

OUR CONCERNS

- ❖ Marginalisation and inappropriate categorisation of those with Severe and Profound Autism (SPA) resulting in deficient outcomes for many of the most vulnerable.
- ❖ Systemic under-representation for autistic persons (SPA) with complex and high support needs.
- ❖ The Guiding Principles exclude diversity of opinion (e.g. SPA) and support contentious viewpoints.
- ❖ Accordingly, some Commitments are not inclusive of SPA.
- ❖ Vital issues including restrictive practices, abuse, research, schooling, health, housing and augmented communication and general services are inadequately addressed.
- ❖ No clear pathway for how the strategies will be actioned and outcomes measured, nor clarity of government agency roles and accountability.
- ❖ An ableist paradigm is evident, inferring that disability is something to be ashamed of or denied.
- ❖ Implementation of strategies made for SPA, but not with them, creating trauma and confusion.

ABOUT AFSA

The Autism Family Support Association (AFSA) provides a collective voice for people with Severe and Profound Autism¹ (SPA) and their parents, carers and families. We provide fellowship, peer support and information. AFSA actively raises our community's concerns with state and federal government policy makers to achieve better services and outcomes for autistic people and their families. Via our website, social media and meetings AFSA provides links to contemporary evidence-based information and resources, networks and support services. AFSA is managed by a voluntary committee. We represent lived experience and provide a voice for our autistic family members and their loved ones. We partner with like organisations to share our experiences and information.

INPUT TO DRAFT STRATEGY

A group from the AFSA committee provided input to the draft National Autism Strategy (NAS) in October 2023, emphasizing that those with Severe and Profound Autism need to be central to the strategy. It was strongly recommended that the NAS needs to reflect a very broad and balanced representation of realities from the very different worlds that the Autism spectrum covers. This input was in line with the Senate Committee's report on Autism (2022)², which called for the development of a national strategy. The report identified a divergence in views, most apparent between autistic self-advocates and parents of SPA family members, who are heavily or completely reliant on parent or carer advocacy. The Senate committee saw the NAS as an opportunity to find common ground and

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%.

² Senate Select Committee on Autism (2022), Exec Summary p. x-xi, [Services, support and life outcomes for autistic Australians – Parliament of Australia \(aph.gov.au\)](#)

recommended an inclusive co-design process, drawing on autistic people, as well as parents, carers, researchers, and policy makers.

Several AFSA families also submitted individual testimony of lived experience as input to the draft strategy. It appears that this input has been effectively ignored.

FEEDBACK TO DRAFT STRATEGY

As foundational elements, the Vision Statement and Goal look solid and broadly appropriate to a wide range of cohorts within the autistic population. The Guiding Principles however reflect some partisan perspectives on contentious issues; they appear inevitably divisive. From the orientation established in these principles, the draft strategy appears limited to a course that fails to adequately consider the diverse circumstances, needs, challenges and preferences of many autistic people and their families. In particular, the principles appear to force-fit a neurodiversity-affirming approach too broadly, and to prioritise intersectionality over SPA. Many elements of the strategy are filtered by these contentious perspectives. We take this opportunity to provide feedback and suggestions on various elements of the draft strategy from the perspectives of many people with SPA and their parents, carers, and families.

Statements on Language and Neurodiversity

These statements show partiality and marginalise the viewpoints of those with different preferences. We recommend the use of identity-first and person-first language in combination, rather than selecting one position that is not appropriate to all people with Autism³. The claim that “This approach is supported by current research” needs explaining. What research? Did the research include profoundly autistic people and their families? If so, how was that research carried out? It is acknowledged by researchers that Profound Autism is dramatically underserved by research. It is concerning that highly relevant and important research and recommendations presented by the Lancet Commission (2021)⁴ seem to have been overlooked.

The proposition is made that many neurodivergent people believe that there is no “normal” or “healthy” type of brain or mind. However, there are many others in the Autism community who would disagree. Their viewpoints, often forged in some of the most challenging lived experiences imaginable, are not reflected. This appears to present a risk that the NAS may foster the normalisation of behaviours of concern (BOC), lack of functional communication, limited interaction with others, self-harm (SIB), absconding and endangering life.

