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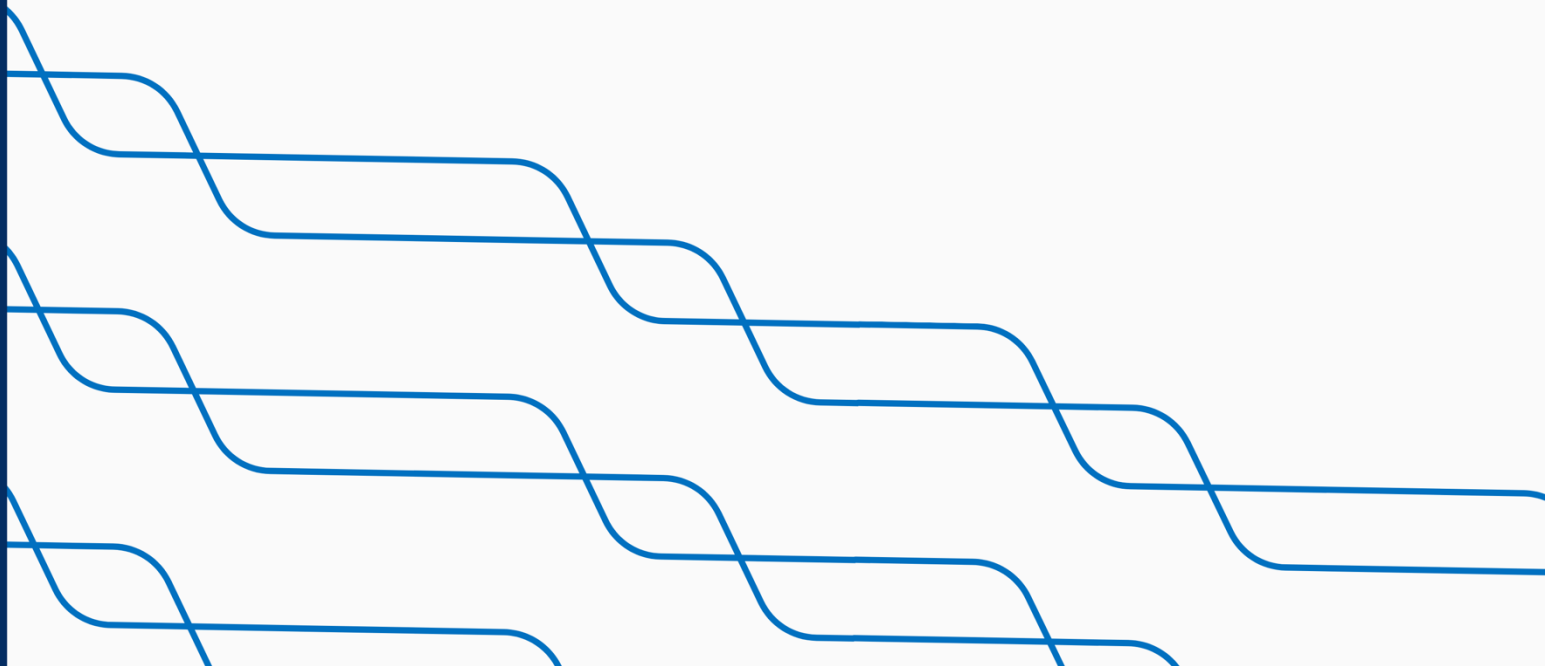
The Tier 2 tipping point: access to support for working-age Australians with disability without individual NDIS funding

Research Report

June 2022

Prepared by

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We acknowledge the traditional owners of the lands on which this research was conducted, and pay our respects to Elders past, present and emerging.

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Foreword: Professor Bruce Bonyhady AM

The ground-breaking research presented here by Dr Sue Olney, Dr Amber Mills and Liam Fallon has, for the first time, systematically collected information on what life is like for adults of working age with a disability who are not able to access NDIS funding.

It is a shocking picture of avoidable human costs and failed policy implementation, which is totally at odds with the purpose, philosophy and sustainability of the NDIS.

These failings must be addressed as a matter of urgency.

It is a time bomb which has been ticking loudly for too long and whose consequences are best expressed by people with disability, their families and their advocates experiencing it:

*“In Victoria, there’s only about 100,000 people who can get the NDIS, but there’s 1.1 million people with a disability in Victoria...advocacy organisations are so overwhelmed with sorting out NDIS problems and they’re very time limited...the people outside the NDIS are missing out.” - **Advocacy organisation***

*“My ability to access the supports I need to maintain good health are entirely reliant on my capacity to earn an income. In the periods where I cannot work, I have to choose between spending more than I have and getting the care I need.” - **Person with disability***

*“Particularly, a point of frustration for a number of people we work with is that when they get rejected from the NDIS and their letter says, ‘a local area coordinator will be in touch to help you connect to mainstream services’. And we have seen that happen precisely never.” - **Advocacy organisation***

With the NDIS now moving into an era in which evidence and codesign should drive essential improvements, this report provides crucial insights into the experiences of adults in Victoria, South Australia and Tasmania with a disability without NDIS funding. They should receive what was described as “Tier 2 supports” by the Productivity Commission in its 2011 report on Disability Care and Support.

The reality is very different, because the NDIS has become an “oasis in the desert”.

There are three principal findings.

First, there is an enormous human cost for people with a disability with complex needs and circumstances who find themselves unable to access the NDIS and so in Tier 2. The toll on them and their families is extraordinarily high, unsustainable and avoidable.

Second, this situation is a time bomb which represents an existential threat to the NDIS, the role it now plays directly supporting more than 500,000 Australians, and the position of the NDIS as one of the pillars on which the decency and fairness of Australian society is built.

Third, all governments and the NDIA have contributed to the current Tier 2 problems and must now act together to fix them urgently.

For the NDIS to be sustainable and fair it must be built on firm foundations. There must be little difference in the supports available to the last person who gains access to the NDIS and the first person to “miss out”.

Those people with disability not accessing the NDIS need essential, timely supports, not so-called “information” and “linkages” through the Information, Linkages and Capacity Building or ILC program which lead to...nothing.

With the introduction of the NDIS, a range of supports for those not eligible for the Scheme were cut to help fund the NDIS. Notable examples include two Commonwealth Government mental health programs: Partners in Recovery (PIR) and the Personal Helpers and Mentors Scheme (PHaMS). Both programs had eligibility criteria broader than the NDIS and their closure has directly contributed to the current “desert” surrounding the NDIS. State and Territory Governments also withdrew crucial supports, while local governments have largely vacated the field and discontinued Home and Community Care programs for many adults with a disability.

In the research presented in this report, some survey respondents have applied for access to the NDIS, and this has been declined. In other cases, participants have decided not to apply, because of fear of the paperwork and stress. The report therefore refers to Tier 2 as including “people with disability not able to access the NDIS”.

The report begins with a review of what is said about Tier 2 supports in government policy statements and on government and the NDIA websites. The gap between what is said is available and what is actually available to people with disability of working age could not be more stark.

It is not only that the claimed supports for people with disability under the age of 65 who are not able to access the NDIS are exaggerated and fragmented, but numerous websites encourage people to go looking for these non-existent or unaffordable supports, wasting their time and leaving them angry, exhausted and disillusioned with governments.

As a result, the main support for this group of people is their families. But family resources are not equal, and so the current approach risks both multiple and multi-generational disadvantage.

Over time, families burn out and age and, in the absence of adequate support, the functional impairments of those not eligible for the NDIS increase. The inevitable consequence will be more and more people needing the NDIS. This will add to NDIS cost pressures. However, because their entry to the NDIS will almost inevitably be due to crisis, it will in fact be an avoidable return to the crisis-driven short-term disability services system which existed before the introduction of the NDIS.

The problems with Tier 2 have been exacerbated by the role played by Local Area Coordinators (LACs). Since the introduction of the NDIS, staff caps at the NDIA have meant that LACs have spent more than 90 per cent of their time on planning. The much-needed work building community capacity and inclusion, and supporting those not eligible for the NDIS, has not been done.

It is a totally false economy and deeply regrettable that the NDIA does not see investing in Tier 2 as a priority, even though it is part of its mandate. Every effective social insurer looks beyond the short-term and takes a broader perspective on its role. They practice enlightened self-interest. Motor vehicle insurers invest in better roads, in order to preserve public health and to reduce costly accidents, injuries and claims. Similarly, workplace accident insurers invest in occupational health and safety.

Investments by the NDIA in Tier 2 support programs are the safer roads and OH&S of the NDIS.

Now, coordinated, corrective action by governments and the NDIA is essential. Demand for support for people with disability outside the NDIS is approaching a tipping point. Left alone, the Tier 2 time-bomb revealed in this study will explode.

Finally, this research would not have been possible without the involvement and support of our partners, the Brotherhood of St. Laurence and Baptcare, and I would like to thank them for their shared commitments to evidence-based policy improvement and a fairer and better Australia for people with disability not able to access the NDIS.

A handwritten signature in blue ink, appearing to read 'B. Bonyhady'.

Professor Bruce Bonyhady AM

Executive Chair and Director
Melbourne Disability Institute

Executive Summary

This report presents findings from research conducted by The Melbourne Disability Institute, in partnership with the Brotherhood of St. Laurence and Bapcare, in 2021. The research aims to build understanding of how working-age Australians with disability without individual funding from the National Disability Insurance Scheme (NDIS) are finding and using any support and services they need to participate in society and the economy. This group constitutes approximately 12 per cent of Australia's working age population.

Why this research is needed

More than 500,000 Australians receive individual funding through the NDIS to purchase support and services to meet their disability-related needs. They are called *NDIS participants*. But inclusion of people with disability in mainstream society is a critical component of the NDIS insurance model. For that reason, the NDIS is also intended to help all Australians with disability - including **2.4 million people aged under 65 years** - connect with a larger ecosystem of services and supports, and to help communities become more welcoming and inclusive.

This element of the original three-tiered structure of the NDIS - **Tier 2**, implemented as *Information, Linkages and Capacity Building* – is not achieving its stated aims. Questions about the availability, accessibility, affordability and adequacy of services and support for people with disability without NDIS funding – including promised support from the NDIS – and the relationship between the NDIS and key policy areas like health, education, employment, transport, housing and aged care, demand answers. Tier 2 has reached a tipping point that threatens the scheme's future.

Tier 2 of the NDIS is critical because:

1. the financial sustainability of the NDIS hinges on people with disability being able to access mainstream services and activities; and
2. there are people with disability who are not NDIS participants who need dedicated support, in the face of entrenched socio-economic disadvantage, to maintain their wellbeing and the wellbeing of their families. They include people who may be eligible for individual NDIS funding who face barriers to successfully applying for entry to the scheme; people with disability outside the scheme's eligibility criteria who have lost access to services and supports previously block-funded by Commonwealth, state and territory governments; and people living in places where affordable and accessible services, housing options, technology, and employment opportunities are limited.

Tier 2 of the NDIS is an underexamined, high-risk and complex policy environment that is shaping the life course of some of Australia's most marginalised citizens, with far-reaching social and economic costs. Without intervention, it will generate significant future increases in NDIS costs.

This research sheds direct light, for the first time, on the experiences of people with disability who are not NDIS participants navigating universal service systems.

About Tier 2

Tier 2 of the NDIS is intended to help all people with disability, and their families and carers, access services and support beyond the scheme itself (Figure 1). Operationalised as the *Information, Linkages and Capacity Building* (ILC) program, it currently has two elements:

- a grants program, administered by the Department of Social Services (DSS), which provides fixed-term grants to organisations to deliver projects in the community to benefit all Australians with disability, their carers and families; and
- a referral function via NDIS Local Area Coordinators (LACs), overseen by the National Disability Insurance Agency (NDIA), to help connect all people with disability and their families and carers to their community and to services within each ILC stream (DSS 2022a).

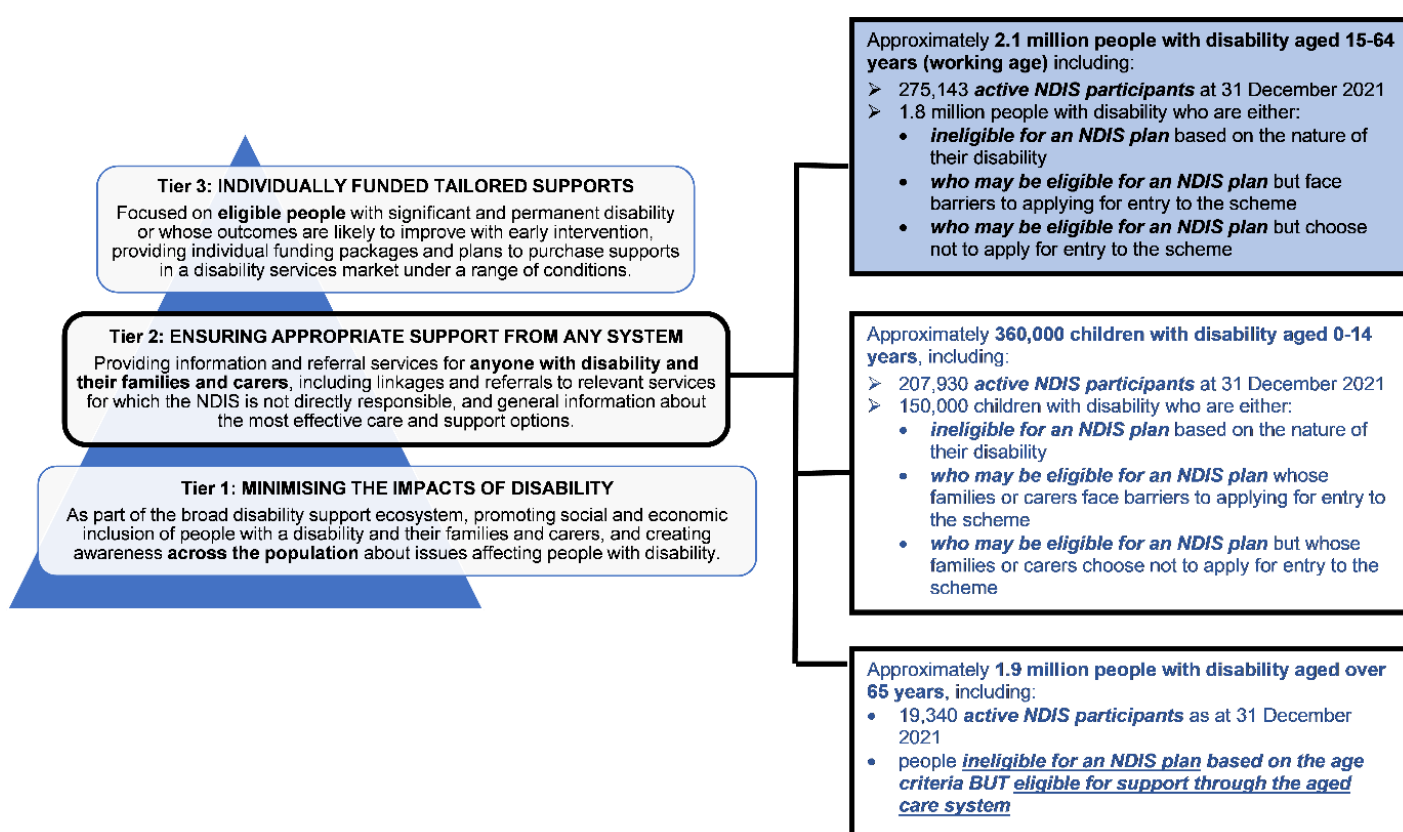


Figure 1: NDIS intended tiers of support and people in Tier 2

Sources: Productivity Commission 2011 pp 158-165; ABS 2019; NDIS 2022a. Alt text provided.

Evidence about the extent to which ILC is effective in improving outcomes for people with disability who are not eligible for individualised funding, or whether ILC is reducing demand for NDIS funding packages, is lacking (Productivity Commission 2017:232). In 2021, DSS commissioned the Centre for Social Impact at Swinburne University of Technology to undertake an analysis of gaps and unmet needs in the ILC program. Among its findings, that review revealed that LACs have not been able to deliver community capacity building and linkages as intended; that ILC grants have become the main investment in community capacity building and linkages and are inadequate for that purpose; and that both what is available in Tier 2, and the level of need, are unclear (Wilson et al 2021:19).

About this research

There are **1.8 million people with disability of working age – approximately 12 per cent of Australia’s working age population – who are not NDIS participants**. That group is the focus of this research.

This research examined *if* and *how* working-age Australians with disability who are not NDIS participants are finding and using any support and/or services they need to participate in society and the economy.

Method

The research involved:

1. **A desktop environmental scan** of services, resources, programs and activities promoted as disability inclusive and available to people with disability living in Victoria, South Australia or Tasmania. The scan is not intended to be an exhaustive directory or map, and it does not aim to verify or disprove published information from every provider. It is designed to capture what types of services, support and activities are promoted as available to people with disability.
2. **Two online surveys** – one for **people with disability aged 18-64 years living in Victoria, Tasmania or South Australia who are not NDIS participants** (198 responses), and one for **families and carers of people with disability with the same criteria** (53 responses). The surveys were promoted on social media and by email to organisations and agencies working with people with disability, and were open to anyone who met the criteria of age, state of residence, and not having individual NDIS funding. The surveys were designed to capture information about their needs and circumstances; if and how they are finding any services or support they need in their day-to-day lives; the adequacy of information, support and services available; and financial and personal costs incurred.
3. **Focus groups** involving representatives from service providers, peak bodies, advocacy organisations and Disabled Peoples Organisations (DPOs) operating in Victoria, Tasmania and South Australia, exploring their experiences and perceptions of the service environment and challenges facing people with disability who are not NDIS participants (19 participants across 7 focus groups).

Limitations

The data collected is not representative of all stakeholders in the landscape of services and support available to people with disability who are not NDIS participants. However, it provides important insights into financial, logistical, and personal challenges faced by people with disability in their day-to-day lives.

This research is limited to three Australian states and was conducted during the COVID-19 pandemic. Rolling state lockdowns and health risks to people with disability precluded face-to-face data collection. This excluded some people with disability from participating in the study.

Open calls for survey responses tend to attract responses from people dissatisfied with the status quo, with capacity to respond. People with disability, families and carers who completed surveys were predominantly Australian born, English speaking, with formal education of secondary school or above. However, their survey responses are a red flag for what may be hidden in populations with complex needs missing from current datasets informing disability policy and practice.

Other voices missing from this study are LACs. Permission to include them in focus groups was denied by the NDIA, closing off access to their insights into how the NDIS operates at the point where it intersects directly with people with disability who are not NDIS participants.

Key findings



“I can’t find what I need because I don’t know what support would be useful to me... Every website ends with the phone numbers to Lifeline and Beyond Blue. But I’m not in crisis. I just want a list of instructions, things to work on so I can function in a society that was designed without me (and many others) in mind.”

- Survey participant

Our research reveals complex, disconnected and incomplete markets of services and supports being navigated by people with disability and their families and carers; a service ecosystem riddled with inconsistent costs, eligibility criteria, information, priorities and availability of services; and heavy reliance on informal support networks and personal resources among people with disability without NDIS funding.

Access to services and support

- Ninety per cent of survey respondents said that the support and services they rely on in their day-to-day lives are inadequate to meet their needs. They attributed this to issues related to the availability and accessibility (including costs) of suitable services and support, unreliable information about the service landscape, and not knowing how or where to find support. Focus groups revealed that disability advocacy organisations

also struggled to find clear information about support for people with disability who are not NDIS participants.

- One in four people with disability and one in three family members and carers who completed surveys reported that either they or the person they provide care for had applied unsuccessfully for NDIS funding.
- Cross-analysis of the desktop scan, survey responses and focus group findings indicates that access to services and support in Australia, including NDIS funding, varies for people with disability, their families and carers according to where they live, their income, the language they speak at home, their education, their gender, their age and their individual needs and circumstances.
- Clear discrepancies emerged between the **promoted availability and accessibility of support and services to people with disability who are not NDIS participants**, and **people's experiences of attempting to find and use them**.

Online information

- The desktop environmental scan found extensive information online about services and activities open to people with disability, including dedicated resources and databases created and designed to help people with disability find services and support. Many of these resources are products of short-term ILC grants, frozen in time when funding ended. Surveys and focus groups revealed that details important to prospective service users - including costs, accessibility for particular needs, location, wait times, and eligibility for support or concessions - were often missing, inaccurate or outdated online.

Frequently, when prospective service users followed up with individual services, they found that those services did not fit their needs and circumstances or were unavailable. Many survey respondents mentioned the time and effort involved in navigating and sifting the volume of information online, and finding it overwhelming and frustrating. The time and effort involved also emerged clearly in our own scan of the service landscape, despite the advantages of having dedicated resources, sound understanding of the environment, and years of research experience.

The role of Local Area Coordinators

- Surveys and focus groups indicated a stark gap between the clearly stated role of LACs to connect all people with disability to their community and to mainstream services, and people's experiences of seeking services and support. No survey respondents said that they had received support or advice from the NDIS or Local Area Coordinators beyond information about eligibility for individual NDIS funding. Disability-specific organisations reported providing unfunded support to fill that gap, and described themselves as struggling to meet demand. There were numerous mentions in surveys and focus groups of circular referrals between people with disability, advocacy organisations and LACs with no satisfactory outcome.

Sources of information about support

- Common sources of referral or advice about available support named in survey responses were GPs and disability advocacy organisations, and to a lesser extent, local community organisations and networks.

