

# AUTISM TAKIWĀTANGA

Contemporary issues for Midwifery

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# TOPICS

- What is Autism
- Gender and Autism
- Research



# WHAT IS AUTISM? ACCORDING TO THE DSM-V

## MAIN FEATURES

- Persistent deficits in social communication and interaction as manifested by the following deficits in;
  - Social-emotional reciprocity;
  - Nonverbal communicative behaviours used for social interaction;
  - Developing, maintaining, and understanding relationships
- Restricted, repetitive patterns of behaviour, interests or activities.

## TRAITS AND BEHAVIOURS

- Deficits in social-emotional reciprocity;
- Abnormal eye contact/body language;
- Hypo- or hyper-sensitivity to sensory input;
- Lack of facial expression;
- Difficulties in developing, maintaining, and understanding relationships;
- Repetitive motor movements, use of objects, or speech (Stimming);
- Intense, restrictive special interests;



# CO-OCCURRING CONDITIONS

- Executive Dysfunction
  - Disruption in processes of goal formation, planning, attention span
    - Example: Missed appointments
- Dyspraxia
  - Disruption in fine and gross motor control and verbal control
    - Example: Clumsiness
- Issues with Interoception vs. Sensory issues with external stimuli
  - Example: May not know that a bone is broken or that a cut is infected but bright lights can cause physical pain
- Alexithymia
  - Difficulties in identifying, describing, expressing emotion
- Co-occurring conditions such as
  - ADHD
  - Depression and Anxiety
  - Epilepsy
  - Ehlers Danlos Syndrome
- Sleep Disruption and Insomnia
- Autoimmune disorders
- GI problems



# Autism Spectrum

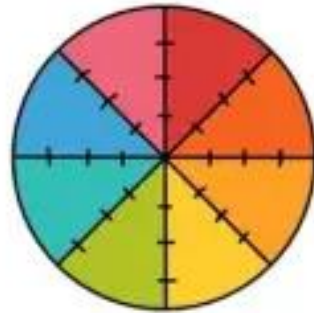
The Autism Spectrum is NOT linear



less autistic

very autistic

The Autism Spectrum looks more like:



