

[REDACTED]

**Attn: Autism Policy**

Department of Social Services  
GPO Box 9820  
Canberra, ACT 2601

**Re: National Autism Strategy**

**Sent by email:** [AutismPolicy@dss.gov.au](mailto:AutismPolicy@dss.gov.au)

To the Department of Social Services.

My name is [REDACTED] and I am writing in response to the national consultation on the development of the National Autism Strategy (NAS).

[REDACTED]

[REDACTED]

**1. What does a National Autism Strategy need to achieve?**

*A successful and fully implemented NAS should ensure that Autistic people of all ages, genders and cultural backgrounds can fully and equally participate in all areas of life, free from all forms of violence, abuse and discrimination.*

As an Autistic, disabled woman, I have experienced multiple and ongoing forms of bullying, violence, abuse and discrimination, including from family members, educators, employers, service providers, medical professionals and the community at large.

As a baby I didn't cry much. I was slow to speak, hard to toilet train and didn't walk until I was more than 18 months old. I was behind many other children in developmental milestones, but, likely due to a lack of understanding of and knowledge about Autism in girls, was never identified as being neurodivergent .

At school, I experienced bullying and misunderstanding from other students, teachers and parents. While academically, I was an average student, I always struggled socially and had severe deficiencies in spatial

[REDACTED]

abilities. I experienced debilitating situational mutism for most of my childhood, which was labelled as extreme shyness. Among other children and adults, I was pressured to assimilate through verbal communication and physical play. I was told I was rude or weird for not responding when others talked to me and offered zero supports or accommodations.

While others kids were playing sport or running in the playground, I preferred to get lost in books or video games. I would delve into specific subjects I was interested in and spend hours learning everything I could about them. While I saw boys (who may or may not have been Autistic) around my age do these things freely, I was treated differently. Other students often teased me and called weird for not being interested in dolls and not wanting to play make believe families with the other girls.

When given instructions or information, I took everything literally. When I was in early primary school, I remember getting in trouble for breaking rules I didn't know existed at school. My mum went in to meet with the teacher and told me to sit on a seat outside and "not move." During the meeting, I desperately needed to go to the toilet, but I knew I was told not to move. When my mum came out of the meeting, I had wet myself and I got in trouble for doing so. I was extremely confused as I had done exactly as she had told me to.

By the time I was in high school, I had learned to assimilate to the extent that I rarely got in trouble. However, my black and white, literal thinking still greatly impacted me. When I was in year nine for example, I was given the task of doing a presentation on teenage pregnancy. Taking this entirely literally, I did a presentation on all the options available to pregnant teenager, including parenthood, adoption and termination. What I did not consider was that my school was extremely religious. Again, I in this instance, suffered the consequences of being Autistic.

As an adult, I have continued to experience discrimination on the basis of my Autism.

In higher education, I have been called out and humiliated for fidgeting, stimming or not making eye contact in tutorials and lectures, despite being an average High Distinction student. In workplaces, I have been bullied by other staff and reprimanded by employers for not being chatty and making small talk. During my university studies, I worked in hospitality. I was often excluded from staff gatherings and lost shifts during popular times because of the 'impression' I had on customers.

Through my career in politics and the non-government sector, I have had to leave workplaces because of bullying from other staff and employers and inaccessible, open plan offices. I have been discriminated against, harassed and ostracised because I have called out *events* which I have seen as incongruent with organisation ethos; and have been denied basic leave entitlements.

In healthcare settings, I have had had severe chronic illness and autoimmune conditions overlooked because I have been unable to explain my symptoms in ways that are expected. I have experienced

restraint and violence in hospital settings and have been gaslit and labelled with incorrect psychosocial conditions by medical professions.

While I could continue to write about my experiences for 1000 pages, the common thread throughout all of them is that I have faced a lifetime of misunderstanding bullying, discrimination and exclusion purely as a result of being an Autistic woman. Like me, what many Autistic people need is a strategy that empowers us to realise our full and equal range of human rights, as individuals. That accepts us for, embraces and accommodates our differences and does not force us to assimilate to world that is built for the neurotypical.

