Submission to the Parliamentary Inquiry into Loneliness and Isolation

Support Groups Queensland Inc

Support Groups Queensland welcomes the Queensland parliament's commitment to addressing loneliness and social isolation. We are a small health promotion charity that supports people to join, to start and to run support groups. We work with over seven hundred support groups across Queensland. Most groups are led by volunteers.

Our reflections on the inquiry topics are:

The nature and extent of the impact of social isolation and loneliness in Queensland.

Our client group represents some of the most isolated people in Queensland. They are those experiencing major health challenges or life transitions. Across the broad spectrum of health[1], there are many underlying issues that cause social isolation, including chronic disease, illness, injury, disability, addiction, genetic conditions, bereavement, violence, trauma, relocation, carer responsibilities and mental health concerns.

The impact of chronic loneliness has been compared to smoking 15 cigarettes per day and carries an increased risk of early mortality.[2] Thus the return on investment of programs that reduce loneliness can be quantified as substantial.

In 2018, the prevalence of people who were currently lonely in Australia was estimated at one in four.[3] Emerging research from Covid-19 indicates increased loneliness, yet those who were lonely are not necessarily feeling increased loneliness. This can be illustrated by this remark by a client "My life is no different during lockdown. The only times I leave the house are for medical appointments and groceries. I talk to people in the checkout queue."

Examples where people may be feeling increased loneliness include carers and those with higher Covid-19 risk factors. Covid-19 has caused many services to use a "drop at the gate" policy. This applies to schools, respite services, aged care and other programs. This

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[1] The World Health Organisation defines health as a "state of complete physical, mental, and social wellbeing, and not merely the absence of disease or infirmity."

[2] Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and Social Isolation as Risk Factors for Mortality: A Meta-Analytic Review. Perspectives on Psychological Science. 2015;10(2):227-237. doi:10.1177/1745691614568352

[3] Australian Psychological Society 2018. Australian loneliness report: A survey exploring the loneliness levels of Australians and the impact on their health and wellbeing. Melbourne: APS.

approach has severely limited interactions between people with carer responsibilities, particularly when coupled with privacy policy. Suddenly, the first Tuesday of the month morning tea that has run for years is no longer happening. The local art group has been shut down. Unfortunately, many organisations have taken a narrow view of their primary client role, rather than a support system/community development approach, and these interactions have not restarted or continued in any form. Fortunately, there are also many who have increased their check-ins, phone trees, social media groups and inventive projects that are shared yet undertaken alone. For example, the Mt Gravatt Stroke Friendship Group, supported by their leader Sydney, changed their format to smaller coffee gatherings and phone check-ins. Many of this group are anxious about their vulnerability to adverse Covid-19 outcomes.

The causes and drivers of social isolation and loneliness, including those unique to Queensland.

People can be isolated and lonely in the middle of cities or in rural settings. In cities, there are those who don't know a single neighbour. In rural settings, the nearest neighbour can be distant. If you have a rare health concern, the closest people to share your experience may be interstate or international. Sometimes people don't want others who are close to them to know about their diagnosis or face taboos in speaking freely. To overcome social isolation in these circumstances, the internet has been a lifeline for many. However, this requires people to have skills and access to digital technology, and the digital divide is a major issue in Queensland.[4]

While people may have supportive family and friends, they still may feel isolated in living with their issue. In our experience, many people are directed to a support group after struggling with a serious health concern for many years. Suddenly, they discover they are not alone, there are people who share their lived experience. At one support group meeting we hosted, one participant had never met anyone with their condition before, although their diagnosis was ten years previously. To attend this meeting, people travelled to Brisbane from the Sunshine Coast, Toowoomba and the Gold Coast. They talked non-stop for three hours.

It can take multiple attempts for someone to join a group. Barriers are: transport, fear, anxiety, lack of resources and ill health. Sometime the health issue itself creates a barrier to entry. One group told me about one of their members – "When he first came he never spoke, not one word. Now, he talks."

