

# How autistic people navigate pregnancy, childbirth and the postnatal period

SARAH HAMPTON

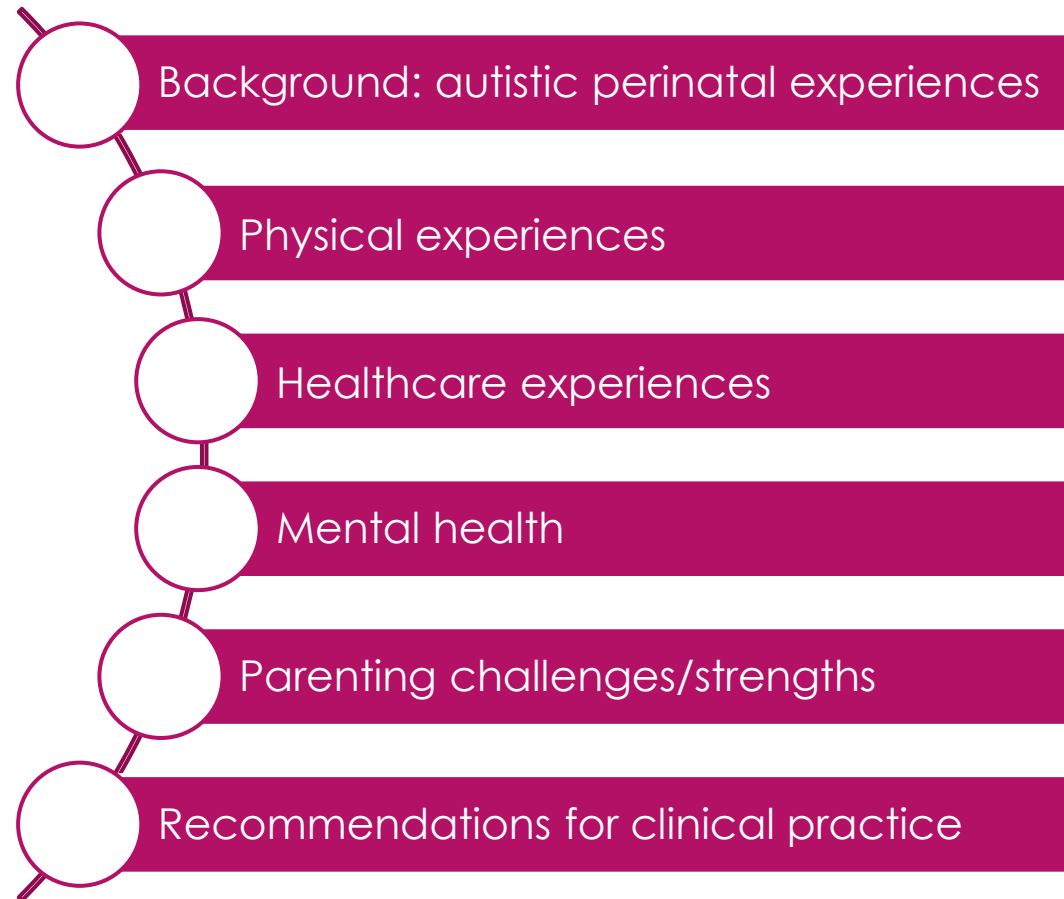
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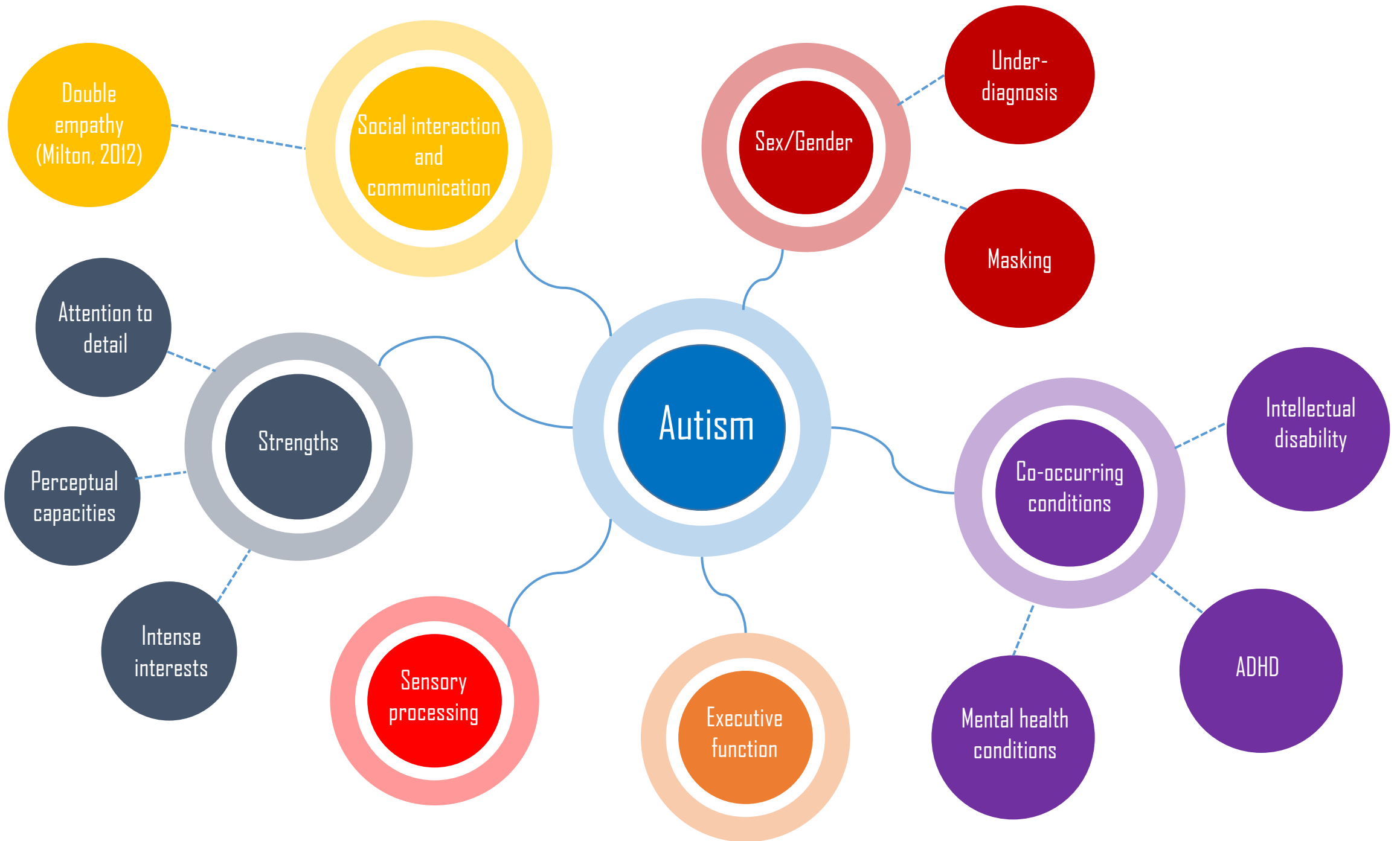


