



Survey Report

Foundational Supports

For submission to Part 1 of the Foundational Supports consultation (General supports)

4 December 2024

Table of Contents

Publishing Information.....	4
Language note	4
Acknowledgement of Country	4
Submission Contacts	4
About the authors.....	5
About Foundational Supports.....	6
About the survey	6
Recommendations	8
Individual capacity building	8
Peer support	8
Self-advocacy support	8
Individual advocacy.....	8
Supported decision making.....	8
Disability employment supports	9
Barriers to general supports.....	9
Shopping and cleaning	10
Aids and assistive technology	10
Support or care at home	11
Support or care in the community	11
Psychosocial disability supports.....	11
Support for life transitions	11
Barriers to accessing targeted supports.....	11
Other supports	12
Finding out about supports	13
Survey information and method	14
Demographics of respondents	15
General foundational supports	20
What are people accessing?.....	20
Information and advice.....	21
Individual capacity building	21
Peer support	22
Self-advocacy support	23

Individual advocacy.....	23
Supported decision making.....	24
Disability employment supports	24
Barriers to accessing general supports.....	25
Targeted supports.....	32
What targeted supports are people accessing?	32
Shopping and cleaning	33
Aids and assistive technology	33
Support or care at home	34
Support or care in the community	34
Psychosocial disability supports.....	35
Support for life transitions	36
Barriers to accessing targeted supports.....	36
Other supports	39
Healthcare	39
Sexuality and sexual health	40
Housing.....	40
Parenting	41
Support within mainstream services	42
Participation in the local community.....	42
Education.....	43
Finding out about supports.....	43
Word of mouth	44
Social media	44
Community organisations	45
Online	45
Support coordinator, Local area coordinator, NDIS provider lists	46
Disability gateway	46
Other ways to find supports	46
Conclusion	47

Publishing Information

The moral rights of the authors have been asserted.

Author(s): Women with Disabilities ACT, Women with Disabilities Australia and Women with Disabilities Victoria.

Title: Survey Report: Foundational Supports

Language note

This submission reflects the overlapping experiences of marginalisation experienced by women, girls, non-binary and gender diverse people in our membership and broader community. Though these groups all experience gendered discrimination and marginalisation, not all identify as women. Where possible we have disaggregated data and experiences to highlight the specific experiences of trans, non-binary and gender diverse people with disabilities.

This submission uses ‘person first’ language (for example, women with disabilities). We acknowledge people describe their experience of disability in different ways, and for many people, ‘identity first’ language is a source of pride and resistance.

Acknowledgement of Country

The authors acknowledge the traditional owners of the land on which this publication was produced. We acknowledge First Nations people’s deep spiritual connection to this land. We extend our respects to community members and Elders past, present and emerging.

Submission Contacts

Kat Reed
Chief Executive Officer
Women with Disabilities ACT
(WWDACT)
E: ceo@wwdact.org.au

Julie Kun
Acting Chief Executive Officer
Women With Disabilities Victoria
(WDV)
E: julie.kun@wdv.org.au

Sophie Cusworth
Chief Executive Officer
Women With Disabilities Australia
(WWDA)
E: sophie@wwda.org.au

About the authors

The following organisations worked together to produce this joint submission:

Women with Disabilities ACT (WWDACT) is a Disabled Person's Organisation (DPO) that practices systemic advocacy on behalf of women, girls, and gender diverse people with disabilities in the ACT. We follow a human rights philosophy, based on the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW). WWDACT has won several awards for our work, including a Commendation at the 2019 Inclusion Awards for Excellence in Championing Human Rights and Equality, the 2015 Chief Minister's Inclusion Award for Excellence in Championing Human Rights and the 2012 International Women's Day Award, Community Category.

Women with Disabilities Australia (WWDA) is the National Disabled People's Organisation (DPO) and National Women's Alliance (NWA) for women, girls, feminine identifying, and non-binary people with disabilities in Australia. As a DPO and an NWA, WWDA is governed, run, led, staffed by, and constituted of, women, girls, feminine identifying, and non-binary people with disabilities. WWDA operates as a transnational human rights organisation - meaning that the impact of its work extends beyond Australia. WWDA's work is grounded in a human-rights based framework which links gender and disability issues to a full range of civil, political, economic, social and cultural rights.

Women with Disabilities Victoria (WDV) is a not-for-profit Disabled People's Organisation (DPO) representing women with disabilities in Victoria. The organisation is operated by and for women and non-binary people with varied disability experiences. WDV has a diverse membership of people from different backgrounds. Women with disabilities face intersecting forms of structural gender and disability discrimination. WDV actively advocates for our rights to safety and respect, with particular emphasis on disability policy, health services, violence prevention, workforce development and leadership. WDV envisions a world where all women are respected and can fully experience life.

Preamble

About Foundational Supports

On 20th September 2024 the Department of Social Services (DSS) opened their consultation period for designing a new system of disability supports, called 'Foundational Supports'. This concept was outlined in the Final Report from the Independent Review into the National Disability Insurance Scheme (NDIS). These supports were described as 'supports that offer people with disability a foundation to live a good life, included in the community, regardless of whether they are in the NDIS or not'¹.

In late 2023 National Cabinet agreed to jointly design these additional Foundational Supports to be jointly commissioned and funded by the Commonwealth and the States. Foundational supports are due to become available from mid-2025.

Women with Disabilities ACT (WWDACT), Women with Disabilities Victoria (WDV) and Women With Disabilities Australia (WWDA) welcome the introduction of additional funding for disability supports available to all people with disabilities in Australia. As the national and state/territory representative organisations for women, girls, non-binary and gender diverse people with disabilities, we urge the Commonwealth and State governments to design these new supports considering the gendered impacts, and the difference in access to disability supports that exists in the current support system.

Article 6 of the Convention on the Rights of Persons with Disabilities (CRPD) explicitly recognises the impact of multiple discrimination at the intersection of gender and disability. The Article emphasises the need for State Parties, of which Australia is one, to take focused, gender-specific measures to ensure that women with disabilities experience full and effective enjoyment of their human rights. The Australian Government must consider gendered impacts in designing and implementing reforms to the NDIS and the broader 'foundational supports' landscape.

About the survey

Given the significance of the proposed foundational supports system, we began consulting with our community before the formal consultation period. As a result, we designed a survey questionnaire before the consultation paper for general foundational supports was released. Some of the ideas and language used to

¹ Commonwealth of Australia, Department of the Prime Minister and Cabinet (2023). Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report. <https://www.ndisreview.gov.au/sites/default/files/resource/download/working-together-ndis-review-final-report.pdf>

describe categories of supports and what is 'in scope' for foundational supports has shifted since our survey report was designed. Where possible we have aligned our findings with the structure of foundational supports as laid out in the consultation papers.

The survey includes comments about funding for advocacy, employment supports and targeted foundational supports. Although this was not explicitly in scope for the current consultation process, we have included these areas in this survey report. These supports are integral to our community and should be considered and funded as the government designs this new system of supports.

Recommendations

Individual capacity building

Recommendation 1: Fund capacity building activities that are inclusive of people with disabilities who do not have a diagnosis or do not access NDIS.

Recommendation 2: Continue to fund and preference Disabled Persons' Organisations, Disability Representative Organisations and other community organisations to provide capacity building support under a new model of Foundational Supports.

Peer support

Recommendation 3: Include peer support activities within the remit of general foundational supports available to all people with disabilities.

Recommendation 4: Increase funding for peer support activities outside of those provided through the NDIS.

Self-advocacy support

Recommendation 5: Increase funding for self-advocacy supports and include it within the remit of general foundational supports available to all people with disabilities.

Recommendation 6: Fund support for people with disabilities to participate in policy co-design processes.

Recommendation 7: Fund additional self-advocacy supports for people with disabilities, including but not limited to education on disability rights, the Disability Discrimination Act, and violence against women, girls and gender diverse people with disabilities.

Individual advocacy

Recommendation 8: Fund individual advocacy under a new system of general foundational supports available to all people with disabilities.

Recommendation 9: Fund individual advocacy services to provide case management and longer-term advocacy support for people in complex circumstances.

Recommendation 10: Boost funding to individual advocacy organisations to meet demand during a time of transitional service provision.

Supported decision making

Recommendation 11: Fund supported decision making under a new system of general foundational supports available to all people with disabilities.

Recommendation 12: Fund support to improve decision making around sexual and reproductive health for people with disabilities.

Disability employment supports

Recommendation 13: Explore a wider range of employment supports available to people with disabilities under the new system of general foundational supports.

Recommendation 14: Explore how general foundational supports can support people with disabilities to advocate to their employers for reasonable adjustments.

Recommendation 15: Fund entrepreneurship and small business mentorship and support for people with disabilities, as a component of employment supports available in a general foundational supports system.

Barriers to general supports

Recommendation 16: Ensure that foundational supports are free for all people with disabilities.

Recommendation 17: Ensure a system of foundational supports promotes equity in access, and addresses unmet need. This includes ensuring that:

- (a) Funding for general foundational supports is directed to supports that operate at different times and in different locations.
- (b) Funding for foundational supports in regional areas is increased to address thin markets and promote growth in the number and range of supports available.

Recommendation 18: Fund Disabled Peoples' Organisations and Disability Representative Organisations under a new system of general foundational supports, as preferred providers of all general supports including capacity building, advocacy and information and advice. These organisations should be given preference over NDIS service providers or centralised government-provided services.

Recommendation 19: Increase funding to advocacy organisations under a new system of general foundational supports.

Recommendation 20: Transition away from time-limited grant funding models to sustainable and ongoing funding models for smaller disability organisations.

Recommendation 21: Resource Disabled Peoples' Organisations to provide case management and longer-term advocacy support, especially for individuals who are ineligible for the NDIS.

Recommendation 22: Create a system of general foundational supports that does not reproduce the gender bias of the medical system and is available to all regardless of diagnosis, age, or visa or residency status.

Recommendation 23: Ensure that general foundational supports are available to all people with disabilities, including those over the age of 65.

Recommendation 24: Design general foundational supports with a gendered lens, addressing the systemic gaps to ensure that women, girls and gender diverse people have access to the supports that they need.

Recommendation 25: Investigate opportunities for information sharing and linkages between the healthcare system and disability services, as part of the roll out of general foundational supports.

Recommendation 26: Provide training and information to GPs and allied health professionals about local foundational supports that are available. Fund community sector organisations to do advertising and outreach to the healthcare system to ensure the referral information is up to date.

