

Submission
No 118

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

Organisation: Mental Health Carers NSW Psychosocial Disability Systemic
Advocacy

Date Received: 1 November 2024

Psychosocial Disability, Stigma, and Loneliness.

Inquiry into the Prevalence, Causes, and Impacts of Loneliness in NSW

Submission to the NSW Government Standing
Committee on Social Issues

Chair: The Hon Dr. Sarah Kaine



31 October 2024

Mental Health Carers NSW – Psychosocial Disability
Systemic Advocacy Provider

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**Mental Health
Carers NSW**

For general inquiries:



Introduction

About Mental Health Carers NSW

As the peak body for mental health carers in NSW, MHCN represents the interests of mental health carers to the NSW Ministry of Health, and provides information, capacity development and systemic advocacy on behalf of mental health carers. It regularly consults with carers across NSW to gain information on their opinions and experiences with the mental health system. MHCN uses the information gained in these consultations to provide feedback on policies and services on behalf of carers to NSW Health and to other health services and policy makers. With its core functions funded by the Mental Health Branch of NSW Health, MHCN developed the Mental Health Carer Advocacy Network (MHCAN) to broaden its engagement with mental health carers in its advocacy and to assist roll out of the NSW Lived Experience Framework.

By influencing changes in policy, legislation, and service provision, MHCN aims to make a positive difference to the mental health system for carers and through the MHCAN to empower carers to become champions for change, sharing their lived experience to evoke the solidarity of humanity to promote mental health reform.

In October 2022, MHCN was awarded the tender for Department of Communities and Justice Disability Advocacy Futures Program (DAFP) for psychosocial disability systemic advocacy. Over the next two years, MHCN will deliver systemic advocacy through this project that includes liaising with Individual Advocacy Providers, stakeholders, government, and non-government decision-makers, and DCJ to improve understanding of the unique issues faced by people with psychosocial disability. This Policy Manager role will also coordinate MHCN's general carer advocacy program with the psychosocial disability advocacy in the Policy and Advocacy Team.

Note

This submission identifies people with psychosocial disability at risk of loneliness and social isolation. A second submission by MHCN into this Inquiry has been produced that mental health carers being at risk of loneliness and social isolation.

About

This NSW Parliamentary Inquiry has been called for by the Minister for Mental Health in response to rising concerns about loneliness and isolation. In response to the inquiry, Mental Health Carers NSW, in our capacity as the NSW Psychosocial Disability Systemic Advocacy Provider through the Disability Advocacy Futures Program, presents relevant insights about the social determinants of health, the stigmatization of psychosocial disability, and how these compound with loneliness, social isolation, and service disengagement. We ask that the NSW Government take active and meaningful steps to reduce the prevalence and impact of loneliness for people with psychosocial disability, their families, carers, and kin by improving education and awareness around psychosocial disability, addressing stigma, and supporting advocacy and community outreach initiatives.

Summary of Recommendations

1	Promotion of mental health literacy across NSW government and non-government services to address stigma and discrimination that compounds loneliness.
2	Sustained funding into systemic, individual, and representative advocacy services to better reach and engage with stakeholders, provide support, and raise awareness to government.
3	Ensure long-term, sustainable funding to peer support networks and workers, and community programs for people with psychosocial disability to build connection, foster community, and access support for service navigation.

Introduction

Loneliness is inextricably linked to physical and emotional health and wellbeing.¹ People with disability experience loneliness, disengagement from social activities, and social isolation at much higher rates than people without disability.² A 2024 Australian research report found that “disability-related inequalities in loneliness have persisted for two decades in Australia without improvement”.³ A person’s disability is not the driver of their loneliness. Instead, social, systemic, and environmental factors are primary causes, and are therefore associated with poor health outcomes.⁵ Several studies have shown that loneliness is associated with increased mortality, metabolic changes, cardiovascular disease, and worsening psychosocial and emotional health.⁶ As loneliness causes poor health and mental health, the risk factors of loneliness for people with disability are a public health crisis that must be addressed.

