



Culture and Capability of the National Disability Insurance Agency

**Summer Foundation submission to the Joint Standing
Committee on the National Disability Insurance Scheme**

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The Summer Foundation acknowledges and thanks all staff and storytellers for their contributions to this submission.

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Executive Summary

The Summer Foundation welcomes the opportunity to make submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) on the capability and culture of the National Disability Insurance Agency (NDIA) and the impacts on the experiences of people with disability and NDIS participants (participants). Many Australians depend on the NDIS to live an ordinary life. It is crucial that the NDIS and the NDIA strengthen the rights and choices of Australian participants and build their capacity to live independently and well in the community.

It is essential that people with disability are at the centre of all policies and solutions. Better outcomes for participants are more likely if defined by participants through meaningful co-design and self determination. To that end, we have sought the contributions of participants and their supporters, to ensure their views are central to the development of recommendations for an improved NDIA.

Summer Foundation's key recommendations for action

Meaningful co-design with people with disability must be built into each of these actions.

1. The NDIA must listen to NDIS participants and recognise them as experts in their own lives
2. The NDIA must ensure all communication with participants is clear, sets accurate expectations and reflects the way the NDIS operates in practice
3. NDIA systems and processes must be simplified for clarity and transparency and to improve the timeliness and consistency of decision-making
4. The NDIA must release clear guidelines, standards and templates for evidence required for NDIS planning decisions
5. The NDIA must improve capacity, training and expertise of NDIA staff, in particular disability-specific expertise
6. The NDIA must implement a participant-first culture in which the needs of NDIS participants are central to all decision-making
7. The NDIA must measure and regularly report on their progress towards improving participant outcomes and experiences, and how participant input will shape improvements to the NDIS.

Improving the capability of the NDIA

Enable people with disability to live an ordinary life

People with disability should have the same opportunities as anyone else. They should not have to worry about whether they have enough NDIS plan funding to meet their support needs or how much longer they will have to wait for NDIA to approve funding for the support they need. They want to be able to focus on the things in life that matter to them; visiting friends and family, going out into the community, shopping, learning and working. They want choice and control on how they live their own life.

“My own disability is only part of my identity, but it takes up a disproportionately large part of my life. I want to contribute more to society but I am being held back by an insecure disability workforce and insecure NDIS funding.”

- Angela*, NDIS participant

Summer Foundation and People with Disability Australia conducted a national survey of NDIS participants in July 2022.¹ The survey asked participants to reflect on the strengths and weaknesses of the NDIS, as well as to comment on possible improvements. Participants identified examples of the NDIS working well, such as the benefits of having access to NDIS-funded supports and the independence and opportunities for community engagement that comes from that support. Participants also shared frustration and criticism about NDIS processes. Common issues include living in fear of funding being cut, a lack of communication, collaboration and relationship building, and poor timeliness and efficiency. These findings will be explored in more detail throughout this submission.

“I am very grateful for the NDIS and what it does. Although it is working well for me personally, I am appalled at how complex, time-consuming and sophisticated I had to be to get what I have.”

– Jackie*, NDIS participant

Getting the language right

There is a disconnect between the goals and intentions of the NDIA and the experiences of participants using the NDIS. Under the *National Disability Insurance Scheme Act 2013*, the function of the NDIA is to “support the independence, and social and economic participation of people with disability” as well as “ensure that the decisions and preferences of people with disability are respected and given appropriate priority”²; however, feedback from participants suggests this is not the experience of many, who have lost trust and confidence in the NDIA. Participants report feelings of stress, confusion and being fearful that the improved quality of life that the NDIS has brought could be taken away at any moment by a change in policy or simple miscommunication.¹

¹ Winkler, D., Brown, M., D'Cruz, K., Oliver, S., Mulherin, P. (2022). Getting the NDIS back on track: A survey of people with disability. Summer Foundation, link [here](#)

² *National Disability Insurance Scheme Act 2013 (Cth)*

To 'get the language right' the NDIA must ensure their communication with participants, from formal documentation to conversations at planning meetings, is clear, sets accurate expectations and reflects the way the NDIS operates in practice. Participants have identified the importance of NDIA staff communicating respectfully, listening to the participant and recognising them as experts of their own lives.³

The NDIA must strive to deliver the commitments of their Participant Service Charter which requires engagement to be transparent, responsive, respectful, empowering and connected.⁴ There must be a shared understanding between the NDIA and participants in order for trust to be restored.

