30 October, 2023

Reframing Autism, National Autism Strategy Submission

Reframing Autism offers this submission with the understanding that the key messages already noted by the NAS as outlined in the NAS Discussion Paper (i.e., 'what we have heard from the Autistic community and other stakeholders already' and 'some of the key issues and barriers Autistic people face') underpin our submission.

We offer this submission acknowledging that so many of our community have already shared their lived experiences, knowledge, and insights to define the many, systemic, and far-reaching challenges we face collectively as a community, and as individuals. We take those problems as recognised and understood by Strategy personnel.

Our purpose with this submission, then, is to complement those stories, shared so generously, with some overarching principles and suggestions addressing the broad submission discussion questions.

We thank you for the opportunity to contribute to the National Autism Strategy.

The Reframing Autism Team

The Reframing Autism team would like to acknowledge the Traditional Owners of the many lands on which we have the privilege to learn, work, and grow. We are committed to honouring the rich culture of the Aboriginal and Torres Strait Islander peoples of this Country, and the diversity and learning opportunities with which they provide us. Sovereignty was never ceded: always was, always will be Aboriginal land.

Introduction

A National Autism Strategy, at its heart, needs to facilitate the equitable inclusion of the Autistic community – regardless of communication or support needs, or of formal diagnosis – across the full lifespan and within the many systems (formal and informal) in which Autistic people operate and live. Such a goal requires (a) challenging the implicit and explicit biases held by non-autistic people about the Autistic community, (b) addressing pervasive, systemic ableism and stigma, and (c) re-educating both broad and specialist communities about Autism and Autistic cognition and experiences.

A National Autism Strategy, then, has the burden of responsibility to 'change hearts and minds' not only within the general community but equally within the autism community (the community of people and systems associated with Autism through profession, support, and/or research).

The most effective way to support the rights, autonomy and diversity of the Autistic community is to listen – deeply, respectfully, attentively and with care – to Autistic voices and experiences. Active listening requires a commitment to taking each individual Autist as a holistic person, whose life is framed by both internal and external influences, whose identity is multifaceted and intersectional, and whose experiences and needs are valid even if they are not echoed by others or if they are complex to access.

Too often, "problems" and "challenges" have been located in the individual, without due consideration paid to the systems, society, communities and contexts within which we exist, and which shape not only our physical experiences, but the messaging we receive and internalise. Even with an increased focus on the social model of disability, insufficient attention has been given to the multiple and transecting systems within which we exist, and which are not designed for – or by – us. Equally, however, the social model of disability has been charged with overlooking or minimising the internal and physical experiences of individuals (Autistic and otherwise), which exist regardless of systems. Taking a multifaceted approach to disability (for example, embracing a complex of the biopsychosocial model of disability alongside a human-rights and an identity model) will result in appropriate attention being paid to external impacts and internal experiences.

Similarly, too often we are asked to separate elements of our identity which are ultimately inseparable; it is only when we are seen as complex, unique, intersectional individuals that our rights as human beings can be truly upheld. The Strategy, therefore, must be underpinned by intersectionality theory (Crenshaw) with deep focus on the way in which multiple elements of identity (race, gender, class, disability, sexuality, neurotype) intersect to result in systemic marginalisation and discrimination.

Being Autistic means we belong to a neurominority, to a marginalised community. Many Autists, though, are also part of other marginalised communities as well. Many multiply marginalised Autists speak of feeling "out of place" or not experiencing welcome in their disparate communities (e.g., the disability community, the Autistic community, the LGBTQIA+ community) because no one space or community is able to understand their unique needs and challenges, which are compounded by each element of identity or marginalisation. The experiences of Autistic women and girls and gender divergent individuals, in terms of barriers to diagnosis as well as being excluded from the more traditional "male brain" descriptions of Autism, is an obvious example. Recognising marginalisation, and the ways in which individuals can be multiply disenfranchised by society's compounded reactions to the intersecting elements of self, will help the Strategy to address such marginalisation proactively.

In other words, the Strategy must make a commitment to Disability Justice. Although broadly, we as a society are more and more coming to recognise our own subjectivities and subconscious biases in many areas, including race, gender and sexuality, bias against the disabled population is still pervasive but unrecognised. Indeed, even disabled people can be ableist, and internalised ableism – a self-loathing because of a disability – is a challenge many Autistic people face.

Disability justice calls for us not just to fight for the rights and inclusion of the disability community but demands that we centre the priorities and needs of those historically excluded, silenced, disenfranchised intersectional groups within the disability community. As Naomi Ortiz argues, "Disability Justice is the cross-disability (sensory, intellectual, mental health/psychiatric, neurodiversity, physical/mobility, learning, etc.) framework that values access, self-determination, and an expectation of difference. An expectation of difference means that we expect difference in disability, identity and culture. To be included and part of society is about being able to be our 'whole self' (all of our identities together). Disability Justice includes space for self-care, reflection and hard discussions". Fundamentally, then, the Strategy should aim to be a conduit for achieving disability justice.