Recommendation 27: Introduce funded positions in hospitals and healthcare settings (Disability Liaison Officers or similar) who can refer healthcare consumers to appropriate general foundational supports as they transition out of the healthcare system.

Recommendation 28: Fund disability representative organisations that work with underrepresented populations (e.g. culturally and linguistically diverse, LGBTQIA+, women and gender diverse) at both the state and National level, to provide general foundational supports that suit the specific needs of their communities.

Recommendation 29: Increase resourcing to community sector organisations to facilitate meaningful collaboration between organisations working with different community groups.

Recommendation 30: Fund new and existing local organisations who can provide a diverse and trusted range of supports for different community groups.

Recommendation 31: Investigate the community sector funding allocations and award rates to encourage staff to remain and be adequately compensated in their roles.

Recommendation 32: Do additional consultation with people with disabilities in regional and remote areas to ensure the rollout of general foundational supports increases the supports available to them in their area.

Recommendation 33: Fund and upskill people with disabilities in regional areas to design supports for their own communities (e.g. seed funding for Disabled Peoples' Organisations in regional areas).

[Shopping and cleaning](#)

Recommendation 34: Include shopping and cleaning supports in a system of targeted supports, available to people who are not NDIS participants but who need this assistance.

[Aids and assistive technology](#)

Recommendation 35: Include aids and assistive technology in a new system of targeted foundational supports.

Recommendation 36: Provide trials of assistive equipment to people with disabilities in regional and remote areas through a system of targeted supports.

Support or care at home

Recommendation 37: Include support at home in a new system of targeted foundational supports.

Support or care in the community

Recommendation 38: Include support in the community in a new system of targeted foundational supports.

Recommendation 39: Ensure people with disabilities are funded to access community activities.

Recommendation 40: Ensure people with disabilities are funded to arrange their own transportation to medical appointments.

Recommendation 41: Include support for exercise and healthy living in a new system of targeted foundational supports.

Psychosocial disability supports

Recommendation 42: Fund psychosocial supports under a new system of foundational supports, ensuring they are freely accessible to everybody.

Recommendation 43: Investigate disability training options for mental health and crisis services, including helpline services such as Lifeline.

Support for life transitions

Recommendation 44: Fund support for life transitions under a new system of targeted foundational supports.

Barriers to accessing targeted supports

Recommendation 45: Examine the interaction between targeted foundational supports and the healthcare system, and reduce the gap funding payments required to access targeted foundational supports.

Recommendation 46: Ensure that there are no out of pocket costs for people with disabilities to access a new targeted supports system.

Recommendation 47: Fund targeted foundational supports that are provided by local groups and organisations, to provide options for support outside of larger registered providers.

Recommendation 48: Ensure that a transition to a targeted foundational supports model does not impact on people's eligibility to access the NDIS or to access the supports they need.

Recommendation 49: Fund and administer the system of targeted foundational supports through community sector organisations run by people with disabilities, rather than through the NDIA or NDIS.

Recommendation 50: Consider funding boosts and incentives to accessible taxi fleets where they exist, to ensure accessible transport is available to people with disabilities when they need it.

Recommendation 51: Subsidise accessible transport for people with disabilities as part of a system of targeted supports to enable them to access the community, appointments and supports they need.

Recommendation 52: Adequately resource organisations and service providers implementing targeted foundational supports to ensure people with disabilities have broad choices and can find supports that suit their needs.

Recommendation 53: Develop rights-based disability training for people such as teachers, youth workers and healthcare professionals to increase knowledge of disability and support options under a new foundational supports system.

Recommendation 54: Fund disability organisations to deliver rights-based training for service providers and for people with disabilities about the intersection of violence and disability.

Other supports

Recommendation 55: Consider how the foundational supports system fits into a broader ecosystem of disability and healthcare supports and ensure that increased access to healthcare services is covered in the disability policy reform agenda.

Recommendation 56: Include gender affirming care, sexual supports and services, intimacy care, and access to disability-specific sexual and reproductive healthcare as part of the foundational supports system.

Recommendation 57: Fund comprehensive sexuality and sexual health education for people with disabilities under the foundational supports system.

Recommendation 58: Fund information, advice and services for perimenopause and menopause, including how it interacts with disability.

Recommendation 59: Consider how foundational supports can include support for housing, including provision of essential services like air conditioning and internet, and assistance with moving house.

Recommendation 60: Consider how the foundational supports system fits into a broader system of housing supports, and ensure that accessible housing is covered in the disability policy reform agenda.

Recommendation 61: Ensure specialised support for parents and carers through the design of the foundational supports system.

Recommendation 62: Fund specialised advocacy and navigation support for people with disabilities to facilitate their access to violence crisis services, community legal services and mental health helplines and intake.

Recommendation 63: Fund mainstream community activities under foundational supports to increase their accessibility to people with disabilities – including funding to hire accessible venues or upgrade existing venues, training for disability accommodations, subsidised cost, and transport options.

Recommendation 64: Ensure foundational supports are connected in with supports available through the education system, so students can access the supports they need.

Recommendation 65: Provide training to teachers and educators on foundational supports, so schools can be a point of referral to disability supports for students and families.

Finding out about supports

Recommendation 69: Fund peer networks and peer groups under general foundational supports, that address overlapping and compounding experiences of marginalisation, to allow people to develop networks of supports.

Recommendation 70: Ensure that disability and community organisations receive dedicated funding for maintaining social media pages and online spaces that provide trusted information about disability supports.

Recommendation 71: Investigate options for online social spaces hosted by disability organisations to enable people to come together and share support options outside of corporate or government programs.

Recommendation 72: Fund disability and community organisations to do advertising and outreach about their programs, and to enable them to share information about supports to the broader community.

Recommendation 73: Facilitate and adequately resource information sharing with community organisations outside of the disability sector, to ensure people from marginalised groups have opportunities to access information about foundational supports.

Recommendation 74: Revisit Disability Gateway and connect in with local disability organisations and partners to ensure that information is relevant and up to date.

Recommendation 75: Diversify plans and funding for information and advice outside of Disability Gateway – though it is an important option, it is not the primary way that people discover disability supports.

Recommendation 76: Prioritise sharing information about foundational supports with people who are not already engaged with the disability sector.

Recommendation 77: Create an information sharing strategy and fund diverse ways of information sharing and collaboration within and external to the disability sector.

Recommendation 78: Engage with the healthcare system and GPs to ensure people can be referred to foundational supports by their healthcare practitioners.

Survey information and method

The survey was open from 12 September to 14 October 2024. There were two versions of the survey: a plain English version available through SurveyMonkey, and an Easy Read version available through Accessible Surveys. Both versions of the survey included a combination of checkbox questions and free response. We asked about what general and targeted supports people currently access, what supports people would like to access but don't currently, and about barriers to accessing supports. We also collected some demographic information. All questions were optional.

The survey was distributed through social media networks and newsletters of Women with Disabilities Australia, Women with Disabilities ACT and Women with Disabilities Victoria. Respondents needed internet access to complete the survey.

We received 195 valid responses over the response period. A valid response had at least one answer to questions concerning foundational supports. Responses which only included demographic information were excluded.

182 responses were from people with disabilities answering about their own experience.

We received 13 responses from parents and carers of people with disabilities, who answered on behalf of someone else's experience. Responses made 'on behalf of' someone else have been excluded from our summary statistics, to ensure our numerical data reflects the lived experience of those who self-identify as people with disabilities. However, the written responses from parents and carers have been included in our survey analysis and has informed our key themes.

We analysed our data in two ways. We did quantitative summary analysis (looking at the number and proportion of survey respondents who accessed a specific type of support). We also did qualitative analysis of written responses. We received a large volume of high-quality written responses, with people generously elaborating on their

experience. We read each response and identified key themes that came up across several responses. We did this for each area of the survey (general supports, targeted supports and finding out about supports). Some people also received support or wanted to receive support that didn't fall neatly into the proposed 'general' or 'targeted' foundational support categories. We included it in this survey report.

Demographics of respondents

The following graphs indicate the demographics of respondents who indicated that they had a disability. Please note that we have only included statistics from respondents who have a disability themselves – we have excluded statistics provided by parents and carers without disability.

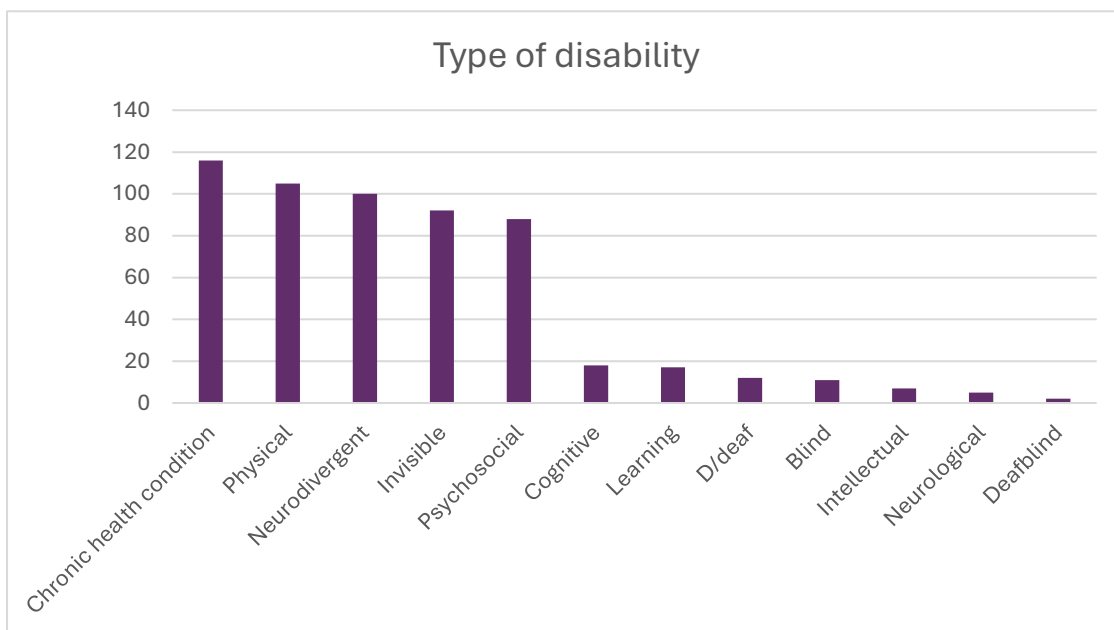


Table 1: Type of disability

The most common type of disability of our respondents was a chronic health condition [Table 1], followed by physical disability, neurodivergence, invisible disability, and psychosocial disability. Other disability types had a smaller number of responses. Most people reported more than one disability (152 people, or 84%).