## **2. How can the National Autism Strategy support the rights, autonomy and diversity of the Autistic community?**

*Positive discrimination requirements on government entities, workplaces, education institutions and the community sector*

As an Autistic disabled person, I have often felt like the onus to have my rights realised is on me. Due to a widespread and systemic failure of governments, institutions, workplaces, education systems, medical facilities and society broadly to recognise and accommodate for Autistic people, and in particular Autistic girls and women, having my needs met has always felt like an uphill battle, rather than a right that is respected.

In line with Recommendation 4.26 in the recent report published by the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, I strongly urge that, in order to realise the rights of Autistic people, the Federal Government should amend the *Disability Discrimination Act (DDA)* to impose a positive duty on government entities, education institutions, employers and services to:

- (a) make adjustments to accommodate people with disability, including Autistic people
- (b) take steps to eliminate discrimination on the grounds of disability, including being Autistic.

The National Autism Strategy, and its subsequent implementation could also have a key role to play in how these positive duties are applied for Autistic people. One way this could be done could be through the implementation of a set of **national accessibility standards for Autistic and neurodivergent people**.

*A requirement for government entities at all levels to work in co-design and co-development with Autistic people on all policies and programs for and about the Autistic community*

Incorporating Autistic voices and perspectives into the design and development of programs, services, and policies is not just a matter of inclusivity but also of effectiveness, ethics, and respect for the dignity and autonomy of autistic individuals. It fosters a more equitable and understanding society for Autistic people, gives us employment opportunities and ensures that services and programs that are designed for us

support our agency and autonomy, rather than infantilising us like we are children or burdens on parents, carers and services.

#### *Adequately and sustainably resourced organisations run by and for Autistic people*

Too often, organisations that 'represent' Autistic people are run and led by parents, carers and professionals who are not Autistic themselves and lack understanding of the specific needs and experiences of Autistic people. While these individuals likely mean well, the reality of this lack of representation is that the organisations that are meant to advocate for us reinforce infantilising and disempowering stereotypes about our community and provide services, programs and supports in ways that are incongruent with our needs or experiences.

Even as a vocal and rights based human rights advocate, I myself have experience ableism and infantilising attitudes from 'Autism' organisations and have had my views and recommendations ignored in systemic advocacy efforts, in favour of those of parents and carers, who are agreeable with the organisation.

In order to ensure Autistic people are empowered to have our voices heard, are given opportunities for employment and economic empowerment and can access programs that are tailored to our needs and experiences, governments must invest in organisations that are run and governed by and for Autistic people.

### **3. What needs to improve so Autistic people are better supported across their whole life?**

#### *Early, timely and accessible diagnosis*

Early, timely and accessible diagnostic processes are critical for ensuring that Autistic people, our families and carers receive the support and resources we need as early as possible, including access to support programs such as the NDIS, as well as well as education and information to promote better acceptance and understanding within families, education and more broadly.

While, as an Autistic woman, I have been Autistic all of my life, a lack of knowledge about Autism, and how it presents in women and girls, within my family, the healthcare system and the community, combined with other factors such as a lack of accessible diagnostic services prevented me from accessing a diagnosis and in turn, appropriate supports and services until I self-referred myself to a diagnostic service at the age of 27.

#### *Promoting understanding and acceptance, not pathology*

While receiving a diagnosis at age 27 has allowed me to gain a better understanding of myself, my needs and experiences, three years later, I am still hesitant to disclose I am Autistic to employers, professionals,

organisations, services and even family members, due to the repercussions associated with Autism being viewed as a deficit.

Due to ableist attitudes and the dominance of the Medical Model in healthcare and diagnostic services, and in understandings of what constitutes Autism more broadly, Autism is still considered a disease or deficiency in individuals, rather than a neurological difference that can come with unique and positive strengths and differences.