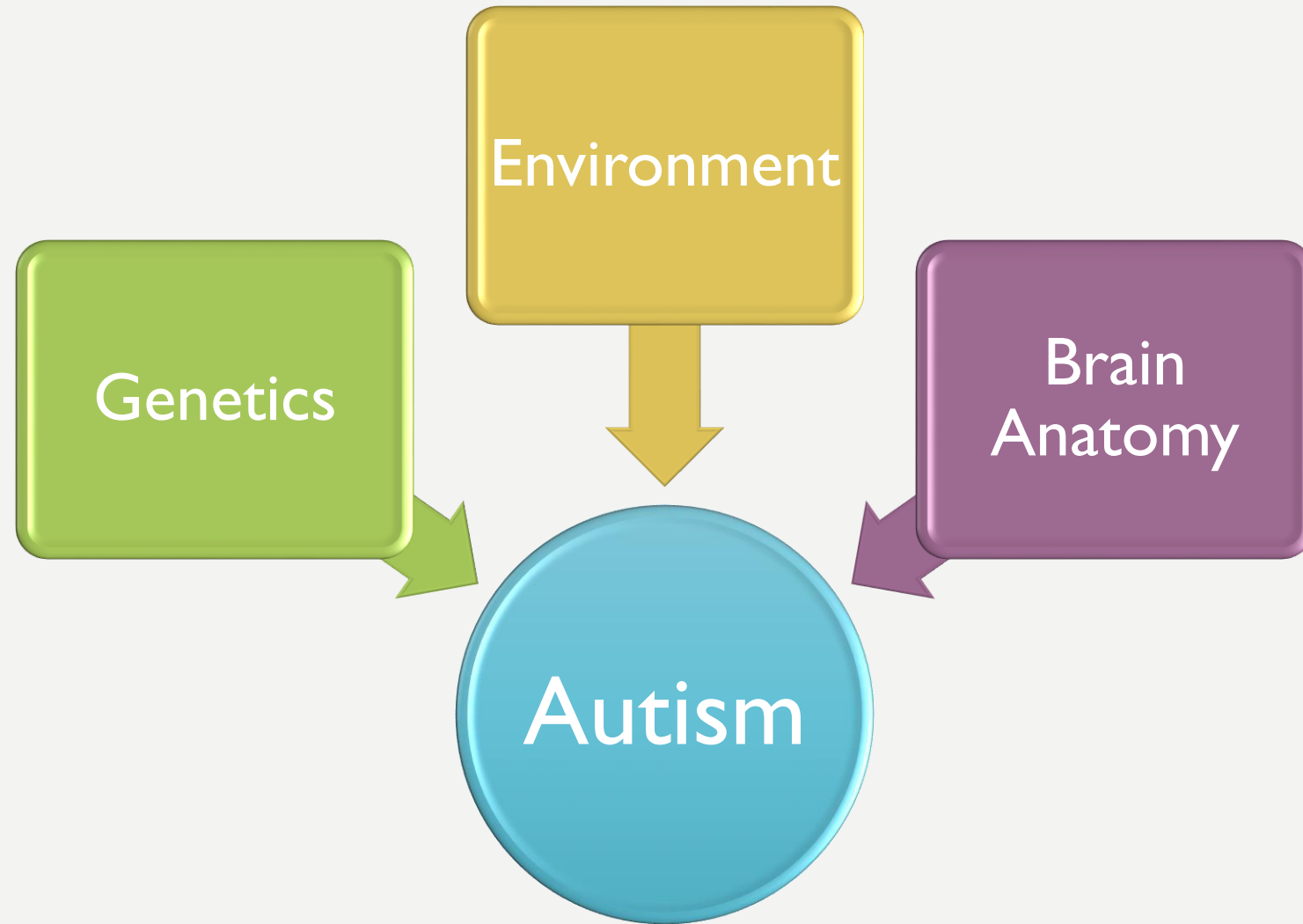
- Social differences
- interests
- repetitions
- sensory sensitivities
- emotional regulation
- perception
- executive functioning
- other

Terms like "high functioning", "low functioning" and "Asperger" are harmful and outdated.

Autism\_sketches



# WHAT CAUSES AUTISM?



## AUTISM RATES

- 1-1.6%; 48,000 New Zealanders
- Māori
  - Drysdale & van der Meer, 2020
  - Bevan-Brown, 2004
- Male-to-Female:
  - Children 4:1; Adults 3:1
    - (Bowden et al., 2020; Loomes et al., 2017).

