

2024

ANNUAL REPORT

Lived Experience Australia Ltd



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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.

From the Chair

After my own diagnosis of ADHD a few years ago I experienced the challenges of navigating the private mental health sector first hand. I am also a practising pharmacist who has seen the effects of mental ill-health not only on individuals, but also their carers, families and kin. I was successful in joining the LEA Board in 2023, leveraging my experience serving on boards and committees within the pharmacy sector.

This year we were pleased to welcome two other new Directors to our Board, bringing a diverse range of experiences both professionally and through personal lived experience. We also said goodbye to long term Board Director and NSW Coordinator Simone Allan who finished her final term at LEA at our 2023 AGM. We would like to thank Simone for her dedication, commitment, and support since she commenced on LEA's Board in 2016.

Our focus this year has continued to be on strengthening our governance framework,

realising our strategy (aligned to advocacy, research, capacity building and partnerships), and refining our core



Krysti-Lee Patterson
Chair, LEA

values. Earlier this year we held a strategy day attended by our Board, operational staff and contractors from across Australia. What I was most taken by at this event was the openness, genuineness and dedication from ever person in the room.

On behalf of LEA's Board, I would like to thank Sharon Lawn and Christine Kaine who led our operations team for the significant outcomes and impact we have seen this year. We also send our appreciation to all of our staff, contractors and lived experience representatives who help us achieve all that we do and who are essential to our success.

Krysti-fee Patterson

Responsibility:

We make a difference, persevere, and have a strong responsibility to our community.

Tenacity, Courage and Determination:

We understand courage because we live it ourselves. We are prepared to challenge the status quo and always strive for improved mental health services and system reform.

Integrity and authenticity:

We provide opportunities for all voices to be heard. We advocate authentically, sharing stories and experiences respectfully.

Our values are more than statements, our team live and breathe our values in the decisions we make and actions we take every single day.

From the Executive Director

Lived Experience Australia's activities during this 2023-2024 financial year reflect the hard work, passion and commitment that the LEA team delivers every day to advocate for public and private mental health system improvement and build capacity for lived experience voices to be heard in mental health reform across Australia.

It has been another year of significant achievements, strengthening existing partnerships and making many new friends with equally committed advocates, allies and organisations in the mental health sector.

LEA has been highly engaged in the government reform agenda, which has been moving at a significant pace and with a substantial agenda during this past year.

There have been many inquiries focused on the big structural issues within the health and mental health system and in the wider community that impact mental health and wellbeing across the life course. It has been an exciting time to see the enormous goodwill and evolving maturity in the sector; a real sense of opportunity to make reform count.

Across all of LEA's four strategic pillars (Advocacy, Research, Capacity Building, and Partnerships), we have seen an exponential increase in our activities and impact. This could not be achieved without the wonderful staff team that supports and

works alongside me to deliver on our activities, and the support of the LEA Board.



Sharon Lawn
Executive Director, LEA

I want to thank our

large and loyal 'Friends' network across the country, and particularly our representative panel members whose lived experience expertise and contributions to our work is undeniable. It's been a real pleasure to connect with you, work with you, and serve you.

I have greatly valued the enormous support and collegiality shown by the many colleagues and collaborators in organisations also working with us to improve mental health policy and services. We've had a lot of fun, learned a lot too, and established enduring relationships and friendships which no doubt are central to sustaining us all in this often-challenging work.

I look forward to continuing to work with you all to elevate mental health lived experience voices. Thank you.

Sharon Jawn

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 and their families, carers
and kin.

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
lived or living experience of mental
ill-health as consumers, carers or both.

Our Four Pillars

Lived Experience Australia (LEA) is committed to elevating the voices of lived and living experience from 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, community, 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, families and communities. This expands the lived experience evidence base to support system-wide improvements.

