal stress increasing methylation of the glucocorticoid receptor gene (involved in the development and regulation of the HPA axis) in offspring (Radtke et al., 2011).

1.5.2 Maternal postnatal wellbeing and child outcomes

Postnatal maternal mental health (with most studies focusing on depression and anxiety) shows similar associations with child outcomes as prenatal maternal mental health, including associations with behavioural and emotional problems and lower cognitive outcomes across childhood and adolescence (Goodman et al., 2011; Netsi et al., 2018; Prenoveau et al., 2017). While studies of postnatal maternal mental health often do not account for prenatal maternal mental health or maternal later history of mental health symptomology, those that do account for these variables tend to find that associations persist after doing so (e.g. Barker et al., 2011; Korhonen et al., 2012). Severity and chronicity can influence the strength of the association with child outcomes, with more severe symptomology and chronic symptomology that persists beyond the postnatal period showing stronger associations than brief postnatal episodes (Brennan et al., 2000; Cornish et al., 2005).

Postnatal maternal mental health may in part exert its effects through its influence on parenting behaviour. The quality of parent-child interactions has consistently been linked to child developmental outcomes. In particular, maternal sensitivity (the ability to correctly identify and respond to the infant's cues and to provide appropriate warmth and acceptance; Ainsworth et al., 1971) may influence child outcomes. Maternal sensitivity has been associated with infant temperament (Kivijärvi et al., 2005), child executive function (Bernier et al., 2010), attentional abilities (Belsky et al., 2007), language and communication (Leigh et al., 2011; Silvén et al., 2002), emotional problems (Mount et al., 2010) and behavioural problems (Campbell et al., 2010). Parental control is also thought to influence child outcomes (Yap et al., 2014). Parenting style has commonly been conceptualised as falling into three categories: authoritative (high sensitivity alongside an appropriate degree of control according to the child's developmental level); authoritarian (low sensitivity and high control); and permissive (high sensitivity and low control; Baumrind, 1978). Authoritative parenting has been associated with more positive child outcomes than authoritarian and permissive

styles, including behavioural (Rinaldi & Howe, 2012), cognitive and social outcomes (Stright et al., 2008).

There is evidence that mothers with depression (Field, 2010; Lanzi et al., 2009; Lilja et al., 2012; Stanley et al., 2004) and mothers with anxiety (Feldman et al., 2009; Nicol-Harper et al., 2007) show less sensitivity with their infants during the first year of life. Furthermore, parenting behaviour (in particular, reduced sensitivity and increased harsh or authoritarian parenting) has been shown to mediate the relationship between maternal postnatal mental health and child behavioural, cognitive and linguistic development (Baker & Kuhn, 2018; Bouvette-Turcot, et al., 2017; Calzada et al., 2019; Edwards & Hans, 2016; Feldman et al., 2009; Giallo et al., 2014; Mulraney et al., 2019).

During interactions with their mother, infants of depressed mothers and infants of anxious mothers show less social engagement than infants of mothers without anxiety or depression (Feldman et al., 2009; Reck et al., 2018). Atypicalities in maternal and infant behaviour may in part be due to bidirectional, interactive processes of maternal and infant factors (Goodman & Gotlib, 1999). Mothers with mental health conditions may show atypical behaviours which influence the development of their infants. In turn, infants of mothers with mental health conditions may show atypical behaviours (due to a genetic propensity towards atypical development, as well as in utero and other environmental factors) which then influence the behavioural response of their mother (Newland et al., 2016). Furthermore, there is evidence of gene-environment interactions such as that prenatal adversity (including maternal depression and anxiety) interacts with child genetic factors to influence later child outcomes (Silveira et al., 2017). These influences likely also interplay with broader familial and environmental factors, such as parental relationship quality (Crockenberg & Leerkes, 2003). Indeed, it is important to take into account the mediating influence of environmental factors on the relationship between maternal mental health and child outcomes, including poverty (Petterson & Albers, 2001), maternal education (Pearson et al., 2013), marital discord (Dawson et al., 2003), single parenthood and ethnicity (Goodman et al., 2011). As such, the association between maternal mental health and child outcomes likely depends on environmental factors (exposure to the uterine environment, parenting behaviours, socio-economic and familial factors), genetic predisposition and interactions between these factors. For infants of autistic mothers, who themselves have an increased genetic likelihood of an

atypical developmental trajectory (see below), it may be particularly important to cultivate positive maternal experiences and wellbeing.

1.6 Early development in autism and prospective longitudinal studies of autism

The causes of autism are diverse, and its emergence likely depends on complex interactions between genetic and environmental factors. These factors may give rise to early brain and behavioural differences (such as atypical attentional preferences) which then affect the child's experience of their environment and thus reinforce developmental differences (Jones et al., 2014). Gaining insight into these mechanisms is important for improving early detection and informing early intervention, which can in turn improve child outcomes (Webb et al., 2014). As autism cannot reliably be diagnosed before around 3 years old (Woolfenden et al., 2012), investigations of the emergence of autism before this age have employed prospective longitudinal designs tracking the development of infants who have an increased genetic likelihood of being autistic due to having an older autistic sibling. Indeed, infants with an older autistic sibling are approximately 20 times more likely than those without a family history of autism to go on to receive a diagnosis (Ozonoff et al., 2011).

Prospective studies have yielded a number of insights into the early development of autism, with social behavioural differences tending to become evident during the second year of life. Differences in social behaviours such as attention to faces, social smiling and directed vocalisations, for example, do not appear to be evident at 6 months old (Ozonoff et al., 2010; Rozga et al., 2011) though differences in these behaviours, alongside others such as communicative gesture use and responding to social cues, become apparent within the second year of life (Hutman et al., 2010; Ozonoff et al., 2010; Sullivan et al., 2007; Talbott et al., 2015). Differences in non-social behaviours appear to become apparent from the latter half of the first year of life onwards, such as differences in disengagement of attention (Zwaigenbaum et al., 2005), greater spontaneous attention to non-social stimuli (Bhat et al., 2010) and better working memory for non-social stimuli (Noland et al., 2010), compared with typically developing infants. Social and non-social attention during infancy have been found to independently predict later autism diagnostic outcome, suggesting that each have a cumulative impact upon later outcomes (Bedford et al., 2014). Explorations of change over time may be better predictors of later autism diagnosis than cross-sectional analyses. For example, despite no cross-sectional group differences, Jones and Klin (2013) found that time

spent looking to eyes declined between 2 and 6 months in infants who went on to receive a diagnosis and increased in typically developing infants, highlighting the importance of a longitudinal approach.

Furthermore, neural differences may precede behavioural ones. For example, differences in neural responses to social cues such as dynamic eye gaze may be apparent within the first year of life despite the absence of behavioural differences (Elsabbagh et al., 2012). Infants who go on to receive an autism diagnosis have been shown to have higher structural brain connectivity (in terms of fractional anisotropy values of white matter tracts) at 6 months compared with typical infants, but lower structural connectivity at 24 months, following a slower change over time (Wolff et al., 2012). A similar pattern of early increased connectivity followed by reduced connectivity by the second year of life has been found for studies of functional connectivity (Keehn et al., 2013). These dynamic trajectories once again highlight the need for longitudinal approaches.

Given the importance of the early social-interactive environment for development (Feldman & Greenbaum, 1997), it may be important to consider the emergence of autism within the context of early social interactions. For example, dyadic mutuality during play between infants with an older autistic sibling and their parent predicts later autism diagnosis (Wan et al., 2012). Wan et al. (2012) suggest that initial behavioural atypicalities of the infant may influence their early social interactions with their caregiver which may in turn reduce social learning opportunities and reinforce an atypical trajectory. This is not to say that caregivers are the cause of their infant's autism, rather that interpreting and responding appropriately to their infant's cues may be more challenging for parents of infants who show atypical communicative signals. Providing support for the importance of the early social environment, intervention aiming to help parents understand and adapt to their infant's communication styles has been shown to reduce autism symptoms in infants with an autistic sibling (Green et al., 2017).

Prospective studies of infants with an autistic parent have not previously been conducted and the likelihood of such infants being autistic themselves is not known. However, given the heritability of autism, it is likely that these infants will have an increased genetic likelihood of being autistic. Furthermore, having an autistic parent may confer different environmental experiences upon these infants. Children of autistic mothers may experience alterations to

the uterine environment due to elevated rates of hormone-related conditions (e.g. polycystic ovary syndrome) among autistic women which may alter hormone levels during pregnancy and increase the likelihood of their infant developing autism (Cherskov et al., 2018).

Autistic parents will also influence their children through their parenting behaviours. Little is known about the parenting styles of autistic parents. It is possible that autistic parents are well placed to identify any potential autistic characteristics of their child and to help implement coping strategies they themselves have learned. Given evidence of more successful communication among autistic people than among autistic and non-autistic people (Crompton et al., 2020), autistic children may find it easier to interact with an autistic parent and autistic parent and child dyads may therefore involve more synchronous bonds than would be possible with a non-autistic parent. Sensory interests and enjoyment of repetition could play a positive role in parent-child play, with autistic parents appreciating the repetitive and sensory-based play that aids early learning and development (Page et al., 2013). Enhanced attention to detail may allow autistic parents to attend closely to their child's cues. Alternatively, social differences in autism may make identifying their child's cues more challenging. Autistic parents may also find aspects of pretend play challenging, given difficulties with pretend play in autism (Rutherford et al., 2007). Furthermore, barriers to adequate perinatal healthcare for autistic women may influence their child through increased risk of pregnancy complications and poorer birth outcomes. Finally, if autistic mothers experience lower perinatal wellbeing, this too may impact upon their child.

1.7 Objectives

The perinatal period may pose particular physical, communication and healthcare related challenges for autistic mothers. Furthermore, infants of autistic mothers have an increased genetic likelihood of an atypical developmental trajectory and this propensity may interact with environmental factors such as their early social-interactive context and factors relating to maternal experiences. This thesis aims to explore the perinatal experiences and wellbeing of autistic mothers, their parenting behaviours, and the development of their infants within the context of maternal factors. Chapters 2 and 3 aim to identify how autistic people can be better supported during the perinatal period. Chapter 2 explores perinatal experiences from a qualitative perspective, including the physical challenges of pregnancy and birth, experiences of healthcare and the benefits and challenges of parenthood. Chapter 3 aims to

explore whether the findings of Chapter 2 generalise to a larger sample using quantitative, survey methodology. Chapter 4 aims to explore autistic people's stress, anxiety and depression from pregnancy until 6 months after birth, as well as their parenting styles and parenting confidence. Chapters 5 and 6 pertain to the development of infants of autistic mothers within the context of maternal factors. Extending the explorations of self-reported parenting styles in Chapter 4 to an observational context, Chapter 5 investigates how autistic parents play with their infants, in order to identify strengths as well as areas where support may be beneficial. This chapter also explores the social development of infants of autistic mothers within the context of interaction with their mothers. Chapter 6 aims to explore associations between prenatal and postnatal mothers' stress, depression and anxiety and their infant's structural brain development during pregnancy and after birth, in order to gain insights into the timing of associations between maternal wellbeing and child development.

1.8 Participant cohorts

The Cambridge Human Imaging and Longitudinal Development (CHILD) study is a prospective longitudinal study exploring the development of infants with an autistic mother or sibling. Through neuroimaging and behavioural assessments, the study explores early developmental differences in autism from the third trimester of pregnancy until 3 years of age. The study is the first to follow the development of infants with an autistic mother and the first to test the feasibility of recruiting pregnant autistic people and employing magnetic resonance imaging (MRI) with this population. Participants attend in-person visits at 30-33 weeks of pregnancy, 2-3 months after birth and 6 months after birth, with online follow-ups at 18 months and 30 months (Figure 1.1). In addition to administering measures pertaining to the infant, qualitative interviews and self-report questionnaires explore the wellbeing of the mothers.

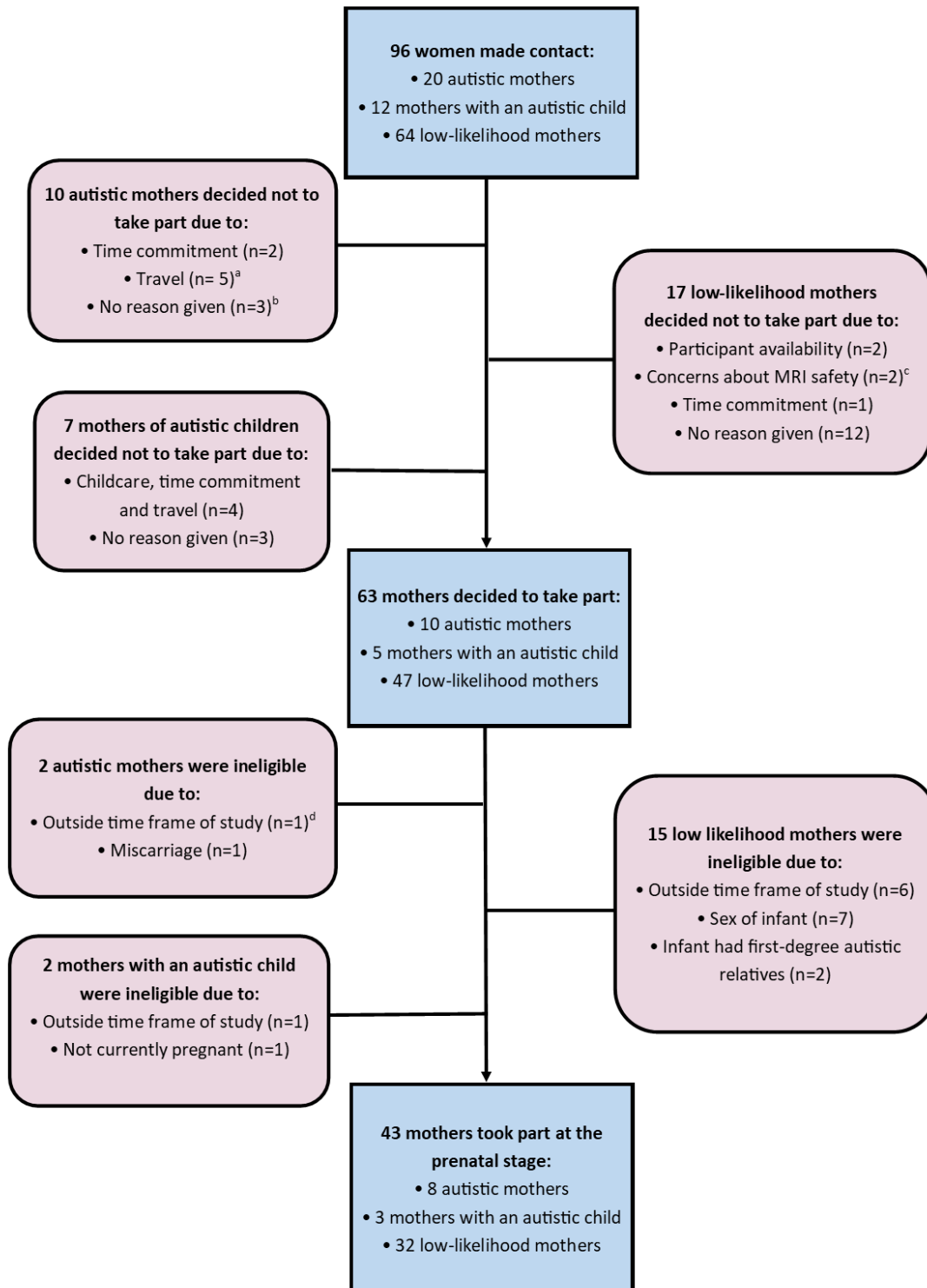
Prenatal	2-3 months	6 months	18 months	30 months
<ul style="list-style-type: none"> •Fetal MRI •Pregnancy experiences interview •Mother's wellbeing questionnaires •AQ (for the mother) •Pregnancy history questionnaire •Background information questionnaire <p>For the father:</p> <ul style="list-style-type: none"> •Cohens Perceived Stress Scale •AQ 	<ul style="list-style-type: none"> •Infant MRI •Parent-child play •Neonatal Behavioural Assessment Scale •Growth measures •Saliva collection •Birth information questionnaire •Motherhood experiences interview •Mother's wellbeing questionnaires <p>For the father:</p> <ul style="list-style-type: none"> •Edinburgh Post-natal Depression Scale 	<ul style="list-style-type: none"> •Parent-child play •Mullen Scales of Early Learning •Eye-Tracking •Growth Measures •Saliva collection •Infant-Toddler Sensory Profile •Infant Behaviour Questionnaire Revised •Motherhood experiences interview •Mother's wellbeing and parenting style questionnaires 	<ul style="list-style-type: none"> •Quantitative Checklist for Autism in Toddlers (Q-CHAT) •Ages and Stages Questionnaire •MacArthur-Bates Communicative Development Inventory •The Early Childhood Behaviour Questionnaire •Infant-Toddler Sensory Profile •Edinburgh Postnatal Depression Scale 	<ul style="list-style-type: none"> •Quantitative Checklist for Autism in Toddlers (Q-CHAT) •MacArthur-Bates Communicative Development Inventory •Child Behaviour Checklist •Infant-Toddler Sensory Profile •Developmental Diagnostic Dimensional Interview (3Di)

Figure 1.1 CHILD study measures.

Pregnant autistic women and pregnant non-autistic women with an older autistic child (high-likelihood group) were recruited, alongside a comparison group of pregnant women whose unborn child had no first-degree relative with autism (low-likelihood group). To recruit the low-likelihood group, the author approached pregnant women in the waiting room of the Rosie Maternity Hospital ultrasound unit; this occurred one morning each week for 43 weeks. 16 participants were recruited either this way or through posters in the ultrasound unit. The author also visited pregnancy yoga classes in Cambridge and the surrounding area though this was not successful. The remaining low-likelihood participants were recruited through a related study, the Cambridge Ultrasound Siblings and Parents (CUSP) study. Participants in the high-likelihood group were recruited through the Cambridge Autism Research Database (CARD), a database of UK-wide volunteers. Adverts were sent to approximately 1100 CARD volunteers each month, resulting in 3 participants. The author also contacted approximately 1000 autism-related support groups across the UK, resulting in 2 participants. Adverts were also disseminated through twitter and were placed in relevant magazines, resulting in 1 participant. A Spectrum News article about the study attracted 1 participant. 1 participant

was recruited through word of mouth. 3 high-likelihood participants were recruited through the CUSP study. Recruitment ran from January 2017 until March 2019.

Exclusion criteria included twin pregnancy, contraindications for MRI, mothers younger than 18 years old and non-UK residents (due to flight restrictions during pregnancy). In order to have an approximately matched infant sex ratio between the high and low likelihood groups, some potential low-likelihood participants were excluded at screening due to the infant's sex. In order to provide information on the feasibility of recruiting this sample, Figure 1.2 outlines reasons for exclusion and non-participation and Figure 1.3 outlines reasons for attrition. Low-likelihood participants primarily resided in Cambridgeshire and high-likelihood participants resided across the UK. No participants reported smoking or regularly drinking alcohol during pregnancy. No infant was born before 36 gestational weeks nor weighed below 2.5kg. NHS ethics approval was gained. Participants gave their informed consent to take part at each visit.



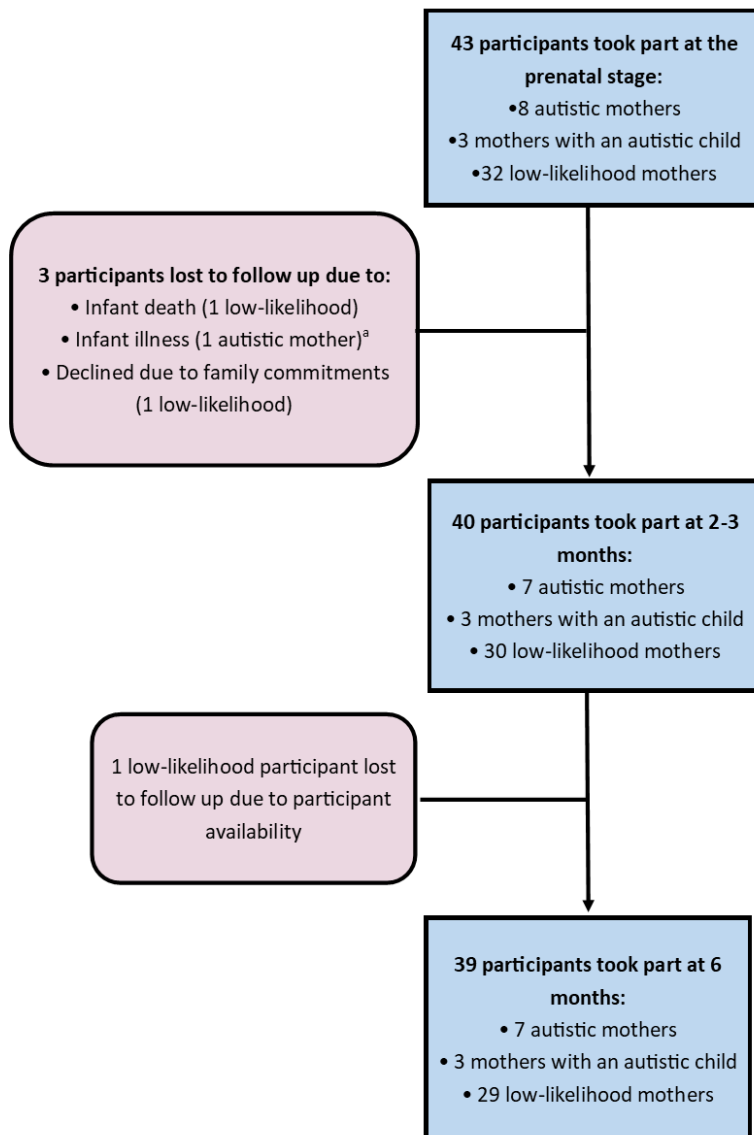
^aThree of these participants completed wellbeing measures but did not attend in-person visits

^bTwo of these participants completed wellbeing measures but did not attend in-person visits

^cOne of these participants completed wellbeing measures but did not attend in-person visits

^dThis participant completed wellbeing measures but did not attend in-person visits

Figure 1.2 Reasons for exclusion and non-participation in the CHILD study.



^aThis participant continued to complete wellbeing questionnaires for the 2-3 month and 6 month time-points but did not attend in-person visits

Figure 1.3 Reasons for participant attrition for the CHILD study.

The PEA (Perinatal Experiences and Autism) study involved remotely administering the same maternal wellbeing-related measures as the CHILD study (i.e. pregnancy/motherhood experiences interviews and mother's wellbeing questionnaires) at 30-33 weeks of pregnancy, 2-3 months after birth and 6 months after birth. No measures other than the maternal wellbeing interviews and questionnaires were administered. This study was created in order to recruit a greater sample size of autistic mothers for the wellbeing interviews and questionnaires than was possible through the CHILD study alone, due to the difficulty of

recruiting currently pregnant autistic people able to travel to Cambridge and to commit to a 3 year longitudinal study and willing to undergo MRI while pregnant. Only autistic mothers were recruited, due to the small sample of autistic mothers obtained in the CHILD study compared with the relatively larger sample of non-autistic mothers. Pregnant autistic people were recruited through social media, autism-related and pregnancy-related support groups across the UK, the CARD database and word of mouth. Ethics approval was obtained from the University of Cambridge Psychology Research Ethics Committee. Participants gave their informed consent to take part at each visit. All pregnant autistic people older than 18 years were eligible to take part (unlike the CHILD study, twin pregnancy, contraindications for MRI and residence outside the UK were not exclusion criteria). Details of the sample sizes for each group and details of participant attrition are given in Chapters 2 and 4.

Chapters 2 and 4 involve participants from both the CHILD and PEA studies (Figure 1.4). Chapters 5 and 6 involve participants from the CHILD study only. Chapter 3 reports on a separate survey study.

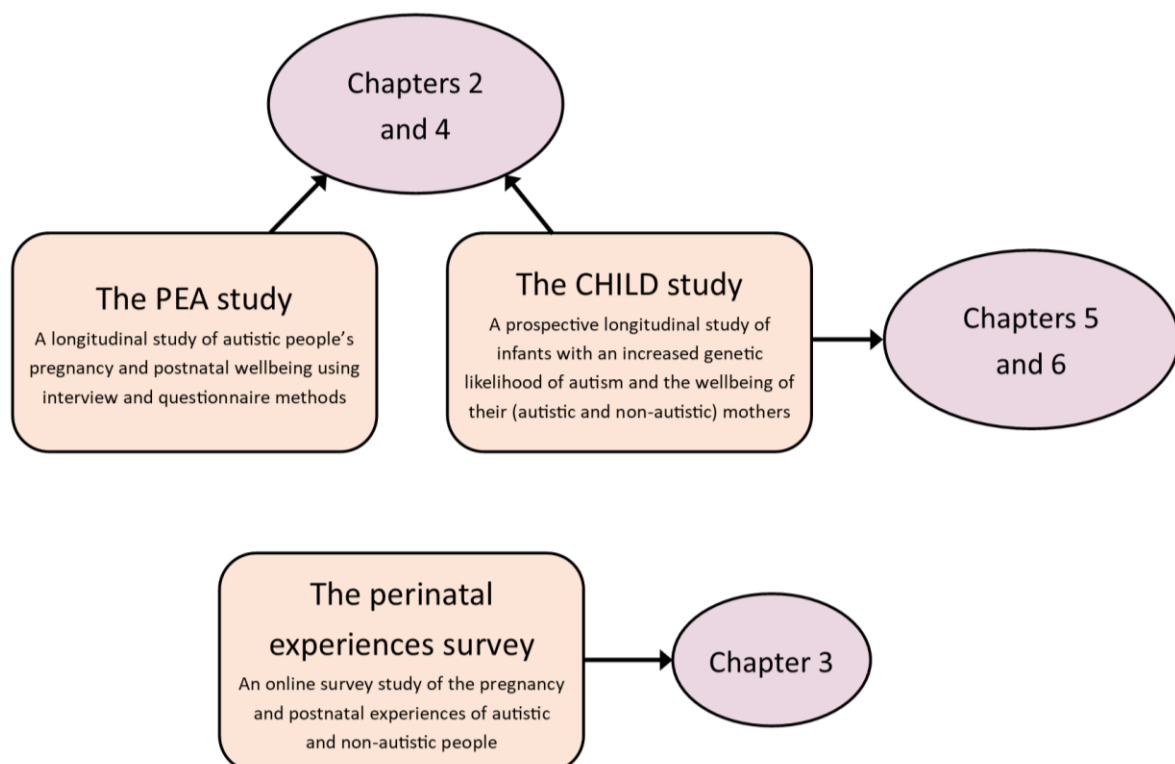


Figure 1.4 Datasets used in each chapter.

Chapter 2: Autistic mothers' pregnancy, childbirth and postnatal experiences: a qualitative study.

2.1 Introduction

Research exploring the perinatal experiences of autistic people is scarce. The perinatal experiences of women with intellectual disability (ID) and women with mental health conditions are better documented and may help to inform understanding of autistic people's experiences, given that such conditions often co-occur with autism and may bring similar challenges. While pregnancy and parenthood can be experienced as happy and welcome events for mothers with ID, such mothers can experience anxiety over the uncertainty of maintaining custody of their child (Höglund & Larsson, 2013). Indeed, women with ID are more likely to come into contact with social services and are more likely to lose custody of their children due to child welfare concerns (Booth & Booth, 2005). Mothers with ID can feel that health and social care professionals have negative expectations about their ability to care for their child, leading to reluctance to disclose postnatal changes in mood in case such a disclosure negatively affects professionals' attitudes (Malouf, McLeish et al., 2017). Women with ID can sometimes feel they are not sufficiently involved in choices about their medical care and do not always feel they are provided with information they can understand (Malouf, McLeish et al., 2017). Having an advocate such as a doula has been identified as beneficial in supporting mothers with ID to make informed choices and to communicate with professionals about their care (McGarry et al., 2016).

Mothers with mental health conditions are also more likely to have come into contact with social services and to lose custody of their child (Park et al., 2006). Fear of losing custody of their child is common among mothers with mental health conditions and can lead to masking of difficulties and reluctance to seek help (Montgomery et al., 2006). Mothers with mental health conditions also report having limited social support and encountering feelings of isolation (Montgomery et al., 2006). The importance of peer support to combat isolation and to share experiences among mothers with mental health conditions has been emphasised by several studies (Alakus et al., 2007; Diaz-Caneja & Johnson, 2004).

Regarding health professionals' perspectives, midwives and other maternity care professionals can feel that they lack sufficient training to provide appropriate care for women

with ID (Castell et al., 2016; Homeyard et al., 2016), women with physical conditions (Smeltzer et al., 2018) and women with mental health conditions (Higgins et al., 2016).

Only four studies have explored the parenthood experiences of autistic people. Three of these used a qualitative approach and tended to report issues surrounding sensory experiences and difficulties interacting with professionals. Rogers et al. (2017) conducted a case study of one Australian autistic woman's experiences. The woman reported that sensory sensitivities were heightened during pregnancy and that she became particularly sensitive to touch, making medical examinations challenging. She also reported difficulties communicating with midwives and other health professionals who she felt did not respect her wishes nor treat her respectfully. She also felt that midwives and other health professionals judged her parenting ability negatively due to being autistic and had little understanding of how autistic people experience pregnancy.

Gardner et al. (2016) explored the perinatal experiences of eight autistic women who commented on their experiences retrospectively. The mothers reported enhanced sensory sensitivities to bright lights, sound, smell and touch during pregnancy. Sensory sensitivities sometimes made certain aspects of prenatal appointments challenging, such as bright lights and touch. During childbirth, they experienced difficulties with bright lights and the sounds of other women in labour. Sensory issues surrounding touch could also make breastfeeding challenging. The mothers reported that they did not always disclose their autism diagnosis to professionals and that they required direct and clear information when interacting with professionals, including greater information about the purpose of appointments. They described not having had sufficient support for caring for their infant, such as understanding their baby's facial expressions and connecting emotionally with their baby. They also felt that others had judged their parenting and desired to approach parenting on their 'own terms' rather than following others' expectations.

Donovan (2020) interviewed 24 autistic women from the USA, UK and Australia who had given birth within the previous ten years about their experience of childbirth. Participants expressed difficulty communicating with professionals, including difficulty conveying needs and understanding what was said to them. Difficulties in communication often led to feelings of anxiety and inhibited future attempts at communication.

One quantitative study has explored autistic mothers' experiences. Pohl et al. (2020) surveyed 355 autistic mothers (two thirds of whom had an autism diagnosis and one third of whom self-identified as autistic) and 132 non-autistic mothers about their experiences of pregnancy, birth and motherhood. Autistic mothers were more likely to have had prenatal and postnatal depression and less likely to feel that the process of birth was adequately explained to them. Autistic mothers were just as likely to attempt to breastfeed, to have low milk supply and to have difficulties breastfeeding their first child, though they were more likely to have difficulties breastfeeding their second child than non-autistic mothers. Autistic mothers were more likely to report difficulties in communicating with professionals (e.g. teachers, clinicians, social workers) about their child, more likely to experience so much anxiety that it affects their ability to communicate when interacting with professionals and more likely to feel misunderstood by professionals. The majority of mothers reported that they disclosed their autism diagnosis to professionals 'never', 'rarely' or 'sometimes' as opposed to 'often' or 'all the time', and worried that professionals' attitude towards them would change if they disclosed.

Autistic mothers experienced a number of parenting challenges. They reported greater difficulty with the multi-tasking involved in parenting, with domestic responsibilities and with creating social opportunities for their child. They were also less likely to see themselves as organised parents. Autistic mothers were more likely to report not coping, to find motherhood isolating, to feel judged and to feel unable to ask for support. They were also less likely to find motherhood rewarding. There were no differences, however, between autistic and non-autistic mothers in prioritising their child's needs above their own and in seeking opportunities to boost their child's confidence. The majority of autistic mothers surveyed felt they should be given extra support with being a mother due to being autistic and, of those who had requested support with parenting from agencies, the majority felt that they did not receive the support they required. These findings suggest that autistic parents of school-age children may face a unique set of parenting challenges. Parenting challenges are likely, however, to differ depending on the age of the child and it is currently unknown what particular parenting challenges may arise for autistic people during the postnatal period.

This study aimed to explore the perinatal experiences of autistic people, including the physical experiences of pregnancy and childbirth, interactions with healthcare professionals during

the perinatal period and the benefits and challenges associated with being a parent to a young baby. Autistic women were interviewed longitudinally, once during pregnancy and once during the postnatal period, in order to ensure greater accuracy of reporting than may be possible with retrospective methods. A comparison group of non-autistic women allowed for an exploration of the experiences that are unique to autistic mothers and those that are common to autistic and non-autistic mothers alike. The study is also the first to focus primarily on experiences of mothers in the UK, who may have different healthcare experiences to those residing in other countries.

2.2 Method

2.2.1 Participants

Participants were 24 autistic women and 21 non-autistic women at the prenatal stage and 21 autistic women and 25 non-autistic women at the postnatal stage. 12 of the autistic participants and all of the non-autistic participants took part in the interviews as part of the CHILD study. The remaining autistic participants were interviewed as part of the PEA study. Details of both studies are presented in Chapter 1. 4 non-autistic mothers who took part at the postnatal stage did not take part at the prenatal stage as the CHILD study did not yet have ethics approval to interview participants at the time of their prenatal participation. 4 autistic mothers who took part at the prenatal stage chose not to take part at the postnatal stage due to time or family commitments (3 participants) or for reasons surrounding mental health (1 participant). One autistic participant took part at the postnatal time point only and commented on her pregnancy experiences retrospectively.

Demographic data is displayed in Table 2.1. For this chapter, as well as all subsequent chapters, group differences in demographic data were explored with independent t-tests (or Wilcoxon rank-sum tests for data that were not normally distributed) and Fisher's exact tests. Values are given for both the prenatal and postnatal time points, though demographic questions and the Autism Quotient (AQ) were only administered once at the prenatal time point. As such, changes in demographic variables (other than age) from the prenatal to the postnatal time-point are due to differing samples at the two time-points. All infants were born at 36 weeks gestation or later. All mothers were married or in a partnership apart from one participant in the autistic group who took part at the prenatal stage only. The autistic group were significantly younger (at the postnatal stage only), significantly less likely to be non-

white (at the prenatal stage only), had a significantly lower level of education and lower annual household income, were significantly more likely to have a co-occurring psychiatric condition, were significantly more likely to reside in a country other than the UK (at the postnatal stage only) and had significantly fewer children (at the postnatal stage only). Mothers in the autistic group had significantly higher AQ scores than the non-autistic mothers. The groups did not significantly differ on type of delivery, pregnancy conditions or age of the child at the time of the interview.

Table 2.1 Demographic information for the autistic and non-autistic groups for the prenatal and postnatal time-points.

	Prenatal			Postnatal		
	Autistic (n= 24)	Non- autistic (n= 21)	p-value (FDR corrected)	Autistic (n= 21) ^a	Non- autistic (n= 25)	p-value (FDR corrected)
Mean age (SD) ^b	31.10 (4.14)	33.30 (2.44)	0.05	31.10 (3.13)	34.02 (2.76)	0.01
Mean age of child in weeks/gestational weeks (SD) ^b	32.29 (2.60)	31.01 (2.39)	0.11	10.76 (1.54)	10.77 (1.56)	0.98
Ethnicity ^c			0.03			0.08
White	24 (100%)	16 (76%)		20 (100%)	20 (80%)	
Non-white	0 (0%)	5 (24%)		0 (0%)	5 (20%)	
Educational level ^c			0.03			0.01
Undergraduate or above	14 (58%)	19 (90%)		11 (55%)	23 (92%)	
A level or below	10 (42%)	2 (10%)		9 (45%)	2 (8%)	
Annual household ^c income (£)			0.001			0.001
>50,000	7 (29%)	18 (86%)		6 (30%)	22 (88%)	
≤50,000	17 (71%)	3 (14%)		14 (70%)	3 (12%)	
Psychiatric conditions ^c			0.002			0.001
None	8 (33%)	19 (90%)		7 (35%)	23 (92%)	
Depression	2 (8%)	1 (5%)		1 (5%)	1 (4%)	
Depression and anxiety	7 (29%)	1 (5%)		6 (30%)	1 (4%)	
OCD and anxiety	2 (8%)	0 (0%)		2 (10%)	0 (0%)	
Other	5 (21%)	0 (0%)		4 (20%)	0 (0%)	
Country of residence ^c			0.10			0.01
UK	19 (79%)	21 (100%)		15 (71%)	25 (100%)	
USA	4 (17%)	0 (0%)		4 (20%)	0 (0%)	
Ireland	1 (4%)	0 (0%)		2 (10%)	0 (0%)	

Number of children (not including current pregnancy) ^c	0.11		0.04	
0	18 (75%)	12 (57%)	16 (80%)	14 (56%)
1	2 (8%)	7 (33%)	1 (5%)	9 (36%)
2	4 (17%)	2 (10%)	3 (15%)	2 (8%)
Pregnancy conditions ^c	0.38		-	
Gestational diabetes	5 (21%)	1 (5%)	-	-
Polyhydramnios	1 (4%)	0 (0%)	-	-
Pre-eclampsia	0 (0%)	1 (5%)	-	-
Type of delivery ^c	0.25			
Vaginal	-	-	-	9 (43%) 16 (64%)
Assisted vaginal (forceps or ventouse)	-	-	-	2 (9%) 3 (12%)
Caesarean section	-	-	-	10 (48%) 6 (24%)
Mean AQ score (SD) ^b	39.8 (5.54)	15.2 (7.67)	<0.001	40.6 (4.68) 16.5 (7.65) <0.001

Note. SD = Standard deviation

^aDemographic data is not available for one participant in the autistic group for all but country of residence and type of delivery

^bT-test performed

^cFisher's exact test performed

2.2.2 Procedure

2.2.2.1 Semi-structured interviews.

Semi-structured interviews were conducted once during the third trimester of pregnancy and once 2-3 months after giving birth. Interviews lasted between 20 minutes to one hour, depending on the level of detail the participant wished to provide. Prior informed consent was gained from all participants. Participants were made aware in advance that the interview may concern sensitive topics, that they could decline to answer any question if they wished to do so and that they could withdraw their participation at any time. For those participants who took part in the in-person aspects of the CHILD study, interviews took place face-to-face during the CHILD study testing sessions. For all other participants, interviews were conducted by video call, telephone or email depending on the preference of the participant. A script of open-ended questions and potential prompts was used to guide the interviews (Appendix 1). The scripts were developed in consultation with an autistic mother in order to ensure that the content reflected the issues most relevant to autistic mothers and that the wording of the questions was acceptable to the autistic community. Questions at the prenatal time-point

concerned the physical and sensory experiences of pregnancy as well as interactions with health professionals. Questions at the postnatal time-point concerned the experience of childbirth, interactions with health professionals since giving birth and the experience of being a parent to a young baby.

2.2.2.2 Quantitative questionnaires.

Participants were asked to complete the Autism Quotient (AQ; Baron-Cohen et al., 2001) once during the third trimester of pregnancy. The AQ is a 50 item self-report measure of autistic traits. Items are rated on a scale from 'definitely agree' to 'definitely disagree' and the higher the score, the greater the autistic traits of the respondent. Since the development of the AQ, awareness has increased of sex/gender differences in the presentation of autism and the increased tendency of autistic females to mask their autistic characteristics (Mandy et al., 2012). The AQ therefore may be less sensitive to capturing female presentations of autism. Furthermore, some studies have found the AQ to have low to fair sensitivity and specificity in terms of its ability to identify those who are and are not autistic (Connor et al., 2019) and may have limited ability to differentiate between autism and some other conditions (Naito et al., 2010). Nevertheless, the AQ has been shown to have good reliability (Baron-Cohen et al., 2001), autistic people tend to score higher than non-autistic people on the measure, it is widely used in research, and there are few alternative well-validated measures available. It is used throughout this thesis to give an approximate indication of the level of autistic traits of the autistic and non-autistic groups.

Self-report measures of wellbeing for this sample, including stress, anxiety and depression are presented in Chapter 3.

2.2.3 Data analysis

Interviews were audio recorded and transcribed in their entirety by the author. To preserve anonymity, any identifying information was removed from the transcripts and initials rather than names of the participants were used throughout. Analysis of the interviews was conducted using NVivo software (version 12). Interviews were analysed according to a process of inductive, thematic analysis as outlined by Braun and Clark (2006). This method of analysis was chosen as it focuses on extracting themes from the data rather than approaching the data through the lens of pre-existing theories, making it particularly appropriate for exploratory research examining under-researched topics.

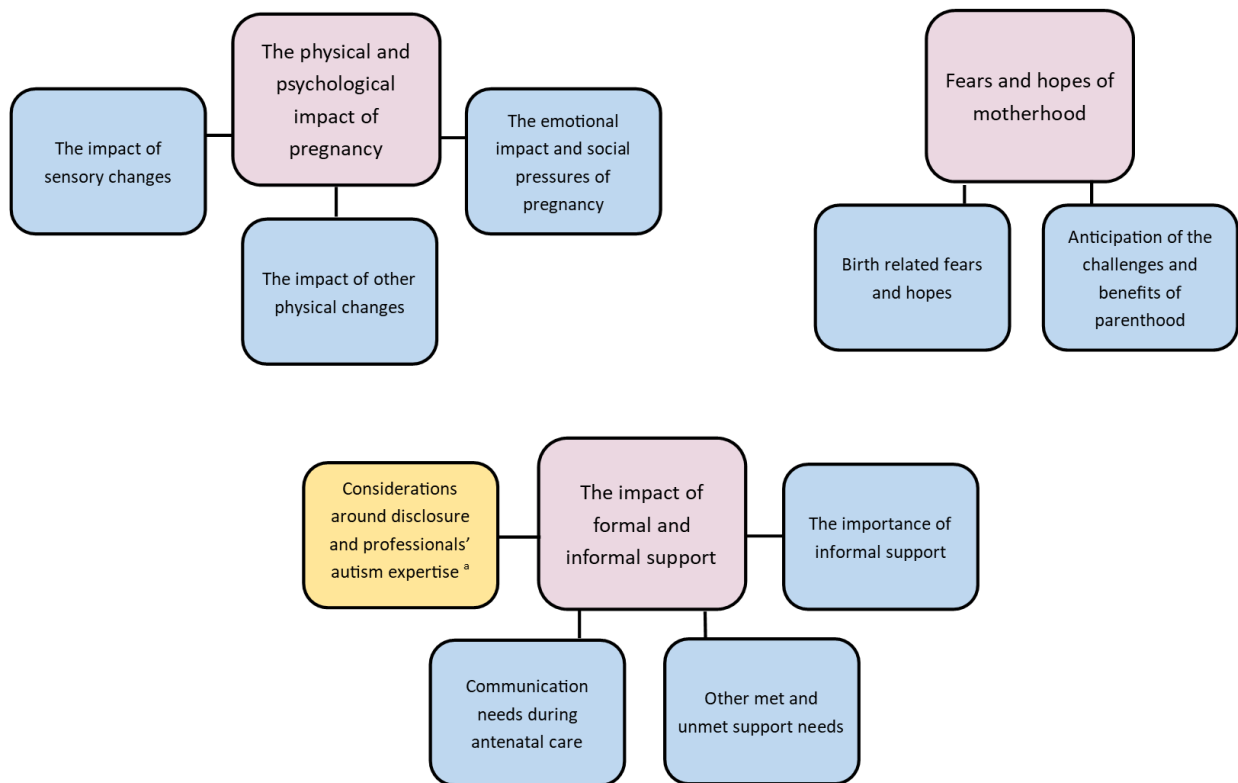
Prenatal and postnatal interviews were analysed separately. Following data familiarisation (re-readings of each transcript), each interview was analysed line-by-line for initial codes. Next, the initial codes were grouped into midlevel subthemes and final-level themes. Themes and subthemes were checked for internal coherence and lack of overlap by removing, splitting, or combining themes or subthemes where necessary. Data from the autistic and non-autistic groups were analysed together. A consensus approach (Barker & Pistrang, 2005) was used in which the author took the lead in the analysis and themes were reviewed and revised with another researcher (JM) during regular discussions at each stage of the analysis. Finally, 10% of the transcripts (split evenly across the autistic and non-autistic groups) were second coded by JM according to the themes and subthemes already generated and Cohen's kappa (Cohen, 1960) was calculated as a measure of inter-rater reliability. Kappa values of 0.00-0.20 are considered slight, 0.21-0.40 fair, 0.41-0.60 moderate, 0.61-0.80 substantial, and 0.81-1.00 as almost perfect agreement (Cohen, 1960). If Cohen's kappa was below 0.70 for any theme or subtheme, this theme or subtheme was discussed and revised with JM and 10% of transcripts were once again coded by JM. For the prenatal interviews the initial mean kappa of all themes/subthemes was 0.78 (range = 0.53-1.00). The final mean kappa, after revision and recoding, was 0.91 (range = 0.78-1.00). For the postnatal interviews the initial mean kappa of all themes/subthemes was 0.81 (range = 0.00-1.00) and the final mean kappa was 0.90 (range = 0.70-1.00). (See Appendix 2 for a full list of kappa values).

2.3 Results

In this section, the themes that arose for the prenatal interviews are presented first, followed by postnatal themes. Results are presented for both groups together for ease of comparison. Pseudonyms are used throughout to preserve anonymity.

2.3.1 *Pregnancy interviews*

Three themes, comprising 9 subthemes, were identified for the pregnancy interviews (Figure 2.1): 1) 'The physical and psychological impact of pregnancy' which explores experiences of bodily and emotional changes during pregnancy; 2) 'The impact of formal and informal support' which explores experiences with support during pregnancy and areas where further support and adjustments would be beneficial; and 3) 'Fears and hopes of motherhood' which explores feelings surrounding the anticipated benefits and challenges of birth and parenthood.



^aSubtheme in yellow is specific to the autistic group

Figure 2.1 Themes and subthemes for the pregnancy interviews.

2.3.1.1 The physical and psychological impact of pregnancy.

This theme explores the impact of the bodily, emotional and social changes that accompany pregnancy. Three subthemes emerged: 1) 'The impact of sensory changes'; 2) 'The impact of other physical changes'; 3) 'The emotional impact and social pressures of pregnancy'.

The impact of sensory changes.

This subtheme relates to the impact of changes in smell, taste, touch, sound and vision during pregnancy. Participants in both groups commonly reported increased sensitivity to unpleasant smells and tastes during pregnancy, '*my smell is much, much more sensitive than it was and certain smells now I really dislike.*' (Leah, non-autistic). While sensory changes in the non-autistic group were limited to smell and taste, the autistic group commonly reported changes in the domains of sound, bright lights and touch, '*I have like a sensory processing disorder with noises and light touching and smells and sounds and all of that is magnified and amplified.*' (Sally, autistic). One participant reported heightened synaesthesia, '*If I hear a loud*

noise I'll feel it on my back, it's like someone's punching me on the back is what it feels like, if I hear a really loud car horn or something for example, it feels like I'm being hit by something. So that one has got a lot more intense since being pregnant' (Juliette, autistic).

The autistic group often found these sensory changes overwhelming, *'because all of them were heightened, they've all been coming together and it's been overloading me much quicker and more intensely.'* (Morgan, autistic). This sensory overwhelm made coping with day-to-day tasks more challenging, *'some things that I would be able to cope with normally, I wouldn't be able to cope with or would stress me out even more. Just general things like the supermarket and stuff'* (Isla, autistic). Some autistic participants linked sensory issues to an increase in meltdowns and shutdowns.

'since becoming pregnant, it's a lot more difficult to predict when you're going to have a meltdown or a shutdown because it seems to just come on all of a sudden. I haven't really been able to identify if an environment or a situation is going to cause me a lot of stress and it just kind of comes on very suddenly and a lot more intensely than before, so that's where the coping strategies that I had before don't really work' (Juliette, autistic).

The impact of other physical changes.

This subtheme explores morning sickness, pain, tiredness, feeling the baby move and adapting to changes in body size. Some participants in both groups reported few or no issues with morning sickness while others encountered greater challenges. While those in the non-autistic group who experienced issues tended to report that morning sickness abated after the first trimester, *'it waned at around the sort of time that it was supposed to wane, so that was all right'* (Vanessa, non-autistic), some autistic participants experienced sickness throughout the entire pregnancy. Three autistic participants reported that morning sickness caused disruption to their work, *'I was off work for 7 weeks in my first trimester because, I wasn't actually throwing up loads but I felt sick 24/7 and even if I repositioned on a sofa, I'd be gagging into a bucket.'* (Suzi, autistic). Several autistic participants reported experiencing hyperemesis or very frequent vomiting, *'at one point I was vomiting 20 times a day'* (Beatrice, autistic). Two autistic participants felt that their hyperemesis was linked to heightened sensory issues, *'maybe it is worse for people with a sensory aversion to smell anyway because it's heightened.'* (Isla, autistic).

Several members of autistic group expressed issues surrounding joint and ligament pain, *'it might just be ligament stretching, but it gets really intense quite frequently when she sits on it. And I have to try and like move her or lie down and it's so intense I can't speak'* (Tara, autistic). Three autistic participants reported experiencing SPD (symphysis pubis dysfunction) or pelvic girdle pain, two of whom linked their pain to hypermobility, *'I know ASD can be associated with loose ligament issues, but my hips for three out of the four [children] completely unravelled and the fourth, which would be the one in question, I had the hip coming apart, SPD'* (Clarissa, autistic). One non-autistic participant described similar issues with pelvic girdle pain, *'I've had difficulty walking and not been able to pick her [participant's older child] up for five months now'* (Angela, non-autistic).

While both groups talked of the physical toll of tiredness, several members of the autistic group commented on mental fatigue and the impact of this upon their ability to process information.

'things that autism generally makes harder for me, so if I need to go into a store and process lots of different options, I don't have the energy to do that anymore. And that sort of took me off guard, because what I was expecting was to have to take lots of naps, not like, I can't go into a store and process everything' (Simone, autistic).

Another participant commented, *'Because you're more tired and you're thinking about a lot of things when you're pregnant, I find speech has been a lot more difficult to understand or process. I've been a bit behind when people have been telling jokes or just asking me simple questions'* (Juliette, autistic).

Members of both groups found their baby's movements reassuring, *'As long as I can feel it, I kind of figure everything's all right'* (Tiffany, non-autistic). They also valued feeling the baby move as a connective experience between them and their baby, *'Usually if he kicks, I rub my belly and I talk to him so that's really nice and that's something I share with my partner'* (Suzi, autistic). Both groups also discussed sometimes finding the movements uncomfortable and unusual, *'It's weird having something move inside you'* (Vanessa, non-autistic). However, finding the movements unusual was mentioned more commonly by the autistic group, *'It feels really strange when the baby moves around, it took me a really long time to figure out what*

it was and just to be able to distinguish it from some of the other normal things I feel in my body' (Lydia, autistic).

The autistic group additionally found it challenging to adapt to changes in body size and shape.

'with my body changing shape, my centre of gravity changing, my balance changing, it feels like, OK, I've had 30 years to get used to this body and now it's different, the rules have changed. I have to figure out new ways of moving and being in my body.' (Simone, autistic).

Autistic participants emphasised that rapid bodily changes within a short period of time could be difficult to adjust to, *'as soon as you adapt to a change, there's another change, that's quite difficult'* (Lily, autistic).

The emotional impact and social pressures of pregnancy.

This subtheme relates to positive and negative emotions during pregnancy and feelings surrounding the social attention that pregnancy attracts. Participants in both groups discussed positive emotions surrounding pregnancy such as enjoyment and excitement, *'I'm feeling happy and positive and really enjoying it'* (Brooke, non-autistic). One autistic participant expressed experiencing better mental health and social functioning when pregnant, *'since being pregnant I feel like I've got this clarity in my head. I look at situations and people and I can think of both sides of how people are thinking, whereas before I'd be like, 'why is that person saying that, I don't understand'. But now I feel like I've fine-tuned my brain, like the pregnancy chemicals have given me a bit of an extra mutant power!'* (Melinda, autistic).

However, some participants in both groups felt that negative emotions were heightened, *'emotions are amplified as well and I start to cry for nothing.'* (Diana, non-autistic), and *'my coping levels are not as high as they were, so I can get very emotional very easily and very sensitive'* (Sanya, autistic). Participants in the autistic group also mentioned having increased anxiety and low mood during pregnancy, with some linking these changes to hormonal influences, *'I find that I'm pretty hormonally sensitive, which talking to other women with Asperger's I think they are too. So I've just been really moody and extra anxiety.'* (Olivia, autistic). Participants in both groups also experienced worry surrounding their baby's health,

particularly at the start of pregnancy, *'I guess I've found it quite anxious, just because I think I didn't want to emotionally invest too much at the very beginning in case things did go wrong.'* (Vanessa, non-autistic).

Both groups mentioned that being pregnant attracted social attention, *'you get a lot of comments and questions and people talking to you'* (Katie, non-autistic). The non-autistic group tended to find these conversations pleasant, though some found them boring or did not enjoy being the centre of attention. The increase in social attention was sometimes experienced as tiring by the autistic group, *'they just come up to you and say, 'Oh how long left?', or 'How many months are you?', 'Is it a boy or a girl?', and in everyday life that's exhausting for me'* (Lily, autistic). Some autistic participants felt pressure to respond in a normative way, *'I'm supposed to act a certain way, give certain answers when people ask me, 'Isn't being pregnant great?', 'Don't you love this?', 'Aren't you excited?''* (Olivia, autistic). However, some members of the autistic group appreciated that conversations about their pregnancy gave them a social script, *'it's a little bit easier because there's a thing to talk about, there's a baby coming so people say stock things to you and you say stock things back.'* (Beatrice, autistic).

2.3.1.2 The impact of formal and informal support.

This theme explores experiences with both professional and informal support, including areas where greater support or adjustments would be beneficial. Four subthemes emerged: 1) 'Considerations around disclosure and professionals' autism expertise'; 2) 'Communication needs during antenatal care'; 3) 'Other met and unmet support needs'; and 4) 'The importance of informal support'.

Considerations around disclosure and professionals' autism expertise.

This subtheme explores considerations around whether or not to disclose an autism diagnosis, professionals' reactions to disclosure and professionals' knowledge of autism. Those participants who disclosed their autism diagnosis to professionals did so to bring about improvements in care, *'I just thought, make it easier, tell everyone so that they know and try and make adjustments where possible'* (Kayleigh, autistic). Those who did not disclose worried that professionals would react negatively, *'some medical professionals think that Asperger's is a kind of hypochondriac fake excuse disorder so I'm afraid that if I brought up other concerns maybe they would treat me differently'* (Olivia, autistic). Some participants talked of making

their challenges known without using the label of autism due to concerns about professionals' reactions, *'I prefer to instead say things like, 'I do better when I have everything explained to me in detail', or, 'I have some sensory sensitivities', specific practical things that don't have the baggage of autism'* (Simone, autistic).

Participants sometimes felt that disclosure was met with disbelief due to professionals lacking knowledge of autism among women, *'I had a doctor the other day say, 'I've worked with autistic kids, and you're not like them'. And I was like, 'OK, I'm probably not, and probably they're mainly boys as well''* (Debbie, autistic). Participants felt that professionals possessed a textbook understanding of autism, *'the doctor had said, 'You have Asperger's?', and I said, 'Yes', and she said, 'Well you seem just fine, you can look me in the eye.'"* (Sally, autistic), and, *'she assumed that I wasn't able to read, because I'm autistic'* (Pearl, autistic).

Participants sometimes felt that professionals' lack of autism knowledge was a barrier to having their needs met, *'I mentioned it at the first appointment and she was a bit like, 'oh, what does that mean?' and I had to explain it. But she's not really brought it up since then.'*. However, some felt that lack of awareness could be compensated for by an individualised approach, *'[My midwife] doesn't have a lot of experience of autism but she listens to what I have to say about my experiences and then she adapts.'* (Juliette, autistic).

Those who had been referred to a specialist mental health midwife tended to report that they had better autism awareness than professionals in mainstream services, *'she was really good on the autism stuff, she really knew what she was talking about.'* (Morgan, autistic). However, not all participants had such a positive experience with specialist midwives, *'they said well there's a mental health midwife. Apparently they spoke to her and she didn't know anything about autism so she wouldn't take me on either.'* (Isla, autistic).

Participants sometimes felt that professionals' lack of autism awareness led to a break down in trust. One participant reported that discussing meltdowns with her midwife led to an unwarranted referral to social services.

'with the referral to social services and everything, I feel like I've been defined as the worst version of myself. I think I'd like them to understand the strengths and the good qualities that autism can bring.' (Morgan, autistic).

Morgan felt that this misunderstanding eroded her trust, *'I have a certain amount of fear of being honest because they seem so focused on the negatives, I feel like if I say that I'm struggling they're going to forget all the ways in which I'm coping well. And like with the social services thing being triggered, it has made me feel a bit not sure about what I can and can't say without it being misunderstood.'* Others echoed this lack of trust, *'I have to really fake neurotypical enough, I have to fake sane enough, I have fake you know, capable of adulting enough to not raise any red flags for fear that they'll take my kid off me.'* (Pearl, autistic), and, *'I've been asked by a couple of the midwives how I think I can be a mum if I'm autistic. [...] I would never put my daughter in danger, but there's been very much a feeling that that would be a possibility'* (Debbie, autistic).

Communication needs during antenatal care.

This subtheme relates to experiences surrounding communication with professionals during pregnancy. Participants in both groups emphasised the need for clear information surrounding their care. Both groups would have appreciated more information about what appointments to expect and what resources are available, *'they just haven't mentioned something and I've come across on the internet or friends have told me about and I've followed up myself and I find it a little bit disconcerting'* (Cassandra, non-autistic).

The autistic group in particular emphasised the need to be given detailed information about what to expect in appointments.

'If everything could be structured and written down so that I could see, 'this week you're going to see this person, these are the things we're going to talk about, these are the possible outcomes'.' (Beatrice, autistic).

Autistic participants also stressed the importance of being kept informed during appointments of what would happen next, *'I didn't understand why I was there. I thought someone would come and get me and explain to me why I'm here but it was like, 'come in here and do this and then go and wait over there and do that''* (Lily, autistic). Some of the autistic group reported needing to be kept informed of who they will see at appointments, *'I was told it was going to be one midwife and it turned out to be another I'd never met before and I just completely shut down'* (Pearl, autistic).

The autistic group emphasised the need for facts and statistics, *'everything is sugar-coated and made to seem a little more hopeful than they should, I wish they'd just give black and white statistics'* (Sally, autistic), as well as detailed information, *'they don't gloss over the details or just assume I know what something is. I saw my midwife and she said I might need to have a drip and I asked her exactly how to spell it so I could look it up later and she was happy with that'* (Melinda, autistic). Some autistic participants felt that information was not adequately explained, *'I want to understand what's going on with my body and they don't seem to want to properly explain it.'* (Laney, autistic), while others had more positive experiences, *'[My midwife] seems to be making sure that I understand everything and if I'm not clear on things she's been finding different ways to explain.'* (Morgan).

The non-autistic group tended to feel comfortable asking professionals for more information, *'I wouldn't think twice about asking her anything.'* (Tiffany, non-autistic) and some of the autistic group felt similarly, *'My midwives have been very supportive, they're always there to answer questions'* (Kayleigh, autistic). However, members of the autistic group sometimes felt uncomfortable asking questions, *'I feel like I've asked so many questions that I don't want to ask more questions, but actually I have more questions'* (Paige, autistic). Members of the autistic group also emphasised the importance of having time in appointments to ask questions, *'with the midwife you don't really have time, it's a really quick in and out. You feel like you've got time for one or two questions.'* (Suzi, autistic).

The autistic group sometimes reported not feeling listened to by professionals, *'they tend to come across as though they're not really taking on board what you're saying or sometimes I feel like they think I'm lying about a lot of things, which is quite difficult.'* (Juliette, autistic). In particular, some felt that professionals dismissed their knowledge of their bodily experiences.

'I may not be good at reading people, but I'm really good at reading my body. And I'm not a hypochondriac, I can say something is happening and it's happening, which I guess people think is kind of weird, they don't believe you.'
(Olivia, autistic)

Another autistic participant commented, *'she sort of said, 'oh pregnancy will be uncomfortable' and I wasn't sure whether it was me being pathetic and hyper-sensitive to pain or whether it was her not realising how much pain I was in'* (Tara, autistic).

Members of the autistic group also appreciated being given extra time to process verbal information as well as being given written information, *'she writes things down as she's saying them and then gives me the notes so that during the appointment if I've kind of lost myself half way through I can always read the note afterwards'*. (Juliette, autistic). Processing information over the phone could be challenging, *'she gave me a load of information over the phone and I'm not very good at taking in lots of information, especially when there's other stuff going on.'* (Yvette, autistic). Some preferred email or text while others preferred in person communication, *'I have a lack of phone contact and face to face only, so [my partner] does every email and phone contact for me and that has made all sorts of awkwardness. Access to services is really hard.'* (Debbie, autistic). The autistic group also reported that specific rather than open-ended questions were necessary in order to elicit accurate responses, *'if someone says, 'How are you?', I just say, 'Alright'. Whereas if someone said to me, 'How's your pelvic pain?', I'd say, 'It's been terrible', or 'It's okay'. If it was more specific, I'd probably answer it a bit more.'* (Beatrice, autistic).

Some autistic participants felt that having an advocate present was helpful for communication.

'I've always tried if I can to have my mum with me at the appointments, because I do struggle sometimes to take in things they say to me, and because I struggle to take things in I do then end up getting railroaded into making decisions that I might not actually agree with or might not be in my best interests.' (Jolene, autistic).

Another participant commented, *'I really like [my partner] coming to every single meeting because I get lost in masking so I sometimes say the wrong thing and I'm like, 'Yeah, yeah, everything's fine', and [my partner] is like, 'No, everything hasn't been fine, you want to tell her about this''* (Debbie, autistic).

Other met and unmet support needs.

In addition to issues surrounding communication, participants discussed their experiences with several other areas of professional support: continuity of care, sensory issues and antenatal classes. Continuity of care was often desirable but non-essential for the non-autistic group, *'I never had the same midwife for any of the appointments I've had. Because they don't*

know you it feels like you might get less support, but at the same time, I've not had any issues.' (Sadie, non-autistic). The autistic group valued continuity of care for building trust, *'seeing the same person week after week so that you can build up that trust.'* (Pearl, autistic) and understanding, *'she understands me so it's helpful having her instead of having to explain or having someone else who doesn't understand'* (Ethyl, autistic). This group also valued continuity for ease of communicating their medical history, *'they've made sure that I see the same person each time, which has been really good, because my medical history is quite extensive'* (Tara, autistic).

During appointments, some members of the autistic group found the sensory environment of the hospital challenging, *'I find it really hard in the waiting room where I see the midwives because they often have music on and the lights are really bright and it's just horrible.'* (Pearl, autistic). For one participant, a negative hospital experience had an enduring impact, *'I got quite avoidant and I stopped eating and got stress and had to go to the hospital because it was so chaotic and bright and people rushing around and not very direct advice. I found that really difficult and I shutdown for a period afterwards, after my first scan.'* (Yvette, autistic).

Some participants in both groups valued antenatal classes as a way of meeting other parents, *'it is nice going through similar things with parents that are in the same sort of bracket as you'* (Lisa, non-autistic). Members of the autistic group, however, sometimes found the social aspect challenging, *'everyone meets at the same time, they've not known each other before and then at the break they'll all go for coffee and I'll be left alone.'* (Lily, autistic). Some found smaller classes desirable, *'you feel like it's kind of overwhelming, or you have to talk to a lot of strangers - but if it's a small class and they do like hands on stuff those are really helpful.'* (Olivia, autistic). Some autistic participants found online classes or one-to-one classes with a midwife or doula preferable, *'I hired a doula who's coming to my home to do it and that's better for us because I don't like big crowds and groups'* (Sally, autistic).

The importance of informal support.

This subtheme explores experiences with support from informal sources such as partners, family and friends. Both groups tended to feel well supported by their partners, both emotionally and practically, *'He's been incredibly supportive, he enjoys finding out about what's going on, he wants to be as active a participant as possible.'* (Leah, non-autistic). Both groups also tended to feel well supported by family, though some did not have family nearby,

'my parents aren't close by but they're going to come up and visit and they're trying to do as much as they can from far away' (Simone, autistic). The non-autistic group valued the practical and emotional support of friends who were also parents, *'it's been really helpful to share experiences'* (Danielle, non-autistic). The autistic group tended not to mention having support from friends, with some identifying a lack of such support, *'And also having a lack of friends, I feel like I've got a lack of female... people who've been through pregnancy'* (Morgan, autistic). Autistic participants often felt they would benefit from peer support from other autistic parents, either through social media or in-person groups, *'I don't really know anyone else with autism who's had a baby and there's not really much out there to find out about it, so that's been quite isolating as well.'* (Irene, autistic) and,

'talking to other autistic moms was really helpful, to find out that we all really loved our kids, we just didn't process and experience the social element of pregnancy the way other people do.' (Olivia, autistic).

