Reforming WA disability legislation

A Dementia Australia submission.

June 9, 2023

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Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the more than 400,000 Australians living with dementia and 1.5 million people involved in their care. Founded by carers more than 35 years ago, our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the lived experience of dementia across Australia. Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive disorders which cause a progressive decline in a person's functioning. Dementia is the second leading cause of death in Australia, yet it remains one of the most challenging and misunderstood conditions. Without a significant medical breakthrough, it is estimated that there will be more than 800,000 people living with dementia in Australia by 2058.[i]

The 2008 United Nations Convention on the Rights of People with a Disability (UN-CRPD) recognised dementia as a cognitive disability but unlike physical disability, community understanding of dementia as a disability remains limited. This is at least in part because, unlike a physical disability, the cognitive and other changes that are associated with the condition are often under recognised or rendered 'hidden' or 'invisible.' People living with dementia relate the common experience of being told that they 'can't possibly have dementia' because they don't appear, speak or act in a way that corresponds with community expectations or understanding of the disabling nature of dementia.[ii]

> 'If you just saw them and didn't know them, how would you even know if they had dementia?" (Australian resident with no lived experience of dementia)[iii]

The 'invisible' nature of a cognitive disability and the attitudinal and other societally imposed barriers mean people living with dementia can experience additional stigma or challenges when undertaking daily activities, engaging with the health care sector or interacting with people in the broader community. Dementia Australia believes the 'invisible' nature of dementia as a disability must be an important consideration and inform all aspects of the proposed changes to the 1993 WA Disability Services Act.

Introduction

We are grateful for the opportunity to make a submission to this consultation. As the peak body for dementia advocacy in this country, we regularly survey the community we represent on the issues that are important to them. Our submission is informed by feedback from people living with dementia and former and current carers who participate in our Dementia Advocates program.

Dementia Australia is in broad agreement with the intent and purpose of the WA Disability Services Act, and the principles of the 2008 UN-CRPD that underpin the current legislation. We believe the proposed changes to the 1993 Disability Services Act, and the ongoing role of the Disability Services Commission and Ministerial Advisory Council on Disability will assist in addressing dementia-related stigma and the associated discrimination that people living with the condition experience in health care settings and in the community. The revision of the Act will make a positive contribution to ensuring that people living with dementia, their families and carers, have equitable access to services and supports and can fully and equally participate in their communities.

Our submission responds to the questions identified by our Dementia Advocates as addressing the most relevant and important concerns related to their support and care.

1. **Do you think the current definition of ‘disability’ in the DS Act adequately covers all types of disability? Why? If not, how would you change or improve the definition?**

As noted above, community awareness of dementia as a disability remains limited and the ‘invisible’ nature of the condition means that that people living with dementia, and their families and carers, experience stigma and discrimination in ways that are unique to this cohort. We are pleased to note that the definition of disability includes cognitive disability. However, given the invisible nature of some forms of disability, including dementia, we feel that the definition should reflect this more accurately. The exposure draft for the Victorian Disability Inclusion Bill 2022 includes the following definition of disability:

‘ Any impairment (including physical, mental, intellectual, cognitive, learning, communication or sensory impairment) or functional limitation (whether or not the impairment or limitation is permanent, temporary, episodic in nature **or evident**) that, in interaction with a barrier, hinders a person's full and equal participation in society.

We believe the inclusion of **whether or not the impairment is evident** is an important acknowledgement of the hidden nature of some disabilities and we strongly support following the Victorian Act in adopting this wording in the WA Disability Services Act definition.

We also believe there is a compelling argument for wording in sections of the legislation to specifically acknowledge and emphasise the unique circumstances and needs of people living with dementia. These suggested changes are outlined in our response to subsequent questions.

2. **Would you change the current Principles in the DS Act, including adding new Principles or excluding current ones? Why?**

Dementia Australia supports the current Principles in the DS Act but believes the inclusion of an additional Principle acknowledging the importance of the active involvement of people living with disability in the planning and provision of services and supports that affect them, would strengthen the Act. This Principle could be worded along the following lines:

‘People living with disability will be actively involved in the consultation, design and implementation of all government and government-funded programs, services and policies that affect people with disability.’

Half the Story, Dementia Australia’s guide to meaningful consultation with people living with dementia, their families and carers, is an important resource in this context. The guide was co-authored by people impacted by dementia, and offers information and strategies to support organisations to increase the participation and engagement of people impacted by dementia in consultation processes.

Dementia Australia supports future aspirations in the consultation paper to enshrine ‘ … specific principles applicable to people with disability who are children, Aboriginal or Torres Strait Islanders or from culturally and linguistically diverse backgrounds.’ In this context, we would argue that people living with cognitive impairment, including dementia, have unique circumstances and needs. Specific principles recognising these circumstances and needs should also be considered in any future revision of this section of the DS Act.