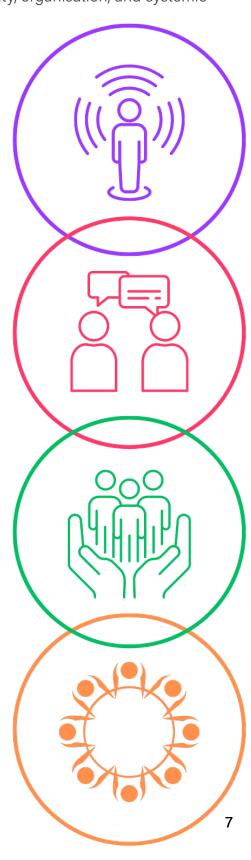
3 CAPACITY BUILDING

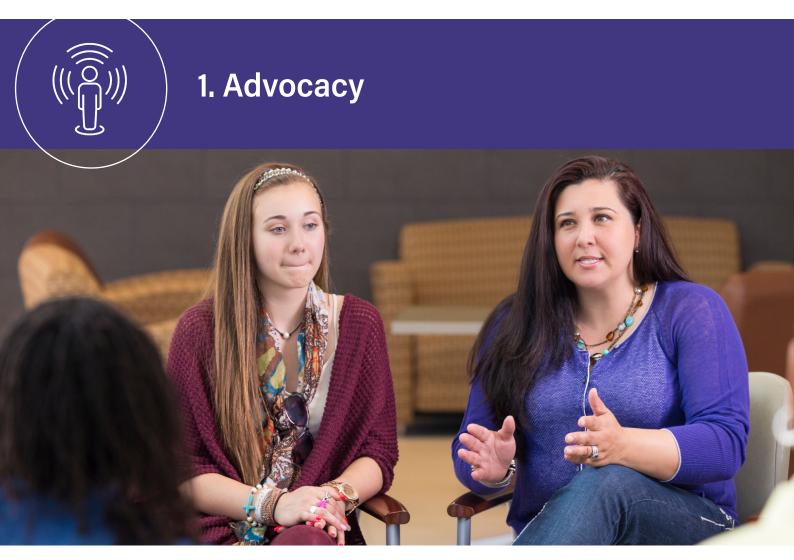
Our learning programs cover two key areas:

- 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

We work with other organisations to strengthen lived experience voices and partnerships. We come together to increase our impact and improve mental health services and the Lived Experience (Peer) workforce.





Lived Experience Representative Panel

Our Representative Panel continues to be an important part of providing responsive lived experience input to support Government, service providers, researchers and projects. Our representative panel currently has 85 members and continues to grow. Panel members bring their extensive experience covering a broad range of lived and living experiences, from locations across Australia including metro, rural and remote locations, representing diverse perspectives such as Australia's First Nations people, CALD, LGBTIQA+, gender, NDIS recipients, disabilities, and a broad range of socio-economic backgrounds.

This year we continued to support organisations with their engagement of lived experience perspectives including providing representatives and faciliating training, consultancy and support for safe and inclusive focus groups and interview processes. We have also facilitated focus groups and provided lived experience peer support for organisations commencing the lived experience engagement journey.

"On behalf of the team at the Pharmaceutical Society of Australia, thank you very much to you and LEA for your nominees to last night's focus group. They were an impressive group – fully engaged, informed and spanning many lived experience perspectives. There were many rich insights arising from the discussion that will now be reflected in the report."



Our submissions are informed by lived experience input from consumers, families and carers through focus groups, surveys, research, and advisory forums. This year we were invited to present at the Parliamentary Inquiry into the recognition of unpaid carers and appeared at the Senate Hearing for NDIS rural perspectives. We are able to provide extensive lived experience representation thanks to our diverse and engaged Representative Panel.

"I have enjoyed being a part of this project and have learned a lot about the crucial input of LE personnel from the outset of a project. If I had read a hundred articles, I would still not have come up with some of the important messaging that emerged from these groups."

- Researcher involved in our Gambling Harm Resources project for the Office of Problem Gambling (SA)

Working group examples:

- Minister Butler's Mental Health Reform Advisory Committee.
- Australian
 Private Hospitals
 Association
 (APHA)
- NDIS National Stakeholder Reference Group
- Royal Australian and New Zealand College of Psychiatry through multiple committees
- Australian

 Eating Disorders
 Research and
 Translation Centre
 National Network
 Advisory
- Equally Well DMAAC Committee

- Orygen's Lived Experience Reference Group for Social Inclusion Research
- Human Rights and Coercion Reduction Committee (SA)
- National Psychosocial Support Advocacy Alliance Committee
- National Mental Health Consumer Carer Forum
- Mental Health Australia, Board and Governance Committee
- Australian Self-Care Alliance, Lived Experience Board

