

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 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/nominees¹ 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. 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 neurosarcooidosis 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 their system with their 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... And I 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 watchdog 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

