Submission Cover Sheet

Inquiry into Loneliness and Social Isolation in the ACT

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Submission: Inquiry into Loneliness and Social Isolation

This submission has been prepared by the Australian Capital Territory (ACT) Mental Health Consumer Network (the Network) in response to Inquiry into Loneliness and Social Isolation in the ACT and we thank the Standing Committee on Education and Community Inclusion for this opportunity.

Acknowledgment of Country

We wish to acknowledge the Ngunnawal people as traditional custodians of the land upon which we sit and recognise any other people or families with connection to the lands of the ACT and region. We wish to acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region. We would also like to acknowledge and welcome other Aboriginal and Torres Strait Islander people who may be reading this submission, and we recognise the ongoing contributions of all Indigenous peoples to ACT society and Australia more broadly.

The ACT Mental Health Consumer Network

The Network is a consumer-led peak organisation representing the interests of mental health consumers in the ACT in policy and decision-making forums. The Network is committed to social justice and the inclusion of people with experience of mental illness. Run by consumers for consumers, our aim is to advocate for services and supports for mental health consumers which better enable them to live fuller, healthier and more valued lives in the community.

This submission incorporates information gathered from: a consumer forum; previous conversations held with residents of Gawanggal Mental Health Unit (Gawanggal) in 2022 and 2023; previous conversations with consumers; and additional feedback received from mental health consumers via email.

General Comments

According to the World Health Organization (WHO), 'loneliness' is "the pain we feel when our social connections do not meet our needs", while 'social isolation' is "the state of having a smaller number of social contacts, which may contribute to loneliness.".[1] Consumers identified with both of these definitions, though did agree that social isolation does not necessarily lead to loneliness if you are happy with the number of social contacts you have.

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[1] (Sane.org, accessed 23/02/2024).

SANE, Australia's leading national mental health organisation for people with complex mental health issues, has recently reported that 32 per cent of respondents to a national survey identified that they "felt lonely all the time"[2]. This survey also identified that more than half of the respondents were dissatisfied with their life as a whole.

Our discussions with mental health consumers (consumers) identified the endemic levels of social isolation and loneliness for consumers in the ACT and the impact it has on their mental illness and/or disorder (mental illness). Consumers regularly identify social isolation and loneliness as a contributing factor to the worsening of their symptoms that can result in the need to access crisis mental health services.

> *…its not good for my depression if I don't get to participate in things, and I can't find anything to do that I can afford or that is welcoming…*
>
> *…since the Rainbow room closed I have lost touch with my friends there and I know my mental illness symptoms have worsened…*
>
> *When facing loneliness, [I was] calling Lifeline because I was lonely. Talk for a short amount of time. Ask same questions, [but] they don't refer you to anything else [or] provide other options. Didn't find this good enough.*

Consumers identified the introduction of the National Disability Insurance Scheme (NDIS) as negatively impacting the socialisation opportunities for consumers. This impact was twofold: the closing of several safe community groups; and, the disparity in access to social activities between those who have NDIS supports and those who do not. This impact was especially felt by those consumers who were unable to access NDIS funding as they not only lost access to community spaces that were unable to continue operations, they were also unable to engage with incoming NDIS services. This notwithstanding, the future of the NDIS was of considerable concern to consumers as the Federal Government discusses the removal of psychosocial services from the NDIS.

The wide range of issues discussed are included in this submission under the following themes: Welcoming Psychosocial Supports, Crisis Supports, Forensic Mental Health Services, Housing and Increasing Cost of Living, Use of Information Technology post COVID-19 pandemic and Lived Experience Workforce. We have also included consumer

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[2] Results are in: Our community are feeling alone and unsupported (sane.org), accessed 23/02/2024)

identified recommendations to help mitigate loneliness and social isolation in the ACT and direct quotations from consumers where relevant.

