

## Activating Lived Experience Leadership (ALEL) Project Newsletter. No 2 April 2020

Welcome to the second edition of our newsletter!

The Activating Lived Experience Leadership (ALEL) Project is a partnership between LELAN (SA Lived Experience Leadership & Advocacy Network) and UniSA (Mental Health and Suicide Prevention Research Group). The Project is a participatory action research and co-design project which aims to generate knowledge and action regarding successful lived experience leadership, influence and change. The outcomes of the project will be training and learning resources for lived experience leadership and change as well as the activation of lived experience networks throughout South Australia. The project is funded as a [Discovery Grant by the Fay Fuller Foundation](#) and is supported by the [SA Mental Health Commission](#) also. The project will end in June 2021.

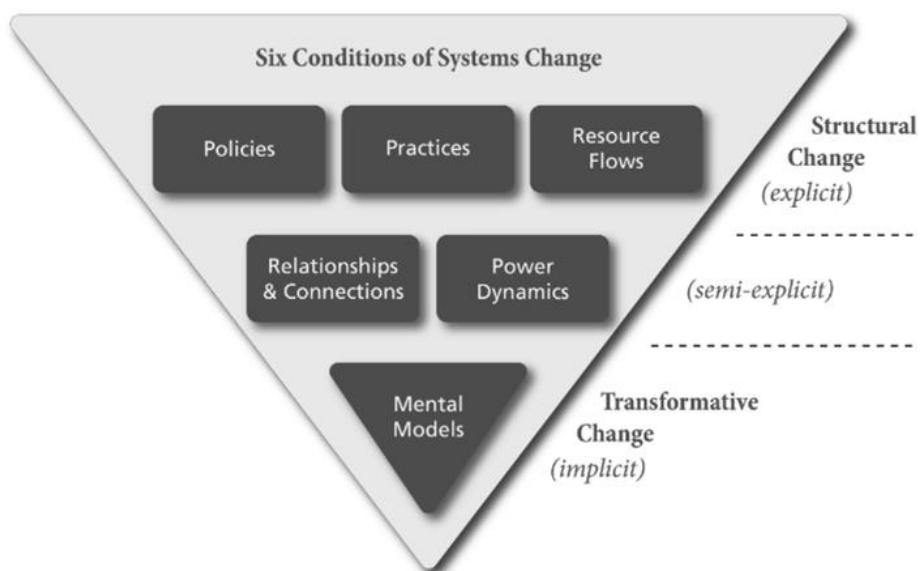


Following are some of the key activities since we shared our [first newsletter](#) in December 2019.

### Summary Report of the System and Sector Leaders Summit

A Summary Report of the *System and Sector Leaders' Summit* held last October has been released and can be accessed [here](#).

Summit participants used the [Six Conditions of Systems Change](#) model (pictured below) to unpack the key factors that reinforce current conditions and hinder progress for lived experience leadership and change.



Some highlight quotes from the Summary Report are:

- *People very much felt that the time is right for lived experience leadership to be developed and embedded in our systems, are frustrated that it has not already been done and acknowledge the challenge presented in moving forward.*
- *Other structural challenges identified were linked to the current dominance of the medical model for understanding and responding to mental health issues as well as the lack of political will and ineffectiveness of policy to drive change. Current approaches to change were deemed too narrow, short-sighted and without leadership.*
- *Collective efforts were seen as the only way to move forward on strengthening, embedding and creating space for lived experience leadership to flourish. There was a strong suggestion that progress will occur only if it is led by an identified and recognised entity, so that it doesn't get lost in the churn and existing demands of services and the system.*

The ALEL Project Team will continue to expand on the ideas generated at the Summit and take action on the suggested solutions. Some of these initiatives are addressed further down in this newsletter.

## Lived Experience Leadership and Change Community of Practice (CoP)

In response to the System and Sector Leaders Summit we have been convening a [Community of Practice for Lived Experience Leadership and Change](#). We have had two sessions so far filled with passionate people and rich conversation on important topics, including how we co-design the sessions for maximum engagement and impact.

Our March CoP started with this inquiry question: how do we use our own, or draw on, lived experience as a 'lens' in what we do and how we think about things rather than confining it to a 'role' that we have at any particular point in time and potentially narrowing the use and value of lived experience? In preparation we shared [this article](#) on consumer perspective from the [Centre for Psychiatric Nursing at the University of Melbourne](#).

