EMERGING INSIGHTS

On Our Own Terms

Systems change through Lived Experience Leadership

Unearthing practices and possibilities of lived experience-led change

morgan & co | RMIT UNIVERSITY

Project team

Morgan Cataldo
Project Convenor
Visiting Fellow, RMIT School of Global, Urban and Social Studies

Professor Robyn Martin
Associate Dean, Social Work and Human Services, RMIT School of Global, Urban and Social Studies

Associate Lecturer Suzi Hayes
Researcher, Social Work and Human Services, RMIT School of Global, Urban and Social Studies

Perrie Ballantyne
Visiting Fellow, RMIT School of Global, Urban and Social Studies

Kelsey Dole
Visiting Fellow, RMIT School of Global, Urban and Social Studies

Design team

Yvette English
Graphic design

Jess Holdaway
Illustration

Lisette Charlotte
Illustration (original cover)

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This shorter form can also be used in discussion, presentations or internal documents where repeating the full title is unnecessary.

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Acknowledging Country and First Nations peoples

We acknowledge Aboriginal and Torres Strait Islander peoples as the Sovereign Custodians of the lands, waters and skies where we live and work. We honour their enduring relationship with Country and recognise the lived, embodied and intergenerational wisdom carried through story, relationship and practice for over 60,000 years.

We recognise the depth of this connection and, in doing so, commit to ongoing listening, unlearning and relearning needed to dismantle systems of domination and supremacy – especially those that govern knowledge, voice and ways of knowing.

We honour the long arc of advocacy, truth-telling and cultural strength within First Nations communities – enduring practices that have protected and sustained wellbeing and knowledge systems across generations, often nurtured outside or in resistance to colonial structures and their lasting logics.

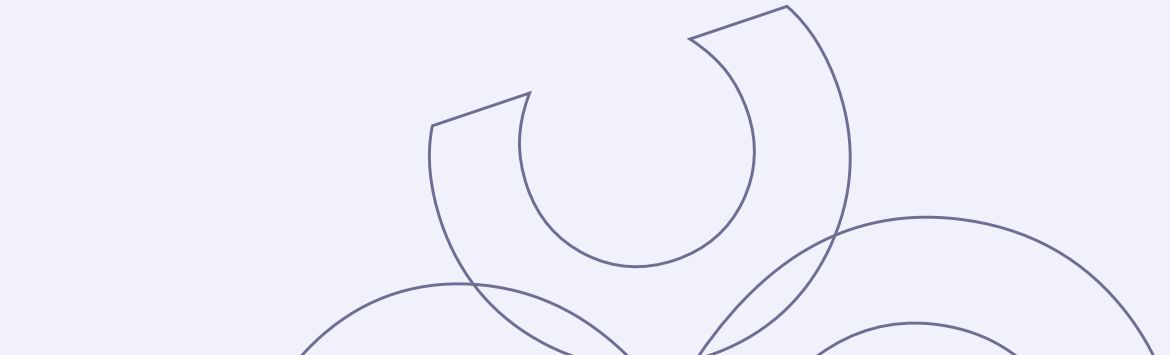
This leadership is long-standing and deeply rooted. It names what must change and continues to chart paths of resistance, renewal and remembrance, showing again and again what is possible.

Recognising the broader context and the leaders

We extend our sincere gratitude to the leaders whose reflections and insights have shaped – and will continue to shape – this work. We hope their words reverberate, echoing through systems, catalysing shifts and taking root in ways that unfold steadily over time.

We dedicate this work to all who choose an orientation grounded in lived and living experience, especially those who are no longer with us. We honour the legacy of those who came before and acknowledge the many who laid the groundwork for this movement. Their courage, tenacity and vision continue to guide and ground what is possible.

We also recognise the impact of systemic exclusion, discrimination, violence and oppression on those with lived and living experience. The wisdom these people carry is hard-earned – and the toll this work takes on them, and on those they love, must not be overlooked. And yet, they continue to carve pathways and possibilities, stretch the collective imagination and invite us into alternate realities, deeper understandings and ways of seeing otherwise.



An invitation to readers

This insights report is intended for people in dedicated Lived Experience roles, and for those who lead from the standpoint of lived and community-oriented experience. It is also for allies identified and invited by Lived Experience leaders to walk alongside and contribute to social systems change.

We recognise that Lived Experience leaders are doing extraordinarily difficult work – often in unforgiving, under-resourced or unwelcoming environments. And yet, they continue to flourish and to make a significant difference within these same spaces. Our engagement with these leaders illuminated both the persistent challenges and the possibilities that emerge through this work.

The quotes and reflections in this report often speak to the weight these leaders carry. We understand this not as a deficit, but as a raw and honest account of the terrains they navigate, shaped by the systemic conditions within which their leadership endures.

When reviewing this report, several leaders observed that while the themes resonated, the portrait of Lived Experience Leadership could appear overly weighted towards struggle. We encourage readers to hold this tension: the terrain is difficult, often harsh. It is also a place of growth, deep connection and hard-earned skill.

This insights report is not a comprehensive critique or an overhaul. It is a record of what we have learnt so far: insights, challenges and possibilities offered by the leaders. Where critique appears, it is in service of learning and change. Above all, this is an invitation to keep building, questioning and imagining together.

A note to Lived Experience leaders

We recognise the many people in dedicated Lived Experience and community roles who lead in their own right, whether or not they connect with or agree with the language or concepts of lived experience or leadership. In this report, we use the term “leaders” to honour the role people play in shaping change, while acknowledging that many are uncomfortable with or actively resist this label – a point we return to in the *Key Terms* and *Key Insights* sections.

For this project, we have chosen to use the language of *Lived Experience*, while recognising that it cannot capture the full picture of the activities or identities encompassed within this form of leadership. Our use of the term is influenced by the work of Dr Louise Byrne and colleagues,[1] whose distinction has been important in shaping our approach.

They write:

"The term 'Lived Experience' when referring to roles or the workforce, is capitalised to distinguish the professional from the personal, i.e. working in a Lived Experience role as opposed to 'having a lived experience.'"

Grounded in this distinction, we offer our respect and recognition to the Lived Experience leaders who contributed to this project, and to those who have informed us over many years, for:

- the value of their perspectives, knowledge and efforts
- the distinctiveness of their leadership contributions
- their connection to and influence on social and systemic change
- the difficulty, tensions, trade-offs and harms that come with this work.

We hope this work affirms the difference they are already making and offers recognition and support for the complexity of what they hold. We also hope the insights and knowledge generated through this project lay important groundwork for deeper support and stronger allyship, especially from the institutions that rely on their expertise and collaboration.

A note to allies

Identified and invited allies also enact a form of leadership by creating enabling conditions, stepping back when needed, advocating within dominant systems, committing to their own learning and becoming proactive educators and connectors.

We hope allies, both within and beyond institutions, come away with a deeper understanding of Lived Experience Leadership and of what it takes to lead from positions rooted in lived and community experience.

We also hope the insights shared here prompt more discerning and nuanced action and inspire reflection on how to build safer practices and foster more compassionate and liberatory conditions for change.

1 National Mental Health Commission, *National Lived Experience (Peer) Workforce Development Guidelines* (Australia: National Mental Health Commission. 2023)

Key terms

Throughout this project, we've used specific terms to communicate complex ideas, knowing that no single definition can fully capture their depth, diversity or dynamism.

What follows are definitions we hold lightly – grounded in analysis and research, shaped through dialogue, refined through practice. They are not fixed truths, but starting points for shared understanding, critical reflection and ongoing evolution.

We recognise the limitations of these terms – particularly in the context of the current fascination with all things "Lived Experience" – and offer them here as both anchors and invitations to challenge and change.

Before providing our working definitions of *lived experience, Lived Experience and lived expertise*, we note that distinctions between these concepts are not consistent across issues, domains and systems. Too often, these distinctions position lived experience as valuable only when it complies with institutional expectations. We affirm the value of all forms of lived experience, regardless of their presentation or challenge to institutional legibility.

Lived experience

Challenges with distress and adversity that significantly impact a person's life to the point that they redefine their idea of themselves, their vision for the future and their place in the world.[2]

Lived Experience

When referring to a distinct discipline, body of knowledge and practice wisdom, we capitalise *Lived Experience* to reflect its legitimacy and growing recognition as a field. Our understanding is informed by the work of Dr Louise Byrne and colleagues.[3]

Lived expertise

The knowledge, insight, understanding and wisdom that emerges through lived experience – or what has been intentionally learned from that experience and how it is applied to benefit others.[4]

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2 Lived Experience Leadership, *Understanding and Defining the Roles* (Australia: Lived Experience Leadership. 2026)

3 National Mental Health Commission, *National Lived Experience (Peer) Workforce Development Guidelines*

4 Lived Experience Leadership, *Understanding and Defining the Roles*

Lateral violence

We acknowledge an important nuance raised by one of the First Nations leaders who contributed to this project.

Lateral violence is often described as interpersonal conflict within communities - but First Nations perspectives highlight its roots in colonial violence and systemic oppression.

It is tied not only to interpersonal harm, but to the long and ongoing legacy of colonisation – a system designed to divide and dismantle First Nations communities. Through colonisation and the systems it entrenched, Aboriginal and Torres Strait Islander peoples were deliberately dispossessed, displaced and pitted against one another, forced to compete for limited resources within structures never built to serve them.

This history of structural deprivation and cultural disruption has, over generations, created conditions where anger, grief and the fight for survival are too often turned inward – or redirected towards fellow community members – rather than at the systems that caused the harm. What is frequently labelled "lateral violence" in First Nations communities must be understood within this historical and political context, not as a reflection of cultural deficit, but as a legacy of colonial violence, erasure and forced fragmentation.

The fight for resources has never been only material; it has also been about the right to belong, to lead and to be heard. Acknowledging this lineage is essential to any respectful and accurate use of the term.

Lived Experience Leadership

Building on the work of Loughead and colleagues[5], we have developed our own working definition as part of this project:

Lived Experience Leadership is a transformative social movement that operates across both formal and informal spaces to restore justice and drive systemic change. It builds relationships, coalitions and movements within and beyond organisations, recognising the political nature of the personal and confronting epistemic and structural injustices – including colonisation.

Leaders draw on their lived expertise to innovate, influence and create meaningful impact with and for the communities they represent. This leadership challenges dominant power structures, reimagines how systems function and repositions lived knowledge as central – rather than secondary – to social change.

5 Loughhead et al, *A model of lived experience leadership for transformative systems change: Activating Lived Experience Leadership (ALEL) project* (Online: Leadership in Health Services. 2023)

Introduction

Across Australia, there is growing momentum to involve people with lived expertise in social sector change. This is a welcome development and a sign that government and social sector leaders increasingly recognise the value of Lived Experience for service improvement, innovation and systemic change aimed at better outcomes and greater equity and justice.

At the same time, there are persistent tensions in how this work is understood, valued and resourced. Engaging with the same systems and institutions that have failed or harmed us can be precarious for those who take on Lived Experience roles. For some years, we have observed health and social sector organisations grappling with how to engage with communities and people with lived expertise in service, policy and practice development, delivery and evaluation.

In practice, institutional engagement presents a mixed picture: at times powerful and transformative, often limited in its ability to influence genuine change, and too often showing insufficient care for the people involved. Institutions frequently fail to grasp the depth of what is at stake for the communities and people with lived experience who step into this work.

On Our Own Terms grew from a desire to pause and reflect on what is really happening in change projects that involve communities and people with lived experience and expertise. How does the work make people feel? What sense are 'lived experts' making of the roles they are invited into? And how do people approach the work differently?

