

NDIA

Focus Group Research Report

March 2023

Executive Summary

- Respondents across all cohorts exhibited a remarkable degree of emotional engagement with the NDIS and the plight of Australians with disabilities, regardless of their initial knowledge or experience of the Scheme. That is, even those who had a low understanding of the Scheme at the outset still exhibited care and concern about the issue, and revealed more passion about it and its importance as each group progressed. Indeed, those with no lived experience of disability generally demonstrated as much emotional connection as those with such experience. The universality and degree of empathy and compassion that respondents from all demographic segments exhibited towards people with a disability was notable.
- This extended to a universality of support for *the concept and intent* of the NDIS. Such support is predicated most powerfully on a) a sense of moral duty (that is tied to national identity) and b) its capacity to empower Scheme participants to live a fulfilling (and productive) life. Other key features included: i) provision of a ‘safety net’ for all Australians and ii) its facilitating the destigmatising and mainstreaming of disability. Critical to this sense of ‘moral duty’ is a view, even among conservative respondents, of people with disabilities as being ‘the *deserving* in-need’, for whom Government support is necessary and desirable. Respondents identify with disabled Australians and see our treatment of them as indicative of the kind of country we are, or want to be. The NDIS is viewed by many as a fundamental government service, on a par with Medicare.
- While support for the Scheme was universal prior to showing respondents the video clip of disability rights advocate, Elly Desmarchelier, after viewing the clip, the intensity of support grew significantly. This clip spoke effectively to both the sense of moral duty and the benefits of the NDIS in empowering people to lead productive, independent and fulfilling lives. Indeed, the clip even greatly softened the attitudes of individual respondents who expressed hesitations about NDIS.
- While respondents are deeply committed to the idea and intent of the NDIS, there are significant concerns about the *reality* of the Scheme. NDIS “horror stories” about barriers to access/fairness in the Scheme and system rorting are widespread and, for many, define their ‘experience’ of the Scheme, i.e. that is all they hear about it. This presents a central communications challenge: to supplant the prevailing narrative of stories entailing problems with access, equity, system rigidity, and rorting, with the accounts of the NDIS’s capacity for transformational change.

- Barriers to access and inequities in the NDIS may constitute the most significant communications challenge as these stories are, typically, received via NDIS participants (or those who have unsuccessfully applied for the scheme) known to respondents (or second hand). This gives the stories immediate credibility. As such, there is a sense among some respondents that there are undeserving participants who are able to ‘work the system’, while more deserving applicants have been rejected. A considerable number of group respondents with disabilities spoke of the Kafkaesque barriers to their being able to access the Scheme. System rigidity that does not account for the complexity of disability is also cited as a significant concern by a number of respondents - particularly those with disabilities.
- Rorting is also seen as problematic by many respondents - particularly among providers who price gouge, exploiting participants and carers. These stories are seen in the media and while there is a generalised distrust of news reporting, the “horror stories” respondents hear from people they know connected to the Scheme make these media reports credible. However, the ‘victim’ of such rorts is not necessarily seen as the taxpayer, but rather the deserving people with disabilities who are denied support, or whose support is constrained, because of cost blowouts and over-charging.
- None of these concerns, however, prompted respondents to call for cuts to - or scrapping of - the Scheme, even when groups were “stress tested” by contextualising the NDIS (and its costs) within discussions about respondents’ personal economic anxieties and concerns over government spending/waste. *Support for the idea/intent of the NDIS is resilient.* Rather there are calls to audit, reform, and streamline it to address rorts and inequities, so that those who require support can more readily obtain it. Participants want “transparency” and “accountability” – not cuts per se. Indeed, when talking about reforming the NDIS, respondents are explicit about not wanting to see anything that would hurt, or make life more difficult for, NDIS participants. For most respondents, the desire to reform the NDIS was about “protecting” it – to take away the arguments of those who may seize upon rorts, inequities, and blowouts to attack or diminish the Scheme.
- There was inconsistent awareness of NDIS cost blowouts and, once prompted, variable levels of concern about it. Once again, the primary concern about these blowouts was that they might jeopardise the Scheme by undermining its social licence and create pressure to cut budgets, depriving those needing support. Even when treated with information about the \$54b ‘blowout’, respondents echoed their responses to accounts of rorts and advocated for maintaining the Scheme (and its funding levels) while cracking down on fraudulent and other problematic activity. A significant number of respondents viewed the cost overruns as a) an inevitable by-product of any Government programme and/or b) the product of ‘teething problems’ that come with any new initiative. Many respondents were eager to explain the cost blowouts via factors beyond the NDIS’s control, such as inflation, COVID, and the increasing preparedness of people to seek help for various conditions. Others placed the blame on those who created the initial budget (under) estimates. In short, respondents sought to rationalise or minimise the blowouts.

There is a risk, however, that such latitude may not be so readily granted once people are aware that the NDIS is approaching its 10th anniversary, as many respondents are under the impression that the Scheme is only a few years old.

- 'Economic multiplier' arguments in support of the NDIS generally failed to resonate with respondents who see any economic benefits as secondary to the human benefits of the Scheme. Indeed, the economic frame had primed a number of respondents to ask questions about the NDIS's economic soundness and efficiency, or debate the validity of economic claims, when they otherwise would not have embarked on such a line of enquiry.
- More effective than arguing for the NDIS's broader economic benefits as justification for its existence is the articulation of 'concentric circles of benefit' that the Scheme affords - namely that the Scheme liberates the capacities of individuals with disabilities, their loved ones, and society's systems (i.e. hospitals). Respondents then draw the link independently with the scale of economic benefits that are the result of this liberation of capacity. In this context, respondents see the NDIS as one of the most beneficial things that Government could fund. A common refrain was that, *of all the things that Government could spend taxpayer money on, respondents were happy for it to go to the NDIS*. Again, they explicitly liken it to Medicare.
- Respondents consider Scheme participants and their families and carers to be trusted sources of information about the Scheme, as well as the NDIS website itself. This is a key part of the appeal of (and risk for) the NDIS: the vast majority of respondents know someone who is connected to the Scheme. They are greatly influenced by the human stories/experiences, both good and bad. Critically, it is the positive human stories that respondents explicitly identify as "missing" from the public/media discourse. They want these stories - they are engaged and inspired by them. Indeed, respondents consistently talk about how such stories are central to their perceptions of the Scheme's performance. There is then a desire, among some respondents, for more statistical information to buttress the human stories about the benefits, reach and accessibility of the Scheme (i.e. how many Australians it is helping).

Communications Recommendations

The communications objective this research sought to address is: to identify the narrative framework that is best to build the Australian Public's support and understanding of the value of the NDIS.

It is noted that public opinion and sentiment is never static and subject to measurable change, contingent on both internal and external circumstances. The assessments found in the current research could change within six months or they might not. But based on what we have found here, we suggest six key messaging principles:

1. **The value of the NDIS is measured in human terms – not economic.** There may be positive economic consequences of those human benefits, but they are secondary. Indeed, trying to engage on an explicitly economic argument just muddies the water.
2. The core value of the NDIS is **the empowerment of people with a disability to lead as fulfilling and independent a life as possible.** This outcome is meaningful in itself.
3. **This human benefit extends beyond the individual participant, the effects of the NDIS ripple out.** That is, benefits exist in the empowerment of the individual and unlocking their capacity/potential – capacity to lead a better life: a happier and more confident life, a more independent life, a more connected and productive life. That empowerment then unlocks the capacity of family members who may otherwise be dedicated to caring for their disabled loved one. This unlocked capacity – for both the participant and their family – flows out through community (e.g. through contribution and involvement), support services (e.g. by taking pressure of health services), and the economy (e.g. through workforce participation).
4. **We talk about these ‘flow-on’ benefits in terms of benefit to the participant ... not the benefits to the economy or others per se.** For example, we don't talk about savings to the health system. We talk about participants being able to lead healthier and safer lives, and not being dependent on trips to the ICU. We don't talk about the economic value add of having X number of participants in the workforce. We talk about the benefits of having a sense of being productive, we talk about self-worth. Our audience will join the dots.
5. **There is an emotional value to the NDIS for non-participants and people without a disability.** The NDIS fulfills a sense of moral duty and is integral to national identity. It reflects who we *should* be as a nation: people who help out those less fortunate than ourselves (in reality, there is a caveat: so long as those less fortunate are no threat to our status). In this sense, Australians do not see people with a disability as an 'other' or 'out group'. They are 'ours' to help ... and a failure do so would create an image of ourselves that we don't like.