Informal supports

- Survey responses and focus group discussions revealed that people with disability who are not NDIS participants, and their families and carers, are heavily reliant on unpaid support from family and friends in their day-to-day lives, in the absence of viable and affordable alternatives.

Financial burden

- People with disability face extra costs of living that people without disabilities do not incur. Survey responses revealed that the costs of accessing necessary services and support were putting households under financial pressure, both in terms of direct costs (such as equipment purchases, medical and pharmacy out of pocket expenses, service fees, transport costs and housing modifications) and indirect costs (such as time away from work). The most frequently reported annual household income across both surveys was less than \$30,000.

Trust in government

- Findings indicate that lack of transparency and ongoing shifts in disability policy and practice have eroded trust in government and institutions, and particularly, trust in the NDIS. Ongoing public consultations with short timelines during the COVID-19 pandemic stretched people with disability, their families, carers and the disability sector beyond 'consultation fatigue' to breaking point, where they feel frustrated, resentful, excluded, and powerless. Survey responses and focus group discussions revealed widespread belief that issues related to the administration and funding of the NDIS have pulled resources and focus away from the majority of Australians with disability, who are unable to access individual NDIS funding.



“The NDIS has soaked up all funding and anybody else without NDIS just misses out. Living in rural area further impacts the above issue, as out here, we do not have enough workers in the NDIS let alone if we ever get any mainstream funding, to even create a local support would be ridiculous considering the lack of professionals.”

- Survey participant

Emerging risks

The NDIS is a key part of the ecosystem of supports for Australians with disability that call for a whole-of-community paradigm shift. That is not easy to operationalise. How each worker, organisation and institution interacts with people with disability is shaped by societal norms, their own governance, financial and management structures and priorities, government policy levers, the legislative environment, and (where applicable) contractual arrangements with Commonwealth, state and territory, and local governments. In addition, the capacity of people with disability to navigate that environment is contingent on their own needs, circumstances, energy, and connections, and that capacity can fluctuate over time. The risks of misreading this environment cannot be ignored.

In that context, we identify the following risks for governments in our research findings:

- There is a clear gap between *what is promoted* and *what is happening* in the interface between people with disability who are not NDIS participants and the NDIS. This emerges as a major fault line in Australia's Disability Strategy 2021-2031.
- Existing data on the availability, accessibility, affordability and adequacy of mainstream services for people with disability is unreliable. This is skewing policy and practice across the ecosystem of disability-related supports, including the NDIS.
- Sustained financial and emotional pressure on people with disability without NDIS funding, and their families and households, is likely to have compounding effects across a range of service systems.
- Current investment in information, linkages and capacity building is inadequate and misdirected. This poses threats to the sustainability of the NDIS through demand for higher levels of support when people enter the scheme than might otherwise be necessary in a more inclusive society, and demand for entry to the scheme from people with disability who cannot find or access alternative support to meet their needs.
- Informal supports for people with disability are precarious and unsustainable at existing levels.
- Market-based principles now underpin many services provided directly by government, as well as outsourced and private activity, in this arena. This creates perverse incentives for cost-shifting until a crisis arising from market-produced inequity forces government intervention.



“Receives only unpaid care from us as parents. Our person is permanently housebound and needs help with all food preparation often including making decisions about what to eat. Our person cannot change their bedding nor do their own washing. Needs support with anything requiring cognitive function, example filling in forms.”

- Survey participant



“My 88yo mother helps me with meals, and phoning people. My son helps wheel my wheelchair on the rare occasions I leave my house and drives me. He also helps with outside chores and putting my bins down and getting mail from my mailbox as I am too exhausted to walk outside. He does my shopping and puts it away for me as I cannot drag/lift online grocery shopping deliveries from the front door into the house. I have a paid council home help lady once a fortnight to change my sheets and hang them on the line, she does the housework I cannot do. I cannot tolerate her coming more than once a fortnight due to sensory overload and sensory processing issues.”

- Survey participant

Policy considerations

This research highlights significant inequalities and inconsistencies in costs and access to services and support for Australians with disability in three states. Both markets and core government services have shown that in some circumstances, they are unwilling or unable to bear the costs of providing services to people with disability or adapting to meet their needs. These findings are consistent with the findings of numerous government inquiries and public consultations related to the design and implementation of the NDIS. What this research adds are the voices of people with disability without access to NDIS funding, and their families and carers.

The findings flag a potential ‘double driver’ of future government costs. When people with disability and their families are unable to afford or access support that could delay or prevent their entry to the NDIS, and exhaust their personal resources and informal supports to the point of crisis, they will ultimately need higher levels of support from both the NDIS and other government services.

We offer the following considerations for policy makers:

- The financial impact of being in or out of the NDIS is significant for people with disability and their families. The “cliff” at the edge of the NDIS between support available to NDIS participants and those outside the scheme must be addressed to reduce pressure on the scheme. Current approaches to referring people with disability to mainstream services do not address entrenched socio-economic disadvantage; the impact of the NDIS market model on community supports; or risks associated with people being unable to find or afford the services and support they need to maintain their wellbeing.
- Under the umbrella of Australia’s National Disability, Tier 2 of the NDIS must be supported by whole-of-government commitment to address entrenched socio-economic marginalisation of people with disability, with clear and measurable accountability for outcomes across jurisdictions. This work should include consideration of whether and how existing data and data analytics can identify critical risks and opportunities in that environment.

- People with disability, and representative organisations, should co-design how ILC resources intended to serve their interests are prioritised, applied and structured, with a focus on sustainable inclusion in society and the economy.
- Universal platforms routinely accessed by people with disability and their families - such as schools, GPs, allied health services, Neighbourhood Houses, local government, pharmacies, Medicare, and Centrelink – could be better used both to flag service gaps and to provide information to people with disability about mainstream services and support aligned to their needs and circumstances. Providing intuitive and user-friendly access points for information would significantly reduce the administrative burden for people with disability and their families of sifting through information about services and support online.
- Local Area Coordinators are a national, street-level gateway for people with disability to access disability-related support from government. They can play a critical role as a bridge between government, people with disability and communities, and in building community capacity and social capital at a local level. They should be equipped and resourced for that role, as originally intended.

Recommendations for future research

This research demonstrates the current and future risks of misreading the environment navigated by people with disability in Australia, and the importance of capturing their perspectives and experiences, and activity surrounding them, to shape policy and practice.

In terms of future research, we recommend:

- Research into the cost benefits and public value of targeted, timely and early investment in supporting people with disability who are not NDIS participants, and the economic risks of inaction.
- Targeted, participatory research into the experiences of people with disability across Australia facing intersectional and compounding barriers to finding and accessing services and support. This research could also examine the feasibility of hybrid block-funded models in thin service markets, jointly funded by Commonwealth, state and territory governments, to respond flexibly to support needs that do not call for an annual NDIS plan. The findings should underpin strategic policy action across state, territory and Commonwealth governments to address complex disadvantage.
- Mapping the level and impact of investment in general/mainstream supports for people with disability across all levels of government, including the role of LACs in supporting people with disability who are not NDIS participants. This will highlight gaps in service provision and unmet needs, and pinpoint key leverage points in the service ecosystem where governments can improve and sustain inclusion for all Australians with disability.

Section 1: Background

Ensuring people with disability can participate in all aspects of Australian life

Australia's Disability Strategy 2021–2031 calls on all Australians to ensure people with disability can participate as equal members of society. The Australian Government says success “rests in a whole-of-community response, inclusive of business, the non-government and services sectors and individuals. Only by working together can we ensure all aspects of Australian life are inclusive and accessible” (DSS 2021b:1).

There are approximately 4.4 million people with disability in Australia – one in six of the country's whole population. This diverse group includes 2.4 million people aged under 65 years, and approximately 2 million aged over 65 years. Twenty per cent of Australians with disability aged under 65 receive individual funding through the National Disability Insurance Scheme (NDIS) to purchase support and/or services to help them pursue their goals (NDIS 2022a). They are called *NDIS participants*. More broadly, the NDIS is intended to work at both an individual and systemic level to help all people with disability connect with universal or ‘mainstream’ services and activities in their communities, and to make communities more welcoming and inclusive. It is a key part of the ecosystem of supports for Australians with disability.

It is widely assumed that NDIS participants are the people with disability most in need of specialist support, and that is largely true. A person is eligible for individual NDIS funding if they have “a disability that is attributable to an impairment that is permanent or likely to be permanent and that results in substantially reduced functional capacity” or where there is evidence of “potential benefits of early intervention on the impact of the impairment on the person's functional capacity” (NDIS 2019a). Since the creation of the NDIS in 2013, many people meeting these criteria have been able to access the support they need for the first time.

However, the movement of funding from Commonwealth, state and territory governments to the NDIS meant that people with types of disabilities excluded from the scheme's eligibility criteria, such as those with disabling health conditions (NDIS 2019b), lost access to services and supports that were previously block-funded by those governments with different eligibility criteria. There is also mounting evidence that some people who may be eligible for NDIS funding face barriers to successfully applying for entry to the scheme, tied to their access to support and information, language and literacy, access to technology, previous experiences or perceptions of dealing with government service systems, and/or their capacity to bear the financial and psychological costs of establishing their eligibility for support (VCOSS 2021; Malbon, Carey & Melzer 2019; Carey et al 2018; Warr et al 2017).

This suggests that **among the eighty per cent of Australians with disability aged under 65 who are not NDIS participants, there are people with complex support needs** who are wholly reliant on mainstream service systems, community resources, and their own knowledge, resources, families, and networks, to participate in society and in the economy. Many are navigating this environment from a position of socio-economic disadvantage. Yet little is known about how they are faring, whether and how their needs are being addressed, or the ripple effects of failing to meet their needs. For the most part, the knowledge and experiences of these people, their families, friends, carers, and

advocates, and those interacting with them in the community, are not captured in evidence informing disability-related policy and practice.

Among them are 1.8 million people of working age (NDIS 2022a; ABS 2019) – approximately 12 per cent of Australia’s working age population.

Looking beyond individual NDIS funding

To date, much of the effort and attention of the NDIS has been focused on NDIS participants, and issues related to access to individual funding, planning, and utilisation of funding packages. However, there were three tiers of support built into the scheme’s original design (Table 1). The tiered design acknowledges that while people with disability who are not NDIS participants should – and in theory, can – have their needs met by mainstream services, those services can be difficult to access and navigate for those with limited personal support networks, resources or capacity.

Who is the NDIS for? ("populations of customers")	Tiers of support	Functions
People with support needs that would otherwise not be reasonably met without taxpayer funding, and that are not more appropriately met by other systems	Tier 3	Funding individualised supports
All people with, or affected by disability	Tier 2	Providing information and referral services
All Australians	Tier 1	Providing insurance against the risk of acquiring significant disability and promoting opportunities for people with a disability and creating awareness of the issues that affect people with a disability

Table 1: *NDIS intended tiers of support*

Source: *Productivity Commission 2011 p 158*

Tier 2, since renamed *Information, Linkages and Capacity Building (ILC)*, is intended to maximise the potential for all people with disability to use mainstream services “on an equal basis with others” (United Nations 2007) and to reduce the likelihood that they will need individual support from the NDIS. The rationale for shifting away from the term ‘Tier 2’ was to remove “the potential for misinterpreting the NDIS as a hierarchy of supports, which was implied by references to ‘tiers’” (NDIS 2020b, 1).

On paper, these tiers of support are clear. But information and support available to people with disability who are not NDIS participants – including access to NDIS funding – can vary according to their income, where they live, their age, their education, their gender, their language and literacy, their access to technology, their individual needs and preferences, their personal support networks, and the nature of their disability. Many of those factors fluctuate. There is no clear data about *who* sits within the Tier 2 box in the NDIS structure, and *what* services and support they need and are able to access.

On that basis, the Tier 2 box in the NDIS structure stands out as an underexamined, high-risk and complex policy environment that has significant impact on the lives and livelihoods of some of Australia’s most disadvantaged citizens (Figure 1).

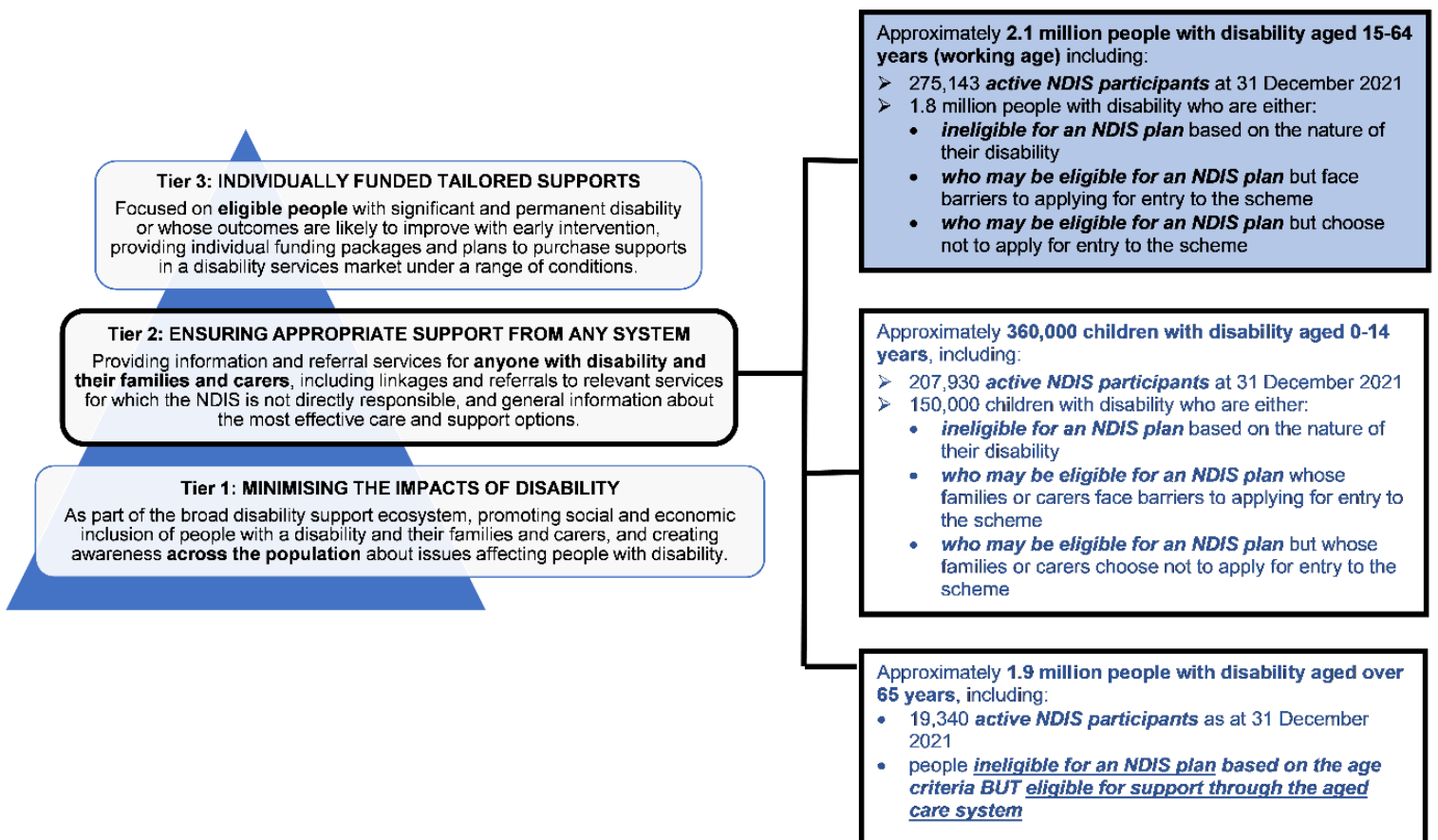


Figure 1: NDIS intended tiers of support and people in Tier 2

Sources: Productivity Commission 2011 pp 158-165; ABS 2019; NDIS 2022a. *Alt text provided.*

Unpacking Tier 2

The design and implementation of Tier 2 of the NDIS has changed over time, but it remains problematic. It has two components: the ILC grants program, which funds short-term initiatives designed to connect people with disability to support outside the NDIS, and referral, information and capacity building support provided by NDIS Local Area Coordination Partners in the Community (LACs). Responsibility for the ILC grants program transferred from the National Disability Insurance Agency (NDIA) to the Department of Social Services (DSS) in October 2020, with the aim of aligning its activity with other national disability policies and programs, including Australia's National Disability Strategy, Disability Employment Services, the National Disability Advocacy Program, the Disability Gateway and the Carer Gateway (DSS 2022a).

It provides grant funding to organisations to deliver projects serving the interests of people with disability across four streams: Individual Capacity Building; National Information Program; Economic and Community Participation; and Mainstream Capacity Building. The LACs “continue to help all Australians with disability, their families and carers access a broad range of community and government services... [and] work at both the individual and systemic level to support Australians with disability to access and enjoy services available to all Australians” under the oversight of the NDIA (NDIS 2021b). The structure of the ILC program, and its aims and funding, are set out below (Table 2).

ILC Program Stream	Aims	Grant rounds	NDIS LAC PARTNERS IN THE COMMUNITY
Individual Capacity Building	Seeks to enable systemic, nationwide access to peer support, mentoring and other skills building for people with disability, their families and carers.	2020-2023 \$105.9m committed to 105 3-yr grants 2020-2021 \$64.9m committed to 138 2-yr grants	
National Information Program	Focuses on providing information on support and/or services to people with disability, their families and their carers through consistent national information programs and products.	2020-2023 \$65m committed to 37 3-yr grants	
Economic and Community Participation	Focuses on improving pathways to employment and increasing participation by people with disability.	2020-2023 \$32.7m committed to 28 3-yr grants 2021-2022 \$36m committed to 160 project grants	
Mainstream Capacity Building	Focuses on improving the capacity of mainstream services to respond to and include people with disability, increasing accessibility and use of mainstream services.	2020-2023 \$35.1m in grants to 28 organisations across Australia, funding three years of activities.	

Table 2: Overview of the Information Linkages and Capacity Building (ILC) program

Source: DSS 2022a

Evidence on the extent to which ILC is effective in improving outcomes for people with disability who are not eligible for individualised funding, or if ILC is reducing demand for NDIS funding packages, is lacking (Productivity Commission 2017:232). The service landscape for people with disability has changed significantly since the NDIS was enacted in 2013.

The ILC program has been under federal government review since 2020 “to better understand the program, including the role of local area coordination”, and its place in the broader disability landscape (DSS 2022b). In 2021, the department commissioned the Centre for Social Impact at Swinburne University of Technology to undertake an analysis of gaps and unmet needs in the ILC program. In brief, the review found:

- LACs not been able to deliver community capacity building and linkages as intended
- ILC grants have become the main investment in community capacity building and linkages and are insufficient
- Increased client capture resulting from the NDIS market based system
- Community inclusion is commodified and requires funding
- Contraction of services available to people with disability without NDIS funding
- It is unclear what is now available in Tier 2, and the level of need also unclear (Wilson et al 2021:19)

Tier 2 support for all Australians with disability is critical to the sustainability of the NDIS. It can reduce the likelihood that people with disability on the edges of the scheme will need NDIS funding in both the short and long term; and it can reduce the likelihood that their disability will be exacerbated by social and economic exclusion, generating higher costs if they ultimately enter the scheme.

More broadly, it can build the capacity of business and communities to be aware of and respond to issues affecting people with disability; link people with disability to mainstream services and activity; and promote sustainable attitudinal and systemic change. Questions about the availability, accessibility, affordability and adequacy of services and support for people with disability without NDIS funding – including promised support from the NDIS – and the relationship between the NDIS and key policy areas like health, education, employment, transport, housing and aged care, demand answers.

The aims of this research

The research aims to build understanding of how working-age Australians with disability without individual funding from the National Disability Insurance Scheme (NDIS) are finding and using any support and services they need to participate in society and the economy. This group constitutes approximately 12 per cent of Australia’s working age population.

The aims of the research are to:

- capture the experiences, perceptions, and demographics of Australians with disability participating in society without NDIS funding, and information about their networks of support

- expand understanding of the interface of the NDIS with people with disability who are not NDIS participants, and with services, programs, activities and infrastructure provided by federal, state, territory and local governments, the community sector, the private sector, and individuals that should be accessible to people with disability.
- build a foundation for broader and deeper research into the NDIS and the intersecting services intended to support people with disability to participate in society
- understand risks and opportunities for all people with disability, their families, civil society, and governments in that environment.

The research questions

- How do people with disability aged 18-64 years who do not receive funding through the NDIS find and use any support and/or services they need to participate in society and the economy on an equal basis with others?
- Are there access and equity issues for people with particular characteristics and/or in particular locations?
- Is there unmet demand for services and support to participate in society and the economy among people with disability aged 18-64 years who are not NDIS participants?

Research methods

Detailed descriptions of the methodology and parameters for each component of this research is provided in appendices to this report. This study was undertaken between April to October 2021 and employed mixed quantitative and qualitative research methods. Data was collected across three states in which the Brotherhood of St. Laurence (BSL) and Baptistcare TAS & SA operate as NDIS Partners in the Community – Victoria, Tasmania and South Australia.

