Dementia Australia™

# Promoting Inclusion

## A submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

7 April 2021

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# About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

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 across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

# Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in response to the Promoting Inclusion Issues Paper.

Our submission is informed by the lived experience of people living with dementia, their families and carers.

Dementia Australia advocates for improvements in policy, resources and service delivery to ensure equity of access to quality health, aged and disability services that are responsive to the needs of people with dementia, their families and carers.

Historically, people living with dementia have not experienced full inclusivity within society. However, the past decade has seen increased human rights recognition in the coming into force of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD requires people with disability (including people living with dementia) to enjoy the same rights as everyone else, including rights to autonomy in decision making, independent living, community inclusion, and liberty.

The challenge, however, is to shift attitudes, and design and deliver services that are flexible, innovative, appropriate and culturally safe to ensure people with dementia, their families and carers are well supported and included within the Australian community.

# Dementia in Australia

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.

Dementia is one of the largest health and social challenges facing Australia and the world. It is estimated that there are more than 459,000 Australians living with dementia in 2020[1] and around 1.6 million people[2] involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.[3]

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

[2] Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016, Department of Health; Dementia Australia (2018) Dementia Prevalence Data 2018–2058, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), Global estimates of informal care, Alzheimer's Disease International; Access Economics (2010) Caring Places: planning for aged care and dementia 2010–2050

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

Dementia is not a natural part of ageing. Although it is more common in older people, it can affect people in their 40s, 50s and even their 30s.[4] Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2020, there are an estimated 27,800 people with younger onset dementia. This number is expected to rise to almost 29,500 people by 2028 and more than 41,000 people by 2058.[5]

Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.[6]

It is not widely understood that dementia is a progressive cognitive disability. It is the single greatest cause of disability in older Australians (those aged 65 and over) and the third leading cause of disability overall.[7]

## The impact of younger onset dementia

Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2021, there are an estimated 28,300 people living with younger onset dementia in Australia. This number is expected to rise to 29,353 people by 2028 and 41,249 people by 2058.[8]

The misconception that dementia is a condition of old age contributes to, and exacerbates, multiple challenges experienced by younger people with a diagnosis of dementia. Overall, the experience for people with younger onset dementia – who often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family – is different from those diagnosed with dementia at a later stage of life. Loss of income, self-esteem and perceived future purpose can pose multiple physical and psychological challenges for people with younger onset dementia, their families and carers.

Younger onset dementia is difficult to diagnose, often taking three to five years and is under recognised, resulting in community ignorance and stigma. This can result in delays in accessing necessary supports and also means that dementia programs, designed for the frail aged, don’t fit the needs of people impacted by younger onset dementia, who are seeking to maintain active and engaged lives.

Younger onset dementia has a profound impact on individuals as well as their families, carers and friends. This cohort experience higher levels of unmet needs in many important areas of life, such as socialisation, intimate relationships, communication, memory, mobility, psychological distress and needs for information.

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[4] There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

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

[6] Australian Bureau of Statistics (2018) Causes of Death, Australia, 2017 (cat. no. 3303.0)

[7] Australian Institute of Health and Welfare (2012) Dementia in Australia

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

Most people living with younger onset dementia report experiencing one or more of the following:

- problems with language and forgetting words;
- losing track of time and place;
- impaired judgement, e.g.they may find it hard to drive a car or they may buy things they do not need;
- problems with abstract thinking, e.g. they may not know what the numbers on their bank statement mean;
- losing or misplacing things regularly; and/or
- changes in mood or behaviour.

The severity, type and frequency of these symptoms gets progressively worse over time, requiring an increased amount of support. Significant changes in needs can occur rapidly and without warning. People with younger onset dementia can also experience changes in personality, as well as having depression, anxiety, hallucinations and aggression.

The impact of dementia on younger people is quite different than the experience of older people with dementia. People living with younger onset dementia, their families and carers often face the following challenges:

- impact on employment as people are usually still in the workforce and may be the primary income earner (affecting a family's finances);
- disruptions or changes to family relationships and dynamics, especially carer 'burn out';
- isolation and a disengagement from everyday activities long before the condition requires them to; and
- difficulties accessing appropriate services and supports as they find themselves caught in the gaps between the disability and aged care systems.

People with younger onset dementia are required to navigate their way through multiple care systems as their dementia progresses. While people living with younger onset dementia are generally eligible to access the National Disability Insurance Scheme (NDIS), due to the progressive nature of their condition and need for increasing supports – which may not be available in the disability system – many people with younger onset dementia also require support from aged care services. As such, people with younger onset dementia are typically required to straddle both the aged care and disability systems – neither of which is currently fully equipped to respond to the complex needs of people living with younger onset dementia. Not only is it confusing to juggle two support systems, but the lack of a clear diagnosis and care pathway often results in people with younger onset dementia, their families and carers falling through the cracks.

