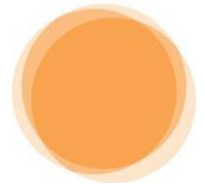


SUMMER  
FOUNDATION



# Consultation on Support for Decision Making

Submission by the Summer Foundation

September 2021

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# Executive Summary

The Summer Foundation welcomes the opportunity to contribute to the National Disability Insurance Agency's (NDIA) consultation into Supports for Decision Making.

Our submission responds to the key themes in the consultation paper and makes recommendations to uphold human rights and increase participant choice and control over their lives.

The proposed Supports for Decision Making Policy is a significant step towards securing better outcomes for National Disability Insurance Scheme (NDIS) participants. A person-centred and supportive approach to participants and their decision supporters is essential to stop younger people with disability from being forced into Residential Aged Care (RAC) and to meet the outcomes outlined in the [Younger People in Residential Aged Care Action Plan](#).

Our submission supports the new approach to supports for decision-making outlined in the consultation paper and we make the following recommendations to:

- Ensure participants have the time, support and information required to participate in decision-making, in a format that is most useful for them.
- Provide and invest in accessible information around the rights and supports available to participants.
- Provide funding for independent advocacy and decision-making support.
- Allow participants to choose the most appropriate decision supporters.
- Invest in capacity to access circles of support and microboards for participants requiring supports with decision-making.
- Build the capacity of decision supporters to understand dignity of risk.
- Provide decision supporters with advice around where to get support and who to connect with.
- Fund decision supporters to access training around the participant's preferred means of communication.
- Provider training to decision supporters around communication; consequences and practicalities; listening and engaging; creating opportunities; and breaking things down.
- Ensure that the Supports for Decision Making Policy is consistent with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- Enact legislative changes in line with the [Tune review](#) to mitigate the risk of conflicts of interest.
- Ensure independent decision supporters are available where participants feel their main decision supporters are not supporting the will and preferences of the person with disability.
- Ensure participants requesting a new service, such as different support coordination from the same agency, are provided with options that respond to and meet their needs.

# Best supports for supported decision-making

The proposed Supports for Decision Making Policy is a significant step towards securing better outcomes for National Disability Insurance Scheme participants. Our submission responds to the key themes in the consultation paper and makes recommendations to uphold human rights and increase participant choice and control over their lives.

## The right to make decisions

Everyone has the right to make decisions and people with disability are no exception. Often a person with disability will need a support person to facilitate decision-making. This support can come in many forms and may include assistance with communication (such as training in the use of assistive technology or augmentative and alternative communication methods) or facilitated discussions around the consequences of decisions.

Every Australian is allowed to make mistakes and learn from their decisions. People with disability should be permitted the same opportunities to learn from the decisions they choose to make. However, this is often not the case. People with disability are often forbidden from making decisions due to predetermined ideas around their capabilities and capacity to make good decisions. People with disability are often prevented from making decisions altogether rather than finding a way to support and build capacity around their decision-making. Consequently, decisions are made for them rather than by or with them.

## Emphasising a person-centred approach

Decision-making needs to take a person-centred approach. This means that the person needs to be at the centre of the decision-making process and they are able to express their views in a way that works for them, but they are listened to by everyone involved in the decision-making process. For people with disability who have reduced capacity, extra time and support must be provided to allow them to be fully involved in the decision-making process. Providing extra time and support allows people with disability to not only participate well in decision-making processes but also to make better decisions.

*“My main challenge was communication. Sometimes people (professionals, workers) are too quick to assume they know what I think, and not take the time to actually listen to what I want. Unfortunately you just have to live with it and accept it. NDIS should provide more hours for your support workers to be together with the client so that they are hearing the same message. So more training is needed. The NDIS provides funding for the support hours, but not enough for the other peripherals, like training. I have to eat into my support hours to do this, but I need these support hours for actual support.”*

**Karlie\* – Participant**

## Recommendation 1

**The NDIA must ensure participants have the time, support and information required to participate in decision-making, in a format that is most useful for them.**

Staff must have sufficient training and enough time allocated to provide the necessary support, especially when working with people who have complex communication needs.

