

NOVEMBER 2021

# Lived Experience LEADERSHIP

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



# ACKNOWLEDGEMENTS

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# ABOUT THIS REPORT

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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.

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## TERMINOLOGY

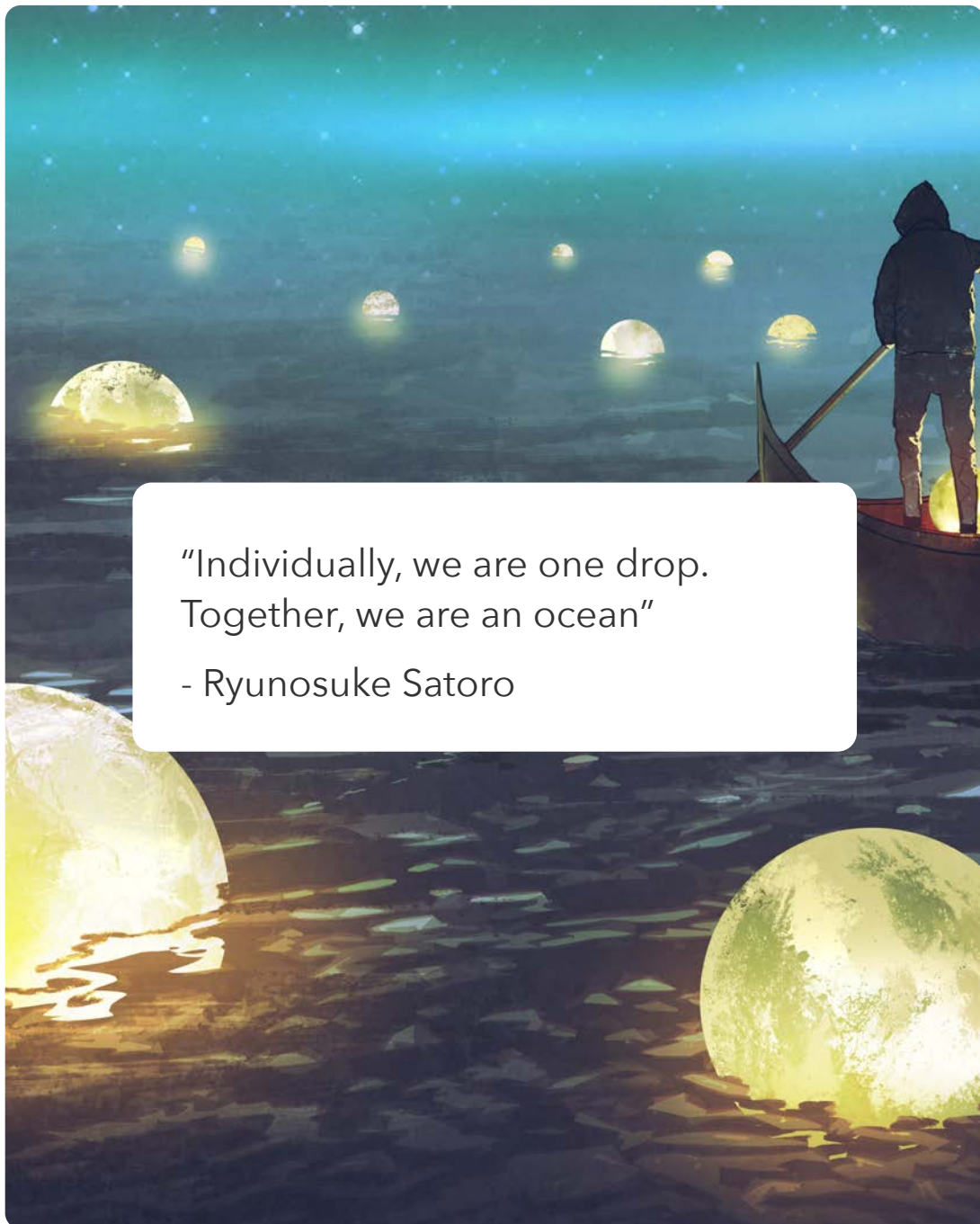
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This report uses the following terms as broad umbrellas. They are imperfect and are not intended to override the words we find for our own experiences and activities.

**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).

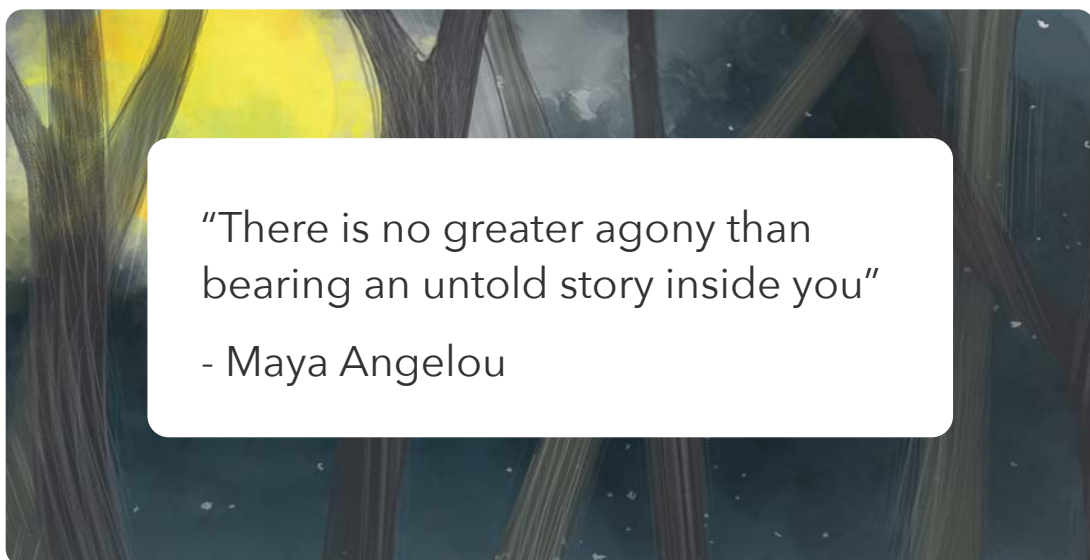
**Lived Experience Leadership (LEL):** A broad term used to describe what happens when people use their Lived Experience to change, shape or create something to benefit others in the broad field of mental health.

**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).



"Individually, we are one drop.  
Together, we are an ocean"

- Ryunosuke Satoro



"There is no greater agony than  
bearing an untold story inside you"

- Maya Angelou



# KEY FINDINGS

## UNPACKING LEL

Lived Experience Leadership is a contentious term that can evoke strong feelings. It can validate 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.

Contributors highlighted the complexities around what might constitute LEL, what it might look like and how it relates to other 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**

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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?**

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### **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

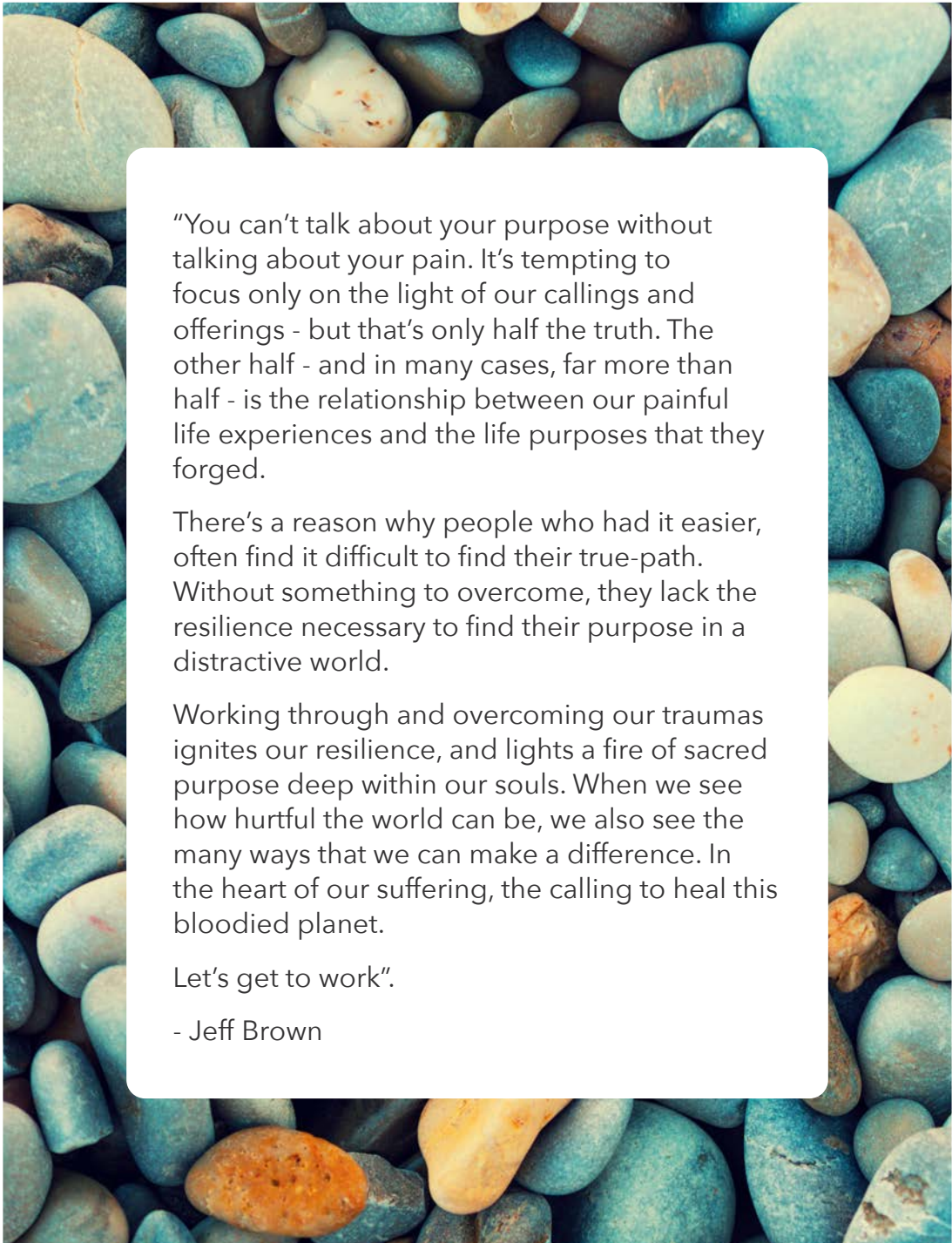
Supporting organisations to develop structures, career progression routes and commissioning processes that support LEL.

#### 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.



"You can't talk about your purpose without talking about your pain. It's tempting to focus only on the light of our callings and offerings - but that's only half the truth. The other half - and in many cases, far more than half - is the relationship between our painful life experiences and the life purposes that they forged.

There's a reason why people who had it easier, often find it difficult to find their true-path. Without something to overcome, they lack the resilience necessary to find their purpose in a distractive world.

Working through and overcoming our traumas ignites our resilience, and lights a fire of sacred purpose deep within our souls. When we see how hurtful the world can be, we also see the many ways that we can make a difference. In the heart of our suffering, the calling to heal this bloodied planet.

Let's get to work".

- Jeff Brown



# INTRODUCTION

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"Every day across the UK and beyond, people with direct, first-hand experience of social issues - or 'Lived Experience' - are taking up change-making and leadership roles to address the unique needs, challenges and injustices their communities face. These leaders are affirming and building upon the remarkable work of many community and grassroots leaders and activists who came before them"

- Baljeet Sandhu<sup>1</sup> (2019)

## SOME OF THE ROOTS OF LIVED EXPERIENCE LEADERSHIP

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The idea that people with Lived Experience can help others and push for change in the mental health system and society is nothing new. From the acts of resistance in early asylums to the radical ex-patient/survivor groups of the 70s - activism, peer support and community organising are some of the key threads woven throughout our history.

As the 80s progressed, and some groups connected to form larger networks, the landscape began to shift. Whilst some groups focused their efforts on creating social support networks and organisations outside the establishment, others began to demand a seat at the table to help improve mental health services, policy and research<sup>2</sup>.

### GETTING A SEAT AT THE TABLE

"Speaking in broad terms, in 1985 service users were nowhere; in 2005 they are everywhere" - Peter Campbell<sup>2</sup> (2005)

In tandem with the work of activists, the disability rights movement and wider health reforms, it became good practice to invite people patients and members of the public to input into health and social care service design, evaluation and policy. Services were expected to seek out the views of potential recipients, to consult and engage with them. Yet the context of these opportunities and the limits of their influence were still often set by professionals.

### LEADERSHIP OR PARTNERSHIP?

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"Co-production: A relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities" - Slay and Stephens<sup>3</sup> (2013)

In the last 10 years we have seen an increasing shift between the goal of 'doing for' to 'doing with' in mental health services. Policy rhetoric in the NHS in England<sup>4</sup> and Wales<sup>5, 6</sup> emphasises the importance of putting service users at the 'heart of service design and provision'<sup>7</sup> and involved at all levels. That this aspiration is enshrined in policy is a credit to the work and dedication of pioneers, both with and without Lived Experience. Yet in comparison with contemporary Canadian<sup>8</sup> and Australian<sup>9</sup> policies there is a marked difference in tone.

“Unlike participation, leadership assumes people with mental health problems have the power to set the agenda, make major decisions and control resources” - **Mary O’ Hagen<sup>10</sup> (2009)**

Whilst we were still talking about involvement, participation and co-production, In Canada the rhetoric was moving towards people with Lived Experience having leadership roles<sup>8</sup>. Little has changed. The most recent policy documents from the NHS and Welsh Government include a focus on leadership<sup>6, 11</sup>, but the absence of Lived Experience or Patient Leadership in these sections is concerning. Is our focus on co-production in some way inhibiting the need to go further?

## **WE DO NOT WAIT TO BE GIVEN PERMISSION TO LEAD**

Irrespective of the terms used, people with Lived Experience can, and do, take up leadership positions inside and outside of the mental health systems. Our experience and expertise can be found throughout the sector. We design, establish and manage projects, services and organisations. We have designed approaches and ways of working. We create spaces of solidarity. We lead on research and evaluation. We speak out in the media, we create protest art, we campaign and we use all of the resources we have to fight for change. We can be quiet, we can be loud. We can be ‘out’ and we can be anonymous. We are already doing the work, whether or not it is recognised as leadership.

## **CHANGING TIMES**

In recent years there has been a language-shift towards Lived Experience Leadership in the mental health field<sup>12</sup>. It is unclear where the term first originated, yet it has begun to gather pace. An increasing number of academic articles are using it, and there are now funding streams<sup>13</sup> and training programmes aimed at supporting it across the health, social care and social justice fields.

These developments stand on the shoulders of a growing interest in Patient Leadership<sup>14</sup>, a particular form that has a stronger focus on leadership within healthcare settings. Lived Experience Leadership, however, has the potential to encompass a wider field – bringing together those who work inside and outside of systems, in groups, collectives and as individuals.

## **A SOMETIMES PAINFUL BUT IMPORTANT PATH**

As this report shows, these developments are not straightforward. There is no single voice that can represent such diversity, and attempts to enforce this can create much pain. The diversity of people, initiatives and contexts can make it difficult to speak in a way that welcomes and values all. As this report demonstrates, oppression and misuse of power is a significant part of many - but not all - of our histories that can make talk of leadership particularly sensitive.

We do not lead in isolation, and we are not immune to the social forces that are at play. The shift in power, resources and mindset that this thing some people call Lived Experience Leadership requires to be fully realised is huge, and there is much work to be done.

“Never doubt that a small group of thoughtful, committed, citizens can change the world. Indeed, it is the only thing that ever has.” - **Margaret Mead**

One of my overriding feelings in completing this report is of gratitude - of gratitude to those who contributed so openly, of gratitude to the allies I heard about who were there at the right time and in the right way, of gratitude to those whose dedication, tenacity and creativity continue to help move things forward to create a better future for ourselves and others.

# WHAT WE DID

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## Includes:

How we gathered contributions

Who took part

Limitations

## HOW WE GATHERED CONTRIBUTIONS

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Contributions were collected via a survey, an online whiteboard, focus groups and individual interviews conducted by phone or on Zoom.

The Survey (n=106) was intended to provide scope, enabling us to take the 'temperature' of people's experience of, and attitudes towards, Lived Experience Leadership. It included some very detailed answers that helped shape the analysis.

We ran 7 focus groups with a total of 31 participants. Each focus group lasted 1.5 hours and used quotes taken from the survey as a 'jumping off' point for discussion.

I conducted 32 interviews, each one lasting between 60 and 90 minutes. The interviews were unstructured, beginning from an initial question around what motivated them to contribute to this project. This provided participants with the freedom to shape the discussion and talk about aspects of their experience in greater depth than a more structured interview would allow.

## RECRUITMENT

Hearing a diverse range of voices was central to the success of this mapping project. So, to increase participation we implemented the following strategies:

### PROMOTION VIA NSUN WEBSITE

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The NSUN website acted as a hub for all project materials, including:

- Project introduction (in Welsh and English)
- A video explaining my motivation in undertaking the project and inviting people to take part. The aim of this was to put a face to what is a very sensitive area of inquiry. This video was subtitled (in Welsh and English) to increase accessibility.
- PDF and online versions of the survey (in Easy Read, English and Welsh)
- An online whiteboard to enable people to contribute visually
- The opportunity for people to contribute by sending a recording to increase accessibility
- A sign up sheet to enable people to indicate interest in taking part in a focus group or individual interview (in Welsh and English)

These materials were distributed via the NSUN Newsletter and social media accounts.



## TARGETED PROMOTION

To supplement the recruitment process I sent project information to a range of groups and organisations, paying particular attention to LE-led groups and those serving people from particularly marginalised groups. Towards the end of the project I targeted my promotion to recruit from groups and types of LEL that were not well represented (e.g. Welsh people with LE).

## SELECTION

### SURVEY:

The survey open to all and hosted on Typeform and available via PDF and Easy Read. Only responses from people with Lived Experience who lived in England and Wales were included in the analysis.

### FOCUS GROUPS AND INTERVIEWS:

Potential contributors were asked to indicate interest via a sign up sheet. Respondents were sorted into groups, based on their preference for focus groups and/or interviews, geographical location and areas of experience. Participants were selected at random to ensure an even spread amongst these groups. When an invite went unanswered after a few attempts, others were invited.

Towards the end of the process selection shifted to a more targeted approach, filling in gaps to ensure a wide range of LE-fields were included.

When invited to take part in Focus Group or Interview participants were given detailed information around what to expect and clear information around the implications of accepting the offer of a £50 gift to facilitate informed choice.

## WHO TOOK PART

### SURVEY

113 responses by people with Lived Experience.

England: 98 | Wales: 8 | Other: 7 (Scotland, Ireland, Canada, US and Australia).

Note: Only respondents from England and Wales (n=106) were included in the analysis.

59% had experience of Lived Experience Leadership roles. 11% had no experience of a LEL role. 1% did not identify with the term LEL. The remaining respondents (29%) were unsure whether their experience counted or not.

### FOCUS GROUPS AND INTERVIEWS

63 contributors (31 in focus groups and 32 in individual interviews).