Advocacy submission examples:

- NHMRC Consumer Statement
- Early Childhood Health Checks
- Unleashing Workfaorce Terms of Reference & Scope of Practice Reviews
- NDIS Registration of Providers, NDIS Rural Experiences, and NDIS Review
- After Hours Primary Care
- Royal Commission into Defence and Veteran Suicide Entity
- COVID-19 Response Inquiry
- National Housing and Homelessness Strategy
- National Eating Disorders Strategy
- Disability Services Inclusion Bill
- National Consumer Engagement Strategy
- Recognition of Unpaid Carers



This year LEA has continued to focus on strengthening evidence through lived experience research to support advocacy. We commenced 13 new research projects as partners during the year, with a further 4 research projects completed.

We also provided to the Department of Health and Aged Care a rapid review of international peerreviewed literature, and targeted environmental scan of the grey literature, to identify innovative service delivery models to support increased engagement of the peer workforce for the Department of Health and Aged Care.

Our key research partners this year include:

- Flinders University
- SANF
- Orygen
- AMHOCN
- Equally Well, Charles Sturt University
- The Matilda Centre, University of Sydney
- Monash University
- Monash Rural Health
- TANDEM

- Central Adelaide Local Health Network
- RMIT
- La Trobe, University of Melb, University of Sydney, University of QLD
- ALIVE, University of Melb
- Australian Health Policy Collaboration (AHPC), VIC University
- B-Hart

- Office of Problem Gambling (SA)
- University of Newcastle
- Australian Commission on Safety and Quality in Health Care
- Riverland Academy
 of Clinical Excellence,
 Riverland Mallee Coorong
 Local Health Network
- University of California San Francisco



Research projects partnerships exploring:

- Supporting social inclusion-focused care for people with mental ill-health including loneliness.
- Identifying social determinants of mental health for young people from refugee backgrounds to improve mental health.
- Understanding personal recovery among individuals with gambling harm and cooccurring issues and their families/friends in the NT
- Development and evaluation of Lived
 Experience Peer Support Intervention for
 Mental Health Service Users in Primary Care
- Increasing the capacity of CMOs to provide preventive care to people with a mental health condition
- FACTORS: Factors affecting community treatment orders research study.
- Consumers and carers as Physical Health Care Navigators in rural Australia.
- We also provided opportunities for Advanced Medical Studies students to partner in LEA research including:
- Men's experiences of disengagement from mental health services
- Men's experiences of loneliness
- GPs', psychiatrists' and MH nurses' perceptions of responsibility for metabolic monitoring of for people with schizophrenia treated with antipsychotic medications
- Mental health professionals' attention to consumers' physical health: consumer and carer perspective
- Oral health and mental health
- Cancer screening and mental health.

- Bringing consumer/carer lived experience expertise to inform improved service responses to distress, suicidal thoughts and actions.
- BPD as Social Phenomena
- Impacts of implementing the Living in the Community Questionnaire for consumers and Mental Health professionals
- Building capacity of community MH services to address chronic disease risks of people with a mental health condition
- No-women's-land: female veterans, gender, transition and support for mental health
- Experiences of Seclusion and Restraint.
- Personal recovery needs of people who experience severe mental health challenges.
- A study of CES and YES surveys.
- Mortality of people using MH services and prescription medications.
- In-Tough-Times-Text suicide prevention

"Thank you for providing me such a wonderful, safe and respectful experience within the group. This is what co-design really looks like."

- Lived Experience Working
Group member



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 and to 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 Natalie Puchalski, reflected on the importance of consumers and carers as being an equal part of the care team and collaboration towards a formal plan and a collective care plan that can be shared with subsequent providers promoting continuity of care.

1,262

Consumers, carers, peer workers, leaders and clinicians accessed training

1,624

Active online learning user accounts







Our most popular workshops and programs facilitated this year:

For consumers, carers and peer workers:

- Communities of Practice
- Sharing your lived experience story to influence positive change
- Boundaries and self-care
- Advocacy Skill Building

For organisations and clinicians

- Organisational readiness for lived experience/peer workers
- Integrating lived experience into our workforce
- Establishing and improving lived experience communities



"I wanted to extend a heartfelt thank you on behalf of the Perspectives 2024 team for your generous support and invaluable training to assist our speakers in preparing for the event. The feedback from our speakers regarding the training sessions has been overwhelmingly positive. They've expressed how instrumental these sessions have been in refining their presentations and enhancing their overall preparedness for Perspectives 2024. The contribution of Lived Experience Australia has undoubtedly played a significant role in ensuring the success of our event, and for that, we are truly grateful."