The fact that a majority of respondents had a chronic health condition reflects the higher prevalence of these conditions amongst women and non-binary people. Many of these conditions, including autoimmune conditions, are less likely to meet NDIS access requirements due to their episodic nature². This means that respondents with a chronic health condition are less likely to currently have access to supports.

² Yates, S., Carey, G., Hargrave, J. et al. Women's experiences of accessing individualized disability supports: gender inequality and Australia's National Disability Insurance Scheme. *Int J Equity Health* 20, 243 (2021).

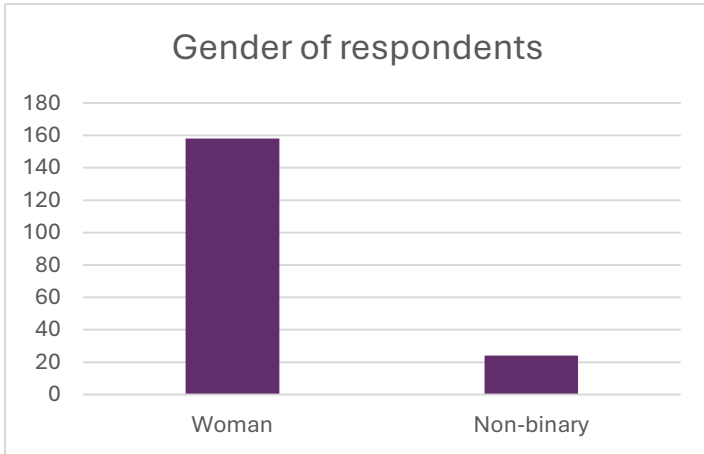


Table 2: Gender of respondents

87% of our respondents were women, and 13% were non-binary or gender diverse [Table 2].

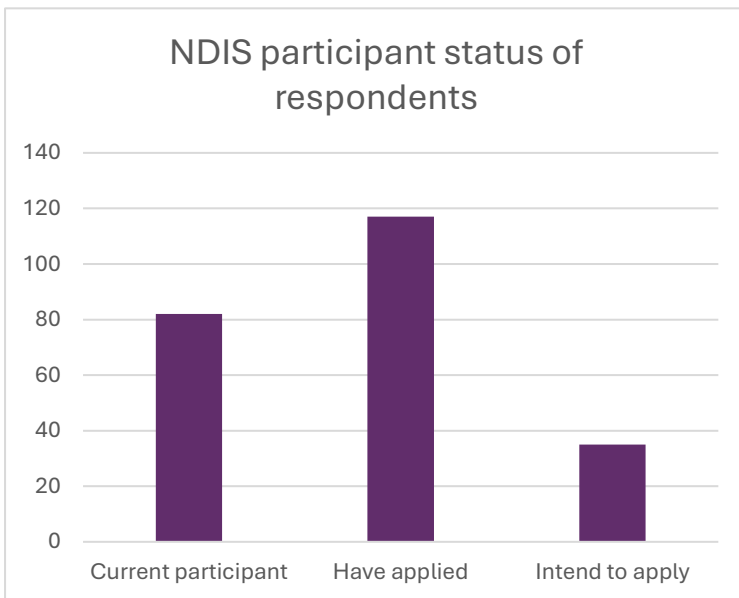


Table 3: NDIS participant status of respondents

45% of our respondents accessed the NDIS. 64% had applied at some point, and 19% intended to apply in the future [Table 3].

This means that nearly 20% of our survey respondents have applied to the NDIS but were not accepted. This reflects a systemic issue of underrepresentation of women, non-binary and gender diverse people accessing NDIS. Women and girls are less likely to be found eligible for the NDIS compared to men; and make up only 37% of NDIS participants.³

³ National Disability Insurance Agency (NDIA). (2021). Quarterly Report to Disability Ministers: 2021-22 Q1; National Disability Insurance Agency (NDIA). (2023). Quarterly Report to Disability Ministers: 2022-23 Q1. Supplement E

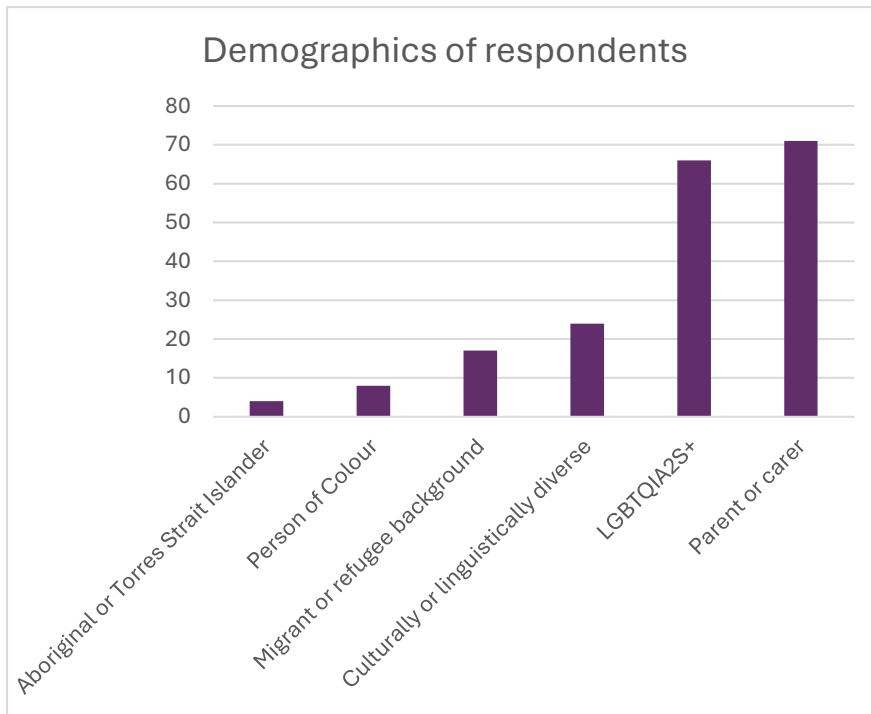


Table 4: Demographics of respondents

Our survey had a very small number of respondents who were Aboriginal and Torres Strait Islander people, people of colour, or people from a migrant or refugee background. This is a limitation of our survey analysis as it will not adequately represent the experiences of these groups. There are many reasons why our survey may not have reached these groups: these could include that it was only available and promoted online, and it was only produced in English.

We know that these groups of people experience multiple forms of discrimination and compounded barriers to supports. For example, some people from a migrant or refugee background will not be eligible for the NDIS as they are not permanent residents of Australia, or they cannot access information about supports in their language.

It is important that consultation processes engage specifically with these groups and involve them in a meaningful co-design process to ensure foundational supports will meet their needs. In many cases more resources will be needed to meaningfully engage with these groups – which is additional reason to invest in consultation as their perspectives may not be captured otherwise.

Larger proportions of our respondents were members of the LGBTQIA+ community (36%) or were parents or carers (39%) [Table 4].

Our large proportion of respondents from the LGBTQIA+ community reflects the demographic of our membership of our organisations, and the fact that queer people

are more likely to have a disability as a result of their marginalisation⁴. Queer people with disabilities experience compounding discrimination at the intersection of queerness and disability, and experience additional barriers to finding safe and inclusive disability supports.

The large proportion of parents and carers with disabilities who completed the survey reflects the fact that over 40% of primary carers in Australia are people with disabilities themselves.⁵ Many service settings conceive of people with disabilities as recipients, rather than providers, of care. This means that people with disabilities who are parents or carers rarely receive adequate support for their parenting and caring responsibilities. The lack of support available for parents and carers with disabilities has significant and harmful consequences, including over-representation in the child protection system. The design of the foundational supports system must consider supports for parents and carers specifically.

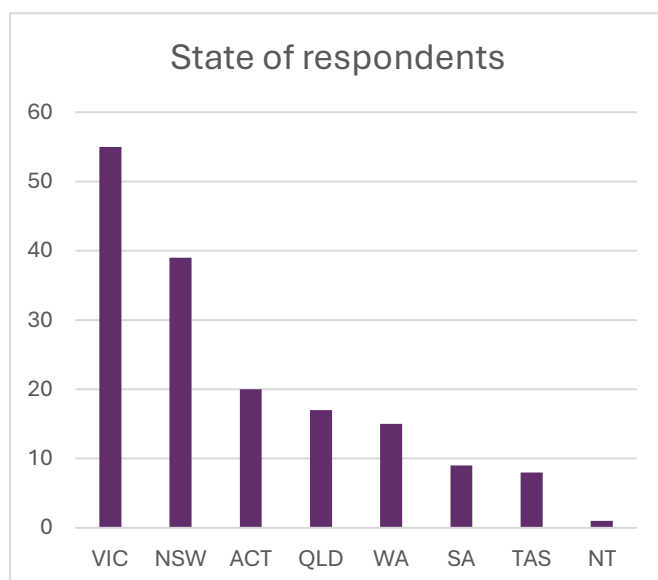


Table 5: State of respondents

Our largest percentage of respondents was from Victoria (30%), followed by NSW (21%) and the ACT (11%) [Table 5]. The spread of respondents reflects the differing populations in Australian states and territories, as well as the demographics of our organisational memberships (with additional responses from the ACT and Victoria). People residing in different jurisdictions have disparate experiences of accessing disability supports, so it is important to note that our survey analysis may not adequately reflect the experience of accessing supports in states other than NSW, ACT and Victoria as fewer responses were received from these areas.

⁴ O'Shea A, Latham JR, McNair R, Despott N, Rose M, Mountford R, Frawley P. (2021). *Experiences of LGBTIQ+ People with Disability in Healthcare and Community Services: Towards Embracing Multiple Identities*. Int J Environ Res Public Health. 17(21):8080. doi: 10.3390/ijerph17218080.

⁵ Australian Bureau of Statistics (ABS). (2022). Disability, Ageing and Carers, Australia: Summary of Findings. <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>.