## What makes an inclusive society?

People living with dementia have the human right to participate in all decisions which affect their lives and wellbeing. This is inclusivity and should be embedded throughout society regardless of whether a person has a dementia diagnosis.

One of the biggest barriers to a human rights approach to dementia is that it is still poorly understood by the community, including by many people working in the health, disability and aged care sectors. There is an obligation for all levels of government, health, disability and aged care sectors and their workforce to ensure people living with dementia are treated with the same dignity, respect and rights as everyone else.

An inclusive society allows for participation, respect and decision-making. It is more than equality of all humans, it is about equity of access and for all people to feel safe to meaningfully participate in and contribute to society.

> “The ability to be able to access the community and be involved in community groups and organisations. Being valued still, as a person, being respected and included. Being asked for my opinion and input.” – person living with dementia
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> “Inclusion means to me that I have the exact same rights as anyone else in society. That there are allowances and alterations, if required, in my society and environment to live alongside all other human beings. That people without disabilities value my rights to be able to live a normal life, as they do. That I have the same access to services as they do. That I should never have to explain why I need to be treated as everyone else.” – person living with dementia
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> “Being accepted, no matter what.” – former carer
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> “From a dementia perspective, inclusion means giving (better) recognition and acceptance of cognitive disability throughout societal structures, rules and behaviours, and making adjustments to support continuing participation in "life" and in the community.” – former carer

Specifically, what makes a society inclusive for people living with dementia, their families and carers is a community anchored in respect. Having a commitment to value all people as equal, irrespective of their abilities, and being pro-active in anticipating appropriate requirements to meet their needs. This can include building supportive environments through design, for example, signage, ramps, colours used for the interior of buildings etc; and supporting people to support those who need assistance - be it advocacy, help completing daily tasks or accessing information.

> “An inclusive community: * Does everything that it can to respect all its citizens, gives them full access to resources, and promotes equal treatment and opportunity; * Works to eliminate all forms of discrimination; * Engages all its citizens in decision-making processes that affect their lives; and * Values diversity.” – current carer

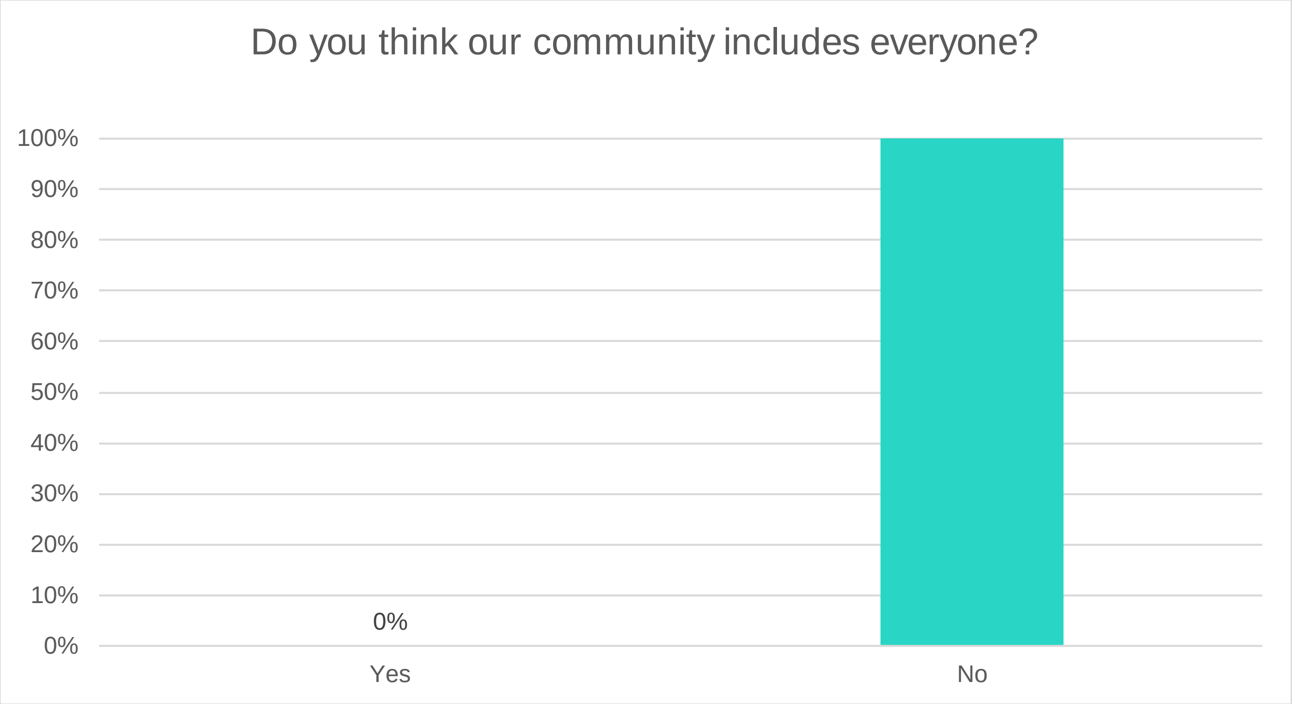
## Promoting an inclusive society and supporting people with disability to live free from violence, abuse, neglect and exploitation

