SUMMARY REPORT

System & Sector Leaders' Summit : Dialoguing for Change

Activating Lived Experience Leadership (ALEL) Project

[November 24th 2019]

Welcome and Acknowledgement

Professor Nicholas Procter

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initial thoughts on lived experience leadership in SA

- 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 also acknowledge the challenge presented in moving forward

  - *Essential, opportunity … Increasing appetite*
  - *Thirst for change in the State*
  - *Consumers and carers achieving new heights*
  - *Frustrating when people don't get it*
  - *Fascinating challenge*
  - *Collaboration at all levels*

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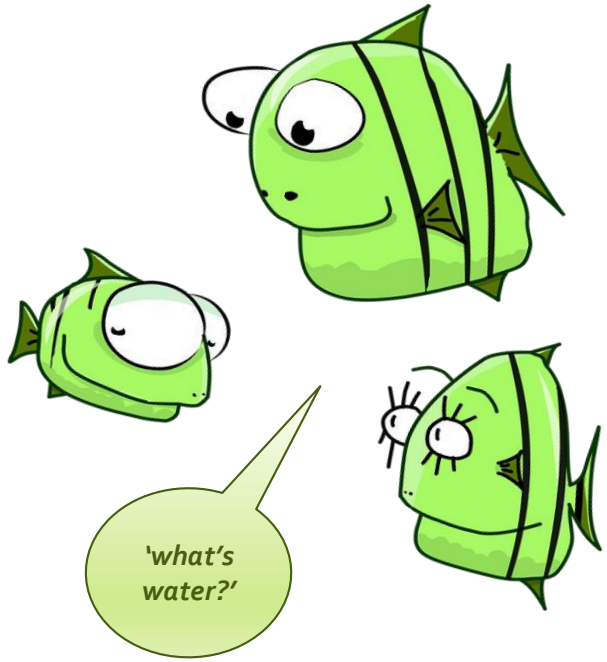

Summit Pre-Meeting's

Ellie Hodges, Executive Director, LELAN

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important themes people told us about

- Lack of opportunity for lived experience involvement and leadership
- **Challenges linked to organising lived experience**
- Challenges for system and sector leaders
- On the peer workforce
- **Culture**
- **Issues of power**
- **Resourcing issues**
- What we need
- The action we could take

recurring themes pre-Summit and during, as well as the need for ***broad-based leadership***

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Approaching Systems Change

Ellie Hodges and open discussion

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'Mental health leaders, policy makers and successive national and state governments have tried countless incremental reforms. Yet, for decades in Australia, independent inquiries and reports have concluded that **our mental health 'system of care' is a misnomer. It is fragmented, ineffective, inefficient and unfair.** For far too long, people, families and communities have paid a heavy price for this.

Reform in itself will not be the solution that we can hang all our hopes on. Disruptive innovations are now sneaking into the mental health sector and beginning to be taken up en masse. Sitting alongside this is a budding revolution – an unrest stirring in our communities that has not been seen before in the history of mental health. People are raising their expectations and communities are demanding better.

With external (revolution, disruption) and internal (reform) forces colliding at a similar time, a perfect storm is being created for what could be the long-awaited and much-needed change we have longed to see. But it will not be without pain because, given a choice, most will opt for stability over change. But ignoring what is coming may not be wise'

[Crowe, 2017: *Reform, Revolution and Disruption in Mental Health Care: A Consumer's Perspective*, p. 1]