The draft contains not a single mention of ‘profound’, ‘severe’, ‘severity’, ‘behaviours of concern’ (BOC), ‘self-injurious behaviours’ (SIB), pica, absconding and other everyday terms in the Severe and Profound Autism space. By contrast, ‘autistic burnout’, ‘camouflaging’, and ‘masking’ are listed. ‘Complex support needs’, although an inadequate proxy for SPA, is only mentioned once and well down the list of “intersectional” categories. It is certainly not central to the Strategy at all. It should not be classified as intersectional; it is part of the presentation of Autism.

³ 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.

⁴ The Lancet Commission on the future of care and clinical research in autism, [2021 Lancet Commission report](#)

Limits to Neurodiversity Affirmation

Although the Neurodiversity Paradigm is useful to many, it has substantial shortcomings that must not be ignored. 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.

"Neurodiversity-affirming" supports and services are appropriate to some autistic people, but not others. We recommend the inclusion of other viewpoints and paradigms to reflect the very substantial diversity of the Autism spectrum. Valuing each person for who they are is of course important and right, however conflating their Autism and identity is inappropriate for many. The reality of a profoundly autistic person in torment, inflicting devastating self-harm and facing unfathomable adversity each day is not appropriately considered difference to be affirmed. That person's Autism may never be core to their self-identity either. Accordingly, 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 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)

Intersectionality prioritised over Severe and Profound Autism

The Strategy intends to include a focus on intersectional (overlapping) disadvantage or discrimination experienced by autistic people, based on attributes such as: Aboriginality; age; disability; ethnicity; gender identity; race; religion; and sexual orientation. However, this focus appears to marginalise or even replace the much-needed focus on those with SPA. At best it conceals them and inappropriately categorises their profound disability as an intersectional attribute.

Under the principle of "Individualised and Holistic", severity of Autism is not considered. Impacting factors mentioned include disability, race, gender, sexuality, culture, age, body shape/size, religion, geography, socio-economic status, where they live, income, education, and the extent of support networks, but the critical factor of severity of impairment is omitted.

We propose adopting the term 'Profound Autism' as per the Lancet Commission's recommendation. That will enable critical distinction and reduce offence and misunderstanding if the various cohorts in the Autism community are humble enough to represent themselves and not claim to represent others who are not like them.

"There is a danger in our admirable desire to "bust" myths and "break" stereotypes of Autism, that we make those with severe challenges invisible in discussions and planning."

(Liz Websdale, AFSA Committee member)

Partnership, Universal Design and Governance

"In partnership" is the first listed principle, however it is our impression that families of profoundly autistic people have been left out of sight and their input to the draft strategy overlooked. The NAS oversight committee looks significantly under-represented of lived experience of Profound Autism. The

acute challenges of SPA are not like those of many self-advocates. Both types of experience are important and valid, but very different. Both cohorts have wonderful people with individual experiences and challenges, but the Strategy must go much further in adding SPA representation.

The second principle “Accessible based on Universal Design” prescribes co-leadership by autistic people and the Australian Government. How can those with SPA be involved? They are inevitably marginalised as the draft NAS demonstrates very well. The Senate committee report (2002) prescribed 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” (Executive Summary). The Strategy needs to greatly increase the inclusion of those with SPA and their families.

Commitment 21 relates to governance and the development of a framework to support co-leadership. It rightly includes autistic people but implicitly relegates parents and carers to a secondary level, again demonstrating the marginalisation of profoundly autistic family members who may not be able to participate directly in such processes.

Research Priorities and Discrimination

Commitment 22, relating to Research, reads “Explore how autism research can best be fostered and applied to policy and service delivery and underpinned by the Strategy’s Guiding Principles.” We contend that current Autism research in Australia is not adequately inclusive of autistic persons with complex and high support needs and those with limited functional communication. This is not addressed in the Strategy and the Guiding Principles as drafted are likely to perpetuate the current discrimination that research efforts in Australia demonstrate towards those with Profound Autism.

