STANDING COMMITTEE ON EDUCATION AND COMMUNITY INCLUSION Mr Michael Pettersson MLA (Chair), Miss Laura Nuttall MLA (Deputy Chair), Ms Nicole Lawder MLA (Member)

Submission Cover Sheet

Inquiry into Loneliness and Social Isolation in the ACT

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Legislative Assembly for the ACT Standing Committee on Education & Community Inclusion GPO Box 1020 CANBERRA ACT 2601

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HCCA Submission:

ACT Legislative Assembly Inquiry into Loneliness & Social Isolation

We are pleased to provide our submission to the above Inquiry.

We provide input from our members on:

- the Inquiry's process and conceptualisation of social isolation & Ioneliness;
- general impacts of and factors affecting social isolation & loneliness
- impacts of social isolation & loneliness on specific groups;
- structural and economic impacts on social isolation & loneliness; and
- suggestions on finding and developing solutions.

The volume of responses received from HCCA members demonstrates the breadth and depth of the impact of social isolation and loneliness in their lives and the lives of their families and friends. Members expressed that the Inquiry is important, relevant and timely.

Yours sincerely

Darlene Cox

Executive Director

23 February 2024



SUBMISSION

ACT Legislative Assembly Inquiry into Loneliness & Social Isolation

February 2024

About HCCA

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- · community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is a Health Promotion Charity registered with the Australian Charities and Notfor-Profits Commission.

Introduction

The negative health impacts of social isolation and loneliness are well documented both nationally^{1 2} and internationally^{3 4 5 6} and we do not repeat them here as we take them as known and understood by the Inquiry and the motivation for it. What HCCA's submission provides is how social isolation and loneliness are experienced by health consumers in Canberra and their perceptions and understandings of its causes and ideas for solutions.

Inquiry's process and conceptualisation of social isolation & loneliness

Inquiry process

One of our members commented that targeted and proactive strategies to engage with socially isolated and lonely people was needed in the Inquiry process:

You can't conduct an effective inquiry into loneliness and social isolation without putting in effort to consult with isolated people. An online process is not sufficient. How are you going to get to understand the isolated people and what they want and need? The consultation process needs to invite/facilitate the participation of targeted cohorts.

Conceptualising & understanding social isolation & loneliness

A HCCA member felt that "social connectedness" was a clinical term and that framing it this way would lead to 'clinical' rather than 'human' solutions.

One member pointed out that:

Social isolation and loneliness are not the same thing. An individual can be one and not the other. There may be different solutions for each.

Another member when referring to her adult aged daughter wrote that:

Loneliness is not just having none or few friends - it can be a feeling of disconnectedness from others. even family.

General impacts of and factors affecting social isolation & loneliness

Effects compound over time

Highlighting the importance of prevention, a HCCA member noted the spiralling downward effect of social isolation & loneliness:

The effects of loneliness compound over time. People lose touch and it is extremely difficult to meet new people if there are no events or no way to attend them.

Dealing with shame and stigma attached to social isolation & loneliness

A HCCA member said that often there was shame and stigma surrounding social isolation and loneliness:

There is shame attached to being lonely. A sense that no one wants to spend time with you and you're not trying hard enough.

Impact of self-service

A HCCA member noted that the move towards self-service in the retail and banking sectors reduced opportunities to socialise for people experiencing isolation and loneliness. This was particularly true for older people who they felt would benefit most from incidental social contact day to day.

Transient populations

The high proportion of people who move to Canberra as short-term residents is seen as having an impact on Canberra's ability to build a strong sense of community.

Social isolation & loneliness in specific groups

People with caring responsibilities

Social isolation and loneliness are significant issues for people with caring responsibilities:

This is a big issue for carers. There is a lack of resources, a lack of respite and a lack of staff. No respite means no accessing your community, no going out, no time to rest and recover to continue caring.

A member shared an article on the carer burden in couples where one is neurodivergent and the other is neurotypical. Caregiver burden was comparatively high and related to feelings of social isolation and loneliness ⁷. Community connection, support and recognition of neurodivergent relationships can improve the caregiver burden of social isolation and loneliness for neurotypical partners.

Access to and availability of respite is an ongoing issue for people with caring responsibilities:

To provide social opportunities for carers, the main thing I would suggest that many or most need is good old respite! If there are new policies to bring this change it would be fantastic!

