

Profound autism in Australia

Making people with profound autism visible in
policy, research and services.

Prepared by the Profound Autism Advisory Committee
Autism Association of Australia
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Some autistic Australians need lifelong, round-the-clock support. Our systems can't yet see them.

Understanding of autism has changed considerably over recent decades. Autism is now recognised as encompassing an exceptionally broad range of presentations, from people who live independently with relatively modest support needs to people with profound communication, cognitive and adaptive impairments who require lifelong, 24-hour care.

As the autism spectrum has broadened, the term autism on its own has become less informative about an individual's functional abilities, level of disability or support needs. Clinical diagnostic criteria remain, but the way autism is described and understood across research, policy and public discourse increasingly encompasses people whose experiences and needs may be fundamentally different.

At the same time, international understanding of profound autism is becoming more clearly defined. Emerging consensus around this population creates an opportunity to identify, measure and respond more effectively to autistic people with the greatest functional impairments and support needs.

That diversity is one of the defining characteristics of autism. It is also one of the greatest challenges for public policy.

Within the broader autistic population is a substantial group of people with very significant cognitive, communication and adaptive impairments who require intensive, lifelong support. Increasingly, international researchers and surveillance bodies have used the term profound autism to identify this population for research, epidemiology and service planning.

HOW THE DEFINITION HAS DEVELOPED

2021

The Lancet Commission introduces *profound autism* as an administrative term for autistic people with the most substantial cognitive, communication and support needs (Lord et al., 2022).

Since

The US Centers for Disease Control and Prevention applies similar criteria in autism surveillance (Hughes et al., 2023).

2026

A multi-stakeholder Delphi process involving researchers, clinicians, autistic adults and caregivers produces the first consensus research definition of profound autism (Siegel et al., 2026).

The definition identifies a population characterised by substantially impaired adaptive functioning, a need for adult supervision to maintain health, safety and wellbeing, and severely impaired cognitive abilities and/or minimal functional communication.

Terminology continues to evolve. What is becoming increasingly clear, however, is the importance of being able to identify and study autistic people whose disability and support requirements differ substantially from those of autistic people with greater functional independence.

The size of this population is significant. International estimates suggest profound autism may represent approximately 25 to 30 per cent of autistic people. Australian research provides further evidence of a substantial cohort. In a study of 513 autistic children aged 1 to 16 years attending a multidisciplinary diagnostic and assessment service in Sydney, approximately one quarter met criteria indicating they were at risk of profound autism (Hodge et al., 2025).

25–30% of autistic people may meet criteria associated with profound autism, on international estimates.	513 autistic children aged 1 to 16 years took part in an Australian diagnostic and assessment study in Sydney.	24% of them met, or were at risk of meeting, criteria for profound autism (Hodge et al., 2025).
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Yet people with profound autism remain poorly visible across many of the systems intended to understand and support autistic Australians.

They are underrepresented in research. Their experiences can be obscured when outcomes are reported for autistic people as a single population. Many cannot participate independently in conventional consultation, advocacy or co-design processes. Their lifelong support requirements have significant implications for disability services, health care, housing, crisis response, workforce planning and family support.

This creates a fundamental policy problem.

When governments cannot reliably identify a population, they cannot accurately measure its outcomes. When they cannot measure outcomes, they cannot confidently determine whether services are effective, whether resources are appropriately allocated or whether policy is improving people's lives.

Recognising and reporting on profound autism is therefore essential to good public policy. This is a population with substantial and often lifelong support needs, with significant implications for disability, health, housing and other government systems. Australia needs to be able to identify this population, understand its needs and outcomes, and accurately plan for the services and long-term expenditure required to support it.

This requires the information, structures and policy mechanisms to ensure autistic people with the most substantial disability are visible in government decision making.



This paper proposes six priorities.

Recognition

Australia should adopt an internationally aligned working definition of profound autism for appropriate research, data and policy purposes.

Representation

Consultation and co-design models should recognise that some autistic people cannot participate independently in conventional advocacy and policy processes.

Services and systems

Education, disability, health, behavioural, crisis and housing systems should be capable of responding to people with profound autism and high and complex support needs.

The purpose of this paper is to ensure that the profound and lifelong impairments experienced by some autistic Australians are fully recognised and addressed in policy, research and service design, and that people with the greatest support needs are visible in the decisions that affect their lives.

