A model of lived experience leadership for transformative systems change: Activating Lived Experience Leadership (ALEL) project

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Abstract

Purpose – This discursive paper presents a lived experience leadership model as developed as part of the Activating Lived Experience Leadership (ALEL) project to increase the recognition and understanding of lived experience leadership in mental health and social sectors. The model of lived experience leadership was formulated through a collaboration between the South Australian Lived Experience Leadership & Advocacy Network and the Mental Health and Suicide Prevention Research and Education Group.

Design/methodology/approach – As one of the outcomes of the ALEL research project, this model incorporates findings from a two-year research project in South Australia using participatory action research methodology and cocreation methodology. Focus groups with lived experience leaders, interviews with sector leaders and a national survey of lived experience leaders provided the basis of qualitative data, which was interpreted via an iterative and shared analysis. This work identified intersecting lived experience values, actions, qualities and skills as characteristics of effective lived experience leadership and was visioned and led by lived experience leaders.

Findings – The resulting model frames lived experience leadership as a social movement for recognition, inclusion and justice and is composed of six leadership actions: centres lived experience; stands up and speaks out; champions justice; nurtures connected and collective spaces; mobilises strategically; and leads change. Leadership is also guided by the values of integrity, authenticity, mutuality and intersectionality, and the key positionings of staying peer and sharing power.

Originality/value – This model is based on innovative primary research, which has been developed to encourage understanding across mental health and social sectors on the work of lived experience leaders in seeking change and the value that they offer for systems transformation. It also offers unique insights to

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guide reflective learning for the lived experience and consumer movement, workers, clinicians, policymakers and communities.

Keywords Mental health, Rural areas, Health leadership initiatives, Empowerment, Consumers, Lived experience, Leadership, Transformational leadership, Participatory action research, Rural, Cocreation, Systems change, Health service, Lived experience leadership, Leadership model

Paper type Research paper

Introduction and context

In Australia, reform in mental health care is constant with history indicating a long line of inquiries, reviews, strategies and national plans (Australian Health Ministers, 1992; Australian Health Ministers' Advisory Committee, 2003; Commonwealth of Australia, 2009; Commonwealth of Australia, 2011; Department of Health, 2017; Productivity Commission, 2020; State of Victoria, 2021). A key expression of most of these processes has been the continuing failure of services to meet community needs and expectations. These include standards of safety and care, service availability or accessibility, consumer experience, carer/family inclusion, recovery orientation, integration with larger health systems and service models and service outcomes. Accompanying all reform efforts has been the consistent voice of consumers and carers calling for change, through detailed testimony on experience, iatrogenic traumas, gaps, benefits and preferred outcomes (Fisher and Spiro, 2010; Sweeney *et al.*, 2018). There has also been an increasing recognition of peer-led models and alternatives (State of Victoria, 2021).

A significant feature of local, state and national planning of services has been the involvement of consumers and carers in service planning and evaluation. Consumer and carer participation is the dominant way of organising and inviting people to have a voice in expressing experience, seeking change and shaping systems. Many would say that achieving consistent and sustained levels of lived experience involvement is variable and arbitrary in public mental health services with a range of well-documented barriers and limitations (Byrne *et al.*, 2019; Gee *et al.*, 2016). Many lived experience contributions are constrained in impact or co-opted via complex interests and processes shaping health service environments, including stigma and clinical paradigms. The challenges in reorientating towards a consumer-focused and defined-recovery approach are a key example (Le Boutillier *et al.*, 2015).

In more recent times, the creation of state and national Mental Health Commissions operating at higher levels of policymaking has arguably worked to increase opportunities and voice for lived experience (Department of Health, 2017). The growth of the lived experience workforce has also raised the profile and need for inclusion and recognition of the value of lived experience expertise (Byrne *et al.*, 2021). Similarly, the growth of the suicide prevention sector has occurred with increasing levels of lived experience influence and community action. In Australia, all governments are now encouraged to [. . .] "commit to integrate lived experience knowledge into national priority setting, planning, design, delivery and evaluation of suicide prevention services and programs [. . .]". And "[. . .] integrate lived experience expertise into leadership and governance structures" (National Suicide Prevention Adviser, 2020).

