OFFICE OF THE PUBLIC ADVOCATE

Office of the Public Advocate
South Australia

Submission

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Supported Decision-making and Guardianship: Proposals for Reform

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1. Introduction

The Public Advocate in South Australia welcomes the opportunity to provide a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) on supported decision-making and guardianship proposals for reform.

The Chair of the Australian Guardianship and Administration Council, John Chesterman has made a joint submission to the Royal Commission on this topic, and we acknowledge and support the matters raised. This submission by South Australia is intended to be complementary to that joint submission.

The Public Advocate believes strongly in supported decision-making as an important way to promote the right of people with disability to make their own decisions and enjoy equal recognition before the law. The roll-out of supported decision-making is required as a best practice standard.

In recent years, my office has invested in five projects with the aim of developing our practice in supported decision-making and embedding the principles in the way we work with our clients where possible and practicable.

The *Supported Decision-making Pilot Project* currently underway in South Australia is trialling existing and newly developed tools to ascertain the will and preference of people under Public Advocate guardianship, and to explore the application of such tools for supported decision-making practice within OPA.

Supported decision-making is not currently recognised in the *Guardianship and Administration Act 1993* (SA) and nor is it resourced in practice.

We do acknowledge, however, that unless another mechanism for substitute decision-making is developed, with appropriate safeguards, there is a role for substitute decision-making to prevent serious harm to a person and the community. However, this should follow the principles of least restrictive and last resort guardianship.

2.The Public Advocate

The Public Advocate in South Australia is a statutory official appointed by the Governor to implement the provisions of Section 21 of the *Guardianship and Administration Act 1993,* (the GAA). The Public Advocate is supported by the Office of the Public Advocate (OPA) to assume guardianship, and provide advocacy, support, and education for people with mental incapacity and the systems and services around them. This includes speaking for and on behalf of people and their families, carers, and supporters, educating the sector and identifying areas of unmet need for reporting to the Minister.

The Public Advocate acts as guardian of last resort for people with impaired decision-making capacity, when appointed by the South Australian Civil and Administrative Tribunal (SACAT) under the GAA. The SACAT will only appoint the Public Advocate as a person's guardian if it is satisfied that no other order would be appropriate. What this means in practice is that the Public Advocate will only be appointed if there is no one else in a person's life able or willing to make necessary decisions, or if there is family conflict meaning that agreement on decisions is difficult or not possible. Consequently, the Public Advocate often must make decisions for people who have complex needs or experience complex situations and who may be without support networks.

The Public Advocate's role as guardian is to make decisions, including giving the relevant consent about a person's health care services, accommodation and access arrangements where there is the requisite authority to do so under the guardianship order.

3. Disability Advocate

The Disability Advocate is a position located within the Office of the Public Advocate and was established in November 2018. The purpose of the role of the Disability Advocate is to "ensure that South Australians with a disability and their families are getting a good deal from the National Disability Insurance Scheme (NDIS)."

Throughout 2019 the Disability Advocate attended over 150 meetings with people with disability, family, advocates, and carers to speak with people about their experiences with the NDIS, what was working well and areas for improvement. Regular reports were presented to Ministers and senior State and NDIA officers.

The role has since been extended with funding until 2023. COVID-19 and other work (such as the Safeguarding Taskforce) made it difficult to undertake face to face meetings in 2020 however the Disability Advocate managed to conduct over 270 virtual meetings with external stakeholders during the year. Meetings continued in 2021 and regular reports were prepared for the NDIA and State ministers. All reports are available on the OPA website at opa.sa.gov.au.

4. National Supported Decision-making Framework

4.1 National Principles

The proposed principles appropriately capture the relevant aspects of a best practice national framework.

As part of the current project on supported decision-making being conducted by OPA in South Australia, the La Trobe practice framework was considered. The La Trobe practice framework centres around three practice principles: commitment to the person and their rights; orchestration of others involved in the person's life; and reflection and review on your own values, influence and support.

There is an inherent tension between the right to risk-taking and safeguarding requirements which would be difficult to codify in a national framework that is applicable across 8 jurisdictions and numerous sectors. There would need to be specific practice examples and ongoing training and support for people implementing the framework on the ground.

