



Finding support outside the NDIS: issues and opportunities in the aims, design and implementation of 'Tier 2' of the scheme.

Submission to the NDIS Review

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This submission is underpinned by research conducted by the Melbourne Disability Institute and the Brotherhood of St. Laurence Social Policy and Research Centre in 2021. The research aimed to build understanding of *if* and *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.

The research findings are available online:

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Contents

Key issues.....	3
Understanding the ‘Tier 2’ policy landscape.....	3
Clarifying the aims of Tier 2 of the NDIS.....	4
The design of Tier 2 of the NDIS.....	4
Implementation of Tier 2 of the NDIS.....	5
Recommendations	6
Policy recommendations.....	6
Recommendations for research	7
Who are the people with disability outside the NDIS?	8
References.....	9

Key issues

Understanding the ‘Tier 2’ policy landscape

- The overwhelming majority of the 4.4 million Australians with disability rely on universal or ‘mainstream’ service systems, community services, and their own knowledge, resources, and networks, to maintain their wellbeing and participate in society and the economy ([Table 1](#)). Yet there is no robust data on how they are faring, what support they need and want, whether and how they are finding the support they need, and the public and private flow-on effects if they are unable to find or afford the support they need.
- Inclusion of people with disability in society and the economy is a critical component of the NDIS insurance model, to delay or prevent or reduce people’s need for individual funding for tailored support. It is also their right as equal citizens.
- Recent research into Tier 2 of the NDIS compared what is *promised* with what is *experienced* by people with disability of working age who are not NDIS participants (Olney, Mills & Fallon 2022). It revealed:
 - a disconnected and incomplete ecosystem of services and supports being navigated by people with disability and their families and carers, riddled with inconsistent legislative and regulatory frameworks, costs, eligibility criteria, priorities, and availability of services; incomplete and contradictory information; and circular referrals with no outcome that impose a significant administrative, financial and emotional burden on households under pressure;
 - heavy reliance on informal support networks and personal resources among people with disability without NDIS funding; and
 - gaps in data about the service landscape, the needs and circumstances of people with disability outside the NDIS, and extra costs of living incurred by people with disability and their households.
- Australia’s Disability Strategy is intended to provide national leadership towards greater inclusion and to drive mainstream services and systems to improve outcomes for people with disability (Australian Government 2021a:5). Slow progress on that front is compounding pressure on the NDIS. National Cabinet has developed an *NDIS Financial Sustainability Framework* which aims to moderate growth of the scheme, and the Minister for the NDIS has said that states and territories “can’t retreat from supporting people with disability outside the scheme” (Shorten 2023a, 2023b). Understanding the broad range of needs of Australians with disability over their life course, 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.**
- Issues arising from contested, blurred and shifting boundaries between the responsibilities of the NDIS and other service systems to meet the needs of Australians with disability are well-documented in academic research, stakeholder investigations and reports, government and independent inquiries and reviews, Royal Commissions, the media and the legal system. Many of these issues lie outside the direct control of the NDIS and its agents, its Minister, and the Department of Social Services. Consequently, the NDIS Review must be both *strategic* and *tactical* in identifying key leverage points where it can influence the broader policy landscape to promote inclusion for people with disability in both the short and long term.

Clarifying the aims of Tier 2 of the NDIS

- There were three tiers of support built into the original design of the NDIS - individually funded and tailored supports *for people who met the scheme's eligibility criteria*; ensuring appropriate support from any system for *all people with disability*; and promoting social and economic inclusion more broadly to *minimise the impacts of disability*. The tiered design acknowledged that while people with disability should be supported by mainstream and community service systems, those services might be difficult for some people to find, access and navigate. It also acknowledged that mainstream and community services had to become more inclusive and accessible for people with disability.
- 'Tier 2' was intended to help all Australians with disability - both NDIS participants and those without NDIS funding packages – and their families and carers connect with service systems and supports outside the NDIS, to promote local collaboration and partnerships to improve outcomes for people with disability, and to build the capacity of local communities and services to meet the needs of people with disability. Local Area Coordination was envisaged as a key driver of that paradigm shift.
- This layer of support was particularly important for people with disability ineligible for NDIS funding packages with limited personal support networks, resources or capacity to navigate mainstream service systems, and for those who had previously accessed block-funded federal, state and local government programs with broader eligibility criteria which were restructured or disappeared as the NDIS rolled out. Failure to connect them with necessary support was likely to generate far-reaching public and private costs.
- In 2020, the Disability Reform Council agreed to remove references to 'tiers' in the NDIS structure because of the potential for seeing the NDIS as a hierarchy of supports. 'Tier 2' became *Information, Linkages and Capacity Building (ILC)*. Government messaging about whether ILC is intended to support *all* people with disability is inconsistent. However, the ILC Framework states that "the focus of ILC is not on who will access it, but on the supports offered." This was more than a change of terminology. It was a shift from a *population* lens to a *program* lens in Tier 2 support.
- It is unclear how ILC relates to Australia's Disability Strategy released in 2021, both in aims and in practice. References to the NDIS in both the Strategy and the Outcomes Framework are limited to individual NDIS funding and NDIS participants (Australian Government 2021a, 2021b).

