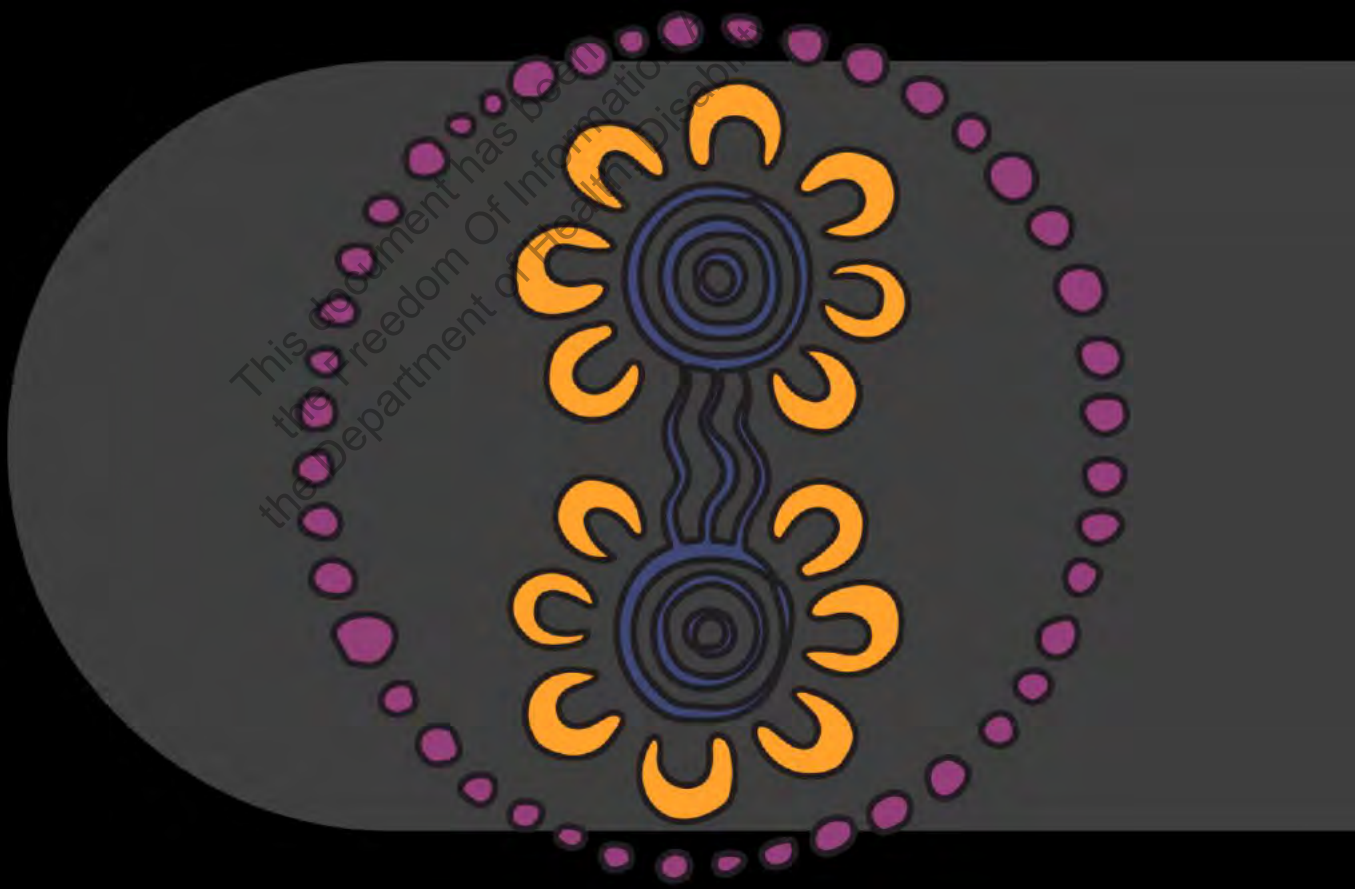
Foundational Supports

First Nations Consultation Report



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This artwork was designed and produced by Gubbi Gubbi and Githabul artist, Shauna Hill for The Social Deck.

Acknowledgement of Country

The Social deck wrote this report on the unceded lands of First Nations peoples. We acknowledge the Traditional Custodians, who have lived on and cared for Country for thousands of generations, and recognise their continuing connection to land, waters and community. We pay our respects to them and their cultures, and to Elders past and present.

Language used in this report

We use the terms ‘First Nations people’, ‘Aboriginal and Torres Strait Islander peoples’ and ‘mob’ in this report. We understand that every mob is different and there are a range of nations, cultures and languages across mainland Australia and throughout the Torres Strait. We use these terms with respect.

Contents

Recognition

The Department of Social Services and The Social Deck would like to thank the following organisations and their staff for their help and support in bringing Mob together for yarning circles:

- East Arnhem Kids Hub
- SSI – First Nations Reference Group
- Far North Community Services
- Moonaboola Community Development Aboriginal and Torres Strait Islander Corporation
- Soward Consultancy
- Goorroomba Consultancy

Introduction

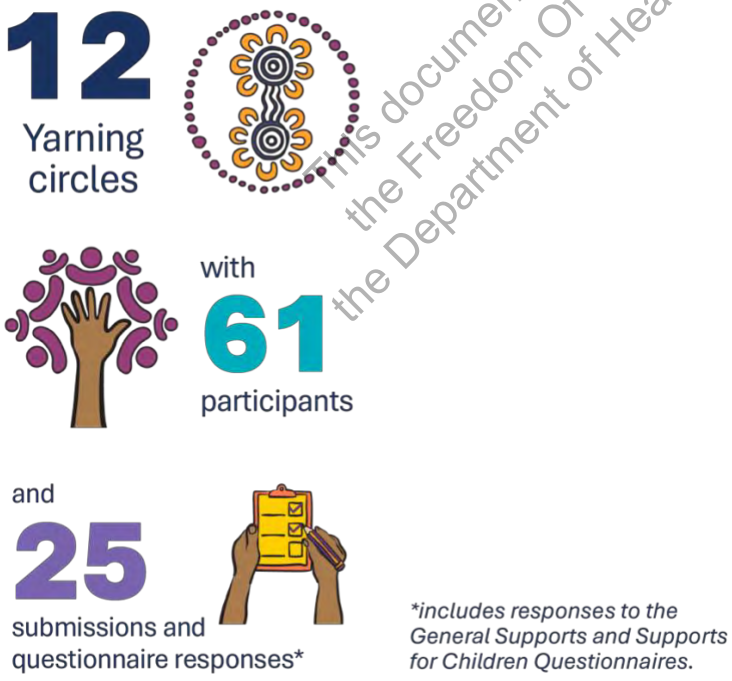
This report summarises consultations with First Nations communities about foundational supports for people with disability and their families. The feedback from yarning circles is mostly focused on general supports which include information, advice and referrals, and capacity building for individuals, families and community. Some conversations also included a focus on Targeted Supports for children with developmental delay, concern and/or disability and their families, carers and kin.

We drew the information contained in this report from what people told us at events and from submissions and questionnaire responses submitted by First Nations people and organisations.

These were initial consultations to help design general supports and supports for children with developmental delay, concern and/or disability. There is a need for co-design and additional engagement with First Nations people in communities to design the specific supports needed relevant to different cultures and locations. A community-led approach will help to support self-determination, and governance is in place for the delivery of foundational supports. It will allow mob to work WITH mob and FOR mob in an effort to address the National Agreement on Closing the Gap measures.

This report accompanies the full **Consultation Report on General Supports** and the **Consultation Report on Targeted Supports for Children under 9,** which include more detail.

Who and how we engaged



From September to November 2024, The Social Deck organised 12 yarning circles with Aboriginal and Torres Strait Islander peoples, and national, state and local organisations who support them. Yarning circles are the preferred method of engagement with communities and participants. Story-telling and truth-telling are important concepts in Aboriginal and Torres Strait

Islander culture, so engaging with participants in this way encourages genuine and active engagement in a safe and trusted space.

Yarning circles occurred in both face to face and online settings and included representation from First Nations people in:

- Nhulunbuy – Gove Peninsular (Northern Territory)
- Alice Springs (Northern Territory)
- Campbelltown (New South Wales)
- Maryborough (Queensland)
- The Kimberley (Western Australia)
- Canberra (ACT)

Participants from different regions across the country took part in 3 of the online yarning circles. A breakdown of engagement in yarning circles is available at appendix B.

Wodi Wodi woman, Vikki McIntyre from The Social Deck, facilitated most of the yarns, with the active help and participation of Aboriginal and Torres Strait Islander organisations within the communities. Some discussions were led by local Aboriginal facilitators.

Areas of discussion

Participants yarned about:

- **Existing Supports** - supports that work well for mob, and what doesn't work well.
- **Information, advice and referral** - getting good information and advice about disability and information on disability supports for mob and their families/carers and kin, including how to get help to find and connect with the right supports.
- **Individual and family capacity building –** areas such as peer support and self-advocacy, education, rights awareness, decision making, leadership, relationship building and life skills.
- **Community capacity building** - building the capability of community and non-government organisations to deliver services that are inclusive and accessible. It included providing advice and resources that support equal access to good and inclusive community services for mob with disability.
- **Targeted supports for children 0-9 years,** covering:
  - capacity building for families and caregivers of children with developmental concerns and disability
  - getting good information and advice
  - types of additional supports needed
  - trusted services
- **Quality and safety** - What we need to think about to make sure extra supports outside of the NDIS are good quality and keep our mob safe?

NB. Targeted supports and quality and safety were only included as topics in engagement depending on location and audience.

Summary of identified themes

This report highlights the urgent need for foundational supports tailored to the unique challenges experienced by First Nations people and communities. Supports must prioritise cultural safety, accessibility, and collaboration with First Nations organisations and communities. This will ensure better outcomes for mob with disability and their families. Participants called for urgent action to address existing gaps and empower communities to implement and lead solutions that are:

→ culturally appropriate
→ culturally safe
→ easily accessible
→ First Nations centred

In yarning about solutions for these challenges, Aboriginal and Torres Strait Islander peoples identified these key findings:

Limited effective supports:
→ Existing services are scattered and often inaccessible, especially in remote areas.
→ Long wait times and lack of culturally safe options deter mob from engaging with supports.

Access to information and advice
→ Communities face difficulty navigating fragmented systems.
→ Language and transport barriers exacerbate access challenges.

Individual and family capacity building
→ Individuals need peer support, life skills training, and advocacy resources.
→ Families require culturally relevant parenting workshops and leadership training.

Community capacity building
→ Services must integrate cultural competence and infrastructure upgrades.
→ Collaboration across service providers is essential to reduce fragmentation.

Targeted supports for children 0–9 years
→ Early intervention services are critically lacking in remote areas.
→ Tailored hubs could provide therapy, developmental monitoring, and parent training.

Quality and safety concerns
→ Workforce development is essential to ensure culturally safe and high-quality services.
→ Certification for accessible venues could improve trust and usability.

Other considerations
→ The **need for self-determination**
→ Changes to the justice system to account for disability and cultural needs.
→ The need for adequate **funding, staffing and training for Aboriginal community controlled organisations** to reach out directly into communities in ways that are culturally safe and effective.

Engagement insights & findings

General supports

Existing supports

There are broad systemic challenges faced by Aboriginal and Torres Strait Islander peoples in accessing existing supports, preventing them receiving timely and effective support.

Across all First Nations engagement, it was rare to get a positive response from participants when talking about current supports. When there was mention of a service or support that works well, this was generally followed by 'however' or 'but' and an existing drawback or challenge.

Participants specifically talked about:

- long wait times
- a lack of awareness of available supports
- a lack of cultural sensitivity
- insufficient funding
- bureaucratic complexities
- transport issues

'There is not really anything that works WELL for mob now...' – ***Participant, Alice Springs***

Story

A participant in the Alice Springs yarning circle, came from a remote Homelands community and regularly travels over 400 kms to access his current disability support service face to face. He generally tries to tie these visits in with other medical appointments, but these can be few and far between and not necessarily in Alice Springs.

While there is a large Aboriginal Health Service (AHS) in his community and within the local Alice Springs area, these services focus on treating and supporting Aboriginal people with prevalent chronic diseases and illnesses like kidney disease, diabetes and rheumatic fever. This means there is a large gap in services for anyone who has other disabilities as the AHS are not funded, resourced or trained to support them.

Most existing services are not First Nations specific and mob are reluctant to ask for help from services they aren't familiar with. In addition, existing services are often difficult to access, particularly for mob in rural and remote areas.

> *'The lack of resources in rural areas means we have to travel great distances in order to access services. There is almost no public transport. So this is a big expense and burden.'* – ***Individual respondent, general support questionnaire***

The lack of culturally safe options, together with long wait times, deter mob from engaging with supports. Many said they 'gave up' because they were frustrated, confused or felt disrespected.

Stakeholders also said barriers to accessing supports often stem from **systemic racism and a general distrust of government and non-Indigenous organisations**. Current disability and some community systems and supports are set up in a way which disadvantages First Nations people when their culture, language and connection to Country is not reflected.

Some stakeholders felt they were 'set up to fail' with a **lack of sufficient funding and resourcing**. They talked about the 'inevitable change of government', changing priorities and the withdrawal of existing funding being a consequence. In addition, the inability to adjust policy and processes to better address the needs of First Nations people with disability, and their families, is frustrating and unhelpful.

> *'there needs to be committed and adequate funding provided to Aboriginal and Torres Strait Islander disability services to ensure they can meet demand in a culturally responsive and safe manner '* – ***Submission***

A lack of long-term funding also impacts local organisations' abilities to engage and keep local workers. Some participants suggested funding be delivered differently in First Nations communities to increase supports and help strengthen local service delivery.

> *'Put funding in to create businesses so there are workers to actually be had, instead of companies having not enough staff '* – ***Individual respondent, general supports questionnaire***

Information, advice and referral

Mob find it difficult to navigate what they see as the existing fragmented systems and bureaucratic processes in the disability support space. Often, the participants we spoke to were unfamiliar with the services and supports that may be available to them and, in some cases, are steered away from non-Indigenous supports to specific First Nations organisations.

Participants said this happened due to the misconception by non-Indigenous organisations that mob 'get funding for everything' so all Aboriginal and Torres Strait Islander organisations are able to help them. This is not often the case as these organisations are not resourced, funded or equipped to support people with disability.

> *'These ways result in engagement and delivery disconnect when interacting with colonial systems as these systems are not designed to support Aboriginal and Torres Strait Islander people.' – **Submission***

Language barriers exacerbate access challenges, especially in rural and remote areas. For those who don't have English as their first language or with literacy challenges, the sometimes complex information around disability and available supports can be difficult to understand. In addition, existing information is rarely translated into Aboriginal languages, is not effectively shared or not disseminated at all.

> *'...good information and advice from the government and service providers about what supports are available and how to access them are not disseminated effectively to the community, as information is being provided by multiple bodies, in multiple formats.' – **Submission***

Mob can feel uncomfortable or fearful approaching non-Indigenous services, especially where they are not known. Culturally, 'shame' plays a big part in Aboriginal and Torres Strait Islander culture and prevents many from making an approach to ask for help. They want their information and advice to come from **known and trusted sources within the community and prefer it delivered face to face.** However, organisations trusted by mob do not necessarily have referral processes, information or advice for people with disability, within their remit.

> *'I'd wanna [sic] have a place where I could go straight to. That's culturally safe. That's run by blackfellas that I can walk in and I can say I'm struggling. It's hard.' – Participant, ACT*

Story

A participant in the online yarns, from metro Sydney, related how he had taken some time to convince himself to call a non-Indigenous service and ask for help. He only did this because he was not aware of a specific Aboriginal service in his area that could help him with his issue. He had a long wait before being able to talk to someone on the phone and when he eventually spoke to a worker, he was told someone would get back to him about his particular issue. He never heard back from them and was 'too shame' to approach them again.

> *'I'm not going to beg for their help if they don't want to help me' – **Online participant***

Individual and family capacity building

In every yarning circle there was a call for individual peer support, life skills training, and advocacy education and resources. Without exception, however, participants stressed the success of building capacity for both individuals and families would only be achieved if delivered **'by mob for mob'**. The need for cultural safety, awareness and for trust within the families and the community, is considered paramount, as the general consensus among mob is **culture comes before disability.**

For families

Participants said families require culturally relevant parenting workshops, peer support and leadership training. Having these types of supports would give families the tools they need to be more effective in managing the challenges they may encounter while supporting their loved ones with disability. Mob spoke about the need to have mentors, peers and leaders who understand the dynamics of First Nations communities and families to ensure effective outcomes.

The way these programs are delivered needs to meet the needs of families who are in different circumstances, including having options for one-to-one capacity building and access to group programs.

Some mob raised concerns about the ability of single parent families to access capacity building services due to their circumstances. There is a belief those who are less financially 'well off' and who may have more complex challenges, are missing out on supports in favour of those in better circumstances.

> *'Mother capacity building - single parent disability families need A LOT more financial and social support - make an adversity scoring and triage via adversity. Those that are most disadvantaged are missing out to richer, easier families to support.'* – *Individual response, general supports questionnaire*

For individuals

For individuals, mob yarned about the lack of education around what is available in terms of supports and the lack of training around simple life skills or the support for families and communities to fill the roles of trainers and educators for people with disability, especially in rural and remote communities where services are almost non-existent.

> *'Educating educators and having consistent guidelines on care and supports across the state and country.'* – *Individual response, supports for children questionnaire*

Advocacy and self-advocacy

There is a little awareness of advocacy services or what advocacy is or can achieve. The complex kinship systems in Aboriginal and Torres Strait Islander cultures also mean there can be many potential advocates who are not directly related to a person but are seen as the spokesperson for the family. Therefore, there is an urgent need for individuals and their families and carers to be educated about advocacy and self-advocacy services. Specifically:

- what they are
- how they can help
- how to access them.

> *'I think it's [advocacy] definitely a big area of need that's not well supported or not really known about in the region.' – **Participant, Nhulunbuy***

Community capacity building

The most frequent response to questions asked about community capacity building was the need to institute cultural competence and awareness training for all staff and volunteers in community organisations who deal with First Nations people. Again, this was deemed a priority but should go hand in hand with more disability awareness training on a broad scale (include ALL forms of disability.)

Community organisations need to understand the intersectional challenges that mob with disability face. This could be achieved through more thorough cultural awareness training that encompasses truth-telling and focuses on the causes of intergenerational trauma, introduced diseases and systemic racism.

