



Report for

NDIS Independent Review Panel

Consultation

August 2023

Contents

Context	4
Forums - Development & Implementation	5
1. Safe and chosen places to live now and in the future (housing and living, Quality, Safeguards, Choices)5	
2. Access, planning, reasonable and necessary supports.....	5
3. Capacity building	5
4. Navigators.....	5
5. Services, quality, outcomes (markets and providers)	5
Themes raised in forums.	7
1. Safe and chosen places to live, now and into the future (housing and living, quality, safeguards, choices)	7
1.1 Waste, costs & burden of reporting	7
Suggested solutions – 1.1	8
1.2 Lack of individualisation & choice, respect for individuals	8
Suggested solutions – 1.2.	9
1.3 Good provision changes lives & saves money.	10
1.4 Communication & transparency, accountability	11
Suggested solutions - 1.3 & 1.4.....	11
1.5 Training & experience, humanisation & empathy	11
Suggested solutions – 1.5	11
2. Access, planning, reasonable and necessary supports.....	12
2.1 Waste, costs, & burden of reporting	12
Suggested solutions – 2.1	13
2.2 Lack of individualisation & choice, respect for individuals	14
Suggested solutions – 2.2	14
2.3 Availability of care, role of families & informal carers, State Government, and other agencies.....	14
Suggested solutions – 2.3	14
2.4 Good provision changes lives & saves money.	14
2.5 Communication & transparency, accountability	15
Suggested solutions - 2.4 & 2.5.....	16
2.6 Training, experience & empathy.....	16
Suggested solutions – 2.6	16
2.7 Reasonable & necessary supports	17
Suggested solutions – 2.7	17
2.8 Lack of individualisation & choice, respect for individuals	18
2.9 Availability of care, role of families & informal carers, state government and other agencies.....	18
Suggested solutions - 2.8 & 2.9.....	18
2.10 Communication & transparency, accountability	18
2.11 Training & experience, humanisation & empathy	19

Suggested solutions – 2.10 & 2.11	19
3. Capacity building	20
3.1 Waste, costs & burden of reporting.....	20
Suggested solutions – 3.1	20
3.2 Lack of individualisation & choice, respect for individuals	20
Suggested solutions 3.2	20
3.3 Availability of care, role of families & informal carers, state government and other agencies.....	21
3.4 Good provision changes lives & saves money.	22
3.5 Communication & transparency, accountability	22
Suggested solutions - 3.4 & 3.5.....	22
4. Navigators.....	23
4.1 Lack of individualisation & choice, respect for individuals	23
Suggested solutions - 4.1	23
4.2 Availability of care, role of families & informal carers, state government and other agencies.....	23
Suggested solutions – 4.2	24
4.3 Communication & transparency, accountability	24
Suggested solutions – 4.3	25
5. Services, quality, outcomes (markets and providers)	25
5.1 Waste, costs & burden of reporting	25
Suggested solutions – 5.1	27
5.2 Lack of individualisation & choice, respect for individuals	28
5.3 Availability of care, role of families & informal carers, state government and other agencies.....	28
Suggest solutions – 5.3	29
5.4 Good provision changes lives & saves money.	30
5.5 Communication & transparency, accountability	30
Suggested solutions – 5.4 & 5.5.....	31
5.6 Training & experience, humanisation & empathy	32
Suggest solutions – 5.6	34
6. Appendix 1: Forum Agenda	35
7. Appendix 2: Attendees Demographics	41

Context

In October 2022, Minister for the NDIS, the Hon Bill Shorten, announced a review of the NDIS. As part of that review, the independent NDIS Independent Review Panel (Review Panel) was established to seek public feedback on the NDIS.

As a major stakeholder in the disability community, the Review Panel sought out Every Australian Counts (EAC) to organise 10 public-facing NDIS Review Forums to be held online; with four to be devoted to people from rural and regional Australia. Those sessions, which had a capacity of 30 people each, were all filled.

Eleven days before the first session (9 May 2023, 11 am to 12:30 pm) there was media from the NDIS (Department of Social Services), that the Federal Government earlier announcement was to get the National Disability Insurance Scheme (NDIS) back on track by improving outcomes for participants and ensuring the sustainability of the Scheme for future generations.

The following provides a detailed report on the Forums along with a thematic layout of responses and suggestions provided by the attendees.

Forums - Development & Implementation

1. Proposed themes.

The NDIS review group proposed five overarching topics for discussion:

1. Safe and chosen places to live now and in the future (housing and living, Quality, Safeguards, Choices)
2. Access, planning, reasonable and necessary supports
3. Capacity building
4. Navigators
5. Services, quality, outcomes (markets and providers)

2. Forum locations, dates, and times

All sessions took place online over Zoom. Some forums were dedicated to rural and regional attendees. Forums for everyone also attracted a number of attendees beyond the major cities.

Forums for everyone:

- Tuesday 9 May, 11:30 am – 1 pm
- Thursday 11 May, 2 pm – 3:30 pm
- Saturday 13 May, 2 pm – 3:30 pm
- Tuesday 16 May, 11:30am – 1 pm
- Wednesday 17 May, 11:30 am – 1 pm
- Wednesday 17 May, 7:30 pm – 9 pm

Forums specifically for people living in regional and rural areas:

- Monday 22 May, 11:30 am – 1 pm
- Tuesday 23 May, 11:30 am – 1pm
- Thursday 25 May, 2 pm – 3:30 pm
- Saturday 27 May, 11:30 am – 1pm

3. Invitations

EAC invited people with a disability and their families to join the forums to have their say on the scheme and advised that the one-and-a-half hour sessions would focus on and seek feedback around housing and living, quality, safeguards, and choices, and were also advised that there would be plenty of time to discuss other topics.

Indigenous Australians, LGBTQIA+ Australians, CALD Australians, and those in remote or regional Australia were encouraged to take part in the forums via our website, eDM and social media (Facebook, Instagram, Twitter) communications. Invitees were advised that live captioning would be available, and AUSLAN interpretation on request.

For those unable to make it to a live session, EAC provided a feedback form on its website. 116 people submitted feedback forms in addition to the 141 Forum attendees.

4. Forum attendance

Every session was attended by an EAC facilitator, an administrator from AFDO, live captioners (with other accessibility needs requested on registration such as Auslan, etc.) and at least one representative from the NDIS Review Panel Secretariat representative. The secretariat representative introduced themselves and their role to attendees.

Attendees registered for sessions via Eventbrite, with 30 spaces available per session, and attended sessions over Zoom. Attendees were encouraged to turn on their cameras and efforts were made to encourage every attendee to speak. Attendees were also able to add comments to the chat thread and were directed to NDIS review and EAC websites to submit any further feedback after the live session.

5. Representation

The 141 Forum attendees had a wide variety of lived experiences with disability, including people with intellectual and/or physical disabilities, carers for people with disability, and people who were both carers for people with disability and had a disability themselves.

There were also a couple of attendees who were not currently on the NDIS but thought that they ought to be.

Throughout this report 'attendee' is used to refer to those who attended the sessions, who may or may not themselves be participants in the NDIS.

- Approximately 79% of attendees were women, possibly reflecting the fact that women are more likely to be carers and more likely generally to attend feedback sessions.
- An estimated 16% of attendees were from a CALD background.
- 47% of attendees were from rural and regional areas.

6. Facilitators

All facilitators were people with disability.

Dr George Taleporos is a member of the Independent Advisory Council for the NDIS and the Independent Chair of Every Australian Counts. Dr George is also a NDIS participant.

Kirra Blanca-Jackson, Australian Federation of Disability Organisations (AFDO) - Project Officer

Carl Thompson is a wheelchair-using NDIS participant and disability advocate who runs 'Sort Your Support', a NDIS support coordination business. Carl is also a NDIS participant.