The design of Tier 2 of the NDIS

- ILC now has two components:
 - a grants program, administered by the Department of Social Services, which provides fixed-term grants under four streams to organisations to deliver projects in the community to "benefit all Australians with disability, their carers and families"; and
 - a referral function through Local Area Coordinators (LACs), overseen by the National Disability Insurance Agency, to help connect all people with disability and their families and carers to their community and to services within each ILC stream.
- With regard to the **grants program**, there is no strategic or overarching needs assessment, measurement of return on investment, or tracking of either short- and long-term impacts of ILC grants on demand for the NDIS or inclusion across other service systems (Olney, Mills & Fallon 2022; Wilson et al 2021). Competitive approaches to funding and reporting on ILC activity are perpetuating piecemeal and unsustainable

interventions, duplication of effort, and gaps in data that directly affect the lives and livelihoods of people with disability and their families and carers. In applying for ILC grants, individual organisations are incentivised to present themselves as *uniquely positioned* to address persistent marginalisation of people with disability in society and the economy within narrow parameters and short timeframes. In reporting outcomes, there are perverse incentives for grantees to withhold some information about their knowledge, networks, activity and processes for competitive advantage, while others under-report their activity because they are not adequately resourced to track it. This skews consolidated data on the service landscape.

- With regard to the **referral function through LACs**, which is promoted by both the NDIS and DSS, research shows that it is not working effectively (Olney, Mills & Fallon 2022; Wilson et al 2021). This can be attributed in part to resource constraints, and in part to issues surrounding the availability, accessibility and affordability of services, support and activities for people with disability outside the NDIS. The referral function is of little use where there is nowhere for people to be sent.
- In some cases, ILC grants have supported projects that duplicate the promoted referral function of LACs, with no evidence of system improvement or institutional learning (Olney, Mills & Fallon 2022:63).
- Despite a clear warning from the Productivity Commission six years ago that the interface between the NDIS and other disability and mainstream services is critical for participant outcomes and the financial sustainability of the scheme (Productivity Commission 2017:2), investment in ILC is still less than one percent of overall investment in the NDIS (D’Rosario 2023:37).

Implementation of Tier 2 of the NDIS

- The NDIS Guidelines on Mainstream and Community Supports say the scheme "can't fund supports that mainstream and community services should provide, *even if the other service system doesn't actually provide it*" [emphasis added] (NDIS 2021). However, there is no consistent measurement or monitoring of service gaps or barriers to social and economic inclusion experienced by people with disability and their families and carers. The NDIS does not capture data from people with disability who are not NDIS participants at a local level to flag service gaps, and it has no authority to direct external services to fill service gaps identified by NDIS participants.
- Compounding lack of clarity in this arena, there are instances of the NDIS funding supports for people with disability within other service systems where accountability for support is blurred, or in cases of market failure, in response to legal action or media scrutiny.
- The interface between the NDIS and other service systems is where *legislative and policy coordination across government is needed*. It calls for policy scaffolding and legislation with scope to meet the changeable and wide-ranging needs of all Australians with disability over their life course, while advancing their rights as equal citizens. This is ostensibly driven by Australia's Disability Strategy, but there is little evidence of concerted reform to date (Olney S, Bonyhady B, et.al. 2023).
- The sustainability of the NDIS hinges on governments developing **clear and mutually reinforcing levers to address inequities for people with disability across a range of service systems, including disability, social security, mental health and psychosocial disability, early childhood, child protection and family support, education, employment, housing and community infrastructure, transport, justice and aged care.**

