

Submission
No 66

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

Organisation: Being Mental Health Consumers

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Loneliness

BEING's submission to the NSW Government
Inquiry into Loneliness

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Introduction

BEING – Mental Health Consumers is the independent, NSW peak organisation speaking with and for people with lived/living experience of mental health issues and emotional distress. Our primary focus is to ensure the voices of people with mental health challenges (“consumers”) are heard by decision makers, service providers, and the community, to lead and influence systemic change.

BEING – Mental Health Consumers is committed to human rights principles and believes that recovery is possible for all people who live with mental health issues and emotional distress. BEING would like to see human rights conventions upheld across the whole mental health sector, inclusive of but not limited to the Convention on the Rights of Persons with Disabilities (CRPD). More work needs to be done in this area.

There are several important ways in which mental health issues and loneliness intersect. People living with mental health issues are already subject to stigma and to the discrimination that can result from bearing a stigmatised identity. ⁱ Those who live with already stigmatised identities will struggle to be fully open to others and to find full recognition and acceptance. ⁱⁱ Making new friends always involves asking yourself whether to share the stigmatised identity you bear or not and hence also whether to risk the judgement, or rejection of others. This is true whether you are lgbtqia+, live with a mental health issue, or struggle with addiction, to offer just a few examples. To add to this, the lived experience of certain mental health conditions also makes it inherently more difficult to reach out to and connect with others. Whether it is social anxiety, fears and concerns about other people's intentions towards you, or low self-esteem, mental health issues can be a significant barrier to connecting with others and to sustaining those connections.

Another important example of the impact of intersectionality in relation to loneliness and psychosocial disability is neurodiversity. Both Autism Spectrum Condition and ADHD are closely associated with social interaction challenges that can make it significantly more difficult to build and maintain relationships with others. Likewise, both groups are also more likely to live with other stigmatising mental health labels as well.

We strongly believe that loneliness needs to be addressed as part of a more intersectional approach to mental health issues which would regularly and effectively review and support the physical health, social wellbeing and mental health of mental health consumers. ⁱⁱⁱ

A rights-based perspective on loneliness?

While some issues that significantly impact people living with mental health issues are clearly and helpfully addressed in currently existent international human rights frameworks, including involuntary treatment, supported decision making and social inclusion, there is currently no established right to social connection. The *Convention on the Rights of People with Disabilities (CRPD)*, ^{iv} the human rights framework that is most relevant to people living with mental health issues, does not include a right to social connection, although it does protect the right to workplace and educational inclusion. That said, rights to education, ^v rehabilitation ^{vi} and workplace participation ^{vii} do provide a foundation for a less lonely world for people living with psychosocial disabilities by protecting incidental social inclusion. There is some current research that argues in favour of a right to social connection ^{viii}, however it has not yet been integrated into any major human rights statements that Australia is a signatory to.

Preparation of this submission

In preparing this submission as well as carrying out desk research, we carried out a survey of people who live with mental health issues to try to understand some of the lived experiences of people living with mental health issues in NSW. We have used the results of this survey to supplement the work done on much larger samples by other researchers and advocates in the space and in particular the most recent large-scale research carried out in *Social Connection in Australia* which was released in 2023. Note also that we have only responded to those questions which we felt we were able to helpfully respond to.

Key takeaways from BEING's Loneliness survey

Some of the key findings from BEING's survey which targeted the experience of people living with mental health issues were that **many respondents (75%) agreed that others would judge them if they admitted to feeling lonely**. Further to that **85% said that fear of other people's judgement had stopped them from reaching out in the past**.

Respondents identified psychologists as the main individuals they reached out to for support when they felt lonely, however some people also included partners, friends and immediate family members to this list. Some of the activities that were helpful for respondents when they were trying to address their feelings of loneliness were exercise, sport, caring for a pet, studying and using social media.