7. Captioning and AUSLAN

All sessions featured live captioning so attendees could follow the discussion aurally and/or in writing. AUSLAN interpretation was made available on request from participants. We released the AUSLAN interpreters each session, once checking with attendees and it became clear that their services were not required.

Themes raised in forums.

1. Safe and chosen places to live, now and into the future (housing and living, quality, safeguards, choices)

1.1 Waste, costs & burden of reporting

- Several attendees mentioned being offered housing that was inappropriate for their needs, despite submitting long and detailed reports with advice from expert service providers.
- There was frustration at the time and effort being put into housing applications that appeared not to have been read or followed, and which then caused more work for participants and the NDIA via time consuming early reviews or appeals. Some attendees said planners had directly told them they don't read the reports.

"The current application template does not make it clear about who is to complete the form and a functional assessment is usually required alongside this form. Perhaps the form could be Part A -participant and/or plan nominee to complete and Part B - Allied Health Professional."

- Some attendees felt the assessors had cherry picked individual lines or phrases from expert reports to justify lower funding, rather than looking at the overall recommendation of the report.
- Attendees reported that no explanations were given where decisions were not in line with applications, making it difficult for them to know how to approach appeals or reviews. They were often left living in inappropriate or even unsafe accommodation for years while waiting for a resolution.
- Attendees reported living with uncertainty and in unsuitable and at times unsafe accommodation for months or years while waiting for a resolution to their application.
- Housing modification applications can take so long to process and approve that suppliers move on in between submitting an application and its approval. The effects of this are exacerbated in rural areas where services are more limited.

"Our OT - we haven't even submitted our application into our third year, and she's left...she's no longer doing home mods, too hard"

Suggested solutions – 1.1

- 1) NDIS should be involved from the beginning of the process with participants, not just at the end.
- 2) *“When any client is looking for a SIL accommodation or an SDA accommodation, the NDIS involvement in that process comes as a last stake, that we have found a provider, we have found a good SIL house, we have found SDA accommodation and then we go to NDIS and get a SIL approval and get an SDA approval. Why can it not be a collective process?”*
- 3) NDIS to establish greater cooperation with other agencies such as state housing departments.
- 4) Daily administrative support from relevant departments, including a direct phone number.
- 5) Shorter time frames for a NDIA Home and Living Decision
- 6) Letter / Email outlining why a decision has been made with a direct phone number for queries.
- 7) Regular audits on the spending of SIL and SDA, checking with the participants and/or family/nominee on how the payments for these are being utilised.
- 8) *“There is a lot of misuse in SIL/SDA because the majority of participants don't have parents or anyone else to speak for them.”*
- 9) Put 'transition' strongly into the ongoing conversation about living arrangements.

1.2 Lack of individualisation & choice, respect for individuals

- Attendees feel the importance of choice and individual needs and circumstances are not recognised sufficiently in SDA and SIL offers. For example, participants may want to live with family members or friends, who may or may not have disabilities of their own. Group housing with other residents selected solely due to their disability does not always appeal or suit. Choice and control for the participants is paramount.

“...[for] people with psychosocial, autism, other sorts of disabilities, the option is SIL and..not right for people with autism.

- Housing location is important for transport, work, and social reasons, but this was not always reflected in final decisions.

“The decision came back totally opposite to what we had asked for. I live in [city]. I asked for north side, where I work and where my...extended family are...We got south side.” [The attendee had MS and had submitted a 175-page report backing their SDA application]

- The generally tight housing market compounds availability issues.

- Supply and options are particularly tight in rural and remote areas, and attendees felt these additional challenges were not properly understood by LACs and planners.
- Some attendees felt that people with intellectual disabilities were being unfairly penalised:

"...in our experience there's an assumption that SDA eligible people with physical disability are treated as entitled to live alone but...SDA eligible people with intellectual disability are...constantly pushed towards congregate care and have to fight very hard for anything else."

- People trying to do things differently, in a way that works for the individual, report roadblocks in approvals and difficulties finding providers.

"There's some...[SDA-certified] building inspector...certified bods that will do new build self-owned, but nobody will touch refurbishment self-owned out of the entire list of accredited people, inspector people - assessors..."

- Attendees were concerned that the system doesn't support participants to stay in the family home, as they or their family carers age.

"...teenagers that have just turned into adults 18 and need greater 1 to 1 support...these children are being told you need to leave the family home because you're now 18 and an adult, so go into SDA to get that same 1 to 1 support or 1 to 3 support, whereas they could still be staying at home with their parents where they want to be but the NDIA won't fund the support. It's either parental responsibility and your parents look after you or now that you've turned 18, go to SDA, and it shouldn't be that way".

Suggested solutions – 1.2.

- 1) Some attendees would like to see SIL or SDA housing, as well as a broader range of possibilities, offered to all NDIS participants.
 - a. *"...the categories [e.g., Robust, Fully Accessible, Improved Liveability] are too rigid. The funding should be targeted at the needs the individual has, not a rigid category which may not provide all features required."*
- 2) A wider range of options for a wider range of people. Particularly ILO and home modifications to allow people with disabilities to remain in their own home or the family home.
 - a. *"Granting more people ILO arrangements will save the NDIS long-term. It's cheaper to pay a host family a stipend amount per week to support someone than to pay for the same amount in drop-in support from disability support workers. Anyone who needs daily support should be eligible not just those who*

need more than 6 hours per day. They could fund it pro rata...Encouraging people with disabilities to board with families/normal share houses would also have 2 benefits – inclusion in the community and creating a short-term solution to the housing shortage.”

- 3) Offering more single occupancy accommodation options.
- 4) Some attendees wanted to see village like housing developments:
 - a. *“...similar to over-50s resorts, where facilities are available on-site as well as services e.g., physio, OT, hydro, podiatry, community dining room, recreation facilities...Everyone should be able to choose to participate socially or not, choose their staff, be it independent or agency...”*
- 5) Flexibility and supporting an individual’s need and preferences should be the primary consideration.
- 6) The NDIS should maintain a team responsible for home modifications state-wide, that could support planning, application, and execution.
- 7) Ensure that every person in the home has a say in how it’s run and not be made to fit in with the carers schedule.
- 8) Ensure sufficient staff so that participant can choose not to join in or must attend another participant doctors or other appointment.
- 9) Widen the appropriate building and design categories in the current legislation, especially for rural areas. For instance, for acreage there’s only one option that really doesn’t suit everyone.

1.3 Good provision changes lives & saves money.

- Suitable accommodation provision supports participants to live full lives, including attending work, maintaining, and building family and social bonds, and participating in their community.
- Some attendees reported trying unsuccessfully for years to get independent housing for their child or themselves, and finally succeeding thanks to the NDIS funding.

“I’m a happy person who moved out of a nursing home and I’ll be forever grateful and if they undermine in any way the ability for someone else to do a similar thing, to move out of home, to live a life that’s great, I think that would be a very sad thing”.

1.4 Communication & transparency, accountability

- There was scepticism around the quality of services when the housing and services are both provided by the same business. Many found this consumed most of the NDI'S funding and the benefits and expenditure are very opaque. Many felt this was also a conflict of interest.

"...of course, the SIL/SDA group home has been a great money spinner for providers with no oversight of the huge conflicts of interests."

- Some reported that funding and expenditure through SILs is so opaque that people can't figure out how to access and spend allocated funds.

"Quality and Safeguarding have not responded to my request to investigate why [name] cannot use the funds he was allocated. This is not only non-compliance, but fraud. Why is there no clear avenue for me to follow this up...?"

Suggested solutions - 1.3 & 1.4

- 1) Ensure participant to support worker ratios are adequate.
- 2) Provide modifications to ensure participant and worker safety.
- 3) Ensure providers provide a safe and appropriate living arrangement.
- 4) Regular independent reviews
- 5) Accreditation

1.5 Training & experience, humanisation & empathy

- Many attendees felt SIL employers have a profit focus at odds with skilling a workforce to best care for people with a disability.

