



Support for Decision Making consultation

National Disability Insurance Scheme

August 2021

Please find following our submission to consultation on Support for Decision Making in the National Disability Insurance Scheme.

FPDN welcomes the opportunity to provide input to the NDIS consultation paper “Supporting you to make your own decisions”. This is an overdue step by the NDIA to prioritise supported decision making (SDM), and develop a framework that upholds the rights of people with disability.

FPDN believes that the NDIS, as a matter of urgency, needs to look at the specific intersectional policy implications for SDM in the NDIS context, and co-design a framework with First People with disability.

Everyone makes decisions with support, from small decisions about what to eat and what to wear, to big decisions about where to live and how to handle conflict. People talk with friends and family about their decisions and weigh up different choices and consequences. For many people with disability, they do not have the same opportunities to be supported to make big and small decisions, instead they are often assumed not to ‘have capacity’.

The NDIS, with its grounding in the rights of people with disability, must incorporate the legal right to make decisions in a supported way in all aspects of the Scheme, and provide strong guidance and support for every organisation and person in receipt of NDIS funding to move to this regime.

At the same time, First Peoples have the right to decide about what happens to them, and to make decisions in the way that suits them. First People with disability have these rights to make decisions about our lives protected by two international rights instruments, which must be implemented in this NDIS policy.

In addition, the NDIA can play a significant role in modeling a new way to support people with disability to make decisions that can influence state and territory jurisdictional guardianship regimes.

We do not believe that the framework in its current form will deliver real decision making for First Peoples with disability, and needs much more careful and comprehensive work, in full consultation with First People with disability, to ensure that the policy reflects the intersectional complexity of decision making in our community.

FPDN also endorses the submission from Inclusion Australia, and the recommendations they have made to improve this policy so that the rights of people with disability can be realised.

First Peoples Disability Network (FPDN) believes there needs to be in depth consultation with First People with disability to develop an appropriate and culturally safe framework for our communities.

About us

FPDN is a national organisation of and for Australia’s First Peoples with disability, their families and communities. Our organisation is governed by First Peoples with lived experience of disability.

We proactively engage with communities around Australia and advocate for the interests of First Peoples with disability in Australia and Internationally. We follow the human rights framework established by the United Nations Convention on the Rights of Persons with

Disabilities, to which Australia is a signatory, and the United Nations Declaration on the Rights of Indigenous Peoples.

First Peoples with disability and their families are amongst the most seriously disadvantaged and disempowered members of the Australian community. We give voice to their needs and concerns and share their narratives of lived experience.

We work for the recognition, respect, protection and fulfilment of the human rights of First Peoples with disability and their families.

We work within a social model of disability, in which we understand 'disability' to be the result of barriers to our equal participation in the social and physical environment. These barriers can and must be dismantled. The social model stands in contrast to a medical model of disability, which focuses on diagnosis.

Please do not hesitate to contact me if you would like any further information

A handwritten signature in black ink, appearing to read 'D. Griffis', with a stylized flourish at the end.

Damian Griffis

CEO, First Peoples Disability Network

Recommendations

- That the NDIS urgently co-design a SDM framework for First People with disability, with First People with disability
- That the NDIS SDM policy assumes people with disability have capacity as a starting point.
- That the NDIS incorporate the Australian Law Reform Commission report recommendations into their SDM policy.
- That the NDIS SDM framework explicitly rules out any role for disability service providers as substitute-decision makers for any person with disability they support
- That the NDIS SDM framework discusses state and territory guardianship schemes and works to create a coordinated supported-decision making framework in all jurisdictions.
- That peer support for decision making is considered as part of the SDM framework

We have the right to decide

The NDIS Supported Decision Making (SDM) policy must begin with the rights of people with disability, including that all people with disability have decision-making capacity, the capacity to act on these rights and for that to be recognised under the law. The UN Convention on the Rights of Persons with Disabilities (CRPD) says in Article 12 that Australia “shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” and “shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.”¹

That starting point must inform all policy development, which would focus on making sure that people with disability have all the supports they need to exercise that right, rather than assumptions about their capacity to make decisions.

Australia has not fully endorsed Article 12, and instead has said that substitute decision making, such as guardianship, complies with the CRPD. The most recent review of Australia’s performance in meeting its obligations under the CRPD found that “the Committee is concerned about the lack of progress to abolish the guardianship system and substituted decision-making regime, particularly in decisions concerning forced psychiatric treatment, and at the lack of a timeframe to completely replace it with supported decision-making systems.”²

This interpretation of Article 12 also extends to allowing forced sterilisation of people with disability using substitute decision making. Disabled Organisations Australia says that “forced sterilisation of people with disability, particularly women and girls with disability, and people with intersex variations, is an ongoing practice that remains legal and sanctioned by Governments in Australia.” The Australian Government response to the 2013 Senate Inquiry indicated that this was solely a responsibility of the state and territory governments, but it is clear that the NDIS SDM framework, and the national move away from substitute decision making, must include recognition of the need to remove the legal right to forcibly sterilise of people with disability.

