



# Dementia Alliance International

Submission to the UN OHCHR in relation to the  
Assistive Technology review

**Submission from:** Dementia Alliance International (DAI)

**Submitted by:** Ms. Theresa Flavin, Human Rights Advisor, on behalf of the  
Board of Directors and Australian Membership of people with dementia.

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# Submission to the UN OHCHR In Response To Resolution 55/8 (A/HRC/RES/55/8)

## About Dementia Alliance International

Dementia Alliance International (DAI) is a registered international charity, whose mission is to provide support globally including in Australia for people with dementia, and local, national and global advocacy for timely and accurate diagnosis, improved post diagnostic support and services including access to rehabilitation, to ensure a higher quality of life and independence for longer. DAI campaigns for the human rights of all people living with dementia, in community and residential care and for equitable inclusion in the community, and for dementia to be supported as a condition causing disability (WHO:2024). DAI is the global voice of people with dementia, whose vision is a world where all people are valued and included.

Notably, for this submission, Dementia Alliance International is the only NGO exclusively representing people diagnosed with any type or cause of dementia of any age in Australia, who are also people with disabilities with equal human rights and disability rights to all others including access to the Convention on the Rights of Persons with Disabilities (CRPD) and the Optional Protocol to the Convention Against Torture (OPCAT).

**DAI is the only organisation representing people living with dementia exclusively in Australia; it is the only independent and autonomous voice of people of any age, diagnosed with any type of dementia in Australia, and globally.**



## Preamble

The World Health Organisation confirms “dementia is a major cause of disability and dependence globally”<sup>1</sup>, and beyond the biomedical definition, have defined it this way for over a decade. Hence, people with dementia have the same disability rights under the Convention on the Rights of Persons with Disabilities (CRPD), as all others.

While Australia is a signatory to the CRPD, in practice, government funded disability specific support is only funded by the Australian government for people diagnosed with a disability aged under 65 years, and even that is increasingly difficult to access. International human rights instruments do not contain age limits, however Australia’s interpretation of the CRPD remains farcical. People aged under 65 years are eligible for disability specific support from the National Insurance Disability Scheme and people over 65 (50plus in the context of Aboriginal heritage) have access to ‘age related support’ under the Age Care Act. The Age care system provides approximately 3 hours per day 5 days per week of government funded in-home support with an additional \$10 per day of ‘dementia supplement’. When support needs exceed the ‘cap’, the Australian government funds ‘residential aged care’ as the only alternative. Choice to remain in the community for people living with dementia, chronic illness, frailty etc remains not only elusive and untenable, but consumer choice is out of reach for the majority of people who require support.

For people who wish to remain at home or in the community with their family and friends, and reject institutional life, and who have the means to do so, they can ‘top up’ their 15 hours per week of support through their private funds. However, this privately

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funded care does not attract legal or human rights protections, with the only legal recourse being general consumer law.

The Australian Government is currently reviewing the 1997 Age Care Act and the NDIS Act with a view to creating service lists including Assistive Technology Lists limiting the choice and control of appropriate AT options to a government department. Proposed amendments for the age care system, AT will be managed through a 'loan scheme' again with predetermined items. The current Aged Care Act is as it is not fit for purpose, and the proposed new Aged Care Act will also be unfit for purpose if it is not amended to reflect the human rights or indeed, the disability rights including equal access to the CRPD and other Conventions, of all consumers.

As Dementia Alliance International exclusively a membership of people living with dementia, it is impractical for us to prepare an Australia wide analysis of two separate systems such as the NDIS and the Age Care System. Alternatively, our responses will be tailored to the 'needs' of people living with dementia throughout the life course in relation to Assistive Technology, and the humans who support us, as opposed to describing solutions that we don't have access or input to at present.

As such our recommendations will be set at a strategic international level in the hopes that at least some other countries will have access to personal choice, person led solutions and innovation in the context of Assistive Technology.