The research encompassed:

1. **A desktop environmental scan** of services, resources, programs and activities promoted as disability inclusive and available to people with disability living in Victoria, South Australia or Tasmania. The scan is not intended to be an exhaustive directory or map. It is designed to capture what types of services, support and activities are promoted as available to people with disability.
2. **Two online surveys** – one for **people with disability aged 18-64 years living in Victoria, Tasmania or South Australia who are not NDIS participants** (198 responses), and one for **families and carers of people with disability with the same criteria** (53 responses). The surveys were promoted on social media and by email to organisations and agencies working with people with disability, and were open to anyone who met the criteria of age, state of residence, and not having individual NDIS funding. The surveys were designed to capture information about their needs and circumstances; if and how they are finding any services or support they need in their day-to-day lives; the adequacy of information, support and services available; and financial and personal costs incurred.

3. **Focus groups** involving representatives from service providers, peak bodies, advocacy organisations and Disabled Peoples Organisations (DPOs) operating in Victoria, Tasmania and South Australia, exploring their experiences and perceptions of the service environment and challenges facing people with disability who are not NDIS participants (19 participants across 7 focus groups).

Data from all sources was triangulated to provide a 360-degree view of what works well, what is not working well, what is missing, and what is needed by people with disability of working age to participate in the community without NDIS funding.

Limitations in the research design

The data collected is not representative of all stakeholders in the landscape of services and support available to people with disability who are not NDIS participants. However, it provides important insights into financial, logistical, and personal challenges faced by people with disability in their day-to-day lives.

This research is limited to three Australian states and was conducted during the COVID-19 pandemic. Rolling state lockdowns and health risks to people with disability precluded face-to-face data collection. The use of online surveys excluded some people with disability from participating in the study.

The surveys were promoted on social media and by email to organisations and agencies working with people with disability, and were open to anyone who met the criteria of age, state of residence, and not having individual NDIS funding. Open calls for responses tend to attract responses from people dissatisfied with the status quo, with capacity to respond, and we considered this risk in analysing the findings. People with disability, families and carers who responded to the open call to complete surveys were predominantly Australian born, English speaking, with formal education of secondary school or above. Their survey responses are a red flag for what may be hidden in populations with complex needs missing from current datasets informing disability policy and practice.

We planned to host three focus groups for contracted Local Area Coordinators (LACs), to draw their insights on local demand, local needs, local activity, and local service environments into the research. Consequently, we sought permission from the NDIA to invite people employed in LACs in Victoria, South Australia, and Tasmania – eight people in each of those states – to participate in a ninety-minute focus group. Our request was refused on the basis that the high workload of the NDIA and its partners prevents such a large commitment of resources from the NDIA's Partners in the Community and Contact Centre Partners. At the time of our request, that workforce comprised over 5,000 people (NDIS 2021c).

Finding best practice and leverage points for effort and investment outside the NDIS that could improve the lives of people with disability, their families and carers is critical to the sustainability of the NDIS, both in terms of people not having to enter the scheme and for participants to be able to reduce or transition out of NDIS funded support over time. Restricted access to LACs working at the frontline of the NDIS is a limitation in understanding how the scheme operates at the point where it intersects with citizens. However, the findings from focus groups and surveys about their interactions with LACs were illuminating.

Advisory group

A Project Advisory Group, comprised of people with expert knowledge of the NDIS, disability-related policy and research, and lived experience of disability, was formed to guide the project through its design, implementation and analytic phases. The Group met four times over the life of the project – at the outset (before data collection), at the mid-point (before data analysis); after data analysis (reviewing early findings) and at the end of the project (to review the final report). The remit of the Advisory Group was to provide strategic advice and guidance to the research team on the project's implementation, findings and outputs.

The Advisory Group provided strategic advice on:

- recruitment of research participants;
- priorities for data analysis;
- research translation, including the planning of research-related events;
- further research opportunities;
- related research and policy;
- potential conflicts of interest.

The Group also provided strategic advice and guidance to the research team on sharing the project findings and outputs.

Section 2: Environmental scan – searching for support

A desktop environmental scan was undertaken of services, resources, programs and activities promoted as disability inclusive and available to people with disability living in Victoria, South Australia or Tasmania. The scan is designed to capture what kind of services, support and activities are promoted as available to people with disability, with the aim of comparing it to survey and focus group data capturing people's experiences of seeking services. The scan doesn't serve as an exhaustive service 'directory' or 'map', but instead *indicates* what types of support are available, where and to whom. It is not a categorical reflection of the service environment.

The six policy outcome areas outlined in the National Disability Strategy 2010-2020 (Council of Australian Governments 2011:10) were used as categories to frame the search parameters of the scan, and these are:

- Inclusive and accessible communities
- Rights protection, justice and legislation
- Economic security
- Personal and community support
- Learning and skills
- Health and wellbeing

Details of these policy areas as they are described in the National Disability Strategy 2010-2020 are provided in Attachment 1 of this report.

Findings from the environmental scan

Inclusive and Accessible Communities

Based on the interventions described within the National Disability Strategy 2010-2020, the scan categorised interventions under Inclusive and Accessible Communities as being (at least) one of:

- Sport and recreation
- Social connection and civic participation
- Transport services
- Home and building modifications
- Communication technologies and support

Sport and recreation programs appear to be common in metropolitan areas in South Australia and Victoria but less common in rural areas, while in Tasmania there seems to be inconsistent availability state-wide. They are largely fee-paying services.

Social connection and civic participation interventions were found inconsistently across the states. A handful of services look to be operating in Adelaide and

Melbourne, with very little else in rural areas. The scan only came across one state-wide service in Tasmania.

Transport services, such as free or concession public transport, and subsidised taxi services and medical travel, are available in each state. The vast majority of these interventions are state government funded. Few privately operated supports, such as community taxi services, were found.

Home and building modification interventions were found to be scarce. Those few services that are available are largely delivered by NDIS providers and so carry significant costs to those seeking access from outside the Scheme. In Tasmania and some Victorian local government areas, the Home and Community Care program may provide this service at a cost.

Communication technologies and support, such as Auslan services and accessible equipment, mostly appear to be delivered nationally by both the Commonwealth Government and private providers, the majority of which look to be at least partially subsidised.

Rights Protection, Justice and Legislation

Based on the interventions described within the National Disability Strategy 2010-2020, the scan categorised interventions under Rights Protection, Justice and Legislation as being (at least) one of:

- Advocacy services
- Complaints handling and resolution services
- Legal support services

There is a strong representation of **advocacy services** across the states, particularly in Victoria and South Australia. Many are location-specific, including advocacy groups servicing rural areas. Self-advocacy groups helping people with disability build capacity in advocating for their rights were also commonly found. Both of these intervention types are often aimed at specific demographic groups, determined by disability, location, age, sexual orientation, issue (e.g. housing), ethnic background, or other signifier (e.g. parents with a disability).

In Victoria, advocacy services appear consistently across metropolitan and rural areas. In contrast, advocacy services in South Australia seem to be less locally rooted and are instead advertised as being 'state-wide' (despite still operating primarily out of Adelaide). Similarly in Tasmania, the handful of advocacy services are largely offered on a state-wide basis.

Complaints handling and resolution services, largely delivered nationally and state-wide, are fairly common and usually take the form of phone hotlines, such as those assisting people with making submissions to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Legal support services were found consistently in all three states. Common supports include diversion programs, casework, legal representation and guardianship. They are largely offered state-wide by state and private providers. Often, they target particular demographic cohorts, including women, first nations

people, people experiencing homelessness, and people with intellectual and psychosocial disabilities.

Indeed, a significant proportion of interventions in this policy area seem to be targeted to people with intellectual disabilities. This was particularly the case with advocacy and legal support services.

Federal and state governments oversee the bulk of service funding and delivery, while very little seems to come from the non-government sector or ILC grants. Across all jurisdictions, the states play a more active role in both these aspects, with much of the Commonwealth's funding delivered through the National Disability Advocacy Program. Nearly all interventions under this policy area are fully funded.

Economic Security

Based on the interventions described within the National Disability Strategy 2010-2020, the scan categorised interventions under Economic Security as being (at least) one of:

- Financial assistance (incl. income support and cost of living subsidies)
- Job opportunities and early career development pathways (incl. internships and volunteering)
- Supported housing

The Commonwealth delivers a much higher proportion of interventions under this policy area than the other five, which is perhaps unsurprising given its responsibility for income and employment services in Australia.

Financial assistance is available for income, housing, veteran and carer support, among other things. These comprise direct payments and subsidies; for example, the Commonwealth's Disability Support Pension.

In terms of **jobs and employment**, there appears to be a stronger focus on work experience, volunteering and job preparation (such as skills development), as opposed to ready-made job opportunities. The scan found a significant number of these interventions offered across the country by the Commonwealth and private providers, many of which specifically target people with autism and psychosocial and sensory disabilities.

Job opportunities and recruitment initiatives feature in Melbourne, but there are no more than a few in each of Tasmania and South Australia. Aside from Disability Employment Services, which are spread across Australia at almost 2000 sites (DSS 2021a), the availability of employment-focused interventions is notably lacking in many rural areas.

The states manage **supported housing**. In Victoria there are several supported housing options offered. While the majority of these are offered universally, there are several which target people with psychosocial disabilities – particularly those experiencing homelessness. Several supported accommodation options are available in South Australia, either exclusively to people with disability, such as the Mental Health Supported Social Housing Program, or more broadly to people experiencing disadvantage. Tasmania's supported accommodation services are scarcer; however the scan found some options available to people involved in the

mental health system. These comprise subsidised rent and assistance in securing housing. The vast majority of supported housing is subsidised. Services that are fully funded usually target people facing intersectional disadvantage, such as homelessness.

Personal and Community Support

Based on the interventions described within the National Disability Strategy 2010-2020, the scan categorised interventions under Personal and Community Support as being (at least) one of:

- Independent living and domestic support
- Inclusion and participation in the community support
- Assistive technology, aids and equipment
- Family and carers support

Independent living and domestic support options are common. These interventions often include support coordination and medical care assistance. They appear to be delivered largely by private providers, at a fee. Such providers are usually NDIS providers, so it is not uncommon for the NDIS pricing schedule to be applied to anyone seeking to access the service outside of the Scheme.

Both Victoria and South Australia look to have solid service availability in metropolitan areas. While there looks to be scarce local service provision in rural areas, there are several services advertised as having state-wide coverage. The few domestic support services the scan found in Tasmania look to have state-wide coverage.

Interventions supporting **inclusion and participation in the community**, commonly peer support groups, were found to be well featured in the scan. Peer support groups are largely free, with wide eligibility, and unlike many other interventions, have been able to continue online during COVID-19. These groups often cater to specific communities such as the LGBTQIA+ community, CALD groups, suicide survivors, and specific disability groups.

In Victoria and South Australia, supports for inclusion and participation in the community appear to be common in metropolitan areas and inconsistent in regional areas, while in Tasmania, the regions covering Launceston and Hobart have considerable representation.

State governments generally fund and provide **assistive technology, aids and equipment**. There are also a limited number of private providers across the three states. Supports offered may include vehicle modifications and assessments and animal assistance. These supports are mostly offered state-wide, at varying price points.

Family and carers support usually took the form of respite and peer support interventions. However, these were not found to be common. Victoria was the exception, as the scan found a few such supports as well as the Victorian Support for Carers Program, which is delivered by dozens of public and private providers across the state.

Learning and Skills

Based on the interventions described within the National Disability Strategy 2010-2020, the scan categorised interventions under Learning and Skills as being (at least) one of:

- Vocational education and training and further education
- Study support (financial or otherwise)
- Pathway programs from education to employment
- Lifelong learning

Vocational education and training and further education is readily available through each states' TAFE institutions and Registered Training Organisations (RTOs). RTOs deliver courses tailored to people with disability, such as the Certificate in Work Education. They are funded by both federal and state governments and fees are partially subsidised. TAFE is free in Victoria for select courses.

Non-financial **study supports**, such as classroom assistance, are provided by individual educational institutions, such as TAFE and universities, for free. Financial assistance does exist, in the form of Commonwealth-provided support, however it seems to target students generally, not people with disability specifically.

Aside from the aforementioned RTOs, there looks to be few **pathways between education and employment**, except in Victoria where the scan found several public sector scholarship programs tailored to young people with disability which comprise financial and non-financial support.

Lifelong learning interventions had considerable representation in the scan. Capacity building workshops, recreational learning, skills training, and art practice are common. Funding sources vary, while costs are generally at least partially subsidised. Victorian metropolitan areas tend to have greater availability than rural areas, South Australia shows inconsistent availability, and Tasmania a general lack of services.

Health and Wellbeing

Health and Wellbeing comfortably comprises the most interventions recorded in the scan. For the purposes of the scan, the interventions recorded within this policy area were considered under the general banner of 'health services', given the National Disability Strategy didn't provide a clear framework with which to categorise these services.

However, a number of sub-categories did consistently emerge, such as counselling and therapy, mental health support, medical equipment provision and subsidies, health assessments, rehabilitation, nursing and residential care, general practice, allied health, alcohol and other drug (AoD) support, addiction support (incl. eating disorders), and suicide support.

Interventions supporting people with psychosocial disabilities are very common, such as services for people challenged by Post-traumatic Stress Disorder, suicide, anxiety (a particular focus during the COVID-19 pandemic), and related comorbidities (e.g. alcohol and substance abuse).

Governments overwhelmingly provide the funding for health interventions. Across the three states there looks to be a general split between federal and state funding for health interventions. Federally funded services across the states are mostly delivered through Primary Health Networks.

A vast majority of interventions under this policy area are fully funded. The main exception to this would be allied health services, which generally carry out-of-pocket costs to consumers.

There doesn't seem to be many gaps in terms of service provision across the regions, except that the metropolitan regions show a wider and more diverse offering of supports.

Discussion of the scan findings

The findings of the scan sketch a service landscape populated by a variety of support and services available across the three states. Sports and recreation programs, advocacy services, domestic assistance, peer support groups, vocational education and training, lifelong learning programs, allied health and mental health supports were commonly found in the scan. However, this picture can be misleading. Much of this has to do with the high-level approach of the scan, which meant that a deeper analysis of service availability and accessibility could not be undertaken. (For instance, the scan doesn't record whether a given support has a waitlist.) In the discussion below we examine the scan findings in light of such considerations, and observe some key issues across the service ecosystem which the scan identified.

Regional comparisons about availability and accessibility of services are difficult

NDIS regions are limited as a framework to provide greater detail about the location and availability of disability interventions due to the large variance in geographical size and population between regions. This should be kept in mind during any regional interpretation of the scan. Some regions extend across huge swathes of territory, while others only cover a relatively small metropolitan area. While it is understandable that some regions (particularly those in rural, sparsely populated areas) are larger in size than others, their sheer breadth likely decreases accessibility. For example, to drive from end-to-end of the Murray and Mallee region in South Australia would take over 2.5 hours. A service located at the northern end of this region would have limited accessibility for someone living at its southern end – a nuance the NDIS regions framework does not capture. Despite this limitation in using the NDIS framework, the scan data is still useful in highlighting several key findings across the ecosystem of services.

Gaps in service delivery are greater in rural areas

The scan findings do suggest that there are numerous gaps in service delivery. This was particularly apparent in rural areas, with metropolitan areas generally having a higher representation of services. Aside from the Health and Wellbeing policy area, which had a fairly even distribution of services (perhaps a result of the role of PHNs and local health networks) and a few other common interventions (for example, sports and recreation programs, advocacy services and domestic assistance), there appears to be an uneven distribution of supports from region to region and state to state.

Promoting services as 'state-wide' conceals lack of regional coverage

While several services are promoted as operating 'state-wide', further investigation consistently revealed that many of these only had one physical access point – usually a metropolitan location – suggesting this state-wide status indicates the service has state-wide *eligibility*, not coverage. Proximity to that physical access point will presumably still impact accessibility. This represents one of many ways the scan found information about interventions to be misleading.

Information about support and services is often inaccurate or outdated

The issue of inaccurate or outdated online information about the availability of services arose consistently when service providers were contacted to confirm missing program details. For instance, a program that ended several years ago may still be advertised as operational. Crucial details about program costs and eligibility requirements – such as whether an NDIS plan is needed to access the service – were also often unclear. Follow-up contact with service providers was consistently required to confirm details and these calls regularly involved lengthy phone waiting times, or having to organise return calls which may only happen days or weeks later, if at all.

Accessing reliable and accurate service information is difficult and time-consuming

The consistently unreliable and outdated nature of online information about services demonstrates that the process of finding supports doesn't only require the means to locate the relevant information, but also additional time and effort to confirm whether the service is indeed available. This may make it even more difficult for people with disability to find the services and supports they need, when they need them.

It is unlikely that the average person has the same time or resources to find available interventions as the researcher who conducted the scan. Consider that the researcher has experience in desktop research, advanced computer skills and no accessibility requirements, and was able to conduct the scan without significant time pressures. Compare this to the average person, who may need to spend considerable time outside of their own employment, study or daily commitments to find the services and support they need – a potential indirect cost.

Despite these advantages, the researcher still consistently experienced difficulty discerning accurate information. This raises a pressing question as to how others with much more limited time and resources are supposed to navigate this complex service environment. It is important to stress these points given that, as the survey responses show, many people with disability are not accessing the services and support they need as they are unsure how or where to look for them.

Information about ILC-funded support is unreliable

The Information, Linkages and Capacity Building (ILC) funding model exemplifies many of the issues described above. Details about ILC-funded projects contained in grant round lists are regularly incomplete or incorrect, while the names of projects and the organisations funded to provide them often change when the projects are

delivered. There is scant information online about the current status of many approved projects, even for those awarded funding several years ago. This opacity makes it difficult to know if ILC funding is being used as intended, or to assess its impact.

The pandemic has strained service delivery and access

COVID-19 and the attendant lockdowns have had a significant impact on the delivery and availability of services. The scan regularly came across services that were no longer operational, or had to significantly amend or scale back their activities. It found that the commencement of several ILC-funded programs had been delayed. These effects were particularly acute in Victoria, which experienced protracted lockdowns throughout 2020-2021. Some services (for example, peer support groups) were able to shift to virtual modes of delivery, and this widened accessibility to people with internet access. However, most other services that rely on face-to-face engagement were required to wait out the lockdowns.

Inconsistent role of local government in service provision

The provision of disability services by local governments was found to vary considerably from municipality to municipality. For example, Victoria's Home and Community Care Program for Younger People (HACC PYP) – of which 'local councils are major providers' (Department of Health 2022) – is not provided by every local council. This variability may make it harder for consumers to know where to turn for a given support.

Limitations of the desktop environmental scan

There are several limitations with the desktop environmental scan methodology worth noting. Given how extensive the disability service environment is, the scan couldn't find and record every available disability support intervention. As such, any findings drawn from the scan – such as an apparent service gap – are informed approximations. That we are unable to fully capture the service landscape as it is on the ground may illustrate a broader limitation of the desktop environmental scan method.

Another limitation with our scan method is that in striving to be thorough and comprehensive in surveying the service environment, we risk straying away from the process by which people with disability, their families and carers might reasonably come to find supports. We should be mindful that it is unlikely the average person has the same resources to find interventions as the researcher who conducted the scan.

Our approach is also limited in the extent to which it evaluates service accessibility. This is apparent on two fronts. Firstly, due to time constraints we were unable to measure the extent to which the online information captured in the scan adheres to web accessibility standards. This should be an important consideration as poor web accessibility may impede awareness of available supports. Secondly, and more broadly, determining what is 'accessible' for people relies on a high level of speculation. The inclusion of interviews with people with disability in future research may improve understanding of how people access services.

Considerations related to the scan

The above discussion illustrates that although the scan found a range of interventions and services across the three states reviewed, a combination of additional factors complicate and qualify this picture. Unreliable and misleading information about services, service gaps, unclear responsibility for service delivery, and unforeseen external circumstances, all contribute to making it difficult for people to find services and, crucially, to trust that those services and support are in fact available, accessible and affordable.

This complexity emerges strongly in the findings of the surveys and focus groups presented in the following sections of this report. Those findings demonstrate that the scan's picture of service availability does not align with the experiences of people in trying to find and use the services they need.

Section 3: The Surveys – how people are faring

We know that access to services and support in Australia can vary for people with disability according to where they live, their income, the language they speak at home, their education, their gender, their age and their individual needs. This section presents the findings of two online surveys, which were designed to capture the perspective of service users and challenges and barriers to accessing support outside the NDIS.

We built two online surveys to capture the experiences of people with disability without access to NDIS funding – one to be completed by a person with disability (Person with Disability survey) and the other to be completed by a family member or carer of a person with disability (Families/Carers survey). This design balanced research ethics considerations about the capacity of people with cognitive impairment to provide informed consent, and the importance of capturing the experience of all people with disability. Copies of each survey are provided in Attachment 2 of this report.

Findings from the surveys

Demographics of the survey respondents

A total of 251 people completed the survey questions. Of the 231 responses to the Person with Disability survey, 198 completed the survey questions. The eligibility and consent questions filtered out 33 responses (14%). Of the 84 responses to the Families/Carers survey, 53 completed the survey questions about the experiences of the person with disability they provide care for. The eligibility and consent questions filtered out 31 responses (37%).

Demographic data are shown in Table A. The number of responses varied by question as there were no compulsory questions (once they completed the eligibility and consent phase of the survey). The majority of survey respondents:

- were born in Australia and are English speaking
- identified as female. On the Families/Carer survey the person with disability for whom the respondent provides care was predominantly male.
- indicated they live in Victoria.

A quarter of respondents to the Person with Disability survey and a third of the Families/Carers survey had previously applied for NDIS funding.

