THE TRANSITION TO PARENTHOOD – CARE-GIVING EXPERIENCES AND SUPPORT NEEDS OF NEURODIVERGENT PARENTS

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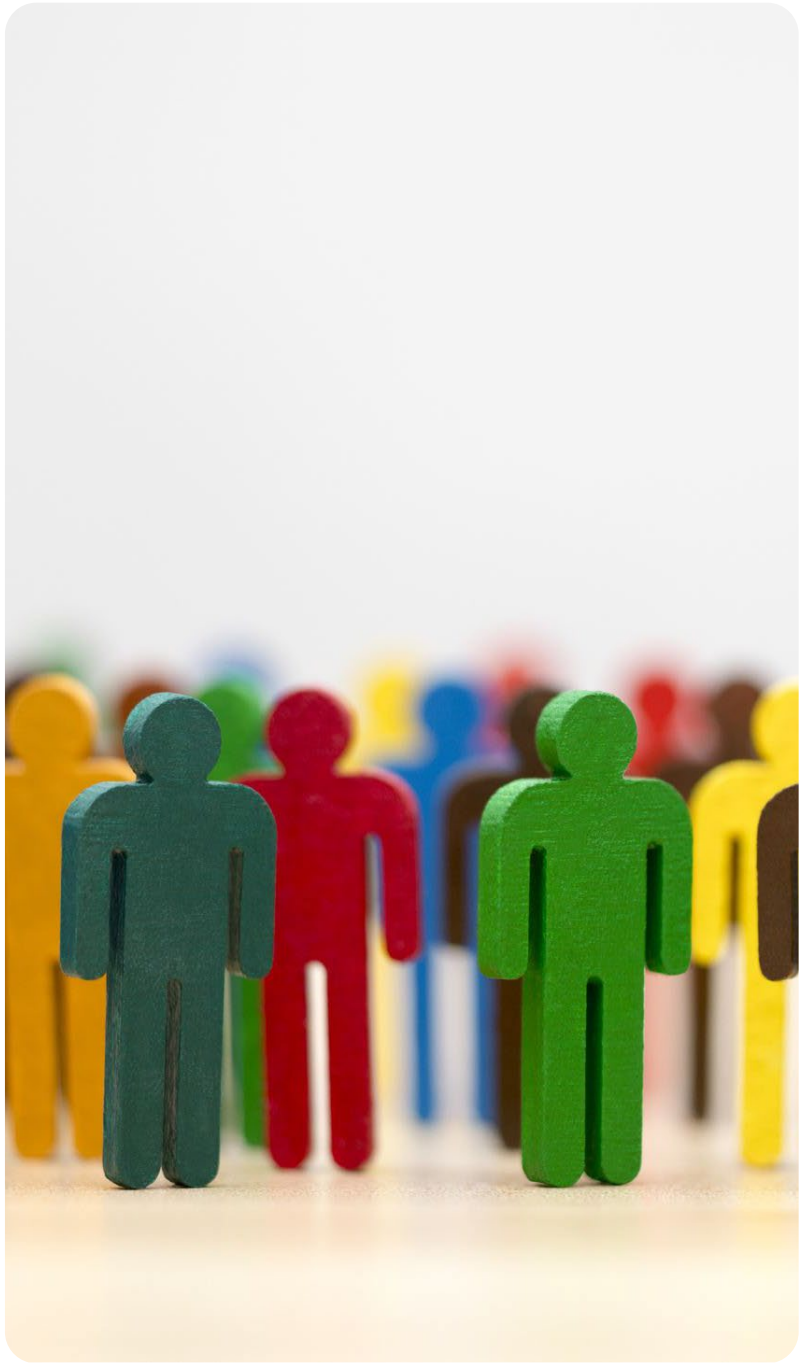
LA TROBE UNIVERSITY



A NOTE ABOUT LANGUAGE

Neurodiversity describes the full range of differences in human brain function and cognitive processes, and includes neurotypical people.

Neurodivergence refers to people with a range of conditions, with the most common being Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) (Legault et al., 2021).



A NOTE ABOUT LANGUAGE

In our discussion, we have used both person-first and identity-first language, as there is no consensus within neurodivergent communities regarding language preferences (Bottema-Beutel et al., 2021)

Our participants referred to themselves as “a person with autism” or an “autistic person”, so our discussion reflects their language.

