

25 August 2021

National Disability Insurance Agency
GPO Box 700
Canberra ACT 2601
Via email: agencypolicy@ndis.gov.au

Feedback in response to the Support for Decision Making Policy Framework and approach to Home and Living consultation papers.

Thank you for the opportunity to contribute to the NDIS consultation papers; support for decision making policy and living an ordinary life at home, July 2021.

As the Public Advocate for Queensland, I undertake systemic advocacy to promote and protect the rights and interests of Queensland adults with impaired decision-making ability.¹

People with impaired decision-making ability are a broad and diverse group. They can be all ages, cultures, and demographics. As with all people, they have the right to be included in our community, have opportunities to contribute to the decision-making process, and be connected with our community in a meaningful way.

Advocating for adults with impaired decision-making ability to be supported to participate in decision-making processes in accordance with their will and preference, regardless of their cognitive ability level, is of significant importance to my role as the Public Advocate.

It is clearly articulated in the 2006 United Nations Convention of the Rights of Persons with Disabilities that all people with a disability have a right to participate in the making of decisions that affect them.²

Article 12 of the convention holds signatory nations, including Australia, responsible for supporting persons with disabilities to access the support they require to exercise their legal capacity, inclusive of developing appropriate measures and resources. In 2014, the Australian Law Reform Commission (ALRC) proposed a set of National Decision-making principles and guidelines outlining the importance of a person's "will and preference" to guide decisions, and that appropriate access and support be provided to a person to enable them to communicate and participate in decisions that affect them.³

In this context, I strongly support the commitment by the NDIS to develop the Support for Decision-Making and Homes and Living policies, which are intended to enable NDIS participants to access appropriate support to participate in decision-making processes, and exercise additional choice and control over their living arrangements.

I have made comments below regarding each policy for consideration by the NDIS.

¹ *Guardianship and Administration Act 2000* (Qld) s209.

² United Nations (UN). Geneva. Convention on the Rights of People with Disabilities; 2006

³ Australian Law Reform Commission, Sydney (NSW): Equality, capacity and disability in Commonwealth laws (DP 81); 2014

The Support for Decision Making Policy

The consultation paper acknowledges inclusion of a range of ideas drawn from several resources including the supported decision-making framework, other peak bodies and advocacy organisations and an independent report published by the Independent Advisory Council of the NDIS.

I note additional resources developed by the Office of the Public Advocate Victoria⁴ and National Disability Services NSW.⁵ These resources include frameworks and guides which may assist providers to operationalise the policy and contribute to its successful implementation, particularly for people with impaired decision-making ability.

It is suggested that the policy refer to the specifics of these resources and potentially use them as examples of how to implement the policy so that its operationalisation can be guided by researched and tested processes, particularly in relation to engaging people with impaired decision-making ability.

Operationalisation of the policy

Decision making capability framework

I acknowledge the proposed NDIS Decision-Making Capability Framework has largely been developed following review of research undertaken at the Living with Disability Research Centre, La Trobe University, which is certainly inclusive of adults with impaired decision-making ability. Whilst it is recognised that the “person” is at the centre of the proposed NDIS framework, I suggest the framework be extended to include additional information on knowing, and getting to know the person, as it is essential to the decision-making process. The La Trobe support for Decision-making practice framework provides additional details describing in a practical way, what “knowing the person” refers to. The addition of this information may be considered useful in supporting the implementation of the framework, which in turn will support optimal operationalisation of the Supported Decision-making policy.

Funding to support operationalisation of the policy (including the framework)

It is suggested that the current funding model be reviewed, to ensure it is reflective of the additional time required when introducing new processes and support for decision making, particularly for more complex clients with impaired decision-making ability. This may include reviewing resources required to develop, trial, and implement training packages, additional time to support staff to participate in training and education, and additional time and support allocated in participant plans to enable appropriate communication and engagement strategies to be adopted to provide participants with the best opportunity to benefit from the policy. I also refer to the Independent Advisory Council to the NDIS paper titled “support for decision making in the NDIS”, which is referred to in the NDIS consultation paper. This paper describes concerns about Local Area Coordinators and NDIA planners, relating to their focus on high level NDIS decisions and limited ability (due to a lack of time and resources) to develop an intimate knowledge and/or understanding of a participant. This paper also recognises the limitations of support coordinators and their ability to exercise the skills required to effectively deliver support for decision making. It is suggested that these two concerns are prioritised when reviewing funding and resources required to operationalise the policy.

⁴ Office of the Public Advocate, Victoria, 2018; Guide to NDIS decision-making

⁵ National Disability Services, NSW, 2019; (SDM) People with disability and supported decision making, a guide for NDIS providers in NSW.

Education and training

It is suggested that education and resources developed for NDIS staff and partners, support coordinators, plan managers, support workers, providers and nominees who are supporting participants in decision-making processes should include:

- understanding the fundamental human rights principles that underpin supported decision making;
- supporting the development of reflective ability around the decision-making process;
- facilitating appropriate documentation of supported decision-making processes used;
- understanding and identifying biases and undue influences; and
- articulating the benefits of supported decision making.

It is also suggested that any education and resources developed to support this policy include a review of already developed resources, specifically in relation to adults with impaired decision-making ability. La Trobe University has developed a Support for Decision Making Practice Framework Learning Resource that is highly applicable to people with intellectual disability or acquired brain injury.⁶

Safeguarding

It is suggested that information about safeguarding for participants and support persons be detailed in the policy. I note reference in the consultation paper to publishing guidance material for support coordinators, plan managers, support workers, providers and nominees and suggest consideration be given to the provision of guidance material for the documentation of practices used during decision-making processes, including processes enabling a participant's dignity of risk to be exercised. This may include reference to the use of scaffolding techniques to demonstrate outcomes of possible poor decisions and provide learning opportunities.

