

Submission on the National Autism Strategy

Thank you for the opportunity to contribute to the development of the National Autism Strategy.

My submission is based on my own lived experience and I acknowledge that other Autistic people have a vast range of experiences, challenges and support needs that are equally valid. We all deserve to access services, information and other resources that are appropriate to our needs, whatever our stage of life and circumstances.

While I have covered the four key outcome areas identified in the Discussion Paper, I will focus on elements within those that are directly connected to my experience.

Background

I was diagnosed Autistic three years ago at the age of 48 and I also have diagnoses of ADHD and generalised anxiety disorder. I am part of the LGBTQ+ community and co-parent my teenage daughter with her other mother who I separated from six years ago. I identify as female but not with the limited gender roles ascribed to women. Gender is one of many social constructs that make little sense to me.

The main reason it took me so long to identify that I was Autistic was that I didn't see myself in mainstream representations of autism. It simply didn't occur to me that autism could be the thing unifying the many challenges I experienced in life as well as my strengths.

I feel strongly about improving understanding of Autistic experience as the way towards a more accessible and inclusive world for Autistic people. I would like to see more widespread acceptance of neurodiversity as a natural part of human variation and a move away from imposing normative ways of being and pathologising those who don't fit into them.

Social inclusion

Like many late-diagnosed Autistic people, my life has been characterised by a feeling of being different to other people but not knowing why. I did not grow up in a world that encouraged difference, so instead I felt deficient and less worthy and at times wrong or just bad. The only option I had was to try harder to be like everyone else and to fit in. But as Brene Brown tells us, fitting in isn't the same as belonging and for an Autistic people with no sense of who they are, true belonging can be elusive.

In the Autistic community, we refer to this process of trying to fit in as *masking*. On some level I knew that being in the world was harder for me but it wasn't until much later in life that I understood the cost of masking to my mental health. To go through life closed off from my authentic self has caused profound damage that I am only now beginning to repair.

Even communities that should have given me a sense of belonging failed me because of unwritten expectations that I could never understand let alone meet. Coming out as LGBTQ+ in my early twenties was traumatic on two counts: rejection from members of my family and the rejection I felt due to not being able to navigate the LGBTQ+ community. Unfortunately the LGBTQ+ community is nowhere as inclusive as it could be and as a whole hasn't yet successfully grappled with issues of intersectionality.

The significant overlap between the LGBTQ+ and neurodiverse populations is well documented. Therefore, it is surprising that there are so few spaces we can connect in a safe and comfortable way.

It is hard enough finding a safe space as an LGBTQ+ person without having to also accommodate the layer of need that comes with being neurodivergent.

A notable feature of the LGBTQ+ community is that many social events occur in high sensory environments and this can be a significant barrier to connection. We need environments in which we are comfortable to be ourselves. Those of us who are parents need accessible social events that are also welcoming and inclusive of family diversity.

Ideally, Autistic-led organisations would be funded to develop more opportunities for social connection for members of the Autistic community, including LGBTQ+ focused events. Depending on unpaid voluntary efforts of Autistic individuals is unsustainable and unfair when we already have so much to keep on top of in our lives.

Further, mainstream LGBTQ+ organisations should be funded to explore ways of making events more inclusive for Autistic members of their communities in consultation with Autistic-led organisations. There is scope for more events that are centred around shared activities and interests beyond noisy and high-sensory environments like pubs and clubs.

It is often assumed that Autistic people's avoidance of spaces where people socialise means that we don't want to connect with people. However, most of us want and deserve social connection as much as anyone else but we need to be supported to do it in ways that work for us.

Economic inclusion

As a result of gaining a university education and building a career as a professional, I've reached mid-life financially secure and with stable housing. I know this puts me in a much better position than many other Autistic people but it has come at a cost to my mental health. I have had to accept that workplaces are not healthy places for me and that the only way to accommodate my needs is to work for myself.

