General Foundational Supports

A model that supports access to information and community for all Autistic people and their families, carers and kin.

Amaze submission to Foundational Supports (General Supports) Consultation Paper.

5 December 2024

Contents

Executive Summary

We welcome this opportunity to help design a General Foundational Supports model that places people with disability and their families, carers and kin at the centre and can deliver meaningful outcomes, including long-term systemic change.

At Amaze, the experiences and perspectives of Autistic people, and their families, carers and kin are at the centre of everything we do. We are committed to delivering comprehensive and well-connected Information Support and Referral (ISR) services, and capacity building initiatives, that work together to improve outcomes for Autistic people and their families, carers and kin.

For example, we currently deliver the national Autism Connect ISR service which has assisted over 25,000 contacts over the past two financial years. We deliver (and link Autism Connect contacts to) a large range of connected evidence- and lived- experience informed individual capacity building initiatives and resources, including our Autism Peer Assist program (an autism specific 1:1 peer support program connecting vulnerable or isolated parents with lived experience peers) and our Autism Connect @ Work initiative (supporting Autistic individuals to attain desirable employment and thrive at work). We work hard to drive autism access and inclusion via our community capacity building initiatives and consultancy services, including our A-Plus program which empowers organisations and employers to create inclusive work environments that better support their Autistic employees. We are committed to data collection and measuring the impact of everything we do through a comprehensive impact framework.

We are pleased to share our experiences, learnings and expertise to help shape the new model of General Foundational Supports, including its design, implementation and measurements of success. We are grateful to community members who have helped inform our submission, including participants in a small Foundational Supports community survey and focus group held in October.

Our submission focusses on the needs of Autistic people and their families, carers and kin, and emphasises the importance of the new model of Foundational Supports being informed by their diverse experiences and perspectives.

To achieve long lasting and meaningful change for our community, we submit that the new model must:

- Meet the diverse needs of all Autistic people (and their families, carers and kin), including people with high and complex support needs, and undiagnosed individuals seeking to understand their differences/identity and support needs, and/or access a pathway to affordable and timely diagnosis.
- Provide well-connected and aligned ISR services and capacity building supports, delivered via a network of proven and trusted disability organisations.
- Drive a systematic approach to improving accessibility and inclusion across all aspects of our diverse community (for Autistic people and their families, carers and kin), including all places that people live, learn, work, play and visit.
- Extend to social media campaigns that build community understanding and acceptance of disability, including autism.

- Support all Autistic people, and their families, carers and kin across the entire life course, including older people with disability.
- Fund autism specific ISR services and capacity building initiatives (including peer support) that compliment and help inform the accessibility and inclusion of all other ISR services and capacity building initiatives and resources.
- Meet the needs of Autistic people in emergency or crisis situations, including health crisis, family violence or when experiencing Autistic burnout, meltdown or engaging in behaviours of concern.
- Deliver neuro-affirming, sustainable and reliable ISR services and capacity building supports, including peer supports, that are tailored to diverse individual needs, and are well promoted and delivered via multiple accessible and inclusive channels (phone, email, online, in person, group and 1:1).
- Invest in research and data collection, transparently measuring outcomes and with a commitment to ongoing growth through learnings.
- Drive a systematic approach to building sector capacity and delivering capacity building initiatives across diverse organisations, including through the development of a capacity building framework, training accreditation program and skills register.

We are ready to assist!

To inform the new model of General Foundational Supports, we welcome further opportunity to share our experiences, learnings and expertise gained through delivering Autism Connect and our capacity building supports and initiatives.

We would also welcome further opportunity to share our expertise and experiences in data collection and evaluation to help inform the Foundational Supports model and support other government and non-government entities to deliver transparent and accountable services and supports, capable of achieving the model's intended outcomes.

We look forward to working together to achieve a model of Foundational Supports that can meet the needs of all Autistic people (and their families, carers and kin), connect them to accessible and inclusive information, supports and communities, and empower them to live their best lives!

Mr. David Tonge

Chief Executive Officer

Summary of Recommendations

A Foundational Supports model that meets the diverse needs of all Autistic people, and their families, carers and kin.

1. Create a Foundational Supports model that can meet the diverse needs of all Autistic people (and their families, carers and kin), including:

   ➢ Autistic individuals with complex and high support needs, including complex communication and behaviour support needs.

   ➢ Autistic individuals experiencing co-occurring conditions and/or intersectional disadvantage that may require wrap around supports.

   ➢ Autistic individuals who have traditionally fallen through the cracks, including those deemed ineligible for the NDIS and other support services.

   ➢ Undiagnosed individuals seeking to understand their differences/identity and support needs, and/or access a pathway to timely and affordable diagnosis.

2. Work with the Australian Bureau of Statistics, autism sector and researchers to understand the true prevalence of autism in Australia, rates of co-occurring conditions and levels of intersectional disadvantage.

Intended Outcomes: a model that drives full access to inclusive ISR services and communities

3. Review and amend Intended Outcomes to ensure they:

   (a) are clear, transparent and measurable.

   (b) place people with disability at the centre.

   (c) increase screening and access to diagnosis.

   (d) provide full and equal access to inclusive communities (incl. education and employment).

   (e) support people with disability to achieve their short- and long-term goals and aspirations.

   (f) improve mental health and wellbeing.

   (g) increase access to supports at all points of the life continuum.

4. Remove the age criteria for Foundational Supports and ensure they meet the needs of older people with disability.

5. Provide further opportunities to comment on the intended outcomes of Foundational Supports as the full framework, and the NDIS reforms evolve.

Accessible and inclusive ISR services

6. Deliver accessible and inclusive ISR services (and capacity building initiatives) via a network of proven and trusted organisations led by people with disability and their families, carers and kin.

7. Design a framework for ISR services that incorporates the following key elements.

   (a) People with disability, and their families, carers and kin, are at the centre.

   (b) Trusted autism specific ISR services compliment and help build the accessibility and inclusion of other ISR services.

   (c) Services are accessible, with multiple access points and modes of service delivery, including crisis support.

   (d) Inclusion and cultural safety is embedded, including for First Nations, CALD and LGBTQI+ communities.

   (e) The wide and well targeted promotion of services is sustained.

   (f) Services are well-coordinated and connected to local services and supports.

   (g) Robust and reliable measures for service evaluation, accountability and transparency are embedded.

8. Engage with Amaze to explore how our expertise, Autism Connect data and outcomes framework may be shared with government and non-government entities (including grassroots organisations) to support the capacity of all ISR service providers to collect and manage data, measure impact and deliver transparent and accountable ISR services.

Accessible and inclusive capacity building initiatives and resources

9. Drive the creation of individual and community capacity building resources and initiatives that can build full community inclusion, including across all places that people live, learn, work, play and visit.

10. Extend Foundational Supports capacity building to social media campaigns that can build the general community's understanding and acceptance of disability, including autism.

11. Recognise that trusted autism specific information resources and initiatives, including peer support, are in high demand and must compliment and inform other capacity building supports.

12. Deliver capacity building resources and initiatives that are co-designed, neuro-affirming and tailored to the needs of all Autistic people, including people with complex and high support needs and vulnerable and hard to reach cohorts.

13. Ensure capacity building resources and initiatives are well promoted, with multiple touch points for engaging.

14. Deliver peer support programs that are tailored to the individual needs of participants and delivered via a range of modes (including online, in person, group and 1:1).

15. Take a whole of government approach to ensuring Foundational Supports are delivered as one part of broader reforms to enhance accessibility and inclusion, with long term funding for organisations to wholistically embed accessibility and inclusion.

16. Drive a systematic approach or framework to delivering capacity building initiatives across diverse organisations.

17. Commit to long term funding of capacity building initiatives, including to ensure sustained positive change and enable resource maintenance and evaluation.

A systemic approach to building sector capacity

18. Drive a systemic approach to building sector capacity, including through the development of a capacity building framework, training accreditation program and skills register.

19. Commit to long term funding of capacity building initiatives, including to ensure sustained positive change and enable resource maintenance and evaluation.

1. Background

(a) About Amaze

Amaze is a leading autism organisation driving change so that Autistic people and their families can live their best lives. For over 50 years, Amaze has been supporting Autistic people and their families. While based in Victoria, we have an Australia-wide reach and are the home of Australia's national autism helpline – Autism Connect.

We are here for all Autistic people of all ages, and we work together with the autism community and a broad range of supporters to create a more autism-inclusive Australia. As well as working to increase broader community understanding and acceptance of autism and providing high-quality advice and support, we translate autism community experiences into broader policy needs.

Our Mission is to create positive change with Autistic people and their families at all life stages by advocating, influencing, innovating, mobilising efforts and opening doors. This ambition will be realised by being a trusted source of information, advice and support and a willing partner in the development of new practices and approaches.

Our Vision is an Australia that embraces Autistic people and their families living their best lives.

