![Inclusion Australia logo]

Inclusion Australia

Submission to the NDIS Support for Decision Making consultation

September 2021

Inclusion Australia: Submission to the NDIS Support for Decision Making consultation, September 2021

Acknowledgments

Inclusion Australia acknowledges the traditional owners of the land on which this publication was produced. We acknowledge the deep spiritual connection to this land of Aboriginal and Torres Strait Islander peoples. We extend our respects to community members and Elders past and present.

Inclusion Australia recognises the efforts of self-advocates who have courageously told their stories and worked tirelessly over the years for equality and human rights for all.

Inclusion Australia prepared this submission. To write this submission, we listened to the voices and concerns of people with intellectual disability and their families and advocates. We thank them for sharing their lived experiences.

Contact

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About Inclusion Australia

Inclusion Australia is the national Disability Representative Organisation representing the rights and interests of Australians with intellectual disability and their families.

We have state members in New South Wales, Queensland, South Australia, Tasmania, Victoria and Western Australia:

- Council for Intellectual Disability (CID)

- Parent to Parent (P2P)

- South Australian Council on Intellectual Disability (SACID)

- Speak Out Association of Tasmania (Speak Out)

- Victorian Advocacy League for Individuals with Disability (VALID), and

- Developmental Disability WA (DDWA)

Inclusion Australia was founded in 1954 and was previously known as the National Council on Intellectual Disability (NCID). Our mission is to work to make sure people with intellectual disability have the same opportunities as people without disability.

Inclusion Australia works in systemic advocacy, projects, information and communication activities that advance the rights and interests of people with intellectual disability.

Supported Decision Making is one of Inclusion Australia's highest priorities. Our work in this area includes an Information, Linkages and Capacity Building (ILC) funded project called *Make Decisions Real*. This is a 3-year national project that aims to improve supported decision making for people with intellectual disability (ID) and their decision supporters through co-designed resources and peer-led workshops.

Contributors

We thank our members for their contributions to this submission:

This submission is also endorsed by:

- First Peoples Disability Network

- Amaze

- Children and Young People with Disability Australia

- Disability Advocacy Network Australia

- Young People in Nursing Homes National Alliance

- Deakin University Disability and Inclusion team

Introduction

The National Disability Insurance Agency (NDIA) released their 'Supporting you to make your own decisions' consultation paper in June 2021. It is all about supported decision making (SDM) in the National Disability Insurance Scheme (NDIS). In this submission we will call it 'The SDM Paper' for short.

The SDM Paper talks about the suggested NDIS Support for Decision Making policy. This policy aims to maximise opportunities for NDIS participants to make their own decisions. The NDIA has asked people with disability, their families, advocates and carers to share what they think about the suggested Support for Decision Making policy.

The NDIA also released a consultation paper about their new approach to Home and Living, called 'An Ordinary Life at Home'. This new approach to Home and Living is closely related to the Support for Decision Making policy.

The NDIA has recognised the importance of supported decision making for the 60% of adult NDIS participants with a disability that affects the way they think, including people with intellectual disability.

Inclusion Australia thanks the NDIA for listening to the concerns of the disability community and developing a Support for Decision Making policy. We are pleased to see many of the important issues have been heard and are included in the 'Supporting you to make your own decisions' companion paper.

While the SDM Paper does talk about lots of the important issues, our concerns are that the suggested policy does not address all these issues.

To write this submission, Inclusion Australia listened to our member organisations around the country and their networks of people with intellectual disability, families, carers and advocates. We have also engaged with the *Make Decisions Real* peer workers with intellectual disability and other content experts involved in that project.

Our submission includes feedback on the SDM Paper, recommendations for the NDIS Support for Decision Making policy and case studies to help the NDIA better understand the lived experiences of decision makers and their supporters.

Rights

People with disabilities have rights to make their own decisions. This is covered by Article 3, Article 4 and Article 12 of the United Nations Convention on the Rights of Persons with Disability (UNCRPD).

Australia has signed the UNCRPD and the Australian Law Reform Commission (ALRC) has suggested ways to make these rights part of Australian law.

Inclusion Australia believes the NDIA understands that people with disability have the right to supported decision making.

People also have the right to change their mind. One supporter has shared a story with us about people with intellectual disability changing their mind and having that used against them as proof that they are unable to make decisions. NDIS supports are often so rigid that NDIS participants cannot change their mind about the most mundane decisions in life. As one supporter put it:

"A lot goes on in a year… I might not want a shower in the morning anymore, I might want a shower at night, or I might want two showers a day! It's ridiculous that you can't get that."

People with intellectual disability commented that it was good to see the NDIA wants to have support for decision making in participants' NIDS plans. They thought the SDM Paper made some good points about the rights of decision makers. People with intellectual disability liked that the SDM Paper talks about people with disability making their own decisions and having support when they need it. They liked that decision supporters will have information about how to support decision making.

Recommendations

We recommend the NDIS Support for Decision Making policy better acknowledges and upholds the right of NDIS participants to change their mind.

Definitions

The SDM Paper talks about the difference between 'supported decision making' and 'support for decision making'. While we understand these terms have slightly different meanings, the definitions are not that helpful. It is a difficult distinction for people to understand. This is especially true for people with intellectual disability.

People with disability, families, advocates and other supporters have told us that one of the barriers to doing supported decision making is the overly complicated and academic language often used to describe it.

Recommendation

To reduce confusion, we recommend the NDIA uses one term consistently.

We would suggest using the term 'supported decision making' because it has been used for a longer time and people are more familiar with it.

Principles

The NDIA explains the key principles of their Support for Decision Making policy (p. 9) as:

1. Every person, without exception has the right to make decisions (or contribute to decisions) about things that affect them.
2. Decision making capability varies between people. It also varies across different areas of life. Having experience making decisions increases your capability.
3. Your decision making capability can be increased by:
    a. Having support tailored to you, what supports you already have and type of decision you need to make
    b. Increasing the opportunities for you to make decisions yourself
    c. Increasing the capacity of your support network.
4. Making sure you have the information, supports and resources you need to understand and communicate your choices and your capability to make decisions, in whatever format you need.

It was confusing to our community why the NDIA wrote these new principles when the Australian Law Reform Commission (ALRC) has already developed National Decision-Making principles in their 2014 report[1].

The ALRC National Decision-Making Principles are:

1. All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
2. Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
3. The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
4. Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

The ALRC principles were made to guide reform of Australian laws and policies, like the NDIS Support for Decision Making policy.

The ALRC principles are evidence-based and they cover all the information included in the NDIA's key principles. The ALRC principles also include important detail about respect, communication, will and preference, rights and safeguards that the NDIS key principles do not.

Recommendation

We recommend the NDIS Support for Decision Making policy uses the ALRC National Decision-Making Principles instead of the key principles in the SDM Paper.

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[1] ALRC (2014) 'Equality, Capacity and Disability in Commonwealth Laws'. Available here: https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/

Cultural Diversity

The SDM Paper does not say much about Culturally and Linguistically Diverse (CALD) or Aboriginal and Torres Strait Islander people.

The NDIA speaks a little about how it is important to acknowledge cultural perceptions of disability and family, and that different cultural communities understand and approach disability and decision making differently.

This is an especially important consideration because the suggested Support for Decision Making policy relies on informal decision supporters to work. Informal supporters are embedded in their cultures and so the NDIA must give adequate consideration to cultural perspectives on decision making.

Recommendation

We recommend the NDIA undertakes much more research and consultation for CALD and First Peoples' communities before finalising their Support for Decision Making policy.

Complex Communication Support Needs

Complex communication support needs are mentioned in the SDM Paper but have not been considered enough.

For example, the 'Decision Making Continuum' (p. 11) describes decision making capacity according to how well a participant can communicate their preference. Beyond our other concerns with this continuum (see Decision Making Capability Framework, pp. 21-33 of this submission), it relies too heavily on communication. Inclusion Australia is very concerned that the suggested approach will negatively impact participants with complex communication support needs.

The SDM Paper mentions 'participants with other sensory, physical or communication disability may also need support for decision making from time to time' (p. 6). It also talks about developing communication (verbal or alternative) as a strategy to build decision making capacity (p. 12). However, these ideas need to be unpacked and considered more deeply.

From the SDM Paper alone, we are not confident the NDIA has an adequate understanding of complex communication support needs in the context of supported decision making. There is a significant body of work by Australian researchers on this topic.

All participants with complex communication support needs require ongoing capacity building opportunities to develop the different ways that they communicate – through their natural language as well as through the use of alternative and augmentative communication strategies. It is essential too, that participants with complex communication support needs, regardless of their age, receive ongoing capacity building to develop the skills of their paid and informal support people in observing, recognising, understanding and supporting the continued development of the participant's expressive communication.

Steven is a 25 year old man who has complex communication support needs, significant physical disability and developmental disability.

As a child, Steven attended a separate "special" school for children with disability. He was not educated alongside his same aged peers without disability and even with the special school environment he was educated in a class of children all of whom had significant physical disability and complex communication support needs. Steven was not educated alongside peers who could walk and talk independently. He was therefore deprived of an educational environment that was rich in the age-appropriate language of children his own age.