2.3.1.3 Fears and hopes of motherhood.

This theme explores participants' feelings as they look ahead to childbirth and beyond. Two subthemes emerged: 1) 'Birth related fears and hopes'; 2) 'Anticipation of the challenges and benefits of parenthood'.

Birth related fears and hopes.

In this subtheme, participants discuss their worries surrounding childbirth. Childbirth often represented an unknown for both groups due to the inability to predict in advance how events would unfold, *'it is frightening to think about certain elements of delivery or if you imagine things one way but then if it doesn't go a certain way, it's hard to imagine all the outcomes'* (Lisa, non-autistic). For the autistic group in particular, worries around uncertainty were often linked to a desire for predictability and control, *'there's the uncertainty of when it's going to be and how long it's going to take and what's going to happen, that uncertainty is adding to my fear of it because I don't like the unknown, I like to plan'* (Melinda, autistic). Some autistic participants felt that a detailed birth plan and visiting the labour ward in advance would help with these concerns, *'just like the room I'm going to be in or the ward, that sort of thing would make a huge difference to me, just so I can anticipate what it sounds like, what it smells like, that would really help'* (Pearl, autistic). A minority of autistic participants, however, avoided planning for the birth in detail so as to minimise anxiety if things did not go to plan, *'I'm trying*

my very hardest to be open and play it by ear because I don't want to be too rigid in my thinking and then be disappointed with the outcome' (Sally, autistic).

Some concerns surrounding birth were specific to the autistic group, including concerns about communication with professionals. Some participants worried that they may experience a shut down during the birth and that this would impact upon communication with staff, *'am I going to be able to not just communicate during labour but to understand what people are saying to me? If I'm being given any instructions to push or whatever, how am I going to process that?'* (Juliette, autistic). Juliette further mentioned concerns that professionals would not correctly interpret her expressions of pain during a shut down, though this was not mentioned by other participants, *'because I do shut down and my facial expression goes very, kind of, stern, I find that if I am in extreme pain and I'm telling someone that I'm in extreme pain, it doesn't come across'*.

Autistic participants also expressed concerns that professionals would not keep them adequately informed during childbirth. One participant who had given birth before commented, *'quite often midwives, when you're in labour, will really try not to tell you what's going on, because they think it will make you more anxious if you know what's going on. And they'll downplay things, whereas for me I would much rather be told what's going on, what the consequences of that are, what that means'* (Isla, autistic).

Autistic participants also expressed concerns about the hospital environment while giving birth, particularly from a sensory perspective. Some felt that giving birth in a birthing centre would mitigate some of these concerns, *'I'm due to go into one of the birthing centres where you can have your own music on and the lights are quite low and they don't have a lot of people coming in and out. I think that will help me a lot with my sensory issues really.'* (Jolene, autistic). Others chose a home birth in order to avoid the challenges of the hospital environment, *'At home you have control over your environment, you can control the lighting, the noise, you know exactly who is going to be in the room'* (Clarissa, autistic).

Anticipation of the challenges and benefits of parenthood.

This subtheme relates to the positive anticipation participants feel as they look forward to parenthood as well as concerns about the challenges they may face. Both groups looked forward to motherhood with positive anticipation, expressing excitement to meet their baby,

'I really, really can't express how excited I am about being able to meet her and cuddle her' (Paige, autistic). Both groups looked forward to seeing their baby develop, learn and grow, *'you get to see them develop, you get to see them learn and see what's exciting, what's different'* (Leah, non-autistic).

Participants in both groups expressed concerns about the unknowns of parenthood, particularly first-time parents, *'A little bit anxious, because I don't know what to expect'* (Brooke, non-autistic). Participants in both groups also expressed concerns and hopes about rising to the responsibility of motherhood, *'It's a big things babies, very important, and I want to make sure I do right.'* (Yvette, autistic). Some autistic participants discussed wanting to be an understanding parent, *'I don't want to be one of these parents that's like always just saying that their child's naughty, I want to understand what's triggering it rather than blaming and punishing, like try and understand. I don't know whether that's because I've felt misunderstood so much'* (Morgan, autistic). In both groups, those who were not first-time parents expressed concerns about the demands of looking after a baby alongside older children, *'I won't be able to sleep when the baby sleeps because I've got a very active toddler'* (Danielle, non-autistic).

The autistic group expressed additional challenges. Some worried about feeling isolated after the baby was born, *'I worry about being isolated. I know everyone says about going to mother and baby groups, which I will go to, but I just don't want to sit in a room with a load of women I have nothing in common with'* (Kayleigh, autistic). Some participants were concerned about the executive functioning demands of parenthood, including completing day-to-day tasks.

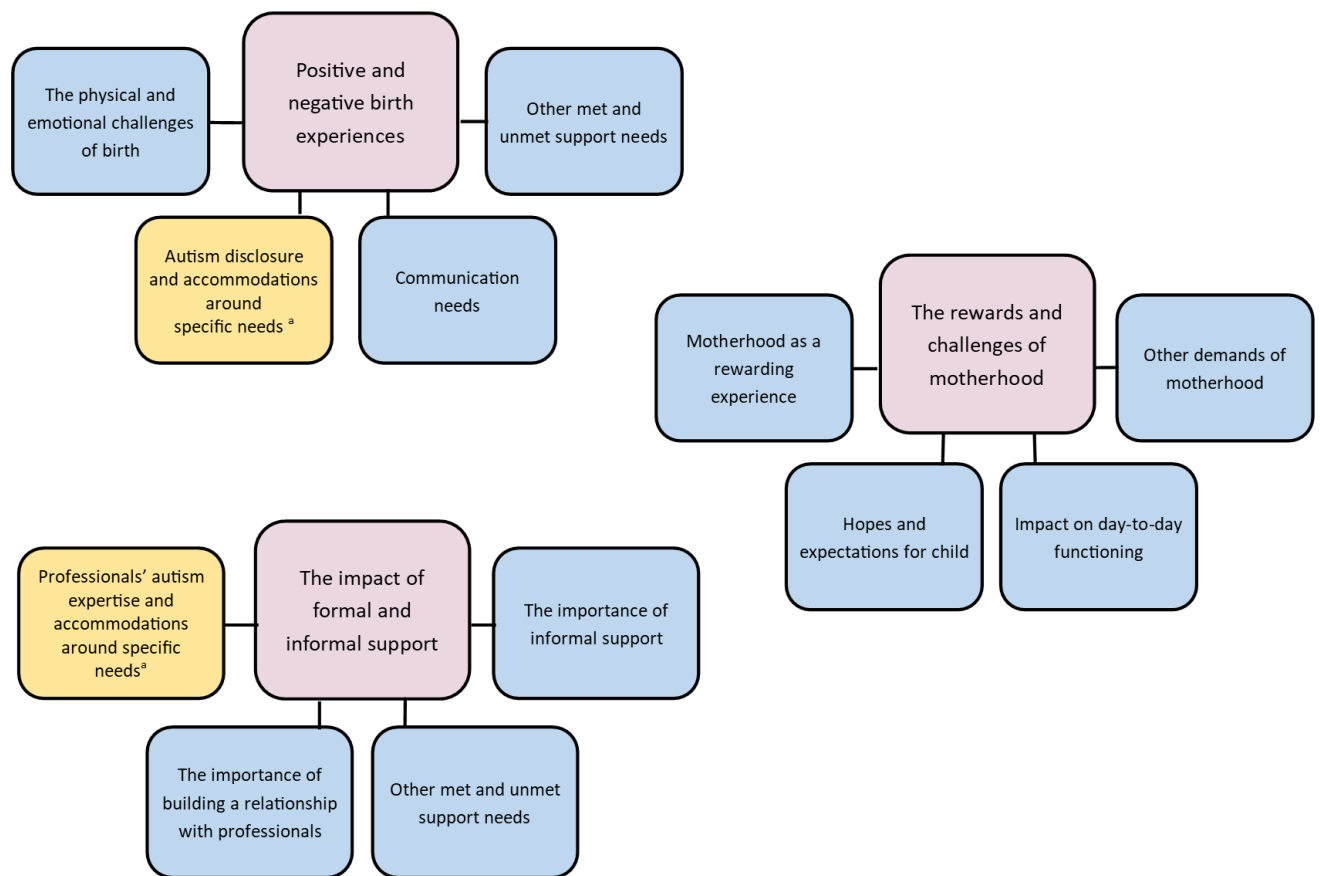
'once I've got going I'm alright, but getting going can be very slow. I worry about looking after myself, cooking and things can be very difficult, so I guess support with that would be useful in some ways. If I had someone who could pop in every now and again if I was struggling and just give me a nudge in the right direction' (Yvette, autistic).

Another participant commented, *'I'm already exhausted after going out to a coffee shop with friends, so how am I going to do anything with that added layer of difficulty. If it's difficult for people who already have lots of energy for that kind of stuff, where am I going to find it?'* (Simone, autistic).

Another consideration specific to the autistic group was the possibility of having an autistic child. Some were concerned about their child's quality of life if they were to be autistic, *'I sort of was hoping that my child wouldn't be autistic because I didn't want them to go through what I had to.'* (Paige, autistic). While some parents were concerned about the demands of having an autistic child, others were confident about navigating those challenges, *'I know we have enough coping mechanisms between us to deal with it'* (Melinda, autistic). Some participants, in contrast, expressed that they would find it more challenging to be a parent to a non-autistic child than an autistic child, *'If she doesn't have it and she's quite different to both of us, it's going to be an interesting thing to navigate.'* (Tara, autistic). Some participants questioned whether their autism would impact upon their child's social communication development, *'One of the things I always wonder about is if me being autistic is going to affect the way the baby is going to develop and what the baby's going to learn in terms of social skills and communicating and things like that. I wonder if I'm going to make her different because I'm different.'* (Morgan, autistic). Similarly, one participant expressed that having autism in the family made them particularly aware of the importance of supporting their baby's development, *'I did loads of research on bonding with babies, loads of eye contact and all of that. So that's something that was in my head with my second child, that kind of connection between mum and baby.'* (Beatrice, autistic).

2.3.2 Postnatal interviews

Three themes, comprising 12 subthemes, were identified for the postnatal interviews (Figure 2.2): 1) 'Positive and negative birth experiences' which explores the physical and emotional challenges of birth as well as experiences with birth-related services; 2) 'The rewards and challenges of motherhood' which explores coping with the demands of motherhood and enjoying its benefits; and 3) 'The impact of formal and informal support' which explores positive and negative experiences with support during the postnatal period and areas where further support and adjustments would be beneficial.



^aSubthemes in yellow are specific to the autistic group

Figure 2.2 Themes and subthemes for the postnatal interviews.

2.3.2.1 Positive and negative birth experiences.

This theme explores feelings surrounding the experience of birth. Four subthemes emerged: 1) 'The physical and emotional challenges of birth'; 2) 'Autism disclosure and accommodations around specific needs'; 3) 'Communication needs'; and 4) 'Other met and unmet support needs'.

The physical and emotional challenges of birth.

This subtheme explores participants' appraisal of aspects of childbirth such as pain, sensory experiences and unmet expectations. Both groups found the pain of childbirth challenging, *'it's bloody horrible, it's really, really horrible.'* (Lindsay, non-autistic). Some members of the autistic group felt that pain was less challenging than sensory issues, *'I have 7 IV sites in my arm and I had my blood pressure taken every 10 minutes and I was touched out. I didn't have*

a problem with the contractions and all the other pains, but just having someone touch me while doing all those things would set me over my limits' (Sally, autistic). One participant described the combined effect of pain and sensory overload,

'I was in pain but confined to the bed. And I was all hooked up to the machines and everything. And like all of that was really sensory crazy, I just felt really trapped like I couldn't move, so like I was quite overwhelmed and had a couple of meltdowns.' (Morgan, autistic).

Some autistic participants found the sensory environment of the postnatal ward challenging, *'I just couldn't cope with the noise, visitors coming in and out and people talking and playing music and other babies crying as well as her'* (Tara, autistic).

While some participants in both groups felt that the birth was, *'as good as it could be'* (Jessica, non-autistic), others had more complicated births that did not meet initial expectations. Both groups found it challenging to adapt to unexpected circumstances including having an emergency caesarean section and giving birth in hospital rather than at home, *'The C-section broke my heart because I wanted a home birth and then had to settle for a hospital birth and to then concede and settle for a C-section'* (Sally, autistic).

Autism disclosure and accommodations around specific needs.

This subtheme explores disclosure of an autism diagnosis during the birth and experiences with autism-related adjustments. Several autistic participants talked of disclosing their autism diagnosis, and typically this was achieved through mentioning their diagnosis in their birth plan. Some felt that this disclosure was overlooked, *'I don't think any of them were aware of how to handle autism at all. No-one mentioned it, no-one asked if I was coping, it just never came into play really'* (Irene, autistic). This was sometimes felt to be linked to a lack of sufficient autism awareness, *'I just think they don't understand it. And most people I met sort of read it and you could sort of see it on their face go, 'oh I don't know what that is so I'll just ignore it''* (Isla, A). Others, however, felt that their disclosure led to having their needs met,

'when they moved me around they put something over my eyes so I wouldn't be blinded. They told me exactly when people were going to come and who was going to come. They tried to give me my own midwife where possible, so I saw the same person all the time and they told me when they were changing. They

gave me my own room so I didn't have to go on the ward. I can't fault them. Hospitals are very traumatic places for me, but they did absolutely everything they could to make it easy.' (Yvette, autistic).

Several other participants also emphasised the importance of being given their own room on the postnatal ward, *'The consultants and everyone else I came across were all brilliant and very supportive during the labour. I was given a separate room to stay in afterwards due to being autistic, so managed to avoid the noisy ward with the other mums and babies.'* (Jolene, autistic). Participants also appreciated accommodations around sensory issues, *'They kept the lights dim, except for when they needed the lights bright'* (Karen, autistic), though some felt that knowledge of sensory issues among professionals could be improved, *'I didn't feel that they would understand the sensory overload and getting overwhelmed and having a bit of a meltdown. But they certainly did have some understanding of things, like they tried to keep the lights low.'* (Morgan, autistic).

Communication needs.

In this subtheme, participants discuss their experiences with communicating with professionals during the birth. Non-autistic participants tended to feel kept informed by professionals, *'the actual team around me while getting him out were brilliant and all kept me informed, which made it a lot less scary'* (Courtney, non-autistic). Some of the autistic group felt similarly, *'They were very good at talking to me and telling me what was going on and answering any questions I had.'* (Stacey, autistic). Autistic participants particularly appreciated receiving factual details, *'It was helpful when nurses were very direct, 'this is what we're going to do, because of the nature of you being induced we have to monitor the baby's heartrate this way, we can't do it this way, we're going to do it this way'. I asked questions and they answered me directly and honestly and that helped build a lot of trust.'* (Olivia, autistic).

However, some autistic participants felt they were not adequately kept informed.

'They kept saying that they were going to break my waters and we'd wait like five hours and go and chase them up and they'd be like 'oh no, we haven't got anyone to do it now', but they hadn't come and told us that. And so on the fourth time that happened, I just completely lost it and cried for about six hours.' (Isla, autistic).

Another participant commented, *'If somethings going wrong this should be logically explained to the woman, rather than just trying to scare her into going along with a plan without making her aware of what is going on and why. I would have felt far more at ease if things had just been explained to me.'* (Laney, autistic). Several autistic participants felt that clearer explanations would have been beneficial.

'I needed to explain to every new midwife when I was staying in hospital that I needed 100% clear information at all times and no fluffy language. I need to know what's going on. I did have a few midwives who would be not so clear about things and I did say 'I need you to be clear, I'm autistic' and some of them got it and some didn't.' (Melinda, autistic).

Some members of both groups felt that professionals listened to their concerns and requests, *'any concern that I had, people responded to quickly and thoroughly'* (Caitlin, non-autistic). Some members of the autistic group, however, felt that their wishes were dismissed, *'When they tried to break my waters, I wasn't warned about the tools they use. I was in dreadful pain and screamed from them to stop, but they didn't.'* (Laney, autistic). One participant felt the midwives had not believed her when she said her waters had broken, *'I just kind of got a general feeling that they thought I was exaggerating things and trying to make things seem further along or a bigger deal than they were. But I'm quite literal'* (Tara, autistic).

Other met and unmet support needs.

Participants also discussed continuity of care and the kindness of professionals. Both groups valued continuity of care, *'the second midwife was lovely as well, but it meant having to get to know another person and it was a bit weird.'* (Kimberley, non-autistic) and, *'[I] hardly saw the same midwife twice. Every midwife told me to do something different, they would burst into the room without knocking or introducing themselves.'* (Laney, autistic). Some members of the autistic group felt that continuity of care allowed staff to get to know their needs, *'it was really nice that they got to know all of my weirdness and quirks and preferences.'* (Sally, autistic).

Members of both groups appreciated the kindness of staff, *'very supportive and did exactly the right thing by just basically saying, 'You're doing ok, you're doing ok''* (Jessica, non-autistic) and, *'they were so lovely and so understanding and I just had a really good experience'* (Paige,

autistic). However, a minority of the autistic group felt that some staff had not behaved compassionately, *'I was yelled at by a health care assistant for trying to get an hour's sleep, she shook me awake and tried to grab my baby from my husband.'* (Laney, autistic).

2.3.2.2 The rewards and challenges of motherhood.

This theme explores the demands and benefits of being a parent to a young baby. Four themes emerged: 1) 'Motherhood as a rewarding experience'; 2) 'Hopes and expectations for child'; 3) 'Impact on day-to-day functioning'; 4) 'Other demands of motherhood'.

Motherhood as a rewarding experience.

In this subtheme, participants discuss the benefits of parenthood. Both groups emphasised finding their relationship with their baby rewarding, including feelings of love and connectedness *'we have a really good bond and we kind of know what each other's thinking'* (Danielle, non-autistic). Both groups found smiles and cuddles rewarding, *'Baby snuggles are the best'* (Simone, autistic) and enjoyed observing their baby develop and grow, *'seeing how every day he's learning something new, that's really cool I think'* (Lisa, non-autistic).

Participants in both groups identified what they felt their strengths were as a parent, including taking a relaxed approach and being patient, *'just patience really, that's all you really need with a newborn, just patience'* (Lindsay, non-autistic). Both groups also discussed being attentive, *'Just giving him as much love and attention as much as possible'* (Monica, non-autistic) and, *'I've done a lot of reading about babies, being responsive to them'* (Beatrice, autistic). Reading their baby's cues was another strength identified by both groups, *'I just went through all these tiny little signs, like well that cry means he's wet and that cry means that, because I just pay lots of attention to those little cues.'* (Suzi, autistic). Another autistic participant felt that her sensory sensitivities helped her understand her baby's cues,

'you're so used to looking for the super vague, sub-textual clues from adults but the good thing about babies is that they kind of have universal cries and I'm good at listening to noises. I can tell the difference between people's sets of keys, who's coming based on what kinds of keys are jingling, so I figure that if we can do that, we can tell what kind of cry a baby has.' (Olivia, autistic).

Other autistic participants also felt their sensory abilities were a strength, *'sensitivity to hearing probably helps sometimes, because I can hear her stir before she starts crying at night'*

(Tara, autistic) and, *'Babies are very sensory-oriented, which I fully understand. In some sense it makes it easier for me to anticipate his needs, like 'oh he probably just wants to be held, he needs that contact to feel secure''* (Lydia, autistic).

Some autistic participants mentioned perseverance with goals such as breastfeeding and sleep routines.

'I've persevered with the breastfeeding and kept on doing that, that's been something that's really important to me. And people have commented that me being so stubborn about it is probably in part because of my autism and I made it into a bit of a special interest and was reading everything and researching everything' (Morgan, autistic).

Hopes and expectations for child.

Looking ahead to their goals for their child as they grow up, both groups emphasised their child's happiness, *'to be secure and happy and know that she's loved.'* (Heather, non-autistic) as well as supporting their child to find their own path in life, *'to find her own path, to do what is fulfilling and meaningful for her.'* (Kelly, non-autistic). Some parents in both groups also hoped for their child to enjoy learning and education, *'I'd like for him to be able to be happy and enjoy school and study easily. I don't care if he has any diagnoses like me and his sisters as long as he's able to enjoy school and enjoy the things he likes.'* (Clarissa, autistic).

Impact on day-to-day functioning.

In this subtheme, participants discuss challenging aspects of parenting such as lack of sleep and the relentless nature of parenthood. Both groups found lack of sleep challenging, *'if there is a bad night, you just get more tired and you're irritable'* (Kelly, non-autistic). One autistic participant talked of finding it *'impossible to hide'* her autistic traits when tired (Jolene, autistic). Some autistic participants talked of the mental fatigue of executive functioning demands, *'I have at times exaggerated my sleep deprivation to explain executive function problems, because it's easier than saying 'I'm really mentally fatigued from learning all these new things plus my executive functioning is terrible to begin with''* (Simone, autistic).

Both groups commented on the relentless nature of motherhood, such that they had little time to themselves, *'I'm never off.'* (Vanessa, non-autistic). One autistic participant commented, *'Usually when I feel overloaded and therefore low I deal with that by doing very*

little to recover but you can't do that with a baby.' (Irene, autistic). Both groups also found it challenging to look after their older children in addition to their baby.

In addition, some of the autistic group found the unpredictability of their baby disruptive to their routine, *'I found it very hard to accept the lack of a rigid routine, especially when she was newborn, she could wake up any minute so I was on edge the whole time.'* (Melinda, autistic).

Other demands of motherhood.

In this subtheme, both groups discuss other issues such as worry about their baby and breastfeeding challenges, while the autistic group identify additional issues with sensory sensitivities and play. Both groups discussed worrying about their baby, *'for the first couple of weeks, you're constantly checking that's she's still breathing.'* (Kimberley, non-autistic). Breastfeeding issues were also common to both groups, including pain, mastitis, tongue-tie and jaundice. Some autistic participants additionally found breastfeeding challenging from a sensory perspective, *'about half way through a feed I feel like there's some sort of needle that being threaded up almost right the way to my back.'* (Debbie, autistic) and, *'I started getting the visual snow stuff and I'd realise [my husband] would be talking to me and I couldn't process the words'* (Yvette, autistic).

Several autistic participants found their baby's cries difficult, both from a sensory perspective, *'that's quite difficult because it hurts my ears, if she's crying loudly'* (Tara, autistic) and from an emotional perspective, *'on an emotional level definitely made me feel horrible to hear her crying'* (Morgan, autistic). One autistic participant mentioned issues with touch, *'It's definitely hard when he wants to be on me all of the time, because I'm kind of touch avoidant.'* (Lydia, autistic). However, some of the autistic group did not find motherhood challenging from a sensory perspective, *'nothing she does bothers me! The crying, the breastfeeding, whatever, none of it adds to my sensory input for some reason'* (Sally, autistic), with one participant even reporting reduced sensory sensitivities since giving birth, *'Things that used to really bother me just don't bother me at the moment, which is marvellous, I can go around Tesco without the fridges being really loud, which is a new experience!'* (Karen, autistic).

Finally, some members of the autistic group found knowing how to play with their baby challenging, *'talking to her and playing, they're definitely the areas where I've found it harder.'*

It didn't come very naturally and I was worried that I wasn't doing it enough, or doing it right.'
(Morgan, autistic) and,

'I was nervous about doing the play stuff. When I'm with him by myself it's fine, but when there's people around like my family or anyone else, then I feel a bit self-conscious.' (Suzi, autistic).

2.3.2.3 The impact of formal and informal support.

This theme covers experiences with professional and informal support during the postnatal period and contains four subthemes: 1) 'Professionals' autism expertise and accommodations around specific needs'; 2) 'The importance of building a relationship with professionals'; 3) 'Other met and unmet support needs' and; 4) 'The importance of informal support'.

Professionals' autism expertise and accommodations around specific needs.

This subtheme explores professionals' knowledge of autism and experiences with autism-related adjustments and support. Echoing similar experiences during pregnancy and birth, some participants felt professionals were dismissive of their autism diagnosis, *'Although they've been aware of it, I'm not sure it's really influenced them in any way. I think they've kind of just discounted it.'* (Tara, autistic). Once again, this was sometimes felt to be linked to a lack of autism awareness, *'I don't think people have a knowledge of it really, it's just a word that they think they know what it means, I don't really think they know how to put that into practice'* (Irene, autistic). When professionals did have good autism knowledge, this tended to be due to personal connections rather than professional training, *'she was sort of autism friendly because she's got an autistic son, so she was the autism friendly health visitor'* (Morgan, autistic).

While some participants felt their diagnosis was overlooked, some participants received additional support, such as additional health visitor appointments or visits from a support worker, *'The support worker I've had has been really good because she does just talk through what I struggle with and then she came with me to the children's centre for the first time because those things I get really nervous about.'* (Suzi, autistic). However, most often support was provided due to a diagnosis of one or more psychiatric conditions rather than due to autism, *'I've also got extra health visitor appointments. So I get to see mine every week and it's going down to every two weeks over the next two months and then it goes down to*

monthly. It's quite nice to have that extra support. I wouldn't have got that just for my autism, which kind of sucks.' (Debbie, autistic). Debbie's support arose after an initial referral to social services due to disclosure of mental health difficulties, *'finally we met some intelligent people who said this didn't need to be done. So I've been given extra support but she's not on any child protection'*. Yvette also experienced a referral to social services, however her referral did not lead to receiving sufficient support, *'They keep spelling his name wrong, they don't communicate with each other, they said they were going to fund someone to come and help me with certain things but then they couldn't fund it so they said they'd refer me to a charity but didn't say what charity or how long the referral would take. There was so much anxiety just based on their input.'* Echoing the reports above of limited autism knowledge among professionals, Yvette said of social services,

'they kept referencing Anne Hegerty in the jungle and saying, 'I know a bit about autistic women now, because Anne Hegerty in the jungle said this and now I understand what you're saying'. These are health professionals and they're getting their information from 'I'm a Celebrity Get Me Out of Here', otherwise they'd have had no understanding of me at all. I just thought that was the most awful thing, that reality TV is educating people who have the power to possibly take my child away from me, more than training.' (Yvette, autistic).

The importance of building a relationship with professionals.

In this subtheme, participants discuss their relationships with professionals, including continuity of care. Both groups appreciated having a friendly rapport with professionals who they felt cared about their wellbeing, *'It's been good to have the health visitors there and talk through and yeah, the health visitors just checking up on how I'm doing'* (Heather, non-autistic). Both groups appreciated continuity of care for establishing a relationship, *'I'd had a relationship with her while I was pregnant so it was really nice to see her again'* (Vanessa, non-autistic). The autistic group particularly emphasised the value of continuity of care for being understood, *'I did phone up one time and I didn't really manage to get what I was trying to say across to the person on the phone and I feel like if it was someone I knew, maybe they would understand what I was saying more.'* (Morgan, autistic) and, *'[My health visitor] knows that I'm not fantastic at socialising and things and how difficult the little one's been at the*

start' (Ethyl, autistic). Some autistic participants talked of the impact of a lack of continuity of care on trust,

'I had a few worries and I didn't know how she would react and I couldn't cope with her not reacting in the patterns that I'd already seen before, because I didn't really know her that well. With a new person I find that quite difficult. I felt that I had to kind of strategize, if I said something too concerning I didn't know how she'd react, so I felt that I had to be super OK and fake it a bit.'
(Yvette, autistic).

Other met and unmet support needs.

Participants also discussed their experiences with advice, practical support, group-based support and home visits. Participants in both groups appreciated useful advice from professionals surrounding their baby's health, *'the midwife and the home visitor care was great, in terms of like if you had questions it was really helpful'* (Lisa, non-autistic). Some participants in both groups, however, felt that they received unhelpful or contradictory advice. Contradictory advice was most often received in relation to breastfeeding, *'each midwife seemed to have a different opinion about what I should be doing about breastfeeding, which wasn't very helpful because I didn't know which one I should be following.'* (Tara, autistic). Participants in both groups who were able to access breastfeeding support groups tended to find these useful, *'it was really useful just to speak with people and they were like, 'you're doing great','* (Lisa, non-autistic). However, some of the autistic group found it challenging to access group-based support, *'they're like, 'If you're having problems with breastfeeding there's a breastfeeding café and you can go along and meet all the other breastfeeding mums' and I don't really feel able to do that. So I guess just more individual support generally.'* (Morgan, autistic).

Regarding home visits, some of the autistic group found it difficult when they were not informed in advance of what time professionals would visit their home, *'Knowing that someone could invade your safe space at any time was quite difficult. I'd be scared to do things in case they came, so I'd put certain routines on pause because I couldn't bear to be disrupted once I'd started'* (Yvette, autistic).

The importance of informal support.

This subtheme explores support from sources such as partners, family, friends and parent and baby groups. Both groups valued practical and emotional support from their partner and family. Participants valued help with household tasks, *'[my partner] was cooking and looking after us so I got to rest a lot with [my baby] and just feed him and cuddle him.'* (Beatrice, autistic) and being allowed a break from caring for their baby, *'[my mum] was here the first week, for four days and she was taking care of the baby and saying, 'You go to sleep and I'll call you when she needs you'* (Diana, non-autistic).

Both groups also appreciated being able to share experiences with other parents, *'There's a couple of mums who I see probably twice a week, we never run out of things to talk about.'* (Danielle, non-autistic). The non-autistic group often found attending parent and baby groups useful for forming connections with other parents, however the autistic group sometimes found this more challenging,

'I've been going to a baby group but I don't feel like I've made much of a connection with anyone. I keep going but I've found it really hard. Everyone goes on about how you need a mum network but I don't have that.' (Kayleigh, autistic)

Another participant commented, *'my anxiety's really bad about going to the group things and stuff. So I guess if other people were not sure about what they were doing on their own they'd feel able to go to a group and see what other people are doing and meet other people that way'* (Morgan, autistic). The autistic group additionally felt that peer support from other autistic parents was desirable, *'I think it would be really nice if there was more of a network for autistic mums, kind of like the NCT group'* (Suzi, autistic) and, *'it's nice to talk to other people who have similar sensory experiences and social experiences while also dealing with pregnancy and babies.'* (Simone, autistic).

2.4 Discussion

This study provides insights into the perinatal experiences of autistic people and identifies key areas in which autistic people can be better supported during this time. The physical symptoms of pregnancy tended to be heightened for the autistic group, including experiencing sensory changes, morning sickness, joint pain and mental fatigue more acutely

than the non-autistic group. Increased sensory challenges echo prior qualitative reports of heightened sensory experiences for autistic people during pregnancy (Gardner et al., 2016; Rogers et al., 2017) and fit with the presence of sensory sensitivities among autistic people more generally (Tavassoli et al., 2014). Participants offered speculation for their heightened experiences including increased morning sickness due to sensory sensitivities and increased joint pain due to hypermobility. These speculations could provide avenues for further research.

Some participants did not disclose their autism diagnosis to professionals during pregnancy due to fear of receiving a negative reaction, echoing similar reports by Gardner et al. (2016) and Pohl et al. (2020). During prenatal appointments, childbirth and postnatal appointments, when participants did disclose they often felt that professionals had limited awareness of autism among women, with some feeling that this lack of awareness led to their diagnosis being overlooked and adjustments not being made. These findings fit with prior research showing that autistic women feel that maternity care professionals lack knowledge of autism (Rogers et al., 2017), as well as prior findings that maternity care professionals feel they lack sufficient training concerning intellectual disability and mental health (Castell & Stenfort Kroese, 2016; Higgins et al., 2016).

A lack of autism understanding among professionals occasionally led to participants feeling unable to reveal difficulties they were experiencing for fear that they may be misunderstood or that their child may be taken away. Indeed, one autistic participant during pregnancy and two autistic participants postnatally experienced a referral to social services that they felt was based on misunderstandings. This is consistent with findings that mothers with intellectual difficulties and mothers with mental health conditions are more likely to come into contact with social services (Booth & Booth, 2005; Park et al., 2006) and that they can fear being honest with professionals due to concerns that they may lose their child (Malouf, McLeish et al., 2017; Montgomery et al., 2006). Greater understanding of autism among professionals would help avoid misunderstandings and create an environment in which autistic patients feel able to disclose difficulties to professionals. Continuity of care during prenatal and postnatal appointments may also help to build a sense a trust and understanding between autistic people and professionals, and may therefore be an important adjustment to make for autistic people.

Both prenatally and postnatally, autistic participants sometimes found group-based support, such as antenatal classes, breastfeeding classes and parent and baby groups, challenging. This is in keeping with reports that difficulties attending group-based support can be a barrier to accessing mental health services for autistic people and that person-centred support adapted to an individual's needs is sometimes preferred (Tint & Weiss, 2017). However, group therapy can be successful for autistic individuals. This is particularly the case when group sizes are small and participants can therefore benefit from a somewhat individualised approach while also benefiting from the support and motivation of others, and forming relationships with people who share similar challenges (Weiss & Lunsky, 2010). The provision of maternity-related support in alternative formats such as smaller classes, one-to-one support with a midwife or health visitor, or online support may be beneficial and was sometimes preferred in our sample. Group-based peer support involving autistic parents may also be preferable to similar support aimed at non-autistic parents. Indeed, consistent with previous findings establishing the value of peer support among mothers with mental health conditions (Diaz-Caneja & Johnson, 2004), the autistic group tended to feel that peer support from other autistic parents was desirable, in order to share atypical experiences of pregnancy and motherhood.

The autistic group emphasised the importance of receiving clear information from professionals about what to expect in appointments, who they would see and (for postnatal home visits) when they would arrive. During prenatal appointments, autistic participants appreciated factual, statistical information about their pregnancy and valued being given sufficient time to ask questions. Autistic participants sometimes experienced difficulties processing verbal information in prenatal appointments and preferred written information and alternatives to phone communication such as email. These communication preferences are in keeping with prior findings of communication related barriers to healthcare for autistic people (Nicolaidis et al., 2015; Raymaker et al., 2017), in addition to qualitative reports that autistic women require clear and direct information when interacting with maternity care professionals (Gardner et al., 2016). In line with research suggesting that an advocate such as a doula can be beneficial for mothers with ID (McGarry et al., 2016), some autistic participants found the presence of an advocate helpful for communication during prenatal appointments.

During pregnancy, autistic participants sometimes had concerns about experiencing communication difficulties with professionals during childbirth. When it came to the birth, autistic participants had mixed experiences in this regard with some feeling they received clear communication and others feeling they were not adequately kept informed. Autistic participants stressed the importance of being kept informed and receiving clear explanations and factual information. Together with the Pohl et al. (2020) finding that autistic mothers were less likely to feel that the process of birth was adequately explained to them, these findings highlight the need for professionals to communicate clearly with autistic patients during childbirth. Autistic participants sometimes felt that professionals were dismissive or mistrustful of their reports of their physical symptoms during pregnancy and birth. This may potentially be due to a lack of knowledge among professionals of how autistic people may experience physical symptoms differently, a speculation that warrants further research.

During pregnancy, autistic participants also had concerns that the sensory environment of the hospital may be challenging while giving birth. Some participants did go on to find sensory aspects such as the noise of the hospital and being touched challenging during the birth. Accommodations around sensory issues were made for some and participants emphasised the importance of adjustments such as dimming the lights during the birth and being provided their own room on the postnatal ward. These findings are consistent with previous reports of autistic mothers findings bright lights and the sounds of the hospital challenging while giving birth (Gardner et al., 2016). Autistic participants also sometimes found the sensory environment challenging during prenatal appointments, once again highlighting the need for sensory accommodations for autistic people within the hospital environment.

During pregnancy, both groups looked forward with excitement to meeting their baby and watching them develop, and both groups enjoyed experiencing these benefits once their baby had been born. Both groups felt they possessed a number of parenting strengths including patience and attentiveness. Autistic participants additionally reported that their attention to detail and heightened hearing abilities enabled them to understand their baby's cries well. Other strengths reported by the autistic group included persistence with parenting goals and being able to better empathise with their baby's sensory needs due to experiencing their own sensory sensitivities.

Both groups found lack of sleep and the relentless nature of parenthood challenging. During pregnancy, some autistic participants had concerns about the executive functioning demands of parenthood and some did report finding this aspect challenging once their baby had been born. Other demands identified by the autistic group included the inability to maintain routines due to the unpredictability of a newborn, finding their baby's cries challenging from a sensory perspective and knowing how to play with their baby. Both groups experienced breastfeeding challenges, though echoing the findings of Gardner et al., (2016), some autistic participants additionally experienced sensory difficulties with breastfeeding.

2.4.1 Limitations

While the inclusion of a non-autistic comparison group assists in determining which experiences of the perinatal period are unique to autistic people and which are common to autistic and non-autistic people alike, there are several limitations associated with selection of the non-autistic group. The non-autistic group all resided in the Cambridgeshire area. As such, their healthcare experiences may have been less varied than the autistic group who resided throughout the UK, USA and Ireland. Furthermore, the non-autistic group had a higher level of education and higher income than the autistic group which may have afforded them access to better healthcare. The autistic group were also more likely to have co-occurring mental health conditions and it is possible that some experiences of the autistic group are influenced by the presence of other conditions in addition to autism. Furthermore, the researchers could not be blind to the group membership of the participants and as such their interpretation of differences between the groups may have been influenced by any biases they may hold.

The study could only capture the experiences of those with the verbal ability to take part in an interview and those who felt able to dedicate the necessary time and energy to take part. Indeed, four autistic participants did not feel able to complete the postnatal interview and it is possible that these parents may have had more challenging experiences that were unable to be captured by the study. Furthermore, parents experiencing challenging circumstances may have been unwilling to take part due to fear of disclosing difficulties they were facing. The study therefore likely only captures the perinatal experiences of a subset of the autistic community.

2.4.2 Conclusions and considerations for clinical care

This study is the first longitudinal, non-retrospective study of autistic people's experiences of the perinatal period and yields important implications for clinical practice. The findings highlight a need for greater autism training for professionals involved in perinatal care. Greater autism awareness, in addition to continuity of care, would help build trust and avoid misunderstandings between professionals and autistic patients. The findings support the provision of accommodations surrounding communication during prenatal and postnatal appointments, including the provision of clear, factual information, written information and alternatives to telephone contact. During childbirth, autistic people should be kept informed and provided with clear, direct information. The findings also point towards the need for sensory accommodations during prenatal appointments and during childbirth, including dimming bright lights, minimising noise and providing a private room on the postnatal ward. Such adjustments could be documented in a care plan. The provision of one-to-one antenatal classes and breastfeeding support may be preferable to group support for autistic people. Furthermore, autistic parents may benefit from support with challenging aspects of parenting such as executive functioning demands, the sensory aspects of breastfeeding and knowing how to play with their baby. Professionals should also be aware of the strengths that autistic parents possess, including perseverance and attention to their baby's cues. Despite group differences, the findings also highlight many commonalities in the experience of motherhood and many adaptations to care may serve to benefit both autistic and non-autistic mothers.

Chapter 3: Autistic mothers' pregnancy, childbirth and postnatal experiences: a survey study

3.1 Summary⁴

Studies exploring the perinatal experiences of women with disabilities⁵ have found that disabled women tend to have lower satisfaction with perinatal healthcare and poorer pregnancy and birth outcomes. However, little quantitative work has explored the perinatal experiences of autistic people. This online survey study explored perinatal experiences among 252 people with a diagnosis of autism, 177 people who self-identified as autistic and 551 non-autistic people. The survey was divided into three parts: pregnancy, birth and postnatal experiences and the findings of these are reported on in three separate results sections below. Compared with non-autistic people, autistic people were more likely to find the sensory and physical aspects of pregnancy and birth overwhelming as well as being more likely to experience prenatal and postnatal depression and anxiety. Autistic people experienced lower satisfaction with their relationships with perinatal healthcare professionals, tended not to disclose their autism diagnosis to professionals and tended not to feel that professionals had a good understanding of autism. In their qualitative responses, autistic participants emphasised the need for clear, detailed information and time to process information in perinatal appointments. This study identifies key areas where adjustments can be made to perinatal healthcare for autistic people and highlights the need for greater autism understanding among professionals.

3.2 Introduction

There has been very little work exploring autistic people's parenthood experiences using quantitative methods. There is a growing body of literature, however, assessing the motherhood experiences of disabled women, including those with mental health challenges and those with intellectual disability. The experiences of such women could inform understanding of autistic people's experiences given that conditions such as intellectual

⁴ Due to the length of the chapter, a summary is provided in order to highlight the main results.

⁵ The term disability is used here to encompass a range of conditions that can have disabling effects, including physical conditions, mental health conditions and intellectual disability. It should be noted, however, that not all individuals with such conditions may consider themselves to have a disability.

disability and mental health conditions often co-occur with autism and may bring similar challenges.

Women with disabilities have been found to be at increased risk of poorer birth outcomes. Women with physical disabilities are more likely to have assisted vaginal births, planned caesarean sections and emergency caesarean sections compared with women without disabilities (Malouf, Henderson & Redshaw, 2017). Furthermore, women with intellectual disability are more likely to have caesarean or induced births than women without intellectual disability (Brown et al., 2016), to have poorer birth outcomes such as preterm delivery and low birth weight (Mitra, Parish et al., 2015) and higher risk of pregnancy conditions such as preeclampsia (Brown et al., 2017).

Only one study has explored pregnancy and birth outcomes for autistic women. Using Swedish national medical data from 2006-2014, Sundelin et al. (2018) compared the pregnancy and birth outcomes of 2198 autistic women and 877,742 non-autistic women. They found that autistic women had increased risk of moderately preterm birth (32 to <37 weeks), but no difference in risk of preterm birth from 28 to <32 weeks or preterm birth below 28 weeks. This increased risk in moderately preterm birth was likely due to increased risk of medically indicated preterm birth (preterm birth due to induction of labour or caesarean section before labour); no risk of increased spontaneous preterm birth was found. Autistic women were more likely to have an elective caesarean and more likely to have induced labour than non-autistic women. Autistic women also had an increased risk of preeclampsia, which the authors speculated may be due to altered immune response in autistic people. Autistic women were found not to be at increased risk of gestational diabetes nor still birth. All findings remained significant after covarying for the mother's age, country of birth, smoking, BMI, parity, psychotropic and antiepileptic medication during pregnancy and the year the mother gave birth.

Secondary analyses of UK national survey data have revealed gaps in care for disabled women during the perinatal period. Malouf, Henderson and Redshaw (2017) analysed survey data from 2015 relating to the maternity experiences of disabled and non-disabled women. They found that disabled women (including those with physical disabilities, mental health conditions, sensory disabilities and intellectual disabilities) had lower perceptions of pregnancy care including being less likely than women without disabilities to report being

spoken to by health professionals in a way they could understand and being less likely to report being involved in decisions about their care. Additionally, women with physical and mental health disabilities were less likely than women without disabilities to report having time to ask questions in prenatal appointments and less likely to feel listened to by professionals during pregnancy. Disabled women also had lower perceptions of labour and birth care, with women with physical, mental health and learning disabilities being less likely to have trust in staff, less likely to be spoken to by staff in a way they could understand and less likely to report always being treated with respect by staff. Women with mental health and intellectual disabilities were less likely to report that their concerns were taken seriously by staff during labour and birth. Low perceptions of healthcare were also common postnatally. During postnatal appointments, women with disabilities were less likely to feel listened to by professionals, to have trust in their midwives and to receive the help they needed from midwives. Women with physical and mental health disabilities were also less likely to report being treated with kindness and understanding during their postnatal hospital care, less likely to report receiving support for infant feeding during their hospital stay and during the six weeks after birth and less likely to have received sufficient information about their physical recovery after birth or possible mood changes after birth.

These results echo those of a previous analysis of national survey data from 2010, which also found lower perceptions of perinatal care among women with disabilities, particularly those with mental health and learning disabilities (Redshaw et al., 2013). In addition, this study further indicated that disabled women were less likely than non-disabled women to attend antenatal classes, less likely to breastfeed and less likely to be given the pain relief they wanted during labour. A further survey study focusing on women with mental health conditions found that they had lower satisfaction concerning the experience of birth and perceived maternity care less positively than women without mental health conditions (Henderson et al., 2018). This included being less likely to feel that doctors talked to them in a way they could understand, treated them respectfully and listened to them. A small study of disabled women's experiences in the UK and Ireland found that the majority of disabled women surveyed felt that reasonable adjustments to maternity care had not been made for them and that maternity care professionals did not have appropriate awareness of disability (Hall et al., 2018).

These first-hand perceptions of poorer healthcare among disabled women have been supported by research exploring healthcare professionals' perspectives on delivering care to women with disabilities. Research examining midwives confidence in caring for women with disabilities has revealed that midwives do not feel they have sufficient education and information to adequately care for women with mental health conditions (Noonan et al., 2018) nor intellectual disability (Homeyard et al., 2016). In addition, there is evidence from Swedish data that midwives can possess negative attitudes such as the belief that women with intellectual disability cannot satisfactorily manage the role of being a mother (Höglund et al., 2013). In addition, a UK survey revealed that the majority of NHS trusts did not have routine antenatal information adapted for women with intellectual disability nor routinely offered extra time in appointments to women with intellectual disability (Homeyard & Patelarou, 2018).

Only one quantitative study has explored autistic mothers' experiences (Pohl et al., 2020; outlined in greater detail in Chapter 2). Echoing the findings outlined above of lower satisfaction among disabled women regarding communication with professionals, Pohl et al. (2020) found that autistic mothers experienced communication difficulties with professionals and were reluctant to disclose their autism diagnosis. Autistic mothers were also more likely to experience prenatal and postnatal depression, less likely to feel that the process of birth was adequately explained to them, just as likely to attend antenatal classes and just as likely to attempt to breastfeed, though were more likely to have difficulties breastfeeding their second child. They were also more likely to experience difficulty with the multi-tasking and organisation involved in parenting and more likely to find motherhood isolating. There were no differences, however, in their ability to prioritise their child's needs above their own.

There is currently no quantitative research focusing solely on the perinatal experiences of autistic people. This study aimed to explore perceptions of pregnancy, birth and postnatal healthcare among autistic people, in order to identify gaps in current practice. The survey also aimed to explore physical and sensory experiences during the perinatal period in addition to pregnancy conditions and birth outcomes for autistic people. Finally, the survey aimed to capture the strengths and challenges autistic people face as a parent to a young infant.

3.3 Method

3.3.1 The survey

The survey contained three sections: pregnancy experiences, childbirth experiences and postnatal experiences. The pregnancy section was broken down into questions assessing: 1) the physical and sensory experiences of pregnancy; 2) experiences of prenatal appointments; 3) support. The childbirth section covered: 1) birth outcomes; 2) sensory and physical aspects of birth; 3) healthcare experiences; 4) postnatal hospital stay and postnatal health. The postnatal section covered: 1) breastfeeding; 2) experiences of postnatal appointments; 3) parenting challenges and strengths; 4) support.

The survey contained both forced choice and open-ended questions. The forced choice questions most often required a yes/no response or one of the following six responses, 'strongly agree', 'somewhat agree', 'somewhat disagree', 'strongly disagree', 'don't know' or 'not applicable'. The open-ended questions provided a text box for respondents to elaborate on their experience. Each section of the survey ended with an open-ended question giving the option to elaborate on any aspect of the participant's experience relevant to that section. Open-ended questions were also used to achieve clarification after some of the forced-choice questions, for example, if respondents indicated they had not attended antenatal classes they would be asked, 'Please say why you have not attended antenatal classes'. Some questions were only presented depending on the response given to a previous question. For example, 'I have had difficulties breastfeeding my baby' was only asked if respondents had answered 'yes' to 'Did you breastfeed or attempt to breastfeed your baby?'. Questions concerning autism were only asked to those who indicated that they either had a diagnosis of autism or self-identified as autistic.

The survey also contained demographic questions and the AQ-10, a short version of the Autism Spectrum Quotient (Allison et al., 2012). The AQ-10 is a self-report measure of autistic traits containing 10 items with responses on a four point Likert scale ('definitely agree', 'slightly agree', 'slightly disagree' and 'definitely disagree'). Scores range from 0-10, with a score of six or above indicating that an individual may warrant a clinical assessment for autism.

When designing the survey, the findings from the qualitative interviews presented in Chapter 2 were initially used as a foundation for choosing the topics covered. Additionally, feedback from the autistic community was sought through Twitter. Tweets were posted asking for autistic followers to comment on which aspects of pregnancy, childbirth and early parenthood they would like to see more research on. These comments were then taken into account when creating the survey questions. After an initial draft of the survey questions had been produced, three autistic mothers were consulted for feedback. As well as having direct experience of motherhood as an autistic person, each of the mothers worked with other mothers in a professional capacity, one as a midwife, another as a doula working specifically with autistic women and another as a researcher exploring autistic motherhood. Feedback was gained through email exchanges concerning the phrasing and content of the questions, in order to ensure that the topics covered were those most important to autistic mothers and that the questions were phrased appropriately. Those consulted were offered reimbursement for their time. The final draft was then piloted with five non-autistic mothers to check for errors and the functioning of the survey in Qualtrics.

Participants completed the survey online through Qualtrics and indicated their informed consent electronically. The survey took around one hour to complete. Responses were anonymous, though participants were asked to provide a code (consisting of the first letter of their first name, the last two digits of their birth year, the last letter of their last name and the first two characters of their post code) in order to allow their responses to be withdrawn if requested and to allow for eliminating duplicates. Ethical approval was obtained from the University of Cambridge Psychology Research Ethics Committee. The full survey can be found in Appendix 3.

3.3.2 Participants

Participants were recruited through the Cambridge Autism Research Database, through parenting groups, autism support groups and through social media (Facebook and Twitter). Participants were eligible to take part if they were 18 or more years old and had either given birth at least once or were currently in the third trimester of pregnancy.

Participants were asked to fill in the pregnancy questions if they had given birth at least once or if they had never given birth but were currently in the third trimester of pregnancy. Those in the first or second trimester were not asked to complete the pregnancy questions as many

of the questions were less relevant to those in the early stages of pregnancy (e.g. questions about medical appointments and antenatal classes). It was chosen not to ask participants currently in the first or second trimester to reflect on a previous pregnancy that reached the third trimester, as their experience of their current pregnancy may have affected their recollection of past experiences. For those who were not currently pregnant, participants were asked to reflect on their most recent pregnancy that went to term.

Participants were asked to fill in the childbirth questions if they had ever given birth. They were requested to reflect on their most recent birth experience. Respondents were asked to fill in the postnatal questions if they had a child who was at least three months old at the time of completing the survey. For these questions, participants were asked to reflect on their experience with their youngest child who they gave birth to. Respondents were asked to focus on their experiences with their most recent pregnancy/birth and their youngest child given that their most recent experience would be most fresh in their mind.

A priori power analyses based on a range of effect sizes found by Pohl et al. (2020) for similar questions to those in the present study (e.g. differences between autistic and non-autistic mothers concerning breastfeeding and communicating with professionals) indicated a required total sample size between 591 and 969, given 80% power and a two-tailed alpha of 0.05. In total, 252 people with a diagnosis of autism, 177 people who believed themselves to be autistic but did not have a diagnosis of autism and 551 non-autistic people (who neither had a diagnosis nor believed themselves to be autistic) were included in the study. Post hoc sensitivity power analyses indicated that for the total sample ($n=980$), there was adequate (80%) power to detect small effect sizes (odds ratio ≥ 1.68), with a two-tailed alpha of 0.05.

Those who believed themselves to be autistic but did not have a diagnosis were included in the autistic group along with those with an autism diagnosis. This is because the mean AQ-10 score of the group who self-identified as autistic was above the cut-off of six (mean = 7.05, SD = 2.09) and, even though their AQ-10 mean score was significantly lower than that of those with a diagnosis (mean = 7.90, SD = 1.66, $p < .001$), they scored significantly higher than the non-autistic group (mean = 1.98, SD = 1.65, $p < .001$). This approach follows that of Pohl et al. (2020).

Demographic characteristics are outlined in Table 3.1. Participants were mostly from western countries, primarily the UK, USA and Ireland. Participants were predominantly of white ethnicity, tended to have a university level education and to have given birth to their most recent child in their early thirties. The autistic and non-autistic groups did not differ significantly on current age, education, ethnicity, whether their most recent pregnancy was singleton or multiple, or on total number of pregnancies, live births, miscarriages or terminations. The groups significantly differed on country of residence, age at most recent birth and current partner status. The autistic group had significantly lower annual household income, were significantly more likely to have ever been diagnosed with a psychiatric condition, gave birth to their youngest child significantly longer ago than the non-autistic group and their youngest child was more likely to have an autism diagnosis.

Table 3.1 Demographic information for the autistic and non-autistic groups.

	Non-autistic group	Autistic group	p-value (FDR corrected)
Mother's current age ^a			0.06
N	551	419	
Mean (SD)	41.30 (10.00)	42.60 (9.28)	
Mother's age at most recent birth ^a			0.003
N	551	419	
Mean (SD)	33.10 (5.07)	32.00 (5.38)	
Education ^b			0.10
N	551	429	
Completed high school	98 (18%)	98 (23%)	
Undergraduate degree	231 (42%)	159 (37%)	
Postgraduate degree	196 (36%)	143 (33%)	
Other	26 (5%)	29 (7%)	
Income ^b			<0.001
N	539	422	
Greater than £100,000	92 (17%)	44 (10%)	
£50,000-£100,000	187 (35%)	97 (23%)	
£25,000-£50,000	172 (32%)	145 (34%)	
Less than £25,000	88 (16%)	136 (32%)	
Current partner status ^b			<0.001
N	551	428	
Married/in a partnership	483 (88%)	324 (76%)	
Divorced/separated/widowed	36 (7%)	62 (14%)	
Single	32 (6%)	42 (10%)	
Country ^b			<0.001

N	551	429	
UK	382 (69%)	254 (59%)	
USA	53 (10%)	89 (21%)	
Ireland	69 (12%)	12 (3%)	
Other	51 (9%)	74 (17%)	
Ethnicity ^b			0.69
N	548	424	
White	517 (94%)	404 (95%)	
Non-white	31 (6%)	20 (5%)	
Psychiatric condition(s) ^b			<0.001
N	548	423	
Yes	201 (37%)	284 (67%)	
No	347 (63%)	139 (33%)	
AQ-10 score ^a			<0.001
N	550	426	
Mean (SD)	1.98 (1.65)	7.55 (1.89)	
Total number of pregnancies ^c			0.50
N	551	429	
Median (IQR)	2.00 (2.00)	3.00 (2.00)	
Total number of live births ^c			0.14
N	551	429	
Median (IQR)	2.00 (1.00)	2.00 (2.00)	
Miscarriages (percentage of total number of pregnancies) ^a			0.98
N	551	429	
Mean (SD)	6.57% (6.77)	6.75% (6.87)	
Terminations (percentage of total number of pregnancies) ^a			0.98
N	551	429	
Mean (SD)	3.68% (3.88)	3.74% (3.96)	
Age of youngest child in years ^a			0.001
N	551	429	
Mean (SD)	8.19 (8.45)	10.60 (8.83)	
Singleton or multiple birth (youngest child) ^b			0.98
N	551	429	
Singleton	419 (98%)	538 (98%)	
Multiple	10 (2%)	13 (2%)	
Autism diagnosis (youngest child) ^b			<0.001
N	546	429	
Yes	95 (17%)	141 (33%)	
No	451 (83%)	288 (67%)	

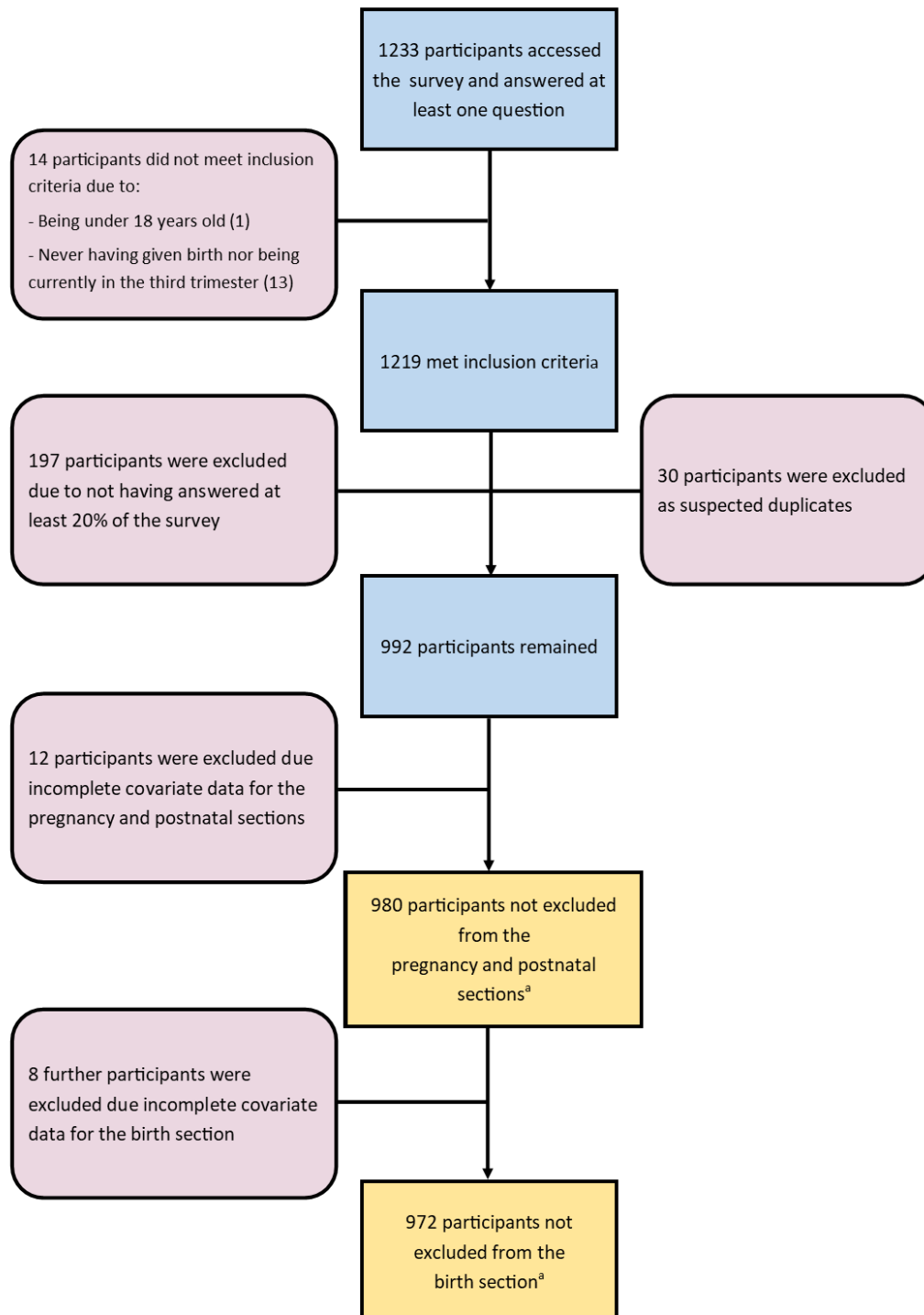
^aT-test performed

^bFisher's exact test performed

^cWilcoxon rank-sum test performed

3.3.3 Data analysis

Ineligible participants were excluded, including those under 18 years old (1 participant) and those who had never given birth nor were currently in the third trimester of pregnancy (13 participants). Participants were excluded if they were suspected to be duplicates, that is, if they had the same identifying code as another participant and gave the same responses for the demographic questions (30 participants excluded). Anyone who had not answered at least 20 percent of the survey questions beyond the demographic questions was excluded, resulting in 197 people removed. Reasons for participant exclusion are shown in Figure 3.1.



^aNot all non-excluded participants took part in every section due to participant attrition throughout the survey

Figure 3.1 Reasons for participant exclusion.

3.3.3.1 Quantitative data

For each of the Likert scale questions, 'strongly agree' and 'somewhat agree' were combined to form an 'agree' category and 'strongly disagree' and 'somewhat disagree' were combined to form a 'disagree' category. Similarly, for questions about satisfaction, 'very satisfied' and 'somewhat satisfied' were reduced to 'satisfied', and 'very dissatisfied' and 'somewhat dissatisfied' were reduced to 'dissatisfied'. 'Don't know' and 'Not applicable' responses were excluded from statistical analysis. Each question was then analysed using binary logistic regression. This approach of collapsing Likert scales to two categories and performing binary logistic regression has been taken in prior survey studies of perinatal experiences (e.g. Redshaw et al., 2013).

Where possible, thematically similar items were analysed in a multivariate manner in order to account for correlations among items. This was achieved by reshaping the data into long format such that responses for all items were aggregated into one binary (agree/disagree) outcome variable. In this manner, items were effectively treated as repeated measures. A multilevel binary logistic regression was then performed with the agree/disagree response variable as the outcome and group as a predictor. Each model included a random intercept for participant to account for dependency due to repeated measures. A group by item interaction term was included in each model in order to obtain odds ratios and confidence intervals for each individual item. Items that correlated negatively with the other items within the multivariate analysis were reverse scored prior to analysis. To obtain an omnibus analysis of the effect of group across the items as a whole, a likelihood ratio test was performed comparing the model with group as a predictor and the model without group as a predictor; if the model with group as a predictor was a significantly better model than that without, group was considered to have a significant effect on responses across the items as a whole. Only if this omnibus test was significant were analyses relating to individual items presented. Decisions to group items together in a multivariate analysis were based on theory, taking into account thematic similarity between items (e.g. questions regarding prenatal appointments were analysed together, questions regarding senses were analysed together etc.). Polychoric correlations between theoretically related items were also conducted (see Appendix 4). Thematically similar items were generally at least moderately correlated (following interpretation of correlation effect sizes according to Cohen (1992), $r \geq .30$ was considered

moderate), supporting a multivariate analysis. Some items were only weakly correlated with others and were excluded from the multivariate analysis. For example, items concerning attending appointments were strongly correlated with each other though had few correlations of $r=.30$ or above with other prenatal healthcare items and therefore were analysed together in a multivariate analysis but excluded from the main prenatal healthcare multivariate analysis.

Some items that were logic-dependent (only presented depending on the response to a prior question) were excluded from multivariate analyses. For example, the item, 'I found it helpful to have an advocate during prenatal appointments' was asked only if participants previously indicated having an advocate and the item, 'I would have found it helpful to have an advocate during prenatal appointments' was asked if participants indicated not having an advocate. These questions were therefore not entered together into a multivariate analysis and were instead analysed individually.

FDR correction for multiple comparisons was not applied to analyses of individual items within a multivariate analysis, though all other analyses were FDR corrected (i.e. analyses of individual items not included within a multivariate analysis and omnibus tests of the overall effect of group on multiple items). FDR correction was applied to the pregnancy, birth and postnatal sections separately (i.e. all comparisons within the pregnancy section were corrected for together, all questions within the birth section were corrected for together and all comparisons within the postnatal section were corrected for together).

All analyses included the following covariates: mothers' age at the time of giving birth, time passed since giving birth (age in days of their youngest biological child), the number of previous live births the participant had experienced, and country of residence. Questions concerning birth experiences also included gestational age at birth and type of delivery (vaginal, assisted vaginal, planned caesarean or emergency caesarean) as covariates. While current partner status, income and the presence of psychiatric conditions significantly differed between the two groups these were not included as covariates. Current partner status may not reflect partner status at the time being reported on (i.e. most recent pregnancy/birth) and as such may be less influential upon results than other factors. Missing data was greater for income than other covariates and as such including income would have resulted in a reduced sample size (see below for details of the treatment of missing data for

covariates). Finally, as psychiatric conditions commonly co-occur with autism (Lai et al., 2019) and factors surrounding autism may in fact contribute to the development of psychiatric conditions (Cage et al., 2018), attempting to disentangle autism from these other conditions may lead to a significant aspect of the autistic experience being obscured.

The adjusted odds ratio (aOR), after including covariates, is reported for each analysis. Those participants with missing data for any of the covariates were excluded from analyses. This led to 12 people being excluded for the pregnancy questions and the postnatal questions and an additional 8 people being excluded for the birth questions. As this led to less than 5 percent of participants being excluded it was decided to exclude these participants rather than impute the data.

3.3.3.2 Qualitative data

While the quantitative data are the main focus, data from the open-text responses are reported in order to elucidate the quantitative data. The open-text responses were organised into topics for each group for each question and pertinent quotes were selected to illustrate these. While this chapter serves as a preliminary reporting of the open-text data, a full thematic analysis with a consensus approach and inter-rater reliability checks (e.g. Barker & Pistrang, 2005) was not conducted. As such, the open-text data are intended to provide preliminary, speculative elucidation of the quantitative findings and should be interpreted tentatively. As a full thematic analysis was not conducted, and as the purpose of the qualitative data is to illustrate the relevant quantitative data, both data types are presented together (e.g. quantitative questions about attending appointments are followed by qualitative data on reasons for doing so).

