



A Dementia Australia submission on the proposed Disability Inclusion Bill for Victoria

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Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the estimated half a million Australians living with dementia and 1.6 million people involved in their care.ⁱ 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. There are estimated to be up to half a million Australians currently living with dementia and around 1.6 million people involved in their care. Without a significant medical breakthrough, it is estimated that there will be almost 1.1 million people living with dementia by 2058.ⁱⁱ

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 '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.ⁱⁱⁱ

“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)^{iv}

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 current 2006 Disability 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. We selected key questions from the Disability Inclusion Bill 2022 Exposure draft overview and surveyed over one hundred Victorian Dementia Advocates. People living with dementia, former and current carers were equally represented in the survey responses and their observations, in addition to other forms of Advocate feedback, form the basis of our submission.

Part 1: Purposes, Defined entities and Definitions

Dementia Australia is in broad agreement with the intent and purpose of the Victorian Disability Inclusion Bill and the principles of the 2008 UN-CRPD that underpin the proposed legislation. We believe the proposed changes to the 2006 Victorian Disability Act, the creation of a Disability Commissioner and changes to the membership and role of the Victorian Disability Advisory Council will assist in addressing dementia-related stigma and the associated discrimination that people living with the condition experience when interacting with organisations and entities identified in the Bill. The Bill 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 society.

Our survey respondents were unanimous in their support for a new principal Act for Victoria relating to disability inclusion.

“A new & modernised Victorian legislation bill for disability inclusion is long overdue!”

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 and ‘ ... whether or not the impairment or limitation is permanent, temporary, episodic in nature *or evident*’ (our italics). While acknowledging the inclusive intent of the proposed definition of disability, we believe there is a strong argument for wording in sections of the legislation to specifically acknowledge and emphasise the unique circumstances and needs of people living with dementia as reflected in the Advocate observation below. These suggested changes are outlined in the relevant sections of our submission.

“I sincerely consider, that specific protection, should be included, for people experiencing dementia 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, which would also arguably reduce the strain on the public health system.”

Dementia Australia endorses the purposes, and the endeavour to encompass a wider range of government and defined entities, in the new Bill. As identified in the exposure draft,

support and education will be critical in encouraging newly included entities to conform with the requirements of the Disability Inclusion Bill. As a number of our Advocates observed, rigorous monitoring and evaluation will also be key to ensuring the efficacy of the disability inclusion requirements for these entities.

‘Yes I do as long as government departments are thorough and follow these consistently to protect the most vulnerable people in society.’

Reinforcing the issues outlined in our introduction in relation to the lived experience of dementia-related stigma and discrimination, Advocates also supported an expanded definition of entities to include smaller organisations or groups as reflected in the following responses.

“Why should entities only consist of 50 people or more? Let's disregard this definition and, “included all entities to be inclusive of people living with a disability” under a new disability inclusion bill.”

“No, I think it should cover every employee an employer can take advantage of small number of employees long before it can take advantage of 50 or more people.”

Part 1: Objectives

Dementia Australia endorses the proposed objectives but with the following reservations in relation to objective (f). The wording currently specifies:

‘to promote the involvement of people with disability in the design of government and government-funded programs, services and policies that affect people with disability.’ We believe this objective is too modest in its wording and ambition and should aim for active consumer engagement in these programs, services and policy.

This objective could be reflected and enacted through more forceful language, for example:

‘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.’

This would also ensure that this objective aligns with the inclusion principle that follows in the next section of the Bill that states that:

‘People with disability offer valuable expertise in the design of programs, services and policies that affect people with disability.’

Part 1: Inclusion principles

Dementia Australia supports the intent and requirements of the proposed inclusion principles, noting that they are underpinned and informed by the UN-CRPD, amongst other foundational documents. We understand that the remit of the Bill is restricted to the new entities as in the proposed definitions, but we include the following comments from our Advocates to reflect their ongoing concern with the way in which people living with dementia, their carers and family members, experience stigma and discrimination in interacting with the community including small businesses, groups and organisations.

“The inclusion principles reflect human rights and the current social mores in the workplace, so I believe that they are appropriate. However, I do not see it as reflective of the social environment in which people live as members of society e.g. when a person with dementia is being served in a small shop, what in the Act protects their dignity of treatment? How do we as a society treat those with a disability? And that too should be enshrined in an Act for it to be reflective of the protection/respect of all citizens.”