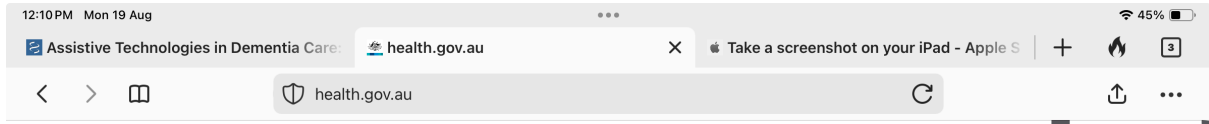


## Governance, Access to Information and Privacy

### Governance coordination and transformation in Australia

The Australian Department of Health and Age Care are currently in the process of a [‘digital transformation’ project](#) which aims to digitise, and automate data points in the age care context. Information provided to date indicates that the project aims to support the industry to exchange information.

There is scant evidence that the project will provide direct access or control to older people in general to their own information. This is best illustrated in the following diagram provided as part of the public facing project resources.



Older people and their support networks can navigate and actively participate in their care and wellbeing.

OUTCOME 1

| PRIORITY  | ACTIONS   | STATUS  |
|---|---|---|
| <p style="font-weight: bold; color: white; border-radius: 50%; width: 20px; height: 20px; display: flex; align-items: center; justify-content: center; margin: 0 auto;">P1</p> <p>Promote healthy ageing, independence and choice</p> | <p>Healthy ageing support tool - LiveUp™</p> <hr/> <p>Digital and health literacy</p> <hr/> <p>Translation of emerging digital technology</p> | <p style="text-align: right;">(</p> <p style="text-align: right;">(</p> <p style="text-align: right;">(</p> |
| <p style="font-weight: bold; color: white; border-radius: 50%; width: 20px; height: 20px; display: flex; align-items: center; justify-content: center; margin: 0 auto;">P2</p> <p>Create simplified, user-friendly experiences</p>    | <p>My Aged Care enhancements</p> <hr/> <p><u>Aged care digital design standards</u></p>   | <p style="text-align: right;">(</p> <p style="text-align: right;">(</p>                                     |

While priority 1 and 2 relate to older people, there is no improvement of agency in their care data or arrangements. These are solutions that suggest that older people and people with dementia simply need more information about lifestyle choices and the age care system. It is an information delivery system with no link to the individual's information either to read, interact with or update. In other words, for many older people and people living with dementia this is essentially a 'dead end'.

Many people living with dementia have provided feedback that the description of 'person centred technology' is counterproductive, as it strongly implies, reflects and promotes passivity of the older person. Furthermore, the term reinforces the fact that



'others' are working together around, and for us, but there is little to no two-way interaction between the people and systems sharing of information and the older person themselves. There is minimal, if any support for us to be our own advocates, or to manage our own care and support. The system is systematically discriminatory, and does not provide an accessible format, aligned to any Reasonable Adjustments that should be made for people with disabilities.



## Recommendation

DAI recommend that any member state who is a signatory to the CRPD is required to employ a team of people with *living experience* to consult on any proposed changes to policies and systems that affect their ability to live safely and well in the community in an accessible way that provides agency to the older person. This team should commence advisory services at the development stage - prior to the issue of any tender and should be involved all the way through tender development to implementation and review phase.

DAI recommend that Member States commit to providing accessible communications as a matter of course in seeking 'consultation' on policies and decisions that affect us. In the context of digital communications, this could be facilitated by a 'click here' button for example. People living with disability, particularly cognitive and intellectual disability, should not have to use an inaccessible system of email trails to beg for accessible materials. DAI notes that the current review of Australia's disability strategy does not facilitate verbal submission to a human being. They also recommend all policies, systems and services are accessible.

*'Unfortunately, due to the volume of submissions we are receiving for the ADS Review, we are unable to offer individual phone/virtual calls to receive responses.'*

DAI recommend that Member States be required to investigate and report on the **exact** mechanisms used for consultations involving people living with a disability, and explain decisions made when prioritising proxy voices such as government funded advocacy organisations and NGOs, government funded academics, clinicians, health



professionals, and other 'interested parties' to the exclusion or marginalisation of the very people these decisions will affect.