While becoming a lawyer might sound impressive, it was not a good choice for me. Throughout my education I did not receive any guidance on what career choice might suit me based on my strengths. Although I worked hard, it took all my energy to survive, while the possibility of thriving remained out of reach. The shame in feeling as though I couldn't cope was immense so I put a lot of effort into appearing as though I could.

Litigation was such a deeply ableist environment that asking for help was out of the question. It would have meant exposing myself as someone who couldn't cope and just wasn't up to the job. Even when I was bullied by judges, I was expected to suck it up as though it just went with the territory. There was no support from colleagues, managers, court registries or the legal profession generally. They are collectively responsible for allowing such a damaging work environment to operate unchecked with harmful consequences for me and many others.

For many years I felt like a failure, realising only after my diagnosis that it was the work environment that had failed me. My mental health suffered and I believe that it was during this time that I developed generalised anxiety disorder. It impacted on my parenting because I was experiencing day-to-day life with such a heightened state of stress that I couldn't be present for my small child. Feeling like an inadequate human being made me feel even more socially isolated.

After leaving litigation work, I was able to find roles that were less stressful. However regardless of the workplace setting, I felt that I was working harder to navigate processes, practices and communication that were based on neurotypical ways of being. At the time I learned I was Autistic, I

was employed as a legal professional in a large organisation. Although the organisation holds itself out as being inclusive, it fell short when it came to accommodating employees with disability, particularly with invisible conditions like Autism. The 'reasonable adjustments' process was hard to access and outdated. It was typical of process that are directed at physical conditions and tangible responses, not invisible disabilities like autism and the nuanced responses required.

The overall understanding of Autistic experience and neurodiversity generally was shockingly low for a large public sector organisation. It placed a significant burden on me educate people before I could even start to articulate what my needs were.

While the input of Autistic people in developing the systems we work within is essential, we can't shoulder the burden of driving change without support. Too often I was made to feel as though my attempts to build a more inclusive workplace were a fanciful distraction from the core business of the organisation. This was certainly the mindset of a number of managers who consistently disregarded their obligation to support neurodivergent staff.

It's a story I hear frequently from other Autistic adults trying to make changes for themselves in the workplace post-diagnosis. Advocating for your needs as an Autistic employee is difficult and exhausting. Autistic-led organisations working with employers to help facilitate mentoring, peer support and advocacy would provide much-needed support for Autistic employees.

Many individuals and Autistic-led organisations have been providing lived-experience education to workplaces. My own experience indicates that companies are interested in the insights of Autistic adults to inform their disability inclusion policies and practices. There is potential for this work to be rolled out on a larger scale if supported by government funding, particularly for public sector employers that have a responsibility as model employers.

It is also important to strengthen the legislative framework to move beyond a tokenistic and piecemeal approach to accommodating disabled people in the workplace. Such approaches place the burden on individual employees to prosecute a case that their need to be accommodated in their workplace is 'reasonable'. Instead, there needs to be a shift to imposing a positive obligation on employers to provide an accessible workplace environment for all employees.

A lot of the attention around Autistic employment in recent years has centred on large organisations launching specialised recruitment programs that harness the economic benefit of employing Autistic people with specialised skills, particularly in the technology sector. But as research has evaluated such programs as having limited impact due to the narrow focus on certain types of work and the segregation of Autistic people within workplaces.

There needs to be greater recognition that Autistic people have skills and aptitude across all areas of employment, and that many are already in employment. Obtaining employment is important but we need support to sustain it and to access a range of alternatives including self-employment. There also needs to be meaningful career planning available in school and beyond.

Growing acknowledgement of the prevalence of neurodiversity for adults already in the workforce and children and young people who will enter it in coming years requires a shift from normative workplace systems and processes based on the needs of neurotypical employees towards those which are inclusive towards all neurotypes.

