Service and Program Awards Application Cover Sheet

Category: Lived Experience Leadership

Entry Title: Making a difference with and for consumers and carers

Name of Applicant: Lived Experience Australia Ltd

Organisation: Lived Experience Australia Ltd
Lived Experience Australia has more than 20 years’ experience in understanding and advocating for the needs of mental health consumers and carers. We are a recognised peak body for mental health consumers and carers across Australia, with a focus on the private sector and system-wide advocacy. Every board member and all staff have a lived experience of mental ill-health as a consumer, carer or both. As consumers and carers ourselves, we have direct insight into the experiences of those who are going through mental ill-health and the people who support them. Lived Experience Australia is a public company (limited by Guarantee) and is recognised as a charity by the ACNC and a Health Promotion Charity by the ABR.

Since its inception, we have become an integral part of key policy and decision-making processes affecting many Australians, providing a strong representative voice for mental health consumers, families, and carers. We facilitate the sharing of the lived experience of mental health problems, address common issues, and encourage people to seek help.

We operate with a small team of 4 staff (2.3 FTE) with an additional 6 consumers/carers who hold positions as Board Directors and/or State Advisory Forum Coordinators and a multicultural officer. We also have a ‘Representative Panel’ comprising skilled and experienced consumer and carer advocates. Members from this panel are available to participate in key advisory groups or on committees regarding consumer and carer inclusion. Representatives have participated in Government, Private and Community Mental Health Sector advisory groups, panels, inquiries, conferences, and presentations.

We are a small organisation that makes a big impact in the field of mental health.

From grass roots to governance level we are in tune with the needs of consumers, families and carers in mental health and advocate for improved services, policy, reform and outcomes at state and national levels.

Lived Experience Australia:

- Transforms mental health services and policy through our lived experience advocacy
- Supports policy development and planning using insights based on mental health lived experience led, co-designed, and rigorous research
- Represents people who have a lived experience and those that care for them
- Develops resources that educate and support consumers, carers and clinicians to work in partnerships for the best outcomes for all
- Conducts professional, ground-breaking research about matters affecting people’s mental health and the broader mental health system
- Has a database of over 2,000 consumers, families, carers and service providers who are key to providing feedback and insight regarding mental health policy, design and evaluation.
Address the following Criteria (max. 10 X A4 pages).
Judges allocate marks to each criterion

1. Evidence of a significant contribution to the field of mental health on a local, state or national level.

We have four (4) key areas of focus: advocacy, research, training and national projects. These are some of our notable achievements providing significant contributions to the mental health sector in these areas of focus.

1. Advocacy - We are active advocates in the mental health sector. We hold the respect of Government and have been invited to appear before ten federal parliamentary inquiries and made eighty-three formal submissions to Government (twenty-four in the past 12 months). In 2020 alone, LEA provided submissions to 12 inquiries, including the Royal Commission into Aged Care Quality and Safety, the Productivity Commission Inquiry into Mental Health, and the Suicide Prevention Taskforce.

Our expertise is regularly sought on expert working groups and committees, national forums and boards, providing mental health consumer and carer representatives from a range of backgrounds, experiences and expertise (last year we provided 27 formal representations for the Commonwealth, state governments and non-government organisations), and

We facilitate regular State Advisory Forums across Australia which provide us with up to date, grass roots consumer and carer perspectives on issues of state and national significance.

2. Research – We have undertaken many national research projects exploring Borderline Personality Disorder, National Standards (Carer Participation), adult mental health centres, telehealth psychiatry services, the ‘Missing Middle’, and service provider engagement with consumers and carers. More details are provided under the next section 2. Our research is lead by Professor Sharon Lawn and Ms Janne McMahon, Executive Director and includes our own research along with many research projects undertaken in partnership with several Australian Universities which recognise LEA’s high standing and expertise as a lived experience peak.

3. Training – We are committed to advancing the peer workforce nationally and therefore provide sponsorships for up to 12 consumers and carers to undertake Certificate IV Mental Health Peer Work (each year: 2019-2021). Our training includes communities of practice and mentoring for consumers and carers, as well as specialised training for clinicians and service providers. This training draws on lived experience expertise and provides emerging advocates with the opportunity to develop their skills and confidence to support effective consumer and carer engagement and inclusion, now and in the future.