Recommendations

- Develop a more holistic approach to mental health care that integrates physical health care and social wellbeing including loneliness.
- Improve community education in relation to loneliness to reduce the stigma of telling others you are lonely
- Improve community education in relation to loneliness to ensure that stigmatising and unsupportive responses to loneliness are less likely.
- Include loneliness in the current business as usual of mental support services to provide advice and support with reconnecting with the community

The extent of loneliness and social isolation in NSW and how this is measured and recorded including opportunities for additional and/or improved data capture

The Covid 19 pandemic and its aftermath has produced a greater awareness of loneliness in the community and a series of recent investigations into the prevalence and causes of loneliness in Australia have followed. These have included *Strong*

Together – Loneliness and Social Connection in Australia^{ix}, *Understanding Loneliness and Mental Health*^x, *Loneliness in Focus*^{xi} and *Social Connection in Australia*^{xii} which was released only last year.

The most recent and extensive of these investigations, ***Social Connection in Australia***, found that **29% of people in NSW experience loneliness**.^{xiii} This is roughly aligned with other states with around a third of people experiencing loneliness in each Australian state. This makes loneliness a significant problem across Australia. Greater loneliness is also experienced in rural and remote areas in NSW with **35% of people living in rural and remote areas feeling lonely by contrast with 30% in metropolitan areas**.^{xiv}

The NSW Mental health commission, in *Loneliness in Focus*, which referred to data from 2020 and 2021 found that in 2020 29% of the NSW population were experiencing loneliness and in 2021 around 37%.^{xv} This suggests that the levels of loneliness experienced in NSW may now have moved back to a pre-covid level, but that they are still nevertheless at alarmingly high levels given the correlations between loneliness and other health and mental health issues that have been identified.

The identification of populations most at risk of loneliness and social isolation

In line with our comments in the introduction, people with mental health issues are one of the groups that has been identified as being at a significantly elevated risk of loneliness in recent research. **People who are feeling severely lonely are 4.8 times more likely to be living with depression and 4.5 times more likely to be living with anxiety**.^{xvi} There is also a correlation between severe loneliness and living with chronic disease.^{xvii} As the direction of causation is not clear here, it may well be that it is bidirectional as it is with substance abuse issues and mental health issues. In some cases, living with a mental health issue may come first and in other cases loneliness may come first. More research is needed.

An important point in relation to the identification of populations at risk of being lonely is that being socially isolated does not necessarily mean that you are at greater risk of loneliness. Likewise, being surrounded by people does not necessarily mean that you are at less risk either.

As noted in *Loneliness in Focus* (pg 4 section 3.1) and by the Australian Institute of Health and Welfare (AIHW)^{xviii}, social isolation is the objective state of having only a limited number of social relationships and roles, while loneliness is a subjective feeling. However, some people feel lonely despite seemingly having relationships with others including family members. An example of this is that **49% of people living with extended family are lonely and 34% of people living with housemates**.^{xix} Likewise, it is possible to have objectively few connections with other people and objectively few social roles and yet not to feel lonely.

Social isolation is not necessarily a primary indicator of loneliness risk. As a subjective experience, loneliness is not necessarily preceded by social isolation and greater numbers of connections to others and greater numbers of social roles are not necessarily preventive of loneliness. Genuine connection to others is required.

In the survey carried out by BEING as part of developing this response all respondents identified themselves as living with a mental health issue. **We found that 50% of respondents felt lonely some of the time and 30% felt lonely often or always.**

Evidence of the psychological and physiological impacts of loneliness on people, including young people, the elderly, those living with disability, those living in regional areas and the bereaved.

Perhaps the most striking finding in the most current research is that Australians tend to stigmatise loneliness. The result of this is that people who are struggling with loneliness also often struggle with shame and embarrassment about their loneliness and those who aren't struggling with loneliness have a tendency to not want to befriend those who are. People seem to see loneliness as a sign of social unfitness.

57% of respondents to the *Social Connection in Australia* survey felt that they would not like a person who was lonely^{xx} and **50% said they would not want to be friends with someone who was lonely.**^{xxi} Furthermore 31% of respondents were ashamed of feeling lonely and 46% said they were too embarrassed to admit they were lonely. Also noteworthy is that those people who say they are experiencing severe loneliness are 4.6 times more likely to also say they are experiencing depression and 4.1 times more likely to say that they are experiencing social anxiety.^{xxii}

In the survey which BEING carried out in preparation for writing this submission we also found that 75% of respondents felt they would likely be judged by others if they shared their experience of loneliness. One of our respondents shared that:

“I feel I will be judged for complaining about being lonely. It's embarrassing to say I feel lonely when you have people around me but they don't connect to me in a way that I need/meaningful way. I feel alone as in I don't connect or feel seen by people around me.”