*“Just say a client was choosing the colour of which to paint their room, the influencer might influence based on their own personal preference, not based on what they know the client prefers. You need to live in that room every day, so this matters.”*

Rachel\* – Participant

### Information for decision-making

Some people with disability may not know their rights around decision-making or have access to information that may assist them in making the best decision for them. Therefore, people with disability can be better supported by being educated on the rights and services available to support them in making decisions, including the provision of information in varying accessible formats about the implications of decisions so people with disability are better able to weigh up the pros and cons of what a decision may mean for them.

*“Create awareness of the different options and choices, so a person can choose what will work best for them, as a person. Write questions in a specific form, so anyone reading it can understand exactly what they are asking - make it black and white, direct and to the point. ‘Don’t fluff around!’”*

Rachel – Participant

## Recommendation 2

**The NDIA must provide and invest in accessible information around the rights and supports available to participants.**

This information must be tailored to the needs of each participant and should take into account their preferred method of communication.

### Independent advocacy and support

Investment into independent advocacy and support services is essential to ensure people with disability have the support they need to make decisions. These services allow people with disability, who do not have supports available, to access appropriate support for decision-making.

People with disability must be informed that they can bring trusted support people to all meetings, such as an NDIS planning meeting or to meet a provider. Some people with disability may be hesitant to bring support people because this has previously not been encouraged. This attitude must change to enable people with disability all that they need to make informed decisions.

### Recommendation 3

**The NDIA must provide funding for independent advocacy and decision-making support.**

Participants must have access to high-quality independent advocacy to assist them with decisions.

## Choosing your decision supporters

People with disability must be in charge of who supports them to make decisions. For some people, the best decision supporters may be family members – such as parents or siblings. However as people grow up, they have a need to establish more independence from their families and therefore, benefit from support for decision-making from outside of their families.

Whoever is supporting the person to make decisions must be committed to do this in a way that is impartial and that focuses on the interests and preferences of the person they are supporting.

### Access to paid decision supporters

Family members may not always be able to be impartial. In these situations, paid decision supporters such as advocates may be more appropriate to assist the person with disability in navigating life and the NDIS without passing judgement.

There are no hard and fast rules and what works for one person often does not work for others. It is important that the person with disability can choose the best decision supporter for them.

*“Personally I think it would be support coordinators or family members or a very trusted support worker.”*

**Karlie – Participant**

*“For people without family [close others], their support team who would have the best knowledge of the person’s needs and wants – it’s people in that person’s life, who know you really well and have your best interests at heart.”*

**Rachel – Participant**

### Recommendation 4

**The NDIA must allow participants to choose the most appropriate decision supporters.**

Paid supporters may be participants’ preferred decision supporters. Independent decision supporters should be provided where a participant is unable to make final decision.

## Circles of support and microboards

Circles of support and microboards offer an approach that takes pressure off family being solely responsible for supporting a person with decision-making. Wider involvement through circles of support and microboards creates a more robust and sustainable situation for participants.

### Recommendation 5

**The NDIA must invest in capacity to access circles of support and microboards for participants requiring supports with decision-making.**

Funding for the establishment and maintenance of circles of support and microboards must be made available in plans. Information, Linkages and Capacity Building (ILC) funding should be directed towards peer led organisations who support participants and families to develop mechanisms for decision-making supports.

## Capacity building

### Upholding dignity of risk

Dignity of risk is a concept that is an important consideration in the discussion about decision-making. Dignity of risk is important because it recognises the benefits of having the freedom to take risks, make mistakes and learn from our mistakes. People with disability are often prevented from making decisions that involve taking risks and the opportunity to learn from their mistakes is not available to them.

*We all need the opportunity to make our own choices as individuals. Just because my disability is physical, it hasn't affected my ability to understand and make my own choices. You need the facts, so you understand the options. 'Informed choices...isn't that just life?'*

Rachel – Participant

Decision supporters must be educated about dignity of risk for people with disability to facilitate greater autonomy over decisions. For one of the authors of this paper, Rebecca, one concern her parents had when making the decision to move out of home, was the fact that she would be alone for periods of time. If their concept of dignity of risk had been better formed, her experience in being supported to make this decision of moving out of home would likely have been better.

