**10 September 2020**

**Submission to National Disability Insurance Agency**

https://www.ndis.gov.au/community/have-your-say/support-decision-making-consultation

# Support for Decision Making Consultation

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## The NDIS CMH Interface group

The Victorian Statewide Clinical Mental Health NDIS Interface group consists of NDIS Program Leads who are specialist clinicians based at tertiary Mental Health services across the state of Victoria. These NDIS Program Leads provide the interface between the NDIS and tertiary mental health treatment providers. These clinicians do not provide NDIS services, but rather work with clinical staff groups as they support and treat people with mental ill-health and associated psychosocial disabilities.

The following is the Clinical Mental Health NDIS interface group submission to the National Disability Insurance Agency’s consultation regarding its proposed Support for Decision Making Policy. This submission does not intend to represent the organisations with which the NDIS Program Leads are engaged, but rather represents the views of this collective group.

We welcome consideration into support for decision making and value that the NDIA continue to deliver individualised support. However, some of the key messages within this paper continue to articulate the misunderstanding of psychosocial disability and associated complexity of decision making support. There are several assumptions within this paper that do not reflect the experience of clinical mental health workforce working alongside people with psychosocial disability. It is important that moving forward the NDIA consider the unique difference for people with psychosocial disability, that it cannot be grouped with intellectual disability or acquired brain injury. Decisions on policy and procedure that fail to listen to the voices of people with or support people with psychosocial disability will not meet the needs of these participants, impacting on their ability to improve their future capacity and resulting in greater demand on the NDIS.

## Summary

1. The idea of a person’s capacity for decision making is complex, and particularly variable for individuals with psychosocial disability.
2. Support for decision making is nuanced and needs to be individualised. People with psychosocial disability benefit from relationships developed over time to enable effective support for decision making.
3. The NDIA 2020, Participant Outcomes Report has identified that participants of the NDIS with psychosocial disability are more likely than other disabilities to have no friends other than family or paid staff. Identification of key supports requires careful and skilful assessment alongside the clinical supports.

## Recommendations

1. Intentionally safeguarding support for decision making over a person’s lifetime for people who experience psychosocial disability. This can best be provided through maintained NDIS funding to support decision making.
2. There needs to be accessible resources available to inform decision making, including NDIS funded supports ensuring informed decision making.
3. Consideration to maintain nominees to support decision making for people who are unable to engage with services. Ongoing relationship building between clinical services and NDIS providers is essential.

## Discussion

***1. A person’s capacity for decision making is complex, and particularly variable for individuals with psychosocial disability.***

Decision making capacity may not be stable

Assessing the decision-making capacity for people who have psychosocial disability can be complicated and variable. A person’s ability to make decisions may not be consistent and is complicated by their disability. Completing an assessment on a person’s capacity to make decisions at access or planning as discussed in this paper will not be accurate or fair.

For a person with a psychosocial disability, they can experience episodic fluctuations in symptoms and changes in the way they think. And therefore, have periods of time where they may lose sight of their goals. While the Mental Health Act safeguards high risk decision making, decision making that supports recovery and wellbeing can have just as much impact on a person’s long-term disability and supports. Therefore, the NDIA needs mechanisms to safeguard decisions they may make when they are unwell or in early stages of recovery from an acute episode. This cannot be made on a single assessment of their capacity to make decisions.

*Example 1: A person who experiences schizophrenia can be well for long periods of time, at these times is able to have clear and positive goals associated with social connection. However, at a time of increased paranoia refuses all supports to engage in social connection and given the symptoms of their disability, makes active choices to disengage with supports and connections. On improvement with paranoia, supports are already removed, and connections achieved in the past are lost. This results in increased isolation and disconnection.*

Without supports to hold the goals and decisions made while able to make decisions, and skilfully support decision making when the participants ability is limited, the risk of deterioration and further disability is increased, resulting in greater long term demand on the NDIS.