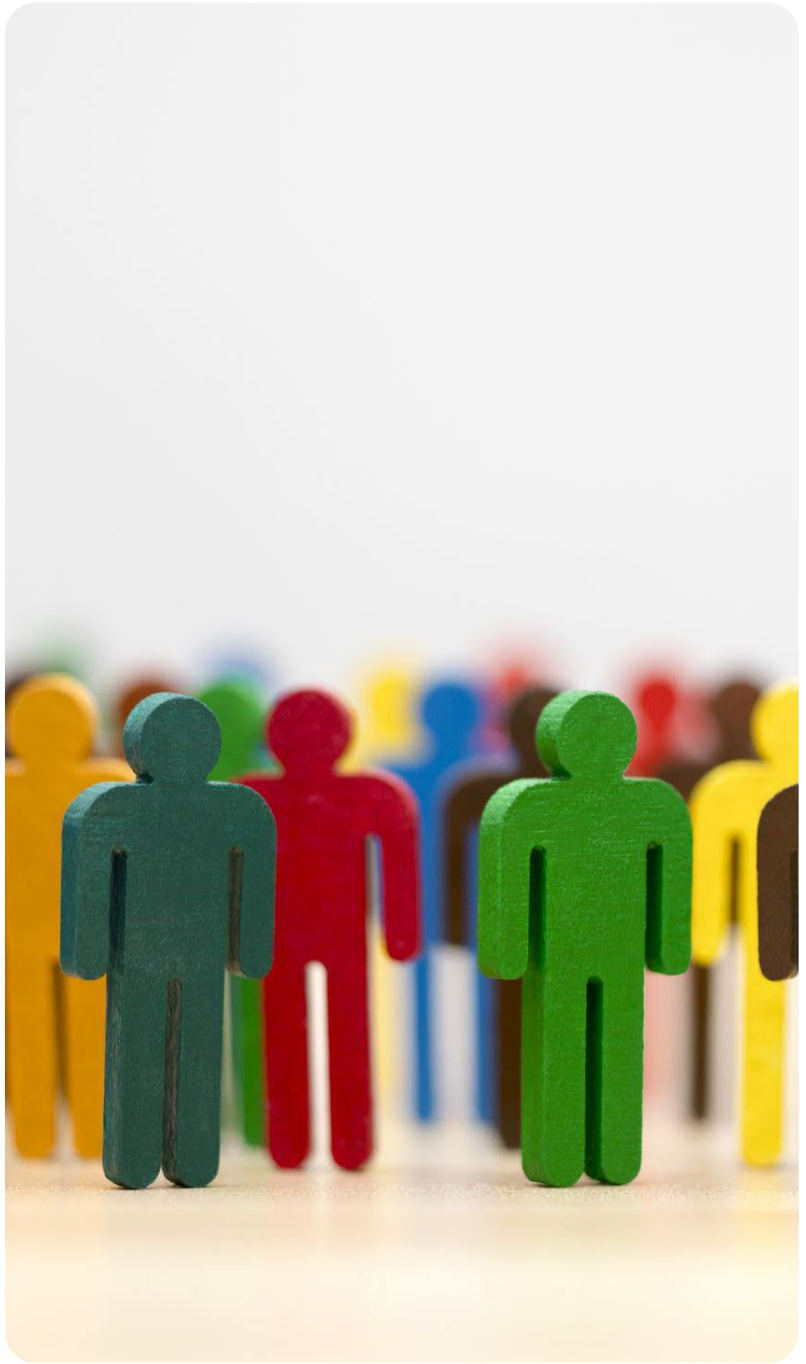


NEURODIVERGENCE

Diagnostic prevalence has increased over the last 20 years, due to a better recognition of ASD and ADHD in women (Russell et al., 2022; Elliott et al., 2024)

Diagnostic gender biases have historically led to underdiagnosis in females (Harmens et al., 2022; Petrolini et al., 2023).

Recent diagnostic trends also highlight an increased prevalence of neurodivergent presentations among individuals of childbearing age (Elliott et al., 2024).

