



Submission to the Joint Standing Committee on the NDIS

NDIS Planning

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About us

The Public Service Research Group at UNSW Canberra¹ has a longstanding commitment to researching public service markets and personalised care systems in Australia and overseas. We welcome the opportunity to contribute to the Committee's inquiry into NDIS planning.

Professor Helen Dickinson² and Dr Sue Olney³ have researched various aspects of the NDIS, including participants' experiences of the scheme during its trial phase in the study *Choice, control and the NDIS*.⁴ A key feature of that study 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,⁵ which provided unique insight into the scheme's planning process from the participants' angle. The findings of that study, together with other relevant research⁶, underpin this submission.

¹ <https://www.unsw.adfa.edu.au/public-service-research-group/>

² <https://research.unsw.edu.au/people/professor-helen-dickinson>

³ <https://research.unsw.edu.au/people/dr-sue-olney>

⁴ 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

⁵ <http://socialequity.unimelb.edu.au/news/news-archive/NDIS-research-presented-to-MPs>

⁶ Olney S & Dickinson H (2019) 'Implementing the Australian National Disability Insurance Scheme: implications for policy and practice', *Policy Design and Practice*
<https://www.tandfonline.com/doi/full/10.1080/25741292.2019.1586083>; Devine A; Dickinson H; Brophy L; Kavanagh A; Vaughan C, 2019, "I don't think they trust the choices I will make' – Narrative analysis of choice and control for people with psychosocial disability within reform of the Australian Disability Employment Services program", *Public Management Review*, <http://dx.doi.org/10.1080/14719037.2019.1648700>; Data Governance and the NDIS <https://www.disabilityinnovation.unsw.edu.au/research/data-governance-and-ndis>

Submission summary and recommendations

Although many participants report that they are satisfied with the NDIS,⁷ adverse experiences of the scheme's planning process are well-documented.⁸ It is reasonable to expect problems in the early stages of a reform of the magnitude of the NDIS rolled out in a tight timeframe, and changes have already been made in response to issues identified in participant pathways into and through the scheme.⁹ However, research suggests there is still a gap between participants' expectations and experiences of the NDIS planning process, and unequal outcomes based on participants' capacity to navigate the planning process.¹⁰ Both issues have flow-on social and economic costs.

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

- the experience, expertise and qualifications of planners;
- the ability of planners to understand and address complex needs;
- the adequacy of the planning process for rural and regional participants

Our recommendations:

1. Planners should have a strong commitment to working respectfully with people with disabilities and their families and carers, and capacity to understand their diverse goals, needs and circumstances.
2. Planners should be equipped to understand the local service environment and developments in the field of disability care and support.
3. Assessment of what is reasonable and necessary to fund from participants' preferences raised in the planning process should be transparent, clearly explained and well-documented.
4. Planners should ensure participants know how and where to access services and support included in their NDIS plans.

⁷ <https://www.ndis.gov.au/news/1001-ndis-participant-satisfaction-hits-93-cent>

⁸ Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs* <https://www.pc.gov.au/inquiries/completed/ndis-costs/report>; Morton, R. 2018. 'NDIS legal bill hitting \$10m a year' *The Australian* 17 May 2018 <https://www.theaustralian.com.au/nation/health/ndis-legal-bill-hitting-10m-a-year/news-story/c048d6028a8363597a30115d3cdb921f>

⁹ NDIS pathway reform <https://www.ndis.gov.au/about-us/ndis-pathway-reform/pathway-reform-whats-happening-2019>

¹⁰ Malbon E; Carey G; Meltzer A (2019) 'Personalisation schemes in social care: Are they growing social and health inequalities?', *BMC Public Health*; Olney S & Dickinson H (2019) 'Implementing the Australian National Disability Insurance Scheme: implications for policy and practice', *Policy Design and Practice* <https://www.tandfonline.com/doi/full/10.1080/25741292.2019.1586083>; Devine A; Dickinson H; Brophy L; Kavanagh A; Vaughan C, (2019), "I don't think they trust the choices I will make' – Narrative analysis of choice and control for people with psychosocial disability within reform of the Australian Disability Employment Services program', *Public Management Review*, <http://dx.doi.org/10.1080/14719037.2019.1648700>; 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 & 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; 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.

The experience, expertise and qualifications of planners

In our study of *Choice, control and the NDIS*,¹¹ participants described lack of clarity in the planning process, particularly in relation to planners' assessment of what was 'reasonable and necessary support' for them. Many said that planners making decisions about their funding lacked understanding of their disability and failed to consider their preferences. Examples include:

*Our first case worker had never done work with disabilities before. Had no knowledge of what could be given, what was required – a person with a disability required. She did not last long.*¹²

*I brought in hospital files, the whole medical background, very organised, different files for different things, and at the end of the interview this planner said, "Has anyone ever suggested [a different diagnosis]?" ... you feel like you have been talking to a brick wall. There were quite a lot of problems that went on and I thought is this a personal thing between me and the planner or is this actually that this planner has just not got a clue?"*¹³

*When they were giving me another planner, I said, 'I want to know whether this planner has any understanding of [my specific disability].' They said I wasn't allowed to ask that question.*¹⁴

