



Advocacy for Inclusion

Incorporating People with Disabilities ACT

2.02 Griffin Centre

20 Genge Street

Canberra City 2601

(02) 6257 4005

ABN: 90670934099

www.advocacyforinclusion.org

Standing Committee on Education and Community Inclusion
ACT Legislative Assembly
GPO Box 1020, Canberra ACT 2601

Via email: LCommitteeECI@parliament.act.gov.au

Dear Standing Committee,

Inquiry into Loneliness and Social Isolation in the ACT

Thank you for the opportunity to make a submission to this Inquiry.

This is an important inquiry, emerging at a time when the causes and consequences of loneliness and social isolation are particularly acute. This submission addresses, to varying extents, the social, economic, and health consequences of loneliness and social isolation for people with disability. It also emphasises the continued impact of COVID-19 for people with disability. It concludes with a focus on some of the causes of loneliness and isolation amongst people with disability plus policy priorities and initiatives which might start to address these.

About us

Advocacy for Inclusion incorporating People with Disabilities ACT¹ is an independent organisation delivering reputable national systemic advocacy informed by our experience in individual advocacy and community and government consultation. We provide dedicated individual and self-advocacy services, training, information and resources in the ACT.

As a Disabled People's Organisation, the majority of our organisation, including our Board of Management, staff and members, are people with disabilities. Advocacy for Inclusion speaks with the authority of lived experience. It is strongly committed to advancing opportunities for the insights, experiences and opinions of people with disabilities to be heard and acknowledged.

¹ On March 24, 2021, Advocacy for Inclusion (AFI) officially merged with People with Disabilities ACT (PWDACT), a systemic advocacy organisation based in the ACT. Herein, reference to 'AFI' also acknowledges the values and philosophies of PWDACT.

Advocacy for Inclusion operates under a human rights framework. We uphold the principles of the United Nations Convention on the Rights of Persons with Disabilities and strive to promote and advance the human rights and inclusion of people with disabilities in the community. Advocacy for Inclusion is a declared public authority under the Human Rights Act 2004.

Disability and the ACT: Background

Around 1 in 5 Canberrans has a disability. The proportion of people with disability in the ACT has increased over time, rising from 15.8% in 2012 to 16.2% in 2015, to 19.4% in 2018. The ACT also has a greater prevalence of reported disability across all age groups, compared to the rest of Australia.

Across the ACT, people with disability have a lower participation rate in terms of employment and full-time work. People with disability are more likely to rely on government pension or allowance as a primary form of income and are far less likely to own their own home. This means many people with disability experience poor economic outcomes, health inequities, financial hardship, un(der)employment, housing insecurity, and poverty. All these factors put people with disability at a heightened risk of loneliness and social isolation.

Human Rights

Advocacy for Inclusion are invested in social isolation and loneliness because it is an issue experienced by our members contributing to poor life outcomes, there is an evidence base and role of accessibility, inclusion and participation as Human Rights within the UN Convention on the Rights of Persons with Disabilities (CRPD). Relevant articles of the CRPD include: [Article 9 – Accessibility](#), [Article 19 – Living independently and being included in the community](#) and [Article 30 – Participation in cultural life, recreation, leisure and sport](#).

The impacts of social isolation and loneliness

The degree to which individuals are interconnected and embedded in communities has a powerful impact on their health and wellbeing. Social isolation and loneliness are associated with declines in physical and mental health. There is consistent evidence linking social isolation and loneliness to, for example, worse cardiovascular and mental health outcomes.² The impacts of loneliness also include an increased risk of cancer, high blood pressure, and decreased resistance to infection. Loneliness is a bigger risk factor for mortality than obesity and physical inactivity and is reported to have health effects equivalent to smoking 15 cigarettes per day.³

Without broad community and political recognition of social isolation and loneliness, and urgent support through policy and investment, the health and wellbeing of people with disability is increasingly at risk. To ensure well-targeted support, it is

² Freak-Poli, R., Ryan, J., Neumann, J.T., Tonkin, A., Reid, C.M., Woods, R.L., Nelson, M., Stocks, N., Berk, M., McNeil, J.J. and Britt, C., 2021. [Social isolation, social support and loneliness as predictors of cardiovascular disease incidence and mortality](#). *BMC geriatrics*, 21(1), pp.1-14.