> *'Outreach support, a lot of people we meet, a referral and information service isn't what they need. They have broken relationships or fallen on hard times, information services just don't really do much, but outreach programs like what TJ does meet the person where they're at and follow up with them to help them continue to attend the services. Cross sectoral and holistic approach to helping people.' – **Participant, Kimberley***

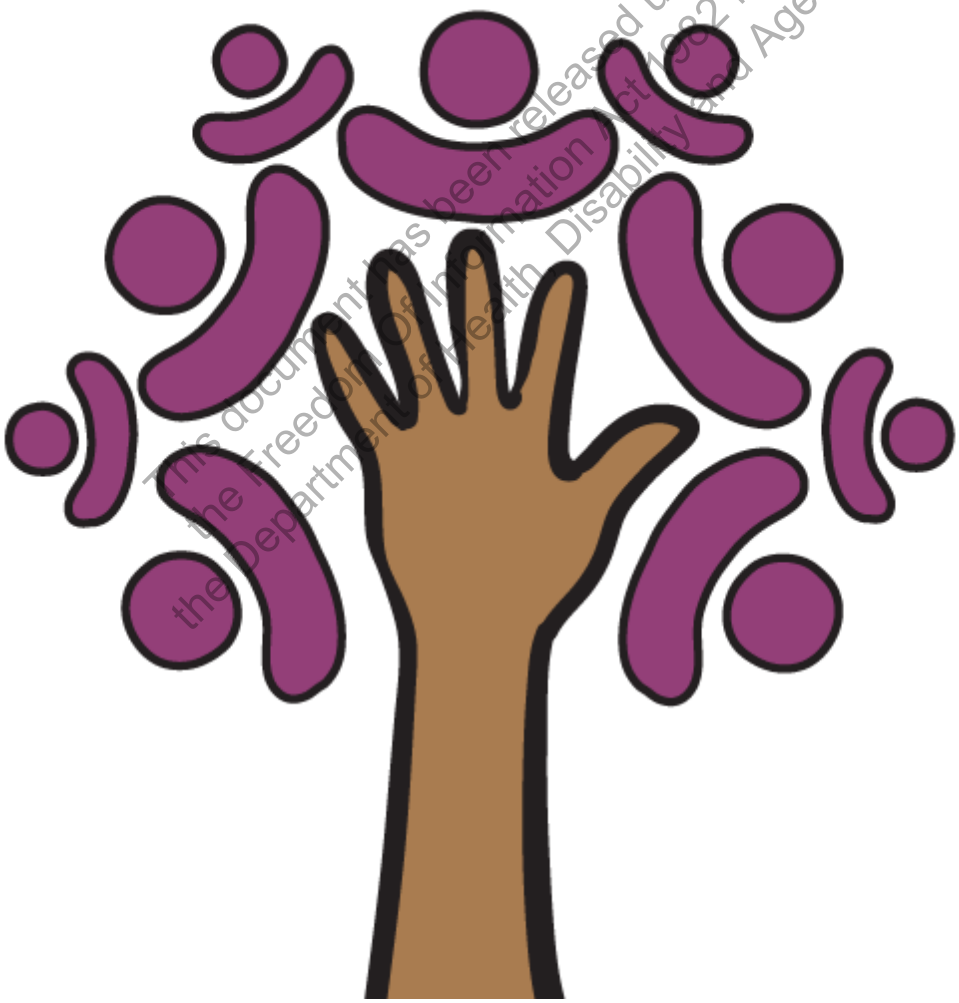
In addition, participants talked about non-Indigenous organisations often steering mob away from their services because they feel ill equipped, or they are 'not inclined to help us'. In some circumstances, participants were aware of non-Indigenous services receiving a portion of their funding that is specifically meant to cover First Nations support but they do not see the organisations putting those funds to use in supporting Aboriginal and Torres Strait Islander peoples with disability.

*'Mainstream services need to be held accountable for the Aboriginal and Torres Strait Islander funding they receive. Better yet, this funding would be better suited going to Aboriginal services that are providing culturally responsive and safe support for our mob'. – **Submission***

Participants talked about accessibility issues when visiting community organisations and services and said infrastructure upgrades are needed to make all buildings physically accessible.

In addition, mob talked about the lack of cohesion between different services. There is frustration they have to 'shop around' service providers in order to find the correct supports for themselves or their family members. Collaboration across service providers would help to reduce this fragmentation.

*'We need blak fullas who understand us. And we need one place for everything. We need all the different things in one place instead of going to all different places.' – **Participant, Kimberley***



Targeted supports for children under 9 years

Governments are working on the design of targeted supports for children under 9 years old who have developmental delay or concern. Some of the yarns focused on the kinds of targeted supports that might be needed and what else should be considered about supports for young children and their families.

Many participants called for further detailed consultation and co-design to take place in relation to targeted supports for First Nations children, given the very real gaps that exist in the health and treatment options between them and the rest of the Australian population.

Early intervention

Participants talked about the importance of targeted supports so children with developmental delays or disability do not 'fall through the gaps.' This includes a focus on diagnostic, monitoring development, and therapies for identified conditions.

> *'Our kids are falling through the gaps, and they're not getting the help that they need. That early intervention process needs to happen.' – Participant, Maryborough*

Early intervention tailored to the needs of Aboriginal and Torres Strait Islander children was seen as a critical service that would have a major impact on reducing reliance on more intensive services being needed. But some community and other organisations suggested early intervention services are critically lacking in most areas, and specific disability services tailored for First Nations children are almost non-existent, despite the high rates of development delay and health conditions First Nations children experience.

> *'the high rates of developmental vulnerability, preventable developmental conditions and disabilities among Aboriginal and Torres Strait Islander children and adults indicates decades of missed opportunities for early assessment, identification and provision of developmental supports. In many cases, this is the result of inaccessible or non-existent early years services where people live; [sic] market failures of universal service systems. It is essential that the foundational supports system does not mirror these failures.' – Submission*

Capacity building for parents and carers

In line with family capacity building, mob want to see programs to empower parents and caregivers with the knowledge and skills to identify and address developmental delays early. This would empower parents/carers with the knowledge and ability to identify development delay in their children before early learning commences.

As noted under family capacity building, the way these programs are delivered must suit the needs of different families. Many families will not have other care arrangements or respite options for their young children so they can attend parenting programs. One-to-one capacity building supports may be important to help address this but should be combined with local supports that help to build connections between parents and community.

Use of community controlled organisations in service delivery

Participants have suggested that local Aboriginal Medical Services (AMS) and other types of community controlled organisations be funded and resourced to deliver specific health and community services for children. Overwhelmingly, participants said the AMS was their preferred

way to seek advice about any health issues and these organisations receive a high level of trust and respect in the community.

> *'The aboriginal health service is a single point of contact for all services and supports but has resourcing issues resulting in huge waitlists.' – **Individual respondent, supports for children questionnaire***

> *'telling the aboriginal medical centre helps because they know our mob' – **Individual respondent, supports for children questionnaire***

Participants also stressed the need for cultural exposure and connection to identity for children who live with, or are fostered by, non-Indigenous families. There is concern fostered Aboriginal and Torres Strait Islander children are losing touch with kin, culture and their country because non-Indigenous foster families don't understand the need for children to have these connections. Mob want to see a holistic approach that prioritises cultural identity alongside developmental needs.

> *'have family support workers and aboriginal health workers in mainstream general practice.... the town/area I live in has a [First Nations] population of 9.8%, however there is NOT ONE Aboriginal Health, Family Support or Occupational therapist accessible through GPs in the town.' – **Individual respondent, supports for children questionnaire***

While in many comments block funding wasn't preferred, (it was seen to preference larger organisations rather than community-controlled or local community organisations), a few stakeholders suggested it will be needed to sustain early intervention programs that are integrated with other types of services (e.g. through schools and early childhood), particularly in regional and rural areas.

> *'some block funded supports is what is needed .....to support individuals to get that early intervention and then hopefully not need ongoing services' – **Participant, Nhulunbuy***

Implementation, quality and safety

Ensuring quality and safety in foundational supports was a central concern, with a particular focus on workforce development and 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.

Participants also discussed the value of safe physical environments, including accessible venues that reflect cultural considerations. They highlighted the importance of services maintaining strict quality assurance frameworks so supports provided outside of the NDIS are reliable and deliver the desired outcomes.

When yarning with First Nations stakeholders, concerns were raised about how foundational supports will be implemented and whether it would be based on large grants or tenders. They noted that larger block funding can disadvantage smaller Aboriginal and Torres Strait Islander organisations who are unable to compete with the larger, mainstream services.

Stakeholders suggested that this may not support community-led and community-controlled approaches that are critical to effective service delivery in First Nations communities.

Other considerations

In the justice system

Concern was raised around the inability of the criminal justice system to evaluate and treat mob with disability or take these into account. This issue is one of many intersectional challenges that face mob with disability. This extends to child safety and the juvenile justice system where children with often undiagnosed disability, particularly with conditions like Foetal Alcohol Syndrome Disorder (FASD), are constantly shifted around locations, families and institutions without ever being given the treatment or support they require to become well-functioning members of the community.

'Lack of culturally responsive and safe disability services and racist stereotypes are not acceptable reasons to incarcerate our mob.' – ***Submission***

Self-determination and community-controlled

The need for self-determination and making sure there is adequate funding, staffing and training for Aboriginal and Torres Strait Islander controlled organisations to reach out directly into communities in ways that are culturally safe and effective would enhance the effectiveness of foundational supports. Participants underlined how self-determination, advocating for increased funding and resources for Aboriginal and Torres Strait Islander controlled organisations could help in leading community-focused initiatives. Empowering First Nations organisations with adequate staffing and training was seen as a vital step to ensure culturally safe and effective outreach into communities.

Collaboration

Mob also spoke about the need for inter-agency collaboration. They called for improved integration between sectors such as justice, health, and education to address systemic gaps.

'Government departments fight against each other... Education fights against health, saying, "It's your problem." Health fights against NDIS, saying, "That's your problem'' and then this child's in the middle, not getting any services.' – ***Participant, Nhulunbuy***

Addressing intergenerational trauma and systemic racism through culturally grounded programs and outreach is essential, and this requires a whole of system response. Truth-telling, along with intersectional and cross-cultural training for all service providers would strengthen relationships and foster trust.

Summary of community suggestions

Disability hubs

Participants overwhelmingly supported a hub model, with a 'no wrong door' approach, to simplify access and reduce fragmentation of services. These hubs should provide a centralised space for disability support, education and advocacy, while also serving as a trusted point of contact for families and individuals. Tailored hubs could provide diagnosis, therapy, developmental monitoring, and parent training. A suggestion was made to **base these hubs on the NT Disability Hub model** that existed before the NDIS was implemented.

In the absence of a physical hub, mob called for **a dedicated phone number** where they could ring and speak to another Aboriginal and/or Torres Strait Islander person to give them the correct information and advice or refer them to a service. They suggested mob with disability could also staff this service as it would not be contingent on physical location and First Nations staff with lived experience of the intersectional challenges are best placed for these roles.

> *'Rather than a hub being just a physical place, if that can't be done, the next best option is to have a 1300 number staffed by First Nations people.' – Participant, Maryborough*

Workforce development

Employing and training mob with lived experience to deliver supports and provide mentoring. In addition, non-Indigenous services should be required to deliver and maintain **training on cultural and intersectional competencies** to ensure services are safe and responsive.

> *'take some black people with disability on and skill them up. They've got lived experience. Who better to be the people that are then you know, talking to other mob with disability and you know, giving them advice, giving them referrals?' – Participant, ACT*

Suggestions also included **developing a certification process** to assure mob that organisations were Aboriginal and Torres Strait Islander friendly. This would allay fear and mistrust and give mob confidence to approach non-Indigenous services in the absence of First Nations specific services.

> *'Service providers of foundational supports need to invest in cultural training so staff develop organisational and individual capacity to deliver culturally responsive and safe supports, and build community trust in services.' – Submission*

Holistic education for individuals and families

Supporting individuals and families with disability education programs that place cultural identity and connection at the forefront is vital for cultural and personal safety. Many First Nations families do not recognise disability in the same way as non-Indigenous families. This means those services are not fit for purpose when it comes to educating First Nations people with disability, their families and their communities.

'In our communities, the concept of disability does not exist. Instead of stereotypically categorising people as different or disabled, our people are taken as they are.' – *Submission*

Adequate funding

Dedicated and sustainable funding to enable Aboriginal and Torres Strait Islander-controlled organisations to meet demand in a culturally appropriate manner. Participants talked about the frustrations of having funding that is not sustained for any length of time and prevents real and successful outcomes.

'Community are sceptical about the new foundational supports services being adequately funded due to previous experience with funding being pulled from the services providing the needed support to our mob' – *Submission*

Cultural exposure

Providing cultural exposure and training for non-Indigenous foster carers, workers, and families engaging with First Nations children, would give children with disability and/or developmental delay, a connection to their heritage and enable them to feel included and safe in unfamiliar surroundings.

These recommendations reflect the priorities of Aboriginal and Torres Strait Islander communities to create a system of foundational supports that are culturally safe, accessible, and community-led.

'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*

Appendix A: Engagement methods

Yarning circles

The Social Deck engaged with First Nations people through informal discussion groups in the form of yarning circles. Yarning circles are used to collect information through establishing a relationship with First Nations participants prior to gathering their stories through their own storytelling.

Yarning circles are a culturally appropriate and safe way to engage with Aboriginal and Torres Strait Islander peoples. They create a more comfortable space for people to be able to speak openly and honestly with those who are not from their community. This is especially relevant given the inherent lack of trust some people may feel towards government institutions and their agents.

Yarning has its own protocols that go hand in hand with other conventions and practices when engaging with First Nations people. For each yarning circle, our First Nations consultant reached out to trusted community members or local organisations to get advice on community protocols. We invited trusted community members or organisations to be present to help with the yarning circles.

Each yarning circle was different and developed with relevant local leaders and organisations. Based on their advice for each location, the consultation may have focused on particular topics or deliberately avoided certain areas of discussion.

Participants

The yarning circles drew participants directly from the community. Local Aboriginal organisations were instrumental in helping to distribute information about the yarns and provided advice and guidance on where and when the yarns should take place.

Participants included those with disability, carers and family of people with disability and stakeholders from within local Aboriginal organisations.

All states and territories were represented and included participants from metro, regional and remote areas.

Submissions and questionnaire data

Information in this report has also drawn from submission and questionnaire data submitted from various First Nations organisations and survey answers where the respondents identified themselves as being Aboriginal and/or Torres Strait Islander.

Appendix B: Participation data

Face to face and online events

State	Location	Event date	Partner	Attendees
NT	Alice Springs	29/10/2024	Disability Advocacy Service	4
NSW	Online	13/11/2024	SSI – First Nations Reference Group	5
NT	Nhulunbuy	14/11/2024	East Arnhem Kids Hub	2
ACT	Weston	19/11/2024	Soward Consulting	8
ACT	Ainslie	19/11/2024	Soward Consulting	1
National	Online	25/11/2024	Recruited	6
National	Online	26/11/2024	Recruited	6
QLD	Maryborough	27/11/2024 - AM	Moonaboola Aboriginal Corporation	2
QLD	Maryborough	27/11/2024 - PM	Moonaboola Aboriginal Corporation	13
National	Online	28/11/2024	Recruited	7
WA	Kimberley	November	Goorroomba	7

Submissions and questionnaire responses

	No.
Submissions and responses to the questionnaire	25

Foundational Supports

General Supports Consultation Report

The SOCIAL DECK

Contents

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:

- Jane Britt (multiple locations and online roundtables)
- Amanda Lawrie-Jones, Accessible Action (online and WA)
- Samantha Jenkinson (WA and webinar)
- Tricia Malowney (Melbourne)
- Heidi La Paglia (Tasmania and online roundtables)
- Belle Owen, Purple Orange (South Australia)
- Dr George Taleporos (webinar)

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

LGBTIQA+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 verse 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.

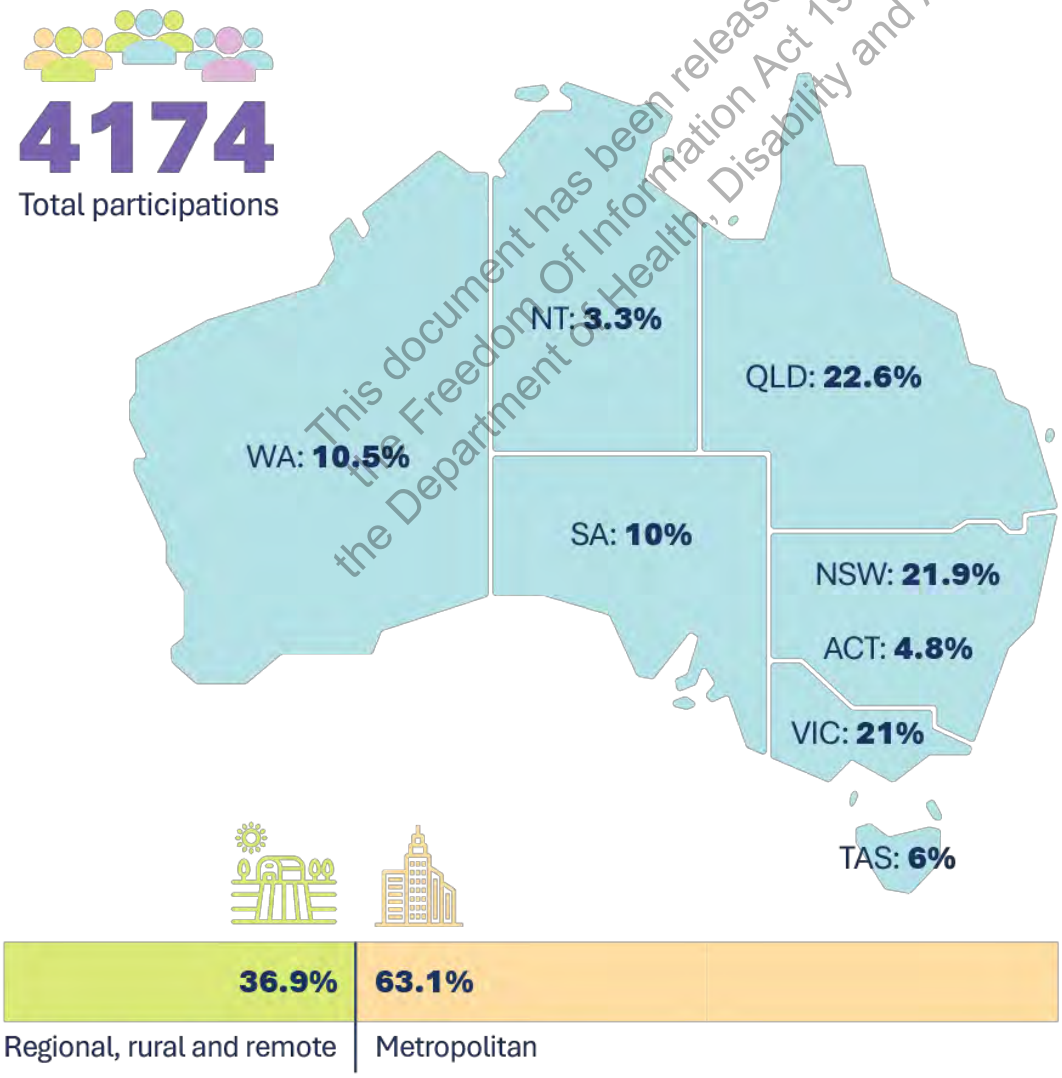


Figure 1: Total participations, and percentages across states and territories, and location.

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%) *.

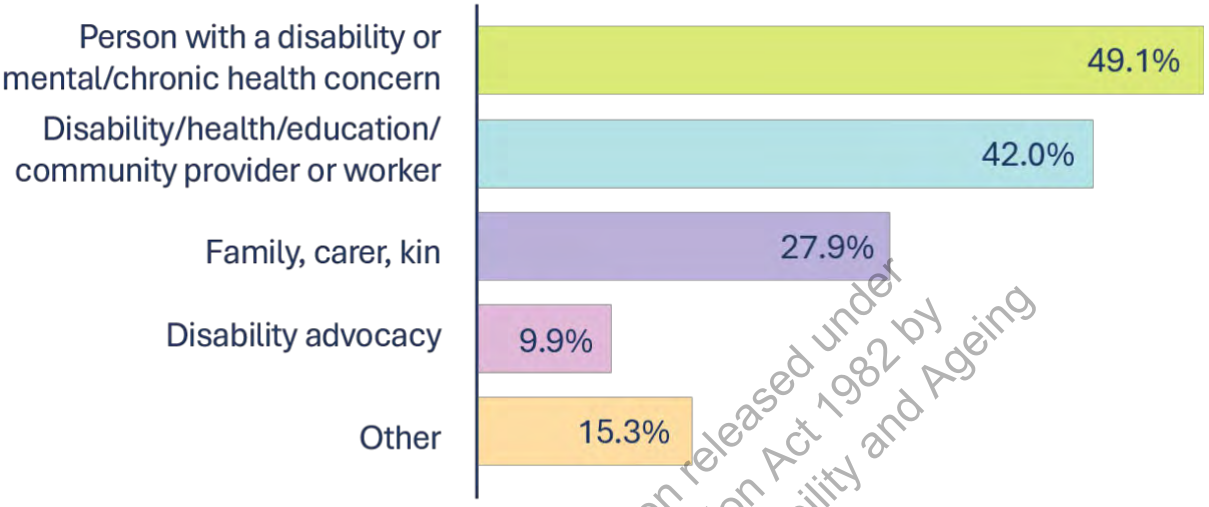


Figure 2: Participation percentages across interest groups

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 LGBTIQA+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:

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.