# Outline



## Terminology:

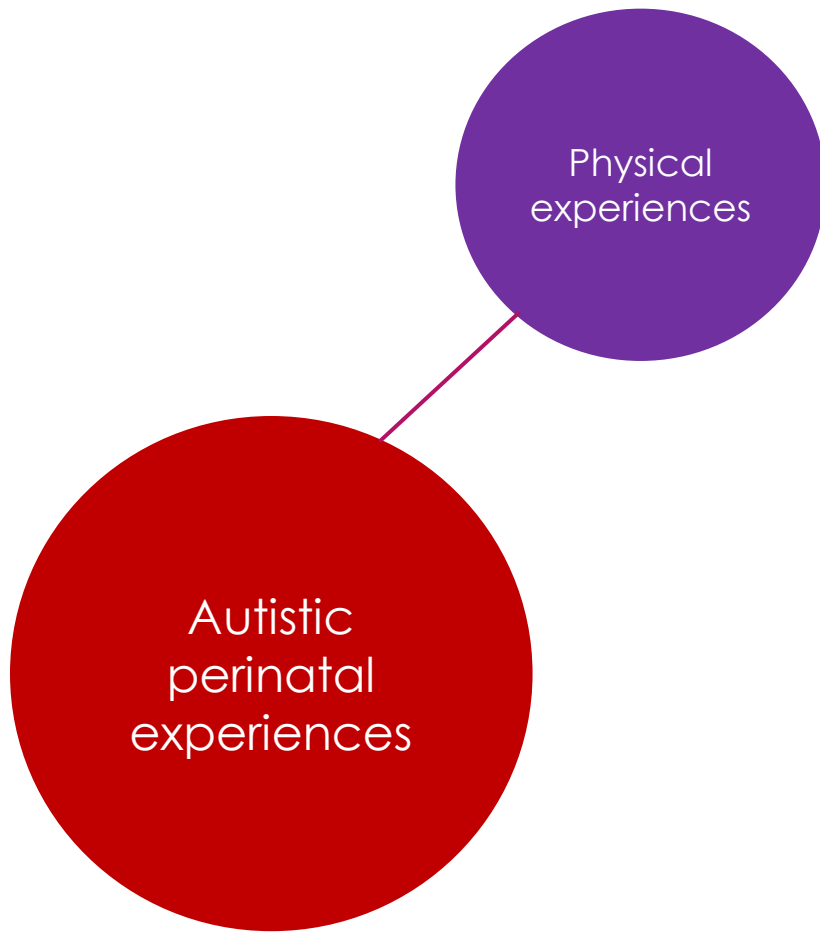
- Perinatal: Pregnancy and first few months postpartum
- Identity first ('autistic person') rather than person first ('person with autism') (Kenny et al., 2016)
- Non-gendered language
  - AFAB/AMAB=Assigned female/male at birth



## Autistic perinatal experiences: An under-researched area

- ▶ Autistic AFAB people under-researched (Watkins et al., 2014)
- ▶ Majority of autism research focused on child samples (Edwards et al., 2012)
- ▶ Need for research to explore adult life events including relationships and family
- ▶ Lack of evidence base to inform best practice guidelines





- Physical health

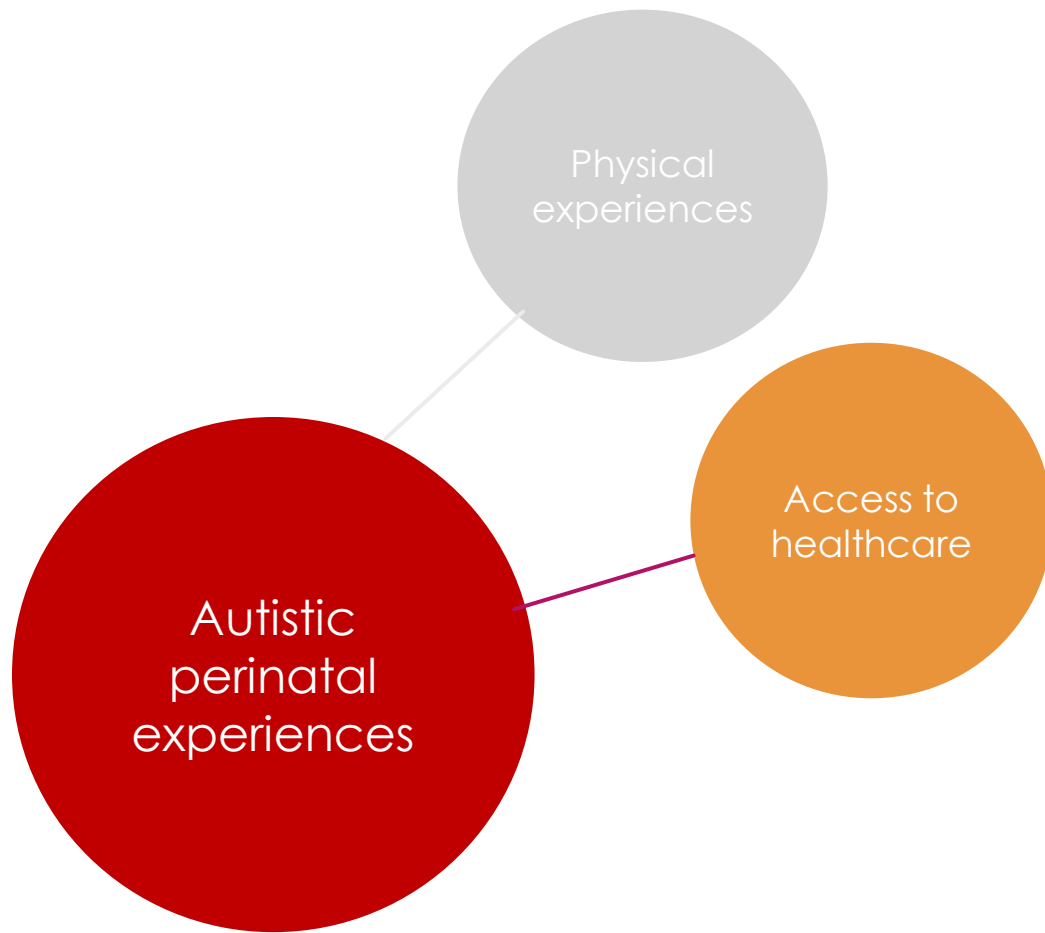
- People with disabilities can have worse birth outcomes (Malouf et al., 2017)
- Increased risk of physical health conditions among autistic people (Weir et al., 2021)
- Increased likelihood of preeclampsia, induced labour and elective caesarean among autistic people (Sundelin et al., 2018)