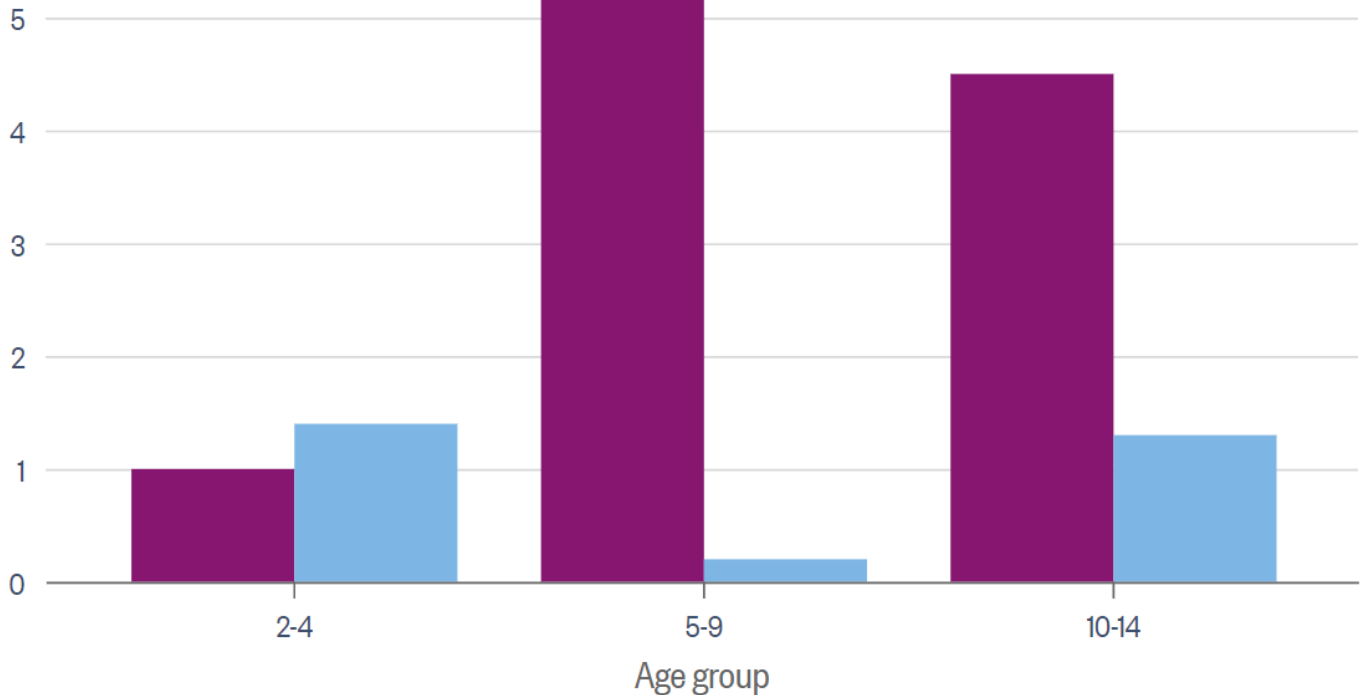


# New Zealand children diagnosed with Autism Spectrum Disorder (including Asperger Syndrome)

By gender and age group, year ended June 2021, % of children within group

Provider: Ministry of Health

