

Planning for Inclusion

Amaze Submission to the Next Disability Plan
2021 - 2025



About Amaze

Amaze is a community organisation established over fifty years ago by autistic people and their families. We work to build community understanding of autism, influence policy change for autistic people and provide independent, credible information and resources to individuals, families, professionals, government and the wider community.

Amaze seeks to achieve the following outcomes:

- Community understanding of autism increases over time
- Attitudes and behaviours towards autistic people by the community improve over time
- Opportunities for meaningful participation and valued contribution increase for autistic people

We are closely connected with the autistic community through our national help line Autism Connect, our peer support networks and community capacity building initiatives.

Amaze is *not a service* provider (for NDIS or otherwise). Amaze is a partner of the Australian Autism Alliance.

About autism

Autism Spectrum Disorder (or ASD) is a neurodevelopmental condition. Autism is not a disease. People are born autistic. It is a lifelong condition and there is no cure, but the way it affects people may change over time as a person grows and matures. Every autistic individual is different.

Autism frequently co-occurs with other conditions including other neurodevelopment conditions (e.g. ADHD, Dyslexia) and Intellectual Disability. 50-70% of autistic people also have mental health conditions.

For further information

Amaze stands ready to assist in the development of Victoria's next state disability plan. Nicole Rees, Deputy CEO and Executive Manager of Policy & Advocacy can be contacted at Nicole.rees@amaze.org.au to discuss this submission.



Overview

Amaze has high aspirations for the next iteration of Victoria's Disability Plan.

We call for a fundamental reorientation to drive inclusion of people with disability in mainstream life, to actively tackle discrimination – including ableism – and to reflect and accord human rights.

Strong targets to improve outcomes and inclusion across a broad range of life domains ought to be a feature of the next plan. A future Disability Inclusion Commissioner could co-ordinate, drive and monitor progress, and build capacity and capability in both the public sector and the broader community.

Disaggregated data to shine a spotlight on outcomes across and within the disability community is needed. An urgent focus on the plight of groups with the poorest outcomes – including autistic people – is warranted.

Shared governance and co-production with people with disability and their organisations will be critical to driving change. We urge the Victorian Government to move from the current information sharing and consultative approaches to true collaboration and empowerment – drawing inspiration from processes with First People's communities.

Enabling the voice of people with disability and their representatives through support for individual, self and systemic advocacy is foundational to a human rights approach. Ensuring systemic policy capability resides in the disability sector is a pre-requisite to meaningful co-production of policy and programmatic responses.

Stronger alignment of efforts across the Victorian public sector – government departments, agencies and local governments – would be significant improvement. Likewise, the change to strengthen connections between mutually reinforcing initiatives, such as embedding the Victorian Autism Plan in the next iteration of the state disability plan, ought to be grasped.

Continued efforts to educate the general community are pivotal to building an inclusive Victoria. Without changing community attitudes, little else will change.

Victoria's Covid recovery efforts need to include a strong focus on the disability community, many of whom have done it particularly tough during the pandemic. Skills and labour shortages, exacerbated by border restrictions, create an unprecedented opportunity to move the dial on the stubbornly poor employment outcomes for autistic people and others with disability.

Most of the autistic community already have co-occurring mental health conditions. For many, the pandemic has aggravated this. The needs of people with disability have to be top of mind in the design and implementation of recommendations of Victoria's Mental Health Royal Commission.

As Australia's most socially progressive jurisdiction, the next disability plan is an opportunity for Victoria to not just catch up with other jurisdictions, but to seed a legacy for change that will lead the nation.

Topic Area 1 - Improving how we describe disability and disability inclusion in the next plan

Recommendations

1. Re-orient the next plan to be the Victorian Disability Rights and Inclusion Plan

A new name for the forthcoming state disability plan will play an important role in setting the tone and ambitions for the next five year period:

- It needs to reflect an unequivocal commitment to operationalising major human rights frameworks, particularly the United Nations (UN) Convention on the Rights of Persons with Disabilities.
- Explicitly referencing inclusion in the title would indicate an overarching commitment to drive inclusion of people with disability in all aspects of mainstream life (as distinct from inclusion in disability settings).
- Naming “inclusion” would catch Victoria up with other states including New South Wales and South Australia who have already taken similar steps.

Recommendations

2. Reflect the Social Model of Disability in both the Plan and the Act

3. Highlight the damage caused by ableist perspectives and use the next Plan to address and prevent ableism

Amaze adheres to the Social Model of Disability. Our work is based on the idea that with the right supports, community attitudes, and environment, people with disability can thrive in society. The next plan needs to tackle the systemic barriers, derogatory attitudes and social exclusion practices that serve to disable our community.

