

# General Supports Consultation Report

Consolidated feedback from national consultations for the design and delivery of additional supports for people with disability in the community



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## Acknowledgement of Country

The Department of Social Services acknowledges the Traditional Owners of Country throughout Australia on which we gather, live and work. We acknowledge all Traditional Custodians, their Elders past, present and emerging and we pay our respects to their continuing connection to their culture, community, land, sea and water.

The consultations informing this report took place on the unceded lands of First Nations peoples across Australia. The Social Deck acknowledges the Traditional Custodians who have lived on and cared for Country for thousands of generations, and recognises their continuing connection to land, waters and community. We pay our respects to them and their cultures, and to Elders past and present.

### A note on language

We acknowledge people use different words to talk about disability and each person will have a way of talking about disability and about themselves they like best. Some people like to use 'disabled person' (identity-first language), while some like to use 'person with disability' (person-first language), and some are fine with using either.

We use person-first language to talk about disability. This means we usually use the term 'person with disability' in this report. The language used in this report is not intended to diminish an individual's identity as a person with disability.

We recognise the appropriate use of language varies between individuals and disability communities. We acknowledge the importance of having conversations with individuals about their preferred language.

# Contributors

The Social Deck wish to acknowledge the invaluable contributions of many people and groups who took part in the consultations informing this report. Thank you to the thousands of people with disability, their families and communities, as well as other stakeholders, who gave their time and shared their experiences and ideas.

## **Contracted facilitators:**

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## **Members of the project advisory group**

The following organisations and individuals provided advice on the engagement and communication approach as part of a project advisory group during the early consultation phase.

- Children and Young People with Disability Australia – represented by Sonia Regan
- First Peoples Disability Network – represented by Damian Griffis
- National Ethnic Disability Alliance – represented by Neha Prakash
- Mental Health Australia – represented by Emma Coughlan and Ingrid Hatfield
- Inclusion Australia – represented by Brooke Canham
- Disability Advocacy Network Australia – represented by El Gibbs
- Australian Autism Alliance – represented by Jenny Karavolos
- Dr George Taleporos, Consultant
- Dr Josephine Barbaro, Consultant
- Tricia Malowney, Consultant

## **Partner organisations**

A special thankyou to the following partners who led or helped to coordinate engagement activity:

- ACT Down Syndrome Institute and Intellectual Disability
- Association for Children with a Disability (ACD)
- Australian Autism Alliance
- Broome Youth and Families Hub
- Child and Family Disability Alliance (CAFDA)
- Children and Young People with Disability Australia (CYDA)
- Different Journeys (VIC)
- Inclusion Australia
- Inclusive Rainbow Voices
- JFA Purple Orange (South Australia)
- Kiind (WA)
- Kindred (NSW)
- National Mental Health Consumer Alliance (NMHCA)
- National Ethnic Disability Alliance (NEDA)
- Parent 2 Parent
- Self-Advocacy Resource Unit (SARU)
- Settlement Services International (SSI)
- Soward Consultancy (ACT)
- Speak Out Advocacy (Tasmania)

# Foundational supports and scope of consultations

Foundational supports are specific supports additional to mainstream services and supports accessed through the National Disability Insurance Scheme (NDIS). They will help people with disability, and their families and carers in a number of important areas.

Foundational supports were one of the key recommendations of the Independent Review into the NDIS (NDIS Review), which handed down its [final report](#) in December 2023. This consultation builds on the significant engagement the NDIS Review undertook with the disability community, to further understand what foundational supports may look like.

Governments are working together to design foundational supports. They would be jointly planned and funded by the Commonwealth and state and territory governments.

Foundational supports will be delivered in two forms:

**‘General’ supports** to deliver access to trusted information and advice and build the capacity of all people with disability. These are being designed for people to fully participate in the community, and to make decisions and advocate on issues that impact them. Information, advice and referrals are for everyone. Capacity building supports would be for people under 65.

**‘Targeted’ supports** would operate between inclusive mainstream services (for example in areas like early childhood, schools and community mental health) and the specialist supports accessed through the NDIS. These supports will focus on helping certain groups of people who are not accessing or not eligible for support delivered through the NDIS, in areas where the need is greatest.

## Scope of consultation and this report

This consultation process and report focuses on **information, advice and capacity building supports**. Targeted supports are not within the scope of this consultation report.

The report is based on engagement (between September and December 2024) to gather input from community and stakeholders about how general supports should be designed. Feedback will inform the reform of an existing program known as the Information, Linkages and Capacity Building (ILC) program and other additional information, advice and capacity building supports.

The report includes some feedback on areas beyond the scope of the general supports consultation paper (for example, the need for targeted supports for psychosocial and ideas about what could be done in education settings).

Insights about general supports for children with developmental delay, concern and/or disability are in the separate [Supports for Children under 9 Consultation Report](#).

Throughout this report, we use examples and quotes to demonstrate more clearly some of the issues and barriers people spoke about. These are based on real contributions, however, they have been deidentified to protect the privacy of individuals.

# Executive summary

## Initial consultations to design general supports

In September 2024, the then Minister for Social Services, the Honourable Amanda Rishworth MP, [announced consultations on foundational supports](#), starting with general supports. These consultations took place from 20 September to 5 December 2024.

More than 4,000 people gave feedback during the consultations. This demonstrates the interest in foundational supports across the community and the disability, mental health and chronic health sectors.

We thank people with disability, people living with mental health challenges and chronic health issues, and their families, carers and kin for sharing their experiences and their ideas about what is needed. With so many changes and reforms underway, we acknowledge the time and efforts of the community and stakeholders in the sector to contribute to this consultation process.

The feedback received responds to the questions in the [General Supports Consultation Paper](#). This paper, as well as other materials such as information sheets, frequently asked questions and translated materials were available throughout the consultation period to help people think about what general supports might look like or include in the future and respond to questions at events, via video or interviews, or in writing.

Throughout this report, we share more about the ideas, examples and models of support community members and stakeholders have said would be most helpful in a general supports service system.

Some of the feedback highlights the concerns in the community and sectors about how reforms underway in the disability systems in Australia, and specifically the NDIS, will impact them. Community members and stakeholders consistently noted:

- there is urgency in implementing these reforms and supports, including to begin the design and implementation of targeted supports for other cohorts such as people with psychosocial disability, as recommended by the NDIS Review
- people need reassurance appropriate actions and programs will remain in place to maintain supports for people, including for those currently in the NDIS and those who need additional supports in the community now

To best support the needs of people with disability and their families, carers and kin, community members and stakeholders indicated a strong system of support for the many people in Australia with disability is required, particularly for those not accessing or not eligible for supports delivered through the NDIS. This is in addition to making changes to improve the NDIS and continuing to improve the inclusion and accessibility of mainstream services all Australians rely on.

## Main themes

This report provides an extensive set of issues and ideas about what is needed to improve information, advice and capacity building. Feedback and ideas came from people with disability, their families and carers, and stakeholders across the disability, mental health, allied health and chronic health sectors.

### What will be most helpful

Based on the consultation feedback, there are 9 main areas participants consistently said would be most helpful in a general supports system. Throughout this report, we provide specific examples and ideas about how these could be achieved.

- **Trusted organisations in the community** delivering information, advice and capacity building with sufficient and longer-term funding to deliver tailored supports and programs. This included local, state-based and national representative and advocacy organisations.
  - There was a focus on more opportunities for these organisations to work together with longer-term funding arrangements and different commissioning models that ‘allow disability-led peak bodies and grassroots groups to partner together and seek funding for the vital local solutions to advocacy, peer support and capacity building already existing or vitally needed’
- **Delivery of general supports in local place-based settings with wraparound services.** This included community hubs and use of neighbourhood centres, libraries and other community places.
  - A critical part of this was ensuring local supports across disability, health and mental health come together to offer information, advice, referrals and capacity building programs tailored to different groups.
- **Investments in peer support networks** to ensure they are sustainable and available to more people in the community. This included support for online, social media and in-person forums.
- **Support for systemic advocacy alongside self-advocacy and family advocacy programs.** This will drive long-term changes, particularly in access and inclusion to the additional supports in the community and in mainstream services.
- **Digital and centralised platforms and services** that provide tailored, searchable and local information about supports in the community.
  - It was more common for people to suggest these platforms and services be delivered by non-government, trusted and expert organisations who have the appropriate knowledge. However, many suggested governments invest in a better centralised system to find quality providers and supports.

- **Delivering effective information, advice and capacity building through touchpoints and other support systems.** For example, participants suggested information, advice, referrals and capacity building need to include delivery through services like GPs, allied health including social workers, schools and early childhood centres.
- **Training and education programs** to improve disability awareness and knowledge to key workforces. It was suggested this should be delivered by people with disability and disability-led organisations and be delivered to community supports and organisations, disability supports and mainstream services. People also focused on the need for broad public education.
- **Investing in a sustainable and trained workforce, including suggestions for case management or navigator roles within general supports.** Workforce needs were a particular theme in feedback about services in regional, rural and remote areas.
- **Improving communication and information** about what foundational supports are, how they will be delivered alongside the NDIS and mainstream services and who will be eligible.

## Quality, safety and accountability

Following are the main things people said are needed to ensure quality, safety, accountability and innovation in the delivery of general supports.

**Strengthen and increase the workforce that will deliver foundational supports.** Workforce shortages are a particular issue in regional, rural and remote areas where it can be difficult to attract and retain staff without job security or the ability to match incentives or benefits given by other sectors or industries. For organisations to retain quality staff to provide supports, they will need:

- investment/funding for training, placement of the right people and professional development opportunities for staff
- incentives for regional, rural and remote staff, and support for outreach activities can be particularly difficult
- the capacity to build a strong sense of team and connection with community

**Have longer-term funding to deliver the ‘base’ of general supports, with grants and flexibility to encourage innovation.** Participants identified longer-term arrangements will:

- strengthen information systems and accuracy of information and advice
- ensure advice is evidence-informed
- provide time to build and sustain localised and place-based initiatives
- increase collaboration
- lead to more reliable and ongoing capacity building supports
- better involve representation of people with intersectional identities
- sustain self-advocacy and peer groups, including workforces and volunteers supporting these

**Ensure quality and safety in services and programs** through:

- registration and compliance
- having a good complaints system
- investing in systemic advocacy
- ensuring all people with lived experience, including from diverse and marginalised groups, are involved in monitoring and evaluations

**Progress and effectiveness of general supports must be measured and evaluated**, through defined outcomes and indicators Commonwealth and state and territory governments are accountable to. Co-design of these outcomes with community and ‘users’ of general supports, and how they are measured, is critical.

**Build on what’s working and ensure existing support systems are sustained.** Participants reiterated the need to:

- use existing trusted, credible organisations and services to ensure quality and safety of supports for people with disability
- have a fair and transparent transition process and period for any changes in NDIS supports.

## Other specific considerations for the design of general supports

There weren’t a lot of differences in the type of feedback provided about general supports between states and territories. When it came to general supports, the most common differences were related to specific issues for regional and rural areas or certain groups and demographics. As a result, this report doesn’t provide specific findings and recommendations by state and territory.

### Regional, rural and remote delivery

There was not a lot of differences in the feedback provided across states and territories. While people mentioned specific state-based programs work well, differences in what should be considered when implementing general supports was more commonly about service gaps, workforce issues and considerations for people living in regional, rural and remote areas.

Regarding regional, rural and remote areas, people acknowledge issues exist in the availability of adequate supports and a workforce to deliver NDIS supports in these areas. Many people said the design of general supports needs to take account of this and include specific models for regional, rural and remote areas. Most often this included suggestions for:

- services that are place-based and community-led, to help make sure they are trusted and sustained in local areas, and designed with people with disability
- services and programs to be integrated with existing support systems.

### Meeting the needs of people from diverse and intersectional groups

There was very strong and consistent feedback that supports need to be equitable and effectively meet the needs of people from diverse and intersectional groups, including First Nations people, people from culturally and linguistically diverse backgrounds and people in the

LGBTIQ+SB community. It was common for community members and stakeholders to highlight the following:

- Supports must be **trauma-informed, culturally safe, accessible and neuro-affirming**. This includes ensuring self-determination for First Nations people.
- **Specific supports need to be tailored for young people and children**, especially through key life transitions.
- There needs to be **different types of general supports delivered for all types of disability**. This acknowledges there are different considerations and capacities to engage in-person versus online, and people have varying needs.
- Supports should include help to address gaps in information and supports for **people with psychosocial disability, mental health challenges or diagnosis and people with chronic health issues** who need extra support but may not be eligible for the NDIS.

### Alignment with other strategies and reforms

We heard there is a need for governments to better link the design of foundational supports with other strategies, in particular [Australia's Disability Strategy 2021-31](#) (ADS). Foundational supports also need to be delivered alongside:

- potential reforms and updates to the Disability Discrimination Act 1992 and other specific responses to the Disability Royal Commission would ensure people have the right to access information and supports required to take part in the community
- Australia's obligations under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- broader NDIS reforms based on recommendations of the NDIS Review, including in areas such as legislative changes in the NDIS and provider and workforce registration
- state and territory disability plans
- the Australian Government's gender equity, Closing the Gap, mental health reforms and other related strategies.

### Accompanying reports

This main consultation report on general supports in the community is accompanied by:

- [A Summary Report of the key themes](#). An Easy Read version and Auslan version is available.
- [Consultation Report on Supports for Children under 9, their families, carers and kin](#), including summary with Easy Read and Auslan version. This consolidates feedback from families, carers, the early childhood sectors and other stakeholders is specific to how general supports and targeted supports might work to support children 0-9 years and their families, carers and kin.
- [First Nations Consultation Report](#). This report provides a summary of the feedback and considerations provided during First Nations-specific engagements and from organisations who represent and support First Nations people and communities.

# How and who we engaged

## Participation

In total, there were 4,174 participations in the foundational supports engagement process held between 20 September and 5 December 2024. This included participation in consultations on general supports and supports for children, their families, carers and kin.

Over 800 participations occurred in face-to-face events, and over 1,400 in online events.

In total, there were over 1,400 questionnaire responses and submissions, and just under 500 entries to the ideas wall.

Participation included over 2,100 people with disability or people living with mental health challenges or chronic health diagnosis or concern, and their families, carers and kin. This was more than 50% of total participation.

People from all states and territories took part in the consultations. More than one-third were from regional, rural or remote areas.

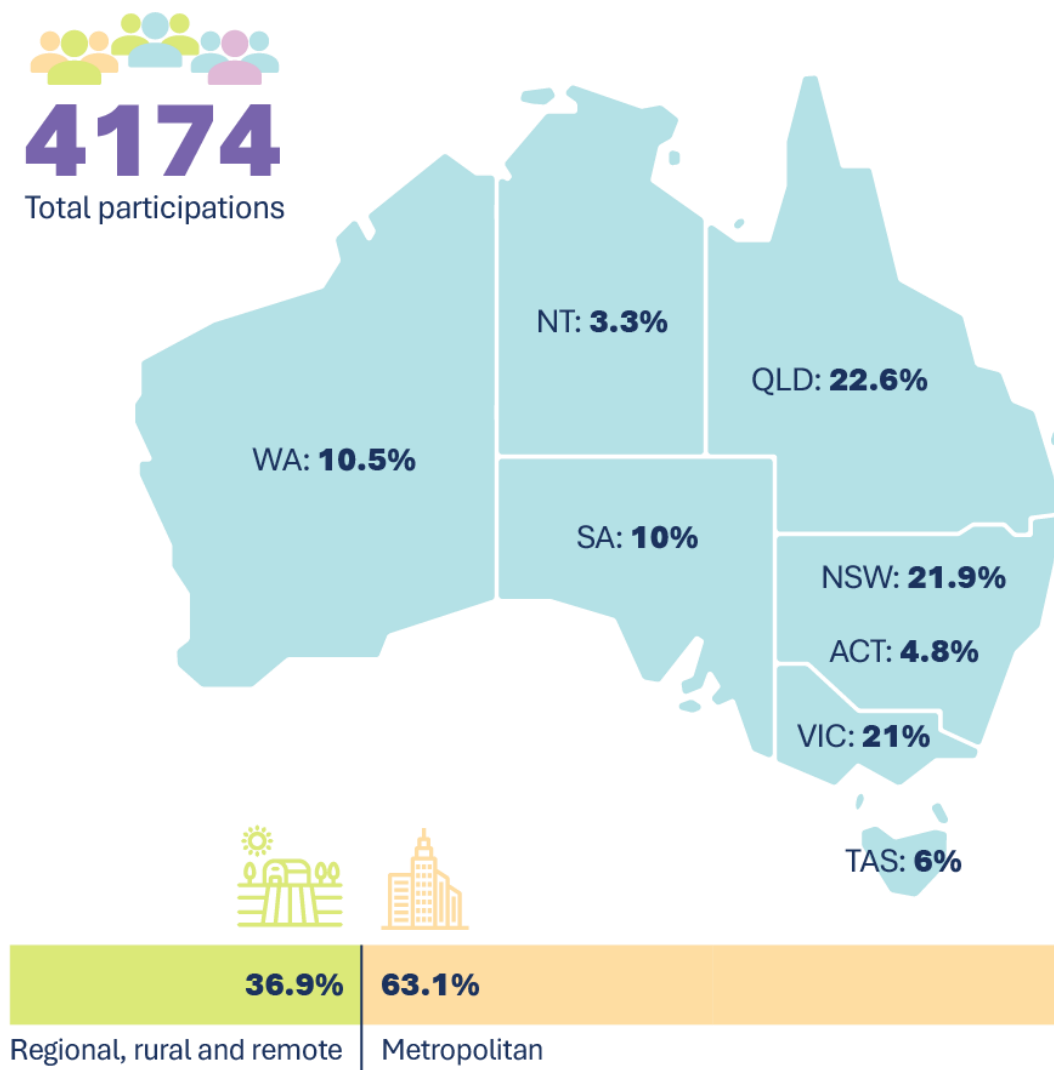


Figure 1: Total participations, and percentages across states and territories, and location.

## General supports participation

The majority of this report is based on feedback from those who contributed to the general supports consultation process. A [separate report](#) is available about supports for children under 9 and their families, carers and kin.

Within general supports consultations, the largest number of participations were from people with disability or people living with mental health challenges or chronic health diagnosis or concern (49.1%) \*.

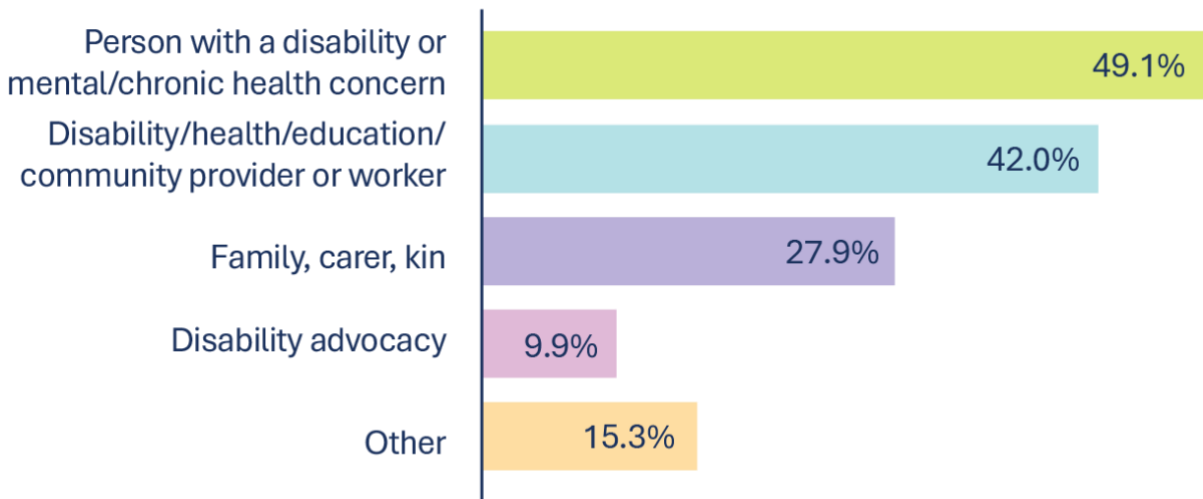


Figure 2: Participation percentages across interest groups

\*Note: Demographic data was not collected at all events, and participants could select multiple categories.