Suggested solutions – 1.5

- 1) More training for staff. They should be paid to attend training to incentivise the casualised workforce to participate.
- 2) Let participants choose their own overnight supports.
 - i. *"This doesn't make me feel safe and comfortable."*
- 3) Recognise a sense of urgency and the disruption delayed decision making has on participants' lives.
- 4) SIL staff should be allowed to accompany residents to hospital as required in case of an emergency.

2. Access, planning, reasonable and necessary supports

2.1 Waste, costs, & burden of reporting

- The cost and waste of reporting requirements was one of the most strongly and consistently reported issues by participants. Reports are time consuming, expensive, and often emotionally taxing to compile. On top of this, many attendees reported that final plans are so at variance with the reported needs, that they suspect the reports have not been read, and/or that the planner did not have the appropriate knowledge to interpret and apply the information in the reports. This theme also connects to concern regarding the training and experience of delegates and assessors, who may not understand the reports or how a participant needs, and funding correspond.

“Often...whoever is applying exercise extraordinary due diligence, they do all the right things, get all the reports put together, the necessary paperwork, letters or whatever else, and then people - it can become apparent that the people that make the decisions...either don't read it fully, don't ask questions about it if there's something that needs to be clarified, or don't read it at all.”

- There were also reports of plans being reviewed and updated with no input from the participant:

“In applying for the scooter through my OT, unbeknown to me, my whole plan was redone without any input from myself and then it was presented to me. Now, in redoing my plan, which had been approved to 26, my new plan is \$22,500 short in physio that I desperately need.”

- These burdens are increased in rural and regional areas where services are limited and often have long waiting lists.

“Being in a rural area, there are long waiting lists and often poorly trained...therapist[s] who do not deal well with a person with complex needs.”

- Where requests are rejected, there's often no reason given, so participants don't know what they need to address, or whether the assessor has overlooked something,

"...substantial investment at this point can create big savings later, so if you get that right and invest in the education and I would say recruitment and retention of good people to act in those critical roles."

- Attendees reported being given inconsistent advice about whether plans will roll over or not, resulting in waste or confusion. For instance, some procured reports after being told their plan would be reviewed, only for their plan to then be rolled over.
- Planning and review processes are stressful and can even exacerbate disability.

"The system is incredibly disabling to deal with".

Suggested solutions – 2.1

- 1) Allow plans to last longer than a year.
- 2) Reduced reporting requirements where relevant, for instance, where a participant has a lifelong disability that is unlikely to change, or to change along a fairly predictable path.
 - a. *"The people that I care for have lifelong disabilities and I'm being asked to prove that they have lifelong disabilities every time there's a review. It's an absolute waste of money because we already know that they're lifelong...not only that...to go through that process of all those different assessments and what not, it's really demoralising for them, it's cruel."*
- 3) Look for universal design solutions rather than disability-specific solutions – these are likely to be more widely available and less expensive.
- 4) Where more than one family member is a NDIS participant, they should have the same planner and consistent review dates.
 - a. *"These families need a specialist team to review the whole family plans together with an overview & understanding of what the whole family needs."*

2.2 Lack of individualisation & choice, respect for individuals

- The system still feels precarious to many participants. A number of people spoke of the fear, anxiety and stress caused by annual reporting, media and political narratives around the expense of the system and fraud by participants.

"We are human, we are people, but we're not respected with it. I am a person with a disability."

- Some attendees spoke about difficulty getting on to the NDIS because their diagnosis was ineligible, or not a 'primary disability' when the focus should be on functional capacity.

Suggested solutions – 2.2

- 1) Should be able to talk to the NDIS and make small tweaks and updates to the plan as things change, rather than having a whole review process to make a small change.
- 2) Focus on a person's functional capacity rather than their diagnosis.

2.3 Availability of care, role of families & informal carers, State Government, and other agencies

- Parents worry about who will gather the information required for the reports when they are no longer able to do so. Who else will be motivated to fight so hard for their child in a system that seems not to be working in their favour?

Suggested solutions – 2.3

- 1) Provide participants with advocates or case managers.
- 2) Focus on supporting individuals rather than barring access.

2.4 Good provision changes lives & saves money.

- One participant reported that the NDIS has meant his children don't need to be his carers. It's given his children their childhood back.

"It is an emotional subject and matter for us. The NDIS really matters for this impact it has."

"The NDIS costs a lot of money. But it is well worth it. Analysis of the issue shows that investing money pays off. Every \$1 invested in the NDIS, the GDP goes up by \$2.25. Plus, so much benefit for community, individuals etc. It's a lazy trope that it's costing too much money. How can we tackle that narrative in the media and from politicians."

2.5 Communication & transparency, accountability

- There was a lack of common understanding on whether, where and how attendees were able to access their approved plan documents. Some people said they get hard copies of the plan, some said they didn't. Some feel they are meant to access it online, but they don't know how.
- A number of attendees reported that the complexity of the online portals is too challenging for some people with disability and their careers.
- There was a feeling that which planner you get makes a big difference to outcomes.
- Attendees want to see and comment on draft plans.
- Many recounted discussing the plan and their needs with one person (eg an LAC), then the notes were given to a planner and the final approved plan was not in line with the discussion nor the participants' needs.
- They have no way of contacting the assessor to ask questions or provide supplementary information.
- Attendees would like to see the NDIS proactively seeking clarity or ask for missing information before making a final decision:

"I feel a lot of the administration kind of responsibility is passed on to me. So, the ability [for the NDIS] to request specific forms, specific assessments, would be great."

- Once a plan has been delivered, if it contains errors, participants' options are to accept an inappropriate plan and request an early review to address any issues, or to go through a lengthy, opaque and costly appeals process. The former path is often advised as the easier path, but many participants feel they shouldn't accept an erroneous or inappropriate plan.

"It's no way for a responsive organisation to operate."

- There were also many examples of poor communication within the system, often resulting in more waste:

"Our own personal experience was the LAC rang us, said go and get all these reports. We got those reports. Then I get a letter in the mail saying, "Your plan has been rolled over", so there was no communication between the LAC and planner."

- Some CALD attendees felt racism and prejudgements based on their English-language capacity affected their outcomes, and some single parents likewise felt their status adversely affected their outcomes.

Suggested solutions - 2.4 & 2.5

- 1) The person with whom participants discusses their needs should also be the person making the decision.
- 2) There should be a cooperative and ongoing exchange of information in the planning and drafting stages.
- 3) Allow planners to ask specific questions or provide specific feedback on what is missing or unclear.
 - *"You can't make a decision if you don't have a relationship with someone."*
- 4) Decisions taking so long can lead to risk and poor care, especially if circumstances have changed rapidly or significantly.
- 5) Allow participants to see what material has been provided to a delegate without requiring a lengthy FOI request.
- 6) Consistent criteria for decision making.

2.6 Training, experience & empathy

- There was a general feeling that staff seemed not to have the expertise needed to complete and review plans:

"You are sort of left in the dark when you're doing all these plans and reviews and you're talking to people that don't understand intellectual impairment, always repeating yourself."
- Attendees felt that participants with multiple disabilities were not well understood by the NDIS.

Suggested solutions – 2.6

- 1) Attendees felt NDIS staff need training in disability.
- 2) Ideally staff would also have lived experience of disability themselves or with a close friend or family member.
- 3) General life experience and empathy were also seen as important assets, and a recognition that this is a human and emotional process.
- 4) Attendees understood that staff cannot be experts in all conditions but suggested that a stronger knowledge of the range of disability, backed by an expert reference group for LACs and planners that staff can consult, might be beneficial.