Psychosocial disability is the least understood and most stigmatised disability.⁴ A disability that arises due to a mental health condition/s, psychosocial disability is not solely about diagnoses but also about the social, functional, and environmental barriers that people with mental health conditions face. Psychosocial disability arises when an individual with a mental health condition engages in an environment that presents barriers to their equality. This also relates to social situations (education, employment, housing) and attitudes (stigma, discrimination, lack of awareness). The *National Mental Health Consumer & Carer Forum* (NMHCCF) highlighted that “psychosocial disability is not about a diagnosis and is not necessarily limited to people with “severe”

¹ Tani, M., Z. Cheng, M. Piracha, & B.Z. Wang, 2020. ‘Ageing, Health, Loneliness, and Wellbeing’, *Social Indicators Research* 160: 791-807.

² Emerson, E., N. Fortune, G. Llewellyn, & R. Stancliffe, 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): 100965.

³ Bishop, G.M., G. Llewellyn, A.M. Kavanagh, H. Badland et al., 2024. ‘Disability-related Inequalities in the Prevalence of Loneliness Across the Lifespan: Trends from Australia 2003 to 2020’, *BMC Public Health* 24: 621.

⁴ Australian Broadcasting Corporation, April 30, 2024. ‘What is Psychosocial Disability, How is it Different to Mental Health, and Where Does it Fit into the NDIS?’ <https://www.abc.net.au/news/2024-04-30/psychosocial-disability-mental-health-ndis/103690958>

mental health conditions” but is about how systems, situations, and environs have direct functional and attitudinal barriers.

“Psychosocial disability is about the functional impact and barriers which may be faced by someone living with a mental health condition.” – NMHCCF

Psychosocial disability can be episodic and vary according to the individual; meaning that, at one time, a person with psychosocial disability may feel comfortable going outdoors, getting exercise, or eating well while other days they may be bedridden, unable to take care of themselves, and experiencing ideations. They might respond well to certain treatments, management, and/or supports but this does not mean that their experiences and symptoms fluctuate, and treatments cannot be based solely on medication but require diverse and multi-modal approaches. One individual with psychosocial disability described their everyday experience to MHCN as alternating between:

“One moment I want to get outside, see people, and eat well. But the next I can’t get out of bed, brush my teeth, wash my hair, or even drink water because my depression and suicidal ideation crushes me”.

Feelings of loneliness, isolation, and like nobody understands you or wants to understand you are all too well-known for people psychosocial disability. This submission advocates for three key recommendations to help address this public health concern and positively contribute to the wellbeing and safety of people with psychosocial disability. These are:

- Promotion of mental health literacy across NSW government and non-government services.
- Sustained funding into systemic, representative, and individual advocacy services who provide support and awareness raising.
- Dedicated peer support networks and community programs for people with psychosocial disability to build connection, community, and support them in their service navigation and access.

Structural Inequities Driving Loneliness

People with disability are more likely to experience co-occurring and intersectional risk factors for loneliness. The *ABS 2018 Disability, Ageing, and Carers Survey* found that “almost one-quarter (23.2%) reported a mental or behavioural disorder at their main condition”.⁵ At the global level, WHO identified psychosocial disabilities as the leading causes of disability worldwide and that this could worsen within the decade if intervention methods are not implemented.⁶ Moreover, given the known impacts of the Covid-19 pandemic, lockdowns, and isolation on people’s sense of health and wellbeing, further research is needed into how these factors intersected and continue to intersect experiences of psychosocial disability from 2020 onwards.

People with psychosocial disability have faced and continue to face significant barriers to accessing federal support through the NDIS. These have been identified in numerous reports from the Productivity Commission, Australian universities, and non-government organisations.⁷ Identified barriers include eligibility barriers, need to demonstrate permanence of disability, lack of awareness to psychosocial disability by NDIS staff, workers, and auditors, and decreasing local and community-based supports that would assist people with psychosocial disability understand and access available services and supports. Key recommendations for improved access to state and federal supports include targeted support, advocacy resourcing, psychosocial-specific capacity building