6. **The NDIS is new and needs to be improved to ensure it is delivering the best possible support to those who need it most.** At the moment, it's not perfect, but it's not broken. We don't talk about improvements as being aimed at cracking down on costs or making things more efficient. We are making improvements to ensure those who need the most, get the most – i.e. a Scheme that is responsive to the participant. If we must talk about “rorts”, for example, we don't talk about the cost to the Scheme, we talk about the impact on participants not getting the supports they need/deserve.

In narrative terms:

The NDIS represents what's best about this country. That we look after one another and, most importantly, look after those less fortunate than ourselves. We are a lucky country and we can't allow people to be excluded from that because of a disability. We should be proud of the NDIS. Along with Medicare, there is no better use of tax-payers' money.

The NDIS enables Australians, regardless of their level of ability, to lead the most fulfilling life possible. A life of independence and dignity. A life of contribution to the community with the sense of self-worth that comes from feeling productive. A life of improved health and personal safety. A life of connection to others through being able to do the simple, everyday things that we take for granted. It unlocks the great potential of disabled Australians – and their families – and enables them to participate in the life of our country on their own terms.

The Scheme is not perfect, but it's not broken. It's still young – growing and learning. But we can make it fairer, more transparent, more compassionate and more accountable to those it supports. We must ensure that those who need it most are getting the supports they need.

Conveying the Narrative

This narrative works through all media channels and platforms but is most effective and persuasive when communicated by Scheme participants and their loved ones and carers.

NDIS platforms, including its website are the most trusted source of information, in terms of accuracy and reliability. NDIS social media channels are also effective for humanising information about the scheme, particularly where the voices of participants, loved ones and carers are used.

Consideration should be given to provision of quantitative information to be readily and easily available on the NDIS home page that details the ways in which the scheme transforms the lives of participants. While such information is currently available, it is recommended that it be given more prominence and accessibility.

What We Did

- 16 x online (Zoom) focus groups comprising approximately 160 respondents¹:
 - 14 groups comprising seven attitudinal constituencies across Australia
 - 2 x *Future Shock - Millennials* (18-39 yo), university educated, living with economic anxiety, typically renters, living in the inner and middle suburbs of major cities (Syd/Mel/Bris) highly socially progressive; 1 group comprising males, 1 group comprising females
 - 2 x *Homebuilders* (30-49yo), mix of genders, university-educated professionals, raising/starting families, experiencing economic stress due to mortgages, leaning socially progressive; living in the outer suburbs of major cities (1 x Melb/Syd/Bris; 1 x Perth/Adel)
 - 2 x *Progressive Middle* (45 yo+), mix of genders, university educated, typically homeowners, working in high-paid employment, leaning socially progressive, living in the inner and middle suburbs of major cities (1 x Melb; 1 x Syd)
 - 2 x *Aspirational Aussies*, mix of ages and genders, university or vocationally qualified, business owners or working in well-paid employment in either skilled trades or business/technical professions, leaning socially conservative, living in the middle and outer suburbs of major cities or larger regional centres (1 x QLD regional; 1 x Perth/Adel)
 - 2 x *Outsiders*, mix of ages and genders, with a vocational or high school education, working in lower-paid, precarious employment, high levels of economic stress, leaning socially conservative, living in the outer suburbs of major cities (Syd, Mel, Bris); 1 group comprising males, 1 group comprising females
 - 2 x *Regional Progressives*, mix of ages and genders, with a similar profile to *Homebuilders* but living in regional areas and with lower levels of economic stress (1 x NSW; 1 x VIC)
 - 2 x *Working Townies*, mix of ages and genders, with a similar profile to *Outsiders* but living in regional towns/centres (1 x Nth Tas; 1 x QLD)
 - 2 groups comprising people with a disability, mix of ages, living in the suburbs around Sydney, Canberra, Melbourne, Brisbane, Hobart, and Adelaide; 1 group comprising males, 1 group comprising females
- Groups explored a) awareness/understanding of and experiences with the NDIS, b) where and how respondents obtain their knowledge of the NDIS (ie media/social media/broader social network sources), c) positive and negative aspects of the NDIS, the importance of the NDIS to individuals and the community, d) values underpinning the NDIS, e) awareness of and responses to NDIS funding issues and cost blowouts, f) expectations of Government with regard to the NDIS
- Fieldwork took place between 6 and 22 Feb 2023

¹ Of note, recruitment occurred without disclosing that the topic of the focus groups would be the NDIS, thus ensuring there was no selection bias of respondents

What We Found

An Extraordinary Degree of Engagement with the Issue

Respondents across all cohorts demonstrated an extraordinary degree of emotional engagement with issues pertaining to the NDIS, regardless of their initial knowledge or experience of the Scheme.

People who had had no lived experience of disability and who had little knowledge of the Scheme demonstrated as much emotional involvement with the issue as those who had experience of disability - whether their own, or the experience of loved ones. Those who were learning about the NDIS in the groups very quickly began to speak with considerable confidence about the essential nature of the Scheme: “Such a great idea! So glad that I live in a country where these sorts of things are in place!”

Across all cohorts, those who had a low understanding of the Scheme at the outset of the focus groups became more passionate about it and its importance as each group progressed. We were consistently struck by the universality and degree of empathy and compassion respondents from all demographic segments exhibited towards people with a disability, as well as the degree to which they were moved by accounts of the NDIS’s capacity to offer Scheme participants transformational change in their lives.

Any variation in response was generally minor and personality based - i.e. not cohort dependent. Indeed, there was a remarkable consistency in support among all respondents for the idea and intent of the NDIS. As will be discussed further in the report, however, issues with the scheme’s implementation - particularly with regards to equity and access, and problematic provider practices - have the capacity to negatively impact respondents’ perceptions of the Scheme in practice. For those whose views of the NDIS had not been tarnished by such issues, the capacity of the NDIS to deliver fulfilment, empowerment, and transformation to beneficiaries of the Scheme was particularly resonant, as discussion centred on the Scheme’s provision of essential things which able-bodied people take for granted. This remained intense and consistent across the groups: “There’d be people that without NDIS can’t shower every day, can’t feed themselves, can’t get to appointments. We talk about all these extra things, but for some people, it is just the basics, and that’s just a humanitarian thing.”

This respondent’s assessment of the Scheme was emblematic of broader sentiment: “[The NDIS] is about helping people thrive because it’s actually looking at what every individual person needs, making that available to them.”

Another common refrain was that the NDIS is a basic human right on par with universal healthcare, if not an inextricable part of that healthcare: “It’s just universal healthcare. It’s a must. It’s a human right. And we have the capital for it!”

While support for the Scheme, in principle, was universal prior to showing respondents the video clip of disability rights advocate, Elly Desmarchelier speaking on the ABC's Q&A programme, after viewing the clip, the intensity of support grew significantly: "She's got an equitable existence now and she's making the most of it! It's incredible!" and, "It's fantastic that she's gained independence and she's looking forward to life again!"

This support was particularly notable among those without any experience of disability, who had not considered any of the issues presented in the clip prior to the group: "It's something, as an able-bodied person, I overlook - just help with the practical day to day things that I would take for granted, like having a shower, doing the groceries. And the other thing that stuck out for me was [the NDIS] helping people be independent. That was a major thing! Just the fact that [Ms Desmarchelier] could only think of a future where someone else had to look after her [and] be responsible for her, whereas now she's experienced transformation."

As will be discussed further in the report, issues of the Scheme's cost were secondary - if a consideration at all - to respondents. Primary for them - particularly after viewing the clip of Ms Desmarchelier - was the NDIS's capacity to transform lives: "She was able to rejoin society, rather than being on the fringe. I couldn't imagine being in a place where I'm dependent on somebody else, to have to do the basic necessities of life. To have your independence back, to have a better self worth and be part of society would be very uplifting."

This sentiment may have found such strong support, regardless of cohort, due to the sense among respondents that people with a disability comprise a group that is inherently 'deserving' of support, without caveat.

As this respondent argued, "If I could describe [the NDIS] in one sentence, it would be to provide a safety net to those who have disabilities **through no fault of their own**, to give them access to the capital they need in order to go about everyday life and get the same opportunities as everyone else."

