

6 September 2021

Ms Corrine McMillan MP
Chairperson
Community Support and Services Committee
Parliament House
George Street
BRISBANE QLD 4000

e: CSSC@parliament.qld.gov.au

Dear Chairperson,

Can I begin by thanking the Committee for accepting this submission; I only began my role as Public Advocate for Queensland on 13 August 2021.

As members of the Committee will know, the role of Public Advocate is to be a systemic advocate for adults with impaired decision-making capacity. It is about this group of Queenslanders that I write this submission.

The submission focusses on two overlapping cohorts of people; older Queenslanders and adult Queenslanders with cognitive disability.

For older people, there are demographic trends that make the risk that they will experience isolation and/or loneliness somewhat greater than has been the case in the past. People are living longer, with declining mobility as they age. People now have, on average, smaller families, with fewer extended relatives with whom to interact.

In addition to these trends, people who receive aged care services are increasingly receiving these services in their own homes. While this carries the benefit of enabling people to live in their own homes longer, it also carries the risk of isolation for the recipient.

The national Royal Commission into Aged Care Quality and Safety recently summarised the situation for many older people well:

We heard that for many people, the experience of growing old is a lonely one. It can be isolating to be reliant on others for essential physical and social support. Declining cognition and mobility and increasing frailty can make it harder for those receiving care at home to maintain contact with family and friends. Loneliness and social isolation are often exacerbated by mobility issues and difficulties in accessing transport to leave the house.¹

One of the Royal Commission's recommendations was to seek 'a social supports category within the aged care program' that will assist to provide 'supports that reduce and prevent social isolation and loneliness'.²

¹ Aged and Community Services Australia in Royal Commission into Aged Care Quality and Safety, *Final Report Care Dignity and Respect – Volume 3A: The New System*, 1 March 2021, p 93 <<https://agedcare.royalcommission.gov.au/publications/final-report-volume-3a>>.

² Royal Commission into Aged Care Quality and Safety, *Final Report Care Dignity and Respect – Volume 1: Summary and Recommendations*, 1 March 2021, p 232 <<https://agedcare.royalcommission.gov.au/publications/final-report-volume-1>>

For Queenslanders with disability, who number more than 900,000 people, a combination of factors can lead to their isolation. This includes low employment rates, with people with disability experiencing twice the rate of unemployment of people without disability.³ Employment itself typically provides a significant avenue for social engagement – in the workplace and travelling to the workplace – while unemployment carries the obvious additional impact on a person's ability to fund social engagement activities. Other factors also inhibit the social engagement of people with disability, including limited accessible transport options, particularly for people living outside cities. Stigma related to disability can also affect a person's social engagement. A 2021 national survey undertaken by the Centre of Research Excellence in Disability and Health, found that 'people with disability report experiencing discrimination and prejudice in their day-to-day life which excludes them from many domains of life including work, school, accessing services and the community'.⁴

Institutional settings

For many adult Queenslanders with cognitive disability who reside in institutional settings, such as residential aged care facilities, or in shared disability accommodation (including residential supported accommodation), social engagement can often be limited to involvement with paid carers and support providers.

For people living in these types of facilities (particularly during the COVID-19 pandemic), there is a sense of exclusion, initially generated by residing in accommodation that is 'different' to the rest of the community, and then with rules that govern visitation by friends and family and limit the opportunity for more spontaneous social interaction.

Professor Henry Brodaty AO, a psychogeriatrician, physician, psychiatrist and Scientia Professor of Ageing and Mental Health at the University of New South Wales, said, at a hearing of the Royal Commission into Aged Care Quality and Safety:

We see that residents are very lonely in nursing homes. I had a PhD student who, her thesis was on social relationships in nursing home. The median number of relationships that a person in a nursing home had was one. That means 50 per cent had zero, and most of the relationships are with the staff.⁵

The Royal Commission concluded that:

The lack of care and support for people's social and emotional needs is a consequence of several problems in the current aged care system. Staff do not have the time or skills to provide individualised care to people in residential aged care. The task-based focus of work in residential aged care does not sufficiently allow consideration for the person who is being cared for, their wants or social and emotional needs. There is an inadequate focus on helping people receiving aged care services stay connected to the broader community.⁶

Consequently, one of the Royal Commission's recommendations was to rename the federal Community Visitors program as the 'Aged Care Volunteer Visitors Scheme' and expand its operations 'to provide extended support for older people receiving aged care who are at risk of social isolation'.⁷

³ Australian Institute of Health Welfare (AIHW), *People with Disability in Australia 2020*, p 255
<<https://www.aihw.gov.au/getmedia/ee5ee3c2-152d-4b5f-9901-71d483b47f03/aihw-dis-72.pdf.aspx?inline=true>>

⁴ Centre for Research Excellence in Disability and Health, *Attitudes Matter: Findings from a national survey of community attitudes toward people with disability in Australia – Executive Summary*, Melbourne, Australia, 2021, p 4
< https://melbourne.figshare.com/articles/online_resource/_/15176013?file=29162736>

⁵ Royal Commission into Aged Care Quality and Safety, *Final Report Care Dignity and Respect Volume 2: The Current System*, p 135, 1 March 2021, < https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-2_0.pdf>

⁶ Royal Commission into Aged Care Quality and Safety, *Final Report Care Dignity and Respect Volume 2: The Current System*, p 135, 1 March 2021, < https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-2_0.pdf>

⁷ Royal Commission into Aged Care Quality and Safety, *Final Report Care Dignity and Respect Volume 1: Summary and Recommendations*, p 239, 1 March 2021, < <https://agedcare.royalcommission.gov.au/publications/final-report-volume-1>>

Loneliness is also particularly evident in the lives of younger people with disability who reside in residential aged care facilities. A witness to the Royal Commission into Aged Care Quality and Safety, Mr Kevin Littley, said this about his daughter's experience as a younger person in residential aged care:

So, yes, she was pretty much—very lonely. If it wasn't for Carol and myself and her sister, she wouldn't have had any visitors and any outside contact because she was pretty much in her room.⁸

The federal government has now made a range of commitments regarding younger people in residential aged care, including that no person under the age of 45 years will be residing in residential aged care from 2022 and no person under the age of 65 years from 2025.⁹

In-home isolation

Increasingly we are witnessing a changing pattern for the delivery of social services, away from provision in institutional settings, to more service delivery occurring to peoples' homes in the general community. This trend is happening more quickly in the delivery of disability services with the introduction of the NDIS, but increasingly we are also witnessing it in the delivery of aged care services.

In part, this trend has resulted from a burgeoning human rights awareness, particularly in relation to the rights of people with disability, which has been informed by important international conventions including the Convention on the Rights of Persons with Disabilities (which Australia signed in 2007 and ratified in 2008). This convention holds, for instance, that peoples' human rights are better served in home-like settings and not in institutions.

The trend toward in-home delivery of services has also resulted from the 'consumer choice' principle that increasingly underwrites social service delivery, particularly in the delivery of disability services under the NDIS, and now becoming more evident in the provision of aged care services. This is a development about which I wrote in a recent report from the Victorian Office of the Public Advocate (where I was until recently Deputy Public Advocate): *Decision Time: Activating the rights of adults with cognitive disability*.

The move towards increased levels of in-home rather than institutionalised care has largely been a positive one; but it can result in an increased degree of isolation when services 'come to' the homes of recipients, rather than the recipients either travelling to where services are provided or being among other people where services are provided.

More than 90,000 Queenslanders with disability now receive NDIS-funded supports, with these supports being increasingly delivered in people's homes (much more than was the case with pre-NDIS disability services). This can mean, at times, that individuals with disability, particularly people with little or no involvement of family members in their lives, rarely interact with people who are not paid to deliver services to them. This has the potential to have catastrophic implications, as the death from malnutrition of Ms Ann-Marie Smith in Adelaide demonstrated. Ms Smith was an NDIS participant who received services from a sole carer. Her horrific death identified the very real dangers that social isolation can pose to at-risk adults, which should lead to major adult safeguarding reforms, particularly in relation to the delivery of NDIS services.

