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INFLUENCE WITH INTEGRITY

# 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 respondents[1]:
    - 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

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[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 license 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/nominees[1]
  - 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.

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[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/carer Facebook pages (“That’s where I learn the most”) while recognising that such channels are suboptimal because of the prevalence of misinformation. *There is a sense of a system designed to keep people out*.

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

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

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

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of her grief at the crucial early intervention that was denied to her child – seemingly due to specialist reports being out of date.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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

## Responses to Policy Proposals

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

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

### Cynicism: Urgency and Strength of Intent

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

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

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

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

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

### *What Works When Talking About this Reform*

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

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

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

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

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

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

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

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

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

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

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

## Increasing the NDIA Workforce and its Specialisation

### *What Works When Talking About this Reform*

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

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

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

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

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

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

Furthermore, they want to see the 'upskilling' and specialisation as an ongoing process - not a 'quick fix' course, but rather continuous professional development so that workers are able to stay abreast of the changing evidence base, medical science, and technology in their fields. For example, one respondent with Parkinson's spoke about the emerging 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 precusor to how the others get done. For example, once we started testing this reform first, qualms around the viability of other reforms were mitigated.

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

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

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

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

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

## Addressing Fraud and Compliance

### *What Works When Talking About this Reform*

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

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

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

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

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

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

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

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

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

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

## Addressing Spiralling Service Costs

### *What Works When Talking About this Reform*

This reform found broad appeal across cohorts, particularly as a means of 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 | The idea here is to increase the NDIA workforce, but most importantly improving/upskilling the *specialisation* of the people making decisions about a participants' funding – so participants are dealing with someone who understands their disability and understands (based on evidence) what is going to be effective for them.  So they can talk participants through what they recommend for their funding and why.<br><br>It's intended that participants will get more time, more consistency and more understanding from the people they deal with in the Agency. |
| Moving to long-term life-course and life-goal planning that prioritises early intervention | 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).<br><br>The idea here is to break the cycle and stress and cost of short-term planning.  It would involve developing long-term plans – targeted to participants' needs and goals, with the flexibility to adapt to changes in participants' condition and their lives.  And once you have a long-term plan, *that plan is supported*. So, you would still review what's needed from time to time, but it won't be the all or nothing process it is at the moment.<br><br>This is intended to provide greater certainty for NDIS participants, giving them better support to achieve their goals and removing the fear around plan reviews and the stress and cost of having to keep proving they are disabled. |
| Addressing fraud and compliance | With more staff available to oversee providers and respond to complaints, there is an opportunity to move from just focusing on criminal cases of fraud or rorting to address *unethical* behaviour seeking to take advantage of participants, such as:<br>*pressuring participants to ask for services they don't really need<br>*spending participant's money contrary to their plan<br>*asking for or accepting additional fees for a service<br>*offering rewards for taking particular services not on a participant's plan |

| | |
|---|---|
| Addressing spiralling service costs (which are increasing well above inflation) | The NDIS is responsible for setting prices under the Scheme and has created a marketplace where providers can charge the maximum allowed, every time. We have to fix the system so that participants get fair value for their money, while ensuring their quality of care is maintained. We can address this by:<br>*Freezing prices that providers can charge for coordination, plan management and therapy (e.g. capped at inflation)<br>*Increasing oversight of provider charging, e.g. re-negotiating prices by the NDIA on behalf of participants and<br>* Establishing approved provider panels, and then increasing competition with an online marketplace – like Gumtree or eBay – for services from those providers, so participants can have options for not just who they want to work with but how much they want to pay |
| Improving community and mainstream supports | Having independence and the opportunity to meet and connect with other people is critical for everyone, including people with a disability.<br><br>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.<br><br>It's about doing these things in addition to properly funding the NDIS. Because the NDIS in isolation can't deliver independence. It can't be the only lifeboat in the ocean. |
| Temporary limitation on new Supported Independent Living plans | Under the NDIS, some participants receive Supported Independent Living supports. This is for participants who are typically profoundly disabled and require more intensive care. The idea behind SIL is to give people as much independence as is possible and get them out of institutions.<br><br>The concern here is that Supported Independent Living is driving the very outcomes the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability told us we need to reduce. For example, splitting up families/couples and driving people into accommodation situations (e.g. group housing) that don't support independence and positive outcomes. At the same time, SIL is growing at a rate that was never anticipated (around $4b per year more than expected), which represents significant challenges to the financial sustainability of the Scheme. A full and proper review of SIL is needed and until that happens there should be a limitation on *new* SIL plans (e.g. only approve new participants where there is significant need, not impacting existing SIL arrangements). |

# NDIA
# Communications Research

redbridge

INFLUENCE WITH INTEGRITY

October 2023

# What We Did

- 14 focus groups, incl:
  - 7 general population groups – covering a range of socio-demographic profiles
  - 5 groups with participants or their carers/guardians
  - 2 groups with support workers

- Gauged underlying sentiment toward the scheme and tested 8 reform territories:
  1. Increasing the focus on goals vs impairments
  2. Budget-first planning
  3. Early childhood supports in mainstream settings
  4. Investment in Foundational Supports
  5. Improving mainstream service accessibility
  6. Addressing confusion around ‘reasonable and necessary’
  7. Addressing confusion around roles/responsibility of intermediaries in the Scheme
  8. The general approach to transition (i.e. urgency vs consultation)

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# What We Found

- Social licence in the general population hasn't changed – 'cost cutting' narrative faces *opposition* as perceptions tend to be informed by participant experiences, not the media
- Participant views seem to have sharpened – a degree of disillusionment is entering discussions and there is no awareness of reforms announced in May 23
- While there is support for reforms aimed at making the NDIS better and lasting, specific reforms run into three 'core truths':
  - The NDIS is incredibly and *inherently* complex
  - It is being rorted (mostly by providers), and
  - Governments never fund social programs sufficiently

# What We Found

- What the ‘complexity truth’ does:
  - Makes complexity a conflicted space
  - Fixing the complicity is relatively less credible than fixing rorting of the Scheme
  - All good in principle, but *how*? Focus on *the how* makes it almost impossible to sustain values-based conversations.  Reactions to reforms are defined by the present, not by what they could be
- Opportunity: *humanising is the how*
  - Participants’ core frustrations stem from a ‘faceless bureaucracy’ attempting to deliver person-centre care at scale.  They want someone to connect with
  - Shift the discussion from process to people … people enable empathetic change in the system and provide the channel for difficult communications

# What We Found

- What the ‘rorting truth’ does:
    - Rorting is *the* sustainability issue
    - Puts a sensitivity around reforms that are seen to loosen financial controls … in the context of a zero sum game
- Opportunity: *tackle the rorts head on*
    - There is a strong appetite for this from both participants and non-participants
    - There is a believable valued-based story here: preventing exploitation of people with a disability

# What We Found

- What the ‘funding truth’ does:
    - Agreement that NDIS *shouldn’t* be the only safety net … but reforms aimed at reducing load on the NDIS become seen as “passing the buck”
- Opportunity: *build credibility by tackling rorts, while making these reforms tangible*

Overall…

- The disability community is definitely winnable: active participants in the evolution to making it better/lasting
- General population wants to know we have values of fairness and equity at heart … humanising and tackling rorts can tell that story better

# Thank you for your time

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INFLUENCE WITH INTEGRITY

# NDIA
# Communications Research

redbridge

INFLUENCE WITH INTEGRITY

October 2023

# What We Did

- 14 focus groups, incl:
  - 7 general population groups – covering a range of socio-demographic profiles
  - 5 groups with participants or their carers/guardians
  - 2 groups with support workers

- Tested how best to communicate 8 reform territories:
  1. Increasing the focus on goals vs impairments
  2. Budget-first planning
  3. Early childhood supports in mainstream settings
  4. Investment in Foundational Supports
  5. Improving mainstream service accessibility
  6. Addressing confusion around ‘reasonable and necessary’
  7. Addressing confusion around roles/responsibility of intermediaries in the Scheme
  8. The general approach to transition (i.e. urgency vs consultation)

# What We Found

- Social licence in the general population hasn't changed – 'cost cutting' narrative faces *opposition* as perceptions tend to be informed by participant experiences, not the media
- Participant views seem to have sharpened – a degree of disillusionment and desire to see bold action
- While there is support for reforms aimed at making the NDIS better and lasting, in communicating specific reforms we run into two 'core truths':
  - The NDIS is incredibly and *inherently* complex
  - It is being rorted (mostly by providers)

# What We Found

- What the ‘complexity truth’ does:
  - Makes complexity a conflicted space
  - Fixing the complicity is relatively less credible than fixing rorting of the Scheme
  - All good in principle, but *how?* Agree, goals are important to treating people as individuals, participants should have more control over their budgets, and NDIS *should not* be ‘the only safety net’ for people with disabilities
  - Focus on *the how* makes it almost impossible to sustain values-based conversations:
    - Need for detail
    - Reactions to reforms are defined by the present, not by what they could be
    - Raises issues of equity
    - Reforms aimed at reducing load on the NDIS become seen as “passing the buck”

# What We Found

- Communication opportunity: *humanising is the how*
  - Participants' core frustrations stem from a 'faceless bureaucracy' attempting to deliver person-centre care at scale. They want someone to connect with
  - Shift the discussion from process to people … people enable empathetic change in the system and provide the channel for difficult communications

# What We Found

- What the ‘rorting truth’ does:
  - Rorting is *the* sustainability issue … and seen as important to public trust
  - Puts a sensitivity around reforms that are seen to loosen financial controls … in the context of a zero sum game
- Communication opportunity: *tackle the rorts head on*
  - There is a strong appetite for this from both participants and non-participants
  - There is a believable valued-based story here: preventing exploitation of people with a disability

# Ways Forward

- Win the disability community first: active participants in the evolution to making it better/lasting
- General population wants to know we have values of fairness and equity at heart … humanising and tackling rorts can tell that story better

# Thank you for your time

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# NDIA Communications Research September-October 2023

## Conclusions and Recommendations

For the vast majority of general population respondents, NDIS participant experiences remain the most powerfully defining force in their views of the Scheme (aided and abetted by many ‘switching off’ from mainstream media). We again see attitudes to the NDIS that are defined by their empathy and an aversion to cost-cutting – indeed, a distaste for cost cutting narratives which are seen to contain a commentary about the “worth” or “value” of the lives of Australians with a disability. In short, compared with our research from early 2023, there is no real change to the underlying social licence of the Scheme *at this stage*.

However, it should be noted that – if anything – attitudes toward the Scheme from participants seemed to have sharpened since the previous research. Participants and carers spoke of the intensity of their fear with regard to NDIS funding and the bureaucratic decisions which – for them or their children – are often existential. This profound fear is accompanied by intense frustration and confusion in response to the Scheme's perceived complexity and “inconsistency”. While such sentiments were present in the previous research, in this round of research, we also find a degree of disillusionment: participants had expected change from the incoming Labor Government and, instead, there remains a sense that no change is coming. The reforms announced in May 2023 are simply not known or recalled.

This research suggests that a continuing decline in participant attitudes toward the Scheme represents a bigger risk to public sentiment/social licence than negative media coverage about NDIS costs. Indeed, the media narrative only seems to work where it reinforces what the general public is hearing about the Scheme through their personal networks, not the other way around. This makes the more recent coverage of mistreatment of disabled Australians potentially problematic for the Scheme’s social licence.

Within in this attitudinal landscape, there is recognition of the need for reform to the NDIS that a) makes it better for participants and b) makes it lasting/sustainable (it most certainly needs to be there in the future). Framing the objective of reforms with these dual goals works well to speak to participant and non-participant concerns about the Scheme.

Making the NDIS better for participants speaks to a ‘core truth’ that the Scheme is immensely complex and, furthermore, hostile in its complexity (i.e. where the complexity works against the interests of those the system is supposed to serve). Even in the general population groups, it seems everyone knows someone with a NDIS horror story.

Making the NDIS lasting speaks to the ‘core truth’ that the Scheme is being abused or rorted – primarily by “dodgy” providers – and that participants (not taxpayers per se) are largely the *victims* of this (robbing them the ability to get the quality support they need at a fair price). This is compounded by a perception of NDIS services being “over-priced” – the idea of the ‘wedding cake tax’ applying to all this NDIS.

Thus, the critical piece to a ‘making it last’ reform story is a) addressing fraud and “dodgy” practices by provider and b) normalising pricing under the NDIS, so participants aren’t robbed of their value for money by over-priced services being written into the way the Scheme works: “Don’t talk to us about cost blow outs when you set the prices!”

A key finding of this research is that talking about reform to the complexity of the NDIS is difficult. Firstly, from those with any direct contact with the Scheme, there is a sense that complexity will *always* be there – it’s inherent to a system that attempts to provide person centred care. This adds a degree of conflict around complexity: no-one wants to lose the aim of making disability care person-centred. Secondly, in relative terms, addressing fraud and unethical behaviour in the Scheme is believed to be a more credible/believable aim for government compared with fixing the complexity. Thirdly, when talking about reforms in this space, the complexity puts the focus – for both participants and non-participants – on the *how*: a) how it will be done, in a way that doesn’t add further complexity or increase opportunities for financial abuse of the Scheme, and b) how it is different to what exists now. Thus, we see discussions in these groups veer into issues of implementation or confusion that proposed reforms simply seem to be re-stating existing practices (or just disconnection, if participants have no frame of reference for the specific issue of complexity we’re seeking to fix). Either way, reactions are *framed by existing experiences of the Scheme*. So, a focus on goals raises concerns about one participant’s increases in funding coming at the expense of another who can’t advocate for their goals as effectively, or a move to budget first planning puts more burden on people with a disability to manage their money and increases the fear of an NDIA audit for those self-managing, while both are also seen to open the door to ineffective (i.e. non-capacity building) use of funds. Put another way, the changes tested here just aren't different enough.

The result is that it is *very hard to sustain a values-based conversation around fixing the complexity* – it drags you into the weeds. By contrast, previous research found it is easier – but still requiring careful treatment – to sustain a values-based conversation about fixing fraud in order to stop the exploitation of Australians with a disability.

The 'making it last' reforms tested in these groups did not include any related to targeting fraud or unethical behaviour. Rather, the reforms tested here were more around investment in the supports that sit *outside* the NDIS (in order to take pressure off the Scheme), i.e. early childhood supports in mainstream settings, foundational supports, and mainstream supports.

While there is generally agreement with the proposition that 'the NDIS can't be – *and shouldn't be* – the only safety net', these particular reforms run into a third 'core truth': that governments never fund services in this space to the degree that would enable them to work well. For example, there is no trust that governments will appropriately resource our already "over-loaded" schools in the early intervention of children with developmental issues, or that they will resource foundational support providers sufficiently so we don't just recreate waiting-lists and pay-to-jump-the-queue practices in that space. In this context, these reforms come to be seen as "passing the buck".

So, what are our ways forward?

1. The twin pillars of 'making it better' and 'making it lasting' work as the aims of our reform package – they speak to those core truths as outlined earlier. The opportunity is to wrap this up under a reform campaign brand that speaks to the core values that respondents see as being under-represented in the reality of the NDIS: "fairness", "equity" and "care". To that end, participants favoured brands like *Levelling the field or Putting participants first* because they spoke to these underlying values – vs *Putting the NDIS back on track*, which was inherently political (even for those who liked it), being seen as a kind of Trumpian slogan or an admission/accusation of (previous) government failure.

2. In terms of providing 'proof points' to create credibility for a claim of 'making it lasting', there is a strong need to have reforms that speak to addressing

(provider) fraud, as well as normalising prices. Noting that care needs to be taken to convey that we are not talking about cost cutting here, *but the protection of both participants and the future of the Scheme from exploitation*. Respondents want such reform and they are prepared to believe/trust it of the government. Without it, the risk of being seen as "buck passing" is high.

3. In terms of 'making it better', the current and previous research points to an opportunity around *humanising* the Scheme – i.e. humanising is '*the how*' to addressing hostile complexity. In the previous research we found that bringing *specialised* people into the Scheme – specifically into the interaction between participant and the Scheme – was seen to be a credible driver of greater empathy and understanding. It tells a (believable) values-based story because it is about people not processes. Indeed, in the current research, we again see this core frustration/anger from participants that decisions are made about them (their worthiness/humanity) by a faceless bureaucracy. Putting people (with relevant experiences that make them capable of introducing empathy and understanding) into the story could provide a foundation that then makes other changes – like greater focus on participants' goals – believable.The current research would also suggest that the interaction of such specialised NDIS workers with participants is the only real way to address information/knowledge gaps like explaining the meaning of 'reasonable and necessary'. At present, 'reasonable and necessary' is seen as a blunt bureaucratic tool used for beating participants over the head. A generic education campaign attempting to explain what we mean by 'reasonable and necessary' to people who feel victimised by the term could be disastrous.

4. Win the disability community first. While this is very much about their substantive experience of living with the Scheme, in a communication sense a key part is talking about the 'timetabled journey to making it better and lasting'. Participants in this and the previous research don't expect or want "quick fixes" or isolated "band aids" (that just sounds like a recipe for more complexity). They want serious, substantive, systemic changes to the Scheme, with recognition of the need to "learn as we go". Put simply, 'making it better' is an evolutionary process, not some quick outcome achieved through the rapid application of a series of reforms. It is not tick and flick. But neither can it be put on the never-never. We need a timetable for the changes that are on our horizon now, with consultative processes ongoing to identify the next horizon. Critically, consultation is not just about future changes, participants want to be involved in the implementation and evolution of

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# NDIA

# Communications Research

# September-October 2023

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## Our aims

- We're going to humanise the NDIS – giving participants a better experience and more control by making the Scheme more about people and less about bureaucracy
- We're going to ensure that the Scheme will be there for the future – stopping the exploitation of participants and making sure the money gets to those in-need for what they need

## How we will humanise the system (proof points)

*Humanising the bureaucracy*

- All participants will have the option to be supported by a Navigator[1] – a person who will guide them through their NDIS journey.
    - Navigators will be available from the very start to help people apply and not feel intimidated about accessing the Scheme.
    - They will guide participants through the process and help them make choices about how to spend their funding. This includes helping participants understand what the Scheme allows them to spend funding on and what things are proven to actually make a difference.
    - Navigators will be chosen and paid for by participants from their funding, replacing Support Coordinators and Local Area Coordinators.
    - They will be locally-based, bringing local knowledge about what supports are available where participants live, including those outside the NDIS as well. For complex cases, they will be specialised in a participant's disability.

*Humanising assessment*

- For those joining the Scheme, the government will now pay for the professional assessments required to apply for funding. Access to the Scheme will no longer be limited by someone's ability to afford the required assessments.
- Also supporting participants will be another new role, their Assessor. Assessors will be specifically trained in assessing participants' support needs. They will personally meet with participants on multiple occasions to understand their situation and develop an assessment that is then used to determine a support budget.
- For most participants, they will have just two people to deal with: their Navigator and their Assessor – streamlining the relationships they need to manage within the Scheme.

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[1] Alternative wording: All participants will now be given the option to access a Support Coordinator – a person who will guide them through their NDIS journey. The Support Coord role will be expanded so they will be available from the very start to help people apply and not feel intimidated about accessing the Scheme. They will guide participants through the process and help them make choices about how to spend their funding. This includes helping participants understand what the Scheme allows them to spend funding on and what things are proven to actually make a difference. They will be chosen and paid for by participants from their funding. They will be locally-based, replacing Local Area Coordinators and bringing local knowledge about what supports are available where participants live, including those outside the NDIS as well. For complex cases, they will be specialised in a participant's disability.

*Humanising budgeting*

- Participants will receive a budget package – rather than a line-by-line budget – that gives them flexibility to choose how their funding is spent. Avoiding the situation where participants can have thousands of dollars sitting in parts of their budget that they can't spend, as they run out of money in other areas of more pressing need.
- Budget packages will also be longer-term – 3 to 5 years rather than 1 or 2 years to reduce the stress and cost of annual reviews. But participants will still be able to request changes to their budgets if there are changes in their lives.

*Early Intervention – a key pillar of humanisation*

Supporting these changes will be other improvements that will make it easier and quicker for people to access support:

- Investment in foundational disability supports available outside the NDIS (e.g. information resources, support groups, services like meals on wheels or cleaning). So participants don't have to spend their funding on things that should be available through other sources.
- The introduction of early intervention supports for people with a psychosocial disability. This would provide them with early supports in that critical period while they undergo a proper assessment of their needs. After that period, they will either enter into the full Scheme or into the mental health system for ongoing support.
- Significant investment in early intervention for children by increasing the availability of specialist supports through kinders, childcare and schools.

## How we will ensure the Scheme is there for the future (proof points)

- Too many participants are subject to fraud or unethical behaviour. A stronger hand is needed to protect participants. There will be increased monitoring and auditing of service providers in the Scheme – both in terms of where participants' money is going and the quality of services that participants receive in return. The role of the 'watch-dog' in the Scheme will be strengthened to give it better powers to hold providers to account. So we don't slow the whole Scheme down with red tape, a risk-based approach will be used: so there is 'light touch' over-sight for low risk providers and heavier over-sight for high risk providers.
- Participants should not have to pay extra for the things they need just because they're being paid for through the NDIS. An Independent Pricing Authority, like they have under Medicare, will be established to set fair prices that reflect both the right of participants to pay a competitive price and the requirements for providers in supporting people with a disability.

If we are to ensure the NDIS is there for the future, in some parts of the Scheme we do need to address the realities of its cost.

- One possible change is **raising the threshold to access the Scheme for children with developmental delays**. This would mean that only those children with more significant impairments would access the NDIS.
- However, this would only be done in conjunction with the investment in early intervention for children via schools, kinders, etc, as discussed earlier.
- So the change to the NDIS would be balanced by those who 'miss out' on NDIS funding having access to an improved safety net outside of the NDIS.

- **Supported Independent Living** is one type of support to help people with a disability with higher support needs to live in their home. It is for people who need some level of ongoing help at home.
- Currently, SIL participants can be funded for 1-on-1 support – where they have a dedicated support worker helping them 24 hours a day. While some participants will always require, and will always receive, 1-on-1 support, many do not need this intensity of support.
- Where possible, such participants would move to a 1-to-3 support model – one worker for three participants.
- This change would be balanced by: a) improvements in outcomes for many participants, as the 1:3 model offers increased social connection and reduces isolation and b) innovation in the way support is delivered so people can live independently but with shared care, and avoid the old ‘group home’ model of care.

# NDIA Reform Communications Testing: Round Two Focus Group Research Report

# October 2023

## Executive Summary

- Respondents broadly welcomed the two principal objectives of the reforms:
  - To humanise the NDIS – giving participants a better experience and more control by making the Scheme more about people and less about bureaucracy; and
  - To ensure that the Scheme will be there for the future by stopping the exploitation of participants and making sure the money gets to those in-need for what they need.
- There was particular enthusiasm for the humanisation aspect. The idea *and language* around humanising the Scheme was quickly embraced by participants and prompted optimism for the "more personal approach" these reforms represented. Key to this optimism is the sense of equity and agency enabled by a more human-centred system.
- There was also significant respondent concern regarding the threat that spiraling costs might pose to the Scheme – giving its critics a weak spot to attack. Indeed, when we presented rorts, fraud, and unreasonable pricing as posing an existential threat to the NDIS, we were able to create an environment in which respondents were amenable to reforms designed to counter these things.
- After accepting the dual objectives as both legitimate and desirable, a series of 'proof points' were presented to respondents to explore to what extent they built credibility for the objectives. Largely, these proof points worked well in this role.

### Humanising the Scheme Proof Points

- The new **navigator** role – and to a lesser extent the **assessor** role – was effective in building credibility for three principal reasons:

1. **Equity –** respondents viewed the new roles and pathway into the NDIS as constituting the removal of critical ‘barriers to entry’ for new participants, i.e. the bureaucratic burden and sense of overwhelm at having to navigate its labyrinthine nature. While for many this alone was sufficient to see these new roles as transformative, many also believed these new roles/pathways would provide more equitable outcomes for existing participants whose current access to support is often dependent on their capacity to navigate the bureaucracy and advocate for themselves.

2. **Agency –** at present, participants’ sense of agency (i.e. their confidence and control) within the Scheme is felt to be undermined by a) their lack of understanding of the system and b) their disabilities and circumstances not being understood by the system. *Dealing with a human addresses these weaknesses in the system*. The new roles provided many respondents with greater confidence that they would be both better understood within the system and better able to navigate its complexity. Navigators, particularly, provide agency. This is enhanced to the extent that Navigators are a) local and b) specialist – although often respondents would value specialisation over localisation.

   Because of this emphasis on agency, it was important for respondents to feel that Navigators specifically “worked for them”, not for the NDIS. To this end, they were very receptive to the idea that they would have choice over their Navigator and that they would pay their Navigator from their budget package (with sufficient allowance for that in the package, of course).

   This agency framing also applies to reforms regarding *evidence-based supports*. Taken in the abstract, there was a lack of understanding of what ‘evidence-based’ refers to among many respondents, and a profound resistance to the idea of participant choice being restricted in this way. This is because presenting evidence- based supports within a ‘deficit model’ compromises respondents' sense of “choice and control”, leading to angst and opposition. Instead, framing the reform as Navigators using local and specialised knowledge to guide participants in making informed decisions about using their money effectively, and being protected from unscrupulous and exploitative providers/practices, restores respondent confidence and sense of agency.

3. **Streamlining relationships** - Respondents broadly welcomed the streamlining of the NDIS experience to reduce the number of

relationships they need to manage. This was about both a) the burden in managing multiple relationships and b) the strain in having to repeatedly re-tell their stories.

- **The new budget package** arrangement constituted the second proof point which provided most respondents with a sense of confidence that the reforms were being implemented for their benefit. Respondents viewed these budget reforms as countering current frustrations and perverse outcomes, such as having thousands of unspent dollars in one category as they run out of money in another, far more urgently needed, category. Respondents viewed this reform as assisting them in "getting what I need" and countering the sense that they must "use it or lose it" - that is, they currently feel forced to spend on unnecessary goods and services in order for their funding not to be cut at the next review. Once again, respondent agency afforded by this reform was a central pillar of their support for it…. so long as there are simple processes to vary plans as life circumstances change.

- Similarly, the agency afforded by the reforms enabling **longer term NDIS plans** formed the basis for respondent support. They felt that the certainty and reduction in stress and costs that longer term plans would provide would enhance their sense of control over their lives.

- A further proof point constituted the **Government-funded initial assessments**. These were greatly appreciated for the increased equity they would afford prospective participants who might otherwise not be able to afford to apply for the Scheme - a "game changer." Most respondents strongly supported removing barriers for the most vulnerable so that they would have the opportunity to enter the Scheme and would not feel forced to "give up". There was particular appreciation for these barriers being removed for parents of children requiring support who currently cannot afford the assessments required to apply for the Scheme. The capacity for this reform to remove intergenerational barriers to accessing support was another potent factor in generating support.

- The three adjunct funding commitments – **i) funding for foundational/mainstream supports, ii) funding for early childhood intervention in mainstream settings, and iii) changes to psychosocial supports with an emphasis on early intervention** - also worked as proof points for humanising the Scheme when framed within three critical contexts:
    - That these initiatives are geared towards facilitating **early intervention**. Early intervention is universally perceived as an

    unalloyed good with transformative potential - both for the lives of the affected individuals and also for the broader benefit of society/the community at large through preventing the harms that accrue with untreated/unsupported disabilities.
    - That these reforms constitute a critical part in **combating social isolation** that often comes with disability and have the potential to facilitate "connectivity" - that is far greater social connection and the mainstreaming of those with disabilities.

That these reforms represent a **safety net**, preventing people - particularly children - from falling through the cracks. This was particularly appealing for those with experience of somewhat less severe disabilities that they term "edge cases" that until now may have been neglected when it comes to government support.

**Sustaining the Scheme Proof Points**

- **The new pricing authority and strong regulation of providers** were also welcomed as proof points of a suite of reforms designed to protect participants from exploitation and restore equity and agency to them. This contrasts with their current experience of being at the mercy of spiralling costs and potentially unscrupulous providers, against whom they feel they have little recourse. The new and strengthened watch-dog role was therefore also welcomed. Participants want accountability for providers. Indeed, demonstrating that we are *first* addressing providers and pricing is <u>critical</u> before discussing reforms that impact participant accessibility or funding.
- After presenting respondents with the above proof points that provide vital, believable context of reforms designed to benefit participants, we were able to elicit a degree of *qualified tolerance* for reforms that would restrict either eligibility for the Scheme (raising the threshold for children with developmental delay) or the amount of support high-need participants would receive (moving to a 1:3 care model for Supported Independent Living participants). Respondents do not like these reforms but they may be willing to tolerate them where there are/is:

    - Carve-outs for exceptional circumstances (i.e. we're not forcing everyone into the same box, and the most in need are still fully supported);
    - Initial goodwill generated by the measures to humanise the Scheme and to protect participants (and the Scheme) from exploitation. Conversely, there is a strong resistance to any discussion of costs alone as a driver of reforms; and
    - Alternative or 'offsetting' benefits in place. For example, in relation to the threshold for developmental delays, there is more (but not out-

right) acceptance once respondents had been treated with the idea of investing in mainstream supports for children (through schools/kinders/etc) to enable earlier intervention and improve the safety net. In relation to the Supported Independent Living (SIL) changes, these become more acceptable when couched in benefits around reducing social isolation and ensuring people don't fall through the cracks. Conversely, proposing to 'grandfather' changes to SIL did *not* work as a way of 'offsetting' the impacts.

