

FEEDBACK TO NATIONAL AUTISM STRATEGY

By parents of a profoundly autistic young man
20 January 2025

As parents of an inspiring young man with Profound Autism¹, we have taken a keen interest in the development of the National Autism Strategy (NAS). We appreciate the efforts of many involved, and the intention to provide a national strategy.

We contributed extensively to the Senate Select Committee on Autism² and to the NAS. We raised concerns related to the marginalisation of the most vulnerable from early in the process. Our written response to the draft NAS concluded with the challenge that if it is to achieve its stated goal, it must be substantially revised to address the needs of individuals with Severe and Profound Autism.

We are pleased that the feedback and rework following the draft NAS appears to have moved things in a better direction and added some vital aspects to the scope, but disappointed that this is still nowhere near sufficient. The strategy now acknowledges that those with Severe and Profound Autism exist, however it seems to treat the highly vulnerable people in these cohorts as marginal 'intersections' rather than as central to the strategy. This is overall a poor outcome for those with Severe and Profound Autism and their families and carers.

We list 20 observations and thoughts as feedback and for consideration in future efforts:

1. **Vision Statement and Goal** look solid and broadly appropriate to a wide range of cohorts within the autistic population. The **Focus Areas** look appropriate and have been filled out to include some vital issues.
2. **Guiding Principles** are improved in some cases from the draft NAS but still contain some contentious viewpoints, reflecting partisan perspectives, so are inevitably divisive. In some respects, these are less appropriate to those with Severe and Profound Autism than they were in the draft NAS. The implied conflation of Autism and identity is problematic for many.
3. **Severe and Profound Autism:** Marginalisation and inappropriate categorisation of those with Severe and Profound Autism will result in deficient outcomes for many of the most vulnerable. The NAS cannot fairly claim to be appropriate to every Autistic person in Australia. It predominantly uses "partial representation"³ which results in over-generalisations and leaves the most vulnerable behind.

¹ **Profound Autism** is defined according to the 2021 Lancet Commission recommendation, which includes being nonverbal or minimally verbal, with IQ < 50 and needing 24/7 support. This definition provides critical specificity to the extremely broad spectrum. A 2023 CDC Public Health Report on The Prevalence and Characteristics of Children with Profound Autism, using data from the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, found that 26.7% of 8-year-old children with Autism suffer from Profound Autism, with an overall birth-cohort prevalence of 0.46% of 8-year-olds. For the children with IQ data available in the records, the Profound Autism rate was 29.4%.
<https://autismsciencefoundation.org/profound-autism/>

² Senate Select Committee on Autism (2022), [Services, support and life outcomes for autistic Australians – Parliament of Australia \(aph.gov.au\)](https://aph.gov.au/Services_support_and_life_outcomes_for_autistic_Australians_-_Parliament_of_Australia)

³ McCoy et al. (2020) coined the term "**partial representation**" to describe situations in which an actor or subset of a population claims to represent an entire group of people but appropriately engages with only a subset of that group. Common in autism advocacy, the term "partial" reflects that such advocacy is necessarily both incomplete and biased.

