Discussion Paper

NDIS Review: Mainstream and Tier 2

Rethinking 'Tier 2' of the NDIS:
Investing in real inclusion of people with disability.

DANA Disability Advocacy Network Australia

Foreword

DANA has commissioned a series of four discussion papers as part of our contribution to the National Disability Insurance Scheme (NDIS) Review.

Disability advocates across the country spend close to half their time on NDIS related matters. This means advocates have a wide range of expertise and experiences about what is, and isn't, working in the Scheme.

The NDIS Review is interested in learning from this expertise, and to hear about how to make sure the Scheme is delivering for people with disability, their families and supporters.

DANA has considered what is important for the NDIS Review to understand, both now and into the future.

In addition to these discussion papers, DANA will hold workshops and survey advocates and people with disability. The feedback will be delivered to the NDIS Review.

We want to ask for your big ideas on the following key ideas:
- Fires, floods and COVID-19
- Tier 2 and mainstream supports outside the NDIS
- Quality and safety
- Support for decision making for advocacy

DANA is also working with Inclusion Australia on issues that particularly impact on people with an intellectual disability.

Please get in touch if you have any questions or comments and we look forward to hearing from you.

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Acknowledgements

Introduction

The majority of Australians with disability rely on universal or 'mainstream' service systems, specialist and general community services and their own resources to stay well, study, find housing, work, move around, and participate in and contribute to their communities. And all Australians with disability have a right to access information, activities and services on an equal basis with every other citizen, especially public services.

These public services are not working for people with disability and that needs to change. People with disability who do not use the NDIS, and their families, are struggling to cope with high costs of living and service gaps.

There are 4.4 million Australians with disability – about 20% of our total population. Approximately 350,000 are under 14 years of age, just over 2 million are aged 15-64 years, and just under 2 million are aged 65 years and over. Approximately 590,000 Australians with disability are NDIS participants.

Inquiries, research and legal challenges reveal a substantial gap between what is *said* about the availability of services and support to Australians with disability outside the NDIS, and what is happening on the ground (Olney, Mills & Fallon 2022; Wilson & Brown 2021a; D'Rosario 2023; Parliament of Australia 2023; Victoria Legal Aid 2022). Responsibility to ensure that people with disability of all ages can be part of the community and the economy is dispersed in legislation, policy and practice, and government resources to support people with disability continue to be largely rationed on the basis of a medical model of disability (McVilly et.al 2022:119). There has been slow progress on inclusion in key policy areas like health, education, employment, housing, transport, early childhood and aged care.

Australian governments cannot afford to treat twenty per cent of our population as outliers in designing and delivering universal services.

People with disability can't continue to be sent to service systems outside the NDIS that don't exist or don't include them. The NDIS has increased prices and availability of all disability services, including those outside the NDIS.

Many people with disability who do not use the NDIS have low, fixed incomes and face barriers to work outside their control (Olney & Devine 2022).

There are **economic risks for every level of government** when people with disability and their families are unable to find or afford the services and support they need and exhausting their personal and financial resources. They ultimately require significantly higher levels of intervention and investment in areas like the NDIS, health, housing, justice, aged care, and welfare.

To date, there is no strategic or coordinated effort across government to understand the wide-ranging and shifting needs of Australians with disability throughout their lives, and the capacity of governments, civil society, business and individuals – including people with disability themselves – to meet those needs at different times and in different places. There are gaps in governments' understanding of what support people with disability need and want, whether and how they are finding the support they need at different stages of their

lives, who is bearing the costs, and what it means for people with disability, their households and Australia if they are pushed into crisis.

Both Australia's Disability Strategy and the National Disability Data Asset have limitations for governments attempting to understand and address intersectional disadvantage and inequality faced by people with disability in society and the economy. **There is no accountability for the gap between rhetoric about the availability of services and support and what is actually available, accessible and affordable to people with disability and their families. There's also no mechanism to capture the experiences and knowledge of people with disability who rely heavily on family or informal support and who are likely to be missing from government datasets driving policy reform and the allocation of public resources.** They are most at risk of needing urgent and intensive support if their family circumstances change.

Inconsistent eligibility, availability and accessibility of support across different service systems and places, out-of-pocket costs, significant gaps between supply and demand for services and support, and confusing and competing sources of information about the service landscape are preventing people from being able to find - or even begin to ask for – support outside the NDIS.

All of this is putting unsustainable pressure on the NDIS now and into the future.

What is the problem?