## Risks to Reform Credibility

- While respondents had a number of questions regarding implementation of these reforms, typically, these questions constituted curiosity regarding how such reforms would practically impact them. Such questions were generally not borne of hostility or opposition to the principles underpinning the reforms.
- However, it must be noted that amid the myriad respondent questions relating to the detail there is one critical, missing component compromising the credibility of the suite of reforms: **workforce issues.** Specifically, where the promised staff - with local knowledge and expertise for complex cases in the case of Navigators and Assessors, and allied health professionals and volunteer/other personnel necessary to staff the early intervention and foundational/mainstream supports initiatives - would come from. Furthermore, who will be training these new roles – especially Navigators – to ensure they can fulfil the varied tasks they are taking on? These questions around staffing and workforce occurred across all proof points and in each reform area. That is, unaddressed workforce concerns can undermine confidence in the new Navigator and Assessor roles, government paying for assessments (thereby, creating a "bottleneck" and exacerbating waiting lists), investment in early intervention and foundational supports, and the capacity to address pricing (without causing an exodus of vital allied health professionals). Qualitatively, failure to address these questions poses the most immediate risk to acceptance of these reforms among the disability community.

- Other frequently asked questions included:
    - Who pays for the Navigator's support before you enter the Scheme?
    - What will the changes to pathway and personnel mean for current participants? Some respondents asked whether existing participants would "go back to square one"?
    - Who pays for assessments/reports when going for a plan review?
    - Will such changes to the workforce compromise participants "continuity of care"? Such fears were particularly acute in regional areas.
    - How will the Scheme ensure that participants do not run out of money

    before their plans are due for renewal or, alternatively, do not spend their money too slowly and have their funding reduced at the next plan review?
    - There were also questions regarding whether the new budget/planning and pricing/workforce regulation reforms would increase the bureaucratic burden for participants.
    - How will longer term plans/budgets account for inflation and rising costs?

- The full breakdown of the composition of each group is provided in Appendix A.
- The final form of wording tested in relation to the reforms is provided in Appendix B.

The explanatory diagram presented to respondents in the humanisation reform testing cohorts is provided in Appendix C.

## What we did

- 14 x online (Zoom) focus groups (mix of ages and genders), including:
    - Nine groups comprising people in the disability community, and/or their carers/family members/nominees[1] and/or their support workers, living Australia wide, testing reforms associated with humanising the NDIS
    - Five groups comprising people in the disability community, and/or their carers/family members/nominees and/or their support workers, living Australia wide, testing reforms associated with ensuring the Scheme's sustainability
    - The detailed breakdown of group profiles is provided in Appendix A.
- Groups testing proposed reforms associated with the humanisation of the NDIS explored:
    - The proposed role of the Navigator and changes to the scheme associated with that role, including -
        - initial guidance for those applying for the Scheme (including introduction to mainstream and foundational supports)
        - support in accessing the Scheme
        - the addition of specialist Navigators for complex cases
        - the changes entailing new government funding for initial assessments for the Scheme
        - the replacement of support coordinators with Navigators and respondent sentiment to this
    - The proposed role of the Assessor and the ways in which Scheme assessments may be conducted

  - The proposed changes to budget, planning, and duration of individual plans
  - Responsiveness to an emphasis on evidence-based supports
  - Disposition towards proposed increased funding for mainstream and foundational supports
  - Disposition towards funding and resources for early intervention for children within mainstream settings such as schools and kindergartens
  - Assessments of proposed changes to management of supports for participants with psychosocial disabilities within the NDIS

- Groups testing reforms associated with the sustainability of the NDIS explored:
  - Proposed changes to pricing in the NDIS via an Independent Pricing Authority
  - Proposed changes to regulation and oversight of NDIS providers
  - Proposed changes to NDIS housing and living supports

Fieldwork took place between 16 October and 24 October 2023.

## What we found

### The Two Objectives: Humanisation and Sustainability

Respondents broadly welcomed the two principal objectives of the reforms: a) to humanise the NDIS, giving participants a better experience and more control by making the Scheme more about people and less about bureaucracy; and b) to ensure that the Scheme will be there for the future by stopping the exploitation of participants and making sure the money gets to those in-need for what they need.

*“I'm hopeful. There's always a possibility for improvement.”*

*“I think [these reforms are] a good thing. Definitely needs an overhaul.” “It definitely needs more humanising, less bureaucracy.”*

*“Humanising is incredibly important. It’s about people, it’s about putting people at the centre of the Scheme.”*

*“The current system can be very alienating. My husband and I are highly educated and we have problems understanding the system.”*

*“Things need to change, it is just growing so fast.”*

*“I can only go off what the politicians have been saying. And that is, in a few years, this will be costing us something like $70 to $80 billion per year. So it's an exponential growth [and] it's at risk of collapsing, is what we keep getting told. And so when it's your family that is affected, and if it’s rorting that's causing this, because where there's money, there's greed, and exploitation [then action must be taken].”*

*There was particular enthusiasm for the humanisation aspect. The idea and language around humanising the Scheme was quickly embraced by participants and prompted optimism for the “more personal approach” these reforms represented. Key to this optimism is the sense of equity and agency enabled by a more human-centred system.*

*“I think that this humanising element is incredibly important. We felt really alienated. We’re both highly educated people. And what we keep saying to each other, if we were not as educated as we were, and if we were struggling more than we are, we could not access the Scheme… So I think this is really positive.”*

*There was also significant concern among some respondents regarding the threat that spiralling costs might pose to the Scheme, giving its critics a weak spot to attack. Indeed, when we presented rorts, fraud, and unreasonable pricing as posing an existential threat to the NDIS, we were able to create an environment in which respondents were amenable to reforms designed to counter these things. There was very strong support for clamping down on the pricing by providers with most able to recount some specific stories of apparent fraud or at the very least “working the system” or “playing the game”. Their concerns about changes to NDIS are underpinned by their assessment that ultimately they - or others like them - will lose funding while those who “work the system” will continue to “play the game” and rort the system.*

*“It’s costing the government so much money it’s inevitable there will be changes.” “I think given the politics of it, it’s realistically going to change in the future.”*

*“I think they are [important reforms]. There's so many people out there that deserve the care and support. I have family members in there. It's about time that [those rorting the system] get stopped, and the money gets put in the right pockets. There's so many young children out there that are deserving of it. And it's about time our government put it in the right places in the right pockets with the right families.”*

*“[The] most compelling [reform aspect] would be the oversight and a governing body to investigate and make sure all of those checks and balances are in place… Because I've got incidents in my town where people are taking advantage. There's lots of fraud going on out there.”*

*After accepting the dual objectives as both legitimate and desirable, a series of 'proof points' were presented to respondents to explore to what extent they built credibility for the objectives. Largely, these proof points worked well in this role.*

*"[I support] anything that could make the program last for people and they get the help they need.*

*Indeed, some respondents who had been Scheme participants since its inception, pointed out that the reforms described seemed to be reflective of the initial intent of the Scheme - an intent that had not yet been realised: "It's turning the clock back versus what it's developed into… It is a good model".*

### Humanising the Scheme Proof Points: Creating A Context for Trust

#### ***The new navigator and assessor roles***

The new **navigator** role – and to a lesser extent the **assessor** role – was effective in building credibility for three principal reasons:

1. **Equity** - respondents viewed the new roles and pathway into the NDIS as constituting the removal of critical 'barriers to entry' for new participants, i.e. as removing the bureaucratic burden and the sense of overwhelm at having to navigate its labyrinthine nature.

Many respondents recounted the overwhelming experience of initially trying to understand the Scheme, first as applicants and then as new participants (spending "three months scrolling through Facebook groups for reviews [of providers]," and, "I still don't really understand the categories [of budget items]"). Thus, having a person to inform and guide during that process was considered a very good thing, as opposed to the "trial and error" or "Going through Facebook groups looking for reviews".

*"[The new navigator role] could make it easier. I tend to get overwhelmed easily. We need more support and this looks like it would provide more support."*

*"It's quite confronting as an outsider"*

*"I would have loved someone like that! I almost gave up"*

*"On the face of it, it is great. It's so important to know what's available on the outside of NDIS."*

Non-participants also profoundly appreciated the Navigator concept, describing being "scared" to apply for the NDIS. While a number of these respondents had health professionals recommending they apply to the Scheme, they had not because the bureaucratic and cost barriers were simply too high.

*“It just sounds good to me. I'm not on NDIS. I have applied a few times. And I'm actually too scared to even apply again. But I like [this] idea. Like you said, [the navigators] are there for you.”*

*“Everybody needs a Support Coordinator!”*

While for many this alone was sufficient to see these new roles as transformative, many also believed these new roles/pathways would provide more equitable outcomes for existing participants whose current access to support is often dependent on their capacity to navigate the bureaucracy and advocate for themselves.

*“[Currently], access to NDIS successfully depends on your education levels and English skills.”*

*“You don’t know what you don’t know, so this should make things much easier.”*

*“People are floundering in the system. They need support to help them better understand.” “Anything that makes it simpler and more accessible!”*

*“I think it'll help because we're trying to get access to services. So having that [navigator] might just help me find [those] because a lot of the stuff on the internet's outdated. [I’ve spent] a lot of time ringing up and you gotta wait for people to call you back. It's a bit of a pain. I think [this new role] will be better.”*

2. **Agency -** At present, respondents’ sense of agency (i.e. their confidence and control) within the Scheme is felt to be undermined by a) their lack of understanding of the system and b) their disabilities and circumstances not being understood by the system. <u>Dealing with a human (in the form of a navigator and/or assessor) therefore addresses</u> <u>these weaknesses in the system</u>. The new roles provided many respondents with greater confidence that they would be both better understood within the system and be better able to navigate its complexity. Navigators, particularly, provide this agency. This is enhanced to the extent that Navigators are a) local and b) specialist – although often respondents contended that they would value specialisation over localisation.

Indeed, Respondents viewed such reforms as acknowledging their past experiences of the system not understanding their disability and their frustration in having to repeatedly explain themselves. They viewed this lack of understanding as a key barrier to accessing to the Scheme, with decisions being made based on a written report: *"It's hard to put down in writing how much your disability affects you,"* and, *"It's really important that it's humanising… for access, for understanding and for trying to be helped as an individual"*. It is in this context that those particularly enamoured of the humanisation process described the new navigator function as a "monumental" change.

*"You said they might be more specialised in the field. So for example, my brother who's quite disabled, he has to live in a center. He has very high needs [and] people are paid a lot of money to keep him alive. So if there's people who are across [that complexity] and [have] more in depth [knowledge], that might be helpful to him."*

*"You mentioned specialised training. We [have] very high, complex needs. And, and [we] need someone who's across complex disability."*

*"I think yes, specialists with particular specific knowledge about specific disabilities, and local is a bonus!"*

*"When you're in a remote area, it's impossible to have local, whereas if you had [access to] someone in a capital city that knew what to look for, and knew what to find, and could refer [you] in that way, that would possibly help."*

*"For me, I'd go with a specialist before local."*

*"I'm only very new to [the NDIS]. I found a really great support coordinator that's helped me do all this. So I think it's a good idea if they can help with navigating more supports for the people on NDIS. Because [currently], they don't tell you what you can and can't use it for. So it's really hard to know what you can and can't do."*

*"My experience with my clients - most of them get really overwhelmed with who to ask for certain things and having a navigator is a really simple and easy way to have that one person. So I think that's it's really straightforward in that way and that could be super easy for [my clients]."*

*"I was diagnosed with neurosarcoidosis last year, and I was living up in Catherine in the*

*Northern Territory [where] the doctors would go, 'What's that? Do you mind if I Google that?' What I had was quite rare…to the point of I couldn't find a neurologist who understood it.*

1. *Anyway, I ended up in Melbourne, and I got diagnosed down there… I had a hospital liaison officer, and I think that's the only reason my case got progressed at all this year, because of that support. My daughter is autistic with Tourette's and we've been trying for a couple of years to navigate the*

> *system. And to be honest, I don't think we're getting anywhere. So this idea of a navigator is good."*

A number of respondents spoke of wanting navigators to be people who have "walked in our shoes" and are "related to disability"; people with a disability themselves, parents of children with a disability, etc. Thus, what qualifies people for the role can be their life experience: *"I'd like to hear that there's people that have lived experience."* They viewed such lived experience as a key component of the understanding that would lead to practices that enhanced participant/carer agency.

Indeed, couching such innovations in the language of the agency it will afford prospective participants facilitates this confidence: *"I like the idea of linking in with someone at the start, who can tell you about the supports available. And then, even if you don't get approved for a plan, you at least have that information. I think that's really good, because otherwise you have to seek it out for yourself. And if you're someone who's applying for NDIS, for yourself, then you may not have the capacity to do that. So I like that idea."*

Critically, this agency framing also applies to reforms regarding **evidence-based supports.** Taken in the abstract, there was a lack of understanding of what 'evidence-based' refers to among many respondents, and a profound resistance to the idea of participant choice being restricted in this way. This is because presenting evidence-based supports within a 'deficit model' compromises respondents' sense of"choice and control", leading to angst and opposition.

Many respondents challenged the basis for what might constitute 'evidence-based' ("Evidence-based just means that it works for some people") and presented anecdotes of a) how un-supported therapies have helped them or someone they know or b) how supported therapies have been "disastrous" ("Once upon a time, evidence-based meant ABA"). This led to respondents arguing that should an intervention work for the individual, it should be covered, regardless of what the academics say, with one participant asking, "[What about] the evidence of what I can see [working] for my child?"

*"Who's to say what works? It may work for your son. It's the people [directly affected] who know."*

*"What works for one person is not going to work for another, so [how do we reconcile that with the] evidence base?"*

*"[Evidence-based is good in theory] unless you talk to the parents or the kids that go to equine therapy, and you see the difference that it makes in those kids."*

There were profound concerns in particular among those who feared that rare and under- studied disabilities lacked a sufficient evidence base to begin with: *"I still think that alternative therapies are valid and should be approved. And I think if you're going to label*

*something 'evidence-based', that opens a can of worms for…when somebody needs a front running new therapy. There are wild disabilities and gene mutations that don't even have a proper name yet. And the cures and fixes for these things are so far out of the realm of anything that might be evidence based, that we're throwing things at them and hoping it'll stick. And if that's not allowed, then we're doing some people a disservice."*

When, however, we framed the reform as navigators using local and specialised knowledge to guide participants in making informed decisions about using their money effectively, and being protected from unscrupulous and exploitative providers/practices, restored respondent confidence and sense of agency.

*"[This reform] is very important. It's very significant, to go through what's the best for the participants - how the money could be spent, and also [helping] them navigate to [make] a good choice and understanding the whole system - what can be done and what can't be done. I imagine it will be really helpful at the beginning."*

*"I think it's really important because [without this guidance], what happens is funding gets used by someone who's got bad intentions, and then that client doesn't get renewed because they don't have the funding [because they've] used it on inappropriate things. [That means such participants] are unable to get the support they really need. So I think it's really important."*

*"It needs to be done - [every] dollar being spent in the right manner. Because as I see it, now, the dollar is definitely not being spent in the best interest of the participant. There's a lot of people that are getting very wealthy at the expense of others."*

*"Yes, [it's] a really good idea [to] watch how the money's being spent and to make sure it's 100% [to the] benefit of participants. That's really great."*

*"I feel like given the demands on NDIS funding, I reckon it would be fair enough to say it needs to be evidence-based… Then if there's other things you want to explore yourself, then you just do that with your own money."*

*"I think that's helpful. Because I was just picturing a couple of my previous clients, who are extremely vulnerable, who would jump at the chance of something that is not evidence based. So I agree with it!*

**Streamlining relationships** - Respondents broadly welcomed the streamlining of the entry pathway and processes as a means of reducing the bureaucratic burden and providing greater clarity regarding processes and pathways.

*"I think the streamlining of the process just makes it simpler. Anything that makes it more accessible [is good]."*

*"I think streamlining is definitely the way to go in the NDIS."*

*"I think [the new pathway] could be good because it might make things a little bit easier in terms of the one stop shop when you're trying to find stuff out."*

There was particular appreciation for the removal of extraneous personnel/relationships from the NDIS experience that respondents contended too often led to frustration, time wasted via having to re-tell their stories, and suboptimal outcomes.

*"I find it really frustrating that I end up having to repeat myself a lot of the time. It's like, 'I've already told you this. You already know. I've sent three emails where I've said the exact same thing!"*

*"Seems better, having [only] two roles - less chance for miscommunication and misunderstandings."*

*"I have to deal with an area coordinator, a plan manager, a support coordinator. It's a bit much on my plate… Only dealing with 2 people is easier to manage".*

*"It would be great to just have that one person to deal with. [It] would make life easier, especially when we already have to deal with so many other people, like specialists and therapists. It would just make life that little bit easier. We already have a lot on our plate. So anything that's going to make our lives just that bit easier, is helpful. We don't have a lot of time to waste going over the same things that we've already gone over. There's much more productive, efficient things that we can do with our time than just constantly repeat ourselves."*

*"Yeah, I'd love [this streamlining]. I think that the fewer people you're communicating with and who are communicating with one another, the less chance there is of miscommunication- the whole Chinese whispers thing - which often happens where a message doesn't get passed along to someone else… Because that happens quite a lot with various things. So I think if you just have one or two key people who are there for [to] champion you [and] give you guidance and support, then you're going to feel a lot better supported and there's going to be less confusion."*

A number of respondents observed that having fewer people involved would also present the NDIS with significant cost savings that would mean *“[more] money can be spent on the person being treated”*, constituting an unprompted acknowledgement of the importance of the Scheme’s sustainability.

*“I also think, from an NDIS perspective, surely streamlining is going to be more cost-effective for them. Because you start to wonder how much money is being spent on administration.*

*So I think that anything that's going to streamline it for participants, and also streamline it for the NDIS as an organisation [or] scheme, that's going to be helpful for everyone. So I think it's a positive thing. The win-win.”*

*“Having those two roles would be more cost effective, streamline the process but also make it more clear about roles and functions. How much is already spent on administration?”*

While there was a mixed response regarding whether it would matter if support coordinators or local area coordinators were unhappy with these changes, a number of respondents argued strongly that, “It’s us that suffer not them”.

*“I think they're very likely to not support this. However, I do think that they would be best positioned to take on this role…I do think that a support coordinator is already pretty well equipped to do most of [the tasks involved] and they probably unofficially do more [of these] than they're supposed to. So they might not like it, but I think that hopefully, they will be the ones directly employed by the NDIS to do this.”*

**Respondent opinions regarding the new nomenclature -** While respondents were divided regarding the issue of nomenclature, many did support the novel ‘navigator’ terminology, largely due to its a) acknowledging the novel functions of the role as well as the reforms of which that role is a part, b) ‘navigator’ explicitly expressing the purpose of the role, and c) removal of “expectations” that might be a product of the previous system, but which are no longer applicable after the reforms have been implemented.

*“’Navigator’ is fitting, it explains the role, it’s clear what their job is and what are the expected outcomes.”*

*“’Navigator’ and ‘Assessor’ explains the role and removes any questions about what they are supposed to be doing.”*

*“I think if you're making a transformational change, you need to [move] away from the tradition.”*

*"I prefer 'navigator'. It means somebody's going to be navigating me around if I was new to the system. It's always quite daunting when you first get started."*

*"I like the word, 'navigator' because it really is [that]. I've actually used the [terms] 'navigate the system', 'navigate the NDIS' a lot when I've been talking about the struggles that we've had with navigating it. And so I think the word 'navigator' is very fitting, and it's got a positive vibe in that [it implies there is] someone to help me navigate this rocky, difficult journey - especially when you have your own health issues as well."*

Those opposing the new name did so on the basis of a) habit ("I still call Woolworths Safeway") - although many picked up the new terminology quickly, or b) because, "[I like 'support coordinator'] purely because of the role they play. It's not just purely navigation. It's the thought behind it"... meaning that they also help participants with articulating their needs, selecting providers and how best to spend their funding.

*"Calling them 'navigators' suggests that you are navigating <u>their</u> system with <u>their</u> assistance. That's not what we're looking for. We're looking for support. I think the term's kind of standoffish, and I would be a bit put off [about] using the system. Whereas 'support coordinator' - that's what you want, you want someone who's going to support you to meet your goals and use this system effectively."*

*"I think it sounds [like] a lot less support which I personally don't like. It sounds very government-like… So I think I'm opposed to it at the moment."*

A number of people also found the term 'navigator' confusing, believing that it referred to an app, rather than a person, even after considerable explanation.

*"It does sound a lot more like a computer [programme]."*

*"It just seems like a computerised system. I manage my son's process, and I go through the myGov thing. And that's confusing enough as it is, and it's not clear. And I'm just worried that this navigator thing might be something similar."*

### ***The new budget package***

Appreciation for the new navigator role also alleviated a potential concern (for non-participants) about long-term budgets being "daunting". When one non-participant raised this, we asked whether having a navigator there to offer guidance would ease some of that anxiety with the answer being, "Absolutely!"

However, for almost all current NDIS participants, there was profound appreciation for the new budget package ("Absolutely life changing!"), while many non-participants had heard from those they know who are already on the Scheme of the current situation leading to perverse outcomes that they were able to see the benefits: *"If we're about supporting people, it's about where you need it most".*

Indeed, the new budget package arrangement constituted the second proof point which provided most respondents with a sense of confidence that the reforms were being implemented for their benefit. Respondents viewed these budget reforms as countering current frustrations and perverse outcomes, such as having thousands of unspent dollars in one category as they run out of money in another, far more urgently needed, category. Once again, issues of "choice and control" - that is, participant agency - underpinned the strong support for this measure.

*"You can use it where you need it!" "People's needs change in 6-12 months!"*

*"I like that, it's a brilliant idea. I can't fault it, there's been a number of times I've run out of funds in one area but have thousands sitting in another area unused."*

*"It's easier to have it in one pack of dollars. I have had receipts rejected because I put it in the wrong budget and I am a nurse so I wonder what it's like for others if I make those mistakes."*

*"It's an overcomplication - the current system. This seems to be more streamlined and less confusing."*

*"I like the long-term budget, that's very good. It removes some of the endless paperwork and administration that we spend most of our time on."*

*"I like the idea of it being one category. [The current system] just seems so crazy - the fact that I might have more money in a bucket to go and socialise than I do for personal training or physio or occupational therapy, which is what's helping my condition [whereas] being social isn't really [helping] so I like the idea. I think it's good!"*

Respondents viewed this reform as assisting them in "getting what I need" and countering the sense that they must "use it or lose it" - that is, they currently feel forced to spend on unnecessary goods and services in order for their funding not to be cut at the next review. Once again, respondent agency afforded by this reform was a central pillar of their support for it with the significant caveat there are simple processes to vary plans as life circumstances change.

There was particular opprobrium for the current perversity of having to pay for an assessment to support a change to budgets/plans in order to be able to spend that "idle" money on something that the participant actually needs. One participant gave the example of having to spend $200 with an OT to get an assessment to allow a change to her plan to buy a $50 item: *"Our OT had a recommendation for something* *we’re not covered for. So we had to put in an application. It’s been 60 days and we haven’t heard anything!”*

*“We received $7,000 for a section we just couldn’t use… it’s just sitting there and we couldn’t move it to another budget!”*

*“It would be good to be able to use that one part [of the budget] that wasn't using a lot of it into another part that was so much [more] necessary, rather than just going back for a review for that. Going off my experiences, of how often I've had to go back even on a 12 month plan - most of it is because it is running out too much in one category and there's still plenty in another category because of how they're categorised it, [but] I can't physically use it.”*

Of note, in this round of research, we did not encounter the respondent fear that should they make a mistake they might be audited and have to pay funding back. We believe that the humanisation context operated as a counter to many of the anxieties present in the first round of research into these reforms - specifically, the presence/role of the navigator offering a humanising interface into the Scheme: someone who would guide participants with regard to using their funding countered such anxiety as opposed to their having to make such assessments on their own.

*“I like [the new budget arrangements] being sort of open. It's really annoying that they're like, ‘Oh, you've got all this money, which is really great. But then [with] this certain type of therapy, you only have this much even though it's something you need, and there's money elsewhere in the plan [that] you can't access for this thing that you still need. I think that's really frustrating... AndI also like the navigator and assessor titles, because everyone in my family is autistic, excluding me. And they are very literal people. So the fact that you have a navigator that will help you find your way through the system will be like, ‘Yeah, cool!’ That is that person. That is what they do. You have an assessor who will assess you and your needs. It's very literal… Even [though] the support coordinator role is helpful, if they're doing a whole bunch of other things, then that label doesn't really specify exactly what they are doing.”*

### ***Longer term NDIS plans***

Similarly, the agency afforded by the reforms enabling longer term NDIS plans formed the basis for respondent support. They felt that the certainty and reduction in stress and costs that longer term plans would provide would enhance their sense of control over their lives - particularly as it counters respondent resentment at having to *“prove your disability every time you get a new plan”.* Long-term planning therefore reduces that indignity. Additionally, there was appreciation for the savings in time and resources required every time they have to go in for a new plan: “You wouldn’t believe the time I spent!” and, “[Reviews are] a very arduous time!”

Indeed, one participant was genuinely “excited” about the prospect as, *“It gives us a chance to plan. That’s hard to do if you don’t know one year to the next if this is the year you’re gonna get shafted.”*

*“I do like the idea of the longer term package.”*

*“I like the idea of a three to five year plan. I think that'd be good, because you don't go through the process every year!”*

*“I think a lot of my clients would be relieved to not have assessments as often. Assessment time is always a time of anxiety and stress and worry. And I think anything that reduces that would be welcome for them.”*

*“[We] won’t feel like we need to cram in the budget because it’s coming up to the end of the year. You can pace it out to what you need. It’s not linear.”*

*“A little bit more streamlined. I like the longer budget idea. I actually hate it when you have to sit and justify every year and the different therapies needed.”*

However, it is extremely important that such flexibility is emphasised to allay concerns about plan rigidity that a number of respondents held - that there is room to request a variation should circumstances change. This was something that was especially important for parents as the needs of children change more rapidly than adults

*“Receiving the long term budget package, to me, is a scary thing. I know, some of you say that, that's a good thing. But then for a child where the goals change, and if [you’re] not aware how funding works [and] you run out - if you're on a long term budget package to get more funds if you need it [could prove complicated].”*

### *Government-funded initial assessments*

A further proof point constituted the Government-funded initial assessments. These were greatly appreciated for the increased equity they would afford prospective participants who might otherwise not be able to afford to apply for the Scheme - a “game changer.” Most respondents strongly supported removing barriers for the most vulnerable so that they would have the opportunity to enter the Scheme and would not feel forced to “give up”.

“*I'm really excited over the funded assessments. We're fine for that now. But we do have friends, family, relatives who can't afford all these assessments that they* *supposedly have to get before they can even properly apply. So to me, that's really exciting. Really exciting!"*

*"This is the big game changer. A lot of vulnerable people will be able to access it now."*

Having had to pay for the assessments/reports themselves ("around the $3000 mark"), many respondents understood that this acts as a barrier to accessing the Scheme for people without the money to do so. They described parents currently

having to make a choice about whether to apply or not because of their capacity to pay for these assessments: *"A lot of parents feel they can't afford that diagnosis, so they don't do it".*

*"[I support this reform because] otherwise, you're essentially creating a scheme for people who are wealthy enough to access it. And that's a real huge problem!"*

*"A lot of people don't have that kind of money to be getting the assessments done in the first place. You can't just assume that people have that money, and it's not fair that they're going to be disadvantaged. I think 100% the government should be [paying]. No doubt about it in my mind!"*

*"It's so costly to not just pay for the assessments out of your own pocket but also travel costs too. We live regionally and it costs us at least $150 to travel for appointments."*

There was particular appreciation for these barriers being removed for parents of children requiring support who currently cannot afford the assessments required to apply for the Scheme. The capacity for this reform to remove intergenerational barriers to accessing support was another potent factor in generating support.

*"I think it would take a lot of pressure off parents of children that need to be on the NDIS if you know the government is going to help out with that."*

*"It's a great idea. We spent $4,000 on assessments for my kid. We had the money but a lot of people don't."*

*"We've got NDIS support for one of our kids but we haven't for another kid because of the cost of reports and the waitlist. With the cost of living pressures everyone is under we just don't have the money for an assessment."*

### *The three non-NDIS adjunct funding commitments*

The three adjunct funding commitments - **i) funding for foundational/mainstream supports, ii) funding for early childhood intervention in mainstream settings,**

**and iii) changes to psychosocial supports with an emphasis on early intervention** - also worked as proof points for humanising the Scheme when framed within three critical contexts.

The first context entailed these initiatives being geared towards providing faster and easier access to critical supports facilitating **early intervention**. Early intervention is universally perceived as an unalloyed good with transformative potential - both for the lives of the affected individuals and also for the broader benefit of society/the community at large through preventing the harms that accrue with untreated/unsupported disabilities.

Early intervention in the psychosocial context proved powerful because mental health issues can produce an immediate “risk of life and harm”, while early intervention for children was perceived as a critical means of preventing such crises into the future.

*“Early intervention is key!”*

*“I think it's a great idea to put it into schools for the kids, because if I had gotten that [intervention] early on, I think I wouldn't have the issues I have today.*

*“[Kids who don’t get early intervention] are not going to be patients now. They're going to be patients when they're adults. Yeah, early intervention [is important]!”*

*“Every study that I've read indicates the massive advantage of early intervention. And I would agree, wholeheartedly, not from a parent's point of view, but from a teacher's point of view, that it makes a drastic difference in the lives of those kids, because they can experience success, they can have modifications provided for them - assistance given to them. That means they can do the things that they are capable of!”*

*“I think specifically, that early intervention for those psychosocial disabilities is important, because if they are left, they can compound and end up [becoming far worse]. Early intervention does lead towards better outcomes for the participant themselves.”*

*“A bit of early intervention actually saves money down the track too, from a system point of view!”*

*“I think the significant investment in early intervention and early support is absolutely vital. Particularly with children with autism spectrum disorder, where early interventions can stop things being as needy, as costly down the track. It can improve a sufferer's life immensely.”*

*"We caught our son this year for early intervention, but it could have been caught earlier in daycare."*

The second context involves these reforms constituting a critical part in **combating social isolation** that often comes with disability and have the potential to facilitate "connectivity" - that is far greater social connection and the mainstreaming of those with disabilities, as living with disabilities can be "very isolating".