While trying to “deliver the best outcomes for autistic people of all ages”, this does not appear to extend to Autistic people of all levels of severity of impairment. It is reasonable to suggest that the principles underpinning the Strategy are likely to influence research direction in a manner that perpetuates the discrimination and marginalisation of those with severe and Profound Autism.

For example, UK Autism Research Charity Autistica⁵ In their study *Estimating Life Expectancy and Life Lost For Autistic People In The UK* found that while autistic people have a life expectancy 16 years less than the average population, those with co-occurring ID have a life experience that was 30 years less than the average. Further examples highlighting SPA distinctives are provided in the Appendix. Stratified research is required to properly address the widely varying needs of the various cohorts.

Economic Inclusion and Education

Regarding economic inclusion, it appears that employment is held up as the gold standard to achieve for autistic people. Where does that leave those with complex and high support needs? In abject poverty? With no accessible housing in the community? Unable to afford repairs amid frequent property destruction? No liveable pension? Their families, who often bear the costs, including being unable to work as they must care for their disabled family members, especially as children, are expected to live in poverty? These significant and relevant considerations appear out of scope.

AFSA would like to see robust housing at affordable prices in the rental market across the community in society and not just isolated in remote areas with limited or no access to services. More of such houses are needed also in Public Housing to reduce the lengthy waiting list. Otherwise, this cohort of autistic persons are marginalized, isolated, and put at great risk. They often find themselves homeless as landlords aren’t prepared to rent to them. Families struggle to maintain and repair the homes at their own costs so as not to breach leases. All of this adds to the deterioration of the mental health of the person themselves, their families and carers. It perpetuates the revolving door of homelessness in

⁵ UK Autism Research Charity Autistica (<https://www.autistica.org.uk>)

an already overstretched and burdened public housing situation. AFSA would like to see incentives for the private rental market to build accessible and robust housing.

Regarding access to education, those with SPA are funnelled into special school settings, frequently part time, regularly sent home or unable to attend school. Some are not afforded safety at school and may not attend as a result. No supports are provided when these students sent home, only permitted to attend a few hours, or unable to attend at all. Suspension (formal and informal) and expulsion disproportionately impact students with such disabilities.⁶ To support many autistic people, Tases and Universities need to invest in NDIS / Disability Officers that assist people with disabilities to pick the right course BEFORE they enrol. The inability and impediments to accessing education impacts on economic opportunities and in some cases keeps autistic people and their families relatively poor. Where are the outcomes from research done on the literacy levels of a special education Autism specific school compared to general population? Substantial barriers to employment not mentioned in the draft Strategy include Intellectual Disability and other co morbid diagnoses. The Strategy also makes no mention of supported employment, yet this exists and was raised by the Royal Commission with a call for award wages.

Safety, Health and Wellbeing

It is concerning that considerations of safety, health and wellbeing don't even mention self-injurious behaviours or the safety and wellbeing of family and carers. The complex needs of a single SPA family member can have a significant impact on a whole family, which may include other autistic people. The DSM-5 appears to be largely ignored, perhaps reflecting that the Neurodiversity Paradigm has been used in place of existing scientific and medical frameworks.

Practical safety issues are also inadequately addressed the draft NAS. Royal Life Saving research shows that autistic children and adolescents are three times more likely to drown than children without ASD.⁷ There is a recommendation for additional precautions to prevent drowning, including avoiding swimming alone and ensuring adequate supervision and swimming programs for SPA persons likely to abscond or be at risk in and around water.

There are also many stories in the news of SPA persons absconding, and endangering life. We include a sample compilation of these in the Appendix which comes with a warning that these stories are confronting and may be triggering, but they cannot be ignored when developing the NAS.

AFSA would like to highlight how inappropriate and unskilled care for autistic individuals can put health at serious risk, cause unnecessary restrictive practices like over medication and restraints, and lasting mental trauma. These experiences seem to occur predominately with the severe and profound autistic cohort. The NAS therefore needs to be inclusive of all autistic people and their experiences. The need for specialised training for supporting SPA individuals needs to be acknowledged in the strategies.