Submission and Recommendations

1. Welcoming Psychosocial Supports

The common theme during discussions with consumers was that the community groups and services which they used to engage with have closed as a result of ACT Government budgeting decisions, such as the ACT Recovery College; the introduction of the NDIS, such as the Rainbow Group; and, individual cost of living financial pressures making it impossible to access a somewhere communal to go when not in crisis.

The Rainbow Group was operated by the Mental Health Foundation, using ACT Government block funding, and is fondly remembered as a welcoming, fit for purpose, psychosocial day program that included informal and formal drop in and group classes such as music and art groups. When the NDIS was introduced and some people with psychosocial disability were able to obtain individual funding for individual classes that were run by NDIS approved service providers, the Rainbow Group closed.

The ACT Recovery College[3] was funded by the ACT Government for a two year trial and was co-designed and co-run by consumers. Opening in 2018 it quickly became a place where consumers could go and learn and mingle in a welcoming, supportive and understanding place. Classes were co-produced and co-led, developing consumers understanding of mental illness and different ways of managing and living with mental illness with the focus on recovery.

Despite glowing reviews and recommendations for the continuation of the college[4] the ACT Government decided to withdraw funding resulting in the closing of the College. The impact of having this space removed from the community was significant, with the Network

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[3] Recovery College is an adult learning centre at which all courses focus on an individual's management of mental illness and promote self-directed individual recovery, https://www.health.act.gov.au/sites/default/files/2021-08/Attach%20B_ACTRCEvaluation_FinalReport_4.6.21.pdf (accessed online 23/02/2024)

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noticing a spike in consumers looking for a drop-in type place. Consumers still advise us that they continue to struggle with finding another supportive, recovery focussed space that they can engage with.

While some consumers felt safe enough to join non-mental health focused groups, others reported that the stigma surrounding mental illness often meant that they felt even more lonely attending these groups. The tolerance threshold of the general community can be very low leading to some consumers being asked to no longer come to group meetings as they were incompatible with the other members, as illustrated below:

> *…joined social groups – sometimes they ignore me and I don't know why. It is a horrible feeling being ignored.*
>
> *…I experience communication breakdown.*
>
> *…drop in with like minded people – difficult to join other groups because of stigma and seen to be 'strange'…*

Recognising that their needs can be different to other people, consumers advised that the qualifications of people leading more general clubs and societies are not the same as specific groups for mental health consumers. This can lead to an unsupportive environment and a potentially esteem-degrading experience for the consumer.

> *Previously, I had people that were art graduates, post-grad in art therapy. Officials [of general groups] had no previous training, and the one size fits all attitude doesn't work.*
>
> *My social-prescription recommended I join a group but couldn't find anything for over 35 year olds and under 55 year olds. I was put in groups with people younger than me. Need groups to fit all development stages.*

In addition, consumers reported issues with accessing spaces and services via public transportation. Due to the effects of medication and the cost of private transport, consumers tend to be more reliant on using public transport than the wider general public. Consumers advised that the buses from where they live, in the poorer areas of Canberra, are not express and often do not take you to a major hub. The problem this creates for consumers is that accessing locations not on the general express route takes a long time and often requires physical activity to walk from the bus stop to the venue.

Additionally, Consumers find using public transport very difficult when unwell making it difficult to travel long distances to support services such as the Safe Haven in Belconnen.

Access to supportive groups around Canberra would decrease the number of people who end up in crisis as a result of their worsening symptoms due to their lack of socialisation.

Where do I go when I am lonely and need to stop escalate[ing]… physical or mental health challenges.

Consumers are extremely worried about what will happen when the expected reduction in psychosocial care plans offered under the NDIS occurs. The services they receive through these care plans are essential in maintaining their socialisation and consumers have reported that there is little to nothing available outside of the NDIS.

Recommendation 1: Increase funding and reintroduce safe psychosocial programs throughout the ACT
Consumers strongly recommend the reintroduction of safe psychosocial programs throughout the ACT to decrease both social exclusion and isolation. They recommend that several different programs be run in different town centres of the ACT so that consumers can attend with their limited public transport access and that there be choice for such programs.

