

## Activating Lived Experience Leadership (ALEL) Project Newsletter. No 1 December 2019

Welcome to our first 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 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 that have been completed so far.

### Project Team



The ALEL project started in July this year. Ellie Hodges (Executive Director, LELAN) and Nicholas Procter (Chair Mental Health Nursing, UniSA) were the first members of the project team. Heather McIntyre (Research Assistant, UniSA) and Mark Loughhead (Senior Research Fellow, UniSA) were recruited soon after. The role of the team is to facilitate key actions of the project, in connection with the many people who are and will be involved.

[Photo: Professor Nicholas Procter, Niall Fay (Fay Fuller Foundation, Mark Loughhead, Ellie Hodges, Heather McIntyre is on the right in the photo below]

### The Project Advisory Group (PAG)

In August, we advertised for lived experience advisors to join the Project Advisory Group (PAG). The role of this group is central to the project. Members of the PAG are active in guiding the design of the research project and also assisting with decisions about recruitment strategies, the types of research questions, analysis of themes and research findings, and helping to generate change as a result of the findings.

Apart from researching leadership, the ALEL project has community development activities, which are about



building networks, and engaging service leaders in conversations about the big picture of lived experience advocacy and change in South Australia. The Project Advisory Group members are also a part of these discussions.

We received great interest for the positions that were offered for the Project Advisory Group and seven people with lived experience from a variety of backgrounds joined the group in August this year. Among this group are five members representing key organisations in the mental health sector.

## Research Workshop

As a community development activity, we held a half day introduction to lived experience research workshop on October 1. This workshop focused on identifying the skills involved in searching for information and research that can be used in advocacy or learning about a particular topic, practice, or issue. The session focussed on exploring the area of lived experience engagement in research activity, and how consumers and carers can help to shape project design, aims, questions, recruitment and promotion. Seventeen people attended the workshop and provided positive evaluations and ideas for how we could build on the content. We are interested in refining and offering the workshop again, please let us know if you would like to be involved in this.



## The Mental Health Leaders Summit

In late October we held our first System and Sector Leaders' Summit. South Australia's key mental health and community service leaders, including peak body representatives, were invited to attend and to consider how we can improve the way lived experience is defined, recognised and utilised in South Australia. This is the key question at the heart of the research project.

Prior to the Leaders' Summit, Ellie and Mark met individually with a variety of the invited leaders to discuss their perspectives on the current status of lived experience leadership, advocacy and engagement in sector decision making, and what changes could be considered for better recognition, partnership and influence. Themes from these discussions were used as a basis of the summit meeting, to encourage reflection and to look at how we can make changes to culture, structures, policies and practices.

Many ideas were expressed at the Summit and we plan to release a report in the new year. A number of



potential actions were identified as important to the project and the sector. These are:

- Looking at the evidence base of lived experience involvement, particularly in terms of improving the quality and design of mental health services. We can then use evidence to promote further levels of investment and opportunity in codesigned services or lived experience led services
- Setting up a community of practice, which brings people together to collaborate in sharing knowledge and experience around engagement, partnership and supporting lived experience leaders
- Developing a lived experience framework for South Australia, similar to those being developed in other states. A framework could help promote the roles of advocacy, representation, education and peer support as key contributions that people provide to the wellbeing of South Australians



## Research project

There is a formal research part of the ALEL project that will start in February 2020. The research activity has taken some months to design. This has involved working up a research protocol and sets of focus group and interview questions and an application for human research ethics approval with UniSA.

The research project will involve focus groups across parts of the state where people who are active in lived experience advocacy, representation, education or peer work will be invited to become participants in the research.

The focus of the discussions will be to explore the concept of lived experience leadership. What does it look like? How is it related to the different roles and activities that people do when supporting others, or seeking change, or raising community awareness? What pathways help people to become active? How is being a leader connected to personal recovery? And how the sector and services can better recognise and support leadership roles.

After the first round of focus groups, participants will be invited to participate in some online discussions which reflect on the first round of findings. Participants will also be able to contribute other ideas about leadership, mentoring having influence, or receiving or, providing support in the lived experience space. Everyone participating in the research will be able to access the same online discussions.

The third round of involvement will be further focus groups which are aimed at sharing the learning and from this premise cocreating training materials, resources and networks. These will be discussions which help create the content and format of future training resources.

A further part of the research project will be one-to-one interviews with service leader's (directors, managers, safety and quality and policy leaders) around perceptions of and experience in the area of lived experience leadership and engagement. We will ask what in their experience suggests best practices in the area of mental health service, and ways to support people to become effective and influential lived experience leaders.

We will have more information about the research activities in February next year. But please get in touch if you have questions.

## Communities of Practice

In the new year we will be convening an ALEL Community of Practice focused on lived experience leadership and change.

Communities of practice typically involve people who don't necessarily work alongside each other every day, but they find value and meaning in their interactions or shared area of inquiry. Members of the community consider new ideas and discuss possibilities on new ways of working and responding. They may share or develop resources, tools or guides, or generate co-production in key areas of interest. The ALEL community of practice will be developed as a 'safe space' to encourage discussion, information exchange and capacity building on lived experience leadership and advocacy in mental health.

Meetings will be held every six weeks starting Wednesday February 12<sup>th</sup>, 9.30-11am. Let us know if you would like to be a part of these conversations.

## ALEL Project Key Contacts:

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