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[1]. 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.

[1] A joint submission from Disability Representative Organisations, 12 December 2024, https://www.dana.org.au/wp-content/uploads/2024/12/DRO-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[2] 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

[2] 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.

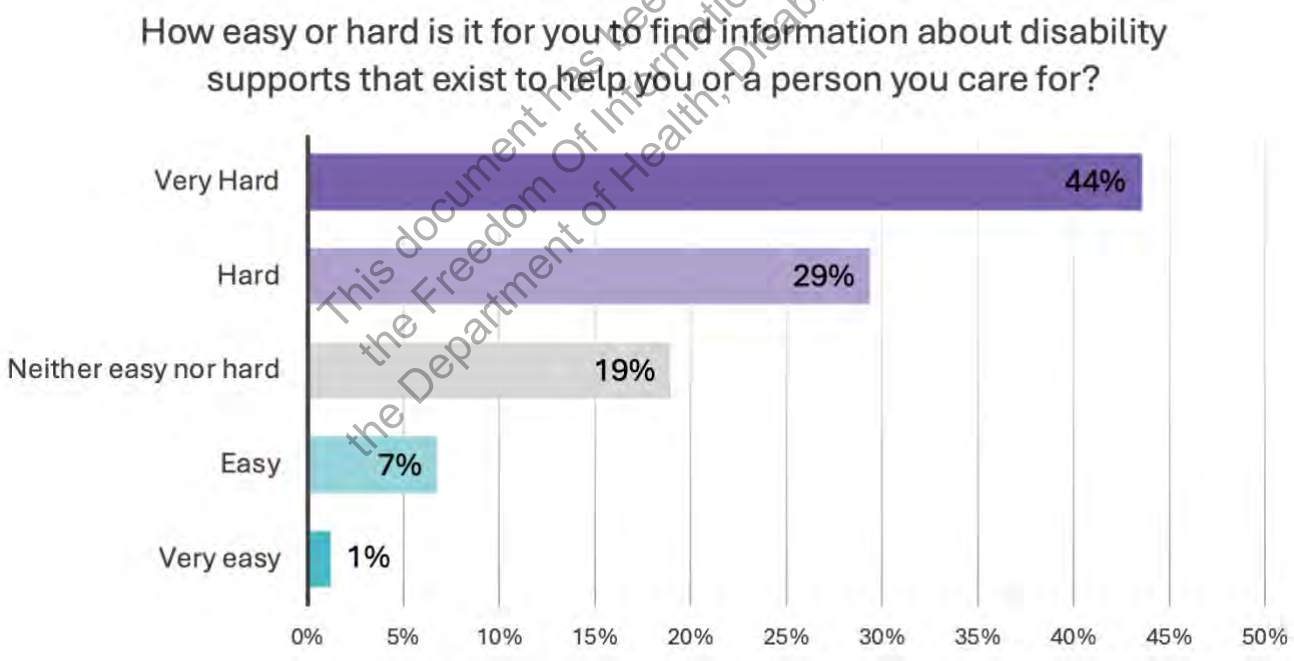


Figure 4: How easy or hard it is for people to find information about disability supports (n=500)

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).

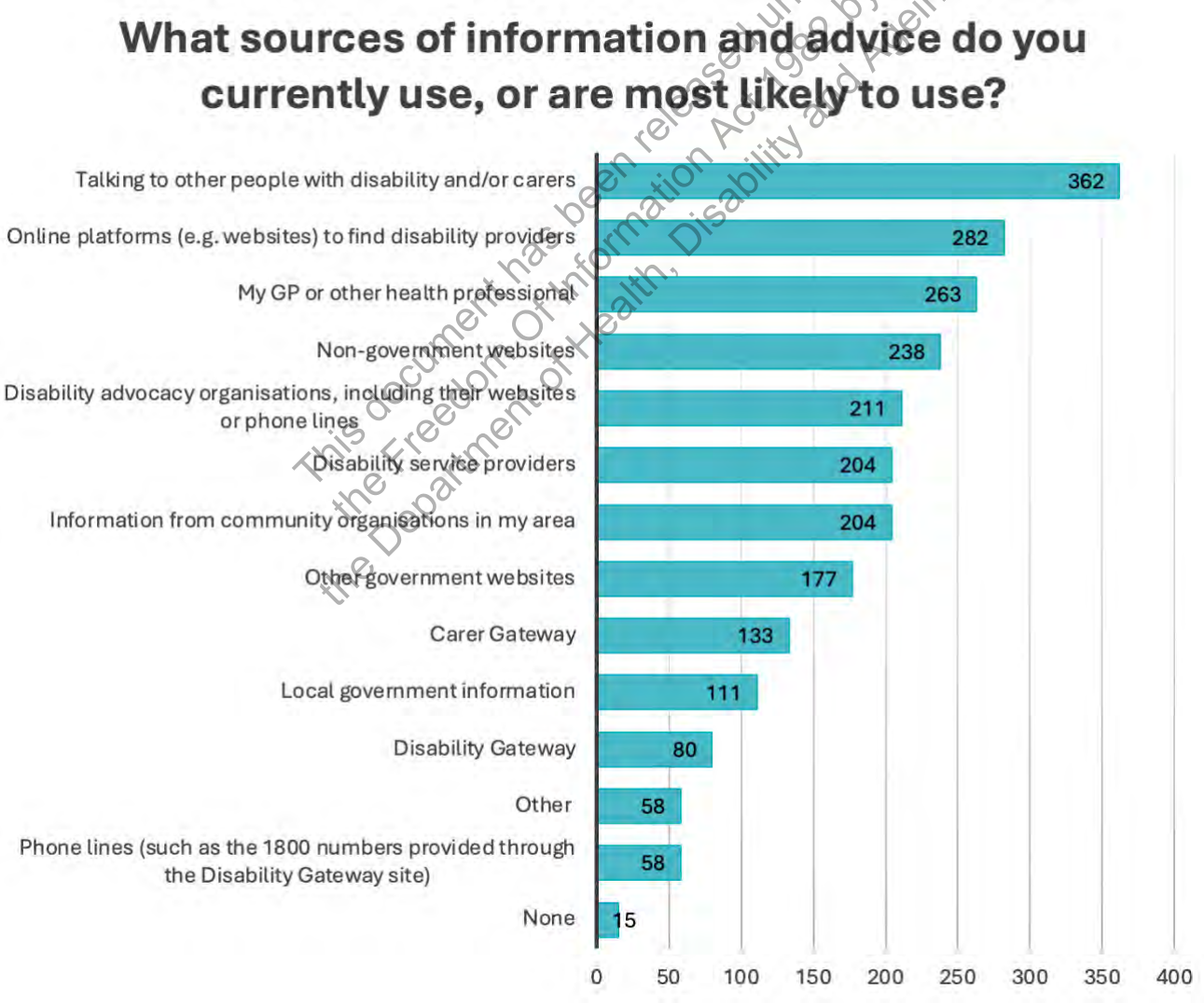


Figure 5: Sources of information and advice currently used or most likely to be used (n = 500)

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 LGBTIQA+ 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 LGBTIQA+ 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 LGBTIQA+ people with disability

People with disability who are LGBTIQA+ 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 LGBTIQA+ community in the organisation
- whether there are staff trained within the organisation to support LGBTIQA+ 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 LGBTIQA+ 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 LGBTIQA+ 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 LGBTIQA+ people.

> *'Having options to find providers who are knowledgeable and non-judgemental of LGBTIQA+ 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

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 for 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 LGBTIQA+ 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 LGBTIQA+ 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

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 'siloing'**. 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 or 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 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

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 reprise) 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, LGBTIQA+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 indictors 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.

Foundational Supports

Supports for Children under 9
Consultation Report

The SOCIAL DECK

Contents

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 and present 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

Any reference to **parents, carers and families** in this report is intended to include the diversity of people who fulfil these important relationship roles for the children in their lives, including biological and adoptive mothers and fathers, LGBTIQA+ parents, kin / kinship systems, guardians and other carers, and extended family members (and many combinations of these).

When we refer to **stakeholders**, we are referring to the whole range of organisations, professionals and experts who contributed to the consultation process.

Throughout this report we use the term 'developmental delay' and 'developmental concern'. When young children are slower to develop physical, emotional, social, communication or thinking skills than expected (beyond usual differences in development between children of the same age), it's called **developmental delay**. Developmental delay can be identified in the way children move, communicate, think and learn, or behave with others. **Developmental concern** is where someone identifies there may be a difference in development and are not sure if it is significant and there is no diagnosis.

We know people use different words to talk about disability and each person has 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 paper 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 as part of the consultations informing this report. Thank you to the hundreds of people with disability, their families and communities, as well as other stakeholders, who gave their time and shared their experiences and ideas.

A special thank you to the following partners who facilitated or coordinated events, and without whom the consultations would not be possible.

Partner organisations and individuals who led or coordinated engagement activity specific to the support for children consultations:

- Kindred
- Association for Children with a Disability (ACD)
- Kiind
- The Child and Family Disability Alliance (CAFDA)
- Soward Consultancy (First Nations engagement)
- Australian Autism Alliance
- Broome Youth and Families Hub (WA)
- East Arnhem Kids Hub (NT)
- National Ethnic Disability Alliance (NEDA)
- Different Journeys (VIC)
- Heidi La Paglia (Online workshop)

Foundational supports and scope of consultations

This report is about the design and delivery of foundational supports for children under 9 with developmental concern, delay and/or disability and their families, carers and kin.

Foundational supports are specific supports that are 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.

Scope of consultation and this report

This report includes consultation insights about both general and targeted supports for children under 9 and their families, carers and kin. It accompanies the General Supports Consultation Report. Feedback was provided in response to the Consultation Paper on foundational supports for children with developmental concern, delay and/or disability and their families, carers and kin.

It consolidates feedback from community members (mainly families and carers), disability advocates, allied health and other professionals who contributed to the supports for children questionnaire, or participated in dedicated online or in-person events about supports for children with disability, developmental delay and/or concern and their families and carers. Additional insights about general supports, for all people with disability and families and carers, can be found in the General Supports Consultation Report.

This report includes some feedback on areas that go beyond the scope of foundational supports, including the supports for children consultation paper. For example, feedback relating to education and schooling policies, health, mental health, employment and justice. Comments sometimes also focused on areas for change or improvement in the NDIS.

Feedback which is outside of the scope of the foundational supports consultations has been shared with governments but are not a focus of this report.

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

Executive summary

Governments are working together to design and deliver additional supports in the community. These are known as **foundational supports**. They are specific supports that are additional to mainstream services and supports accessed through the NDIS.

During October to December 2024, families, carers and stakeholders were asked to contribute their views on foundational supports for children with developmental concern, delay and/or disability and their families, carers and kin (supports for children).

There are different types of foundational supports. This report covers **general supports (Chapter 1)** and **targeted supports (Chapter 2)** for children, and their families, carers and kin. It also includes considerations about **how they should be delivered (Chapter 3)**.

General supports would be for all children and families, regardless of whether they are in the NDIS. Targeted supports would be for children under 9 with developmental delay and their families who would not be in the NDIS, and need more assistance than mainstream services and general foundational supports.

What we heard

More than 1,000 people provided feedback as part of the consultation process on supports for children. This feedback is in addition to feedback received from families and carers during general supports consultations (refer General Supports Consultation Report).

Families and carers shared their experiences about supporting their children and family in accessing supports. They focused heavily on the need for foundational supports to:

- **support existing programs that are working well**
- **be delivered in natural settings**, trusted places and through trusted organisations
- **prioritise family-centred practice** and ensure supports focus on the whole child and whole family
- **provide access to accessible and timely allied health supports**, delivered by a strong allied health workforce.

Consultations took place at a time of uncertainty for many families. Due to this, feedback about supports focused a lot on issues about access, reassessments and eligibility for the NDIS. Parents and carers specifically shared concerns about losing NDIS supports for their children and wanted to better understand **how the NDIS and targeted supports outside of the NDIS would work together**. While we acknowledge this feedback, this report doesn't cover many of the areas specific to concerns about eligibility or assessments for the NDIS.

The feedback has been shared with governments.

What will be most helpful

Common types of supports that families and carers said would be helpful in foundational supports for children and families, carers and kin included.

One-to-one advice and referrals through allied health and multidisciplinary teams

Allied health supports were the most common type of support families and carers mentioned their child and family would need to help them build skills and capacity, including to connect with other services and supports.

When it came to capacity building and providing direct supports to children, families reiterated the importance of integrated and multidisciplinary teams across allied health, other health and education.

Local peer, family and support groups

Families and carers spoke about the importance of having peer support groups to get advice from other parents and carers, particularly those who may be further ahead in their journey to access supports. This included playgroups which also provide children with direct supports and opportunities to build social connections and skills.

Families particularly focused on support groups being available in their state or region, as they understand what is available locally and can provide the most relevant information and advice.

Peer supports also referred to online networks and discussions on platforms such as Facebook.

Parenting programs and education

We heard programs that help to build skills and confidence of parents, families, carers and kin to support their child, and the whole family, are important.

These programs include training, mentoring and tailored resources to provide parents and carers with practical skills to support their children's needs including in areas such as speech and language development and to better communicate with and understand their loved one's experience.

Programs for children, and including families and siblings

We heard programs and services that provide different types of therapies should be an important part of targeted supports for children with developmental delay.

This included **play, art, music and other therapies, as well as sports.**

Consistently parents and carers suggested programs and supports be inclusive of the wider family, in particular siblings, where appropriate.

Culturally safe and relevant supports

Many participants reiterated the importance of having well-funded and sustainable organisations that are locally-based and provide relevant and culturally safe supports to families based on their needs. This included Aboriginal community controlled organisations, faith-based organisations (including churches), ethnic community councils and groups, and support services for people who are LGBTIQA+ are a central part of the foundational supports system for children and their families, carers and kin.

Digital directories of services, with regional networks

Families and carers said digital directories of disability services for young children are important to support foundational supports, including to get access to supports and to find out more information and advice.

There were strong views this should not be an information website, but a directory of what services are available to children, including at a regional level.

What is needed to make foundational supports for children under 9 and their families, carers and kin work

Stakeholders broadly supported the need for a redesigned system for general supports, particularly for improving the funding and commissioning of important disability and family-led advocacy organisations, and information, advice and capacity building programs in community.

Consistent with the General Supports Consultation Report, there was broad agreement family capacity building needs to include longer-term and sustained supports (rather than one-off) and be delivered through a range of ways including place-based and community-led programs.

The need for targeted supports for children with developmental concern, delay and/or disability is also strongly supported, noting there is a critical gap in the current service system providing supports for young children between the NDIS and mainstream services.

Representative organisations (including disability, early childhood, allied health and First Nations organisations) often highlighted the need for supports for children to:

- be **transitional and universal**, so no child falls through the cracks
- be designed and delivered with **longer-term and more flexible funding arrangements** to enable a national approach to sustain programs, while allowing for flexibility to address local community needs
- include **multidisciplinary teams** with key workers or similar models in place to improve the integration of supports across systems and reduce burden on families and carers
- be available to people locally and in regions
- allow for supports to be **delivered through a range of natural settings**, such as schools, early childhood settings and in the home.

Stakeholders also reiterated governments should focus on:

- better explaining foundational supports including clarifying eligibility
- reducing complexities and costs in the assessment processes
- invest to build a sustainable and diverse workforce, including in regional areas, to deliver supports for children and their families.

Note: There weren't a lot of differences between states and territories in relation to general supports or targeted supports for children. Where there are differences between states and territories or geographic regions, these are highlighted in relevant sections of the report.

How and who we engaged

Participation

There were 1,020 participations in the specific consultations on supports for children. Of the total participations, 554 (or 54%) were family, carers or kin of children with disability.

Participations came from every state and territory with 32% from regional, rural and remote areas.

Families and carers, other community members and stakeholders provided feedback through workshops, targeted discussions, submissions and a questionnaire.

We held 21 events online and in-person as part of specific supports for children consultations. Online events were held for each state and territory. Four (4) of the events were yarning circles with Aboriginal and Torres Strait Islander families and stakeholders including in Nhulunbuy (NT), Kimberley (WA) and Canberra (ACT).

Figure 1: Number of events and participations across workshops and discussion

Some of the events with family, carers and kin were with specific population groups such as First Nations families, families from a culturally and linguistically diverse (CALD) background, families with autistic children, and parents of people (including children) with complex and high needs.

There were a total of 573 responses to the questionnaire, with families, carers and kin making up more than 64% of the responses*. An additional 26 respondents provided submissions by email specifically about supports for children.

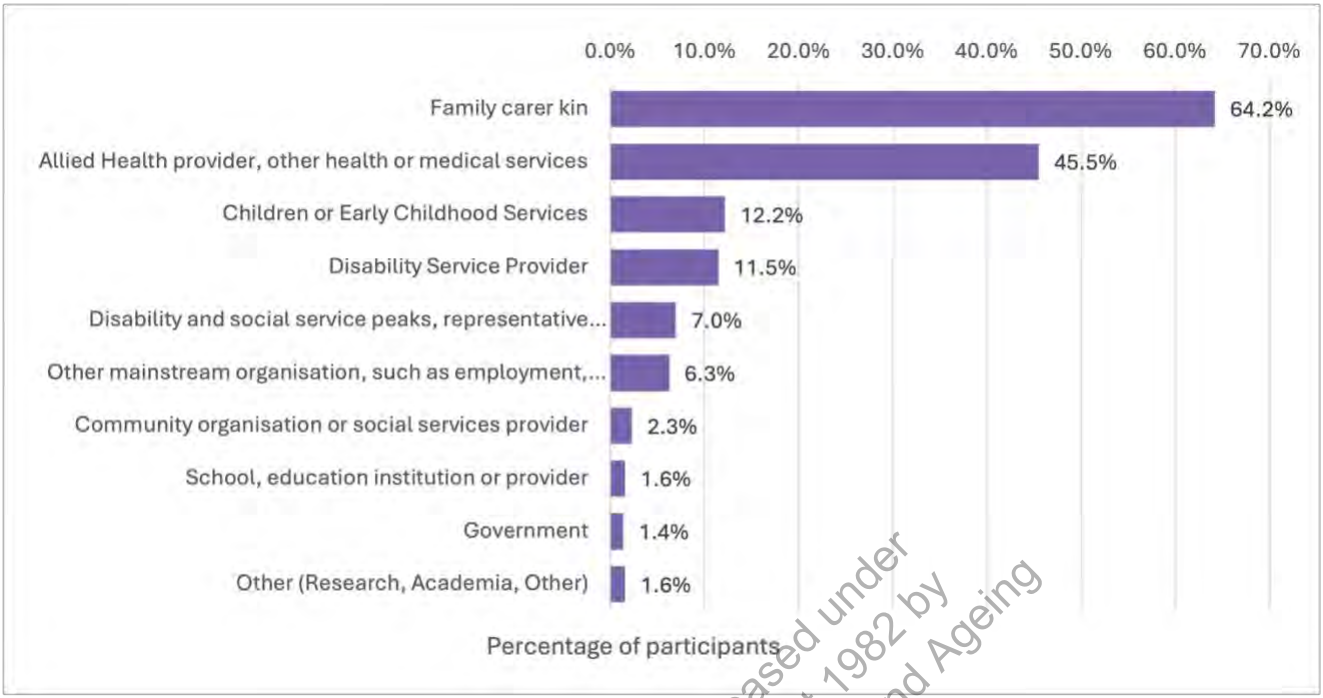


Figure 2: Participation percentages for the online questionnaire and submissions
**Note: Participants could select multiple options*

In addition to the questionnaire and submissions, families, carers, people with disability and other stakeholders contributed to an online Ideas Wall.