Among our many training courses available, we developed 5 online modules for clinicians titled ‘Consumers and Carers as Educators’ that provide practical guidance on how to involve consumers and carers in meaningful ways in patient centred care models. These modules are endorsed by the Royal Australian and New Zealand...
Annual Awards ‘Best Practice in Consumer and Carer Inclusion’ - We provide two annual awards for Clinicians focused on best practice partnerships with consumers and carers. The first annual award is with the Royal Australian and New Zealand College of Psychiatrists (RANZCP) for psychiatric trainees who undertake our Consumers and Carers as Educators modules and write a reflective piece on how the learnings have changed their clinical practice. Over the past 3 years, 35 psychiatric trainees have applied for the award which is presented to the winner at the annual RANZCP Congress. The second annual award is with the Australian Private Hospitals Association (APHA) which has been introduced for the first time in 2021 with the winner to be announced in October this year. This award has the same criteria and requirements for clinicians undertaking the online module as detailed above.

Our first winner in 2019 was Dr Katherine Moss. Katherine reflected that: *The modules have encouraged me to see the consumer as an individual person – with hopes, aspirations and plans for their life – above and beyond a diagnosis or illness. In addition, the modules have highlighted to me the importance of working alongside the consumer and their carers towards recovery. In the future, improved communication and collaboration with the consumer, carer and health practitioners will help me to understand what the consumer was like before they became unwell, what the consumer wants their future to be like and what recovery looks like from the consumers perspective. By looking past the illness, I hope to be able to see more clearly who the individual is, and assist in their journey of recovery*.

Our second winner in 2020 was Dr Sally Sinclair who is a Psychiatry trainee working within acute adult mental health. In her feedback after undertaking the learning modules, Sally said “*The modules have highlighted and re-emphasised the importance of several areas in which I can change my clinical practice. A key message from the modules was the frustration individuals (consumers, carers and health professionals) experience when appropriate implementation of collaboration, communication and cooperation does not occur*”.

Our third winner in 2021 was Dr Catherine Tarning who said “*These modules 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*.”
Our connection webinar series - In early 2020 during COVID-19, we provided a series of six fortnightly webinars with over 100 consumers and carers attending each webinar. The webinars were aimed at promoting and facilitating connectedness for the mental health lived experience community during uncertain times. Webinar recordings are available on our website. This is what some of the participants had to say:

- *This was a great way to connect. Lovely to see many peer workers on here too.*
- *I just wanted to say how much I felt connected to everyone and it was a positive experience. I also have now got more resources for my work as a Peer Specialist.*
- *I am fairly new to LEA, having attended my first state Forum in March. I found it very interesting and informative. I also found this webinar, my first, most informative and helpful. Thank you!*
- *I managed to join one webinar live and watch the others later. They have been very informative, thank you.*

Advocacy Skills Building Programs - we provide webinars, online training, a 2 x 2-hour zoom training series and most recently added a Communities of Practice to support consumers, families and carers to enhance their skills and build confidence and effectiveness in their advocacy efforts.

Certificate IV in Mental Health Peer Work Sponsorships – We approached the Australian Government Department of Health, to seek funding to cover course fees for 12 people per year over 3 years (36 in total) to complete their training in this national qualification. As a requirement, each applicant must have a lived experience of mental ill-health either as a consumer or carer. To date, we have sponsored 24 consumers and carers to undertake the training with a further 12 to be selected later this year. One successful applicant responded to this opportunity saying, “*Words can't describe how excited I am to finally be able to gain more skills and knowledge around my lived experience.*”

Training and Webinars for Staff and Clinicians – we provide webinars, online training modules and workshops (facilitated by consumers and carers) for staff and clinicians to support inclusion and engagement with consumers and carers including models for consumer/carer committees.

4. National Projects

We have undertaken nine (9) significant national projects including ‘Identifying the Carer Project’ across both private and public mental health sectors (Commonwealth Government); A National feasibility study into the development of a national membership organisation for the Peer Workforce (National Mental Health Commission); and A Practical Guide to Working with Carers of People with a Mental Illness (national collaboration with Mind Australia, HelpingMinds, Mental Health Carers Australia and Mental Health Australia) which also included an online library, App, self-assessment tools and an organisational reporting portal. In addition, we piloted the Practical Guide with a number of South Australian services which
highlighted the positive impact of implementing the Partnership Standards within the Practical Guide on practitioner and service engagement with carers, highlighting the translational value of this work. Full details of each of these projects is available for anyone to freely access via our website

2. Evidence of innovation and/or recognised best practice.

LEA has a very active research program, established in 2011 and headed by Professor Sharon Lawn and Janne McMahon, provides national research and published papers, contributing to mental health best practice and innovation in policy, reform and service delivery.