4. **Strengths based- and neurodiversity-affirming practices** are chosen as “the standard”. This is problematic. The approach of force-fitting this paradigm onto all autistic people is a disservice to many, especially many of those with Severe and Profound Autism. It inevitably marginalises many of the most vulnerable and causes offence and deep hurt to their families and carers. Despite strong warnings from many in these cohorts, in response to the draft NAS, the authors have unfortunately chosen to proceed with this divisive approach.
5. **“Non-speaking” or “minimally speaking”** is a poor choice as it does not adequately reflect those with Severe and Profound Autism, or the terminology of many of those who are in these cohorts. It sounds like the authors assume that those who are non-speaking can just communicate fluently with AAC or sign. For many that is not the case.
6. **“Very high support needs” or “Complex”** is inadequate proxy terminology for Severe and Profound Autism. It skips right over the person living with diagnosed conditions to their support needs. The use of this as a misleading placeholder for Severe and Profound Autism is a key weakness infecting the entire Strategy, hiding the most vulnerable and distinctly different cohorts from view.
7. The **Statement on Language** is partisan and divisive. We recommended the use of identity-first and person-first language in combination, rather than selecting one position that is not appropriate to all people with autism. Person-first terminology is seen by many as more respectful and valuing of the person. Many of our family members live with autism, which can't be cured, but which also doesn't define them. They are greatly valued as unique individuals, but their "neurodiversity" is not always something to be celebrated or "affirmed". The “Medical model” in the glossary is also a misrepresentation based on an inappropriate conflation.
8. **Heterogeneity ignored:** Saying that terms such as ‘high functioning’, ‘low functioning’, ‘profound’, ‘severe’ and ‘mild’ autism may be used by some people to describe the challenges and barriers experienced by Autistic people and their families and carers is misleading and fails to reflect the input from families and carers. Severe and Profound Autism describes the internal condition, not the environmental challenges and barriers.

In choosing to avoid the preferred terminology of those in the cohorts of Severe and Profound Autism and instead using a catch-all term **‘all’ Autistic people**, critical specificity is hidden and **FROM THIS POINT THE NAS IS DESTINED TO FAIL THE MOST VULNERABLE**. Mashing data together from totally different cohorts into ‘autistic averages’ is highly misleading, hides vital nuance and distinctions and very substantial differences in life outcomes. Strategies based on averages will be frequently inappropriate.

Sample data from UK Autism Research Charity Autistica⁴:

- Epilepsy and Autism but no ID in 8% of population.
- Epilepsy with Autism and an ID in 20% of population.
- Epilepsy with Autism and a severe ID, potentially as high as 40% of the population.
- Often epilepsy presents differently in Autism; onset is often in adolescence not childhood and potentially more resistant to treatment.
- Of all autistic people with a concurrent ID, half don't make it to see their 40th birthday.

In their study *Estimating Life Expectancy and Life Lost For Autistic People In The UK*:

- Autistic people have a life expectancy 16 years less than the average population.
- Autistic people with an ID have a life experience that was 30 years less than the average.

⁴ UK Autism Research Charity Autistica (<https://www.autistica.org.uk>)

Quoting the 'Autistic averages' means that shocking statistics like this, for those with Severe and profound Autism are obscured, watered down and do not attract desperately needed attention. Those with ID live much less than average, those without do not (in fact, almost in line with average life expectancy!) This is clearly a major flaw in the strategy.

9. **'Lanes' analogy:** A helpful analogy is different 'lanes' in the spectrum, which are so different that it requires a high level of grace and humility to interact respectfully but allow the different cohorts to speak between lanes. The very different cohorts can cheer each other on and take a keen interest in each other's progress, even offer help and ideas, but if one lane dominates the public discourse and claims to represent all lanes, it works very poorly. It lacks respect and humility and results in discord and misunderstanding. The NAS has facilitated domination by the neurodiversity-affirming lane and essentially proposed to force that single lane upon a highly heterogeneous population. At the very least, a "Profound Autism" lane is desperately needed.
10. **Statement on Autism** is not appropriate to those with Severe and Profound Autism - Autism seems to have been reinvented in Australia and our loved ones are now out of the frame (or squeezed into 'complex support needs' near the bottom of a long list of 'intersectional' attributes). Severity of Autism should not be classified as an "intersectional" attribute as it is part of the presentation of Autism. The statement and About Autism sections come nowhere near adequately describing the condition as our son experiences it. It doesn't acknowledge that for some Autism is a profound disability. The definition doesn't even mention the DSM-5 or severity levels. It is manifestly inadequate.
11. **Intersectionality** is far too prominent. The NAS should be focused on Autism and its wide range of presentations. It appears that intersectional attributes are used to effectively replace severe/profound disability. These other factors are already considered widely however this strategy should be focused on Autism.
12. **'Autism affirmation'** as a blanket approach represents a substantial overreach and is offensively inappropriate to many. Assuming 25-40% of autistic people in Australia fit the Lancet criteria for Profound Autism, that is a substantial cohort that needs to be central. This seems to be the elephant in the room. It seems the NAS authors reluctantly acknowledge some aspects or symptoms of the elephant, but conflate or group those with 'intersectional attributes', thus obscuring the elephant. This emphasis seems relentless in Australia. Even after the INSAR event in Melbourne in 2024, with Dr. Mathew Siegel's challenge to face into Profound Autism, the NAS authors failed to take heed, rather continuing to pretend that the elephant is not there.
13. **Ableist paradigm** is evident, inferring that disability is something to be ashamed of or denied.
14. **Proportional under-representation** remains systemic. For the NAS this was likely influenced by the selection of a heavily unbalanced NAS Oversight Council. The NAS should rather have reflected a very broad and balanced representation of realities from the very different worlds that the Autism spectrum covers, in line with the Senate Committee's report on Autism (2022)⁵. The process used did not achieve this, nor was there any apparent genuine attempt to.