## Reaching targeted population and intersectional groups

The experiences and ideas of priority population and intersectional groups was a key focus of the consultations. In addition to attendance at open community events, a number of activities were facilitated through partner organisations to engage in safe and inclusive environments.

Twenty-three (23) events were specifically with targeted populations and organisations representing diverse, marginalised and intersectional groups, including:

- Aboriginal and Torres Strait Islander people
- people with culturally and linguistically diverse backgrounds
- young people
- people in the LGBTIQ+SB community
- people living in rural and remote areas.

Fifteen (15) of the events and engagement activities were delivered with specific disability cohorts including organisations and people with lived experience of:

- autism
- intellectual disability
- Down syndrome
- mental health challenges
- deaf-blindness

- neurological disorders
- developmental disability
- chronic health conditions.

## How we engaged

The consultations included a wide range of activities, with the mix of methods designed to ensure people with disability and others across the community could take part. In total, more than 100 separate events or discussions were held.

Activities were available on the DSS Engage website and promoted through DSS channels. Key stakeholders were invited directly and encouraged to invite members to participate. In some cases, The Social Deck partnered with disability and other organisations to recruit and facilitate group discussions with members.

## General supports engagement activity

For general supports, 78 consultation events were held. The following mix of methods were used:



### Online roundtables and webinars:

- **9** events
- **926** participants (doesn't include introductory webinar – informational only)



### Face to face workshops and roundtables:

- **30** events
- **567** participants



### Focus groups/small group discussions:

- **38** events
- **325** participants



### Questionnaire responses and submissions: **861**



### Ideas wall entries: **498**

Figure 3: Number of events and participations across engagement types (general supports)

## Engagement content and activities

Methods of engagement were designed to gain qualitative feedback on key barriers, experiences and ideas to guide the design and development of foundational supports.

Engagement activities focused on 5 areas:

- **What supports are working well now or have worked well in the past**
- **Information, advice and referral**, including:
  - access to quality and trusted information and advice about disability, child development and disability rights
  - linking to existing resources
  - information on disability supports are available to people and their families/carers and kin.
- **Capacity building, including:**
  - **for individuals**, such as access to peer support groups, support for self-advocacy, decision-making, leadership development, relationship building and life skills development
  - **for families**, such as peer support, parenting groups and workshops, education and training, building skills in advocacy, family leadership and development
  - **for communities**, such as building the capability of community organisations – like sporting clubs, arts groups or community services – to be responsive to the needs of people with disability.
- **Quality, safety and accountability**, including sector capacity and workforce considerations
- **Implementation, measurement and evaluation.**

Discussions were tailored according to the experiences and interests of participants, so the time spent on each topic varied according to participant input.

Events on supports for children focused on:

- Information, advice and referral
- Children and family capacity building
- **Targeted supports for children**, including lower intensity or periodic child and family-centred allied health supports.

More information about how engagements were delivered and analysed is at [Appendix 1](#).



# Chapter 1: Outcomes and considerations for the design and implementation of general supports



# Overview from consultation paper

General supports covers information, advice and capacity building supports.

## What are information, advice and capacity building supports

These are designed to help people with disability participate more fully and go beyond the reasonable adjustments expected from inclusive and accessible mainstream and community supports. This includes:

- trusted information about disability, rights, and services to empower people with disability
- supports and tools to build the skills, capacity and independence of individuals to make and sustain social networks and community connections, to make decisions (including supported decisions) and to advocate on issues that impact them
- information, advice and supports to empower and build the capacity of families, carers, and kin in supporting people with disability to participate and exercise choice and control over their own lives
- assistance to find and access mainstream, community or disability specific services and activities appropriate to needs and goals
- information and advice to assist community organisations and non-government public services/activities to become more inclusive and responsive to the needs of people with disability.

Once fully implemented, supports will be available nationally, fully accessible and where appropriate, tailored to meet the needs of diverse communities. For example, First Nations people with disability and culturally and linguistically diverse people with disability; or for particular population groups, such as people with intellectual disability or psychosocial disability. They will also be designed to connect with other services and tap into local community knowledge and networks. Accessing general supports would not preclude someone from accessing the NDIS or other supports in the community.

## Outcomes for general supports

The consultation paper proposed some intended outcomes general supports should aim to achieve. People were asked if the intended outcomes are the right ones and if there are any gaps.

## What we heard

Stakeholders and some community members gave specific feedback about the outcomes, mostly through submissions. Stakeholders generally agreed with the intended outcomes, with some highlighting the importance of certain outcomes proposed or suggesting additional outcomes foundational supports could seek to achieve. Key outcomes mentioned are listed here.



## For people with disability:

- greater independence and autonomy
- improved quality of life, emotional wellbeing, mental health and self-esteem
- improved ability to achieve goals and aspirations
- increased community access and ability to engage
- increased access to culturally safe and appropriate services that meet their unique needs
- improved inclusion in early learning and education settings (for children with disability)
- increased economic participation / participation in education and employment
- reduced discrimination / stigma.

In submissions, stakeholders highlighted an outcome from foundational supports should be for people to have **access to additional and tailored supports during key transition points across the lifecycle**, such as entry to school, the workforce, transition into or out of care or hospital, etc.



## For parents, carers, families and kin:

- greater understanding of disability
- reduced levels of carer stress / burnout
- improved mental health and physical and emotional wellbeing
- reduced isolation and increased community engagement
- strong familial and community relationships.



## For organisations, groups and non-government entities servicing the community:

- Increased organisational and worker awareness about disability and the rights of people with disability. Feedback suggested this outcome was important but needs to include **improving understanding**, with training and accreditations suggested to ensure the needs of people with disability are met and supported through organisations funded or paid to deliver services.
- Services and community activities which are more responsive, accessible and meet the needs of the diversity of people with disability and their families, carers and kin. Feedback suggested this outcome include a focus on having more organisations with a strong understanding of the Disability Discrimination Act and other legislation to ensure supports and services can be accessed by all people with disability.



## For the broader service system/community:

- Increased community understanding and acceptance of disability and the rights of people with disability.
- More accessible and inclusive services and communities, including reduction in inaccessible infrastructure.
- Reduced segregation between people with disability and people without disability.
- Increased collaboration and integration across mainstream services (including primary care, transport, education, etc.), foundational support services and the NDIS noting the need for clarity around funding, roles and responsibilities.
- Improved competency of service providers and their staff in supporting people with disability.



## Linking outcomes

Responses to the consultation paper highlighted the importance of linking the three key areas of **empowering individuals**, having **strong community networks** and **accountability** of government and non-government services to deliver safe, quality and accessible foundational supports. A strong theory of change would show how outcomes across these areas link together and can be achieved.

Outcomes measurement for foundational supports should also link to the other measurement frameworks, particularly the [outcomes framework](#) and measurement for ADS as the outcomes general supports could help enable in the community, are highly aligned with ADS policy objectives and outcomes.

More information about measurement is in [Chapter 6](#).



**Empowered  
Individuals**



**Strong Community  
Networks**



**Accountability**  
of government and  
non-government services

## Outcomes for diverse and intersectional groups

People who are from specific minority, diverse or intersectional groups and organisations who support them highlighted foundational supports should focus on promoting and achieving:

- **systemic equity** in access to services and supports, and ensuring specific needs of marginalised groups within the disability community are met
- **availability of safe and inclusive supports** for all people with disability
- **tailored supports** appropriate to the person, accounting for intersecting identities, different types of needs and disabilities, co-morbidities and cultural needs or preferences
- a more **strengths-based** approach that focuses on the value people with disability bring to our communities
- **sustainability of disability-led and trusted organisations** that support intersectional and diverse groups who have specific needs.

Some suggested measurement of outcomes for additional supports in the community must include qualitative experiences and feedback, as well as specific data that tracks engagement and equity, to show whether outcomes are being achieved for people from different backgrounds, circumstances, geographic locations (e.g. rural and remote) and intersectional identities.

*‘Measure the extent to which people with disabilities are able to engage in community life, including social, educational, and employment opportunities. The goal is not only about independence but about being integrated and valued in society.’ – Submission*

## Self-determination in First Nations communities

For positive outcomes to be seen in First Nations communities, we heard First Nations people and community-controlled organisations must have sovereignty over the design and delivery of foundational supports delivered in their communities. First Nations people spoke about their right to self-determination where they have choice in the types of supports they access ensuring services are culturally safe, relevant and appropriate in their lives and communities.

*‘For the new foundational supports to be culturally relevant, responsive, and safe for Aboriginal and Torres Strait Islander people, the supports must be infused with Aboriginal ways of knowing, being, and doing.’ – Submission*

## Concerns about service gaps or negative impacts

We heard from people who previously experienced a loss of **continuity of supports** during the introduction of the NDIS. Some people expressed concerns foundational supports may disrupt or reduce supports for some people, including those who are currently in the NDIS, if NDIS eligibility was changed under a future system and there was no appropriate alternative. People wanted to ensure there would be a strong commitment by governments to having additional supports in place before there are any impacts on people's current supports and access to the NDIS.

Other feedback from people with disability and stakeholders also raised significant concerns about service gaps, and the potential for a foundational supports system to have unintended impacts on people with disability and the wider community. Most commonly people mentioned they were concerned about:

- reduced funding in NDIS plans for individuals
- removal from the NDIS, which was a particular fear raised by people with psychosocial disability and some families and carers of young children
- impacts on services and markets in regional areas as a result of services needing to support another service system
- marginalised communities missing out on supports if they're not designed well and programs aren't inclusive, affordable, and accessible to all
- a lack of communication and understanding about what foundational supports are or will look like in the future
- funding and programs doing 'much of the same things that aren't working'
- proof of diagnosis and eligibility requirements limiting people's ability to access additional supports in the community. This was a particular issue for people with psychosocial disability and mental health challenges.

*'This [regional, rural and remote] cohort is quite fearful that the few supports currently available are going to disappear due to changes to the NDIS, and foundational supports will not reach small towns and remote communities where people with disability have no public transport, no taxi services, few health services and rely on family and friends informal support for their day-to-day living.'* – **Submission**

## Diagnosis and eligibility as a barrier to getting supports

A common concern among people with disability and people living with mental health challenges is the potential for governments to require a formal diagnosis for people to be eligible for foundational supports. Some people wanted to better understand how those not in the NDIS and who aren't able to afford or access a diagnosis would access foundational supports if there were eligibility criteria in place. This related to general supports and targeted supports for certain groups.

A number of respondents felt there should be no eligibility criteria to access general supports, noting it can be onerous, expensive and challenging for people to prove their disability. Where there is a need for eligibility within programs, clear guidance is needed to ensure individuals can get help without undue delay or complexity.

*'That's probably what we're talking more about, particularly in outback Queensland, is that a lot of people are not diagnosed. They don't have the privilege of diagnosis because of access, cost, you know, a range of different reasons.'* – Participant, *Outback Independent Living (QLD) discussion*

## Priorities to address key concerns that may impact outcomes for people in the community

Stakeholders suggested priorities to address these concerns:

- The implementation of **interim supports and programs** to bridge gaps and prevent disruptions in essential services<sup>1</sup>. This included interim funding arrangements to ensure continuity of services and existing ILC funded projects are sustained while further design and implementation of foundational supports is done.
- **Integration and collaboration between service systems**, particularly in regional, rural and remote areas and to support people living with mental health challenges or chronic health issues.
- Being clear about areas where the foundational supports system will be **co-designed**.
- **Establishing a robust communication plan** and ensuring all **information and resources are fully accessible** and available in multiple languages.
- **Communicating directly to NDIS** participants 'to ensure they are clearly and directly informed of changes that have a direct impact on their lives'.
- **Having a clear strategy for measurement and evaluation**, including tracking and reporting of real outcomes (whether positive or negative), with people with disability involved.

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<sup>1</sup> A joint submission from Disability Representative Organisations, 12 December 2024, <https://www.dana.org.au/wp-content/uploads/2024/12/DR0-joint-submission-Foundational-Supports-DSS-FINAL-241212.pdf>

## Supports for psychosocial disability

Feedback strongly encouraged governments to prioritise targeted supports for people with psychosocial disability alongside general supports. People with psychosocial disability and mental health challenges noted there are urgent gaps in the supports available to them. While information could be improved, they often suggested information and referrals are lacking because of the limited supports available between the NDIS and health systems.

Stakeholders, such as Mental Health Victoria, reiterated the importance of having a cross-jurisdictional approach to harmonise disability and mental health reforms, noting this would be critical to ensure there are no gaps, and to minimise overlaps, in support delivery.

## Building on existing supports

The consultation process included asking people about what is working, or is not working, within current information, advice, referrals and capacity building supports in the community. The feedback explored where improvements could be made to existing supports, such as the ILC program and other services including the Disability Gateway. It builds on feedback provided in previous reviews of ILC<sup>2</sup> and the [NDIS Review](#).

## ILC Program

The Australian Government has agreed to reform the ILC program as one component of a broader information, advice and capacity building support offering within general supports.

Stakeholders expressed mixed views about the value of the existing ILC program. Some noted it was a ‘crucial component’ of Australia’s disability services system, enabling providers to trial and pilot service innovations that can provide great benefit to the sector. It was recognised this model of funding is crucial to facilitate and encourage innovation and enable providers to try out new ways to meet diverse needs and address market gaps.

However, some respondents highlighted the limitations of the ILC Program, including:

- the program largely funded short-term supports
- did not provide adequate or effective supports to account for needs across regions and cohorts in an equitable way
- did not sufficiently increase inclusion or make mainstream services more accessible.

Some felt the short-term nature of the grants:

- restricted the sector’s ability to recruit, train and retain a sufficient and skilled workforce
- lead to a lack of coordination and unified approach – programs were rolled out piecemeal, which diluted impact, limited reach and required the information seeker to know who and where to go to get the required information

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<sup>2</sup> Informing Investment Design: Information Linkages and Capacity Building (ILC), Centre for Social Impact at Swinburne University of Technology <https://www.dss.gov.au/funding-disability-projects/reviewing-ilc-program>

- do not facilitate continuity of support for people with disability, ‘even where there is demonstrable evidence that programs are working well’
- do not allow sufficient time to establish a program, evaluate its effectiveness and implement continuous improvement strategies.

We heard from organisations and key stakeholders that the short-term nature of ILC funding has increased staff turnover and decreased organisational stability. These stakeholders suggested the program be adjusted to provide ongoing funding for ‘core activities’ that provide a consistent, reliable service and drive systemic change.

*‘(With) short funding cycles, when they get year to year funding or two year to two year funding, they cannot employ and retain staff on the basis of the fact that they know they’re going to be out of a job in a year or two years’ time. Longer funding cycles for those programs will make them more viable.’ – Participant, National Online Roundtable*

Community feedback during consultation events echoed stakeholder concerns. People said funded programs often ended just as they were beginning to gain traction, trust and impact within a community. Other issues with ILC raised by community members during events:

- The ILC program failed to account for the needs of people located in different regions, with variable access across regions to many of the initiatives.
- There is a gap in funding provided through the ILC program for capacity building for families and carers.
- There is limited funding for smaller, local organisations. People suggested grant funding is going to the ‘bigger players’ who may not always have the same reach into local communities.



## **Sustaining and building on effective ILC programs**

Participants noted the importance of sustaining programs and initiatives that have been working well, particularly projects supported through current and previous ILC funding rounds.

There was significant concern that new foundational support programs would duplicate or fail to build on what is already in place, and past learnings and successes. Some people expressed concerns that the design of foundational supports and changes in service design will take a lot of time, whereas there are existing ‘foundational supports’ that could receive additional and longer-term investments now. This feedback came from both users of some of the initiatives and programs, or those supported by organisations with ILC and other similar funding, and the organisations who are eligible for or who have received ILC funding.

Governments should use evaluations of ILC funded programs and feedback from community involved to determine where existing programs could be continued or expanded to provide immediate additional supports in the community under a general supports system.

## Programs in place prior to NDIS

People suggested there were a range of supports working well in states and territories that were lost or changed when the NDIS came into place. Examples included state-based programs that existed prior to the NDIS such as Ability Links in NSW, WA's local area coordinators, and Partners in Recovery for psychosocial disability.

*'[Ability Links] was an amazing program and some of it was targeted to Aboriginal families or people with disabilities and the whole point of that program was just to work in the space of outside any kind of funded services, but just connecting people to the community and building up that sort of social capital stuff.'* –

*Participant, Online roundtable*

A person in an online roundtable suggested there were supports for transitions to adulthood and mental health services that existed before NDIS and don't anymore, and there isn't somewhere for people to go now when they need those supports (or people don't know where to find them).

It was suggested rebuilding these types of effective past programs and supports alongside the NDIS is critical as part of future models for delivery.

*'One of the many things that we lost at the state level was that sort of connecting, you know, people in the Community really funded to connect people to other parts of the Community.'* – *Participant, Online Roundtable*


## Continuing support for advocacy organisations and existing support networks

Many comments and submissions mentioned existing organisations and networks who already effectively support people with information, advice and referrals related to disability and mental health. This included national representative organisations through state and territory peaks and locally-based networks and support groups.

However, people also consistently said these existing organisations and local groups or programs often have little funding and may be overwhelmed by current demand.

Representative and peak organisations, including Disability Representative Organisations (DROs), called for governments to prioritise investments to enable stronger partnerships between the disability community and their representative organisations. This would ensure additional supports in the community build on the effective work of existing organisations (large and small) and ensure the active involvement of people with disability in decision-making processes.

Deafness Forum Australia provided specific feedback which established organisations connected to communities of people who are deaf or have hearing loss should be supported to continue providing services throughout the transition with funding from the ILC program or



its equivalent. This support should include organisations who offer specialised support to under-serviced, and vulnerable cohorts, such as those with Usher Syndrome or who are Deafblind.

People in regional areas were also particularly concerned about ensuring local existing organisations doing good work in the community are supported. In regional areas, people often noted there is only one, or very few, information, advice and referral services so the sustainability of existing and trusted organisations is critical. In submissions, many stakeholders spoke about the value of regionally based supports and strongly recommended foundational supports recognise and include investment in grassroots organisations to develop and deliver person and community-centred support.

# Chapter 2: What supports are needed for information, advice and referrals



# Overview from consultation paper

Governments want to know how information, advice and referrals could be improved through the design and implementation of general supports.

People were asked about:

- whether information about supports is currently easy or hard to find
- what information services they use now and find helpful, and what additional information and advice they would find helpful
- how supports could be better tailored to meet the needs of diverse groups
- what sources of information and advice people use and trust.

## What we heard

### Key issues and barriers in accessing information, advice and referrals

The community and stakeholders have suggested information is currently difficult to find. Out of 500 respondents to the questionnaire less than 10% said they found it easy or very easy to find information about disability supports. More than 73% said it is hard or very hard to find information.