The conversation wandered far and over many landscapes, including: power imbalance and humanising systems; where our voice fits, particularly the quieter voices; how we make space for everyone in the collective; being a change agent and how we support people to amp this up; boundaries and feeling our way to where we stand; and practical tools we could develop to support people in their own reflection and action.

The next CoP will be held via Zoom on Wednesday May 6<sup>th</sup>, 9.30-11am. Broad starting point topics will relate to tensions within power imbalance and ally leadership. We know the conversation will go much further. If you would like to join us for the CoP please email [info@lelan.org.au](mailto:info@lelan.org.au).



## Project Advisory Group: Lived Experience Member Spotlight

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



Intro to Jill and why she is active in the lived experience space: Jill is co-founder and executive officer of [MOSH \(Minimisation of Suicide Harm\)](#) which has been operating a community drop-in centre in Thebarton since 2008.

In 2001 Jill lost her sixteen year old son Michael to suicide and soon realised there was a great need for a service where people could go whenever they needed to, without an appointment or cost. Since losing Michael, Jill has worked in a voluntary capacity as Facilitator of the Bereaved Through Suicide Support Group, a board member of Suicide Prevention Australia, Member of the steering committee of Grieflink and SA chair of NALAG. She is currently a Board member of Postvention Australia and a member of the Premier's Council on Suicide Prevention. Over the years Jill has acquired a vast knowledge of many areas of Mental Health and Suicide Prevention and has presented workshops at National Conferences.

What excites you about the ALEL Project and why it is important for you to be involved: I'm excited by the growth in acknowledgment of the value of Lived Experience in our field and am constantly in awe of the amazing contributions made by the Lived Experience community often against overwhelming odds. The inclusion of carers and the respect given to their experience and knowledge heartens me greatly and I'm excited to see this progressing. We still have a long way to go in reducing the stigma around mental illness but the more we get to see people with Lived Experience succeed in this and any other space, the greater the likelihood of others stepping forward and having the courage to raise their hand to be involved.

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: I would encourage everyone to look at ways they can share their experience with the wider community, especially at the moment where everyone is reading and listening more than ever. Be positive where you can, without glossing over the hardships and don't be afraid to let your true self shine through. Find a mentor or be one yourself, contribute to this project, or other supportive forums where you can. Don't be afraid to try new technology and experiment with those you trust first, maybe write a blog.

Is there something about you, unrelated to your lived experience involvement, that you would like to share: I find great enjoyment in being in the shed playing with timber. I love to restore old forgotten pieces and find new uses for them (a bit like me I guess!)

And an invitation from Jill to close: When we can all get out and about again, we would love to see you at MOSH House at 86 George St Thebarton. Even now you can leave us a message on 84438369 if you would like a chat with one of our volunteers, or leave us a message on [Facebook at Mosh Australia](#) #loveMOSH.

## Our Literature and Evidence Review ... so far

We have been doing a significant search of published literature to identify evidence about many aspects of lived experience leadership and systems change. This includes:

- 1) A specific literature review on the concepts and qualities lived experience leadership in a broad sense, as well as identifying enablers and barriers to the creation and success of leadership positions. Our review is looking across areas of advocacy, representation, peer work, consumer run organisations, education and research
- 2) Identifying significant studies and existing literature reviews which help answer the questions we have and can be shared across the project.



So far have found reviews on:

- The benefits of consumer run organisations in terms of empowerment and recovery
- The benefits of peer work programs for a variety of mental health outcomes
- The role of allies in supporting lived experience leadership and empowerment
- The experience of peer workers and implementation issues in organisations.

We hope this will complement and inform the project and be a basis for shared learning with our Community of Practice and Leaders Summit activities. This work will also bring in experience of what other states and countries have attempted and achieved on a systems change level.

## Research Focus Groups

A large milestone of the ALEL project has been reached this month through the commencement of Research Focus Groups with lived experience leaders. The focus groups were originally scheduled to begin in mid-March but due to COVID19 restrictions we had to resubmit to the Ethics Committee and move the sessions online.

People based in South Australia who self-identify as a lived experience leader (consumer or carer) are encouraged to participate. Those that get involved may be active as an advocate, representative, community speaker or peer worker. These are all roles where leadership skills come into play in terms of raising awareness, working with services and systems, and promoting lived experience perspectives.

Whilst we have general dates set for focus group's we also invite groups or organisations with lived experience leaders wishing to 'host' a focus group to get in touch with us.