Engaging in decision making process can be challenging

In addition to fluctuating needs for support around decision making, the functional impairments that make consumers NDIS eligible are the same reasons they struggle to engage in decision making process even when they have capacity

* Difficulties establishing trust, engaging with others and misinterpreting events o Impaired concentration, decision-making and organisational skills, motivation and judgement
* Difficulty coping with situations involving stress, pressure or performance demands o Impulsivity o Slowed thoughts
* Understanding information clearly from others o Engaging with or understanding written material
* Managing correspondence o Holding reciprocal conversations o Articulating needs and seeking help o Being understood by others
* Regulating emotions and managing interpersonal conflict o Navigating service systems
* Lack of informal networks

*Example 2: A person who experiences major depression, when well is independent in all areas of self-care, and has a strong value in their personal presentation, however at a time of relapse does not to engage in in any self-care activities. They do not have the ability due to their symptoms to ask for help, even though these tasks are important to them. This results in decreased participation and limited engagement in everyday activities.*

Supports that ensure a person’s voice is heard are required so that a decision can be supported. Unless participants understand choices available and are able to articulate that need at times of most need they will not seek these. This can only be achieved with support from existing trusted supports. Many people with psychosocial disabilities will not be able to access the supports they need when needed the most. With deterioration in mental state there is a risk of further disability, resulting in greater demand on the NDIS.

***2. Support for decision making is nuanced and individualised. People with psychosocial disability benefit from relationships developed over time to enable effective support for decision making.***

Access to resources to understand choice

It is important that there are sufficient resources to support informed decision making. It is great that the NDIA are considering what resources are required for participants and their supports, to support decision making.

Resources available on the internet or via phone are not accessible to a significant proportion of the population with psychosocial disability.

A quick review of consumers of our community clinics found

* Only 50% of consumers have reliable access to a phone (25-35% have a smart phone, 1030% have landline or other mobile phone).
* This dramatically reduces for the people who are engaged in with our homeless and outreach services who have greater disability. Less than 10% of this consumer group have access to a phone.
* 10-15% have access to tablets/computers and Wi-Fi
* 50 -75 % have difficulty engaging with phone (won’t answer, difficulties with concentration, comprehension and memory, paranoid and/or delusional ideas connected to phone). In the current pandemic crisis, those that do have access to tablets and computers, prioritise data use for connection and key supports. Without accessible, reliable information that people can apply to their own needs, a person cannot make an informed decision.

Relationships in support of decision making are important

Consideration of information provision needs to be more diverse and available in individually tailored ways. Given the fluctuation in needs of people with psychosocial disability, having key relationships are important. While the Local Area coordinators are skilled at information provision, many people who experience psychosocial disability have difficulty establishing trust, engaging with others and misinterpreting events. Their ability to maintain focus on key goals can be impaired. Therefore, long term relationships and understanding of a person over time is important to support decision making, particularly on important choices associated with support and social participation.

*Example 3. A Participant had a support coordinator who supported decision making on the types and implementation of supports. They were able to maintain progress on goals of the participant despite fluctuations in capacity to make decisions. At a planning meeting, this funding was ceased. The participant was not able to make decisions without the support of the coordinator and the essential support network ceased. The participants mental health deteriorated and required hospital treatment.*

Supportive relationships are able to help support decision making. The Local Area Coordinators are not able to build the essential relationships that these participants need to support decision making. There needs to be an opportunity for a participant to build a relationship with support. When supports are in place, a person is more capable and confident to make decisions, even when their ability may be challenged. Withdrawal of these supports can increase disability, resulting in greater demand on the NDIS, including an increase in unscheduled reviews and increased funding in future plans.

Nominees play a key role in supporting decisions and engagement of people with psychosocial disability.

While it is important to keep reviewing systems where people are nominated to act on another’s behalf, it is also important to ensure that these roles continue to support people who need nominees.