87% of contributors had current experience of Lived Experience Leadership roles. 8% were unsure if their experience counted as LEL.

Those who self-defined as having first hand experience of a Lived Experience Leadership role were involved in the following sectors:

Voluntary Sector (34), Supporting Others (29), User/Survivor-Led Groups (27), Activism (24), Research/Evaluation (23), NHS (19), Community Groups (16), Independent (15), Commercial (7), Regulatory Bodies (6) and Social Care (6).

## GEOGRAPHIC SPREAD

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33% of contributors lived in the Midlands and the East of England, 19% in Greater London, 26% in the North of England and 14% lived in the South of England. 8% of contributors lived in Wales.

	Focus Groups	Interviews	Total
East Midlands	5	4	9
East of England	4	2	6
Greater London	8	4	12
North East England	1	3	4
North West England	4	3	7
South East England	2	2	4
Wales	0	5	5
West Midlands	2	4	6
Yorkshire and the Humber	3	2	5
<b>Total</b>	<b>31</b>	<b>32</b>	<b>63</b>

## LIMITATIONS

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Whilst every effort was made to engage people from Wales in this Mapping Project it is clear from the above figures that we were largely unsuccessful. Only 8 people from Wales completed the survey, and only 5 people took part in an individual interview. All survey respondents completed the English language form and the Welsh language form was unused.

When promoting the initiative we, swiftly, became aware of the importance of using Welsh Language materials. Whilst this gap was hastily rectified and NSUN commissioned training on the Welsh context, we were visibly playing 'catch up'. I am wondering if this created some negative feelings which may have hampered people's willingness to both distribute and contribute to the project. Additionally, a key contact in the Welsh Lived Experience field raised a concern around distributing materials that were not explicitly Welsh-focussed (naming NSUN and Mind, rather than Mind Cymru). In retrospect, we wandered unknowingly into a sensitive and political field and - in doing so - made mistakes that adversely affected the way in which this project was perceived.

Interestingly, there were no substantial differences between the interviews conducted with Welsh contributors and England contributors. Despite the very different contexts and structures around Lived Experience Leadership, it seems that the challenges and supporting factors are very similar. This suggests that some of these themes may be of use to colleagues from Wales.

However, the difference in attitude to the term Lived Experience Leadership between Wales and England was stark. Welsh contributors responded much more negatively to the term. Without further investigation it is impossible to know whether this is an artificial distinction amplified by the low number of contributors, or if it is connected with a deeper difference in preferred terminology and context.

If possible, it would be helpful to look deeper into the Welsh context in future projects - preferably in partnership with a Welsh Lived Experience-led organisation.





# FINDINGS

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## Includes:

Unpacking Lived Experience Leadership

Lived Experience Leadership in context

Some of the challenges of Lived Experience Leadership

What has helped so far

## UNPACKING LIVED EXPERIENCE LEADERSHIP (LEL)

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As many contributors have pointed out, 'Lived Experience Leadership' is a deceptively simple term that has no universally agreed meaning. This section begins to unpack the term, highlighting some of the key areas of tension expressed by contributors.

### WHAT IS LIVED EXPERIENCE LEADERSHIP? TWO LENSES

Contributors seemed to approach the meaning of 'Lived Experience Leadership' using two main lenses, each one highlighting different elements.

#### A LIVED EXPERIENCE LENS

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"I have had so many of my life plans destroyed as a result of my mental health. To see someone like me in a leadership role would be life affirming" - **Survey respondent**

From this angle LEL is simply any kind of leadership enacted by someone with Lived Experience. The focus is on what the person has overcome to become a leader, rather than what their leadership looks or feels like. For some contributors, their existence provided a powerful symbol of hope, challenging dire predictions of lifelong incapacity and powerlessness.

#### A LEADERSHIP FOCUS

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"We've all got Lived Experience, but what makes us leaders? Leadership involves more than Lived Experience. When we seek to commodify Lived Experience and make that the basis of the currency between us it's as reductive and limited as a psychiatric label"  
- **Interview participant**

From this angle, LEL can be understood as a particular form of leadership that goes beyond someone's experience of mental health problems and any associated inequalities. The focus, instead, is on what someone does and how they do it.

Many contributors emphasised the importance of a values-based approach to leadership that contrasts with prior experience of disempowerment and oppression. From this perspective, it is important for LEL to go beyond the traditional hierarchies prevalent in mental health and social care settings and find a more ethical and collaborative way of getting things done. For example, some contributors talked about the importance of using one's power to create space for other voices to be heard.

## WHO COUNTS AS A LIVED EXPERIENCE LEADER?

Whilst reflecting on Lived Experience Leadership, many contributors explored the extent to which they, themselves, could count as a 'Lived Experience Leader'. This section reflects some of the different ways in which contributors attempted to draw a line around the concept and make sense of their relationship to it.

### WHAT COUNTS AS LIVED EXPERIENCE?

It is self-evident that Lived Experience Leadership involves some form of 'Lived Experience', yet this is a broad term with no universal meaning. Some contributors valued its breadth and its links with other areas of Lived Experience (e.g. poverty, being in care and/or the criminal justice system). Others found it too vague; a term that is increasingly used yet says very little at all.

Stepping aside from these ongoing debates, this section shares some of the tensions that emerge when we try to draw lines around what is, and isn't, Lived Experience in the context of LEL.

### EXTENT OF LIVED EXPERIENCE?

Contributors talked about different ways of defining 'Lived Experience' within a leadership context. These included experience of mental health problems, a formal diagnosis, secondary services, hospital, coercion, trauma and/or extreme states.

#### Relying On Self-Definition

Defining what Lived Experience is involves defining what it is not. Drawing this line risks negating someone else's experiences, a painful prospect that many have been through first-hand.

Attempts to judge the extent of someone else's Lived Experience can be fraught and bring us close to commodifying it; playing 'top trumps' with trauma and adversity. To avoid this, some contributors advocated the importance of self-definition. Given the prevalence of prejudice and discrimination faced by those who are 'out' about their mental health issues, some contributors suggested it was unlikely anyone would choose this identity for the glamour; thus it was unlikely to need policing.

#### Setting A Threshold

"Is a psychiatrist with anxiety issues a Lived Experience Leader? No. Is their experience life-interrupting? I've had limited experience of services, but my experiences have been life interrupting" - **Interview participant**

Some contributors raised a concern that the inclusivity of the word 'Lived Experience' provides scope for people with very limited LE to take up leadership roles. This was often linked with a concern that organisations may take the easy route - recruiting those with more limited and/or socially acceptable forms of Lived Experience over those with more messy, complex and long-term challenges.

Focusing on experience of secondary care, inpatient or coercive mental health services is one way of drawing a stronger line around the term. One contributor suggested considering whether someone's experiences had been life-interrupting as a more inclusive way of tightening the boundaries around what counts as Lived Experience in the context of LEL. Yet, as described above, any rigid pre-defined criteria risks exclusion and requires the individual to justify themselves.

## TYPE OF LIVED EXPERIENCE?

"It's not about my LE but what has taught me in terms of valuing people for what they bring ... I've learnt so much through what I've moved through in my life [that] gives me a certain value space around what I bring and influences all I do" - **Interview participant**

In some roles, especially those with a strategic, research, or training component, contributors emphasised the importance of the values, sensitivities, and skills they had developed through their Lived Experience. Rather than feeling restricted to roles and projects that directly map on to their direct LE, some contributors felt able to use their skills more widely. From this perspective LE may be 'activated' as a form of training that connects personal experiences with a wider collective body of service user / survivor knowledge. It also speaks to the resistance some articulate in relation to the idea that those with LE should be tied to, and limited by, their own story.

While over-specifying the nature of someone's Lived Experience can be intrusive and risk commodification, some contributors emphasised the importance of knowing one's limits.

"Being a 'psychiatric patient' is not a licence to all Lived Experience knowledge. I've seen examples in my field of work - peer support - where I would consider myself to have specialist expertise, where a 'Lived Experience' consultant has come in and advised in my field at higher levels than me. The 'Lived Experience' broad term got them the ticket for the consultancy, but they had no experience in peer support. So, the result was bad advice. I see this as a responsibility on Lived Experience leaders not to overstretch for work or to advocate in areas where they don't have expertise, but instead to open the platforms and opportunities for people that do" - **Survey respondent**

In addition to the overstretching mentioned above, some contributors also raised concerns around the potential for people from more privileged backgrounds to take up spaces that may be better served by someone from the marginalised group the initiative is aiming to serve. Some contributors highlighted the harm that can be caused, sometimes unwittingly, when someone wrongly assumes their Lived Experience maps into another area.

"What we teach our children from the womb - don't talk about what goes on behind closed doors. There is a part of us, if we're honest, that knows this ain't right. But I don't want to challenge it. If I challenge it I'll lose my standing in the community, the church will come after me, my community will come after me, my family will come after me. It's OK you telling me to challenge it, but where are you going to be? It's me risking everything" - **Interview participant**

This emphasises the point that we do not always know what we do not know.

## HOW RECENT IS IT?

"Am I the right person to do this? Is my Lived Experience out of date?" - **Interview participant**

Some contributors questioned how recent one's Lived Experience should be in order to be a 'Lived Experience Leader'. Is it important to be still living one's experience? If it's in the past, is there a time limit on its relevance? Aside from recognising when specific aspects of one's experience are out of date, there were few clear answers.

Many focused on person's relationship to their Lived Experience, its place in their life and the context in which they are using it. It was suggested that those with more distant LE may mitigate



this by taking on a more facilitative role, making space for others. Yet, equally, there was a concern that people may draw more heavily from other aspects of their life and work as their Lived Experience fades.

## WHAT COUNTS AS A LEADER?

An important part of the Lived Experience Leadership discussion is exploring what is understood by the terms “leader” and “leadership”. This section explores some of the different themes raised by contributors.

### SOMEONE WITH POWER?

“It’s not being scared to voice uncomfortable things in these meetings; getting people to think outside their frame of reference” - **Interview participant**

Some contributors described leaders as influencing others, making decisions, inspiring actions, creating knowledge, changing services, and shaping policies. This influence may be linked to being in a particular role, having access to particular decision-making spaces, wielding privilege, being well-connected, and/or particular personal characteristics (such as charisma and determination).

“I didn’t want to be a leader. I was someone who was trying to be honest, trying to change things and have an impact. It suggests a hierarchy that isn’t very helpful. We’ve had enough power hierarchies. So much of mental illness is about power hierarchies – it’s crushing”  
- **Interview participant**

However, in this project talk of influence and leading were often associated with issues around use and misuse of power.

“It creates division when we should be lifting people up and supporting each other”  
- **Survey respondent**

Some contributors described a concern that identifying as a leader means joining and sustaining the same oppressive hierarchies that so many are harmed by - inside and outside the mental health system. From this perspective, stepping into a position of power involves stepping away from important values and a recognition of our collective inherent worth.

Some contributors responded to the concept of leadership with words like ‘repulsive’, ‘cruel’, ‘toxic’ and ‘invasive’. The intensity of feeling behind such words demonstrates the serious nature of these concerns. It is clear that there are many who view leadership as pushing oneself forward and trampling on other service users / survivors. Understandably, from this perspective, being called a leader could feel like an insult.

“The wider system - I never see me as leading it ... nudging it as best I can in a direction I think it should go in” - **Interview participant**

Many contributors highlighted the scale of the systems and attitudes they are working to change. In comparison to those occupying top positions in the NHS, Social Care, Government and larger mental health charities, those engaged in LEL often described feeling relatively powerless.

When the scale of the hoped-for change is so big, it may be hard to identify oneself as being a

leader when the power you have to influence it is comparatively small.

“Lived Experience Leadership should lead the research into mental health and mental health treatments and turn the current hierarchical structure of ‘evidence-based practice’ in psychiatry upside down” - **Interview participant**

However, the importance of having people with Lived Experience in decision-making spaces and in positions of power was named by many as a crucial step in creating the services, systems, and knowledge frameworks that are needed. For some, this leadership is an essential part of wider systems change.

## AN ICON?

“People like Eleanor Longden. People who do stuff that changes people’s perception. I’m not sure if I consider myself a leader” - **Survey respondent**

Some contributors described an aspirational, yet unobtainable, image of what it is to be a leader. Leaders were often described as brave, strong, inspiring, moral, accountable, and selfless.

“There’s this archetype leader - endlessly patient, compassionate - I don’t live up to that, I’m flawed, I’m lazy sometimes and judgemental sometimes .... I try and cut myself some slack ... shame runs deep ... I’m never good enough - I think ‘who do you think you are?’”  
- **Interview participant**

For some, the title of ‘leader’ and its associated moral and practical obligations feels a heavy burden.

“People are selling themselves rather than their ideas” - **Interview participant**  
“Some people, it’s all about them. It’s a platform” - **Interview participant**

On the flip side, some contributors were concerned that the focus on a leader’s individual characteristics amplifies ego-centric forms of leadership and risks disconnection from values seen as central to the user/survivor movements.

“[It’s] not about you telling your story to look good. It’s about you making sense of your story to change the system” - **Interview participant**

For some, LEL has a moral component. Rather than being about self-advancement and publicity, those deemed as leaders must be led by an intention to serve others.

“People are put on a pedestal” - **Interview participant**

However, those perceived as leaders do not always ask for - or are comfortable with - an elevated position or relative fame. Some contributors commented on how being seen as a leader is a trap; that once you take up the mantle (or are given it by others) you can never fully meet the expectations placed upon you. This can result in a damaging cycle where people are lifted up and then, in time, tore down.

## SOMEONE WHO LEADS IN A PARTICULAR CONTEXT?

“Using snippets of your experience to make a difference” - **Interview participant**

Many contributors shifted away from the global binary identity of leader where you're either a leader or you're not, to a more pragmatic definition - a leader as someone who is leading on something at a particular point in time.

This approach includes a degree of fluidity - it is possible to take on a leadership role at one point and, later, put it down again as someone else steps forward. By reducing the focus on the characteristics of any one 'leader', this approach may reduce the pressure of living up to the ideals described above. It is a more contained and specific form of leadership that may be easier for people to step in to.

“However having been one of those leaders [of a user-led group] I have come to understand that as a movement the leadership is everyone who sticks their head above the parapet and speaks out on behalf of anyone who has mental health issues” - **Survey respondent**

This both widens the concept of leadership beyond identified leaders and highlights the risk and vulnerability involved in speaking up or out, discussed in more depth below.

“Collective leadership. Everyone participates and joins with their brilliance. What bonds us is the eagerness to go the extra mile - not to let the experience isolate us as individuals, to seek companionship with others” - **Interview participant**

Many contributors highlighted the importance of working in collectives, resisting the pull of more traditional hierarchical structures. This is highlighted by the example of a peer support group that - together - applied for and used the NSUN-managed COVID-19 fund to keep connections throughout the pandemic. To this contributor, the idea of a single leader emerging from the group made little sense.

## SOMEONE WHO USES A LIVED EXPERIENCE LENS IN LEADERSHIP

“For me, in the world of research, it's about leading the way with Lived Experience expertise and knowledge. Whether it's being a co-applicant on a project, whether it's about being a Principal Investigator or doing user-led research. Carving out that space” - **Interview participant**

Many contributors emphasised the importance of using one's Lived Experience to shape or guide whatever project or initiative you are embarking on; providing a unique perspective that would otherwise be absent. Lived Experience can, potentially, be a space where people develop a range of values, sensitivities and skills that inform what they see, prioritise and do across multiple domains. It might include:

- A sensitivity to, and commitment to challenge, power hierarchies
- De-centring one's own experience and creating space for others' voices to be heard
- Engaging with Mad Studies, the Hearing Voices Movement, Intentional Peer Support and other forms of collective knowledge generated within the user/survivor movements

“LEL is a lot about the values of peer support, to me. Being able to amplify what that community believes is important .. to spread that upwards or outwards” - **Interview participant**

As pivotal as this ‘Lived Experience Lens’ appears to be, there is no single understanding what this looks like. In an area where our experiences can vary wildly, any attempt to create a global definition risks dismissing or erasing the experience and perspective of more marginal voices. Furthermore, many contributors highlighted the range of different forms of knowledge they bring to their work (academic and vocational). This included psychology, nursing, management, journalism, community development and policy development knowledge bases.

This raises some questions: how central does one’s Lived Experience need to be to your work for it to ‘count’ as LEL? How does one’s Lived Experience relate to other forms of knowing? Do we need to be aware of what kind of experience we’re using in a particular situation? Is that even possible?

Some contributors raised concerns around the potential for people to ‘claim’ Lived Experience in order to gain access to an opportunity and then, knowingly or not, draw heavily on more credible ways of knowing that enable them to slot more easily into existing practice. The implication is that, whilst the LE Lens is hard to define, it can be painfully missed when perceived as absent.

#### REFLECTIONS:

There are no easy answers to these - often fraught - dilemmas. However, creating more spaces where we can continue to ask questions, reflect and become curious about them feels crucial.

### LIVED EXPERIENCE LEADERSHIP - IS IT A USEFUL CONCEPT?

18% of survey respondents viewed the term LEL negatively, 37% viewed it positively and 45% felt OK with it. Within this, 7% of respondents hated it, and 10% loved it.

Analysing Welsh respondents separately, 62% rated the term LEL negatively and only 3% rated it positively. 38% of Welsh respondents hated it, and none loved it. This may suggest a dramatically different relationship to the term LEL in Wales. However, given the small sample size it is hard to know if this is accurate representation or not.

### BEING SEEN AS A ‘LESS-THAN’ LEADER?

“Carving out the special [LEL] title means you’re creating a ghetto. You’re not a manager properly, you’re only a Lived Experience manager” - **Interview participant**

For some, the addition of ‘Lived Experience’ to leadership is a qualifier that minimises, silos and/or denigrates both the leader and the initiative they’re leading. Against a backdrop of enduring societal stigma and the ever-changing terminology used to describe us, there is a risk that ‘Lived Experience Leadership’ provides the illusion of power whilst maintaining the status quo.

#### SERVICE LEADERS: A CASE OF DOUBLE SPEAK?

Opal Ward (Sussex Partnership NHS Foundation Trust) asked those admitted to the ward what they wanted to be called. They chose service leaders or service users, as opposed to patients. Opal Ward staff now regularly tweet about their Service Leaders. Service Leader, in this way, has become a euphemism for patient, stripping the concept of leader of any tangible meaning.

- **Case study highlighted by a focus group participant**



Many contributors raised a concern that the current enthusiasm to promote LEL risks organisations recruiting people into untenable and toxic positions, without making the changes necessary to shift or redistribute power. In effect, as described in the challenges section below, many contributors described a culture of tokenisation across the NHS, statutory sector and non-LE-led mental health charities.

## ENCOURAGING PIGEON-HOLING - OBSCURING OTHER TALENTS

“The reason I was able to do it was almost nothing to do with being decimated by the psych system. I don’t want to be a LE leader. I want to be an x, y and x who just happens to have a label she ignores” - **Interview participant**

Some contributors talked about how being defined as a Lived Experience Leader negates the many other forms of knowledge and expertise that they bring. For some, whilst their personal experience may add an extra layer to contribution, it is not their defining characteristic.

