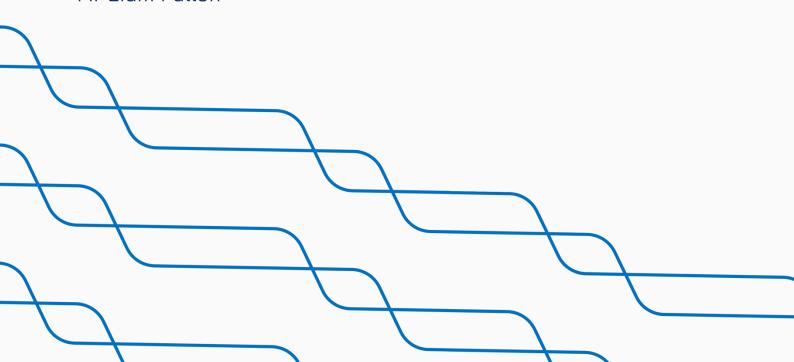# The Tier 2 tipping point: access to support for working-age Australians with disability without individual NDIS funding

Executive Summary

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Acknowledgements

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Executive Summary

This report presents findings from research conducted by The Melbourne Disability Institute, in partnership with the Brotherhood of St. Laurence and Baptcare, 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).
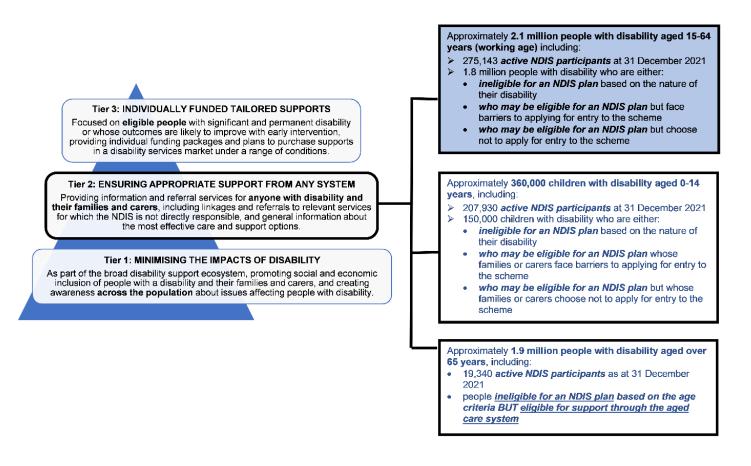

Figure 1: *NDIS intended tiers of support and people in Tier 2*

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

> **"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**

Key findings

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 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:

- 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 (DSS.

- 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. This is 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 of this research 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 Disability Strategy 2021-2031, 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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