The unintended consequences of this work – particularly the harm experienced in Lived Experience roles – have spurred us to ask questions that trace a progression from practical readiness, to care and support, to the cultural transformation required for genuine change:

- what learning and preparation do organisations and institutions need in order to be 'ready enough' for this kind of work?
- what supports should be in place for people who step into these roles and participate in these approaches?
- how deeply must an organisation or institution shift its culture and ways of working to engage with the Lived Experience workforce responsively and with integrity?

These questions, and the shifts they signal in service and policy design, are critical. What happens *within* existing institutions and systems striving to work differently with Lived Experience is only part of the picture.

The people we knew who took on Lived Experience roles in institutional contexts stepped in and out of different change initiatives and arenas. They carried a drive and commitment to create change across all kinds of conversations and contexts. Sometimes they worked with or within institutions. Sometimes their work took on the qualities of activism and external agitation. Some leaders took a clear and principled decision not to engage with existing systems or change processes led by institutions, instead building their own movements towards different futures – on their own terms.

There has always been a strong correlation between a lived experience of systemic oppression and marginalisation and the kind of leadership that emerges from these contexts to drive change. Leadership that draws from personal experience is woven through all social change movements. We don't always bring this context to mind when we think about Lived Experience, but we should.

On Our Own Terms grew from a recognition of the diverse forms of leadership that people with Lived Experience step into, embody and demonstrate.

We wanted to hear directly from the leaders who take on this work: what inspires and motivates them, the choices they make about where and how to influence change, the tensions they navigate, and the practices that sustain their energy and hope through the difficult work of making change.

Our aim in this project has been to understand more deeply the distinctive qualities and potential of leadership grounded in Lived Experience and expertise – and to bring that nuance and richness into sharper view. We wanted to gather insights that might help us all to work in better, more equitable ways with the people who hold this critical form of knowledge, capability and drive for change.

As this work developed, we came to see something that has always been abundantly present but is sometimes difficult to perceive through a narrow focus on 'lived experience'. Many of the leaders we engaged are interested in ambitious and large-scale systemic change, while others argued for the benefit of combining the incremental and the big picture. The leaders communicated a strong desire for a positive reinvention of the way we support and uplift one another. They bring radical visions for change – some well-formed, some still seeds and shoots to be nurtured and developed, all emergent and growing through the work they are doing.

For many leaders who lead from a place of Lived Experience, systems change is both the compass and the commitment, shaping both *what* they do and *why* they do it.

Our work to date has been limited in size and scope, drawing insights and proposals from ten leaders. However, they are a diverse group situated in a wide variety of communities and represent a snapshot of Lived Experience Leadership in Australia.

While these insights reflect a small-scale inquiry, they surface significant depth. Further work is needed to test these insights with more leaders, to build a richer and more nuanced picture that can be translated into a larger pool of practice-ready principles for allies, institutions, organisations, educators, researchers and policy makers to implement.

About the project

On Our Own Terms began as a conversation between social sector practitioners, researchers and innovators drawn together by a shared interest in how lived expertise intersects with social sector change.

Although our professional backgrounds and experiences are different, we share a conviction that Lived Experience is a critical force for understanding the problems with current systems of health and wellbeing support, and for imagining the potential of social and systems change. We also shared a deep curiosity about the Lived Experience Leadership work we were contributing to – and shaped by.

We developed the idea of a project that could hold space for conversations with a diverse group of health and social sector leaders who draw on lived expertise or community perspectives in their work to challenge and change systems.

We wanted to explore:

- the distinctive qualities and value of leadership that draws from Lived Experience and/or community knowledge
- the choices leaders make about where and how to act to influence change
- the different things required of individuals to be successful as leaders and influencers of change across different contexts
- the things that help and hinder people in their stewarding of change.

In doing so, we hoped to learn about the fullness and diversity of leadership styles and approaches, and to bring more nuance and richness to our understanding, paving the way for new leadership practices and change possibilities to be articulated and explored.

We took our plan into conversation with peers at the *Paul Ramsay Foundation*, who agreed to support our work in its first phase. With funding in place, we developed a shortlist of ten leaders to invite into 90-minute reflective conversations. Following these conversations, we worked together to draw out themes and new insights about Lived Experience Leadership of change, which we present here.

We have always imagined this work as the start of a conversation that would involve a much wider group. We see this as an initial offering – a conversation starter and an invitation to broaden and deepen the work. We look forward to bringing together more people to explore the insights presented in this report, with a view to growing new angles and possibilities.

About the leaders

The ten leaders involved in this first phase of the project bring a wide range of lived, cultural and community knowledge to their work. Many work across social, policy and advocacy settings, and their leadership is expressed in different forms, including:

- actively challenging and changing systems that contribute to poor wellbeing and health outcomes
- holding influence across communities, sectors and institutions
- navigating a mix of roles – formal and informal, paid and unpaid, visible and behind the scenes.

Their work is often culturally grounded, relational and future-facing – shaped by histories, lineages and commitments that extend beyond organisational roles or titles.

They come from diverse backgrounds, spanning experiences such as systemic racism and gender-based violence; domestic, family and sexual violence; child sexual abuse; LGBTIQA+ discrimination and stigma; mental ill-health and distress; housing insecurity and homelessness; and incarceration. They bring system-changing ambition and vision to their work. Lived Experience is central to their drive, practice and influence, alongside other capabilities and qualities.

Our conversations with these leaders explored diverse leadership experiences and change contexts in Australia. Each was well placed to reflect on this evolving 'movement' and developing form of leadership.

The leaders involved in this phase:

Cass Corrone • Debbie Kilroy • Ellie Hodges

Emilie Cuinn • Fetle Wondimu • Flick Grey • Joe Ball

Leilani Darwin • Lyn Mahoub • Tess Moodie

Analysis and insight generation

In the first phase of our work, we developed project principles, conducted a non-exhaustive scan of academic and grey literature, built an online stakeholder community and created a model illustrating the spheres of action and influence within which Lived Experience leaders operate **(see Figure 1)**. The spheres model captured what we already understood about the tensions faced by people working across institutional, systemic and community-led contexts.

In our early conversations and reflections, it became clear that many leaders make deliberate choices about where and how they seek to influence change – positioning themselves *outside, adjacent to* and *within* dominant institutions. These choices often reflect a belief that meaningful change must also be nurtured in spaces beyond the systems that uphold current conditions.

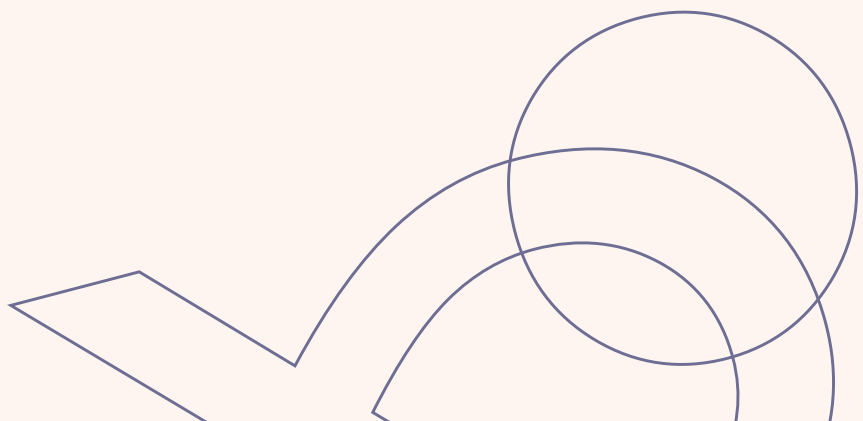
The spheres model became a tool in our discussions. We invited people to share stories of their leadership journeys in relation to the spheres it describes – helping surface the strategies, tensions and values that shape Lived Experience Leadership across different contexts.

Important caveats about the spheres model

The diagram was never intended to represent a fixed dichotomy of roles or activities. We recognise that most leaders move fluidly between domains, and that impactful leadership occurs both within and beyond institutional contexts.

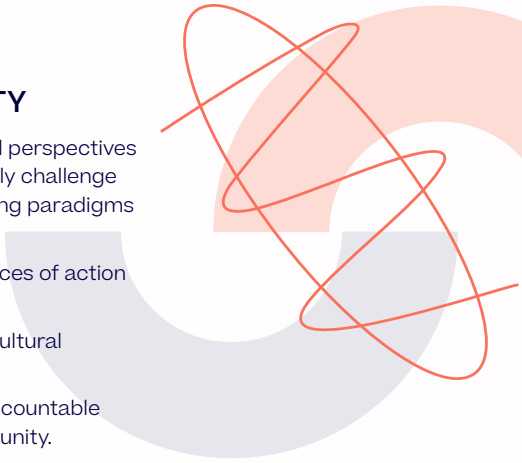
Our interest lay in understanding what different domains ask of leaders – and what is required to influence change across them. We began with the assumption that leading from within institutions can be just as personally demanding as leading from outside, albeit for different reasons.

We were also curious about the unique possibilities that arise when a leader brings together insider knowledge of institutions and systems with deep community wisdom. This combination, we suspected, may offer distinct opportunities for learning, innovation and influence.



Spheres of action and influence

Where and how are leaders working and to whom are they accountable?



LEADERSHIP IN COMMUNITY

- Holding ideas and perspectives that fundamentally challenge and disrupt existing paradigms and systems.
- Creating new spaces of action and influence.
- Building countercultural movements.
- Predominantly accountable to self and community.

LEADERSHIP WITHIN INSTITUTIONS

- Holding Ideas and perspectives that fundamentally challenge and disrupt existing paradigms and systems.
- Leading change and seeking influence from within existing systems and institutions.
- Joining spaces, participating in activities and taking on roles run by and operating within institutions.
- Predominantly accountable to institutions.

Key caveats and assumptions to be tested further:

- This is not a leadership dichotomy. Most leaders work and move between domains.
- Leading within and beyond institutions can be equally challenging personally, though often for different reasons.
- All leadership can be powerful and effective at changing and transforming systems.
- Innovation often happens at the intersection of tension and dialogue, giving rise to new ventures and models.

Figure 1: Spheres of action and influence

This first phase of our work involved engaging with ten Lived Experience and community leaders in conversation, undertaking collaborative sensemaking and data analysis as a team, and developing a suite of emerging insights. The leaders were invited to review these insights, and any differences or nuances were acknowledged and incorporated. The following is a synthesis of this work.

The next proposed phase – pending funding – will involve testing these preliminary insights with a broader group, including a dedicated cohort of First Nations leaders. While a small number of First Nations leaders contributed to this initial phase, we recognise the need for deeper, more deliberate engagement led by First Nations Lived Experience leaders themselves, in ways that uphold cultural authority from the outset.

Insights from this expanded engagement will inform a series of project outputs, including a proposed model of values-informed leadership, a set of sector provocations and a final report with recommendations.

Gathering information

Data was collected through ten in-depth, semi-structured, qualitative interviews with leaders living and working in the Australian context. Indicative interview questions were developed into a conversation framework, which was shared with leaders in advance of the interviews **(see Appendix 2)**. The project received ethics approval through RMIT University (approval number 26037). Conversations took place online and Lived Experience leaders were able to choose which project team members they spoke with. Two team members attended all but two interviews, in line with interviewee preferences.

Leaders received consent forms before their interviews and prepaid debit cards afterwards in recognition of their time and expertise. Interviews were initially transcribed by Microsoft Teams or Zoom, then reviewed and cross-checked by the project team. Each leader was also invited to review their transcript and make amendments.

