



National Disability Services

Submission to the Disability Royal Commission on the Supported decision-making and guardianship: Proposals for reform and roundtable documents

1.0 Overview

National Disability Services (NDS) is pleased to make a submission to provide support and information to the Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) regarding the Supported decision-making and guardianship: proposals for reform, related hearings and [Roundtable documents](#) from the Royal Commission.

Supported decision-making is the best practice approach to uphold the rights and individual autonomy of people with disability and to enhance the ability of people with a disability to make their own decisions. When someone makes a decision on behalf of another person without their consent, a fundamental right is being denied. For people who need support when making a particular decision, supported decision-making is an approach that demonstrates respect for peoples' rights to make decisions about their own lives.

A long-term vision of an Australian society that embeds supports for decision-making, appropriately funded for all those who require it, is a welcome goal for us all to work towards.

2.0 Scope of this Submission

Supported decision-making can appear as a straightforward concept but can be complex to do well. NDS acknowledges the depth of exploration by the Royal Commission on these concepts and principles.

NDS wholeheartedly agrees with other comments in the [Roundtable - Supported decision-making and guardianship: Summary report](#) (The Royal Commission, October 2022, page 3) that view the proposed national supported decision-making framework as an opportunity to establish a shared understanding of concepts and principles of supported decision-making.

NDS also concurs with the general support provided for the need to move towards supported decision-making and away from substitute decision-making, with some cautions around potential gaps, the complexity of multiple systems and ensuring clarity of roles and responsibilities.

In this submission, NDS will comment on considerations for successful implementation that relate to the challenges presented by the systemic context, the critical role of providers, safeguarding mechanisms and the importance of broad stakeholder education.

3.0 Policy Environment

United Nations Convention on the Rights of Persons with Disabilities

The work of the Royal Commission is guided by the [United Nations Convention on the Rights of Persons with Disabilities](#) (UNCRPD) which aims to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities”. Under the Convention, Article 3 outlines the general principle of Article 3 of “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons”. A supported decision-making framework based on the will, preferences and rights of individuals is an essential component of a mature rights-based model of support, and of an inclusive society.

There was discussion in the reform proposals of the differing interpretation of Article 12: 'Equal recognition before the law'. The need to move towards supported decision-making and away from substitute decision-making, supported by NDS and stakeholders in the Roundtables must be well paced and include checks that do not leave gaps and risks for participants.

Effective, safe supported decision-making requires relationship building, time to understand a person's communication, build trust and develop skills. NDS submits there will always be gaps where trusted people move on, where people's capability deteriorates, where thin markets for specialised supported decision-making support is identified, where current supports may be identified as having a conflict of interest on a particular issue and so on. If last resort substitute decision-making is not available it is possible a quasi-system may develop, placing people with disability and other stakeholders at risk.

While we move away from substitute decision-making, NDS is mindful that the Australian Law Reform Commission model (Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Report 124, August 2014, p 68, cited in Royal Commission, Supported decision-making and guardianship: Proposals for reform, May 2022, p.27), which retains substitute decision-making as a last resort, still has relevance where reforms cannot resolve these gaps.

Incorporating supported decision-making into guardianship processes is keenly supported by NDS, noting the resourcing pressures that can impact this in practice.

National Disability Insurance Scheme (Restrictive Practices and Behaviour Support) Rules 2018 and related State and Territory legislation

Where guardianship is a component of authorisation of restrictive practices providers are bound to follow these processes. Reducing and eliminating the use of restrictive practices takes time, and a consistent concerted focus on practice delivery. This can be difficult in the context of high levels of reporting and red tape that the current system of positive behaviour support and restrictive practices entails. Where authorisation systems remain connected to guardianship orders (or during transition periods away from this model) it is important to consider:

- Proposed shorter term appointments of guardians for the purpose of authorising restrictive practices may have unintended consequences of clogging the system with additional requests and increasing timelines. Reducing restrictive practices take time and new plans are required on a 12 month or less basis. Changing the authorisation via guardians will need to consider the broader picture.
- Reform proposal 16 suggest safeguards for restrictive practices within guardianship.
 - Education for approving guardians in supported decision-making and positive behaviour support is a necessary safeguard.
 - Other safeguards and monitoring must be integrated and streamlined into existing models of safeguarding. Adding further components to existing systems is untenable and again reduces the time available to implement the positive strategies that can influence behaviour change.