This goes hand in hand with the need to address and prevent ableism, which positions people with disability as inferior or needing to be fixed. The next plan provides a critical opportunity to educate about the impact of ableist perspectives. Much can be learnt from initiatives to address sexism, racism and homophobia.

Recommendations

4. Sharpen the focus on invisible disabilities, which have not historically had the level of focus and attention warranted

The experiences of people with invisible disability need to be brought into much sharper focus. Outcomes for cohorts with invisible disability are demonstrably poorer across key like domains particularly education, employment, and mental health. This needs to be explicitly called out and addressed in the plan through purpose-built measures and initiatives.

Topic Area 2 – Finding better ways to include people with disability in making the next plan

Recommendations

5. Ensure Co-Production and shared governance is at the heart of the next Disability Plan


Lived Experience must be properly valued at all stages in the next Plan. Reflecting the principle of “nothing about us without us,” the next plan needs to be **co-produced** from end to end (design, measures and indicators, implementation, oversight, evaluation) with people with disability.

The [IAP2 Spectrum of Public Participation](#) (see below) maps the continuum of public participation. We urge the Victorian Government to move beyond the current consultative approaches into the collaborate/empower zone.

IAP2 Spectrum of Public Participation



IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

INCREASING IMPACT ON THE DECISION 					
	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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Shared governance is crucial for sustained attention and accountability. It provides safeguards and continuity as department staff and governments change. Inspiration can be drawn from the recent refresh of Closing the Gap – along with the [Victorian Marrang Education Plan](#) and [Burra Lotjpa Dunguludja Aboriginal Justice Agreement](#) – which have advanced governance and co-production processes, including at local, regional and state levels.



Recommendations

6. Ensure that ongoing engagement includes a range of lived experience voices, reflecting the diversity of the disability community

Special efforts are needed to ensure ongoing involvement of hard-to-reach groups. This will require sustained work by connected community sector partners and the dissemination of specialised materials in Easy and Plain English; in multiple community languages; through social scripts; through in person meetings and accessible and inclusive online forums.

Engagement needs to include place-based approaches to avoid a 'metro-centric' plan.

Topic Area 3 – Strengthening the State Disability Plan Outcomes Framework

Recommendations

7. Improve the measurement, monitoring and tracking of the plan by:

- Developing online reporting tools aligned to Disability Plan outcomes framework
- Disaggregating outcomes data to allow comparisons by disability type, locality and other intersecting factors (e.g. cultural and linguistic diversity, gender diversity)

Public access to consistent and easy to understand data is needed so that we can collectively monitor and track progress and understand in real time what is (or isn't) working.

Data that measures outcomes by disability type, place, and other intersecting factor such as cultural background is critical.

Recommendations

8. Establish stretch targets for increased participation in economic and community life, and for inclusion in mainstream settings

The next plan needs to be driven by ambitious targets to improve real outcomes in major life domains such as school and work. Corresponding targets to lift inclusion in mainstream settings are also needed. Such targets are conspicuously absent in recent major policy frameworks such as the recent Disability Inclusion Education Reforms. Some examples of possible participation and inclusion targets for education are set out below:

Participation (indicative targets by x%)	Inclusion (initiative targets by x%)
Increasing Year 12 completion rates	Increasing the proportion of students sustaining their enrolment in a mainstream school
Increasing completion of further and higher qualifications	Increasing the rate of uptake and completion of further and higher education
Increasing employment and labour market participation rates	Increasing participation in the open job market Increasing the proportion of people working in a job well-matched to their skills/experience

Recommendations

9. Improve transparency and accountability through the establishment of an independent report to Parliament, by a new Disability Inclusion Commissioner

In line with the idea of a new Disability Rights and Inclusion Plan and Act, reporting on outcomes could take the form of an Independent Report to Parliament by a new Disability Inclusion Commissioner (more in Topic Area 6).

Recommendations

10. Expand the Outcomes Framework to include three new areas:

- **Positive Identity and Acceptance**
- **Personal Relationships and Connections**
- **Agency and Decision Making**

Amaze supports the intentions behind the proposed new Outcome Area of 'Recognition and Pride', but cautions against co-opting the language of 'pride' from the LGBTIQ+ community (while noting there is much to learn from this movement). Instead, we suggest the alternative framing of **Positive Identity and Acceptance**.