*My first experience with NDIS, I had a planner who didn't listen to me. Still to this day, on the plan there is something in there for [my teenage son] to play [a particular sport]. [My son] doesn't play sport. [The planner] seemed to have it in his head that he needs to play sport... I just thought, well, there were some things that he did that were good, but what I found was the most difficult part was not having someone setting it up for me. They organised this wonderful plan with all this funding and it was going unused because I didn't know where to start.*¹⁵

*In the first planning phase we probably knew more than the planners did. That was our experience. Things like when I said, "You'll have to put something in her plan to cover her transport because she'll use the mobility allowance," they looked at me like I was an idiot and said, "No, she won't." I said, "Yes, I believe she will." Then they had to get back to me later on and say, "You were right. We didn't know that." There's a lot of things that the planners initially didn't really know.*¹⁶

*...when we go into a plan, we do a lot of preparation with our therapists. Hours and hours of talking about what do we need for the next 12 months, what are we going to forecast, what shall we ask for in terms of therapy hours and time. They do a lot of research at their end, go to a lot of effort. We put together the therapy reports and also my husband and I sit down together and we talk about it as a family...what I find really frustrating is you sit there and you have an hour chat with the planner and they sit there saying they get it, they sit there jotting notes. Then they give you a plan... [Our planner said] "I felt that the goals the therapist were working towards overlapped, so I felt that you did not need that many hours with your therapist.' That was it. She moved to another job. So, I could not get any more information. I said, I would really like to know how you have worked it out. What is the frequency of therapy? What are the goals you felt overlapped? How am I going to make this budget work for [my preschool aged son]? I just need more information. But there was no information to be given.*¹⁷

¹¹ 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

¹² Warr et al (2017) p28-29

¹³ *Choice, Control and the NDIS* interview #03

¹⁴ Warr et al (2017) p49

¹⁵ *Choice, Control and the NDIS* interview #08

¹⁶ *Choice, Control and the NDIS* interview #33

¹⁷ *Choice, Control and the NDIS* interview #02

Interviews in this study revealed widespread frustration with staff turnover and capability throughout the annual planning process.¹⁸ Some of these issues are already being addressed with the NDIS pathway reform, through staff training and provision of a consistent NDIS point of contact.¹⁹ This is a welcome development.

Planners' capacity to understand the individual needs and preferences of the rapidly growing number of participants and the evolving and complex service environment is limited. Research reveals that participants accustomed to the logic of meetings, budgets and liaising with professionals are more confident and assertive in their interactions with planners than participants who have had limited exposure to these kinds of processes, and tend to achieve better outcomes.²⁰ People with low socio-economic status are particularly disadvantaged in this process and this perpetuates inequality in the scheme.²¹ NDIS planners need skills to understand and address this inequality.

The ability of planners to understand and address complex needs

Participants' stories of difficulties they experience in the planning process highlight the ways in which factors that drive inequities in general - such as age, gender, health, ethnicity, education, socioeconomic status, residential location, and household structure – become fault lines in NDIS plans.²² The operational boundaries of the NDIS are still blurred despite principles to determine the responsibilities of the NDIS and other service systems having been agreed by COAG.²³ Clarifying 'who supplies what' to people with disabilities in mainstream services like health and education, or what is a 'primary disability' for participants with co-morbid conditions, are lingering challenges for the NDIS and Australian governments more broadly. **These should not be categorised as 'complex' needs - they are simply individual needs.** This is what the NDIS was designed to address.

Local area coordinators should be equipped to understand the diverse needs and preferences of people with disabilities, and to understand and be able to explain the service system to those who rely on it.

The adequacy of the planning process for rural and regional participants

Many participants in the *Choice, control and the NDIS* study said they were unable to access services approved in their plan, a finding consistent with the NDIS budget underspend.²⁴ This was a significant issue in negotiating annual plans, where participants cited examples of requests for funding being denied on the basis that funds previously allocated for similar items had not been spent.²⁵ Underutilisation of agreed services, equipment and support was prevalent in rural and regional areas.²⁶

In some rural locations, access to disability support has been complicated and sometimes made more expensive by reforms to other community services, which limit local providers' capacity to pass economies of scale on to service users. These locations are highly susceptible to market failure, a risk flagged in the initial Productivity Commission report recommending the creation of the NDIS.²⁷ If the aim of the NDIS is to give people with disabilities more control over their care and support through choice and competition, the planning process must acknowledge that not all individuals have access to robust or functioning markets in which to exercise this control.

¹⁸ Warr et al (2017) p.29

¹⁹ NDIS pathway reform <https://www.ndis.gov.au/about-us/ndis-pathway-reform/pathway-reform-whats-happening-2019>

²⁰ Warr et al (2017) p.47; Malbon E; Carey G; Meltzer A (2019) 'Personalisation schemes in social care: Are they growing social and health inequalities?', *BMC Public Health*

²¹ Warr et al (2017) p.27

²² Olney S & Dickinson H (2019) 'Implementing the Australian National Disability Insurance Scheme: implications for policy and practice', *Policy Design and Practice*
<https://www.tandfonline.com/doi/full/10.1080/25741292.2019.1586083>

²³ 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>

²⁴ <https://www.afr.com/politics/federal/ndis-underspend-to-be-1-6b-20190331-p519am>

²⁵ Warr et al (2017) p.45

²⁶ Warr et al (2017) p.8

²⁷ 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>.