⁵<https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#disability>

⁶ <https://www.who.int/news-room/fact-sheets/detail/mental-disorders>

⁷ Examples include Fernandes, H., & S. Cantrill, 2016. *Inclusion of People with Psychosocial Disability in Low and Middle Income Contexts: A Literature and Practice Review*. TEAR Australia; Smith-Merry, J., N. Hancock, J. Gilroy, G. Llewellyn, & I Yen, 2018. *Mind the Gap: The National Disability Insurance Scheme and psychosocial disability. Final report. Stakeholder Identified Gaps and Solutions*, Sydney: The University of Sydney Policy Lab and Community Mental Health Australia; Hamilton, D., N. Hancock, J.N. Scanlan, & M. Banfield, 2020. ‘The National Disability Insurance Scheme and People with Severe and Persistent Mental Illness/Psychosocial Disability: A Review, Analysis and Synthesis of Published Literature’, *Australian & New Zealand Journal of Psychiatry* 54(12): 1162-1172; Wilson, E., R. Campaign, S. Pollock, L. Brophy, & A. Stratford, 2022. ‘Exploring the Personal, Programmatic and Market Barriers to Choice in the NDIS for People with Psychosocial Disability’, *Australian Journal of Social Issues* 57(1): 164-184.

for assessors and staff, including lived experience in service and policy design, and increasing the peer workforce.

Barriers at the federal level impact the state level. MHCN consulted with people with psychosocial disabilities, carers, families, and loved ones, peer workers, and mental health professionals between January to March 2024. Consultations identified ongoing systemic misconceptions and prejudices against people with psychosocial disability based on limited understanding, awareness, and empathy. When trying to access services and support that will drastically improve their lives, they experience interactions where personnel appear ill-equipped to understand and unsure how to identify and assist in their requests.

There are several broader social misconceptions and prejudgments concerning psychosocial disability, which negatively impact service use and engagement. A significant factor is that it is a hidden/invisible disability, Thus, it is imperative to identify and remove barriers within the systems that people with psychosocial disability need to access.⁸

Social Determinants

People with psychosocial disability are more likely to experience employment insecurity and unemployment and live in low-income, insecure, or unsuitable housing.⁹ They do not have the same social networks and security as people without disability, which create barriers to mitigating loneliness.¹⁰ In health, the prevalence of depression among Australians with disability is 5 times the rate for people without disability, and the prevalence of anxiety is 3.4 times the rate for

⁸ Temple, J.B., M. Kelaheer, & R. Williams, 2018. 'Discrimination and avoidance due to disability in Australia: evidence from a National Cross Sectional Survey', *BMC Public Health* 18: 1347.

⁹ Centre of Research Excellence in Disability and Health, 2022. *Disability and Wellbeing Monitoring Framework: Baseline Indicator Data for Australians Aged 18–64 years*. <https://doi.org/10.25910/ffxs-wd42>; World Health Organization, 2022. *Global Report on Health Equity for Persons with Disabilities*.

¹⁰ Emerson, E., N. Fortune, G. Llewellyn, & R. Stancliffe, 2021. 'Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: cross-sectional study', *Journal of Disability & Health* 14(1): 100965.

people without disability.¹¹ Australians with disability have 2 times the rate of asthma diagnoses and 1.7 times the rate of diabetes than people without disability.¹² Australians with disability also have a lower subjective perception of their health and wellbeing, are more likely to smoke daily, and 72% of people with disability are affected by weight and obesity.¹³

Social determinants of health intersect with the experiences of people with disability in terms of how they access and experience their environs, which varies according to type and severity of disability, as well as gender, age, ethnicity, and identity. These include accessibility, transport, information technologies and communication, income and employment, housing, education, relationships and social activity, discrimination. Baseline data from the *Disability and Wellbeing Monitoring Framework 2022* highlights the people with disability fare far less than those without. They face greater difficulties finding appropriate healthcare and information, are twice as likely to live in low-income households, have around 40% less disposable income and experience financial stress, and are 1.6 times more likely to experience housing stress. Just one half of people with disability and one quarter of people with severe disability have a job, are 3.5 times more likely to experience long-term unemployment (minimum 12 months), and 1 in 5 people with disability reported not gaining employment because of discrimination against their disability.

What compounds these issues even more is the fact that people with disability also perceive their access to social supports at much higher rates than people without disability.¹⁴ This can result in smaller friendship and social groups, less opportunities to connect and communicate, as well as barriers to employment and financial resources that facilitate social connection and activities. Accordingly, strategies at both state and federal levels need to identify and mitigate social determinants of loneliness and perceived loneliness.

¹¹ Centre of Research Excellence in Disability and Health: 14.

¹² Ibid.

¹³ Ibid. 14, 17.

¹⁴ Emerson et al. 2021: 100965.