the need for a systems approach to change

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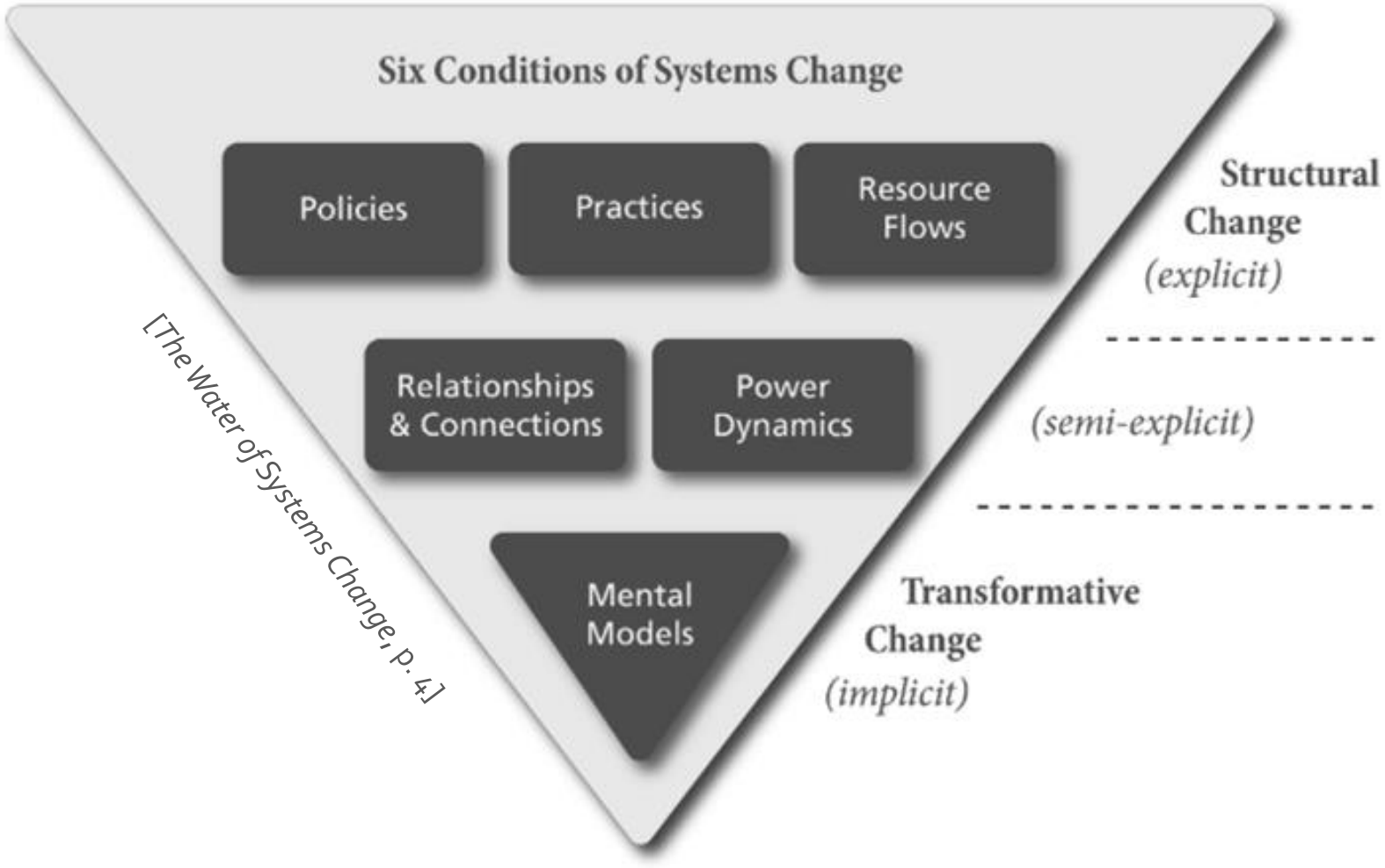
the six conditions of system change that we did a deep dive into



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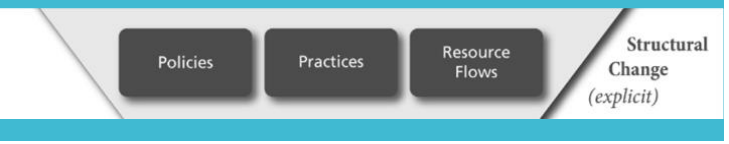
the first level of change

elements reinforcing current conditions and hindering process / what we can shift to progress change



- **Policy was seen as a power down strategy from government that does not match needs and frequently includes only a small, and often the same, people in their development.** This is an area that needs: increased expertise; more localised development; and the intent better matched to practice
  - *Policy* [needs to be] *developed independently of political cycles. Long-term bipartisan policy shifts*
  - *Shift from consultation to negotiation with diverse lived experience cohorts and groups for power equilibrium*

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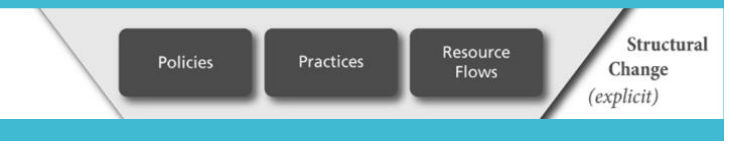

- **Education was identified as a core strategy for improving practices.** Effective education methods would: change culture; increase staff knowledge on lived experience; increase trauma-informed care; and provide more compassionate responses

  - *Lack of respect for lived experience*
  - *How do we formulate new arrangements for trauma informed care and education – constantly falling on deaf ears*

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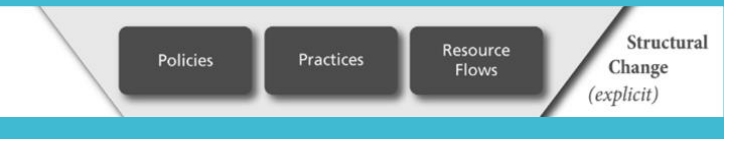

- **Key resource flow considerations related to monetary and mindset issues.** It was discussed that funding often comes with constraints or the lack of it is an easy out for not making changes that are known to be needed. Also discussed was the conservative approach within our system to doing things differently and the fear of doing things wrong being so entrenched in the culture of services

