

Lived Experience Australia

Annual Report

2023



Lived Experience
A U S T R A L I A



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Acknowledgement of Country

We acknowledge the traditional custodians on the lands on which we undertake our work, and we pay our respects to their Elders past, present and emerging. We recognise and respect their cultural heritage, beliefs and continual relationship with the land.

Acknowledgement of Lived Experience

We recognise all people with lived experience of mental ill-health and recovery, and those who are carers, family members, supporters and kin. We acknowledge that we can only provide leadership in systemic advocacy through valuing, respecting and drawing upon their lived experience expertise and knowledge. We acknowledge their enormous contribution to our work.

Introduction from LEA's Chair & Executive Director

Lived Experience Australia's activities during this 2022-2023 financial year reflect a very big year of community activity and engagement in reform and renewal. No doubt, our path out of the COVID pandemic had a lot to do with this and the establishment work by the incoming Labour government as we began this period.

I can't think of another time when there have been so many policy reform processes set in motion. With it came a wave of consultations and advocacy opportunities across multiple big issues and multiple parts of the mental health and psychosocial disability sector and community. Across all of Lived Experience Australia's four strategic pillars (Advocacy, Research, Capacity Building, and Partnerships and Collaboration), we have seen an exponential increase in our activities and impact.

So, my first thanks must go to the incredible support I've received this past year from Lived Experience Australia's dedicated Board and staff who have worked so hard during this very lively time. My second thanks must go to our community of friends who have shared their lived experience expertise, skills, and ideas with us. This includes the many people within our Communities of Practice

and Representative Panel. Without your commitment, courage, and passion in sharing your lived experience voice, much of our work would not be possible.

Our four pillars have again served us well in focusing our efforts. We have maintained strong advocacy representation through forty seven significant national working groups and committees and thirty submissions. These covered a wide range of topics including big issues like eating disorders, family violence, Robodebt, long-COVID, unpaid carer leave, cancer care, better access to psychological therapies, telehealth, NDIS, physical health and mental health, and more.

As part of our commitment to larger and even deeper engagement with the issues that impact mental health, our four Pillars stand individually yet also integrate and inform each other. For example, our lived experience projects (which are largely identified and drawn from concerns raised by our grassroots 'friends' communities), provide essential lived experience evidence to inform our advocacy.

Our research projects have shone a light on important issues such as loneliness, and its mental health and physical health impacts. The increase in our partnerships in many national research projects is a sign that LEA has a trusted reputation for amplifying lived



Sharon Lawn

Chair and Executive Director
Lived Experience Australia

experience voices. These partnerships have allowed us to focus research on physical health and mental health and new models of service that include the lived experience Peer Workforce. As the Peer Workforce continues to make real strides across our mental health service systems, Lived Experience has proven to be a provider of choice for capacity building for the lived experience sector and for the many organisations who are striving to build a culture of inclusion for Peer Workers.

All this work would not be possible without the support of many individuals, and generous collaboration and partnership with many organisations. Together, our advocacy is stronger. I particularly wish to thank the Australian and New Zealand College of Psychiatrists (RANZCP), the Australian Private Hospitals Association (APHA), Australian Psychological Society (APS) and Healthscope. I also want to thank our many lived experience colleagues and allies across so many organisations representing consumers and carers for your

generosity, collegiality, and commitment. It has been so great working with you this year.

The future seems promising. There are several major reviews that will deliver recommendations over the coming year. With these comes the opportunity to participate in yet more advocacy, which we willingly raise our hands for. We are here to play our part in the significant mental health reforms that will no doubt arise out of these.

Lived Experience Australia's goals are clear – to continue ensuring that we bring strong lived experience voices to the many tables to influence change that will improve the lives of all those impacted by mental ill-health, distress, and psychosocial disability.

Warm regards,

Sharon Lawn

About Lived Experience Australia

For over 20 years, Lived Experience Australia (LEA) has been advocating on behalf of all those with a lived experience of mental ill-health, their carers and family members.

We are a national systemic advocacy, research, and capacity building organisation, and are also the peak for private sector consumers and carers. All board directors 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 broader mental health sector to reform.

