

SUMMARY REPORT

System & Sector Leaders' Summit #2 : Dialoguing for Change

Activating Lived Experience Leadership (ALEL) Project

[February 18th 2021]



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FOUNDATION



Welcome and Acknowledgement

Professor Nicholas Procter, UniSA



Summit Context and Purpose

Ellie Hodges, Executive Director LELAN



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the Activating Lived Experience Leadership (ALEL) Project

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- A **partnership** between LELAN (Lived Experience Leadership & Advocacy Network) and UniSA's Mental Health and Suicide Prevention Research and Education Group
- **Research and capacity building** with the lived/living experience community and social sector
 - Predominantly mental health focused at the systemic level, knowing that the learnings are highly relevant to other sectors (eg homelessness and housing, alcohol and other drug, etc)
- A **systems focus to embed and enable lived experience leadership to thrive and have impact**

the relevance of a systems change approach

- *The biggest social challenges of our times are **entrenched and systemic**.*

[Tara Anderson. (2019). [What Can Collective Impact Offer](#). ProBono Australia]

- *Yet today's ways of working together **often aren't deep enough, disruptive enough, or exploratory enough** to produce thinking and action beyond the incremental.*

[Collective Change Lab. [Our Work](#)]

*Programmatic interventions help people beat the odds. **Systemic interventions** can help change their odds.*

[[Karen Pittman](#), CEO of the Forum on Youth Investment]



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including
people with
lived/living
experience is
essential

- *It is essential that systems interventions **remain rooted in action** and **do not become removed** from the people in society they are designed to help.*

[Abercrombie et al.(2015). [Systems Change: A Guide to What it Is and How to do It](#), p.10. New Philanthropy Capital]

- ***Plugging the voice of the community into the right kind of political power grid will do more to create health and wellness than any other single intervention.***

[*Building Healthy Communities (BHC)* cited in Kania et al. (2018). [The Water of Systems Change](#), p.13. FSG]

