INQUIRY INTO PREVALENCE, CAUSES AND IMPACTS OF LONELINESS IN NEW SOUTH WALES

Organisation: NSW Council for Intellectual Disability

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Submission to Inquiry

Prevalence, causes and impacts of loneliness in New South Wales

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Introduction

The New South Wales Council for Intellectual Disability (CID) welcomes the opportunity to submit our insights to the New South Wales (NSW) Government's Parliamentary Inquiry into Loneliness. This issue significantly impacts the wellbeing of many Australians, and it is especially pronounced for individuals with intellectual disabilities. For those with intellectual disability, loneliness is often exacerbated by social isolation, exclusionary practices, and various societal barriers. This submission emphasises the distinct experiences of loneliness encountered by individuals with intellectual disability, supported by extensive research, and presents recommendations to tackle the structural, social and personal obstacles that contribute to this issue.

To prepare for our submission, we engaged with Council Members and Project Workers at CID, all of whom have an intellectual disability. By consulting individuals with intellectual disability, we gained valuable insights into their lived experiences of loneliness. We developed a series of questions derived from the committee's questionnaire and created an easy read format for individuals with intellectual disability. Our recommendations, detailed in the submission, are a reflection of these findings.

Who We Are

NSW Council for Intellectual Disability (CID) is a disability rights organisation led by people with intellectual disability. For more than 65 years we have been working to ensure a community where all people with intellectual disability are included and valued.

We speak up on the big issues, we provide information and learning opportunities, and we empower individuals and communities.

Defining Loneliness

Loneliness is a complex and multifaceted experience characterised by a subjective feeling of disconnection, isolation and a lack of meaningful social relationships. Unlike social isolation, which is an objective assessment of social connections, loneliness can be felt by individuals who are not necessarily isolated (Park, Majeed, Tamura, Ho, Mansur, Nasri, Lee, Rosenblat, Wong & McIntyre, 2020). Research shows that loneliness can have significant negative impacts on various aspects of health and wellbeing, including mental health issues such as anxiety and depression.

Loneliness is inherently subjective and is often described as a sense of lacking – whether it be companionship, understanding or a feeling of belonging. People with intellectual disability are particularly susceptible to loneliness due to the barriers they face in accessing social opportunities and building meaningful relationships. It is important to note that loneliness and social isolation are two distinct concepts; a person may be alone without feeling lonely, while another may be surrounded by others and still experience deep loneliness. This distinction is crucial, especially for those with intellectual disability who may be physically present in social spaces but still feel disconnected due to a lack of genuine social inclusion.

The Impact of Loneliness on People with Intellectual Disability

Research consistently indicates that individuals with intellectual disability face higher rates of loneliness compared to the general population. Studies reveal that up to 50% of those with ID experience chronic loneliness, in contrast to about 15-30% of the general population (Gilmore and Cuskelly, 2014;) (Petroutsou, Hassiotis and Afia, 2017). This significant gap stems from social exclusion, a lack of opportunities for meaningful connections, and societal attitudes that undermine the value of contributions from individuals with disabilities. Typically, people with intellectual disabilities have smaller social circles, with relationships primarily limited to family members or paid support staff, which further alienates them from wider community engagement (Petroutsou et al., 2017).

Relationship between Loneliness and Health

The effects of loneliness on health are extensively documented. Individuals with intellectual disabilities already experience higher rates of mental and physical health challenges, and loneliness can worsen these existing health disparities. Research indicates that loneliness can result in elevated stress levels, decreased physical activity, and deteriorating mental health, all of which lead to a diminished quality of life (Bishop, Llewellyn, Kavanagh, Badland, Bailie, Stancliffe, Emerson, Fortune & Aitkin, 2024).

Those with intellectual disabilities are particularly vulnerable to mental health issues due to barriers in accessing appropriate healthcare and support. Additionally, chronic illnesses can trigger or exacerbate mental health conditions like depression and

anxiety, potentially increasing the risk of suicidal ideation (Gilmore and Cuskelly, 2014). The additional weight of loneliness can further heighten this vulnerability, posing a significant public health issue.

Barriers to Social Participation and Inclusion

People with intellectual disability encounter numerous barriers to social inclusion, which heightens their risk of loneliness. These barriers include:

- **Societal attitudes and stigma:** Stigma and a lack of understanding from the broader community often prevent individuals with an intellectual disability from forming meaningful relationships with peers without disability. According to a study by Wilson et al. (2016), people with intellectual disability often face negative attitudes and discrimination in public spaces, which discourages them from participating in community activities. These attitudes create environments that are unwelcoming, making it difficult for individuals to establish and maintain social connections.