“It’s weird. There is this assumption that when someone steps into that space as having Lived Experience they leave behind all their other skills ... a finance degree, PhD ... It all evaporates. It’s ignored whatever terminology we use” - **Interview participant**

Some contributors emphasised that this tendency goes beyond the concept of LEL, linking to the endemic prejudice still found within the mental health sector. This, in combination with a pressure to meet involvement targets, can lead to people being uncomfortably positioned in terms of their Lived Experience irrespective of their role in a particular meeting or initiative.

“I was invited to give a talk at a clinical forum about my project. Just as I was about to step up, I heard the Chair say how important it was that they listened to the ‘service user voice’. It stopped me in my tracks. He effectively invited everyone to listen to me as an individual service user, rather than as someone who had set up a project that presented a challenge to the status quo. It felt like they were patting themselves on the back for inviting me, rather than actually listening to what I had to say” - **Interview participant**

## ASSUMING ANYONE WITH LIVED EXPERIENCE CAN LEAD

“If we believe [Lived Experience Leadership involves the] sharing of power, making space for polyphony - it’s a skill that you learn ... Lived Experience cannot be the defining factor that makes you able to do that. You may be so traumatised from your experience that you can’t enter into that mutually respectful place” - **Interview participant**

Some contributors raised a concern that the focus on Lived Experience as a qualifying factor can result in people being recruited to leadership positions that they are not (yet) equipped for. The emergent nature of LEL makes it easy for people and organisations to create roles and recruit into them without the necessary understanding.

A reticence to talk, respectfully and clearly, about the expectations and skills needed for LEL roles can mirror other forms of tokenism found in involvement. If people are automatically deemed as less capable by those in power, difficulties are easily glossed over rather than worked with. Furthermore, when challenges arise it can be easier to blame and pathologise the individual than address the underlying systemic problems.

## HONOURING LIVED EXPERIENCE AS EQUAL, BUT DIFFERENT, TRAINING

"It firmly puts people alongside other leaders in health and social care recognising that Lived Experience has value in its own right every bit as much as book learned stuff"

- **Survey respondent**

For some, the term and concept of Lived Experience Leadership is an important move towards an explicit valuing of the skills and wisdom (individual and collective) developed through Lived Experience. I heard some share hopes that this recognition may help challenge the glass ceiling experienced by many in peer support or involvement roles.

In a field where a professional or academic qualification is often an essential criterion for top level decision-making roles, LEL may offer an alternative route. For some, the increasing recognition of LE as a credible source of knowledge promises a future where they no longer need to hide important parts of their identity and life to retain credibility and a source of income.

## PROVIDING A SENSE OF HOPE FOR SELF AND OTHERS

"Trying to bravely wade through the treacle of life with mental ill health and make sure I leave a path behind me for others to follow" - **Survey respondent**

For some contributors, the concept of Lived Experience Leadership provides an important sense of hope that their difficult experiences can be a source of value. The idea of using one's experiences to help create a path that eases the way for others can also provide a useful frame for those who are entering into unwelcome organisational territory; conveying a sense of being a pioneer and having a purpose bigger than oneself.

## IT'S JUST A WORD - WHAT MATTERS IS HOW AND WHERE IT'S USED

Some contributors spoke about the importance of the organisational context people with Lived Experience are working within. From this perspective, the idea of people with Lived Experience leading is not new and - as such - the focus on its meaning can be a red herring. What may be more productive is being curious about why the term is being used now - who and what is it serving?

'It means creating an environment where people with Lived Experience are able to take on and sustain leadership roles' - **Survey respondent**

Whatever term we use, some contributors highlighted the importance of focusing our attention on the impact of the organisational culture and environment within which people are leading. Much of the remaining report explores the nature of this environment, how people navigate it and what helps make this process less painful and isolating.

## REFLECTIONS:

Lived Experience Leadership may have utility as a concept, yet it can also be used in damaging ways. It is important that we do not focus solely on individuals, but give attention to the wider contexts (organisational and societal) that shape what is, and isn't possible. It seems clear that the stigma and discrimination faced by many with Lived Experience cannot be erased by changes in terminology. It feels important that those wishing to support LEL recognise the potential for opportunities to echo existing power imbalances and take steps to mitigate this.

## ROUTES INTO LEADERSHIP

Contributors described many different routes into leadership, each one influenced in part by the persons' prior experience and context. What follows are some of the themes I identified. However, it's important to emphasise that the complexity of people's lives is not adequately described by this structure.

### TAKING THE SCENIC ROUTE

The route into leadership is not always straightforward. Many contributors described a series of small steps, building confidence, skills and connections.

#### SMALL STEPS - BUILDING CONFIDENCE

"I signed up for Time to Change 10 years ago. I did nothing for 5 years - I didn't have enough confidence. The local hub invited me to a meeting. It was a big deal. It gave me confidence. I felt support, valued and listened to. People hadn't listened to me for years. People finally saw me as a person" - **Interview participant**

A number of contributors described how their Lived Experience (of mental health problems, the mental health system, trauma and/or the prejudice and discrimination they encountered) had stripped them of their confidence, self-esteem and personhood.

For some, this was compounded by experiences of racism, homophobia, transphobia, sexism, poverty and encounters with the DWP. For those who have been repeatedly told, explicitly and implicitly, that they are defective and unimportant, the idea that they might step into a leadership position can feel alien.

"I'd had a number of psychotic breakdowns and felt like I'd crashed out of life and that there wasn't anything left for me, but through being a co-facilitator I restored a sense of self-esteem and self-confidence" - **Interview participant**

Thankfully, a number of contributors described a series of opportunities that had both a healing and developmental effect. Some described these opportunities as a central part of restoring their sense of being in the world. Some highlighted the way in which they gently built confidence, providing a taste of what they might offer others without applying undue pressure.

"I saw a leaflet on the coffee table in a waiting room - a Community Mental Health Development Worker setting up self-help groups. I took the leaflet home and wrote a letter. I was at a point in my life where I wanted to find out - surely there was something else. By the end of the conversation with the worker I was agreeing to help run a self-help group. Bloody hell - how did that happen? She said 'Don't worry, I'll be there. We'll do it together'. We started the group. When I became confident enough, I hosted it" - **Interview participant**

Some contributors talked about the pivotal role of allies in this process - providing encouragement and, at times, a not-so-gentle push. For others it was more a matter of taking a leap into the unknown. A common strand seems to be the desire to do something with one's experiences; a seed that can be nurtured and grown if one finds fertile soil.

## TAKING AN UNEXPECTED PATH

"I shifted into this post [NHS peer support manager] fluidly and chaotically - as much as I enjoy it, it felt a bit thrust upon me. There was no guidance to say - this is what leadership looks like, in terms of peer support. How do [these values] translate into leadership?"

- Interview participant

The "fluid and chaotic" journey described above reflects, in part, the developmental and pioneering edge of many of the roles discussed by contributors within larger organisations. The absence of a standard progression route in such places means that leadership roles tend to appear suddenly in conjunction with a new initiative and/or funding source. It may also reflect a characteristic of the wider sector, where roles are often temporary and people end up 'mixing and matching' before, eventually, realising that their CV looks unexpectedly respectable.

"I became a member of the NHS Trust and saw an evening talk advertised. I was nosy and thought 'shall I go'? There were free sandwiches. I sat next to a really old guy who was the chair of [an NHS trust]. I stood out. I was half the age of everyone else there. Patient experience was on the look-out for someone outside of the norm ... fresh meat" - Interview participant

Some people described their route to leadership as the culmination of a series of moments, choices or opportunities. In this trajectory, chance meetings with people in a position of power have opened doors that may otherwise have been hidden. As in the example above, these meetings are sometimes aided by unseen and unknowable shifts in organisational priorities. Such routes often have an element of luck as well as skill, of being in the right place at the right time.

"I was elected [Chair] at a meeting. It wasn't part of my life plan. I got a lot out of this organisation. I thought I should do something, rather than just attend a workshop"

- Interview participant

Some described moments of 'stepping up' or 'stepping forward' inspired by a sense of obligation to a person, group, cause or movement. Irrespective of the, often considerable, skill they brought to the role, a number of people described situations where they were the person in the room least willing to say 'no' or avert their eyes from the vacuum left by an unfilled role.

## A NATURAL EVOLUTION

"It wasn't an active decision, it just happened organically. Whenever I started drawing it just opened a new door - both to myself, my healing and my understanding, and communicating with others around me. When I started sharing these online, seeing how people responded. It was a natural evolution - I responded to how people were responding" - Interview participant

For some contributors, their route into leadership seemed like an unfolding path; each new step revealing further possibilities. This path was rarely taken in isolation, with others playing a crucial role in shaping it for good or ill.

Some described the way in which the response and acknowledgement from others provided a motivating force, spurring them on to stretch further. Some talked about the way in which they learnt from the openness of others, taking new risks to reveal parts of themselves that they had previously hidden.



"At the time I was in a more clinical role - facilitating psychoeducation groups. It was a Peer Worker, Clinical Psychologist and me. We knew we each had this golden thread of LE, but it was unspoken. We all sat there in our roles. I noticed how group members saw us differently. As soon as I changed the way I was talking about self-care ... saying 'when I'm struggling with negative thoughts ...', 'one thing that really helps me ...'. It massively changed how people in the group related to me. It was almost this light-bulb moment - so you work here ... you are the NHS and you can be depressed as well?" - **Interview participant**

For those who approached leadership roles from a more professional route, this evolution often involved a degree of soul searching and dissatisfaction with the oft-accepted barrier between professional and Lived Experience. Acknowledging the risks inherent in explicitly using their Lived Experience within their role, some described it as the only authentic way forward they could see.

"How can what I am doing contribute towards something bigger - selfless service, fearless? ... One way of characterising Sikhs in history, they're seen as being rebellious, agitating ... wanting to further social justice" - **Interview participant**

For some contributors, their evolution into leadership roles was intrinsically related to their wider social, political and religious beliefs. The connection with a wider movement gave some contributors inspiration, energy and an ethical compass to help guide their efforts. For some, this wider connection involved people (wholly, or in part) de-centring themselves and focusing their attention on the community or cause they wished to serve.

## GATHERING MOMENTUM

"I was excited ... reading about involvement, activism, Recovery In The Bin (RITB). I went to a Lived Experience conference run by pioneers. A door had been opened and these very difficult experiences I'd had could change things" - **Interview participant**

Some contributors described a sense of gathering momentum. Whilst sometimes fuelled by the energy sparked by a single formative event, often it was the culmination of a series of smaller steps that began to gather pace.

"I really got a buzz for research and I could see how I could use my Lived Experience on this project - that I could use some of the darkest most distressing moments of my experience, that I could use that for good" - **Interview participant**

For some, this process involved both the realisation that one's Lived Experience can be used for good and - importantly - that one has the skills, connections or opportunities that make this use possible.

"I did well on this "developing expertise" course (I got an A). I thought 'actually, I can do it'. I got hungry ... read a lot. When there was an opportunity to get involved - I did it (whether it was tokenistic or not). I started to network, listening to people, making links" - **Interview participant**

Some talked about becoming aware of a sense of hunger to connect with more opportunities and stretch themselves. This was often linked with an increasing degree of intentionality - a sense of agency and feeling increasingly able to put oneself forward - and connectedness with others.

"[I] accepted that I had childhood abuse, trauma ... accepting it's not my fault ... it's my journey ... adds layers to it. I didn't know I could 'activate it'" - **Interview participant**

For some, this process involved accepting elements of one's own Lived Experience that they had previously struggled with; a particularly challenging process for those whose experiences had left them with feelings of shame or brokenness. Yet, in amongst this, a number of contributors described moments and connections that helped them recognise themselves as OK-enough to be in the world and/or as having something useful to offer in leadership spaces.

Conversely, some contributors emphasised that one does not need to feel 'healed' to do some good. Many of us are finding our way into these spaces and roles whilst simultaneously tending to our wounds. From this perspective, expectations of confidence, self-esteem and balance can be unrealistic and exclusionary. Instead, it can be about trying to create the connections and networks that sustain us as we continue to put ourselves in situations that we rarely feel ready for.

### REFLECTIONS:

For many the route into leadership involved the, sometimes unexpected, realisation that they had something to offer. Often the support of others, with and without LE, is crucial. Some of the experiences described to me highlighted the degree of luck or timing involved in finding certain opportunities: the impact of factors beyond their control. This is not to say that leaders following this route are undeserving - far from it. Yet it seems crucial to acknowledge that there are many more people out there who are inadvertently excluded from taking similar routes. Investing in creating opportunities that develop people's skills and confidence, wherever they are on their journey, feels crucial when building leadership capacity. Any such support should support people in creating and accessing supportive networks to help mitigate the role of luck and privilege.

## CHANGEMAKER ROUTES

Changemaker routes have a focus shaped, at least in part, by response to a particular experience, gap or injustice that is felt or witnessed. They often involve creating new possibilities and/or finding ways of addressing issues guided by one's Lived Experience.

### RESPONDING TO THE GAPS

"My friend had took her own life a few years before [starting in the role]. She had told services repeatedly she was going to do that, there was no acknowledgement. I felt she had been let down by services. I took that experience into this work, hoping to make people uncomfortable - to change something" - **Interview participant, re: taking on a strategic LE role in the NHS**

Many contributors talked about how their Lived Experience shaped the focus on their leadership - their purpose. Often this was inspired by addressing actions, words or neglect that had caused immense harm with the hope of improving things for others.

The desire to use Lived Experience to push for change can be a powerful force and yet, as described below in the challenges section, it can exact a heavy toll as people engage with the same toxic spaces, practices and attitudes that have caused the harm they seek to address.

"Punjabi and Sikh communities - folks who are experiencing the same kind of things as me. Folks who are experiencing challenges but didn't have access to be heard, talk openly and connect with people in a different way" - **Interview participant**

Conversely, some contributors talked about how some of their positive experiences inspired the focus of their leadership activities. Often, this path seemed shaped by the recognition that the influences they found so valuable are rare. As such, the goal is often to create, nurture and extend opportunities across communities to increase equity of access.

## IT CAN BE A MATTER OF NECESSITY

"I kept thinking of all my friends who have been denied care and denied. I don't think I can live with myself if I don't attempt to punch the monster. Even if I don't win, they know it's wrong and I know it's wrong" - **Interview participant, describing their rationale for pursuing a legal case**

Some contributors describe their acts of leadership as inevitable - something that they cannot avoid or step away from. These routes are often stimulated by an urgent and pressing need within a community that has a personal resonance. It can exist at the meeting point between righteous anger at the status quo, and a sense of responsibility to act; a refusal to be a bystander.

"There was nothing out there and the black community was imploding. Literally falling off a cliff straight into the mental wards. We were just sitting there watching it happening, watching our people piling up" - **Interview participant**

For some contributors, prior experience of silence and shame fed their commitment and urgency to speak out and fight for change. Whilst this can be a powerful and generative force, I also heard an undercurrent of moral duty. Is it possible for someone to put down their sword without feeling complicit in these ongoing harms? This route can be associated with overwork, personal cost and burn out - especially for those who are working alone or in inhospitable territories.

"I needed to find a way of using it [Lived Experience]. If I pretend it doesn't exist it'll come out" - **Interview participant**

For some contributors, finding a way of using their Lived Experience within their work (in formal and informal leadership roles) is essential to their own wellbeing. For some, this is linked to a sense of authenticity where silence feels akin to the denial of an important aspect of themselves. For some, using one's Lived Experience to effect change and/or help others can help make painful and traumatic experiences feel more possible to live with.

## CARVING OUT YOUR OWN SPACE

"I couldn't get any funding for it, I couldn't get anybody to work with me. And so I thought 'oh, OK - so you're not going to help me then. So I've come to your table and asked for a seat at your table and you've told me 'no'. So I went over there and got some wood, a hammer and some nails, and I built my own table" - **Interview participant**

For some, the direction and shape of their leadership was set, in part, as a response to a series of closed doors. Sometimes this involved active exclusion from existing spaces and initiatives (sometimes within an organisation or group).

Some contributors talked about a clear sense that the existing opportunities did not welcome or serve people from their background or community. Some went on to create charities, others developed peer support groups or learning communities that operated in a more inclusive way. Some went on to focus on activism (either alone or with like-minded allies).

## HYBRID ROUTES

Many contributors described a mix of different opportunities, stretches, roles and initiatives that culminated in what one contributor called a 'portfolio career'. Some described this as a journey, a necessary exploration to find one's place in all of this without a guidebook. Others described a trajectory necessitated by multiple blocks, glass ceilings and a shifting landscape where projects pop up and disappear with worrying regularity. For some, especially those who follow a freelance route, it is simply how things work.

## WHEN THE ROUTE IS BLOCKED - BELONGING TO AN 'OUT GROUP'

### WHEN PEOPLE TRY TO STEP FORWARD

"I'm mixed race. I'm used to the aunties doing the social justice thing. Strong-willed. Opinionated. But people don't see me as mixed race, so I'm seen as weird. I don't quite fit in" - **Interview participant**

A number of contributors described leadership positions and opportunities being closed to them because their 'face doesn't fit'. This experience of being an undesirable other occurred across contexts - in the NHS, mental health charities, academia and grassroots survivor-led organising. It encompassed classism, racism, ableism, sexism, homophobia and transphobia.

Contributors described judgements being made on how they talk, how they carry themselves and what they say. Irrespective of how these judgements were conveyed (explicitly or implicitly) the message was received loud and clear - 'people like you are not welcome here'.

"If someone was challenging in a meeting the manager would just not invite them to another one. As they weren't employed, there was no recourse" - **Interview participant**

The combination of being superficially welcomed into a space in order to bring a different perspective and learning that this difference needs to stick within poorly defined limits can be incredibly stressful. It is akin to walking a tightrope whilst everyone keeps insisting that you're on a sturdy path. This point is covered further within the section that highlights some of the challenges faced by those engaged in Lived Experience Leadership.

"Whoever you were, whatever your story was - it didn't matter. The NHS was pure evil. It was almost as if you've gone to the dark side - you went in as a raven and came out as a chicken, and therefore you're different now" - **Interview participant describing their experience of a survivor-led event**

Othring can occur between those of us with Lived Experience. Some contributors shared times when they realised that they had crossed an often invisible line that rendered them as 'other' in the eyes of those they considered peers. Sometimes this seemed connected with profound differences in ideologies and the assumptions made around each other's agenda. In some situations it seemed connected to judgements around a person's moral worth.

The net effect of all this is that pathways to leadership are affected by the biases of those in a position of power to choose someone as a leader or accept their leadership. This can create an echo chamber where it is easier for those who fit, or can be shaped into, a particular mould to take up leadership roles.



## FACTORS THAT MAKE STEPPING FORWARD EVEN HARDER

"I come from a background where women don't have any power and you don't get educated. A mixed-race background where there was a huge amount of violence, abuse and racial trauma. There's a soup going on, I'm conflicted. An undeserving thing - that part of me has this tension. To be called a leader almost feels embarrassing" - **Interview participant**

In considering the impact of othering and exclusion on leadership pathways it is important to consider the impact of living in a world that continually tells you that you're not good enough, not clever enough and are fundamentally flawed.