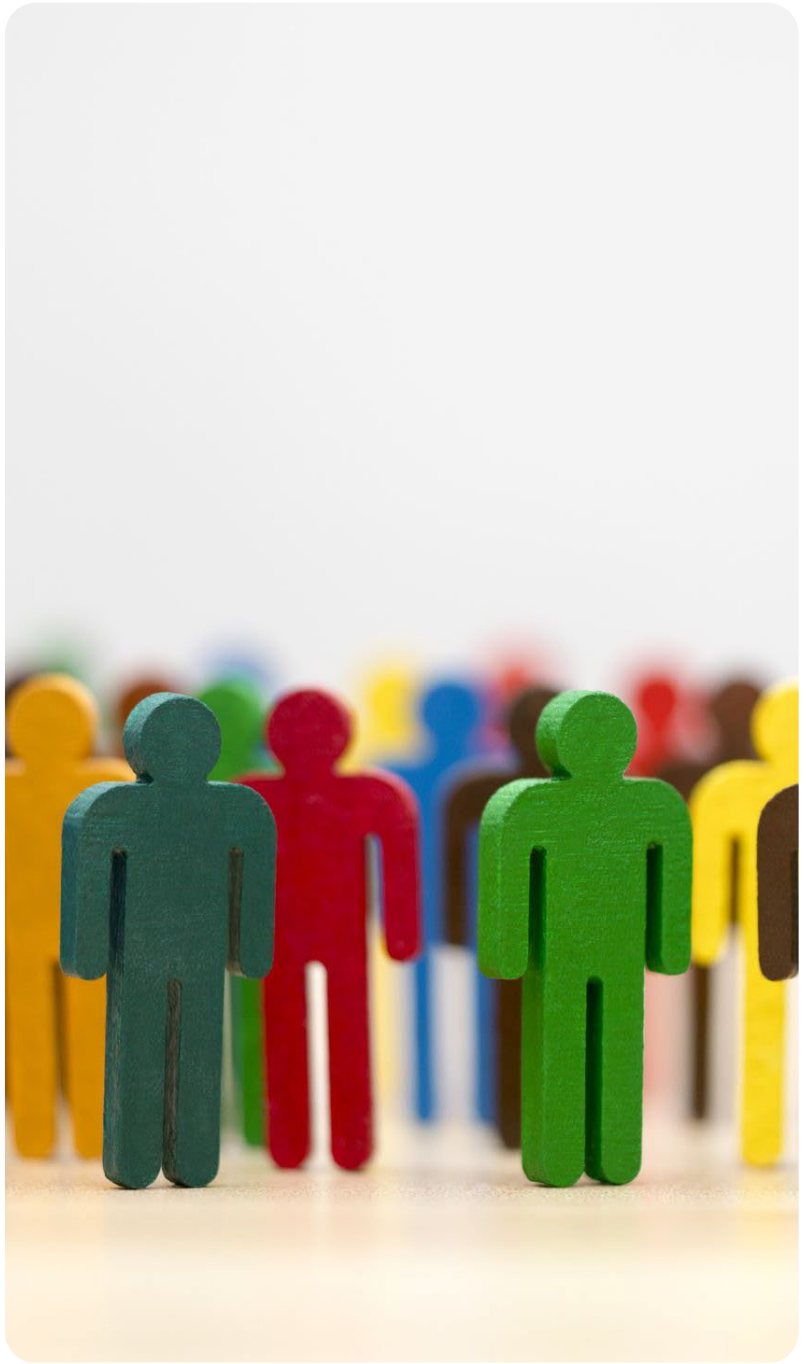


NEURODIVERGENCE

Many neurodivergent individuals experience challenges in navigating the complexities of the healthcare system.

Two Australian Senate inquiries have reviewed support services for people with ASD or ADHD, highlighting the need to address healthcare practitioners' skills and knowledge to improve support for neurodivergent people (Commonwealth of Australia, 2022, 2023).

Despite comprising a significant proportion of our community, little is known about the caregiving experiences of neurodivergent (autistic and/or ADHD) parents and their parenting support needs.



OUR STUDY

We aimed to identify the strengths and challenges faced by neurodivergent parents (with autism and/or ADHD) in their transition to parenting.

Our project uses a co-created qualitative approach to learn from neurodivergent individuals about the support needed around the transition to parenting.

The study is a collaboration between neurodivergent parents, child and family health nurses, and academic researchers.



CONCLUSIONS

Our findings identified major challenges in the transition to parenting:

- heightened sensory sensitivities that can make everyday tasks more difficult.
- overload from routine activities, which can lead to significant stress and anxiety,
- not able to access the usual strategies for self-soothing, reducing stimuli (headphones, etc) while still having responsibility for an infant/child



CONCLUSIONS

However, the parents in our study emphasised the resilience, adaptability, and strong emotional ties within neurodivergent families.

- They believe they have a better understanding of their child’s needs.
- They are more attuned to their child and better able to empathise with their autistic child(ren) because they are also autistic
- the parents' role as advocate for their child.



RECOMMENDATIONS

- Parents called for neuroaffirming health practices and settings, recognising the increased knowledge and skills healthcare practitioners need to provide effective support.

- Supporting neurodivergent parents requires an understanding of autism and other neurodivergent traits, and inherent communication patterns and behavioural characteristics.