Lived experience leadership

> We want lived experienced leadership that rises out of our lived experience and reflects our unique learnings and experiences; we want leadership that is built on difference, creativity and deep participatory democracy; and we want horizontal power (not hierarchical power), shared networks, full consultation and networks of shared leadership roles (lived experienced leader participant).

During the 2000s, another paradigm of lived experience started to gain prominence. From a New Zealand context and consumer perspective, Gordon's (2005) paper encouraged a shift towards leadership in a way that transcended the common power relations of consumer participation, which often limited consumer and carer leaders to participating as advisors and consultants, rather than decision makers. Consumer leadership was about having leadership within:

> [. . .] the managerial and governance structures that plan, fund and deliver mental health services, the provision of service user managed and delivered services and the central involvement of service users in mental health advocacy, training, education and promotion (Gordon, 2005, p. 365).

Lived experience leadership as a concept, and as recognition of who leaders are and what leaders do, raises consciousness towards the widespread activities of psychiatric survivor, empowerment and consumer movements in mental health (Daya *et al.*, 2020). Although not always named directly as leadership, consumers have established the international peer work movement, and collectively promoted the recovery paradigm (Byrne *et al.*, 2018). Consumers also engage in program consultancy and governance (Cleary *et al.*, 2011), create, operate and manage consumer-run organisations (Grey and O'Hagan, 2015), lead community advocacy and awareness raising and prompt systems change (Campbell, 2020). Understanding the breadth of this work as leadership demonstrates the power of the concept, as it points to the role of leading change as well as actions across different levels of society. This includes a focus of formal activity within government and organisations and in public places, as well as informal work, such as local advocacy and support. If we think only from the perspective of public mental health services, we lose sense of the broad scope of leadership action and contribution (Scholz *et al.*, 2017).

In terms of leadership models, there is little in the way of established research. A key discursive paper is Mary O'Hagan's (2009) proposal for a model of leadership. O'Hagan (2009) argued that an understanding of leadership needed defining from the context of the lived experience movement, which already had established purpose, shared values and a shared history of injustice and disempowerment. These aspects provided the basis of understanding what leadership was for and how it could be evaluated. Generalist models such as transactional and transformational leadership had limited applicability and relevance given the assumptions of corporate or organisational positioning, or workforce leadership. O'Hagan's model proposed a leadership model featuring a moral purpose, and approach of "power with" rather than "power over", as well as appreciating diversity of lived experience. It also sought to define the key competencies qualities, skills and learning needs.

There has been some primary research on aspects of consumer leadership within public mental health services, most of it with an Australian focus. Qualitative work from Stewart *et al.* (2019) suggested that the leadership concept was undefined yet clearly evident in the roles that people with lived experience, both consumers and carers, play in public services. Participants in their study saw leadership evident across many of the common designated roles and activities. These included advocacy, representative work, support work, leading education and awareness raising, service evaluation and planning and in management funding and governance. The authors analysis found that leadership is about the key processes facilitating change. This change is based on a shared purpose, communicating, applying lived experience, influence of others, establishing relationship for change and contributing peer culture within mental health settings.

The Activating Lived Experience Leadership project

The ALEL project was a South Australian participatory action research (PAR) project (2019–2021), which aimed to raise the recognition, valuing and use of lived experience

leadership for systems transformation. As a research collaboration between, the South Australian Lived Experience Leadership & Advocacy Network (LELAN) and the Mental Health and Suicide Prevention Research and Education Group (UniSA), the work of the ALEL project was to generate an improved understanding of lived experience leadership. This was achieved by gathering insights from local leaders, including service and industry leaders, in creating a shared agenda for collaborative, systems change.