"Treat us with dignity and respect as equal and worthwhile humans deserving of being treated well." – Nick*, NDIS participant

In addition, the Summer Foundation conducted a survey of occupational therapists in July 2022⁵ and support coordinators in July 2021⁶ to gather insights on their experiences with the NDIS. These professionals who work alongside the NDIS reported a lack of a shared understanding between the NDIA and the sector. They highlight the need for the NDIA to improve their communication and collaboration with the sector and professionals.

Occupational therapists reported a lack of clarity about the NDIA's expectations of their work and confusion regarding the lack of consistency in NDIA decision-making.³ Support coordinators report a lack of communication and transparency, highlighting that after they submit an application they are unable to determine how it is progressing and may not hear anything from the NDIA for months.⁶

"The NDIS website is very geared toward consumers, without much guidance for providers. Feedback on reports and reasons for decisions (not just cutting and pasting the reasonable and necessary criteria) or a provider panel who can offer feedback would be helpful. Decisions seem so random."
– Alex*, Occupational Therapist

Participants and the sector want a more transparent and collaborative relationship with the NDIA that would replace the transactional and adversarial relationship they experience now.³

Suggestions from participants, occupational therapists and support coordinators:

- Easy to understand language and less use of acronyms
- More accessible information on the NDIA website for participants and the sector
- Clearer definitions of funded supports
- Communication of legislation changes
- Greater focus on monitoring, reporting and evaluating NDIA performance against the Participant Service Charter and NDIS legislation.

³ Winkler, D., Brown, M., D'Cruz, K., Oliver, S., Mulherin, P. (2022). Getting the NDIS back on track: A survey of people with disability. Summer Foundation, link [here](#)

⁴ National Disability Insurance Agency (2022). Participant Service Charter, link [here](#)

⁵ Winkler, D., D'Cruz, K., Minter, E., Mulherin, P. (2022). Providing an evidence base for Home and Living decisions: A survey of occupational therapists writing functional assessment reports for NDIS participants. Summer Foundation, link [here](#)

⁶ Summer Foundation (2022). Research summary, Survey of support coordinators; essential features of support coordination assistance for pursuing home and living goals', link [here](#)

Improving administrative process

We are encouraged to see the NDIA's recent announcements to improve the efficiency of internal systems and processes, such as the new Information and Communication Technology (ICT) system PACE.⁷ PACE is said to deliver an improved participant experience and we look forward to this system improving the experience of participants.

However, there are many NDIA systems and administrative processes that are opaque and create stress, uncertainty and unnecessary delays for participants.⁸ Many participants who require funding for supports have no way of understanding the process by which the NDIA will come to a determination.⁹ The process by which a support is funded or not is unclear, including how the legislated criteria of reasonable and necessary supports are weighted¹⁰ particularly against the demonstrated needs and preferences of the participant. Participants and professionals in the sector report being unsure what applications or reports are likely to achieve the right outcome and have little to no direct communication with the NDIA to be able to discuss the needs of the participant or understand decisions.

"Make it simpler - Stop making participants who already struggle in life have to battle a bureaucracy and system that is complex and exhausting to understand and deal with..." – David, NDIS participant*

Participants expressed frustration with very long wait times for funding decisions.⁸ Participants and professionals support reduced wait times across all areas of funding, especially identifying people in 'at risk' situations and prioritising those decisions.¹¹

"It would be great if there was a NDIS process in place that could fast track applications that are urgent due to a participant's risk, notice to vacate etc." – Mario, Support Coordinator*

Participants and the sector also spoke about the inability to plan long-term because of plan and funding restrictions and expressed frustration with having to repeatedly 'prove' their level of disability at planning meetings.

"Removing the repeated burden of proof - these are people with severe permanent disabilities already accepted onto the scheme, we should not have to prove this each time, nor have to endlessly justify to NDIS staff with NO health background or understanding, the recommendations we are making based on our degrees, ongoing CPD [Continuing Professional Development] and years of experience." – Stephanie, Occupational Therapist*

⁷ National Disability Insurance Agency (2022) 'Progressing towards our new Information and Communication Technology (ICT) business system', link [here](#)

⁸ Winkler, D., Brown, M., D'Cruz, K., Oliver, S., Mulherin, P. (2022). Getting the NDIS back on track: A survey of people with disability. Summer Foundation, link [here](#)

⁹ Summer Foundation (2022) 'Supported Independent Living costs and impacts Policy Position Statement', link [here](#)

¹⁰ *National Disability Insurance Scheme Act 2013, Section 34*

¹¹ Summer Foundation (2022). Research summary, Survey of support coordinators; essential features of support coordination assistance for pursuing home and living goals', link [here](#)

Participants and professionals suggested improvements to systems and processes to better support the development of a collaborative and productive partnership between participants and the NDIA. These include allowing participants to see and comment on a draft of their plan before the NDIA adopts it, such that there's an opportunity to informally correct mistakes or misunderstandings¹² and a single contact person at the NDIA providing a personalised and continuous relationship.¹³

"To be able to actually contact the person at the NDIA who is named as contact person on my plan so that my plan and my life are not set adrift and left confused when support coordination is not available or working well."