Our core values are:

- Community centric
- Collaboration and Partnership
- Constructive and Solutions Focused
- Determination and Independence
- Evidence Informed and Outcomes Driven
- Strengths Based.

How we create and measure impact:

We work towards our vision and mission by enabling our community, shifting organisations' attitudes and behaviours, and influencing systems changes. We measure our impact across these areas to understand the difference we are making.
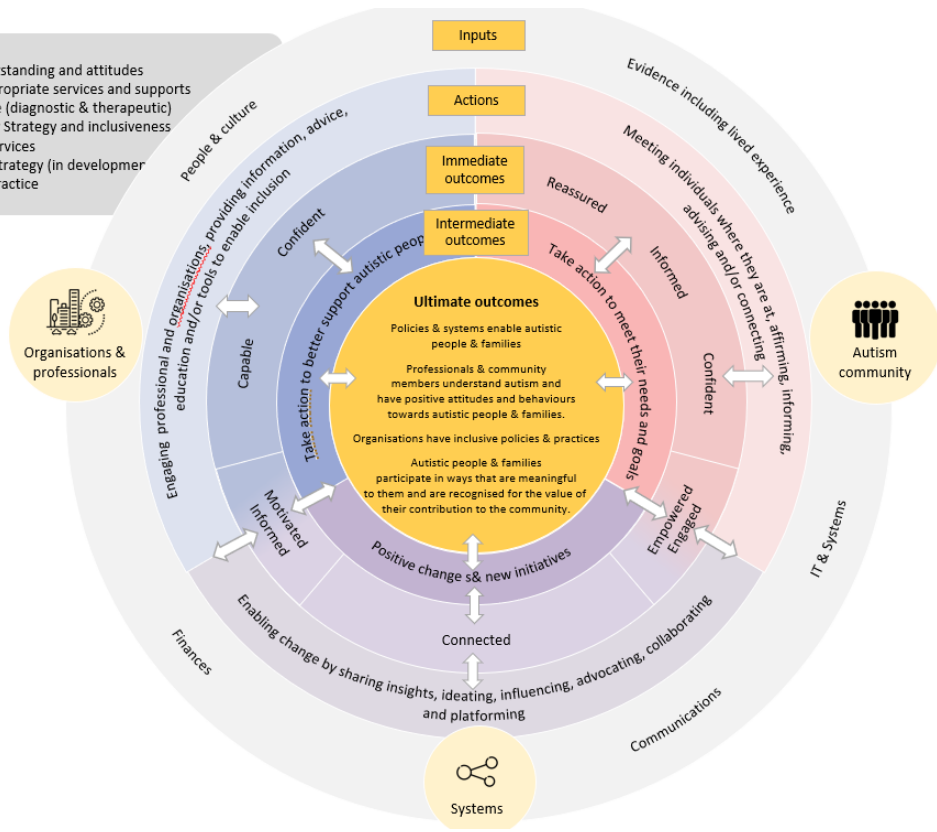
We use a variety of methods to measure our impact including:

- Surveys
- Interviews
- Case studies
- Focus groups
- Reviewing documents and policies
- Monitoring data.

Our impact framework

External Factors
- Community understanding and attitudes
- Availability of appropriate services and supports for Autistic people (diagnostic & therapeutic)
- National Disability Strategy and inclusiveness of mainstream services
- National Autism Strategy (in developme...
- NDIS policy and practice

Inputs

Actions

Immediate outcomes

Intermediate outcomes

Ultimate outcomes

Policies & systems enable autistic people & families

Professionals & community members understand autism and have positive attitudes and behaviours towards autistic people & families.

Organisations have inclusive policies & practices

Autistic people & families participate in ways that are meaningful to them and are recognised for the value of their contribution to the community.

People & culture

Engaging professional and organisations, providing information, advice, education and/or tools to enable inclusion

Confident

Capable

Take action to better support autistic peop...

Motivated

Informed

Enabling change by sharing insights, ideating, influencing, advocating, collaborating and platforming

Positive change s& new initiatives

Connected

Evidence including lived experience

Meeting individuals where they are at, affirming, informing, advising and/or connecting

Reassured

Informed

Confident

Take action to meet their needs and goals

Empowered

Engaged

IT & Systems

Communications

Finances

Organisations & professionals

Autism community

Systems

(b) A foundational Supports model that meets the diverse needs of all Autistic people, and their families, carers and kin.

Estimating autism prevalence in Australia is challenging due to the limitations of available data and a global trend of increasing diagnoses over time.[1] Statistics vary considerably between different research studies and surveys, due to different data sources, time ranges and age ranges included. Our most recent data, from the Australian Bureau of Statistic's 2022 Survey of Disability, Ageing and Carers (SDAC) reported that in 2022:

- There were 290,900 (1.1%) Autistic Australians or 1.1% of Australians with an autism diagnosis (a 41.8% increase from 205,200 (0.8%) Autistic Australians in 2018)

- Autism prevalence was higher for males (1.6%) than females (0.7%), but that there had been a significant increase in female diagnosis (with males twice the rate of females in 2022, compared to three times the rate in 2018)

- Autism prevalence was higher for people aged under 25 years (3.1%) than people aged 25 years and over (0.3%), with the highest rates of diagnosis amongst school-age children.

- Almost three quarters (73.0%) of Autistic people had a profound or severe disability.

However, prevalence rates are likely much higher than indicated by this data given many Autistic people, particularly Autistic adults, remain undiagnosed or mis-diagnosed. While there is no data on the number of undiagnosed Autistic adults in Australia, the SDAC data would suggest that this number is significant. The SDAC reported that 4.4% of 10–14-year-olds are diagnosed with autism, compared to 0.6% of adults aged 18+. Given Autistic children grow into Autistic adults, there would very likely be a similar percentage of Autistic adults (4.4%) across Australia. Based on this data, and evidence from the United Kingdom and United States regarding undiagnosed adults, we would estimate that around 85% of Autistic Australian adults may remain undiagnosed.

The SDAC reported that while there has been some improvement in employment rates (with 42% of Autistic people employed in 2022, compared to 27.3% in 2018) there has been little improvement in educational attainment. It reported an increase in unmet need, with 66.4% indicating they needed more help with at least one activity, compared to 51.7% in 2018.

Available data does not indicate the number of diagnosed Autistic people that are not NDIS participants. However, it is expected that the proportion is significant given many are or will not be eligible for the NDIS based on their functional capacity, many vulnerable or hard to reach cohorts may face systemic barriers to applying, and some individuals may not apply for a range of personal or other systemic reasons, or because they are receiving supports from other service systems.

In 2020 the Australian Autism Alliance conducted a community survey to inform the Select Committee on Autism's inquiry into services, support and life outcomes for autistic people. Of the 769 adult Autistic respondents to this survey, only 34% had applied to the NDIS for support and of those, only 64% had received funding. Of those whose applications were unsuccessful, 86% did not receive information on other supports that may be available to them.

It is essential that the numbers of Autistic people (including likely numbers of currently undiagnosed Autistic people) that will be seeking to rely on Foundational Supports is not underestimated. Data must also capture any co-existing health, mental health and/or disability related conditions, together with any intersectional disadvantage, to ensure Foundational Supports meet the diverse and complex needs of all Autistic Australians. It must also meet the needs of undiagnosed individuals (of all ages) seeking to understand their differences/identity and support needs, and access a pathway to timely and affordable diagnosis.

RECOMMENDATIONS

1. **Create a Foundational Supports model that can meet the diverse needs of all Autistic people (and their families, carers and kin), including:**

   ➢ **Autistic individuals with complex and high support needs, including complex communication and behaviour support needs.**

   ➢ **Autistic individuals experiencing co-occurring conditions and/or intersectional disadvantage that may require wrap around supports.**

   ➢ **Autistic individuals who have traditionally fallen through the cracks, including those deemed ineligible for the NDIS and other support services.**

   ➢ **Undiagnosed individuals seeking to understand their differences/identity and support needs, and/or access a pathway to timely and affordable diagnosis.**

2. **Work with the Australian Bureau of Statistics, autism sector and researchers to understand the true prevalence of autism in Australia, rates of co-occurring conditions and levels of intersectional disadvantage.**

2. Intended Outcomes: a model that drives full access to inclusive ISR services and communities.

We welcome the early identification of Intended Outcomes in the consultation paper, these are key to transparency, accountability and measuring success. However, it is difficult to comprehensively comment on their appropriateness or scope in the absence of a detailed legislative or policy framework for Foundational Supports, including further insight into targeted supports or all age groups or how Foundational Supports will intersect with existing services and resources. It is difficult to comment during the early implementation of the NDIS Supports lists, without insight into how they are being applied and the types of supports that are being excluded (and therefore needing to be encompassed in the Foundational Supports model).

We would therefore ask that further opportunities to comment on intended outcomes be provided as the full framework for Foundational Supports, and the NDIS reforms evolve.