Loneliness, isolation, and suffering should not be a standard or shared experience of people with psychosocial disability. NSW is the only jurisdiction to have decreased its investment into mental health over the past decade, and this is compounded by the fact that psychological distress, namely anxiety, depression, and suicidality, has doubled in NSW during that time.¹⁵ The psychosocial risks of reduced funding cannot be overstated. NSW residents experience long waitlists for services, reductions in the number of bulk-billing GPs, unaffordable or inaccessible psychological services, compounded by housing unaffordability, the cost-of-living crisis, and the wider global context of conflict affecting residents of all backgrounds and beliefs. Cost-cutting measures exacerbate the gap between NSW mental health service supply and demand, further driving social isolation and disengagement from services, support, and community.

This does not have to be the norm. With proper investment into mental health literacy, advocacy services, and community support networks, NSW residents, children, families, older people, carers, consumers, and workers can see improvements in their mental health outcomes.

Recommendation 1: Promotion of mental health literacy across NSW government and non-government services.

The Issue

People with psychosocial disability report stigma and discrimination at far higher levels than people with other types of disability. Complaints by people with psychosocial disability related to the *Disability Discrimination Act* to the *Australian Human Rights Commission* (AHRC) are disproportionately higher than any other disability or complaint.

¹⁵ Health Stats NSW, 2021; Productivity Commission, 2023; Australian Institute of Health and Welfare (AIHW), 2023.

Perceived stigma and discrimination factor into experiences of loneliness. Limited awareness of the realities and diversities of psychosocial disability contributes to people with this disability experiencing ongoing stigma and discrimination. This means that they are more likely to disengage with services and supports because they believe they will continue to experience stigma and discrimination. MHCN compared data from the AHRC on the number of complaints made since 2017 related to the *Disability Discrimination Act*.

The following table summarises the data:

Reporting Year	No. complaints	% disability complaints
2021-2022	793	31%
2020-2021	506	31%
2019-2020	396	27%
2018-2019	393	32%
2017-2018	303	26%

This comparative data shows that discrimination and stigma remain key barriers to participation for people with psychosocial disability. Moreover, this data only comprises complaints registered to the AHRC. It is possible that unreported experiences of anticipated, perceived, and/or experienced discrimination, stigma, and micro-aggressions are far higher than this. According to the *State of the Nation Report: Social Connection in Australia 2023*, “people who are lonely report more everyday discrimination compared with people who are not lonely”.¹⁶ While there are legislative protections against discrimination, it is still prevalent and continues to impact on people with psychosocial disability feeling understood, included, and supported to participate in society and exercise their rights.

One consumer pointed out that people with psychosocial health issues and disability are often portrayed in the media as:

¹⁶ Ending Loneliness Together, 2023. ‘State of the Nation Report: Social Connection in Australia 2023’: 31.

“We are represented as crazy, deviant - burdens that don’t contribute to society. If that’s all people see then that’s all they know, and it couldn’t be further from reality.”

Attitudinal barriers such as stigma and discrimination also create structural and service barriers for people with psychosocial disability attempting to connect with their communities, access information, and find support. Data from the *2018 Survey of Disability, Ageing, and Carers* identified that two-thirds of people with psychosocial disability (67.0%) avoided situations because of their disability “higher than any other disability group”.¹⁷ The most common forms of discrimination listed in the data were in the workforce (employer and/or colleagues), service and hospitality, and family and friends. The most avoided situations were visiting family and friends, visiting restaurants, cafes, and/or bars, and going to shops, banks, etc. There are evident links between attitudinal barriers and discrimination, accessing support and services, and connecting with people. This can result in people with psychosocial disability feeling misunderstood and reluctant to seek assistance and seek out connection.¹⁸

The Strategy

Building a society with good mental health literacy requires leadership from government, services, and providers. When a person feels understood and accepted, they are less likely to disengage. One consumer said that:

“It is important for staff to have some good education around how hard and complex some services can be for people like us. What might seem very easy to some is almost impossible for me and when staff don’t understand it can cause triggers, traumatise, and isolate me.”