3.4 Results

3.4.1 Pregnancy experiences

3.4.1.1 Sensory and physical experiences during pregnancy.

Sensory experiences.

Participants were asked whether each of their senses were heightened, reduced or stayed the same when pregnant compared to when not pregnant. A multivariate multinomial logistic regression was performed across the five senses as a whole. A model including group as a predictor was a significantly better fit than the model without group, $\chi^2(10)=251.64$, $p<0.001$,

indicating that there was a significant effect of group across the senses as a whole. For each sense, the autistic group was more likely than the non-autistic group to report that the sense had been heightened (as opposed to no change) during pregnancy (Table 3.2). There were no significant group differences in reporting a reduction in sensation (as opposed to no change) for smell, taste or vision. The autistic group was more likely than the non-autistic group to report a reduction in touch and hearing during pregnancy.

Table 3.2 Sensory changes during pregnancy.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value
Smell				
N	523	413		
Heightened	401 (77%)	344 (83%)	2.28 (1.12 - 4.66)	0.02
Stayed the same	120 (23%)	64 (16%)	-	-
Reduced	2 (0.38%)	5 (1%)	4.51 (0.68 - 30.03)	0.12
Taste				
N	524	413		
Heightened	281 (54%)	288 (70%)	3.78 (1.95 - 7.24)	<0.001
Stayed the same	226 (43%)	114 (28%)	-	-
Reduced	17 (3%)	11 (3%)	1.18 (0.41 - 3.42)	0.76
Touch				
N	522	413		
Heightened	119 (23%)	217 (53%)	9.43 (4.89 - 18.18)	<0.001
Stayed the same	399 (76%)	188 (46%)	-	-
Reduced	4 (1%)	8 (2%)	4.27 (1.04 - 17.63)	0.045
Hearing				
N	521	411		
Heightened	47 (9%)	144 (35%)	11.31 (6.36 - 27.06)	<0.001
Stayed the same	463 (89%)	248 (60%)	-	-
Reduced	11 (2%)	19 (5%)	3.54 (1.28 - 9.76)	0.02
Vision				
N	521	409		
Heightened	20 (4%)	66 (16%)	6.12 (2.52 - 15.06)	<0.001
Stayed the same	440 (84%)	293 (72%)	-	-
Reduced	61 (12%)	50 (12%)	1.22 (0.61 - 2.42)	0.58

Notes. CI=confidence intervals. Multivariate multinomial logistic regression performed.

Participants were asked how frequently they became overwhelmed by each sense when pregnant. For each sense, a score from 0 to 8 was allocated ('Never' = 0, 'Several times a day' = 8, intermediate response categories are detailed in Table 3.3). A multivariate negative binomial regression was performed across the five senses as a whole. Negative binomial analysis was considered appropriate due to the right skewed nature of the data and the variance of the data being larger than the mean. A model including group as a predictor was a better fit than the model without group, $\chi^2(5)=434.38$, $p<0.001$, indicating that there was a significant effect of group across the five senses as a whole. Participants were also asked how frequently they were overwhelmed by each sense when not pregnant. The frequency of being overwhelmed by the senses when not pregnant was included as a covariate so as to account for baseline differences in sensory experiences between the groups. For each sense, the autistic group were overwhelmed significantly more frequently than the non-autistic group.

Table 3.3 Sensory overload during pregnancy.

	Non-autistic group	Autistic group	Rate ratio (95% CI)	p-value
Sensory overload: Smell ^a			2.91 (2.42 - 3.49)	<0.001
N	520	402		
Several times a day	214 (41%)	262 (65%)		
Once a day	58 (11%)	45 (11%)		
More than once a week but less than everyday	50 (10%)	37 (9%)		
Once a week	16 (3%)	15 (3%)		
Once every two weeks	19 (4%)	6 (1%)		
Once a month	31 (6%)	6 (1%)		
Once every six months	16 (3%)	3 (1%)		
Less often than every six months	18 (3%)	7 (2%)		
Never	98 (19%)	21 (5%)		
Sensory overload: Taste ^a			1.99 (1.69 - 2.38)	<0.001
N	514	397		
Several times a day	119 (23%)	183 (46%)		
Once a day	51 (10%)	47 (12%)		
More than once a week but less than everyday	72 (14%)	53 (13%)		
Once a week	26 (5%)	15 (4%)		
Once every two weeks	14 (3%)	10 (3%)		
Once a month	26 (5%)	14 (4%)		
Once every six months	14 (3%)	7 (2%)		
Less often than every six months	27 (5%)	13 (3%)		

Never	165 (32%)	55 (14%)		
Sensory overload: Touch			1.97 (1.67 - 2.33)	<0.001
N	514	400		
Several times a day	48 (9%)	194 (48%)		
Once a day	29 (6%)	45 (11%)		
More than once a week but less than everyday	49 (10%)	60 (15%)		
Once a week	30 (6%)	21 (5%)		
Once every two weeks	11 (2%)	12 (3%)		
Once a month	32 (6%)	12 (3%)		
Once every six months	14 (3%)	6 (2%)		
Less often than every six months	35 (7%)	4 (1%)		
Never	266 (52%)	46 (12%)		
Sensory overload: Hearing			2.32 (1.96 - 2.75)	<0.001
N	516	396		
Several times a day	39 (8%)	193 (49%)		
Once a day	22 (4%)	48 (12%)		
More than once a week but less than everyday	43 (8%)	53 (13%)		
Once a week	22 (4%)	23 (6%)		
Once every two weeks	12 (2%)	13 (3%)		
Once a month	36 (7%)	13 (3%)		
Once every six months	20 (4%)	4 (1%)		
Less often than every six months	43 (8%)	8 (2%)		
Never	279 (54%)	41 (10%)		
Sensory overload: Vision			2.60 (2.18 - 3.10)	<0.001
N	508	392		
Several times a day	16 (3%)	95 (24%)		
Once a day	18 (4%)	53 (4%)		
More than once a week but less than everyday	22 (4%)	65 (17%)		
Once a week	18 (4%)	22 (6%)		
Once every two weeks	20 (4%)	17 (4%)		
Once a month	22 (4%)	22 (6%)		
Once every six months	21 (4%)	13 (3%)		
Less often than every six months	43 (8%)	23 (6%)		
Never	328 (65%)	82 (21%)		

Note. Multivariate negative binomial regression performed

^aAs data were left skewed, responses were reverse scored to be suitable for negative binomial regression. The inverse of the rate ratio and confidence intervals are reported.

Bodily changes during pregnancy: interoception and proprioception.

A multivariate binary logistic regression was performed for the items concerning interoception (awareness of one's internal bodily sensations) and proprioception (awareness of the position and movement of the body). A model including group as a predictor was a better fit than the model without group, $\chi^2(2)=98.22$, $p<0.001$, indicating a significant group difference. The autistic group were significantly more likely than the non-autistic group to report changes in their interoception (69% vs. 42% reported a change) and proprioception (38% vs. 15%; Table 3.4). An individual binary logistic regression revealed that the autistic group were significantly more likely to report difficulty adjusting to bodily changes associated with pregnancy (54% vs. 31%).

Participants in both groups responded to the open text question asking them to describe their interoception changes by reporting that they felt their baby move early on in the pregnancy. The autistic group also reported feeling very aware of their baby's movements, *'I correctly identified an anterior placenta in two pregnancies because of the way the movements felt, this was confirmed by ultrasound'*.

Some participants in both groups reported feeling bodily sensations more acutely while others reported feeling these sensations less clearly, *'When pregnant, I'm less able to feel inside my belly and I feel less ownership of it. Like an alien is inside me'* (non-autistic participant). Autistic participants most commonly reported an increase in interoception, for example *'incredibly intense and overwhelming. I felt everything inside my body'*, though a minority reported a decrease, *'I was somewhat disconnected from my body and was less able to recognize how I felt'*.

Changes in perceiving hunger and thirst were reported by both groups, with some reporting an increase and others reporting a decrease in awareness. For the autistic group, an increased ability to recognise hunger or thirst was often contrasted with a reduced or non-existent ability to feel these sensations when not pregnant, *'usually I am not good at recognising when I'm hungry/thirsty/in pain but during pregnancy became much more in tune with my body'*.

Participants in both groups often responded to the open-text question asking them to describe their proprioception changes by indicating that they felt clumsier when pregnant. While for the non-autistic group this tended to occur in later pregnancy due to weight gain,

the autistic group frequently mentioned that that this began earlier in pregnancy, *'I struggled with balance even before I had a big tummy'*. While, for the non-autistic group, proprioception changes were limited to balance, the autistic group reported a reduction in the ability to situate their body in space, *'I had no idea where I started and finished'* and, *'I felt like my body was coming apart'*. While many reported a worsening of existing proprioception difficulties, proprioceptive experiences improved during pregnancy for some, *'I had problems knowing the position of my body/limbs before pregnancy without being able to see them but when pregnant I was much more aware of them and felt more in control'*.

Table 3.4 Interoception, proprioception and bodily changes during pregnancy.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value	p-value (FDR adjusted)
Interoception changes			3.87 (2.69 - 5.56)	<0.001	-
N	523	417			
Yes	218 (42%)	286 (69%)			
No	305 (58%)	131 (31%)			
Proprioception changes			3.97 (2.70 - 5.85)	<0.001	-
N	523	416			
Yes	81 (15%)	158 (38%)			
No	442 (85%)	258 (62%)			
Difficulty adjusting to bodily changes ^a			2.87 (2.15 - 3.84)	<0.001	<0.001
N	524	413			
Agree	165 (31%)	223 (54%)			
Disagree	335 (64%)	167 (40%)			
Don't know	5 (1%)	10 (2%)			
Not applicable	19 (4%)	13 (3%)			

Note. Multivariate binary logistic regression performed

^aItem analysed with individual logistic regression due to weakly correlating with other items

Nausea during pregnancy.

The autistic group were significantly more likely to report experiencing more frequent nausea, with over half (51%) of this group reporting experiencing nausea all day every day (Table 3.5). Participants were asked to report the frequency of their nausea only for the time of their

pregnancy when they were experiencing nausea (for example, someone who experienced nausea throughout the first trimester would be reporting on the first trimester only).

Table 3.5 Frequency of nausea during pregnancy.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value	p-value (FDR adjusted)
Nausea			1.65 (1.28 - 2.14)	< 0.001	<0.001
N	506	386			
Nausea every day and it lasted throughout the day	196 (39%)	197 (51%)			
Nausea every day and it did not last throughout the day	119 (24%)	74 (19%)			
Nausea less frequently than every day	115 (23%)	72 (19%)			
No nausea during the pregnancy	76 (15%)	43 (11%)			

Note. Ordinal logistic regression performed

Meltdowns and shutdowns during pregnancy.

Scores from 0 (never) to 8 (several times a day) were allocated for the frequency of meltdowns and for the frequency of shutdowns during the pregnancy as a whole. Questions concerning the frequency of meltdowns and shutdowns during pregnancy were explored with a multivariate negative binomial regression. A model including group as a predictor was a better fit than the model without group, $\chi^2(2)=131.32$, $p<0.001$. The frequency of experiencing meltdowns and shutdowns when not pregnant was included as a covariate to account for baseline differences between the two groups. The autistic group were significantly more likely than the non-autistic group to report a higher frequency of experiencing meltdowns and shutdowns during pregnancy, with approximately one third of the autistic group indicating that meltdowns and shutdowns occurred twice a week or more (Table 3.6). Questions concerning whether meltdowns and shutdowns were more intense during pregnancy than when not pregnant were analysed with multivariate binary logistic regression. A model including group as a predictor was a better fit than the model without group, $\chi^2(2)=7.84$, $p=0.03$. The groups did not significantly differ in the tendency to report that the meltdowns experienced during pregnancy were more intense than those

experienced when not pregnant, though the autistic group were more likely to indicate that shutdowns experienced during pregnancy were more intense than when not pregnant. In both groups, more participants agreed that meltdowns and shutdowns were more intense during pregnancy than disagreed.

Participants were asked to give an open text response describing the cause or trigger of their meltdowns or shutdowns during pregnancy. Both groups identified life stressors such as marital, family, childcare, financial and job issues as causes. Also mentioned were physical and emotional causes such as anxiety, hormones, tiredness, nausea, feeling a lack of control and worrying about their baby's health.

The autistic group gave additional reasons not mentioned by the non-autistic group. The autistic group emphasised sensory overload as a trigger, *'Sensory overwhelm and exhaustion; I have trouble with noises and smells and touching and handling other people's emotional expressions. The "volume" on all these got "louder"'*. This group also mentioned the pressures of social interactions, *'problems processing information and making myself understood. Communication was very challenging & stressful'*. The autistic group also highlighted feeling misunderstood or not listened to by medical professionals as a trigger, *'If I felt I was misunderstood or if I felt that my painful symptoms were being dismissed'*.

Table 3.6 Frequency and intensity of meltdowns and shutdowns during pregnancy.

	Non-autistic group	Autistic group	Rate ratio (95% CI)	p-value
Frequency of meltdowns ^a			1.35 (1.19 - 1.54)	<0.001
N	524	414		
Several times a day	7 (1%)	19 (5%)		
Once a day	13 (2%)	35 (8%)		
More than once a week but less than everyday	38 (7%)	82 (20%)		
Once a week	24 (5%)	35 (8%)		
Once every two weeks	29 (6%)	37 (9%)		
Once a month	67 (13%)	53 (12%)		
Once every six months	44 (8%)	33 (8%)		
Less often than every six months	60 (11%)	33 (8%)		
Never	236 (45%)	59 (14%)		
Frequency of shutdowns ^a			2.35 (2.01 - 2.75)	<0.001
N	523	416		
Several times a day	5 (1%)	37 (9%)		
Once a day	12 (2%)	35 (8%)		
More than once a week but less than everyday	14 (2%)	82 (20%)		
Once a week	8 (1%)	30 (7%)		
Once every two weeks	7 (1%)	29 (7%)		
Once a month	24 (5%)	45 (11%)		
Once every six months	17 (3%)	23 (6%)		
Less often than every six months	29 (6%)	27 (6%)		
Never	402 (77%)	90 (22%)		
	Non-autistic group	Autistic group	aOR (95% CI)	p-value
Meltdowns more intense ^b			0.58 (0.12 - 2.83)	0.50
N	249	349		
Agree	129 (52%)	194 (56%)		
Disagree	59 (24%)	84 (24%)		
Don't know	23 (9%)	46 (13%)		
Not applicable	38 (15%)	25 (7%)		
Shutdowns more intense ^b			6.54 (1.07 - 40.10)	0.04
N	93	315		
Agree	41 (44%)	179 (57%)		
Disagree	24 (26%)	76 (24%)		
Don't know	17 (18%)	43 (14%)		
Not applicable	11 (12%)	17 (5%)		

^aMultivariate negative binomial regression performed^bMultivariate binary logistic regression performed

Pregnancy conditions.

Each pregnancy condition was analysed with individual logistic regression due to the distinct nature of each condition. The autistic group were significantly more likely to have pelvic girdle pain and vaginal bleeding during pregnancy, as well as being significantly more likely to report having developed anxiety and depression during pregnancy (Table 3.7). The increased likelihood of reporting pelvic girdle pain remained after including hypermobility as a covariate and therefore accounting for baseline differences in hypermobility between the groups. The groups did not significantly differ in their likelihood of reporting gestational diabetes, high blood pressure, preeclampsia, eclampsia, infection of the amniotic sac, polyhydramnios, placenta previa, placental abruption or hyperemesis gravidarum.

Table 3.7 Pregnancy conditions.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value	p-value (FDR adjusted)
Pelvic girdle pain			1.76 (1.30 - 2.38)	<0.001	0.001
Pelvic girdle pain (with hypermobility as a covariate)			1.57 (1.15 - 2.15)	0.01	0.01
N	523	412			
Yes	145 (28%)	144 (35%)			
No	378 (72%)	268 (65%)			
Gestational diabetes			1.47 (0.92 - 2.36)	0.11	0.16
N	523	412			
Yes	40 (8%)	45 (11%)			
No	483 (92%)	367 (89%)			
High blood pressure			1.34 (0.83 - 2.17)	0.23	0.31
N	523	412			
Yes	39 (7%)	41 (10%)			
No	484 (93%)	371 (90%)			
Preeclampsia			0.96 (0.56 - 1.61)	0.87	0.87
N	523	412			
Yes	36 (7%)	31 (8%)			
No	487 (93%)	381 (92%)			
Eclampsia			0.60 (0.03 - 4.98)	0.66	0.69
N	523	412			
Yes	3 (1%)	1 (0.24%)			
No	520 (99%)	411 (99.76%)			
Infection of the amniotic sac			0.29 (0.01 - 2.25)	0.29	0.38
N	520	410			
Yes	4 (1%)	1 (0.24%)			

No	516 (99%)	409 (99.76%)			
Polyhydramnios			1.24 (0.63 - 2.43)	0.53	0.59
N	520	410			
Yes	20 (4%)	19 (5%)			
No	500 (96%)	391 (95%)			
Placenta previa			0.85 (0.40 - 1.75)	0.66	0.69
N	520	410			
Yes	19 (4%)	14 (3%)			
No	501 (96%)	396 (97%)			
Placental abruption			0.66 (0.24 - 1.69)	0.39	0.45
N	520	410			
Yes	12 (2%)	8 (2%)			
No	508 (98%)	402 (98%)			
Vaginal bleeding			1.72 (1.24 - 2.40)	0.001	0.002
N	520	410			
Yes	92 (18%)	108 (26%)			
No	428 (82%)	302 (74%)			
Hyperemesis gravidarum			1.21 (0.83 - 1.76)	0.32	0.38
N	524	415			
Yes	75 (14%)	76 (18%)			
No	449 (86%)	339 (82%)			
Anxiety			3.96 (2.84 - 5.58)	<0.001	<0.001
N	523	412			
Yes	72 (14%)	157 (38%)			
No	451 (86%)	255 (62%)			
Depression			3.21 (2.15 - 4.86)	<0.001	<0.001
N	523	412			
Yes	45 (9%)	97 (24%)			
No	478 (91%)	315 (76%)			

Note. Binary logistic regressions performed

3.4.1.2 Prenatal appointments.

Autism disclosure, adjustments and autism understanding during prenatal appointments.

When asked whether they had disclosed their autism to medical professionals, almost half of autistic respondents indicated that this question was not applicable to them (Table 3.8). Many indicated in their open text response that this was because that they had not received an autism diagnosis at the time of their most recent pregnancy. Of those who felt that the question was applicable, the majority did not disclose their diagnosis. Participants were

marginally more likely to disclose to a doctor (13%) than a midwife (10%) or a sonographer (3%).

Participants indicated in the open text response that their reasons for disclosing included hoping that disclosure would lead to adjustments. Those who chose not to disclose often gave concern about negative reactions as a reason, *'I do not think my midwife or doctor would know what that means or what to do with this info. I fear that would make them doubt my feelings and answers and take me less seriously'*. Some participants even feared that their child may be taken away, *'they would either not believe me, or if they did they might want to take my children away from me.'*

Those who indicated they had disclosed were asked if any adjustments had been made for them. The majority (83%) reported that they were not offered home visits nor for a community midwife to accompany them to appointments (91%). 12 participants indicated that they were offered another form of adjustment. The open text responses indicated that these adjustments included being able to wait for appointments in a quiet area, having blood tests done at home, longer appointment times and being allocated a temporary social worker. Participants also gave details of adjustments they would have liked. These included not having to book appointments by telephone, longer appointment times, being given clear explanations, being given clear information about what would be involved at hospital appointments, being provided with a written summary of discussions after appointments, and having an advocate with good understanding of autism.

When asked whether they felt that medical professionals had a good understanding of how autism affected them during pregnancy, the majority (69% for midwife, 62% for doctor and 70% for sonographer) indicated that this was not applicable (possibly due to not having disclosed their autism or not having been diagnosed). Those for whom this question was applicable tended to disagree that professionals had a good understanding of how autism affected them (12% disagreed versus 7% who agreed for midwife, 17% versus 8% for doctor and 11% versus 5% for sonographer). Participants described in their open text responses what they would like professionals to understand about autism. Participants emphasised a need for time to process information in appointments, with some participants saying that time to process information is essential for giving an accurate response, *'I need time to process and will give a stock response if pressed rather than the real one which takes too long to get there.'*

Participants also highlighted the importance of being allowed to ask questions, *'I need to ask a lot of questions in order to manage my anxiety'*. Many participants also emphasised the importance of being listened to and not dismissed, for example, *'listen to me when I tell them things are happening and not dismiss me. I know my body'*.

Sensory issues were highlighted by many participants. Participants wanted professionals to know *'how difficult it can be to be examined and touched'*, and the importance of giving prior warning and seeking consent for touch, *'Touch can be shocking when unanticipated'*. Participants wanted professionals to understand that they may express pain differently, *'I am not good at communicating the degree of pain or distress I'm in because my facial expressions become more flat when I am distressed. I also have more trouble expressing myself verbally when I'm in distress'*.

Table 3.8 Autism disclosure, adjustments offered and autism understanding in prenatal appointments.

	N	Yes	No	Don't know	Not applicable
Disclosed autism to:					
Midwife	411	41 (10%)	169 (41%)	-	201 (49%)
Doctor/GP	413	52 (13%)	169 (41%)	-	192 (46%)
Sonographer	409	14 (3%)	205 (50%)	-	190 (46%)
Adjustments offered:					
Home visits	58	10 (17%)	48 (83%)	-	-
Accompaniment by community midwife to appointments	58	5 (9%)	53 (91%)	-	-
Other	45	12 (46%)	33 (54%)	-	-
	N	Agree	Disagree	Don't know	Not applicable
Health professionals have had a good understanding of how being autistic affects me:					
Midwife	401	30 (7%)	50 (12%)	46 (11%)	275 (69%)
Doctor/GP	399	33 (8%)	67 (17%)	51 (13%)	248 (62%)
Sonographer	400	19 (5%)	46 (12%)	55 (14%)	280 (70%)

Attending prenatal appointments.

A multivariate binary logistic regression was performed for questions concerning attending prenatal appointments. A model including group as a predictor was not a significantly better fit than the model without group, $\chi^2(3)=3.53$, $p=0.38$, indicating that the groups did not significantly differ in their likelihood of attending ultrasound, midwife and doctor appointments as a whole (Table 3.9). Participants gave open text responses concerning the reasons for not attending all their appointments. Both groups mentioned practical barriers such as work commitments, travel issues and moving home, in addition to not feeling that the appointments were useful or necessary. The autistic group often reported that anxiety prevented from attending appointments, '*I would get very nervous and anxious and felt like it was impossible to do*'. The autistic group reported additional reasons including difficulties booking appointments (such as appointments only being bookable by telephone), difficulty coping with the hospital environment and difficulty with being touched during appointments.

Some autistic participants also mentioned a lack of trust in their midwife or feeling that health professionals were judgemental.

Table 3.9 Attendance of prenatal appointments.

	Non-autistic group				Autistic group			
	N	Yes	No	N/A	N	Yes	No	N/A
Attended all ultrasound appointments	524	514 (98%)	7 (1%)	3 (1%)	417	392 (94%)	18 (4%)	7 (2%)
Attended all midwife appointments	524	457 (87%)	6 (1%)	61 (12%)	416	324 (78%)	21 (5%)	71 (17%)
Attended all doctor/GP appointments	523	465 (89%)	5 (1%)	53 (10%)	414	356 (89%)	18 (4%)	40 (10%)

Other aspects of prenatal appointments.

For the remaining questions concerning prenatal healthcare, a multivariate binary logistic regression was performed. A model including group as a covariate was a better fit than the model without group, $\chi^2(13) = 467.21$, $p < 0.001$.

The autistic group were significantly more likely than the non-autistic group to feel overwhelmed by the sensory environment of prenatal appointments (76% vs 14%; Table 3.10). When asked to elaborate on which aspects of appointments they found overwhelming, the autistic group mentioned noisy and crowded waiting areas, physical examinations involving touch, bright lights, smells and heat.

The autistic group were more likely to report seeing a greater number of midwives throughout their pregnancy than the non-autistic group, yet were more likely to feel that seeing the same midwife at each appointment was important to them (77% vs. 68%). The autistic group were more likely than the non-autistic group to find it stressful when they saw a professional who they were not expecting to see at an appointment (68% vs. 37%) and more likely to agree that being informed of which professional they would see in advance of an appointment would be helpful (86% vs. 59%).

The autistic group were significantly less likely than the non-autistic group to feel that professionals took their questions and concerns seriously (55% compared with 84% of the

non-autistic group), less likely to feel comfortable asking questions to professionals (57% vs. 90%), less likely to feel that professionals treated them respectfully (63% vs. 88%), less likely to trust professionals (57% vs. 87%) and more likely to feel negatively judged by professionals (54% vs. 26%).

The autistic group were significantly less likely to have received as much information as they would have liked during prenatal appointments (56% vs. 80%) and were significantly less likely to be satisfied with the way in which information was presented to them during prenatal appointments (61% vs. 85%).

When asked to describe what additional information they would have liked, both groups responded that they would have liked more information about pregnancy conditions, what each prenatal appointment would involve, the meaning of test results as well as the risks involved and reasons behind interventions. Both groups would have liked more information about birth options, what to expect during the birth, physical recovery after giving birth, how to care for a baby, breastfeeding and prenatal and postnatal mental health. When asked to describe in what format they would prefer to receive information, both groups felt they would have benefitted from more online information, more information in video format, more detailed explanations and more statistical information. The autistic group frequently commented that they would prefer written information due to difficulty processing verbal information, including written summaries of what had occurred during appointments.

The autistic group were significantly less likely than the non-autistic group to report that they knew when to seek help with pregnancy concerns (67% vs. 89%). The groups did not significantly differ on whether or not they had someone to advocate for them during prenatal appointments. Among those who reported having an advocate, the autistic group were significantly more likely than the non-autistic group to feel that this was helpful (85% vs. 67%). Similarly, among those who reported not having an advocate, the autistic group were significantly more likely than the non-autistic group to feel that having someone to advocate for them would have been helpful (53% vs. 18%).

The autistic group were significantly less likely than the non-autistic group to report being satisfied with the healthcare they received during pregnancy (70% vs. 91%). Participants were asked to describe which aspects of their healthcare they were not satisfied with. While

participants in both groups felt that they had not received continuity of care, often seeing many different professionals throughout their pregnancy, this concern arose more commonly for the autistic group, *‘there are quite a lot of facts that need to be laid out to explain how autism might affect me, it's really, really hard to have to go over those issues time and again with different health professionals’*.

Both groups additionally felt that their concerns had not been taken seriously and that professionals had taken a dismissive, and at times judgemental, attitude. While this was a concern for participants in both groups, these feelings were expressed more commonly among the autistic group, *‘Not listening to what I say and instead going by other professionals written word over my knowledge of me’*. Additionally, the autistic group often felt uninvolved in decision making about their healthcare, with some participants feeling pressured into making certain decisions. Other participants reported that procedures were performed without their consent and without adequate explanation.

Participants were also asked to describe what they had liked about the healthcare they received. Both groups emphasised the importance of continuity of care and valued qualities such as being knowledgeable, competent, warm, kind and caring among the professionals they saw. Participants also valued feeling listened to and feeling that their choices were respected. Both groups had appreciated frequent, longer appointments and the opportunity to ask questions.

Table 3.10 Prenatal healthcare.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value	p-value (FDR adjusted)
Overwhelmed by sensory environment ^a			92.59 (56.82-149.70)	<0.001	-
N	523	417			
Agree	71 (14%)	318 (76%)			
Disagree	425 (81%)	84 (20%)			
Don't know	4 (1%)	7 (2%)			
Not applicable	23 (4%)	8 (2%)			
Number of midwives seen ^b			(rate ratio) (1.09 -1.35)	1.21 <0.001	0.001
N	516	408			
0	59 (11%)	63 (15%)			

1	95 (18%)	63 (15%)			
2	110 (21%)	81 (20%)			
3	91 (18%)	56 (14%)			
4 or more	161 (31%)	145 (36%)			
Important to see the same midwife at each appointment ^a			6.33 (3.57 - 11.21)	<0.001	-
N	516	414			
Agree	349 (68%)	320 (77%)			
Disagree	112 (22%)	25 (6%)			
Don't know	9 (2%)	17 (4%)			
Not applicable	46 (9%)	52 (13%)			
Stressful when health professional saw was not the one expecting to see ^a			17.64 (10.64 - 29.24)	<0.001	-
N	520	417			
Agree	194 (37%)	285 (68%)			
Disagree	217 (42%)	43 (10%)			
Don't know	4 (1%)	11 (3%)			
Not applicable	105 (20%)	78 (19%)			
Being informed of which health professional will see in advance of appointment would be helpful ^a			13.35 (7.30 - 24.45)	<0.001	-
N	520	416			
Agree	308 (59%)	358 (86%)			
Disagree	122 (23%)	20 (5%)			
Don't know	12 (2%)	13 (3%)			
Not applicable	78 (15%)	25 (6%)			
Professionals took my questions and concerns seriously			0.13 (0.08 - 0.20)	<0.001	-
N	511	409			
Agree	429 (84%)	225 (55%)			
Disagree	79 (15%)	176 (43%)			
Don't know	0 (0%)	3 (1%)			
Not applicable	3 (1%)	5 (1%)			
I felt comfortable asking questions to professionals			0.07 (0.05 - 0.12)	<0.001	-
N	509	408			
Agree	456 (90%)	231 (57%)			
Disagree	52 (10%)	172 (42%)			

Don't know	0 (0%)	4 (1%)			
Not applicable	1 (0.20%)	1 (0.25%)			
Professionals have treated me respectfully			0.13 (0.08 - 0.21)	<0.001	-
N	511	408			
Agree	451 (88%)	257 (63%)			
Disagree	59 (12%)	148 (36%)			
Don't know	0 (0%)	1 (0.25%)			
Not applicable	1 (0.20%)	2 (0.49%)			
I have felt negatively judged by professionals ^a			6.71 (4.42 -10.20)	<0.001	-
N	511	408			
Agree	132 (26%)	221 (54%)			
Disagree	363 (71%)	165 (40%)			
Don't know	3 (1%)	10 (2%)			
Not applicable	13 (3%)	12 (3%)			
I have felt able to trust professionals			0.11 (0.07 - 0.18)	<0.001	-
N	511	408			
Agree	442 (87%)	234 (57%)			
Disagree	68 (13%)	168 (41%)			
Don't know	1 (0.20%)	4 (1%)			
Not applicable	0 (0%)	2 (0.49%)			
Received as much information as would have liked			0.22 (0.14 - 0.33)	<0.001	-
N	519	414			
Agree	414 (80%)	233 (56%)			
Disagree	102 (20%)	173 (42%)			
Don't know	2 (0.39%)	4 (1%)			
Not applicable	1 (0.19%)	4 (1%)			
Satisfied with way information presented			0.17 (0.11 - 0.27)	<0.001	-
N	516	411			
Agree	439 (85%)	251 (61%)			
Disagree	72 (14%)	146 (36%)			
Don't know	2 (0.39%)	10 (2%)			
Not applicable	3 (1%)	4 (1%)			
Known when to seek help with pregnancy concerns			0.14 (0.09 - 0.23)	<0.001	-
N	510	407			
Agree	454 (89%)	272 (67%)			

Disagree	48 (9%)	120 (29%)			
Don't know	3 (1%)	6 (1%)			
Not applicable	5 (1%)	9 (2%)			
Had advocate during appointments ^c			0.79 (0.60 - 1.05)	0.10	0.15
N	511	409			
Yes	292 (57%)	208 (51%)			
No	219 (43%)	201 (49%)			
Advocate during appointments was helpful ^c			3.15 (1.74 - 5.96)	<0.001	0.001
N	288	204			
Agree	193 (67%)	174 (85%)			
Disagree	58 (20%)	16 (8%)			
Don't know	8 (3%)	5 (2%)			
Not applicable	29 (10%)	9 (4%)			
Advocate during appointments would have been helpful ^c			7.13 (4.29 - 12.11)	<0.001	<0.001
N	222	200			
Agree	40 (18%)	106 (53%)			
Disagree	129 (58%)	44 (22%)			
Don't know	10 (5%)	18 (9%)			
Not applicable	43 (19%)	32 (16%)			
Satisfaction with healthcare received during pregnancy			0.14 (0.08 - 0.23)	<0.001	-
N	510	403			
Satisfied	466 (91%)	281 (70%)			
Dissatisfied	43 (8%)	114 (28%)			
Don't know	1 (0.20%)	3 (1%)			
Not applicable	0 (0%)	5 (1%)			

Note. Multivariate binary logistic regression performed

^aItem reverse scored prior to multivariate analysis. Inverse of aOR and CIs presented

^bNegative binomial regression performed

^cItem not included within multivariate analysis due to survey logic

Experiences with antenatal classes.

The groups did not significantly differ with regard to whether or not they had attended antenatal classes (62% of the non-autistic group and 63% of the autistic group reported attending; Table 3.11). The autistic group were more likely to find it difficult to attend antenatal classes (56% vs. 14%). For the six questions about difficulties with antenatal classes,

a multivariate binary logistic regression was performed. A model including group as a predictor was a better fit than the model without group, $\chi^2(6) = 57.34$, $p < 0.001$. The autistic group were significantly more likely than the non-autistic group to agree that the size of the group at antenatal classes is too large (72% vs. 30%), that antenatal classes are too noisy (64% vs. 19%), that there is too much pressure to socialise at antenatal classes (87% vs. 54%), that information at antenatal classes is presented too quickly (41% vs. 18%) and that the content of antenatal classes can be distressing (31% vs. 15%). The groups did not significantly differ in their tendency to feel that the content of antenatal classes was not useful to them, with the minority of both groups (45% of the autistic group and 31% of the non-autistic group) reporting that classes were not useful.

Those who had not attended classes were asked to describe why they had not attended. Participants in both groups often responded that classes were not available to them or that classes were not necessary due to having had previous pregnancies. The autistic group additionally mentioned that the social aspects of antenatal classes were a barrier to attending, *'I didn't want to face the anxiety of a social situation like a class, and preferred to independently research anything I wanted to know'*.

Table 3.11 Antenatal classes.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value	p-value (FDR adjusted)
Attended antenatal classes ^a			1.22 (0.91 - 1.63)	0.18	0.25
N	524	416			
Yes	326 (62%)	264 (63%)			
No	198 (38%)	152 (37%)			
Difficult to attend antenatal classes ^a			9.98 (6.89 - 14.39)	<0.001	<0.001
N	523	415			
Agree	74 (14%)	234 (56%)			
Disagree	306 (59%)	100 (24%)			
Don't know	16 (3%)	20 (5%)			
Not applicable	127 (24%)	61 (15%)			
Size of group too large			9.56 (4.15 - 22.00)	<0.001	-
N	74	233			
Agree	22 (30%)	168 (72%)			
Disagree	32 (43%)	36 (15%)			
Don't know	11 (15%)	24 (10%)			
Not applicable	9 (12%)	5 (15%)			
Too noisy			10.90 (4.51 - 26.20)	<0.001	-
N	74	232			
Agree	14 (19%)	148 (64%)			
Disagree	37 (50%)	55 (24%)			
Don't know	13 (18%)	24 (10%)			
Not applicable	10 (14%)	5 (2%)			
Too much pressure to socialise			6.29 (2.52 - 15.70)	<0.001	-
N	74	233			
Agree	40 (54%)	202 (87%)			
Disagree	17 (23%)	16 (7%)			
Don't know	10 (14%)	12 (5%)			
Not applicable	7 (9%)	3 (1%)			
Information presented too quickly			3.34 (1.40 - 7.99)	0.01	-
N	74	232			
Agree	13 (18%)	96 (41%)			
Disagree	39 (53%)	101 (44%)			
Don't know	13 (18%)	28 (12%)			

Not applicable	9 (12%)	7 (3%)			
Content is distressing			2.48 (1.00 - 6.12)	0.049	-
N	74	232			
Agree	11 (15%)	722 (31%)			
Disagree	42 (57%)	122 (53%)			
Don't know	12 (16%)	24 (10%)			
Not applicable	9 (12%)	14 (6%)			
Content is not helpful			1.58 (0.72 - 3.45)	0.25	-
N	74	231			
Agree	23 (31%)	103 (45%)			
Disagree	33 (45%)	95 (41%)			
Don't know	11 (15%)	25 (11%)			
Not applicable	7 (9%)	8 (3%)			

Note. Multivariate binary logistic regression performed

^aItem not included within multivariate analysis due to survey logic

3.4.1.3 Support during pregnancy.

For questions concerning support from partners, friends and family, a multivariate binary logistic regression was performed. A model including group as a predictor was a better fit than the model without group, $\chi^2(3) = 106$, $p < 0.001$, (Table 3.12). The autistic group were significantly less likely to agree that they had received all the support they needed from their partner/spouse (62% vs. 80%), family (50% vs. 77%) and friends (51% vs. 85%). The majority of the autistic group (95%) reported that they had not received peer support from other autistic pregnant people or parents. Of those who did receive peer support, 100% of those who responded indicated that they found this support helpful. Of those who did not receive peer support, 59% of those who responded would have found such support helpful.

Participants were asked to describe what support would be helpful for pregnant people. Both groups felt that more practical help with domestic tasks would be been valuable as well as more support surrounding mental health during pregnancy. Both groups felt that more peer support from other parents would be helpful, such as support groups, online groups and mentoring. The autistic group often felt that peer support from other autistic parents would be beneficial, *'talking to other women who have the experience would have been so helpful'*. The autistic group also frequently commented that having the support of an advocate with awareness and understanding of autism such as a doula or specialist midwife would be valuable.

Table 3.12 Support received during pregnancy.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value
I have received all the support I need from:				
Partner/Spouse			0.30 (0.19 - 0.48)	<0.001
N	490	391		
Agree	390 (80%)	242 (62%)		
Disagree	90 (18%)	135 (35%)		
Don't know	1 (0.20%)	3 (1%)		
Not applicable	9 (2%)	11 (3%)		
Family			0.17 (0.11 - 0.27)	<0.001
N	490	389		
Agree	379 (77%)	196 (50%)		
Disagree	94 (19%)	171 (44%)		
Don't know	0 (0%)	3 (1%)		
Not applicable	17 (3%)	19 (5%)		
Friends			0.12 (0.07 - 0.20)	<0.001
N	490	390		
Agree	415 (85%)	198 (51%)		
Disagree	56 (11%)	134 (34%)		
Don't know	1 (0.20%)	8 (2%)		
Not applicable	18 (4%)	50 (13%)		
I had peer support from other autistic pregnant people/parents				
N	-	383	-	-
Yes	-	21 (5%)	-	-
No	-	362 (95%)	-	-
I found peer support helpful				
N	-	20	-	-
Agree	-	20 (100%)	-	-
Disagree	-	0 (0%)	-	-
Don't know	-	0 (0%)	-	-
Not applicable	-	0 (0%)	-	-
I would have found peer support helpful				
N	-	355	-	-
Agree	-	208 (59%)	-	-
Disagree	-	27 (8%)	-	-
Don't know	-	56 (16%)	-	-
Not applicable	-	64 (18%)	-	-

Note. Multivariate binary logistic regression performed

3.4.2 Childbirth

3.4.2.1 Birth outcomes: delivery type and gestational age.

No significant group differences were found for delivery type nor gestational age at birth (Table 3.13).

Table 3.13 Delivery type and gestational age.

	Non-autistic group (n=492)	Autistic group (n=384)	aOR (95% CI)	p-value	p-value (FDR adjusted)
Delivery type: ^a					
Vaginal	309 (63%)	249 (65%)	0.96 (0.71 - 1.30)	0.80	0.90
Assisted vaginal	52 (11%)	34 (9%)	0.99 (0.61 - 1.59)	0.95	0.95
Planned caesarean	52 (11%)	42 (11%)	1.12 (0.71 - 1.76)	0.62	0.79
Emergency caesarean	79 (16%)	59 (15%)	1.01 (0.68 - 1.50)	0.95	0.95
Induced	108 (22%)	94 (24%)	1.11 (0.80 - 1.56)	0.52	0.78
	Non-autistic group (n= 492)	Autistic group (n=384)	B (SE)	p-value	p-value (FDR adjusted)
Mean gestational age at birth (days)(SD) ^b	276 (17.80)	275 (15.10)	0.64 (1.14)	0.57	0.79

^aBinary logistic regressions performed

^bMultiple linear regression performed

3.4.2.2 Childbirth experiences.

For questions concerning birth experiences, a multivariate binary logistic regression was performed. A model including group as a covariate was a better fit than the model without group, $\chi^2(9) = 253.24$, $p < 0.001$, indicating that the groups significantly differed.

The autistic group were significantly more likely to feel overwhelmed by sensory input during the birth (66% vs. 29%; Table 3.14). When asked to describe what they found overwhelming, both groups mentioned bright lights, the noisy hospital environment, beeping machines, many different medical professionals being present, smells and heat. Both groups mentioned finding being touched by many different professionals overwhelming, though this was

discussed more frequently by the autistic group who often felt that they were touched without adequate warning or explanation. The autistic group additionally mentioned that the overwhelming sensory environment interacted with their experience of the social aspects of birth. Some felt that the sensory environment made processing social interactions more challenging, *'the light and noise made it difficult to filter important information'*, others mentioned that the social demands of birth made coping with the sensory environment more difficult, *'This kind of social distraction heightens the sensory stimuli for me because it takes up processing power'*.

There was no significant group difference in having access to sensory items (such as a weighted blanket, scented oil, fidget toys etc.) during the birth. However, for those who did have access to sensory items, the autistic group were significantly more likely to feel that these items were helpful (92% vs. 68%), though this difference did not remain significant after correcting for multiple comparisons. For those who did not have access to sensory items, the autistic group were significantly more likely to feel that these items would have been helpful (50% vs. 17%). When asked what items would have been helpful, both groups responded in their open-text response that they felt that essential oils, music, soft lights, soft blankets, a weighted blanket and a stress ball or other squeezable item would be helpful. The autistic group additionally felt that ear plugs would have been helpful.

The autistic group were significantly less likely to agree that they felt aware of their body's signals and how to correctly interpret them during the labour/birth (51% vs. 65%). The autistic group were also significantly more likely than the non-autistic group to have experienced a meltdown (29% vs. 17%) and significantly more likely to have experienced a shutdown (38% vs. 8%). When asked to describe the cause of their meltdown or shutdown, both groups identified pain, exhaustion, fear and sensory overload. Both groups mentioned not feeling listened to, though this was particularly emphasised by the autistic group who often felt that their wishes were not respected, *'I tried communicating my needs but when they weren't heard I felt unable to talk about that subject or express my feelings adequately.'* The autistic group additionally mentioned being asked many questions, many people being present and being touched as reasons for a meltdown.

The autistic group were significantly less likely than the non-autistic group to agree that professionals responded to their meltdown in the way they would have liked (31% vs. 59%),

however the group difference for the same question was not significant for shutdowns (34% vs. 50%). When asked to describe how they would have liked medical professionals to respond, both groups often commented that professionals had not noticed their meltdown or shutdown, *'They did not even notice the shutdown, they just kept handling/moving my body and being very proud of themselves. It was my doula who noticed that I am out, that I have a blank stare and have stopped communicating'* (autistic participant). Both groups felt that they would have liked professionals to respond with compassion, understanding and a calm, reassuring attitude.

The autistic group particularly highlighted a need for more understanding of shutdowns, *'When I was crying/shouting they seemed to understand what I was feeling, but most of the time I was shut down and silent and they didn't seem to understand that it was a shutdown and that I wasn't able to focus on anything in the room or understand anything being asked of me'*. Some highlighted that shutdowns could be misinterpreted by professionals, *'They thought I didn't want the baby. They acted as if I was cold and distant. I recall the nurse saying, "here, daddy will love you instead." I did want to hold the baby, but I needed time to shut my systems back on'*.

The autistic group emphasised the need to be given time to respond during meltdowns and shutdowns, such as, *'waiting for verbal answers and/or repeating the question or statement until they knew I understood'*. This group often felt that not being given adequate opportunity to communicate during shutdowns could be a barrier to giving informed consent, *'I would have liked to have been given adequate time to respond to their requests rather than being forced into their desired positions/actions'*.

Regarding relationships with professionals, the autistic group were significantly less likely to agree that they were kept adequately informed by professionals of what was happening (54% vs. 74%), less likely to agree that professionals listened to their requests (57% vs. 75%), less likely to agree professionals had an accurate understanding of what they were perceiving physically (39% vs. 73%) and more likely to agree that they felt pressure to behave in a socially normative way during the birth (64% vs. 35%).

When asked to describe how they could have been better kept informed, both groups would have liked more frequent updates, more frequent checks and clearer explanations of what

was happening and why. Both groups felt they would have benefitted from receiving information from one person rather than many different professionals. Some participants in the autistic group would have preferred written information and participants in this group also highlighted that they would have benefitted from more time to process what was being said to them.

The groups did not significantly differ on whether or not they made a birth plan, though the autistic group were significantly less likely to agree that medical professionals took their birth plan into account (52% vs. 65%). The groups did not differ on whether or not they had someone to advocate for them during the birth (70% of the autistic group and 75% of the non-autistic group did). For those who had an advocate, the groups did not differ in their tendency to agree that having an advocate was helpful (82% of the autistic group and 87% of the non-autistic group agreed). For those who did not have an advocate, the autistic group were significantly more likely to agree that having an advocate would have been helpful (64% vs. 33%). The autistic group were also significantly less likely to feel satisfied with the medical care they received during childbirth (71% vs. 86%).

When asked whether professionals had a good understanding of how being autistic affected them during the birth, the majority (64%) of autistic participants felt that this questions was not applicable to them (possibly due to not being diagnosed at the time). 21% disagreed and 2% agreed that professionals had a good understanding of how autism affected them. When asked what they would have liked professionals to understand about how autism affected them during the birth, participants mentioned the need for clear communication, *'During labour I am not able to talk in full long sentences, I am even worse than usual at interpreting vague hints, so I needed short, clear info'*. They also mentioned feeling the pressure of social expectations during the birth, *'I needed to not have to worry about other people's needs - social expectations etc.'*

Participants wanted professionals to understand that they may express pain differently from non-autistic patients, *'My outward appearance of whether I am in pain or not does not generally reflect my inner experience'*. They wanted professionals not to dismiss their concerns even if what they reported experiencing seemed atypical, *'they treated me as 'a bit weird' and a nuisance and didn't listen to my concerns which ended up with me starting to*

give birth on the patient corridor floor.' Some participants felt acutely aware of their bodily signals, *'I wanted them to understand that as weird as it may seem to them, I acutely know my body. I can feel when things are wrong'*. Others found interpreting bodily signals more challenging, *'I am not always fully aware of how my body is feeling. Asking me things like "do you need to push" can be confusing.'* Participants also wanted professionals to understand the importance of sensory issues and that physical touch can be distressing, *'I did not appreciate my body being touched or moved without warning. My legs being pulled up without warning gave me a panic attack (sent me into a meltdown)'*.

Table 3.14 Childbirth experiences.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value	p-value (FDR adjusted)
Overwhelmed by sensory input ^a			9.17 (6.17 - 13.70)	<0.001	-
N	491	383			
Agree	141 (29%)	251 (66%)			
Disagree	321 (65%)	105 (27%)			
Don't know	4 (1%)	8 (2%)			
Not applicable	25 (5%)	19 (5%)			
Had access to sensory items ^b			1.07 (0.69 - 1.66)	0.76	0.90
N	490	381			
Yes	68 (14%)	49 (13%)			
No	422 (86%)	332 (87%)			
Access to sensory items was helpful ^b			7.26 (1.38 - 59.92)	0.03	0.09
N	68	48			
Agree	46 (68%)	44 (92%)			
Disagree	11 (16%)	3 (6%)			
Don't know	2 (3%)	0 (0%)			
Not applicable	9 (13%)	1 (2%)			
Access to sensory items would have been helpful ^b			9.57 (6.20 - 15.04)	<0.001	<0.001
N	420	331			
Agree	71 (17%)	167 (50%)			
Disagree	225 (54%)	53 (16%)			
Don't know	66 (16%)	86 (26%)			
Not applicable	58 (14%)	25 (8%)			

Aware of body's signals and how to interpret them			0.45 (0.30 - 0.68)	<0.001	-
N	483	375			
Agree	315 (65%)	193 (51%)			
Disagree	110 (23%)	129 (34%)			
Don't know	3 (1%)	16 (4)			
Not applicable	55 (11%)	37 (10%)			
Experienced a meltdown during the birth ^a			2.44 (1.61 - 3.69)	<0.001	-
N	485	372			
Yes	81 (17%)	109 (29%)			
No	404 (83%)	263 (71%)			
Experienced a shutdown during the birth ^a			11.14 (6.94 - 17.83)	<0.001	-
N	485	373			
Yes	39 (8%)	142 (38%)			
No	446 (92%)	231 (62%)			
Professionals responded to the meltdown in the way I would have liked ^b			0.39 (0.19 - 0.76)	0.01	0.02
N	80	108			
Agree	47 (59%)	34 (31%)			
Disagree	26 (33%)	55 (51%)			
Don't know	6 (8%)	8 (7%)			
Not applicable	1 (1%)	11 (10%)			
Professionals responded to the shutdown in the way I would have liked ^b			0.53 (0.21 - 1.28)	0.16	0.29
N	38	141			
Agree	19 (50%)	48 (34%)			
Disagree	13 (34%)	65 (46%)			
Don't know	5 (13%)	15 (11%)			
Not applicable	1 (3%)	13 (9%)			
Kept informed by professionals of what was happening			0.31 (0.21 - 0.46)	<0.001	-
N	488	377			
Agree	360 (74%)	205 (54%)			
Disagree	108 (22%)	155 (41%)			

Don't know	3 (1%)	7 (2%)			
Not applicable	17 (3%)	10 (3%)			
Professionals listened to my requests			0.27 (0.18 - 0.41)	<0.001	-
N	485	376			
Agree	365 (75%)	214 (57%)			
Disagree	82 (17%)	139 (37%)			
Don't know	9 (2%)	7 (2%)			
Not applicable	29 (6%)	10 (4%)			
Professionals had an accurate understanding of what I was perceiving physically			0.14 (0.09 - 0.21)	<0.001	-
N	487	376			
Agree	355 (73%)	149 (39%)			
Disagree	97 (20%)	185 (49%)			
Don't know	7 (1%)	16 (4%)			
Not applicable	28 (6%)	26 (7%)			
I felt pressure to behave in a socially normative way ^a			5.85 (3.92 - 8.77)	<0.001	-
N	484	375			
Agree	168 (35%)	240 (64%)			
Disagree	266 (55%)	98 (26%)			
Don't know	14 (2%)	21 (6%)			
Not applicable	36 (7%)	16 (4%)			
Made a birth plan ^b			1.27 (0.93 - 1.72)	0.13	0.26
N	484	376			
Yes	293 (61%)	239 (64%)			
No	191 (39%)	137 (36%)			
Professionals took birth plan into account ^b			0.49 (0.32 - 0.73)	<0.001	0.001
N	293	238			
Agree	190 (65%)	124 (52%)			
Disagree	71 (24%)	90 (38%)			
Don't know	7 (2%)	8 (3%)			
Not applicable	25 (9%)	16 (7%)			
I had someone to advocate for me ^b			0.83 (0.61 - 1.15)	0.26	0.42
N	484	374			
Yes	363 (75%)	263 (70%)			
No	121 (25%)	111 (30%)			

Having an advocate was helpful ^b			0.62 (0.35 - 1.07)	0.09	0.19
N	363	263			
Agree	316 (87%)	216 (82%)			
Disagree	30 (8%)	36 (14%)			
Don't know	6 (2%)	8 (3%)			
Not applicable	11 (3%)	3 (1%)			
Having an advocate would have been helpful ^b			8.02 (3.71 - 18.57)	<0.001	<0.001
N	121	110			
Agree	40 (33%)	70 (64%)			
Disagree	58 (48%)	13 (12%)			
Don't know	6 (5%)	14 (13%)			
Not applicable	17 (14%)	13 (12%)			
Satisfaction with medical care received			0.32 (0.21 - 0.50)	<0.001	-
N	480	370			
Satisfied	414 (86%)	262 (71%)			
Dissatisfied	64 (13%)	104 (28%)			
Don't know	2 (0.42%)	4 (1%)			
Not applicable	0 (0%)	0 (0%)			
Professionals had a good understanding of how autism affected me during the birth ^b					
N	-	377	-	-	-
Agree	-	9 (2%)	-	-	-
Disagree	-	79 (21%)	-	-	-
Don't know	-	47 (12%)	-	-	-
Not applicable	-	242 (64%)	-	-	-

Note. Multivariate binary logistic regression performed

^aItem reverse scored prior to multivariate analysis. Inverse of aOR and CIs presented

^bItem not included within multivariate analysis due to survey logic

3.4.2.3 Postnatal hospital stay.

For questions concerning postnatal hospital stay experiences, a multivariate binary logistic regression was performed. A model including group as a predictor was a better fit than the model without group, $\chi^2(2) = 71.96$, $p < 0.001$. Of those who indicated that they stayed on a shared postnatal ward at the hospital, the autistic group were significantly more likely to

agree that they found being on a shared postnatal ward overwhelming in terms of sensory input (88% vs. 61%; Table 3.15). The autistic group were significantly less likely to feel satisfied with the services they received during their postnatal stay (52% vs. 69%). When asked to comment on their postnatal stay, both groups highlighted that the environment was busy and noisy and that they struggled to sleep. They also felt that staff were over-stretched and that they were consequently often left alone without assistance, not given sufficient advice and discharged before feeling ready.

Table 3.15 Postnatal hospital stay.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value
Shared postnatal ward overwhelming ^a			6.99 (3.75 - 12.99)	<0.001
N	280	193		
Agree	172 (61%)	169 (88%)		
Disagree	101 (36%)	22 (11%)		
Don't know	2 (1%)	0 (0%)		
Not applicable	5 (1%)	2 (1%)		
Satisfaction with services during postnatal stay			0.30 (0.20 - 0.46)	<0.001
N	476	368		
Satisfied	327 (69%)	192 (52%)		
Dissatisfied	105 (22%)	138 (38%)		
Don't know	0 (0%)	4 (1%)		

Note. Multivariate binary logistic regression performed

^aItem reverse scored prior to multivariate analysis. Inverse of aOR and CIs presented

3.4.3 Postnatal experiences

3.4.3.1 Postnatal physical and mental health.

Questions about postnatal physical symptoms were explored with multivariate binary logistic regression (these questions were strongly correlated, $r=0.67$, $p<0.001$). A model including group as a covariate was a better fit than the model without group, $\chi^2(2)= 74.49$, $p<0.001$. The autistic group were significantly less likely to have felt prepared to cope with physical postnatal symptoms after giving birth (56% vs. 73%; Table 3.16) and were significantly less likely to have known when to seek help with physical postnatal symptoms (59% vs. 83%).

Individual binary logistic regressions revealed that the autistic group were significantly more likely to have been told by a medical or health professional that they had postnatal depression (30% vs. 12%) and postnatal anxiety (19% vs. 7%). When asked if they would like to comment on their physical or psychological wellbeing after giving birth, some participants in both groups commented that they thought they had experienced postnatal depression or anxiety but had not disclosed this to a health professional. While some participants who had sought help felt that they received adequate support, others felt that their concerns were dismissed, *'My GP told me I did not have depression or anxiety following my last birth, that it was a common feeling. I was dismissed'* (autistic participant). Participants in the autistic group described having masked the fact that they were struggling, *'I hid my postnatal depression and anxiety very well, masking is almost a reflex really'*. Some autistic participants worried that if they did not mask, their child may be taken away from them, *'It's easy to cheat the tests they do with questionnaires. I was so worried they would take my son away that I made the form look like I was fine'*.

Table 3.16 Postnatal physical and mental health.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value	p-value (adjusted)
Felt prepared to cope with physical postnatal symptoms			0.22 (0.12 - 0.38)	<0.001	-
N	446	362			
Agree	324 (73%)	201 (56%)			
Disagree	118 (26%)	157 (43%)			
Don't know	0 (0%)	2 (1%)			
Not applicable	4 (1%)	2 (1%)			
Known when to seek help with physical postnatal symptoms			0.11 (0.06 - 0.20)	<0.001	-
N	446	362			
Agree	370 (83%)	215 (59%)			
Disagree	66 (15%)	135 (37%)			
Don't know	2 (0.45%)	9 (2%)			
Not applicable	8 (2%)	3 (1%)			
Postnatal depression ^a			3.19 (2.19 - 4.70)	<0.001	<0.001
N	446	360			
Yes	55 (12%)	108 (30%)			
No	391 (88%)	252 (70%)			
Postnatal anxiety ^a			2.89 (1.80 - 4.72)	<0.001	<0.001
N	445	361			
Yes	32 (7%)	69 (19%)			
No	413 (93%)	292 (81%)			

Note. Multivariate binary logistic regression performed

^aItem not included within multivariate analysis

3.4.3.2 Breastfeeding experiences.

For questions concerning breastfeeding, a multivariate binary logistic regression was performed. A model including group as a predictor was a better fit than the model without group, $\chi^2(3) = 23.79$, $p < 0.001$. The groups did not significantly differ on whether or not they breastfed or attempted to breastfeed their baby (94% of the autistic group and 92% of the non-autistic group breastfed or attempted to breastfeed their baby; Table 3.17). Among those who had breastfed or attempted to breastfeed, the groups did not significantly differ on the likelihood of having had difficulties breastfeeding (60% of the autistic group and 57% of the non-autistic group). Among those who had experienced difficulties breastfeeding, the autistic group were significantly more likely to have had difficulties due to sensory issues (46% vs. 10%). When asked to describe why they had experienced difficulties with breastfeeding, both

groups commented on issues such as pain, low milk supply, cracked nipples, mastitis, thrush, tongue tie, difficulty latching and having a premature baby. The autistic group additionally often mentioned finding breastfeeding difficult due to sensory issues, including feeling touched out, *'I find it very physically overwhelming'*.

Among those who breastfed or attempted to breastfeed, the autistic group were significantly less likely to agree that they had found it easy to access support (48% vs. 60%) and were significantly less likely to be satisfied with the support they received (48% vs. 57%). When asked to describe what support they would have found helpful, both groups would have appreciated more acceptance and understanding of the choice not to breastfeed. They also felt that ongoing support (rather than one-off sessions), video-based demonstrations, peer support from other mothers, more home visits and more help with latching on would have been helpful. While both groups felt that support groups had been beneficial, participants in the autistic group often mentioned finding group-based support challenging, *'I also don't want to go to a "support group" setting and meet people. I'm really not a huge people person, I can if I have to but, right after giving birth, it would've overloaded everything in my head'*.

Table 3.17 Breastfeeding experiences.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value	p-value (FDR adjusted)
Breastfed or attempted to breastfeed ^a			1.40 (0.79 - 2.56)	0.26	0.28
N	448	367			
Yes	410 (92%)	346 (94%)			
No	38 (8%)	21 (6%)			
Had difficulties breastfeeding ^b			1.45 (0.87 - 2.40)	0.16	-
N	410	346			
Agree	234 (57%)	209 (60%)			
Disagree	173 (42%)	135 (39%)			
Don't know	1 (0.24%)	1 (0.29%)			
Not applicable	2 (0.49%)	1 (0.29%)			
Had difficulties breastfeeding due to sensory issues ^a			7.57 (4.50 - 13.16)	<0.001	<0.001
N	234	209			
Agree	24 (10%)	97 (46%)			
Disagree	194 (83%)	98 (47%)			
Don't know	4 (2%)	6 (3%)			
Not applicable	12 (5%)	8 (4%)			
Found it easy to access breastfeeding support			0.31 (0.18 - 0.53)	<0.001	-
N	410	345			
Agree	247 (60%)	164 (48%)			
Disagree	120 (29%)	141 (41%)			
Don't know	5 (1%)	9 (3%)			
Not applicable	38 (9%)	31 (9%)			
Satisfaction with breastfeeding support			0.38 (0.22 - 0.65)	0.001	-
N	409	346			
Satisfied	232 (57%)	165 (48%)			
Dissatisfied	118 (29%)	132 (38%)			
Don't know	8 (2%)	9 (3%)			
Not applicable	51 (12%)	40 (12%)			

Note. Multivariate binary logistic regression performed

^aItem not included within multivariate analysis due to survey logic

^bItem reverse scored prior to multivariate analysis. Inverse of aOR and CIs presented

3.4.3.3 Postnatal appointments.

Autism disclosure, adjustments and autism understanding.

When asked whether they had disclosed their autism during postnatal appointments, the majority (67% for midwife, 66% for health visitor and 62% for doctor) of autistic participants felt that the question was not applicable (Table 3.18). Of those who felt the question was applicable to them, the majority had not disclosed. 26% did not disclose to their midwife (compared with 7% who disclosed), 26% did not disclose to their health visitor (compared with 8% who disclosed) and 27% did not disclose to their doctor/GP (compared with 11% who disclosed). When asked what had influenced their decision whether or not to disclose, many responded that they were not diagnosed at the time. Those who did not disclose often described fear that disclosure would lead to discrimination, *'I would never disclose for fear of discrimination. I'll tell a perfect stranger before I'll tell a doctor or a nurse, because I want to be believed'*. Some participants feared that their child may be taken away if they disclosed, *'primarily fear - that I would be deemed inadequate or have my child removed'*. Those who did disclose most commonly gave wanting to receive more support and accommodations as the reason for disclosure.

Of those who had disclosed, 34% indicated that adjustments were made for them after disclosure. These adjustments included home visits, longer appointments, accommodating sensory issues and giving information in a visual format. Among those who had disclosed, 46% agreed that there were adjustments they would have liked but that were not offered to them. When asked to describe what adjustments would have been helpful, participants mentioned home visits, longer appointments, dimming the lights in appointments, giving written information, and being able to book appointments through another method than telephone.

When asked whether health professionals they have seen during postnatal appointments have had a good understanding of how being autistic affects them, most participants indicated that the question was not applicable. Only a small minority of autistic participants agreed that their midwife, health visitor or doctor/GP had a good understanding of autism (7%, 6% and 9% respectively). Participants were asked what they would like professionals to understand about how autism affects them in relation to postnatal appointments. Many reported that they would like professionals to understand that they need more time to process information as well as the opportunity to ask questions outside of the appointment.

Participants also expressed that they require more detailed information and explanations, *'I need them to try to keep their promises or inform me of changes - as to who I am going to see, at what time they are going to come, that I would appreciate a rundown of what they are planning to do - what physical checks on me or the baby'*. Participants also commented that they would like professionals to appreciate that they may need support to understand whether what they are experiencing is typical, for example, *'how to tell if my pain is abnormal'* and, *'I don't have a good handle on "what's normal" and so I often will drastically underreport so that I don't get flagged as "weird".'*

Table 3.18 Autism disclosure, adjustments and autism understanding at postnatal appointments.

	N	Yes	No	Not applicable	
Disclosed autism to:					
Midwife	359	25 (7%)	92 (26%)	242 (67%)	
Health visitor	359	29 (8%)	94 (26%)	236 (66%)	
Doctor/GP	361	40 (11%)	97 (27%)	224 (62%)	
Adjustments offered	50	17 (34%)	33 (66%)	-	
Adjustments desired that were not offered	50	23 (46%)	27 (54%)	-	
	N	Agree	Disagree	Don't know	Not applicable
Health professionals have had a good understanding of how being autistic affects me:					
Midwife	357	25 (7%)	33 (9%)	39 (12%)	260 (73%)
Health visitor	355	22 (6%)	39 (11%)	42 (12%)	252 (71%)
Doctor/GP	358	31(9%)	51 (14%)	47 (13%)	229 (64%)

Attending postnatal appointments

For questions concerning attending postnatal appointments, a multivariate binary logistic regression was performed. A model including group as a covariate was a better fit than the model without group, $\chi^2(4) = 14.11$, $p = 0.01$. However, individual analyses of each appointment type revealed no significant group differences (Table 3.19). Those who did not attend all of their appointments were asked to describe why. Both groups identified practical barriers to attending such as transport issues, childcare and exhaustion in addition to feeling that appointments were not useful due to not being a first-time parent. The autistic group also mentioned finding the sensory environment of the clinic challenging.