- Sensory experiences

- Enhanced sensory sensitivities
- Difficulty breastfeeding

(Gardner et al., 2016; Rogers et al., 2017; Talcer et al., 2021)



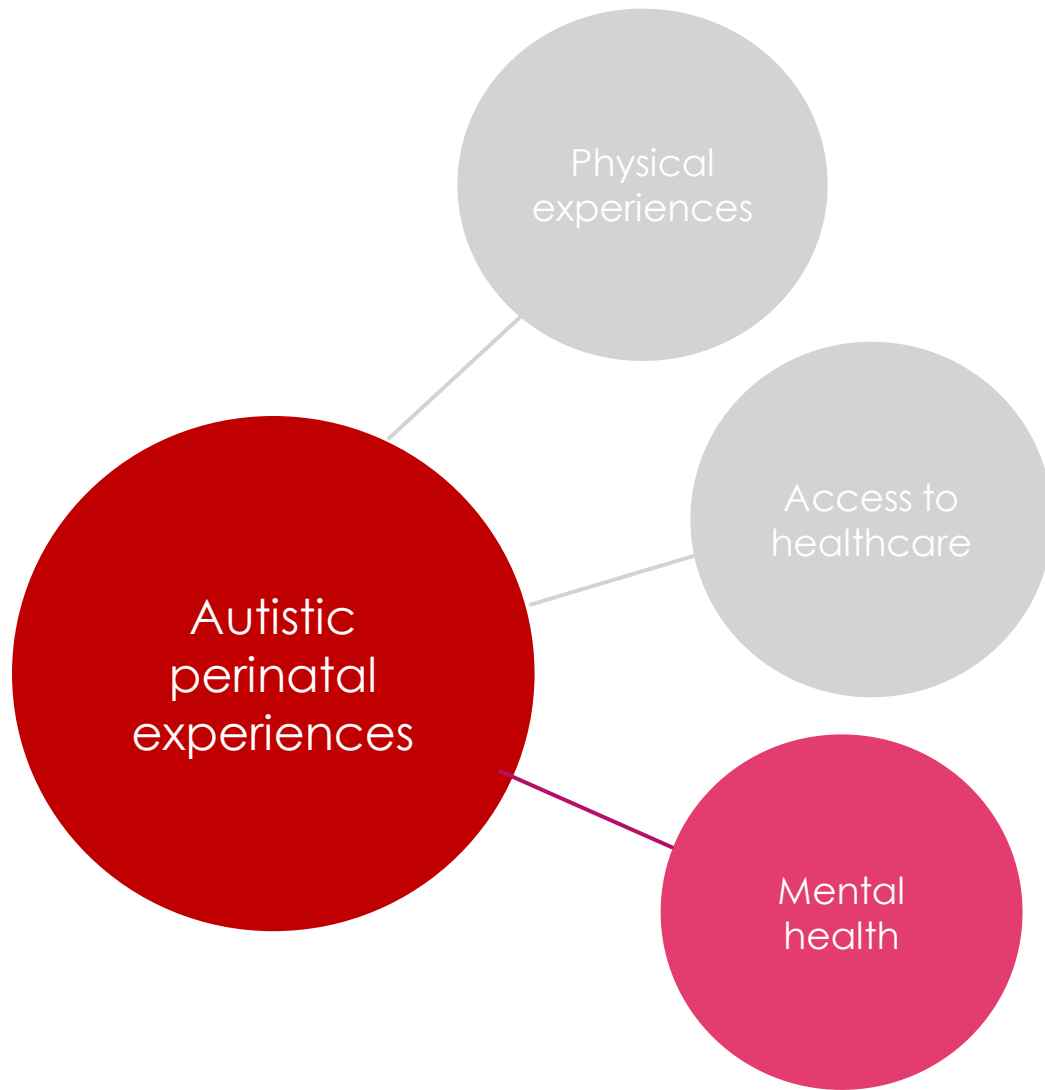


- Autistic people can face barriers to accessing healthcare (Nicolaidis et al., 2015; Raymaker et al., 2017; Tint & Weiss, 2018):