It is also suggested that a review process is established, to ensure that supported decision-making practices adopted by staff are appropriate and in accordance with the policy. This will enhance the accountability and transparency of supported decision-making, including reference to the identification and consideration of the will and preference of the participant, and/or in the instance of substitute decision making as the last resort, evidence of actions that have been undertaken prior to this decision to support the person expressing their will and preferences.

Role clarity and communication

It is suggested that consideration be given to establishing best practice communication pathways both internal and external to the NDIS, to ensure a collaborative approach when working with adults with impaired decision-making ability. When working with complex clients, including those with impaired decision-making ability, it is often the case that many agencies and systems are involved in providing care and supports, and are ultimately providing decision making support functions. Many decisions that clients are being supported to make, may in fact be influenced by other supports in their lives, outside of the NDIS. Establishing communication pathways will support NDIS staff to facilitate communication across systems (including health/justice/mental health/guardianship) to ensure that all factors encompassing the client and the decision at hand, are taken into consideration. It is also suggested that clear documentation outlining the roles and responsibilities of support persons is articulated, as this will provide clarity and ensure professionals are working within their scope of practice.

⁶ The La Trobe Support for Decision Making Practice Framework Learning Resource, living with disability research centre. <https://www.supportforddecisionmakingresource.com.au/>

Support for participants subsequent to change in practice

It is recognised that for some participants with impaired decision-making ability, decision making support will be a significant transition, potentially something that they have not experienced during their lifetime. In these circumstances, it is suggested that additional capacity building support be provided to participants to “get them ready” for decision making support. This may include increased resources in capacity building which are reflective of the participant's abilities that have been identified using the decision-making capability framework. For example, some participants may require additional capacity building supports provided by an Occupational Therapist, psychologist, or speech therapist, to provide therapeutic strategies and techniques to assist with understanding, processing and/or vocalisation/expression of the decision. Other support could also include additional funding in support coordination during this transition phase.

The Home and Living Policy

In response to the NDIS consultation paper, “*An Ordinary Life at Home*”, in addition to the suggestions I have made with respect to supported decision making, I would like to add the following regarding adults with impaired decision-making ability.

Operationalisation of the home and living approach:

Supporting participants to be an informed and empowered consumer – use of peer networks, circles of support and “microboards”

It is suggested that reference be made in the policy to already established peer connect programs specialising in connecting people with impaired decision-making ability. Networks such as “Peer Connect” provide practical information about peer networks across Australia, with a focus on the disability community.⁷

Education and training

It is suggested that resources be developed to support participants with impaired decision-making ability to better understand the alternative living options available to them, particularly those people who have lived in institution-like settings for most of their lives and therefore may find it difficult to conceptualise what may actually be possible.

Safeguarding

One of the critical issues that needs to be considered in a home and living policy for NDIS participants with impaired decision-making ability is the provision of appropriate safeguards and protections. Properly developed safeguards will protect a person's autonomy and rights, as well as providing an appropriate level of oversight consistent with the maintenance of their health and wellbeing, particularly if the participant lacks community-based support networks, is non-verbal or not able to make their wishes and preferences heard or has complex health conditions.

An example of a program with this purpose in Queensland is the Office of the Public Guardian's Community Visitor Program, which aims to protect the rights and interests of adults, children and young people living at visitable sites.

The definition of a visitable site is of importance to the NDIS Home and Living Policy, as visitable sites under the provisions of the *Public Guardian Act 2014*⁸ do not include a “private dwelling house”, which includes a premises where an adult with impaired decision-making ability lives alone,

⁷ Peer Connect <https://www.peerconnect.org.au/>

⁸ *Public Guardian Act 2014* (Qld) s39

irrespective of the services or interventions being delivered by the NDIS. Under the Act, community visitors are only required to visit “visitable sites” which are defined as:

- an authorised mental health service providing inpatient service;
- the forensic disability service; or
- premises other than a private dwelling house, where an NDIS participant receives a certain class of NDIS-funded supports under his or her NDIS plan.

This needs to be considered in the context of an NDIS participant moving from a group or shared living arrangement to a private dwelling house where they are the sole occupant. It means that they will no longer receive a visit from a Community Visitor. If this is coupled with the participant not having a strong family or support network that visit regularly or community or social connections, it means that they can be extremely isolated, with the only people they see on a regular basis being their service provider. These circumstances are the ones in which Ms Ann-Marie Smith, an NDIS participant in South Australia, found herself – living alone in a private dwelling with extremely limited family and social contact and service provision from a sole provider. The tragic outcomes associated with this circumstance for Ms Smith cannot be repeated and need to be considered in the Home and Living Policy. If NDIS participants do potentially face these circumstances it certainly should not preclude their ability to exercise choice and control over their living arrangements however it will need to be considered from a safeguarding perspective in terms of additional measures and oversights that can be put in place to facilitate this choice safely.

Thank you for the opportunity to provide feedback regarding these two NDIS consultation papers. Both constitute extremely important issues for the NDIS moving forward, particularly in relation to the Scheme providing adequate policy frameworks for people with impaired decision-making ability to exercise choice and control over their lives. If you require clarification of any recommendations raised in this correspondence, please contact my office on 07 3738 9513.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'John Chesterman', with a long horizontal flourish extending to the right.

John Chesterman (Dr)
Public Advocate