I [would] like the Network to strongly recommend to get the Rainbow back, and [I would] go there to have coffee, go to groups and meet some other people. Strongly recommend that they set up the Rainbow again.

2. Crisis services
Consumers identified the impact that the in-patient treatment models for mental illness often left them isolated with little ability to interact with friends and family. Consumers repeatedly advise the Network that having their mobile phone removed from them when admitted, along with all their contacts and photos that are within their phones, removes their ability to stay in touch with family and friends:

I fear that I wouldn't even know if my mother died…

Consumers also feel very lonely and socially isolated when trying to access Emergency Departments, PACER and other crisis support services. Stigma and labels, such as the term 'frequent flyer', can result in consumers feeling that they are being judged and not seen for the person that they are.

When trying to get help through Access Mental Health and PACER, consumers stated that when they are advised that they are not sufficiently unwell to be treated as a crisis patient, they feel like they are left with no options and that they have nowhere else to go. Consumers reported these experiences as being very isolating, worsening feelings of loneliness.

Recommendation 2: Provide alternative services for people when not considered to be in crisis, including transport services
Consumers recommend that alternatives need to be provided when they are advised that they are not in enough of a crisis to be admitted to hospital or to be picked up by the PACER team. When the PACER team make this determination and leave you at your home there is a real feeling of isolation and consumers feel disregarded and left to their own devices.

3. Forensic Mental Health Services
Consumers that have been admitted to the Secure Adult Mental Health Unit, known as Dhulwa, have also identified that feelings of loneliness and social isolation experienced whilst in Dhulwa impacted on their mental health.

> *Having made friends in AMC, a consumer was transferred to Dhulwa and was not permitted to maintain any kind of contact with the person with whom they had formed a friendship.*

> *While in the AMC, consumers could email their loved ones every day whereas they could not do this in Dhulwa.*

> *The consumer-accessible phone was broken [in Dhulwa] and not fixed or replaced for 3 months, leaving consumers with limited ability to reach loved ones.[5]*

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[5] These quotes are attributable Gawanggal residents and were obtained during meetings held at Gawanggal in 2022 and 2023. This was prior to the Dhulwa Independent Inquiry into the Legislative, Workplace

The situation is reportedly the same for when consumers leave Dhulwa, with consumers not being able to remain in contact with those they developed relationships with. For some, these contacts are the only positive relationships they have with other people and the grief of losing them was significant for those affected.

Consumers in Gawanggal advised that they were lonely and felt like 'leftovers' as there were only 6 – 8 of them in the entire complex.

Recommendation 3: Activities within voluntary and involuntary mental health units be run consistently to a timetable
Consumers recommend that in both voluntary and involuntary mental health units, scheduled activities be made available throughout the day and that they be offered consistently using a timetable to reduce feelings of isolation.

4. Housing and rising cost of living
Consumers advised that public and private housing insecurity, as well as rising living costs have contributed to their social isolation and feelings of loneliness.

Private rentals are becoming scarcer as well as more expensive, making them increasingly difficult to obtain and retain. Consumers have told us that they are moving more regularly due to rent increases meaning that they are increasingly disconnected from their local community, resulting in intensified feelings of loneliness. Additionally, frequent relocation disrupts consumers' access to their preferred General Practitioner and other local medical and social supports which are vital to identifying and mitigating the causes and effects of social isolation and loneliness.

> *When I have to move I disconnect with people/GP and [I] am not very good at meeting people. I have decision fatigue when get to a new place and new people…*

Rising living costs, such as petrol, electricity and groceries, also directly impact consumers' ability to engage in social activities by reducing their capacity to afford to go out and socialise with friends specifically and in their local community more generally.