This initial phase of consultation did not include specific engagement with children. However, this would be recommended as part of designing specific parts of foundational supports for children in the future.

Engagement content and activities

Methods of engagement were designed to gain qualitative information on key barriers, experiences and ideas to guide development of foundational supports. Engagement activities were focused around 3 areas of discussion:

- **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 the engagements were delivered and analysed is at **Appendix 1**.

Outcomes and considerations

Focus and scope of supports for children

We heard the focus on **targeted supports for children with developmental concern, delay and/or disability** is a positive move, noting this is a critical gap in the current service system. It was noted a pathway to access such supports outside of the NDIS is needed, particularly given the importance of timely and early intervention for children.

Respondents broadly endorsed the focus on supporting families holistically and the vision of children thriving in their families and communities.

> *'It is wonderful to see a focus on providing early childhood intervention to children with developmental delays recommended as part of targeted foundational supports for children and families. We see this as one of the biggest gaps for the existing system and observe this delaying timely intervention for children and families in need.'* – *Submission*

Outcomes

There wasn't a lot of specific feedback about the intended outcomes, noting they are broad and cover the main areas mentioned by families, carers and stakeholders.

One outcome some people identified as missing was **improved inclusion in early learning and education settings**. They suggested:

- general supports should include further developing the capacity of education and other mainstream settings to be more inclusive of children with disability
- targeted supports for children should aim to ensure families have the necessary information and supports in place to support their children in mainstream schooling.

Additional outcomes for families, carers and kin have been listed in the full General Supports Consultation Report.

Considerations

Three key principles were commonly identified for the design and delivery of targeted supports:

- Design of supports are **person-centred** and consider the whole of child and should adopt a whole of family approach and family-centred practice.
- Models of supports are **co-designed** with families and carers, as well as children where it is appropriate.
- Early childhood supports, including targeted supports for children that sit alongside the NDIS, should be available **to all children who need them**—no matter where they live in Australia or what their circumstances are—to ensure all children have the opportunity for the best start in life. This included ensuring more equitable access to supports for children who may experience disadvantage or have additional barriers to accessing appropriate supports, such as children in rural and remote areas, who are First Nations, or from families who may not speak English as a first language.

Chapter 1: What is needed in general supports for children under 9

General supports:
Overview from consultation paper

General foundational supports are intended to support children with developmental concern, delay (including suspected delay) and/or disability and their family, carers and kin. Children getting the NDIS and children not getting the NDIS may be able to access general foundational supports relevant to their needs.

The consultation paper included the following examples of what these supports could look like:

- **Information, resources and advice** to help parents to understand their child's needs, build their capacity and navigate service systems. This includes building knowledge about their child's developmental milestones in terms of physical, emotional, social, communication and cognitive skills. Information may offer advice on how to set routines and to support a child with developmental concern, delay (ensuring information is neuro-affirming), disability and how to advocate for their child.
- **Facilitated parenting groups/peer support groups** to give general information and advice about parenting and delays in their child's development. This includes social and emotional support for families and carers.
- **Shorter or one-off courses or workshops** on specific topics. For example, child development, supporting emotional regulation, how to prepare for important transition points in a child's life.
- **Evidence-based online and in-person programs on development** to provide tools and practical ways to support parenting and child development.

What we heard

Key issues and barriers

Families and carers suggested information is currently difficult to find. Out of 268 families and carers who responded to this question, only 10% said they found it easy or very easy to find information about disability supports and 76% said it is hard or very hard to find information.

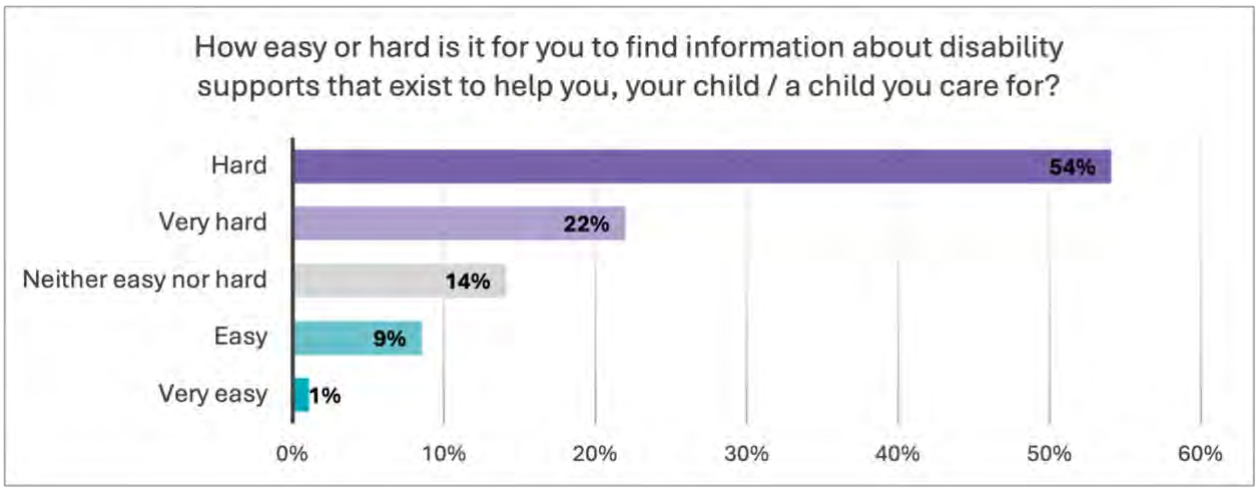


Figure 3: How easy or hard it is for people to find information about disability supports (percentage of respondents) (n=268)

The following specific issues and barriers were often raised about finding information and advice, or connecting with support groups and programs (capacity building).

Families are time poor and over-burdened

We heard many families are time poor and over-burdened with the amount of work, time and effort they need to put in to find and navigate services. This was particularly prevalent among single parents who described difficulties in having the mental capacity and time to find, navigate and access supports for their children. A number of single parents reiterated the importance of having people walk alongside them, such as case workers and in-home supports, to support the whole family.

Lack of information and confusion navigating systems

We heard many families find it hard to navigate different systems and to understand who to reach out to for supports for their children and families. This was particularly an issue for those with newly diagnosed children, and those who are not in the NDIS and so don't have access to support coordinators and support workers.

Disconnected with early childhood and community supports

People suggested families who are not connected with any existing services in the community find it particularly hard to find supports when they identify their child may be experiencing developmental delay or concern.

Some communities are disconnected with early years supports so don't receive early information and advice about their child's development at all. One example of this was in relation to Aboriginal and Torres Strait Islander families in rural and remote areas where early childcare supports may be limited. It was noted supports need to be universal.

As noted in SNAICC's submission 'the high rates of developmental vulnerability, preventable developmental conditions and disabilities among Aboriginal and Torres Strait Islander children and adults indicates decades of missed opportunities for early assessment, identification and provision of developmental supports. In many cases, this is the result of inaccessible or non-existent early years services where people live; market failures of universal service systems. It is essential the foundational supports system does not mirror these failures.'

Building on what works

There were many examples of existing programs people said are working well. These were most often family-led or peer-run programs or supports available in a family's local area.

Families and stakeholders reiterated the need to **build on what is already available.** This included supporting existing family support groups and successful parenting skills and education programs in their regions. A few stakeholders suggested governments should ensure there is more awareness among the community of existing programs in place as part of building the foundational supports system.

Families, carers and stakeholders also said new programs and implementation of general supports for children and families must be **co-designed with families, carers, children and siblings**, so programs are informed by what has worked and helped in the past.

The solutions – what's needed

Preferred sources for information and advice

Respondents were asked to choose their top 3 sources of trusted information and advice about supports and services. As shown in Figure 1, the most common 3 sources selected were:

- talking to other people with disability and/or carers (185)
- referrals from GPs or other health professionals (184)
- family peer or support groups (148)

The least commonly selected sources of trusted information were 1800 phone lines (7), the Disability Gateway (9) and the Carer Gateway (28).

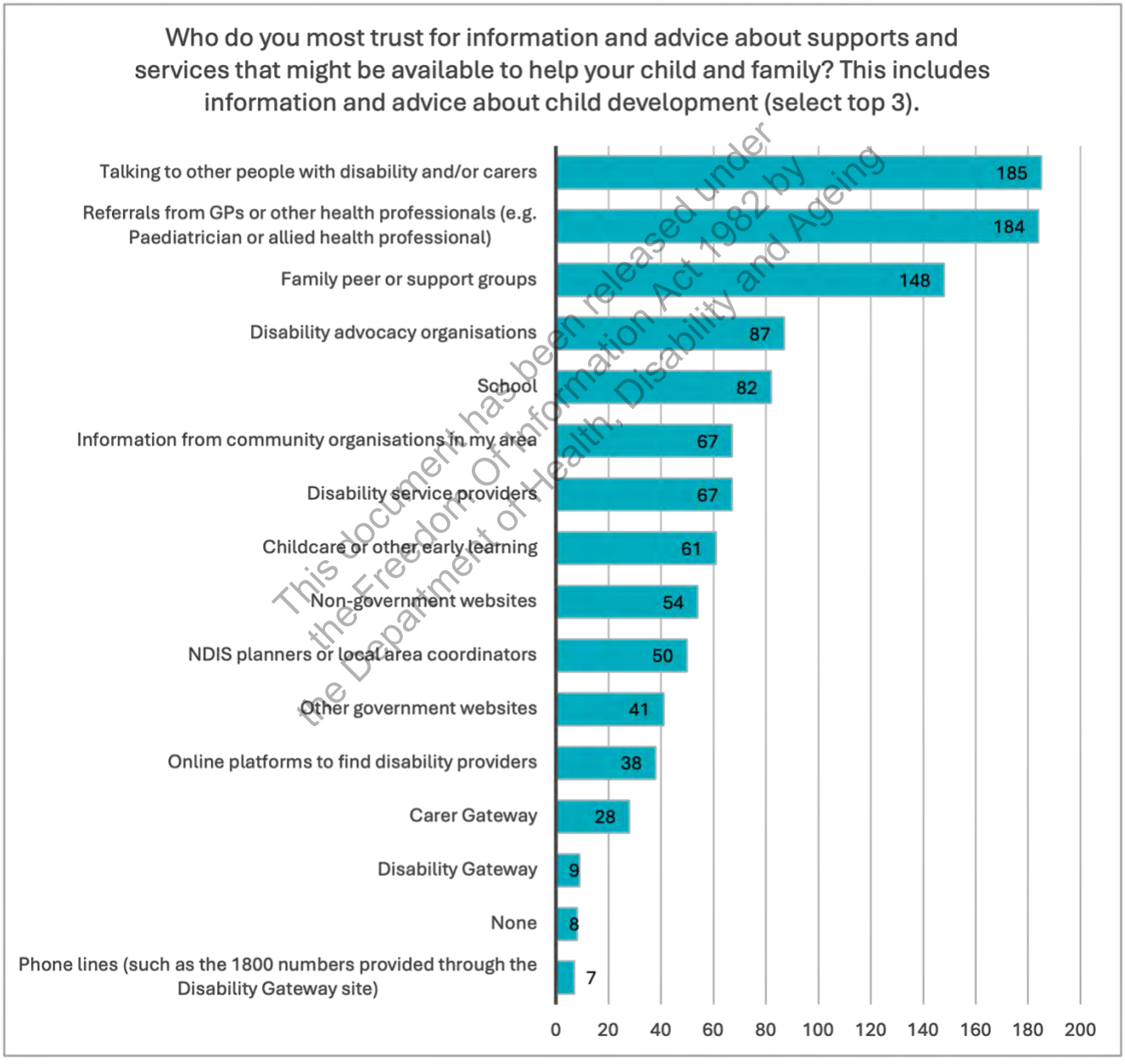


Figure 4: Sources of trusted information and advice (select top 3) (n=268)

People with lived experience and other families and carers

Overwhelmingly **other parents, families, carers and people with lived experience of disability** were named as the most trusted sources of information and advice. Parents often explained this is because information from other parents is credible and honest, whereas other sources of information about supports can be inaccurate or designed to 'sell you a service'.

Parents, in particular, noted people with lived experience were the most helpful in providing advice about what supports their child can access or may need in the future. They often raised the importance of someone understanding their needs, but also being able to talk to them and their child in an empowered, informed and neuroaffirming way, and this often came from peers or organisations led by lived experience.

> *'We prioritise engaging with disabled-led organisations (like Aspect or Reframing Autism) and value the advice of autistic adults and/or carers of children with similar profiles.' - **Individual respondent, supports for children questionnaire***

Referrals from GPs and allied health professionals

We heard often that allied health and other health professionals, for example occupational therapists (OTs), speech pathologists, therapists, paediatricians and GPs, are key helpers in finding the right support for families. In addition to providing therapy, they **point families to other services they might need**, help them with NDIS paperwork, and recommend or connect them with trusted colleagues and other supports in the community.

For example, a number of families from the NT said their child's OTs had been the best source of information and support, generally because they have the best knowledge about what a child needs and what supports exist in the system for them that are available in their region.

Peer and family support groups

Parents frequently mention **word of mouth from other families** has been more helpful than official channels, particularly for understanding what services are available locally, how to navigate the NDIS, and which approaches work best. Families and carers identified **family-led peer groups** and disability advocacy organisations are critical for connecting families with supports and running peer support and education programs.

> *'We're now a part of a home education community and the support that we have found there... I have found out about other service providers, other peer support groups, other social skilling groups for my kids that were just not coming up in my online searches. That word of mouth has been crucial.' – **Participant, QLD family and carer online roundtable***

Parents provided numerous examples of peer support groups and local organisations they connect with, which were frequently mentioned as being helpful for families to connect with other families and share resources and experiences.

> *'Being able to be around peer-led, family-led and people with disability-led organisations that offer supports for families that are free, that are strength-based, that are family-centred, that are empowering and evidence-based, and really be able to build on my skills as a family leader.' – **Participant, ACT family and carer online roundtable***

Networks supporting culturally diverse and migrant families

Peer and culturally specific networks emerged as being especially important in supporting people from CALD backgrounds with information and advice, in particular for engaging parents from migrant and refugee communities.

Staff supporting these communities suggested often people will only reach out to familiar networks and faith-based or religious leaders for advice because 'a lot of time this is the only thing people know…they won't trust the GPs, mental health nurses etc.'

They also suggested community hubs provide a more familiar space for people from CALD backgrounds to visit, which is important for 'helping to create a socially safe model'. It allows families who frequent the area to 'drop-in' so when programs come and go, 'the doors stay the same'.

In the focus group with parents and carers hosted by the National Ethnic Disability Alliance (NEDA), a number of parents suggested having culturally competent volunteers they can connect with can help to bridge gaps in understanding.

Playgroups supporting peer connections

Playgroups were a particular type of support parents and carers suggested need to be continued and, in some cases, better supported through foundational supports. These were particularly mentioned as being important for:

- connecting families and children with supports for the first time
- offering tailored and culturally safe spaces for parents and carers to find out about available supports in the community that suit their needs
- supporting children's social and other developmental needs.

First Nations playgroups

Playgroups were often described as working well to support First Nations families, particularly in regional areas. Examples of playgroups that are culturally safe and responsive included those which:

- had routines and activities that are culturally-led so trust and relationships with families can develop
- embed evidence-based approaches such as the SWAY (Sounds, Words, Aboriginal Language and Yarning) model, an oral language and literacy program based on Aboriginal knowledge, culture and stories
- use the trusted space for staff to connect families with a wide range of services within a Hub, including health services (immunisation, developmental checks, allied health), housing, food bank, schools, counselling, family violence services and drug and alcohol services.

Online discussions

Parents often use **Facebook groups and other social media platforms** to find and access services, particularly groups run by other parents with similar experiences. These online communities are often seen as more helpful than official government sources or professionals for getting practical advice and service recommendations. However, many responses noted while these groups are valuable, relying on social media isn't ideal as information can be inaccurate and it takes significant time to find reliable information.

> *'Most information is from online support groups, set up by other families. But it's been hard to access information from other sources, be they government agencies or other support organisations. Schools have little idea.'* – ***Individual respondent, supports for children questionnaire***

Disability and family advocacy organisations

We heard existing **disability and family advocacy organisations are very helpful in providing information**, and need to be sustained. Parents and carers described support from advocacy organisations as being helpful and trusted because they 'don't have a hidden agenda'. People raised concerns organisations like this may be lost as they often only receive short-term, one-off funding for programs which end when funding runs out, even if they are working well. Many noted they should be better supported to meet the demand from families who need help, advice and support.

Information and resources through education settings

Schools

As expected, schools were identified as one of the most useful sources of information about supports for children, often because families are already engaging with teachers and other school staff about their child's requirements and development. However, some also described experiences where schools had provided inaccurate information or dismissed the need for supports in the early years of a child's life.

There were suggestions for:

- ensuring staff within schools have more information about how families and children with disability can access support
- schools to maintain a list of practitioners already working with kids in their community so this can be shared with parents, particularly parents and carers accessing supports for their child for the first time
- parents receive direct emails from schools with contact and localised support information for children with disability and developmental delay.

Further information about delivery of supports in education settings is discussed in Chapter 3.

Childcare and early education centres

We heard early childcare centres are often important sources of information and can support families to find supports for their child, including for finding allied health supports and connecting with families in similar situations. However, there were also mixed experiences about the availability and accuracy of information provided through childcare centres.

Parents and carers reiterated the importance of:

- training for childcare workers in disability so they can share the right type of information with parents
- having more information provided to and available at childcare centres
- possibility of using childcare centres as 'hubs' of information and advice
- having allied health and other professionals visiting centres to provide information to families.

Local government, community organisations and local places

Places and hubs in communities were identified as important sources of information, however, often aren't equipped with the most up to date information about what supports are available for children with disability, developmental delay and/or concern. Some stakeholders, families and carers mentioned more needs to be done to improve the understanding of community organisations to ensure they are a useful part of a general supports system.

Many families and carers said they'd benefit from having more places in the community where they can come together to get advice and information. Some suggested parental supports groups and education could be run out of local community hubs. Noting the importance of allied health in providing trusted information to families, they also suggested it would be helpful to have permanent or visiting allied health professionals, supports or services available at community hubs or within existing community organisations, offered for free to families who need information, advice or referrals.

Some suggested local council support should be available for the family across the lifespan. This included offering things like social groups for parents, school holiday programs, playgroups, informal gatherings and cook ups.

Information and support through Aboriginal medical centres and community controlled health organisations

A number of stakeholders reiterated the importance of having information available at places where First Nations families already feel comfortable. An example of this was Aboriginal Medical Services and community controlled health organisations or local centres. Stakeholders noted this requires them to be supported and well-equipped to provide information and advice to parents, carers, families and kin about supports available for children and families.

