NDIA - Policy Proposal Testing Focus Group Research Report March 2023

Executive Summary

- Across the NDIS participant and non-participant cohorts involved in this research, there is an appetite for reform in the NDIS that leads to the Scheme working better for participants … not for the providers or the bureaucrats that the Scheme seems to serve today. At the moment, participants are caught between predatory providers on one hand and an impersonal bureaucracy on the other. There is, therefore, a desire to humanise the Scheme by centring it on the needs of (vulnerable) people. Even in non-participant cohorts, the compassion for people with a disability and the nature of the circulating "horror stories" mean there is a desire for substantive reform – "not band-aids".

- Desired priorities and principles for reform centre on:
  - Addressing the burden of dealing with a complex, inconsistent, costly and impersonal bureaucracy, i.e. the NDIS should be about respecting participants and making their lives easier not harder.
  - Addressing the rorts, scamming and wastage that inflate Scheme costs and rob participants of value for their funding, i.e. ensuring that the money goes to those who need it and they can pay a fair price for what they need.

- The (six) reforms tested in the research, a) generally receive high-levels of support and b) work effectively as proof points for the reform priorities/principles above (i.e. they are seen to put those principles into effect). While the reform relating to Supported Independent Living has some real communication challenges, there are no failures in this package … and, indeed, the package lends a kind of credibility (quantity is a quality).

- Key insights regarding the communication of the reforms include:
  1. **Increasing the NDIA workforce and its specialisation** – the key here is specialisation and the idea of participants being able to deal with, and have decisions made by, someone who understands their disability and what supports will be effective. There is a clear connection for respondents: specialisation = understanding … and understanding brings some humanity into the system. The capacity for someone to explain "the why" behind decisions regarding plans is also important here. There is also positive

sentiment around bringing call-centre workers “in-house” – linking that to increased training and, therefore, making things easier for participants. The challenges here are concerns around a) the ability to recruit new staff in the middle of a perceived labour shortage, and b) the ability to train people up in a timely manner. We need to talk about this reform first – it is, in a sense, a precursor to others by providing an answer to how the others get done.

2. **Moving to long-term planning** – the stress and costs associated with (short-term) planning reviews are concerns for all respondents (including for non-participants, once it is explained to them). The demand placed on participants to repeatedly “prove” they are disabled is particularly animating. There is a strong positive response to this reform based on those factors. It is seen to deliver certainty and security – while reducing stress, cost and frustration. The only hesitation is a desire to retain “flexibility” within those long-term plans. This either relates to a) participants’ whose conditions fluctuate significantly (to ensure their changing needs are met) or b) participants’ whose needs might reduce over time (to ensure their funding reflects this).

3. **Addressing unethical practices** – NDIS participants and non-participants alike are aware of issues around “dodgy” practices by providers. There is no need to prove their existence. Among participants there is a particular anger/frustration at the treatment by providers: participants feel they are being de-humanised and exploited by agencies that only see them as “cash-cows”. This sense of exploitation and even predation fuels a strong positive emotional reaction to reforms aimed at addressing unethical practices. It taps into an underlying desire (from participants and non-participants) for more regulation of providers in order to protect participants.

4. **Addressing spiralling costs** – while there is an alertness (and dislike) for anything that signals cost cutting, there is support for price freezing based on perceptions of over-charging in the NDIS, an understanding that high costs in one area means participants have less to spend in another, and a desire to see participants get fair value for their funding. Participants are acutely aware of the NDIS’ ‘own goal’ in setting high caps, so don’t want to see providers exclusively blamed for inflated costs – but they do agree the current system promotes a pattern of behaviour where providers will charge the maximum amount, every time. As such, renegotiating caps – especially given that the Scheme is now more mature and we have a better understanding of costs – is seen as a positive move: it improves the value of their funding. There is also a very positive response to the “online marketplace” idea, particularly from participants (non-participants can be a little more unsure about it’s capacity to work). It is seen as giving an option for not just who participants want to work with, but how much they want to pay – something missing at the moment. There was also a positive response to the idea of participants being able to rate providers in the marketplace: “So we’re more valued as customers, not just people with a disability who don’t matter.”

5. **Increasing community/mainstream supports** – among non-participants, the challenges here are a) a sense that the heavy-lifting on improving accessibility of mainstream services has been done and b) an understanding on what is meant by community services/programs. Once that is achieved (e.g. by talking about community sport programs, community education programs – like cooking or resume writing), there is strong support, particularly on the grounds of the social connection this would provide. Among participants, the challenge is to ensure that this is not seen as a replacing NDIS funding by investing in these programs. Again, once it's explained as separate to NDIS funding, there is strong support with social connection and independence being very highly valued benefits. Indeed, participants who have engaged with such community programs have only enthusiastic support for them – they love their programs, whether it be "Parkinson's Boxing", dancing classes or wheelchair tennis. It makes sense to participants and non-participants that we should invest to enable these types of community programs and then make better use of them in people's plans. Respondents agree with the proposition that the NDIS can't (and shouldn't) do everything in isolation – they refer to the adage "it takes a village".

6. **Reviewing Supported Independent Living (SIL)** – respondents will generally accept the proposition that the SIL program is delivering poor outcomes for many participants (their awareness or experience of "horror stories" makes that real). They will accept the cost of SIL is heavy and that it is a challenge to the sustainability of the Scheme. They will readily accept that a 'full and proper' review of SIL is a necessary and good thing. However, two challenges then arise: a) "government review" means something that is slow, long and probably fruitless, and b) the idea of limiting access to SIL for anyone is uncomfortable for most respondents. While some (including those or caring for people on SIL plans) would agree that if it's producing poor outcomes we shouldn't be putting more people in, there are counter concerns for the strain and risk that places on persons with a disability and their carers while we wait for a review (refer back to the preceding point a). Ultimately, most respondents are just not sure what they think about this reform but, while their discomfort is evident, it doesn't seem to affect their enthusiasm for the other reforms.

- The final form of wording tested in relation to each reform category is provided in Appendix B.

