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Review of the Disability Inclusion Act (NSW)

A response from Dementia Australia

March 2020

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people of all ages impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we can advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people of all ages living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.



Introduction

Dementia Australia welcomes the opportunity to provide a submission to the review of the Disability Inclusion Act (NSW). Our submission responds to questions 3-7 posed in the discussion paper that informs the review.

Dementia is the term used to describe the symptoms of a large group of conditions which cause a progressive decline in a person's functioning. Symptoms include; loss as well as changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning.

Dementia is one of the largest health and social challenges facing Australia and the world. In 2020, there is an estimated 459,000 Australians living with dementia. This includes 27,800 people living with younger onset dementia – which is a diagnosis of dementia under the age of 65. Younger onset dementia can impact people in their 50s, 40s or even as early as their 30s. By 2058 the number of people with younger onset dementia is expected to rise to 41,250.¹ Dementia is the single greatest cause of disability in Australians over the age of 65 years, and the third leading cause of disability burden overall.²

In NSW alone, there is an estimated 153,000 people living with dementia, including 8,990 people living with dementia under the age of 65.³

Whilst a dementia diagnosis is upsetting for anyone, people with younger onset dementia may still be in employment, have financial responsibilities, and have families who they are providing for. As such, receiving a diagnosis of younger onset dementia can be a particularly upsetting time for the individual and their wider family and network of friends.

Unlike many disabilities, dementia is not necessarily a visible condition and often people with a diagnosis can still be physically well. Without sufficient awareness of dementia, the 'invisibility' of dementia symptoms can make it difficult for communities to recognise the challenges that a person with dementia faces, understand their symptoms or know how to respond to them. Consequently people with younger onset dementia often receive less acknowledgement and support in their communities compared to individuals with other, more visible, disabilities.

People with dementia of all ages also experience discrimination and often report feeling socially isolated from their communities as a result of their diagnosis. A recent Dementia Australia survey found that a quarter of respondents felt uncomfortable communicating with people living with dementia, and were concerned that they would say the wrong thing.⁴ A general lack of knowledge of dementia also contributes to individuals avoiding engagement with people with dementia.

Tackling discrimination of people living with dementia, and increasing community inclusion of people with a cognitive impairment, is integral to improving the quality of life of younger people living with dementia, their families and carers. Dementia Australia therefore supports

¹ Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra

² Australian Institute of Health and Welfare (2012) Dementia in Australia

³ Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra

⁴ Dementia Australia (2018) Inclusion and Isolation: the contrasting community attitudes to dementia

the intentions of the NSW Disability Inclusion Act – a piece of legislation that is integral to improving the lived experiences of people with a disability in NSW.

This submission focuses on the NSW Disability Inclusion Plan (DIP) and subsequent Disability Inclusion Action Plans (DIAPs), which are directed under the Act. Dementia Australia's primary concern is the need for increased recognition of people living with a cognitive disability, such as people living with younger onset dementia – who are often overlooked as their disability is not always physically visible in communities – and our submission highlights how the NSW Disability Inclusion Plan can be adapted to better respond to the needs of younger people with dementia in NSW.

Dementia Australia makes the following recommendations:

1. The NSW DIP must acknowledge the unique challenges faced by people with different types of disability, including the barriers faced by people with an 'invisible' cognitive condition like dementia. Raising awareness of dementia and promoting dementia friendly communities would improve the experiences of people with younger onset dementia.
2. The NSW DIP should reference the dementia-friendly community resources, produced by Dementia Australia, to support the development of dementia inclusive communities in NSW.
3. The NSW DIP should create an action to develop 'Employer Guidance on supporting people with a cognitive disability in the workplace'. Guidance could include:
 - Policies that support people with a cognitive impairment, such as dementia-friendly workplaces and environmental adaptations, staff education on dementia, and promotion of dementia awareness and activities in the workplace.
 - Supporting employees with cognitive disability/dementia to transition out of the workplace.
 - Providing supports to carers of people living with dementia.
4. The NSW DIP includes a specific action to deliver meaningful activities, such as volunteering, for individuals with dementia who are transitioning out of work.
5. A NSW register of organisations with an implemented DIAP should be used to track disability friendly organisations and to facilitate information sharing on good practice between organisations.

Reviewing the NSW Disability Inclusion Plan (DIP)

Question 3: Are the provisions relating to the State Disability Inclusion Plan still correct and relevant? Do you think a State plan is necessary, and if so, what do you think is most important to be included in the plan?

Whilst the NSW DIP has progressed objectives to reduce discrimination and increase inclusivity for people with a disability, many people living in NSW still experience isolation and discrimination as a consequence of their disability. People living with younger onset dementia frequently report this to be the case.

Dementia Australia is concerned that the NSW DIP does not adequately acknowledge the needs of people with a cognitive disability, in the same way that physical and intellectual disabilities are considered. Objectives 1, 2 and 4 of the DIP provide a good framework for improving inclusion for people with dementia.

