

National Autism Strategy Feedback

KEY DISCUSSION QUESTIONS

What does a National Autism Strategy need to achieve? How can the Strategy support the rights, autonomy, and diversity of Autistic people? What needs to improve so Autistic people are better supported for their whole life? What can we do to better support Autistic people from different population groups? What might help to improve people's understanding of Autism? Are there any areas missing from this discussion paper that should be a priority in the Strategy?

Living in Australia as an Autistic person is incredibly hard. We're not only experiencing difficult circumstances such as the cost-of-living, housing crisis, and loss of free medical care like most Australians, we are living in a society that does not cater for neurodivergent people. I want to be able to live my life to the fullest, to my full potential, and to achieve my life goals while doing so. However, that is not currently attainable. For the National Autism Strategy to succeed it needs to improve life for **all** Autistic Australians so that we can live life to our full potential and live the lives we want.

The Autistic community is a diverse community. We all present differently on the spectrum, and every Autistic person will require different supports. Additionally, every Autistic person is different outside of being Autistic. Whether that is them being a child or adult, a woman, man, or someone who is gender diverse, white or a person of colour, straight or LGBTIQ+, or is disabled through a separate disability. When the National Autism Strategy comes to the stage where actions are occurring, this is incredibly important to factor in. Autistic people face ableism, but they may also face racism, sexism, misogyny, or ageism simultaneously. To assist the Autistic people who are apart of different demographics, it is necessary to consider the other factors that may hinder them alongside their Autism. From a personal standpoint, I am an Autistic 20-year-old woman. I have experienced ableism from people who believe that Autism only presents in children and men, which impacted the support that I required. It is also very important to remember that the Autistic community is not a hive mind. We all have different opinions and every Autistic person engaging with supports needs to be asked what their preferences are. If the National Autism Strategy doesn't include the diversity and autonomy of the Autistic community in its plan, the bulk of Autistic Australians will be, once again, left behind.

I think a misunderstanding of what Autism is plays a major part in how Autistic people are treated in society. Education, that is approved and made by Autistic people, would go a long way in ensuring that Australians have a correct understanding of Autism.

SOCIAL INCLUSION QUESTIONS

What has prevented you from being included in your community? How could services and supports be improved to help you live the life you want? How can we improve community attitudes towards Autistic people? How would you describe better social inclusion for Autistic people?

I face social exclusion on a daily basis. I cannot drive, I live in an area with inadequate public transport, and I struggle to enter the community without a support person. Of those three factors, the lack of sufficient public transport contributes the most to my social exclusion.

When I am unable to travel in a car with a family member or friend (which is majority of the time), I have to rely on public transport. I live in regional Queensland, where our current public transport (buses) is not 100% accessible to Autistic people. Only a few bus routes occur regularly (i.e. every 30 minutes as opposed to every hour), and several areas are not serviced at all by a bus route. Personally, my area has a single bus (that does not travel to the city centre) that comes every hour, but it is often late. This means that I often miss my connecting bus, so I either have to wait for the next bus (resulting in a late or missed appointment) or I have to catch the bus an hour earlier to ensure I don't miss appointments. As a result, this means that I am in the community for longer than necessary, and combined with the absence of a support person, I often experience burnout and severe sensory overload. Additionally, the electrical buses are much more Autistic friendly than the original buses. While there are electrical buses in the fleet, they need to be fully utilised. Not only for the positive benefits for the environment but because of the level of accessibility. The electrical buses are quieter, bigger, and have more disability seating. Accessing the community independently through public transport negatively impacts the rest of the week and my day-to-day life. I no longer access the community during the weekdays for enjoyment, only when it is absolutely necessary, so I spend most of my time at home due to the social exclusion I face from the lack of accessibility. It is really disheartening especially when there are improvements being continuously made to public transport in and around Southeast Queensland (i.e. Brisbane and Gold Coast). The Queensland Government has reassured regional areas that public transport improvements are planned, yet instead of focusing on areas that desperately need improvements, the Brisbane and Gold Coast areas are prioritised again and again. This prioritising has only resulted in the accessibility gap between urban and regional/rural Queensland to widen. It means that many Autistic people are having to choose between leaving their location for a major city or to stay and continue to experience the difficulties of living as an Autistic person in a regional/rural area.