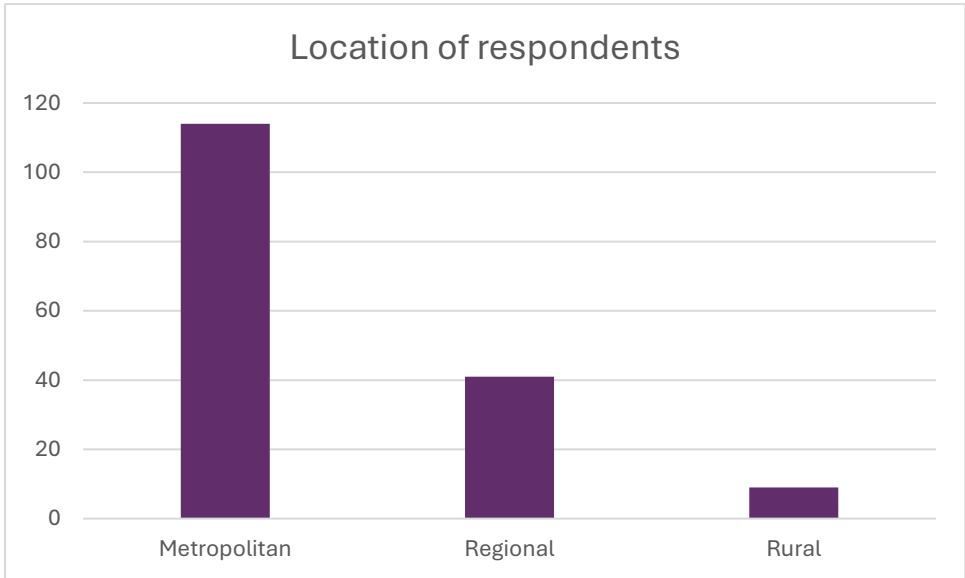


Table 6: Location of respondents

63% of our respondents were from metropolitan areas, with 23% living in regional areas and 5% living in rural areas [Table 6]. Many people reported additional challenges accessing supports in rural areas, and these are discussed further in the key themes.

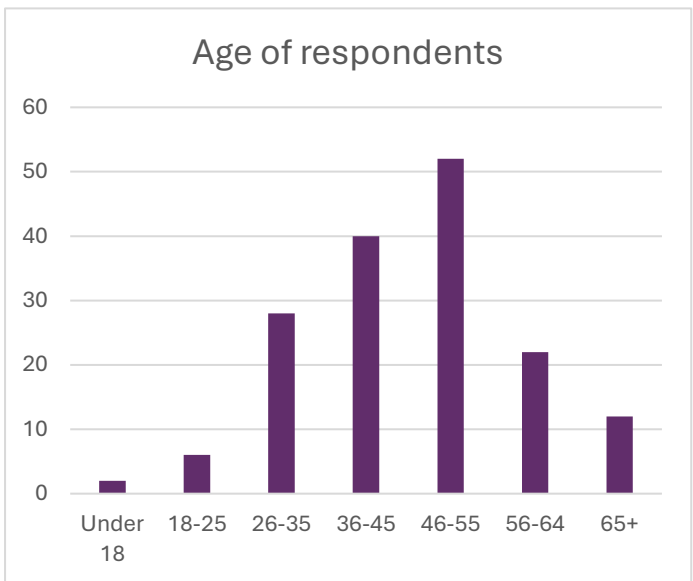


Table 7: Age of respondents

Most of our respondents were in the age range of 46-55 (29%), followed by 36-45 (22%). We had very few responses from young people with disabilities (only 4% of responses were from people under 25) [Table 7].

We included people over 65 in our survey because older people with disabilities often fall in the gaps between formal disability support systems like NDIS and aged care supports. Although the new system of foundational supports is designed to work alongside the NDIS, most foundational supports should be available to everyone at

any age. Disability does not disappear at the age of 65, and a joined-up system of supports is needed so everyone can be included and access the supports they need.

General foundational supports

What are people accessing?

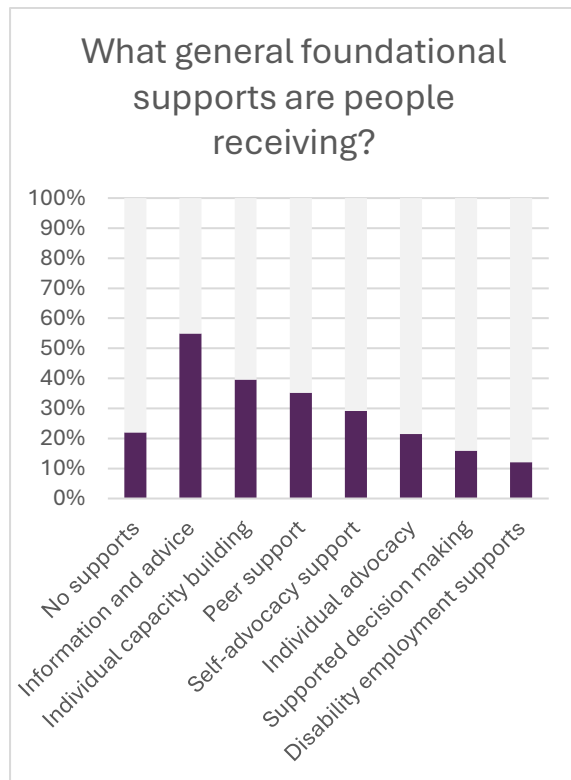


Table 8: What general foundational supports are people receiving?

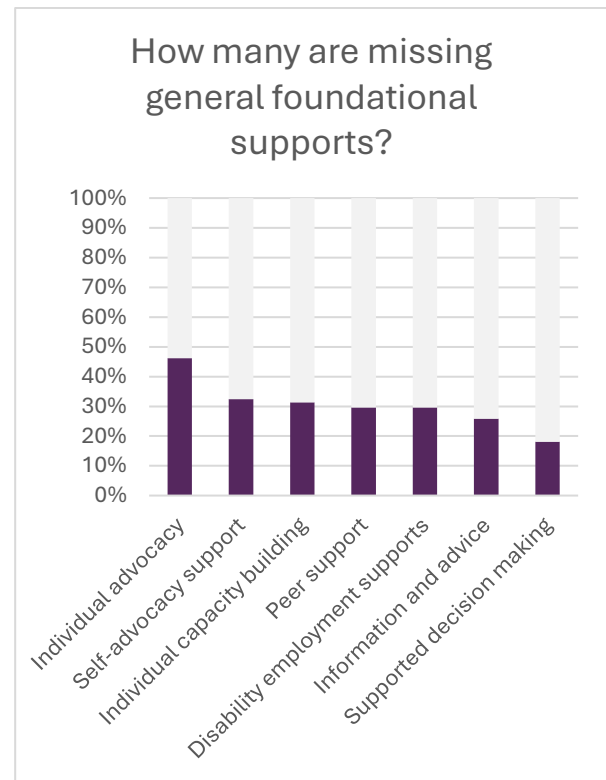


Table 9: How many are missing general foundational supports?

We asked our survey respondents about supports in the following categories: information and advice, individual capacity building, peer support, self-advocacy support, individual advocacy, supported decision making, and disability employment supports. These kinds of supports are consistent with the proposed definition of 'general foundational supports'.

140 respondents (77%) indicated that they received some form of general foundational support.

There was a stark difference in access to general supports across different geographical areas – 82% of respondents in metropolitan areas accessed some sort of general support, compared with only 66% in regional and rural areas.

85% of respondents who are NDIS participants had access to general foundational supports, compared to 70% of respondents who were not on the NDIS.

132 respondents (73%) were missing some form of general foundational supports – meaning a huge proportion of survey participants are not receiving the supports they need under the current system.

Information and advice

“The information seems out of touch with the reality of what’s actually available and how it will play out for me if I do reach out to those services. So I just stop trying.”

100 respondents (55%) indicated that they access information and advice.

Facebook groups were mentioned by several respondents as the most valuable general support they accessed. Facebook groups also functioned as a trusted way to receive information about other supports and engage with a peer network. Many respondents also mentioned getting information and advice from healthcare professionals such as GPs, as well as doing their own research online.

47 people (26%) said they were not receiving the information and advice they need.

We asked a separate question about how people find out about supports, and this analysis is included in the section on ‘finding out about supports’ below.

Individual capacity building

“I just feel like both myself and my 8 yo daughter were diagnosed like "okay, you're right, you're definitely autistic, good luck with that " There's no follow up, no guidance, no - okay, well what next then?”

72 respondents (40%) indicated that they access individual capacity building supports, defined as ‘supports that help you build skills and confidence’. People mentioned accessing these supports through many different places, including through Disabled People’s Organisations, Families or Carers organisations, diagnosis-specific organisations, women’s organisations, and government disability services (state or local government). Many of the people who had access to these supports were already NDIS participants (49 out of 72, or 68%)

57 respondents (31%) said that they wanted access to more individual capacity building supports, or that they had no access to capacity building supports. Some suggested capacity building supports included education for people with disabilities (for example education on disability rights and the disability discrimination act), or training about violence against women and gender diverse people with disabilities. Other supports that our respondents suggested included building social skills, support to participate in co-design processes (particularly in policy), and life admin support.

Several people mentioned the need for capacity building for people who are not diagnosed, who are newly diagnosed or who only recently acquired a disability. Women, girls and gender diverse people with disabilities are already less likely to receive a diagnosis due to gendered biases in the medical system.⁶ This means there is a gap in capacity building supports that disproportionately impacts women, girls and gender diverse people with disabilities.

Recommendation 1: Fund capacity building activities that are inclusive of people with disabilities who do not have a diagnosis or do not access NDIS.

Recommendation 2: Continue to fund and preference Disabled Persons' Organisations, Disability Representative Organisations and other community organisations to provide capacity building support under a new model of Foundational Supports.

Peer support

“There is a need for more community based peer support groups for people with disabilities who don't have the NDIS. Everything has been absorbed into the NDIS funding stream leaving nothing for those who don't have funding to participate in without cost”

64 respondents (35%) said that they access peer support. Respondents highlighted the importance of peer support with many indicating it as the only foundational support they regularly accessed. Different cohorts benefitted from having in-person and online options. Respondents appreciated having peer support from groups which shared their disability type (e.g. neurodivergence), as well as generally for all people with disabilities. Respondents also appreciated the chance to interact with community-based supports and supports outside of the government and NDIS.

54 respondents (30%) indicated that they would like to access peer support but don't currently have access. Several people referred to the fact that NDIS had absorbed pre-existing peer supports, meaning that people who were not NDIS participants struggled to find ways to participate and to find peer networks.

Recommendation 3: Include peer support activities within the remit of general foundational supports available to all people with disabilities.

Recommendation 4: Increase funding for peer support activities outside of those provided through the NDIS.

