

## Learning from Lived Experience (LfLE) Project

Newsletter. No 1 April 2020

Welcome to the first edition of our newsletter!

The Learning from Lived Experience (LfLE) Project centres the experiences of people with lived/living experience of crisis and distress related to suicide through the creation of video and print resources as well as the development of an advocacy platform that will be used to influence change.

Our inquiry is focused on understanding what helped, what harmed, and what people hope for in the future around these experiences and the types of help or support that is available.

This specific focus was chosen as people often share that service responses in times of crisis are inadequate and frequently even compound the distress they are experiencing.

Following are some of the key activities of the project since it began in January 2020.



### Introducing the Learning from Lived Experience Project Worker

In January we welcomed Tanya Blazewicz to the LfLE Project Worker role. On her first day Tanya shared some insights into who she is and why this project feels so important. A snapshot of the interview is below or can be read in full over [here](#).



Why the Project is important to Tanya: Suicide prevention has always been something that I've been passionate about. Through my own person lived experience, I know that the mental health system as it stands is not working. I believe it is actually harming people, particularly harming people that are in crisis. I think that this project could make a big difference in helping rather than harming people by creating system reform; if that's even the most appropriate thing. Maybe we need a new system all together.

What 'doing the project justice' looks like: What I want is for people in the community to have enough time to hear about the project AND to have their voice heard. I want it to reach the far corners of our communities, to people that we don't often hear from.

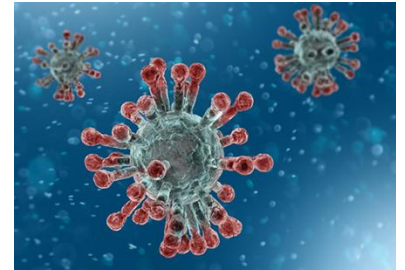
What excites Tanya about the project and about LELAN as an organisation: I'm really excited to hear from people about what worked actually. I don't necessarily mean what worked in the system, but what works for them. If people have survived a suicide attempt(s) or survived distress then they are still here, so something must have helped and that might not have been anything to do with the mental health system. It might have been spirituality, a hobby or community – and I want to know those things. Everyone has resilience within them and if we could somehow share those stories of hope it could be really helpful for others. I really foresee LELAN becoming known as a platform or amplifier for people to get their voice heard. I hope that LELAN is seen as a collective voice and I want people to know that LELAN belongs to the

whole community. I think that this project could be a starting point for amplifying the voices and showing that, but it could also lead on to addressing and providing advocacy around some of the other issues that we uncover in our conversations with people.

### Changes to the Project due to COVID19:

The LfLE Project is a short-term project that was due to be delivered January to June 2020. We all know the significant impact that COVID19 has had on the world and the disruption to so many well laid plans.

Since mid-March LELAN has been [adhering to physical distancing measures](#), whilst remaining socially connected. We have taken advantage of online platforms such as Zoom to continue to carry out staff meetings, PAG meetings, workshops and other connections where appropriate.



Due to the nature of the LfLE Project some aspects of it have been affected, including significant delays to filming of the video content that was originally scheduled for April.

The good news though is that the Project will go ahead with no reduction to our vision. Our new end date is now October 2020.

### Our Project Advisory Group (LfLE PAG)

The first action of the LfLE Project Worker was to recruit people to the Project Advisory Group (PAG). We were overwhelmed with the amount of interest in joining the PAG and received many passionate responses to the Expressions of Interest questions.

Below are some of the reasons that people gave for why it is important to be talking in different ways about responding to crisis and distress in South Australia:

- *Currently there is a lot of discussion on suicide and mental health however while people are encouraged to get help, they soon realise there are not many options or the options provided are ineffective.*
- *The way we talk about responding to crisis/distress is currently, I believe, very misunderstood by the general public. People in general are familiar with terms – wellbeing and resilience, however the mechanisms that make us resilient are not. I feel that we need to incorporate learning about the brain and stress and that mental illness is not a choice but we can control it with the right tools and supportive network.*
- *The current systems are not working, they are fragmented, too clinically focussed, politics impact on client care and big change is needed. I have seen/heard of too many clients being dismissed based on outdated assessments. The focus on risk categorisation is impacting on how people are actually treating in a negative way. We need more holistic care and we need to really listen to what the people who have been through it need.*
- *There is so much that is misunderstood and known about crisis/distress and suicide prevention, and the more we shed light on it hopefully the better the outcomes for all involved. Hearing from those that have lived experience is essential in breaking down these stigmas and by talking about it from*

*the perspective of the person who has been through it, I hope will create greater healing and understanding not only for those affected but the wider community. Everyone needs to feel safe and this is one area that needs work around how to support people to feel safe.*

Applicants were interviewed by phone in early February and ultimately 6, rather than 5 individuals were chosen. We are fortunate to have two regional/rural PAG members and other identities and experiences represented to bring diverse perspectives to our PAG meetings.