How easy or hard is it for you to find information about disability supports that exist to help you or a person you care for?

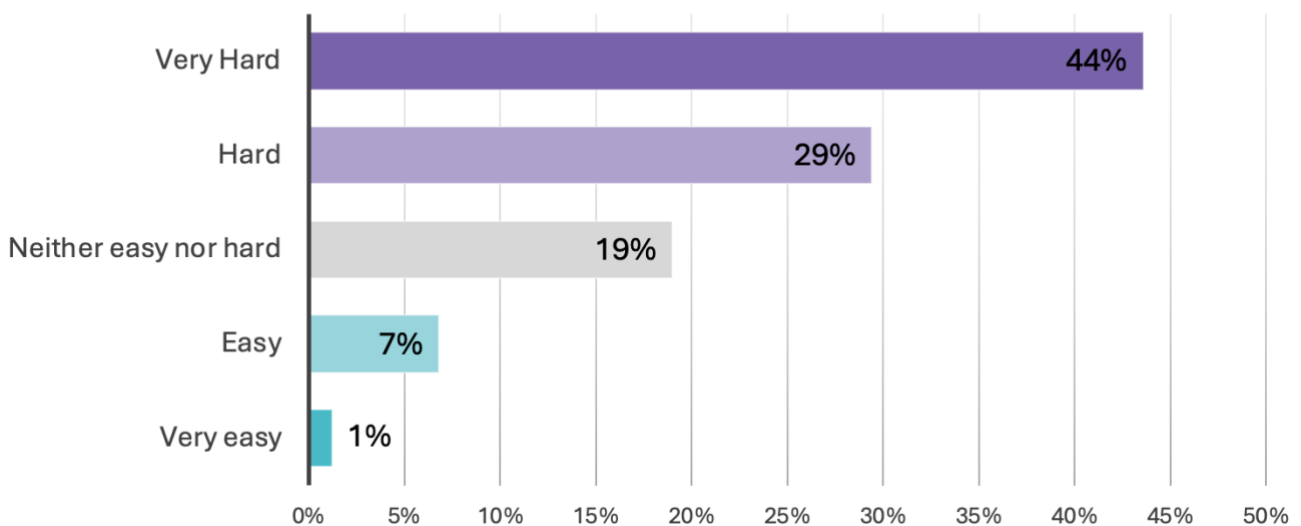


Figure 4: How easy or hard it is for people to find information about disability supports (n=500)

In free text responses and during events, the following key issues were often raised about finding information and advice.

- **Content is too complex**, including terminology used. People reported feeling overwhelmed by a lot of information that ‘doesn’t clearly say what to do next’.

- **Difficulties navigating and finding information online.** This partly relates to websites having too much information, but mostly is about information not being set up well and filterable and is hard to navigate on government websites and portals.
- **Lack of awareness of Disability Gateway and Carer Gateway and missing critical local support information that is relevant.**
  - Organisations and workers, in particular, noted many clients and community members they work with aren't aware of the gateways and services, or people often don't think they're relevant for them.
- **Disconnect between intermediaries, touchpoints and places where people should expect accurate information** about government and community supports – (e.g. schools, hospitals and other medical centres, Centrelink offices). People suggested these mainstream settings often don't have sufficient and accurate information about NDIS and other disability supports, even though people working in these settings mostly work for government. People said there are silos in service sectors that impact quality of information.
- There's a **growing demand on disability advocacy organisations.** Both individuals seeking information and disability and advocacy organisations noted having significant constraints to support people with information due to limited resourcing. People mentioned organisations being de-funded or not having enough funding to support the number of people who need help with information and advice.
- **Inconsistencies and out of date information.** This was particularly raised as an issue for people when calling the NDIA and other government services.
- **Information is lacking outside of NDIS.**
  - People described a lack of information being available and additional barriers to finding and accessing information for people who don't fit within the NDIS or aged care and health systems, such as older people (over 65) who are Deaf. Some suggested specific groups get lost between the systems when it comes to finding supports. This also included lack of information for people with chronic health who often sit between disability and health supports about what they're eligible for and where to get referrals and information.
  - Information is not available for those who need it with significant barriers (e.g. in prison or coming out of prison).
- **Lack of knowledge among those who should know the most** - for example, support coordinators. People also mentioned there is a lack of training about disabilities for those who have key roles in providing information and advice, such as NDIA staff and LACs.
- **Lack of trained professionals** - for example, allied health expertise within government services that provide advice (such as having experts who can understand the needs of a person to make appropriate referrals on the other end of the phone in the Disability Gateway and other platforms).

- **Limited access to individualised and tailored information** to what a person or child needs.
- **Closure of organisations when the NDIS was introduced** due to no ongoing support for community organisations to focus on disability.
- **Lack of real in-person advice and support.** In particular, people noted regional and remote areas are most disadvantaged when it comes to getting the right information, where there is no face-to-face services or hubs to access.

## Lack of available supports outside of the NDIS

Many people said the reason information, advice and referrals are often hard to find or use is because the supports aren't available. A lack of information was often attributed to a void in supports being available for that person or for what they need or are looking for. This is particularly an issue raised in regional areas and for people outside of the NDIS. People in regional and rural areas who are in the NDIS also noted this issue because the supports – (e.g. for capacity building or advocacy) – don't exist. These concerns reiterated the need to ensure supports between the NDIS and mainstream services are available for people at the same time as improving information and referrals to them.

## Inconsistent information from government sources and those they fund

While there was a strong desire to be able to access information directly from government, some people raised issues with trusting the accuracy of information coming from government sources noting it can be inconsistent and, at times, incorrect.

In particular, there was a lot of feedback the current NDIS and NDIA systems aren't working well to provide accurate and timely information about supports.

*'Most of my information and advice comes from the support of my organisation and colleagues as it is often quite difficult to navigate how to find supports... I have found calling the NDIA with families has also resulted in information being told to us that we later found was incorrect.'* – **Individual respondent, general supports questionnaire**

*'The NDIA provides no advice regarding local or regional services and the LAC model seems ineffective in that they have limited scope of information available and are unable to provide accurate or even up to date information on local services or referral pathways.'* – **Individual respondent, general supports questionnaire**

## Low confidence among workers in finding and accessing information

Many of those who reported they work in the disability field said they find it hard to find and navigate information about services and supports. This impacted their ability to refer and provide accurate information to the people they support.

## Disability Gateway

Feedback from many people and organisations showed a platform and service like the Disability Gateway is needed, but improvements need to be made. Consultation feedback shows awareness and use of the Disability Gateway as a trusted source of information and advice is relatively low. This was compared to other sources of information such as using local peer networks, organisations and other services and touchpoints such as GPs and schools.

As shown in Figure 4 on the next page, when asked to select the sources they currently use, relatively few people (80 people out of the 500 who responded) said they use or are likely to use the Disability Gateway. Of those respondents who had used the service, many reported it did not meet their needs.

The key issues raised about the Disability Gateway platform and services were:

- It provides information that is not relevant or appropriately tailored to the individual (often providing generalised advice which did not address specific circumstances or directing individuals to services that were not relevant, appropriate or available in their area).
- It did not identify all relevant NDIS providers / supports in the area (when compared against results using the NDIS Provider Finder).
- Information can be inconsistent with other websites or services.
- Information is not always presented clearly and simply for people to find and understand. People said there should be a focus on making sure support information and resources are in Plain English.
- Information was not consistently accessible for people with different disabilities (e.g. for people who are blind or Deaf). This included the overreliance on the National Relay Service (NRS), Type and Listen (TTY) calls or interpreting services as the access option for Auslan users (noting even where interpreting services are free, they are subject to workforce limitations).

Some people mentioned the 1800 number is an important part of the Disability Gateway service, and this sometimes works well to get information about specific supports. However, people also noted information provided wasn't consistent and people answering phone lines didn't have local knowledge of supports. People suggested phone lines may be more effective when resourced within independent advocacy and peer support networks who have more knowledge of disability types and support networks.

## The solutions – what’s needed

### Investing in sources where people are most likely to look for information and advice

When asked to select which sources of information and advice they currently use, or are most likely to use, survey respondents most commonly selected:

- talking to other people with disability and/or carers (362)
- online platforms to find disability providers (282)
- health professionals (263)
- non-government website (238)
- advocacy organisations (211).

The least commonly used sources of information among the questionnaire respondents were 1800 phone lines (58), the Disability Gateway (80), Local government (111) and the Carer Gateway (133).

### What sources of information and advice do you currently use, or are most likely to use?

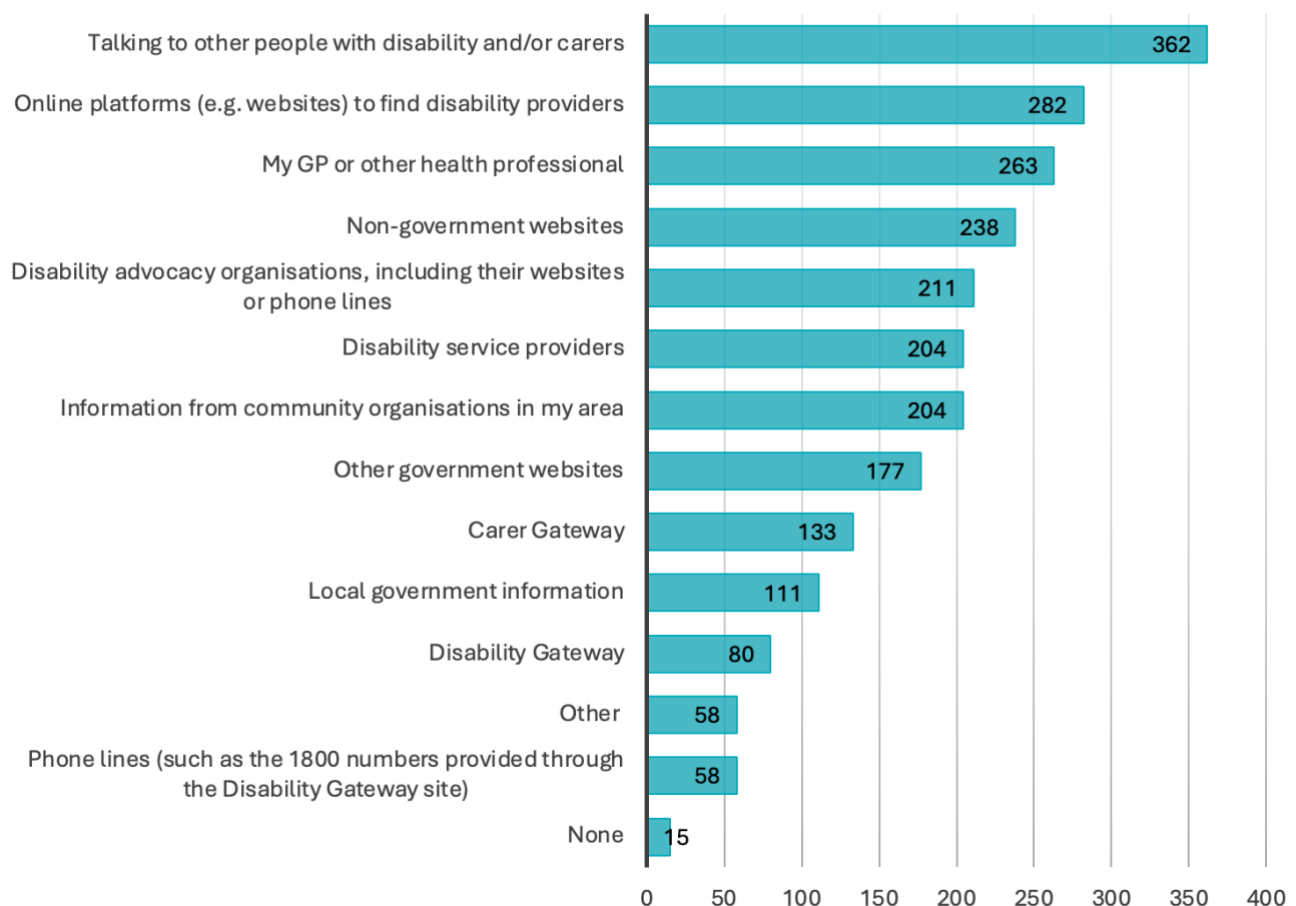


Figure 5: Sources of information and advice currently used or most likely to be used (n = 500)

This tells us there's a need to invest in information, advice and referral supports delivered outside of government, as well as improve government information and channels, to ensure people can find and access the information they need.

The most common sources of information people would use were further described in the free text comments.

- [Peer to peer and word-of-mouth](#)
- [More searchable website functions](#)
- [Touchpoints such as GPs, health professionals and education settings](#)

## Peer to peer and word-of-mouth

There is a significant reliance on word-of-mouth, particularly through family, friend and peer connections. Some people noted being disadvantaged themselves, or being concerned about inequities for others, where people don't have strong peer and community connections or family. Some people with disability and people living with mental health challenges or diagnosis reported they can face barriers to building these social and peer connections and feel isolated by the lack of information for those who aren't within these connected networks.

A strong theme across all audience groups was the need to invest in community connections and peer to peer information. This included:

- **Social media groups** - One of the most common ways people are accessing information from other people with disability, chronic health or mental health challenges is through social media (mainly Facebook) pages and groups. Many people suggested ensuring organisations are supported to maintain these groups, which are generally run by volunteers or on very small budgets even though they make up a significant information source for many people with disability in the community.
- **Non-government organisations and networks** – People said sustainable funding for representative organisations (large and small) and local support networks who help with information and advice is important to maintain in-person and online peer support, advice and information. Non-government websites and channels were often preferred over government sources.
- **Equipping families, carers and friends with information** – People noted the importance of family, carers, kin and the broader community having access to accurate information they can share with people in the community who might need extra support.

## Example: Importance of regional support networks

Local organisations and support networks play a critical role at the local level to connect people with disability in regional areas with resources and support.

During consultations a number of people, most prominently from regional areas and in WA, talked about the importance of regional support networks in their lives. They described these services as ‘a lifeline for people with disability in our community’. Features people often mentioned that make the services helpful include:

- Providing support in formats that suit the needs of the people accessing it, including adapting as those needs change.
- Acting as both a means of identifying and connecting with local supports and a source of information and advice to make informed decisions about their options.
- Applying a rights-based approach to supporting people to have their needs met.
- Providing a welcoming and inclusive environment for all people with disability, their family and carers.
- Providing and connecting support free of charge.
- Offering support ‘regardless of circumstance and without any prejudice’.

*‘We can contact them at any time for information, peer support or advocacy to meet our needs, in the way that we prefer (email, SMS, phone call, in-person meeting or on Zoom). We can also contact them on social media. It’s free and they have so much knowledge about what is available in our area, what isn’t, and give us options and support to decide what to do.’ – Individual respondent (NDIS Participant), general supports questionnaire*

## Searchable website functions

In the questionnaire, a large number of comments mentioned using internet searching to find information, and this has mixed results. A risk with internet searching is it often leads people to services who have paid for advertising rather than the most appropriate and credible types of supports.

There was strong feedback that **there is a need for investment in a more searchable, filterable, easy to navigate database of disability supports** – with federal, state and territory governments all contributing. Many suggested this type of search platform could include the ability for users to provide information about supports they found helpful and/or reviews.

People also reiterated more personalised pathways and support (such as having a phone line) when searching websites for information is important.

## Example: Portals and helplines for specific disabilities or conditions

People mentioned a number of non-government (often government funded) websites and associated helplines that are working well. This most often included websites and helplines which provide access to specific information and answer questions people have about their specific disability or condition, for example, including people living with rare and complex diseases. People said these are helpful when they are staffed by personnel with specific knowledge of the disability or condition, and with qualifications in psychology, social work and Mental Health First Aid.

*'I recently had an excellent experience with the RARE helpline where I went on their website, answered some questions, and then an experienced and exceptional person rang me to find out a bit more and then sent me an email with links to the things I needed. It was personal, caring and so very, very good. I wish the greater medical and disability services were like this.'* –

**Individual participant, small group discussion**

### Touchpoints such as GPs, health professionals and education settings

It was very common for people to say they access most information and advice about disability supports from their GP, allied health professional, or other specialist clinicians. Some respondents also mentioned peer groups within hospitals.

Others, particularly parents, mentioned finding information most helpful when it is provided through schools and early childhood centres. They are regular touchpoints for information about supports for their child.

There were strong suggestions for improving information sharing between the health (including mental health and allied health), disability and education sectors who all need to be involved in supporting the ecosystem of general supports in the community.

### What people want to know about

Feedback suggests people want more information and advice about:

- **Eligibility** for supports and services, including but not limited to the NDIS.
- **Accessing in-home care and supports** available through NDIS funding but also other programs including not-for-profits who might support people with meals or other needs in the home.
- **Mental health information** - for example, what is currently available in the community, for people who do experience mental health challenges, but do not qualify for the NDIS.
- **Information and advice about specific or rare disabilities and health conditions**, with some respondents suggesting they need to go out of Australia to find credible and sufficient information about their disability. People living with rare diseases or disabilities suggested there is very limited information available and often only a few support services.
- **How NDIS plans work**, with many NDIS participants, their family members and people who work in the sector suggesting there is not enough information available to support people to use their plans and to understand their rights and obligations.

## What is helpful when accessing information, advice and referrals

Participants were asked about what would help make finding and accessing the right supports easier. Common themes included:

- [‘No wrong door’](#)
- [Trusted relationships delivering independent and consistent information](#)
- [Improving knowledge of supports available](#)
- [More supported referrals](#)
- [Accessible, quality and disability-aware information](#)
- [Information and referral supports for people from diverse backgrounds and intersectional groups](#)

### ‘No wrong door’

Participants in events talked often about **having ‘soft entry points’** so people are welcomed and supported to connect wherever and however, they turn up.

As mentioned earlier, this included ideas for ensuring there is a **wider distribution of knowledge and resources** to key touchpoints such as hospitals, child and family nurses, GPs, schools and Early Childhood Education and Care (ECEC), libraries and physical community notice boards.

People also suggested governments could invest in more intentionally designed and specific places in the community to share information and to provide referrals to specific supports.

*‘Well informed GP’s who can and do provide Chronic Disease Management Plans or Mental Health Care plans are able to connect participants with providers and can support people to apply for the NDIS, or access Medicare supports.’ –  
Individual respondent, general supports questionnaire*

Many people mentioned having **social workers more available at hospital and health centres** to support people as they go back into community. Other suggestions focused on the need for roles within existing community, education and health settings. These are further discussed in [Chapter 4](#).

*‘I find it helpful to be able to access someone who is knowledgeable in the availability of services; this might be a wellbeing officer within a school, a local community health service or an experienced allied health professional’ –  
Individual respondent, general supports questionnaire*

A **‘no wrong door’ approach was particularly important for people with psychosocial disability and mental health** challenges where having support at the time it is needed is critical to avoid crisis. Mental health organisations emphasised the importance of a ‘no wrong door approach’ and having engagement at multiple touchpoints for families, carers and people with psychosocial support to seek out services and supports. They reflected consumers have a strong desire to be able to be connected with a support pathway, from whatever point of initial contact they have made to seek support (e.g., hospital, GP, community service etc.)

*'Decision making and self-advocacy is often time sensitive. It needs to happen quickly- either because the consequences are time sensitive, or the mental health consequences of carrying the emotional burdens are detrimental. Having services readily available for me to drop in to and speak to someone would be so helpful. This would help me to not wait until things were at crisis level.'* –

*Individual respondent, general supports questionnaire*

## Trusted organisations

A common theme across audience groups was the importance of having **trusted** and **values-based** organisations (e.g. not-for-profits) delivering **independent** information and advice (separate from service provision).