Promoting an inclusive society is not simply about more funding. It is about collaboration within and across governments, sectors, communities, businesses and organisations. There needs to be prioritisation of:

- innovation – thinking outside the box to allow for dignity of risk;
- inclusion, participation and decision-making;
- training and building the capacity of the health, disability and aged care workforce to understand dementia and acquire the necessary skills, knowledge and capacity to deliver high quality dementia care;
- involving carers, families and advocates as partners in care and supporting them with decision-making and care planning;
- creating and delivering meaningful activities for people living with dementia to engage with or participate in;
- building supportive environments that are dementia-friendly and create a sense of homeliness, familiarity and participation;
- feedback and complaints systems that take people living with dementia seriously and facilitate their involvement; and
- building a culture that encourages an understanding of dementia and responding effectively to the needs of the person living with dementia, their families and carers.

> “Respect for the individual. By having an inclusive community that is accountable for its actions. By having strong advocacy assistance if needed. By ensuring quality standards are maintained in all care environments i.e. home care and residential care. By ensuring appropriate checks are made of all places providing care and services to people with disabilities. By treating others as you would want to be treated yourself!” – person living with dementia

Dementia Australia conducted a survey with people with a lived experience of dementia, and when asked the question, do you think our community includes everyone,  100% of the respondents indicated “no.”



There are two fundamental issues that need to be present to achieve quality dementia care, inclusivity and the recognition of human rights:

- a clear understanding of the clinical aspects of dementia and the disease trajectory; and
- a holistic and person-centred approach, including high-quality communication, with every individual.

> “It is having the time to spend with people. Getting to know who they are, their likes and dislikes. That’s what matters.” – current carer

The concept of person-centred care has been around for many years, but it is clear from what people with a lived experience of dementia tell us that the mechanisms to achieve this – leadership, culture, regulation and workforce development – are still falling short.

Through transparency, accountability, greater collaboration and awareness raising activities, these things can be achieved through existing structures, frameworks and policies, but it also requires a shift in attitude.

> “Where we accept all people for who and what they bring to their community.” – person living with dementia

This shift in attitude requires education. For societies to be inclusive, people need to be taught about disability, to bust the myths and misconceptions that exist that keep people with disability feeling excluded and isolated.

A key component of this is that dementia is often not recognised as a disability and this perpetuates unmet need, misunderstanding and exclusion. The capacity and rights of individuals with disability are poorly understood at a community level and widespread education is needed to shift this. The disability, health and aged care sectors have a key role to play here to build understanding about the rights of people with disability, including those living with dementia.

> “You need a strong legal framework then a strong desire to enforce it. There must be strong education programs specifically aimed at sectors within the community such as employers, board members, children, the aged, specific cultural groups, etc. This education should include showcasing the value to the community that is provided by some disabled members of community but this must not imply that only the disabled who can demonstrate worth to the community are worthy of support and protection.” – current carer

> “Education first and foremost. Eradication of fear and stigma through learning encourages increased awareness, inclusion and lack of fear. I think we all want to be seen as the good guys and we benefit from helping. Everyone feels connected after performing a helpful act.” – former carer

> “It’s really important to keep up the momentum of the disability sector gains in community understanding and acceptance and now focus on dementia being firstly a disability caused by a degenerative brain disease and not a diagnosis overshadowing / excluding by the old definition of dementia not be able to be changed in any way shape or form.” – person living with dementia

Disability rights activist James Charlton’s quote – “Nothing about us without us” still rings very true. It is important to involve people with a disability, including people living with dementia in the policy development process. They need to be given a voice and to be empowered to not only speak up if they experience injustice and report inappropriate behaviour, but to contribute ideas to facilitate the promotion of a more inclusive society.