NDIS (Provider Registration and Practice Standards) Rules 2018

The NDIS Quality and Safety Commission embeds participants' rights in the Practice Standards required for registered NDIS providers. Independence and informed choice are captured in Part 2(6) of the NDIS (Provider Registration and Practice Standards) Rules 2018 states that "Each participant is supported by the provider to make informed choices, exercise control and maximise their independence in relation to the supports provided." Still, there will be variation in the degree to which an individual provider (and worker) has developed supported 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.¹

Also of note is that while providers continue to further embed choice and control in their service delivery systems, only registered providers are monitored and required to be responsive to the expectations outlined in the Practice Standards. The Practice Standards provide other safeguards that intersect with choice and control, and decision-making.

¹ 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.

Legislative reforms for supported decision-making may need to consider how unregistered providers will be responsive to expectations and if the legislation is discreet enough to stand alone.

NDIS Review - an integrated approach

The current review of the NDIS includes a focus on the NDIS Quality and Safeguarding Framework (the Framework). With an end date of October 2023 and a remit to implement changes throughout the review timeframe, this presents an opportunity to take an integrated approach to enshrining supported decision-making, not just in terms of the Framework but across NDIS policies, processes, and systems more broadly.

4.0 Relevant Issues

4.1 Systemic issues

A broad systemic opportunity

Importantly, the wide remit of the Royal Commission presents the opportunity to recommend wide scale rollout of reform to embed supported decision-making as an essential human rights-based tool. NDS supports the reform proposals to introduce the framework across all relevant contexts. This is essential to uphold the rights of people with disability and may contribute to shifts in community attitudes.

A shared framework also enables disability service providers to engage with other sectors and the community from a shared point of understanding, towards a greater realisation of rights and autonomy for the people they support.

Gaps in advocacy

This year, only 14 per cent of providers identified that there was “sufficient advocacy for people we support” ([State of the Disability Sector Report, NDS, 2022](#)). It may be that this can be resolved through greater funding input. However, whilst speculative, it is possible that workforce gaps for advocacy, related expertise for developing and providing supported decision-making will remain a challenge. Workforce shortages and the potential for a thin market in capability development for supported decision-making need to be realistically considered.

Thin markets can have a range of impacts. For example, alongside other challenges, the limited availability of skilled behaviour support practitioners is one of the ongoing contributors to the continued high level of unauthorised restrictive practices. One impact here is that regulatory actions for supported decision-making may see more time spent reporting than creating change.

NDS supports recommendations related to supported decision-making that also expand the availability of advocacy (and self-advocacy development) for people with disability. It is also suggested that the relationship between regulatory and workforce levers for change are considered.

Uncertain policy environment and involving providers in design

Changes to the regulatory environment have been a constant over the last few years within the disability sector with 79 per cent of providers agreeing or strongly agreeing that the NDIS policy environment is uncertain ([State of the Disability Sector Report, NDS, 2022](#)). Disability providers are optimistic about change and wish to see plans turn into action. Reform that considers the operating environment and experience of providers allows services to better reach quality goals.

One recent change implemented by providers related to the development of emergency plans for people with disability. It is hoped that this has increased safeguards for the many Australians subject to natural disasters and the impact of COVID-19 over the last year. However, it is noted that the roll out of such changes has room for improvement. As shared by a provider in the State of the Disability Sector Report- “[the] NDIA implement policies without thinking of implications (e.g. the emergency plans for participants can take 20 hours to do but [there’s no] line item or funding” ([State of the Disability Sector Report, NDS, 2022](#)). They were not alone in this perception and NDS is presenting recommendations to the NDIS Review in this context.

Co-design with people with disability is essential to getting supported decision-making reform right. Providers are well placed to contribute to system improvements and collaborate with stakeholders to identify and work through any unintended consequences of change. NDS asks that recommendations from the Royal Commission also promote the involvement of providers in designing systems given

their critical role in supporting the successful implementation of these systems. This includes those related to supported decision-making.