Finally, too often have Autistic voices been silenced because there is not sufficient correlating "evidence" or "data" to support our unique perspectives, or because our voices have simply not been sought out. Entrenched stereotypes, outdated approaches and information, and poor diversity representation mean that Autism is not often embraced as a heterogeneous neurodevelopmental condition. Thus, parents still report their children being denied formal diagnosis because their child speaks or makes eye contact, and adults seeking diagnosis are similarly denied for arbitrary reasons that betray a fundamental misunderstanding of the heterogeneity of the Autistic experience. This is, in effect, a type of gaslighting, and its antithesis is to develop knowledge through exposure to diverse Autistic presentations, to accept individual experiences and needs as valid, and to meet these with compassion and empathy.

The Strategy, too, must reflect the needs of those who are most often excluded from research and indeed advocacy, or are only represented by proxy report. Primarily, the experiences of Autists who are non-speaking (especially those who do not or cannot use recognised or approved AAC methods) and those with co-occurring Intellectual Disability are discounted, ignored, or omitted because (at best) it is not known how to engage with this community, or (at worst) these individuals are assumed to have nothing of value to communicate. We implore those leading the Strategy to take the time and effort to develop relationships with those in our community who do not have the means to participate in traditional data gathering processes. We will return presently to the requirement for a presumption of competence, and more specifically the presumption of communicative competence, and these should underpin the Strategy at every level. Investing in our most marginalised communities is unequivocally both vital and achievable, for example, through spending prolonged and quality time in supported housing accommodation, in day programs, and, indeed, in the nursing home and respite facilities often relied upon for support, to develop relationships and see firsthand the lived experiences of these Autistic community members.

Ultimately, it is only through centring and amplifying Autistic voices, above and beyond all others, that the rights, autonomy, and diversity of the Autistic community can be established and maintained. This is not to say that other stakeholders, including families, allied and medical health professionals, support workers, educational staff, and researchers do not have valuable input to offer the Strategy, but rather that the only way to ensure that Autistic rights are upheld, and that Autistic autonomy is prioritised, is to centre Autistic experiences as valued and valuable, and accepted and acceptable. The Strategy, then, must embrace lived experience as its core evidence, and frame existing research and "evidence-base" within lived experiences and stories. This will allow the Strategy to reassess received evidence-bases, to interrogate *what* is evidenced and how, and to align the Strategy with Autistic needs, priorities, and experiences rather than with outdated principles which are misaligned with the Autistic community.

Theoretical approaches for the Strategy

It is vital that the Strategy examines and acknowledges the theoretical and ideological models it is working within, since it is impossible to develop such a Strategy without such underpinnings. As we have prefaced above, we wish to see the Strategy represent certain theoretical and ideological principles, which will ensure it achieves its goals. These include:

a. "Nothing about us without us." Often in the past, this has been taken to mean *consulting* us about potential changes and developments. The Strategy, however, should aspire to ascend Arnstein's Ladder of Participation from consultation to at least co-design, or (ideally) genuine coproduction. Consultation is often tokenistic when the people consulted have limited power to influence decisions, or when power differentials between decision-makers and marginalised people are not actively addressed. Consultation has until now been a cornerstone of Government engagement with the Autistic community, which has allowed for the identification of problems. However, if the Strategy is to be solutions-focussed, it must be co-produced so that power differentials are dismantled, Autists lead not only conversations but also strategy, policy, and design, and equity is established through the acknowledgement of the systemic disenfranchisement of our community. The Strategy, then, should embrace "nothing about or for us, if not by and with us".

b. Neurodiversity-affirming. Whilst the term "neurodiversity-affirming" is frequently used, it is not necessarily well understood or applied. In reality, what we advocate for is "neurodivergent-affirming" practice, that is, practices which respect, value, affirm, accept and validate neurodivergent experiences and identities, and which address both challenges and strengths from the approach of building individual autonomy, self-determination, self-acceptance, and authenticity (cornerstones of neurodivergent wellbeing).

c. Double empathy approach. The Strategy must operate from a double empathy problem approach, as proposed by Dr Damian Milton. The double empathy problem approach means recognising the bidirectional responsibility for (mis-)communication, and the real challenges experienced by both Autistic and non-autistic individuals in understanding and relating across neurotype. Moreover, the double empathy problem requires that we further recognise and address the disproportionate blame for miscommunications laid on Autistic individuals, and the unequal responsibility loaded on Autistic individuals to "act" non-autistically and learn non-autistic culture and communication norms, without commensurate effort from non-autistic people. Double empathy, then, insists on at least equal effort from non-autistic counterparts to meet the Autistic community "half-way". The double empathy problem also allows us to understand and frame Autism as a culture (just as non-autistic culture exists). Such a framing means that the Strategy has a duty to be culturally responsive, or responsive to Autistic people as a distinct cultural group.

