



Mental Health Lived Experience Advocacy

“A United Voice”

Pre-budget Submission 2022-23

Lived Experience Australia Ltd

Sharon Lawn

Chair & Executive Director

Phone 0459 098 772

slawn@livedexperienceaustralia.com.au

www.LivedExperienceAustralia.com.au

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Authors:

Professor Sharon Lawn, Chair & Executive Director

Janne McMahon OAM, Strategic Advisor

Christine Kaine, Manager Administration, Communication & Projects

De Backman Hoyle, Senior Collaborations Coordinator

Heather Smith, Marketing and Communications Officer

Introduction

For over 20 years, Lived Experience Australia (LEA) has been advocating on behalf of all those with a lived experience of mental ill-health, and their carers and family members. LEA is a national systemic advocacy, research, and capacity building organisation. It is also the peak for private sector consumers and carers. All board members and staff each have their own lived experience of mental ill-health as either a consumer, carer, or both. Because of this, LEA is an informed, authentic, lived experience organisation that is trusted by consumers and carers to understand and advocate for their unique needs and perspectives.

LEA feels a deep sense of responsibility for providing direction, and decision-making with lived experience expertise, and supporting government and the mental health sector more broadly to reform. We believe LEA has a role promoting a culture of engagement with consumers and carers in an active and meaningful way. We understand the need for destigmatising mental ill-health and base our work on our own experiences and those of others who share their stories with us.

LEA brings the voices of both consumers and carers together while recognising and appreciating the diverse views and different challenges the two groups may face, regardless of whether their experience is of public, private or non-government mental health services.

What makes us different is that LEA is a leader in and has a strong focus on using translational research to inform our systemic advocacy.

Over the past 2½ years alone, we have provided detailed lived experience research on: Adult Mental Health Centres; The Missing Middle Reports; Telehealth Psychiatry; Consumer and Carer Experiences of Psychology Services; Support needs of families of Veterans and Emergency Services First Responders; Review of Physical and Mental Health Care in Australia; and The Carer Experience Survey (SA), amongst others.

This is one of the most powerful and valuable assets LEA offers to government. Lived experience research, conducted by, with, and for, people with lived experience.

LEA provides this rigorous statistical and qualitative data, and diverse anecdotal data to ensure that lived experience is valued and embedded within mental health and suicide prevention reforms; enabling improved outcomes and experiences within mental health services.

LEA is a conduit for people with lived experience to have their voice heard and make a difference in mental health in Australia, with extensive existing networks in all states and territories.

We provide support to government in bringing lived experience perspectives that are essential to drive change at the national level. We champion the government in achieving national key deliverables and outcomes like the 5th National Mental Health and Suicide Prevention Plan, through our lived experience led research, submissions, and providing lived experience representatives.

The Challenge

In 2022 and onwards, there is a clear need and a tremendous opportunity for Australia's mental health system to be informed and driven by the knowledge, experiences, and perspectives of people with lived experience.

Lived experience is needed to drive mental health and suicide prevention reform processes. These are the people who are best placed to inform how we support those experiencing mental ill-health and implement solutions for prevention.

WITHOUT A SHADOW OF A DOUBT,
LIVED EXPERIENCE IS A 'MUST HAVE'.

Christine Morgan, CEO, National Mental Health Commission

Christine Morgan is leading the way in championing the need for strong, responsible collaboration and partnerships with people with lived experience. This need was articulated in Ms Morgan's launch of LEA's ground-breaking research report, [Lived Experience Perspectives and the Missing Middle](#) in March 2021.

One sector – many parts

The mental health consumer and carer sector has many organisations representing people with a lived experience; all with valid feedback and insights from the people they represent and advocate for.

For the government, this means having to work through a very large number of submissions and responses, and pieces of advice, with the potential for conflicting information and messages.

It is, of course, important to acknowledge that consumers and carers have unique and different experiences and perspectives of mental health care, and each have rights and advocacy needs of their own. It is an important recognition that, while carers may advocate for their loved ones, many have their own advocacy needs, and benefit from representation which is specific to this.

Through the coming months and years, as governments deal with increased mental ill-health because of COVID-19 and the effects of natural disasters affecting our communities, a strong and united mental health consumer and carer voice is the way to ensure the mental health and wellbeing of all Australians.

This can be achieved by bringing like-minded groups within the mental health lived experience sector into a coalition willing to collaborate for the greater good, based on shared values and a passion to improve the national mental health care system and outcomes for all consumers and carers.

