

Neurodiversity in pregnancy, birth and early parenting:

Exploring the experiences of Tangata Whaitakiwātanga (Autistic) and Aroreretini (ADHD) consumers

Contents

The "WHY" behind the DAY	2
Notes on Language	3
Best practices for Neurodivergent-friendly meetings	4
Tentative Timetable	5
Topics	6
Autism, ADHD. And Disability: Implications for childbirth in New Zealand	6
Pregnancy and Birth	6
Adjustment to Early Parenting	6
Birth for everybody and for every mind	6
Selected Topics in Pharmacology	6
Supporting Neurodivergent Persons with Infant-Feeding	6
Sensory-Friendly Spaces	6
Neurodivergent Health Care	6
Speaker Bios	7
Brian Almand	7
Hannah Chandler	7
Sam Copeland	8
Janieke de Graf	8
Hayley Jeffrey	8
Jeremy Kemp	9
Rachel Noble, MNZM	9
Jenifer M Parker	10
Leslie Paton	10
Alice Richardson	10
Bronwyn Rideout	11
Rich Rowley	11
Jolene Stockman	11
Amy Taylor	12

The "WHY" behind the DAY

Neurodiversity is the idea that the range of brain types and neurological functioning, particularly in the areas of sociability, learning, attention, and mood, is quite broad and should be regarded as part of normal human life. This term was originally coined in 1998 by Australian Sociologist Judy Singer, an Autistic woman, to challenge the prevailing paradigm that certain neurodevelopmental conditions were pathological and required a cure. Singer argued in place of the medical model of disability, a social model should be adopted instead, allowing the focus to shift from curing to addressing societal barriers that isolate, disenfranchise, and otherwise contribute to poorer outcomes for disabled persons.

Boys are diagnosed with neurodivergent conditions more often than girls. It is hypothesised that this is due to the tendency of boy's to outwardly and/or aggressively express their frustration when experiencing difficulty with learning tasks, therefore their disruption in the classroom initiates more referrals.

Currently, there is a growing body of research which demonstrates that while there can be some differences in function and structure of neurodivergent female brains, binary thinking about neurology can negatively impact everyone. Neurodivergent people are more likely to be gender diverse and LGQBTQI+, meaning that males (including CIS and CISHET males) miss out on diagnosis and support over their lifespan when they do not demonstrate the stereotypically "male" traits.

Issues particular to midwifery and obstetrics can include:

- Increased challenges with education and information sharing to meet needs of those with challenges in motor coordination, reading/mathematical comprehension, inattention, pain perception;
- Mental health support within scope of practice but access for support from Maternal Mental Health can be limited depending on severity;
- Minimal research into birthing outcomes/choices but lots about birth defects and how paracetamol can Autism/ADHD;
- Therapeutic Orphans: Pre-existing mental health/diagnosed neurodivergent conditions may require medications with teratogenic effects. Women are often put in the position of stopping necessary treatment regimes in exchange for reducing risk to baby. Certain medications can also interfere with treatments for pregnancyrelated conditions.
- Missing out on the publically-funded pathway for assessment. While there is an adult assessment pathway, funding is available through Adult mental health services. Thus women are having to pay out-of-pocket for assessment from private clinical psychologists;
- Poor knowledge of current research regarding women and neurodivergence amongst health professionals, thus being prevented from accessing assessments or being misdiagnosed;
- More likely to be unemployed or underemployed. Experience less career progression despite academic success;

- Greater social burden/judgement as not adhering to gender norms; bearing blame if children like them or causing the condition in children due to antenatal/pregnancy choices;
- Increase psychosocial risks like eating disorders, self-harm, exposure to IPV/Sexual
 assault, mental health, misdiagnosis, social isolation, increased surveillance from
 child services.

Notes on Language

Identity-first language is favoured by many autistic persons, reflecting the belief that being autistic is a core part of a person's identity. Hence, one will hear "I am/ They are Autistic" instead of person-first language such as "I am a person with Autism" or "I have autism.

