ADA Australia
Your aged and disability advocates

18 August 2021

Committee Secretary
Community Support and Services Committee
Parliament House
George Street
Brisbane Qld 4000

By email: CSSC@parliament.qld.gov.au

Dear Committee Secretary

Social isolation and loneliness in Queensland

Thank you for the opportunity to provide feedback on the inquiry into social isolation and loneliness in Queensland (the **Inquiry**). Aged and Disability Advocacy Australia (**ADA**) appreciates being consulted on the investigation into these issues which have significant impacts on many Queenslanders.

About ADA Australia

ADA is a not for profit, independent, community-based advocacy and education service with nearly 30 years' experience in informing, supporting, representing and advocating in the interests of older people, and persons with disability in Queensland.

ADA also provides legal advocacy through ADA Law, a community legal centre and a division of ADA. ADA Law provides specialized legal advice to older people and people with disability, including those living with cognitive impairments or questioned capacity, on issues associated with human rights, elder abuse, and health and disability legal issues related to decision-making.

Review of Inquiry

ADA has reviewed the terms of reference and provides the following comments for the Committee's consideration.

1. *The **nature and extent** of the impact of social isolation and loneliness in Queensland, including but not limited to:*
   a) *identification of and consultation with vulnerable and disadvantaged individuals or groups at significant risk across the life course;*
   b) *the interplay of COVID-19 with this issue.*

Advocates report that feelings of loneliness are expressed by a significant portion of clients that ADA services. Whilst clearly apparent for many older people, it is also an issue for persons with disability.

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In some cases, social isolation for persons with disability is exacerbated by cultural and social characteristics of their community. Where shame is associated with presence of disability, a family may withdraw a person from contact with the community with the intention of shielding the family and the person from receiving negative attention. This social isolation may lead to, or intensify, feelings of loneliness experienced by the person with disability.

Social isolation and expressions of loneliness are widespread amongst older people, particularly persons who live alone, and amongst those who reside in aged care accommodation.

The World Health Organisation's advocacy brief, 'Social isolation and loneliness among older people'[1] analyses the percentage of persons who report feelings of loneliness and considers intersecting factors such as age, gender and accommodation. The brief finds that social isolation and loneliness amongst older people is widespread, and those in long term institutional care are more likely to be lonely than those in the community. The analysis considers various reports, and whilst a single age bracket is not unanimously identified as carrying the highest risk, several found that likelihood of loneliness and social isolation was increased for older persons. Upon review of 11 studies, the brief found that 35% of older people in residential and nursing care homes identified as being 'very lonely'.[2]

These figures support the experiences reported by ADA clients and observed by advocates.

Individual and systemic discrimination and unconscious bias against older persons and people with disability is common. Discriminatory behaviours minimise a person's opportunity to participate in their community, effecting factors which contribute to isolation and loneliness. Examples of this include:

- actions by adult children who rely on their appointment as enduring power of attorney to place parents into residential care, and in some cases, rarely visiting. Once placed within residential aged care, attorneys may also choose to restrict visitors, phone calls and visits from the facility, serving to further socially isolate older people. Aged care facilities consider that they are bound to follow the attorney's decisions in all circumstances;
- a person who is diagnosed with dementia and admitted to a secure aged care unit who is unable to communicate or make friends with other residents because of the dementia of those residents being more advanced. In some cases, residents with less advanced dementia are prevented from moving into the general care section of a facility because the diagnosis classes them as a flight risk;
- residents who live in a facility where many of the staff are from different cultural backgrounds to their own. In the absence of providing training to staff about how to bridge experiential and cultural differences, communication and connection suffers and the resident is left feeling misunderstood and frustrated. These interactions intensify feelings of loneliness, particularly where a resident's only contacts are staff. Older people for whom English is a second language and who experience cognitive decline may begin to struggle with English, and revert to their native tongue. This can cause further isolation as the number of persons with whom they can verbally converse further reduces.

[1] World Health Organisation, *Social isolation and loneliness among older people: advocacy brief* https://www.who.int/publications/i/item/9789240030749.
[2] Ibid, 3.