– Lloyd*, NDIS participant

Suggestions from participants, occupational therapists and support coordinators:

- Clear and objective assessment processes and transparency in decisions
- NDIA share their draft plan with participants before finalising
- A single contact person at the NDIA available for discussion, feedback on decisions and an ongoing relationship
- Ensure participants do not have to unnecessarily 'prove' their level of disability once they are a participant
- Provision of detailed feedback with reasoning for funding decisions
- Locking in parts of plans to be reviewed less frequently, such as every 2 years
- Being able to request funding changes without the threat of a reduction in funds
- Having the option for participants to renew their current plan without reassessment.

Using evidence to inform decision-making

The NDIA relies on the evidence provided by the NDIS participant to make a funding decision. However, at present there is very little guidance from the NDIA regarding the specific evidence needed to make a decision. One consequence of this is that there is huge variation in the amount, quality and relevance of the information provided to the NDIA as part of a funding request.¹⁴

Considerable knowledge and experience is required to successfully prepare evidence for funding requests but this is often lacking among allied health professionals (AHPs) or other supports. Though the NDIA has begun some work to address the lack of guidance and clarity on evidence to inform decision-making, as well as broader work to improve their resources and communication with participants and the sector, more must be done to address all aspects of this issue.

¹² Summer Foundation (2022). Research summary, Survey of support coordinators; essential features of support coordination assistance for pursuing home and living goals', link [here](#)

¹³ Winkler, D., Brown, M., D'Cruz, K., Oliver, S., Mulherin, P. (2022). Getting the NDIS back on track: A survey of people with disability. Summer Foundation, link [here](#)

¹⁴ Skipsey, M., Winkler, D., Cohen, M., Mulherin, P., Rathbone, A., & Efstathiou, M. (2022). Housing delayed and denied: NDIA decision-making on Specialist Disability Accommodation. Public Interest Advocacy Centre and Housing Hub, link [here](#)

“(We need) Clearer guidelines for OTs delivering this service. More openness and transparency within the process on the NDIA's behalf. In my practice I do not see any consistency between one determination to the next and I clearly believe this is unfair and some people are missing out on opportunities they deserve just as much as the ones who are receiving them.”

– Jin*, Occupational Therapist

Clearer guidance from the NDIA would assist participants to provide concise and relevant evidence as part of their application. This will not only improve experiences and outcomes for participants but also streamline NDIS decision-making processes.

“Having the opportunity to understand what was missing for the reader, we know the situation and are assuming that we have communicated the detail we think is important but we are guessing really. It will depend on the person's experience and understanding of the disability but the response provided back is 'it doesn't meet reasonable and necessary...' But how? I would love to interview panel members to understand what they want as we interpret things so differently.” – Ross*, Occupational Therapist

Suggestions from participants, occupational therapists and support coordinators:

- Develop written guidelines regarding the specific evidence needed for a timely decision, targeted towards different stakeholders including participants, support coordinators and AHPs
- Develop template reports which clearly outline the legislated eligibility criteria and word limits to assist AHPs to provide more concise and rigorous reports
- Publish a list of objective measures that must be addressed in evidence to assist the NDIA to make timely and accurate funding decisions
- Specialised training for AHPs completing NDIS reports.

NDIS Staff

There is a need for more capacity, training and expertise in the workforce supporting people with disability,¹⁵ including NDIA staff. A lack of training and expertise within the NDIA can create excessive delays in decision-making and increase the likelihood of inaccurate decisions, creating the need for reviews and appeals that contribute to further delays and risks to participants. We commend NDIA for setting goals to improve accessibility and inclusion for people with disability working at the NDIA through their Disability Inclusion Plan,¹⁶ but more must be done to build capacity in all NDIA staff.