- Overall, the biggest risk to the credibility of this reform package is a cynicism around the strength of intent to deliver it. All respondents – especially NDIS participants – are sceptical about meaningful improvements being delivered in this space. While action is the ultimate measure, in a communication sense, reflecting a greater sense of urgency in messaging goes some way to demonstrating a strong intent.

- Finally, in a general communication sense, there is an extreme aversion to bureaucratic jargon. Respondents want clear, plain and honest language.

Communications Recommendations

In framing and talking about a NDIS reform package, this research points to the importance of:

1. Engaging the participant community in support of the reforms – engaging the participant community in these reforms is, of course, the right thing to do on ethical and integrity grounds. We also need to recognise and leverage the impacts that participant voices have on the 'general population'. Th current research has again reinforced that everyone seems to know someone who is connected to the NDIS … even if they don't, for many, the bar of acceptance is determined by what participants have to say about the reforms. To the point that, ultimately, the success or failure of any reform package in the eyes of the 'general population' will be significantly influenced by the views of participants and their families/carers.

2. A strong and unequivocal commitment to purpose of these reforms as *making the NDIS work better for participants and addressing the burden felt by them and their families*. It is about putting the participant back at the front of the Scheme. To achieve this, we are focussing on two key principles:
    a. The NDIS should work to make participants lives easier and better, not harder – this means humanising the Scheme and addressing its complex and daunting bureaucracy
    b. Ensuring the money needs to go to those who need it and they can pay a fair price for what they need

3. We should <u>avoid</u> foregrounding issues of Scheme "sustainability" or cost – as we have seen in the groups, these ideas speak to a cynicism about government action in this space that then cues audiences to a sense that "cost-cutting" might be the real motivation here. There is no willingness to stomach cost-cutting as a motivation in this space – it is antithetical to what both participants and non-participants want for the Scheme.
    a. If it is claimed by others that we are just trying to cut costs, our response could be something along the lines that: *if putting participants back at the front of the NDIS results in some cost savings, because we're fixing the imbalances that have put the interests of others ahead of participants, then good. But that's not why we're doing these things*

4. Our particular reform areas/ideas then act as 'proof points' for how we are implementing our key principles. For example:
    a. Workforce specialisation makes life easier/better by giving participants the opportunity to speak with someone who understands their

disability. It drives more empathetic – and less bureaucratic – decision-making. This specialisation, along with an increase to the NDIA workforce is what enables the other reforms in practice.

b. Long-term planning makes life easier/better by reducing the stress, cost and indignity of short-term planning cycles, where participants have to regularly "prove" they are still disabled and live with the uncertainty of having funding cut-off. It gives participants greater security. It also opens opportunities for early intervention that 'front-ends' support for long-term benefits.
c. Addressing unethical practices ensures money goes to those who need it by protecting participants from predatory behaviours by some providers, who only see participants as a "money pit" to be exploited.
d. Addressing service costs ensure participants can pay fair prices for what they need. Currently participants might have a choice on *who* they work with, but no control on *what they pay*. We are changing things to give participants fairer value for their money and give them more power as consumers in the Scheme.
e. Investing in community/mainstream supports makes life easier/better by making things like school and holiday programs, sports and recreation activities, community-based education and health programs more accessible for people with a disability. These things allow people with a disability to connect with their communities, to make friends and do the things we all take for granted. It puts fun and fulfillment in their lives. We do these things *not* as a substitute to the NDIS, but *in addition to*. It takes a village to raise a child, and we should also be thinking that it also takes a village to support people with a disability in having a fulfilling life.
f. A SIL review will make life and outcomes better. SIL is producing many of the outcomes that the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability told us we need to reduce. We need to better understand how to properly fix this problem – but we can't leave people hanging in the current circumstances. An urgent review is needed and we will be doing that.

What we did

- 16x online (Zoom) focus groups (mix of ages and genders), including:
    - Nine groups with NDIS participants and/or their carers/family members/nominees (*referred to a "carers" for brevity*).
    - Three groups with persons with a disability and/or carers/family members who are not on the NDIS.
    - Four groups with "general population" respondents, covering regional/rural and metropolitan areas.

The detailed breakdown of group profiles is provided in Appendix A.

- Groups explored:
    - Positive and negative aspects of the current iteration of the NDIS;
    - Unprompted suggestions/priorities for areas of improvement to the Scheme, including guiding principles.
    - Responses to the reform proposals around: i) moving to long-term life-course & life-goal planning; ii) increasing the NDIA workforce and its specialisation; iii) addressing fraud and compliance; iv) addressing overcharging by providers; v) improving community & mainstream supports; vi) temporary limitations of newSupported Independent Living plans.
    - Respondent trust in Government to deliver improvements to the NDIS.
- Fieldwork took place between 13 March and 23 March 2023.

What we found

The Attitudinal Landscape – Strong Support and Consciousness of Benefits

Consistent with our findings from the first round of research into broader attitudes towards the intent of the NDIS, support for the Scheme remains extremely strong across cohorts. We again find themes around:

- Seeing the NDIS as critical to the good functioning of Australian society and integral to who we are as a nation: “[We] definitely [need to be] providing the services and the money that's needed for the people to get the help that they need to live in the community, because otherwise, we're not a fair and just society if we've got people who have terrible quality of health and life”

- The transformative nature of the Scheme for disabled people and the empowerment and dignity it enables. NDIS participants and carers readily spoke of positive aspects of the Scheme. Specifically, the simple outcome of providing funding that enables them to access supports they could not otherwise afford and which makes a material difference to their lives, including a degree of social connection they never otherwise would have: “It allows people with a disability to have carers… I’d sit at home the whole day without the NDIS.” There is a genuine sense of gratitude for the Scheme among participants/carers: “[I] still feel lucky I’m able to have those supports, without which I wouldn’t be breathing the same air as you all.” Some even spoke of the integral role the NDIS plays in preventing family breakdown: “It’s been life changing. If I didn’t receive the help … I don’t think I’d be able to have my kids here Monday to Friday,” and “It helps me to parent and be the best I can be”

