



National Disability Insurance Scheme

Our Supported Decision Making co-design story - summary

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1. Introduction

This paper is about how we worked with people with disability on the Supported Decision Making Policy and implementation plan.

The policy and implementation plan will guide how we:

- support participants to make decisions
- enable opportunities to make decisions
- build the knowledge and skills of people with disability (and people who support them) to make decisions

Background

The National Disability Insurance Agency (NDIA) is committed to working in partnership with people with disability to co-design improvements to the National Disability Insurance Scheme (NDIS).

Co-design means we work alongside people with disability, the disability community, and other interested groups. We do this by collaborating on specific problems, issues and situations requiring improvement or change.

Through the NDIA's Co-design Advisory Group, the disability community agreed the Supported Decision Making Policy would be co-designed.

A Co-design Steering Committee was set up to guide the development of the Supported Decision Making Policy. People with disability were key members of this Co-design Steering Committee. Their participation in the Committee meant lived experience directed the co-design process. The NDIA Board endorsed the advice from the Independent Advisory Council (Council) on [Support for decision making in the NDIS](#), and accepted the management response in August 2020. The advice proposed a support for decision making framework and a plan of work to operationalise support for decision making across the NDIS.

In line with that advice, we have developed an overarching policy on supported decision making. In this policy we take a lifespan approach reflecting the changing decision making support needs of people throughout their life and as they make more complex decisions.

The image below shows the supported decision making co-design journey.

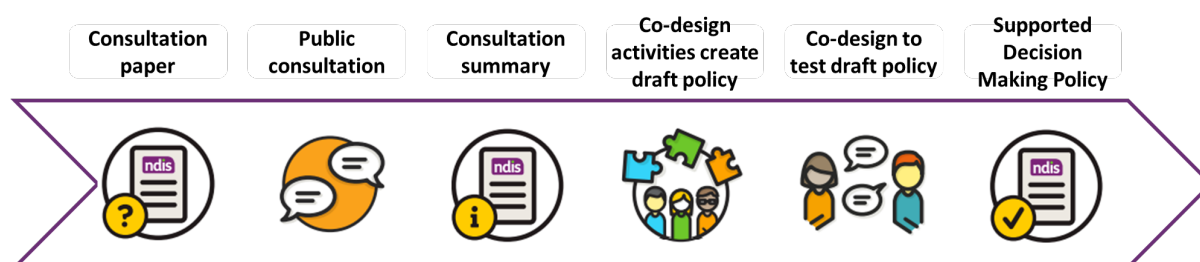


Figure 1. Supported decision making co-design process.

2. What we co-designed

“Supported decision making” describes the process of providing support to people to make decisions and remain in control of their lives.

The policy

The policy sets out supported decision making principles and focus areas to support people with disability to make decisions in the NDIS.

The implementation plan

The implementation plan has five key actions. These are:

1. Increase opportunities for participants to make decisions
2. Support participants to develop skills and knowledge
3. Build skills and knowledge of decision supporters
4. Build skills and knowledge of NDIS Agency staff and partners
5. Strengthen supported decision making approach in the appointment, operation and review of nominees.

3. How we worked with people with disability

Over the last two years we worked with participants, their families and carers, and the disability community in different ways so that as many people as possible could help develop the Supported Decision Making Policy and implementation plan.

We received feedback through engagement activities, written submissions and responses to an online survey. Engagement activities included:

- 2 public information sessions and 16 national online consultation sessions

- 3 sessions with members of the [Participant First Engagement Initiative](#)
- Conversations with groups and organisations who may benefit from support for decision making.

3.1 Public consultation

In 2021, we asked for submissions to a consultation paper called [Supporting you to make your own decisions](#). We used this feedback as the basis for co-designing the policy and implementation plan.

We developed this consultation paper by working with the NDIS Participant Reference Group, the Independent Advisory Council and members of the Intellectual Disability Reference Group, academics, and members of our [Participant First Engagement Initiative](#).

Over a 12 week period, we asked for feedback on:

- How we can help improve experiences of making decisions
- How to help the people around participants to support them to make their own decisions.

We received feedback on the consultation paper through:

- An online survey (created with advice from Council and the Intellectual Disability Reference Group)
- Written submissions
- Online events across Australia
- Conversations with people who might benefit most from supported decision making
- Conversations with disability community representatives and peak bodies
- Conversations with participants through the NDIA's Participant First Initiative.

We received 280 submissions. This number does not include people who gave feedback at the engagement sessions. Their feedback was also recorded and considered in developing this policy. The 280 submissions included:

- 195 survey responses
- 85 written submissions (35 of them by direct email).

Of these:

- 182 responses were from individuals (people with disability or people who support people with disability)
- 98 responses from organisations (including disability organisations, NDIS service providers, advocacy organisations and peak bodies).

We received lots of recommendations and specific actions to improve supported decision making for people with disability.

In January 2022, we shared results of the consultation in a paper called [Consultation summary report – Support for Decision Making](#).

Through the consultation we identified common themes. These included:

- Make sure people have informed decision supporters and the time and resources they need to make decisions
- Make sure we are learning from existing work about supported decision making, and work with the disability community and other government departments
- Do more work to get our approach right. People wanted us to co-design with them.

We are very grateful to everyone that took the time to provide feedback.

3.2 Co-design activities

Inclusion Australia is the national peak body for intellectual disability. In 2022 we engaged Inclusion Australia to lead our co-design workshops with people with disability. We worked with a co-facilitator who is a person with disability and a NDIS participant. The co-facilitator has a background in co-design and peer work, including with VALID. We worked with Inclusion Australia to plan the co-design sessions, prepare the materials, and run sessions in a way that made sure all people could share their experiences.