Measurement

Autism data should better capture differences in functional communication, behaviour, cognitive and adaptive impairment, medical complexity and support needs.

Research

Australian autism research should explicitly consider whether people with profound autism are included, excluded or affected by its findings.

Lifelong planning

Policy must take a genuine lifespan approach, accounting for education, transition to adulthood, meaningful daily activity, housing, ageing and the changing capacity of families to provide intensive care over a lifetime.



Autism is a spectrum. Policy needs to recognise what that means.

Autism encompasses an extraordinarily broad range of presentations. Its core diagnostic features include differences or impairments in social communication and social interaction, alongside restricted or repetitive behaviours, interests or activities, which can include significant differences in sensory processing.

How these features present, and their impact on everyday life, varies enormously. Some autistic people communicate fluently, live independently, participate in employment and advocate effectively for their own interests.

Others experience profound disability. This may include minimal functional communication, severe intellectual impairment, substantially impaired adaptive functioning and significant sensory and behavioural challenges. Some require assistance with most aspects of daily life and continuous supervision to maintain their health, safety and wellbeing.

These distinctions matter. Intellectual functioning, functional communication and adaptive functioning are related but different dimensions, and each can have a substantial impact on an autistic person's independence, safety and support requirements.

These differences have significant implications for autism policy and the way services and supports are designed.

Public systems need to accommodate the diversity of autistic experience without assuming that the needs, preferences, outcomes or life trajectories of one part of the autistic population can be generalised to all.

Profound autism has emerged internationally as a way of improving the visibility of autistic people with the most substantial functional impairments and support needs.

The Lancet Commission took an important step by introducing profound autism as an administrative term to identify autistic people with the most substantial cognitive, communication and support needs (Lord et al., 2022). The US Centers for Disease Control and Prevention subsequently applied similar criteria in autism surveillance (Hughes et al., 2023). This work has since progressed to a more clearly defined international position.

In 2026, a multi-stakeholder Delphi process involving researchers, clinicians, autistic adults and caregivers produced the first consensus research definition of profound autism (Siegel et al., 2026). The definition identifies a population characterised by substantially impaired adaptive functioning, a need for adult supervision to maintain health, safety and wellbeing, and severely impaired cognitive abilities and/or minimal functional communication. It applies from eight years of age and is intended primarily as a research definition rather than a clinical diagnosis.

There will continue to be discussion about terminology and criteria. That should not prevent Australia from addressing the underlying policy problem.

Governments, researchers and service systems need a reliable way of identifying autistic people with profound functional impairment and very substantial lifelong support requirements. Without that distinction, important differences in disability, need and outcomes can disappear within the breadth of the autism spectrum.

TWO IDEAS THAT ARE OFTEN CONFUSED

Profound autism

A particular functional profile: substantial adaptive impairment and severe cognitive and/or functional communication impairment, together with the need for ongoing adult supervision.

High or complex support needs

The level or nature of support a person may require. This can arise for many reasons, and does not describe the same thing.

An autistic person may have complex support needs without meeting criteria for profound autism, while a person with profound autism may require intensive lifelong support that is not necessarily complex. Recognising profound autism therefore complements, rather than replaces, broader approaches to identifying people with high or complex support needs.

Without that distinction, important differences in disability, need and outcomes can disappear within the breadth of the autism spectrum.



A substantial population with substantially different needs

Profound autism is not a marginal issue affecting a very small number of people.

International surveillance and research cited in this paper suggest approximately 25 to 30 per cent of autistic people may meet criteria associated with profound autism. An Australian clinical study similarly found that 24 per cent of autistic children in its sample met, or were at risk of meeting, criteria for profound autism (Hodge et al., 2025).

The Australian findings are particularly important because they also demonstrate the level of risk, complexity, and intensity experienced within this group.

AMONG CHILDREN MEETING, OR AT RISK OF MEETING, THE CRITERIA

49.6%

exhibited behaviours posing a safety risk, including elopement and drowning.

22.5%

engaged in self-injury.

38.2%

demonstrated aggression.

These figures should not be read as defining individuals by behaviour. They illustrate the level of complexity that families, schools, health services, disability providers and governments may need to respond to. Source: Hodge et al., 2025.