  Members of CID with intellectual disabilities shared their experiences within the community, highlighting instances when they faced discrimination from others.

"Those words, I hear them on the bus sometimes… spastic, retard, you're useless, are still very much around in the community… even though we're in 2024 some of the things we still experience as people with a disability, we cop all the time, people's attitudes is one of the biggest things" - CID Advocacy Group Member with Lived Experience

- **Limited opportunities for participation:** Individuals with intellectual disabilities often do not have access to regular community-based activities that promote social inclusion. Many experience segregation in educational settings, the workforce, and leisure activities. When speaking to members of CID with intellectual disability we found that they had not accessed a community activity aimed at promoting social inclusivity, and had no knowledge of any in their local area. Those that did, relied on support workers or friends to seek out activities.

- **Over reliance on formal programs**: While formal disability services provide important support for people with intellectual disability, they often do not offer the same opportunities for spontaneous social interactions that occur in more inclusive and mainstream settings. A significant number of people with intellectual disability rely on structured social groups for social interaction, but these groups can sometimes reinforce segregation rather than promote true inclusion (Wilson et al., 2016). The disability support sectors over reliance on a casual and often underpaid workforce can also impact the social dynamics of these formal programs, with day-to-day variations affecting their utility for providing social connection.

- **Lack of accessible transport:** Many individuals with intellectual disability rely on public transport or supported transport, and limitations in these services restrict their ability to engage socially. Without reliable transport, people with intellectual disability are often unable to attend social events, recreational activities or employment opportunities.

- **Lack of accessible information:** People with intellectual disability find it difficult to navigate government websites and apps. Information is difficult to find and as a result people with intellectual disability need to rely on others to find the information they require and then act on it. This is demeaning and, in many cases people do not have access to the support of family members or support services. The ability to access information plays a crucial role in allowing people with intellectual disability to participate in the community.

Barriers to Employment and the Impact on Loneliness

Employment plays a crucial role in social inclusion, providing individuals with opportunities to build relationships and participate in their communities. However, people with intellectual disability face significant barriers to employment, which can exacerbate their feelings of loneliness and exclusion. Merrells et al. (2019) revealed that many young adults with ID face challenges in securing employment and often experience rejection from employers due to their disability. This exclusion from the workforce not only impacts their financial independence but also limits their ability to form social connection with colleagues, and integrate into their community.

"When I was sitting at home it made me feel bored and when I was at home I just wanted to be out working and earning more money, because I was getting more from the DSP (Disability Support Pension) than I was from working... I sort of felt unimportant and no one valued what I can do" – CID Project Worker with Lived Experience

Despite the NSW Government's target for 5.6% of public sector roles to be held by individuals with disabilities by 2025, current representation only sits at 2.5%. Additionally, those with intellectual disabilities in these roles remains even lower. The NSW Premier's Priority to enhance public sector employment for people with disabilities must include targeted initiatives to ensure equitable opportunities for people with intellectual disabilities.

Currently the NDIS reports that 29% of participants with an intellectual disability are in paid jobs. However, more than 70% of these people are working in Australian Disability Enterprises, where people are segregated from society and wages are as low as $2.50 per hour. Segregated employment, coupled with the scarcity of job opportunities in mainstream environments, makes it hard for people to truly integrate into the workforce and leads to feelings of social isolation and loneliness.

Recommendations for Addressing Loneliness in People with Intellectual Disability

1. Foundational and General Supports to Address Loneliness

The implementation of Foundational and General Supports by the NSW Government presents an opportunity to address loneliness and social exclusion experienced by people with intellectual disability. These supports can provide a holistic approach to assist individuals in accessing the resources they need to participate fully in their communities. The NSW Government should align these supports with initiatives aimed at expanding social inclusion and combating loneliness.

Expand Structured Social Programs

Structured social programs have proven effective in fostering inclusion and reducing loneliness among people with intellectual disability (Wilson et al., 2016). The NSW Government should invest in community-based social groups that provide individuals with opportunities to build relationships, engage in shared activities, and develop social skills. These programs should focus on creating environments where participants can form meaningful connections and feel a sense of belonging.

