



Submission to the Standing Committee on Health, Ageing and Community Services

Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT

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About us

The Public Service Research Group at UNSW Canberra⁴ and the Centre for Social Impact at UNSW⁵ have a longstanding commitment to researching public service markets and personalised care systems in Australia and overseas. Associate Professors Dickinson and Carey are Chief Investigators in the Centre of Research Excellence in Disability and Health⁶ funded by the National Health and Medical Research Council (NHMRC) and our portfolio of work includes a number of research projects investigating various aspects of the NDIS. Our research underpins this submission in response to the second of the Committee's terms of reference - (b) *Practical outcomes of implementation in relation to disability workforce development strategies; the Human Services Registrar; the availability of services for eligible NDIS participants; the availability of early childhood intervention services; the implementation of local area coordination; and supports for people with psycho-social disabilities* – focusing on the availability of services for eligible NDIS participants and the implementation of local area coordination.

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Overview of our submission

The National Disability Insurance Scheme (NDIS) promises a different way of designing and delivering disability services, one firmly committed to equity, self-directed support and service user choice and control. Although many participants report that they are satisfied with the NDIS,⁷ adverse experiences of the care planning process and variable access to services and resources under the scheme are well-documented.⁸ Teething problems can be expected in a reform of this magnitude enacted and implemented in a tight timeframe, but our research reveals deeper issues at play in the gap between some participants' expectations and experiences of the NDIS to date.⁹ The scheme's rollout is outpacing the readiness of people with disabilities, disability service providers, local area coordinators and the National Disability Insurance Agency to achieve its stated aims, and its sustainability hinges on its interface with mainstream public and community services, which is a minefield of competing priorities and jurisdictional ambiguities across federal, state, territory and local government.

Focusing on the **availability of services for eligible NDIS participants** and the **implementation of local area coordination**, our submission addresses the second of the Committee's terms of reference:

(b) Practical outcomes of implementation in relation to disability workforce development strategies; the Human Services Registrar; the availability of services for eligible NDIS participants; the availability of early childhood intervention services; the implementation of local area coordination; and supports for people with psycho-social disabilities.

In brief, we recommend providing clearer information about 'who should supply what' to people with disabilities so they can make informed choices about their care; ensuring local area coordinators understand disability and the local service environment and are better equipped to develop viable plans to help people with disabilities to achieve their goals; building a coherent regulatory regime that rewards collective-action solutions and partnerships between disability services and complementary services focused on consumer-centred support; and encouraging and supporting a diverse range of service providers to support people with disabilities in their local community. The rationale for these recommendations is provided below.

Issues

The availability of services for eligible NDIS participants

In 2017 we released a report on the findings of our research into *Choice, control and the NDIS: Service Users' Perspectives on Having Choice and Control in the New National Disability Insurance Scheme*.¹⁰ The project's participatory and multidisciplinary research method gives unique insight into the evolution of the scheme, and how it is translated from policy into practice in different contexts, from the perspective of participants in one of the NDIS trial sites. Many people involved in that study told us they were unable to find and access services approved in their plan. This emerged as a significant issue in negotiating annual plans, where participants cited examples of requests for funding being declined on the basis that funds previously allocated for similar items had not been spent. Underutilisation of agreed services, equipment and support was particularly prevalent among participants living in regional areas

⁷ <https://www.ndis.gov.au/medias/documents/h91/hbc/8805559468062/Report-to-the-COAG-Disability-Reform-Council-for-Q1-of-Y5.pdf> p.4

⁸ Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs* <https://www.pc.gov.au/inquiries/completed/ndis-costs/report>

⁹ For example: Carey G, Dickinson H, Malbon E & Reeders D (2018) 'The Vexed Question of Market Stewardship in the Public Sector: Examining Equity and the Social Contract through the Australian National Disability Insurance Scheme', *Social Policy and Administration*, vol. 52, pp. 387 - 407, 10.1111/spol.12321; Carey G, Malbon E, Olney S & Reeders D (2018) 'The personalisation agenda: the case of the Australian National Disability Insurance Scheme', *International Review of Sociology*, vol. 28:1, pp. 20-34, DOI: 10.1080/03906701.2018.1425084; Warr D, Dickinson H, Olney S, Karanikolas A, Peters D, Katsikis G, Wheeler J, Ozge J, Hargrave J, Wilcox M & Kasidis V (2017) *Choice, Control and the NDIS: Service Users' Perspectives on Having Choice and Control in the New National Disability Insurance Scheme*. Melbourne: University of Melbourne; Dickinson H & Carey G (2017) 'Managing care integration during the implementation of large-scale reforms: The case of the Australian National Disability Insurance Scheme', *Journal of Integrated Care*, vol. 25, pp. 6 - 16, 10.1108/JICA-07-2016-0026