This tension has been identified as part of the current supported decision-making project with the OPA in South Australia. A legal tension exists for staff in terms of positive risk taking and the current duty under the GAA to provide 'proper care and protection.' Even if legislative change were to overcome this tension, there are community expectations when it comes to ensuring people who require decision support are not put at unacceptable risk of harm or exploitation. Similarly, Ministers and the community expect service systems to provide full safeguarding and lambast service systems when risk-taking leads to bad outcomes. These are complex considerations.

Careful consideration is required around principle three and the right to dignity of risk in intimate relationships, particularly in the context of domestic and relationship violence situations. This highlights that for supported decision-making to be effective, a range of reforms and efforts in other service sectors are also needed, including holding perpetrators to account.

Access to decision-making support as outlined in principle five has resource implications. Supported decision-making cannot just be embedded into existing practice, as it takes specific skills and time to do properly. Also, clarity is required in terms of a process for defining who has access to the support envisaged through the framework. What would 'trigger' someone being assessed for whether they need support in decision-making (i.e. scope)?

4.2 Supported Decision-making Model

The proposed model provides an important set of steps before moving to substitute decision-making, thereby supporting the principle of guardianship as a last resort. It is noted however that the proposed model does not do away with guardianship/substitute decision-making altogether, i.e. the model recognises 'substituted judgement' as being part of the spectrum of decision-making.

Substituted judgement, informed by a person's will and preference as far as reasonably practical, is regarded as best practice over a 'best interest' approach.

To avoid unintended consequences or barriers to implementing this proposed model, careful consideration should be given to how the two roles of 'supporter' and 'representative' interact in practice. For example, would a 'representative' providing decision-making support also be a 'supporter. If substitute decision-making (done by the representative) is just part of the spectrum of supported decision-making (done by a supporter) might the roles be joined? There needs to be caution in relation to the complexity of the system where there are many roles, all of which need to be clearly defined otherwise the potential for overlap could cause confusion and dispute.

Additionally, a formal recording of decisions and an appeals process are needed, all of which could be daunting for people wanting to make best use of the system. This could have the opposite effect to that intended for the proposed scheme by deterring people from acting as supporters.

4.3 Role of supporters

It is recognised that often support in decision-making comes informally from family members and trusted carers, and the appointment of a supporter needs to acknowledge these informal arrangements, whilst ensuring that the person with disability retains their right to make decisions. Consideration needs to be given to whether informal arrangements can also be supporters.

A formalised framework for supported decision-making will provide greater clarity to third parties about the nature and extent of the arrangement, giving them more confidence to interact with a supporter. However, this will require awareness raising and education of organisations, in particular financial institutions, to ensure supporters can effectively execute their role.

Issues around legal responsibly for ‘supporters’ need to be clarified, including where their ‘duty of care’ lies if they support someone to make a decision that goes wrong.

A risk in standardising the role of supporters is that it may not be appropriate for people from culturally diverse backgrounds. There needs to be sufficient flexibility in recognition of how this will work for different groups, including Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse background. Co-design with these communities will be critical to building a framework that is culturally appropriate.

4.4 Role of representatives

Greater clarity is needed about the circumstances when substitute decision-making ‘kicks-in’. What is the threshold, for example “risk of serious harm”, and how will this be consistently applied?

The proposed framework avoids the use of the term ‘substitute decision-maker’ in favour of the term ‘representative’ but it is acknowledged that substitute decision-making (albeit in a very limited form) remains part of the model.

4.5 Guidelines

It is noted that the proposed series of guidelines would aim to assist with implementing the national principles.

<u>Support guideline</u>

The La Trobe practice framework was considered as part of the current project on supported decision-making being undertaken by OPA in South Australia. The La Trobe practice framework includes the following steps:

- Knowing the person
- Identifying and describing the decision
- Understanding the person's will and preferences
- Refining the decision and taking account of constraints
- Reaching the decision and associated decisions
- Implementing the decision and advocating if necessary.

The proposed guideline on support is missing the first important step above, which is to know the person well. This highlights that supported decision-making is resource intensive and takes time. It cannot just be seen as a process to be followed. It is about relationships, trust and engagement.

The 'support' aspect of supported decision-making needs to be interrogated and defined. This is important to maintain the integrity of the overall scheme and move towards greater consistency. One person's idea of support might actually be 'taking over' or applying their own personal opinions, thinking that they are helping or trying to speed up the process.

The right of the individual to choose their supporter is a worthy aspiration but not always possible in a practical sense. It requires the individual to engage sufficiently to make those decisions in the first place.