Many assumptions were made about Steven that limited his access to learning how to use alternative and augmentative forms of communication (AAC). It was thought his cortical vision impairment would mean he would not be able to see symbols well enough to use AAC. It was thought his motor skills were too impaired for him to be able to use an AAC device. It was thought he did not have enough intellectual capacity to understand language, to understand how symbols could be used to communicate, to learn how to use AAC.

Consequently, he was left unable to express his basic needs or wants, unable to report incidents of abuse, unable to share ideas, opinions or feelings, unable to tell people when he was feeling unwell or in pain or to express where that pain was. He was unable to participate in meaningful education and was frequently bored, in pain, distressed, frustrated and lonely. He engaged in self-injurious behaviours as a result of his frustration and distress.

When Steven left school, he had no way of communicating effectively and was not included in decision making processes in a meaningful way.

Luckily, Steven's family believed more was possible for him and they wanted him to have control over his adult life. They connected with a group of families of other young adults with developmental disability and complex communication support needs who were together exploring learning to use comprehensive AAC systems with the support of a Speech Pathologist with specialist skill, training and experience in AAC interventions with successful outcomes.

Each family was actively exploring a Microboard model to better support their family member with complex disability. Each family and developing Microboard recognised the need for their family members with complex disability to be better supported to communicate their wishes for their life, to be better supported to make and communicate choices and decisions that affected their life, to have increase autonomy and control.

Steven and his supporters were introduced first to a simple Aided Language Display so that his paid and unpaid supporters could get used to providing aided language stimulation with a simple tool. They quickly realised they needed more language and were provided with an Early Functions Pragmatically Organised Dynamic Display (PODD) communication book. They were taught how to model using this book in all their interactions with Steven and they were taught how to provide partner assisted auditory and visual scanning so that Steven could also explore using the book. They were coached in the way they observed and responded to Steven so that they improved their understanding of his natural language but could also support him to learn ways of moving that could be more easily recognised as a yes or no response by all of his communication partners.

Quickly, Steven showed he needed more language and a more sophisticated Partner Assisted Auditory and Visual Scanning PODD book was personalised for him. He also began to explore using a switch to call attention to those around him, to let them know he had something to say so they could scan his book. And the Speech Pathologist organised trials with an eye gaze computer interface.

Because his support team had been so effective in making the tools consistently available and consistently modelling how to use them, Steven was able to demonstrate the potential to learn how to use the eye gaze system with a PODD page set for more independent, spontaneous and autonomous communication.

Steven is now using his AAC toolkit to communicate clearly that he wants to engage in paid work, that he wants to tell children in schools their rights, that he wants to talk to medical students, so they know that people with disability want to live, have good lives and want to be listened to. He wants to employ his own staff and his Microboard are facilitating this. Steven is communicating his ideas for the support worker adverts, he is co-designing the questions to include in the interviews and he is choosing who will be on the interview panel with him.

When he has become so unwell that he has been unable to use his AAC toolkit, his family, Microboard and paid supports know him well enough and have listened to his opinions that they feel more confident they can make decisions he will be happy with in urgent medical situations. They have been able to strongly advocate on his behalf for further medical investigation or treatment when Doctors have been reluctant to intervene because they know that Steven loves his life and wants to live.

We are concerned that people with complex communication support needs may be inaccurately assessed by the proposed *Decision Making Capability Framework*. The NDIA needs to consider that a perceived lack of decision making capacity can point to an issue with the supports rather than the decision maker themself.

> David is a man in his 50s who has complex communication support needs.
>
> When David was recently released from a psychiatric facility, his family engaged the support of a communication consultant to help him make some decisions about his next steps in life.
>
> David's family described him as unable communicate or make decisions. Yet within an hour with his new communication consultant, David began to show some consistent signs for 'Yes' and 'No'.
>
> Only a skilled person was able to recognise and support his decision making. If David did not have access to this formal decision support, his supporters would have continued to presume he was unable to make decisions.

We believe the NDIS Support for Decision Making policy needs to be stronger about presuming competence. All people with disability, including people with complex communication support needs, should be presumed to have capacity to make their own decisions. When someone is described as being unable to make decisions, it should be a red flag for NDIS Planners and LACs to consider whether the participant has appropriate communication and decision-making supports in place.

Recommendation

We recommend the NDIA undertakes much more research and consultation on complex communication support needs before finalising their Support for Decision Making policy.

We recommend the NDIS Support for Decision Making policy takes a stronger stance on presuming the capacity of all people with disability to make decisions with the right supports.

Consent

The suggested Support for Decision Making policy relies on participants giving their consent. While this appears fine on the surface, this can be a problem for people with intellectual disability, especially those with complex communication support needs.

Some people cannot or will not consent to supported decision making, but they still have the right to it. The Support for Decision Making policy and NDIS operational framework for Consent and Informed Decision making needs to consider both these groups.

Those who will not consent

This is the story of a young man who will not consent to supported decision making:

> Grahame is a young man with Down syndrome.
>
> Grahame is a very independent person who takes pride in his ability to live an ordinary life.
>
> He is so keen on living an ordinary life that he tells everyone that he no longer has a disability and has 'grown out' of his Down syndrome, despite the fact it is a lifelong condition.
>
> Grahame requires significant NDIS supports in all areas of his life from home and living to self-care and personal safety. He currently relies on informal support from his family and friends to make his own decisions.
>
> Grahame, however, will insist that he does not need any support because he does not identify with his disability.
>
> For these reasons, Grahame has an NDIS nominee appointed. His nominee collaborates with Grahame and his network of family, friends and paid supports to make sure his will and preference is included in his NDIS plan and his right to make his own decisions is being upheld.
>
> Even though he is able to communicate verbally, Grahame would not consent to support for decision making because he does not identify as having an intellectual impairment.

Grahame is not the only NDIS participant who will not consent to supports. Other examples include people with psychosocial disability who require episodic decision-making support and may not consent to that level of support when they are feeling well.

Those who cannot consent

The definition of consent as something that is either written or verbal (p. 28) entirely leaves out people who use alternative forms of communication. Using this definition of consent, many people with complex communication support needs will be unable to consent to support for decision making.

There are other ways to consent. For example, DDWA communication consultants have supported people to give informed consent using alternative communication tools such as Talking Mats[2].

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[2] Talking Mats are a communication symbols tool. More information available here: https://www.talkingmats.com/

Recently, a government department engaged a group of adults with developmental disability in paid work as models. The photographs would be used by the department to ensure that their web and print materials were inclusive in their representation of a more diverse range of people accessing their services.

The group of adults had shared information about the work opportunity and agreed to be involved prior to the photoshoot. At the photoshoot, representatives from the department brought out consent forms. These forms were standard consent forms. They were not in an Easy Read or easy to understand format. There were no images, only small text on one page.

The Department representatives realised that this was not accessible. They suggested that the models could take the consent forms away and a parent or guardian could sign the form and return it.

No attempt was made to make the consent process accessible to the adults themselves, and there was no consideration that it was possible for this group of adults to each make their own decision and give their own consent about how the photos could be used. This led to a complaint to that Department.

Several years ago, the same group of people were involved in a film project with some university students.

The university lecturer engaged a Speech Language Pathologist (SLP) with experience, skill and expertise in supporting people with developmental disability and complex communication support needs to make complex decisions. The lecturer wanted to know to what extent the adults with disability were happy to share the films that they appeared in.

The university required signed consent for the film to be shown by the lecturer in class, for the film to shared on the university intranet, and for the film to be shared more widely on social media or the university website. There was also a requirement for all students and actors to give consent for the tutors to view the films for marking and for the films to be shared with the all students who had participated in the film making process.

The SLP broke each of these concepts down carefully, explaining what it would mean to each of the adults with disability involved, giving examples of who would or might be able to view the film if consent was given to each separate request to share the film.

The SLP used a Talking Mats approach to explore with each individual how they felt about different people viewing the film – if they were "OK with that" , "not OK with that" or "not sure" about the tutors viewing the film to mark the students, about the students they worked with watching the film, about students they did not know watching the film in class, about their family, friends or people they did not know well watching the film on social media or the website.

Their responses were given through either their known natural language that included gestures and facial expression or changes in breath and vocalisations, but also included pointing, tapping, use of symbols and single message switches. The responses were mapped via the Talking Mat and the Talking Mat was revisited several times by both the SLP and supporters to check that it had accurately captured the way the felt and whether or not they were giving consent (saying "I'm OK with that") or not.

> It was a lengthy but important process that gave control to the actors with developmental disability and complex communication support needs in the decision making process.
>
> Each person was able to give or refuse their consent in a supported but autonomous way.

There are also people who cannot consent at all. However, their rights to supported decision making should still be upheld.

Recommendation

We recommend the NDIA considers people who cannot or will not consent to supported decision making and ensure their rights are still upheld in the Support for Decision Making policy and operational framework for Consent and Informed Decision Making.

State and Territory Guardians / Trustees

The SDM Paper talks about the intersection between NDIS nominees and state and territory guardianship legislation and acknowledges these are inconsistent due to different laws and rules in each state and territory (p. 7). While the issues have been recognised in both the SDM Paper and the companion paper (p. 8), we cannot see how the proposed Support for Decision Making policy intends to overcome them.