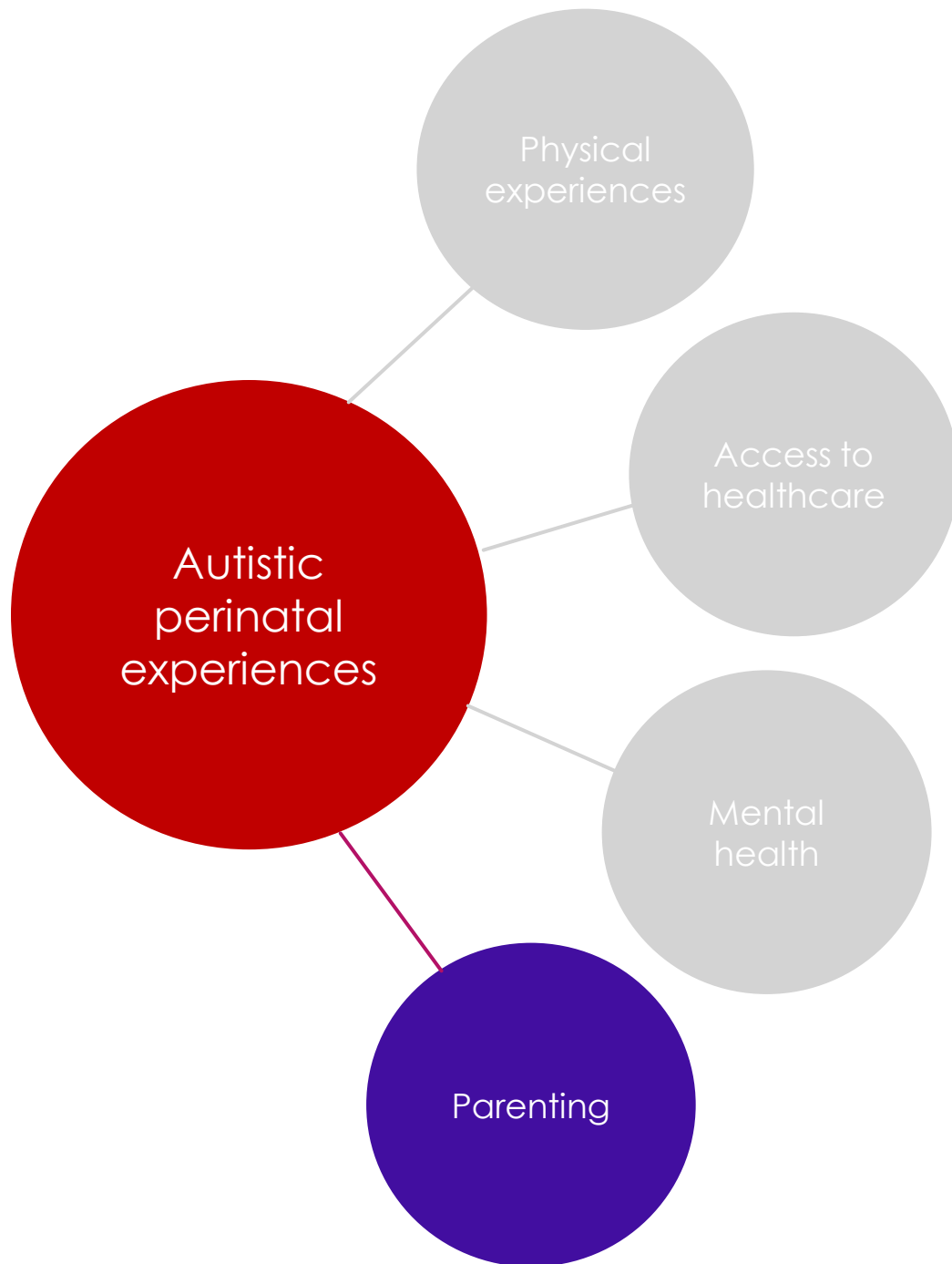
- Sensory barriers
  - Sensory environment of healthcare facilities
  - Touch
- Social and communication barriers
  - Difficulty processing verbal information
  - Lack of accessible communication formats
  - Need for clear, direct information
  - Masking can lead to underestimation of needs

- Professionals' autism understanding and disclosure

(Donovan, 2020; Gardner et al., 2016; Lewis et al., 2021; Rogers et al., 2017; Talcer et al., 2021)



- Co-occurrence of autism and mental health conditions (Lai et al., 2019)
- Prior history of mental health conditions is a predictor of perinatal mental health (Lancaster et al., 2010)
- Higher likelihood of prenatal and postnatal depression among autistic people (Pohl et al., 2020)

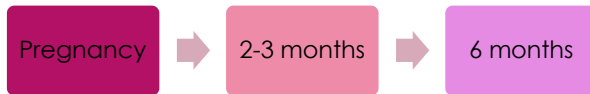


- Can feel their parenting is judged by others (Dugdale et al., 2021; Gardner et al., 2016; Pohl et al., 2020; Rogers et al., 2017)
- Receive insufficient support for caring for their infant (Gardner et al., 2016)
- Greater difficulty with multi-tasking and domestic responsibilities, though just as prioritise their child's needs above their own (Pohl et al., 2020)



# Interviews

- Semi-structured qualitative interviews



- 24 autistic (age  $M=31.10$ ;  $SD=3.13$ ) and 25 non-autistic women (age  $M=34.02$ ;  $SD=2.76$ )
- Majority UK based (87%), first-time mothers (65%) of white ethnicity (87%)
- 65% of the autistic group and 8% of the non-autistic group with a psychiatric condition
- Majority educated to undergraduate level (55% of autistic group and 92% of non-autistic group)

# Survey

- 429 autistic (177 self-identified) and 551 non-autistic people
- Retrospective reporting on most recent pregnancy/birth (gave birth 9 years prior on average)
- Consulted panel of three autistic mothers
- Logistic regressions controlling for: Age at giving birth, age of child, parity, country, income, partner status, psychiatric conditions, gestational age at birth, delivery type

Original Article

## A qualitative exploration of autistic mothers' experiences II: Childbirth and postnatal experiences

Sarah Hampton<sup>ID</sup>, Joyce Man, Carrie Allison<sup>ID</sup>, Ezra Aydin<sup>ID</sup>, Simon Baron-Cohen\* and Rosemary Holt\*

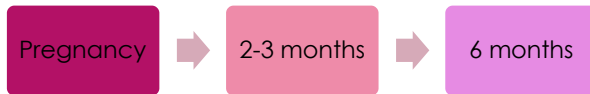


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# Interviews

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- Majority UK based (87%), first-time mothers (65%) of white ethnicity (87%)
- 65% of the autistic group and 8% of the non-autistic group with a psychiatric condition
- Majority educated to undergraduate level (55% of autistic group and 92% of non-autistic group)