⁶ Yates, S., Carey, G., Hargrave, J. *et al.* Women's experiences of accessing individualized disability supports: gender inequality and Australia's National Disability Insurance Scheme. *Int J Equity Health* **20**, 243 (2021). <https://doi.org/10.1186/s12939-021-01571-7>

Self-advocacy support

“Like what is the point of self advocacy if no one is listening to me and dismissing and gatekeeping further compounding my experience of discrimination and marginalization?”

53 respondents (29%) said they accessed self-advocacy support. 59 people (32%) said they would like to but don't currently have access. Respondents suggested that these supports should include education on disability rights and self-advocacy, learning about the disability discrimination act, and support to participate in co-design processes for policy (including self-advocating through this process). They also indicated that they wanted increased knowledge of gendered violence, the intersection of sexism and ableism in driving violence and how to identify the different and specific forms of violence experienced by women, girls and gender diverse people with disabilities.

Recommendation 5: Increase funding for self-advocacy supports and include it within the remit of general foundational supports available to all people with disabilities.

Recommendation 6: Fund support for people with disabilities to participate in policy co-design processes.

Recommendation 7: Fund additional self-advocacy supports for people with disabilities, including but not limited to education on disability rights, the Disability Discrimination Act, and violence against women, girls and gender diverse people with disabilities.

Individual advocacy

“I find it very, very difficult to find these supports and when I do find them I am either ineligible because that service supports a specific demographic, or the waitlist is so lengthy it cannot assist my needs”

39 respondents (21%) accessed individual advocacy support. Many more indicated that they would like to but don't currently have access (84 people, or 46%). Respondents talked about barriers to accessing this support, including the low capacity of individual advocacy services and long wait times. There was also a lack of case management and longer-term advocacy support for people in complex circumstances, who need advocacy support to navigate different services.

Recommendation 8: Fund individual advocacy under a new system of general foundational supports available to all people with disabilities.

Recommendation 9: Fund individual advocacy services to provide case management and longer-term advocacy support for people in complex circumstances.

Recommendation 10: Boost funding to individual advocacy organisations to meet demand during a time of transitional service provision.

Supported decision making

“People are taking advantage of people with disability and people are making judgements on their decisions.”

29 respondents said they accessed supported decision making (16%), with a further 33 people (18%) who don't currently access it but would like to. People particularly mentioned gaps in access to decision making support around sexual and reproductive health.

Recommendation 11: Fund supported decision making under a new system of general foundational supports available to all people with disabilities

Recommendation 12: Fund support to improve decision making around sexual and reproductive health for people with disabilities

Disability employment supports

“Most disability employment supports are either related to things like resume writing, which I don't need or jobs that are inaccessible to me e.g. hospitality which I would struggle with due to the physical exertion and customer service. There is not enough support specific to accessible jobs or training to help get those jobs.”

22 respondents said they were receiving disability employment supports (12%) with a further 54 (30%) wanting to access them. People gave detailed accounts of their experiences with disability employment supports through DES and through other services. Experiences were overwhelmingly negative, ranging from being unhelpful, to actively harming people's capacity to get a job. Respondents reported feeling dehumanised through their engagement with these kinds of supports.

Employment supports tended to be catered to entry level jobs and were not tailored to people's capabilities. Those with physical disabilities or chronic conditions reported the only available jobs involving manual labour or lifting which was not possible due to their disabilities. Other people mentioned that support with their

employment would be valuable for roles above entry level. Many people wanted support to talk to their employers about their disability, and to advocate for reasonable adjustments to allow them to do their job. These adjustments included flexible working times or transitioning to part time work, including in high level roles.

People mentioned a desire for more disability-aware workplaces. Some respondents reported working additional unpaid hours to get the job done, in a workplace which did not give adjustments for their disabilities.

Several people mentioned wanting help to start or maintain a small business, recognising that this form of work suits many people with disabilities as it can be flexible. Other supports that were missing included careers counselling tailored to people with disabilities.

Recommendation 13: Explore a wider range of employment supports available to people with disabilities under the new system of general foundational supports

Recommendation 14: Explore how general foundational supports can support people with disabilities to advocate to their employers for reasonable adjustments

Recommendation 15: Fund entrepreneurship and small business mentorship and support for people with disabilities, as a component of employment supports available in a general foundational supports system.

Barriers to accessing general supports

Cost

“Due to the housing crisis & cost of living crisis I am living below the poverty line. I cannot afford to access any support services.”

Cost was the major barrier to accessing supports – it was mentioned by nearly every survey respondent. Respondents struggled to find free or low-cost supports. This was especially difficult for those who were not receiving funding for disability supports through other means such as the NDIS. Some reported being turned away from supports because they were not a NDIS participant, leaving them no options for supports without paying a high price.

Recommendation 16: Ensure that foundational supports are free for all people with disabilities.

Time to access supports and range of supports available

“The energy it takes to find any supports has not been worth it”

Many respondents noted the huge amount of time and energy needed to find supports and access them – for those whose disability leads to limited energy or fatigue, this process is draining. There is little planning support available particularly for those not on the NDIS.

Although some spoke about limited general supports available in their area such as peer support and individual capacity building, the few supports that did exist often ran at times that were not suitable.

In regional areas there were few general supports available, meaning that the range of times they were offered was small. For respondents who are employed and working to support themselves, who have caring responsibilities, or who have difficulties accessing transportation outside of particular times, the small range of general supports available are inaccessible.

Some respondents noted that the only supports available for them were in person and were not COVID-safe, which was a barrier to access.

Recommendation 17: Ensure a system of foundational supports promotes equity in access, and addresses unmet need. This includes ensuring that:

- (a) Funding for general foundational supports is directed to supports that operate at different times and in different locations.
- (b) Funding for foundational supports in regional areas is increased to address thin markets and promote growth in the number and range of supports available.

Organisational capacity

“peer networks and advocacy organisations like Queenslanders with Disability Network (QDN) and Women With Disabilities Australia (WWDA) have been instrumental in creating spaces for individuals to share experiences, support one another and advocate for systemic change. Despite the benefits, peer support and advocacy are sometimes underfunded or undervalued within the broader disability service sector”

Community sector organisations (including disabled people’s organisations) were mentioned as important general supports by many survey participants. However, many struggled to access supports through these organisations as they had long waitlists and low capacity for both systemic and individual advocacy.

Several respondents mentioned the importance of smaller diagnosis-specific community organisations. These organisations also suffer low capacity and limited ability to help everyone who reaches out for support. Smaller organisations often have limited funding through grants, and limited capacity to grow. This has resulted in a community sector ecosystem where some of the more common conditions don’t

have representative organisations that are funded to design and provide supports tailored for that diagnosis.

Several respondents indicated a need for coordinated case management and for organisations to be resourced to do longer-term advocacy support. This need was particularly acute for those who were not on the NDIS and did not have a support coordinator or local area coordinator.

Recommendation 18: Fund Disabled Peoples' Organisations and Disability Representative Organisations under a new system of general foundational supports, as preferred providers of all general supports including capacity building, advocacy and information and advice. These organisations should be given preference over NDIS service providers or centralised government-provided services.

Recommendation 19: Increase funding to advocacy organisations under a new system of general foundational supports.

Recommendation 20: Transition away from time-limited grant funding models to sustainable and ongoing funding models for smaller disability organisations.

Recommendation 21: Resource Disabled Peoples' Organisations to provide case management and longer-term advocacy support, especially for individuals who are ineligible for the NDIS.

Eligibility for supports

"I am not considered eligible for most supports. My capacity is not taken into account when evaluating this, nor are my illnesses."

A theme that came up in the survey responses was that many 'foundational supports' disappeared with the introduction of the NDIS a decade ago. Many have now struggled to access any disability supports as they are not eligible for the NDIS. This of course disproportionately affects women, girls and gender diverse people with disabilities, who are underrepresented on the NDIS making up only 37% of total participants⁷. This additionally impacts groups who have never been eligible for NDIS, such as people who are not yet permanent residents of Australia. It also impacts those whose find the NDIS application process too complex to navigate.

12 of our survey respondents were over the age of 65. These respondents indicated huge difficulty with finding any disability supports they were eligible for. Although foundational supports are aimed as a 'stop gap' for people under the age of 65, older Australians with disabilities have been falling through the cracks since before the

⁷ National Disability Insurance Agency (NDIA). (2021). Quarterly Report to Disability Ministers: 2021-22 Q1; National Disability Insurance Agency (NDIA). (2023). Quarterly Report to Disability Ministers: 2022-23 Q1. Supplement E

NDIS was introduced and rendered them ineligible for support. Disability does not disappear at age 65, and older Australians with disabilities would greatly benefit from being eligible to the same foundational supports as the rest of the population.

Recommendation 22: Create a system of general foundational supports that does not reproduce the gender bias of the medical system and is available to all regardless of diagnosis, age, or visa or residency status.

Recommendation 23: Ensure that general foundational supports are available to all people with disabilities, including those over the age of 65.

Recommendation 24: Design general foundational supports with a gendered lens, addressing the systemic gaps to ensure that women, girls and gender diverse people have access to the supports that they need.

Knowledge of where to find supports

“I have no idea where to access them or even where to find out about accessing them”

For some people completing the survey, this was the first time they had heard about disability supports available outside of the NDIS. These respondents were not aware of any supports that could be currently available to them. Some assumed that they were ineligible for any disability supports because they were not eligible for NDIS.

Some groups of people miss out on hearing about supports. This includes people who newly acquire disability, especially those whose disability is classed as a chronic health condition or mental health condition. Transitioning out of receiving medical support (e.g. in hospital), these respondents were not given any information about additional supports available to them. Several mentioned that the medical environment did not support connection or information sharing, with privacy policies preventing social connections with peers in these settings. Other people mentioned that their regular points of contact in the healthcare system, such as GPs, did not have information about disability supports outside of the NDIS.

Many respondents said that they did not know what supports were out there, and what could be beneficial to them. Respondents didn't know the right search terms to type into the internet or social media, and did not find out about support that could have been relevant to them.

People mentioned anxiety about changes to the NDIS and the aged care system, which was a barrier to attempting to apply for supports through these systems.

Many respondents mentioned the isolation between disability services and organisations, and the healthcare system. The lack of linkage and communication

between these key players represent a lost opportunity for information and referrals for people with disabilities.

Recommendation 25: Investigate opportunities for information sharing and linkages between the healthcare system and disability services, as part of the roll out of general foundational supports.