*"I think [the adjunct funding] is really good. My cousin really struggles with finding social outlets. So I think having someone that knows places that he could just go and have a consistent thing to do… would be fantastic."*

*"My son went to an autistic school, because he was classed as severely autistic. And the problem was that there was no incentive for that school to try and assist my son to function better or to achieve or to integrate, or to climb ladders and to achieve milestones. So it wasn't until we found him a place, which was very difficult, in the public system, with a support worker, that we really saw improvement, and he really started to flourish. So I think mainstream development for most of the children is probably the ideal because kids are copycats, especially autistic kids. And if they're copying good behaviors, then they're going to learn more about how to behave in our world. [Otherwise], they will fall into habits that are not going to assist them by being surrounded by severely autistic kids, even though my son is nonverbal. So yeah, I think any push towards bringing them into the mainstream does two things that assist a child with a disability and also builds a society that understands that there are disabled children in amongst the kaleidoscope of life. And they're just like us. And you can get great reward and great enjoyment from having a relationship with someone with a disability. So I think that's a good thing."*

The third contextual element involved these reforms representing a **safety net**, preventing people - particularly children - from falling through the cracks. This was particularly appealing for those with experience of somewhat less severe disabilities that they term, "edge cases" that until now may have been neglected when it comes to government support. Indeed, these often segued into equity arguments, as well as the agency such reforms would afford parents of children requiring assistance, with more unprompted arguments that the equitable, widespread distribution of early intervention supports would yield wider social and economic benefits.

"*Early intervention is the best thing that they could ever do. There's so many kids that fall under the radar, I was so lucky that my kinder picked up my eldest. Without that, I just thought he was one of those out there boys. I had no idea. I'd never even really understood or heard of autism at that point. So luckily, one of the kinder teachers had two autistic boys. So having that knowledge within the system to get* *early intervention, it gives them the best start and chance that they have to have a normal life. So 100% The best thing to do!"*

*"I think it's amazing. If you have the money, spend it, because time and time again, [with] child protection, child welfare, you've got a child there with autism or ADHD who needs special care, needs physical care, and they're too busy to help those other kids. So what happens is those kids who really need that help, they grow up, but then they go through the system. So when they hit 21, there's a whole different, new thing. It costs more money. If you think that education, at the moment for a child, is just going to cost too much, you're creating more social problems - that's where the money pit is. You spend it now or you spend it later."*

*"I absolutely agree with it. There are large gaps in the supports needed and the supports that are currently available or even provided. Some of my participants are unable to drive but are not considered disabled enough to get taxi vouchers or anything like that. And that leaves them with trying to arrange for public transport or community based taxi services…. So anything that provides more support for these edge cases is excellent."*

*"I think it's a good thing. [Too many people] are not getting the services they need… When you're talking about Asperger's [there's] not much at all provided for them [but support for them] is such an important thing. …They may need some help. And this is a good avenue. And it's well worth spend[ing] the money for those people that fall outside of [NDIS eligibility]."*

*"I think it might be really good for regional centers, as well. I think that that would create some more services for regional areas, to be able to have a bit more funding on that, or some of those services that aren't actually already in the area, to be able to put [it] in."*

There were, however, some caveats with such support being conditional on there being improvements to the quality and availability/accessibility of such mainstream services: *"It'd be great to see the quality [of mainstream and foundational services] improved, and hopefully that would increase with more popularity, which would be the reason that I wouldn't use those services right now. I have used them in the past, but the quality is quite poor. So all power to them, if they can get increased promotion and up their standards a bit. Fantastic!"*

It is important to note that with among a number of respondents with psychosocial disabilities, any (qualified) support for this reform was predicated on their highly negative experience of - and consequent extreme aversion to - the public mental health system, particularly hospitals, which many described as "traumatising". Not only do respondents view the public health system as inherently inequitable, they also view it as one of the most egregious examples of a system which robs them of their agency - to the point of dehumanisation.

*“All of my experiences with the public [mental] health system were shocking…The public system is just not good enough.”*

*“The public mental health system is absolutely bullshit.”*

*“I still have to have private health insurance, just in case the worst happens. Because the public [mental health] system is just that shocking!”*

One respondent with a schizophrenia diagnosis therefore supported putting early intervention supports around people (even if only for a limited time to allow a proper assessment of their condition and needs), arguing that this is important because a) the “broken” mental health system can not be relied on to help people in that moment and (because of that) b) too often *“it’s cheaper and easier to just throw [people in the throes of a mental health crisis] in jail”.*

However, for some respondents with psychosocial disability, this reform itself outside of concerns about the public mental health system - offered the promise of greatly increased agency/control over their lives, describing illnesses such as depression or anxiety as transforming them into their “own worst enemy” in terms of being able to help themselves: *“I think it's step in the right direction. Personally, I've suffered depression and anxiety on and off for years related to a brain injury. And depression is really unfortunate, in that it basically stops you being able to get the help that you need. So if you have somebody actually reaching out to you to be like, ‘Hey, let's go down this route. Like, let's try this. Then, going on to NDIS after that, [that could be great]. But a lot of people don't actually realise that they need help, like, depression is its own best friend. You don't want to reach out and talk to people. And a lot of times, you can't actually see how bad you're feeling. Until somebody else pointed it out to you.”*

## Sustaining the Scheme Proof Points

### *The new pricing authority and regulations for providers*

The new pricing authority and strong regulation of providers were also welcomed as proof points of a suite of reforms designed to protect participants from exploitation and restore equity and agency to them. This contrasts with their current experience of being at the mercy of spiraling costs and potentially unscrupulous providers, against whom they feel they have little recourse. The new and strengthened watch-dog role was therefore also welcomed.

Participants want accountability for providers. Indeed, demonstrating that we are *first* addressing providers and pricing is critical before discussing reforms that impact participant accessibility or funding: *"The NDIA has the power to do something about costs".*

Indeed, a number of respondents attribute the sustainability pressures to NDIS providers who many believe are *"working the system"* or they *"know how to play the game."*

*"I think [this reform] is very needed because it's vulnerable and desperate people. People are taking advantage of that. Businesses are taking advantage of that. And there's a lot of people too, who really don't understand the plan and the money and how it's being used. And they won't know where to look to find out that they've been charged exorbitant amounts until it's all run out. And then suddenly, they have no idea how that's happened. And there's no one who's been around to put them in check."*

*"Any funding is open to abuse. There is opportunity to improve the system and weed out some of the rorts."*

*"The exercise physiologist we go to actually advertises in reception the prices for patients and specifically puts down how much for those on NDIS. That's how blatant they are these days."*

*"The NDIS is getting a little bit out of control and there are some providers who are really ripping off the system."*

*"My pet hate is when they discover you are on NDIS and then they charge you more."*

*"Before we were on NDIS, we were paying for different therapies out of our own pocket and the minute we qualified the invoices changed and almost doubled."*

*"I think it's a good idea. I live in a regional/rural area, which means we don't get a lot of choices with the providers, or people that we can use… Someone can literally just start up a business and say, 'Look, we came for NDIS.' And that's it."*

The only caveat - particularly among self-managed respondents - entailed ensuring that any such reforms did not remove choice/agency from participants with regard to the providers that they use: *"[These reforms] sound good, as long as there's still that choice and control for us to be able to [choose our providers]. "*

### Changes to Supported Independent Living and Developmental Delay Threshold: Proof Points Provide Qualified Tolerance for Otherwise Unpalatable Reforms

After presenting respondents with the above proof points that provide vital, believable context of reforms designed to benefit participants, we were able to elicit a degree of *qualified tolerance* for reforms that would restrict either eligibility for the Scheme (raising the threshold for children with developmental delay) or the amount of support high-need participants would receive (moving to a 1:3 care model for Supported Independent Living participants). That is, respondents do not like these reforms but they may be willing to tolerate them where there are certain compensating factors.

1. Carve-outs for exceptional circumstances (i.e. we are not forcing everyone into the same box, and the most in need are still fully supported).

*[If] they're very, very low risk, then yes, I think it might work. But [some] people need extra care. And some of them need more than one person for themselves. So I think it's a bit risky."*

*"It just depends on the individual's needs, like how much care they need, what, the severity of their needs [are]."*

2. Initial goodwill generated by the measures to humanise the Scheme and to protect participants (and the Scheme) from exploitation. Conversely, there is a strong resistance to any discussion of costs alone as a driver of reforms. Indeed, cost discussion without prior contextualisation via the humanising reforms led to opposition that was considerable and intense. We therefore do not recommend discussing either reform in isolation.

*"[1:3] is a horrible way to save money. It just goes backwards. And it's just horrible. There's no thought around the actual person [and] what they need!"*

*"The most concerning [reform idea] was definitely the 1:3. That's just awful!"*
*"[Regarding raising the threshold], leave the kiddies alone!"*

A number of respondents in the earlier groups believed that the 1:3 changes would mean the return of group homes to which they were implacably opposed: "*So they're going backwards into group homes? That's horrible!"*

Indeed, decontextualised cost discussions often led respondents to argue that raising the threshold and 1:3 reforms constituted a false economy that would result in far greater costs to government in the long run.

*“My daughter is going to go to university next year and it’s because of early intervention. Without early intervention she’d probably have to go on the dole so it’s important for productivity that young people like her are able to be productive. Also, because of NDIS, it’s added to my productivity as a taxpayer too.”*

*“Early Intervention actually costs the government less in the long term. They could prevent more major issues, or somebody descend[ing with their] mental health, because it gets aggravated. And then the support worker also struggles [in the case of 1:3], of course, and then they lose the support [worker] as well. So there are lots of factors [to take into consideration].”*

3. Alternative or ‘offsetting’ benefits in place. For example, in relation to the threshold for developmental delays, there is more (but not out-right) acceptance once respondents had been treated with the idea of investing in mainstream supports for children (through schools/kinders/etc) to enable earlier intervention and improve the safety net. In relation to the Supported Independent Living (SIL) changes, these become more acceptable when couched in benefits around reducing social isolation and ensuring people don’t fall through the cracks.

*“For the younger kids, I think [1:3] will work great if they don't need that 24 hour care around the clock. It'll get them to become more independent, socialise more, interact more. And that's what we need these days.”*

*“[It’s] an opportunity for participants to interact socially, share experiences, just have some company”*

*“[Raising the threshold for developmental delay] is a tough one. It's just moving the goalposts, isn't it? My concern is, in theory, sounds great. In practicality, where are we going to drag all these resources from?*

*“I think [the balance between raising the threshold and the adjunct funding] will definitely help it become more mainstream. I think we need to funnel it through the existing, public system that we have, which is the education system. I think that there needs to be better assessment, which they're trying to propose.”*

*“I think [these reforms overall are] a step in the right direction, they've just really got to nail the change management. You can't just get rid of something [like raising the threshold] straightaway. If you're going to implement that early detection thing, you've got to have that overlap. That's part of good change management, as opposed to just taking it off people all of a sudden. But overall, it seems like they've got some good ideas that could really work, if they make it work.”*

Conversely, proposing to ‘grandfather’ changes to SIL did *not* work as a way of ‘offsetting’ the impacts.

*"My concerns remain the same!"*

*[Grandfathering suggestions] don't change it at all. No. Follow the Commission's report!" "That will be totally unfair."*

*"It's not really equitable, is it?"*

### Risks to Reform Credibility

While respondents had a number of questions regarding implementation of these reforms and - at times - the reforms' feasibility, broadly, these questions constituted curiosity regarding how such reforms would practically impact them and/or be implemented. Such questions were generally not borne of hostility or opposition to the principles underpinning the reforms.

Importantly, unlike in the previous round of research, there was a marked shift in tone among most respondents (with certain notable exceptions - primarily among those living in regional areas). Where anxiety had been the dominant sentiment in the previous round, in this round that transformed for many into their feeling "hopeful". While respondents had many questions, these were often not posed as reasons to disqualify the reforms; rather, their questions led to discussion of how such reforms could be made to work better for participants/carers. The focus on humanising the Scheme allowed respondents to accept the positive intent of the reforms and created a tolerance of imperfection, inclining many to focus on the positive aspects, as opposed to the previous round in which respondents adopted a more defensive posture and sought to ascribe nefarious intent such as abrogation of government responsibility.

However, it must be noted that amid the myriad respondent questions relating to the detail there is one critical, missing component compromising the credibility of the suite of reforms: **workforce issues** - specifically, where the promised staff - with local knowledge and expertise for complex cases in the case of Navigators and Assessors, and allied health professionals and volunteer/other personnel necessary to staff the early intervention and foundational/mainstream supports initiatives - would come from.

Furthermore, who will be training these new roles - especially Navigators - to ensure they can fulfil the varied tasks they will be required to undertake? There were also specific concerns regarding teachers and childcare workers having the requisite existing knowledge for the mainstreaming of early intervention to be effective. One respondent's assessment of their capacity to fulfill this early intervention role was: "That's complete bullshit".

*“[These are] ambitious goals. You are aware there's a massive shortage of staffing across the board in our social services, education and health department? It's immense!”*

“*It's just a lot of us live regionally so local [expertise/support] isn't always an option.”*

*Where are we going to get those people in the schools that have the qualifications? Through the Education Department, early intervention, whatever label they want to put on it - where are these [experts]? Where's it coming from? It's like our health system. [It’s fine to] throw some money in [but] we need nurses. But where do they come from? That's a big concern that I have.”*

These questions around staffing and workforce occurred across all proof points and in each reform area. That is, unaddressed workforce concerns can undermine confidence in the new Navigator and Assessor roles, government paying for assessments (thereby, creating a “bottleneck” and exacerbating waiting lists), investment in early intervention and foundational supports, and the capacity to address pricing (without causing an exodus of vital allied health professionals). Qualitatively, failure to address these questions poses the most immediate risk to acceptance of these reforms among the disability community.

*“You can’t get specialist appointments in 30 days. Not here anyway. It’s a 9 month wait here.”*

*“They’ll have to do more training to get people on the ground to do this.”*

*“Having a speech therapist assigned within centers and the school would be beneficial but obviously, again, you need that backup of enough staff to be able to man that as well as the extra demand.”*

*“I agree that the teachers don't have the time for doing the teaching [let alone other tasks involving early intervention]. They don't have enough staff as it is now. They can have their education assistants with them, but even then…I just don't see it as a feasible thing that would work. I think it would end up costing more later on without the early intervention, the proper early intervention that can really help turn things around and help the kids. That is what's needed.”*

*“I work in incident support for a lot of educational institutes and there is just a lot of burnout. The child to educator ratios are never good. And so not only are these kids falling through the cracks, because there's not enough support for those kids, but the educators themselves are needing to protect themselves, so they can't put themselves forward to take on that sort of journey with those children. So it's an area that desperately needs more resources.”*

There were particular workforce concerns with regard to navigators and continuity of care particularly (but not only) for those with complex needs. The favourable disposition towards the new navigator role is predicated on the human connection - something requiring sufficient staffing for continuity. There were therefore a number of questions relating to this issue.

*“Will that turn-over [of navigators from the workload] be more than now?”*

*“Sounds fantastic but we cycle through LACs all the time here. They either leave the system or go somewhere else in the system, so we are constantly having to get to know a new LAC and explain everything to them. I’m not sure how this new arrangement would change that.”*

*“We've had a couple of different support coordinators, just because people have gone on leave or whatever. And I think the quality of your experience has a lot to do with the quality of your support coordinator… So it doesn't really matter whether they're a navigator, or they're like the old support coordinator. It depends on how good at their job they are.”*

*“I just think it's hard enough to get in contact with support coordinators because they're already handling 30 different clients sometimes. Adding another role to them - is that not gonna make them even less accessible because they're so overworked?”*

### Other frequently asked questions

Below are some of the other frequently asked respondent questions.

Who pays for the Navigator’s support before you enter the Scheme? Respondents wanted to know whether a navigator would be as staunch an advocate for participants as their current support coordinator and who pays for the navigator constituted a critical factor in determining whether the navigator “works” for the NDIA or works for the participant - that is, whose interest take primacy for the navigator? The interests of the NDIA or the interests of the participant?

*“I think if you do have a good support coordinator, or you’re with an independent support coordination company, there's generally that feeling that they've got your best interests in mind. The thing that concerns me is that if the support coordinators are part of NDIS, to me that introduces a bit of thinking of whose best interests that they have in mind. Is it mine? Or is it NDIS? That's my concern regarding that.”*

What will the changes to pathway and personnel mean for current participants? Some respondents asked whether existing participants would “go back to square one”?

*“You guys could actually cause a bit more damage than good!”*

*“They can't change the system and then then go, ‘Oh, we better get a lot more providers, because that's not gonna work.”*

A number of respondents very much wanted to know whether they would have “choice” with regard to their navigators, with the option to change navigator should they not “gel” with them.

*“If it's a really humanised approach, you're talking to human beings, you're just not reading something on the screen. If you're got that one individual human being that you're talking to, and maybe if that person isn't right for you, you [should] have the right to say, ‘Hey, this is not for me, and I'd like someone else to support me.’”*

Will the government still pay for the initial assessment even if a prospective participant is not accepted into the Scheme?

*“What happens if they don't get the diagnosis as such? [Do] you have to repay that money, or is that, ‘Alright, sorry. We tried, we've covered it still.’ Because it's hard enough getting to a point where you qualify, but would there [also] be the impact of having to reimburse a specialist and individually pay for all those testing? It's very expensive, very expensive!”*

*“If you've got to go and have two different assessments, do they pay for both of those or you just pay for one? And that's it? [What] if you've got to keep on testing?”*

Who pays for assessments/reports when going for a plan review: *“For the review of your plan, who's going to pay?”*

How will the Scheme ensure that participants do not run out of money before their plans are due for renewal - or, alternatively - do not spend their money too slowly and have their funding reduced at the next plan review?

*“[What if my daughter has] no ability to manage the money and make it last for that amount of time.? What happens if she isn't able to do that and she runs out of funding?”*

*“If it is a longer plan, a longer duration, there needs to be some mechanism that is going to alert [you] that you’re running out of money, or you're not spending enough money.”*

There were also questions regarding whether the new budget/planning and pricing/workforce regulation reforms would increase the bureaucratic burden for participants.

*"If [funding] is all in one bucket, does that mean every time you want to access a new type of therapy or whatever, you have to go through a request and approval process? Because if that is the case, that's probably going to be far more painful!"*

*"I have been on the NDIS maybe four or five years and I've done yearly plans, and I've done two yearly plans. Even two yearly was an absolute disaster for me [because] my multiple diagnoses are very up and down all the time… I've been going back with support coordinators and reports after two, three months. So the idea of getting a plan [for] five years, I'm not sure if that's just more hassle for me to have to constantly go back."*

*"What about providers? So when you mentioned gardeners, our gardener doesn't even know I'm on NDIS. So what happens? We obviously do due diligence checks - ABN and insurance, but haven't done police checks. So I guess for self managers, you'd have to look at the private providers."*

Other respondents wanted to know how longer term plans/budgets would account for inflation and rising costs.

*"I'd be concerned about the impacts of CPI on your budget. In five years time it will probably be worth a lot less the way that CPI is going. The longer the time frame, the more flexibility you'll need."*

*"[t will need to be] reviewed every year or every two years because we're in a period of high inflation and [cost of living] crisis, so you'd want to review it regularly."*

# Appendix A – Group Composition

- Group 1 comprised NDIS support workers and/or NDIS guardians/nominees/carers/family members (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme.
- Group 2 comprised NDIS participants and/or their guardians/nominees/carers (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme.

- Group 3 comprised NDIS participants and/or their guardians/nominees/carers (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme.
- Group 4 comprised NDIS support workers (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme.
- Group 5 comprised NDIS participants and/or their guardians/nominees/carers (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme.
- Group 6 comprised parents of children under the age of 9 who are NDIS participants (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme.
- Groups 7 comprised NDIS support workers (mix genders and ages), living Australia-wide, exploring reforms designed to make the Scheme sustainable.
- Group 8 comprised NDIS participants and/or their guardians/nominees/carers (mix genders and ages), living in WA, SA, NT, and QLD, exploring reforms designed to make the Scheme sustainable.
- Group 9 comprised parents of children under the age of 9 who are NDIS participants (mix genders and ages), living Australia-wide, exploring reforms designed to make the Scheme sustainable.
- Group 10 comprised parents of children under the age of 9 with a disability, with a mix of NDIS and non-NDIS participants (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme.
- Group 11 comprised people with a disability and/or their guardians/nominees/carers, with a mix of NDIS and non-NDIS participants (mix genders and ages), living Australia-wide, exploring reforms designed to make the Scheme sustainable.
- Group 12 comprised people with a disability and/or their guardians/nominees/carers, with a mix of NDIS and non-NDIS participants (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme.
- Group 13 comprised close family members of someone with a disability who are not primary care-givers (mix genders and ages), living Australia-wide, exploring reforms designed to make the Scheme sustainable.

- Group 14 comprised close family members of someone with a disability who are not primary care-givers (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme.

# Appendix B – Final Set of Wording Tested

- We're going to humanise the NDIS by making the Scheme more about people and less about process and bureaucracy
- We're going to ensure that the Scheme will be there for the future by protecting participants from exploitation and making sure that every NDIS dollar is going toward improving outcomes for participants

How do they sound as our aims/objectives? Right direction, wrong direction, somewhere in between?

**How we will humanise the system (proof points)**

- All participants will have the option to be supported by a Navigator – a person who will guide them through their NDIS journey. Navigators will be available from the very start to help people apply and not feel intimidated about accessing the Scheme. They will guide participants through the process and help them make choices about how to spend their funding. This includes helping participants understand what the Scheme allows them to spend funding on and what things are proven to actually make a difference. Navigators will be chosen and paid for by participants from their funding, replacing Support Coordinators and Local Area Coordinators. They will be locally-based, bringing local knowledge about what supports are available where participants live, including those outside the NDIS as well. For complex cases, they will be specialised in a participant's disability.

Responses and concerns/hesitations to this?

If not, prompt with: what about the idea of Navs helping participants understand what the Scheme allows them to spend funding on and what things are proven to actually make a difference? Any concerns/hesitations there?

    - If they raise concerns around who gets to decide what's 'proven' or 'reasonable and necessary', ask: There will always be rules in the Scheme around what you can and can't spend money on. Given that, how important is it to have someone who can guide you on those rules so you can make informed choices?

    - Also test: what if a price limit was set, such that (for example) there's more flexibility for something that costs less than, say, $100?

- For those joining the Scheme, the government will now pay for the professional assessments required to apply for funding. Access to the Scheme will no longer be limited by someone's ability to afford the required assessments.
- Also supporting participants will be another new role, their Assessor. Assessors will be specifically trained in assessing participants' support needs. They will personally meet with participants on multiple occasions to understand their situation and develop an assessment that is then used to determine a support budget.
- For most participants, they will have just two people to deal with: their Navigator and their Assessor – streamlining the relationships they need to manage within the Scheme.

Responses and concerns/hesitations to this?

- Participants will receive a budget package – rather than a line-by-line budget – that gives them flexibility to choose how their funding is spent. Avoiding the situation where participants can have thousands of dollars sitting in parts of their budget that they can't spend, as they run out of money in other areas of more pressing need.
- Budget packages will also be longer-term – 3 to 5 years rather than 1 or 2 years to reduce the stress and cost of annual reviews. But participants will still be able to request changes to their budgets if there are changes in their lives.

Responses and concerns/hesitations to this?

If yes, ask: on balance do you think the positives outweigh the negatives?

Supporting these changes will be other improvements that will make it easier and quicker for people to access support:

- Investment in foundational disability supports available outside the NDIS (e.g. information resources, support groups, services like meals on wheels or cleaning). So participants don't have to spend their funding on things that should be available through other sources.
- The introduction of early intervention supports for people with a psychosocial disability. This would provide them with early supports in that critical period while they undergo a proper assessment of their needs. After that period, they will

either enter into the full Scheme or into the mental health system for ongoing support.

Responses and concerns/hesitations to this?

- Significant investment in early intervention for children by increasing the availability of specialist supports through kinders, childcare and schools.

Responses and concerns/hesitations to this?

**How we will ensure the Scheme is there for the future (proof points)**

- Too many participants are subject to fraud or unethical behaviour. A stronger hand is needed to protect participants. There will be increased monitoring and auditing of service providers in the Scheme – both in terms of where participants' money is going and the quality of services that participants receive in return. The role of the 'watch-dog' in the Scheme will be strengthened to give it better powers to hold providers to account. So we don't slow the whole Scheme down with red tape, a risk-based approach will be used: so there is 'light touch' over-sight for low risk providers and heavier oversight for high risk providers.

- Participants should not have to pay extra for the things they need just because they're being paid for through the NDIS. An Independent Pricing Authority, like they have under Medicare, will be established to set fair prices that reflect both the right of participants to pay a competitive price and the requirements for providers in supporting people with a disability. NOT UNDERSTANDING

Any concerns/hesitations in this?

If we are to ensure the NDIS is there for the future, in some parts of the Scheme we do need to address the realities of its cost.

Test: do participants accept some aspects of NDIS costs need to be addressed to 'futureproof' the Scheme? Why/why not?

Now, let's talk through some specific examples

- One possible change is **raising the threshold to access the Scheme for children with developmental delays**. This would mean that only those children with more significant impairments would access the NDIS.

- However, this would only be done in conjunction with the investment in early intervention for children via schools, kinders, etc, as discussed earlier.

So the change to the NDIS would be balanced by those who ‘miss out’ on NDIS funding having access to an improved safety net outside of the NDIS. Thoughts/reactions?

Are the impacts sufficiently balanced here? If not, what would be needed to better balance the impacts for children with developmental delays?

How big a challenge do participants think it would be to bring our schools/kinders/etc up to an acceptable level in this space?

- **Supported Independent Living** is one type of support to help people with a disability with higher support needs to live in their home. It is for people who need some level of ongoing help at home.
- Currently, SIL participants can be funded for 1-on-1 support – where they have a dedicated support worker helping them 24 hours a day. While some participants will always require, and will always receive, 1-on-1 support, many do not need this intensity of support.
- Where possible, such participants would move to a 1-to-3 support model – one worker for three participants.

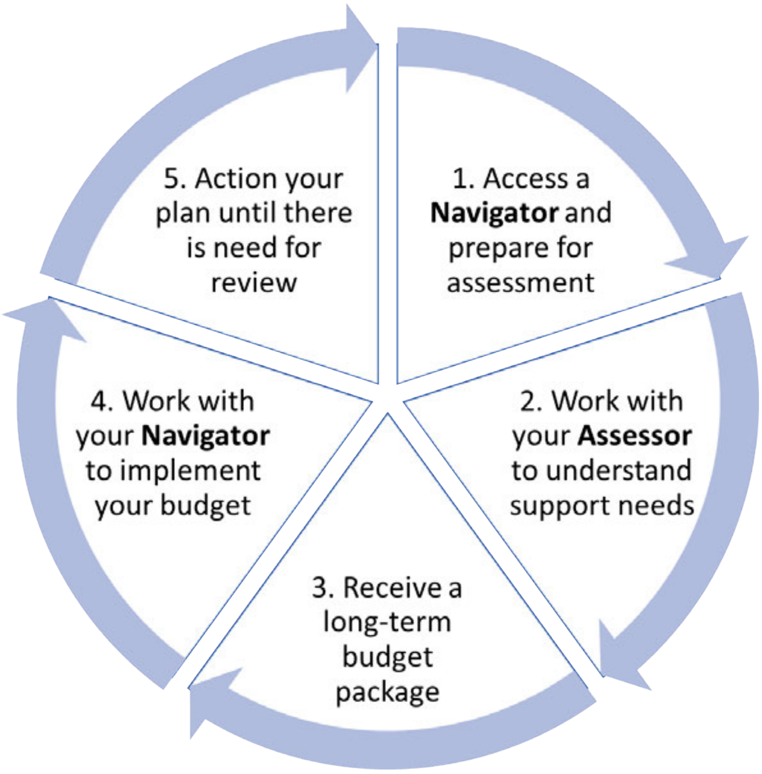
This change would be balanced by: a) improvements in outcomes for many participants, as the 1:3 model offers increased social connection and reduces isolation and b) innovation in the way support is delivered so people can live independently but with shared care, and avoid the old‘group home’ model of care.

Thoughts/reactions?

Are the impacts sufficiently balanced here? If not, what would be needed to better balance the impacts for SIL participants?

Thinking back on everything we’ve discussed tonight – covering all the things about ‘humanising’ the Scheme through to the things about pricing, exploitation and how to balance out changes. Overall, do you think these things would help or hinder participants on balance?

# Appendix C – Scheme Humanisation Reforms Explanatory Diagram



redbridge
INFLUENCE WITH INTEGRITY

# NDIA Reform Communications
# Focus Group Research Report
# October 2023

## Summary and Recommendations

For the vast majority of general population respondents, NDIS participant experiences remain the most powerfully defining force in their views of the Scheme (aided and abetted by many ‘switching off’ from mainstream media). We again see attitudes to the NDIS that are defined by their empathy and an aversion to cost-cutting – indeed, a *distaste* for cost cutting narratives which are seen to contain a commentary and politicisation of the “worth” or “value” of the lives of Australians with a disability. In short, compared with our research from early 2023, there is no real change to the underlying social licence of the Scheme *at this stage*.

However, it should be noted that – if anything – attitudes toward the Scheme from participants seemed to have sharpened since the previous research. Participants and carers spoke of the intensity of their fear with regard to NDIS funding and the bureaucratic decisions which – for them or their children – are often existential. This profound fear is accompanied by intense frustration and confusion in response to the Scheme's perceived complexity and “inconsistency”. While such sentiments were present in the previous research, in this round of research, we also find a degree of disillusionment: participants want and expect serious, systemic change and, instead, there remains a sense that no change is coming. The reforms announced in May 2023 are simply not known or recalled.

This research suggests that a continuing decline in participant attitudes toward the Scheme represents a bigger risk to public sentiment/social licence than negative media coverage about NDIS costs. Indeed, the media narrative only seems to work where it reinforces what the general public is hearing about the Scheme through their personal networks, not the other way around.