# Survey

- Demographics:
  - Age at most recent birth:
    - Autistic group:  $M=32.00$ ,  $SD=5.38$ ;
    - Non-autistic group:  $M=33.10$ ,  $SD=5.07$
  - Mostly UK based (65%), second-time parents of white ethnicity (95%)
  - 67% of the autistic group and 37% of the non-autistic group with a psychiatric condition
  - Majority educated to undergraduate level (70% of autistic group and 78% of non-autistic group)
  - Group differences in: age, age of child, gender, partner status, income, country, psychiatric conditions

Original Article

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# Physical and sensory Pregnancy

*'I have like a sensory processing disorder with noises and light touching and smells and sounds and all of that is magnified and amplified.'*

- ▶ Autistic participants more likely to report heightened senses

|         | <b>% agree (autistic vs. non-autistic)</b> |
|---------|--|
| Smell   | 83% vs. 77%<br>OR=2.28 CI=1.12-4.66**      |
| Taste   | 70% vs. 54%<br>OR=3.78 CI=1.95-7.24***     |
| Touch   | 53% vs. 23%<br>OR=9.43 CI=4.89-18.18***    |
| Hearing | 35% vs. 9%<br>OR=11.31 CI=6.36-27.06***    |
| Vision  | 16% vs. 4%<br>OR=6.12 CI=2.52-15.06***     |

*'If I hear a loud noise I'll feel it on my back, it's like someone's punching me on the back. So that one has got a lot more intense since being pregnant'*

*'because all of them were heightened, they've all been coming together and it's been overloading me much quicker and more intensely.'*

*'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'*

\*p < .05

\*\*p ≤ .01

\*\*\*p ≤ .001

OR=Odds ratio

CI=95% confidence intervals

Physical and sensory experiences: Pregnancy

Meltdowns and shutdowns

Increased intensity of meltdowns (56% agreed) and shutdowns (57% agreed) during pregnancy

'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.'

Pelvic girdle pain

More likely to experience pelvic girdle pain (35% vs. 28%; OR=1.76 CI=1.30-2.38\*\*\*)

'maybe it is worse for people with a sensory aversion to smell because it's heightened.'

Nausea

Autistic participants report more frequent nausea (OR=1.65 CI=1.28-2.14\*\*\*)

Fatigue

'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.'

Medical appointments

More likely to be overwhelmed by sensory environment of appointments (76% vs. 14%; OR=92.59 CI=56.82-149.70\*\*\*)

'it was so chaotic and bright and people rushing around. I found that really difficult and I shutdown for a period after my first scan.'

Bodily changes

More likely to report difficulty adapting to bodily changes (54% vs. 31%; OR=2.87 CI=2.15-3.84\*\*\*)

'as soon as you adapt to a change, there's another change, that's quite difficult'

\*p < .05  
\*\*p ≤ .01  
\*\*\*p ≤ .001

## Sensory input

More likely to feel overwhelmed by sensory input during birth (65% vs. 29%; OR=7.63 CI=5.08-11.44\*\*\*)

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

## Bodily signals

Less likely to feel aware of their body's signals and how to interpret them (52% vs. 65%; OR=0.53 CI=0.35-0.80\*\*)

*'I am not always fully aware of how my body is feeling. Asking me things like "do you need to push" can be confusing.'*

## Meltdowns and shutdowns

- 29% of autistic participants experienced a meltdown
- 38% experienced a shutdown
- 51% of autistic participants who had a meltdown and 46% of those who had a shutdown felt that professionals did not respond how they would have liked

## Physical and sensory experiences: Childbirth

*'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'.*

## Postnatal ward

More likely to be overwhelmed by sensory environment of the postnatal ward (88% vs. 61%; OR=7.41 CI=3.86-14.27\*\*\*)

\*p < .05

\*\*p ≤ .01

\*\*\*p ≤ .001

# Healthcare experiences: Autism disclosure

- ▶ A minority disclosed their autism diagnosis to professionals

|                | % disclosed |           |
|----------------|-------------|-----------|
|                | Prenatal    | Postnatal |
| Disclosed to:  |             |           |
| Midwife        | 20%         | 22%       |
| Doctor         | 24%         | 29%       |
| Health visitor | NA          | 24%       |

*'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'*

*'primarily fear - that I would be deemed inadequate or have my child removed'*

# Healthcare experience and understanding

*'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.'*

*'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'*

*'She was like, 'oh, what does that mean?' and I had to explain it. But she's not really brought it up since then.'*

|                                     | % agree vs. disagree |             |
|-------------------------------------|----------------------|-------------|
|                                     | Prenatal             | Postnatal   |
| Had a good understanding of autism: |                      |             |
| Midwife                             | 24% vs. 40%          | 26% vs. 34% |
| Doctor                              | 22% vs. 44%          | 24% vs. 40% |
| Health visitor                      | -                    | 21% vs. 38% |

*'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''*

*'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.'*



# Healthcare experiences: Relationships with professionals

*'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.'*

|   | % agree (autistic vs. non-autistic)     |  |
|---|---|--|
|   | Prenatal                                | Postnatal                              |
| Less likely to feel able to trust professionals                         | 57% vs. 87%<br>OR=0.11 CI=0.07-0.18***  | 56% vs. 82%<br>OR=0.18 CI=0.11-0.28*** |
| Less likely to feel that professionals treated them respectfully        | 63% vs. 88%<br>OR=0.13 CI=0.08-0.21***  | 71% vs. 90%<br>OR=0.17 CI=0.10-0.29*** |
| More likely to feel negatively judged by professionals                  | 54% vs. 26%<br>OR=6.71 CI=4.42-10.20*** | 49% vs. 23%<br>OR=4.93 CI=3.26-7.46*** |
| Less likely to feel professionals took questions and concerns seriously | 55% vs. 84%<br>OR=0.13 CI=0.08-0.20***  | 59% vs. 82%<br>OR=0.22 CI=0.14-0.34*** |

