NSW Restrictive Practices Legislative Framework For People Living With A Disability

A Dementia Australia submission

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Introduction

Dementia Australia is the peak dementia advocacy and service delivery organisation in Australia. As the trusted source of information, education and support services, we elevate the living experience of people impacted by dementia to advocate for positive change.

Dementia is a broad term describing more than one hundred different forms of neurocognitive disorder that can result in changes in mood, behaviour, thinking and the ability to carry out tasks of daily. Changed behaviours are one of the most common symptoms associated with various forms of dementia, particularly in the later stages of the condition. Leading researchers in the dementia care field suggest changed behaviour must be understood as a response to the person's environment and a form of communication about an unmet need. Psychosocial approaches and interventions are effective in responding to most changed behaviour. Despite consistent evidence of their limited efficacy and a high associated risk of adverse effects, psychotropic medications – a form of chemical restraint - are still widely prescribed for the management of changed behaviour for people living with dementia.

Dementia Australia believes that any restrictive practice (RP) represents a potentially harmful measure and a potential infringement of the human rights of a person living with a disability, including dementia. The application of any form of RP must involve a discussion with the person with the disability and/or their support person (s) wherever possible, to ensure there is informed understanding and consent for the implementation of the RP measures. The application of RP warrants rigorous safeguards in terms of its application, ongoing assessment and review, and transparency in terms of the broader governance and regulatory frameworks and requirements relating to authorisation of RP.

Question 1: Should the proposed legislative framework cover the out of home care setting?

In 2021, there were 2,273 Australians living with childhood dementia, including 1,396 children under the age of 18. Dementia Australia believes that regardless of the setting in which they live and are cared for, all children deserve the right to have their safety and wellbeing supported, and this includes the use of RP with the appropriate safeguards in place.

Question 2: Should the proposed legislative framework cover any other setting?

The application of RP in mental health, general disability, aged care and health settings differs significantly, with many of these settings having specific, legislated authorisation requirements and others having general laws or departmental guidelines and directives. It is a complex regulatory area and the lack of consistency across different sectors and settings means it is open to potential misinterpretation and misapplication of RP for people living with disability. Dementia Australia believes that the regulations and guidelines for RP requirements should be consistent and harmonised across all settings involving people living with a disability.

It is estimated that 54% of people living in residential aged care have a cognitive disability in the form of a dementia diagnosis (Australian Institute of Health and Welfare, 2024). Given the significant levels of disability in the residential aged care population, and that current definitions of restrictive practices are consistent with those outlined in the NDIS Act, this offers a compelling argument for the application of the proposed RP framework in the aged care setting.

Dementia Australia believes that harmonising the RP framework in the disability and aged care settings would assist in ensuring that the appropriate protections are in place for the use of restrictive practices and that all employees involved in the application of RP (who can and do work across a range of disability, aged and community care settings) understand the requirements and comply with them.

Question 3: What issues and challenges are raised by there being different frameworks for the authorisation of restrictive practices in the disability service provision setting and the aged care setting?

As noted in the response to the previous questions, the current lack of consistency in RP frameworks across these two settings has a number of potentially significant consequences as follows:

- Different frameworks and requirements in the disability services and aged care settings governing the use of RP, including authorisation and oversight, would be potentially confusing for the person with the disability and those involved in application of the RP, arguably resulting in inadequate human rights protections for people subject to RP
- Other workers involved in applying RPs might have different levels of understanding of RPs with the associated potential for poor compliance including the misapplication of RPs across the two settings
- A person with a disability might move from one setting to another and be subject to different RP requirements with potentially unhelpful, confusing or distressing consequences for that person
- Education and training around RPs would have different requirements in different settings, potentially increasing the workload on education and training providers and in turn on disability services and aged care providers

Question 4: Do you support legislation requiring that restrictive practices on NDIS participants in the disability service provision, health, education and justice settings should be governed by the principles recommended by DRC Recommendation 6.35(b)?

Yes. Dementia Australia supports the general principles recommended by the DRC, particularly in relation to the three requirements for sector-specific settings i.e. that RP should only be used as a last resort, in response to a serious risk of harm, be the least restrictive response possible, be proportionate, and be for the shortest time possible; that decisions to authorise restrictive practices should be subject to independent review, and that the use of restrictive practices should be subject to independent oversight and monitoring.

Question 5: Are there any other principles that should be considered?

The four principles outlined in Recommendation 6.35(b) of the DRC Final Report are important in providing the appropriate safeguards for the application of RP. However, Dementia Australia believes the first and most critical principle is one that stipulates that RP must be applied in consultation with the person with a disability and/or their supporter wherever possible, involve a supported decision-making approach and are consistent with the human rights-based principles of the 2008 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

Question 6: Should a legislative framework prohibit any practices? If so, which practices and in which settings?

We would like to take this opportunity to reiterate our earlier observation that *any* RP represents a possibly harmful measure and a potential infringement of the human rights of a person living with a disability, including dementia. The application of any form of RP therefore warrants rigorous safeguards in terms of its application, ongoing assessment and review, and transparency in terms of the broader governance and regulatory frameworks and requirements relating to authorisation of restrictive practices.