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. LEA is a conduit for people with lived experience to have their voice heard and make a difference to how mental health services are provided in Australia.

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.

We are 100% lived experience!

All LEA board directors and staff have a lived or living experience of mental ill-health as consumers, carers or both.

Our four pillars

Lived Experience Australia (LEA) is committed to amplifying the voices of lived experience of consumers, families, carers, and kin, 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 levels.

LEA provides four key pillars of focus for our work:

1 ADVOCACY

Our representations and submissions enable lived experience voices to be heard by decision makers and considered in policy development, service design, and evaluation.



2 RESEARCH

We collect lived experience voices to strengthen our advocacy and learn what is important to individuals. This expands the lived experience evidence base to support system-wide improvements.



3 CAPACITY BUILDING

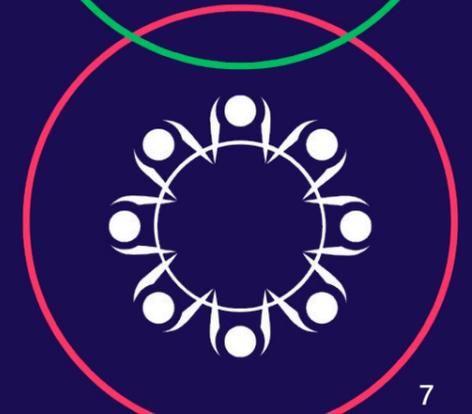
Our learning programs cover two key areas:

1. To build capacity and capabilities of consumers and carers in their own advocacy and representations; and
2. For clinicians and service providers to effectively engage and partner with consumers, carers, families and kin.



4 PARTNERSHIPS & COLLABORATION

We work with other organisations to strengthen lived experience voices and partnerships. We come together to increase our impact and improve mental health services.





1. Advocacy

Our submissions are informed by the experiences and input of individuals with lived experience of mental ill-health and their families, carers, and kin. Feedback is sought through surveys, research, focus groups, advisory forums, and our large panel of lived experience representatives who provide insights across a diverse range of experiences.

47 government and national working groups and committees provided with lived experience representation

30 formal submissions from lived experience to shape mental health policy and reform

12 State and Territory advisory forums held to identify local priorities for advocacy action

Examples of the working groups and committees LEA representatives provided input into this year includes:

- ACSQHC Mental Health Advisory Committee & Patient Safety Reporting Project
- Australian Health Policy Collaboration Strategic Advisory Group
- Australian Private Hospitals Association Psychiatric Committee
- Better Access Evaluation Committee
- ICARE Expert Advisory Committee
- Mental Health Australia Board
- NDIS Stakeholder Reference Group
- Australian Eating Disorders Research & Translation Centre National Network Advisory Committee
- DVA Families Strategy Lived Experience Advisory Group
- National Mental Health Consumer Carer Forum
- Equally Well Advisory Group
- SA Lived Experience Workforce Taskforce Committee
- Royal Australian and New Zealand College of Psychiatrists Clinical Practice Guidelines
- SA office of Chief Psychiatrist Human Rights and Coercion Committee
- World Association for Psychosocial Rehabilitation Australia Branch
- World Federation for Mental Health Advisory Committee

A key strategy to support Government reform and service design and evaluation is LEA's ability to source and facilitate lived experience focus groups to hear from those with lived experience about what works and important considerations prior to decision making. We are trusted by the lived experience community to provide safe, inclusive forums where individuals can share their lived experience perspectives related to the topic area. Our extensive networks and broad reach enable us to engage with a diverse range of lived experience perspectives.

"On behalf of all lived experience peers, I would like to say thank you for reaching out and having the opportunity for all of us to provide valuable feedback... I can say it sure is exciting times and life changing work we all do together. Thank you for all the great work Lived Experience Australia does through empowering others to have a voice and promote self-advocacy."

- Georgina Moshudis (feedback following consultations to develop a national self-care charter)



2. Research

"I appreciate you sharing [Loneliness in Mental Health] with me and commend LEA on its compassionate portrayal of loneliness and social isolation.