The 2014 review by the Australian Law Reform Commission (ALRC), *Equality, Capacity and Disability in Commonwealth Laws*³, comprehensively looked at different state, territory and federal systems and made a series of recommendations that would bring Australia into compliance with the CRPD. These included setting out key principles of supported decision making, called the National Decision-Making Principles (Recommendations 3-2 to 3-4) that need to be the starting point of any future policies in this area.

The UNCRPD Committee recognised the ALRC recommendations and recommended that they were fully implemented.

The UN Declaration on the Rights of Indigenous Peoples (UNDRIP) also includes the right to decide for ourselves, with our communities. We have “the right to participate in decisions that

¹ UNCRPD Article 12,

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html>

² UN outcomes report on Australia 2019,

<https://www.afdo.org.au/wp-content/uploads/2019/09/UN-Outcomes-Report-on-Australia.pdf>

³ Equality, Capacity and Disability in Commonwealth Laws Australian Law Reform Commission, 24 Nov. 2014,

<https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-alrc-report-124/>.

affect us. This should be guided by and include the principle of free, prior and informed consent.”⁴

Recommendation: That the NDIS urgently co-design a SDM framework for First People with disability, with First People with disability

Recommendation: That the NDIS SDM policy assumes people with disability have capacity as a starting point.

Recommendation: That the NDIS incorporate the Australian Law Reform Commission report recommendations into their SDM policy.

⁴ https://humanrights.gov.au/sites/default/files/declaration_abridged_community_guide.pdf

The NDIS and supported decision making

There have been a number of reviews and recommendations about the urgent need for the NDIS to develop a supported decision making framework, but also for there to be a wider review of all substitute decision making regimes, such as guardianship, as part of how they impact on people with disability who are using NDIS supports.

The recent Tune Review of the NDIS recommended that the NDIA “commission a review of the interoperability between Commonwealth and state and territory legislation as it applies to nominee and guardianship provisions. The intent should be to identify opportunities to ensure a nationally consistent approach to nominee, guardianship and supported decision-making arrangements for people with disability.”⁵

FPDN, in our submission to the Joint Standing Committee on the National Disability Insurance Scheme in 2020, said that:

“How, and by who, decision making support is provided for First Nations peoples with disability at different points on their NDIS pathway, requires careful and informed consideration. This is a sensitive and complex area that cannot be addressed in this consultation. Once again, this must be led by community organisations which best understand aspects such as; local cultural norms and values, community and individual trauma and fear of authorities; informal family networks and current decision making support and processes; and are aware of limitations around culturally competent services in local areas.”⁶

There are concerns that substitute decision making is actually increasing since the introduction of the NDIS. A submission by Queensland Advocacy Incorporated⁷ this year found that there are a rising number of applications for guardianship and administrative appointments to Queensland’s Civil and Administrative Tribunal, many from disability service providers. They have also seen an increase in requests for assistance with these kinds of issues and applications that are submitted with little evidence to corroborate the claims being made, or misusing evidence intended for another purpose, such as to make an access claim to the NDIS.

In 2011, a study found that the Queensland guardianship system had a disproportionate impact on Aboriginal and Torres Strait Islander people with disability. The study found that “a pervasive theme of mistrust and suspicion of the Guardianship and Administration system in Queensland was strongly evident from all sources of data.”⁸ It follows that, given the increasing number of guardianship applications being lodged, that these are having a disproportionate impact on First People with disability.

The Office of the Public Advocate in Victoria found that the “marketisation of a social care sector increases the likelihood that the care providers will want to transfer risk and reduce

⁵ Tune Review

https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

⁶ Joint Standing Committee on the National Disability Insurance Scheme – General Issues around the implementation and performance of the NDIS submission, October 2020

⁷ <https://qai.org.au/2021/03/26/increasing-guardianship-applications-in-the-ndis/>

⁸ Impaired Decision-Making Capacity and Indigenous Queenslanders Final Report 2011, https://www.justice.qld.gov.au/__data/assets/pdf_file/0011/153398/final-report-december-2011.pdf

uncertainty by seeking contractual relationships with decision-makers who have legal capacity.”⁹

This link, between applications for substitute-decision making power and the NDIS, needs particular attention in the SDM framework, including whether disability service providers should have any role as substitute-decision makers in the lives of the people with disability they support. In addition, the links between the state and territory guardianship systems and the NDIS need far more attention.

Recommendation: That the NDIS SDM framework explicitly rules out any role for disability service providers as substitute-decision makers for any person with disability they support

Recommendation: That the NDIS SDM framework discusses state and territory guardianship schemes and works to a coordinated supported-decision making framework in all jurisdictions.