¹⁷ <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#disability>

¹⁸ National Mental Health Consumer & Carer Forum, 2022. *Unravelling Psychosocial Disability*. <https://nmhccf.org.au/our-work/nmhccf-library/unravelling-psychosocial-disability-position-statement-on-psychosocial-disability-associated-with-mental-health-conditions/download>

Capacity building is crucial. Many organisations, MHCN included, have mandatory staff training in cultural competency, priority populations, service navigation, as well as both hard and soft skills training. There is, however, a distinct gap between genuine knowledge and understanding of psychosocial disability and perceptions of it. Investing in mental health literacy can address attitudinal barriers through education. It can raise awareness of the diversity of psychosocial disability experiences and reduce misconceptions around it. If people in NSW have a better understanding of what psychosocial disability is, we can all be more empathetic, open-minded, and stronger as a society.

“A lot of assumptions about us come from the stigma and misunderstanding of invisible disabilities, and they don’t know how impactful that can be on a person’s life.”

Addressing the stigma that drives social isolation, and loneliness must involve structured training developed specifically on psychosocial disability and delivered to staff and volunteers. It is important that service personnel are aware of the power they have in an individual’s experience of service and their capacity to access support. To raise awareness to the reality and visibility of a hidden disability without being tokenistic, MHCN recommends that people with psychosocial disability, their carers, families, and loved ones be involved in the consultation and design process from the outset and throughout.

This would involve a commitment to establish a lived experience consultation with stakeholders who are paid and supported to participate (safe meeting environments, breaks, peer support etc). People with psychosocial disability, their carers, families, and loved one are the best sources of information about lived experience and have experiential expertise using services and can identify the barriers, generalisations, and misconceptions that impact their lives. Including them in the design process would ensure that the awareness-raising is not tokenistic but a genuine effort to improve mental health and disability literacy in the state.

The Outcomes

- Improvement in individual's sense of self, place within society, and feeling understood and accepted.
- Staff and personnel will be upskilled and better equipped to interact with, understand, and service people with psychosocial disability.
- People with psychosocial disability will be less likely to disconnect from services and more likely to want to participate in society.

Recommendation 2: Sustainable funding into systemic, representative, and individual advocacy services who provide support and awareness raising.

The Issue

People should feel they can speak up for themselves and their loved ones and empowered to make choices. People with psychosocial disability, their carers, family, and kin often find it difficult to have their voices heard and this impacts crucial life decisions about care, support, and services.¹⁹ These compound feelings of loneliness and social isolation. Our psychosocial disability focus group pointed out that:

“When you already feel like society doesn’t get you or people like you, there aren’t a lot of places you can turn to for help.”

When people with psychosocial disability perceive and experience disconnects between stigma and who they are, it is the responsibility of advocacy organisations to step up and ensure representation and visibility in society. Advocacy organisations are fundamental to policy and systems review and reform because they protect stakeholders and ensure quality in our systems and services.²⁰

¹⁹ Salomon, C., and B. Hamilton, 2013. ‘All Roads Lead to Medication? Qualitative Responses from an Australian First-Person Survey of Antipsychotic Discontinuation’, *Psychiatric Rehabilitation Journal* 36(3): 160-165.

²⁰ Page, S.L., 2023. ‘The Power of Advocacy’, *ASA Monitor* 87(23):

<https://doi.org/10.1097/01.ASM.0000989908.94610.1a>

At present, there have been key funding programs dedicated to bolstering disability advocacy in NSW, but case workers remain significantly unsupported, understaffed, and overworked. In a recent NSW parliamentary question time, one member asked if there was a link between the number of suicides among young people (13-17 years old) in 2022 and the possibility that their cases had been closed by DCJ because of “competing priorities or caseworker workload”.²¹ Although the question was taken on notice, it points to a sad reality that, when our services are ill-equipped, people can disengage, become isolated, and experience significant and life-threatening distress. This can be mitigated by ensuring that fundamental advocacy services and providers are funded properly and have sustainable staffing and workloads.

The Strategy

Specialist advocacy is consistent with Australia’s obligation under the *Convention on the Rights of Persons with Disability*. The awareness-raising, campaigning, and representation provided by advocacy services are crucial to destigmatizing psychosocial disability, which in turn can foster the understanding and social cohesion needed to address loneliness and isolation. With proper funding, advocacy organisations can be even more proactive and equipped to seek out stakeholders as well as support existing ones. They can advertise their programs better, reach more people, deliver more effective advocacy, and in turn provide sound, evidence-based information to government.