This needs to be done in an integrated, focused, national way to be able to see better mental health outcomes, greater satisfaction with services, more engaged sector workers, and more community support for the government's ability to deliver high quality mental health care.

The Solution

A united mental health sector requires both leadership and passion, to bring the consumer and carer sectors together, across a range of mental health environments, in a collaborative effort to drive mental health lived experience across all levels of government, nationally.

This approach acknowledges the Productivity Commission's recommendation to establish separate consumer and carer organisations. This method ensures that both perspectives are considered individually yet collated and shared collectively for co-designing future policy and providing feedback to government on current models.

Building on a strong foundation

LEA is already committed to amplifying the voice of lived experience of consumers, and their carers and families, through engagement and participation. This is an essential approach that gives respect to people's human rights and represents genuine partnerships to deliver the best outcomes at individual, service, organisation, and systemic level.

Using LEA's 'four pillars'

- Systemic advocacy and advice
- Collaboration and partnerships
- Capacity building for people with lived experience and clinical staff and organisations
- Translational research to inform advocacy and advice to government

LEA will expand our existing structure to create separate consumer and carer arms, each with a

dedicated Manager to oversee engaging, collaborating, and coordinating activities, advice, representation, and advocacy.

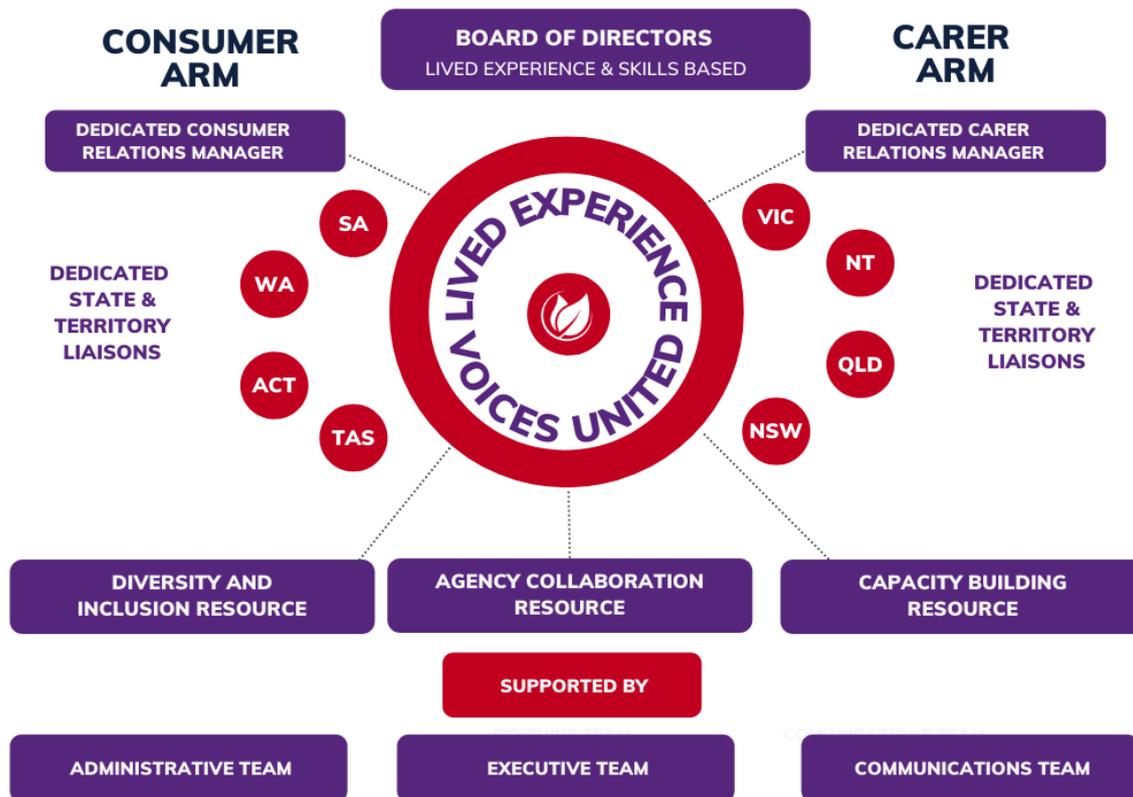
LEA will increase participation in the states and territories by mobilising Liaison Officers in each jurisdiction. These officers will enhance collaboration with local PHNs, mental health organisations and professional colleges whose workforces are tasked with delivering mental health services. Each state and territory will have dedicated equal feedback into advocacy and representation.