CONCLUSION

If the National Autism Strategy is to achieve its stated goal, it must be substantially revised to address the needs of SPA individuals. The NAS will set the tone for future generations diagnosed with Autism, including SPA, and needs to be a dynamic document which includes the specific needs and complexities of all autistic persons. As a very important foundational document, to do the NAS true justice, it must be comprehensive to include those with Severe and Profound Autism.

⁶ Victorian Ombudsman (2017) *Investigation into Victorian government school expulsions*. [Investigation-into-Victorian-government-school-expulsions.pdf \(ombudsman.vic.gov.au\)](https://www.ombudsman.vic.gov.au/investigation-into-victorian-government-school-expulsions.pdf)

⁷ Peden, A. E. & Willcox-Pidgeon, S. (2020) 'Autism Spectrum Disorder and unintentional fatal drowning of children and adolescents in Australia: an epidemiological analysis'. *Archives of Disease in Childhood* <https://adc.bmj.com/content/early/2020/03/13/archdischild-2019-318658>

REAL STORIES FROM AFSA FAMILIES

(WARNING - these stories are very distressing - please take care)

Vital issues inadequately addressed include restrictive practices, abuse, research, schooling, health, housing, augmented communication, and general services. We offer the following vignettes of real stories of lived experience of AFSA families and family members to illustrate the challenges that the NAS should be addressing for those with SPA.

Education

"Our child was only allowed to attend school for 1 hour a day, for multiple years for BOC. He is non-verbal and was totally segregated from all the students, even at lunch time." (AFSA member)

"My 16yr old SPA son was put alone into an empty room during school hours for 6 weeks, isolated from classmates before getting back-to-back suspensions because the Specialist Autistic School didn't know how to deal with challenging behaviours." (AFSA member)

"Our precious child has suffered hundreds of head banging incidents at school in recent years. School documentation shows seclusion recorded on numerous occasions. The Crisis Action plan directs staff to evacuate the courtyard area when staff safety is compromised, leaving our son without support when he needs it most, resulting in devastating SIB. The adjustments and supports provided have proven insufficient. No parent could or should be asked to send their child to an environment where brain damage is a possibility if a meltdown occurs. We have withdrawn him from school for his safety." (AFSA member)

"My son is now 23 years old and the transition from special setting to tertiary has not been easy with the introduction of NDIS. There are barriers that still exist such as lack of career counselling for students in special schools. Tertiary and Universities websites are not easy to read or supportive of students that need visuals or easy English approach. Accessibility Officers in Universities or TAFE settings can only support once a participant is enrolled, not before." (AFSA member)

Augmentative Alternative Communication

"My child is non-verbal and uses Augmentative Alternative Communication (AAC) to communicate. We were told in writing that he wasn't allowed to use his AAC at school until he knew how to use his AAC 100%. The teachers and leaders of the school even wrote this in the school BSP. This was a Special School. We removed him from the school." (AFSA member)

"We asked for a Communication Plan at school and for our non-verbal child to use his AAC. We would provide his AAC each day and this is to be used across all settings in his day, every day. They said they don't have the resources to support a communication partner while attending school every day." (AFSA member)

Restrictive Practices

"My child was put in restraints, harnesses, tied up to chairs and toilets, put in adult strollers all day, every day at school for years. He is non-verbal with no physical disability. They did this because he continuously absconded. There was no Communication Plan, Behavioural Plan, or Individual Learning Plan. We have many photos taken by the teachers, of our child in these restraints, who obviously don't see anything wrong with this. This is at a special school." (AFSA member)

Health

"At 16 this non-verbal SPA young man displayed BOC, police and ambulance were called. He was handcuffed, sedated, and sent to hospital from the DHHS house (now known as DFFH) where resided. He was sent without any disability support worker or any form of communication device and so was unable to express himself. At the hospital the ambulance handover included just the

name of the young man and that he came from a DHHS house. The doctor was unable to get any information from child nor house. FAIL.” (AFSA member)