Using these trusted organisations was particularly important for people from diverse and intersectional groups who rely on information that can be tailored to meet their needs.

**People with intellectual disability shared that they rely on organisations to help them understand information** about services and supports. Disability and advocacy organisations were mentioned as being able to provide information which is credible, accurate and relevant to individuals, and to deliver it in ways right for them. People noted this can be difficult for governments and government websites to do given the breadth of information and needs they need to cover. As a result, organisations and channels already trusted in the community should be utilised and supported for information sharing and advice.

*'I always go to a condition specific organisation as they have up to date and the latest information available. They have qualified allied health professionals available so I know the supports and services they provide are safe and evidence-based.'* –

*Individual respondent, general supports questionnaire*

Among people who are First Nations, from culturally and linguistically diverse (CALD) backgrounds and people who are part of the LGBTIQ+ community, we heard strongly trust in information and the people who deliver it is very important. Some people suggested more involvement of **community leaders and organisations** (e.g. faith-based) to ensure community awareness and buy-in, especially for First Nations and CALD communities. People talked about the importance of having services for diverse groups, led by known and trusted organisations who specifically work with these communities.

## Information and advice for people from CALD backgrounds

People with disability from CALD backgrounds highlighted people in their communities often go to local community or neighbourhood spaces, or to cultural leaders, for information and advice. Often this information and advice is not described as ‘disability supports’ but may be specific services or supports people need in their home or to be able to access the community due to disability or chronic health issues.

They noted this is especially true for older generations and more recent arrivals, who may not have much contact with ‘mainstream’ services and other community touchpoints.

People explained:

- community and faith-based spaces are trusted and regularly accessed
- a lot of people seek information in community because they do not know where or how to access support
- information from people in high regard in community, such as Elders and faith leaders, is taken more seriously than other sources
- people view support and information from community leaders as safe, which means they are more likely to use it
- information and advice which comes from community is often more accessible, because it is in language and/or because it is in line with cultural understanding.

People suggested making sure trusted community figures are given accurate and up to date information to share with people, as well as working with local communities to organise tailored materials and sessions.

*‘Such information is easily more understood when it’s been dispersed from a person of your own tribe, who you understand in terms of language.’ – CALD person with disability (focus group)*

In addition, people spoke about the importance of ‘two-way training’ – this was training for CALD community organisations in disability awareness, and training for disability organisations in ensuring people from CALD communities are supported in culturally safe ways.

*‘When it comes to the CALD community, we are in a bit of a difficult situation, because on one hand we have a CALD organisation that doesn’t know much about disability, ... and then on the other hand we’ve got disability organisations, mainstream I mean, who are not very proficient in supporting a CALD participant or CALD community.’ – CALD support worker / person with disability*

## More supported referrals

When it came to referrals, people described the importance of having supported referrals. Most often people described this as having **warm referrals** and handovers, with support to take the next steps, rather than just information and links for people to find the information themselves. They said **follow-ups** are important and could be better embedded in program design, as appropriate, by trusted individuals and organisations.

Some participants from the allied health sector mentioned warm referrals and follow-ups work well where social workers, speech pathologists, other occupational therapists and allied health are seen as central to a person's support system, so they are able to come together with that person and other mainstream services they're accessing (e.g. schools, hospitals) to share advice and next steps.

Some also suggested there be more opportunities for NDIS Participant to NDIS Participant referrals and referrals from other family and caregivers. This was in recognition that peers are trusted sources, and people should be enabled to share information about good quality supports with each other. Ideas for how this can be supported included:

- support for online peer support networks and groups to share information and referrals
- better review systems for supports (e.g. some suggested having ways to share reviews and experiences with supports, in a safe and moderated way)

*'The only thing that works for me is being referred by another participant to a high quality service provider they have discovered.'* – *Individual respondent, general supports questionnaire*

## Accessible, quality and disability-aware information

One of the most common themes in relation to information and advice was ensuring resources are produced by people with disability who have the knowledge and experience of the issues and content. In particular, people suggested the need for quality, disability-aware information and resources that are:

- **accurate**, clear and consistent
- **disability-aware**, neuro-affirming and rights-based
- **unbiased** by commercial interests
- developed using **culturally appropriate** and safe language
- **individually appropriate and tailored**, not a 'one-size-fits-all'
- **co-designed** with the specific groups and communities the resources are intended to support.

The other common feedback was to ensure governments continue to invest in tailored and accessible information, for example:

- formats like **Easy Read and Easy English**
- having **Auslan and other in-language resources** wherever possible
- all information being **accessible for screen readers**
- **free interpreting services**, whether a person is in the NDIS or not
- delivery in a **variety of ways**, including digital/online, paper, phone and in-person

*'I find that resources produced by disabled people for other disabled people to have the most relevant information. They include hints and advice that other people might not even consider. They often are more focused on the social model of disability, which I find to be more useful and less pathologizing [sic].'* – *Individual respondent, general supports questionnaire*



## Sharing information through journeys

A number of people suggested using journeys to show the pathways a person may take in accessing supports, particularly outside of the NDIS. They suggested this may be more helpful for people who are looking for supports for the first time, rather than sharing lots of content and information about various programs.

Digital tools and websites could potentially have more interactive journeys where people can find information based on where they are in their process for finding and accessing supports.

## Information and referral supports for people from diverse backgrounds and intersectional groups

Much of the feedback about what is helpful for people from diverse and intersectional groups was consistent with the themes presented in this section. Additional considerations that were common or strong within the feedback included:

- ensuring safe supports, relevant information and referrals for people from the LGBTIQ+ community
- the importance of information being presented clearly with enough explanation of what to expect from services and programs for people who are neurodiverse. Information for autistic people also needs to come from trusted sources
- using trusted sources and community leaders when sharing information with CALD people with disability, and the importance of having critical information available in languages
- information in Easy Read and Easy English, video or use of imagery to make it more accessible for people with intellectual disability or people who have lower literacy levels
- both the general supports service system and information that explains foundational supports in the community needs to be relevant to children and young people, and consider the different experiences of individuals across different identities, different life experiences, and different geographical locations.

**First Nations people and organisations strongly suggested information is co-designed with communities and this is further discussed in the complementary [First Nations Consultation Report](#).**

## Safe support settings for LGBTIQ+ people with disability

People with disability who are LGBTIQ+ said it was important to have access to safe support settings that are inclusive for different sexualities and genders. This includes making sure information supports and referrals take into account specific factors such as:

- considering the types of questions a person is asked when accessing a service for the first time
- whether there are peers or people with lived experience from the LGBTIQ+ community in the organisation
- whether there are staff trained within the organisation to support LGBTIQ+ people with disability
- whether a faith-based organisation/service will be appropriate to send someone to.

People noted a service 'just being labelled as inclusive does not necessarily mean it is'. Therefore, transparency about how the service supports LGBTIQ+ people and details like having lived experience in the operation is important.

It was suggested training for organisations in supporting people who are part of the LGBTIQ+ community is needed and organisations could show when they have undertaken this training—for example, through an accreditation or other form of recognition—to increase visibility of safe support settings and services for LGBTIQ+ people.

*'Having options to find providers who are knowledgeable and non-judgemental of LGBTIQ+ populations, because it can be daunting finding a provider and not knowing whether they will openly or in quiet be judging this.'* – **Individual respondent, general supports questionnaire**

## General supports for people in the justice system


There is a significant over-representation of people with disability in the youth and adult justice systems and the forensic mental health system. They often have limited contact with mainstream health and disability services in the community. Stakeholders requested the design and implementation of foundational supports needs to be accessible to this population.

A number of stakeholders expressed strong views this is an opportunity to provide a critical support system for those who need it most. They said general supports was an important opportunity to get more information about and referrals to much needed disability and psychosocial supports to people who are living in prisons or other settings.

Children and Young People with Disability Australia (CYDA) also noted there have been minimal supports for children and young people with disability who are dually engaged in state-based systems, including child protection and youth justice. They suggested the design of foundational supports must take into account the complexity of these intersecting systems.



# Chapter 3: Capacity building supports

- [Capacity building for individuals](#)
  - [Capacity building for families and carers](#)
  - [Capacity building in the community](#)
- 

## Overview from consultation paper

Governments recognise a range of different kinds of capacity building support is required for individuals, families, carers, kin, and communities. As stated in the consultation paper, a reformed capacity building program should seek to offer:

- consistency and equity of access, such as to peer support that is tailored to meet the needs and experiences of disability specific or intersectional experiences
- longer-term access to skills building support
- information and advice which lifts the capacity of community organisations, services and activities to be responsive to the needs of people with disability and to improve accessibility and inclusion
- evaluation processes that are embedded in design to support the sharing of best practice from funded capacity building projects.

This will make sure activities capitalise on investments made, help uplift sector-wide capacity and inform future investment.

In relation to capacity building supports, people were asked:

- what types of supports are helpful to make and maintain community connections and be involved in community
- what kinds of decision-making supports and supports for self-advocacy are needed
- what supports can help families, carers and kin to support their loved ones with disability
- what services and supports are needed to improve the capacity of communities to be inclusive, accessible and welcoming spaces for people with disability
- how supports can be better tailored to meet the needs of diverse groups.



## Capacity building for individuals

As stated in the consultation paper, **capacity building for individuals** might look like improved access to peer support groups or group information sessions. This might also include projects that support:

- self-advocacy and rights awareness
- supported decision-making
- leadership development
- relationship building
- life skills development.

It may also focus on particular groups within the broader disability community, such as people with intellectual disability and First Nations people with disability.

These supports would be focused on:

- reducing isolation
- facilitating networks so people with disability can learn from the experience of others
- empowering people to self-advocate for their rights
- supporting people to participate in their community.

There could also be a focus on supports being delivered by people with disability such as neuro-affirming care or other disability specific organisations who promote contemporary models of disability, positive visioning and inclusion.

## What we heard

### Key issues with current individual capacity building supports

Within submissions, stakeholders provided feedback on current barriers or issues impacting the effectiveness of existing capacity building services, including:

- **Traditional, generic or rigid service models** that do not accommodate different needs, learning styles and goals
  - Respondents felt many service providers did not have a well-developed understanding of how to help people with disability build meaningful skills, knowledge and connections.
- **Lack of tailored, relevant support**
  - Stakeholders noted a lack of services offering tailored, person-centred or one-to-one capacity building support. It was noted people with disability are often placed in a group and treated as if they are facing a homogenous set of issues, rather than

recognising each individual's unique circumstances, goals and objectives and designing services around these.

*'My son attended a generic capacity building program that didn't offer things he was particularly interested in. He basically had to fit in with what was offered so there was a lack of tailored support.'* – **Organisation submission**

- **Low expectations / aspirations**

- Some stakeholders suggested capacity building services often set a low bar, so people with disability are not challenged to reach their full potential, 'hindering growth and confidence'.

- **Active segregation**, where people with disability are not supported to join mainstream services (such as community art classes, sporting clubs, etc.).

- Some stakeholders noted this often results in further ostracism and stigmatisation

*'Congregating people under the pretence of capacity building has done little to build capacity and, in many cases, as reported by people with disabilities and families, has often seen competencies become eroded as well as reinforcing a limited vision based on a 'special' segregated life.'* – **Submission**

- **Staff not adequately trained, skilled or supported**

- It was noted the effectiveness of a program can often hinge on the staff leading it and whether they are appropriately skilled and equipped to offer fit-for-purpose, tailored support.

- **Bureaucracy and complex systems**, making it difficult for people to access the capacity building supports they need.

## The solutions – what's needed

Key areas of feedback about individual capacity building included the need for:

- [Whole-of-life approaches with a focus on key transition points](#)
- [Person-centred and individualised approaches](#)
- [Rights and self-advocacy](#)
- [Peer supports led by people with disability](#)
- [Supported decision-making](#)
- [Rights awareness](#)
- [Allied health supports](#)
- [Alternative therapies](#)
- [Personalised supports](#)
- [Support for youth transitions including through school and pathways to employment](#)
- [Sports, recreation and leisure programs](#)
- [Online discussion forums](#)

## Whole-of-life approaches with a focus on key transition points

A strong theme was the need for personalised approaches to capacity building that are tailored and flexible as people's life stages and situations change. We heard of the need to better integrate **whole-of-life planning and goal setting, especially for key transition points**.

Some participants mentioned using **community development approaches** as a framework to make sure people and communities are at the centre of capacity building and support for capacity building is holistic, considering a person's whole environment and community.

*'Capacity-building prioritises the person's motivations and preferences, understanding their changing situation, interests and goals.'* – **Organisation submission**

## Person-centred and individualised approaches

A common theme raised in events and submissions was the need for **approaches and models that centre the person with disability in models of care** that are personalised and empowering. Examples of this included models such as Circles of Support and Microboards.

Participants often talked about the importance of capacity building that is **person-centred and individualised**. Many emphasised this requires providers and support organisations to invest time in building a relationship with a person and their family / support network, and to understand their goals and aspirations for a meaningful life. It means designing tailored supports to help meet their individual needs.

Many people suggested the NDIS and some disability funding programs don't support this as well as they should. They noted while the premise of the NDIS is to be individualised, its current implementation and rigid service models make it difficult to use supports in a way that helps them build skills aligned with their goals, or connect with peers /support networks or mainstream services in their community.

Outside of the NDIS, feedback from participants and families showed there was a lack of individualised supports for skill-building, with some reporting they're mostly non-existent in the community (outside of NDIS supports). People mentioned many state and territory government capacity building programs had ended when supports moved to the NDIS.

Within submissions received from organisations, it was consistently reiterated **rigid service models**, where supports are not designed around the individual and their interests, abilities and goals, lead to tokenistic programs that do not achieve any long-term, sustainable or meaningful outcomes for people or communities.

## Rights and self-advocacy

Within submissions, a number of stakeholders felt building self-advocacy was critical for empowering people with disability to be independent. They suggested capacity building supports should include **self-advocacy workshops** designed to empower individuals with disability to speak up for themselves and provide practical tools for navigating bureaucratic systems, understanding legal rights and advocating within the disability support system.

*‘Self-advocacy training will make a real difference to the ability and confidence of people with disability and carers to actively and successfully get access to services and advocate for disability friendly communities, as well as to boost their own overall sense of self-agency and confidence to pursue goals.’ –*

**Submission**

*‘The Deafblind Café serves as a gathering space where deafblind individuals can discuss public issues, especially around accessibility in areas such as public transport and emergency services. The café invites guest speakers and provides an avenue for members to give feedback on issues such as ambulance service protocols and accessibility reform, helping to bring attention to the unique needs of the deafblind community.’ –* **Submission**

Across all locations and events, people spoke about the important role self-advocacy groups play in individual capacity building, creating positive changes for people over the long-term and providing connection to others in the community that is protective and supportive. People said this is because self-advocacy groups can:

- talk about issues and rights from the perspective of those directly affected and there are opportunities to influence more inclusive mainstream and community services through self-advocates and self-advocacy groups in advisory roles
- have broader benefits, such as providing peer support, leadership opportunities, and may directly employ people with disability or give opportunities for skills building for future employment
- provide a strong purpose for people to be and stay connected and involved in the community for the good of others as well as individual benefits.

*‘Self-advocacy groups empower people to learn about and enact their human rights. By offering supportive environments to develop new skills and share personal experiences, these groups enable people to advocate for themselves across many areas of their lives.’ –* **Submission**

Participants often talked about the need to ensure a greater voice for people with intellectual disabilities, acquired brain injuries and complex communication needs, as these groups are often spoken for. For people with disabilities that affect the way they think, such as intellectual disability, self-advocacy groups are an important way for people to support and strengthen the capabilities and confidence of individuals in the groups, while advocating for other people in their community and for more inclusive communities.

*‘I worked at a supermarket as a shelf packer and felt lower than everyone. I went to day service, then found self-advocacy. I didn’t even know about discrimination before. Now I know my rights and can advocate for change in Victoria. Without this work, I’d be behind closed doors, suffering from depression and anxiety. This work is my purpose.’ –* **Submission**

## Peer supports led by people with disability

One common thing people said is important about self-advocacy and peer supports is that they're led by those with lived experience of disability or mental health challenges. Many noted people with disability often face unique barriers and can provide each other with advice, skills, and encouragement to navigate everyday activities. Having local leaders and peers with disability can help to demonstrate and lead change in peoples' lives and adjust expectations or commonly held beliefs about what is possible.

*'Investing in intentional leadership of people with disability and families can have an impact on personal and community development, as well as peer learning and sustainability.'* – **Submission**

*'Since its founding in 2007, DBV [DeafBlind Victoria] has worked to slowly build a community where deafblind individuals can teach each other skills such as Braille, technology, communication, and tactile Auslan. The goal is to create a safe and empowering environment that recognises the unique ways in which deafblind people interact with the world.'* – **Discussion group**

Some also noted it is important people with disability are paid in roles where they are coordinating or facilitating groups and/or providing capacity building support to improve community inclusion. A number of stakeholder organisations noted many capacity building and self-advocacy organisations directly employ people with disability in roles as experts, and this would be important to continue to enable through general supports.

*'A lot of projects that I've seen that have that lived experience, built on a foundation of peer review and contribution, seem to be a lot more successful, a lot more trusted. And a lot more useful.'* – **Participant, Adelaide community workshop**

## Supported decision-making

In submissions, many stakeholders commented on need to enhance the ability of individuals with disability and their carers, families and kin to engage in supported decision-making. It was recognised this is pivotal to enabling people with disability to **exercise their human rights of autonomy, choice and self-determination**. Respondents noted decision-making supports should extend beyond merely explaining the options available and seek to empower individuals to take full ownership of their choices.

*'There is a significant opportunity for Foundational Supports to make an enormous impact on a person's ability to experience autonomy of decision making. Funding must be put towards a range of programs to make supported decision making accessible to those people whose informal support networks are lacking, and all others who would benefit from a range of supports for developing their decision-making abilities.'* – **Submission**

This was also a common theme throughout events, with people reiterating the importance of:

- having access to rights-based supported decision-making supports and resources, especially for people with intellectual disability, families and carers
- the role of disability advocacy organisations in providing a vital role in helping people to understand their rights and advocate for themselves (and others) in communities and in systems such as health, justice and education.

*'It is only through strengthening peoples' informal support networks (e.g. circles of support) that peoples' supported decision-making needs will ultimately be met.'* – Submission



## Improving knowledge of supported decision making

Stakeholders suggested there is an opportunity to build people's capacity through foundational supports by further improving knowledge of the various ways in which supported decision-making can occur. This included through:

- delivering training in active support models
- workforce education and training in understanding and application of supported decision-making
- carers, families and friends helping a person explore to new interests
- supporting a person with disability to take reasonable risks to achieve personal growth
- balancing the duty of care owed to individuals with actions that afford each person dignity of risk, allowing them to learn from mistakes and enhance their self-esteem and overall quality of life
- education in various state-based legal frameworks and the role of guardians, substitute decision-makers, etc.

## Rights awareness

It was noted **education about rights** is crucial for ensuring people with disability can make informed decisions about their lives. Some suggested training on the UNCRPD should be more widely available and adapted to suit the diverse needs of people with different disabilities. This should include a mix of online modules and in-person sessions, making learning accessible in multiple formats. Additionally, self-advocacy workshops should integrate these rights into everyday contexts so people with disabilities can actively participate in and understand decisions that affect them.