- Hayley Harris, Lived Experience Project Lead Finding North Network

"I enjoyed and learnt so much from both the presenters and every member of the group. There was so much information to absorb and I feel I will draw on the resources provided and the input of every participant and the group's leaders for years to come. I am inspired and uplifted and more hopeful than I anticipated."

- Lived Experience Participant

"I learned that lived experience needs to be echoed throughout the organisation. That we need to apply principles across existing staff, and we need to be aware that for non-identified lived experience roles who are drawn on organisationally for their expertise. We need to be careful not to burden them with this responsibility. We also need to respectfully know that they are okay to share this expertise rather than assume in some cases"

- Organisational Readiness Participant

https://learn.livedexperienceaustralia.com.au



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 is an expert member of the Mental Health Reform Advisory Committee, established by The Hon Mark Butler MP, Minister for Health and Aged Care to guide consultation and engagement

with the sector and people with lived experience to help shape the future of mental health reform.

Australian Private Hospitals Association Psychiatric Committee

Lived Experience representation to Australian Private Hospitals Assoc Psychiatric Committee alongside the CEOs of Australia's private hospitals. Together we completed significant shared advocacy on private hospital closures, workforce shortages and financial viability.

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





























Royal Australian and New Zealand College of Psychiatrists (RANZCP)

LEA is a member on multiple committees including the Community Collaboration Committee, Committee for Research, Gambling Harm Reduction Guidelines, Gender Equity Committee and the Steering Committee overseeing Hereco Independent Review of Clinicial Guidelines within the college. LEA also provided two symposia in partnership with the College on Human Rights and Mental Health and the Future Development of Clinical Practice Guidelines.

Patient Voice Initiative

In collaboration with 52 other diverse consumer-led organisations representing 14 million consumers of health services across Australia, LEA provided mental health lived experience voice to advocacy on the safe use of medicines, with submission to the national Health

Technology Assessment (HTA) Policy and Methods Review Committee.

Mental Illness Fellowship of Australia (MIFA)

LEA's Executive Director, Sharon Lawn collaborated with MIFA to deliver an address on lived experience of Unmet Need to the Parliamentary Friends of Mental Health at Parliament House in Canberra. This collaboration delivered powerful national advocacy for psychosocial disability reform.

TANDEM and Monash University

LEA joined in this heartfelt partnership to develop and deliver a significant project on Carers' Human Rights that included a workshop with almost 100 family carers at the TheMHS conference Carer Day. This work has led to the group developing 'A joint statement of rights for Australian families, carers and supporters in mental health.'

Patient Voice Initiative

























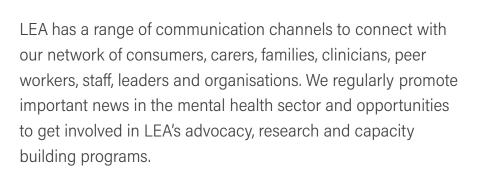








Communications & Networks



LEA continues to see significant growth in our network reach.

Our network of subscribers increased by 45% to a current membership of 3,110 subscribers. We have an average of 15% action rate with subscribers engaging with our eNews (the industry average is 3.29%).

Our total social media following increased by 221%. Of note, our LinkedIn following increased by 132%. This highlights the value of our communications through this professional network