LEA will expand our strong relationships with public and private health organisations, state and territory governments, Commissions, mental health directorates, Chief Psychiatrists, and mental health advocacy organisations.

There will be an increased focus on diversity and inclusion, providing dedicated collaboration with expertise in Aboriginal and Torres Strait Islander, CALD, LGBTQI+, homelessness and other minority and priority groups.

LEA's capacity building resources will adapt and upscale to the changing needs of the mental health landscape. We will increase capacity building programs to support consumers, carers, and families in their advocacy, and clinicians and organisational staff. These opportunities to engage with and learn from consumers, carers, peer workers, agency groups, clinicians, and staff who participate, will further inform our advocacy.

As with all LEA activities, the solution will be designed, created, led, and staffed by people with lived experience of mental ill-health.



Dedicated consumer and carer arms representing the unique and differing needs of both consumers and carers while providing a single conduit for feedback to government.

Lived experience liaison officers in each jurisdiction to establish learning communities, expand existing State Advisory Forums, develop formal links with state and territory mental health bodies, and providing feedback on implementation of National Mental Health and Suicide Prevention Agreements.

A collaborations coordinator to seek out key collaboration opportunities across both public and private mental health sectors, to unite and strengthen the lived experience voice.

A Capacity Building Officer to coordinate capacity building for consumers, carers and clinical staff offering online modules, webinars, capacity building workshops, communities of practice (CoP) and mentoring support.

A Diversity and Inclusion Officer to increase engagement with minority representatives and ensure advocacy is representative of each community's needs.

This solution provides:

- Dedicated consumer and carer channels united through structure and leadership
- Collaboration with and advocacy for disadvantaged groups
- Expanded capacity building for consumers and carers
- Translational research-based data
- Significant outcomes and substantial return on investment for government funding

Lived Experience Community Benefits

- Passionate lived experience staff and board who understand the urgency for improved mental health for all Australians
- More lived experience people trained, enabling an increase in capacity and workforce capabilities
- Consolidating resources and sector intelligence through deliberate collaboration efforts
- A dedicated peer support hub, able to meet the increasing demands of consumers and carers
- A strategic approach to collaboration between agencies and peak bodies
- Valuable resources designed for clinical staff that have been informed, developed, and delivered by people with lived experience to improve clinical outcomes
- Exponential growth, impact, and achievement for consumer and carer representation and advocacy

Government and Agency Benefits

- A coordinated national approach to lived experience advice with representation across all states and territories
- Access to a pool of skilled, competent, and informed lived experience representatives available at short notice with experiences across a range of speciality areas
- Leadership that incorporates the needs of both consumers and carers and across both public and private mental health sectors
- Collaboration with other organisations to coordinate input of the issues and needs of the lived experience community
- A Committed partner as dedicated as the government in delivering best practice mental health
- Responsive access to lived experience driven data from LEA's translational research

Funding the Solution

The funds LEA seek are to enable all strategic activities to be realised over a three-to-five-year period. We have the leadership expertise, dedicated, competent and passionate staff, all with lived experience and a skills-based board that enables all LEA personnel to deeply contribute to better outcomes for consumers and carers, clinicians, and allies.

This funding will allow LEA to bring more consumers and carers into decision-making and allow them to participate in development of, and advocacy for, more appropriate, available, and affordable mental health services.

It also allows LEA to engage more deeply with all levels of government, and health services, collaborating to achieve improved outcomes for all mental health service participants across

public and private sectors. All additional roles required for this model to succeed will be staffed by people who have lived experience either as consumers, carers, or both.

The following investment would enable delivery of the entire scope of the service described within this submission. LEA is of the full belief that this investment request will provide significant returns for government.

Although another of the recommendations from the Productivity Commission is extending the funding cycle for advocacy peak bodies to a five-year minimum, to improve business planning and capability development, LEA has presented this budget based on both the current model of 3 years of funding and an extension to 5 years.

LEA would welcome the progression to a five-year contract term.

Budget	Year one 2023/2024	Year two 2024-2025	Year three 2025/2026	Year four 2026/2027	Year five 2027/2028
Salaries	797,000	813,000	829,000	846,000	863,000
Core activities	185,000	189,000	192,000	222,000	229,000
Overheads	113,000	115,000	117,000	119,000	121,000
Capacity Building Program	50,000	50,000	50,000	50,000	50,000
Totals	1,145,000	1,167,000	1,188,000	1,237,000	1,263,000
Total funding required over 3 years = \$3.5 million Total funding required over 5 years = \$6 million					

Why LEA?