Our approach to our research is:

- Informed by lived experience perspectives
- Undertaken by lived experience researchers
- Used by lived experience advocates
- Informs processes from a lived experience perspective
- Used as the driving force for change in policy, practice and reform nationally.

The purpose of our research is to bring the perspectives, experiences and needs of both consumers, families and carers, which must be recognised and acknowledged, into the forefront of policy and reform processes of service planning, design, implementation, and evaluation.

This enables us to provide a translational research base into our advices and advocacy.

**Borderline Personality Disorder (BPD)** – the first issue we researched was Borderline Personality Disorder in 2011. We conducted research to explore the experiences of both consumers with a diagnosis of BPD and the experiences of their carers; the largest survey so far of its kind nationally and internationally on BPD.

- 2015: Experiences of Consumers with the Diagnosis of BPD – cited in 83 publications by mental health researchers internationally (Google Scholar)
- 2015: Experiences of Carers Supporting Someone with the Diagnosis of BPD – cited in 56 publications by mental health researchers internationally
- 2019: Stigma perpetuation at the interface of mental health care: a review – cited in 28 publications by mental health researchers internationally

In 2017 we conducted this research again to understand if the NMHRC Clinical Practice Guidelines for the Management of BPD had made a difference to the experiences of consumers and carers. We have published the following papers linked to this research:

- How are the NHMRC BPD guidelines faring in practice? A consumer perspective.
- Stigma perpetuation at the interface of care
- The Importance of Relationship in Understanding the Experiences of Spouse Mental Health Carers
- BPD, early development and peer victimisation: Australian family carers’ perspectives
The ‘Missing Middle’ – Lived Experience Perspectives - This research is the first of its kind in Australia and sought to understand why people don’t engage or why they disengage from mental health services, what happens to them and what it would take from services to re-engage them (a question that they have never been asked before). This data provides, for the first time, lived experience perspectives into the discussion that has, until now, been unavailable. The voices and statistics of 535 people who responded are captured in our landmark reports which were launched by Ms Christine Morgan Prime Minister's National Suicide Prevention Adviser and CEO of the National Mental Health Commission in March 2021. The reports faithfully detail the experiences of consumers, families and carers which were confronting and compelling in a way that cannot be ignored:

- **Lived Experience Perspectives** – this is the full research report analysing data collected from consumers and carers accessing both private and public mental health services across Australia.
- **Missing Middle 'Our Voices'** - in their own words. This powerful document gives voice to those who have these lived experiences.
- **Lived Experience Perspectives - Private Sector report** analyses data from consumers, families and carers who access predominantly private mental health services and private psychiatric hospitals.
- **Lived Experience Perspectives - Private Psychiatric Hospitals Report** analyses data from consumers, families and carers accessing private psychiatric hospitals.

We are now undertaking further exploration of this research to understand:

- Experiences of accessing General Practitioners as the first and last ‘port of call’, and
- What is needed to support people to re-engage with mental health services.
- Whether experiences of engagement, disengagement and re-engagement differ by gender, age or location

**Telehealth Psychiatry Consultation National Survey** – a national collective voice of consumers’ and carers’ experiences of accessing telehealth psychiatry services. This research provided input and influence to the 2021-2022 budget announcement including the commitment by the Government of $204.6 million to extend telehealth.

**Adult Mental Health Centres** – providing consumers and carers perspectives which was used to inform and advise the technical group responsible for development of 8 new adult mental health centres across Australia. This data provided input into the 2021-2022 budget announcement of a further 24 satellite centres.

**A Practical Guide for Working with Carers of People with a Mental Illness** – we were the lead organisation in this national consultation project to inform the
development of this Practical Guide in partnership with Mind Australia, HelpingMinds, Mental Health Carers Australia and Mental Health Australia. Following the development of the Practical Guide, we undertook further research and demonstration projects including:

- **Collaboration in Care with Family Carers**
- **Implementing Carer Partnership Standards**
- **Carer Guide Demonstration Project with Ramsay Health Care**

**National Peer Workforce Feasibility Study** – We were engaged by the National Mental Health Commission to undertake work to investigate the feasibility of establishing a member-based national organisation for the peer workforce in Australia. Our Final Report explores potential governance structures and models of a national organisation which is being used to support further exploration of this model. We created a full research report, summary report, tip sheets to support peer workers during COVID-19 and a literature review of best practice models in mental health peer work to inform the establishment of a national professional membership organisation.

