**Consultation Paper: Supporting you to make your own decisions Submission**



Australian Community Industry Alliance

2021

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# Introduction

Australian Community Industry Alliance (ACIA) welcomes the opportunity to provide this submission to consultation on supporting you to make your own decisions.

# Background on ACIA

ACIA is the national peak body representing community care and support providers, including private, not-for-profit and charitable organisations. Nationally ACIA represents over 100 provider organisations, which collectively employ more than 150,000 FTE workers. ACIA also supports the disability and aged care sectors and works with government departments and authorities, including:

* State Disability Agencies such as Department of Family and Community Services, Ageing Disability and Home Care NSW, Department of Health Human Services Victoria and Disability Services QLD
* iCare NSW which includes: Lifetime Care and Support Authority, Workers Insurance, Dust Diseases Care, Self-Insurance and Builders Warranty.
* Lifetime Support Authority South Australia
* Motor Industry Accidents Board, Tasmania
* Transport Accident Commission Victoria
* Workers Compensations Schemes in multiple states
* Representation at the National Aged Care Alliance
* Department of Health
* Department of Social Services

ACIA’s vision is for a community care and support industry that is known and respected as a provider of quality services. To achieve this vision, ACIA provides education, resources and support to the industry, as well as developing and administering its own quality standard and scheme (endorsed by the Joint Accreditation System for Australia and New Zealand JAS-ANZ).

ACIA seeks to be involved in the future development of policy and service reform, by bringing to the discussion our experience and expertise, including:

* Membership of over 100 provider organisations and individuals nationally, representing around 150,000 FTE workers
* Membership across the disability and aged care sectors
* Specific expertise in the delivery of support to people living at home or in supported and shared accommodation arrangements
* Lengthy provider experience of delivering individualised support according to the wishes of the individual in line with their funding
* Experience in compensable and business markets
* Experience in the development implementation and administration of quality certification systems that meets the national standards for disability services and home and community care standards (for example the ACIMSS 2008 and the ACIS 2013)
* Proven track record of engaging positively with reform processes, and working collaboratively with governments, providers, consumers and interested stakeholders.
1. **How can we help people with disability to make decisions for themselves?**

The consultation paper should be commended on a strong and measured approach for providing a structure to which people with disabilities can be supported to make decisions. The concept of supported and substitute decision makers is indicative of a strong argument for encouraging decisions based on the elements identified in the decision-making capability framework.

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

**(We call them decision supporters)**

The role of a supporter, either informal or formal remains questionable in the decision-making framework. The guidance around this needs to be considered further as to their motives, their experience, and their relationship to the person with a disability. Whilst they can sit on the continuum as indicated in Figure 4 this is such a variable yet influential skill and role that they play. In particular there is less of a descriptor to separate out formal decision supports that may be support providers who are in charge of managing monies or plans on behalf of a person with a disability and that of a substitute decision maker. The substitute decision maker should be the formal decision supports for a person as their liabilities, bias and responsibilities have been clearly articulated in legislative documents.

1. **What should they do to help with decision making?**

The scale depicted in Figure 2 provides good context for the decision making continuum. All reasonable efforts should be undertaken to ensure that the person with a disability can as actively as possible contribute to the decision making process. Care must be given though to the formal support decision makers where their motives and bias may be not clearly evidenced to the participant.

1. **How can they get better at helping?**

Our learnings would suggest that decisions can not be rushed and needs to be practiced. Allocation in their support plans should be in almost always be allocated with time to practice decision making as it should be a guided and supported process. A specific strategy should be, in almost all cases be allocated to the support plan to do such an activity regularly. This acknowledges that decision making for persons with a a disability can be time consuming and challenging, impacting on other parts of a normal routine, however it is important that these be considered in such a manner.

1. **How can we make sure the right people are helping? For example: that they are building the capacity of the person with disability, that they are considering what the person with disability wants.**

This is a challenging question that is one not well articulated in the document. Providing informal decision is both reasonable and justified, however the case of those who are formal decision support persons, with the exception of substitute decision makers is less clear. Formal support decision makers where they are unskilled and their motives and bias is less closely defined. There needs to be a matrix of decision making to help guide the process.

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

There needs to be some guidance around the type and impact of the decision to who should be involved in the decision. We would suggest a matrix to guide the development of this work. It has consideration to the experience and relationship of the supporter to the decision to what level of involvement should be engaged.