- 5) Focus on functional impairment, not the diagnosis.
 - *"...even [to] ask a family "what's your child's diagnosis" when it's a functional capacity needs-based scheme is insulting. Only 30 to 50% of families will get a diagnosis for their child's genetic condition".*
- 6) Training in supporting skills such as co-decision making, trauma-informed practice (many people with disability will experience trauma in their lives) and mental health first aid.

2.7 Reasonable & necessary supports

- The long waiting times for work to be approved introduce waste and safety risks. One respondent reported spending lots of funds on rental beds while waiting for approval to replace, rather than attempt to fix, an old and broken bed which was repeatedly fixed but kept breaking.
- One attendee felt that in order to receive support to stay in employment, she had to make herself sound incapable, and had to prove every year that she couldn't do tasks to ensure she kept her funding.
- The same attendee reported that she must retain a DES provider in order to continue to receive NDIS employment support funding. They never hear from the DES and can't see that they do anything.

Suggested solutions – 2.7

- 1) Streamlining the installation of common aids such as safety rails, ramps, assistive technology would save time, money, and injuries.
 - *"...it took many months to get a handrail installed next to my steps by the time an OT assessed the risk, prepared her report and sourced quotes; and yet I still had to traverse the steps several times a day which was extremely anxiety inducing."*
- 2) Listen to participants and reduce red tape for requested supports.
- 3) Funding for finding and staying in employment needs to stay in the NDIS, not go to the DPS.
- 4) Funding for employment support should be protected and not up for review so you have the security ongoing.
- 5) Drop requirement to have a DPS provider.

2.8 Lack of individualisation & choice, respect for individuals

- Attendees reported that being left short of funding while lengthy reviews and reporting were being undertaken was stressful and left participants in a precarious position.

"Instead of totally abandoning people with disabilities, there should be some sort of... review fund pot or something that money is drawn from to maintain a certain level of support for people with disabilities when their funding is depleted, before the end of their term."

- Some reported that to be seen as eligible, you needed to prove reliance on services and/or equipment in the past.

2.9 Availability of care, role of families & informal carers, state government and other agencies

- Responsibility for expenditure can be unclear, resulting in gaps that can have big impacts:

"...NDIS refused to fund gloves because they said it should be provided by the staff or the provider. Now, my staff would lose over \$100 in their short shifts if they provided gloves because of the amount of gloves we all wear and that's not what they want to do. Why would they do that when they can go elsewhere and get another job that they don't need to wear gloves and, you know, be funded - be funded to support someone that's not complex. So that's one story about the ridiculousness of NDIS not funding gloves."

Suggested solutions - 2.8 & 2.9

- 1) Allow flexibility in the budget for people to use their budget in whatever way is needed without always tying it to disability. For instance, if a child needs 24/7 support, the parent might not be able to do the garden due to caring commitments, and so want to pay someone to do the garden instead.

2.10 Communication & transparency, accountability

- Attendees reported that you have to know the legislation intimately and use exactly the right words to prove something is a reasonable and necessary support.
- Inconsistent advice on status of requests and plans from different people in the system.
- Some found planners were using a duplication of support rationale to deny funding requests when they weren't duplicated.

2.11 Training & experience, humanisation & empathy

- Some feel they are now discouraged from using their funding to support fun and social events. The political and media narrative around waste makes them feel targeted. But people with disabilities don't use these funds wastefully:

"I love my support workers, they're amazing, but who wants a support worker around when you don't need them, you know? Who wants to go to occupational therapy when you don't need it? I just feel like there's this culture that we're all using supports that we don't need, and it really needs to change."

- People with disabilities have a huge stake in the efficient functioning of the NDIS.

"...ministers come and go, organisations come and go, you can always get another job, but like I've always been disabled...So if the NDIS collapses in a pile, it doesn't matter, they can go and get some cushy retirement, but we're the ones at the end of the day who are still here...I'd love there to be this culture where there's an attitude that as people with disability of all levels of capacity, all levels of decision making ability, we really own the NDIS, that we own our individual packages, but also that we own this system, that we feel a sense of pride and ownership in what's going on and in the supports that we're getting."

- Some attendees reporting feeling shamed or judged for their requests.

"I've seen...planners unintentionally shaming people for requesting supports and then that stops them from then asking them in the future...I just think there's a real lack of understanding about what it takes for people to ask for help".

"Best practice for neurodivergent people should be standard. Co-decision making should be standard. People needing accommodations and getting truly customised care should be standard."

Suggested solutions – 2.10 & 2.11

- 1) More people with disability working within the NDIS, NDIA and service providers, on boards of organisation. Also, better UX and plain English on the website and other resources.
 - *"We need more of an attitude of things at every level of NDIS being for all disabled people."*
- 2) A number of attendees mentioned they'd like to see ongoing community forums like these runs by EAC to encourage ongoing input and ownership by people with disabilities and their carers.

3. Capacity building

3.1 Waste, costs & burden of reporting

- Endlessly reporting and fighting to achieve and maintain basic requirements means a focus on goals and capacity building is lost.

"I had thought one of the fundamental reasons for the NDIS is to support people to become a contributing, working, tax paying member of society - so why make it hard for people to get into & keep work".

Suggested solutions – 3.1

- 1) Instead of focusing on what people spent their money on compared to budget, the NDIA should focus on how the funding is improving the lives of participants and others in the community.

3.2 Lack of individualisation & choice, respect for individuals

- Attendees felt goals needed to be important and specific for the person, measurable, realistic, and maintained.

"People with disabilities should be able to develop their own plan that works for them.

- There was a general mood against what attendees felt was a systemic bias towards group and disability-specific activities.

"I found that the LACs kept pushing my daughter to just do disability group programs... The whole point of the NDIA was for people to be out in the community and part of the world and I'm pushing very hard for that for my daughter to broaden her world and God forbid that I ask for support for her to attend mainstream and community activities or education or employment or any of those supports."

Suggested solutions 3.2

- 1) Focus on supporting people with a disability to live a full life according to their own needs and interests.
 - a. *"We need a community that doesn't just look at us as our NDIS packages, but that provides mainstream supports for everyone, including making it inclusive for people with disabilities."*
 - b. *"If the point of the NDIS is to make a real difference in people's lives, where they are awarded dignity and opportunity, then the only way to genuinely achieve this is by backing the people who know best - the individuals living their lives with a disability."*
- 2) Focus on strengths not just limitations.

- 3) Specific and targeted support for employment and careers, not just social enterprise
- 4) Listen to participants who know what works for them in building capacity.
- 5) Flexibility to use funds to support a variety of goals, for instance to establish a micro enterprise and thus self-employment.
- 6) Client portal listing goals, actions, and outcomes, for individual tracking by participants. Aggregated, anonymised data could be shared with the NDIS to demonstrate outcomes vs expenditure. (This should not be mandatory).
- 7) Support participants to build their capacity around thinking and planning for what they want to achieve them longer term.
 - a. *"It's not just about getting the funding. It's what the funding is going to be used for...that planning process isn't just an hour meeting with a planner once a year or whatever providing, you know, a zillion functional capacity assessment. It's a actually a deeper conversation that might need to occur with somebody either independent of the NDIS or an LAC..."*

3.3 Availability of care, role of families & informal carers, state government and other agencies

- Attendees felt that the states had given over their disability work to the NDIS, and likewise other agencies, such as Carers Gateway, hear 'disability' and defer the question to the NDIS, or closed down following its introduction.

"Partners in Recovery is the best. Keeps people from becoming homeless- they stopped it when the NDIS came in. PIR was supposed to be replaced by other supports but didn't happen."

- Some attendees called for a return of state-funded drop-in centres for training and job support.

"...they used to provide food sometimes...they'd negotiate with job service providers and Centrelink...they used to organise bus tickets and transport. Like pretty much - not quite no questions asked, but it wasn't - you know, like you didn't have to go to a doctor and prove something".

- Likewise, frustration at educational supports not being provided due to the NDIS not funding educational supports, and the Department of Education refusing to fund disability supports.