A participant in our Focus group commented:

"There is a lot of focus on what kind of seems like busy work, and referral to supports and services that aren't there yet....so I don't know how to do a submission on this as I don't know what targeted supports are going to look like and where mainstream supports are going to step up".

(c) Foundational Supports must support people with disability to access a fully inclusive community, meet their goals and aspirations and thrive.

The Foundational Supports model should place people with disability at the centre and help them to access services and their community in full, supporting them to achieve their goals and aspirations and maintain strong mental health and wellbeing.

The intended outcomes for people with disability should include:

- **People with disability are at the centre**: People with disability must be at the centre of the development, implementation/delivery and evaluation of Foundational Supports. The model cannot be successful in the absence of a commitment to co-design and meaningful ongoing community consultation. It must be informed by a diversity of lived experiences and expertise, including from Autistic people, their families, carers and kin, and their representative organisations. This must include Autistic people of diverse age, backgrounds, identities and experiences, and ensure that cohorts most at risk and/or hardest to reach are engaged. These cohorts can include First Nations Autistic people and Autistic people from culturally and linguistically diverse backgrounds, as well as Autistic people with complex and high support needs (and their families and carers).

- **Improved access to screening and diagnosis:** The model should drive a comprehensive approach to enhancing screening and increasing access to diagnosis for children and adults. It should build the capacity of all potential screening touch points (including early childhood services, schools, GPs and allied health to screen for developmental delay and disability) and ensure individuals and their families can access a clear and smooth pathway to diagnosis and in turn, appropriate services and their community.

- **Increased community access (in the broadest possible sense)**: To the extent not covered by other service systems, the Foundational Supports model should aim to support people with disability to access all organisations, entities, sectors or places, including anywhere they may be visitors, learners, customers, clients or workers. This should include workplaces, schools, health services, public places, clubs and organisations, recreational facilities, retail outlets and shopping centres, banks and the list goes on. People with disability have equal rights to access these places and must be supported to do so.

- **Greater economic participation**: While economic participation is key to independence, social connection and community, it is not clear whether it is captured in the outcomes identified. It is vital that the Foundational Supports model wholistically supports individuals to get and retain a job, and employers and organisations to provide accessible and inclusive workplaces, to the extent that supports are not provided by other service systems or targeted supports.

- **Greater access to inclusive education**: As per economic participation, it is unclear whether education is captured in the outcomes identified. To the extent that access to education is not supported by other service systems or targeted supports, General Foundational Supports must step in and provide the supports required to ensure adjustments are made and equal access to education is guaranteed.

- **Access to services to meet goals and aspirations**: Foundational Supports must provide access to services that are not only relevant to short term needs and goals, but that help people with disability meet their longer-term goals and aspirations.

- **Improved mental health and wellbeing**: While many of the outcomes identified may contribute to improved mental health and wellbeing, we are concerned that this crucial outcome is not explicitly identified as an intended outcome, particularly given the disproportionately high rates of poor mental health and wellbeing among people with disability, including Autistic people, across Australia.

- **Greater whole of life support**: Foundational Supports should provide a continuity of supports for people with disability across their life span, including through life transitions.

(d) Foundational Supports must extend to supporting the needs of all parents, families, carers and kin and ensure their community inclusion.

The 2022 SDAC data and 2024 National Carer Survey confirm that parents, families, carers and kin of people with disability experience disproportionate levels of isolation and poor mental health, and are more likely to be unemployed or experience under-employment. Foundational Supports must wholistically support this cohort to live meaningful lives, including through social connection, employment and equal access to all aspects of their community.

The intended outcomes for parents, families, carers and kin should include:

- **Increased "understanding and acceptance" of disability and the rights of people with disability**: The intended outcomes must move beyond "awareness" to understanding and acceptance, with the desired outcome that parents, carers, families and kin will have a greater understanding of the lived experience of disability, systemic barriers to accessibility, inclusion and participation, and how to best support people with disability.

- **Improved mental health and wellbeing**: General Foundational Supports must explicitly support the mental health and wellbeing of parents, carers, families and kin, including by increasing access to support services.

- **Increased access to services for parents with disability**. It is important to remember that many Autistic people have Autistic parents that require tailored supports to meet their own needs as parents, and to support the needs of their family members. Accordingly, the Foundational Supports model must support access to services tailored to the needs of parents with disability, including Autistic parents.

- **Reduce isolation and support access to community in the broadest sense possible**: Parents and carers should be supported by General Foundational Supports, including with information about rights and self-advocacy, to participate in all aspects of their community, including education and employment.

- **Increased whole of life support**: The Foundational Supports model must provide continuity and support the needs of parents across their child's life cycle, including future planning, estate planning etc.

(e) Foundational Supports must support full community access and inclusion, including in workplaces and education.

As discussed above, people with disability, and their parents and carers, should be provided with General Supports to access all aspects of their community, in the widest possible sense. However, the onus cannot be on individuals alone to navigate barriers and advocate for their rights. It is well recognised that under the social model of disability that it is the obligation of communities, services and spaces to be inclusive and accessible.

Accordingly, we are concerned that this intended outcome only applies to "organisations, groups and non-government entities servicing the community". By limiting it to those "servicing the community" it would appear to encompass only community or disability services organisations when in reality, the General Foundational Supports model should be aimed at increasing accessibility and inclusion across all parts of our community, including across all organisations, groups, entities and sectors. For example, to the extent not covered by other service systems, the model should be explicitly aimed at building the capacity of workplaces and education providers to be inclusive and meet the accessibility needs of all people with disability.

Furthermore, organisations, groups, entities and sectors should not aim to only have the resources and capacity to be "responsive" to the needs of people with disability, they should aim to be pro-active and innovative in how they can meet the diverse needs of people with disability and support them to achieve their goals and aspirations.

(f) The Foundational Supports model must be accountable and transparent.

We strongly urge the inclusion of the intended outcomes recommended above to ensure the General Foundational Supports model is accountable to, and measures progress towards these vital outcomes. The measurement of these outcomes will be essential to ensure learnings continue to inform and improve the model as it evolves.

The outcomes against which the model is measured must include:

- people with disability at the centre.

- increased access to inclusive communities (in the broadest possible sense).

- increased education and employment rates and outcomes.

- achievement of short- and long-term goals and aspirations.

- improved mental health and wellbeing.

- increased access to supports at all points of the life continuum.

(g) Remove the age criteria for Foundational supports and ensure they meet the needs of older people with disability.

How the needs of older people with disability will be met remains unclear. While we understand that many General Foundational Supports will be utilised by older people with disability, they are not expressly targeted at this cohort and are not being designed with this cohort or their needs in mind.

A joint Discussion Paper by the Australian Federation of Disability Organisations and the Older Person's Advocacy Network, titled Supports for Older People provides a comprehensive, solutions focussed discussion on how the needs of older people with disability may be better supported by Australia's ecosystem of disability supports.

A clear framework for supporting older people with disability is urgently needed and the Foundational Supports model should support access to information, support and referral services, and capacity building supports, in a manner that is equal for all age groups. There is no room for age discrimination in this model and Foundational Supports should be available to all age groups. The insights, perspectives and diverse needs of older people with disability should inform this consultation and the ongoing development, implementation and evaluation of Foundational supports (including Targeted Supports).

RECOMMENDATIONS

3. Review and amend Intended Outcomes to ensure that they:

    (a) are clear, transparent and measurable.

    (b) place people with disability at the centre.

    (c) increase screening and access to diagnosis.

    (d) provide full and equal access to inclusive communities (incl. education and employment)

    (e) support people with disability to achieve their short- and long-term goals and aspirations.

    (f) improve mental health and wellbeing.

    (g) increase access to supports at all points of the life continuum.

4. Remove the age criteria for Foundational Supports and ensure they meet the needs of older people with disability.

5. Provide further opportunities to comment on the intended outcomes of Foundational Supports as the full framework, and the NDIS reforms evolve.

3. Accessible and Inclusive Information, Support and Referral Services.

We welcome the proposed reform to the ILC grants system and this opportunity to reflect upon how we may strengthen Information, Support and Referral services (ISR services) for all people with disability, including all Autistic people.

Autism Connect provides a valuable example of a successful and trusted national ISR service. An overview of Autism Connect is provided in Table 1 and learnings from this model are discussed throughout this submission and inform our recommendations.

Table 1. Autism Connect.

Autism Connect is an ILC funded, free national Autism helpline that provides independent and expert information by phone, email and webchat. It helps people find resources, connect with supports, and receive evidence-informed information. While the helpline is open to anyone, the majority of contacts are from Autistic people (31%) and their family members (47%), and professionals (including a range of allied health and medical professionals, NDIS workers and educators (15%).

Autism Connect advisors offer expert advice on a vast range of matters, including exploring autism and Autistic identity, assessment and diagnosis, school and education, behaviour and communication strategies, the NDIS, transition to employment, and creating inclusive workplaces. It provides referrals to peer support groups and links contacts to a range of internal and external resources and supports, including through our Autism Connect search engine.