People from a non-English speaking background are vulnerable to loneliness and social isolation. In Queensland, this issue is complicated due to limited numbers in some language

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[4]Thomas, J, Barraket, J, Wilson, CK, Rennie, E, Ewing, S, MacDonald, T, 2019, Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2019, RMIT University and Swinburne University of Technology, Melbourne, for Telstra. https://www.csi.edu.au/media/2019_ADII_Report.pdf

groups and a dispersed geographic approach to refugee settlement. There is a need to support quality conversations, not just translated fact sheets. Community leaders are overloaded and bi-cultural workers are not sufficiently funded. Support Groups Queensland has assisted with a large variety of community group requests. For example, sourcing a Chinese diabetes educator for the Happy Seniors Club, hosting a Wheel of Wellbeing mental health session for group leaders, and supporting a Zoom community gathering with an Amharic speaking psychologist during lockdown.

The protective factors known to mitigate social isolation and loneliness.

An important factor to mitigate social isolation and loneliness is building quality relationships and increasing opportunities for social interaction.[5] Coolum Women's Shed have a strong and growing membership, of diverse ages and backgrounds. They note that many women who join are new to the area.

Volunteering is also a protective factor and it is the backbone of many support groups. ARAFMI support people caring for a loved one experiencing mental illness. Their volunteer support group facilitators run monthly meetings in a dozen locations, including Bundaberg, Ipswich and Toowoomba.

The benefits of addressing social isolation and loneliness, examples of successful initiatives undertaken nationally and internationally and how to measure social isolation and loneliness in Queensland to determine if implemented strategies are effective.

As well as increased social connectness, support groups assist members to feel confident to self-advocate, to exchange information and to manage their health concern. More than twenty research studies have investigated the effectiveness of support groups.[6] Queensland has many effective support group programs. For example, the Amputees and Families Support Group Qld Inc. runs regular support groups, diabetes education, seated yoga and many more events for people affected by amputation, in twenty locations across Queensland, including Cairns, Kingaroy and Acacia Ridge.

For people with autism spectrum disorders, friendship-making can present potential challenges.[7] However, peer-led organisations like Asperger Services Australia at Virginia and

[5] Hawkley, L and Cacioppo, J. (2013) Loneliness Matters: A Theoretical and Empirical Review of Consequences and Mechanisms. Ann Behav Med. Available at https://ncbi.nlm.nih.gov

[6] Lonczak, Dr H. February 2021. Support Groups for Mental Health: 53 Proven Benefits & Tools https://positivepsychology.com/support-groups/

[7] Mendelson, J. L., Gates, J. A., & Lerner, M. D. (2016). Friendship in school-age boys with autism spectrum disorders: A meta-analytic summary and developmental, process-based model. *Psychological Bulletin, 142*(6), 601–622. https://doi.org/10.1037/bul0000041

Steps Autism Treehouse at the Sunshine Coast provide effective and inclusive programs that address social isolation. Both these organisations work with children, adults and families.

Support Groups Queensland co-facilitates one support group for people with a hoarding disorder, in association with the Sherwood Neighbourhood Centre. The methodology for this group is based on "Buried in Treasures", a peer support group system that has proved equally effective as therapist led support.[8] A proven, standard methodology like this can be rolled out Queensland-wide with more resourcing, and would target one of the most socially isolated groups in our society. Hoarding prevalence is estimated at 2.6% of the population.[9]

Support Groups Queensland auspices Happy Chat in Stanthorpe, a mental health support group, and ICESUP CQ in Yeppoon, a family support group for recovery from methamphetamine addiction. Funding and supporting small groups like this, who are on-the-ground with a plan that connects people to people. While many groups aren't resourced for large scale evaluation, performance measures such as recurring attendance, self-reported confidence levels, number of disclosures and new information acquired, can be used. The field of action research[10] also has a broad range of tools that are centred in community practice.

The work of the Community Controlled Health Centres, such as Wuchopperen, demonstrate a holistic view of health and wellbeing that combats loneliness and social isolation. Projects like new Mums, exercise classes, sport and yarning circles offer safe spaces that lead in supporting Aboriginal and Torres Strait Islander community groups. Many Aboriginal and Torres Strait Islander services address transport to groups, child care and soft entry approaches to health which should be models of inclusive practice for mainstream organisations.

How current investment by the Queensland Government, other levels of government, the non-government, corporate and other sectors may be leveraged to prevent, mitigate and address the drivers and impacts of social isolation and loneliness across Queensland.