¹⁰ Warr D et al (2017) http://socialequity.unimelb.edu.au/data/assets/pdf_file/0010/2364499/Choice-Control-and-the-NDIS-Report-Melbourne-Social-Equity-Institute.pdf

or those needing highly specialised services and supports – ‘thin markets’ of limited appeal to providers of goods and services seeking economies of scale. However, the supply side of the equation was not the only issue. Our research also revealed that some participants were ill-equipped to push for new services or to utilise different services, either because they could not access information about their entitlements in a form that suited their needs and circumstances or because they were concerned about being labelled ‘difficult’. Furthermore, if their health and wellbeing fluctuated over the life of their plan, as is common among people with both physical and psychosocial disabilities, they only needed some services, equipment and support on an ad hoc basis. This scenario generated anxiety among some participants about the future consequences of not having access to required services. Others were concerned about rising costs for the same services after transitioning into the scheme: “[My daughter] is getting more money but the service really is just about the same...Everything’s costing more than it was before because her program hasn’t changed a whole lot.”¹¹

Rather than one national market, the NDIS relies on many local markets reflecting and responding to geographic and consumer diversity. The challenge of structural adjustment in these markets is compounded by factors like cultural and linguistic diversity, and scattered demand for highly specialised services. In rural and remote areas, the reform of disability services is further complicated by changes to complementary community care roles, for example aged care, which will reduce local service providers’ potential to find economies of scale. These local markets are highly susceptible to failure due to difficulty in planning and budgeting with variable income and retrospective payment for services delivered. This risk is predictable, and it was mooted in the initial report recommending the NDIS that “there may still be a role for some block funding where markets would otherwise not support key services.” The Linkages and Capacity Building (ILC) component of the NDIS is intended to prevent inequities between areas and/or groups by supporting communities and mainstream services to become more inclusive, but concerns have been raised about the capacity of those responsible for delivering ILC supports - local area coordinators – to manage the potential workload. This is discussed in the section below examining local area coordination.

The NDIA is confronted with a ‘chicken and egg’ problem as it rolls out nationally – to implement without the markets in place; or try to generate new market arrangements and then push towards implementation of care packages. In our research into markets in the NDIS, we found that policymakers hope that choice will increase over time, as participants become more sophisticated in understanding what the NDIS is and how they can use it and as the market becomes more innovative and responsive, so the aims of the NDIS can be realised.¹² However, coevolution might be better supported by allowing policymakers to have a greater role in shaping the market and to push the boundaries between services. This points to the need for government to clarify what role it will play in the development and management of disability markets, and where responsibility for stewardship of services accessed by people with disabilities should lie. If the aim of the NDIS is to empower people with disabilities through choice and competition, it must acknowledge that not all individuals will have access to robust or functioning markets in which to exercise this control. Currently, there is a risk of two schemes emerging – one in urban areas with robust markets, and a second, lesser scheme subsidised by government in rural and remote areas that will offer little choice and control to people struggling with multiple forms of disadvantage.

The implementation of local area coordination

Our research reveals lack of clarity in the operational boundaries of the NDIS and how it works with other services in the provision of seamless and consumer-direct care,¹³ despite principles to determine the responsibilities of the NDIS and other service systems having been agreed by the Council of Australian Governments in 2015.¹⁴ As the scheme rolls out, we are detecting the sorts of ‘buck-passing’

¹¹ Warr et al (2017) p.28

¹² Carey G, Dickinson H, Malbon E & Reeders D (2018) ‘The Vexed Question of Market Stewardship in the Public Sector: Examining Equity and the Social Contract through the Australian National Disability Insurance Scheme’, *Social Policy and Administration*, vol. 52, pp. 387 - 407, 10.1111/spol.12321

¹³ Carey G et al (2018)

¹⁴ COAG (2015) *Principles to Determine the Responsibilities of the NDIS and Other Service Systems* <https://www.coag.gov.au/sites/default/files/communique/NDIS-Principles-to-Determine-Responsibilities-NDIS-and-Other-Service.pdf>

tendencies between mainstream and NDIS services that have been observed in the English context.¹⁵ This issue is compounding as local area coordinators are under pressure to meet exacting targets to sign people on to the NDIS and develop plans for those participants, which comes at the cost of time to invest in local service coordination and capacity building. Our research also reveals frustration among NDIS participants about staff turnover in the NDIA and local area coordinators and having to deal with workers in the planning process who have varying levels of familiarity with disability and disability services and support.¹⁶ One person involved in the *Choice, control and the NDIS* study had six case workers over the trial period.¹⁷ This churn and lack of knowledge at the coal face diminishes trust in the scheme when people first interact with it, and trust is hard to regain once lost.