Table A: Demographic Data

	Person with Disability Survey	Families/Carers Survey
Survey Responses (n)	198	53
Question Responses (% , response rate)		
Female	82% 162/198	40% 21/53
Born in Australia	83% 119/144	86% 44/51
English Spoken at Home	95% 191/200	76% 39/51
Applied for NDIS Funding	25% 49/197	34% 18/53
Location:		
Victoria	68% 128/189	59% 29/49
South Australia	17% 33/189	18% 9/49
Tasmania	15% 28/189	22% 11/49

Figure 2 shows the percentage of responses by age by the person with disability who completed the survey (Figure 2a); the person with disability who receives care from families/carers (Figure 2b); and the person who provides the care (Figure 2c) and reveals that:

- 44% of respondents to the Person with Disability survey (n=198), were aged 45 years and over.
- 64% of people being cared for in the Families/Carers survey (n=53), were younger than 34 years
- 59% of family members or carers completing the Families/Carers survey (n=51) were older than 45 years.

Figure 2: Age of survey respondents

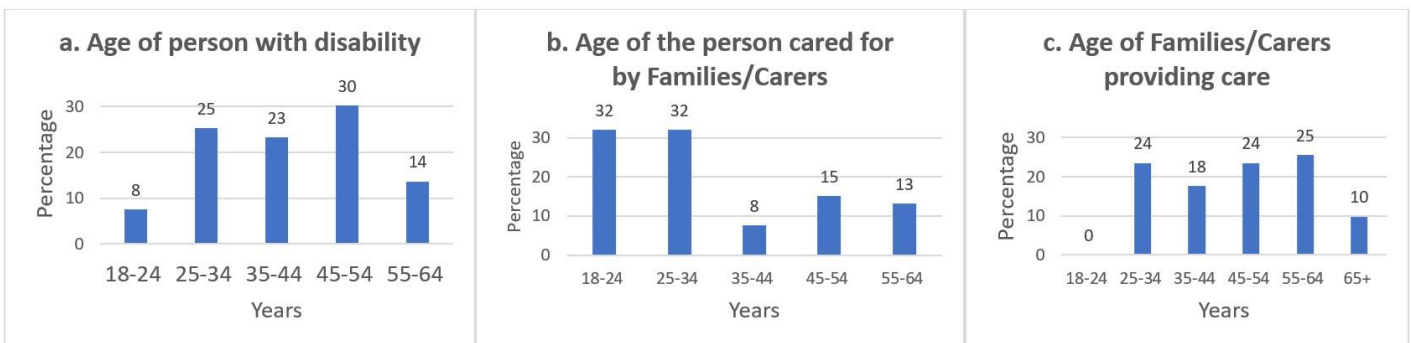


Figure 3 shows the percentage of survey respondents by the highest levels of education attained (from secondary school to tertiary education) and reveals that:

- Respondents to the Person with Disability survey reported their highest level of education to be mostly skills training (Certificate IV – Diploma) and tertiary education.
- Respondents to the Families/Carers survey indicated that the highest level of education of the person they provide care was secondary school, with lower levels of tertiary education and skills training reported. About a third of respondents indicated the person they provide care for had not completed secondary school.

Figure 3: *Highest level of education*

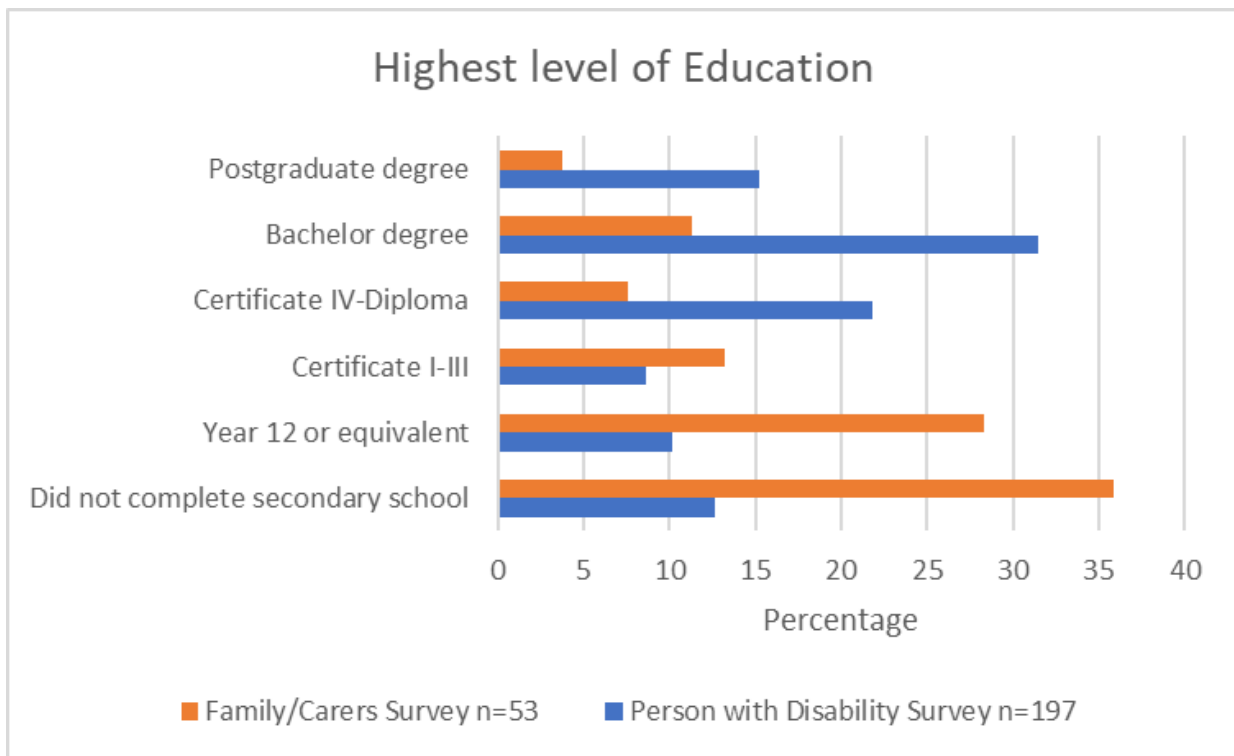
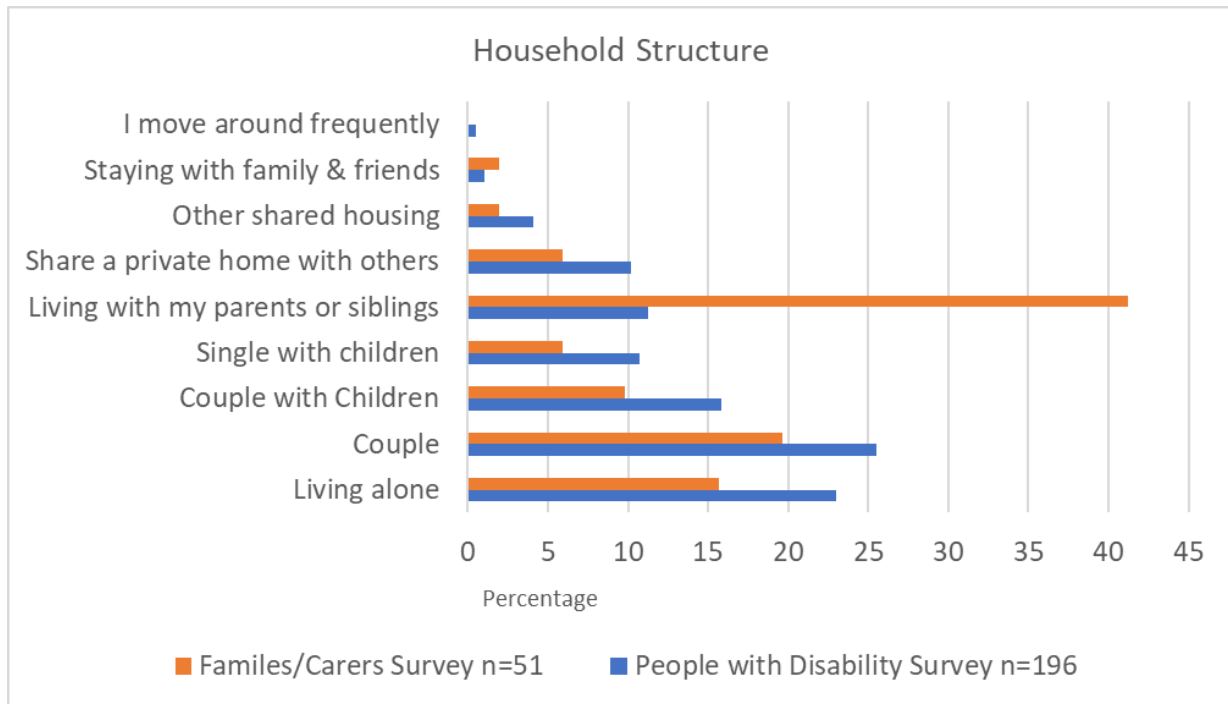


Figure 4 shows the percentage of survey respondents by household structure, where multiple responses were permitted. Respondents to the Person with Disability survey indicated they mostly live as a couple, followed by living alone, or as a couple with children. On the Families/Carers survey the person with disability mostly lives with their parents or siblings.

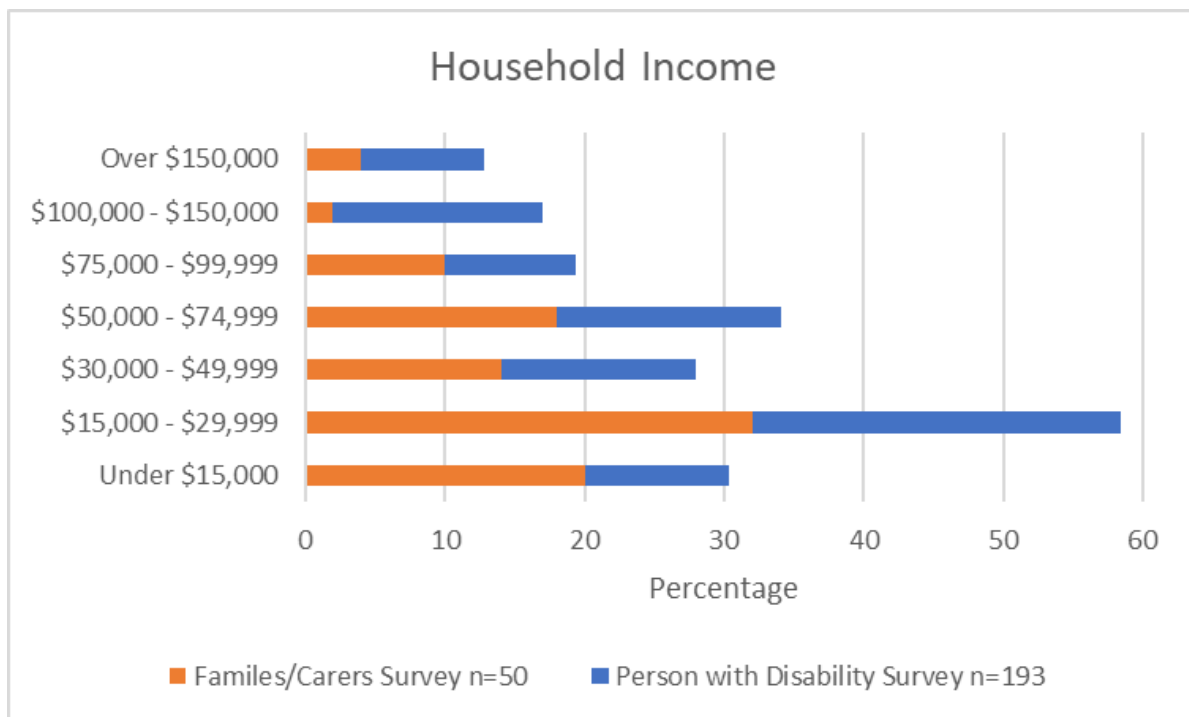
Figure 4: Household structure



The household income of the Person with Disability is shown in Figure 5, where the percentage of survey responses is plotted by income brackets. On both surveys the most frequently reported household income was between \$15,000 and \$29,999. Half of the respondents to the Person with Disability survey reported an income of between \$30,000 and \$49,999 or less.

On the Families/Carers survey more than half of the respondents reported an income for the person for whom they provide care of between \$15,000 and \$29,999 or less.

Figure 5: Household income



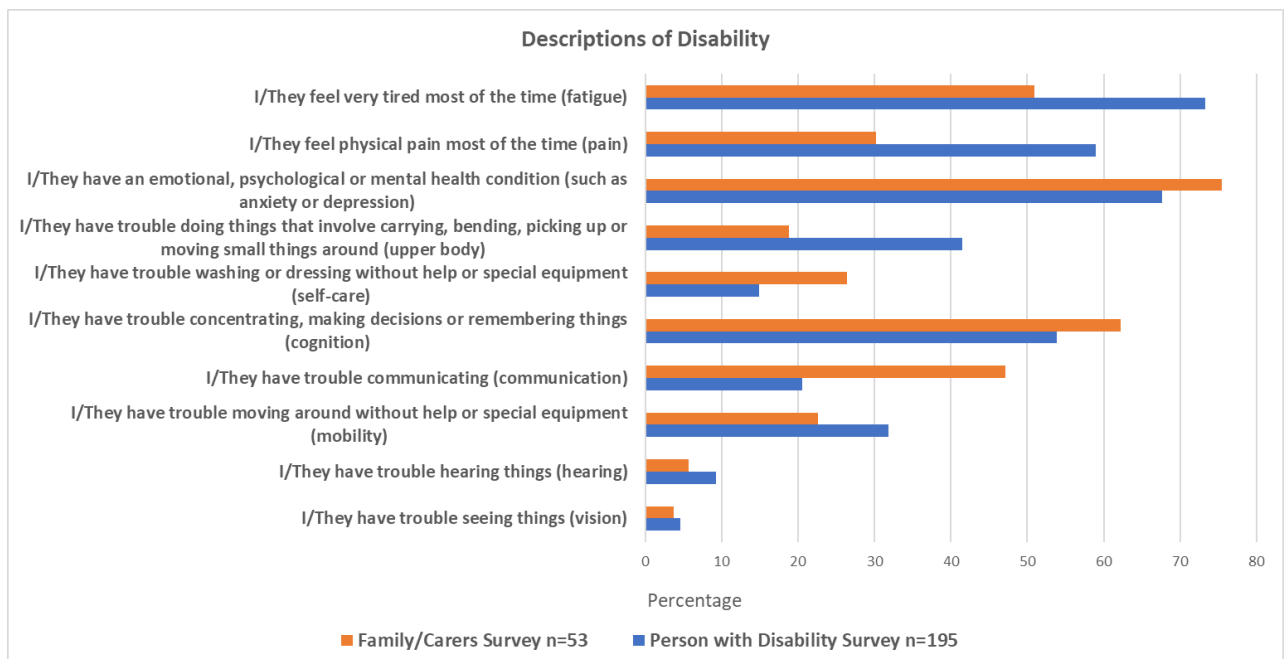
In order to describe their disability and its impact, survey respondents were asked to choose as many of the provided descriptors as applied to them, or the person they provide care for. These descriptors are plotted as a percentage in Figure 6. The most commonly selected descriptors on the Person with Disability survey related to:

- experiencing fatigue
- emotional, psychological or mental health conditions
- experiencing pain; and
- difficulty concentrating.

Respondents to the Families/Carers survey indicated that the person they provide care most commonly experiences

- emotional, psychological or mental health conditions;
- has difficulty concentrating;
- feels fatigued; and
- experiences difficulty in communicating.

Figure 6: Description of disability



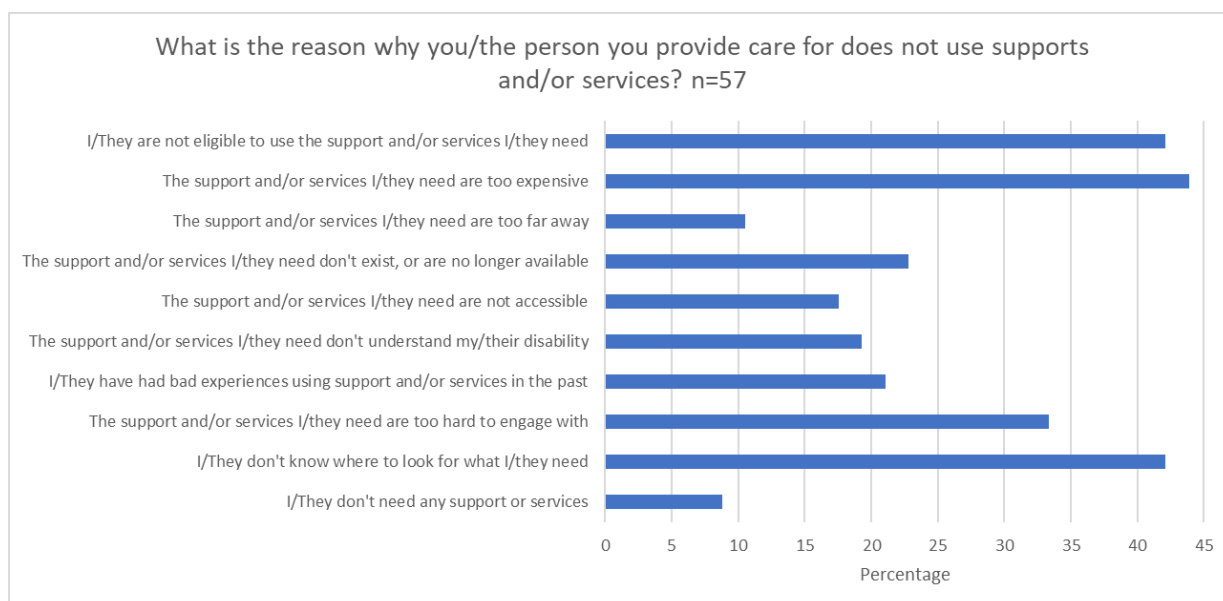
Finding and using support and/or services

Respondents to both surveys were asked *if* they use support and/or services in their day-to-day living. While most (75% of all survey respondents) indicated they or the person they provide care did use supports, 52 respondents to the Person with Disability survey and 11 respondents to the Families/Carers survey stated that they did not. A follow up question was asked as to why not, and the answers were pooled across both surveys (a total of 57 responses were recorded, with 47 from the Person with Disability survey and 10 from the Families/Carers survey). Multiple responses were permitted. The percentage of respondents who selected each option are shown in Figure 7.

Reasons for not using support and/or services

The most commonly reported reasons why support and/or services were not used are that the person with disability is ineligible for what they need; the supports are too expensive; they don't know where to look for what they need; and the services are too hard to engage with. A small percentage (9%) stated they did not need any support and/or services.

Figure 7: Reasons why people with disability do not use support and/or services



Types of support and/or services used

The *types* of support and/or services used in their day-to-day living are summarised in Table B. The majority of respondents on both surveys indicated they received unpaid assistance from family, friends and housemates, and these include direct assistance with domestic support as well as more general statements about the provision of 'unpaid help'. Domestic assistance referred to support for domestic tasks (cleaning, cooking, laundry, gardening, home maintenance, grocery shopping) and

personal care (dressing, showering) tasks. Another sizeable group of respondents indicated they received ongoing medical care, in the form of visits to their GP or other specialist, psychiatric and psychological services, other mental health services and allied health. In the Person with Disability survey, one person described their reliance on support from family as follows:

My 88yo mother helps me with meals, and phoning people. My son helps wheel my wheelchair on the rare occasions I leave my house, and drives me. He also helps with outside chores and putting my bins down and getting mail from my mailbox as I am too exhausted to walk outside. He does my shopping and puts it away for me as I cannot drag/lift online grocery shopping deliveries from the front door into the house. I have a paid council home help lady once a fortnight to change my sheets and hang them on the line, she does the housework I cannot do. I cannot tolerate her coming more than once a fortnight due to sensory overload and sensory processing issues.

A family member/carer of a person with disability described their circumstance:

Receives only unpaid care from us as parents. Our person is permanently housebound and needs help with all food preparation often including making decisions about what to eat. Our person cannot change their bedding nor do their own washing. Needs support with anything requiring cognitive function, example filling in forms. As the carer I am the nominee with Centrelink and always speak on the person's behalf due to limited cognitive function.

Administrative support, transport, assistive technology (hearing aids, mobility aids, assistance dogs, parking permits, and communication technology such as voice-to-text), and advocacy (including emotional support) were also among the highly reported support and/or services used by respondents.

Other types of support noted include social support (informal and formal social support groups including sport and recreation); financial support (income support payments; compensation and insurance payments; and reliance on family for financial assistance); education support; housing support (to accommodate accessibility needs and to ensure affordable rent, these properties were described as owned by or rented by family members to the person with disability) and accessing disability specific organisations (peak bodies and other charitable organisations).

About a quarter of respondents on the Families/Carers survey indicated the person they provide support for uses administrative support for assistance with banking, completing forms, coordinating appointments and interacting with government service agencies on their behalf.