This sense among some respondents that people with disabilities do not constitute a 'status anxiety' threat - to those for whom people are divided into 'deserving' and 'undeserving' in need - may have been key to the universality of respondent support for the NDIS's existence.

This respondent's assessment was representative of this subset's view: "This [the NDIS] is for disabled people. But if we talk about the Centrelink benefits, the dole, that goes to people who actually can work. If you compare it, I think NDIS should be funded more than the other one, because the other assistance goes to people who can actually do things, but sometimes choose not to."

Moral Duty, Empowerment/Fulfilment, and the “Safety Net”

The remarkable consistency of support for the NDIS, crossing all cohorts and demographic groups, and transcending political divides, was driven by three dominant themes:

1. the **moral duty** of all Australians to support those with disabilities, core to many respondents’ national identity
2. the capacity of the NDIS to **empower** people with disabilities to live **fulfilling** lives
3. (to a lesser degree) the provision of a **safety net** for all Australians who might succumb to disability in the future: a sense of, ‘there but for the grace of God, go I.’

Moral duty and Australian national identity

Respondent sentiment regarding the NDIS as a good use of taxpayer funds was inextricably linked for many with the idea that the NDIS is Australians’ moral duty: “Giving people access to help they need [is] the Government doing [its] duty.”

Many respondents framed their taxes funding the Scheme as a key practical manifestation of that collective duty, with a number going further and arguing that such tax expenditure is integral to the broader good functioning of Australian society.

As one Millennial male observed, “If I go through life paying tax, it goes towards the NDIS, and I’m never in that position where I ever have to claim, I’m completely happy with that. There’s a psychological safety net, but also, you have to incorporate everyone - all citizens - for a well functioning society.”

This respondent spoke further about the NDIS’s integral role in the fabric of a thriving society, which numerous other respondents from various cohorts echoed, framing the NDIS as a key good whose positive effects are felt well beyond the individual beneficiaries of the Scheme. This will be discussed later in the report in the sub-section titled, ‘Concentric Circles of Benefit’.

The Millennial male went on to say, “I would hate for a portion of society that might find it hard to get into jobs [to then be excluded] and I think being able to find a way of integrating them both from a capacity point of view and a community point of view is incredibly important. I’m imagining a world where NDIS is well funded. They’ve got the right checks and balances in place. If you hit those nails in the head, I think you’d be proud to be part of a country that offers something like this.”

This respondent compared Australia and its provision of the NDIS favourably to other countries in which such a Scheme does not exist: “Just going back to India and seeing family and seeing the system there - it’s completely different. Even the US... ***I think it’s part of our national identity that we’ve got care like this for people.*** Yes, taxes are high, but it’s critical to a well functioning society.”

This sense of national pride in Australia developing a novel initiative such as the NDIS, was a recurring theme among respondents, as was their willingness to fund such a scheme with their taxes.

Another respondent contrasted Australia's provision for people in need with other countries thus: "Whenever I'm [talking to] friends and family and people that live outside of Australia, one of the first things they [talk about] is the universal health care. That's one of the big factors for why I chose Australia. So I think that's something great to be celebrated."

In another group, a woman compared the dire situation her disabled sister would have suffered, had their family remained in Malaysia, with her current life in Australia: "[The NDIS] is really helpful. My sister has a great life [because] of it. I compare what her life could have been in Malaysia. We know of people in Malaysia with the same disability - severe autism. But in Malaysia, they won't even let you out of your room and they won't give you any support. So I mean, in comparison, this is such a blessing to have!"

For many, these sentiments tied into the notion of Australia as, "The Lucky Country," with all the attendant moral responsibilities such 'luck' entails. As this respondent from the Philippines observed, "It is a very lucky country. The difference in terms of public health [between Australia and the Philippines] is like hot and cold. It's a must for a progressive country like Australia to have NDIS. I feel like it's the most humane thing by Government to do for its own citizens to try to take away one barrier that would otherwise add another stressor for vulnerable people. [Barriers like], how am I going to fund this? Or how am I going to be able to financially support this part of this condition?"

Other respondents echoed this sentiment: "Not a lot of countries have this [the NDIS]. **So I think it's a really important part of our national identity**, where we, we are **the lucky country**, we look after everyone," and, "Australia's the lucky country and I think something like the NDIS really helps cement and establish that. In principle, it's wonderful that the really vulnerable members of our society get the support they need with something like this."

Even among those without experience of disability or other countries which lack disability support schemes, there was nevertheless a universal sense of the NDIS's crucial role in constituting Australia's moral fabric and integral to a positive sense of one's national identity: "[The NDIS] is there for those who need the most help in our community and it's an approach that Australian society [wasn't] taking great responsibility for until [recently]. It's been a massively important and positive step that we as a community have taken!"

As mentioned above, many respondents view the NDIS as akin to Medicare in the essential role it plays in Australian society, and at times see the Scheme as a critical component of universal healthcare itself.

As this respondent observed, “[The NDIS] is essentially just giving people the support they need. Growing up in Australia, where you’ve got Medicare and things like that, I kind of expect that our society should support those that need support and give them whatever it is they need to get the support and medical treatments, regardless of the costs.”

Within this frame, it is therefore unsurprising that respondents view the NDIS as a fundamental “human right”: “[The NDIS] is about wanting to implement your rights as a human. Not just as a disabled person, [but] as a *human* to access the world and everything that you need.”

Empowerment and fulfilment

While respondents’ sense of moral duty formed the foundation of their universal support for the NDIS in principle, the Scheme’s capacity to empower people with disabilities (and their families) to lead fulfilling lives equally animated and emotionally resonated with people in the groups.

As mentioned previously, the Elly Desmarchelier clip provided a powerful account that moved respondents deeply: “That was so powerful! At its core, [the NDIS] is definitely an amazing thing!”

This was a common refrain among respondents: “It was quite inspiring, just seeing how much the NDIS changed her life. Obviously, there’s a huge difference between before and after.”

Many respondents were struck by Ms Desmarchelier’s account of the transformative nature of a scheme which places the individual at the centre of it: “It’s a people based initiative with real lives that are genuinely impacted by the funds that they get. I know someone who is in that position, and his and his parents’ lives are just completely different. [It’s] genuinely life changing. The fabric of their day is just completely different because of the support that they get from the NDIS.”

The reactions from some respondents without any experience of disability were also instructive: they expressed a degree of shock as well as intense sadness that prior to the NDIS’s implementation, the situation had been so dire for people like Ms Desmarchelier. In response to her account of having to use an unsuitable wheelchair from Aldi prior to the NDIS’s implementation, one respondent remarked, “How heartbreaking that she had to have a wheelchair from Aldi before NDIS!”

Another respondent observed, “I thought it was very, very powerful. Extremely powerful! People absolutely do need this [the NDIS] and I would hope that that is what it’s trying to do - [to] give them a quality of life back again. That was the most powerful sentence of all. What’s life without a bit of quality - if you can’t go anywhere, you can’t do anything practically? You’re relying on [others], you can’t shower, you can’t eat - particularly in a wheelchair situation. It’s no point living to your 90s or 80s if you can’t do anything. What’s the point of living? They’ve got their life back again!”

This respondent's palpable excitement was echoed throughout the groups, across all cohorts, with one caveat that will be discussed further in the report: those with experience of barriers to Scheme participation found the clip a bittersweet reminder of the Scheme's noble goals that - for them - are yet to be realised.

With that caveat, most respondents felt that Ms Desmarchelier - and people like her - could now enjoy independence, productivity, and a fulfilling existence which would have otherwise been impossible: "It sounded like [people like Ms Desmarchelier] didn't have any kind of quality of life, and that it was completely transformative for them. They didn't realise they could have a job, they could be independent. So there isn't a financial price you can put on that kind of transformation for someone."

Even among more conservative respondents, for whom employment and self-worth are inextricably linked, the idea that the NDIS is able to free-up people (participants and their family members) to work is significant: "Instead of being a burden on society, costing us money to support, they're actually paying taxes and contributing to society and the economy. So it's actually a win-win for everybody. They're getting a sense of worth, they're paying taxes. They're having a semblance of a normal life and feeling like they're some value to society."

