

SUBMISSION TO THE DEVELOPMENT OF THE NATIONAL AUTISM STRATEGY

I am the mother of a 14 year old who was identified as autistic earlier this year. Our path has been rocky and has involved years of school refusal, loneliness, exclusion, rejection and stress. Over the last twelve months I have recognized signs of autism in myself, as I reflected on my own experience growing up and across my lifespan. I am now 50 years old and am sadly coming to realise how much of my life has been wasted because I didn't know about my neurodivergence and autistic nature.

I know the discussion paper posed some very targeted questions and these are good, but I was hoping you would consider this submission as a heartfelt request for change for autistic people, particularly girls and women who have gone un-identified and unsupported for most of their lives – whether they are 15 or 50.

1. **Language matters.** I would welcome the use of terms that no longer refer to autism as a disorder. I am not disordered, though I am different. Words like disorder, symptoms, deficit are common in much of the medical and health community. Autism does not require treatment, though there are so many things that can help autistic people move through the world more easily. Language, and not feeling as though we are inherently broken in some way, is important.

Suggestion for the strategy: improve education for health care providers especially general practitioners, nurses and hospital-based clinicians on the reality of autism as a neurodevelopment difference not a deficit, disorder or illness.

2. **Improve the early identification of autism in girls and gender-diverse young people.** When my now-teen was around three years old, her long day care centre staff noticed she engaged more in parallel play than cooperative play as might be expected of kids her age. They arranged for an early intervention service to provide some play therapy with her. I did not understand at the time that this may have been an early marker for autism, and because everyone told me how bright she was I was unaware that there might be value in looking a little more closely at her social engagement approach. Teachers in primary school told me she was bright and well behaved, and liked to understand the reason for instructions. Again, I did not have the knowledge that this need to understand and the constant questioning of instructions may be in a marker for autism. She was never invited to classmates parties – once, a family held a joint birthday party for their three young kids, inviting every child in the three classes. Except my child. Struggles through primary school ensued and now we have a teen who has no friends, has only been identified as autistic for less than a year and is not currently attending school.

Suggestion for the strategy: Early screening for nuanced or internalized presentation of autism in pre-school or primary school might be valuable, but the research shows that autism in girls is frequently well-hidden until the social complexities of teen relationships, and the organizational and sensory demands of high school, outstrip their coping abilities. I would love to see a better strategy for identifying girls around year 7, which is when my daughter really began to struggle and, looking back, I did too.

3. **Meet the needs of unidentified autistic adults because we are struggling.** We need to address the assessment and identification of a lost generation of autistic women, gender-

diverse, and internally-presenting men who are autistic but who didn't meet the rigid diagnostic criteria of the 80s, 90s and early 2000s. We have made it through to adulthood, though we have lost many along the way to suicide, eating disorders, drug and alcohol addiction as we have tried and failed to fit into the roles and identities society offered us. I am, by all external accounts, a successful person: a good career, a marriage, a child, a nice home to live in. But I suffer every day: I can no longer work as an employee and have to work freelance for the flexibility I need. My marriage is suffering because I still don't truly understand who I am or where I came from, and because we are raising an autistic child and have been without support for 14 years. I can't keep my home tidy or clean because my executive functioning capabilities are compromised. There is no support for me because I am, to all outward appearances, highly functioning. I have also been medicated for chronic depression and anxiety for thirty years, have been self-funding psychological support for twenty years, have experienced several episodes of severe burnout and increasingly find myself looking for ways out, happily anticipating an end to life. I don't wish to hasten it, but I won't grieve when it comes.

Suggestion for the strategy: make assessment and post-assessment support accessible for adults who suspect they may be autistic. It currently costs \$2500 for an autism assessment. In the last eighteen months, we have paid nearly \$7,500 for assessments and tests for our daughter. My husband suspects he too is autistic. Assessment and answers are beyond our financial means...but an assessment might provide life-changing and life-saving answers for us.

- 4. Require an autism lens in government.** I believe SA is the only state with an Office for Autism. Every single state government should have an Office for Autism and Neurodivergence.

Suggestion for the strategy: An Office for Autism and NeuroHealth, educational, public safety and community services policies should be reviewed and informed by experts in autism and neurodivergence. Government services should be rethought, to provide different options for engagement including accessible communication options, quiet hours for face-to-face service provision, autism-aware and informed driving assessors, and so on.

- 5. Rethink education.** We need teachers who understand and can teach to neurodivergent kids and adults. We need a school system that prioritizes psychological safety. This is an incredibly big ask but it is achievable. My daughter was diagnosed with ADHD and Autism. She was unable to complete a day at school. The school advised me they were unable to support her, and would be lucky to get an hour a day SLSO support approved for her. The one autism class at her high school was already over—subscribed. She missed six months of schooling, and has been in distance education since June. I had to leave my job (ironically, I worked for the state education department) to support her education. She has now been diagnosed with a congenital heart condition and can no longer take ADHD meds...meaning she is unable to focus and attend to her studies. We have no support. She is not learning. She has no social connections. She is at risk of self-harm.

Suggestion for the strategy: Require state education authorities to provide sufficient school learning support officers, autism-specific classes, inclusive environments and educational practices. Link this to funding. Integrate support to families dealing with complex cases so that education, health and NDIS support are all working towards the best interest of the

child. At the bare minimum, require the provision of alternative pathway schools such as the Big Picture Program in every educational region so that parents everywhere can choose welcoming, safe and bullying-free environments for their autistic kids.

Thank you for the opportunity to contribute. I am hopeful that the strategy will change the landscape for people with autism in Australia, but my experience cautions me to manage my expectations. Best of luck with the development of the strategy.