Impacts of COVID-19

The COVID-19 pandemic and associated impacts upon freedom of movement and gathering have caused increased isolation and fear, particularly amongst persons with existing health conditions. For example, a current ADA client in her early 70s lives with chronic obstructive pulmonary disease (**COPD**) and anxiety. The client is frequently hospitalised with chest infections and is understandably concerned about the risks associated with a COVID-19 infection for a person with chronic inflammatory lung disease. COPD causes decreased lung capacity, meaning it is difficult to breathe whilst wearing a mask. As a result, the client rarely leaves her home and has avoided any form of social interaction. Concerns about the risk of infection, alongside the client's changed behaviours, have exacerbated pre-pandemic challenges with anxiety. Flow on impacts include an elevation in feelings of isolation, hopelessness, and loneliness.

Clients who reside in residential aged care facilities and in communal disability accommodation have experienced greater limitations upon their movements and social interactions than other community sectors. This includes stringent constraints on social visitors as well as some service providers, such as persons delivering rehabilitative programs and advocacy services.

ADA acknowledges that these measures have been implemented with the intention to reduce risk of COVID-19 infection amongst persons considered to be at a higher probability of experiencing significant harm associated with the virus. However, the inconsistent application of protective measures by individual accommodation providers continues to be a concern. Some providers have adopted a rigid approach and continue to restrict resident movement and visitors at times when similar restrictions have not been in place in the community. Other services closed communal areas at residential facilities at the outset of the pandemic, and in some cases, have never reopened these areas. These restrictive measures are far beyond the Health Directives issued by the Chief Health Officer.

Removal of common areas and forcing residents to stay in their rooms has drastically reduced opportunities for residents to interact within the confines of a facility. These measures have not always been adequately justified as commensurate to the risk of infection at a point in time, with consideration given to local vaccination rates and extent of community transmission. The effect for persons in accommodation services is a cumulative escalation in isolation and loneliness, compounded by the duration of the pandemic and ongoing restrictions. A consequent decline in mental health amongst persons in residential accommodation services has become apparent.

2. The causes and drivers of social isolation and loneliness, including those unique to Queensland

We refer to our response to the above question and particularly the examples of institutional, community and individual bias against persons with disability and older people. This bias facilitates processes and acceptance of behaviours which minimise the inclusion of the person in their community. This results in greater isolation and loneliness for affected people, as well as a despondency about their ability to influence change where the processes are dictated by organisational procedures or culture. Ageism and ableism permeate community and institutional attitudes, resulting in actions, processes and cultures which deliver inferior outcomes for older people and persons with disability, which are easily evidenced when comparing the standards and norms which are applied to younger persons without disability. In relation to older people,

discriminatory attitudes and behaviours are very well documented, and particularly prevalent in provision of health care and aged care. The report 'What can you expect at your age?!' compiled by the Older Women's Network NSW and Health Consumers NSW (the **NSW Report**)[3] found that agism was at the core of discrimination towards older people in healthcare, with five major themes identified:[4]

1. Medical professionals not listening to concerns of older people
2. Minimising and dismissing illness concerns
3. Patronising language
4. Lack of appropriate care
5. Intersectionality of various forms of discrimination

A normalising attitude that 'this is just the way things are' is widespread amongst residential facilities, care institutions and is reflected by affected residents. The NSW Report considers, '*the older generation may have internalised discriminatory attitudes and ageist view themselves as a result of deeply entrenched societal norms that accept age discrimination as typical.*'[5] This attitude is emphasised in regional and remote areas of Queensland where choice of care and other service providers is limited, and there may be no alternative available.

ADA advocates describe examples where organisational attitudes and behaviours are lacking. These include unreasonable time pressures on staff – the adverse impacts associated with inadequate staff to resident ratios at residential care facilities are well known. These constraints are also pertinent for staff who provide specialised services for residents, such as physiotherapy or counselling. An ADA advocate gave a current example of this at an aged care facility, where the client is experiencing loneliness and a decline in mental health. The advocate has attempted to speak with the facility's divisional therapist on multiple occasions to discuss pathways which might assist the client, but has been unable to connect with the therapist as they are attending other residents.