Boys  
Girls

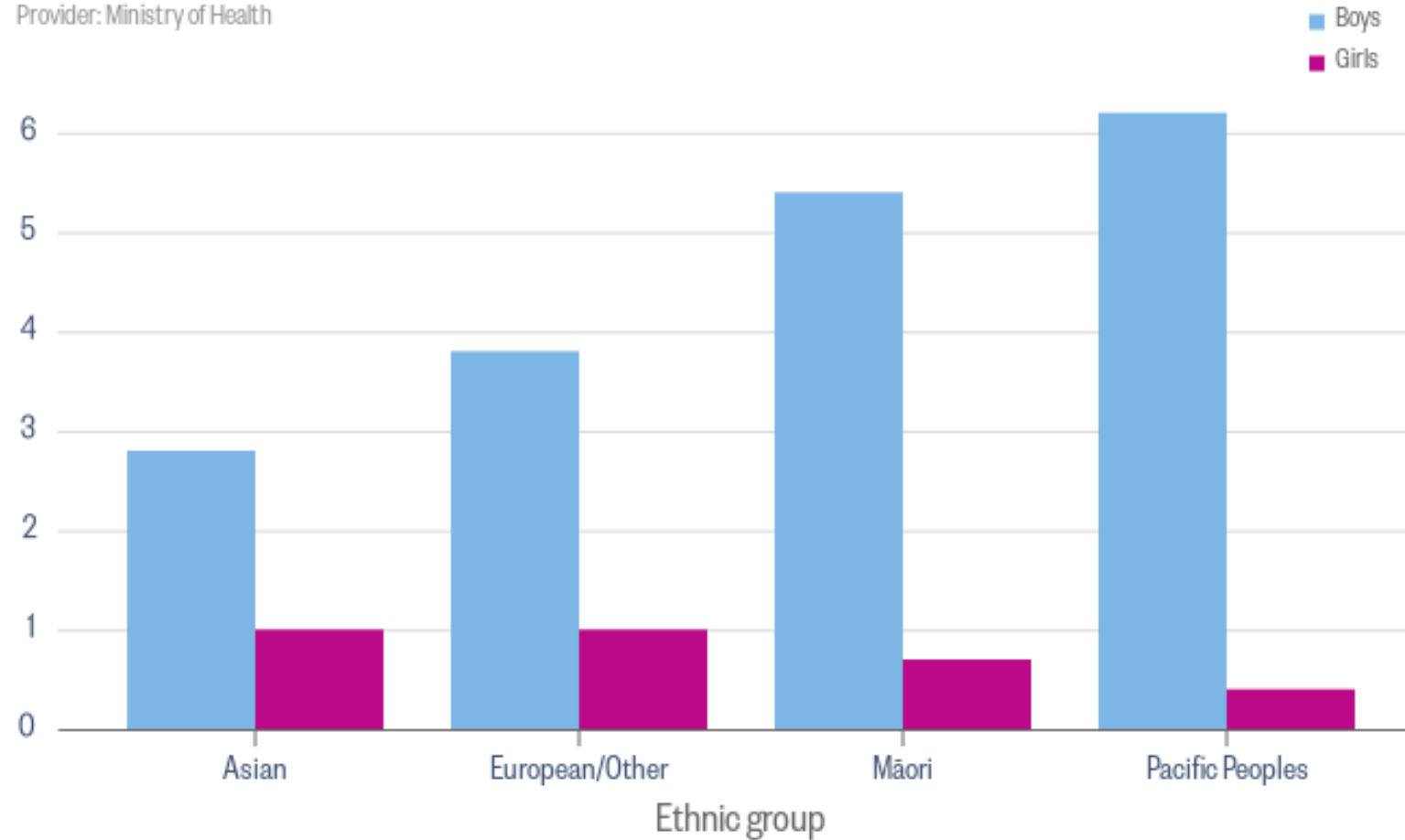




## New Zealand children diagnosed with Autism Spectrum Disorder (including Asperger Syndrome)

By gender and ethnic group, year ended June 2021, % of children aged 2-14 within group