Similar preferences for identity-first language can be seen in the Blind and Deaf communities while person-first is common when speaking about Downs Syndromes and specific mental health conditions. Nevertheless, the autistic community is diverse and individuals will have their own preferences as to how they incorporate autism into their daily speech.

High-functioning and low-functioning labels, as well as mild/severe autism, have fallen out of favour amongst autistic persons because they misrepresent the diversity in capabilities and challenges faced by individuals.

Persons who received the diagnosis of Asperger's may still prefer using this term but it is not interchangeable with describing someone with what appears to be mild autism. Asperger's has been incorporated into the broader diagnosis of Autism Spectrum Condition

(Care of Autism New Zealand)

Instead of	Please use
Person with autism or person who has autism	Person on the autism spectrum or autistic person
High-functioning autism or mild autism	Person with less obvious support needs or person with lower support needs
Low-functioning autism, severe autism, or profoundly autistic	Person with complex support needs or person with higher support needs
Autism treatment or autism intervention	Autism support service or autism support therapy
Person affected by autism, person living with autism, or person suffering from autism	Person on the autism spectrum

Co-morbid conditions	Co-occurring conditions

Here are a selection of articles which explore this matter:

ASAN: Identity-first language

National Autistic Society: How to talk and write about autism

<u>Autism Journal: Autism Terminology Guidelines</u>

'Autistic person' OR 'Person with autism': Is there a right way to identify people?

Which terms should be used to describe autism? Perspectives from the UK autism community

Best practices for Neurodivergent-friendly meetings

You may notice that this study day is a bit different than others you will have attended. We endeavouring to make this day sensory-friendly for our presenters and for many in the audience.

A separate space has been set aside from catering. Please do not bring any food or beverages with strong odours into the auditorium.

A sensory-friendly room has been provided by Hayley Jeffrey for presenters and attendees who require a quieter setting. The webinar will be accessible from this room but persons are expected to bring their own devices and headphones. This space is not available receiving and taking of mobile calls.

Fidget toys will be available in the sensory room dependent on COVID levels and with cleaning materials provided. Attendees and presenters are free to bring their own to use during panels as long as their volume does not interfere with the panels.

This study day is supportive of stimming behaviours as described in this Spectrum News article: Repetitive and stimming behaviours in autism explained.

This study day also utilises colour communication badges. A colour sticker on the name badge will indicate the level of interaction an attendee wishes to have with strangers. You do not have to partake if you do not wish to but please respect the wishes of those who do. The colours and their meaning are as follows (adapted from here):

Green	Actively seeking communication and happy to be approached by strangers	
Yellow	Only wants to be approached by people they know; may initiate communication with strangers	If you are only acquainted via social media, do not approach unless invited.
Red	Does not want to talk or be approached	

For further information on supporting neurodiversity in meetings or in the workplace, check-out these resources provided by the Neurodiversity Hub at https://www.neurodiversityhub.org/resources

Tentative Timetable

Morning Session (open to all 3DHB staff and members of the public)

0900-0910: Opening. Karakia, Waiata. Housekeeping
0910-1000: Autism, ADHD, and Disability: Implications for childbirth in New Zealand
Bronwyn Rideout
Amy Taylor
Rachel Noble
Catherine Trezona
1000-1100: Panel on pregnancy and birth (4 presenters)
Sam Copeland
Leslie Paton
Jolene Stockman
Alice Richardson
1100-1115: Morning Tea (Provided)
1115-1215: Panel on adjustment to early parenting (3 presenters)
Jenifer Parker
Rich Rowley
Jeremy Kemp
• TBC
1215-1230: Break
1230-1300: Panel on Gender Diversity
Leslie Payton
Amy Taylor
• TBC
• TBC

Afternoon Session (for Health Professionals only)

