



National Autism Strategy

Submission

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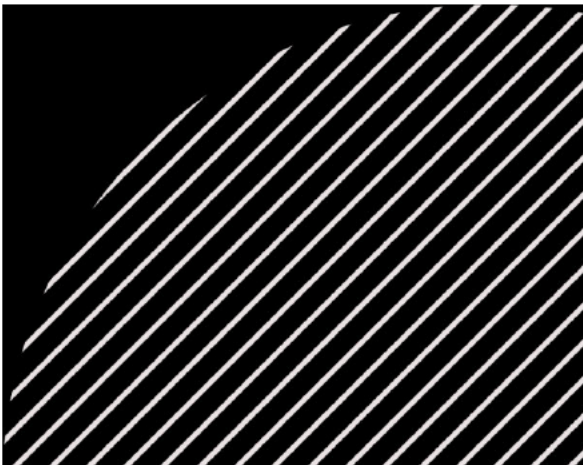
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We are Kiind.

Kiind is a family-led, not-for-profit, member-based organisation with 36 years of operation supporting families raising children living with a disability, developmental delay, autism, genetic, rare, undiagnosed and/or chronic condition, from birth to age 25.

We provide thousands of WA families with practical assistance, peer support, and help with navigating services and systems to enable children and families to live their best lives.

Families with experience of autism represent more than 50% of Kiind's membership, and many of our staff also have living experience of raising a child or young person with autism.

This submission contains our responses to some key questions for Developing the National Autism Strategy, drawing from the lived expertise of our staff and members.

What does a National Autism Strategy need to achieve?

Challenging stigma and ableism

A National Autism Strategy should help Australians understand that neurodiversity is just a part of the spectrum of human experience. We want mainstream systems to begin to see the ableism in their assumptions and service designs. We want zero tolerance for ableism.

A neuro-affirming world

The National Autism Strategy should set out to change beliefs, attitudes, and practices.

We want a neuro-affirming world where being autistic is a source of pride and celebration. We want a world where every person's unique biopsychosocial make-up is celebrated.

We believe autism is a difference, not a disability – embracing a neuro-affirming approach may in time lead to cultural change, where society is more inclusive and welcoming of neurodiversity. Moving from a deficit-based to a strengths-based understanding of autism, we want Australian communities to understand that autism is not a 'problem' that needs to be 'fixed' (or worse: cured) but is a unique and valued neurotype with inherent strengths.

Holding accountability and sharing power

For the National Autism Strategy to have meaning and effect, it needs to be seen as a process of cultural change. Co-designed, local solutions will help us achieve this change.

Implementation should be a simultaneously top-down and bottom-up process, with support from all levels of government and at grassroots and local levels to enact meaningful changes in communities, led by autistic voices and their allies.

Accountability for implementation of the Strategy needs to be embedded in all levels of government. Alignment with other key disability reforms, including state-based legislation changes, the NDIS Review, and the Disability Royal Commission report, will be essential.

What needs to improve so Autistic people are better supported across their whole life?

Better provision for autistic people in mainstream services

Currently the mainstream education and health systems are not delivered using a neuro-affirming lens. System design is often ableist and does not adequately cater to autistic needs. These settings are typically experienced as hostile or traumatising for autistic people. This contributes to poor health, mental health, employment, and social outcomes for many in the autistic community.

Many medical specialists lack basic training in how autistic people's symptoms and signs may differ, for example in mental health presentations or differences in pain tolerance. The result is often misdiagnosis, medical gaslighting, or inadequate or ineffective treatments. Many educators do not know how to create safe, inclusive social and physical environments. This results in exclusion, bullying, and low educational attainment.

Health professionals, educators, and community services need better training in what the 'spectrum' of autism means, and how autism can present alongside co-occurring conditions. Training and professional development in co-occurring presentations is especially vital for the professions that specialise in common co-occurring conditions such as ADHD, OCD, anxiety or eating disorders.

We need mainstream models of care and education that are designed for inclusion. These should be co-designed with autistic people to address ableism in all its forms. Mainstream services should be scrutinised using a neuro-affirming lens, then audited and improved in conjunction with autistic service users. Multidisciplinary models of care that holistically respond to autistic needs and preferences should be designed, tested, and developed with the autism community. Education settings should be designed with the students who have the greatest support needs. By first considering those with the greatest needs, we can design better systems to meet everyone's needs.

Holistic family support

We know that supports for autistic people in education, community and health settings are essential. However, when we prioritise the struggle to support autistic people in the public sphere, we inadvertently fail to consider the struggles in the private, domestic sphere where many families supporting autistic children and young people are simply not coping.

We would like to see greater prioritisation of supporting autistic people in the private sphere, within the family systems that they belong to. By this, we do not mean provision of support workers or carers, or even respite, necessarily. Support for the family system would involve providing families with strategies to better understand autistic perspectives and create autism-friendly environments in the home (our social and physical environments).

This support could take the form of an autistic advocate visiting the home, with the aim to help families understand autistic children's behaviours and minimise conflict. It may include regular visits, coaching and mentoring of parents and siblings, or environmental

adjustments to help people self-regulate. It could mean specialist behaviour support that works with the whole family from a strengths-based, neuro-affirming approach.

There is a further need to increase support for families where more than one family member lives with disability or neuro-divergence. There is a significant need for neurodiverse parents and carers to be better understood in the context of providing support for the whole family. We need the NDIS, Centrelink, and other disability services to understand that families are systems – not groups of autonomous individuals. Where there are multiple people with disability in a family, it is important to assess the family's needs, goals and capacities as a whole system, not as separate individuals in a vacuum. This is especially true for functional capacity assessments in the NDIS, such as determining what is reasonable or necessary, and the limits of 'parental responsibility' for children in the NDIS.