A number of Aboriginal and Torres Strait Islander participants pointed out having advice and referrals available through trusted, local places helps to avoid asking families to retell their stories many times, or to share their family or child's circumstances with people outside of community.

'telling the aboriginal medical centre helps because they know our mob.' – ***Individual respondent, supports for children questionnaire***

Other trusted sources

Other trusted sources for information, advice and resources commonly identified were:

- disability providers, support coordinators and disability support workers, where families recognised these roles as working well for them
- NDIS planners and Local Area Coordinators, noting a relatively high number of parents and carers suggested they don't get consistent information through these roles
- websites by community organisations, and some government-funded website and platforms.

'Our disability support providers understand the needs of our children and target their advice to our specific needs. Our support providers have worked with our children since we first engaged with disability support, this provides them with a unique perspective that is essential to provide support to our ongoing information needs'. – ***Individual respondent, supports for children questionnaire***

Sharing information at the right times and in different formats

Families and carers said it is important to receive information at the right time and there needs to be a mix of formats. They consistently mentioned 3 important considerations about this.

Information in range of ways to meet different needs. We heard information and advice needs to be delivered in a range of ways. Each family has different communication needs. For example, some families will not answer private numbers or open official looking mail. They suggested linkages with local trusted supports are often needed to 'vouch for health professionals' so a family can trust them and bring them into their support network.

Information tailored to children under 9. We heard there should be more information available to children under 9 and this needs to be tailored specifically for them. This might include, for example, interactive or visually engaging tools like social stories. A number of parents mentioned their child needs to feel comfortable with the supports they are accessing so better information about how services and supports work they can engage with is a critical part of general supports for children.

Information on a journey. Consistent with the General Supports Consultation Report, families and carers reiterated the need to have information relevant to each part of their and their child's journey.

'I'd have loved a journey planner- a step by step guide on what to do and where to find help. A list of services and how they help. A list of issues you might face and who can help you with them. You don't know what you don't know and I feel we missed out on a lot of help because I didn't know it was available. Or I spent hours online researching to find services.' – ***Individual respondent, supports for children questionnaire***

'The Government needs to provide a list of places and people to reach out to for newly diagnosed people. We had no idea what to do or where to start, it was sink or swim. There needs to be a clear and concise step by step guide of what to do, what you are entitled to, what to apply for e.g. NDIS, carers payment etc, who you can connect with for supports.' – ***Individual respondent, supports for children questionnaire***

Phone lines to direct and relevant information and advice

Parents and carers reiterated tailored phone lines and counselling services are important referral services for families. They shared that these services should be:

- specifically for parents and carers with information relevant to their state or region
- strength-based
- focused on the family and not clinical.

A common example of a support line working well to deliver specific information and advice was Parent Line NSW.

'Parentline NSW is probably the absolute most help out of any service we access. The staff are amazing, they seem to have a lot of experience and give really respectful strengths-based, practical advice. … they listen first, and understand what you have already tried before they start giving you advice. That is so helpful, particularly for parents of older children/ teens who have already tried so many things. … you don't have to wait a really long time when you call.' – ***Individual respondent, supports for children questionnaire***

'Parent line New South Wales has given us direct advice but they always suggest other resources including websites and training so that we can continue to follow up after the phone call.' – ***Individual respondent, supports for children questionnaire***

Concerns with government sources and services

Consistent with feedback in the general supports report, families and carers also raised issues with the accuracy of information they receive when contacting government services, such as Carer Gateway and from NDIS planners. They mentioned government sources of information, such as websites, can be difficult to navigate with so much information on them.

There is also a feeling of distrust associated with accessing government services for information. A few parents and carers expressed concerns about relying on government information while there are risks their child's funding and plans will be cut, or what they share might cause them to lose government supports. There was distrust of government among many families and carers of children with disability, including those who are in the NDIS.

Strengthening trust

Based on the feedback and fears raised by families and carers, work is needed to reset the relationships and trust between government and families in relation to supports for children with disability, and in the design and implementation of foundational supports. Families and carers raised concerns their children may lose supports from the NDIS prior to having other supports in the community in place.

Peak organisations such as Children and Young People with Disability Australia (CYDA) also highlighted the concerns of families about the foundational supports design. 'Respondents to CYDA's foundational support survey were overwhelmingly worried and confused about the introduction of foundational supports and believe they will be worse off in the short to medium term. Survey respondents also echoed a general lack of trust in government processes, voiced in several recent consultations across the disability community and sector, regarding recent changes to the NDIS and disability related programs and legislation' (CYDA submission).

Delivering general supports for children and families

Types of models and settings

Refer to the full General Supports Consultation Report for more detailed feedback from community and stakeholders about models for delivering general supports.

The types of supports, models and settings for how and where general supports should be delivered was consistent with the feedback in the full general supports consultation report, with families, carers and organisations suggesting general supports for children be delivered through a mix of:

- place-based hubs and supports that come together in locations
- case workers, navigators or connectors
- digital platforms, directories and phone services
- existing family services.

These were in addition to suggestions to integrate general supports and targeted supports for children with schools and other mainstream settings, which is further discussed in the implementation section in Chapter 3.

Place-based and community hubs

We heard about the need for place-based hubs and supports that bring services and supports together in locations, to support children and their families and carers.

> *'Hubs where child and family services and GPs are located, and where childcare, preschools, and schools are at the centre could be one way to create a community around the child and make it easier for families to find the right service for them. Where provider lists and registers within a hub area are collated for families to help access appropriate and relevant services.' – Individual respondent, supports for children questionnaire*

This included suggestions for hubs to be placed within or linked to schools, early childhood settings and local government settings where parents and children already interact. There were examples provided of existing early childhood hubs offering safe places for families to access quality services.

> *'Early Childhood Hubs offer safe, welcoming, inclusive and high-quality services for children and families, relevant to community context. A multi-disciplinary 'no-wrong-door' approach and support for collaborative operation overcome barriers to access for families and provide an excellent platform for capacity building across the various mainstream and targeted services delivered from Hubs. Early Childhood Hubs are trusted by families, offering many soft entry points and create a space where families don't need to 'come looking' for disability supports.' – Submission*

Case workers, navigators or connectors

Multiple comments suggested case workers in settings such as schools, community hubs or local government buildings. This also included having allied health or social workers within schools and childcare centres to provide guidance to families and carers.

Case management and key workers are further discussed in Chapter 2. Targeted Supports.

'Bring back community support coordinators into community organisations like a case worker for each family.' – ***Individual respondent, supports for children questionnaire***

'Early Childhood Education and Primary Schools having a dedicated Social Worker inhouse to support Educators and Families engage in services. Social workers are great at bringing families on a journey and taking steps to ensure the child is engaged. Many schools will not let Allied health into the school system - this is wrong and affects the outcomes.' – ***Individual respondent, supports for children questionnaire***

Programs for the whole family, including siblings

We heard about the importance of delivering high-quality family-centred practice. People said services need to prioritise family-centred approaches and be supported to deliver services in this way. Family-centred practice was considered to be 'inherently inclusive, culturally safe and will better respond to families from diverse backgrounds and with diverse needs'.

'All families need to be considered on an individual basis, time is required to invest in building a relationship with a family, developing mutual trust, exploring and understanding family routines, individual needs, hopes and dreams, and enabling provision of family centred practice.' – ***Submission***

During consultation events, parents often spoke about the importance of having access to programs that involve the whole family, in particular siblings. Some families and other stakeholders noted general supports are an opportunity to ensure outcomes are improved for the whole family, including siblings of children with disability.

'The importance of giving siblings a chance to connect with each other and learn from each other, and just for them to have those kind of peer supports as well.' – ***Participant, Tasmania family and carer online roundtable***

'We had a touch football program that was set up to for my son's gross motor skills, but his brother was encouraged to come along and participate. He was able to then support other kids that needed more support, so it was a really inclusive, lovely environment.' – ***Participant, NSW family and carer online roundtable***

Digital platforms, directories and phone services

It was common for people to suggest a central hub or directory of information that is accessible and welcoming for parents and carers to use would help to make it easier for families to find information. Most often families and carers said useful websites or platforms would:

- have a directory of disability-specific supports that can be searched by local areas, and not just general information
- provide the opportunity for families and carers to review, rate and comment on services that worked for them, and why
- include spaces for families to connect online.

'A centralised register which includes real time information about availability, waiting times, method of service delivery (clinic, mobile), target group etc where users can leave reviews.' – ***Individual respondent, supports for children questionnaire***

It was often suggested these need to be staffed by allied health (e.g. social work or children's development and allied health specialists) who can give parents accurate and useful information and refer them to the right places for supports based on their / their child's needs.

Some stakeholders, including First Nations services, noted while existing websites such as Raising Children Website are useful at providing information for all developmental concerns, these could be 'redesigned to be more easy read and culturally appropriate'.

While 1800 numbers were not generally selected as preferred sources of information, a number of comments from parents and carers suggested phone lines to provide tailored information, would be helpful.

'A service I could call for advice that will answer and provide advice when I call.' – ***Individual respondent, supports for children questionnaire***

'A phone service which families can ring to know what services are locally available. This service should have a "real time" understanding of wait times for services'. – ***Individual respondent, supports for children questionnaire***

Existing family services

Stakeholders noted the important role existing services which support families experiencing vulnerability, complexity or trauma play in sharing information and advice. These should also be considered as part of the foundational supports service system, for example child protection, family violence services, and family and relationship services.

Chapter 2: Targeted supports for children under 9

When reading this section of the report, it is important to note people provided extensive feedback about areas of support they or their children need, which included through the NDIS and other mainstream systems. Some submissions also focused on the need for targeted supports for people aged 9 to 25. **Only feedback related to the scope of targeted supports for children under 9 has been included in this section of the report**.

Targeted supports for children under 9: Overview from consultation paper

Targeted foundational supports are for children with developmental delay who need more support than (or in addition to) mainstream services and general foundational supports.

The consultation paper outlined the types of targeted supports for children with developmental delay and/or concern might include:

- **Low intensity or periodic child and family-centred allied health supports**. Dependent on the child this might include support from one or more of the following:
    - speech pathology
    - physiotherapy
    - psychology
    - occupational therapy or other allied health specialists (could in some cases include providing one-off/low-cost assistive technology to make everyday tasks easier and safer).
- **One-on-one capacity building**. Some families who need more support, may need more intensive, one-on-one capacity building. A suitably qualified and experienced worker could provide coordination and help families get appropriate supports.

Why are targeted supports for children under 9 needed

An independent review of the NDIS found current services and supports for children with developmental delay or concern and their families, need to be better. It also found the support system around the NDIS needs to be stronger.

The Review recommended the establishment of targeted supports for children with developmental delay to address gaps in access to necessary services and interventions.

What we heard

Key issues and barriers

Diagnosis, including costs of assessments

Families and carers reported they face significant barriers to having their child or children assessed and, where needed, diagnosed, due to long waitlists and difficulty in accessing supports at this early stage of a journey. This, combined with issues around perception, stigma and discrimination, mean many children with developmental delay and/or concerns are still not being assessed and therefore referred to the right supports.

Stakeholders highlighted the impacts poor diagnosis, or a lack of diagnosis, has on children in terms of accessing supports. Some suggested children are being removed from the NDIS for not having a diagnosis, and noted high costs for assessments to prove their child has a disability make them inaccessible. It was noted parents often share experiences about spending lots of money upfront for assessments and then being told their child isn't eligible for supports. Some

said many Medicare items cannot be used for assessments and diagnostic processes, and funds to support families with assessments are not readily available.

There were concerns, as a result of the barriers to assessments, the benefits of getting a child diagnosed early are not being realised. Some respondents raised concerns if families, particularly who are on low incomes, don't think their child will get in the NDIS or get access to funded supports, they are less likely to bother getting an assessment for their child. As a result, it would be important to ensure targeted supports are available to children and families prior to a formal diagnosis.

Diagnosis for girls was also a particular issue raised, particularly in relation to not having early diagnosis and supports for young girls because they can present differently for autism, ADHD and/or developmental delay. Comments mentioned the need to ensure schools and health services better understand how disabilities or developmental delay may present in girls, including issues with masking, so girls are included and are equally eligible for supports.

> *'My youngest child does not 'meet criteria' for autism and only has suspected ADHD until she reaches 6 and can be properly diagnosed. Girls present differently and their internalized [sic] presentations are not always recognized [sic] young. But the time for early intervention is now while she is young. With my son being diagnosed both ASD and ADHD there should be a program for siblings of children with ASD- who are much more likely to have autism as well. It could be play-based Floor time therapy or a group play group run by an OT or speechie' – **Individual respondent, supports for children questionnaire***

Stakeholders also identified children living in communities with fewer available services (such as regional, rural and remote areas) generally have poorer access to early childhood services, which can result in delays to health and development checks and assessments, which subsequently postpones diagnosis and appropriate intervention.

> *'Where services are available, families facing disadvantage experience barriers that others typically don't – access to the current support options relies on families' navigating multiple referrals with hidden costs and long wait lists, lack of culturally safe practices, long travel distances and limited transport options.' – **Submission***

Streamlining assessments and eligibility

The way assessment processes work together between supports for children in the community and the NDIS needs to be considered in the design of foundational supports.

The Centre for Excellence in Child and Family Welfare suggested 'Better service integration and coordination could be gained by streamlining assessments where appropriate and standardising the eligibility criteria for foundational supports and the NDIS.'

Some people noted the NDIS and foundational supports should be closely connected so that when children need to transition to NDIS support, they can do so easily without the need to resubmit diagnosis and documentation.

Availability of supports and wait times, particularly in rural and remote areas

Parents and carers reported they are being referred to supports that don't exist or are often told there are no supports available for their children. This related mostly to:

- not having a diagnosis
- eligibility criteria
- services not taking on new clients or having very long waitlists.

This was particularly an issue in regional and remote areas. Where parents and carers have found available supports, they are often not able to access them immediately, with many reporting wait times are at least 6-12 months.

> *'We live in the Territory and there is a shortage of health professionals so the waitlists are crazy and then when you get to see someone there's never enough funding allocated to include the travel that we need'. – **Individual respondent, supports for children questionnaire***

Families and carers, and people who work in the disability and health sectors, all shared concerns that supports are often non-existent in rural and remote areas.

> *'We can't access Face to face support in the town I live in… Without high travel costs they make us pay. Like OT, SPEECH, psychology, community access programs, physio, and other services for people with disabilities.' – **Individual respondent, supports for children questionnaire***

Confusion between disability and health systems

Parents and carers often described having a lack of clarity about which system they could use to get supports for their child. This mainly included confusion between whether something was a health-related support or a disability support. Some parents and carers also mentioned confusion about whether supports and assessments would be done through early childhood centres and schools in their early years. A few mentioned the need for a consistent policy about what schools and early childhood centres can offer in regard to assessments and supports.

Some people reported their child's NDIS plans have been reduced for allied health supports, as these duplicate health system supports. However, they report there often isn't a clear pathway to access those supports outside of the NDIS without significant costs, (e.g. paying for private providers).

> *'I have been told by NDIS that my son could not access psychology as this could be accessed through medicare. Then the GP told me, his thinking and emotional needs were due to his disability so she wouldn't write a mental health care plan.' – **Individual respondent, supports for children questionnaire***

Insufficient Medicare support for children with developmental concerns

Some parents and carers identified costs as a barrier to accessing supports. They, and many stakeholders, suggested there is not sufficient support for children with developmental concerns as part of Medicare. For example, having access to sufficient number of psychology or other specialist appointments.

Building on what works

Many saw the opportunity for targeted foundational supports to **build on and upscale** what is already working in various states and territories.

Mapping existing supports

Multiple stakeholders suggested, in designing foundational supports, governments should undertake detailed mapping to identify successful programs, supports and services, including those that require additional resources to meet community demand.

What families and carers find useful now

The consultation paper specifically asked families and carers what allied health or family services they have found useful.

Across the responses parents and carers listed the wide range of **allied health services** including OT, physiotherapy, psychology and speech pathology. They also sometimes mentioned social workers and peer support through family-led organisations who support their family to get support and connect with other services.

> *'The best support we have had was finding the right psychologist and occupational therapist. Ones that have taught my child skills and techniques. She has finally finished year 12 this year, hasn't self injured in 4 years and is heading to uni. This would not have been possible without them. She would not have attended groups, would not have attended a school for support.' – **Individual respondent, supports for children questionnaire***

They noted allied health supports and other services are most helpful when they are consistent and their child is able to build relationships with the supports over time. Related to this, parents and carers with children in the NDIS often said support coordinators and workers have been helpful as they provide one-to-one supports relevant to their child's needs.

Families and carers also often mentioned the following types of supports are helpful:

- playgroups, particularly with an early intervention focus
- other therapies such as art and music therapy and equine therapy
- camps, sports programs and family day outs
- in-home help
- individualised parenting coaching
- family-led peer groups and education programs.

> *'The most valuable supports for my child and family have been a combination of services that build a strong network around her. These include Art Therapy, Deaf Camps, Social Work, Occupational Therapy, Behavioral [sic] Support, Auslan and English tutors, and Support Workers. These services have been instrumental in helping her build skills, confidence, and connections.' – **Individual respondent, supports for children questionnaire***

The solutions – what's needed

Universal Early Childhood Education and Care system

Stakeholders including children and family peak bodies, such as CYDA and SNAICC, proposed 'building an inclusive, universal, and high-quality Early Childhood Education and Care (ECEC) system that sits alongside NDIS's Early Childhood Intervention program to cater to children with disability in partnership with the disability sector'. This included recommendations for the commissioning of supports and providing interim funding through the ECEC Inclusion Support Program.

Early childhood stakeholders supported targeted supports as a way of ensuring early childhood services and supports are enabled to be proactively set up to support children with disability, developmental delay and/or concern, rather than being delivered retrospectively.

Types of supports people need

The main types of targeted supports families and carers said are needed outside of the NDIS:

- **Early intervention**, including delivered through settings (e.g. hospitals, health centres, early childhood settings and schools) where young children are already interacting.
- **Access to allied health**, with the need to make these more available to children by reducing wait times to access assessments and supports.
- **Play, art, music** and other similar type of therapies.
- **Practical supports**, including in the home.
- **Aids and equipment**.
- **Social workers**.

There were also many mentions about having tailored targeted supports for:

- specific types of disability and learning difficulties
- for children and families who are from diverse backgrounds, for example First Nations and Culturally and Linguistically Diverse, and who are part of the LGBTIQA+ community.

Common areas for targeted supports

Early intervention

Early identification of disability (or change in a person's condition) and intervention were seen as critical – particularly for children with developmental concern, delay or disability. This enables appropriate supports, therapies and management strategies to be put in place quickly, which can help to minimise stigma, address complex behavioural needs and enable the individual.

> *'The quality of support received early in life has a direct impact on the amount of care and support a person with developmental disability or delay will require in adolescence and adulthood. It is therefore critically important to ensure these families receive the services and care they need.'* – ***Submission***

'With many systems and sectors now, there is too much focus on 'proving' eligibility which ties up an already strained and limited workforce in tasks associated with trying to get supports for children which are then even more limited.' – *Submission*

Early intervention also focused on improving earlier diagnosis. Some parents and stakeholders suggested this is an opportunity for better supports to enable early diagnosis, including earlier screening for vision hearing and speech and upskilling of ECEC professionals and support staff.

'If we had been referred to an early intervention partner instead of being told "the kids will grow out of it" then perhaps we could have engaged some supports. But no one knew or engaged with us.' – *Individual respondent, supports for children questionnaire*

Families of autistic children very often raised the need for better access to early screening and early intervention supports. Many said not being able to get an early diagnosis for autism or ADHD, especially among girls, was causing them to not receive adequate supports in their early years.