Table 3.19 Attending postnatal appointments.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value
Attended midwife appointments			7.38 (0.69 - 79.20)	0.10
N	446	361		
Yes	377 (85%)	280 (78%)		
No	15 (3%)	9 (2%)		
Not applicable	54 (12%)	72 (20%)		
Attended health visitor appointments			0.31 (0.01 - 1.51)	0.15
N	445	359		
Yes	398 (89%)	279 (78%)		
No	16 (4%)	20 (6%)		
Not applicable	31 (7%)	60 (17%)		
Attended mother's 6 week check			11.30 (0.86 - 149.00)	0.86
N	444	361		
Yes	420 (95%)	338 (94%)		
No	11 (2%)	8 (2%)		
Not applicable	13 (3%)	15 (4%)		
Attended baby's 6-8 week check			9.08 (0.50 - 165.00)	0.14
N	441	362		
Yes	429 (97%)	350 (97%)		
No	5 (1%)	5 (1%)		
Not applicable	7 (2%)	7 (2%)		

Note. Multivariate binary logistic regression performed

Other aspects of postnatal appointments

The remaining questions concerning postnatal appointments were explored with a multivariate binary logistic regression. A model including group as a predictor was a better fit than the model without group, $\chi^2(19) = 386.53$, $p < 0.001$.

The autistic group were significantly more likely to indicate that they found it stressful to have professionals visit their home (63% vs. 22%; Table 3.20). Both groups worried that professionals would judge them if their house was unclean or untidy, *'my anxiety would go through the roof and I'd feel compelled to clean thoroughly. I'd have a sleepless night and be worn out and by the time they'd come I'd look confused and rough.'* (autistic participant). Participants in both groups commented that they did not like it when strangers visited their home and for the autistic group this was sometimes linked to considering their home a safe place, *'My home is my place of refuge and calm. Where I remove my mask and often retreat to when shutdown'*. Both groups also commented that not being given a fixed time for appointments caused stress, *'they don't give a time, so there's no planning or routine and I worried all day till they arrived.'* (autistic participant).

The autistic group were significantly less likely to see the same professional at each postnatal appointment e.g. the same midwife at each midwife appointment (39% vs. 40%). The autistic group were significantly more likely to agree that seeing the same professional at each appointment was important to them (89% vs. 76%). The autistic group were also significantly more likely to have found it stressful when the professional they saw was not who they were expecting to see (59% vs. 31%).

The autistic group were significantly less likely to agree that professionals took their questions and concerns seriously (59% vs. 82%), to have felt comfortable asking questions (59% vs. 86%), to feel that professionals treated them respectfully (70% vs. 90%) and to have felt able to trust professionals (57% vs. 82%). 49% of the autistic group felt negatively judged by professionals during postnatal appointments, significantly more than the non-autistic group (23%).

The autistic group were significantly less likely to have received as much information as they would have liked during postnatal appointments about their mental health (36% vs. 60%), looking after a baby (30% vs. 43%), how to interpret a baby's cries (59% vs. 70%) and how to

play with a baby (34% vs. 44%). The autistic group were also significantly less likely to be satisfied with the way in which information was presented to them (58% vs. 80%). When asked to describe how they would prefer for information to be presented to them, both groups would have liked more online information, video information, practical demonstrations and detailed explanations. Both groups would have preferred more written information, though this was particularly emphasised by the autistic group. Participants in both groups felt they would have benefitted from more information on how to look after a baby, *'I felt that my health and that of my baby were checked but very little was done by way of practical assistance (e.g. how to interpret my baby's cries) and my mental health'* (autistic participant). Participants in the autistic group also mentioned finding open-ended questions challenging, *'It would have been helpful if the questions were more precise, like, 'Do you feel pain during breast feeding?', 'Does anything worry you?', 'What worries you?''*.

The groups did not significantly differ on whether or not they had someone to advocate for them at postnatal appointments. Among those who had someone to advocate for them, the groups did not differ on whether or not they agreed that this was helpful (85% of the autistic group and 79% of the non-autistic group agreed). However, among those who did not have an advocate, the autistic group were significantly more likely to agree that an advocate would have been helpful (57% vs. 23%).

The autistic group were significantly less likely to be satisfied with their midwife appointments (60% vs. 78%), their health visitor appointments (51% vs. 72%) and their doctor/GP appointments (62% vs. 81%). When asked to describe what aspects of their postnatal appointments they had not been satisfied with, both groups discussed that appointments sometimes felt rushed, with professionals working through a checklist rather than taking a more individualised approach that tailored advice to their particular situation. Both groups also commented that they had encountered judgemental or condescending attitudes from professionals about their parenting decisions and that they felt their concerns about their health or that of their child had been dismissed, *'Health visitors were incredibly judgemental. Did not seem to listen.'* (non-autistic participant). Some felt that concerns were dismissed as being overly anxious, *'Midwife didn't take me seriously in terms of physical concerns with my recovery. Same with doctor. I had to change doctors to be taken seriously.'* (autistic participant). Furthermore, participants in both groups mentioned feeling that the information

they received during appointments with health visitors was inconsistent, not evidence-based or out of date.

In terms of physical health, both groups felt that they did not receive enough information about their physical recovery and healing after birth. Participants in both groups also felt that postnatal appointments focused on the physical health of them and their child with very little discussion of mental health, *'there was nothing about my mental wellbeing brought up except to be told not to worry so much'* (autistic participant). Participants in both groups felt that closer monitoring of mothers' mental health would be beneficial and some participants in the autistic group commented that they had not felt comfortable disclosing the extent of their mental health concerns to professionals, *'I disclosed to my GP I was depressed and suicidal but said I would not do it only in fear they would take the baby away. In fact I was in a terrible state but my lie put me back in the queue for mental health services'*. Some autistic participants talked of masking issues with mental health, *'we are taught all our lives to mask and fear showing these weaknesses.'*

The autistic group were significantly more likely to have found it difficult to attend drop-in clinics to get their baby weighed (48% vs. 29%). When asked to describe why they found attending drop-in clinics difficult, both groups mentioned lack of transport, childcare issues, the organisational demands of leaving the house with a young baby and postnatal depression. The autistic group further commented that the sensory environment and the lack of specific appointment time were barriers, *'Without a specific appointment I find it impossible to just turn up and wait. It is even harder in a brightly lit, noisy waiting room, packed with strangers.'*

The autistic group were also significantly more likely to have found it difficult to attend parent and baby groups (80% vs. 40%). Both groups gave practical reasons such as work commitments, lack of time, lack of transport, childcare issues, and the organisational demands of attending. Participants in both groups also felt that social anxiety or shyness was a barrier to attending and found it difficult to fit in with other mothers who they felt often formed 'cliques'. This issue was particularly emphasised by the autistic group, *'What do you say? How do you communicate with being judged and ending up feeling like a complete freak and wished you never went in the first place?'*

Table 3.20 Postnatal appointments.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value	p-value (FDR adjusted)
Found home visits stressful ^a			10.40 (6.41 - 16.83)	<0.001	-
N	302	209			
Agree	66 (22%)	131 (63%)			
Disagree	230 (76%)	76 (36%)			
Don't know	3 (1%)	2 (1%)			
Not applicable	3 (1%)	0 (0%)			
Seen the same professional at each appointment			0.88 (0.61 - 1.29)	0.52	-
N	437	357			
Yes	175 (40%)	140 (39%)			
No	262 (60%)	217 (61%)			
Seeing the same professional at each appointment is important ^a			5.35 (3.12 - 9.17)	<0.001	-
N	439	359			
Agree	333 (76%)	320 (89%)			
Disagree	98 (22%)	25 (7%)			
Don't know	2 (0.46%)	11 (3%)			
Not applicable	6 (1%)	3 (1%)			
Stressful when health professional saw was not the one expecting to see ^a			16.23 (9.71 - 27.10)	<0.001	-
N	439	357			
Agree	135 (31%)	210 (59%)			
Disagree	189 (43%)	33 (9%)			
Don't know	6 (1%)	12 (3%)			
Not applicable	109 (25%)	102 (29%)			
Professionals took my questions and concerns seriously			0.19 (0.13 - 0.30)	<0.001	-
N	436	353			
Agree	359 (82%)	207 (59%)			
Disagree	64 (15%)	127 (36%)			
Don't know	3 (1%)	7 (2%)			
Not applicable	10 (2%)	12 (3%)			
I felt comfortable asking questions to professionals			0.13 (0.08 - 0.20)	<0.001	-
N	434	350			

Agree	372 (86%)	205 (59%)			
Disagree	51 (12%)	136 (39%)			
Don't know	3 (1%)	5 (1%)			
Not applicable	8 (2%)	4 (1%)			
Professionals have treated me respectfully			0.15 (0.09 - 0.25)	<0.001	-
N	434	352			
Agree	391 (90%)	248 (70%)			
Disagree	34 (8%)	94 (27%)			
Don't know	2 (0.46%)	7 (2%)			
Not applicable	7 (2%)	3 (1%)			
I have felt negatively judged by professionals ^a			5.53 (3.69 - 8.27)	<0.001	-
N	436	351			
Agree	100 (23%)	173 (49%)			
Disagree	312 (72%)	154 (44%)			
Don't know	1 (0.23%)	12 (3%)			
Not applicable	23 (5%)	12 (3%)			
I have felt able to trust professionals			0.17 (0.11 - 0.26)	<0.001	-
N	435	351			
Agree	358 (82%)	200 (57%)			
Disagree	67 (15%)	143 (41%)			
Don't know	3 (1%)	4 (1%)			
Not applicable	7 (1%)	4 (1%)			
Received enough information about mental health			0.21 (0.14 - 0.31)	<0.001	-
N	440	358			
Agree	266 (60%)	129 (36%)			
Disagree	127 (29%)	188 (53%)			
Don't know	9 (2%)	13 (4%)			
Not applicable	38 (9%)	28 (8%)			
Received enough information about looking after baby			0.37 (0.25 - 0.55)	<0.001	-
N	439	357			
Agree	189 (43%)	106 (30%)			
Disagree	175 (40%)	200 (56%)			
Don't know	7 (2%)	15 (4%)			
Not applicable	68 (15%)	36 (10%)			
Received enough information about interpreting baby's cries			0.40 (0.26 - 0.61)	<0.001	-
N	440	356			
Agree	306 (70%)	209 (59%)			
Disagree	80 (18%)	111 (31%)			

Don't know	4 (1%)	6 (2%)			
Not applicable	50 (11%)	30 (8%)			
Received enough information about how to play with baby			0.45 (0.30 - 0.66)	<0.001	-
N	440	358			
Agree	192 (43%)	120 (34%)			
Disagree	171 (39%)	186 (52%)			
Don't know	4 (1%)	7 (2%)			
Not applicable	73 (17%)	45 (13%)			
Satisfied with way in which information presented			0.23 (0.15 - 0.35)	<0.001	-
N	440	359			
Agree	353 (80%)	209 (58%)			
Disagree	67 (15%)	123 (34%)			
Don't know	5 (1%)	14 (4%)			
Not applicable	15 (3%)	13 (4%)			
Had advocate during postnatal appointments ^b			0.92 (0.68 - 1.24)	0.58	0.58
N	434	357			
Yes	211 (49%)	163 (46%)			
No	223 (51%)	194 (54%)			
Advocate was helpful ^b			2.21 (0.98 - 5.30)	0.06	0.08
N	207	162			
Agree	163 (79%)	138 (85%)			
Disagree	22 (11%)	11 (7%)			
Don't know	8 (4%)	8 (5%)			
Not applicable	14 (7%)	5 (3%)			
Advocate would have been helpful ^b			7.89 (4.63 - 13.80)	<0.001	<0.001
N	225	192			
Agree	52 (23%)	109 (57%)			
Disagree	114 (51%)	29 (15%)			
Don't know	15 (7%)	29 (15%)			
Not applicable	44 (20%)	25 (13%)			
Satisfaction with midwife appointments			0.23 (0.13 - 0.41)	<0.001	-
N	436	351			
Satisfied	338 (78%)	209 (60%)			
Dissatisfied	30 (7%)	56 (16%)			
Don't know	4 (1%)	7 (2%)			
Not applicable	64 (15%)	79 (23%)			
Satisfaction with health visitor appointments			0.34 (0.22 - 0.54)	<0.001	-
N	435	351			
Satisfied	314 (72%)	178 (51%)			

Dissatisfied	72 (17%)	89 (25%)			
Don't know	1 (0.23%)	10 (3%)			
Not applicable	48 (11%)	74 (21%)			
Satisfaction with doctor/GP appointments			0.26 (0.17 - 0.41)	<0.001	-
N	435	353			
Satisfied	353 (81%)	218 (62%)			
Dissatisfied	59 (14%)	104 (29%)			
Don't know	0 (0%)	10 (3%)			
Not applicable	23 (5%)	21 (6%)			
Difficult to attend drop-in clinics ^a			4.72 (3.12 - 7.14)	<0.001	-
N	435	354			
Agree	125 (29%)	170 (48%)			
Disagree	243 (56%)	102 (29%)			
Don't know	3 (1%)	5 (1%)			
Not applicable	64 (15%)	77 (22%)			
Difficult to attend parent and baby groups ^a			14.90 (9.43 - 23.47)	<0.001	-
N	436	355			
Agree	176 (40%)	283 (80%)			
Disagree	217 (50%)	45 (13%)			
Don't know	3 (1%)	3 (1%)			
Not applicable	40 (9%)	24 (7%)			

Note. Multivariate binary logistic regression performed

^aItem reverse scored prior to multivariate analysis. Inverse of aOR and CIs presented

^bItem not included within multivariate analysis due to survey logic

3.4.3.4 Parenting challenges and strengths.

For questions concerning parenting, a multivariate binary logistic regression was performed. A model including group as a covariate was a better fit than the model without group, $\chi^2(14)=352.30$, $p<0.001$. The autistic group were significantly less likely to have found it easy to play with their baby, to feel confident that they were able to understand what their baby needs, to agree that being a parent is enjoyable in terms of sensory input, to feel they are able to be extremely focused on caring on their baby and to feel able to be very patient with their baby (Table 3.21). The autistic group were significantly more likely to have researched parenting in a lot of detail, to find the organisational demands of parenting challenging, to find being a parent overwhelming in terms of sensory input, to find that not being able to predict their baby's behaviour causes them anxiety, to feel a strong pressure for their parenting to fit with society's expectations, to worry about how others will perceive their parenting and to find

being a parent an isolating experience. The autistic group were also more likely to worry that their baby would be taken away from them and less likely to agree that being a mother is a positive experience. The majority of those autistic participants who considered the question applicable felt that others had judged their parenting negatively due to being autistic (41% of all who responded). The majority (78%) of autistic participants felt that being autistic gave them strengths as a parent.

When asked to describe which aspects of being a parent can be overwhelming in terms of sensory input, both groups reported findings smell, exhaustion and not having any time to oneself overwhelming. Both groups emphasised finding the sound of their baby's cries challenging, *'I find the crying really overwhelming and often just want to block my ears'* (non-autistic participant). The autistic group highlighted finding the emotional aspect of their baby's cries difficult, *'I felt hugely overwhelmed by my own emotions in response to hearing my baby cry, so sorry for the tiny darling and not wanting him to suffer or feel sad.'* Participants in this group commented that they felt able to put their baby's needs before theirs despite finding the sensory input overwhelming, *'I put my babies first and thought I can ride it through until they are bigger'*. Participants in both groups struggled at times with frequent physical touch. While many participants in the autistic group found physical touch challenging, some expressed finding touch very enjoyable, *'I love touch (if it is firm) so holding my baby all the time came naturally to me, and this is what she wanted too'*.

When asked to describe what they find enjoyable about being a parent, both groups commented on the love they feel for their child, *'I love her very, very much and waking up every day knowing that I have that love in my life is wonderful.'* (autistic participant). Both groups also highlighted the enjoyment they experienced from watching their child learn and develop, *'The look in their eyes as they're figuring things out is pure joy. Facilitating that makes parenting an exciting adventure.'* (autistic participant). Participants in both groups felt their child allowed them to develop as a person, *'I enjoy that my children push me out of my comfort zone, they force me to look at myself. Because of that, they make me a better person'* (autistic participant). The autistic group further emphasised that their child made them feel accepted for who they are, without judgement, *'I'm less self-conscious since I've given birth; I hide my stims a lot less now, for example, because suddenly her opinion is the only one that matters and she doesn't care.'* Finally, both groups enjoyed the sensory aspects of having a

young baby, for example, *'The scent of babies and calm physical contact. I get that both the baby and the parent regulate one another.'* (autistic participant).

When asked what aspects of parenting they find challenging, both groups mentioned lack of sleep, exhaustion, the organisational demands of juggling domestic tasks while caring for their children, balancing parenting and work, and a lack of support from family. Both groups often mentioned that not having time to oneself was challenging. Both groups also felt that parenting could bring feelings of isolation and loneliness, as well as finding judgemental attitudes from others (including other parents) challenging. The autistic group further mentioned finding knowing how to play with their child difficult, *'It's always been hard to figure out how to play with my child. His "rules" for play are nonsensical and my imagination is just not strong enough to keep up with his.'* The autistic group additionally felt that the social demands of parenting were challenging, *'Juggling the social demands outside of our home (e.g. Interacting with other parents, managing expectations such as being expected to leave my baby to be babysat by family).'*

When asked to describe their strengths as a parent, both groups highlighted the unconditional love they felt for their child. The autistic group in particular stressed that being able to empathise with their child was a strength, *'I'm tremendously affectionate and I care very much about how my children are feeling.'* Some participants linked their heightened empathy to being autistic, *'My autism gives me a hyper-awareness of other people's emotions. Rather than not being able to read them, I am painfully aware of every moment of emotion passing on someone's face'*.

Both groups reported that being understanding was a strength. The autistic group in particular frequently commented that they felt able to accept their child for who they are and often linked this tendency to an ability to reject societal norms when necessary, *'I am open to my son being different and don't try to force him to be 'average'.'* Some of the autistic group felt that this made them able to take a more flexible approach to their parenting, *'I am not so tied to societal expectations as other people so I can follow my daughter's lead and parent in a way that works for both of us'*.

The autistic group additionally often felt that they had a good understanding, and acceptance, of atypical development due to being autistic, *'I don't feel the need to put their developmental*

needs into a box. Yes, I'm aware that they should be doing something by a certain age, but if they don't, sometimes they need a bit more time.' Having a deep understanding of their autistic children was often highlighted as a strength, *'I deeply understand my daughter's way of being, as we are both autistic and ADHD and I wish to God I had had parents who "got" me. I model coping skills and self-compassion and teach my daughter how to get by in the NT world with her integrity intact, but still functioning as a member of the shared enterprise of society.'*

Both groups also commented on strengths relating to planning and organisation, as well as establishing routines, *'I'm orderly and predictable. Kids need that. The whole 'schedule' thing was right up my alley and very helpful.'* (autistic participant). Participants in both groups also discussed researching parenting approaches. This was particularly common among the autistic group who often commented that parenting was a special interest for them, for example, *'My child is my special interest and I devote a lot of time to researching how best to meet his needs and practice being the best parent I can be'.*

Further strengths mentioned by both groups included patience, attentiveness, being able to put their child first and having a sense of humour. Participants in the non-autistic group reported that being able to play well with their child was a strength. Despite having been discussed as a challenge by many autistic participants, some autistic participants considered being able to play with their child a strength, *'If anyone thinks Autistic people can't role play or improvise should see our story sessions, and adventure playing. Other families seem pretty dull.'*

Those participants who agreed that being autistic gave them particular strengths as a parent, were asked to describe what these strengths were. Of the strengths mentioned above, those that participants linked to being autistic included planning and organisation, an ability to advocate for their child, having a drive to research child development and parenting, being able to resist societal expectations, being non-judgemental, honest and empathetic. In addition, participants emphasised detail focus as a strength, for example, *'I feel like I can pick up on small noises/movements more quickly than others. I can tell from the next room if they're getting into something they shouldn't.'* Participants also reported that being able to hyperfocus on their child allowed them to understand them well, for example, *'I've spent so much time focusing on my children, I feel like I never miss a cue with them, and I know before they do how they're going to feel or react to most situations.'*

Some autistic participants mentioned that having atypical sensory experiences enabled them to have a better understanding of the sensory experiences of their baby, for example, ‘*Very aware of sensory cues and willing to look for unexpected causes. Empathy for any being who finds everything confusing and overwhelming*’.

Table 3.21 Parenting strengths and challenges.

	Non-autistic group	Autistic group	aOR (95% CI)	p-value
I find it easy to play with my baby			0.13 (0.09 - 0.21)	<0.001
N	430	352		
Agree	366 (85%)	196 (56%)		
Disagree	58 (14%)	154 (44%)		
Don't know	1 (0.23%)	2 (1%)		
Not applicable	4 (1%)	0 (0%)		
Confident that able to understand what baby needs			0.34 (0.21 - 0.54)	<0.001
N	431	352		
Agree	380 (88%)	269 (76%)		
Disagree	47 (11%)	81 (23%)		
Don't know	0 (0%)	1 (0.28%)		
Not applicable	4 (1%)	1 (0.28%)		
Being a parent is enjoyable in terms of sensory input			0.12 (0.06 - 0.22)	<0.001
N	431	352		
Agree	407 (95%)	278 (79%)		
Disagree	16 (4%)	69 (20%)		
Don't know	2 (0.47%)	5 (1%)		
Not applicable	5 (1%)	0 (0%)		
Have researched parenting in a lot of detail			2.41 (1.42 - 4.08)	0.001
N	431	351		
Agree	352 (82%)	316 (90%)		
Disagree	71 (17%)	30 (9%)		
Don't know	3 (1%)	2 (1%)		
Not applicable	4 (1%)	3 (1%)		
Able to be extremely focused on caring for my baby			0.39 (0.21 - 0.73)	0.003
N	431	351		
Agree	403 (94%)	312 (89%)		
Disagree	21 (5%)	36 (10%)		
Don't know	2 (0.47%)	2 (1%)		
Not applicable	4 (1%)	1 (0.28%)		
Able to be very patient with my baby			0.53 (0.33 - 0.85)	0.01

N	431	350		
Agree	367 (85%)	275 (79%)		
Disagree	57 (13%)	71 (20%)		
Don't know	3 (1%)	2 (1%)		
Not applicable	3 (1%)	2 (1%)		
I find the organisational demands of parenting challenging ^a			1.73 (1.73 - 1.73)	<0.001
N	436	353		
Agree	283 (65%)	263 (75%)		
Disagree	148 (34%)	87 (25%)		
Don't know	3 (1%)	1 (0.28%)		
Not applicable	1 (0.23%)	2 (1%)		
Being a parent is overwhelming in terms of sensory input ^a			9.17 (6.14 - 13.70)	<0.001
N	437	352		
Agree	126 (29%)	244 (69%)		
Disagree	304 (70%)	103 (29%)		
Don't know	2 (0.46%)	3 (1%)		
Not applicable	4 (1%)	2 (1%)		
Not being able to predict when my baby will need changing, feeding, or when they will fall asleep causes me anxiety ^a			3.72 (2.51 - 5.50)	<0.001
N	431	352		
Agree	122 (28%)	183 (52%)		
Disagree	293 (68%)	156 (44%)		
Don't know	0 (0%)	1 (0.28%)		
Not applicable	16 (4%)	12 (3%)		
Felt strong pressure for my parenting to fit in with society's expectations ^a			3.73 (2.48 - 5.62)	<0.001
N	429	351		
Agree	228 (53%)	266 (76%)		
Disagree	188 (44%)	76 (22%)		
Don't know	2 (0.47%)	3 (1%)		
Not applicable	10 (2%)	6 (2%)		
I worry about how others perceive my parenting ^a			3.52 (3.52 - 3.53)	<0.001
N	431	352		
Agree	250 (58%)	278 (79%)		
Disagree	173 (40%)	67 (19%)		
Don't know	2 (0.47%)	4 (1%)		
Not applicable	5 (1%)	3 (1%)		
Being a parent is an isolating experience ^a			3.70 (2.44 - 5.62)	<0.001
N	427	351		

Agree	250 (59%)	280 (80%)			
Disagree	173 (41%)	65 (19%)			
Don't know	1 (0.23%)	3 (1%)			
Not applicable	2 (0.47%)	3 (1%)			
I worry that my baby will be taken away from me ^a				16.47 (10.06 - 26.95)	<0.001
N	436	352			
Agree	35 (8%)	149 (42%)			
Disagree	368 (84%)	162 (46%)			
Don't know	4 (1%)	12 (3%)			
Not applicable	29 (7%)	29 (8%)			
Being a mother is a positive experience				0.46 (0.26 -0.80)	0.01
N	431	350			
Agree	398 (92%)	298 (85%)			
Disagree	31 (7%)	44 (13%)			
Don't know	0 (0%)	7 (2%)			
Not applicable	2 (0.46%)	1 (0.29%)			
	N	Agree	Disagree	Don't know	Not applicable
Others have judged my parenting negatively because I am autistic ^b	350	144 (41%)	20 (6%)	46 (13%)	140 (40%)
Being autistic gives me particular strengths as a parent ^b	351	275 (78%)	33 (9%)	32 (9%)	11 (3%)

Note. Multivariate binary logistic regression performed

^aItem reverse scored prior to multivariate analysis. Inverse of aOR and CIs presented

^bItem not included within multivariate analysis

3.4.3.5 Postnatal support.

For questions concerning postnatal support, a multivariate binary logistic regression was performed. A model including group as a covariate was a better fit than the model without group, $\chi^2(3) = 74.57$, $p < 0.001$. The autistic group were significantly less likely to feel they had received all the support they needed from their partner/spouse (52% vs. 73%), from family (43% vs. 71%) and from friends (41% vs. 71%; Table 3.22).

The majority (83%) of autistic participants did not have peer support from other autistic parents, though 98% of those who did agreed that they had found it helpful and 60% of those

who did not have peer support agreed that they would have found such support helpful. In their open-text responses, many participants in the autistic group felt that peer support from autistic parents, in the form of online groups, in-person groups or befriending, would have been particularly helpful, *‘Knowing other autistic mums. It’s a time when seeing all the “normal” mums doing it so naturally really drives it home that you’re different.’*

Table 3.22 Postnatal support.

		Non-autistic group	Autistic group	aOR (95% CI)	p-value
Received all the support needed from:					
Partner/spouse				0.33 (0.21 - 0.51)	<0.001
N		428	350		
Agree		312 (73%)	182 (52%)		
Disagree		108 (25%)	150 (43%)		
Don’t know		0 (0%)	2 (1%)		
Not applicable		8 (2%)	16 (5%)		
Family				0.21 (0.14 - 0.33)	<0.001
N		428	349		
Agree		303 (71%)	151 (43%)		
Disagree		114 (27%)	181 (52%)		
Don’t know		1 (0.23%)	3 (1%)		
Not applicable		9 (2%)	14 (4%)		
Friends				0.24 (0.15 - 0.38)	<0.001
N		428	350		
Agree		305 (71%)	145 (41%)		
Disagree		107 (25%)	154 (44%)		
Don’t know		5 (1%)	6 (2%)		
Not applicable		10 (2%)	45 (12%)		
	N	Agree	Disagree	Don’t know	Not applicable
Had peer support from other autistic parents ^b	340	58 (17%)	282 (83%)	-	-
Peer support helpful ^b	57	56 (98%)	0 (0%)	1 (2%)	0 (0%)
Peer support would be helpful ^b	280	167 (60%)	17 (6%)	47 (17%)	49 (18%)

Note. Multivariate binary logistic regression performed

^bItem not included within multivariate analysis

3.5 Discussion

This is the first in depth quantitative study of the perinatal experiences of autistic people. The findings indicate lower perceptions of perinatal healthcare as well as atypical physical and sensory perinatal experiences among autistic people. The findings additionally highlight a number of parenting challenges and strengths experienced by autistic people.

Autistic participants had lower perceptions of prenatal, birth and postnatal healthcare than non-autistic participants. While the autistic group were no less likely to attend all their prenatal and postnatal appointments, they were more likely to find postnatal home visits stressful, possibly due to factors such as not having a fixed appointment time and worrying that they would be judged by professionals. These findings indicate the need to make appointments more accessible for autistic parents by reducing uncertainty, sensory stimuli and social demands. Replicating the findings of Pohl et al. (2020), autistic and non-autistic participants were just as likely to attend antenatal classes, though the findings indicate that several aspects of antenatal classes may not be adequate for autistic people and that smaller classes with less pressure to socialise may be more appropriate. The autistic group were more likely to consider continuity of care to be important, yet were less likely to have experienced continuity of care. Ensuring continuity of care is an important adjustment that should be offered to autistic people, in addition to being kept informed of who will be providing their care.

Echoing prior findings that autistic mothers prefer not to disclose their autism diagnosis to professionals (Pohl et al., 2020), participants tended not to disclose to various health professionals during prenatal and postnatal appointments. Similarly to Pohl et al. (2020), participants indicated that they chose not to disclose for fear of negative attitudes from professionals. Indeed autistic participants were more likely to feel judged by and unable to trust professionals, and less likely to feel treated with respect in prenatal and postnatal appointments. This is in keeping with the findings that autistic mothers are more likely to feel misunderstood by professionals (Pohl et al., 2020) and that midwives can hold negative attitudes towards mothers with a disability (Höglund et al., 2013). However, research seeking the perspectives of professionals themselves would be necessary to establish what attitudes maternity professionals hold towards autistic mothers.

Participants were often not offered autism-related adjustments during appointments and tended to feel that professionals did not have a good understanding of autism during prenatal and postnatal appointments, nor during the birth. These findings fit with those of Hall et al. (2018) that women with disabilities commonly feel that reasonable adjustments are not made for them in maternity appointments and that professionals do not have awareness of disability. However, it is important to note that some participants may not have received adjustments due to not having received a diagnosis of autism or not having disclosed their diagnosis.

Participants highlighted the need for adjustments such as more time to process information and adequate opportunities to ask questions in appointments, given difficulties processing verbal information. The idea that professionals may need to make communication adjustments for their autistic patients fits with prior findings that autistic people experience communication-related barriers to healthcare (Nicolaidis et al., 2015; Raymaker et al., 2017) and that autistic mothers are more likely to experience issues communicating with professionals about their child (Pohl et al., 2020). It also builds on findings that women with disabilities are less likely to be spoken to by professionals in a way they could understand and less likely to feel they have time to ask questions in prenatal and postnatal appointments (Malouf, Henderson & Redshaw, 2017; Redshaw et al., 2013). Importantly, issues of communication were often linked to consent, with some participants stressing that inadequate opportunity to process information may lead to compliance and a lack of ability to give informed consent. Autistic people indicated requiring clear, detailed information during prenatal and postnatal appointments, as well as the option of this information being delivered in a variety of formats such as written, online and video formats due to difficulty processing verbal information. Similarly, autistic participants were less likely to feel that they were kept adequately informed during the birth. This echoes the finding of Pohl et al. (2020) that autistic mothers were less likely to feel that the process of birth was adequately explained as well as findings that women with disabilities are less likely to be spoken to in a way they could understand during childbirth (Malouf, Henderson & Redshaw, 2017). These findings indicate the need for adjustments for autistic people during childbirth such as frequent updates, clearer explanations, written information and more time to process information.

Autistic participants stressed that they felt their concerns, and their knowledge of their own body, were dismissed by professionals. This is in keeping with previous findings that women with disabilities are less likely to feel listened to in prenatal and postnatal appointments and less likely to feel that their concerns are taken seriously during labour (Malouf, Henderson & Redshaw, 2017; Henderson et al., 2018). Indeed, autistic participants were less likely to feel that professionals took their concerns seriously in prenatal and postnatal appointments as well as being less likely to feel that their birth plan was taken into account and their requests listened to during childbirth. They also felt that experiencing physical sensations atypically may lead to being dismissed, such as expressions of pain during labour not being taken seriously due to being less overt. Indeed, the majority of autistic participants did not feel that professionals had an accurate understanding of what they were perceiving physically during birth. Some felt that atypically acute awareness of bodily signals during labour was dismissed by professionals. However, the autistic group were also less likely to feel aware of their bodily signals during labour. It may be that some autistic people experience heightened awareness during labour while others have reduced awareness. These findings suggest that professionals may need to communicate differently with autistic and non-autistic patients about their bodily signals during childbirth.

The communication issues identified above, in addition to the overwhelming nature of the sensory environment during the birth, were key factors that led to approximately a third of autistic participants having a meltdown or shutdown during the birth. Furthermore, the majority of autistic participants felt that their meltdown or shutdown was not handled optimally by professionals. This highlights the need for professionals to understand how to identify meltdowns and shutdowns among autistic patients and how to respond appropriately. Importantly, not receiving adequate time to process information during shutdown was identified as a barrier to giving informed consent during childbirth. While 17% of the non-autistic group reported a meltdown, only 8% reported shutting down during birth, perhaps indicating that non-autistic people are more likely to externalise than internalise their distress during childbirth. The opposite may be the case for autistic people (38% of whom reported shutting down vs. 29% who reported a meltdown). It is important for professionals to be aware that distress during childbirth may be expressed differently by autistic and non-autistic patients. Having an advocate present during childbirth may be

particularly important for autistic people given issues of communication and the possibility that shutting down may make communication additionally challenging. Indeed, the majority of autistic participants felt favourably about having an advocate present during the birth as well as during prenatal and postnatal appointments. For those who did not have an advocate, the autistic group were more likely than the non-autistic group to feel that an advocate would have been beneficial.

Participants in both groups reported that they did not receive enough information about postnatal physical recovery or postnatal mental health. In addition, the autistic group were less likely to feel able to cope with postnatal physical symptoms and less likely to know when to seek help. These findings echo those of Malouf, Henderson & Redshaw (2017) that women with disabilities are less likely to receive sufficient information about physical recovery and mood changes after birth. Consistent with prior findings of increased risk of postnatal depression among autistic mothers (Pohl et al., 2020), the autistic group were more likely to experience postnatal depression and anxiety, with 30% experiencing postnatal depression and 19% experiencing postnatal anxiety (compared with 12% and 7% respectively for the non-autistic group, figures that are in line with previous estimates in the general population; Henderson & Redshaw, 2013b; Leahy-Warren & McCarthy, 2007). It is worth noting that it is not clear how the levels of postnatal depression and anxiety reported relate to participants' baseline level of depression and anxiety outside of the perinatal period; future longitudinal studies could tease apart these issues. Autistic participants sometimes reported masking mental health issues from professionals due to fear that their child would be taken away. These findings indicate the need for greater monitoring of, and support for, mental and physical postnatal health among autistic people.

Similarly to Pohl et al. (2020), it was found that autistic and non-autistic participants were just as likely to breastfeed, though unlike Pohl et al. (2020) autistic and non-autistic participants were just as likely to have difficulties breastfeeding. Autistic participants were, however, more likely to have difficulties breastfeeding due to sensory issues as well as being less likely to find it easy to access breastfeeding support and less likely to feel satisfied with support they received. This fits with prior findings that women with disabilities are less likely to report receiving infant feeding support (Malouf, Henderson & Redshaw, 2017). Breastfeeding

support in different formats such as online and video support may be beneficial for autistic people who may find attending group-based support challenging.

In addition to being less satisfied with perinatal healthcare, the autistic group were also less satisfied with support from informal sources such as partners, friends and family. Peer support from other autistic parents was desired by the majority of participants, though only 5% had received peer support during pregnancy and only 17% postnatally. This echoes reports in Chapter 2 of the importance of peer support for wellbeing.

Physical perinatal experiences were also found to differ among autistic and non-autistic people. Sensory experiences during pregnancy were heightened, and more likely to lead to feeling overwhelmed, among the autistic group. This was the case not only for smell and taste but also for touch, hearing and vision - senses less commonly associated with changes during pregnancy. These findings echo themes from Chapter 2 concerning heightened sensory experiences across the five senses. Some of the autistic group reported feeling their bodily sensations, including their baby's movements, very acutely during pregnancy, while others reported experiencing bodily sensations less clearly when pregnant. This is in keeping with the prior literature surrounding autism and interoception that suggests there is heterogeneity among autistic people's interoceptive experiences, with some experiencing increased and others decreased subjective perception of internal states (Elwin et al., 2012; Garfinkel et al., 2016). It may be that some autistic people are able to acutely sense their baby's movements, and other pregnancy-related sensations, and such reports should not be dismissed by professionals. For those who experience heightened interoceptive experiences during pregnancy, adjusting to the somatic changes of pregnancy may be particularly challenging. For those experiencing reduced interoceptive awareness, such as reduced ability to recognise hunger, nutritional support may be beneficial (e.g. advice on the frequency of eating and drinking).

Echoing reports in Chapter 2, autistic participants also experienced nausea more frequently than non-autistic participants, potentially due to the aforementioned greater increase in intensity of smell and taste among this group. Autistic participants frequently experienced shutdowns and meltdowns during pregnancy, with over half experiencing meltdowns and shutdowns at least once a fortnight and the majority reporting a greater intensity of meltdowns and shutdowns during pregnancy. This finding fits with reports outlined in Chapter

2 of more frequent and intense meltdowns and shutdowns during pregnancy due to heightened sensory experiences. These findings highlight that support with sensory changes during the perinatal period may be beneficial for autistic people. Additionally, it was found that autistic people were more likely to feel overwhelmed by sensory input during childbirth due to lights, noise, being touched and being seen by many different professionals. Similarly, autistic participants were more likely to feel overwhelmed by sensory experiences during prenatal appointments and when staying on a shared postnatal ward. These data corroborate similar findings in Chapter 2 and highlight the need to make sensory accommodations for autistic people before, during and after birth.

Evidence was found of increased rates of pelvic girdle pain and vaginal bleeding during pregnancy among the autistic group. The increased risk of pelvic girdle pain may partially be explained by increased hypermobility among autistic people (Cederlöf et al., 2016), though this is unlikely to provide a full explanation given that the group difference remained significant after controlling for hypermobility. Increased risk of pelvic girdle pain may also be due to the fact that autistic people tend to be at greater risk of chronic pain than non-autistic people (Whitney & Shapiro, 2019). An increased risk of vaginal bleeding may in part be due to hormonal factors, given that differences in endocrine system function has been associated with autism (Sarachana et al., 2011). The finding of no increased risk of gestational diabetes among autistic people fits with Sundelin et al. (2018), though the finding of no increased risk of preeclampsia is in contrast with the findings of this paper. It may be that null findings concerning pregnancy conditions are due to having a smaller sample size than would typically be expected for epidemiological studies of relatively rare conditions. A post-hoc power analysis for preeclampsia indicated that for the total sample of 935, there was adequate (80%) power to detect an odds ratio of ≥ 1.94 , with a two-tailed alpha of 0.05, indicating that null results may have been due to a lack of power. It is also possible that pregnancy conditions may be underdiagnosed among autistic people, given that 89% of participants in the present sample did not know when to seek help with pregnancy concerns. Greater prenatal anxiety and depression among the autistic group than the non-autistic group fit with findings of an increased prevalence of mental health difficulties among autistic people compared with the general population (Lai et al., 2019) and increased prenatal and postnatal depression among autistic women (Pohl et al., 2020). It may be that the stressors of increased physical issues

during pregnancy and lower satisfaction with maternity care may contribute towards greater feelings of anxiety and depression among autistic people during this time.

In contrast with Sundelin et al. (2018), no increased risk of induction or caesarean delivery was found. The authors suggest that increased risk of induction and elective caesarean may be due to a tendency to commence labour based on maternal wellbeing, possibly due to the stresses of different sensory processing among autistic people. If this is the case, this phenomenon may be less common in non-Swedish healthcare systems (such as the UK).

The findings also highlight a number of areas of parenting in which autistic parents may need more support. The autistic group were more likely to feel pressure for their parenting to fit with societal expectations, to worry about how others perceive their parenting and to worry that their baby would be taken away. In addition, 41% felt that their parenting had been judged due to being autistic. These findings build on the Pohl et al. (2020) finding that autistic mothers were more likely to feel judged and highlight the need for more understanding of autistic parents. The findings compliment those of Pohl et al. (2020) by demonstrating that autistic parents can find the organisational demands of parenting more challenging than non-autistic parents as well as being more likely to find parenthood isolating. The autistic group were also more likely to experience difficulties such as finding their baby's unpredictability challenging and finding parenting overwhelming in terms of sensory input. These findings highlight that the sensory and executive function challenges that some autistic people face may make parenting additionally challenging and that more support may be needed for autistic parents in these areas. However, it is important to note that not all autistic parents considered organisational demands challenging, indeed some considered organisational skills and establishing routine a strength in the open-text responses.

The autistic group were less likely to be confident about aspects of parenting such as understanding what their baby needs, being focused on caring for their baby and being patient with their baby. Nevertheless, over two thirds of the autistic group agreed that they possessed these skills. The autistic group were also less likely to agree that they found playing with their baby easy, though 56% of the autistic group agreed and some considered play a strength in the open-text responses. Support to feel confident caring for and playing with their baby may nevertheless be beneficial for some autistic parents. It should be noted that autistic parents may have a greater genetic likelihood of having a child with a

neurodevelopmental condition and may therefore find some aspects of parenting more challenging due to this. Furthermore, as autistic participants were more likely to experience postnatal depression and anxiety, this difference may in part explain the additional parenting challenges experienced by the autistic group. Despite the challenges faced, autistic participants emphasised in the open-text responses that they felt able to overcome these challenges in order to put their child first. This echoes the Pohl et al. (2020) finding that autistic and non-autistic mothers were equally able to prioritise their child's needs above their own.

While the autistic group were less likely to find parenthood a positive experience, 85% nevertheless did find parenthood a positive experience. Many positives of being a parent were identified by autistic participants such as feelings of love, the joy of supporting their child's development and experiencing personal growth. The findings also highlight a number of strengths of autistic parents (indeed, 78% felt that being autistic gave them strengths as a parent). For example, the autistic group were more likely to have researched parenting in a lot of detail, reporting in the open-text responses that their hyper-focus and tendency to see parenting as a special interest allowed them to research parenting extensively in order to best meet their child's needs. The autistic group also reported a strong sense of empathy, a non-judgemental nature and an enhanced understanding of difference. Despite the challenges involved in parenting, the open-text responses painted a picture of parents who were loving, empathetic and committed to doing the best for their children.

3.5.1 Limitations

The sample may not be representative of all autistic mothers. Many of the autistic group did not have a diagnosis of autism or had not yet been diagnosed at the time of their most recent birth. Parents without a diagnosis may have different experiences to those with a diagnosis, including being treated differently by professionals and receiving fewer accommodations. Further, the survey may not have been accessible to parents with an intellectual disability and as such, the experiences of these parents may not have been captured. The experiences of autistic parents were not compared with those of parents with other disabilities, meaning that it is unclear whether the issues raised are specific to autistic parents or common to disabled parents more broadly. Similarly, background group differences in mental health conditions were not controlled for and it is therefore possible that some group differences

(such as differences in interactions with professionals or parenting challenges) may be due to the increased likelihood of mental health conditions among this group.

It is possible that the survey attracted respondents who felt particularly strongly about the subject matter (such as those who had a negative experience) and the sample may therefore be unrepresentative. The sample was also predominantly composed of participants of white ethnicity from western countries and may not be representative of other populations.

Furthermore, participants often reported on experiences that occurred several years ago. Recollection of these experiences may not be as reliable as when reporting on more recent events. In addition, healthcare systems may have changed considerably over time and reports of experiences that occurred several years ago may be less relevant to current healthcare. Furthermore, participants from a range of different countries (all with differing healthcare systems) are represented and it is therefore not possible to draw conclusions specific to any particular healthcare system. The survey relies on self-report and as such, triangulation using other methods such as medical records (for pregnancy conditions and birth outcomes) and studies seeking the perspectives of professionals are necessary to corroborate findings. The latter would help to establish the level of autism-related knowledge maternity professionals possess and the attitudes they hold towards autistic parents.

3.5.2 Conclusions and considerations for clinical care

This study identifies key gaps in perinatal healthcare for autistic people. The findings highlight the need for adjustments to prenatal and postnatal appointments in order to bring about improvements for autistic people. These include the need to be given time to process information and ask questions, and to be given clear, detailed, factual information. The availability of information in a variety of formats (such as written, online and video formats), including written summaries of discussions during appointments, would be beneficial due to challenges processing verbal information. Some autistic people may benefit from the presence of an advocate to assist with communication during appointments. Professionals should also be aware that adjustments to the sensory environment may be necessary during appointments and that touch may be challenging for autistic patients. Due to potential difficulties accessing group-based support (such as antenatal classes and breastfeeding support), the provision of alternative formats such as one-to-one or online classes would be beneficial for autistic people.

During childbirth, there is a need for awareness among professionals of the non-normative ways that autistic people may express pain, in addition to awareness of how to identify and appropriately respond to meltdowns and shutdowns. Accommodations to the sensory environment should be made for autistic people during childbirth and where possible autistic people should be provided their own room on the postnatal ward due to the sensory challenges of shared rooms.

Greater autism awareness among perinatal healthcare professionals, in addition to greater continuity of care, would help to build trust between professionals and their autistic patients. Fear of a lack of understanding from professionals can be a barrier to disclosure of an autism diagnosis and therefore a barrier to accessing adjustments and support. In addition, fear of negative attitudes can impede seeking support for mental health conditions. Greater mental health support for autistic people is essential, given an increased risk of perinatal depression and anxiety.

Autistic parents may also need more practical support for certain challenging aspects of parenting such as organisational and sensory demands as well as support concerning how to play with their baby. The study highlights that autistic parents nevertheless possess strengths and are able to overcome challenges to prioritise their child's wellbeing.

Chapter 4: The wellbeing of autistic mothers during pregnancy and the postnatal period

4.1 Introduction

Symptoms of mental health conditions are common during the perinatal period, with recent reviews of prevalence estimates suggesting 17% during pregnancy and 13% during the first postnatal year for depressive symptomology (Underwood et al., 2016) and 18-25% across pregnancy and 15% over the first 6 postnatal months for anxiety symptomology (Dennis et al., 2017). Explorations of the trajectories of anxiety and depression across the perinatal period have found a decrease in symptomology from pregnancy to the postnatal period (Evans et al., 2001; Figueiredo & Conde, 2011; Heron et al., 2004). This pattern of decreased symptomology over the perinatal period may be due to biological factors such as hormonal influences or due to certain concerns (such as the physical symptoms of pregnancy, birth-related fears or anxieties around the unborn child's health) having been resolved by the time of the postnatal period. Similarly, an increase in satisfaction with life from the third trimester of pregnancy to the postnatal period has been found (Gebuza et al., 2014).

Perinatal wellbeing is an important public health concern due its impact on both mother and child. Perinatal anxiety, depression and stress have been associated with adverse pregnancy and birth outcomes as well as child developmental outcomes (as outlined in Chapter 1). An additional concept, pregnancy-related anxiety, refers to worries specific to pregnancy such as concerns about childbirth and the health of the developing child. It is a separate clinical phenomenon from generalised anxiety, with distinct associations with birth outcomes such as lower birth weight (Blackmore et al., 2016) and child development. For example, pregnancy-related anxiety has been associated with lower cognitive and motor development in infancy (Huizink et al., 2003) and executive function in childhood (Buss et al., 2011).

The perinatal wellbeing of women with disabilities has received little attention. The limited evidence available suggests that women with (physical, mental or emotional) disabilities may be at increased risk of postnatal depression symptomology after accounting for socio-economic factors and a history of depression (Mittra et al., 2015). The wellbeing of autistic people across the perinatal period remains unexplored.

Outside of the perinatal period, autistic people are more likely to encounter mental health difficulties than non-autistic people (Lai et al., 2019). This may be due to biological factors (e.g. overlapping genetic influences of autism and other conditions; Carroll & Owen, 2009) in addition to the challenges of the autistic experience. For example, difficulties caused by sensory sensitivities (Uljarević et al., 2016) and intolerance of uncertainty (difficulty coping with ambiguity; Boulter et al., 2014) have been associated with increased anxiety among autistic people. Autistic people can be more vulnerable to negative life experiences such as unemployment and domestic abuse, and this increased vulnerability has been associated with depression and anxiety symptomology (Griffiths et al., 2019). Further, societal attitudes towards autism may influence autistic people's mental health. Non-autistic people can judge autistic people negatively and feel less favourably about engaging socially with autistic than non-autistic people (Sasson et al., 2017). Such negative perceptions may impact upon mental health, with a lack of external acceptance (feeling accepted as an autistic person by society, family and friends) and personal acceptance (accepting oneself as an autistic person) having been associated with depression among autistic people (Cage et al., 2018). Autistic people often also mask their autistic characteristics in order to fit in with neurotypical society, which can lead to feelings of inauthenticity and poorer mental health (Cage & Troxell-Whitman, 2019; Hull et al., 2017). Despite being at greater risk of poor mental health, autistic people can lack access to appropriate mental health support due to factors such as poor autism understanding among mental health professionals, communication difficulties with professionals and the unavailability of support adapted to the needs of autistic adults (Camm-Crosbie et al., 2019).

Autistic people may be at increased risk for lower perinatal wellbeing given the high co-occurrence of autism and mental health conditions and that a prior history of mental health conditions is a risk factor for poorer perinatal mental health (Lancaster et al., 2010). Indeed, findings from Chapter 3 and Pohl et al. (2020) suggest an increased risk of prenatal and postnatal anxiety and depression among autistic people. Findings from Chapters 2 and 3 point towards a number of stressors that autistic people face, including an increased physical toll of pregnancy, sensory difficulties during pregnancy and birth, challenges surrounding interactions with healthcare professionals and a lack of adequate adjustments to healthcare. These additional challenges may lead to a reduction in wellbeing during the perinatal period.

The findings of Chapters 2 and 3 also indicate a number of parenting strengths and challenges experienced by autistic people. Autistic parents sometimes expressed a lack of confidence in aspects of parenting such as knowing how to play with their child. Confidence concerning one's parenting ability within the first year of infancy has implications for the wellbeing of both parent and child, including associations with parenting satisfaction (Elek et al., 2003) and child developmental outcomes (Coleman & Karraker, 2003). As such, it is important to identify whether autistic people may be at risk of lower parenting confidence during the postnatal period.

Little is known about the parenting styles of autistic people. Given associations between parenting styles and child outcomes (as outlined in Chapter 1), it is important to understand what parenting strengths and challenges autistic people may face in order to identify potential targets for further support.

This study explored autistic and non-autistic people's self-reported anxiety, depression, stress and satisfaction with life during the third trimester of pregnancy, 2-3 months after birth and 6 months after birth. Pregnancy-related anxiety was explored during the third trimester of pregnancy and parenting confidence and parenting styles were explored at 6 months after birth. It was hypothesised that autistic people may experience higher anxiety, pregnancy-related anxiety, depression and stress and lower satisfaction with life across the perinatal period, in addition to lower parenting confidence.

4.2 Method

4.2.1 Participants

Participants completed questionnaires at 3 time-points: the third trimester of pregnancy, 2-3 months after birth, and 6 months after birth. A priori power analyses based on the large effect sizes found by Griffiths et al. (2019) for comparisons between autistic and non-autistic adults on self-report depression, anxiety and satisfaction with life measures (Cohen's $d=0.84$, 0.86 and 0.87 respectively), indicated a required total sample size of up to 46, given 80% power and a two-tailed alpha of 0.05.

Participants were: 27 autistic women and 25 non-autistic women at the pregnancy time-point; 24 autistic women and 26 non-autistic women at the 2-3 month time-point; and 22 autistic women and 29 non-autistic women at the 6 month time-point. 12 of the autistic

participants and all non-autistic participants took part through the CHILD study. The remaining autistic participants were part of the PEA study. Reasons for participant attrition are given in Figure 4.1. In addition, one autistic participant filled in only the Cohen's Perceived Stress Scale and State-Trait Anxiety Inventory at the 2-3 month time-point. One non-autistic participant completed all but the Edinburgh Postnatal Depression Scale at the 6 month time-point. One autistic participant completed only the Cohen's Perceived Stress Scale and State-Trait Anxiety Inventory at the 6 month time-point.

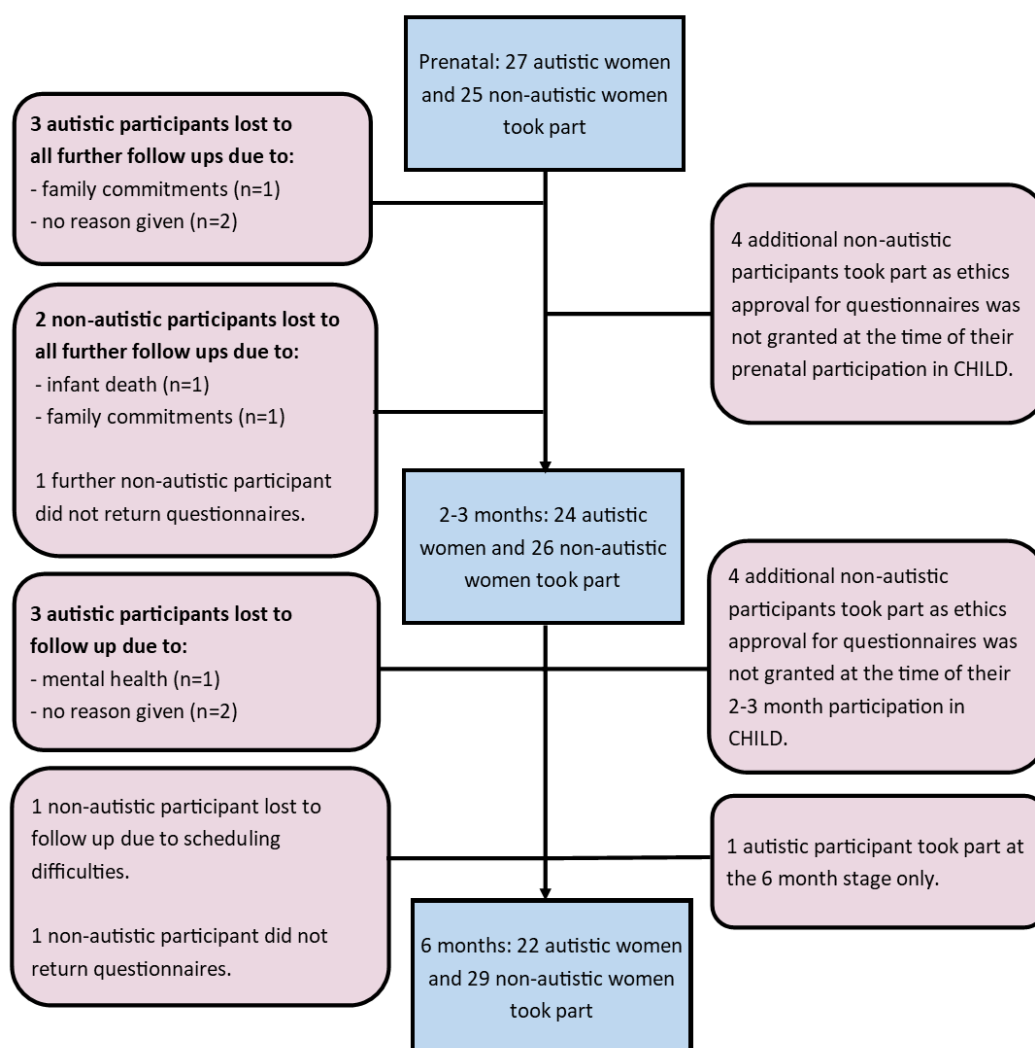


Figure 4.1 Reasons for participant attrition at each time-point.

Demographic information is presented in Table 4.1. Values are given for all time-points, though demographic questions and the AQ were administered only once at the prenatal time point. As such, changes across time-points (other than for age) are due to differing samples across time-points. The autistic group were significantly younger than the non-autistic group, had significantly lower education and income and were significantly more likely to have a diagnosis of a psychiatric condition. The autistic group also had significantly fewer children (at the 2-3 month and 6 month time-points only) and were significantly more likely to reside in a country other than the UK (for the 2-3 month and 6 month time-points only). The autistic group scored significantly higher on the AQ than the non-autistic group. The groups did not significantly differ on the age or sex of their child, ethnicity, pregnancy conditions or type of delivery. All infants were born at 36 weeks gestation or later. All mothers were married or in a partnership apart from 2 participants in the autistic group who took part at the prenatal time-point only.

Table 4.1 Demographic information for the autistic and non-autistic groups at each time-point.

	Prenatal			2-3 months			6 months		
	Autistic (n=27)	Non- autistic (n=25)	p-value (FDR corrected)	Autistic (n=24)	Non- autistic (n=26)	p-value (FDR corrected)	Autistic (n=22)	Non- autistic (n=29)	p-value (FDR corrected)
Mother's mean age (SD) ^a	30.84 (4.05)	33.84 (2.69)	0.01	31.04 (4.07)	34.33 (2.75)	0.01	31.48 (3.07)	34.89 (3.48)	0.002
Mean age of child in weeks/gestational weeks (SD) ^a	32.01 (2.58)	31.22 (2.26)	0.31	11.05 (1.67)	10.78 (1.58)	0.63	27.42 (1.41)	26.70 (1.01)	0.08
Sex of child ^b (female:male)	13:13	11:14	0.81	12:12	11:15	0.81	10:12	14:15	1
Ethnicity ^b			0.18			0.08			0.10
White	25 (93%)	19 (76%)		24 (100%)	21 (81%)		21 (100%)	24 (83%)	
Non-white	2 (7%)	6 (24%)		0 (0%)	5 (19%)		0 (0%)	5 (17%)	
Educational level ^b			0.01			0.01			0.01
Undergraduate or above	15 (56%)	23 (92%)		14 (58%)	24 (92%)		12 (57%)	27 (93%)	
A level or below	12 (44%)	2 (8%)		10 (42%)	2 (8%)		9 (43%)	2 (7%)	
Annual household income (£) ^b			0.001			0.002			0.004
>50,000	8 (31%)	20 (80%)		8 (33%)	22 (85%)		7 (33%)	23 (79%)	
≤50,000	18 (69%)	5 (20%)		16 (67%)	4 (15%)		14 (67%)	6 (21%)	
Psychiatric conditions ^b			<0.001			<0.001			<0.001
None	8 (30%)	23 (92%)		8 (33%)	24 (92%)		7 (33%)	26 (90%)	
Depression	2 (7%)	1 (4%)		2 (8%)	1 (4%)		1 (5%)	2 (7%)	

Depression and anxiety	9 (33%)	1 (4%)		6 (25%)	1 (4%)		6 (29%)	1 (3%)	
OCD and anxiety	2 (7%)	0 (0%)		2 (8%)	0 (0%)		2 (9%)	0 (0%)	
Other	6 (22%)	0 (0%)		6 (25%)	0 (0%)		5 (24%)	0 (0%)	
Country of residence ^b			0.11			0.03			0.01
UK	21 (77%)	25 (100%)		18 (75%)	26 (100%)		16 (73%)	29 (100%)	
USA	5 (19%)	0 (0%)		5 (21%)	0 (0%)		4 (18%)	0 (0%)	
Ireland	1 (4%)	0 (0%)		1 (4%)	0 (0%)		2 (9%)	0 (0%)	
Number of children (not including current pregnancy) ^b			0.18			0.03			0.04
0	21 (77%)	16 (64%)		19 (79%)	15 (58%)		17 (77%)	17 (59%)	
1	2 (7%)	7 (28%)		1 (4%)	9 (35%)		1 (5%)	10 (34%)	
2	4 (15%)	2 (8%)		4 (17%)	2 (8%)		4 (18%)	2 (7%)	
Pregnancy conditions ^b			0.43			-			-
Gestational diabetes	4 (15%)	1 (4%)		-	-		-	-	
Polyhydramnios	1 (4%)	1 (4%)		-	-		-	-	
Pre-eclampsia	0 (0%)	1 (4%)		-	-		-	-	
Type of delivery ^b			-			0.81			0.56
Vaginal	-	-		11 (46%)	15 (58%)		9 (41%)	17 (59%)	
Assisted vaginal (forceps or ventouse)	-	-		3 (12%)	3 (11%)		3 (14%)	3 (10%)	
Caesarean section	-	-		10 (42%)	8 (31%)		10 (45%)	9 (31%)	
Mean AQ score (SD) ^a	39.56 (5.39)	14.40 (7.46)	<0.001	39.58 (5.69)	15.69 (7.86)	<0.001	40.76 (4.59)	15.62 (7.39)	<0.001

Note. Information unavailable for one autistic participant who took part at the prenatal time-point only for mother's age, sex of child and income. Information unavailable for one autistic participant who took part at the 6 month time-point only for mother's age, ethnicity, education, income and psychiatric conditions.

^a T-test performed

^b Fisher's exact test performed

4.2.2 Procedure

Participants completed questionnaires once during the third trimester of pregnancy, once 2-3 months after giving birth and once 6 months after giving birth (questionnaires can be found in Appendix 4). Questionnaires were completed either in person as part of the CHILD study, via post or online through email or Qualtrics. The Cohen's Perceived Stress Scale, State-Trait Anxiety Inventory, Edinburgh Postnatal Depression Scale and Satisfaction with Life Scale were completed at all 3 time-points. The Pregnancy-Related Anxiety Questionnaire-Revised was completed at the prenatal time-point only. The Karitane Parenting Confidence Scale and Infancy Parenting Styles Questionnaire were completed at the 6 month time-point only.

4.2.2.1 Cohen's Perceived Stress Scale (CPSS).

The CPSS (Cohen et al., 1983) is a self-report questionnaire measuring stress. The CPSS consists of 10 items, which ask respondents to indicate how they have felt in the past month. The items are scored on a 5-point scale from 0 to 4, 'Never', 'Almost Never', 'Sometimes', 'Fairly Often', 'Very Often'. Items indicating a lack of stress are reverse scored and an overall score is obtained by summing the scores for all items. Scores range from 0 to 40, with higher scores indicating higher stress. A cut-off score of 20 or more indicates high stress. The CPSS has a Cronbach's alpha between 0.84 and 0.86 (Cohen et al., 1983), and has been widely used in both pregnant and postnatal populations.

4.2.2.2 State-Trait Anxiety Inventory (STAI).

The STAI (Spielberger et al., 1983) is a self-report questionnaire measuring anxiety. The STAI consists of two subscales: state anxiety and trait anxiety. Trait anxiety reflects a personality style of proneness to anxiety whereas state anxiety denotes a transient state of anxiety. In order to minimise participant burden, participants completed only the state anxiety subscale. This subscale consists of 20 items, scored on a 4-point scale from 1 to 4, 'not at all', 'somewhat', 'moderately so' and 'very much so'. Items measuring a lack of anxiety are reverse scored and the scores for each item are summed to create an overall score. Scores range from 20-80, with higher scores indicating greater anxiety. A cut-off score of 40 is commonly used to indicate potential clinical levels of anxiety. The STAI has been widely used during pregnancy and postnatally and has good validity and internal consistency in this population (Meades & Ayers, 2011).

4.2.2.3 Pregnancy-Related Anxiety Questionnaire-Revised (PRAQ-R2).

The PRAQ-R2 (Huizink et al., 2016) is a self-report measure of pregnancy-related anxiety. It consists of 10 items scored on a 5-point scale from 1 ('definitely not true') to 5 ('definitely true'). Scores range from 10 to 50 with higher scores indicating greater anxiety. The PRAQ-R2 consists of 3 subscales: 'Fear of giving birth', 'Worries about bearing a physically or mentally handicapped child' and 'Concern about own appearance'. The PRAQ-R2 is widely used during pregnancy has good psychometric properties with a Cronbach's alpha above 0.80 for the overall scale and above 0.70 for each of the subscales in both parous and nulliparous women (Huizink et al., 2004; Huizink et al., 2016).

4.2.2.4 Edinburgh Postnatal Depression Scale (EPDS).

The EPDS (Cox et al., 1987) is a self-report questionnaire designed to measure symptoms of depression. It consists of 10 items, which ask the respondent to indicate how they have been feeling in the past 7 days. The items are scored on a 4-point scale from 0 to 3 and items indicating a lack of depressive symptomology are reverse scored. A total score is obtained by summing the scores of the 10 items, with scores ranging from 0 to 30. Higher scores indicate greater depressive symptoms, with scores of 13 or above indicating the presence of a depressive illness. The EPDS is commonly used as a screening tool for perinatal depression and is has good reliability and validity when used during pregnancy and postnatally (Bergink et al., 2011; Eberhard-Gran et al., 2001).

4.2.2.5 Satisfaction with Life Scale (SWLS).

The SWLS (Diener et al., 1985) is a self-report measure of satisfaction with life. It consists of 5 items, scored on a 7-point scale from 1 ('strongly disagree') to 7 ('strongly agree'). Scores for each item are summed to create a total score, ranging from 5 to 35. Higher scores correspond to greater satisfaction with life (scores of 5-9 = 'extremely dissatisfied', 10-14 = 'dissatisfied', 15-19 = 'slightly dissatisfied', a score of 20 = 'neutral', 21-25 = 'slightly satisfied', 26-30 = 'satisfied', 31-35 = 'extremely satisfied'). The SWLS measures subjective satisfaction concerning one's life as a whole, rather than specific domains (e.g. employment or relationships). As such, it does not rely on normative ideas of what constitutes positive wellbeing and therefore may be particularly suited to capturing the wellbeing of neurodiverse populations. The scale is widely used and has good reliability and validity in the general population (Pavot & Diener, 2008) and during the perinatal period (Aasheim et al., 2014).