The broader functional profile described across international research includes minimal or absent functional communication, significantly impaired cognitive abilities, substantial adaptive impairment, high medical complexity, intensive daily support requirements, elevated safety risks and lifelong dependence on carers and formal services.

For families, phrases such as "24-hour support" are not abstract service categories.

- Supervision during every waking hour.
- Assistance with eating, dressing, bathing or toileting.
- Support to communicate basic needs.
- Active management of safety risks.
- Assistance to access health care.
- Behaviour support.
- Overnight supervision.
- Long-term decisions about housing, guardianship or supported decision making.

For many families, there is also the knowledge that this responsibility will continue long after childhood. That reality needs to be recognised in policy.

Policy designed around an average autistic person risks describing nobody particularly well.

The support needs of an autistic adult who lives independently are fundamentally different from those of an autistic adult who requires continuous assistance for communication, personal care and safety.

Both belong within autism policy. But they do not necessarily require the same policy response.

Australia's National Autism Strategy does not adequately make this distinction. While it acknowledges autistic people with very high support needs, it does not identify profound autism as a distinct priority cohort or provide a dedicated policy response to the markedly different needs and life trajectories of this group. As a result, some of the most significant differences within the autism spectrum remain insufficiently visible in the national policy framework.





The danger of the autistic average

Australia collects significant information about autism, disability and the NDIS. Yet broad population categories can obscure substantial differences within those populations.

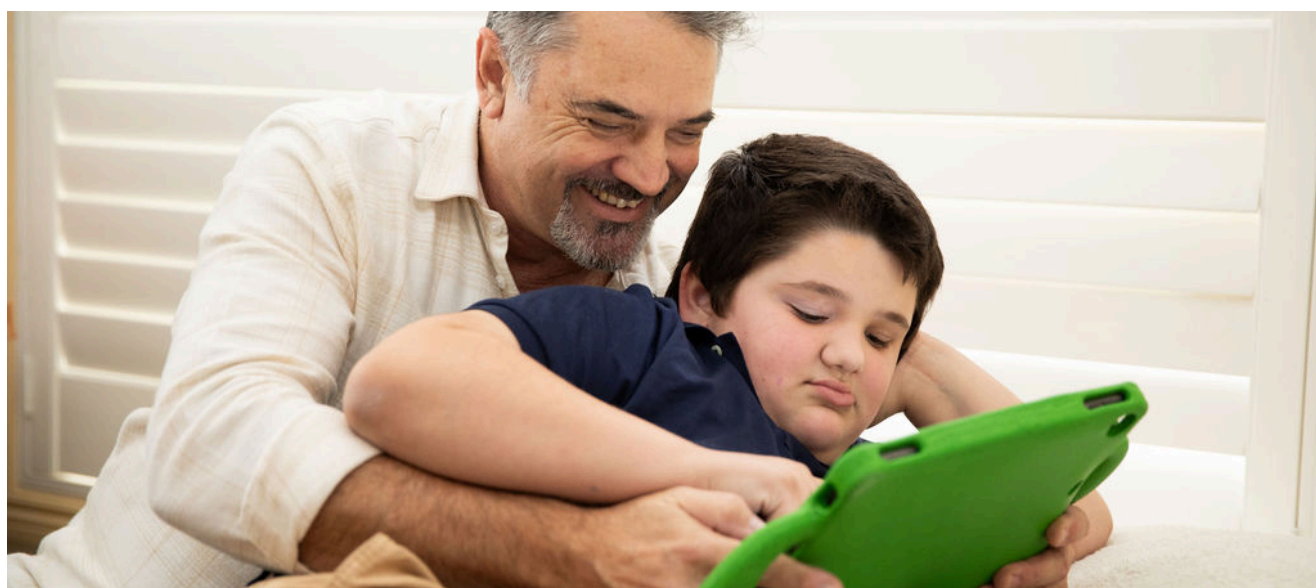
Averages can therefore be misleading. They can mask important differences in disability, support needs and outcomes, while still shaping how governments understand need, allocate resources, commission research and measure success.

If outcomes for autistic Australians are reported primarily at population level, substantial disparities between people with different functional profiles can remain hidden.

Without severity-specific information, Australia has limited ability to identify and respond to markedly different needs and outcomes within the autistic population.

