Dementia Australia™

Safeguards and quality

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

1 February 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.

Executive summary

A whole of system approach is needed to safeguard people with disability. The next National Disability Strategy and a contemporary version of the National Disability Agreement will provide an important foundation to improve the wellbeing of people with disability, their families and carers and frame the development, review and implementation of policy, practice and legislation that recognises the human rights of people with disability in Australia. Dementia Australia strongly encourages a co-design approach to this work, which recognises the experiences of people with disability, their families and carers as well as service providers and the workforce. We also recommend adopting both a proactive and a reactive approach to quality and safeguards.

Dementia Australia supports an approach that includes goals for the immediate-, medium- and long-term to safeguards and quality, in order to address the barriers, issues and challenges present in the current system. The approach should also promote an inclusive society that seeks to eliminate the disability barriers people experience in their everyday lives. Our submission provides suggestions to improve the existing systems and also areas that would require a more significant commitment and considerable change to plan, implement and evaluate.

Although Dementia Australia would like to see a shift to a supported decision making model, we recognise this will take time to introduce and implement, and therefore not address more immediate needs of people with disability. Appropriate information and resources on violence, abuse, neglect and exploitation need to be accessible for all audiences and should include information on what to do if people have concerns. To further support people to remain independent for as long as possible, options could include:

- Access to affordable supports and services to help people maintain their independence, such as home modifications and meal services.
- Strategies to avoid isolation for people with disability and their carers.
- Utilising technology.
- Strategies to encourage inclusion of people with disability to be part of ‘mainstream’ activities.

Informal carers not only need supports and services to assist in caring for the person with disability but also access to supports and services themselves to reduce the likelihood of, and respond to, burnout. Accessible systems also need to be in place for times of crisis.

Dementia Australia’s publication, *Our Solution: Quality Care for people living with dementia*, maps key activities that organisations can use to assist them to meet the aged care standards, and can be readily adapted to other services who provide care and support to people with disability. It includes eight focus areas:

- Understanding diversity and maintain identity through relationships;
- Involve carers and advocates as vital partners in care and support;
- Flexibility in provision of care and support and how and when services are received;
- Inclusion in community, meaningful activities and decision making;

- Community/home-like setting design, look and feel for residential services;
- Feedback and complaints are taken seriously;
- Dementia trained staff; and
- Change leadership and culture to understand and support dementia.

There are a range of issues that create barriers for people with regards to making a complaint, with many of them having a strong focus on fear of negative consequences and not being listened to. Systems need to seek to address these concerns and foster a strong focus on communication and respect as well as having clear and transparent processes in place.

Opportunities to promote good practice should be actively explored and ways to encourage creativity and innovation to address disabling barriers in society should also be supported as a proactive approach to quality and safeguards.

> **“We should support the person to live an active life in the manner they prefer. We should provide aids and an environment that facilitates independence. We should always respect the person's choices and if their choices increase their risk of harm or injury, we should explain how, when and why. We should also communicate in the ways that are most intelligible for the person.” – former carer**

Introduction

Dementia Australia welcomes the opportunity to provide this submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in response to the Issues Paper on safeguards and quality. Our submission responds to most of the questions identified in the paper, focusing on people living with dementia and draws on the experience of people living with dementia, their families and carers as well as the experience of Dementia Australia as a National Disability Insurance Scheme (NDIS) Registered Provider.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person's functioning. Symptoms can include memory loss as well as 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 472,000 Australians living with dementia in 2021[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]

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 2021, there were an estimated 23,800 people with younger onset dementia. This number is expected to rise to 29,353 people by 2028 and 41,249 people by 2058.[5]

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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.

[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.

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]

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]

Safeguards and quality

People with disability

Independence, choice and control

> **“We should support the person to live an active life in the manner they prefer. We should provide aids and an environment that facilitates independence. We should always respect the person's choices and if their choices increase their risk of harm or injury, we should explain how, when and why. We should also communicate in the ways that are most intelligible for the person” – former carer**