> “Stand up for unrighteousness. Advocate for inclusion. Employ people with a disability. Give them a voice - encourage them to speak up!!! Report inappropriate behaviour!!! Empower them.” – person living with dementia

> “Have them first, their representatives second involved across all community life-beginning with full representation on all bodies and ideally using basic principles of co-design to re-engineer the community. Inclusion comes from within the community, not by a dictate or directive from outside.” – person living with dementia

An inclusive society that supports people with disability to live free from violence, abuse, neglect and exploitation has a focus on celebrating diversity and making people feel valued, welcome, integrated and included instead of feeling discriminated and isolated. People have an awareness and acknowledge unconscious bias, practice empathy and have an openness to learn. Inclusive societies are culturally aware and create a transparent environment in which all people feel empowered to express their opinions and ideas freely.

## Barriers to an inclusive society for people with disability

There are a number of barriers that prevent people living with dementia from being fully included in society, such as stigmatisation, invisibility, conflicts between safety and duty of care, and a lack of community support. Dementia Australia supports the findings in the *Safe and Just Futures* report, which advocates that the recognition of human rights for people living with dementia, their families and carers need to challenge current practice and begin from the premise that people living with dementia are full humans, equal to everyone else. This is necessary in order to prevent the ideas about dementia (which might be buried in seemingly apolitical and medical ideas about dementia) being transplanted into the way human rights are interpreted and applied on the ground. To this end, work needs to be done to improve sector and community views about dementia and support the development of communities that are inclusive and supportive to people living with dementia.[9]

Many factors stop people with disability, including people living with dementia, being respected, promoted and realised. Some of the key barriers as identified by people with a lived experience of dementia include:

- unconscious bias;
- a lack of experience with people with a disability, which leads to misunderstanding, inaccurate assumptions and a failure to recognise their rights in one form or another;
- ignorance;
- poor education;
- low profile of disability in the community;
- low diversity literacy.

These barriers are linked, in their most extreme forms, to violence, abuse, neglect and exploitation because dementia as a disability is not part of most people's consciousness until they need to consider it. This lack of consideration of how the needs of people with a disability differ can perpetuate negative treatment of people with a disability and the cycle of ignorance and disrespect. Additionally, as many people with a disability do not have a voice themselves (especially where that disability results in cognitive impairment or decline), these barriers to equal human rights and respect remain overlooked unless advocacy organisations and/or support is available and governments prioritise the needs of people with a disability.

> "Firstly - Know the rights - Expect those with disabilities to have something to contribute and take the time to listen and comprehend what they are saying. Don't talk over the top of them or FOR them unless they ask you to. Have the Shire councils with a Disability Access reference group for all public works, have a Dementia Friendly Community be established and train the various shop owners, business people, care practices and care homes in the best inclusive practice. Lead by personal example of inclusion too." – person living with dementia

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[9] Dementia Alliance International (2020) Safe and Just Futures for People Living with Dementia in Residential Aged Care https://www.dementiaallianceinternational.org/wp-content/uploads/2020/03/Safe-and-Just-Futures-Project-Report-for-Web.pdf

## Practical and sustainable steps government, non-government and private sector organisations can take to promote a more inclusive society

> “Governments have to take the lead - to show the way. Whether by example, by laws, by regulations, by funding, by promotion, etc - they all help. Those with disability need support across a range of areas for them to be included.” – former carer

To promote greater inclusivity in society for people with disability, including people living with dementia, there needs to be direct recognition and inclusion of these individuals in policy development and program design. This requires the leadership of governments to see the value lived experience perspectives have in improving the way care is delivered, and in creating supportive environments for people with disability. Some examples of good practice include:

- people with disability sitting on project specific working groups and/or steering committees;
- people with disability being consulted with about policy, programs, and/or service redesign that directly impact them;
- people with disability being listened to and their ideas taken seriously by decision-makers when they provide feedback, share insights, or provide guidance;
- seeing people with disability as equals and engaging with them from this perspective;
- promoting supportive and positive images, stories and contributions of people with disability, particularly in policy and program development;
- introducing disability awareness training in school based programs; and
- not excluding people from consultation processes based on their disability.

> “Lead by example! From Federal - State to Local government bodies. Those that are most enabling and inclusive are at a local level - recognize and acknowledge this - then build upwards and outwards.” – person living with dementia

Furthermore, to help prevent and improve responses to violence, abuse, neglect and exploitation of people with disability there needs to be greater education driven by government and non-government organisations alike.

This education needs to start from a young age, communicating human rights – that all people have the right to be treated with respect regardless of their ability. It starts with changing attitudes within families and the broader community, as well as how care is delivered through the disability, health and aged care sectors. Due to a lack of awareness about disability and dementia, many people are unaware of how to support people with disability or meaningfully engage with them.