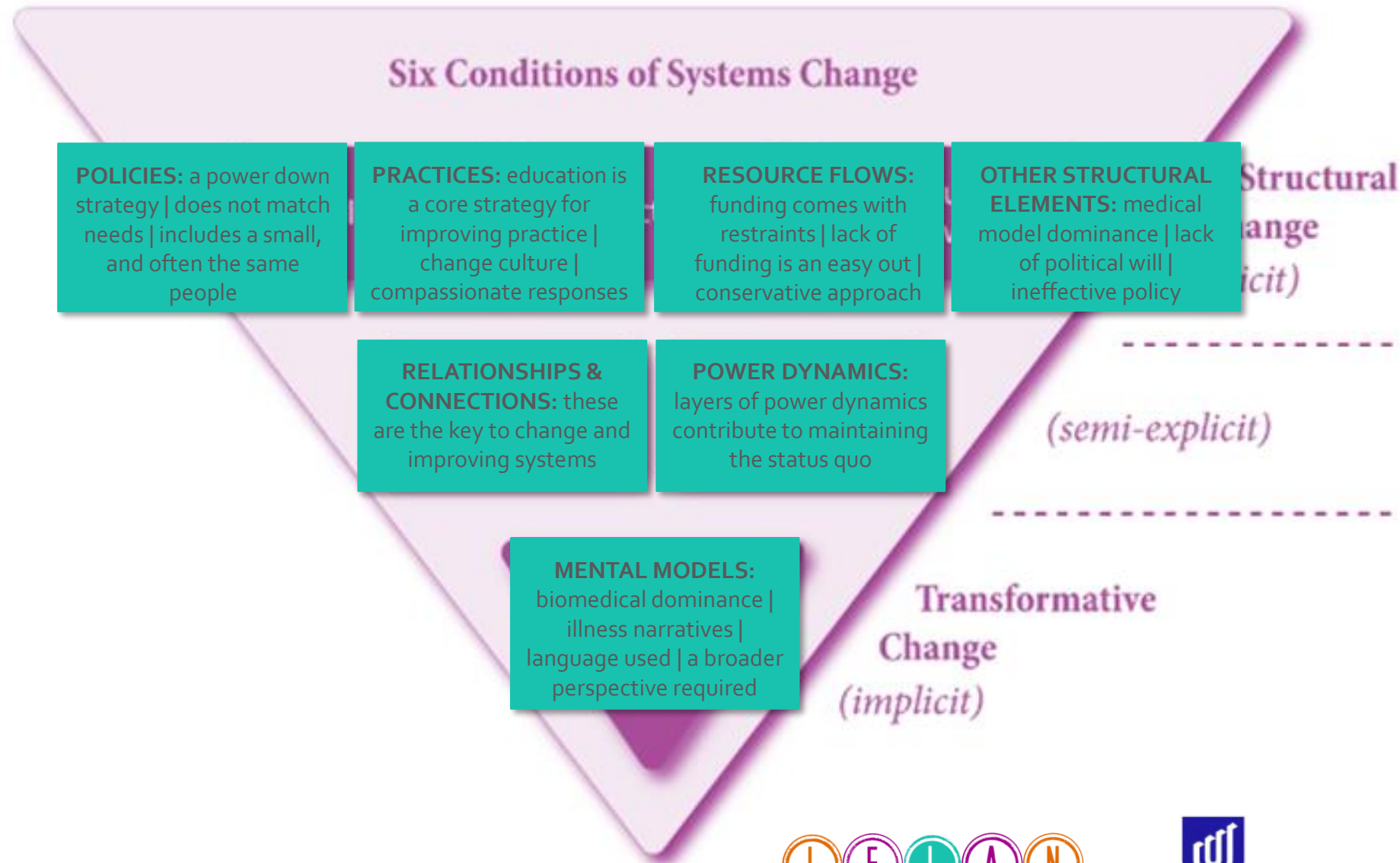
recap of Summit #1

[held October 24th 2019]

- We heard unequivocally that ***the time is right** for lived experience leadership to be developed and embedded in our systems*
- We used *The Water of Systems Change* approach to unpack current conditions reinforcing and/or hindering progress for lived experience in SA ... **we wanted to know what we can shift to progress change.** What we discovered is summarised on the next slide

the six conditions of system change that we did a deep dive into

[summarised from [Summit #1 Summary Report](#)]



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- **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

*Power of demonstration ... Power of collective change
It needs to be led, it needs to be someone's job
Lived experience voice should outline conditions for change and others try to support it*

the ideas
people had
about taking
action
together

[\[Summit #1 Summary Report\]](#)



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1. **Convene a 'Community of Practice'** focused on gathering and disseminating evidence related to, and examples demonstrating, the value of peer work, lived experience advocacy and leadership

The Lived Experience Leadership and Change Community of Practice has been meeting every six weeks since February 2020



2. **Hold a follow-up Summit** focused on mapping current work in this space, roles, collaborations, gaps, needs and intersections, opportunities for – and commitment to – action, etc

The focus of the follow-up Summit changed due to COVID-related delays



3. **Consider steps to develop a 'Lived Experience Framework'** that is inclusive of advocacy, partnerships, the peer workforce and is cross-sector ensuring government, NGO and community environment's are accounted for

Extensive work is being done in the sector to develop a Lived Experience Strategic Framework for SA. Learnings and documents from the ALEL Project have been shared with the Taskforce and LELAN is a member of the group

Summit #1
recommendations
that have
been actioned

[\[Summit #1 Summary Report\]](#)



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a collective impact approach informs the ALEL Project and LELAN

[from [Collective Impact Forum](#)]

Collective impact brings people together, ^[1]_[2]^[3]_[4] in a structured way, to achieve social change.



It starts with a common agenda.

That means coming together to collectively define the problem and create a shared vision to solve it.



It fosters mutually reinforcing activities.

That means coordinating collective efforts to maximize the end result.



It establishes shared measurement.

That means agreeing to track progress in the same way, which allows for continuous improvement.



It encourages continuous communication.

That means building trust and relationships among all participants.



And it has a strong backbone.

That means having a team dedicated to orchestrating the work of the group.