Diagnostic services and support

I was able to access the autism assessment process through a private clinic in a metropolitan area. However, I know that a lot of adults within the Autistic community are not so fortunate. Paying upwards of \$1000 with no Medicare rebate is prohibitive for many. There is a shortage of practitioners qualified to assess autism and those who live in regional and remote areas have even fewer options. Others go through the process only to find that the assessing practitioner is not sufficiently familiar with the diversity of autistic presentation and is limited by the misconceptions and stereotypes prevailing in the general community.

While I was assessed by a psychologist experienced in Autism assessment, I found the deficit-based approach quite confronting. It was only through connecting with online Autistic communities that I was able to develop a sense of my strengths and start to rebuild my identity as an Autistic person. I was referred to another psychologist at the centre but the need to process decades of trauma soon exhausted my mental healthcare plan.

I felt like I was on my own in navigating what came after the diagnosis. There was no post-diagnosis pathway or any integration of the diagnostic process with the process of obtaining services and support.

Learning you are Autistic as an adult is a massive adjustment internally and externally. What I needed was someone to guide me in working through what it meant for me and how to change my life to meet my needs. But it didn't matter how many times I searched the internet, there was nothing like this available. The one Autistic telephone information service I found connected me with a non-Autistic person who didn't get what I was talking about.

I had hoped to find an occupational therapist to help me manage my sensory and cognitive load but gave up when I couldn't find one that worked with adults from a mental health perspective. I also found very few opportunities to connect with other Autistic adults in person.

There are some amazing Autistic-led organisations with a wealth of experience and knowledge about what works for Autistic people and I've relied on them as sources of online information. They should receive funding through ongoing grant programs to provide telephone information and referral, peer support, mentoring, courses, social events and other means of supporting newly identified Autistic adults.

The NDIS has become synonymous with disability support services and the options for people outside of the NDIS are very limited as state-based providers have reportedly vacated this space. Some level of support also should be available to Autistic adults without having to get over the hurdles of qualifying for the NDIS and it should also be available to those without a formal diagnosis.

I am aware that as an Autistic person I am entitled to apply for NDIS funding, but I face a number of barriers before I even submit the application form. It's not just the numerous accounts of the convoluted and time-consuming processes and inconsistent outcomes for Autistic people that dissuade me from applying for the NDIS. Internalised ableism is an obstacle to admitting that I need help and the temptation is to push through and try and cope as I have always done.

I can't help feeling guilty about depriving others who are considered 'more deserving', even though I know logically this is not how the NDIS works. I feel like I'm battling a narrative that deems the needs of late-diagnosed Autistic adults as less important. Because I have masked for so long, it can be difficult to make people understand how much I have struggled just to get by.

Autistic people who are educated and articulate are frequently disbelieved and our need for support dismissed. We're in a bind because if we don't go to efforts to explain our experiences, we run the risk of being misunderstood and subjected to misconceptions about autism. We're good at articulating our experiences because we've had to do it so many times.

Even if I was prepared to pay for services myself, they're just not there. We need support that is tailored to the individual needs of Autistic people, whatever their stage of life. It has to be driven by our assessment of what we need, not preconceived and misinformed ideas of non-Autistic led service providers of what our needs are.

It's unfortunate that we've moved to an all-or-nothing approach to supporting Autistic people when for many of us a small outlay could make a big difference.

Health and mental health roadmap

As I'm now in my 50s, I'm having to access the healthcare system more frequently. I'm generally in good health but have medical issues that require monitoring. I have had very few negative experiences with medical professionals who generally treat me with respect and communicate information effectively. However, I am also mindful that I am playing the role of the model patient, something that not everyone has personal resources for and indeed there may be times in the future when I don't either.

The main challenge I have in my contact with the health system is dealing with convoluted, mishandled processes and administrative staff who are unhelpful and lacking in empathy. I suspect that they have no idea about how their processes impact on Autistic people and how much harder we have to work to do things they take for granted. As a result, apparently straightforward tasks as making appointments, getting tests results or prescription renewals can be frustratingly complex.

