Getting the NDIS back on track
A survey of people with disability

NDIS participants recognise how the Scheme benefits their lives, but also lack trust in the way it is run.

Trust between people with disability and the NDIA has suffered a series of setbacks in recent years. The new Federal Government acknowledges deep seated concerns voiced by many participants and has promised to review and reform the NDIS. The government’s commitment is welcome. However, campaign promises will need to translate into concrete action before trust can be properly restored.

What were the aims of the survey?

To help ensure that the voices of people with disability are central to the reform of the NDIS, the Summer Foundation, supported by People With Disability Australia (PWDA), conducted a national survey of NDIS participants in July 2022. The aims were to:

1. Obtain the perspective and priorities of people with disability regarding the changes the NDIS needs
2. Identify stories that illustrate the benefits of the NDIS
3. Inform the development of a vision for the NDIS

The survey asked participants 3 things about the NDIS: what works well; what they would change; and, how the NDIS has supported them to live an ordinary life.

“Listen to us about our lived experience and what we need, we know.”
– NDIS participant

What were the key findings?

In total, 477 NDIS participants or a family member or friend of a participant responded to the survey. Many participants reported that the NDIS has helped them to achieve important and transformative outcomes in their lives.

However, the survey also revealed that:

- Accessing and navigating the NDIS is difficult, time-consuming and stressful
- Participants fear that the improved quality of life resulting from NDIS funding could be taken away at short notice
- Participants worry that funding cuts could stem from a change in government, updated policy, or due to miscommunication and error at planning reviews.
Recommendations

Participants and their allies want a more transparent and collaborative relationship with the NDIA that is built on mutual trust. This would replace the current pessimistic and adversarial relationship. Participants expect that a restored relationship will not only bring benefits to themselves, but also to the Agency as more efficient and less wasteful processes emerge. A range of pragmatic and clear recommendations emerged from the analysis of the survey responses.

These include the following:

**Improved communication:** NDIS participants want the NDIA to improve its communication.

**Human approach and inquiring mindset:** NDIS participants want NDIA staff to demonstrate a humanistic and inquiring approach to their interactions with participants.

**Timeliness and efficiency:** NDIS participants want more timely and efficient processes regarding funding decisions.

**Evidence and reports:** NDIS participants want the NDIA to revise its requirements for providing evidence at all planning reviews.

**Expertise:** NDIS participants want the NDIA to increase staff’s disability expertise, especially for positions making decisions on funding.

**Not living in fear of funding being cut:** NDIS participants want the NDIA to restore participants’ confidence in the Scheme, particularly with regards to fears of funding cuts.

**Supporting people with disability to live well:** NDIS participants want to partner with the NDIA to create a scheme that is innovative, responsive and supportive of people with disability living rich and rewarding lives.

Conclusion

The survey findings highlight the importance of having trust in the NDIS, in addition to being satisfied with the opportunities afforded through the Scheme.

One risk to the reform of the Scheme is that it is largely informed by NDIS participants who have a voice and are able to effectively advocate for themselves. This survey makes a significant contribution by giving a voice to a broad range of NDIS participants.

Participants have a wealth of knowledge of insights and goodwill that can be harnessed to transform the Scheme to be more equitable and sustainable.

NDIS participants want to see the NDIS provide great value for money and are interested in partnering with the NDIA to co-design solutions to restore trust and confidence in the Scheme.

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

“The concept of NDIS is great. The implementation and delivery needs to be improved.”
– NDIS participant

“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.” – NDIS participant