Since the first PAG meeting in February we have come together as a team 3 times. PAG members bring lively discussion and creative ideas to the project ensuring our work remains true to peoples' real experiences, considers accessibility and is trauma-informed and recovery-focused. In between meetings the PAG contributes to the project and stays connected via Trello.

### Project Advisory Group: Lived Experience Member Spotlight

We are fortunate to have a wonderful group of people with lived experience advising the project team and helping to guide the project. In this newsletter we introduce you to Courtney.

Intro to who you are and why you are active in the Lived Experience Space: I've been the sole Peer Specialist in the State Forensic MHS for 7 years. My lived experience is not as a forensic patient, so I also want to use the knowledge gained from my experiences of trauma, recovery and service use across different spaces. When I was a psych student considering my options after Honours, I thought my personal struggles with sanity disqualified me from working as a mental health practitioner, and in this profession I'm over qualified with expertise!



What excites you about the LfLE Project and why is it important for you to be involved? I would love to contribute my heart and knowledge to this project and be a part of the excellent advocacy work LELAN is doing to promote real change lead by lived experience voices. When acute risk of suicide is highest after a discharge from inpatient psychiatric hospitalisation, support services provided by the current system are not fit for purpose. Research shows us that mental health stigma in the community is increased by biogenetic language perpetuated by awareness campaigns, while people who are struggling respond best to opportunities for connection, strengths-based support and self-empowerment. Experience in the mental health system tells us there is not so much a lack of awareness in the community about seeking help, but a lack of availability of the help we need when in crisis.

Why do you think involving people with lived experience in change, or having them lead it, matters: Paternalistic systems that don't do so, aren't working effectively to support people out of distress now and they haven't for hundreds of years, simple as that.

One radical or innovative idea for how to better support people in crisis and distress in SA: The establishment of safe and comfortable spaces for crisis support away from the distressing environment of EDs, such as the "Urgent Mental Health Care Centre" and "Safe Haven Café" suggested in the SA Mental Health Services Plan 2020. Staffed by peer workers and trauma-informed practitioners of diverse cultural identities, to provide personalised and practical support based on care and listening, with less emphasis on diagnosis and medication, and less reliance on restrictive practices.

Any tips or advice for other people with lived experience about small (or big) actions they can take to get involved and/or be a leader in the lived experience community: Discover and follow your strengths and passions, be open to different types of roles and ways of contributing outside what you've done before, nurture relationships with lived experience colleagues, and seek out professional development of leadership skills that current peer roles don't give us the opportunity to build. These days I'm interested in using my knowledge to subvert the system to my mad agenda for equity and humane healing, so I speak up for our workforce needs, and branch out into advisory groups for research and projects both within my health network and outside it, as well as professional groups united around supporting each other to grow and strengthen lived experience influence through leadership. I'm considering if academic work might suit me if the opportunity arises too.

Something about you: I'm a fan of fantasy and sci-fi books/films and love escaping to other worlds in reading and writing, maybe this helps me imagine how ours could be different!

### The video component of our project so far:

We have had lots of open and enriching conversation planning the video interviews, particularly around the 'look and feel' of the video content and ensuring we make the process 'safe-enough' for the people that generously volunteer to be interviewed.



We have decided to use a filming style similar to – but not exactly the same as – [ABC's 'You Can't Ask That'](#) in order to focus on the advocacy points around what helped, harmed and could be done better in suicide prevention here in SA. It was also discussed that filming in this style would help bring people's voices to the forefront and highlighting human connection by allowing the possibility to film multiple people at once. We have thought hard about how to make the video unique whilst also adding a touch of humanity.

Due to COVID19 delaying our filming timeline, promotion of the Expression of Interest for people to be interviewed on film has been paused but will restart as soon as we judge it to be safe to do so. Watch this space.

### The survey component of our project so far:

The Project team and PAG have been working on a survey to hear from even more people about their experiences of crisis and distress and the support they received. Results of the survey will be used to develop an advocacy document that LELAN will use in our future work. We expect the survey to be released in May.

### LfLE Project Key Contacts:

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