Sensemaking

The project team came together for a series of sensemaking conversations to reflect on the interviews. This included an informal discussion after the first four interviews and a formal discussion after all ten were complete. These conversations were guided by inductive analysis.[6]

The first informal discussion was recorded and transcribed. It helped generate initial themes in areas such as terminology, drivers and motivators, accountability, representation and identification, safety and wellbeing, colonisation, co-option and commodification, lateral violence,[7] engaging with institutions, compromise and ambivalence, leadership, new organisational forms and approaches, development and support and sustainability.

These themes then shaped the focus areas for transcript reflection sheets developed by the project team. This process enabled documented and transparent sensemaking by team members allocated transcripts to code and thematically analyse. The reflection sheets were then used in the formal workshop to discuss, compare and refine emergent themes, supported by quotes and examples from leaders.

Two team members then drew on the reflection sheets to deepen the analysis, arriving at four initial themes: contexts, orientations, harms and hope. At the same time, two others generated an 'output frame' that visually condensed a slightly modified set of themes across four key areas: context, leadership characteristics, 'what is the work?' and sustainability and wellbeing.

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6 **Inductive analysis** is an approach that allows themes and insights to emerge from the material itself rather than being shaped by predetermined frameworks or assumptions. In this project it meant listening closely, attending to nuance and allowing the reflections of leaders to guide our sensemaking process.

7 **Lateral violence** is defined as "the organised, harmful behaviours that we do to each other collectively as part of an oppressed group – within our families, within our organisations and within our communities. When we are consistently oppressed we live with great fear and great anger, and we often turn on those who are closest to us." – R Frankland and P Lewis, in *Social Justice Report 2011* (Australia: Aboriginal and Torres Strait Islander Social Justice Commissioner. 2011)

As a team, we encountered challenges during the sensemaking stages, reflective of our different disciplinary, community and social locations. Despite our project principles and shared values, our divergent practices across community and academic contexts meant different lenses shaped how we represented the preliminary findings.

While we shared a common sense of what we heard in the interviews, we differed in how we articulated, represented and weighted the themes. This underscored the reality that themes do not simply emerge from data but are constructed through interpretation and perspective.[8]

Although these experiences were initially disruptive to team cohesion, they invited us into more intentional and transparent dialogue about difference. By slowing down and moving deliberately through the discomfort, we recognised that disagreement was not a barrier but a catalyst – one that challenged us to sit with complexity, sharpen our thinking and surface deeper insight. Ultimately, it strengthened our relationships and helped us arrive at more coherent and aligned understandings of the final themes presented here. We now carry a greater appreciation for each other's differences – and for the necessary, generative role that conflict can play in collaborative knowledge-making.

From here, we share the key insights gained from our engagement with Lived Experience leaders.

8 V Braun and V Clarke, *Thematic analysis: a practical guide* (London: SAGE Publications Ltd. 2022)

Key insights

Through conversation, reflection and collective sensemaking, we identified ten key insights shared by the leaders.

These themes were significant across their leadership experiences:

1. A purposeful orientation to systems change
2. Engaging across different spheres of action and influence
3. Ambivalence about Lived Experience
4. Alignment with collective movement building
5. Resisting dominant forms of leadership
6. Navigating competing accountabilities
7. Bearing the costs of leadership
8. The necessity of authentic allyship
9. Wellbeing through connection and community
10. Growing power and possibilities

Each insight is explained and supported by quotes from the Lived Experience leaders in the pages that follow.

INSIGHT 1:

A purposeful orientation to systems change

Each leader held a clear and unwavering aim: to enact, shape and contribute to social and health systems change. They operate in contexts that are often unsafe, transactional, extractive and harmful. Their leadership arises as a politicised response to systemic exclusion, discrimination, violence and oppression – rooted in lived and collective experience, not merely individual motivation.

The leaders emphasised that they are not interested in tinkering at the edges of current services and systems. They are pursuing full-scale transformation – reimagining and rebuilding with justice and equity at the centre. Their approach reflects a deliberate stance: principled, critical of dominant norms, disruptive in practice and grounded in courage.

> "I came in with the motivation that there were so many fucking people that this had happened to, and I wanted to change it. I felt like, you know, I knew I had my experience and then when I started working with other victim-survivors, I was like 'oh my god, there's so many of us, this shit has got to change'. So that was my initial motivation. But I think to be really, truly honest, in the initial motivation, I perceived that I would get healing from speaking truth to power because my voice had been taken away so much through violence, poverty, classism."

This deep orientation to systemic change is often misunderstood or underestimated by those working within mainstream institutions. Yet even at the edges of institutional reform, these leaders commit to remaining anchored, guided by politicised experience rather than individual effort alone. Their hope is not naïve; it is a deliberate form of strategic resistance – a belief that systems can, and must, be transformed.

> "Another thing that drives me is the thought that institutions could change, and mindsets can change, and I know it's possible… it's just a time thing, you know? So yeah, I have a lot of hope. Most of it is hopeful."

Many of these leaders began by making change in small, localised ways. Over time, they have built connections with others who share Lived Experience, aligned with allies and broader movements, and sharpened their focus. They have engaged more deeply with the systems they seek to influence – the often-hidden dynamics that underpin and sustain them – and sought out better alternatives that could be configured. What they bring is more than 'lived expertise', it is a breadth and depth of wisdom that informs their approaches to enacting leadership.

> "I really see myself as someone who can look for platforms for [Lived Experience practitioners] to… [make things better] and make sure that I negotiate those platforms so that they are safe, and that they are engagements that are done in a meaningful way, that are not just 'can we talk to you about something we've already decided?', but actually that they [the Lived Experience practitioners] are involved from the beginning, and they really enjoy the experience they have and then the outcome is something that is somewhat significant."

As we detail in Insight 7, however, Lived Experience Leadership comes at a cost – one that is carried most heavily by First Nations women and by those most subject to systemic violence.

INSIGHT 2:

Engaging across different spheres of action and influence

The leaders we engaged with make deliberate choices about where and how they work. These choices are rooted in their visions for change, core values and a deep sense of accountability to themselves and their communities. Their decisions reflect an understanding that influence is relational and situational, shaped by histories, contexts and collective aspirations.

> "It's slow changes but I'm hopeful. I feel like it's important to be in the system channelling the money to the right hands. I don't trust where the money is being held at the moment."

For some leaders, **working with** mainstream institutions runs counter to their values and strategies for change – especially when those institutions continue to cause harm and threaten to dilute or co-opt their influence. They choose instead to build power through alternative avenues, forming movements outside or alongside harmful systems as a deliberate, strategic stance.

> "A theory I have held is that we need to build power ourselves and then the system will come to us for the answers, rather than us trying to fit into their structures and processes."

Other leaders recognise that **working within** existing systems can offer strategic benefits: proximity to institutional power, influence and opportunities for change from the inside. They believe that change can and does happen through these relationships. Some also highlighted the vital role of allies – partners who share radical aspirations for systemic transformation and are prepared to leverage their power and privilege in service of this vision.

> "I think the other thing that's been helpful is that there are certain people across different organisations, across the different streams of work who really get it and are using their power and their privilege to make sure that we are included. I have mad respect for those people; I would back them 1000 per cent every which way I could."

A third perspective involves leaders **moving between** engagement and disengagement with mainstream systems and institutions, shifting across different leadership styles and approaches. They take on varied roles at different times, describing this kind of "dance" as helping them understand systems from multiple vantage points, build alliances and extend influence across different spaces.

> "I feel like I do this dance where I am [working] in one [space] and then I go, 'fuck this', and I'm like 'I want to be over in the other space,' and then when I go over to the other space, I'm like 'oh gosh, the lateral violence here is really [bad]... I can't do this on my own over here. Maybe I'm more protected if I'm doing that in an institution', so then I move back ... Then when I'm in the institution I'm like 'oh my god, this is just like the system that's harmed me, I don't want to be here'... Maybe there's room for another space?"

This fluid movement reflects the relational and strategic navigation required to influence systems – stepping in and out as needed, depending on context, opportunity and collective goals. It underscores the interdependence between leaders, allies and communities, recognising that influence is cultivated across spheres, and shapes change through ongoing collective effort.

INSIGHT 3:

Ambivalence about Lived Experience

All the leaders we spoke with expressed a degree of ambivalence and scepticism about the social sector's current interest in 'Lived Experience'. Many were critical of terms like 'Lived Experience' and 'Lived Experience Leadership', arguing that these terms often lack specificity and fail to reflect the purposeful work they do.

> "We talk about lived expertise, not just lived experience, because yes, true, most people have it. Great. It doesn't mean you're using it at all in decision making, work or any contribution to society at all… it's lost its roots [and place] in broader social movements as well."

While open to unpacking language and terminology, most did not identify or describe themselves as Lived Experience leaders, nor feel comfortable being labelled as such. Instead, they used a range of terms to describe what they do and the roles they hold.

> "I'm using 'lived expertise', I think it's time we chucked 'lived experience' in the bin. This is a profession by nature; that's how I see it. We've built our professional cred by using what we have as an expertise. I think when we keep using 'lived experience', we're keeping people victim-survivors, I'm saying victim-survivors but I mean anyone with lived experience of all the marginalisation stuff, I think we're still keeping them in a box of, 'they're a person whose had something happen to them', so I don't like it. I've found my brain lately looking for other words to use instead of 'lived experience'. I've used 'lived expertise', 'lived experience consultant', 'victim-survivor consultant', 'victim-survivor expert'. I'm trying to move away from that because I think that needs to go."

Many leaders raised objections to the prominence and current uses of the term in social sector change initiatives, warning that a narrow focus on individual lived experience risks quantifying personal stories rather than engaging with the historical and structural roots of injustice. Some argued that this focus diverts attention from the broader systemic change that is urgently needed.

> "I think we've become a bit too self-absorbed in the growth of our own workforce and our own validation… I feel like we have lost sight of the systems transformation or what we're actually trying to do for our communities."

Some expressed concern that focusing too narrowly on lived experiences of adversity, oppression or discrimination risks de-politicising the systemic struggles these experiences are grounded in. When lived experience is reduced to personal testimony alone – rather than recognised as part of a collective body of knowledge – it can strip away context and political specificity, obscuring the structural change communities are fighting for.

> "I use the [term] politically… I'm talking about it in a particular positionality around oppression, and I don't think that's well understood."

These reflections extend to concerns of the increasingly hyper-individualistic framing of Lived Experience, rather than something deeply embedded within and borne out of collective and shared experience.

> "I think the other thread for me… is that it feels too individualistic… I look generationally at systems, you know it always feels like it's nested within bigger and bigger systems…"

Co-option of Lived Experience emerged as a significant concern, particularly where institutions take control of community-driven goals or reshape them in ways that no longer reflect their original intent. These approaches risk disempowering communities, undermining their visions and obstructing transformative change.

> "The biggest thing we face is co-option and dilution of the perspective and politics that we bring."

Some leaders recognised that the current interest in 'Lived Experience' has created new opportunities, which they were willing to pursue cautiously, while remaining aware that the term offers only a partial and, at times, reductive lens on their work. As a result, they were comfortable holding the term lightly and using it as a point of connection when it served a purpose.

> "Lived Experience, I think it is as equally helpful as it is problematic. Sometimes I feel we need a language that is shared across the social issues that people have. But it then becomes reductionist, and we lose the nuance, the depth, the beauty, the brutality and the reality of it all."

Leaders also shared reflections on the state of the 'Lived Experience movement', including Lived Experience Leadership. Their perspectives touched on professionalisation and mainstreaming, where professionalisation was associated with formal qualifications, and mainstreaming with the increasing presence of lived experience roles within dominant systems.

> "[Community leadership] morphed into being owned by institutions… a whole range of things that people on the ground had set up for their peers… and they said, well, you've gotta be qualified now, you've gotta be, you know, a whole range of criteria have to be met in order to keep running."