- A benefit that did emerge more strongly in this research compared with the previous phase was the role the NDIS plays in allowing carers respite, peace of mind, and the capacity to care properly because they are not exhausted, was another feature lauded by respondents with experience of the Scheme:

    "[From] a carer's perspective, it's good if a carer needs support and timeout away from the person that they're looking after. So then the carer gets the time away to just take a break, relax but also [there is] that support, so the person that they're looking after is still so cared for." Importantly, this feature of the NDIS is liberating for participants as well who are able to avoid feeling like a burden on loved ones: "I don't drive anymore and I'm relying on my wife to drive me around. The biggest thing for me is the support workers. I have one young fellow [who] takes me to different activities. It relieves stress and pressure on my wife to do everything. I can do some things independently of her. So I'm really, really grateful for the whole Scheme"

  - Even for those respondents with disabilities (or their carers/family members) who are not on the NDIS, there was a strong sense of the benefits the NDIS enables: "[I'm] hearing really good things about [the NDIS] in terms of the way the whole Scheme works - in the way it supports people with disability. It's actually giving people with a disability a chance to have a better life!"

- A priority on NDIS participants' being able to access the necessary funding and supports, over concerns about cost-blowouts

- That the experience of NDIS participants (and by extension, their families and carers) constitutes a particularly trusted source of information regarding whether the NDIS is functioning as intended.

Importantly, we did not find that any general population responses contradicted any accounts or opinions expressed by people with disabilities or their carers. The only notable divergence entailed, as might be expected, familiarity with certain practical details involving the NDIS/NDIA.

Improving the NDIS- Guiding Principles

Participants (across cohorts) were asked what they see as a) "guiding principles" that should be followed when thinking about how to improve the NDIS and b) the priorities for improving the NDIS. While many specific issues were raised, there was an underlying consistency to these issues:

1. For many NDIS participants and carers, their experience of the Scheme is painful: they are caught between "predatory" providers on the one hand, and a complex, impersonal bureaucracy on the other. Even non-participants recognise this. Thus, overall, respondents talk about making the Scheme work better for participants. Putting participants' needs at the centre … not the needs of providers or the needsof bureaucrats. More specifically this means a combination of…

2. Addressing the burden of dealing with a complex, inconsistent, costly and impersonal bureaucracy, i.e. the NDIS should be about respecting participants

and making their lives easier not harder.

3. Addressing the rorts, scamming and wastage that robs participants of value for their funding, i.e. ensuring that the money goes to those who need it and they can pay a fair price for what they need.

The NDIS should be about respecting participants and making their lives easier not harder

As mentioned above, participants feel caught between predatory providers and impersonal bureaucracy. There is a sense that their individuality and their humanity gets lost. They feel, in this sense, disrespected. They want this humanity put back at the centre of the Scheme: “We're human. We're not a liability on society”. When asked which single guiding principle they would like to see implemented by the NDIS, cohorts with experience of the Scheme most often cited the necessity of humanising it - that is, creating a Scheme that is “human centred.” Or as these respondents put it, “Just that human aspect - keeping in mind that we're living with this,” and, “You know, we’re dealing with a human’s life!

Respondents from all cohorts were often most animated by their perceptions of the bureaucratic burden placed on participants (and prospective participants). Mirroring our findings from the first round of research, there was considerable awareness in the general population groups of “horror stories,” in which vulnerable people are denied necessary care: “I have a family member who has a Down Syndrome child. I know from speaking to them, it takes forever to get anything approved.”Participants spoke regularly and extensively about the complexity of the system – just coming to understand how it works and who to talk to is a process that takes years. Indeed, one carer spoke about how she had been in the Scheme for nearly five years and still “I don’t have a clue.” They spoke derisively of the NDIA distributing “300 page documents” and of Agency staff who are not “forthcoming” or simply don’t know the answers to questions. A number of participants talked about obtaining information through participant/carer Facebook pages (“That’s where I learn the most”) while recognising that such channels are suboptimal because of the prevalence of misinformation. There is a sense of a system designed to keep people out.

This complexity comes at a personal toll on participants’ mental health: “You get worse, while waiting, because it's that extra stress. We do not need that! You can’t control these things that have happened to you, and then they're going to fight you on the fact that it's happened to you, and they don't believe you! It's just a massive stress, which doesn't help. I've had to go for an ECG Recently, because of all the stress I'm getting caused by them [because] no one knows what they're doing.”

In this context, Support Coordinators become something of a guardian angel in the system: “I like the use of the Support Coordinators that work as a bridge between you and the NDIS. I find them really helpful and good.” Support Coordinators are almost universally viewed by NDIS respondents as critical allies in a system which can, at times, feel overly bureaucratic and overwhelming: “I found the Support Coordinator was really kind of integral for me as far as setting goals, and then within those goals, drilling down to get what I really needed. She was really good at getting me to think about what will really make a difference.”

Importantly, the bureaucratic burden of the NDIS is not just about complexity and the time/stress costs of that, but also the material financial cost.

One mother spoke of her grief at the crucial early intervention that was denied to her child –seemingly due to specialist reports being out of date. She then faced having to make costly appointments with specialists to get new reports: “All these new appointments, we just didn't have the money for them.

Participants are greatly animated by what they perceive as a profound hypocrisy inherent in the system: the NDIA demands that they spend hundreds, even thousands, of dollars on reports from various allied health providers and/or specialists to inform their support plan because the NDIA insists on “evidence-based” care. Then the NDIA is seen to simply reject what these professionals recommend because it costs too much: “They go against all the recommendations and reports … why keep asking for it if you’re going to ignore it?”

One respondent who is an allied health professional, as well as a carer for a disabled family member, described abandoning all work associated with the NDIS because his support recommendations were so consistently over-turned and the emotional toll became too much as he witnessed his clients failing to receive what he believed were necessary supports:“Part of the reason why I stopped working as an NDIS provider is, big clinical decisions were being overturned by bean counters and soulless bureaucrats who didn't know what they were talking about. It also does the participants a grave disservice, because all this funding is spent on functional capacity assessments, which are then overturned because of the semantics around words like, ‘reasonable and necessary,’ and ‘good economic value for money.’”