Regardless of political orientation, however, there was broad support for the notion that the NDIS's intent is integral to fairness, "levelling the playing field," not just for respondents, but for their families as well: "We've always had people who've had a need but [prior to the NDIS, that meant] the better off were able to afford that because they've got a higher disposable income. [Now] the NDIS levels that playing field. **So as long as you can qualify, then you're in as good a position to get care as anybody else.**"

These themes of equity and opportunity were uppermost in the minds of respondents: "I think [the NDIS] is really important because it's about equity - having the same opportunities as everyone else, despite your circumstances," and, "Equity - where we're making sure everyone has good quality of life [is key]."

Equity and opportunity were linked by a number of respondents to their opposites - i.e. in the absence of supports such as the NDIS, respondents pondered the consequences for those with disabilities: "Whether it's a physical or mental disability, that can be very isolating. I think that it is an important Scheme because it can give these people independence, it can help them have a voice. I'd like to think it's to help with independence and social assimilation."

One respondent, whose ridesharing service is used by people on the Scheme spoke of the independence she has witnessed first hand that was a result of the NDIS: "I drive two young girls who are actually on NDIS. They are disabled mentally and physically but they are still independent, to go to work, go to school, go to education centres."

This respondent lauded the flexibility inherent in the NDIS for these young women, who could take taxis, but feel safer using the respondent's women-only ride-sharing business. She spoke with delight about the empowerment the Scheme affords: "They actually utilise it because they feel safe. One girl has Down Syndrome. She is very independent. She actually goes for evening activities, and she goes on her own."

Indeed, the choice that the NDIS affords was a subject that resonated for a number of respondents: "User choice sounds like an absolutely good idea. Everybody has their own specific needs, their individual circumstances, "and, "The big part about [the NDIS] was the actual participants get choice and more empowerment: so much more choice for the consumer!"

This sentiment was shared by this respondent: "I feel like NDIS plays a strong role in giving people choice and control. Often, when disability strikes, you lose those two things. And that person can choose to bring back that satisfaction, fulfillment."

A number of respondents spoke of the tangible ways in which the NDIS facilitates choice and empowerment: "My sister's got two kids with ADHD and autism. The NDIS do buy things like laptops [and] they do weekly things with a woman from some service and they go out and go bowling and stuff like that. Her school [also] gets funding to help prepare."

Another respondent recounted, "**If people can navigate [and] access it, there's some really good supports in place.** My friend whose son has autism was able to access funds to get a cleaner because [her son] gets really overwhelmed and terrified by the sound of the vacuum cleaner. So even just something simple, like cleaning her house, she couldn't do when he was there. So being able to access a cleaner meant she could take him out of the home so he didn't get distressed."

This respondent went on to describe how the NDIS facilitated a support dog for her friend's son as well: "They could even apply to get a therapy dog through NDIS, purchasing the dog and paying for all the training. So I think there's some really fantastic things in place."

Stories from people other than Ms Desmarchelier were also extremely moving for respondents, including accounts from loved ones whose lives had been transformed by the NDIS, or, for those without a prior connection to the NDIS, other respondents' stories of the Scheme's transformational potential.

This account from one respondent struck others in her group as particularly profound: "I know someone whose children inherited genetic disorders. One of them's slowly deteriorating, the other one passed away. But [the NDIS] is a massive support for her because she could never physically even assist them in getting up and that sort of stuff. So it helped them getting the right chairs, the right support staff, and getting them into the right facilities. [It] even gives them a little bit of life and comfort. It's a massive thing, helping the family live and cope - not just the person with the disability."

The “safety net”

A number of respondents cited the “safety net” aspect of the NDIS as particularly important, invoking a sense of, ‘there but for the grace of God, go I’ with regard to the role that randomness and luck play in disability.

As this respondent observed, “When we’re talking about disabled people, I think it’s important to remember, that can be any of us tomorrow. All it takes is a car accident or a disease that leaves us altered. So really, an insurance scheme that can look after people with a disability is [actually] looking after all of us.”

This sense of the safety net crossed cohorts: “[The NDIS] is a fantastic idea. You never know if you’re going to develop anything that will permanently disable you and you will need extra funds, or you may not have enough savings. You will need some sort of safety net to rely on.”

Another respondent spoke of the psychological aspect of the safety net the Scheme provides people she knows who have accessed it: “The lack of anxiety that they have [because of the NDIS] is transformative. That safety net is there for them. So I’ve got all the time in the world for the NDIS!”

This theme of the “psychological safety net” also crossed cohorts: “It provides us a bit of a psychological safety net, knowing that no matter what happens, the worst thing could go wrong tomorrow [but the Scheme would be there].

Others, however, were keen to point out that *the NDIS should be about more than preventing people from ‘falling’, rather, it should bounce them back up, affording them a life that is “as normal as possible”*.

Pushback on the ‘right to an ordinary life’

This discomfort among some respondents regarding the idea of the NDIS as a “safety net”, because they worried that such framing did not aim sufficiently high in providing empowerment and fulfillment to people with disabilities, was replicated and magnified when we presented them with the phrase, ‘the right to an ordinary life.’

Most respondents objected to that framing as an abrogation of the moral duty Australians owe to people with disabilities to provide them with the necessary means to live empowered and fulfilling lives: “‘Ordinary’ is a very ordinary word! We want people to have an *extraordinary* life. So I do have a problem with that statement,” and, “It should be about giving people what they need to support them as best as they can to live the most fulfilling lives.”

One respondent felt that such a statement both discounted the hurdles people with disabilities face while also underplaying the enormous potential people with disabilities have to lead extraordinary lives: “Someone in a wheelchair [is] not going to live an ordinary life. They’re not going to be able to walk because of NDIS funding, but you want to be able to give them dignity. We do see people with disabilities participating in Olympic events, so they can inspire people in their situations to reach out for those dreams as well. It may not be their original dream [but we] should still motivate people to find fulfillment and I don’t think there should be limits on that - just keep persisting and reach that ultimate dream.”

Other respondents had a darker view of the phrase. One with a significant disability remarked, “An ordinary life, working nine to five and then dying - it’s the shits. Support me so I can fulfill my best possible life and all my ambitions.”

Another respondent in the same group, but without a disability concurred, “Yeah, get them integrated, giving them that sense of connection and community. [It’s] not just about leveling the playing field, but how do you make it even better?”

The NDIS as a means of destigmatising and mainstreaming disability

A subset of respondents – particularly Millennial respondents – identified the destigmatisation and mainstreaming of disability as another important component of the NDIS. Just as others, described above, likened the Scheme to Medicare in its foundational nature to the good functioning of Australian society, there were those who viewed the establishment of the Scheme as significant in its capacity to raise awareness about, and demystify, disability through being a core function of Government in much the same way as the broader health system has become. These respondents therefore viewed the NDIS as framing disability as a core part of life and society in the same way that visits to the GP are normalised.

As this respondent argued, “The importance of NDIS is on a national scale. The existence of the NDIS plays an important role in the language and dialogue of disability. I think the very existence of it helps destigmatise disability to some extent - at least, I would like to hope so! Make it more known that this can strike anyone at any point in time, that we should all be allowed choice and control.”

Another respondent concurred, “I agree. Dylan Alcott winning Australian of the Year - all those kinds of things added together, destigmatises. So I think it’s really important that we have the Scheme and [that we’re aware of] a stat like one in five [people have a disability]: it could happen [to anyone].”

Areas of Concern

“Horror stories”, access, and equity

While there is commitment to (even passion about) the idea of the NDIS, when it comes to the reality of the Scheme, respondent views were heavily influenced by the “horror stories.”

As one respondent noted, “We’ve all heard the horror stories” - the corollary being that they are *not* hearing the positive stories. This presents a central communications challenge: to supplant the prevailing narrative of stories entailing problems with access, equity, system rigidity, and rorting, with the accounts of the NDIS’s capacity for transformational change.

While the prevalence of NDIS “horror stories” from traditional and social media (as well as people’s own social networks) was a significant feature of respondent knowledge of the NDIS, there was, a degree of latitude afforded by some due to the Scheme’s newness - a sense that these issues are inevitable “teething problems” for an initiative of such scope and ambition.

“You always hear the horror stories, and the stories of people that miss out. [But] I didn't realise how new NDIS was, it's only been around for a couple of years so that helps contextualise it a little bit for me and understand how new it is.”

It is worth noting, however, that the Scheme’s ‘newness’ is conceived of by many respondents as constituting only a few years - many seem unaware that the Scheme is approaching its 10th anniversary. Awareness of the Scheme’s actual age could, therefore, militate against this latitude.