1300-1330: Lunch (self-catered)	
1330-1415: Pharmacology	
Brian Almand	
1415-1445: Lactation Consultant	
Kate Anderson	
1445-1515: Sensory Friendly Spaces	
Hayley Jeffries	
1515-1600: Neurodivergent Healthcare	
Hannah Chandler	
Bronwyn Rideout	
Amy Taylor	
Janieke de Graf	

Please note: While all speakers listed are confirmed, the exact order of panels and their participants may still change

Topics

Autism, ADHD. And Disability: Implications for childbirth in New Zeala Panelists Rachel Noble, Bronwyn Rideout, Amy Taylor, and Catherine Tre current international and national research and policies.	
Pregnancy and Birth Sam Copeland, Leslie Paton, Alice Richardson, and Jolene Stockman share pregnancy and birth, with and without a diagnosed neurodivergent cond	•
Adjustment to Early Parenting Jeremy Kemp, Jennifer Parker, and Rich Rowley korero on adjusting during parenting.	ng the early days
Birth for everybody and for every mind Leslie Payton, and Amy Taylor discuss the intersection of gender diversity during the childbearing journey.	y and neurodiversity
Selected Topics in Pharmacology Brian Almand, Senior Pharmacist (Mental Health), speaks on selected top care of neurodivergent persons during pregnancy.	pics relevant to the
Supporting Neurodivergent Persons with Infant-Feeding Kate Anderson shares her knowledge on how to best support families wi	th infant-feeding.
Sensory-Friendly Spaces Hayley Jeffrey, the visionary behind our sensory room, discusses her wor you can make your clinic space neurodivergent-friendly in a sustainable r	·
Neurodivergent Health Care Hannah Chandler (Hawke's Bay), Janieke de Graf, Bronwyn Rideout, and their realities as neurodivergent health practitioners alongside the practicare to neurodivergent consumers	

Speaker Bios

Brian Almand



I have twenty four years of experience in pharmacy practice, twenty two years of that in Hutt Hospital Pharmacy associated with the Acute Adult Inpatient Psychiatry Unit, Te Whare Ahuru. I am employed half time by the 3DHB-MHAIDS, working closely with the various community mental health teams, and responding to General Practitioner and other enquiries and referrals where specific medicines information is appropriate.

My role in psychiatry includes medication reconciliation and review; attendance at multi-disciplinary team meetings (MDT); frequent medication and therapeutics education for various professional groups and a number of outpatient groups, individual inpatients and their families; provision of medicines information for psychotropic medications, maternal mental health and neurology; full time availability for consultation by anyone. I am

also involved in a good deal of behind the scenes communication between the various teams.

I have had the pleasure of educating for or consulting with many departments and groups within the 3DHB and with several organisations outside of the 3DHB.

Women's mental health has always been of interest to me, and demystifying the use of psychotropic medication around pregnancy is core business for a Pharmacist in Mental Health. I hope my research into this presentation is of help to the midwifery team and your clients. I have made every effort to access current and relevant practice where commercial information is often very limited. Please contact me if I can be of assistance in the future.

Kate Anderson



My name is Kate Anderson, pronouns She/Her. I am a NZ Registered Nurse, an IBCLC (Lactation Consultant) and Biodynamic Craniosacral Therapist. I am a mother to three wonderful children, ages 13, 11, and 3. Our 11 year-old has ADHD, ODD, Anxiety and Autism. I myself am yet undiagnosed however I strongly suspect I have ADHD as many adult family members have ADHD. Through the journey of learning about our 11-year old, I have certainly learnt some things about myself.

I have worked in the health industry for 15 years and the last 3-4 of these I have been in private practice as a Lactation Consultant and Craniosacral Therapist. In my practice I work with many neurodivergent people and families and am

blessed to be invited into their spaces to walk alongside them on their journeys. I am passionate about normalising neurodiversity and I hope by participating in the upcoming discussion I will be able to help spread some knowledge to other health professionals on how we can better support neurodivergent individuals particularly at the vulnerable time of child birth and early parenting.

