



Tasmanian Disability Inclusion Bill

Dementia Australia Submission

September 2023

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia.

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 living 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.

The Dementia Australia Policy team can be contacted on policyteam@dementia.org.au

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of complex neurocognitive conditions which cause progressive decline in a person's functioning.

Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia is one of the largest health and social challenges facing Australia and the world. In 2023, it is estimated there are more than 400,000 people living with all forms of dementia in Australia. This number will continue to grow to more than 800,000 by 2058.¹

In February, the Australian Institute of Health and Welfare released data showing dementia is now the leading cause of disease burden among Australians aged 65 and over. Dementia is the second leading cause of death for Australians and the leading cause of death of women².

In 2023, it is estimated there are more than 10,300 people living with all forms of dementia in Tasmania. This figure is projected to increase to more than 16,000 by 2058.³ In Tasmania, there are an estimated 680 people living with younger onset dementia, which is dementia diagnosed before the age of 65.⁴

¹ AIHW (2023) *Dementia in Australia*. <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

² AIHW (2023) *Dementia in Australia, Summary, Impact* <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

³ [Dementia in Australia](#)

⁴ [Younger Onset Dementia in Australia](#).

Dementia Australia's response

Dementia Australia appreciates the opportunity to provide feedback on the Tasmanian Disability Inclusion Bill 2023. We have also circulated the consultation opportunity to our network of Dementia Advocates in Tasmania, who are people living with dementia and their carers. We recommend continued engagement of people living with dementia in Tasmania in the development and implementation of the Tasmanian Disability Inclusion Bill.

Dementia Australia advocates for improvements in legislation and policy to improve quality of life for people living with dementia. We work to build dementia-friendly, inclusive communities which support people living with dementia to continue engaging in the activities that are important to them. More information about building dementia-friendly communities is available at <https://www.dementiafriendly.org.au>.

Dementia Australia is in broad agreement with the proposed Objects of the Disability Inclusion Act 2023. In this submission we outline issues for consideration in relation to the unique circumstances of people living with dementia. We note that the principles and approaches of the Act should apply more broadly than the disability services sector, and include aged care, health and other sectors that people with disability interact with.

Dementia is a disability

Dementia is a cognitive disability which affects people of all ages, causing difficulties with thinking, memory and behaviour. Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease. Dementia affects people of all ages including in childhood - there are approximately 2,300 Australian children living with dementia.⁵

Community awareness of dementia as a disability is limited. The cognitive and other changes that are associated with the condition are often 'invisible' or under-recognised. 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.⁶

Cognitive disability is an umbrella term that can broadly be conceptualised as difficulties with memory and thinking that arise from intellectual disability, dementia, brain injury, autism, neurological disorders, fetal alcohol spectrum disorder, learning disorders or mild cognitive impairment. People with cognitive disability may have challenges with remembering, learning, concentrating, decision-making, attention, communication and problem-solving, among other difficulties⁷.

⁵ [Childhood Dementia](#)

⁶ [Dismantling Dementia Discrimination](#).

⁷ [Cognitive Impairment, Identifying and managing cognitive impairment, Indefinite detention of people with cognitive and psychiatric impairment in Australia, Issues Paper: Health Care for People with Cognitive Disability, Cognitive Impairment and the NDIS](#).

The understanding of dementia as a disability is critical to ensuring that people living with dementia have full realisation of their human rights and full inclusion in the community.

Dementia Australia supports the definition of disability included in the proposed Act. We believe the inclusion of **whether or not the impairment is evident** is an important acknowledgement of the hidden nature of some disabilities such as dementia, and we strongly support the adoption of this definition in the Act.

“People experiencing dementia should not feel isolated at home. People living with dementia should be supported within the community. Specific designs should exist within society, enabling people living with dementia, to participate in society...”

~ Dementia advocate

Inclusion Principles

The Inclusion Principles in the draft Act are likely to make a positive contribution to promoting inclusion and equal participation of people living with dementia in the Tasmanian community. Dementia Australia recommends some minor amendments which would improve inclusion of people living with dementia.

In reference to point 1 (e) we note that people with disability interact with a range of support systems, not only the National Disability Insurance Scheme. Point 1 (e) should also assert that people with disability have the right to receive necessary support from the aged care and health systems. As previously stated, dementia is a disability which affects people of all ages and is prevalent among the population which accesses aged care services.

Dementia Australia consistently receives feedback from people living with dementia that they are discriminated against because of dementia, including in access to aged care services such as respite.

It is important that the Tasmanian Disability Inclusion Bill not only apply services accessed in the disability services sector but takes account of the experiences of people with disability in other contexts and in the community more broadly.