Regulation and risk enablement

Providers supporting a person with a disability to make their own decisions need to respect that person's right to take risks, even if there is the potential to make a mistake. They must balance dignity of risk and duty of care. Supporting a person to make genuine decisions, even when that may pose harm to themselves, and helping them understand and manage the risk is part of this work. Such choices can still involve providers handing over an element of control, and result in substantial reporting obligations to the NDIS Commission. This may be for example related to health or lifestyle choices. Providers may be reluctant to take a risk enablement approach in cases where they retain the risk, should the choice result in harm to the service user. Anecdotal reports from providers suggest legal advice sought on these issues has pointed to caution and risk reduction. The attitudinal barriers identified by participants in the Royal Commission discussions manifest as regulation and advice that providers are obliged to follow.

The ongoing cultural shift to risk enablement and a human rights approach within disability service organisations is the role of providers. However, introducing new reforms regarding supported decision-making without formally reconciling the relationship to existing regulation and external contexts will lead to confusion and impede implementation.

Providers also balance dignity of risk with their duty of care to staff, as outlined in workplace health and safety legislation and other instruments. Any reforms must not compromise staff safety or increase risk to staff or others. For all of us, our choices and decisions must respect the rights and safety of others.

4.2 The role of service providers

The role of disability services providers

People with disability make decisions in all parts of their lives. For the 554,917 Australians who are supported by the NDIS ([NDIS Quality and Safeguards Commission Activity Report 1 July to 30 September 2022](#)), many of those decisions are within the context of the Scheme and direct support.

Disability service providers have a key role to play in supporting decision-making, ranging from weaving supported decision-making into everyday services to providing dedicated capability-building supports. By design disability service providers are integral to the successful implementation of the human rights-based model expressed in supported decision-making. To deliver a successful model NDS notes that the following will be necessary:

- Talk with providers – providers need to be included in designing the implementation of supported decision-making education and regulatory approaches
- Listen to providers – good practice from disability service providers should be highlighted to provide direction and foster commitment.
- Ensure the cost model can meet goals – a funding approach to develop the capacity of people with disabilities, supporters, families, and disability support staff should be sufficient and well considered.
- Reforms for supported decision-making need to reflect both the everyday building of skills and frequent everyday decisions that disability service providers will be championed to deliver.

In practice, people with disability should be routinely asked about their wishes, preferences, and decisions – for all types of decisions, large and small.

Safeguards

NDS is aware of cases raised with the Royal Commission where guardianship has been sought by providers inappropriately and has caused harm to people with disability ([The Disability Royal Commission examines the effect of the NDIS on guardianship and financial administration orders \(nds.org.au\)](#)). It is important that future reform reduces these instances. Reform proposal 15 ‘Best Practice safeguards in guardianship’ suggests additional oversight of providers initiating guardianship and administrative orders. NDS has identified some issues with this proposal:

- Providers are legislated or legally advised to seek guardianship and administrative orders in many circumstances. Changes to these contexts would provide improved guidance and support for providers to implement alternatives.

- Providers may sometimes make an application where potential abuse from other parties has been identified and other efforts to address this have not been effective.
- Where applications are raised it is the role of guardianship tribunals and Trustees to undertake the relevant (revised) due process and assess each application on their merit. Where inappropriate guardianship decisions have been made, these are not made by providers.
- For this additional monitoring from the NDIA and NDIS to add value it is important to highlight that this may cover registered and unregistered providers differently.

The Royal Commission has also identified the possibility of a new governance body to provide guidance and oversight to the implementation of supported decision-making. NDS acknowledges this body would have oversight over many contexts, however, any additional monitoring for the disability sector should take an integrated approach to existing regulatory mechanisms.

Funding models and supported decision-making

NDIS service providers have been encouraged to think of service provision in blocks of 'billable hours. Where individualised funding is tight and without recognition of the time and resources genuine decision-making support takes, there is a risk that everyday opportunities for decision-making may be missed, or 'getting the job done' may take precedence. Whilst speculative, gaps in funding for an individual could drive the need for substituted decision-making higher.

Funding capability development for people with disability and ensuring equitable access to support have been considered in Roundtable discussions led by the Royal Commission. NDS welcomes this and wishes to highlight early work towards this. Providers have trailed equipping participants with quotes to use in NDIS planning processes that include time for participants to develop their decision-making skills. Currently it does not appear that this has been well supported.

4.3 Stakeholders education

Building capability to support decision-making

The presumption of capability of people with disability to make decisions is a critical premise. NDS has supported providers to consider policy and procedure to embed this human rights approach in their service provision (People with Disability and Supported Decision-Making and the NDIS, NDS).