Importantly, these horror stories revolve around a central idea/fear that *the people who need help the most are not getting it* under the Scheme. Such stories therefore represent the blockers to the fundamental purpose of the Scheme: equity and opportunity.

Critically, in these horror stories, the ‘victim’ is not seen as the taxpayer, rather the victim is the Scheme participant who might miss out on the supports they need. While the ‘villains’ in these accounts are either the rorters taking advantage or those making poor decisions about people’s support needs, and there is a sense of latitude in that the Scheme is new and unique (“things always go sideways at the beginning”), *there is nonetheless an expectation that “fine tuning” now must occur.*

Again, this “fine tuning” is not about trying to reduce the cost of the Scheme per se, but about ensuring participants receive what they need and that fairness underpins the Scheme. As such, it’s about “accountability” and “checks and balances” to make sure the money is going to where it is needed most.

Or as this respondent framed the issue: “[Do] not cut the funds of the NDIS. Just make it better!”

The horror stories which had most resonance for respondents did not centre on cost blowouts. While a number did cite accounts of NDIS rorting by providers (and to a much lesser extent, Scheme participants), the truly resonant negative accounts centred on people with disabilities whom respondents felt had been unfairly brutalised by a Scheme that constituted a “bureaucratic nightmare.”

These accounts varied from media stories, to stories from friends and family, to the personal experiences of respondents themselves, trying unsuccessfully to access the Scheme.

One respondent stated, “I've heard a lot of negative things about the NDIS. I know it's a fairly new initiative and it's to help those with disabilities live a normal life [but] I've heard that it's very difficult to be approved for NDIS funding [and that] it's very difficult to keep that funding because there are constant reviews. I used to work in debt collection and I've heard stories of customers that have been relying on this NDIS funding, and then they've had a treatment or something, and then it's been taken away.”

Too ill/disabled to earn the money required for diagnoses that would grant access to the NDIS

Some respondents, who suffer from numerous disabling conditions, spoke about the perceived impossibility of applying for the NDIS. Negative media stories about a difficult system instilled anxiety around the Scheme and combined with the Kafkaesque situation of their being too ill or disabled to earn the money to afford the medical specialists who would provide the diagnoses which would qualify them for the NDIS.

One woman, whose child has been accepted into the Scheme observed, “**Because I've never had adequate mental health support, I don't have the finances to seek mental health support. I don't have the finances to get a diagnosis.** But that doesn't remove the fact I have a lot of support needs. So I'm stuck in a situation now where NDIS aren't going to help me because I don't have words on a piece of paper from a psychologist or psychiatrist explaining that I need it.”

This situation was echoed across cohorts: “Everything's privatised. As a middle aged woman trying to get an ADHD diagnosis or [be] on a waitlist for autism, I can't afford the assessment. There's lots of barriers to treatment, it's absolutely horrific, trying to understand and navigate [to] get any sort of help and support.”

One respondent with severe mental health issues had been so traumatised by other experiences with Government departments, including trying to get her mother into a dementia unit, that she decided she simply could not face even applying for the NDIS: “**I'm just not strong enough to go through the hoops.**”

One respondent had attempted to access the NDIS for his wife suffering severe mental health challenges which had made it impossible for her to work. She was, however, rejected, and the respondent spoke with resignation: “So now we're a one income family”.

Importantly, for many respondents, this sense that people's economic situations are harmed by their disabilities constitutes a critical litmus test. That is, where disability interferes with the capacity to work and/or adversely affects a family's standard of living because of the costs associated with the disability, there is an expectation that the NDIS will be made available to render support so that the central aim of the scheme - equity and fairness - is realised: "[The NDIS's] role is to make sure that the world at least a fair playing field at the end of the day."

A respondent with a suite of significant disabilities from a different cohort stated, "Every time you go to a doctor or a specialist, you're out for the money to get that report. And then [those reports] expire after a year or two. Nothing's changed with my condition. It is what it is. It only gets worse. And [it costs] \$40 gap [and] specialists at \$200 if you don't wait two years on the public system... It's just too much work [and] the negative [sentiment] would be coming from TV current affairs shows, news, and that, where people are trying to access care or trying to access continuity of care [and] they've had the care and it's taken away."

Another respondent with a disability who had been rejected by the NDIS assessed it thus: "[It's] a scheme that sets you up to fail - that's my experience. It's a very stressful scheme."

A common response to these stories, from those without disabilities, is represented by this respondent's observation: "**I would rather see some people get in who aren't supposed to, than see so many people being left out.**"

Variability and fairness issues regarding eligibility

It is notable that a number of respondents saw inequity and capriciousness in the approval process itself.

A respondent observed that while some deserving applicants had been rejected from the Scheme, "I've heard stories of other people that are basically getting some NDIS company to drive them to the airport to pick up a friend from the airport [when they] can actually drive and things like that. I think it's about making sure the balance of funding goes to where it needs to be and there needs to be more regulation around it."

Of note, however, this respondent argued for more flexibility in assessments to assess genuine need: "The assessment, in terms of actually who needs more funding, [should be] less black and white."

As one respondent who works with children with disabilities observed, "Who gets help from NDIS and who doesn't? That's an area that I'm a bit confused by, because when I work with children, some of them do get funding, and then some of their parents say, 'It's so hard to get funding and we're not allowed to use it.' So I'm not sure how they decide who does and who doesn't."

Another respondent recounted the difficulty she had accessing assistance from the NDIS for her daughter who is on the autism spectrum: "12 months ago, my daughter received an autism diagnosis. Because she's level one, I believe that we can't really access the NDIS."

Falling through the gaps of siloed systems

Others argued that there is an urgent need to rationalise and interlink disparate systems and services, such as Medicare, various welfare payments, and the NDIS, in order to minimise these accounts of people falling through the gaps, while avoiding unnecessary bureaucracy and waste: “I think [the NDIS] should be more linked with the broader health [system] for everyone so they don't have to jump through the hurdles of getting a diagnosis. They should be helped to get into the right system to get the right diagnosis. Even if they don't make the leap to get the funding, they should be able to access some sort of help and assistance, not just, ‘You don't tick the boxes and go away!’”

Another respondent concurred: “We've got Centrelink. Okay: so for some people, they are on high medication, but they can't get the assistance from Centrelink to get a healthcare card or pension card, because it's not recognised. So the two systems should be working together to support the person who needs [help].”

It is notable that these issues of access and equity were the only elements that elicited any negative responses to the Elly Desmarchelier clip, as respondents contrasted her transformative experience with their perception that too many people are unable to access the Scheme due to bureaucracy and/or excessive costs: **“It definitely changed [Ms Desmarchelier's] life. She's highlighted that very well. For some people, they don't have that. So it doesn't work for everybody.** Some participants need a nominee that can [advocate] for them. [Ms Desmarchelier] got a better advantage but people who can't [advocate] for themselves, it is hard because they're not getting the funds.”

Similarly, respondents living in regional areas remarked that Ms Desmarchelier likely enjoyed ease of access to diagnosis and care because she lives in a major city and that such services are not equitably distributed across the country: “I think the clip shows exactly what it should be about: the optimum goal. [But I thought to myself], ‘Oh, I bet you're in a central city and you've got a great support coordinator. You're definitely not regional or rural Australia. I reckon for at least half [outside the cities, they] are just still scraping to get basic needs.”

Even those respondents with disabilities who had been accepted into the Scheme and were enjoying its many benefits identified these access and equity gaps: “I live with a chronic disability. And two years ago, I had an occupational therapist, who really fought for me. So now I receive six hours of support every day. But it is very easy to see where the glaring gaps are!”

Another respondent spoke of the challenges of navigating the system for CALD families: “It is stressful trying to navigate through it. **My family is non-English speaking background. We had the nightmare of having to go through a lot of bureaucratic red tape.** So that part is very stressful - especially when you're waiting for approval, or not even sure if you're gonna get the approval. **It's as if you're waiting on the lottery, and it's just luck,** if you end up getting someone actually giving you the ticket or not.”

Of note, however, was the significant subset of respondents - albeit, those without disability who had never interacted with the system - who treated such negative news stories about the NDIS with a degree of scepticism, due to a broader distrust of the news. As this respondent observed, “Whatever I hear about the NDIS from the media is always going to be the 1% stories - the nightmare stories. It's going to be the headline making stories. It's never going to be the reality of the NDIS.”