Within this attitudinal landscape, there is recognition of the need for reform to the NDIS that a) makes it better for participants and b) makes it lasting/sustainable (it most certainly needs to be there in the future). Framing the objective of reforms with these dual goals works well to speak to participant and non-participant concerns about the Scheme.

Making the NDIS better for participants speaks to a ‘core truth’ that the Scheme is immensely complex and, furthermore, *hostile* in its complexity (i.e. where the complexity works against the interests of those the system is supposed to serve). Even in the general population groups, it seems everyone knows someone with a NDIS horror story.

Making the NDIS lasting speaks to the 'core truth' that the Scheme is being abused or rorted – primarily by "dodgy" providers – and that participants (not taxpayers per se) are largely the *victims* of this (robbing them the ability to get the quality support they need at a fair price). This is compounded by a perception of NDIS services being "over-priced" – the idea of the 'wedding cake tax' applying to all this NDIS.

Thus, from a communication perspective, the critical pieces to a 'making it last' reform story are a) addressing fraud and "dodgy" practices by provider and b) for participants, normalising pricing under the NDIS, so they aren't robbed of their value for money by overpriced services being written into the way the Scheme works: "Don't talk to us about cost blow outs when you set the prices!"

A key finding of this research is that the 'complexity truth' makes communicating reform to practice or process within the NDIS is difficult. Firstly, from those with any direct contact with the Scheme, there is a sense that complexity will *always* be there – it's inherent to a system that attempts to provide person centred care. This adds a degree of conflict around complexity: no-one wants to lose the aim of making disability care person-centred. Secondly, in relative terms, addressing fraud and unethical behaviour in the Scheme is believed to be a more credible/believable aim for Government compared with fixing the complexity. Thirdly, when talking about reforms in this space, the complexity puts the focus – for both participants and non-participants – on the *how*: a) how it will be done, in a way that doesn't add further complexity or increase opportunities for financial abuse of the Scheme, b) how it will be paid for, and/or c) how it is different to what exists now.

Thus, we see discussions in these groups quickly veer into issues of implementation. There is general agreement with the principles used to frame the reform territories tested – e.g. goals *are* important to treating people as individuals, participants *should* have more control over their budgets (and their knowledge of their needs should be respected), and NDIS *should not* be 'the only safety net' for people with disabilities. However, the focus on the 'how' means *it is very hard to sustain a values-based conversation around fixing the complexity* – it drags you into the weeds.

So, for example, a focus on goals raises concerns about one participant's increases in funding coming at the expense of another who can't advocate for their goals as effectively, and a move to budget first planning puts more burden on people with a disability to manage their money and increases the fear of an NDIA audit for those self-managing, while both are also seen to open the door to ineffective (i.e. non-capacity building) use of funds. Similarly, moves to improve supports outside the NDIS become seen as "passing the buck" on to already "overloaded" education and health systems.

By contrast, previous research found it is easier – but still requiring careful treatment – to sustain a values-based conversation about fixing fraud in order to stop the exploitation of Australians with a disability.

So, what are our ways forward?

1. The twin pillars of ‘making it better’ and ‘making it lasting’ work in communicating the aims of our reform package – they speak to those core truths as outlined earlier. The opportunity is to wrap this up under a reform campaign brand that speaks to the core values that respondents see as being *under*-represented in the reality of the NDIS: “fairness”, “equity” and “care”. To that end, participants favoured brands like *Levelling the field* or *Putting participants first* because they spoke to these underlying values – vs *Putting the NDIS back on track*, which was inherently political (even for those who liked it), being seen as a kind of political slogan or an admission/accusation of (previous) government failure.

2. In terms of providing communication ‘proof points’ to create credibility for a claim of ‘making it lasting’, there is a strong need to have reforms that speak to addressing (provider) fraud, as well as (for participants) normalising prices. Noting that care needs to be taken to convey that we are not talking about cost cutting here, but *the protection of both participants and the future of the Scheme from exploitation*. Respondents want such reform and they are prepared to believe/trust it of the government. Without it, the risk of being seen as “buck passing” is high.

3. In terms of providing ‘proof points’ for ‘making it better’, the current and previous research points to an opportunity around *humanising* the Scheme – i.e. humanising *is* ‘the how’ to addressing hostile complexity. In the previous research we found that bringing *specialised people* into the Scheme – specifically into the interaction between participant and the Scheme – was seen to be a credible driver of greater empathy and understanding. It tells a (believable) values-based story because it is about people not processes. Indeed, in the current research, we again see this core frustration/anger from participants that decisions are made about them (their worthiness/humanity) by a faceless bureaucracy. Putting people (with relevant experiences that make them capable of introducing empathy and understanding) into the story could provide a foundation that then makes other changes – like greater focus on participants’ goals – believable.

   The current research would also suggest that the interaction of such specialised NDIS workers with participants is the only real way to address information/knowledge gaps like explaining the meaning of ‘reasonable and necessary’. At present, ‘reasonable and necessary’ is seen as a blunt bureaucratic tool used for beating participants over the head. A generic education campaign attempting to explain what *we* mean by ‘reasonable and necessary’ to people who feel victimised by the term could be disastrous.

4. Win the disability community first. While this is very much about their substantive experience of living with the Scheme, in a communication sense a key part is talking about the ‘timetabled journey to making it better and lasting’. Participants in this and the previous research don’t expect or want “quick fixes” or isolated “band aids” (that just sounds like a recipe for more complexity). They want serious, substantive, systemic changes to the Scheme, with recognition of the need to “learn as we go”. Put simply, ‘making it better’ is an evolutionary process, not some quick outcome achieved through the rapid application of a series of reforms. It is not tick and flick. But neither can it be put on the never-never. They want a timetable for the changes that are on our horizon now, with consultative processes ongoing to identify the next horizon. Critically, consultation is not just about future changes, participants want to be involved in the implementation and evolution of changes being made. Put simply, they want to be *participants in change,* not recipients of change.

The full breakdown of the composition of each group is provided in Appendix A.

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

# What We Did

- 14 x online (Zoom) focus groups (mix of ages and genders), including:
    - Seven groups with "general population" respondents, covering regional/rural and metropolitan areas
    - Five groups with NDIS participants, support workers, and/or their carers/family members/nominees[1]
    - Two groups with parents of children under the age of 9 who are in the Scheme

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

- Groups explored:
    - What respondents had been hearing about the NDIS - either in the media or within their social circles
    - Unprompted suggestions/priorities for areas of improvement which respondents believe the current review into the Scheme should examine - specifically whether cost concerns or reforming the system to better serve participants should take primacy
    - Responses to the reform areas with the primary goals of making the Scheme work better for participants and making the Scheme sustainable over the longer term: i) a focus on goals, not impairments; ii) budget and planning ; iii) reasonable and necessary supports (NDIS participants and/or their carers) ; iv) early childhood support; v) foundation support; vi) mainstream support; vii) intermediaries (NDIS participants and/or their carers); viii) the transition
    - Responses to reform branding
    - Trust in Government to deliver improvements to the NDIS

- Fieldwork took place between 21 September and 2 October 2023.

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[1] Referred to as "carers" for brevity

# What We Found

## Part One: The Attitudinal Landscape

### The NDIS maintains strong community support

Consistent with our findings from earlier rounds of research, broad community attitudes towards the NDIS were characterised by strong support for the Scheme's intent, with no discernible movement in attitudes towards the Scheme or its funding.

The NDIS maintains its place, across-cohorts, as a key pillar of a functional and ethical society to which people are happy for their tax dollars to be allocated - a sentiment driven by empathy and compassion for people with a disability, with a clear, strong consensus that NDIS funding constitutes a priority for Government.

*"I agree with no hesitation! [I'm] very happy for tax to go [to the NDIS and I'm] happy with the amount that seems to be going to it at the moment."*

*"I would happily give my tax to [the NDIS]."*

*"I think it's an essential service and it should be supported wholeheartedly, and I have no problem with paying for that with my taxes."*

*"I think it should be at the top [of our Government's spending priorities]."*

*"It's essential. These are our most vulnerable people in our community and they need the support. So, it has to come from society and society is Government - that's who runs things for us. It's essential, it's got to happen, but it needs to be monitored."*

Once again, these sentiments were predicated for a number of participants on their sense of 'there but for the grace of God go I': *"I want to have something like this in the country I live in. It's important for me to know that my Government takes care of people who need the help, and that my tax money is helping people who need it. Because maybe one day, I'll need it."*

As in previous research rounds, numerous general population and NDIS participant/carer respondents spoke of the transformative nature of the Scheme due to its capacity to empower participants and provide them with a dignified and meaningful life. A number of general population respondents characterised the NDIS as delivering "life changing" outcomes for people they know.

*"It's really helping a lot of families."*

*"It's helping thousands and thousands of Australians with their everyday life."*

One respondent who had succeeded in helping his elderly parents participate in the Scheme remarked, *“I couldn’t speak highly enough of it!”*

There was discussion of supports the Scheme makes available that under other circumstances, would be unaffordable; however, while there were a number of positive accounts of the Scheme (either first or second hand), these were often accompanied by caveats, that such stories were not universal.

*“I have a nephew who's on it. And his mother has a lot of great professionals behind her and she seems to have a lot of access to a lot of things she wouldn't be able to [otherwise] access if she didn't have the Scheme. From what she has said to me, she's quite happy with the Scheme. So I've heard that positive. But I've also heard of other people that have had it and now lost it and they're struggling without it. There was a crackdown on who was on it.”*

As with earlier rounds of research, we did not find any meaningful difference in sentiment or assessment of the importance of the NDIS’s intent between the general population and people with disabilities or their carers. The only notable distinction, once again, and as might be expected, involved knowledge of the NDIS’s practical details, which was greater among those with direct experience of the Scheme.

## Awareness and assessments of improvements to the NDIS

Among disability community respondents, while there was some awareness of a review, their perception of the Government’s intent/direction for the Scheme was often framed by a sense of disillusionment in that long-desired change/improvement to the Scheme still doesn’t yet seem to be coming.

*“I was hopeful for the Scheme… the intent is there. Unfortunately, we’re not seeing any changes. [Government] is not putting money where their mouth is.”*

*“Government should get more involved. We need a long-term plan [for the Scheme].”*

*“I don’t feel like anything is changing and that anything is going to change. The rhetoric I’ve heard is winding back not giving more.”*

“*When you’re sick it’s hard to fight. I just don’t have it in me”.*

Others in these participant/carer cohorts were unaware of any pending improvements: *“I’m on the community Facebook groups and I haven’t heard any direction,”* and, *“Haven’t heard from anyone, but I get the impression they’re trying to tighten how they give out budgets and what’s included.”*

There was no awareness of the reforms announced in May 2023.

There were, however, concerns about novel processes that have been implemented without explanation or warning. For example, *"It seems to be common across the board that everyone gets rolled-over"* - that is, their plans are all just being rolled over without review. According to these respondents, this "should be a good thing"; however, it induces anxiety because they do not know - and no one has told them - whether this is a deliberate new approach or a harbinger of something that will prove deleterious to their care: *"My LAC can give no explanation [of why] but did say it can be reviewed [by the NDIA] at any point, so it doesn't guarantee funding for 12 months."*

Indeed, communication more broadly constitutes a significant problem - particularly for those entering the Scheme: *"We just started [on the Scheme] with my son with autism. They need clearer instructions on how to apply and what to do. Going through Facebook groups was the only way to find out what to do. It's stressful."*

Among general population respondents, meanwhile, there was limited awareness of the current review into the NDIS, with only the most engaged possessing any prior knowledge - usually because they had some connection to the NDIS whether through friends, family, colleagues, or personal experience.

*"Nothing in particular [has reached me from the media], but I have a couple of friends. Both of them have autistic children, and they get some support from NDIS. That's how I know about it."*

*"I'm not too sure if they have some review or they're going back to a review."*

*"There's talk of reviewing how it's currently rolled out and looking at ways that it could be improved. I can't remember specifics on what they're calling for, or what needs to be done."*

## The public sentiment: the importance of fraud vs costs

Even among the engaged general population respondents there was limited cut-through of media narratives regarding NDIS cost blowouts per se, with accounts of fraud taking primacy in terms of which media narratives had reached them. This, too, was consistent with earlier rounds of research and, again, this was most often framed as *problematic for Scheme participants* and not as a reason for cutting the Scheme's budget.

*"Lot of money being misused and [providers] not passing on value to their clients."*

*"Clients are getting conned out of money by providers. There's good people and bad people in the system."*

*"I have heard on the news about people not using the system correctly - like dodgy providers."*

When respondents were asked directly about why they believed NDIS costs were blowing out, rorting remained the focal point. They argued that the costs of the scheme were "exploding" due to "rorting by suppliers". However, it is notable that those in the general population with direct experience of the NDIS observed that when reporting such rorts, a lack of action by the NDIA seemed to be characteristic and itself a key contributor to cost overruns.

*"There are definitely people doing the wrong thing. I've personally made fraud responses [that is, reports to the NDIA] which are then never actioned. So that in itself is like, 'Why do I bother highlighting these things?' and then watching for the next few years, the same thing happening and nobody being held accountable. So when they say to me, there's not enough funds to meet the need, and I'm working with people with some of the most profound disabilities and they want to cut those people's funding, [and] not deal with the places [engaging in fraud]."*

Conversely, when general population respondents were asked directly whether cost blowouts should be addressed by cutting funding, the response was adamant and instructive: funding must not be cut but should instead be made to work better for the participants in need of supports. There was, again, consensus that the review's focus should be on determining how to "better manage" the Scheme, "not cost cutting". Indeed, such cost cutting was deemed "cruel". For these general population respondents, "better managing" the scheme means improving the experience for participants and making sure the money gets to them for the things they need.

*"If we come out [of this review] and the outcome is to cut [spending] down that's the worst possible outcome."*

*"[It] definitely [should] not [be about] reducing the cost - definitely [about] trying to improve the system!"*

*"When you're making it better, or you're trying to make it lasting, you don't want to just be focusing on money. If you're not making it better, it doesn't mean that you're going to be saving money."*

*"[The Government] shouldn't cut the funding of it. Just overhaul the system and make it fair and [ensure] the funds are going to those who really need it."*

*"[We] shouldn't cut the funding of it, just overhaul the system and make it fair and [ensure] the funds are going to those who really need it."*

*"I hear it's difficult for people to get the money they need. So it needs to look at how that's allocated. It's about streamlining".*

*"More policing of the money and [make it] slightly easier for people who need it to get it."*

*"At the moment, anyone can just go and set up their own support coordination company. And then they're just charging the plans minimum $100 an hour."*

*"It's about better management [and] get[ting] more value for the money - not the actual funding itself. I don't think it's about cost cutting, I think it's about getting the most value for the money that we have. The experience of the participants, from what it sounds like, it could be quite a difficult, painful process to even get the help. So there's probably administration problems that need to be looked at."*

Of the minority of general population respondents who were aware of the media discourse regarding cost blowouts, there was a degree of scepticism - and at times anger - at some of these reports. As this general population respondent with professional experience with the NDIS observed, *"Just because the plan is funded for X amount [doesn't mean all that funding is being used]. The percentage of those funds used across the board is something like 70%. So you've got 30% of the allocated amount of funds across the year for the entire cohort not actually being spent. But they're not reflecting that in the data [or] the news media."*

When this respondent was asked why she believed the media had failed to report this aspect, she answered, *"That doesn't suit the agenda!"*

Indeed, some general population respondents in the Perth/Adelaide Aspirational cohort (a cohort traditionally associated with conservative political inclinations) took particular exception to people with disabilities being "politicised" by the media coverage around the Scheme: *"The spin is so negative and hurtful because it's really asking whether people with a disability are worth it."*

Among the small minority of respondents for whom Scheme costs concerns were at issue, a number identified the 'wedding tax' phenomenon - that is, *"something that costs $50 to a normal person, goes to $600."* Among these respondents there was the belief that when the NDIS sets prices, the suppliers simply charge the maximum amount for everything they can.

A number of disability community respondents, however, pushed back on the notion of cost-blowouts at all. This sentiment was founded not only on the exploitative practices of some providers, but was a response to the system itself, designed by the Government, which they believe incentivises predatory pricing in an exploitatively priced market: *"Don't tell us it's too expensive and not reasonable when you set the prices!"*

Significantly, some respondents from the disability community expressed the hope that the current Government's approach to cracking down on fraud would maintain focus on providers, rather than "nickel and diming" participants who are simply trying to live their lives.

Indeed, the Group 9 disability support workers were notable (among disability community stakeholders) for being much more positive towards improvement within the NDIS. The reason for this positivity was that there was seen to be actions aimed at tackling fraud and exploitation – describing it as "cleaning it up", "like when they cleaned up the RTOs a few years ago." They like changes that mean the Scheme is "less able to be messed with" and want government to be "a sheriff" to enforce proper conduct, especially when "there's people in it for the wrong intention, profit ahead of outcomes."

There was, however, some nuance in this group with regard to the "clean up". As one respondent explained, *"I can see we do need a lot more policing of the NDIS… there's a lot of shonky people out there. But it's not the only answer. [We have to be careful that it doesn't] slow things down even more, mak[ing] it a less dynamic system."* The concern here is that the system could become over-tightened, adding to its complexity and slowness.

## The public sentiment: the importance of participant experience

More broadly, despite the prevalence of the cost blowout narrative in the media, a considerable number of respondents across-cohorts observed that they were hearing about *inadequate* funding and/or plans to cut funding to the Scheme.

*"It's such a great program, that every time I hear that they are thinking about cutting funding to it, it's quite concerning, because obviously it does help a lot of people."*

*"I think [the current review] is probably to try and cut - to save money. It's all about costs, and spending, especially looking at what's going on with bulk billing - that's being pulled back [too]."*

*"I've been reading about some people getting cut off from funding."*

*"I've mostly heard negative things - that the Government's cutting a lot of funding, especially in the space that I work in, and also having two children on the NDIS. [They are] cutting funding for children with disabilities such as autism. That's mostly what I've heard."*

*"I'm fairly pessimistic about how long it's going to take for our luck to run out basically [with regard to NDIS funding]."*

*"I'd heard about funding cuts for clients [who] have been on the NDIS for some time…. People aren't able to get the resources that they actually need."*

*"I have heard about a lot of people getting their plans slashed, although, thankfully, we haven't had ours [cut]. And it is a very critical moment for us because my son is going into adulthood. So he needs a lot of support with independence or getting there."*

Once again, the overarching concerns among those in the general population cohorts, revolved around the difficulty of accessing and/or navigating the scheme and/or the negative impacts of problematic providers on participants, rather than concern regarding cost blowouts: *“That's the number one thing that needs to be rectified: just making it easier for people who clearly have a disability and the need to for the services.”*

As a result, because the daily experience of the NDIS of disability community respondents is not changing, their disillusionment with the Scheme is filtering through to family, friends, and colleagues.

*“The Government has created a big conflict [with regard to the NDIS] and the media helped the Government to do that. [The Government made] promises [and] they gave them to the public [but] nothing happened and nothing has changed!”*

Others observed, *“It’s just not user friendly.”* NDIS participant accounts of the constant “fight” with bureaucracy, the complexity, and “the barriers” to getting and keeping funding therefore colour not just their experience of the Scheme, but broader societal assessments as well.

The Kafkaesque nature of participant’s experience is characterised by issues such as plan reviews requiring participants to obtain expert reports which cost “$3,000 on average” - which has to be paid for out of their funding package. Upon approaching their Local Area Coordinator (LAC) with their reports and their goals and their proposed plan (itself requiring copious research or paying extra for a Support Coordinator to do it for them), participants recount their LAC sometimes telling them, “I’m not going to read the reports.” After discussing the proposed plan with the LAC, the LAC then passes that information to the person who makes the decision to approve/reject the plan - a person whom the participant never meets. That assessor (who is not a health professional) will then often make a decision which directly contradicts the advice of the health professionals in the $3,000 report: “The NDIS just says ‘nup’.” Numerous participants contented that such decisions are often not due to the substance of their request, but because of how the request was expressed: *“Sometimes they say it’s just your wording”.*

After such rejections, participants are forced to choose whether they 1) start the process again and either a) hope to find a more sympathetic assessor who will deliver a different outcome (which happens frequently) or b) ask for less; or 2) go to adjudication, where upon the NDIA pays for a lawyer to represent them. Participants cannot understand the logic of this process: *“They’re just flushing money down the drain,”* because whatever the assessor had hoped to save by rejecting the plan is spent (with additional costs) because of the lawyers’ bills.

As a result, Scheme participants often feel the bureaucratic process is a direct judgement of their worth as a human being, placing a price-tag on their very existence: *“Are you entitled to support? Are you worth the money?”*

Apart from the human cost, there is a critical communications component to this profound loss of hope: the entrenchment of negativity, exhaustion, and hopelessness is happening to the very people who are critical informational nodes within their familial, social, and professional circles. They are the means by which information about the Scheme is most likely to be transmitted and their experience of the Scheme is therefore crucial in any advocacy for the current suite of reforms.

*"What am I hearing about it? I don't really hear much about it on the news or anything like that. But in my role, I do work with young people that do have disabilities [who are] on the NDIS."*

*"So I hear from two different sides. I've got a cousin who is a recipient of a package and she gets in excess of what I would ever have imagined anyone on the NDIS would get. And then my niece, who is a hairdresser, has a number of clients who talk about their children who have struggled to get any kind of assistance from NDIS. And then just general social contacts - that comes up every now and then. But it's generally on the negative side about how hard it is to get packages and to get your foot in the door."*

*"I know, it's a lot of hoops to get some of the young people onto it. [But I hear] mostly negative things - never positive - when it comes to the NDIS. Just lots of difficulty."*

*"[I'm not hearing] much positive stuff. I hear how many hoops it takes to jump through to get there and also [to] maintain it [and] keep it. In my role I work with the Job Access part of disability funding, and I am amazed at how speedy things are in that side of things. And I just hear the opposite about NDIS. I hear how slow it is and how hard."*

## Priorities for improvement in the NDIS: streamlining and fraud

It is therefore unsurprising that many respondents, when asked what they would prioritise in improving the NDIS, argued that the accessibility and simplicity of the system should be at the forefront. Indeed, the word "*streamline*" emerged across-cohorts as respondents called for a "better managed" Scheme, with some respondents suggesting the NDIS establish more "contact centres" in which prospective or current participants could speak to someone in person. Critically, this is about improving the human interface of the Scheme more than anything else - that is, addressing systems complexity not with additional systems complexity via multitudinous alterations to processes, but rather to improving the accessibility of participants/carers to the decision-makers and - importantly - to the rationale underpinning the decisions that are made.

For a number of respondents, the bureaucratic burden constituted a particular threat to the essential equity of the scheme with, *"some getting so much… spending it on holidays to Queensland… while some don't have enough."*

*"They are not very stringent on how they spend money but for some people it's hard to get funding."*

These respondents identified an equity issue in the NDIS that those who have the ability to argue or advocate for their package (or can access support to that end) are better placed to receive more than their fair share: *"So quite capable people get extra funding."*

Direct experience of the system (or the experience of loved ones and/or colleagues) led to many respondents - in both general population and disability community groups - arguing that the system is "messy," complex, inconsistent, and "hard". They argued that it is precisely this complexity that inevitably leads to inequity.

*"You've got the individuals who are milking the system and getting far more support than they need, but then the people who are least able to advocate for themselves and have the parents who are in burnout, unable to have that fight. They end up getting less support. It's the squeaky wheel type scenario. And those families don't have the time to do that."*

*"I have a friend with MS. It took her four applications and seven months to get in."*

*"The bureaucracy: it's onerous on people to prove their need. It's a bit unfair and complicated."*

*"I looked into early intervention support for my 6 year old son. The questions asked seemed so age inappropriate… tasks beyond any 6 year old. So that went nowhere."*

*"For some people, it's relatively OK, for others it takes time and time again."*

As with previous rounds of research, there was nuanced acknowledgement among disability community respondents of the difficult balance which an agency such as the NDIA needs to strike in terms of ensuring that only those who need it, receive support, while not making the process of applying for such support an arduous bureaucratic burden.

*"We've been saying all along how many hoops you have to jump through to get on it. [We must ensure] you're getting on it for the right reasons but also, you don't want to limit that because we already know that there are people who need it who aren't getting it. It's a really hard one."*

There was also a recognition among disability community respondents that the complexity of the Scheme is somewhat inevitable: *"The complexity varies with the individual participants."* - that is, the idea of person-centred care renders complexity unavoidable.

However, when respondents across cohorts were asked which they found a more credible motive for the Government's current review into the NDIS - making the Scheme better for participants or cracking down on fraud - the latter was overwhelmingly chosen.

As this general population respondent observed, *“Probably to crack down on fraud [would be the more credible motive]. I'm only 25, but so far, I've got the gist of how the system works [and it] is usually not in our favour. I know that sounds horrible, but I feel like it wouldn't be in the disabled people's favour, it would be more because [the Government] want to bring in the money.”*

*“I think it's probably to try and cut [to] save money. It's all about costs, and spending, especially looking at what's going on with bulk billing - that's being pulled back. We don't know if there's even going to be bulk billing in a few years, the way things are going. So I think it's more believable that they're doing it to cut down on fraud and save some dollars.”*

*“I think from the Government's point of view, they're not worried about making it less complex, which they probably should be. I think it's more about the fraud because they've been embarrassed by the fraud.”*

Attacking provider fraud is particularly desirable across-cohorts because of a) the resentment toward those profit-focussed, “dodgy” operators, but also b) that cracking down on fraud would result in “better PR” for the Scheme. Indeed, many participants were profoundly worried by news stories about fraud - less because of the fraud itself, and more because if *“the general population only sees fraud in the new stories,”* it may cause politicians to make bad decisions regarding the Scheme. They therefore view addressing provider fraud as critical to the sustainability of the Scheme both in a financial sense and in a public trust sense.

# Part Two: Responses to the Eight Reform Territories

## 1. A focus on goals, not impairments

### *What Works When Talking About this Reform Area*

General population respondents who supported this reform area did so principally because of the agency it would afford people with disabilities and/or their carers, and because it recognises that different people need different supports.

"*Sounds fantastic!"*

*"What they should have been doing all along!"*

*"I like it. These people know what they need and most of them are asking just for what they need... So a classic example in my mind is a visually impaired person. And the assessors [attempt to provide them with someone to] do their washing and hang their laundry out. But this person just wants a suitable path out to her own line to be able to hang up her own washing. And so the difference between the cost of a level footpath versus ongoing care for this person to have her laundry done for her which is not what she wants - it seems [like] a no brainer. Give her a path! But that's not happening because it's not apparently assessed in that way."*

Those in the disability community who supported this reform did so for similar reasons.

*"Every person needs to be treated as an individual and assessed on their needs."*

*"I liked it because with clients that I have, some of them have the same disability, but they don't have the same goal. Some of them are quite happy to not play sport on a Sunday and use their funding elsewhere."*

*"Yeah, their focus should be more on the goals. They should be driven by the goals and not just the impairment. There should be more reforms done around the individual."*

*"That's a step in the right direction…. One diagnosis does not fit everything. And we need to stop labeling people by their diagnosis. Some people with ASD are completely normal [and] don't need help. Some people with ASD do need [someone] to help them. That's where the goals come in. And every person needs to be treated as an individual and assessed on their actual needs."*

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

**The need for limitations -** Considerable concerns emerged in both the general population and disability community cohorts about the potential for abuse of the system. There was specification that funding for 'goals' should only be there, *"if they can prove their basic support needs are being met"*.

That is, there was scepticism that participants would prioritise the right things, instead choosing funding for less necessary luxuries: *"I'd put my hand in my pocket every time to really help someone, but spend it on what they need not what they want."* There was therefore, even among those in favour of this reform a call for "safeguarding" to ensure the money will not simply be spent on *"someone to drive me to the shops to buy some darts."*

While these respondents were happy to *"widen the box"* to help Scheme participants achieve their goals, they nevertheless believed in the necessity of limits around this because, *"I am worried about dodgy providers exploiting the loop holes."* As a result, these respondents argued that participants should be supported in making good decisions about how to spend their money by those with the requisite expertise and good intent to help them achieve their goals.

Similarly, for a number of the general population respondents with direct or indirect experience of the Scheme's complexity/unfairness, this reform area seemed to complicate an already overwhelming process: *"I just don't know how it would work… don't know if we've got the resources. It would increase admin costs to personalise it. Everyone's different, but I do feel like it would increase the admin side of it".*

This sentiment was echoed by other general population respondents who worried about the cost burden of such a reform - not the cost of the supports themselves, but the cost of administration that these reforms would entail.

*"It's tailored to the individual which is good but at what cost?"*

*"I see dollar signs."*

*"Sounds good [but] the only thing is they haven't mentioned the cost."*

*"I just don't know how it's gonna work. It seems like an unrealistic target. I don't know if we've got the resources.*

*"I'm of the view it is about money. And it's also about image control."*

In accordance with this, respondents working in the disability space, described their worry that there is a zero sum game within the NDIS: that funding someone's (expensive) goals might cause someone else to miss out on basic needs. As one participant explained, *"I have clients with the same disability and not the same goals. [One has a goal] for example, of playing sport, hockey. It costs a lot but that's her priority. But is someone else missing out because of that?"*

This then prompted a discussion among these respondents about NDIS funding being used to enable participants to go "skydiving" or do "equine therapy", which "costs a fortune". *"The sky's the limit with goals"*, while *"people have difficulty getting funding to do basic stuff."* As another respondent observed, *"Assessing goals needs to be realistic."*

**Cost-cutting fears -** There was also anxiety in both the general population (where there was knowledge and/or experience of the NDIS) and the disability/carers communities about putative cost-cutting which led to fears that this measure had been designed for that purpose: *"That is just another cost-cutting mechanism that is not going to result in people getting the adequate supports, because ultimately, it is about functional capacity."*

**Equity issues -** Considerable concerns also emerged around a potential to create additional burdens for participants in having to manage/administer their money or force them to seek out additional assessments and/or professional assistance to ascertain good uses for their support funding, exacerbating inequity.