Finally, some leaders expressed concern about the isolation, lack of community accountability and siloed nature of much Lived Experience work:

> "These people are operating in isolation and they're not being accountable to [their community] … [Without community accountability] you're operating from a position of 'power over.'"

INSIGHT 4:

Alignment with collective movement building

The leaders we spoke with align themselves closely with communities, collectives and often overtly political movements. While personal and lived experiences provide motivation and drive, this work is about far more than the self. It is anchored in solidarity with and accountability to others, and resists individualised notions of Lived Experience Leadership. This orientation is evident both in what drives the work and in what sustains leaders when conditions are most challenging.

> "I do have some sort of hope most days. This is the love for the community."

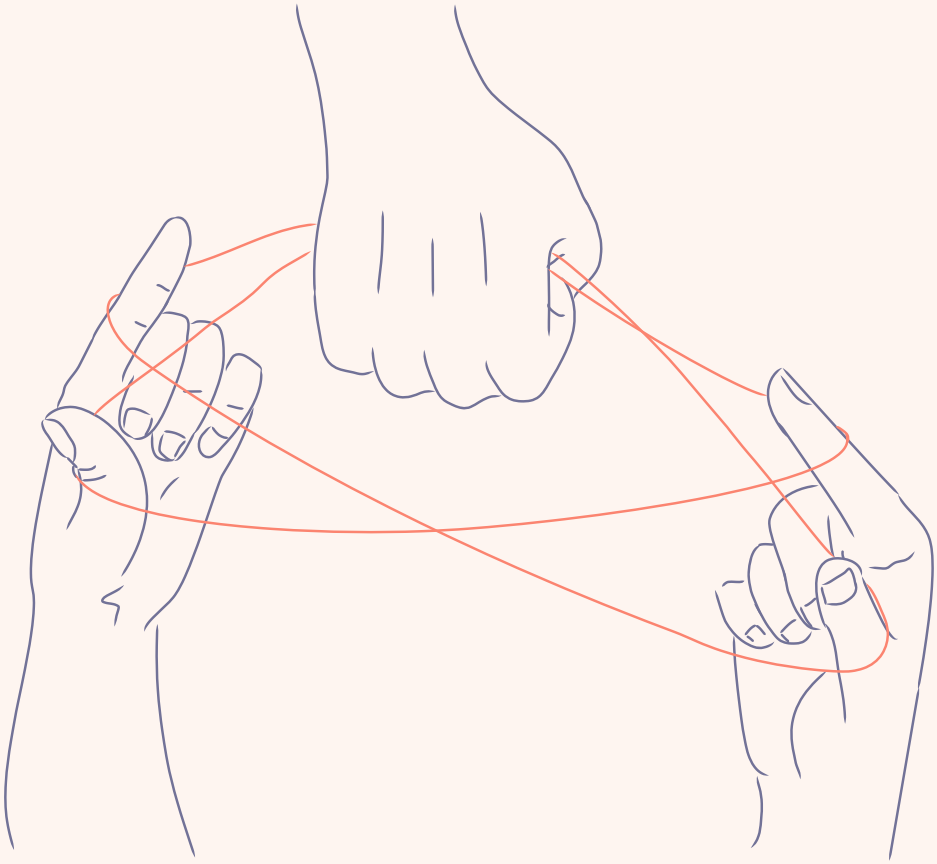
The deep sense of connection and movement-building that leaders bring is not always visible to others. Too often, the social sector elevates individuals disconnected from collective struggle, while sidelining those whose leadership is forged in community, conflict and care. This makes clear that Lived Experience Leadership is not about representing a single 'voice' of lived experience, but about ensuring communities have what they need to speak, organise and lead on their own terms.

This leadership is carried through relationships and grounded in a strong sense of collective purpose. Building coalitions, creating alternatives and generating power through collective action are central to their approach.

> "One of the shifts that really did for me is the sense of [moving]...
> from 'ego-led' to 'eco-led.'"

Lived Experience Leadership involves representing experiences of exclusion, discrimination, marginalisation and oppression to inform systems change. Leaders are accountable to communities with shared identities and experiences, prioritising collective insight over individual perspective or the promotion of solely personal lived experience.

Operating from a collective lens resists the tendency of systems and institutions to individualise lived experience – a tendency evident in the reliance on individual metrics, the elevation of so-called 'media-friendly' leaders and narrow definitions of legitimacy that fail to value, or that actively undermine, community-based leadership.



INSIGHT 5:

Resisting dominant forms of leadership

The notion of being a ‘leader’ sat uncomfortably with many of the people we spoke with. Some hold designated leadership roles within large organisations or in entities they have founded themselves. Others move in and out of advocacy and leadership positions, working across different settings to influence change and support the communities to whom they are accountable.

Many explicitly reject institutional models of leadership that reinforce colonial, patriarchal and capitalist values and practices. Some leaders argued that these dominant models are not neutral: they function as tools of oppression, sustaining hierarchies that elevate individuals above collectives and marginalise community-based forms of leadership. They also emphasised that when institutions fail to recognise leadership grounded in community, this is more than an oversight – it actively protects exclusionary power structures.

> "We can't do this work individually. That's just not reality. We can only do it together. I think that's where the idea of 'leadership' has really been misused, in abusive, even vile ways, to suggest that one person can lead alone. But real leadership happens in relationships, and in relationships, you're accountable. That's what a true relationship is. Honest relationships mean recognising that we're not individuals out on little boats, sailing the ocean alone – we're connected. And because we're connected, we have to be open to criticism and to being held accountable for what we do."

Others described strategies they use to resist individualised notions of leadership, instead placing emphasis on groups, collectives and those they work alongside:

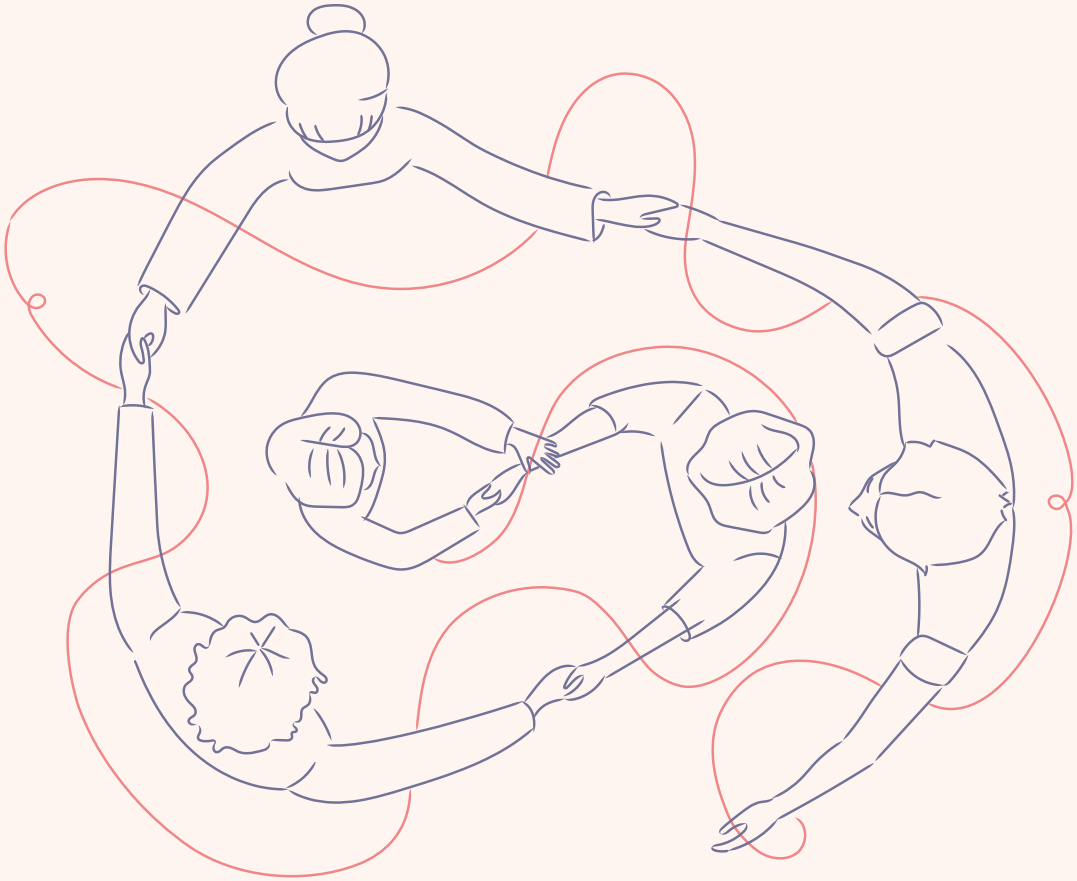
> "And so, I proactively, every time when I'd go into spaces and say, 'no I'd recommend other people' and I'd get other people to do it because I didn't want to be the only person, and I knew I wasn't the only person. The strength comes in the collective insights, it's not just one story or one perspective and I didn't talk on behalf of everyone... I think that's a point of difference when you see this."

Many of the leaders we spoke with are reluctant to speak about their own reach or influence, yet they are recognised and respected by others as leaders of change. For most, leadership is something they step into with hesitation, driven by a deep sense of responsibility to take action that benefits others.

> "I realised it's because a lot of people don't understand my lived experience so it's impactful for others and even more impactful for my community to see someone older than them navigating the spaces we navigate. It was really important for me to be able to see people with my lived experience in positions I wanted to be in and in places I wanted to go."

Institutions frequently overlook or undervalue community-based leadership, along with the relationships and accountabilities that Lived Experience leaders carry. This not only makes engagement with institutions challenging, but also compounds the tensions leaders navigate. It raises a deeper question: when community-based leadership is dismissed, is it simply a gap in recognition – or a deliberate strategy to protect dominant power structures?

> "Sometimes, and I think this seems to be fairly common as well, you can be quite highly respected outside of the organisation, like even to the point of internationally and yet inside of your organisation, not always so much."



INSIGHT 6:

Navigating competing accountabilities

Leaders hold a strong sense of accountability in the change ambitions they pursue – one that is unwavering and non-negotiable. This accountability is directed first and foremost to those most affected by systemic harms and injustices.

> “I am accountable to the people at the end or the bottom.
> To service users and the people who have the most to lose.”