This outcome area should go beyond awards and community celebrations, to meaningful indicators such as whether people with invisible conditions (such as autism) feels comfortable and safe to disclose, and the extent which the disability community is an accepted and embraced part of the diversity of the Victorian community.

Amaze welcomes the proposal for a new Outcome Area of 'Intimate Lives'; however, believes this outcome could be better understood and measured if split into two distinct areas:

- one specifically covering the **personal relationships and connections**
- the other addressing the ability to have **agency and decision making** across all areas in their own lives and care.

Topic Area 4 – Introducing overarching approaches to strengthen government commitments under the new plan

Recommendations

- 11.** Include commitments in the Plan to support individual and systemic disability advocacy, including autism advocacy

Access to advocacy, self-advocacy and self-determination supports, including mechanisms to self-represent to government, are enshrined in the United Nations Convention on the Rights of Persons with Disabilities.

Advocacy services support people with disability to exercise their rights and freedoms by the provision of individual advocacy support; enabling people to advocate for themselves; and influencing long-term, systemic change.

The Victorian Government's advocacy program currently provides legacy funding to a select group of organisations. Funding has been incrementally extended, with no opportunity for new entrants. Autism has long been overlooked.

International studies have revealed challenges faced by general disability advocacy services in supporting autistic people.¹ The findings align with recent commonly reported experiences of autistic people in Australia.² There needs to be scope for funded advocacy services that are designed to work with autistic people and their families, in parallel to generalist services for people with disability. With the advocacy movement for neurodiverse and autistic people being relatively new compared to those for physical disabilities, there is much ground to catch up in terms of the realisation of the rights of autistic people.

The introduction of the NDIS has vastly increased demand for individual advocacy support as people navigate a new, complex, marketised system – autistic people are the biggest NDIS cohort. Likewise, the NDIS has increased the need for systemic and structural advocacy capability, particularly in light of the significant changes that have been foreshadowed.

The current review of disability advocacy funding by the Victorian Government presents an important opportunity to revisit the structure and focus of government-funded disability advocacy programs. The next state disability plan must reflect an ongoing commitment to state support for both individual and systemic disability advocacy – including for autism.

¹ National Autistic Society, 2003. *Autism: The Demand for Advocacy*. Available at: <https://www.scie-socialcareonline.org.uk/autism-the-demand-for-advocacy/r/a11G00000017ykclAA>

² The Australian Autism Alliance's 2020 survey revealed more than 22% of autistic adults respondents did not know where to get help if they were experiencing violence, abuse or neglect; 45% did not know where to get help if they were experiencing discrimination or exclusive practices; 39% did not know where to get help to speak up themselves and self-advocate in general.

Recommendations

12. Embed connections to the Victorian Autism Plan in future iterations of the Disability Plan and Act

A real strength of Victoria's Autism Plan is its connections with the state disability plan, including the shared outcomes framework and connected reporting with the state disability plan. This mutual dependency needs to be embedded and strengthened in the next Disability Plan and Act to drive a mutually reinforcing approach and to ensure sustained and concerted commitment to lifting outcomes for autistic people.

Recommendations

13. Prioritise changing community attitudes and behaviours as a foundational plank of the next plan, including by:

- **Teaching disability as part of human diversity at school. Embed this in the curriculum and create high quality teaching resources.**
- **Investing in community awareness and behaviour research and public education campaigns.**

We welcome the intention to include Community Attitudes as overarching approach to strengthen Government Commitments under the plan. Without favourable community attitudes, little else can change.

Public education campaigns to promote social behaviour change, showing the diversity of disability have been shown to have an impact on community attitudes. An example is **Change Your Reactions**, a collaboration between Amaze and the Victorian Government to promote better understanding and inclusion of people with Autism. The first burst of the campaign evaluated very strongly, with nearly one in five autistic people and their families surveyed reporting "a change in the way people treated me", 68% of those who saw the campaign reporting having a better understanding of autism and 85% intended to refrain from being judgmental.

Recommendations

14. Increase the disability competencies of the workforce across all mainstream services. This should include comprehensive units on disability rights, access and inclusion as mandatory learning/professional development

Building the disability competency – including the autism competency – of key mainstream services workforces is a top priority. We note that the Victorian Autism Plan commits to the development of an Autism Workforce Capability Framework but understand this has yet to be operationalised. Implementation and monitoring of its impact are a must.