4.2.2.6 Karitane Parenting Confidence Scale (KPCS).

The KPCS (Črnčec et al., 2008) is a 15 item self-report questionnaire measuring perceived parenting confidence in parents of children aged 0-12 months. Items are scored on a 4-point scale from 0 to 3 (0 = 'no, hardly ever', 1 = 'no, not very often', 2 = 'yes, some of the time', and 3 = 'yes, most of the time'). Scores for each item are summed to create a total score ranging from 0 to 45, with higher scores indicating greater confidence. A cut-off score of 39 or below indicates clinically low parenting confidence (36-39 = 'mild clinical range', 31-35 = 'moderate clinical range', 30 or less = 'severe clinical range'). The KPCS has a Cronbach's alpha of 0.81 and test-retest reliability of 0.88 (Črnčec et al., 2008).

4.2.2.7 Infancy Parenting Styles Questionnaire (IPSQ).

The IPSQ (Arnott & Brown, 2013) is a 25 item self-report questionnaire measuring parenting styles in parents of children aged 0-12 months. Items are scored on a 5-point scale (1 = 'strongly disagree', 5 = 'strongly agree'). The IPSQ consists of 5 subscales: 'discipline' (belief that an infant can be naughty and need to control the infant's behaviour), 'routine' (encouragement of strict sleep and feeding routines), 'anxiety' (anxiety about the infant's health or development), 'nurturance' (responding promptly and sensitively to the infant) and 'involvement' (promoting the infant's development). Discipline and routine are intended to correspond to the dimension of control, and nurturance to the dimension of warmth, in relation to models of parenting styles for older children (Baumrind, 1978). Cronbach's alpha for the subscales range from 0.65 to 0.88 (Arnott & Brown, 2013).

4.2.3 Data analysis

At the prenatal time-point, data was missing for one item on the CPSS for one autistic participant and for one item on the EPDS for one autistic participant. To avoid reducing the sample size, rather than exclude these participants the missing values were imputed using the individual participant's mode for that questionnaire. While multiple imputation methods are often considered preferable to single imputation, when less than 10% of values are missing single imputation can be considered appropriate for item non-response on questionnaires (Eekhout et al., 2014; Shrive et al., 2006). Questionnaire item imputation using an individual's score has been shown to be preferable to using the overall sample score (Shrive et al., 2006). Data for income was unavailable for one autistic participant who took part at the prenatal time-point only and one autistic participant who took part at the 6 month

time-point only. Data for psychiatric conditions was unavailable for one autistic participant who took part at the 6 month time-point only. To avoid excluding these participants from analyses involving income or depression/anxiety as a covariate, and given the small amount of missing data, the missing values were imputed with the mode of the autistic group.

For those questionnaires completed at one time-point only, group differences were explored through multiple linear regression, with group membership (autistic/non-autistic) as a predictor and scores on the questionnaires as the outcome. Regression was considered preferable to ANCOVA due to assumptions of ANCOVA not being met, including an unbalanced design, non-normality of some dependent variables and a lack of independence between the independent variable (group membership) and covariates.

Parity (whether or not the participant had previously experienced a live birth) was included as a covariate in all regressions due to associations between parity and perinatal wellbeing (Di Florio et al., 2014). Income was also included as a covariate given the association between socio-economic factors and perinatal mental health (e.g. Lancaster et al., 2010). Income was chosen rather than education as, while various socio-economic factors impact upon maternal mental health, financial factors are a particularly strong predictor (Crosier et al., 2007; Kahn et al., 2000). While the autistic group was significantly younger than the non-autistic group, age was not included as a covariate as the difference in mean age was small (both groups were on average in their early thirties). A prior history of mental health conditions is an important risk factor for poorer perinatal mental health (Lancaster et al., 2010). In order to take into account a history of depression, whether or not participants had received a prior diagnosis of depression was included as a covariate in the analysis of depression scores. Similarly, a prior diagnosis of anxiety was included as a covariate in the analysis of anxiety scores.

In order to provide descriptive statistics on how prior and current mental health compare, for both depression and anxiety, the percentage of participants in each group with a prior diagnosis is reported alongside the percentage of participants scoring above the cut-off at each time point (Table 4.5 and Table 4.8 for depression and anxiety respectively). The percentage of participants scoring in the clinical range is also reported for stress and parenting confidence. For stress, depression and anxiety, the percentage of participants scoring above the cut-off during pregnancy who do not go on to score above the cut-off at either postnatal

time-point are reported, in addition to the percentage scoring above the cut-off during at least one postnatal time-point who had not scored above the cut-off during pregnancy. These data are presented in order to provide an indication of the timing of the onset of clinical levels of psychiatric symptomology over the perinatal period.

For those questionnaires completed at all three time-points, group differences and differences across time-points were explored using multilevel models (using maximum likelihood estimation). Multilevel models were considered preferable to repeated-measures ANOVAs due to the ability of multilevel models to better accommodate missing data and their greater flexibility. In all models, group membership, time-point, an interaction between group and time-point, income and parity were included as fixed effects, with scores on the questionnaires as the outcome. For each model, a random intercept for participant was included to account for non-independence due to repeated measures. Models additionally involving a random slope for time-point (to allow for the effect of time-point to differ across participants) and models involving a random slope for time-point and a first-order autoregressive covariance structure (as time-points were approximately evenly spaced) were also considered. For each outcome, the inclusion of random slopes and covariance structures did not significantly improve the model and resulted in higher AIC/BIC values and therefore random slopes and correlation structures were not included in the final models presented.

The median and interquartile range (IQR), rather than the mean and standard deviation (SD), are reported for any non-normally distributed variables. For some linear regressions and multilevel models the assumptions of normality of residuals and/or homoscedasticity were violated. In these cases, robust standard errors and p-values were calculated through bootstrapping with 2000 replications.

4.2.3.1 Treatment of missing follow-up data.

It is possible that participant attrition may influence results, particularly if those participants lost to follow-up were those experiencing greater challenges and, as such, lower wellbeing. Analyses were run with and without those with incomplete data for one or more time-points and results did not substantially differ. As such, only analyses involving all participants (including those with incomplete data) are reported.

4.3 Results

4.3.1 Stress

The autistic group had higher stress scores than the non-autistic group at each time-point and stress scores for both groups decreased over time (Table 4.2; Figure 4.2). A greater percentage of the autistic group than the non-autistic group scored above the cut-off for stress at each time-point. For the autistic group, a minority of those who scored above the cut-off during pregnancy did not go on to score above the cut-off at either postnatal time-point (29%) and similarly, only a minority of those who scored above the cut-off during at least one postnatal time-point had not scored above the cut-off during pregnancy (13%; Table 4.3). Conversely, for the non-autistic group, all of those who scored above the cut-off during pregnancy did not go on to score above the cut-off at either postnatal time-point and all of those who scored above the cut-off during at least one postnatal time-point had not scored above the cut-off during pregnancy.

Table 4.2 Stress scores and the number and percentage of participants scoring above the cut-off at each time-point for the autistic and non-autistic groups.

	Prenatal		2-3 months		6 months	
	Autistic (n=27)	Non- autistic (n=25)	Autistic (n=24)	Non- autistic (n=26)	Autistic (n=22)	Non- autistic (n=29)
Mean stress score (SD)	23.48 (7.17)	14.08 (6.26)	20.04 (7.78)	13.00 (6.15)	19.00 (5.82)	12.35 (6.17)
N (%) above cut-off (≥ 20)	20 (74%)	4 (16%)	14 (58%)	3 (12%)	11 (50%)	4 (14%)

Table 4.3 Number and percentage of participants scoring above the cut-off for stress prenatally who do not score above the cut-off postnatally and number and percentage of participants scoring above the cut-off for stress postnatally who do not score above the cut-off prenatally.

	Autistic (n scoring above cut-off prenatally = 14)	Non-autistic (n scoring above cut- off prenatally = 2)
N(%) of those who score above the cut-off prenatally who do not score above the cut-off postnatally ^a	4 (29%)	2 (100%)
	Autistic (n scoring above cut-off postnatally = 15)	Non-autistic (n scoring above cut- off postnatally = 3)
N(%) of those who score above the cut-off postnatally who do not score above the cut-off prenatally ^b	2 (13%)	3 (100%)

^aOnly participants with complete data for all time-points included in calculations (n=21 (autistic group), n=20 (non-autistic group)).

^bOnly participants with data for the prenatal time-point and at least one postnatal time-point included in calculations (n=24 (autistic group), n=23 (non-autistic group)).

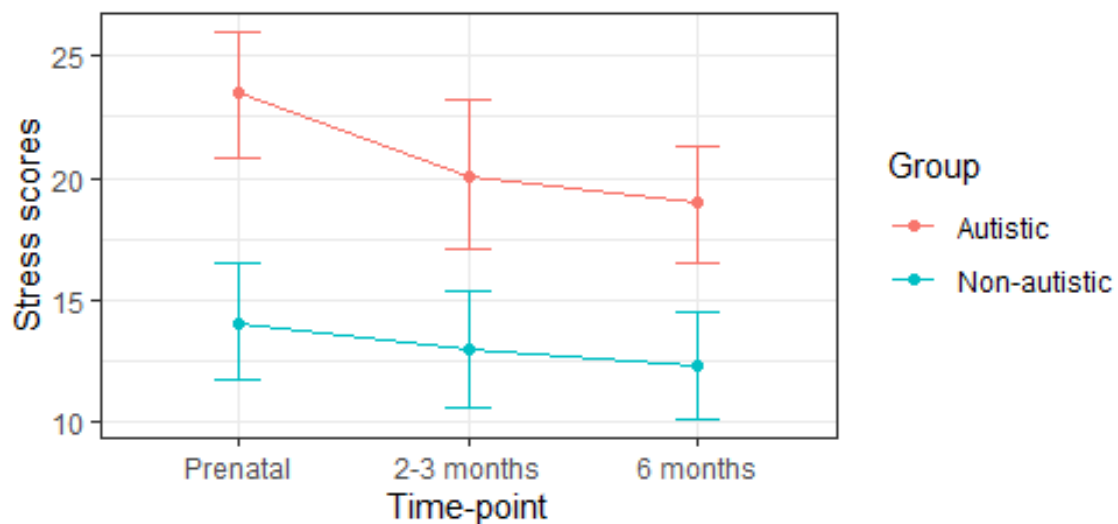


Figure 4.2 Mean stress scores for the autistic and non-autistic groups at each time-point (error bars represent 95% confidence intervals).

A multilevel model was conducted to explore the effects of group, time-point and their interaction on stress scores (Table 4.4). There was significant variance in intercepts across participants, $SD=4.53$ (95% CI: 3.48, 5.88), $\chi^2(1)=51.70$, $p<0.001$. Group significantly predicted

stress scores, indicating that the autistic group scored significantly higher across the 3 time-points as a whole. Post-hoc tests (with Tukey adjustment) confirmed that the autistic group scored significantly higher at all 3 time-points (prenatal: $B(SE)=7.62(1.98)$, $p=0.004$; 2-3 months: $B(SE)=6.50(2.02)$, $p=0.02$; 6 months: $B(SE)=6.28(1.99)$, $p=0.03$). Time-point did not significantly predict stress scores, indicating that the decrease in scores over time was not significant. There was no significant interaction between group and time-point, indicating that the autistic and non-autistic groups did not significantly differ in how their stress scores changed over time.

Table 4.4 Results of the multilevel regression model for stress scores.

	B (SE)	p-value
Group	7.50 (1.84)	<0.001
Time-point	-1.00 (0.66)	0.12
Group*Time-point	-0.74 (0.91)	0.43
Income	-3.35 (1.67)	0.05
Parity	1.76 (1.55)	0.26

4.3.2 Depression

The autistic group had higher depression scores than the non-autistic group at each time-point and depression scores for both groups decreased over time (Table 4.5; Figure 4.3). A greater percentage of the autistic group than the non-autistic group scored above the cut-off for depression at each time-point and a greater percentage of the autistic group had a prior diagnosis of depression. For both groups, a similar percentage scored above the cut-off at each time-point as had a prior diagnosis of depression. For both groups, many (autistic group: 43%; non-autistic group: 67%) of those who scored above the cut-off during pregnancy did not go on to score above the cut-off at either postnatal time-point and around half (autistic group: 54%; non-autistic group: 50%) of those who scored above the cut-off during at least one postnatal time-point did not score above the cut-off during pregnancy (Table 4.6).

Table 4.5 Depression scores, the number and percentage of participants scoring above the cut-off and the number and percentage of participants with a prior depression diagnosis at each time-point for the autistic and non-autistic groups.

	Prenatal		2-3 months		6 months	
	Autistic (n= 27)	Non- autistic (n=25)	Autistic (n=23)	Non- autistic (n=26)	Autistic (n=21)	Non- autistic (n=28)
Median depression score (IQR)	11.00 (8.50)	7.00 (6.00)	11.00 (10.50)	6.00 (5.00)	8.00 (9.00)	4.50 (6.50)
N (%) above cut-off (\geq 13)	13 (48%)	3 (12%)	11 (48%)	2 (8%)	8 (38%)	3 (11%)
N (%) with a prior depression diagnosis	14 (52%)	2 (8%)	11 (48%)	2 (8%)	9 (43%)	3 (11%)

Table 4.6 Number and percentage of participants scoring above the cut-off for depression prenatally who do not score above the cut-off postnatally and number and percentage of participants scoring above the cut-off for depression postnatally who do not score above the cut-off prenatally.

	Autistic (n scoring above cut-off prenatally = 7)	Non-autistic (n scoring above cut-off prenatally = 3)
N(%) of those who score above the cut-off prenatally who do not score above the cut-off postnatally ^a	3 (43%)	2 (67%)
	Autistic (n scoring above cut-off postnatally = 13)	Non-autistic (n scoring above cut-off postnatally = 2)
N(%) of those who score above the cut-off postnatally who do not score above the cut-off prenatally ^b	7 (54%)	1 (50%)

^aOnly participants with complete data for all time-points included in calculations (n=20 (autistic group), n=19 (non-autistic group)).

^bOnly participants with data for the prenatal time-point and at least one postnatal time-point included in calculations (n=23 (autistic group), n=23 (non-autistic group)).

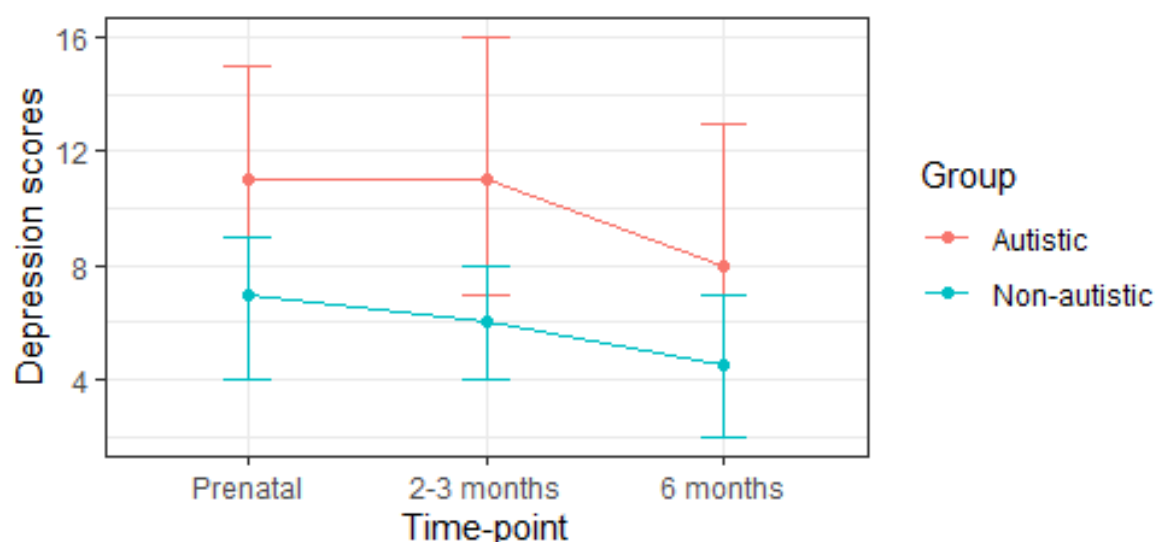


Figure 4.3 Median depression scores for the autistic and non-autistic groups at each time-point (error bars represent 95% confidence intervals).

A multilevel model was conducted to explore the effects of group, time-point and their interaction on depression scores (Table 4.7). There was significant variance in intercepts across participants, $SD=4.00$ (95% CI: 3.15, 5.08), $\chi^2(1)=56.74$, $p<0.001$. Group significantly predicted depression scores, indicating that the autistic group scored significantly higher across the 3 time-points as a whole. Post-hoc tests (with Tukey adjustment) confirmed that the autistic group scored significantly higher at all 3 time-points (prenatal: $B(SE)=5.34(1.69)$, $p=0.03$; 2-3 months: $B(SE)=5.37(1.72)$, $p=0.03$; 6 months: $B(SE)=5.62(1.71)$, $p=0.02$). Time-point did not significantly predict depression scores and there was no significant interaction between group and time-point.

Table 4.7 Results of the multilevel regression model for depression scores.

	B (SE)	p-value
Group	3.72 (1.69)	0.03
Time-point	-0.70 (0.50)	0.18
Group*Time-point	0.19 (0.71)	0.79
Income	-0.75 (1.44)	0.60
Parity	-0.07 (1.33)	0.94
Diagnosis of depression	3.80 (1.51)	0.01

Note. Bootstrapped standard errors and p-values reported

4.3.3 Anxiety

The autistic group had higher anxiety scores than the non-autistic group at each time-point and anxiety scores for both groups tended to decrease over time (Table 4.8; Figure 4.4). A greater percentage of the autistic group than the non-autistic group scored above the cut-off for anxiety at each time-point and a greater percentage of the autistic group had a prior diagnosis of an anxiety disorder. For both groups, a greater percentage scored above the cut-off at the prenatal and 2-3 month time-points than had a prior diagnosis of an anxiety disorder, and a greater percentage of the non-autistic group scored above the cut-off at the 6 month time-point than had a prior diagnosis of an anxiety disorder. For both groups, many (autistic group: 40%; non-autistic group: 40%) of those who scored above the cut-off during pregnancy did not go on to score above the cut-off at either postnatal time-point (Table 4.9). The percentage of those who scored above the cut-off during at least one postnatal time-point having not scored above the cut-off during pregnancy was greater for the non-autistic group (40%) than the autistic group (20%).

Table 4.8 Anxiety scores, the number and percentage of participants scoring above the cut-off and the number and percentage of participants with a prior anxiety disorder diagnosis at each time-point for the autistic and non-autistic groups.

	Prenatal		2-3 months		6 months	
	Autistic (n= 27)	Non- autistic (n=25)	Autistic (n=23)	Non- autistic (n=26)	Autistic (n=22)	Non- autistic (n=29)
Median anxiety score (IQR)	47.00 (17.50)	31.00 (13.00)	49.00 (26.25)	27.50 (12.25)	39.00 (20.00)	28.00 (10.00)
N (%) above cut-off (≥ 40)	21 (78%)	7 (28%)	13 (54%)	5 (19%)	10 (45%)	3 (10%)
N (%) with a prior anxiety disorder diagnosis	14 (52%)	1 (4%)	11 (48%)	1 (4%)	10 (45%)	1 (3%)

Table 4.9 Number and percentage of participants scoring above the cut-off for anxiety prenatally who do not score above the cut-off postnatally and number and percentage of participants scoring above the cut-off for anxiety postnatally who do not score above the cut-off prenatally.

	Autistic (n scoring above cut-off prenatally = 15)	Non-autistic (n scoring above cut-off prenatally = 5)
N(%) of those who score above the cut-off prenatally who do not score above the cut-off postnatally ^a	6 (40%)	2 (40%)
	Autistic (n scoring above cut-off postnatally = 15)	Non-autistic (n scoring above cut-off postnatally = 5)
N(%) of those who score above the cut-off postnatally who do not score above the cut-off prenatally ^b	3 (20%)	2 (40%)

^aOnly participants with complete data for all time-points included in calculations (n=21 (autistic group), n=20 (non-autistic group)).

^bOnly participants with data for the prenatal time-point and at least one postnatal time-point included in calculations (n=24 (autistic group), n=23 (non-autistic group)).

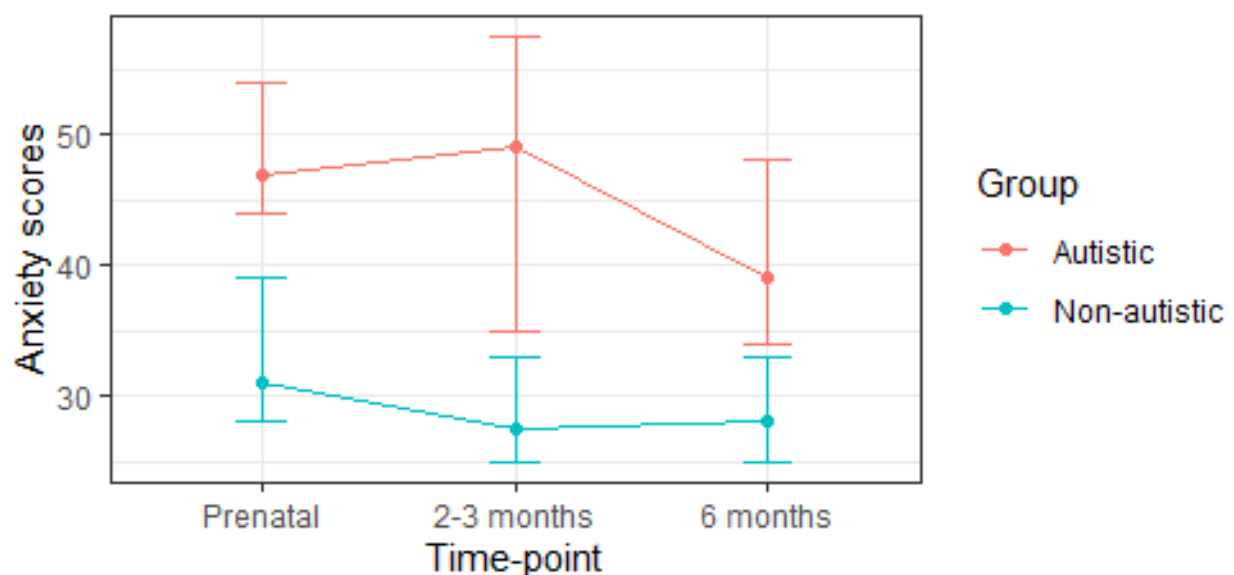


Figure 4.4 Median anxiety scores for the autistic and non-autistic groups at each time-point (error bars represent 95% confidence intervals).

A multilevel model was conducted to explore the effects of group, time-point and their interaction on anxiety scores (Table 4.10). There was significant variance in intercepts across participants, $SD=8.00$ (95% CI: 6.09, 10.52), $\chi^2(1)=44.33$, $p<0.001$. Group significantly predicted anxiety scores, indicating that the autistic group scored significantly higher across the three time-points as a whole. Post-hoc tests (with Tukey adjustment) confirmed that the autistic group scored significantly higher at all time-points (prenatal: $B(SE)=11.05(3.66)$, $p=0.04$; 2-3 months: $B(SE)=15.48(3.72)$, $p=0.002$; 6 months: $B(SE)=14.04(3.68)$, $p=0.004$). Time-point significantly predicted anxiety scores, indicating a significant decrease in anxiety scores over time. Post-hoc tests (with Tukey adjustment) revealed a significant decrease from the prenatal to the 6 month time-point ($B(SE)=-6.34(2.39)$, $p=0.02$), though there was no significant difference between the prenatal and 2-3 month time-points ($B(SE)=-5.45(2.40)$, $p=0.06$). There was no significant interaction between group and time-point.

Table 4.10 Results of the multilevel regression model for anxiety scores.

	B (SE)	p-value
Group	10.18 (4.00)	0.01
Time-point	-3.11 (1.23)	0.01
Group*Time-point	1.50 (1.74)	0.37
Income	-3.29 (3.13)	0.29
Parity	0.81 (2.95)	0.80
Diagnosis of anxiety	3.63 (3.65)	0.32

Note. Bootstrapped standard errors and p-values reported

4.3.4 Satisfaction with life

A multilevel model was conducted to explore the effects of group, time-point and their interaction on satisfaction with life scores (Table 4.12). There was significant variance in intercepts across participants, $SD=4.86$ (95% CI: 3.87, 6.10), $\chi^2(1)=70.40$, $p<0.001$. While the autistic group scored lower than the non-autistic group at each time-point (Table 4.11; Figure 4.5), neither group nor time-point significantly predicted satisfaction with life scores and there was no significant interaction between group and time-point.

Table 4.11 Satisfaction with life scores at each time-point for the autistic and non-autistic groups.

	Prenatal		2-3 months		6 months	
	Autistic (n= 27)	Non- autistic (n=25)	Autistic (n=23)	Non- autistic (n=26)	Autistic (n=21)	Non- autistic (n=29)
Median satisfaction with life score (IQR)	23.00 (10.50)	30.00 (5.00)	25.00 (8.50)	31.00 (7.00)	27.00 (9.00)	29.00 (6.00)

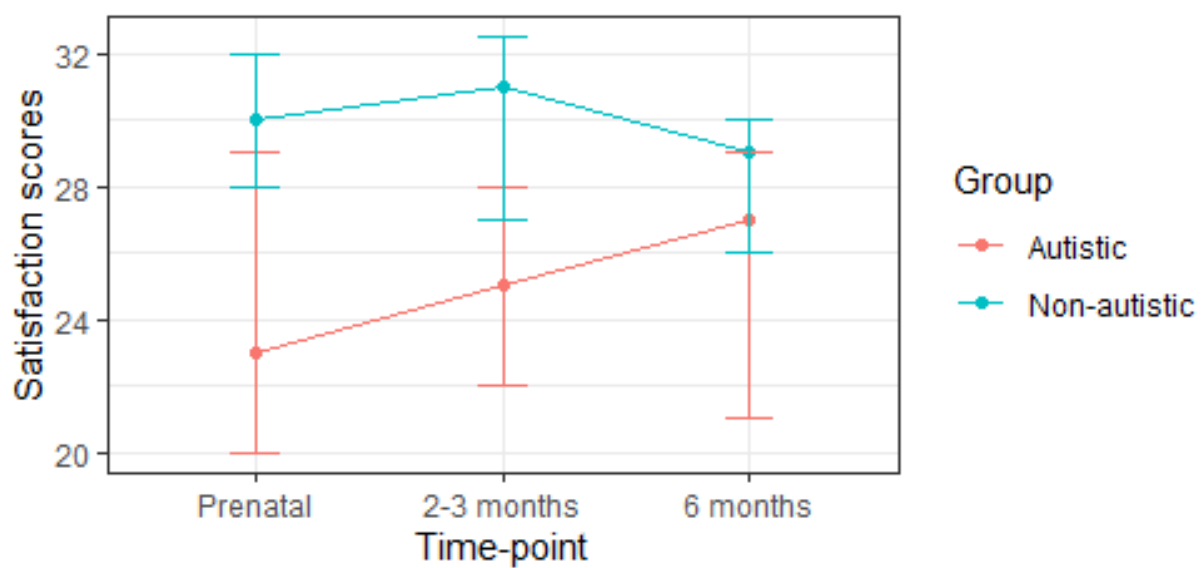


Figure 4.5 Median satisfaction with life scores for the autistic and non-autistic groups at each time-point (error bars represent 95% confidence intervals).

Table 4.12 Results of the multilevel regression model for satisfaction with life scores.

	B (SE)	p-value
Group	-2.81 (1.83)	0.13
Time-point	0.53 (0.51)	0.28
Group*Time-point	0.44 (0.74)	0.56
Income	4.56 (1.68)	0.004
Parity	-0.37 (1.53)	0.84

Note. Bootstrapped standard errors and p-values reported

4.3.5 Pregnancy-related anxiety

Multiple linear regression revealed that group was a significant predictor of PRAQ-R2 total score, indicating that the autistic group scored significantly higher than the non-autistic group (Table 4.13; Figure 4.6). Group was not a significant predictor of scores on any of the PRAQ-R2 subscales, 'Fear of giving birth', 'Worries about bearing a physically or mentally handicapped child' or 'Concern about own appearance'.

Table 4.13 PRAQ-R2 total scores and subscale scores for the autistic and non-autistic groups and results of the regression models for PRAQ-R2 total scores and subscale scores.

	Autistic (n=27)	Non-autistic (n=25)	B (SE)	p-value
Mean PRAQ-R total score (SD)	31.96 (7.76)	26.04 (7.86)		
Group			5.55 (2.59)	0.04
Income			0.06 (2.58)	0.98
Parity			-2.97 (2.48)	0.24
Model: F(3, 48)=2.97, p=0.04, R ² =0.16				
Mean fear of giving birth (SD)	10.37 (3.20)	8.64 (3.25)		
Group			1.47 (1.08)	0.18
Income			-0.27 (1.07)	0.81
Parity			-0.91 (1.03)	0.38
Model: F(3, 48)=1.48, p=0.23, R ² =0.08				
Mean worries about bearing a physically or mentally handicapped child (SD)	13.44 (4.07)	10.12 (4.51)		
Group			2.56 (1.39)	0.07
Income			-0.83 (1.39)	0.55
Parity			-2.53 (1.33)	0.06
Model: F(3, 48)=3.91, p=0.01, R ² =0.20				
Median concern about appearance (IQR) ^a	8.00 (6.50)	8.00 (6.00)		
Group			1.52 (1.11)	0.15
Income			1.16 (1.14)	0.29
Parity			0.47 (1.11)	0.70
Model: F(3, 48)=1.17, p=0.63, R ² =0.04				

^aBootstrapped standard errors and p-values reported

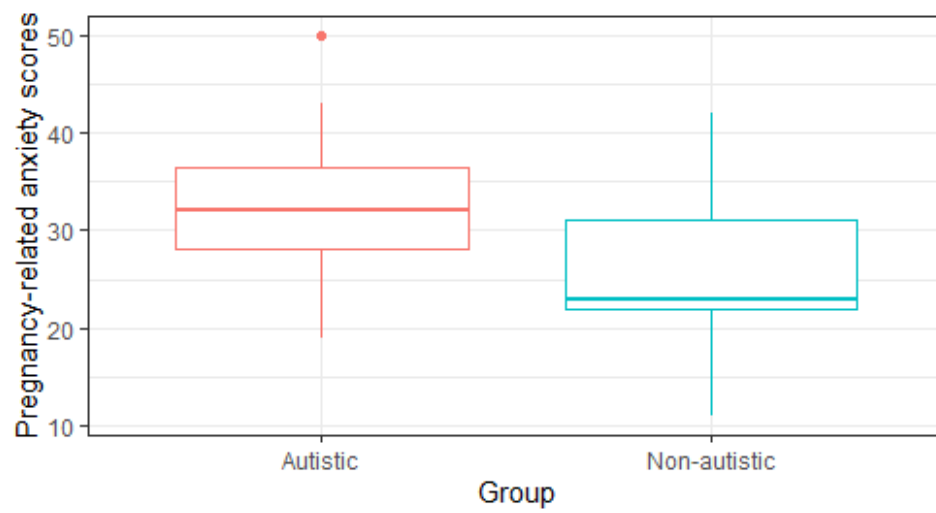


Figure 4.6 PRAQ-R2 total scores for the autistic and non-autistic groups.

4.3.6 Infancy parenting styles

Multiple linear regressions revealed no significant associations between group and any subscale of the IPSQ (Table 4.14).

Table 4.14 IPSQ subscales scores for the autistic and non-autistic groups and results of regression models for the IPSQ subscale scores.

	Autistic (n=22)	Non-autistic (n=29)	B (SE)	p-value
Mean anxiety (SD)	11.10 (3.27)	9.28 (2.62)		
Group			1.12 (0.93)	0.24
Income			-0.57 (0.92)	0.54
Parity			-2.34 (0.84)	0.01
Model: $F(3, 46)=4.42$, $p=0.01$, $R^2=0.22$				
Median discipline (IQR) ^a	10.00 (4.00)	10.00 (6.00)		
Group			-3.53 (1.73)	0.05
Income			-1.93 (1.84)	0.30
Parity			-1.90 (1.31)	0.18
Model: $F(3, 46)=2.26$, $p=0.09$, $R^2=0.13$				
Mean involvement (SD)	17.91 (3.00)	18.76 (2.57)		
Group			-1.35 (0.93)	0.16
Income			-0.56 (0.92)	0.55
Parity			-1.21 (0.84)	0.16
Model: $F(3, 46)=1.16$, $p=0.33$, $R^2=0.07$				
Mean nurturance (SD)	14.48 (2.89)	12.76 (2.08)		
Group			1.38 (0.84)	0.11
Income			-0.69 (0.83)	0.41
Parity			0.08 (0.76)	0.92
Model: $F(3, 46)=2.18$, $p=0.10$, $R^2=0.12$				
Mean routine (SD)	15.86 (4.66)	16.90 (3.36)		
Group			-0.49 (1.36)	0.72
Income			0.78 (1.34)	0.56
Parity			0.89 (1.22)	0.47
Model: $F(3, 46)=0.54$, $p=0.66$, $R^2=0.03$				

^aBootstrapped standard errors and p-values reported

4.3.7 Parenting confidence

The autistic group scored on average lower than the non-autistic group on the KPCS and a greater percentage of the autistic group than the non-autistic group scored within the moderate and severe clinical ranges for low parenting confidence (Table 4.15). However, multiple linear regression revealed no significant association between group and scores on the KPCS (Table 4.16), indicating that scores did not significantly differ between the groups.

Table 4.15 KPCS scores and the number and percentage of participants scoring in the clinical range for the autistic and non-autistic groups.

	Autistic (n=22)	Non-autistic (n=29)
Median KPCS score (IQR)	40.00 (8.00)	42.00 (4.00)
N (%) below clinical cut-off (≤ 39)	10 (48%)	8 (28%)
N (%) Mild clinical range (36-39)	4 (19%)	7 (24%)
N (%) Moderate clinical range (31-35)	3 (14%)	1 (3%)
N (%) Severe clinical range (≤ 30)	3 (14%)	0 (0%)

Table 4.16 Results of the regression model for KPCS scores.

	B (SE)	p-value
Group	-1.97 (1.45)	0.18
Income	1.69 (1.51)	0.25
Parity	2.17 (1.16)	0.07
Model: $F(3, 46)=3.16$, $p=0.03$, $R^2=0.17$		

Note. Bootstrapped standard errors and p-values reported

4.4 Discussion

This is the first study to explore trajectories of wellbeing across the perinatal period among autistic and non-autistic people. The findings indicate that autistic people experience lower wellbeing during pregnancy and the first postnatal 6 months. Findings of higher perinatal stress, depression and anxiety symptoms among autistic people is consistent with evidence that autistic people have an increased risk of anxiety during pregnancy and the postnatal period (Chapter 3) as well as an increased risk of depression during pregnancy and the postnatal period (Chapter 3; Pohl et al., 2020).

Higher perinatal stress, depression and anxiety among autistic people compared with non-autistic people may in part be due to the negative experiences that autistic people can face during the perinatal period, as identified in Chapters 2 and 3. Prenatally, an increased physical toll of pregnancy (such as heightened sensory experiences, pain and morning sickness), a lack of autism understanding among healthcare professionals and inadequate adjustments to healthcare may contribute towards lower wellbeing. Postnatally, sensory and communication issues during childbirth, a lack of autism understanding among postnatal healthcare

professionals, fear of losing custody of one's child, the autism-specific demands of parenthood and a lack of support from friends may contribute towards lower wellbeing among autistic people. Susceptibility to lower wellbeing may also be due to hormonal differences between autistic and non-autistic people. As reported in Chapter 2, some participants felt that perinatal changes in mood may be linked to increased hormonal sensitivity among autistic people. This possibility is at present speculative, though is consistent with findings of altered hormone levels and increased risk of hormone-related conditions among autistic females (Gasser et al., 2020; Pohl et al., 2014). The groups did not significantly differ on satisfaction with life scores. This may have been due to lack of power, though a simulation-based post hoc sensitivity power analysis for mixed models indicated that the sample size was sufficient (for the total sample ($n=56$), there was adequate (80%) power to detect a beta of 0.25 or greater, with an alpha of 0.05). While the measures of stress, depression and anxiety focus on current or recent feelings, the SWLS focuses on overall satisfaction with one's life as a whole and as such may be less sensitive to current changes in wellbeing.

In addition to experiencing greater generalised anxiety during pregnancy, the autistic group scored higher on pregnancy-related anxiety. This may indicate that autistic people have greater pregnancy-specific concerns such as fears of childbirth and worries about their unborn child. This finding should be interpreted with caution, however, given that differences on the pregnancy-related anxiety subscales did not reach significance. This lack of significance may plausibly be due to a lack of power, however, given that a post hoc sensitivity power analysis indicated that for the total sample ($n=52$) and an alpha of 0.05, there was adequate (80%) power to detect an f^2 of 0.16 or greater, and f^2 ranged from 0.40-0.70 for the subscales.

It is possible that group differences in wellbeing are not particular to the perinatal period but rather reflect lower baseline wellbeing among autistic people. Indeed, a prior history of mental health conditions is an important risk factor for poorer perinatal mental health (Lancaster et al., 2010) and approximately two thirds of autistic participants in the present sample had a prior diagnosis of a psychiatric condition compared with approximately 10 percent of the non-autistic group. However, group differences in depression and anxiety scores remained after accounting for a prior diagnosis of depression or anxiety respectively. This suggests that higher depression and anxiety among the autistic group are not solely the

result of baseline group differences in mental health. For both groups, the percentage of participants with a prior diagnosis of depression and the percentage of participants scoring in the clinical range for depression were similar. However, the percentage of participants scoring in the clinical range for anxiety was substantially greater than the percentage with a prior anxiety diagnosis. This may suggest that the majority of cases of perinatal depression are preceded by a diagnosis of depression whereas a substantial percentage of cases of perinatal anxiety may not be preceded by an anxiety disorder diagnosis. This may be due to new cases of anxiety arising during the perinatal period or may reflect under-diagnosis of anxiety pre-pregnancy.

Stress, anxiety and depression scores tended to decrease over time for both groups, though this decrease only reached significance for anxiety. This pattern reflects prior findings in the general population of higher depression and anxiety during pregnancy than postnatally (Evans et al., 2001; Figueiredo & Conde, 2011; Heron et al., 2004). The present findings suggest that autistic people may follow a similar trajectory to non-autistic people in this regard. Improved wellbeing postnatally may be due to pregnancy-related worries (such as those outlined in Chapter 2, including anxiety concerning the unborn child's health and the uncertainty of childbirth outcomes) becoming resolved after the birth of a healthy child. It may also be due to physiological factors such as changes in hormone levels or the alleviation of the physical symptoms of pregnancy, such as nausea, pelvic pain and fatigue. Improved wellbeing may also be due to the benefits that parenthood brings (as outlined in Chapters 2 and 3), including feelings of love, connectedness and enjoying watching one's child learn and grow. For both groups, many of those scoring above the cut-off on the questionnaires during pregnancy no longer scored above the cut-off postnatally, while many of those scoring above the cut-off postnatally had not previously scored above the cut-off during pregnancy. This suggests substantial movement across the thresholds for stress, depression and anxiety symptomology over the course of the perinatal period and echoes similar prior findings for depression (Underwood et al., 2016).

There were no significant group differences on any subscales of the infancy parenting styles questionnaire, indicating that the groups did not differ in their self-perception of their parenting anxiety, discipline, involvement, nurturance or routine. This suggests that autistic and non-autistic people may be able to parent their children equally as effectively, including

being just as likely to provide an appropriate level of control (discipline and routine) and warmth (nurturance). However, this finding should be interpreted with caution, given that a post hoc sensitivity power analysis indicated that for the total sample ($n=51$) with an alpha of 0.05, there was adequate (80%) power to detect an f^2 of 0.16 or greater, and f^2 ranged from 0.003-0.13 for the IPSQ subscales. The groups did not significantly differ on parenting confidence, indicating that despite the parenting challenges that autistic participants identified in Chapters 2 and 3, autistic and non-autistic parents may be similarly confident in their parenting abilities. However, a greater percentage of autistic than non-autistic participants scored in the clinical range. This may indicate that despite the lack of a significant overall group difference, there may be a greater proportion of autistic parents who would benefit from support to improve their parenting confidence. Furthermore, the lack of group difference may be due to lack of power, given that a post hoc sensitivity power analysis indicated that for the total sample ($n=51$) with an alpha of 0.05, there was adequate (80%) power to detect an f^2 of 0.16 or greater, and the f^2 obtained was 0.04.

4.4.1 Limitations

Due to the challenges of recruiting currently pregnant autistic people, the study sample size is smaller than is typical of a longitudinal questionnaire study. It is possible that some null findings may be due to a lack of power and future studies employing larger samples would be necessary to corroborate the present findings. So as to minimise participant burden, questionnaires were administered at one prenatal time-point only. Wellbeing may vary across pregnancy due to changing physical experiences and changing concerns as the pregnancy progresses. It remains unclear, therefore, how the wellbeing of autistic people may change across pregnancy.

The autistic group and non-autistic comparison group were not well matched. The comparison group all resided in Cambridgeshire (and as such had access to a similar quality of perinatal healthcare) whereas the autistic group resided throughout the UK, USA and Ireland. In addition, the groups differed on demographic variables including socio-economic factors. The inclusion of income as a covariate in the analyses may have mitigated the effect of such differences, though future studies would benefit from the inclusion of a well-matched comparison group.

Baseline stress, depression and anxiety scores prior to pregnancy were not collected and it is therefore unclear whether the perinatal period represents a particularly vulnerable time for lower wellbeing among autistic people. Prospective studies exploring wellbeing from before pregnancy until the postnatal period could tease apart these issues.

4.4.2 Conclusions and considerations for clinical care

This study demonstrates that autistic people may be vulnerable to higher perinatal stress, depression and anxiety and higher pregnancy-related anxiety than non-autistic people. Perinatal healthcare professionals should be aware of this increased vulnerability. Together with reports of masking of perinatal mental health concerns among autistic people (Chapters 2 and 3), the findings highlight the need for effective screening and support surrounding perinatal wellbeing for autistic people. The tentative finding of an improvement in wellbeing from pregnancy to the postnatal period may indicate that, for both autistic and non-autistic people, pregnancy may be a period of increased need for support. Some autistic parents may particularly benefit from support to improve their parenting confidence. However, professionals working with autistic parents should be aware that autistic people may be no less likely than non-autistic people to engage in competent parenting, including providing appropriate warmth and control.

Chapter 5: Parent-infant interactions between autistic mothers and their infants.

5.1 Introduction

Caregiver-infant interactions are an important aspect of an infant's social environment, yet relatively little is known about how early social and communicative differences in autism manifest within this context. It is possible that parent and infant behaviour have a bidirectional effect, with infant and caregiver behaviour impacting upon each other (Sameroff, 2009). Exploring caregiver-infant interactions may therefore provide insights into the development of social differences in autism, in addition to identifying potential targets for caregiver-based interventions (Green et al., 2017).

Prospective studies of parent-infant interactions involving infants with high genetic likelihood of being autistic due to having an autistic sibling (hereafter 'HL infants') have revealed social differences between such infants and those with a low-likelihood of being autistic (hereafter 'LL infants'). These differences often become more evident from the latter half of the first year of life onwards and tend to be more pronounced for those HL infants who go on to receive a diagnosis of autism than those who do not.

HL infants tend to show delays in gesture use and parent-directed initiations during parent-infant interactions. This includes making fewer requesting behaviours at 12 months (Rozga et al., 2011) and at 14 months (Yirmiya et al., 2006) and making fewer show and point gestures and fewer gesture and non-word vocalisation combinations at 13 and 18 months (Winder et al., 2013). Regarding attentiveness to the parent, HL infants have been found not to differ from LL infants in gaze behaviour at 4 months (Yirmiya et al., 2006) parent-directed gaze, smiles and vocalisations at 6 months (Rozga et al., 2011), nor in time spent attending to the parent at 9 months (Northrup & Iverson, 2015) and 12 months (Steiner et al., 2018). However, HL infants later diagnosed with autism have been found to exhibit lower attentiveness to the parent at 12 months (though this difference was not yet evident at 6 months; Wan et al., 2013). Wan et al. (2013) found that HL infants scored lower than LL infants on liveliness at 6 months old (though this difference was not apparent at 14 months old) and those HL infants who later received an autism diagnosis showed more negative affect than LL infants at 14 months old (though this difference was not present at 6 months old).

In terms of parent behaviour, there is some evidence that parents of HL infants show greater directiveness (directing the infant's behaviour or attention) than parents of LL infants. Greater directiveness among parents of HL infants has been found at 9 months (Harker et al., 2016) and at 6 and 14 months (Wan et al., 2012, 2013), though others have found no differences (Campbell et al., 2015). While directiveness is often considered an undesirable behaviour, it is possible to show directiveness while responding sensitively to the infant's needs (Lloyd & Masur, 2014). However, many studies do not distinguish between desirable and undesirable forms of directiveness. Steiner et al. (2018) distinguished between synchronous demanding behaviours (behaviours that are consistent with the infant's focus of attention and that suggest that the infant perform a new behaviour) and non-synchronous demanding behaviours (behaviours that are inconsistent with the infant's focus of attention and that suggest that the infant perform a new behaviour). They found that parents of HL infants showed more synchronous-demanding behaviours than parents of LL infants at 12 months old. The groups did not differ in non-synchronous behaviour, suggesting that parents of HL infants may be just as sensitive as those of LL infants while making greater attempts to expand their infant's play through directive behaviour. It is possible that higher directiveness among parents of HL infants may be due to characteristics of the infant (e.g. fewer parent-directed initiations) or a learnt behavioural style developed in response to their older autistic child (Harker et al., 2016).

The majority of studies have found no differences between parents of HL and LL infants on sensitive responsiveness (Campbell et al. 2015; Harker et al., 2016; Leezenbaum et al., 2014). Campbell et al. (2015) further found no group differences in parental praise, scaffolding (providing support for problem solving and learning) or warmth at 11 months old. Schwichtenberg et al. (2019) found no group differences in parents' looking to the infant's face, positive affect or vocalizations during interactions with their 6, 9 or 12 month old infants. Furthermore, Leezenbaum et al., 2014 found that parents of HL infants showed greater labelling of their infant's gesture referents at 13 months old. The authors suggest that this may be an attempt to increase scaffolding due to concern about their infant's communication development. This is consistent with findings that mothers of HL infants (who did not go on to receive an autism diagnosis) use gestures more frequently than mothers of LL infants at 12 months old (Talbot et al., 2015).

Studies exploring dyadic aspects of parent-infant interactions have found lower synchrony among HL dyads than LL dyads at 4 months old (Yirmiya et al., 2006). For each second of play, Yirmiya et al. (2006) coded maternal and infant behaviours into categories (avert, object attend, social attend, object play, social play, and (for infants only) protest). Synchrony was defined as the existence of a significant cross-correlation between the mother's and infant's time series. Associations have also been found between later autism outcome and infant social reciprocity at 11 months (Campbell et al., 2015) and dyadic mutuality at 14 months (Wan et al., 2013).

There is no existing research exploring interactions between autistic parents and their infants. Findings from Chapters 2 and 3 suggest that some autistic mothers find play particularly challenging. It may therefore be important to identify areas of parent-infant play where autistic mothers may benefit from greater guidance. Conversely, play was identified as a parenting strength by a minority of autistic participants in Chapter 3. It is possible that some of the parenting strengths and challenges associated with being autistic identified in Chapters 2 and 3 could influence mothers' behaviour during interaction with their infants. For example, researching child development in detail could improve scaffolding behaviours, and a drive to be an understanding and accepting parent could result in greater sensitivity and lower directiveness. Greater attention to detail among autistic people (O'Riordan et al., 2001) may also result in greater attention to, and therefore sensitivity to, their infant's cues. Conversely, difficulty knowing how to play with one's infant could result in lower scaffolding and lower directiveness due to difficulty knowing how to direct play. Furthermore, differences in social communication among autistic people could make identifying and responding to their infant's social cues more challenging. Given findings that communication occurs more effectively within pairs where both members are autistic than within mixed autistic/non-autistic pairs (Crompton et al., 2020), it may be that synchrony within parent-child interactions is greater for dyads with matched rather than different neurotypes.

This study aimed to explore how autistic and non-autistic parents play with their infants, in order to identify potential areas of strength as well as areas where greater support may be beneficial. In addition, the study aimed to explore the behaviour of infants with an increased genetic likelihood of being autistic due to having an autistic mother or sibling. As parent and infant behaviour may have bidirectional influences and dynamically evolve over time, it is

important to explore these behaviours from a longitudinal perspective. As yet, only one study has explored interactions between HL infants and their parents within the first 6 months of life and this study involved only one time point within the first year of life (Yirmiya et al., 2006). Exploring parent and infant behaviours over the course of the first year is important in order to understand the timing of the emergence of behavioural differences and identify possible targets for parent-mediated interventions. This study investigated parent-infant interactions involving HL infants (infants with an autistic mother or sibling) and LL infants at 2-3 months and 6 months old.

Based on findings from prior prospective studies, it is possible that parents of HL infants will show more negative control than parents of LL infants, though no differences in sensitive responsiveness, scaffolding or affect. Given the scarcity of prior evidence concerning autistic parenting, specific hypotheses based on theorised autistic parenting styles are not made. Differences in parent behaviours may be more apparent than differences in infant behaviours, which may not yet be present at this young age. Based on prior findings (Yirmiya et al., 2006), there may be lower dyadic reciprocity among HL dyads.

5.2 Method

5.2.1 Participants

A simulation-based a priori power analysis based on the effect size found by Pijl et al. (2021) for their significant result (beta of 0.30 for initiations) indicated a required total sample size of 80, given 80% power and an alpha of 0.05. Pijl et al. (2021) were unable to detect effects for the other scales measured with a sample of 62 HL and 47 LL infants at 5 months and 101 HL and 77 LL infants at 10 months. Given the difficulties involved in recruiting autistic parents, however, useable data was obtained for 37 (10 HL and 27 LL) parent-infant dyads at the 2-3 month visit and 40 (11 HL and 29 LL) dyads at the 6 month visit. Adequate data was unable to be obtained for 3 of the 30 LL dyads who took part in the CHILD study visits at the 2-3 month stage: one parent did not wish to be video-recorded, data collection was interrupted for one dyad due to infant distress and for one interaction both parents were present. One of the 30 participating LL dyads did not return at the 6 month stage due to scheduling difficulties and one HL dyad took part in the CHILD study from the 6 month stage onwards and therefore data for this dyad is not available at the 2-3 month stage. Non-autistic parents with an autistic older child (sibling group) made up 3 of the HL group at the 2-3 month stage and 4 of the HL

group at the 6 month stage; all other parents in the HL group had an autism diagnosis (1 of whom also had an autistic older child). Parents in the sibling group did not have a diagnosis of autism and had a mean AQ score below the cut off of 32 (2-3 month mean=18.7 (SD=16.1), 6 month mean=15.5 (SD=14.6)). One father took part (LL group) and all other dyads involved the mother.

Demographic data are presented in Table 5.1 and Table 5.2. The HL and LL groups did not differ significantly on sex of the infant, gestational age at birth or birth weight. Infants in the HL group were significantly older than those in the LL group at the 6 month stage, though the groups did not significantly differ on corrected age (number of weeks between due date and the date of data collection) at either time-point. The groups did not significantly differ on ethnicity of the parent, psychiatric conditions of the parent, the parent's number of children or the parent's depression scores. At both time-points, parents in the LL group were significantly older, had significantly lower anxiety scores, had a higher educational level and higher income than the HL group. Parents in the HL group scored significantly higher than the LL group on the AQ.

Table 5.1 Demographic data for infants.

	2-3 month			6 month		
	High likelihood (n=10)	Low likelihood (n=27)	p-value (FDR corrected)	High likelihood (n=11)	Low likelihood (n=29)	p-value (FDR corrected)
Sex (female:male) ^a	5:5	14:13	0.92	6:5	15:14	0.87
Mean age in weeks (SD) ^b	11.58 (1.52)	10.96 (1.46)	0.60	27.43 (0.51)	26.77 (0.97)	0.04
Mean corrected age in weeks (SD) ^b	10.93 (2.72)	10.74 (1.80)	0.92	26.83 (1.72)	26.48 (1.65)	0.72
Mean gestational age at birth in weeks (SD) ^b	39.43 (1.68)	39.97 (1.19)	0.60	39.46 (1.59)	39.87 (1.32)	0.72
Mean birth weight in kilograms (SD) ^c	3.71 (0.57)	3.46 (0.41)	0.60	3.73 (0.54)	3.47 (0.40)	0.43

^aFisher's exact test performed^bT-test performed^cWilcoxon rank-sum test performed

Table 5.2 Demographic data for parents.

	2-3 month			6 month		
	High likelihood (n=10)	Low likelihood (n=27)	p-value (FDR corrected)	High likelihood (n=11)	Low likelihood (n=29)	p-value (FDR corrected)
Mean age (SD) ^a	31.22 (2.61)	34.25 (2.68)	0.01	31.88 (2.74)	34.84 (3.47)	0.02
Ethnicity ^b			0.30			0.16
White	10 (100%)	22 (81%)		11 (100%)	23 (79%)	
Non-white	0 (0%)	5 (19%)		0 (0%)	6 (21%)	
Educational level ^b			0.002			0.002
Undergraduate or above	4 (40%)	25 (93%)		4 (36%)	27 (93%)	
A-level or below	6 (60%)	2 (7%)		7 (64%)	2 (7%)	
Annual household income ^{b,d}			0.001			<0.001
>50,000	1 (10%)	22 (85%)		1 (10%)	23 (82%)	
≤ 50,000	9 (90%)	4 (15%)		9 (90%)	5 (18%)	
Psychiatric conditions ^b			0.10			0.13
None	6 (60%)	24 (89%)		7 (64%)	26 (90%)	
Depression	1 (10%)	2 (7%)		1 (9%)	2 (7%)	
Depression and anxiety	2 (20%)	1 (4%)		2 (18%)	1 (3%)	
OCD and PTSD	1 (10%)	0 (0%)		1 (9%)	0 (0%)	
Number of children (including infant) ^b			0.07			0.13
1	6 (60%)	15 (55%)		6 (55%)	17 (59%)	
2	1 (10%)	11 (41%)		2 (18%)	11 (38%)	
3	2 (20%)	1 (4%)		2 (18%)	1 (3%)	
4	0 (0%)	0 (0%)		0 (0%)	0 (0%)	
5	1 (10%)	0 (0%)		1 (9%)	0 (0%)	
Mean AQ score (SD) ^c	34.30 (14.2)	16.22 (7.43)	0.004	31.73 (15.9)	15.93 (7.25)	0.02
Median depression score (IQR) ^{c,e}	9.50 (11.00)	6.00 (4.50)	0.20	7.00 (7.50)	4.50 (6.75)	0.16
Median anxiety score (IQR) ^{c,f}	38.50 (12.20)	29.00 (10.50)	0.01	39.00 (11.50)	28.00 (9.50)	0.02

^aT-test performed^bFisher's exact test performed^cWilcoxon rank-sum test performed

^dIncome data was unavailable for 1 HL and 1 LL participant

^eDepression data was unavailable for 4 LL participants at 2-3 months and 3 LL participants at 6 months

^fAnxiety data was unavailable for 4 LL participants at 2-3 months and 2 LL participants at 6 months

5.2.2 PCI procedure

Parent-infant dyads were video recorded engaging in free play, once at the 2-3 month time-point and once at the 6 month time-point. The researchers left the room for the duration of the play. Parents and infants played together for 5 minutes without toys, after which the researcher brought a selection of toys for the dyad to play with for a further 5 minutes. Parents were instructed to play as they would at home and (during play with toys) told that they could use as many or as few toys as they wished. At 2-3 months, infants were positioned on their back on a changing mat and parents sat on the floor facing their child. The mat was raised slightly under the infant's head to ensure that their face was viewable by the camera. A mirror on the wall faced the parent in order to capture their facial expression. One camera was positioned to capture the parent's reflection in the mirror. An additional camera was positioned to capture the infant's face. At 6 months, parent and infant sat on a mat and a camera was positioned facing them. Toys were chosen from seven categories: pretend play, a doll, a stuffed animal, a spinning object, a book, an exploratory toy and a construction play toy (see Appendix 7 for toys used). These categories were chosen to match the EuroSibs cohort protocol (the cohort with which the coding scheme used (the PInTCI) was developed). The toys were consistent across the 2 time-points. The same parent was involved for both time-points. 2 LL parents spoke French with their child during the interaction and 1 LL parent who took part only at the 6 month time-point spoke Greek, all other parents spoke English during the interaction. Following the PInTCI protocol, only the 5 minutes of play with toys was coded (these 5 minutes were timed from the moment the researcher left the room).

5.2.3 Parent-Infant/Toddler Coding of Interaction (PInTCI)

The PInTCI (Pijl et al., 2016) was developed by adapting scales from a broad range of existing measures, such as Coding Interactive Behavior (Feldman, 1998), Dyadic Communication Measure for Autism (Aldred et al., 2004) and Manchester Assessment of Caregiver-Infant Interaction (Wan et al., 2012). The PInTCI was selected as it was developed in order to assess parent-child interactions across a broad age range of early development including young

infants (5-36 months old) and to include all the parent-infant interaction constructs found to predict later child development. It was also chosen as it was designed for use with both typically developing children and those with a high likelihood of developing autism. The PInTCI has not yet been validated for use in infants younger than 5 months old. The scheme was nevertheless employed with the present cohort given the lack of reliable coding schemes for use with infants with an increased likelihood of autism as young as 2-3 months old. The PInTCI consists of 11 scales: 5 child scales (initiations, attentiveness, sharing of affect, positive affect, absence of negative affect), 5 parent scales (sensitive responsiveness, absence of negative control, scaffolding, positive affect, absence of negative affect) and 1 dyadic scale (dyadic reciprocity; Figure 5.1). Descriptions of each scale can be found in Appendix 8. Each construct is rated on a 1-7 scale, with lower scores indicating less optimal behaviour and higher scores indicating more optimal behaviour.

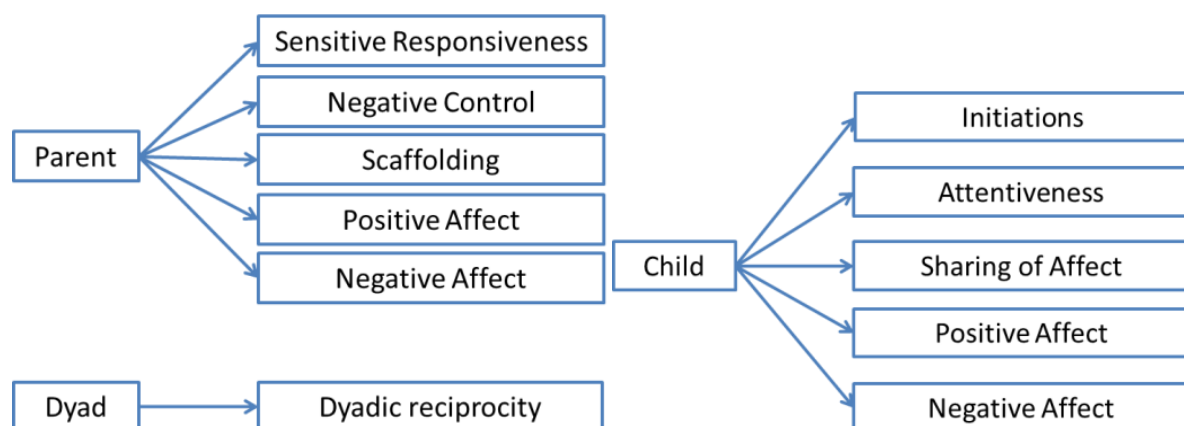


Figure 5.1 The PInTCI scales. Taken from the Parent-Infant/Toddler Coding of Interaction Manual (Pijl et al., 2016).

5.2.3.1 Coding procedure

Two coders (the author and an undergraduate research assistant) were trained on the coding scheme. Training was delivered by the creators of the PInTCI via regular video calls. The coders first watched recordings of an in-person training session used to train coders for another project. Two training clips taken from the EuroSibs cohort (one involving a 5 month old and one involving a 10 month old) were then coded. Scores were discussed with the trainers who gave feedback via video call. This procedure was repeated for a further 8 clips. The coders

then proceeded to the reliability phase, given that they had achieved at least 2 subsequent clips with a percentage agreement with the trainers of 90% or more. The reliability phase involved coding 8 clips and coders were considered reliable when they achieved at least 85% agreement with the trainers across all clips.

The research assistant then coded all videos for the 2-3 month time point and the author second coded 12 (32%) of these videos. The author coded all videos for the 6 month time point and the research assistant second coded 12 (30%) of these. The main coder (the coder who coded the whole dataset) at each time-point was not aware which videos were the reliability videos. The main coder's scores were used in data analysis, while the second-coder's scores were used to calculate reliability. Coders could not be blind to the group membership of the participants (HL or LL) due to having been involved in data collection.

Weighted kappa rather than intraclass correlation (ICC) was used as a measure of inter-rater reliability, as a range of at least 5 is recommended in order to use ICC with ordinal data (Bajpai et al., 2015). As not all scales had a range of at least 5, weighted kappa was considered appropriate. Agreement between coders on the PInTCI is defined as scoring the same code or 1 point difference. As such, kappa weights were defined as follows: perfect agreement = weight 0; 1 point apart = weight 0; 2 points apart = weight 1; 3 points apart = weight 2 etc. Kappa values of 0.00-0.20 are considered slight, 0.21-0.40 fair, 0.41– 0.60 moderate, 0.61– 0.80 substantial, and 0.81–1.00 as almost perfect agreement (Cohen, 1960). Kappas at the 2-3 month stage ranged from (0.29-1.00), with a mean of 0.65. Kappas at the 6 month stage ranged from (0.38-1.00), with a mean of 0.75 (see Appendix 9 for all kappa values).

Inter-rater reliability was generally greater at the 6 month stage than the 2-3 month stage, with infant initiations being particularly low at the 2-3 month stage (0.29). It may be that some infant behaviours are too subtle to be coded reliably at this age, given that clear initiations and behaviours such as pointing and joint attention tend to develop from the latter half of the first year onwards (Bates & Dick, 2002). Kappas for absence of negative control and dyadic reciprocity were particularly low for the 2-3 month stage. This may be due to the limited opportunities for infant contribution to the interaction at this age, which may make reliably judging the appropriateness of parent behaviour challenging. Due to low reliability, initiations, negative control and dyadic reciprocity were excluded from analysis at the 2-3 month stage. The 2-3 month kappa values may show that the PInTCI is somewhat reliable

when used with infants younger than 5 months, though reliability is greater when used with older infants.

5.2.4 Questionnaires

Participants were asked to complete the Autism Quotient once during the third trimester of pregnancy. Self-report measures of wellbeing, including depression (Edinburgh Postnatal Depression Scale) and anxiety (State-Trait Anxiety Inventory) were completed at both the 2-3 month and 6 month time-points (these measures are described in more detail in Chapter 4).

5.2.5 Data analysis

Given the ordinal nature of the data, multilevel ordinal regressions were conducted for each scale. In all models, group membership (HL/LL), time-point, an interaction between group and time-point and income were included as fixed effects, with scores on the scale as the outcome. For each model, a random intercept for participant was included to account for non-independence due to repeated measures. Models were estimated via maximum likelihood using the adaptive Gauss-Hermite quadrature approximation with 5 quadrature points.

Income was included as a covariate, given associations between parent-child interaction and socio-economic factors (Justice et al., 2019). Models including parental age, infant age and parental anxiety as covariates can be found in Appendix 10.

Data for income was missing for one LL participant and one HL participant who took part at the 6 month time-point only. To avoid excluding these participants from analyses, and due to the small amount of missing data, the missing values were imputed with the mode of the relevant group (HL or LL).

While the primary focus of this chapter is autistic mothers and their infants, the HL group also included non-autistic mothers with an autistic child (sibling group). Explorations of group differences between these two HL groups using Wilcoxon rank-sum tests can be found in Appendix 11. As minimal differences were found, only analyses including both autistic mothers and sibling group mothers within the HL group are presented, so as to maximise the sample size of the HL group.

Medians and interquartile ranges (IQR), rather than means and standard deviations, are reported due to the ordinal nature of the data.