  - *Services choose where they spend their money*
  - *Identify the wanted result and then fund*
  - *Showcase lived experience benefits brighter -> add the VALUE*

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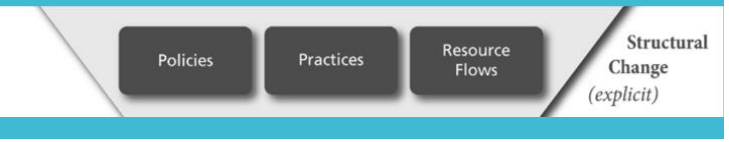
the first level of change

elements reinforcing current conditions and hindering process / what we can shift to progress change



- 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**
  - *New leadership models*
  - Idea of the *NZ Wellbeing Budget. Three things …*

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the second level of change

elements reinforcing current conditions and hindering process / what we can shift to progress change

- **A greater focus on relationships and connections as central determining factor's for change, and improving the system, was highlighted**
  - *Education –lived experience group, Cert IV, peer workforce*
  - *Relational continuity*

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the second level of change

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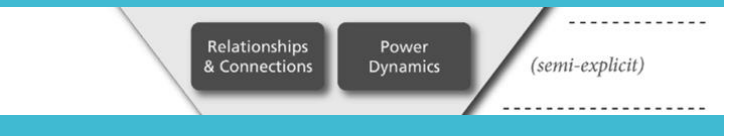

- **Multiple layers of power dynamics were identified as contributing to the status quo**, these being: legislative power; institutional power; psychiatric power; political power; physical power; union power; medical model dominance; and the disempowering position of consumers and carers in accessing care and treatment

  - *GIVE US MORE RIGHTS AND POWER*
  - *More advocates and advocacy (and more available)*
  - *Legislation shifts … what people want questioned in the Mental Health Act*
  - *From a COST to a VALUE lens – shift from this model*

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the third level of change

elements reinforcing current conditions and hindering process / what we can shift to progress change

- **Biomedical dominance, illness narratives and the language used in mental health were identified as the greatest challenges for making progress.** A broader perspective is needed
  - *Flip understandings – medicalization of crisis as mental illness to human experience; community misunderstanding of illness leads to medical response*
  - *Support people with lived experience to see and/or prepare self as leaders*
  - *Consider a Citizen's Jury – powerful, flipped accountability and power balance. Confronting and useful*

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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

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our ideas for taking action together

- *Empower people to have voice; **diverse voices**, training and support*
- ***Peer-led** organisations*
- ***A strategy which is a driver*** – lived experience workforce and systemic advocacy
- *Define what skills we need*
- ***Spotlight and lever our good work, provide examples***
- *Education*
- *Connect with other states*
- Change at *organisation and government level*
- ***Organisational leadership***
- *Diverse mental models*
- *Ask what would young people do? How would young people change the situation?*

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Summary and Wrap-Up

Professor Nicholas Procter and Ellie Hodges

some of THE most important thing's identified by people about lived experience leadership in SA

- *For success to happen there **needs to be a sustained funded driver plus levers for cultural (wide culture and mental health culture) change** and a recognition that it will take a big reshuffle – it won't be an easy fix. PS Doesn't have to take a long time*
- *Lived experience leadership enables marginalised people who have historically little say in how they are represented and articulate their experience and empower them to provide their legitimate and powerful skills and experience to their community, as any professional should*
- *5 R's: relational, relevant, realistic, rewarded, rights-based*
- *Passion, persistence, creativity*
- ***Accountability to <u>demonstrate</u> VALUE***

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more of some of THE most important thing's identified by people about lived experience leadership in SA

- *The most important thing is about change.* ***Our systems, at all levels are disempowering. This needs to be turned upside down***
- *CONSISTENCY and sustainability, both in approach and appreciation of lived experience within and outside systems levels!*
- *BUILD SERIOUS MOMENTUM NOW! Pick good things to do. Don't forget the strength of a lived experience peak body*
- ***Naming it, funding it and embedding it in ALL processes and levels of the 'system'***

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recommended actions for moving forward

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

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

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

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making contact with us

Ellie Hodges – Project Lead

SA Lived Experience Leadership and Advocacy Network (LELAN)

ehodges@lelan.org.au | 0422 888 157 | www.lelan.org.au

Mark Loughhead – Research Lead

Mental Health and Suicide Prevention Research Group (MHSPRG)

mark.loughhead@unisa.edu.au | (08) 8302 1267

Heather McIntyre – Research Assistant

Professor Nicholas Procter – Chair of Mental Health Nursing & Mental Health and Suicide Prevention Research Group

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references

- Crowe, J. (2017). Reform, Revolution and Disruption in Mental Health Care: A Consumer's Perspective in *Public Health Research and Practice*, Vol 27(2)

- Kania, J., Kramer, M. & Senge, P. (2018). *The Water of Systems Change*. FSG (www.fsg.org)

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