For those with less awareness of these burdens, their shock at the current state of affairs, once these were described by other respondents, was considerable “The thing that will stick to my mind is that some people are really in need of the help, and they are not getting it just because things are delayed and because everything has to be in proper place, in the sense of the paperwork and the bureaucracy. This is really bad, and it hurts when you think of it."

In terms of the bureaucratic burden of the NDIS, the (consistent) message is simple. As this non-participant put it: "Make it easier! If I was a parent of a young child with a disability, either intellectual or physical, they've got enough stress going on. The last thing you need is extra stress." The core idea here is that the NDIS exists to serve participants … not bureaucrats.

Importantly for communications: the sensitivities around the bureaucratic burden result in their being extremely sensitive to the language used to describe reforms. There is an extreme aversion to bureaucratic jargon, such as, "enhancing the NDIA workforce," with one respondent remarking, "I don't like the word, 'enhancing.' What - are they giving them all a facelift? To me, that's very unclear, what enhancing is. Does that mean having a bigger NDIA workforce? It just sounds sort of bureaucratic BS and vague to me."

Respondents were adamant that clear language is always preferable - i.e. that if there is an intent to upskill existing staff, use specialist staff, or increase staff numbers, then this must be expressed in plain language. There was a similar aversion to metaphors and similes used to illustrate principles.

Ensuring that the money goes to those who need it and they can pay a fair price for what they need

Again, the "horror stories" of rorts and wastage (particularly in the form of unnecessary "middlemen" "clipping the ticket", or providers gouging the Scheme with inflated costs and non-essential services) are prevalent … and again the main victim of such problematic practices are people with disabilities, denied adequate support and funding, not the taxpayer per se. The core concern is that the money simply isn't getting to the people who need it for the things they really need it for.

For participants, there is a clear and consistent sense of having their funding de-valued by over-charging providers or poor quality services.

With regard to overcharging, there is a sense of being captive … as opposed to the choice and empowerment the Scheme was supposed to bring. For example, one respondent spoke about how his Psychologist refused to take him under the Mental Health Plan once he found out this participant was in the NDIS: "[When] my psychologist found out I was on the [NDIS] they didn't take them [the Mental Health Care Plans] anymore, apparently. It has to be through the NDIS. The charges [were] double. If you've got the NDIS then bad luck."

A similar account emerged in another NDIS participant: “Because I'm self managed, the therapist suddenly increased the amount that they charge, and I [feel forced to pay because I] don't want to lose that because I'll go back to the long waiting list. Some service providers are taking advantage of the system.”

With regard to service quality, a major concern is provider hiring unqualified support workers and that these workers being only motivated by money (i.e. not there for the right reasons) … and then charging high rates for unqualified workers: “They need to blow away the shonkiness [with] what they’re charging. For two night’s care for my mother they quoted me over $1200… and it’s not a nurse. I’d pay that for a registered nurse [but] it’s just a carer”. Another commented on the lack of regulatory oversight, “It’s very scary. If I had to leave my 15-month old - who is non-communicative - with [an unqualified carer]... well, their life is in their hands”.

Interestingly, this concern about unqualified workers in the Scheme is, in part, fuelled by Facebook ads calling “any Joe Bloggs” to become a care worker: “I keep seeing ads on my Facebook page about how easy it is to become an NDIS provider. You don't really [have to] do anything: just join up and you can become a provider. It reads like a scam, but apparently it's not. So if it's that easy to become a provider, that's a bit strange.”

However, this de-valuing of their funding is almost a secondary concern to a more generalised sense of themselves being devalued and exploited. That is, they feel that providers only see them in terms of the money to be made from them. Participants talk about providers only seeing them as “a money pit” or a “cash cow” – anything but a person or even a customer: “I feel like the moment you say NDIS, all most services see is dollar signs flashing. Everyone wants to make money.”

A consistent theme among participants and non-participants alike is a desire for more“regulation” to protect vulnerable people. They want standards, they want “vetting,” and they want “auditing”.

Even those who have worked in the disability space called for urgent reform: “I believe they need to be more diligent at auditing the providers. I've seen that in the workplace when I was a disability support worker for five years. I see it and hear of it daily, some terrible things.”

Critically, participants and non-participants alike emphasised that they do not want “band aid” solutions. They want systemic change. Indeed, respondents from the general population shared a scepticism with the other cohorts regarding Government “reviews” that don’t lead to action. They want substantive change – not just “a headline in the Daily Tele for catching a couple of rorters”

Responses to Policy Proposals

Overall, the package of proposed reforms received high levels of support among both participant and non-participant cohorts. Indeed, taken together as a package there is a credibility to the reforms that goes some way to balancing out respondents' cynicism about whether they will actually be delivered.

The feedback from respondents in how the reforms are framed and described ultimately resulted in the set of words used in Appendix B. The rest of this report outlines how we arrived at those words.

Cynicism: Urgency and Strength of Intent

Importantly, the degree to which respondents had had negative experiences with the NDIS coloured their receptiveness to the various policy ideas presented to them. However, even among those who were sceptical of Government's capacity to execute - and at times, the Government's intent (i.e. whether these reforms were simply cost-cutting exercises) - there was nevertheless broad acknowledgement of the necessity for reform.

Often, a key critique among those who were sceptical, was the omission of any language regarding the urgency of these reforms. As this carer of a person who is not an NDIS participant observed, "The Government is so slow doing anything and all these all these point's you've brought up [i.e. policy ideas] - everyone's agreed with it. So everything should be urgently done, because it's to do with disabled people!"

Or as this respondent summed up, "It needs to be done with urgency. Not one of those Government months-long reviews, with people on hold while they're writing a report a year later!"

Without that sense of urgency, respondents are sceptical about the strength of the Government's will/intent to deliver these reforms.