5.3 Results

5.3.1 Child scales

No significant differences between the HL and LL groups were found for any of the child subscales (Table 5.3). There were no significant differences between time-points, nor any significant group by time-point interactions for any of the child subscales.

Table 5.3 Medians and inter-quartile ranges, and results of regression models, for scores on the PInTCI child scales

	2-3 months		6 months		B (SE)	p-value (FDR corrected)
	High- likelihood (n=10)	Low- likelihood (n=27)	High- likelihood (n=11)	Low- likelihood (n=29)		
Initiations ^a (Median; IQR)	-	-	2.00 (1.00)	2.00 (1.00)		
Group					0.38 (0.90)	0.81
Time-point					-	-
Group*Time- point					-	-
Income					-0.01 (0.84)	0.99
Attentiveness (Median; IQR)	3.50 (3.00)	5.00 (2.00)	4.00 (2.00)	4.00 (2.00)		
Group					-1.55 (1.05)	0.73
Time-point					-0.95 (0.52)	0.19
Group*Time- point					1.58 (1.00)	0.32
Income					0.09 (0.76)	0.99
Sharing of affect (Median; IQR)	2.50 (3.50)	3.00 (2.00)	2.00 (1.00)	2.00 (1.00)		
Group					-0.40 (1.03)	0.81
Time-point					-0.76 (0.51)	0.23
Group*Time- point					-0.25 (0.98)	0.91
Income					-0.23 (0.80)	0.95
Positive affect (Median; IQR)	1.50 (2.75)	2.00 (3.00)	3.00 (3.00)	3.00 (2.00)		
Group					-2.01 (1.12)	0.73
Time-point					0.27 (0.52)	0.60

Group*Time-point					1.56 (1.00)	0.73
Income					-0.38 (0.82)	0.24
Absence of negative affect (Median; IQR)	6.50 (2.75)	7.00 (2.50)	6.00 (1.00)	6.00 (2.00)		
Group					-1.00 (0.90)	0.73
Time-point					-0.32 (0.50)	0.60
Group*Time-point					0.58 (0.97)	0.32
Income					-0.87 (0.61)	0.15

^aResults presented for the 6 month time-point only

5.3.2 Parent scales and dyadic scale

There was a significant effect of time-point on sensitive responsiveness and positive affect, indicating a decrease in scores from 2-3 months to 6 months (Table 5.4), though there was no significant effect of group nor a group by time-point interaction for either scale. There were no significant effects of group, time-point nor group by time-point interactions for any other scale.

Table 5.4 Medians and inter-quartile ranges, and results of regression models, for scores on the PInTCI parent scales and dyadic scale

	2-3 months		6 months		B (SE)	p-value (FDR corrected)
	High-likelihood (n=10)	Low-likelihood (n=27)	High-likelihood (n=11)	Low-likelihood (n=29)		
Sensitive responsiveness (Median; IQR)	5.00 (0.00)	6.00 (1.00)	5.00 (1.00)	5.00 (0.00)		
Group					-0.30 (0.88)	0.81
Time-point					-1.78 (0.57)	0.01
Group*Time-point					0.95 (0.99)	0.67
Income					2.32 (0.70)	0.01
Absence of negative control ^a (Median; IQR)	-	-	5.00 (1.00)	5.00 (1.00)		
Group					0.39 (1.08)	0.81
Time-point					-	-

Group*Time-point					-	-
Income					1.36 (1.03)	0.24
Scaffolding (Median; IQR)	4.00 (1.50)	4.00 (1.00)	4.00 (0.50)	5.00 (1.00)		
Group					0.66 (0.91)	0.81
Time-point					0.56 (0.52)	0.37
Group*Time-point					0.05 (0.97)	0.96
Income					1.89 (0.71)	0.04
Positive affect (Median; IQR)	5.00 (0.00)	6.00 (2.00)	5.00 (1.00)	5.00 (1.00)		
Group					-0.94 (0.97)	0.73
Time-point					-1.58 (0.58)	0.03
Group*Time-point					0.73 (0.98)	0.72
Income					1.45 (0.79)	0.17
Absence of negative affect (Median; IQR)	7.00 (0.75)	7.00 (0.00)	7.00 (0.00)	7.00 (0.00)		
Group					0.01 (1.36)	0.99
Time-point					-1.64 (1.01)	0.21
Group*Time-point					2.58 (1.58)	0.32
Income					2.89 (1.27)	0.08
Dyadic reciprocity ^a (Median; IQR)	-	-	4.00 (1.00)	4.00 (1.00)		
Group					1.22 (0.99)	0.73
Time-point					-	-
Group*Time-point					-	-
Income					1.66 (0.94)	0.17

^aResults presented for the 6 month time-point only

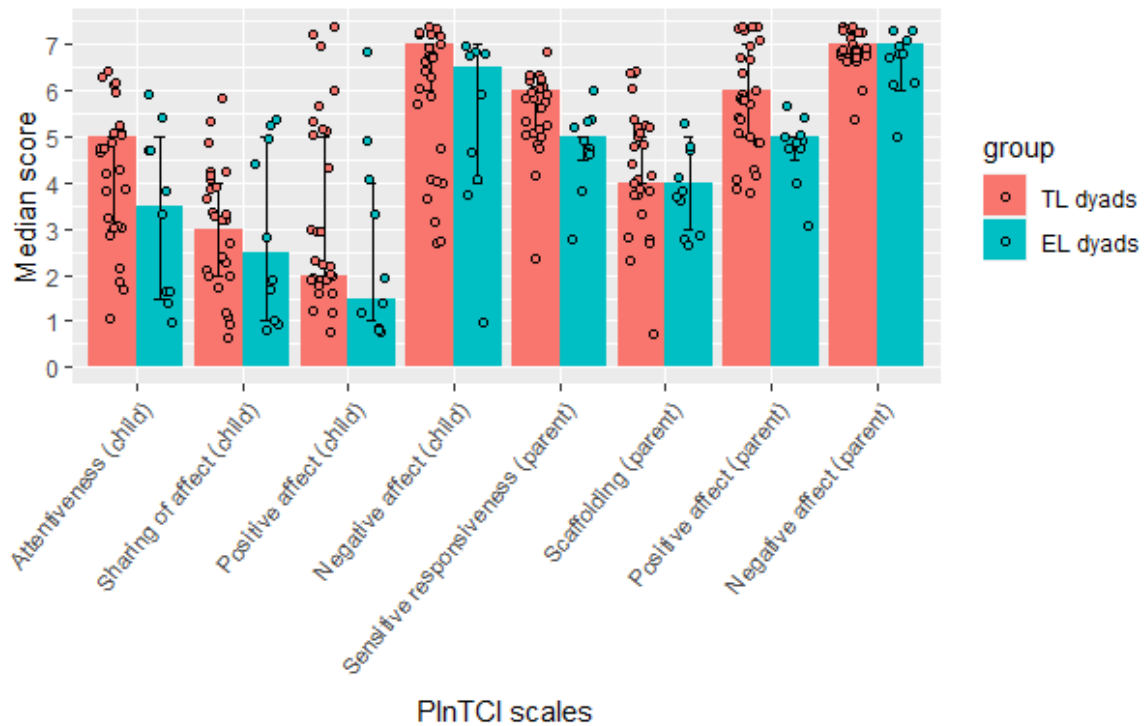


Figure 5.2 Median PInTCI scores at the 2-3 month time-point for EL and TL dyads (error bars represent 95% confidence intervals)

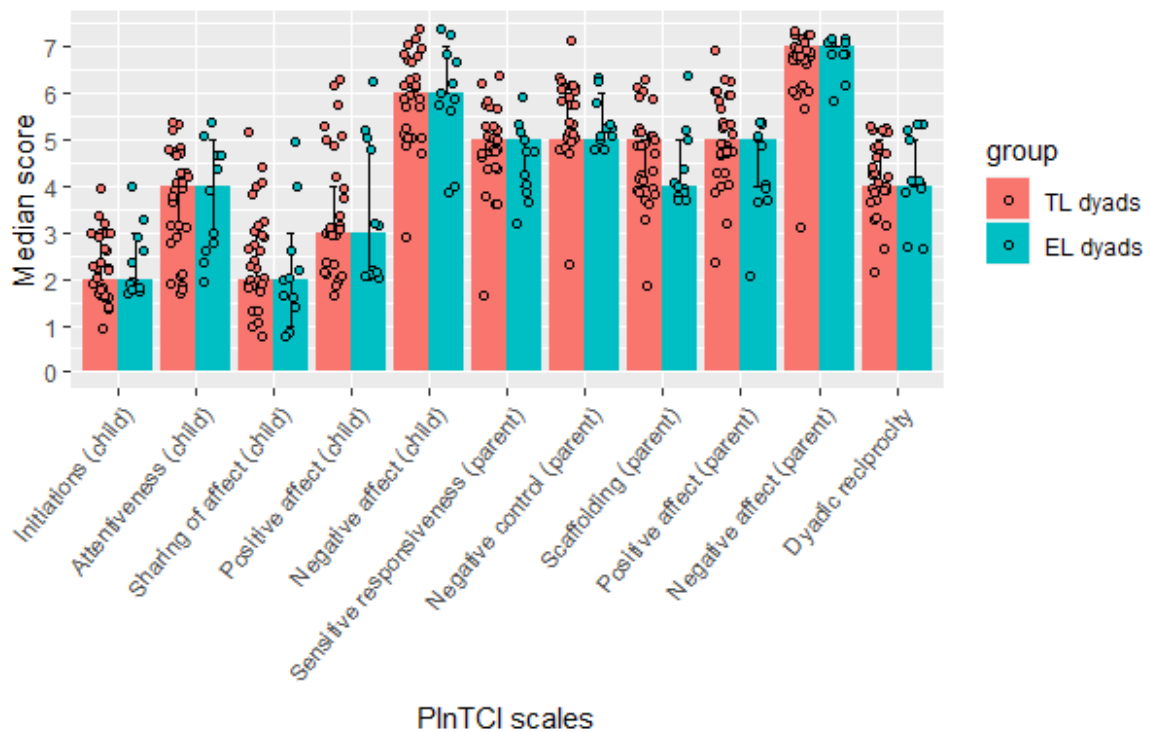


Figure 5.3 Median PInTCI scores at the 6 month time-point for EL and TL dyads (error bars represent 95% confidence intervals)

5.4 Discussion

This study is the first to explore interactions among autistic parents and their infants. While the HL and LL groups did not significantly differ on infant and parent behaviour, parents in both groups demonstrated a decline in sensitive responsiveness and positive affect over time. A lack of differences in infant behaviour at either time-point is consistent with prior prospective parent-infant interaction studies. These studies have found that differences between HL and LL infants in behaviours such as attentiveness, affect and initiating social interaction tend to become apparent from the latter half of the first year onwards (Rozga et al., 2011; Wan et al., 2013). The present study corroborates this tendency and extends the findings to a younger cohort. The lack of significant differences in infant behaviour between time-points further suggests that the social-interactive behaviours measured here among HL infants do not decline between 2-3 months and 6 months of age.

Decreases in scores between 2-3 months and 6 months were found for parent sensitive responsiveness and parent positive affect. It may be expected that sensitive responsiveness would increase over time as a greater range of play behaviours may be possible at later ages (certain toys may be more appropriate for older infants for example), and this could provide the parent with greater opportunities to respond to their infant. Conversely, however, play at younger ages may involve fewer opportunities for parents to respond insensitively to their infant as the infant's desires may be less clear (2-3 month olds are less likely to reach for a toy they desire than 6 month olds, for example). Insensitive responding may therefore be more apparent at older ages. Similarly, parents may rely on face-to-face interaction involving positive affect to engage their infants at 2-3 months, while at 6 months toys may form a greater basis for the interaction.

No group differences were found for absence of negative control at 6 months. This is in contrast to previous findings of higher directiveness among HL parents (Wan et al., 2012; 2013). There is some evidence that HL parents demonstrate greater levels of adaptive forms of directiveness than LL parents though do not demonstrate greater levels of maladaptive directiveness (Steiner et al., 2018). This may explain why the HL group did not exhibit greater negative control in the present study. The HL sample in the present study consisted primarily of autistic parents, while prior HL samples have consisted of non-autistic parents of autistic children. Therefore, while behavioural differences among HL and LL parents in previous

studies may have been driven by a parental style developed in response to having an older child with autism, parental behaviour of the HL group in the present study may also be related to higher autistic characteristics of the parents. It is possible that some of the parenting styles associated with being autistic identified in Chapters 2 and 3 could influence parents' behaviours. Having researched child development in detail or possessing a drive to be understanding and accepting of their child, for example, may result in a fewer controlling behaviours. Furthermore, a reduced tendency towards conformity among autistic people (Yafai et al., 2014), as well as first-hand awareness of neurodiversity, may enable a more accepting approach towards their child's development.

No group differences were found for scaffolding, sensitive responsiveness and parental affect. This is consistent with prior findings of no group differences in these behaviours between HL and LL parents (Campbell et al., 2015; Schwichtenberg et al., 2019). The present study extends these findings to dyads involving a younger cohort (below 6 months of age) as well as to parents who themselves have an autism diagnosis. There was significantly lower sensitive responsiveness and positive affect among the HL parents, however, for the model controlling for parental age (see Appendix 10). As this is in contrast to prior findings of no group differences in these behaviours for studies for which the HL group consists of non-autistic parents of autistic children, this may suggest that autistic parents could benefit from support to increase sensitive responsiveness and positive affect during play with their infants. However, given the lack of group differences on these scales for the models controlling for income, infant age and parental anxiety, it may be that any group differences are attributable to other such factors rather than to the autistic characteristics of the parents. Indeed, there is some evidence that mothers with anxiety show less sensitivity with their infants (Feldman et al., 2009; Nicol-Harper et al., 2007), and prior prospective studies have demonstrated an association between socio-economic factors and parental behaviours such as vocalising with their infants (Schwichtenberg et al., 2019) and the quality of the home language environment (Swanson et al., 2019). The precise influence of socio-economic factors on the parent-infant interaction behaviours of HL dyads is unclear, however, and further research addressing its role is necessary. The results as a whole suggest that, despite the difficulties with play expressed by some autistic parents in Chapters 2 and 3, autistic parents may be just as likely as non-autistic parents to engage in adaptive parenting behaviours with their infants.

5.4.1 Limitations

Due to difficulties recruiting participants, given the rarity of the sample in the correct time window, the sample size for the HL group is small. As such, null findings should be regarded tentatively and require replication in larger samples. A simulation based post-hoc sensitivity power analysis indicated that for the total sample, there was adequate (80%) power to detect betas of 0.75 and above, with an alpha of 0.05, indicating that some null results may be due to a lack of power.

Due to the small sample, it was not possible to analyse the two HL groups (the group of autistic parents and the group of non-autistic parents of an autistic child) separately. As such, it is unclear whether results involving HL parents are due to these parents being autistic or due to having an autistic child. Similarly, for the HL infants, the study is ill equipped to disentangle the environmental influence of having an autistic mother (such as potential differences in parenting styles between autistic and non-autistic parents) from the impact of having an increased genetic likelihood of being autistic. Furthermore, it is unknown whether the infants in the HL group will go on to receive a diagnosis of autism. As such, some HL infants may be typically developing, or they may possess the broader autism phenotype but not go on to meet criteria for an autism diagnosis, potentially influencing null findings.

Some scales had a very low IQR, particularly parental negative affect, and at 2-3 months, parental positive affect and sensitive responsiveness. Given this lack of variability in scores, findings concerning these scales should be interpreted tentatively. The coders were aware of the group membership (HL or LL) of the participants. As such, the data may have been affected by any biases the coders possessed. However, the fact that few group differences were found may indicate that coders expectations of how the two groups would perform did not unduly influence results. The time-points were scored by different coders and differences in scores between time-points may therefore reflect different coding strategies between coders. Findings of differences between time-points should consequently be considered tentative, though the generally high inter-rater reliability may suggest that coders were similar in their coding approach.

A greater proportion of the HL parents than the LL parents had a diagnosis of a psychiatric condition (though there was not a significant difference between the groups) and the HL

group scored higher on anxiety. However, it is unlikely that this difference affected results given that similar results were found when controlling for parental anxiety (see Appendix 10).

Three of the parents spoke a non-English language during the play session. As some scales, such as sensitive responsiveness and scaffolding, took spoken language (e.g. praising behaviour) into consideration, coding for these scales may have been less reliable for these 3 participants. Similarly, the LL group contained one father, who may have exhibited different behaviours to the mothers in the remainder of the sample.

The play sessions took place in a laboratory setting. Although parents were instructed to play as they would at home, parents' behaviour may have differed from what would be typical in a more naturalistic setting. HL parents may have felt greater pressure than LL parents to modify their behaviour, given autistic parents' reports in Chapters 2 and 3 of concerns that others may negatively judge their parenting.

The PInTCI scheme was designed for use with non-autistic parents and therefore may be less appropriate for use with autistic parents. Future research could develop schemes appropriate for autistic parents, including scales that capture potential autistic parenting strengths, such as attention to detail and encouragement of their infant's sensory interests. Further, some group differences in infant behaviour may have been too subtle to be captured by a global coding scheme such as the PInTCI. Future studies employing micro-analytic coding schemes may be better able to distinguish subtle behaviours at this early age.

5.4.2 Conclusions

This is the first study to explore parent-infant interactions involving autistic parents. The findings suggest no differences between autistic and non-autistic parents in scaffolding, responding sensitively to their infant, demonstrating negative control and showing positive and negative affect with their infant. It is important for healthcare and education professionals working with autistic parents to be aware that there is no evidence that autistic parents are any less likely than non-autistic parents to engage in positive parenting behaviours. The findings also suggest a lack of social-interactive differences between HL and LL infants within the first half of the first year of life. The study therefore adds to a growing body of literature indicating that such differences may only arise later in infancy. Though not possible in the present study, further studies should explore the relationships between

parent-infant interaction behaviours and later child developmental outcomes, in order to identify potential targets for support.

Chapter 6: The relationship between maternal perinatal mental health and fetal and infant regional brain volumes

6.1 Introduction

Maternal mental health is associated with child developmental outcomes (as outlined in Chapter 1). This relationship is likely to reflect genetic factors as well as both prenatal and postnatal influences. However, the precise mechanisms involved, in addition to the developmental timings of these mechanisms, remain unclear. Greater knowledge of these mechanisms would allow for a better understanding of the optimal timing of interventions and support. While most research has focused on childhood outcomes, there is a growing body of literature exploring the impact of maternal wellbeing on prenatal and early infant development. This early developmental perspective is important in order to tease apart the mechanisms through which parental mental health influences offspring development.

Maternal wellbeing during the perinatal period has effects on diverse aspects of offspring behaviour and brain development. Many studies exploring the impact of maternal wellbeing on offspring brain development have tended to take the amygdala and hippocampus as their focus (this literature is summarised in Table 6.1). This is because these regions have been consistently implicated in psychiatric disorders (Bellani et al., 2011; MacQueen & Frodl, 2011), they undergo vast development during the perinatal period (Seress et al., 2001; Ulfig et al., 2003) and are particularly sensitive to levels of glucocorticoids (such as cortisol) in pregnancy (Teicher et al., 2003). During pregnancy, it is thought that maternal stress causes the fetus to be exposed to increased levels of glucocorticoids, which increases hypothalamic-pituitary-adrenal (HPA) axis reactivity and causes downregulation of glucocorticoid receptor in the hippocampus (Harris & Seckl, 2011). Non-human animal studies provide evidence for links between maternal stress and the development of the amygdala and hippocampus in offspring. Maternal stress in rats has been linked with reduced cell proliferation in the hippocampus and reduced amygdala neuronal and glial cells (Kawamura et al., 2006), as well as reduced hippocampus volumes in both rats and monkeys (Coe et al., 2003; Lemaire et al., 2000).

Studies in humans have found relationships between prenatal depression and amygdala connectivity. Posner et al. (2016) found that exposure to prenatal maternal depression in the

third trimester was associated with altered amygdala connectivity with prefrontal regions in five week old infants, using both fMRI and diffusion MRI. They also found that this altered amygdala connectivity was related to greater fetal heart rate reactivity to *in utero* perturbation, suggesting a link between maternal wellbeing, fetal brain development and fetal stress response. Similarly, studies have found an association between prenatal depression and reduced right amygdala anisotropy (but not volume) in neonates (Rifkin-Graboi et al., 2013), increased amygdala functional connectivity in six months olds (Qiu et al., 2015) and amygdala connectivity differences in four year old children (Soe et al., 2018).

Buss et al. (2012) found that mothers' cortisol levels during pregnancy were associated with larger right amygdala volume in their child at 7 years old, although this was only seen in girls and not in boys. They also found that amygdala volume mediated the association between mothers' cortisol levels and higher affective problems in girls at age 7. They did not find any significant association between mothers' cortisol levels during pregnancy and hippocampus volume. Prenatal maternal stress has also been associated with amygdala connectivity. Evidence has been found for a relationship between a maternal diagnosis of prenatal depression and/or anxiety and reduced amygdala functional connectivity in preterm neonates (Scheinost et al., 2016), and higher prenatal cortisol has been linked with increased internalising symptoms in 24 month old females, mediated by increased neonatal amygdala connectivity (Graham et al., 2019). Furthermore, pregnancy-related anxiety in the third trimester of pregnancy has been associated with larger left relative amygdala volume in 4 year old children (Acosta et al., 2019).

Similar connections between child brain development and maternal mental health have been found for postnatal mental health. While prenatal maternal wellbeing may influence brain development through changes in the uterine environment, postnatal maternal wellbeing may influence infant brain development through the impact of maternal wellbeing upon parenting practices (Biederman et al., 2001). Indeed, maternal behaviour has been associated with child brain volumes, including hippocampus volumes (Lee et al., 2019; Luby et al., 2012). Lupien et al. (2011) found that 10 year old children who had been exposed to maternal depression symptoms since birth showed increased left and right amygdala volumes, but no difference in hippocampus volumes, compared with children not exposed to maternal depression symptomology. Wen et al. (2017) explored associations between prenatal and postnatal

maternal depression and amygdala volume in 4 year olds. Greater prenatal depression symptoms were linked to increased right amygdala volume, whereas greater postnatal depression symptoms were linked to increased FA of the right amygdala. This suggests that there may be differential effects on the amygdala depending on timing (prenatal or postnatal exposure). Taken together with the findings of Buss et al. (2012), the results could also suggest that the right amygdala may be particularly susceptible to the influence of maternal depression symptoms.

Qiu et al., (2013) explored the relationship between maternal prenatal and postnatal anxiety and infant hippocampus volumes over the first 6 months of life. Prenatal anxiety was not associated with hippocampus volume at birth or at 6 months old, though higher prenatal anxiety was significantly associated with reduced growth of the hippocampus bilaterally from birth to 6 months old, controlling for household income, the time interval between the two MRI scans and the growth of intracranial volume between birth and 6 months old. When controlling for maternal anxiety at 3 months after birth, this effect remained significant for the right hippocampus, though was no longer significant for the left hippocampus. Infants of mothers with greater postnatal anxiety showed significantly smaller left, but not right, hippocampus volumes at 6 months old, as well as reduced growth of the right, but not left, hippocampus from birth to 6 months old when controlling for prenatal anxiety. The authors concluded that maternal anxiety has differential effects on the size of the left and right hippocampus. The growth of the right hippocampus may be reduced in response to prenatal anxiety but increased in response postnatal anxiety. In contrast, left hippocampus size at 6 months may be reduced in response to postnatal, but not prenatal, anxiety.

Table 6.1 MRI studies exploring prenatal and/or postnatal maternal wellbeing and children's amygdala and/or hippocampus development

Author	Brain region(s)	Aspect of maternal wellbeing	Sample	Gestational weeks/infant age at time of wellbeing measurement	Results
Depression					
Lupien et al. (2011)	Amygdala; hippocampus	Depressive symptoms	N=38, 10 year old children	Children were exposed to maternal depressive symptomology since birth	Children of mothers with depressive symptomology had larger left and right amygdala volumes. There was no group difference in hippocampus volume.
Posner et al. (2016)	Amygdala	Depressive symptoms	N=64, Infants (mean age = 5.8 weeks)	34-37 gestational weeks	Infants exposed to maternal prenatal depression had altered functional and structural connectivity between the amygdala and the prefrontal cortex.
Qiu et al. (2015)	Amygdala	Depressive symptoms	N=24, Infants (6 months old)	26 gestational weeks and 3 month after birth	Infants of mothers with higher depression scores had greater functional connectivity of the amygdala with the left temporal cortex and insula, the bilateral anterior cingulate, medial orbitofrontal and ventromedial prefrontal cortices.
Rifkin-Graboi et al. (2013)	Amygdala	Depressive symptoms	N=157, Neonates (6-14 days old)	26 gestational weeks	Infants of mothers with high depression scores had lower fractional anisotropy and axial diffusivity, but not volume in the right amygdala.
Scheinost et al. (2016)	Amygdala	Depression and/or anxiety diagnosis	N=26, Extremely preterm neonates with (n=16) and	Presence of prenatal stress defined as a diagnosis of depression and/or anxiety	Extremely preterm neonates with prenatal stress exposure had less left amygdala connectivity with the thalamus, the

				without (n=10) prenatal stress exposure	in the maternal medical chart	hypothalamus and the peristriate cortex.
Soe et al. (2018)	Amygdala	Depressive symptoms	N=128, Children aged 4.4 to 4.8 years	26 gestational weeks	Maternal depression scores were associated with functional connectivity of the amygdala with the orbitofrontal cortex, insula, subgenual anterior cingulate, temporal pole, and striatum.	
Wen et al. (2017)	Amygdala	Depressive symptoms	N= 235, 4.5 year old children	26 gestational weeks and 3 months after birth	Higher prenatal maternal depression scores were associated with larger right amygdala volume (but only in girls). Higher postnatal maternal depression scores were associated with higher right amygdala FA in the overall sample and in girls, but not in boys.	
<u>Stress/anxiety</u>						
Buss et al. (2012)	Amygdala; Hippocampus	Cortisol	N=65, 6-9 year old children	15, 19, 25, 31 and 37 gestational weeks	Higher maternal cortisol in earlier but not later pregnancy was associated with larger right amygdala volume (but only for girls). Maternal cortisol was not associated with hippocampus volume.	
Graham et al. (2019)	Amygdala	Cortisol	N=70, Neonates	12, 20 and 30 gestational weeks	Higher maternal cortisol was associated with increased amygdala connectivity to sensory and default mode network regions in girls, and with decreased connectivity between these regions in boys.	
Acosta et al. (2019)	Amygdala	Pregnancy related anxiety	N=27, 48-54 month old children	24 and 34 gestational weeks	Higher third trimester anxiety scores were	

						associated with larger left relative amygdala volume.
Qiu et al. (2013)	Hippocampus Anxiety	N=175 neonates at baseline (mean age=10 days), N=35 at follow-up (mean age=28 weeks)	26 gestational weeks and 3 months after birth			Prenatal maternal anxiety was not associated with hippocampus volume in neonates, but was associated with slower hippocampus growth from birth to 6 months old. Postnatal maternal anxiety was associated positively with right hippocampus growth and negatively with left hippocampus volume at 6 months.

The brain changes associated with perinatal maternal wellbeing may be similar to those implicated in mental health conditions. For example, depression in adults has been associated with increased amygdala volume (van Eijndhoven et al., 2009) and altered amygdala connectivity (Ramasubbu et al., 2014), and anxiety has been associated with altered hippocampus volumes (Gorka et al., 2014; Koolschijn et al., 2013). The brain alterations associated with perinatal maternal mental health may therefore be implicated in the subsequent development of anxiety or depression in offspring.

A potential mechanism in the link between maternal mental health symptomology and offspring outcomes is the hormone cortisol. There is evidence for an association between perinatal maternal mental health and increased offspring cortisol. Both prenatal and postnatal maternal depression have been associated with increased infant cortisol levels at 6 months of age (Brennan et al., 2008). One study linked third trimester prenatal exposure to maternal depression and anxiety with subsequent infant increased methylation of a glucocorticoid receptor gene, NR3C1, which in turn was associated with increased salivary cortisol at 3 months of age, suggesting an epigenetic mechanism linking prenatal maternal wellbeing and infant stress response (Oberlander et al., 2008). Prenatal anxiety has additionally been associated with increased cortisol levels in 7 month old infants (Grant et al., 2009). Furthermore, cortisol levels have been associated with hippocampus and amygdala volumes (Schuhmacher et al., 2012; Wiedenmayer et al., 2006). Infant cortisol levels could

therefore potentially be involved in the link between maternal wellbeing and infant brain development outcomes.

An unexplored avenue of research is how maternal mental health may affect offspring whose development is already atypical due to a neurodevelopmental condition, with the relationship between perinatal maternal wellbeing and offspring brain development tending to focus on typically developing offspring. The brain areas that have been associated with maternal perinatal mental health also tend to be implicated in neurodevelopmental conditions, such as autism. For example, autistic individuals have been found to show increased hippocampus and amygdala volumes compared with non-autistic individuals in childhood (Mosconi et al., 2009; Schumann et al., 2004). It is not clear how offspring who may have developmental differences due to having an increased genetic likelihood of being autistic are affected by perinatal maternal mental health. For infants who have an increased genetic likelihood of experiencing an atypical developmental trajectory, it is particularly important to identify areas in which better support can be provided early on in development, and this may include supporting mothers throughout the perinatal period.

This study aimed to explore the relationship between both prenatal and postnatal maternal stress, depression and anxiety and offspring hippocampus and amygdala volumes during pregnancy and infancy. The relationship between maternal mental health and fetal brain development has not previously been explored using MRI. The research so far suggests that both pregnancy and postnatal maternal mental health make important contributions to offspring brain development. However, there is a scarcity of research exploring fetal brain development, with studies focusing on children and infants. While there is evidence from ultrasound research that maternal wellbeing (cortisol levels) is associated with reduced fetal brain growth (Li et al., 2012), the association between maternal wellbeing and fetal brain development has not yet been explored in further detail using MRI. It is not clear, therefore, at what developmental stage maternal mental health begins to impact upon offspring brain development.

This study additionally aimed to explore associations between maternal mental health and the anterior cingulate cortex as this is another area of the limbic system, alongside the amygdala and hippocampus, that is consistently implicated in mood disorders. Depression has been associated with smaller anterior cingulate volumes in both childhood (Boes et al.,

2008) and adulthood (Caetano et al., 2006) and there evidence for smaller anterior cingulate volumes in anxiety disorders (Asami et al., 2008). Despite this, the anterior cingulate has not yet been explored in relation to perinatal maternal mental health and offspring development.

In sum, the main aims of the study were to explore the relationships between maternal prenatal stress, anxiety and depression and 1) fetal amygdala and hippocampus volumes 2) infant amygdala and hippocampus volumes and 3) the growth in amygdala and hippocampus volumes from pregnancy until the postnatal time point. Relationships were also explored between maternal postnatal stress, anxiety and depression and infant amygdala and hippocampus volumes. Further, it was explored whether any of the above relationships differed between offspring with high or low likelihood of being autistic.

In addition to these primary aims, a number of exploratory research questions were also investigated. The above relationships were also explored in relation to fetal and infant anterior cingulate volumes. Further, the role of infant cortisol and the role of maternal play behaviour in the relationship between maternal stress, anxiety and depression and infant amygdala, hippocampus and anterior cingulate brain volumes were investigated.

6.2 Methods

6.2.1 Participants

At 30-33 weeks of pregnancy, participants underwent an MRI scan in order to acquire fetal MRI data. During this visit, participants also completed self-report questionnaires. The Cohen's Perceived Stress Scale (CPSS) measures stress; scores range from 0 to 40, with higher scores indicating higher stress. The State-Trait Anxiety Inventory (STAI) measures anxiety; scores range from 20-80, with higher scores indicating greater anxiety. Depression was measured using the Edinburgh Postnatal Depression Scale (EPDS), for which scores range from 0 to 30 with higher scores indicating greater depressive symptoms. These questionnaires are described in more detail in Chapter 4, section 4.2.2.2. At 8-12 weeks after birth, infants underwent an MRI scan and mothers completed the same stress, anxiety and depression questionnaires.

A priori power analyses indicated a required total sample size of 55, in order to detect a medium effect size ($f^2=0.15$), or a sample of 26 in order to detect a large effect size ($f^2=0.35$), given 80% power and an alpha of 0.05. Post hoc sensitivity power analyses indicated that

there was adequate (80%) power to detect medium effect sizes ($f^2 \geq 0.26$), with a two-tailed alpha of 0.05 for analyses involving prenatal wellbeing and fetal volumes ($n=33$); large effect sizes ($f^2 \geq 0.41$) for analyses involving prenatal wellbeing and infant volumes ($n=22$); large effect sizes ($f^2 \geq 0.47$) for analyses involving prenatal wellbeing and volume growth ($n=20$); and large effect sizes ($f^2 \geq 0.37$) for analyses involving postnatal wellbeing and infant volumes ($n=24$).

A total of 43 participants underwent scanning at 30-33 weeks of pregnancy, of these 2 participants in the low-likelihood (LL) group were excluded due to movement artefacts. Useable data was therefore obtained from 41 participants: 30 fetuses in the LL group and 11 fetuses in the high-likelihood (HL) group. One LL participant and one HL participant withdrew from the study after the prenatal stage due to family commitments and did not return for an infant scan. One infant in the LL group passed away shortly after birth. Scanning was therefore attempted with a total of 40 participants at the postnatal stage, of these one participant in the HL group was excluded due to movement artefacts and data was unable to be obtained from 11 participants (of whom one was in the HL group) due to the infant becoming distressed or due to the inability of the infant to achieve sleep. Data was not obtained from one participant in the HL group due to the relevant sequence accidentally being skipped. Useable data was therefore obtained from 27 participants: 20 LL infants and 7 infants in the HL group.

Of the mothers for whom MRI data was obtained, 33 (22 in the LL group, 11 in the HL group) had questionnaire data at the fetal stage and 24 (17 in the LL group, 7 in the HL group) had questionnaire data at the postnatal stage. Data was unable to be collected from 8 LL participants at the prenatal stage and 3 LL participants at the postnatal stage as ethics approval for the collection of the questionnaire data was not obtained until after their participation.

Data for 22 participants (15 in the LL group and 7 in the HL group) was available both for the prenatal questionnaires and for the infant MRI scan. Data for 20 participants (13 in the LL group and 7 in the HL group) was available both for the prenatal questionnaires and for the growth in volumes from the prenatal to the postnatal scan. 2 LL participants did not have cortisol data and 2 LL participants did not have parent-child interaction data.

Demographic data is displayed in Table 6.2 and Table 6.3. The HL and LL groups did not differ significantly on infant sex, age, gestational age at birth, birth weight or type of delivery, nor on pregnancy conditions, mother's ethnicity nor mother's psychiatric conditions. There were significant group differences in mother's educational level, household income and mother's age (at the prenatal time point only). Mothers in the HL group scored significantly higher on the AQ than LL mothers (at the prenatal time-point only).

Table 6.2 Fetus/infant demographic information for the high-likelihood and low-likelihood groups.

	Prenatal			Postnatal		
	High-likelihood (n=11)	Low-likelihood (n=22)	p-value (FDR corrected)	High-likelihood (n=7)	Low-likelihood (n=17)	p-value (FDR corrected)
Sex (female:male) ^b	5:6	9:13	1.00	3:4	8:9	1.00
Mean postconceptual age in weeks (SD) ^a	31.86 (1.19)	31.86 (1.24)	1.00	50.57 (2.52)	50.29 (1.67)	0.91
Mean gestational age at birth in weeks (SD) ^a	-	-	-	39.29 (1.12)	40 (1.17)	0.31
Mean birth weight in kilograms (SD) ^a	-	-	-	3.83 (0.45)	3.38 (0.45)	0.11
Type of delivery ^b						0.71
Spontaneous vaginal delivery	-	-	-	4 (57%)	10 (59%)	
Assisted delivery (forceps or ventouse)	-	-	-	0 (0%)	3 (18%)	
Caesarean section	-	-	-	3 (43%)	4 (23%)	

^aT-test performed

^bFisher's exact test performed

Table 6.3 Mothers' demographic information for the high-likelihood and low-likelihood groups.

	Prenatal			Postnatal		
	High-likelihood (n=11)	Low-likelihood (n=22)	p-value (FDR corrected)	High-likelihood (n=7)	Low-likelihood (n=17)	p-value (FDR corrected)
Mean age (SD) ^a	31.0 (2.50)	33.50 (2.68)	0.03	32.30 (1.38)	34.0 (2.75)	0.12
Ethnicity ^b			1.00			0.56
White	11 (100%)	17 (77%)		7 (100%)	13 (77%)	
Non-white	0 (0%)	5 (23%)		0 (0%)	4 (23%)	
Educational level ^b			0.01			0.02
University	4 (36%)	20 (91%)		1 (14%)	15 (88%)	
A-level or below	7 (64%)	2 (9%)		6 (86%)	2 (12%)	
Annual household income ^b			0.002			0.02
>50,000	2 (18%)	19 (86%)		1 (14%)	14 (82%)	
≤ 50,000	9 (82%)	3 (14%)		6 (86%)	3 (18%)	
Psychiatric conditions ^b			0.41			0.07
None	7 (64%)	20 (91%)		4 (57%)	17 (100%)	
Depression	1 (9%)	1 (5%)		1 (14%)	0 (0%)	
Depression and anxiety	2 (18%)	1 (5%)		1 (14%)	0 (0%)	
OCD and PTSD	1 (9%)	0 (0%)		1 (14%)	0 (0%)	
Pregnancy conditions ^b			1.00			0.68
Gestational diabetes	1 (9%)	1 (5%)		1 (14%)	0 (0%)	
Preeclampsia	0 (0%)	1 (5%)		0 (0%)	1 (6%)	
Polyhydramnios	0 (0%)	1 (5%)		0 (0%)	0 (0%)	
Mean AQ score (SD) ^a	35.1 (13.70)	14.6 (7.27)	0.003	32.30 (16.3)	14.90 (6.18)	0.09

^aT-test performed

^bFisher's exact test performed

6.2.2 MRI measures

6.2.2.1 MRI acquisition

Scans were completed using a GE Optima MR450w 1.5-Tesla scanner at the Evelyn Perinatal Imaging Centre, Addenbrookes. Total scan time for each participant was approximately 30 minutes. At the postnatal stage, scans were completed during natural sleep, without sedation. Minimuff ear pads were used to protect the infants from scanner noise and a trained radiographer was present during all scans. Mothers accompanied their infants in the scanner room throughout the scan and were able to request to stop the scan at any moment by triggering an alarm. Scanning was stopped if the infant became distressed.

The imaging protocol at both the prenatal and postnatal scan included 1) a 3pl FIESTA Localizer scan (echo time (TE) = minimum; 45° flip angle; field of view (FOV) = 48 cm; matrix size = 256 x 128; 19 slices of 10 mm thickness); 2) a calibration scan (field of view (FOV) = 48 cm; 15 mm slices) and; 3) an axial 3D FIESTA scan (echo time (TE) = minimum; 55° flip angle; field of view (FOV) = 48 cm; matrix size = 224 x 224; 1 slice of 1 mm thickness). A number of other structural scans and a resting state functional scan were conducted but these are not reported here. All scans were reviewed by a doctor to ensure there were no abnormalities.

6.2.2.2 Preprocessing and calculation of regional brain volumes.

The following steps were completed by another member of the research team. Firstly, the orientation of the fetal scans was determined. This was achieved through manually drawing an oil capsule next to left temporal lobe using an image viewer which does not employ orientation codes (MRICro) and then, using an image viewer which does employ orientation codes (itksnap), manually resetting the orientation code so that the oil capsule appears on the left. The image origin was then reset to the ACPC fibre bundle. To perform skull stripping brain ROIs were manually drawn and multiplied with original head images. A study specific template was then created from a random sample of participants with corresponding fetal and infant scans using the 'buildtemplateparallel.sh' script from the Advanced Normalisation Toolkit. To move STA31 anatomical ROIs (Gholipour et al., 2017) into participant space the STA31 template was co-registered to the study specific template, the study specific template itself being co-registered to each participant. After concatenation of the resulting transformations and re-slicing of ROIs, the number of voxels under each warped STA31 ROI

was counted and multiplied by appropriate millimeter dimensions resulting in a volume estimate.

6.2.3 Cortisol

The SalivaBio Infant Swab by Salimetrics Ltd was used to collect saliva (passive drool), according to the company's specifications. Two swabs were attempted for each infant, unless the infant became distressed. The swabs were subsequently stored in the Swab Storage Tube and centrifuged in a temperature of -5 °C. The collected liquid saliva was aliquoted into labelled cryovials and stored at -80 °C prior to analysis. Samples belonging to the same participant were mixed into one cryovial. The time of collection, time of centrifugation, time of freezing, as well as the time since last waking of the participant were noted down.

Saliva samples were shipped in dry ice to the Anglia Ruskin Biomarkers Laboratory in Cambridge. After thawing, concentrations of cortisol were measured via manual enzyme-linked immunosorbent assays (ELISA) in duplicates, using antibodies certified by Salimetrics Ltd for this collection method. The final result per participant was based on the mean between the two measurements, providing that the coefficient of variation for the concentration between the duplicate repeats did not exceed 15%.

6.2.4 Parent-child interaction

Parent-child interaction (PCI) data at the 2-3 month time point was collected and scored as described in Chapter 5.

6.2.5 Data analysis

To explore relationships between maternal wellbeing (stress, depression and anxiety) and fetus/infant regional brain volumes (amygdala, hippocampus and anterior cingulate), multiple linear regression analyses were conducted with wellbeing score as a predictor and regional brain volume as the outcome. Separate regressions explored associations between each prenatal wellbeing measure and a) fetal brain volumes for each region b) infant brain volumes for each region c) the growth in volume for each region (i.e. the difference score between fetal and infant volumes for each region). Regressions also explored associations between each postnatal wellbeing measure and infant brain volumes for each region. As stress and

anxiety were highly correlated ($r=.90$ prenatally, $r=.68$ postnatally), scores on both measures were converted to z scores and a composite score was created representing a combined anxiety/stress score; regressions were performed with this composite score as the outcome.

Fetal/infant total brain volume and post-conceptual age of the fetus/infant on the day of the scan were included as covariates in each regression. Sex of the fetus/infant was also included as a covariate, given associations between sex and amygdala and hippocampus volume during development (Uematsu et al., 2012). For those analyses involving brain growth, the difference in age between the fetal and infant scans and the difference in total brain volume between the fetal and infant scans were included as covariates instead of age at scan and total brain volume. Postnatal wellbeing scores were included as covariates for those regressions with prenatal wellbeing as the predictor and either infant brain volume or growth in brain volume as the outcome, in order to assess the contribution of prenatal wellbeing independently of postnatal wellbeing. Prenatal wellbeing was not included as a covariate in the regressions exploring postnatal wellbeing and infant brain volumes given that three participants with both infant MRI and postnatal wellbeing data did not complete the prenatal wellbeing questionnaires, and therefore including this covariate would have reduced the already modest sample size. Group by wellbeing interactions were included in all regressions in order to explore whether the relationships between wellbeing and brain volumes differed between the HL and LL groups. Fetal right amygdala and left and right hippocampus volumes were log transformed prior to analysis to approximate a normal distribution.

Correction for multiple comparisons was conducted using FDR; those analyses that remained significant after correction are indicated below. FDR correction was conducted within each of the 18 outcomes (fetal left and right amygdala, left and right hippocampus and left and right anterior cingulate volumes; infant left and right amygdala, left and right hippocampus and left and right anterior cingulate volumes; the growth of left and right amygdala, left and right hippocampus and left and right anterior cingulate volumes) separately. For example, correction for the infant left amygdala would involve correction for 4 tests (associations between the infant left amygdala and prenatal anxiety/stress and depression and with postnatal anxiety/stress and depression).

Mediation analyses were also conducted in order to explore whether cortisol levels mediated the relationship between maternal wellbeing and infant brain volumes. Cortisol concentrations were log-transformed to approximate a normal distribution. Cortisol values were standardised via linear regression to time in minutes since waking and the resulting residuals and intercept of the model were used to calculate the final standardised cortisol value. Mediation analyses were also conducted in order to explore whether mothers' behaviour during parent-child interaction mediated the relationship between postnatal maternal wellbeing and infant brain volumes.

6.3 Results

6.3.1 Scores on mother and fetus/infant measures

Mothers in the HL group scored significantly higher than LL mothers on stress, depression and anxiety prenatally, though did not differ on postnatal wellbeing nor parent-child interaction scores (Table 6.4). The groups did not significantly differ on any brain region volume prenatally or postnatally, on brain region growth, nor on infant cortisol levels (Table 6.5). All brain regions significantly increased in volume from the prenatal to the postnatal time-point (Appendix 12).

Table 6.4 Mothers' stress, anxiety, depression and parent-child interaction scores.

	Prenatal			Postnatal		
	High-likelihood (n=11)	Low-likelihood (n=22)	p-value (FDR corrected)	High-likelihood (n=7)	Low-likelihood (n=17)	p-value (FDR corrected)
Mean stress score (SD) ^a	22.50 (7.80)	14.00 (6.61)	0.01	17.90 (6.64)	13.10 (7.07)	0.23
Mean anxiety score (SD) ^a	47.30 (10.20)	35.40 (11.70)	0.01	39.30 (7.57)	29.70 (9.03)	0.15
Median depression score (IQR) ^b	10.00 (8.50)	7.50 (5.00)	0.046	9.00 (8.00)	6.00 (5.00)	0.37
Median PCI sensitive responsiveness (IQR) ^b	-	-	-	5.00 (0.00)	5.00 (1.00)	0.23
Median PCI negative control (IQR) ^b	-	-	-	6.00 (1.00)	6.00 (0.50)	0.23
Median PCI scaffolding (IQR) ^b	-	-	-	4.00 (1.00)	4.00 (1.50)	0.37
Median PCI positive affect (IQR) ^b	-	-	-	5.00 (0.50)	6.00 (2.00)	0.16
Median PCI negative affect (IQR) ^b	-	-	-	7.00 (0.50)	7.00 (0.00)	0.23

^a T-test performed^b Wilcoxon rank-sum test performed

Table 6.5 Brain volumes (mm³) and cortisol levels (µg/dL) for the high-likelihood and low-likelihood groups.

	Prenatal			Postnatal			Brain volume growth		
	High-likelihood (n=11)	Low-likelihood (n=22)	p-value (FDR)	High-likelihood (n=7)	Low-likelihood (n=17)	p-value (FDR)	High-likelihood (n=7)	Low-likelihood (n=13)	p-value (FDR)
Mean left amygdala volume (SD) ^a	215 (45.30)	198 (40.20)	0.60	329 (71.80)	348 (54.40)	0.57	100 (51.90)	142 (71.70)	0.29
Mean right amygdala volume (SD) ^a	224 (37.10)	232 (63.70)	0.81	374 (54.10)	390 (53.20)	0.57	164 (37.40)	160 (57.80)	0.99
Mean left hippocampus volume (SD) ^a	921 (155.00)	908 (113)	0.81	1631 (220)	1852 (286)	0.36	707 (145)	912 (287)	0.24
Mean right hippocampus volume (SD) ^a	978 (178)	1057 (329)	0.60	1932 (255)	2004 (299)	0.57	952 (118)	945 (292)	0.99
Mean left anterior cingulate volume (SD) ^a	1413 (349)	1378 (315)	0.81	3646 (459)	3466 (731)	0.57	2288 (302)	2130 (652)	0.99
Mean right anterior cingulate volume (SD) ^a	1220 (221)	1354 (323)	0.60	3402 (481)	3550 (745)	0.57	2126 (401)	2285 (664)	0.87
Mean total brain volume (SD) ^a	351596 (52707)	343696 (37914)	0.66	717977 (105064)	741091 (107640)	0.64	370888 (76560)	414607 (96979)	0.25
Median infant cortisol (IQR) ^b	-	-	-	0.17 (0.13)	0.22 (0.11)	0.86	-	-	-

^a T-test performed

^b Wilcoxon rank-sum test performed

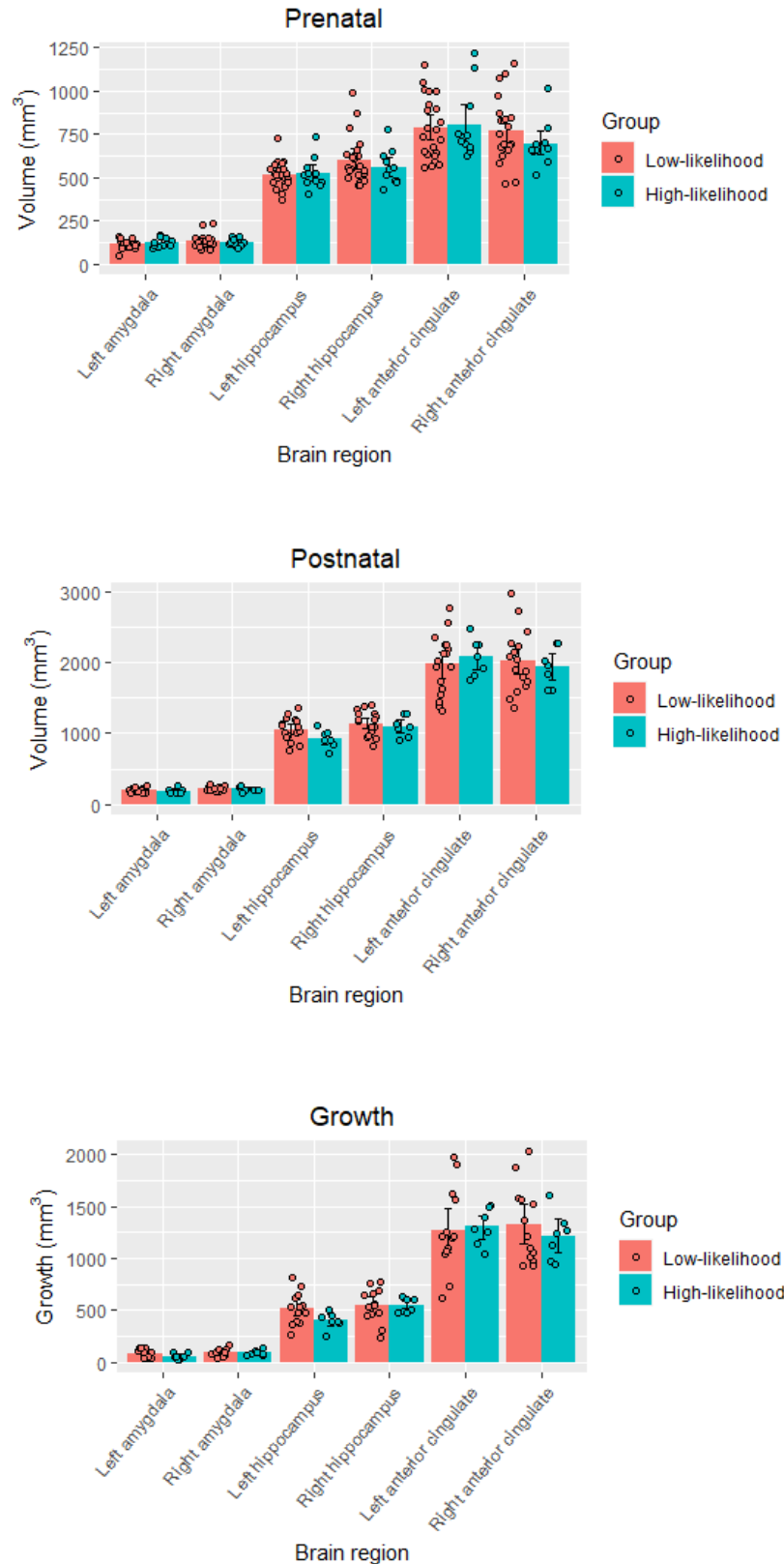


Figure 6.1 Mean regional brain volumes at the prenatal (top) and postnatal (middle) time-points and mean brain volume growth from the prenatal to the postnatal time-point (bottom). Error bars represent 95% confidence intervals.

6.3.2 Relationships between prenatal wellbeing and fetal regional brain volumes

No significant associations were found between any of the prenatal wellbeing measures and any of the fetal regional brain volumes (see Appendix 13).

6.3.3 Relationships between prenatal wellbeing and infant regional brain volumes

No significant associations were found between any of the prenatal wellbeing measures and any of the infant regional brain volumes (see Appendix 13).

6.3.4 Relationships between prenatal wellbeing and the growth of regional brain volumes

A significant relationship was found between maternal prenatal anxiety/stress and the growth of the left hippocampus from the prenatal to the postnatal time-point, with higher maternal anxiety/stress associated with reduced growth of the left hippocampus (Table 6.6; Figure 6.2). There were no other significant associations between prenatal wellbeing and growth of regional brain volumes (see Appendix 13).

Table 6.6 Results of the regression model of the relationship between prenatal anxiety/stress and growth of the left hippocampus.

	B (SE)	β	p-value (uncorrected)	p-value (FDR corrected)
Prenatal anxiety/stress	-120.30 (33.77)	-0.81	0.004	0.01
Total brain growth	0.002 (0.001)	0.63	0.01	0.04
Sex	100.90 (46.96)	0.35	0.05	-
Age difference	-0.35 (1.27)	-0.04	0.78	-
Postnatal stress	95.20 (30.21)	0.59	0.01	0.02
Group	-37.63 (45.15)	-0.13	0.42	-
Group*Prenatal anxiety/stress	-5.80 (40.83)	-0.04	0.89	-
Model: $F(7, 11)=11.09$, $p<0.001$, $R^2=0.88$				

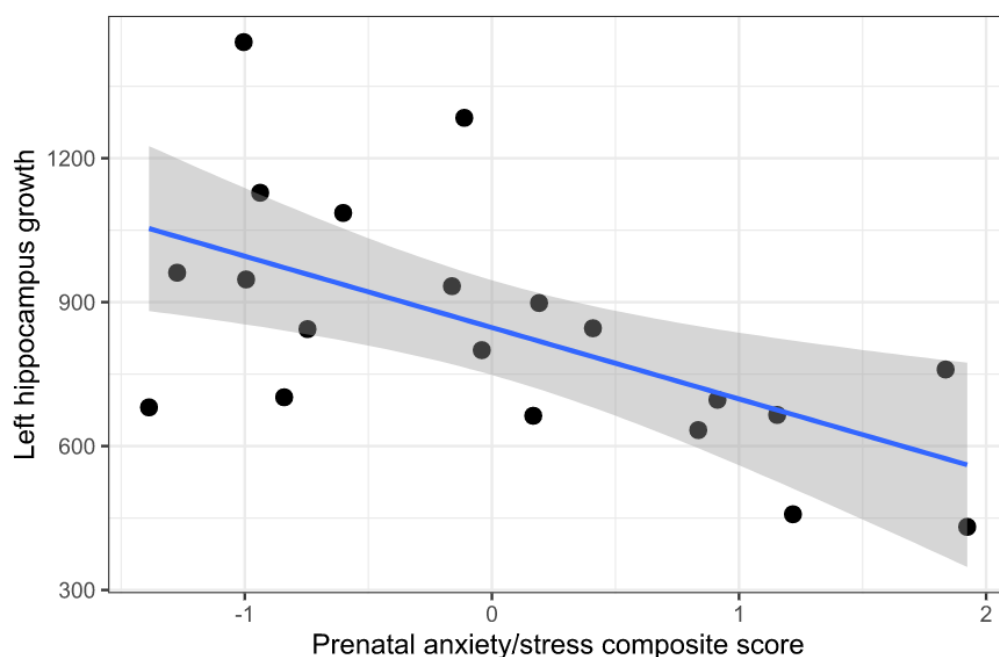


Figure 6.2 The relationship between prenatal anxiety/stress scores and the growth of left hippocampus volumes (mm³; shaded region represents 95% confidence interval).

6.3.5 Relationships between postnatal wellbeing and infant regional brain volumes

There was a significant association between postnatal anxiety/stress and infant right amygdala volume, though this did not survive correction for multiple comparisons (Table 6.7; Figure 6.3). A significant group by anxiety/stress interaction indicated that anxiety/stress was associated with larger amygdala volume in the LL group and smaller amygdala volume in the HL group.

Table 6.7 Results of the regression model of the relationship between postnatal anxiety/stress and infant right amygdala volume

	B (SE)	β	p-value (uncorrected)	p-value (FDR corrected)
Postnatal anxiety/stress	9.38 (5.35)	0.29	0.10	-
Total brain volume	0.0004 (0.0001)	0.78	0.001	0.001
Sex	2.14 (9.93)	0.04	0.83	-
Age	-0.12 (0.34)	-0.05	0.72	-
Group	3.17 (11.03)	0.05	0.76	-
Group*Postnatal anxiety/stress	-25.37 (11.10)	-0.77	0.04	0.04
Model: $F(6, 17)=7.59$ $p<0.001$, $R^2=0.73$				

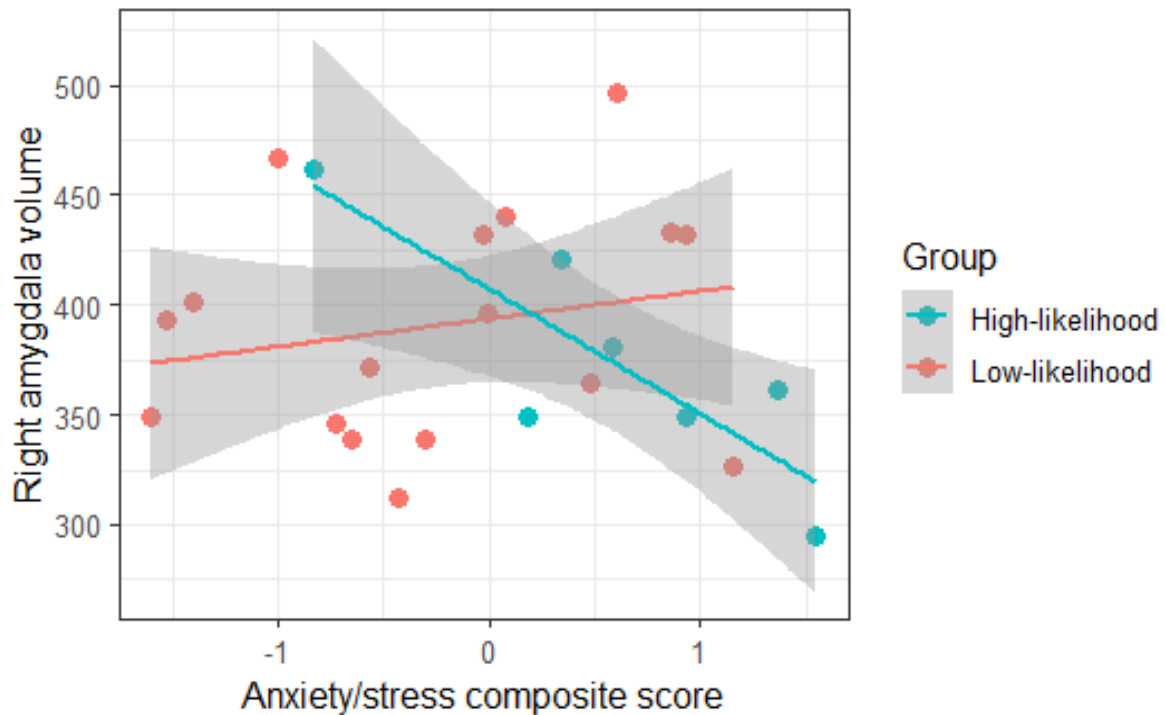


Figure 6.3 The relationship between postnatal anxiety/stress scores and infant right amygdala volumes (mm^3) for the HL and LL groups (shaded regions represent 95% confidence intervals).

A significant group by depression interaction was also found for the model exploring postnatal depression and infant right amygdala volumes, indicating that depression is associated with larger amygdala volume in the LL group and smaller amygdala volume in the HL group (Table 6.8; Figure 6.4). No other associations between postnatal wellbeing and postnatal brain volumes reached significance (see Appendix 13).

Table 6.8 Results of the regression model of the relationship between postnatal depression and infant right amygdala volume.

	B (SE)	β	p-value (uncorrected)	p-value (FDR corrected)
Postnatal depression	3.78 (1.81)	0.38	0.05	-
Total brain volume	0.0003 (0.0001)	0.63	0.003	0.003
Sex	-10.10 (16.36)	-0.01	0.55	-
Age	-0.15 (0.55)	-0.04	0.78	-
Group	58.96 (24.05)	0.52	0.03	0.04
Group*Postnatal depression	-8.19 (2.51)	-0.83	0.01	0.01
Model: $F(6, 17)=9.79$ $p<0.001$, $R^2=0.78$				

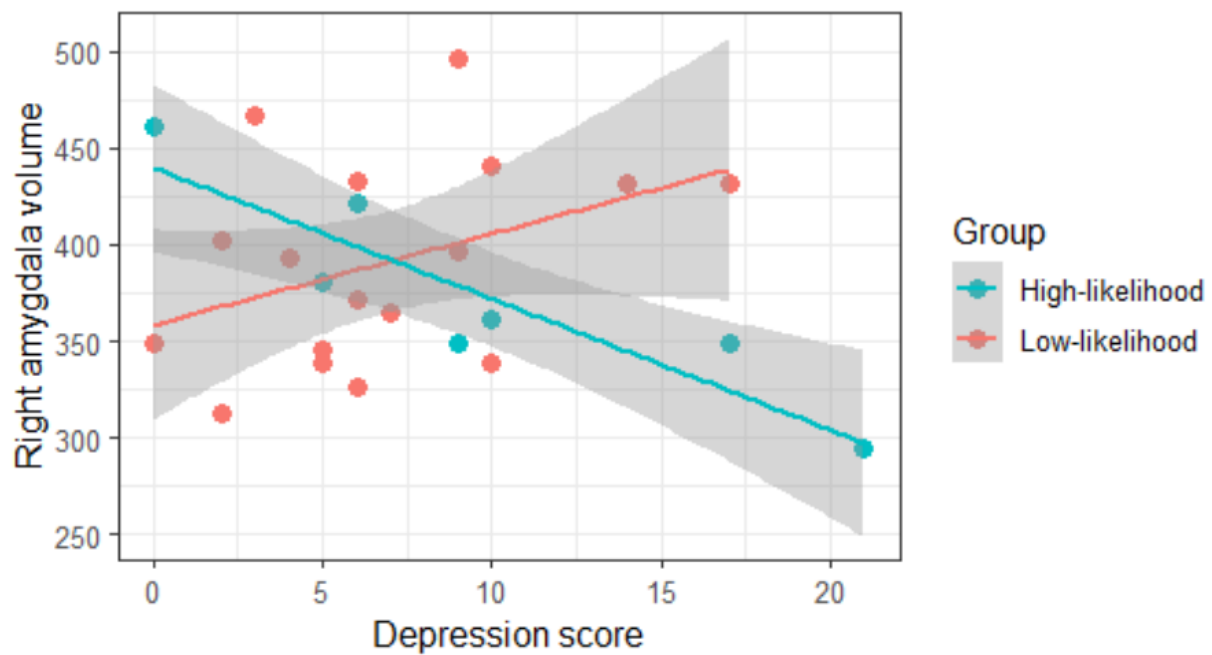


Figure 6.4 The relationship between postnatal depression scores and infant right amygdala volumes (mm³) for the HL and LL groups (shaded regions represent 95% confidence intervals)

6.3.6 Cortisol as a mediator between maternal wellbeing and infant brain volumes

Mediation analyses were conducted to explore whether infant cortisol mediated the relationship between postnatal maternal wellbeing and infant regional brain volumes, or the relationship between prenatal maternal wellbeing and growth of regional brain volumes. Cortisol did not significantly mediate any of the relationships explored (see Appendix 14 for full results).

6.3.7 PCI scores as a mediator between postnatal maternal wellbeing and infant brain volumes

Mediation analyses were conducted to explore whether mothers' PCI scores (sensitive responsiveness, scaffolding, negative affect and positive affect) mediated the relationship between postnatal maternal wellbeing and infant regional brain volumes. Mothers' PCI scores did not significantly mediate any of the relationships explored (see Appendix 14 for full results).

6.4 Discussion

Prenatal maternal anxiety/stress and depression did not significantly affect amygdala, hippocampus or anterior cingulate volumes at the fetal or infant stage. Prenatal maternal

mental health was associated with the growth of brain volumes over time, such that greater anxiety/stress was related to reduced growth of the left hippocampus. Finally, maternal postnatal mental health was associated with infant brain volumes, such that greater anxiety/stress and depression were associated with larger right amygdala volumes for the LL group and smaller right amygdala volumes in the HL group.