Respite could mean more in-home care support for the care recipient, as with Mum - sending her even to a dementia cottage to give me, as her carer, a break would actually cause a lot of extra stress for both of us. It's better for Mum, for example, to just stay at home in familiar surroundings and routines and have a support worker "live in" (or shifts of a few familiar workers), than to be sent to an institution or strange place. That would potentially send Mum into major stress, which would in turn take us several steps backwards with cognition etc, from which she may not spring back to her "normal". Respite has to be what is actually best for each situation, not insisting on an option that isn't appropriate e.g. "just send her to an aged care home for a week".

On that, even an aged care home isn't an option at the moment, as I mentioned, a well-established home in the ACT told me they offer short-term respite, but are booked out til 2025...

People living with chronic conditions

A member shared their positive experiences of being able to attend support and information groups related to their conditions, particularly when these conditions are uncommon. The group meets weekly and this frequency is important to participants. Living with chronic conditions intersects with all the other dimensions listed here which can then compound feelings of social isolation and loneliness.

People living with disabilities

People living with disabilities experience exclusion which contributes to social isolation and loneliness:

Many of the activities combatting isolation for people with disabilities are either attached to NDIS funding or run with specific grants that aren't sustainable. They are also often paternalistic or exclusionary – e.g. a social worker running special days out for people with disability like it's a supported living activity, rather than making general community events more accessible to all of us. I would much rather that public events have better transport and venues so that I can hang out with my non-disabled peers as well.

There is a continued need for education on eligibility and assistance with applying for NDIS funding:

People with disability living at home can be eligible for home care packages but not everyone knows they are eligible.

Increased education on NDIS eligibility and funding will assist people living with disabilities to address their feelings of social isolation and loneliness, enabling them to more fully participate in our communities.

People living with mental health conditions

People living with mental health conditions can need active strategies to assist them to attend activities, including a group leader or facilitator to encourage participation and monitor their wellbeing when they do attend:

My daughter would need a 'group leader' to initiate connections as she would not be able to begin conversations and connections off her own bat due to her social anxiety and as a person living with ADHD she doesn't read people well.

People from multicultural backgrounds

HCCA members said social isolation and loneliness are serious issues for people from multicultural backgrounds, exacerbated by the ongoing impacts of racism. Members felt that when people from multicultural backgrounds did attend events/gatherings they did not feel included and feel there are no opportunities to share their own situations and experiences. Language and cultural barriers both affect social isolation and loneliness.

There are a range of cultural barriers including the high prevalence of alcohol at social events.

Addressing racism in schools and workplaces is important to prevent feelings of exclusion because of race and/or cultural background.

The intersections of being from a multicultural background and being female, or being LGBTIQA+, or being younger or being older lead to increased feelings of social isolation and loneliness.

While the Multicultural Festival is viewed positively there was a call for more multicultural events throughout the year particularly for younger people:

I've had various conversations from the multicultural youth perspective who don't have their families here, how disconnected they feel from people, language, culture, and how outside of the Multicultural Festival they feel very isolated/that there is a lack of a multicultural identity in Canberra.

Older people

The impacts of social isolation and loneliness in older people are well known.^{8 9} A consumer observed:

Elderly people are often looking for places to connect – sometimes this ends up being unnecessary GP appointments.

As noted above, older people from multicultural backgrounds are seen as being particularly prone to social isolation and loneliness. For example, members mentioned the loneliness of grandparents with little or no English coming to assist with the care of grandchildren who are very lonely and isolated.

Younger people

We note that more younger people aged 15-24 now report feeling lonely than those aged 55 and over with young females more likely to report experiencing loneliness.² 10

Structural and economic impacts on social isolation & loneliness

Cost of living pressures reduce ability to connect

Rising costs of living and the difficulties in meeting these whilst on a fixed income reduces people's abilities to connect:

Living on a fixed income is difficult – cost of living pressures increases social isolation. We need to increase people's financial capacity to reduce isolation.

Transport

The importance of accessible and affordable forms of transport was raised several times by our members. Not being able to access transport had significant impacts on their mental health and wellbeing and social connectedness:

Transport is by far the biggest thing that creates loneliness and isolation for me and other friends living with disabilities.

- Many of my friends can't drive, and the public transport system is so patchy, particularly on weekends, that we may go months without seeing friends. It is particularly bad for people living in the outer suburbs, where it may take 2+ hours to reach a friends' home in another part of town.
- Through COVID, ride shares and taxis have continued to be more expensive so that is not an option for many it easily costs me \$80 just to visit a friend or attend an event. Even if I bus part way and then get a ride share, in most cases that's still easily \$30-40 each way.
- For many of us younger LGBTQIA+ people, community events are held at night, but buses stop at 10pm, so we have to miss a large number of the big social events.
- Where there are free events put on, e.g. support groups, health seminars, group exercise classes, it is often the cost and time needed for transport that stops myself and others I know from participating.
- The answer to a lot of these transport woes has been to move events online. However online options are not always good replacements for face-to-face, and for myself and others I've spoken to. Participating in only online spaces in fact contributes to feelings of isolation.