3. **What safeguarding mechanisms do you think would protect people with disability from violence, abuse, neglect and exploitation?**

Dementia Australia supports the existing safeguarding mechanisms in the DS Act including screening of workers supporting people with disability, conditions around the use of restrictive practices and state-based complaints mechanisms. In relation to the current provider registration and other regulatory checks, we would make the following general recommendations:

1. To support robust governance and ensure familiarity and compliance with safeguarding processes, information and resources should be made readily available to all disability providers. This could include a sector-appropriate version of the information from the Australian Commission on Safety and Quality in Health Care for The National Safety and Quality Health Service (NSQHS) Standards. These provide a detailed breakdown of each standard by action, and information on intent, reflective questions, key tasks and strategies for improvement. Making information and resources available will support providers in their safeguarding compliance and quality improvement activities, and will be

particularly significant for smaller organisations that may not resourced to engage staff in dedicated governance and quality improvement roles.

2. The implementation and review of safeguarding policies and procedures should also include training and education for staff encompassing:

- clear definitions of abuse, violence, neglect and exploitation;
- an overview of the policy and procedures that support staff to follow up and report their concerns;
- the importance of good communication and language use;
- ways to raise concerns outside the organisation;
- where to find information for the service users and the broader community; and
- debriefing and supports available for staff.

Dementia Australia also makes the following specific observations in relation to the importance of safeguarding mechanisms for people living with dementia. Feedback from our Dementia Advocates on the implementation and efficacy of safeguarding mechanisms cohered around two, interconnected themes: the need for improved awareness and knowledge about dementia, and the importance of effective communication with people living with dementia. Both issues are fundamental to supporting someone living with the condition to live as well as possible, including protecting them from potentially abusive or exploitative situations.

Providing information and resources that set out clear definitions of what constitutes abuse, violence, neglect and exploitation will be critical to the protection of people with disability. Our Dementia Advocates emphasised that strategies to educate, support and enhance the resilience of carers and family members will play an important role in reducing the risk of violence, abuse, neglect and exploitation and must be considered as an essential part of the safeguarding process.

All information and resources must be provided in a range of accessible formats that at a minimum, accommodate the needs of people with vision, hearing and cognitive impairments, to ensure that people with disability are fully informed and that safeguarding mechanisms are understood, accessible and effective.

We note the reference to the NDIS Quality and Safeguards Commission in the consultation paper and the further safeguarding protections offered for NDIS participants under the Commission. The NDIS Quality and Safeguarding Framework emphasises that “giving people with disability choice and control over their supports can improve their outcomes.” [iv] Improved outcomes would necessarily include reducing vulnerability to abuse and exploitation. Adopting a consistent and inclusive decision-making approach is a critical part of supporting people with disability to exercise choice and control.

Dementia Australia believes that a person living with dementia has the right to be involved in decision-making about all aspects of their lives wherever possible and that a supported decision-making model enables this. Our recent **Position Statement on Supported Decision-making** outlines the appeal of this approach. A supported decision-making model recognises that a person living with dementia will experience cognitive and other changes over time that will have an impact on their decision-making ability. The changes experienced with dementia may require corresponding changes in protections, but these must be balanced with respect for the person’s right to privacy, dignity, and wherever possible, the continued opportunity to be involved in decisions about their wellbeing and health.

4. As one aspect of safeguarding, how can complaint mechanisms be made easier to use for those persons with disability receiving State services?

Clear and transparent processes to support people with disability who do raise concerns will be key to effective safeguarding mechanisms. Dementia Australia Advocates noted that people living with dementia do not always have their concerns taken seriously. Fear of the potentially negative consequences for the person making the complaint represented a significant barrier to reporting concerns.

> “Fear of not being taken seriously or listened to – a ‘paternalistic’ attitude of trivialising the issue as we know best for you.” – person living with dementia “
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> “They may fear it may jeopardise their level of care and attention. They may worry they are being a nuisance or a burden. They may worry carers may not have the time to listen and heed their complaints.” – former carer
>
> “Being believed, not assumed that they’re just confused.” – carer

Complaint processes and quality improvement systems must address these concerns by having a strong focus on respectful and effective communication when dealing with people living with dementia, and their family members and carers.

Information about the rights of people with disability and their families and carers in potentially abusive or exploitative situations, including clearly outlining who to consult and how to make a complaint, will be central to an effective safeguarding strategy.