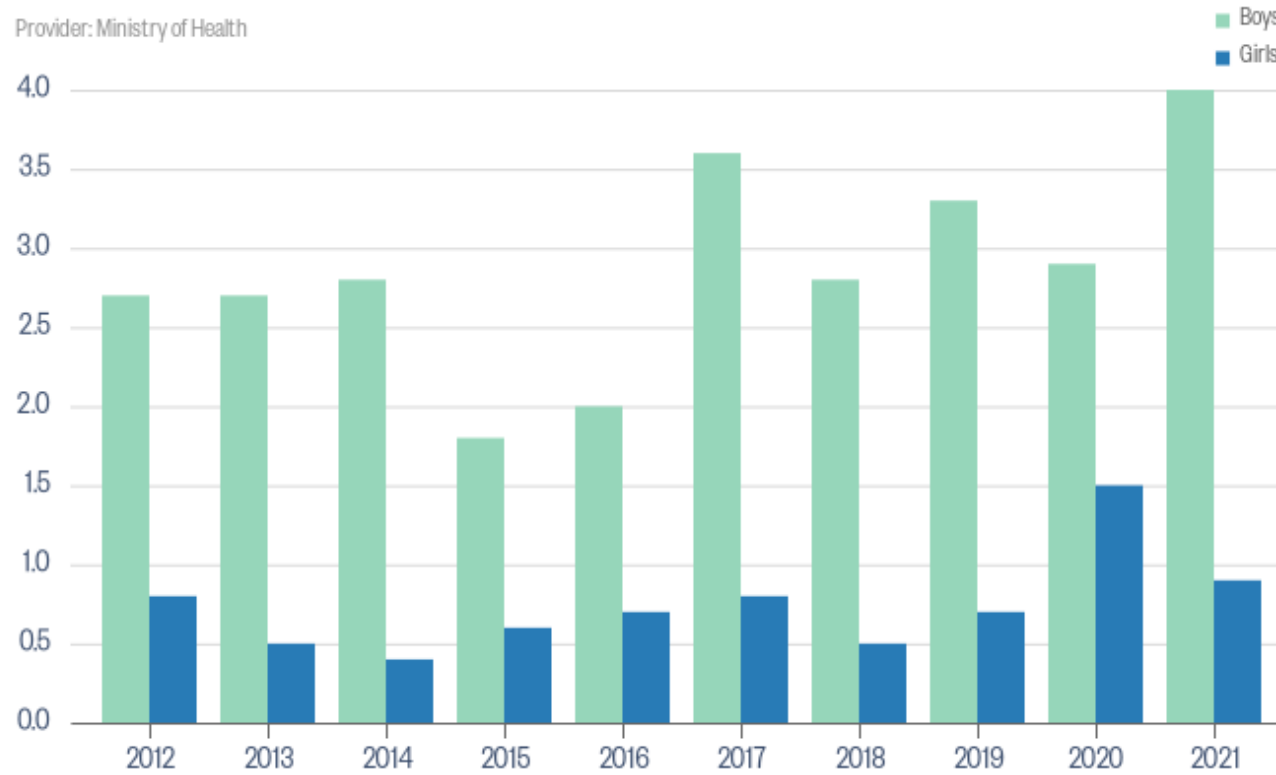
Provider: Ministry of Health



## New Zealand children diagnosed with Autism Spectrum Disorder (including Asperger Syndrome)

By gender, year ended June 2012-2021, % of children aged 2-14

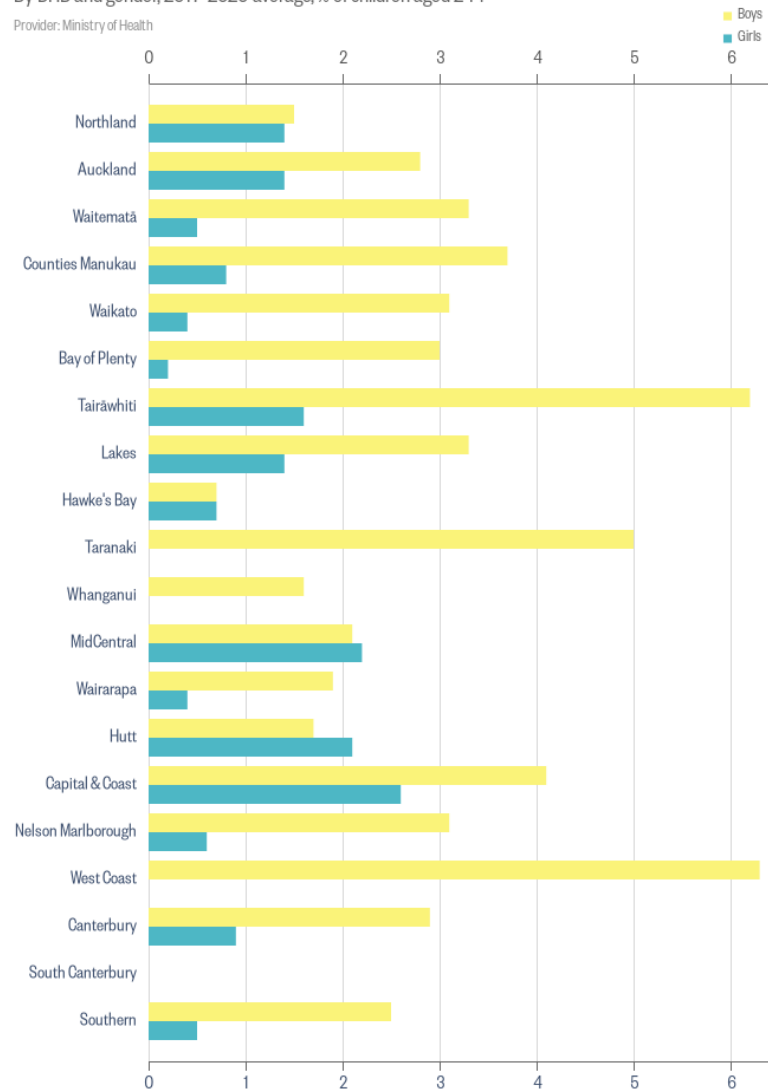
Provider: Ministry of Health



### New Zealand children diagnosed with Autism Spectrum Disorder (including Asperger Syndrome)

By DHB and gender, 2017-2020 average, % of children aged 2-14

Provider: Ministry of Health



# POPULAR THEORIES



- **Autism and the gender binary** (Warrier et al., 2020)
- **Grunya Sukhareva** (Simmonds, 2019)
- **Assessed against male exemplars**
  - Repetitive behaviours and special interests within accepted gender norms (Bargiela et al., 2016; Kanfischer et al. 2017)
- **Internalising versus externalising**  
(Lai et al., 2011)
- **Masking**
  - Not gender or culturally specific
  - Vulnerable to addictive behaviours
  - **Anxiety and Depression** (Bargiela et al., 2016, Lai et al., 2011)

## AUTISM AND THE FEMALE PHENOTYPE

Females and Mis(se)diagnosis



## Diagnostic Pathway

- Publicly-funded for children, adolescents, and adults with intellectual disability only
- Private for majority of Adults  
– \$1000+
- Average age: Children is 6.4;  
Adults is 38.7 (van der Meer & Evans, 2021)



## AUTISM ACROSS THE LIFESPAN

Implications for adulthood

- Diagnosis achieved often after children are diagnosed
- Lower rates of occupational and academic success and a mortality rate more than twice of that of the general population (Australian Bureau of Statistics, 2018; Hwang et al., 2019)
- Increased incidence of co-occurring mental health conditions and 10x higher risk of suicide (Hirvikoski et al., 2016)