Recommendation 26: Provide training and information to GPs and allied health professionals about local foundational supports that are available. Fund community sector organisations to do advertising and outreach to the healthcare system to ensure the referral information is up to date.

Recommendation 27: Introduce funded positions in hospitals and healthcare settings (Disability Liaison Officers or similar) who can refer healthcare consumers to appropriate general foundational supports as they transition out of the healthcare system.

Compounding marginalisation, discrimination and tailored supports

“I want support from a professional advocate or disability employment supports at times but I don't believe that what's currently available would be useful for me because of being trans and disabled”

“There were so many gaps and barriers for me and most of the disability advocacy in Australia don't have CALD people with disabilities working. This severe lack of representation, equity and inclusion is problematic because I don't feel seen and heard when dealing with women with disabilities organizations both state and nation wide.”

People mentioned a wealth of issues with supports they had accessed, through NDIS providers or through community organisations. Many experienced discrimination – racism, ageism, sexism, ableism, and queerphobia were mentioned across the responses. People accessed supports that were not trauma informed and not culturally safe. Some supports had an emphasis on the medical model of disability, viewing disability as a deficit. People struggled to access supports that affirmed neurodiversity. There were also gaps in supports for people with multiple disabilities, or people with multiple marginalised identities (e.g. trans women and gender diverse people with disabilities).

A key theme throughout responses was that currently available supports are not relevant or affirming for people who experience multiple and compounded forms of marginalisation. This was particularly mentioned for culturally and linguistically diverse people (CALD) trying to access supports. Respondents mentioned that organisations don't have good representation of CALD people, including advocacy organisations. This leads to related issues, like disability resources not being

available in different languages, and no connections or referrals between CALD organisations and disability organisations.

There were also a lack of gender responsive or gender specific disability supports. People wanted access to violence awareness training and to information about healthcare for women and gender diverse people with disabilities, but this was not available. People also mentioned very few or no supports available for parents with disabilities.

All of these are barriers to people accessing supports. In the words of one respondent, 'bad care causes more harm than good'. If people cannot trust that they will receive affirming and safe care, they will not feel confident to access supports.

Recommendation 28: Fund disability representative organisations that work with underrepresented populations (e.g. culturally and linguistically diverse, LGBTQIA+, women and gender diverse) at both the state and National level, to provide general foundational supports that suit the specific needs of their communities.

Recommendation 29: Increase resourcing to community sector organisations to facilitate meaningful collaboration between organisations working with different community groups.

Recommendation 30: Fund new and existing local organisations who can provide a diverse and trusted range of supports for different community groups.

Issues with larger providers

“The most egregious of the bad experiences have been at the hands of registered providers”

Registered providers were mentioned by several survey respondents as a key barrier to accessing supports due to experiences of misconduct. Many mentioned that it is the bigger organisations that can get away with this misconduct, including abuse and grooming that is not addressed when reported to providers. Respondents emphasised the importance of small, local organisations and individuals who provide tailored and safe support, and maximise choice and control.

A related issue was the turnover of staff in organisations where respondents were accessing supports. Respondents were frustrated with the process of re-explaining their support needs and sharing their experience – this process was noted as traumatising or triggering.

Turnover of staff means that staff who are trained don't always stay in those organisations. This means that trust is not developed in service providers.

Recommendation 31: Investigate the community sector funding allocations and award rates to encourage staff to remain and be adequately compensated in their roles.

Services in regional areas

“The geographical location does have a huge impact on available services. There’s a lot of overlapping of services...what I see as conflicts of interest...NDIS coordinators who are employed by an NDIS provider and whose clients use the services of that NDIS provider.”

Respondents in regional areas mentioned that there was an extremely limited number of supports. A few respondents mentioned having exhausted all available supports in the area.

Recommendation 32: Do additional consultation with people with disabilities in regional and remote areas to ensure the rollout of general foundational supports increases the supports available to them in their area.

Recommendation 33: Fund and upskill people with disabilities in regional areas to design supports for their own communities (e.g. seed funding for Disabled Peoples’ Organisations in regional areas).

Targeted supports

What targeted supports are people accessing?

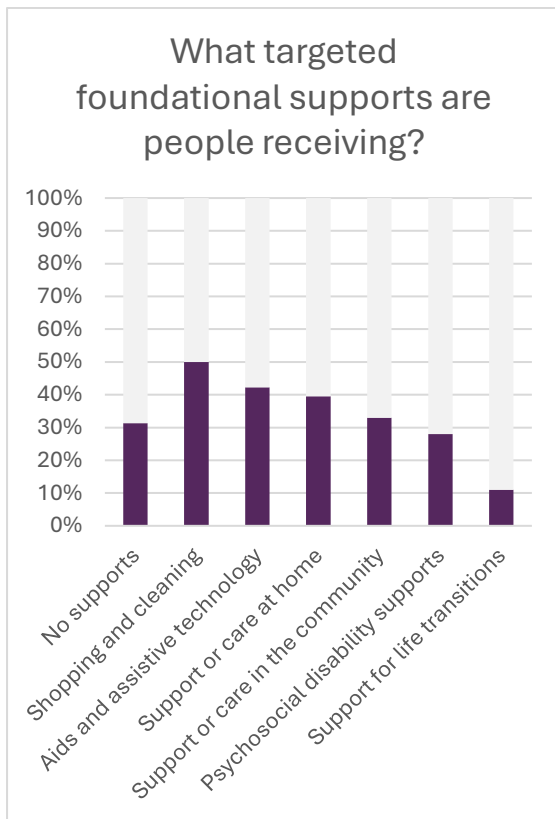


Table 10: What targeted foundational supports are people receiving?

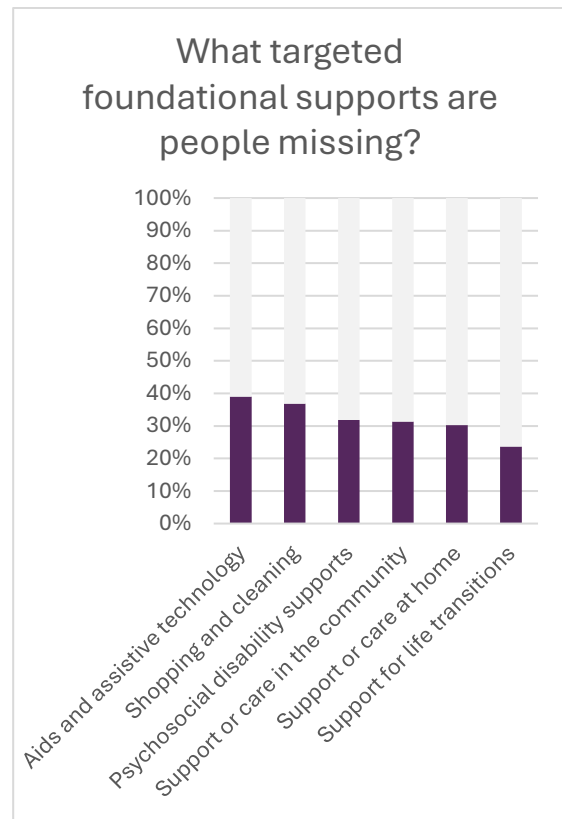


Table 11: What targeted supports are people missing?

We asked our survey respondents about supports in the following categories: shopping and cleaning, aids and assistive technology, support or care at home, support or care in the community, psychosocial disability supports, and support for life transitions. These kinds of supports are consistent with the proposed definition of ‘targeted foundational supports’.

122 respondents (67%) indicated that they received some form of targeted foundational supports.

Again, there was a difference in access across different geographical areas – 70% of respondents in metropolitan areas had access to some sort of targeted support, compared with only 64% in regional and rural areas.

93% of respondents who are NDIS participants had access to targeted foundational supports, compared to 45% of respondents who were not on the NDIS. This huge discrepancy reflects the fact that the proposed list of targeted supports overlaps with supports currently provided through the NDIS.

127 respondents (70%) were missing some form of targeted foundational supports – an overwhelming majority of respondents are not receiving the supports they need under the current system.

Shopping and cleaning

“I desperately need support with cleaning in particular. I suffer terribly with pain from arthritis but have no help at all.”

91 survey respondents had access to support with shopping and cleaning (50%). This included through domestic services, online food delivery services, family and informal supports, and paid support workers. Most of these respondents received these supports through the NDIS (70%).

An additional 67 people wanted access to support with shopping and cleaning but can't currently access it (37%). Of these, 82% are not currently NDIS participants.

Recommendation 34: Include shopping and cleaning supports in a system of targeted supports, available to people who are not NDIS participants but who need this assistance.

Aids and assistive technology

“I use aids and assistive tech every day, and get help from my partner several times a week. This has been mostly positive but really expensive to self-fund my own assistive tech”

77 survey respondents had access to aids and assistive technology to support them with managing their disability (42%). Some supports and technologies mentioned included home adjustments like a flashing doorbell, adaptive clothing, menstrual underwear, a robot vacuum, and CPAP machines. Some respondents indicated a lack of training on how to use this technology, which would be worthwhile both for people with disabilities and for their carers and people they are in contact with. Most of these respondents received these supports through the NDIS (74%).

71 respondents indicated they wanted access to aids and assistive technology but didn't currently have it (39%).

Many respondents indicated that they funded this themselves, and the expense was out of reach for many. An issue for respondents in smaller cities or regional areas was a lack of options, and no ability to try tech before purchasing it. For these respondents, they were unable to see if a technology or aid would be useful for them without buying it, and the cost could be prohibitive.

Other respondents advocated that being allocated funds to purchase aids and equipment would reduce or eliminate their need for a support worker. This is far cheaper and increases the independence and control of people with disabilities.

Recommendation 35: Include aids and assistive technology in a new system of targeted foundational supports.

Recommendation 36: Provide trials of assistive equipment to people with disabilities in regional and remote areas through a system of targeted supports.

Support or care at home

“Basically there are very few supports. Councils used to provide a lot of home help and they don’t do that anymore”

72 respondents received support or care at home (40%). This care included things like showering, dressing, gardening, help with technology, help with administration, cooking and laundry. It was provided by a support worker or informally by friends or family members. 75% of respondents receiving support and care at home were NDIS participants.

55 respondents needed additional support at home but are not currently able to access it (30%). Of these, 78% are not currently NDIS participants.

Recommendation 37: Include support at home in a new system of targeted foundational supports.

Support or care in the community

“I need assistance to access the community at times - shopping, attending appointments, accessing social connection opportunities.”