Of all contacts who completed Autism Connect's feedback survey in the 2023-34 Financial Year:

- 91% said they would recommend Amaze to others in a similar situation.

- 78% of Autism Connect contacts took action to meet their needs one month after contacting us.

- 86% said they felt reassured by the Advisors.

- Many of our Advisors are Autistic, a parent/carer of an Autistic person and/or neurodivergent. People said they find it valuable to talk to someone with lived experience.

- 91% said the information provided by our Advisors was relevant to them.

Qualitative feedback included:

"I felt heard and validated from the first 30 seconds of calling Amaze, and I didn't think I had done anything bad which is the way I usually feel. They weren't trying to fix anything with me, they just were understanding where I was at. It gave me hope. My sense of gratitude was overwhelming."

"If I hadn't had a good experience, I might not be where I am now because I have realised there are so many people going through the same thing, particularly at my age as a woman. I would definitely recommend the service to other people."

(h) Design a comprehensive framework for accessible and inclusive ISR services that meet the needs of all people with disability, including autism.

ISR services, together with capacity building services, must be delivered via a network of proven and trusted organisations led by people with disability and their families, carers and kin.

Drawing on our experience and expertise delivering and evaluating Autism Connect, and evidence obtained through our survey and focus group, we strongly recommend the development of a framework for ISR services that incorporates the following key elements.

I. **People with disability, and their families, carers and kin, are at the centre**.

The successful delivery of accessible and inclusive ISR services will require a commitment to a rights-based framework, with people with disability, and their families, carers and kin at the centre. The early development of a co-design and community engagement framework will be essential to ensuring all ISR services (disability and non-disability specific) are informed, delivered and evaluated by people with disability, and their families, carers and kin, moving forward.

Our comprehensive quantitative and qualitative evaluation of Autism Connect, informed by Autistic users and their families, carers and kin at the centre, is core to understanding and continually improving our service delivery.

Feedback from service users consistently demonstrates the importance of Autism Connect being delivered by Advisors with a wealth of experience and expertise (including early childhood, education, disability rights and healthcare), with many Advisors having lived experience as Autistic individuals and/or family members, carers or kin of Autistic people.

"She had lived experience, you know, she was much more holistic. It's one thing to study something and know about it and another if you have to get up and live that day to day…that lived experience is really important to me."

Our Focus Group participants spoke about the importance of having access to information and support service staff with lived experience, with one participant expressing that for her, it could be the difference between feeling safe or unsafe.

II. **Trusted autism specific services compliment and inform other accessible and inclusive disability and general ISR services.**

People with disability, including Autistic people access a wide range of disability and non-disability ISR services, including government services. Some of these services can lack the expertise needed to meet the information support or communication support needs of contacts with specific disabilities, impacting their accessibility and inclusion. Generalised information provided by advisors about disability or developmental delay can also be inadequately tailored to meeting the needs of individuals, and family members and carers of, people with specific disabilities.

For example, Autistic people have unique support needs, with autism presenting very differently in each Autistic person, and each person can face unique barriers to support. A significant level of expertise is needed to meet the diverse needs of Autistic people (particularly those with complex and high support needs), and provide up-to-date, accurate information, support and referral tailored to the needs of each individual. Significant expertise are also needed to provide neuro-affirming support to individuals and their family members that may be seeking access to diagnosis, including to understand autism and the diagnosis process. It is for all of these reasons that in 2022, the Senate Select Committee on autism, in its report titled Support and life outcomes for autistic Australians, recommended the establishment of a one-stop shop to support Autistic people to find appropriate support services, accessible via a range of platforms (including online, print and phone support services). This recommendation was one of the leading contributors to the national roll out of Autism Connect.

A key strength of Autism Connect is that it is housed by Amaze, a known and trusted organisation with over 50 years' experience supporting access to information and referrals. Advisors have access to a range of expertise and are supported to access a repository of up to date, high quality, and evidence and/or lived experience informed resources. We house a wealth of community knowledge to ensure people are referred to neuro-affirming services and where appropriate, autism specific services that are evidence informed. Autistic people can have unique communication support needs. Our advisors are supported to deliver information in accordance with these needs and in a range of formats, including easy read.

There is a strong demand for trusted autism specific services. Over the past two Financial years (2022-24) Autism Connect has assisted 27,504 contacts. The most common primary reasons for contacting Autism Connect related to diagnosis, Autistic person-centred support, therapy and support, family and community information and supports, and education. Caller feedback demonstrates that ISR services provided by Autism Connect have significantly increased understandings of autism, the NDIS, rights and how to access services and community opportunities.

ISR services must of course have a strong understanding that people with disability can often present with co-occurring disability, health and mental health conditions. Our Autism Connect advisors have a strong understanding of co-occurring conditions and have built relationships with other sector organisations to facilitate warm and safe referrals to these organisations whenever possible, ensuring that the support needs of individuals are wholistically met.

Many participants in our focus group and survey highlighted their preferences for skilled and evidence informed autism specific ISR services, and reported higher levels of autism understanding, accessibility and inclusion when utilising these services, compared to more generalised sector or government ISR services.

Many focus group participants spoke emotionally and passionately about the need to build autism understanding in non-Autism specific government and non-government ISR services to improve their autism inclusion and accessibility. For example, focus group participants highlighted the need for all ISR service providers to

understand Autistic burnout[1] and how to support callers that may be experiencing it. They spoke of the impact Autistic burnout can have on their capacity to process the information they are given, complete plans, actions for forms following a call, or attend recommended group or online information or capacity building sessions. They consistently highlighted the need for advisors to understand the impacts of Autistic burnout and their need for ongoing, one to one support (delivered in the mode they prefer, by phone, online or in person) to work through these types of resources and next steps.

> *"(It is) so hard when you've got nothing left to give when you are expected to try and find supports, having someone to help you would make a big difference". Focus group participant.*

The Foundational Supports model should therefore explore how autism sector organisations work with ISR services to build their accessibility and inclusion of Autistic people.

III. Services are accessible via multiple touch points and modes of service delivery (including online, phone and in person), and including crisis support.

Autistic people can experience a range of different barriers to communication, and bring different communication styles and preferences, it is therefore vital that they have access to different modes of communication that are accessible and inclusive. One of our Focus Group participants spoke about the inaccessibility of a government agency that required a call back by phone only. While experiencing Autistic burn out, that requirement made the agency inaccessible to them.

Autism Connect is delivered via multiple modes and touch points that allows individuals to access support in a way that is accessible for them. Over the past two Financial Years, 51.42% of contacts to Autism Connect were by phone, 30.59% by email or contact form, 17.44% by webchat and 0.55% by other means (including walk-ins). Contacts are referred to or hear about Autism Connect through a range of different mechanisms and people. In the 2023-24 Financial Year, 59.2% found Amaze via a Google search/ web search, 6.8% via another autism association, 4.4% via a Friend/ family member, 4.3% via a Allied Health professional, 3.9% had known about Amaze for a long time and 21.5% found Amaze via other means (advertising, Amaze activities, campaigns, colleagues, community organisations, conferences, education professionals, government department, HCWA, Maternal/child health nurses, mental health professionals, NDIA/LAC/ECP staff, other medical professionals, other support lines, paediatricians, peer support groups, social/case worker, social media, TV/Radio/Press).

Accessible crisis support is urgently needed to ensure the needs of Autistic people in crisis can be met. It is vital that all crisis ISR services are trained in supporting Autistic people, including by understanding their communication support needs and characteristics of autism that may impact service delivery. As discussed above, a strong understanding of the impact of Autistic burn out is needed across all ISR services. Services must have a strong knowledge of services that are neuro-affirming if referring people on to ensure their safety.

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[1] Autistic burn-out refers to intense physical, mental or emotional exhaustion. It can include a loss of skills such as memory, speech, executive function or ability to cope with sensory overload. It can have a range of causes, including repeatedly being in situations where your needs as an Autistic person are not being met.

The new Foundational Supports model provides a potentially lifesaving opportunity to review the accessibility of emergency ISR services for Autistic people experiencing family violence, and family members and carers experiencing carer targeted violence. Through Autism Connect and our community engagement work we repeatedly hear of Autistic people being unable to find accessible or neuro-affirming emergency services. We hear of siloed approaches and responsibility shifting between the justice, family violence and disability sectors. Recent studies and work by [Australia's National Research Organisation for Women's Safety (ANROWs)](#) should be reviewed to inform how the Foundational Supports model, together with the NDIS may better support the needs of Autistic people, and their families and carers experiencing, or at risk of experiencing family violence.

IV. Inclusion and cultural safety is embedded, including for First Nations, CALD and LGBTQI+ communities.

Inclusion and cultural safety for vulnerable and hard to reach cohorts must be embedded in all ISR services and where needed, ISR services targeted to the needs of specific cohorts (including First Nations, CALD and LGBTQI+ communities) must be established. ISR services must be led and informed by the communities they seek to support.

