

National Disability Strategy Governance and Engagement Section
Department of Social Services
Via email disabilityreform@dss.gov.au

20 October 2020

To whom it may concern,

Re: A new National Disability Strategy – Stage 2 consultations

Dementia Australia welcomes the opportunity to comment on the proposed architecture of the new National Disability Strategy (the Strategy) as outlined in the Position Paper. Dementia Australia is supportive of the proposed architecture of the Strategy, including the vision, the six outcome areas and the guiding principles. Our response addresses the importance of engaging people with disability and their carers, including a focus on community attitudes, and ensuring transparency and accountability is embedded in the Strategy.

Dementia is a disability

In 2020, there are an estimated 459,000 Australians living with dementia, including almost 28,000 people with younger onset dementia (dementia diagnosed under the age of 65). Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.

Dementia is the term used to describe the symptoms of a large group of 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.

Although dementia is commonly perceived to be an age-related illness, it is not a normal part of ageing. Dementia is more common in older people but it can affect people in their 40s, 50s and even their 30s. Dementia is a terminal condition and there is currently no cure.

It is generally not well understood that dementia is a progressive cognitive disability. Dementia is the single greatest cause of disability in older Australians (those aged 65 and over) and the third leading cause of disability overall.

Involvement and engagement

Dementia Australia supports the involvement and engagement of people with disability at all stages of the Strategy process. It is also important to engage carers and families – for people living with dementia, carers and families become increasingly important as an advocate as dementia progresses. An engagement strategy is therefore essential to facilitate the participation of people with lived experience from strategy design through to implementation and evaluation.

Dementia Australia would welcome the opportunity to participate in the Strategy processes and facilitate the involvement of people impacted by dementia through the Dementia Advocates program. The Dementia Australia [Dementia Advocates Program](#) provides an opportunity for people living with dementia, carers and former carers to share their stories, identify current issues and positively effect change.

Community attitudes

Dementia Australia supports the focus on engaging the broader community and supports the proposal for the new Strategy to have a stronger emphasis on improving community attitudes across all outcome areas.

Improving community attitudes and understanding of disability, including less recognised disabilities such as dementia, is critical. Indeed, community misunderstanding, stigma and discrimination impact significantly on people living with dementia, their families and carers.

In 2019 more than 5,000 people from across Australia completed a survey to help Dementia Australia better understand how discrimination for people living with dementia occurs and what it would take to end discrimination. Key findings included:

- 63% of people living with dementia who responded to the survey believe discrimination against people living with dementia is common or very common;
- 73% of family, friends or carers of people living with dementia who responded to the survey believe discrimination against people living with dementia is common or very common;

- More than 90% of professionals, volunteers and people not impacted by dementia who responded to the survey believe people living with dementia were likely to be treated differently once they are diagnosed.¹

Dementia Australia has developed campaign to combat discrimination of people with dementia, improve community knowledge and attitudes, and change behaviour toward people impacted dementia. Further information is available at <https://discrimination.dementia.org.au/>

Dementia Australia also operates the Dementia Friendly Communities program which aims to address the stigma, isolation and discrimination experienced by many people living with dementia through the development of inclusive communities that enable people living with dementia to live well. A dementia-friendly community:

- Involves people living with dementia.
- Challenges discrimination and builds an understanding of dementia.
- Supports accessible community activities for people living with dementia.
- Acknowledges the potential of people living with dementia.
- Engages people living with dementia, and their carers, in community life.
- Offers community-based solutions to enable people to live independently.
- Promotes easy-to-navigate environments.
- Enables accessible and responsive businesses and services.

Further information is available at <https://www.dementiafriendly.org.au/>

The National Disability Strategy could build on the achievements of local accessible and inclusive community initiatives by providing local governments and organisations with resources and integrating their activities with measures at other levels of government.

Transparency and accountability

The review of the previous Disability Strategy found that the “implementation of the Strategy had been uneven, and a consistent, systematic approach to implementation across Australia had been absent.”² It also found that no one was truly accountable for its implementation and there was no real mechanism for measuring its impact.

¹ Dementia Australia (2019) *Dementia Action Week Discrimination Survey 2019*

² Davy, L., Fisher, K.R., Wehbe, A., Purcal, C., Robinson, S., Kayess, R., Santos, D. (2019) *Review of implementation of the National Disability Strategy 2010-2020: Final report*. (SPRC Report [4/19]). Sydney: Social Policy Research Centre, UNSW Sydney



With this in mind, there is a need for clearly defined roles and responsibilities for each government and other key stakeholders in the new Strategy to overcome the current confusion. Likewise, transparency and clear communication on the Strategy's progress to the public is needed, at least yearly.

It is necessary to have targeted action plans to ensure action and accountability for the implementation of the Strategy. There also needs to be a clear mechanism for evaluating its impact and an evaluation framework must be designed and implemented.

Dementia Australia looks forward to the new National Disability Strategy and to working with key Government and disability sector stakeholders to improve outcomes for people living with dementia, their families and carers. We would welcome the opportunity for further consultation as the development of the new strategy progresses including supporting the National Disability Strategy Governance and Engagement Section to consult with people living with dementia and carers.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Maree McCabe", written in a cursive style.

Maree McCabe

CEO Dementia Australia