Respondents from other cohorts expressed similar sentiments. One, after watching the Desmarchelier clip stated, “I couldn't help but feel maybe the media has skewed my opinion of [of the NDIS] slightly, because media would only ever [give] you negative stories. In a perfect world, we should be hearing 95% positive, important stories, and 5% being like: we need to work on things. [There is] the 80%, the 90% of the people you don't hear about, but benefit every day from it.”

Or as this respondent observed, “The media does a great job of telling us when something's gone wrong. It'd be great to see some advertising or just some positive stories, like how the NDIS transforms someone's life.”

It must be emphasised, however, that this scepticism was the *sole* preserve of respondents *without* any connection to - or experience of - disability. For those respondents who did have a connection to/experience of disability, negative news stories often acted as a powerful disincentive to even attempt to apply for the Scheme or confirmed negative accounts they had either heard or experienced first hand.

System rigidity

Key to many respondent concerns regarding access and equity issues with the NDIS is the perception that the systems in place for Scheme approval are too rigid, precluding people who are deserving of the Scheme's benefits from obtaining them.

As this respondent observed, “I think there needs to be a lot more outside of the square thinking in the approach to something like this because [with] disabilities, you can't pigeonhole everyone into [just] 10 different boxes and say, ‘Okay, you're here. This is what your funding will be.’”

This sentiment was echoed across cohorts: “I guess it comes down to criteria and becomes very black and white [regarding] assessment - who gets the funding. This person happened [to be] a winner for whatever reasons, this person doesn't [get accepted], for whatever reason, just because of some nuancing.”

One respondent who is an NDIS recipient, with a broadly positive experience of the Scheme, framed the issue thus: “One of the problems is, there's very limited oversight. I've got a [rare] condition and here's the problem: they don't understand how much I suffer. And they actually never met with me. They've never lived a day in my shoes. [Only] because of excellent staff fighting for me, I've got a really good package [but] I've got a lot of friends that just don't get anywhere near enough money. It is not anywhere near fair enough yet. [There has to be] a whole lot more oversight, or even simply proof that the person assessing the claim has even Googled the condition, because my understanding is that [assessments are done] without any medical training [so] there's no way that they can understand.”

Or as another respondent succinctly stated, “Too much cookie cutters - too much tick a box... a little too black and white!”

Rorting and cost blow outs: respondent concerns remain centred on equity and access

Nearly all respondents raised (unprompted) - or were aware (once prompted) - of the issue of rorts within the NDIS - primarily regarding problematic providers. This extends from outright unethical (even “criminal”) rorting through to providers who simply charge the maximum amount possible for a service, regardless of the scope of the service actually provided: “From a lot of press, I feel like that there's a lot of criminal organisations that are rorting it. [Perhaps it's] a small percentage, but it sounds like people are being extorted - especially those with a disability that can be the most vulnerable.”

It should be emphasised, however, that concerns regarding rorting of the Scheme were primarily framed as problematic because *they constitute an impediment to access/support or worse: something that might put the Scheme itself at risk*. It was not viewed by any cohorts as a reason for cutting the Scheme.

As these respondents observed, “My concern is the flaw in the system [that allows] people who don't need it so much taking advantage of it. So it's going to impact upon the people who really do need it,” and, “For example, the private sector people who inflate their invoices, that money could be going to someone else who needs a wheelchair. So maybe they need someone else to audit and make sure that some people aren't taking advantage of it.”

Similarly, rorts inspired concern among respondents that harm could come to the most vulnerable, as opposed to being a problem for the country's bottom line: “Are all of those providers that are approved actually providing what they're supposed to? Or are they taking advantage of those people in our society that may have less of a voice?”

Of those respondents for whom rorts were a major concern, providers inflating prices was a recurring theme: “As soon as there's the word NDIS involved, they're putting out inflated invoices or charges. So they will get paid at this higher rate, because they know it's going to be covered by this person's NDIS support package.”

Or as this respondent observed, “My son receives funding from the NDIS for speech therapy and occupational therapy and after he got approval from the NDIS, they jacked up their fee by 30 bucks per session.”

When these rorts were discussed, there was some degradation of social licence for the Scheme among certain respondents; however, they were adamant that this degradation should *not* result in funding cuts or the scrapping of the Scheme, but rather the streamlining of processes necessary to rein in problematic practices.

It is also notable that many respondents considered the rorting of Government benefits an inevitable by-product of any provision of a social safety net and therefore, any social licence degradation as a result of problematic practices is, therefore, minor.

Indeed, the costs themselves were posited as secondary to the *moral* blight of rorts which respondents viewed as compromising people’s access to much needed support. The most fervent objections to rorts centred on the threat they posed to the Scheme’s existence and its capacity to help those most in need.

As this respondent observed, “The cost blow-out isn't so much the issue. All these stories about people rorting the system have now quite negatively impacted my view. Before this meeting, I wasn't overly aware of that. So now [I think] this seems to be quite a large problem. And I know that it's not necessarily just the NDIS system. I know that it's pretty systemic across quite a lot of government funding. [But I'm] not feeling as great about it, as I probably initially did because the system isn't working as intended.”

Another respondent echoed this sentiment: “[The rorts have] negatively impacted my perception of this social licence, because I have high expectations for the Government. They should have structures in place to administer that money for the people who need it.”

One respondent with severe mental health challenges who has accessed the Scheme spoke of its critical role in keeping her alive due to the isolation her condition otherwise causes (“without my funding, I wouldn’t be here today - I would have spiralled out of control”); however, she noted that the system had become less user-friendly, due to crack-downs on fraud: “It’s getting worse with the recent audits, because so many people are getting away with ripping the system off.” She described how these audits have become much more stringent but this has rendered the experience of the Scheme much worse for her, while acknowledging, “[The NDIS] is a massive undertaking from the Government and they’re learning as they’re going. People can claim really good dollars [from the Scheme].”

Some respondents, primarily from cohorts comprising women under the age of 40, viewed the rorts as an inevitable consequence of privatised services coexisting within a publicly administered system: “The fact that all of these private sectors have popped up around the NDIS kind of indicates to me that the Government has failed in that sense. The private sector shouldn't need to step in to such a public initiative. The government is giving out money [and] the middleman shouldn't exist.”

Discussion of rorts often prompted respondents to call for greater transparency and accountability: “I don't think there's a lot of transparency from the Government. How does it work? How does the funding for it, and the budgeting work?” and, “Make it transparent for taxpayers to understand how the Government's spending money.”

There are , however, two conundrums here.

Firstly, respondents were particularly animated by stories of those unable to access the Scheme because of having to repeatedly jump through bureaucratic hoops (e.g. the idea of parents having to repeatedly “prove” their child is still disabled was particularly distressing for some) in order to get or maintain funding: “You seem to have to do the same thing over and over again, to prove that your child has a difficulty. Life's probably hard enough if you're in that situation without having to do that all the time!” Thus, the capacity of ‘transparency and accountability’ mechanisms to worsen problems around accessibility was raised. Indeed, respondents were quite clear that whatever happens in the reform space around NDIS must *not* make life harder for those who need the Scheme.

Secondly, open discussion of the prevalence of rorts primed respondents to question the efficacy and social license of the Scheme where they might otherwise have not considered the issue. There is a risk that by talking about “transparency and accountability” – in the wrong way – we reinforce the ‘truth’ of rorts and Scheme failures.

Furthermore, respondents’ calls for transparency generally occurred *after* discussion of rorts and cost blowouts - calls for greater transparency rarely emerged unprompted. So while there may seem, qualitatively, like there is appetite for greater transparency, an overemphasis on problematic practices may prove counterproductive by reinforcing negative perceptions. Instead, a number of respondents spoke of their desire to see more statistical information about how money is spent on the NDIA website, in an easily accessible format. Such information - *about how the funding benefits Scheme participants* - would likely satisfy those advocating for greater transparency from the Agency. That is, greater transparency around its impact/benefit, not just its operation.

Cost Blowouts

Patchy awareness and pushback against cuts

Awareness of NDIS cost blowouts specifically was generally quite low among respondents. Only a few were aware of the extent of the issue, having heard about it from media reports.