In the past 2 financial years (2022-24), at least 8% of contacts to Autism Connect were from a CALD background, 1.4% identified as Aboriginal or Torres Strait Islander and at least 6% identified as LGBTQI+. Of our enquiries from Autistic people, 703 were from LGBTQIA+ people, 180 were from Aboriginal and Torres Strait Islander people and 925 were from CALD people.

We work to meet the needs of these, and other vulnerable or at-risk cohorts by:

o Providing translation services on live calls that require them.

o Linking contacts, wherever possible, to culturally safe information tailored to their needs and peer support groups that may suit them. Unfortunately, there is often a lack of resources or peer groups that will meet the needs of these of vulnerable cohorts and this gap must be addressed by the new Foundational Supports model.

o Connecting individuals to local resources wherever possible. Autism Connect partners with state-based autism organisations to help ensure local knowledge is identified and shared.

o Building relationships with other disability, health and mental health organisations to ensure we can support contacts in having any broader needs met, for example Autistic people with co-occurring conditions.

o Attending community specific events to provide advice and promote Autism Connect and Amaze's capacity building work.

While we have worked hard to meet the needs of these cohorts, we readily acknowledge there is more to be done. We welcome the opportunity the new Foundational Supports model provides to further explore how services such as Autism Connect can better reach and meet the needs of these communities, together with community led organisations.

V. Wide and targeted promotion of services is sustained.

Sustained and well targeted investment is needed in the promotion of ISR services to ensure cohorts in need of these services are aware of them, when they need them. The needs of people with disability and their families change over time, with families of newly diagnosed children having very different needs to those of adults with disability. Targeted investment is needed to ensure people from vulnerable cohorts, including in regional and rural areas are reached.

Amaze continues to promote Autism Connect directly to Autistic people and their families and carers (including via online advertising and social media), to professionals who support Autistic people (including health and allied health professionals, educators and disability employers) and to mainstream and community organisations. Autism Connect is also promoted by our partner organisations to increase our reach. This approach has driven direct contact with Autistic people and their families and cares across Australia and has grown awareness of the service and referrals from providers and supporters.

VI. Services are well co-ordinated and connected to local services and supports.

ISR services must be well-coordinated and connected to local services and supports to provide effective and safe information and referrals. Amaze partners with state-based organisations and has built a network of relationships with other organisations to ensure that our referrals are culturally safe and capable of meeting the individual needs of the people we refer.

Advisors are supported to refer contacts (where appropriate) to linked evidence and lived experience informed Amaze programs and initiatives. These include Autism Connect @ Work, which supports and empowers Autistic individuals to make informed decisions about employment and achieve greater success in the workplace, and Autism Peer Assist, which is a one-to-one peer support program for carers of Autistic people, with a focus on assisting families with complex need. Autism Connect @ Work and Autism Peer Assist are discussed in further detail (under capacity building) below.

VII. Robust and reliable measures for service evaluation, accountability and transparency are embedded.

Amaze's approach to data collection, independent evaluation and information sharing enables us to report on the impact of Autism Connect and its deliverables, and inform governments of matters of key interest and concern to the autism community. It provides a direct lens into the autism community and has helped inform policy reform across a range of areas, including the NDIS, education and development of the National Autism Strategy.

It is vital that all ISR services be required to embed robust, reliable and transparent evaluation frameworks into their service provision to ensure they are accountable to the intended outcomes of Foundational Supports, drive continued improvement and provide learnings for governments and other sectors.

(b)   Sharing our data and expertise to build sector capacity.

Amaze has developed considerable expertise in the collection, management and sharing of ISR service data for a range of purposes (including, as discussed above Autism Connect reporting and to inform learnings and policy development). This data has the breadth and specificity to provide unique insights into the demographics of contacts, their reasons for contacting Autism Connect and the information, support and referrals provided by our advisors. Our independent evaluations of caller experiences provides further unique insight into the experiences, preferences and needs of ISR service users.

While aspects of our data and evaluations have been shared nationally, we would welcome discussions on how we may share our expertise, and this data more broadly, to help inform the Foundational Supports model and support other government and non-government entities (including grassroots organisations) to deliver transparent and accountable ISR services that incorporate robust data collection and comprehensive evaluation and impact reporting. These reforms provide a valuable opportunity to consider how ISR service data may be designed to measure progress towards Foundational Supports outcomes and shared publicly to promote transparency, build community understandings and help inform policy design and reform.

RECOMMENDATIONS

6. **Deliver accessible and inclusive ISR services (and capacity building initiatives) via a network of proven and trusted organisations led by people with disability and their families, carers and kin.**

7. **Design a framework for ISR services that incorporates the following key elements:**

    a. **People with disability, and their families, carers and kin are at the centre.**

    b. **Trusted autism specific ISR services that compliment and help build the accessibility and inclusion of other ISR services**.

    c. **Services are accessible, with multiple access points and modes of service delivery, including crisis support**

    d. **Inclusion and cultural safety is embedded, including for First Nations, CALD and LGBTQI+ communities**

    e. **Wide and targeted promotion of services is sustained, via accessible information resources.**

    f. **Services are well-ordinated and connected to local services and supports.**

    g. **Robust and reliable measures for service evaluation, accountability and transparency are embedded**

8. **Engage with Amaze to explore how our expertise, Autism Connect data and outcomes framework may be shared with government and non-government entities (including grassroots organisations) to support the capacity of all ISR service providers to collect and manage data, measure impact and deliver transparent and accountable ISR services.**

4. Accessible and Inclusive Capacity Building resources and initiatives

We support your proposal for a reformed capacity building offering within Foundational Supports. We agree that it should support meaningful access by people with disability, and their families and carers, to inclusive mainstream, community and disability services and settings, including peer support programs. However, as discussed above, this opportunity must be taken to build full community access and inclusion, and build understandings and acceptance of disability across the entire community.

We agree that comprehensive longer term funding opportunities are needed to build meaningful supports and programs, co-designed, implemented and evaluated by people with disability. We strongly agree that a focus should be on supports being designed and delivered by people with disability and disability-specific organisations.

(a) Drive the creation of individual and community capacity building resources, programs and initiatives that can build full community inclusion.

As discussed above, Foundational Supports must aim to build access, understanding and inclusion across all aspects of our community, including all places that people live, learn, work play and visit. While the interaction between Foundational Supports and other service systems remains unclear, the Foundational Supports model should drive a systematic and co-ordinated approach to building full community accessibility and inclusion, in co-ordination with other sectors and with clear understandings of roles and responsibilities.

Siloed approaches cannot be taken to the delivery of individual and community capacity building supports. They must be systemically designed and delivered together to ensure that a wholistic approach is taken to improving accessibility and inclusion, the onus cannot be solely on people with disability to improve their capabilities.

At Amaze, we work hard to deliver ISR services, individual capacity building and community capacity building initiatives, including peer support initiatives, that together, comprehensively support accessibility, understanding and the delivery of inclusive environments. By way of example, please refer to:

- **Table 2** for an overview of the wholistic approach we have taken during the 2023-24 Financial Year to building accessibility and inclusion across our strategic priority areas (autism assessment and diagnosis, employment and training, employment, NDIS and health and mental health services).

- **Table 3** for an employment case study, demonstrating how together, individual and community capacity building supports (aligned with ISR services) can wholistically improve accessibility and inclusion.

As demonstrated in **Table 2**, we deliver a large range of individual capacity building resources, funded by governments and other entities and sectors, that are evidence informed and/or co-designed with people with disability and their families, carers and kin. These resources are aimed at helping individuals and families understand Autistic identify and rights, build self-advocacy and decision-making skills, increase access to services and supports, navigate systems and environments, and in turn increasing participation and independence.

We deliver targeted peer support to parents and carers of Autistic people in the form of mentoring, via our [Autism Peer Assist](#) program discussed in further detail below, and by supporting peer group leaders across Victoria. These programs must form an essential element of Foundational Supports, however they cannot be expected to make up for services and supports that may be otherwise lacking in the system. Peer support should also not be trying to make up for individualised supports that are needed from skilled allied health providers.

We provide accessibility advice to organisations that enable them to create autism-friendly venues and events by offering the following services. Our consultancy clients include State Library Victoria, Science Gallery Melbourne, Northland Shopping Centre and Bunjil Place}

- **Environmental audit:** assessing the sensory and accessibility aspects of a space/site and providing a report with recommendations on sensory considerations, wayfinding and signage, relaxed events, staff training, and accessibility information.

- **Development/review of accessibility resources**: such as social scripts and sensory maps to better support an Autistic persons experience at a specific space or event.

