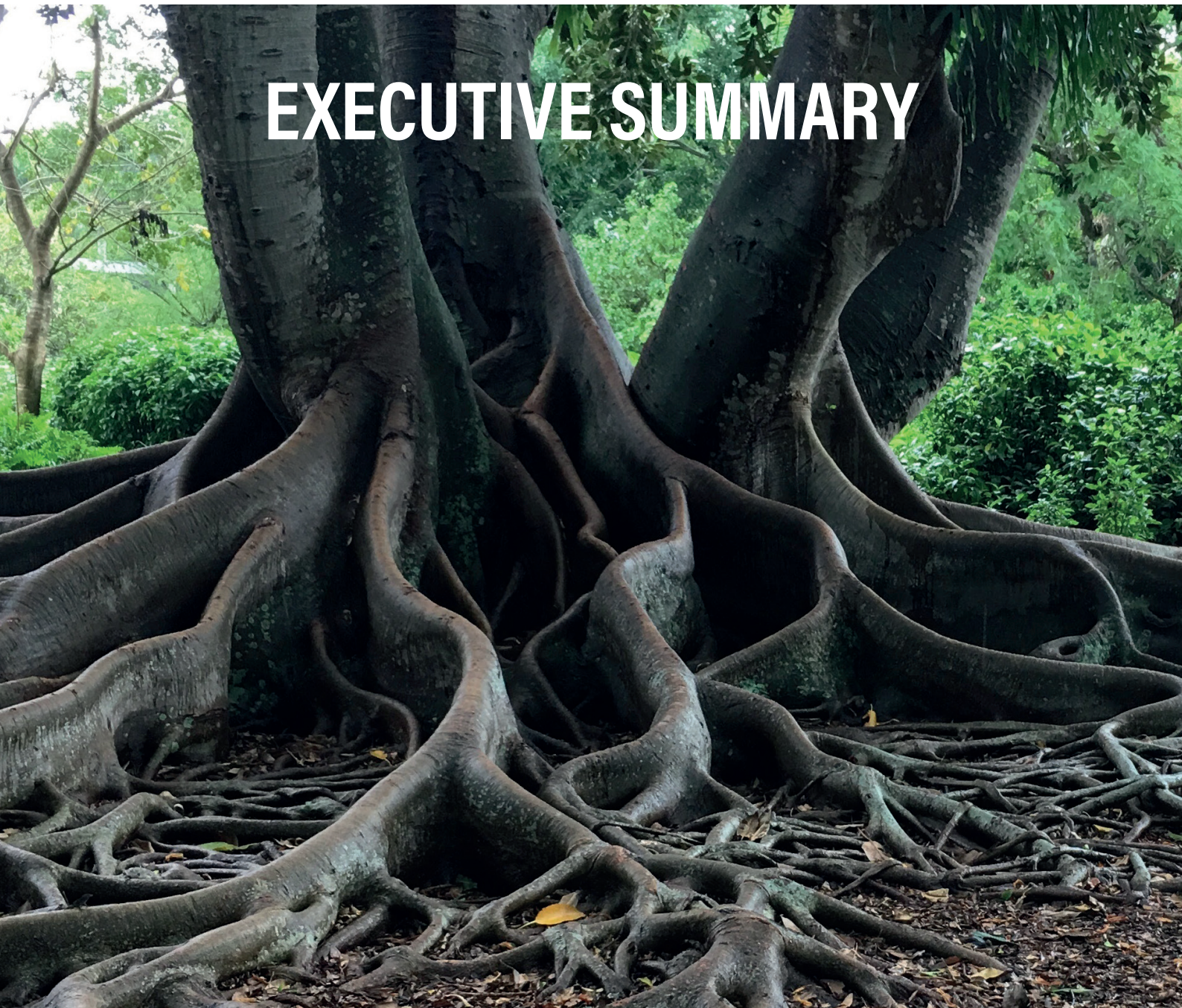


NOVEMBER 2021

Lived Experience LEADERSHIP

Mapping the Lived Experience Landscape in Mental Health
- a project commissioned by NSUN and Mind

EXECUTIVE SUMMARY



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ABOUT THIS REPORT

Commissioned by Mind and NSUN, this report collates the contributions provided by people with Lived Experience through 106 survey submissions, 32 interviews and 7 focus groups with 31 people. It was inspired by a desire to understand the complexities of the 'Lived Experience Leadership' field and determine any supportive role Mind, NSUN and other mental health organisations might play. Contributions were gathered from August 2020 until January 2021.