The NDIS promises participants choice and control in planning their care, but their options for support are bounded by cost-benefit analysis and discretionary decision-making on the part of the scheme's care planners. Local area coordinators are charged with helping people with disabilities navigate the service system, but their capacity to understand the individual needs and preferences of the rapidly growing number of participants and the complex local service environment is limited. Our research reveals that participants who understand the logic of meetings, budgets and liaising with professionals – usually linked to their professional experience - are more confident and assertive in their interactions with the NDIS and local area coordinators than participants who have limited exposure to these kinds of processes.¹⁸ Access to computers, the internet and other material and digital resources also enable some participants to research and identify options to achieve their goals, while others are left in the dark. The onus is on participants to understand the options available to them. *“If you did not know the jargon you virtually got zilch”*, one person involved in the *Choice, control and the NDIS* study told us.¹⁹ Another said *“You go to these planning meetings and nothing's presented. It's only what you are prepared to ask for.”*²⁰

The complexity of the service system and the need to synthesise complex information about administrative procedures and service providers means that many participants - particularly if they do not have access to informal sources of support from families and carers - struggle to access, process and apply this information. This inequity raises practical and ethical questions that are largely unaddressed in the scheme's design and implementation, especially in relation to local area coordination and care planning. Yet even those who put significant effort into preparing for planning meetings including sourcing reports from doctors and therapists, can come away confused and unhappy.²¹ Describing the process, one NDIS participant told us *“They tell you one thing, write down another thing and you get something else.”*²² Another showed us large ring binders of letters, forms, reports and notes – a fraction of the amount of paperwork the scheme generated.

The NDIS promises participants choice and control in planning their care, but their options for support are bounded by cost-benefit analysis and discretionary decision-making on the part of the scheme's care planners. The scheme's firm stance that it will not fund support that should be offered to people with disabilities by mainstream public services is complicated by variations in the funding and organisation of non-NDIS supports across jurisdictions. This challenge is not unique to the NDIS, but it has significant ramifications in this case. The scheme's emphasis on “mainstream interface” and the 2017 review of its costs flag a need for it to work across service boundaries to achieve its aims.²³ Clarifying ‘who supplies what’ to people with disabilities is a lingering challenge for the NDIS and Australian federal and state governments more broadly, and it is unreasonable to expect NDIS participants to ‘navigate’ their way around it. The local area coordinators must be better equipped to

¹⁵ Glendenning C, Nicola M, Challis D, Fernandez J, Jacobs S, Jones K, et al. (2011) ‘Personalisation and partnership: competing objectives in English adult social care? The individual budget pilot projects and the NHS.’ *Social Policy & Society* 10(2):151-62.

¹⁶ Warr et al (2017) p.28-29

¹⁷ Warr et al (2017) p.29

¹⁸ Warr et al (2017) p.47

¹⁹ Warr et al (2017) p.27

²⁰ Warr et al (2017) p.27

²¹ <https://www.arennews.com.au/story/5268841/disabled-people-to-be-excluded-from-griffith-community-transport/>

²² Warr et al (2017) p.34

²³ Productivity Commission (2017) National Disability Insurance Scheme (NDIS) Costs <https://www.pc.gov.au/inquiries/completed/ndis-costs/report> p.2

understand the needs and preferences of people with disabilities, and to understand and be able to explain the service system to those who rely on it.

Our recommendations

1. Clarify 'who is responsible to supply what' to people with disabilities at an operational level, and ensure this information is publicly available and in formats accessible to people with a range of disabilities in the NDIS planning process. The scheme's firm stance that it will not fund activities and support that should be offered to people with disabilities by mainstream public services is complicated by variations in the availability, funding and organisation of these services across state, territory and local government jurisdictions. This should be acknowledged and addressed in assessing what constitutes 'reasonable and necessary' support for NDIS participants in the planning process.
2. Ensure local area coordinators are equipped to develop viable plans for people with disabilities, reflecting the individual needs and preferences of NDIS participants and the capacity of the local service environment to respond to those needs.
3. Build a coherent regulatory regime that rewards collective-action solutions and partnerships between disability services and complementary services focused on consumer-centred support.
4. Encourage and support a diverse range of service providers in the market to minimise risk of oligopolistic practices and/or exploitation and neglect of people with disabilities in thin markets. Levers for this include incentives for remote, niche and/or non-profit providers and firms employing people with disabilities to enter and remain in the market; a system of soft checks to identify supports that providers in thin markets may need to stay in business; and the use of discrete seed funding and grants for types of service provision identified as thin markets.