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Productivity Commission Submission on the NDIS

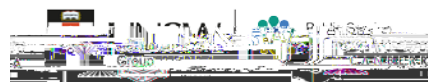
Why are utilisation rates for plans so low? Are the supports not available for participants to purchase (or are there local or systemic gaps in markets)? Do participants not require all the support in their plans? Are they having difficulty implementing their plans? Are there other reasons for the low 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 f 6(er)-4(i)-7(ng)11(t)(e s)-2(o as-6(2))JTJ Td (or





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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)

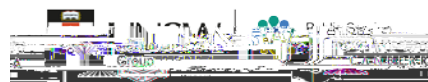
Is the current split between the services agreed to be provided by the NDIS and those provided by mainstream services efficient and sufficiently clear? If not, how can arrangements be improved?

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





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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:

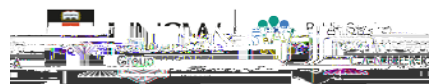
With the second plan (...) I was thinking there's not a lot of fine motor stuff and was wanting to make sure we had OT [occupational therapy] hours allocated for that. I said [to the planner] I thought we needed an extra goal there around fine motor skills (...) to improve [my son's] fine motor skills 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.







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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 (Q.2)

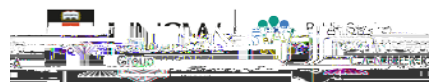




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explanations, seemingly poor communication between the NDIA and service users, a lack of clarity about why and how decisions are made were combining to undermine participants trust and confidence in planning processes.

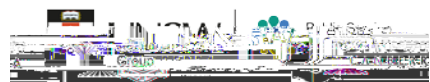




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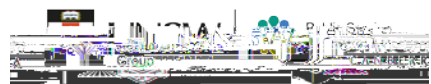
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Disability Insurance Agency or a third party), however self-management targets have been set at just 12%. These low targets, and potentially continued low take up, of self-management could be prohibitive to market growth with Scheme participants potentially having less freedomTj 0 Tc 0 Tw 1.002 Tu22(wi)Tc 0 T-0.002 Tc 0.002j -0.002 Tc 0.002 T





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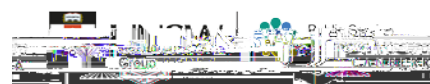




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While we have focused on the example of rural and remote communities, these concerns are also applicable to individuals with rare or low prevalence disabilities that require specific services, resulting in an inability to access appropriate care even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





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