Lived Experience Leadership: A call for radical systems change

The first phase of the *On Our Own Terms* project is a small-scale, in-depth inquiry based on conversations with ten Lived Experience and community leaders across Australia. It offers insights, challenges, provocations and possibilities for systems change, grounded in the standpoints of people with lived and living experience.

People who step into leadership grounded in Lived Experience as a deliberate and accountable practice carry a gravity that institutions often fail to recognise. Their commitment grows from activism, community responsibility and a clear sense of purpose. For many, systems change is both a direction and a discipline – shaping not only what they work on, but why they stay in the work.

These leaders are driving change across the country. Some are reshaping long-standing organisations. Others are building new structures altogether.

Together, they are strengthening the legitimacy and influence of Lived Experience Leadership, while challenging the conditions that have historically constrained how change is imagined, led and sustained.

Key insights: unearthing practices and possibilities

Ten key insights emerged through conversation, reflection and collective meaning-making. They map the complex terrain of Lived Experience Leadership and the radical possibilities it opens for systems transformation.

INSIGHT 1

A purposeful orientation to systems change

These leaders hold a clear and unwavering intent: to reimagine and rebuild social and health systems through justice and equity. Their work is a politicised, collective response to systemic exclusion and harm.

INSIGHT 2

Engaging across different spheres of action and influence

Lived Experience leaders move fluidly between the inside and outside of systems, sometimes engaging, sometimes withdrawing, as a deliberate strategy to protect integrity and purpose. This movement recognises that real change often begins beyond the institutions that maintain the status quo.

INSIGHT 3

Ambivalence about Lived Experience

The leaders expressed scepticism about the growing prominence of 'Lived Experience' as a dominant framing in the social sector. They cautioned that it can individualise and depoliticise collective struggle, reduce expertise to personal testimony, and narrow how authority and leadership are recognised. Many also warned that institutional uptake risks co-option and dilution, softening or reshaping community-driven goals in ways that limit systemic change.

INSIGHT 4

Alignment with collective movement building

While motivated by personal and lived experiences, this work is not individualistic. Leaders align themselves with communities, collectives and political movements, grounding their leadership in solidarity, accountability and shared struggle. Their focus is on building collective power – ensuring communities have the resources, voice and autonomy to organise and lead on their own terms.

INSIGHT 5

Resisting dominant forms of leadership

Leaders consciously resist hierarchical and individualised leadership frameworks that reinforce control and exclusion. They practise relational, collective and care-based forms of leadership, grounded in accountability to communities and responsibility to others, rather than personal status or recognition.

INSIGHT 6

Navigating competing accountabilities

Leaders hold themselves first and foremost accountable to the communities most affected by injustice. Balancing this with institutional demands creates ongoing tension and cost, yet this moral clarity anchors the integrity and direction of their work.

INSIGHT 7

Bearing the costs of leadership

The toll of Lived Experience Leadership is profound: emotional, psychological and social. Leaders often carry harm and absorb conflict, paying what some describe as a 'lived experience tax' – a cost rarely acknowledged or compensated by institutions.

INSIGHT 8

The necessity of authentic allyship

Authentic allyship is reciprocal and power-aware. Allies must be willing to leverage privilege, resist tokenism and co-option, and act with humility as co-conspirators. These actions lend credibility, build connections and open space for different knowledges and alternative pathways to take root.

INSIGHT 9

Wellbeing through connection and community

Leaders sustain their energy and hope through connection to community. They emphasised wellbeing as relational and intergenerational – grounded in purpose, legacy and mutual care rather than individualised self-care. They also highlighted the importance of creating spaces for people with lived experience to come together, connect and support one another in the work.

INSIGHT 10

Growing power and possibilities

These leaders are challenging business-as-usual approaches while actively building alternatives. Through networks, collaboration and collective action, they are growing new possibilities, shaping alternatives that challenge dominant power arrangements and placing communities in control.

Institutions and systems hold responsibility

At the heart of these insights is a non-negotiable foundation: community-controlled approaches across all settings. The future of Lived Experience Leadership depends on systems and institutions recognising – and acting on – their responsibilities, which are currently not enacted in systematic, consistent or rigorous ways.

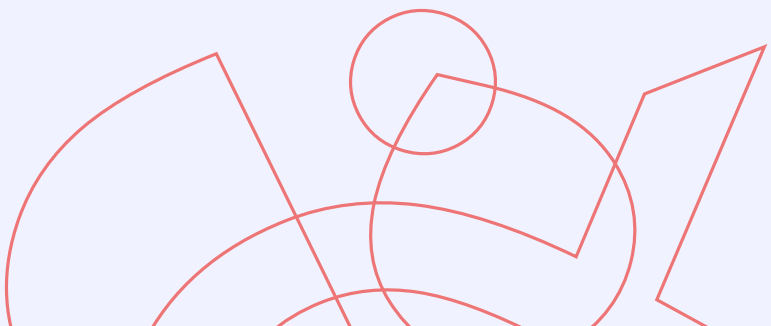
This work cannot rest on the shoulders of those most harmed by current systems. It requires institutions to move beyond symbolic commitment and act with courage, care and integrity.

This includes:

- **Institutional responsibility:** Moving beyond tokenism towards restorative approaches that recognise and address structural harm.
- **Resourcing imagination and action:** Investing in community priorities in ways that protect autonomy and resist co-option.
- **Strengthening connections:** Building infrastructure for dialogue, shared learning and collective wellbeing.
- **Supporting rather than directing:** Allies and professionals stepping back so lived experts and communities can lead.
- **Allowing time for trust and deliberation:** Slowing processes to enable relationship-building, complexity and careful decision-making, rather than prioritising speed or outputs.

Lived Experience Leadership draws on knowledge held in relationships, communities and movements that have always imagined fairer futures. It brings radical imagination – the capacity to think beyond what exists, to challenge imposed limits and to refuse the narrowing of vision shaped by harmful systems.

If we want systems that support rather than harm, this leadership must be valued, resourced and respected in how we listen, decide and design what comes next.



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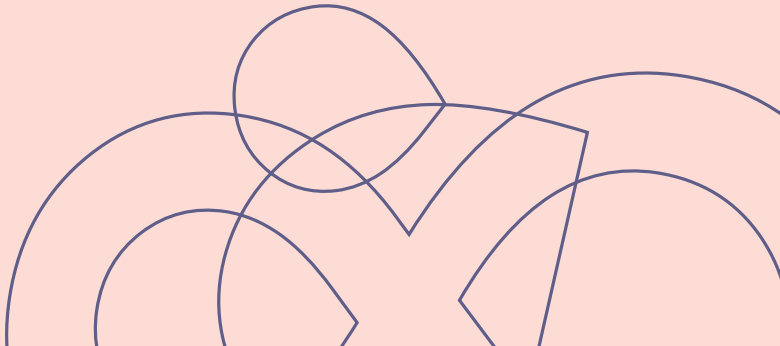
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