In line with Medical Model logic, many researchers and clinicians who advocate for early intervention and diagnosis are doing so from the perspective that Autism can or should be cured or prevented, rather than from a place of acknowledging that Autism is an unchangeable and inherent neurological difference that should be supported and accepted

More and more, we are seeing this false idea of prevention creep into funding, research, children's programs and even pre-natal screening, and entrench ableism into service implementation.

Approximately a year after I received my Autism diagnosis, I fell pregnant with my first child and accessed pre-natal services through the public health system [REDACTED]. While I knew that many aspects of the 'support' I was receiving (or not receiving) was not accessible to me or responsive to my needs as an Autistic individual, I was too scared to disclose my Autism out of fear that I may be judged, discriminated against or even have my growing baby screened for neurodevelopmental conditions.

In order to avoid Autistic people continuing to receive discriminatory and ableist treatment, the National Autism Strategy should pave the way for a society which is informed by the Human Rights Models of Disability, which pivots disability as being a natural part of human diversity, not a disease or deficit to be addressed.<sup>1</sup>

#### **Q 4 What can be done to better support Autistic people from different population groups**

*Ensuring that diagnostic services are accessible, affordable, gender responsive and culturally appropriate.*

There is evidence to suggest that autism diagnosis rates are lower among certain populations due to bias in diagnostic processes and in healthcare. As discussed above, I, like many other Autistic women and girls, have experienced the direct impact of the gender bias that is inherent in the healthcare system.

Additionally, once I did identify as an adult that I was likely Autistic, my diagnosis was delayed for over a year due to the extremely high cost and long wait lists associated with accessing a diagnosis. [REDACTED], where I reside, there are very few diagnostic services available, and those that do exist either do not cater

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<sup>1</sup> See for example: Disability Advocacy Resource Unit (2019) '**Introducing the human rights model of disability,**' Viewed 25 October 2023 <<https://www.daru.org.au/how-we-talk-about-disability-matters/introducing-the-human-rights-model-of-disability>>.

for adults or have extremely long waiting lists. For this reason, I chose to access a diagnostic assessment through an online telehealth provider based ( [REDACTED] ), but was further disincentivised by the assessment cost which was nearly \$2000 Aus. While Medicare rebates are available for children and young people for diagnostic services, the Medicare Benefits Schedule (MBS) as it currently stands, caps this at age 25.<sup>2</sup> I first identified that I might be Autistic at age 26.

While I have not experienced them directly, I am also aware that there are a number of cultural and language barriers which prevent specific populations of Autistic people from accessing diagnoses, healthcare and supports.

*Services that are accessible, trauma informed, culturally responsive, rights based and person-centred.*

Services that are accessible, trauma informed, culturally responsive ensure that all individuals, have equal access to the support they need. This promotes inclusivity and reduces disparities in care, which is essential for the Autistic community who face a number of barriers based on factors such as cost, geographical location, sensory sensitivities, ableist attitudes and more.

As an Autistic person with multiple chronic health conditions and psychosocial disabilities, I have often avoided seeking care or support until my conditions become acute or severe due to the inaccessibility of medical services, hospital wards and emergency departments. On multiple occasions, I have experienced severe symptoms such as chest tightness, fainting or unbearable pain but not sought help or called an ambulance due to my fear of the sensory inaccessibility of emergency departments and the hospital system.

Additionally, I have the added barrier of having a history of trauma associated with being mistreated as an eating disorder inpatient when I was a teenager. In what was my first ever hospital admission at the age of 15, I was subject to an inhumane, disempowering and traumatic treatment regime which involved a number of violations of my rights and freedoms. In this admission, I was for example, physically restrained to the space of a hospital bed in a room of other patients, force fed foods I had aversions to, denied access to visitors, presents and letters without them first being vetted, and watched 24/7, including while I used the shower and toilet.