*'She 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.'*

\*p < .05  
\*\*p ≤ .01  
\*\*\*p ≤ .001

# Healthcare experiences: Communication during appointments

*'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.'*

*'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''*

*'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''*

|  | % agree (autistic vs. non-autistic)     |   |
|--|---|---|
|  | Prenatal                                | Postnatal                               |
| Less likely to feel satisfied with how information was presented during appointments | 61% vs. 85%<br>OR=0.17 CI=0.11-0.27***  | 58% vs. 80%<br>OR=0.25 CI=0.16-0.38***  |
| Less likely to feel comfortable asking questions to professionals                    | 57% vs. 90%<br>OR=0.07 CI=0.05-0.12***  | 58% vs. 85%<br>OR=0.14 CI=0.09-0.22***  |
| More likely to agree that advocate was helpful                                       | 85% vs. 67%<br>OR=3.15 CI=1.74-5.96***  | 85% vs. 79%<br>OR=2.03 CI=0.85-5.16     |
| More likely to agree that advocate would have been helpful                           | 53% vs. 18%<br>OR=7.13 CI=4.29-12.11*** | 57% vs. 23%<br>OR=6.67 CI=3.73-12.27*** |

\*p < .05

\*\*p ≤ .01

\*\*\*p ≤ .001

## Feeling kept informed

Less likely to feel adequately kept informed (55% vs. 73%; OR= 0.37 CI=0.25-0.56\*\*\*)

*'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'.*

*'my facial expressions become more flat when I am distressed'*

## Professionals' understanding

Less likely to agree that professionals had accurate understanding of what perceiving physically (40% vs. 72%; OR= 0.17 CI=0.11-0.25\*\*\*)

*'someone with me who could understand and advocate on my behalf when I became non-verbal through overwhelm'*

# Healthcare experiences: Communication during childbirth

## Feeling listened to

Less likely to agree that professionals listened to requests (57% vs. 75%; OR=0.32 CI=0.21-0.49\*\*\*)

## Advocate

- Majority of both groups (82% vs. 87%; OR=0.64 CI=0.35-1.17) found it helpful to have an advocate
- More likely to agree that having an advocate would have been helpful (64% vs. 33%; OR=7.55 CI=3.27-18.90\*\*\*)

\*p < .05

\*\*p ≤ .01

\*\*\*p ≤ .001

# Healthcare experiences: Group support

*'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'*

- ▶ More likely to find it difficult to attend antenatal classes (56% vs. 14%; OR= 9.98 CI=6.89-14.39\*\*\*)
  - ▶ More likely to agree the size of antenatal classes is too large (72% vs. 30%; OR= 9.56 CI=4.15-22.00\*\*\*)
  - ▶ More likely to agree there is too much pressure to socialise at antenatal classes (87% vs. 54%; OR= 6.29 CI=2.52-15.70\*\*\*)
- ▶ More likely to find it difficult to attend parent and baby groups (80% vs. 41%; OR= 13.25 CI=8.33-21.10\*\*\*)



*'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.'*

\*p < .05

\*\*p ≤ .01

\*\*\*p ≤ .001

# Social support

|   | % agree (autistic vs. non-autistic)    |  |
|---|--|--|
|   | Prenatal                               | Postnatal                              |
| Less likely to have received all support needed from: |  |  |
| Partner   | 62% vs. 80%<br>OR=0.30 CI=0.19-0.48*** | 52% vs. 72%<br>OR=0.45 CI=0.29-0.70*** |
| Family  | 50% vs. 77%<br>OR=0.17 CI=0.11-0.27*** | 44% vs. 71% OR=0.31<br>CI=0.20-0.48*** |
| Friends   | 51% vs. 85%<br>OR=0.12 CI=0.07-0.20*** | 42% vs. 71% OR=0.34<br>CI=0.21-0.53*** |

*'And also having a lack of friends, I feel like I've got a lack of female... people who've been through pregnancy'*

\*p < .05  
 \*\*p ≤ .01  
 \*\*\*p ≤ .001

# Social support

*'it's nice to talk to other people who have similar sensory experiences and social experiences while also dealing with pregnancy and babies.'*

|  | % agree  |           |
|--|----------|-----------|
|  | Prenatal | Postnatal |
| Had peer support from other autistic parents | 5%       | 17%       |
| Found peer support helpful                   | 100%     | 98%       |
| Would have found peer support helpful        | 59%      | 60%       |

*'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.'*

# Mental health

## ▶ Greater risk of depression:

- ▶ Prenatal: 24% vs. 9%; OR= 3.21 CI=2.15-4.86\*\*\*
- ▶ Postnatal: 30% vs. 13%; OR=2.31 CI=1.54-3.49\*\*\*

## ▶ Greater risk of anxiety:

- ▶ Prenatal: 38% vs. 14%; OR= 3.96 CI=2.84-5.58\*\*\*
- ▶ Postnatal: 19% vs. 7%; OR=1.92 CI=1.16-3.24\*

## ▶ Less likely to receive as much information as they would like about their postnatal mental health (36% vs. 60%; OR=0.24 CI=0.16-0.35\*\*\*)

## ▶ Masking

*'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.'*

*'I felt that my health and that of my baby were checked but very little was done by way of my mental health'*



*'I hid my postnatal depression and anxiety very well, masking is almost a reflex really'*

*'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'*

\*p < .05

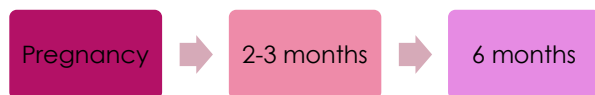
\*\*p ≤ .01

\*\*\*p ≤ .001



# Mental health: perinatal patterns

- ▶ 27 autistic and 29 non-autistic participants
- ▶ Questionnaires:
  - ▶ Edinburgh Postnatal Depression Scale
  - ▶ State Trait Anxiety Inventory
  - ▶ Cohen's Perceived Stress Scale



- ▶ Linear mixed models controlling for income, parity and prior history of depression/anxiety

Original Article

## Autistic mothers' perinatal well-being and parenting styles

Sarah Hampton , Carrie Allison , Ezra Aydin ,  
Simon Baron-Cohen\* and Rosemary Holt\*



