 **COMMUNITY ACCESS WESTERN SYDNEY - CAWS**

PO Box 4016, Lalor Park NSW 2147

ABN 25 382 697 278

NDIS 4050015560 office@caws.com.au [www.caws.com.au](http://www.caws.com.au/)

**Community Access Western Sydney Incorporated (CAWS)**

**Submission to National Disability Insurance Agency (NDIA)**

**Supporting you to make your own decisions 10th September 2021**

Community Access Western Sydney Inc. (CAWS) welcomes the opportunity to make a submission to the NDIA consultation on the direction of the NDIA Support for Decision Making policy.

CAWS is a disability advocacy service that also provides NDIS services in Western Sydney. We have been discussing Supported decision Making with many of the participants that come to us for assistance through Advocacy or Support Coordination. We would like to share some of the issues that we have identified in relation to these discussions.

The people that we support always have as much opportunity as possible to make their own decisions. Those that have an intellectual disability and may have no literacy often depend on us greatly to help them make decisions and in some cases will just agree with what a person tells them. In order for people to make decisions about their own life it is important that they receive as much information as possible, in a format that works for them and over a period of time that allows them to engage appropriately with the information.

Training planners and LAC’s on the use of open questioning and the delivery of information will be useful but often everything is delivered at the planning meeting and the participant is asked to make a decision without time to process it. Particularly people with an intellectual disability or cognitive impairment, need sufficient funding in their plan for the Support Coordinator to spend time in the preparation for the planning meeting, providing choices and making sure the participants is informed before making a decision.

As an advocate we are often asked to assist people with decision making, our independence allows us to be sure that the participant is getting accurate advice and information to make the decision on services.

When conducting planning meetings there is a significant risk of people not having a decision supporter with them. Many participants have people in their lives that they get assistance from informally, but that person doesn’t always know about the planning meeting and is not invited. This is not because the participant does not want them there, it is often because they don’t think they are allowed to bring people. Asking the participant, or their decision maker, who they want to attend each planning meeting would assist them to have the right people to support them. We have experienced many times attending a planning meeting and the participant has not been asked who they want at the meeting.

Consideration in capability needs to be given to the person’s history. The consultation paper talks about how people start making decisions early in life, however if a person has lived in institutional care for most of their life, their opportunity to make decisions has been minimal. A person may have the cognitive capability to make decisions, however if they have never had the opportunity this will be a new concept. We have

Page **1** of **2**

experienced situations where a person is given the opportunity to choose and make decisions but has not been given the education and experiences to support this. NDIS should consider an education program that could be used by support workers to provide some of the decision making framework for an individual within their package.

Part of the role of decision supporters needs to include when a person cannot make their own decision. For example during a covid lockdown they have to follow the Covid rules for their location and they do not have a choice, another may be wanting the right to have their transport payment paid by cheque if that is not an available option. This is an area of decision making that has had little attention and resources about the times when you cannot have a choice would be helpful to decision supporters.

Decision Supporters need to be able to demonstrate that they are genuinely assisting the person to make decisions. Referrals for advocacy should be made if there is any question about the decision supporters motive and independence.

Support Coordinators often fill the role of decision supporters, it is their role to provide information so that decisions can be made and they should demonstrate in their reports that they are working with the participant to build the capacity of the person with disability, and that they are considering what the person with disability wants.

Our experience has shown that participants are not provided with sufficient opportunity to understand their plan and give feedback on what the final plan contains. Participants need to see a draft of their plan before it is approved so that they can provide this feedback to the planner.

The NDIS needs to implement a way for informal decision supporters to be registered and informed by the NDIS when a plan or other decision making activity is occurring, at present the only way is for the participant to have a nominee or guardian. In order for people to have a least restrictive option they need to be able to give authority for a friend or informal advocate to be notified so that they can assist the participant. Participants don’t necessarily want a formal nominee as they value their independence and feel this may mean the nominee can make decisions for them. A system of notifying the participant and a decision supporter without allowing that person to act on the participants behalf would be helpful.

Many NDIS participants do not have the capacity to make their own decisions and do not have a formal decision maker such as a guardian. Guardianship is only awarded if there is an issue of concern and not just for the purpose of the NDIS plan. In this case it is important that the person has someone independent to assist with the planning process and to ensure that the participant is being engaged in decision making as much as possible. At present most of the people in this situation attend their meeting with their group home provider and they are not given the opportunity to have some input. Many SIL providers are also Support Coordination providers, particularly with the larger agencies. Separation of SIL and Support Coordination should be a priority for NDIA. An independent Support Coordinator or Advocate should be in place if the person with disability has limited capacity to communicate their preference or be involved in decision making and they do not have informal supports.

Thank you for the opportunity to provide feedback

Chris Laurie

Manager CAWS

Page **2** of **2**

**Support for Decision Making consultation submission**

**Name:** Community Access Western Sydney (NSW)

**Date and time submitted:** 9/10/2021 4:27:00 AM

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

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

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

See attachment

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

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

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

Not applicable

## **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: No
* Information and Resources: No
* Guidance Tools: No
* Not Sure: No
* Other: Yes

Draft plans before being approved so that the decision supporter can ensure the participants views were considered and documented

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

**An intellectual disability:** Yes, Capacity to understand the decision that is being made. The history of the person may impact, if they have been in institutional care for most of their lives and are now in a group home that does not promote decision making they may not have the foundation on which to build capacity. The foundation may need to be built first.

**A disability that impacts how they think, a cognitive impairment:** Yes, As with intellectual disability.

**A psychosocial disability:** Yes, People with a mental illness may act quite paranoid about people who they perceive as government officials making decisions on their behalf. It is important that the person has access to a person who is skilled in working with people with a psychosocial disability to ensure that they are not disadvantaged in any way.

**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?**

SIL Providers should not be providing Support Coordination to the same participant. When a person lives in a home with others and has many aspects of their life attended to by one organisation they must have someone independent from their accommodation to assist them. In some cases participants choose to have only one service engage with them and they have the right to make this choice but it needs to be shown that the participant made that choice. Many SIL providers participants don't know who their Support Coordinator is.

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

As above

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

It is important that they are given the opportunity to learn about decision making and also about when they cannot make a choice such as during Covid lockdown.

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

See attachment

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

No response recorded