Principles of Practice

Design and implement the initiative with a priority placed on equity.

Include community members in the collaborative.

Recruit and co-create with cross-sector partners.

Use data to continuously learn, adapt, and improve.

Cultivate leaders with unique system leadership skills.

Focus on program and system strategies.

Build a culture that fosters relationships, trust, and respect across participants.

Customize for local context.

we are organising for impact, more commitment and resourcing is needed to sustain action and impact

[from [Stanford Social Innovation Review](#)]

Phases of Collective Impact

Components for Success	PHASE I Initiate Action	PHASE II Organize for Impact	PHASE III Sustain Action and Impact
<i>Governance and Infrastructure</i>	Identify champions and form cross-sector group	Create infrastructure (backbone and processes)	Facilitate and refine
<i>Strategic Planning</i>	Map the landscape and use data to make case	Create common agenda (goals and strategy)	Support implementation (alignment to goals and strategies)
<i>Community Involvement</i>	Facilitate community outreach	Engage community and build public will	Continue engagement and conduct advocacy
<i>Evaluation and Improvement</i>	Analyze baseline data to identify key issues and gaps	Establish shared metrics (indicators, measurement, and approach)	Collect, track, and report progress (process to learn and improve)



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the purpose of Summit #2

- Elevating lived experience leadership beyond projects and services, **a systems approach**
- **Evidence-informed** opportunities and a shared commitment to act in meaningful, collective and sustained ways
- A '**Consensus Statement**' of key actions that make sense for system and sector leaders and lived experience leaders to pursue in South Australia



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Our Imperative to Act

Open discussion at the Summit



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why it is
important to
act ... now ...
and together

- There was an **enthusiastic and genuine recognition of the value and importance of centering lived experience** for change as well as a sense that the time to do this is now, **as a collective**
 - *Need is visible*
 - *Lived experience voice is becoming louder, let's capitalise!*
 - *Conditions for change are right, planets aligned*
 - *Maturity of service sector to embrace lived experience*
 - *There's systemic motivation*
 - *Brings immediate change as there will be a response*
 - *If you want to go fast, go alone, if you want to go strong, go together*
 - *Togetherness provides holistic lens and breaks down silos*
 - *ACTION NOW, not in years time*

why it is
important to
act ... now ...
and together

- **Clear systemic reasons and particular policy levers inform the need to act**
 - *Stop breaching human rights*
 - *Medical model dominance remains*
 - *Co-design delivers social and economic outcomes*
 - *Giving control back*
 - *At a National level people are pivoting to lived experience model*
 - *Because it's way too late [in Health] ... contract reform [in Homelessness]*
 - *Formal systems review demand engagement and participation*
 - *Human, heart and healing-led, not risk and clinical lens/framework*



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why it is
important to
act ... now ...
and together

- There was a strong feeling that **there is no question that action to value and develop lived experience leadership needs to occur** and that the impact could be profound
 - *Why not?*
 - *Strength in numbers ... momentum, capitalise*
 - *Broadening reach and maximising impact*
 - *The current system doesn't work for many now, if it doesn't change many more will suffer*
 - *System is stuffed and ridiculous not to have a system driven by lived experience*
 - *We have an incomplete, inconsistent and unjust system. Co-design is the only methodology for this space*

our vision for lived experience leadership in SA

- The vision for lived experience leadership and future services are where **humanity and connection are prioritised** and where people with lived experience meaningfully and equally contribute **at all levels**, to the point that it *becomes the norm*
 - *Creating a humanised system*
 - *Compassionate responses ... deep listening and therapeutic ... human-based and healing*
 - *Health system and care system where humans are valued and relationship not marred by power dynamic*
 - *No more tokenistic engagement ... Accountability measures for incorporating lived experience, eg co-design standards*
 - *Lived experience to be viewed as a strength and inner skill*
 - *Value and prioritise, take action and ensure involvement in decision making processes ... at all levels of government and down to agencies and communities*