Support Groups Queensland is partially funded by Queensland Health ($93 236 in 2020/21). This funding enables us to maintain a directory of support groups, to assist the public in finding a group, and provide support to existing and emerging groups as requested by them.

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[8] Mathews CA, Uhm S, Chan J, Gause M, Franklin J, Plumadore J, Stark SJ, Yu W, Vigil O, Salazar M, Delucchi KL, Vega E. Treating Hoarding Disorder in a real-world setting: Results from the Mental Health Association of San Francisco. Psychiatry Res. 2016 Mar 30;237:331-8. doi: 10.1016/j.psychres.2016.01.019. Epub 2016 Jan 21. PMID: 26805562; PMCID: PMC6020681.

[9] Greater Brisbane Hoarding and Squalor Strategies Group. (2021) Too Much Stuff, Too Little Support: A Call for Coordinated Action to Address Hoarding and Squalor in Queensland. Available at https://supportgroups.org.au

[10] McTaggart R. Principles for Participatory Action Research. *Adult Education Quarterly*. 1991;41(3):168-187. doi:10.1177/0001848191041003003

Queensland Health also committed additional funds to us in March 2020 to assist our service delivery during Covid-19. This support is invaluable in addressing social isolation. One client said to us, "before you arranged that Zoom for us, I was feeling absolutely desperate."

While Support Groups Queensland works with neighbourhood centres, libraries and other organisations that are quick to say *Yes, I'll fit them in, no charge*, there are others who quickly say … *not after 5 o'clock, they can't use the coffee machine, they can't do any physical activities, they need separate insurance*… The barriers pile up and volunteers become discouraged. Sourcing affordable and welcoming venues for support groups is one of Support Groups Queensland's most common tasks.

We would particularly note the need for all levels of government to include performance indicators in contracts and leases that require large organisations to facilitate on-the-ground support of community groups. Corporate Social Responsibility[11] is now recognised in the corporate sector, all kinds of entities including larger health and community organisations need to recognise their responsibility to local communities.

While support groups do wind up, many groups provide ongoing interactions that extend well beyond a three-year funding program. There is a tendency for governments to support workshops or time limited interventions, which do not match the ongoing need of people for long-lasting connections. Some support groups become the main friendship circle of isolated people, for regular coffee and conversations. A recent meeting of long-standing cancer support group talked about the fear of recurrence. Another group never talks about their condition, they welcome the opportunity to be removed from it while knowing everyone there is dealing with it.

The role, scope and priorities of a state-wide strategy to address social isolation and loneliness, considering interactions with existing Queensland and national strategies.

Our recommended priorities are:

One: A commitment to social prescribing

Connect people to people, not just to services. We call on medical and health professionals, government and non-government, to demonstrate an increased commitment to social prescribing.[12] Recommend that people join support groups, patient organisations and social

[11] https://humanrights.gov.au/our-work/corporate-social-responsibility-human-rights

[12] Kellezi B, Wakefield JRH, Stevenson C, *et al* The social cure of social prescribing: a mixed-methods study on the benefits of social connectedness on quality and effectiveness of care provision *BMJ Open* 2019;**9:**e033137. doi: 10.1136/bmjopen-2019-033137

groups that can connect people to other people that share the same journey. Peer support should not be an afterthought.

Two: A commitment to enabling support groups

The Queensland strategy must be focussed on community-led solutions. While Helplines support people in crisis and home support packages underpin people's essential needs, it is small gatherings of people with shared experiences that can build quality relationships. Some groups work on-line and more work is needed to address the digital divide. However, in-person interactions are essential to overcome loneliness and social isolation.

Three: Increased support for peer-led work across all systems

"Nothing about us, without us" is a slogan and principle that describes a commitment to fully engage the people who are affected by a decision or process. The voices of people who have lived experience need to be heard in designing strategies. Where people are viewed as the expert in their own life, systems become more responsive to the people involved in them.

Conclusion

Support groups are an effective strategy to combat social isolation and loneliness in Queensland. Over 700 successful groups already exist.   We hope that the many real life experiences we have provided of support groups across this submission will inform the committee's inquiry. We call for a commitment to social prescribing, a commitment to enabling support groups and increased support for peer-led work across all systems.

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