The consequences extend beyond statistics. Without appropriate differentiation, policy may underestimate support intensity, workforce requirements and service complexity.

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- **Research findings** generated predominantly from autistic participants with fluent communication and greater functional independence may be assumed to apply more broadly than the evidence warrants.
 - **Service models** may be designed around people able to navigate appointments, communicate symptoms, tolerate and / or modify standard environments or participate independently in programs.
 - **Government** may struggle to accurately forecast long-term demand for disability supports, crisis services, housing and specialist health care.



The Australian Bureau of Statistics (ABS) provides an important starting point for understanding the extent of substantial disability within the autistic population.

73.0% of autistic Australians were reported as having a profound or severe disability.	59.7% had a profound or severe communication restriction.	47.7% had a profound or severe self-care limitation.
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2022 Survey of Disability, Ageing and Carers (Table 7.3, Australian Bureau of Statistics, 2024). Under the ABS framework, profound disability means a person is unable to perform, or always requires assistance with, at least one core activity of communication, mobility or self-care, while severe disability includes people who sometimes require assistance with a core activity or experience substantial communication difficulty.

Australia now needs to build a clearer picture of how functional impairment, communication, cognition, medical complexity and support needs interact within the autistic population.

The goal should not be to divide autistic Australians unnecessarily. It should be to ensure that differences relevant to health, safety, service planning and quality of life can actually be seen.





The people who can't advocate for themselves can be the easiest to overlook

Australia has rightly increased the role of lived experience in public policy. Autistic people should have meaningful opportunities to influence decisions affecting their lives.

But the autism spectrum creates a particular challenge for conventional models of consultation and co-design.

Most public consultation mechanisms rely on participation by people who are able to engage with the process in some way. Participants may be expected to complete written submissions, respond to surveys, attend workshops, understand complex policy questions, communicate abstract preferences, participate in committees or publicly advocate for their position.

The vast majority of people with profound autism cannot do these things independently.

Academic literature has described this as a problem of "partial representation", where advocacy and consultation can disproportionately reflect the experiences of autistic people who are able to participate in these processes. People with more substantial communication and cognitive impairments may consequently be less visible in policy development and public debate (McCoy et al., 2020).

Their absence should not be mistaken for an absence of interests, preferences or rights.

Nor does recognising this problem require diminishing autistic self-advocacy. It requires a more sophisticated model of representation.

Wherever possible, people with profound autism should be supported to participate and communicate their preferences in ways appropriate to them.

At the same time, policy affecting people who cannot independently participate must draw on additional sources of knowledge. These include parents and family carers who know the individual intimately, clinicians, researchers, behaviour professionals and specialist service providers with direct experience of profound disability.

No single group should be assumed to represent every autistic person.

The appropriate question is not which voice is legitimate. It is whether decision-making structures collectively contain the expertise and experience required to understand the people whose lives will be affected by the decisions being made.

For people with profound autism, representation must therefore be designed, monitored and reported rather than assumed.





The evidence base has its own blind spots

The same participation barriers affecting consultation also affect research.

Much autism research depends on participants being able to understand questions or instructions, comprehend what is being asked of them and communicate a response that can be meaningfully interpreted by researchers. Standard research methods may also require participants to read, complete assessments, describe their experiences or tolerate unfamiliar people and environments. For many people with profound autism, these requirements can make participation difficult without appropriate adaptations.