Autism  
1-16

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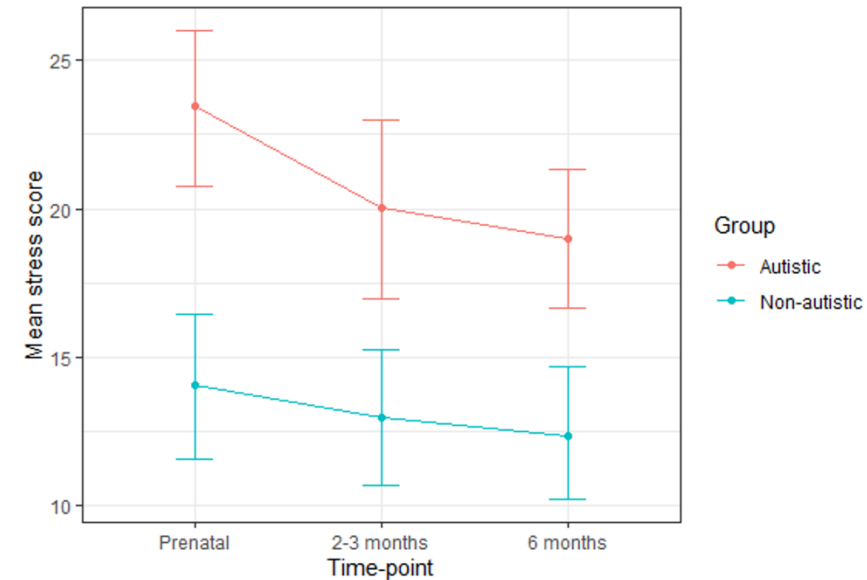
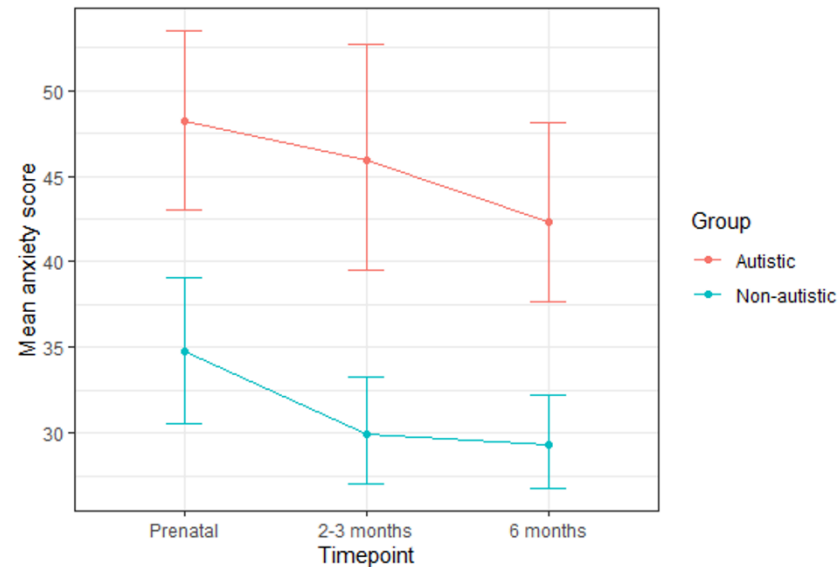
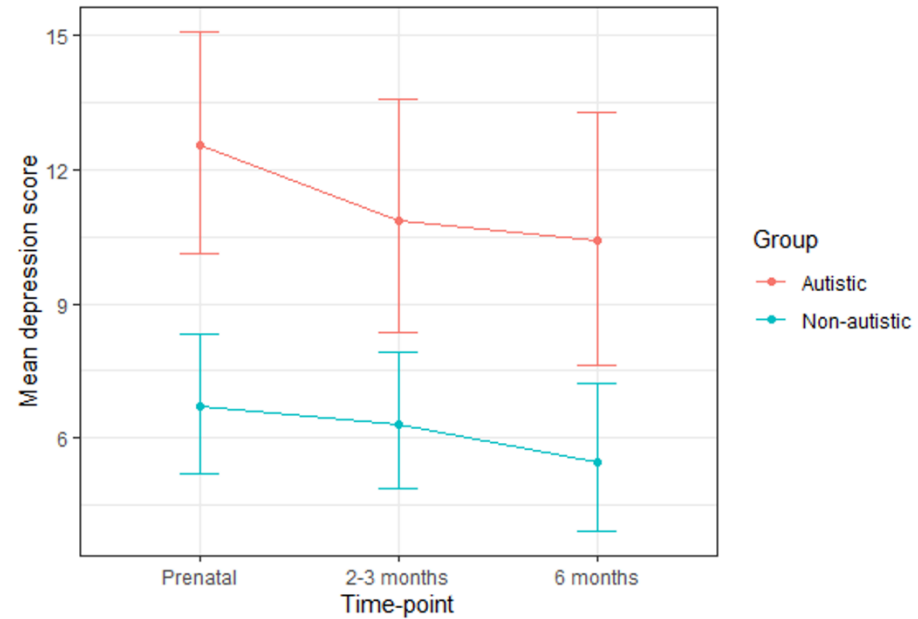
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# Mental health: perinatal patterns

- ▶ Significantly greater:
  - ▶ depression (B(SE)=3.72(1.69)\*)
  - ▶ anxiety (B(SE)=10.18(4.00)\*\*)
  - ▶ stress (B(SE)=7.50(1.84)\*\*\*)

- ▶ Scores tended to decrease over time for both groups (significant for anxiety (B(SE)=-3.11(1.23)\*\*))



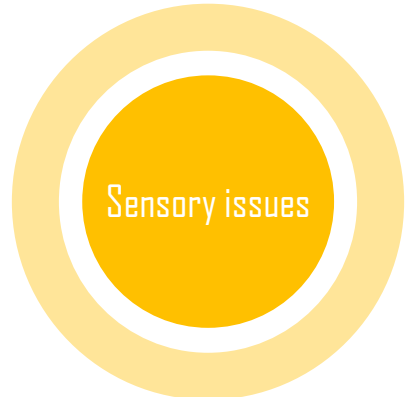
\*p < .05

\*\*p ≤ .01

\*\*\*p ≤ .001

*'It's definitely hard when he wants to be on me all of the time, because I'm kind of touch avoidant.'*

- More likely to find parenting overwhelming in terms of sensory input (69% vs. 29%; OR=5.70 CI=4.13-7.93\*\*\*)
- More likely to have had difficulties breastfeeding due to sensory issues (47% vs. 10%; OR=6.88 CI=3.93-12.46\*\*\*)

