



ACT Disability Inclusion Bill

Dementia Australia Submission

March 2024

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Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated 400,000 Australians living with dementia, and the more than 1.5 million people involved in their care. We advocate for positive change and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible. Founded by carers more than 40 years ago, today we are the national peak body for people living with dementia, their families, and carers.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

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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 2024, it is estimated there are more than 421,000 people living with all forms of dementia in Australia. This number will continue to grow to more than 812,500 by 2054.¹

In 2024, it is estimated there are almost 5,900 people living with all forms of dementia in the ACT. This figure is projected to increase to almost 12,300 by 2054.² In the ACT, there are an estimated 430 people living with younger onset dementia, which is dementia diagnosed before the age of 65.³

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. It is now also recognised that

¹ Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

² Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

³ Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

dementia affects individuals across the lifespan including children, teenagers, and young adults. There are over 100 rare genetic conditions that can cause childhood dementia.⁴

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.⁵

Dementia or 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, foetal 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 difficulties.⁶

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.

“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...” - Carer

Introduction

Dementia Australia supports the principles and objectives outlined in the ACT Disability Inclusion Bill 2024. Our commitment to fostering an inclusive environment and supporting care providers is pivotal in ensuring that individuals with disabilities, including those with dementia, are not further disadvantaged by their environment. This submission outlines our support for the Bill, emphasising the importance of adopting a social model of disability, ensuring high-quality life of life for people with disabilities, and advocating for specific considerations and inclusion of individuals with dementia.

We endorse the social model of disability, which recognises that societal barriers, and not just the physical or medical condition itself, disables individuals. It is imperative that the ACT Government's efforts through this bill focus on dismantling these barriers, enabling all individuals, including those living with dementia, to be supported to live as well as possible, with dignity and independence. The quality of care provided, and the physical and social environment, play a crucial role in this context. Dementia Australia encourages a concerted focus on these considerations in creating a supportive environment and community that empowers people living with dementia.

⁴ Childhood Dementia Initiative (2024). <https://www.childhooddementia.org/>.

⁵ Dismantling Dementia Discrimination (2022). <https://www.dementia.org.au/sites/default/files/2022-09/DAW-Policy-Piece-Dismantling-dementia-discrimination.pdf>

⁶ Dementia Australia, 'What is dementia?', (2022), <https://www.dementia.org.au/about-dementia/what-is-dementia>

Discrimination and human rights approach

Discrimination remains a significant barrier to inclusion. Feedback from people impacted by dementia highlight the prevalence of discrimination faced by individuals with dementia.

“Discrimination means ignoring someone as though they are invisible or being treated as someone too stupid to follow a conversation or simple requests.” -Carer of a person living with dementia

“Discrimination means when other family members and friends choose to alienate or leave out that person with dementia in social situations.” -Carer of a person with dementia

A human rights-based Disability Inclusion Bill is essential for the ACT community. As part of our commitment to human rights, Dementia Australia notes that the aged care sector's shift towards a human rights approach in care and support and believes that this should be reflected in the provisions of this bill. Protecting older ACT citizens from discrimination, and fostering dignity and autonomy, should underpin all aspects of the provision of support and care for older people. It is imperative that older people's rights and the principles of choice and control (including self-determination, consumer-directed care, and self-management) are reflected consistently in aged care policy, guidance material and decision-making and in the Bill itself.

Dementia friendly design

Dementia Australia works towards to the creation of dementia-friendly communities. Dementia-friendly communities are places where people living with dementia are supported to live a high quality of life with meaning, purpose, and value. They are places where people with dementia are understood, respected and supported, and confident they can contribute to community life.

Dementia progressively impacts on people's cognition, thinking, mobility, emotional and social skills. In a dementia-friendly community people will be aware of and understand dementia, people with dementia will feel included and involved, and they will have choice and control over their day to day lives.⁷

Dementia Australia's research has found that people living with dementia and their carers are significantly more lonely than other members of the community.⁸ People living with dementia want our communities to be more dementia-friendly, and to them to continue to live well and to be involved in the activities they enjoyed before diagnosis.

The ACT Disability Inclusion Bill has the potential to significantly improve the quality of life for individuals with dementia by focussing on removing barriers to accessibility and inclusion.

⁷ Dementia Australia (2014) [A Guide to Becoming a Dementia-Friendly Community.](#)

⁸ Dementia Australia (2019) [Creating Dementia-Friendly Communities – Community Toolkit.](#)

This includes support for the creating environments and communities that are navigable, accessible, safe, and supportive of their needs.