While prior research has established a link between prenatal maternal mental health and infant brain development, research has not explored whether prenatal maternal mental health affects fetal regional brain volumes. No evidence was found for such a relationship, suggesting that the impact of prenatal maternal mental health on offspring outcomes may not yet be observable at 30-33 weeks of pregnancy. While there is evidence that prenatal stress is associated with reduced fetal brain growth using ultrasound methods (Li et al., 2012), the present study did not find evidence for this relationship when exploring regional amygdala, hippocampus and anterior cingulate volumes using MRI.

No significant relationships were found between prenatal maternal mental health and infant brain volumes. A lack of association between prenatal anxiety/stress and infant hippocampus volumes is consistent with the findings of Buss et al. (2012), who found no effect of pregnancy cortisol on hippocampus volume in 7 year olds. However, while previous studies have tended to find associations between prenatal depression and the amygdala in infancy and childhood (Posner et al., 2016; Rifkin-Graboi et al., 2013; Scheinost et al., 2016; Qiu et al., 2015), in the present sample prenatal depression was not associated with infant amygdala volume. This may be due to the fact that previous studies have found links with amygdala connectivity rather than structure, suggesting that depression during pregnancy may affect functional and structural connectivity of the amygdala rather than volume. Alternatively, null findings may be due to a lack of power, given that the study was adequately powered to detect large effects and effect sizes for the associations between prenatal depression and infant amygdala volumes were medium ($f^2 = 0.14$ and 0.16 for the left and right amygdala respectively).

Prenatal anxiety/stress was related to reduced growth of the left hippocampus. This is in keeping with the findings of Qiu et al. (2013) who found that higher prenatal anxiety was associated with reduced growth of the hippocampus bilaterally from birth to six months old. The findings suggest that the association between prenatal anxiety and the growth of the hippocampus may be present not only during the first 6 months of life, but may begin as early

as pregnancy. In contrast to the present findings, Qiu et al. (2013) found that only the growth of the right hippocampus was related to prenatal anxiety after controlling for postnatal anxiety. This may be due to the difference in age between the present sample and that of Qiu et al. (2013); it is possible that the growth of the left hippocampus is more affected by prenatal anxiety from pregnancy to early infancy whereas the right hippocampus may be affected more during the first six months of life. Qiu et al. (2013) also collected information on prenatal anxiety at 26 weeks of pregnancy, several weeks earlier than this information was collected in the present study, and it is possible that prenatal anxiety may impact upon offspring outcomes differently at this earlier stage.

Prior research has found evidence for a link between postnatal depression and increased amygdala volume in childhood (Lupien et al., 2011). This is consistent with the finding that, in the LL group, postnatal depression and anxiety/stress were associated with increased infant right amygdala volume. The opposite pattern was the case for the HL group. This may be due to altered amygdala development among autistic individuals, given that autistic individuals across the lifespan tend to show differences in amygdala volume compared with non-autistic individuals. The fact that such interaction effects were found predominantly for associations with postnatal rather than prenatal mental health may suggest that this differential effect has its roots in postnatal influences such as maternal behaviour rather than the prenatal environment. It is unclear whether postnatal mental health may exert different effects on the behaviour of autistic and non-autistic mothers and whether any such differences may in turn impact upon the development of their offspring. It is possible, for example, that autistic mothers may have increased awareness of the challenges they may face as a parent due to having received an autism diagnosis and may therefore attempt to compensate for these challenges to a greater extent than non-autistic mothers. It may also be possible that experiencing worse mental health may exacerbate any aspects of being autistic that might make parenting more challenging (such as sensory overload or organisation skills). However, evidence was not found for a mediating role of maternal behaviour during parent-child play in the relationship between maternal postnatal mental health and infant brain volumes. This may suggest that this relationship is not due to changes in maternal behaviour as a result of maternal mental health. Alternatively, it may be that the measures used were not sufficiently

sensitive; a five-minute play session under laboratory conditions coded with a global coding scheme may not have been able to capture the relevant maternal behaviours.

The brain volume patterns found to be associated with perinatal maternal wellbeing in the present study (i.e. reduced left hippocampus growth and increased right amygdala volume) are similar to those implicated in mental health conditions. Reduced left hippocampus volume, for example, has been associated with mental health outcomes such as anxiety in adults (Gorka et al., 2014) and internalizing symptoms in adolescents (Koolschijn et al., 2013). Similarly, the right amygdala (including increased right amygdala volume) appears to be implicated in mood disorders such as anxiety and depression (Abercrombie et al., 1998; De Bellis et al., 2000; van Eijndhoven et al., 2009). As such it may be that maternal perinatal wellbeing can influence the subsequent development of mood disorders in offspring through its association with increased infant amygdala volume and reduced left hippocampus growth. Indeed, there is some evidence that increased right amygdala volume in childhood mediates the relationship between maternal prenatal stress and greater affective problems in childhood (Buss et al., 2012) and that increased neonatal amygdala connectivity mediates the link between maternal prenatal stress and internalizing symptoms in toddlers (Graham et al., 2019). This may suggest that the associations seen in the present study between maternal wellbeing and offspring brain volume may have an influence upon the child's later emotional development. However, as the present study did not explore associations between brain changes and later developmental outcomes, this interpretation remains speculative.

Evidence was not found for a mediating role of infant cortisol levels in the relationship between maternal mental health and offspring brain volumes. This may be due to issues with sample size, given that cortisol data was present for slightly fewer infants than was MRI data.

6.4.1 Limitations

Stress, depression and anxiety were measured through self-report questionnaires and were not corroborated with clinical assessment. Further, the questionnaires were administered at only one point in pregnancy, during the third trimester. In contrast, prior studies have tended to measure mental health slightly earlier, around the end of the second trimester, meaning that the present findings are not directly comparable. The perinatal period is a time of great developmental change and maternal mental health may have different effects depending on the timing at which it occurs. As the questionnaires were administered at only one point in

pregnancy and at only one point postnatally, it is not possible to determine the precise timings of the effects of perinatal maternal mental health symptomology on offspring brain development. Furthermore, data concerning child outcomes is not yet available and as such it is not yet possible to establish the significance of these early brain changes for long-term child behavioural development. It will be important for future research to relate infant brain changes to later behaviour in order to establish the clinical significance of these findings.

Due to the difficulty of recruiting currently pregnant women to take part in a longitudinal MRI study, and due to the challenges involved in infant MRI scanning, the sample size is modest and failure to replicate results in the previous literature may have been due to lack of power. Given the small sample, it was not feasible to include all potentially relevant covariates and it is possible that group differences may be influenced by differences in other factors such as socio-economic status. Due to the small sample size and the exploratory nature of the study, findings should be interpreted tentatively and replication in larger samples is required before any strong conclusions can be drawn. Despite this, the results provide promising avenues for such future research.

6.4.2 Conclusions

The findings add to a growing body of literature indicating a role for perinatal maternal mental health in infant brain development. The findings suggest a link between prenatal maternal anxiety/stress and left hippocampus development from pregnancy until 8-12 weeks of life, in addition to a link between postnatal anxiety/stress and depression and the development of the right amygdala. These findings contribute to a growing evidence base that the perinatal stage is an important period for the development of the brain and that differences in brain structure associated with neurodevelopmental and psychiatric conditions may have their root in perinatal development. The results have important implications for policy surrounding supporting women during the perinatal period. They highlight that it is imperative to protect maternal perinatal mental health, not only for the benefit of women themselves but also for their children. Given that the majority of the mothers did not exhibit clinical levels of stress, depression or anxiety, the results indicate that appropriate perinatal mental health support is crucial for all women and not only those with a clinical diagnosis of anxiety or depression. Future research should involve longitudinal studies with larger sample sizes, more

developmental time points throughout infancy and childhood and the linking of brain and behavioural data.

Chapter 7: General discussion

7.1 Summary of results

This thesis aimed to explore the perinatal experiences and wellbeing of autistic mothers, their parenting behaviours, and the development of their infants within the context of maternal factors. Chapters 2, 3 and 4 addressed autistic people's experiences and wellbeing during the perinatal period. Chapters 2 and 3 reported on perinatal experiences using qualitative interviews and a quantitative survey method, respectively. Both chapters indicated that autistic people experience greater pregnancy-related physical challenges than non-autistic people and greater sensory challenges during childbirth. Autistic people also face barriers to adequate prenatal, birth-related and postnatal healthcare, including difficulties with the sensory environment of healthcare settings and challenges surrounding communication with healthcare professionals. Autistic people can find aspects of parenting challenging during the postnatal period, including the executive function and sensory demands of parenting, though possess strengths such as researching child development in detail. Chapter 4 found that autistic people scored higher than non-autistic people on self-report measures of stress, anxiety and depression during the third trimester of pregnancy, 2-3 months after birth and 6 months after birth. Scores on stress, depression and anxiety decreased over time for both groups, though this was only significant for anxiety. Autistic people also scored higher on self-report pregnancy-related anxiety though no group differences were found on self-reported satisfaction with life. No differences were found in the self-reported parenting styles of autistic and non-autistic parents, including parenting anxiety, discipline, nurturance, involvement and routine, nor were any group differences found in parenting confidence.

Chapters 5 and 6 report on the behaviour and brain development of infants with an autistic mother or sibling within the context of their mother's wellbeing and behaviour. Chapter 5 revealed no differences between parents in the high-likelihood (HL) or low-likelihood (LL) groups on sensitive responsiveness, scaffolding, positive affect and negative affect during play with their infants at either 2-3 months or 6 months old. Parents in both groups demonstrated a decline in sensitive responsiveness and positive affect between 2-3 months and 6 months. Infants in the HL and LL groups did not significantly differ on social initiations, attentiveness, sharing of affect, positive affect or negative affect during play with their parent at either 2-3 months or 6 months old. Chapter 6 indicates that mothers' prenatal self-reported stress and

anxiety are associated with reduced growth of their infant's left hippocampus from the third trimester of pregnancy until 8-12 weeks after birth. Maternal postnatal stress and depression are associated with larger right amygdala volume in LL infants and smaller amygdala volume in HL infants.

7.2 Autistic people's perinatal experiences

Chapters 2 and 3 point towards a number of ways in which autistic people can be better supported during the perinatal period. The preliminary qualitative findings of Chapter 2 are supported by the larger, quantitative sample of Chapter 3, allowing for greater confidence in the generalisability of the implications for clinical practice that both chapters reveal.

Both chapters indicate that the physical demands of pregnancy are particularly challenging for autistic people. These demands include experiencing overwhelming sensory changes across a range of modalities, experiencing greater frequency and duration of nausea and vomiting during pregnancy compared with non-autistic people and increased risk of pelvic girdle pain and vaginal bleeding during pregnancy. Healthcare professionals should be aware of these physical challenges and their impact on quality of life and wellbeing. Such awareness could allow for more effective identification and treatment of these conditions. Healthcare professionals should also support autistic people to identify when to seek help with physical issues, given that autistic people are less likely to know when to seek help with pregnancy and postnatal physical symptoms.

Chapters 2 and 3 highlight a number of barriers to adequate maternity care. Autistic people can be reluctant to disclose their diagnosis to maternity care professionals due to fear of discrimination, and this can be a barrier to accessing adjustments and support. Those who do disclose can be met with a lack of understanding of autism, sometimes leading to their disclosure being overlooked. These findings are in keeping with prior accounts of a lack of autism-related knowledge among perinatal care professionals and other healthcare professionals (Gardner et al., 2016; Nicolaidis et al., 2015). It is essential that perinatal healthcare professionals receive training concerning autism and its presentation in women in order to provide appropriate care for autistic people.

Consistent with prior evidence that autistic people face communication-related healthcare challenges (Gardner et al., 2016; Raymaker et al., 2017), difficulties processing verbal

communication could be a barrier to effective prenatal and postnatal healthcare. The provision of written information, extra time in appointments to process verbal information and alternatives to phone contact were highlighted as important accommodations. An advocate with a good understanding of autism, such as a doula or specialist midwife, may be helpful for supporting communication between autistic people and healthcare professionals. Autistic people should be provided with clear, detailed, factual information in appointments in order to support them to have informed control of their care. Ensuring predictability is also essential, including providing clear, detailed information about what to expect in appointments and keeping autistic people informed of any changes of plan. Continuity of care can be helpful for increasing the predictability of appointments, in addition to helping to build trust and understanding. Echoing prior findings that the sensory environment of healthcare settings can be a barrier for autistic people (Raymaker et al., 2017), autistic people can find perinatal appointments overwhelming from a sensory perspective (including bright lights and crowded waiting rooms). Sensory accommodations should be made for autistic people, such as dimming lights and providing access to quieter waiting spaces. Group support such as antenatal and breastfeeding classes can also present sensory (as well as social) challenges and online classes or one-to-one classes with a midwife or doula may represent accessible alternatives.

Being kept informed with clear, direct information, and being given adequate time to process this information, is also crucial for supporting autistic people to feel in control of their childbirth experience. Once again, the presence of an advocate to assist with communication may be beneficial during childbirth, as autistic people report that the efforts of childbirth can leave little capacity for processing verbal communication. Furthermore, autistic people can feel that professionals do not listen to their concerns and requests during childbirth and are dismissive of their knowledge of their body. This may in part be due to atypical ways of experiencing and expressing bodily sensations. Autistic people may express pain differently than non-autistic people, for example, with a less expressive outward appearance than is typical of non-autistic people. Professionals should therefore not be dismissive if their autistic patients' reports of their bodily experiences seem atypical or do not match with outward appearance.

Autistic people are also more likely to experience sensory overload during childbirth, highlighting the need for sensory-related accommodations such as dimming lights, minimising the number of people in the room and avoiding unannounced touch if possible. Sensory overload, in addition to issues surrounding communication, can cause a meltdown or shutdown during childbirth. Birth-related healthcare professionals require training to be able to identify meltdowns and shutdowns and to respond appropriately. Professionals should be aware that autistic people may not be able to communicate during a shutdown or may need to be given adequate time to respond. The environment of the postnatal ward can also be overwhelming from a sensory perspective and, where possible, autistic people should be offered their own room. Some of the adjustments outlined may fit within the framework of universal design (ensuring that services are accessible to all). Non-autistic participants also sometimes felt they would benefit from similar adjustments (e.g. clearer communication surrounding their care), indicating that implementing changes that would benefit autistic people may improve care for all.

7.3 Autistic people's perinatal mental health and infant development

Findings across Chapters 2, 3 and 4 indicate a greater risk for lower perinatal wellbeing among autistic people. Chapter 3 revealed that autistic people are more likely than non-autistic people to experience both prenatal and postnatal depression and anxiety. These findings give support to the Pohl et al. (2020) findings of greater prenatal and postnatal depression among autistic than non-autistic mothers and furthermore indicate greater risk of anxiety. However, these findings rely on retrospective reports (for some participants in Chapter 3 and Pohl et al. (2020) many years had passed since the birth of their youngest child) and do not employ validated measures of depression and anxiety. Furthermore, the cross-sectional approach employed allows limited conclusions to be drawn concerning the timing of onset of symptoms. Chapter 4, employing a longitudinal design with validated measures, provides further evidence of greater prenatal and postnatal depression and anxiety among autistic people, as well as greater prenatal and postnatal stress. These differences arise for both continuous measures of symptoms as well as the percentage of individuals scoring above clinical cut-offs.

These findings of increased risk highlight that screening and support for perinatal depression and anxiety among autistic people is essential, and this may involve the development of novel

screening measures and interventions that are appropriate for the needs of autistic people. Particular attention may need to be paid to the screening of perinatal depression and anxiety for autistic people. In Chapter 3, some autistic participants reported masking their mental health struggles from professionals, including masking their difficulties in their responses to screening instruments, for fear of losing their child. Indeed, Chapter 3 revealed that autistic people are more likely to worry that their child will be taken away from them and Chapter 2 revealed that a lack of autism knowledge among professionals can lead to unwarranted scrutiny from social services for autistic mothers. Greater autism understanding among professionals, in addition to greater continuity of care, may help to build trust between autistic parents and professionals, which may facilitate disclosure of perinatal mental health difficulties. Professionals should also be aware that responses to existing perinatal mental health screening measures may not be accurate for autistic people, and therefore should not rely solely on these measures to assess wellbeing.

Greater risk of poorer perinatal mental health among autistic people likely in part reflects an increased risk of mental health conditions among autistic people more generally (Lai et al., 2019), though plausibly also reflects the impact of the stressors identified in Chapters 2 and 3, such as an increased physical toll of pregnancy and barriers to adequate healthcare. Providing better access to appropriate perinatal healthcare for autistic people (as outlined in the section above) may therefore be important for reducing the risk of perinatal depression and anxiety among autistic people.

Screening and support for mental health during pregnancy may be particularly important for both autistic and non-autistic people, given tentative findings in Chapter 4 that stress, depression and anxiety may be higher during pregnancy than the postnatal period. This is corroborated by reports in Chapter 2 that pregnancy can amplify negative emotions such as anxiety and low mood for autistic people. Given findings in Chapter 4 of greater pregnancy-related anxiety among autistic people, one potentially beneficial form of prenatal support may be to target anxieties specific to pregnancy. Qualitative reports in Chapter 2 suggest that autistic people's anxieties surrounding the upcoming birth such as uncertainty, concerns about communication with medical staff and worries about sensory issues may be important targets, and the assurance of adequate adjustments to birth-related care may help to allay these worries. It should be noted, however, that while Chapter 4 suggests that cases of

depression and anxiety during pregnancy can abate by the postnatal period, new cases can also arise during the postnatal period, indicating that adequate screening and support for postnatal depression and anxiety is also essential, even in the absence of prenatal depression or anxiety.

Perinatal anxiety has been overlooked in research, with most studies focusing on perinatal depression (Ross & McLean, 2006). However, the findings of Chapter 4 point towards the importance of good quality research, screening and support surrounding perinatal anxiety. Chapter 4 found that, both during pregnancy and postnatally, a greater percentage of both groups scored above the cut-off for anxiety than for depression. Furthermore, while almost all of those scoring above the cut-off for depression had a prior depression diagnosis, many of those scoring above the cut-off for anxiety did not have a prior anxiety diagnosis. This indicates that screening for anxiety among all mothers, including those with no prior history of anxiety, may be particularly important. The findings of Chapter 6 further highlight the need for effective support for perinatal anxiety due to its association with infant brain development.

Indeed, good quality perinatal mental health support is important due to its impact not only on mothers but also on their children. The findings of Chapter 6 may suggest that both prenatal and postnatal maternal wellbeing influence infant structural brain development, underscoring the importance of effective screening and support for mental health both during pregnancy and the postnatal period. Furthermore, there were differential effects of postnatal maternal wellbeing on right amygdala volume depending on high-likelihood or low-likelihood group membership. This may indicate that the impact of maternal wellbeing on infant brain development interacts with factors related to having an autistic mother or sibling, though it is unclear whether these factors are biological (such as genetic factors) or environmental influences such as parenting behaviours and socio-economic factors. These findings should, however, be interpreted with caution due to the small sample size. Nevertheless, they may suggest that ensuring the perinatal wellbeing of autistic mothers is particularly important in order to not only support the mothers themselves but also to support the development of their infants.

7.4 Autistic people's parenting experiences and infant development

Qualitative reports in Chapters 2 and 3 reveal that parenthood can be a rewarding experience for autistic people, with autistic and non-autistic parents alike forming an affectionate bond with their child and enjoying seeing their child develop. These qualitative reports also indicate that autistic and non-autistic parents share parenting strengths such as being attentive, understanding and empathetic. Additionally, autistic parents identify strengths in attending to the detail of their infant's cues, understanding their infant's sensory needs, persevering with parenting challenges, understanding atypical development and researching parenting in detail. It is important that healthcare and education professionals working with autistic parents are aware of these strengths. Qualitative reports of successful parenting among autistic people are supported by the quantitative findings of Chapters 4 and 5. Chapter 4 revealed no differences in the self-reported parenting styles of autistic and non-autistic parents across a number of parenting aspects, including parenting anxiety, discipline, nurturance, involvement and routine. Chapter 5 extends this finding of similar parenting styles between autistic and non-autistic parents to an observational context, finding no differences in sensitive responsiveness, scaffolding, positive affect and negative affect between HL and LL parents. Positive parenting styles such as high sensitivity and an appropriate level of control are influential upon child outcomes (Silvén et al., 2002; Yap et al., 2014) and it is important that professionals working with autistic parents are aware that there is preliminary evidence that autistic parents engage in these behaviours.

However, despite the strengths detailed above, qualitative findings in Chapters 2 and 3 indicated that both autistic and non-autistic parents face challenges such as lack of sleep and lack of time to oneself. Autistic parents also identified challenges with the demands that parenthood places on executive function and organisational abilities, in addition to challenges with sensory demands such as the sound of their infant's cries and the sensory aspects of breastfeeding. Support with the executive and sensory aspects of parenthood would therefore be beneficial for autistic parents. Despite no evidence of difficulties with the aspects of parent-infant play measured in Chapter 5, some autistic parents find knowing how to play with their infant challenging. Furthermore, Chapter 4 revealed that a greater percentage of autistic than non-autistic parents scored above the cut-off for clinically low parenting confidence (though there was no difference in continuous scores). Support to improve

parenting confidence may therefore be beneficial for some autistic parents, particularly in areas where they may be more likely to lack self-efficacy such as parent-infant play. Given that supporting parents to play with their infants can lead to better outcomes for infants with an increased genetic likelihood of being autistic (Green et al., 2017), supporting autistic mothers with play may also benefit their infants. However, it should be noted that infants in the HL group did not differ from LL infants on initiating social interaction, attentiveness to their parent, sharing affect, showing positive affect or showing negative affect during play with their parent in Chapter 5. This may indicate that infants of autistic mothers show typical social behaviours during the first 6 months of life (though this conclusion cannot be firmly drawn due to the limited sample size). Nevertheless, social behaviours of infants of autistic mothers may begin diverge from typical behaviours later in development (as is the case for infants with an autistic sibling) and effective parent-infant play may help to support these infants towards a developmental trajectory that best allows them to flourish.

7.5 Personal reflections

Throughout the PhD, I aimed to produce a piece of research that would be consistent with the priorities of the autistic community and would contribute positively to the lives of autistic people. This is a perspective that influenced my approach to the CHILD study. The CHILD study was originally intended to focus solely on the development of the infants of autistic mothers. When I joined the project, I added maternal wellbeing and experiences measures so that the study could also have a direct impact upon autistic mothers themselves. Before beginning the research, I was aware from anecdotal accounts that autistic mothers could fear being judged due to being autistic and could even fear having their child taken away. I was keen not to contribute towards negative perceptions of autistic mothers and, as such, have attempted to take a balanced approach, making sure to allow the strengths of autistic mothers to emerge as well as addressing areas where autistic mothers can face challenges and may need support. I was also influenced by the idea of double empathy (Milton, 2012; as outlined in Chapter 1). This theory influenced my discussion of the communication-related support needs of autistic mothers, leading me to frame these issues as a difference in communication style between autistic mothers and professionals rather than a failing on the part of autistic mothers. Throughout the thesis, especially within those chapters with qualitative elements, these personal perspectives may have influenced the results and their presentation.

7.6 Limitations

The CHILD study is a small-scale, exploratory study of a novel population and as such possesses a number of limitations that affect the data reported on throughout this thesis. Currently pregnant autistic women are a rare and challenging group to recruit. Women are diagnosed with autism less frequently than men and the women recruited were required to be in a narrow 4 week window of pregnancy in order to take part. Furthermore, the study required participants to travel to Cambridge, to commit to a longitudinal study over the course of 3 years, to be willing and able to undergo MRI scanning while pregnant, as well as to be willing to allow their infant to undergo MRI scanning. The logistical requirements of participating in such a study can also be prohibitive for those who are pregnant or have a young infant and who may also have caring responsibilities for their children with additional needs. These recruitment challenges have resulted in a small sample size, limiting the generalisability of the results and reducing opportunities for exploratory analyses and the inclusion of potentially important covariates. Furthermore, it is unclear whether some null findings may be due to a lack of power to detect differences. The sample is not only small but also heterogeneous, including both infants of autistic mothers and infants with an autistic sibling. This heterogeneity, and the inability to explore subgroups due to the sample size, makes it challenging to tease apart the effects of having an increased genetic likelihood of autism, having an autistic mother and having an older autistic sibling.

Data concerning later child outcomes, including autistic characteristics, is not yet available. As such, it is not yet possible to verify that the LL infants are in fact typically developing, nor is it yet possible to determine whether the HL infants will go on to meet diagnostic criteria for autism, will follow an atypical trajectory without meeting autism diagnostic criteria, or will be typically developing. This uncertainty limits the ability to make conclusions about differences between autism and typical development. The lack of data concerning child outcomes also means it is not possible to make conclusions about the clinical significance of findings. It is unclear, for example, whether group differences (or lack thereof) reflect difficulties, strengths or compensatory effects.

The thesis only captures the experiences of those with the capacity to take part in time-consuming research relying on verbal communication and as such may not reflect the needs of those unable to do so, such as those with greater mental health challenges, those with

greater caring responsibilities or those with intellectual disability. Furthermore, the comparison groups used throughout the studies differed from the autistic/high-likelihood groups on a number of demographic variables such as socio-economic status and the presence of mental health conditions. As such, the findings may in part reflect these differences.

There are also limitations associated with the measures used. The wellbeing and experiences measures rely on self-report. While it is important that autistic people are given a voice to share their experiences, self-report may be less reliable than observation and clinical assessment. Furthermore, the questionnaire measures and parent-child interaction measures were originally designed for use with non-autistic people and it is possible that the creation of novel measures targeting autistic people may better capture autistic wellbeing and parenting.

7.7 Future directions

This thesis provides a preliminary account of autistic mothers and their infants during the perinatal period and serves as a foundation for further exploration of this under-researched area. The thesis suggests that autistic people experience poorer perinatal mental health than non-autistic people and this should be corroborated in larger samples across a number of time-points throughout pregnancy and the postnatal period. The causal mechanisms underlying this increased risk of poorer mental health should also be addressed, with both qualitative and quantitative studies assessing the role of potential predictors such as the physical and healthcare-related stressors identified in this thesis, socio-economic factors, level of social support, hormonal factors and prior mental health history. Greater understanding of trajectories of perinatal mental health and the causal factors at play will allow for the creation of screening measures, interventions and support appropriate to autistic people's needs. The autistic perspectives reported in this thesis offer a number of recommendations for clinical practice and can form the basis of guidelines for perinatal healthcare professionals. Further research should additionally seek the perspectives of perinatal healthcare professionals in order to develop a fuller picture of their autism knowledge, the level of autism-related training they receive and the barriers they may face to providing care for autistic people. Evidence of increased risk of pregnancy conditions and physical symptoms among autistic people should be corroborated using health record data in

a larger sample. Mechanisms for this increased risk should be explored including barriers to healthcare, increased risk of hypermobility and chronic pain, and hormone levels.

While this thesis provides insights into parenting during the postnatal period, future studies should explore how autistic parents' strengths and challenges evolve as their child grows. Further studies of interactions between autistic parents and their children should employ coding schemes tailored to autistic parents, including capturing their strengths, as well as assessing how the presence of a mental health condition impacts upon parenting behaviour for autistic people. The thesis provides a preliminary exploration of the social interaction behaviours of infants of autistic mothers, though these behaviours should be further explored using sensitive, micro-analytic coding schemes across infancy and toddlerhood. Further studies should explore the relationships between parent-infant interaction behaviours and later child developmental outcomes. This will allow the identification of potential targets for support. Similarly, exploring the relationships between maternal wellbeing, infant brain development and later child outcomes will allow a better understanding of the clinical significance of potential associations between maternal wellbeing and infant brain development. Finally, the relationship between maternal wellbeing and child development is complex and likely involves a broad range of influences, including genetic and other biological factors such as birth outcomes, in addition to socio-economic, familial and cultural factors. Further studies should take into account the role of these factors when considering the relationships between maternal wellbeing and child development.

7.8 Conclusions

Maternal wellbeing during the perinatal period is important due to its impact upon both mothers and their infants. However, autistic mothers and their infants have been neglected in research. This thesis is the first in depth exploration of autistic perinatal experiences using both qualitative and quantitative methods, and the first exploration of the development of the infants of autistic mothers. The thesis yields important implications for clinical practice. Autistic people are at greater risk of poorer perinatal mental health, indicating that mental health screening and support that is appropriate to the needs of autistic people is essential. Autistic people face a number of barriers to adequate perinatal healthcare, including a lack of autism knowledge among professionals, as well as communication and sensory challenges. Accommodations should be made to enable effective healthcare such as the provision of

clear, detailed information, extra time in appointments and sensory accommodations in healthcare settings. Greater autism training among perinatal healthcare professionals is essential. Healthcare professionals should be aware that the preliminary evidence presented suggests that autistic parents are not less likely to engage in adaptive parenting behaviours than non-autistic parents, though they may benefit from support with the executive function, sensory and play related challenges of parenthood. This thesis suggests that infants of autistic mothers may not demonstrate atypical social interaction behaviours within the first 6 months of life, though their brain development may be differently affected by their mother's wellbeing compared with infants without an autistic family member. The results have important implications for perinatal care, highlighting that effective support surrounding maternal perinatal mental health is essential not only for the benefit of mothers but also for their infants. For infants who have an increased genetic likelihood of an atypical developmental trajectory due to having an autistic family member, such support may be especially important.

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Appendix 1: Qualitative interview scripts

Pregnancy Questions

Overall experience of pregnancy:

- Could you tell me a bit about what being pregnant is like for you?

Sensory/physical experiences:

- What have the physical aspects of pregnancy been like for you?
- Have you noticed any changes since becoming pregnant in your sensory experiences?

Relationships with professionals:

- How would you describe your relationships with healthcare professionals throughout pregnancy?
- [autistic group only] Have professionals been aware of your autism diagnosis?
- [autistic group only] Is there anything that you would like professionals to understand about autism in relation to prenatal appointments?
- Do you feel you have had all the information you need throughout your pregnancy?

Feelings about childbirth/parenthood:

- How are you feeling about giving birth?
- How are you feeling about becoming a mother?

Support:

- Do you feel you have all the support you would like?
- What support/adjustments do you think would be helpful for pregnant [autistic] people?

Postnatal questions

Birth experiences:

- What was giving birth like for you?
- How would you describe your relationships with medical professionals throughout giving birth?
- Throughout giving birth, did you feel you were kept adequately informed by health professionals?
- [*autistic group only*] Is there anything you would like professionals to understand about autism in relation to giving birth?

Breastfeeding:

- What has your experience of feeding your baby been like?

Postnatal appointments:

- How would you describe your relationships with healthcare professionals during postnatal appointments?
- [*autistic group only*] Have health professionals been aware of your autism diagnosis?
- [*autistic group only*] Is there anything that you would like professionals to understand about autism in relation to postnatal appointments?
- Do you feel you have had all the information you need?

Parenting:

- What has being a mum been like for you so far?
- Is there anything you have found challenging about motherhood?
- Is there anything you have found rewarding about motherhood?
- What would you say are your strengths as a parent?
- Do you have any goals for your child?

Support:

- Do you feel you have all the support you would like?
- What support do you think would be helpful for [*autistic*] mothers?

Appendix 2: Cohen's kappa values for interview data inter-rater reliability

Appendix Table 2.1 Cohen's kappa values for the pregnancy themes and subthemes

Theme/subtheme	Initial Kappa	Final Kappa
Theme 1: The physical and psychological impact of pregnancy	0.79	0.87
1a. The impact of sensory changes	1.00	1.00
1b. The impact of other physical changes	0.94	1.00
1c. The emotional impact and social pressures of pregnancy	0.59	0.80
Theme 2: The impact of formal and informal support	0.96	0.96
2a. Considerations around disclosure and professionals' autism expertise	0.73	1.00
2b. Communication needs during antenatal care	0.56	0.78
2c. Other met and unmet support needs	0.53	0.94
2d. The importance of informal support	0.88	1.00
Theme 3: Fears and hopes of motherhood	0.78	0.84
3a: Birth related hopes and fears	0.78	0.78
3b: Anticipation of the challenges and benefits of parenthood	0.83	0.92

Appendix Table 2.2 Cohen's kappa values for the postnatal themes and subthemes

Theme/subtheme	Initial Kappa	Final Kappa
Theme 1: Positive and negative birth experiences	0.91	0.91
1a: The physical and emotional challenges of birth	0.70	0.70
1b. Autism disclosure and accommodations around specific needs	0.65	0.88
1c: Communication needs	0.77	0.91
1d. Other met and unmet support needs	0.88	0.81
Theme 2: The rewards and challenges of motherhood	1.00	1.00
2a. Motherhood as a rewarding experience	0.95	0.88
2b. Hopes and expectations for child	1.00	1.00
2c. Impact on day-to-day functioning	0.78	1.00
2d. Other demands of motherhood	0.79	0.90
Theme 3: The impact of formal and informal support	0.95	0.95
3a. Professionals' autism expertise and accommodations around specific needs	1.00	1.00
3b. The importance of building a relationship with professionals	0.00	1.00
3c. Other met and unmet support needs	0.82	0.82
3d. The importance of informal support	1.00	0.79

Appendix 3: Perinatal experiences survey questions

Demographic Questions

Please create an identification code. This will enable you to withdraw your responses if you choose not to continue with the study.

Please use the following format:

Character 1: The first letter of your first name (e.g. S for Sarah)

Characters 2 and 3: The last two digits of your birth year (e.g. 79 for 1979)

Character 4: The last letter of your last name (e.g. E for Doe)

Character 5 and 6: The first two characters of your post code (e.g. CB for CB2 8AH)

The code for the example given would be S79ECB.

Please answer the following questions about you.						
What is your date of birth? (dd/mm/yyyy)						
Which gender were you assigned at birth?	Male		Female		Other (please specify)	
Which gender do you currently identify as?	Female	Male		Non-binary	Other (please specify)	
How would you describe your ethnicity?	White		Asian (please specify)	Black Caribbean		Black African
	Mixed background (please specify)		Other (please specify)			Prefer not to say
In what country do you live?						
What is your nationality?						
What is the highest academic qualification you have completed?	Postgraduate Degree	Undergraduate degree	Completed secondary school/high school	Some secondary school/high school	None	Other (please specify)
What is your current employment status?	Employed full time	Employed part time	Unemployed	In full time education	Voluntary worker	Carer or homemaker
What is your total annual household income at present?	<£25,000	£25,000-£50,000	£50,000-£100,000	£100,000-£150,000	>£150,000	Prefer not to say
What is your current marital status? (please choose all that apply)	Single	Married	In a partnership but not married	Divorced/ Separated	Widowed	Other (please specify)
[If married/in a partnership] Do you live with your partner/spouse?	Yes			No		

[If married/in a partnership] Does your partner have a diagnosis of an autism spectrum condition?	Yes				No (and I do not believe they are autistic)				No (but I believe they are autistic)			
How would you describe your sexuality?	Homosexual		Heterosexual		Bisexual		Pansexual		Asexual		Other (please specify)	
Do you have a diagnosis of an autism spectrum condition?	Yes				No (and I do not self-identify as having an autism spectrum condition)				No (but I self-identify as having an autism spectrum condition)			
[If yes to diagnosis] In which year did you receive this diagnosis?												
Have you ever been diagnosed with any psychiatric or psychological condition(s) (e.g. bipolar disorder, depression, schizophrenia, borderline personality disorder, anorexia nervosa etc.)?	Yes (please specify)				No				Prefer not to say			
Have you ever been diagnosed with any other medical conditions?	Yes (please specify)				No				Prefer not to say			
Are you currently pregnant?	Yes						No					
[If yes] How far along in your pregnancy are you today? (please specify how many weeks and days)												
[If yes] Are you in the first, second or third trimester of pregnancy?	First				Second				Third			
[If yes] What is the sex of your baby?	Male				Female				Not known			
[If yes] Are you expecting a multiple birth?	No		Yes (twins)		Yes (triplets)		Other (please specify)					
Have you ever had a pregnancy that has resulted in a live birth?	Yes						No					
How many times have you been pregnant	0	1	2	3	4	5	6	7	8	9	10	

(including miscarriages, terminations and still births)? If you are currently pregnant, this includes your current pregnancy.											
The following questions will ask about the outcome of your previous pregnancies including miscarriage, still birth and termination. Please remember that you do not have to answer any question you do not feel comfortable answering.											
[Loops for number of pregnancies] What was the outcome of your first/second/third pregnancy?	Live birth			Miscarriage			Still birth			Termination	
Please say how many weeks and days into the pregnancy the birth occurred (e.g. 39 weeks, 6 days) (repeat for miscarriage, still birth, termination).											
How many children do you have?	0	1	2	3	4	5	6	7	8	9	10
What is the date of birth of your first/second/third etc. child? (dd/mm/yyyy)											
What is the sex of your first/second/third etc. child?	Female			Male				Other (please specify)			
Does your first/second/third etc. child have a diagnosis of an autism spectrum condition?	Yes			No				I believe they are autistic but they do not have a diagnosis			
Does your first/second/third etc. child have a diagnosis of any other medical, psychiatric or psychological conditions?	Yes (please specify)						No				
Did you give birth to this child?	Yes						No				

Pregnancy questions

This part of the survey asks about your experiences during pregnancy. If you are currently in the third trimester of pregnancy, please answer the questions in relation to your current pregnancy. If you are not currently pregnant, please answer the questions in relation to your most recent pregnancy that resulted in a live birth.

This part of the survey has 4 sections: Sensory and physical experiences, antenatal appointments, medical professionals and support.

Sensory and Physical Experiences			
The following questions will ask about your physical experiences during pregnancy. Remember to answer these questions in relation to your current pregnancy or most recent pregnancy that resulted in a live birth.			
Please indicate whether your experience of the following senses became heightened, reduced or stayed the same when pregnant as compared with before you became pregnant:			
• Smell	Heightened	Stayed the same	Reduced
• Taste	Heightened	Stayed the same	Reduced
• Touch	Heightened	Stayed the same	Reduced
• Hearing	Heightened	Stayed the same	Reduced
• Vision	Heightened	Stayed the same	Reduced
• Other (please specify)	Heightened	Stayed the same	Reduced
<i>[Repeat question for each of the senses above]</i> Please indicate how often, on average, you would get overwhelmed by the each of the following senses BEFORE BECOMING PREGNANT.			
• Several times a day			
• Once a day			
• More than once a week but less than everyday			
• Once a week			
• Once every two weeks			
• Once a month			
• Once every 6 months			
• Less often than every 6 months			
• Never			
• Other (please specify)			
<i>[Repeat question for each of the senses above]</i> Please indicate how often, on average, you would get overwhelmed by the each of the following senses SINCE BECOMING PREGNANT. If you are not currently pregnant, please think back to when you were pregnant.			
• Several times a day			
• Once a day			

• More than once a week but less than everyday		
• Once a week		
• Once every two weeks		
• Once a month		
• Once every 6 months		
• Less often than every 6 months		
• Never		
• Other (please specify)		
While pregnant I have experienced: [Please answer this question in relation to the period of time during your pregnancy when you were experiencing nausea.]		
• nausea less frequently than every day		
• nausea every day, and it did not last throughout the day (e.g. only in the morning/afternoon)		
• nausea every day and it has lasted throughout the day		
• I have experienced no nausea during my pregnancy		
• Other (please specify)		
While pregnant, during which weeks of your pregnancy did you experience nausea? (e.g. from week 6 to week 15).		
Did you experience hyperemesis gravidarum (severe vomiting) while pregnant?	Yes	No
Did you develop any of the following conditions during this pregnancy? (please choose all that apply)		
• Pelvic girdle pain (e.g. Symphysis pubis dysfunction (SPD))		

<ul style="list-style-type: none"> • Gestational Diabetes 		
<ul style="list-style-type: none"> • Preeclampsia • (a pregnancy complication characterised by high blood pressure and signs of damage to another organ system, most often the liver and kidneys) 		
<ul style="list-style-type: none"> • High blood pressure 		
<ul style="list-style-type: none"> • Eclampsia • (preeclampsia in addition to seizures) 		
<ul style="list-style-type: none"> • Depression 		
<ul style="list-style-type: none"> • Anxiety 		
<ul style="list-style-type: none"> • Other (please specify) 		
<ul style="list-style-type: none"> • None 		
Do you have hypermobility (e.g. joints that can move beyond the typical range)?	Yes	No
Did you have any of the following complications in your pregnancy? (please choose all that apply)		
<ul style="list-style-type: none"> • Infection of amniotic sac and/or membranes 		
<ul style="list-style-type: none"> • Polyhydramnios (too much amniotic fluid) 		
<ul style="list-style-type: none"> • Placental abruption (premature detachment of the placenta) 		
<ul style="list-style-type: none"> • Placenta previa (overattachment of the placenta) 		
<ul style="list-style-type: none"> • Vaginal bleeding during pregnancy 		
<ul style="list-style-type: none"> • Other (please specify) 		
<ul style="list-style-type: none"> • None 		
Did you notice any changes since becoming pregnant in your interoception? (This is defined as awareness of what you can feel inside your body (e.g. your ability to recognise whether you are hungry or thirsty). An example during pregnancy would be feeling in your body that you are pregnant very early on in the pregnancy or feeling your baby kicking very early on in the pregnancy)? [Please specify]	Yes	No
Did you notice any changes since becoming pregnant in your proprioception? (This	Yes	No

is defined as the awareness of the position and movement of your body in the environment e.g. your ability to balance, knowing that your arm is raised above your head even with your eyes closed). [Please specify]		
Before becoming pregnant, on average how often did you experience meltdowns? <i>[multiple choice]</i> (A meltdown can be defined as becoming completely overwhelmed by the current situation and expressing this verbally (e.g. shouting, screaming, crying) or physically (e.g. kicking, lashing out, biting)).		
• Several times a day		
• Once a day		
• More than once a week but less than everyday		
• Once a week		
• Once every two weeks		
• Once a month		
• Once every 6 months		
• Less often than every 6 months		
• Never		
• Other (please specify)		
While pregnant, on average how often have you experienced/did you experience meltdowns?		
• Several times a day		
• Once a day		
• More than once a week but less than everyday		
• Once a week		
• Once every two weeks		
• Once a month		
• Once every 6 months		
• Less often than every 6 months		
• Never		
• Other (please specify)		
Before becoming pregnant, on average how often did you experience shutdowns? (A shutdown can be defined as withdrawing from the world around you. This may include, for example, being unable to communicate, lying down and being completely still, not being able to move.)		
• Several times a day		
• Once a day		
• More than once a week but less than everyday		
• Once a week		

• Once every two weeks						
• Once a month						
• Once every 6 months						
• Less often than every 6 months						
• Never						
• Other (please specify)						
While pregnant, on average how often have you experienced/did you experience shutdowns?						
• Several times a day						
• Once a day						
• More than once a week but less than everyday						
• Once a week						
• Once every two weeks						
• Once a month						
• Once every 6 months						
• Less often than every 6 months						
• Never						
• Other (please specify)						
[If indicate experienced meltdowns/shutdowns] Since becoming pregnant the meltdowns/shutdowns I experienced have been more intense than those I experienced before becoming pregnant.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't know
[If indicated that experience more shutdowns/meltdowns while pregnant] What has tended to be the cause or trigger of the meltdowns/shutdowns you have experienced while pregnant? [open text response]						
Since being pregnant, I found it very difficult to adjust to the changes my body went through.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't know
If you have any other comments relating to your sensory and/or physical experiences during pregnancy, or if you would like to clarify any of your answers, please do so here.						
The next section will ask about your experiences of medical appointments during pregnancy.						

Attending antenatal appointments/accessing services						
This section will ask about your experiences of medical appointments during pregnancy. Please answer in relation to your current pregnancy or your most recent pregnancy that resulted in a live birth.						
I have disclosed my autism spectrum condition to the following health professionals during pregnancy: <i>[Multiple choice]</i>						
• Midwife	Yes	No	Not applicable			
• Doctor/GP	Yes	No	Not applicable			
• Sonographer	Yes	No	Not applicable			
• Other [Please specify]	Yes	No	Not applicable			
What influenced your decision whether or not to disclose your autism spectrum condition to health professionals during pregnancy? [Open text response]						
<i>[If indicated that have disclosed]</i> Following disclosure of your autism spectrum condition, did medical professionals make any of the following adjustments for you?						
• Offering home visits	Yes	No				
• Offering the choice of being accompanied by your community midwife to scans and hospital appointments.	Yes	No				
• Other (please specify)	Yes	No				
• Are there any adjustments that you would have liked that were not offered to you? <i>[Please specify]</i>						
During pregnancy I have attended all of:						
• my ultrasound appointments	Yes	No	Not applicable			
• my midwife appointments	Yes	No	Not applicable			
• my GP appointments	Yes	No	Not applicable			
• any other appointments that were offered to me (please specify)	Yes	No	Not applicable			
[If no to any of the above] If you have not attended all of your antenatal medical appointments, please say why. [Open text response]						
During my medical appointments, I have felt overwhelmed by the sensory environment (e.g. noise of the radio, bright lights, lots of people being in the hospital, being touched by medical professionals).	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
[If agree] Please say what aspects you have found overwhelming.						
Have you attended antenatal classes?	Yes	No				

[If no] Please say why you have not attended antenatal classes.						
[If yes] How many antenatal classes have you attended?						
[If yes] Who was the provider (e.g. NCT, Children's Centre, NHS hospital etc.)?						
I have found it difficult to attend antenatal classes.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
[If yes] Please indicate whether you agree with the following statements:						
• The size of the group is too large at antenatal classes	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• Antenatal classes are too noisy	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• There is too much pressure to socialise at antenatal classes	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• Information is presented too quickly at antenatal classes	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• The content of antenatal classes can be distressing	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• The content of antenatal classes is not helpful to me	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
If you have any other comments about antenatal classes, please write them here. <i>[open text]</i>						
How many different midwives have you had appointments with during your pregnancy?	0	1	2	3	4 or more	
It is very important to me to see the same midwife at each appointment.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
During pregnancy, I found it stressful when I attended an appointment and the health professional I saw was not the person I was expecting to see. <i>(Please choose 'not applicable' if the health professional you have seen has always been the person you were expecting to see)</i>	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
I would find it helpful to be informed of which professional I will see in advance of my appointments.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
The next section will ask about your relationships with medical professionals during pregnancy.						

Relationships with medical professionals						
The following questions will ask about your relationships with medical professionals during pregnancy and potential service improvements. Please answer in relation to your current pregnancy or your most recent pregnancy that resulted in a live birth.						
	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
During pregnancy, I have received as much information as I would have liked. [If disagree, please specify]						
During pregnancy, I was satisfied with the way in which information was presented to me.						
[If disagree] Please say what format would be helpful (e.g. written information, online information, more statistics, more detailed explanations).						
During pregnancy, I feel that health professionals have taken seriously any questions or concerns I have had.						
During pregnancy, I have felt comfortable asking questions to health professionals.						
During pregnancy, I feel that health professionals have treated me respectfully.						
During pregnancy, I have felt negatively judged by health professionals.						
During pregnancy, I have felt able to trust health professionals.						
I have known when to seek help with pregnancy-related concerns.						
I have had someone to advocate for me during pregnancy appointments (e.g. friend, partner, doula).	Always		Sometimes		Never	
[If agree] I have found it helpful to have someone to advocate for me during pregnancy appointments.						
[If disagree] I would have found it helpful to have someone to advocate for me during pregnancy appointments.						
During pregnancy, I feel that the following health professionals have had a good understanding of how being autistic affects me:						
• Midwife	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know

• Doctor/GP	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• Sonographer	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• Other [Please specify]	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
What would you like health professionals to understand about how autism affects you in relation to pregnancy? [open text response]						
Overall, how satisfied have you been with the health care you have received during pregnancy?	Very Satisfied	Somewhat Satisfied	Somewhat Dissatisfied	Very Dissatisfied	Not applicable	Don't Know
<i>[If not satisfied]</i> Please say why you have not been satisfied with the health care you have received during pregnancy. <i>[Open text response]</i>						
<i>[If satisfied]</i> Please say what you have liked about the health care you have received during pregnancy.						
Is there anything else you would find helpful with regard to improving your relationships with healthcare professionals?						
If you have any more comments about your experience of medical appointments throughout pregnancy, or if you would like to clarify any of your answers, please do so here.						

Support						
These questions ask about support during pregnancy. Please answer in relation to your current pregnancy or your most recent pregnancy that resulted in a live birth.						
	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
During pregnancy, I received all the support that I needed from:						
• Partner/Spouse						
• Family						
• Friends						
• Other (please specify)						
During pregnancy, I had peer support from other autistic pregnant people/autistic parents.	Yes			No		

1. <i>[If yes]</i> I found it helpful to have peer support from other autistic pregnant people/parents.						
2. <i>[If no]</i> I would have found it helpful to have peer support from other autistic pregnant people/parents (e.g. mentoring or support group)						
During pregnancy, what support have you found helpful? [open text response]						
What additional support do you think would be helpful to (<i>autistic</i>) pregnant people, if any? [open text response]						
If you have any further comments about your experience of pregnancy, please write them here.						
If you would like to comment on any experiences you have had during other pregnancies, please do so here.						
This is the end of the pregnancy experiences part of the survey.						

Childbirth and infancy questions

This part of the survey asks about your childbirth and postnatal experiences.		
The following questions ask about your experience of childbirth. Please answer the following questions in relation to your most recent childbirth that resulted in a live birth.		
Labour and birth information		
How was your baby delivered? <i>[Multiple choice]</i>		
Spontaneous vaginal delivery		
Vacuum-assisted delivery (also called a ventouse or kiwi delivery)		
Forceps-assisted delivery		
Caesarean		
<ul style="list-style-type: none"> Pre-labour elective caesarean 		
<i>[If yes]</i> Please specify what influenced this decision		
<ul style="list-style-type: none"> Pre-labour emergency caesarean 		
<ul style="list-style-type: none"> Intrapartum emergency caesarean 		
Induced labour		
<i>[If yes]</i> Was this due to:		
<ul style="list-style-type: none"> Postterm pregnancy (beyond 42 weeks of gestation, or estimated due date + 14 days) 		
<ul style="list-style-type: none"> ruptured membranes not in labour 		
<ul style="list-style-type: none"> being over 40 years old 		
<ul style="list-style-type: none"> diabetes/gestational diabetes 		
<ul style="list-style-type: none"> baby was small for gestational age 		
<ul style="list-style-type: none"> baby was large for gestational age 		
<ul style="list-style-type: none"> Other (please specify) 		
<i>[If yes]</i> What was the method of induction (e.g. drip/pessary/gel)?		
Where did you give birth? Please indicate all that apply <i>[Multiple choice]</i>		
<ul style="list-style-type: none"> At home 		
<ul style="list-style-type: none"> Hospital delivery unit 		
<ul style="list-style-type: none"> Midwife led birth centre 		
<ul style="list-style-type: none"> Other (please specify) 		
Please say why you chose to give birth here.		
Was this how you had planned to give birth? <i>[If no, please specify]</i>	Yes	No
Were there any complications during the labour/birth? <i>[If yes, please specify]</i>	Yes	No

How many hours did your labour (including the birth) last for? <i>[Open text response]</i>		
What pain relief did you use during the labour/birth?		
<ul style="list-style-type: none"> • Gas and air • Epidural • Injection of painkiller (e.g. pethidine) • TENS machine • Birthing pool • Other (please specify) • None 		
<i>[If used pain relief]</i> Were there any complications with the pain relief you received? <i>[Please specify]</i>	Yes	No
Did you have any anaesthetic during the labour/birth?	Yes	No
<i>[If yes]</i> Were there any complications with the anaesthetic you received? <i>[Please specify]</i>	Yes	No
How many weeks into your pregnancy were you when your baby was born?		
What was your baby's birth weight?		

Childbirth experiences						
	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
Throughout the labour/birth:						
I was overwhelmed by sensory input (e.g. bright lights, the sounds of hospital machines, lots of medical professionals coming into the room, being touched by medical professionals). <i>[If yes, please specify what in particular you found overwhelming]</i>						
Did you have access to sensory items (e.g. scented oil, fidget toys, a weighted blanket etc.). <i>[Please specify which items]</i>	Yes			No		
<i>[If agree/if disagree]</i> I found/would have found it helpful to have access to sensory items (e.g. scented						

oil, fidget toys, a weighted blanket etc.). <i>[Please specify which items]</i>						
I was kept adequately informed by health professionals of what was happening.						
[If disagree] Please say how you could have been kept better informed.						
Health professionals listened to my requests.						
Health professionals had an accurate understanding of what I was perceiving physically (e.g. they were able to correctly interpret the way I expressed being in pain, they understood how close contractions were etc.).						
[If disagree] Please elaborate. [open text response]						
I felt very aware of my body's signals and how to correctly interpret them (e.g. knowing when the baby was coming, knowing what labour position I needed to be in etc.).						
Did you make a birth plan?	Yes			No		
[If yes] Medical professionals took my birth plan into account during my care.						
I felt pressure to behave in a socially normative way during the labour/birth (e.g. to say the 'right' thing or to use a tone of voice that others would consider appropriate).						
Health professionals had a good understanding of how autism affected me during labour and birth.						

If applicable, what would you have liked health professionals to understand about how autism affected you during labour/birth?						
I experienced a 'meltdown' during labour/birth. (A meltdown can be defined as becoming completely overwhelmed by the current situation and expressing this verbally (e.g. shouting, screaming, crying) or physically (e.g. kicking, lashing out, biting.)	Yes			No		
<i>[If yes]</i> What was the cause or trigger of the meltdown(s)? <i>[Open text response]</i>						
I experienced a 'shut down' during labour/birth. (A shutdown can be defined as withdrawing from the world around you. This may include, for example, being unable to communicate, not being able to move.)	Yes			No		
<i>[If yes]</i> What was the cause or trigger of the shutdown(s)? <i>[Open text response]</i>						
<i>[If yes to meltdown or shutdown]</i> Medical professionals responded to the meltdown(s)/shutdown(s) in the way I would have liked them to. <i>[Please specify]</i>						
I had someone to advocate for me (e.g. a partner, friend, doula) during the labour/birth.	Yes			No		
<i>[If disagree]</i> I would have found it helpful to have						

someone to advocate for me during the labour/birth.						
[If agree] I found it helpful to have someone to advocate for me.						
Overall, how satisfied were you with the medical care you received during the labour/birth?	Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied	Not applicable	Don't know
What, if anything, could have improved your experience of labour and birth? [open text response]						
If applicable, what were the positive aspects of the medical care you received during labour and birth? [open text response]						
Is there anything else you would like us to know about your experience of labour and birth? [open text response]						

Postnatal appointments and relationships with medical professionals

The following questions ask about your experience of postnatal appointments. Please answer these questions in relation to your postnatal appointments concerning your youngest child who you gave birth to (e.g. your midwife appointments, health visitor appointments and GP checks). If you have more than one child, please remember to answer the questions in relation to your youngest child only.

I have disclosed my autism spectrum condition to the following health professionals who I have seen during postnatal appointments:

• Midwife	Yes	No	Not applicable
• Health visitor	Yes	No	Not applicable
• Doctor/GP	Yes	No	Not applicable
• Other (please specify)	Yes	No	Not applicable
What has influenced your decision whether or not to disclose your autism spectrum condition? [Open text response]			
[If indicated that have disclosed] Following disclosure of your autism	Yes		No

spectrum condition, did professionals make any adjustments for you? <i>[please specify]</i>						
Are there any adjustments that you would have liked that were not offered to you? <i>[Please specify]</i>	Yes		No			
I attended:						
<ul style="list-style-type: none"> All of my postnatal midwife appointments 	Yes	No	Not applicable			
<ul style="list-style-type: none"> All of my postnatal health visitor appointments 	Yes	No	Not applicable			
<ul style="list-style-type: none"> My 6 week check 	Yes	No	Not applicable			
<ul style="list-style-type: none"> My baby's 6-8 week check 	Yes	No	Not applicable			
<i>[If no] Please say why you have not attended. [Open text response]</i>						
Where did your postnatal appointments take place (please choose all that apply)?						
<ul style="list-style-type: none"> Home 						
<ul style="list-style-type: none"> Doctors surgery 						
<ul style="list-style-type: none"> Hospital 						
<ul style="list-style-type: none"> Other (please specify) 						
[If indicated home] I have found it stressful to have health professionals (e.g. midwives, health visitors) visit my home.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
[If agree] Please say why						
Have you seen the same health professional at each postnatal appointment (e.g. the same midwife at each midwife appointment, the same health visitor at each health visitor appointment etc.)?	Yes		No			
It is very important to me to see the same health professional at each postnatal appointment (e.g. the same midwife at each midwife appointment, the	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know

same health visitor at each health visitor appointment etc.).						
I found it stressful when I attended a postnatal appointment and the health professional I saw was not the person I was expecting to see.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
I feel that the following health professionals who I have seen during postnatal appointments have had a good understanding of how being autistic affects me:						
• Midwife	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• Health visitor	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• Doctor/GP	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• Other (please specify)	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
Please say what you would like health professionals to understand about how autism affects you in relation to your postnatal appointments. [open text response]						
During postnatal appointments, I have received as much information as I would like about:						
• My mental health	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• Looking after my baby (e.g. how to hold the baby, how to bathe the baby etc.)	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• How to interpret my baby's cries	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• How to play with my baby	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
• Other (please specify)	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
I am satisfied with the way in which information was presented to me during postnatal appointments.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
[If disagree] Please say how you would have preferred information to be presented						

to you (e.g. written information, online information, more statistics, more detailed explanations).						
During postnatal appointments, I feel that health professionals have taken seriously any questions or concerns I have had.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
During postnatal appointments, I have felt comfortable asking questions to health professionals.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
During postnatal appointments, I feel that health professionals have treated me respectfully.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
I have felt negatively judged by health professionals during postnatal appointments.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
I have felt able to trust health professionals during postnatal appointments.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
I worry that my baby will be taken away from me.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
Overall, how satisfied have you been with the following postnatal appointments:						
• Midwife appointments	Very Satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied	Not applicable	Don't know
• Health visitor appointments	Very Satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied	Not applicable	Don't know
• Doctor/GP appointments	Very Satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied	Not applicable	Don't know
• Other (please specify)	Very Satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied	Not applicable	Don't know
<i>[If not satisfied]</i> If you have been dissatisfied with any aspects of your postnatal appointments, please say why. <i>[Open text response]</i>						
<i>[If satisfied]</i> If you have been satisfied with any aspects of your postnatal appointments, please say why.						

I have had someone to advocate for me during postnatal appointments (e.g. friend, partner).	Always		Sometimes		Never	
[If yes] I have found it helpful to have someone to advocate for me during postnatal appointments.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
[If no] I would have found it helpful to have someone to advocate for me.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
What would you find helpful with regard to improving your experience of postnatal appointments? <i>[open text response]</i>						
I have found it difficult to attend drop-in clinics to get my baby weighed.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
<i>[If agree]</i> Please say why.						
I have found it difficult to attend parent and baby groups.	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
<i>[If agree]</i> Please say why you have found it difficult to attend parent and baby groups.						

Parenting demands and strengths

The following questions ask about your experience of being a parent to a young baby. Please answer these questions in relation to your youngest child who you gave birth to. Please answer these questions based on the first year of this child's life. If you have more than one child, please remember to answer the questions in relation to your youngest child only.

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
I find the organisational demands involved in parenting challenging.						
I find that being a mother to my baby is overwhelming in terms of sensory input (e.g. the baby crying loudly, the frequent physical contact involved in caring for a baby)						
<i>[If agree]</i> Please say what in particular you find overwhelming.						

Not being able to predict when my baby will need changing, feeding, or when they will fall asleep etc. causes me anxiety.						
I have felt a strong pressure for my parenting to fit in with society's expectations.						
I have felt that others have judged my parenting negatively because I am autistic.						
I worry about how other people perceive my parenting.						
I have found being a parent to my baby an isolating experience.						
I find it easy to play with my baby.						
I feel confident that I am able to understand what my baby needs (e.g. to understand why the baby is crying).						
I find being a parent to my baby enjoyable in terms of sensory input (e.g. I enjoy the smell of my baby, the feel of their hair, the feeling of cuddles, etc.)						
I have researched parenting and/or child development in a lot of detail.						
I am able to be extremely focused on caring for my baby.						
I am able to be very patient with my baby.						
Overall, I find being a mother to my baby is a positive experience.						
Is there anything you particularly enjoy about being a parent? <i>[Open text response]</i>						
Is there anything that you find challenging about being a parent? <i>[Open text response]</i>						
What would you say are your strengths as a parent? <i>[Open text response]</i>						
Being autistic gives me particular strengths as a parent.						
<ul style="list-style-type: none"> <i>[If agree]</i> Please say what you think these strengths are <i>[open text response]</i> 						
If you have any other comments about being a parent to a young baby or if you						

would like to clarify any of your answers, please do so here.	
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Support						
These final questions ask about support with being a parent. Please answer these questions in relation to your youngest child who you gave birth to.						
	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree	Not applicable	Don't Know
I have received all the support with being a parent to my baby that I have needed from:						
• Partner/Spouse						
• Family						
• Friends						
• Parent and baby groups						
• Other (please specify)						
I have had peer support from other autistic parents.	Yes			No		
• <i>[If agree]</i> I have found it helpful to have peer support from other autistic parents.						
• <i>[If disagree]</i> I would find it helpful to have peer support from other autistic parents.						
What support have you found helpful with being a parent to a young baby? <i>[open text response]</i>						
What additional support do you think would be helpful for [autistic] parents with young babies, if any? <i>[open text response]</i>						
If you would like to comment on any experiences you have had with any of your other children, please do so here.						
If you have any other comments about your parenting experiences or would like to clarify any of your answers throughout this survey, please do so here.						
This is the end of the survey. Please press 'next' to save your responses.						