¹⁵ Disability Royal Commission (2021). Public Hearing Report, Public Hearing 10; Education and Training of Health Professionals in relation to people with cognitive disability, link [here](#)

¹⁶ National Disability Insurance Agency (2022). Disability Inclusion Plan 2022-2025, link [here](#)

Many participants raised concerns as to whether reports are read in full by the NDIA, citing a lack of disability and allied health knowledge as a barrier to NDIA staff understanding the content of reports¹⁷. Occupational therapists and support coordinators expressed a loss of trust in the system and frustration at the devaluing of their professional judgement.¹⁷

“Occupational Therapists would have enhanced capacity if the NDIS were more timely in their responses and if they had staff who had a basic understanding of disability so that they could understand our reports and therapists weren't required to write 60 page reports when the information could be accurately depicted within 20 pages - quality over quantity should suffice but not when it comes to NDIS.”

– Catherine*, Occupational Therapist

Participants indicated that by having staff with more disability experience there would be better understanding of people's needs, as well as empathy and a motivation to get the decision right for each participant. Participants suggested assigning planners to participants based on disability-specific expertise and suggested increased accountability and consequences for funding decisions.¹⁸

“The NDIS needs to understand the complexity of living with a disability and be trained to respond with care and compassion.”

– Sam*, NDIS participant

Suggestions from participants, occupational therapists and support coordinators:

- Build the capacity of NDIA staff to consistently make funding decisions that align with participants' needs and preferences as well as the NDIS legislation
- NDIA must hire staff with expertise and skills in disability, including AHPs
- As much as possible, the NDIA must assign planners to participants based on disability specific expertise
- Training for NDIS staff co-designed by and delivered by people with disability.

¹⁷ Winkler, D., D'Cruz, K., Minter, E., Mulherin, P. (2022). Providing an evidence base for Home and Living decisions: A survey of occupational therapists writing functional assessment reports for NDIS participants. Summer Foundation, link [here](#)

¹⁸ Winkler, D., Brown, M., D'Cruz, K., Oliver, S., Mulherin, P. (2022). Getting the NDIS back on track: A survey of people with disability. Summer Foundation, link [here](#)

Culture

Welfare mentality

Though the NDIS is intended to operate as an insurance model that supports participants throughout their life, the NDIA often operates with a ‘welfare’ mentality. There is an unconscious bias underlying funding decisions that people do not need or deserve all the supports and services they require to live an ordinary life. That they should be grateful for whatever level of support they receive, even if it is insufficient.

Under legislation, the function of the NDIA is to “ensure that the decisions and preferences of people with disability are respected and given appropriate priority”¹⁹ however there appears to be an idea that some supports are “too good” for people with disability or too costly and participants will be approved for a less expensive support even if it does not meet their needs and preferences. These supports can often reflect outdated models of disability support, for example segregated, congregate housing, even if the participant wishes to live independently in individualised housing.

A pattern of funding participants ‘80% of the way’, rather than consideration of what an ordinary life could look like, has emerged. With participants feeling pressure from the NDIA to justify support needs above and beyond evidence. Likewise participants have expressed feeling tension between asking for a new support and maintaining what they already have, with requests often resulting in reductions elsewhere in their plan.

Participant-first culture and restoring trust

A participant-first culture describes a way of working in which the impact on needs and preferences of participants is central to all decision-making and that co-design with people with disability is standard practice. A participant-first approach is supported by the United Nations Convention on the Rights of Persons with Disabilities.²⁰

Though the NDIA state that participants are at the heart of everything they do,²¹ participants have reported not feeling listened to by the NDIA and frustration at not being seen as experts in their own lives.²² There appears to be a culture within the NDIA of a lack of trust in participants and an assumption that many ask for more than what is reasonable and necessary.

“Maybe walk in my shoes for 48 hours, instead of saying things are unreasonable and not necessary.” – Aisha*, NDIS participant

¹⁹ National Disability Insurance Scheme Act 2013 (Cth)

²⁰ Australian Human Right Commission (2002). Overview of the articles of the Convention on the Rights of Persons with Disabilities, link [here](#)

²¹ National Disability Insurance Agency (2022) Community participation, link [here](#)

²² Winkler, D., Brown, M., D’Cruz, K., Oliver, S., Mulherin, P. (2022). Getting the NDIS back on track: A survey of people with disability. Summer Foundation, link [here](#)

One impact of this mismatch in culture is an increasing number of NDIA decisions that do not align with participants' needs and preferences or the legislation. This has led to increased numbers of participant appeals to the Administrative Appeals Tribunal. In looking at Home and Living decisions, recent analysis by the Housing Hub and Public Interest Advocacy Centre highlights that 92% of participants received the determination they had originally requested,²³ suggesting that the majority of NDIA Home and Living decisions are fundamentally incorrect.