"Confidence is unequally distributed to people in our society - confidence to make decisions, to say 'this is the correct answer'. It's part of a process that tells you your voice is valued, and that it's valued relative to other voices. There are folks who were praised as confident and folks who were racialised as arrogant. How do we create the space to help people to find the confidence that they've not been afforded by the spaces they've been in?"

- **Interview participant**

Whilst most people with Lived Experience can recall experiences of stigma and discrimination, the world does not treat all people with mental health issues equally. This may stop people from even thinking it is possible for them to throw their hat into the ring.

### REFLECTIONS:

It is crucial for any LEL training or development initiative to be visibly plural and welcoming. Those of us who are designing and promoting opportunities must work to recognise and address our own biases. This may, at times, include serious consideration of our role and whether there is another person, agency or collective that might be better suited. It may also include seeking out meaningful collaborations that have tangible decision making powers.

## WHO IS LEADING WHO, AND WITH WHOSE PERMISSION?

“Recently I came across “Lived Experience Ambassador” on Twitter and the person had appointed themselves that title and moreover said they had invented it. There was also a person on the Trust board who called himself a “Service User Champion” but when service users asked for help he didn’t really do anything at all” - **Survey respondent**

When someone takes up a leadership position in a project or organisation there is often a sense of clarity around who or what is being led. For example, a team leader leads the team. This authority is conferred by the role and the management structure. Often talked about in abstract, disconnected from a particular role or context, LEL can evoke questions around the role and rights of followers: who is being led, did they consent to this and can they choose a different leader?

### NOT ‘OUR’ REPRESENTATIVES

“How can you have a representative from a group that didn’t chose to be represented by that person? If you’re going to put in leaders or representatives - you should have a vote/say on who is taking up that space” - **Interview participant**

Often people with Lived Experience are talked about, or treated, as if we are a homogeneous group - a group where any one of us can step forward as a representative. This effectively erases our many differences of experience, perspective and priorities. Additionally, those with Lived Experience who sit on boards and advisory groups are often in the impossible position of being perceived to be representative without the resources or infrastructure to make this possible.

Those who look to members of committees with Lived Experience may, understandably, feel frustrated that their perspective is not being sufficiently voiced. In these situations a sense of organisations ‘cherry picking’ acceptable voices are common, especially when those with LE are perceived to be taken from a narrow pool (gender, racialised identity and/or ideology, for example). Whilst individual members with LE can be targeted as ‘the problem’, some contributors emphasised the need to look wider. They highlighted the way in which such practices provide organisations with the virtuous appearance of valuing LE whilst simultaneously maintaining the status quo. From this perspective it becomes imperative to challenge the structures that facilitate and sustain this.

It is of note that whilst some contributors have been engaged in a representative role (for example, as part of a committee), this assumption of representativeness is a wider issue that extends to other forms of LEL. See the challenges section for a deeper discussion on this topic.

### NOT ‘OUR’ LEADERS

“[A group] promoted themselves as ‘our’ leaders, and did so in a way that didn’t involve others in the thinking, and didn’t recognize those who had gone before them” - **Survey respondent**

Some contributors raised concerns around ‘self-appointed leaders’, ego, hierarchies and the implied demotion of others to followers who are being ‘led’. This is tricky territory. On one hand, stepping into the spotlight to campaign or work around a particular issue can be valued. On the other, it can be associated with a range of expectations around humility, virtue, authenticity and selflessness. Too little ego and it’s hard to get started. Too much and you risk vilification.

"One person can't represent all Lived Experience and all Lived Experience expertise, and this underpins my concern about taking 'Lived Experience' from a personal experience or a personal story and making it mean 'collective representation'" - **Survey respondent**

Contributors navigated this in different ways. Some highlighted the importance of connecting with wider social justice movements as a compass. Some talked about the importance of knowing our (survivor) histories and seeing ourselves and our roles in a wider context. Given the ease at which we can be positioned as a representative and given the power to speak for others, some contributors highlighted the importance of clearly expressing who and what we are speaking for.

## A NEED FOR DIVERSITY

"While [lived] experience often leads to political and ethical commitments to change, this is not always the case, and it's important not to take this link for granted" - **Survey respondent**

The survivor movement is, most often, associated with a values-based way of approaching mental health. This includes a commitment to human rights, choice and creating spaces for marginalised voices to be heard. Yet this is not universal. Some contributors spoke about the inequalities that have played out, and continue to play out, within and around our movement(s). Everyone's experience of mental health issues, treatment and society is not the same.

If we value Lived Experience Leadership are we valuing all leaders with LE, or are we valuing a particular form of leadership linked with a particular political or social orientation? Is one form of LEL morally superior to another? If so, do we risk holding those wanting to use their Lived Experience to create change to a higher standard than those without Lived Experience?

## WE NEED A MORE NUANCED DIALOGUE AROUND POWER & LEADERSHIP

"What I dislike about the term leadership is that for some people it could imply power or seniority differentials which to me goes against survivor communities/movements"  
- **Survey respondent**

### REFLECTIONS:

Given that many people with Lived Experience know what it's like to be spoken for, ignored or invalidated, finding ways of navigating some of the thorny issues described above feels a crucial part of moving forwards in an ethical way.

It can be easy to dismiss those who feel suspicious of LEL as 'the problem'. It is easy to dismiss those who lead without engaging people in the communities they relate to as 'the problem'. Yet, in doing this we may miss an important opportunity to have a more nuanced dialogue around the challenges of leading, issues around power and an appreciation of what it is that people are stepping in to and how it might be more clearly navigated.

We need spaces to more fully explore this tension around leadership and representation, the individual and the collective. How can we talk about leadership and leading in a way that does not co-opt people into being followers or being spoken-for? If representativeness is sought or needed - what is it that leaders need in terms of resources and support to do this in a way that engages with diversity. What is it that organisations need to put in place to facilitate this?

Spaces to explore what leadership can look like from a Lived Experience perspective - rather than replicating leadership templates given by NHS. A focus on collective and ethical leadership.

# LIVED EXPERIENCE LEADERSHIP IN CONTEXT

"I would prefer a focus on what it is that people are leading in. E.g. survivor research, service development, peer support, peer training, human rights etc. rather than a catch-all word"  
- **Survey respondent**

The above section demonstrated a wide diversity of perspectives on, and experiences of, this thing we're calling Lived Experience Leadership. Whatever we call it, it is clear that there are many people out there who are using their Lived Experience to create change in the mental health field. The concept of leadership can both evoke an unwelcome sense of hierarchy and provide a powerful emblem of hope. It seems there is a need for any conception of 'Lived Experience Leadership' to acknowledge and celebrate our diversity and, if needed, provide strength in solidarity.

## THE DIVERSITY OF LIVED EXPERIENCE LEADERSHIP

In the survey we asked respondents to suggest additional words that might describe the work of people who lead with LE. The descriptors suggested seem to, roughly, map on to five different areas of work - with the addition of a few more generic terms that may apply across the board.

**SUPPORT**  
Authentic Giver  
Coach  
Group Guide  
LE Companion  
LE Guide  
**LE Practitioner**  
Open Heart Listener  
Peer Support Group Facilitator  
Peer Support Leader  
Mentor

**KNOWLEDGE**  
Consultant  
Expert  
**Expert by Experience (EBE)**  
Equality advisor  
Knowledge sharer  
LE Advisor  
LE Ambassador  
LE Representative  
LE Researcher  
Strategic EBE

**ORGANISING**  
Community Leadership  
**Coordinator**  
Co-production Lead  
Director  
Disruptive innovator  
**Facilitator**  
Founder  
Peer-led  
**Survivor-led**  
Initiator  
Innovator  
Manager  
**Organiser**

**ACTIVISM**  
(Mad) **Activist**  
**Advocate**  
(Mad Pride) Campaigner  
Champion  
Change Agent  
Change Catalyst  
Change Maker  
Creator  
Influencer  
LE Driver  
Pioneer  
Reformer

**ACROSS AREAS**  
Creator  
**Leader** (with LE)  
Leader in Mental Health  
Understanding and Change  
LE Representative  
LE Volunteer  
**LX Supervisor**  
**Patient leader**  
**Peer**  
Peer Leader  
Pioneer  
**Survivor leader**

**KEY:**  
  
Popular terms are marked in **bold**. Terms that included qualifiers are included in brackets.  
  
E.g. (Mad) **Activist** denotes a number of contributors suggesting Activist and a few suggesting Mad Activist.



## WHERE CAN YOU FIND LEL?

- Social Media
- Community
- Academia
- Research
- Independent / freelance
- NHS, Social Services, Job Centre Plus – statutory / PPI / CCG
- Policy / think tanks
- Voluntary sector
- Creative Arts / Media
- Other issue organisations (e.g. BAME, Disability, Human Rights, Homelessness, Substance Misuse)
- Grants panels
- Counselling

## AREAS OF LEL THAT OFTEN GO UNDER THE RADAR

### QUIET GRASSROOTS ACTIVISM

“Grassroots, local action that is unattached to an organisation, unpaid, and has no agenda but to genuinely improve things for an individual or group gets largely ignored and forgotten about. But I personally feel this is the bravest and more meaningful form of Lived Experience Leadership” - **Survey respondent**

“Activists, those telling their stories on twitter” - **Survey respondent**

### INFORMAL ORGANISING BETWEEN FRIENDS

“Groups of friends informally helping each other on roads hopefully tilted toward recovery paths. This could be purely on a friendship level or also including a project covering blogging, film screenings, magazine production or simply mutual support” - **Survey respondent**

### PEOPLE, QUIETLY, USING THEIR LIVED EXPERIENCE TO SUPPORT OTHERS

“I have experienced peer support and that is like a ‘light bulb’ moment in a dark place. The peers that have walked with me along my path may not have been in a leadership role per se, but they led me to a place where I could ‘be’ - **Survey respondent**

### DOUBLY MARGINALISED GROUPS

“People who have been imprisoned, refugees and people who have had children removed from their custody” - **Survey respondent**

“Indigenous/ native communities & the impacts of colonisation” - **Survey respondent**

“Those those in locked up places, those with no access to social media, transgender people, people of colour, non academics, non researchers, those that don’t attend or speak at conferences, the most socially disadvantaged” - **Survey respondent**

### PROFESSIONALS WITH LIVED EXPERIENCE

“Those in professional roles who can’t talk about it” - **Survey respondent**

## EXAMPLES OF LIVED EXPERIENCE LEADERSHIP

### MY ILLUSTRATED MIND: CARDS FOR HONEST CONVERSATIONS ABOUT FEELINGS

CREATIVITY . ARTS . ENTREPRENEUR . FREELANCE

**my illustrated mind: cards for honest conversations about feelings** is the work of Kathryn Watson. Kathryn created this card deck based on her own Lived Experience of mental health issues. She hopes that it might help people to feel less alone and make it a bit easier for people to understand and talk about difficult feelings."



"A few years ago, I discovered that drawing really helped me understand and communicate how I felt. When I shared my work with others, they said it also helped them. So, I created these cards to help my work reach even more people. The first illustration I shared was about 3 years ago - on social media. Although I've now shared my work in lots of other places, my wonderful Twitter and Instagram community were pivotal in helping me decide to use my work to create a visual card deck and in helping shape the design of the cards"

- Kathryn Watson

Kathryn has crowdfunded the creation of these cards through a Kickstarter campaign that ran between April and May 2021. The initial £5,253 goal was raised within 36 hours.

**Find out more:** <https://www.kickstarter.com/projects/kwatson/myillustratedmind>.

**Twitter:** @myillumind | **Instagram:** @myillustratedmind | **Web:** [www.myillustratedmind.com](http://www.myillustratedmind.com).

### NOTTINGHAM UNIVERSITY: ASSOCIATION OF MENTAL HEALTH PEER RESEARCHERS

ACADEMIA . RESEARCH . PEER SUPPORT

The **Association of Mental Health Peer Researchers** was launched in 2019 by peer researchers with the aim of raising the profile of peer research and supporting one another. It is open to people engaged in research around mental health and/or trauma who are affiliated at the University of Nottingham and self-identify as a service user / survivor / Lived Experience researcher. The collective intentionally set themselves up within existing university structures and made links with key allies from different schools and research groups.

"We've seen experiential knowledge being utilised (and sometimes exploited) to improve the design and conduct of (often other people's) research. We're thrilled that people with Lived Experience are now conducting research into topics they have personally experienced. We know that the marginalised, and oppressed, can see and experience the world differently from the mainstream and the privileged - this opens up new possibilities for knowledge, for critiquing the social centre from which we are excluded, for challenging the blind-spots of those who are centre-stage" - <https://b.link/AssocMHPRes>

**Twitter:** @AssocMHPRes

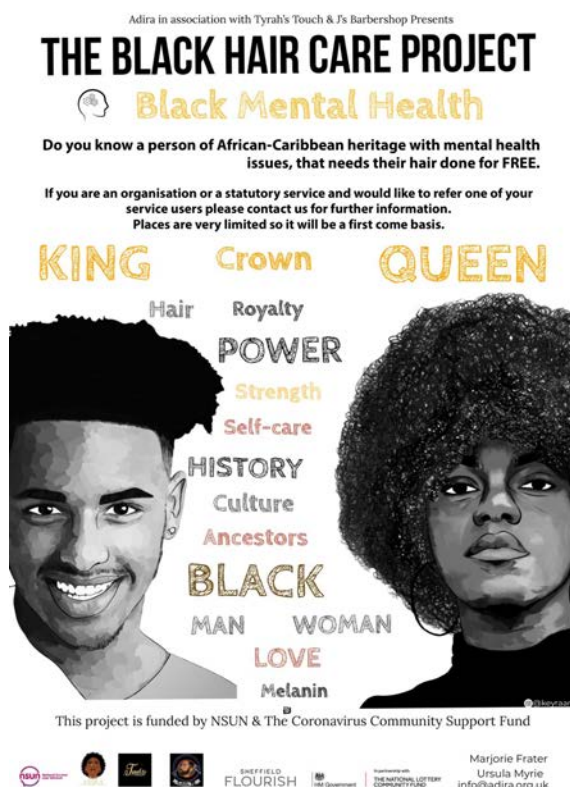
## ADIRA

### COMMUNITY ORGANISING . SERVICE PROVISION

**ADIRA** was launched by Ursula Myrie and Majorie Frater in 2012 for black people (of all ages) who have been affected by a variety of different factors that affect their mental health and/or emotional wellbeing. From the Black Hair Care Project, the ADIRA Food Pharmacy to their Listening Service, ADIRA specialising in creating innovative culturally appropriate and supportive spaces.

"ADIRA was born out of my pain, my trauma, my Lived Experience and I wanted to make sure that it became a safe haven for the black community. Somewhere that the black community can come and the first person you see is somebody who looks like you, it's somebody who is black. It's somebody who's going to understand you. Understand your faith, your culture, your history, your religion, your background"

- Ursula Myrie (Founder) <https://youtu.be/nwiSVlyjmTA>



Ursula and Majorie are open about their own Lived Experience and how it connects with their mission. It is prominent, sitting alongside their main focus - providing services for others.

**Find out more:** <https://www.adira.org.uk>

## STOPSIM COALITION: MENTAL HEALTH IS NOT A CRIME

### ACTIVISM . CAMPAIGNING . MEDIA

**StopSIM** is coalition of service users and allies that campaign for the termination of the Serenity Integrated Monitoring (SIM) model and the launch of a national independent enquiry. Led by people with LE, they have used twitter, protest art, FOI requests, the media and comprehensive evidence-based critiques to highlight issues and garner support. Their work helped bring attention to a thorny topic, encouraging an increasing number of professional bodies and NHS Trusts to distance themselves from the approach. Their petition has over 61,000 signatures.

**Find out more:** Website <https://stopsim.co.uk> | **Petition:** <https://b.link/StopSIM>

## NHS ENGLAND - NATIONAL STRATEGIC COPRODUCTION GROUP

### STRATEGY . CO-PRODUCTION . PARTICIPATION . COLLABORATION

The **National Strategic Coproduction Team** is an initiative developed by the NHS England Lived Experience Team that brings together 'Peer Leaders' to providing input into policy and decision-making at a strategic national level around Personalised Care. Members are recruited through the Peer Leadership Academy and include people with a range of long term conditions, disabilities and carers. The group forms a collective, meeting together rather than being spread across different groups and boards as sole representatives. Attention is giving to upskilling people so they are on an equal footing and prioritising a trusting and collaborative relationship with services and professionals.

**Find out more:** <https://b.link/stratcopro>

# SOME OF THE CHALLENGES OF LIVED EXPERIENCE LEADERSHIP

## UNREALISTIC / IMPOSSIBLE EXPECTATIONS

“Advanced Peer Support Role – it’s not understood. Strategic Leadership ... what does this mean? What is the ethos of Lived Experience Leadership? How do I get it into my role? Beating myself up to get it into the role. Am I doing it right? Wrong?” - **Interview participant**

Many of those who worked in Lived Experience Leadership roles within non-LE-led organisations described at least one role (past or present) marred by unclear or unrealistic expectations.

### AN EXPECTATION TO .. BE AN EXEMPLAR

“The meetings I go to which aren’t populated by peers, I feel very exposed. I second guess as I think it’s going to be heard through the filter of ‘she’s got Lived Experience’. Whatever I say, I’m tarring the whole of peer support ... if I make a bad joke will they think it’s because I’m crazy ... or think all peer supporters do” - **Interview participant**

### AN EXPECTATION TO .. BE ‘OUT’

“Part of me thinks that, to get to the next level of pioneering activism/change, I have to step up and share. But then, I’m wary of the implications of doing that. I’m just not sure. I don’t want to have a boxed ticked. I don’t want people to consult with my organisation because of Lived Experience Leadership” - **Interview participant**

“Can you do it anonymously? That would be fantastic. Then you don’t have that baggage to carry, the demands, the triggering stuff. In work environments when you’re expected to show yourself, I find it triggering. That’s why anonymity is so attractive” - **Interview participant**

### AN EXPECTATION TO .. BE ‘RECOVERED’

“People aren’t so interested in my LE. They want someone who will lead on training, write strategies ... But don’t take a day off - LE should be in the past” - **Interview participant, talking about the shift that happened when they moved to a senior role**

Some contributors described a sense that once they were promoted into leadership roles within organisations that their Lived Experience should be in the past; that it was necessary to have Lived Experience, but that it shouldn’t influence or affect them in the role. The message received is that current Lived Experience is messy, unprofessional and can get in the way.

### AN EXPECTATION TO .. CHOOSE A SIDE

“Dual hat - service user and researcher. Depending on what setting I’m in, people put me in one camp or the other ... [they] don’t see me in this third space” - **Interview participant**

“Coming out with Lived Experience in a mental health setting is really difficult ... it feels like you’re losing your credibility. For a lot of people, we’re a separate group. We are professionals. We don’t have mental health problems. And that’s a challenge” - **Interview participant**



## FIGHTING FOR CREDIBILITY

"Can people with MH problems be leaders? The perception of the masses is probably not. [They think] at times we should not have autonomy and need to be taken care of"  
- **Interview participant**

Many contributors highlighted the impact of living and leading in a society where one is immediately positioned as being vulnerable, fragile and lacking credibility.

