



Submission to the Joint Standing Committee on the NDIS

Market Readiness for the National Disability Insurance Scheme

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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. We welcome the opportunity to contribute to the Committee's inquiry into market readiness for the scheme.

In 2017 we released a report on the findings of our research into *Choice, control and the NDIS*.⁷ A key feature of this project was the participatory and multidisciplinary research method applied to gathering, analysing and presenting data on service users' perspectives of having choice and control in the NDIS in one of its trial sites.⁸ This approach gives unique insight into the evolution of the scheme from the perspective of participants, and how policy decisions are translated into practice in different contexts. This evidence, together with findings of other recent research projects, underpin our comments on the following terms of reference for the Committee: participant readiness to navigate new markets; the role of the NDIA as a market steward; and market intervention options to address thin markets.

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⁵ <http://www.csi.edu.au/>

⁶ <http://credh.org.au/>

⁷ 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
http://socialequity.unimelb.edu.au/_data/assets/pdf_file/0010/2364499/Choice-Control-and-the-NDIS-Report-Melbourne-Social-Equity-Institute.pdf

⁸ <http://socialequity.unimelb.edu.au/news/news-archive/NDIS-research-presented-to-MPs>

Summary and recommendations

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,⁹ adverse experiences of the care planning process and highly variable access to services and resources under the scheme are well-documented.¹⁰ Teething problems are to be expected in a reform of this magnitude enacted and implemented in a tight timeframe, but our research suggests there are deeper issues at play in the gap between participants' expectations and experiences of the NDIS to date.¹¹ The scheme's rollout is outpacing the readiness of service users, service providers and the agency charged with implementing it 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.

Our submission addresses the following terms of reference from the Committee:

- participant readiness to navigate new markets;
- the role of the NDIA as a market steward;
- market intervention options to address thin markets (excluding advice on remote Indigenous communities).

Our recommendations

1. Rather than focusing on the capacity of participants to navigate complex systems, make information about new markets and NDIS resources and processes more intuitive, transparent, streamlined, and more accessible for people with limited resources and/or limited decision-making support.
2. Give due consideration to participants' preferences in the care planning process and ensure that assessment of what is reasonable and necessary to fund from their preferences is transparent, clearly explained and well-documented.
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 could 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.

⁹ <https://www.ndis.gov.au/medias/documents/h91/hbc/8805559468062/Report-to-the-COAG-Disability-Reform-Council-for-Q1-of-Y5.pdf> p.4

¹⁰ Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs* <https://www.pc.gov.au/inquiries/completed/ndis-costs/report>

¹¹ For example: Warr et al (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; Carey G, Dickinson H, Malbon E & Reeder 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; 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 .

Participant readiness to navigate new markets

Issues

The NDIS aims to increase both the funding available for disability services and support, and the control that people living with disabilities have over the design and delivery of their care. The first object of the NDIS Act is to give effect to Australia's obligations under the Convention on the Rights of Persons with Disabilities, and the case for creating the scheme was underpinned by evidence that Australian disability services were not up to that task.

The rise of markets and personalisation in public services is based on the assumption that these approaches are more efficient and effective than universal, state-provided services, and improve citizen's welfare by empowering them to choose and shape the public services they need.¹² However there is mounting evidence that markets, particularly in social services, can exacerbate inequality, generating significant flow-on costs.¹³ In *Choice, control and the NDIS*, participants' stories of general difficulties they experienced in navigating the NDIS system highlighted the ways in which factors that drive inequities, such as age, gender, socioeconomic status, residential location, and household structure, operated as fault lines in the system by constraining potential for choice and control. These issues were rarely directly raised in participants' accounts, but surfaced in discussions of related issues. For example, one participant observed that the concept of choice is more familiar to individuals encouraged and accustomed to making decisions based on their personal preferences:

*A lot of families of people with disabilities didn't really seem to know actually what they want to do because they're not practiced at making choices, or making real choices. They're practiced at making choices from what's available, but not necessarily saying, 'I don't like anything that you've got available for me, this is what I want 'cause that's what will make a difference to my quality of life.'*¹⁴

More broadly, participants who understood the logic of meetings, budgets and liaising with professionals – usually linked to their professional experience - were more confident and assertive in their interactions with the NDIS than participants who had limited exposure to these kinds of processes. Access to computers, the internet and other material and digital resources also enabled some participants to research and identify options to achieve their goals, while others were left in the dark. “*If you did not know the jargon you virtually got zilch*”, one participant said.¹⁵ This inequity raises practical and ethical questions that are largely unaddressed in the scheme's design and implementation.