- 3x incidence of sexual assault (Barigela et al., 2016; Hefferon, 2019; Hill, 2017, Kanfischer et al., 2017; Ohlsson et al., 2018)





# **IMPLICATIONS FOR MIDWIFERY**





# STUDIES

- Donovan, J. (2020). Childbirth Experiences of Women With Autism Spectrum Disorder in an Acute Care Setting. *Nursing for Women's Health*.
- Gardner, M., Suplee, P. D., Bloch, J., & Lecks, K. (2016). Exploratory study of childbearing experiences of women with Asperger syndrome. *Nursing for Women's Health*, 20(1), 28-37
- Hampton, S. (2020). *Autistic mothers and the perinatal period: Maternal experiences and infant development* [University of Cambridge]. <https://doi.org/10.17863/CAM.71112>
- Pohl, A. L., Crockford, S. K., Blakemore, M., Allison, C., & Baron-Cohen, S. (2020). A comparative study of autistic and non-autistic women's experience of motherhood. *Molecular autism*, 11(1), 1-12.
- Rogers, C., Lephurd, L., Ganguly, R., & Jacob-Rogers, S. (2017). Perinatal issues for women with high functioning autism spectrum disorder. *Women and Birth*, 30(2), e89-e95.
- Sundelin, H. E., Stephansson, O., Hultman, C. M., & Ludvigsson, J. F. (2018). Pregnancy outcomes in women with autism: a nationwide population-based cohort study. *Clinical epidemiology*, 10, 1817.
- Talcer, M. C., Duffy, O., & Pedlow, K. (2021). A Qualitative Exploration into the Sensory Experiences of Autistic Mothers. *Journal of Autism and Developmental Disorders*, 1-16. <https://doi.org/10.1007/s10803-021-05188-1>
- Tint, Brown, H. K., Chen, S., Lai, M.-C., Tarasoff, L. A., Vigod, S. N., Parish, S., Havercamp, S. M., & Lunsky, Y. (2021). Health characteristics of reproductive-aged autistic women in Ontario: A population-based, cross-sectional study. *Autism : the International Journal of Research and Practice*, 25(4), 1114–1124. <https://doi.org/10.1177/1362361320982819>



