

Centring Lived Experience Video Transcript

Hi. My name's Ellie Hodges, and I'm the Executive Director of LELAN. The Lived Experience Leadership and Advocacy Network, South Australia. I'm really proud to be here today supporting the work of the Fay Fuller Foundation as they go out looking for people to apply for their Discovery Grant. We were really fortunate to receive a Discovery Grant, in 2019 and worked in partnership also with the University of South Australia. Since that time, our relationship with Fay Fuller has strengthened and evolved into a Strategic Partnership. Which means we support each other to improve our understanding of each other's core areas of expertise and knowledge. And for LELAN, that's supporting Fay Fuller to integrate, and understand the complexities and nuances around lived experience to improve grant making, but also to ensure that lived experience is incorporated in the projects and programs, services, initiatives that they fund as well. So I'm here today to talk a bit about how we make sense of lived experience and some things that you could consider, in as you put in your application, but also think about, how you do things in the future as well. There's a great article that will be linked, that came out a couple of years ago. And it really defines lived experience as experiences that impact significantly on how people make sense of themselves and their place in the world. And what we need to really remember about lived experience is it's contextual. And so for us at LELAN, we do systemic advocacy in the mental health space. And so lived experience it has to be about that, but we know that mental health covers many areas, and it's about trauma and social determinants of health and, other things that go on in people's lives and experiences.

If you are a homelessness service, then the people with lived experience that you'll be needing to target and talk to are people who've had experiences of homelessness, housing instability, it may be rough sleep as it may not be depending on which part of the sector, and spectrum that you're looking to influence. If you work with young people, then it's really ensuring that young people are involved and young people who had the experiences that you are trying to understand and impact and improve. Something I really want people to know is that people with lived experience have many other skills and, ideas that they bring to the table as well. So it's how we approach lived experience, not from a deficit viewpoint, but really seeing the strength in it. Everyone that works at LELAN, our Volunteers, our Board, all have declared lived experience, and we use that in our work. We we have a, not that it's been easy or great, but there is a pride in knowing that our lived experience matters and we embody that in our work and that we are stronger and we can have better policy, better services, and better outcomes and lives for people if the real experiences are considered, and they're contributing to it as well. Another thing that will be linked in, under this video is a paper that we've put together at LELAN around the enabling conditions for including people with lived experience based on lots of reading, research, and our own experience of representing

ourselves and our community at State and National level. And so some of those, there are eight that are identified. I'll just go into a few of the really cool ones. Otherwise, I could keep you a really long time. But the thing that we talk about is, we really urge people to co-produce services, ideas, programs at a minimum and a genuine partnership with people with lived experience. Historically, people have talked about consumer engagement or lived experience engagement or including the voice of lived experience. We actually talk about engagement and the idea of that being about fifteen years ago. We've moved on. And the difference is that it's a true commitment to sharing power with people with lived experience. So seeing them as equal in contribution, in expertise, in having ideas for making things better. And doing that walking beside them, not over, not doing too but doing with. And it's also about creating space at the next step around lived experience leadership and where people with lived experience can lead initiatives or aspects of them, and it's how we can get out of the way to enable them to do that. So it's really important that it's not tokenistic and that people are supported to be involved in a way that they are most comfortable and able for them. When we're talking about lived experience as well, it's really important that it's collective, inclusive, diverse, and intersectional. What that means is that you get a range of perspectives of people with lived experience. I know that my experience as a white woman accessing inpatient mental health services is different to someone on the street who's hearing voices, and may have the police called and things like that. So our contact with services will be different because of our identity, our life experiences, our education, the communities that we live in, regional rural remote, metro, all different experiences of having contact with services and our mental health and wellbeing or other social issues. So it's really getting that cross section of perspective. This work is really values based. It's values based in terms of it adds value to what you design and put out to the world. It also adds valued people's lives who get involved and validated and honored for their contributions. It also has a value in that it saves money when people with lived experience are included in the design and implementation that's proven around person centered care and things like that. It's the ethic that you bring to this as well and what I talked about before in terms of how seeing people as people not as the hardships and struggles they've had in life, but for what they have got through, what they can contribute and the immense knowledge that they now have in the wisdom and expertise that comes from that. It's also really important if you do invite and support people with lived experience to get involved in your work to ensure it's safe enough for them to do so. That means that you create conditions that are supportive of them to attend, that's accessibility and basic stuff like that. It's the relationship that you build. And it's about give and take. Historically services take a lot from people. And give nothing back and really encourage you to think about what you are giving back to people in terms of debriefing, briefing, remuneration, supporting them,

answering their questions, feeding back about what you do with their contributions is really important as well. So this is just a quick snapshot. There's more information and LELAN has, more things that you can link to on our website as well.

But people with lived experience have a wisdom that they bring to the table to your design plans to your prototyping, to your organisations, that everyone benefits from when it's done well. And I wish you the best in your application process.