As part of the implementation of Foundational Supports the NSW Government must consider ways of fostering relationships between people with and without disability. These programs need to be varied in interest to allow for the inclusion of different demographics, and mimic mainstream activities. They must also be low cost for people with disability to access, to ensure individuals can overcome financial barriers to participation. There are examples of activities and initiatives already in communities that could be expanded upon and applied across NSW. These include:

- Gig Buddies Sydney: Is a program that pairs people with intellectual disabilities with volunteers, with similar interests, to attend concerts, events and social activities together. Gig Buddies Sydney - Disability, Socialising and Volunteering - Australia
- Purple Hearts: Is a program run by Randwick City Football Club, open to anyone with a disability who is interested in football. It aims to promote friendship through sport. Randwick City Football Club - Purple Hearts
- Refettorio OzHarvest: Is a social impact partnership between OzHarvest and chef Massimo Bottura's 'Food for Soul'. It is a restaurant that offers free meals to those experiencing food insecurity, in a social and mainstream setting. Charities are able to book groups for lunch during the week. Refettorio OzHarvest Sydney | Australian-first, social impact restaurant

- Active and Creative Kids Vouchers: NSW Government currently provides parents, guardians and carers receiving Family Tax Benefit a $50 voucher twice a year to use towards sport, creative and cultural activities. Expanding this to go to families with children with intellectual disability, increasing the frequency and amount, to ensure access to available programs.

Support the Development of Peer Networks

Peer supports have already been acknowledged as a priority within the framework of Foundational Supports. CID supports the expansion of both peer support and mentorship programs, as they provide an important network for individuals with intellectual disability to form meaningful relationships with others who share similar experiences. These programs should be designed to promote the development of friendships and social networks, helping to mitigate the isolation that many individuals face.

Additionally, all programs, activities and initiatives need to be promoted in a way that is accessible for those with intellectual disability. Currently information is hard to understand and difficult to access. This extends beyond the NSW Governments commitment to produce government information in Easy Read. As part of Foundational Supports the NSW Government needs to address the way information on programs, activities and initiatives is distributed to people with intellectual disabilities.

"It is very difficult to find the information you want... talk to services but they can never help, you go round in circles trying to get information" – CID Advocacy Group Member with lived experience

2. Improve Access to Employment

The NSW Government is committed to 5.6% of its employees being people with disability. However, at current only 2.5% has been achieved, with people with intellectual disability representing an even smaller proportion. One small but positive step is a current pilot project in Revenue NSW specifically employing people with intellectual disability.

Use Job customisation as a key employment strategy. Job customisation involves reallocating tasks from other roles or adapting a role to suit both candidates and the needs of the organisation. See CID's Inclusive Employment Guides for more information https://cid.org.au/resource-category/jobs-and-education/

There is also scope to require organisations that procure services from the Government to be referenced if they employ people with intellectual disability. See

CID submission to Inquiry on Procurement Practices of Government Agencies. [0051 Council for Intellectual Disability.pdf (nsw.gov.au)](nsw.gov.au)

CID's 'More Than Just a Job' program provides a strong example of how tailored training for employers can help create more inclusive workplaces for people with intellectual disability. By equipping both government and non-government employers with the skills needed to support employees with intellectual disability, programs like this provide opportunities to build relationships with colleagues and ultimately a sense of belonging.

3. Promote Inclusive Community Practices

To foster true inclusion, the NSW Government must address the attitudinal barriers that contribute to the exclusion of people with intellectual disability. Public awareness campaigns that challenge negative stereotypes and highlight the value of diversity in social relationships are essential. These campaigns should promote inclusive practices in schools, workplaces, and community settings, encouraging the active participation of people with intellectual disability in all aspects of life. In establishing these campaigns, people with intellectual disability must be central in the creation and execution.

4. Increase Transportation and Improve Accessibility

One of the key barriers to social inclusion identified in the research is the lack of accessible transportation options (Merrells, Buchanan and Waters, 2019). The NSW Government should ensure that public transportation is fully available and accessible to people with intellectual disability, allowing them to participate more freely in community activities.

Additionally, accessible community spaces and events must be prioritised to ensure that individuals with intellectual disability can engage in social interactions without facing physical or cognitive barriers.

5. Supported Decision Making

CID recommends that Supported Decision Making (SDM) be integrated as a core element of employment and community inclusion strategies for people with intellectual disability. Everyone has the right to be an autonomous decision maker, including the right to good support to maximize autonomy and build ability (Bigby, Carney, Then, Wiesel, Sinclair, Douglas and Duffy, 2023).

SDM highlights the importance of social connections and meaningful relationships which are based on dignity and respect. This shift to focusing on the strengths of the person contributes to reframing social attitudes towards people with disabilities and assists to break down barriers that can lead to loneliness. SDM empowers individuals by providing the support needed to make their own decisions, thereby enhancing autonomy and self-determination.

For people with intellectual disability, having the right support to make decisions about their own lives—including employment and community participation—can reduce the risk of loneliness and foster greater social inclusion. CID believes that embedding SDM principles across government policies, workplaces, and community services can lead to more meaningful opportunities for people with intellectual disability to participate fully in society, make informed decisions about their future, and feel more connected.

For more information about these recommendations please contact CID.

Citations

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