Recognised Leadership

LEA has achieved national recognition twice; first as the winner in 2015 for *The Mental Health Services Awards for Australia and New Zealand* for the Consumer Led category: Significant and sustained consumer and carer advocacy.

In 2021, LEA was announced as the winner in the *Lived Experience Leadership* category of *The Mental Health Services Awards for Australia and New Zealand*. This recognition was for significant and sustained consumer and carer advocacy with the citation reading: Making a difference with and for consumers and carers.

This was achieved through our activities and their translational impact, particularly over the past 3 years, with an increasing number of submissions to support inquiries into mental health and suicide prevention, our capacity building program and our lived experience led research achievements.

LEA leadership is requested for plenary and symposium speaking engagements at conferences, webinars, by the media, and at inquiries as a trusted and authentic voice for lived experience.

Experience and Maturity

LEA has operated within the mental health sector since 2002, evolving from a private health sector focus, to now supporting all Australians with a lived experience of mental ill-health.

Organisational Impact

LEA has provided >60 submissions to state and federal governments in just over two years. These have provided the voices and perspectives of lived experience in a consolidated, coordinated way.

On a national level, LEA has contributed to (amongst others) the Productivity Commission Inquiry, The 2021-2022 Federal Government Budget \$2.3 billion announcements for mental health, The Prime Minister's National Suicide Prevention Officer Final Advice, Vision 2030, NDIS Reforms, COVID-19 Effects, Obesity Strategy, and the Development of Peer Workforce Guidelines.

Our state input has included Victoria's Royal Commission into Mental Health, a review of Victoria's Mental Health Legislation, Aged Care Reforms in South Australia, a Review of Western Australia's Mental Health Legislation, the South Australian Suicide Prevention Bill, and the Queensland Mental Health Commission's establishment of a consumer organisation.

In addition, we take great pleasure in the testimonial feedback we receive through our research and capacity building arms that show the impact of our work. Examples of this feedback are provided on page 12.

A strong history of collaboration

At the Federal Government level, LEA has established ties with the Assistant Minister to the Prime Minister for Mental Health and Suicide Prevention, Minister for Health and Aged Care's senior advisors, Deputy Chief Medical Health Officer for Mental Health, the Prime Minister's Advisor on Suicide Prevention, National Mental Health Commission, Department of Health and the NDIS Mental Health Advisor via quarterly meetings or as needed.

At the State Government level, LEA has established relationships with State-based Mental Health Commissions and Chief Psychiatrist/Mental Health Directorates.

LEA has existing collaborations with the Royal Australian and New Zealand College of Psychiatrists, the Australian Psychological Society, Australian Clinical Psychology Association, the Australian Private Hospitals Association and Private Healthcare Australia. We also work with national organisations including Mental Health Australia, Community Mental Health Australia, National Mental Health Consumer Carer Forum, and Mental Illness Fellowship of Australia to name a few, along with many state-based and grassroots consumer and carer organisations.

Appendix 1: Annual Report 2021 Summary provides an overview of our core work over the past 12 months.

Appendix 2: Strategic Plan 2019-2022 provides an overview of our focus areas over the past 3 years.

LEA's Impact

The following testimonials have been received by LEA through forums, webinars, and many other avenues.

This feedback motivates us to continue in our work to support all Australians to improve the mental health system.

Clinician and Staff Feedback

"The work you do changes the lives of patients and the healthcare system" – sector stakeholder

"[LEA's training] encouraged me to reflect on how to undertake recovery-oriented practice which resulted in me looking further than just the consumer, towards their primary and secondary carers and extended care network. Prior to undertaking these modules, I had a poor understanding of the vital role that carers have in our consumers lives. Now I have realised that I need to make sure that I am not acting as a barrier to the consumer receiving the right supports" – Psychiatry registrar

"I gained an insight of some continuous improvement I can implement in my project work when talking to organisations who utilise our Reps to make sure they are trauma informed" – Staff webinar attendee

"I am part of designing a new service and we have been involving consumers throughout the process. My next step will be to work on formalising a consumer engagement strategy so that consumer and carer input can be embedded into organisation practice once the new service opens" – Staff webinar attendee

"After doing the module, I could reflect on the fact that consumer and carer involvement is the cornerstone of every clinical interaction" – clinician completing LEA online modules