"Supporting education for children, educational therapy for children, in the long run will probably save a lot of money and is so much better for them."

- Businesses and other organisations also need to step up and improve their employment and engagement practices.

3.4 Good provision changes lives & saves money.

"...what's working well for us with the NDIS is being able to build my daughter's capacity. She's walking with her support worker, a dog, we never thought she'd do that."

"Nobody, including the taxpayer, is well served by a half-baked NDIS with a focus on "limiting costs". The focus and narrative should be on the benefits provided to all Australians by supporting people with a disability – less burden on our education system, our health system, our care system and so much more. I have seen so much growth in my son thanks to the amazing work of his speech and occupational therapists. He has gone from not being able to talk at all, to a young boy who participates in school, enjoys sport and has lots of friends. This is great for him and us of course – but it's also good for his teacher, the other kids in his class, his future employer and ultimately the taxpayer. My son is one of so many who benefit from support like this. Added up, the return on the NDIS investment is incredibly positive- a return that in financial terms far outweighs the cost, to say nothing of the human impact. The government should be using language like "investment" and "impact" when it comes to the NDIS, in the same way we invest in education and vital infrastructure."

3.5 Communication & transparency, accountability

- Many reported that in order to get the funding you need to know the language, and that this isn't a fair way to operate.

"We actually managed to get the funding for some...functional numeracy support because as the years go by, we kind of became NDIS smarter and we kind of know what words to use and not to use"

Suggested solutions - 3.4 & 3.5

- 1) Understanding that someone may be presenting well because of the support they are getting – doesn't mean they don't require ongoing support. Consideration needs to be given to the current moment, but also the pathway to the future and what capacity will be required then.
- 2) When money isn't being spent from an individual's plan, the NDIS should check in to see if that person requires assistance navigating the system. Some might also need assistance making sure service providers are using funds appropriately.
- 3) Where multiple family members have plans, have one LAC/planner doing all, looking at the needs holistically and aligning dates where possible to reduce complexity for people.

- 4) Consistency for all is paramount it shouldn't depend on the quality or quantity of the reports to get the Reasonable & Necessary Supports & Services

4. Navigators

4.1 Lack of individualisation & choice, respect for individuals

- Needs to be better safeguards and supported decision-making for people with communication difficulties or significant disability.

Suggested solutions - 4.1

- 1) Listen to the recipient and their carers about actual needs.
 - a. *"A solution to the issue I raised about barriers in NDIA in implementing innovation is to have a designated NDIA team/contact to navigate innovation implementation. And for complex issues there needs to be timely access to the right people in NDIA to resolve more complex issues (particularly for people with very high intensity needs) as the 1800 Call Centre is totally useless for anything but the most basic things"*
- 2) Make the applications for NDIS support more user friendly.
- 3) Make the NDIS form paperwork that providers and NDIS participants fill out easier to read and process.
- 4) Don't force NDIS participants to go to the tribunal if additional support for funding is rejected, find another easier way that is easier to process and navigate.
- 5) NDIS participants require an advocate who can help understand their rights, communicate with housing providers, and resolve any disputes or complaints that may arise. At the moment this role is often undertaken by family members, but this is not always possible and requires a lot from the family member.

4.2 Availability of care, role of families & informal carers, state government and other agencies

- A number of attendees were the parents of children with a disability, who were concerned about their child's future with the NDIS once the parent would no longer be able to support them. Beyond the difficult tasks of navigating the system, completing paperwork, checking bills etc, someone needs to understand what it actually is that the NDIS participant needs/wants and how to meet those needs and wants. Where will the understanding, advocacy and empathy come from once the parents are no longer able to provide it?

"It is every carer's worst nightmare who is going to advocate for our kids when we are not around. the real emotional toll taken by problems and failings in the systems, and the real risks to being physical and mental health".

"Who's going to argue, who's going to rejustify every year for my son if I'm not here to do this?"

- GPs are time poor often don't understand the NDIS well. They will assume that if somebody has a disability, the NDIS will accept them.
- Likewise, many therapists don't understand what the NDIS needs in reports.

Suggested solutions – 4.2

- 1) Provide advocates and funded case management.
- 2) Listen to parents and carers.

4.3 Communication & transparency, accountability

"...basically, NDIS doesn't do what it's supposed to do. It's very reckless, it's tortuous, it's - I've heard the word Kafkaesque, going around in circles, like somebody else said about punitive, like with the Centrelink systems, like they'd punish you for no reason other than you have a disability or you're poor."

- Parents go to extraordinary lengths to fill gaps in communications between providers and staff. One parent created an app to ensure good continuity of care across shifts.

"I've actually now designed an application to help my daughter - all the notes be captured every shift. The support workers are just entering - going to be entering - notes about what did they do, did they help to meet her goals overall, any issues or challenges and any achievements that she had during that shift, so that as she has different support workers over the years, I start to accumulate a library of how she's progressing...we want the client to be at the centre and not the businesses at the centre"

- Some attendees are very tech savvy, other are not. English-language skills also varied widely.
- One parent with a disability with a son on the NDIS reported frustration that people they communicated with could not understand that neither she nor her son had the cognitive ability to use MyGov:

"...My son's S100 review dropped on the XXth of [date]. 28 days has passed. We've been ringing and emailing and asking for a copy of his S100 because we wanted to go to the AAT and we no longer can. We still don't have a copy of it...I don't even have NDIS, I don't want it, because it's too hard to think of two plans in the family."

- Changes are so frequent it's hard to keep up.

"I feel like we need a book of acronyms, or a book of terms and we can look it up and it can say oh, yeah, no, that's a review of a reviewable decision, this is change of circumstances, what that means, what you might want to prepare."

Suggested solutions – 4.3

- 1) Clarification of the NDI system and laws in several languages through brochures and courses.
- 2) Providing a hotline that can give callers useful and accurate answers to their inquiries.
- 3) Providing a hotline that receives complaints immediately and deals with them without delay or many transfers.
- 4) Equip both hotlines with interpreters and a call back service that is followed up.
- 5) Provide a range of avenues for communication and a consistent contact person:
 - a. *"...give people an address, email address, make it really clear on how they can advocate for change".*
- 6) The NDIA needs to be able to speak to all participants across all levels, meeting them where they are instead of expecting participants to become fluent in NDIS speak.
 - a. *"So, I actually went in to talk to an LAC in person because I've never dealt with an organisation that doesn't provide an in-person experience or at least talking to them over the phone, but everything is online and email, so they don't have to take responsibility or accountability for giving the information, as far as I can tell."*

5. Services, quality, outcomes (markets and providers)

5.1 Waste, costs & burden of reporting

- Attendees reported frustration at not always being allowed to see invoices. When they do they report regularly finding errors, fraud and/or invoicing for work or products that have not been satisfactorily supplied, which only the participant or their advocate is likely to know.

"...if mistakes are made and the plan managers have paid, we pay it back, not the providers. We are seen as making the mistake."

- Some attendees reported providers encouraging them to engage in fraud.

"[I] put a complaint in against the LAC we had at the time for telling us to commit fraud. So, my son was given \$23,000 in SLES funding last year. We said, "We never asked for it, he's not a school leaver, he has his own business", and she said, "Well, what you do is you use those line numbers, and you allocate them to other invoices and providers" and we said, "That's fraud"."

- NDIS rates were felt to be unnecessarily high and pushing up expectations for rates in given areas. Many reported seeing one rate quoted for 'regular' customers, and another, much higher, rate for people with NDIS funding – a 'disability tax'. This affects not just disability professionals but also domestic support services. For instance, one attendee recalled a provider who had been charging \$85 an hour raising their rate to \$135 an hour when they realised the NDIS were involved.

"Prior to the NDIS, when participants or people, family members were under the DHHS with an ISP, they engaged therapists and they were charging something like \$100 an hour and now that it's the NDIA, it's suddenly increased to \$200 an hour."