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





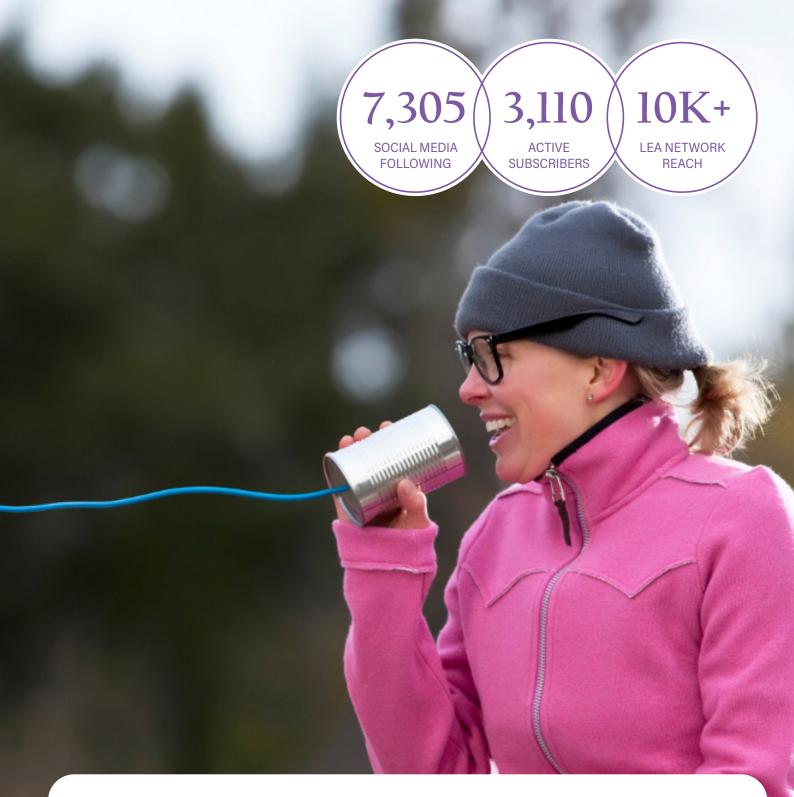






45% subscriber increase





Examples of media interviews and articles:

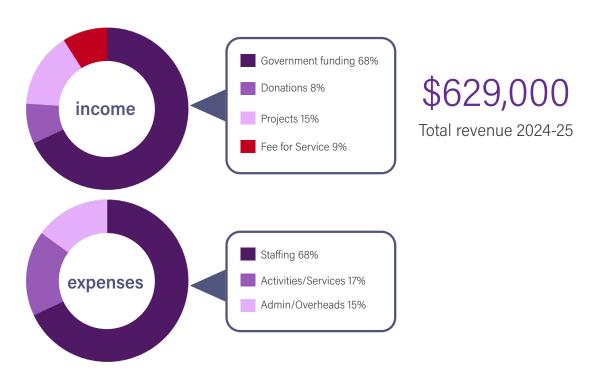
This year we engaged in a number of media activities with interviews and articles including:

- "Unmet Need: Holes in South Australia's Mental Health System" interviews with SA and National Radio channels, article in <u>InDaily</u>
- "Impacts of lack of services for adult ADHD" interviews with <u>ABC TV 7pm News</u> and ABC
 Radio and <u>ABC Online article</u>
- "Are Mental Health Issues Impacting your Workplace?" Article in Human Resource Director

 Magazine

Financial Snapshot

We would like to thank those that have supported Lived Experience Australia over the past year with funding and donations to help us achieve our objectives. We appreciate the Australian Government Department of Health and Aged Care for funding LEA as the national private mental health advocacy peak and to our major donors this year including the Royal Australian and New Zealand College of Psychiatrists (RANZCP), the Australian Psychological Society (APS) and the Australian Private Hospitals Association (APHA). We continue to limit our overhead costs focusing over 85% of total expenditure directly for activities and services.





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

Our People



Krysti-Lee Patterson

Board Chair



Sharon Lawn

Executive Director



Paul Milne Board Director



Zsofi de Haan Board Director



Lorraine Powell Board Director



Christine Kaine
Operations Manager



Heather Smith

Marketing & Comms

Coordinator



Liz Asser
Training Coordinator
& Facilitator



Heather Nowak
Facilitator



De Backman-Hoyle Facilitator



Lorna Downes
Facilitator



John Milham

NSW Liaison Officer



Gerard McDonald VIC Liaison Officer



Carmel Denholm

TAS Liaison Officer



Janne McMahon, OAM
Founder, Patron
& SA Liaison Officer

LEA can only achieve what we do with the help of our dedicated team. Thank you to all of our Board Directors, Patrons, Staff, Contractors and our Representative Panel for your contributions to our successful outcomes in this year.

Above is our team at 30 June 2024.



Professor Allan Fels, AO

Patron





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