Excessive procedural rigidity commonly reduces opportunities for interaction and social activities in institutional and residential care settings. A 'one size fits all' approach is applied, and in cases where this approach is incompatible with an individual there is rarely any further effort to engage a resident or to offer alternatives. When this is raised by ADA advocates on behalf of a client, the response is usually *"We offer that they come along to our activities"*, with no follow up or investigation about why the offer is not taken up. ADA's clients describe the activities offered as limited and of little interest in attending more than once – usually bingo, and card making.

In another example, a client who resided in the independent living section of a residential facility suffered a fall and became confined to a wheelchair. In need of higher care, he was moved to the 'nursing home' section of the facility. The client wished to visit his friends and support circle who remained in the independent living section and asked to attend the weekly bowls session that he enjoyed. Staff at the facility responded that they were not allowed to push residents between residential sections, and no compromise was offered. An ADA advocate investigated a taxi service to transport the client 200 metres, an option that was neither cost nor time effective. Without

[3] Chhetri A & Kanawait N, Older Women's Network NSW and Health Consumers NSW, 'What can you expect at your age?!': An investigation of recent experiences of age discrimination by older adults accessing health care, (2021)
[4] Ibid, 21.
[5] Ibid, 29.

meaningful participation by the service provider, a reasonable solution was not found and consequently the client is not able to catch up with his social support network.

Other causative factors include a lack of funding for specialised services that provide culturally safe support for Aboriginal and Torres Strait Islander persons. An ADA client seeking to attend a local indigenous respite centre has been unsuccessful because the centre is at capacity and not able to accept new bookings.

Absence of a support network is common for older persons and people with disability. Other drivers include lack of finances or services (for example, a transport service), or inadequate skills or resources to investigate and procure those support services that are available. Persons with a cognitive impairment, communication difficulty, and persons from culturally diverse or non-English speaking backgrounds face additional obstacles in seeking out accessible avenues for social interaction.

3. Protective factors known to mitigate social isolation and loneliness

Factors that are likely to reduce incidence of isolation include having a strong network of support, which may be comprised of family, friends, neighbours, community-based groups, or a combination of these.

Other factors include where an individual has educational, cognitive, financial and personal capacity to take steps towards social engagement and maintaining relationships – such as initiating conversations, investigating community activities (including computer skills), keeping appointments, and transportation to attend a meeting or activity.

4. Benefits of addressing social isolation and loneliness, examples of successful initiatives undertaken nationally and internationally and how to measure social isolation and loneliness in Queensland to determine if implemented strategies are effective

There is significant evidence that social isolation and loneliness increase risks of physical health conditions for older persons, including stroke, cardiovascular disease and mental conditions.[6]

It follows that mortality risk also increases. A study which reviewed data collected through 148 studies found that the influence of social relationships on risk for mortality is comparable with well-established mortality risk factors, such as smoking and alcohol consumption, and exceed the influence of risk factors such as physical activity and obesity.[7]

Addressing social isolation and loneliness will not only improve an individual's quality of life, it will also reduce the corresponding financial burden on society. A study in the United Kingdom estimated that excess costs for health and long-term care due to loneliness was £11,725 per person over 15

[6] Ibid, 4.

[7] Holt-Lunstad J, Smith T, Bradley Layton J. Social Relationships and Mortality Risk: A Meta-analytic Review (2010) PLOS Medicine 7(7), < https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000316>.

years.[8] Older people experiencing loneliness are likely to visit their doctor for social interaction even when medical treatment is not needed, increasing the costs of service provision.[9]

Initiatives supported by the Older Person's Advocacy Network (**OPAN**) have demonstrated successful methods for increasing social connectedness and decreasing isolation and loneliness amongst older people. OPAN joined with the ABC in the delivery of the televised social experiment 'Old People's Home for 4-Year-Olds', which brought together older persons experiencing loneliness with a group of 4-year-olds in an environment of intergenerational play and learning. Participants overwhelming reported outcomes of greater connection and friendship, with decreased feelings of isolation and loneliness.

Other services and initiative associated with the ABC/OPAN partnership include programs to teach online skills to older people, telephone support lines, and intergenerational playgroups.[10] These programs have been well-received with demonstrated positive impacts for older participants.