Another risk confronting NDIS participants in the consumer choice environment is what is known as 'market failure'; the situation where a person has funds available to pay for the delivery of a service, but where no service is available to be delivered. In this sense, consumer choice also means

⁸ Royal Commission into Aged Care Quality and Safety, *Final Report Care Dignity and Respect Volume 2: The Current System*, p 135, 1 March 2021, < https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-2_0.pdf>

⁹ Royal Commission into Aged Care Quality and Safety, *Final Report Care Dignity and Respect Volume 1: Summary and Recommendations*, p 121, 1 March 2021, < <https://agedcare.royalcommission.gov.au/publications/final-report-volume-1>>

'provider choice', the result of which is that people, particularly those living in rural or remote regions, can remain isolated even though they may have a significant entitlement to funded services.

While the consumer choice principle increasingly underwrites the delivery of social services, this does not always translate into choice about where and with whom people live. The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability noted, for instance, that: 'lack of choice in where people can live and with whom they live (particularly in a group home environment) ... contributes to a sense of isolation, loneliness and increased risk of abuse and neglect'.¹⁰

Covid-19

We know too that the Covid-19 pandemic has increased the isolation of marginalised Queenslanders, whose health is often more compromised than that of other Queenslanders. This has occurred both as a direct result of public health requirements (which have limited people's ability to travel outside their homes and to receive visitors, particularly those in residential care facilities like disability accommodation, supported accommodation and residential aged care) and has also resulted in some degree of self-isolation (where, for instance, people with compromised health have withdrawn even from outside activities that they have been permitted to continue).

Potential reforms

In contemplating possible reforms, it is important to acknowledge that people can be isolated and not lonely. People have varying levels of what for them constitutes the right amount of social engagement. Equally people can be lonely and not isolated. This can happen, for instance, when people live with others in settings that are not of their choosing. The key here is that we need to provide opportunities that facilitate a person's choice and control over their level of, and access to, social engagement.

A report by the Commissioner for Senior Victorians on isolation and loneliness identified six 'building blocks' and called for coordinated state government action in each of these areas.¹¹

The six areas covered:

- transport and personal mobility;
- education and access to information
- referral pathways
- local inclusion
- purposeful ageing
- a seniors action plan

These areas provide a good basis for considering reform opportunities and could potentially be incorporated into the Queensland government's age-friendly community strategic direction and action plan (or equivalent).

A new National Disability Strategy is also being developed which has the potential to address the isolation experienced by many people with disability. The new State Disability Plan, which will follow development of the national plan, has perhaps even greater potential in this regard.

Actions at a state level to reduce the incidence of social isolation and loneliness amongst people with disability could include:

- ensuring that mainstream services (health, education, transport) are accessible to people with not only physical but also cognitive disability;

¹⁰ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Third Progress Report*, p 32, February 2021, < https://disability.royalcommission.gov.au/system/files/2021-02/Third%20Progress%20report_0.pdf>

¹¹ Commissioner for Senior Victorians, *Ageing is everyone's business: A report on isolation and loneliness among senior Victorians*, 2016, < <https://www.seniorsonline.vic.gov.au/-/media/seniors/files/commissioner-for-senior-victorians/ageing-is-everyones-businessweb.pdf?la=en&hash=E7A9C37DB2DEA4D1ACDA9EE2D52670C644B24635>>

- requiring 'universal design' principles to apply not only to the built environment, but to the delivery of social support programs and services; and
- leading innovative developments in the creation and design of inclusive communities, which, for instance, encourage and prompt 'unplanned' social interactions.

I would be pleased to make myself available to the Committee or your staff if you would like to discuss any of the issues raised in this letter. I can be contacted on [REDACTED] or via email at [REDACTED]

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'John Chesterman', with a long horizontal flourish extending to the right.

John Chesterman (Dr)
Public Advocate