3. **Evidence of participation of mental health consumers in the planning, implementation and evaluation of mental health service delivery. Evidence of prioritising increased level of engagement and influence of consumers and where higher level participation such as authentic co-design is highly favoured.**

Mental health consumers and carers are central to all of our work. All staff and Directors have a lived experience as consumers and/or carers, demonstrating clear participation in the planning, implementation and evaluation of all service delivery.

We have a database of over 2,000 consumers, families and carers that are key to accessing local, state and national information and data to inform activities, research and our advocacy efforts. Our national surveys allow us to maintain strong reach and consultation, which empower people with lived experience to have direct input into mental health reform. The data from these surveys is analysed and reports generated which are distributed to government, our advocacy peers in other mental health consumer and carer organisations, other relevant entities such as workforce and regulatory bodies, and the public sector to inform implementation and evaluation of mental health service delivery.

Our representative panel of consumers and carers are sourced to participate in working groups, consultations, forums and committees at state and national levels to support co-design, provide lived experience perspectives and provide input and feedback into mental health service delivery, policy and reform.

All of our training programs are designed and developed by consumers and carers with many also developed in partnership with mental health providers, clinicians, GPs, psychiatrists and psychologists.
4. Evidence of partnerships and linkages with all key stakeholders (collaboration for continuity between organisations).

Our strong relationships within the mental health sector are key to supporting our research and advocacy. We have strong relationships with complementary organisations that can influence positive changes in mental health education and service culture. We collaborate with a number of key entities including consumer and carer networks, universities, and government.

**Organisational partnerships** – we work closely with other organisations to support collaboration and continuity including but not limited to:

- **National and State Mental Health Commissions** – undertaking research, providing consumer and carer representatives for expert advice and input and working in partnership to co-facilitate consultation forums (eg. SA Statewide Peer Workforce Framework; Queensland Mental Health Consumer Peak).
- **National Disability Insurance Agency** - providing consumer and carer representatives for expert advice and input on reference groups, providing formal submissions, responding to consultation requests, and working in partnership to co-facilitate consultation forums and focus groups.
- **Royal Australian and New Zealand College of Psychiatrists** – providing training, undertaking research, providing an Annual Award for Best Practice in Consumer and Carer Inclusion for Trainee Psychiatrists, providing consumer and carer representatives for expert advice and input to their committees.
- **Australian Private Hospital Association** – providing training, undertaking research, providing an Annual Award for Clinicians for Best Practice in Consumer and Carer Engagement, providing consumer and carer representatives for expert advice and input.
- **Australian Psychological Society** – providing consumer and carer representatives for expert reference groups, development of national mental health training (SRFs), and research (Foundation for Rural Regional Renewal).
- **Mental Health Carers Australia** – provision of Working with Families & Carers online library and Carer Guide online self-assessment and reporting portal, and collaborative projects.
- **Australian Government Department of Health** - providing consumer and carer representatives for expert advice and input (various committees & submissions)
- **Australian Government Department of Social Services** - providing consumer and carer representatives for expert advice and input (eg. advocacy re Robodebt and Carer Allowance/Carer Guide and mental health needs).
- **Australian Commission on Safety and Quality in Healthcare** - providing consumer and carer representatives for expert advice and input and working in partnership to provide consultation forums seeking lived experience perspectives (eg. review of national standards/mental health standards).
- **South Australian Government** - providing consumer and carer representatives for expert advice and input.
- **South Australian Chief Psychiatrist** - providing consumer and carer representatives for expert advice and input (eg. SA Mental Health Services Plan)
- **Australian Institute of Health Innovation** - providing consumer and carer representatives for expert advice and input, and collaborative projects.
• **Brain and Mind Centre** – collaborative research and projects

• **The Productivity Commission** - providing consumer and carer representatives for expert advice and input.