Participants, their families and close others, are best placed to advise on what are reasonable and necessary supports for them to live an ordinary life. The NDIA needs to implement a participant-first culture by understanding participants' needs and goals and ensuring funding decisions actively enable choice and control.

In the 2022 federal election, the Labor Government campaigned on a promise to overhaul the NDIS and restore it to its original intent.²⁴ The Minister for the NDIS, the Hon Bill Shorten MP, has spoken about his priority to rebuild trust in the NDIS.²⁵ He identified a number of issues with the NDIS he wants to address to improve the experience of participants. The Minister has committed to changes within the NDIA which will improve the capability and culture, including a review of the NDIS and getting participant plans right the first time.

"This scheme is about empowering people, not causing pain. At the moment, I still think it's causing more pain than it should, so let's get that right."²⁵

– Minister Bill Shorten

Co-design is used widely across the disability sector, but it often lacks authenticity and control by people with disability. A strengthened and authentic approach to co-design is needed for the work on the NDIA to deliver innovative solutions for participants.²⁶ In addition, the NDIA must measure, report and evaluate progress made towards improving participant outcomes and experiences, and how participant input will shape improvements to the NDIS.

²³ Skipsey, M., Winkler, D., Cohen, M., Mulherin, P., Rathbone, A., & Efstathiou, M. (2022). Housing delayed and denied: NDIA decision-making on Specialist Disability Accommodation. Public Interest Advocacy Centre and Housing Hub, link [here](#)

²⁴ ALP (2022). A better future for the NDIS. Australian Labor Party. link [here](#)

²⁵ Summer Foundation (2022). 'Reasonable and Necessary', NDIS deep dive: Interview with Minister Bill Shorten, 18 August, link [here](#)

²⁶ Summer Foundation (2021). Storytellers with lived experience strengthening opportunities for people with disability to live independently, link [here](#)

Conclusion

The current culture and capability of the NDIA is not meeting the needs of participants, but it can be changed. Through the Summer Foundation's survey, participants reported that they live in fear of funding being cut, experience a lack of communication, collaboration and relationship building with the NDIA, as well as poor timeliness and efficiency. Trust and confidence in the NDIS and the NDIA can only be restored if participants are seen as experts in their own lives.

NDIS legislation and NDIA governing documents outline a framework to "ensure that the decisions and preferences of people with disability are respected and given appropriate priority",²⁷ but there must be active changes to ensure that language is operationalised to change the day-to-day experiences of participants. In addition, the NDIA must invest in capacity building and training for their staff, simplify NDIA systems and processes and release clear guidelines for reports and other evidence.

Though many including the Minister for the NDIS, the Hon Bill Shorten MP, have recognised the "the slow pace of change" at the NDIA²⁵, with the powerful voice of the Joint Standing Committee on the NDIS, real systemic change can be effected at the NDIA so participants across the country are able to live well in the community and exercise true choice and control over their lives.

²⁷ *National Disability Insurance Scheme Act 2013 (Cth)*

About the Summer Foundation

The Summer Foundation was established in 2006 and exists to permanently stop young people with disability from being forced into residential aged care (RAC), ensuring people with disability have access to the support required to be in control of where, how and with whom they live.

The Summer Foundation works to support people with disability who have high and complex disability support needs. It has a strong focus on supporting people with disability to access quality housing, which meets their needs and preferences, and enables them to live well in the community.

The Summer Foundation has established a number of social enterprises, including the Housing Hub and UpSkill. Capacity building of people with disability, their close others, support coordinators, allied health professionals and other key supporters is a central feature of the work of the Summer Foundation.

The Summer Foundation works to influence, challenge and build capacity of the systems, policies and markets that need to change; to permanently eliminate the need for young people with disability to live in RAC.

We focus on unique, high impact interventions that complement the efforts of government, relevant sectors, markets and other organisations. We use a range of tools including:



EVIDENCE BASE

Our research informs the development and evaluation of potential solutions, resources and tools.



EXPERT KNOWLEDGE FROM LIVED EXPERIENCE

We build on the expert knowledge from those with lived experience of the issue of young people in aged care to inform, co-design and evaluate our resources, tools and interventions.



KNOWLEDGE OF GOVERNMENT AGENDA AND DRIVERS

We leverage our knowledge of government drivers to establish best practice policy, to facilitate understanding and implementation of policy and inform government agenda.



CLINICAL EXPERIENCE

We use clinical experience that tells us what is happening on the ground to develop and share resources and tools designed to build the capacity of the system and market users.



DEMONSTRATION PROJECTS OR SOCIAL ENTERPRISES

We design, test, evaluate and improve potential solutions and market interventions to develop social enterprises.