This accountability – to those with less institutional power who are experiencing systemic harm – is not abstract for leaders working within and alongside communities and collectives. Their choices and actions are subject to direct accountability from the very communities they represent. As one leader put it:

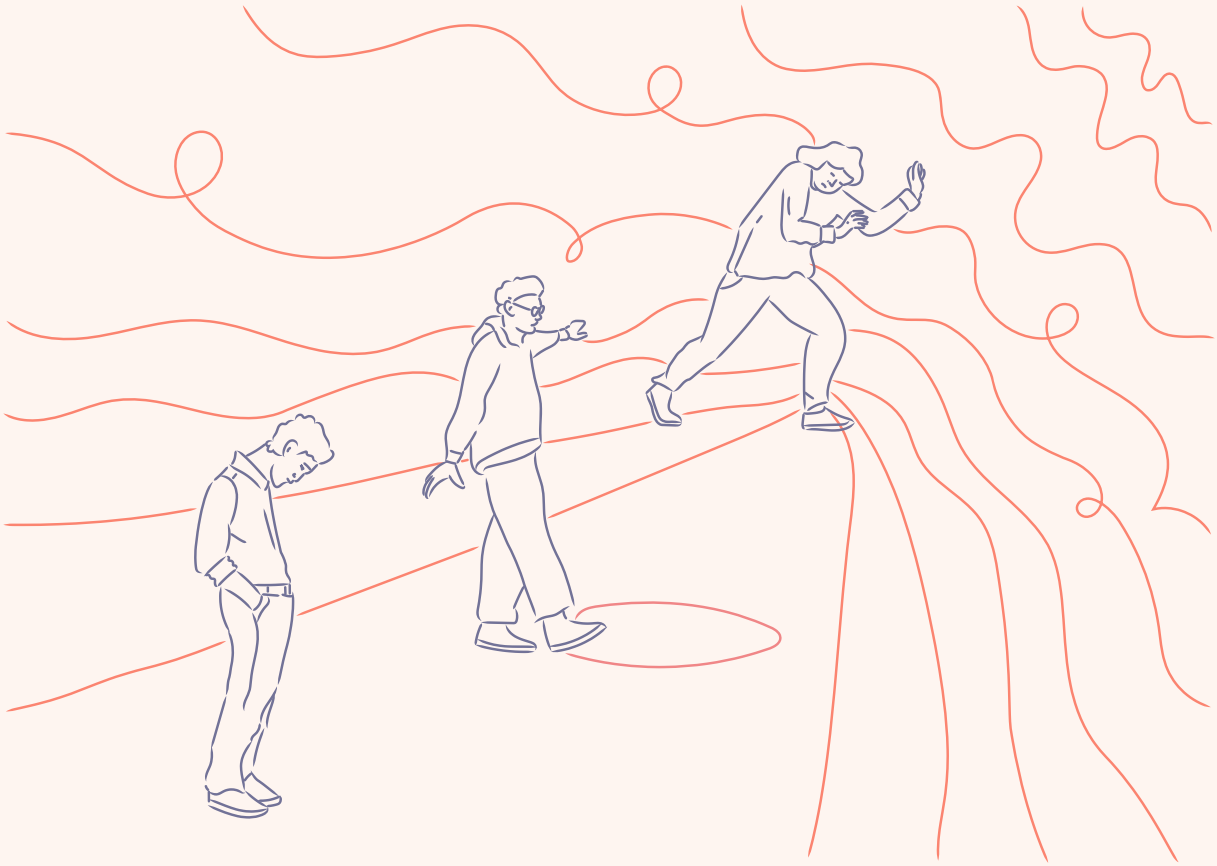
> “I would never speak about women and girls in cages unless I’m being held accountable by the women and girls in those cages. It’s about going back into the prison and being part of those conversations, hearing what’s happening on the inside, in order to do the work on the outside. Otherwise, you’re operating from a position of ‘power over’: ‘I’ve had an experience; therefore I know what’s best for everyone else.’ And that’s just not true.”

Some leaders operate with a singular sense of accountability – not to dominant systems, but to their communities, ancestors and those yet to come. This sense of purpose extends beyond institutional expectations, rooted instead in cultural, intergenerational and relational commitments that feel bigger than one person.

> “I don’t feel accountability to dominant systems… What I feel accountable to… it feels greater than me… like accountable to my ancestors and accountable to those who come after me.”

Other leaders navigate competing accountabilities to both communities and institutions. When working within systems, the tension between these obligations is almost always present, pulling the work in different directions and placing considerable pressure on leaders and their decisions. This often unseen complexity can make the work especially challenging and fraught, but it can also create conditions for critical reflection, creativity and breakthrough. At times, this may mean making a conscious decision to disengage from institutions and dominant forms of leadership altogether.

These breakthroughs can sometimes arise not despite the tension, but because of it, compelling leaders to move beyond surface-level reform and pursue more courageous, values-aligned solutions. Yet such moments come at significant cost; for many, the friction between institutional constraints and community expectations often leads to burnout, tokenism and co-option. Leaders who remain steadfast in their accountability to communities often face institutional resistance and backlash, which further intensifies these costs. Even so, when breakthroughs do occur, the tension can act as a catalyst for deeper change, revealing pathways that neither system alone could generate.



INSIGHT 7:

Bearing the costs of leadership

Leadership carries harms, hazards and costs. These impacts vary in form, intensity and effect, and can be caused both intentionally and unintentionally. Some are overt and observable, while others are hidden and deeply felt, manifesting personally, professionally or both.

Leaders spoke of carrying invisible burdens on behalf of their communities, often absorbing harm to protect or hold space for others. The emotional and psychological toll of this work is significant. Leaders described loneliness, isolation, re-traumatisation and interpersonal conflict – including lateral violence within peer relationships – as persistent challenges.

Simply put, the work is not only demanding – it can be wounding.

> "As Lived Experience practitioners, we hold one shield that's fending off the system and another shield that's fending off the organisations that we have to work with and then another that's defending victim-survivors, then we don't have anything left for ourselves, to protect ourselves."

Institutions and organisations often operate in transactional, project-based ways that create harm – not only for Lived Experience leaders, but also for the communities they represent. Several leaders shared stories of organisational leadership, policy or strategic direction changing suddenly – halting, diluting or reshaping work that leaders had contributed to and aligned themselves with in good faith.

Leaders described these moments as deeply disempowering, comparable to the harms experienced through poor service delivery – where voices are dismissed, agency is denied and people are left feeling used or disregarded. Many spoke at length about the emotional and structural toll of such encounters, emphasising that institutions rarely recognise the extent of the impact on both leaders and their communities.

> "And the other thing as a blackfulla too irrespective, is if the organisation doesn't have a good structure and brings one blackfulla in sitting at a certain level… there's such a burden put on them when they can't actually influence change. So there's that side of it, but the other side of it is that everyone comes to them for everything. So if they are not protected properly, if the work isn't done with the workplace first around 'you're not to just go around and ask every single blackfulla every question that you possibly have.' I mean, irrespective sometimes when you do the work and as you build relationships and people feel more comfortable, they start doing it anyway, but – work then with that person about how they can be strong on their boundaries and that it's up to them individually if they choose to want to share or if they go, 'I don't have capacity to respond' because that sense of burden and pressure to… well actually this is about making a difference and if I can just educate… then that's just adding more pressure and stress to us because we feel like we have to do it because we want things to be different."

Leaders emphasised that institutions, organisations and systems rarely accept, acknowledge or apologise for the harm they cause. In effect, leaders are left carrying the weight of both institutional actions and communities' expectations and responses. This dynamic is disempowering, immobilising and deeply frustrating – not only for leaders, but also for the communities they represent.

> "Because at every moment… you know, what cost… this could be your last invitation to the table."

Leaders described the emotional and psychological costs associated with their work – costs they often absorb in their own time and with their own resources. This can be considered a **lived experience tax**:[9] a draining of personal capacity, time and energy from leaders who frequently volunteer significant amounts of time in service to the work.

> "I still feel the effects of the system while working for the system. Even though I'm [no longer] a client of the system, I [still] feel the effects as a service user a lot of the time… Because you know, when I have those meetings in those glass rooms, it reminds me of the ones I was in when I was a child. Where a certain type of ceiling air vent, or a certain type of beeping, reminds me of the hospitals."

While leaders were well versed in the concept of the *lived experience tax*, they noted that it is rarely acknowledged or openly discussed:

> "Something we don't talk about enough is the price that we pay for being someone who chooses, on the regular, to share their lived and living experience. We choose to do it because we genuinely care about people we've never met, because we genuinely want people to live, because we genuinely want the systems that continue to fail them to change and to make things better for them. The toll that takes on us as individuals, the exhaustion, the trauma that's constantly brought up, the feelings of being less than everyone else around you at the table, of not being valued, of not being heard, of not being considered, and yet still choosing to fight each and every day for the right reasons is more than what anyone could ever possibly imagine because for what we choose to share and keeping it real, there's still a large percentage that we keep inside around how this actually impacts and affects us in our daily life… We care so much even when it's to our utmost detriment."

9 **Lived experience tax** refers to the draining of personal capacity, time and energy – alongside the emotional and psychological costs – carried by Lived Experience leaders who often contribute significant amounts of unpaid labour outside their formal roles. We have chosen not to capitalise it, grounding the term in everyday reality rather than framing it as a formalised or institutionalised concept.

In addition to the harms and hazards of engaging with institutions, leaders also spoke about the challenge of lateral violence. This refers to harm enacted within or between marginalised communities – often emerging in environments shaped by scarcity, competition or unresolved trauma[10].

While the term itself can be contested or imprecise, the impact is real.

These experiences compound an already significant emotional load, particularly when leaders are positioned as both representatives and targets within their own communities. Some spoke of feeling stuck in these dynamics – aware of the harm, but also of their continuing responsibility to stay and lead.

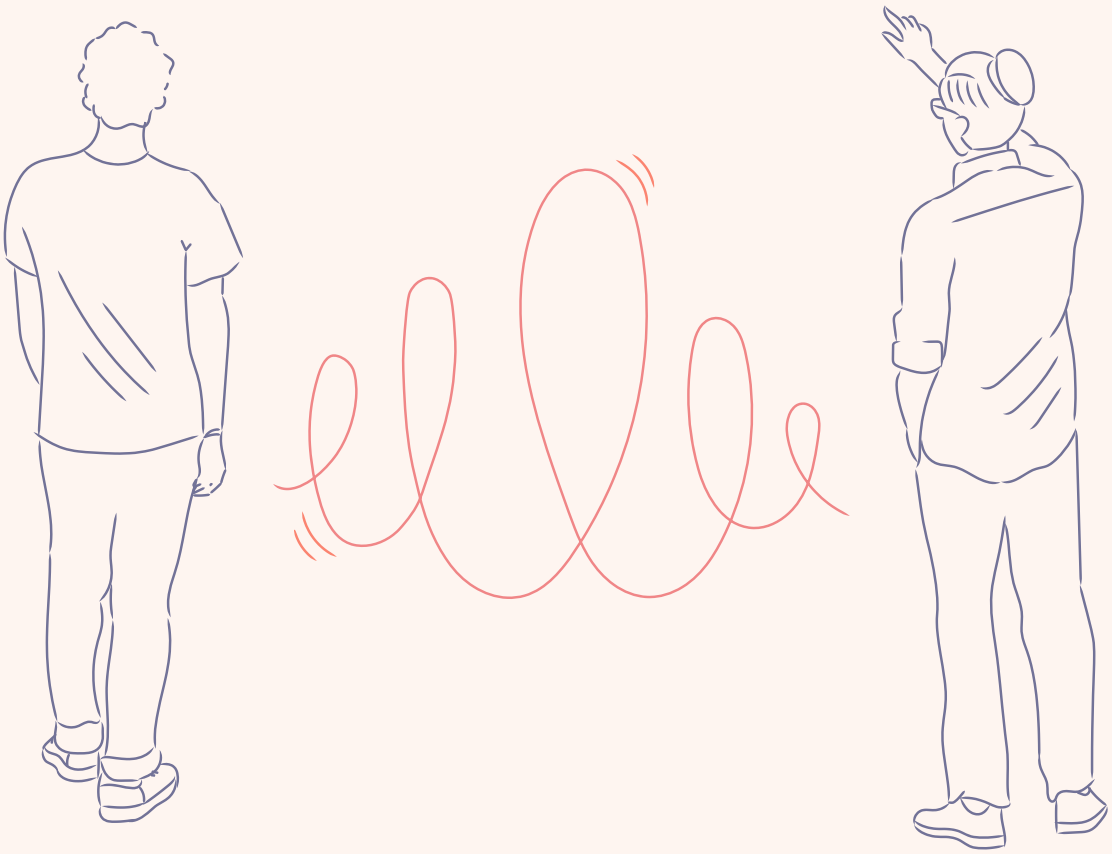
> "There are some things you have a right to and there are some things you don't… I have moments where I get a lot of lateral violence. I think at some point I need to think more about what I mean when I say lateral violence, because I think that that gets thrown around a lot and in really harmful ways. I've been told because something happened, and there were witnesses to it, that there's jealousy, there's assumptions, there's not knowing the full picture, that there's just assholery behaviour… And I guess I know that I will leave, at some point, but it's not yet."