Question 7: Do you agree that:

• the framework should use the NDIS definitions of restrictive practices?

Yes – this is consistent with the framework and definitions of restrictive practices in the aged care setting.

• the Senior Practitioner should have the power to issue guidelines that clarify how the definitions apply in different situations?

Yes. Dementia Australia believes that it is appropriate that the Senior Practitioner (SP) have responsibility to oversee the authorisation of aged care restrictive practices, including issuing guidelines on how these apply in different settings. This SP-led model has been effectively implemented with variations in various State and Territory settings, including Victoria, South Australia, the ACT and Tasmania.

Question 8: What role should the Senior Practitioner play in regulating behaviour support plans?

Dementia Australia believes that the SP must play an integral role in the development and authorisation of behaviour support plans (BSP) given their central role in determining the application of RP. We believe that the qualifications of the behaviour support practitioner must include an understanding of dementia, and how to support effective communication and wellbeing for a person living with dementia. The practitioner must also have a thorough knowledge of and ability to apply a supported decision-making approach, as this will also be critical to the inclusive and genuinely consultative approach required in developing a BSP with and for a person living with dementia, and their support person (s).

Dementia Australia supports the consideration of ‘cultural factors’ in the development of BSPs (p. 27) but suggests that this inclusive perspective needs to be broadened to include other diverse and minority populations, including care leavers, survivors of child abuse, the LGBTIQ community, war veterans and others who may need a specific approach to the development of their BSP. Behaviour support practitioners must have appropriate training, awareness and the relevant skills, including a trauma-informed approach, to be confident and competent to develop an individualised BSP for people with disability with these specific living experiences.

We also support the suggested requirement that ‘ … that BSPs containing restrictive practices contain a summary of the views of those consulted’ (p. 28). Dementia Australia believes that this should be shared with those who were consulted, prior to being included in any assessment or report, to ensure the accurate representation of those views. This measure would provide an important safeguard to ensure that whenever possible, consultation in relation to the BSP had been undertaken with the person with the disability and their support person (s).

Question 9: Is there anything else the proposed framework should do to improve the quality of BSPs?

No additional comments.

Question 10: Should APOs be empowered to either:

• authorise particular categories of restrictive practices without separate Senior Practitioner authorisation (a partially delegated model). If so, what categories of restrictive practices should be able to be authorised by APOs? Should these be prescribed by legislation, or through class or kind orders?

• provide preliminary approval of restrictive practices, with final authorisation provided in all cases by the Senior Practitioner (a two-step model)?

Dementia Australia has significant concerns in relation to the role of Authorised Program Officers (APOs) in the proposed framework and does not therefore support a model that includes APOs. Dementia Australia believes that a preferable model would be one that requires the SP to have oversight and ultimate authority in relation to every decision about the development of a BSP and the nature and application of RP.

Question 11: Are there alternative approaches to authorisation that would be preferable to these models?

No additional comments.

Question 12: Should APOs be required to be employed by a single provider? Or should APOs be permitted to be consultants to a number of providers? If so, what safeguards should there be in relation to this?

As noted in response to Q 10., Dementia Australia does not support the role of APOs in the proposed framework.

Question 13: Do you support the proposed duration of authorisation and emergency use proposals for restrictive practices?

Dementia Australia supports the definition of an 'emergency process' and the use of RP in this context. We agree with abolishing the 'the current "interim authorisation" process of 6-months, a time frame that does not appear to conform with what constitutes an 'interim measure'.

Question 14: Are there any additional grounds on which the Senior Practitioner should be able to cancel an authorisation?

No additional comments.

Question 15: Should authorisation decisions:

- **be open to internal review?**
- **be reviewable at NCAT?**

Dementia Australia agrees with the proposal that authorisation decisions should be both open to internal review and subject to review by the NSW Civil and Administrative Tribunal. We believe there should be multiple avenues and opportunities for decision reviews in relation to RP to ensure that the rights of the person with a disability are always the primary focus.

Question 16: Should rights to seek review be limited to the person or a person concerned for their welfare? Should the service provider have a right to seek review of a decision not to authorise a restrictive practice?

The service provider should be allowed to seek the review of a decision not to authorise a restrictive practice but with specific criteria in place to ensure that the NSW Civil and Administrative Tribunal is not subject to, or burdened by, unjustified or unnecessary provider appeals and reviews.

Question 17: Should a person have a right to request the service provider review the BSP at any time?

Yes, as we noted in relation to an earlier question, the person with the disability and/or their support person should always be consulted in relation to the use of RP, and the development of a BSP. Equally, the person with the disability and/or their support person should have the right to request a review of the BSP at any time.

Question 18: Should the Senior Practitioner have complaints handling and investigation functions either on receipt of a complaint, on its own motion, or both?