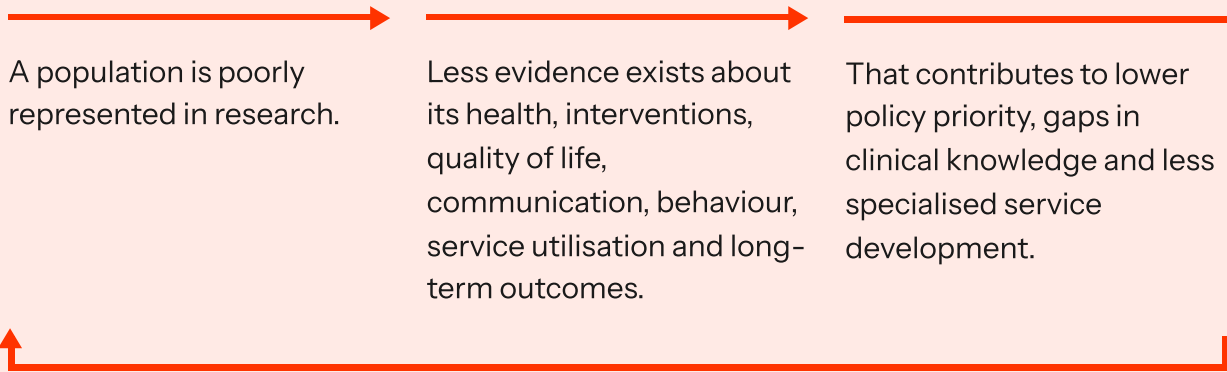
A DIFFICULT RESEARCH PARADOX

The autistic people with some of the most substantial health, communication, behavioural and support needs may also be among the least represented in conventional autism research.

Evidence suggests that autistic people with severe cognitive, communication and adaptive impairments have been systematically underrepresented in autism research. An analysis of 367 autism treatment studies published between 1991 and 2013 found that study participants became progressively less representative of people with more severe presentations over time, with increasing average IQ, communication and adaptive functioning among research participants (Stedman et al., 2019).

This has contributed to an evidence base increasingly shaped by autistic participants with fluent language, greater functional independence and, in important respects, different needs from people with profound autism. Findings from these populations may then be applied more broadly across the autism spectrum, including to people for whom the evidence is less certain.

THE CYCLE REINFORCES ITSELF



People with profound autism have historically been more difficult to include using conventional research methods, but this is not an insurmountable research problem. Established approaches can enable participation by adapting research methods to different levels of communication, comprehension, cognitive and adaptive functioning, and by involving families and support people where appropriate. Research examining the inclusion of autistic children with profound communication difficulties has identified practical strategies for addressing barriers to participation, including adaptations to recruitment, consent, assessment and study procedures (McKinney et al., 2021).

The involvement of families and carers also requires care in how evidence is interpreted. For people who cannot independently describe their experiences, parents, carers and other support people can provide essential information about health, behaviour, communication, daily functioning and quality of life. But a proxy perspective is not the same as the perspective of the autistic person themselves, and should not be presented as such.

The reverse is also important. The views and experiences of autistic people who can participate independently in research should not automatically be assumed to represent autistic people with profound autism. Different levels of cognitive, communication and adaptive functioning can produce materially different experiences, priorities and support needs. A rigorous evidence base should therefore distinguish between these perspectives rather than treating any one group as speaking for the entire autism spectrum.

The issue is therefore not whether people with profound autism can be included in research, but whether studies are designed from the outset to accommodate the diversity of the autistic population. This may require additional time, specialist expertise, adapted assessment methods and different approaches to participation and consent. In clinical and health research, it may also require greater flexibility in the environments in which research and assessment take place, particularly where standard clinical settings create additional barriers to participation.

INTERNATIONALLY, THERE ARE SIGNS OF A RESPONSE

In 2026, the Autism Science Foundation established its Profound Autism Pilot Grants and Pre-doctoral Fellowships program, supporting research focused specifically on people with profound autism, including work addressing some of the methodological challenges associated with studying this population (Autism Science Foundation, 2026).

Australia should consider the same underlying principle. Not every autism research project can or should include people with profound autism. But exclusion should be visible.

Researchers and funding bodies should be able to explain who has been included, which populations findings are likely to apply to, and where further research is required. Research funding should also recognise that including people with profound autism may require additional resources, specialist expertise and methodological flexibility.

The solution to difficult research should not be an evidence base that systematically knows least about the people with the most substantial support needs.



Invisibility has consequences for services and public expenditure

The needs of people with profound autism exist whether or not systems identify them explicitly. Where appropriate supports are unavailable, the consequences may emerge elsewhere.

Families absorb increasing levels of unpaid care, while support services face increasing pressure.

Disability services may struggle to respond to complex behaviour or communication.

Health needs may go unrecognised or become more difficult to treat.

Crises result in emergency department presentations, hospital admission, police involvement or emergency disability responses.

The National Autism Strategy recognises people with very high support needs as a priority cohort and acknowledges profound autism within its definition of that group (Australian Government, 2025). However, it does not provide a distinct policy response to the particular service, expenditure and planning implications associated with profound autism. Its broader approach is to address the needs of “all” autistic people, despite the materially different levels of impairment and support need across the spectrum.