Once made aware, the quantum of the budget blowout did concern some respondents – particularly among those already anxious about their personal economic circumstance and the direction of the national economy. For this subset, a cost overrun in the order of 50% was not acceptable, especially in the context of massive government debt following COVID. This impacted the social licence to some extent by drawing focus towards “the competence of the people running the program” and the efficient/equitable use of money within it.

However, once again, the solutions posited did not involve scrapping the Scheme. Rather, it prompted calls for better accountability to ensure every dollar is going to where it’s needed. Respondents wanted Government to “find the cost efficiencies”, where efficiency means the people who need the most, get the most. They then wanted to hear the stories of “the positive ROI” – being the stories of transformation and benefits to the lives of NDIS participants (as mentioned earlier, this is missing in the discourse to which most respondents are exposed).

Of note was the intensity of the pushback from respondents in all cohorts against cutting funding to the NDIS as a panacea to the blowouts. While a number of respondents, as described above, called for better regulation and oversight to prevent rorts, many other respondents were adamant that such a new scheme could not be expected to accurately judge the quantum of funding that would actually be required: “From what I've heard in the news, I think the NDIS overall has been severely underfunded,” and, “Anyone who thinks that the NDIS should be cut, or that people get too much money from the NDIS, just don't know anybody who accesses the NDIS!”

Or as this respondent observed, “Initially, things are a little bit more expensive as you get them set up and working - understanding how much you actually need.”

When asked whether the cost blowouts signified an ‘unfixable mess or teething problems,’ the response was unanimous: rectify abuses of the Scheme, but the Scheme itself is sacrosanct: “It does provide a valuable service for those who do use it correctly. So cutting funding to people who are in need [is] not great,” and, **“Talk about cutting the funding to the NDIS made me feel really uncomfortable because I feel like we spend so much public money on other things and this is an area where, if anything, NDIS probably needs more funding!”**

As mentioned earlier, these respondents often cited, unprompted, the novelty of the Scheme and its lack of precedence around the world as leading, inevitably to ‘teething problems:’ “We're the first country to do this Scheme So [it is difficult to be] coming up with a budget for it without knowing anything about like costs.”

Of note, was the determination so many respondents displayed when searching for reasons *other* than rorts and fraud for the cost overruns - *that is, seeking to minimise any argument for cuts*. Inflation and the rising cost of living was regularly cited as a key driver of increasing costs: “There are a lot of factors that are out of our control. [For example,] the CPI was really significantly increased.”

A related respondent hypothesis involved the labour shortage among allied health professionals, thus driving up prices: “There’s not enough services for everyone and that could lead to the cost blow up. Because if everyone’s inflating their costs by 20%, then that will add up to a few billion if you think about all the people who provide services.”

Others attributed the blow outs to factors such as the destigmatisation of many conditions, leading more people to seek treatment and support, as well as an aging population: “On gut feeling, I think [there is an] increasing population [seeking support] - a lot of people [are being] diagnosed with mental illnesses more often. [And] this might affect everyone, because we get old and are getting diseases. So maybe it’s just that we’re qualifying more because of this.”

This sentiment was echoed by another respondent: “I think there’s a lot more awareness about what issues need support. And I’m also thinking about the change in conversation and the change in awareness for everyone across the board. If I were to have children, I think I would be so much more attuned and aware to their needs, and perhaps be more willing to seek support, if it was relevant. But I think about my own parents, and I think they wouldn’t have done so. And that’s only 30 years ago! So along the way, there’s just been a huge shift in people understanding what the spectrum of disability is, and what support looks like, which is a conversation that we might not even have been having to the same standard, even five or ten years ago.”

Or as these respondents succinctly stated, “**It just highlights that there is a bigger need than we anticipated in this area,**” and, “[There has been] a lack of anticipation and preparation for growing need.”

Indeed, some respondents pushed back on the assertion that rorts could be behind the enormity of the cost-blowouts: “Billions and billions of dollars of rorts? You can’t blame it all on that side of things! [They] might not have accounted for the aging population. But I think no one is really safe from the increasing costs of everything. Labour is getting more expensive. Products are getting more expensive, getting things to Australia is getting more expensive. So I don’t think any industry is necessarily safe from huge cost blowouts because of all those things.”

On a related note, a number of respondents cited COVID as another factor in driving up costs: “I think the pandemic is partly responsible - the circumstances surrounding the pandemic are the cause of these cost blowouts. [There are] people suffering long term COVID symptoms, people whose lives will never be the same, people maybe who already had disabilities that just got worse, or maybe just led to many other types of sicknesses from that.”

As mentioned above, for many respondents, there is an in-built assumption that cost blowouts are an inevitable feature of any Government programme, and that such expenditure has inherent social licence when it is directed to people with disabilities. On numerous occasions, respondents declared their preparedness to pay extra tax if it meant, “making a difference to somebody’s life.”

Or as this respondent framed the issue, “For me, it comes down to the reason for the cost blowout: if the NDIS is very poorly run [with] money being thrown in all the wrong places, then yeah, [that] would degrade the social licence. But if it is just a cost blowout [because of] more people needing support, then that’s different and doesn’t affect it.”

This was a common sentiment among respondents: “I think, obviously, it is a really high priority and we shouldn’t be looking to cut down in terms of where people need the money. But I think what we should be looking at is ways to streamline and make the NDIS Scheme more efficient, so that you’re getting those savings without removing the outcomes.”

A significant subset of respondents specifically identified the NDIS as worthy of whatever taxpayer money would be required: “As a taxpayer, you see a significant chunk of your paycheck goes away. And at the time it hurts, but you can really rationalise it to yourself: someone who needs this a lot more than I do is getting it!”

Or as this respondent observed, “It’s as necessary as public transport!”

Of note, a number of respondents specified their preference for their tax dollars to go to the NDIS over defence spending. “My brother in law is part of the Army Reserves and hearing his stories about how much the Government spends on Reserves shocks me. I think we’ve missed a lot of money there!” and, “[Regarding] the Defence budget, if they’ve got money for that, they should always have money going towards health!”

Or as this respondent summed up the broader mood, when discussing cost blowouts, **“My mind doesn’t jump to being concerned about tax raises: my mind just jumps to being concerned that people won’t be getting what they need!”**

'Economic multiplier' arguments: either a side issue or a prompt for negativity

It is within this frame that we might best appreciate the failure of the 'economic multiplier' argument to resonate with respondents as a core justification for the NDIS.

While there was appreciation for the savings and efficiency that resulted from taking pressure off the hospital system (as evidenced by Elly Desmarchelier's account of the NDIS allowing her to avoid stays in intensive care due to preventable infections), most respondents were adamant that economic benefits accruing from the NDIS were secondary to the human reasons for it.

Interestingly, when talking about the importance of the Scheme, beyond references to helping disabled people be work-ready, the notion of an 'economic multiplier' justification did not really occur to respondents. When presented with that idea - i.e. that the NDIS delivers an economic benefit beyond its cost (through employment, workforce participation, etc) - there was a recognition in some quarters that that would be a good story to tell (with none having thought of it before being prompted).

However, using an economic multiplier narrative precipitated an economically-minded response. That is, respondents then (for the first time) raised concerns about the economic "efficiency" of the Scheme. This included the rorts discussions, but also the idea that the NDIS was creating "industries within industries" - creating layers of services/activity (e.g. an industry around just helping people navigate the NDIS) that do not constitute a good use of taxpayer money, perhaps even taking that money away from where it is needed most.

Priming respondents to talk about economics alone provoked a rigour and mindset that was actually less favourable to the Scheme than discussing the broader, human narrative of transformational change: "All policies will have positive and negative externalities. But you can't cater to that: you've got to stay true to purpose. What is the purpose of the NDIS? And what is the impact on it to those who need it? **The only success should be if the people on the Scheme are getting the value they need. If it's creating some jobs on the side, that's not [the main point].**"

Another respondent concurred: "If you talk pure economics, [are you] just creating the industry within itself, where you're taking money from taxpayers, [and] giving it to people that don't really need things? And potentially, you're creating jobs that aren't really needed. You're creating this circular effect, where it's essentially just taking money [from] tax to generate jobs that aren't necessarily needed - as opposed to giving it to people that really actually need it."

Similarly, while some respondents mentioned people with disabilities entering the workforce as part of a fulfillment narrative, they did not raise economic impact/benefit as being of primary importance. When prompted, many rejected that narrative as being a side-benefit of the true "return on investment" - the human benefit/story: "It's not economic output!"