Table B: *Types of support and/or services used by people with disability*

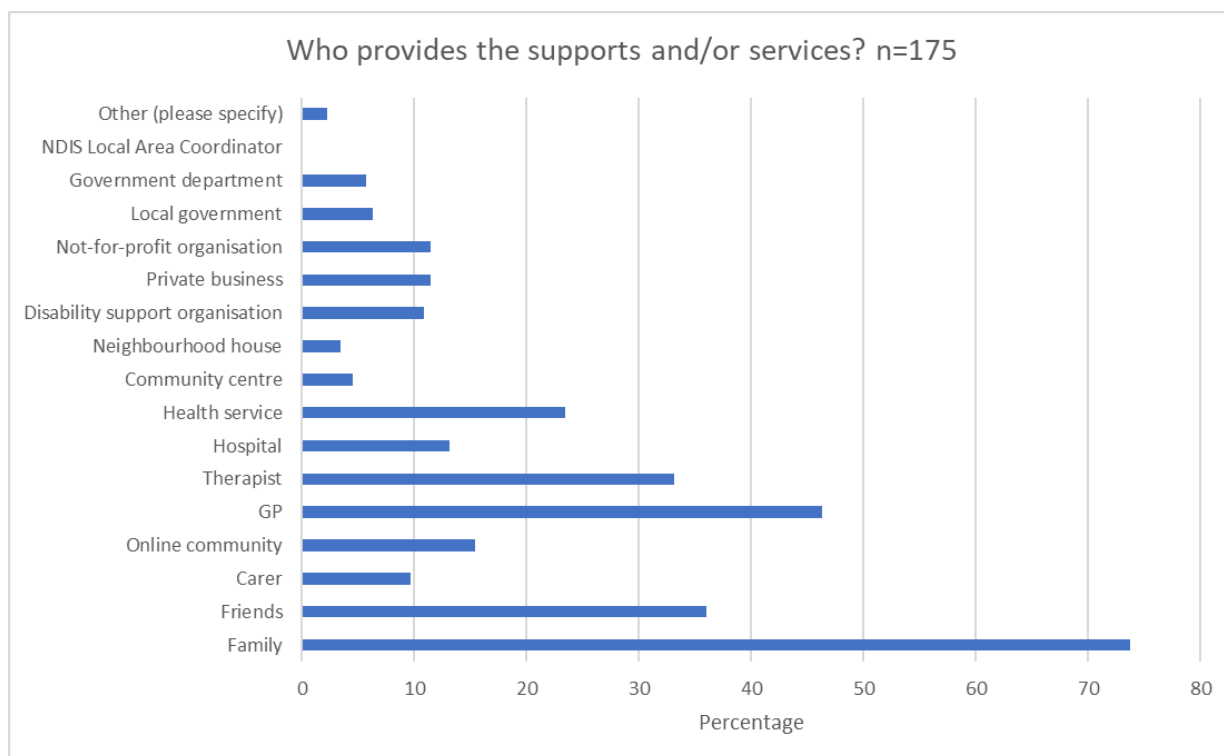
	Person with Disability survey	Families/ Carers survey
Number of survey responses	131	37
Types of support and/or services	n %	n %
Unpaid support from family & friends	87 66	29 76
Domestic assistance and personal care	82 63	18 47
Medical care	44 34	10 26
Transport	29 22	7 18
Assistive technology	23 18	1 3
Income support	16 12	2 5
Advocacy support	14 11	5 13
Social support	12 9	6 16
Administrative support (such as banking, forms, dealing with govt agencies, coordinating appointments)	11 8	9 24
Support from disability organisations (charities, peak bodies, specialist organisations such as disability employment services)	10 8	1 3
Housing support	7 5	1 3
Education support	5 4	3 8
Employment support	5 4	2 5

Who finds and provides the supports and/or services needed?

Figure 8 shows *who provides* the support and/or services identified by a person with disability (n=133), or by a family member/carer about the person they provide care for (n=42), and multiple responses were permitted. Reflecting the types of support used in Table B, these responses show that it is predominantly provided by families, friends, a GP or a medical service.

No one on either survey indicated they received support and/or services from the NDIS Local Area Coordinators. A small number of respondents indicated the involvement of disability support organisations, community centres or neighbourhood houses.

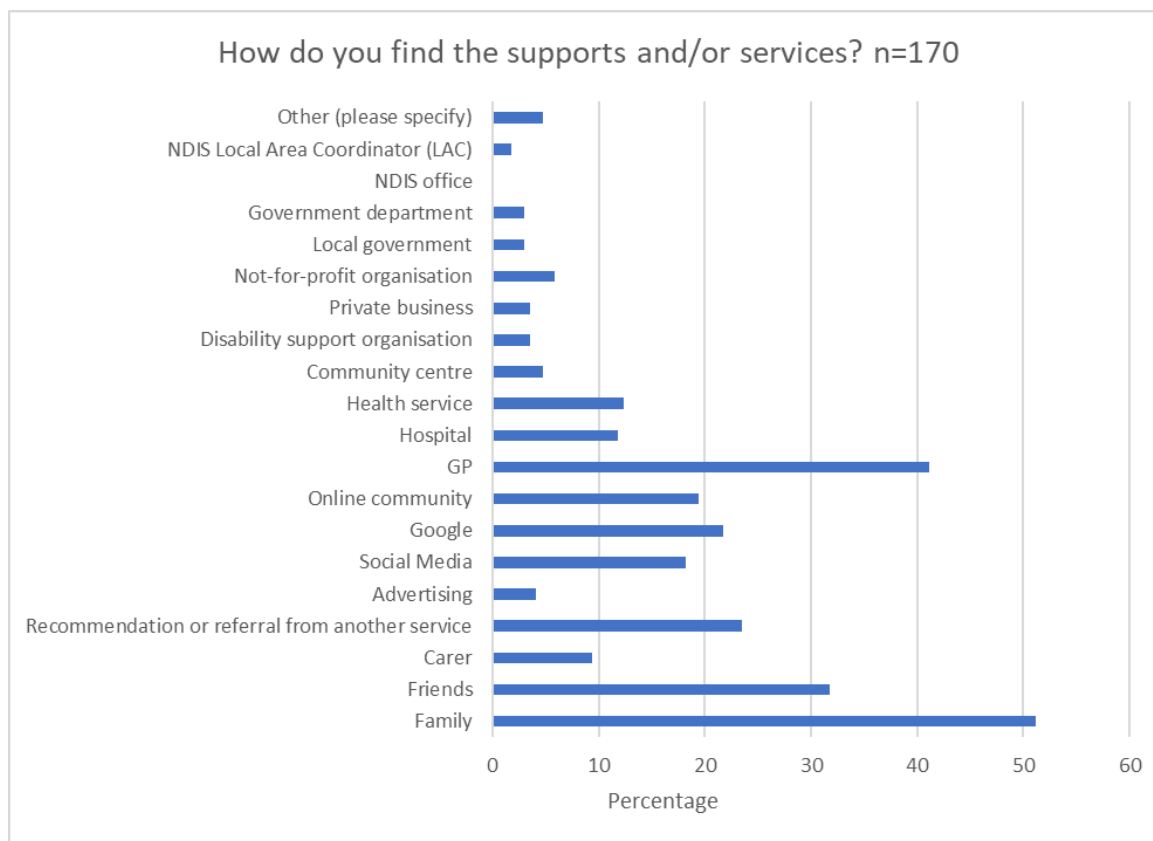
Figure 8: *Who provides the support and/or services used by people with disability*



A follow up question asked respondents to identify *how* they found the support and/or services they used. These are displayed in Figure 9 as the percentage of respondents by a person with disability (n=131), or by a family member/carer about the person they provide care for (n=39), and multiple responses were permitted.

Again, the predominant sources were family, friends, carers and a GP (likely as the source of referral to specialist medical care as well as the provider of primary health care). Other sources included social media and Google, online communities and recommendations again reflecting a reliance on personal resources.

Figure 9: How do you find the support and/or services used by people with disability?



A small number of additional text responses were provided only on the Person with Disability survey. They refer to the uncertainty about how to find what is needed:

(I) don't know what is really available to help me at all

(I) don't know how to get help.'

In these text responses, very small numbers of respondents indicated they tried to use the NDIS offices or Local Area Coordinators as a source to find support and/or services. One person described the process as follows:

Support requested from LAC but did not give any support for access to NDIS (said to check on NDIA website) or for knowledge of other services or how to access. When directly asked about council services, LAC said she didn't have that knowledge so not able to advise and told to call council directly.

Another person described the impact of fatigue and needing to source information and support themselves:

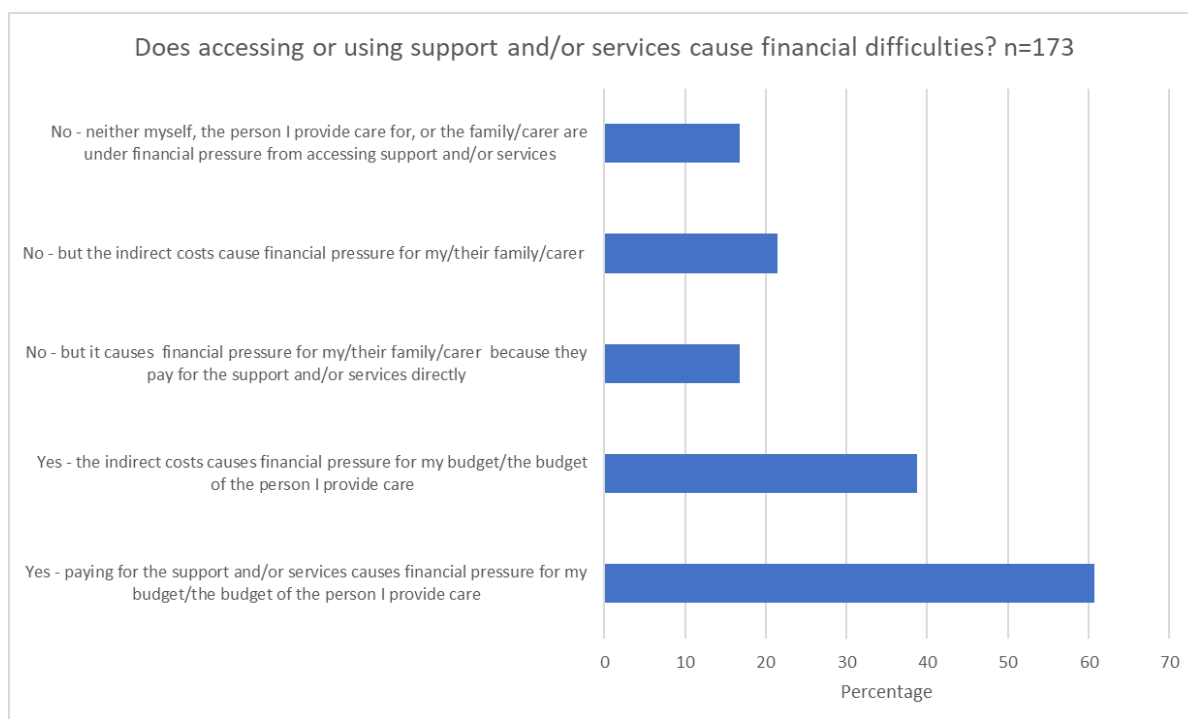
NDIS and LAC were not helpful and process is so hard that for someone with significant fatigue it is too hard, so I have had to work it out a little bit at a time.

Pressure on household budgets

Survey respondents were asked about the impact of costs on household budgets. This included direct and indirect costs (such as time away from work or the cost of transport) of accessing support and/or services, and the impact of costs on their own household budgets, and those of their family and carers.

Figure 10 shows the percentage of respondents and whether the costs of access caused financial pressure across both surveys (Person with Disability survey n=134, or by a family member/carer about the person they provide care for n=39). Multiple responses were permitted. Overall, the majority of respondents stated that paying for support and/or services themselves caused financial pressure on the budgets of the person with disability, taking account of direct and indirect costs. The role of family support is also evident with respondents citing the impact of direct and indirect costs in creating financial pressure for families and carers.

Figure 10: *The impact of paying for support and/or services on people with disability*



One person described the precarity of their financial situation as a result of paying for support and/or services:

While I am not concerned now about being able to afford support services, I feel my ability to continue to work is precarious, and without family, I am reliant on my own resources. It only takes a bad month or so, and I could be in a dire financial situation.

Respondents were also asked about which support and/or services they pay for. Responses to this question the answers were pooled across both the surveys and are presented in Table C (a total of 103 responses were recorded, with 92 from the Person with Disability survey and 11 from the Families/Carers survey). The majority of people stated they paid for, or the person they provide care for paid for medical care, followed by domestic assistance. One person stated that they are unable to afford the costs of the support and/or services they require, and are reliant on family members for support:

I can't afford to (pay). My daughter is my carer, helps me with appointments and personal care, medications, does the leg massages that I can't afford to pay therapist to do, my son shops for me and helps keep my house clean and tidy and does my lawns.

Table C: Types of support and/or services used by and paid for by people with disability

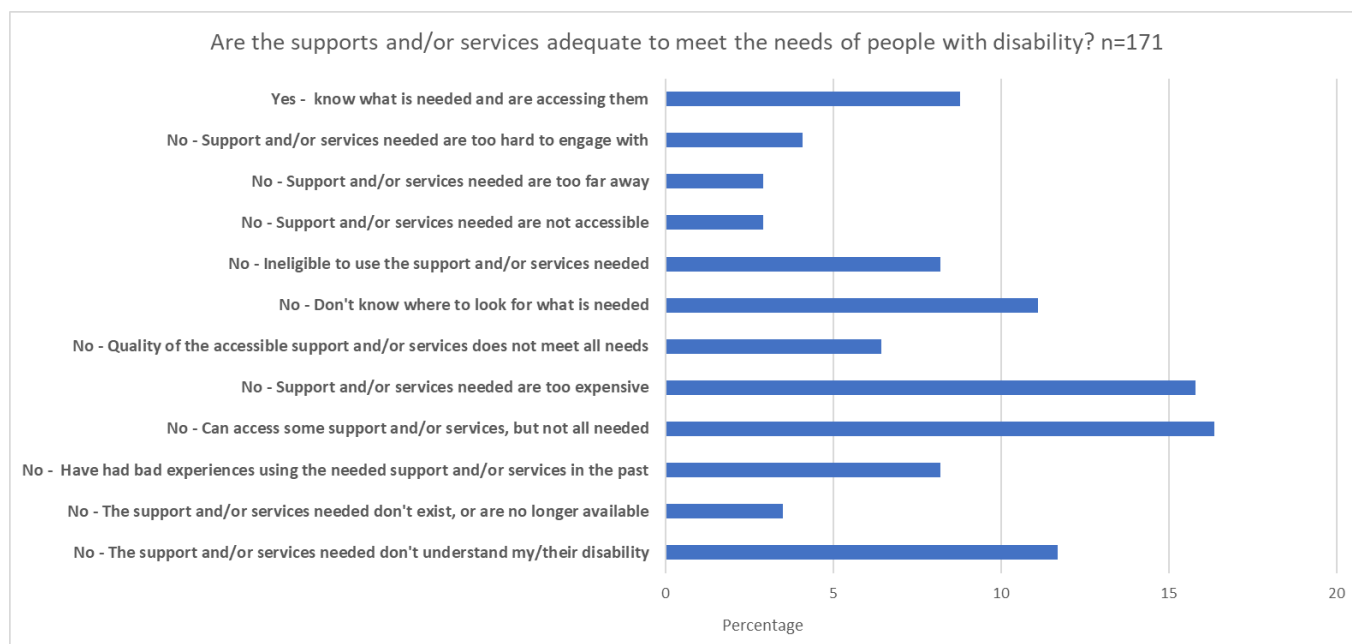
Number of survey responses	103
Types of support and/or services	n %
Domestic assistance and personal care	39 38
Medical care (including costs of medical care and cost of medications)	71 69
Transport	8 8
Assistive technology	13 13
Social support	3 3
Other (respite care, child care, community arts group, paying contractors, pool use, relocation costs to a more suitable residence)	7 7

Are support and/or services used meeting people's needs?

Respondents were asked whether the support and/or services that are accessed are adequate to meet their needs, or the needs of the person they provide care for. Figure 11 shows these responses as a percentage from the Person with Disability survey (n=133) and the Families/Carers survey (n=38), where multiple responses were permitted. Less than 10% of respondents stated they knew what support and/or services were needed and were accessing them.

Of the majority who stated the support and/or services were not adequate, the main reasons provided were that they are too expensive; the person with disability was able to access some but not all that they need; the person with disability did not know where to look for what they need; the services don't understand their disability; and the person with disability is ineligible to use the services they need.

Figure 11: Adequacy of support and/or services accessed by people with disability



Open comments in surveys

Survey respondents had the option of writing comments in an open text field at the conclusion of the survey. In the Person with Disability survey comments were left by 101 respondents, and in the Families/Carers survey comments were left by 34 respondents. A number of issues emerged in these comments, as outlined below:

Some people are reluctant or frightened to engage with the NDIS

Some respondents described that they had chosen not to engage with the NDIS, and were put-off from applying for NDIS funding as they felt the stress of putting together an application was too onerous:

Many of my peers with more mobility, perhaps higher levels of functioning, still find NDIS so difficult and stressful, that I have decided not to put myself through it for the sake of uncertain benefit and likely stress and exhaustion.

Others described feeling frightened by the prospect of engaging with the application and appeals process:

We fall into a situation where we receive financial assistance from Centrelink but it (is) not enough to cover expenses. Engaging with the NDIS frightens us – the legal battles and going to the AAT (Administrative Appeals Tribunal) scare(s) us so much.

Finding services can be exhausting and frustrating

Respondents referred to the physical and emotional fatigue that comes with finding the support and/or services they need:

I feel too tired and disheartened to look into support.

Others described the sense of frustration that they feel around not having access to the support and/or services they need:

Supporting your child through illness and disability is difficult enough. Not having medical and government (degree of disability) recognition and support makes it so much more difficult to live with, both for the person and all...who care for them.

Cost considerations force juggling of priorities

Respondents described the decision making around choosing which support and/or services to access, in terms of affordability or other considerations:

My ability to access the supports I need to maintain good health are entirely reliant on my capacity to earn an income. In the periods where I cannot work, I have to choose between spending more than I have and getting the care I need.

The impact of providing care also has direct and indirect costs to households:

The lack of adequate support has a direct impact on their (person with disability) ability to live independently. It also has a secondary effect of limiting her parents' participation in the workforce.

Decisions about using support and/or services are complex

Respondents indicated that there are a range of intertwined and complex issues involved in decision-making about accessing services and supports:

Guilt relying on family funds and reluctance to overuse or spend on myself and difficulty accessing systems prevents getting the help I need as well as difficulty finding them and decision making. Tried accessing community supports and they deemed me ineligible – difficulty describing my difficulties with an extreme fatigue condition.

I've had to force myself to be employed full time for me to afford to keep a roof over my head and eat even though it causes extreme distress and burn out. I live a half life. I have no energy or space to do anything to better myself because I'm constantly trying to keep my head above water. I'm 'too high functioning' for support but too low functioning to be unsupported. I feel guilty asking my family and friends for help and my partner often feels like my unpaid carer and it makes me feel inhuman and ashamed. I wish that I had the support to look after myself.

Discussion of the survey findings

The survey findings are limited but yield important insights

The data collected through our surveys does not represent the experiences of all people with disability who are not NDIS participants, or their families and carers. However, it provides important insights into financial, logistical, and personal challenges faced by people with disability in their day-to-day lives.

Our call for survey participants yielded a lower and narrower response rate than we hoped. This could be attributed to consultation fatigue, exacerbated by the COVID-19 pandemic. We are also aware that running an online survey meant some people were not able to participate. We weighed this limitation up in choosing an approach that afforded us the greatest potential reach at a time when face-to-face contact and travel to collect data was not possible.

The data we collected in the online surveys is skewed, as our respondents were primarily Australian born and English speaking. Most respondents resided in Victoria (reflecting the location and networks of the research team). Participants on the Person with Disability survey were mostly female, mostly tertiary educated, slightly older and reported higher incomes than the survey designed for families and carers. The Families/Carers survey collected information from people who mostly provided care for males, with secondary school education. Most of the respondents on the Person with Disability lived alone or as couples, and the Families/Carers survey reported the person they provide care mostly lived with their parents and siblings.

Personal networks and health service providers are the main sources and providers of support for people with disability

The source and provision of support and/or services for people with disability was typically family and friends, a GP or health service (as a likely referral source and for primary health care), and other personal networks for referrals and recommendations. A remarkably small number of people indicated they found support from specialist disability organisations (including the NDIS). This reliance on personal networks and resources is unlikely to be sustainable. People referred to their older parents providing everyday support, and families reported being the only carers for the person with disability. Any threats to these personal networks and resources are likely to have significant individual impact, given the descriptions of effort in finding and accessing the support and services that are needed to participate in the community. Many respondents spoke of the impact of these efforts on physical fatigue, and on their personal relationships where partners also become carers.

Support for daily living is provided by families, friends and carers

Most people reported that they relied on unpaid help from families, friends and carers to provide domestic assistance (including household management such as grocery shopping, cooking, cleaning, and gardening), personal care, transport, and assistance with administrative tasks such as making appointments, banking, and completing forms. The most commonly cited service that was paid for using personal resources by people with disability was medical care, and this includes out-of-pocket expenses for non-bulk billed appointments, medications and pharmacy items.

Second to this was expenditure on domestic assistance and personal care, often as a co-payment on council run services. Other sources of costs for families that are often hidden include housing, where families have purchased or leased suitable residential premises for a person with disability. These costs place pressure on household budgets in terms of direct costs, as well as the indirect costs such as transport and time away from work, not only for people with disability but also their families and carers.