⁵ Senate Select Committee on Autism (2022), Exec Summary p. x-xi, [Services, support and life outcomes for autistic Australians – Parliament of Australia \(aph.gov.au\)](#)

The National Autism Strategy should be co-designed by the autism community. The inquiry found that the diversity of views within the autism community is linked, at least in part, to the breadth of the spectrum itself. The divergence in views was most apparent between autistic self-advocates and parents of autistic children with more complex presentations, who are heavily or completely reliant on parent or carer advocacy ... Accordingly, the committee believes that an inclusive co-design process— drawing on the autistic community, as well as parents, carers, researchers, and policy makers—must underpin development of the strategy.

15. **Service and Supports:** The following is highly problematic: “Actions delivered under these commitments will take into account: the differences in presentation by different cohorts (for example: girls, women and gender diverse people); intersectionality; and the need for tools, supports and services to be tailored for different cohorts and to be neurodiversity-affirming. The development and delivery of actions will seek to be co-designed or involve Autistic community/academics as appropriate.” This appears to indicate that services and supports will not consider severity of autism, or those with Severe and Profound Autism, and will exclude any representation from those cohorts in co-design. Supports mitigating harm from very serious Self Injurious Behaviours will not be treated appropriately if these are normalised and affirmed and no one with lived experience is involved in co-design. That ideological lens only helps some people in the spectrum, while the horrors of seclusion and restraint will continue to harm many others. It is telling that restrictive practices (and Profound Autism) are only mentioned in the glossary. Even a 6-year Royal Commission does not seem to have raised this as worthy of proper consideration in the NAS! We think this is an egregious oversight.
16. **Health and Mental Health:** The draft Autism Health Roadmap is also not appropriate to those with Severe and Profound Autism. It presents glaring omissions, incredible ignorance of a large, vulnerable group, and rank ideology-driven selectivity. In its current form, we’d need to ask for a separate roadmap that properly includes our son and those with severe/profound disability. This roadmap is nowhere near satisfactory from our perspective and should not be referenced by the NAS.
17. **Economic Inclusion:** One major oversight, which highlights the problem of treating all autistic people as one group, is the large number of autistic people who can’t join the paid workforce; vocational considerations for them are absent from the NAS. Even the placeholder action ‘building a better understanding of the needs of Autistic people and their carers who are not in the workforce to inform future actions’, appears to be appended to the bottom of the ‘Improving employment opportunities and support for all Autistic people in the workplace’ action, and is aligned to address the issue ‘Improve employment supports and opportunities for Autistic people’. It seems to be very much an afterthought and void of a suitable context or any content. Many families and carers spend a great deal of time and effort preparing meaningful programs and activities for profoundly autistic family members. This vital activity is not visible in the NAS.
18. **Research:** The approach of treating all autistic people as one group is also likely to render the proposed epidemiological study of Autism in Australia ineffective as it will overlook critical specificity as has been done in recent research. Publications by Autism CRC, including national guidelines meticulously screen out Severe and Profound Autism and adopt an exclusive and exclusionary neurodiversity affirmation ideology. It is a shame and renders their work close to useless, even detrimental, to those most severely disabled. We asked CRC’s CEO how we can complain, but didn’t get a response on that – is there any accountability? Will the NAS require any accountability in the future?
19. **Diversity of terminology**⁶: Regarding the stated intent to find definitions and terminology for Autistic people to reflect the full diversity of the Autistic community, the stubborn resistance to