- Attendees also felt that travel for providers was unnecessarily expensive, particularly travel to regional areas, for participants and providers.

"...therapists charge 200 bucks...an hour just for travelling to the service, which is probably not so relevant in the cities, but in rural and regional areas, remote areas, it chews up a lot of the funding "

- There was scepticism about the idea of preferred providers, as many worry these will be the big providers, whereas some have had better experiences with small and boutique providers.
- Widespread sense that provider admin, management and bureaucracy eat up a lot of the funding, particularly in the larger providers.

Suggested solutions – 5.1

- 1) Self-management and employing plan managers were seen as time consuming but ultimately worthwhile, providing much better value for the funding money.
- 2) Many felt that directly managing support workers led to better and more stable relationships between carers and participants. This takes a lot of work from families however, and attendees recommended that the NDIS establish some shared supporting resources.
 - a. *“The self-manager hub is brilliant for a lot of that, but it would be great to have resources and some development for participants and self-managers to learn how to do this stuff. I know there's a lot of resources from Western Australia as well.”*
- 3) Funded case management and support. This is beyond capacity building to make sure someone is there to continue to support and help a participant as their life situation may change.
 - a. *“Allow participants to access providers of consumables outside the registered ones. Nitrile gloves at \$24 per 100 at a registered provider as against \$8.95 per 200 elsewhere (Medical Grade). Hoist battery for \$600 through Registered provider against \$246 aftermarket.”*
- 4) Caps on transport costs.
 - a. *“The recent change to transport fees when using a support worker's own car is fine within a typical day's support running errands, appointments and shopping at \$1/km but after say 30 km it should then go down in price per km or is an outrageous cost for a day trip or long-distance travel.”*
- 5) Active monitoring for fraud.

5.2 Lack of individualisation & choice, respect for individuals

- Many attendees were frustrated by the restrictions on employing family members as carers. For instance, one attendee asked for her mum to be a support worker as she had been sexually assaulted and didn't feel safe with strangers but told she can't employ a family member or friend.
- Not allowing family and friends as support workers also affects privacy - e.g. taking someone to a birthday party, would rather that be a carer/family member/friend, rather than an outside carer.
- Attendees felt the challenges of transport in regional and rural areas were not well understood. Many don't have access to public transport and very limited taxi options.
- Some services seem to be less about supporting the person with disability to live their life and achieve goals, but more about the business.

Suggested solutions – 5.2

- 1) Allow participants more discretion in hiring and expenditure.
 - a. *"I would like to see the funding where I can hire someone, they don't even know I'm on the NDIS, I can pay their invoice and seek reimbursement, or I can pay it out of a fund that I have access to."*

5.3 Availability of care, role of families & informal carers, state government and other agencies

- Provider shortages were widely reported and particularly bad in regional and rural areas.
- At times the only service providers were the same person as, or worked in the same agency as, service coordinators or LACs. This meant the service provider could not be engaged due to a conflict of interest.
- In other cases, service providers have been employed in such circumstances, resulting in a conflict of interest.
- Some reported that where the LAC and/or planner was not located in the same area as the participant, the LAC or planner failed to appreciate the realities of service delivery in the area.
- Attendees reported that a number of state or community organisations had stopped offering services with the introduction of the NDIS.

- Many felt that the expectations of levels of family support were unrealistic, especially as parents age. One carer reported requesting six weeks of support care to recover from surgery, as recommended by the hospital. The NDIA denied this and offered four weeks instead.

Suggest solutions – 5.3

- 2) The NDIS needs to engage with and communicate better with rural and regional services and people to understand the reality of life in a given area.
- 3) Direction-the-ground oversight of service providers.
- 4) Family members should be allowed to be paid carers.
- 5) NDIS and disability services need to link better.
- 6) Some recommended that genetic counsellors be added as allied health professionals.
- 7) Maintain services beyond the NDIS.
- 8) Establish a 'service of last resort' problem-solving function managed in the NDIA, for self-managers as well as group homes.
- 9) Caring for people with disabilities and navigating the system advocating for them can be taxing, particularly for ageing parents. Recognising this and supporting family members with carers payments and facilitated planning sessions and acknowledging these family members as experts in the care and support of their loved ones.
 - a. *"Practically a full-time job."*
- 10) Establish supported decision-making that enlists the services of independent complex communication experts able to work with persons with cognitive disabilities to ensure their voice is actually heard. Abuse and misuse of guardianship authority is rife in Australia.
- 11) Educate parents and carers in how to use the NDIS.

5.4 Good provision changes lives & saves money.

- Attitudes to support coordinators (SCs) varied widely. Some reported that their SC provided no support and seemed only interested in money. Others found their SC invaluable:

"A great Support Coordinator is GOLD."

"Everyone having the option of a support coordinator and providing ADEQUATE funding for this (my latest plan only included 18 hours per year- hardly enough to ensure quality and safety). The option for support coordination should be tick the box like the options for plan management"

- Many reported services and equipment provision, sometimes for small items, that had a big impact on their lives.

"I have a watch that calls people if I have a hard fall. This has happened twice, and I am so grateful for that device. I could not have paid for it pre-NDIS."

"The NDIS has changed my life for the better. I used to use all of my savings on disability services I paid for myself (speech therapy etc.). I couldn't afford a support worker before, instead I relied on charity from ladies at my church (resulting in feelings of guilt and shame). But now thanks to the NDIS I'm actually hopeful about getting a job in the near future. I just pray that the government doesn't kick me off the scheme before I've had an opportunity. I have so much to give to the community, I just hope the government doesn't give up on me."

"I am a daughter helping to support my father who is supported by the NDIS. We are located in rural area and are very lucky to be supported by amazing carers (organisation based). As the carer, I value carers who communicate Dad's needs with me but also demonstrate initiative to assist in his day to day living. They demonstrate respect towards both of us. And as Christine speaks - those carers have a genuine rapport with us."

5.5 Communication & transparency, accountability

- Some attendees reported frustration at being unable to spend allocated funds or support agreed goals because they couldn't access the relevant service providers or find the right people within the NDIA to liaise with around the item, even after years of trying.

"Being able to implement the kind of innovative approach that we have for him requires communicating with somebody in the SDA and we have a planner, we have an allocated planner who's this lovely woman and she cannot find in the organisation anybody in the NDIA to help us get through the barriers to implement this thing that we've got the funding for in his plan."

- There was frustration at the lack of clear complaints procedures.

"Biggest problem is the lack of integrity. There is no effective resolution process. The NDIA shut down complaints without addressing them. The NDIA doesn't ring back when it says it will, doesn't respond to complaints when it says it will."

- Some attendees reported abuse claims to the agency and not being taken seriously.

"We also always need to have someone to call - the 1800 number is terrible!!! Usually they are nice (though we've had one abusive call with someone who didn't know the legislation), however they often don't know the answer anyway? Having call centre staff that specialise in different areas might be an idea?"

- Some attendees reported that their confidentiality and privacy had been breached by service providers.
- Where no family is available to act as a plan nominee for the NDIS, a service provider may be selected as the plan nominee. Some felt this is a conflict of interest and should be prohibited.
- Service providers can sometimes avoid working with higher needs individuals, especially in rural areas where demand is high.

"NDIS refuse to give us specialist support coordination because he's so complex and typical support coordinators won't take him on because it's too complex - the plan is too high, that's the message I get. So, it's just ridiculous."

Suggested solutions – 5.4 & 5.5

- 1) Clear and quick complaints procedures.
 - a. *"...there was a critical incident with our severely disabled daughter in December. I made a complaint to the NDIA. It... could have been a fatal incident. I made a complaint...and went to the service, to the CEO. We asked for these two support workers to be removed and there was a blatant no, refusal. So I went to the NDIA, made a complaint there. They listened to me, they gave me a number. That was in December. I haven't heard a cooee...So, you know, I send an email saying, "When is the date for the review?" No response." [this comment was made in May]*
- 2) Support coordination should be independent to act as a safeguard in regard to plans, services and supports. Ensuring that they are on the participant's side, not on the business's side.