Moving to long-term life-course and life-goal planning that prioritises early intervention

What Works When Talking About this Reform

Respondents across all cohorts were most enthusiastic about the aspect of this reform idea that would remove the need for NDIS participants to continually "prove" their disability at each review.

As these NDIS participants observed, “Not having to do annual plan reviews [is a positive]. They’re really stressful. Living with a disability is stressful enough, let alone hanging for weeks waiting for that plan to be approved,” and, “I always find it pretty intimidating going through the plan review.”

One NDIS participant observed that such a reform would “open up opportunities” not currently available if one is on short-term rolling plans. This respondent described needing an assistance dog, to enable him to venture into public and complete simple tasks, such as shopping for himself. His goal is independence; however, a dog costs $50,000 over ten years. Because this respondent is on short-term plans, the NDIS will not grant funding for an assistance dog. It will, however, spend far more money (ultimately) on short term fixes, such as paying someone else to do his shopping for him, simply because the cost seems less when it is viewed only within a 12 month-time frame. Long-term planning would offer an opportunity to provide support for his goals by opening up the horizon on funding decisions. As he concluded, “We all want to be independent. It would literally change my life. You lose sleep over it”.

Even in the general population groups, there were respondents who were aware of the current situation and remarked, unprompted, at the outset of the discussion, “I read that applicants who are complete paraplegics have to go through reassessments. So it's not just one assessment process - [they] have to then be reassessed every couple of years or something. And that would seem to be overly bureaucratic.”

Emphasis on the improvement to participants’ quality of life - and reduction in stress - as a result of no longer having to “prove” disability is therefore central to the appeal of this reform.

What We Need to Be Careful of When Talking About this Reform

People across cohorts did express concern that the longer-term plans might lack the necessary flexibility to manage the inherent fluctuations of capacity that characterise so many disabilities: “I think it could work. I guess it just depends on the logistics because people's lives and circumstances change all the time.”

“Flexible and adaptive” as well as long-term, are therefore key criteria for respondents which would give them confidence in such a reform. There is a strong desire among those interacting with the NDIS not to have to engage in further battles for funding: “I’m going to have to fight more!” Clear communication around inherent flexibility within this new framework would therefore be welcomed.

These concerns were shared by people from the general population cohorts. There was considerable worry among some that this reform proposal might mean the abandonment of those with a disability, if safeguards were not put in place: “It needs to have good individual case managers, keeping an eye on people, because we don't want the clients just to think they've been forgotten about.”

Language that reassures both participants and the wider population that such changes will not compromise supports and will allow for flexibility that accounts for participants’ changing needs will therefore be helpful.

Of note, there did not seem to be any unprompted assumption that this reform idea was intended as a cost-saving measure. However, when we explicitly stated that this wasn’t about cutting costs but making them more predictable, that prompted respondents to become suspicious of the motivations for the reform. They then assumed that any statements about this not being about cost-savings were disingenuous. Avoidance of discussion of cost-savings is therefore advised.

Increasing the NDIA Workforce and its Specialisation

What Works When Talking About this Reform

There was broad and at times, intense support for this particular reform idea in principle. Many respondents - particularly those with experience of the NDIS - cited this as the most compelling of the policy proposals that had been put to them.

However, it was specifically the idea of greater specialisation - rather than the increase in numbers per se - which most animated respondents: “Not necessarily bigger, just more specialised … that’s the critical bit,” and, “Specialisation is really good. If they know the disability, they’ll know what you really need. It’ll make a huge difference and smooth the planning experience.”

This NDIS participant explained why she found this reform idea particularly compelling: “Specialised staff, down to the call centre people and the planners! If they know more about what they're talking about, it's easier for them and it's easier for us to actually get answers that you can be confident in.”

Respondents made clear that in addition to the current situation causing stress, frustration, and time-wasting (“I think [this reform] is extremely important because I am sick of my time being wasted. Just because I have a disability doesn't mean I am not valuable!”), it is the Agency workers’ knowledge and coordination gaps which result in their mishandling of issues and/or cases - “that’s where stuff falls down,” i.e. that is where important information gets lost and the potential for harms to the participant to accrue.

The idea of more ‘in-house’ staff also worked well across cohorts. Respondents believed that dispensing with inexpert and uninvested contract workers would be beneficial and that this would be integral to the effective implementation of the specialisation process: “I liked the idea of not outsourcing because it would then hold NDIS employees accountable for what they do. Once you start outsourcing, that goes.”

Similarly, face-to-face contact was viewed by a number of people interacting with the NDIA as an important component in helping Agency workers truly understand their needs: “In-store staff that's tailored to meet the needs of your specific disability that can help you navigate things [is most compelling], especially if you are confused and really don't understand what's going on. Just having a face-to-face person that you can rely on and engage with.”

Furthermore, they want to see the ‘upskilling’ and specialisation as an ongoing process - not a ‘quick fix’ course, but rather continuous professional development so that workers are able to stay abreast of the changing evidence base, medical science, and technology in their fields. For example, one respondent with Parkinson's spoke about the emerging technologyof “exoskeletons” that would enable people like him to walk; however, when he raised this topic with his planner, they were unaware of its existence.

Emphasising upskilling and ongoing professional development, more face-to-face contact, and more in-house staff would therefore be welcomed.

It is also important to note that there was an order effect in relation to this reform. That is, increasing the workforce was seen to enable the other reforms. It is, in a sense, the precusor to how the others get done. For example, once we started testing this reform first, qualms around the viability of other reforms were mitigated.

What We Need to Be Careful of When Talking About this Reform

The primary concern regarding this reform proposal centred on whether it was, indeed, feasible, considering the various issues with labour-force shortages generally, and the shortage of allied health and care workers, specifically: “Gonna need a magic wand to find all these skilled people.” Avoiding too much emphasis on the increased number of Agency staff is therefore advised.

Should implementation be feasible, another objection of note was from a subset of NDIS participants/carers for whom Support Coordinators are a vital component of their being able to access the support they need from the NDIS. Any sense that such a reform might compromise their access to their Support Coordinators induced considerable anxiety among this group: “Sounds fantastic to me, but I wouldn’t want a bar of it without my Support Coordinator.”