## BEING SEEN AS 'LESS THAN'

"Being the face of someone with Lived Experience is challenging as I don't feel taken seriously. I've got a lot of professional experience, I've had to earn that place - but it still feels like a battle. [It's] a double whammy as I'm working in a hub challenging stigma and discrimination. It's an extra stress. It feels so unjust. Really hurtful" - **Interview participant**

## ASSUMPTION OF ILLNESS

"When you say 'no', or 'I need to step outside' ... immediately it become because you have LE. Every time I put a boundary in [they assume] it's because you're not very well. No, it's because I'm a human being" - **Interview participant**

## HAVING TO BE SANER THAN SANE

"[I asked] Do you think I should say that to my supervisor? [They said] 'it wouldn't serve you to say that right now .. to frame yourself as vulnerable and weak.' In my previous roles I would have expected to be met with compassion. Then it was like 'it's dangerous to be thinking along those lines' ... a powerful message to 'pull yourself together'. It was like someone had pulled the carpet out and there was this chasm underneath. It was scary" - **Interview participant**

"The onus is on us to prove we're sane" - **Interview participant**

For some, this assumption of vulnerability and the tenuous nature of one's credibility has led to an (often unspoken) need to appear more grounded, competent and professional than one's colleagues in order to be taken seriously. Some people found that this led them to accept poor working conditions, over-work and avoid seeking help at times of stress.

## LIMITED OPPORTUNITIES

"I'm sat around the table and everyone is a Band 8 and I'm a Band 4, but I'm contributing equally. To be a decision maker and work in strategy, that's Band 8 and above. You can work to that level, but you'll never have that decision making power as a Band 4" - **Interview participant**

Some contributors shared a frustration with the limited opportunities to lead within non-LE-led organisations within the voluntary, statutory and academic sectors. This included a sense of Lived Experience Leadership being defined and bounded by people who don't fully understand it. The resultant silos created fulfil the dual function of appearing to value LE leadership whilst simultaneously protecting the organisation's core from substantive change.



## SERVING SOMEONE ELSE'S AGENDA

"The peer workforce continues to grow and grow, but the leadership element doesn't. It's a constant battle to get LEL central to everything" - **Interview participant**

## USING OUR FACES FOR CREDIBILITY / IDENTITY FIRST

"I'm invited because we need a young person from x background, rather than them being truly interested in what I have to say" - **Interview participant**

"I thought from the off, I don't want to be a show pony. It was a case of 'we've got these Lived Experience / mentally ill people - look how good we are'. Not respecting us as individuals. I didn't want to be involved - it was not healthy" - **Interview participant**

Many contributors described being recruited or invited into situations on the basis a characteristic (e.g. mental health issue, racialised identity, age) to meet a target and/or provide a veneer of credibility for a project or organisation. Being engaged in these 'opportunities' can be crazy-making - on the one hand you might be told you are valued, but on the other you are surrounded by a structure and practices that makes it clear your value is largely performative.

"Although I was used a lot tokenistically in campaigns, images and media, I was never asked for my actual opinions / experiences and when I offered them they were often ignored" - **Interview participant**

Some contributors talked about the way in which some organisations had been keen to use their face and Lived Experience in public facing advertising, media opportunities, and reports - yet failed to engage with their experiential knowledge on a deeper level.

"It's tokenistic - [they think] 'we must have someone with Lived Experience because it's our strategy', but not thinking through what this role means" - **Interview participant**

Overall, there was a sense that in the rush to appear (or feel) progressive many organisations have created roles and opportunities that lack substance and demonstrate little understanding of LEL.

## TOKENISM AND SILOS - BEING PRESENT, BUT LACKING POWER

"We supported people to help identify themselves as leaders within the organisation. But they kept hitting up against challenges in the wider world. In the NHS you're not a leader - we'll listen to you - but you're not a leader, not part of the decision making" - **Interview participant**

Despite the growing interest in LEL and Experts by Experience (EBE), many contributors highlighted a lack of decision-making power in many (but not all) roles situated within non-LE-led organisations. Some contributors talked of the prevalence of silos, where projects led by people with LE are cut off from the main organisational decision-making spaces.

In these situations, project managers or leads with LE were sometimes put in difficult positions - having to pass on decisions to their team which felt unethical or problematic, and yet having no real power to challenge or influence them.

In academia, contributors noted the chronic underfunding of LE research groups, and the scarcity of people with LE working as 'principle investigators' in charge of their own research teams.

## EXPLOITATION

"Being forced into the 'recovery' agenda – on the surface being held up as recovered and going around the country giving talks, but being left feeling suicidal" - **Interview participant**

"We have had people parachute in .. picking our brains and make it seem like they're trying to help. I've had this happen to me, personally. They go away with the information I've given them, put it into a massive funding bid. They use my name, use [my charity's] name, get the funding and I don't see them again. I don't get any of that funding. I don't know what they've done with it. And that's really hurts" - **Interview participant**

"The charity has had many people. Before me there was a man called Steve\* He warned me they will use you, your Lived Experience and image. Till your worn out" - **Interview participant**

## CONDITIONAL SEATS AT OTHER PEOPLE'S TABLES

"If I rock the boat in the wrong space I will be excluded from that space ... they won't invite me back. It's a fine balance between challenging enough so they do know good practice, and knowing when to back off" - **Interview participant**

Many contributors articulated a keen awareness that their place at someone else's table was contingent on adhering to a set of, often unwritten, rules and expectations. The conditional nature of such opportunities can be othering, demonstrating that LEL is not yet fully accepted or seen as crucial in many non-LE-led groups and organisations.

"The contract changed. The new entity had their own ideas and changed the advisory group. It caused lots of tense moments. I was co-opted. They said "we want you to come on board to help out". I'd like to think it was because of my skills and experience, but possibly they just wanted to placate me and avoid bad press. It eats away at you .... I thought here we go again. I started to deteriorate. There were health consequences. I've seen it several times over. It's a bit painful ... I thought, do I want to carry on and do anything?" - **Interview participant**

Some contributors talked about the challenge of projects being supported (or funded) by key people (allies) without more widespread acceptance in the organisation. Whilst these allies often go to great lengths to secure and safeguard the work, it is fundamentally unstable. When the contract ends, or the ally moves on, change is enforced. The regular shifting of user-led projects between larger organisations can create a disorienting and disempowering context that may stifle growth. If projects have been championed by a particular ally, their departure can herald a drying up of funds and opportunities.

## ABSORPTION AND SANITISATION

"Large charities have absorbed and changed/diluted user led initiatives" - **Interview participant**

A number of contributors talked about how survivor/user-led initiatives have been absorbed into larger charities/organisations. Whilst this can sometimes make the difference between survival and folding, some contributors highlighted potential culture clashes and a gradual erosion of independence, power and influence.

Some contributors raised a concern that those with more radical, challenging and uncomfortable perspectives are being shut out of these more mainstream spaces, as organisations are perceived

to prioritise relationships with funders, donors and statutory services. A few contributors talked about a process of learning what can, and can't, be heard within a particular context. Whilst this can be understood as a natural relational process, when it involves portraying one's own Lived Experience in a way that does not feel authentic it can be profoundly damaging to one's sense of self. One contributor talked about this provoking such a dissonance that they felt suicidal. Another talked about feeling like a 'minion' of an organisation's agenda.

## NOT BEING VALUED

### A MARGINALISED KNOWLEDGE BASE

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"I was a patient representative [for a professional body]. I said 'in my experience ...'. They said 'that's opinion not evidence'. We have RCTs at the top and patient experience right at the bottom of the hierarchy. I had it dismissed as it's just opinion. I believe that it should be the other way around. LE should be at the top" - **Interview participant**

A number of contributors talked about the way in which experiential knowledge is neither fully understood nor valued in many spaces (including involvement, coproduction, policy, service development and academia).

"It's a space where it's harder for LE to have an impact because a lot of the direction of travel is owned by academics with only a subject knowledge base" - **Interview participant**

Contributors described a myriad of ways in which the knowledge gained through Lived Experience is poorly understood and, sometimes unintentionally, devalued by the some of same people and organisations that are seeking to bring people with LE to decision-making tables.

"At the beginning of each meeting we would be asked 'do the service users and carers have anything to contribute?' It sounded inclusive, but it effectively shut us out of the rest of the meeting which ran at 1000 miles an hour as professional experts clambered to get their voices heard. Our expertise felt like an afterthought even though it was at the top of the agenda" - **Interview participant re: NICE Guideline Development Group**

Some contributors shared the way in which the structures created to promote involvement could stifle it. At times, this felt purposeful; a way of containing voices that some fear may derail a process or workflow. Sometimes it felt unintentional and even well-meaning. Some described it as a consequence of the uncomfortable and emerging relationship non-LE-led organisations have with the more embodied and experiential ways of knowing often championed by leaders with LE. Whatever the intention, these practices can reinforce many of the challenges raised in this section.

"Not everyone is on the same playing field. Faith based, indigenous and racialised communities. Elderly South Asian women within healthcare talking about experiences physically - 'my feet are on fire' ... their experiences easily shrugged aside. If you're someone whose knowledge is already pushed aside, it's adds an extra layer. How does that impact on how they are perceived as a Lived Experience Leader" - **Interview participant**

A recurring theme of the project was a hierarchy of knowledge - how some forms of knowing and ways of expressing knowledge were continually prioritised over others. Whilst Lived Experience knowledge is largely undervalued, there are sub genres of Lived Experience knowledge (and knowers) who are further marginalised.

"Every one's experience is valid. But if look at how system favours those who experiences have been less disruptive (e.g. years of inpatient admissions, homeless without other support factors)" - **Interview participant**

Some contributors also highlighted the structural barriers that can effectively exclude whole groups of people from entering into the LEL arena, ensuring their knowledge and wisdom remains unheard or on the margins. This includes digital poverty, social exclusion and those in prison and/or long stay psychiatric wards.

## BEING TREATED AS A COMMODITY NOT A PERSON

"It's a conveyor belt. They can replace you, but people put their lives in to it. They churn people out and leave you drained and done" - **Interview participant, speaking about mental health charities**

Some contributors talked about being treated like a commodity to be used, rather than a person to be appreciated and developed. This included trainers being 'dropped' for less experienced and cheaper people with Lived Experience who had been 'groomed' through a recruitment process that, they felt, encouraged gratitude and reduced unwanted challenges. It also included people who were recruited to leadership roles yet excluded from the protection and support that comes with being properly employed, making it easier to 'drop' them without consequence when they are no longer of use. Whilst some contributors shared experiences of being valued and developed within larger organisations, this was not the norm.

## MONEY TALKS: THE GAP BETWEEN RHETORIC AND REIMBURSEMENT

"I think it's great that [Recovery Colleges] have someone with an academic knowledge base and LE knowledge base. What I didn't realise is that they never pay the LE contributor. It's all done on your own generosity. I'm delivering this alongside a professor in mental health nursing who probably doesn't care that he's given up a day of his time because he's got his massive salary. But I've spent a day delivering training and there's no payment for that. It feels like you're being exploited" - **Interview participant**

Whilst Lived Experience is being increasingly valued in mental health sector rhetoric, with universities, NHS trusts and charities promoting their engagement with 'Experts by Experience', many contributors highlighted the paucity of financial reimbursement as a major issue.

"I'm trying to put food on the table. I'm on endless zoom calls where I'm the only one not getting paid" - **Interview participant**

Across sectors, an expectation to work for free (aka volunteer one's time) or to be paid less than staff/contributors who bring professional expertise is the norm rather than the exception.

"They said: 'We saw you speak at this conference, it'd be great to get you in .... but we don't have a budget, so it's not going to be paid. Can we use all your artwork and images anyway?'" - **Interview participant**

Beyond the experience of financial hardship and inequity, many contributors highlighted how tokenistic offerings are connected with a systemic undervaluing of their work. One contributor compared it to offering a master craftsperson a £20 gift voucher. It is an insult.

"It's paralleled in debates around pay. I believe I'm not worthy. Then they say we won't pay you properly either - you're not worthy" - **Interview participant**

Yet, many contributors talked about times where they have gratefully taken up unpaid and underpaid opportunities. Whilst at times this might be connected with 'paying their dues', fulfilling a social mission and building experience and connections, it can also be part of wider feelings of unworthiness. If one lives in a world that continually tells you you're broken, it is unsurprising that many of us feel indebted to the ones who ultimately benefit from our expertise.

"Unlike other services where you're selling a product or something, in freelance work you're selling yourself, basically, your time and your services. The negotiation around that - how do you value me - is so difficult. It's compounded by widespread bad practice, tokenistic practice" - **Interview participant**

This issue plays out across different sectors and opportunities. Many freelancers, for example, talked about the challenges of pricing their own services. In doing this they navigate moral dilemmas, the (potential and actual) judgement of others and a deep sense of confusion over what one's experience is worth in financial terms. For some, this has resulted in underpricing their own services and/or a reluctance to invoice or collect money owed.

"Millions are being poured into the sector, and who are taking those millions? It's not us. Our organisations are becoming extinct" - **Interview participant**

Some contributors highlighted the crisis of funding experienced by many LE-led groups and organisations. In addition to the worrying number of closures in recent years, some contributors linked the lack of investment in LE-led organisations to the increasing trend for larger charities to host and lead on user-led initiatives. Of particular concern is the way in which funding streams are magnifying the issues around power, exploitation and sanitisation, discussed above.

"If I applied for a job at [a LE research group] it'll not be a problem. But, because Lived Experience is valued less, [they] have no money to bring in people. They don't bring in the big bucks. There's less money. They're treated as less valuable"- **Interview participant**

The lack of investment in Lived Experience / Survivor Research can present a barrier to those with Lived Experience wishing to gain a PhD studentship and/or develop their research skills at a higher level. Survivor Research often exists in silos, and those silos are comparatively under-resourced. This creates a self-fulfilling prophesy which can constrain LEL within academic settings, encouraging researchers with LE to join teams and projects led by those without LE.

## WORKING IN DANGEROUS TERRITORIES

### YOU ALWAYS GET TROLLS - SPEAKING OUT IN THE MEDIA

"Most comments were nice. On insta - someone told me I was wasting a hospital bed. That I should go and die. That I was choosing these things" - **Interview participant**

Most contributors who have spoken about their experiences in the media, social media and/or in person had some experience of being attacked or discriminated against. Tellingly, this was often framed as an inevitable consequence of 'sticking your head above the parapet' and using your experience to push for change.



"A lot of judgement, a lot of keyboard warriors and trolls on social media ... I'm not saying they don't affect me. I've learnt to think - 'what's your insecurity?'. There are judgemental people, but it drives me to make a difference" - **Interview participant**

However, the level of abuse and judgements received can take a toll. Some contributors described feeling extremely exposed and vulnerable after 'going public', with negative comments acting like arrows that strike already sore spots. They can bring a stark reminder of the prevalence of prejudice and stigma, something that may not be immediately obvious in everyday interactions within supportive social circles. This can be disappointing, devastating and, at times, galvanising.

## MICROAGGRESSIONS CAN BECOME PART OF THE WORK

"I came in expecting to be equal. I had to learn I was not an equal. Only through getting knocked back I learnt that" - **Interview participant**

Within an organisation, prejudice and discrimination may be more subtle and difficult to define or talk about. This can leave the person on its receiving end under no illusion about their status within the organisation. They are continually reminded of their 'otherness' and that they don't really belong. One contributor spoke about how all of their interactions are filtered through the lens of being perceived as a patient.

"Have you not taken your meds" - **Interview participant, asked this at work**

"You'd never guess you'd had that diagnosis" - **Interview participant, told this at work**

Sometimes these words and actions are guided by a sense of kindness (e.g. checking on someone's welfare), yet they often seem to be shaped by deep seated stereotypes that arise from the worker/client well/ill divide. Often, these situations involve pathologising someone's natural response to challenging situations.

## GASLIGHTING

"I was gaslighted. I thought 'am I mad?' I spent 5 years thinking everything I think is wrong. That I'm defective. But I was perfectly sane" - **Interview participant**

Repeated instances of being 'put in your place', blocked, pathologised or talked down to can have a massive impact on your physical and emotional health. It can also create a culture that enables extreme examples of discrimination and harm. In this project I heard two examples of this that particularly shocked me.

"I introduced a service user to a medical director at a public event who then got her an appointment for the following day. She was suicidal and had been discharged without follow up, breaking legislation. The project manager phoned and screamed at me. I was sent home for several weeks and asked not to come in because I was 'ill'." - **Interview participant**

In the first, a contributor recounted being shouted at for advocating for a service user, introducing them to someone who had the power to resolve their concerns. Rather than recognising it as a clash of cultures, where the contributor prioritised advocacy over an unwritten expectation around protocol, it was framed as a sign of illness. They were effectively silenced and locked out of the organisation. It can be hard to hold on to one's reality when everyone around you denies it.

"I was being blacklisted. I knew I was being left out, but I couldn't prove it. It frazzled my brain, literally - I had a seizure and was ambulated out of work. Adding insult to injury, two days after I'd been off they held a steering group for the project. It was being done. I was the reason it was being done, but she'd organised it without me. They had blocked me. I knew I couldn't go back into the same situation" - **Interview participant**

In the second, a contributor described pervasive experiences of dismissed, blocked and silenced. After having a hand in creating initiatives, they described the pain of being manoeuvred into a bystander role as they witnessed the work they'd instigated being implemented in ways that contravened their core values. Listening to their experiences, it struck me that the level of silence and denial surrounding this situation was particularly maddening.

"I put in formal complaint. They wrote back and tried to imply that I'm mentally ill"  
- **Interview participant**

"They said sorry for the distress caused, but that it wasn't within their gift to redress. They weren't admitting discrimination and harm" - **Interview participant**

"Sometimes you can't see it [racism] - sometimes there's no evidence. It's not taken seriously. People are ignored or told to shush - to drop it, or they're paid off" - **Interview participant**

"It hasn't been an emotionally safe culture where people feel they can be challenged in a way that is responded to safely. It's closed down" - **Interview participant**

A particularly worrying feature of these situations, and others shared during the project, is that complaints, grievances and the raising of concerns can be met with further invalidation, silencing and the closing of ranks.

## TOXIC CULTURES

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"They have a toxic culture - they don't realise it at all ... they think it's fine to speak about service users like that" - **Interview participant**

Many contributors, working within both voluntary and statutory organisations, described experiences of unhealthy and/or toxic cultures that impacted on their wellbeing and ability to lead.

One aspect of this is workplaces where structural sanism is the norm, enabling the situations described above to become part of the fabric of the Lived Experience Leadership landscape.

"We work in environments that are not particularly caring employee cultures ... You see it within blue light services 'we're strong, we're resilient, we're the NHS- we get on with it'. A macho culture. It's toxic in these organisations" - **Interview participant**

Overwork is rife in both the voluntary and statutory sectors. All employees should expect a healthy working culture with breaks, boundaries around work/home life and realistic expectations. However, for those navigating the additional challenges of mental and physical health problems, the stakes can be higher. One contributors described LE-leaders as 'canaries in the coal mine', referring to the toxic nature of overwork cultures that ultimately affects everyone.