⁹ Office of the Public Advocate, Decision Time: Activating the rights of adults with cognitive disability, Feb 2021, <https://www.publicadvocate.vic.gov.au/opa-s-work/research/141-decision-time>

Peer support for decision making

FPDN has long argued for a significant investment in peer support, so that First People with disability can work with their peers to break down barriers to accessing disability services. A peer support system would also help to develop decision making capacity, but also to provide independent advocacy and resources for Aboriginal and Torres Strait Islander people with disability who are facing substitute decision making regimes.

Currently, FPDN successfully operates two community resource hubs, the Paterson Street Hub and NuunaRon Art group, designed to provide a soft access point to local services and supports via the guided referrals model. The hubs provide a venue for community to access guidance and support around barriers they face in accessing culturally appropriate support and information across disability, education, health and justice with a focus on skill building for individuals to drive opportunities in community for local economic development. Both hubs have shown how important peer support is for community, and could be the basis for significant expansion.

This is one option that needs to be explored further as part of the co-designed First People with disability SDM framework.

Recommendation: That peer support for decision making is considered as part of the SDM framework

Responding to the SDM paper

The NDIS Consultation paper, Supporting you to make your own decisions, has some significant limitations and shortcomings. The comments below refer to specific numbered sections of the paper.

The SDM paper needs to emphasise that people with disability have the right to make decisions about our lives, and that we should be assumed to be capable of doing so.

2: The paper states that because we are not 'recognised as having capacity to make decisions' this can lead people with disability to having low expectations of ourselves. This is incorrect - often it is the low expectations of non-disabled people that limits our lives and opportunities.

The SDM paper does not pay enough attention to the barriers that we face in making decisions about our lives, including that there are legal means for substitute decision making.

3, 3.1: The SDM Framework consultation paper recognises that Aboriginal and Torres Strait Islander people may understand decision making in different ways, and utilise a wide range of decision making supports¹⁰, however, none of this is acknowledged or addressed in the paper. In addition, the role of kinship relationships in supporting decision making is absent from this paper.

4.1: The key principles must include 'independent' in point 4 - there must be independent support available for people with disability to assist with decision making, and this must not be the disability support provider/s who are providing direct support.

4.2: The goals need to be much stronger, and reflect the need to ensure that providers are required to recognise the will and preference of people with disability. Building capacity is just one part of this, enforcement and regulation are the other parts.

4.3: The time taken to make decisions also needs to be incorporated into the Framework here - time to get support, time to think about and get information about decisions, and not be rushed. Timeframes that work for people with disability, and not service providers, government agencies or departments.

4.3.1: The decision making continuum is seriously flawed and needs to be changed. No person makes decisions in total isolation nor fully independent of another person. The expectation that that is how people with disability should be making decisions is incorrect. Decision making should not be measured by 'autonomy', particularly for First People with disability.

The life stages section assumes that people with disability have the same experiences and move through life in the same way. This is incorrect, particularly for First People with disability, who often face significantly different experiences. The circumstances in Figure 3: Life State, decision making examples and strategies to build capacity do not take any of these different experiences into account, nor the barriers that many First People face when making decisions. For example, the discussion of children excludes the experiences of First Peoples with disability who may face exclusion from school, contact with the criminal justice system,

¹⁰ p6 Supporting you to make your own decisions consultation paper,
<https://ndis.gov.au/community/have-your-say/support-decision-making-consultation>

barriers to accessing disability support and contact with the child protection and out of home care systems.

There is little discussion of what the incentives are for existing systems to change to as to recognise the right for First People with disability to have a say about their lives.

4.3.2: Again, the discussion of informal and formal decision supports omits the experiences of First People with disability, and doesn't take into account the significant power imbalance experienced by many people with intellectual and cognitive disability in the different systems and structures, including disability support.

There needs to be an explicit banning of support providers being substitute decision makers. There also needs to be consideration given to requiring any substitute decision maker to be independent of support provision entirely. Independent disability advocate, funded via the National Disability Advocacy Program, should also not be substitute decision makers for people with disability.

It is not good enough for the NDIS to say that they 'will try to influence substitute decision authorities to help their staff to' involved people with disability in decision making. This is an appropriation of the NDIS's role in ensuring that the rights of people with disability are upheld.

5: The co-designed First People with disability SDM framework will include significant attention to young people with disability in out of home care, and look at what needs to change to ensure their right to have a say about their lives is upheld.

Appendix B: This section does not include specific provisions for dealing with the conflicts of interest that many disability support providers have as substitute decision makers for people with disability. There needs to be a much stronger framework to deal with this.

Appendix C: It is unclear how decision making supports are to be funded now that the personalised budget tool process isn't to continue. This needs to be clarified. In the measures of success, a reduction in guardianship applications also needs to be included.