Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Rights and Attitudes issues paper

Dementia Australia

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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 Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission), in response to the issues paper on rights and attitudes. Our submission has been developed in consultation with people living with dementia, families and carers, and addresses their experiences of these issues including how they may be linked to violence, abuse, neglect and exploitation, as well as examples of good practice.

Dementia Australia strongly advocates for any policies and programs, particularly in relation to people living with dementia, their families and carers, to be developed in the context of a Human Rights based approach. This approach should emphasise participation, freedom, dignity, empowerment, accountability and equality. Additionally, Dementia Australia strongly advocates for a Human Rights Approach to Ageing and Health, which focuses on a person centred framework being meaningfully connected to practice. People living with dementia, their families and carers need to be at the centre, and the workforce supported to build their capacity to deliver consistent high-quality care. Building workforce capacity is key in relation to changing attitudes towards people living with dementia, their families and carers, which we document in our communique Our Solution: Quality care for people with dementia. While this communique has a specific focus on aged care, the principles are relevant in the context of this issues paper to reduce risk of exposure to violence, abuse, neglect and exploitation.

There are a number of barriers that prevent people living with dementia from receiving equal human rights, such as stigmatisation, invisibility, conflicts between safety and duty of care, and a lack of community support. Dementia Australia supports the findings in the recent *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 logics and 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.[1]

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.

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[1] https://www.dementiaallianceinternational.org/wp-content/uploads/2020/03/Safe-and-Just-Futures-Project-Report-for-Web.pdf

Younger Onset Dementia

Of the more than 459,000 Australians living with dementia in 2020, an estimated 27,800 people are living with younger onset dementia. This number is expected to rise to 29,353 people by 2028 and 41,249 people by 2058.[2] Younger onset dementia describes any form of dementia diagnosed in people under the age of 65.

Although it is more common in older people, dementia is not a natural part of ageing and it affects people in their 40s, 50s and even 30s.[3] 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 and their families.

Learning about the rights of people with disability and how these could be improved

Societal learning about the rights of people with a disability is inconsistent and varied, and the understanding of dementia as a disability (and that people with dementia have certain, fundamental rights) is also inconsistent. This is particularly the case with younger onset dementia (YOD) which is often poorly understood.

People with YOD are required to navigate their way through multiple service systems as their dementia progresses. As such, people with YOD are typically required to straddle both the aged care and disability systems – neither of which fully understands or is equipped to respond to the needs of people with YOD.

People with YOD have long battled the challenges of straddling the disability and the aged care systems, with both systems often regarding the other as best placed to respond to the needs of younger onset dementia. This attitude creates issues in access to services and people with YOD receiving quality care that meets their needs. Critically, as the NDIS does not yet provide respite or permanent residential care options for people with YOD, people are required to access residential care through the aged care system.

More broadly, in Australia, we have a myriad of socio-economic levels and ethnicities all with their own beliefs, cultures, education levels, home lives and broadness of thinking. The easy and obvious approach to helping resolve the issue of misunderstanding about disability,

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

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

including YOD, is to introduce education programs into schools at a very early age and continue them throughout the education continuum.

Formative experiences will result from the modelling by parents, other relatives, day care staff, pre-school educators, teachers and community leaders such as elders, ministers of religion, bosses, scout leaders, sporting coaches and friends. The fundamental value is respect for all people and then applying that respect to people with disabilities including those living with dementia. - Carer

Additionally, dementia is often not recognised as a disability and this perpetuates unmet need and misunderstanding. The capacity and rights of individuals with disabilities and/or dementia 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 with YOD.

Another way in which this could be achieved, is through giving people with YOD 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 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, there needs to be information and education that portrays disability in an accurate light.

A recent 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 YOD are the same as the rights of others but the means of achieving their rights requires additional support from governments, workforce, communities and the disability sector.

Barriers to the rights of people with disability being respected, promoted or realised

There are many factors that stop the rights of people with disability being respected, promoted and realised. However, 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.

"Governments can be complacent at times and disability is put in the too hard basket." – Carer

Advocacy and advocacy assistance

There are various avenues where advocacy support is available for people with dementia. The issue is more along the lines of whether people know where they can access such support and navigate the system to find it.

"If you know where to access assistance, there is plenty available but knowing where to access this is a major problem." – Carer

Dementia Australia undertakes systemic advocacy on behalf of people living with dementia, their families and carers, and have a role to play in informing people about what advocacy support is available. However, we are not an organisation focussed specifically on individual advocacy.