> “We have to go back to the root question; why is this happening? It is not because of a lack of advocacy groups or the availability of tax-funded programs, it’s finding a solution to the poor home environments. All the education and advice in the world is

> futile unless further reinforcement is provided in the home by respectful, knowledgeable and empathetic parents." – current carer

Disability organisations and all levels of government have a responsibility to promote disability awareness raising messages as well as ensure service providers are meeting high standards of care.

> "There must be the five R's: Right People, Right Training, Right Place, Right Time and Right Pay." – Former carer

Another way in which this could be achieved, is through giving people with dementia a stronger voice through advocacy organisations and mechanisms such as Dementia Alliance International (DAI) and Dementia Australia. These organisations are equipped to help people better understand dementia, its progressive nature and how needs can be best met.

This can be achieved through awareness campaigns that build broader understanding and target the community, which will help dispel myths, stigma and misunderstanding. This is effective because a key source of our learning about disability is often through the media and social media. Unfortunately, there is also negative education on social media and other online sources that portrays a disrespectful attitude towards disability.

To shift people's attitudes and perceptions about disability to be more respectful and inclusive, there needs to be information and education that portrays disability in an accurate light. An example of how an awareness campaign delivered via media can help shift attitudes is in our Keep the world open campaign. This looked specifically at the discrimination faced by people living with dementia, who experience greater levels loneliness and isolation and urging people to stay connected with them.

Living with dementia changes how people experience the world. Dementia impacts people in different ways. People can experience changes to their memory, intellect, rationality, social skills and physical functioning. Many people experience other changes too. Changes in how people relate to them. People might stop talking to them, staying in touch and inviting them to things. That is not dementia, it is discrimination. The rights of people with disabilities including those living with dementia are the same as the rights of others but the means of achieving inclusivity requires additional support from governments, workforce, communities and the disability sector.

Building on improving and increasing education about disability, could be the development of supports and forums to provide greater and easier access to information. This reduces barriers and creates support environments for people to discuss disability, gain an understanding of what are appropriate responses towards disability, and how to meaningful engage with people with disability.

Through education, awareness campaigns, specific training and the promotion of advocacy groups, improvements can be made help prevent and improve responses to violence, abuse, neglect and exploitation of people with disability.

> "My view is that it starts at the top, so Government is responsible in the first instance. Dementia should be always listed as a disability and treated accordingly. This will help

> to de-stigmatise dementia. There are very few other diseases that create disability where there is a stigma.” – former carer
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> “Legislation making non-inclusiveness illegal. A willingness to enforce this legislation such as Anti-Discrimination laws.” – current carer
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> “PROACTIVELY: * ACTIVELY promoting Awareness; * Having high regard community profiles (Role Models) not afraid to speak out; * Lobbying and calling out people / groups bucking the trend; * Intentional, sufficient, and supported interactions between peers with and without disabilities; * Specialized, individualized supports; * Family involvement; * Inclusive, interdisciplinary services and collaborative teaming; * A focus on critical sociological outcomes; * Effective, ongoing administrative supports; and * Ongoing Education.” – current carer
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> “Councils can support and encourage by simple things like ease of access, disabled parking, ambulant toilets and clear signage. How about families "adopting" someone in their own community that they engage with and visit once a week. Often contemporary families do not have access to grandparents and this would benefit both parties.” – former carer
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> “Adopt a policy to 'support people with disability'. Use that policy to create processes and procedures to actively support. This would include removing the discriminatory action of banning people over 65 from the cover of the NDIS. Mandating care standards such as support staff ratios in residential facilities. Providing Medicare coverage of ALL health initiatives for people with a disability. Fund all aids used by people with a disability.” – current carer
>
> “Have respect for all people. To take pride in knowing that their organisation is committed to valuing people and making the organisation disability friendly. To be proactive in ensuring their environments are disability friendly. By training all staff to help them to understand disabilities and how they can alter the current environment to make them disability friendly. By helping staff to know how to personally assist people if required.” – person living with dementia

## Conclusion

The extent to which an inclusive society is realised in practice and in everyday life depends not only on the willingness of politicians and policymakers to change legal and regulatory frameworks, but on the support from civil society for human rights – the attitudes and enthusiasm of community members, people living with dementia and those who provide advocacy and support.

People living with dementia have the human right to participate in all decisions which affect their lives and wellbeing. This approach should be embedded in practice as a foundational component of care, regardless of a dementia diagnosis. There is an obligation for all levels of government, the disability, health and aged care sectors and their workforce to ensure people living with dementia are treated with the same dignity, respect and rights as everyone else.