DAI further notes that bulk email surveys with closed ended questions developed by intermediaries where responses are rolled up, interpreted and passed on is not consultation.

In this format, no information is provided to the person living with dementia, no context is given for the questions, no human interaction is available to ask for clarity and no briefing or support is offered when the survey questions remind the person of exactly how vulnerable they are simply cannot be countenanced as truth.



## Challenges and successes in using digital technologies in the context of dementia.

### Access to information

There are three fundamental pillars to support people living with dementia to access both private and public information. These comprise:

Access to the hardware

Access to the Internet

Access to support to use the technology

Access to the hardware is limited for many people living with dementia in Australia, and will be potentially limited further through upcoming implementation of 'service lists' in both age care and disability care. Practical examples of where such lists are inappropriate include limits to the size of tablet that will be provided - excluding people with low vision and parkinsonian type motor symptoms. Limits on the brand of tablet, making some incompatible with phones, speakers for reminders, and smart home technology. This is exacerbated by difficulty in learning new platforms without support.

There are still many 'institutional care' premises that do not support access to technology through discouragement, lack of support and fear of the older person becoming emboldened to complain or reach out to advocacy services.

DAI recommends Member States commit to equitable access to hardware required to participate actively in life. Large scale transition to digital communication and



self-service models of sourcing support must be equally matched with the technology required to access such communication. This of course extends to vision and hearing technology and simple access to paper-based communication when this meets the person's needs.

In Australia, we do not have consistent country wide coverage of either telephone, mobile or internet. Service can be poor, erratic and subject to weather conditions making it quite unreliable as a core element of safety, risk or communication in an emergency. In Rural Regional and Remote Areas, we have some access to Starlink, however the cost is out of reach of most pensioners. On average a disability support pension is \$2500 per month. Internet costs can be as high as \$139 per month, a recurring fee which is substantial, for a service that is very often unreliable. Many institutional settings simply do not provide wi-fi, others charge additional high fees for wi-fi (when it's working of course).

DAI recommends Member States to consider if Digital Technology is appropriate for people without reliable access to the internet at an affordable cost. Banking, government and disability support as well as participation in civic life now requires such access. Technology platforms in areas of unreliable access lock out a great many people from participating in these fundamental areas of life and remove agency. Accessible alternatives must be provided to ensure equitable access to information and promote individual autonomy.

Many people living with dementia have a strong desire to use technology, however the impediments can be overwhelming. Reports of older people rejecting technology are



vastly overrated, and based on grass roots feedback, the truth is that many older people use that excuse because they don't want to burden their families for the support to use it well and safely.

Broadly speaking, care workers and support workers do not have the skills to support people living with dementia to use technology, and this is often overlooked in training programs - despite their being provided mainly online. However, even if support workers were skilled, we would have to trade our privacy for their support without any safeguards in place. This places risk not only on the individuals' personal information, but places the support worker in a difficult position.

DAI recommends that each rollout or review of digital platforms develops a training module that can be accessed by people living with disability and our supporters. This training should also be available in formats other than digital only such as paper based or in person options.

### Social Protection

We are unclear what is meant by 'social protection'. For the purposes of this submission DAI infer that this can be interpreted as access to online management and information in relation to their government funded supports.

In the Australian context, there is ongoing upgrade and rollout of 'digital solutions'. These are described as being 'person centred' however much of the work seems to centre around the "institutional care industry" and streamlining data from providers. The support recipient has little or no access to their own data, and no ability to consent

or refuse aggregation of personal data for other use. While this may improve in the future, it seems impractical for many people living with dementia to 'self-serve' and 'self-source' information online. Not only because of the practical impediments referred to above, but due to declining functionality as neurodegeneration occurs over time.