Table 2: Amaze's wholistic approach to building accessibility and inclusion during the 2023-24 Financial Year

Strategic priority	ISR Services	Capacity building
Assessment and Diagnosis	Supported 3,429 enquiries about diagnosis from Autistic people and families contacting Autism Connect. These informed our advocacy to the government for increased access to diagnosis.	Supported the IPC Health Assessment and Diagnosis model development and trial for cost-effective and timely diagnosis. It was successful, and families in the trial found it affirming and timely enabling them to access interventions sooner if required. Supported individuals and families to access assessment and diagnosis through our website and Autism Connect search engine..
Education and Training	Supported 1,025 enquiries about education from Autistic people and families contacting Autism Connect.	Informed Autistic people and families on transition to life after high school in our webinar. Supported students and families to access education and training through our resources, including our website and inclusive education resources and Autism Connect search engine.
Employment	Supported 632 employment-related enquiries from Autistic people and families contacting Autism Connect. Designed and successfully piloted Autism Connect @ Work supporting Autistic individuals to attain desirable employment and thrive at work.	Launched the A-Plus program. Delivered 34 autism inclusion and employment-related trainings to increase workplaces' capacity to be neuro-inclusive. Supported access to employment through our website and Autism Connect search engine.
National Disability Insurance Scheme	Supported carers of Autistic people with NDIS, with 52% of Autism Peer Assist sessions about NDIS. Supported 970 NDIS inquiries from Autistic people and families contacting Autism Connect. Empowered people to confidently navigate the NDIS through 9 webinars. Supported 125 enquiries about the NDIS from professionals contacting Autism Connect.	Informed professionals who attended our NDIS webinars on ways to support their clients accessing NDIS. Supported individuals to access the NDIS through our accessible website and resources, and Autism Connect search engine.
Health and Mental Health	Supported carers in Autism Peer Assist with self-care strategies and supports they can access. Informed people on topics around Autistic Health and Wellbeing in workshops across Victoria. Informed people on sexuality and relationships in a webinar with the Association for Children with a Disability (ACD). Supported accessible enjoyment of the Australian Open by running activities for families and children at the Australian Open All Abilities day.	Informed Disability Liaison Officers on how to support Autistic people accessing public hospitals, with tailored resources. Advocated for increased accessibility in sports at the FIDA 2024 launch, and in a presentation to Sports Inclusion Australia. Supported individuals to access health and mental health through our website and resources, and Autism Connect search engine.

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TABLE 3: Employment case study

At Amaze, we work to improve employment rates and outcomes for Autistic people. In the 2023-24 Financial Year, we supported 632 employment-related enquiries from Autistic people and families contacting Autism Connect, designed and successfully piloted Autism Connect @ Work (supporting Autistic individuals to attain desirable employment and thrive at work) and launched the A-Plus program (empowering organisations and employers to create inclusive work environments that better support their Autistic employees). We also created a range of information resources and provided accessible information via our website, see for example,10 things employers can do to support Autistic staff.

Autism Connect @ Work

Autism Connect @ Work supports Autistic people who are currently employed and underemployed, as well as jobseekers/unemployed to make informed decisions about employment and achieve greater success in the workplace. With a designated specialist Advisor, users receive up to 4 sessions where they will be equipped with the tools, knowledge and advice they need to build their confidence and capability in the workplace. This service launched in October 2023 and warm referrals into this program are made through Autism Connect.

During the reporting period October 2023 – June 2024, Autism Connect @ Work supported 53 people covering the following key topics: Understanding employee and workplace rights, self-advocacy for reasonable adjustments, navigating workplace social environments, pathways of support and understanding support needs. Multiple participants interviewed said that they found Autism Connect @ Work neuro-affirming, and that they valued how it provides coaching from a lived experience perspective.

"There is something so affirming about speaking to someone who understands, through lived experience, what you're going through. The Advisor that I spoke to, while of course always remaining professional, had a real kindness and empathy, and I found it so much easier to receive advice and coaching from someone like that."

Autism Connect @ Work has helped both unemployed and employed Autistic people. We heard from interviewees that our service has enabled them to feel better prepared to advocate for themselves, gain knowledge about potential employers who would be supportive, create 'ways of working' documents to reduce burnout, decide whether to disclose that they are Autistic to their workplace and better understand their autism and sensory needs.

A-plus program

Our A-Plus program empowers organisations and employers to create inclusive work environments that better support their Autistic employees. We do this through training and developing solutions, including practical and sustainable strategies that promote a culture of diversity and acceptance and attract and retain Autistic talent.

Over the 2023-24 Financial Year, the team delivered 34 Autistic inclusion and employment related training sessions. The training sessions are focused on meeting the needs and objectives of the audience so that practical actions can be taken, success achieved, and meaningful impact is made. Of 196 participant survey responses, 95% agreed that the topics covered were relevant to their role's needs or field of work. They indicated that their most important takeaways, that they will be likely to utilise to create change in their workplace, included implementing flexible workplace practices and supporting sensory adaptions.

"Amaze's training for managers is comprehensive, detailed, well-presented and thought-provoking. I'd highly recommend other organisations or workplaces run it for managers regularly to better support neurodivergent team members!"

(b) Extend Foundational Supports capacity building to social media campaigns that can build the general community's understanding and acceptance of disability, including autism.

Foundational Supports should extend beyond services and settings to driving social behaviour change media campaigns that can build the general community's understanding and acceptance of disability. Enhanced community understanding and acceptance is urgently needed to promote inclusion (and its benefits for everyone), reduce stigma and discrimination and promote inclusion, together with the strengths, needs and equal value of all people with disability, including Autistic people.

Learnings may be taken from the Change Your Reactions campaign, delivered by Amaze in partnership with the Victorian Government. Change Your Reactions was Australia's first social behaviour change campaign to promote understanding and inclusion of Autistic people.

To date it has been delivered over two phases.

- Phase 1 launched a broad mass media campaign spanning television, radio, digital platforms, social media, print, and outdoor advertising. The goal was to raise awareness among Victorians of the challenges Autistic people and their families face and how community reactions can either ease or exacerbate these challenges. The campaign featured Autistic actors in real-life situations demonstrating how simple changes in people's actions can create a more inclusive world for autistic people, including in a supermarket and café. The key insight was that little changes to others' behaviour can make a big difference to an Autistic person experience in the world. By increasing our own understand and taking simple actions - we can all help to create a more welcoming and inclusive environment.

- Phase 2 of the campaign built on this, focusing on workplace inclusion. Structured as a multi-year initiative over two years, Phase 2 began with Year 1, which targeted leaders in the workplace as key drivers of change, while Phase 3 would expand on this foundation. The campaign featured Autistic individuals, sharing messaging designed to dispel misconceptions and highlight practical ways that people can support Autistic employees and why these strategies can benefit others in the workplace. A range of resources was created to support the key messages, including social media content that directed viewers to a dedicated landing page. This page provided managers and organisations with practical guidance on building an inclusive workplace.

To further address stigmas and promote Autistic inclusion, the campaign expanded to include case study-style video and radio ads showcasing diverse Autistic experiences across different workplaces. These videos targeted organisations and leaders and were distributed primarily across two waves in 2024.

The campaign has been very successful in its reach and impact. For example, the "supermarket" ad has had over 800,000 views on YouTube. The campaign videos were shown across tv (adverts and news), radio, and billboards. Our evaluation to date has found that since launching phase 1, almost 1 in 5 autistic people and their families having "noticed a change in the way people treated me". Of those who saw the campaign, 90% reported that they felt concerned about how Autistic people were currently treated and 85% said they intended to refrain from being judgemental. Autistic people expressed relatability to the campaign and the hope that people continue to change how they react towards others.

Achieving population level social behaviour change requires sustained effort, which led to the phase approach outlined above. To ensure a sustained approach and continuation in building understanding, acceptance and the positive engagement with autistic people this campaign needs to continue and evolve.

To drive social behaviour change across Australia, consideration should be given to rolling out this, and other social behaviour change campaigns nationally as part of Foundational Supports.

(c) Recognise that trusted autism specific information resources and initiatives, including peer support, are in high demand and must compliment and inform other capacity building supports.

Autistic people and their families can have unique information and information support needs, requiring tailored evidence- and lived- experience informed solutions. Our experience delivering Autism Connect and capacity building resources and initiatives has highlighted the need for trusted resources and services that meet our community's individual needs.

Autistic people continue to feel excluded from their community and are searching for information on how to access community supports. In the past two years, 15% (or 3,560) of all contacts with Amaze, were individuals seeking information relating to family and community supports (as the primary or secondary reason for their call). Of these, 27.8% (565) related to finding peer supports.

Information on our website is frequently viewed and our information resources are regularly downloaded. For example, between 22 September and 22 October 2024, our website was viewed 5,875 times. The overwhelming interest in our community capacity building initiatives, such as A-plus has demonstrated that organisations want to do better and are actively seeking support to make their services and places accessible and inclusive to Autistic people.

Our community is actively seeking out peer support and mentoring programs that meet their individual needs as Autistic people and/or Autistic parents or carers. Respondents to our survey, and Focus Group participants reported a very strong preference for peer support programs, delivered via a range of modes (including online, in person, group and 1:1) tailored to their needs as Autistic people and/or Autistic parents or carers. The crucial role of autism specific peer support is discussed below.