³ Holt-Lunstad, J., Smith, T.B., Baker, M., Harris, T. and Stephenson, D., 2015. [Loneliness and social isolation as risk factors for mortality: a meta-analytic review](#). *Perspectives on psychological science*, 10(2), pp.227-237.

worth stressing that loneliness and social isolation are separate and distinct concepts. Social isolation is generally defined by a low frequency of social contact while loneliness has been defined primarily as an emotional state.⁴ Researchers have found, for example, that the correlation between loneliness and social isolation is moderate at best: some people appreciate solitude, while others can be surrounded by people but still feel lonely.⁵ Loneliness and social isolation have deleterious effects when coupled with a desire for more, or satisfying, social relationships and inclusion.⁶

The evidence base on social isolation by people with disabilities needs improvement but what we do know indicates that boredom, loneliness and isolation are recurrent experiences by people with disability.

Over the past twenty years, the prevalence of loneliness has been greater among people with disability in Australia. Preliminary research using the Household, Income and Labour Dynamics in Australia (HILDA) has indicated that people with disability are **1.5 to 1.9 times** more likely to experience loneliness than people without disability.⁷ It also shows more than 1 in 4 people with disability reporting loneliness. In 2020, the prevalence of loneliness was considerably higher for people with intellectual and learning disability, psychological disability or brain injury or stroke, compared to sensory and speech, physical, or 'other' disability.

Work by the ABS, including [Social Participation of People with a Disability, 2011](#) shows lower participation in just about every domain:

- Over 37,000 people with disability don't leave their homes.
- Many people don't take part in sport and people with intellectual or physical disability reported a lower attendance at sporting events (31 and 41 per cent respectively), compared to people who didn't have a disability (58 per cent).
- People go out less - whether visits to parks, attending community arts activities or going to the movies.
- People have fewer friends and are more likely to nominate a family member they could rely on than friends. They also had fewer people they could rely on in an emergency.
- People are also less likely to attend community events whether they live in city, regional or remote. And if they do people are much more likely to participate in groups with a health/welfare focus which may be related to care and support arrangements.

⁴ For a full overview, see Emerson, E., Fortune, N., Llewellyn, G. and Stancliffe, R., 2021. [Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: Cross-sectional study](#). *Disability and health journal*, 14(1), p.100965.

⁵ See e.g., Macdonald, S.J., Deacon, L., Nixon, J., Akintola, A., Gillingham, A., Kent, J., Ellis, G., Mathews, D., Ismail, A., Sullivan, S. and Dore, S., 2018. 'The invisible enemy': disability, loneliness and isolation. *Disability & Society*, 33(7), pp.1138-1159.

⁶ Badcock JC, Holt-Lunstad J, Garcia E, Bombaci P and Lim MH (2022) [Position statement: addressing social isolation and loneliness and the power of human connection- external site opens in new window](#), Global Initiative on Loneliness and Connection (GILC).

⁷ Bishop, G.M., Llewellyn, G., Kavanagh, A.M., Badland, H., Bailie, J., Stancliffe, R., Emerson, E., Fortune, N. and Aitken, Z., 2023. [Disability-related inequalities in the prevalence of loneliness across the lifespan: trends from Australia, 2003 to 2020](#). Preliminary research.

Reasons included costs, a feeling of nowhere to go, lack of transport, no carer to go with, no companions or friends, and fear and anxiety. Safety was also mentioned, including the possibility of not having someone else around to provide help in the case of a mishap, such as a fall.

The COVID-19 pandemic, resulting policy actions (and inactions) pertaining to national lockdowns, social distancing, and the continued shielding of at-risk persons have also exacerbated loneliness and reduced social contact for people with disability.⁸ It is important to stress that social isolation and loneliness among people with disability are further compounded by the lack of consistent COVID-19 measures. The true impact of the ongoing pandemic, and the community's experience of Long COVID, is still unfolding.