Appendix 4: Correlations between perinatal experiences survey questions

Appendix Table 4.1 Polychoric correlations between each of the five senses for sensory changes during pregnancy

	Smell	Taste	Touch	Hearing	Vision
Smell	1.00				
Taste	.64***	1.00			
Touch	.32***	.41***	1.00		
Hearing	.40***	.31***	.67***	1.00	
Vision	.30***	.27***	.47***	.68***	1.00

Note. Correlations $\geq .30$ in bold

*** $p \leq 0.001$

Appendix Table 4.2 Spearman correlations between each of the five senses for feeling overwhelmed by the senses during pregnancy

	Smell	Taste	Touch	Hearing	Vision
Smell	1.00				
Taste	.71***	1.00			
Touch	.52***	.55***	1.00		
Hearing	.41***	.44***	.75***	1.00	
Vision	.40***	.46***	.68***	.70***	1.00

Note. Correlations $\geq .30$ in bold

*** $p \leq 0.001$

Appendix Table 4.3 Polychoric correlations between interoception, proprioception and bodily changes during pregnancy

	Interoception changes	Proprioception changes	Difficulty adjusting to bodily changes
Interoception changes	1.00		
Proprioception changes	.47***	1.00	
Difficulty adjusting to bodily changes	.19**	.25***	1.00

Note. Correlations $\geq .30$ in bold

** $p \leq 0.01$

*** $p \leq 0.001$

Appendix Table 4.4 Correlations between questions relating to meltdowns and shutdowns during pregnancy

	Frequency of shutdowns	Frequency of meltdowns	Meltdowns more intense	Shutdowns more intense
Frequency of shutdowns	1.00			
Frequency of meltdowns	.60^{a***}	1.00		
Meltdowns more intense	-	-	1.00	
Shutdowns more intense	-	-	.54^{b***}	1.00

Note. Correlations $\geq .30$ in bold

^aSpearman correlation

^bPolychoric correlation

** $p \leq 0.01$

*** $p \leq 0.001$

Appendix Table 4.5 Polychoric correlations between prenatal healthcare questions

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
1. Attended ultrasound Appointments	1.00															
2. Attended midwife Appointments	0.72***	1.00														
3. Attended doctor Appointments	0.87***	0.87***	1.00													
4. Professionals have taken seriously any questions or concerns	0.19	0.16	0.27*	1.00												
5. Professionals have treated me respectfully	0.21	0.22	0.27*	0.81***	1.00											
6. Felt able to trust professionals	0.29**	0.27*	0.36**	0.79***	0.82***	1.00										
7. Felt comfortable asking questions to professionals	0.24*	0.34**	0.37**	0.77***	0.68***	0.69***	1.00									
8. Felt negatively judged by professionals	-0.36**	-0.14	-0.35**	-0.69***	-0.74***	-0.67***	-0.59***	1.00								
9. Satisfaction with the health care received during pregnancy	0.13	0.32*	0.27	0.81***	0.79***	0.83***	0.72***	-0.62***	1.00							
10. Received as much information as I would have liked	0.20	0.16	0.26*	0.62***	0.57***	0.56***	0.61***	-0.45***	0.66***	1.00						
11. Satisfied with the way in which information was presented	0.25*	0.29*	0.39**	0.70***	0.66***	0.68***	0.65***	-0.55***	0.79***	0.80***	1.00					

12. During my medical appointments, I have felt overwhelmed by the sensory environment	-0.25*	-0.31**	-0.28*	-0.53***	-0.58***	-0.60***	-0.62***	0.58***	-0.53***	-0.45***	-0.51***	1.00				
13. Known when to seek help with pregnancy-related concerns	0.08	0.22	0.27*	0.54***	0.48***	0.50***	0.58***	-0.41***	0.54***	0.48***	0.49***	-0.50***	1.00			
14. It is very important to me to see the same midwife at each appointment	-0.14	-0.29*	-0.01	-0.30***	-0.30***	-0.27***	-0.30***	0.31***	-0.37***	-0.19**	-0.23**	0.46***	-0.16	1.00		
15. I would find it helpful to be informed of which professional I will see in advance of my appointments	-0.03	-0.32**	-0.32	-0.36***	-0.38***	-0.31***	-0.47***	0.36***	-0.36***	-0.34***	-0.36***	0.53***	-0.30***	0.75***	1.00	
16. I found it stressful when the health professional I saw was not the person I was expecting to see	-0.34**	-0.40**	-0.27*	-0.39***	-0.44***	-0.44***	-0.54***	0.45***	-0.39***	-0.34***	-0.38***	0.68***	-0.35***	0.78***	0.84***	1.00

Note. Correlations $\geq .30$ in bold

* $p \leq 0.05$

** $p \leq 0.01$

*** $p \leq 0.001$

Appendix Table 4.6 Polychoric correlations between antenatal classes questions

	Group too large	Too noisy	Too much pressure to socialise	Information presented too quickly	Content can be distressing	Content not helpful
Group too large	1.00					
Too noisy	.72	1.00				
Too much pressure to socialise	.60	.69	1.00			
Information presented too quickly	.39	.50	.52	1.00		
Content can be distressing	.22	.33	.26	.59	1.00	
Content not helpful	.15	.26	.41	.09	.23	1.00

Note. Correlations $\geq .30$ in bold

*** $p \leq 0.001$

Appendix Table 4.7 Polychoric correlations between prenatal support questions

	Partner	Family	Friends
Partner	1.00		
Family	.55***	1.00	
Friends	.41***	.75***	1.00

Note. Correlations $\geq .30$ in bold

*** $p \leq 0.001$

Birth questions

Appendix Table 4.8 Polychoric correlations between birth questions

	1	2	3	4	5	6	7	8	9	10	11
1. Overwhelmed by sensory input	1.00										
2. Aware of body's signals during birth	-.28***	1.00									
3. Had meltdown during birth	.44***	-.21**	1.00								
4. Had shutdown during birth	.50***	-.16*	.27***	1.00							
5. Kept informed professionals of what was happening	-.53***	.22***	-.35***	-.42***	1.00						
6. Professionals listened to my requests	-.55***	.30***	-.36***	-.42***	.78***	1.00					
7. Professionals had accurate understanding of what perceiving physically	-.58***	.31***	-.38***	-.41***	.75***	.78***	1.00				
8. Felt pressure to behave in a socially normative way	.56***	-.32***	.16**	.36***	-.44***	-.47***	-.49***	1.00			
9. Satisfaction with medical care received	-.51***	.26***	-.35***	-.45***	.78***	.85***	.68***	-.39***	1.00		
10. Shared postnatal ward overwhelming	.44***	-.07	.27***	.24**	-.21**	-.21**	-.32***	.29***	-.29**	1.00	
11. Satisfaction with services received during postnatal stay	-.32***	.21***	-.18**	-.19**	.27***	.39***	.33***	-.21***	.55***	-.47***	1.00

Note. Correlations $\geq .30$ in bold

* $p \leq 0.05$

** $p \leq 0.01$

*** $p \leq 0.001$

Appendix Table 4.9 Polychoric correlations between postnatal questions

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
1. Attended midwife appointments	1.00																						
2. Attended health visitor appointments	.56***	1.00																					
3. Attended 6 week check	.72***	.58***	1.00																				
4. Attended 6-8 week check	.42*	.61**	.58***	1.00																			
5. Seen the same professional at each appointment	-.06	.08	.58	.33***	1.00																		
6. Seeing the same professional at each appointment is important	-.27	.01	-.21	-.19*	.28***	1.00																	
7. Stressful when professional not who expecting	-.14	-.06	-.14	-.24	-.03	.79***	1.00																
8. Found home visits stressful	-.16	-.22	-.05	-.16	-.12	.30***	.52***	1.00															
9. Professionals took concerns seriously	.01	.16	.38***	.31*	.35***	-.15*	-.38***	-.39**	1.00														
10. Professionals have treated me respectfully	.13	.22*	.16	.20	.26***	-.18*	-.37***	-.44***	.78***	1.00													
11. I have felt able to trust professionals	.02	.29***	.27**	.19	.26***	-.22***	-.43***	-.46***	.76***	.82***	1.00												

12. Comfortable asking questions to professionals	-.03	.25**	.22*	.30*	.29***	-.28***	-.52***	-.47***	.83***	.82***	.80***	1.00																	
13. I have felt negatively judged by professionals	-.24	-.28**	-.23*	-.37*	-.27***	.24***	.43***	.50***	-.62***	-.70***	-.68***	-.59***	1.00																
14. Received information on mental health	.16	.18	.21	-.04	.13*	-.19***	-.37***	-.19*	.50***	.50***	.55***	.58***	-.41***	1.00															
15. Received information on looking after baby	.13	.29*	.11	.09	.11*	-.13	-.25***	-.13	.42***	.36***	.33***	.46***	-.18	.60***	1.00														
16. Received information on interpreting baby's cries	.11	.26**	.16	.31*	.09	-.18*	-.26***	-.13	.43***	.41***	.43***	.53***	-.28***	.61***	.79***	1.00													
17. Received information on play with baby	.13	.15	-.05	.06	.04	-.08	-.19*	-.14	.28***	.28***	.22***	.33***	-.10***	.56***	.88***	.77***	1.00												
18. Satisfied how information presented	.09	.32**	.32*	.29	.21***	-.25***	-.32***	-.24***	.73***	.64***	.69***	.75***	-.46***	.69***	.67***	.70***	.59***	1.00											
19. Satisfaction midwife appointments	.02	.11	.21	.06	.32***	-.27***	-.36**	-.44**	.67***	.66***	.76***	.69***	-.51***	.50***	.44***	.54***	.37***	.69***	1.00										
20. Satisfaction health visitor appointments	.07	.58***	.14	.43**	.24***	-.15	-.24**	-.38***	.51***	.68***	.67***	.65***	-.59***	.33***	.33***	.41***	.24***	.58***	.58***	1.00									
21. Satisfaction doctor appointments	.06	.17	.26	.23	.26**	-.20**	-.32**	-.19**	.64***	.65***	.63***	.56***	-.43***	.42***	.32***	.37***	.25**	.60***	.59***	.58***	1.00								
22. Difficult to attend drop-in clinics	-.04	-.24*	-.19	-.50***	-.08	.31***	.45**	.30***	-.36***	-.38***	-.31***	-.47***	.29***	-.19***	-.20***	-.24***	-.15**	-.34***	-.13*	-.24***	-.35***	1.00							

23. Difficult to attend parent and baby groups

	-.18	-.13	-.24	-.16	.10	.34***	.52***	.54***	-.36***	-.32***	-.38***	-.45***	.38***	-.38***	-.31**	-.21**	-.27***	-.29***	-.29***	-.20**	-.25***	.58***	1.00
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Note. Correlations ≥ .30 in bold

*p≤0.05

**p≤0.01

***p≤0.001

Appendix Table 4.10 Polychoric correlations between breastfeeding questions

	Had difficulties breastfeeding	Found it easy to access breastfeeding support	Satisfaction with breastfeeding support
Had difficulties breastfeeding	1.00		
Found it easy to access breastfeeding support	-.41^{***}	1.00	
Satisfaction with breastfeeding support	-.52^{***}	.90^{***}	1.00

Note. Correlations $\geq .30$ in bold

^{***} $p \leq 0.001$

Appendix Table 4.11 Polychoric correlations between postnatal support questions

	Partner	Family	Friends
Partner	1.00		
Family	.58^{***}	1.00	
Friends	.37^{***}	.66^{***}	1.00

Note. Correlations $\geq .30$ in bold

^{***} $p \leq 0.001$

Appendix Table 4.12 Polychoric correlations between parenting questions

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. Find it easy to play with baby	1.00													
2. Confident able to understand what baby needs	.57***	1.00												
3. Being a parent is enjoyable in terms of sensory input	.54***	.44***	1.00											
4. Have researched parenting in a lot of detail	-.07	.01	-.04***	1.00										
5. Able to be extremely focused on caring for my baby	.37***	.47***	.56***	.50***	1.00									
6. Able to be very patient with my baby	.46***	.56***	.30***	.10***	.58***	1.00								
7. Organisational demands of parenting challenging	-.18**	-.32***	-.20***	.03***	-.28**	-.27***	1.00							
8. Being a parent is overwhelming in terms of sensory input	-.50***	-.61***	-.65***	.10***	-.38***	-.52***	.46***	1.00						

9. Not being able to predict causes me anxiety	-.42***	-.58***	-.40***	.18***	-.32***	-.49***	.44***	.61***	1.00						
10. Felt strong pressure for parenting to fit in with society's expectations	-.36***	-.51***	-.35***	.20***	-.12	-.30***	.33***	.40***	.61***	1.00					
11. I worry about how others perceive my parenting	-.41***	-.39**	-.33**	.22***	-.25**	-.37***	.39***	.40***	.60***	.78***	1.00				
12. Being a parent is isolating	-.45***	-.47***	-.36***	.19***	-.28***	-.42***	.42***	.53***	.56***	.52***	.48***	1.00			
13. I worry that my baby will be taken away	-.32***	-.18	-.38***	.19***	-.18*	-.25***	.10	.45***	.34***	.48***	.48***	.26***	1.00		
14. Being a mother is a positive experience	.51***	.49***	.58***	.08	.55***	.63***	-.25**	-.60***	-.49***	-.36***	-.41***	-.56***	-.30***	1.00	

Note. Correlations $\geq .30$ in bold

* $p \leq 0.05$

** $p \leq 0.01$

*** $p \leq 0.001$

Appendix 5: Wellbeing questionnaires

Appendix 5.1: Cohen's Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month.
In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

Name _____ Date _____

Age _____ Gender (Circle): **M** **F** Other _____

0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often

- | | | | | | |
|----------------------------------------------------------------------------------------------------------------------|---|---|---|---|---|
| 1. In the last month, how often have you been upset because of something that happened unexpectedly? | 0 | 1 | 2 | 3 | 4 |
| 2. In the last month, how often have you felt that you were unable to control the important things in your life? | 0 | 1 | 2 | 3 | 4 |
| 3. In the last month, how often have you felt nervous and "stressed"? | 0 | 1 | 2 | 3 | 4 |
| 4. In the last month, how often have you felt confident about your ability to handle your personal problems? | 0 | 1 | 2 | 3 | 4 |
| 5. In the last month, how often have you felt that things were going your way? | 0 | 1 | 2 | 3 | 4 |
| 6. In the last month, how often have you found that you could not cope with all the things that you had to do? | 0 | 1 | 2 | 3 | 4 |
| 7. In the last month, how often have you been able to control irritations in your life? | 0 | 1 | 2 | 3 | 4 |
| 8. In the last month, how often have you felt that you were on top of things? | 0 | 1 | 2 | 3 | 4 |
| 9. In the last month, how often have you been angered because of things that were outside of your control? | 0 | 1 | 2 | 3 | 4 |
| 10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? | 0 | 1 | 2 | 3 | 4 |

Appendix 5.2: Edinburgh Postnatal Depression Scale

As you are pregnant or have recently had a baby, we would like to know how you are feeling. Please check the answer that comes closest to how you have felt **IN THE PAST 7 DAYS**, not just how you feel today.

Here is an example, already completed.

I have felt happy:

- ☐ Yes, all the time
- ☒ Yes, most of the time This would mean: "I have felt happy most of the time" during the past week.
- ☐ No, not very often Please complete the other questions in the same way.
- ☐ No, not at all

In the past 7 days:

- | | |
|---------------------------------------------------------------|-----------------------------------------------------------------------------------|
| 1. I have been able to laugh and see the funny side of things | *6. Things have been getting on top of me |
| <input type="checkbox"/> As much as I always could | <input type="checkbox"/> Yes, most of the time I haven't been able to cope at all |
| <input type="checkbox"/> Not quite so much now | <input type="checkbox"/> Yes, sometimes I haven't been coping as well as usual |
| <input type="checkbox"/> Definitely not so much now | <input type="checkbox"/> No, most of the time I have coped quite well |
| <input type="checkbox"/> Not at all | <input type="checkbox"/> No, I have been coping as well as ever |
| 2. I have looked forward with enjoyment to things | |
| <input type="checkbox"/> As much as I ever did | |
| <input type="checkbox"/> Rather less than I used to | *7. I have been so unhappy that I have had difficulty sleeping |
| <input type="checkbox"/> Definitely less than I used to | <input type="checkbox"/> Yes, most of the time |
| <input type="checkbox"/> Hardly at all | <input type="checkbox"/> Yes, sometimes |
| | <input type="checkbox"/> Not very often |
| *3. I have blamed myself unnecessarily when things went wrong | <input type="checkbox"/> No, not at all |
| <input type="checkbox"/> Yes, most of the time | |
| <input type="checkbox"/> Yes, some of the time | *8. I have felt sad or miserable |
| <input type="checkbox"/> Not very often | <input type="checkbox"/> Yes, most of the time |
| <input type="checkbox"/> No, never | <input type="checkbox"/> Yes, quite often |
| | <input type="checkbox"/> Not very often |
| 4. I have been anxious or worried for no good reason | <input type="checkbox"/> No, not at all |
| <input type="checkbox"/> No, not at all | |
| <input type="checkbox"/> Hardly ever | *9. I have been so unhappy that I have been crying |
| <input type="checkbox"/> Yes, sometimes | <input type="checkbox"/> Yes, most of the time |
| <input type="checkbox"/> Yes, very often | <input type="checkbox"/> Yes, quite often |
| | <input type="checkbox"/> Only occasionally |
| | <input type="checkbox"/> No, never |
| *5. I have felt scared or panicky for no very good reason | |
| <input type="checkbox"/> Yes, quite a lot | *10. The thought of harming myself has occurred to me |
| <input type="checkbox"/> Yes, sometimes | <input type="checkbox"/> Yes, quite often |
| <input type="checkbox"/> No, not much | <input type="checkbox"/> Sometimes |
| <input type="checkbox"/> No, not at all | <input type="checkbox"/> Hardly ever |
| | <input type="checkbox"/> Never |

Administered/Reviewed by _____ Date _____

¹Source: Cox, J.L., Holden, J.M., and Sagovsky, R. 1987. Detection of postnatal depression: Development of the 10-item Edinburgh Postnatal Depression Scale. *British Journal of Psychiatry* 150:782-786.

²Source: K. L. Wisner, B. L. Parry, C. M. Piontek, Postpartum Depression N Engl J Med vol. 347, No 3, July 18, 2002, 194-199

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Appendix 5.3: Satisfaction with Life Scale

Instructions: Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disagree
- 3 - Slightly disagree
- 2 - Disagree
- 1 - Strongly disagree

_____ In most ways my life is close to my ideal.

_____ The conditions of my life are excellent.

_____ I am satisfied with my life.

_____ So far I have gotten the important things I want in life.

_____ If I could live my life over, I would change almost nothing.

Appendix 5.4: Karitane Parenting Confidence Scale

KARITANE PARENTING CONFIDENCE SCALE

FOR PARENTS OF INFANTS

Reference as: Čmčec, R., Barnett, B., & Matthey, S. (in press: 2008). Development of an instrument to assess perceived self-efficacy in the parents of infant. *Research in Nursing and Health*.

Your name: _____

Baby's name: _____

Your age: _____

Baby's age (months): _____

You are baby's (circle): mother / father

Number of children including baby: _____

Cultural background: _____

Today's date: _____

This scale has 15 items. Please underline the answer that comes closest to how you generally feel.

Here is an example already completed:

eg. I am confident about holding my baby

No, hardly ever

No, not very often

Yes, some of the time

Yes, most of the time

Office use only.

Page 1 _____

Page 2 _____ +

Total _____

This would mean "*I feel confident about holding my baby some of the time*".

Please complete the other questions in the same way.

1. I am confident about feeding my baby

Not applicable (my partner feeds the baby)

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

2. I can settle my baby

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

5. I understand what my baby is trying to tell me

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

6. I can soothe my baby when he / she is distressed

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

7. I am confident about playing with my baby

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

8. If my baby has a common cold or slight fever, I am confident about handling this

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

3. I am confident about helping my baby to establish a good sleep routine

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

4. I know what to do when my baby cries

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

10. I am confident that my baby is doing well

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

11. I can make decisions about the care of my baby

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

12. Being a mother / father is very stressful for me

Yes, most of the time
Yes, some of the time
No, not very often
No, hardly ever

13. I feel I am doing a good job as mother / father

No, hardly ever
No, not very often
Yes, some of the time
Yes, most of the time

9. I feel sure that my partner will be there for me when I need support

Not applicable (I don't have a partner)

No, hardly ever

No, not very often

Yes, some of the time

Yes, most of the time

Reproductions of this scale must include the full scale title and reference and no alterations to wording or formatting.

Office use only:

All items scored 0,1,2,3. N/A=2.

14. Other people think I am doing a good job as a mother / father

No, hardly ever

No, not very often

Yes, some of the time

Yes, most of the time

15. I feel sure that people will be there for me when I need support

No, hardly ever

No, not very often

Yes, some of the time

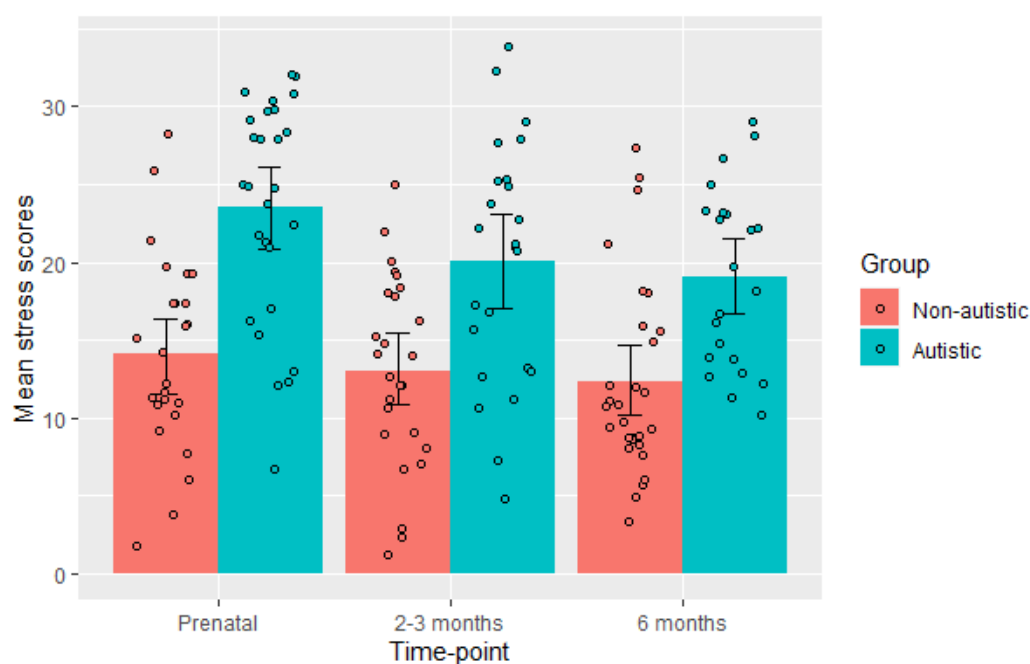
Yes, most of the time

Appendix 5.5: Infancy Parenting Styles Questionnaire

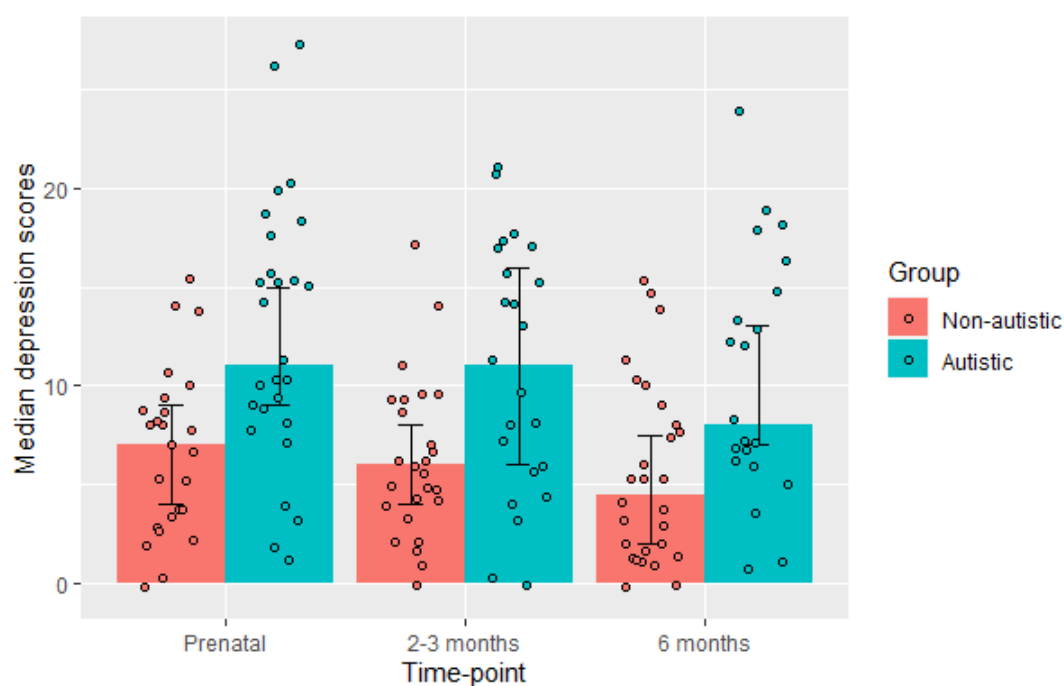
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. You can spoil a baby	1	2	3	4	5
2. My baby needs to learn the difference between right and wrong	1	2	3	4	5
3. It is never too young to start disciplining a child	1	2	3	4	5
4. Sometimes my baby cries to try and manipulate me	1	2	3	4	5
5. My baby sometimes does things that are naughty	1	2	3	4	5
6. Babies under one year do not need discipline	1	2	3	4	5
7. I have a strict day to day routine for my baby	1	2	3	4	5
8. Babies need a routine	1	2	3	4	5
9. People who don't use a routine make a rod for their own back	1	2	3	4	5
10. Everyone is happiest when the baby is in a routine	1	2	3	4	5
11. My baby sets their own routine	1	2	3	4	5
12. A routine makes a baby calm and secure	1	2	3	4	5
13. I regularly ask other people advice about my baby's behaviour	1	2	3	4	5

14. I worry a lot about my baby	1	2	3	4	5
15. I regularly seek advice from my health visitor/GP about my baby	1	2	3	4	5
16. I often check baby books to see if my baby is on target	1	2	3	4	5
17. Babies should be encouraged to entertain themselves	1	2	3	4	5
18. I make sure I put my baby down regularly	1	2	3	4	5
19. Cuddling babies all the time makes them too dependent	1	2	3	4	5
20. I generally like to keep my baby as close as possible to me	1	2	3	4	5
21. I encourage my baby to develop skills such as walking or talking	1	2	3	4	5
22. I do lots of organised activities with my baby	1	2	3	4	5
23. I make sure I play, read or sing with my baby very regularly	1	2	3	4	5
24. Babies need lots of parental input such as reading and activities	1	2	3	4	5
25. It is very important my baby meets developmental milestones	1	2	3	4	5

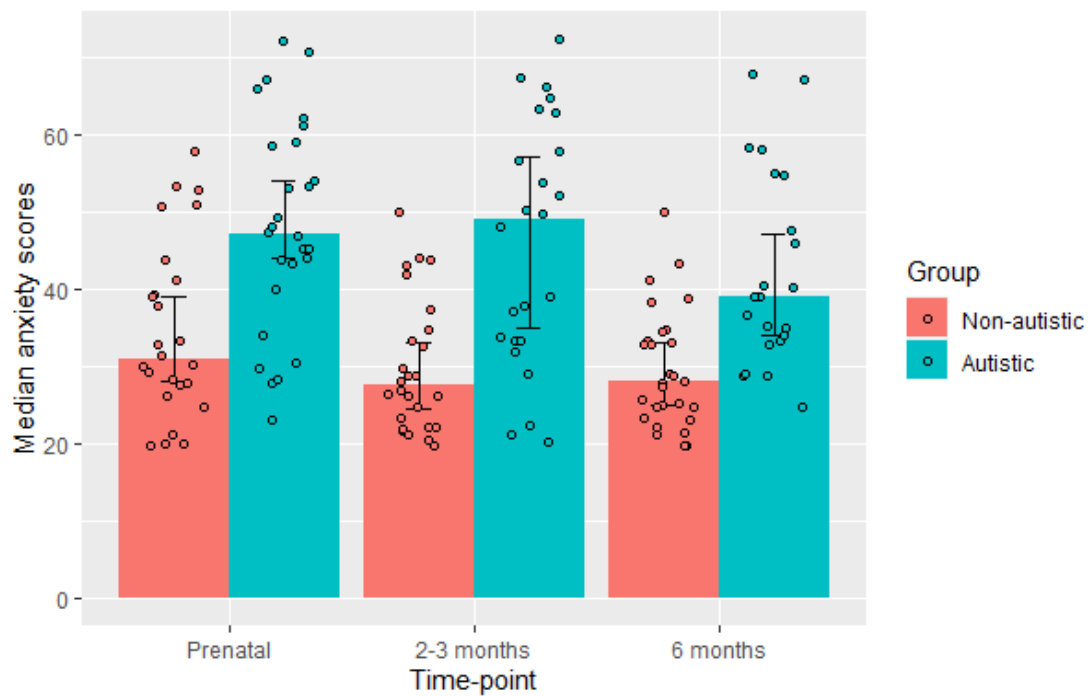
Appendix 6: Bar plots representing data for each of the wellbeing questionnaires



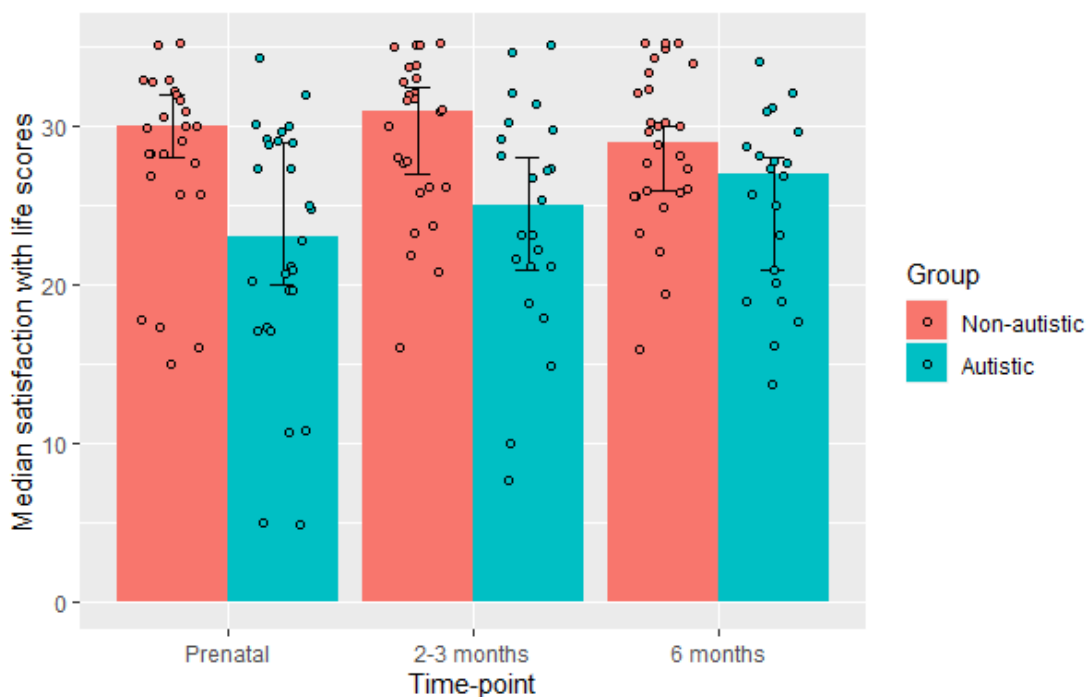
Appendix Figure 6.1 Mean Cohen's Perceived Stress Scale scores at each time-point for the autistic and non-autistic groups (error bars represent 95% confidence intervals)



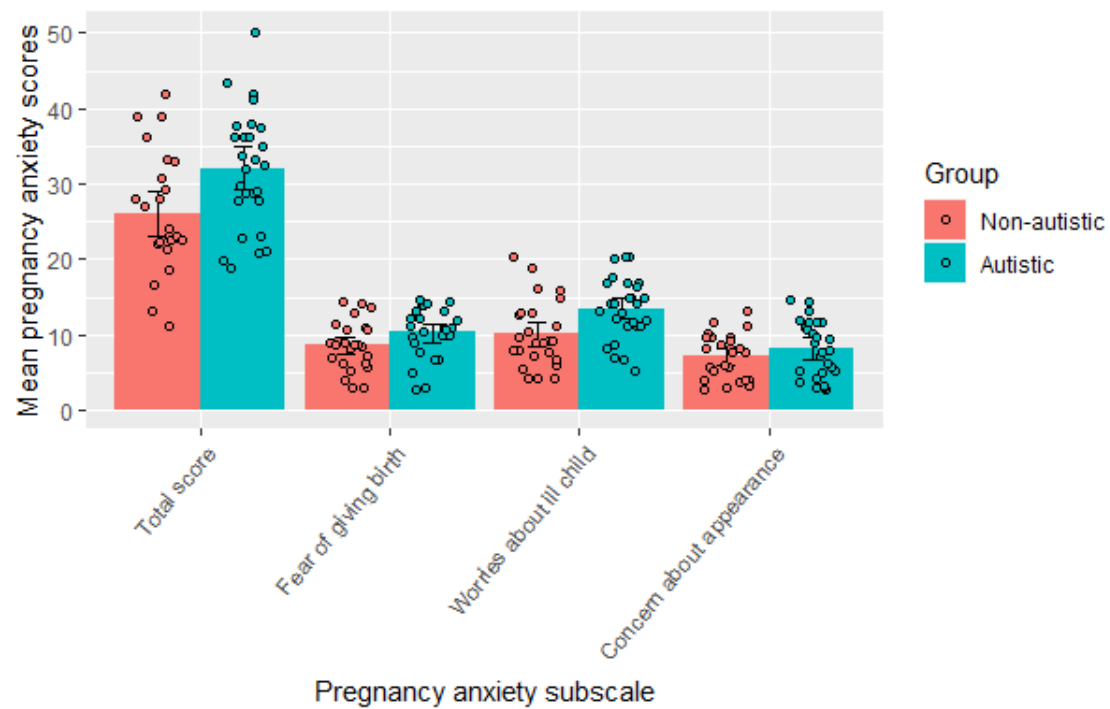
Appendix Figure 6.2 Median Edinburgh Postnatal Depression Scale scores at each time-point for the autistic and non-autistic groups (error bars represent 95% confidence intervals)



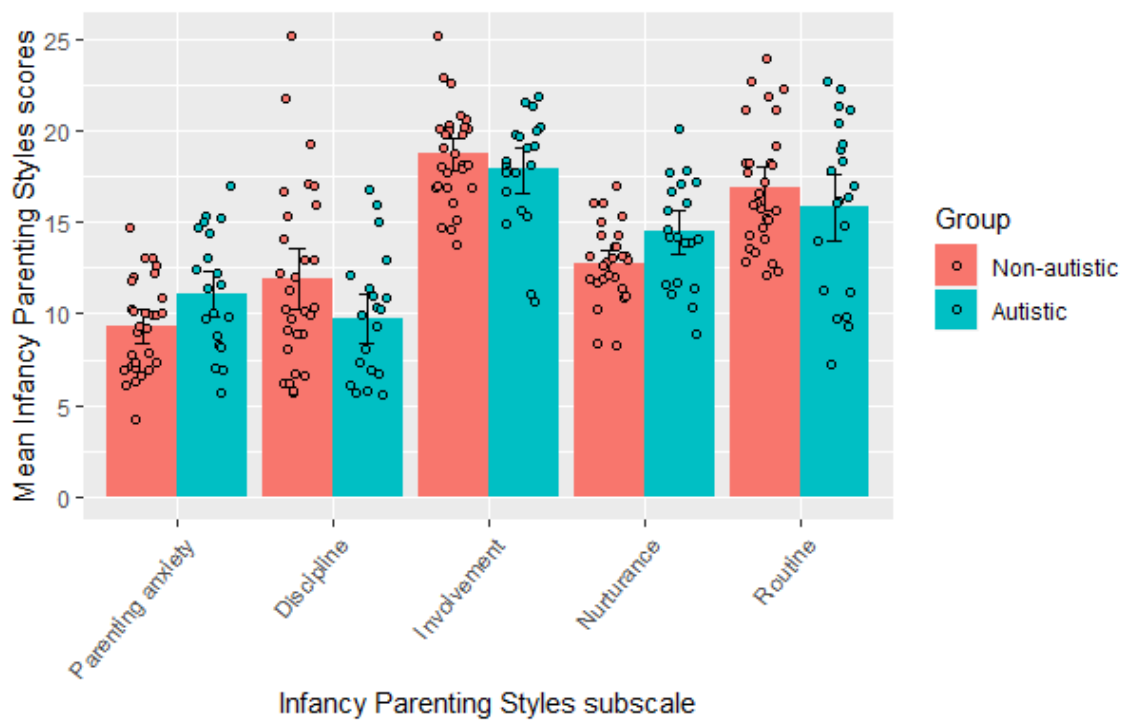
Appendix Figure 6.3 Median State Trait Anxiety Inventory scores at each time-point for the autistic and non-autistic groups (error bars represent 95% confidence intervals)



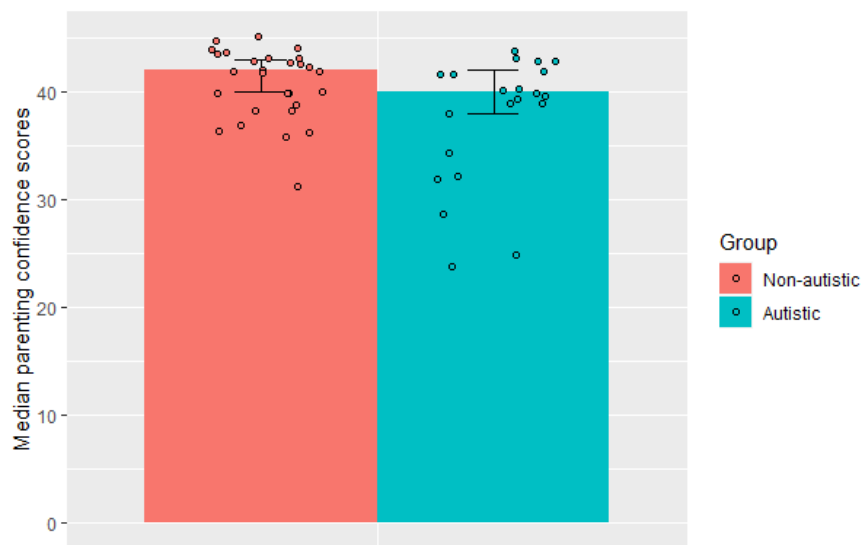
Appendix Figure 6.4 Median Satisfaction With Life Scale scores at each time-point for the autistic and non-autistic groups (error bars represent 95% confidence intervals)



Appendix Figure 6.5 Mean Pregnancy Related Anxiety Questionnaire scores for the autistic and non-autistic groups (error bars represent 95% confidence intervals)










Appendix Figure 6.6 Mean Infancy Parenting Styles Questionnaire scores for the autistic and non-autistic groups (error bars represent 95% confidence intervals)



Appendix Figure 6.7 Median Karitane Parenting Confidence Scale scores for the autistic and non-autistic groups (error bars represent 95% confidence intervals)

Appendix 7: Toys used during parent-child interaction

1. Chatter Telephone (Pretend Play)	
2. Baby doll and bottle (Doll)	
3. Soft Toy Bunny (Animal)	
4. Illumination Station (Spinning Object)	
5. Soft Book (Book)	
6. Whoozit (Exploratory Toy)	
7. Blocks (Construction Play)	

Appendix 8: Parent-Infant/Toddler Coding of Interaction (PInTCI) scale descriptions

<i>Infant</i>	Initiations	Amount and quality of social initiations directed to the parent, either verbal (e.g. vocalizing, babbling) and/or nonverbal (e.g. sharing affect, showing, giving).
	Attentiveness	Amount and quality of 1) infant's spontaneous orientation to the parent, not elicited by parental behaviour; and 2) infant's responsiveness to parental behaviour, either positive or negative.
	Shared affect	Amount and quality of the infant's sharing and directing affective states with/to the parent. Affect can be either positive or negative, but must be shared with the parent.
	Positive affect	Amount and quality of infant's positive affect, e.g. relaxed body language, smiles, laughs, giggles, happiness, enthusiasm, excitement, positive vocalizations, positive facial expressions.
	(Absence of) Negative affect	Amount and quality of infant's negative affect, e.g. body language (i.e. tension, discomfort, restlessness), showing anger, dislike, or hostility, negative facial expressions, negative vocalizations, negative bodily gestures (e.g. distress, rejection).
<i>Parent</i>	Sensitive responsiveness	1) The accuracy of identification and interpretation of the infant's cues or needs, and 2) the timing and appropriateness of the parent's responses to these cues.
	(Absence of) Negative control	The extent to which the interaction is determined by the infant's preferences and the infant's focus of attention, or whether the parent mainly determines the course of the interaction in a directive, controlling, and/or intrusive way.
	Scaffolding	The level of adequately facilitating the infant's development and guiding the infant's actions so that the child can do and say things that he/she would likely not achieve without guidance and encouragement.
	Positive affect	Amount and quality of parent's positive affect, e.g. positive tone of voice, enthusiasm, smiles/laughter, happy facial expressions, relaxed body posture, and physical affection toward the infant.
	(Absence of) Negative affect	Amount and quality of parent's negative affect, e.g. negative tone of voice, tightened or angry facial expressions, tense body posture and angry or hostile acts.
<i>Dyad</i>	Dyadic reciprocity	The amount and quality of engagement, mutuality, cooperation, reciprocity, and sharedness between parent and infant.

Appendix 9: Cohen's kappa values for parent-child interaction inter-rater reliability

Appendix Table 9.1 Weighted Cohen's kappa values for PInTCI scales at 2-3 months and 6 months

Scale	Kappa value (2-3 months)	Kappa value (6 months)
Child initiations	0.29	0.61
Child attentiveness	0.72	0.79
Child sharing of affect	1.00	1.00
Child positive affect	0.69	0.71
Child absence of negative affect	1.00	0.70
Parent sensitive responsiveness	0.80	0.65
Parent absence of negative control	0.25	0.38
Parent scaffolding	0.42	0.80
Parent positive affect	0.65	1.00
Parent absence of negative affect	1.00	0.72
Dyadic reciprocity	0.30	0.85

Appendix 10: Results of linear mixed models for the PInTCI scales, adjusted for parental age, infant age and parental anxiety

Appendix Table 10.1 Results of linear mixed models for the child scales of the PInTCI

	Initiations ^a		Attentiveness		Sharing of affect		Positive affect		Negative affect	
	B (SE)	p-value (FDR corrected)	B (SE)	p-value (FDR corrected)	B (SE)	p-value (FDR corrected)	B (SE)	p-value (FDR corrected)	B (SE)	p-value (FDR corrected)
Adjusted model (parental age at 2-3 months)										
Group	-0.02 (0.74)	0.98	-1.78 (0.93)	0.13	-0.37 (0.90)	0.75	-2.06 (0.95)	0.11	-0.49 (0.77)	0.64
Time-point	-	-	-0.94 (0.52)	0.20	-0.75 (0.51)	0.23	0.29 (0.51)	0.57	-0.30 (0.50)	0.57
Group*Time-point	-	-	1.61 (1.00)	0.31	-0.23 (0.98)	0.92	1.58 (1.00)	0.31	0.49 (0.96)	0.81
Parental age	-0.14 (0.11)	0.33	-0.05 (0.09)	0.63	-0.04 (0.09)	0.66	-0.12 (0.09)	0.40	-0.08 (0.07)	0.33
Adjusted model (infant age)										
Group	0.24 (0.73)	0.82	-1.82 (0.92)	0.17	-0.24 (0.86)	0.82	-1.71 (0.92)	0.18	-0.38 (0.76)	0.82
Time-point	-	-	-0.91 (0.53)	0.22	-0.77 (0.52)	0.22	0.25 (0.51)	0.62	-0.30 (0.50)	0.62
Group*Time-point	-	-	1.58 (1.00)	0.32	-0.23 (0.98)	0.93	1.57 (1.01)	0.86	0.44 (0.97)	0.32
Infant age (2-3 months)	-	-	0.06 (0.19)	0.80	0.09 (0.20)	0.80	0.28 (0.20)	0.66	-0.04 (0.15)	0.80
Infant age (6 months)	0.21 (0.38)	0.80	0.27 (0.31)	0.72	-0.23 (0.98)	0.92	-0.27 (0.31)	0.72	0.22 (0.23)	0.72
Adjusted model (parental anxiety)										
Group	0.36 (0.81)	0.73	-1.90 (1.00)	0.16	-0.50 (0.98)	0.73	-1.99 (0.97)	0.14	-1.04 (0.90)	0.46
Time-point	-	-	-0.92 (0.57)	0.21	-0.76 (0.58)	0.31	0.57 (0.56)	0.41	-0.37 (0.56)	0.58
Group*Time-point	-	-	1.63 (1.03)	0.45	-0.29 (1.02)	0.78	1.32 (1.02)	0.48	0.85 (1.03)	0.55
Anxiety	0.001 (0.04)	0.98	0.01 (0.03)	0.98	0.001 (0.03)	0.98	0.04 (0.03)	0.50	0.06 (0.03)	0.50

^aResults presented for the 6 month time-point only

Appendix Table 10.2 Results of linear mixed models for the parent scales of the PInTCI

	Sensitive responsiveness		Negative control ^a		Scaffolding		Positive affect		Negative affect	
	B (SE)	p-value (FDR corrected)	B (SE)	p-value (FDR corrected)	B (SE)	p-value (FDR corrected)	B (SE)	p-value (FDR corrected)	B (SE)	p-value (FDR corrected)
Adjusted model (parental age at 2-3 months)										
Group	-2.60 (0.81)	0.02	-0.87 (0.78)	0.42	-1.07 (0.81)	0.34	-2.53 (0.90)	0.03	-2.84 (1.45)	0.13
Time-point	-1.74 (0.57)	0.02	-	-	0.63 (0.53)	0.31	-1.53 (0.58)	0.04	-1.48 (1.01)	0.23
Group*Time-point	1.07 (0.99)	0.55	-	-	0.04 (0.96)	0.97	0.69 (0.96)	0.78	2.53 (1.59)	0.31
Parental age	-0.21 (0.08)	0.12	-0.08 (0.10)	0.50	-0.11 (0.09)	0.33	-0.18 (0.09)	0.17	-0.26 (0.14)	0.17
Adjusted model (infant age)										
Group	-2.13 (0.75)	0.05	-0.26 (0.78)	0.82	-0.66 (0.80)	0.74	-1.93 (0.86)	0.14	-2.03 (1.40)	0.32
Time-point	-1.81 (0.57)	0.01	-	-	0.62 (0.53)	0.32	-1.59 (0.59)	0.03	-1.63 (1.03)	0.22
Group*Time-point	1.09 (0.97)	0.52	-	-	0.002 (0.96)	0.99	0.74 (0.97)	0.72	2.59 (1.62)	0.32
Infant age (2-3 months)	0.22 (0.16)	0.66	-	-	0.06 (0.18)	0.80	0.08 (0.19)	0.80	-0.28 (0.32)	0.80
Infant age (6 months)	0.03 (0.26)	0.93	-0.56 (0.38)	0.72	-0.22 (0.29)	0.72	-0.24 (0.29)	0.72	0.04 (0.51)	0.93
Adjusted model (parental anxiety)										
Group	-2.18 (0.84)	0.11	-0.45 (0.83)	0.73	-0.76 (0.79)	0.54	-1.99 (0.87)	0.12	-1.65 (1.32)	0.46
Time-point	-1.98 (0.61)	0.01	-	-	0.22 (0.55)	0.69	-1.72 (0.62)	0.02	-2.15 (1.12)	0.15
Group*Time-point	1.20 (1.02)	0.48	-	-	0.34 (0.95)	0.78	0.85 (0.98)	0.55	2.68 (1.55)	0.45
Anxiety	-0.003 (0.02)	0.98	-0.01 (0.04)	0.98	-0.01 (0.02)	0.98	-0.01 (0.03)	0.98	-0.05 (0.03)	0.50

^aResults presented for the 6 month time-point only

Appendix Table 10.3 Results of linear mixed models for the dyadic scale of the PInTCI

	Dyadic reciprocity	
	B (SE)	p-value (FDR corrected)
Adjusted model (parental age at 2-3 months)		
Group	-0.60 (0.72)	0.56
Time-point	-	-
Group*Time-point	-	-
Parental age	-0.21 (0.11)	0.17
Adjusted model (infant age)		
Group	0.17 (0.71)	0.82
Time-point	-	-
Group*Time-point	-	-
Infant age (2-3 months)	-	-
Infant age (6 months)	-0.31 (0.37)	0.72
Adjusted model (parental anxiety)		
Group	0.12 (0.75)	0.88
Time-point	-	-
Group*Time-point	-	-
Anxiety	-0.02 (0.04)	0.98

Note Results presented for the 6 month time-point only

Appendix 11: Comparisons on the PInTCI scales between dyads involving infants with an autistic sibling and dyads involving infants with an autistic mother

Appendix Table 11.1 Medians (interquartile ranges) and results of Wilcoxon rank-sum tests exploring differences on the PInTCI scales between dyads involving infants with an autistic sibling and dyads involving infants with an autistic mother

	2-3 months					6 months				
	Autistic mother (n=7)	Autistic sibling (n=3)	W	p-value	p-value (FDR corrected)	Autistic mother (n=7)	Autistic sibling (n=4)	W	p-value	p-value (FDR corrected)
Child scales										
Initiations	-	-	-	-		2.00 (1.00)	2.00 (0.50)	15.00	0.91	0.99
Attentiveness	3.00 (2.50)	5.00 (2.00)	9.50	0.91	0.99	4.00 (2.00)	3.50 (1.50)	16.50	0.70	0.99
Sharing of affect	2.00 (2.50)	5.00 (2.00)	9.00	0.82	0.99	2.00 (1.00)	2.00 (1.00)	13.00	0.92	0.99
Positive affect	1.00 (2.50)	3.00 (1.50)	9.00	0.81	0.99	2.00 (2.00)	4.00 (2.25)	10.50	0.55	0.99
Absence of negative affect	7.00 (3.00)	6.00 (1.00)	10.00	0.99	0.99	7.00 (1.00)	6.00 (0.50)	21.50	0.15	0.84
Parent scales										
Sensitive responsiveness	5.00 (0.50)	5.00 (0.00)	9.00	0.78	0.99	5.00 (0.00)	4.00 (0.25)	26.50	0.02	0.16
Absence of negative control	-	-	-	-		5.00 (0.50)	5.00 (0.25)	14.50	0.99	0.99
Scaffolding	4.00 (2.00)	4.00 (0.00)	10.50	0.99	0.99	4.00 (0.50)	4.00 (0.25)	15.00	0.90	0.99
Positive affect	5.00 (0.00)	5.00 (1.00)	14.00	0.40	0.99	5.00 (1.00)	4.50 (1.50)	16.50	0.67	0.99
Absence of negative affect	7.00 (0.50)	7.00 (1.00)	12.00	0.78	0.99	7.00 (0.00)	7.00 (0.25)	15.50	0.78	0.99
Dyadic scale										
Dyadic reciprocity	-	-	-	-		4.00 (1.00)	4.00 (0.50)	17.00	0.61	0.99

Note. FDR correction completed for all 11 scales within each time-point separately

Appendix 12: Explorations of the effect of time on brain region volumes

Appendix Table 12.1 Results of linear mixed models exploring the effect of time on brain region volumes

	B (SE)	p-value (uncorrected)	p-value corrected	(FDR
Left amygdala	37.88 (4.53)	<0.001	<0.001	
Right amygdala	46.75 (3.20)	<0.001	<0.001	
Left hippocampus	240.25 (16.23)	<0.001	<0.001	
Right hippocampus	273.03 (15.05)	<0.001	<0.001	
Left anterior cingulate	640.35 (37.62)	<0.001	<0.001	
Right anterior cingulate	640.90 (36.17)	<0.001	<0.001	

Appendix 13: Null results of regressions exploring relationships between maternal wellbeing and fetal/infant regional brain volumes

Appendix Table 13.1 Results of regressions exploring relationships between fetal regional brain volumes and prenatal maternal anxiety/stress and depression

	B (SE)	β	p-value (uncorrected)
Left amygdala			
Left amygdala volume and prenatal anxiety/stress combined	5.49 (6.49)	0.22	0.41
Left amygdala volume and prenatal anxiety/stress combined by group interaction	-15.00 (10.92)	-0.61	0.18
Left amygdala volume and prenatal depression	-0.42 (1.35)	-0.10	0.76
Left amygdala volume and prenatal depression by group interaction	0.93 (1.74)	0.22	0.60
Right amygdala^a			
Right amygdala volume and prenatal anxiety/stress combined	-0.07 (0.06)	-0.32	0.20
Right amygdala volume and prenatal anxiety/stress combined by group interaction	0.07 (0.09)	0.30	0.48
Right amygdala volume and prenatal depression	-0.01 (0.01)	-0.25	0.41
Right amygdala volume and prenatal depression by group interaction	-0.001 (0.02)	-0.02	0.96
Left hippocampus^a			
Left hippocampus volume and prenatal anxiety/stress combined	-0.0006 (0.05)	-0.004	0.99
Left hippocampus volume and prenatal anxiety/stress combined by group interaction	0.08 (0.08)	0.48	0.36
Left hippocampus volume and prenatal depression	0.001 (0.01)	0.02	0.95
Left hippocampus volume and prenatal depression by group interaction	0.01 (0.01)	0.22	0.57
Right hippocampus^a			

Right hippocampus volume and prenatal anxiety/stress combined	0.02 (0.05)	0.08	0.73
Right hippocampus volume and prenatal anxiety/stress combined by group interaction	-0.06 (0.08)	-0.28	0.50
Right hippocampus volume and prenatal depression	0.01 (0.01)	0.40	0.17
Right hippocampus volume and prenatal depression by group interaction	-0.02 (0.01)	-0.49	0.19
<hr/>			
Left anterior cingulate			
<hr/>			
Left anterior cingulate volume and prenatal anxiety/stress combined	-59.98 (36.79)	-0.32	0.12
Left anterior cingulate volume and prenatal anxiety/stress combined by group interaction	63.91 (61.95)	0.34	0.31
Left anterior cingulate volume and prenatal depression	0.04 (7.78)	0.001	0.99
Left anterior cingulate volume and prenatal depression by group interaction	-2.74 (10.04)	-0.09	0.79
<hr/>			
Right anterior cingulate			
Right anterior cingulate volume and prenatal anxiety/stress combined	-28.29 (36.08)	-0.16	0.44
Right anterior cingulate volume and prenatal anxiety/stress combined by group interaction	36.58 (60.75)	0.21	0.55
Right anterior cingulate volume and prenatal depression	-5.26 (7.24)	-0.18	0.47
Right anterior cingulate volume and prenatal depression by group interaction	9.23 (9.34)	0.31	0.33

^aRegression performed on log-transformed outcome

Appendix Table 13.2 Results of regressions exploring relationships between infant regional brain volumes and prenatal maternal anxiety/stress and depression

	B (SE)	β	p-value (uncorrected)	p-value (FDR corrected)
Left amygdala				
Left amygdala volume and prenatal anxiety/stress combined	-1.78 (12.80)	-0.05	0.89	-
Left amygdala volume and prenatal anxiety/stress combined by group interaction	-2.09 (15.60)	-0.06	0.90	-
Left amygdala volume and prenatal depression	2.80 (2.27)	0.51	0.24	-
Left amygdala volume and prenatal depression by group interaction	-0.71 (2.56)	-0.13	0.79	-
Right amygdala				
Right amygdala volume and prenatal anxiety/stress combined	-11.95 (9.01)	-0.37	0.21	-
Right amygdala volume and prenatal anxiety/stress combined by group interaction	-5.79 (10.98)	-0.18	0.61	-
Right amygdala volume and prenatal depression	-0.23 (1.81)	-0.05	0.90	-
Right amygdala volume and prenatal depression by group interaction	-1.62 (2.04)	-0.34	0.44	-
Left hippocampus				
Left hippocampus volume and prenatal anxiety/stress combined	-97.84 (44.89)	-0.57	0.048	0.08
Left hippocampus volume and prenatal anxiety/stress combined by group interaction	20.32 (54.73)	0.12	0.72	-
Left hippocampus volume and prenatal depression	-17.46 (9.13)	-0.68	0.08	-
Left hippocampus volume and prenatal depression by group interaction	13.07 (10.28)	0.51	0.23	-
Right hippocampus				

Right hippocampus volume and prenatal anxiety/stress combined	-52.32 (44.50)	-0.33	0.26	-
Right hippocampus volume and prenatal anxiety/stress combined by group interaction	-14.36 (54.25)	-0.09	0.80	-
Right hippocampus volume and prenatal depression	-3.45 (9.29)	-0.14	0.72	-
Right hippocampus volume and prenatal depression by group interaction	2.10 (10.45)	0.09	0.84	-
<hr/> Left anterior cingulate				
Left anterior cingulate volume and prenatal anxiety/stress combined	-59.51 (85.23)	-0.15	0.50	-
Left anterior cingulate volume and prenatal anxiety/stress combined by group interaction	-4.39 (103.95)	-0.01	0.97	-
Left anterior cingulate volume and prenatal depression	22.17 (16.16)	0.38	0.19	-
Left anterior cingulate volume and prenatal depression by group interaction	-22.09 (18.20)	-0.38	0.25	-
<hr/> Right anterior cingulate				
Right anterior cingulate volume and prenatal anxiety/stress combined	-1.74 (91.29)	-0.004	0.99	-
Right anterior cingulate volume and prenatal anxiety/stress combined by group interaction	-7.71 (111.13)	-0.02	0.95	-
Right anterior cingulate volume and prenatal depression	12.42 (17.48)	0.20	0.49	-
Right anterior cingulate volume and prenatal depression by group interaction	-5.68 (19.68)	-0.09	0.78	-

Appendix Table 13.3 Results of regressions exploring relationships between regional brain volume growth and prenatal maternal anxiety/stress and depression

	B (SE)	β	p-value (uncorrected)
Left amygdala			
Left amygdala growth and prenatal anxiety/stress combined	-0.01 (18.12)	-0.0001	1.00
Left amygdala growth and prenatal anxiety/stress combined by group interaction	6.66 (21.18)	0.18	0.76
Left amygdala growth and prenatal depression	5.15 (2.93)	0.90	0.11
Left amygdala growth and prenatal depression by group interaction	-2.57 (3.11)	-0.45	0.43
Right amygdala			
Right amygdala growth and prenatal anxiety/stress combined	-4.32 (15.51)	-0.15	0.79
Right amygdala growth and prenatal anxiety/stress combined by group interaction	7.74 (18.14)	0.27	0.68
Right amygdala growth and prenatal depression	1.79 (3.05)	0.42	0.57
Right amygdala growth and prenatal depression by group interaction	-1.40 (3.23)	-0.33	0.67
Left hippocampus			
Left hippocampus growth and prenatal depression	-12.05 (7.91)	-0.54	0.16
Left hippocampus growth and prenatal depression by group interaction	-4.82 (8.40)	-0.22	0.58
Right hippocampus			
Right hippocampus growth and prenatal anxiety/stress combined	-44.15 (48.44)	-0.32	0.38
Right hippocampus growth and prenatal anxiety/stress combined by group interaction	88.28 (56.63)	0.65	0.15
Right hippocampus growth and prenatal depression	-9.19 (10.23)	-0.45	0.39
Right hippocampus growth and prenatal depression by group interaction	10.92 (10.86)	0.54	0.34
Left anterior cingulate			

Left anterior cingulate growth and prenatal anxiety/stress combined	33.55 (104.89)	0.11	0.76
Left anterior cingulate growth and prenatal anxiety/stress combined by group interaction	-44.19 (122.62)	-0.14	0.73
Left anterior cingulate growth and prenatal depression	17.85 (21.56)	0.38	0.43
Left anterior cingulate growth and prenatal depression by group interaction	-13.91 (22.89)	-0.30	0.56
Right anterior cingulate			
Right anterior cingulate growth and prenatal anxiety/stress combined	67.87 (114.20)	0.21	0.57
Right anterior cingulate growth and prenatal anxiety/stress combined by group interaction	-42.48 (133.60)	-0.13	0.76
Right anterior cingulate growth and prenatal depression	11.99 (21.39)	0.24	0.59
Right anterior cingulate growth and prenatal depression by group interaction	-1.00 (22.72)	-0.02	0.97

Appendix Table 13.4 Results of regressions exploring relationships between infant regional brain volumes and postnatal maternal anxiety/stress and depression

	B (SE)	B	p-value (uncorrected)
Left amygdala			
Left amygdala volume and postnatal anxiety/stress combined	8.64 (7.03)	0.24	0.24
Left amygdala volume and postnatal anxiety/stress combined by group interaction	-18.12 (14.57)	-0.49	0.23
Left amygdala volume and postnatal depression	1.20 (1.48)	0.19	0.43
Left amygdala volume and postnatal depression by group interaction	-3.06 (2.06)	-0.49	0.16
Left hippocampus			
Left hippocampus volume and postnatal anxiety/stress combined	48.10 (30.27)	0.27	0.13

Left hippocampus volume and postnatal anxiety/stress combined by group interaction	-97.35 (62.75)	-0.55	0.14
Left hippocampus volume and postnatal depression	10.51 (6.39)	0.35	0.12
Left hippocampus volume and postnatal depression by group interaction	-16.66 (8.87)	-0.56	0.08
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Right hippocampus			
Right hippocampus volume and postnatal anxiety/stress combined	33.34 (31.10)	0.19	0.30
Right hippocampus volume and postnatal anxiety/stress combined by group interaction	-87.15 (64.48)	-0.50	0.19
Right hippocampus volume and postnatal depression	6.69 (6.68)	0.35	0.33
Right hippocampus volume and postnatal depression by group interaction	-11.97 (9.27)	-0.56	0.21
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Left anterior cingulate			
Left anterior cingulate volume and postnatal anxiety/stress combined	97.48 (61.09)	0.24	0.13
Left anterior cingulate volume and postnatal anxiety/stress combined by group interaction	-66.60 (126.60)	-0.16	0.61
Left anterior cingulate volume and postnatal depression	21.07 (12.94)	0.30	0.12
Left anterior cingulate volume and postnatal depression by group interaction	-20.91 (17.96)	-0.30	0.26
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Right anterior cingulate			
Right anterior cingulate volume and postnatal anxiety/stress combined	29.64 (54.96)	0.07	0.60
Right anterior cingulate volume and postnatal anxiety/stress combined by group interaction	80.16 (113.90)	0.19	0.49
Right anterior cingulate volume and postnatal depression	-5.42 (11.42)	-0.08	0.64
Right anterior cingulate volume and postnatal depression by group interaction	20.47 (15.85)	0.29	0.21
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Appendix 14: Results of analyses exploring cortisol and parent-infant interaction as mediators between maternal wellbeing and fetal/infant regional brain volumes

Cortisol

Infant cortisol was explored as a mediator for each of the significant associations found between maternal wellbeing and fetal/infant brain volumes (i.e. prenatal anxiety/stress and left hippocampus growth, postnatal anxiety/stress and infant right amygdala volume, and postnatal depression and infant right amygdala volume). In order to find evidence for mediation: 1) the independent variable (maternal wellbeing) should be significantly associated with the dependent variable (fetal/infant brain volume); 2) the independent variable (maternal wellbeing) should be significantly associated with the mediator (cortisol); and 3) the mediator (cortisol) should be significantly associated with the dependent variable (fetal/infant brain volume) after controlling for the independent variable (maternal wellbeing). The 'mediation' package in R was used, which employs bootstrapping to assess the significance of the indirect/mediation effect (i.e. the effect of the independent variable on the dependent variable minus the effect of the independent variable on the dependent variable for a model in which the mediator is also a predictor). All bootstrapped analyses involved 1000 replications. All p-values presented in this appendix are corrected for multiple testing using FDR.

Cortisol was not significantly associated with maternal wellbeing (prenatal anxiety/stress: $B(SE)=-0.26(0.49)$, $p=0.89$; postnatal anxiety/stress: $B(SE)=-0.06(0.41)$, $p=0.89$; postnatal depression: $B(SE)=-1.78(2.54)$, $p=0.89$). There was no significant mediation effect of cortisol on the relationship between postnatal anxiety/stress and infant right amygdala volume ($B=0.04$, 95% CI = -3.31 – 3.54, $p=0.94$), the relationship between postnatal depression and infant right amygdala volume ($B=0.05$, 95% CI = -0.46 – 0.64, $p=0.94$), nor the relationship between prenatal anxiety/stress and left hippocampus growth ($B=-0.29$, 95% CI = -11.50 – 9.64, $p=0.94$).

Parent-child interaction

Mediation analyses involving parent-infant interaction variables were conducted in the same manner as for cortisol. Scores on the parent scales of the PInTCI scheme (sensitive responsiveness, scaffolding, positive affect, and negative affect (negative control was not

explored due to low reliability; see Chapter 5) were explored as mediators for each of the significant associations found between postnatal maternal wellbeing and infant brain volumes (i.e. postnatal anxiety/stress and infant right amygdala volume, and postnatal depression and infant right amygdala volume).

Sensitive responsiveness

Sensitive responsiveness was not significantly associated with maternal wellbeing (postnatal anxiety/stress: $B(SE)=-0.51(0.28)$, $p=0.23$; postnatal depression: $B(SE)=-3.23(1.80)$, $p=0.23$). There was no significant mediation effect of sensitive responsiveness regarding the relationship between postnatal anxiety/stress and infant right amygdala volume ($B=3.83$, 95% CI = -2.53 – 12.29, $p=0.99$), nor the relationship between postnatal depression and infant right amygdala volume ($B=1.22$, 95% CI = 0.19 – 2.73, $p=0.14$).

Scaffolding

Scaffolding was not significantly associated with maternal wellbeing (postnatal anxiety/stress: $B(SE)=0.01(0.17)$, $p=0.96$; postnatal depression: $B(SE)=1.15(1.05)$, $p=0.57$). There was no significant mediation effect of scaffolding regarding the relationship between postnatal anxiety/stress and infant right amygdala volume ($B=0.01$, 95% CI = -3.55 – 3.05, $p=0.99$), nor the relationship between postnatal depression and infant right amygdala volume ($B=-0.17$, 95% CI = -0.97 – 0.38, $p=0.99$).

Positive affect

Positive affect was not significantly associated with maternal wellbeing (postnatal anxiety/stress: $B(SE)=-0.32(0.14)$, $p=0.23$; postnatal depression: $B(SE)=-0.16(1.00)$, $p=0.96$). There was no significant mediation effect of positive affect regarding the relationship between postnatal anxiety/stress and infant right amygdala volume ($B=0.35$, 95% CI = -4.05 – 5.52, $p=0.99$), nor the relationship between postnatal depression and infant right amygdala volume ($B=-0.02$, 95% CI = -0.53 – 0.43, $p=0.99$).

Negative affect

Negative affect was not significantly associated with maternal wellbeing (postnatal anxiety/stress: $B(SE)=-0.16(0.38)$, $p=0.96$; postnatal depression: $B(SE)=-0.19(2.44)$, $p=0.96$). There was no significant mediation effect of negative affect regarding the relationship

between postnatal anxiety/stress and infant right amygdala volume ($B=-0.42$, 95% CI = $-4.70 - 3.02$, $p=0.99$), nor the relationship between postnatal depression and infant right amygdala volume ($B=0.89$, 95% CI = $-0.70 - 0.38$, $p=0.99$).