All staff who have contact with the public need to be educated about the needs of Autistic people. Better co-ordination between health providers would mean that the onus isn't always on the Autistic person to follow up referrals and other steps.

The physical environment of healthcare settings can be difficult to navigate and can fuel anxiety that is already heightened. Clear signage and making information and maps available online ahead of time would ease some of the mental load. More attention also needs to be given to the sensory impact of such things as harsh lighting and loud conversations.

I have an excellent GP who manages my primary care and provides referrals as necessary. I can be open with her about my experience as an Autistic person and the needs that flow from this. GPs have a vital role and it is crucial that they have up to date knowledge about the Autistic experience.

There are factors associated with aging that can be particularly challenging as an Autistic woman. I am currently in late-stage peri-menopause which has exacerbated many sensory and cognitive issues. In the last two years I have experienced a significant decline in my executive functioning which led to me being diagnosed with ADHD this year. I had executive functioning issues all along, but my ability to mask and compensate for them had broken down.

Middle age can represent a high-water mark of stress; the point at which a life-time of masking, coping mechanisms and trauma gives way to burnout and the inability to function. Many of us also have the usual stresses of teenaged children, aging or dying parents, relationship breakdowns and demanding jobs.

I know many women who have been diagnosed in their 40s and 50s because they get to a point where they can't absorb any more and reach crisis point. Women generally carry a disproportionate mental load in society and this is even heavier with the additional layers of work necessitated by being a neurodivergent person in a neurotypical world. It is crucial that medical practitioners have an understanding of the complex interaction of these factors for Autistic women.

The mental health needs of Autistic adults are ongoing and this needs to be recognised in the funding of mental health services through Medicare so that it is universally available to all who need it. This could be supplemented by telephone support lines run by mental health professionals who are neuro-affirming, if not neurodivergent themselves.

Recommendations

Summarised below are ways of supporting me and other Autistic people.

Social inclusion

- Funding Autistic-led organisations to provide opportunities for social connection including LGBTQ+ specific initiatives in environments that are accessible to Autistic people.
- Funding for mainstream LGBTQ+ organisations to explore ways of making events more inclusive for Autistic members of their communities in consultation with Autistic-led organisations.

Economic Inclusion

- Scaling up of workplace education about lived experiences of Autistic people provided by Autistic-led organisations
- More employers, particularly large corporations and public sector agencies to work with Autistic-led organisations to develop processes to support Autistic employees.
- Strengthening the legislative framework to place a positive obligation on employers to provide an accessible workplace environment for all employees.
- Providing meaningful career planning and guidance in school and beyond.

Diagnostic Services and Support

- Diagnostic guidelines and education to ensure practitioners are familiar with the diversity of Autistic presentations.
- Post-diagnosis pathways integrated with the process of obtaining support and tailored to the needs of Autistic individuals.
- Better integration of services at different levels of government and with the private sector to address gaps in service provision.
- Funding Autistic-led organisations through ongoing grant programs to provide telephone information and referral, peer support, mentoring, courses, and other means of supporting newly identified Autistic adults.
- Development of a government-backed website providing a gateway to reliable and neuro-affirming information and resources for parents of Autistic children and Autistic adults.
- More support available outside the NDIS and for Autistic people who have not received formal diagnosis.

Health and mental health

- Provision of clear, sufficiently detailed information about healthcare in a variety of formats.
- Clear signage and making information and maps available online ahead of appointments.

- More attention to the sensory and cognitive impact of healthcare environments.
- Better co-ordination of health services to remove the burden of mental labour from individuals.
- All staff who have contact with the public to be educated about the needs of Autistic people.
- Better co-ordination between health providers to relieve Autistic people of some of the organisational burden.
- Information available to GPs and health practitioners to enable understanding of the complex interaction of factors affecting Autistic adults, particularly women.
- Training to ensure mental health practitioners are neuro-affirming and support for more neurodivergent people to become mental health practitioners.