Consumers in public housing also advised that when you are moved you lose all connection with the community you were enmeshed with. They also noted that when you

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Governance and Clinical Frameworks of Dhulwa Secure Mental Health Unit but this should not detract from the stories that they have shared and the lessons that can be learnt.

are being moved, you often don't know what sort of local situation you are moving into and what type of people will be around you in your new housing space. Consumers in public housing have also advised that they can experience social isolation due to being afraid to leave their housing as a result of the behaviours of some people in the local community because they do not know what might be outside their front door.

Recommendation 4: Specific housing supports be provided to consumers
It is essential that people are provided with choice when it comes to public housing, especially regarding where they will be moving to. Specific supports for mental health consumers in maintaining there private rentals and accessing stable public housing would allow stronger ties to be made within the local community, reducing loneliness.

5. Use of Information Technology post COVID-19 pandemic
Consumers expressed concern that the reliance that workplaces, CITs, Universities and medical practitioners place on information technology is increasing their loneliness and social isolation. The benefits to consumers feelings of social inclusion when they have to get up and go to class, meet and connect with other people, are immeasurable.

In addition, having medical appointments online removes the connection the consumer may have with their health provider and this can also lead to increased feelings of isolation.

6. Lived Experience Workers
Our final, but no less significant, issue is the loneliness and social isolation in the workplace felt by many lived experience workers in the ACT, and in Australia more broadly. Lived Experience workers draw on their own life-changing experience, service use and journey of recovery and healing, to support others. The relationships they develop based on the shared experience provide those they support with understanding and hope[6].

The numbers of lived experience workers in the ACT is relatively small compared with other States in Australia. However, various Australian Government as well as ACT Government policies are seeing this vital part of the mental health workforce increase.

While the literature focuses on lived experience workers helping to end the loneliness of others, there is relatively little work committed to how the lived experience worker themselves manages in the workplace. As there is such a small number in the ACT, lived

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[6] https://www.mentalhealthcommission.gov.au/lived-experience/lived-experience-workforces/peer-experience-workforce-guidelines (accessed 23/2/2024)

experience workers generally don't have a 'group' to hang out with where they work, nor have any one in other positions that they can mirror or talk with. Lived experience workers have reported difficulties working with other clinical workers who may not see them as equals in the treatment pathway or understand their value.

This lack of understanding of the lived experience worker role was identified as a key challenge[7] that can lead to the lived experience worker feeling isolated within the workplace. Education of co-workers, managers and health professionals is key to ensuring that they feel welcomed and part of the overall team and that their role in the multidisciplinary team is valued.

To try and combat this, the Network has set up a peer catch up monthly for the current Mental Health Peer Worker scholarship holders. This provides a place for external support and a safe environment for the new peer workers to share tips and vent frustrations with others that may be facing the same challenges.

Recommendation 5: Ensure that mental health peer workers are well supported
The Network applauds the addition of two Lived Experience Directors recently employed in the Office for Mental Health and Wellbeing and Mental Health, Justice Health, Alcohol and Drugs (MHJHADS) Division, Canberra Health Services. The Network also welcomes the development of a strong and supported structure for lived experience workers in the ACT that will embrace them as their numbers increase in the ACT.

The Network recommends that all lived experience workers are provided the same level of clinical (external) supervision as their clinical counterparts so that they can develop the skills necessary to reduce social isolation and work in a multi-disciplinary team.

Conclusion
The Network welcomes this Inquiry into social isolation and loneliness in the ACT. This submission, based on the lived experience of mental health consumers, identifies the impact that loneliness and social isolation can have on consumers health and wellbeing, increasing their reliance on crisis mental health support services.

The following recommendations to reduce both loneliness and social isolation in the ACT are included in this submission:
1. *Increase funding and reintroduce safe psychosocial programs throughout the ACT*
2. *Provide alternative services for people with mental illness when not considered to be in*

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[7] Psychiatr Rehabil J, 2012 Spring;35(4):337-40. doi: 10.2975/35.4.2012.337.340.

crisis, including transport services

3. *Activities within voluntary and involuntary mental health units be run consistently to a timetable*
4. *Specific housing supports be provided to consumers*
5. *Ensure that lived experience workers are well supported*