“SIB includes banging his head against walls, glass, doors, etc. has been described to us as sounding like a watermelon being thrown against a wall. Our son can’t explain this to us, or to a counsellor or psychologist. Accessing medical help is near impossible. It takes years just to get a dental check up!” (AFSA member)

Housing

“A young male child moved through seven non disability specific DHHS houses without a dedicated disability support worker or disability specific case worker in 8 months. In these houses he was attacked, sworn at, punched, neglected all day with staff too scared to go near him. Some staff couldn’t speak English and could not communicate with child or family. As a result, the young man was in an unsuitable residence which put himself and other young residents and staff at risk. To potentiate this, the case workers involved were unknowledgeable in autism and disability. It is no wonder this young man now suffers to this day with PTSD, severe anxiety and depression, and self-harm.” (AFSA member)

“A 22-year-old SPA young man, with ID, predominately non-verbal, an absconder with challenging behaviours, OCD etc. is on the homeless register for 12 years, unable to find safe and secure housing in the public system. With his DSP income, he cannot acquire a lease or afford the private rental market. He currently lives with family in unsuitable community housing on a busy main road. The house has stairs which he frequently throws himself down. He kicks and bashes his head through the walls, smashes glass with his body, has incontinence accidents on the carpet and absconds through unsecured front door and side gate. The house is not suited to his needs but to fix and make safe would breach the restrictive practices guidelines. This is the 5th house in 6 years he has lived in; he can ill afford to move again unless to a more permanent and suitable location. Mother and support staff and rest of family spend 90% of the day trying to keep the young man safe in the house and safe in the community.” (AFSA member)

AFSA COMMITTEE

Submission jointly prepared by the Autism Family Support Association Committee, presenting a collective voice for people with Severe and Profound Autism and their parents, carers and families.

Sarah Weinstock (AFSA President)

Tracey Hayes (Vice President)

Despina Havelas (Secretary)

Tim Pryde (Treasurer)

Liz Websdale (Committee member)

Joe Stosser (Committee member)

APPENDIX

Incidence of Autistic People with Intellectual Disabilities

- Italy research: 40% of people with an ID are autistic. 70% of autistic persons have an ID.
La Malfa, et al 2004 'Autism and intellectual disability a study of prevalence on a sample of the Italian population', *Journal of Intellectual Disability Research*.
- In the UK and US 40-60% of autistic persons have an ID
Buescher, et al 2014 'Costs of ASD in the United Kingdom and the United States', *JAMA Paediatrics*.

Prevalence of Profound Autism

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/>

Co-occurring Conditions

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

- 60-79% of the autistic population experience at least one mental health condition.
- Epilepsy with Autism and an ID in 20% of the population.
- Epilepsy and Autism but no ID is 8% of population.
- 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.

Abseonding and danger to life

(WARNING - these stories are very distressing - please take care)

- ✘ July 2023, Aluel Ajak a 9-year-old non-verbal autistic girl killed on busy Sayers Road, Werribee at night. She climbed out of her bedroom window and ran onto the road.
- ✘ Jan 2023, missing 9-year-old non-verbal autistic boy missing from Braybrook for 2 hours. Found tired and exhausted in the Maribyrnong River 2.5km from home.
- ✘ Sep 2021, 3-year-old Anthony Elfaalah, non-verbal, missing from rural NSW property found in a gully 3 days later.
- ✘ 2018, Alex Raichman, autistic, non-verbal, after repeated attempts absconded from respite and hit by a train. Coroner found his death completely preventable had safety measures been put in place.
- ✘ 2011, 6-year-old autistic boy dressed only in a nappy and in bare feet wandered from his Corio home, hit and killed by a train. Several people had sighted him on the Princes Hwy but didn't stop.
- ✘ November 2013, Felix Hua, 14, autistic, who had an attraction to water and couldn't swim drowned in the Yarra River near Fairfield, left unattended by his untrained support worker.
- ✘ Nischal Ghimire the carer for Kevin Maghsoodi drowned in the Glenelg attempting to save the 10-year-old non-verbal autistic boy. The family then used up all their NDIS funding on 2 carers rather than one. The NDIA agreed to fund 2:1 care for the boy, however too late for his carer, Nischal.