I have asked the Department of Health and Aged Care to share this report with the National Health and Medical Research Council for their information in relation to growing evidence around social determinants of health. I also share in your acknowledgement of people with lived and living experience of mental ill health who participated in this research and shared their stories and suggestions..

I am grateful to hear from people with lived or living experiences of mental ill-health. Thank you and the team at LEA for your extensive work to facilitate such partnerships, and to embolden diverse lived experience voices."

- The Hon Emma McBride MP, Assistant Minister for Mental Health and Suicide Prevention

This year LEA has seen an increase of 62% in the number of research projects and collaborations compared with the previous year. We completed three major national research projects including 'Understanding Loneliness and Mental Health' with the RANZCP Community Collaboration Committee, 'Development of a Self-Care Charter' for the National Self Care Alliance and 'Mental Health Advance Directives & My Health Record' for Mental Health Australia.

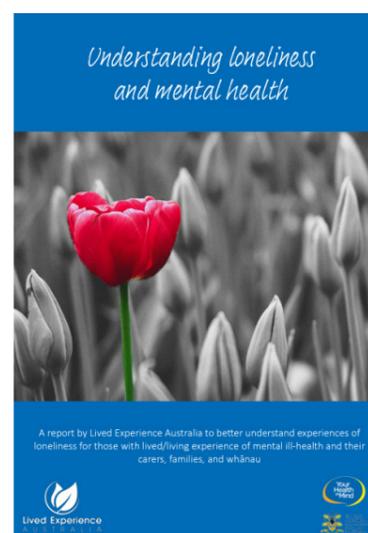
18

University research partnerships exploring:

- Understanding personal recovery among individuals with gambling harm and co-occurring issues and their families and friends in the NT
- Peer Workers in Primary Care
- Variation in Community Treatment Orders across Australia
- Veteran suicide projects
- Personal recovery needs and mental health carers
- Increasing the capacity of community managed organisations to provide preventative care for people with mental health conditions
- Borderline Personality Disorder as a social phenomenon
- Building the capacity of community mental health services to address chronic disease risks of people with mental health conditions.

3

independent research projects including Loneliness and Mental Health; Carer Experience of Service (SA) and My Health Records & Advance Care Planning.



"Thank you for sharing the Understanding Loneliness and Mental Health Report with the [QLD Mental Health] Commission. I would like to congratulate Lived Experience Australia for your work on this report and for raising awareness of the impact of loneliness. This study has brought a clearer understanding of the definition and impact of loneliness for readers. The lived experience comments included in the report have painted a good picture about what people's experiences of loneliness is like.....research like this one will raise awareness for the general public and the health sector"

- QLD Mental Health Commission

[View Lived Experience Australia's research
livedexperienceaustralia.com.au/research](https://livedexperienceaustralia.com.au/research)



3. Capacity Building

Lived Experience Australia provides online learning, webinars workshops and customised in-service training. The aims of our capacity and capability building programs are to support individuals with lived experience in their representation and advocacy roles, support the peer workforce, and support clinicians and service leaders with appropriate and effective lived experience engagement and partnership.

This year we sponsored another \$1,000 Lived Experience Australia Award for Best Practice in Consumer and Carer Inclusion with the Royal Australian and New Zealand College of Psychiatrists. The winner, Dr. Calina Ouliaris reflected on their approach to bring together mental health service providers and GPs in a 'Circle of Care' approach.

1,565

Consumers, carers and peer workers accessed training (increased by 36%)

667

Clinicians and service leaders accessed training (increased by 80%)

1,011

Active online learning user accounts (increased by 89%)

836

Online courses completed by consumers, carers, peer workers, and clinicians (increased by 31%)

29

Online learning courses with 56 individual modules (increased by 93%)



"I am thrilled to inform you that the workshop had a profound impact on my ability to deliver an impactful speech at Parliament House. When I spoke there in November, my message was powerful, but I failed to provide direct calls to action. I unintentionally left the politicians an easy way out by using phrases like "I hope you can make something happen"... However, things took a different turn when I had the opportunity to speak again at Parliament House following the Writing for Advocacy Workshop. As a direct result of the workshop, I was able to provide clear and actionable steps.

I am delighted to share that the office of Emma McBride has reached out to me.... I believe this positive response is, in large part, thanks to the invaluable skills and knowledge gained from the Writing for Advocacy Workshop."