The need for the project was based on sustained observations about inconsistent recognition and support of lived experience leadership across metropolitan, regional and rural areas of South Australia. There are high-quality examples of partnership and shared leadership, ally support and peer workforce development across South Australia. Yet, the project observed that this was often dependent on sector levels and managers who understood, valued and embraced lived experience and also the hard-fought ground gained by individual lived experience leaders that could easily be lost. It was also felt that public health services invited leaders into positions to meet accreditation standards by having people or just one person with a lived experience on various committees without the adequate training, support and mentorship. These experiences were more widely felt in regional and rural South Australia, where there were less health resources to support leadership across large geographical spaces of country health services. However, rural South Australia also demonstrated significant grass roots lived experience leadership activity, in terms of advocacy, support group formation and contributions to suicide prevention activity and policy development. The numerous challenges of recognising, valuing, resourcing and embedding lived experience leadership, as well as its tremendous potential and justice based demands for change, required much stronger efforts for its systematic development and implementation. Resourcing and implementing a universal approach with education training and opportunities for building community and/or networking across the sector would be of extreme value in building the lived experience leadership in metropolitan, rural and remote areas.

A participatory action research approach (Baum *et al.*, 2006) was chosen to enable a focus on discovery, shared planning, action and reflection. With a systems focus, the project aimed to shift power dynamics and progress strategic and cultural change across the mental health ecosystem towards supporting lived experience leadership and enabling it to flourish. Generously funded through the Fay Fuller Foundation, we believe this was the most significant funding allocation towards researching and building capacity for lived experience leadership we have seen in Australia. The funding supported a full-time Project Director, 0.5 FTE Research Fellow and 0.3 FTE Research Assistant, for two years. Approval was gained from the Human Research Ethics Committee of the University of South Australia in January 2020.

Strategies of the project: an action research process

The project used specific qualitative methods within an overall participatory action approach (PAR). The project included specific data generation methods, including online focus groups (because of COVID-19) with lived experience leaders, and an online discussion forum with these participants; one-to-one interviews with sector managers from South Australia were also conducted. This was followed by a national online survey for lived experience leaders.

These research processes were augmented with project management, including engaging with a project advisory group of lived experience and sector representatives, information literacy workshops, a community of practice group run six-weekly plus two Systems and Sector Leaders' Summits and a project outcome launch where all project outcomes were

released to the sector. During the second Systems and Sector Leaders' Summit, a consensus statement was developed by those present (Hodges *et al.*, 2021b). This project also supported LELAN, a previously unfunded representative group, to establish its role as the peak body for lived experience in South Australia enabling leadership from LELAN to impact the mental health ecosystem on a broader scale. LELAN provided network leadership, consultancy with NGOs, systems advocacy and facilitated coproduction processes with sector organisations. The levels of recognition for the ALEL project reflected further significance with the South Australian Minister of Health launching its final products.

Participatory action research was used to guide the planning of all of these project strategies and specific methodologies relating to three points of data collection. As a methodology, PAR is highly suitable to working from a lived experience perspective and involving community. PAR is an inclusive approach with a social justice and emancipatory perspective (Benjamin-Thomas *et al.*, 2018). This approach flattens power structures, overcome barriers to involvement and recognition by democratising knowledge production and enabling transformative action (Benjamin-Thomas *et al.*, 2018).

The research team included two researchers with lived experience, a lived experience carer and a mental health nurse academic. Therefore, the project was lived experience led and focused with strategies for working collaboratively with the local lived experience community and leaders, service managers, executives and policy leaders. The interpretive work of the project was led by the team yet also collaborative with the project advisory group and research participants.

The project advisory group comprised seven lived experience leaders and five sector representatives, and met 12 times within the two-year timeframe of the project. The group worked through major planning decisions regarding project design, focus of the literature reviews, recruitment of formal research participants, focus group methods and schedules and interview schedules. The group also advised on project strategies for higher level engagement and influence with sector leaders. Once data collection for interviews and focus groups were complete, the project advisory group met to discuss themes of the data and outcomes.