d. Intersectionality theory (Kimberlé Crenshaw). Intersectionality theory allows the Strategy to adopt a holistic approach to Autistic identity, and to appreciate the intersecting ways that Autistic people experience marginalisation and discrimination.

e. Ecological systems theory (adapted from Bronfenbrenner). Similarly to intersectionality theory, an ecological systems theory approach would give the Strategy a sophisticated lens through which to appreciate the ways in which interactions and relationships with ecological systems and environments impact the Autistic experience.

f. Moving beyond the simplistic binary between the social and medical model. A solutions-focussed Strategy must acknowledge that – as much as it is a deeply flawed and problematic approach – Autism is currently diagnosed and described within a medical model of disability. Whilst the Strategy may ultimately aim to remove Autism completely from this pathologised, individual-deficit conceptualisation, such a multi-systemic change will be slow. Whilst the DSS and Government have

advocated for a move to understand Autism (and disability more broadly) within a social model of disability, this approach is not unproblematic either, since the social model has not always captured adequately the relationship between an individual's impairment and the disabling society. Or, as Tom Shakespeare has argued, "the social model so strongly disowns individual and medical approaches, that it risks implying that impairment is not a problem", and the "crude distinction [made in the social model] between impairment (medical) and disability (social)" is reductive. We would advocate for the Strategy to adopt a complex and intersecting model of disability, above and beyond the binary social-medical divide, to include a human rights and identity model of disability within a broader biopsychosocial construct.

g. Presumption of competence. The presumption of competence rests upon the principle that all humans – Autistic or not – are intrinsically and inherently valued and valuable. It eschews entrenched capitalist notions of "productivity" and "contribution" tied to employment and output. Autistic people defy such limited constraints, and our lives must be valued as worthwhile and constructive, regardless of our educational, employment, housing or financial status, and regardless of our communication needs. The Strategy, then, must be built on a premise of value and consciously move away from the construct of Autistic burden. To do so, the Strategy must work from the presumption that all Autistic people, regardless of support and communication needs, and regardless of how a person communicates, can think, can learn, can understand. This extends to a presumption of communicative competence – that is, that speech or sanctioned AAC methods are not the only conduit to communication, and that those who communicate non-traditionally (e.g., through gesture, behaviour, vocalisation, or assisted communication) have worthwhile and valuable messages to communicate.

h. Self-determination and causal agency theory. One way that the Strategy could adopt such a presumption of competence, and protect the rights and autonomy of *all* Autistic people, regardless of support and communication needs, is through the use of self-determination and causal agency theories as developed by Michael Wehmeyer and Karrie Shogren for the Intellectual and Developmental Disabilities population. These theories provide frameworks within which rights-based solutions can be developed and implemented to build the autonomy of the Autistic community, with all of its diversity.

i. Autists can thrive. There is often the assumption that Autists cannot thrive or flourish, and that our internal experiences of the world preclude us from subjective wellbeing. This is untrue. The Strategy must operate from the position that Autists can and do thrive across systems, and when our families and allies are also supported to thrive and to help us to thrive. Traditional stereotypes and pathologised descriptions of Autism are often based on observations of Autistic distress or overwhelm responses, and thus Autistic thriving is regularly disregarded or discounted by those who work with us. This must change.

j. Masking is dangerous. The Strategy has a duty of care to recognise the inherent, lifelong and significant dangers of masking (i.e., internalising or suppressing authentically Autistic traits), which is associated with increased anxiety, depression and suicidality. The Strategy must be underpinned by a commitment to eschew any solution that promotes masking, and must work to educate people (especially families, educators, and professionals) about these dangers to instead promote authenticity and acceptance.

These principles and theories will support a Strategy to improve Autistic lives across domains and life stages.

A solutions-focused Strategy

Utilising the above theoretical framework allows the Strategy's focus to be on solutions. The community has thoroughly defined and explicated the many, systemic, intersecting, and complex problems and challenges facing us every day in education, employment, service provision, inclusion, and communities.

We offer the following ideas as examples of a solutions-focused approach. These suggestions are not, by any means, exhaustive, but rather simply representative of possible ways that change can occur in small but meaningful ways for the Autistic community.