"Lived Experience leaders work in an environment that doesn't allow them to be Lived Experience Leaders" - **Interview participant**

## THE SHIP IS SO BIG IT'S HARD TO CHANGE ITS COURSE

"There are still battles that I was fighting 20 years ago" - **Interview participant**

Whilst contributors highlighted many successes and examples of progress, these often took place within or around larger systems that are incredibly difficult to change at pace.

"My first year I felt I like I was battling against culture. Initially a real resistance against peer support" - **Interview participant**

Some contributors highlighted the challenges inherent in introducing counter-cultural ways of understanding and responding to mental health difficulties within organisations.

"In big organisations risk is managed so tightly that only things that are predictable are safe and good for their reputation. The more senior the decisions, the greater the risk"  
- **Interview participant**

In organisations where there is a vested interest in maintaining the status quo, taking the risk of fully integrating LEL and LE-led initiatives may feel too high. As such, innovative spaces can be tightly defined and controlled, leaving the rest of the organisation able to go on as usual.

"We're having the conversations and they want it to happen. They don't realise all the stuff in the middle that's stopping it" - **Interview participant**

Some contributors described frustration at working at higher organisational levels to agree radical shifts in practice, only for them to become policies or frameworks that remain on the shelf. One contributor remarked at how those in leadership positions within larger organisations (e.g. NHS) may be disconnected from what is happening within their own organisation. This can set up situations where people feel let down, or even betrayed, as promises fail to materialise.

## THIS WORK CAN TAKE A (PERSONAL) TOLL

"I don't talk about my Lived Experience all the time, but I feel from my personal view of authenticity that it does seep into all aspects of what you do, which leaves you in some way exposed and vulnerable. If you're being authentic there's always some vulnerability"  
- **Interview participant**

The majority of contributors discussed the personal costs of Lived Experience Leadership, and – more widely – work using one's Lived Experience. Some of these costs seem to be associated with a particular aspect of the work, for example, the use of one's own experiences as a training tool. Others seem to be responses to toxic working environments and practices that can be hard to distance oneself from. Often, these situations may overlap with and echo the kinds of experiences and injustices that lit the fire for this work.

## ISOLATION: BEING LEFT OUT ON A LIMB

"It doesn't feel that anyone's got my back" - **Interview participant**

Some contributors talked about isolation as an integral part of their experience of Lived Experience Leadership. This was often linked to a sense of being out on a limb – occupying

a liminal space between words (that of the service user/survivor and that of the practitioner/worker); of being an outsider.

"There's loads happening where I can't talk to anyone about everything. I don't want to be seen as gossiping. At times my body was like [sighs] because I can't tell anyone"

- **Interview participant**

For some, this sense of isolation seemed linked to the stigma and prejudice described above. Speaking openly and being oneself risks losing credibility. This operates on a personal level, but can also extend to a fear of bringing the whole LEL field, or a subset of it, into disrepute. For others it was more connected with wanting to shield the next generation from the harsher and more painful realities of LEL. As such, some contributors described being extremely careful about what they do, and don't, share.

The relative rarity of people with explicit Lived Experience in leadership roles can impede the development of peer networks. It was marked how, in many of the focus groups, participants remarked on how nourishing it was to speak with others who had experienced similar challenges.

## UNLOCKING PANDORA'S BOX

"There are some aspects of my story that I have to lock in what I call a Pandora's box inside my head. And when you ask me to tell it I have to unlock that box to let them out to tell that story, then I have to put them back and lock that box" - **Interview participant**

Authentic use of Lived Experience has the potential to connect us with some of our most raw, painful and disempowering memories, whether these are shared explicitly or not.

"Every thread of experience that I use to make a point is linked to a tangled web of other experiences that, whilst remaining unspoken, are ever-present. Making peace with that, allowing the feelings to be there, has taken a lot of work over the years. Even now I need to spend time in silence after allowing myself to be particularly vulnerable, moving from a position of being there for others to tending to my selves. I need to restore my energy and, sometimes, grieve" - **Interview participant**

Whilst many contributors talked about a range of practices they have developed to make this use possible, it is rarely fully mitigated. For some, this is an essential aspect of the way they work.

"The one time I allowed any authentic anger into my talk, and was open about recently being suicidal, was the one time I was never invited back. It was too raw, evidently. I broke an unspoken code" - **Interview participant**

Some contributors described an expectation that Lived Experience should be shared with just the right amount of emotion and vulnerability for a particular setting. Contributions that step beyond these tight limits of acceptability risk the individual being pathologised, discredited and/or excluded from future opportunities. Worryingly, some described these exclusions as being justified as being 'for their own good', as the line between patient and provider is redrawn.

This emotional labour involved in using one's Lived Experience in these contexts, and the toll it takes on people's mental and physical health, often goes unacknowledged. In addition to further depleting people's wellbeing, this lack of acknowledgement can also perpetuate the unrealistic and toxic demands placed on those with Lived Experience around their use of their narrative.

## WORKING AT THE EXPENSE OF ONESELF

"I reached a crisis point, spreading self too thin" - **Interview participant**

Many contributors talked about the impact of being attuned, through their Lived Experience, to both the urgency and size of the problems they are working to address. Given this, they are also often painfully aware of their own limitations and the insufficiency of what can realistically be offered. This, in combination with many of the other challenges mentioned in this section, can drive people to extend themselves beyond what is healthy or sustainable. Many contributors described skirting the edges of burnout, or experiencing it in its totality.

"Me not protecting myself, giving to much - not consider own needs. I adapt to everyone else's tune, not having any fundamental worth myself. I care too much ... to the point at which it almost kills me" - **Interview participant**

Additionally, some contributors explored how their own histories of trauma (before, and during, mental health service use) could make it particularly hard to set limits around what they offer of themselves, prioritising others needs above their own. This can be intensified when organisations benefit from this dynamic and encourage people to overstretch, through unhealthy working cultures and/or by pushing a virtuous narrative that makes putting in limits feel selfish.

"I'm 43. I don't know if I will ever own a home, have kids ... they've kept me in stasis for so long. They can never fully compensate me" - **Interview participant**

"I had to be willing to lose friends, lose family and lose the support of my community in order to start [my charity]. And it has cost me dearly. People ask me if you could go back, would you do it again? Honestly, no. The price I've had to pay and will continue paying is too great" - **Interview participant**

Some contributors talked about how LEL can involve taking a stand for what you believe, even when that position means losing people close to you, turning your back on accepted narratives and risking your financial security. For some, the cost has been incredibly high. This further underscores the level of urgency that may push leaders with LE beyond what is expected of those who lead from a more academic or professional knowledge base.

## RE-OPENING OLD WOUNDS AND CREATING NEW ONES

"Emotional energy around the frustrations and injustice. Have to absorb. And process. It takes its toll" - **Interview participant**

Creating, inspiring and fighting for change in spaces, systems and communities often involves being exposed to the attitudes, actions and beliefs that one is trying to challenge. Working in, and around, these beliefs can be toxic - taking a toll on one's own wellbeing.

"My local community did a protest about a housing project I worked on. I was sent to this big public meeting to represent the service. Looking back it was extremely traumatic ... [I heard] 'we don't want people like them in their area'. I saw people I knew. They said incredibly hurtful things" - **Interview participant**

Sometimes these situations were obvious, exposing contributors to overt prejudice, discrimination and abuse. However, often these situations occurred in the contact of a 'normal'



working day in statutory or voluntary sector services. As described above, many contributors talked about micro-aggressions as part of their daily experience of work - moments of othering when the veneer of being equal slips and it is clear that you are perceived differently and of less worth.

“I try and build a bridge [when people say something horrible]. Some people might just be on the edge but you might just change their mind. But it might be very difficult. A lot of emotional labour” - **Interview participant**

Some contributors described the importance of engaging with people who say horrible and hurtful things, with the rationale that doing so provides the potential for change. Yet, the degree of emotional labour this can take should not be underestimated.

“At one point I realised I had to back out of these spaces all together - even those that were meant to be progressive. I realised that, in giving others the benefit of the doubt and trying to see the bigger picture I’d been eroding tiny parts of my soul. After one bad experience I realised I had little left of myself to give” - **Interview participant**

The desire (or urgent need) to address some of these toxic and harmful practices is what drives some of us with Lived Experience into acts of leadership. However, without the power and resources to effect substantial change, this can have a devastating impact on the individual if they are bearing this weight of responsibility alone.

“I felt like I’d let people down ... shame that I hadn’t been able to get my message across. I sat down, frozen .. tears coming down. Everyone could see it. I felt really vulnerable. They’re carrying on the meeting. They’re uncomfortable. It’s being ignored. I just wanted the ground to open me up. I had to sit through till the break. I was utterly shamed and humiliated” - **Interview participant, describing a situation of silencing at a board level that led up to a suicide attempt**

Such situations can lead to the person with Lived Experience being seen as ‘the problem’, or their distress being pathologised and used to justify why they weren’t listened to in the first place.

**BURNING OUT - LOSING THE FIRE**.....

“I feel burned out, drained, undervalued and unappreciated” - **Interview participant**

Many contributors described at least one point when they felt burnt out, or at least found their energy depleted and were questioning whether it was possible to continue. Considering the extent of the challenges described in these pages, it is hardly surprising that those doing their best to create and sustain change are often left exhausted. However, this is not a situation that we should accept as an integral part of LEL.

Engaging in Lived Experience Leadership - or any form of changemaking - should not involve accepting harm to oneself. There is something to be learnt here about both resourcing people who enter in to Lived Experience Leadership, and the importance of allies being allies (rather than perpetuating the problem). Naming injustices and harmful practices can be crucial, as can working together to build healthier cultures.

## ATTACKING EACH OTHER

“People can feel a lot of hurt in conversations ... feeling invalidated, a lack of compassion and empathy” - **Interview participant**

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 Lived Experience have faced before, and during, their work. Working in unfriendly and unhealthy environments can take its toll. Moreover, this is personal – not academic. People's lives are at stake. A question that I kept returning to in these interviews is how can we lead for change, fight for change and also nurture our sense of compassion and humanity.

## HIDING OUR DIVERSITY UNDERNEATH THE 'WE'?

“I've worked for national organisations when I've had to try and assimilate different people's opinions and experiences, and it's really hard to try and bring it together in themes”  
- **Interview participant**

Many contributors highlighted the diversity of people who have Lived Experience. We each have different experiences, different priorities and different ideas about what change might look like and the best way to achieve it. One of the challenges is the expectation that there is some kind of unifying Lived Experience voice that we can all stand behind. Some of the differences of opinion are fundamental. Discussing them can evoke a great deal of pain.

“We've not thought about ethnicity and inclusion. We're all in this together, but some of us are more in it than others” - **Interview participant**

Some contributors talked about the challenge of talking about inequalities within the Service User / Survivor movements. Terms like 'privilege' triggered some difficult conversations within this project. Some found it crucial in terms of being aware of the wind behind their back when others may be walking into a gale. In becoming more aware of this, some contributors emphasised the importance they place on using their privilege to widen access for others.

However, some heard the term as an accusation that minimised their own experience of poverty, prejudice and social exclusion. These conversations can be painful on lots of levels. And yet, some contributors emphasised the need to create spaces to talk about racialisation, class, gender, sexuality, disability and difference in order to explore how LE-led spaces can be more equitable and inclusive.

## I DON'T BELONG HERE

“I've gone to things, but when I'm around anger I find it difficult. I can get scared and intimidated. I can feel “I don't belong here”. It puts me off engaging with that”  
- **Interview participant**

Some contributors talked about the energy, passion and anger they experience in LE-led spaces. Whilst for some this can be very affirming, for others it can be intimidating and feel unsafe.

"I had a passionate discussion with the guy next to me. I said 'I have Lived Experience and I'm a professional'. He said "I bet you've not been sectioned". I went off with depression a few days after – I was in a sensitive and emotional place. I was so upset and hurt. You have no idea what happened to me, in my life and my past ... I just shut up and didn't contribute to any discussion. I detached myself. I felt like there was no room for whoever I am, whoever I was" -

**Interview participant, talking about their experiences as a LE-led event**

Some contributors talked about memorable and painful times when their own Lived Experience has been brought into question - times when others have made assumptions about who they are, what they have been through, and found them wanting. This seems to happen when a dominant narrative arises around what 'real' Lived Experience is and this bar is used to embrace or exclude others. Given the challenges discussed in the 'Unpacking LEL' section, and the difficult times we are living in, anger and suspicion are understandable. Yet, the pain caused is there regardless.

## BEING POSITIONED AS THE ENEMY

"For some people I've sold out and joined the dark side of the force. I'm a traitor to the cause. I find that really hard. I'm sympathetic to it, but I'm also hoping that at least people can see we're trying to do research in things that matter to others and not just ourselves"

**- Interview participant**

"In this big meeting – with 100s of survivors/service users – I opposed a ban on ECT and I was actually threatened with violence. This one guy physically threatened me. One woman said 'the only thing that helps me at some points is to have ECT'. She got vilified. Someone said 'whose pay are you in?'"

**- Interview participant**

"It's hard to feel you're part of the movement when part of the movement is criticising what you're doing. I know I work in compromise"

**- Interview participant**

The debates in mental health are personal, political, and have high stakes. There is no single service user / survivor / Lived Experience perspective on mental health, and some of the differences are 'hot issues'. It's beyond the scope of the report to comment on the rights/ wrongs of any particular position. What was marked in these interviews was the sense of moral judgements and exclusion experienced by those who have worked in the NHS or share opinions that are outside of accepted narratives.

"Although I think I'm, mostly, respected – I know that's contingent on me being seen as humble, ethical, respectful and authentic. I remember speaking about how diagnosis had helped me, at one point in my journey. Within minutes, there was a storm on twitter with people who had never met me and had no idea what I was saying piling on to say how terrible I was. In a flash a group of people had already defined me as the enemy, irrespective of my prior activism. It was brutal"

**- Interview participant**

This feels linked to a sense of being a strong dividing line between them and us, moral and immoral. The words used to describe this – traitor / betrayal – suggest that the person concerned ceases to be 'one of us' and becomes part of the problem; that they profit from the problem. Contributors who experienced this expressed a sense of being dehumanised and devalued, the stripping away of context and story.

"We get shit from both sides. People don't realise you get a lot of critique and pushback from other service users. If anything, that's harder mentally to take ... it's kind of like we're 'the other'"

**- Interview participant**

The net effect is a group of people who occupy a space that, in addition to the challenges described in this section, feel homeless and don't have access to the resources and solidarity found within service user / survivor spaces.

**(NOT SO) FRIENDLY FIRE**

“Leaders stick their head above the parapet. You get shot at, usually by your own. We eat our own babies in the survivor movement” - **Interview participant**

Across all sectors, many contributors talked about the risks of being shot at once your step forward. One contributor talked about leadership as a ‘trap’. There’s a sense that once you step forward you, in some ways, become disconnected from your peers and can be both idolised and vilified. In this way, leadership can be exposing. On the one hand people talked about developing a ‘thick skin’ as a way of coping with attacks. On the other, it was clear that these attacks can be more devastating than the ones launched by those without LE. In a challenging field where solidarity can be a key source of resourcing, these attacks and the awareness that one might be cast as a traitor for any perceived misstep can erode the safety found in LE-led spaces and increase isolation.

“A lot of things are thrown at me from other service users - a lot of viciousness. I meet with other people and encourage them to use their voices. I don't tell them about the shit” - **Interview participant**

This brings a major challenge to the development of Lived Experience Leadership. How can we create spaces safe enough to talk about the pain we cause one another without discrediting LEL in a world that already sees it as problematic? How honest should we be about it when nurturing future leaders? There is, perhaps, an understandable instinct to only speak it in whispers. Yet, in doing so, we may also miss out on the opportunity to create a more supportive and inclusive culture. If this is what we want to develop, then the question arises - what support and structure is needed to have such challenging conversations?

**SOME REFLECTIONS**

Writing this section was, at times, more painful than hearing people’s individual stories. There is something about listing the many different ways in which people with Lived Experience have been silenced, discriminated against, gaslighted, excluded, exploited and harmed that left me wondering: Why are we still here? Why do we keep coming back for more? I also began to wonder if it is ethical to promote Lived Experience Leadership if, in doing so, we simply bring in a new generation of people to experience the same harms that have left so many of us feeling burnt out, undervalued and - in many cases - deeply angry.

Yet, these challenges are not the end of the story. Yes, they are woven into the fabric of so many of the experiences shared with me - but they sit alongside the creative and courageous ways people have found to keep going, without denying their existence. It feels crucial to hear, validate and address the harms contained within these pages, rather than avert our eyes and move swiftly on to the next section’s more positive tone. This need, I feel, must be an essential part of any development programme seeking to support Lived Experience Leadership. Attempts to skirt around it only seem to cause more harm and prevent the possibility for deeper healing and a healthier way forward.

## WHAT HAS HELPED PEOPLE SO FAR?

All contributors described at least some strategies, support networks and/or experiences that have helped them navigate the challenges described in the previous section.

The existence of these strategies does not negate the need for more systemic change, but they do celebrate the tenacity and resourcefulness of people with Lived Experience and can, perhaps, provide an indication of what further support might be offered.

### CONNECTIONS ...

Lived Experience Leadership can be, as described above, a lonely endeavour. Many contributors described the ways in which a sense of connection with something beyond themselves provided a sustaining force.

#### ... WITH EACH OTHER - PEER SUPPORT AND CAMARADERIE

"It's the collective – the connection with others. It's how I go on" - **Interview participant**

Many contributors talked about the power of peer support – formal and informal opportunities to connect with others who will listen, understand and validate their experiences. This can happen within teams, within organisations, at events, in friendships and via social media.

"I can end up feeling like the bad person, the person who can't cope. We don't realise it's a systemic thing – it's all over. I started a YouTube channel to connect with others"  
- **Interview participant**

Such solidarity has had practical benefits (e.g. making it possible to attend training or conferences) and emotional ones (e.g. a space to offload). Some contributors talked about how these connections have helped ground them and reconnect with what they know to be right, mitigating against gaslighting.

#### ... WITH OUR LIVED EXPERIENCE

"I needed a rocky patch to connect with my own experience. I needed to have a wobble"  
- **Interview participant**

"A lot of people try to be professional and in that we lose our identity. There's something raw about being yourself, no matter what space you're in – and others accept it, or they don't"  
- **Interview participant**

Some contributors described the pull of more professionalised ways of interacting/relating and a process of grounding oneself in one's Lived Experience.

For some, especially when their experience is historic, this has included making a concerted effort to connect with the elements of their experience that are still 'live'. It can also involve de-centring one's own experiences and highlighting the experiences of others.



## ... WITH WHY WE ARE REALLY DOING THIS

"You can get as many awards as you like – but what does it matter? If I change one person's life – it means a lot" - **Interview participant**

"I really got a buzz for research. I saw that I could use some of the darkest and most distressing moments of my experience, that I could use that for good" - **Interview participant**

"I see myself as a modern-day Harriet Tubman. I can either go on and live my best life or I can go back in and find other people – black people who are still there and struggling and say 'guess what – I found the way out'" - **Interview participant**

The transformative nature of this work, for oneself and for others, was a recurring theme across all aspects of this project. Focusing on these tangible and meaningful impacts can be a source of strength and nourishment. It can, in some cases, also create challenges when combined with the toxic cultures described above – leaving people feeling they 'ought' to continue in spaces which are harmful and degrading.

