

Discussion Paper

NDIS Review: Supported Decision Making

Advocates and supported decision making
for people with disability.



DANA Disability Advocacy
Network Australia

Foreword

DANA has commissioned a series of four discussion papers as part of our contribution to the National Disability Insurance Scheme (NDIS) Review.

Disability advocates across the country spend close to half their time on NDIS related matters. This means advocates have a wide range of expertise and experiences about what is, and isn't, working in the Scheme.

The NDIS Review is interested in learning from this expertise, and to hear about how to make sure the Scheme is delivering for people with disability, their families and supporters.

DANA has considered what is important for the NDIS Review to understand, both now and into the future.

In addition to these discussion papers, DANA will hold workshops and survey advocates and people with disability. The feedback will be delivered to the NDIS Review.

We want to ask for your big ideas on the following key ideas:

- Fires, floods and COVID-19
- Tier 2 and mainstream supports outside the NDIS
- Quality and safety
- Support for decision making for advocacy

DANA is also working with Inclusion Australia on issues that particularly impact on people with an intellectual disability.

Please get in touch if you have any questions or comments and we look forward to hearing from you.

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Introduction

The National Disability Insurance Scheme (NDIS) has been a game-changer for people with disability, with many thousands of people with a disability now receiving supports for which they would once have waited many years, if ever, to receive.

But too many people with disability don't have greater social and economic participation, as well as greater self-determination, choice, and control.

That's because while there is more investment in disability services, the way those services work may not have changed. Laws and policies often pay lip service to the rights of people with disability without actually serving them and services and programs may be developed for people with disability, without accountability to them.

This is particularly true for people with disability who need support for decision making. There is too much reliance on substitute decision making, such as guardianship, within the NDIS and in disability services. Advocates are often called upon to work with people with disability who haven't had any say about where they live, who they live with, what they do each day or any other part of their lives. Independent disability advocates play a vital role in the lives of many people with disability who use the NDIS, and those who don't.

Supported decision making recognises that everyone has the capacity to make decisions about their lives. The Australian Law Reform Commission outlined the principles¹ of decision making:

- everyone has an equal right to make decisions and to have their decisions respected;
- persons who need support should be given access to the support they need in decision-making;
- a person's will and preferences must direct decisions that affect their lives; and
- there must be appropriate and effective safeguards in relation to interventions for persons who may require decision-making support.

A welcome recent change has been the release of the new Supported Decision-Making policy from the NDIS (hereafter the Policy).² This policy starts the change that is needed to ensure that all people with disability can make decisions about their lives and their supports.

Supported decision making imagines a different worldview for people with disability. Imagine if people who have been subject to substitute decision-making throughout their lives, whether it be by the appointment of a guardian or by the decree of a dominant family member, were offered solid, reliable, trustworthy support to assert themselves? Imagine if everyone who delivered services through the NDIS were to commit to their common mission – supporting people with a disability to achieve their goals and fulfil their potential? Imagine if the NDIS committed to holding itself and its funded agencies truly accountable to that mission? And –

¹ https://www.alrc.gov.au/wp-content/uploads/2019/08/alrc_124_whole_pdf_file.pdf

² <https://www.ndis.gov.au/about-us/policies/supported-decision-making-policy>

dare to dream - imagine if they truly embraced and engaged with people with disability and those who live and work alongside them – as partners?

Independent advocates have a long and proud tradition of supporting people with a disability to express, defend and assert their will and preference. It is a role that may come under increased demand as people with disability want to make more of their own decisions.

This discussion paper begins to ask about the resources needed to deliver on the promise of decision-making for people with disability and what is needed for independent decision-making support.

It is crucial that the Policy has positive and meaningful impacts, and that it amplifies the voice of people with a disability. To this end, it needs the decision-making support of independent advocates, and the resources to deliver that support.

What is the problem?

The Policy has a range of key roles and responsibilities, including dedicated decision support, as well as a potential role for advocates. This is likely to increase the volume and complexity of advocacy work as the policy rolls out and the need for independent advocacy grows.

At the same time, years of underfunding for advocates and advocacy services has reduced funding available for training and development, as well as time and resources for advocates to dedicate to intensive work such as supported decision making.

The Policy

The Policy defines Supported Decision Making as:

The process of providing support to people to make decisions to remain in control of their lives. This is every person's human right. It involves building the skills and knowledge of people, their families, carers, peers and professionals. (p 4)

The Policy is expressed in the following statement:

Everyone has the right to make decisions that affect their life and to have those decisions respected. People must be provided with the support necessary to make and communicate decisions that affect their lives. Supporting people with disability to make decisions is a central part of the NDIS Act. The NDIA has an important role to recognise and adopt supported decision-making principles and practices in all its interactions with participants. (p 5)

The Policy identifies two types of roles which help make decisions:

- **'Representatives'** assist a person who requires support to make decisions or, where necessary, makes decisions on their behalf
- Supporters assist a person who requires support to make decisions. A supporter does not make the decision. We say **'decision supporters'** in this policy...