The identification of existing initiatives by government and non-government organisations to mitigate and reduce loneliness and social isolation

Some peer-run mental health services have a focus on stigma reduction in the way they provide services that could be a useful model for services seeking to support people struggling with loneliness. We are not suggesting that there be dedicated loneliness

services, but rather that all services that could be touchpoints for people who could be struggling with loneliness ensure that they provide non-stigmatising points of contact for people to seek support and advice if they do feel lonely. As already noted, stigma has been identified as a significant barrier to reaching out for lonely people and a barrier to providing support for people who are not lonely.

The service models discussed below focus on creating non-stigmatising, non-judgemental relationships with clients as an important component of providing support to people struggling with suicidality and mental health issues. Being able to share experiences without fear of judgement, or rejection is itself often a powerful supportive experience.

Safe havens ^{xxiii}

As part of the broader towards zero suicides program safe havens have been opened across NSW as alternatives to emergency departments for those people who experience suicidality, or who require more support after being in emergency even though they have not been admitted to a Psychiatric Emergency Care Centre (PECC) or inpatient. Although the model is established in different ways in different Local Health Districts (LHD) across NSW, broadly speaking it provides a drop in space for people experiencing suicidality where you can sit down and have a chat and perhaps also have a cup of tea or coffee. Most importantly you can be open about your experiences of suicidality without fear of immediately being shunted into a clinical service to be managed rather than heard.

Alt2su ^{xxiv}

Alternatives to suicide groups are groups in which people can share their experiences of suicidality, or suicidal ideation with other people living with suicidality and provide support to others in the group. Alternatives to suicide allows participants to share their suicidal ideation without fear of judgement, or of immediately being sent to emergency, or hospitalised. Alt2su ensures that dignity of risk is respected. Consumers need to be able to make their own choices as much as possible. ^{xxv} Just as other community members do.

Safe havens and alt2su give people permission to talk about suicide and mental health more broadly. As already stated, with the stigma associated with loneliness it is often hard to admit to others that you are feeling lonely. Touchpoints which provide people with permission to talk about loneliness would also be helpful in relation to loneliness. Given the close correlation between mental health issues and loneliness those may in fact be the same places for some people. For others it could be their GP, a psychologist, or a non-medical contact point.

In our own survey respondents identified various people who they had shared their loneliness with. For the majority this was a psychologist, however others also shared that they had shared their loneliness with a partner, a friend, or an immediate family member. This suggests that public education around loneliness is also important, so that if those close to them reach out for support with loneliness they do not simply judge them or view them as being responsible for their own problem.

Developments in other jurisdictions regarding the implementation of policies and initiatives relevant to the treatment of loneliness as a public health issue

As noted above alternatives to suicide is a model that has been widely implemented in South Australia which could be seen as an example of how to create supportive and non-stigmatising environments. NSW health has a growing network of safe havens, and it is likely that the peer workers who staff them would also have an important contribution to make in developing alternative service models to support people living with loneliness. This is especially so since peer work itself is founded on building connection through shared experience.

Steps the state government can take to reduce the prevalence and impacts of loneliness in the community

BEING strongly believes that more spaces for people experiencing loneliness to receive non-judgemental support are needed. These could be modified peer run mental health services which have loneliness support added in as an additional offering.

However, it is also vital to ensure that those who are struggling with loneliness do not feel the kinds of shame or embarrassment that is a barrier to sharing with others. So, there is an educational task here as well, for both people living with loneliness and for those who aren't but could have a friend, or family member raise the issue with them.

The BEING survey found that people managed their loneliness both by sharing their loneliness with other people and by engaging in activities, like exercising or playing sport and caring for a pet. This suggests further target groups when it comes to educating the community about loneliness. Given the widespread enthusiasm Australians have for sport, sports clubs could be a particularly good touchpoint when it comes to loneliness support. Especially bearing in mind that you can be lonely in structured social situations.