However, we need to take care in assuming all supporters – families, professionals in other sectors and disability support staff, have the skills to support decision-making. In this context, NDS agrees that the measures identified in the [Roundtable - Supported decision-making and guardianship: Summary report](#) (page 15) are important components for a successful implementation of reform:

- “education and training opportunities for people with disability to develop rights awareness, self-advocacy, and other relevant skills;
- co-designing resources on best practice supported decision-making with people with disability, that are targeted to different audiences;
- building in mandatory training modules on supported decision-making for health and other professional recertification;
- engaging in more robust piloting of supported decision-making practices and broadly sharing learnings across jurisdictions;
- strengthening education and capacity building of supporters given the integral role they play in implementing supported decision-making in practice.”

NDS would also add, the need for training in specific skill sets such as decision-making in financial management and in the light of COVID-19, vaccine and other health related decision-making. Additionally, as above, all new policy development and programs must involve service providers in design to enhance implementation.

The Royal Commission also identified that the role of being a supporter can be a heavy responsibility, with fears of doing the wrong thing ([Roundtable - Supported decision-making and guardianship: Summary report](#), p. 17). Providers are very susceptible to this as the implications of ‘doing the wrong thing’ can be significant. Education approaches for all supporters would benefit from resources that

acknowledge these valid concerns and provide practical solutions to be effective. This is particularly relevant in a legal context as noted above in 'Regulation and Risk enablement'.

Clear plans are needed for building knowledge and skills of supporters

Like any group of people or organisations there is a continuum of knowledge participants have of the workings of the Scheme. For example, many participants and their families are unaware that NDIS Worker Screening is optional for unregistered providers. Making a choice between providers or workers without the knowledge of the existence of NDIS Worker Screening mechanisms or perhaps of supported decision-making concepts can present risks for people with disability.

In the recent [NDS State of the Disability Sector Report](#) (2022) 75 per cent of providers agreed or strongly agreed that "helping people to understand and navigate the Scheme is taking us away from service provision". This unpaid work is undertaken to achieve positive and necessary outcomes for people with disability. Providers are often turned to as they represent a familiar and trusted connection for participants and their families. Disability support providers may often be the only tangible connection a participant has with the Scheme. NDS recommend that where an education component is developed for supported decision-making that the following ideas may be considered:

- A planned approach and accountability for disseminating information is designed to prevent this from defaulting to an additional unpaid role for disability service providers.
- Strategies to reach NDIS self-managing participants and their families are developed.

5.0 Conclusion

NDS welcomes the robust discussions and exploration of supported decision-making led by the Royal Commission. Integrating supported decision-making within multiple contexts is essential for embedding a human right based model of support in service provision and shifting community attitudes. People with disability make decisions across all aspects of their lives and

NDS values the opportunity to contribute this discussion. Overall key considerations for effective implementation include:

- **Talk to providers.** As reforms and improvements are identified, the sector will need support to implement them. This will require clear communication to people with disability and providers. Involving providers can support design of appropriate timeframes and resourcing, flagging potential barriers and mitigation of any unintended consequences.
- **Keep it simple.** The sector wants reform but is fatigued by change. The NDIS Review is underway and will have wide ranging impacts for service provision. New reforms relating to supported decision-making need to sit within this context, ideally identifying where integration can occur.
- **Education and implementation across all contexts are the key to successful cultural change.** Providers working to embed risk enablement and supported decision-making will have greater success, and changes will be faster where other contexts (health, justice, families and so on) are involved in creating environments where the rights of people with a disability are actively and consistently upheld.

NDS and our members stand ready to engage in these important discussions and reforms.

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About National Disability Services

National Disability Services (NDS) is Australia's peak body for non-government disability service organisations, representing more than 1000 non-government service providers. Collectively, NDS members operate several thousand services for Australians with all types of disability. NDS provides information and networking

opportunities to its members and policy advice to State, Territory and Commonwealth governments. We have a diverse and vibrant membership, comprised of small, medium, and larger service providers, supporting thousands of people with disability. Our members collectively provide a full range of disability services, from supported independent living and specialist disability accommodation, respite, and therapy, to community access and employment.

NDS is committed to improving the disability service system to ensure it better supports people with disability, their families, and carers, as well as supports building a more inclusive community.