As identified in the NDIS Quality and Safeguarding Framework, “giving people with disability choice and control over their supports can improve their outcomes”[8] and, ideally, would help reduce people’s vulnerability to abuse. One way to support people to exercise choice and control is to introduce a consistent decision-making approach that aligns with the Convention of the Rights of Persons with Disability, such as the National Decision-Making Principles and Guidelines recommended by the Australian Law Reform Council in 2014. A supported decision making approach may challenge us to reconsider assumptions made on people’s capacity to make their own decisions and live the life they desire, including the right to make poor choices and bad decisions.[9] The adoption of a supported decision making model would need to find the delicate balance between several concepts including risk enablement/dignity of risk, accountability, responsibility, duty of care, legal and ethical considerations and also includes a well-considered transition from moving from one decision-making process to another.[10] There are not only challenges presented in the significant legal and policy changes required but also the need to support people to make the required shift in their thinking and encouraging them to become decision makers in their own right. Whilst the adoption of a supported decision-making approach would not be without its challenges, especially given

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[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] Department of Social Services (2016) *NDIS Quality and Safeguarding Framework*, p.6.
[9] New South Wales Parliament Legislative Council, Standing Committee on Social Issues (2010) *Substitute decision-making for people lacking capacity*.
[10] T Carney (2015) Searching for workable alternatives to guardianship for vulnerable populations? *Ethics, Medicine and Public Health*, 1 (pp.113-9).

the limited evidence available,[11] the introduction of the NDIS that actively encourages the use of a person’s informal network with no safeguards in place to support decision making, introduces its own risks and disadvantages and can reinforce paternalism and result in exploitation and neglect.[12]

Although Dementia Australia would like to see future safeguard and quality legislation, policy and programs provide a framework for a shift to a supported decision making model, it recognises that this would take some time to plan and implement. As such, Dementia Australia also encourages ongoing and future work to support people to make decisions using the growing evidence base. While a new approach may be introduced in time, this is a ‘live system’ in which people with disability have immediate needs for support in maintaining their independence, choice and control and having safeguards in place that respond to the risks of violence, abuse, neglect and exploitation. Appropriate information and resources on the support, training and education opportunities should be readily available to people with disability, their families and carers that provides clear definitions of their rights as well as abuse, violence, neglect and exploitation and what they can do if they are concerned.

> **“By providing easy access opportunities for advocacy, both self and by others.” – carer**

Similar to the policy approach identified in aged care, which has a focus on ‘ageing in place’, people with disability, their families and carers also need support and services to assist them to maintain their independence and connections within their existing communities. Opportunities to maintain and expand peoples’ networks should be actively explored and encouraged and could include initiatives such as dementia-friendly communities and supports through local councils.

Dementia Australia received feedback from people living with dementia, current and former carers on suggested approaches to support independence, choice and control when implementing safeguards. Many of the suggestions received included a focus on the importance of communication (verbal and non-verbal) and access to (and knowledge of) education.

In addition to these suggestions, consideration could also be given to the following:

- Having service providers advise on home modifications and equipment that could be installed/provided, especially if they are available under funded schemes and programs, for example, handrails, wheelchair access, lifting equipment.
- Community education programs to encourage inclusion of people living with dementia in ‘mainstream’ activities.
- Access to peer support and/or system navigator-type roles.

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[11] M Donnelly (2019) Deciding in dementia: the possibilities and limits of supported decision-making. *International Journal of Law and Psychiatry*, 66.

[12] C Bigby (2020) Dedifferentiation and people with intellectual disabilities in the Australian National Disability Insurance Scheme: Bringing research, politics and policy together, *Journal of Intellectual & Developmental Disability*, 45:4 (pp.309-319).

> **“at the time of diagnosis the person need to be linked with a support person who knows to navigate the system for them…” – person living with dementia**

- Opportunities (and access) to utilise technology, for example:

> **“I have my phone connected with my husband – my guardian, so he knows my appointments and where I am. I also have a ‘bossy watch’ which if I fall can call SOS – I can also phone from it if I’m at risk.” – person living with dementia**
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> **“I now have just my bank account so I can’t be rorted for thousands of dollars from the main account. My credit cards have to have a pin …and I can’t do international purchases.” – person living with dementia**
>
> **“I have a team of people looking out for me.” – person living with dementia**

- Access to local services and supports to maintain physical and mental wellbeing.
- Ensuring people living with dementia and their carers have the opportunity to undertake activities away from their home.
- Strategies to avoid isolation for the person living with dementia and their carers, which could include ensuring they both have separate opportunities to undertake activities away from home and regular visits from a service or organisation to check on everyone’s wellbeing.
- Access to affordable support and services that can help people maintain their independence, such as meal services, respite care, personal care, home modifications and domestic assistance.