Increasing social inclusion

- Government-provided community network supports that assume that Autists are part of the broad community and accept this reality and our presence as valuable. Such community network supports would connect neurodivergent people with each other and tailor their services to meet Autistic needs. For example, the provision of community-based mothers' or parents' groups for neurodivergent parents or identified atypically developing babies. These groups could consider venues with ample and easily accessible parking, fully-fenced play areas, and sensory toys.

- Better social inclusion for Autistic people is made possible when the community clearly expects Autistic presence, and accepts and welcomes that Autistic presence and involvement. Some ways to achieve such welcome is through the proactive publication of preparatory information, such as Accessibility Guides (see this example), which is vital for Autistic adults and families of Autistic people. The government might, then, develop training (with the Autistic community) in preparing such informational guides and incentivise their use (e.g., as a condition of grant funding for cultural or artistic events). Similarly, mandating that organisations provide a way to make disability-accessible bookings online would support inclusion. For example, when an Autist has accessibility needs, they are frequently required to call a booking hotline (e.g., an airline or venue or ticketing service) to make their accessibility request via phone rather than having the option to book online. For the Autistic population, communication and executive functioning differences can make such a phone-call an impossibility, meaning that we simply are excluded from such activities.

- Making these accommodations expected and clearly visible not only improves Autistic social inclusion, it normalises different people's needs (and, indeed, is best practice for the broader community also), and so might help improve non-autistic community understanding and acceptance of Autists and break down existing stereotypes.

Increasing economic inclusion to ensure there is "nothing about us without us"

- Learn from the mental health sector's increasing use of a paid peer workforce to develop appropriate frameworks to allow Autistic people to be employed as peer workers and as professionals within service provision and educational institutions. Such a workforce of "out" Autistic workers would have the dual benefits of increasing Autistic economic inclusion and ensuring neurodiversity-affirming services and education. Service providers should be interpreted generously, to allow for, for example, Autistic maternal healthcare workers, Autistic midwives, Autistic dental care teams, Autistic palliative care, Autistic researchers for co-production, and Autistic education specialist officers, who could provide consistent, trauma-informed, consultancy support for staff and students. This could be aided by government incentives for such employment strategies.

- Co-design appropriate, responsive, and Autistic-specific employment support programs with the Autistic community. For example, a co-designed employment support program might address

sensory, communication, processing, and mental health needs, as well as sensitive and accessible recruitment and retention policies, to support ongoing Autistic employment.

Improving diagnosis, services and supports

- Within a paid peer workforce model, train Autistic people to implement The Learning About Neurodiversity in Schools program (LEANS) developed and evidenced by the University of Edinburgh to introduce the concept of neurodiversity into primary school settings. This participatory research project produced free educational resources about neurodiversity to introduce children aged 8-11 years to the concept, and to how it impacts their own and their peers' experiences at school. The LEANS program promotes inclusive actions and attitudes in teachers and students alike and, since it is for all members of the school community, it "upskills all pupils and staff members, focusing on capacity for positive future changes" (Alcorn et al., 2021) including understanding concepts of equity and individual, specific needs.

- Move Autistic-informed healthcare beyond the departments of speech, psychology and occupational therapies and integrate it in everyday healthcare. Mandate a module on neurodivergent needs in the training of daycare educators, mental health and social work counsellors, physiotherapists, sex educators, maternal healthcare workers, parenting mentors, retirement home and aged care providers, etc. Supports need to reflect that Autistic children grow up to be Autistic adults and we will require tailored support across the lifespan.

- Build in age-based, screening checks, performed by GPs, for the entire population at different life stages. Collecting data longitudinally (for example at key transition periods and life stages, like early childhood, primary school, puberty, post-school, parenthood, menopause) will allow for more sensitive, accurate and timely identification not only of Autism, but frequently co-occurring (and frequently misidentified) conditions. This process, then, would not need to be Autism specific, but could equally identify conditions commonly experienced at greater rates in the Autistic population. For example, when talking to a GP about family-planning, questions around hypermobility, sensory sensitivities, and autoimmune disorders could highlight a pattern that requires further investigation. When a teenager attends an appointment, a standard assessment for eating disorders, mental health issues, gender divergence, mood irregularities or sleep problems might indicate unmet Autistic support needs. Early identification and being connected with neurodivergent-affirming services could vastly improve the health outcomes for our community.

- Rewrite the government-provided baby health record book and overhaul the community health nurse check-up process so that these validate, rather than pathologise, atypically developing babies. For example, reframe questions like, "does my baby play appropriately with toys?" to acknowledge that all play in which the child feels safe and supported is "appropriate play". If a baby is to grow up feeling that they are valued by society exactly as they are, it begins with affirming their mother that their baby is valued as they are. Diverse development in all its guises needs to be normalised and valued.

These suggestions are just some ways that a Strategy could direct change and improve the lives of the Autistic community, across the lifespan.