The research-focused outcomes of this project have already been published by LELAN and UniSA as industry-level reports. These include a roadmap for strengthening lived experience leadership for transformative systems change (Loughhead *et al.*, 2021a), a model of lived experience leadership (Hodges *et al.*, 2021a), a consensus statement process for strengthening lived experience leadership for transformative systems change (Hodges *et al.*, 2021b) and a scoping literature review (Loughhead *et al.*, 2020).

Formal research methods

Focus groups

Seven online focus groups were conducted with diverse lived experience leadership participants across the community, including people from rural and urban settings, LGBTIQA+ communities, culturally and linguistically diverse groups and people with disability. Participants were emerging and experienced leaders and had worked in suicide prevention, mental health and peer work from the non-government and government sectors.

Focus groups were conducted online through a video platform and followed up with an asynchronous online discussion forum on a secure platform where all focus group members could contribute to further conversations on topics raised. A total of 31 lived experience leaders participated in the focus groups and discussion forum. Recruitment was purposive and snowballing, seeking an intersectional approach for inviting lived experience leaders to the project. All participants had experience in various roles such as community advocacy,

community speakers, peer support workers, awareness raisers, project workers and consultants.

Round 1 focus groups (Participant group 1) were followed by a double-blinded online discussion forum, which enabled anonymous commentary and reflection to occur on emerging findings with all focus group members in one forum. Round 2 focus groups were held again through a video platform, this time focusing on the required resources, education and practices to enable lived experience involvement in systems change. Mind maps were created and were used as a visual representation of emerging themes and key findings. These are reported elsewhere (Loughhead *et al.*, 2021b).

Interviews

The second data strategy featured interviews with mental health system and sector leaders (n = 14) (Participant group 2). Leaders were recruited purposively, and interview schedules were co-created with the project advisory group. These schedules focused on the challenges around holding lived experience leadership positions, such as barriers, enablers, impacts on personal recovery and suggested changes to drive systems change and enable lived experience leadership to thrive and have impact. Further mind maps were generated and discussed and compared with the focus group and forum participants. A summary report about the interviews is published elsewhere (Loughhead *et al.*, 2021c).

Surveys

A third data generation strategy was implemented with lived experience leaders (Participant group 3) via a national online survey. It was decided to offer the survey nationally to broaden the knowledge available and to explore data around the different investment and mobilisation efforts that have occurred across different jurisdictions around Australia. Specific lived experience and carer organisations were identified and invited to advertise the survey within their networks. A total of 48 responses were provided and analysed separately to identify themes. The results of the survey have been reported elsewhere (Loughhead *et al.*, 2021d).

Analysis, reflection and action

All qualitative data from the three groups of participants was coded and thematically analysed by the research team. A separate analysis was completed for each group. As an iterative process, emerging themes were then shared with participants and project advisory group members via text summaries and mind maps. This encouraged reflection and refinement of the themes over time, across the different participant groups involved. During communications, our work sought significant transparency in sharing our analytical processes and acknowledgement of our interests in seeking improved recognition of the lived experience movement and its value to organisations and systems when embraced.

The research team were also informed by the systems change approach of 'collaborative impact' and utilized their own systems change experience and practice. The "six conditions of systems change" were used as a framework to guide collaborative analysis and decision-making across our advisory group meetings, leaders' summit events and interpretation of data (Kania *et al.*, 2018, p. 4). Two System and Sector Leaders' Summits were also held in October 2019 and February 2021 (see Hodges *et al.*, 2019; Hodges *et al.*, 2021c) as a means of participatory action to test ideas and encourage a shared understanding, vision and commitment to change. Over 40 executive leaders across government and non-government agencies and sectors, including peak bodies, attended at least one of the summit meetings.