Ironically, one respondent, an economist, used an economic argument to push back on the use of economic multiplier frames to analyse the worth of the Scheme, speaking of “opportunity costs” - meaning: what else is Government going to spend money on that’s more important than the NDIS and what are the consequences of not spending that money? There was broad assent for this position as another respondent remarked, “We’ll look back fondly in 30 years and be proud of the NDIS, like we’re proud of Medicare”

Of note, in all 16 groups, only one respondent (from the Progressive Middle cohort) cited, unprompted, the economic multiplier aspect as a key benefit of the NDIS: “Since it was introduced, it’s created an economy in terms of new businesses providing services to the disabled that were never that weren’t there before. That was long overdue.”

Importantly, respondents’ knowledge gaps regarding the actual cost of disability care left the most room for rorts and waste discourse: “People being fraudulent would be my gut feeling [regarding cost overrun]. I can’t really think of what else would be costing that much money other than people trying to be sneaky.”

Because of the remarkable consistency across cohorts in support for the NDIS in principle, regardless of cost blowouts, in the latter groups, we commenced ‘stress testing’ respondent support. We did this through priming respondents by asking about their own economic situations and associated stressors of the cost of living crisis. We then asked them to speak about their thoughts regarding Government waste. It is notable that even under such conditions, respondent support for the NDIS remained emphatic, with no appetite for cutting funding to the NDIS. This resolve was significantly strengthened by Ms Desmarchelier’s account: “I think [Ms Desmarchelier] just reiterated what we said before: not to cut the funds of the NDIS. But just make it better!”

However, the stress test did result in economic arguments being more readily accepted. Within this context, after viewing the Elly Desmarchelier clip, respondents viewed the NDIS as affording those on the Scheme, as well as their carers, the capacity for economic independence and the opportunity to be economically productive; however, this was very much an extension of the empowerment/fulfilment narrative.

It is noteworthy that in this context, there was no need for an economic argument to be made explicitly, as respondents were able to make that connection themselves: “There is economic benefit if you’re helping people with disabilities become productive members of society and, you know, get jobs rather than be on a disability support pension.”

Concentric circles of benefit

Indeed, it appears that the way in which the economic arguments for the NDIS may be best prosecuted is via its *tacit* acknowledgement through the notion of ‘concentric circles of benefit’ - i.e. the NDIS’s ability to unlock the capacity of carers, as well as those with disability, to contribute to society, while also removing pressures from other support systems, such as hospitals; all of which deliver net benefits to society at large.

The capacity of the NDIS to transform the life of the individual with a disability, delivering empowerment/fulfillment also liberates their loved ones from caring responsibilities and economic hardship, all the while avoiding costly and traumatic hospital stays due to NDIS support.

As this respondent observed, “How much health care has been saved [by the NDIS]? How many of those people are able to return to work or their carers were able to return to work? Because unpaid care is a huge part of the economy that doesn't have a value!”

This sentiment was echoed across cohorts: “I'm thinking [the NDIS] is not only for the disabled people, but also for those around them: the carers, family, friends who are supporting [them] - make sure that they are getting support as well!”

One father spoke of the hopes for his son that the NDIS had afforded: “You're helping people with disabilities become productive members of society and get jobs rather than be on a disability support pension for their whole life. Look at my son: he's got autism.” He went on to speak of friends in similar situations whose children had thrived because of early intervention therapies, “By the time they're about 10, they're pretty normal and they go on to have normal lives. So that's the hope with my son.”

A respondent from a different cohort spoke of the broader implications for families of people with disabilities: “I think [the NDIS] is important, because someone may actually be able to get back into the workforce has prolonged benefits, not just for them, but their family and the wider economy. [And regarding children on the autism spectrum] - their being able to get support means their parents or their mum can probably go back and work, which is ultimately better for the household, economically. It also breaks the cycle of being stuck or not able to work or long term unemployment or even long term poverty because you are able to work, because you've got that support, or somebody in your family can work because you've got that support.”

Indeed, these concentric circles of benefit were most acutely - and universally - appreciated by respondents after they were shown the Desmarchelier clip: “I love the comparison from before and after the Scheme [of Ms Desmarchelier's life]. But I think the fact that the independence [afforded by the NDIS]... that means the money's well spent. There's places where you could improve it, but overall, it sounds like it was transformational!”

This was a common sentiment: “It's amazing to see how her life has transformed. She has gained so much independence!. But the thing that stuck out to me the most was the fact that she had to go to the ICU so often [before accessing the NDIS]. That's something I could not have seen happening - it's something we all take for granted [as a person without a disability]. But the NDIS is just enabling her to live a proper life with dignity, and not having to pick up on resources that could be better spent on all the people that also need the ICU services. It is mind blowing!”

These economic benefits were clear to people across cohorts *without having to be explicitly articulated*: “If providing the NDIS takes pressure off our hospital system, if that

takes pressure off our aged care homes, which probably have a much higher cost per person or whatever metric you want to use, then that's a good thing, because it's a lot cheaper to send the district nurse to somebody's house and an hour's work there than having somebody in a hospital and using up 10 nurses in a bed for three days."

Trusted Sources of Information: From Whom Do Participants Want to Hear?

When asked from whom respondents wanted to hear regarding the NDIS and whom they would trust, there was a clear consensus that Scheme participants were chief among those whose accounts were important. Similarly, a number of respondents wanted to hear from their loved ones/carers as well - namely, people whose lives are directly affected by the NDIS: "The participants and the people receiving the funding - I will listen to them!"

There was no desire to hear from the media, or NDIS providers who are seen to come with an implicit "conflict of interest".

Importantly, many respondents said that they would indeed trust information on the NDIS website itself and expressed a desire for quantitative information to be readily and easily available on the home page that details the ways in which the scheme transforms the lives of participants. While such information is currently available, we note that it may currently be difficult to find and could benefit from being made more easily accessible for those seeking such information.

While some mentioned the ABC as a trusted source, many said that they would prefer their information unmediated and direct from the NDIS site itself. "[I would trust] Government websites and also people who have experienced using the system themselves."

Of note, many younger respondents specified their own social networks as trusted sources of information and described a tendency to avoid traditional news sites. Indeed, many respondents of all ages, as described above, expressed significant scepticism about the accuracy of news: "I would not trust anything from the Murdoch media about the NDIS under any circumstances. Like everyone said, I would trust firsthand knowledge the most, but it's not what's most readily available to me. So Government websites or the ABC would be my go to."

As mentioned above, however, this scepticism of the media is far from absolute. When news stories confirm the accounts respondents hear within their social networks - or indeed their own lived experience - of problematic aspects of the Scheme, such news items serve to entrench negative sentiment about a Scheme which, in principle, all respondents support emphatically and wish to see work as intended - as a fulfillment of society's moral duty and a manifestation of the best of Australian national identity.

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.

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/nominees¹
 - 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 new Supported Independent Living plans
 - Respondent trust in Government to deliver improvements to the NDIS
- Fieldwork took place between 13 March and 23 March 2023.

¹ Referred to as “carers” for brevity

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 needs of 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/carers 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 inexperienced 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 technology of “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 precursor 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 addressing predatory 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 believed this 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 | <p>The idea here is to increase the NDIA workforce, but most importantly improving/upskilling the <i>specialisation</i> 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.</p> <p>It's intended that participants will get more time, more consistency and more understanding from the people they deal with in the Agency.</p> |
| Moving to long-term life-course and life-goal planning that prioritises early intervention | <p>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).</p> <p>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, <i>that plan is supported</i>. 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.</p> <p>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.</p> |
| Addressing fraud and compliance | <p>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 <i>unethical</i> behaviour seeking to take advantage of participants, such as:</p> <ul style="list-style-type: none"> *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 |

| | |
|--|---|
| <p>Addressing spiralling service costs (which are increasing well above inflation)</p> | <p>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:</p> <ul style="list-style-type: none"> *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 |
| <p>Improving community and mainstream supports</p> | <p>Having independence and the opportunity to meet and connect with other people is critical for everyone, including people with a disability.</p> <p>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.</p> <p>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.</p> |
| <p>Temporary limitation on new Supported Independent Living plans</p> | <p>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.</p> <p>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 <i>new</i> SIL plans (e.g. only approve new participants where there is significant need, not impacting existing SIL arrangements).</p> |