

National Autism Strategy submission 2023

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I am a late-in-life diagnosed autistic adult, having been assessed earlier this year. This also came with diagnoses of autistic burnout and severe depression and the months that followed have resulted in under-employment, illness, family issues, and a breaking point that has led to thoughts of self-harm. Autism and burnout haven't just been a diagnosis for me. It has felt like a death.

I have been contributing to the consultation process for the National Autism strategy and it has highlighted how unprepared society can be for those on the autism spectrum. Since my diagnosis, I've struggled to find work, identify resources, and access the right support. I know that for many autistic people, specialists can be uninformed, employers can be reluctant, and friends and family can be sceptical. I have lost some of my executive function this year, so I will keep this submission direct and personal. I concede my reflections may not always be fully accurate, or ideal for some.

The National Autism Strategy is well-designed and an important first step, but in a country where autistic people have a nine-fold increased risk of suicidality and the average life expectancy of an autistic person is well below that of the general population, we don't just need a strategy. Many need a safety net to survive.

When I was diagnosed, I came to realise that my own understanding of autism was woefully inadequate. Not only was my understanding of autism out-of-date, there weren't obvious resources available. Over and over again, I found my ignorance reflected in individuals and services around me.

The general understanding of autism can still be fairly superficial. People can seem to understand autism only through stereotypes, characters from film and television. People's understanding of autism may be older than the 2013 changes to the DSM5, or taken from their direct experiences of one autistic individual they know (I often have to explain to someone that autistic traits differ from person-to-person, and that we don't all present the same way).

We need to build a newer, fuller understanding of autism across community and society. We need to rebuild the understanding of autism from the ground up, in schools, in social institutions, in workplaces, in health services and mental health services. We can't just add to what people know, to add footnotes, but to start the story of autism all over again; what it is, what it means for people, how we can respond.

Since I was diagnosed, I became underemployed while trying to provide for a family during a cost-of-living crisis. Searching for work while coming to terms with the strengths and challenges I face as an autistic person was incredibly hard. I was not successful in finding more work, and have been told by specialists that I shouldn't take on more work in my state of burnout as it is.

We need workplaces to be more informed about autism. We need more employers open to interviewing openly autistic-identifying people for jobs. We need more work environments making spaces for autistic people in jobs. We need workplaces to be more flexible for the sensory needs of autistic people. We need more jobs specifically created for autistic people.

The diagnosis itself was a learning experience for me and to be blunt about it, there aren't enough places that offer diagnosis, the wait lists are too long, and the costs are far too high. There is often no obvious resources or pathway of support for people following their diagnosis. The processes of finding a service, making a booking, securing the costs, presenting for the diagnosis, and knowing what to do afterwards are not clear for many on the spectrum.

Some on the spectrum may face challenges around personal organisation, financial security, new social scenarios, and clinical environments, so imagine having to make an appointment months in advance, have over \$1000 on hand, and front up to a service to be interviewed by strangers. While I had a functional and relatively constructive experience of diagnosis, for many on the spectrum this process is inaccessible at every point.

While I acknowledge the diversity of language used in the autism community, this is jarring when we consider this in the context of autism as disability/disorder; you can have a disability that means it is difficult for you to make appointments, secure finances, and negotiate clinical environments, yet face every one of these obstacles in the process of diagnosis. I can only imagine that there are people in this country that cannot get the diagnosis they need because of the process of diagnosis is often at odds with the nature of the disability itself.

I have had some positive experiences with GPs, and mental health professionals, but I know of many autistic people who have not. Therapists and counsellors can be woefully uninformed about the autism spectrum, discouraging diagnosis, or questioning diagnosis once it is made. People can be told that they are 'not autistic' because they can make some eye contact, work a job, can make small talk, or have imaginative skillsets. People can be told that autism and neurodivergence is 'a fad' or a phase.

This is what lies at the heart of the challenges we face, a lack of information. Yes, we need more accessible spaces and sensory allowances, more inclusive schools and universities and workplaces and footy clubs and places of worship. We need teacher and trainers and employers and doctors and therapists to have the education and methodologies to work with autistic people. We need more training and job opportunities, more support and funding, but what we primarily need is a more informed society. We need a whole new story of autism, told by those on the autism spectrum.

I want to affirm the National Autism Strategy's approach, and reflect on some steps going forward;

- Consultation and submissions process should continue. I know of so many autistic people, carers, support workers, and specialists who did not know the National

Autism Strategy consultation process was taking place and have not contributed. Some of the most informed voices haven't been heard yet.

- The National Autism Strategy should be data-driven and evidence-based and the most effective components in all this are the voices of autistic people. When autistic people speak about what it is like to live with autism in society, it changes the listener.
- Implementation of the National Autism Strategy should increasingly include autistic people, with volunteer roles but certainly with paid positions. Lived-experience is a resource and I can't stress enough how much autistic people should be driving this strategy and be properly employed to do so, if they aren't already.

The National Autism Strategy is an important opportunity. This is a chance to see autistic people in this country not just survive, but thrive, to work towards a safety net but to start with a whole new story. That is primarily what we need; a new story of autism, told by autistic people, shaping the supports we need. My diagnosis has felt like a death this year, but with the right supports, with the right story, it could be a new beginning.