

## **Submission to the NDIA consultation paper on Support for Decision Making**

National Disability Services (NDS) welcomes the NDIA's focus on support for decision making, a fundamental element in the realisation of a robust and effective NDIS. As a market-based scheme, the NDIS is based on the idea that all service users have access to clear and consistent information, and the ability to choose between multiple service options. While there is heartening evidence of this being realised for many people with disability, for many others a significant amount of support is still required. This submission provides some suggestions for where attention should be given in order to realise genuine support for decision making for NDIS participants.

### **Decision making and the NDIS**

Being able to make a decision about something is a fundamental right, and often a necessary component for exercising other rights – such as the right to vote. Decisions range from the relatively mundane (which pair of socks to wear) to the life-changing (where to live). For people who haven't had the opportunity to make decisions about their life previously (due to having grown up in an institution, for example), practice making 'smaller' decisions is a necessary step towards being able to navigate 'big questions' – such as where and with whom to live, and what to do for work.

The consultation paper recognises decision making varies across life stages. It is important to note that a person's decision-making ability may not be static. It may increase over time through capacity building, decrease due to a degenerative condition, or be episodic (for people with particular psychosocial disabilities, for example). A consideration of this should inform any plans the NDIA has for assessing a person's decision-making capability. A simple 'check-on-entry' to the scheme may not be appropriate for many participants, for example.

Also, a person's decision-making ability is not necessarily universal. All approaches to decision making should begin with the assumption that a person has the ability to make decisions. Where it is determined that a person is unable to make *some* types of decisions, this should not diminish perceptions about their ability to make any other decision. Best practice considers a person's capability as 'decision-specific' rather than presuming a lack of capability around one type of decision necessarily carries onto other decisions.

In this vein, there is scope for the key principles provided to be more aspirational – for example, by acknowledging the importance of decision making in people with

## **National Disability Services**

Submission to the NDIA consultation paper on Support for Decision Making

disability realising their human rights. Aspirational principles give providers, the NDIA and others a high bar to work towards in supporting decision making in all cases and for people of all capabilities.

Supporting decision making involves allowing people to make mistakes. The disability sector is familiar with the concept of 'dignity of risk': people with disability have a right to make decisions, including 'bad' decisions. A genuine commitment to decision making for people with disability recognises that supporting people to make decisions is often 'resource-inefficient' in the short term. This is true on multiple levels. For example, in a service setting, cooking *for* a person might be quicker than supporting them to cook for themselves – but it fails to build their capacity over time. On a larger scale, the ability to try out different things – from different accommodation settings to new service providers – can be an important way for people with disability to determine what they want and what suits them best. However, such exploration requires resources. As such, a genuine commitment to decision making must come with a commitment to support it with the requisite resources.

Further, decision making inevitably hangs on other elements beyond the control of individual participants, supporters or service providers. For example, 'thin' geographic or service-type markets may mean a person has a 'choice' of only one service provider. In such scenarios, building a person's capability to make decisions may be undermined by environmental constraints.

### **The role of service providers**

Disability service providers have a key role to play in supporting decision making, ranging from dedicated capability-building supports to weaving support for decision making into everyday services.

Some people will require specialised, dedicated support to build their decision-making capability: they may be people with significant intellectual disability, acquired brain injury, significant autism, certain psychosocial disabilities, or people who haven't had the opportunity to develop decision-making skills (due to having been institutionalised, for example). This type of support may need to be built over several years and is often most effective when those providing the support have a strong and consistent relationship with the person. Where this support is required, a dedicated support type should be available to be claimed against. There is reference to 'fixed budget' supports in an appendix of the consultation paper, however the threshold indicated (of no or limited informal supports and only one service provider) is too high. For people who require significant support to build their decision-making capability, they should be able to receive this regardless of their current formal/informal support arrangements.

Providers also have a role in weaving support for decision making into everyday service provision. Providers often support participants to make many decisions throughout their day – about what to wear, what to eat, or what to do with their spare time. Still, there will be variation in the degree to which an individual provider (and

## **National Disability Services**

Submission to the NDIA consultation paper on Support for Decision Making

worker) will prioritise decision making as part of their provision of support. For some providers, decision making is such a focus they have developed extensive material to guide their staff.<sup>1</sup> (The NDIA may wish to draw on resources such as these before developing more.) Other providers will require education and support to embed good practice decision-making principles into everyday service provision. While this second form of support for decision making is threaded throughout other service provision, it will still require resources. For example, workers may need to be trained to think self-reflexively about their own wishes and beliefs, and how these may influence the decisions of the person they are supporting. They will need to take time to communicate and listen properly. They may need to learn specific techniques to help someone to weigh up various choices. Constant reinforcement is necessary; including via good organisational supervision and mentoring, and embedding support for decision making into processes and into everyday discussions about service provision.

