Public Service Research Group

Productivity Commission Submission on the NDIS

Submission to Productivity Commission on the NDIS by the Public Service Research Group (PSRG)

This submission is on behalf of the Public Service Research Group, University of New South Wales, Canberra.

The Public Service Research Group (PSRG) was established to partner with organisational clients to produce new insights into effective public service implementation and evaluation. We perform timely, high-quality and reliable research into public policy implementation. We bring a breadth of knowledge and a depth of experience to our work, taking an inter-disciplinary and inter-methodological approach that recognises the complexity of contexts and plurality of interests involved in any policy implementation.

Our research projects build local practice while advancing global knowledge. We enable independent practice and collaborative thinking, and provide educational activities that embed new policy and program implementation insights into practice settings. In doing so the CPSR is guided by five commitments:

- We use a recognition of the messy reality of implementation to inform our choices of different knowledge and tools to create novel insights
- We foster a holistic, system focused approach in all that we do, enabling a better understanding of the causes, rather than symptoms, of issues
- We engage in mutually beneficial relationships with partners, adopting an asset-based approach that enables the partner to achieve better outcomes and develop new capabilities
- We provide thought leadership and contribute to both local practice and global knowledge of public service delivery, implementation and evaluation

We are professionals who deliver projects in a timely, quality and reliable manner.

As part of our portfolio of work we have a number of research projects investigating various aspects of the National Disability Insurance Scheme (NDIS). The submission made here is based on these various research projects. We have provided responses to a number of the questions outlined in the issues paper.

Why are utilisation rates for plans so low? Are the supports not available for participants to purchase (or are there local or systemic gaps in markets)? Do participants not require all the support in their plans? Are they having difficulty implementing their plans? Are there other reasons for the low utilisation rates?

Our research into participants' experiences of the NDIS (1) revealed that in most cases where participants are not purchasing all of the support in their plans, it is because the market for those supports is not yet developed. Underutilisation of agreed services, equipment and support is particularly evident among participants living in regional areas 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 is not the only issue. Our research also found that some participants are ill-equipped to push for new services or to utilise different services, either because they cannot access information about their entitlements in a form that suits their needs and circumstances or because they are concerned about being labelled 'difficult'. Furthermore, if their health and wellbeing fluctuates over the life of their plan, as is common among people with both physical and psychosocial disabilities, they may only need some services, equipment and support on an ad hoc basis (1).

The NDIS is confronted with a 'chicken and egg' problem – 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 (2) we found that policymakers hope that "over time as participants become a bit more sophisticated in understanding what the NDIS is and how they can use it, and also as the market then becomes a bit more innovative and responsive, there'll be much more choice, so the aspirations of the NDIS can be realised". However, co-evolution might be better supported by allowing policymakers to have a greater role in shaping the market. This points to the need for government to become clearer about what role it will play in the development and management of disability markets (2).

Why are more participants entering the scheme from the trial sites than expected?

Based on anecdotal evidence, we believe that more participants are entering the scheme as they represent the un-identified unmet need in local areas. In some cases we have been told that individuals were not known to services previously because they believed there was little available for people such as them within previous services. The advent of the NDIS and the attendant publicity that the scheme garnered raised expectations about disability services and suggested to individuals and families that there might be something available to them and of sufficiently high quality to motivate them to make contact with the NDIA.

Our research into participants’ experience of the NDIS suggests that the scheme’s emphasis on early childhood intervention is a key driver of increased uptake of services in trial sites. We found that parents of young children tended to have high expectations of the NDIS, were well-informed, and were strongly motivated to obtain comprehensive packages of services and support (1)

Is the current split between the services agreed to be provided by the NDIS and those provided by mainstream services efficient and sufficiently clear? If not, how can arrangements be improved?

Is there any evidence of cost-shifting, duplication of services or service gaps between the NDIS and mainstream services or scope creep in relation to services provided within the NDIS? If so, how should these be resolved?

How has the interface between the NDIS and mainstream services been working? Can the way the NDIS interacts with mainstream services be improved?

Individuals and families do not live their lives in the same ‘neat’ way that government services are organised. If you live with a complex or chronic disability, you face challenges and issues that cross multiple administrative boundaries. Our research into participants’ experiences of the NDIS uncovered some debate concerning what services (and therefore responsibility for funding) sits within the NDIS and what should reside with mainstream services (for example, health and education) (1, 3).