Support and services are inadequate to meet the needs of people with disability

Nearly all survey respondents reported that the support and/or services they accessed were inadequate in meeting their needs. The most commonly cited reasons were that they found them to be too expensive; that they couldn't access everything that they needed; that they didn't know where to look for what they needed; that their needs were not well understood (by service providers); and that they had had bad experiences in the past. These were amplified by free text comments which described the juggling of financial and personal resources, the decision making and rationing of services and of energy reserves.

Reluctance to engage with the NDIS

Some survey participants discussed their reluctance to engage with the NDIS. Only 6 of 251 survey responses replied in text comments that they sought information on service provision from an NDIS office or Local Area Coordinator. A quarter of responses on the Person with Disability survey, and a third of people on the Families/Carers survey indicated they had applied for, or the person they provide care for had applied (unsuccessfully) for NDIS funding. Yet the description of their disability was not insignificant - with descriptors of fatigue; emotional, psychological or mental health conditions; experiencing pain; difficulty concentrating; and difficulty in communicating. One person described themselves as being 'too high functioning' for support but too low functioning to be unsupported.' Other people described their aversion to preparing an application for NDIS funding, citing the anticipation of stress and the amount of energy and effort required as off putting. These findings illustrate that the very mechanisms to support people potentially eligible for Tier 3 funded supports are not working, to the extent that in some instances people are not even trying to apply.

Considerations related to the surveys

The findings discussed above highlight the distinction within service provision of those who receive NDIS funding and those who don't, and the inequities in access experienced by people who are reliant on personal resources. Further data sampling from diverse communities is needed to fully explore the impact of this; to examine the longevity and sustainability of reliance on family-based support, and the impact on people with disability who are unable to have their needs met by mainstream services but cannot access NDIS funding. We also need to understand the perspective from organisations working outside the NDIS. The views expressed in the focus groups in the next section of this report are essential to round out the survey data and environmental scan in this project.

Section 4: The Focus Groups: bridging gaps in support

This section of the report presents the findings from seven focus groups conducted during September and October 2021, involving a mix of disability-specific service providers, disability advocacy organisations, Disabled Peoples Organisations (DPOs), and disability-related peak bodies. All the organisations involved operate in Victoria, South Australia, and/or Tasmania and interact directly with people with disability who may or may not be NDIS participants. The aim of the focus groups was to capture the perspectives of these organisations about the service environment, and challenges facing people with disability without NDIS funding in finding services and supports. Due to COVID-19 pandemic restrictions, the focus groups were conducted online.

Discussion in each focus group was guided by the following questions, spanning five key areas of inquiry (Table F):

Table C: Key areas of inquiry for the focus groups

<p>Organisational activity & sources of funding</p>	<ul style="list-style-type: none"> • What types of assistance (including advice) does your organisation offer people with disability aged 18-64 years who do not have NDIS funding, and/or their families and carers? • Does your organisation receive funding to provide assistance or advice people with disability aged 18-64 years without NDIS funding, and/or their families and carers? If yes, who funds that activity? • How much unpaid time would you estimate your organisation puts into learning about and building relationships with other services?
<p>Data</p>	<ul style="list-style-type: none"> • Is your activity captured in data or reports collected by any part of government?
<p>Service environment</p>	<ul style="list-style-type: none"> • Are you aware of unmet demand for services and support among people with disability aged 18-64 years without NDIS funding? • Are you aware of any issues or challenges in mainstream services adapting to the needs of adults with disability? • In your experience, what are the main barriers to collaborating with other services?
<p>Impact of the NDIS</p>	<ul style="list-style-type: none"> • How have your services changed since the transition to the NDIS? • Have you had any connection or interaction with Information, Linkages and Capacity Building (ILC), via the grants scheme or through NDIS Partners in the Community/Local Area Coordinators?
<p>Accountability</p>	<ul style="list-style-type: none"> • Who do you think should have overarching responsibility to ensure people with disability can participate meaningfully in society and the economy?

Findings from the focus groups

Themes that emerged in the focus groups encompassed governance challenges, policy implementation challenges, inequality, how evidence is captured and used, and funding issues. Many of the issues discussed were not specific to disability, but reflected broader systemic issues facing service providers and marginalised citizens in siloed and competitive service environments.

It is difficult to understand the service environment

There was consensus that navigating the external service environment and keeping pace with changes in policy and practice across multiple service systems is challenging. State-based and local government support for people with disability has become harder to find, and eligibility for available services has tightened.

Organisations in the field have multiple roles

It was evident that many of the organisations involved in the focus groups could not be neatly categorised as a single 'type' of organisation. Responses to questions and discussion revealed blurred boundaries in the activities and priorities of advocacy organisations, peak bodies, and service providers. Most organisations assumed different roles for different people or groups as need and opportunity arose, including providing services, advice, individual advocacy and systemic advocacy. Motivation for action and advocacy was also complex, as it often combined organisational self-interest – for example financial sustainability and growth – with acting in the interests of the group the organisation served.

Piecemeal funding mechanisms are inefficient and ineffective

Most of the organisations involved relied on multiple funding streams – primarily fixed term (1-2 years) and piecemeal government grants and philanthropic funding – to provide support and advice to people with disability without NDIS funding. Chasing funding to sustain these services is ongoing, resource-intensive and unfunded. There is limited opportunity for organisations to build on previous work, as activity ceases and organisational expertise is lost when dedicated funding ends. In particular, the ILC program was not seen as a strategic or well-targeted investment.

Reporting requirements are onerous but miss vital unfunded activity

Organisations said they report on what they are funded to deliver to discrete funding sources. Some organisations document their unfunded activity for advocacy or to report to their own governance structures. Others lack the resources to document unfunded activity. No one was aware of any overarching mechanism to collect or consolidate this data.

LACs provide little or no help to people who are not funded by the NDIS

Local Area Coordinators were described as being of limited or no help to people outside the NDIS, and there were several examples of circular referrals between LACs and

advocacy organisations provided. The gap between the LACs stated role and what they have capacity to deliver was generally attributed to lack of funding.

Access to services and support is inconsistent

There was consensus that access to services and support for people with disability both within and outside the NDIS, and costs of services and support, are inconsistent. There were numerous examples of lack of coordination of effort and investment to support people with disability outside the NDIS, and a vacuum of responsibility and accountability to address that. There was agreement in each focus group that government had a responsibility to step in, but no consensus within the groups about which level of government or jurisdiction should have overarching accountability to ensure that people with disability can find the support they need.

Core issues and suggested action raised in the focus groups

The findings of the focus groups are sorted under the following three broad themes in Table H:

- NDIS design issues
- organisational sustainability and funding
- unmet demand for services and support

Table D: Findings from focus groups

Theme: NDIS design issues				
Sub theme	Issues identified in groups	Desired change	Perceived Responsibility	Domain for action
Information and Community Linkages (Tier 2 support)	<ul style="list-style-type: none"> • Allocation of ILC grants is not strategic • ILC grants do not leverage on previous work • Timelines are too short to achieve meaningful and sustainable outcomes/ programs/ activity • The application process is cumbersome and costly • Successful applications generally reflect top-down priorities • “Meagre funding as a proportion of the NDIS” 	<ul style="list-style-type: none"> • Longer term, targeted funding • Need to build bridges to mainstream services, not referrals 	DSS, NDIA, LACs	Systemic
The role of Local Area Coordinators in supporting people with disability who are not NDIS participants	<ul style="list-style-type: none"> • LACs are not performing their duty as it is described • Circular referrals between advocacy organisations, service providers and LACs • “They don’t have the expertise needed to help people navigate the system” • Strong frustration with LACs, but some sympathy/ recognition of constraints like high staff turnover, bureaucratic processes 	<ul style="list-style-type: none"> • Clearer role for LACs in supporting people with disability who are not NDIS participants 	NDIA	Institutional

	<p>and systems, and being overburdened with responsibility</p> <ul style="list-style-type: none"> • LACs have a ‘tick a box’ role with no follow-up accountability • “The LACs’ role is supposed to not just help people get on to the NDIS but those who aren’t eligible, to connect them to community services...that’s not actually happening...LACs aren’t resourced enough to be able to do that community bit.” 			
Inequitable and/or inconsistent access to NDIS funding	<ul style="list-style-type: none"> • People with similar disabilities in similar circumstances receive different supports • People who need specific support or equipment (e.g. travel support for people living regionally) settle for things they don’t really need • Access to funding is very dependent on the individual planner • The process of determining eligibility is convoluted and not transparent • Specific disabilities are excluded (eg CF, psychosocial disability, incomplete spinal injury, chronic conditions) • Big part of work is helping people (often unsuccessfully) get NDIS funding • Must ‘play the game’ in order to be successful in receiving funding. 	<ul style="list-style-type: none"> • Transparent criteria and processes • Safety net for people outside the NDIS 	NDIA, Minister	Institutional

	<ul style="list-style-type: none"> • Language and processes are alien, unfriendly. People with poor language, IT skills and accessibility are at a major disadvantage in accessing funding/services • Indigenous people, CALD, and people living in regional areas are highly disadvantaged' • Lack of diagnosis or misdiagnosis is an issue (eg women with autism) • People who "clearly need funding" have none 			
Theme: Organisational sustainability and funding				
Reliance on piecemeal, short-term funding	<ul style="list-style-type: none"> • Most organisations survive on patchwork funding from governments and donors • Applying for funding is ongoing, time and resource intensive, and unfunded. • Not aware of any overarching measurement of outcomes or impact of total investment in support and/or services • Tasmania is often excluded from funding opportunities or unable to compete nationally for funding 	<ul style="list-style-type: none"> • Transparent criteria and processes • Strategic investment focused on sustainable impact 	Whole of government	Systemic
Unfunded work not captured by government	<ul style="list-style-type: none"> • Provide extensive 'in-kind' support to fill the gaps left by government, NDIS • Developing funding applications is time-consuming with low odds of success 	<ul style="list-style-type: none"> • Track all activity, costs and outcomes 	Individual organisations	Organisational

	<ul style="list-style-type: none"> • Other activity not generally funded by donors or grants includes “community building”, organisational running costs, general information and referral services, following developments in the policy environment, and writing submissions 			
Dominance of NDIS-related issues	<ul style="list-style-type: none"> • Advocacy orgs overwhelmed with NDIS concerns, meaning there’s no time for those outside NDIS • Lack of community trust in the NDIS • Self-advocacy is tiring, resource intensive and overly bureaucratic; appealing decisions causes trauma • “Like many advocacy organisations, we are a small team. Our agency is a team of two. We are both part time and we cover seven local government areas...we need to triage requests for advocacy.” • “In Victoria, there’s only about 100,000 people who can get the NDIS, but there’s 1.1 million people with a disability in Victoria...advocacy organisations are so overwhelmed with sorting out NDIS problems and they’re very time limited...the people outside the NDIS are missing out.” 	<ul style="list-style-type: none"> • Dedicated resources to support people trying to access the NDIS • Dedicated resources to support people managing without NDIS funding 	NDIA, Minister	Institutional

Theme: Unmet demand for services and support				
<p>Inequity for people with disability outside the NDIS</p>	<ul style="list-style-type: none"> • “Vacuum of responsibility” post NDIS • The service environment is fragmented • Huge regional vs metro discrepancies in availability of adequate mainstream and specialist services • State gov not delivering on commitment to continue to provide services for people with disability who are not NDIS participants (SA, Tas) • Lack of awareness of available services/ supports (numerous directories, but information about supports is often out of date, inaccurate) • Mainstream services pushing people back to disability organisations • “People outside NDIS not able to live full lives” – lacking access to transport, housing and employment • “Hugely disadvantaged financially” • Situation is one of ‘haves’ and ‘have-nots’ • Available programs have long wait lists or are time-limited • Mainstream services not adequate to meet basic level of accessibility requirements for people with disability (although COVID has 	<ul style="list-style-type: none"> • “Policy environment is very messy” • Need for service system oversight and adjustment • “Universal, holistic approach is the key” – alliances of organisations and a “societal values shift” • Need clearer reporting mechanisms, and measures of what organisations are doing for people with disability 	<p>Whole of government</p>	<p>Systemic</p>

	<p>forced some to re-evaluate how accessibility can be improved). “That should start at the highest levels of government - that universal design is just what we do, in every system, in every facility we build, and that that should be embedded...it helps everyone.”</p> <ul style="list-style-type: none"> • Even disability specific systems (ie. DRC) are not always accessible 			
Direct and indirect costs	<ul style="list-style-type: none"> • Reliance on family and friends to fill service gaps • Covering costs of support and equipment • Turning to gig workers for support • Price variations for the same services and equipment between NDIS participants and others (NDIS costs are higher) • Mainstream services and LACs pushing back on disability organisations 	<ul style="list-style-type: none"> • Address pricing issues • Address service gaps • Address competing priorities 	Whole of government	Systemic

Discussion of the focus group findings

The findings from the focus groups reflect themes that persist in the study of complex system design and network governance, including asymmetrical access to resources and information, red tape, inconsistent problem-framing, cost-shifting, fragmented evidence, blurred accountability, competing priorities, and tensions between market forces and calls for collaboration and co-production of public policy outcomes (Alford & O'Flynn 2012; Carey et al 2017; Klijn & Koppenjan 2016; Olney 2021). Alongside data from collected from other sources collected in this study, the focus group data offers new insights into systemic, institutional and financial issues and risks facing people with disability, their families, carers and advocates, and governments, in complex service environments.

Considerations related to the focus groups

The ways in which focus group participants are supporting people with disability outside the NDIS appear, on the basis of discussions, to be unsustainable and under resourced to meet overwhelming demand. Much of their activity and knowledge is not captured in data held by governments, and therefore not reflected in evidence informing disability-related policy and practice. The findings indicate that participants are keen to connect people with disability to other service systems, but what those people need and want is not widely available.

These organisations are putting Australia's Disability Strategy 2021-2031 into practice and filling gaps in the architecture of the national disability services system with piecemeal, short-term and non-strategic funding from a range of government and private sources with diverse agendas. Significantly, much of their activity and focus duplicates the *stated* role of NDIS partners in the community in assisting eligible people to access the scheme and supporting people with disability without NDIS funding to connect with mainstream services. This indicates that the NDIS is under-performing on that front. The findings of the focus groups in this study flag that Australians with disability outside the NDIS need more financial and strategic support to participate in society on an equal basis with others.

Section 5: Drawing the research findings together

Examining the evidence

The overwhelming majority of Australians with disability rely on universal or 'mainstream' service systems, and their own knowledge, resources and networks, to participate in society. Yet little is known about how they are faring, what support they require, whether and how they are finding the support they require, or the public and private flow-on effects if they are unable to find the support they need.

Understanding the range of needs of all Australians with disability, and the capacity of governments, civil society, business and individuals – including people with disability themselves – to meet those needs, is critical both to the sustainability of the NDIS, and to Australia meeting its obligations as a signatory to the UN *Convention of the Rights of Persons with Disability*. These are significant governance risks.

This section of the report examines consistencies and inconsistencies in the findings of this research across all data sources to understand *if* and *how* people with disability who are not receiving funding through the NDIS are finding and using any support and/or services they need to participate in the community and the economy. It compares what is *written* about the availability of services, programs and activities to people with disability without NDIS funding with first-hand accounts of what is happening on the ground. These sources of evidence are discussed in detail in earlier chapters of this report as follows:

- Section 2 of this report discusses the parameters, limitations and findings of a **desktop environmental scan of services and support promoted as disability-inclusive**
- Section 3 discusses the parameters, limitations and findings of **online surveys of people with disability and their families and carers**
- Section 4 discusses the parameters, limitations and findings of **focus groups involving organisations providing advice, referral or services to people with disability without NDIS funding**

Drawing the data together

People with disability face financial and psychological costs to participate in society on an equal basis with others. Accessing services, activities and spaces primarily designed by or for people without disability involves planning and resources. The findings of this research indicate that people with disability of working age in Australia are struggling to find and access the support they need.

Overall, the findings:

- show that participation in society can vary for Australians with disability based on their income, where they live, their education, their gender, their language and literacy, their access to technology, their individual needs and preferences, their personal support networks, their age, and the nature of their disability, and that some of these factors fluctuate.

- reveal discrepancies between promoted availability and accessibility of support, goods and services, programs and activities to people with disability without NDIS funding, and the experiences of people with disability and their families and advocates attempting to find and access them.
- reveal that cost is generally a significant barrier to accessing mainstream services for people with disability and their families and carers.
- reveal gaps in data collected and used to inform disability policy and practice.
- highlight a significant gap in support available to people of working age who qualify for NDIS funding and those who just miss out, and the failure of the Information, Linkages and Capacity building (ILC) program to mitigate it.
- show that people with disability of working age without NDIS funding rely heavily on informal support from families and friends to participate in society, incurring unsustainable direct and indirect costs for their households. These include out-of-pocket financial costs of finding and using services and supports; costs to households of family members being unable to work or working reduced hours to provide unpaid support; and the physical and emotional load of providing care and support.
- suggest that online gateways or databases of services lead people with disability and their families into an overwhelming labyrinth of information as they seek the right fit for their needs and financial circumstances, in many cases unsuccessfully.
- reveal that disability-specific organisations are providing unfunded support to people with disability without NDIS funding and their families to fill gaps between the promoted role of NDIS partners in the community to connect those people with the NDIS or other services and what is happening on the ground, and are struggling to meet demand.
- reveal circular referral processes between government and agencies where responsibility to provide advice, information and services sought by that people with disability, their families and advocates is unclear, or where support and/or services are unavailable.
- reveal gaps and overlap in government-funded services and support emerge where accountability for funding and outcomes between levels of government and/or state and federal jurisdictions is not clearly defined or agreed. When these services and support are delivered on behalf of government by non-government organisations, who is accountable for outcomes is even less clear to service users and advocates.
- suggest that differences between states in the provision of state-funded services accessed by people with disability, and lack of uniformity in disability support and/or services delivered by local governments across municipalities in different states, is inequitable, confusing, and hampers service coordination.
- demonstrate that people with disability who are not NDIS participants have no choice and control over how public funding is used to support their

participation in society, and that many of those of working age are not receiving the support they need and want

- suggest that lack of transparency in decision-making is eroding the trust of people with disability outside the NDIS, and their families, in governments, institutions and the scheme itself.
- highlight tensions between market forces and government calls for co-production of an inclusive society.
- highlight the potential ‘timebomb’ for future government costs in escalating future needs for disability-related support and exhausting informal supports.
- suggest that ongoing public consultation in relation to disability policy during the COVID-19 pandemic has stretched people with disability, their families, carers and the disability sector beyond ‘consultation fatigue’ to breaking point. While there is limited data captured by government about the day-to-day lives of people with disability outside the NDIS and their networks of support, there is a wealth of evidence of long-standing gaps and inequalities in service systems captured in consultation processes and inquiries that is not getting policy traction.

Common themes across all data sources

The following themes emerged in all elements of this research.

Inequity

- The significant financial impact on individuals and households of being in or out of the NDIS
- Administrative burden / complex processes to find and access support and/or services
- Inconsistent criteria for funding and services accessed by people with disability
- People with disability without NDIS funding have no choice and control over how ILC funding is applied to support their participation in society

Uncertainty

- The stress of constant shifts in policy, rules, processes, availability, and eligibility criteria across systems of services and support accessed by people with disability, including the NDIS, Australia’s Disability Strategy 2021-2031, employment support, income support, and universal service systems such as education, health, housing, and transport.
- Unclear responsibility and accountability to support people with disability who are not NDIS participants
- Information about available services and supports is often inaccurate and out-of-date

Unintended consequences

- Shrinking options for support outside the NDIS
- Unmet demand for services and support
- Socio-economic ripple effects of financial and emotional pressure on individuals and households

Money

- Finances driving decisions and behaviour
- Direct cost-shifting of service delivery, particularly for people who are expensive or challenging to service
- Indirect cost-shifting, by passing the administrative burden of navigating systems and processes to service users
- Reliance on unpaid labour to fill service gaps and to conduct unfunded activity to support service delivery and organisational sustainability
- Lack of strategic investment across government

Trust

- Low trust in governments and institutions among service users and their advocates
- Disengagement from seeking out support, including NDIS funding, as a consequence of their own or other people's experiences with the bureaucracy
- Importance of networks and relationships
- Reliance on (family) informal supports
- Lack of transparency in decision-making at multiple levels of the process of service design and delivery, in relation to allocating and rationing access to resources

Data

- Incomplete data on the service environment, activity, stakeholder knowledge management, costs, and impact
- The evidence base informing policy and allocation of resources is skewed towards what is measured by government
- People facing intersectional barriers to engaging with service systems, as well as those who have personal resources and networks that enable them to manage on their own, are invisible in data sets captured by most service systems. However, both groups are in a situation that could change at any moment, requiring government intervention.

Cross analysis of the data

Information labyrinths

The findings and the methodology of the desktop environmental scan of services in this study each provide important insights into how people with disability are expected to participate in society. Both indicate that simply referring people with disability to services, or directing them to online gateways or databases, does not

guarantee they will find what they need. Being directed to a website or phone number does not smoothly translate to finding available, accessible and affordable services. It ignores the time and effort required to sift through services to find the right fit, and to confirm that the service is operational and available. In many cases, particularly in regional areas where demand for services is high and access is patchy and geographically dispersed, it can lead people into an overwhelming labyrinth.