60 respondents received support or care in the community (33%) – of these, most were NDIS participants (85%). Support or care in the community includes support to participate in community activities, support to travel to medical appointments, social support, and community mental health. This was provided by support workers or family members, with a few respondents mentioning that supports were provided by their local council. Another 57 respondents wanted additional support in the community but do not currently access it (31%). People mentioned cost of activities and lack of transport options as key barriers to accessing this kind of support. 75% of these respondents are not NDIS participants. Several people mentioned a desire for additional support to exercise, including accessing classes or support in community pools.

Recommendation 38: Include support in the community in a new system of targeted foundational supports.

Recommendation 39: Ensure people with disabilities are funded to access community activities.

Recommendation 40: Ensure people with disabilities are funded to arrange their own transportation to medical appointments.

Recommendation 41: Include support for exercise and healthy living in a new system of targeted foundational supports.

Psychosocial disability supports

“I cannot afford any more psychology appointments, despite REALLY needing them. 10 Medicare funded psychologist appointments goes in the first half of the year”

51 respondents receive support for psychosocial disability (28%). Another 58 would like to access these supports but don't currently (32%).

Lacking the ability to access psychosocial supports was a common theme across all areas of the survey, with many respondents struggling to find the support they need. The most commonly cited reason was cost – many people felt that psychosocial supports were a huge gap and were completely unaffordable, and not covered by DSP or a NDIS plan. Those supports that did exist were limited in number (e.g. only 10 sessions funded under Medicare). Respondents mentioned that some mental health support services were not disability informed, particularly helpline services, and that more training was needed.

Psychosocial disability was also mentioned as a huge barrier to accessing supports in general. When psychosocial supports are missing, people do not have the tools, energy or confidence to access peer support, individual capacity building, self-advocacy or lots of other supports. This is a key gap in the NDIS and disability support system as it currently exists.

Recommendation 42: Fund psychosocial supports under a new system of foundational supports, ensuring they are freely accessible to everybody.

Recommendation 43: Investigate disability training options for mental health and crisis services, including helpline services such as Lifeline.

Support for life transitions

“Life transitions cause major disruptions for my children and there is no support available currently.”

20 respondents received support for life transitions (11%), with a further 43 wanting this support but not currently accessing it (24%). People wanted more support for transitioning from primary school to high school, and from high school to university or employment.

Recommendation 44: Fund support for life transitions under a new system of targeted foundational supports.

Barriers to accessing targeted supports

Cost

“I have accessed my super to purchase assistive tech which isn’t sustainable in the long term and when I need to upgrade.”

Similarly to general supports, cost was cited as the biggest barrier to accessing targeted supports. Many people mentioned that they had to self-fund any targeted supports they accessed. An issue specific to targeted supports (particularly psychosocial supports and other healthcare adjacent supports) is that they often require a gap payment. Although they may be subsidised by Medicare or by insurance, the large gap payment required means many cannot afford to access these supports.

Recommendation 45: Examine the interaction between targeted foundational supports and the healthcare system, and reduce the gap funding payments required to access targeted foundational supports.

Recommendation 46: Ensure that there are no out of pocket costs for people with disabilities to access a new targeted supports system.

Provider fraud

“We live in a small town with a toxic, self-serving service provision network. I have dealt with all the reg/unreg providers in the district & have caught them all out in one form of fraud, misconduct or other sharp-practices”

A common theme in the responses was experiences of provider fraud. Those who mentioned experiences of provider fraud made clear that ‘the most egregious of the bad experiences have been at the hands of registered providers’. The experiences

ranged from providers taking advantage of funds in a participant's plan, to covering up experiences of abuse and grooming behaviour.

One participant mentioned living in a small town and having used all the providers in the district, and experiencing fraud or misconduct from all of these providers. In places where supports are already limited, reporting to the NDIS Quality and Safeguards commission resulted in their isolation from options for service provision.

Recommendation 47: Fund targeted foundational supports that are provided by local groups and organisations, to provide options for support outside of larger registered providers.

NDIS limitations

"I am incredibly stressed by the new NDIS changes and whether I would even be eligible for anything."

Most of the survey's recipients of targeted supports received these through the NDIS. There were a range of issues that came up, including difficulty accessing supports because their disability was no longer recognised under the NDIS, losing out on supports because of reductions or locks on funding, and not learning about supports because support coordinators were uninformed. Many respondents reported feeling scared about the recent changes to the NDIS and the disability support landscape and feeling worried that their supports would be swept out from under them.

Many respondents reported mistrust in the NDIA. Respondents shared that their local area coordinators would not listen to their goals and that their plans would not be funded for the supports that they need. Additionally, the plans for similar diagnoses and support needs were inconsistent between people. Responses included experiences where the NDIA and staff had been neglectful, abusive or enabling provider fraud. This impacted the respondents' experience of accessing disability supports or in some cases was a barrier to attempting to access the NDIS at all. Many reported that it was not worthwhile to get stuck in the bureaucracy of the NDIS to be able to access the most basic of supports.

Recommendation 48: Ensure that a transition to a targeted foundational supports model does not impact on people's eligibility to access the NDIS or to access the supports they need.

Recommendation 49: Fund and administer the system of targeted foundational supports through community sector organisations run by people with disabilities, rather than through the NDIA or NDIS.

Transport

“I need support for personal care, transport and a powered mobility aid. I have very limited stamina for mobilising with a manual wheelchair and so cannot get out of my house without assistance.”

Many respondents reported struggling with transport to get to support activities. For those who do not drive, many rely on public transport as an affordable alternative. However, our respondents indicated that public transport can be unsafe, both from an accessibility and physical safety standpoint, as well as a risk of violence. Additionally, in many locations respondents indicated that public transport doesn't run frequently on the weekends, locking them out of accessing supports outside of working hours and being involved in the community.

Other forms of support were also infrequent or unsafe. Respondents spoke about accessible taxis being unreliable and leaving people stranded without transportation to and from events. Taxis and rideshare were also expensive, leaving many respondents reliant on family or support workers to transport them to their supports.

Recommendation 50: Consider funding boosts and incentives to accessible taxi fleets where they exist, to ensure accessible transport is available to people with disabilities when they need it.

Recommendation 51: Subsidise accessible transport for people with disabilities as part of a system of targeted supports to enable them to access the community, appointments and supports they need.

Communication and safety

“The current language and communication method and how information is distributed by the NDIA and advocacy services/groups are not accessible for people with disabilities from CALD background.”

Respondents talked about their different needs when accessing targeted foundational supports, needs that were not always met by the service or support provider. This included communication difficulties with support workers where someone's disability impacted their speech, hearing or communication. This can make things like understanding an accent or understanding someone with a speech impediment or tracheotomy difficult, for both the support worker and for the person being supported. For those who speak a language other than English, finding support that is in a preferred language is next to impossible.

Many respondents found that those who were providing support (e.g. support workers, teachers in schools) were not well educated about disability and not well informed about other support options. Many struggled to find culturally sensitive help, or to find disability support that was responsive to their diagnosis.

Several respondents mentioned the need for better training for service providers and for people with disabilities about the intersection of violence and disability.

Recommendation 52: Adequately resource organisations and service providers implementing targeted foundational supports to ensure people with disabilities have broad choices and can find supports that suit their needs.

Recommendation 53: Develop rights-based disability training for people such as teachers, youth workers and healthcare professionals to increase knowledge of disability and support options under a new foundational supports system.

Recommendation 54: Fund disability organisations to deliver rights-based training for service providers and for people with disabilities about the intersection of violence and disability.

Other supports

Respondents to our survey made it clear to us that creating a new and isolated system of disability supports will not be enough – disability intersects with many systems and the foundational supports conversation cannot be separated from a broader conversation about the accessibility of healthcare, housing, education, and community accessibility.

We have included the themes that came out of written responses to the survey. Though many of these comments fall out of scope of Foundational Supports as currently envisioned by the Government, it is important to consider how the foundational supports, NDIS and disability policy reform will address these areas as vital to people with disabilities' wellbeing and participation in the community.

Healthcare

“How ridiculous is it that adults with ADHD and/or ASD have nowhere to go to in the public system for diagnosis or treatment?! It means that only adults with enough money can access diagnosis and treatment through the private system, with huge costs and wait times. It is grossly unjust.”

Respondents mentioned that they struggle to access the following essential supports:

- Medicine and pharmaceuticals (particularly essential medicine that is not on the PBS)
- Telehealth appointments and accessible doctors appointments
- Access to pain management
- Transport to and from essential medical supports
- Dental work

- Affordable diagnoses or diagnoses available through the public healthcare system
- Support to manage the risk of COVID (e.g. masks and rapid antigen tests)
- Palliative care and hospice supports
- Affordable allied health (occupational therapy, physio, psychology, psychiatry)
- Access to dieticians

Recommendation 55: Consider how the foundational supports system fits into a broader ecosystem of disability and healthcare supports, and ensure that increased access to healthcare services is covered in the disability policy reform agenda.

Sexuality and sexual health

“Autistic women are also more likely to experience abuse and so it would be amazing if we could have positive experiences/support with something like sexual health or relationships.”

Respondents mentioned that they struggle to access the following essential supports:

- Gender affirming care (including hormone replacement therapy, affirming surgery, or access to gender affirming products)
- Sexual supports and services and intimacy care
- Access to contraceptives
- Sexuality and sexual health education
- Supports for perimenopause and menopause, including how it interacts with disability

Recommendation 56: Include gender affirming care, sexual supports and services, intimacy care, and access to disability-specific sexual and reproductive healthcare as part of the foundational supports system.

Recommendation 57: Fund comprehensive sexuality and sexual health education for people with disabilities under the foundational supports system.

Recommendation 58: Fund information, advice and services for perimenopause and menopause, including how it interacts with disability.

Housing

“We need support with securing safe & accessible housing”

Respondents mentioned that they struggle to access the following essential supports:

- Accessible and affordable housing
- Accessible respite and crisis housing, and short term accommodation
- Air conditioning at home
- Internet at home
- Assistance with moving house

Recommendation 59: Consider how foundational supports can include support for housing, including provision of essential services like air conditioning and internet, and assistance with moving house.

Recommendation 60: Consider how the foundational supports system fits into a broader system of housing supports, and ensure that accessible housing is covered in the disability policy reform agenda.

Parenting

“As a disabled person, I receive 0 support. As a parent of two disabled children, I’ve had to fight for their support. With their schools, with the NDIS... There is no support for me. I’m burnt out and have been for years.”