Results: the model of lived experience leadership

The formulation of the model (Hodges *et al.*, 2021a) occurred as a narrative synthesis of the themes and subthemes generated from the three participant groups outlined above. Initially, the themes and findings from each group were reported separately in project-level reports (Loughhead *et al.*, 2021b, 2021c, 2021d). A higher order analysis combining findings then brought together a rich array of characteristics, values, qualities and skills that participants identified as critical to effective leadership and the change that is generated by people with lived experience.

The overall model is represented by Figure 1. It is composed of six leadership themes as well as key values which guide the actions and decisions that leaders do and make, and their relationships with peers and others. Each of the six leadership themes refers to characteristics, qualities and skills identified through the research process. As the model states:

> The model embeds the values base of the mental health consumer movement and reflects an intersectional social justice approach [...] Lived experience leaders connect their personal, professional and socio-political worlds in unique ways to lead change, linking local experience with organisational and systems change endeavours. It operates both within and outside of roles, organisations and settings (Hodges *et al.*, 2021a, p.1).

(1) Centres lived experience:

- Works from lived experience lens and positioning.
- Stays true to recovery values and the peer movement.
- Recognises strength in vulnerability.
- Supports diverse lived experience: gender, sexuality, ability, culture and locality.
- Articulates distinction between consumer and carer perspectives.

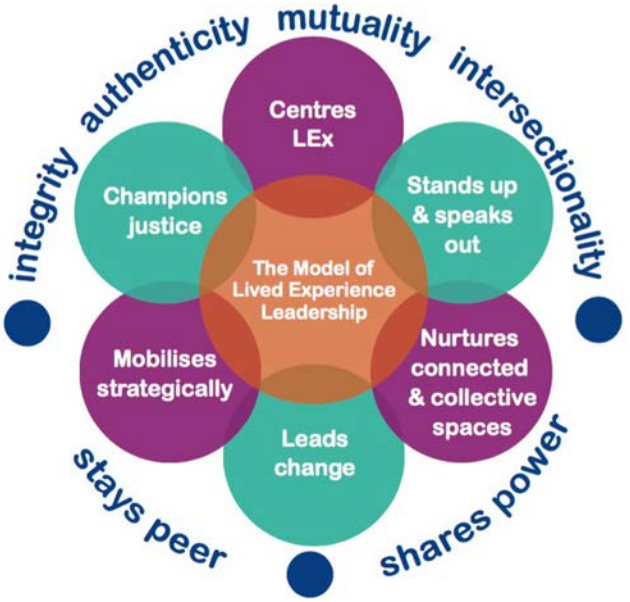

Figure 1.
Values and leadership themes

(2) Champions justice:
- Seeks to rebalance power in policy and service contexts.
- Interrupts and innovates for social justice.
- Challenges stereotypes, discrimination, and injustice.
- Advocates for authentic coproduction and opportunities for lived experience-led action.

(3) Mobilises strategically:
- Builds relationships and networks with peers and allies.
- Responds to dilemmas and complexity using peer values.
- Works for big picture and long-term change.

(4) Stands up and speaks out:
- Speaks with courage and conviction.
- Stands tall in "being out".
- Shapes communication and expectations effectively.
- Uses personal story and collective perspective appropriately.

(5) Nurtures connected and collective spaces:
- Creates safe spaces and empowers voices and action of others.
- Connected to consumer or carer lived experience movements.
- Supports own and others' self-care.
- Promotes peer culture and values.

(6) Leads change:
- Does not settle for the status quo.
- Communicates with influence.
- Builds collective responses and articulates solutions.
- Proactive in working with discomfort.
- Thinks deeply and reflects on leadership experience.

Discussion

There are many significant features of the model that could be discussed, particularly how it describes the range of characteristics and qualities that lived experience leaders often bring to their work. A key focus is how the model can stimulate awareness for policymakers and other leaders in mental health about lived experience, and how the model also offers a training/reflection opportunity for lived experience leaders themselves. The other two important features of the model are its grounding within the social movements of lived experience recovery, rights and empowerment and its connection to systems-level change.