## ... WITH SOMETHING BIGGER THAN OURSELVES

"There's a moral imperative – a realisation that I could be part of something bigger. That is powerful. Emancipation" - **Interview participant**

Some contributors talked about the importance of connecting with something bigger than oneself. This might involve feeling part of a social mission, drawing strength from the awareness that you are part of a bigger movement.

"People got excited and volunteered their time. Someone did the paperwork. Another decided to buy the envelopes and did drawing with colours. Someone had a printer"  
- **Interview participant, describing a collective approach to leadership in a self-help group**

It might also involve de-centring one's own experience and leadership role and looking across to our friends, colleagues and allies. It can involve a recognition of the strength of collaboration, with each person contributing what they are able at any given time – rather than leadership being a fixed position that weighs heavy on an individual.

"I am in a leadership role, but I'm not the face of it. I'm providing a platform for volunteers to be leaders" - **Interview participant**

"Whatever this is, it's something that recognises other folks around you as human, recognises you all as imperfect. That recognises we should be working for the upliftment of those around us, rather than for our own benefit" - **Interview participant**

It can also involve a sense of humility; of using one's position and skills to create space for others to come forward. Sometimes this kind of leadership is less visible as it can involve being comfortable stepping off the stage.

"I didn't have the language – I didn't even know I could talk about it. It was very internal to me. Finding labels and a wider community – it gave me a new platform to understand it, to articulate it" - **Interview participant**

Rather than being a single person trying to make sense of things alone, some drew strength and

a sense of direction from their connection with wider ideas and perspectives (e.g. Mad Studies, Disability Studies and the Hearing Voices Movement).

"The whole reason this exists is back in the 60s they said – ‘we don’t want to be in high chairs anymore, we’re adults’. They were taking the power back. The only reason this exists is the activists” - **Interview participant**

Some contributors framed their experience as an extension of the groundbreaking work done by previous generations of activists. Feeling rooted in our collective histories can provide a source of strength and, at times, a reference point for how much has changed. In these conversations there was often a sense that disconnection with what has gone before can lead to a loss of ground as we lose track of lessons learned.

... **WITH ALLIES** .....

"She said ‘don’t worry, I’ll be there ... we’ll do it together’. We started the [self-help] group. When I became confident enough I hosted it. It was a bit scary, but I took it gently. It was an emancipatory path. She was in the background, then stopped coming in – but she was always available” - **Interview participant**

Many contributors talked about the encouragement they had gained through allies that have supported their endeavours in different ways. Some provided the emotional support and guidance needed when contributors were extending themselves and learning new skills.

Successful allyship seemed, in these cases, to be linked with being both present and believing in the potential of the contributor, whilst de-centring themselves and being willing to step back. Some allies helped secure resources for new projects, helped contributors make connections and provided practical support.

"I contacted Mind’s Policy Director. She immediately got back in touch and said ‘I’ve contacted the organisations and told them, unless they invite you to run it with me I’m not doing it.’ I was immediately invited to run the workshop with her when she complained about them excluding me. Our workshop got excellent ratings!" - **Interview participant, at the time a Patient Representative for an organisation that had invited a Policy Director without LE to run a workshop on Patient Involvement**

A few contributors highlighted the importance of allies who use their power to create spaces for the voices of people with Lived Experience. This includes those who refuse to talk at events where there is little/no representation from people with Lived Experience and those who asked themselves whether they are the right person to be taking advantage of a particular invitation.

"A Chief Exec introduced me to a leadership programme – leadership in a disability context. I remember having a mentor who was a disabled person, a diplomat. I remember the mentor more than anything. It was about connections. Who you know"- **Interview participant**

Some contributors described key figures in their journey that acted as mentors or guides. These often had access to specialist knowledge, resources or connections that would otherwise have been opaque to the contributor. These mentorship relationships, importantly, involved a sense of being respected and challenged. They were aspirational.

## ACCESS TO GENUINE MEANINGFUL OPPORTUNITIES

### INCREASING ACCESS WITHOUT BEING TOKENISTIC

“[It was] Masters level content – but done in an engaging way. Meaningful opportunity structured bearing in mind access issues” - **Interview participant**

Some contributors talked about the importance of opportunities that helped them develop the skills and knowledge needed in their roles. The most useful opportunities seemed to be ones that were attuned to the additional challenges people with Lived Experience may face, without mistaking this for a lack of ability or commitment. Some contributors framed this as making ‘reasonable adjustments’ within a disability rights framework.

This links with the importance of being specific about use of the word leadership. In line with the section ‘Unpacking Lived Experience Leadership’, it involves resisting the urge to call everything ‘leadership’ and everyone a ‘leader’.

### SEEING CHANGE HAPPEN

“Strategy and advisory panel work. They incorporated our views. We had it reflected back. Genuine attempts. They went out of their way” - **Interview participant**

One key aspect of a meaningful opportunity is seeing tangible change as a result of one’s input. This is particularly relevant to opportunities that are created by those without Lived Experience, including statutory organisations, academies, and charities. This involved organisations having the right structures in place, open-minded high-level staff involvement and clarity over what is, and isn’t, possible.

This openness and responsivity was particularly valued when contributors shared input/perspectives that they perceived to be marginal or departing from the expected norm.

### FUNDING

“The process of applying for a grant was a revolution - a user-friendly application, followed by an online chat where we could engage in an honest conversation about our needs and capacity. We were anxious – what would the terms of the agreement be. We got a £200 micro grant in return for a self-styled visual report with quotes” - **Interview participant**

Some contributors highlighted the role of flexible and accessible funding – the right amount at the right time. This includes access to small grants that are easy to access, flexible and supportive for small groups and emerging organisations that would be excluded by more traditional grant givers.

One contributor also valued the generosity of an individual donor and their willingness to purchase project items, rather than provide a larger grant that they would have struggled to manage when they were just starting out.

## OWNERSHIP

### LIVED EXPERIENCE CONTROLLED INITIATIVES

"I think when you've got a critical mass, particularly if the idea itself has come from service users and we've identified this as an issue, we've decided how this issue is going to be explored, methodology, methods ... we're conducting it ourselves or as co-researchers with others. It's just got a completely different tone and feel to it because it's generated by us. It's our project. We've not been co-opted to work on someone else's colonisation" - **Interview participant**

Some contributors emphasised the difference between being a lone voice on a project convened and populated by those speaking from a primarily professional or academic position, and being in a project that is fully led by people with Lived Experience.

For some, the negative experiences described above could be mitigated if Lived Experience ran through the whole project and organisation, at all levels. This can require organisations to dramatically rethink their structure and the position of Lived Experience within their work. It can require robust training opportunities for people with Lived Experience who wish to increase their skills in HR, management and other essential elements of leadership roles in larger organisations.

"People from our self-help group said 'that's not my experience'. We started speaking out. Started opposing what they were saying. We said - let's have our own campaign, an event. In our own small way we took control and we promoted our Lived Experience"  
- **Interview participant**, speaking about an initiative in response to an awareness campaign around depression

For some contributors, releasing themselves from pre-organised campaigns and organisational structures was a crucial part of engaging their creativity and refocusing their energies on the things that matter to them. This included a people who have taken a freelance route, as well as those who have gone on to set up their own initiative, campaign, group or organisation.

For some, this has provided the freedom to set the agenda, recruit people they connect with and ensure that they are centring the issues that feel most important. Yet, such routes are not stress free. Whilst minimising tokenism and exploitation, some contributors talked about the challenge of isolation and burn out. Some felt ill-prepared for this more autonomous path, wishing in retrospect that they had access to guidance and support along the way.

### MAKING LIVED EXPERIENCE LEADERSHIP A GENUINE CHOICE

"Part of Lived Experience Leadership is being able to have the conversation with those you are surrounded by ... does this still work for you? Are you happy to still be identified by it? If not, what are their pathways out? Some people might be happy with it. Others may be so sick of the peer identity, and say I'm going to go out and do nurse training ... a PhD ... A lot of peers face the question if I want to become a band 5, do I have to be a nurse?" - **Interview participant**

Some contributors, with reference to peer support in the NHS and voluntary sector, talked about a concern that becoming a Peer Support Worker is often portrayed as an optimal career choice for people with Lived Experience. Whilst progression is limited and contentious, there is a concern that some people engaged in LEL may be there because of choices they made years ago in a vacuum of alternative opportunities.

Can someone, for example, engaged in management with Lived Experience easily swap over to a non-mental health sector? Is there a route out, or is one forever defined by one's Lived Experience? One contributor, in particular, emphasised the need to send a message that there are multiple careers possible for those who want them rather than to funnel people into a pre-determined path.

## FINDING A SPACE TO BE ME IN ALL THIS

### FINDING ONE'S OWN LEADERSHIP STYLE

"The way I personally define a leader changed and this has changed my perception of where I sit within that. It was a pivotal moment. As soon as I could redefine [what a leader is], it made me stronger. It's not about fighting and being the loudest. That's not who I am. I lead in my own way" - **Interview participant**

Some contributors described a process of making sense of themselves as either a leader or someone who leads. This often involved questioning their prior assumptions of leadership and a growing appreciation of their own style. Some were inspired by forms of leadership that they felt sat more comfortably with their values - such as collective leadership and servant leadership. These forms provided a framework that enabled them to avoid positioning themselves as above others and, instead, balance hearing other voices without losing their own.

### SETTING LIMITS AND PROTECTING ONESELF

"I've learnt over the years - every time I tell my story you have to give me a date and time. I have to put things in place for before, during and after. I never talk through my story I talk over my story. I don't go into details" - **Interview participant**

Some contributors highlighted the ways in which they'd developed strategies to limit the negative impact of using their Lived Experience in a public way. This included knowing one's own limits; creating supportive structures before/after situations likely to be challenging; resisting the expectation to 'tell all'; being clear about one's rationale (and expectations) for sharing and learning that it's OK to say 'no' to questions and opportunities. Trusting one's instincts and walking away from toxic or harmful situations has, for some, been a key aspect of finding a healthy way of being in leadership roles.

Underneath all this was, I think, the recognition that we are not obligated to share anything of ourselves that does not feel OK. For some, especially those who identify as survivors of trauma - inside and/or outside of the mental health system - identifying one's own limits has been a journey in and of itself. Whilst some have developed this awareness on their own terms, others described the supportive role of connecting with others (online and/or in person).

"I had to make sure that my process with the image was done before I put it online, so it had already done its job for me. Although I do it for other people, its firstly for myself as I'm struggling with something. Sometimes an image makes me feel anxious. If that's the case I can't put it out there" - **Interview participant**

Sharing Lived Experience in public via social and mainstream media brings a particular set of risks. In comparison to more immediate forms of sharing, within a relationship or training room, this form entails a loss of control, a sense of permanence in whatever goes out there and



exposure to negative reactions and seeming indifference (where there is no response at all).

For some contributors, feeling that what is shared is complete, or at least not acutely 'live', is an essential part of the process. Others described a sense of disconnecting between themselves and the image others create based on what they see/read/hear. Such dissociation can provide protection from 'trolls' and mitigate concerns around the potential to be seduced by positive feedback and losing one's centre.

## BALANCING THE BIGGER PICTURE WITH SMALL CHANGES

"If you keep focusing on the wall being there you're not going to change the wall, but you miss the small things" - **Interview participant**

Some contributors emphasised the value of limiting their expectations of what can be accomplished in any meeting, project or lifetime. Seeing oneself as part of a larger whole, a larger movement, can give one the freedom to step back from the bigger picture and focus in on the tiny changes that can, in time, lead to larger shifts.

"I keep very local, very close to me ... there are so many bigger issues. I keep it very tight, very one step at a time, very close to home" - **Interview participant**

For some, engaging with the extent of things that need changing can provide the urgent energy that can be channelled into activism and changemaking. For others, it can become an overwhelming and insurmountable task that induces a sense of powerlessness. Finding sustainability within activism, leadership and/or changemaking can involve an awareness of what is needed to keep one's fire going, with the permission to take breaks or restrict one's focus as required.

## WE ARE MORE THAN THIS ONE ASPECT OF OUR EXPERIENCE

"My understanding of my faith - it's a huge part of how I relate to Lived Experience Leadership. It all meshes into one. There are more to these identities than one term. Folks will bring in all parts of their life" - **Interview participant**

"I had a career. I was a change manager. IT consultant. I was a youth worker"  
- **Interview participant**

Some contributors highlighted the importance of acknowledging and valuing the range of different experiences they bring to the table, rather than perceiving themselves (or being perceived) as always speaking from their Lived Experience. They emphasised the importance of acknowledging their whole person and how their wider experiences influence the way in which they relate to their Lived Experience.

For some, this breadth of experience increased their confidence and the range of skills they were able to offer in LEL roles. In some cases, the acknowledgement of a plurality of identities helped contributors manage having two roles that could often be in conflict with one another - for example: lived and professional experience, or lived and academic experience.

## FINDING SPACE TO QUESTION THINGS

### HOW CAN I USE MY LIVED EXPERIENCE MORE INTENTIONALLY?

"If you're going into an LE leadership role and say 'I'm going to bring my experience to this role', I'm not comfortable. It's 'how am I going to bring a diverse voices in?' Checking yourself - How much of this is catharsis?" - **Interview participant**

Some contributors found it important to question their rationale for using Lived Experience in a given setting, and how it can serve a greater purpose than self-expression. This can be seen as bringing a degree of intentionality and reflexivity to the work. For some, this is connected to the values base intrinsic in some interpretations of LEL.

"It's not about my experience now, it's about expanding it for others: opening up opportunities; to make sacrifices; to pave the way for others. It is about my experience in a way, but it's not just about my experience. I've changed how I've used it. It's learnt experience in the role ... learnt Lived Experience" - **Interview participant**

"It's not about my Lived Experience, but what it has taught me in terms of valuing people for what they bring. It gives me a certain value space around what I bring. It influences all I do" - **Interview participant**

Some contributors, reflecting on their move from frontline work to managerial positions, highlighted a shift in the way they draw upon their Lived Experience and how it has shaped the way in which they are in the role and what they prioritise.

### QUESTIONING THE STATUS QUO

"Re-imagining professionalism ... re-imagining how people can be organised to work together" - **Interview participant**

Rather than accept traditions handed down through the generations, some contributors spoke with energy about the potential to challenge norms and create the kinds of spaces and organisations they want to see. This included questioning some commonly held language and definitions, the set up of meetings and committees, and what an ideal leader might look like.

"You don't have to be white middle class to be in it" - **Interview participant**

Recognising some of the additional barriers people who are additionally marginalised face, this re-imagining feels part of changing the context rather than expecting individuals to conform.

## EMBRACING THE COMPLEXITY

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"Being able to be raw, being able to be vulnerable, being able to be wrong"

- **Interview participant**

Some contributors talked about how, when entering the field of Lived Experience Leadership, they felt a pressure (internal and/or external) to leave any vulnerable or messy aspects of their LE at the door. Whilst prevalent in non-LE-led organisations, this also occurred in the context of public speaking, activism and LE-led initiatives.

In response, some contributors described a process of consciously reconnecting with their own vulnerabilities and continually resisting the pressure to wear a mask of sortedness.

"It makes it complex, but we have to embrace the complexity. If we don't embrace the complexity we're doing exactly what the psychiatrists do and try to slot everyone into categories"- **Interview participant**

Another aspect of this complexity is the way in which we perceive one another. Whilst some find power in taking a strong and singular position, others talked about the importance of remaining open to the range of perspectives and positions held within and between people. From this angle, a commitment to nuance and context can help centre Lived Experience and mitigate against the potential of stepping on others in service of an ideology.

"At the NSUN AGM I was applauded when I told a speaker not to impose 'models' of distress upon us, but respect each individual's right to choose their own model. Self-help groups changed my life, but benzos were invaluable (using them as I decided). The fact that they published my comments in full in their report demonstrates that they recognise the validity of diverse lived experience however complex it may be; an example other organisations should follow and promote as a way forward" - **Interview participant**

The ability of groups and organisations to visibly hear and value multiple viewpoints can be crucial in creating spaces where people feel able to step forward and share experiences they have reason to believe will be dismissed or marginalised. Those facilitating such spaces have a key role in setting expectations around how counter narratives are responded to.

"Working in the NHS I feel the conflict of peer support, and I know a lot of the PSWs do as well. ... We are making compromises, working in this system. What are the acts of the resistance? Holding the nuance of that conversation ... not getting in to demonising, nurse-bashing or psychiatrist bashing" - **Interview participant**

Yet, as described above, there are very clear ethical dilemmas in and around this work. Some contributors, particularly those engaged with statutory mental health services or non-LE-led national charities, valued spaces where they can both acknowledge ethical dilemmas and explore 'acts of resistance' without demonising their professional colleagues.

This, to me, feels like another aspect of complexity: recognising the grey areas and supporting those who navigate them.

## PLAYING TO OUR STRENGTHS

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"People have issues but they won't go to citizens advice, so we brought citizens advice here. Let's bring the dentists here. I was already bringing [my project] through the food bank, I just wasn't telling anybody what I was doing" - **Interview participant**

In many of the interviews, I was struck by the creativity and resourcefulness contributors brought to their chosen path. For some, this involved enacting their vision through existing structures. This sometimes enabled people to gain the experience and credibility needed to gain funding, allies or simply to take the next step.

"If your face fits ... which mine did at the time. Knowing people. Sitting down to dinner with them. Using your position. Leveraging it to get funding that benefits others. I was quite a good diplomat" - **Interview participant**

Some contributors talked about using elements of their own privilege to benefit others. This includes, as in the example above, using one's class privilege to access and navigate exclusive spaces and highlight those messy realities that might otherwise remain hidden. Another contributor recognised the role of their upbringing and academic experiences in helping develop the confidence needed to create open spaces within their community.

"I've learnt you don't have to do that - I can have an informal conversation, I didn't know that at the time. Partly being flung into this leadership role, all I had was HR policies - quite black and white and punitive policies" - **Interview participant**

Some contributors, especially those entering in to managerial roles, described a process of understanding and unpicking organisational norms; working out which norms are essential and which ones can be shifted. This includes, as above, ways in which to have potentially challenging conversations with supervisees; balancing one's organisational role and the ethical commitments of being part of the Survivor Movement and engaged in peer support.

"If we're talking leadership, I think it has to be relational. You almost need to disregard the formal structures. It's knowing that pathways and flowcharts are, at best, really sketchy approximations ... real work happens with interpersonal relations. Having influence over people - the backchannel stuff ... that's how decisions get made" - **Interview participant**

Those contributors who had experience of organisational change or development often talked about learning how decisions are really made - as opposed to how we imagine they are made. One contributor highlighted the relational nature of high-level decisions in the Health and Social Care sectors. Whilst these spaces may feel (or be) off-limits for many, this contributor emphasised how building strong local relationships and working alongside our communities can help create context-specific solutions to the thorny issues statutory services struggle to address.