Through the NDIS, service providers have been encouraged to think of service provision in blocks of 'billable hours'. Without recognition of the time and resources genuine decision-making support takes – including funding to train organisations and staff – there is a risk that everyday opportunities for decision making may be missed, or 'getting the job done' may take precedence. Further, there is the balance between dignity of risk and duty of care which service providers navigate daily. Allowing service users to make genuine decisions within services involves providers handing over an element of control. Providers may be reluctant to do this in cases where they retain the risk, should the choice taken result in harm to the service user. Greater clarity and support for providers to navigate this balance is required.

The importance of building an organisational culture of supporting in a self-reflexive way and exploring alternatives has been illustrated recently throughout the Covid-19 pandemic. Lockdowns have had severe impacts on people with disability and have proved particularly difficult for providers to navigate. However, NDS has received anecdotal reports that there have been some positive responses from service users to unexpected changes in routine; some providers suggest this may have translated to reductions in behaviours of concern. Where there are positive lessons from these situations, they should be harnessed. It is also potentially an opportunity to reflect on the fact that some people with disability may be particularly acquiescent. It is possible for people to be content with the status quo, but to also enjoy change when it occurs. Providers, the NDIA, families and the community have a role in ensuring people with disability are empowered and encouraged to try different things.

### **The role of the NDIA**

The consultation paper is a welcome step towards greater support for decision making for people with disability. If done well, support for decision making has the

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<sup>1</sup> For example, see [Scope's suite of resources](#). They include booklets and videos for providers, families and legal professionals, and info sheets for support workers.

## **National Disability Services**

Submission to the NDIA consultation paper on Support for Decision Making

ability to better ensure the promise of the NDIS is realised in giving people with disability genuine choice and control.

The paper does not distinguish between decisions being made regarding and within NDIS supports, and decisions NDIS participants may need support with regarding their day-to-day lives. In some cases, this may be difficult to distinguish. Still, the NDIA has a clear role – in funding decision-making capability building for people who need significant support; in the education of disability support providers in support for decision making; and in promoting and funding services which allow NDIS participants to build the social/informal networks which will – over time – support their independence.

While the paper provides some useful indications regarding ideas being considered, the lack of operational detail makes it difficult to comment decisively on many areas. A key question is where and how an NDIS participant's decision-making capability will be assessed. If it is assessed during a planning meeting, how will the NDIA ensure the person making the assessment has the required skills? How will variability in a person's decision-making capability – from decision to decision, and over time – be accommodated? Where there are suggestions of measuring success (in Appendix C), these should be measurable and quantifiable. At the same time, quantitative data should be paired with qualitative information, where appropriate, to guard against overly blunt measurements. For example, page 24 suggests a KPI of reduction in nominee appointments; it would be concerning if this were considered to be an indicator of success on its own.

The NDIS is a complex scheme and can be difficult to understand. Recent endeavours from the NDIA to simplify the scheme from a service user perspective are positive and NDS welcomes further work in this area.<sup>2</sup> Making the complex simple is a necessary step towards people with disability being able to understand and make informed decisions about the services they use.

Where NDIA and LAC staff perceive opportunities for supporting decision making of NDIS participants, this should be identified and encouraged. However, more significant decisions should be met with the requisite support. It is unlikely that the development of guidance referred to in the consultation paper would be sufficient for a junior NDIA staff member to support a person with significant disability to make a decision about housing options, for example. The consultation paper acknowledges the possibility of undue influence; there is no reason to expect NDIA staff would be immune to this in some circumstances. Additionally, there would be few if any cases in which it would be appropriate for the NDIA to make the determination that a participant does not have decision-making capability.

We have previously noted the fact that support for decision making, done well, can be resource intensive. An acknowledgement of this fact by the NDIA (perhaps as an additional 'key principle' to those in the paper) would be welcome.

