WA Department of Communities’ Response to the National Disability Insurance Scheme Consultation Paper:

Supporting you to make your own decisions

Contents

[1. Introduction 3](#_Toc5503)

[2. Submission 3](#_Toc5504)

[2.1 Assisting people with disability to make decisions for themselves (Question 1) 3](#_Toc5505)

[2.2 The role of supporters (Questions 2, 3, 5 and 6) 3](#_Toc5506)

[2.3 Cultural background and other factors (Question 9) 4](#_Toc5507)

[2.4 Concerns – including challenges (Question 12) 4](#_Toc5508)

[2.5 Proposed actions in Appendix C (Question 14) 5](#_Toc5509)

[3. General feedback and conclusion 5](#_Toc5510)

# Introduction

The WA Department of Communities (Communities) welcomes the opportunity to provide feedback on the ‘National Disability Insurance Scheme Consultation Paper: Supporting you to make your own decisions’ (the Paper). Communities’ submission addresses relevant questions in the Paper and how the proposed Support for Decision Making Policy (the Policy) can best be implemented to enhance the capability of National Disability Insurance Scheme (NDIS) participants with reduced decision-making capacity.

# Submission

## Assisting people with disability to make decisions for themselves (Question 1)

NDIS participants, and more generally, all people with disability, need to be empowered to make decisions for themselves. For people with reduced decision-making capacity, this empowerment may be achieved by Support for Decision-Making (SDM). To effect positive change, the individualised, specific and circumstantial nature of SDM, and its existence on a continuum, must be recognised. The Policy – which includes key principles, goals, and the Decision-Making Capability Framework (the Framework) as referred to in the Paper – is an important step towards this change, because it proposes acknowledging and assessing the self-determination capability of NDIS participants with reduced decision-making capacity. However, to better assist people with reduced decision-making capacity to make decisions for themselves, there needs to be a cultural shift. As acknowledged by the ‘National Disability

Insurance Scheme Companion Paper: Supporting you to make your own decisions’ (Companion Paper), the historical default position of substitute decision-making needs to be altered to considering SDM as the first option. People with reduced decision-making capacity need to be involved in SDM in a meaningful way and given relevant information and supports to maximise their participation in decision-making. Information and education in appropriate formats must be available, ongoing and delivered in a manner that is accessible to and understandable by each individual.

## The role of supporters (Questions 2, 3, 5 and 6)

As discussed in the Companion Paper, there are a range of supports and resources that can support a person with reduced decision-making capacity to make decisions. Importantly, SDM supporters (whether informal and formal) must understand their role as supporting decision making and building the capacity of people with reduced decision-making capacity to consider and determine their preferences. Key to this is supporter knowing the person they are supporting well, in terms of the person’s will and preferences. They should be able to help the person communicate these preferences, rather than make decisions for them based on perceived best interest (substitute decision-making). It is also recognised that while SDM may significantly build a person’s capacity the implementation of SDM may also be time and resource intensive. Supporters need adequate resourcing to ensure appropriate SDM models and supports can be implemented to uphold the rights of people with disability. To further assist supporters, guidance materials need to be readily available and peer support networks established (such as a SDM Community of Practice). Regular refreshers or workshops should also be provided for supporters to ensure they do not resume old substitute decision-making practices out of habit, for ease or efficiency.

## Cultural background and other factors (Question 9)

The implementation of SDM may vary for people with reduced decision-making capacity depending on their cultural background, disability, life stage or demographics. Specific SDM resources focussed on transitioning from best interest to will and preference decision-making need to be developed and available for young people, people in regional and remote areas, people from different cultures, Aboriginal and Torres Strait Islander peoples, and people with specific support or accessibility needs. Further, consideration needs to be given to how the implementation of SDM will co-exist with the process of collective decision-making as practiced by some cultures.

## Concerns – including challenges (Question 12)

The primary purpose of SDM is to maintain dignity of risk (or ‘reasonable risk’) and determine how a person with reduced decision-making capacity can be supported to understand and comprehend the potential widespread impact of their decision-making before they make their decision. It is not unusual for a person, at a difficult stage in their life, or with certain personal beliefs, to make decisions against their best interests or against societal or legal expectations, regardless of their decision-making capacity. However, the decisions of people with reduced decision-making capacity are often subject to increased scrutiny. Rather than unwarranted interference, SDM should (in practice) promote autonomy balanced with the correlating risk to the community (if any).

It is also acknowledged that despite the general preference for SDM and dignity of risk, which for a very small complex cohort of individuals, formal substitute decision-making may be essential at a particular point in time or with regards to a specific subject. For example, for a person with reduced decision-making capacity exiting the justice system, income support, housing and service provision need to be put in place before they can be released in the community. While the person remains in custody, implementing SDM when setting-up arrangements for their release is challenging and may often delay release. In this instance, a representative or substitute decision-maker may aid the process, with a view to involving the person in, and introducing supports for, SDM once they are back in the community. Therefore, the challenge is to implement SDM in a manner that is fluid, on a continuum and amenable to the needs of every individual with reduced decision-making capacity.

## Proposed actions in Appendix C (Question 14)

The public consultation process, the Policy and proposed next steps in Appendix C of the Paper comprise of positive, aspirational concepts. However, the success of SDM in practice depends on how these aspirations and consultation outcomes are implemented and used to refine the Policy. The indicators of success need to be further developed. For example, to be proper indicators of success, an increase in the number of people involved in SDM and a decrease or variation in nominee appointments must also be assessed in terms of the level and meaningfulness of involvement by people with reduced decision making capacity in the SDM process. The feedback of people who are involved in SDM, and their progressive awareness of SDM processes, may also be considered markers of success.

# General feedback and conclusion

Communities supports the vision, intent, and aspirations in the Paper. However, the success of SDM will depend on how the Policy is refined and the way SDM is implemented as best practice, reviewed, and continuously improved. People with reduced decision-making capacity must be kept at the centre of the SDM process. Consideration needs to be given to:

* how the Policy:

o may more broadly guide people with disability who are not NDIS participants o will be monitored and regulated by the National Disability Insurance Agency (NDIA) o may apply to providers (including in the context of behaviour support services and the authorisation of restrictive practices arrangements in each State and Territory)

* what can be done for people with reduced decision-making capacity and no decision making supporters
* how a formal process to identify a person’s decision-making capacity will be developed and align with the Framework
* how the proposed operational framework for Consent and Informal Decision-Making will capture the consent requirements across States and Territories.

For these reasons, Communities seeks ongoing progress updates on the National

Disability Advocacy Program’s Decision Support Pilot which is referred to in the Companion Paper and focuses on NDIS participants with reduced decision-making capacity and no relevant supporters (noting the pilot has been extended to 2022). Moreover – to ensure the positive change introduced by SDM is maximised – Communities strongly encourages the NDIA to undertake consultation on the outcomes from consultation on the Paper, the refinement of the Policy and the draft SDM implementation plan before its intended release later in 2021.

**Support for Decision Making consultation submission**

**Name:** WA Department of Communities (WA)

**Date and time submitted:** 9/10/2021 4:57:00 AM

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

* Resources: No
* Information: No
* Decision Guides: No
* 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: No
* LAC: No
* NDIA Partners: No
* Advocates: No
* Service Providers: No
* Other: No

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

No answer recorded

# **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: 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: No
* They are a registered provider: No
* 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: No
* 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?**

No answer recorded

## **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: No
* Peer Support Networks: No
* 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