In our research (1) several participants discussed the need to navigate the boundaries of various service systems when requests for support and resources were deemed to be for the purposes of rehabilitation (which sits under the responsibility of health services) or education, for example, were refused. Older participants were more likely to struggle to justify that needs were not for the purposes of rehabilitation. One participant living with a physical disability explained his struggles to obtain exercise equipment:

> *They said to me, ‘We’re not going to fund that for you because its rehab and we don’t fund rehab’. I said, ‘That’s fine. What you don’t understand, my needs are not rehab. I don’t expect to get better’. (IV35)*

These system boundary issues were also raised by parents of young children who were keen to integrate education and disability support activities to intensify potential benefits, but this proved difficult to achieve in practice:

> *They have a very strong policy about keeping the NDIS separate to the Department of Education. I am really worried about it. I have heard a lot of things about how therapists cannot go into the classroom and things like that. Really worried about how that is going to impact his learning, basically, and*

> *how that is going to work. It has impacted us already. Before he was accepted into kinder, there was no day care centre that basically wanted us. They turned us away. (IV02)*

Some participants recognised the importance of framing goals and activities to ensure they would fall under the remit of the NDIS:

> *With the second plan (…) I was thinking there's not a lot of fine motor stuff and was wanting to make sure we had OT [occupational therapy] hours allocated for that. I said [to the planner] I thought we needed an extra goal there around fine motor skills (…) to improve [my son's] fine motor skills so he can learn to write. She said she was really sorry but that's education goal and they don't fund those. I literally sighed at her and said, 'I'd like to work on [my son's] fine motor skills so he can learn to do up his buttons. She said that was great, and an excellent goal. (IV09)*

However, it is important to note that not all services users or carers have the insight or capacity to be able to do this.

Where significant changes are made with an oft-reported large price tag then many will be feeling that responsibility for disability services should lie with others. It can be difficult in this setting to distinguish between what is a care need and what should sit with other mainstream services such as health or education. This is particularly the case with mental health, which was a late addition to the scheme. The episodic nature of NDIS, along with many people suffering from mental illness not identifying as having a disability, makes it in the word of one of our interviewees "strange bed fellows" (3).

Overall, our research (1, 3) has shown that there is a lack of clarity in terms of the boundaries of the NDIS and how it will work with a range of different services in the provision of seamless and consumer-direct care. It is concerning that the boundaries of the scheme are quite opaque. We have identified challenges in terms of what is seen as sitting within the NDIS and what should be in mainstream services. To this extent we have detected some of the same sorts of 'buck-passing' tendencies between mainstream and NDIS services that Glendinning et al (4) observed in their research of the English context.

What, if anything, can be done to ensure the ILC and LAC initiatives remain useful and effective bridging tools between services for people with disability?

One of our current research projects 'Collaborative Governance Under the National Disability Insurance Scheme' (funded by the Australian and New Zealand School of Government) has found that LACs need to be freed up from planning in order for them to be able to devote time to bridging services for people with a disability. We expect the ILC will assist with this, but given that it is yet to implemented this remains unknown. Our research has identified the need for more support for community development and advocacy, which hopefully will be filled by the ILC component.

Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved?

In our research with NDIS participants and their perspectives on the scheme (1), a number of concerns were expressed in relation to the planning processes. Some felt that as the scheme settled in and 'teething problems' were resolved they were gaining improved understanding of processes and there was increased flexibility to respond to emerging contingencies by adjusting funding allocations so long as they stayed within their budgets. Many participants, however, expressed frustration at apparently high staff turnover in NDIA offices and having to constantly engage with new planners who had varying levels of familiarity with disability services.

> *They (the NDIA) got a lot of staff come in and then some of them said it was just too hard with chopping and changing in the NDIA itself. Even that staff did not really know what was going on. A lot of the NDIA staff left and new people came in. We are on our sixth case worker. They just chop and change all the time. (IV01)*

Many participants made negative comments about the planning processes because of the time and effort that was involved, and because they felt that this was overlooked by the NDIS planners. A mother of a four-year-old child with a physical and cognitive disabilities explained the effort they go through in preparing their annual plans:

> *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 foresee, what shall we ask for in terms of therapy hours and time. They do a lot of research at their end [the therapists], go to a lot of effort (…) my husband and I sit down together and we talk about it as a family (…) we go in and have this meeting with our planner (…) what I find really frustrating is that you sit there and you have a chat (…) [the planner] sits there jotting notes. Then they give you a plan. They email you a plan and that is it (…) I was horrified at some of the goals she came up with (…) I did not feel comfortable with these goals. One of the goals was for [the child] to continue living with his family at home! (…) I was horrified that it was even in there as a goal, as if he might be taken away from us. It just did not feel right at all. (IV02)*
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> *Initially, moving from the basic setup they had before the NDIS was quite complicated (…) purely because of the amount of information that was given, it was given in bulk. I mean I understood it but I know there are a lot of people like myself who did not quite understand what the information was for, what to do with it, how to use it to your advantage (…) the Case Manager*

> *who put me onto this actually helped me with my housing, with the real estate and with the landlord and all that sort of thing. She recommended that I go onto it and see how it goes and see whether I can get another form of social life, moving on, a little bit of extra help with living on my own and getting around where I'm not able to and stuff like that. (IV16)*

Despite complex planning processes, some participant-carers felt that their views and experiences were overlooked:

> *You feel like you have been talking to a brick wall*. (IV03)

Another participant reported that,

> *We had a lot in place and then it was slightly changed. They tell you one thing, write down another thing and you get something else.* (IV01)

Another participant wondered if these situations arose because:

> *There's not adequate induction support and supervision training provided to the people who are doing the planning (…) If we can't get the planning right we're not going to get the scheme right.* (IV33)

While there was wide acceptance among participants on the need for accountability in distributing public funds, they reported that requirements could be disproportionate and time-consuming. Examples of requirements of approval processes being both confusing, arduous and inflexible, were given by a number of participants:

> *[The planner] told my husband and I to go and look at these things and make a list and say*, *'Yes, do you think that they would be suitable or not'. Then she told me she didn't tell me that, and that I needed an OT [occupational therapist]. Then we got the OT out [and they] wrote the report. Then [the planner] said, 'No, you can't have it because [it's not] to my standard, to what she thought was reasonable for me having these pieces of equipment (…) Aldi had kettle tippers for $29 (…) and [it] ended up costing nearly $100 which to me was ridiculous and unwarranted. (IV11)*
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> *Let's say what I wanted to use the dietician money on physio. If we're staying within the budget, who cares? How much nit-picking are you [NDIS] going to do? How much are they spending at that end to do that nit-picking that could be better spent? That's pretty frustrating. (IV09)*

In another interview, the elderly parents of an adult with physical and cognitive disabilities who lived in a supported accommodation setting, related their efforts to procure a footrest for their daughter whose feet clearly didn't touch the floor when sitting down. An occupational therapist was required to assess and approve the purchase and, six months later, they were still waiting for the footrest to arrive. Along with other participants, these parents had since engaged a ‘plan management service’ to assist them in navigating the NDIS.

The following participant felt that the efforts of clients of were being taken for granted:

> *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. The other thing is 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. (IV22)*

Emerging concerns for some participants in their second or third round of planning processes were that previous levels of funding were being cut. One participant explained that this had recently happened despite her efforts to demonstrate their value:

> *[E]ven therapists that my kids were already using, under the plan, the therapists have to show that they [meeting’ requirements] on the plan (…) provide a report to say what he did about gains and stuff because if you’re not meeting the goals in the report they’re going to say its insufficient (…) the lady who does the hippotherapy (…) she fulfilled her goals, the speech did her letter, the psychologist did her letter (…) this year [we were told], ‘No, you’re not going to get it [the planner] dismissed [the hippotherapy] and the after-school program. (IV40)*

Despite limited household resources, this parent had obtained some of these reports at the family’s own expense to ensure the smooth implementation of her children’s plans and she was perplexed and upset about the decision not to fund some requests. These issues were linked to growing concerns expressed by many participants that in recent planning processes, the NDIA were concerned with reining in escalating costs:

> *I think the initial start, the commencement of NDIA was great, the approach was great with the plan as they were very generous in what they gave me and I know with other clients as well, they're very generous, and I know now they're pulling back on that. Pulling back on that big time, with the money things. I think there's been some clients who have been disadvantaged and I know the NDIA's motto was that a client wouldn't be disadvantaged. I don't believe that's true. I don't believe that's true at all. (IV38)*

Other participants were also concerned about perceived cost-cutting measures in the scheme. They said these measures were leading to requests for services being rejected despite being approved in previous plans. In the absence of official explanations, seemingly poor communication between the NDIA and service users, a lack of clarity about why and how decisions are made were combining to undermine participants trust and confidence in planning processes.