A decade of pushing 'Tier 2' to the side

Being in or out of the NDIS has a significant financial impact on people with disability and their families. In failing to deliver effective support for people with disability beyond NDIS funding, often called 'Tier 2', all governments and the NDIA have contributed to the NDIS becoming an "oasis of support, surrounded by a desert where little or nothing is available" (Productivity Commission 2017:29).

Access to activities, services and support outside the NDIS is a critical component of the NDIS insurance model. Firstly, and importantly, it can improve the lives of people with disability and their families by connecting them with their communities. Secondly, it can prevent, reduce or delay people with disability needing specialist disability services and individual NDIS funding packages.

For that reason, the NDIS was designed to help *all* Australians with disability connect with an ecosystem of activities, services and supports in their communities, and to help communities become more welcoming and inclusive, through a national platform of Local Area Coordinators. There were three tiers of activity in the original model of the NDIS – providing individually funded and tailored supports for *people who met the scheme's eligibility criteria*; helping *all people with disability* connect to support and services in their communities; and promoting social and economic inclusion to *minimise the impacts of disability*. That model acknowledged that people with disability *should* be supported by mainstream and community service systems, but that it might be difficult for some people to find and use those services. It also acknowledged that universal service systems needed to be encouraged and helped to become more accessible for people with disability.

The second tier of that model – helping people to connect with services and support outside the NDIS in their local communities - was particularly important for people with disability ineligible for NDIS funding packages who might need extra guidance and support to find the services they need, or who had been using services that were restructured or disappeared as the NDIS rolled out.

Although the term 'Tier 2' is still widely used, in 2020, the Disability Reform Council agreed to remove references to 'tiers' in the NDIS structure. 'Tier 2' became *Information, Linkages and Capacity Building* (ILC), which 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

- Local Area Coordinators (LACs), overseen by the National Disability Insurance Agency, whose ILC role is described as "Linking you to information and support in your community…even if you're not eligible for an NDIS plan" (NDIS 2023a).

There's no evidence that *either* of these components is contributing significantly or effectively to the sustainability of the NDIS, or to improving outcomes for people with disability (Independent Advisory Council to the NDIS 2021:4, Wilson et al 2021b:19; Productivity Commission 2017:232; Olney, Mills & Fallon 2022:34, 57, 65). More broadly, there's no reliable data on the level of demand for support outside the NDIS and what is currently available, and no clear relationship between ILC and Australia's Disability Strategy, which is intended to provide national leadership for greater inclusion for people with disability (Australian Government 2021a:5).

LACs are not delivering information, linkages and community capacity building as intended. Disability advocacy organisations report that they are providing unfunded support to fill that gap, and struggling to meet demand (Olney, Mills & Fallon 2022:14). Circular referrals with no resolution are commonplace (Olney, Mills & Fallon 2022:65). It is clear that LAC's capacity to support people without NDIS plans has been hampered by under-resourcing and heavy emphasis on working with people who are eligible for NDIS funding in their service contracts. But even with additional resources, **promises to link people to supports in their communities are meaningless when there is nowhere for them to be sent**. At the very least, LACs should be equipped to capture evidence of service gaps and barriers to inclusion at a local level that could be aggregated and tracked to drive systemic change, in line with federal government's current commitment to "gain insights and put data in the hands of communities to help guide local decision making and better direct funding" (DSS 2023).

On the ILC grants front, there is no strategic or overarching needs assessment, measurement of return on investment, or tracking of the impact of ILC grants on demand for NDIS funding. Evidence about the extent to which ILC is effective in improving outcomes for people with disability, or whether ILC is reducing demand for NDIS funding packages, is lacking (Productivity Commission 2017:232). The grants don't appear to leverage on previous work or contribute to institutional learning (Olney, Mills & Fallon 2022:61-62). Online information about ILC-funded projects contained in grant round lists is regularly incomplete or out of date, making it difficult to track if ILC funding is being used as intended, or to assess its impact (Olney, Mills & Fallon 2022:33-34).

The glaring holes in the evidence base for ILC are astounding. 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. **The interface between the NDIS and other disability and mainstream services is critical for the financial sustainability of the NDIS** (Productivity Commission 2017:2). The lack of services and supports outside the NDIS are pushing people with disability and their families into individualised funding packages, because there is no other choice. This adds significant numbers of people to the NDIS. In addition, the lack of preventative supports for people with disability early in their disability means that they will become eligible for the NDIS due to a worsening of their disability. Despite that, investment in ILC is still less than one percent of overall investment in the NDIS (D'Rosario 2023:37). But an equally significant concern is that people with disability have no say over how that investment is distributed, applied or evaluated.