University of South Australia

**RESEARCH PROJECT**

**Focus Groups with Lived Experience Leader's**

As part of the Activating Lived Experience Leadership (ALEL) Project by LELAN and UniSA

This project may be relevant to you if you have personal lived experience or are a carer of a person living with mental health issues and are active as an advocate, representative, community speaker or peer worker. These are all roles where leadership skills come into play in terms of raising awareness, working with services and systems, and promoting lived experience perspectives.

register or more information [info@lelan.org.au](mailto:info@lelan.org.au)



90 min sessions

Wed 15/04  
Tues 21/04  
Thurs 23/04

on Zoom

Some of what we have been hearing in the focus groups:

- *'So, I see the [lived experience] leadership being across organisations and being above organisational wants and desires and things, a bit more of a collective community. And I think that leadership is that person who brings all of the different parts of lived experience together, who builds those networks, and I also think it's about who is strategic and thoughtful in how we can mobilise.'*
- *'In my messaging what I try to get across is that I'm not that broken or defective, I just experience things differently than somebody else might and, for whatever reason, history has called it mental illness and perhaps that might change at some time down the track.'*
- *'There is a lived experience community that's waiting for you'.*
- *'I think that's really important because lived experience is so much about systemic change, isn't it; it's always about fighting oppression and stigma, and if we have a leader who is stuck in their ways, who is refusing to be vulnerable, who is not engaging with us in a present, vulnerable way, then how can we effectively support ourselves and support other people to be engaging in that way?'*
- *'We need people to actually commit and say, "This lived experience leadership stuff is valuable; we're going to put some money at this and make sure that it happens, and it happens properly.'*

A future research activity will be a national survey to hear from a wider group of lived experience leaders.

To be involved in this research and register for a Focus Group during April or May please get in touch with Ellie ([ehodges@lelan.org.au](mailto:ehodges@lelan.org.au)) or Mark ([mark.loughhead@unisa.edu.au](mailto:mark.loughhead@unisa.edu.au)).

## Project Advisory Group: Service Member Spotlight

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

Intro to Lisa's work and role: My role is Principal Officer in the [Office of the Chief Psychiatrist](#). I lead the Corporate and Strategic Advisory Team. Among other things, this team manages all the Ministerial and Chief Executive correspondence coming into the Department for Health and Wellbeing, the team also undertakes policy and project work. We seek to inform this work with the lived (and living) experience of others – particularly those for whom being heard and understood is more of a challenge. For example, seeking input from Aboriginal people using mental health services is a part of the expertise of our Principal Aboriginal Mental Health Advisor, Ian James, and carer perspectives are something Camilo Guaqueta brings to the team as the Carer Consultant Senior Project Officer.

What excites you about the ALEL Project and why it is important for you to be involved: ALEL can provide richness to the Lived experience landscape that we're unable to obtain on our own (as a small office with limited capacity). It is also gathering the evidence base needed to form a solid foundation for growth and legitimacy.



Why you think involving people with lived experience in change, or having them lead it, matters: There is still have work to do in breaking down power imbalances and stigma within our services and having a truly shared value system across all involved in delivering care and support. We need the voices of people with lived experience to inform this.

Do you have one radical or innovative idea for how to improve lived experience voice, influence and leadership in SA: The new Urgent Mental Health Care Centre – when it is working as people with Lived Experience co-designed it – will be a pretty radical metropolitan service for SA.

Any tips or advice for other services, organisations, departments or people in work roles about small (or big) actions they can take to support the involvement and leadership of people with lived experience: That we all keep talking and moving forward – with kindness and patience.

Is there something about you, unrelated to work, that you would like to share: I have double joints, albeit less flexible than they used to be – but I did some wicked contortionist moves (Party tricks) in my heyday! Just to be clear, mainly with my arms and hands 😊

## Workshop on Lived Experience Considerations and Opportunities in Systems Change

To build on the systems and change aspects of the project we are offering a [workshop](#) on *Systems Change: Lived Experience Considerations and Opportunities* on April 29<sup>th</sup>. We know that a collaborative, cross-sector and multi-level approach is the best way to tackle these challenges and are committed to increasing knowledge, skill and action in this space.

The project team is delighted that in less than one week 45 people signed up for the workshop. Clearly this is an area of great interest!

For now, we have made the decision to close registrations but aim to run another session soon, as well as share our learnings in other ways.



## ALEL Project Key Contacts:

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