(d) Deliver capacity building resources and initiatives that are co-designed, neuro-affirming and tailored to the needs of all Autistic people, including people with complex and high support needs and vulnerable and hard to reach cohorts.

In our experience, the most impactful information resources are those that are neuro-affirming, created in co-design or close engagement with our community, are delivered via a range of modes (including easy read, video, webinars and podcasts) and are widely promoted via social media, GPs, schools etc.

Examples include our:

- "School Can't" resources for parents/carers and teachers funded by the Victorian Department of Education. These co-designed resources comprise a video and two written resources on the topic of school can't. These resources provide insights into understanding and identifying the early signs of school can't, as well as how to implement strategies that support Autistic students to re-engage with the schools..

- Executive functioning resources funded by the Victorian Department of Education and created in co-design with Autistic people, an occupational therapist and education professionals. They comprise a video and written tip sheet to provide insight into the lived experience and feelings of young Autistic people, as well as practical strategies young people can use to build their executive functioning skills.

- Health gaming resources funded by the eSafety Commissioner's Online Safety Grants Program and co-designed and -delivered with Autistic people. They comprise of written documents, videos and webinars to support parents and carers with practical strategies to help ensure young Autistic gamers in their lives have a balanced, positive and fun relationship with video gaming.

- Autism and sleep resources developed with the support of Aspen Australia and co-designed with parents and carers of Autistic children. They comprise a 'Autism and Sleep' podcast resource, a digital sleep booklet for parents/carers and their children, a long form fact sheet focused on lived experience case studies and video resources for health professionals and parents/carers.

Our Focus group spoke about the importance of accessible information delivery, including through courses and the need for information to be delivered in ways that are quickly accessible during a crisis, including while experiencing Autistic burn out. For example. one of our focus group participants spoke of the difficulty they had with online courses that were time and mentally intensive, when they were experiencing burn out and were time poor. The participant spoke about the need for wholistic support to access, understand and act on information in these resources during these times. Another participant spoke about their reliance on online groups, and difficulty engaging in-person.

"*I really prefers online groups as that is where I find my space*". Focus group participant.

A further key focus of the Foundational Supports model must be increasing capacity building resources and initiative, co-designed with, and tailored to the needs Autistic people with high and complex support needs and vulnerable and hard to reach cohorts. One participant in our focus group spoke of the difficulties in accessing neuro-affirming and safe healthcare in rural and remote locations. They recommended that a systematic approach to building capacity building skills in rural and remote locations, among locals with local knowledge and understanding of need, to deliver capacity building initiatives and training in those local areas.

The Foundational Supports model must support a systematic approach to building the capacity of local organisations, and First Nations and CALD organisations, supporting them to co-create and -deliver autism accessible capacity building initiatives and resources tailored to their cohorts needs.

(e) Ensure capacity building resources and initiatives are well promoted, with multiple touch points for engaging.

Many individuals and organisations are searching for information resources and initiatives to improve their disability capacity but can have difficulty finding and accessing resources tailored to their specific needs. In our focus group, participants spoke about GPs, therapists and friends directing them to capability building supports and resources, but said that it can be otherwise difficult to know what is available and may meet their particular needs. Well targeted promotion (including via social media and professionals across relevant sectors) is therefore vital to ensuring the community are aware of the types of resources available to them.

The importance of utilising social media in a targeted way was recently demonstrated by our LinkedIn A-plus initiative. LinkedIn awarded Amaze a grant to run a campaign promoting employment opportunities and outcomes for disadvantaged groups in Nov-Dec 2023. We used this grant to generate awareness of the A-Plus program with professionals from human resources, diversity and inclusion, and C-Suite/ management, facilitate engagement with the A-Plus program across digital platforms, increase awareness and understanding of the program and its unique benefits to organisations, acquire leads we could engage with to potentially enrol in the program, test and validate key messaging and program direction with target groups and build understanding around autism-inclusive employment and practices.

This project has helped increase awareness of our A-Plus program, and has enabled us to engage organisations from a variety of sectors. Throughout the campaign, it led to significantly increased traffic to our A-Plus program website (9000+ visitors) and delivered 251 leads (individuals/organisations that provided their contact details for further information about the A-Plus program).

Our experience delivering workplace initiatives, including A-plus, has shown us that many organisations want to effect change and build their accessibility and inclusion, but don't know where to begin or what is available to them. For organisations that don't have disability and inclusion strategies or disability action plans, or employees dedicated to inclusion or change, it can be even more difficult.

Active promotion of community capacity building initiatives is therefore essential, together with initiatives and resources that access multiple touch points within organisations and sectors, from Human Resources, to executives and to employees with lived experience. Parents and carers of people with disability, including autism, are often key champions of driving change internally and are highly motivated to effect change for others. Initiatives and resources that target this cohort to be "champions" in their organisations can be highly effective in driving organisational change.

(f) Deliver peer support programs that are tailored to the individual needs of participants and delivered via a range of modes (including online, in person, group and 1:1)

As discussed above, people with disability and their families and carers require peer support programs that are tailored to their individual needs and delivered via a diversity of accessible modes (online, in person, group and 1.1). There is continually emerging evidence that peer support increases well-being and quality of life, and can provide emotional support and enhance empowerment and resilience. Evaluations of the Autistic-led peer support and mentoring being delivered by the I CAN Network, across more than 100 government schools, have

demonstrated that they are having a positive impact by improving social and communication skills, building connections and a sense of belonging, and building self-confidence and self-acceptance.

Amaze delivers targeted peer support to parents and carers of Autistic people in the form of mentoring. Our **Autism Peer Assist program** is outlined below. We support peer support leaders in their creation and delivery of peer support groups across Victoria. We are pleased to have recently received a grant from Carers Victoria that will enable us to provide more support and resources to unpaid carers in our community. We will use this funding to convene a peer leaders' community of practice and have commenced with an in-person networking/team building event in November.

Table 4: Autism Peer Assist.

Autism Peer Assist is an independent peer mentoring program that pairs community members with mentors, all of whom are employed on a lived experience basis. Working together over up to 10 sessions, carers are supported to build their understanding of autism, their familiarity with mainstream carer supports, their confidence to self-advocate and importantly, to connect with peers and families in their local neighbourhoods. In the 2023-24 Financial Years, 77 carers were supported and 605 sessions were delivered. The topics covered across sessions included the NDIS, understanding Autistic behaviours, therapies, carers support and education.

Autism Peer Assist is free and primarily supports families who are experiencing considerable complexity in their lives, which includes experiences of social disadvantage, single parenting, housing insecurity and under- and unemployment. It is a crucial link between isolated carers and their communities and forms an important thread in the safety net that supports the autism community.

Feedback surveys completed by participants, following their final session with their mentor between March 2024 and October 2024 (20 responses) included:

- 95% (19) said they feel more confident to advocate for themselves, with 65% strongly agreeing.
- 100% (20) agreed they feel more confident to advocate for the Autistic person they support, with 70% strongly agreeing.
- 100% agreed (95% strongly agree) they are satisfied with APA.
- 100% strongly agreed they would recommend APA to others in a similar situation.

Other positive feedback provided by participants includes:

"[My mentor] was able to provide support and clear advice when I as a parent felt isolated and overwhelmed by the processes that were unfolding when we first met. My main objective was to be better informed and help implement better supports for my child. The information provided by [Autism Peer Assist] was fundamental in creating a path forward for positive change whilst navigating the challenges of the school system and NDIS… [my mentor] gave me the confidence to advocate for my child more directly…"

"[My mentor] was so understanding & supportive throughout the whole process. Her knowledge & advice in the planning stages of our boy's plans is the reason we had such a positive result with our first plans & I know we will be well supported moving forward because of [my mentor's] support."

Our learnings from delivering our peer support and mentoring services, and from our survey and focus group participants include:

- **Peers support must be tailored to the needs of individuals, provided via multiple modes, (including in -person, online, group and 1:1) and be well promoted**: Our focus group participants highlighted the importance of peer support being tailored to individual needs, with multiple options being available such in person, online, group or one to one. One participant spoke about everyone's experiences being different and their difficulties finding a peer support group that could meet their individual needs. They spoke of needing 1:1 support and their poor experience with a large disability ISR service peer support group that contained carers with very different backgrounds and needs to them. Another spoke about their difficulty engaging in in-person peer support and the benefits of accessing peer support online, including that they had grown in confidence and their ability to help others. The diversity of need, and the importance of groups well targeted to the needs of participants is consistent with advice received from our community via Autism Connect and our peer support and community engagement activities. The numerous contacts with Autism Connect seeking information about peer support programs highlights the need for greater investment in promotion via multiple challenges, including social media, GP's, therapists, schools etc.