### Recommendation 6

**The NDIA must build the capacity of decision supporters to understand dignity of risk.**

The Support for Decision Making Policy must ensure that supporters are trained around and understand dignity of risk in order to enable participants to make decisions that involve risk and learn from their experiences.

## Supporting the decision supporters

Decision supporters should know that they do not have to go about this process alone. 'Flying solo' may place them out of their depth and result in inadequate support for decision-making. Having the opportunity to connect with others supporting similar types of decisions is essential. Everyone needs a support network.

Education and training for the decision supporters is available, but often hard to find. Having a network may also help to identify individuals the decision supporter might be able to lean on (either for support or to act as a co-decision supporter).

### Recommendation 7

**The NDIA must provide decision supporters with advice around where to get support and who to connect with.**

Access to regular check-ins, guidance and capacity building will help to ensure the people supporting a person with disability is supported.

## Preferred forms of communication

It is important that people with disability are able to communicate in a way that works for them. Establishing a preferred form of communication between the person with disability and the decision supporter is essential. Extra education may be pertinent if a decision supporter is working with a person with disability who is not able to use verbal communication and therefore requires the use of alternative methods of communication.

### Recommendation 8

**The NDIA must fund decision supporters to access training around the participant's preferred means of communication.**

Build the capacity of decision supporters to communicate through the person with disability's preferred means of communication.

- a. Information provided to participants should be available in a range of formats including plain English, easy English and audio visual (with captions and audio-described).
- b. For people with cognitive disability, information should be provided in a way that can be understood, checking understanding of content provided on multiple occasions to gauge retention of information and, where appropriate, including closer others (e.g. family) in these conversations.



*“I make my decisions based on the information given to me by people like my parents, my support coordinator, for what I need to progress in my goals.*

*I assume they are getting this information from the NDIS.*

*I get my information through talking. I have difficulty reading because of my double vision. The format of information I get is important to make sure I can use and understand it.”*

**Karlie – Participant**

## **La Trobe University Support for Decision Making Practice Framework**

The NDIA should consider the La Trobe University [Support for Decision Making Practice Framework](#). The Framework aims to develop and evaluate an evidence-based practice guide for engaging in effective support for decision-making with people with cognitive disability. The Framework should be incorporated into capacity building for decision supporters.

### **Recommendation 9**

**In line with the La Trobe Framework, decision supporters must have education and training around:**

- a. **Attention to communication** - pitching information and communication at the right level; awareness of verbal and behavioural cues; and checking back for understanding
- b. **Consequences and practicalities** - making information understandable; doing research; presenting options and pros and cons; and explaining consequences of decisions and that priorities can be undermined by small decisions
- c. **Listening and engaging to ensure all options are considered** - attentiveness to will and preferences; taking the time; and using others as sounding boards
- d. **Creating opportunities** - active reframing that invites participation; providing a sounding board; acknowledging low expectations and building confidence; testing options; introducing and nurturing the seeds of ideas; bringing in others to trial a situation; and creating distance to enable greater autonomy
- e. **Breaking things down** - breaking into smaller components that are shared across the person and supporter; and teacher and shaping skills

## Safeguards around decision supporters

### Reducing undue influence

It is important to consider that decision supporters do not always act in the best interests of the person they are assisting. This can be the case whether the decision supporter is informal or formal, paid or unpaid. People with disability are at a higher risk of financial abuse, which can often be inflicted by the people around them who make decisions.

It is important to have safeguards in place to ensure that the decision supporters of people with disability are acting in the best interests of the person they are supporting.

Decision supporters should avoid imposing their own opinions or allowing personal gain or satisfaction to impede their decision-making support. This enables the person with disability to make a decision that is truly their own, without feeling they have to make a certain decision because someone they depend on wants them to do so.

*“It is important to make sure the influencers are not benefiting from the decisions that they are influencing the client/decision maker to make. Should be based purely on what is best for the client, taking into account their circumstances and the situation they are in. I felt very angry when this [i.e. when people influence you and don’t have your best interests in mind] happened – I felt like people could ‘use and abuse me’.”*

Rachel – Participant

As a signatory to the United Nations [Convention on the Rights of Persons with Disabilities](#) (UNCRPD), Australia must uphold the rights stipulated in Article 12 which state:

*“Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.”*

### Recommendation 10

**The NDIA must ensure that the Supports for Decision Making Policy is consistent with Article 12 of the UNCRPD.**

Decision supporters must ensure that the person with disability is listened to without judgement and advised without undue influence.