As described in Section 2 of this report, the search parameters for the desktop environmental scan of services were framed around the six policy outcome areas in Australia's National Disability Strategy 2010-2020 – Inclusive and accessible communities; Rights protection, justice and legislation; Economic security; Personal and community support; Learning and skills; and Health and wellbeing. The scan captured dedicated information resources and datasets that are available to help people with disability find the services and support they need. Over the six policy outcome areas, there were over one hundred. Yet despite (or perhaps because of) the volume of information available, the survey responses and focus groups in this study show that people with disability, their families, carers and advocates are struggling to find and access the services and support they need, when they need them. Increasing the amount of information available to people with disability about services that exist in their community is unlikely to change that. It calls for a more nuanced, targeted and strategic approach.

Availability, affordability and awareness of support options

It is clear from the survey and focus group findings that the scan is not an accurate reflection of the environment people with disability and their advocates face. And yet, all of the information in the scan is based on current, published information promoting accessible services, programs and activities. Closer analysis of the survey data provides insight into the specific challenges faced by people with disability in trying to find and access services and support in this way.

Utilising postcode data supplied voluntarily by survey respondents, we matched responses to regions covered in the scan. We then compared the scan data with their responses to questions related to difficulty in accessing support and/or services, and relevant responses to open questions about their circumstances. Respondents consistently identified high service costs, lack of service availability, and not knowing where to find what they needed as reasons why they were not accessing adequate supports.

Digging deeper revealed a more nuanced range of challenges and dead ends. One respondent said they could not find a support group specific to their disability, and the scan confirmed that there were no such groups in their region. Another respondent identified significant out-of-pocket costs for allied health supports as a barrier to accessing that support, explaining that the nature of their disability requires them to access several allied health supports concurrently. The scan shows that these services are available in this person's region, but they were out of reach to that person financially. *Availability* and *affordability* of suitable services is the issue in these two instances, respectively. Another respondent, who was seeking domestic assistance, said they 'don't know where to look for what I need'. The desktop environmental scan showed that there were several domestic support services in that person's local area. Another respondent said they wanted, but could not afford,

speech pathology, but the scan revealed a nearby speech pathology practice advertising subsidised and flexible fee structures. In each of these cases, *awareness* of suitable services is the issue.

What is common in all instances is the effort required to sift through services without a roadmap, often without success. The financial and psychological toll of this effort is compounded by a range of other pressures on people with disability and their support networks.

Compounding marginalisation through policy and practice

As explained in Section 3 of this report, the surveys in this study did not capture the experiences of people with disability or their families facing multiple and complex disadvantage. However, the survey responses received are a red flag for what may be hidden in populations with complex needs outside the NDIS, such as people with disability experiencing homelessness, people living in remote areas, people without access to technology, people living with family violence, or people from culturally or linguistically diverse communities.

Together, the elements of this research reveal piecemeal funding and provision of vital services and support sought by people with disability and their families, underpinned by varying interpretations of disability and accessibility, with no overarching collection of data or assessment of collective impact. This is problematic when the bulk of funding to support inclusion of Australians with disability in mainstream service systems is doled out in competitive short-term ILC grants by government to organisations with varied agendas, priorities and capabilities. The desktop environmental scan found that it was common for ILC projects to cease operations once their allotted funding ended, and this finding also emerged in the focus groups. It indicates that the ILC model, which purports to build lasting community capacity to contribute to the sustainability of the NDIS, achieves the opposite – the delivery of discrete, short-term programs that fail to become self-sustaining or part of the mainstream. Data from the surveys and the focus group suggests this leaves people with disability, their families, carers and advocates with little certainty about who they can turn to for support. This in turn raises questions about accountability for service provision and whose interests are served by the ILC model. More broadly, it indicates that in addition to the ILC program missing the mark with available resources, it is under-resourced to achieve its very broad aims.

Implications for policy and practice

Understanding the service landscape

The overwhelming majority of Australians with disability do not receive NDIS funding. Yet for the most part, the knowledge and experiences of those people, their families, friends, carers, and advocates, and those interacting with them in the community, are not captured in data informing disability-related policy and practice. Evidence that could illuminate service gaps and overlap, economies of scale, ancillary activity and outputs, and the flow-on effects of decisions made in a range of contexts, is patched together by governments from multiple sources, presenting a skewed and incomplete picture of the service landscape. This must be addressed to ensure that

all people with disability in Australia can participate in society on an equal basis with others, in accordance with their rights.

This research set out to capture experiences, perceptions, and demographics of working-age Australians with disability without NDIS funding navigating mainstream service systems, and information about the support they draw on or are seeking to participate in society and the economy. It reveals that they are struggling. While the NDIS was designed to support all Australians with disability, to varying degrees and by different means according to their needs, the findings of this study indicate that its attention is heavily focused on NDIS participants. They further suggest that this is at the expense of people with disability who are either ineligible for the scheme or reluctant or unable to navigate the requirements for entry. Failure to address this could have significant long-term costs. The interface of the NDIS with people with disability who are not NDIS participants, and with mainstream services, programs, activities and places that should be accessible to people with disability, emerges as a potential fault line in Australia's Disability Strategy 2021-2031.

Overall, the findings of this study suggest that framing people with disability as empowered consumers of mainstream services with choice and control is masking the public and private costs of government failure to address their needs across multiple domains. More research is needed into specific barriers to support faced by people with disability with complex needs; the design of systems within and surrounding the NDIS and Australia's Disability Strategy 2021-2031 intended to support all people with disability to participate in society; and risks and opportunities for people with disability, their families, civil society, and governments in that environment.

Inconsistent access to support outside the NDIS is increasing demand for NDIS funding from people with disability underserved by mainstream service systems; entrenching labour market disadvantage for people with disability and their families; keeping people with disability and their families under financial and emotional pressure; and exacerbating disability for people unable to afford or access essential services and support. Without adequate investment in information linkages and support for people with disability outside the NDIS, individual funding through the NDIS has become an "oasis of support, surrounded by a desert where little or nothing is available" (Productivity Commission 2017, 29).

The 2021 *Review of NDIA actuarial forecast model and drivers of Scheme costs* notes that "ultimately, financial sustainability [of the NDIS] is tied to the willingness of government (and taxpayers) to meet Scheme costs" (Taylor Fry 2021). Over time, that is likely to hinge on evidence of public value.

Emerging risks

The NDIS is a key part of the ecosystem of supports for Australians with disability undergoing a whole-of-community paradigm shift. That shift is not easy to operationalise. How each worker, organisation and institution interacts with people with disability is shaped by societal norms, their own governance, financial and management structures and priorities, government policy levers, the legislative environment, and (where applicable) contractual arrangements with Commonwealth, state and territory, and local governments. In addition, the capacity of people with

disability to navigate that environment is contingent on their own needs, circumstances, energy, and connections, and that capacity can fluctuate over time.

The risks of misreading this environment cannot be ignored.

In that context, we identify the following risks for governments in our research findings:

- The gap between *what is promoted* and *what is happening* in the interface between people with disability who are not NDIS participants and the NDIS is a major fault line in Australia's Disability Strategy 2021-2031.
- Existing data on the availability, accessibility, affordability and adequacy of mainstream services for people with disability is unreliable. This is skewing policy and practice across the ecosystem of disability-related supports, including the NDIS.
- Sustained financial and emotional pressure on people with disability without NDIS funding, and their families and households, is likely to have compounding effects across a range of service systems.
- Current investment in information, linkages and capacity building is inadequate and misdirected. This poses threats to the sustainability of the NDIS through demand for higher levels of support when people enter the scheme than might otherwise be necessary in a more inclusive society, and demand for entry to the scheme from people with disability who cannot find or access alternative support to meet their needs.
- Informal supports for people with disability are precarious and unsustainable at existing levels.
- Market-based principles now underpin many services provided directly by government, as well as outsourced and private activity, in this arena. This creates perverse incentives for cost-shifting until a crisis arising from market-produced inequity forces government intervention.

Section 6: Next steps

This report draws together evidence from multiple sources to illuminate the environment in which people with disability who are not NDIS participants are seeking and using the services and supports they need. What emerges is heavy reliance on informal support and personal resources; a complex and yet incomplete market of services and supports to navigate; and a service ecosystem that is fragmented by unreliable information, competing priorities, inconsistent eligibility criteria, variable costs, and patchy availability.

This report only scratches the surface of these issues, but it provides a sobering picture of the future. More research and policy action is needed to achieve the paradigm shift needed to ensure that people with disability who are not NDIS participants can participate in society and the economy on an equal basis with others.

Policy considerations

This research highlights significant inequalities and inconsistencies in costs and access to services and support for Australians with disability in three states. These findings are consistent with the findings of numerous government inquiries and public consultations related to the design and implementation of the NDIS.

The findings flag a potential ‘double driver’ of future government costs. When people with disability and their families are unable to afford or access support that could delay or prevent their entry to the NDIS, and exhaust their personal resources and informal supports to the point of crisis, they will ultimately need higher levels of support from both the NDIS and other government services.

On the basis of our findings, we raise the following policy considerations:

- The financial impact of being in or out of the NDIS is significant for people with disability and their families. The “cliff” at the edge of the NDIS between support available to NDIS participants and those outside the scheme must be addressed to reduce pressure on the scheme. Current approaches to referring people with disability to mainstream services do not address entrenched socio-economic disadvantage; the impact of the NDIS market model on community supports; or risks associated with people being unable to find or afford the services and support they need to maintain their wellbeing.
- Under the umbrella of Australia’s National Disability, Tier 2 of the NDIS must be supported by whole-of-government commitment to address entrenched socio-economic marginalisation of people with disability, with clear and measurable accountability for outcomes across jurisdictions. This work should include consideration of whether and how existing data and data analytics can identify critical risks and opportunities in that environment.
- People with disability, and representative organisations, should co-design how ILC resources intended to serve their interests are prioritised, applied and structured, with a focus on sustainable inclusion in society and the economy.

- Universal platforms routinely accessed by people with disability and their families - such as schools, GPs, allied health services, Neighbourhood Houses, local government, pharmacies, Medicare, and Centrelink – could be better used both to flag service gaps and to provide information to people with disability about mainstream services and support aligned to their needs and circumstances. Providing intuitive and user-friendly access points for information would significantly reduce the administrative burden for people with disability and their families of sifting through information about services and support online.
- Local Area Coordinators are a national, street-level gateway for people with disability to access disability-related support from government. They can play a critical role as a bridge between government, people with disability and communities, and in building community capacity and social capital at a local level. They should be equipped and resourced for that role, as originally intended.

Recommendations for future research

This research demonstrates the current and future risks of misreading the environment navigated by people with disability in Australia, and the importance of capturing their perspectives and experiences, and activity surrounding them, to shape policy and practice.

In terms of future research, we recommend:

- Research into the cost benefits and public value of targeted, timely and early investment in supporting people with disability who are not NDIS participants, and the economic risks of inaction.
- Targeted, participatory research into the experiences of people with disability across Australia facing intersectional and compounding barriers to finding and accessing services and support. This research could also examine the feasibility of hybrid block-funded models in thin service markets, jointly funded by Commonwealth, state and territory governments, to respond flexibly to support needs that do not call for an annual NDIS plan. The findings should underpin strategic policy action across state, territory and Commonwealth governments to address complex disadvantage.
- Mapping the level and impact of investment in general/mainstream supports for people with disability across all levels of government, including the role of LACs in supporting people with disability who are not NDIS participants. This will highlight gaps in service provision and unmet needs, and pinpoint key leverage points in the service ecosystem where governments can improve and sustain inclusion for all Australians with disability.

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Appendices

Attachment 1: Scan parameters

The scan parameters

The environmental scan was conducted through desktop research. Relevant data about advertised services and support was sourced online – an approach which may reflect the process by which people with disability may come to find and access the services and support they need.

The scan was undertaken between April and September 2021. The scan data may have changed or been removed from their original web locations by the web hosts since then. Given that the data included in the scan was sourced from thousands of websites, it was not feasible with the limited resources of the project to maintain a record of webpage access dates.

Data sources

Key data sources included websites of service providers, official government webpages, government and non-government-managed service directories, and Information, Linkages and Capacity Building (ILC) grant recipient lists. These sites were examined for existing interventions.

Relevant data

The scan was focused on interventions that are:

- Targeted toward people with disability
- Available to people aged 18-64 years
- Available to people living in Victoria, South Australia or Tasmania
- Not exclusive to people with NDIS funding
- Universally available services that are promoted as inclusive of people with disability

There were also some secondary considerations which determined the scan criteria. Firstly, only those services and support that people with disability, their families and/or carers can access directly were deemed relevant. This excluded interventions and resources aimed exclusively at service providers, employers, disability workers and the general public; for example, a workplace inclusion education program.

Secondly, personal and environmental accessibility support features were not included in the scan, such as hearing loops, braille and scooter charging stations. The commonplace nature of these interventions meant it was not feasible to record them all.

Universally available interventions were included where relevant to people with disability. Common examples would be rent assistance and other forms of Commonwealth cost of living subsidies, public housing and mainstream employment programs which focus on people experiencing disadvantage.

The scan excluded services and support which were offered only to NDIS participants. Programs available to both NDIS participants and people with disability who are not NDIS participants were included.

Data categories

Intervention details which were recorded in the scan included:

- Target demographic (if any), including disability cohort and age
- Eligibility requirements (if any)
- Location(s) the intervention is offered
- Funding source(s)
- Costs involved for recipients

While many of the interventions recorded in the scan apply to all people with disability, others are aimed towards people belonging to specific disability cohorts. We recorded where this was the case. Common disability types that the interventions recorded in the scan addressed include:

- Psychosocial
- Physical
- Neurological
- Intellectual
- Spinal cord injury
- Alcohol and other Drug
- Autism Spectrum Disorder
- Acquired Brain Injury
- Sensory

In terms of location, the scan recorded the state (or combination of states) in which an intervention is delivered. National interventions were also recorded. We recorded whether an intervention was available state- or nation-wide, or whether it was only available in specific locations. This data served to inform later analyses of the proximity and accessibility of services to survey respondents, and helped identify potential service gaps. This regional breakdown of service availability is discussed further below.

The scan recorded the contributor(s) of funding for each intervention. The following sub-categories were used:

- Federal government
- State government
- Information, Linkages and Capacity Building grants
- NDIA
- Non-government
 - Corporate

- Philanthropic
- Other (e.g. membership fees)
- Any combination of the above

Whether any direct costs are involved for consumers accessing a service was also recorded. Each intervention was categorised as being either:

- Fully funded
- Partially subsidised, or
- Fee for service (including membership fee-based services)¹

It was not always clear whether to categorise an intervention as fully funded or partially subsidised. This was particularly the case in regard to various forms of financial assistance. In these instances, we took into account the mechanism and design of the intervention. Often this meant that if the financial support provided by the intervention has a limit, it is designed as a subsidy, even if that amount covers the whole fee.²

Where any of the aforementioned intervention details were absent or unclear, significant additional research was undertaken to obtain them. In the instances where they could not be ascertained, the scan indicated that this data point remains unknown.

Framing the scan

We adopted the six policy outcome areas outlined in the National Disability Strategy 2010-2020 (Council of Australian Governments 2011, 10) as categories to frame the scan search and how we tabulated the data. These are:

- Inclusive and accessible communities
- Rights protection, justice and legislation
- Economic security
- Personal and community support
- Learning and skills
- Health and wellbeing³

This framework was chosen as it outlines a wide range of available interventions, such as sport and recreation, accessible transport, advocacy, employment opportunities and support, financial assistance and subsidies, personal care, physical support, assistive equipment, education and training, and general and mental health services. Its use as a framework guided the scan toward the kinds of services and support Australian policymakers ostensibly see people with disability using and needing.

Categorising interventions in this way also allowed us to specify and compare delivery, cost, eligibility and availability characteristics across different service types. In doing so we may better identify the kinds of interventions that lack availability.

Survey respondents were also invited to consider the types of interventions listed under the six policy areas when indicating the services and support that they use. This more closely aligned the survey responses with the environmental scan, which may help highlight any tension(s) between what the scan shows to be available, and survey responses which speak to a different experience.

Storing the data

All data was recorded in Excel spreadsheets. Each of the six policy areas have their own spreadsheet list into which relevant interventions were categorised. While there is overlap across these policy areas, efforts were made to ensure consistency in the categorisation of interventions in the spreadsheet. In categorising interventions in the scan, we took into account the following considerations:

- The objective (stated or inferred) of the intervention⁴
- Funding source⁵

In cases where it was unclear under which policy area a given intervention should be categorised, the research team conferred and decided the most appropriate.⁶

Scan process

A decision was made not to rely on browser search engines to find available interventions for several reasons. Firstly, the information presented on search engines is highly transient and subject to change at the discretion of its private administrators. Given the scan was to be conducted over several months, using such a transient data source did not align with the aims of the scan. Secondly, the market logic of search engines means that sites paying advertising fees will invariably be promoted at the expense of those that don't. This may lead to a potential bias of the scan data. And lastly, the information hubs and service directories provided by government and non-government bodies for the express purpose of referring consumers to relevant services seemed a more appropriate avenue for the scan to pursue.

The scan began by looking at services directly delivered and commissioned by the Commonwealth government. This entailed scoping government departmental and agency websites for relevant interventions. The scan then repeated this process in Victoria, Tasmania and South Australia.

Disability service directories were used to find a range of public and non-government interventions. Any relevant webpages identified on these initial searches were also subsequently examined. This approach led the scan to many local and community-level interventions delivered by private operators.

Directories scanned:

- Disability Gateway
- NDIS directory, which included services and supports relating to:
 - Aboriginal and Torres Strait Islander Australians
 - Advocacy
 - Crisis supports
 - CALD Australians

- Education
- Employment
- Health interface
- Housing
- Information for parents and carers
- Justice
- Legal aid
- Mental health
- Mental health support for young people
- Transport
- Sector and disability-specific directories
- DSS directories, which included:
 - Organisations funded by the National Disability Advocacy Program
 - Employment programs and supports
 - Carers supports
 - Benefits and payments available
- Australian Human Rights Commission directory of legal supports for people with disability
- Carer Gateway
- Mental Health Australia directory of mental health services and organisations
- Centrelink payment and service finder
- Head to Health
- Disability Advocacy Finder
- Better Health (Victoria)
- Tasmania Health service finder
- Australian Federation of Disability Organisations advocacy organisation list
- Services Australia payments and services finder

Following this, ILC grant recipient lists were examined for relevant interventions. Previous years' grant rounds were considered to allow for lag between grant approval and service delivery, and the disruption COVID-19 was likely to have caused service delivery. As such, grant rounds which funded projects to operate into at least 2020 were considered, which totalled seven rounds:

- 2018 ILC Rural and Remote
- 2018 Disabled People and Families Organisations (DPFO)

- 2019 Economic Participation of People with Disability
- National Information Program
- Individual Capacity Building Program
- Economic and Community Participation
- Mainstream Capacity Building

A browser search using key terms relating to these ILC-funded projects was regularly performed to glean further information about the intervention and its current status. If this search found that a given project either hadn't yet commenced, or had already concluded, it was not included in the scan.

Websites of Primary Health Networks in the three states were then examined for any relevant interventions. This mainly included disability, mental health and alcohol and other drug services.

The scan then focused on disability services at the local government level. Due to the significant variations in service delivery across local government areas and the sheer number of them, it would not have been feasible to examine the services offered by each. Instead, we kept a separate list of the legal and regulatory frameworks which cover the responsibilities and duties performed by local councils concerning disability.

Beyond recording available disability interventions, the scan also maintained a list of information resources developed to help people with disability navigate the service environment. This list proved to be extensive, with the scan recording over 100 such resources across the six policy areas.

In most cases the accuracy of the information recorded in the scan has not been cross-checked due to limited resources. Where we were unable to ascertain critical details about various interventions – such as costs involved, service eligibility and location coverage – service providers were contacted directly either by email or phone for clarity.

Regional breakdown

The interventions recorded in the environmental scan went through further categorisation, based on which regions they are available. Recording the specific location(s) where interventions are offered helped to identify any potential place-specific service gaps. Interventions offered in specific locations were sorted into new spreadsheets – one each for Victoria, South Australia and Tasmania. Each state's spreadsheet was then further specified into sub-state regions, based on those set out under Schedule B in the NDIS Operational Guidelines (NDIS 2019c).⁷ Under this framework, Victoria has 17 regions, South Australia has 13 and Tasmania has four.

Generally speaking, the split of these regions should serve as a guide only. There are a multitude of variables across each region – such as geographical size, population and quality of infrastructure – which are likely to influence the accessibility of the interventions located within them. Due to our limited resources, we were unable to examine these additional factors in significant depth.

Policy area	National Disability Strategy 2010-2020 definition
Inclusive and accessible communities	The physical environment including public transport; parks, buildings and housing; digital information and communications technologies; civic life including social, sporting, recreational and cultural life.
Rights protection, justice and legislation	Statutory protections such as anti-discrimination measures, complaints mechanisms, advocacy, the electoral and justice systems.
Economic security	Jobs, business opportunities, financial independence, adequate income support for those not able to work, and housing.
Personal and community support	Inclusion and participation in the community, person-centred care and support provided by specialist disability services and mainstream services; informal care and support.
Learning and skills	Early childhood education and care, schools, further education, vocational education; transitions from education to employment; life-long learning.
Health and wellbeing	Health services, health promotion and the interaction between health and disability systems; wellbeing and enjoyment of life.

