Getting Real About Lived Experience Influence:
How we Lead, Advocate and Activate Change

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Acknowledgement & thanks

• The traditional owners of this land, the Turrbal people
• People with lived / living experience
• Everyone who shoulders us up in this work
Who I am

Plan for this session

- What I mean when I say ‘lived experience’
- The state of lived experience
- Dilemmas and lessons we grapple with
- Our movement for change
- LEAD – ADVOCATE – ACTIVATE
- For influence
How do we see and feel about the future of lived experience?

Fred Polak. (1973). *The Image of the Future*
What I mean when I say 'Lived Experience'

- And why I don't talk about peer work
Observations that sparked my curiosity

Particular to the South Australian context

• No single unified way for people with lived experience to have a voice and influence policy

• No single unified and consistent way that lived experience voice is nurtured and developed to inform and set an agenda of our own
Tension and division is rife

- Consumers and carers
- ‘Us’ and ‘Them’ – who?
- Who even is a ‘real’ consumer?
- Self-protection and self-preservation
- A lot of calling-out rather than calling-in

What is the ‘best’ way?

- From within the system or from the outside?
- (R)evolution?
- Bringing down the system, opening space within the system for something new or starting fresh?
- Enemies or comrades?
The heart of my exploration and my concern

- It’s been on the shoulders of a few individuals
- Lived experience is not adequately resourced
- The status quo is maintained
- Lots of rhetoric
- Structural stigma and discrimination continue to harm us
Additional dilemmas and lessons we grapple with along the way

Difficult realities

- The way that lived experience is **viewed and reduced** does harm
- **Unrecognised and/or dismissed** *spiritual pain* crushes people
- **This isn’t ‘safe’ work**
  - It can be **lonely** ...
    - *where do people with lived experience belong?*
- **Power imbalance** is the elephant in the room that has the potential to get in the way of everything
Spiritual pain

Theory and practice are central to the work of counselling, but they exist in relationships with ethics. When counsellors are able to work in accord with their ethical stance, sustainability becomes possible. But social structures and limited resources, which force counsellors to work in ways that go against their ethics, result in spiritual pain. This spiritual pain I’m talking about is the discrepancy between what feels respectful, humane, generative, and contexts which call on us to violate the very beliefs and ethics that brought us to counselling work. Accommodating people to privatized lives of hell is nothing any of us wants to do, but I think it is a possibility given the helping field’s problematic connections to ideas of neutrality and objectivity (Waldegrave & Tamasese, 1993; Cushman, 1995).

Fostering sustainability in the face of this spiritual pain is difficult when the unjust conditions of people’s lives do not improve, and counsellors experience their work as shoveling water. We know we’re working hard, and working harder isn’t working. The smell of a particularly individual incompetence begins to creep in.

[Vikki Reynolds]

Vikki Reynolds, Collective Ethics as a Path to Resisting Burnout

Cultural Safety

cultural competence

cultural sensitivity

cultural awareness

cultural safety
A movement for change that includes lived experience

Change will happen, (in words at least) it already is

• It’s not a question of whether the NHS will change, but **how and with whose interests and needs at its heart**

• The challenge is **existential in scale**, and the solution will be too: requiring change both in structure and systems, and in interpersonal relationships; how professionals go about their work and how we engage much more intensively with communities and community organisations, if we are not to ‘kill what we commission’

(Anu Singh, NHS England’s Director of Patient & Public Voice)

Nesta, Health as a Social Movement: The Power of People in Movements
The power of social movements

Elements of a social movement

Nesta, Health as a Social Movement: The Power of People in Movements
Perhaps it’s time to shift our focus.

- The secret of change is to focus all of your energy not on fighting the old, but on building the new.

  (Dan Millman, Way of the Peaceful Warrior)

Strategic foresight
Why we need lived experience

- Including people with lived experience ‘at all levels’ is enshrined in policy and accreditation processes for health and mental health services.
- Including people with lived experience benefits everyone.

Tension is inevitable in such an approach

- In their purest form movements are messy, vibrant, spontaneous and uncontrollable. They bubble up outside of formal institutions and from beyond established power structures. They challenge and disrupt. They are restless and determined. They often make society, elites and institutions deeply uncomfortable as they challenge accepted values, priorities and procedures.

(Halima Khan, Executive Director at Nesta Health Labs)
Lead

Whilst there is rhetoric there is great challenge

- The leadership of people with lived experience of mental health problems is underdeveloped, when it comes to leadership in one's own recovery, at the service level, and at the systemic level.

- The movement has not yet created an explicit model of leadership based on these values [of empowerment and equality].