The NDIA has suggested that under the new policy, guardians 'should still try to give you opportunities to be part of making decisions about you and your life. They should also try to understand your will and preference… We will keep encouraging substitute decision makers to involve you in decisions about you' (p. 15). Most guardianship statutes around the country do not mention support for decision making or will and preference. These laws are set by the states and the NDIA does not have authority here.

There needs to be clearer information on how the NDIS interacts with guardianship. It is not enough to say that '[a]n NDIS nominee only makes decisions that are related to the NDIS' (p. 7). NDIS staff need sufficient understanding of the role and authority of guardians, so they do not either ignore or overstate their role.

A person may have a guardian, but that guardian might only have decision making authority in very few areas of a person's life. Consider an NDIS participant under NSW guardianship who only has an accommodate function included in their guardianship order. The guardian is the legal decision maker for accommodation decisions, and they make those decisions by following state legislation. However, the guardian cannot make decisions about other things in that person's life, like the services a person receives.

The NDIS Support for Decision Making policy should not imply guardians have plenary decision making authority and should not overstate a guardian's authority to make decisions based on will and preference. A guardian's authority is bound by each state and territory's laws and the participant's individual guardianship order. The NDIA needs to engage with both the 'will and preference' model of supported decision making *and* the 'best interests' model of guardianship. The ALRC has already anticipated this challenge.

The NDIA should look more closely at the guidance that the ALRC has already provided on supported decision making at a Commonwealth level[3].

Recommendations

We recommend the NDIA clearly explains the limitations of its policy on guardianship, its relationships between different state/territory guardianship systems and how the NDIS Support for Decision Making policy will interface with those systems.

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[3] See Chapter 4, especially Articles 4.8, 4.9 and 4.10 of ALRC Report 124. Available here:
https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/

We recommend the NDIA provides clear guidance for LACs, planners and other NDIS staff around the role and authority of guardians in their specific state/territory, and how the NDIS policy interacts with state/territory guardianship systems.

We recommend the NDIA more closely follows the recommendations made by the ALRC around supported decision making at a Commonwealth level.

Decision Making Capability Framework

Ordinary decision making and dignity of risk

The description of decisions in the *Decision Making Capability Framework* is not true to life. It holds people with disability to a much higher standard of decision making than 'ordinary' decision makers use.

For example, the SDM Paper states the NDIA thinks 'you should be able to weigh up the positives and negatives for each option and consider alternatives… for real decision making, you must also be able to consider the consequences of each option and then decide which one is best for you' (p. 10). This is an unrealistic portrayal of how people ordinarily make decisions, especially smaller everyday decisions. Often, people simply make decisions based on what they feel in the moment. This ordinary decision making style should be included in any description.

The NDIA description also implies that people must make the decision that is in their best interest. This issue is more obvious in the Easy Read version. For example, on page 15 it reads 'When you make a decision, you should think about who can support you to make a good decision.' People with intellectual disability picked up on this wording and commented: supported decision making is not about making good decisions, it is about making the right decision for you. This might sometimes be a bad decision! But it is still our right to make bad decisions – just like everyone else.

Only making 'good decisions' is not in line with dignity of risk. The NDIA previously recognises that dignity of risk is an important part of building your decision-making ability (p. 5) however this principle is not carried through in the *Decision Making Capability Framework*.

People with disability have the right to make risky and unwise decisions and should be supported to do so. Supported decision making is about the process, not the outcome.

"Supported decision making is not about making good decisions, it is about making the right decision for you. This might sometimes be a bad decision! But it is still our right to make bad decisions – just like everyone else."

Risk enablement[4] should be better considered in the framework. People with disability told us:

- We should be supported in knowing how to understand the consequences and the risks,

- We should be supported to take risks if that's what we want to do,

- People should know that it is okay to make mistakes, and this is how we all learn and become better, more independent decision makers.

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[4] Relevant resources developed by Christine Bigby and Jacinta Douglas from the Living with Disability Research Centre with input from people with disability, supporters and stakeholders includes NSW CID. Available here: https://www.enablingriskresource.com.au/

Recommendations

We recommend the NDIA describes decision making in the *Decision Making Capability Framework* in a more true-to-life way.

We recommend the NDIA changes the emphasis of the Support for Decision Making policy away from 'making good choices' and towards 'having good support to make choices'.

We recommend the NDIA better considers dignity of risk, enabling risk and the right to make unwise decisions in the *Decision Making Capability Framework.*

Capability and Capacity

The NDIA has used the words 'capability' and 'capacity' interchangeably throughout the SDM Paper. There needs to be a greater distinction between these. This becomes especially confusing in the *Decision Making Capability Framework* as 'capability' is the central part.

'Capability' seems to imply that some people are not capable of making decisions, whereas 'capacity' means that everyone has some ability to make decisions. This small semantic difference makes a very big practical difference.

In the *Decision Making Capability Framework*, capacity is included under 'circumstances that influence decision making' (p. 10). This is problematic and implies that capacity to make your own decisions is something that you either do or do not possess.

This framing of capacity is not in line with current understandings of supported decision making or the UNCRPD, in particular, Article 12 – Equal recognition before the law.

If everyone has the right to make decisions, it follows that everyone has the capacity to make decisions regardless of their capability. Capacity must be framed not as a circumstance, but a quality that all people possess.

We understand that capacity can be built with the right supports. Decision-making is a skill that can be learned. A more appropriate 'circumstance that influences decision-making' would be access to the appropriate decision making supports.

People with intellectual disability were not sure about the capability section of the Easy Read version of the SDM Paper (p. 11). They commented that everyone can make their own decisions, it is about having the right support and being supported to build skills. People with intellectual disability felt that this was missing from the SDM Paper and that including more information about this would make it more person-centred.

"Everyone can make their own decisions, it is about having the right support and being supported to build skills."

Recommendations

We recommend that all people should be presumed to have capacity for supported decision making under the Support for Decision Making policy.

We recommend the NDIA defines and uses the terms 'capability' and 'capacity' more clearly.

We recommend the NDIA replaces 'capacity' with 'access to good decision making supports' under section 4.3.1 Circumstances that influence decision making.

We recommend the NDIA includes more information about how they will determine capability, including how they will look for:

1. The strengths a person already has,
2. The supports that a person already has or needs in their life,
3. How the NDIS can support people to build skills.

Decision Making Continuum

The Decision Making Continuum as described on page 11 of the SDM paper is highly flawed.

Firstly, we see the same issue as described above of confusing capacity and capability. The continuum uses 'capacity' to describe participants at one end and 'capability' at the other end of the scale. This runs into the same issues of contradicting both current academic knowledge of supported decision making and the UNCRPD.

Secondly, the definition of 'autonomy' needs improvement. The SDM Paper defines autonomy as 'how much you can do without help'. This is limited and not in line with current knowledge and understanding of autonomy. Academics studying autonomy have found it is not just something that arises individualistically, but through relationships to others. Relational autonomy acknowledges that autonomy is an outcome of the deeply interpersonal and relational aspects of human nature[5]. Relational autonomy is also more in line with other cultural understandings of decision making.

Thirdly, the continuum should not be from low to high capacity at all. This approach is based in a deficit, medical model of disability. Rather the focus should be on the level of supports required. Describing capacity in terms of how people with disability can be supported to make their decisions is more in line with the social model of disability that underpins the NDIS.

Very few, if any, people make all their decisions independently and this should not be the goal of building the capacity of people to make decisions. Every person consults others to make decisions in their life, from asking a friend's opinion in a retail dressing room to engaging the services of a mortgage broker and real estate agent when buying a home. Getting help with decisions is an ordinary part of decision making.

Learning how to seek advice and research options to make an informed decision are skills that can be built with the right supports. All people with cognitive disability need opportunities to learn decision-making skills and should not be boxed into categories of low and high capacity in order to qualify for support.

Recommendations

We recommend the NDIA redefines autonomy to include relational autonomy.

We recommend the NDIA redesigns this continuum to focus not on capacity/capability but on the level of support required.

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[5] Watson, J (2016) 'The right to supported decision-making for people rarely heard' (pp. 62-67), available from: https://dro.deakin.edu.au/eserv/DU:30083812/watson-theright-2016A.pdf

Decision factors

The *Decision Making Capability Framework* describes different decision factors including type of decision, level of decision and impact of decision, however it is unclear *how* these factors interact with the suggested policy.

Inclusion Australia assumes that certain decisions will trigger more supports, but we need more detail on how these factors will be used in the framework before we can provide meaningful feedback.

Recommendations

We recommend the NDIA consults more deeply with people with disability, families and other supporters, and disability representative organisations on how decision factors interface with the NDIS Support for Decision Making policy.

Decision examples

The examples of decisions in the SDM Paper do not reflect the complexity of real-life decision making; they tended towards low-level, repetitive stories. For instance, a child choosing to wear a blue t-shirt on a cold day.

These examples run the risk of encouraging supporters to oversimplify supported decision making, and to frame decisions with 'only good options' – that is, where the decision maker is only supported to choose from pre-approved options that are desirable to the decision supporters.

The NDIS Support for Decision Making policy is an opportunity to lift people's expectations around the ability of people with cognitive disabilities to make important life decisions.

To uphold a person's will and preference, people with disability need support both to make decisions and to have their decisions acted upon. This second step of enacting a decision can look very different with more complex decisions.

It would be beneficial to see how the *Decision Making Capability Framework* might work with a more complex life decision, for example a person with intellectual disability choosing to have a baby.