... In the NDIS, the term **'decision supporter'** means anyone chosen by the participant or person with disability to support them to make a decision. They can ask any person they would like to be their decision supporter and may select more than one.' (p 8)

The Policy says:

Together with our **partners** we can help participants through the decision-making process by providing information and communicating in their preferred way.' (p 8)

Independent disability advocates and advocacy organisations are essential partners in the effort to ensure people with disability have greater control and choice in their lives. The Policy, however, says little about the fact that people with disability often require decision supporters who are independent of services, of family, and other conflicting interests. There is also scant detail on how people might be supported to decide who they wish to support their decision-making, or how this process might be safeguarded. Finally, and crucially, the Policy does not address the decision supporter role of advocates, or the fact that access to advocacy is already thinly stretched.

The Policy directly references advocacy. On the one hand, the Policy is clear it does not cover advocacy, and states that 'individual advocacy ... is different from supported decision making' (p 3) even though effective advocacy will use supported decision making. Other references makes it clear that the NDIS will not fund advocacy. On the other hand, the Policy sees that advocates might be called upon as decision supporters. This is a fundamental tension in the Policy and threatens to seriously undercut its efficacy in practice.

Advocacy capacity and capability

Supporting people with disability to make their own decisions invariably generates conflict because it challenges existing norms. Many substitute decision-makers are self-appointed and do not readily give up or share their power. They don't trust the rhetoric of self-determination, and they don't buy the idea of supported decision-making. They see any attempt to foster self-determination as just another way of minimising support needs and cutting costs.

From this standpoint, there is a great deal of work to be done to overcome the historical and deeply entrenched social barriers faced by people with disability in their struggle for recognition and rights.

Advocates and advocacy organisations are committed to that same vision. Individual advocates are actively engaged in empowering people with disability to grow, to develop, and to aspire to take charge of their own lives, by embracing their rights and responsibilities, and by making and learning from the consequences of their own decisions. The provision of independent support for decision-making – and all that it entails - is one of the most common and most vital roles played by individual advocates. The individual advocate's role requires a fundamental commitment to discover, affirm, and respect the person's choices and decisions. There is a need to recognise and build upon this body of expertise that exists across advocacy organisations,

Individual advocates have the potential to be a powerful partner. However, people with disability who dare to assert themselves will continue to be marginalised and harmed without recognition and support for the role of independent individual advocates under the Policy. In this respect, the lack of adequate funding for advocates on the ground over many years, as well as the lack of funding for professional development, has resulted in the advocacy sector being under-resourced to support the complex challenges and conflicts that will arise. The implementation of the Policy needs to ensure that the promise that is being made to people with disability – the promise of leadership of their own lives - is backed up by the necessary resources and supports.

Furthermore, support for decision making is important for the many people with disability outside the NDIS. In this respect, the Policy may play an exemplar role, embedding support for decision making principles more widely in all aspects of advocacy practice.

What are the solutions?

The Policy recognises that the NDIS cannot succeed without the support and commitment of its partners, including advocates and advocacy organisations.

This proposition in itself raises a number of questions, including:

- what should the NDIS do to ensure that all people with disability understand and know about the Policy?
- what do advocates and advocacy organisations need to implement supported decision-making principles across their practice (both for people with disability that use the NDIS, and those that don't)?
- what role does the NDIS have in funding advocacy?

What should the NDIS do?

The NDIS has released an implementation plan for the Policy that includes the need to promote this change. They need to implement a **comprehensive awareness campaign** co-designed with, and delivered by, people with disability, self-advocates and advocacy organisations: not only because the NDIS needs to practice what it preaches, but because people with disability need to see that others are out there making their own decisions and leading their own lives, with the support of their trusted allies, and without losing their support or suffering recrimination.

There were significant projects about supported decision making developed through the Information Linkages and Capacity Building program. The NDIS could engage with advocacy and self-advocacy groups to **share the ideas and findings that have come from SDM-related projects**, with a view to co-designing strategies and resources that build upon their experience.

The NDIA must **sit down with advocacy representatives** to address the potential impact of the Policy upon the advocacy sector, and to identify strategies for addressing potential problem areas.

What do people with disability need?

People with disability, particularly those who experience substitute decision making, will need support to build their capacity to have more of a say over their own lives. It isn't clear how this capacity will be built to engage with the new Policy, nor how that will be delivered.

Self-advocates, independent advocates and organisations need to be at the forefront of designing, testing and implementing capacity building programs for people with disability about making decisions, often building on existing work.

There needs to be dedicated funding for independent organisations to deliver Supported

Decision-Making capacity building for people with disability and their families and supporters.

What do independent disability advocacy organisations need?

The Policy aims to build the capacity of people with disability to make their own decisions. However, it is unclear if a commitment to fund capacity-building for decision-making is currently available and how widespread the use of this support might already be. Some **research and analysis of this data** would be potentially helpful in determining the cost of delivering support for decision making in advocacy organisations.

Advocates and advocacy organisations need resources, training and ongoing capacity to ensure they can support an expanded role for supported decision making in the lives of people with disability, their families and supporters.

If advocacy organisations are to be capable of responding to the anticipated rise in demand flowing from the release of the SDM Policy, they will need greatly enhanced opportunities for professional development, training, and policy development.

This also raises the question of how advocacy organisations should be funded to deliver support for decision making for the NDIS.

Additional questions

- The Policy proposes a new role of decision supporters - should that be a role for advocates and organisations?
- What else do organisations and advocates need to deliver Supported Decision Making?

Bibliography

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