- Hayley Harris - Lived Experience Representative and Peer Lead



4. Partnerships & Collaboration



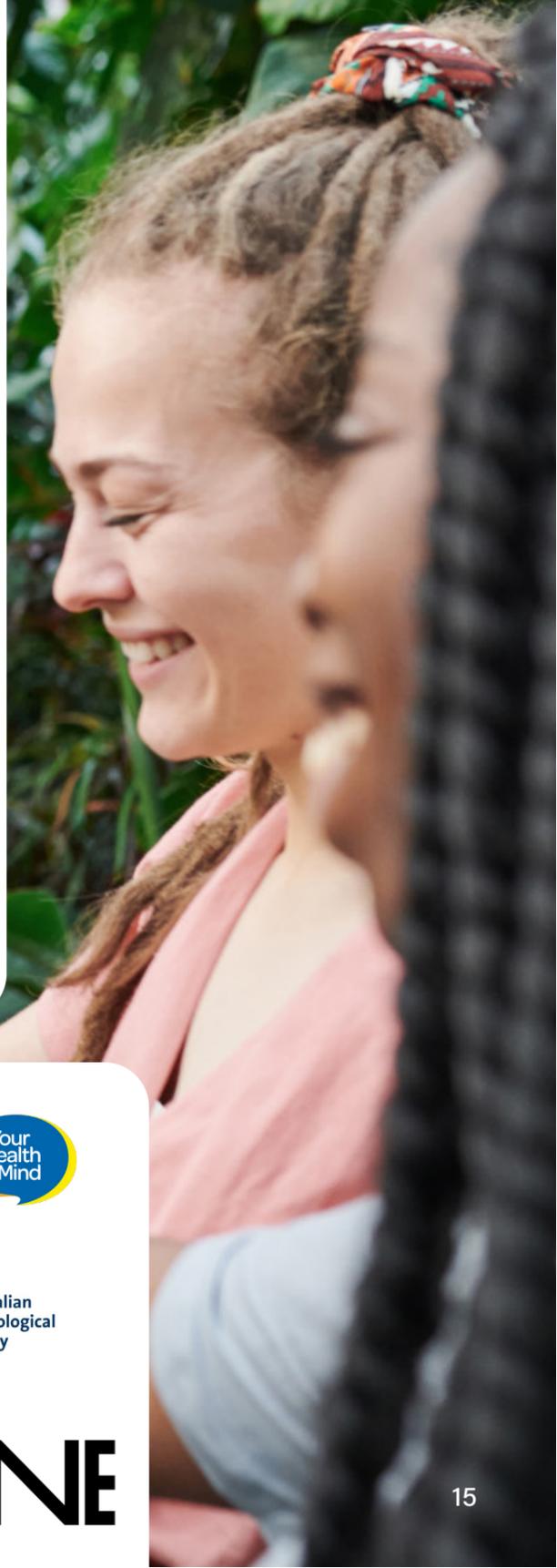
Effective lived experience advocacy cannot be done in isolation. We are stronger when we work together, and Lived Experience Australia has many partnerships to support our combined efforts to improve mental health services. Examples of partnerships this year include:

Australian Government - LEA's Executive Director, Sharon Lawn was invited by The Hon Mark Butler MP, Minister for Health and Aged Care to join as an expert member of the Mental Health Reform Advisory Committee established to guide consultation and engagement with the sector and people with lived experience to help shape the future of mental health reform.

National Indigenous Radio Service (NIRS) - LEA provided an interview with NIRS exploring how loneliness can impact mental health over the Christmas period and strategies for support during this time.

In Tough Times Text (ITTT) - LEA formed a close collaboration with the ITTT team, providing lived experience voices to support this resource that offers downloadable texts which can be forwarded by friends and family to a person who is experiencing suicidal thoughts. ITTT is helping them 'find the words' that may just make all the difference.

Australian Psychological Society (APS), Australian Clinical Psychology Association (ACPA) - LEA partnered to provide joint media releases advocating for improved psychology services and support for the psychology workforce.