RECOMMENDATIONS

- Well-educated health care professionals may help reduce stigma by understanding communication and sensory needs

- Inclusive policies and neurodiversity-affirming approaches must shift the burden from individuals “fitting in” to systems designed to meet neurodivergent needs.



OUR STUDY

Twenty-three neurodivergent parents explored their experiences of parenting infants and children, identifying the support that would have assisted them in their transition to parenting.



DEMOGRAPHICS

Twenty-three participants (fifteen metro and 5 rural)

All assigned female at birth, one identified as non-binary.

All late-diagnosed – between the ages of 28 and 50 (majority in their mid-30s)

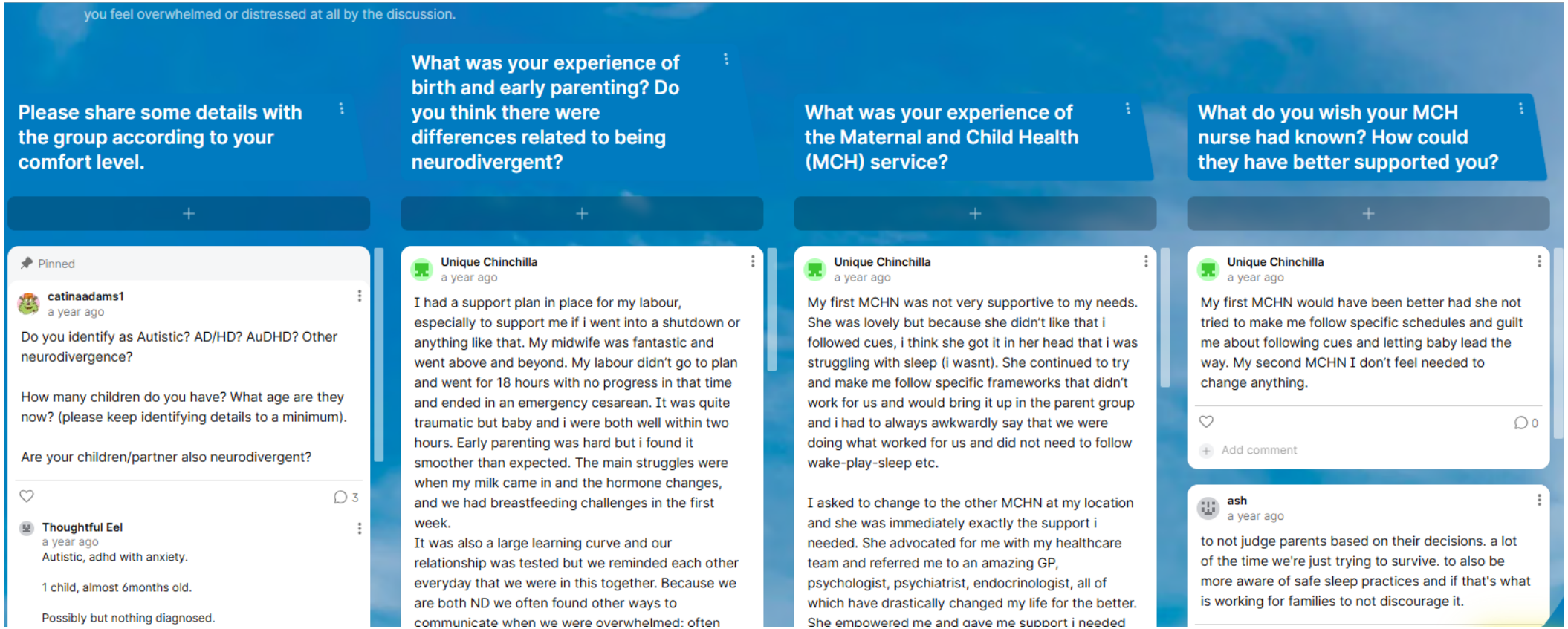
Often diagnosed when their children were diagnosed with ASD and/or ADHD

17 – diagnosed AuDHD
4 – ADHD
2 – Autistic



OUR STUDY

We conducted online group interviews using Padlet. This platform allows participants to consider and review their responses and interact with other participants. Data were analysed using thematic analysis.