In discussions with Amaze staff to inform the preparation of this submission, a constant theme is that mainstream workforce capability is critical. One of our Autism Connect advisers observed:

“Many autistic children and young people are spending much of their day with adults who do not understand autism. We constantly hear from families facing the challenges of moving from one school to another in search of teachers that understand autism. This has huge impacts on their mental health and wellbeing.

The world would change for autistic people if they were appropriately supported from a young age by autism-proficient schools, with positive impacts and benefits across their life.”

Recommendations

15. Create consistency of reporting requirements under Disability Action Plans for government agencies and local councils to increase alignment and improve accountability

16. Strengthen local government capacity and capabilities to advance implementation of the next disability plan

A revised Plan and Act offer the irresistible opportunity to drive alignment of efforts, outcomes and reporting across the public sector. Public sector bodies are currently required to report, via their annual plans, on their Disability Action Plans. However, there is no consistency on the scope and depth of the reporting, no central source of insights, and a lack of comparable outcomes data for aggregation and analysis. The new plan and act presents an opportunity to clearly align objectives, measures and reporting across all aspects of Victoria’s public sector.

Bolstering the capacity of local government to enable place-based implementation of the next disability plan ought to be considered. This might include reviving effective aspects of the previous MetroAccess / RuralAccess program to underpin a co-ordinated approach across the state.

Topic Area 5 – Supporting the interface between NDIS and mainstream services

Recommendations

17. Strengthen the Victorian Government’s oversight of the NDIS consistent with the role of scheme funder and custodian

Autistic people comprise the biggest cohort of participants in the NDIS (31% of participants have autism as their primary disability; another 5% have autism as a secondary disability). Recent attempts by the Federal Government to introduce mandatory “independent” assessments that will determine scheme access and plan budgets; put funding caps on reasonable and necessary supports for autistic children; and efforts to slow the intake of participants and reducing plan budgets has highlighted the precarious position current and prospective NDIS participants find themselves in.

It underscores the needs for stronger oversight and governance about the future direction of the NDIS by state and territory governments who are partners in the Scheme.

As part of this, APTOS (Interface) Principles need to be overhauled, with inter-governmental mechanisms to oversee these reinstated and designed to include disability representatives.

Recommendations

18. Sharpen the focus on support for people with disability who do not qualify for individualised plans under the NDIS. Develop safeguards for those exited from the NDIS

90% of people with disability do not receive individualised funding plans under the NDIS. Lack of tier two support creates a huge ‘cliff’ that those who cannot establish or maintain eligibility for the NDIS risk falling off.

Recommendations

19. Invest in building and training the next generation of Victoria’s disability workforce, including allied health professionals. Undertake real time analysis of the impact of current initiatives (e.g. Free TAFE)

The skills and labour shortage in a disability workforce is projected to increase, exacerbated by the likelihood of an extended period of closed/restricted borders. Increasing demand in the broader social care sector is amplifying this.

The plan needs to turbo charge efforts to cultivate the next generation of disability sector workers and to retain the existing workforce. Growing the representation of people with disability in the disability workforce is a real opportunity. Real time evaluation of current measures such as free TAFE, disability worker registration and portable long service leave is needed.

Recommendations

20. Provide disability services to temporary visa holders, who are ineligible for NDIS supports

People on temporary visas are not eligible for NDIS supports. Changes to federal immigration laws have further extended the wait period for access to Medicare, social services and eligibility for permanent residency. Most permanent residents and new citizens come through temporary visa pathway.

The state has played a vitally important role in providing stop gap supports for some temporary visa holders with disability, particularly for early intervention support for children.

Recommendations

21. Strengthen the interface with the justice system including by

- Ensuring all people entering correctional facilities are screened for cognitive disability, including autism.
- Implementing protocols to identify whether individuals entering justice system are eligible for NDIS and facilitate Access Requests as needed
- Introducing policy that allows NDIS-funded supports to be delivered on justice premises.

We support the recommendations made by the Office of the Public Advocate (OPA) in [their submission to the Disability Royal Commission's Criminal Justice Issues Paper](#) and recent position paper '[Decision Time: Activating the rights of adults with cognitive disability](#)'. People with complex support needs are the most likely to fall through the cracks of systems' interface.

Topic Area 6 – Strengthening disability inclusion through the review of the Disability Act 2006

Recommendations

22. Legislate a new Disability Rights and Inclusion Act to replace Disability Act 2006

The upcoming review of the Act provides an opportunity for Victoria to lead the nation in disability rights and inclusion. With so much that has changed since the Disability Act 2006 was passed (UNCRPD; NDIS; Inclusion Movement; pandemic) it is timely to purpose design a new Act underpinned by strong aspirations and bold objectives.