## Alternative therapies

Respondents to the questionnaire and participants in events often mentioned alternative therapies, such as art/music therapy, exercise (e.g. swimming, yoga), meditation, animal

therapy and social skills supports, are an important part of individual capacity building. There were concerns these supports might be lost from within the NDIS, with some people noting the significant negative impacts on people and children in losing these types of supports before there is a strong system of foundational supports available in the community.

People also expressed significant confusion about whether these supports would be considered part of foundational supports.

*‘Therapy-Led Social Skills Groups: Occupational therapy or psychology-led social skills groups, designed for different age groups and abilities, would help individuals develop interpersonal and emotional regulation skills. These programs are essential in regional areas where mainstream activities often fail to accommodate specific needs.’ – Individual respondent, general supports questionnaire*

*‘Living with severe mental health challenges diminishes social connection and creates huge isolation and disconnection issues. Engagement with art and music such as art therapy or choir has been of enormous benefit and this should be accessible and made a priority for all.’ – Individual respondent (family member), general supports questionnaire*

## Allied health supports

Individuals, as well as families and carers spoke about the importance of allied health supports, in particular social workers, in supporting them, their child or loved one in capacity building. People said allied health workers often give them and the whole family advice and supports about choices and to help make decisions.

*‘Social workers have the ability to navigate these barriers by offering personalised guidance and advocating for individuals within these limited systems. They can help identify alternative solutions, support individuals in accessing resources despite constraints, and ensure that people are not left behind due to funding or administrative issues.’ – Individual respondent, general supports questionnaire*

## Supports in day-to-day activities

Some people with disability talked about needing more personalised supports that help with day-to-day activity. These might complement supports delivered through NDIS but be for everyone who needs extra help whether or not they’re in the NDIS.

## Capacity building supports for people with intellectual disability

People with intellectual disability said types of capacity building supports that would be helpful:

- One-on-one support with daily activities.
- Transport, including support with learning to drive.
- Relationship supports, including for intimacy.
- Business development support.
- Support setting and achieving goals.
- Support and education with specific tasks and scenarios like voting.

## Support for youth transitions including through school and pathways to employment

Many participants shared the need for a focus on capacity building with young people as they navigate key life transitions. This also comes with the understanding that supports may need to have more flexibility for change to support different life stages and changes. We heard capacity building supports often help to connect young people to their communities so they are learning skills in the community and not just through parents and carers.

Capacity building supports that directly support people with disability, including young people, towards pathways to employment are highly important. People suggested this might include a focus on things like:

- mentorships and helping people to find employment pathways based on unique strengths and capabilities
- building life skills
- encouraging entrepreneurship and development of small businesses
- digital capacity building.

### Children and young people 10-25

There were specific concerns raised about the lack of supports within the scope of general supports and targeted supports for young people aged 10-25 who 'are in arguably the most disruptive phase of lifespan development'.

Some people suggested additional supports are needed for children and young people in the school years from age 10 to adulthood. One questionnaire respondent noted 'many adolescents with disability struggle with the enormous developmental and social and academic changes that happen during this period of their lives'. They, and other respondents, suggested there are few social opportunities for young people with disability who are not segregated or therapy-focused. It was suggested, due to exclusion from activities other children might have during these schooling years, there's a need for foundational supports to focus on helping young people in building connections and peer supports. This can help with issues that may develop during this period of life such as development of co-occurring conditions including anxiety, depression and eating disorders, and prevent loneliness and isolation of children, young people and their families.

The importance of dedicated programs for young people was also identified by organisations for specific disability types. For example, Vision Australia highlighted peer connection and mentoring programs for young people are difficult to administer in a NDIS context and should be funded through the foundational supports framework. Blind Citizens Australia proposed students with vision impairment have support in education settings through mechanisms such as a vision resource centre, an assistive technology library and professional practice guides.

## Sports, recreation and leisure programs

Opportunity exists for inclusive community capacity building projects that assist mainstream offerings to be more inclusive of different disability experiences. People suggested work is needed to ensure sports, recreation and leisure programs are inclusive and accessible rather than being further segregated. Participants also suggested sports, recreation and leisure programs are important for building individual capacity and improving connections with peers and the broader community. Suggestions related to this included:

- offering recreation and leisure programs that cater to people with different disabilities, ensuring they are integrated into sports, arts and social activities
- expanding adaptive and para sports programs within mainstream sporting associations.

## Online discussion forums and phone support

Social media including pages such as NDIS Grassroots and parent forums were often raised as being an important avenue for families to build understanding of disability and how to support their child or loved one. People also mentioned phone supports are important to have attached to website and online systems.

*'I'm predominately housebound, so face-to-face is too difficult for me. Online and video calls are best for me.' – Participant, Online roundtable*

## Concerns about prioritising capacity building before other supports

Some people provided feedback that individual capacity building is not the solution to ensuring people with disability, mental health challenges and chronic health conditions live a good life. There was multiple feedback that governments should first invest in fixing gaps in supports, particularly in-home supports and basic supports for people to live and be safe in the community. This included in areas such as access to in-home care supports, transport and housing.

People acknowledged, for those in the NDIS, these supports may be available in their plans, but they are significantly lacking in the community for people not in the NDIS. Some NDIS participants and families also expressed concerns reduced funding in NDIS plans is limiting access to supports for basic living needs.

Some people said 'capacity building' for people with disability is a deficit model, suggesting it assumes people don't have capacity or are incapable due to their disability.

*'None. I need care, equipment and therapy - not capacity building. Saying that disabled people need capacity building is putting the blame for disability on the disabled person. It assumes that we are all incapable.'* – **Individual respondent, general supports questionnaire**

People with energy-limiting conditions, such as ME/CFS and long COVID, reiterated the importance of prioritising practical support and advocacy services tailored to the specific needs of individuals, rather than generalised capacity building initiatives.

*'People with disability who are unable to access the NDIS and have a level of substantially reduced functional capacity require support in the home. The government should move as a matter of urgency to work with the state governments to reinstate domestic assistance services as a foundational support.'* – **Submission**



## Capacity building for families and carers

As stated in the consultation paper, **capacity building for families, carers and kin** might look like better information, peer support, parenting groups and workshops, education and training (i.e. online or in-person parenting courses). This would have a focus on:

- disability and rights awareness
- building skills in decision-support
- enabling independence and participation
- family leadership and development.

These supports would be focused on helping families, carers and kin of a person with disability to build their own knowledge and skills so they can support the person with disability to exercise choice and control and fully participate.

A lot of discussion about capacity building for families and carers focused on parents and carers of children 0-9. This feedback is a focus of the [Consultation Report on Support for Children under 9](#) and their families, carers and kin, which complements this report.

## The solutions – what’s needed

Feedback about capacity building for families and carers included the need for:

- [Whole-of-family approaches](#)
- [Self and family advocacy](#)
- [Rights-based awareness and education for families and carers](#)
- [Peer support groups](#)
- [Emotional support for families, including foster parents](#)
- [Practical supports for families and carers](#)

### Whole-of-family approaches

One of the strongest themes we have heard when it comes to families is the need to take a whole family-centred approach to capacity building and support for families with children with disability. This is also important for the many parents, siblings and carers who also have disabilities themselves.

Many people told us while individualised funding through the NDIS has been important and, in many cases, life-changing, there is a need for broader support for family members to build knowledge, skills and capacity to best support their family member/s with disability. This includes support for siblings and extended family members.

We heard of the need to ‘walk alongside’ families rather than just pointing them to specific services, with a more holistic view of need and opportunity to thrive for the whole family. To do

this effectively, organisations must be independent from service delivery to prevent conflicts of interest and there is a need for more collaboration across organisations and sectors to create **more ‘wraparound support’**.

People also suggested capacity building approaches with families focus on things in the home and in natural settings where children – including siblings where appropriate – live and play. This can help to prevent family members being left out and would improve their capacity to provide the best support for their children in these settings themselves.

Some noted the success of **parenting programs** in harnessing the power of parents as critical ‘agents of change’, noting such programs can be a cost-efficient solution to addressing children’s needs over different developmental periods, building the capacity of family members to be independent, confident and equipped to meet the everyday challenges of parenting, and reducing the need for more intensive supports later.

## Capacity building for children and families

We heard about the importance of holistic goal setting and life planning, as well as helping to build capabilities in self-advocacy as children become able to do this for themselves in their environment. This should be supported by information for parents that is future-focused so they know what the next steps are and can support their children to develop capacity and independence. Further information about feedback on capacity building supports for children under 9 and their families, carers and kin are in the [Supports for Children under 9 Consultation Report](#).

## Self and family advocacy

Families and carers suggested more supports are needed to help them advocate for their child’s and whole family’s needs. It was noted family and carer capacity building was generally not a focus of existing ILC funded projects and while there are a range of general parenting programs, there are limited specific programs for parents and carers of people with disability. This not only included parents and carers of children with disability, but those who have adults with disability in their care.

*‘To support carers in how to advocate - we need to advocate with multiple systems including the medical system, education system, government services such as Medicare, Services Australia, NDIS. There is a lack of advocacy supports when carers need support to navigate these multiple systems. Particularly at key points in a person's life - when they start/end their journey with the education system, navigating government systems as an adult.’ – Individual respondent, general supports questionnaire*

## Rights-based awareness and education for families and carers

We heard there is a need for more tailored education and resources for families and carers on disability rights and how they can best advocate for family members with disability in mainstream and community settings.

Many families told us it was highly important they were given rights-based, disability-aware and neuro-affirming education, training and support in the early years or soon after a diagnosis of disability or assessment of developmental delay, and this helped them not only advocate for their own children but also to provide better information and support to other parents.

Families often cited workshops with other parents in supportive environments, and online courses that build skills and confidence to best support their children as highly important and effective. This type of skill-building has flow-on effects as many parents told us as a result of their increased awareness and confidence, they are now working in or with organisations to help support other families so they can continue to help others.

Families told us it's important they are recognised as experts in their own, and their children's lives, especially in schools and healthcare settings.

*'By fostering family leadership, our family members can better navigate complex systems, influence policies, and create more inclusive, supportive environments for people with disabilities.'* – **Organisation submission**

In addition to education, a number of organisations suggested family capacity building should include **legal supports**, focused on having education and advice about disability rights, people and families in supported decision-making and guardianship frameworks.

## Peer support groups

We've heard peer groups provide a trusted place for parents to share experiences, learn from each other and become connected in a safe and supported environment. This can be online or face-to-face or both, depending on the preference of families and their location. We've heard peer support may be especially crucial for families in rural and remote areas who may have limited access to services.

Some suggested there is a need for more investment in parent and carer peer support groups to connect and stay connected, recognising many people who are facilitating or working in organisations providing parent peer support are parents of children with disability or have a disability themselves. While they are best placed to do this work, there is a real risk of burnout for people if this work isn't appropriately supported with ongoing funding and resources to ensure the loads can be appropriately shared.

*'As a parent with multiple children with disability, online parent forums have been the biggest source of relevant and useful information for me over the years. Lived experience and parent recommendations have been amazing. I have also gained tips on how to advocate strongly for my children's needs.'* – **Individual respondent, general supports questionnaire**

*'Communities of Practice are great for getting like-minded people together to improve services - I host a FREE one in the Perth CBD with 100 members so far. These people then discuss new issues and training needs, and then also develop relationships with one another to form solid teams around their participants.'* – **Individual respondent, general supports questionnaire**

## Emotional support for families, including foster parents

Many people suggested more needs to be done to support families of children with disability emotionally and with self-care. We heard playgroups and parent support groups can reduce isolation, provide emotional support and create better connections with community. Parents and carers also talked about the importance of ‘soft engagement’ in the early years of a child’s life through inclusive groups who are welcoming for families and can also provide a support network for later years.

Groups who provide support for specific disabilities or medical conditions, or with an intersectional lens where appropriate, were also highly valued by parents and carers. This type of support can be especially beneficial for parents of children experiencing challenging behaviours, with parents being able to share experiences and practical strategies in a safe and supported environment.

## Practical supports for families and carers

Respondents highlighted **many carers are overwhelmed** by the day-to-day demands of their role and the systemic pressures placed on them, leaving them with insufficient time or energy to engage in additional learning or advocacy activities. As a result, it is not enough to provide carers with theoretical tools and self-advocacy training without offering practical support to address the barriers they face. Some stakeholders suggested the primary focus of capacity building must, therefore, be on reducing the strain on carers by addressing their most urgent needs. This includes providing practical support that goes beyond workshops and training, such as improved access to respite, holistic planning or a professional to oversee the logistics of accessing supports and shoulder some of the administration burden.

*‘Feedback strongly addressed the desire that capacity building should be focused on supporting the attainment of typical pathways rather than segregated or ‘special’ lifestyles. This included mainstream paid employment, education, club and group membership and the development of community connections. This in turn assists people to develop an identity in their local community based on valued roles.’ – Organisation submission*

*Recognise the importance of capacity-building supports... to assist parents, guardians, and families of children with disability to navigate service systems, unlearn low expectations, and build a strong vision for each child’s life.’ – Organisation submission*



## Capacity building for communities

As stated in the consultation paper, **community capacity building** would focus on building the capability of community organisations (e.g. sporting clubs, arts groups) and at the whole-of-community level to deliver disability-inclusive and accessible services. Projects would focus on driving equitable access to quality and inclusive community services. They would complement (rather than substitute) current/future government initiatives.

Information, advice and projects would be focused on ensuring providers understand and meet their responsibilities and are better equipped to be inclusive for people with disability.

### The solutions – what’s needed

There was considerable feedback **building more accessible, inclusive and welcoming communities is critical** for enabling people with disability to live more connected, engaged and fulfilling lives.

Many participants noted there are many policies, laws, programs and campaigns aiming to do this, but it is not clear how these are coordinated. One of the key areas of feedback in relation to community capacity building was genuine, positive change across community and other services would require significant organisational change and service redesign for many businesses and service providers. It must also be underpinned by increased community awareness and understanding of disability and changes in public attitudes.

Common areas of feedback about community capacity building included the need for:

- [Education and training for community organisations](#)
- [Recognition of inclusive community organisations and services](#)
- [Education and capacity building for key roles / touchpoints](#)
- [Public awareness and attitudes](#)
- [More community education about invisible disabilities](#)
- [Local government involvement in community capacity building](#)
- [Towards full inclusion and away from segregated settings and programs](#)

### Education and training for community organisations

We heard there is a need for more work to be done with community organisations to build their awareness and capability to become more inclusive and accessible for people with disability. People said this could look like workshops or consultants who work with sporting groups and other organisations in the community to provide education and resources.

Many people said because community organisations are often volunteer-run, on strict budgets and time-poor, there would need to be specific incentives and/or free education or support to make sure organisations take up the opportunity.

In general, stakeholders supported the idea of **targeted funding** to enable community organisations and service providers to grow and build their capacity, including by drawing on the expertise of advocacy and disability groups.

It was noted foundational supports should include initiatives that enable community organisations to **advise and assist each other** in adopting inclusive practices. For example, inclusion grants, mentorship programs and resources to empower community organisations to support others in becoming disability-inclusive spaces.

*‘Capacity building initiatives should focus on creating sustainable change in how communities’ function, moving beyond individual skills development to build collective capability. This approach recognises that when communities build their capacity to be inclusive, it benefits all members, not just those with disabilities.’ – Submission*

## Recognition of inclusive community organisations and services

We heard having some recognition of community organisations and non-government services that are inclusive and accessible might help to increase awareness and provide incentives for organisations. This would also provide guidance to other organisations about what more inclusive services in the community look like.

One idea shared by a few participants was having a ‘disability tick’ similar to the ‘Rainbow Tick’ (Western Australia) quality framework for safe, inclusive and affirming LGBTIQ+ services and employers.

## Education and capacity building for key roles / touchpoints

Key touchpoints (organisations people regularly interact with) help people with disabilities and their families and carers to find information and support and better navigate systems.

We’ve heard touchpoints can have varying levels of knowledge and expertise about disability. Many participants suggested capacity building support include a focus on touchpoints so they become more disability-aware and knowledgeable. In particular, participants identified the need to deliver more capacity building and knowledge about disability to existing services like GPs, Maternal and Child Health centres and workers, schools and educators, in early childhood settings and to employers (small and large).

We heard this can be provided by reputable and trusted disability and family-led organisations with a strong knowledge of disability rights, local information and connections, and inclusion and accessibility.

A common idea in relation to these types of organisations people regularly interact with was supporting organisations to develop communities of practice so they can share learning and resources.



## People with lived experience leading capacity building in the community, and in touchpoints and service providers

We heard very strongly that people with disability should be leading the way in building the capability of community organisations and services to become more inclusive and accessible.

People with experience of specific disability types and barriers, and specific intersectionality, should be supported to lead education and training in addressing specific needs of diverse groups. This might be people representing First Nations, multicultural or LGBTIQ+ groups, or with specific disability needs and considerations such as intellectual disability, sensory disability, including the Deafblind community, and people with complex needs and communication barriers.

In submissions, some stakeholders suggested dedicated funding could be provided for disability organisations to work with touchpoints and service providers to build their capacity to support people with disability.

People with disability are experts in the barriers that exist in the community and ways to overcome them. Sharing their experiences can also be a powerful way of communicating the importance of accessibility in the community.

Another example of how people with disability can lead capacity building in the community was the formation of community disability advocacy boards or networks. These have people with lived experience of disability in paid roles in local communities providing advisory services on inclusivity to a range of community organisations and services.

*‘Ensure community capacity building is led by people with disability and local communities, drawing on their expertise to increase awareness and enhance community’s capacity to support people with disability.’ – Organisation submission*

## Public awareness and attitudes

In relation to community capacity building, people suggested improving public awareness and attitudes about disability is an important action. Under general supports, supports could contribute to this through:

- community campaigns
- requiring government funded organisations and services to have people with disability employed and on boards
- investing in cultural and artistic events that showcase disability in a positive way.

## Community education about invisible disabilities

A lot of feedback mentioned the need to ensure invisible disabilities and people's needs are better understood by the community and, in particular, community and mainstream services.

We heard poor awareness and understanding about invisible disabilities, for example autism, ADHD and psychosocial disability, can create major barriers in accessing work, education and community settings. Poor community understanding is linked to stigma and discrimination.

There can also be perceptions a person with invisible disability doesn't need as much support as people with a physical disability. General supports need to include specific programs that focus on building community capacity and understanding about all types of disability.

*'People with hidden disabilities, including autism, are often misunderstood and mistaken for not needing as much support as they actually do. They need more than just basic supports and information — they need programs and services that enable them to thrive.'* – Individual respondent, general supports questionnaire

## Local government involvement in community capacity building

We heard local governments should be a key player in supporting local organisations to be more inclusive and accessible. Several people talked about key roles within Councils that had or were useful to support community organisations, whether a part of their access and inclusion plans or as separate capacity building projects. These roles or functions within Council were recognised as important in holding knowledge of the breadth of community organisations and opportunities and can be a key conduit or partner for organisations providing capacity building services.

## Employers and business owners

In submissions, stakeholders suggested ways community capacity building could be delivered with employers and business owners. Specific suggestions:

- Training programs for employers to promote disability awareness, reduce stigma, and encourage inclusive attitudes, including for example workshops on inclusive hiring practices, disability etiquette, addressing unconscious bias and negative assumptions, creating welcoming environments, etc.
- Require employers / business owners to meet certain obligations or minimum standards to enable disability accessibility and inclusion.
- A system focused on increasing employment opportunities for people with disabilities, including through adopting the Customised Employment model.
- Training programs dedicated to helping people with disability find employment in sectors where workers are needed (such as hospitality, support and care, etc.)