It was also noted the earlier a developmental delay or concern in a child is identified, the more support parents and carers will have to understand what is happening with their child and to connect with supports. We heard from organisations who support families from CALD backgrounds that early intervention can be particularly important for first generation parents of children with disability who are isolated from support and resources.

Allied health

Parents and carers consistently said more allied health supports are needed to support children with disability, developmental delay and/or concern and families. This covered the range of allied health supports listed in the consultation paper, including speech pathology, physiotherapy, psychology, occupational therapy or other allied health specialists.

Families and allied health professionals also suggested dieticians be specially included in targeted supports for children, given *'feeding milestones directly correlate to developmental milestones - therefore most children with developmental delays will be at nutrition risk.'*

Many comments spoke about the importance of **individualised one-on-one supports**, with some suggesting it is most effectively delivered in the home in a child's natural environment, but there should always be a mix of options.

In general, families, carers and sector stakeholders agreed allied health supports can be costly for families to access in private practice, and families need to be supported financially to access these services. A number of respondents highlighted, given the cost of living pressures many people and families with disability experience, it is important there is ongoing funding to provide access to essential allied health services for those who are not eligible for the NDIS. This was seen as particularly critical for children with disability or developmental delay as lack of access to required supports when a child is very young can have significant long-term consequences for the child and their family.

Allied health gaps in regional, rural and remote areas

There was a lot of feedback about the need to address gaps in specialist allied health supports in regional, rural and remote areas. Some suggested governments first need to invest in building the allied health workforce, particularly in these areas, and including to ensure there is a diversity of allied health workers trained to deliver culturally safe care to children and families.

Most often people said it can be hard to attract and retain allied health workers in regional areas and there are expectations on those who are there to service very large geographic regions, which contributes to these issues.

There were some other suggestions for improving access to allied health services, and increasing the diversity of providers, in regional, rural and remote areas including:

- place-based design of allied health support networks so gaps and needs specific to regional and rural areas are identified
- regional hubs and centres bring services together on certain days, including shared resources to help address unplanned shortages
- rural placements and internships
- outreach supports, such as mobile services and mobile playgroups 'that visit remote communities and provide a playgroup to the community who would otherwise miss out'
- Telehealth, noting some respondents suggested telehealth had not worked well for their children (more feedback about telehealth is available on page 45).

Play, art and music therapies

We heard art, music and play therapies are important for many children and to support their development. Parents, in particular, said these types of programs need to be more accessible and offered to children with disability, developmental delay and/or concern, whether or not they're in the NDIS.

Parents who raised these types of therapies often talked about the importance of them to ease anxiety when children are engaging with supports.

> *'My son will not engage with OT or speech due to his anxiety- one on one equine therapy eases his anxiety and stress and allows him to find levels or calm where he has greater capacity to function and learn'. – **Individual respondent, supports for children questionnaire***

> *'My toddler has always had a natural connection with music, making it the most effective tool for her learning and development. She has learned more words through singing than any other method, and the impact on her emotional regulation has been extraordinary.' – **Individual respondent, supports for children questionnaire***

> *'Children 9 and under often do not have the verbal language as yet to express what they need, or their psychosocial and emotional worries about disability experience. Increasing access to Arts therapies for non NDIS Clients helps express and find a language words of the Clients experience not a clinicians. Targeted help. Especially when non verbal, autism or language delay'. – **Individual respondent, supports for children questionnaire***

Practical supports, including in the home

Many families and carers said in-home supports and visits by allied health services to their homes was very helpful, for them and their child or children.

Some parents and carers suggested targeted supports outside the NDIS should include funding for support workers who can work directly with children and families in their home, particularly if children are going to be removed from the NDIS or not given access to it in the future.

Related to this, people noted many carers are overwhelmed by the day-to-day demands of their role. 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 focus of supports 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.

Some parents and carers suggested in-home supports also help to remove specific barriers they face in accessing supports, particularly those barriers that can prevent them from taking children to clinics and other settings for supports, such as:

- having other siblings and children (including with disabilities) at home
- issues with transport
- not having internet or phone connectivity to call for services.

> *'Them coming to me. Me not having to ring or email because sometimes I don't have credit on my phone.'* – ***Individual respondent, supports for children questionnaire***

Aids and equipment

Multiple respondents to the questionnaire mentioned targeted supports should include support for aides, equipment and technologies as these allow children to participate in school and the community.

Aids and equipment was a particular focus for families and carers with autistic children, and children with learning or communication difficulties. Some noted when a child has an invisible disability they often miss out on having the same access to supports a child with a physical disability might have, most often because teachers, health professionals or others who make decisions about these supports don't understand their needs.

The need to ensure Augmentative and Alternative Communication (AAC) devices are more available to children was a particular concern for some allied health professionals.

> *'There seems to be a lot of misunderstanding about the types of children who require and can benefit from AAC. There appears to be a trend of AAC being considered as essential only for children who are non-speaking. It is essential that AAC is available to children where the speech does not fulfill all of their communication needs, not just for children who are non-speaking. Access to AAC assessment and prescription for AAC for children inside and outside of the NDIS is essential'.* – ***Organisation representative, supports for children questionnaire***

Social workers

People working in the allied health sector and a number of parents and carers said it will be important to include social work in general and targeted supports for children and their families and carers. Some suggested social workers play a key role in supporting families to find the right supports and might be best placed to be case managers/key workers within a multidisciplinary team.

Having neuroaffirming social workers was mentioned as particularly important. People also suggested having more training for social workers in understanding disabilities and child development to be able to support children and their families.

Targeted supports for the whole family

While a lot of feedback focused on the specific types of supports children need early in life, families and carers also described a need for specific supports that help them and the whole family. We heard from parents they need more supports to help them:

- **navigate systems** and be connected with the right services
- **undertake the administrative work, such as** organising reports and coordinating assessments, required to make sure children with disability or development delay are supported to get the supports they need
- **in the home**, such as with basic cleaning, maintenance, gardening and administration, acknowledging the significant time spent on caring for their child or children, especially where they have multiple children with disabilities.

A few people noted Carer Gateway support is currently not filling this gap for parents.

We also heard about the importance of having supports for siblings.

> *'My other two kids have access psychology to help them understand their brother's disability and why we have some of the challenges we face. Organisations like Siblings Australia are so valuable in building the capacity of families to support siblings too.'* – *Participant, NSW family and carer online roundtable*

> *'I think siblings are often unsupported and a lot of supports don't stretch to siblings, and they are such a key relationship. I speak to so many families who, that is one of the biggest challenges that they're facing over anything else. And we need to make sure that not only the parents and carers are supported, but the siblings are supported as well, the entire family.'* – *Participant, NSW family and carer online roundtable*

Targeted supports for children in the NDIS

While governments have suggested targeted supports would be for children not in the NDIS, families, carers and stakeholders highlighted many children with disability who may be in the NDIS (or able to access it in future), will still require access to short-term early intervention support outside the NDIS. For example, children with vision and/or hearing impairment require supports to access early childhood, schools and places in the community that may not be fully funded in their plans. Some stakeholders also pointed out where supports are lacking, such as in regional, rural and remote areas, group programs for children that may come under targeted supports may be the best or only option for supports available.

Other needs to ensure children and families access targeted supports

Parents and carers noted specific things they need to make sure they and their children could access supports including:

- Having adequate information about supports available and these supports are promoted through campaigns and other awareness strategies.
- Respite supports which parents said makes a big difference to their ability to engage with capacity building programs. This was a very common thing parents and carers said they need but do not have access to. Respite was often linked to the need for time and opportunity for one-to-one capacity building.
- Transport to access services and supports, which was particularly an issue for families in regional and rural areas.

*'I think support in funding transport costs and/or having someone to drive us to access supports that are further away would be incredibly helpful. I have to spend hundreds of dollars each week on fuel because I have to travel so far for my children's therapies and it is increasing the stress on our already stressed family due to costs'. – **Individual respondent, supports for children questionnaire***

Delivering targeted supports through playgroups

Stakeholders shared different examples of how targeted supports could be delivered through family-centred initiatives to help to break down barriers to access.

This included examples where playgroups are delivered through mobile 'play vans'.

The 'play vans' provide bespoke, place-based wraparound supports to families who face barriers to accessing services. These might include lack of access to transport, language barriers, lack of knowledge of services available and where to find them and distrust of government services. Playgroup sessions are led by experienced facilitators and respond to the needs of individual children and families who participate. The sessions are inclusive of children of all abilities.

These examples reiterated the importance of using playgroups as a soft entry point for families into other services. Facilitators engage with a range of community supports including the local health networks, dentists, Service NSW, Centrelink, allied health professionals and libraries to help families access crucial supports along with many other essential services families may not gain access to independently.

Delivering targeted supports

How should targeted supports be delivered

For families and carers, there were three common themes about how targeted supports should be delivered.

- The need for targeted supports to be **delivered where children live, learn and play**.
- The need to have supports **delivered in different ways**—such as one-on-one (in different environments and settings) and in group settings, so they meet the needs of the child and family.
- The need for **governments to invest to make sure supports for children and their families are available and accessible**. Limited availability of allied health and other types of supports, costs to access them in private practice and long wait times makes it difficult for families and children to access supports, especially if they're not in the NDIS.

Choice and control

Having choice and control over the supports children and families access remained an important feature of how targeted supports should be delivered, noting even families not accessing supports in the NDIS should still be able to plan for and access supports to meet their child's individual needs, goals and aspirations.

One key aspect of choice and control was to make sure there are different types of models of support available, from smaller local or specialised providers through to larger organisations.

Stakeholders noted it is important families receiving these services are enabled to access a variety of providers, including private practices, small businesses, and sole providers.

*'It is important that families are given choice and control in what supports they access as a parent or guardian knows first hand which supports have and have not been effective.' – **Individual respondent, supports for children questionnaire***

Integrated support models

Care coordinators / key worker model

Case management and worker models were identified as critical for supporting families and children, particularly between the NDIS and mainstream services. This was consistent with the findings in the General Supports Consultation Report.

Families particularly suggested a single coordinating point would reduce burden and help to improve their child's and family's access to supports. This also provides a stronger person-centred and whole of family approach.

*'Having a care coordinator who is also a trained therapist to reduce the number of people in the care team. Occupational Therapists and Speech Therapists are great at care coordination and can use a therapeutic approach to support the family and the child together.' – **Individual respondent, supports for children questionnaire***

In considering models of service delivery, many stakeholders commented specifically on the key worker model (variously referred to as lead clinician / practitioner model) – particularly in the context of supports for children with developmental concern, delay and/or disability and their families. 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 as:

- **families feeling more connected** throughout their journey
- **minimising the number of relationships** families need to navigate
- **improving collaboration** across diverse teams of professionals
- **supporting access for children and families in rural and remote settings to** reduce the need to have all relevant allied health professionals available on site and they can be consulted with as needed.

Retelling stories

One of the main barriers to supports many families identified was having to share their story multiple times, and/or having to fill out many sets of paperwork and make appointments each time their child needed to re-engage with supports or access different types of supports.

Some families, and many of the organisations who support them, mentioned the key worker model or similar case management/coordination roles can reduce this burden. They often suggested a key worker facilitates sharing of information, knowledge and skills for a child and family across environments, reducing the need for a family to retell their story across stakeholders as their child transitions into a new environment.

'The key worker model of care has been really helpful for my family, who has multiple neurodivergent children. Having one person I can speak to, instead of having to tell my story over and over again, and she just organises the therapies, has been the best.' – ***Submission***

It was noted these models required highly experienced professionals across the multidisciplinary team and, to be successful, the key worker must be determined based on the child's needs. Others suggested the key worker model is not universally appropriate, particularly for children with invisible disabilities, developmental delays or complex needs.

These stakeholders suggested a **wraparound allied health model, where families have access to discipline-specific expertise**, is crucial for accurate assessment and targeted intervention.

Integrated, multidisciplinary teams and supports

Regardless of the specific model used, one of the main areas of feedback was the importance of having collaborative team approaches, such as transdisciplinary, multidisciplinary, key worker and interdisciplinary teams. This was seen as integral in early childhood intervention.

Many noted access to a multidisciplinary team was critical and children and families should have access to key workers with diverse skill sets. The discipline of a key worker should best suits their needs, while still ensuring access to other experienced professionals within the multidisciplinary team, and specialised, discipline-specific interventions are available.

It was also discussed these models should help to connect disability supports with early intervention, by being inclusive of early childhood intervention providers (e.g. allied health and qualified early childhood teachers), ECEC educators and schoolteachers, paediatricians, early childhood nurses etc.

Ideally, they would better integrate and leverage child and family needs across both targeted and general supports, with case managers/key workers being able to offer individualised supports and advice while also connecting families and children with programs and other opportunities happening in their community.

'The key worker is supported by an active, wider 'village' of supports – a diverse team of professionals who collaborate closely with the keyworker, sharing their skills and knowledge and expanding the key worker's capacity.' – ***Submission***

Supports delivered in group environments

Some families and carers described positive experiences with group programs and noted these are important in their child's development. While supports delivered in group environments may not suit all children's and families' needs, many suggested having more of these available would be an effective way of delivering some supports to more children and may be more accessible for families considering supports for the first time.

Some families described benefits of group environments where there are children with mixed disabilities and disability/non disability groups, including those who involve siblings, as this can help to increase social skills and encourage a positive understanding of differences in children at an early age.

‘One-stop shop’ for services

A common idea from families and carers was to have a single hub or ‘one-stop shop’ where they could find and connect with services. This included:

- **Place-based hubs** where they could speak with similar services in the one location.
- **Digital platforms or hubs**, where they could search for local supports and services specific to their child’s needs. Respondents reiterated services listed need to be available or clearly list their wait times, to avoid them spending time contacting services that aren’t accepting new clients or have 12 month wait times.

‘Without clear and straightforward pathways, families may struggle to navigate the system. There is a pressing need for a streamlined, user-friendly online referral system and database that offers consistent information about available services, referral processes, eligibility criteria, and access points for families and professionals.’ –
Individual respondent, supports for children questionnaire

Some stakeholders also agreed with this, suggesting a single point of entry for disability services is important. For example, the Centre for Excellence in Child and Family Welfare suggested ‘a platform linking all available service offerings together could be implemented to streamline access for families. Establishing a single point of entry for all disability services where families can access information, apply for support, and receive guidance on available resources could reduce the administrative burden on families. This could be a centralised online portal, complemented by regional service centres, that could act as a ‘one-stop shop’ for families—like the Child and Family Hubs that can provide families with access to a range of services and supports in one place.’

Chapter 3: Implementation, workforce and integration with community and mainstream supports

Commissioning and funding

Disability representative organisations (DROs) proposed there needs to be short, medium and long-term funding solutions for foundational supports, and these need to be co-designed with representative organisations. Transitional funding for general supports is important and covered in more detail in the full General Supports Consultation Report.

We heard strong commissioning and contracting arrangements are required for the successful implementation of foundational supports for children under 9 and their families, carers and kin, in order to build a stronger, more sustainable and equitable support system.

Many stakeholders recommended that commissioning and funding models for targeted supports for children need to be **coordinated and have a national approach to sustain funding and programs, while allowing for flexibility to address local community needs**, such as taking into account differences across regions and the need for tailored and culturally appropriate supports. Many said this would improve equity and ensure more consistency in available quality supports across states and territories.

Improved coordination in commissioning

Many stakeholders noted that foundational supports are an opportunity to improve coordination and streamline responsibilities for funding, to improve outcomes for children. Some suggested this include joint commissioning for programs and supports between Commonwealth and state and territory governments. CYDA, for example, recommended governments 'coordinate the commissioning of inclusion support in ECEC and foundational supports to streamline responsibilities and funding'.

Flexible and longer-term funding models

A lot of families and carers, allied health workers and other stakeholders, spoke about the importance of having **flexible funding models** to access targeted supports for children. They explained that flexible funding helps to:

- have and adapt approaches to suit families and children, accounting for their specific circumstances (e.g. living in regional verse urban areas) and culture
- account for different stages of life and development
- improve integration between this and other supports, (e.g. if there are mainstream services—such as programs at a child's school or local government program they can access for free, then funds could be spent on other areas of the child's needs or development).

There were mixed views about **block funding** for foundational supports. While some stakeholders suggested that block funding models will be needed to implement foundational supports effectively, particularly to ensure programs for children and families are available in the community, many strongly disagreed with reintroducing block funding and instead suggested prioritising funding and investment in **localised, community-driven programs**.

In addition to flexible funding arrangements, we heard that long-term funding is important to sustain organisations who are delivering child and family programs, so they can sustain and build on models of supports over time. People identified that local organisations, especially regional disability and family advocacy organisations who are known in the community become the first point of contact for many families so it's important they remain in place with sufficient funding to support all needs.

Flexible delivery

Having a variety of supports and programs delivered at different times and in a variety of ways was important to many families. This included having programs available out of hours and the ability for programs to do outreach into rural and remote areas.

To deliver this, there needs to be **funding that accounts for the different modes of delivery**, avoiding a 'one-size-fits-all' approach so travel, out of hours work, repeat visits and other factors are allowed for.

Some stakeholders suggested 'rigid block funding isolated to a narrow range of commissioned services will restrict access and reduce service quality, which will impact on children's developmental outcomes'.

Rural and remote delivery

As a result of workforce and service gaps, **different types of funding and service models may be needed in rural and remote areas**.

The design of these should be community-led so they are relevant to the context of a location and consider the environment, local community needs and the existing service footprint of the region.

First Nations delivery

Peak First Nations organisation and National Voice for Aboriginal and Torres Strait Islander children, SNAICC, recommended, to ensure no Aboriginal and Torres Strait Islander child misses out on foundational supports, governments should:

- provide funding to establish and sustain Aboriginal Controlled Community Organisations (ACCOs) integrated early years services empowered to provide general and targeted foundational supports in all communities, underpinned by the dedicated funding model
- prioritising ACCOs, provide interim funding through the ECEC Inclusion Support Program to provide foundational supports to all Aboriginal and Torres Strait Islander families in all communities, including funding for mobile provision of foundational supports in regional and remote locales

Furthermore, SNAICC recommended the design of foundational supports for children include a needs based, sustainable funding model for ACCOs and governments commit to commissioning foundational supports through building on and enhancing the early years ACCO funding model.

Workforce capacity and capability

Governments recognise, to make sure a foundational support system works well for children and their families, it will be important to build workforce capacity and capability. For some of the services described, the workforce and services already exist and might need to be expanded, for others emerging practice or new services will be required.

Workforce

Priority workforces

The consultation paper proposed foundational supports could look to be delivered through existing services where appropriate but would need to be phased in over time.

Families, carers and other stakeholders consistently raised concerns about not having a sufficient workforce to deliver foundational supports, if further investments are not made in new roles. This included in areas with longer waitlists, such as allied health and mental health supports, as well as putting in place roles to make it possible for families and carers to navigate a new foundational supports service system.

When it came to leveraging existing workforce and services, families, carers and other stakeholders most often mentioned workforces in early childhood development such as:

- early childhood education providers
- child and family support workers
- maternal and early childhood health professionals
- allied health workers
- supported playgroup facilitators
- sibling support workers

Workforce diversity

We also heard about the need to have diversity in the workforce so supports for children can be tailored and appropriate. It was noted some families may feel more comfortable accessing supports from workers and organisations who identify with their culture, disability or speak their language. Stakeholders suggested a focus on having a stronger workforce of people from First Nations and CALD backgrounds, as well as providers who have disabilities themselves.