- 3) All documents from the NDIA, NDIS and service providers should be in plain language, work with screen readers and meet other accessibility standards.
- 4) Whistle-blower protection: workers shouldn't face cut shifts or unemployment for raising concerns.
- 5) Don't allow providers to decline care based on level of need. Potentially higher pay rates for working with people with complex needs.
 - a. *"Because we are in a thin market [in a rural area], our example of an SDA, supported disability accommodation, or a SIL, supported independent living, they won't take my son. [local providers] say, "He is too complex, and we have no staff available to support him."*
- 6) Employ specialist to deal with complex cases.
 - a. *"My solution is that we should have complex delegates that deal one on one with the situation and grant the funding, not going back between two or three people."*

5.6 Training & experience, humanisation & empathy

"I would like to see systems in place that puts the client, the disabled person, back to the centre of the NDIS. I've found that support agencies, support workers and all the people who help run our system tend to focus on their own business or their own needs and tend to forget the client."

- Many attendees wanted to see accreditation and monitoring of service providers and their performance. Accreditation status should be clear to participants.

"...the current SIL provider where my son is takes...about 75% of his DSP for board and lodging and you have no accountability for what food they provide, you can't see menu plans, they refuse to provide it."

"YES, I agree...we also employ staff with their own ABN for my son and I insist on all checks including First Aid and the NDIS Quality and Safeguard Support worker Modules to be completed"

"When you're working with a vulnerable participant, it's pretty important that you've got to have somebody who knows what they're doing."

- Others want the right to choose.

“disabled people still have the choice and ability to make decisions over their own lives, even if that might be a different decision that someone else might not make, and if we overregulate something, that might be taking people’s ability to have choice over who’s providing their support away and that’s the main, I suppose, issue that I have with that as a concept, of how can we ensure that people’s supports are quality and are not likely to be harmful to them, while still ensuring that people have the ability to make the choice over who’s best to support them and that might be the person they met down the road who works at Coles, or whatever, because, you know, they seem like a nice person and that might work really well for them.”

“One of the biggest things that concerns me at the moment is all the conversations happening around having mandatory checks and training for providers. I employ our own people and I would really like to continue doing that and I hate people who have had training because usually they come in and tell us how to live our life and we’ve always been treated very poorly by people who have been trained because they - it seems to be something in training that they feel like they have to come in and they’re the people to help you and I’m like I just need someone to do the dishes, like I’m living my life just fine, yeah.”

“I’m in regional and I’m very concerned about the proposal that all disability support workers have to have a qualification. In some regional communities...the pool to draw from is very small. Not only that, in rural and remote areas it’s very hard to get access to training.”

- A requirement for police checks was more widely supported.
- Restrictive practices caused some concern. Some felt that providers shirked responsibilities, such as keeping a room hygienic and clean, under the guise of avoiding restrictive practices. Others were concerned that the current model encouraged stakeholders to overlook restrictive practices to avoid reporting on them.
- Casual support staff are poorly trained and have little incentive to skill up.
- Participants reported that a lack of training and expertise from providers has resulted in some serious incidents, including child abuse and endangerment of life.

“The NDIA often just doesn’t do what it is supposed to do - reckless and has had some very serious outcomes including precipitating child abuse. - the fix - just do your job, comply with the Code of Conduct. Admit when a mistake is made and just fix it instead of trying to cover it up.”

Suggest solutions – 5.6

- 1) Make it mandatory to train staff to look out for signs of abuse or when the participants are acting out of character.
- 2) Train participants in safety. Do this on a regular basis and make it part of daily conversation.
- 3) Make sure staff are not alone in high-risk activities where abuse can occur.
- 4) Train staff to treat participants as equals and not pupils or children.
- 5) Train staff in acceptable language and to encourage participants.
- 6) Pay them to attend training.
- 7) Regular compliance visits and follow ups.
- 8) Better case management of 'high needs' clients
- 9) Make it easier to screen potential Support Workers.
- 10) Better training in how to work with CALD and indigenous participants.

6. Appendix 1: Forum Agenda

Contents

Page 1	Introduction
Page 2	Scene setting – about the independent NDIS Review What the Review has heard so far
Page 3	Discussion guide: topics and prompts
Page 5	Background information Consultation questions on the Review website now

Every Australian Counts virtual forums

- NDIS participants and families
- Small group discussions
- Facilitated by [Name]
- NDIS Review observer [Name] takes notes

Forums for everyone	Forums for people living in regional and rural areas
Tuesday 9 May, 11:30 am – 1 pm	Monday 22 May, 11:30 am – 1 pm
Thursday 11 May, 2 pm – 3:30 pm	Tuesday 23 May, 11:30 am – 1pm
Saturday 13 May, 2 pm – 3:30 pm	Thursday 25 May, 2 pm – 3:30 pm
Tuesday 16 May, 11:30am – 1 pm	Saturday 27 May, 11:30 am – 1pm
Wednesday 17 May, 11:30 am – 1 pm	
Wednesday 17 May, 7:30 pm – 9 pm	

EAC forum Tuesday 9/5/23

11:30am – 1:00pm, 1.5 hours total

Prior to session - EAC administrator

15 mins before session

- Admit captioners

Throughout

- Record session
- Admit and record attendees
- Monitor chat and message Facilitator directly on Zoom to flag any important comments/questions
- Note key issues for wrap up and send to Facilitator

Intro, Acknowledgement and housekeeping

0-20 mins

- Facilitator - Welcome to Country

- Facilitator - Introduction
 - Introduce self, EAC, and Independent NDIS Review panel secretariat team - they join us to listen to your feedback and may ask a few questions
 - Please note: In order to provide a confidential and safe space for all participants, we request that no NDIA, LAC or provider staff attend this forum, even if they identify as a person with a disability or family member.
 - Every Australian Counts are running the forum for the NDIS Review to understand what's working well, and what needs to change so that the NDIS works for you and your family.
 - This is a dedicated rural and regional forum to make sure your voices and concerns are heard too.
 - Reminder that sessions will be recorded for note-taking purposes.
 - The information that you share with the group today will be used in written reports to the review and to the government but you and/or the person that you support will not be identified.
 - I will now hand over to the NDIS review for some background.
- NDIS Review observer - Outline broader purpose of sessions
 - Independent Review of the NDIS was set up by the government in October last year to recommend improvements to how the NDIS works so people with disability and their families can get the supports they need to live good lives, participate actively in community and progress their dreams and goals. Report and recommendations to all governments in October this year.
 - We encourage you to share your views and experiences so that you can help shape improvements to the NDIS.
 - NDIS Review Panel is independent, not linked to NDIA in any way. The NDIA is not included in this session, and no information will be shared with the NDIA. This is a safe place.
 - Panel consists of seven members who:
 - have a disability, or
 - are close family members of people with disability or
 - have strong professional and personal links to people with disability, including people from the autistic community and people with mental health conditions.
 - Panel is led by co-chairs Bruce Bonyhady and Lisa Paul. Bruce helped build the NDIS. Other panel members are Dougie Herd and Kevin Cox, Kirsten Deane, Judy Brewster and Stephen King.
 - Panel is supported by a team of policy and engagement professionals, some of them have a disability or are close family members of disabled people.

NDIS Review observer - What Review has heard so far

- Review has asked for and received more than 1,000 submissions and had hundreds of conversations with people with disability, their families and carers, disability and carer representative organisations, community groups, disability service providers and others.