In the ACT, people with disability reported a lower sense of belonging in the community.⁹ As indicated by the ACT Wellbeing Framework, a sense of belonging corresponds to a capacity to access support during difficult times and give support to others. People with disability also report a lower sense of inclusion in their local community. Finally, people with disability were almost twice as likely to have experienced discrimination in the ACT in the past 12 months. The data emerging from the ACT Wellbeing Indicators demonstrates the heightened risk of loneliness and social isolation for people with disability in the ACT.

Some groups of people with disability in some settings are more cut off from contact with the world than the inmates of a supermax prison facility.

A [2015 submission](#) by the Summer Foundation to the Senate Inquiry into the circumstances of younger people with disability in aged care stated that 21 per cent of younger people in nursing homes *never* go outside, 34 per cent never participate in activities such as shopping, leisure or visiting friends and family, and 53 per cent receive a visit from a friend *less than once a year*.

To conclude, loneliness and social isolation have significant social, health and human rights implications. However, a recent report also highlights the significant economic impacts of loneliness. The Connection Matters report estimates that the overall average cost associated with each person who becomes lonely is \$1,565 per year, or \$2.7 billion for the whole population.¹⁰ Loneliness and social isolation are also likely to place additional strain on the health system as the need for and use of services increases.

Policy issues, priorities and solutions

Loneliness and social isolation have a disproportionate presence and impact on people with disability. It is present and consequential. For instance, they contribute to the people most needing to have a friend to call on in an emergency being the least likely to have one.

⁸ Australian Institute of Health and Welfare, 2022, [People with disability in Australia 2022: In brief](#), p. 31.

⁹ See, <https://www.act.gov.au/wellbeing/explore-overall-wellbeing/identity-and-belonging/sense-of-belonging-and-inclusion>

¹⁰ Groundswell Foundation, 2022. [Connections Matter: A report on the impacts of loneliness in Australia](#). KPMG Australia.

Our policy issues and priorities therefore focus on some of the causes of loneliness and isolation, the need to prioritise this as a public policy issue plus policy priorities and initiatives which might have an impact.

Access to transport, spaces and places

Some people with disabilities are socially disconnected because they are unable to access spaces and places in their local communities in ways that are safe, affordable and appropriate. The ACT's public transport system including its bus fleet are not fully accessible. Too many of our streets, cycle paths and shared pedestrian areas present accessibility challenges. A single element of cracked paving or non-compliant curbing can prevent people from being able to access their local shops or community centres within a seamless path of travel. Building work and urban disruption across the city have created more barriers over the last several years as the city undergoes rapid development. Some of Canberra's community hubs are located in older schools with inconsistent levels of accessibility. Some group centres lack disability toilets. Poorly lit paths and paths and streets can also deter vulnerable people from going out at night. Two of the ACT's major event spaces, Epic and Bruce Stadium have poor general accessibility including parking, general access and egress and disability toilets.

Recommendation:

The ACT should fully implement the ACT Disability Strategy, build a focus on social planning in the new planning system and undertake dedicated work to improve accessibility in places and spaces which foster social connections including a grants program aimed at addressing accessibility blackspots.

COVID safe spaces

The ongoing COVID19 pandemic means that people with disability must now factor in the risk of acquiring a life-threatening illness when considering whether to gather in social settings. Inconsistent messaging about masks, clean air and health risks mean that COVID cautious people cannot be confident that indoor events will be safe. Some people with disabilities have now been in an effective personal lockdown since uncontrolled community wide transmission of COVID began in September 2021. Since 2020/21 has been no recognition of this issue or work to address the needs of people who continue to isolate for their safety such as provision of in-reach social supports, community development work or the fostering of peer support activity.

Recommendation:

The ACT should respond to AFI's White Paper on COVID-19 and adopt recommendations aimed at encouraging COVID safe spaces and offering community development and in reach to Canberrans who continue to be isolated in the pandemic.