• **SANE Australia** – collaborative projects including partnership for the SANE forums for consumers and carers accessible from our website [https://livedexperienceaustralia.saneforums.org/](https://livedexperienceaustralia.saneforums.org/)

• **Mind Australia** – collaborative projects

• **Mental Health Australia** – collaborative projects

• **HelpingMinds** – collaborative projects

• **Ramsay Health Care SA** – collaborative projects

**University partnerships** – we are actively engaged with a number of universities partnering on current projects including:

1. RMIT University, Borderline Personality as Social Phenomenon (ARC grant) - funded
2. Newcastle University, Contributing family and lived experience input to NHMRC/MRFF application on physical health and mental health - funded
3. Monash University, Partnering in NHMRC Synergy Grant - Application submitted (Physical health and mental health)
4. LaTrobe University, Psychosocial Disability and the NDIS: Research Forum Improving Health and Wellbeing Outcomes for People with Cognitive Disability: The Role of the NDIS
5. UNISA – Helping Australians to better manage stress, adapt to change and improve their mental health with a free, tailored, online, self-help tool.
6. University of NSW, Brain and Mind Centre – national modelling (Suicide)
7. Mitchell Institute and University of Victoria, Self-Care for Health: A national policy Blueprint Oct 2020
8. Melbourne University, Melbourne School of Psychological Sciences, Ethics and decision making in leadership: A Qualitative Delphi Study
10. Flinders University, Suicide Prevention Australian, PhD Scholarship, BPD distress, suicidality and self-harm
11. Melbourne University, ALIVE

5. **Verification of effectiveness (quality improvement activity, data collection and its use, including graphs and tables, achievement of performance indicators, e.g. attendance figures, outcome measures, number of document downloads, page views, click through rates etc).**

Lived Experience Australia verifies our effectiveness through evaluation against specific key performance indicators. We measure effectiveness by:

- **Communication** – via number of eNews distributed and engagement statistics, unique website visits, number of subscribers, number of social media followers (Facebook, Twitter, LinkedIn), number of media releases,
- **Training** – number of training activities provided, number of consumers, carers, clinicians participating, number of private psychiatric hospitals attending training, satisfaction levels, key learnings, opportunities for
improvement regarding training and services provided which are recorded via evaluation forms and analysed on a quarterly basis,

- **Advocacy** – number of formal submissions made, number of times we have represented lived experience perspectives on expert advisory panels, working groups, forums, etc
- **Research** – number of research projects conducted, distribution of research reports, number of times our research is cited in other publications, impact on changes to mental health policy, reform of government budget announcements.

**Below are some examples of our effectiveness results:**

**Communication:**
Website – in the past 6 months we have had 5,408 unique visitors to our website and 18,254 page views. The most accessed pages included – Missing Middle research, resources, consumer and carer training, and peer research project.

Social Media – we joined: Facebook in late 2020 and have over 1,000 followers; LinkedIn in early 2021 and have 187 followers; Twitter in March 2021 and have 72 followers. We post on social media at least twice a week.

**Training:** provided over the last 6 months (January – June 2021):

**For Staff/Clinicians**
- Webinar - Taking Inspiration from Standard 2 = 84 participants
- Webinar - Insights into Accreditation = 73 participants
- Webinar - CEO Perspectives of Standard 2 = 70 participants
- Webinar - Consumers, Carers and Committees = 106 participants
- Webinar - Maximising consumer and carer engagement = 109 participants
- Zoom Workshop – Working towards Standard 2 x 3 sessions = 29 participants

Feedback Received: from staff and clinicians participating in our webinars, workshops and online modules:

- The presenter gave practical examples of consumer input into Health Service delivery, as well as some great success stories.
- That both consumer and carer representatives AND consumer and Carer Committees are the best way forward. This will incorporate lived experience perspectives across the full range of governance at the organisational level.
- Thought the webinar was very professional, the speakers amazing, and I learnt a lot which I will use going forward
- I enjoyed the opportunity to hear from consumers who work as consumer advisors and from colleagues from within the industry more broadly about the work they are doing in relation to consumer engagement / advocacy.
- This training was well-delivered. It was interesting and there was a good variance of questions. I enjoyed the case examples and liked the things to think about that popped up once I had submitted my response.
For Consumers, Families and Carers:

- Webinar - Looking after yourself = 123 participants
- Webinar - How to be heard = 128 participants
- Webinar - Preparing for advocacy - briefing and debriefing = 126 participants
- Webinar - Keeping the enthusiasm going = 146 participants
- Webinar – Self-reflection and self-evaluation = 148 participants
- Workshop (2 x 2 hour zoom training) x 3 series = 28 participants
- Communities of Practice 6-month program x 2 = 24 participants

Feedback received: from consumers and carers regarding the impact of our advocacy skill building training and programs:

- The best part was hearing information that I can relate to - for my personal growth in advocacy and - to discuss with the advisory committee I am part of, to perhaps enhance the role of this committee for the benefit of consumers and carers receiving care. Being able to interact on the chat and also ask questions for the panel.