## CREATING CULTURES THAT CARE (AND CARING FOR OURSELVES)

### HAVING ANCHORS

“My faith. Music, My children. That’s what keeps me going .. When I’m having a bad day and they come to me and want a cuddle - that jars me back to say this is why. This is something for you to look at as an achievement. You broke the cycle” - **Interview participant**

“What helps? Mood stabilising meds - it all goes over my head. Having a chemical (shield) to keep me going” - **Interview participant**

“Coming home and looking after my cat, my plants. Just the little things” - **Interview participant**

Many contributors talked about the importance of having anchors that help ground, connect or soothe them. These anchors included people, pets, objects, activities, medication and values. Knowing these anchors and having access to them can provide the kind of nourishment and/or space needed in order to continually enter challenging spaces.

### NORMALISING SELF-CARE CULTURES

“When you create that culture, talk about self-care, it allows people to not feel strange or different” - **Interview participant**

“In order to be a person who can make space for others you need the tools and resources to support yourself and not put yourself aside” - **Interview participant**

Some contributors talked about the importance of resisting cultures of overwork and invulnerability (across all sectors). Rather than seeing it as something those with Lived Experience need because of their vulnerability, a number of contributors highlighted its universal importance. Some contributors reflected on the way in which senior managers could shape and resource this. For example, this may involve investing money and time in staff wellbeing. Those without LE can have an important role in creating a culture where self-care is valued.

### REFLECTIVE PRACTICE AND SUPPORTIVE SPACES

“Leadership training feeds into the bigger melting pot of me trying to negotiate the world. If you start unpicking stuff you can make yourself quite vulnerable. Safety is crucial - a safe environment and support mechanisms” - **Interview participant**

To mitigate the emotional toll of Lived Experience Leadership, some contributors described the value of reflective practice and/or peer supervision groups; spaces where they could explore some of the tensions and challenges of the work and think together about ways of navigating them. Talking about the reality of support needs without framing them as a weakness seems important. Exploring such painful and resonant areas can lead to deep learning - for the individual and the organisation.

“Like a plant that needs the right environment to flower and show how beautiful they are” - **Interview participant**

Building in space for reflection and mutual support can be part of creating a culture where people can flourish.



## ACKNOWLEDGING THE GOOD BITS

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"I was able to be entirely myself - I didn't need to hide anything" - **Survey respondent**

"I loved it - a good trip, meeting really interesting people" - **Interview participant**

"I enjoyed the research, and being paid for doing research!" - **Survey respondent**

"I have the best job in the world ... I had more experiences in the last 5 years than I'd had in my first 25. It's not glamorous, it's exhausting - but it has its perks" - **Interview participant**

Whilst all contributors emphasised the importance of thinking beyond the self and benefiting the wider community, some also talked about the personal benefits that can come with Lived Experience Leadership.

These benefits included: travel; meeting different people, recognition; further opportunities; the buzz that comes with making a difference; those times people are paid well for their work. Being able to talk about these benefits without feeling embarrassed or ashamed could be an important part of balancing some of the moral expectations of Lived Experience Leadership.

"I like bringing together clinicians and people with lived experience and exploring the benefits of collaboration and co-production. I love it when clinicians really understand how working with service users and carers can really benefit them. And I love it when I can feel myself become passionate about something and then I see that passion start to infect the people I'm talking to" - **Survey respondent**

"Being able to lead in a way that is aligned to my values, using the values of peer support within training and supervision. Being able to be open about my lived experience without being defined by it. Working alongside so many incredible peer workers and hearing about/ learning from the work they do" - **Survey respondent**

# RECOMMENDATIONS

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## Includes:

Nurturing Lived Experience Leadership

- Underpinning approach
- A buffet of different options

Creating supportive contexts for Lived Experience Leadership

## WHAT MORE IS NEEDED? SUPPORTING LIVED EXPERIENCE LEADERSHIP

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This section explores some of the things contributors said that might help the development of Lived Experience Leadership and the supportive role mental health charities could play in this.

### NURTURING LIVED EXPERIENCE LEADERSHIP

#### UNDERPINNING APPROACH

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Contributors raised the following as values that should run through any initiative that hopes to support and nurture Lived Experience Leadership:

#### INDEPENDENT AND LED BY LIVED EXPERIENCE

The majority of contributors expressed some scepticism around the potential of organisations led by people without Lived Experience to lead on initiatives aimed at supporting Lived Experience Leadership. For these contributors, it would be important for any opportunities to transcend organisational agendas and be visibly centred around the needs and wishes of people with Lived Experience.

#### LEARNING FROM THE PAST, LOOKING TO THE FUTURE

Some contributors, especially those involved in this field for decades, raised the importance of hanging on to some of the learning and progress made since the 80s. Whilst the language and context we work in has developed in this time, similar challenges seem to crop up. Finding a way of acknowledging and learning from the past when creating new opportunities can help avoid us reinventing the wheel and, where things did not go so well, making similar mistakes. Lived Experience Leadership has roots ... the key may be connecting with these roots without becoming stuck in them.

#### ACKNOWLEDGING INEQUALITIES

It is clear that the inequalities within our society are also found within the fields of mental health and Lived Experience Leadership. It's important to acknowledge the sexism, racism, classism, ableism, transphobia, homophobia, colourism and other forms of prejudice and discrimination we are surrounded by and, potentially, enact.

It's important to recognise the additional barriers faced by those in, or recently released from, long term mental health units, prisons, immigration removal centres and other custodial settings. It's important to consider the impact of poverty and social exclusion on people's willingness and ability to access, or even find out about, opportunities.

Overall, a number of contributors expressed a desire for us to stretch further, looking wider than those who already feel confident enough to enter the room. They call us to ask: Who isn't in the room? How could we connect with them? What can we do to ensure the next generation of leaders include more people from additionally marginalised communities?

**ACKNOWLEDGING HARM**

The harm experience by people engaged in LEL cannot be ignored or minimised - whether it occurs within organisations, in encounters with the general public or between those of us with Lived Experience. Attempts to side-step it only amplify the pain and exclusion felt. Creating spaces where this harm and hurt can be openly discussed, heard and validated may be a central part of creating a healthier and more sustaining context for LEL.

**BEING VISIBLY DIVERSE**

"It has to be representative - non-binary, trans, the weird and wonderful flavours. Fierce in the way of doing it" - **Interview participant**

Many contributors highlighted the importance of ensuring that any training, resources and networking opportunities are visibly and genuinely diverse. By centring diversity in all aspects of the offer, it may help people feel like these are spaces and initiatives that they can be part of.

People from different backgrounds and minorities need to be actively and visibly engaged in shaping, creating and delivering content. This diversity can help lift the content of any offer above the standard Lived Experience Leadership package, including creative and vibrant content that is relevant to people from different backgrounds (class, gender, racialised minorities, survivors etc.).

**A BUFFET OF OPTIONS FOR DIFFERENT PEOPLE/CONTEXTS**

This diversity also includes explicit valuing of different forms and styles of Lived Experience Leadership occurring in different contexts. It involves creating a space where both community activists and NHS managers can feel welcomed, recognising the value of all.

This does not mean that we need to avoid brave conversations and smooth over significant areas of difference. The key may be to generate structures and a shared ethos that is robust and supportive enough to encourage mutual respect and dialogue.

Rather than assuming every offer will be useful to everyone, some contributors suggested leaning into the idea of a world buffet - where people can pick and choose the dishes that resonate with them.

**SPACE TO RE-EVALUATE WHAT LEL MEANS ON OUR OWN TERMS**

Some contributors expressed a desire to create spaces where we can go deeper into what Lived Experience Leadership might look like within a survivor context. This might involve exploring other forms of leadership (including the field of Critical Leadership Studies) to help widen our thinking and see beyond the leadership forms prevalent in hierarchical and non LE-led organisations.

With the growing pace of LEL-related initiatives and roles, there is some urgency around creating spaces for these conversations as the field is at risk of being defined for us. However, rather than arriving at a strict definition for all, the hope would be to keep any exploration in line with the plurality and diversity inherent in our movement(s).

## **LE-SPECIFIC LEADERSHIP TRAINING, MENTORING, NETWORKING AND SUPPORT**

Most contributors raised the need for LE-specific leadership training, mentoring, networking and support opportunities. Given the diversity of LEL, this is an opportunity to create connections across organisations and contexts within an atmosphere of mutual respect and learning.

### **Supportive networks/reflective practice groups**

A space for solidarity and mutual growth. These should be trauma-informed and skilfully held, preferably by people with Lived Experience. Some contributors valued online spaces to reduce geographical inequality, yet - equally - there was a concern expressed around digital exclusion. A mix of formats (in person and online) could be helpful. There is value in both groups that are organised around similar roles/contexts (e.g. CEOs) and ones that cross boundaries.

### **Leadership training with a radical edge**

A buffet of options created by people from different backgrounds that cover essentials such as finance, fundraising and demystifying commissioning alongside content that speaks specifically to common dilemmas and challenges.

This might include, for example:

- Recognising and responding to gaslighting
- Dealing with trolls
- Saying 'no' when everyone wants you to say 'yes'
- Avoiding (re) traumatisation
- Values-based supervision
- Acts of resistance within mainstream organisations
- Recognising and responding to microaggressions

### **Mentoring**

Mentoring opportunities might include:

- Peer mentoring
- Mentoring with someone who has trodden a similar path, but is more experienced
- Mentoring beyond Lived Experience (e.g. by lawyers, CEOs, diplomats who have a solid values base and can demystify particular processes and facilitate introductions).

## **ACCESS TO MAINSTREAM LEADERSHIP TRAINING**

Whilst LE-specific leadership training is important, some contributors highlighted the value they found in attending mainstream leadership courses as part of NHS or NIHR roles. However, access to these courses is limited and some contributors described having to fight for places.

Mental health charities wishing to support LEL could use their influence to encourage organisations to increase access to this form of leadership training. To mitigate against potential othering and exclusion, they could also fund/develop supportive networks for trainees with LE.

## INVESTING IN LEL AND INCREASING ACCESS TO RESOURCES

Some contributors highlighted the value of accessible resources as a way of sharing knowledge and power across different communities, creating situations where people can develop their own solutions to local issues rather than requiring people to adopt a particular framework designed in a different context. Resources can include funding, connections, administrative support, technical support, guidance and access to opportunities.

The resources identified by contributors included:

- Starting with a blank slate, give the control and resources to someone from within a marginalised community and support them to develop solutions from the ground up. This involves accessible grant making and access to training/support (above).
- Supporting LE-led initiatives to develop guides and toolkits to share knowledge and provide inspiration to support others to create similar initiatives in their local area, taking in to account local need.
- Improving access to previously published information created by people with Lived Experience (as a resource to draw on, rather than a definitive guide of how things should be)
- An (online) space where people can ask anonymous questions around navigating Lived Experience Leadership and others can respond with their ideas/perspectives (encouraging plurality and respect rather than the 'right' answer). Community sourcing.

## HAVING SOMEONE IN YOUR CORNER - AN INDEPENDENT BODY OR UNION

Tokenism, exploitation, silencing and isolation are prominent features of Lived Experience Leadership in all sectors and contexts. Some contributors expressed a wish for an external and independent body that they could go to for advice and, when necessary, representation.

Whilst some contributors were already members of unions such as Unison, there was a concern that they are ill-equipped to understand and address the particular issues faced by people engaged in Lived Experience Leadership. Whilst this may be remedied by providing training and support to unions, this leaves the majority of contributors unrepresented.

## CREATING SUPPORTIVE CONTEXTS FOR LIVED EXPERIENCE LEADERSHIP

Many contributors highlighted the important role mental health charities can play in helping to create the context for sustainable Lived Experience Leadership in the mental health and social care sectors.

## LEADING BY EXAMPLE

Some contributors emphasised the importance of large mental health charities (like Mind, Together, and Rethink Mental Illness) to be examples of best practice and promote Lived Experience Leadership throughout the entire organisation. In doing so, they have the potential to build up valuable practical expertise that can be shared with other organisations in the form of supportive structures, expectations and standards.

Bluntly put, if organisations already expressing a commitment to Lived Experience Leadership continue to create silos rather than create opportunities that weave through the organisation at all levels, they are ill-equipped to advocate for change in other, less progressive, spaces.



## **HIGHLIGHTING THE VALUE OF LIVED EXPERIENCE LEADERSHIP**

Contributors discussed the importance of being clear about the added value Lived Experience can bring to leadership roles in practice, strategy, research, service design, management and policy. This includes engaging with CEOs, funders and commissioners – people with the power to channel resources and create structures that foster, rather than constrain, Lived Experience Leadership. This may include stretching the way organisations conceive of issues like risk and professionalism, supporting creative, non-linear thinkers and resisting the urge to de-claw and sanitise LEL. It may also involve supporting organisations to think about how they create person specifications; finding ways of valuing Lived Experience and non-standard career paths.

## **THINKING SYSTEMICALLY - SUPPORTING ORGANISATIONS TO EMBED LIVED EXPERIENCE LEADERSHIP**

Organisations require support and guidance to create opportunities, structures and career progression routes whilst avoiding the many pitfalls described in this report. Rather than take the relatively easy route of recruiting lone Lived Experience Leaders or creating small relatively powerless teams, many contributors called for deeper structural changes that create a healthy and generative working environment for all.

Outside of employee roles, some contributors called for organisations to create commissioning processes that are accessible to freelancers, consultants with Lived Experience and LE-led organisations. Overall, there is a need for increased options and opportunities that encourage and support progression.

## **MAKING A SUBSTANTIVE COMMITMENT AND INVESTING RESOURCES**

Many contributors called on organisations and funders to back Lived Experience Leadership with more than words and sentiment. This includes creating funding streams that recognise the value of LEL and, as a result, are accessible to those with Lived Experience at different stages of their development and in different contexts.

With organisations wishing to champion and/or benefit from Lived Experience Leadership, it is important to ensure roles are paid appropriately and projects are sufficiently resourced. Beyond payment, organisations can show they value LEL by ensuring that they implement the necessary supportive structures that encourage development and support wellbeing.

In short, many contributors highlighted the importance of organisations removing the unnecessary barriers they face that can take up so much physical and emotional energy. Mental health charities could play an important role in both modelling and setting expectations around this.

## **HAVING BRAVE INTRA-ORGANISATIONAL CONVERSATIONS**

Some contributors emphasised the need for us to have difficult (aka brave) conversations within organisations in order to enact the level of structural change necessary to move beyond tokenism and support Lived Experience Leadership to flourish.

This may include people and organisations acknowledging tokenistic and harmful practices (however unintentional) and committing to change. One contributor likened this to a process of truth and reconciliation. Such processes may help restore some of the trust needed to work collaboratively to benefit all.

# APPENDICES

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## Includes:

References and additional reading

Examples of existing leadership support networks

Examples of existing leadership training

## REFERENCES

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## EXAMPLES OF EXISTING LEL SUPPORT NETWORKS

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Most networks of support seen to be informal collectives, established by people using their connections to create the support they need. They happen within friendship groups, via work and through events/conferences. Some are created or accessed at work. However, the adhoc nature of this means many remain isolated and unsupported. The following are some opportunities that are openly accessible.

**Lived Experience Leaders Movement** - <https://lexmovement.org>

LEx Movement is a collective impact network connecting, supporting and strengthening the capacity of Lived Experience Leaders to create systems-level change.

**Pioneer LXP** - <https://www.pioneerlxp.co.uk>

A grassroots collective of Lived Experience Practitioners (LXPs). In addition to hosting groups for LXPs they also brought people together in a Lived Experience Leaders conference in 2019.

**Survivor Research Network** - <https://survivorresearcher.net>

A network that offers peer support for survivor researchers

**Peer Hub CIC** - <https://www.peerhub.co.uk/peer-support-groups>

A survivor-led organisation that offers peer support spaces for Lived Experience Workers.

**Sciana: The Health Leaders Network** <https://www.health.org.uk/funding-and-partnerships/fellowships/sciana-the-health-leaders-network>

'An initiative that brings together outstanding leaders in health and health care policy and innovation across Europe'.

## EXAMPLES OF EXISTING LEADERSHIP TRAINING

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Only the first two opportunities are specifically aimed at people with Lived Experience. The remaining opportunities are theoretically accessible but would likely be out of reach without an organisation advocating for, and potentially funding, inclusion.

### LEL-SPECIFIC TRAINING

**Peer Leadership Academy:** <https://www.futurelearn.com/info/courses/peer-leadership-foundation-step-1/0/steps/145402>

A free stepped programme aimed at people who might benefit from personalised care, including disabled people and people with a long-term health condition. Completion of the course provides access to the NHS England Strategic Coproduction Group.

**InHealth Associates Patient Leadership Training:** <https://www.inhealthassociates.co.uk>

Online training from David Gilbert for Patient and Carer Leaders, health professionals, managers and non-clinical staff from across the sector

### VOLUNTARY SECTOR-SPECIFIC TRAINING

**Open University: Free leadership courses for the voluntary sector** <https://www.open.edu/openlearn/education-development/free-leadership-courses-the-voluntary-sector>.

Including developing leadership practice in voluntary organisations and collaborative leadership

**Enterprising Leadership for the Third Sector** <https://your.socialenterprise.academy/course/view.php?id=175>

Free for volunteers in community groups, linked to ILM accredited Award

## HEALTH & SOCIAL CARE SECTOR-SPECIFIC TRAINING

**Imperial College Business School: Executive Health Innovation Management Programme:**

<https://www.imperial.ac.uk/business-school/executive-education/short-courses/executive-health-innovation-management-programme/>

Aimed at 'health leaders who can affect innovation in their workplaces' and policymakers.

**NHS Leadership Academy:** <https://www.leadershipacademy.nhs.uk/programmes/>

Training aimed at different levels, from aspiring managers to senior leaders

**NIHR Future-Focused Leadership and Mentoring Programmes** <https://www.nihr.ac.uk/explore-nihr/academy-programmes/nihr-leaders-support-and-development-programme>

A two-stream programme that includes early to mid-career researchers taking up their first significant leadership roles and current leaders within NIHR who are developing into senior leadership roles.

**Skills for Care - Leadership Programmes:** <https://www.skillsforcare.org.uk/Leadership-management/developing-leaders-and-managers/Developing-leaders-and-managers.aspx>

Aimed at different levels, from aspiring to senior managers in the social care sector.

**Royal College of Nursing Leadership** - <https://www.rcn.org.uk/professional-development/professional-services/leadership-programmes>

Training aimed at nurses and, on occasion, other health professionals at different stages of their leadership development. Includes a system leadership programme.

**Skills for Health: Leading Integrated Systems of Care** <https://skillsforhealth.org.uk/integrated-solutions/lmod/open-programmes/leading-integrated-systems-of-care/>

Experiential training for people in senior roles who want to develop their skills and have a greater impact on integrated care systems.

## CROSS-SECTOR TRAINING

**LSE Leadership and Change** <https://onlinecertificatecourses.lse.ac.uk/presentations/lp/lse-leadership-and-change-online-certificate-course/>

8 week online course exploring leadership, collaboration and ethics.

**Leaders Plus Fellowship:** <https://www.leadersplus.org.uk/fellowship/>

A fellowship programme for parents who have a young child and are committed to progressing their career. This programme includes people from a range of sectors. Hardship fund places are available for those in challenging financial circumstances.