our vision for lived experience leadership in SA

- Work to **develop the system** will need to occur to enhance the experience of people within it as well as the outcomes that it produces. **Expanding how 'the system' is defined must broaden** to reach people in their communities and with a prevention focus
 - *Systems with heart ... leading with compassion*
 - *Systemic development ... dismantling of systemic barriers*
 - *Review RISK ADVERSE culture, departments need to be open to criticism*
 - *Effective ... measure what's important*
 - *People don't need to 'qualify' for support*
 - *'Practical' supports and resources, support people and what they need*
 - *Increase capacity for community response*
 - *Right questions asked first time to ensure prevention*
 - *Lived experience at the heart ... action from that voice*

the impact of these actions

- **Shifting the narrative around 'mental illness'** was seen as a core component of change efforts and an outcome that is needed. **Learning from the activation of lived experience in mental health settings and applying that knowledge to other settings offers a huge opportunity** for addressing complex social issues
 - *Shift away from medical model / illness narrative*
 - *Discourse / language / thinking shifts*
 - *Focus away from illness*
 - *Reorientate / shift public health message (come out from behind the walls, into community)*
 - *Reducing systematic stigma / discrimination*
 - *Inform recovery stances and understanding now so lived experience can be translated beyond mental health*
 - *Translating lived experience frameworks / concepts into other injustices (eg LGBTIQ, Aboriginal and Torres Strait Island contexts, homelessness, alcohol and other drug, etc)*



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the impact of these actions

- The benefits for people with lived experience, both those who use services and/or actively get involved, and for service providers were clear. Particularly in regards to **shifting power and control to people**
 - *Those with lived experience will live better lives, safer to speak, people educate, stigma reduced, awareness raised*
 - *Empowerment of service users ... People feel safe and take power and control*
 - *Service delivery will change for the better*
 - *Human-led, people feel heard, supported, cared for, feel more trust, compassionate and healthy ... People won't feel so disconnected*
 - *Increase in proactive engagement in services*
 - *Better outcomes (for the person and 'community' surrounding the person)*
 - *Increase social services, decrease medical / crisis services*



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the impact of these actions

- People shared that when these changes are made the broader social sector and communities will benefit, resulting in **increased capacity for addressing complex social issues**
 - *Builds capacity of the whole sector, one person can kickstart change*
 - *Community buy-in, increased social capital, connection ... Builds community*
 - *Enables equality*
 - *Cost savings*
 - *We will understand and measure systems with heart*
 - *Opportunities to learn for other issues ... Flow on effects to other social determinants*

ALEL Research Findings

Mark Loughhead, Senior Research Fellow UniSA



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research and project methodology



planning:
goals and strategies for change



reflection/analysis:
on culture, practice, relationships

action: sharing insights, formulating responses, influencing practice

data/observation: what do we know is happening?

PAR (Participatory Action Research) | 'insider' LEx research | collective impact



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data generation and analysis

11 * focus groups + online discussion group
31 LEx participants

1 * online qualitative survey available nationally
48 LEx participants

14 * service/sector leader interviews
14 participants

12 * sector leader conversations before Summits
12 participants

qualitative coding and analysis of texts

Codes – 500+
References – 1800

Codes – 200+
References – 600

Codes – 200+
References – 1000

thematic analysis

analysis summarised as 65 main themes (as current)