Recommendations

We recommend the NDIA provides examples for how the *Decision Making Capability Framework* would support people with disability to make complex life decisions.

Person-centred, strengths-based and accessible

People with intellectual disability made many comments and suggestions about how the *Decision Making Capability Framework* could be more person-centred, more strengths-based and more accessible.

The SDM Paper talks about making information easy for everyone to use and understand, but the NDIA does not say how this will be done. It also mentions creating new information to help people with disability learn about making their own decisions, but again there is no explanation of how that

information will be created or what kinds of information will be included. People with intellectual disability were concerned the information won't be accessible.

People with intellectual disability were also concerned about how the NDIA would determine their capability. They wanted more information on how the policy will help NDIS staff to look for:

1. The strengths and experiences of the decision maker,
2. The supports that a person already has or supports that they need in their life,
3. How the NDIS can support people to build their decision making skills.

People with intellectual disability cautioned that there is no one size fits all in supported decision making. They told Inclusion Australia, 'we don't all make decisions in the same way' and suggested that the NDIA should explain different ways for making and supporting decisions so that people can choose a way that is right for them. Likewise, information for decision supporters cannot be generalised and should be centred around the individual person they are supporting.

Recommendations

We recommend the NDIA co-designs the *Decision Making Capability Framework* with people with cognitive disabilities (including intellectual disability, autism and acquired brain injury), their families and other supporters, and disability representative organisations.

We recommend accessible information is designed for decision makers that focuses on the strengths and skills people already have to make their own decisions, the supports that a person has or needs in their life, and how the NDIS can support people to build skills.

We recommend the NDIA explains different ways for making and supporting decisions so that people can choose a way that is right for them.

We recommend information designed for decision supporters is centred around the person with disability they are supporting.

Safeguards

Inclusion Australia was pleased to see the NDIA wants to identify appropriate safeguards (p. 17), however we need more detail on how this will look in the proposed policy.

The SDM Paper is clear that the NDIA wants to reduce the number of nominee appointments. While it is important to reduce substitute decision making, there need to be appropriate guard rails in place.

Here are some risk factors for people with intellectual disability and how they might play out in and NDIS planning situation:

Risk factor	Example
Acquiescence[6]	A participant agrees with their planner's suggested option even though they do not

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[6] The Speak Out resource, *Communication – it's not a spectator sport* describes acquiescence as follows: "Many people with intellectual disability say 'yes' to questions or accept and agree with things, regardless of

	understand it. Sometimes this could be choosing an option that goes against what the participant's will and preference.
Echolalia[7]	A participant repeats back the last option given by their planner without intending that to be their decision.
Deciding to make no change	A participant makes no changes to their current plan or goals. This is still a decision and should be supported as such.
Making decisions that go against one's own human rights	A participant choosing to stay in a home environment where they experience violence, abuse, neglect or exploitation.
Inadequate support for people with borderline or mild intellectual disability	A participant with borderline intellectual disability that comes across as very capable may not be provided appropriate decision-making support at a planning level, thus leading to inadequate funding for decision-making supports in their plan.

We can see some of these risk factors play out in this story of a person who appears to make a decision to stay in a home that is not ideal:

Edward is an older person with intellectual disability who lived in a large Victorian institution for many years.

The long history of violence, abuse, neglect and exploitation in this institution has been well-documented. In one such incident, Edward witnessed a fire that killed 9 of his co-residents.

When the institution was shut down, Edward was moved into a state-run Supported Independent Living (SIL) group home with four strangers.

While Edward's new group home is a marked improvement on the institution, he has experienced violence and abuse while living with there.

When Edward was asked by his NDIS planner if he wanted to move out of his SIL accommodation, he emphatically responded no.

what has been asked, and often without really wanting to. This is called acquiescence. People with intellectual disability often mask their communication difficulties to avoid the stigma of being labelled as having a disability. It is very common for people to adopt a passive communication style, allowing the more powerful person to control the conversation."

[7] Echolalia is the repetition of words or phrases made by another person and may or may not reflect comprehension or communicative intent. It is commonly seen in people with autism spectrum disorders, intellectual disability, acquired brain injury and psychosocial disability.

However, the planner did not appropriately support Edward to make this decision. Compared to his years spent living in an institution that many compared to a prison, his current group home seems like the far better option.

Edward was not given the information or opportunity to try out other living options. Based on his experiences of home and living, Edward is not aware that he could be living somewhere free from violence – for example – in an apartment with one other housemate of his choosing.

People with intellectual disability need opportunities to try different options before making a decision. Having an intellectual disability makes it difficult for people to understand abstract concepts. Unless people have viable options on the table, they are not being supported to make a real decision.

'Exploration and design' funding is mentioned in the NDIS Home and Living Paper but there is no clear guidance on this yet. Perhaps this could be a way for participants to try out different options before making a decision.

Further, family members sometimes step into the nominee role in an attempt to safeguard their loved one from inadequate or inappropriate NDIS plans. Research has shown that an important part of supported decision making is knowing the person[8], and NDIS Planners do not typically know their participants as well as their nominee. By removing nominees, this risks NDIS Planners becoming substitute decision makers.

Inclusion Australia believes there is an important role for independent advocates in safeguarding the supported decision making for people with intellectual disability in the NDIS. This is discussed in more detail in the following *Formal Decision Supporters* section of this submission.

People with intellectual disability have put together some advice for decision supporters to ensure they are building the capacity of the decision maker and considering what the person with disability wants:

Advice for decision supporters:

- Keep a record of the different parts of the supported decision making process so there is something to look back on

- Be honest about the supported decision making process and what is or isn't working

- If the decision maker is comfortable with it, share the process with others (like a peer support group)

- Get feedback from the person with intellectual disability! Ask them if the support is right for them or if they want things to be different.

- Get feedback from other people in the person's life if they are comfortable with it

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[8] Douglas, J., & Bigby, C. (2018). Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability. Disability and Rehabilitation, 1-8. Available here: https://www.supportfordecisionmakingresource.com.au/uploads/1/1/0/7/110745505/douglas_and_bigby_2018_-sdm.pdf

- Reflect on the process together afterwards

- Always listen to the decision maker and make sure they are at the centre of the supported decision making process

Recommendations

We recommend the NDIA provides more detail on safeguards in the proposed Support for Decision Making policy.

We recommend the NDIA develops and implements adequate supported decision making training for NDIS Planners and Local Area Coordinators (LACs). This training should be co-designed and presented by people with cognitive disabilities – including intellectual disability, autism and acquired brain injury.

We recommend 'exploration and design' funding is included in the Support for Decision Making policy to enable participants to make decisions based on real, viable options.

We recommend the NDIA refers participants to independent advocacy organisations when there is a need for formal, independent support for decision making.

Formal decision supporters

Inclusion Australia welcomes the idea of formal decision supporters, especially for people with no or little informal supports. We thank the NDIA for responding to concerns of advocates here.

To reduce conflict of interest and undue influence, the NDIA must ensure that formal decision support is provided *independent of service provision*.

It would be highly inappropriate for service providers to support their customers to make decisions between different provider options. This issue has already been well discussed in submissions and reports on Support Coordination, including submissions to the NDIS Support Coordination Discussion Paper and the Tune Review.

The SDM Paper suggests that providing formal decision support will be the role of Support Coordinators. We do not agree that this is the role of a Support Coordinator and that formal decision support should sit with an *independent decision supporter*. There is an important distinction here – the role of a Support Coordinator is to take direction from the participant to make a decision; whereas an independent decision supporter should support the participant to make the decision itself. This is particularly important in areas where there are thin markets, or if the participant's decision is unpopular.

Our position is that independent decision-making support is best placed within independent advocacy organisations and Disability Representative Organisations (DROs) to reduce conflict of interest or undue influence, and to harness the supported decision making skills and capacity already present in these agencies. Independent advocates and DRO staff have been supporting people with disability to make their own decisions for decades.

Inclusion Australia has previously asserted in our submission to the Support Coordination Discussion Paper in September 2020:

"There is definitely a difference between the role of a support coordinator and an independent advocate who works for a government-funded disability advocacy organisation. The key difference is that an independent advocate is always 'on the side of the person with disability and no-one else's'. Most support coordinators understand that their loyalties are divided between the NDIS participant (who presumes the support coordinator is on their side), their employer (who relies on billable minutes and repeat business), and the NDIA which is an essential source of participant referrals.

The relationship between support coordination and independent advocacy needs to be clearly defined and agreed to by the NDIA, the NDIS Quality and Safeguards Commission and DANA as a priority. Most importantly, support coordinators - and all providers working under the NDIS Practice Standards - need to know when to call in an independent advocate.

In general, we suggest good practice for support coordinators includes contacting an independent advocate when

- There is conflict about choices or decisions that need to be made that cannot be resolved by talking it over with the person, family, friends and paid staff

- The participant is under undue or inappropriate influence by any person or organisation

- The person and their support network do not have the advocacy skills or knowledge to resolve it themselves (e.g. an abuse investigation, making an application to a Tribunal)

In the same way that independent advocacy might be necessary when support coordination cannot resolve a problem, independent support for decision-making is fundamental to ensuring that support coordinators are taking direction, not making decisions.