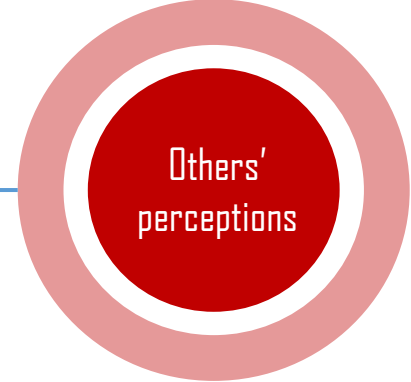
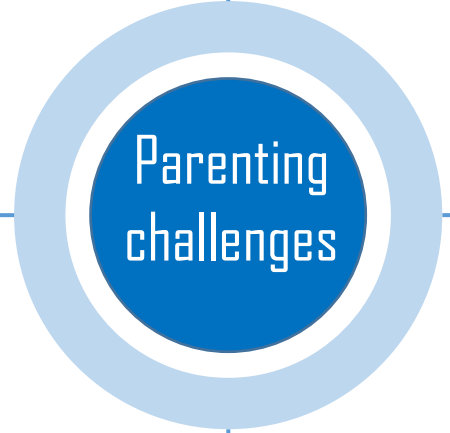


*'about half way through a feed I feel like there's some sort of needle that being threaded up almost right the way to my back.'*

*'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'*



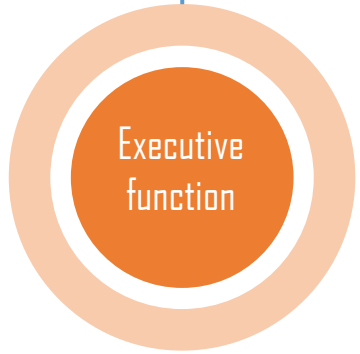
- Less likely to have found it easy to play with their baby (56% vs. 85%; OR=0.21 CI=0.15-0.30\*\*\*)



- More likely to worry about how others will perceive their parenting (79% vs. 58%; OR=3.52 CI=3.52-3.53\*\*\*)
- 41% felt that others had judged their parenting negatively due to being autistic
- More likely to worry that their baby would be taken away from them (42% vs. 8%; OR=10.65 CI=6.89-16.90\*\*\*)

*'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.'*

- More likely to find the organisational demands of parenting challenging (75% vs. 65%; OR=1.59 CI=1.14-2.21\*\*)

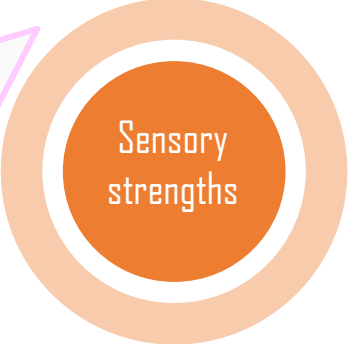
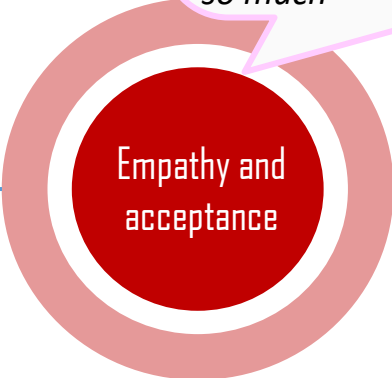
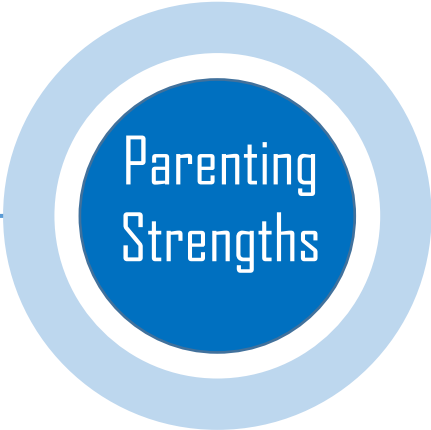
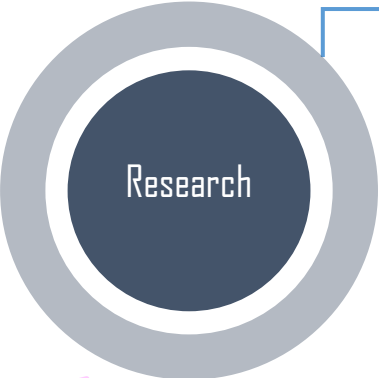


- The majority (85%) of autistic participants felt that being a parent was a positive experience
- The majority (78%) felt that being autistic gave them strengths as a parent

*'I love her very, very much and waking up every day knowing that I have that love in my life is wonderful.'*

*'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'*

*'I have strengths and weaknesses like any other mum.'*



- More likely to have researched parenting in a lot of detail (90% vs. 82%; OR=1.92, CI=1.21-3.10\*\*)

*'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'*

*'You're so used to looking for the super vague clues from adults but the good thing about babies is that they have universal cries and I'm good at listening to noises.'*

*'Very aware of sensory cues and willing to look for unexpected causes. Empathy for any being who finds everything confusing and overwhelming'.*

\*\*p ≤ .01  
\*\*\*p ≤ .001

# Summary

- Physical/sensory experiences heightened
- Increased likelihood of prenatal and postnatal depression and anxiety
- Autistic parents can be reluctant to disclose their diagnosis and can feel judged by professionals
- Communication can pose challenges in healthcare settings
- Autistic parents may value peer support
- Autistic parents can face some additional parenting challenges as well as possessing strengths

# Limitations

- ▶ Sample may not be representative of all the autistic community
  - ▶ Mostly UK-based, highly educated parents of white ethnicity
  - ▶ Only those able to take part in interviews and surveys
- ▶ Findings may not be specific to autistic parents
- ▶ Many survey respondents did not have a diagnosis at the time of their most recent birth
- ▶ Retrospective, self-report methodology

# Recommendations for clinical care

- ▶ Greater autism related training needed
- ▶ Sensory adjustments
- ▶ Communication adjustments and option of an advocate
- ▶ Individualised support
- ▶ Alternatives to group support
- ▶ Peer support
- ▶ Greater mental health support and appropriate screening





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