*'I think there's a lot to be done and I hope NDIS will create awareness with employers and work with employers and to create the awareness that people with disability have the capacity to work.'* – Organisation submission

## Towards full inclusion


In submissions, some stakeholders suggested **accessibility and inclusion** should be mandated across core community services and programs, while others felt it should be framed as an opportunity for businesses and organisations to expand their service footprint and benefit from the business and contributions of people with disability ('not an obligation'). It was repeatedly noted inclusion should be prioritised over segregation and inclusive mainstream services are preferable to specialised or targeted programs for people with disability.

*'Segregated and congregated services do not advance people into inclusive lives in the way well-orchestrated inclusive services do. Proper inclusive education is better than segregated 'special' education at positioning students for an inclusive adult life.'*


*– Organisation submission*

*'Foundational Supports should not duplicate opportunities already present in communities, for example setting up a 'special' art class, choir, community garden, or similar, for people with disability when the local community already has these. When disability services create these duplicate services, not only is it a poor use of resources but it also serves to render genuine inclusion further out of reach.'*

*Organisation submission*



# Chapter 4: Types of supports, models and settings for delivering general supports

- [Types and models](#)
  - [Mainstream settings](#)
  - [Roles](#)
  - [Other types of supports](#)
- 

# What we heard

## Types and models for delivery of general supports

### Local place-based settings and wraparound services

One of the most common suggestions for how additional supports should be delivered was through place-based settings like **local hubs or neighbourhood centres**. This was suggested in cities and regional and rural areas.

*‘A place where you can drop in and have a conversation and be referred for appropriate support would be ideal’ – Individual respondent, general supports questionnaire*

A common feature of community hubs that work well was where they are **attended by locals and local services in the community**, such as local peer groups and networks, and other grassroots organisations who are connected into the community. Many people mentioned the importance of having hubs that include different types of services so there were more wraparound supports and referrals between services and systems would be easier to navigate—for example, people could interact in one ‘place’ with local disability supports, capacity building and community mental health services. Several participants noted hubs would help to **break down or minimise ‘siloeing’**. For example, having a presence from disability and also health, such as the involvement of local PHNs.

To make this model happen, some people suggested **local groups could be funded or supported to be present at a hub at certain times throughout the week**. Given the range of people who might access place-based hubs like this, they need to have a wide range of programs, advice and referrals available.

We also heard information and services provided at hubs should be **locally relevant**, and the spaces **accessible and welcoming** for all people in the community. A few people suggested also using **libraries** as information hubs to share information on a rolling basis about local services and supports for people with disability would also be a helpful option.

*‘The Hub at ACD Tas have been really helpful cause they explain stuff in a way that I understand. They don’t speak to me like I’m an idiot. I like I can speak to someone on the phone or I can go into the office and see them.’ – Individual respondent, general supports questionnaire*

*‘Here is a buffet – come to it as you wish, drop-in, you don’t ‘have to identify’ as a certain disability or with a group. It is for everyone’ – Person with disability, workshop event*

Hubs should include information and advice/referral services but also aim to **bring together supports** to help people take the next steps or support referrals, (e.g. ‘admin’ support for identification, applications, assessments etc., where appropriate).

## Example: Burnie Community House

During consultations we visited the Burnie Community House. A number of people in Burnie, Tasmania described this local place-based hub as critical to getting information about supports and having a safe and welcoming place to access advice and programs.

People who visited the Hub and spoke to us about foundational supports agreed this type of place is an ideal setting to get information, advice and referrals. The availability of different kinds of programs (from food support, to kids and parenting programs, to drug prevention) means people can be referred to different types of supports when they need in the local area.

However, some suggested even more could be done to enhance access to supports at local settings such as this, and more tailored programs and supports are needed to make sure these types of community hubs work for all.

### ‘Hub and spoke’

‘**Hub and spoke**’ models were also suggested, where outreach is included and/or in regional or remote areas more specialised or specific services may need to fly/ drive to further locations / individuals in need. There is a need for increased outreach to engage those who aren’t currently connected, especially in regional and remote areas.



## Place-based service design

Place-based approaches to entrenched social disadvantage have been underway internationally and in Australia for decades. Feedback from organisations and the community suggested place-based initiatives, particularly in regional and rural areas, should be a part of foundational supports.

There is an opportunity to leverage the Australian Government’s place-based initiatives such as Stronger Places, Stronger People focusing on children and families and Partnerships for Local Action and Community Empowerment (PLACE). Governments could trial how disability specific place-based community hubs and initiatives can be a part of helping government and other stakeholders work closer with people with disability and local services to implement more innovative community-led approaches that include greater shared decision-making, monitoring and outcomes.

Through these consultations, we heard funding and service models should involve local delivery based on **localised decision making**, with the flexibility to respond to the needs of communities and iterate or be agile to emerging needs as required. This might be supported by investing in **regional mapping of needs** and service landscapes across states and territories.

## Peer support networks and groups

Consistently, people provided feedback that the best and most trusted sources of information, advice and capacity building are from peers or those who have or have had similar experiences.

Peer connections provide emotional support and reduce social isolation. We heard peer groups specific to certain diagnosis or cohorts are particularly useful and trusted when it came to sharing information and advice.

*‘Peer groups and channels are credible sources of information and support to the community.’ – Submission*

Many people and stakeholders suggested peer support and local advocacy groups should be central to a foundational supports service system. It was noted:

- this requires **resourcing and funding for groups** to sustain the work they do, and in some cases, supporting new opportunities in areas where there are gaps in peer supports
- there should be support for **both online and in-person peer groups**, as either format can be most appropriate/ needed, depending on the cohort or preference of people
- **people with lived experience should be paid** for the work and expertise they provide.

Many stakeholders echoed this community feedback, highlighting peer-led models can help to build capacity within the sector, provide empowerment, connection and economic participation for people with disability and provide a broad range of trusted, practical support.

*‘Peer support creates natural learning environments where people feel safe to ask questions and share experiences. Through these connections, people gain real-world knowledge about navigating support systems and build confidence through shared experiences.’ – Submission*



### Micro-grants for smaller peer groups

Some stakeholders suggested offering ‘micro-grants’ for small peer support groups to enable them to provide tailored, community-specific supports that respond directly to local needs. This would help to build a sustainable, stronger, more connected support network, reaching individuals and families who might otherwise be underserved.

*‘Fund programs leveraging peer networks to support the development of localised information and support hubs.’ – Organisation submission*

## Peak and advocacy organisations

People often mentioned the need for governments to continue to resource and fund advocacy organisations. This included both large, national organisations, and smaller community based advocacy supports.

In particular, disability organisations and other stakeholders noted self-advocacy must be accompanied by broader, systemic advocates to help ‘raise larger and more complex advocacy matters’. They reiterated advocacy, awareness and promotion of disability and inclusivity are critical to address systemic stigma and discrimination, which act as a key barrier to social, community and economic participation.

Some people mentioned the need for advocacy to be jointly funded by Commonwealth and states and territories to avoid gaps in support within states/territories and/or regional areas. For example, in one state where a organisation focused on the needs of a specific cohort was not successful in a grant round it was mentioned on multiple occasions as causing a significant gap in information, advice and capacity building for autistic people in the region.

*‘Funding and support need to be poured into Disability Advocacy groups. A broad lack of funding means that they have extremely limited capacity to engage with the significant demand for supports in cases ranging from fighting the NDIS for supports, advocating for children to be included in Units OR mainstream schooling services, gaining supports to engage in employment, supported or otherwise, and helping families navigate systems that often feel designed to exclude people with disabilities.’ – Individual respondent, general supports questionnaire*

## Digital solutions that provide accurate, locally relevant and/or cohort-specific information and supports

Across consultations, we heard digital solutions can be important. But the feedback was also consistent that current government portals are not working well to give individuals the specific information and access to find the supports they need, that’s relevant to them.

People described the need for a better ‘centralised online portal’, ‘one-stop shop’, ‘single point of access’ that could provide consistent and clear information about a range of available services and supports, referral processes and clear guidelines on eligibility and access points for families and professionals.

The types of digital platforms suggested by participants and stakeholders included:

- A **comprehensive online platform** that consolidates information on various disability supports – this would need to be a more easy to navigate, ‘single source of truth’ regarding the services available to people with disability.

Respondents noted such a platform should include:

- a searchable database
- details regarding the services, eligibility criteria, cost, access requirements and availability

- local information about the specific programs and services available in each Local Government Area (LGA)
- information available in accessible formats
- information specific to different cohorts, including different disabilities and cultural groups.
- **Digital referral systems** - a number of people mentioned the idea of having digital referral systems include a ‘search tool that helps to match people with supports that suit their specific needs, preferences and location’. Some suggested with use of AI this should be able to be built to be tailored to specific supports people are looking for.

### Appropriate use of digital

Noting it is difficult to find a ‘one-size-fits-all’ digital solution, we heard online systems should be used **where digital is preferred and appropriate to suit the needs of the person with disability**, and where they can be tailored to those needs. For example:

- where it might be useful to have a centralised directory of supports that are relevant to type of disability, (e.g. supports relating to certain diagnosis or cohort, parents and carers), in a person’s local area
- to provide information and advice for people who have limited mobility to access supports outside the home
- to find relevant online support groups and networks
- digital/online solutions supporting and connecting with in-person and phone-based services as part of a continuum of channels and modes of information delivery, and so people can choose their preferred way to engage
- where technology could support very tailored solutions for people, e.g. through the use of AI chatbots or similar that are able to provide accurate information and funnel people to what they need through a language/chat interface

People particularly highlighted the use of digital communication, other than phone calls, can improve accessibility, for those who speak other languages, are hard of hearing and for autistic people or people who are non-verbal.

*‘It has been very difficult finding support. Practically impossible during times that I have not been able to speak. There is always the requirement to phone to get help from a service which is impossible for people who are non verbal or have phone call anxiety.’ – Individual respondent, general supports questionnaire*



## Centralised platform to connect people

Some people suggested a centralised, accessible platform that connects people with services, peers, networks and community activities. Comments suggested this would be different to traditional government websites which are one-way and share information. It should be interactive, searchable and able to have users contribute information.

In particular, it was suggested the platform include a directory of local events, support groups and social opportunities tailored to different types of disabilities and interests and searchable by location. People suggested this is a tool that doesn't exist within the existing Disability Gateway platform.

Ideally, the platform could facilitate online and in-person peer networks where individuals can share experiences and advice in a supportive environment.

## Concerns about reliance on digital platforms

However, we also heard some concerns about the use of online platforms or a 'digital-first' approach to information about disability supports. It was noted not all people with disability have access to digital services and the internet so digital should not be relied upon. Issues included:

- the need for people to be aware of the websites, apps or other digital solutions available, rather than 'meeting them where they are at'
- digital divides for people with limited access to hardware, data availability or affordability and low digital literacy
- some people in regional, rural and remote areas with limited access to internet
- lack of culturally appropriate/safe online environments.

Some people said governments would need to invest more to improve awareness of any digital platforms. Many noted there's low awareness and use of the Disability Gateway platform currently available with significant investment already put into this site. While there was slightly more awareness or familiarity with tools such as 'Ask Izzy', it was still not mentioned as often as sites developed by organisations that are for specific audiences/groups. If organisations are funded to develop digital tools (such as those who have received ILC funding), some mentioned they should have longer-term support to ensure they're promoted and used throughout the community they're designed to support.

## Recognising the unique nature of different territories

### **In the Northern Territory (NT)**

Participants in the NT stressed it is very different to most other states and territories, and the same approaches and solutions do not always apply. They explained it is important to understand the impacts of factors like distance, culture, cultural protocols in remote areas and language. They advised systems and processes need to be locally designed from the start, not attempted to be retrofitted from other locations.

Stakeholders mentioned providers and recipients in the Northern Territory feel neglected in the design and implementation of nationally funded programs.

First Nations representatives and some stakeholders reiterated the importance of coming back to properly co-design foundation supports in the NT so they met specific needs, particularly co-design led by local people and organisations in their remote communities. Foundational supports will look very different in First Nations remote communities to what is provided in regional areas.

### **In Norfolk Island**

In Norfolk Island, community members and stakeholders spoke about the unique challenges in accessing disability services due to its remote location and isolation. Key issues included no access to mainland support phone lines, a severe shortage of healthcare professionals (especially for children's services) and limited funding opportunities since the island falls outside normal state and territory systems.

Many families struggle financially to access support, and the current system relies heavily on volunteers and visiting therapists, making it unsustainable in the long-term.

## Mainstream settings where general supports could be delivered

The most common settings people suggested information, advice and referrals could be delivered were in the following mainstream, community and government services. This indicates people expect more linkages in information and referrals to occur between government services and settings.

### Local governments

Local government (councils), with a reach to the local area through properties and public infrastructure such as local hubs, libraries, parks and other community spaces. In addition, the importance of key roles in local government, such as access and inclusion, or disability inclusion officers, who could help in understanding and coordinating what is available in the local area, as well, as being a key touchpoint for the community.

### Schools and ECEC settings

People expressed schools and ECEC settings (including very early years like playgroups) should be encouraged and supported to provide information and advice where appropriate. Many people suggested the need for dedicated roles within schools or ECEC settings, or support that is 'brought into schools', that could help parents or carers by:

- providing accurate information and advice to parents when a disability or delay has been identified for the first time in the school or ECEC setting
- directing or referring parents to appropriate supports (including peer supports) outside of the school / ECEC setting.

Schools and other education settings were also identified as important settings for child, family and community capacity building. Specific suggestions:

- Additional incentives and programs to help teachers learn more about different disabilities, discrimination and rights, strategies for managing behaviours and how they can support children with disability to participate equitably.
- Additional free education and training for teachers to help them communicate and adapt their teaching style to children with different disabilities.
- More programs, after school clubs, social activities and sporting events that are inclusive for children with disability.
- Additional supports and aids for children with disability to help improve their educational outcomes ensuring they're able to participate at school and minimise disruption for families.

*'We want our children with disabilities to be valued at school, not to be seen as disruptive or difficult.'* – **Submission**

## Healthcare services or professionals

Healthcare services or professionals are key touchpoints for parents and people with disability, such as GPs and Maternal and Child Health Nurses.

Importantly, both people with disability and other stakeholders noted healthcare professionals need to first be equipped with more information, and accurate information, about what people might be eligible to access and where to find information. Due to the amount of information professionals would need to be across, some people also suggested there be specific roles within these settings—e.g. hospitals and health services—who hold and are responsible for keeping up to date with this knowledge in order to guide people to the most appropriate supports.

This may be particularly helpful, for example, for people who acquire disability and are in hospital settings, people living with mental health challenges and people who are looking for supports for the first time.

## Roles (new and existing) to deliver general supports

Feedback from community members and stakeholders highlighted the following roles that would be helpful in delivering general supports.

### Existing roles in the NDIS system

#### NDIS support coordinators

Some NDIS participants and families said support coordinators are one of their most trusted sources of information. Some mentioned more could be done within general supports to equip support coordinators to better deliver information, advice and referrals for those in the NDIS. This included training for support coordinators in how to find information, including about new programs available for people to access and what is available to people locally. This would help make sure support coordinators have access to the right information so they know where to refer participants to when they need new information (e.g. changes happening in the NDIS) or different types of supports.

#### Local Area Coordinators (LACs)

LACs (also referred to in some areas as Partners in the Community) were identified as an important source of information about the NDIS, when they work well. Some suggested their roles in the past had included more opportunity to connect people who are not in the NDIS with local supports, however, there is a perception this function has reduced within the LACs day-to-day role.

There was also some feedback the LACs model doesn't work well to deliver localised and targeted information and referrals. For example, DRO have suggested moving away from the LAC model.

*'There is an opportunity to reevaluate the tenders that favour large organisations, disconnected from the communities they serve, and instead consider which organisations are best placed to deliver the right services to the communities they support.'* – *DRO joint submission*

Others suggested continuing and enhancing the role of LACs, but ensuring:

- they employ people with enough knowledge and skill to share accurate information
- they have capacity to provide more information and be a 'one-stop-shop' for people in and outside of the NDIS

*'The LAC and there [sic] offices need to be a one stop shop of all information in all formats, maybe some community computers and staff who can either show someone or if needed have the time to explain if a client can't use them and may need it in simpler written terms.'* – *Individual respondent, general supports questionnaire*

## Case management models

Many people raised the need for a person (role) to work alongside people in the community who need extra supports to help them find, navigate and access the supports they need.

While the specific roles proposed were named and described in many different ways, common features of this model were that the roles would:

- provide more tailored and individualised supports, information and referrals
- have local knowledge
- be available in settings where people are likely to find them

In addition to providing these benefits for people who need extra support, it is proposed these roles could enhance system efficiency by bridging gaps between health, mental health, aged care and disability sectors, improving coordination of information and efforts.

The following specific types of roles were mentioned:

### Case management / coordination

In submissions, a number of stakeholders suggested general supports should include tailored case management, involving ongoing assessment, planning and coordination of a person's supports. It was noted people who are not eligible for NDIS supports, but still have complex or intersectional needs, may require specialised support to manage their ongoing and changing needs. Suggestions included:

- employing dedicated case managers / care coordinators in local service hubs to:
  - develop individualised support plans in collaboration with individuals with disability, their carers, families and broader support networks
  - bring multiple services or supports (e.g. disability and health) together to supporting an individual they are working with
- help people in the community navigate the intersection between foundational supports and NDIS supports

- case managers as a dedicated outreach service to ensure individuals are aware of and accessing the supports they need.

*'[We] see a strong need for case managers or coordinators to help individuals navigate the complex disability system and interlinked sectors and systems, and recommend that support staff receive training to effectively communicate with individuals with diverse needs.'* – **Submission**

*'In the Deafblind community there is a need for more knowledgeable and experienced consultants or case managers available on an ongoing basis to support people as they seek advice, information and support.'* – **Submission**

Some suggested these roles could be done by local allied health or social work professionals who have a good knowledge of the intersections between health, mental health, education and disability supports in the community. These roles would be essential for ensuring supports have longer-term benefits and outcomes for people who need extra support.

## System navigators and connectors

A number of stakeholders suggested the creation of a system navigator role to help individuals with disability and their carers, families and kin to navigate the complex service landscape. This recognises fragmentation and duplication of services, coupled with insufficient availability and awareness of culturally tailored or lifecycle-specific supports, remain significant challenges.

It was suggested system navigators could be available in each LGA and through various modes (such as websites, online apps, online chat, phone services and face-to-face meetings). Where they are available, they may be responsible for upskilling and raising awareness in their local area of the services available to people (including by educating health professionals, teachers and others at key system entry points).

Within these roles, it would be important people are:

- trained to deliver person-centred, culturally sensitive support
- equipped with expertise in various lifecycle stages would ensure that individuals receive age-appropriate and relevant support
- able to provide responsive support, helping to prevent crises and unnecessary incidents / hospitalisations
- able to draw on peer workers and networks to leverage lived experience of disability alongside their connections to local communities and services.

*'Having access to dedicated helplines with trained staff who can offer personalised guidance would make everything feel more manageable. It would be helpful to have more localised information that points to nearby services and support.'* – **Submission**

The Queensland Alliance for Mental Health suggested 'Wellbeing Connectors'. These would be 'place-based navigator support based on social prescribing that helps people to identify their wellbeing goals and develop a plan to meet those needs'. They added Wellbeing Connectors

should be wellbeing focused, not illness or disability focused. They should utilise trauma-informed approaches and aim to develop individual, family and community capacity.