Together with Inclusion Australia we held co-design workshops with people who benefit most from supported decision making. The purpose of these workshops was to:

- Build on the feedback we received through the public consultation
- Build a strong and shared understanding of the challenges and barriers participants, child representatives, nominees, families, carers and providers experience about supported decision making
- Co-design a new policy for supported decision making.

3.3 Hearing from diverse audiences

In planning our activities, we made sure to consider how we engage with:

- People with complex communication needs
- Culturally and linguistically diverse people (CALD)
- People with psychosocial disability
- People who identify as LGBTQIA+
- First Nations peoples in remote communities.

We also engaged with groups and organisations who have an interest or a role in supported decision making. We asked about their opinions, policy gaps, and roles and responsibilities.

We did this through:

- A virtual workshop with academics, public advocates, and Disabled Peoples' Organisations
- The Disability Representative and Carer Organisations Forum
- Intellectual Disability Reference Group
- Independent Advisory Council
- Engagement with a small group of family members
- NDIS Partner organisations including Local Area Coordinators and Early Childhood Partners

During August, September and October 2022 we held 7 co-design workshops and engaged with 33 people.

4. What people told us

Key themes in what we heard are described below.

4.1 Reconsider the policy approach and language

People involved in consultation and co-design told us to:

- Recognise that **everyone** draws on people or information to help make decisions and that some people may **need support for most or all decisions** they make
- Consider adopting the **Australian Law Reform Commission's National Decision-Making principles**
- **Focus on the support a person needs** to make decisions, and the impact of the environment on their decisions, rather than their capacity
- **Take a person-centred approach** rather than rely on 'typical' life stage transitions that may not map onto the experiences of individuals (in context of intellectual disability, cognitive impairment and or psychosocial disability)
- Recognise that decision-making **happens on a continuum** or could be represented as a spectrum. This means supported decision making can involve different amounts of support. A person may make decisions with little guidance, some guidance, or significant guidance from decision supporters in their support network. What matters is that the person is supported to act on their own will and preference
- **Define and use 'supported decision making'** as a phrase which can be used for process, resources, and tools
- Make sure everyone can **understand our information**.

4.2 Look at the broader context and don't reinvent the wheel

People involved in consultation and co-design told us:

- We should **lead change** – that what we say and do in supporting people to make decisions is important and can impact others to act

- We need to **learn from the disability community and existing work** and not re-do things that have already been done. This includes encouraging the role of Information, Linkages and Capacity Building (ILC) in supporting people to make decisions. The ILC program provides funding to organisations to deliver projects in the community that benefit all Australians with disability, their carers and families. The ILC program is administered by the Department of Social Services
- **Work with others** to get this right – from the disability community to other government departments
- We need to **be clearer** about how our work on supported decision making (including Nominees) fits in with legal frameworks including Guardianship and Trustees.

4.3 Uphold the rights of people with disability

People told us that we need to **understand and explain** the rights of people with disability better and **uphold** people’s right to make decisions.

4.4 Recognise the importance of relationships

People involved in consultation and co-design told us that:

- **Relationships** – including trust, respect and collaboration – are key to supporting a person with disability to make decisions
- Relationships can have challenges, for example where parents are over-protective and don’t allow the participant to make their own decisions.

4.5 Effective supported decision making

People involved in consultation and co-design told us that:

- Making decisions **within the NDIS could be easier** if our information was easy to find and understand and our systems were easier to use. We need to communicate in the way that works for each person and check they have understood
- **Effective** supported decision making needs time, funding, choice of decision supporters who are skilled.

4.6 Recognise disability-specific and culturally-specific needs

People involved in consultation and co-design told us that:

- We need to ensure **what we do works** for people who have complex communication or support needs, people with intellectual and psychosocial disability and people who interact with multiple service systems like health, justice and child protection

- We need to **better understand the perspectives** of Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse communities.

4.7 Explain our approach to safeguards

People involved in consultation and co-design told us that:

- We need to provide **more detail** about the safeguards in the policy
- The **NDIS Quality and Safeguards Commission** should have a role in ensuring people are supported to make decisions
- **Making sure people are getting the support they need** to make decisions (accountability) is very important.

5. How we confirmed the final policy

We heard a lot about what is important to include in the policy and implementation plan. The Inclusion Australia network reviewed the draft policy and confirmed that it reflected the co-design process. The Steering Committee also reviewed the draft policy and provided feedback. The NDIA Board endorsed the policy and implementation plan in January 2023.

6. Lessons

As well as developing the policy, we have also learnt about how the consultation, co-design and engagement process can continue to be improved. Lessons we have learnt include:

- It takes significant time to do proper co-design
- It is important to have facilitators and co-leaders from the disability community. Their skills in inclusive engagement practices are very beneficial
- Partner with Disability and Carer Representative Organisations to reach communities to learn about their diverse perspectives
- NDIA needs to support people in co-design activities to understand their role
- Carefully consider the types of engagement activities e.g., break out rooms for large groups to ensure all people can contribute and have their say
- Some people found talking about the NDIS upsetting and frustrating. We need to be mindful of this and make sure appropriate supports are in place
- Include participants on steering committees and create opportunities for people with disability to provide advice and leadership. This leads to better co-design and empowers the person with disability
- Build in the time and skills to create information in Easy Read, Plain English, and other accessible formats to work effectively with people with intellectual disability.