In addition to having a diverse workforce, many stakeholders recommended that dedicated strategies should be in place to grow the workforce in specific areas of intersecting need. For example, to develop local Aboriginal and Torres Strait Islander early years workforces.

Workforce training

There was a strong focus on training for the workforces that may deliver foundational supports. Families and carers specifically mentioned more training to be given to allied health and early childhood education workers about different disabilities. Additional training was also suggested for teachers, and other roles in schools, to better understand disabilities and developmental delays in children, and how this presents. Some suggested teachers need more training and awareness of what disability and early childhood supports are available to help children and parents, so they can refer them to supports including in their local community.

Integrating with community and mainstream settings and services

Participants were asked for their ideas about how different sectors (e.g. disability, health, early childhood settings and education) can work together to better support children with developmental concern, delay and/or disability, and their families and carers.

Families noted the value of broader support systems working together. They often named mainstream settings such as kindergartens, playgroups, primary schools, local hospitals, health services and local governments as important for providing information, advice and programs. They suggested these services often have trusted existing relationships with families and offer appropriate, trustworthy capacity building resources and supports.

Families talked often about the need to have more coordinated care focused on the whole child and family, rather than having to negotiate between systems about who is responsible for what.

> *'Parents shouldn't have to negotiate the boundaries of the services and their child should always be seen as a whole child'. – **Individual respondent, supports for children questionnaire***

However, some people also highlighted risks with integrating foundational supports within health, medical and education settings, noting targeted supports should be strength-based and family focused. For example, the Private Practice Early Childhood Intervention (ECI) Community of Practice noted in their submission 'foundational supports must remain distinct from health services to avoid reverting to a medical model of ECI'.

Health services

Community health

Many stakeholders, as well as families and carers, acknowledged health supports for children with developmental concerns are often delivered through different types of community health services, and this should be integrated with a targeted supports system.

The use of local Aboriginal community controlled health centres was particularly important in the context of services for First Nations children and families.

Local health networks were also identified as important for supporting collaboration between public and private providers and continuing education opportunities that would support a foundational supports system.

Example: Kimberley Aboriginal Medical Service

Kimberley Aboriginal Medical Service is an example of a community controlled health service already delivering programs that provide effective early childhood supports in a remote setting. Their Remote Early Childhood Supports Program is a blocked funded program that delivers occupational therapy and speech pathologists to the remote Kimberley and is free for families.

Maternal and child health services

Many noted existing services such as **maternal and child health services** play a significant role in providing reliable entry point for younger children with developmental concern, delay and/or disability. They noted these services are established, trusted sources of information and are well integrated with community-based services and networks.

Some stakeholders noted they provide an important touchpoint to families because they are already frequented and trusted by a broad section of the community and are able to provide an accessible, and supportive avenue to foundational supports, while ensuring the family and child remain connected to their existing community networks.

> *'Existing services such as Maternal and Child Health services, early childhood education services, schools and Community Health Centres have already established reputations as trusted sources of information and have built connections to other community-based services and networks... this makes them invaluable as avenues through which families can connect easily with appropriate, trustworthy, resources and supports.' – Submission*

> *'Local communities and systems can be an asset for a parent or carer, particularly when they first have a concern about their child's development. It is often the maternal and child health nurse, GP, early childhood educator, friend or family member who is the first contact point responder and has the opportunity to provide information to link a parent/carer to the right supports.' – Submission*

Telehealth to address workforce, location gaps in services

The consultation paper specifically asked about opportunities for use of telehealth in rural and remote areas, noting the issues with availability of allied health and other health professionals in these areas. Stakeholders generally indicated telehealth is an appropriate service model in the context of children and families in rural and remote setting as in any other, to the extent that the **appropriateness of telehealth** remains dependent on the needs and capacity of the family and child, regardless of geographical location.

Some noted telehealth has proven to be a valuable tool for families, particularly those in rural and remote areas, by reducing the need to travel to access services. Some families and carers named telehealth as an important service in accessing support for their child.

Others noted telehealth has its limitations, and it should not become a replacement for face-to-face interactions. They expressed concern:

- it doesn't become an excuse to drop the ball on providing staff, and investing in services, to regional and rural areas
- some families within rural and remote areas do not have reliable access to internet, a suitable device, or do not have the skills with technology to access telehealth
- some individuals, particularly those with higher needs are not able to engage with telehealth
- some types of assessments or interventions are not suitable for telehealth (for example, equipment prescription).

Some also noted children with developmental delay are likely to have reduced verbal capacity and may prefer to communicate through drawings or play, which do not lend themselves to online communication.

Early childhood and school education

There was a significant focus on the role of schools, early childhood setting and teachers in being an integral part of the system that supports children with disability, developmental delay and/or concern and their families, carers and kin. As discussed throughout this report, the roles of schools and early childhood education is very important in children's lives, and the lives of their families including siblings.

Many stakeholders, families and carers agreed **embedding supports across environments**, including early learning and school settings is critical. The benefits included:

- **More collaborative and coordinated supports.** We heard from families and carers about the importance of coordination and collaboration between their child's allied health supports and the early learning environment. In addition, people suggested delivering targeted supports in schools and early childhood settings could help to increase collaboration between disability support providers and education providers, improving access to the specific supports a child needs.
- **Reduced time and burden**. Some families suggested supports delivered in a child's school or education setting would support the whole family by reducing the need for parents and carers to move children between settings (e.g. school to clinics or community programs) on a regular basis.
- **Natural setting.** Some stakeholders suggested there are benefits in implementing therapy and strategies in the child's natural environments, which includes there they learn and play, and this help to ensure a more seamless integration of support into their daily life.
- **Improved inclusion.** Some suggested embedding access to disability service practitioners where children learn creates opportunity for greater understanding among parents in the school community about the needs of children with disability, development delay and/or concern.

*'Having a therapist attend kinder has helped my child enormously! We have KIS funding but that is mostly to help all the children at kinder and ensure the children are safe. Having the therapist attend allows for any challenges in the mainstream setting to be immediately rectified or noted and worked on in therapy. My child can now actually engage in kinder not just attend'. – **Individual respondent, supports for children questionnaire***

Role of teachers and early childhood educators

People noted a strong relationship between teachers and parents is key in supporting children and building partnerships with families to ensure inclusivity and accessibility in education environments. Feedback from participants on the **role of teachers** and **early childhood educators** strongly supported their value as part of a multidisciplinary team. Comments, which often came from parents, representative organisations and allied health sector professionals, included:

- the teaching profession has specialist skills in early childhood development norms and the capacity to identify where children may have developmental differences outside of these norms across developmental domains

- teachers are essential members of multidisciplinary teams
- teachers are valuable in providing parent capacity building, information and training sessions, facilitation of group programs for children and young people and support for allied health staff to work with children and young people
- teachers are a particularly essential component of ECI teams in regional, rural and remote areas, where it is difficult to attract and retain allied health.

> *'Early Childhood Teachers are a critical service and support to help support families and professionals to build knowledge, skills and abilities. They have extensive training in childhood development and are able to consider learning needs and strategies relevant to children and integrate this into interventions.'* – *Submission*

> *'Foundational supports should reflect and leverage the important relationship that early childhood educators have with children and families, including their deep knowledge of behaviour, development and wellbeing of children in their care.'* – *Submission*

A small number of school sector stakeholders contributed to the consultation process. Further consultation with educators and schools would be needed to consider how targeted supports for children under 9 and the roles of teachers and early childhood educators might work together.

Roles within schools and school regions

Stakeholders and parents consistently raised a need for specific roles within schools or school regions to better support and coordinate access to targeted supports for children such as allied health supports.

Many noted access to and coordination of allied health professionals in schools varies greatly depending on the school and leaders, and this should be made more consistent with stronger national and state/territory policies to support the integration of additional supports that children need, and their early childhood education and schooling.

Both stakeholders and parents and carers, however, also noted schools have limited time and capacity to coordinate with many allied health and other support providers and so there needs to be a more coordinated system to support this.

Some stakeholders suggested a **small panel of providers** could be established to perform the role of a 'Transdisciplinary ECI Provider' for each school region. They suggested this would have the benefit of:

- facilitating and continuing to give families choice and control
- reducing the number of providers schools need to liaise with, thereby reducing administrative burden
- ensuring smooth transitions between early childhood education and primary school settings.

Notable issues or concern with the delivery of foundational supports in schools and early childhood settings

Some people raised issues or concerns about the delivery of capacity building supports in schools and early childhood settings. This included:

- **Increasing expectation of teachers,** noting there is a limit to what can be expected of teachers. Some noted while mainstream services should be inclusive, and teachers have a key role as a regular contact point for families in the provision of information, their primary role is the education of children.
- **Potential to limit / reduce capacity building.** Some noted while some parents may find it more convenient for therapy to take place at school, this can hinder the transfer of skills and capacity building where families are indirectly engaged.
- **Inconsistent approaches to supports in schools, with a few responses noting some schools** make a choice not to allow access for external service providers. Stakeholders Education services and settings must be designed with adequate resourcing and physical space to enable inclusive practices to be implemented.
- **An over-reliance on early education settings can disadvantage some children and their families** who may not engage in these systems early in a child's life.

Mental health system and care

Families and carers raised the need for improved access to psychology and mental health services for children as part of targeted supports.

They shared experiences of not being able to get help through current mental health systems, and there are significant wait lists and costs associated with accessing services especially if they are required to go through the private system.

Families, carers and some stakeholders suggested targeted supports include access to mental health supports, such as through:

- better pathways and referrals between different health, education, early childhood and mental health supports—carers reported their children get lost between these systems when they are in crisis
- increasing Medicare access for children to get more support for mental health (without a formalised mental health care plan)
- providing wraparound family-centred supports in psychology, mental health and social work

Local government

Some families and carers suggested having supports available within local government settings, including recreation and community centres who already provide some therapies or programs to support different parts of the community. Some allied health and other professionals also suggested integrating supports with local government and local facilities.

Other considerations in the design and delivery of foundational supports for children

Community attitudes and awareness

Some feedback mentioned the need for improving community attitudes and awareness about disability and developmental delay in children. Some parents and carers said there are barriers to asking for help and accessing supports due to stigma and discrimination. This impacted supports for their children to participate in the community, in group programs and at school.

Working in partnership

It was particularly important to families, carers, and organisations who represent them, governments commit to working in partnership with them to make sure a foundational supports service system is safe for all types of children and families.

Some specific areas this was highlighted included for:

- **parents with a disability**, including intellectual disability, it's important to work with them and representative organisations to tailor information and support, recognising where they may need extra support to engage and to ensure information and advice about their children is provided in accessible ways
- **Aboriginal and Torres Strait Islander children and families**, it is important governments co-design supports in line with agreed Closing the Gap frameworks **and** to ensure they experience cultural safety across all parts of the foundational supports system
- **multicultural families**, it's important governments work closely with community, faith and cultural leaders and organisations to engage parents in language and culturally safe ways, particularly new and recent migrants who rely on these trusted community networks for support.

Best practice guidelines

Many stakeholders noted the intent of foundational supports must align with the approved Best Practice Guidelines for Early Childhood Intervention, and other strategies such as the Early Years Strategy and Australia's Disability Strategy.

Data, measurement and reporting

Stakeholders recognised the importance of making sure the design of foundational supports includes appropriate monitoring and sharing of information across early childhood, disability, education and health to measure needs, progress and outcomes for children.

A specific data framework and outcomes measurement should be set up for the monitoring and evaluation of supports for children, particularly targeted supports which will have different inputs and outcomes to what is covered in the general supports service system. Stakeholders identified some additional accountability measures such as reporting regularly under the Early Years Strategy and to the Joint Council on Closing the Gap.

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. These included:

- **Group discussion with posters** – participants contributed ideas through discussions at their table and on sticky notes.
- **Targeted discussions** with stakeholders and priority groups. These were held with organisations and groups while on location.
- Use of an accessible **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 across all supports for children consultation events and written, audio and video feedback was then consolidated into this report.

Foundational Supports

Foundational Supports Consultation Report

The SOCIALDECK

Contents

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.

Executive summary

In 2024, The Social Deck consulted over 4,000 people across Australia about foundational disability supports. This report summarises key insights specifically on disability advocacy, highlighting its critical relationship with foundational supports.

Participants clearly indicated advocacy—people speaking up for themselves or others—is vital for foundational supports to be effective.

Disability advocacy and foundational supports are closely connected. Effective foundational supports help people engage in different types of advocacy, while advocacy improves the quality and relevance of supports. Consultation participants emphasised advocacy ensures people with disability can access services, uphold their rights, and participate fully in their communities.

Advocacy's role in information, advice and referrals

Disability advocacy organisations are trusted sources of information and were identified as the fifth most likely source people would use. They contribute by:

- providing accessible, tailored information
- offering personalised advice
- making appropriate referrals
- supporting communication for people who struggle with written materials
- acting as trusted sources of up-to-date information.

Key barriers include limited availability of advocacy services to address issues such as NDIS eligibility restrictions, and accessibility issues including a lack of advocacy access in regional, rural and remote areas. NDIS eligibility restrictions include people with disability who do not meet section 24 of the *National Disability Insurance Scheme Act 2013* relating to eligibility and List A criterion, or section 25 relating to early intervention requirements. Advocates supporting people with disability with referrals to the NDIS have reported getting up-to-date supporting documentation, especially evidence addressing the exact criteria the NDIS needs, is a major issue. DANA advocated for minimal eligibility requirements for foundational supports, pointing to the issues already faced for advocates getting evidence for NDIS.

DANA noted in their submission ‘demand for advocacy sharply increased with the introduction of the NDIS, and funding injections have not effectively addressed this increase in need’ (p.16), including people who had been deemed ineligible for Scheme access. Family Advocacy suggested in their submission this spike in demand following NDIS introduction may be replicated when foundational supports are rolled out: ‘advocacy will be required to rectify individual and systemic issues caused by unintended consequences or the lack of clarity around roles and responsibilities’ (p.31).

Advocacy's role in capacity building

Advocacy plays an important role in building capacity for people with disability, their families, and communities by:

- providing information and education about rights and systems
- supporting skill development in communication and decision-making
- linking people with services and resources
- strengthening informal support networks
- identifying barriers and service gaps.

Participants valued peer-led advocacy organisations, community programs with lived experience involvement, and online groups who provide practical advice and emotional support.

Design, delivery and governance

Strong, independent advocacy is essential for the success of foundational supports. Participants suggested:

- advocacy must be considered in design, implementation and review
- people with lived experience and advocacy organisations should be involved in co-design
- advocacy organisations could form part of an oversight council for implementation of foundational supports.

Funding and independence

Participants frequently raised concerns about insufficient funding and unreliable funding cycles. Views were mixed on whether advocacy funding should be included in foundational supports or kept separate to maintain independence.

Meeting diverse needs

The consultations identified specific considerations for different populations:

- **First Nations** need culturally grounded advocacy, increased awareness of advocacy services, and representation in systemic advocacy.
- **Culturally and Linguistically Diverse** people need to navigate cultural conventions and attitudes, and address barriers to participation.
- **Regional, rural and remote** have significant gaps in service availability, with localised disability-led advocacy programs showing promise when adequately resourced.
- **Specific disability groups** have unique advocacy needs requiring targeted, lived experience-led approaches.
- **People with disability who have intersectional identities** need targeted supports that understand those intersecting needs.

Opportunities for strengthening advocacy

The report identifies several ways to strengthen advocacy's impact:

- Expand access to independent advocacy organisations, including for people not eligible for NDIS
- Provide long-term, reliable funding rather than short-term project funding
- Ensure advocacy services are accessible across all geographic regions
- Fund peer-led and disability-led advocacy programs based in lived experience
- Provide training for advocates to support people with diverse needs
- Recognise advocacy's role in working with families and informal supports
- Ensure advocates are trained in disability-specific needs, cultural safety, and trauma-informed approaches
- Include advocacy in the design, implementation and governance of foundational supports.

Background

In 2024, The Social Deck was engaged to undertake consultations to inform the design of foundational supports for people with disability. We held more than 78 consultation events and engaged with more than 4000 people.

The consultations focused on general supports and supports for children.

In this paper we have been asked to review the feedback we received through the general supports consultations to get an understanding of the perspectives shared on disability advocacy through this consultation process.

The purpose of the general supports consultations was to get feedback and ideas relating to the following key areas.

Information and advice: Access to quality information and advice on disability supports available to people and their families/carers and kin, and including help to find and connect with the right supports for their needs.

Capacity building for individuals: Improved access to peer support groups, support around self-advocacy, rights awareness, decision-making, leadership development, relationship building and life skills development.

Capacity building for families and carers: Peer support, parenting groups and workshops, education and training, building skills in advocacy and rights awareness, family leadership and development.

Capacity building for the community: Building the capability of community organisations (like sporting clubs, arts groups) and at the whole-of-sector or community level to deliver disability-inclusive and accessible services. Projects would focus on providing advice and resources to support equitable access to quality and inclusive community services for people with disability.

Other foundational supports consultation reports are available at:
https://engage.dss.gov.au/foundational-supports/consultation-reports

Types of disability advocacy and consultation themes

Disability advocacy and foundational supports are closely linked. Effective foundational supports help individuals and groups undertake different types of advocacy. Similarly, advocacy activities improve the quality and relevance of foundational supports.

Feedback from the consultations emphasised advocacy ensures people with disability can access supports, uphold their rights, and participate fully in their communities. It plays a key role in making the foundational supports system accountable, inclusive, and effective. Many organisations provided feedback that advocacy must be involved from the outset — in design, governance, and delivery — to ensure the system works for everyone, especially people who have historically been underserved.

A number of key overarching themes from the foundational supports consultations are directly relevant to different types of advocacy.

Self-advocacy

Self-advocacy occurs when people with disability speak up for themselves about their rights and preferences. To support self-advocacy, foundational supports must provide clear information, training, and capacity building programs.

Key themes related to self-advocacy:

- **Information and advice from trusted organisations:** People emphasised the need for organisations to receive reliable, long-term funding to offer advice and education. These organisations empower individuals by helping them understand and communicate their needs and rights clearly.
- **Local community delivery:** Providing foundational supports in welcoming community settings (such as neighbourhood centres and libraries) enables people to learn self-advocacy skills and access resources.

It should be noted organisations had varying definitions of self-advocacy (some included representative organisations advocating on behalf of their members).

Peer advocacy

Peer advocacy is where people with disability support each other based on shared experiences. Foundational supports can help peer advocacy through sustainable networks and peer groups.

Key themes related to peer advocacy:

- **Investing in peer support networks:** People strongly supported peer networks, saying these groups help individuals share knowledge about navigating disability support systems. Peer groups build confidence and understanding in a natural, supportive environment.

It should be noted it is also common among some groups and individuals who participated in consultations to use the term 'self-advocacy' to refer to systemic and individual advocacy and support delivered by lived experience groups. For clarity, this report will refer to this as peer advocacy.

Individual advocacy

Individual advocacy involves providing personal support to help a person address specific issues such as housing, health care, or discrimination. Foundational supports are essential for individual advocacy, providing access to advocates and experts who can offer practical help.

Key themes related to individual advocacy:

- **Digital and centralised platforms:** People wanted reliable digital platforms where they can find advocates and tailored support information. They also emphasised the importance of trained staff who can provide individualised advice through dedicated helplines.
- **Workforce training and sustainability:** Respondents emphasised the importance of having a trained workforce, particularly case managers or navigators. These workers can assist people directly with personalised advocacy needs, especially in regional or remote areas.

Family advocacy

Family advocacy involves family members advocating on behalf of a relative with disability. Foundational supports can provide family members with essential resources, education, and training so they can advocate effectively.