⁶ From [A full semantic toolbox is essential for autism research and practice to thrive - Singer - 2023 - Autism Research - Wiley Online Library](#): *The push for neutral language robs the scientific community of the ability to describe, with accuracy, the day-to-day realities of life of people with autism, particularly those with profound autism. No one should have the power to limit language to exclude the observable realities of autism. Clinicians and scientists need access to the full semantic toolbox to describe the multiple realities of autism and make progress toward understanding patient experiences and needs, the various underlying causes and the future for meaningful treatments.*

acknowledge the existence and preferences of those in the Severe and Profound Autism cohorts suggests that this is an empty statement. The NAS has remained so far off course, from the establishment of the NAS OC onwards, that it doesn't seem likely that the diversity in the community will be acknowledged by those making such decisions any time in the near future.

20. **Neurodiversity Paradigm:** Useful to many, but it has substantial shortcomings that must not be ignored. The NAS ignores them. Not least is the greatly diminished acknowledgement of the profound disability experienced by many autistic people. A strategy of force-fitting this paradigm onto all autistic people is a great disservice to many, especially many of those with Profound Autism. It can result in the marginalisation of the most vulnerable and offence and deep hurt to their families and carers.

The truth is that for some people, autism may be a gift, while the simultaneous truth is that for other people, autism symptoms are a tremendous burden, a lifelong disorder, for which society should seek understanding, prevention and medical intervention. The tragic irony of the neurodiversity movement, which has dominated federal autism policy for a decade or more, is that, while it is a potent civil rights movement, it has itself resulted in the denial of basic human rights to those suffering with profound autism.

(Autism Science Foundation CARES Act White Paper 2024)

Unfortunately, the authors have chosen to proceed with this divisive approach, prioritising one highly contentious, ideologically loaded, view of autism (neurodiversity affirming) to the exclusion of the most vulnerable, denying basic human rights to those suffering with Profound Autism.

It does appear that there is need for a separate NAS for Severe and Profound Autism, which recognises the reality of severe/profound disability for many. The NAS fails to adequately acknowledge that Severe and Profound Autism exists and to properly consider and include the beautiful, vulnerable people in those cohorts.

Perhaps the most pragmatic application of the NAS to someone like our son is found in p.15, which acknowledges that those people with disability aged under 65 with substantially reduced functional capacity will continue to be supported through the NDIS. One take out may be that the NDIS is there for those autistic people with the greatest functional impairments (profound disability) and the NAS is focused on the others.

While we appreciate the efforts of many advocating for our son and his vulnerable cohort, it was evident from the start, looking at the makeup of the Oversight Council, and at which time we called it out, this was set up to be a neurodiversity fest and heavily weighted to that outcome. The co-design process could not be genuinely called inclusive. We and many others suggested that correcting course would require stepping out of the ideological bubble, taking an ideologically 'agnostic' standpoint, but this evidently did not happen. Accordingly, the NAS has not been constructed to include those with Severe and Profound Autism. This is a substantial missed opportunity and leaves unmet the desperate need for separate strategy for Severe and Profound Autism.