Whatever their circumstances, most participants involved in the study described some gap between their expectations about choice and control and the reality of navigating the NDIS. For those who had campaigned for reform in the lead-up to the NDIS, this was disappointing:

*I reckon we were at a meeting every fortnight about NDIS and NDIA and what it was going to be...with our campaign red t-shirts on, banging things and marching up and down saying, 'This is what we want!' And then it slightly changed from you will get everything and then it was, what is reasonable and appropriate and within reason? All those words suddenly started appearing.*¹⁶

Some participants said that the NDIS offered a clearer and less complicated pathway for integrating services than they had previously experienced, and provided more funding. However, others reported incidents that suggested the scheme had created a new complex system with numerous chances for miscommunication and/or breakdown in continuity of care. The complexity of the service system and the need to synthesise complex information about administrative procedures and service providers

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 Smyth P, Malbon E & Carey G (eds) (2016) *Social Service Futures and the Productivity Commission*. UNSW Canberra & Power to Persuade: Canberra

¹⁴ Warr et al (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 p.46

¹⁵ Warr et al (2017) p.27

¹⁶ Warr et al (2017) p.50

meant that many participants - particularly if they did not have access to informal sources of support from families and carers - struggled to access, process and apply this information. *"With my reading and all that, it's pretty hard. I don't understand a lot of stuff. I'm just thinking, 'Right, that's it, I'm taking that in for you guys [a case manager] to fill in."*¹⁷ Others, however, put significant effort into preparing for planning meetings including sourcing reports from doctors and therapists, and came away confused and unhappy. Describing the process, one participant told us *"They tell you one thing, write down another thing and you get something else."*¹⁸ Another brought large ring binders of letters, forms, reports and notes to show us 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.¹⁹ 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.

How these issues might be addressed

- Rather than focusing on the readiness and capacity of participants to navigate complex systems, make information about the new market and NDIS resources and processes more intuitive, transparent, streamlined, and more accessible for people with limited resources and/or limited decision-making support.
- Give due consideration to participants' preferences in the care planning process and ensure that assessment of what is reasonable and necessary to fund from their preferences is transparent, clearly explained and well-documented.

The role of the NDIA as a market steward

Issues

Our research has shown that there is a lack of clarity in the boundaries of the NDIS and how it will work with other services in the provision of seamless and consumer-direct care.²⁰ As the scheme rolls out, we are detecting the sorts of 'buck-passing' tendencies between mainstream and NDIS services that have been observed in the English context.²¹

Choice, control and the NDIS revealed frustration among participants about staff turnover in the NDIA and having to deal with new planners who had varying levels of familiarity with disability services, with one participant having six case workers during the trial period.²² Another said there was *"a gaping hole between what senior bureaucrats and government think is happening and what's actually happening on the ground."*²³ This diminishes trust in the scheme when people first interact with it, and trust is hard to regain once lost.

¹⁷ Warr et al (2017) p.35-36

¹⁸ Warr et al (2017) p.34

¹⁹ Productivity Commission (2017) National Disability Insurance Scheme (NDIS) Costs <https://www.pc.gov.au/inquiries/completed/ndis-costs/report> p.2

²⁰ 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

²¹ Glendinning 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.

²² Warr et al (2017) p.29

²³ Warr et al (2017) p.36

Participants in our study accepted the need to account for expenditure of public funding, but most felt that accountability requirements for NDIS funds were disproportionately expensive and time-consuming. They cited examples of purchases of small items like a footrest or shoes being mired in an expensive assessment and approval processes. Their insights suggest that it may be more efficient, both for participants and the NDIS, if requests for funds under a certain amount, or requests for equipment where the need is clearly self-evident, could be approved without assessment by health professionals.²⁴ Building scope to respond to unanticipated contingencies into planning processes would also enhance overall efficiency without compromising the integrity of the scheme.

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.²⁵ . 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.

How these issues might be addressed

- Build a regulatory regime that rewards collective-action solutions and partnerships between disability services and complementary services focused on consumer-centred support.

Market intervention options to address thin markets (excluding advice on remote Indigenous communities)

Issues

Many participants in our *Choice, control and the NDIS* study found that 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 evident among participants living in regional areas or those needing highly specialised services and supports - 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.

Rather than one national market, the NDIS requires many local markets that account for geographic and consumer diversity. Developing these markets in culturally and linguistically diverse communities with potentially low prevalence of particular types of disability will be challenging. In rural and remote areas, thin markets will be complicated by changes to other community care roles, for example aged care, which will reduce local providers' potential to find economies of scale. These areas are highly susceptible to market 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

²⁴ Warr et al (2017) p.46,52

²⁵ 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

would otherwise not support key services.”²⁶ 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. However, concerns have been raised about the capacity of those responsible for delivering ILC supports - Local Area Coordinators – to manage the potential workload.

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.

How these issues might be addressed

- 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 could 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.

²⁶ Productivity Commission (2011) *Disability Care and Support: Productivity Commission Inquiry Report*. Report no. 54. page 471 <https://www.pc.gov.au/inquiries/completed/disability-support/report>.