*Example 4. A person with schizophrenia lived in squalor and could not participant in the tasks associated with maintaining their home. This resulted in them leaving their home for extended periods, impacting on increased symptoms, poor nutrition and self-care, and limited positive community engagement.*

*A clinician had discussed NDIS with the consumer who agreed to the supports but would not engage in the process. The clinician was able to act as a nominee, and NDIS services were initiated. With NDIS supports the participant enjoys being at her clean home, eats nutritious food, looks after her self-care and engages socially within the community.*

Without nominee appointments, many people who have would most benefit from NDIS supports to engage in the community will not have access initiated by clinical services. A person with psychosocial disability needs active support to understand what NDIS can offer, understand what their disability is, and stepped through the process of access. The nature of a psychosocial disability means they will need more support to be stepped through the process at times.

***3. NDIS Participants with psychosocial disability are more likely than other disabilities to have no friends other than family or paid staff. Identification of key supports requires careful and skilful assessment alongside the clinical supports.***

While we acknowledge that key supports can be informal, we rarely find people with significant psychosocial disability have good informal support networks. A participant’s psychosocial disability can have a significant impact on social engagement resulting in limited social connection and reduced informal support networks. Many relationships that a person with a psychosocial disability has may already be strained. Often a participant’s informal support network will not be their family member. Sometimes key supports can be a person that does not engage in positive behaviour. Or an identified informal support may be a neighbour that checks on them occasionally but is not in a position to have a role in supporting decision making. Additionally key informal supports may not have the ability to support decision making.

*Example 5. A dependent participant was living with their parent. The participants parent had responsibility to support decision making. However, the parent was also an NDIS participant, and needed support with decisions associated with nutritious meals. The parent did not have the capacity to provide support for decisions around meal choice.*

Clinical services often become the primary support for making decisions, however these services can change rapidly as a participants transition between services.

While it is important to identify key supports and keep this record, it is important to identify these informal supports carefully and skilfully and consider their capacity and ability to support the participant.

**Reference**

NDIA 2020, *PB Participant Outcomes 30 June 2020 baseline*, Chapter 5, page 147

<https://data.ndis.gov.au/reports-and-analyses/outcomes-and-goals/participant-outcomes-report>

**Support for Decision Making consultation submission**

**Name:** Victorian Statewide Clinical Mental Health NDIS Interface group (VIC)

**Date and time submitted:** 9/10/2021 5:08:00 AM

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

* Resources: No
* Information: No
* Decision Guides: Yes
* Having a person help: No
* 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: Yes
* LAC: No
* NDIA Partners: No
* Advocates: Yes
* Service Providers: Yes
* Other: No

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

Inform decisions, listen and hear the choices when need support to engage. Hold decisions when unable to make decisions

# 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: Yes
* Other: No

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

* They are chosen by the NDIS Participant as a decision supporter: Yes
* 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: 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: Yes

Understanding mental ill health and the impact of episodic illness on function and impact on decision making ability.

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

Long term relationships with paid supports to engage the participant over time

# 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:** Yes, See attached:

People with psychosocial disability, due to their disability have, difficulty engaging with supports for decision making. The episodic nature of mental ill health, means there is fluctuations in the level of support they will need for decision-making. People with psychosocial disability have less informal supports than other disability groups.

**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?

Having good mechanisms in place to investigate reports. Mechanisms that support a 3rd party to advocate for a participant when the participant is not able to do so for fear of impact on their supports.

# How can we help reduce undue influence?

Having good mechanisms in place to investigate reports. Mechanisms that support a 3rd party to advocate for a participant when the participant is not able to do so for fear of impact on their supports.

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

See attached:

When people with psychosocial disability make decisions while acutely unwell that at contradictory to those decisions they have made when they are well, the gains they have made when they have been well can be lost. Skillful support on decisions are required to support them.

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

Long term paid supports through NDIS funding to support decision making increases the confidence of a participant to make decisions, and their functional gains and supports can be safeguarded.

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

See attached.