Often, it is the enormity of the bureaucratic burden itself that is fuelling these anxieties. As this NDIS participant explained, “I think [the NDIS] needs to be simplified. If you've read through NDIS documents, you have to be a lawyer to understand! I think that more specialised staff would be great. But also have an easier programme outline, [that] would save so much hassle and I think it would save a lot of money and a lot of time.”

Emphasis on the upskilling of NDIA staff and attendant specialisation as a means of reducing this bureaucratic burden so that life will be easier for participants when dealing with the Agency will work to reassure those who expressed concern.

Addressing Fraud and Compliance

What Works When Talking About this Reform

The idea of reforms that will prevent providers from pressuring participants animated many respondents: “People are being pressured and it's taking away funding they genuinely need… or taking services from someone else who needs it.”

For both general population and NDIS-associated respondents there was moral outrage regarding the exploitation of people with a disability. One NDIS participant, incensed by the advantage some service providers were willing to take of the scheme argued, “I have a gut feeling that the larger community sees the NDIS as a big fat cash cow and there needs to be a public awareness campaign to minimise that.”

Among participants this reform taps into the particular anger/frustration at the treatment by providers: participants feel they are being de-humanised and exploited by agencies that only see them as “cash-cows”.

Speaking about how these measures will protect participants from predatory practices as well as ensuring the long-term sustainability of the Scheme via cracking down on fraudulent providers is likely to resonate with a broad cross-section of the community.

What We Need to Be Careful of When Talking About this Reform

There was, however, considerable disquiet among a subset of respondents in both the general population and NDIS-associated cohorts regarding who is best placed to assist participants in advocating for what they need in their plans.

This disquiet centres on their fear that this new process will only allow participants to negotiate directly with the NDIA without assistance, either because there is a lack of trust in the NDIA to be sufficiently generous, or a lack of trust in NDIA workers to have the requisite expertise to ascertain which supports are necessary. Indeed, some in the general population groups argued that a provider may be the person who is best, “in tune with what the participant needs”.

Another notable objection from some in the general population groups arose when discussing empowering participants and/or their carers to manage problematic provider practices. These respondents expressed considerable concern about any such onus being placed on participants or carers. “A lot of the people that get those services in our area would not be capable of looking after themselves. [It is unreasonable to suggest that they] will just get a big stick out and sort out all the ‘dodgies’ and get rid of them.”

This disquiet was, understandably, magnified in the NDIS-associated groups - particularly among those who saw their providers and/or Support Coordinators as key to helping them navigate an otherwise impenetrable and hostile system: “If you are getting your information through a person that you trust, that should be allowed, because then it takes away the stress of you having to get information.”

Many of these concerns, however, were offered in response to the more abstract elements of the reform and when respondents were provided with specific examples of, ‘sharp practices,’ they were more clearly able to see what the Agency is seeking to eradicate, which they found reassuring. Avoiding abstract discussion of fraud and compliance will therefore remove many of these concerns.

Addressing Spiralling Service Costs

What Works When Talking About this Reform

This reform found broad appeal across cohorts, particularly as a means of addressingpredatory provider behaviour: “Whoever you choose, they feel like you have no other option. You’re not valued but they still keep charging top dollar,” and, “It’s definitely all about charging the cap… and I’m shitted off with that.”

Indeed, this was a common refrain from almost all NDIS-associated respondents - that price gouging deprived them of funding, which too many service providers failed to appreciate and that this is inherently discriminatory and exploitative.

One NDIS participant described a particular rort in which builders are allowed to charge up to $500 simply to provide a quote for works to a participant’s home. This respondent then found that every quote cost $500: “[These builders] say to you, ‘it’s not your money, why do you care so much?’ But that’s $500 I could have done with to get other social support. I need that money to last me and it's difficult to get more”.

Regarding the idea of a provider marketplace, a number of respondents appreciated the agency that such a site might afford NDIS participants, as it could enable them to put their money where they felt they needed it - i.e. pay for a higher level of care in some areas (for example, paying for a nurse), and for lower levels of care in others: “The marketplace idea would give people the chance to select which baskets they want to put their eggs into … you can be more selective on the priorities,” and, “It’s the ability to choose a provider with the ability to filter on what actually suits you.”

The idea of a provider marketplace as a means of addressing costs through competition was viewed as a positive by many, including those NDIS-associated respondents who believedthis is, “A great way to be more transparent,” with many citing it as one of the more compelling reform proposals.

One NDIS participant stated in support of the marketplace idea that, “We should have choice. We can choose who we work with. But we don’t get a choice on the prices we pay”. There was much assent to this comment in the group.

Another NDIS participant described the idea as, “brilliant,” because it would mitigate the adverse effects of what he described as ”an oligopoly” when it comes to service providers. He argued that once one or two providers set competitive prices, others would have to follow. This respondent went on to observe, “The ceilings have to come down. [Current prices are] ridiculous highway robbery!”

Some NDIS participants posited that being able to review and rate providers on the marketplace could have a positive effect: “So we’re more valued as customers, not just people with a disability who don’t matter.”

Once again, centring participants’ needs - that the NDIS is for them and not for providers seeking to price-gouge - works well.

What We Need to Be Careful of When Talking About this Reform

There were, however, concerns regarding this reform - including the marketplace idea. While there was broad agreement that something must be done about problematic differential pricing, there were nevertheless concerns about unintended consequences for an already overstretched provider market: “I love the idea of the capping but I have concerns around reining it in - whether that means we will lose some really good therapists.”

Assurances that fair and competitive prices will be integral to the model will therefore be important.

There was also a sense in some groups, both general population and NDIS-associated, that spiralling service costs was a problem of the Government's own making: "[The] statement to me just screams bullshit because the Government set this system up. And now they're saying they've done it wrong. They've set the rates too high and they want to blame the providers, because they [want] to drop the rates. People do charge more for weddings, and that's called privatisation."