Occupational therapy and social supports in health and care settings

The ACT has people with disabilities in health and care settings like the Canberra Hospital and the University of Canberra Rehabilitation Hospital. Some people are in these settings for many months due to onset conditions requiring extensive health interventions, rehabilitation from accident or injury and complicated by delays in getting modified housing or other disability. This is a group that is extremely isolated

yet our observation is that there are minimal recreation, activities and social work supports, peer support and occupational therapy with the explicit aim of conquering boredom, isolation and loneliness in these settings. Occupational Therapy is available but it tends to be rationed and focussed on assisting people to leave settings rather than providing supports to people to remain engaged while they have to stay within settings.

Recommendation

ACT Health should trial activities officers in rehabilitation settings including UCRH to foster peer support, activities and social connections.

Information and referral services on sports, tourism, recreation and the arts

Since the defunding of the *National Specialist Disability Information Services program* in 2015 by the Abbott Government there has been no reliable comprehensive searchable continuously updated information and referral service linking people to accessible sport, tourism, recreation, accommodation, volunteering and other opportunities. While there are some websites that provide elements of these services what is required is a continuously updated service that is capable of linking people with specialist and mainstream recreation opportunities. The Commonwealth's Disability Gateway is mainly focussed on government services. IDEA's has a good basis for this service but there is a need for more granular, stratified and local information, including on opportunities here in the ACT.

Recommendation:

Governments via the National Cabinet should prioritise the rebuilding of capacity for information and referral services for accessible sports, recreation, tourism, accommodation, volunteering and the arts for people with disabilities. These might usefully be constructed and integrated within the new layer of 'foundational supports' envisaged by the NDIS Review.

Non elite grassroots sports and recreation

There is a lack of consistent policy attention, investment and activity in non-elite sports and recreation activities for people with disabilities. There are some programs focussed on health benefits and active ageing but there is no strong consistent focus on this area. The ACT has made some efforts here in the past such as the Participate and Connect Expos but is required are more accessible and inclusive activities. We advocate for a community development approach which fosters and creates opportunities for people to be involved in a range of activities which keep them involved and connected. These might involve grants and dedicated workers.

Recommendation:

There should be a policy agenda around promoting inclusion within non elite sports, arts and recreational activities for people with disabilities, especially focussed on opening up mainstream participation. Facets of this should include dedicated grants, education and training and community development workers. Again this might be a function of the proposed foundational supports. However this might also be achieved by broadening the remit of employment providers to encompass both social and economic participation. It should be someone's job to help people with major barriers to participation to get active in all parts of their lives, not just into employment.

Need for a disability participation agenda outside employment

Despite evidence that social and economic participation are linked, the Commonwealth, and to some extent the States and Territories, have maintained a narrow focus on employment outcomes for people with disability while there is very little focus on building social connections and participation in sport, recreation, volunteering and community life.

This is problematic on several levels including sustainable employment outcomes. There is good evidence that people who are connected and engaged socially or through sport pick up soft skills, resilience and connections which are valuable in finding and/or sustaining employment. There are also benefits in terms of health and wellbeing. Unemployment means people are more likely to be isolated, but being isolated also means it's harder to find and sustain work.

Recommendation:

Linked to the recommendation above there should be an explicit acknowledgment of the intrinsic importance and value of both social and economic participation of people with disabilities as a policy outcome. Adjacent to that there is a need for a regular focus in data collection on the experiences of social isolation by people with disability. For instance, the last ABS collation on social participation and people with a disability was 13 years ago in 2011.

Thank you for the opportunity to make a submission to the inquiry. Please feel free to contact me or our Head of Policy Craig Wallace. We would be happy to appear before the inquiry or expand on this submission as needed.

Regards,

A handwritten signature in black ink that reads "Nicolas". The signature is written in a cursive style with a horizontal line underneath the name.

Nicolas Lawler
CEO
Advocacy for Inclusion