Some participants need independent support for decision-making to ensure that there is a clear separation between life decisions (e.g. where to live) and NDIS decisions (e.g. in-home personal care services). This can be via individualised funding to facilitate the set-up of a circle of support, or with a volunteer program like Citizen Advocacy, or through peer groups run by Disabled Peoples Organisations. Independent support for decision-making is most important for participants who will predictably need long-term, collaborative decision-making supports (e.g. circle of support)."

In terms of funding formal decision supporters, Inclusion Australia believes this service should be block-funded. The need for formal decision support is likely to be one-off or episodic, such as when a participant reaches a major life transition point like finishing school or moving out of the family home. It is neither efficient, effective nor cost-effective to fund episodic support through individualised plans.

Recommendations

We recommend that formal decision support under the NDIS Support for Decision Making policy be provided by independent decision supporters, best placed in independent advocacy organisations and DROs.

We recommend independent decision support be block-funded.

We recommend the NDIA work closely with DROs to set up formal decision support services.

Young people and children

Inclusion Australia strongly supports the NDIA's proposal to build decision support capacity of young people (p. 17). However, this needs to begin earlier than age 16.

Decision making is a learned skill. A growing body of international research suggests that while non-disabled children tend to learn decision making skills more easily as they grow, children with intellectual disabilities and their families need explicit skill-building from early childhood[9]. We recommend working with children and families from early childhood, so they are well-equipped to do supported decision making by adulthood.

This approach is already being used in a current ILC funded project led by Microboards Australia. We encourage the NDIA to learn from the findings of this project.

In particular, young people and children with complex communication support needs rely on the capacity of their informal supporters to have their wants and needs heard. Ongoing capacity building support for these children and their informal supporters is essential to build capacity to make supported decisions by the time they turn 18. This must include ongoing capacity building for their supporters to provide aided language stimulation using comprehensive full language augmentative communication systems.

For adults with complex communication support needs who have not had this intervention in childhood, there needs to be an opportunity for formal and informal supports to build capacity for aided language stimulation to make decisions.

Capacity building activities also need to be provided to formal supporters, such as school staff. Most children do not have access to a communication partner who is trained in and can support the learning of communication.

Appropriate safeguards must be in place for young people as they transition away from the UN Convention of the Rights of the Child (UNCRC) view of decisions made in 'best interests of the child' and towards the 'will and preference' rights afforded adults under the UNCRPD and other human rights frameworks.

People with intellectual disability are regularly infantilised which affects their transition to independent decision making once they turn 18. Building decision making capacity for young people with intellectual disability and their supporters through peer support and other services is essential.

Special consideration should be given to young people in out of home care and institutional settings, an area in which research and evidence is still emerging. These groups are less likely to have informal supporters and should be thoughtfully supported so they do not fall through the gaps.

Half of all children in out of home care are First Nations people, and many of these children have a disability. In these cases, NDIS nominees and guardians often exclude parents from decisions are prevent the child from receiving culturally appropriate support for decision making.

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[9] Glen, K. B. (2017) Piloting Personhood: Reflections from the first year of a supported decision-making project. Available here: http://dev.supportmydecision.org/assets/tools/Piloting-Personhood-by-Judge-Kristin-Booth-Glen.pdf

Recommendations

We recommend the NDIA provides capacity building supports for decision making and aided language stimulation to children and their families from early childhood.

We recommend the NDIA funds peer support for young people, their families and other informal supporters.

We recommend the NDIA introduces appropriate safeguards for young people as they transition between decision-making frameworks at the onset of adulthood.

We recommend the NDIA gives special consideration to decision making supports for young people in out of home care and institutional settings, particularly First Nations children and young people.

Role of the participant

We noted that the SDM Paper changes language in this section from the right to make decisions to the 'right to make choices' (p. 21). There is a difference between 'choice' and 'decision' – a choice is generally the selection of one option or another; a decision is the entire process from making a choice to having that choice acted upon and followed through.

People with intellectual disability and their supporters have told us that one of the biggest issues they face in doing supported decision making is a lack of action or follow-through on their decisions. Making choices that don't impact a participants life is not a meaningful exercise and funding 'choice-making' alone does not provide value for money to the NDIA.

In addition, the responsibility of participants around decision supporters (p. 21) is confusing. It includes both informal and formal supports (family, friends, peers and support workers). These should be separated out.

There is no mention of participant's right or responsibility to engage a formal decision supporter where appropriate. This should be stated explicitly and separately.

Recommendations

We recommend using the word 'decision' rather than 'choice' under the role of the participant.

We recommend separating out responsibilities for informal and formal supports.

We recommend adding another responsibility: 'to engage a formal decision supporter where appropriate'.

Role of the NDIA

The NDIA will be responsible 'to avoid reliance on substitute decision making wherever possible' (p. 21). Inclusion Australia agrees with this responsibility but adds that in doing this the NDIA must appropriately consider safeguards (see Safeguards, pp. 25-28 of this submission).

The NDIA will also be responsible for ensuring 'connection to other community and mainstream based decision making supports' (p. 21). This was an intended role of LACs and NDIS Partners in

Community under the ILC policy framework, however Inclusion Australia is aware that this is not currently happening.

 LACs have very little awareness of ILC activities in their areas and are not well connected with ILC project teams. LACs are largely unaware of community and mainstream supports for decision making. In our experience, DROs and ILC project teams generally provide capacity building activities to their existing networks of people with disability as they do not receive referrals from their local NDIS offices.

We agree that the NDIA should ensure connection to community capacity building activities, however they cannot rely on existing structures to do so. LACs and Planners need to be properly informed of the supported decision making capacity building activities available in their area. Perhaps a directory of supports could be developed that all NDIS Partners in Community can access.

In order for the NDIA to connect to community and mainstream decision making supports, these supports need to be funded. Inclusion Australia believes decision making capacity building activities fit well under Tier 2 or ILC funding (see Funding, pp. 34-35 of this submission).

One of the NDIA's responsibilities is 'to review progress capacity building of decision making skills plan review' (p. 21). This responsibility was confusing and lacked context. We would like to see more detail on this to give informed feedback.

Recommendations

We recommend the NDIA adequately considers safeguards when moving away from substitute decision making in the NDIS.

We recommend the NDIA develops processes to ensure NDIS Partners in Community are well connected with capacity building supports in their area.

We recommend the NDIA works with Government to ensure adequate funding for community and mainstream decision making supports.

We recommend the NDIA provides more information and seeks feedback on the 'progress capacity building of decision making skills plan review'.

Role of service providers

Inclusion Australia strongly agrees that it is the responsibility of service providers 'to provide the participant with opportunities to explore other options' (p. 22). People with intellectual disability need the chance to try out different options in order to make an informed choice. It seems like the 'exploration and design' funding described in the Home and Living Paper would be relevant here.

We were pleased to see the responsibility 'to safeguard the participant against undue influence in making and implementing decisions' under the role of service providers.

We believe this is an important responsibility for not only service providers but also the NDIA and informal supporters. Appropriate safeguards must be implemented at all levels of supporting decision making in the NDIS.

In particular, there needs to be a separation between disability housing service providers and decision support service providers. People with intellectual disability, their families, supporters and

advocates see group homes as one of the places that most undermines people with disability's rights to make decisions.

Our community told us that people in group homes do not get to choose who to live with, what to eat, what to do or when to do it. These are the most basic everyday decisions.

Service providers need clear guidance on how to support decision making, who can provide independent decision support, undue influence and the consequences of not upholding a person's right to make their own decisions. The NDIS Quality and Safeguards Commission should play a role here.

It's also important to note that sometimes the 'undue influence' can be the NDIS LAC or Planner. There needs to be appropriate mechanisms in place to safeguard against this issue, perhaps through independent advocacy or independent decision support.

Recommendations

We recommend the NDIA ensures appropriate levels of funding are made available so participants can afford opportunities to explore other options.

We recommend the NDIS Quality and Safeguards Commission takes responsibility for guidance and monitoring of supported decision making processes by service providers, especially home and living providers.

We recommend the responsibility 'to safeguard the participant against undue influence in making and implementing decisions' also be applied to the roles of decision supporters and the NDIA.

Funding

During our engagement on the SDM Paper, the Inclusion Australia community asked many questions about how the NDIA will fund supported decision making. The NDIA has previously said that funding is part of the implementation phase. While many of the details will come later, we believe it is critical to think and talk about funding now.

There seems to be two main types of support that would need to be funded under the proposed Support for Decision Making policy:

1. Formal decision supporters, and,
2. Supported decision making capacity building supports.

Formal decision supporters

As mentioned above (see Formal decision supporters, pp. 28-29 of this submission), Inclusion Australia suggests independent decision supporters based in independent advocacy organisations are best placed to provide formal decision support.

These services should be made available for people who do not have informal supporters, or whose informal networks do not have capacity to take on additional decision support responsibilities.

There is a role for independent decision supporters in big life decisions. The NDIA has already identified some major life transitions – Planners and LACs should be trained to recognise these and include independent decision supporter services in NDIS plans accordingly. These decision points are one-off or episodic in nature, so we recommend ongoing funding is more suitable than an individual line item.

Capacity building supports

The SDM Paper talks a lot about capacity building supports for both decision makers and their decision supporters. However, there is very little information on how these will be funded.