Our analysis of the work and activity of lived experience leaders recognises that leadership occurs from a unique positioning that spans personal mental health experience, shared knowledge of peer conversations and connection to broader, consolidated values and knowledge of lived experience movements (Byrne and Wykes, 2020). Leading from a lived experience lens, people are simultaneously active across informal, personal, community and formal organisational spaces. Many of the leaders in the project operated in volunteer

spaces, were peer organisers and supporters, were active with informal social media posts, sat on formal committees as advisors or led discussions at community suicide prevention events. Some were employed in formal peer, project or policy roles. This recognition has many facets that we believe need better acknowledgement and understanding in the sector. The outside/inside positioning means lived experience leaders speak up from a position that is separate to institutional interests and the power that binds the perspectives and decision-making of professional groups, health bureaucracies and governments. This allows leaders to continually develop their leadership knowledge over time, by reflecting on the quality and outcomes of mental health planning and decision-making, and how different influences shape the response to lived experience voices (Campbell, 2020).

A theme from our research was that many leaders have been around in mental health for some time; they are aware of the "long game" of change and the need for a powerful voice and strategy. They see the "burn and churn" of committee work and policymaking, the slow development of progress, the gaps between person-centred care commitments and what they experience or what peers report their experience of service to be. As in the literature, leaders see the isolation of lived experience advisors (McDaid, 2009) and peers (Moran *et al.*, 2013), lack of authentic organisational commitments and invested partnerships (Scholz *et al.*, 2017). Leaders also experience contests with medical approaches (Byrne *et al.*, 2016) and co-option of ideas and concepts relating to recovery and peer work (Byrne *et al.*, 2018; Dent, 2011). Many leaders act from a critical analysis, often expressing the rich and inspiring themes of recovery and shared empowerment as well as insights, while also highlighting the impacts of met and unmet needs of iatrogenic traumas and harms and preferred support and care from mental health practitioners (Daya *et al.*, 2020). To overcome the historical legacies of disempowerment, stigma and "othering" mental health reform requires lived experience leadership as central to organisational and systems-level governance.

The unique lived experience lens, as either consumer, carer or kin, is more than a person being a "critical friend" to health service decision-making, as emphasised in the safety and quality movement (The Kings Fund, 2013). In social movement terms, the model's emphasis is on justice, change and rebalancing power. This points towards the importance of lived experience organisations and coalitions for influencing policymaking, and being key advocates and monitors for the resourcing, safety and quality of mental health services. These groups can also guide how systems should be improved given the experiences of consumers, families and kin of multiple sector services (Gee *et al.*, 2015).

Lived experience groups, while reflecting a diversity of views and political positions regarding psychiatry and treatment, comprise local support groups, information networks, peer worker networks, state peak bodies and associations (Campbell, 2020). Evaluation of the performance and quality of health services and systems, identification of suitable (recovery based) outcomes for services and the upholding of standards of care need to occur from the systematic involvement and leadership of lived experience, rather than being deferred only to established medical and professional interest groups.

The importance of organised lived experience leadership via peak bodies and third sector organisations has been acknowledged at the United Nations level as critical grounding for advancing the recognition and actioning of the Convention on the Rights for Persons with Disabilities (United Nations General Assembly, 2017). We suggest that the model, focused on leading change, championing for justice and human rights and grounded in the social movement lived experience lens, can be used to strengthen lived experience leadership as a central actor in mental health policy. This model has the potential for transformation of services and systems, including shifting mental models of stigma and "othering" that reside

in service culture (Knaak *et al.*, 2017), and in practices which are disempowering and erode personhood (Glover, 2012).

As lived experience leadership is strengthened and becomes more organised, it will include: decision-making about the design of services and systems; be embedded in governance structures; and leading funding and commissioning of new and innovative services (including peer models of service).