MHCN encourages the NSW Government to ensure that psychosocial disability remains a key priority under the *Disability Advocacy Futures Program* (DAFP). The NSW Government should also consult further with these advocacy organisations to assess their funding levels and ensure they are appropriately funded to deliver adequate advocacy to their stakeholders. When discussing the *NSW Performance & Wellbeing Framework*, the NSW Minister for Finance said that:

²¹ Parliament of NSW, Questions on Notice – Hon. Kate Washington MP, 7 Apr 2024: 6.
<https://www.parliament.nsw.gov.au/lcdocs/other/19367/Questions%20on%20notice%20-%20Hon%20Kate%20Washington%20MP%20-%20Families%20and%20Communities,%20Disability%20Inclusion.pdf>

“Engaging with the community will be crucial as we finalise the Framework’s measures to help track government investments as we address the major challenges that NSW faces...In the midst of a cost-of-living crisis and coming after a particularly disruptive period of the Covid-19 pandemic, bushfires and floods, we need to be sharply focused on measuring the impact of our programs for families and households.”²²

To contribute to this vision, advocacy organisations need to be better embedded and consulted across government such as committees, working groups, and in research to ensure that their stakeholders’ needs are on the agenda and taken into consideration. The *NSW Disability Council* is crucial to cross-agency reform, and there are many different advocacy providers with specialist knowledge and stakeholder access that must be consulted more. If governments and providers do not know the different needs of service users and the barriers they face, then the design and implementation of their products risk defunding despite commencing with the good intentions.

Currently, the *NSW Disability Advocacy Network*, part of the DAFP, comprises several key advocacy organisations including systemic, representative, and individual providers. They meet with ministers, communicate service and systems gaps, and develop strategies which contribute to positive change. They are the conduits between government organisations and the people they represent. They encourage and look for opportunities for cross-agency collaboration to deliver improved services, and they must continue to be included and supported in their work. MHCN recommends that continued investment into programs such as these will contribute to the implementation of the *NSW Performance & Wellbeing Framework*, its themes and principles. By funding advocacy properly, people feel more heard, more understood, and more confident in their ability to connect, communicate, and participate in society.

²² <https://www.nsw.gov.au/media-releases/community-consultation-on-performance-wellbeing-framework-continues>

The Outcomes

- Improvements in the reach of advocacy organisations and their connections and communication with individuals.
- Improved evidence-base and data collection for government services.
- Proper inclusion, representation, and visibility of people with disabilities, their carers, family, and kin across government services and policy landscape.

Recommendation 3: Dedicated peer support and community activities for people with psychosocial disability to build connection, community, and support them in their service navigation and access.

The Issue

Social connection is a fundamental human need and contributes to longer lifespan, better wellbeing, safety, and resilience.²³ The *State of the Nation Report: Social Connection in Australia 2023* reported that Australians experiencing loneliness have lower wellbeing, are at higher risk of suffering from depression and social anxiety and are less physically active.²⁴ Opportunities for social contact and connection are effective at combatting loneliness and its associated socio-economic determinants and impacts.²⁵

Socioeconomic disadvantage, stigma and discrimination, and systemic barriers drive social isolation among people with psychosocial disability, their carers, families, and loved ones.²⁶ Opportunities to connect through community activities,

²³ Vella-Brodrick, D., M. Joshanloo, & G.R. Slemp, 2023. 'Longitudinal Relationships Between Social Connection, Agency, and Emotional Well-Being: A 13-Year Study', *The Journal of Positive Psychology* 18(6): 883-893.

²⁴ Ending Loneliness Together, 2023. 'State of the Nation Report: Social Connection in Australia 2023': 14.

²⁵ Holt-Lundstad, J., 2024. 'Social Connection as a Critical Factor for Mental and Physical Health: Evidence, Trends, Challenges, and Future Implications', *World Psychiatry* 23(3): 312-332.

²⁶ Wickramaratne, P.J., T. Yangchen, L. Lepow et al., 2022. 'Social Connectedness as a Determinant of Mental Health', *PloS One* 14: e0275004.

local clubs, sports, and the arts are becoming more financially unattainable.²⁷ This creates huge barriers that further isolate people from community and the connection they need. For example, the costs of running social and wellbeing programs falls at the feet of the organisation, community group, or non-profit who often rely on donations and volunteers. If the running costs for such programs becomes too high, the organisation may have to restrict participation to those who have NDIS packages to alleviate the cost. This is ultimately exclusionary for people with psychosocial disability, who experience difficult application and eligibility tests.