- This Webinar has been very helpful for me personally. I find it difficult on occasions to discuss Mental Illness and other times I’m perfectly fine with it, because of the stigma attached to it, so I guess I’m still a work in progress. Attending these sort of things help me tremendously as I am in a safe place amongst other people who understand. I’m a Disability Support Worker so I’m a very non-judgemental individual with an open heart who works extremely hard at advocating for others when needed (who aren't able to do it for themselves). I also have very close friends with mental illness whom I care for on occasions and have needed to advocate for when they were too ill to do so. I'm also a carer for my elderly mother who lives with me. I have a lived experience myself of mental illness which I try my best to live with each and every day.

- I learned to concentrate on solutions and what I want more of. Start from common ground. Utilise values, my story, emotions, go to the causes of problems, solutions, address barriers, use facts at the end to back up what I have said. Perhaps - win people over rather than being at loggerheads. Try not to cause conflict but start from common ground.

- Very Valuable Information which speaks to what it means to strive to work collaboratively and respectfully within the MH system and never losing sight of those that we seek to represent in our field both Consumers and those that provide care and support (Families and Carers).

Advocacy and Research: In addition to information about the number, distribution and citations already provided in this application, below are recent examples of the impact of our advocacy and research:

- The evidence we collected from the BPD national surveys and the advocacy that we were then able to undertake directly to government was instrumental in the $10.25 million funding to establish the BPD Cooperative in South Australia.

- Our telehealth research was used by the RANZCP to successfully lobby for extension and continuation of telehealth consultations with the easing of COVID restrictions.
Conclusion (1/2 x A4 page).

We are a small, 100% consumer and carer staffed and governed non-profit organisation that has a significant impact on the mental health sector. Our organisation receives limited funding and our achievements would not be possible without the many voluntary hours that our staff, coordinators and directors put into their work.

We provide the lived experience voice of consumers AND families/carers to inform service evaluation, policy and reform at local, state and national levels through our active representative panel, advocacy submissions, collaboration, and research projects. We provide a training program to build the capacity, skills and confidence of consumers, families and carers to advocate at individual, organisational and systemic levels. Our engagement with staff, clinicians, colleges, mental health services, private psychiatric hospitals and community organisations through our research, collaborative projects and training delivery influence mental health services to engage and partner with consumers and carers in a person-centred, recovery-oriented and trauma-informed approach.

Our expertise is sought after across the mental health sector as seen by the number of requests for representatives that we fulfill on a regular basis. Our advocacy makes a difference as seen by changes to government policy and reform, announcements in government budgets and feedback from consumers, families, carers.

Referees (1/2 x A4 page).
Nominate two referees.

1. **Dr Peggy Brown** - Senior Clinical Advisor, Australian Commission on Safety and Quality in Health Care

   Dr Brown is a consultant psychiatrist with extensive experience in health and mental health service planning, delivery, governance, and administration, and has been a leading participant in national mental health policy and planning in Australia for almost two decades.

2. **Dr Ruth Vine** - Deputy Chief Medical Officer for Mental Health, Australian Government Department of Health

   Dr Vine is a consultant psychiatrist with more than 25 years’ experience at a senior level in community and hospital based mental health services, community based aged persons’ mental health services, mental health short stay in Emergency Departments, homeless people with mental illness, and working with police about mental health.
Appendix of Support Material (max. 8 x A4 pages).