With reference to point 1 (o), our view is that this could be strengthened to empower people with disability more fully in their engagement. We recommend amending the wording with broader ambition and the sentiment that:

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

Disability Inclusion Plan

Dementia Australia supports the requirement for a Tasmania-wide Disability Inclusion Plan to coordinate government action to advance inclusion of people with disability across the state. We reiterate that people living with dementia, as with all people with disability, access services and supports from a range of government agencies, including multiple state government funded entities. State government funded and operated health services are significant in this context, including hospital services.

The Disability Inclusion Plan should seek to engage this broad range of entities, not only within state government, but also including Commonwealth-funded disability, aged and primary health care services, and local government.

Engaging these agencies as partners in the Disability Inclusion Plan will make a significant contribution to promoting access and inclusion in Tasmania, including for people living with dementia. The Disability Inclusion Plan should outline how disability, health, primary care and aged care systems will work together deliver on the Objects of the Act.

We also recommend that the requirements for consultation on both the state-wide and agency-based Disability Inclusion Plans should include engagement of people with different types of disability, including cognitive and neurological disabilities.

Dementia Australia supports a network of Dementia Advocates who are people living with dementia, carers and former carers. We would be happy to assist the Department of Premier and Cabinet by providing avenues for further consultation with our Advocate network in the future.

Dementia Australia has developed a comprehensive guide to meaningful engagement with people living with dementia, families and carers in consultation, called **Half the Story**. Meaningful engagement means seeking out, affirming and ratifying the voices of people living with dementia, families and carers. It is necessary to understand the full story.

Meaningful engagement requires us to remove or reduce the barriers that prevent people from participating. It requires us to work differently. Meaningful engagement respects people's dignity and human rights, recognises their knowledge and skills, amplifies their voices, and involves people in decisions that will affect their lives.

The Disability Inclusion Plans developed under the Act must be transparent and accessible to people with cognitive disabilities, including dementia. This means ensuring that there are varied communication channels and formats which are accessible and appropriate to people with a range of communication needs. Accountability and complaints mechanisms should also be appropriate and accessible to people with a cognitive disability.

The current requirement in point 9 (b) for information to be provided in only one accessible format does not promote inclusion. We believe requiring only one communication format is too limited and allows for potential exclusion and discrimination. For example, if communications were only provided in Auslan, this would potentially discriminate against people with a cognitive disability, including those living with dementia.

To be genuinely inclusive, any information about the Disability Inclusion Act, Plans or the Advisory Council should be offered in a range of accessible formats that at a minimum, accommodate the needs of people with vision, hearing and cognitive impairments.

Disability Inclusion Advisory Council

Dementia Australia supports the requirement for the Disability Inclusion Advisory Council to reflect the diversity of backgrounds and experiences of people with disability. We hope that this will include a person living with dementia or a carer of a person living with dementia and would be happy to promote this opportunity to our Dementia Advocates in Tasmania.

With respect to the functions of the Disability Inclusion Advisory Council, we recommend expanding point 20 (e) to include evaluation and monitoring of the success of the Act and contribution to future legislative review.

It would also be beneficial to ensure that there are accessible channels established for people with disability, including people living with dementia, to provide feedback to the Disability Inclusion Advisory Council about their experiences with inclusion, Disability Inclusion Plans and with defined entities.

Disability Inclusion Commissioner

Dementia Australia supports the appointment of a Disability Inclusion Commissioner and the requirement for the Commissioner to be a person living with disability.

With respect to the functions and powers of the Commissioner, point 24 (f) and point 25 could be strengthened by outlining how failures of defined entities to comply with the Act would be dealt with under the Act.

Restrictive Practices

We note that the functions and powers of the Senior Practitioner include the authorisation of restrictive practices by disability services providers as well as oversight of restrictive practices in accordance with the Act.

It would be beneficial to clarify how the functions and practices of the Senior Practitioner apply in relation to people with disability who are subject to restrictive practices in the mental health, health and aged care systems.

Many people living with dementia experience changed behaviours as their dementia progresses. Changed behaviour needs to be understood as a response to the person's environment and a form of communication about an unmet need. This unmet need might be physical, psychological or emotional. Interventions should target the causes of the behaviour, rather than the resultant behaviour itself.⁸

⁸ <https://www.dementia.org.au/sites/default/files/2021-10/PS-Restrictive-Practices-ver1.pdf>

Despite consistent evidence of their limited efficacy and a high associated risk of adverse effects, psychotropic medications are still widely inappropriately prescribed for people living with dementia.

Dementia Australia strongly supports minimising the use of chemical restraint in people living with dementia, as well as inappropriate use of other restrictive practices. People living with dementia have the right to freedom of movement, independence and autonomy while being safe and free from harm.

With respect to the Tasmanian Disability Inclusion Bill, it would be beneficial to outline how the role of Senior Practitioner will interface with other regulatory systems including the Aged Care Quality and Safety Commission.

Thank you for the opportunity to provide feedback on the draft Tasmanian Disability Inclusion Bill 2023. We are grateful for your consideration of our submission and would be happy to discuss any of these issues raised in further detail.