"The work of Dementia Australia is of paramount importance for people living with dementia and their carers." – Carer

Organisations such as the Human Rights Council of Australia, and local and State and Territory governments are important channels for advocacy support. Then there are specific organisations who can assist people with disability with advocacy such as the Older Persons Advocacy Network (OPAN); the Council on the Ageing (COTA); Autism Asperger's Advocacy Australia; Disability Advocacy and Complaints Services; Deaf Australia; Brain Injury Australia; and People with Disability Australia, amongst others.

The challenge here is whether organisations and channels such as these have adequate knowledge and understanding of dementia. As the population ages, there is increased likelihood of co-morbidities and organisations need to understand how other disabilities can be compounded with a diagnosis of dementia.

To help prevent and improve responses to violence, abuse, neglect and exploitation of people with disability there needs to be greater education. 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. This is particularly the case for dementia and people living with YOD. 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 YOD, 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." – Carer

Specific 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

It is not simply about needing significantly more funding, it is about:

- innovation – thinking outside the box to allow for dignity of risk;
- allowing for inclusion, participation and decision making;
- training and building the capacity of the workforce to understand disability and acquire the necessary skills, knowledge and capacity to deliver high quality care;
- involving carers, families and advocates as partners in care and supporting them with decision making and care planning;
- eliminating the over prescription of medication and excessive use of physical and chemical restraints;
- 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 and familiarity;

- having feedback and complaints systems that take people with disability and people living with dementia seriously and facilitate their involvement;
- having the right skills mix amongst staff to meet the needs of the person with disability and the person living with dementia;
- building an organisational culture that encourages an understanding of both disability and dementia that can respond effectively to the staff requirements that help meet the needs of the person; and
- involving people with disability including people living with dementia in program and policy development and decision making to provide a lived experience perspective and highlight key issues and areas of need.

“I’m on our local shire council committee for disabilities and our group has brought in significant changes in public footpaths, housing developments, adult change tables in public loo's and advocates for the various genre of disabilities. Go public education on all means so the ordinary person becomes aware - meets the 'pub test'.” – Person living with dementia

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 disabilities.

“Talking the language the audience gets with suitable illustrations – less jargon and academic terms and reaching the target audience.” – Person living with dementia

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.

Attitudes and awareness

The extent to which human rights are 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 attitudes from society. To address violence, abuse, neglect and exploitation against people with disability, attitudes towards disability need to shift, so that human rights are recognised and upheld.

This is particularly evident in the lack of recognition of dementia as a disability. Disability, in a legal sense refers to the various impairments caused by illnesses and conditions. The *Equality Act 2010* talks about how people should be protected from unfair treatment because of these impairments. Many people with dementia would be classed as ‘disabled’ under law, yet it is often not recognised that way in the community or in service delivery. It can quite often be the case that people living with dementia are often disabled more by their environment and the attitudes of others than they are by their dementia.[4]

A specific example of this, is in receiving a diagnosis of dementia. Many people living with dementia have shared with us negative experiences of how they have received their dementia diagnosis and that they should essentially “go home and prepare to die.” There is

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[4] Mental Health Foundation (2015), Dementia, rights, and the social model of disability, a new direction for policy and practice?

often a lack of post-diagnostic support for people with dementia, particularly those with YOD, who face the pressure to leave work, and additional challenges with finances (such as getting a loan) and insurance.

There are many ways that attitudes contribute to the mistreatment of people with disability, especially those with YOD, such as not speaking up, misunderstanding or a lack of understanding about what is considered appropriate behaviour, and avoiding involvement or responsibility altogether.

“People not realising that they should speak up if they see someone else being mistreated or being afraid of repercussions if they do speak up. People misunderstanding the behaviour of someone with a disability and assuming they are being difficult.” – Carer

Attitudes can significantly impact people’s lives. Particularly community attitudes about disability and the extent to which people with YOD are included in society are largely shaped by societal attitudes. These are embedded in the community as well as policies, legislation and throughout the disability, health and aged care sectors.

Attitudes are a key contributor to the mistreatment of people with disability, including those with YOD. How people feel and think influences their actions. People’s attitudes are shaped by their education, and through their upbringing (culture, beliefs and values). This is why education and the promotion of accurate and informative information about disability is important to improve the quality of life for people with YOD. Any approaches moving forward need to be heavily focussed on a recognition of human rights. People with YOD need to be enabled to contribute and supported to participate in such conversations.

“As the old cliché says, you can’t change what you don't acknowledge, so too when it comes to the rights of people. You can only acknowledge through awareness and openness from of prejudice and bias.” – Carer

Continued advocacy from a holistic and all-inclusive perspective for people with disability is necessary to ensure governments and decision makers remain aware of the issues and develop and implement appropriate policy. Dementia needs to be recognised as a disability, and the way governments communicate messages and raise awareness about disability can greatly impact the way in which community attitudes are shaped. Without positive modelling, there can be minimal progressive changes in how people with disability are viewed and treated.