Failure to adequately identify and understand the population with profound autism also has implications for how governments plan and allocate resources. If materially different levels of functional impairment and support need are not visible in population data, service planning and evaluation, governments risk misallocating resources, underestimating demand for intensive services, responding to preventable crises rather than planning for long-term support, and poorly forecasting future disability and service costs.

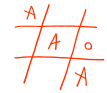
The logic is compelling, but the Australian economic evidence needs to be developed further. A stronger national evidence base should examine the relationship between profound autism and:

- NDIS expenditure and support intensity
- Educational experiences
- Crisis accommodation
- Specialist health care
- Workforce requirements
- Hospital and emergency department utilisation
- High-intensity behaviour support
- Housing and supported living
- Family and informal care
- Long-term government expenditure across disability, health and social services

This is important for reasons beyond cost containment. Good public expenditure should improve outcomes.

Governments need to know whether investment is reducing crisis, improving health and safety, building skills, supporting communication, sustaining families and improving quality of life. Without an appropriate way of identifying the population, answering those questions becomes considerably more difficult.





The school years matter

For children with profound autism, education is a significant part of the lifespan support system. The years between early childhood and adulthood are not simply a bridge between early intervention and transition from school. They are a substantial developmental period during which communication, adaptive functioning, daily living skills, emotional and behavioural regulation, safety and participation can continue to develop.

Conventional measures of educational achievement may not adequately capture progress for students with profound autism. For some students, meaningful educational outcomes may include:

- Developing a reliable means of functional communication
- Increasing independence in personal care and everyday activities
- Learning skills that reduce safety risks
- Increasing tolerance of everyday environments and activities
- Building the capabilities required for greater participation in family and community life

The quality and appropriateness of education therefore have consequences beyond the school years. Skills that are developed and maintained during childhood can influence independence, participation, behaviour, safety and the intensity of support required in adulthood. Equally, educational exclusion, inadequate communication support or failure to address complex learning and support needs can compound disadvantage over time.

The Disability Royal Commission documented significant barriers experienced by students with disability in Australian education, including inadequate adjustments and individualised supports, exclusionary discipline, restrictive practices, insufficient workforce capability and weaknesses in data and accountability. These issues are particularly important for students who have substantial communication and cognitive impairments and may have limited capacity to independently report poor treatment, unmet needs or experiences of abuse, neglect or exclusion.

Australia currently has limited ability to determine how students with profound autism experience the education system or what outcomes it produces for them. Education data should therefore allow outcomes for students with markedly different functional and support profiles to be examined rather than treating autistic students as a single cohort.

Governments should be able to identify whether students with profound autism are:

- Attending school consistently
- Receiving appropriate adjustments and communication supports
- Experiencing suspension, exclusion or restrictive practices
- Developing meaningful skills
- Remaining safe
- Being adequately prepared for adult life





Childhood is only the beginning

Much autism policy and public discussion is concentrated around childhood.

The substantial support needs associated with profound autism do not end with childhood. For many families, the transition from school into adult life marks the beginning of a new and often more fragmented service environment.

School provides structure, a daily destination and a defined service system. When school ends, families may encounter fewer structured opportunities, different health services, workforce shortages and limited housing options.

For the vast majority of people with profound autism, conventional paid employment is unlikely to be a realistic primary pathway in adulthood.

That should not mean a life without purpose, contribution or meaningful activity. With substantial and individualised support, some people with profound autism can participate in vocational, community-based or other purposeful activities as part of their daily lives, even where those activities are not economically productive in a conventional employment sense.

Policy should therefore avoid treating paid employment as the primary measure of successful participation in adult life. Meaningful outcomes may instead include purposeful daily activity, communication, relationships, health, community participation, skill development, greater independence and personal safety.

AREAS REQUIRING GREATER POLICY ATTENTION

- Suitable day programs and meaningful daily activity
- Supported decision making
- Long-term housing and residential options
- Coordinated crisis pathways
- Sustained support for family carers

Housing deserves particular attention. Many adults with profound autism will require highly supported living arrangements throughout their lives. The quality, stability and suitability of those arrangements can have profound implications for health, behaviour, safety and family wellbeing.

There is also a question that eventually confronts almost every family providing lifelong intensive care:

What happens when parents can no longer do it?