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<sup>2</sup> Providers have suggested the 'Would we fund it' resources are helpful, for example.

## **The role of other stakeholders**

NDIS participants may make decisions *about* NDIS supports (which service provider to use, for example), *within* NDIS supports (what to have for dinner) or without regard to NDIS supports at all (who to vote for). The specific decision will impact which stakeholders should be involved and to what degree. In larger decisions, multiple stakeholders may be appropriate. Clear guidance around managing conflicts of interest and undue influence is key. Certain decisions should exclude certain stakeholders – a service provider should not be involved in supporting a person to consider a range of support options which involves their own services, for example.

- **Advocacy**

Not all NDIS participants will regard their service provider as the most appropriate support for decision making in all circumstances. Advocacy organisations have historically supported a significant amount of decision making, often through arrangements that aren't directly funded. Many have a key role in supporting people to become self-advocates – this often requires ongoing capacity-building support. These supports are valuable to people with disability – however we cannot rely on these supports into the future if they are not funded appropriately. Equally, advocacy organisations will likely be reluctant to become registered NDIS providers to provide dedicated support for decision making. Opportunities exist to develop partnerships whereby advocacy organisations train disability support providers in support for decision making, and in developing associated material.

Both advocates and disability support providers can play vital roles in supporting decision making when a person with disability may wish to make decisions which are different from those their family and/or carers would like. Advocates in particular may be able to play a more independent role in supporting a person to think about what their options are and what they would like.

- **Public Trustees/Guardians**

Guardianship is key area of concern which is frequently raised by disability service providers. In particular, the variability of arrangements between jurisdictions is of concern – and is particularly difficult for providers active in multiple states/territories. It is a topic which is primarily outside the scope of this paper, however needs significant attention. NDS would welcome further guidance and clarity around how the NDIA plans to engage in this area.

## **Other items of note**

- [The OVAL Project](#) (2017-2019), codesigned by the Office of the Public Advocate (Victoria) and VALID, used trained volunteers to support decision making for isolated NDIS participants with cognitive impairments. While small, it was considered successful. Further investigation of this model is warranted.

## National Disability Services

Submission to the NDIA consultation paper on Support for Decision Making

- [Western Australia's Individualised Services](#) (WAIIS), a membership organisation of individuals and service providers, has developed a suite of resources around supported decision making, including videos, guides and tools. The videos in particular illustrate not only the significant time that is sometimes required to genuinely support decision making, but the positive impacts on the people who are supported.
- CALD participants  
A key aspiration built into the NDIS is independence: the notion that, with good supports, a person with disability may become less reliant on others, and that this is a positive thing. In many ways, this is closely related to supporting decision making. It may be useful to reflect on the extent to which these may reflect Anglo virtues, where other cultures may prioritise family or community decision-making over individualism and independence. Concepts such as filial piety (that children should care for their parents)<sup>3</sup> and the Spanish concept of *familismo* (the needs of the family are prioritised over individuals in the family)<sup>4</sup> are points of contrast. While independence is a key aspiration for many people with disability, attention should be paid to what the service user's priorities and values are, rather than assume certain values are universal.

## Conclusion

The NDIS is founded on the notion of informed service users having choice and control of their supports and lives. The consultation paper is a positive step towards the realisation of this for many NDIS participants via support for decision making. The paper contains a number of well-placed underlying principles and flags some important concepts to inform implementation. The key to the policy's success will be in its implementation. This submission has provided some suggestions which may aid in its success, and NDS looks forward to being involved in future iterations.

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<sup>3</sup> Shea, J., Moore, K. & Zhang, H. (2020). Introduction. In Shea, J., Moore, K. & Zhang, H. (Eds.), *Beyond Filial Piety: Rethinking Aging and Caregiving in Contemporary East Asian Societies* (pp. 1-40). Berghahn Books Incorporated.

<sup>4</sup> Toro-Morn, M. I. (2012). Familismo. In: S. Loue & M. Sajatovic (Eds), *Encyclopedia of Immigrant Health* (pp. 672-4). Springer, New York, NY.

**National Disability Services**

Submission to the NDIA consultation paper on Support for Decision Making

**National Disability Services** is the peak industry body for non-government disability services. It represents service providers across Australia in their work to deliver high-quality supports and life opportunities for people with disability. Its Australia-wide membership includes more than 1200 non-government organisations which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.