The NDIA could employ several approaches to ensure that decision supporters are acting in the best interests of people with disability. They could implement safeguards that raise red flags that a person with disability is not being adequately or appropriately supported to make decisions. This could be triggered under certain circumstances, such as situations where participants are only receiving support from informal supports, such as family, or from one support person or agency or none at all.

The NDIA must be able to communicate with participants. Planners should have the skills and ability to regularly check-in with a participant during NDIS meetings (such as annual planning meetings) to ensure that the participant is happy with their involvement in decision-making. This may need to be conducted without external parties in the room to avoid undue influence in responses.

*“I felt that the influence from others about my health and disability was said to be to “protect me” but it wasn’t. People need to understand options and impact and risks.”*

**Karlie – Participant**

People with disability are best supported to make decisions when they are surrounded by a reliable circle of supporters that understand the system and the circumstances surrounding the person with disability. These supporters should remain impartial, always thinking in the best interest of the person with disability rather than what they themselves would want.

### **Addressing conflicts of interest**

The NDIA must work to address conflicts of interest among service providers who are involved in supporting people to make decisions. This is especially concerning when the person receives support coordination and decision-making supports from a provider who also provides them with other supports such as housing and SIL. Support coordination and decision-making supports should be independent from other types of support that the person may require.

#### **Recommendation 11**

**The NDIA must enact legislative changes in line with the [Tune review](#) to mitigate the risk of conflicts of interest by requiring providers to:**

- a. Document that support options offered by other organisations were presented to participants, transparently promoting choice and control. If a participant chooses the provider’s supports, providers must document why the participant made that decision.
- b. Give clear and explicit declarations of conflict of interest to participants when providing multiple supports and services or managing plans. Explanations must be provided to each participant in their preferred language and mode of communication.
- c. Avoid referrals to “preferred partners” that funnel participants to particular providers rather than having participants choose their preferred provider.

*“How will the NDIA transition away from how things are done now, when some providers are making so much money? E.g. providers delivering all types of support – SC, SIL, etc – how is choice and control achieved with these providers??*

*People don't feel like they have the power to go elsewhere. These providers have too much control.”*

**Megan – Participant**

### Recommendation 12

**The NDIA must ensure independent decision supporters are available where participants feel their main decision supporters are not supporting the will and preferences of the person with disability.**

*“They have to have the right intentions for the client and in the way they support the client. If these people are not good and honest, they can steal the client's property (“I have had experience with this”), or they might sit around and drink all my coffee and not do their job, sit on the couch, texting, doing [nothing]. I feel annoyed and angry and I just want to yell at them. I would contact my care coordinator and tell them what the person has been doing/not doing – leave it with the care coordinator to deal with.”*

**Rachel – Participant**

### Recommendation 13

**The NDIA must ensure that participants requesting a new service, such as different support coordination from the same agency, are provided with options that respond to and meet their needs.**

This ensures that the final decision is one made with the will and preferences of the person with disability in mind. The NDIA should also play a role in ensuring that people with disability are adequately and appropriately supported to make decisions by implementing processes to safeguard participants unable to make their own decisions – both in the planning process/meeting and beyond.

## Conclusion

In summary, a clear policy and greater investment into support for decision-making is essential to ensure that participants in the scheme can achieve their rights as outlined in the UNCRPD. Furthermore, a comprehensive approach to support for decision-making is essential for the NDIS to fulfil its promise of choice, control and an ordinary life for people with a disability.

## Responses to questions in the consultation paper

Please find below our responses to questions contained in the NDIA's Consultation Paper. Not all questions are addressed.