*"People that are comfortable talking about their needs can advocate for themselves. But if you can't advocate for yourself, it would take a lot of time to figure out the goals. It creates an inequity."*

*"How's the nonverbal person going to tell you their goals? How are they going to be gauged?"*

*"It does put a lot of pressure on the disabled person to articulate their goals - especially if you've come from a disadvantaged background. You don't necessarily know what's your goal. It could just be to survive another day because that's all your life has been up till now. It's putting a lot of responsibility or pressure on the person to already understand what's out there and what supports are available."*

*"I've noticed that with every plan, you really have to know what to say, and how to say it. Because saying it just a little bit wrong will completely affect your funding and it really puts a lot of pressure on you."*

*"There shouldn't be magic words. It shouldn't be, you've got to word that this way, and you'll get more funding. That shouldn't be a thing."*

Another NDIS participant also pointed out the inherent contradiction/risk in a goals based approach: *"To get support you have to show how much of a deficit you have. So working towards a goal risks your funding."*

That is, a number of participants are afraid that actually achieving some progress toward a goal will see bureaucrats decide they are no longer sufficiently disabled to receive funding: *"It ignites fear in me."*

**Assumption that this was already the case -** Some respondents who work in the disability space, meanwhile, were under the impression that this mode of assessment was already the case: *"It's already focused on the person – person-centred care. They don't [emphasise] impairment in the focus."* So while the reform did align with their belief in the centrality of person-centred care, they did not believe it was new.

This perception also existed elsewhere in the general population: *"I always thought it was configured to individual needs anyway."*

Critically, there were a number of NDIS participants themselves who also believed that this system had been there from the outset and, therefore, their reactions to the idea are framed by their previous (bad) experiences in trying to raise goals in the planning process.

*"I've been a participant since the Newcastle roll-out and there's always been talk about funding being determined by goals. But then they turn around and tell you if your goal is worthy. It's disgusting! I'm yet to see it really be a focus on goals."*

*"If they don't like your goal, or even how you word it, [you don't get funding]."*

*"I feel pushed to set goals that aren't reasonable for me - like I'm being told 'try not to be disabled'."*

*"It's always no, no, no. It's only what he needs for everyday life."*

**Misunderstanding the space -** There is also a danger, particularly among general population groups, that this reform area might be misunderstood, predicated on broader misunderstandings of the NDIS and its purpose, as exemplified by this respondent: *"I like the description you just read, I think it's good to move away from physical disabilities, because from my understanding, the assessment that was made, was like, 'Is Kenny functional? Is he walking, talking?' They make it sound like it's all mainly meant to be for physical disability. So I like the shift [away from] physical disability and more [towards] kids, or whoever it is, who are struggling to meet certain needs of their lifestyle, or fulfillment. So that makes it sound a bit more encompassing to everybody. I was just a little bit confused: if we go to this goal system, could more inappropriateness be coming in? Whose goals are deemed to be serviceable and whose goals are deemed not?"*

## 2. Budget-first planning

### *What Works When Talking About this Reform Area*

For those in the general population inclined to support this reform area, such support was, once again, predicated upon the agency and independence it would afford participants and their carers. However, such support often contained the caveat that oversight systems would need to be robust to prevent abuses by unethical service providers (as will be discussed in depth below).

*"I think it could be a good idea if, for example, a person on the NDIS plan has this amount of funds, but is able to go through with an agent or somebody helping that person. So maybe, then they find a cheaper OT specialist or a cheaper alternative to what's actually given by the plan… So hopefully, there's more people out there who could help them and then they have more funds available for a longer time. So if I understood it correctly, I like the idea."*

Those in the disability community were divided about this reform. Those who supported it welcomed the alleviation of the bureaucratic burden - specifically, the idea of having flexibility to reallocate money within their plans (*"regardless of their little codes"*).

*"I think it opens the door for them to use it in their own ways."*

*"I think just having one bundle of funding would be a lot easier. People don't understand all the categories a lot of the time. You might find that your circumstances change after a few months, and you might have gotten a large budget for therapy. But I know, in my instance, my son's therapy resistant, but gets a lot more out of going with a support worker. But I can't chop and change that. So having one bucket of funding where I can go, 'This week, I think it would be better for him to do that!' And then being very flexible, because needs change so quickly in disability."*

A significant factor in this support was due to the 'the thin market' phenomenon - that participants have funding they cannot spend because there are simply insufficient numbers of occupational/speech therapists, psychologists, and other specialised support professionals.

*"We've tripled [my daughter's] package, and it's huge, and it's great, but in one section, we cannot find one worker and it's just ridiculous when we've got money sitting there doing nothing that we can't use… [With] my eldest, we've had to go outside of NDIS to actually get the help she needed. Because last year, she tried committing suicide. And this is all because she needs the mental [health support]. And we were trying to get a behavioural psychologist [but] where we're at there [are none]. We've got 15 grand worth of behavioural funding we can't use. So my child tried to commit suicide."*

This problem is then compounded by the threat of losing funding if they cannot show that they have spent it and, at present, there is no means of reallocating it within their plan. This makes the promise of funding flexibility very appealing to these NDIS participants, albeit with the caveat that, *"I'll believe it when I see it."*

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

This positive response among those in the disability community was not, however, universal. Many such respondents expressed trepidation regarding this reform area.

**Participant fears regarding complexity and punishment -** Indeed, a number of NDIS participants and their carers spoke of the enormity of their fears regarding managing their plans, with some even worrying that an innocent mistake could see them imprisoned for fraud or forced to pay back unmanageable debts. The experience of vulnerable people being brutalised by Government systems often informed a vicarious trauma response in this space.

*"The Government doesn't care about us. They just care about the fraud!"*

*"I mean, Centrelink has been an absolute nightmare to deal with for 20 years. So since when has either side of Government cared about making things simpler for people?"*

*"If you're self-managed and you're audited [by the NDIA] and they don't like it you have to pay it back."*

For a number of disability community respondents, this fear was highly animating. They feel that they are trying to do the right things (in a context of hostile complexity that is marked by inconsistency and poor communication); however, there is the potential for grave penalties if a bureaucrat disagrees with something they have done. The inconsistency of NDIA decision-making means every decision they make carries grave risk.

*"The audit is an ever-present thing in my mind. Will it come back to haunt me in two years? I just don't really know what I'm doing [in terms of what is a legitimate expense and what is not]."*

*"If you're going to do [budget first planning], every single person telling us what you can and can't do has to be trained on the same damn thing! The inconsistency means it won't work."*

*"I'd be too fearful to spend it because it would come back to bite me and have to come out of my pocket. As a parent advocating for a child, there's that fear of what happens if I'm asked to pay it back. They shouldn't add that worry!"*

Similarly, there were general population and disability worker concerns that such a measure would add to complexity for the participant and, *"participants don't always have the knowledge and skillset"* to manage a budget in a complex system.

*"They're gonna need help."*

*"You're gonna end up with people in a worse situation than they currently are."*

*"I know a lot of participants struggle. A lot of red pens going through lines."*

**Exploitation concerns -** Other concerns entailed the potential for exploitation by carers or others taking advantage of a participant's funding with equity once again emerging as a key concern: *"People without good advocates will lose out."*

*"I'm somewhere in between, mainly because I'm worried about exploitation. I think it's a good idea, because there is that lack of flexibility right now. But I'm just worried for people who can't advocate for themselves - [that] the care is not provided to them."*

*"Even more scope for it to be rorted than it already is! It's just gonna be one line of money at the end, so anyone can take from that; whereas at the moment, it's really clear what providers can access out of that fund."*

This concern that participants may not be in a position to make good, informed decisions about how best to spend their money, led a number of respondents to argue that there is a role for some limitations: *"Still needs to be some sub-categories within that".*

A number of general public respondents spoke about "guardrails", "boundaries" and "justifications" of spending. There was the fear that without these, "negative feedback" about the NDIS in the media had the potential to undermine the future of the Scheme: *"It needs to be balanced,"* to pass the court of public opinion.

Another concern was that such changes may mean cuts in critical services to Scheme participants due to unethical providers taking advantage of systems opacity to over-prescribe unnecessary services, meaning that funding would run out for more necessary items: *"So if they're doing extra hours and whatever else, then they might lose out on support hours or speech therapy and all the other things that are included in that plan… Yeah, even more scope for it to be rorted than it already is."*

Among the disability workers, the idea of broadening budget-first planning to *all* NDIS caused a degree of concern because of the (limited) capability of some participants to actually manage their budget and that might cause them problems: *"[Self management] works, but the people I work with are all mentally capable."*

One carer - based on her experience entering the self management process - argued for a much greater emphasis on "education" in this space: *"I self manage for my son. Going in blind, you don't know how it works. You are scrutinised when it comes time for review. You need more education… I can't imagine what it would be like for someone with diminished capability… it is complex."* This led to a number of respondents fearing that 'pushing' self management on people would see them *"end up in strife."*

**Implementation and probity concerns -** Questions of implementation and practicality also emerged among a number of respondents: *"How would it look in practice? I agree putting pressure on the participant is not the purpose of the system, but it would be hard to keep tabs on it and understand where the money is going."*

Some general population respondents were particularly animated by the possibility that this would allow abuse of funding for frivolous things.

*"[I can see how a lack of flexibility would be] irritating like with my health insurance running out of physio cover and I've got all this dental I don't need. But, I agree … it would just get abused."*

*"I don't like the idea of just letting them [the participant] decide."*

*"It leaves things open for abuse."*

*"It turns into a Centrelink scenario where people take advantage of it too much."*

*"It sounds like an easier way to rort the system."*

*"I haven't seen how that looks. So I'm struggling to get my head around that a little bit. I come from an auditing background. So anytime you start reducing [restrictions], taking things out, you lose accountability around those things. So how do we still keep that accountability there if things don't remain broken down?"*

*"It's a double edged sword. If it gives people freedom to spend it as required, without having to fit in certain categories, people could use it in the wrong way. And then how do you manage it? How do you decide [what] is a worthy way to spend it?"*

These respondents contended that there is a need for "guidance" in spending. While there was sympathy for the frustrations which would come with line-by-line reviews, there was a concurrent belief that an overcorrection would be problematic and that a middle ground of balanced limitations on spend would be ideal.

*"I like the idea of the flexibility because I know how irritating it is with my health insurance when I run out of physio, and I've only got dental left. That's really quite frustrating because I need physio more than my teeth clean. But I definitely [worry] whether someone's going to take a bit more than they need or if these people have got the capacity to save for future needs."*

There was also concern from a disability worker that this would become an unworkable system that the Government would then attempt to rectify via automation, leading to a Robodebt-style situation.

*"The Government might do something [here] where it saves money, but also, it could blow out the cost more because they're not auditing it properly. And they'll say, 'Oh, we don't need as much staff now. We'll revert to some AI Robocop sort of system."*

**Areas of confusion and a belief that this is already in effect -** There was also the belief among disability workers and NDIS participants themselves that *"people who are self-managed already do it" and "isn't that what's meant to be happening?"*

This perception existed among some in the general population as well. They had been under the impression that this autonomy was at the core of the NDIS and they were therefore disappointed that this wasn't already a feature: *"Wasn't this supposed to be happening anyway?"*

As with our previous rounds of research, the aversion to bureaucratic language remained a key hurdle for many respondents: "*I thought it was pretty 'Government wordy' to start with - just so many extra words to almost confuse you. It just sounded like a lot of fluff instead of just saying it straight in 10 words!"*

## 3. Better definition of ‘reasonable and necessary’ (disability community groups only)

For most disability community respondents, there was an intense aversion to the words, ‘reasonable and necessary,’ which they found “triggering” due to its connection to the hostile complexity they experienced with the Agency.

*“The fight that I had to have to get my nonverbal daughter a $1,000 iPad with the Pro Logo programme on it was ridiculous. It was beyond a joke. It's so she can communicate! And it wasn't even [for] me - I can understand my daughter because I'm with her every day. But it was so her school could understand her and her therapist could understand her. And doctors could understand her! Because she broke her leg, and they cast the wrong leg, because no one could even tell which leg was broken and she couldn't communicate. So the fight that I had to have just to have an essential device for her is just ridiculous. And I see friends who have children who need wheelchairs, and things so they can just [be mobile] and they have to battle for like a year! By the time they win that battle, their child has outgrown the thing that they need, and then they need a whole different thing. It's just a merry-go-round, constantly!”*

This mother was told by the Agency to buy a specialised device, “*which looked like an iPad, but it was a speech device. And they're $13,500!”* because the far cheaper, $1000 iPad could have other programmes on it which the Agency said her daughter, “didn’t need”, whereas the far more expensive, specialised device could only be used for communication. This mother was distraught that the Agency was prepared to waste $12,500 on what she perceived as a perverse principle - money that could have been spent on therapies that would have helped her profoundly disabled daughter.

She went on to observe, “A*rguably the $13,500 one isn't ‘reasonable’. It’s unnecessary, because ‘reasonable’ is getting the cheapest: it's the same. It'll do the job!”*

Another parent in the same group agreed, *“I found sometimes… where there's something that, on paper, is not a disability device, like an iPad or those big yoga ball things or whatever - because of factors around a disability, it's <u>become</u> a disability device in that specific context. They need the iPad as a communication device [or] they need the big yoga balls, because the kid stims by bouncing off them. And it's the only thing that's stopping him tearing the house apart. And [the NIDA] are really quite resistant to the idea that, ‘Yeah, I wouldn't be buying this iPad if my kid didn't need it for this specific purpose.’ They go, ‘Well, everybody's got an iPad these days so it's not a disability device.’ They’re not able to see that sometimes a mainstream device is a disability device in a specific context!”*

The perceived subjectivity of the application of the words, ‘reasonable and necessary’, led numerous participants/carers to argue that any education programme around those words would be singularly unhelpful: *“I think ‘reasonable and necessary’ are very subjective. And it seems like the NDIS has a very different definition of those words than most of the participants do. So I think maybe they should just acknowledge that what is ‘reasonable and necessary’ for any disabled person is very subjective and give the individual disabled people more say over what that is in their case, because to [Agency staff], I feel like those words are just kind of meaningless.”*

They did not find the Agency’s wording in any way comforting or clarifying and instead, reacted with either resignation or considerable anger - particularly those who believed the definition’s intrinsic subjectivity is wielded by Agency bureaucrats and is integral to inequity in the Scheme.

*“Always quick to say no. That's their favourite word: no. But to [get a] yes [in a way that] is not torture, you've got hoops to jump through. It's just frustration [and] loss all the time. It's not good enough. We've got funding there, why can’t we use it? I'm not asking for anything special. I'm just asking for certain things that are needed to help my father. It's the most ridiculous thing of all time!”*

*“A creative person can really take advantage of that. If someone's in the know or in the field - if you really know how to work things, and you have a good relationship with your LAC or Support Coordinator, then you're gonna get a lot more yeses!”*

*“I <u>hate</u> ‘reasonable and necessary’! It drives me crazy. They throw that around: the favorite little quote in all the reports!”*

*“It's subjective. I'm not happy with [their definition].”*

Participants and carers felt strongly that people with a disability have no ongoing input regarding the implementation of how ‘reasonable and necessary’ is implemented by the Scheme: *“Disabled people should have more say on what that is.”*

‘Reasonable and necessary’ is particularly galling for participants and carers in a context in which the NDIS forces them to spend their money at <u>unreasonably</u> expensive disability stores: *“I could go to Kmart and buy that [sensory toy], but now they say it has from a disability store that changes three or four times the amount. Save the goddamn money!”*

*“[I hate] that it exists at all! They should not be telling any participant what is reasonable or necessary for them and their disability. I understand they need to have boundaries, like we can't go on extravagant holidays or whatever. But if it's related to the person's disability, and it is something that they need, then it's reasonable, and it's necessary. And if it's too expensive for the NDIS, they need to stop putting up their prices!”*

*"Every kid is different. I'm telling you it's reasonable and necessary for my child and they say 'no sensory stuff'. You don't know how much that fucking $5 squishy ball helps with her meltdowns!"*

Indeed, a number of participants described their experiences of NDIA bureaucrats "overriding" what doctors and other experts have said is "necessary" for them. This then led them to question, *"Who is training these people [the bureaucrats] in what reasonable and necessary is? A lot of them have no idea."*

*"We had a medical expert recommend to us swimming lessons for my kid to improve his lungs because he's got chronic lung disease. And [the expert said] swimming is very beneficial for lungs. Then I called up the NDIS and we had to pay for it ourselves. But it goes back to that 'reasonable and necessary' [being arbitrary]."*

*"Who decides what's reasonable and necessary? What's their qualification? Pretty confident they're not an OT and pretty sure they don't understand emotional regulation [in children with autism]."*

Core to much of this consternation was a) that the NDIA uses 'reasonable and necessary' to make certain expenses "parental responsibility", for things that participants argue they are only buying because their child has a disability and b) they are refused things their therapists have said "will benefit" their child: *"What friggin point is the NDIS if it's not giving your kid what they need?"*

Fundamentally, these objections centred around the faceless nature of the bureaucrat making critical decisions about key supports that determine participants' quality of life - a process they find dehumanising: *"The words are nice and reasonable. The definitions you gave us were nicely worded corporate speak, but who actually makes these decisions? Who will actually sit there interpreting in real life cases? Who sits there taking a year, making people jump through barriers for things [that are crucial to their functioning]? So I think the definitions can stay, but who's reviewing these things and making these decisions?"*

As above, a number of these Scheme participants objected less to the definition itself, and more to what they believe is a suite of processes that deliver perverse outcomes too often because a bureaucrat whom they have never met makes a particular judgement. In this context, the participants view 'reasonable and necessary' as something of a weapon that is wielded by the bureaucracy against them.

*"I know they deem that's what we're entitled to… and for some reason that's very little".*

*"Around [what is] reasonable and necessary for the participant, but also backed by their own support professionals who have taken the time to write letters and say, 'This is what this person needs'. And then for the NDIS [bureaucrat to [overturn that]? [That bureaucrat] might not have any experience in the area of disability, but apparently they can override a doctor or clinical psych and just go, 'We don't think that's reasonable or necessary, so it doesn't matter'!"*

We would therefore recommend strongly against mounting a campaign to educate Scheme participants as to what ‘reasonable and necessary’ means. They do not take issue with the definition or its clarity so much as the arbitrary, inconsistent, and - to them - harmful ways in which the bureaucracy has used the terms, particularly when that use has involved directly contradicting (expensive and time-consuming to obtain) expert advice.

## 4. Early childhood support in mainstream settings

### *What Works When Talking About this Reform Area*

There was a degree of support in the general population groups for this reform area; however, as will be discussed below, much of this support was conditional on such reforms being adequately resourced.

Among those who did support this reform, general population respondents argued that children fare better when they can access supports in everyday settings.

*“It’s a great idea. Moving kids out of the usual environment can have psychological issues.”*

*“It just takes the onus away from the parents to go and find out. It's direct help. I liked the directness of being able to recognise when a child's falling behind and then being able to implement support for them in their learning setting. That's a very good idea.”*

*“My children get help through their school for mental health. They often see these things before parents do. It’s a good idea.”*

*“It’s terribly important to get help early. Extremely important.”*

*“We know someone whose child was non-verbal but through early intervention they are now 18 years old and have a driver's license. It means they are off supports and not spending the rest of their life on the NDIS.”*

*“Ongoing monitoring is important. If they are trying something and it doesn’t work they can tell early.”*

*“Any help early is good.”*

One participant supported the idea after seeing a friend’s child “go backwards” when moved into a special school setting: *“It’s pushing people together with all different needs…pushing them together can have them regressing.”*

There was a degree of support among disability workers for this measure who contended that identifying needs and facilitating supports for kids in everyday settings is good in principle.

*"A good outcome because too many kids fall through the cracks."*

*"[If it's about] teachers flagging behaviours, that's crucial for how that child will progress. If you get to year 8 [before problems are noticed], the rest of the school journey is fraught with sadness."*

It must be noted, however, that the credibility of this reform very much rests on providing a convincing case that it will be resourced properly: *"It could work if it's not dumping the whole burden of the thing [on schools etc] … maybe [schools] could monitor and report but not do all the work."*

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

**An already overburdened education system -** While the principle itself may have appealed to a number of respondents, including some who work in the disability space, there was profound scepticism that early intervention could be made to work in existing mainstream settings. There was a widely held, cross-cohort fear about *"over-burdening the school system"* - a school system which many described as already under strain due to a lack of resources. If the pre-existing strain on schools and kinders is not addresses, there is real worry that children needing support would fall through the gaps.

*"At first I thought it was a good idea, but I don't think schools are equipped to handle it… kids will be missed, lost in the system."*

These participants were also particularly animated about placing additional burdens on already overloaded teachers and other educators.

*"There needs to be a huge amount of support to stop teachers fleeing the system."*

*"It's an already strained workforce: overworked and underpaid. They're going to have to find the people [to do this work]"*

*"I love the idea, but I wouldn't work in a childcare centre for quids [if this came in]."*

*"You'll lose even more teachers."*

*"Poor teachers and childcare workers, what they have to deal with. They're already exiting the system."*

*"Teachers don't have the skills or the capacity, and they're already overloaded. [We're trying to make them] jacks of all trades and master of none."*

As a result, a number of respondents insisted that ‘resourcing’ schools, kindergartens, and childcare facilities would have to entail guaranteed provision for “extra staff,” because, *“extra funding is not effective, it’s extra staff [that is needed]”.*

There were also fears about teachers having to manage what would be a *“guarantee for upset parents”* as many parents would react with hostility to the suggestion that their child has a problem.

**Equity, access, and buck passing -** Once again, equity issues were raised: that better funded schools would be able to manage the increased workload far better than schools with less resourcing.

*“I don't think it's a bad idea. I’m just concerned that saying you get resources for something doesn't necessarily mean that you will, and living in a regional area, all of our schools struggle to get any kind of staff in schools…. Having a team of [support staff] - that's a pipe dream where I live. That would never happen. Our schools are struggling to get teachers, let alone other support staff as well and to train them [is another matter again].”*

There were also concerns that only having such supports in school or childcare settings would not allow for interventions elsewhere, where they may be greatly needed.

*“There's a variety of programmes that support early intervention. But the challenge is, then they are limited to those school settings, and nothing is actually applied in community or at home. Yes, the current system is under-resourced in those education settings. But taking away early intervention from the NDIS will just cause more issues down the track.”*

Concerns were particularly acute among NDIS participants and carers who had either extremely negative experiences with schools (e.g. not implementing adaptations for their children) and they therefore do not trust schools to implement such a programme effectively, or, as with some in the general population cohorts, simply see it as “passing the buck”.

These NDIS participants and carers certainly value early intervention; however, they want it done well and cannot conceive of how that might be achieved in a school system that is already over-stretched and under-resourced: *“Early intervention is so important. If I had gotten earlier intervention, my life would have been insanely different - that’s worth addressing. But I’m doubtful how that would be done in the education system.”*

*“With my son's daycare, through NDIS, we got a generous package and we had a support worker installed at daycare that was supposed to look after him. But because of staffing issues or whatever, they just have that person working there as an extra staff member. It's ridiculous. I've put in so many complaints, but it goes nowhere. So, yeah, I'd be pretty wary of leaving control with those institutions.”*

*“I've just gone through changing my daughter's school because she gets a lot of funding through the school system from the Queensland Government. And a lot of it was being used for other kids who weren't getting support... So it's hard to trust the school system.”*

Or as this disability community respondent summed it up: *"It's just gross. They're saying it's too hard for us, you do it."*

This essential, cross-cohort scepticism was founded on the belief that this was simply another means of the Government abrogating its responsibility: *"Sounds like Government trying to shift responsibility to schools … it's a handball."*

**Specialist shortages -** There were also concerns among parents of children with disabilities that there is already a shortage of critical allied health professionals and that this policy proposal would only exacerbate such problems.

*"The problem is there needs to be more people in the fields of speech therapy and occupational therapy and paediatrics… [otherwise] it'll just be a backlog of all the kids that have been screened, waiting for therapy."*

*"How is it supposed to be in kinders and classrooms if they don't have therapists to do it?"*
*"What a lovely world to live in… but where are we pulling these fairies from?"*

*"Put them [OTs, speech therapists] into the list of free Uni courses. We're in crisis!"*

*"I would rather see money invested into OTs and Speechies [rather than foundational support programs]"*

These respondents envisaged this policy proposal creating new stressors for parents - being hamstrung by *knowing* something is wrong while not being able to access the help their child needs: *"It's more frustrating if you know you need support [and can't get it]. It's already a mad scramble with paediatricians closing their books".*

**A belief this is already in effect -** In addition, some general population respondents were under the impression that such services already existed.

*"Is there not a program that does that all already? Like the preschool field offices? That's exactly what they do. I'm just looking at the guidelines. And it says that it's a funded kindergarten programme to provide a variety of settings in children's centres doing exactly that."*

**Confusion -** Once again, confusion regarding this reform area was a key obstacle for a number of respondents - particularly those in the general population cohorts, with some who misunderstood this reform proposal as itself constituting a pathway into the NDIS.

## 5. Increasing foundational supports

### *What Works When Talking About this Reform Area*

This reform area did garner considerable support from a number of respondents who were enthused by the promise of better provision of information and advocacy supports: *"The advocacy part is so important - to give people more information, so people are aware, 'These are the options I have'."*

*"I think the foundation section in particular [is the most compelling reform] - people having access to information and advocacy - because I think that is a massive hole within the current space. There's nowhere for people to go to ask a question, especially regionally."*

*"It seems like there are a lot of organisations providing lots of support and they would benefit from more funding. Giving more money in this sector is great".*

Of note, this reform garnered considerable enthusiasm from a number of respondents working in the disability space: *"A great direction!"*

Their enthusiasm for this reform - beyond an in-principle agreement with the idea that these supports need to be bolstered, especially in regional areas - was based on their belief in a profound information and advocacy gap with regard to the availability of local basic needs services (*"awareness needs to be raised,"* because, *"these supports do exist but its scattered and people don't know where to go"*) and about the complexity of the NDIS: *"Because there's no advocacy, people are trying to navigate the NDIS without the tools to do so."*

As one of these respondents observed, *"You're overwhelmed just living with a disability and then thrown in the deep end [with the NDIS]. So a good starting point is to have basic supports for everyone."*

Of those NDIS participants and carers who supported this idea, they did so principally because a) they supported anything that allows them to avoid dealing with the NDIS and b) *"A lot of our funding goes on foundation things… this will open up your funding for other things."*

*"It's wonderful in theory, but there's so many needs and wants out there. And there's not too many people that you meet that just go, 'I'm so happy with the NDIS they're just wonderful. I'm just so glad that I'm on it. And it's just such an easy process.' I haven't met that person yet!"*

What these respondents would like to see is participant "voice" in defining where the investment goes to enhance these foundational supports: *"They need to get the voice of people on the Scheme to tell them what the supports are and what we need them to be."*

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

**Implementation concerns –** Among participants and non-participants like there was often a sense of confusion about how the improvement of foundational supports would actually be delivered, and through that a concern that the NDIS looking to offload its responsibilities.

*"I just go, 'How'?"*

*"On paper, 'Yes' but not in practice."*

*"[It will be run by] charity, not the Government. The funds are going to be under charity and nonprofit organisations. I think it's not fair. That's a Government job. They have to [ensure] everyone feels safe and feels support and feels the life they live [is worthwhile]!"*

*"We're just going to fix it by increasing access and increasing these things. But how are you going to do it?"*

Once again, the issue of a lack of specialists/therapists was raised as an implementation barrier: *"We don't have enough psychologists as it is! We don't have enough skilled people. Sounds good in theory but it's pie in the sky."*

Even among those NDIS participants/carers who supported the idea, there was considerable concern that if all people with a disability are trying to access these supports, they will just end up on "wait lists" unless they are willing to use their funding to pay for the service, which would leave them no better off than their current situation: *"If everyone all of a sudden can access an OT or a speechy, then you're going back to using your funding because the waitlist is too long."*

**Equity concerns –** There were profound equity concerns as a result of the expense and difficulty in accessing specialists for the diagnoses a number of respondents assumed would be required to access such services: *"It costs a lot to go see medical professionals to get diagnoses. And if you don't have the funds in order to do that, all those people that don't have a diagnosis because they can't afford to see medical specialists, they're never going to be able to access funding."*

Equity issues were also raised in terms of geographical distribution of services, notably that regional areas simply lack many of these foundational supports: *"Are they saying they're going to do that? Or are they saying it's already there because in a regional community, [these] are not available to people with disabilities and I don't know how they could get them to exist in a community like ours without substantial additional support."*

## 6. Improving mainstream support

### *What Works When Talking About this Reform Area*

Where there was support for this area of reform among general population respondents, it was often predicated on two primary reasons:

a) it appealed to the profound empathy and sense that *"we need more done around respect"* for people with disabilities, in order to ensure that supports for them simply become a natural feature of how society operates, including *"the cities we are building, it should be embedded into town planning";* and
b) it provoked a sense that disability should be a "shared burden," in a well functioning society: *"The burden shouldn't just be on the NDIS, but spread throughout,"* with the understanding that some (e.g. governments or the private sector) may be failing in their responsibilities and not doing their share.

As might be expected, a number of those working in the disability space also supported this reform due to their complete agreement with the principle that we need to do more to improve accessibility of mainstream services.

*"There's shops my client wants to go to for lunch and they're inaccessible. In this day and age and with our understanding of human rights, it's not on… if you have to pay extra to fit your shop out, so be it."*

*"I know of a local organisation that provides supported accommodation but their offices aren't accessible for anyone with a disability."*

These respondents' dual belief in a) the primacy of person-centred care and b) the inherent complexity of such care, led them to believe that these challenges may not be able to be solved by the NDIS itself and that is, *"why mainstream supports are so important."*

For similar reasons and because of their belief that the less they had to do with the NDIS, the better - a number of NDIS participants and their carers supported this reform, on the proviso that government intent was genuine and that it would be resourced adequately.