Objective 1: Developing positive community attitudes and behaviours

People living with younger onset dementia frequently report to us that since receiving their diagnosis they have lost social connections with friends and even family members, leaving them feeling socially isolated and lonely. Many also report feeling disempowered as people avoid engaging with them because of their condition.

In 2018, Dementia Australia conducted a national survey to understand why discrimination against people living with dementia occurs and what it would take to shift attitudes and behaviours towards individuals living with dementia.⁵ Responses were received from over 1500 people across Australia – with 32% of respondents from NSW. A quarter of respondents indicated that they were uncomfortable around people with dementia, while almost half of respondents said that they were unsure how to talk to someone with dementia, indicating that they were concerned the person with dementia would get upset, or that they would say the wrong thing.

It is clear that people's attitudes, perceptions and understanding of the nature of dementia can determine how a person with dementia is treated in society. Dementia must be normalised in society by emphasising the retained abilities of a person diagnosed with dementia and their capacity to participate in social and community life.

The NSW DIP can support the inclusion of people with a cognitive disability, by acknowledging the unique challenges faced by people who have an 'invisible' disability and promoting education of dementia and other cognitive impairments.

Recommendation 1: The NSW DIP must acknowledge the unique challenges faced by people with different types of disability including the barriers faced by people with an 'invisible' cognitive condition, like dementia. Raising awareness of dementia and dementia inclusive communities would improve the experiences of people with younger onset dementia.

Objective 2: Creating liveable communities and improving access to mainstream services through better systems and processes

As the disabilities of people with younger onset dementia are not necessarily overtly physical, communities may not recognise the challenges that a person with dementia faces or know how to respond to them.

To support communities to adopt inclusive practices, Dementia Australia developed the Dementia-friendly Communities initiative. A dementia-friendly community encourages organisations, businesses, community groups and individuals to make practical changes that will have a positive impact on the lives of people living with dementia and their carers. As such, in a dementia-friendly community people will be aware of and understand dementia,

⁵ Dementia Australia (2018) Inclusion and Isolation: the contrasting community attitudes to dementia

and people with dementia will feel included and involved, and have choice and control over their day-to-day lives’.

Recommendation: The NSW DIP reference the Dementia-Friendly Communities resources to support the development of dementia-friendly communities in NSW.

Objective 4: Supporting access to meaningful employment

Many people in the early stages of dementia are able to, and want to, continue working after they have been diagnosed with dementia. Employment can provide a sense of purpose and meaningful activity to individuals with dementia. For younger people with dementia, who may have significant financial commitments, continuing employment for as long as possible is important.

As dementia progresses, individuals often find many aspects of working increasingly difficult. For example, the physical environment of the workplace may be too noisy and disorienting, or individuals may find managing work demands and relationships increasingly challenging. Consequently, many people are unable to continue working beyond their diagnosis of dementia.

To enable people with dementia to remain at work and transition out of work into meaningful social activity, it is critical that the following areas be addressed.

- 1. Stigma of dementia:** Many people with dementia enjoy working as it provides stimulation and a sense of identity. In some cases, people with dementia will avoid discussing their condition with their employer as they believe it will negatively impact on their job and potentially lead to discrimination. Employers can support individuals with dementia by promoting a disability friendly working environment where employees feel able to disclose their condition. Outlining the support options available to employees and promoting awareness of conditions like dementia in the workplace will help to reduce stigma in the workplace.
- 2. Transitioning out of work:** Retirement can be a daunting prospect for those who are not prepared for it. Employers can help people with dementia by supporting a gradual transition out of work, and providing employees with dementia options for meaningful activities that are suited to their changed abilities. For example, employers could enable people to reduce their hours at work over a period of time or change their role in an organisation, so the individual is able to manage their role with their changing cognitive function. The State Plan could also introduce volunteering programs which provide meaningful activity for individuals who are no longer able to participate in paid employment.
- 3. Supporting carers of people with dementia:** Carers of people with dementia may be required to significantly reduce their hours of employment, or end employment altogether, to manage their caring responsibilities. This can pose additional financial strain on the families of people with younger onset dementia, and can also trigger a loss of independence for the carer. Employers can help support carers by adopting policies that enable individuals to balance their work and caring responsibilities. For example, offer carers flexible working arrangements, carers leave or career break opportunities.

A report by Carers UK provides useful recommendations for employers to facilitate better supports to employees who are caring for people with dementia.⁶ The report highlights

⁶ Carers UK (2014) Supporting employees who are caring for someone with dementia

that carer wellbeing is positively impacted by the development of carer networks, which enhance social connectedness amongst carers in the workplace. The report also recommends that employers can improve the overall wellbeing of carers by signposting individuals to relevant supports or delivering wellbeing programs which cover topics, such as balancing work and caring duties, looking after carer health and wellbeing.