"I don't have a NDIS package but I've been trying for years. But that means I can't access heaps of the community-ran activities out there for people like me because they need the NDIS packages to keep running the programs. None of us can win if we are locked out of the system because of money."

Pricing out of activities is an inequity that drives loneliness.²⁸ Those who would benefit the most from community building activities such as art groups, respite, social gatherings, book clubs, wellbeing programs, and family and carer support groups face market barriers. The fact that 'loneliness' and 'market barriers' are in the same sentence above is a dire indication of our society's failure to foster and maintain community.²⁹

An indicator of poor access to services, primary, and community health is that people with mental health issues are more likely to experience preventable hospitalisation. According to the *Australian Institute of Health and Welfare*, in 2022–2023, "the rate of overnight hospitalisation with specialised psychiatric care

²⁷ Australian Broadcasting Corporation, 14 Aug 2022. 'Community Events Cancelled, Emergency Services Stretched as Volunteer Numbers Fall', <https://www.abc.net.au/news/2022-08-14/decline-in-volunteering-see-events-cancelled-ses-stretched/101297094>

²⁸ Kung, C.S.J., J.S. Kunz, & M.A. Shields, 2021. 'Economic Aspects of Loneliness in Australia', *The Australian Economic Review* 54(1): 147–163.

²⁹ Franklin, A. 2012. 'A Lonely Society? Loneliness and Liquid Modernity in Australia', *Australian Journal of Social Issues* 47(1): 11–28.

increased with increasing social disadvantage for public hospitals”, and depression and other affective disorders, and schizophrenia were the most common principal diagnoses.³⁰ With difficulties locating GPs offering bulk-billing (now being addressed in NSW by incentives), long waitlists for psychology and therapy services, and the rising cost of living, it is little wonder then that people experience significant distress, which not only increases health system costs; it also creates distress for their carers, families, and kin.³¹ Having someone to talk to, who understands and listens to you, is not judgemental of you, and is free-of-charge could be life changing, not only in emergency departments but across services.

The Strategy

Building connection and community needs to happen by supporting programs that foster understanding, shared experience, and raise awareness. MHCN recommends that programs and activities for social connection, particularly for people with disability and psychosocial disability, be made available to NSW residents regardless of NDIS eligibility. This could take the form of bursaries to local support groups, grassroots organisations, or clubs with stipulations that offer targeted disability community outreach and supporting the development of digital peer support programs.

Providing Australians with the psychology services they need by increasing Medicare-subsidised sessions, particularly for people with or at risk of complex mental health is a national issue that must be addressed. On a state level, however, bridging the gap between loneliness, poor mental health, and social connection can be addressed by supporting and properly funding the work being done by those already working or volunteering in mental health spaces. Peer workers (carer and consumer, paid and volunteer) are invaluable resources to the community and the government. They bridge gaps between existing and

³⁰ AIHW, Mental Health, 2023. <https://www.aihw.gov.au/mental-health/topic-areas/admitted-patients>

³¹ Australian Psychological Society, 15 Aug 2024. ‘People Losing Access to Psychology Services Amid Cost-of-Living Crisis, APS Member Poll Reveals’. <https://psychology.org.au/about-us/news-and-media/media-releases/2024/people-losing-access-to-psychology-services-amid-c>

prospective clients, clinicians, and services, they are active in and have deep knowledge about their communities, they understand how to navigate systems, and know how to thoughtfully explain potentially stressful or triggering processes.

"I would never have been able to go through all the processes and interviews to apply for things without the help of the amazing peer worker."

Interacting with people with similar or shared lived experiences is a source of support in difficult times.³² People without access to formal supports or informal support from family or friends are at risk of further social isolation and ongoing mental health issues. Decreased loneliness can occur when people have multiple sources of support such as in the community, at school, in support groups, and by interacting with people outside your immediate circle.³³ This is where peer support needs to be properly embedded within NSW systems.³⁴ Knowing that you are seen and listened to builds confidence and trust, which can lead to positive mental health and wellbeing and combat the social isolation arising from perceived and reported stigma.