*"Accessibility of services shouldn't have needed the NDIS to [intervene]. They should have been accessible the whole damn time! But [the NDIS is having to intervene] because that's difficult, and nobody wants to do it."*

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

Similar sources of scepticism among general population respondents applied to this reform area as the previous one - namely, with a lack of detail on how it would be delivered it *"just sounds like passing the buck again."*

Respondents across-cohorts were confused about how such a reform would be overseen/implemented, while people with disabilities and/or their carers expressed similar fears to earlier general population respondents that this was 'buck passing' that would see people with disabilities fall through the gaps.

*"Sometimes you fall into this limbo, where mainstream services will say 'No, that's an NDIS thing!' And the NDIS will say, 'No, that's a mainstream thing!' And it's like, well, that's lovely. But could someone just help me? Because especially adults with autism, we fall into the gap between disability and mental health services."*

*"I think it's too hard to give an opinion on that one without knowing what that means. Like, what does that actually look like? You can't just say, 'Things are going to be accessible!' and have everyone go, 'Oh, yeah, awesome!' But how is that going to be accessible? Then I can comment on it. It's also important to remember that lots of people [fail to] thrive in the education system. My daughter, for example, she can't [function in the] mainstream. She needs her support unit and that's how we like it. And I would hate for the Government to try pushing mainstream education on people. It's not for everyone in that regard. I would love accessible buses - that would be amazing and change our lives. But it's too hard to really comment on without knowing what they mean."*

*"Whose responsibility is it? Who's funding it? The office I currently work in isn't accessible. And the reason is that the funding provided can't cover a rental of an accessible building. If we pay for an accessible building, we can't have outreach to as many people, so something has to give. So the office is just mostly for staff to work out of, and then go do outreach. So I think, who's going to fund it? Where's the funding coming from to make things more accessible? Does anything have to give for that to happen?"*

## 7. Intermediaries (disability community groups only)

When talking about would make the biggest difference to clarifying roles/responsibilities, respondents from the disability community focused on three key points:

i. Structural change within the NDIS. As one participant summed up, "*If NDIS would improve on its own structure, and the hierarchy of how people, and the departments are structured, and put in efficient channels to communicate and exchange information, each time a case or request comes from a participant or whatever, then yeah, absolutely It would help! But then the onus is on NDIS [to do that]."*

   A perceived weak-point in the current structure is seen to the Local Areas Coordinators (LACs). One participant put it, *"Ditch the LACs. They're just a middle man… someone else creates the plan, someone we don't get to see or talk to."* The essence of the complaint is that *"the LACs are supposed to be there to support you, but you never hear from them."*

This then led back to discussions of participants' core frustrations with the Scheme. First is their sense that the NDIS is characterised by inconsistency - inconsistency of information (*"There's no clarity on where to go and what to do"*), inconsistency of decisions, inconsistency of process (e.g. having to go to an in-person appointment when others are offered a phone appointment - a small but important thing for this respondent who had a newborn at the time): *"Everybody needs to be trained in the same damn thing! It needs to be consistent."* They contended that it would be far preferable if *"there was just one person"* who could help them.

Secondly, the lack of accessibility to the people making the decision about them. They want to have critical conversations regarding how their care is funded face to face - to have a sense of "accountability" and "transparency". They want to feel as though they are being treated as a person, not a case number. Indeed, this would also allow for the assessor to provide a thorough explanation for the rationale underpinning any decisions and provide guidance regarding the framework for the decision-making.

*"[I want] accountability in how they work, how they actually do the funding, how you can justify [having] two people in identical circumstances, but one person will get more funding over the other. How they can justify the cost of the actual therapy - it keeps going up. So we're now paying $215 an hour for NDIS funding. You actually look at the private fee [and] it's less than the NDIS fee. So that's accountability. It's across everything. It's not user friendly for people with a disability."*

In addition, respondents argued that there is a profound need for NDIS participants to have access to advocates in the Scheme because many people do not have educated, middle class family members to do that for them.

*"I think we still need some sort of support coordination or advocates in the community for adults or people who don't have family. I work with a lot of people who don't actually have anyone else to support them and are falling through those gaps. I still think that's a really important role, but they [need to be] accessible. People [need to] know how to access them."*

ii. An education campaign for participants: *"They need [something] like a blue book.You know, when you have a baby, you get a blue book: all your information is in there and you keep records. [So] when somebody's going on the NDIS, give them a blue book, and it has everything in there."* Some respondents described how they "fumbled through" those early steps with the Scheme with some contending that this is a deliberate strategy to discourage prospective participants from applying. They detailed the numerous things they didn't know until months or years of being in the Scheme, one key example being the availability of carers' payments (via Centrelink). Put simply, *"not enough is explained"* in the Scheme.

iii. "High turnover" in the sector - while they understood that the latter was unlikely to be solved, they nevertheless perceived it as a significant barrier: *"It's destabilising. It's a fractious industry and the participant suffers."*

## 8. The transition

Here we explored how respondents would prioritise the speed of implementation of improvements to the NDIS versus thorough consultation with the disability community, even if that takes longer.

The response from participants and non-participants alike was consistent: *“It needs to be the collaboration [with regard to] the planning [and] implementation of the change. But the urgency needs to be.”*

There was significant concern across cohorts as respondents argued that there is an *obligation* to ensure the transition works *for participants* and that with insufficient consultation, *“You’ll create chaos on chaos.”*

There was the contention that good reform will, *“take a little longer, but do it right,”* and that lack of consultation was a specific, core failing of the set-up/roll-out of the NDIS in the first place: *“People were just not listened to.”*

There was also mention of the importance of profound systemic reform that cannot be rushed: *“You shouldn’t be rushing to put a bandaid on it,”* while at the same time, *“You need to set a timeframe,”* and, *“You’ve always got to have an end point or nothing ever happens.”*

Indeed, many respondents across-cohorts argued that both speed and consultation needed to happen together: *“It needs a balance of both.”* Or as this respondent from an NDIS participants/carers group contended, there must be, *“Consultation with a sense of urgency!”*

## On a reform package brand

**'Levelling the playing field for people with a disability' -** There were mixed responses to this suggested branding.

Some general population respondents liked it most of the three options provided, because it spoke to "fairness" and "equality."

*"Everyone has the same level of opportunity."*

There were, however, concerns among many respondents.

*"[This] one's good, but it just probably needs something better than 'disability'."*

*"I personally don't like that one because we talk about difference between fair or equal and equality and equity. Because some people need more support than others. I don't love that one myself."*

*"There's also negative connotations with the word, 'levelling,' - if you're levelling a building, you're gone."*

**'Getting the NDIS back on track' -** Similarly, there were mixed responses to this suggested branding option.

Some general population respondents believed it was preferable to the other options, principally because they felt it was an acknowledgement that while the NDIS is good, it is also imperfect and that the Government is taking responsibility for fixing it. Of note, however, whether this particular option was received positively or negatively, it was generally perceived as a political statement.

*"I feel the NDIS hasn't quite gone to plan and they'll fix it."*

*"It's taking accountability."*

*"The Government is saying it realises the system needs some repair work."*

*"It shows it's acknowledging the problems and they'll keep on trying."*

"*A vast improvement [on the other branding options]!"*

Other general population respondents, however, were equivocal if not outright hostile:

*"At least it highlights it is broken. But is that what we're looking to do? To say it's broken?"*

*"We've got to get it back on track? Like we're reinforcing that it screwed up?"*

*"I feel like it has some truth to it. It's what needs to happen. But it isn't the right slogan."*

*"It's like a train wreck or something getting back on track!"*

*"[This slogan] sounds like they're just concerned with fixing the NDIS, not helping the participants!"*

*"Sounds like a throw away line."*

*"Sounds too negative… like it's broken."*

*"Sounds like a Sky News headline."*

*"That doesn't sound very fitting for the NDIS - making it great again or bringing it back to what it's supposed to be. A lot of people didn't even understand what it was supposed to be in the first place… That one made me cringe a lot!"*

**'Putting people with a disability first' -** This too received a mixed - mostly negative - response and was only tested within the first two groups, before being changed.

*"It focuses on the disability because it makes us think about physical disability again - people who are in wheelchairs. It doesn't really encompass everybody"*

*"It just sounds like a standard Government slogan that has no meaning."*

**'Putting participants first' -** We therefore altered the previous branding option; however, we found that in the general population groups, there was some lack of knowledge of the term, 'participant,' and its specific meaning within the NDIS context.

*"I think it needs a bit more explanation. I don't know what 'participants' [are]? Is that what you call the people [on the Scheme]?"*

Even among those who did have knowledge of the term, responses to this option were not particularly favourable:

*"I agree with that sentiment. It's pretty obvious that [participants] should be first and foremost - at the heart of everything. I also think that it could be misperceived to mean putting [participants] sort of above everything - it gives the illusion that we are going to give them everything in the world. And some of the public worries about just giving participants money in an uncontrolled way. It could be perceived in a misinformed kind of way. I just feel like we could do better if we're going to have a slogan. That's just not great."*

*"Does it also infer that they weren't putting participants first in the first place when they should have been considered the whole time?"*

# Appendix A – Group Composition

- Group 1 comprised members of the general population (mix genders), aged 18-39yo, living in the inner and middle suburbs of Sydney and Melbourne, with a university education, who are unsure or not confident about their economic outlook
- Group 2 comprised members of the general population (mix genders), aged 30-49yo, living in the suburbs of Melbourne, Sydney, and Brisbane, working as service professionals or administrative/clerical roles, who are unsure or not confident about their economic outlook
- Group 3 comprised members of the general population (mix genders), aged 30-49yo, living in regional Victoria and NSW, working as service professionals or administrative/clerical roles, who are unsure or not confident about their economic outlook
- Group 4 comprised members of the general population (mix genders), aged 40+yo, living in the suburbs of Sydney and Melbourne, with a university education, who are confident about their economic outlook
- Group 5 comprised members of the general population (mix genders), aged 30+yo, living in the suburbs of Perth and Adelaide, with a university or vocational education, working in a skilled trade, business/technical profession, or in an administrative or clerical role, who are confident about their economic outlook
- Group 6 comprised members of the general population (mix genders), aged 30+yo, living in regional NSW and QLD, with a university or vocational education, working in a skilled trade, business/technical profession, or in an administrative or clerical role, who are confident about their economic outlook
- Groups 7 comprised members of the general population (mix genders), aged 18+yo, with a mix of people living in the suburbs of Sydney, Melbourne, and Brisbane, and in regional centres in VIC, NSW, and Tasmania, with a vocational or secondary education (full or part), who are working in retail/hospitality, administrative/clerical roles, essential workers, and not working who are not confident or uncertain about their economic outlook
- Group 8 comprised NDIS support workers and/or NDIS guardians/nominees/carers (mix genders), aged 18+yo, living Australia-wide
- Group 9 comprised NDIS support workers (mix genders), aged 18+yo, living Australia-wide
- Group 10 comprised NDIS participants and/or their guardians/nominees/carers (mix genders), aged 18+yo living in WA, SA, NT, and QLD
- Group 11 comprised NDIS participants and/or their guardians/nominees/carers (mix genders), aged 18+yo, living Australia-wide
- Group 12 comprised NDIS participants and/or their guardians/nominees/carers (mix genders), aged 18+yo, living Australia-wide
- Group 13 comprised parents of children under the age of 9 in the Scheme (mix genders), aged 18+yo, living Australia-wide
- Group 14 comprised parents of children under the age of 9 in the Scheme (mix genders), aged 18+yo, living Australia-wide

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INFLUENCE WITH INTEGRITY

# NDIA

# Reform Communications Testing: Round Two

# Focus Group Research Report

# October 2023

## Executive Summary

- Respondents broadly welcomed the two principal objectives of the reforms:
    - To humanise the NDIS – giving participants a better experience and more control by making the Scheme more about people and less about bureaucracy; and
    - To ensure that the Scheme will be there for the future by stopping the exploitation of participants and making sure the money gets to those in-need for what they need.
- There was particular enthusiasm for the humanisation aspect. The idea *and language* around humanising the Scheme was quickly embraced by participants and prompted optimism for the "more personal approach" these reforms represented. Key to this optimism is the sense of equity and agency enabled by a more human-centred system.
- There was also significant respondent concern regarding the threat that spiralling costs might pose to the Scheme – giving its critics a weak spot to attack. Indeed, when we presented rorts, fraud, and unreasonable pricing as posing an existential threat to the NDIS, we were able to create an environment in which respondents were amenable to reforms designed to counter these things.
- After accepting the dual objectives as both legitimate and desirable, a series of 'proof points' were presented to respondents to explore to what extent they built credibility for the objectives. Largely, these proof points worked well in this role.

***Humanising the Scheme Proof Points***

- The new **navigator** role – and to a lesser extent the **assessor** role – was effective in building credibility for three principal reasons:
    1. **Equity –** respondents viewed the new roles and pathway into the NDIS as constituting the removal of critical 'barriers to entry' for new participants, i.e. the bureaucratic burden and sense of overwhelm at having to navigate its labyrinthine nature. While for many this alone was sufficient to see these new roles as transformative, many also believed these new roles/pathways would provide more equitable outcomes for existing participants whose current access to support is often dependent on their capacity to navigate the bureaucracy and advocate for themselves.

2. **Agency –** at present, participants' sense of agency (i.e. their confidence and control) within the Scheme is felt to be undermined by a) their lack of understanding of the system and b) their disabilities and circumstances not being understood by the system. *Dealing with a human addresses these weaknesses in the system*. The new roles provided many respondents with greater confidence that they would be both better understood within the system and better able to navigate its complexity. Navigators, particularly, provide agency. This is enhanced to the extent that Navigators are a) local and b) specialist – although often respondents would value specialisation over localisation.

   Because of this emphasis on agency, it was important for respondents to feel that Navigators specifically "worked for them", not for the NDIS. To this end, they were very receptive to the idea that they would have choice over their Navigator and that they would pay their Navigator from their budget package (with sufficient allowance for that in the package, of course).

   This agency framing also applies to reforms regarding *evidence-based supports*. Taken in the abstract, there was a lack of understanding of what 'evidence-based' refers to among many respondents, and a profound resistance to the idea of participant choice being restricted in this way. This is because presenting evidence-based supports within a 'deficit model' compromises respondents' sense of "choice and control", leading to angst and opposition. Instead, framing the reform as Navigators using local and specialised knowledge to guide participants in making informed decisions about using their money effectively, and being protected from unscrupulous and exploitative providers/practices, restores respondent confidence and sense of agency.
3. **Streamlining relationships** - Respondents broadly welcomed the streamlining of the NDIS experience to reduce the number of relationships they need to manage. This was about both a) the burden in managing multiple relationships and b) the strain in having to repeatedly re-tell their stories.

- **The new budget package** arrangement constituted the second proof point which provided most respondents with a sense of confidence that the reforms were being implemented for their benefit. Respondents viewed these budget reforms as countering current frustrations and perverse outcomes, such as having thousands of unspent dollars in one category as they run out of money in another, far more urgently needed, category. Respondents viewed this reform as assisting them in "getting what I need" and countering the sense that they must "use it or lose it" - that is, they currently feel forced to spend on unnecessary goods and services in order for their funding not to be cut at the next review. Once again, respondent agency afforded by this reform was a central pillar of their support for it … so long as there are simple processes to vary plans as life circumstances change.

- Similarly, the agency afforded by the reforms enabling **longer term NDIS plans** formed the basis for respondent support. They felt that the certainty and reduction in stress and costs that longer term plans would provide would enhance their sense of control over their lives.

- A further proof point constituted the **Government-funded initial assessments**. These were greatly appreciated for the increased equity they would afford prospective participants who might otherwise not be able to afford to apply for the Scheme - a "game changer." Most respondents strongly supported removing barriers for the most vulnerable so that they would have the opportunity to enter the Scheme and would not feel forced to "give up". There was particular appreciation for these barriers being removed for parents of children requiring support who currently cannot afford the assessments required to apply for the Scheme. The capacity for this reform to remove intergenerational barriers to accessing support was another potent factor in generating support.

- The three adjunct funding commitments – **i) funding for foundational/mainstream supports, ii) funding for early childhood intervention in mainstream settings, and iii) changes to psychosocial supports with an emphasis on early intervention** - also worked as proof points for humanising the Scheme when framed within three critical contexts:
    - That these initiatives are geared towards facilitating **early intervention**. Early intervention is universally perceived as an unalloyed good with transformative potential - both for the lives of the affected individuals and also for the broader benefit of society/the community at large through preventing the harms that accrue with untreated/unsupported disabilities.
    - That these reforms constitute a critical part in **combating social isolation** that often comes with disability and have the potential to facilitate "connectivity" - that is far greater social connection and the mainstreaming of those with disabilities.
    - That these reforms represent a **safety net**, preventing people - particularly children - from falling through the cracks. This was particularly appealing for those with experience of somewhat less severe disabilities that they term "edge cases" that until now may have been neglected when it comes to government support.

### *Sustaining the Scheme Proof Points*

- **The new pricing authority and strong regulation of providers** were also welcomed as proof points of a suite of reforms designed to protect participants from exploitation and restore equity and agency to them. This contrasts with their current experience of being at the mercy of spiralling costs and potentially unscrupulous providers, against whom they feel they have little recourse. The new and strengthened watch-dog role was therefore also welcomed. Participants want accountability for providers. Indeed, demonstrating that we are *first* addressing providers and pricing is critical before discussing reforms that impact participant accessibility or funding.

- After presenting respondents with the above proof points that provide vital, believable context of reforms designed to benefit participants, we were able to elicit a degree of *qualified tolerance* for reforms that would restrict either eligibility for the Scheme (raising the threshold for children with developmental delay) or the amount of support high-need participants would receive (moving to a 1:3 care model for Supported Independent Living participants). Respondents do not like these reforms but they may be willing to tolerate them where there are/is:
    - Carve-outs for exceptional circumstances (i.e. we're not forcing everyone into the same box, and the most in need are still fully supported);
    - Initial goodwill generated by the measures to humanise the Scheme and to protect participants (and the Scheme) from exploitation. Conversely, there is a strong resistance to any discussion of costs alone as a driver of reforms; and
    - Alternative or 'offsetting' benefits in place. For example, in relation to the threshold for developmental delays, there is more (but not out-right) acceptance once respondents had been treated with the idea of investing in mainstream supports for children (through schools/kinders/etc) to enable earlier intervention and improve the safety net. In relation to the Supported Independent Living (SIL) changes, these become more acceptable when couched in benefits around reducing social isolation and ensuring people don't fall through the cracks. Conversely, proposing to 'grandfather' changes to SIL did *not* work as a way of 'offsetting' the impacts.

### *Risks to Reform Credibility*

- While respondents had a number of questions regarding implementation of these reforms, typically, these questions constituted curiosity regarding how such reforms would practically impact them. Such questions were generally not borne of hostility or opposition to the principles underpinning the reforms.
- However, it must be noted that amid the myriad respondent questions relating to the detail there is one critical, missing component compromising the credibility of the suite of reforms: **workforce issues.** Specifically, where the promised staff - with local knowledge and expertise for complex cases in the case of Navigators and Assessors, and allied health professionals and volunteer/other personnel necessary to staff the early intervention and foundational/mainstream supports initiatives - would come from. Furthermore, who will be training these new roles – especially Navigators – to ensure they can fulfil the varied tasks they are taking on? These questions around staffing and workforce occurred across all proof points and in each reform area. That is, unaddressed workforce concerns can undermine confidence in the new Navigator and Assessor roles, government paying for assessments (thereby, creating a "bottleneck" and exacerbating waiting lists), investment in early intervention and foundational supports, and the capacity to address pricing (without causing an exodus of vital allied health professionals). Qualitatively, failure to address these questions poses the most immediate risk to acceptance of these reforms among the disability community.

- Other frequently asked questions included:
    - Who pays for the Navigator’s support before you enter the Scheme?
    - What will the changes to pathway and personnel mean for current participants? Some respondents asked whether existing participants would “go back to square one”?
    - Who pays for assessments/reports when going for a plan review?
    - Will such changes to the workforce compromise participants “continuity of care”? Such fears were particularly acute in regional areas.
    - How will the Scheme ensure that participants do not run out of money before their plans are due for renewal or, alternatively, do not spend their money too slowly and have their funding reduced at the next plan review?
    - There were also questions regarding whether the new budget/planning and pricing/workforce regulation reforms would increase the bureaucratic burden for participants.
    - How will longer term plans/budgets account for inflation and rising costs?

- The full breakdown of the composition of each group is provided in Appendix A.
- The final form of wording tested in relation to the reforms is provided in Appendix B.
- The explanatory diagram presented to respondents in the humanisation reform testing cohorts is provided in Appendix C

# What We Did

- 14 x online (Zoom) focus groups (mix of ages and genders), including:
    - Nine groups comprising people in the disability community, and/or their carers/family members/nominees[1] and/or their support workers, living Australia wide, testing reforms associated with humanising the NDIS
    - Five groups comprising people in the disability community, and/or their carers/family members/nominees and/or their support workers, living Australia wide, testing reforms associated with ensuring the Scheme's sustainability
    - The detailed breakdown of group profiles is provided in Appendix A.
- 
- Groups testing proposed reforms associated with the humanisation of the NDIS explored:
    - The proposed role of the Navigator and changes to the scheme associated with that role, including -
        - initial guidance for those applying for the Scheme (including introduction to mainstream and foundational supports)
        - support in accessing the Scheme
        - the addition of specialist Navigators for complex cases
        - the changes entailing new government funding for initial assessments for the Scheme
        - the replacement of support coordinators with Navigators and respondent sentiment to this
    - The proposed role of the Assessor and the ways in which Scheme assessments may be conducted
    - The proposed changes to budget, planning, and duration of individual plans
    - Responsiveness to an emphasis on evidence-based supports
    - Disposition towards proposed increased funding for mainstream and foundational supports
    - Disposition towards funding and resources for early intervention for children within mainstream settings such as schools and kindergartens
    - Assessments of proposed changes to management of supports for participants with psychosocial disabilities within the NDIS
- Groups testing reforms associated with the sustainability of the NDIS explored:
    - Proposed changes to pricing in the NDIS via an Independent Pricing Authority
    - Proposed changes to regulation and oversight of NDIS providers
    - Proposed changes to NDIS housing and living supports
- Fieldwork took place between 16 October and 24 October 2023.

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[1] Referred to as "carers" for brevity

# What We Found

## The Two Objectives: Humanisation and Sustainability

Respondents broadly welcomed the two principal objectives of the reforms: a) to humanise the NDIS, giving participants a better experience and more control by making the Scheme more about people and less about bureaucracy; and b) to ensure that the Scheme will be there for the future by stopping the exploitation of participants and making sure the money gets to those in-need for what they need.

*“I'm hopeful. There's always a possibility for improvement.”*

*“I think [these reforms are] a good thing. Definitely needs an overhaul.”*

*“It definitely needs more humanising, less bureaucracy.”*

*“Humanising is incredibly important. It’s about people, it’s about putting people at the centre of the Scheme.”*

*“The current system can be very alienating. My husband and I are highly educated and we have problems understanding the system.”*

*“Things need to change, it is just growing so fast.”*

*“I can only go off what the politicians have been saying. And that is, in a few years, this will be costing us something like $70 to $80 billion per year. So it's an exponential growth [and] it's at risk of collapsing, is what we keep getting told. And so when it's your family that is affected, and if it’s rorting that's causing this, because where there's money, there's greed, and exploitation [then action must be taken].”*

There was particular enthusiasm for the humanisation aspect. The idea *and language* around humanising the Scheme was quickly embraced by participants and prompted optimism for the “more personal approach” these reforms represented. Key to this optimism is the sense of equity and agency enabled by a more human-centred system.

*“I think that this humanising element is incredibly important. We felt really alienated. We’re both highly educated people. And what we keep saying to each other, if we were not as educated as we were, and if we were struggling more than we are, we could not access the Scheme… So I think this is really positive.”*

*"I like that general idea. I think it definitely needs some humanising. It is very bureaucratic. So less bureaucracy is good. Just trying to help people to feel actually cared about and not like it's just a money making kind of business for people who are support workers or that sort of thing…. Just having that extra support and extra navigation and guidance is really important. And I think a lot of people need that and [are] floundering and don't really know what they're eligible for, how they can use their funds, where they can use them, and who to go to and who to ask. So, I think [this is] positive."*

There was also significant concern among some respondents regarding the threat that spiralling costs might pose to the Scheme, giving its critics a weak spot to attack. Indeed, when we presented rorts, fraud, and unreasonable pricing as posing an existential threat to the NDIS, we were able to create an environment in which respondents were amenable to reforms designed to counter these things. There was very strong support for clamping down on the pricing by providers with most able to recount some specific stories of apparent fraud or at the very least "working the system" or "playing the game". Their concerns about changes to NDIS are underpinned by their assessment that ultimately they - or others like them - will lose funding while those who "work the system" will continue to "play the game" and rort the system.

*"It's costing the government so much money it's inevitable there will be changes."*

*"I think given the politics of it, it's realistically going to change in the future."*

*"I think they are [important reforms]. There's so many people out there that deserve the care and support. I have family members in there. It's about time that [those rorting the system] get stopped, and the money gets put in the right pockets. There's so many young children out there that are deserving of it. And it's about time our government put it in the right places in the right pockets with the right families."*

*"[The] most compelling [reform aspect] would be the oversight and a governing body to investigate and make sure all of those checks and balances are in place… Because I've got incidents in my town where people are taking advantage. There's lots of fraud going on out there."*

After accepting the dual objectives as both legitimate and desirable, a series of 'proof points' were presented to respondents to explore to what extent they built credibility for the objectives. Largely, these proof points worked well in this role.

*"[I support] anything that could make the program last for people and they get the help they need."*

Indeed, some respondents who had been Scheme participants since its inception, pointed out that the reforms described seemed to be reflective of the initial intent of the Scheme - an intent that had not yet been realised: "It's turning the clock back versus what it's developed into… It is a good model".

## Humanising the Scheme Proof Points: Creating A Context for Trust

### *The new navigator and assessor roles*

The new **navigator** role – and to a lesser extent the **assessor** role – was effective in building credibility for three principal reasons:

1. **Equity -** respondents viewed the new roles and pathway into the NDIS as constituting the removal of critical 'barriers to entry' for new participants, i.e. as removing the bureaucratic burden and the sense of overwhelm at having to navigate its labyrinthine nature.

Many respondents recounted the overwhelming experience of initially trying to understand the Scheme, first as applicants and then as new participants (spending *"three months scrolling through Facebook groups for reviews [of providers],"* and, *"I still don't really understand the categories [of budget items]"*). Thus, having a person to inform and guide during that process was considered <u>a very good thing</u>, as opposed to the "trial and error" or *"Going through Facebook groups looking for reviews*".

*"[The new navigator role] could make it easier. I tend to get overwhelmed easily. We need more support and this looks like it would provide more support."*

*"It's quite confronting as an outsider"*

*"I would have loved someone like that! I almost gave up"*

*"On the face of it, it is great. It's so important to know what's available on the outside of NDIS."*

Non-participants also profoundly appreciated the Navigator concept, describing being "scared" to apply for the NDIS. While a number of these respondents had health professionals recommending they apply to the Scheme, they had not because the bureaucratic and cost barriers were simply too high.

*"It just sounds good to me. I'm not on NDIS. I have applied a few times. And I'm actually too scared to even apply again. But I like [this] idea. Like you said, [the navigators] are there for you."*

*"Everybody needs a Support Coordinator!"*

While for many this alone was sufficient to see these new roles as transformative, many also believed these new roles/pathways would provide more equitable outcomes for existing participants whose current access to support is often dependent on their capacity to navigate the bureaucracy and advocate for themselves.

*"[Currently], access to NDIS successfully depends on your education levels and English skills."*

*"You don't know what you don't know, so this should make things much easier."*

*"People are floundering in the system. They need support to help them better understand."*

*"Anything that makes it simpler and more accessible!"*

*"I think it'll help because we're trying to get access to services. So having that [navigator] might just help me find [those] because a lot of the stuff on the internet's outdated. [I've spent] a lot of time ringing up and you gotta wait for people to call you back. It's a bit of a pain. I think [this new role] will be better."*

2. **Agency -** At present, respondents' sense of agency (i.e. their confidence and control) within the Scheme is felt to be undermined by a) their lack of understanding of the system and b) their disabilities and circumstances not being understood by the system. Dealing with a human (in the form of a navigator and/or assessor) therefore addresses these weaknesses in the system. The new roles provided many respondents with greater confidence that they would be both better understood within the system and be better able to navigate its complexity.  Navigators, particularly, provide this agency. This is enhanced to the extent that Navigators are a) local and b) specialist – although often respondents contended that they would value specialisation over localisation.

Indeed, Respondents viewed such reforms as acknowledging their past experiences of the system not understanding their disability and their frustration in having to repeatedly explain themselves. They viewed this lack of understanding as a key barrier to accessing to the Scheme, with decisions being made based on a written report: *"It's hard to put down in writing how much your disability affects you,"* and, *"It's really important that it's humanising… for access, for understanding and for trying to be helped as an individual"*. It is in this context that those particularly enamoured of the humanisation process described the new navigator function as a "monumental" change.