Recommendations

Policy recommendations

1. 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 just outside the scheme must be addressed for long-term sustainability. Current approaches to directing people with disability with varied and complex needs to other service systems do not adequately factor in their entrenched disadvantage in these systems or the extra costs they incur in daily living; nor do they address risks and future costs associated with people with disability and their families being unable to find or afford the services and support they need. There is a need for – and demand for - tapered transitional or bridging support between the NDIS and other service systems in certain circumstances, informed by lived experience of disability.
2. People with disability, and representative organisations, must be actively involved in deciding how resources intended to serve their interests are prioritised, applied and structured. Recent announcements of changes to the NDIS pre-empting the findings of the NDIS Review have not been well-received. This is a policy landscape rife with competing priorities and public and private interests, and gaps between rhetoric and practice. Effective stewardship of Tier 2 will hinge on rebuilding trust between government and people with disability, demonstrating how evidence provided by people with disability is factored into decisions, and ensuring that any reforms are codesigned, transparent, evidence-based, adaptable to a range of needs, and appropriately resourced.
3. Under the umbrella of Australia's Disability Strategy, the NDIS should revive the original model of Tier 2 support and capacity building, with a new name that signals its purpose. The relationship between the Strategy and this layer of support through the NDIS - both in aims and in practice - must be clear, collaborative and constructive. It should be underpinned by whole-of-government commitment and investment to address entrenched marginalisation of people with disability, with measurable accountability for activity and outcomes across jurisdictions under agreed domains and timeframes. This would become a whole-of-government mechanism for mapping inclusion across publicly funded service systems, identifying whether existing data and data analytics can identify critical risks and opportunities in that environment and where they could be improved, and flagging and addressing service gaps and barriers to inclusion at local, regional and national levels across disability, social security, mental health and psychosocial disability, early childhood, child protection and family support, education, employment, housing and community infrastructure, transport, justice and aged care. Research into a range of reforms of human services in Australia reveals that without careful and coordinated stewardship, market-based models of service provision expose people with complex needs to exploitation and neglect.
4. Local Area Coordinators are now an established, national, street-level platform for people with disability to access disability-related support and advice. They can play a critical role in capturing local intelligence and trends, identifying service gaps, and building community capacity and social capital to reduce pressure on the NDIS. That potential has not been realised. They should be equipped and resourced for that role as originally intended. They should also employ people with disability in both client-facing and strategic roles.
5. 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 also be better utilised to flag service gaps

and to provide information to people with disability about universal 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 without success.

Recommendations for research

6. There is a need for *targeted, participatory research into intersectional barriers to inclusion faced by people with disability*, and their access to necessary services and support, to inform policy and practice across the NDIS and other service systems. This research, grouped by age and combining quantitative and qualitative data, could examine the feasibility of hybrid service models at different life stages, to respond flexibly to people's support needs that do not fit the criteria for NDIS funding. The findings can underpin strategic collaborative investment and policy action across state, territory and Commonwealth governments to address complex disadvantage. The suggested life stages are:
 - 0-7 years (early intervention)
 - 7-14 years (primary school and early secondary school years)
 - 15-24 years (preparing for and transition to work)
 - 25-50 years (peak working age)
 - 50-64 years (mature working age and increasing prevalence of disability)
 - 65 years and over (significantly increased prevalence of disability)
7. Of the 2.1 million Australians with disability aged 15-64 years - 11 per cent of Australia's working age population - just 290,000 are NDIS participants. In 2018 (the most recent available data), 53.4 percent of Australians with disability aged 15-64 years were participating in the labour force and fewer than 50 per cent were employed – significantly below the rates for Australians of working age without disability (Olney & Devine 2022). There is a need for new *interdisciplinary and inclusive research into the persistent gap between the labour force participation rate and employment rate of Australians with and without disability* and its public and private costs. This should encompass research into local and international labour market policies, as well as research into structural and systemic barriers to finding and maintaining work identified by Australians with disability. Those barriers may include, but are not limited to, discrimination in education and training, the job market and in workplaces; the structure of work; inaccessible infrastructure; lack of affordable, accessible and secure housing in areas where work is available; unmet need for health, mental health and disability-related services; socio-economic disadvantage; health risks associated with COVID-19; and welfare conditionality for people with disability who are only able to work part time or episodically, in relation to moving in and out of income support and access to concessions to cover extra costs of living that people without disabilities do not incur.

Who are the people with disability outside the NDIS?

Table 1: Who are the people with disability outside the NDIS?

Australians with disability by age (2018 ABS data)	Active NDIS participants at 30 September 2022 (Q1 FY22/23)	People with disability outside the NDIS
All ages Total 4,367,200	554,917 (up from 502,413 at 31/12/2021)	Approximately 3.8 million people
Aged 0-14 years Total 357,000	221,950 (up from 207,930 at 31/12/2021)	Approximately 135,000 children with disability who are either: <ul style="list-style-type: none"> • ineligible for an NDIS plan based on the nature of their disability • who may be eligible for an NDIS plan whose families or carers face barriers to applying for entry to the scheme • who may be eligible for an NDIS plan but whose families or carers choose not to apply for entry to the scheme
Aged 15-64 Total 2,070,600	290,709 (up from 275,143 at 31/12/2021)	Approximately 1.8 million people with disability of working age who are either: <ul style="list-style-type: none"> • ineligible for an NDIS plan based on the nature of their disability • who may be eligible for an NDIS plan but face barriers to applying for entry to the scheme • who may be eligible for an NDIS plan but choose not to apply for entry to the scheme
Aged 65 years and over Total 1,942,700	21,996 (up from 19,340 at 31/12/2021)	Approximately 1.9 million people with disability over 65 who are ineligible for an NDIS plan based on the age criteria BUT eligible for support through the aged care system

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