This report is explicitly plural. Its intention is to honour and reflect the diversity in experiences and positions expressed by contributors rather than provide a neat narrative. As such, it includes many quotes - some of which may contradict one another, or offer another angle.



KEY FINDINGS

UNPACKING LIVED EXPERIENCE LEADERSHIP

Lived Experience Leadership (LEL) is a contentious term that can evoke strong feelings. It can be validating and encourage a sense of hope. It can also divide, belittle and feel out of step with the more collective values inherent in the survivor movement.

The fuzzy edges of what constitutes Lived Experience can be important. However, some were concerned that this openness allows everyone to claim 'Lived Experience', with organisations likely to favour those with less complex and challenging lives.

TERMINOLOGY

This report uses the following terms as broad umbrellas. They are imperfect and are not intended to override the words we find for our own experiences and activities.

Lived Experience (LE): Direct, first-hand substantive experience of mental distress, illness, diagnosis and/or mental health services. This can be associated with Lived Experience of poverty, trauma and other forms of prejudice and discrimination (e.g. racism and ableism).

Lived Experience Leadership (LEL): A broad term used to describe what happens when people use their Lived Experience to change, shape or create something to benefit others in the broad field of mental health.

LE-led: A term used to describe initiatives, projects, organisations that are run and controlled by people with Lived Experience (e.g. at least 75% of the trustees have LE).

Contributors highlighted the complexities around what might constitute LEL, what it might look like and how it relates to others forms of leadership and experience.

Some contributors articulated concerns that adding the 'Lived Experience' qualifier to leadership lessens it, creating silos and obscuring the range of skills and experience people with LE bring to the table.

Lived Experience can be an equal, but different, form of training. However, having Lived Experience does not mean you have the skills or experiences necessary to lead on a particular project. We need space to talk about this too.

Focusing on acts of leadership rather than the characteristics of a leader can create space for more collective and fluid forms of leadership whilst mitigating concerns around ego and celebrity.

There are many routes into leadership. For some they involve a series of small steps, gathering momentum. They can also involve more focused efforts to address a particular social problem or inequality.

Some routes involve accessing ready-made opportunities. Others involve creating your own table (alone or with trusted allies).

Often, there is an element of luck and timing to people's leadership journeys. It is important to consider how we can support those for whom the path is blocked. This includes people who are additionally marginalised on the basis of class, gender, racialisation, homophobia, transphobia and other forms of prejudice and discrimination. It also includes those who are digitally excluded and those within long-term inpatient and/or custodial settings.

The abstraction of LEL from specific roles and contexts can evoke questions around the limits of the role, the position of 'followers' and who it is that any particular leader is leading, representing and/or speaking for.

Other terms suggested to reflect the diversity of LEL include: Expert By Experience, LE Practitioner, LE Guide, LE Ambassador, Disruptive Innovator, Facilitator, Advocate,

Activist, Campaigner, Change Maker, Patient Leader and Pioneer.

Whatever term we use, it is clear that people with LE are leading on a range of projects, initiatives and organisations. LEL can be found in social media, research, freelance work, grants panels, creative arts, policy/think tanks, community organisations, statutory organisations and across allied sectors (e.g. Human Rights, Disability).

Contributors highlighted the importance of valuing leadership that often goes under the radar. This includes quiet grassroots activism, informal initiatives born out of friendships, leadership by people from doubly marginalised groups and those mental health professionals with LE who are not yet able to be 'out'.

SOME OF THE CHALLENGES

Contributors discussed a worrying range of challenges inherent in LEL, including:

Unrealistic / impossible expectations

This includes an expectation to be an exemplar, to be 'out', to be 'recovered' and to choose a side.

The fight for credibility

This includes being seen as 'less than' others, having attempts at self-care seen as evidence of illness and needing to be 'saner than sane'.

Serving someone else's agenda

This includes the way in which people have felt used, misused and exploited. It includes the conditional nature of one's position at the table, and how this can absorb and sanitise LE voices.