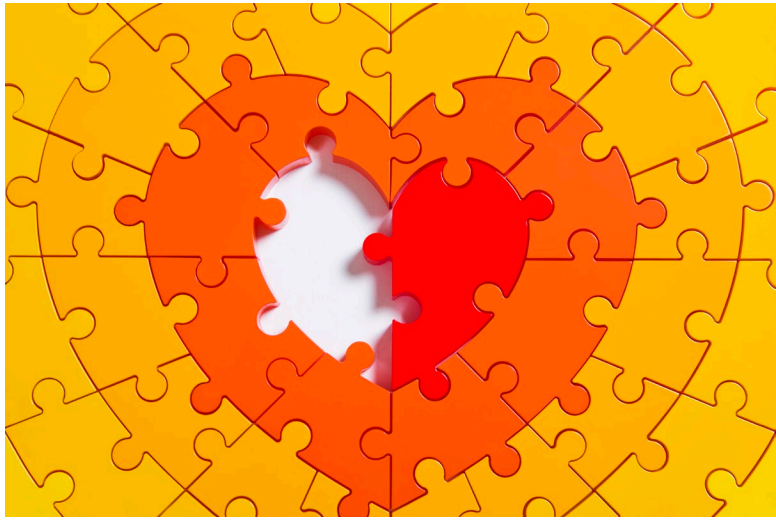


THEMES


Missed or misdiagnosis
Neurodivergent identity
Challenges
Strengths

MISSED OR MISDIAGNOSED

- The impact has been huge in understanding and making sense of myself, my kids, and the way I experience life and parenting. It gave me a deeper feeling of connection to my kids.
- Infuriating, heartbreaking, invalidating. I am the only diagnosed ND in my immediate family, but they're obviously incredibly ND themselves. They have zero curiosity, only judgment.
- I was diagnosed with postpartum depression, but I remember not finding psychology helpful as I didn't know what to talk about; I just wanted a break from it all and would fantasise about getting COVID, so I would have to isolate.
- I didn’t know I was neurodivergent at the time, so I had no self-compassion



NEURODIVERGENT IDENTITY

- Within my home, it gave me a deeper feeling of connection to my kids and a way to communicate with my partner and explain why I react in certain ways
- I am proud of my neurodivergence; I want my kids to see it as simply a difference, not better, not worse.
- Overall, receiving a “diagnosis” has been a helpful and enabling thing for me. I never ‘sought out’ a diagnosis. It was my GP who broached the idea with me in a gentle, curious way. Despite initial pushback (from entrenched internalised ableism), I have only benefited from embracing my neurodivergent identity.



CHALLENGES

- Managing meltdowns when I am overstimulated.
- Dealing with noise coming from everywhere (exhaust fan, TV, child talking, partner talking at the same time)
- Being there for my child when my cup is empty.
- All anyone saw was a baby that grew and was appropriately dressed for the weather. I have no idea how we made it through.
- I remember a couple of occasions where it took everything I had to not completely lose it when both children were crying/unconsolable. It required so much self regulation, which is so challenging when at your limit/so sleep-deprived.



STRENGTHS

- My itchy brain that craves answers to so many questions! I look up almost every random question that flits through my mind. I fall down fascinating rabbit-holes and learn about so many things that end up being relevant.
- The kids find my manic energy fun. I answer all their questions with detail and we research together if I don’t know the answer, so I mirror their curiosity.
- I am incredibly resilient and am hopefully teaching that to my kids



STRENGTHS

- I feel like I am raising my son in the most neuro-affirming way that I can and I try to model not only a neuro-affirming approach but I try my best to be a role model of good self-care, boundaries and self-advocacy. I believe I bring a unique way of thinking, good problem-solving skills and lots of empathy to my parenting.
- Curiosity. Empathy. Kindness. Authenticity. Openness. Understanding my ND child. Advocacy. Passion. Hyperfocus. Creative. Strong sense of social justice. Fierce. Loving.



WHAT I WISH MY CHILD AND FAMILY HEALTH NURSE HAD KNOWN....

- I wish my nurse had known how deeply I was suffering and how great my fear was. I wish they knew how little sleep I was really getting, and that they would have sent me to an MBU. I don't know what they could have done differently because I probably seemed fine, but I wasn’t.
- Health professionals who work in the perinatal space need to have a much better understanding of how undiagnosed neurodivergence is expressed, especially in women



WHAT I WISH MY CHILD AND FAMILY HEALTH NURSE HAD KNOWN....

- Looking back, I would have benefited from some support around what “good enough” parenting means/looks like.
- Better education and support regarding emotional regulation and emotional dysfunction.
- Knowledge of how to support families experiencing fight, flight, freeze, and fawn responses.



NEXT STEPS

In Phase 2 of the project, we will conduct MCH nurse, key stakeholder, and parent focus groups to discuss and identify nursing education approaches, co-designed learning resources, and parenting support tools for parents and nurses.



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