

Dear

Member of National Autism strategy committee

My name is Eibhlis Norton and the following statements you're about to read are the challenges and experiences that I have been facing for the last 18

years and continue to face with the diagnosis autism spectrum disorder

My hope is whilst you are reading these statements you will actually take them seriously and not just ignore them as people have done so many times before

### **What does a National Autism Strategy need to achieve?**

When answering this question, you might like to consider:

- What outcomes would you most like to see from a National Autism Strategy?
- What are your priorities for a National Autism Strategy

It is important that the strategy recognises that by using the term "autism" rather than autism spectrum disorder it is reinforcing a false assumption that autism is the same for every single person. It hides the fact that people with autism fall on a spectrum or continuum and that they don't always neatly fit into the three defined levels used for diagnostic purposes. This means that no two people with autism are the same. Each person needs to be treated as the individual they are, and not just a representation based on a predefined level determining how "autistic" they are. Even just having health professionals acknowledging that having autism does not mean that you have an intellectual deficiency would be an amazing start. Difference is just that - difference. It does not mean deficiency.

I would also like to see better flexibility in and expansion of the current levels for ASD. ASD is a spectrum so trying to box people into three levels is senseless. The end point for many is square pegs in round holes. You can have a high IQ but behavioural issues and high social anxiety meaning you need significant levels of support at least for a while to enable you to better self-regulate and learn strategies to function independently. Others may have a high IQ but no behavioural issues and maybe just a bit of social anxiety so don't need the same level of support. We are all different with different needs but that doesn't mean that we don't need support.

I would also like to see more access to training programs and courses. At the moment it is just too expensive to undertake courses, particularly when you can't work full-time to cover costs. It would be great to have somewhere that specialises in helping us work out our strengths and identifying where we need to do some work - and making suggestions for pathways for careers. Then staying with us on the journey not just casting us adrift to sort out what comes next by ourselves. Connecting us with employers, helping us trial different work options.

We are all different and wish to be treated like the people we are and not put in one of three boxes/levels. Additionally Australia is not in line with countries such as the United Kingdom and does not recognise autism profiles that have been around for decades, such as pathological demand avoidance better known as ASD with a PDA profile. I would have received this diagnosis had I lived in the United Kingdom. Instead this profile was not included as part of my diagnosis until 2019. Had this been diagnosed earlier I could have received a better targeted treatment path.

I was fortunate to be under the care of a psychiatrist who is also on the Autism Spectrum so they had a better and deeper understanding of what the autism spectrum actually is due to lived experience. Importantly they also know what a person with autism can be if appropriately supported and seen as a person with autism rather than a collection of symptoms and issues. Their lived experience made communication so much easier and I felt like I was being treated as a person. I would like to see medical professionals in the field of psychology and medicine, particularly emergency, general practice and psychiatry, to be required to have specialist training as part of recognised training and as part of ongoing CPD in order to be qualified to treat patients with autism. Further I understand that there is currently a consultation underway arising from the Disability Royal Commission looking at the specific inclusion of the voice of people with intellectual disability as an integral part of curricula and as part of CPD. This should also be replicated for autism spectrum disorder.

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

When answering this question, you might like to consider:

- What is affecting the rights of Autistic people?

Attitudes and misinformation are the main things affecting the rights of people with autism - and we aren't always aware of what our rights actually are. Additionally some of us don't like to bother people so we don't speak up. We need to be better educated about our rights - and so do our parents. Lots of parents don't know what they can do to support their children better - particularly in school. Teachers/Principals can make excuses (child is just being difficult; not enough resources; can't treat children differently) and parents need to know exactly what their rights for their children are otherwise they can't advocate for them properly.

We also need to be better educated about our rights. As part of this strategy maybe you need to consult with us and our families about what rights are important to us. Access to mainstream education would have been great for me but instead I was placed in the autism unit (which at highschool had its great points) and provided a modified (dumbed down) education even though my IQ is 136. No-one tried to work out the best way to help me learn to my full potential.

- How can we better make sure the rights of Autistic people are recognised and upheld?

Maybe increasing the number of trained (accredited??) advocates/mediators would be an amazing resource for people with autism and their support people. Having better support for parents - parents are exhausted trying to advocate for us. How can they have energy to support us when advocacy is a constant battle? Having Autism specialists entrenched in government service providers would be also amazing. How can people with autism ever even deal with the police when an autism meltdown is treated as a mental health issue? Making legislative protections more effective would also be great. At the moment everything is couched so vaguely it is hard to get anywhere.

Emphasising and advertising rights is a way for us to be included in society and not as a special favour to keep us quiet. Education!!!!

- How should the Strategy recognise the diversity of the Autistic community?

The strategy needs to be inclusive and should focus on what it can do to promote the strengths of neurodivergence and to have enabling pathways and supports rather than focussing on a deficit model that entrenches barriers and challenges.

Including using the term Autism Spectrum Disorder (or ASD) and not just using the word Autism.

**better supported across their whole life?**

When answering this question, you might like to consider:

- What barriers to social and economic inclusion have you experienced at different stages of life? (this could be things like being out in the community, relationships, having a career or being employed, having access to education)
- What are the biggest improvements you would like to see?

A previous Prime Minister, Scott Morrison, announced on national television in response to a question from a parent with a child with autism spectrum disorder that they were not as blessed as parents who have children without disability. He implied that we are a burden to our parents and community and to society. Such ignorance and bias remains today. I have experienced people telling me that autism is fake and teachers telling me that I would be nothing because I have autism and that I couldn't possibly have an IQ of 136.

