



Surveying the Lived Experience Community

Sharing Lived Experience Wisdom about Community, Connection and Looking after our Mental Health during COVID19

Context:

The Lived Experience Leadership and Advocacy Network (LELAN) acknowledges the significant impact that COVID19 is having on people around the world. In our community there is heightened emotion, uncertainty and confusion on what steps to take to look after ourselves and each other. We recognise that such responses are valid and that they make sense.

LELAN believes that there is expertise gained from lived/living experience; a resilience and courage that gets us through hard times and insights and strategies developed that could be valuable for the whole community to hear about and learn from.

We decided to survey our community to check-in with how people are doing at the moment. The results provide an opportunity to share these experiences and valuable strategies for surviving and living through this uncertain time with our community, decision-makers and service providers.

The findings below are a compilation of responses from the first week of the survey being open.

Advocacy recommendations:

- It is critically important that the needs of people with lived/living experience of distress and/or mental health issues are heard and addressed in our State's response to COVID19. This includes lived/living experience involvement in strategic discussions and decisions regarding the (re)organisation of how services and systems respond to this changing situation as well as the commissioning and design of new ones
- The Peer Workforce is a valuable resource that must be prioritised in all response and support options invested in. Trained Peer Workers are effective, and people want them
- The LETSS Program should be expanded to be available 24/7 and accessible to people in country areas. It is essential that LETSS retains its peer focus
- Mental health resources that validate the mental health and wellbeing impacts of this unique time in history need to be developed and promoted widely, particularly ones that are non-pathologising, non-clinical and practical. LELAN believes that the development of these resources should be lived experience-led and would welcome the opportunity to deliver on this
- Clear, caring and concise 'how-to messages' for people wanting to access mental health services need to be developed and distributed. This will minimise confusion, assist navigation and circumvent the sea of information that people have access to that may no longer be current given current circumstances
- Fund and/or provide devices and data packages to enable or increase access to telehealth and/or other online mental health services to those who may otherwise not be able to engage with them
- Maintain commitment to practices, policies and legislative shifts that prioritise least restrictive options for all people accessing mental health services during the COVID19 crisis

Who we heard from:

We surveyed people with lived/living experience of distress and mental health issues. Respondents included: consumers and carers; people in paid and volunteer lived experience roles; as well as clinicians, practitioners and community workers with a lived/living experience. The majority of those who have completed the survey so far are from South Australia, with ages ranging from 26 to 65 or older. People from diverse communities were represented, including those living with a disability or chronic illness, members of the queer community, people of colour and people who are culturally or linguistically diverse.

Personal lived experience of COVID19 and concerns:

We asked people with lived/living experience how they are going with everything that is happening in the world at the moment. Whilst the main theme from people related to increased *stress* and *anxiety*, there was variance in how those feelings were experienced with several people noting they are *managing ok* or are *not too bad, all things considered*.

People identified the up and down nature of the feelings, *some days are easier than others*, and a number of people shared that their distress related to new work arrangements or was about concern for important people in their lives with existing physical and mental health vulnerabilities. The uncertainty of the current situation and not knowing how long it will go for enhances feelings of being *scared*, *fearful* and *struggling*.

Despite the undeniable distress people with lived/living experience are feeling at the moment when we asked what concerns them the most, they spoke of worry for other people in more vulnerable positions than they are. Many worried about those who are now isolating in homes that are unsafe, those without internet access for telehealth, and those who have not accessed mental health support before and may not have the coping mechanisms or support systems in place.