“I think increased inclusiveness, should include companies. I don't consider, that the 'private world', should be excluded, from increased inclusiveness.”

“The Act is very much directed at those who are employed but the reality is that many people simply interacting with those organisations and who have a disability are not treated with respect or consideration. What about a shopping complex that is only managed by a relatively small number of people but in which many people with a disability are interacting?”

Part 2: Duty to promote disability inclusion

Dementia Australia supports the definition of ‘a new duty’ to actively promote disability inclusion for the relevant government bodies and other entities outlined in the proposed new Bill. We note with some concern conditions associated with clause 2. This requires that when entities are consulting or engaging with people with disability, they are only required to provide communications ‘... in at least one accessible format (such as Auslan or Easy English).’ We believe this is too limited, thereby allowing for potential exclusion and discrimination. If for example, communications were only provided in Auslan, this would potentially discriminate against people with a cognitive disability, including those living with dementia. We would endorse a requirement for entities to provide communications in a *range of accessible formats* that at a minimum, accommodates the needs of people with vision, hearing and cognitive impairments.

Part 3: Disability Impact Assessments

Our Advocates uniformly supported the concept of Disability Impact Assessments and Dementia Australia therefore broadly endorses the role and importance of the proposed Assessments in ensuring that entities are genuinely inclusive. However, we make the following observations and recommendations.

In relation to Part 3 (1), we would like to see a specific reference to the disability impact assessment being *conducted in consultation with persons with a disability* as follows:

A defined entity must conduct a disability impact assessment, in consultation with persons with disability, when developing or reviewing any policy of, or program or service provided by, the entity that has a direct and significant impact on the public.

In relation to Part 3 (2) a) b) and c), we would like to see a specific reference to the requirement to engage in meaningful consultation with persons with disability as follows:

(2) A disability impact assessment must involve meaningful consultation with persons with a disability to -

(a) assess the effects that the policy, program or service may have on persons with disability; and

(b) state how the policy, program or service will be developed or varied in order to— (i) ensure accessibility; and (ii) promote universal design; and (iii) reduce, remove and prevent barriers to disability inclusion; and (iv) promote disability inclusion; and

(c) to the extent practicable, take into account any barriers to disability inclusion that may be compounded by intersectionality.

We warmly recommend Dementia Australia’s recently developed resource **Half the Story** as a valuable guide for how to conduct meaningful consultation with people with dementia, their families and carers.

Part 4: State Disability Plan and Disability Action Plans

Our Advocates were strongly supportive of the proposed State Disability Plan and the entity-specific Disability Action Plans.

“I consider that DAPs are positive. DAPs may go some way to ensure access and inclusion barriers for people with disability, are addressed.”

As noted in the introduction, a number of Advocates emphasised that the efficacy of both would depend to a significant extent on regulatory measures, including rigorous monitoring and evaluation of the plans. In relation to the State Disability Plan, there was strong support for an annual rather than bi-annual reporting process, as reflected in the comments below.

“I believe the bills reporting process should be at least one a year. That way everyone is 'held accountable' for the betterment of people living with disabilities.”

“2 years too long - should be a minimum of 6 months and max of 12 months.”

Part 6: Commissioner for Disability Inclusion

Our Advocates supported the need for a Commissioner for Disability Inclusion and the requirement for the appointment to be someone living with a disability.

“I consider that it is a very positive and validating step, to appoint a Commissioner for Disability inclusion.”

“Love the idea that the commissioner has a disability or be personally familiar with disability.”

Part 7—Victorian Disability Advisory Council

Dementia Australia believes the Victorian Disability Advisory Council has played an important role in promoting disability inclusion in this state. In relation to Section 50, our Advocates support the proposed changes to the constituency of council membership, including the stipulation that 75 per cent of members must have lived experience of disability and that membership must be drawn from socio-culturally and geographically diverse communities. However, we would go further in terms of improving representational diversity and strongly

recommend that the Council includes at least one person with a cognitive disability. People with 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 challenges.

Conclusion

Dementia Australia is grateful for the opportunity to make a submission to this important consultation in relation to the proposed Victorian Disability Inclusion Bill. We thank you for considering our submission and we would welcome further opportunities to discuss the issues and recommendations raised in this submission.

ⁱ Dementia Australia (2018). Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra.

ⁱⁱ Dementia Australia (2018). Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra.

ⁱⁱⁱ 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/>

^{iv} Dementia Friends & Dementia Friendly Communities Program. Exploratory report, Kantar Consultants, 2019