*"You said they might be more specialised in the field. So for example, my brother who's quite disabled, he has to live in a center. He has very high needs [and] people are paid a lot of money to keep him alive. So if there's people who are across [that complexity] and [have] more in depth [knowledge], that might be helpful to him."*

*"You mentioned specialised training. We [have] very high, complex needs. And, and [we] need someone who's across complex disability."*

*"I think yes, specialists with particular specific knowledge about specific disabilities, and local is a bonus!"*

*"When you're in a remote area, it's impossible to have local, whereas if you had [access to] someone in a capital city that knew what to look for, and knew what to find, and could refer [you] in that way, that would possibly help."*

*"For me, I'd go with a specialist before local."*

*"I'm only very new to [the NDIS]. I found a really great support coordinator that's helped me do all this. So I think it's a good idea if they can help with navigating more supports for the people on NDIS. Because [currently], they don't tell you what you can and can't use it for. So it's really hard to know what you can and can't do."*

*"My experience with my clients - most of them get really overwhelmed with who to ask for certain things and having a navigator is a really simple and easy way to have that one person. So I think that's it's really straightforward in that way and that could be super easy for [my clients]."*

*"I was diagnosed with neurosarcoidosis last year, and I was living up in Catherine in the Northern Territory [where] the doctors would go, 'What's that? Do you mind if I Google that?' What I had was quite rare…to the point of I couldn't find a neurologist who understood it. Anyway, I ended up in Melbourne, and I got diagnosed down there… I had a hospital liaison officer, and I think that's the only reason my case got progressed at all this year, because of that support. My daughter is autistic with Tourette's and we've been trying for a couple of years to navigate the system. And to be honest, I don't think we're getting anywhere. So this idea of a navigator is good."*

A number of respondents spoke of wanting navigators to be people who have "walked in our shoes" and are "related to disability"; people with a disability themselves, parents of children with a disability, etc. Thus, what qualifies people for the role can be their life experience: *"I'd like to hear that there's people that have lived experience."* They viewed such lived experience as a key component of the understanding that would lead to practices that enhanced participant/carer agency.

Indeed, couching such innovations in the language of the agency it will afford prospective participants facilitates this confidence: *"I like the idea of linking in with someone at the start, who can tell you about the supports available. And then, even if you don't get approved for a plan, you at least have that information. I think that's really good, because otherwise you have to seek it out for yourself. And if you're someone who's applying for NDIS, for yourself, then you may not have the capacity to do that. So I like that idea."*

Critically, this agency framing also applies to reforms regarding **evidence-based supports.** Taken in the abstract, there was a lack of understanding of what 'evidence-based' refers to among many respondents, and a profound resistance to the idea of participant choice being restricted in this way. This is because presenting evidence-based supports within a 'deficit model' compromises respondents' sense of "choice and control", leading to angst and opposition.

Many respondents challenged the basis for what might constitute 'evidence-based' ("Evidence-based just means that it works for some people") and presented anecdotes of a) how un-supported therapies have helped them or someone they know or b) how supported therapies have been "disastrous" ("Once upon a time, evidence-based meant ABA"). This led to respondents arguing that should an intervention work for the individual, it should be covered, regardless of what the academics say, with one participant asking, "[What about] the evidence of what I can see [working] for my child?"

*"Who's to say what works? It may work for your son. It's the people [directly affected] who know."*

*"What works for one person is not going to work for another, so [how do we reconcile that with the] evidence base?"*

*"[Evidence-based is good in theory] unless you talk to the parents or the kids that go to equine therapy, and you see the difference that it makes in those kids."*

There were profound concerns in particular among those who feared that rare and under-studied disabilities lacked a sufficient evidence base to begin with: *"I still think that alternative therapies are valid and should be approved. And I think if you're going to label something 'evidence-based', that opens a can of worms for…when somebody needs a front running new therapy. There are wild disabilities and gene mutations that don't even have a proper name yet. And the cures and fixes for these things are so far out of the realm of anything that might be evidence based, that we're throwing things at them and hoping it'll stick. And if that's not allowed, then we're doing some people a disservice."*

When, however, we framed the reform as navigators using local and specialised knowledge to guide participants in making informed decisions about using their money effectively, and being protected from unscrupulous and exploitative providers/practices, restored respondent confidence and sense of agency.

*"[This reform] is very important. It's very significant, to go through what's the best for the participants - how the money could be spent, and also [helping] them navigate to [make] a good choice and understanding the whole system - what can be done and what can't be done. I imagine it will be really helpful at the beginning."*

*"I think it's really important because [without this guidance], what happens is funding gets used by someone who's got bad intentions, and then that client doesn't get renewed because they don't have the funding [because they've] used it on inappropriate things. [That means such participants] are unable to get the support they really need. So I think it's really important."*

*"It needs to be done - [every] dollar being spent in the right manner. Because as I see it, now, the dollar is definitely not being spent in the best interest of the participant. There's a lot of people that are getting very wealthy at the expense of others."*

*"Yes, [it's] a really good idea [to] watch how the money's being spent and to make sure it's 100% [to the] benefit of participants. That's really great."*

*"I feel like given the demands on NDIS funding, I reckon it would be fair enough to say it needs to be evidence-based… Then if there's other things you want to explore yourself, then you just do that with your own money."*

*"I think that's helpful. Because I was just picturing a couple of my previous clients, who are extremely vulnerable, who would jump at the chance of something that is not evidence based. So I agree with it!*

**Streamlining relationships** - Respondents broadly welcomed the streamlining of the entry pathway and processes as a means of reducing the bureaucratic burden and providing greater clarity regarding processes and pathways.

*"I think the streamlining of the process just makes it simpler. Anything that makes it more accessible [is good]."*

*"I think streamlining is definitely the way to go in the NDIS."*

*"I think [the new pathway] could be good because it might make things a little bit easier in terms of the one stop shop when you're trying to find stuff out."*

There was particular appreciation for the removal of extraneous personnel/relationships from the NDIS experience that respondents contended too often led to frustration, time wasted via having to re-tell their stories, and suboptimal outcomes.

*"I find it really frustrating that I end up having to repeat myself a lot of the time. It's like, 'I've already told you this. You already know. I've sent three emails where I've said the exact same thing!"*

*"Seems better, having [only] two roles - less chance for miscommunication and misunderstandings."*

*"I have to deal with an area coordinator, a plan manager, a support coordinator. It's a bit much on my plate… Only dealing with 2 people is easier to manage".*

*"It would be great to just have that one person to deal with. [It] would make life easier, especially when we already have to deal with so many other people, like specialists and therapists. It would just make life that little bit easier. We already have a lot on our plate. So anything that's going to make our lives just that bit easier, is helpful. We don't have a lot of time to waste going over the same things that we've already gone over. There's much more productive, efficient things that we can do with our time than just constantly repeat ourselves."*

*“Yeah, I'd love [this streamlining]. I think that the fewer people you’re communicating with and who are communicating with one another, the less chance there is of miscommunication - the whole Chinese whispers thing - which often happens where a message doesn't get passed along to someone else… Because that happens quite a lot with various things. So I think if you just have one or two key people who are there for [to] champion you [and] give you guidance and support, then you're going to feel a lot better supported and there's going to be less confusion.”*

A number of respondents observed that having fewer people involved would also present the NDIS with significant cost savings that would mean *“[more] money can be spent on the person being treated”*, constituting an unprompted acknowledgement of the importance of the Scheme’s sustainability.

*“I also think, from an NDIS perspective, surely streamlining is going to be more cost-effective for them. Because you start to wonder how much money is being spent on administration. So I think that anything that's going to streamline it for participants, and also streamline it for the NDIS as an organisation [or] scheme, that's going to be helpful for everyone. So I think it's a positive thing. The win-win.”*

*“Having those two roles would be more cost effective, streamline the process but also make it more clear about roles and functions. How much is already spent on administration?”*

While there was a mixed response regarding whether it would matter if support coordinators or local area coordinators were unhappy with these changes, a number of respondents argued strongly that, “It’s us that suffer not them”.

*“I think they're very likely to not support this. However, I do think that they would be best positioned to take on this role…I do think that a support coordinator is already pretty well equipped to do most of [the tasks involved] and they probably unofficially do more [of these] than they're supposed to. So they might not like it, but I think that hopefully, they will be the ones directly employed by the NDIS to do this.”*

**Respondent opinions regarding the new nomenclature -** While respondents were divided regarding the issue of nomenclature, many did support the novel ‘navigator’ terminology, largely due to its a) acknowledging the novel functions of the role as well as the reforms of which that role is a part, b) ‘navigator’ explicitly expressing the purpose of the role, and c) removal of “expectations” that might be a product of the previous system, but which are no longer applicable after the reforms have been implemented.

*“’Navigator’ is fitting, it explains the role, it’s clear what their job is and what are the expected outcomes.”*

*“’Navigator’ and ‘Assessor’ explains the role and removes any questions about what they are supposed to be doing.”*

*"I think if you're making a transformational change, you need to [move] away from the tradition."*

*"I prefer 'navigator'. It means somebody's going to be navigating me around if I was new to the system. It's always quite daunting when you first get started."*

*"I like the word, 'navigator' because it really is [that]. I've actually used the [terms] 'navigate the system', 'navigate the NDIS' a lot when I've been talking about the struggles that we've had with navigating it. And so I think the word 'navigator' is very fitting, and it's got a positive vibe in that [it implies there is] someone to help me navigate this rocky, difficult journey - especially when you have your own health issues as well."*

Those opposing the new name did so on the basis of a) habit ("I still call Woolworths Safeway") - although many picked up the new terminology quickly, or b) because, "[I like 'support coordinator'] purely because of the role they play. It's not just purely navigation. It's the thought behind it"... meaning that they also help participants with articulating their needs, selecting providers and how best to spend their funding.

*"Calling them 'navigators' suggests that you are navigating <u>their</u> system with <u>their</u> assistance. That's not what we're looking for. We're looking for support. I think the term's kind of standoffish, and I would be a bit put off [about] using the system. Whereas 'support coordinator' - that's what you want, you want someone who's going to support you to meet your goals and use this system effectively."*

*"I think it sounds [like] a lot less support which I personally don't like. It sounds very government-like… So I think I'm opposed to it at the moment."*

A number of people also found the term 'navigator' confusing, believing that it referred to an app, rather than a person, even after considerable explanation.

*"It does sound a lot more like a computer [programme]."*

*"It just seems like a computerised system. I manage my son's process, and I go through the myGov thing. And that's confusing enough as it is, and it's not clear. And I'm just worried that this navigator thing might be something similar."*

### *The new budget package*

Appreciation for the new navigator role also alleviated a potential concern (for non-participants) about long-term budgets being "daunting". When one non-participant raised this, we asked whether having a navigator there to offer guidance would ease some of that anxiety with the answer being, "Absolutely!"

However, for almost all current NDIS participants, there was profound appreciation for the new budget package ("Absolutely life changing!"), while many non-participants had heard from those they know who are already on the Scheme of the current situation leading to perverse outcomes that they were able to see the benefits: *"If we're about supporting people, it's about where you need it most".*

Indeed, the new budget package arrangement constituted the second proof point which provided most respondents with a sense of confidence that the reforms were being implemented for their benefit. Respondents viewed these budget reforms as countering current frustrations and perverse outcomes, such as having thousands of unspent dollars in one category as they run out of money in another, far more urgently needed, category. Once again, issues of "choice and control" - that is, participant agency - underpinned the strong support for this measure.

*"You can use it where you need it!"*

*"People's needs change in 6-12 months!"*

*"I like that, it's a brilliant idea. I can't fault it, there's been a number of times I've run out of funds in one area but have thousands sitting in another area unused."*

*"It's easier to have it in one pack of dollars. I have had receipts rejected because I put it in the wrong budget and I am a nurse so I wonder what it's like for others if I make those mistakes."*

*"It's an overcomplication - the current system. This seems to be more streamlined and less confusing."*

*"I like the long-term budget, that's very good. It removes some of the endless paperwork and administration that we spend most of our time on."*

*"I like the idea of it being one category. [The current system] just seems so crazy - the fact that I might have more money in a bucket to go and socialise than I do for personal training or physio or occupational therapy, which is what's helping my condition [whereas] being social isn't really [helping] so I like the idea. I think it's good!"*

Respondents viewed this reform as assisting them in "getting what I need" and countering the sense that they must "use it or lose it" - that is, they currently feel forced to spend on unnecessary goods and services in order for their funding not to be cut at the next review. Once again, respondent agency afforded by this reform was a central pillar of their support for it with the significant caveat there are simple processes to vary plans as life circumstances change.

There was particular opprobrium for the current perversity of having to pay for an assessment to support a change to budgets/plans in order to be able to spend that "idle" money on something that the participant actually needs. One participant gave the example of having to spend $200 with an OT to get an assessment to allow a change to her plan to buy a $50 item: *"Our OT had a recommendation for something we're not covered for. So we had to put in an application. It's been 60 days and we haven't heard anything!"*

*"We received $7,000 for a section we just couldn't use… it's just sitting there and we couldn't move it to another budget!"*

*"It would be good to be able to use that one part [of the budget] that wasn't using a lot of it into another part that was so much [more] necessary, rather than just going back for a review for that. Going off my experiences, of how often I've had to go back even on a 12 month plan - most of it is because it is running out too much in one category and there's still plenty in another category because of how they're categorised it, [but] I can't physically use it."*

Of note, in this round of research, we did not encounter the respondent fear that should they make a mistake they might be audited and have to pay funding back. We believe that the humanisation context operated as a counter to many of the anxieties present in the first round of research into these reforms - specifically, the presence/role of the navigator offering a humanising interface into the Scheme: someone who would guide participants with regard to using their funding countered such anxiety as opposed to their having to make such assessments on their own.

*"I like [the new budget arrangements] being sort of open. It's really annoying that they're like, 'Oh, you've got all this money, which is really great. But then [with] this certain type of therapy, you only have this much even though it's something you need, and there's money elsewhere in the plan [that] you can't access for this thing that you still need. I think that's really frustrating... AndI also like the navigator and assessor titles, because everyone in my family is autistic, excluding me. And they are very literal people. So the fact that you have a navigator that will help you find your way through the system will be like, 'Yeah, cool!' That is that person. That is what they do. You have an assessor who will assess you and your needs. It's very literal… Even [though] the support coordinator role is helpful, if they're doing a whole bunch of other things, then that label doesn't really specify exactly what they are doing."*

### *Longer term NDIS plans*

Similarly, the agency afforded by the reforms enabling longer term NDIS plans formed the basis for respondent support. They felt that the certainty and reduction in stress and costs that longer term plans would provide would enhance their sense of control over their lives - particularly as it counters respondent resentment at having to *“prove your disability every time you get a new plan”.* Long-term planning therefore reduces that indignity. Additionally, there was appreciation for the savings in time and resources required every time they have to go in for a new plan: “You wouldn’t believe the time I spent!” and, “[Reviews are] a very arduous time!”

Indeed, one participant was genuinely “excited” about the prospect as, *“It gives us a chance to plan. That’s hard to do if you don’t know one year to the next if this is the year you’re gonna get shafted.”*

*“I do like the idea of the longer term package.”*

*“I like the idea of a three to five year plan. I think that'd be good, because you don't go through the process every year!”*

*“I think a lot of my clients would be relieved to not have assessments as often. Assessment time is always a time of anxiety and stress and worry. And I think anything that reduces that would be welcome for them.”*

*“[We] won’t feel like we need to cram in the budget because it’s coming up to the end of the year. You can pace it out to what you need. It’s not linear.”*

*“A little bit more streamlined. I like the longer budget idea. I actually hate it when you have to sit and justify every year and the different therapies needed.”*

However, it is extremely important that such flexibility is emphasised to allay concerns about plan rigidity that a number of respondents held - that there is room to request a variation should circumstances change. This was something that was especially important for parents as the needs of children change more rapidly than adults

*“Receiving the long term budget package, to me, is a scary thing. I know, some of you say that, that's a good thing. But then for a child where the goals change, and if [you’re] not aware how funding works [and] you run out - if you're on a long term budget package to get more funds if you need it [could prove complicated].”*

### *Government-funded initial assessments*

A further proof point constituted the Government-funded initial assessments. These were greatly appreciated for the increased equity they would afford prospective participants who might otherwise not be able to afford to apply for the Scheme - a "game changer." Most respondents strongly supported removing barriers for the most vulnerable so that they would have the opportunity to enter the Scheme and would not feel forced to "give up".

"*I'm really excited over the funded assessments. We're fine for that now. But we do have friends, family, relatives who can't afford all these assessments that they supposedly have to get before they can even properly apply. So to me, that's really exciting. Really exciting!"*

*"This is the big game changer. A lot of vulnerable people will be able to access it now."*

Having had to pay for the assessments/reports themselves ("around the $3000 mark"), many respondents understood that this acts as a barrier to accessing the Scheme for people without the money to do so. They described parents currently having to make a choice about whether to apply or not because of their capacity to pay for these assessments: *"A lot of parents feel they can't afford that diagnosis, so they don't do it".*

*"[I support this reform because] otherwise, you're essentially creating a scheme for people who are wealthy enough to access it. And that's a real huge problem!"*

*"A lot of people don't have that kind of money to be getting the assessments done in the first place. You can't just assume that people have that money, and it's not fair that they're going to be disadvantaged. I think 100% the government should be [paying]. No doubt about it in my mind!"*

*"It's so costly to not just pay for the assessments out of your own pocket but also travel costs too. We live regionally and it costs us at least $150 to travel for appointments."*

There was particular appreciation for these barriers being removed for parents of children requiring support who currently cannot afford the assessments required to apply for the Scheme. The capacity for this reform to remove intergenerational barriers to accessing support was another potent factor in generating support.

*"I think it would take a lot of pressure off parents of children that need to be on the NDIS if you know the government is going to help out with that."*

*"It's a great idea. We spent $4,000 on assessments for my kid. We had the money but a lot of people don't."*

*"We've got NDIS support for one of our kids but we haven't for another kid because of the cost of reports and the waitlist. With the cost of living pressures everyone is under we just don't have the money for an assessment."*

### *The three non-NDIS adjunct funding commitments*

The three adjunct funding commitments - **i) funding for foundational/mainstream supports, ii) funding for early childhood intervention in mainstream settings, and iii) changes to psychosocial supports with an emphasis on early intervention** - also worked as proof points for humanising the Scheme when framed within three critical contexts.

The first context entailed these initiatives being geared towards providing faster and easier access to critical supports facilitating **early intervention**. Early intervention is universally perceived as an unalloyed good with transformative potential - both for the lives of the affected individuals and also for the broader benefit of society/the community at large through preventing the harms that accrue with untreated/unsupported disabilities.

Early intervention in the psychosocial context proved powerful because mental health issues can produce an immediate "risk of life and harm", while early intervention for children was perceived as a critical means of preventing such crises into the future.

*"Early intervention is key!"*

*"I think it's a great idea to put it into schools for the kids, because if I had gotten that [intervention] early on, I think I wouldn't have the issues I have today.*

*"[Kids who don't get early intervention] are not going to be patients now. They're going to be patients when they're adults. Yeah, early intervention [is important]!"*

*"Every study that I've read indicates the massive advantage of early intervention. And I would agree, wholeheartedly, not from a parent's point of view, but from a teacher's point of view, that it makes a drastic difference in the lives of those kids, because they can experience success, they can have modifications provided for them - assistance given to them. That means they can do the things that they are capable of!"*

*"I think specifically, that early intervention for those psychosocial disabilities is important, because if they are left, they can compound and end up [becoming far worse]. Early intervention does lead towards better outcomes for the participant themselves."*

*"A bit of early intervention actually saves money down the track too, from a system point of view!"*

*"I think the significant investment in early intervention and early support is absolutely vital. Particularly with children with autism spectrum disorder, where early interventions can stop things being as needy, as costly down the track. It can improve a sufferer's life immensely."*

*"We caught our son this year for early intervention, but it could have been caught earlier in daycare."*

The second context involves these reforms constituting a critical part in **combating social isolation** that often comes with disability and have the potential to facilitate "connectivity" - that is far greater social connection and the mainstreaming of those with disabilities, as living with disabilities can be "very isolating".

*"I think [the adjunct funding] is really good. My cousin really struggles with finding social outlets. So I think having someone that knows places that he could just go and have a consistent thing to do… would be fantastic."*

*"My son went to an autistic school, because he was classed as severely autistic. And the problem was that there was no incentive for that school to try and assist my son to function better or to achieve or to integrate, or to climb ladders and to achieve milestones. So it wasn't until we found him a place, which was very difficult, in the public system, with a support worker, that we really saw improvement, and he really started to flourish. So I think mainstream development for most of the children is probably the ideal because kids are copycats, especially autistic kids. And if they're copying good behaviors, then they're going to learn more about how to behave in our world. [Otherwise], they will fall into habits that are not going to assist them by being surrounded by severely autistic kids, even though my son is nonverbal. So yeah, I think any push towards bringing them into the mainstream does two things that assist a child with a disability and also builds a society that understands that there are disabled children in amongst the kaleidoscope of life. And they're just like us. And you can get great reward and great enjoyment from having a relationship with someone with a disability. So I think that's a good thing."*

The third contextual element involved these reforms representing a **safety net**, preventing people - particularly children - from falling through the cracks. This was particularly appealing for those with experience of somewhat less severe disabilities that they term, "edge cases" that until now may have been neglected when it comes to government support. Indeed, these often segued into equity arguments, as well as the agency such reforms would afford parents of children requiring assistance, with more unprompted arguments that the equitable, widespread distribution of early intervention supports would yield wider social and economic benefits.

"*Early intervention is the best thing that they could ever do. There's so many kids that fall under the radar, I was so lucky that my kinder picked up my eldest. Without that, I just thought he was one of those out there boys. I had no idea. I'd never even really understood or heard of autism at that point. So luckily, one of the kinder teachers had two autistic boys. So having that knowledge within the system to get early intervention, it gives them the best start and chance that they have to have a normal life. So 100% The best thing to do!"*

*"I think it's amazing. If you have the money, spend it, because time and time again, [with] child protection, child welfare, you've got a child there with autism or ADHD who needs special care, needs physical care, and they're too busy to help those other kids. So what happens is those kids who really need that help, they grow up, but then they go through the system. So when they hit 21, there's a whole different, new thing. It costs more money. If you think that education, at the moment for a child, is just going to cost too much, you're creating more social problems - that's where the money pit is. You spend it now or you spend it later."*

*"I absolutely agree with it. There are large gaps in the supports needed and the supports that are currently available or even provided. Some of my participants are unable to drive but are not considered disabled enough to get taxi vouchers or anything like that. And that leaves them with trying to arrange for public transport or community based taxi services…. So anything that provides more support for these edge cases is excellent."*

*"I think it's a good thing.  [Too many people] are not getting the services they need… When you're talking about Asperger's [there's] not much at all provided for them [but support for them] is such an important thing. …They may need some help. And this is a good avenue. And it's well worth spend[ing] the money for those people that fall outside of [NDIS eligibility]."*

*"I think it might be really good for regional centers, as well. I think that that would create some more services for regional areas, to be able to have a bit more funding on that, or some of those services that aren't actually already in the area, to be able to put [it] in."*

There were, however, some caveats with such support being conditional on there being improvements to the quality and availability/accessibility of such mainstream services: *"It'd be great to see the quality [of mainstream and foundational services] improved, and hopefully that would increase with more popularity, which would be the reason that I wouldn't use those services right now. I have used them in the past, but the quality is quite poor. So all power to them, if they can get increased promotion and up their standards a bit. Fantastic!"*

It is important to note that with among a number of respondents with psychosocial disabilities, any (qualified) support for this reform was predicated on their highly negative experience of - and consequent extreme aversion to - the public mental health system, particularly hospitals, which many described as "traumatising". Not only do respondents view the public health system as inherently inequitable, they also view it as one of the most egregious examples of a system which robs them of their agency - to the point of dehumanisation.

*"All of my experiences with the public [mental] health system were shocking…The public system is just not good enough."*

*"The public mental health system is absolutely bullshit."*

*"I still have to have private health insurance, just in case the worst happens. Because the public [mental health] system is just that shocking!"*

One respondent with a schizophrenia diagnosis therefore supported putting early intervention supports around people (even if only for a limited time to allow a proper assessment of their condition and needs), arguing that this is important because a) the "broken" mental health system can not be relied on to help people in that moment and (because of that) b) too often *"it's cheaper and easier to just throw [people in the throes of a mental health crisis] in jail".*

However, for some respondents with psychosocial disability, this reform itself - outside of concerns about the public mental health system - offered the promise of greatly increased agency/control over their lives, describing illnesses such as depression or anxiety as transforming them into their "own worst enemy" in terms of being able to help themselves: *"I think it's step in the right direction. Personally, I've suffered depression and anxiety on and off for years related to a brain injury. And depression is really unfortunate, in that it basically stops you being able to get the help that you need. So if you have somebody actually reaching out to you to be like, 'Hey, let's go down this route. Like, let's try this. Then, going on to NDIS after that, [that could be great]. But a lot of people don't actually realise that they need help, like, depression is its own best friend. You don't want to reach out and talk to people. And a lot of times, you can't actually see how bad you're feeling. Until somebody else pointed it out to you."*

## Sustaining the Scheme Proof Points

### *The new pricing authority and regulations for providers*

The new pricing authority and strong regulation of providers were also welcomed as proof points of a suite of reforms designed to protect participants from exploitation and restore equity and agency to them. This contrasts with their current experience of being at the mercy of spiralling costs and potentially unscrupulous providers, against whom they feel they have little recourse. The new and strengthened watch-dog role was therefore also welcomed. Participants want accountability for providers. Indeed, demonstrating that we are *first* addressing providers and pricing is critical before discussing reforms that impact participant accessibility or funding: *"The NDIA has the power to do something about costs".*

Indeed, a number of respondents attribute the sustainability pressures to NDIS providers who many believe are *"working the system"* or they *"know how to play the game."*

*"I think [this reform] is very needed because it's vulnerable and desperate people. People are taking advantage of that. Businesses are taking advantage of that. And there's a lot of people too, who really don't understand the plan and the money and how it's being used. And they won't know where to look to find out that they've been charged exorbitant amounts until it's all run out. And then suddenly, they have no idea how that's happened. And there's no one who's been around to put them in check."*

*"Any funding is open to abuse. There is opportunity to improve the system and weed out some of the rorts."*

*"The exercise physiologist we go to actually advertises in reception the prices for patients and specifically puts down how much for those on NDIS. That's how blatant they are these days."*

*"The NDIS is getting a little bit out of control and there are some providers who are really ripping off the system."*

*"My pet hate is when they discover you are on NDIS and then they charge you more."*

*"Before we were on NDIS, we were paying for different therapies out of our own pocket and the minute we qualified the invoices changed and almost doubled."*

*"I think it's a good idea. I live in a regional/rural area, which means we don't get a lot of choices with the providers, or people that we can use… Someone can literally just start up a business and say, 'Look, we came for NDIS.' And that's it."*

The only caveat - particularly among self-managed respondents - entailed ensuring that any such reforms did not remove choice/agency from participants with regard to the providers that they use: *"[These reforms] sound good, as long as there's still that choice and control for us to be able to [choose our providers]. "*

## Changes to Supported Independent Living and Developmental Delay Threshold: Proof Points Provide Qualified Tolerance for Otherwise Unpalatable Reforms

After presenting respondents with the above proof points that provide vital, believable context of reforms designed to benefit participants, we were able to elicit a degree of *qualified tolerance* for reforms that would restrict either eligibility for the Scheme (raising the threshold for children with developmental delay) or the amount of support high-need participants would receive (moving to a 1:3 care model for Supported Independent Living participants). That is, respondents do not like these reforms but they may be willing to tolerate them where there are certain compensating factors.

1. Carve-outs for exceptional circumstances (i.e. we are not forcing everyone into the same box, and the most in need are still fully supported).

*[If] they're very, very low risk, then yes, I think it might work. But [some] people need extra care. And some of them need more than one person for themselves. So I think it's a bit risky."*

*"It just depends on the individual's needs, like how much care they need, what, the severity of their needs [are]."*

2. Initial goodwill generated by the measures to humanise the Scheme and to protect participants (and the Scheme) from exploitation. Conversely, there is a strong resistance to any discussion of costs alone as a driver of reforms. Indeed, cost discussion without prior contextualisation via the humanising reforms led to opposition that was considerable and intense. We therefore do not recommend discussing either reform in isolation.

*“[1:3] is a horrible way to save money. It just goes backwards. And it's just horrible. There's no thought around the actual person [and] what they need!”*

*“The most concerning [reform idea] was definitely the 1:3. That's just awful!”*

*“[Regarding raising the threshold], leave the kiddies alone!”*

A number of respondents in the earlier groups believed that the 1:3 changes would mean the return of group homes to which they were implacably opposed: “*So they're going backwards into group homes? That’s horrible!”*

Indeed, decontextualised cost discussions often led respondents to argue that raising the threshold and 1:3 reforms constituted a false economy that would result in far greater costs to government in the long run.

*“My daughter is going to go to university next year and it’s because of early intervention. Without early intervention she’d probably have to go on the dole so it’s important for productivity that young people like her are able to be productive. Also, because of NDIS, it’s added to my productivity as a taxpayer too.”*

*“Early Intervention actually costs the government less in the long term. They could prevent more major issues, or somebody descend[ing with their] mental health, because it gets aggravated. And then the support worker also struggles [in the case of 1:3], of course, and then they lose the support [worker] as well. So there are lots of factors [to take into consideration].”*

3. Alternative or ‘offsetting’ benefits in place. For example, in relation to the threshold for developmental delays, there is more (but not out-right) acceptance once respondents had been treated with the idea of investing in mainstream supports for children (through schools/kinders/etc) to enable earlier intervention and improve the safety net. In relation to the Supported Independent Living (SIL) changes, these become more acceptable when couched in benefits around reducing social isolation and ensuring people don’t fall through the cracks.

*“For the younger kids, I think [1:3] will work great if they don't need that 24 hour care around the clock. It'll get them to become more independent, socialise more, interact more. And that's what we need these days.”*

*“[It’s] an opportunity for participants to interact socially, share experiences, just have some company”*

*“[Raising the threshold for developmental delay] is a tough one. It's just moving the goalposts, isn't it? My concern is, in theory, sounds great. In practicality, where are we going to drag all these resources from?*

*“I think [the balance between raising the threshold and the adjunct funding] will definitely help it become more mainstream. I think we need to funnel it through the existing, public system that we have, which is the education system. I think that there needs to be better assessment, which they're trying to propose.”*

*“I think [these reforms overall are] a step in the right direction, they've just really got to nail the change management. You can't just get rid of something [like raising the threshold] straightaway. If you're going to implement that early detection thing, you've got to have that overlap. That's part of good change management, as opposed to just taking it off people all of a sudden. But overall, it seems like they've got some good ideas that could really work, if they make it work.”*

Conversely, proposing to ‘grandfather’ changes to SIL did *not* work as a way of ‘offsetting’ the impacts.