However, it could also be helpful to ensure that mental health clinicians are able to support their clients to develop friendships. One of our survey respondents said that:

“Actually training health and mental health professionals on how to make friends as it seems to be something they don't have advice to give on. Often counsellors and

psychologists I've worked with can't answer or struggle to find ways to ...[support] ... friendship building for adults.”

ⁱ Noting that different diagnoses bear different degrees of stigma with long term schizophrenia and borderline personality disorder being the most stigmatised. In the national survey of mental health related stigma and discrimination released in November 2022, it was found that schizophrenia and borderline personality disorder were the most stigmatised diagnoses See tables 1 and 2. pages 8 – 10. <https://behaviouraleconomics.pmc.gov.au/sites/default/files/projects/stigma-survey-report.pdf>

ⁱⁱ The same study referred to on note one found that 64% of respondents would not want to be friends with someone living with long term schizophrenia and 62% would not want to be friends with someone with a borderline personality diagnosis. The challenging interpersonal dynamics that can result were already explored in Goffman's classic investigation of the topic *Stigma*. Goffman E., (1963), *Stigma notes on the management of spoiled identity*, Simon and Schuster.

ⁱⁱⁱ The most recently released Equally Well report demonstrated a clear correlation between living with a mental health and dying younger than the population in general from preventable health issues. Loneliness and physical health could be integrated into a more holistic view of mental health, physical and social care. Roberts, R, Wong, A, Lawrence, D, Lawn, S, and Johnson, C (2024). Mortality of people using Australian Government-funded mental health services and prescription Medications: Analysis of 2016 Census, death registry, MBS and PBS data. , Charles Sturt University, Bathurst, ISBN 978-1-86-467447-7, <https://osf.io/gmqeb/> .

^{iv} CRPD - <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd>

^v CRPD, Article 24 – Education

^{vi} CRPD, Article 26 – Habilitation and Rehabilitation

^{vii} CRPD, Article 27 – Workplace and employment

^{viii} Brownlee K. (2020), *Being Sure of Each Other An Essay on Social Rights and Freedoms*, Oxford University Press

^{ix} https://bcec.edu.au/assets/2021/11/139532_BCEC-Stronger-Together-report_WEB.pdf

^x <https://www.livedexperienceaustralia.com.au/loneliness>

^{xi} <https://www.nswmentalhealthcommission.com.au/sites/default/files/2023-11/Loneliness%20in%20Focus%20Report.pdf>

^{xii} Ending Loneliness Together (2023) *State of the Nation Report Social Connection in Australia*, <https://lonelinessawarenessweek.com.au/wp-content/uploads/2023/08/state-of-nation-social-connection-2023.pdf>

^{xiii} State of the Nation Report, Social Connection in Australia, Pg 17

^{xiv} State of the Nation Report, Social Connection in Australia . Pg 12

^{xv} State of the Nation Report, Social Connection in Australia – Pg 4

^{xvi} State of the Nation Report, Social Connection in Australia, Pg 23

^{xvii} State of the Nation Report, Social Connection in Australia, Pg 22

^{xviii} AIHW - <https://www.aihw.gov.au/mental-health/topic-areas/social-isolation-and-loneliness>

^{xix} State of the Nation Report, Social Connection in Australia, Pg 21

^{xx} State of the Nation Report, Social Connection in Australia , Pg 28

^{xxi} State of the Nation Report, Social Connection in Australia , Pg 28

^{xxii} Ibid Pg 14 impacts of loneliness - high correlation with mental health issues

^{xxiii} <https://www.health.nsw.gov.au/towardszerosuicides/Pages/safe-haven.aspx>

^{xxiv} Alt2su has been widely rolled out in South Australia. An overview can be found here <https://www.lelan.org.au/alt2su-groups/>

^{xxv} An indicative definition can be found in the Victorian mental health and wellbeing act 2022 - https://classic.austlii.edu.au/au/legis/vic/consol_act/mhawa2022224/s23.html . However respect for dignity of risks also implicit in services available in NSW such as the Housing and Support initiative (HASI). It is even more explicitly a normative assumption of Alt2su and safe havens.



BEING - Mental Health Consumers