A number of respondents with disabilities also worried about the safety aspect of the marketplace initiative: "[This initiative] probably opens it up to scammers. I realise they've got to be licensed and whatever, but I'm sure they're [still able to] take advantage of people with disabilities."

These concerns, however, can be addressed with quality assurance mechanisms built into the marketplace and carefully overseen by the NDIA.

Indeed, some respondents predicated their enthusiasm on such a marketplace being monitored carefully to exclude exploitative and other problematic operators, avoiding,"Scammers, like Facebook Marketplace." The idea of preferred or approved providers did mitigate this concern; however, such oversight would have to be based on quality/standards - i.e. that providers cannot simply pay to be on the site "like Compare the Market." Or as this respondent observed, "As long as they're all qualified to get onto it, then it would give people the opportunity to be more selective about where they put their priorities."

Improving Community and Mainstream Supports

What Works When Talking About this Reform

For those respondents who supported the proposal, there was a strong sense that this, "Would improve your quality of life." In a couple of separate groups, participants likened it to the adage that "it takes a village to raise a child" … in this case being 'it takes a village to support a person with a disability to have a fulfilling life. Another respondent used the phrase, "Many hands make light work," while others discussed opportunities to have partnerships with Meals on Wheels, local Councils, or companies like Woolworths - where companies could put on courtesy buses which, "make a world of difference," to people living with a disability. Critical to this positivity was the social connection and independence offered by such community programs and supports.

Similarly, there was great excitement in another NDIS-associated group when one respondent informed the rest that IGA supermarkets have an app that allows people with disabilities to make advance requests for accommodations that might assist with sensory issues: “It's kind of like what they were doing at the IGA stores. They created a disability app, if you've got sensory sensitivities to light and noise, then they try to accommodate you [and] some select coffee shops [as well] - if you like to sit in the left side of the coffee shop, and you like to have a particular cup or a spoon, they try to accommodate to you.”

Among these respondents, there was an appreciation of the idea of, “collaboration so we’re not just relying on the NDIS.” Similarly, another NDIS participant spoke with delight about how his daughter had found “Parki Boxing” classes for him to attend - physical therapy for people with Parkinsons at a local gym. This is not an NDIS initiative, rather, it is something the gym took upon itself to develop.

There was support among general population respondents as well, “People should be able to get places without taking a taxi or an Uber. I just got back from Europe and the amount of support that people have and the amount of public transport that everyone can get on is crazy compared to Australia. So I think it's just a bit disappointing that we don't cater for those people to even get to [their] appointments [here].”

This reform idea therefore works best when it is framed through the provision of specific examples which illustrate the positive effects on participants’ lives.

What We Need to Be Careful of When Talking About this Reform

Concern regarding this reform most consistently arose as a result of respondents perceiving it as “vague” and not understanding what it might entail. A general population respondent remarked, “Incorporating every type of disability or every type of ability in society into one big system that covers all of it? I just don't think that's a practical solution. It would cost a lot of money getting a lot more people involved. That just may not be a good use of resources.”

Many simply stated, “I don’t get it,” or, “I think it lacks some information.” This general population respondent summed up the broader sentiment among this subset: “I just thought it was, so vague, it lost me. I really couldn't quite understand. That is so nebulous.”

Concern arose from multiple respondents across cohorts regarding their suspicion that this reform idea was about the NDIA seeking to shift responsibility away from itself: “How's that going to work? It's our little kids. It's, in a way, passing the buck,” and, “It's like it's trying to reduce the amount of responsibility away from the NDIS.”

Another common objection involved respondents (again, across various cohorts) that efforts had already been made to make broader society more accessible and what more could be done? One respondent argued, “I feel like [broader society] already do[es] their part. I feel like schools and universities have [become] mainstream places already and are allowing people with disabilities to be more able to approach those services. I don't know how you can make them more accountable as private businesses or whatever. I feel like the NDIS is fobbing their part off, like passing the buck by doing that.”

Once again, providing tangible examples of ways in which mainstream supports can be increased can combat this objection.

Temporary Limitations on New Supported Independent Living (SIL) plans

What Works When Talking About this Reform

With only a few exceptions, there was limited awareness of Supported Independent Living plans (including among NDIS participants) and many respondents required additional explanation of it in order to contribute their opinions to the discussion.

A number of respondents were, however, quite distressed by the idea of problematic group housing situations, likening these to the problems in aged care: “They’ll treat you like crap because they know you’re high cost to them.”

A review of SIL was therefore broadly supported, with many respondents having a general sense that, like much of the NDIS, “Too much money is being charged and people [are] not getting the support they need,” and, “If it’s not working, people could be suffering or just not happy, then you shouldn’t be putting more people into that situation”.

The animating concern here is for people who may be harmed by a malfunctioning system and there is a commensurate desire for a review to happen urgently: “People can take advantage of people in that position. So it's it. It's very scary,” and, “If it's not working, there could be people that are suffering - that aren't happy in the situation. So why put more people into that situation? if you've grandfathered in the other people, they're safe where they're at, as long as things aren't going to be worse for them.”

In one of the general NDIS-associated groups, a respondent in SIL spoke about how there is so much wastage in the system. For example, she lives in accommodation with a gym that’s full of equipment only suited to able-bodied people, as well as a pool that doesn’t have a hoist. The price of this accommodation is commensurate with these facilities - her rent is $850 per week - yet these facilities are unusable.

She views the foundation of this problem as “people not understanding your needs in a building.”

Once again, centring the needs of participants, and emphasising the need to ensure that everyone has access to safe and suitable accommodation, that is tailored to their requirements, is key.

What We Need to Be Careful of When Talking About this Reform

While these respondents readily accepted the need for a review, they did not like the idea of restricting access while that review takes place: “[That means] people who need support can’t get it. The housing situation is terrible already. This would be the opposite of what the NDIS is supposed to do.”

Such reservations were widespread across cohorts: “How do you know that they're going to get the added care that they need?” and, “To me, that sounds like they're just trying to cut costs. I don't like the sound of it at all. It's good for them to have that. Who's looking after them?”