Such a vision points towards establishing senior leadership positions in national policy bodies and state health and human service departments (Government of Victoria, 2022) that carry decision-making power and control of budget resources (Scholz *et al.*, 2017). This vision also enables local development, including alternatives and truly peer-led initiatives where lived experience leadership can be strengthened across metropolitan, rural and remote communities. In this, lived experience leadership will be recognised for setting up local support groups, creating and holding safe conversations, advocacy for increased resources, proposing innovative community or peer sector solutions to distress, crisis and access issues. We suggest the model can be used to assist sector and service leaders to recognise this vision and the tremendous scope for service, organisational and community development that lived experience leadership offers.

The social movement focus of the model and its valuing of intersectionality highlight the connections with leaders whose activities occur in/across other areas of lived experience and public policy. While the model has been developed in the mental health lived experience context, it is relevant and applicable to other areas of lived experience leadership and emancipation given that the underlying positioning, values and characteristics of lived experience leadership are commonly shared by rights-based leaders across diverse public policy spaces. The model points to fundamental aspects of leadership and the value that lived experience leaders can bring to change not only within specific policy areas, but across them. An example might be the intersectionality of experiences relating to homelessness, domestic and family violence and drug and alcohol sectors. Intersectionality in this sense is complex, relating to layers of lived experience, identity and activity. Practically, however, this can encourage lived experience leaders and sector leaders in forming broader alliances and creating better ways for involving peers that meet identity and cultural safety preferences (Roche *et al.*, 2020; Uink *et al.*, 2020). As both allies and lived experience, leaders can enable opportunities for community learning, better recognition of needs and preferences and helping peers to navigate complex health and social service environments (Jeremiah *et al.*, 2020). This work can involve creating innovative pathways and resources that connect local programs/groups to a range of larger health/community services (Meridian, 2021).

A key discussion point of the model concerns its possibilities as a learning framework/tool to guide the training and development of lived experience leaders and articulate the knowledge and skill requirements of training programs (O'Hagan, 2009). All people come to the movement from unique experiences and life situations and memberships. There is great diversity, even across mental health in terms of the types and nature of mental health issues. There is also diversity in the advocacy goals that leaders seek as advisors, representatives and activists or as part of the peer workforce. And there are separate perspectives from consumers, carers, kin and allies (Daya *et al.*, 2020). The breadth of the model, in terms of a focus on social justice, rebalancing power and intersectionality allows different leaders to see how their thinking, activities and goals setting align to these broader aspirations and values. Additionally, the model expresses many central qualities and characteristics that help leaders identify and reflect on their own capabilities in these areas. How they might view strength in vulnerability, the processing of discomfort and conflict or responding to

dilemmas. How they may reflect on their communication skills and influence, their building of local networks and the links between their own self-care, recovery and what experiences support this. It also helps people to see that the spaces they step into as leaders have been forged by others, who have been pioneers for change and the allies and supporters of lived experience working with them. LELAN has already adapted the model into a reflective tool that people with lived experience are using within the organisation's evaluation of a leadership skills project.

Conclusion

This paper has described a model of lived experience leadership that was a key research product from South Australia's ALEL project. The model was derived from a participatory action research process using focus groups and interview data, and iterative layers of reflection and refinement via project team and advisor analysis. The synthesis brings together many characteristics, qualities, actions and skills that are expressed by people with mental health-related lived experience, who become active in leading change. Learning from the experiences, perspectives and reflection of ALEL participants, which included mental health service and sector leaders, the model sees lived experience leadership as grounded in social movement activity and offering unique insights, information and thinking that must be included at systems change level. The model helps to define how lived experience values, lens and positioning are grounded in recovery and peer mental health movements. The model also links with other justice-based movements, which focus on the inclusion, support and agency of different community groups. In this way, it is a framework which can offer learning opportunities and guide training and development, alongside raising recognition of policymakers, health profession leaders and health service executives that lived experience leaders will bring important qualities, informed insights, critical arguments and proactive solutions to the table. Lived experience leadership also aspires to organise, manage and deliver peer-based services. To overcome the historical legacies of disempowerment, stigma and "othering" mental health reform requires lived experience leadership as central to all areas within an organisation from governance to delivery of programs and services.

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