There are also unavoidable resource implications considering the steps involved in providing supported decision-making. This would work when we are talking about 'informal supporters' but if the support is to be provided by a funded service, then the "who does" and "who pays" questions arise.

Will, preferences and rights guideline

Without clear guidance around the indicators for when it is 'not possible' to obtain the person's current will and preference then, in practice, this will play out inconsistently.

Obtaining a person's will and preference should take precedence. However, there needs to be practice examples that guide when decisions are too urgent to involve the person, in recognition that supported decision-making takes time. Equally, there needs to be guidance or safeguards around the threshold for overriding a person's will and preference due to risk of harm. If the framework is based around the presumption that people can and should make their own decisions, when does safety from harm appropriately come into play and how is this appropriately balanced against the dignity of risk principle?

Another important question is how these requirements apply in private informal 'supporter' arrangements. Practically speaking, how could good practice be ensured?

Safeguards guideline

It is acknowledged that supported decision-making is complex to get right. Ensuring the process is free of bias and undue influence is not a straightforward task. This would require substantial upskilling and ongoing training/development of supporters to achieve.

Decision-making ability guideline

The proposed criteria for assessing decision-making ability are similar to 'impaired decision-making capacity' as defined in the *Advance Care Directives Act 2013* (SA), except in reverse.

The definition of decision-making ability needs to avoid creating an unrealistic standard for people with disability. It should better reflect how decision-making actually happens in everyday life, including the fact that often people make spontaneous decisions without necessarily weighing up all the necessary information.

The guideline also needs to be clear that decision-making ability is decision-specific so should be tested in an ongoing manner (i.e. in recognition that a person may be able to make decisions about some matters but not others). Consideration should also be given to the need for a variety of different 'decision-making ability tests' in order to meet the diverse needs of people with disability, who are not a homogenous group.

Clarity is also needed regarding what is meant by the phrase 'will depend on the kind of decisions to be made.' Will there be a different assessment for decisions that are complex or high impact?

The proposed decision-making ability guideline provides for a much more nuanced and complex set of considerations than what is currently assessed. The person undertaking the assessment also needs to have the ability to identify possible coercion or undue influence from others that may be present. Currently, global capacity assessment is made by a medical professional. It would therefore be appropriate for the decision-making ability test to be carried out by a person with appropriate allied health qualifications as a base level, with specific training in determining decision-making capacity (i.e. the bar should be high).

Importantly, the assessor needs to be independent from the person who may be appointed as 'supporter' or 'representative'.

"Recognition of informal supporters" guideline

The important role of informal supporters is recognised. Equally, it is recognised that unintentionally formalising these arrangements, for example by incorporating informal supporters under the national principles, runs the risk of interrupting these relationships.

Reluctance to share information (for example a financial institution) with someone who is not formally recognised as a 'supporter' or 'representative' may be difficult to overcome without some form of legislative recognition. However, there is a risk that informal arrangements will be displaced by new legal arrangements (i.e. the informal supporter unintentionally becomes a 'formal supporter'. What would be the factors that lead to an informal supporter becoming formally recognised in the proposed model?

The “right to dignity of risk” guideline

It is acknowledged that everyone has the right to take risks, including people with disability. It is also acknowledged that risk-taking (and experiencing the consequences of those risks) plays an important role in building decision-making capacity.

Ableist assumptions about people with disability continue to impact on their right to make their own choices. People with intellectual disability, in particular, are too often infantilised so they miss out on opportunities to develop the necessary skills and peer support that make decision-making possible. This needs to be acknowledged as a barrier to supported decision-making and needs to be addressed through individual capacity building.

However, there needs to be an acknowledgement that there is an inherent tension in the shift towards greater supported decision-making between safety and risk. The practical implications of this need to be recognised, particularly in relation to community expectation.

As per previous comment, clarity is also required around where the threshold sits for overriding a person’s will and preference where there are safety concerns.

4.6 Safeguard mechanisms

It is recognised that safeguarding mechanisms are a necessary feature of any supported decision-making framework. However, a safeguarding regime should avoid becoming too onerous and deter informal supporters or the formal appointment of private supporters and representatives. It is acknowledged that this is a difficult balance to achieve.

In terms of a police-check requirement, appropriate processes need to be in place to allow for discretion to avoid potentially disqualifying someone based on an irrelevant or historical criminal record. Equally, consideration should be given to requiring more than a police-check so that other relevant information can be considered when appointing a supporter or representative.