Consumer and Carer Feedback

"The information presented was leading edge and powerful and supported by discussion in the chat" – Webinar Participant

"The training empowered my life. I now want to be a Peer Worker. I now have control of my life in being able to help others" – Cert IV MH Peer Work LEA Sponsorship recipient

"Personally, it makes me more validated. Now I know how to use my lived experience. I feel more like an equal worker in my clinical team" – Cert IV MH Peer Work LEA Sponsorship recipient

"Thank you for this opportunity to take part. It is exciting to feel part of a larger undertaking re peer work nationally" – Webinar participant

"[LEA's training was] personable and practical. Giving personal examples and connecting it to how they have used their experience to deal with the same issues. Giving other resources to go and explore in the same areas" – Webinar participant

Research Participants' Feedback

"Lived experience of consumers and carers needs to work together with organisations and utilising each other's strength to move forward not for our personal gratification but to improve service deliveries that will be beneficial to our wider community"

"Thank you very much for allowing me to be heard and to have my say. I really, really appreciate it"

Lived Experience Australia

SINCE 2002

influencing
**MENTAL
HEALTH**
POLICY & REFORM

OUR CONNECTIONS

2218



1072



357



165



3,812

OUR COLLABORATIONS & PARTNERSHIPS

Representation

37

- 12 Department of Health
- 1 Department of Social Services
- 5 State MH Commissions
- 5 ACSQHC
- 12 Other Organisations



Partnerships

22

- Governments
- Hospitals
- Mental Health Organisations
- Universities
- Agencies

Projects

3



Carer Guide Online Library



Carer Guide Self Assessment Portal



BPD SA Services Website

OUR ADVOCACY

25



Submissions

5



Media Releases

30

OUR RESEARCH

2



Large Scale University Projects

6



Small Scale University Projects

3



Research Positions

11

OUR TRAINING

1863



Consumers & Carers Attending

1005



Staff Attending

24



Communities of Practice

1048



Vimeo Webinar Downloads

3,940

OUR FINANCIAL SUPPORTERS

- Department of Health
- Royal Australian & New Zealand College of Psychiatrists
- Australian Private Hospitals Association
- Australian Psychological Society
- Healthscope

This is a summary of our 2020-2021 Annual Report - see the full report on our website.



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Appendix 2: Strategic Plan 2019-2022

Our vision: To promote effective consumer, family and carer advocacy as the driving force behind all changes in mental health services

SYSTEMIC ADVOCACY	RESEARCH	CAPACITY BUILDING	PARTNERSHIPS & COLLABORATION	SUSTAINABILITY
Lived experience is at the forefront of mental health policy and planning	Lived experience evidence base is created with the voices of consumers and carers	Lived experience influences service design and mental health practice	Making a difference together	Sustainability to support an ongoing, collective voice for consumers, families and carers
<p>We will do this by:</p> <ul style="list-style-type: none"> Ensuring that the issues which impact the lives of mental health consumers, families and carers are raised nationally. Advocating for changes in mental health services to better address the needs of consumers, families, and carers. Representing consumers, families and carers and the Australian community with a strong, collective voice. 	<p>We will do this by:</p> <ul style="list-style-type: none"> Having a national, lived experience-led research agenda that seeks the voices and experiences of consumers, families and carers and translates this to inform systemic advocacy and change in mental health service provision. Mentoring and creating a supported space for people with lived experience to join us in undertaking lived experience-led research. 	<p>We will do this by:</p> <ul style="list-style-type: none"> Providing capacity building training for consumers, families, carers and peer workers in areas such as advocacy and leadership. Providing capacity building training and mentoring for organisations and staff to effectively engage consumers and carers in service design, delivery and evaluation. Providing annual awards for clinicians demonstrating best practice in consumer and carer inclusion. 	<p>We will do this by:</p> <ul style="list-style-type: none"> Working in collaboration with Government and organisations across the mental health system to support changes that value, respect and acknowledge lived experience perspectives. Expanding existing partnerships to add strength to our work. Engaging with new organisations to promote the interests of consumers, families and carers. 	<p>We will do this by:</p> <ul style="list-style-type: none"> Expanding the membership of our state-based advisory forums. Seeking opportunities to develop partnerships that strengthen our work and support our long-term investment in advocacy. Increasing our capacity by recruiting key personnel with lived experience.



Contact:

Professor Sharon Lawn
 Executive Director, Lived Experience Australia
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