Slow progress on social and economic inclusion

Research from the Melbourne Disability Institute and the Brotherhood of St. Laurence into Tier 2 of the NDIS in 2021 compared what is *promised* by the NDIS and other service systems with what is *experienced* by people with disability of working age, who are getting support from the NDIS, seeking support within and outside the NDIS (Olney, Mills & Fallon 2022). The research drew on an environmental scan of information about services, resources, programs and activities promoted as disability inclusive and available to people with disability living in Victoria, South Australia and Tasmania, as well as survey and focus group data from people with disability aged 18-64 years, their families and carers, and representatives from service providers, peak bodies, advocacy organisations and Disabled Peoples Organisations (DPOs) in Victoria, Tasmania and South Australia.

It found that people with disability and their families and carers were navigating complicated, disconnected and incomplete markets of private, community and public services with inconsistent costs, eligibility criteria, information, and availability. Those without NDIS funding were relying heavily on informal support and stretched household resources. Lines between public interest and private interest in these service systems were blurred.

Weaknesses in the 'system architecture' of support for people with disability outside the NDIS that emerged in that research included:

Sources of information about available support

- The *promoted* ILC function of LACs is not being delivered.

- There is 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. However, details important to prospective service users - including **costs, accessibility for particular needs, location, wait times, and eligibility for support or concessions** - are missing, inaccurate or outdated in online databases and gateways. The time and effort involved in navigating and sifting the volume of information online can be overwhelming and frustrating.

Access to services and support

- There are clear discrepancies 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.

- Access to services and support, including NDIS funding, is inconsistent and inequitable. It can vary 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.
- People with disability who are not NDIS participants, and their families and carers, rely heavily on unpaid support from family and friends in their day-to-day lives, in the absence of viable and affordable alternatives.

Costs of living

- People with disability face extra costs of living that people without disabilities do not incur, and this is putting households under financial pressure, both in terms of direct costs (such as medical and pharmacy out of pocket expenses, service fees, equipment purchases, transport costs and housing modifications) and indirect costs (such as time away from work).

Trust in government and the NDIS

- Findings indicated that lack of transparency and ongoing shifts in disability policy and practice have eroded trust in government and institutions, and trust in the NDIS. 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.

Gaps in evidence

- Heavy reliance on informal supports, and lack of coordination between services accessed by people with disability and their families, results in 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.

What is the solution?

For the last ten years, attention has (reasonably) been focused on issues surrounding individual NDIS funding for people with permanent and significant disability – issues like access to the scheme, planning processes, the availability and cost of services, and what is deemed 'reasonable and necessary' use of NDIS funding. But these issues are being magnified by shrinking access to services and support outside the NDIS, and cost-shifting across governments and service systems.

We need coordinated and effective governance, funding to fix gaps in services, and robust evidence about where those gaps are.

Coordinated, effective governance supporting community-driven action.

Evidence over the last decade suggests that people with disability need coordinated, effective and cohesive governance to drive inclusion across all levels of government and the community. Ministerial responsibility is currently split between people with disability who use the NDIS and people with disability who are outside the Scheme. There's no single portfolio or independent statutory body representing all Australians with disability or promoting universal design in policy and practice across government, as there is in Ireland (National Disability Authority 2020) and New Zealand (Whaikaha 2023), for example.

Drawing on both the Closing the Gap model and the Health in All Policies (HiAP) model, a **Disability Inclusion Agency could be established to represent the interests of all Australians with disability - inside and outside the NDIS - in government decision-making.** The agency should be led by people with disability, with a governance structure that includes people with disability and representatives from federal, state, territory and local governments.

The sustainability of the NDIS hinges on governments developing clear and mutually reinforcing legislative and policy levers to stamp out inequity for Australians with disability across the whole of society and the economy. This inequity includes the 'cliff' at the edge of the NDIS between support available to NDIS participants and those just outside the scheme.

Complications arise where the NDIS intersects with other service systems. Australia's Disability Strategy is charged with providing national leadership for greater inclusion, and driving mainstream services and systems to improve outcomes for people with disability (Australian Government 2021a:5), but there's little evidence of concerted reform to date (DANA et al 2023). It's unclear, for example, how ILC relates to Australia's Disability Strategy, both in aims and in practice. Astonishingly – given that the overwhelming majority of Australians with disability do not receive individual NDIS funding and could be driven into the Scheme if their needs are unmet - all references to the NDIS in both the Strategy and its Outcomes Framework are limited to individual NDIS funding and NDIS participants (Australian Government 2021a, 2021b).