Our Executive Director Janne McMahon was in The Advertiser talking about our ground-breaking research into the ‘Missing Middle’ why people miss out on the mental health care they need. A digital copy of the article can be viewed here.
Our Training
Lived Experience Australia has developed the following five training modules for consumer, family, and carer advocacy. LEA provides these modules on an ongoing basis with additional advocacy resources including videos, fact sheets and a webinar freely available from our website:
1. Looking after yourself
2. Briefing and De-briefing
3. Keeping the enthusiasm going
4. Self-evaluation and self-reflection
5. Advocacy and the organisation

Our Webinars
The effects of restrictions placed on people with existing mental health issues and those that support them during COVID-19 was top of mind for LEA. We know that the pandemic has raised anxiety, and many have seen a deterioration in their mental health and wellbeing. Carers also have been struggling with the additional strains that COVID has created for them.

It seemed only natural for LEA to promote and facilitate connectedness for mental health consumers and carers, especially during these uncertain times. We understand how important and essential a sense of connection with others is to our wellbeing.

We know that mental illness can bring loneliness, family disconnection, and difficulties getting through. Now things are particularly difficult as we are required to isolate from and change the way we go about many of our usual activities and contact with others.

We ran a series of six webinars on a fortnightly basis for approximately 45 minutes each. The webinars were run under the banner of ‘Our Connection’ Webinar Series. These were recorded and are now on our website www.livedexperienceaustralia.com.au/ourconnection

The webinars had a total 732 people at the time of writing this report, connected directly with our mental health lived experience community through this means. Feedback demonstrates that the webinars were successful in helping people feel part of a mental health community and connected with their peers.

The webinars ran fortnightly from the 8th of April, to the 17th of June, 2020.

Feedback from Webinar 1:
“I just wanted to say how much I felt connected to everyone and it was a positive experience. I also have now got more resources for my work as a Peer Specialist.”
Feedback from Webinar 2:
“I think parents of kids who have emerging or current mental health issues like depression may find things challenging, given the structure of school and socialisation face to face is so important for keeping any progress going...then COVID came along...hope kids get back to school soon so all those other benefits of being with peers starts up again.”

Feedback from Webinar 3:
“Thanks to Janne, David, Heather and Sharon for sharing your knowledge, skills and understanding of life when living with mental ill health and caring for those who face challenges in life.”

Feedback from Webinar 4:
“Thanks Christine, it’s very encouraging to hear your support for the lived experience workforce.”

“Thank you for being open and genuine, and oh so normal. Thank you Janne, Norm and Christine. Very interesting, informing and heartening.”

Feedback from Webinar 5:
“Thank you again for the brilliant topics and hearing the carer’s perspective”

“Keep doing what you love and with kindness x”

Feedback from Webinar 6:
“Lyn and Jennifer- thank you so very much for this webinar. It has highlighted challenges and potential solutions. Let’s all celebrate the value of peer work and fight for it to be resourced, respected and used as a viable and recovery-oriented approach.”
Media Release:

'Lived experience voices shaping research into service design in suicide prevention'

Lived Experience Australia is delighted to advise that after approaching Flinders University, BPD Co and the developers of Care.Connect we will be working with a PhD student over the next 3 years following a successful application to Suicide Prevention Australia.

Ms Pauline Klein will undertake her PhD Thesis titled: Bringing consumer and carer lived experience expertise to inform improved service responses to distress, suicidal thoughts and actions of people with a Borderline Personality Disorder diagnosis.

Ms Klein’s research aims to enhance understanding of the mechanisms driving suicidal thoughts and attempts among people with BPD. It will involve a further analysis of two surveys of 2011 and 2017 undertaken by Lived Experience Australia of the questions focussing on distress, suicidal thoughts and attempts. It will also examine consumers’ and carers’ perspectives on specific BPD services, what helped, what worked, questions also asked within the surveys.

‘Pauline is an outstanding student and we are delighted that our landmark survey data which is both an Australian and international first is being used to inform improvement in service delivery and suicide prevention for people with BPD’ said Ms Janne McMahon, Executive Director.

‘We have been disturbed that such a high number of survey respondents said they had made a serious attempt to end their lives’ she said ‘and Lived Experience Australia looks forward to working closely with Ms Klein, Flinders University, BPD Co and Care.Connect in this crucial work’

An analysis of the full responses can be found on our website https://www.livedexperienceaustralia.com.au/research-bpd

Analysis from 2011:
Foundations for Change Part 1: Experiences of CONSUMERS with the Diagnosis of BPD
Foundations for Change Part 2: Experiences of CARERS supporting someone with the diagnosis of BPD

A second edition from 2017:
Foundations for Change Part 1: Experiences of CONSUMERS with the Diagnosis of BPD
Foundations for Change Part 2: Experiences of CARERS supporting someone with the diagnosis of BPD

‘A number of research papers have been published from this data, and we are particularly pleased that the focus for Ms Klein’s PhD will be on what we can learn from people who have taken the time to complete our surveys and being so honest in their responses’ said Ms McMahon

Consumer and carer expertise will be provided by Lived Experience Australia, Flinders University will undertake supervision and BPD Co will provide the clinical setting and input into the research. Dr Helen Stellman, the lead developer of the highly successful suicide prevention program Care.Connect, is also involved.