Hannah Chandler Picture and bio to follow

Hannah Chandler is a neurodivergent midwife from the Hawke's Bay

Sam Copeland

Picture to follow

Sam Copeland (She/They), is a late-diagnosed autistic mother of a 10 year old autistic girl. Being diagnosed later in life has explained so many of her experiences over the years, especially how she handled pregnancy, her daughter's early days and navigating the healthcare system.

Janieke de Graf



practitioner.

I (She/her, Pakeha) have worked as a nurse/homeopath at Natural Healing Raumati on the Kapiti Coast for over 10 years.

I am mama to two children both diagnosed with ADHD combined type, and a partner with dyslexia and suspected ADHD. Recently realising that the apple doesn't fall far from the tree, I discovered that what I had previously thought was anxiety and perfectionism are likely compensations for undiagnosed ADHD.

With a new lens on why life has been the way it is, I am excited to share my lens on neurodiversity as a health

Hayley Jeffrey



Hayley Jeffrey (She/Her), is an accessibility consultant, accessible exhibitions curator, sensory and play-scape designer and artist working in Lower Hutt.

She has 15-years of experience in eventplanning for children with diverse needs and 9years working in play-design and art therapy for adults who experience disabilities.

She is a single mother of a neurodiverse child and experiences executive function differences and dysgraphia herself.

She is currently building inclusive playgrounds for primary schools and illustrating maths books for children with dysgraphia. Hayley is currently curating an inclusive exhibition for artists who experience disabilities, set to open later this

year. Hayley is passionate about design as a function of inclusive understanding; she believes disability is an experience of poor infrastructure as much as one's impairments. She often wonders what a world without stairs would feel like.

Visit Hayley's business at https://www.imaginaryumbrella.com/home

Jeremy Kemp



Kia ora, my name is Jeremy. My pronouns are he/him. I have been diagnosed with ADHD, and have self-diagnosed as autistic.

I have two children. Corin, age 13, is diagnosed autistic. Ethan, age 9, is diagnosed autistic and ADHD. I work in tech, supporting digital preservation for the National Library of New Zealand.

I'd like to talk to my experience as an undiagnosed and completely unaware father-to-be through the process of planning the details of Corin's birth with their mum.

Rachel Noble, MNZM



Rachel Noble is the 3DHB General Manager Disability, Strategy, Planning and Performance.

Rachel and her Team work to promote inclusive and accessible healthcare services. Rachel is Deaf herself, and has a team of people who are equally passionate about promoting inclusive and accessible healthcare services so it is comfortable and safe for all people.

Rachel has been active across the Deaf and disability sector for many years as the Chief Executive and prior to held leadership roles within Deaf Education.

The fire in Rachel's belly was lit when working as a teacher with Deaf children and feeling frustrated about the inequities that existed which meant deaf

children were not achieving equally to hearing peers. From then, Rachel has strived to be part of creating an equitable environment through the lens of Deaf and Disabled people.

Jenifer M Parker



I (she/they, neuroqueer) am a gifted mother of one gifted child, born at home, and have also had one miscarriage without medical intervention. We are a gifted family -- my partner is also gifted, as are my parents, my sister, and my nephews.

My sister, partner, father and I were all diagnosed as children, while my mother was not. We are aware that we carry generational trauma from institutional abuse -- which is the methods and impact of practices for conformity as well as exclusion that happen in institutional settings.

I would like to offer my experience and insight into how institutional practices often unconsciously or even unintentionally exclude neurodivergent people so that we may be included and our needs met more effectively in institutional settings, including maternity healthcare.

Leslie Payton



I'm Leslie, an autistic/ADHD mother of two kids both diagnosed with ASD. Pronouns are very challenging for me because in my mind she is very concretely established but I have never identified myself with most things aligned with the female gender.

I had both births at home without intervention or drugs. I learned about my own neurodivergence when my children were diagnosed, similarly to many other parents. But looking back it's clear that my neurodivergence was the driving force behind my voracious information consumption around pregnancy and natural birth in particular.