School was an issue. Highschool wasn't too bad and teachers worked hard to challenge me intellectually but when I went to secondary college, the assumption was that I was stupid. I did not have access to mainstream curriculum as I was placed in a special unit. One of the major issues was that the head of the unit had absolutely no idea how to do their job. They did not have skills in managing people with autism. They had been a dance teacher and clearly had placed a high value on feelings and other abstractions. When it came to managing me there was no common ground or language. I couldn't function in a regular class because of anxiety and behavioural issues but that didn't mean I should only have access to inane subject matter. This exacerbated my behavioural issues and entrenched self-doubt. Teacher education needs to be reviewed so that curricula is explicit that autism does not automatically mean low intelligence.

I was lucky that my mum was able to convince her manager that I should have a chance to train as a swim teacher. He gave me the chance and I have now been working as a swim teacher for 6 years. I can only work for about 10 hours per week otherwise I become just too stressed and exhausted but I love my job. I was given a

chance to succeed and I did. The good thing about my job is that I can choose to work just 10 hours per week so I can always give my best.

Autism needs to be seen as a spectrum. Too often autism is viewed as an intellectual disability which is true for some but not for everyone. People also assume that because autism spectrum disorder involves neurodivergence/diversity it must be a psychiatric disorder like schizophrenia or a mental health issue. These assumptions need to be challenged and dispersed.

Even within the disability space, unless you have level 3 autism with accompanying physical and intellectual disability, you aren't seen as being sufficiently disabled. When I wanted to play sport or be part of an athletics group, I could do this unofficially but I couldn't get a classification to enable me to be part of official teams because the classification system didn't encompass autism without physical or intellectual disability. Playing mainstream sports just wasn't an option. Autism spectrum disorder needs to be recognised and embraced within the disability community as a disability. It is almost as if we don't fit in the disability world but we also don't fit in the neurotypical world.

NDIS also needs to recognise that autism does not go away with age - we just don't grow out of it. It also can't be cured. However, NDIS does not look to help and support us. It sees us as a cost that needs to be minimised. It demands to see improvements and opportunities to cut funding. My support team spends way too much time having to justify their work with me. If I don't improve, I lose funding. If I improve I also lose funding. If I lose funding - I lose supports. If I lose supports, I stop improving or functioning. Then I deteriorate and that impacts on my independence and capacity to work and be part of the community.

You wouldn't take a wheelchair away from a paraplegic because they don't improve enough to walk so why won't NDIS see my support team the same way?

- Is more support needed for Autistic people at certain life stages?

The NDIS is difficult to convince if you don't have physical or intellectual issues. I was kind of fortunate to have had an extreme, rare and adverse reaction to a prescribed medication. I was trialling the medication to help with my ADHD. The adverse reaction resulted in a hospital admission and then a placement in a specialist unit

interstate. I was so fortunate that the staff at the specialist unit were able to not only help with medication but also to set up an amazing support team post discharge. Because of the hospital admissions I have been able to get some NDIS funding, however, this funding is decreasing and I am nowhere near better enough to not have my support team continue to be funded. It takes time for new strategies and thinking to happen.

Younger people with autism have the advantage of early intervention programs that were not in existence when I was growing up. NDIS needs to recognise that I am currently receiving the equivalent to these early intervention programs. NDIS needs to stop trying to rush things. Entrenched behaviours do not change quickly. The money you think you are saving now is just going to result in my needing more support longer term.

- What should be in a Strategy so Autistic people get the support they need early in life, including making sure infants and children have access to diagnosis and adequate supports?

Families need support as well - not just the person or child with autism. It is all very well to have supports for the person with autism but if family members aren't supported how can they effectively provide support at home?

The strategy needs to think holistically. It is not just non-verbal people who need communication support. It needs to have a focus on ensuring supports that will help all of us as individuals break through barriers and live independent and fulfilling lives.

### **What can be done to better support autistic people from different population groups, including:**

- First Nations autistic people?
- autistic people from culturally and linguistically diverse backgrounds? autistic people that identify as LGBTQIA+?
- autistic infants, children and young adults?
- older autistic people?
- Autistic people with common co-occurring neurotypes and conditions, including but not limited to Autistic people with intellectual disability, Autistic people with ADHD and Autistic people with Specific Learning Disorders (SLD) such as dyslexia, dyscalculia and dyspraxia.

- Autistic people with additional and/or complex support needs including communication needs.

When answering this question, you might like to consider:

- How should priority groups be represented in the Strategy?
- What are the specific actions needed to support people from these priority population groups – actions will generally be specific to one of these identified groups.

I think the first thing we need to understand is that autism is a complex spectrum that has a very different look for every person. I also have ADHD, complex PTSD anxiety disorders, mood disorder and mild depression. I also have a profile of pathological demand avoidance with the autism spectrum disorder. I have had a diagnosis of ADHD since I was four, but it wasn't till I was five that my paediatrician would prescribe medication. The best decision my parents ever made was to support my being prescribed Concerta and then when I was about 10, I was put on mood stabilisers (that is, epilepsy medication that is used off label). I was then prescribed sleeping pills for my insomnia. I want to make it quite clear that I was totally on board with this decision and I was never pressured to take my medication. This was fine until I turned 16 and then was too old for my paediatrician. When I was 18 I was off all my medications. Even if I had wanted to continue with my medications there was no continuity of care due to my age. By chance I managed to find a psychiatrist who was accepting new patients and I recommenced medication. This resulted in my adverse reaction to a prescribed medication and a whole different scenario which resulted in a great support team of allied health professionals.

I would not be able to function to be who I am without the help of medication, particularly my anti-anxiety medication. I'm proud of who I am, but I can tell you right now the Royal Commission's recommendation to not use behaviour modification medication is not something I support. My medications are helping me to be open and responsive to therapy by making it easier to regulate my emotions and mood at the same time as doing therapy.