### Key worker model

There were also preferences for models of delivery where **relationships can be built over time** and where there's a lead practitioner who can take the pressure of system navigation off of individuals, and family members and carers. It was noted these models also prevent people from having to tell their stories or experiences over again at many different entry points or services.

The key worker models was mentioned in multiple responses, especially from families and carers and early childhood stakeholders. While there were mixed views as to whether the model is appropriate in all circumstances and settings, those in support of the model noted the benefits of:

- families feeling connected throughout their journey
- minimising the number of relationships families need to navigate.

The key worker model is discussed in more detail in the [Consultation Report for Supports for Children under 9](#), their families, carers and kin.

### Other connector and liaison roles

People in events often talked about similar roles, sometimes referring to them as community networkers, connectors or liaison officers.

Some people suggested all government service shopfronts, employ a dedicated person, (e.g. liaison officer) who can provide additional support and accurate information to people with disability, their carers, families and kin.

*'Dedicated community connectors or engagement officers could help bridge gaps by identifying and linking individuals with suitable activities, programs, or networks. This is especially valuable in our region, where services are often not well-publicized [sic] or easily accessible.'* – **Individual respondent, general supports questionnaire**

### Allied health

As discussed earlier in the report, many people mentioned the important role that allied health professionals play in sharing information and advice to people with disability, and in building capacity of individuals and families. This was particularly mentioned by or in relation to people who are not currently in the NDIS accessing supports and information.

It was suggested general supports seek to improve awareness of the value of allied health interventions in supporting people to live well and build capacity, with comments noting this is important as part of people's pathways to further supports in the community.

*'Capacity building interventions through trained allied health professionals is important before connecting with social and community activities. There are so many mainstream activities that people can join but they need support to access these activities and therapy to work on social interaction, communication, self-management.'* – **Individual respondent, general supports questionnaire**

Some people also suggested more social workers and allied health workers could be placed within community centres and local hubs to share accurate information with people and to give advice about what disability supports a person might need and be eligible to access. This may work alongside, or as alternative to ‘system navigator’ or case manager roles mentioned in the following section.

## Other types of support needed to improve access to information, advice, referrals and capacity building

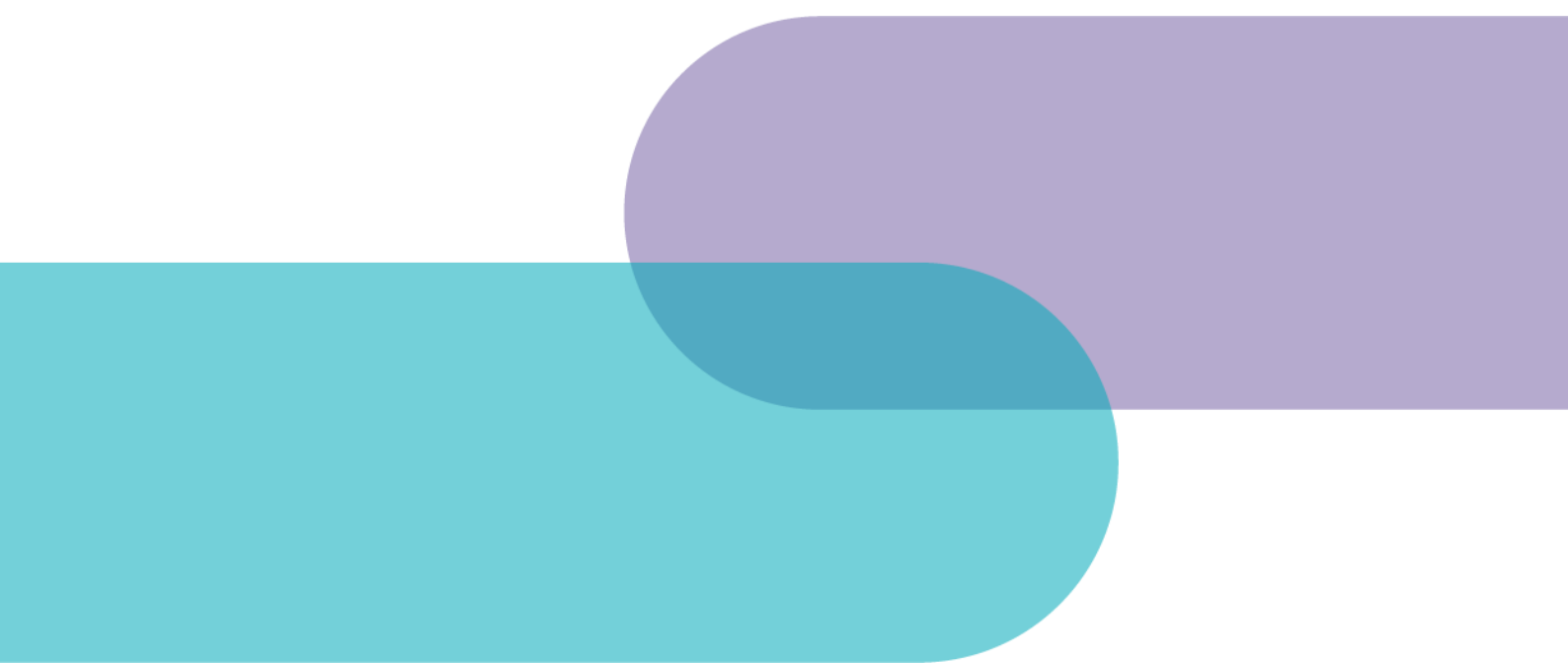
People identified specific things to help make sure more people could access general supports:

- Ensuring **additional supports in community are free**. It was noted paying for services will be a significant barrier for many people.
- **Providing transport assistance or virtual options** for participation to enhance accessibility, ensuring everyone has the opportunity to engage in the additional supports provided within their community. This included supporting people who are not in the NDIS with vouchers to get help with transport, IT or other things they need to be able to access the supports in the first place. It was noted these are often available in NDIS plans but people who are not in the NDIS may not be able to afford the costs to access the additional supports.
- Ensuring all people, whether or not they’re in the NDIS, have **free access to meet accessibility and translation needs**, (e.g. Auslan), to be able to get the supports offered under a general supports system.
- **Working together to improve physical and digital accessibility**. People noted when society and physical places are inaccessible it prevents people from accessing supports, including for capacity building. While mostly out of scope for this consultation, there were multiple mentions of this point and in particular that systems work together to improve:
  - accessibility and availability of public transport
  - accessible infrastructure such as ramps, elevators, wide doorways, accessible restrooms and clear signage
  - accessible public spaces and inclusive recreational facilities
  - accessibility of websites and digital platforms for example, by using screen readers, captioning, etc.
  - accessibility and availability of housing for people with disability.



# Chapter 5: Principles to guide and sustain general supports

- [Guiding principles](#)
- [Sustainability in the delivery of general supports](#)



# Guiding principles for design and implementation

While not specifically asked in the consultation paper, respondents and participants in roundtables and other events spoke a lot about principles that should guide the design and implementation of foundational supports, including general supports.



## Guiding principles for designing and implementing foundational supports

As foundational supports are further designed, stakeholders suggested governments should establish a set of guiding principles. These should guide how foundational supports are implemented. The main areas proposed:

- **Human rights focus** in the design and delivery of foundational supports. This included aligning with the Convention on the Rights of Persons with Disabilities (Disabilities Convention).
- **Supports are co-designed** with people with disability, families and carers in line with the principles of ‘nothing about us without us’.
- **Choice, control and independence** for people with disability is prioritised in the delivery of additional supports in the community. This includes moving away from one-size-fits-all approaches to **tailored, holistic and flexible** services that take into account a whole person, their goals, and right to decision-making and independence in the community.
- **First Nations communities have self-determination in decision-making** for design and implementation of foundational supports.
- **Independence** of organisations delivering information and advice.
- **Continuity of supports** for people with disability whether or not they’re in the NDIS.
- **Equity** including in the eligibility for general supports and in ensuring investment is made into regional areas and other markets where supports are currently lacking.
- **Existing trusted, credible organisations** and services are used and prioritised to ensure quality and safety of supports for people with disability. This includes prioritising disability-led organisations, supports and networks, and ensuring both larger and smaller organisations who work within the community are included.
- Governments will make all efforts to **communicate and explain foundational supports** including eligibility, how they will be delivered and who is responsible.
- General supports consider **whole-of-family approaches** that account for family environment and needs of the whole family, including parents, siblings, extended family, foster carers, and other family members with disability.

# Sustainability in the delivery of general supports

Ensuring best practice implementation and sustainability of general supports will be critical to achieving outcomes for individuals, families, carers and community.

## What we heard

We heard from both community members and stakeholders the following areas are critical for ensuring there's a general supports model that is sustainable and works:

- [Continuity of supports](#) for all people who might be affected by changes to NDIS and who need extra support in the community
- [Longer-term funding arrangements](#) and a different way to commission supports
- [Better integrated supports and service systems](#)
- [Improving collaboration for stronger referral pathways](#)
- [A sustainable workforce](#), including in regional areas

## Continuity of supports

As discussed under [Principles](#), we heard one of the most important things is ensuring there is continuity of supports while foundational supports are agreed and come into place. In relation to this, there were two types of areas discussed:

- **Ensuring people with disability have the necessary funds for continuity of supports.** This was particularly relevant to people in the NDIS. People reported issues with having plans reassessed and a significant fear that supports would be lost prior to having alternatives in place through foundational supports.
- **Maintain funding to advocacy and other disability organisations who already provide 'general supports'** - (e.g. Information, advice, referrals and capacity building) - while new funding arrangements and a foundational supports service system is put into place. People were concerned existing organisations may lose funding and this would create a gap in supports while governments work to implement foundational supports. The joint DRO submission, for example, suggested interim funding agreements to support the transition from ILC grants.

### Supports through a life journey

Another reason that supports need to be sustained for the long-term is to ensure they are available to support people over their life journey. For example, a young person with disability will need different or additional supports as they transition between school to the workforce, then as they move into their own home or become a parent. For people who need additional supports but aren't in the NDIS, it's important for them to have certainty of additional supports in the community.

## Longer-term funding to deliver the ‘base’ of general supports, with grants and flexibility to encourage innovation

A very strong theme across all consultations was the **need for sustained, longer-term funding** to deliver foundational supports across communities. This related to ensuring effective supports continue and are sustained over time. We heard where funding for capacity building is done using short-term grants it leads to issues in continuity of supports and:

- impacts organisational and workforce stability
- causes disruptions within programs and supports on the ground, where there is a need to allocate already stretched resources to apply for more grant rounds or opportunities.

We heard longer-term funding and commissioning should be **driven by strategic national priorities** based on evidence communicated early and clearly. This would help to also provide some consistency across states and territories. It was noted local and state-based data and needs should inform national priorities.

*‘Whatever funding model is decided upon, it is essential for innovation, quality and best practice that each funded organisation and/or body is able to use the funding flexibly to meet the individual needs of their community. Individual children and family needs change over time resulting in flexibility of the types, frequency and location of service delivery options.’ – Submission*



### 5-year commissioning model

It was suggested supports for general supports programs be funded, procured or commissioned for a minimum of 5 years, with the flexibility to adjust approaches as needed within that time period.

Governments are already investing in and implementing longer-term funding arrangements for many social and community services, including through 5+ year funding and commissioning models. For example, in the Department of Social Services longer-term grants are provided for financial wellbeing and capability programs.

Importantly, many stakeholders noted 5-year commissioning models need to prioritise evidence-based programs that deliver holistic supports and promote collaboration across service systems and within locations. For example, in the DROs joint submission they recommended ‘establishing a commissioning framework that would allow disability-led peak bodies and grassroots groups to partner together and seek funding for the vital local solutions to advocacy, peer support and capacity building already existing or vitally needed’.

This was supported by other submissions from organisations who agreed secure long-term funding with local agencies involved is critical.

*‘Federal and State and Territory Governments should ensure all foundational supports are provided with adequate secure long-term funding, with supports commissioned in ways that maximises the benefits from the skills of local agencies as part of a strategically coherent and public-facing foundational supports Strategy.’ – Submission*

## Benefits of longer-term funding models

As we have heard, relationships and trust are highly important when it comes to capacity building activities, and information services need to be built over time. Having time to build relationships is especially important in regional, rural and remote areas, and when delivering general supports to particular population groups and cohorts.

### Information, advice and referrals

Benefits of longer-term funding arrangements to information, advice and referral services:

- The ability to **sustain and improve on information** over time
- **Stronger information systems** that can be built then continually tested and improved rather than set up and then closed down when funding ceases
- Ensuring information and advice is more **evidence-informed and can be co-designed** with the communities they are for
- **Time to build and sustain localised and place-based models** for information, advice and referrals, such as establishing community hubs that bring services together

### Capacity building

Benefits of longer-term funding arrangements to capacity building:

- **Increased collaboration** across organisations to build partnerships over time, based on areas of need
- **More ongoing, dependable and reliable capacity building services**, rather than ‘one-off’ supports
- **Better representation for people with intersectional identities** or who have specific barriers because people are able to be encouraged to take part and engaged over time, rather than in short periods
- **Keeping self-advocacy and peer groups running** so people build relationships and trust and are more likely to continue to engage when they need to.

*‘Achieving success in capacity-building requires taking incremental steps towards long-term outcomes. Maintaining ongoing connections with capacity-building organisations and networks is important.’ – Submission*

## Innovation and grants for smaller organisations

In addition to longer-term funding arrangements, some people suggested shorter time or funding-limited grant rounds to encourage **innovative approaches or pilot projects in specific areas or for specific cohorts** as needed.

Some also suggested opening up grants rounds more to smaller regional organisations who can deliver tailored and safe information and supports.

## Funding operational costs

A number of organisations suggested operational costs need to be considered within funding agreements, including funding that ensures:

- services can provide safe spaces for people to access additional supports in the community

- ongoing training and compliance, particularly for smaller organisations in regional and rural areas
- operational costs that cover additional expenses incurred for servicing regional and rural areas in place-based settings, such as having mobile hubs, to ensure people in these areas don't miss out on in-person supports.

## Co-design and trust with First Nations communities

This is particularly important in the context of First Nations communities. Stakeholders reiterated **longer-term funding arrangements are needed to allow organisations to properly design supports with communities** specific to their local contexts. First Nations people should have self-determination to determine how programs are run in their communities. Once established, programs then need to be in place and consistent for some time to build trust and encourage access by people in the community.

## Support for disability-led organisations in procurement/funding

We heard strongly there should be more capacity building support provided for disability and family/carer-led organisations, as well as First Nations, multicultural and other community-led organisations, to be procured through contracts or grant processes. This is especially important for the many disability-led organisations who are also providing employment for people with disability within organisations, which is an important outcome in itself.

## Types of funding models

Stakeholders expressed polarised views regarding **block funding models** versus **individualised funding**. Some felt block funding models negatively impacted choice and control for people accessing supports, including by restricting service provider options and resulting in long waitlists for services. They also noted block funded models can leave rural communities without access to timely and local supports, where funding tends to go to larger organisations rather than the sole traders and small private practices that are often uniquely positioned to deliver high quality, flexible, and responsive care in rural areas.

However, others felt block funding offered more flexibility, enabling service providers to adapt their supports (and the frequency / intensity of supports) based on the individual's needs and goals. This, in turn, can reduce inefficiencies associated with unnecessarily rigid service schedules and allow for collective use of funds (which is often more cost effective). It was suggested funds linked to specific individuals do not allow for such flexibility or economies of scale, stymie innovation, and lead to unsustainable provider business models.

In submissions, some supported a **needs-based funding** model that considers geographic disparities, population density, and the specific requirements of individuals in different regions.

## Better integrated supports and service systems

A strong theme throughout the consultations has been the need for foundational supports to be well integrated with other service systems, including disability, health, aged care and education. We heard policies and services can operate in silos, with boundaries between medical, educational, and disability support systems that prevent holistic and person-centred support for people with disability. This can create challenges when people with disability have multiple needs or when their needs don't fit into one category or when different types of supports are needed in mainstream settings.

People told us there is a need to 'break down silos' and make sure general supports are well connected with mainstream services and NDIS supports.



### Looking to other models of integrated care and supports

Based on the significant feedback about ensuring there are integrated supports and models of care in place for foundational supports, governments could look to trial programs that involve integrated care and commissioning. There are already some initiatives across the health, care and disability sectors doing this in communities. For example, the [Integrated Care and Commissioning initiative](#) led by Department of Health and Aged Care.

There is an opportunity to look to these models and consider similar approaches in the design of foundational supports.

## Improving collaboration for stronger referral pathways

There were 3 particular areas suggested to improve collaboration in foundational supports:

**Coordinated referral pathways at local, state/territory and national levels:** Delivery of foundational supports should encourage more organisations to collaborate at the local or state level and to develop trusted referral pathways. For example, smaller local organisations could be included more in programs and initiatives proposed and led by non-government peaks. This will be particularly important when providing long-term funding for place-based initiatives. Local organisations would contribute to design of programs ensuring local context is built in. They would also help bring their existing clients to access programs and services, ensuring they more effectively reach people in priority communities.

**Collaboration over competition:** A number of organisations suggested funding structures and programs for information, advice and referrals should support collaboration over competition. It was suggested a change in the way programs are commissioned could support organisations to work together under longer-term funding arrangements where collaborative efforts are prioritised. This would encourage organisations to work together, to share information, learnings and results and offering more coordinated services to clients.

**Data sharing:** A few stakeholders mentioned the need to look at how data is shared between governments and organisations within a foundational supports system. They noted the need to ensure the ability to share information safely and appropriately, as people move between services, and people should have an easier way to share this information when they want to. One of the main priorities for data sharing should be to reduce instances where people with disability and families having to repeat their stories over and over again.

## A sustainable workforce

We heard having consistency of staff is an issue for organisations, and this is particularly affected by short-term funding cycles. Workforce shortages are a particular issue in regional, rural and remote areas where it can be difficult to attract and retain staff without job security or the ability to match incentives or benefits given by other sectors or industries.

Under a foundational support system, stakeholders suggested, for organisations to retain quality staff to provide supports, they will need:

- investment/funding for training, placement of the right people and professional development opportunities for staff
- incentives for regional, rural and remote staff, and support for outreach activities that can be particularly difficult
- the capacity to build a strong sense of team and connection with community

## Using existing workforces to deliver foundational supports

Some stakeholders pointed to the opportunity to build on supports and workforces which are already available and working, particularly for families of young children with disability or developmental concerns. It was noted, with appropriate training, funding and resourcing, the role of these existing services and professions could be expanded to enable delivery of foundational supports. These included, for example:

- early childhood education providers
- child and family support workers
- maternal and early childhood health professionals
- supported playgroups and playgroup facilitators (and services such as Play Connect)
- sibling support programs
- public library staff (and services such as Toy Libraries)
- local community service groups.

The use of existing workforce to deliver foundational supports was an idea that emerged through the consultation process and was not specifically discussed with representatives of these workforce areas.

## Workforce capacity and capability in psychosocial supports

We heard there is a need to invest in a supported, qualified and trained workforce that is able to effectively refer people to psychosocial supports within a foundational supports system. This could include upskilling the peer workforce to provide information, advice, referrals and capacity building specific to psychosocial support. They should work alongside Primary Health Networks (PHNs), community based services, and other support systems.

### Strong governance

Concerns were raised about **fragmentation and inconsistency** where responsibilities are divided across federal, state, and local governments (as well as mainstream and specialised service providers). It was noted this can lead to gaps and overlaps in service delivery, duplication of efforts and missed opportunities to provide timely support.