- Important to Review panel to hear feedback from people with lived experience of disability and their families. This is what we mean when we say people with disability at the heart of Review.
- Review panel has asked EAC to hold safe conversations so Review can understand your views on:
 - home and living supports you or your family member need
 - what you or your family need to feel safe and secure in your home in the community and elsewhere and
 - what information you think NDIS needs to know to make decisions about your plan funding
- These are the focus areas for today's discussion. If you have other issues you want to bring up that's completely fine – the NDIS Review panel want to hear all your feedback about why things don't work well for you now
- In particular the NDIS Review panel really wants to hear from you about **solutions** – what you think needs to change so the NDIS works well. We have heard a lot about the problems over the last couple of months – what we really want to focus on now is what would fix those problems.
- The Review panel wants their recommendations to be as practical as possible – so they want to know what you think would work

Facilitator - Let's Begin

- I will briefly introduce each topic and then there'll be time for a discussion
- What is the most important thing that you want the NDIS Review to know?
- If you raise a problem, please share with us your ideas on how to solve the problem
- If you want to speak, raise your hand and keep it short enough to allow time for everyone to have a say
- Use chat to make additional points as necessary
- Live captioning

DISCUSSION GUIDE

20-80 mins

Topics and prompts to facilitate discussion

Prompts to guide discussion – Facilitator to use as required

Think about...

- How can planning and reviews work better?
- What do you need from the NDIS to feel safe and happy in your home and community?
- What does support look like and how do you find it?
- What support do you need to be in control of your life and make your own decisions?

Think about...

- What's working?
- What's not working?
- What's the solution?

Other prompts

Safe and chosen places to live now and in the future (housing and living, quality, safeguards, choices)

- What do you need to feel safe and secure but also able to live a great life at home, at school, in community, at work, wherever you go?
- How do you make decisions about important things like where you live? What would help you?
- What do you need to live your life, try new things or learn new skills, go out and have fun, make friends and have good relationships
- Do you get good support to do those things at the moment? What do you think would make a difference?
- If you're living with other people like a SIL or group home, what do you need to be safe and well supported, what do you do/who do you go to if you have any concerns
- What do group or share homes provide to people that they can't get elsewhere?
- What supports or services would help people try different housing and living?
- If you don't share your home with others, what do you need to live safely and happily?

Optional additional prompts if people want to talk about non-housing issues

Access, planning, reasonable and necessary supports

- Best ways to get information for NDIS **access and planning** decisions that show the supports you need and why you need them
- Who can help you provide information about your needs and situation to help the NDIS make **better decisions** eg GPs, specialists, OT, LACs, support coordinators, family, friends.
- Barriers to getting this information – eg cost, time, don't know what to do.
- How can you be confident in NDIS decisions
Prompts (but don't use to lead responses)
 - NDIS told/showed me information they used to make decisions about my funding
 - Check a draft plan before it was finalised
 - Planner had skills/experience/qualifications in my conditions/disabilities
 - Funding decisions were made elsewhere

Capacity building

- Ideas on how NDIS and other supports can enable you to **live a great life and achieve your dreams** and aspirations, and how those benefits can be shown to decision-makers
- What would help you to use your NDIS plan funds to live a great life in your broader community?
- Who or what would help you to use your NDIS plan and other supports to live your life better? Eg help from LAC, SC, RC, family, friends, peer networks, providers, planner etc
- If you don't get individual funded support from NDIS, do you get enough support from other government areas like health, education, transport, housing?
- What happens to you if you don't get the right supports?

Navigators

What would be helpful to you to find and use mainstream services, community programs and disability supports. Examples:

- Someone in my local community - must know have knowledge of local services, providers, community groups and be able to help me understand
- Someone with knowledge/experience in the disability services I need – can be local / virtual
- Help when I need it to make decisions about my life from family, friends, peer networks, trusted workers or professionals, LAC or NDIA

Services, quality, outcomes (markets and providers)

- Do you have access to the right services at the right time for your life?
- What are the features of provider services that help people live daily life comfortably without fear of over-spending or over-reliance on paid supports
- How can provider service quality be monitored and improved? How can participants influence that?
- Is there such a thing as too much support - replacing or inhibiting relationships, networks, friendships, different ways of being part of community?
- What is needed for you to negotiate prices and delivery with providers? What or who could help you with that?

Conclusion

80 - 90 mins

Facilitator

- Thanks for coming
- Wrap up of key themes
- Reminder of process from here and the importance of the review and the NDIS
 - Every Australian Counts will compile the feedback we gather throughout forums into a comprehensive report to submit to the NDIS Review.
 - Sometimes you come along to events like today and then later on you remember something you really wanted to say. If that happens just hop on the NDIS Review website and look at the section called “Have Your Say”. You can send a quick email, record a quick video or answer some questions. This section of the website will stay open all the way til mid August so there are lots of chances to still hear your ideas. www.ndisreview.gov.au
 - Or can send additional feedback via the Every Australian Counts website

Post session

- EAC administrator - download and save chat

Background information

National cabinet announcement

- Role of Review
Review getting on with the job, no change to terms of reference
Review panel members have not been able to attend today's session, but Review's responses to current issues have been highlighted in NDIS Review Round Up, published on website.
- 8%
Targets not caps. Review goal to recommend ways to improve NDIS so people with disability can live great lives, Scheme helps achieve great outcomes, demonstrate that NDIS is investment in people. Getting good outcomes will help the sustainability of the scheme
- Questions on autism / list A / access
NDIS based on need not diagnosis. Review seeking ideas on better ways to provide information that explain need and circumstances.
- Co-design
12 month Review isn't long enough to do extensive co-design. Everybody has opportunity to contribute their views, idea, experiences in consultation like EAC, DRO, S&T, Review-led etc. In the next few months we will start sharing our thinking and our ideas so you can give us feedback.
- How to engage
EAC, DROs, S&T, Review-led. Different methods: online written, verbal, consultations, short questionnaires in social media. Review to publish engagement opportunities soon.

Consultation questions on the Review website now www.ndisreview.gov.au

NDIS Quality and Safeguarding Framework

What governments will do to keep NDIS participants safe and make sure the services they receive are good quality. Some ideas based on feedback. Read more in the [NDIS Quality and Safeguarding Framework issues paper](#).

What's coming up?

Consultation opportunities to tell the Review what you think about early ideas on home and living supports, NDIS access and planning, what reasonable and necessary means to you, services, quality and pricing, ways to improve support for children, young people and their families

Have your say online, anytime

Sometimes you come along to events like today and then later on you remember something you really wanted to say. If that happens just hop on the NDIS Review website and look at the section called "Have Your Say". You can send a quick email, record a quick video or answer some questions. This section of the website will stay open all the way til mid August so there are lots of chances to still hear your ideas. www.ndisreview.gov.au

7. Appendix 2: Attendees Demographics

Forum	Total attendees	Gender			Location			State or Territory								
		M	F	U	Regional	Metro	Unknown	ACT	NSW	NT	Qld	SA	Tas	Vic	WA	Not Dec
Open to all																
1	18	3	14	1	8	10	0	0	5	0	5	0	0	8	0	0
2	15	2	12	1	3	12	0	0	5	0	6	1	0	3	0	0
3	18	3	14	1	7	11	0	0	4	0	5	0	0	7	2	0
4	15	2	12	1	6	9	0	0	5	0	1	2	0	4	3	0
5	18	2	15	1	4	13	0	0	5	0	5	2	0	5	1	0
6	14	2	11	1	5	8	1	0	5	0	3	0	0	4	1	1
Regional forums																
7	16	2	13	1	12	3	1	0	7	1	3	0	0	4	0	1
8	14	3	11	0	11	1	2	0	3	0	4	0	0	5	0	2
9	7	3	4	0	4	3	0	0	2	0	2	1	0	1	1	0
10	6	1	5	0	4	2	0	0	3	0	1	0	1	1	0	0
Total	141	23	111	7	64	72	4	0	44	1	35	6	1	42	8	4