18 main themes

Summit 1 Summary Report



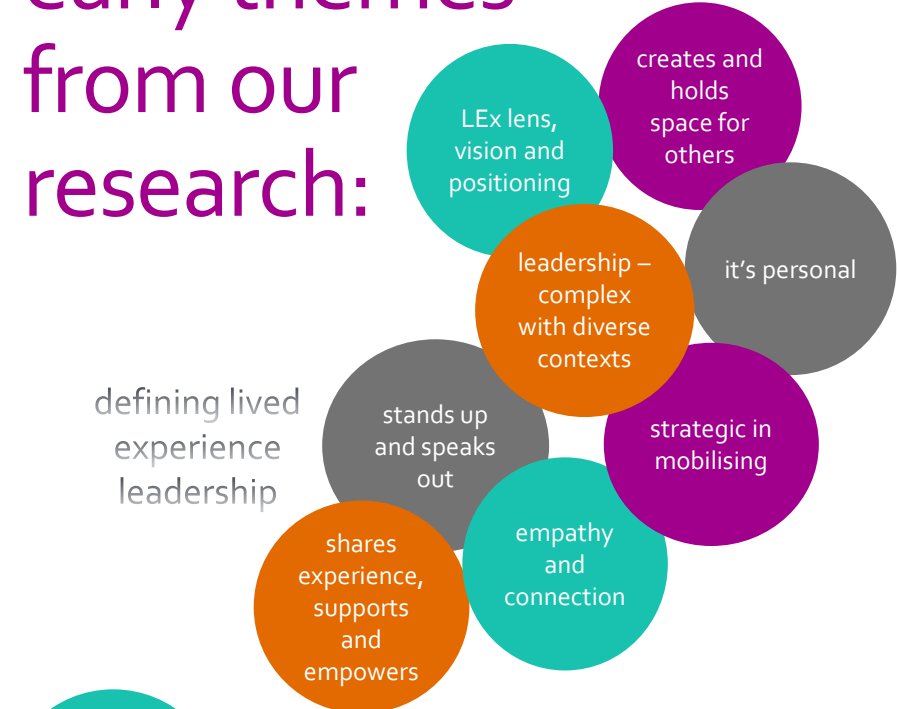
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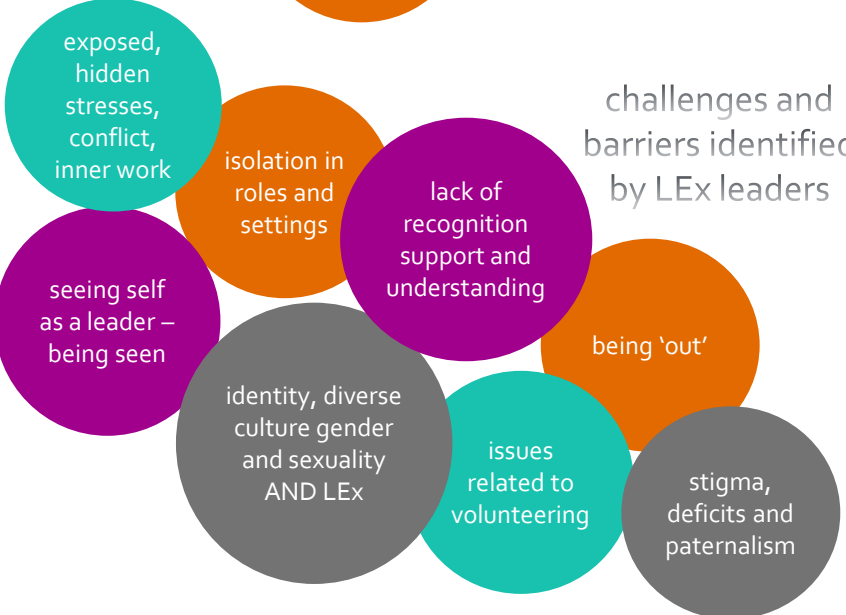
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early themes from our research:

defining lived experience leadership



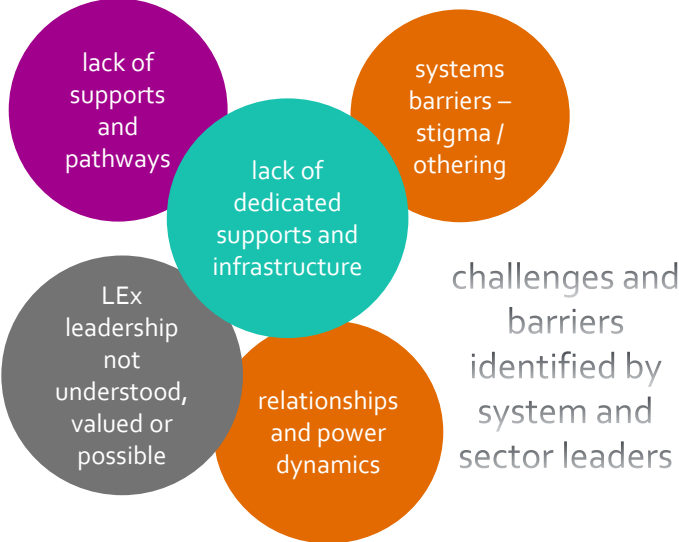
challenges and barriers identified by LEx leaders