Alice Richardson



My name is Alice Richardson (she/her) and I'm an autistic mama of a nearly 3-year old son. After my son's birth, ongoing struggles with my mental health, and looking for answers as to what was going on with me, I happened upon the autistic community.

I deeply related to their experiences and finally decided to pursue a diagnosis, which I got earlier this year at the age of 35.

There is much joy and peace that comes from knowing who you are, and it has made me more confident in my style of parenting. But unfortunately the world around us hasn't quite caught up with that and autistic people are still widely discriminated against.

I'm extremely passionate about helping shift society into being more accepting of us (or at least helping carve out more spaces where we are safe) and protecting future generations of autistic children from the trauma of growing up being shoehorned into a neurotypical ideal.

Bronwyn Rideout



Bronwyn Rideout, BA (Hons), MA, BMid. (She/Her), is the cochair of the Education and Research committee for the NZCOM Wellington branch. Bronwyn currently works as a core midwife at Capital and Coast DHB where she works through the Bureau and in the Staff COVID-19 Vaccination clinic.

She is also completing a Postgraduate diploma in Health (Midwifery Specialisation) at Victoria University.

Since receiving her diagnosis in 2019, Bronwyn has utilised her experience to direct her research interests and postgraduate study towards maternity experiences and outcomes for neurodivergent persons.

Rich Rowley

Picture and Bio to come

Rich Rowley is the Innovations Advisor for Tech Futures Lab. He is also part of the team at "Brain Badge", a New Zealand Certification programmes which aims to reduce un- and underemployment for neurodivergent persons by helping employers create inclusive environments.

Read about Brain badge here: https://www.brainbadge.org/

Jolene Stockman



Jolene Stockman, (Te Ātiawa) is an award-winning Taranaki author, speaker, and instructional designer. She is also tangata whaitakiwātanga, autistic. Since her TEDx Talk in 2018 going public with her adult diagnosis, Jolene has signed with the International Indigenous Speakers Bureau and worked with global giant IBM on their diversity and inclusion training.

Jolene is a member of the advisory panel for Altogether Autism, on the management committee for Autism Connex, and part of the team behind Autism Aotearoa. As a working, married, autistic with two children and a degree, Jolene inspires and surprises with her vision of the world.

Jolene's website: https://www.totalblueprint.com/

Amy Taylor



Amy Taylor, BA (Hons). (She/They) is a queer, neurodivergent LMC midwife working in the region of Te Awakairangi, Lower Hutt with a strong primary birth focus. Amy is an autistic ADHDer; identified and diagnosed later in life.

She has two children with autism and ADHD; the experience of navigating Aotearoa's maternity system as an undiagnosed pregnant person drives Amy's deep passion towards improving recognition and culturally competent care for the next neurodivergent generation.

Amy has a particular interest in the intersection between neurodivergence and the takatāpui/queer community. As an LMC midwife, she has experience in working with a variety of neurodivergent client's; providing continuity of care is an essential part of meeting the nuanced needs of their clients. Amy is working their way through a Postgraduate diploma in Midwifery at Otago Polytechnic.

Catherine Trezona



Catherine Trezona is the General Manager at Altogether Autism.

Catherine is charged with providing quality, evidence-based and timely information to autistic people and the professionals and family/whānau who support them. Catherine is responsible for both the strategic and operational management of Altogether Autism, which is delivered in partnership with Life Unlimited and Parent to Parent.

Catherine joined Altogether Autism as a researcher in 2014 after completing a Master's degree in health psychology, and moved into a managerial role in 2015. She is one of the programme developers and lead facilitators for our Professional Development

(formerly PRISM) series, our specialist autism workforce development series. She brings a passion and commitment to building community and is a strong advocate of seeking and supporting an authentic autistic voice to ensure Altogether Autism is built on the principle and practice of 'nothing about us without us.'

Altogether Autism Website: https://www.altogetherautism.org.nz/