# Submission to the Joint Standing Committee on the NDIS

## *NDIS ICT Systems*

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**About us**

The Public Service Research Group at UNSW Canberra[3] has a longstanding commitment to researching personalised care systems in Australia and overseas. Associate Professor Dickinson is a Chief Investigator in the Centre of Research Excellence in Disability and Health[4] funded by the National Health and Medical Research Council (NHMRC) and our portfolio of work includes research into various aspects of the National Disability Insurance Scheme. We welcome the opportunity to contribute to the Committee's inquiry into the scheme's ICT systems.

In 2017 we released a report on the findings of our research into *Choice, control and the NDIS.*[5] 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.[6] This approach gives unique insight into the scheme from the perspective of participants. This research underpins our comments on the following terms of reference for the Committee, with particular focus on the participant experience of the scheme's ICT systems: participant experiences of the MyPlace Portal; the appropriateness of the MyPlace Portal and agency facing IT systems; and the impact of ICT infrastructure on the implementation of the NDIS.

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[3] https://www.unsw.adfa.edu.au/public-service-research-group/
[4] http://credh.org.au/
[5] 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
[6] 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 have reported that they are satisfied with the NDIS,[7] adverse experiences of the scheme's care planning process and systems are well-documented.[8] Our research indicates that participants' online interface with the scheme is problematic, and flags significant equity issues surrounding the MyPlace Portal and the scheme's ICT infrastructure. Difficulties with technology described by participants in our research included understanding and navigating the system's portal; technical issues with the portal (for example being offline); and ability to access computers and/or the internet. We have quoted several NDIS participants involved in our research directly in this submission so their voices can be heard.

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

- participant experiences of the MyPlace Portal;
- the appropriateness of the MyPlace Portal and agency facing IT systems;
- the impact of ICT infrastructure on the implementation of the NDIS

Our recommendations

1. Involve participants and their support networks in designing their digital interface with the NDIS, drawing on evidence based co-design principles.
2. Acknowledge that some NDIS participants have limited means to access and navigate digital information and offer an alternative to online interface with the scheme.
3. Acknowledge the hidden costs of the NDIS ICT systems, particularly the significant investment of time, money and emotional effort required from NDIS participants and their support networks to acquire new skills and resources to enter and navigate the scheme.
4. Make information about the NDIS and its processes more intuitive, transparent, contextual, streamlined, and more accessible for people with limited time, limited resources, limited access to technology, those who lack trust in technology, and/or those with limited decision-making support.

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[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

**The MyPlace Portal**

*Issues*

A key reason for establishing the NDIS was to address the previous complexity and fragmentation of disability services. It is difficult to definitively answer whether the NDIS offers more streamlined processes and increased efficiency in allocating resources to support people with disabilities than previous arrangements, but we can provide insights into how participants and carers perceive the changes. In our research into participants' experiences of the NDIS in one of its trial sites - *Choice, control and the NDIS[9]* - we asked participants about changes to the system, communication processes, the NDIS portal, and how the NDIS operates alongside other mainstream services, as well as their perceptions of the scheme's efficiency.

While some participants in our study were satisfied with the support they received from care planners, others raised a host of concerns about the complexity of NDIS processes, including the MyPlace portal. Effective communication strategies are critical for complex systems to operate effectively. Access to computers, the internet and other material and digital resources enabled some participants to research and identify available opportunities for care and support, but others were excluded. In interviews for our study, participants raised numerous communication-related issues about the scheme, including difficulties in obtaining reliable and accurate information, communicating with the NDIS when issues arose, and using the MyPlace portal to view plans, keep track of budgets, request payments and manage services. Problems accessing the MyPlace portal led to difficulties in accessing care and resources, as well as frustration, stress and an increased administrative burden for service users and carers.

One participant offered insights into how some of these challenges unfolded in her situation:

> *I am not self-managed but I do get on [the portal] to show my supports left over and who has claimed when. They shut the [portal] down in the middle of June and it is still not back up and running. I cannot see what my son's plan is. He has had two more things approved. Cannot approve it until that MyPlace is up to date. The plan that is on there at the moment is only last year's balance and they have just made up completely different line items. It is just a mess. It is really frustrating. I did not want to self-manage because I thought I would struggle with the paperwork but at the moment I am self-managing because I need to keep a track of what we are missing out on, how we can make it up so that at the end of the plan you have not gone over or have got money left over. No one will return your emails, phone calls. Some people are on hold for four hours on the NDIS. It is a debacle. It is really frustrating. Also, in terms of the therapies provided, we have had two services cancelled so far because of the portal issues. Say for example our psych, who is based in Melbourne. Has not been rolled out there yet. Before they change the portal, could claim, no dramas whatsoever. Works in Geelong with another lady. That lady can claim. She cannot. So, she stopped all services in Geelong.[10]*

Issues with the portal were particularly prevalent in low-income households and we spoke to many participants, particularly those with cognitive disabilities and older parent-carers, who had limited or no access to mobile phones, other devices or the internet. An older parent had recently purchased an iPad at her own expense and was overwhelmed with the amount of information she had to process:

> *For people self-managing it's an awful lot of work and yet if we just let NDIS manage everything we don't know anything about it. Have you seen their portal system?… My IT skills aren't very good but I went to a meeting to try and learn a bit about it and this is what we were given [shows us a lengthy photocopied document]…It's 37*

[9] Warr D 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
http://socialequity.unimelb.edu.au/__data/assets/pdf_file/0010/2364499/Choice-Control-and-the-NDIS-Report-Melbourne-Social-Equity-Institute.pdf
[10] Warr D et al (2017) p37

> *pages with a step by step guide so it gives you some sense of - [interviewer: how complex it is!]. I'm not even sure if it's working 100 per cent. There's been a lot of trouble over it.[11]*

Another told us:

> *I never know how much I've spent because I can't access my portal because I don't have a computer and my mobile phone and home phone are incompatible to it. So, I couldn't tell you if I've spent $2,000 or $3,000.[12]*

For people in regional and rural Australia, the issue of access to the internet caused significant problems:

> *With our first plan, the planners came out to our house and did the planning meeting at home. I thought that was really important 'cause I needed them to understand that when you live in the country there's lots of issues that are not apparent if you live in a larger town. Things like transport and those things are an issue. They wanted to do everything on a computer with access to the internet. They soon found out that that doesn't happen in the country. There were some issues with accessing the tools that they needed to use because our internet service is so poor. We had to revert to using paper forms and taking notes.[13]*

Other people had difficulty using the portal because of their disability:

> *Interviewee: I'm fairly independent anyway so I just jump on the computer and figure it out. Yeah, it's all good. The only problem is that I have some difficulty in physically typing so that slows the process a little.*
> *Interviewer: You do have voice control though?*
> *Interviewee: I do but I'm not very efficient with it because the problem with Dragon Dictate is that you have to be able to spell in order to direct it and my spelling isn't particularly efficient… In my new NDIA stuff hopefully if it's approved we're getting some more consultancy with one of the Dragon providers to try and tidy it up… in my initial plan we meant that sort of stuff like IT related speech but the person that wrote the plan misinterpreted it as requiring a speech therapist which you can see for yourself is clearly not an issue.[14]*

Some participants who were not self-managing their plans had not accessed any information about the NDIS online, nor used the MyPlace portal:

> *Interviewer:    Have you checked out their website at all?*
> *Interviewee:    No.*
> *Interviewer:    Or tried to get information off the internet?*
> *Interviewee:    No. Not really.[15]*

Many complaints about the portal came from carers who had opted to self-manage because they felt sufficiently motivated and competent to take on the administrative tasks to assemble a suitable portfolio of services for a family member. Most participants who were self-managing their packages were parents of young children with disabilities. While they valued the opportunity to tailor a package of services and support that best meet the needs of their child, they reported that administrative requirements were onerous and time-consuming:

> *Working is something I really want to get back into and I will never be able to do the amount of hours a week that I did before. It is not something you can just sit down and the computer say on a Monday. I have thought this through really carefully.*

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[11] Warr D et al (2017) p38

[12] Warr D et al (2017) p44

[13] Interview transcript #33 *Choice, control and the NDIS* p3

[14] Interview transcript #4 *Choice, control and the NDIS* p8

[15] Interview transcript #34 *Choice, control and the NDIS* p8

> *Could I just do three hours on a Monday of NDIS admin, meaning contacting all these people and what is next on the thing. Could I do it like that? No. Because it is picking him up one day at two o'clock from school because this particular person cannot see him at 3:30 or four. They can only see him at 2:15 and they are only available on a Friday. I have to fit in with them in order to make sure he gets his thing.[16]*

Other participants had been cautioned against self-management and in some cases, advice against self-management came from service providers, posing a risk of conflict of interest. Generally, participants described complex systems, challenges accessing and understanding the volume of information required to make decisions, and difficulties navigating administrative requirements. This clearly disadvantaged some participants in exercising choice and control over their care because of the nature of their disability, while others were deterred by the administrative challenges and responsibilities in light of other demands on their time and resources. Many participants told us they felt that the administrative burden of the scheme outweighed its benefits and that the time and effort they put into meeting the scheme's requirements was unacknowledged and undervalued:

> *When we started with the NDIS, they lost all my paperwork twice and I had to fill it in a second time. I had to go to the doctor twice, and it was embarrassing that a government agency lost my paperwork. They were trying to blame me, but I sent it to them in the form that they sent it to me. It got sorted but it took six months.[17]*

**In brief, these are the key issues surrounding the NDIS ICT systems identified by participants in our research:**

- There is inequitable access to online resources and information about the NDIS, related to one or more of the following factors: people's disabilities, their support networks, their access to computers, their access to the internet, their level of education, their location, and their socio-economic status.

- The scheme's online systems are cumbersome, unreliable and counterintuitive.

- The administrative burden of entering and navigating the scheme, particularly for people self-managing their funding allocations, is onerous and underacknowledged.

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[16] Interview transcript #3 *Choice, control and the NDIS* p9
[17] Warr D et al (2017) p44