> **“Just because a person can live independently this does not mean they should be left to struggle when not knowing how to gain assistance.” – carer**

A person living with dementia has the right to choose their formal decision makers wherever possible. Information that outlines the role and responsibilities of these positions, as well as identifying what is not included (for example, what an enduring power of attorney can and cannot do on behalf of the person once they no longer have legal capacity) needs to be readily available and accessible.

As an individual’s ability to maintain independence changes, more safeguards may be required but Dementia Australia emphasises that this must be balanced with respecting the person’s right to privacy, dignity, and continued opportunity to be involved in decisions about their wellbeing and health, wherever possible.

> **“We should ensure people are not humiliated, debased or left feeling they are a burden to others.” – former carer**

Supporting families and carers to support people with disability

In 2020, it was estimated that there were almost 2.8 million informal carers in Australia which would cost $77.9 billion to replace with formal care.[13] We need a strong focus on ways to support the people that provide informal care, not only with services and supports for the person they care for but also for themselves too to, ideally, prevent them reaching a point of physical and emotional burnout.

> **"…carer needs support themselves need to be provided, as some of them may have their own serious physical health issues." – person living with dementia**

Carers and advocates need to be given the opportunity to be actively involved in people's care and support, with greater recognition needed on the layers of safeguarding that the informal care network can provide and how it can complement the formal supports and services. Ways to encourage and support people to expand, or better utilise, their existing networks should be explored. This could assist with minimising dependencies on a single person and assist the primary carer/s in maintaining their own wellbeing.

Accessible information and resources need to be readily available for the person with disability, their families, carers and their broader communities that provides practical information on what is violence, abuse, neglect and exploitation and what to do if they have any concerns. These resources should be co-designed with people with disability, their families, carers and organisations that represent them to ensure the information is appropriate and useful. Resources should focuses on areas that people may not automatically associate with being a problem (for example, some forms of financial abuse and coercion) and also unpack some of the challenges with recognising and reporting concerns, such as the impact on the relationships within the family. Ideally this would be through a national campaign that includes consistent key messages whilst being able to tailor to the specifics of the relevant jurisdiction.

Formal (disability) service provision

Quality services

There is an expectation that service providers have robust corporate, and where relevant, clinical governance practices, that are underpinned by standards that focus on protecting people with disability from harm and improve the quality of disability service provision. However, under the current system the NDIS registered provider meets the NDIS practice standards whilst unregistered NDIS providers do not, noting unregistered providers are only able to provide services to some participants. Given the potential for negative incentives for some providers to register, such as associated costs and if an organisation provides support under categories that do not have any restrictions based on registration, consideration should be given to reviewing the effectiveness of the NDIS Quality Safeguards Framework and the

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[13] Carers Australia (2020), *The value of informal care in 2020*, report prepared by Deloitte Access Economic.

Quality and Safeguards Commission, including potential barriers and issues providers may experience with the registration process.

Resources to support robust governance should be readily available to all disability providers. This could include a sector-appropriate version of the information from the Australian Commission on Safety and Quality in Health Care for The National Safety and Quality Health Service (NSQHS) Standards that provides a thorough breakdown of each standard by action and the provision of information on intent, reflective questions, key tasks and strategies for improvement, which are available for the different settings that the NSQHS Standards are applicable for. Continuing to make information and resources readily available, could support organisations in their quality improvement activities, especially for smaller organisations that may not be able to engage dedicated staff in governance and quality roles.

The implementation and review of policy and procedures should also include training and education for staff that may include:

- clear definitions of abuse, violence, neglect and exploitation;
- an overview of the policy and procedures that support staff to follow up and report their concerns;
- the importance of good communication and language use;
- ways to raise concerns outside of the organisation;
- where to find information for the service users and the broader community; and
- debriefing and supports available for the staff.

Dementia Australia has undertaken extensive consultation with people living with dementia, their families and carers around the provision of quality services in the aged care sector, which has broader applicable to general support and service provision. As stated in *Our Solution: Quality Care for people living with dementia*: “People with a lived experience of dementia want to ensure that their voices are heard, that quality care involves them and that their contribution leads to greater inclusion, support, respect and ultimately, improved quality of life. This is not just about quality dementia care; it is about providing quality aged [and disability] care to people living with dementia as well as their families and carers.”[14]

Our Solution: Quality Care for people living with dementia maps key activities that demonstrates how an organisation may meet the aged care standards, however these activities can also be applied to other services who provide care and support to people with disability (the following table summarises these activities with some minor modifications).