The role of monitors needs to be clarified. Would it involve monitoring every decision or a more overarching responsibility? The former would require significant resources and will be hard to implement in practice.

Requiring supporters to demonstrate that a decision made by a person requiring support is, in fact, *their* decision is an important safeguard. However, this could create an administrative burden which deters people from becoming supporters. This could unintentionally set up a system where supporters are only ever from paid organisations.

Other safeguards beyond statutory forms of *corrective* and *preventative* mechanisms could be considered. For example, *developmental* safeguards are also important, including community education and awareness, as well as individual capacity building of people with disability so they have greater control over their lives.

A tailored approach to safeguarding could be considered. For example, a risk indictor could be triggered when certain characteristics that increase a person's vulnerability are present, warranting additional safeguarding from an agency/body overseeing the process.

4.7 Governance Body

The establishment of a national governance body would require national legislation and then harmonisation of legislation across all states and territories. This will be difficult to achieve. The scope of the body is also not clearly defined. As outlined in reform Proposal six, the national principles would apply to informal supporters. Would the governance body oversee both formal and informal support arrangements? If so, this would be hugely expensive given the large number of people who receive support either formally or informally.

Additional functions or responsibilities of the proposed independent body could include:

- A quality and safeguarding role, including potentially receiving reports of concerns related to activities of supporters/representatives
- Training and accreditation for decision-making ability testing
- Leading the cultural shift and change process required to implement the national framework.

A phased approach would be essential to manage the major paradigm shift required to implement the proposed national framework. For example, the change process could start with education and capacity building or focus on particular groups such as people with complex communication needs.

5. Best Practice Models of Guardianship

5.1 Best practice model of guardianship

OPA in South Australia supports the components of the proposed best practice model of guardianship, namely that it is based on the presumption of decision-making ability and incorporates methods of supported decision-making. As previously stated, OPA in South Australia has investment in various projects to develop our practice in supported decision-making.

Implementation of a best practice model of guardianship will require legislative change in South Australia.

Is the 'national best practice model of guardianship' in addition to the 'national supported decision-making framework'? It is confusing how these two governance arrangements differ or how they complement each other. Clear distinctions and thresholds would be required to provide clarity regarding how they operate and interface.

5.2 Best practice safeguards

Provisions to increase participation of people with disability in the appointment process would be an important safeguard to consider. This would have the benefit of building capacity and awareness of the person to understand the systems and processes that impact on their lives.

The Dispute Resolution Service is an important statutory function within OPA in South Australia. Through this service, disputes about an advance care directive or health issue can be resolved without the need to go through the more formal Tribunal process. This includes providing information and advice, mediating disputes and issuing declarations (in relation to advance care directives only). It also assists in preventing guardianship orders. Such a scheme could be adapted to resolve conflicts in decision-making where no Advance Care Directive exists.

Recent legislative changes in South Australia have established a new authorisation scheme for restrictive practices in the NDIS. Under the *Disability Inclusion Act 2018*, the scheme sets out a tiered approach to authorisation and provides oversight of the use of restrictive practices in the NDIS sector in South Australia.

The new legislation establishes the Senior Authorising Officer position, which has primary oversight of authorisation under the scheme. The Senior Authorising Officer leads the Restrictive Practices Unit within the Department of Human Services. In addition to assessing and making authorisation decisions, the Unit provides training and education to help the sector reduce and eliminate the use of restrictive practices. This means that formal guardianship is not required for the authorisation of restrictive practices for NDIS participants (about 60% of OPA clients) but guardian consent for the use of restrictive practices is still required in aged care.

Enhanced investigation powers for Public Advocates in cases of suspected abuse, neglect and exploitation would create an overlap in responsibilities in South Australia with the Adult Safeguarding Unit (ASU), which commenced operation on 1 October 2019.The ASU has powers in relation to receiving and investigating reports of suspected abuse, neglect or exploitation against vulnerable adults as outlined in the *Ageing and Adult Safeguarding Act 1995*.

5.3 Cultural Safety

Cultural awareness and consideration by tribunal members should be seen as essential for fostering better and more informed decisions about Aboriginal people who may be subject to guardianship orders.

Cultural safety can be achieved through increased use of supported decision-making over guardianship. However, it is acknowledged that there is limited knowledge on how to engage effectively in supported decision-making with Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds. Prioritising research and development in this area should be considered but this requires resources.