Inclusion Australia believes ILC is a good mechanism for funding peer support, self advocacy groups and other decision making capacity building supports like workshops (see ILC/Tier 2 below). Independent advocacy organisations and DROs are a natural fit to provide these services as they already have content expertise and are embedded in local communities around the country.

These kinds of supports are more suited to ongoing program funding as they are drop-in style programs that provide episodic support. It would not be responsive, sustainable or cost effective to fund this through individualised plans.

ILC / Tier 2

The proposed Support for Decision Making policy and the changes suggested in the Home and Living Paper both rely on community and mainstream based capacity building supports, including peer support and self advocacy groups. Inclusion Australia strongly agrees these settings are the best place for people with disability and their supporters to build their supported decision making skills and capacity.

The SDM Paper suggests an action to 'Promote the use of peer support networks and other individual capacity building supports. These are funded through ILC, state and territory governments

or mainstream service systems', but makes no commitments around ongoing funding for these supports.

In our experience, community based capacity building supports are poorly funded. This issue has been worsened by the redirection of state and territory disability funding towards federal grant schemes like the ILC. Peer support networks, self advocacy groups and decision making capacity building activities have recently been propped up by one-off, short-term ILC grant funding, or by not-for-profit organisations with little to spare. Now that the responsibility for ILC has moved to DSS and no plans for the scheme have been published beyond this financial year, it is not clear to these capacity building support providers *how* they will continue to operate.

The Home and Living Paper also talks multiple times about participants using peer support networks to support their decision making. Again, there is no mention of infrastructure to support peer support networks to fulfill this integral function.

ILC, or Tier 2 as it is sometimes called, was specifically established for this purpose. The ILC Policy Framework (p. 6) says:

> 'The NDIS will fund decision support, safeguard supports and capacity building for participants… The NDIS has an important role to play in providing decision-making supports and building individual capacity for people to advocate for themselves (self-advocacy)
>
> …
>
> It will also support peer support, where people with disability or their carers share lived experiences with others on similar journeys. This is an important means of capacity building that acknowledges and respects the lived experience of disability. There is an opportunity through ILC for the NDIS to support people with disability to lead peer support and promote self-advocacy amongst peers, to support individuals in their capacity to effectively exercise choice and control.'

The ILC has given rise to some wonderful decision making capacity building programs and injected new life into peer support and self advocacy groups. Unfortunately, without recurrent funding these programs and groups are rarely able to continue beyond the life of the short-term grants. This is not a good investment of ILC funds. Some ongoing funding to maintain groups and programs beyond the ILC grant periods would ensure they remain available to decision makers and decision supporters.

While we recognise the NDIA no longer manages the ILC program, there is still a responsibility to ensure that the capacity building supports that form part of the NDIS Support for Decision Making policy and the NDIS Home and Living Policy are adequately funded.

Recommendations

We recommend the NDIA provides ongoing funding for independent decision supporters.

We recommend the NDIA works with DSS and other government departments to ensure ongoing funding for decision making capacity building supports, including peer support and self advocacy groups.

Systemic NDIS issues

Inclusion Australia urges the NDIA to look at the systemic barriers to supported decision making within their service and how to overcome them.

Overlaying a Support for Decision Making policy on top of existing systemic issues will not resolve the root causes. For example, the difficulties and lengthy delays people face trying to change their NDIS plans undermines their right to make decisions and to change their mind. This issue will not be resolved by the Support for Decision Making policy proposed in the SDM Paper.

We acknowledge there are limits on everyone's decisions regardless of disability, such as financial constraints or lockdown orders. However, there is room to reduce some of the systemic limits that come from within the NDIS itself.

Also, introducing the Support for Decision Making policy will not remove participant need for advocacy. There will still be times when people need an independent advocate to help them work through NDIS issues. The proposed policy is an important step but not a cure-all.

Recommendations

We recommend the NDIA looks at systemic barriers to supported decision making within the NDIS and how to overcome them.

We recommend the NDIA continues to acknowledge the ongoing need for independent advocacy around NDIS issues.

Accessibility of the consultation process

The NDIA has provided some accessible resources to support the consultation process, including an Easy Read paper and a video. We would like to provide the NDIA with some feedback on the accessibility of the consultation process for the Support for Decision Making policy.

People with intellectual disability made comments on the Easy Read version of the SDM Paper. Each comment was labelled as a plus, a minus or an interesting observation.

Plus

- We like the layout – there is a good amount of space on each page and it is easy to follow

- Like that there is a person with intellectual disability on the front cover

- Good that it has a contents page at the start and a word list at the end

- We like the font

- We like that important words are in bold

- It is good to have all the contact details for people needing other ways to access the document

Minus

- Sometimes too many photos near the words can be confusing

- The sizing of the words needs to be a bit bigger

- Headings should be bigger

- We don't like how they have more than 1 heading on each page – a new heading should have its own page

- They repeat some things under different headings – like the information about nominees and guardians. This comes up a few different times and it was hard to follow

- We don't like that there is a mixture of real people and cartoons in the pictures that are used – pick one or the other [we note this can be a personal preference]

Interesting

- You would need a supporter to go through this with you because there are some hard words (especially about the NDIS) and some of the ways they describe SDM is difficult

- The NDIA says that they will make information easy for everyone to use and understand, but they don't say how this will be done so it is difficult to give our feedback

People with complex communication needs (CCN) and their supporters have also provided feedback:

- Whilst a 10 week turnaround seems like a better allocation of time to respond to a consultation paper, the reality is that for people with CCN and developmental disability who

are not yet literate, this still does not provide enough time when the consultation papers are not provided in an accessible enough form.

- The Easy Read documents are too long to be shared in one sitting or to be shared multiple times – multiple sharings of the text are necessary for processing of the information, but these documents are usually overwhelmingly long.

- People with significant cognitive disability and CCN who are not yet literate need information set out in shorter documents that can be shared multiple times over several days to allow novel language to be explained, modelled using visual supports and added to the person's own comprehensive AAC systems, and modelled over multiple readings of the text with a support person. This gives more opportunity for greater understanding of the information being shared. Greater understanding of the information may allow for greater participation in giving feedback on this information. Only if the information has been understood can participants respond, express their opinions or ideas and ask questions of the information.

- We recommend that consultation processes include resources that are designed to be shared with people with significant cognitive disability and CCN, that break down the information into a series of much smaller documents, presented as picture books with one large main illustration, photo or other image and one to three sentences per page. This could be in a PowerPoint format that can be viewed digitally on a large screen or printed and shared as a picture book. There should be an expectation that all participants will be afforded the opportunity to engage with the consultation process and that paid or informal supporters will facilitate that engagement when more accessible materials are provided.

- Another alternative format that can be useful is a series of short video clips that include simple text (that does not disappear quickly), clear images and keeps background music animation separate to spoken words. Any spoken information should be clear and not too fast with pauses between separate facts or statements. Pauses allow for processing time and also for the support person to stop the video and reinforce what was said, modelling language on the participant's AAC tools and providing an opportunity for a response or question. Currently, we need to use a slower video playback speed on most animations or videos released on the NDIA website.

- Many adults with CCN and significant cognitive disability who are not yet literate have never been given the opportunity to learn how to use comprehensive augmentative communication systems. Many paid supporters of adults with CCN and significant cognitive disability who are not yet literate have not been trained in how to provide access to comprehensive augmentative communication systems, how to model their use and increase access to language and understanding. Consultation processes should recognise this. It would be helpful to include links to information on aided language stimulation and a recommendation that when supporters share the simplified resources with participants, they can model the use of aided language tools to support engagement and participation so that all participants get support to respond to a consultation process and policy.

- Consultation processes should include a well-designed aided language display that includes language needed to chat about and respond to the specific policy or consultation paper so that all participants, including those who have not had adequate access to communication supports can still have the opportunity to participate in the consultation process. The NDIA should encourage supporters to notice and value participants' natural language if they are not yet able to use more formal AAC tools to express themselves. It is not necessary to use formal AAC, or formal speech or sign to be involved in a consultation process *if* information is made accessible and communication partners are skilled in providing adequate time for processing and responding.

The NDIA released both the SDM Paper and the Home and Living Paper at the same time, with the same submission deadline. This has made it difficult for the disability community to coordinate responses. Although the consultation timeline is longer than in past consultations, the sector's attention has been split between the two papers, along with other competing priorities outside of the NDIS. We very much appreciate the NDIA extending the deadline for both consultations as we would not have been able to submit otherwise.

Recommendations

We recommend the NDIA keep listening to feedback from people with disability to continuously improve their use of Easy Read.

We recommend the NDIA Engagement Team coordinate consultations so they do not happen at once.

Proposed Next Steps

While much of the background and theory underpinning the Support for Decision Making policy is sound, Inclusion Australia has concerns with how the policy will be implemented.

To support the development of a high-quality implementation plan, we have provided feedback on each of the suggested 'next steps' as outline in Appendix C of the SDM Paper (pp. 23-27), as well as the suggested timelines.

Implementation timeline

The SDM Paper tells us an implementation plan will be developed 'later in 2021' based on the feedback received in this consultation (p. 18). Given submissions to the consultation paper are not due until late August, we are concerned this timeline is too short.

The implementation plan should be co-designed by the people with disability types most likely to be impacted by the changes (people with intellectual disability, acquired brain injury, and psychosocial disability), DROs and subject matter experts such as academics.