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[14] Dementia Australia (n.d.) *Our solution: quality care for people living with dementia*, p.2.

Activities for organisations to demonstrate quality care for people living with dementia
Understanding diversity and maintain identity through relationships
The workforce understands and recognises the diversity of dementia through building personal relationships with the person living with dementia, their families, carers and advocates.
Additional time is allocated for the workforce to care for a person living with dementia, to understand their needs, behaviours and potential triggers.
All levels of the workforce are trained to communicate effectively with the person living with dementia, their families and carers, with a consistent focus on respect and empathy.
There is a focus on active involvement with the person living with dementia, their families, carers and advocates in decision making and every day choice.
The workforce demonstrates knowledge and practice of what is important to the person living with dementia and respects their preferences through a human rights and person centred approach to care.
There is acknowledgement and inclusion of the person living with dementia as a valued member of the community through engagement, recognition and participation in activities and social gatherings.
There is acknowledgement of dementia as a disability.
Involve carers and advocates as vital partners in care and support
Active involvement of families, carers and advocates with the person living with dementia in supported decision making in all assessment and planning processes.
Initiation of the review of plans is undertaken in a collaborative process between the workforce, people living with dementia, their families, carers and advocates.
The workforce undertakes dementia-specific training and gains an understanding of the person's life to appropriately assess and respond to their personalised needs.
There is timely and ongoing communication between people living with dementia, their families, carers, advocates and care and support staff, as appropriate.
The workforce continually monitors, assesses and adapts their communication and engagement with the person living with dementia as their support and care needs change.
Flexibility in provision of care and support and how and when services are received
Personal and clinical care is delivered flexibly (for example, bathing and timing of meals) and is tailored to the needs of the person living with dementia.
The workforce shares relevant information about the person living with dementia with co-workers and communicates those needs across shifts.
The workforce is trained to recognise triggers, verbal and non-verbal signs of pain/ discomfort in the person living with dementia.
The workforce meets the evolving personal and clinical care needs of the person living with dementia irrespective of the stage of dementia, geographic location, cultural needs/ responsibilities, sexuality or financial status.
The person living with dementia receives timely, respectful and holistic care and support.
End of life care is responsive to the individual needs of the person living with dementia, and involves their families, carers and advocates.
Overprescribing of medication is avoided and families, carers and advocates are engaged in a timely way if any form of restraint is considered.
Inclusion in community, meaningful activities and decision making

A range of meaningful activities are offered to include the person living with dementia, which are tailored to their individual needs, disability and stage of dementia.
The workforce, families, carers and advocates assist the person living with dementia to participate in meaningful activities and maintain a sense of community connectedness.
The person living with dementia is given responsibilities (tailored to their abilities) to remain independent.
Creative arts, music, access to nature, and physical activity are brought into all residential settings to help improve the quality of life of the person living with dementia.
Plans are developed and updated to promote physical health, ability and mobility as key elements of care for the person living with dementia.
Community/ home-like setting design, look and feel for residential services
Adjustments are made to the service environment to make a person living with dementia feel more at home, including the consideration of culture, language, religion and sexual diversity.
The workforce facilitates options for the person living with dementia to move freely around the space (indoors and outdoors) and live as autonomously as possible.
Clear signage is displayed for where and what things are, which meets dementia friendly standards and is language specific.
The layout of the service environment is dementia friendly. This could include using contrasting colours for floors, walls and furnishings for visual identification.
The service environment allows for personal belongings, should the person living with dementia wish to have them, to create a sense of familiarity and identity.
Where possible, the service should be set out as small group homes that welcome family, carers and friends and allow them to come and go as they please, including encouraging flexible visiting hours.
The build environment enables the person living with dementia to continue to participate in day-to-day activities, such as cooking and cleaning. It could also include pets and/or pet therapy, where appropriate.
Feedback and complaints taken seriously
The workforce takes feedback and complaints raised by the person living with dementia seriously and does not discount it because of their dementia.
The workforce actively involves carers, advocates and/or family members in feedback and complaints processes to get a comprehensive picture when the person living with dementia is unable to communicate their own concerns effectively.
The workforce is trained to understand non-verbal communication and recognise when there is a potential issue to address for the person living with dementia. For example, understanding behaviour, frustration, changes in mood as indicators of potential concerns.
The workforce actively seek feedback from the person living with dementia as they may not initiate this themselves or know how to.
There are a number of alternative ways to engage the person living with dementia in the feedback and complaints process through collaboration with the person living with dementia, their families, carers, advocates.
No negative repercussions come to the person living with dementia, their families, carers or advocates for raising a concern or making a complaint.
Dementia trained staff
The workforce receives ongoing, competency based education and training while in their caring roles.