Not being valued

A lack of value of our knowledge base, being treated as a commodity and being chronically underfunded/paid.

Working in dangerous territories

Encountering trolls, encountering micro-aggressions as part of the work and gaslighting. The toxicity of some organisational cultures and the challenges inherent in trying

to change them.

The heavy personal toll

Isolation, the impact of continually unlocking 'Pandora's box', working at the expense of oneself, the re-opening of old wounds and the creation of new ones. The, understandable, prevalence of burnout.

Attacks from others with LE

Given the challenges described above, one might hope that leaders with Lived Experience might find solace within Survivor-Led spaces. Whilst many did talk about the support and solidarity gained through connections with their peers, this wasn't universal.

It is important that these challenges are seen in the context of the trauma, adversity, prejudice and discrimination many with LE have faced both before, and during, their work. Working in unfriendly and unhealthy environments can take a heavy toll.

Many contributors talked about being positioned as the enemy and being seen as morally lacking. Some talked about processes of idealisation and vilification, and how anyone 'sticking their head above the parapet' risks being shot at.

WHAT HAS HELPED SO FAR?

Connections

With each other, with why we are really doing this, with something bigger than ourselves, with allies. Things that can sustain us, as individuals and collectives.

Access to genuine and meaningful opportunities

Moving beyond tokenism towards opportunities that have an impact. Access to flexible and accessible funding for projects and organisations.

Ownership

The difference between being involved and leading initiatives. Ensuring that people can choose not to engage in LE work and LEL and having routes out.

Finding a space to be me in all of this

Finding one's own leadership style, setting limits and protecting oneself, balancing addressing the bigger picture with a focus on smaller changes, recognising the wider context of what we bring.

Finding space to question things.

Using one's LE more intentionally, questioning the status quo, playing to one's strengths and embracing the complexity of this field.

Creating cultures that care (and caring for ourselves)

Having anchors, normalising self-care cultures, reflective practice and supportive spaces and acknowledging the good bits.

WHAT MORE IS NEEDED?

NURTURING LIVED EXPERIENCE

This list includes some of the input and opportunities that might further support the development of LEL.

Underpinning approach

It is important for any supportive endeavour to be underpinned by these principles:

- Independent and led by people with LE
- Learning from the past and looking to the future
- Acknowledging inequalities and harm
- Being visibly, and genuinely, diverse

A buffet of options for different people/ contexts

Rather than creating a single offer, contributors highlighted the need for a range of options that people can choose from at different times.

- Space to re-evaluate what LEL means on our own terms.
- LE Specific-leadership training, mentoring, networking and support. This might include:
 - Supportive networks / reflective practice groups
 - Leadership training with a radical edge

- Mentoring
- Access to mainstream leadership training (see appendix)
- Investing in LEL and increasing access to resources, including:
 - Giving control and resources to those from marginalised communities to develop solutions from the ground up
 - Supporting LE-led initiatives to develop guides and toolkits to share knowledge and provide inspiration
 - Improving access to previously published information created by people with LE
 - An (online) space where people can ask anonymous questions around navigating LEL where others can respond - community sourcing
- Having someone in your corner - an independent body or union.

CREATING SUPPORTIVE CONTEXTS FOR LIVED EXPERIENCE LEADERSHIP

As so many challenges were linked to systemic problems, there is an urgent need to focus on the contexts and organisations people with LE are trying to work with.

Leading by example

Mental health charities can lead by example, ensuring LEL is embedded throughout all levels and parts of the organisation (and not kept in silos or restricted to specific LE-led teams within a larger whole).

Highlighting the value of LEL

Engaging with CEOs, funders and commissioners to promote this.

Thinking Systemically - supporting organisations to embed LEL

Supporting organisations to develop structures, career progression routes and commissioning processes that support LEL.

Making a substantive commitment and investing resources

Backing LEL with more than words; committing financial resources to support LE-led initiatives and organisations; paying staff appropriately, creating suitable funding streams

Having brave intra-organisational conversations

This may include organisations acknowledging tokenistic and harmful practices (however unintentional) and committing to deep and lasting structural change.

"Individually, we are one drop.
Together, we are an ocean"
- Ryunosuke Satoro