	Gardner (2016)	Rogers . (2017)	Donovan, J. (2017, 2020)	Pohl (2020)	Talcer (2021)	Hampton (2020) (Abstract)
STUDY	Qualitative	Qualitative	Qualitative	Quantitative/Mixed Methods	Qualitative	Mixed
SUBJ,	8 women ages 27 to 52.	1 Diagnosed at 17; pregnant at 26	24 women ages 29-65,	355 Autistic Mothers (120 self-diagnosed) 132 Non-Autistic Mothers;	7 English-speaking women over 18	Interview: 24 Autistic 25 non-Autistic  Survey: 429 Autistic 551 non-Autistic
RESULTS	<ul style="list-style-type: none"> <li>• Processing sensations</li> <li>• Needing to have control</li> <li>• Walking in the dark</li> <li>• Motherhood on my own terms</li> <li>• Persevering with breastfeeding</li> </ul>	<ul style="list-style-type: none"> <li>• Communication</li> <li>• Services Difficulties</li> <li>• Sensory Stress</li> <li>• Parenting Challenges</li> </ul>	<ul style="list-style-type: none"> <li>• Having Difficulty Communicating</li> <li>• Feeling Being an Autistic Mother</li> </ul>	<ul style="list-style-type: none"> <li>• 60% diagnosed after birth</li> <li>• 40% experienced AND, 60% PND</li> <li>• Breastfed 1<sup>st</sup> (88%) and 2<sup>nd</sup> (82%) child</li> <li>• 96% Prioritise child's needs above own</li> <li>• 47% cope with domestic responsibilities</li> <li>• 87% worry that disclosure of Autism to a professional will change the person's opinion of them</li> </ul>	<ul style="list-style-type: none"> <li>• Antenatal</li> <li>• Severe sickness</li> <li>• Sensory Experience in Motherhood</li> <li>• Body Awareness</li> <li>• Strategies and Needs</li> <li>• Diagnosis</li> </ul>	<ul style="list-style-type: none"> <li>• Physical burden of pregnancy</li> <li>• Heightened sensory experience, pain, and morning sickness</li> <li>• Lack of understanding</li> <li>• Increase risk of Perinatal depression</li> <li>• Less satisfied with healthcare</li> <li>• Reluctance to disclose</li> <li>• No difference in infant social behaviour or sensitivity responsiveness</li> </ul>



# Communication

	Gardner et al. (2016)	Rogers et al. (2017)	Donovan, J. (2017, 2020)	Pohl et al. (2020)	Hampton (2020)	Talcer et al. (2021)
FINDINGS	<ul style="list-style-type: none"><li>• Needing to have control</li></ul>	<ul style="list-style-type: none"><li>• Communication</li><li>• Services Difficulties</li></ul>	<ul style="list-style-type: none"><li>• Having Difficulty Communicating</li></ul>	<ul style="list-style-type: none"><li>• 87% worry that disclosure of Autism to a professional will change the person's opinion of them</li></ul>	<ul style="list-style-type: none"><li>• Reluctant to disclose diagnosis due to perceived lack of understanding</li><li>• Continuity of care and clear communication important support needs</li></ul>	<ul style="list-style-type: none"><li>• Despite lack of diagnosis, anticipation of sensory issues meant more success in having needs met</li><li>• Having to teach their care providers about autism</li></ul>