Carers age. Their health changes. Their physical capacity changes. Some families have spent decades providing extraordinary levels of supervision, advocacy and coordination.

A sustainable autism policy cannot assume that this informal care will continue indefinitely. Planning for profound autism therefore requires a genuine lifespan approach, extending from childhood through adulthood and into ageing.



A national framework for profound autism

Recognition alone will not improve anyone's life. Its value lies in what it enables Australia to do differently.

A national approach to profound autism should be built around six connected areas.

Recognition

Australia should adopt an internationally aligned working definition of profound autism for appropriate policy, research and data purposes. The definition should not replace individual assessment or clinical diagnosis.

Its purpose should be practical: enabling governments and researchers to identify a population whose support needs and outcomes may differ substantially from those of other autistic people. Terminology should remain responsive to emerging evidence and international consensus.



Measurement

Government data, research and evaluation should capture information that helps distinguish materially different levels of impairment and resulting support needs. Relevant variables may include functional communication, cognitive functioning, adaptive functioning, intellectual disability, medical complexity, the nature, frequency and intensity of behaviours of concern, and level of supervision.

The objective should be to understand meaningful differences in people's lives, including health, well-being, safety, communication, independence, quality of life, participation, education and, where relevant, employment. Measures also need to reflect the circumstances of people with profound autism. Employment, for example, may be an important outcome measure for many autistic adults, but tells us little about the wellbeing or progress of a person who requires lifelong 24-hour support.

For people with profound autism, meaningful outcomes may include improved functional communication, greater independence in daily living, improved health, reductions in the frequency or intensity of self-injury or other behaviours that place the person or others at risk, greater participation in everyday life, fewer crises and improved quality of life. Outcomes for families and carers, including the sustainability of care, should also be measured where relevant.

Government activity should not be confused with outcomes. Funding a program, developing a policy or delivering a service are inputs and outputs. The relevant question is whether those investments produce measurable improvements in people's lives.

Data collection must include appropriate privacy, consent and governance protections, while recognising established mechanisms for supported decision making and proxy involvement where an individual is unable to provide informed consent independently. These protections should enable the appropriate inclusion of people with profound autism, not become a barrier to their representation in data and research.

Excluding people who cannot independently provide consent can itself create an ethical problem, producing data and evidence that systematically underrepresent people with the most substantial disability.

Representation

Autism governance and co-design should use models capable of representing people who cannot independently participate in conventional consultation.

This should include direct participation by people with profound autism where this is possible and meaningful, while recognising that for many people with profound autism the nature of their communication and cognitive impairments makes direct participation in formal policy and co-design processes difficult or not possible. Families and carers therefore have an essential role in representing their interests and providing evidence about their lives and support needs, alongside clinicians, researchers and specialist practitioners with relevant expertise.

Representation should be judged by whether the needs and interests of the population are genuinely present in decision making.

Research

Australian research funding should require greater transparency about inclusion. Applicants should identify whether people with profound autism are included, how they are included and whether the findings are likely to apply to them. Where inclusion is not feasible or appropriate, this should be explained rather than left invisible.

Australia should also consider targeted funding for research specifically relevant to profound autism and for the development of methodologies capable of including participants with high and complex needs.

Services and systems

Profound autism should be visible across disability, education, health and service planning. This includes behaviour support, communication, medical complexity, crisis prevention and response, housing, supported living and specialist workforce capability.

The objective should be to prevent crisis where possible, rather than building systems that respond only when crisis occurs.

Lifelong planning

Government planning should recognise that profound autism is lifelong. Policy should address transition from school, adult health, meaningful daily activity, housing, supported decision making, family sustainability, ageing and long-term care.

The future should not depend on families reaching crisis before permanent solutions are developed.



Seven reforms Australia can begin now

The following reforms would provide a practical starting point.



1. Establish an agreed working definition

Develop and adopt an internationally aligned definition of profound autism for appropriate research, surveillance, policy and planning purposes. This should build on, rather than replace, the detailed clinical information already captured through autism diagnosis, including DSM-5 severity ratings and the presence of intellectual and language impairment.