"Having someone who 'got' me meant I didn't feel so alone or different from everyone else for a second."

MHCN understands that integrating consumer and carer peer workers into clinical settings is not an easy or straightforward task for a range of administrative, logistical, and conceptual reasons.³⁵ However, peer workers are important to

³² Filia, K., H. Jackson, S. Cotton, & E. Killackey, 2019. 'Understanding What it Means to be Socially Included for People with a Lived Experience of Mental Illness', *International Journal of Social Psychiatry* 65(5): 413-424.

³³ Cavanaugh, A.M., & C. Buehler, 2015. 'Adolescent Loneliness and Social Anxiety: The Role of Multiple Sources of Support', *Journal of Social and Personal Relationships* 33(2): 149-170.

³⁴ Gray, M., K. Davies, & L. Butcher, 2016. 'Finding the Right Connections: Peer Support Within a Community-Based Mental Health Service', *International Journal of Social Welfare* 26(2): 188-196.

³⁵ Franke, C.C.D., B.C. Paton, & L-A.J. Gassner, 2010. 'Implementing Mental Health Peer Support: A South Australian Experience', *Australian Journal of Primary Health* 16(2): 179-186; Byrne, L., H. Roennfeldt, P. O'Shea, & F. Macdonald, 2018. 'Taking a Gamble for High Rewards? Management Perspectives on the Value of Mental Health Peer Workers', *International Journal of Environmental Research and Public Health* 15(4): 746; Sinclair, A.,

“supporting mental health recovery, modelling hope, and influencing culture within services” and NSW has seen an encouraging increase in the carer and consumer workforce over the past decade.³⁶ Having lived experience support and understanding fosters community, acceptance, and inclusion.³⁷ MHCN recommends increased funding of the peer workforce as well as supporting community initiatives like support groups as a countermeasure to the sustained decrease in NSW mental health funding over the past decade to support clients and staff. This will promote better health outcomes, build stronger social cohesion, and empower lived experience to combat loneliness.

The Outcomes

- Improved social connection and decreased loneliness by funding programs and initiatives that engage and uplift people with psychosocial disability, their carers, family, and kin.
- Better access to peer support within health and non-health services to improve the interface between clients, practitioners, and services.
- Reduction in stigma associated with mental health and caring by embedding lived experience within systems and fostering community through shared understanding.

Conclusion

Loneliness is inextricably linked to physical and mental health and wellbeing. Psychosocial disability is the least understood and most stigmatised disability and people with psychosocial disability experience a unique set of social determinants that compound their sense of loneliness and isolation. Despite the connotations of loneliness being an individual experience, it impacts not only the individual but also the family, friends, carers, and kin. There are many avenues for NSW

C. Fernandes, S. Gilleatt, & L. Mahboub, 2023. ‘Peer Work in Australian Mental Health Policy: What ‘Problems’ Are We Solving and to What Effect(s)?’, *Disability & Society* 39(7): 1656–1681.

³⁶ NSW Mental Health Commission, 2024. <https://www.nswmentalhealthcommission.com.au/measuring-change-indicator/mental-health-consumer-and-carer-peer-workers>

³⁷ Jackson, F., & T. Fong, 2017. ‘Why Not a Peer Worker?’, *Mental Health and Social Inclusion* 21(3): 176–183.

policymakers to address the rise in psychological distress among residents and, by extension, improve community belonging to combat loneliness, such as stigma reduction, improved advocacy, and community and peer support programs.

MHCN recommends that measures be taken to reduce the stigma associated with mental health, psychosocial disability, and caring by ensuring that service providers and personnel are appropriately trained and educated to understand and support people with psychosocial disability and carers. We recommend that addressing loneliness needs to involve understanding the systemic drivers and that, by engaging with and properly equipping advocacy organisations, governments can learn far more about their constituents' needs and issues. We also recommend that there be sustained funding to community building activities to ensure that NDIS eligibility does not preclude people with psychosocial disability from participating in social and wellbeing activities, and that the peer support workforce is properly funded and embedded within NSW services. While these are just some of the many possible opportunities for change, building community through stigma reduction, capacity building, and lived experience empowerment are important and crucial steps to helping our most vulnerable and lonely citizens.