Other respondents were concerned about possible safety implications of pausing new SIL applications: “[It’s] just insane: it's potentially forcing families into situations that are unsafe, because they've cut funding, and they need it.”

As above, emphasis on ensuring that people requiring care will still be able to access it, is key. Any discussion of limitations to SIL plans should be accompanied by the reassurance that a) those requiring SIL will still be able to access it and b) that existing plans will not be affected.

Appendix A – Group Composition

- Group 1 comprised members of the general population, living in rural/regional NSW and QLD.
- Group 2 comprised members of the general population, living in inner urban/middle suburban Sydney and Brisbane.
- Group 3 comprised people with a disability or carers of people with a disability who are not NDIS participants, living in rural/regional NSW/VIC/TAS.
- Group 4 comprised members of the general population, living in outer suburban Melb/Syd/Adel.
- Group 5 comprised carers/parents of a child with a disability who are not NDIS participants, living anywhere in NSW/QLD/VIC.
- Group 6 comprised adults with a disability or carers of adults with a disability who are not NDIS participants, living anywhere in NSW/QLD/VIC.
- Groups 7 & 10 comprised NDIS participants, living in any metropolitan or suburban area in Australia.

- Group 8 comprised family members/carers & nominees of NDIS participants, living in any metropolitan or suburban area in Australia.
- Group 9 comprised family members/carers & nominees of NDIS participants who are children, living in any metropolitan or suburban area in Australia.
- Group 11 comprised family members/carers & nominees of NDIS participants, living in rural/regional NSW/QLD/VIC.
- Group 12 comprised NDIS participants or carers of NDIS participants who are unemployed or cannot work, living anywhere in Australia.
- Group 13 comprised NDIS participants or carers of NDIS participants, living anywhere in WA.
- Group 14 comprised NDIS participants, living anywhere in rural/regional Australia
- Group 15 comprised NDIS participants or carers of NDIS participants with Supported Independent Living supports funded in their NDIS plan, living anywhere in Australia.
- Group 16 comprised members of the general population, living anywhere in metropolitan or suburban Bris/Syd/Melb.

Appendix B – Final Set of Wording Tested

Overall Frame

Making the NDIS work better for participants. This means:

- *Making sure the money goes to the people who need it and they can pay a fair price for what they need.*
- *Participants are treated and respected as individuals, to make their lives easier not harder.*

Reform messaging

Reform category	Descriptor
Increasing the NDIA workforce and its specialisation	The idea here is to increase the NDIA workforce, but most importantly improving/upskilling the specialisation of the people making decisions about a participants' funding – so participants are dealing with someone who understands their disability and understands (based on evidence) what is going to be effective for them. So they can talk participants through what they recommend for their funding and why. It's intended that participants will get more time, more consistency and more understanding from the people they deal with in the Agency.
Moving to long-term life-course and life-goal planning that prioritises earlyintervention	Currently, NDIS participants are funded on the basis of a support plan agreed between themselves and the NDIS. These plans are typically short-term, e.g. 1 year. At the end of that year, they must renegotiate that plan and there is no guarantee of continuing funding. Sometimes this also involves having to "prove" they are still disabled (with new, expensive doctor reports). The idea here is to break the cycle and stress and cost of short-term planning. It would involve developing long-term plans – targeted to participants' needs and goals, with the flexibility to adapt to changes in participants' condition and their lives. And once you have a long-term plan, that plan is supported. So, you would still review what's needed from time to time, but it won't be the all or nothing process it is at the moment. This is intended to provide greater certainty for NDIS participants, giving them better support to achieve their goals and removing the fear around plan reviews and the stress and cost of having to keep proving they are disabled

Addressing fraud and compliance	With more staff available to oversee providers and respond to complaints, there is an opportunity to move from just focusing on criminal cases of fraud or rorting to address unethical behaviour seeking to take advantage of participants, such as: • pressuring participants to ask for services they don't really need • spending participant's money contrary to their plan • asking for or accepting additional fees for a service • offering rewards for taking particular services not on a participant's plan
Addressing spiralling service costs (which are increasing well above inflation)	The NDIS is responsible for setting prices under the Scheme and has created a marketplace where providers can charge the maximum allowed, every time. We have to fix the system so that participants get fair value for their money, while ensuring their quality of care is maintained. We can address this by: • Freezing prices that providers can charge for coordination, plan management and therapy (e.g. capped at inflation). • Increasing oversight of provider charging, e.g. re-negotiating prices by the NDIA on behalf of participants and • Establishing approved provider panels, and then increasing competition with an online marketplace – like Gumtree or eBay – for services from those providers, so participants can have options for not just who they want to work with but how much they want to pay.

Improving community and mainstream supports	Having independence and the opportunity to meet and connect with other people is critical for everyone, including people with a disability. The idea here is to continue to making existing mainstream services/facilities (like health, education, transport etc) more accessible and supportive for people with a disability, while investing in community-based programs, like sports, hobbies, practical education (e.g. cooking skills) and so forth … and then ensuring these programs are better utilised as part of the support mix for NDIS participants. It's about doing these things in addition to properly funding the NDIS. Because the NDIS In isolation can’t deliver independence. It can’t be the only lifeboat in the ocean.
Temporary limitation on new Supported Independent Living plans	Under the NDIS, some participants receive Supported Independent Living supports. This is for participants who are typically profoundly disabled and require more intensive care. The idea behind SIL is to give people as much independence as is possible and get them out of institutions. The concern here is that Supported Independent Living is driving the very outcomes the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability told us we need to reduce. For example, splitting up families/couples and driving people into accommodation situations (e.g. group housing) that don’t support independence and positive outcomes. At the same time, SIL is growing at a rate that was never anticipated (around $4b per year more than expected), which represents significant challenges to the financial sustainability of the Scheme. A full and proper review of SIL is needed and until that happens there should be a limitation on new SIL plans (e.g. only approve new participants where there is significant need, not impacting existing SIL arrangements).