Respondents who are parents and carers with disabilities reported feeling ‘invisible’ as they tried to get support for themselves and for their children or family members. Overwhelmingly, respondents said they felt burnt out and were struggling to keep going and to access any support. A few respondents said that they only received a diagnosis for their disability after seeking one for their child, particularly diagnoses of neurodivergence. These parents struggled to find supports for themselves whilst juggling the administrative and bureaucratic burden of finding support for their children, at school and outside.

Parents also reported experiences of ableism, with those around them assuming they ‘shouldn’t be a parent’ or being condescending. The attitudes of parents around them also contribute to the isolation felt by parents with disabilities and are additional barriers to receiving mainstream supports.

The lack of support available for parents and carers with disabilities has significant and harmful consequences, including over-representation in the child protection system.

Recommendation 61: Ensure specialised support for parents and carers through the design of the foundational supports system.

Support within mainstream services

“Women girls and gender diverse people should have targeted sexual violence intervention and supports that are specifically disability focussed and have an understanding of the unique experiences of disabled women girls and gender diverse people. This must include experiences of institutional abuse and sexual violence, including in medical settings”

Respondents mentioned a need for targeted or specialist disability support within mainstream services. Specifically, they mentioned domestic and family violence crisis services – which were often not trained in the specific forms of violence experienced by people with disabilities, and were under resourced to be able to do case management or connect people with disabilities to accessible services that can help them. They also mentioned mental health helplines and intake services, which were not always accessible and providers did not always have knowledge of disability. Additionally, they mentioned access to disability-specific legal supports and community legal help.

Recommendation 62: Fund specialised advocacy and navigation support for people with disabilities to facilitate their access to violence crisis services, community legal services and mental health helplines and intake.

Participation in the local community

“I would like to access a whole lot of things that are inaccessible to me: groups, events, activities, culture, people.”

Respondents mentioned that they wanted to access more community activities with the wider community (accessible, but not specific to disabilities). These included art and music groups, exercise and sporting groups, other hobby groups, intergenerational peer spaces, and community events.

Barriers to participating in these events included physically inaccessible venues, a lack of community awareness for disability and accommodations, stigma, transport and cost.

Recommendation 63: Fund mainstream community activities under foundational supports to increase their accessibility to people with disabilities – including funding to hire accessible venues or upgrade existing venues, training for disability accommodations, subsidised cost, and transport options.

Education

“Schools do not have enough staff and funding for teachers with extra education in this field.”

Respondents mentioned the importance of supports received in the education system at all stages. However, many struggled to get this support for themselves or for the people they cared for. Some were able to access individual advocacy support to get the support required in school. Others found the school system was underfunded and unable to provide the supports needed to access an equal education.

Recommendation 64: Ensure foundational supports are connected in with supports available through the education system, so students can access the supports they need.

Recommendation 65: Provide training to teachers and educators on foundational supports, so schools can be a point of referral to disability supports for students and families.

Finding out about supports

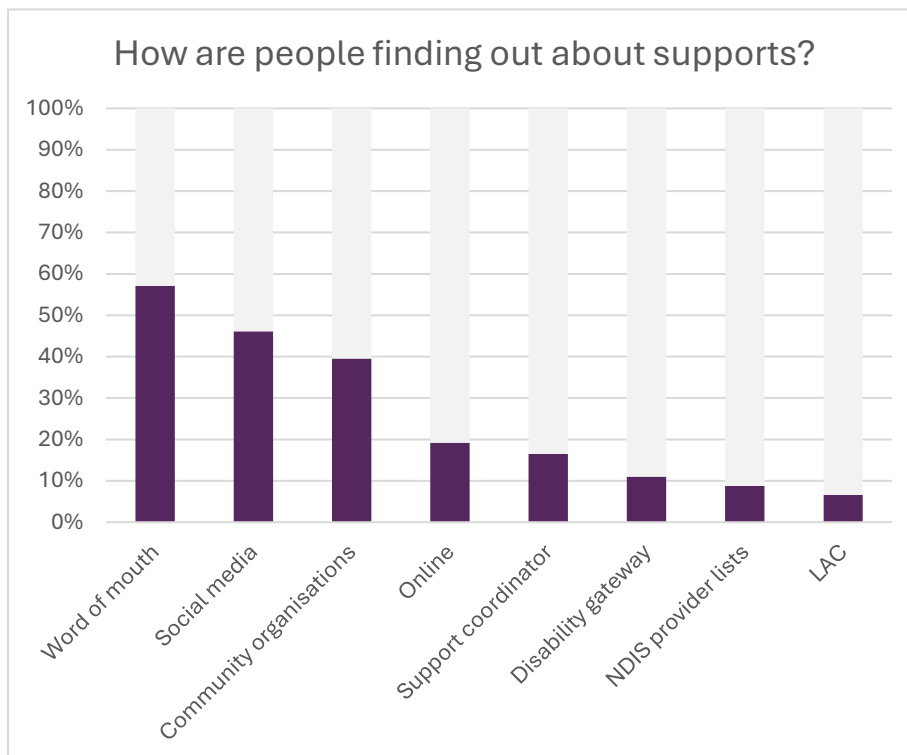


Table 12: How are people finding out about supports?

Word of mouth

“The most reliable method has been word of mouth. And it’s easier to trust the person too”

Word of mouth was the most popular way to find out about supports (over half of respondents used word of mouth to find supports, 104 people or 57%). This was identified as the most trusted way to find out about supports, over and above all other methods. For those who had negative experiences with their local area coordinators or with service providers, they relied on informal networks to receive information about what supports were safe and would work for them.

Word of mouth was particularly important for people who experience multiple and compounded forms of marginalisation (e.g. queer people with a disability) to hear about supports that are suitable and safe.

Finding out about supports in this way is challenging for people with disability who are newly diagnosed, who are isolated and who are yet to develop networks and find others with similar experiences.

<p>Recommendation 69: Fund peer networks and peer groups under general foundational supports, that address overlapping and compounding experiences of marginalisation, to allow people to develop networks of supports.</p>
--

Social media

“My current supports are largely social media (Facebook)-based and provided by volunteer-run, unfunded/underfunded not-for-profits and/or informal (not officially registered NGOs) social media groups. I access the info almost daily.”

Social media was also a popular way to find out about supports (84 respondents or 46%). Many respondents mentioned Facebook groups as a great way to find out about supports. These groups are often run by volunteers, NGOs or community organisations and are spaces to share experiences and information about various supports. People found that social media tended to have up to date information and was often shared by peers or people with lived experience so was more trusted.

A number of responses expressed frustration that information only seemed available through Facebook or other social media platforms, and that there were no alternative spaces to share information that wasn’t through Government or corporate social media.

A reliance on social media also presents barriers to those with low digital literacy or those who may not have private access to technology (e.g. those in supported assisted living or residential settings).

Recommendation 70: Ensure that disability and community organisations receive dedicated funding for maintaining social media pages and online spaces that provide trusted information about disability supports.

Recommendation 71: Investigate options for online social spaces hosted by disability organisations to enable people to come together and share support options outside of corporate or government programs.

Community organisations

“Disability advocacy organisations provide these supports to me; I’ve had positive experiences or neutral (not able to provide the support but attempted or encouraged to look elsewhere).”

72 respondents (40%) found out about supports through community organisations, such as disabled people’s organisations. People relied on email newsletters, Facebook groups, and websites from local organisations. People appreciated these organisations as many were run by and for people with disabilities, leading to a level of trust in the advice and information given.

Recommendation 72: Fund disability and community organisations to do advertising and outreach about their programs, and to enable them to share information about supports to the broader community.

Recommendation 73: Facilitate and adequately resource information sharing with community organisations outside of the disability sector, to ensure people from marginalised groups have opportunities to access information about foundational supports.

Online

“I spend a lot of time searching online”

35 people (19%) found supports online – through Google or through the internet. For many people this was their only attempt at accessing supports. Several people indicated that this relied on knowing what was out there and knowing the right key terms to type into an online search box.

Support coordinator, Local area coordinator, NDIS provider lists

“The NDIS provider list and Disability Gateway are so confusing and don't have enough options to just show what is in my area and it is draining going through all the supports that are in the cities and not finding things in my regional area. I have not had any good experiences with the NDIS LAC's they are useless.”

A few respondents found information about supports through their support coordinator or local area coordinator. However, most people had mixed or negative experiences finding out supports through these means, with recommendations being either unsuitable or not provided at all. Many mentioned the fatigue of self-advocacy required to get information and to follow up with support coordinators and local area coordinators, and that this is a huge barrier to accessing relevant information.

Many respondents reported a lack of trust in information provided to them from their NDIS supports or through NDIS support lists, as these were connected to profit-driven service providers or to what was recognized within the scheme.

Disability gateway

“I contacted disability gateway but unfortunately there was no service in my state to refer me to.”

Although a few respondents reported success with the Disability Gateway website, most had trouble finding supports in this way. For those in regional areas, there were no supports available to be referred to by Disability Gateway. Respondents described it as ‘confusing’, ‘not enough options’ and ‘a waste of time’. It was also difficult to filter for supports available in local areas, and to find in-person supports in areas.

Recommendation 74: Revisit Disability Gateway and connect in with local disability organisations and partners to ensure that information is relevant and up to date.

Recommendation 75: Diversify plans and funding for information and advice outside of Disability Gateway – though it is an important option, it is not the primary way that people discover disability supports.

Other ways to find supports

A few respondents mentioned other ways of finding out about supports, including through support workers, local councils, employers, the news and the Yellow Pages.

Several respondents mentioned that they had regular contact with their GP or with other healthcare professionals (e.g. hospitals, allied health) but their GPs did not

always have up to date information about general or targeted supports that was useful.

A few respondents mentioned that information about supports was especially hard to come by for those who are multiply marginalised. The people who are most in need of foundational supports may be those who are least able to access the information and advice they need.

Recommendation 76: Prioritise sharing information about foundational supports with people who are not already engaged with the disability sector.

Recommendation 77: Create an information sharing strategy and fund diverse ways of information sharing and collaboration within and external to the disability sector.

Recommendation 78: Engage with the healthcare system and GPs to ensure people can be referred to foundational supports by their healthcare practitioners.

Conclusion

Thank you to all the respondents to our survey who shared their experiences of accessing disability supports in Australia. It is important that the experiences of women, girls and gender diverse people with disabilities are used to inform a new system of Foundational Supports, and that the system is gender-responsive. Our organisations look forward to continued engagement with the Commonwealth and State government as this new system of supports is designed and implemented.