Recommendation: The NSW DIP should create an action to develop ‘Employer Guidance on supporting people with a cognitive disability in the workplace’. Guidance could include:

- Policies that support people with a cognitive impairment, such as dementia-friendly workplaces and environmental adaptations, staff education on dementia, and promotion of dementia awareness and activities in the workplace.
- Supporting employees with cognitive disability/dementia to transition out of the workplace.

Recommendation: The NSW DIP includes a specific action to deliver meaningful activities, such as volunteering, for individuals with dementia who are transitioning out of work

Disability Inclusion Action Plans (DIAPs)

Question 4: The Sax Institute review reported on NSW Government agencies and local government DIAPs. Should the Act cover more than just NSW Government agencies and local government, DIAPs? If so, what other groups do you think should be required to have a DIAP?

The Sax Institute review highlights the positive impacts that the adoption of organisational Disability Inclusion Action Plans (DIAPS) has had on the delivery of inclusive practices in multiple organisations.⁷ This is undoubtedly a positive outcome, and Dementia Australia would encourage all businesses and organisations to consider implementing a DIAP to improve inclusivity.

Dementia Australia therefore supports that all NSW business and organisations should implement a DIAP and receive supports from the State to help them achieve this goal. To encourage organisations to engage in this, a state-based register of disability-friendly organisations should be developed. Not only would this inform individuals with a disability about which local organisations are disability-friendly, but organisations participating in DIAPS could benefit from information and idea sharing with other similar organisations.

Recommendation: A NSW register of organisations with an implemented DIAP should be used to track disability friendly organisations and to facilitate information sharing on good practice between organisations.

Question 5: Are DIAPs effective in achieving greater community participation and inclusion for people with disability? If not, how do you think they could be made to better to ensure participation and inclusion of people with disability?

⁷ Dawson G, Tait H, Redman A, Drinkwater A, Dickinson S, Smith-Merry J. Review of the NSW Disability Inclusion Plan 2018. A report by the Sax Institute and the Centre for Disability Policy and Research for NSW Family and Community Services Sydney, 2019

The Sax Institute report highlighted that individuals with an ‘invisible illness’ such as a cognitive impairment or mental health issue, still experience bullying and discrimination in the workplace. This aligns with what people with younger onset dementia tell us about their experiences of exclusion and isolation in the community and in the workplace.

In order to achieve greater participation and inclusion of people with a disability, DIAPs must first acknowledge the different types of disabilities, and understand what types of supports are needed to enable individuals with a physical, intellectual and cognitive disability. Unlike people with a physical disability, people with dementia may be physically well, however they may experience challenges navigating their community or engaging socially.

Understanding and responding to the challenges faced by people with cognitive disability requires community engagement. As such, DIAPs should be co-designed with individuals with dementia, their carers and families.

Question 6: What improvements, if any, could be made to help agencies prepare their DIAPs? What are the steps you think they should be required to complete before drafting their plans?

Access to sufficient resources to help develop and implement an Action Plan was a key theme that came out of the Sax Institute Review. Dementia Australia provides a number of evidence based resources for communities and employers to support the implementation of dementia-friendly environments, and we recommend these resources be promoted by the NSW Government to assist communities. As noted in the future considerations highlighted in the Sax report, effective collaboration and knowledge sharing is critical to the implementation of effective DIAPs. Engagement with Dementia Australia and other advocacy organisations can support the development of practical and achievable plans.

Authentic consultation with people with a range of disabilities is essential to the development of holistic DIAPs. However, some organisations may not have easy access to a people who are willing to consult, or people who represent different types of disability. In these instances, DIAPs will likely reflect a limited amount of views and experiences, and potentially overlook the needs of individuals who were not physically present to represent themselves. Engaging with people with dementia, either directly or through an advocate, would help to ensure that DIAPs reflect the needs of people living with dementia – or more broadly people living with a cognitive impairment, who may require adjustments that differ from individuals with a physical disability.

Dementia Australia supports the recommendation raised in the Sax report, to develop a ‘centre for excellence’ – a centrally owned resource that shares resources, materials and feedback that aligns to different disability types. This initiative would enable all organisations to develop DIAPs which align to the needs of all individuals with a disability – no matter what type of disability.

Question 7: Are the elements included in Disability Inclusion Action Plans still appropriate, or are there parts you think should be removed or added to make them more effective?

Dementia Australia supports the four focus areas identified in the Action plans. However, as stressed throughout this submission, the NSW DIP and DIAPs must acknowledge the

varying needs of individuals living with a cognitive disability, including people living with dementia.

Conclusion

Thank you for the opportunity to participate in this important consultation. Dementia Australia welcomes further discussions with the NSW Government to ensure the needs of people living with dementia are recognised within the NSW Disability Inclusion Act, and subsequent NSW Disability Inclusion Plan and Disability Inclusion Action Plans.