2. Build severity and support-needs information into autism data

Government systems should retain and use relevant information about functional impairment and support need rather than recording autism diagnosis alone. For NDIS participants, this should include, where available and appropriate, the full diagnostic information relevant to autism severity, intellectual and language impairment, functional communication and adaptive functioning. The NDIA is particularly well placed to contribute to a national understanding of profound autism because people with this level of lifelong disability are likely to be substantially represented within the Scheme.



3. Reform representation and co-design

Ensure autism policy structures include appropriate mechanisms for people with profound autism to be represented, including through supported participation, families and carers, and relevant clinical and professional expertise.



4. Strengthen research inclusion and transparency

Require funded autism research to state whether and how people with profound autism are included, whether findings can reasonably be applied to them and how significant evidence gaps will be addressed.



5. Develop high-complexity service pathways

Build more coordinated policy responses across disability, health, behaviour support, crisis response, housing and specialist services for people with profound functional impairments and very substantial, often lifelong, support needs.



6. Strengthen safety and crisis response

National policy should recognise the elevated and distinct safety risks experienced by some people with profound autism and ensure health, disability, education, emergency and justice systems are equipped to respond appropriately. This should include prevention and response to elopement, behavioural and medical crises, communication barriers, emergency department presentations and interactions with police and first responders.



7. Create a lifespan policy response

Give greater national attention to how profound functional impairments affect people across the lifespan, and to the corresponding support needs that arise through the transition out of school, adult life, housing and ageing, including the changing capacity of families to provide lifelong care.

These reforms do not require Australia to create a separate autism system. They require existing systems to become more capable of recognising the substantial differences in functional impairment across the autism spectrum, and responding appropriately to the corresponding differences in support need.



What should Australia be able to answer?

The success of policy for profound autism should ultimately be judged by whether Australia can answer some basic questions.

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- 01 How many Australians live with profound autism or comparable levels of functional impairment and support need?
 - 02 What are their health and well-being outcomes?
 - 03 What are their safety outcomes?
 - 04 What is their quality of life?
 - 05 How frequently do they experience crisis?
 - 06 What are their experiences and outcomes at school? Are education settings able to meet their learning, communication, behavioural and support needs, and keep them safe?
 - 07 What happens when they leave school, and are appropriate pathways in place for the transition to adult life?
 - 08 What housing and daily support arrangements are available?
 - 09 What services and supports do they use, and are those services appropriate to their level of functional impairment?
 - 10 Where are the gaps in services and supports, and what are the consequences of those gaps for their health, safety, well-being, quality of life, families and support networks?
 - 11 Which interventions and models improve outcomes?
 - 12 How do their outcomes compare with those of other autistic Australians?
 - 13 What happens as their parents and carers age?
 - 14 And are government investments measurably improving their lives?
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At present, Australia cannot answer enough of these questions with confidence.

That should concern policymakers, researchers, service systems and families alike. Good policy begins with seeing the population clearly.

CONCLUSION



Australia needs systems capable of recognising multiple truths.

Autism is extraordinarily diverse. That diversity should be recognised and addressed rather than ignored or dismissed.

For many autistic Australians, autism exists alongside substantial strengths, independence and opportunity.

For others, autism is associated with profound and lifelong disability, minimal functional communication, substantial cognitive and adaptive impairment, serious safety risks and dependence on other people for many aspects of everyday life.

This full range of presentations, including profound and lifelong disability, needs to be reflected in Australia's understanding of autism.

Recognition of profound autism does not diminish the rights, identity or experience of any other autistic person.

Equitable policy must recognise the full range of autistic experience, including the reality that for some people autism is associated with profound functional impairment and lifelong disability. Minimising or overlooking these impairments risks excluding the very people with the greatest disability from the policies intended to support them.

There is an additional responsibility when the people most affected by policy are among those least able to participate in the processes through which that policy is made.

Their communication difficulties must not become political invisibility and exclusion.

Their absence from conventional advocacy must not be mistaken for an absence of interests.

Their complexity must not become a reason for exclusion from research.

And the breadth of the autism spectrum must not prevent Australia from identifying and responding to the people within it who have the greatest disability.



**A MATURE AUTISM POLICY SHOULD BE CAPABLE OF RECOGNISING
MULTIPLE TRUTHS AT THE SAME TIME**

**Autistic people are enormously diverse.
And some autistic people experience
profound, lifelong disability.
Australia needs systems capable of
recognising both.**

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