Policy areas in the National Disability Strategy 2010-2020

Schedule B – NDIS Areas included in the scan

South Australia	
NDIS Area	Local government areas comprising the NDIS Area
Barossa, Light and Lower North	Barossa Gawler Light Mallala
Playford Salisbury and Port Adelaide Enfield (East)	Playford Salisbury Port Adelaide Enfield (East)
Tea Tree Gully	Tea Tree Gully
Limestone Coast	Grant Kingston Mount Gambier Naracoote and Lucindale Robe

	Tatiara Wattle Range
Murray and Mallee	Berri and Barmera Karoonda East Murray Loxton Waikerie Mid Murray Murray Bridge Renmark Paringa Southern Mallee The Coorong
Fleurieu and Kangaroo Island	Alexandrina Kangaroo Island Victor Harbour Yankalilla
Southern Adelaide	Holdfast Bay Marion Mitcham Onkaparinga
Eyre and Western	Ceduna Cleve Elliston Franklin Harbour Kimba Lower Eyre Peninsula Port Lincoln Streaky Bay Tumby Bay Whyalla Wudinna
Far North	Anangu Pitjantjatjara Coober Pedy Flinders Ranges Port Augusta Roxby Downs
Yorke and Mid North	Barunga West Clare and Gilbert Valleys Copper Coast Goyder Mount Remarkable Northern Areas Orroroo/Carrieton Peterborough Port Pirie City and Districts Wakefield Yorke Peninsula

Adelaide Hills	Adelaide Hills Mount Barker
Eastern Adelaide	Adelaide Burnside Campbelltown Norwood Payneham St Peters Prospect Unley Walkerville
Western Adelaide	Charles Sturt Port Adelaide Enfield (West) West Torrens

Victoria	
NDIS Area	Local government areas comprising the NDIS Area
Barwon	Colac-Otway Shire City of Greater Geelong Surf Coast Shire Borough of Queenscliffe
North Eastern Melbourne	City of Banyule City of Darebin Nillumbik Shire City of Whittlesea City of Yarra
Central Highlands	Rural City of Ararat City of Ballarat Golden Plains Shire Hepburn Shire Moorabool Shire Pyrenees Shire
Loddon	Campaspe Shire Central Goldfields Shire City of Greater Bendigo Loddon Shire Macedon Ranges Shire Mount Alexander Shire
Inner Gippsland	Bass Coast Shire Baw Baw Shire City of Latrobe South Gippsland Shire
Ovens Murray	Alpine Shire Rural City of Benalla Indigo Shire

	Mansfield Shire Towong Shire Rural City of Wangaratta City of Wodonga
Western District	Corangamite Shire Glenelg Shire Hindmarsh Shire Rural City of Horsham Moyne Shire Northern Grampians Shire Southern Grampians Shire City of Warrnambool West Wimmera Shire Yarriambiack Shire
Inner Eastern Melbourne	City of Boroondara City of Manningham City of Monash City of Whitehorse
Outer Eastern Melbourne	City of Knox City of Maroondah Yarra Ranges Shire
Hume Moreland	City of Hume City of Moreland
Bayside Peninsula	City of Bayside City of Frankston City of Glen Eira City of Kingston Mornington Peninsula Shire City of Port Phillip City of Stonnington
Southern Melbourne	Cardinia Shire City of Casey City of Greater Dandenong
Brimbank Melton	City of Brimbank City of Melton
Western Melbourne	City of Hobsons Bay City of Maribyrnong City of Melbourne City of Moonee Valley City of Wyndham
Goulburn	City of Greater Shepparton Mitchell Shire Moira Shire

	Murrindindi Shire Strathbogie Shire
Mallee	Buloke Shire Gannawarra Shire Rural City of Mildura Rural City of Swan Hill
Outer Gippsland	East Gippsland Shire Wellington Shire

Tasmania	
NDIS Area	Local government areas comprising the NDIS Area
North	Break O'Day Dorset Flinders George Town Launceston Meander Valley Northern Midlands West Tamar
North West	Burnie Central Coast Circular Head Devonport Kentish King Island Latrobe Waratah-Wynyard West Coast
South East	Brighton Clarence Central Highlands Derwent Valley Glamorgan-Spring Bay

Tasmania	
NDIS Area	Local government areas comprising the NDIS Area
	Sorell Southern Midlands Tasman
South West	Glenorchy Hobart Huon Valley Kingsborough

Attachment 2: Survey parameters

Survey design

We built two online surveys to capture the experiences of people with disability without access to NDIS funding – one to be completed by a person with disability (Person with Disability survey) and the other to be completed by a family member or carer of a person with disability (Families/Carers survey). This design balanced research ethics considerations about the capacity of people with cognitive impairment to provide informed consent, and the importance of capturing the experience of all people with disability. Copies of each survey are provided below.

The surveys were uploaded to the SurveyMonkey platform. Each survey was comprised of three sections to be completed in order. The first section presented the Participant Information content and a series of questions to confirm eligibility to participate in the study. Eligibility criteria included age (18-64 years), having a disability and no NDIS plan, and residence in either Victoria, South Australia or Tasmania. The eligibility questions were followed by a second set of questions to confirm the participant's consent to participate. The only compulsory questions were the eligibility and the confirmation of consent questions. All other questions were optional.

The surveys collected:

- demographic information (the age of the person with disability; their gender; residential postcode; highest level of education; country of birth; language spoken at home; household structure and household income);
- information relating to their disability (whether or not the person with disability had ever applied for the NDIS; and a description of their disability). The survey questions related to describing disability are based on Washington questions (Washington Group on Disability Statistics 2020), the WHO Model Disability Surveys (WHO & World Bank 2017) and the Kessler Foundation Employment Survey (Kessler Foundation 2022). The questions on the Families/Carers survey were phrased about the person they provide care for, and a single question about the person completing the survey (their age) was included.

Participants were then asked a series of questions about:

- whether they use support and/or services, and if so, what do they use;
- who provides the support and/or services;
- how do they find them;
- whether the person with disability pays for support and/or services themselves, and whether this causes financial distress; and
- whether the support accessed is adequate to their needs. If the person with disability indicated they did not use support and/or services the follow up question was to ask what was the reason why.
- further comments were captured in an open text question.

Participant recruitment

Surveys opened with a 'soft launch' via the Melbourne Disability Institute (MDI) email newsletter and social media channels on 7 August 2021. This was designed to ensure there were no issues with the online launch of the surveys. Following this week-long pilot release, surveys were promoted more widely. The promotion of surveys was also used to raise awareness of the focus group component of the study.

Full scale rollout of the surveys commenced on 10 August 2021 with social media posts on Twitter, LinkedIn and Facebook accounts from the Brotherhood of St. Laurence and Baptcare. We also emailed DPOs, advocacy groups, peak bodies and service providers operating in Victoria, South Australia, and Tasmania to ask them to pass on the survey information to their contact lists. Some of these organisations had already re-posted the survey information having seen posts from the MDI, Brotherhood of St. Laurence and Baptcare.

Three weeks after the surveys' release date, we performed a check of which areas in the three states where survey respondents were located. This was achieved by accessing the postcode data voluntarily supplied by respondents (Q12). This postcode check revealed a spread of activity across the three states. The surveys closed on 10 October 2021. We anticipated a minimum number of 100 survey responses from each state (Victoria, South Australia and Tasmania), with a minimum overall total of 300 responses.

Data collection & analysis

During the pilot release phase, the research team were made aware of an error in the question logic pathway of the Adults with Disability survey: participants who answered NO to Question 20 (*'Do you use support and/or services in your day-to-day living, at home and in the community? This may include unpaid help from family and friends'*) were not skipped to Question 26 as was intended, but instead were able to answer Questions 21-25. We found that this effected 5 respondents who answered NO. The research team examined these respondents' answers and decided that data from 3 respondents could be salvaged, as the answers were consistent across survey questions. That is, the respondent answered NO but then went on to answer subsequent questions as if they had answered YES to Question 20.

Data collected by the surveys was analysed using the following techniques:

- Descriptive analysis of quantitative data (such as age, postcode, household income)
- Summary review of qualitative data (choose-as-many-as-apply styled questions). For these questions data was pooled across the two surveys, to describe the experience of the person with disability
- Thematic analysis of open text questions and comments fields
- Targeted review of answers and comments. This involved examining the data set for question responses and open text comments and looking for comments that would exemplify or elaborate on the use of support and/or services and challenges experienced with accessing these.

Survey Questions - Person with Disability Survey

Eligibility Questions – Yes/No responses

1. I have a disability
2. I have an NDIS plan
3. I live in Victoria, South Australia or Tasmania
4. I am aged between 18 and 64 years
5. I understand that participating in this research project involves answering questions on an online survey

Consent Questions – Yes/No responses

6. I understand that participating in this project is my voluntary choice
7. I understand that personal information collected from me will be anonymous
8. I know where to seek support if this survey causes me distress
9. I understand that information I provide in the survey will be only used for this research project and that it will be securely stored by the University of Melbourne for 5 years post publication and then destroyed

Survey Questions

10. Gender: How do you identify?
Choose female; male; non-binary or prefer to self-describe (open text field)
11. What is your age?
Choose 18-24 years; 25-34 years; 35-44 years; 45-54 years or 55-64 years
12. Where do you live?
Please enter your postcode in the space below
13. Have you ever applied for NDIS funding?
Yes/No
14. How would you describe your disability?
Select as many as apply:
I have trouble seeing things (vision)
I have trouble hearing things (hearing)
I have trouble moving around without help or special equipment (mobility)
I have trouble communicating (communication)
I have trouble concentrating, making decisions or remembering things (cognition)
I have trouble washing or dressing without help or special equipment (self-care)
I have trouble doing things that involve carrying, bending, picking up or moving small things around (upper body)
I have an emotional, psychological or mental health condition (such as anxiety or depression)
I feel physical pain most of the time (pain)
I feel very tired most of the time (fatigue)
15. What is your highest level of education?
Choose Did not complete secondary school; Year 12 or equivalent; Certificate I-III; Certificate IV-Diploma; Bachelor degree or Postgraduate degree

16. Which country were you born in?
Please enter your answer in the space below (open text field below)
17. What language/s do you speak at home?
Please enter your answer in the space below (open text field below)
18. Tell us about your household structure.
Choose as many as apply to you now:
Living alone
Couple
Couple with children
Single with children
Living with my parents or siblings
Share a private home with others
Other shared housing arrangements
Staying with family & friends
I move around frequently
19. What is your household income each year?
Choose Under \$15,000; Between \$15,000 and \$29,999; Between \$30,000 and \$49,999; Between \$50,000 and \$74,999; Between \$75,000 and \$99,999; Between \$100,000 and \$150,000 or Over \$150,000
20. Do you use support and/or services in your day-to-day living, at home and in the community? This may include unpaid help from family and friends.
Yes/No*
If Yes, please specify which support and/services you use (open text field)
If No, then go to Q26
21. Who provides the support and/or services you use?
You can select more than one option: Family; Friends; Carer; Online community; GP; Therapist; Hospital; Health service; Community centre; Neighbourhood house; Disability support organisation; Not-for-profit organisation; Local government; Government department; NDIS Local Area Coordinator (LAC)
22. How do you find the support and/or services you use?
You can select more than one option: NDIS office; NDIS Local Area Coordinator (LAC); Family; Friends; Carer; Online community; GP; Therapist; Hospital; Health service; Community centre; Neighbourhood house; Disability support organisation; Not-for-profit organisation; Local government; Government department; Other - please specify (open text field)
23. Do you pay for any support and/or services yourself?
Yes/No
24. Does accessing or using support and/or services cause financial difficulties?
Select as many as apply:
Yes - paying for the support and/or services myself causes concern or pressure for my budget
Yes - the indirect costs (such as time away from work, cost of transport etc.) cause financial pressure
No - but it causes my family/carer financial pressure because they pay for the

support and/or services directly

No - but it causes my family/carer financial pressure from the indirect costs involved (time away from work, cost of transport etc.)

No - neither myself, nor my family/carer are under financial pressure from accessing support and/or services

25. Is the support and/or services that you access adequate to meet all your needs?

Please select the most appropriate option from the following:

Yes - I know what I need and I am accessing them

No - I don't know where to look for what I need

No - The support and/or services I need are too hard to engage with

No - I have had bad experiences using the support and/or services I need in the past

No - The support and/or services I need don't understand my disability

No - The support and/or services I need are not accessible

No - The support and/or services I need don't exist, or are no longer available

No - The support and/or services I need are too far away

No - The support and/or services I need are too expensive

No - I am not eligible to use the support and/or services I need

No - I can access some support and/or services I need, but not all of them

No - The quality of the support and/or services I can access does not meet all my needs

26. What is the reason why you do not use any support and/or services? *only if responded 'No' to Q20

You can select more than one option:

I don't need any support or services

I don't know where to look for what I need

The support and/or services I need are too hard to engage with

I have had bad experiences using support and/or services in the past

The support and/or services I need don't understand my disability

The support and/or services I need are not accessible

The support and/or services I need don't exist, or are no longer available

The support and/or services I need are too far away

The support and/or services I need are too expensive

I am not eligible to use the support and/or services I need

27. Please share any other comments you have below
(open text field)

Survey Questions - Families/Carers Survey

Eligibility Questions – Yes/No responses

1. The person I provide care for has a disability
2. The person I provide care for has an NDIS plan
3. The person I provide care for lives in Victoria, South Australia or Tasmania
4. The person I provide care for is aged between 18 and 64 years
5. I understand that participating in this research project involves answering questions on an online survey

Consent Questions – Yes/No responses

6. I understand that participating in this project is my voluntary choice
7. I understand that personal information collected from me will be anonymous
8. I know where to seek support if this survey causes me distress
9. I understand that information I provide in the survey will be only used for this research project and that it will be securely stored by the University of Melbourne for 5 years post publication and then destroyed

Survey Questions

10. Gender: How does the person you provide care for identify?
Choose female; male; non-binary or prefer to self-describe (open text field)
11. What is the age of the person you provide care for?
Choose 18-24 years; 25-34 years; 35-44 years; 45-54 years or 55-64 years
12. Where does the person you provide care for live?
Please enter your postcode in the space below
13. Has the person you provide care for ever applied for NDIS funding?
Yes/No
14. How would you describe the disability of the person you provide care for?
Select as many as apply:
They have trouble seeing things (vision)
They have trouble hearing things (hearing)
They have trouble moving around without help or special equipment (mobility)
They have trouble communicating (communication)
They have trouble concentrating, making decisions or remembering things (cognition)
They have trouble washing or dressing without help or special equipment (self-care)
They have trouble doing things that involve carrying, bending, picking up or moving small things around (upper body)
They have an emotional, psychological or mental health condition (such as anxiety or depression)
They feel physical pain most of the time (pain)
They feel very tired most of the time (fatigue)
15. What is the highest level of education of the person you provide care for?
Choose Did not complete secondary school; Year 12 or equivalent; Certificate I-III; Certificate IV-Diploma; Bachelor degree or Postgraduate degree

16. In which country was the person you provide care for born?
Please enter your answer in the space below (open text field below)
17. What language/s does the person you provide care for speak at home?
Please enter your answer in the space below (open text field below)
18. Tell us about the household structure of the person you provide care for.
Choose as many as apply now:
Living alone
Couple
Couple with children
Single with children
Living with my parents or siblings
Share a private home with others
Other shared housing arrangements
Staying with family & friends
I move around frequently
19. What is the household income each year of the person you provide care for?
Choose Under \$15,000; Between \$15,000 and \$29,999; Between \$30,000 and \$49,999; Between \$50,000 and \$74,999; Between \$75,000 and \$99,999; Between \$100,000 and \$150,000 or Over \$150,000
20. What is your age?
Choose Under 18 years; 18-24 years; 25-34 years; 35-44 years; 45-54 years; 55-64 years or 65+ years
21. Does the person you provide care use support and/or services in their day-to-day living, at home and in the community? This may include unpaid help from family and friends.
Yes/No*
If Yes, please specify which support and/services they use (open text field)
If No, then go to Q27
22. Who provides the support and/or services used by the person you provide care for?
You can select more than one option: Family; Friends; Carer; Online community; GP; Therapist; Hospital; Health service; Community centre; Neighbourhood house; Disability support organisation; Not-for-profit organisation; Local government; Government department; NDIS Local Area Coordinator (LAC)
23. How does the person you provide care for find the support and/or services they use?
You can select more than one option: NDIS office; NDIS Local Area Coordinator (LAC); Family; Friends; Carer; Online community; GP; Therapist; Hospital; Health service; Community centre; Neighbourhood house; Disability support organisation; Not-for-profit organisation; Local government; Government department; Other - please specify (open text field)
24. Does the person you provide care for pay for any of this support and/or services themselves?

Yes/No

If Yes, which ones do they pay for? (open text field)

25. Does accessing or using support and/or services cause financial difficulties for the person you provide care for?

Select as many as apply:

Yes - paying for the support and/or services myself causes concern or pressure for their budget

Yes - the indirect costs (such as time away from work, cost of transport etc.) cause financial pressure

No - but it causes me (the family/carer) financial pressure because they I pay for the support and/or services directly

No - but it causes me (the family/carer) financial pressure from the indirect costs involved (time away from work, cost of transport etc.)

No - neither the person I provide care for, nor myself are under financial pressure from accessing support and/or services

26. Are the support and/or services accessed by the person you provide care for adequate to meet all their needs?

Please select the most appropriate option from the following:

Yes - They know what they need and they are accessing them

No - They don't know where to look for what they need

No - The support and/or services they need are too hard to engage with

No - They have had bad experiences using the support and/or services they need in the past

No - The support and/or services they need don't understand their disability

No - The support and/or services they need are not accessible

No - The support and/or services they need don't exist, or are no longer available

No - The support and/or services they need are too far away

No - The support and/or services they need are too expensive

No - They are not eligible to use the support and/or services they need

No - They can access some support and/or services they need, but not all of them

No - The quality of the support and/or services they can access do not meet all my needs

27. What is the reason why the person you provide care for does not use any support and/or services? *only if responded 'No' to Q21

You can select more than one option:

They don't need any support or services

They don't know where to look for what they need

The support and/or services they need are too hard to engage with

They have had bad experiences using support and/or services in the past

The support and/or services they need don't understand their disability

The support and/or services they need are not accessible

The support and/or services they need don't exist, or are no longer available

The support and/or services they need are too far away
The support and/or services they need are too expensive
They are not eligible to use the support and/or services I need
28. Please share any other comments you have below
(open text field)

Attachment 3: Focus group parameters

Focus group recruitment

We recruited people to participate in the focus groups through a series of direct email, phone and online engagements with stakeholders interacting with people with disability. Initial email contact sought their help in promoting surveys for people with disability and their families and carers through their networks, and expressions of interest in participating in a focus group. We targeted Disabled People's Organisations, peak bodies, advocacy organisations and service providers, filtering out organisations exclusively servicing NDIS participants. The search was informed by the research team's networks, and leads from the project's environmental scan.

Overall, we approached a total of 175 organisations across the three relevant states to promote the surveys – 39 in South Australia, 38 in Tasmania, 64 in Victoria, and 34 national organisations. These organisations included:

- Carers associations
- Mental health associations
- Self-advocacy groups
- Citizen advocacy groups
- Legal advocacy services
- Disability-specific peak bodies
- Recreation and leisure organisations
- Mainstream/universal local service providers (such as Neighbourhood Houses and counselling services)
- Home and personal support service providers (such as personal care, domestic assistance, and mobility aids and equipment)
- Targeted approaches to local governments in areas where there was low or no initial engagement in the surveys.

Of these, 108 organisations were sent follow-up invitations to participate in local focus groups. Those excluded from a follow-up invitation included local councils, national bodies not engaged in place-based activity, and some Victorian organisations, as the quota for participants from that state was swiftly met.

Consultation fatigue was evident in the recruitment process. Many organisations we approached has been stretched thin by ongoing government inquiries, public consultations and evaluations, and had experienced increased pressure on their resources during the COVID-19 pandemic.

We were unable to recruit eight participants from each state as planned, but in total, the focus groups involved 19 participants across the three targeted states. There were nine participants representing nine organisations in Victoria; seven participants representing three organisations in South Australia; and three participants representing three organisations in Tasmania. Several participants came from national organisations, so they had some experience working not only in their home state but in other jurisdictions as well. Participants were overwhelmingly

concentrated in metropolitan areas, with minor representation of regional areas. This is likely a consequence of the kinds of organisations we approached to share information about the project with their networks, such as state-wide peak bodies, operating primarily out of capital cities. Approximately half of the participants in the focus groups identified as having a disability, or having a family member with a disability.

The process of data collection

The seven focus groups for this study were conducted on a select number of dates throughout September and early October 2021 to accommodate the varying schedules of participants (Table G). We had intended to run three focus groups – one for each state – but we chose to add more sessions when participants from the same state were unavailable at the same time as we were keen to include as many as possible. Three of the sessions included single participants who were unable to attend scheduled group sessions. These were conducted as semi-structured interviews between the research team and the participant, using the same questions as the focus groups.

Table E: *Focus group sessions*

	Date	State	Number of participants
Focus group 1	September 9	South Australia	6 (5 from one organisation)
Focus group 2	September 14	Victoria	2
Focus group 3 (interview)	September 21	South Australia	1
Focus group 4	September 22	Tasmania	2
Focus group 5	September 22	Victoria	6
Focus group 6 (interview)	September 23	Tasmania	1
Focus group 7 (interview)	October 1	Victoria	1

The focus group discussions were recorded with the consent of the participants. The recordings were supplemented by notes taken by the research team for cross-reference. Audio files and notes were then compared and analysed to identify common themes within individual focus groups and across the focus groups, and relevant audio content was transcribed. Finally, the findings were compared with themes that emerged in the study’s other sources of evidence.



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