A number of participants also reported that requests for funding in new plans had been declined because funds previously allocated for similar items hadn't been spent. Unspent funds were usually related to difficulties in accessing high-demand services or administrative obstacles (such as plans not being finalised and problems with the portal). These situations elicited much anxiety as participants grappled with the present and future consequences of not having access to required services, and fears that their needs would be deemed redundant.

Overall we found variable practice in terms of the planning processes and that the implication of this is that services are more expensive and less efficient than these might be. This is problematic because the entry point into services is important, particularly so when it is likely that many individuals will interact with the NDIS for a number of years. Damage to the psychological contract at this entry point will likely have significant implications for the operation of the system in the longer term. Greater levels of training and development for planners is needed, as is levels of knowledge around disability and specific impairments. For pieces of equipment below a threshold price level it may be more effective and efficient to allow individuals to purchase these without a professional referral. For example, where a kettle tipper, shower stool or other such pieces of equipment are identified as needed, do we need an Occupational Therapist assessment that costs more than the price of the equipment itself?

Are prices set by the NDIA at an efficient level? How ready is the disability sector for market prices?

It is difficult, if not impossible, for a regulator to set efficient prices for a diverse range of providers and services. Preliminary results from our research, funded by the Australian and New Zealand School of Government, show that pricing has not been efficient for many providers. This has led to the collapse of some providers, the deregistering of providers from the NDIS (including local government providers), providers doing unpaid work in order to retain clients or services, and evidence of providers 'gaming' the pricing system in order to cover their costs. Further, the NDIA has frequently and irregularly changed the set prices throughout trial and full scheme roll out. These factors create uncertainty for service providers and contribute to a more conservative market in which innovation is secondary to survival. Where the collapse, deregistration or lack of innovation of service provision occurs this constrains choice and control for people with disability.

At present the prices paid for services are set by government, but it is imagined that this will not continue as the market begins to self-regulate: This would also require individuals to self-manage their funds (as opposed to being managed by the National

Disability Insurance Agency or a third party), however self-management targets have been set at just 12%. These low targets, and potentially continued low take up, of self-management could be prohibitive to market growth with Scheme participants potentially having less freedom to make decisions about how their funds are used and impeding innovation.

The Productivity Commission vision for the disability service market might be considered idealistic given that worldwide: no public sector market has yet reached the point of being sufficiently self-regulated for government(s) to no longer play a role in price setting (5). The ultimate vision for the NDIS, in some respects, therefore outstrips what has been achieved in public sector markets internationally to date. The challenge for policymakers, is that there is no blueprint to build upon in designing this functional self-regulating market.

How do 'in-kind' services affect the transition to the full scheme and ultimately scheme costs?

The use of in-kind supports and services are limiting the growth of both markets and more innovative use of packages. Based on our research with policymakers at different levels of government, the implementation experiences of the NDIS to date suggest that so called policy layering (where by new policy goals are added to, or layered onto, existing policy commitments without removing others) is occurring within the NDIS.

As our interviews reveal, senior bureaucrats charged with implementing the various elements of the NDIS are very much aware of the potential long-term impact of sticky layers:

> "The NDIS is not an insurance model. It's become a social welfare scheme. Through the negotiations with States and Territories, it evolved from being the model [proposed by] the Productivity Commission, to a sort of more traditional eligibility assessment social support model. It's not an income support model, by any means, but it is an eligibility assessment model." [P26]
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> "[I]n some ways I think…[a] transition of only two or three years is a good thing because it's really hard once you've done something to pull back. There will need to be some pragmatic approaches in transition, but not locked in." [P16]

Hence, while senior bureaucrats could recognise layering and 'stickiness', they were less certain about ways to prevent or interrupt it. Rather, they hoped that over time some of these institutional legacies would be reversed or modified, even though the ways in which they as individual agents – or a collective – could achieve this was not clear. For example, senior bureaucrats are very much aware that the long-term success of the scheme is dependent on the development of a mature market for disability services, but, to date, there is little consensus on what kind of governance model will best facilitate market development or management.

What is the capacity of providers to move to the full scheme? Does provider readiness and the quality of services vary across disabilities, jurisdictions, areas, participant age and types/range of supports?

How ready are providers for the shift from block-funding to fee-for-service?