Home and community care options for older persons have evolved in other jurisdictions, with integrated and individualised models now well-established in Sweden and Japan. Sweden's approach of taking care of older persons in their own home for as long as possible has enabled older people to maintain independence and remain in community for longer. Approximately 94% of people aged over 65 live at home, assisted by a health care worker and delivery services (such as ready-cooked meals) if required.[11]

State and Federal government should collaborate to advance alternative models of care (including dementia care living arrangements) with a focus on increasing support for older persons and people with disability to remain in their own homes. Alongside this, connection programs such as those supported by OPAN should be immediately rolled out into existing residential care facilities and in the community.

5. *How current investment by the Queensland Government, other levels of government, the non-government, corporate and other sectors may be leveraged to prevent, mitigate and address the drivers and impacts of social isolation and loneliness across Queensland, including:*
    a. *services and programs such as health and mental health, transport, housing, education, employment and training, sport and recreation, community services and facilities, digital inclusion, volunteering, the arts and culture, community development, and planning for accessible, inclusive and connected communities*
    b. *targeted support to vulnerable and disadvantaged groups and those most at risk*

[8] Ibid reference 1, 5, referring to: Fulton L, Jupp B. Investing to tackle loneliness: a discussion paper. In: Social Finance. London: Cabinet Office; 2015 https://www.socialfinance.org.uk/sites/default/files/publications/investing_to_tackle_loneliness.pdf.

[9] This is supported by multiple studies. See for example: Gerst-Emerson K, Jayawardhana J. Loneliness as a public health issue: the impact of loneliness on health care utilization among older adults. Am J Public Health. 2015;105:1013–9 http://dx.doi.org/doi:10.2105/ AJPH.2014.302427, and Zhang J, Xu L, Li J, Sun L, Ding G, Qin W et al. Loneliness and health service utilization among the rural elderly in Shandong, China: a cross-sectional study. Int J Environ Res Public Health. 2018;15:1468 (http://dx.doi.org/ doi:10.3390/ijerph15071468).

[10] See for example the services listed at Older Persons Advocacy Network <https://opan.org.au/stayconnected/stay-connected/>.

[11] Global Health Aging, Sweden: A Role Model for Elderly Care, <https://globalhealthaging.org/2014/08/03/sweden-a-role-model-for-elderly-care/>.

Appropriate investment aimed at programs and preventative strategies is required, at a government and industry level. In accommodation facilities, a program should be implemented which seeks to increase opportunities for accessible individual participation in social activities in addition to other strategies, with appropriate resourcing, skillset and cultural intention to manage modification to accommodate an individual's needs.

In aged care accommodation, this might include a dedicated employee who is tasked with facilitating social programs and avenues for residents, including community participation, activities, adaptive tools, and technology. The focus should be on collaborating with a person who is experiencing or at risk of loneliness, to assist them with accessing social interaction strategies and activities that the individual finds enjoyable.

Government must initiative a campaign designed to combat agism, starting with a focus on government messaging or assuming older persons are a homogenous cohort. Mindful communication and policy development with respect to use of the word 'vulnerable' is required, as without appropriate education and context this is commonly interpreted as 'feeble' or being in need of saving, in relation to older people and persons with disability. This thinking disassociates government policy, programs and decision-making from the person as an individual, and is reflected by society and institutions in discriminatory decision-making and standards imposed on or on behalf of the adult.

A whole of government strategy would assist in positively influencing industry and community attitudes towards older people and persons with disability. Current attitudes focus solely on provision of immediate clinical need. This norm is underpinned by societal discrimination outlined above, which does not consider the social needs of persons with disability and older people to be relevant, or as important as those of the wider community.

6. *The role, scope and priorities of a state-wide strategy to address social isolation and loneliness, considering interactions with existing Queensland and national strategies.*

Localised and appropriately funded staff and advocates will be critical to the success of any strategy, if policies are to be effective for affected individuals located across Queensland. Service implementation should be underpinned by consistent standards, with adequate flexibility in programs and delivery options. Design must consider the diversity of isolated individuals, imbedding choice and participation options regardless of geographic location, age and disability.

Thank you again for the opportunity to comment. ADA would be pleased to further assist the Committee with its inquiry. Should you wish to discuss this submission, please do not hesitate to contact Vanessa Krulin, Solicitor and Senior Policy and Research Officer on [redacted] or via [redacted]

Yours faithfully

Geoff Rowe
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