Some leaders reported experiences of lateral violence from within their own communities. This is not an easy thing to manage and can often be distressing, isolating and incredibly difficult to navigate.

In response, leaders reach deep into their own networks for support, drawing strength from trusted relationships and shared values. The work itself demands persistence under the most difficult conditions: personal compromise, constant monitoring of situations, relationships and contexts, holding the pain of communities and individuals and often being discarded once the 'job' is done.

These realities place immense strain on leaders' health and wellbeing. The emotional toll is not incidental; the cost of caring for oneself must be recognised as an intrinsic part of the work and factored into it. Sustaining energy in this kind of leadership is not just difficult – it requires continuous investment in emotional and relational care, grounded in a steady sense of responsibility to community amid persistent pressures. It is an ongoing negotiation of wellbeing, accountability and the demands of the work.

10 See *Key Terms* (page 9) for a more detailed discussion of the nuances surrounding the term 'lateral violence'



INSIGHT 8:

The necessity of authentic allyship

Leaders need allies and supporters to sustain this work. Those we engaged spoke of allied individuals in influential institutional roles who are deeply aligned with the ambitions of Lived Experience Leadership and attuned to the challenges faced by leaders and communities. These allies play a vital role – often over long periods of time and across shifting professional positions. Their support helps drive change from within by lending credibility, building connections, engaging others and opening space for different knowledges and alternative pathways to take root.

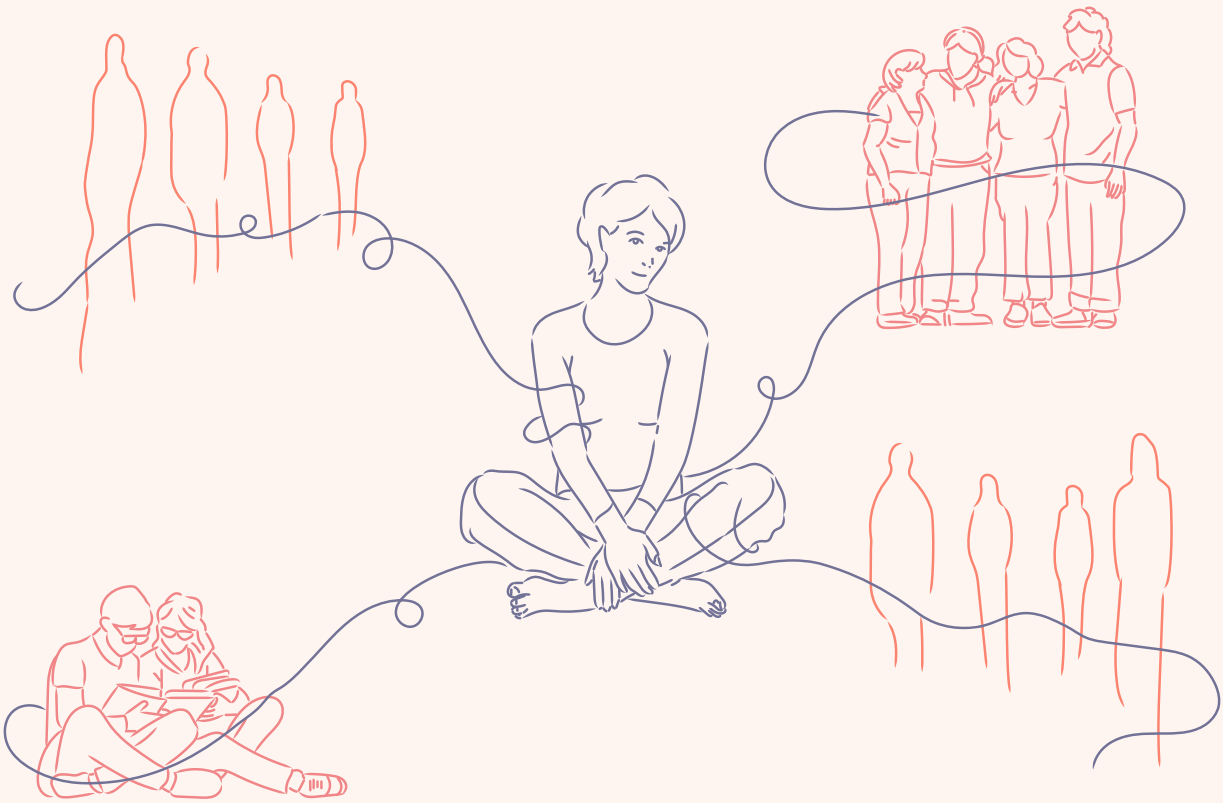
> "If… you've got somebody who also is interested in that mission, then absolutely, I think you can hold those ideas and perspectives and keep challenging existing paradigms and systems much more strongly."

Most leaders are seeking authentic allies and collaborators to help change harmful systems, but these relationships must be grounded in alignment and trust. Without this, they risk causing further harm. Institutional leaders, in particular, must recognise the power and influence they hold – and how this shapes the conditions for Lived Experience Leadership, genuine participation and purposeful partnership.

> "The work of Lived Experience is often dictated by those without lived experience… One thing I have really held onto is, why don't we ask people, 'What do you want to do in the work? Where is the point that you want to get to?' Lived experience work is dependent on those without it and that's what I want to change… When I can, in my spare time, do the work that I want to do, and I've shown people said work, they've gone 'oh my god!' But again, I have to do this in my own time. Which is more often than not, work for the system that should have been paid. But the thing is, it's on me again, with the most to lose, to then bring out something that is of benefit to people without a lived experience."

Concerns are growing about the mainstreaming and co-option of Lived Experience, and of the leaders positioned to represent it within dominant systems. Leaders noted a trend towards de-politicising the work, as core elements of its philosophy are lost or diluted to fit institutional norms and constraints. As Lived Experience leaders navigate competing accountabilities to both institutions and communities, they may feel pressure to compromise on values considered more 'radical' in order to maintain a seat at the table.

Allies and supporters work to understand the contexts leaders are working within, and the depth and breadth of what they hold, do and enable. They call out co-option and other forms of exploitation, and resist romanticising Lived Experience or treating it as a token presence. Instead, they listen deeply, build reciprocal relationships that transcend roles and stay committed to learning how to centre community – and accountability to community – in their work.



INSIGHT 9:
Wellbeing through connection and community

When asked how they sustain their energy and hope, leaders spoke of their connection to and love for their communities as a source of solace and strength. They emphasised the importance of creating spaces for people with lived experience to come together, not only to galvanise change but also to support one another through the work.

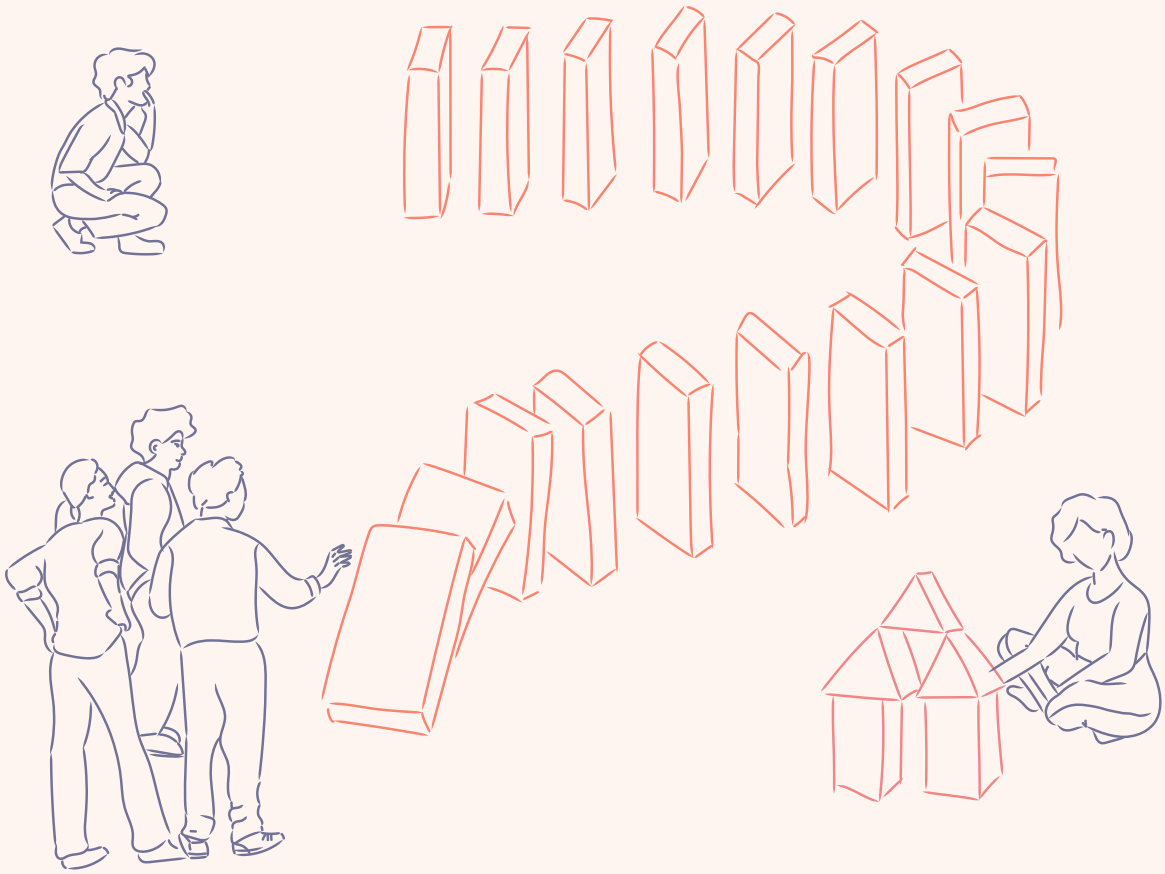
> "...more interconnection between Lived Experience [workers]... Because I do see it as a form of community wellbeing. It also, at the same time, benefits systems because we all come together and we all synthesise and go 'oh, there's this thing that we can do'. And we do that work and then the system looks back and goes 'Yeah sure we'll write our name on that one'. But I think that there is a kind of deliberate... isolation of Lived Experience in systems. There isn't, you know, a kind of, at least in my work, a common forum to come together. You know, how many fucking family violence and you know child health and wellbeing symposiums have we had? Can we have a Lived Experience symposium, or I don't know, like a pub crawl?"

Many people are working in this space without scaffolding and at significant risk to their wellbeing, community connection and capacity to sustain the work. One leader reflected:

> "The answer is relationships – real, long-term relationships. The kind where you can rely on someone when things aren't going well, or call and say, 'I finished high school. Can you come to my celebration?' Absolutely. 'I finished university.' Yes, we'll be there, and we'll have a party. It's about true relationships."

Leaders spoke about caring for themselves and each other not as a personal indulgence but as a political and cultural practice – essential to sustaining movement work and honouring those who came before, whose work they continue. They connected wellbeing to purpose and legacy rather than individualised self-care, and emphasised that it is relational and intergenerational – something sustained in community, not in isolation.

Supporting and resourcing community connection and wellbeing for Lived Experience leaders is essential and remains an urgent and under-addressed gap.



INSIGHT 10:

Growing power and possibilities

The leaders are playing critical roles in disrupting, dismantling and rejecting business-as-usual reforms and practices in the social sector across many different contexts in Australia. They hold visions for alternative ways of doing things and are growing new possibilities in connection with others – possibilities that may one day replace mainstream approaches.