The complexity of systems, the siloing of health/age care/social security, the multiplicity of similar websites, poor design, small font, small devices and lack of support make it impossible for many of us with dementia to participate in the management of our own social support. Exposure draft of the new Age Care Act suggests that older people select a 'nominee' to manage their age care as a proxy. Similar expectations abound in the NDIS system, which places heavy reliance on family and friends to provide full administrative support for the management of care and support services. As many of us know, this is simply out of reach for many people living with dementia - old or young. Similarly, those of us living with dementia are encouraged to seek 'support with our decision making', placing further expectations on unpaid carers. These unpaid carers in many cases simply do not exist in our lives. For those of us with willing, articulate, English speaking, resourceful supporters, they work full time themselves and are raising families, and simply cannot afford to take unpaid leave to administrate for or with us, support us to do it ourselves or support us with other decisions.

The vulnerability of those of us who do not have capacity to use technology cannot be overstated, particularly in the context of insufficient support at home being a fundamental driver towards institutionalisation. Currently in Australia people living



with dementia have only one long term pathway and that is institutionalisation. There is no active deinstitutionalization program being considered for older people in particular. The previous Special Rapporteur for the CRPD, Catalina Devandas recommended deinstitutionalization of all people with disabilities in her final report<sup>2</sup>, and the UN released their Deinstitutionalization Guidelines in 2019<sup>3</sup>.

It is also interesting to note that while Australia provides a Carer Allowance of \$129 per fortnight for informal carers, this only covers face to face personal care, and will not be paid for administrative and supported decision making supports.

There is little to no Assistive Technology available to people living with dementia that is actually useful for us. Primarily it is 'deemed' useful to those around us.

We give the example of the very popular paradigm that people living with dementia have forgotten the past, and that it's a great way to keep us busy to put virtual reality goggles on us so that we can feel like we are in the past (when we were happy). Unfortunately for us, having VR goggles placed on a person that is already struggling with understanding and interacting with space-time simply exacerbates the vulnerability of the person. Such VR programs are never developed with a view to training specialised staff to brief and debrief the older person. There is no reference to whether the content of the VR movie may actually be a trauma trigger, or how sudden transition from one place to another and one time to another may actually make the older person more insecure and unsafe, and doubt their own eyes and ears even more.

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In its current form, VR is simply a cynical 'electronic babysitter', and expressions of fear and confusion will be labelled as 'bpsd'

DAI recommends that digital solutions prioritise accessibility, useability and share ability for people living with disability. Taking into consideration that these systems form the backbone of our safety and security.

DAI recommends that member states be required to ensure that authentic collaborative arrangements be built into any assistive technology development that will service people living with disability. Presently in Australia, terms such as 'co design', 'involvement' and 'consultation' are used interchangeably, and are often used as misdirection, providing the impression that the people living with disability are fully supported to actively participate in the planning, development and implementation of the program. Softly worded best practice 'principles' are being interpreted in ways that minimise us, and keep us at arms length. This must change.

### Passwords Security Spam and Scams

In Australia we have recently lived through a number of major data breaches and most of our personal data is now freely available. As such we are bombarded with scams. Many of us no longer use email, phone or text as it is unreliable and unsafe.

Of course the security response to these data breaches have resulted in the onus for security being placed on the user by way of multiple passwords, authentication apps often requiring multiple devices. All of our passwords had to be changed, and in the context of living with memory issues this is simply overwhelming. While the appetite





for technology for communication and learning is apparent, the ability of many older people and those of us with disabilities to safely engage with the online world has greatly diminished. Trust is gone and it will be difficult to retrieve. There seems to be little acknowledgement that the online world is not safe for us, and that reasonable adjustments need to be baked into every service so that we can continue to engage with life going forward. This may include providing information by mail again.

DAI recommends that member states broaden their consideration of what 'accessible communication' might look like in the context of dementia, intellectual and cognitive disability, supported decision making and potential for abuse.

### Consistency and Innovation in the online world

A major difficulty in navigating the online world for those of us living with dementia is the inconsistency across products, systems, services and security. Incompatible products, numerous complex passwords, fake websites and other misinformation is making online interaction almost impossible for many people with disabilities. While much money is being spent on AT for people living with dementia, the most practical and fundamental piece of software that we need does not exist. We need development of an accessible and safe identity management system that will interface with all private and government online systems. We need the outside systems to no longer record our passwords in a format that can be stolen. We need to be able to hold our own identity data offline, and have it automatically deleted from the outside party by our device at the end of the interaction. We need ways to interact using technology that does not require stable internet connection where we can prepare our interaction offline and send it through our id verification system held on our private device.