*“My concerns remain the same!”*

*[Grandfathering suggestions] don't change it at all. No. Follow the Commission's report!”*

*“That will be totally unfair.”*

*“It's not really equitable, is it?”*

## Risks to Reform Credibility

While respondents had a number of questions regarding implementation of these reforms and - at times - the reforms’ feasibility, broadly, these questions constituted curiosity regarding how such reforms would practically impact them and/or be implemented. Such questions were generally not borne of hostility or opposition to the principles underpinning the reforms.

Importantly, unlike in the previous round of research, there was a marked shift in tone among most respondents (with certain notable exceptions - primarily among those living in regional areas). Where anxiety had been the dominant sentiment in the previous round, in this round that transformed for many into their feeling “hopeful”. While respondents had many questions, these were often not posed as reasons to disqualify the reforms; rather, their questions led to discussion of how such reforms could be made to work better for participants/carers. The focus on humanising the Scheme allowed respondents to accept the positive intent of the reforms and created a tolerance of imperfection, inclining many to focus on the positive aspects, as opposed to the previous round in which respondents adopted a more defensive posture and sought to ascribe nefarious intent such as abrogation of government responsibility.

However, it must be noted that amid the myriad respondent questions relating to the detail there is one critical, missing component compromising the credibility of the suite of reforms: **workforce issues** - specifically, where the promised staff - with local knowledge and expertise for complex cases in the case of Navigators and Assessors, and allied health professionals and volunteer/other personnel necessary to staff the early intervention and foundational/mainstream supports initiatives - would come from.

Furthermore, who will be training these new roles - especially Navigators - to ensure they can fulfil the varied tasks they will be required to undertake? There were also specific concerns regarding teachers and childcare workers having the requisite existing knowledge for the mainstreaming of early intervention to be effective. One respondent’s assessment of their capacity to fulfill this early intervention role was: “That’s complete bullshit”.

*“[These are] ambitious goals. You are aware there's a massive shortage of staffing across the board in our social services, education and health department? It's immense!”*

“*It's just a lot of us live regionally so local [expertise/support] isn't always an option.”*

*Where are we going to get those people in the schools that have the qualifications? Through the Education Department, early intervention, whatever label they want to put on it - where are these [experts]? Where's it coming from? It's like our health system. [It’s fine to] throw some money in [but] we need nurses. But where do they come from? That's a big concern that I have.”*

These questions around staffing and workforce occurred across all proof points and in each reform area. That is, unaddressed workforce concerns can undermine confidence in the new Navigator and Assessor roles, government paying for assessments (thereby, creating a “bottleneck” and exacerbating waiting lists), investment in early intervention and foundational supports, and the capacity to address pricing (without causing an exodus of vital allied health professionals). Qualitatively, failure to address these questions poses the most immediate risk to acceptance of these reforms among the disability community.

*“You can’t get specialist appointments in 30 days. Not here anyway. It’s a 9 month wait here.”*

*"They'll have to do more training to get people on the ground to do this."*

*"Having a speech therapist assigned within centers and the school would be beneficial but obviously, again, you need that backup of enough staff to be able to man that as well as the extra demand."*

*"I agree that the teachers don't have the time for doing the teaching [let alone other tasks involving early intervention]. They don't have enough staff as it is now. They can have their education assistants with them, but even then…I just don't see it as a feasible thing that would work. I think it would end up costing more later on without the early intervention, the proper early intervention that can really help turn things around and help the kids. That is what's needed."*

*"I work in incident support for a lot of educational institutes and there is just a lot of burnout. The child to educator ratios are never good. And so not only are these kids falling through the cracks, because there's not enough support for those kids, but the educators themselves are needing to protect themselves, so they can't put themselves forward to take on that sort of journey with those children. So it's an area that desperately needs more resources."*

There were particular workforce concerns with regard to navigators and continuity of care particularly (but not only) for those with complex needs. The favourable disposition towards the new navigator role is predicated on the human connection - something requiring sufficient staffing for continuity. There were therefore a number of questions relating to this issue.

*"Will that turn-over [of navigators from the workload] be more than now?"*

*"Sounds fantastic but we cycle through LACs all the time here. They either leave the system or go somewhere else in the system, so we are constantly having to get to know a new LAC and explain everything to them. I'm not sure how this new arrangement would change that."*

*"We've had a couple of different support coordinators, just because people have gone on leave or whatever. And I think the quality of your experience has a lot to do with the quality of your support coordinator… So it doesn't really matter whether they're a navigator, or they're like the old support coordinator. It depends on how good at their job they are."*

*"I just think it's hard enough to get in contact with support coordinators because they're already handling 30 different clients sometimes. Adding another role to them - is that not gonna make them even less accessible because they're so overworked?"*

### *Other frequently asked questions*

Below are some of the other frequently asked respondent questions.

Who pays for the Navigator's support before you enter the Scheme? Respondents wanted to know whether a navigator would be as staunch an advocate for participants as their current support coordinator and who pays for the navigator constituted a critical factor in determining whether the navigator "works" for the NDIA or works for the participant - that is, whose interest take primacy for the navigator? The interests of the NDIA or the interests of the participant?

*"I think if you do have a good support coordinator, or you're with an independent support coordination company, there's generally that feeling that they've got your best interests in mind. The thing that concerns me is that if the support coordinators are part of NDIS, to me that introduces a bit of thinking of whose best interests that they have in mind. Is it mine? Or is it NDIS? That's my concern regarding that."*

What will the changes to pathway and personnel mean for current participants? Some respondents asked whether existing participants would "go back to square one"?

*"You guys could actually cause a bit more damage than good!"*

*"They can't change the system and then then go, 'Oh, we better get a lot more providers, because that's not gonna work."*

A number of respondents very much wanted to know whether they would have "choice" with regard to their navigators, with the option to change navigator should they not "gel" with them.

*"If it's a really humanised approach, you're talking to human beings, you're just not reading something on the screen. If you're got that one individual human being that you're talking to, and maybe if that person isn't right for you, you [should] have the right to say, 'Hey, this is not for me, and I'd like someone else to support me.'"*

Will the government still pay for the initial assessment even if a prospective participant is not accepted into the Scheme?

*"What happens if they don't get the diagnosis as such? [Do] you have to repay that money, or is that, 'Alright, sorry. We tried, we've covered it still.' Because it's hard enough getting to a point where you qualify, but would there [also] be the impact of having to reimburse a specialist and individually pay for all those testing? It's very expensive, very expensive!"*

*"If you've got to go and have two different assessments, do they pay for both of those or you just pay for one? And that's it? [What] if you've got to keep on testing?"*

Who pays for assessments/reports when going for a plan review: *"For the review of your plan, who's going to pay?"*

How will the Scheme ensure that participants do not run out of money before their plans are due for renewal - or, alternatively - do not spend their money too slowly and have their funding reduced at the next plan review?

*"[What if my daughter has] no ability to manage the money and make it last for that amount of time.? What happens if she isn't able to do that and she runs out of funding?"*

*"If it is a longer plan, a longer duration, there needs to be some mechanism that is going to alert [you] that you're running out of money, or you're not spending enough money."*

There were also questions regarding whether the new budget/planning and pricing/workforce regulation reforms would increase the bureaucratic burden for participants.

*"If [funding] is all in one bucket, does that mean every time you want to access a new type of therapy or whatever, you have to go through a request and approval process? Because if that is the case, that's probably going to be far more painful!"*

*"I have been on the NDIS maybe four or five years and I've done yearly plans, and I've done two yearly plans. Even two yearly was an absolute disaster for me [because] my multiple diagnoses are very up and down all the time… I've been going back with support coordinators and reports after two, three months. So the idea of getting a plan [for] five years, I'm not sure if that's just more hassle for me to have to constantly go back."*

*"What about providers? So when you mentioned gardeners, our gardener doesn't even know I'm on NDIS. So what happens? We obviously do due diligence checks -ABN and insurance, but haven't done police checks. So I guess for self managers, you'd have to look at the private providers."*

Other respondents wanted to know how longer term plans/budgets would account for inflation and rising costs.

*"I'd be concerned about the impacts of CPI on your budget. In five years time it will probably be worth a lot less the way that CPI is going. The longer the time frame, the more flexibility you'll need."*

*"[t will need to be] reviewed every year or every two years because we're in a period of high inflation and [cost of living] crisis, so you'd want to review it regularly."*

# Appendix A – Group Composition

- Group 1 comprised NDIS support workers and/or NDIS guardians/nominees/carers/family members (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme
- Group 2 comprised NDIS participants and/or their guardians/nominees/carers (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme
- Group 3 comprised NDIS participants and/or their guardians/nominees/carers (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme
- Group 4 comprised NDIS support workers (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme
- Group 5 comprised NDIS participants and/or their guardians/nominees/carers (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme
- Group 6 comprised parents of children under the age of 9 who are NDIS participants (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme
- Groups 7 comprised NDIS support workers (mix genders and ages), living Australia-wide, exploring reforms designed to make the Scheme sustainable
- Group 8 comprised NDIS participants and/or their guardians/nominees/carers (mix genders and ages), living in WA, SA, NT, and QLD, exploring reforms designed to make the Scheme sustainable
- Group 9 comprised parents of children under the age of 9 who are NDIS participants (mix genders and ages), living Australia-wide, exploring reforms designed to make the Scheme sustainable
- Group 10 comprised parents of children under the age of 9 with a disability, with a mix of NDIS and non-NDIS participants (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme
- Group 11 comprised people with a disability and/or their guardians/nominees/carers, with a mix of NDIS and non-NDIS participants (mix genders and ages), living Australia-wide, exploring reforms designed to make the Scheme sustainable
- Group 12 comprised people with a disability and/or their guardians/nominees/carers, with a mix of NDIS and non-NDIS participants (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme
- Group 13 comprised close family members of someone with a disability who are not primary care-givers (mix genders and ages), living Australia-wide, exploring reforms designed to make the Scheme sustainable
- Group 14 comprised close family members of someone with a disability who are not primary care-givers (mix genders and ages), living Australia-wide, exploring reforms designed to humanise the Scheme

# Appendix B – Final Set of Wording Tested

- We're going to humanise the NDIS by making the Scheme more about people and less about process and bureaucracy
- We're going to ensure that the Scheme will be there for the future by protecting participants from exploitation and making sure that every NDIS dollar is going toward improving outcomes for participants

  How do they sound as our aims/objectives? Right direction, wrong direction, somewhere in between?

**How we will humanise the system (proof points)**

- All participants will have the option to be supported by a Navigator[2] – a person who will guide them through their NDIS journey. Navigators will be available from the very start to help people apply and not feel intimidated about accessing the Scheme. They will guide participants through the process and help them make choices about how to spend their funding. This includes helping participants understand what the Scheme allows them to spend funding on and what things are proven to actually make a difference. Navigators will be chosen and paid for by participants from their funding, replacing Support Coordinators and Local Area Coordinators. They will be locally-based, bringing local knowledge about what supports are available where participants live, including those outside the NDIS as well. For complex cases, they will be specialised in a participant's disability.

  Responses and concerns/hesitations to this?

  If not, prompt with: what about the idea of Navs helping participants understand what the Scheme allows them to spend funding on and what things are proven to actually make a difference? Any concerns/hesitations there?

    - If they raise concerns around who gets to decide what's 'proven' or 'reasonable and necessary', ask: There will always be rules in the Scheme around what you can and can't spend money on. Given that, how important is it to have someone who can guide you on those rules so you can make informed choices?
    - Also test: what if a price limit was set, such that (for example) there's more flexibility for something that costs less than, say, $100?

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[2] Alternative wording: All participants will now be given the option to access a Support Coordinator – a person who will guide them through their NDIS journey. The Support Coord role will be expanded so they will be available from the very start to help people apply and not feel intimidated about accessing the Scheme. They will guide participants through the process and help them make choices about how to spend their funding. This includes helping participants understand what the Scheme allows them to spend funding on and what things are proven to actually make a difference. They will be chosen and paid for by participants from their funding. They will be locally-based, replacing Local Area Coordinators and bringing local knowledge about what supports are available where participants live, including those outside the NDIS as well. For complex cases, they will be specialised in a participant's disability.

- For those joining the Scheme, the government will now pay for the professional assessments required to apply for funding. Access to the Scheme will no longer be limited by someone's ability to afford the required assessments.
- Also supporting participants will be another new role, their Assessor. Assessors will be specifically trained in assessing participants' support needs. They will personally meet with participants on multiple occasions to understand their situation and develop an assessment that is then used to determine a support budget.
- For most participants, they will have just two people to deal with: their Navigator and their Assessor – streamlining the relationships they need to manage within the Scheme.

Responses and concerns/hesitations to this?

- Participants will receive a budget package – rather than a line-by-line budget – that gives them flexibility to choose how their funding is spent. Avoiding the situation where participants can have thousands of dollars sitting in parts of their budget that they can't spend, as they run out of money in other areas of more pressing need.
- Budget packages will also be longer-term – 3 to 5 years rather than 1 or 2 years to reduce the stress and cost of annual reviews. But participants will still be able to request changes to their budgets if there are changes in their lives.

Responses and concerns/hesitations to this?

If yes, ask: on balance do you think the positives outweigh the negatives?

Supporting these changes will be other improvements that will make it easier and quicker for people to access support:

- Investment in foundational disability supports available outside the NDIS (e.g. information resources, support groups, services like meals on wheels or cleaning). So participants don't have to spend their funding on things that should be available through other sources.
- The introduction of early intervention supports for people with a psychosocial disability. This would provide them with early supports in that critical period while they undergo a proper assessment of their needs. After that period, they will either enter into the full Scheme or into the mental health system for ongoing support.

Responses and concerns/hesitations to this?

- Significant investment in early intervention for children by increasing the availability of specialist supports through kinders, childcare and schools.

Responses and concerns/hesitations to this?

**How we will ensure the Scheme is there for the future (proof points)**

- Too many participants are subject to fraud or unethical behaviour. A stronger hand is needed to protect participants. There will be increased monitoring and auditing of service providers in the Scheme – both in terms of where participants' money is going and the quality of services that participants receive in return. The role of the 'watch-dog' in the Scheme will be strengthened to give it better powers to hold providers to account. So we don't slow the whole Scheme down with red tape, a risk-based approach will be used: so there is 'light touch' over-sight for low risk providers and heavier oversight for high risk providers.

- Participants should not have to pay extra for the things they need just because they're being paid for through the NDIS. An Independent Pricing Authority, like they have under Medicare, will be established to set fair prices that reflect both the right of participants to pay a competitive price and the requirements for providers in supporting people with a disability. NOT UNDERSTANDING

  Any concerns/hesitations in this?

If we are to ensure the NDIS is there for the future, in some parts of the Scheme we do need to address the realities of its cost.

  Test: do participants accept some aspects of NDIS costs need to be addressed to 'futureproof' the Scheme? Why/why not?

Now, let's talk through some specific examples.

- One possible change is **raising the threshold to access the Scheme for children with developmental delays**. This would mean that only those children with more significant impairments would access the NDIS.
- However, this would only be done in conjunction with the investment in early intervention for children via schools, kinders, etc, as discussed earlier.
- So the change to the NDIS would be balanced by those who 'miss out' on NDIS funding having access to an improved safety net outside of the NDIS.

Thoughts/reactions?

Are the impacts sufficiently balanced here? If not, what would be needed to better balance the impacts for children with developmental delays?

How big a challenge do participants think it would be to bring our schools/kinders/etc up to an acceptable level in this space?

- **Supported Independent Living** is one type of support to help people with a disability with higher support needs to live in their home. It is for people who need some level of ongoing help at home.
- Currently, SIL participants can be funded for 1-on-1 support – where they have a dedicated support worker helping them 24 hours a day. While some participants will always require, and will always receive, 1-on-1 support, many do not need this intensity of support.

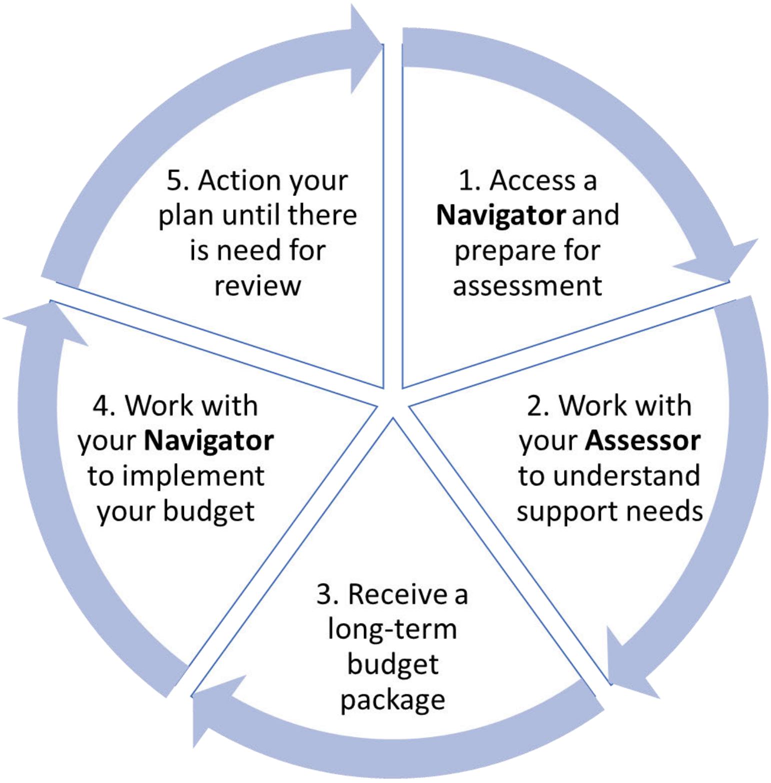
- Where possible, such participants would move to a 1-to-3 support model – one worker for three participants.
- This change would be balanced by: a) improvements in outcomes for many participants, as the 1:3 model offers increased social connection and reduces isolation and b) innovation in the way support is delivered so people can live independently but with shared care, and avoid the old 'group home' model of care.

Thoughts/reactions?

Are the impacts sufficiently balanced here? If not, what would be needed to better balance the impacts for SIL participants?

Thinking back on everything we've discussed tonight – covering all the things about 'humanising' the Scheme through to the things about pricing, exploitation and how to balance out changes. Overall, do you think these things would help or hinder participants *on balance*?

# Appendix C – Scheme Humanisation Reforms Explanatory Diagram



## *Recruitment Specification: Community Issues*

All groups:

- Via Zoom, 90mins duration
- 9 participants; $90 incentive (managed by Focus People)
- Mix genders/ages/locations (Australia-wide)

Profile questions:

Please select your gender
- Male
- Female
- Non-binary

Please select your age range
- 18 to 29
- 30 to 39
- 40 to 49
- 50 to 59
- 60 to 69
- Over 70

What is your highest completed level of education?
- High school
- TAFE or vocational training
- University degree
- Less than year 12

Do you or a close family member have a disability that requires ongoing care/management?

- Yes
- No

If yes, which of the following best describes you [tick all that apply]

- I am a NDIS participant
- I have a disability but am *not* a participant in the NDIS
- I am the primary carer, parent or guardian of someone who is a NDIS participant
- I am the primary carer, parent or guardian of someone with a disability who is not a NDIS participant
- I am the parent of child aged 9 or under who is a NDIS participant
- I am the parent of child with a disability, aged 9 or under, who is not a NDIS participant
- My close family member has a disability, but I am not the primary carer or guardian

Do you work as a support worker in the NDIS?

- Yes
- No

Do you work for the NDIA or a disability service provider (other than as a support worker)?

- Yes [EXCLUDE]
- No

| Group time/date (MELB TIME) | Moderator | Zoom link | Profile |
|---|---|---|---|
| Grp1<br>6.30pm Mon 16 Oct | SW | | Mix: NDIS support workers and/or NDIS guardians/nominees/carers/family members<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp2<br>6.30pm Mon 16 Oct | AF | | NDIS participants and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp3<br>6.30pm Tues 17 Oct | AF | | NDIS participants and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp4<br>5.45pm Tues 17 Oct | SW | | NDIS support workers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp5<br>6.30pm Weds 18 Oct | AF | | NDIS participants and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp6<br>6.30pm Thurs 19 Oct | SW | | Parents of children under the age of 9 who are NDIS participants<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |

| | | | |
|---|---|---|---|
| Grp7:<br>6.30pm Thurs 19 Oct | TB | | Parents of children under the age of 9 who are NDIS participants<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp8<br>5pm PERTH<br>6.30pm DARWIN<br>7.30pm ADEL<br>7.00pm QLD<br>8.00pm MEL<br>Thurs 19 Oct | AF | | NDIS participants and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living in WA, SA, NT, and QLD<br>● Please specify that this group will be discussing the NDIS |
| Grp9<br>5.45pm Mon 23 Oct | AF | | NDIS support workers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp10<br>7.30pm Mon 23 Oct | AF | | Parents of children under the age of 9 with a disability<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● CAN INCLUDE CHILD WHO IS A) NOT ON THE NDIS and B) ON THE NDIS<br>● Please specify that this group will be discussing the NDIS |
| Grp11<br>7.30pm Mon 23 Oct | SW | | People with a disability and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● CAN INCLUDE A) NOT ON THE NDIS and B) On the NDIS<br>● Please specify that this group will be discussing the NDIS |
| Grp12<br>6.30pm Tues 24 Oct | AF | | People with a disability and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● CAN INCLUDE A) NOT ON THE NDIS and B) On the NDIS<br>● Please specify that this group will be discussing the NDIS |

| | | | |
|---|---|---|---|
| Grp13<br>5.45pm Tues 24 Oct | SW | | Close of family of someone with a disability, but not primary care giver<br>• Mix gender, mix age<br>• Living Australia-wide |
| Grp14<br>7.30pm Tues 24 Oct | SW | | Close of family of someone with a disability, but not primary care giver<br>• Mix gender, mix age<br>• Living Australia-wide |

## *Recruitment Specification: Community Issues*

All groups:

- Via Zoom, 90mins duration
- 9 participants; $90 incentive (managed by Focus People)
- Mix genders/ages/locations (Australia-wide)

Profile questions:

Please select your gender

- Male
- Female
- Non-binary

Please select your age range

- 18 to 29
- 30 to 39
- 40 to 49
- 50 to 59
- 60 to 69
- Over 70

What is your highest completed level of education?

- High school
- TAFE or vocational training
- University degree
- Less than year 12

Do you or a close family member have a disability that requires ongoing care/management?

- Yes
- No

If yes, which of the following best describes you [tick all that apply]

- I am a NDIS participant
- I have a disability but am *not* a participant in the NDIS
- I am the primary carer, parent or guardian of someone who is a NDIS participant
- I am the primary carer, parent or guardian of someone with a disability who is not a NDIS participant
- I am the parent of child aged 9 or under who is a NDIS participant
- I am the parent of child with a disability, aged 9 or under, who is not a NDIS participant
- My close family member has a disability, but I am not the primary carer or guardian

Do you work as a support worker in the NDIS?

- Yes
- No

Do you work for the NDIA or a disability service provider (other than as a support worker)?

- Yes [EXCLUDE]
- No

| **Group time/date (MELB TIME)** | **Mod** | **Zoom link** | **Profile** |
|---|---|---|---|
| Grp1<br>6.30pm Mon 16 Oct | SW | https://us02web.zoom.us/j/88527510671 | Mix: NDIS support workers and/or NDIS guardians/nominees/carers/family members<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp2<br>6.30pm Tues 17 Oct | AF | https://us02web.zoom.us/j/82406272387 | NDIS participants and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp3<br>6.30pm Tues 17 Oct | SW | https://us02web.zoom.us/j/82334113464 | NDIS participants and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp4<br>6.30pm Weds 18 Oct | AF | https://us02web.zoom.us/j/81006889108 | NDIS support workers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp5<br>6.30pm Weds 18 Oct | SW | https://us02web.zoom.us/j/89559229348 | NDIS participants and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp6<br>6.30pm Weds 18 Oct | TB | https://us02web.zoom.us/j/84405764166 | Parents of children under the age of 9 who are NDIS participants<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |

| | | | |
|---|---|---|---|
| Grp7:<br>6.30pm Thurs 19 Oct | TB | https://us02web.zoom.us/j/86315505857 | NDIS support workers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp8<br>5pm PERTH<br>6.30pm DARWIN<br>7.30pm ADEL<br>7.00pm QLD<br>8.00pm MEL<br>Thurs 19 Oct | AF | https://us02web.zoom.us/j/89536139127 | NDIS participants and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living in WA, SA, NT, and QLD<br>● Please specify that this group will be discussing the NDIS |
| Grp9<br>6.30pm Thurs 19 Oct | SW | https://us02web.zoom.us/j/89256150708 | Parents of children under the age of 9 who are NDIS participants<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● Please specify that this group will be discussing the NDIS |
| Grp10<br>6.30pm Mon 23 Oct | AF | https://us02web.zoom.us/j/86063705591 | Parents of children under the age of 9 with a disability<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● CAN INCLUDE CHILD WHO IS A) NOT ON THE NDIS and B) ON THE NDIS<br>● Please specify that this group will be discussing the NDIS |
| Grp11<br>6.30pm Mon 23 Oct | TB | https://us02web.zoom.us/j/83558305689 | People with a disability and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● CAN INCLUDE A) NOT ON THE NDIS and B) On the NDIS<br>● Please specify that this group will be discussing the NDIS |
| Grp12<br>6.30pm Mon 23 Oct | SW | https://us02web.zoom.us/j/86225586865 | People with a disability and/or their guardians/nominees/carers<br>● Mix gender, mix age (18+)<br>● Living Australia-wide<br>● CAN INCLUDE A) NOT ON THE NDIS and B) On the NDIS<br>● Please specify that this group will be discussing the NDIS |

| | | | |
|---|---|---|---|
| Grp13<br>6.30pm Tues 24 Oct | AF | https://us02web.zoom.us/j/86775096857 | Close of family of someone with a disability, but not primary care giver<br>• Mix gender, mix age<br>• Living Australia-wide |
| Grp14<br>6.30pm Tues 24 Oct | SW | https://us02web.zoom.us/j/84784032180 | Close of family of someone with a disability, but not primary care giver<br>• Mix gender, mix age<br>• Living Australia-wide |

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# TAX INVOICE

National Disability Insurance Agency
Attention: Department of Human Services
13-19 Malop Street
Geelong Smart Centre
GEELONG VIC 3220
AUSTRALIA
ABN: 25617475104

**Invoice Date**
10 Oct 2023

**Invoice Number**
INV-0749

**Reference**
Consultancy Services
(PO7200010765)

**ABN**
11 650 587 867

Redbridge Group Pty Ltd
Attention: Mr Simon Welsh
s47F - personal privacy

| Description | Quantity | Unit Price | GST | Amount AUD |
|---|---|---|---|---|
| s47G - business information | | | | |
| | | | Subtotal | 42,600.00 |
| | | | TOTAL GST 10% | 4,260.00 |
| | | | **TOTAL AUD** | **46,860.00** |

**Due Date: 25 Oct 2023**
Please pay to:
s47G - business information

redbridge
INFLUENCE WITH INTEGRITY

# TAX INVOICE

National Disability Insurance Agency
Attention: Department of Human Services
13-19 Malop Street
Geelong Smart Centre
GEELONG VIC 3220
AUSTRALIA
ABN: 25617475104

**Invoice Date**
12 Oct 2023

**Invoice Number**
INV-0750

**Reference**
Consultancy Services
(PO7200010765)

**ABN**
11 650 587 867

Redbridge Group Pty Ltd
Attention: Mr Simon Welsh
s47F - personal privacy

| Description | Quantity | Unit Price | GST | Amount AUD |
|---|---|---|---|---|
| s47G - business information | | | | |
| | | | Subtotal | 42,600.00 |
| | | | TOTAL GST 10% | 4,260.00 |
| | | | **TOTAL AUD** | **46,860.00** |

**Due Date: 27 Oct 2023**
Please pay to:
s47G - business information

redbridge
INFLUENCE WITH INTEGRITY

# TAX INVOICE

National Disability Insurance Agency
Attention: Department of Human Services
13-19 Malop Street
Geelong Smart Centre
GEELONG VIC 3220
AUSTRALIA
ABN: 25617475104

**Invoice Date**
26 Oct 2023

**Invoice Number**
INV-0757

**Reference**
Consultancy Services
(PO7200010765)

**ABN**
11 650 587 867

Redbridge Group Pty Ltd
Attention: Mr Simon Welsh
s47F - personal privacy

| Description | Quantity | Unit Price | GST | Amount AUD |
|---|---|---|---|---|
| s47G - business information | | | | |

| | |
|---|---|
| Subtotal | 42,600.00 |
| TOTAL GST 10% | 4,260.00 |
| **TOTAL AUD** | **46,860.00** |

**Due Date: 10 Nov 2023**
Please pay to:
s47G - business information

redbridge
INFLUENCE WITH INTEGRITY

# TAX INVOICE

National Disability Insurance Agency
Attention: Department of Human Services
13-19 Malop Street
Geelong Smart Centre
GEELONG VIC 3220
AUSTRALIA
ABN: 25617475104

**Invoice Date**
2 Nov 2023

**Invoice Number**
INV-0779

**Reference**
Consultancy Services
(PO7200010765)

**ABN**
11 650 587 867

Redbridge Group Pty Ltd
Attention: Mr Simon Welsh
s47F - personal privacy

| Description | Quantity | Unit Price | GST | Amount AUD |
|---|---|---|---|---|
| s47G - business information | | | | |
| | | | Subtotal | 42,600.00 |
| | | | TOTAL GST 10% | 4,260.00 |
| | | | **TOTAL AUD** | **46,860.00** |

**Due Date: 17 Nov 2023**
Please pay to:
s47G - business information