LEx leader values, qualities and skills



challenges and barriers identified by system and sector leaders



strategies for thriving and impact identified by LEx leaders



strategies for thriving and impact identified by system and sector leaders



evidence
supporting
lived
experience
leadership to
thrive and
have impact

- Findings reflect **emerging roles, activities and contexts** of lived experience leadership
- Findings reflect the **complexity of internal and external experiences for leaders** due to legacy of stigma/ othering, change agent aspirations, isolation, intersectionality, mixed expectations, level of supports
- Action areas reflect **need for sustained development** in terms of policy, practice, resources flows, relationships, culture, and mental models

- Action areas reflect typical strategies of **systems and organisational change**: exec leadership, priority setting, commissioning, innovation, education, team development **and community development**: networking and leadership pathways, supporting community initiatives
- Action areas align well with available literature and innovation



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Choosing Priority Actions for South Australia

Shaping a Consensus Statement Together

policy and governance actions

- 1.1 More designated lived experience leadership positions on Boards of management, policy councils, statutory performance / review councils and commissioning groups. **Establish a critical mass** (26 votes)
 - Considerations:
 - Don't be too prescriptive (eg quotas) otherwise you lose power. Until we value all perspectives we remain male, stale and pale
 - Strengthen and ensure best practice standards for welcoming and inclusive boards and chairing to be effective

policy and governance actions

- **1.2 Educational programs on lived experience leadership for Executive leaders, staff and communities** – on stigma, othering, diversity of lived experience, supports and preferences (27 votes)
 - Considerations:
 - How we speak to power and what is it that will change people's minds who are not interested?
 - Develop a business cases to shift. Communicate tools and methods
 - Ensure sustained leadership across programs – not just on individual champions
 - It's more than education, long term sustainable cultural change. How do you make it stick, top to bottom and how to fund?
 - Edu program sounds like we are just teaching you about other's experiences. Own lived experience and using that and acting with allies

growing and
supporting
lived
experience
leaderships
and networks
actions

- 2.1 Strengthen learning pathways and leadership skills development and **enable and encourage opportunities to lead and provide advocacy**. Enable easier access to professional development and formal qualifications (30 votes)
 - Considerations:
 - Some development can be part of existing training and education. Eg Leadership programs. Need to use or build on these . Could this approach be true for other settings
 - One of the barriers is people being critical of each other and seeing small picture rather than big
 - Funding for learning and networks needs to be adequate and sustainable

growing and
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actions

- 2.2 **Fund leading lived experience organisations** to develop and deliver networking activities, including coordination of information, activities and events that support leadership and voice across diverse population groups. **Focus on intersectionality** (25 votes)
 - Considerations:
 - How do we determine who are the leading lived experience organisations?
 - Look at what that is and map networks
 - Coordination of activities is important
 - Look for diverse networks with uniqueness
 - Mentor and support smaller groups as well

service reform and development actions

- 3.1 Enable resource flows for **meaningful co-production of all services and programs**. This should include training of co-production facilitators and chairs, and funding equal places at the table for advisors / leaders (36 votes)
 - Considerations:
 - Need to be broad on how we understand resources, ie. people, funding and time for building relationships

service reform and development actions

- **3.4 Promote lived experience leadership and accountability measures through service agreements (27 votes)**
 - Considerations:
 - We need to be clear on the outcomes. Its not enough to be Indigenous, lived experience and LGBTIQ. Outcomes need to focus on meaningful change for people
 - The outcomes can be changing and fluid. Are you going to keep meeting the same outcome or develop that further?
 - The other place to embed lived experience leadership is into service and quality standards or other standards/accreditation organisations
 - Good governance includes having this in this sector not just external KPIs
 - We need a balanced approach and not to be too onerous for the level of service you are pitching at. Small grants, too many kpis and an administrative burden