The boundaries of the NDIS are complicated because there is no single definition of inclusion or disability to guide policy and practice across government and society. Current

arrangements effectively pit people with disability inside and outside the NDIS against each other for resources in a shifting authorising environment. This has serious implications for people with disability outside the NDIS, on three fronts:

1. governance of the disability service landscape, and the selection and use of policy levers to distribute and ration available public resources;

2. accountability for inclusion of people with disability in universal services, incentives for cost-shifting across service systems, and shifting risk and responsibility to service users to navigate disconnected systems and processes; and

3. systemic barriers to funding, designing and delivering hybrid disability services and universal services across jurisdictions and sectors, and finding economies of scale.

A **Disability Inclusion Agency** would be a touchstone of expertise in disability policy, practice and lived experience across government and be accountable for real change to address the huge inequalities for people with disability in society and the economy. Establishing this Agency will ensure that all people with disability – those who use the NDIS and those outside it - are transparently represented and included in decisions about policy that affects their lives.

To ensure the Agency is not an additional layer of bureaucracy in an already crowded field, it could incorporate the current Information, Linkages and Capacity Building program, the National Disability Data Asset, the National Disability Research Program, and assume responsibility for actioning Australia's Disability Strategy (ADS).

More research and investment is needed to explore the feasibility and effectiveness of hybrid service models at different life stages – early childhood, school years, preparing for and transition to work, working age, ageing and retirement - to respond flexibly to the support needs of people within and outside the NDIS, as well as opportunities to provide tapered transitional or bridging support between the NDIS and other service systems in certain circumstances.

People with disability and their representative organisations must be actively involved in deciding how resources intended to serve their interests are prioritised, applied and structured. Effective governance of 'Tier 2' must start with rebuilding trust between government and people with disability, demonstrating how evidence provided by people with disability and their families and carers is factored into decision-making, and ensuring that any reforms affecting their lives are codesigned, transparent, evidence-based, adaptable to a range of needs, and appropriately resourced.

Increased investment in inclusion

Over 90% of spending on disability related services and programs are now going towards

people eligible for the NDIS, leaving the 90% of those not in the NDIS with the remaining 10% of budgets across all levels of government.

To ensure the sustainability of the NDIS, **there must be focused and increased spending across the next decade** to build capacity and resources for people with disability across all public services.

There needs to be an investment in Tier 2, or ILC, proportionate to the amount spent on individualised funding packages through the NDIS, and at least ten times the current amount.

This ten-fold increase should:
- entail pooled investment from federal, state, territory and local government budgets, with linked KPIs, incentives for place-based collaboration, and return on investment calculated across service systems delivering disability, health, housing, justice, education, employment and income support services (Olney 2021);

- incorporate codesign and coproduction of a revamped and rebranded 'Tier 2' with people with disability and their advocates, delivered through a new Disability Inclusion Agency;

- encompass direct, time-limited investment in building **fully inclusive public services tied to social determinants of health**;

- address labour market disadvantage for Australians with disability of working age, particularly the 1.8 million who do not use the NDIS now;

- support ongoing data collection and analysis to understand and address both disability-specific and intersectional social and economic exclusion;

- support ongoing data collection and analysis to monitor and measure the impact of Tier 2 on the sustainability of the NDIS and Australia meeting its obligations under the UN CRPD; and

- drive whole-of-government cost/benefit analysis of universal design in public policy.

Using both the evidence collection and gap analysis, as well as the coordinated governance, this increased investment would provide targeted support across a wide range of services that would ensure that people with disability and their families were no longer experiencing significant disadvantage and marginalisation.

Strengthening the evidence base with citizen science

The NDIS Review is grappling with governance arrangements for Tier 2, because access to that level of support is critical to the sustainability of the NDIS. But a big challenge in

rethinking Tier 2 is that there's no single portfolio or independent statutory body representing all Australians with disability, capturing data on the service ecosystem, or promoting universal design in policy and practice across government. Australia's Disability Strategy lacks both teeth and resources to enforce structural and systemic change, and the National Disability Data Asset (NDDA 2023) has limitations for informing policy tied to inconsistent definitions of disability across service systems, challenges in capturing intersectional disadvantage faced by different groups of people with disability across service systems, and gaps in government data.

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" (NDIS 2021). Responsibility and accountability to bridge that gap is divided. The anticipated role of Local Area Coordinators as service connectors has not been realised. There is no consistent measurement or monitoring across government of service gaps or barriers to participating in or contributing to the community experienced by people with disability and their families and carers, and no effort to capture the experiences and knowledge of people with disability who rely on informal supports and are likely to be missing from government datasets driving policy reform and the allocation of public resources.