An increase in the number of staff to create the right mix of skills to meet the needs of the person living with dementia.
When recruiting care and support staff, organisations ensure personal qualities of empathy, respect, compassion, kindness and patience if they are to work with a person living with dementia.
There are aspirational goals for an equal gender ratio of staff.
The workforce receives end of life training, which includes grief support.
Change leadership and culture to understand and support dementia
There is a culture at all levels of the organisation, with overarching accountability measures and monitoring mechanisms that meet the needs of the person living with dementia, their families, carers and advocates.
Leaders promote a culture which focuses on understanding and responding to the needs of the person living with dementia and supporting staff to provide care and support from a sound understanding of the person.
There is an organisation culture that values dementia care and educating staff at all levels of the organisation of the specific needs, forms and stages of dementia.
The workforce is collaborative and exchange information about the person living with dementia across all levels of the organisation while maintaining the person’s privacy.
There is transparent accountability for quality dementia care and support, with key performance indicators that are specific, clear and measurable, that are embedded into practice.
Experts in dementia and/or people with a lived experience of dementia are included on organisational boards to help inform service delivery.
Leaders interact with the person living with dementia, their families and carers.

The activities identified in the table represent a person-centred, human rights approach to care and support, which are reliant on a knowledgeable, skilled and committed workforce, who are valued and supported themselves.

Other features of quality services may include:

- A strong focus on quality improvement.
- Networking opportunities to share good practice across services and potentially across sectors.
- A culture of respect for people with disability, recognising them as valued members of a community and/or family and as a recipient of services.
- Training and education is readily available and accessible to staff at all levels of an organisation about violence, abuse, neglect and exploitation, how to recognise it and how to report it. This information should be made available in a number of ways to support uptake, for example, using different medium, case studies and literacy levels.
- Different staff members interact with the person living with dementia, which could assist in identifying any issues or concerns.
- A culture of respect for all staff who work with people with disability, which considers renumeration and career progression pathways.

Challenges with jurisdictional and different types of services

The inconsistent approach to safeguards across jurisdictions introduces several challenges, including:

- There is an inconsistent approach and robustness of response to reports of violence, abuse, neglect and exploitation between state and territories, which, among other things, can be very confusing for national providers.
- There is a risk that people, both people with disability and members of the workforce, may fall through the cracks when relocating between state and territories. This can include one jurisdiction being unaware of concerns raised in another, because information is not passed between state and territories.
- The pathways to information about safeguarding and laws differs between jurisdictions. It can be difficult to find correct and up to date information.
- Providers, staff and volunteers may exploit differences between state and territories.
- There is no clear pathway between disability and the aged care system and so people are at risk of falling through the cracks.

Depending on where the person with disability lives, there can be considerable variation in what is available to them including:

- Availability of provider choice varies across metropolitan, regional and remote regions.
- Availability of computer/internet access and access to a diverse range of programs and supports varies based on physical location.
- Many organisations who support someone with a disability have strict Occupational Health and Safety and organisational safety measures in place, meaning that they may not be able to work within what they consider an unsafe space but someone with disability still needs this support and so may not disclose due to this fear and then may be without much needed services.
- Often NDIS funded supports would assist with higher risk situations, however the amount of funding available in the plan may not cover these supports. The delay in reviewing plans and funding means people with a disability are at risk for a longer period of time than they should be.