As noted above, this information must be made accessible in variety of formats so that people with cognitive impairment, including dementia, can be fully informed about their rights, and the mechanisms and processes involved in lodging a complaint. Dementia Australia supports a requirement to provide all information and communications in *a range of accessible formats* that at a minimum, accommodate the needs of people with vision, hearing and cognitive impairments.

6. Should State legislation make provision for an offence of ill-treatment of people with disability by a carer or service provider? Please give reasons for your answer.

Dementia Australia strongly supports the existing provisions in the legislation that recognise and penalise an ‘offence of ill-treatment’ in relation to the provision of care and care and support for a person with disability. We believe this is an important part of the existing framework for safeguarding and protections. Furthermore, Dementia Australia strongly endorses the expansive understanding of ill-treatment that encompasses actions towards a person with disability, such as physical or psychological abuse and failure to act, including failing to provide adequate food or obtain medical treatment. Dementia Australia believes that the offence of ill-treatment should be applicable to individuals and service providers.

9. The DS Act currently provides for the Ministerial Advisory Council on Disability – is the Ministerial Advisory Council on Disability an effective tool for letting the Minister for Disability Services hear the voices of people with disability? How can this be improved?

Dementia Australia believes the Ministerial Advisory Council on Disability has played an important role in promoting the voices and concerns of people living with disability and the broad agenda of disability inclusion in Western Australia. We note that the current requirements include that the Council is comprised of ‘ …. up to fourteen members who either have a disability or relevant knowledge and lived experience of a disability or are a family member or carer of a person with a disability. Some members are also required to have recent and relevant experience of disability outside the metropolitan region.’ We note that the Council currently comprises nine members.

Our Advocates were united in their opinion that people with living experience of disability (their choice of words) must comprise the *majority members on the Council*. Advocates expressed a strong preference for Council membership to be comprised of a *minimum of 75 per cent of members* with living experience of disability and further, that the membership must be drawn from socio-culturally and geographically diverse communities.

Dementia Australia strongly supports a further improvement in representational diversity by recommending that the Council includes *at least one person with a cognitive disability*. As noted throughout this submission, people living with cognitive impairment, including dementia, experience unique challenges and have specific needs that are different from other conditions affecting brain function. Dementia Australia believes there is a strong rationale have a voice on the Council that can speak directly to and for people living with these specific challenges.

10. How can WA disability legislation ensure the views of the community, particularly those with lived experience, are shared with WA Government?

Dementia Australia believes that the Ministerial Advisory Council on Disability plays a critical role in consulting with and representing the views of people living with disability. As noted in response to Q.9, to ensure that the Ministerial Council is genuinely representative, we believe the Council must be comprised of a minimum of 75 per cent of members with living experience of disability including at least one member with a cognitive disability, and that membership must be drawn from socio-culturally and geographically diverse communities. We could not find any reference in the Consultation Paper or elsewhere in relation to how often Council members are appointed but we strongly support a regular change of Council membership (every 2 years) as important measure to ensure the Council remains relevant and representative of the voices and views of the disability community.

In relation to the specific process of engaging with and listening to people living with dementia, their family members and carers, we would like to again draw attention to our guide to meaningful consultation, **Half the Story**.

12. Would you change the current Objectives in the DS Act, including adding new Objectives or excluding current ones? Why?

Dementia Australia supports the current Objectives outlined in the DS Act but with one exception. Objective 17 states that '… programmes and services are to provide– (a) people with disability and their families and carers with opportunities for participating continually in the planning and operation of services they receive; and

(b) opportunities for people with disability, their families and their carers to be consulted about the development of major policy, programme or operational changes.'

As noted in relation to Q.2, we would strongly support more forceful language in relation to the meaningful consultation with and active participation of people with disability in the design and delivery of all services and supports related to them. We respectfully suggest that rather than 'opportunities' for participation and consultation, this Objective could be revised to emphasise that:

> 'People living with disability will be **actively involved in the consultation, design and implementation** of **all** government and government-funded programs, services and policies that affect people with disability.'

Conclusion

Dementia Australia is grateful for the opportunity to make a submission to this important consultation in relation to the review of the WA Disability Services Act. We thank you for considering our submission and we would welcome further opportunities to discuss the issues and recommendations raised in this submission.

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[i] Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government, accessed 20 January 2023.

[ii] Former CEO of Alzheimer's Switzerland Birgitta Martensen's account of her recent diagnosis includes the most recent and compelling example of this. https://www.alzint.org/news-events/news/my-life-with-alzheimers-disease-living-better-with-a-diagnosis/

[iii] Dementia Friends & Dementia Friendly Communities Program. Exploratory report, Kantar Consultants, 2019

[iv] Department of Social Services (2016) NDIS Quality and Safeguarding Framework, p.6.