Dementia-friendly communities aim to improve access to social engagement, health, and care services to enable people living with dementia to continue living at home. This includes the physical environment, such as signage, lighting and colours, and access to convenient transport.⁹ There are many features of built design that can make the community more dementia-friendly.¹⁰

These features include:

- Affordable, accessible transport.
- Conveniently located community venues.
- Public areas and parklands being clean, well-kept, and pleasant.
- Plentiful outdoor seating which is safe and well maintained.
- Undercover areas in parklands to ensure accessibility in all weather conditions.
- Footpaths being wide, level where possible, non-slip, well maintained and free of obstructions.
- Bicycle paths being separate from footpaths and pedestrian walkways.
- Adequate number of pedestrian crossings which are functional for people with different levels and types of disability, with non-slip markings, visual and audio cues, and sufficient crossing times.
- Visual landmarks in place to assist with wayfinding, such as garden beds, murals, water fountains and features.
- Adequate and evenly distributed street lighting to assist those with dementia and lower visual acuity.
- Level changes are clearly marked and well lit, with handrails and non-slip, non-glare surfaces.
- Building entrances being clearly visible and obvious.
- Buildings being well-signed outside and inside, with sufficient seating and toilets, accessible elevators, ramps, railings and stairs, and non-slip floors.
- Indoor and outdoor public toilets being well-maintained, clean, accessible, and adequate in number with appropriate signage.
- Bus shelters having enclosed and adequate seating.
- Street clutter including excessive signage, music, advertisements, and bollards being minimal.
- Background noise being minimal with acoustic barriers such as trees, hedges and fencing in place, and grass rather than hard surfaces.
- Signs having large graphics and symbols in clear colour contrast to the background, preferably dark lettering on a light background.
- Signs having non-glare lighting and non-reflective coverings.
- Quiet space being available for someone who might be anxious or confused.

⁹ Dementia Australia (2019) [Creating Dementia-Friendly Communities – Community Toolkit.](#)

¹⁰ Dementia Australia (2019) [Creating Dementia-Friendly Communities – Community Toolkit.](#)

We encourage consideration of these elements in the Bill and urge health, planning and design and related departments and services, and other relevant government agencies, to recognise the importance of environments and services designed to promote the participation and engagement of individuals with dementia.

Training and education

Dementia Australia recommends the incorporation of dementia-specific education for healthcare providers, caregivers, and the broader community. This education should focus on understanding dementia, effective communication strategies, and how to support individuals with dementia to live well. We see the provision of dementia education as a core part of the endeavour to improve awareness and understanding of dementia and reduce stigma and discrimination in the health and aged care sector and broader community. Support for this broad objective should be reflected in the Bill and enacted in policy and service provision.

Consultation and participation

The Bill emphasises the importance of consulting with people with disabilities in the development and implementation of inclusion strategies. This means that individuals with dementia, along with their families and carers, should have opportunities to contribute their experiences and perspectives, ensuring that strategies and plans are responsive to their unique challenges.

We recommend that the requirements for consultation 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 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 called **Half the Story**. Meaningful engagement means seeking out, affirming, and ratifying the voices of people living with dementia, families, and carers to understand the full story.

Meaningful engagement requires us to remove or reduce the barriers that prevent people from participating. Meaningful engagement requires an approach that respects the dignity and human rights of everyone, recognising their knowledge and skills, amplifying their voices, and involving people in decisions that will affect their lives.

The Disability Inclusion Bill 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.

Support for carers

Carers and family members undertake a critical role in supporting individuals with dementia. Dementia Australia advocates for provisions that offer them adequate support, resources, and recognition within the Bill. This includes access to respite care, financial support, and inclusion in decision-making processes.

Broadening priority inclusion areas

It is essential that the priority inclusion areas identified within the Bill encompass sectors critical to the inclusion of people with dementia. Employment opportunities for individuals with younger onset dementia, protection against discrimination, and access to appropriate supports are areas that need urgent attention. Addressing stigma and changing community attitudes towards dementia and ageing are fundamental to creating a truly inclusive society. Additionally, the unique challenges faced by individuals living in regional, rural, and remote areas must also be considered. Distance and lack of access to support services exacerbate the barriers to inclusion for people with dementia in these regions. Investment and tailored strategies are needed to ensure that the objectives of the Bill are realised uniformly across the ACT, regardless of geographical location.

Disability Advisory Council

Inclusive representation matters. Appointing people living with dementia or an expert in dementia care to the Disability Advisory Council will ensure that the strategies and actions proposed under the Bill consider the specific and nuanced needs of this group. Australia is a signatory to the Charter of Human Rights Act and an inclusive approach to Advisory Council appointees would reinforce the Bill's commitment to a human rights-based approach to disability.

Additionally, clear accountability mechanisms within the Disability Advisory Council are essential for the effective development and implementation of disability inclusion plans. The annual report should detail the outcomes achieved, actions taken to address any shortcomings, and the ongoing process of engagement and consultation with the disability community, including individuals with dementia.

Conclusion

In conclusion, our submission underscores the importance of including people living with dementia and their family members and carers within the ACT Disability Inclusion Bill 2024. By incorporating a human rights-based approach, enhancing consultation processes, ensuring genuinely inclusive representation, and addressing the unique needs of people with dementia, we can work towards a more inclusive and supportive society for all individuals with disabilities.

We welcome the opportunity to contribute further to the development and implementation of this legislation.