People with intellectual disability are currently building their skills and knowledge in supported decision making, leadership and other professional capabilities as part of Inclusion Australia's *Make Decisions Real* project. Our project peer workers are beginning to roll out pilot training for their peers and supporters to build decision-making skills and knowledge. Through this work, our peer workers are being exposed to a variety of decision makers and decision supporters, giving them an even broader awareness of lived experiences. Later in our *Make Decisions Real* project, the peer workers will be taking a train-the-trainer approach to upskill more people with intellectual disability to deliver supported decision making capacity building workshops around Australia. All the people with intellectual disability involved in *Make Decisions Real* are well-qualified to support the NDIA with co-designing the Support for Decision Making policy and its implementation plan.

We are aware of a several other ILC-funded support for decision making projects that have resulted in knowledgeable and highly skilled people with disability that the NDIA could engage for this co-design work. In our network alone this includes CID's *My Right to Decide* project on support for decision making in group homes, the *My Life My Choices* project being run in partnership by SACID and CID, and DDWA's *Making My Own Decisions: Supporting people with complex communication needs*.

Co-design is a lengthy, though worthwhile, process. The NDIA needs to develop a realistic timeline that allows for adequate co-design and consultation on the implementation plan.

Recommendations

We recommend the NDIA extends their timelines for developing an implementation plan for the Support for Decision Making policy.

We recommend the implementation plan is co-designed by people with disability types most likely to be impacted by the policy, DROs and subject matter experts.

We recommend the NDIA engages people with disability who have already built skills and knowledge in support for decision making projects to support their co-design process.

Goal 1: increase opportunities for participants

Business intelligence

Supporters of people with intellectual disability had concerns about the action to 'Use business intelligence to predict when support for decision making is potentially needed. There will be a specific focus on life stage transitions, i.e. through data driven system alerts' (p. 24)

What does the NDIA mean by 'business intelligence'?

There were concerns that this would be some sort of automated process like the dehumanising 'Robodebt' or 'Roboplanning'. The SDM Paper explains the NDIA has already identified the life transition points that are likely to trigger supports for decision making. We are not sure it is necessary to use automated systems here.

Plan flexibility

One of the indicators of success is that 'participants will be supported to make decisions that relate to their personal budgets, and plan flexibility' (p. 24). The Minister for the NDIS, Senator the Hon Linda Reynolds CSC has explained that personal budgets and plan flexibility are tied to the controversial independent assessments and that we would need legislative change to introduce plan flexibility. Even though independent assessments are not going ahead, we believe plan flexibility can and should still be introduced.

Section 33(3) of the NDIS Act allows the NDIA to describe supports generally to allow for plan flexibility. The Administrative Appeals Tribunal has also said it is okay for Planners to use global, flexible categories, as long as they explain why the funding is sufficient to help the participant meet their goals.

We recognise the proposed personalised budgets reform would require some changes to the NDIS Act, but there is no reason under the existing law that the NDIA cannot be more flexible now. That said, it is important that plan flexibility is properly safeguarded. For example, there is a risk of service providers influencing flexible budgets.

Recommendations

We recommend the NDIA explains what they mean by 'business intelligence' and properly safeguards against the pitfalls of any automated systems.

We recommend the NDIA still introduces some plan flexibility for participants.

We recommend the NDIA considers safeguards for plan flexibility.

Goal 2: Support development of participant capability

Capacity Test

This goal suggests the NDIA will 'introduce a formal process to identify a participant's decision making capacity' (p. 24). This describes a capacity test. After the recent independent assessments campaign, the disability community was understandably alarmed by this suggestion. Further, this seems like important information that should have been included in the policy itself rather than an appendix.

Inclusion Australia would like more information on what is involved in this capacity test. It must be individualised and personalised; and must not be an automated, 'tick-the-box' kind of assessment. Our concerns about the capacity test are in line with the disability sector's concerns about independent assessments[10].

If a capacity test is used, it must not be developed in-house by the NDIA. Any capacity test should be evidence-based and developed independently by experts. Assessments should presume the capacity of people with disability. These capacity tests may look different for different disability types; we understand that supported decision making is not 'one size fits all' so there should not necessarily be a 'one size fits all' capacity assessment.

For some people with complex communication support needs there are no known capacity tests. Rather, that person's decision making capacity might emerge alongside the right kinds of communication support. Capacity tests for this group, in particular, could be dangerous as the person may not be able to participate in the test despite their ability to make decisions with support.

The NDIA should work with the Intellectual Disability Reference Group, DROs, peak bodies, advocacy organisations, specialist organisations and others to advise, test and co-design capacity tests.

Peer Support

Inclusion Australia welcomes the suggested action to 'Promote the use of peer support networks and other individual capacity building supports' and the related indicator of success: 'Participants will be better supported to access peer support networks'. We agree that peer support is essential for the success of the proposed Support for Decision Making policy.

Peer support and self advocacy groups are also a place for people with disability to learn about their rights, including the right to supported decision making.

People with disability and their supporters have shared some stories to show how peer support helps them to explore and make their own decisions:

> Anne is autistic and has two sons, one of them is also autistic.
>
> Anne called Amaze, an organisation that gives advice to autistic people, because she wanted help with getting her son to become an NDIS participant.
>
> Amaze connected Anne to an autistic peer support group in Melbourne's north suburbs, close to where she lives.

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[10] See: 'Disability sector statement on the Australian Governments planned reforms to the NDIS', available here: https://everyaustraliancounts.com.au/ndis-sector-statement/

The group meets every month, and its members give advice and guidance about how to access local NDIS providers, how to help their kids with school and importantly, offer support to each other.

Through the group, Anne was supported to understand her son's rights to access the NDIS, to confidently ask for the budget to fund his therapy needs, and to make sure her own needs were recognised and met.

As mentioned above (see Funding, pp. 34-35 of this submission) there are some funding considerations here to ensure these crucial capacity building supports are able to stay afloat and remain available to NDIS participants and their decision supporters.

Tips from people with intellectual disability

Nothing about us without us!

Decision making supports developed for people with disability must be co-designed by people with disability.

People with intellectual disability have provided some advice for the NDIA on how they would like to be supported to develop their decision making capability:

Tips for supporting people with intellectual disability

- The person with intellectual disability should always be at the centre of decision making.

- Good supported decision making should look at the strengths and skills a person already has.

- Whoever is supporting the person needs to know them well and there should be a trusting relationship between decision maker and decision supporter.

- The person's decision should always be respected even if the supporter does not agree with the decision.

- People with intellectual disability should be allowed to make risky decisions or mistakes – this is how we can learn more about decision making.

- Decision making takes time and it is a journey that never stops.

- We should reflect on our decisions and think about what went well or what didn't work, and what we can do better next time.

- People with intellectual disability need to have good information about the decision they want to make, in a way that is easy for them to understand.

Recommendations

We recommend the NDIA provides more information about their proposed decision making capacity assessment.

We recommend the NDIA works collaboratively with the disability community to co-design their decision making capacity test.

We recommend the NDIA looks more closely at the issues around using a decision making capacity test with people with complex communication support needs.

We recommend that any decision making capacity test should be, at the least:

- Individualised and personalised,

- Evidence-based, and

- developed independently by experts.

We recommend the NDIA develops decision making support capacity testing tools in line with disability sector advice and concerns.

We recommend the NDIA looks to appropriately fund peer support programs to support decision makers and their decision supporters.

We recommend the NDIA listens to the advice of people with disability when developing, funding and promoting participant capacity building supports.

Goal 3: Build capacity of decision supporters

Informal decision supporters

An essential part of good supported decision making is 'knowing the person'[11]. Informal decision supporters (family, friends and carers) are well placed to provide this support as they already know the participant well.

That said, the NDIA needs to be careful of leaning too heavily on informal supports. This places people without informal supports at a higher risk of being left without quality decision making support, and places increased pressure on families.

Families of people with significant disabilities tell us they are time-poor and overwhelmed by the different resources available to them. Families in the Inclusion Australia network were eager to learn more about supported decision making; they told us they would prefer to engage with content in hands-on learning environments – such as face-to-face or online workshops – rather than sifting through lengthy and various resources on their own.

Supported decision making can be very time-intensive, and families may not have the time and energy to engage as decision supporters on top of full-time job, regular caring and other support duties. Other family members and carers are approaching burnout due to the level of support they provide and would not be able to take on an additional decision supporter role.

There is also a risk in leaning on the friends or acquaintances of people with disability to provide decision making support. Australian research suggests that half of all people with intellectual disability are 'chronically lonely'[12]. By asking friends or acquaintances to take on additional decision supporter responsibilities, the NDIA risks driving friends away due to the perceived work attached the friendship and further isolating people with intellectual disability.

These risks need to be safeguarded against. For example, a participant might have family and friends in their network but still be eligible for independent formal decision making supports if the risk of isolation or burnout is too high.

Tools or tests to measure the capacity of a participant's decision making support network should also be evidence-based and independently developed. When looking at a person's decision making support, the NDIA should focus on the strengths of their existing networks[13].

In addition, just as for decision makers, it is essential to fund peer support for families and other decision supporters as they build their decision making capabilities. The vast majority of families and other informal supporters are trying to do the right thing by their loved one with disability in a vacuum of support. Engaging and sharing stories with peer groups helps people learn and troubleshoot their skills.