workforce development actions

- 4.1 Ensure models of care include **equal recognition of lived experience workforces and peer support** (23 votes)
 - Considerations:
 - Urgent MH centre is working toward this action and NDIS with boutique providers
 - Use peer workforce rather than peer support
 - Targets and minimum numbers of designated positions. This is more aligned to public sector considerations. Will the next 5 years go in a different direction?
 - Think broadly to cover all sectors
 - We need a conversation about ratios to know what that looks like

workforce development actions

- 4.5 Ensure range of **organisational and sector infrastructure** for the effective recognition, valuing and embedding of the lived experience workforce (21 votes)
 - Considerations:
 - Care workforce and mandatory training (???)
 - Structural and contractual things make it difficult, like qualification requirements that exclude lived experience potential candidate

Summary and Wrap-up

Professor Nicholas Procter and Ellie Hodges



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standout points from Summit #2

- Commissioning bodies **need to step up and step into the value of lived experience** and the value of its contribution at all levels
- There is value in developing lived experience frameworks
- We can **create a culture** where people can come out
- We can establish clear pathways and embedding
- We will **strengthen Service Agreement's and KPIs**
- Recognition and valuing in language is just as important as infrastructure
- We will consider ratios and what teams/models should look like

challenges we need to meet

- We require **Executive leadership to be truly present and accountable**
- We need to make sustainable change visible for everyone
- We can transform the traditional language of health systems through co-production
- We need to take each of these to the next level and have **cumulative impact**

the time is
now, we are
ready

- The Summit showed that there is **passionate support and genuine commitment to doing more** to strengthen and embed lived experience leadership in our systems
- This is supported by both people with lived experience and system and sector leaders
- **Clear actions were identified** that when pursued will have enduring results
- The biggest challenge is the **continued need for a driving force (a backbone organisation) to sustain focus, build on current momentum and enable collaborative action** that the ALEL Project has created
 - ALEL Project funding ceases June 30th, 2021

three things
will be coming
soon, we all

1. *A Consensus Statement* for the actions system and sector leaders collectively prioritised at Summit #2
2. *A Roadmap for Systemic Development of Lived Experience Leadership in South Australia* [launching in August 2021]
3. Lived Experience Leadership Model [launching in August 2021]

what will your
role be in
making a
difference?

- We will be inviting Summit #2 participants to comment on early drafts of the *Consensus Statement* and *Roadmap*
- We also invite you (and your teams) to meet with us to determine what you can contribute to progressing lived experience leadership systems change in South Australia

some of THE
most important
thing for people
in relation to
enabling lived
experience
leadership to
thrive and have
impact
systemically

- *To appreciate the value, insight, and expertise of those with lived experience in its own right rather than it being an addition to something else ... for **individual experience and voice to be valued in the same way as 'fact'***
- *If done properly, **lived experience can transform the way, the how and the why** to the way in which we make difference in the world*
- *It's important to create a space for people who are already in these roles, positions to come out and be loud + proud. **There is already so much potential + wisdom that hasn't been unlocked yet** so don't discount that*

more of some of
THE most
important thing
for people in
relation to
enabling lived
experience
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thrive and have
impact
systemically

- *Intersectionality + allowing/empowering voices that aren't always heard or are normally considered 'too raw'*
- *The intersection between lived experience in MH and other sectors (AOD, housing/homelessness etc). This creates opportunities for collaboration & wider systems change*
- *Building a structure that embraces & holds space for the dynamism of lived experience*

more of some of
THE most
important thing
for people in
relation to
enabling lived
experience
leadership to
thrive and have
impact
systemically

- *Commitment to ensuring the lived experience is heard, embedded and valued at all times. This includes leadership in your workforce, but in your everyday engagement with people you support or are in your life*
- *ACTIONS FOLLOW WORDS!*
- *Make people **accountable!***
- *Sustained and sustainable long-term commitment to **cultural change***

Ellie Hodges – Project Lead

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connecting
with us



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