Recommendations

23. Establish the statutory office of a Disability Inclusion Commissioner

Establishment of a Disability Inclusion Commissioner would enable independent monitoring and systemic oversight and analysis. The Commissioner would report to parliament and champion advancements of disability rights and inclusion. The remit could be inspired by Victoria's new Gender and Sexuality Commissioner and the Residential Tenancies Commissioner. It could operate as an expansion/replacement of the office of the Disability Services Commissioner.

Recommendations

24. Reaffirm the importance and broaden the mandate of the Disability Advisory Council in legislation. Provide for membership of the Council to reflect the diversity of Victoria's disability community

Strong governance at all levels is needed – from communities up to parliament.

Topic Area 7 – Responding to Coronavirus (COVID-19)

Recommendations

25. Ensure the design and implementation of Victoria’s Mental Health Royal Commission’s recommendations have a strong autism and disability focus

The majority of autistic people have co-occurring mental health conditions. The pandemic has exacerbated this. Australian [research on the impact of the pandemic on autistic people](#) indicated that while some autistic people had positive experiences in lockdown (e.g., appreciating the ‘slowing down’ of pressurised routines and the move to online engagement), the restrictions have dramatically affected people’s social functioning and disrupted everyday routines. Many autistic people reported a decline in their overall mental health and felt worryingly unsupported during the pandemic. Likewise, a [2020 Survey by the Australian Autism Alliance](#) revealed widespread challenges with social isolation and mental ill-health during the pandemic.

This is consistent with international experiences. A [study in the United States](#) reported high levels of stress – particularly around isolation, illness, and finance. A [survey on the impact of the pandemic on autistic adults in the UK](#) found autistic people to be “particularly at risk, as a consequence of a higher prevalence of co-occurring mental health conditions, such as anxiety”.

As the Victorian Government begins implementing the recommendations of the Royal Commission into Mental Health, we urge an approach that keeps people with disability front and centre.

Along with other experts in the autism sector, Amaze has called for a range of measures including the establishment of a distinct autism and neuro-diversity stream within the new Collaborative Centre for Mental Health; autism training in the mental health workforce; autism proficiency in the upcoming Mental Health & Wellbeing Centres and broader access to autism assessment and diagnosis.

Recommendations

26. Invest in measures to support students with disability to re-engage with Education and Training after the disruptions caused by the pandemic

Amaze is particularly concerned about the long-term impacts of extended schooling disruptions on autistic students. Around 70% of families responding to Amaze’s Victorian-based [Learning in Lockdown Survey 2020](#) reported their children experienced deteriorating mental health during school disruptions.

We note the Victorian Government’s commitment to providing mental health practitioners in school settings, including the recent expansion in the 2021/22 Budget. It is critical that mental health practitioners employed for this initiative receive specific training in autism and mental health to ensure they are well-equipped to support autistic students.

Likewise, programs to combat school disengagement and to support re-engagement need to be proficient in working with the high proportion of autistic young people at risk of prematurely leaving school.

Amaze Recommendations

27. Leverage the opportunity presented by Victoria's current skills and labour shortage to markedly improve employment outcomes for people with disability

Autistic people want to work, and they have capabilities and interests relevant to all types of jobs. Despite this, autistic people have long endured among the worst employment outcomes in Australia. 2018 ABS figures revealed a 34.1% unemployment rate among autistic people - *more than three times the rate for all people with disability* and almost eight times the rate of people without disability.³

The covid recovery economy creates a unique opportunity to move the dial on employment outcomes for people with disability – particularly the autistic community. Strong growth coupled with skills and labour shortages exacerbated by border restrictions create the imperative to unlock under-utilised productive capacity. Amaze's [recent submission on the National Disability Employment Scheme](#) outlines a range of demand-side, supply-side and bridging initiatives (demand-led, supply sensitive) including:

- Tailored demand-led pathway in areas of labour and skills needs
- Demonstration projects across a range of sectors for autistic people of varying capabilities
- Replication of the Rise@DHHS program across the Victorian public sector and in the Youth Employment Scheme
- TAFE reform: autism inclusion initiatives and the expansion of work-based training models – see Amaze's [2020 submission on TAFE and Autism](#)

³ Australian Bureau of Statistics, 2018. *4430.0 Disability, Ageing and Carers, Australia: Summary of Findings 2018*. Available at: <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features102018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view=>