Ms McMahon said ‘This is ground-breaking, and this translational research has the potential to save lives.

Having the involvement of Ms Klein in this work will add to Lived Experience Australia’s Research Program.

Enquiries to Janne McMahon, Founder and Executive Director
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A showcase of our key work: https://www.livedexperienceaustralia.com.au/resources:

**The 'Missing Middle' Lived Experience Perspectives**

This research identifies why people drift through the gaps or do not receive the mental health care they need.

**Telehealth Psychiatry Consultation National Survey Report**

This research provides a national collective voice of consumers and carers' experiences accessing telehealth psychiatry services.

**How are the NHMRC BPD guidelines faring in practice? A consumer perspective.**

We asked BPD-identified consumers to share their experiences of care under the NHMRC BPD guidelines, and compared it with data gathered in 2011.

**Understanding the Experiences of Spouse Mental Health Carers**

This research explores the unique role of caring for a spouse with a severe mental illness.

**Adult Mental Health Centre Survey Report**

We conducted a survey with consumers and carers to get their perspectives to inform the 8 Adult Mental Health Centres proposed for Australia.

**Peer Worker Research Project**

We completed a feasibility project exploring the establishment of a member-based organisation for the peer workforce in Australia.

**Exploring GP Views and Experiences of Providing Care to People with BPD**

This research explores the challenges faced by General Practitioners in providing care to patients with BPD.

**Collaboration in Care with Family Carers**

This research explores collaboration in care with family carers of patients admitted to the Jamies Larcambo Centre in South Australia.

**Implementing Carer Partnership Standards**

This research explores the current changes in carer engagement following implementation of the Practical Guide for Working with People with a Mental Illness.
Borderline Personality Disorder

This research explores information from public and private sectors on policies and treatment options for people with BPD and their carers.

Information Booklet

Do you live with, or provide support to, someone with a mental illness?

INFORMATION BOOKLET for Families and other Carers

Information Booklet

This booklet for families and carers provides information to support you in your role of caring for someone with a mental illness.

Lived Experience / Peer Workers

We have research reports, literature reviews and tip sheets on Lived Experience/Peer Workers.

Advocacy Submissions

We actively advocate for mental health consumers, families and carers.

Policies

We have produced Policy Documents articulating our position on various topics.

The Carer Guide

This guide is a practical tool which supports mental health organisations and staff to engage with carers of people with a mental illness.

Free Online Library

This library provides research, practical tools, resources and training to support health practitioners engage with families and carers.
This Borderline Personality Disorder Support Services in South Australia website was developed by Lived Experience Australia and initially funded through the Office of the Chief Psychiatrist's South Australian Suicide Prevention Community Grants Scheme 2016 and Life Without Barriers. Lived Experience Australia now funds ongoing maintenance and access to this site.

The National Health and Medical Research Council's Clinical Practice Guidelines for the Management of Borderline Personality Disorder (BPD) describe BPD as a mental illness. People with BPD can find it hard to access treatment and care in South Australian public, private mental health services and community managed organisations.

It is designed to provide a central point for information for consumers, carers, family members and health providers about Borderline Personality Disorder and the support services including referral requirements, available in South Australia.
Janne McMahon, Executive Director of Lived Experience Australia founded the organisation in 2002 and has been instrumental in significant changes to the mental health system.

2018 Australian Mental Health Prize winners – All in the Mind Radio Program

Nov 10, 2018

Janne McMahon has been advocating for better services for people living with BPD and their carers for many years. She was awarded the 2018 Australian Mental Health Prize, along with Professor Gavin Andrews.

They were interviewed on the ABC radio program All in the Mind

Mental health prize winner says 'we still have a long way to go' with treatment and services

ABC Health & Wellbeing / by Jo-Khan
Posted Sat 20 Oct 2018 at 4:13am