Our study areas in Canberra and Melbourne show that provider readiness varies greatly across types of support, local areas and organizational networks. We did not investigate participant age or broader area effects. Our preliminary analysis suggests that provider readiness is also dependent on whether a provider already had internal systems like to those of a business. The providers who put time and effort into transitioning their internal systems of human resources, IT, finance etc. into a business structure handled the immediate transition better than providers that continued as though block funding would somehow occur again. Supports for getting providers ready for market where present through government and peak bodies (ie: NDS) but were not always comprehensive enough or not taken up to their full potential.

What are the best mechanisms for supplying thin markets, particularly rural/ remote areas and scheme participants with costly, complex, specialised or high intensity needs? Will providers also be able to deliver supports that meet the culturally and linguistically diverse needs of scheme participants, and Aboriginal and Torres Strait Islander Australians?

This is a significant challenge. Rather than one national market, the NDIS actually requires many local markets that account for geographic diversity. The NDIS acknowledges that developing these markets will take time: “developing a strong, contestable market for disability supports is a long term project”. In inner urban centres this may be achievable, but potentially less so in outer urban areas particularly with regard to Indigenous, culturally and linguistically diverse communities with potentially low prevalence of particular types of disability. In rural and, particularly, remote areas ‘thin’ markets (i.e. where only one or two providers exist) are likely to emerge. It is likely that over time these areas will become even more challenging given changes that are taking place in other community care roles (e.g. aged care) and which will inevitably have a flow on effect for disability services. In urban or peri-urban areas with low prevalence of disability (or specific types of disability or particularly challenging situations with few or no support providers) may also present challenges in terms of thin markets. Thin markets are also susceptible to market failure, where no new providers enter the market place due to high costs of entry or lack of business prospects, and existing providers are challenged by being paid retrospectively for business, gaining the necessary breadth and depth of expertise and business costs running higher than the funds collected via individuals.

This is particularly risky while prices are set by the government (something which is hoped by policymakers, in time, will change).

To some extent the existence of thin markets, such as those outlined above, is entirely predictable. This offers a few options in terms of approaches. The first is to anticipate the existence of these and to set up an overarching policy framework that attempts to mitigate against these from the outset by leveraging on the areas that will be more lucrative for providers from the outset. An alternative to this more proactive approach is to pump prime providers and actively capacity build in areas with thin markets. It was mooted in the initial report recommending the NDIS that some ‘block funding’ by governments (i.e. the traditional contracting and procurement processes that currently exist) may continue. Building capacity falls within the ‘Linkages and Capacity Building’ (ILC) component of the NDIS, which recognises that not all needs can be met through personalised funding and that some degree of ‘whole of community’ capacity building is required. The ILC component may therefore act to prevent inequities between areas and or groups through supporting communities and mainstream services to become more inclusive. However, concerns have already been raised about the capacity for ILC supports to be delivered given the potential workload associated with those carrying out this role (known as ‘Local Area Coordinators’), who support NDIS participants with planning and identifying mainstream and disability specific services.

If the core of the NDIS is to offer empowerment through choice and competition, there is a need to recognize that not all individuals will have access to robust or functioning markets by which to exercise this control. Moreover, block funding could limit innovation with regard to services. In essence, we may see two schemes emerge – one in urban areas with robust markets, and a second (lesser) scheme subsidized by government in rural and remote areas that continues to offer little choice. Individuals likely to access these continued block-funded services are also more likely to already be experiencing other forms of inequity and/or disadvantage. For example, individuals living in Australian rural and remote areas have lower incomes, and worse health and wellbeing. They also experience more challenges accessing health, housing and education – compounding social risk factors for health. It is alarming that it has been suggested that people in remote areas with complex needs may need to relocate:

> **“**the diversity and level of care and support available in major cities cannot be replicated in very remote areas. In some cases, Indigenous Australians with complex needs will have to move to regional centres or major cities to receive appropriate care and support (as is also the case with non-Indigenous Australians)” (6: 559).

When considered in light of UK findings (7) that individuals are more likely to experience the promised gains of personalisation when strong support systems are in place, relocating individuals away from such support systems such as kinship, familiarity and community will have serious implications for care outcomes and equity.

While we have focused on the example of rural and remote communities, these concerns are also applicable to individuals with rare or low prevalence disabilities that require specific services, resulting in an inability to access appropriate care even within a metropolitan area. It remains unclear how thin markets (and associated lack of choice and control) will be managed.

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