Key themes related to family advocacy:

- **Information and training programs:** Families benefit greatly from programs which provide clear information about available supports. Respondents suggested foundational supports delivered through general community systems like schools, health services, and early childhood centres, will help families to learn effective advocacy for their family to get access to the most helpful support for their family.

Citizen advocacy

Citizen advocacy involves long-term voluntary relationships between individuals with disability and community members who advocate alongside them. Foundational supports can encourage citizen advocacy by investing in strong community connections and sustainable local initiatives.

Key themes related to citizen advocacy:

- **Local community delivery:** Community hubs and neighbourhood centres provide spaces where lasting relationships and networks can develop, creating opportunities for citizen advocacy.

Systemic advocacy

Systemic advocacy involves changing broader systems, policies, and laws to benefit people with disability. Strong foundational supports depend on effective systemic advocacy, as it ensures services remain relevant and accountable to the community's real needs.

Key themes related to systemic advocacy:

- **Long-term and flexible funding:** Participants stressed long-term funding models enable advocacy groups and grassroots organisations to collaborate on systemic changes.
- **Quality, safety, and accountability:** People said systemic advocacy organisations should play a key role in monitoring quality, improving complaints systems, and ensuring supports remain inclusive and accessible.

Legal advocacy

Legal advocacy provides formal, legal support to protect the rights of people with disability. Good foundational supports include clear pathways to legal advice and representation.

Key themes related to legal advocacy:

- **Information about rights and legal protections:** Participants emphasised foundational supports must include accurate, accessible information about rights and legal protections. Effective legal advocacy ensures individuals can challenge unfair decisions, discrimination, or poor-quality supports.

Advocacy's role in information, advice and referrals

Many organisations said advocacy services are already trusted sources of information, advice and referral. These roles should be recognised and supported. Individual questionnaire respondents chose disability advocacy organisations as the fifth most likely source of information and advice they would use.

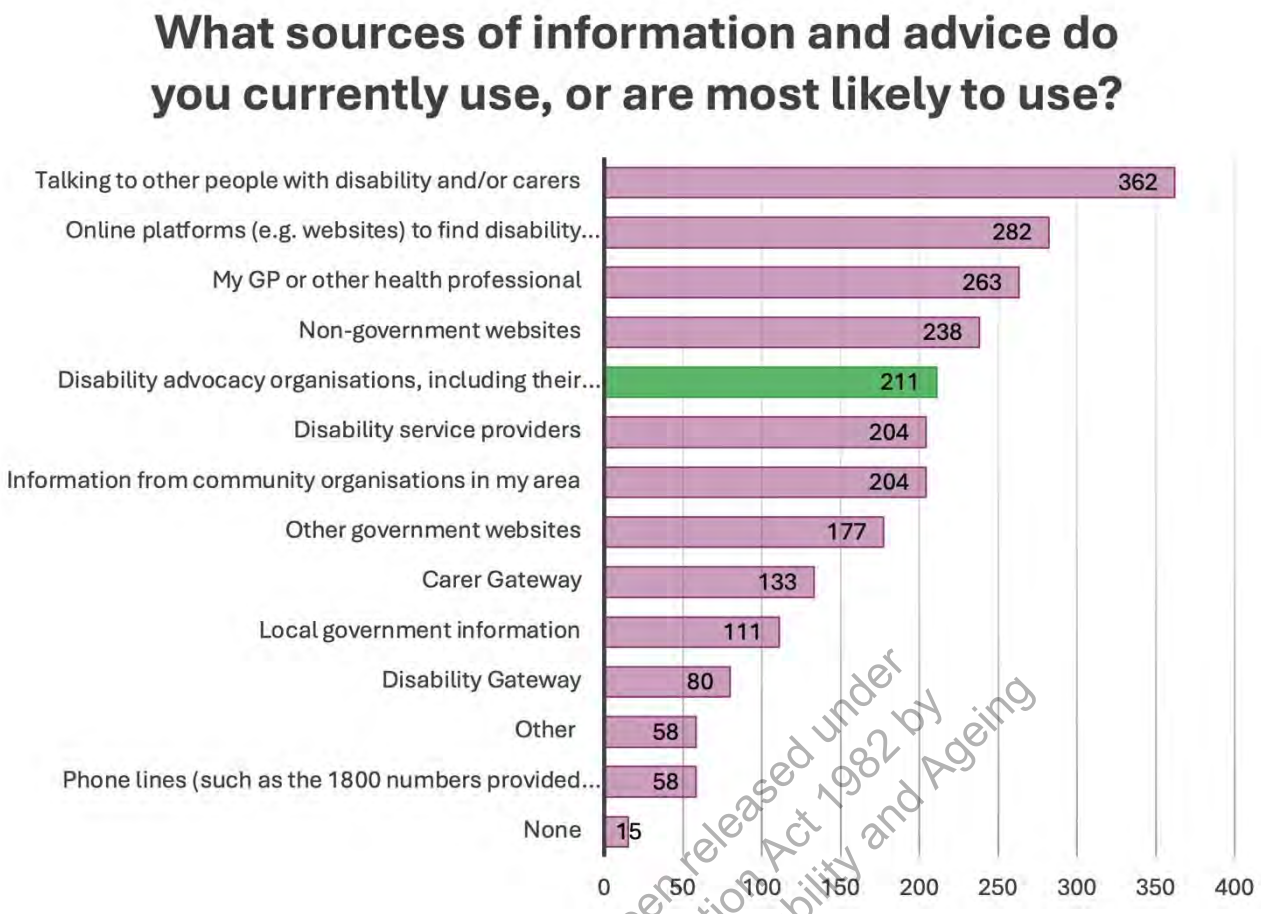


Figure 2: Sources of information with disability advocacy highlighted green (n=500)

How advocacy supports information, advice, and referral

Participants outlined several ways advocacy services and supports contribute to information, advice and referral:

- Advocacy services provide accessible, tailored information by explaining processes, eligibility, and entitlements in plain English or other formats such as Easy Read, videos, or with interpreters. This is especially important for people navigating systems like the NDIS, Centrelink, housing, health, or education.
- Advocates offer personalised advice helping people understand how general information relates to their own situation and figure out the best steps to take. This kind of support is especially helpful during stressful times or when someone doesn't know where to begin.
- Advocacy organisations help people connect with the right services by making referrals to peer networks, allied health providers, legal services, and community programs. Their strong local networks make it easier to find and access the support people need.
- When written materials or websites are hard to use, advocacy organisations provide information over the phone, on video, or in person, making it easier to understand and ask questions.
- Participants said they trusted advocacy groups to provide up-to-date information, often finding them more reliable than government sources, especially when official information was confusing or inconsistent.

Barriers to accessing advocacy for information and referrals

Participants noted a number of barriers to accessing advocacy for information and referrals:

- Many people said they couldn't access advocacy services due to long waitlists or because there were no services available in their area, especially in regional and remote communities.
- Some advocacy services only support people in the NDIS with legal advocacy which means others miss out on advice or help with referrals.
- When advocacy support isn't available, people often rely on parents, peers, or GPs. While these sources can be helpful, they may not have the time or knowledge to give accurate or complete guidance.
- Government services like Local Area Coordinators (LACs) were often described as inconsistent or unhelpful, and many people said their needs weren't being met.
- Some people found written materials and websites hard to use, especially if they had a cognitive disability, were neurodivergent, or had low digital literacy.

Strengthening advocacy's role in information, advice and referral

Participants suggested a number of ways to strengthen advocacy's role in information, advice and referral:

- Expand access to **independent advocacy organisations,** including for people not eligible for the NDIS.
- Fund **ongoing, not just time-limited, advocacy,** so people can receive help across multiple issues which is prohibiting advocates from being able to address issues inside the NDIS and in broader systems including education, employment and medical systems.
- Provide **centralised, easy-to-navigate referral points,** such as a single contact number or local hub connecting to multiple services.
- Ensure **advocates are trained in disability-specific needs,** cultural safety, trauma-informed approaches, and supported communication.
- Recognise the role of **peer-led and lived experience organisations** in delivering advice and referrals, especially where mainstream services are inaccessible.

Advocacy's role in capacity building supports

Consultation participants identified advocacy as playing an important role in building the capacity of people with disability, their families, and carers. Advocacy contributes to capacity building by supporting people to develop the knowledge, skills, and confidence to make decisions, access services, and participate in the community.

How advocacy supports capacity building

Participants described how advocates and advocacy services support capacity building:

- Advocacy services help people understand their rights, what supports are available, and how to navigate different service systems. This often includes using plain language to explain things like NDIS processes, Centrelink, housing, health, and education systems.
- Advocates support people to build skills in communication, self-advocacy, and decision-making. This might happen through one-on-one support, group workshops, or peer programs.
- Advocacy organisations often connect people with services or support networks, which is especially important when systems are complex or hard to access.
- Some advocacy organisations work with families, carers, and community members to help them better support people with disability in respectful and effective ways.
- Through their individual work, advocacy services often uncover systemic barriers and speak up for changes to improve access and support for others in the community.

What's working well to build capacity for families, carers and kin through advocacy

Participants outlined a number of ways advocacy was helping to build capacity for families, carers and kin:

- Advocacy services and peer networks help families build confidence and knowledge about their rights, available supports, and how to navigate complex systems. This includes support from professionals as well as peers with lived experience.
- Practical education and training such as workshops on disability rights, supported decision-making, and navigating services helps families better understand their role and equips them to support the person with disability.
- Clear, accurate, disability-specific information supports families to advocate effectively and build daily care routines. Parents and partners benefit from help translating medical needs into day-to-day actions, especially when communication or health needs are complex.
- Parent mentoring and emotional support help reduce isolation and burnout. Connecting with others who have similar experiences builds both knowledge and resilience.

What's working well in community to build capacity through advocacy

Participants outlined a number of ways advocacy was helping to build capacity in communities:

- Local and peer-led advocacy organisations (e.g. Rights in Action, Disability Advocacy and Complaints Service of South Australia, South West Autism Network, Consumers of Mental Health WA, Youth Disability Advocacy Network) have helped people connect with others in similar situations, understand available supports, and speak up for their needs.

- Community programs that include peer support and people with lived experience are valued. These supports help people share information, reduce isolation, and learn from others.
- Skilled professionals, such as allied health workers, social workers, and some support coordinators, have played a helpful role in connecting people to services and supporting advocacy.
- Online groups and informal networks (e.g. Facebook, webinars, local events) have helped people find practical advice and emotional support from others in their community.

Barriers to advocacy-led capacity building

Participants noted several limitations in the current system reducing the effectiveness of advocacy in building capacity:

- Short-term or project-based funding limits the ability of advocacy services to offer sustained support.
- High demand and long waitlists mean many people cannot access advocacy when they need it.
- Eligibility restrictions can prevent people with disability who are not in specific programs like the NDIS from receiving support. For example, some advocacy services only support NDIS participants or those seeking access to the NDIS, with specialist advocates who work in administrative law relating to the NDIS. Another example included a survey respondent sharing they use privately funded specialist advocacy which only supports advocacy in the education system.
- Limited regional access to advocacy services affects people in rural and remote areas.
- Inconsistent support coordination sometimes places the burden of capacity building on families and informal carers without professional assistance.
- Families often feel alone in advocating for their family member and report a lack of access to coordinated practical information.

Strengthening advocacy in capacity building

Participants made a number of suggestions to strengthen advocacy in capacity building:

- Increase investment in long-term, independent advocacy with a focus on building skills and confidence over time.
- Ensure advocacy services are accessible across all geographic regions, and to people both in and outside the NDIS.
- Include advocacy as part of the foundational supports system, with a clearly defined role in individual and community capacity building.
- Fund peer-led and disability-led programs using lived experience to support capacity building.
- Provide training for advocates to support people with diverse needs, including people with cognitive disability, mental health conditions, or communication barriers.
- Recognise and support the role of advocacy in working with families and informal supports to build understanding and resilience.

Advocacy and the foundational supports system

In submissions, organisations said strong, independent advocacy is essential for the success of foundational supports. Advocacy helps make sure people with disability can access the right supports and have their rights upheld. Organisations suggested:

- advocacy must be considered in the design, implementation and review of foundational supports
- people with lived experience and advocacy organisations should be involved in co-design
- advocacy helps ensure supports are responsive, trustworthy and uphold human rights – not just focused on independence.

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.

The group of Disability Representative Organisations (DROs) recommended a Commissioning Framework to 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. It was further suggested by the same group, advocacy organisations could form part of an oversight council to monitor the effectiveness of foundational supports and provide advice around any future expansion of supports.

Funding and independence for advocacy

Participants 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. Participants frequently raised lack of funding and short/unreliable funding cycles as a major barrier to sufficient and successful advocacy services. Many people reported advocacy services aren't available when needed due to limited capacity.

It was also commonly noted the current demand for advocacy services was far more than the supply and the introduction of foundational supports will likely increase demand for advocacy, similar to what happened with the NDIS.

Views were mixed on whether funding for advocacy should be included in foundational supports or kept separate.

Some organisations argued advocacy should remain separate from foundational supports to protect its independence. They said when advocacy is tied to service delivery, it can create conflicts of interest and reduce trust. Keeping it separate helps ensure clarity about roles and responsibilities and allows advocates to act only in the interests of the person with disability. Independent advocacy is seen as most effective when it has its own structure and funding.

Other organisations said incorporating advocacy into foundational supports could make the system work better. They said it might reduce duplication, streamline service delivery, and make it easier for people to access the help they need. Some functions, like providing information or making referrals, already overlap with advocacy. Including these functions in foundational supports could offer more flexibility and help people receive more coordinated support.

Other feedback

Through submissions, questionnaire responses and consultation activities, participants also provided the following insights into advocacy and its relationship with foundational supports and the broader system.

- Many organisations noted navigation and advocacy roles will have significant overlap with proposed general foundational supports. There is potential to strengthen advocacy/navigator roles for complex systems such as health, education, community supports, and legal services.
- Advocacy services should help people with intellectual disability and their family and carers build capacity for Supported Decision Making alongside individual advocacy when needed. Supported decision-making training should be evidence-based, co-designed, and delivered with people with intellectual disability, including support for families and carers.

Specific population needs

A number of considerations specific to certain cohort groups within the disability community, as well as related to intersectional experiences in general, were identified during targeted consultations.

Meeting specific and intersectional needs

Participants in targeted sessions commonly emphasised the need for diverse options in advocacy supports and services, including targeted services and other appropriate choices and people with disability with intersectional identities and with different disability needs. Some suggested part of this involves improving connections between other targeted services, such as LGBTIQA+ services, and disability advocacy services. Participants explained having an appropriate range of options is important so people have access to advocates and advocacy services who understand needs, barriers and other considerations specific to the cohort, and so they have access to safe and accessible services. This was reiterated in organisation submissions.

Participants also emphasised the importance of intersectional lived experience being part of advocacy, both in terms of having input from different perspectives and in terms of delivering peer advocacy support.

In a focus group with members of Self-Advocacy Resource Unit (SARU), participants advised disability groups who commonly have others speak for them, specifically people with intellectual disability, brain injuries and complex communication needs, should have a greater voice in advocacy. They also advised LGBTQIA+ and CALD people with disability need better representation in advocacy.

First Nations

Input from First Nations people with disability and organisations who support and advocate for them raised the following matters.

Awareness and access

Consultation participants reported there is low awareness among First Nations communities, especially in regional and remote areas, of advocacy services and around the role advocates can perform.

They recommended education for First Nations people with disability and their families and carers about what advocacy and self-advocacy services are, how those services can help and how to access them. They noted this can include for less immediate or direct family members who are in a position of speaking and advocating for the family. They also supported a holistic, 'no wrong door' approach to service provision, through which people with disability in First Nations communities can access advocacy along with other disability and community supports and services under a hub model.

Culturally safe and appropriate support

In submissions, First Peoples Disability Network (FPDN) and the Institute for Urban Indigenous Health (IUIH) each emphasised the need for 'culturally grounded' advocacy services. National Advocacy Collective also echoed this specifically for First Nations parents with intellectual disability in their submission. The organisations noted a lack of culturally safe advocacy creates barriers for First Nations people with disability.

They explained community-driven and peer-led advocacy initiatives 'offer vital emotional and practical support' and facilitate trust and empowerment. They suggested 'dedicated funding for community-controlled advocacy organisations'.

Representation in systemic advocacy

In the context of foundational supports development, FPDN recommended 'a co-design process that centres First Nations communities as partners, rather than recipients', in a way that incorporates localised representation. They advised this would promote better representation of First Nations people in decision-making and systemic advocacy, as well as promoting attention towards 'jurisdictional specific issues'.

Culturally and linguistically diverse

Participants in targeted engagements with CALD communities identified some key considerations for providing advocacy support.

Cultural conventions and attitudes

Participants, including advocacy service providers, identified some common conventions and attitudes affecting how people with disability from certain cultural backgrounds are best supported with advocacy.

- Some cultural attitudes and stigma around disability can mean parents of a person with disability might believe the person is incapable of managing their own life or making their own decisions. This can be a key factor to navigate in advocating for the person's rights.
- The nature of social systems within some cultures can determine who people with disabilities and their families, particularly in older generations, are willing to accept help from, including with people within their own cultural or ethnic group. This needs to be taken into account in ensuring there are culturally appropriate supports available to them.
- People with disability from some CALD backgrounds may have mindsets that discourage complaining or raising concerns.

Barriers to participating in advocacy

Advocacy service providers working in CALD communities identified some clients experience barriers to self-advocacy due to not being taken seriously when engaging with institutions and authorities, despite being fully informed and capable of advocating. This indicates supports designed to build capacity for self-advocacy need to be complemented by culture and practices in the systems people with disability engage with that are respectful to their voices and the voices of their family members.

Consultation participants also noted language barriers and cultural stigma can deter participation with peer advocacy groups.

Regional, rural and remote

Participants discussed some of the barriers and opportunities particular to supporting advocacy to people with disability in regional, rural and remote areas. Lack of availability of advocacy in regional, rural and particularly remote areas was a key barrier identified, which was often connected with lack of funding and resourcing.

Advocates servicing regional areas shared localised, disability-led advocacy programs have been effective while they have been able to run but noted these initiatives 'only last as long as the funding'. Specifically, they referenced a program run in six regional WA communities through which groups of local people with disability actively advocated to local and state government about projects and changes to improve their town for residents with disability. They suggested if these programs could be supported over a longer time period, it could become a fixed group with cycling members who could serve as 'the number one point of call for the local government' on any disability matters.

In discussing what forms of disability advocacy are needed, some regional advocates noted building the capacity of towns to support residents with disability is very helpful but also requires more funding.

Specific types of disability

Targeted consultations also included discussions with people with specific disabilities and their carers, including intellectual disability, autism, psychosocial disability, deafblind, energy limiting conditions and complex needs communities. Input from these groups confirmed the need for intersectional and targeted advocacy support, led by people with lived experience, also relates to the diverse needs and experiences in different areas of disability.

Specific insights:

- People with **intellectual disability** and their families consistently identified advocacy services and programs as a key source of support, particularly in helping to understand services and supports.

- ‘Self-advocacy’ groups are a common form of peer support accessed by people with **intellectual disability**. In their submission, Our Voice SA also recommended provision of ongoing funding for peer network programs ‘empower individuals with intellectual disability to make their own decisions, providing them with accessible information, decision-making tools, and opportunities to participate in advocacy and leadership roles’.
- **Autistic** people and their families identified a need for neuro-affirming advocates.
- Parents of **children with complex needs** would find it helpful to be able to select an independent advocate, such as from a registry, from when their children’s disabilities are first identified, to be a primary touchpoint for assistance. They noted having someone available in this way would also be very valuable as a reliable source of support if the parents became unable to support their children.