Complaints

The feedback Dementia Australia received on the barriers that people living with dementia face with regards to making a complaint strongly focused on not being listened to and fear of the negative consequences of making a complaint. Below are direct quotes about the issues people experience, which has been loosely sorted into various themes:

- Fear of the consequences and not being listened to

> **“They may fear it may jeopardise their level of car and attention. They may worry they are being a nuisance or a burden. They may worry**

carers may not have the time to listen and heed their complaints." – former carer

"Being believed, not assumed that they're just confused." – carer

"fear of not being taken seriously or listened too – a 'paternalistic' attitude of trivialising the issue as we know best for you." – person living with dementia

"Lack of being able to voice their concerns if alone." – carer

- Accessibility of information

  "Too confusing to negotiate and too many agencies…these services need to be handled…[by someone] who knows the person well." – person living with dementia

- Communication barriers

  "inability to communicate verbally is often a barrier to let any carers know of their difficulties." – former carer

  "Being able to articulate what they want to say. Remembering what the problem is. Being believed, not assumed that they're just confused?" – carer

- Respect

  "respecting the person's right to choice and independence." – former carer

- Staff being time poor

  "actually spending time with a person with dementia to fully understand their situation." – carer

In addition to these issues, other barriers to a robust complaints process include:

- Slow response to the complaint and with no clear pathway to follow up.
- No transparency to the complaints process/ hierarchy, for example "If you are not happy with the response at this point in the process, please refer your complaint to ..."
- A family member may not be able to make a complaint or know the full extent of the risk in order to make a formal complaint.

- Many people do not understand where to go and who to talk to in order to make a complaint.
- Stigma attached to disclosing risk/vulnerability by person with disability or their family, concerns about confidentiality – particularly pertinent in regional/remote areas.

Meeting the needs of First Nations people, women, culturally and linguistically diverse people, LGBTIQ+ people, and/or children and young people with disability

Below are some suggested approaches to how safeguards and complaints processes can be improved to meet the needs of First Nations people, women, culturally and linguistically diverse (CALD) people, LGBTIQ+ people, and/or children and young people with disability:

- Whilst NDIS Liaison Officers already exist to support First Nations people, women, CALD people, LGBTIQ+ people and/or children and young people with disability, there needs to be a continued focus to build trust to strengthen internal relationships.
- Communities could identify key specialised team members needed to support the person to form part of the support team, for example staff from a formal service.
- Identify key stakeholders across a community to be drawn on for provision of information and expertise, with a focus on building these relationships and trust.
- Focus on supporting existing work that bring a range of stakeholders together from different sectors, such as law enforcement, services working with people experiencing homelessness, disability and aged care organisations. This type of approach requires a strong focus on networking and relationship building and can result in formation of many subgroups to specialise and support specific areas of the community, for example, mental health, disability, homelessness.
- Education needs to be readily available to all stakeholders, especially broader community. The need to have the education, a system, processes and accessibility for broader support for people across the community to feel safe and to make complaints or raise a concern.
- Staff need to be supported to report and have their own supports available throughout this process, for example, professional counselling and debriefing.
- When family, friends, or support/care workers become aware of abuse, it can be that they are afraid to make reports because of the impact of an intervention on family relationships but at the same time, people can be afraid not to take some kind of action for fear of being complicit in the abuse continuing.
- To become aware of abuse and neglect can be an unsettling experience for anyone, including staff. Anything that helps to normalise this, such as people having (more than one) go to who can offer support, safe-guards for themselves, having a community of support when a complaint is made or abuse/neglect suspected, knowledge that an intervention will be handled well so there will be as good a possible outcome for all or most involved, for example, support and help rather than blame and shame.

- Localised approach to complaints process with good knowledge of the community and not a reliance on online services.
- Plain language and accessible information and processes.
- Enhance the knowledge of the communities for providers.
- Provide opportunities to ask questions and follow up
- Explore ways to better utilise of advocacy programs and for increased advocacy services specialising in disability and family violence.
- Link interpreter services and Aboriginal and Torres Strait Island liaisons with client/person.

Systems: laws, practices and policy

> **“The safeguards are often good 'on paper' but they are not being implemented properly. The issue of informed consent is ignored when a dementia diagnosis is made - which is very wrong.” – former carer**

A whole of system approach is needed to safeguard people with disability. The next National Disability Strategy provides the foundation for this, recognising and responding to the shortcomings identified with the 2010-2020 National Disability Strategy, such as inconsistent implementation and measuring and reporting on key outcomes.[15] This needs to be complimented by a contemporary National Disability Agreement, which should outline the roles and responsibilities of governments and take the opportunity to address gaps and improve accountability and transparency under the current Agreement. Importantly, policy and funding attention must extend beyond the NDIS. The provision of a national policy framework and funding agreement are a fundamental element to improving the wellbeing of people with disability, their families and carers as well as recognising the human rights of people with disability in Australia. These foundations frame the development, review and implementation of policy, practice and legislation that should be developed through a co-design approach with people with disability, their families and carers, representative organisations, service providers and workforce to avoid losing touch with the experience at the ‘coal-face’.