People with disability and their families can fill those evidence gaps, not by responding to endless calls for input into inquiries and reviews, but through **ongoing co-creation of knowledge using models like the CSIRO Citizen Science Principles (CSIRO 2020) or the European Citizen Science Association model (ECSA 2015).** While this approach is traditionally used to promote public participation and collaboration in scientific research, it could readily adapt to building an evidence base for policy.

Evidence-building in real time about what services and support Australians with disability need at different life stages, and what is available to them where they live, could drive investment and reform across governments, and spark solutions involving a range of stakeholders and resources.

Beyond that, the 'ecosystem' of support for Australians with disability should be underpinned by whole-of-government commitment to ensure they can access public services on an equal basis with every other citizen, with measurable accountability across government portfolios under agreed domains and timeframes. Under the umbrella of Australia's Disability Strategy, this could become a whole-of-government mechanism for **mapping inclusion across publicly funded service systems**, identifying whether existing data can identify critical risks and opportunities in that environment and where data collection and analysis could be strengthened, flagging service gaps and barriers to inclusion at local, regional and national levels across jurisdictions impacting on social determinants of health, building shared understanding across government of key leverage points for action and investment, and rewarding Ministers and their departments for marshalling resources for collective action instead of shifting the problem elsewhere.

Ongoing data collection from people with disability and mapping of service gaps should begin on completion of the NDIS Review.

We propose a three-layered strategy for implementing it:

1. Given that Tier 2 is a **critical component** of the NDIS insurance model, to delay, reduce or prevent people with disability needing individual funding packages, the NDIA should lead the call for ongoing place-based data and local intelligence on service gaps and barriers to inclusion encountered by all people with disability and their families and carers, through LACs. This data would feed directly into the National Disability Data Asset (NDDA), rounding out aggregated government datasets.

2. The citizen science tool itself should be a codesigned, joint initiative between disability advocacy organisations, universities and government. It could be led by DANA, in partnership with (for example) the AIHW, the ABS, and/or the Melbourne Institute, to leverage on existing infrastructure with enhanced accessibility. Its value would extend well beyond the NDIS. Capturing place-based, timely data on service gaps impacting on social determinants of health for people with disability and their families and carers will contribute to broader understanding of poverty and inequality in Australia. It will also illuminate the intersectional nature of disability and chronic illness.

3. The pilot phase of the National Disability Data Asset is now complete. The Australian Government and state and territory governments are working on the design of the enduring asset, in consultation with people with disability and the broader disability community (NDDA 2023). This presents an immediate opportunity to embed a citizen science mechanism into the Australian National Data Integration Infrastructure (ABS 2023), to fill data gaps and inform planning for the both the NDIS and Australia's Disability Strategy.

What could be offered under Tier 2?

The increased investment in Tier 2 will need careful co-design with people with disability, but there are some obvious areas where the gaps are well understood. These fall generally into two distinct areas – increased disability services outside the NDIS, and increased inclusion in mainstream services and the community.

Broaden access to low-level disability services and support

Many people with disability or chronic health conditions   are ineligible for NDIS funding, and yet need some disability support services. These services are becoming increasingly difficult for them to access, either priced out of reach or unavailable. Tier 2 investment could support flexible models of home and community care in different communities for people aged under 65 years at well below the cost of annual individual NDIS funding packages.

A relatively low investment in home help and community care could assist in keeping people out of the health system and living independently and delay their need to access specialist disability support. This investment could also support community engagement activities in community and neighbourhood centres, libraries, sports clubs and other local community platforms.

Tier 2 investment could also support broader access to low cost or free allied health through Primary Health Networks, community health facilities and Aboriginal Medical Services and Aboriginal Community Controlled Health Organisations. This model could be tailored to the needs and circumstances of different populations and communities, for example, increasing access to speech therapy for children, physiotherapy for people with disability, exercise programs, and occupational therapy to assist people in their homes. These services are currently out of financial reach for most people with disability and their families. This investment could delay, reduce or prevent the need for people to seek individual support through the NDIS, hospitals and aged care.

Increased access to mainstream services

Significant additional short- to medium-term investment is needed to ensure inclusion of people with disability in services and activities available to all other Australians.

This could range from investment at a local government level to improve the built environment to promote access for people with disability, to a **fixed-term intensive uplift in resourcing** to help universal systems like early childhood services, education, health, employment services, transport and aged care to transition to include people with disability on an equal basis with other citizens. Improving access to employment for people with disability would be an important component of this work.

The proposed Disability Inclusion Agency, supported by pooled investment from federal, state, territory and local government budgets, could drive this development of fully inclusive public services and public spaces, and support ongoing data collection and analysis to understand and address both disability-specific and intersectional social and economic exclusion.

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