Responding to these concerns, stakeholders put forward various suggestions for governance mechanisms to oversee national service delivery, including:

- creating a unified governance framework to address service fragmentation (as mentioned in Australia's Disability Strategy 2021-2031)
- establishing a national framework to define the roles and responsibilities of federal, state and local governments in funding, coordinating and delivering foundational supports
- forming an Advisory Council, comprising disability advocates, service providers and representatives from diverse communities, to oversee and advise on the design and implementation of foundational supports
- establishing a formal intergovernmental coordination body to foster regular communication and collaborative decision-making.

### Delivering supports in regional, rural and remote areas

We heard significant concerns about having a workforce and service system in regional, rural and remote areas to deliver foundational supports. For general supports, many people noted disability and community services in these areas are already overwhelmed with demand for the most critical supports, so delivering additional programs may significantly stretch services and their workers. There needs to be additional investment and strategies to utilise different workforces in regional areas.

Service providers and advocates in regional, rural and remote locations indicated insufficient resource allocation is one of the biggest barriers to people with disability, and their families, accessing appropriate and effective supports. They suggested:

- the number of different locations they cover and the extra costs they, and their support recipients, face because of things like travel, have not been properly considered in how funding is distributed
- the ability to recruit and retain a stable workforce is especially low in these areas, where there may not be infrastructure to support them or opportunities for career progression

- if workers need to move away when a grant period ends, local knowledge and relationships they have built are lost
- short (e.g. 2-3 year) funding cycles are not long enough for delivering effective support in regional, rural and remote areas.
- developing trust and connections with communities is vital and requires an ongoing local presence in regions.

*'I'm in Manjimup for the next two years, but then I'm not going to be there for the next five years. Because next time I've got to give it to Bridgetown, I've got to give it to Boyup, I've got to give it to Donnybrook, I've got to give it to Harvey. Because there's just a tiny bit of money for each time you run a project, that needs to go somewhere else. And so when you get back to Manjimup, and then they go, "You guys were here six years ago, and then you never came back".' – Disability advocate, regional WA meeting*

### **What is needed**

Stakeholder suggested funding models for foundational supports must include adequate pricing for regional supports, taking into account the range of different cost factors including:

- outreach and travel to rural locations to provide in-person supports
- costs to attract staff into programs and services
- investments in regional place-based programs need to be long-term so they are community-led and collaboration can build over time.

The psychosocial support sector also identified in rural areas there can be a lack of, or no service provision for psychosocial supports. They suggested specific investments for delivering information, advice and capacity building for people with psychosocial disability is needed in regional, rural and remote areas.



# Chapter 6: Quality, safety and accountability in general supports

- [Quality and safety](#)
- [Measurement and evaluation](#)

The consultation paper asked people what they think is needed to help support innovation, quality and best practice in the delivery of general supports. It also asked for ideas about what should be measured to demonstrate accountability over time.

## Quality, safety and accountability

### What we heard

It will be important to make sure foundational supports are of high quality, are accountable and keep people safe. In addition to being there for the long-term, people wanted to make sure any new service system would avoid problems of the past and respond or comply in full with recommendations of the Disability Royal Commission.

We heard some concerns from stakeholders there isn't a strong framework between Commonwealth and states and territories for ensuring quality and safety where supports are jointly funded and delivered. Some mentioned in most cases a Commission or similar is set up, such as with the NDIS, to oversee and regulate quality and safety.

A number of comments sought more clarity from governments about what the oversight mechanisms would be when it comes to foundational supports. A few comments also mentioned needing to have the recommendations of the Disability Royal Commission in place in order to have more oversight of general supports and additional supports for people with disability in the community more generally.

The specific areas that community members and stakeholders mentioned would help achieve this:

- [Registration, certification and compliance](#)
- [A good complaints system](#)
- [Investment in training](#)
- [Lived experience involvement in feedback and accountability](#)
- [Systemic advocacy for long-term change](#)
- [Ensuring quality of services for diverse and marginalised population groups](#)

### Registration, certification and compliance

Various forms of registration or certification for organisations were proposed to help ensure quality, however, many people mentioned the need for any registration or certification process to be:

- free or low cost
- highly flexible to adapt to the types of supports being provided and level of risk
- account for existing certification processes.

Another common theme was the need for more consistent and stronger follow-up and enforcement of penalties or other consequences if an organisation has been found to be doing the wrong thing.

We heard there could be some sort of quality framework that resulted in organisations having a ‘tick’ for quality and safety, or use of a star rating or review system that is transparent to users of foundational supports.

Some people mentioned the links between this, and current work being undertaken to better align provider and worker registration systems, particularly between NDIS and allied health sectors. This reform and the design of foundational supports needs to be coordinated with these broader changes in the disability service system.

## National standards to ensure safety and quality

A number of stakeholder respondents recommended the development of national standards to guide the delivery of foundational supports. National standards and guidelines could ensure clarity of expectations and promote greater consistency, while allowing for local adaptations.

Some stakeholders suggested any quality standards must **centre human rights** and align with the UNCRPD. Some cited the National Safety and Quality Mental Health Standards for Community Managed Organisations, which provide best practice guidance for providers delivering mental health supports.

*‘The introduction of national quality standards could result in improved safety and quality assurance for all people accessing foundational supports.’ –*

*Submission*

## A good complaints system

Some people suggested there’s a need for a complaints system that will cover foundational supports. People suggested there would need to be clear processes about how and where people should make complaints about services and supports delivered outside of the NDIS.

People expressed concerns the NDIS Quality and Safety Commission is already overloaded with complaints and work related to specific NDIS supports. Their remit and scope may need to be broadened if they were to have responsibility for ensuring the safety and quality of additional supports in the community under a foundational supports service system.

Stakeholders also reiterated the importance of a good complaints system. In submissions, some suggested establishing accessible and independent complaints and feedback mechanisms to enable service users (particularly people with disability) to easily (and without fear of reprisal) report any concerns or provide suggestions for improvement.

*‘Include a clear, accessible and independent complaints mechanisms that enforce minimum standards and that has enforceable deadlines and processes when needed.’ – Submission*

*‘Establishing accessible third-party complaints and feedback mechanisms are crucial for empowering people receiving supports to express their concerns and experiences without fear of jeopardising their relationship with their service provider. These mechanisms should be designed to ensure confidentiality and encourage open communication.’ – Submission*

## Investment in training

We heard training for organisations is a critical part of delivering quality, safe and effective foundational supports, including general supports. Some suggested mandatory training for all organisations funded or involved in the delivery of foundational supports.

It was suggested the Australian Government should consider funding a centre of excellence for the training of disability workers, potentially via a matched funding model with providers. This would ensure the government could set - in co-design with consumers, providers, and other stakeholders - minimum standards for the training, and ensure any mandatory training is easily accessible to all workers.

A lot of feedback also highlighted the need for governments to fund training for community services, allied health providers and disability providers. For example, some suggested 'offering government funded programs or grants to subsidise training initiatives'.

*'The government should also consider funding a centre of excellence for the training of disability workers, potentially via a matched funding model with providers. This would ensure that the government could set - in co-design with consumers, providers, and other stakeholders - minimum standards for the training, and ensure that any mandatory training is easily accessible to all workers.'* – *General supports questionnaire*

It was also suggested dedicated funding could be provided for disability organisations to work with service providers to build their capacity, such as providing training for staff, support to recruit and retain staff, embedding robust systems and governance frameworks, upskilling leadership and foster partnerships.

## Lived experience involvement in feedback and accountability

We heard there should be more mechanisms for users, such as people with disability and families, to provide feedback. These mechanisms should be available in a variety of formats or ways to ensure they are accessible and the outcomes of the feedback should be transparent and publicly available in some form.

Lived experience organisations could be involved in checking on quality and outcomes and assisting in making decisions on investment in supports.

## Systemic advocacy for long-term change

Stakeholders suggested a robust foundational support system must incorporate **systemic advocacy to drive long-term changes**, particularly in mainstream services. This includes advocating for inclusive policies, training for frontline staff and auditing service accessibility to ensure alignment with inclusivity standards.

A number of comments talked about the importance of organisations and individuals continuing to advocate strongly for universal design and for all people in the community to be able to access and be supported by mainstream services.

It was proposed foundational supports should act as a bridge, not just filling immediate gaps but creating pathways for sustained, systemic improvements.

## Ensuring quality of services for diverse and marginalised populations

People from diverse and marginalised groups, and the organisations who represent them, raised specific concerns about quality and safety of foundational supports.

- **Quality supports that consider intersectionalities:** Recognising the intersectional nature of disability, many people commented on the importance that supports must be culturally appropriate and safe for all people – including for First Nations peoples, CALD people, LGBTIQ+SB people and others at the intersection of disadvantage.
- **Monitoring cultural competency:** In focus groups with National Ethnic Disability Alliance (NEDA) members, people highlighted the need for open feedback channels, enabling people with disability from CALD backgrounds, their families and carers, to anonymously and safely share their experiences with services and supports. As stated in NEDA's submission, such feedback should inform public information about the cultural competence and safety of services, while also providing pathways for people to seek additional assistance to obtain the support they need. Participants emphasised the importance of regular audits, ongoing opportunities for person-led monitoring and evaluation, and prompt responses to quality and safeguarding concerns raised through feedback, with a focus on continuous improvement.
- **Monitoring quality of supports for people living with mental health challenges and diagnosis:** Feedback demonstrated the importance of ensuring robust monitoring for safety and quality, ethical, non-judgemental, supportive and respectful services that support people living with mental health challenges and diagnosis.

## Quality and safety in First Nations supports

A particular focus of quality and safety in supports for First Nations people and organisations we spoke to was on:

- workforce development
- cultural competence.

Participants noted services must be delivered by staff who are both skilled in disability support and trained in cultural safety to build trust and confidence within the community. Certification processes, including cultural competence certifications for venues and staff, were suggested to guarantee consistent standards.

Recommendations from DROs and other stakeholders also included investment in a self-determined, disability rights informed and culturally safe First Nations disability workforce to fill workforce capacity gaps across the disability support sector. This would help to improve the quality and safety of supports for First Nations people.

# Measurement and evaluation

We asked participants about how outcomes should be monitored and measured.

## What we heard

Stakeholders raised the importance of setting up robust governance and systems for monitoring the impact of foundational supports on the lives of people with disability, their families, carers and kin. We heard measurement and evaluation would be critical to the effective design and implementation of foundational supports, including to help identify what is working well, where there are gaps and needs, and to ensure services are responsive and continuously improving. Stakeholders also suggested outcomes, measurement and reporting should be integrated with, or aligned with, existing outcomes frameworks such as for Australia's Disability Strategy.

Participants and respondents mentioned it is important:

- there is transparency regarding the governance of foundational supports, including clear roles and responsibilities
- there are defined outcomes and indicators of success that are relevant for individuals, communities, governments and other stakeholders
- there are robust measurement and monitoring systems, including a system for national data collection
- there should be routine reporting and continuous improvement based on the results.

## Need for clear and transparent governance, roles and responsibilities

We heard there is a need for **increased transparency in how decisions** on funding are made at the state and Commonwealth levels to ensure and maintain trust with stakeholders and community members.

In addition, **clear roles and responsibilities** are needed. Stakeholders consistently highlighted, for foundational supports to be successful, there must be a coordinated effort from all levels of government. It was noted roles and responsibilities should be documented and agreements in place to minimise service gaps and ensure equitable service delivery.

*'For foundational supports to be successful, there must be a coordinated effort from all levels of government. Federal, state, and local governments need to work together to create a unified strategy that addresses the varied needs of people with disabilities.'* – Organisation submission

## Defining outcomes and indicators

Many people mentioned governments and service providers must be **accountable for delivering on outcomes**, not just how many people are supports are being delivered to. This also requires transparency regarding the intended outcomes, funded activities, funding arrangements, and any gaps or limitations of the supports to be delivered through foundational supports.

It was noted the achievement of real and meaningful outcomes can take time, and a range of **short, medium and long-term indicators** might be required to understand the usage, effectiveness and impact of services.

*‘Outcomes for people using Foundational Support services should be measured to demonstrate accountability. Recognising that achieving real and meaningful impact in the human services sector takes time is essential.’ – Submission*

Stakeholders suggested **practical, measurable and meaningful indicators of success must be identified** to enable regular monitoring of foundational supports, including their appropriateness, effectiveness and efficiency.

## Considerations for measuring and monitoring progress and outcomes

**We heard a robust system of monitoring and evaluation must be in place.** It was noted regular progress reviews should involve people with disability, their families, carers and kin. Some suggested government establish client reference groups to provide feedback on the services they access. Others suggested surveys, focus groups, exit interviews, collecting case studies, periodic, longitudinal check-ins with individuals, families and community organisations, and some suggested undertaking independent audits.

However, we heard it is important there is flexibility so outcomes can be accounted for and measured in different ways and over relevant time periods to show progress. This is especially true for organisations delivering supports led by, and who employ/include, people with lived experience in delivering supports.

Related to this, people told us some organisations that are already stretched to provide frontline services have limited capacity for detailed data gathering and reporting. Gathering personal data may also cause additional barriers for people accessing supports who are concerned about privacy or the interaction with other systems such as child safety or immigration. We heard there should be consideration of what and how the most appropriate data can be gathered to demonstrate real outcomes for investment.

It was also recognised there is often limited funding available for data collection and analysis and the evaluation of services, and there are challenges in integrating data across programs and jurisdictions. To address this, some suggested the development of a national framework for data collection and evaluation should form a key component of the design and implementation of foundational supports.

## Reporting and continuous improvement

While respondents identified the need to minimise the administrative burden associated with accessing and delivering foundational supports, it was noted data and reporting would be critical to provide insight as to whether supports are achieving the intended outcomes. It was noted routine reporting is also key to building trust and confidence in the community.

Stakeholders also recommended the outcomes of monitoring and evaluation (including any gaps, issues and potential improvements) should be published, as this would help to quantify

the impact being made by foundational supports and ensure services remain responsive, inclusive and aligned with the intended outcomes.

*‘Fundamental to a successful system of foundational supports is the ability to measure the impact these supports are having on the lives of people with disability, their families and their carers.’ – Organisation submission*

*‘Outcome-based performance indicators should measure success in areas such as inclusion, social participation, and well-being. Regular feedback mechanisms should allow people with disabilities to share their experiences and suggest improvements.’ – Organisation submission*

*‘Monitoring and evaluation are indispensable for maintaining the effectiveness and relevance of foundational supports.’ – Organisation submission*

Some people mentioned direct commissioning or contracting models might provide the opportunity for more quality control through acquittal processes and performance measures in contracts, rather than fee-for-service models.

We also heard about the **need for continuous improvement**. Stakeholders mentioned there should be clear and simple mechanisms for adjusting, removing or replacing supports, processes and service providers who are not delivering outcomes, such that supports are continuously improving.

*‘Independent audits and evaluations should be conducted regularly, with services adjusted based on data and user feedback.’ – Organisation submission*

## Suggested indicators

In submissions, respondents suggested a range of **possible indicators could be used to track progress and success** across information, advice and capacity building services.

For **service use and quality**, suggestions included:

- how quickly individuals can access advice and referrals
- availability and usage of accessible resources
- the number of individuals connected to services, activities and programs that meet their needs
- how many individuals progress through and complete programs versus dropping out part-way through
- individual satisfaction with services
- rate and variety of engagements / activities
- uptake of services tailored for diverse groups
- proportion of resources available in accessible languages / formats
- proportion of services tailored for diverse communities or people with specific needs

To **track outcomes for individuals**, suggestions included:

- ability to navigate service systems independently
- ability for people with disability to self-advocate
- rates of supported decision-making and reduction in use of substitute decision-making
- ability for individuals and families to self-advocate
- where there has been improvement in engagement and social connection / or reduction in reported isolation and loneliness
- engagement in mainstream local activities, including sports, arts and community groups
- changes in standardised quality of life indicators
- progress in achieving personal goals, such as employment, education or independent living
- numbers of children with disability participating in education
- graduation and certification rates
- numbers of people with disability participating in education and employment
- career advancement, progression and job retention rates
- housing stability and accessibility
- tracking and comparing outcomes for people from diverse communities and with different disabilities
- reduced carer stress and burnout.

To track **outcomes for service providers and the community**, suggestions included:

- community sector staff turnover rates
- the number of staff who have participated in relevant training / upskilling (to better meet the needs of people with disability)
- the number of community groups engaged in education programs
- the number of successful partnerships between local service providers
- reduction in stigma and discrimination
- representation in media and culture
- service accessibility and effectiveness in urban, regional, and remote areas.



## An integrated approach to evaluation and continuous improvement

We heard monitoring and evaluation should not be an afterthought; evaluation feedback loops need to be embedded throughout all stages of the design and implementation of foundational supports.

An integrated approach to monitoring of results and evaluation would be critical to the effective design and implementation of foundational supports, including more rapid identification of gaps or issues, a better understanding of specific programs or supports that are effective, and the ability to share good practices across the service system.

This would lead to robust, evolving evidence base to inform future investment in supports and an uplift in sector-wide capacity and responsiveness.

Participants emphasised the importance of regular audits, ongoing opportunities for people with disability to lead monitoring and evaluation, and prompt responses to quality and safeguarding concerns raised through feedback.

Some people suggested a **national framework for data collection and evaluation** should be developed as a key component of the design and implementation of foundational supports. Stakeholders mentioned outcomes of evaluation should be available publicly, to increase transparency of the impact of foundational supports and ensure continued alignment with intended outcomes.

## Acknowledgement and thanks

The Social Deck thanks the thousands of people who contributed experiences, feedback and ideas to this consultation process. In particular, we acknowledge the strength and contributions of people with disability, and their families, carers and kin in sharing your stories.

# Appendix 1. Engagement methods and analysis

The following provides further information about engagement methods used during consultation events, and how data has been analysed.

## Methods for data collection

During engagement events, a variety of activities and materials were used to facilitate input into consultation questions and prompt discussion:

- **Group discussion with posters** – participants contributed ideas at their table, on sticky notes.
- **Workbooks** – participants could answer questions individually.
- **Targeted discussions** with stakeholders and priority groups. These were held with organisations and groups while on location.
- Use of a **digital engagement tool, Mentimeter**, to support:
  - anonymous input
  - preferences for use of digital tools, for example where people prefer not to or can't write answers on paper
  - screen reader accessibility.
- Use of **Chat** within online events (Zoom and Teams).

## Participant accessibility and wellbeing

Auslan interpretation and live captioning were available by request at all events. Larger community events and webinars included Auslan interpretation and live captioning by default. Other accessibility requests such as large print materials and seating preferences were accommodated.

Participants at online and face-to-face community workshops and roundtables received a participant pack up to one week in advance with information about accessing the event, a high-level agenda, and what to expect at the venue or in the video call environment.

Face-to-face and online community events included access to professional counselling services, with a wellbeing officer present at some events and/or available for post-event support and debriefing to support participants.

## Data analysis and presentation

Manual thematic analysis was undertaken for questionnaire responses and submissions. These were analysed for common themes and important differences before being consolidated with other findings in this report.

Data was also collected from multiple input sources at each event, and was consolidated and reviewed for common themes. A summary report was developed for each location.

More than 45 background reports were provided during the consultation process, which were used to inform government discussions and support early considerations about the design and implementation of some additional supports. Data across general supports consultation events and written, audio and video feedback was then consolidated into this report.