We heard about global alliances and movements that connect people around shared change objectives and initiatives, proposing radically different power arrangements that put communities and those most affected in control.

> "I know when I was sitting in the space doing some work with the Wiyi Yani U Thangani...[11] there were victim-survivors that spoke into that work, I was one of them, we were all First Nations. Something happened to me in that time, my whole brain just expanded about all of what we could tap into. I'd really love some of that translated over into the work."

Across many contexts, leaders are actively configuring and reconfiguring alternatives, addressing the practical challenges of creating change and building new, more effective systems and structures. As shared earlier in this report, the leaders we engaged were often uncomfortable identifying as leaders. While this can reflect humility, it also reflects a resistance to how leadership is so often defined in institutional contexts – tied to hierarchy, gatekeeping and narrow forms of recognition. Many instead build horizontal, relational and collective spaces that challenge dominant paradigms of leadership and open different possibilities for power and influence. Even with this discomfort around the label, colleagues, peers, allies and supporters consistently recognise them as leaders whose work drives and influences much-needed change.

While leaders did not explicitly name models such as collective, networked or systems leadership, these concepts offer useful ways to understand their approaches. Many are building coalitions and movements across organisations, using relational skill and influence to mobilise change. They are convening groups, starting new organisations, reimagining service models and offerings, and organising governance in ways that enable accountability to communities.

We need more practical, community-led ways to value, support and invest in this kind of leadership – on terms defined by those leading it, not by the systems they are seeking to change.

11 Wiyi Yani U Thangani, *Elevating First Nations Gender Justice for systems change* (Australia: Elevating First Nations Gender Justice for systems change. 2026)

Lived Experience Leadership characteristics

The table below **(Table 1)** summarises key characteristics of Lived Experience Leadership, as described by the leaders we have engaged with so far. These qualities are not fixed or exhaustive but reflect dynamic, relational and community-driven ways of leading – grounded in justice, shaped by lived experience and responsive to the demands of navigating and challenging systems.

It is important to note that many defining aspects of this kind of leadership are difficult to fully capture. Practices such as resisting extractive relationships, embedding care and reciprocity into leadership, and sustaining community-rooted wellbeing are vital but often invisible.

These are not just strategies – they are also political and ethical commitments.

Table 1: Lived Experience Leadership characteristics

Oriented to systems change	• Bringing Lived Experience to critique existing systems • Highlighting systemic inequalities, breakdowns and harms • Rebuilding systems through a justice and equity lens
Aligned with collective movement building	• Anchored in solidarity and advocacy for and with others • Grounded in and connected to both historical and contemporary movements • Accountable to community and in ongoing dialogue
Bringing radical imagination and radical hope	• Putting forward radical visions and alternatives • Offering thought leadership for systems change • Holding a long-term vision and deep commitment to intergenerational and multigenerational change (building a world for our descendants)

Table 1 is continued on the next page...

Moving between spheres of action and influence	• Engaging with system allies to create change from within • Naming and resisting co-option, tokenism and extractive dynamics in institutional engagement • Agitating from the outside and resisting institutional alignment where necessary • Navigating competing accountabilities and shifting roles • Moving between roles and contexts
Leading through relationships and influence	• Reluctance to self-identify as a 'leader' • Challenging institutional leadership and traditional structures • Rejecting leadership models that elevate individuals above collectives • Learning to influence change through multiple mechanisms and beyond positional power • Weaving care and connection into the work as a shared, political and intergenerational practice
Growing power and possibilities	• Connecting people around shared change objectives • Building new initiatives and movements • Modelling new leadership and governance approaches that centre lived expertise and community-based knowledge

Often carried out quietly, collectively and in ways that resist simplification or formalisation, these practices reflect a political and cultural orientation that centres accountability to community, honours those who came before and creates space for alternative futures beyond the limits of existing systems.

By including these practices within the table itself, we affirm that they are not peripheral – they are central to Lived Experience Leadership. At the same time, the narrative surrounding the table plays an essential role: it holds their ethical, cultural and political depth, offering the space and context they require.

This approach mirrors the kind of leadership we are describing, where formal mechanisms (like frameworks, tools and roles) are held in relationship with narrative, relational and community-based ways of knowing. Together, they make space for nuance, complexity and collective meaning-making.

Call to action

This project has been a small-scale exploration of Lived Experience Leadership, grounded in conversations with ten leaders across different contexts. What follows is not a conclusion, but a call to action – drawn from their insights and shaped by the realities they shared with us.

At the heart of these insights is a non-negotiable foundation: **community-controlled approaches across all settings**, whether government, institutions, social sector organisations, universities or community spaces.

From this foundation, leaders spoke about their **clear and purposeful orientation to systems change**. Their work is not driven by advancing personal agendas but by transforming systems that have caused – and continue to cause – harm. They consistently emphasised the need to address root causes, rather than settle for modest reforms or surface-level adjustments.

The ways leaders pursue this change are fluid and contextual, operating across different spheres of action and influence. Some choose to remain outside institutions, others work within them, and many move between these spaces – adapting their strategies and relationships as needed. What we heard is that there is no singular path to impact; leadership takes shape in many forms.

Leaders were clear that they do not act as individual 'experts', but as members of communities, collectives and movements. While they may be the ones speaking or engaging publicly, they carry the concerns, aspirations and imaginations of many. **For this reason, many were explicit about de-centring themselves – reinforcing that their leadership is grounded in collective accountability, not just personal authority.**

They also resisted dominant framings of 'leadership', emphasising instead that their roles are embedded within – and accountable to – their communities. The collective, relational nature of their leadership is often unrecognised or undervalued by institutions, and at times dismissed as labour-intensive, costly, unnecessary or outside conventional models of influence.

This highlights the complex accountabilities that leaders navigate. Some were clear that their only accountability is to their community. Others described managing multiple and sometimes conflicting accountabilities, including to the systems they engage with or work within. **Despite these differences, one position was consistent: all leaders expressed an unwavering accountability to those most harmed by institutions and systems.**

Lived Experience Leadership often comes with significant harm and cost – much of which remains unseen or unacknowledged by institutions, systems, organisations and at times even the communities leaders represent. **Rarely do institutions take responsibility or apologise for the harm they cause, particularly in Lived Experience-informed change efforts.**

Meanwhile, leaders are held accountable by their communities for how they represent them and engage with systems. At times, this results in lateral violence being directed at the leader. Many described the difficult position of trying to shield their communities from institutional harm while simultaneously absorbing its impacts themselves. It is, in many cases, a no-win situation. **Leaders are often left to carry, contain and respond to harm they did not create but are nonetheless left responsible for managing.**

Despite these challenges, leaders spoke about the crucial role of allies and supporters – those who offer practical solidarity, help shift systems, engage in insider activism and lead from behind. Effective allies work to understand the complexities of Lived Experience Leadership, including the ever-present risk of co-option when institutions treat it as a passing trend rather than a transformative force. **Even so, the hope that leaders described does not stem from institutions, but is generated from community – from connection, shared purpose and a refusal to let harm be the endpoint.**

This hope was also woven through leaders' visions of futures grounded in radically different systems, shaped by collective, networked and systems-based approaches to leadership. **Realising that vision will depend not only on structural change, but also on the love, care and deeply embedded relationships cultivated within and across communities, locally, nationally and internationally.**

The insights generated through this project have important implications for how Lived Experience Leadership is understood and supported across the social sector and within systems change. **While this was a small-scale inquiry, it offers a strong foundation for understanding how this form of leadership is taking shape in Australia. There is a clear need for broader, ongoing work to further explore, test and deepen these insights.**

To help inform that continued effort, we offer the following call to action. It is shaped by our interpretation of the leaders' contributions and grounded in recognition of the profound impact and potential of Lived Experience Leadership, as reflected throughout this project. What follows are possibilities and provocations for the future drawn directly from leaders' visions of what is needed to sustain and strengthen this work.

Across these visions, many underscored the central role of love and community as sustaining forces. This emphasis on love and relationality stands in contrast to dominant ideas about leadership, systems and change. And yet, as this project has shown, they are central to how Lived Experience Leadership is practiced, sustained and imagined into the future.

Building new systems that transform current conditions requires radical imagination – grounded in visions of justice and equity. As this project has shown, Lived Experience Leadership comes at a significant cost. To genuinely support it, those costs must be recognised and leaders' wellbeing resourced and protected so they can sustain their practice.

While many leaders expressed hope, it was often tempered by the slow pace of change and the disconnect between stated commitments to Lived Experience Leadership and the actions – or inaction – of institutions.

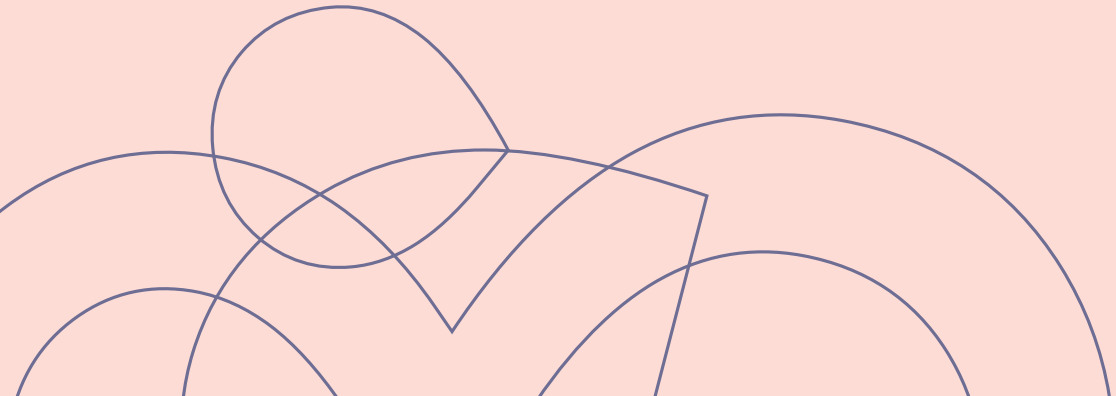
And still, there remains a deeply felt sense that Lived Experience and community leadership can – and does – create real change. While change is often slow, leaders continue the work, sustained by relationships, values and a deep love for community:

> "I do have some sort of hope most days. This is this love for (and belief in) our community. My hope is kept alive due to contact with and serving my community... I feel very blessed because the people that I'm connected to are interested in reflexivity and accountability, and those values are part of me. They are always developing [coz] it's about professional and personal values coming together for me, coz the personal is political."

The future

Building on the wisdom shared by leaders, we offer a set of ideas for reimagined futures – ones where Lived Experience Leadership is not treated as exceptional, nor constrained or conditional, but recognised as foundational to change and resourced accordingly.

These future visions draw on themes shared by leaders - including radical imagination, dismantling silos, strengthening collective approaches and coalitions, embracing complexity, working in partnership with allies, building power and holding fast to the belief that change is possible.



Radical imagination

Lived Experience Leadership brings radical imagination – one of its greatest gifts. We must create conditions for unconstrained thinking: dreaming big, demanding the impossible and daring to imagine otherwise. This stance resists pressure to conform, comply or moderate vision to fit within system norms. It challenges cultures of silencing and reclaims imagination as resistance – pushing beyond what exists towards what could be.

Leaders spoke about the importance of nurturing radical thought and valuing it as a form of leadership in its own right – one that extends far beyond the limits of existing systems. This kind of imagination is not abstract or symbolic – it is part of the hard work of designing systems that are just, accountable and responsive to community needs.