# PROCESSING SENSORY INPUT

	Gardner et al. (2016)	Rogers et al. (2017)	Donovan, J. (2017, 2020)	Pohl et al. (2020)	Hampton (2020)	Talcer et al. (2021)
FINDINGS	<ul style="list-style-type: none"> <li>Processing sensations</li> </ul>	<ul style="list-style-type: none"> <li>Sensory Stress</li> </ul>	<ul style="list-style-type: none"> <li>Feeling Stressed in an Uncertain Environment</li> </ul>	<ul style="list-style-type: none"> <li>40% experienced AND, 60% PND</li> <li>47% cope with domestic responsibilities</li> </ul>	<ul style="list-style-type: none"> <li>Increase in sensory, pain, morning sickness</li> </ul>	<ul style="list-style-type: none"> <li>Increased sensitivity to auditory and tactile input</li> <li>Extra appointments difficult</li> <li>Altered body awareness</li> </ul>



# Early Parenting

	Gardner et al. (2016)	Rogers et al. (2017)	Donovan, J. (2017, 2020)	Pohl et al. (2020)	Hampton (2020)	Talcer et al. (2021)
FINDINGS	<ul style="list-style-type: none"><li>• Walking in the dark</li><li>• Motherhood on my own terms</li></ul>	<ul style="list-style-type: none"><li>• Parenting Challenges</li></ul>	<ul style="list-style-type: none"><li>• Being an Autistic Mother</li></ul>	<ul style="list-style-type: none"><li>• 96% Prioritise child's needs above own</li><li>• 47% cope with domestic responsibilities</li></ul>	<ul style="list-style-type: none"><li>• Greater stress, anxiety, and depression than non-autistic women</li><li>• No differences in parenting behaviours</li></ul>	<ul style="list-style-type: none"><li>• Guilt they are unable to engage in motherly duties</li><li>• Highly prioritise motherhood</li><li>• Finding their tribe</li></ul>



# Breastfeeding

	Gardner et al. (2016)	Rogers et al. (2017)	Donovan, J. (2017, 2020)	Pohl et al. (2020)
FINDINGS	<ul style="list-style-type: none"><li>• Persevering with breastfeeding</li></ul>	<ul style="list-style-type: none"><li>• Services Difficulties</li><li>• Parenting Challenges</li></ul>	<ul style="list-style-type: none"><li>• Being an Autistic Mother</li></ul>	<ul style="list-style-type: none"><li>• Breastfed 1<sup>st</sup> (88%) and 2<sup>nd</sup> (82%) child</li></ul>



**SUNDELIN ET AL.  
(2018)**

– **Population based cohort study**

▪ **2198 singleton births to Autistic women register in the Swedish National Patient Registry**

**Findings**

- 
- **Autistic women are often smokers**
  - **Increased risk for medically indicated preterm birth between 32 and 37 weeks**
  - **Women with autism and without pre-eclampsia were at increased risk of medically indicated preterm birth**
  - **Pre-eclampsia was more prevalent in autistic mothers, especially bi-parous after sensitivity analyses**
  - **Risk of induction increased**



## **Population-based cross sectional study (Canada)**

**6,870 Autistic women (ages 15-44)  
compared with 2, 686, 160 non-Autistic  
women**

- **Similar distributions in neighbourhood income and residential instability**
- **After standardisation, autistic women more likely to live in areas with high maternal deprivation**
- **Autistic women had higher rates of diabetes (4.3% vs 2.3%) and asthma (26.2% vs 17.5%)**
- **After age standardisation, also higher rates of hypertension (5.3% vs 2.8%) and chronic medical conditions (27.3% vs 19.2%)**
- **28.8% used potentially teratogenic medication in previous year (vs 11.2% non autistic)**
- **Higher rates of all psychiatric conditions**

**TINT ET AL. 2021**





# QUESTIONS FROM A MIDWIFERY STANDPOINT

- Pregnancy outcomes
  - Place of birth
  - Perception of foetal movements
  - Pain relief options
- BFHI – Different questions about breastfeeding
  - Duration
  - Methods
- Pregnancy/Postnatal a good time to screen and diagnose?
- Continuity of Care/Carer make a difference?
- Prenatal screening
- Autistic/Neurodivergent whanau



**THANK YOU**