People from multicultural backgrounds reported how difficult it is to navigate public transport systems because of language barriers.

Community transport was mentioned as highly valued way of staying connected. Suggestions for increased free transport to large scale events, such as sporting and theatre events, is seen as important,.

Accessible and affordable public facilities for community groups

Accessible public facilities is a major issue:

- There are very few low-cost accessible public venues for communities to use in the ACT. The Salthouse Community Centre is a perfect example – while accessible, the bond is so much that most small groups I know could not put it up, even if refundable.
- The lack of affordable community facilities for not-for-profits also means they are often far from good public transport (e.g. Hackett and Pearce Community Centres are both at the end of convoluted suburban routes so anyone coming from out of region is looking at 90 minutes travel time) and in older buildings with access issues. This prevents the groups from running accessible face-to-face events for the communities they serve or if they do put on events, attendance is low due to the effort for people to get there.

Finding & developing solutions

Suggestions for solutions from our members included:

 People experiencing social isolation and loneliness need to be involved and listened to in the development of solutions.

- Solutions need to address causes of social isolation and loneliness, not just manage symptoms.
- Plan and build environments that reduce the possibility of social isolation and loneliness. Utilise existing data collection to inform the planning and development of strategies that support future interventions such as through the Census.
- Increase frequency of existing opportunities for social connection:

I've noticed this with activities, e.g. just once a month. It's not enough! If you aren't available that day e.g. at appt, then you have to wait two months to go!

Helping people connect to existing resources and activities:

One of the main issues is finding out about resources. Depending on certain algorithms you could google support services and not have the most suitable place come up. I think this is one of the main problems: people not knowing where to turn for help. This is because just doing a google search may not give you the information you need and if someone is in distress.

There needs to be a website like 'volunteers ACT' which lists all the resources (and is up to date) for people to connect.

- Increased funding for people from multicultural backgrounds to participate and connect, including cultural community organisations and seniors' clubs and societies. Examples of the latter included Bangladesh Senior Citizens organisation and facilities dedicated to senior citizens. People from multicultural backgrounds also suggested increasing and promoting volunteering amongst seniors as a way of promoting connection and inclusion.
- Reducing duplication of existing services and/or concentration of resources and services in the same organisations is important for people from multicultural backgrounds. That is, increase the type and variety of organisations funded to provide services to cover diverse needs within our communities.
- We note the emerging evidence on effective interventions at the personal level documented by the WHO and other sources¹¹ ¹² although it is largely focussed on older people.

¹ https://www.aihw.gov.au/reports/australias-welfare/social-isolation-and-loneliness

² https://www.aihw.gov.au/getmedia/c47cb232-4f6f-4eb0-853e-d6018f6ee01c/aihw-aus-246_chapter_2.pdf

³ https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthyageing/social-isolation-and-loneliness

⁴ https://www.cdc.gov/aging/publications/features/lonely-older-adults.html

⁵ https://publichealth.tulane.edu/blog/effects-of-social-isolation-on-mental-health/

⁶ Leigh-Hunt, N., Bagguley, D., Bash, K., Turner, V., Turnbull, S., Valtorta, N., & Caan, W., 2017. An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health (London)*, *152*, 157-. https://doi.org/10.1016/j.puhe.2017.07.035

⁷ https://www.cambridge.org/core/journals/journal-of-relationships-research/article/abs/caregiver-burden-and-relationship-satisfaction-in-asdnt-relationships/30F2E4E23FA215944DF7BA42380579EF

⁸ Social isolation and loneliness in older adults: opportunities for the health care system. (2020). National Academies Press. https://doi.org/10.17226/25663

⁹ Blazer, D. (2020). Social Isolation and Loneliness in Older Adults—A Mental Health/Public Health Challenge. *JAMA Psychiatry (Chicago, III.)*, 77(10), 990–991. https://doi.org/10.1001/jamapsychiatry.2020.1054

¹⁰ Beam, C. R., & Kim, A. J. (2020). Psychological sequelae of social isolation and loneliness might be a larger problem in young adults than older adults. *Psychological Trauma: Theory, Research, Practice, and Policy, 12*(S1), S58–S60. https://doi.org/10.1037/tra0000774

¹¹ https://www.who.int/initiatives/decade-of-healthy-ageing/evidence-gap-map/sil-inperson

¹² https://nap.nationalacademies.org/catalog/25663/social-isolation-and-loneliness-in-older-adults-opportunities-for-the