Radical imagination must be nurtured systematically. This requires intentional investment by institutions such as government authorities and universities – not to claim or control, but to support and resource community visions in ways that enable them to flourish on community terms. Such investment must honour autonomy, free from conditionalities or co-option, so that radical imagination can take root and grow.

> "Sometimes we have to demand the impossible – we can't always afford to be moderate. For example, the deinstitutionalisation of people with intellectual disabilities and those with complex mental health needs was once deemed impossible. But it happened because people with lived experience and their families pushed for it. Let those with institutional power worry about how they're going to hold us back. I have been known to give this advice: most of the time, you need to sit at the table because collaboration is essential – but sometimes, you do have to flip it. Don't become your own panopticon. You don't have to police yourself – that's their job, not yours."

PROVOCATION:

What if we established spaces like Centres for Lived Experience or Departments for Radical Imagination, designed to elevate and support community-led knowledge, vision and ideas? What role could these spaces play in resourcing leadership, sustaining movements and growing the ideas and systemic connections needed for the futures we want and need?

Building connections

The future of Lived Experience Leadership depends on dismantling the silos created by policy constructs and service systems, and creating dedicated spaces for collaborative thinking and collective action. Leaders spoke of the urgent need to bring people with lived experience into dialogue with one another – to connect across roles, systems and sectors in ways that cultivate shared insight, strategy and momentum.

> "Yeah, and not to be like in this kind of siloed way without critique... where there isn't just like... lived experience of suicide, the experience of mental health, the experience of family violence, the experience of, you know, treatment in a psychiatric facility, you know, it's like compartmentalised... Each one of those is valued experience, but there [are] things that they can learn [from each other]. There are problems if they are not in conversation, not only can they [not] learn from each other, there's a problem when they're not in conversation."

These dialogic spaces where different lived experiences are brought into thoughtful, critical conversation can create the conditions for broader, collective visions to emerge. These are spaces where ideas are challenged and refined, and where support, solidarity and strategy can take root.

This kind of cross-issue connection is a necessary foundation for collective action and can also be a form of harm reduction. As documented throughout this report, Lived Experience Leadership involves deep emotional and structural risk. Opportunities to connect, reflect and organise with others who share the work are critical to wellbeing and sustainability.

Supporting these kinds of conversations are integral to sustaining ethical and effective leadership. When Lived Experience and community leaders are in dialogue with one another and with the communities they belong to and represent, collective power takes precedence over individual prominence.

We reiterate both the opportunity and the responsibility for those supporting Lived Experience Leadership to invest intentionally in dialogue, exchange and the creation of supportive networks and workforces.

PROVOCATION:

How might we connect Lived Experience leaders in ways that enable the sharing of practice, the growth of collective vision and the resourcing of wellbeing – not as an afterthought, but as central infrastructure for change?

Collective approaches, collaboration and coalitions

The future of Lived Experience Leadership lies in collective, collaborative approaches. Leaders consistently emphasised the importance of building coalitions across issues and sectors, working together beyond silos and without the persistent threat of co-option.

Where ego-led approaches focus on individual authority, eco-led approaches recognise the interconnected nature of systems and the necessity of shared power. This shift from "I" to "we" reorients leadership around networked action, mutual accountability and a deep understanding of relational responsibility. Leaders spoke of the need for intentional spaces to reflect together on aims, objectives, tactics and the future of the 'movement' – spaces for alignment, accountability, clarity and support.

In moving towards more collective models of leadership, leaders also acknowledged the value of working alongside others with different forms of expertise. In some cases, this includes collaboration with professionals from disciplines like medicine, law or policy, where technical knowledge is required. These collaborations work best when Lived Experience is not sidelined or tokenised, but held as central.

> "I think we need a mixed model – one that brings lived experience into genuine conversation, rather than treating it as symbolic or tokenistic. That includes community-controlled voices – not just from formal organisations, but also from informal, grassroots spaces. And then there's professional or clinical expertise. We need all of these working together. For example, as a transgender man, I access a medical model of care – this means I rely on GPs, endocrinologists and other healthcare professionals to support my wellbeing. Their expertise matters – but so does the context of my lived experience and the voice of my community."

Investing in this kind of cross-disciplinary, community-led collaboration is essential to the future of systems change. It enables leaders to work with the full range of knowledge, skills and relationships required to solve complex problems and build alternative futures.

PROVOCATION:

What would it take to resource Lived Experience Leadership through interdisciplinary teams that bring together the skills, expertise and influence needed to solve problems and implement new solutions? How can the goals of redesign (not just reform) and shared power be supported and enabled?

Complexity recognised

Lived Experience and community leadership continually reckons with the reality that people hold multiple roles, identities and accountabilities at once. Leaders hold more than one identity – and they should not be expected to choose between them. Yet institutions often prefer to engage with people through a singular lens, simplifying complexity in ways that make engagement easier for systems but less truthful to real lives.

Leaders spoke of the need to make space for this complexity. Attempts to neatly separate personal experience from professional expertise, or community connection from technical knowledge, often miss the point. Many leaders draw on all of these simultaneously as a source of strength and legitimacy.

> "I think there has to be space for when people hold multiple positions, which I feel like we haven't quite worked out… There are people who are working in the trans space, who have family members who are transgender, and there are transgender GPs and, you know, people hold multiple identities and expertise, and that has to be somehow accepted and negotiated, that you don't just park one at the door."

Throughout the project, leaders returned to ideas of interconnection across experiences, systems and movements. Just as individuals do not exist in isolation, neither do their identities or aspects of expertise. Recognising this complexity is a step towards more honest, nuanced and inclusive approaches to leadership. Institutions often struggle to hold this complexity, leaving leaders to face burnout, tokenism or co-option. Yet when complexity is embraced, it can open pathways to richer understanding, stronger accountability and more transformative action.

PROVOCATION:

How can we get better at holding multiple truths and honouring accountability to communities – not leaving leaders to carry the cost through burnout or co-option – so that tensions and discomfort become openings for learning, understanding and collective action rooted in alignment?

Working alongside allies

As explored earlier, allies and supporters play a crucial role in creating access, influencing systems and helping shift change from within. This is particularly important given that institutional co-option can be a deliberate strategy to undermine radical movements. Leaders described the importance of allies who understand these risks and use their institutional power to support rather than steer.

The future of Lived Experience Leadership will continue to rely on allies who are deeply committed to enabling, not directing, the work. These allies lead from behind or beside, check their privilege and ask what they can do to support. They listen, take guidance and act in ways that reflect shared values and relational accountability.

We are reminded here of Slay and Stephens' co-production principles[12], in which professionals take a back seat – enabling and facilitating rather than directing and controlling. These principles emphasise reciprocity and mutuality, offering a helpful foundation for allyship that is responsive and respectful.

PROVOCATION:

How can we get better at supporting health and social sector professionals to enable and facilitate – rather than direct or constrain – work led by lived experts, by practising principles of mutuality and reciprocity?

12 J Slay and L Stephens, *Co-production in mental health: A literature review* (Online: New Economics Foundation. 2013)

Building power

> "There's a white model that needs to just evolve now, I think it's done, it's got us here, but there's so much more that it needs to do now."

The leaders in this project play critical roles in social sector change across Australia. Some are influencing from within established organisations, while others are building capacity and creating new structures beyond existing systems. Together, their efforts are expanding the power, reach and legitimacy of Lived Experience Leadership.

What unites them is a shared vision for doing things differently – modelling new possibilities that challenge dominant approaches and assumptions. They are not simply contributing to reform; they are actively designing what comes next. One leader reflected on the kinds of conditions needed for this work to take root and grow:

> "Prioritising relationship, having time, not having a kind of false urgency, not having a need for outputs trumping outcomes, having space to challenge each other like accountability, an anti-hierarchical kind of approach, being open to learning like not needing to be in an expert stance."

This orientation points to a deeper cultural shift. Building power in Lived Experience Leadership goes beyond influence – it is about reshaping the values, practices and conditions that define how leadership is enacted.

PROVOCATION:

What would it take to slow the work down – to create space for the dialogue, trust-building and deliberation that are essential for deep change, but are almost always missing from how the work is currently structured?

Institutional and system responsibilities

The future imagined by leaders offers a rich and necessary set of opportunities. Some choose not to engage with mainstream systems and institutions. Others work within them. Many move in, around and between these spaces. Regardless of where Lived Experience Leadership is located, systems and institutions hold responsibilities – responsibilities not currently enacted in systematic, consistent or rigorous ways.

Leaders told us that although systems often cause harm, they rarely, if ever, apologise for their decisions, inaction or neglect. We argue there is a clear case for restorative justice – a deep and enduring acceptance of responsibility by institutions for structural violence and harm. This must extend into long-term commitment and concrete action, both to prevent future harm and to attend to harm already caused.

We offer some reflections on how institutions might begin a journey of apology and reparation – a process that requires both acknowledgement and action.

First, institutions must move beyond viewing Lived Experience as a compliance requirement. This begins with a willingness to engage discomfort – especially when leaders speak directly to systemic harm, both past and present. It also means recognising that Lived Experience Leadership is often boundary-riding and boundary-breaking: rarely neat or compliant, and often intentionally disruptive. Leaders influence across multiple spaces – not only within institutions, but often in spite of the constraints they impose.

Institutions must also understand that Lived Experience leaders do not speak only from a personal perspective. They carry the weight of collective experience and accountability to communities that are broad, diverse and sometimes in tension. Meaningful engagement requires staying the course – especially when the work becomes complex or uncomfortable.

This means sitting with discomfort, listening with humility and responding with openness and integrity. It requires a shift in power and recognition that the cost of this work must not only be acknowledged, but also fairly compensated, supported and sustained.

A living invitation

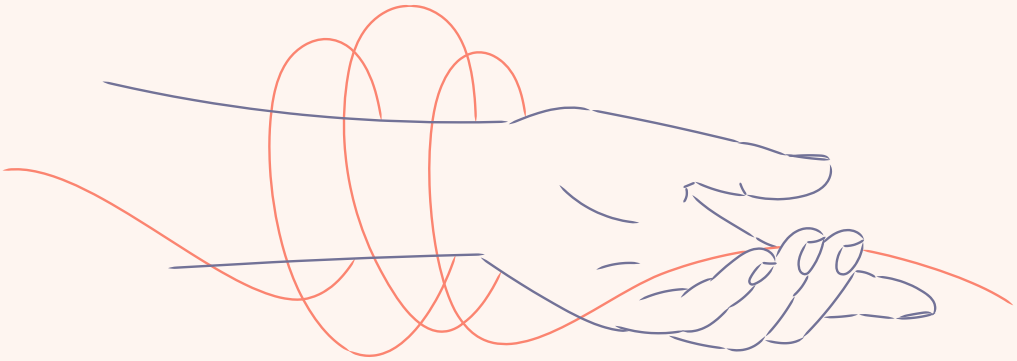
Lived Experience Leadership is not a trend, it is a return – a return to wisdom held in relationships, bodies, communities and movements that have long imagined and enacted futures shaped by justice.

This work is already happening. It is principled, powerful and plural, led by those who transmute pain into practice, and experience into forms of expertise.

If we are to move towards systems that heal rather than harm, we must make space for this leadership – not only in roles, but in how we listen, decide, design and transform.

This project is one contribution to a broader, unfolding conversation. May these insights spark deeper inquiry, braver questions and bolder, more collective action.

We invite you to join us as this work continues to evolve – in dialogue, in practice and in pursuit of change that restores and generates, not just reforms.



For enquiries about *On Our Own Terms* please contact Morgan Cataldo:

Email: morgan@morganandco.au

Web: morganandco.au

To stay updated about the project:

morganandco.au/project/on-our-own-terms

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