Alongside improvements to public transport, more disabled toilets and disability friendly spaces (e.g. quiet room) would be very beneficial.

ECONOMIC INCLUSION QUESTIONS

What has prevented you from being able to fully participate in education and employment, or to get access to transport? How could services and supports be improved to help you participate in education or work, have a career or your own business? How else do you think we can better support Autistic people in education, employment and the workforce?

I have been unable to fully participate in employment due to inaccessible public transport (please read above) and the lack of understanding of Autistic people which led to ableism. Due to the rate that I experience burnout, I cannot work more than 15 hours per week at a maximum, and have yet to hold employment. However, I previously volunteered at an Australian wide not-for-profit charity. Unfortunately, I left that position due to the ableism and bullying I experienced from the manager. Every staff member, in education and employment, especially managers, need to be educated on what Autism is and the best way to support Autistic students and employees. Autistic people should be able to comfortably express what supports they need in the student/workplace, and not fear discrimination and ableism from work colleagues.

There needs to be a serious overhaul of the Disability Employment Services (including Centrelink) and the National Disability Insurance Scheme. I have personal experience with Disability Employment Services (DES) and Centrelink. Unless you are diagnosed as level 2 or level 3 Autistic, the process to obtain support is incredibly difficult. I, regardless of telling my DES that I need clear communication to prevent meltdowns, have always had poor experiences with my DES having poor communication. Due to my previous volunteering experience, I know that I only have a capacity of 15 hours per week. Yet, even though I have several diagnoses (Autism being the primary diagnosis), they disregard this, and I am expected to work more than double my capacity. Accessing the Disability Support Pension is another difficult process to try to obtain support.

DIAGNOSIS, SERVICES AND SUPPORTS QUESTIONS

What has prevented you from getting a diagnosis, or accessing services and supports that would help you live the life you want? What has helped you to access diagnosis, services or supports? How can we better make sure that diagnosis, services and supports for Autistic people are strengths-based, culturally responsive and trauma-informed? How would you describe what better access to diagnosis, services and supports looks like for Autistic people?

Majority of Autistic women are diagnosed during adulthood; therefore we have to access diagnosis services through the private system. Many psychiatrists are not accepting new patients and those that are accepting have long waitlists. It is an expensive process as well. I personally spent over \$2,000 on my Autism diagnosis, which as someone who cannot work is hard to save for. I was very fortunate that I had a positive diagnosis experience. My psychiatrist had knowledge of how Autism presents in women and was open to hearing about my individual experiences. Autism diagnoses need to be more accessibility and less expensive, and the medical professionals who diagnosis need to be knowledgeable in how Autism presents in women.

NATIONAL ROADMAP TO IMPROVE THE HEALTH AND MENTAL HEALTH OF AUTISTIC PEOPLE QUESTIONS

Are there other health and mental health issues experienced by Autistic people that the National Autism Strategy should help to address? What needs to improve about health and mental health services and supports? How else do you think we can support better health and mental health outcomes for Autistic people?

The accessibility of the healthcare system, both physical and mental, is not sustainable. Majority of the Autistic community have experienced anxiety and depression. Autistic people, specifically Autistic women, are more likely to die by suicide than an allistic person. There is a lack of available health professionals (i.e. psychiatrists and psychologists) and for those who have been able to connect with a psychologist, the current Medicare limit of 10 rebated sessions per calendar year is not enough. Personally, I have severe mental health issues that impact my daily life, yet I have not been able to see my psychologist since August because I've used my Medicare limit. Autistic people are disadvantaged career wise, and many are having to survive off Centrelink, so paying over \$200 out of pocket for a single session is not viable. There needs to be improvements done in expanding the number of health professionals as well as the costs/number of rebated sessions that a person can access. It should also be mandated that every health professional needs to be educated on Autistic

people, by Autistic people. If a health professional does not understand what Autism is or how Autistic people communicate it significantly impacts the quality of healthcare that the Autistic person receives. Many health professionals will not consider how Autism impacts other health conditions, physical or mental.