'I am very worried about how people in the community with mental health struggles / challenges are going in this time. A lot of people live alone and their paid support people won't be visiting them anymore. And they might not have the technology to stay in touch online. It really worries me and I'm trying to think of ways to help'

'There are so many struggling on so many levels and not enough available ways to get help. Particularly first timers experiencing distress who want face to face'

What people with lived experience want/need right now from those in positions of power:

When we asked our survey respondents what they wanted to happen around mental health support during this time, many called for announcements from state leadership that directly address mental health and how we can support each other:

'There are so many out there who this virus has made even more self-focussed and anxious. Many more could phone, network on-line with others who need more support. Pathways need to be made, announcement by chief psychiatrist to urge people to do this in the media'

'Get Chief Psychiatrist or LELANs Ellie to make media announcements to get people to support all their friends. Most people know who those who are fragile are'

we amplify the voice, influence and leadership of people with lived experience to be heard and drive change

'It has an incredible impact. Fear and anxiety are heightened for people who may already live with extreme anxiety. Clear, caring and concise messages are important'

Others asked for better access to help and human connection, or at least making it really clear how people get help when they need it.

'People need human connection to stay well. Find more services to meet the needs of people now. Not just those already in the system. Make it clear where these people can get help. They may not feel they are bad enough to go to hospital but unaware of other options. Don't assume all people have internet availability. Libraries are closed. Community hubs are closed. How do they find out how to get help?'

The need for a *hub of peer workers trained in mental health* was spoken about. Some suggested pre-existing services like LETSS are expanded and for peer services to be made available 24/7. Peer Workers provide the opportunity to engage with those amongst us who have already learnt skills to deal with distress and crisis on an individual level.

'People would be best supported by peer workers on the phone as they have skills around social isolation and managing anxiety ... trained peers 24 hours a day'

Reduced access to mental health supports that people already have in place as well as financial insecurity and its impact on people's mental health were concerns that people don't want decision-makers to forget. These were highlighted by individuals themselves as well as by respondent's who work in mental health.

'I hope they won't dismiss the needs of vulnerable people in the community. And maybe being aware that medical / clinical interventions present a portion of support needed but the greater benefits come from genuine connection and care for people who need mental health support'

'That it's tough enough to live with ongoing mental distress and poor financial resources, let alone cope with this new aspect. That folks on Income Support are feeling overwhelmed. That those of us who still work must make difficult decisions on how to provide ongoing support to consumers'

Some people had innovative ideas around the use of technology, and free-to-air television, that would assist the public:

'Each tv channel could dedicate a half hour to a mindfulness session, perhaps spaced throughout the day and evening - it would reach a lot of people and help balance the constant onslaught of frightening news'

'Being able to have software that removes all COVID-19 news or ads from YouTube and other sites people use to distract themselves when they are anxious or distressed'

How people with lived experience are looking after themselves at this time:

Many of our respondents reported using concepts like radical acceptance, mindfulness, focussing on their own circle of influence and taking things *day by day breath by breath* to assist with their own mental health. Others spoke about the importance of routine and distraction activities that they are scheduling into their days whilst at home. The need for humour and laughter was also highlighted.

'Video chats. Phone calls. Netflix and exercise videos. My yoga teacher is streaming on Facebook. I am encouraged by lower pollution etc' ... 'Multiple tasking. Use every part of my mental and physical capacity by writing poems, writing emails, gardening eg weeding one patch per day, r watering 2 trees etc, creating variations in food presentation. Work on a different part of my fitness e.g. hands, arms, shoulders etc' ... 'I remind myself to get some sunshine, drink plenty water, eat fresh foods when I can- all these simple self-care routines do make a big difference'

'Focus on what you can control, and what will remain constant for you throughout a time of societal change'

The above summary articulates the valuable experience and insights from people with lived/living experience of mental health issues in relation to COVID19. Understanding this perspective, addressing concerns raised and learning from tried and tested ways of living through uncertainty makes sense at this time. This paper will be updated as more responses are received.

To discuss the perspective of, implications for and involvement of people with lived/living experience of distress and mental health issues in State or organisational strategy and planning responses for COVID19 please contact Ellie Hodges, LELAN's Executive Director, via the details below.

'It's going to be a very long road back to normality. Please support the poor and brave'

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The survey can be accessed at www.surveymonkey.com/r/T5V25J9 . Please share with your networks.