Below are some potential approaches that could be considered to improve safeguarding laws, practice and policies for people with disability:

- Co-design of aspirational standards to support organisations that would like the opportunity to work towards, and be acknowledged for, achieving standards that are more than the minimal safety and quality required in some mandatory standard programs.
- Opportunities to learn from other jurisdictions and providers about legislative instruments, practices and policies that have been implemented and evaluated, which could be supported through an open access clearinghouse.

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[15] L. Davy et al (2019), *Review of implementation of the National Disability Strategy 2010-2020: Final Report*, Social Policy Research Centre, University of NSW.

- Opportunities to learn from, and potentially partner with other sectors, for example, with organisations working in domestic violence, with the possibility of adopting similar approaches or expanding their work to include a disability-specific element.
- Education and training opportunities for informal carers and families to support them to explore different strategies to respond to challenging behaviours and situations..
- Improved consistency across jurisdictions of the community visitor scheme and potential expansion of the scheme, following consultation, that could include areas such as unannounced visits and access to private homes.
- Consideration of expanding relevant legislative instruments in jurisdictions to undertake worker screening for working with vulnerable people and not only in relation to working with children.
- Explore opportunities to co-design safeguarding legislation, practices and policy with people with disability, their families, carers and advocates, in addition to consultation processes.
- Consider the inclusion of training and education of staff and/or people living with disability, their families and carers on violence, abuse, neglect and exploitation into existing programs funded by the government.
- Evaluation and potential modification of existing practices and policies that ensure they are contemporary (for example, include reference to the NDIS Quality and Safeguards Commission processes) and ensure they are efficient and effective.

Opportunities to promote good practice should be actively explored at all levels, to recognise that safety and quality is not simply a ‘negative obligation’ but rather can and should address the disabling barriers in society through creativity and innovation. This could be through a national focus on building inclusive and accessible communities (for example, approaches like dementia-friendly communities and age-friendly cities) and could also include the introduction of a national award such as the Access City Award organised by the European Commission and the European Disability Forum, which “recognises and celebrates a city’s willingness, ability and efforts to become more accessible, in order to guarantee equal access to fundamental rights and improve the quality of life of its population and ensure that everyone – regardless of age, mobility or ability – has equal access to all the resources and pleasures cities have to offer.”[16]

Conclusion

Dementia Australia supports the development of immediate-, medium- and long-term approaches to safeguards and quality to address the barriers, issues and challenges present in the current system and the shift towards an inclusive society that seeks to eliminate the disability barriers people experience in their everyday lives in Australia. This approach to safeguards should recognise the importance of working with people with disability, their

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[16] European Commission, Access City Award, n.d., https://ec.europa.eu/social/main.jsp?catId=1141

families and carers to co-design solutions, as well as continued support to build on the evidence base on legislation, policy and programs that result in improved outcomes for people. One area that should be a priority is ways to improve and/or maintain independence, choice and control and should not only consider how to better support people to build their ability to make decision but which is part of a broader system that gives the person the right to make their own decisions, as much as, and for as long as possible. The supported decision making model proposed by the Australia Law Reform Council not only provides an opportunity to do this, recognising its shortcomings and challenges, but it also shifts towards a more equable system that aligns with both a person-centred and human rights approach. Significant shifts to the existing systems will require commitment and investment but some of the foundations have already been established, such as the introduction of the NDIS and its push to support people to build on and improve their independence.

One of the considerable challenges of providing a safe and quality system for people with disability is the lack of accessible information on what is violence, abuse, neglect and exploitation and what people can do if they suspect they are experiencing it or have witnessed it. This includes the need for education but also the need for clear and transparent processes to support people who do raise concerns that addresses potential concerns of negative consequences for the person and also do not dismiss people’s concerns out of hand, whilst still finding a balance with fair process for all people involved. In addition to this, ways to reduce the risk of violence, abuse, neglect and exploitation should also consider ways to build on and foster respect as well as ways to enhance resilience and to support someone who is burnt out or is at a crisis point.

This submission has identified how the existing safeguards and quality processes could be expanded and improved to prevent or reduce violence, abuse, neglect and exploitation of people with disability.