

NDIS Support for Decision Making Consultation

Submission from the South Australian Council on Intellectual Disability

Working
towards
an inclusive
South
Australian
community

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South Australian Council
on Intellectual Disability

About SACID

The South Australian Council on Intellectual Disability Incorporated (SACID) is a state-wide not for profit organisation. SACID was founded in 2006 from various iterations of organisations specifically about people with intellectual disability since 1946, all with the goal to work towards achieving a South Australian community in which people with intellectual disability are involved and accepted as equal participating members. This is achieved through consultation with stakeholders, advocating for an inclusive community, promoting the rights of people with intellectual disability and delivering capacity building activities for people with intellectual disability and their families.

All of the work we do is guided by people with intellectual disability and their families. We do this through the following inclusive practices:

Organisational Governance

SACID ensure people with intellectual disability and their families are part of our governance processes with positions on our Board. SACID is run by a Board comprised of self-advocates with intellectual disability, family members of people with intellectual disability and interested community members who have a long history of working in the disability sector.

SACID is guided by the advice of a sub-committee of the Board called the SACID Reference Group. This group is made up entirely of people with intellectual disability. Their role is to advise the Board on issues impacting people with intellectual disability, contribute to decision making about the direction and activities of SACID, and to undertake speaking up activities to build capacity of people with intellectual disability. This group enables more people with intellectual disability to be involved in setting the direction of SACID, ensuring our work meets the needs of our target group.

Employment of People with Intellectual Disability

SACID employ people with intellectual disability as Inclusion Workers to inform the direction of our work by sharing with us what is most important to them. Our Inclusion Workers also play an important role in testing Easy Read information we develop, co-delivering information sessions and supporting our events. This is an open employment position with fair and equal pay.

Membership Base

SACID ensures the majority of our membership base is made up by people with intellectual disability and their families and friends.

SACID represent the voice of people with intellectual disability and their families in South Australia at a national level as a state member of Inclusion Australia. Inclusion Australia is a national Disability Representative Organisation representing the rights and interests of Australians with intellectual disability and their families. All members of Inclusion Australia are connected to people with intellectual disability in their state and are committed to the shared vision of inclusion in all aspects of Australian life.

Our work on Supported Decision Making

Supported Decision Making has been an area that SACID has contributed to for over a decade. Our work in this area began as a steering committee member for a Supported Decision Making Project led by Cher Nicholson through the Office of the Public Advocate (OPA) in South Australia. Since completion of this work the OPA in South Australia have facilitated a Community of Practice at various times that SACID has remained involved in.

More recently, SACID has undertaken a Supported Decision Making Project called *My Life My Choices*, in partnership with the NSW Council for Intellectual Disability, through ILC funding. To date the experiences of people with intellectual disability have generally not informed the development of information and resources on supported decision-making practice in Australia. Through a co-design process, *My Life My Choices* is giving people with intellectual disability the opportunity to share what is important to them in making decisions and when being supported with their decision making. These experiences are forming the basis of information and resources being developed to inform people with intellectual disability about their right to good decision making support. The information and resources will also inform families, service providers and mainstream organisations about how to best support people with intellectual disability with their decision making.

SACID is also contributing to Inclusion Australia's Supported Decision Making Project *Make Decisions Real* as a Project Steering Committee Member.

Our Submission

The Support for Decision Making submission SACID has prepared is largely based on discussions with people with intellectual disability on our Reference Group and people with intellectual disability who are employed by SACID as Inclusion Workers. These discussions were facilitated with reference to the Easy Read Paper 'Supporting you to make your own decisions' and the questions included in the full text paper.

People with intellectual disability who participated in these discussions with SACID noted on page 25 of the Easy Read Paper it refers to a list of questions NDIS wants to ask about the paper, and then provides a link to a 'have your say' section of the NDIS website. It is not clear from here how you find these questions. Only having information about the consultation available through a website, social media and webinar sessions does not recognise that many people with intellectual disability have difficulties with reading, may not have access to technology, and may not have the skills or support to navigate technology. SACID recommends that for future consultations NDIS includes the list of questions they are seeking feedback on in the Easy Read Paper to improve accessibility for those accessing the Easy Read Paper. SACID were pleased to have the opportunity to give in person verbal feedback as well through our local NDIS Community Engagement Team and suggest more opportunities for people with intellectual disability to do this be made available for future consultations.