“The wider community does not always recognise the importance of protecting the rights of all people in the community. This is why philosophies like 'user pays' and constantly trying to minimise tax payments, encourage disadvantage. Many people think that if your life is not wonderful you only have yourself to blame. Consequently, we see token supports given but no concerted policy to improve the conditions for all people.” – Carer

Attitudes can both support people with YOD and equally perpetuate violence, abuse, neglect and exploitation.

“Attitudes may govern whether a person with a disability receives assistance or is ignored when needing help. Raising awareness of the need to protect the rights of others makes it more natural to help than to stand by and do nothing.” – Carer

Informed and educated attitudes are important to ensure safe environments for all people.

"Negative attitudes and ignorance often lead to negative outcomes for people with disability." – Person living with dementia

Where such negative and misinformed attitudes exist, poor behaviour can follow. If people are not taught how to be accepting and respectful of people with dementia, the cyclic nature of inequality is perpetuated. Alternatively, where there is an understanding and greater acceptance of dementia as a disability, people are more likely to report mistreatment and advocate for their rights.

Where people feel that they are unable to relate to the person with disability, particularly those with YOD, they are less likely to call it mistreatment, reinforcing the need for education and awareness raising about disability.

"People do not how to converse with a person with a disability." – Person living with dementia

There have been a number of systems introduced by the Commonwealth Government in the last five to seven years to support people living with dementia, their families and carers (e.g. My Aged Care, NDIS, Carers Gateway). While it is encouraging to see work directed at increasing available funding to support people living with dementia and the introduction of these systems, it has also highlighted some issues. Dementia Australia have witnessed firsthand via clients and Dementia Advocates that having a system (e.g. My Aged Care, NDIS) is not enough if there are not supports for people living with cognitive disabilities to access these systems.

Additionally, the introduction of a separate system for carers to access supports may create challenges and barriers for people to access supports that are beneficial and often needed at times of great stress.

These issues highlight the need, and benefit of a more systematic approach to including people with disabilities in the development of future systems, and in the enhancements of current ones.

"The outcomes of poor rights awareness and discrimination is evident everywhere." – Person living with dementia

"We are isolated, left out, and there is a lack of consultation and involvement." – Person living with dementia

"Unless someone with a disability is on the grass roots of the laws and policies it is pure discrimination as has been proven again and again." – Person living with dementia

To improve attitudes towards, and awareness of people with disability, including those with YOD there needs to be direct recognition and inclusion 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;
- introduce disability awareness training in school based programs; and
- not excluding people from consultation processes based on their disability;

"An example people with disabilities have rights to be on ethics committees but people with the disability of dementia don't - based on old laws re senile dementia and end stage -- not the current practice of early diagnosis and very competent people with various deficits who happen to have dementia who can contribute to policy making relevant to their situation." – Person living with dementia

"As an able-bodied person I have experienced poor healthcare from a practitioner who had been negligent. I had to self-advocate to protect my right to quality healthcare, so I can only imagine how difficult it is for a person with an intellectual disability to receive respectful, quality care without advocacy." – Former carer

The media (including social media) also plays a key role in shifting the attitudes and awareness of disability, as it is able to highlight situations where people with disabilities have been poorly treated. They also have the ability to highlight the voice of people with disabilities. This has the potential to improve attitudes and understanding about dementia as a disability to broader community audiences. As highlighted through this submission, education is key to help prevent and improve responses to violence, abuse, neglect and exploitation of people with disability. It is about a collaborative effort between governments, media, disability sector organisations and peak bodies to share accurate information with the broader community and support those living with disability, including those living with dementia.

"There needs to be appropriate language, imagery and content to be positive." – Person living with dementia

"Social Media could be used to an advantage to spread the word and good-news stories but it is very easily sabotaged and hard to manage a continuously positive message." – Person living with dementia

"Carefully reporting can assist the general public to be aware." – Carer

Conclusion

Undoubtedly, attitudes within the community and those held by each individual impact the ways in which people with disability are both treated and represented. There needs to be a shift in the way people with disability are viewed to ensure the *UN Convention on the Rights of Persons with Disabilities* are upheld in Australia and we continue to work towards a more inclusive society for all.

Dementia Australia welcomes further discussion and consultation as to how the rights of people with disability could be improved and translated into changes in practice throughout the disability, health and aged care sectors. This is important to ensure the needs of people living with dementia, their families and carers receive high quality and safe care provided by appropriate and competent aged care workers.

"It's not until you have the lived experience of having a disability do you get it – it's why we advocate so loudly for inclusion in policy making for us. Even carers aren't the best advocates because it is second hand. We are more than our disability - that needs to be remembered too. Be kind - always be kind and keep on including us." – Person living with dementia