In the model that Dementia Australia supports, the SP would always be involved in both the development and approval of the BSP, and the application of RP. We therefore believe that there is a clear conflict of interest if the SP was involved in handling complaints and initiating investigations in any matters related to the SP. We strongly support a complaints and investigation process that is independent of the SP and is led by an appropriate Government authority, for instance, the NSW Ombudsman or the NSW Civil and Administrative Tribunal.

Question 19: Do you agree the Senior Practitioner should have the proposed powers to respond to misuse of a restrictive practice?

Yes.

Question 20: How should interaction with the NDIS complaints framework be managed?

There are currently 433, 300 Australians living with dementia, and of these, 29,000 are living with younger onset dementia (under the age of 65). These figures are projected to increase to 812,500 and 41,000 respectively by 2054 (AIHW, 2024). Every person living with dementia deserves to have equitable access to services and supports. For many individuals living with younger onset dementia, the services and supports they require will be provided by the NDIS. Dementia Australia believes it is important that the proposed Framework for use of RPs on people with disability is designed to interact with the NDIS complaints framework. We support Proposal 11 in relation to the SP's reporting powers, including referring matters to the NDIS Commission, police or another relevant entity. As we have also noted in relation to Q 18, any complaint involving the approval of a BSP or application of RS necessarily involves the SP and would need to be led by an appropriate Government authority, for instance, the NSW Ombudsman or the NSW Civil and Administrative Tribunal.

Question 21: To which bodies should the Senior Practitioner have the power to share information and in what circumstances should the Senior Practitioner be permitted to share information?

In the event of a suspected misuse or abuse of RP and/or related matters, the SP should be empowered to share information with the Ageing and Disability Abuse Helpline at the office of the Ageing and Disability Commissioner, the NSW Police and the NDIS Quality and Safeguards Commission.

As with the Federal Government's aged care services complaints process and Serious Incident Response Scheme reporting requirements, in the event of the suspected misuse or abuse of RP and/or related matters, Dementia Australia strongly supports an approach which would also mandate the timely sharing of information with the parties involved in the situation including the person with the disability (where appropriate), their support person (s), the staff members and providers concerned. A timely and appropriate response must ensure appropriate action is taken to ensure the safety and wellbeing of the person with the disability.

Question 22: Are the means by which the Senior Practitioner would have visibility of the use of restrictive practices by NDIS providers proposed in this Paper sufficient? If not, what additional information should providers be required to report to the Senior Practitioner? How can reporting burden to the Senior Practitioner and the NDIS Commission be minimised?

Dementia Australia believes the degree of oversight for the Senior Practitioner in relation to the use of restrictive practices by NDIS providers proposed in the paper is appropriate.

Question 23: Do you agree the Senior Practitioner should have the proposed education and guidance functions?

Dementia Australia supports investing the SP with responsibility for education and guidance and regards this as a critical part of their role in ensuring that all parties involved in the exercise of RP are fully informed. Dementia Australia recommends that this education, guidance and capacity building must include a substantive component addressing dementia as a disability. Employees involved in applying RP must receive high quality and ongoing education and guidance on how to best support someone living with dementia to make decisions, develop a behaviour support plan in collaboration with health professionals and family members, and to maintain wellbeing in the context of restrictive practices.

Question 24: Should the Senior Practitioner have the power to impose sanctions for the misuse of restrictive practices, or are existing sanctions for misuse of restrictive practices sufficient? How should the interaction between sanctions provided for under NDIS legislation and the proposed framework be managed?

Dementia Australia supports the SP having the power to impose sanctions for the misuse of RP and as noted in relation to Q 21., we support the constructive interaction between the proposed Framework and the NDIS legislation in ensuring that that misuse of RP is identified, responded to and sanctioned in a timely and appropriate way that safeguards the wellbeing of the person with the disability.

Question 25: Should the proposed framework provide for a legislated immunity from liability from the use of restrictive practices where the use was in accordance with an authorisation and done in good faith?

Dementia Australia believes that individuals and agencies involved in the use of RP have a duty of care in the assessment, review and safe application of RP. These requirements should form a mandatory component of the education, guidance and capacity building provided by the SP. If there are serious consequences as a result of the use of RP (injury, illness or death for example), even if ‘in accordance with an authorisation and done in good faith’, we believe the individuals and agencies involved should not be able to rely on automatic, legislated immunity but rather, that they should be accountable for their actions and liable for any adverse outcomes or consequences.

Question 26: Are there any other functions which the Senior Practitioner should have? Should providers in the disability service provision setting be subject to any other requirements?

We do not have any further comment in relation to SP functions or provider obligations but would like to take this opportunity to reiterate the need for a rights-based, supported decision-making approach to any application of restrictive practices for people living with a disability, including dementia. There must be independent, transparent processes to ensure that the unmet needs of people living with dementia, such as expressions of pain or distress, have been assessed and properly responded to prior to use of any restrictive practices, including chemical restraint. These are the views and experiences of our stakeholders - people living with dementia, their families and carers - and what they have advocated for over many years. Dementia Australia strongly encourages the NSW Government to ensure that any legislative framework that is adopted to regulate RP reflects these views and is underpinned by these principles.