SACID would like to acknowledge the submission Inclusion Australia have made to the NDIS Support for Decision Making Consultation. SACID support all recommendations Inclusion Australia have made in their submission supported by their members around Australia.

SACID have responded to the questions NDIS were seeking feedback on through the 'Supporting you to make your own decisions' consultation paper. Additional comments and questions from people with intellectual disability that were raised while discussing the consultation paper have also been included.

How can we help people with disability to make decisions for themselves?

People with intellectual disability should have the right to access support for decision making. Drawing from their own supported decision making experiences, people with intellectual disability SACID spoke with identified key areas that assist in effective supported decision making:

- People with intellectual disability should be asked about their will and preferences
- People with intellectual disability should be able to explore possible options to make an informed decision
- People with intellectual disability should be respected when they express their preferences and decisions
- People with intellectual disability should be given time to make decisions.
- People with intellectual disability should have opportunities to build their capacity to make decisions

Who are the best people to help you to make decisions?

People with intellectual disability emphasised the positive impact of their family members as their main decision supporters. Other decision supporters that were identified included close friends and partners. Formal decision supporters were also identified such as trusted support workers, mentors, NDIS support co-ordinators and service providers. There was acknowledgment of the role people with intellectual disability can play in supporting their peers with intellectual disability. People with intellectual disability also mentioned building their decision making capacity through workshops, training programs, peer support networks, and conferences.

What should they do to help with decision making?

People with intellectual disability commented that, when making a decision, their supporters should assist and support them by:

- Talking through the decision with them
- Respecting their decisions
- Speaking to them with respect and without judgement

- Allowing time to decide

It is also important that decision supporters and support workers receive training in promoting decision making. Opportunities for decision making should be utilised, no matter how small the decision is. This could be as basic as supporting the person choose what colour top to wear. It is important to include the person in their everyday life and do WITH the person, not for the person.

How can they get better at helping?

People with intellectual disability commented that their supporters can get better at:

- Ensuring that they are included in discussions about them.
- Working from a person-centred, strength-based perspective—considering their preferences and goals.
- Relationship and rapport-building – people with intellectual disability said that the most effective approach to support for decision making is building a relationship with them and getting to know them as an individual. Learning and understanding about what is important to them and how they live their lives.

People with intellectual disability expressed that constant communication with them is important when working with formal decision supporters such as service providers.

How can we make sure the right people are helping?

People with intellectual disability expressed that person-centred practice is important for them. Ensuring that their supporters understand and acknowledge their preferences and goals. Some examples of this included:

- Ensuring NDIS plans are accurate with personal preferences and goals reflected. A person with intellectual disability we spoke with explained her NDIS plan said she liked playing golf when she did not. When she raised the issue of incorrect information being included in her plan with her coordinator, she was told to ignore it.
- Ensuring NDIS participants are at the centre of their decision-making. A person with intellectual disability recalled expressing to her service provider her preference to meet with supports before they started working with her, however her provider went ahead and scheduled her shifts with new people before giving her the chance to meet them.
- Ensuring regular communication and transparency. Continuous communication ensures service delivery is person-centred, rather than service/systems centred. A person with intellectual disability explained that if a service provider did not have available supports to take her to her appointment, it would be preferable they tell her in advance. This would provide her with the opportunity to decide if she needs to cancel the appointment so she does not get charged.

What should decision supporters know about so they can help people with disability make decisions?

When discussing formal decision supporters such as NDIS co-ordinators and providers, people with intellectual disability said their decision supporters should know their NDIS goals and their personal preferences when they are working with them.

Some people with intellectual disability expressed concerns that others often make decisions for people with intellectual disability without including them in the decision. Sometimes the decisions that are made do not reflect the preferences of the person with intellectual disability. Decision supporters need to ensure they include the person with intellectual disability in the decision making process and that they have a strong understanding of the person's rights as outlined in the United Nations Convention on the Rights of Persons with Disabilities.

Can you tell us about a time when someone helped you (or a person with disability) to make a big decision? What worked well? What could have been better?

A person with intellectual disability commented that their father and aunt were their decision supporters when she was considering applying for a new job. She said that she had asked her father and aunt their thoughts about applying for the job, and her family members were encouraging and supportive of her decision. They helped her with explaining the forms and the application process, recalling, "They broke it down in a way I understood rather than overloading me with information."