DAI are not experts in IT design, but surely there are new and better ideas to support people living with cognitive and intellectual disability to keep our information safe in a consistent way that gives us agency.

People living with dementia and those around us who support us are creative, innovative and do their best to be adaptable. We have numerous workarounds and props to assist us to live to the best of our abilities in the moment. These individual solutions remain embedded at the individual level. Peer support groups such as DAI enable people living with dementia to share these solutions, however our 'Wishlist' of assistive technology remains unavailable as we have no direct conduit or input into the idea, design or implementation. These processes are guided by the business community who have no access or requirement to work 'with 'us. The 'product development' model in use today results in inefficient and impractical assistive technology that we really don't want. Collaborative development schemes where people actually living with dementia drive the innovation and useability is a more economical, practical and efficient model, however ableism and ageism continues to work against us at a systemic level.

DAI suggests that member states give consideration to funding more and better research into practical assistive technology that will assist us to navigate the digital world easily and safely, that will support our dignity and independence without sacrificing our privacy and digital security.



## Training

There are numerous individual small scale training programmes across Australia supporting people to learn to use technology, however they are difficult to find, and almost impossible to discern legitimate businesses from fraudulent ones. In-home support workers don't have the funds or capacity to upskill and residential care providers are already loaded with training and development in so many areas that it would be difficult for them to prioritise digital and person specific AT training.

A consistent approach to supporting us to use technology across government and private enterprise would build momentum and perhaps begin the journey of redeveloping trust in online interactions. For example, current funding tools for age care do not have reference to AT support in the digital realm.

If the CRPD were to be applied across the life cycle, accessibility to digital technology and innovative individualised AT would be baked into the systems that are being built to support us.

In the external world, technology is moving at a fast pace with self-service options such as digital ordering of fast food and digital self-service checkouts. The increasing lack of human interaction in the food banking and service industries excludes many or most people living with dementia from participating in these fundamental activities of daily living. The flat terminals don't allow us to ask questions, confusion at checkouts draw attention from zealous security guards and staff, and essential services such as phone, internet and electricity can only be invoiced and paid for online. Many older people find themselves disconnected from these essential services as they have already been



‘scammed’ and no longer look at email as part of their lives. Similarly, phone scams have resulted in never answering unknown phone calls, and in the absence of a paper invoice, cannot access support to continue living independently - thus becoming a ‘captive market’ for institutionalisation. Technology in fact is quite a significant driver of institutionalisation, and this is rarely taken into account - particularly in the award of government support and contract arrangements for services.

DAI recommends member states ensure that training in the use of assistive technology is a core part of professional standards and training courses for support personnel.



## General information

Broadly speaking, people living with dementia, particularly in the prodromal and early stages are extremely creative in finding ways to support themselves to continue to live well independently and lower the 'burden' on our carers both paid and unpaid. However creativity and ingenuity can only take us so far, and isn't scalable.

DAI recommend that the final report highlights the necessity of co-developing policies, products and services with us, not for us.

This specifically means, co-design with, and inclusion of members our membership, and not only relying on engaging advocates with living experience of dementia through the other charities and organisations. As discussed on pX, DAI is the only independent, direct and autonomous voice of people of any age, diagnosed with any type of dementia in Australia, and globally.

We are systematically and legally excluded from having any impact on our own lives as we remain on a planet with a worldview that dementia 'starts at the end', and that we suddenly wake up at the end stage of the disease, with no acknowledgement or understanding that dementia is a progressive neurological condition.

While many may think that the concept of 'nothing about us without us' was embedded in society many years ago, and in the realms of certain disabilities this is the case, the hard fact is that people living with dementia are systematically 'excluded, ostracised,



demoralised, collateralised, and institutionalised without ever having the opportunity to contribute meaningfully and practically in influencing the world around them.

Thank you,

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Prepared and submitted on behalf of the Board of Directors and Members

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