Mary O'Hagan, Leadership for Empowerment & Equality
And we need to define it ourselves for ourselves

Need to develop a more nuanced understanding of this emerging group of leaders:

- What are the origins of user/survivor leadership?
- What defines it?
- How does it need to be developed?
- What roles and practices support it?
- What are the unique competencies required to be a user/survivor leader?

Mary O’Hagan, Leadership for Empowerment and Equality

Social movement leadership

Leadership is accepting responsibility to create conditions that enable others to achieve shared purpose in the face of uncertainty

Linking a desire for change with a capacity to make change

(Marshall Ganz)

Leadership is essential

- For organising, mobilising and sustaining the effort
- Must be adaptive and transformational

Advocate
• Storytelling is about taking what’s intangible, what’s invisible, what’s ephemeral, and then giving it shape and form, painting a picture so people can see it, describing the desire versus complications so people can feel it, and then presenting the evidence that supports that context and that emotion so that people can believe it

(Michael Margolis of Get Storied)

• ‘help isn’t help if it’s not helpful’

• ‘help that is not helpful can actually do harm’

• ‘help becomes something that is co-created between the disabled person and the professional’
Facilitating action

Activate

Thinking in a disruptive way

- What can you **invert**?
  - What if what you were doing was the complete opposite of what you are doing?

- What can you **deny**?
  - What can you take away from what you are doing?

- What can you **scale**?
  - What can you distort or exaggerate?

We develop our community (ABCD)
Campaigns that target consumers **statistically and without context** are akin to launching a rocket into space with a faulty guidance system.

The solution isn’t a shinier, more technologically advanced rocket. A ‘ripple’ system – a people-powered engine that continuously energises and innovates in congruence with its environment – **is the answer**.

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*Stephen Scott Johnson, Emergent*
Honouring and amplifying the value of lived experience

- Realise the **unique value and position** of people with lived experience
- Lived experience offers an alternative perspective
- Lived experience offers a **nuanced understanding**; from knowledge to wisdom

The experience of lived experience is critical

- Lived experience is often of experience(s) related to issues associated with **stigma, vulnerability, distress and despair**
  - what we may wish to hide and shrink from
- Lived experience is also of experiences(s) that are related to **recovery, healing and living well despite**
  - what has the potential to make us come alive and thrive
  - and where the focus of any involvement needs to be
Our foundation needs to be strong

- Language
- ‘Strategic’ relationships
- Our why and our how
- .... yet life happens

We need a toolbox of methods and practices

- Create shared understanding
- Maintain connection
- Innovation without alienation
We don't need to reinvent the wheel

Voice alone is not enough

- It starts with having a voice
- We need influence
- We seek change
We have to do it together

- Allies
- Co-production
- Partnership

Partnership (beyond participation and engagement)
Domains of involvement …
a parallel process with integrity

We need to embrace values at the heart of lived experience activism

- Social movements are a hope and power out of our current predicament
  
  (Helen Bevan, Chief Transformation Officer, Horizons Group, NHS England)

- This is about justice-doing (Vikki Reynolds)
The position we take adds to our influence and to our longevity.

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<td>Non-influential</td>
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Dulwich Centre, Narrative Therapy Training Intensive
What is the lived experience imperative?

- What is our space and place for action?
- How do we start to lead, advocate and activate what we want? What will happen when we start?
- Who will we invite in?
- What is our imperative?

Stephen Scott Johnson, Emergent

There are some things we have to be really sure of

- Our purpose and our ethic
- What we will not move on
- How firm we will stand
- Keeping ego – and/or opportunity – out of it
As I said, having a seat at the table and raising our voice is one thing, speaking with our own integrity, authority and being influential is another.
• You never change things by fighting the existing reality. To change something, build a new model that makes the existing model obsolete

(Buckminster Fuller)

it's not rocket science - it's ripple science

Stephen Scott Johnson, Emergent

A guiding quote

start where you are, use what you have, do what you can

[Arthur Ashe]
THROUGH REGULAR GATHERINGS, CONVERSATIONS, WORKSHOPS AND EVENTS WE STRENGTHEN THE VOICE AND INFLUENCE OF LIVED EXPERIENCE IN SOUTH AUSTRALIA. IN DOING THIS WE KNOW THAT HOW MENTAL HEALTH ISSUES, AND THE PEOPLE WHO EXPERIENCE THEM, ARE UNDERSTOOD AND RESPONDED TO WILL IMPROVE.

ourvoicesa.org
facebook.com/livedexperiencecollective

Ellie Hodges
from the speaking of love

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