Another person with intellectual disability said that their parents supported her decision to live out of home independently. She said she made the decision to have her own bank card instead of using cash. She explained that her father helped her to set up an account and she felt she was supported to live independently. She has also expressed that she feels "frustrated" when her parents "push me to do things or talk over me" or do not involve her in conversations about her.

A person with intellectual disability said she was supported in her goal to move out of home. A close family friend and her sister helped her to make the decision. "I like that I can have a say," she commented. Her supporters went through the steps with her, communicated effectively through methods such as Easy Read. However, on the other hand, she says that "It is hard when my sister makes decisions without me".

A person with intellectual disability said he was not happy with a job agency that was helping him to learn new skills to find a job. He said they were not helping him in a way that he wanted. His mother supported him to make the decision to change the person he was working with. He said talking it through with his mum was helpful because he felt he was being listened to and felt empowered to make the decision.

What is the best way to support people with disability to make decisions about their NDIS plan? This includes decisions about using or changing their plan.

People with intellectual disability identified that the best ways to support people with disability about their NDIS plan are:

- Being direct and using facts.
- Making information accessible such as providing resources in different formats. For example, Easy Read information, videos and brochures.
- Explaining things in a way that is easy to understand/breaking down the process.
- Communicating slowly and at the person's level/pace.
- Listening to what the person says and wants.
- Regular and timely communication. Agencies should ensure more regular communication with participants.
- Ensuring that supporters such as family members parents and friends are supported with decision making. They too can have difficulty understanding the NDIS system and processes too.
- Allowing funding to be able to be used for support for decision making – people often don't have people in their lives to support with decision making and support coordination is still not approved.
- Simplifying procedures. Changing NDIS plans can be very confusing and can involve a lot of back and forth.
- More helpful support coordinators. People are not following up on what they say they will.
- Correct information in plans. There can be incorrect information/missing information in plans and when this happens they are tricky to update.

Are there different things to consider for people with different disabilities or cultural backgrounds?

People with intellectual disability commented that there are different needs for people with different disabilities and people from culturally and linguistically diverse (CALD) backgrounds and must be respected. People with intellectual disability acknowledged the need to work with Aboriginal and Torres Strait Islander peoples in a respectful way, with consideration of the effects of trauma. In addition, people with disability from CALD backgrounds should have their decisions respected in how they choose to live their lives and their culture.

People with intellectual disability recognised that there are different needs for people with different disabilities, which require prior planning and an understanding of their individual support needs. For example:

- People with hearing impairment may require having information presented in a different way such as Auslan/Easy Read documents.

- People who are non-verbal or have limited communication may use alternative communication methods such as assistive technology or visuals or who may need to rely solely on the support of people who know them best.
- People from CALD backgrounds may have English as a second language and therefore, require an interpreter for meetings.

How can we help reduce conflict of interest?

To reduce conflict of interest, people with intellectual disability suggested ensuring:

- Getting the right people who are trained and experienced with working with people with intellectual disability
- Better auditing processes
- Utilising services from a range of organisations in preference to a single provider

A person with intellectual disability explained that her current disability service provider had told her that their organisation would be the best option for her. After choosing this provider, she had found that they did not follow through with their promise to provide services that she wanted. She said that their communication with her is infrequent, leading her to miss appointments that were important to her wellbeing.

A way to reduce this influence is for the NDIA to ensure that participants and their supporter/s are provided the relevant resources and tools to make decisions regarding accessing NDIS services, such as an independent advocate.

How can we help reduce undue influence?

- Better ways to report undue or inappropriate influences if they happen.
- More training for support workers on their legal responsibilities.
- Participants to have access to training to enable them to understand their rights and responsibilities and to recognise undue influence.
- Participants to have more confidence to stand up for themselves and know their rights.
- People get warnings/registration revoked if they are a repeat offender.

What are your concerns (if any) around people with disability being more involved in making decisions for themselves?

People with intellectual disability recommend that the NDIA ensures that people are being protected. For example, if a person isn't good with money but are given control of all their money, ensure that there are safeguards in place.

People with intellectual disability believe that there should also be safeguards in place to protect them and others who may be too trusting to ensure they are not taken advantage of.