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[11]See La Trobe Support for Decision Making Practice Framework for more: https://www.supportfordecisionmakingresource.com.au/step-1-knowing-the-person.html

[12] Gilmore, L & Cuskelly, M (2014), 'Vulnerability to loneliness in people with intellectual disability: an explanatory model' available at: https://doi.org/10.1111/jppi.12089

[13] Information on the 'Strengths Based Network Activation SDM Model' developed in the ACT and evaluated by Paul Ramcharan is available here: http://www.adacas.org.au/media/1109/evaluation-report-of-the-link-and-learn-supported-decision-making-project.pdf

Recent research on building the capacity of decision supporters[14] explains the importance of training for supporters, particularly families of people with severe and profound intellectual disabilities who are not always able to access self advocacy and other capacity building activities themselves. The researchers suggest:

> '[O]ngoing strategies to assist supporters to maintain momentum for change, retain their focus on good practice, extend their skills, and reinforce its value to the quality of life of participation in decision-making. The findings also suggest that in parallel to building the capacity of supporters, greater attention could be given to the potential for continued learning about expressing preferences and decision-making of people with intellectual disabilities, particularly those with more severe levels of impairment who often do not participate in self advocacy groups which support learning and confidence about speaking out.'

> (Bigby et al. 2021, p. 8)

Service providers

There are issues involved with service providers delivering decision support.

First, service provider staff may exert undue influence on participants and encourage them to make decisions to benefit the service provider, such as purchasing additional services from the same provider or remaining with a provider that doesn't best fit their will and preference.

Second, it has proven difficult for service providers to strike a balance between duty of care and enabling risk. People with intellectual disability, their families and advocates tell have told Inclusion Australia that service providers often don't allow people with intellectual disability to make risky decisions and cite their 'duty of care' as the reason. Others described 'a culture of fear around perceived risks' in service providers.

There needs to be more direction for service providers on how they can support people to make their own decisions and take risks. The NDIS Quality and Safeguards Commission may be well-positioned to support this effort.

Tips from people with intellectual disability

As above, the NDIA should be led by people with disability, families, advocates and representative organisations in developing guidance and resources for decision supporters.

People with intellectual disability have provided some advice for decision supporters on how they can support decision makers:

Tips for decision supporters

- The supporter should understand personal bias.

- The supporter should help the person with intellectual disability to think about consequences and make sure they have all the information in a way that they can understand it.

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[14] Bigby et al. (2021) '"I used to call him a non-decision-maker – I never do that anymore": parental reflections about training to support decision-making of their adult offspring with intellectual disabilities' available at: https://doi.org/10.1080/09638288.2021.1964623

- Supporters should ask the person with intellectual disability for feedback about how they have supported them to make decisions.

Who are the best people to help you (or a person with disability) to make decisions?

- Supporters need to know the decision maker well and there should be trust between them.

- Supporters should be respectful, patient, honest and trustworthy.

- Do not rush the decision making process!

- Family members, support workers, friends, mentors, advocates can all be supporters. It must be someone or a group of people the person with intellectual disability trusts and is comfortable with.

What should they do to help with decision making?

- They need to understand human rights and respect the rights of people with disability.

- They should do a training in supported decision making.

- They should be patient and really understand the person well – respond to what it is they need and offer the support that is right for them.

- They should think carefully about if they are the right person to support a decision – maybe they are not the right person!

- They should have lots of practice at supporting decisions.

How can they get better at helping?

- By having access to more training and ways of continuing to get better at supporting people.

- They should care about the decision maker.

- Think about their rights.

- They should be patient and really understand the person well – respond to what it is they need and offer the support that is right for them.

- They should understand what personal bias is.

- They should think carefully about if they are the right person to support a decision – maybe they are not the right person!

- They should have lots of practice at supporting decisions.

- People need to understand complex communication needs and communicate in a way that is right for the person.

- Supporters should always be culturally sensitive – maybe they can do training in understanding and respecting different cultures.

- Build skills in listening!

Recommendations

We recommend the NDIA:

1. Safeguards against the risks of leaning too heavily on informal support networks.
2. Works together with other government bodies to ensure appropriate funding of peer support and capacity building for decision supporters.
3. Safeguards against the potential undue influence of service providers and provides guidance around how they can enable risk.
4. Develops guidance for decision supporters based on the lived experience advice of people with disability, families, advocates and representative organisations.

Goal 4: Strengthen support for decision making approach – Nominees

The SDM Paper talks about how a reduction of nominee appointments will show that support for decision making has been strengthened in the NDIS (p. 27).

Inclusion Australia does not agree that a reduction of nominee appointments is necessarily a good measure of whether people with intellectual disability are being supported to make their own decisions. This may mean that other people are unduly influencing the decision maker or that NDIS Planners and LACs are becoming substitute decision makers.

Nominees are often trying to safeguard their loved ones against risks association with the NDIS – including inadequate plans, poor decision-making support from NDIS Partners in Community staff, inaccessible plans and systems (for example, MyGov), and inadequate plan management funding that limits participant choice and control.

The vast majority of participants with intellectual disability cannot navigate the NDIS on their own, but they should be able to exercise the same control over their plans as self-managed participants are afforded. Nominee appointments can give the flexibility offered by self-management to NDIS participants that would otherwise be Agency managed.

The story below shows how nominees can be an important safeguard for NDIS participants with intellectual disability:

> Tony is a young person with a moderate intellectual disability.
>
> Tony's mother, Gianna, is his NDIS nominee.
>
> When Tony was born, Gianna realised there was very little support in their local area for children with intellectual disability and their families. Gianna founded a support group and has been heavily involved the disability and advocacy sector ever since.
>
> Through Gianna's work in the field, she has learned about the NDIS and the services available to support people to navigate the system.
>
> Gianna accessed community-based pre-planning services for Tony through her networks. At these pre-planning sessions Tony was supported to make decisions about what he wanted and needed in his upcoming NDIS plan.
>
> Gianna was able to use the pre-planning information and her expertise in the disability space to advocate for the right supports at Tony's NDIS planning meeting. She was able to back up all requests with specific NDIS line item numbers and relevant evidence.
>
> As a result, Tony has a well-funded NDIS plan that supports him to live the life he chooses. He has increased control over his supports as Gianna is well-equipped to self-manage his plan as his nominee.

Inclusion Australia would also like to ensure the NDIA's 'focus on cohorts with disproportionate nominee appointments' (p. 27) is not simply a cost-saving measure. We know that effective nominees often advocate for, and receive, higher-value NDIS plans. Is there a correlation between nominee appointment and plan value? We encourage the NDIA to share this data for transparency and accountability.

We recognise there are also nominees that override the will and preference of NDIS participants. Nominee appointments are made without appropriate checks and balances, which has led to people with disability being disempowered and subjected to violence, abuse, neglect and exploitation. We believe the NDIA already has a good understanding of this issue and are taking steps to improve the situation.

The story below shows some of the risks associated with plan nominees:

Grace is a 21-year-old female with intellectual disability who is a participant of the NDIS.

A strong self-advocate and representative of others with intellectual disability, Grace is a very independent person with well-established social networks and friendship groups who enjoys 'being herself'. She is on many statewide committees and her committee colleagues report Grace is a great self-advocate – for herself and others with an intellectual disability.

Grace's mother is the nominee of her NDIS plan. Grace's mother and the coordinator of supports do not involve Grace in the decision making related to her NDIS plan. There have been times when they have attended the NDIS meetings without her being present.

Grace's goal is to move out of the family home and live independently, but she is constantly told by her family that she is not capable of living independently.

Grace knows that she is capable of this with some capacity building supports but she has not put this as one of her goals as the nominee will not allow it.

At times Grace needs some support around making decisions. As she feels this is not something her nominee does well, she contacts her local advocacy service for this support around her rights and supported decision making.

Nominee appointments are a complex issue, and the proposed actions in the SDM Paper are over simplified.

People with intellectual disability were confused about the information on nominees in the Easy Read SDM Paper (p. 17). They commented on how important it is for people with intellectual disability to choose a nominee who is right for them, who can get to know them and has an understanding of what they want and need. People with intellectual disability asked for more information about when nominees are helpful and when they are not.

The nominee process needs to be overhauled to improve supported decision making in the NDIS, but this overhaul is more than simply reducing nominee appointments. Here are three changes that can reduce substitute decision making by plan nominees:

1. More stringent checks and safeguards put place for nominee appointments,
2. Compulsory supported decision making training and resources to be made available to all nominees, and
3. Restructure the nominee role to better support decision making.

In restructuring the nominee role to better support decision making, the NDIA can look to other jurisdictions for alternatives. For example, Victoria's Office of the Public Advocate has introduced a 'supportive attorney' as an alternative to guardianship to help people make decisions with support. A supportive attorney cannot make decisions for someone. Instead, a supportive attorney helps the person by accessing information, communicate with organisations and taking reasonable steps

needed to make the decision happen. The NDIA could consider a 'supportive nominee' with fewer substitute decision making powers than a plan nominee, but a more active role than correspondence nominees.

Recommendations

We recommend the NDIA redesigns Goal 4 to better reflect the complexities around nominees and decision making.