1. **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?**

Decision making about when to engage in a relationship which may be emotional or physical. It has taken a series of carefully planned conversations around timing that suits all parties. This has then engaged the development of scenario and role play discussions to support the best outcome for all interested parties to consider all sides of the relationship. To reiterate, to get the best outcome, this has taken a substantiated period of discussion and engagement at suitable occasions to foster trust in the relationship, carefully consider all parties and outcomes.

1. **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.**

The best way to support a person with a disability to make decisions is with practice, patience and supportive persons around to facilitate a measured and minimal risk approach. The support plans for all should include adequate time to practice decisions whether they be big for small as this takes practice and patience. Without this opportunity this is a skill that cannot be fostered nor excepted to get a good outcome and set the person up for success.

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

All disabilities, all cultures, all personal preferences will make a difference on a person with or without a disability, as decision making respects the individual who is at the heart of all issues. Each individual requires a different approach to their decision-making choices and capability to do such.

1. **Conflict of interest is when a person or organisation takes advantage of their position for personal or corporate benefit. How can we help reduce conflict of interest?**

This is the most significant gap in the documentation provided for consideration. This is particularly relevant for the formal support decision makers as informal decision-making support provides less risk for the decisions at hand. Formal decision makers who are managing the support plans and/ or financial matters of a client must acknowledge their conflict of interest. One options at hand is where decisions are or have the potential to impact on a participant then shared decision making should be considered as an option to minimise the conflict of interest. This process could involve sharing the decision and the direction of the decision with a colleague or key stakeholder. This process where risk is high, impact or type of decision has greater risk or influence then a share decision making approach should be considered and documented to validate the approach an minimised the conflict of interest.

**Undue influence is when a support person makes the person being supported do something they don’t want to do by making them feel scare, by being mean or by threatening or lying to them.**

1. **How can we help reduce undue influence?**

An approach to minimise any undue influence could be to encourage shared decision making approaches. This would involve discussions and an awareness of the risk of undue influence. Through a transparency of shared decision making, the risks would be minimised.

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

The only risks could be in relation to conflict of interest which already exists and potentially is the reason this topic has come to light where this has been unduly utilised to not consistently support the best interests of participants.

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

The relevant topics have been considered as a part of this presentation of topic issues.

1. **Do you have any feedback on our proposed actions in Appendix C of this paper**

**Support for Decision Making consultation submission**

**Name:** Australian Community Industry Alliance (National)

**Date and time submitted:** 7/25/2021 11:04:00 PM

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

* Resources: No
* Information: No
* Decision Guides: Yes
* Having a person help: Yes
* Other: No

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

* Family: No
* Friends: No
* Peer Support Networks: No
* Mentors: No
* Coordinators: No
* LAC: No
* NDIA Partners: No
* Advocates: Yes
* Service Providers: No
* Other: No

# **What should they do to help with decision-making?**

Encourage a transparent shared decision approach.

# **How can they get better at helping?**

* Getting to know the participant well: No
* Doing some training on decision support: No
* By having resources and information about providing decision support: Yes
* Other: No

# **How can we make sure the right people are helping?**

* They are chosen by the NDIS Participant as a decision supporter: No
* They value the rights of people to make decisions with support: Yes
* They are a registered provider: Yes
* They enable the participant to take risks: No
* Other: No

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

* Guidelines for decision supporters: Yes
* Scenarios or Examples: No
* Information Sessions: No
* Support Networks: No
* Other: No

# **Can you tell us about a time when someone helped you (or a person with disability) to make a big decision?**

Yes

## **What worked well?**

No answer recorded

## **What could have been better?**

No answer recorded

# **What is the best way to support people with disability to make decisions about their NDIS plan?**

* Practice: Yes
* Peer Support Networks: Yes
* Information and Resources: No
* Guidance Tools: No
* Not Sure: No
* Other: No

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

**An intellectual disability:** No

**A disability that impacts how they think, a cognitive impairment:** No

**A psychosocial disability:** No

**A disability that impacts their ability to communicate:** No

**From a CALD community:** No

**From an Aboriginal or Torres Strait Islander Community:** No

**From the LGBTIQA community:** No

# **How can we help reduce conflict of interest?**

No response recorded

# **How can we help reduce undue influence?**

No response recorded

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

No response recorded

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

No response recorded

# **Do you have any feedback on our proposed actions in Appendix C of the paper?**

No response recorded