- **Individuals and grass roots organisations need greater support to run peer support groups**: The current system is over reliant on people starting up peer support groups themselves, with little funding or guidance about establishing and delivering peer support. The Foundational Supports model should support the establishment and sustainability of peer support groups and drive a consistent and systematic approach to their creation, delivery and evaluation.

- **Long term investment is needed in peer support groups that can meet the needs of vulnerable cohorts**: In our experience, Australia lacks peer support groups that can meet the needs of vulnerable and hard to reach cohorts, including people with disability and their families, carers and kin, from First Nations and CALD communities. The Foundational Supports model should drive a targeted approach to supporting cohort led organisations to build their capacity to create, deliver and evaluate peer support programs tailored to the needs of their diverse cohorts. Long term investment is needed, as opposed to annual grants, to enable these groups to develop and evolve, create connections and deliver meaningful outcomes for participants.

(g) Take a whole of government approach to ensuring Foundational Supports are delivered as one part of broader reforms to enhance accessibility and inclusion, with long term funding for organisations to wholistically embed accessibility and inclusion.

Foundational Supports must be delivered as part of wider policy and legislative reforms to drive a wholistic approach to improving the accessibility and inclusion of all organisations, sectors and places, including through reforms to the *Disability Discrimination Act* 1992 and requirements for mandatory Disability Action Plans.

Consideration should be given to how providers of capacity building initiatives may be funded to provide comprehensive and long-term offerings to organisations and sectors, as opposed to siloed or short-term training. For example, Foundational Supports could provide longer term funding to organisations that enables them to truly embed accessibility and inclusion across the entire organisation, including by supporting the development of disability and inclusion strategies, disability action plans, employee resource groups and early career and leadership programs. Longer term support could help drive sustained change, regardless of organisational change. Expertise or consultancy to build accessibility and inclusion should be required as standard across all public organisations and sectors at the very least.

(h) Drive a systematic approach or framework to delivering capacity building initiatives across diverse organisations.

Organisations and sectors vary significantly, and their capacity to embed accessibility and inclusion can be influenced by a range of factors, including their size, organisational capacity, systems, culture and values. A-plus is attempting to address this by asking – how can Amaze create a framework that organisations can implement effectively at scale – regardless of their differences. We are working hard to ensure that A-plus is delivered via a validated and proven framework that can be applied across diverse industries, contexts and workplace cultures – servicing as a foundation for broader application in the future.

The Foundational Supports model should similarly drive a systematic approach or framework to building accessibility and inclusion across organisations, ensuring change can happen across diverse organisations and sectors, regardless of their characteristics, capacity or existing culture. Further investment in technology and funding is needed to enable the flexible delivery options that meet the needs of different organisations, while also meeting learning needs, such as interactive virtual leaning.

Our experience delivering A-plus has demonstrated that change within organisations, such as restructures or key personnel leaving, can impact the delivery of capacity building initiatives and their capacity to effect long term change. As discussed in further detail below, a comprehensive systematic approach is required to ensure capacity building can withstand workforce changes.

(i) Commit to long term funding of capacity building initiatives, including to ensure sustained positive change and enable resource maintenance and evaluation.

Long term funding is needed to ensure organisations that access inclusion education and training are supported to maintain their commitment to access and inclusion after the initial training or resource is delivered. It will be important that Foundational Supports moves beyond simply improving understanding and acceptance, to achieving sustained behavioural and organisational change.

Capacity building initiatives and resources funded by Foundational Supports cannot be funded only for outputs, or the initial creation and delivery of supports, the model must also fund evaluation and maintenance/updates. As demonstrated in Tables 1 and 2 above, evaluation is essential to understand relevance and reach, ensure learnings continue to inform the delivery of capacity building projects and ensure they remain sustainable, reliable and relevant.

Long term and ongoing funding is needed to ensure resources can be maintained and updated. New evidence is constantly emerging, and policy change is constantly coming into effect which can impact the reliability or accuracy of information resources and initiatives. It is vital that the Foundational Supports model provides long term ongoing support to ensure the resources and initiatives it delivers are sustainable, accurate and appropriate for the community.

RECOMMENDATIONS

9. **Drive the creation of individual and community capacity building resources and initiatives that can build full community inclusion.**

10. **Extend Foundational Supports capacity building to social media campaigns that can build the general community's understanding and acceptance of disability, including autism.**

11. **Recognise that trusted autism specific information resources and initiatives, including peer support, are in high demand and must compliment and inform general capacity building supports.**

12. **Deliver capacity building resources and initiatives that are co-designed, neuro-affirming and tailored to the needs of Autistic people, including vulnerable and hard to reach cohorts.**

13. **Ensure capacity building resources and initiatives are well promoted, with multiple touch points for engaging.**

14. **Deliver peer support programs that are tailored to the individual needs of participants and delivered via a range of modes (including online, in person, group and 1:1).**

15. **Take a whole of government approach to ensuring Foundational Supports are delivered as one part of broader reforms to enhance accessibility and inclusion, with long term funding for organisations to wholistically embed accessibility and inclusion.**

16. **Drive a systematic approach or framework to delivering capacity building initiatives across diverse organisations.**

17. **Commit to long term funding of capacity building initiatives, including to ensure sustained positive change and enable resource maintenance and evaluation.**

5. A systemic approach to building sector capacity

The Foundational Supports model must drive a comprehensive and systematic approach to creating accessible and inclusive community and mainstream organisations and settings. It must also drive a well targeted approach to capturing and sharing data, knowledge and expertise that can inform understandings of community need, appropriate responses and how success can be measured.

(a) Drive a systemic approach to creating sustainable inclusive community and mainstream settings.

A systematic approach must be taken to building the capacity of organisations and settings to be accessible and inclusive. It should not be left to individual organisations and settings to navigate and identify their training needs or goals, or how to embed the expertise and training required.

The Foundational Supports model provides a critical opportunity to consider how governments can work with the sector to deliver a scalable, deliverable product or solution that can be consistently utilised to build accessibility and inclusion across all community and mainstream organisations (including workplaces) and meet the needs of all people with disability (including people with complex and high support needs and those experiencing intersectional disadvantage).

The model should incorporate a framework that drives a consistent evidence and lived experience informed approach to training about disability, access and inclusion (including the needs of people with different types of disability, including autism), supports organisations and settings to identify touch points for training and upskilling (including executives, managers, HR and "champions" with lived experience) and ensures that a sustainable approach to accessibility and inclusion can be entrenched in organisations, including with skills and expertise not being lost (or work to embed accessibility and inclusion compromised) when employees leave. It should drive incentives, pathways and supports for people with lived experience of disability to become experts in community access and inclusion and the delivery of capacity building Foundational Supports.

We recommend exploring the benefits of a centralised sector organisation, or centre of excellence, working with governments to create a capacity building framework and designing evidence and lived experience informed training and development that could be flexibly delivered via multiple modes, including by regional, grassroots and community led organisations. As discussed above, it may also drive a consistent expert approach to supporting organisations to embed accessibility and inclusion more broadly, including through the development of disability inclusion strategies and action plans.

As part of this approach, we recommend that consideration be given to accreditation to drive the development of high-quality evidence and lived experience informed capacity building training and development programs. Accreditation would ensure that individuals who have undergone accredited training and development can be recognised and can take their transferable skills and expertise to their next role. An accreditation model may also provide incentives to employees to undertake capacity building training and development, as an asset and skill/qualification that may be recognised and sought by future employers. Most importantly, a register could

then be developed of individuals that have these skills to enable people with disability, and their families, carers and kin, to identify organisations/staff with these recognised skills and expertise.

Learnings may be taken from the approach to capacity building in Victorian TAFE's. This model utilises an [Educator Passport](#) app which enables educators to plan, access and record/track their professional development. Educators can use the app to search and register for quality education and training programs that will meet their capability requirements, identified through completion of a profiling tool in the app. The app provides a centralised location for educators to record their professional development which may be shared with current and future employees. Similarly, an access and inclusion capacity building skills passport could support access to tailored evidence and lived experience informed capacity building training and development options, provide a centralised place for employees to record their achievements and link to a register accessible by the public.

(b) Explore how community insights may be captured and shared, including through a capacity building community of practice.

We agree that consideration should be given to how community insights can be better captured to inform understandings of community needs, appropriate responses and how success is measured.

As discussed above, we would welcome the opportunity to explore how our expertise and data may be more widely shared with government and non-government entities to support the capacity of all ISR service providers to collect and manage data and be autism accessible and inclusive. This data also has the unique capacity to provide a lens into the key concerns and needs of the autism community.

We welcome the opportunity explore how we may share our capacity building expertise and learn from others, such as through a community of practice, as well as how we could support autism informed and responsive capacity building across the Australian community.

RECOMMENDATIONS

18. **Drive a systematic approach to building sector capacity, including through the development of a capacity building framework, training accreditation program and skills register**

19. **Explore how community insights may be captured and shared, including through a capacity building community of practice.**