Here are some of the organisations we collaborated with this year:

Click the logos to learn more about each organisation

Build your own path to better health



Choosing self-care to reduce health risks enables me to live well, and creates better health outcomes for me

The Australian Self-Care Alliance approached LEA to lead the development of a Self-Care Charter for individuals with lived experience of chronic health conditions (inclusive of mental health and allied health services).

The Self-Care Charter was informed through extensive consultation with service users. The project involved a series of focus groups with consumer-focused/chronic condition advocacy self-care organisations and a survey distributed to the wider community of service users.

Following this work, we were subsequently engaged to support endorsement of the charter from key health organisations. The outcome of this work was launched in July 2023 with over 30 organisations formally endorsing the finalised self-care charter.

View the charter and supporters at selfcarealliance.org.au/self-care-charter

Resources for the Australian Commission on Safety and Quality in Health Care (ACSQHC)

ACSQHC approached LEA to develop resources for the lived experience community to support the National Safety and Quality Mental Health Standards for Community Managed Organisations.

The resources were co-designed with a lived experience working group and informed by extensive focus group consultation with a range of demographics including minority communities.

The final resources were delivered to the Commission in early July and are expected to be released later this year.

We are continuing to work with the Commission to develop a series of videos to accompany these resources.

Communications & Social Media

LEA has a range of communication channels to provide updates and opportunities for advocacy, research, capacity building, and partnerships. We also regularly promote important news in the mental health sector and provide information through our networks for smaller organisations who may not have the reach we do.

LEA has seen substantial growth over the past 12-months in our marketing and communications following.

Our network of Friends (subscribers) increased by 27% to a current membership of 2,137 subscribers. Subscribers acting on our information in our emails is 17% (the industry average is 3.29%).

Of note, our LinkedIn following increased by 228%. This highlights the value of our communications through this professional network

Click on the icons below to join us on your preferred platform.



Growth in subscribers



Growth in social media

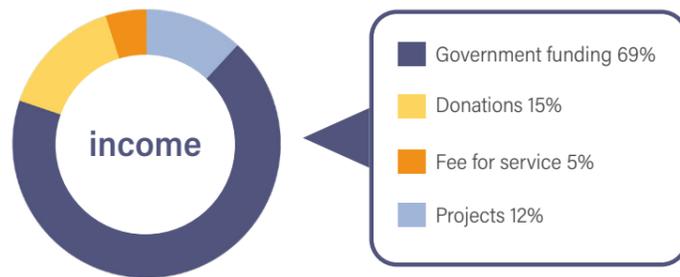


Growth in website visitors



Financial Snapshot

We would like to thank those that have supported Lived Experience Australia over the past year with funding and donations. We can only achieve the outcomes we do with the kind contributions from our collaborators. LEA limits overheads and administration costs with staff operating from virtual offices across Australia. We focus over 86% of our total expenditure on direct service delivery.



\$464,000

Total revenue 2022-23



Lived Experience Australia is a registered charity. To contribute to our advocacy, research, and capacity building you can [donate](#) via our website, or [contact us](#) for more information (donations are tax deductible).

LEA's Board

We would like to thank our Board Directors who continue to volunteer their time to support the achievements of Lived Experience Australia.

Board Directors as at 30 June 2023:

Sharon Lawn | Lorraine Powell | Simone Allan | John Khateeb

During the year, we also said goodbye to the below long standing Board Directors. We would like to say a special thank you to each of you for your time, commitment and dedication to LEA.

Darren Jiggins | Judy Bentley | Helene Langley

In July 2023 we commenced a process of external recruitment to appoint four additional Board Directors to continue guiding our activities in 2023-24 and beyond.

Staff and regular contractors

Sharon Lawn, Chair and Executive Director, SA Coordinator

Christine Kaine, Operations Manager

Heather Smith, Marketing & Communications Officer

Emily Unity, Webinar Coordinator

Liz Asser, Training Coordinator & Facilitator

Heather Nowak, Facilitator

De Backman-Hoyle, Facilitator

Lorraine Powell, WA Coordinator

Simone Allan, NSW Coordinator

Janet Milford, QLD Coordinator

Carmel Denholm, TAS Coordinator



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