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

- a. Ensure decision-making is *with* the person with disability, not *for* the person with disability – a person-centred approach.
- b. Support people with disability to learn from their decisions – taking risks and making mistakes are an opportunity to gain experience in decision-making and to better understand the consequences of our actions.
- c. Provide greater support in the form of assistance with communication (such as training in the use of assistive technology or augmentative and alternative communication methods) or facilitated discussions around consequences of decisions.
- d. Allow extra time for decision-making.
- e. Educate people with disability on their rights and the services available to them.
- f. Invest in independent advocacy, circles of support and support services to facilitate supported decision-making.
- g. Ensure that people with disability know they can bring trusted support people to meetings, such as NDIS planning meetings.

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

- a. This depends on the person with disability and the decision in question.
- b. For some people, family members (such as parents or siblings) will be the preferred decision supporters - but this is not always sustainable.
- c. Decision-making supporters must always have the interests and preferences of the person with a disability at the centre of the decision.

### 3. What should [decision supporters] do to help with decision-making?

- a. Ensure knowledge around dignity of risk.
- b. Listen to the person with disability without judgement.
- c. Avoid imposing personal opinions or allowing personal gain and/or satisfaction to impede decision-making support.
- d. Take the time to break down a decision and related conversations as required, to ensure they are easily understood in a form of communication that is best and most accessible for the person with disability.

- 4. How can [decision supporters] get better at helping?**
  - a. Be well informed about the NDIS and the circumstances surrounding the person with disability they are supporting.
  - b. Ensure that they remain impartial – at the forefront of their mind should be the person with disability.
  
- 5. How can we make sure the right people are helping? For example: that [decision supporters] are building the capacity of the person with disability, that they are considering what the person with disability wants.**
  - a. Establish safeguards that raise red flags when a person with disability is not being adequately or appropriately supported to make decisions.
  - b. Check-ins during NDIS meetings (such as annual planning meetings) to ensure that the participant is happy with their involvement in decision-making.
  
- 6. What should decision supporters know about so [decision supporters] can help people with disability make decisions?**
  - a. Methods for communication, particularly for people with disability who are not able to use verbal communication.
  - b. There is no reason to ‘fly solo’ – people with disability may have multiple decision supporters who are able to work with each other to ensure the best decisions (and therefore outcomes) are made for the person with disability that they support.
  
- 7. 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. The best support to make a big decision revolves around being provided, without bias, all the options available on the table.
  - b. It may help to talk to someone who is in similar circumstances and has been through a similar decision-making process before. This can be both from the perspective of the person with disability or the decision supporter.
  - c. Decisions forced upon people with no consideration for what the preferences and desires of the person with disability are, or what is in their best interest, do not work well.
  - d. The correct decision is not always what has often/always been done in the past.
  
- 8. 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.**
  - a. For many participants, having a good circle of supports that can understand the system is vital.
  - b. Provide funding for support coordination. Support coordinators can play an important role to support for decision-making.
  - c. It is important that NDIS planners are knowledgeable of methods to support decision-making – both in the planning process/meeting and beyond that.

**9. How can we help reduce conflict of interest?**

- a. Fund an independent decision supporter, circles of support and microboards.
- b. Multiple decision supporters should be involved to keep each other accountable for the decisions being made.
- c. Implement a system of documentation where decisions are detailed along with the reasons why a particular decision was selected.
- d. Reduce the involvement of people who have a vested interest in the chosen decision (for example, employees of a service provider who will benefit from a person with disability choosing to use their services).

**10. How can we reduce undue influence?**

- a. Similar to safeguards discussed above, undue influence can be reduced by putting in place procedures and policies around decision supporters and decision-making, ensuring that more than one decision supporter is involved for people with disability who are vulnerable, and putting in place safeguards that raise red flags for people who may be at greater risk of undue influence (such as those who are solely reliant on one person or one provider for their support).

# About the Summer Foundation

Established in 2006, the Summer Foundation works to change human service policies and practices related to younger people (18-64 years old) living in, or at risk of entering residential aged care facilities.

Our Vision is that younger people with disability and complex support needs live where and with whom they choose, with access to high-quality housing and support options that enhance health, wellbeing and participation.

Our Mission is to create, lead, and demonstrate long-term sustainable systems change that stops younger people from being forced to live in aged care because there is nowhere else for them.

The Summer Foundation has worked extensively with people with complex disability support needs to ensure they have access to all the NDIS supports essential to living the life they choose. Supported decision-making is essential for people with disability to have control over all aspects of their lives.