Developing the behaviour support sector

Many of Kiind's member families contact us for support to find behaviour support services. Such requests often arise when the family has reached crisis point, experiencing significant behaviours of concern, stress, and conflict in the home. We want no more families in crisis.

We want to reduce the demand for crisis services to address challenging behaviours, through proactive, evidence-based interventions that help families reduce children's distress and dysregulation that can lead to challenging behaviours. Providing services or interventions that assist families to understand autistic needs and preferences (thus reducing distress and dysregulation, and the consequent behaviours of concern) may reduce the demand for behaviour support services to address challenging behaviours.

There needs to be a professionalisation of the behaviour support workforce. We need professional pathways for behaviour support practitioners to build capacity and expertise in the sector. We need more research to build the evidence base for effective, proactive behaviour support. Developing the behaviour support sector should incorporate lived experience, such as building the evidence for autistic-led behaviour support approaches.

What can be done to better support autistic infants, children and young adults, including their families and carers?

Early childhood screening and family screening

Early childhood developmental screening should be universal and conducted at multiple stages through a child's development (e.g. during infancy in child health nurse appointments, with school health nurse on entry at pre-primary). This screening should be free to access with streamlined referrals, information, and navigation services to support families where developmental concerns are identified.

Family screening and assessment should be offered after any family member receives a diagnosis. This would help many parents who self-identify as neuro-diverse but unable to access supports because they can't prioritise a diagnosis for themselves; many times the whole family is needing assessment, which is costly and time consuming.

Improve access to diagnosis and early intervention

We need to reduce barriers to diagnosis and early intervention, including financial/costs (particularly where multiple family members may need assessments), waitlists and referrals, and geographic access (e.g. transport, accommodation or fly-in/fly-out clinics).

Family support and capacity building

Children and their families need support to process the impact of diagnosis, learn about contemporary neuro-affirming approaches to raising children with autism, and to connect with others with similar experiences through peer support - for example, mentors who are further along in their journey who can be a source of wisdom, encouragement, and hope.

Parents, siblings, and other supporters need recognition and additional help to sustain and thrive in their roles supporting autistic children in home and community. They need more positive training on the rights of people with disability, their strengths and gifts.

Families need clear information, resources and psychosocial support, from the point of diagnosis, to address the wellbeing of the family as a system across multiple domains – such as physical, social, emotional, and financial wellbeing. This support should continue over time, throughout the family's journey raising their children.

We need universal supports for all families to help them navigate systems and understand neurodiversity. Helping in this way could help families reduce stress, improve relationships, and respond to children's needs so they don't reach crisis point.

Families are struggling with behaviours they don't understand and often don't have the skills to effectively respond. We need to build family capacity, expertise, and leadership in behaviour support, to build a community of families that can become less reliant on professionals to 'fix' things.

Inclusive and neuro-affirming environments and practices

We need improved awareness and implementation of neuro-affirming environments and practices across systems, including health, community services and education, to improve inclusion and reduce distress in public places for autistic children and their families.

We want to see training for educators in approaches that improve conditions for autistic children. This training should be focused not on reducing behaviours but on meeting children's needs – e.g. sensory processing, environmental and emotional needs - with the aim of inclusion. We call for more resourcing for inclusive education models that support smaller class sizes and individualised learning (i.e. improved teacher: student ratios). We also want to see more professional learning including peer coaching and autistic-led training, with better career pathways for educators with expertise in autism.

What would improve community attitudes and people's understandings of Autism?

Autistic leadership

We need more autistic leaders and role models to be seen in all sectors of society, including media, the arts, education, and politics. We need more autistic people in power, and in advisory functions, in all the systems that are traditionally terrible at meeting autistic needs such as justice, health, mental health and education. We need tougher legislation and stronger consequences for discrimination and violation of autistic people's human rights.

We believe that greater community understanding of autistic perspectives can help with greater acceptance and inclusion. We would like to see autistic-led advocacy campaigns, where autistic voices raise awareness of the issues and prejudices affecting them.

We want to see more autistic community leadership, where autistic adults and young people are given leadership development opportunities to design and deliver autistic-led parenting support and coaching, peer support, workplace learning, and youth mentoring.

Community awareness campaigns

There is a recent trend of more adults self-identifying as autistic and gaining social media followings for their awareness-raising and stigma-busting. This is an encouraging social movement, importantly as it is an autistic-led movement. Let's help this movement grow.

We need more autism awareness campaigns, including in social media and television, in all early learning and education settings beginning in infancy and early childhood, and in all workplaces. All of these community awareness campaigns should be autistic led.

Families are community, too

Community awareness and education about autism should occur in all systems, including family systems. Family support services should address the stigma surrounding autism and disability, which may be internalised. Awareness-raising should take a person-centred approach with a neuro-affirming philosophy grounded in human rights and inclusion.

Consultations with cultural groups including CaLD, ATSI and religious communities should take place to identify different language, conceptions, and attitudes towards disability, with the goal of improving access and design of autistic supports to include people who don't identify with labels, or western medical models of disability and neuro-divergence.

How should autistic children, young people, and their families continue to be involved in the National Autism Strategy?

Autistic people and their families need to be at the centre of the National Autism Strategy. This includes its development and implementation, and all media engagements about the Strategy. This involvement must not be tokenistic. Autistic views, values and perspectives must be embedded in the Strategy.

Autistic people and their families should be employed at all levels of government to help implement the Strategy. There should be a robust and long-term advisory function built into the strategy's implementation, with broad representation from the autistic community including autistic children, young people, their families, and supporters.