What else could we do to help people with disability to make decisions for themselves? Is there anything missing?

People with intellectual disability recommend that other people with intellectual disability have access to workshops and resources that allow them to build upon their decision-making capacity and provide information that assists them to make decisions. They emphasised the importance of having opportunities to learn and practice decision making, and that this learning should start at school.

People with intellectual disability that SACID spoke with specifically referenced capacity building workshops delivered by SACID and other Inclusion Australia members including:

- **Staying Safe Workshops:** Teaches people with intellectual disability to recognise and respond to abuse.
- **Your Service Your Rights Workshops:** Teaches people with intellectual disability about their rights when accessing NDIS Registered Providers, how to make a complaint, and the role of the NDIS Quality & Safeguards Commission.

People with intellectual disability also recommended increasing the possibility of peer supports through co-delivering the workshops mentioned above or other self advocacy training opportunities. Peer supports could share with new participants their decision making experiences. This provides a holistic approach to ensuring that new participants are sufficiently supported when starting with the NDIS and aids in supported decision making.

People with intellectual disability noted that on page 6 of the Easy Read Paper it says 'We can help people to support you to make decisions on your own'. They suggested NDIS provide funding for people with intellectual disability to be peer mentors to help other people with intellectual disability through their decision making. Peak bodies, advocacy groups and peer support groups could be targeted to facilitate this.

Dignity of risk was mentioned by people with intellectual disability as an important consideration in decision making. They explained that people with intellectual disability should be given a chance to make mistakes so they can learn and grow from them.

NDIS Resources for Support for Decision Making

People with intellectual disability that SACID spoke to were pleased to see the consultation paper refer to additional resourcing for support for decision making. The Easy Read Paper mentioned:

- 'We want to help you learn new skills so you can make decisions on your own' – page 16
- 'We want to teach people who support you how to help you make your own decisions' – page 16

- ‘We want support for decision making to be there when you need it’ – page 18

People with intellectual disability wanted to know how NDIS is going to do all of this great work around support for decision making? Is NDIS saying they will put funding into this and will develop resources to help? This was not clear in the Easy Read paper.

People with intellectual disability noted this point about creating support for decision making resources:

- ‘We will create new information that will:
 - help you learn how to make your own decisions
 - explain how to support someone to make decisions.’ – page 19

They noted that there is already existing information about support for decision making. There have been a number of ILC funded projects that focus on Supported Decision Making, some of the people with intellectual disability we spoke to are currently involved in these projects. They suggested NDIS connect with these projects to learn from them and to utilise the resources they have already made instead of NDIS creating new resources.

People with intellectual disability said that all information would need to be easy to use and understand. It is not useful to provide a 40+ page Easy Read document because 40+ pages is not easy. NDIS need to think about simple summaries, using more videos, and other formats for information.

People with intellectual disability were surprised about this point:

- ‘We will make sure everyone who works for the NDIS understands how to support participants to make their own decisions.’ – page 19

They said this was a “big call” and it would be better to make sure the right people at NDIS understand how to support participants to make their own decisions.

Whose role is Support for Decision Making?

People with intellectual disability commented that based on the Easy Read Paper they were unclear whose role support for decision making would be under the NDIS support for decision making framework. On page 16 it says – ‘We want to teach people who support you how to help you make your own decisions’. People with intellectual disability asked, will NDIS pay for this training through my NDIS plan? Or, will they train the Support Coordinators and give them more time and capacity in their jobs to help people with this? People with intellectual disability were worried that this role could be given to Local Area Coordinators who they feel already do not have the time, knowledge and capacity to support them in their current role.

People with intellectual disability commented on page 21 where it mentions – “People who work for the NDIA can be your decision supporters for your NDIS decisions”. Again, they want to know which

NDIA people this was referring to. They reiterated that Local Area Coordinators do not have capacity, they just make plans and that this could be seen as a conflict of interest. They wondered if it would be a totally new role that sits under community engagement or partners in the community? Would it be a new group of organisations contracted to do it? Or would it be something like an online training for all NDIS staff? People with intellectual disability did not feel there was adequate explanation in the Easy Read Paper about the framework for NDIS delivering support for decision making.



South Australian Council
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Thank you for your interest in the work of SACID.

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