Any reforms with the aim of improving cultural safety require genuine partnerships with Aboriginal and Torres Strait Islander people to design culturally appropriate processes in line with commitments under the National Agreement on Closing the Gap.

5.4 Transitions out of guardianship

Guardianship should only be applied for the least amount of time necessary and in the least possible areas of a person's life.

Under current legislation, it is possible for the SACAT to include provision for an order to lapse, but this is not common practice. Most orders will have effect until a review is required.

There are also numerous examples of orders in place as a 'formality'. This has contributed to the increased numbers of people under guardianship. Among the examples are national service system requirements such as consenting to NDIS processes or restrictive practices arrangements in aged care. In South Australia, a 2019 Supreme Court ruling in relation to the detention of people with impaired decision-making capacity in their places of residence clarified the circumstances in which guardians require special powers under section 32 of the GAA. This has resulted in the need for a greater number of ongoing SACAT orders.

Overall, the effect of the above scenarios means there are less opportunities to revoke orders.

Fatigue among private guardians can also be a factor when it comes to reducing the number of public guardianship orders. Families and other informal arrangements need to be provided with adequate support, resources and guidance to keep them involved for as long as possible. The lack of case management by the NDIA and in aged care means that private guardians are left to sort out service needs which can be overwhelming. The loss of state-funded case management services has put a vastly increased workload on all guardians, including the Public Advocate

Whilst it is important that guardianship is in place only for as long as is necessary, measures to decrease numbers should focus on whether it is the right outcome for the individual. For example, consideration needs to be given to alternatives to guardianship, particularly where a person has no family or other informal support in their life. When an order is revoked, there must be adequate oversight and an 'extra pair of eyes' looking out for the person, especially if they are in an institutional-style environment or under the care of a single service provider.

5.5 Data collection and reporting

OPA in South Australia supports a consistent approach to the collection and reporting of data.

The collection and reporting of guardianship and administration outcomes would need to be monitored and managed by the relevant tribunal. Consideration needs to

be given to the resource implications of this. Processes and documentation will likely need to change to accommodate nationally consistent data collection and reporting.

Additional information such as the type of appointment, term of appointment, details of the appointed person and whether it is public or private could also be captured.

Resourcing and change of processes will need to be worked through as there will be variances across jurisdictions. Determining who has access to the data and where the data will be stored is critical.

If this proposal effectively involves a national registry of tribunal orders, then privacy is an issue. If it were more a requirement for each jurisdiction to collect common data which allows for national comparisons, then that need not breach privacy.

Disclosure to all parties that this data is being collected will be essential. Consideration should also be given to the risks and benefits of regular reports of de-identified data being made public.

6. Conclusion

Achieving the goal of a nationally consistent supported decision-making framework would require large-scale legislative reform and harmonisation both with the Australian Government and within each jurisdiction (for example, numerous Acts in South Australia would need to be amended). This will be a difficult and slow process. Equally, one of the challenges with establishing a prescriptive national approach is the difficulty in then allowing for the important differences and local innovations that make a scheme workable in different contexts. It would be more effective to focus on nationally agreed principles, to drive change so that the specifics can be adapted by each jurisdiction or sector.

Supported decision-making is complex to get right. Removing bias and influence when supporting someone to make a decision is not a straightforward task. It takes self-awareness and sustained effort. It requires specialised skill and ongoing knowledge development.

It would also take wide-spread community effort and cultural change across numerous sectors to make a nationally consistent supported decision-making framework effective. This requires significant investment and ongoing resources in upskilling, building expertise and setting up the supporting structures (such as safeguarding mechanisms). The practice of proper supported decision-making also takes time. As outlined in the reform proposal paper, OPA supports the idea that supported decision-making be funded through a person's NDIS plan. Similar funding arrangements could be put in place for people receiving aged care packages or mental health support.

There needs to be an acknowledgement of the inherent tension in the shift towards greater supported decision-making between safety and risk.

It is recognised that a formal framework for supported decision-making will allow for greater monitoring and safeguards than informal arrangements. However, the benefit of this needs to be balanced against the risk of displacing the value of organic arrangements whereby those with an ongoing relationship who know the person well are providing the support. Priority should be given to fostering these informal arrangements to develop their supported decision-making capacity without creating an overly bureaucratic system.

The impact on guardianship of new thinking on the primacy of supported decision-making and the ascertainment of will and preference must not be underestimated. It has a huge impact on the need for substantial legislative change within each jurisdiction.