Despite being Autistic and displaying a number of, what I now know were quite obvious Autistic traits, my personal needs were given no consideration in the 'treatment' I received, and no one ever questioned that I might be neurodivergent.

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<sup>2</sup> See: Services Australia (2023) 'Medicare items for Complex Neurodevelopmental Disorders and eligible disabilities,' Australian Government, Viewed 25 October 2023 < <https://www.servicesaustralia.gov.au/medicare-items-for-complex-neurodevelopmental-disorders-and-eligible-disabilities>>.

As a result of this abject failure to meet my needs or work with me to identify what supports might be helpful, the system not only prolonged my symptoms, but also resulted in me developing a number of secondary chronic illnesses and disabilities, including physical conditions such as food intolerances, and Osteoporosis as well as psychological conditions such as Anxiety, Obsessive-Compulsive Disorder (OCD) and post traumatic medical trauma.

#### *Services and professionals that are trained to identify signs of neurodivergence*

In order to ensure that Autistic people, including children and young people can access appropriate supports, services and accommodations, it is important to ensure that there is the expertise among professionals to identify signs of neurodivergence.

While prior to my diagnosis, I had accessed more than a decade of regular services, including through General Practitioner's, gastroenterologists, endocrinologists, psychologists, psychiatrists, allergists and mental health support groups, all for conditions which are common among Autistic people, not one service, clinician or person ever identified or even questioned that I might be Autistic.

#### **5. What might help to improve people's understanding of Autism?**

Having done research and evaluation of programs aimed at attitude change and prevention, I am aware that the most successful approaches are multi-faceted or aimed at multiple levels, including at the individual or community level, at the service or organisation level and at the legislative or policy level. In order to answer this question adequately, I have provided recommendations for the strategy as a whole at the end of this paper, which include the following three sections:

- (a) Strengthening the rights of Autistic people through policy and legislation
- (b) Improving the capacity and capability of healthcare systems, services and community sector to understand and respond to the needs of Autistic people, deliver supports and services to Autistic people in ways that are accessible, trauma informed, gender and culturally responsive, rights based and person centred.
- (c) Platforming Autistic voices and improving community attitudes towards Autistic people.

#### **6. Is there anything else you would like to tell us?**

It is essential to recognise that the disadvantage that impacts Autistic people is entrenched in society, in institutions, in attitudes and in legislation. Many of us have experienced a lifetime of misunderstanding and discrimination and many Autistic people, especially those of us who are women, girls, gender diverse, culturally and linguistically diverse and First Nations, do not even know that they are Autistic. Addressing all of the issues that impact Autistic people requires significant systemic and structural change; which cannot be achieved in a vacuum or through the implementation of one government strategy. I see this NAS as only the beginning and like to think that it will progress in a similar fashion to other strategies, such

as the National Plan to Reduce Violence Against Women. That is, through multiple phases and action plans and editions. Like the National Strategy to Reduce Violence Against Women, the NAS will need to be accompanied by state and territory strategies, be applied in different ways in different geographical locations and for different intersectional cohorts and be evaluated through a rigorous monitoring and evaluation process.

## 7. Recommendations

In order to improve the experiences and life outcomes of Autistic people and ensure Autistic people are empowered to realise their full range of human rights, on an equal basis the Federal Government, through the National Autism Strategy, the Australian Disability Strategy and other relevant frameworks must:

- (a) Strengthen the rights of Autistic people through policy and legislation. Including by:
  - i. Implementing all of the recommendations from the Disability Royal Commission which pertain to the *DDA*, including introducing positive duty requirements on government entities, business and the community sector to prevent discrimination.
  - ii. In line with the recommendations from the Disability Royal Commission, introduce a Federal *Disability Rights Act* to complement the *DDA*, which....
  - iii. Introducing and fully fund a national supported decision-making framework which empowers Autistic people to make informed decisions about all areas of their life.
  - iv. Introducing nationally binding legislation which prohibits the use of all restrictive practices which constitute violence under the *UNCRPD* and other international human rights instruments, across all states and territories
  - v. Appointing a Federal Assistant Minister for Autism that has responsibility to operationalise and implement the National Autism Strategy, in collaboration with Autistic people.
  - vi. Working in co-production with Autistic people, develop national accessibility guidelines that inform government entities, business and non-government organisations on how to ensure that are accessible to Autistic and neurodivergent people.
  - vii. Working with state and territory governments to fund and develop and implement an Autism Strategy in all States and Territories.
  - viii. Introducing an Federal *Autism Act* which enshrines the National Autism Strategy and its implementation into Federal legislation.
  - ix. Implementing, as part of the Autism Act, clear NAS accountability measures, including:
    - clear and measurable actions, targets and milestones;
    - an implementation plan with clearly defined responsibilities;
    - continuous monitoring and annual reporting requirements; and



evaluation reports through re-engagement with the Autistic and autism community no less than every 3 years.

- built in timelines for review and renewal of the strategy (every 5 years), based on the aforementioned monitoring and re-engagement process, and with the support of a majority-led Autistic and autism community oversight council
- a dedicated, independent, Autistic-led taskforce to oversee progress on implementation KPIs on the local, state/territory, and national level.

(b) Improve the capacity and capability of healthcare systems, organisations, services and community sector to understand and respond to the needs of Autistic people in ways that are accessible, neuro-affirming, trauma informed, gender and culturally responsive, rights based and person centred. This should include through:

- i. Working in co-production with Autistic people develop and implement a nationally accredited, mandatory training program that educates workers in the Autism, disability and broader support and care sector on the Social Model of Disability and how to provide support in ways that are accessible, neuro-affirming, trauma informed, gender and culturally responsive, rights based and person centred.
- ii. Providing training for early childhood educators, teachers, healthcare workers and other professionals who have contact with children and young people who have disabilities or conditions which are common among Autistic individuals to identify signs of and screen for neurodivergence. This should include but not be limited to professionals who work with children and young people who have or display signs of ADHD, developmental delay, sensory sensitivities, chronic pain, gastrointestinal conditions and eating disorders.
- iii. Requiring all services and organisations that work with Autistic people to have Neurodiversity inclusive Disability Inclusion Action Plan's (DIAP's) as internal mechanisms to drive, monitor and evaluate the inclusion of Autistic people within organisations.
- iv. Working in co-production with Autistic people, develop and implement a national program to upskill and build the capacity of workplaces, employers and professionals to support and cater to the needs of Autistic people, from all intersectional backgrounds in levels of employment.
- v. Working in co-production with Autistic students, develop and implement a national program to upskill and build the capacity of mainstream education institutions, educators and frontline professionals to support and cater to the needs of Autistic students in mainstream education.

(c) Platform Autistic voices and improve community attitudes towards Autistic people. Including by:

- i. Committing adequate, ongoing and sustainable funding to at least one non-profit advocacy organisation in each state, territory and region that is led by and for Autistic people.
- ii. Ensuring that any government policy, strategy or framework regarding Autistic Australians is led by and co-developed with Autistic people, their families, carers and representatives.
- iii. Working with national media incorporations such as the ABC, Invest in initiatives which platform the experiences, stories and leadership of Autistic people from all intersectional backgrounds and with a diverse range of experiences.
- iv. Working in co-production with Autistic people design, develop and implement targeted education and campaign initiatives that:
  - raise awareness about Autism, our experiences, strengths and support needs
  - challenge ableist attitudes about Autistic people
  - include, promote and platform real stories told about and by Autistic people
  - showcase best practice examples of how to support, include and accommodate for Autistic people.

Thank you for taking the time to consider this personal submission. While I do not believe that this paper is at all comprehensive of the full diversity of the Autistic experience, I have attempted to use this opportunity to highlight some key areas that need to change through my own lived experience as an Autistic individual.

