



Hello \$[UD:FIRST_NAME]]\$

This month, you'll notice the focus on Unmet Needs with the recent release by government's national report which provides transparency to the community on this significant concern for people with lived experience of mental health challenges, families, carers and supporters.

You'll also see specific reference made to mental health and the private sector in some of this month's stories, given LEA's national role in advocating for the many people who use these services to support their mental health.

We also enjoyed some time at TheMHS Conference at the end of August, and we'll provide some updates a little later in the next eNews.

Take care,

Sharon Lawn

Executive Director

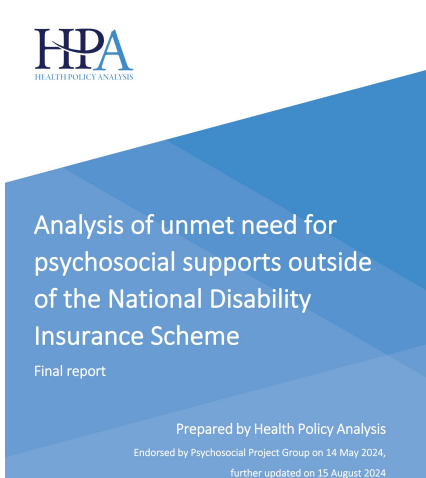
Lived Experience Australia

slawn@livedexperienceaustralia.com.au



LEA News and Updates

National Unmet Needs Report Released



Federal Health Minister Butler and Health Ministers from across the states and territories came together on the 16th of August to discuss priority issues facing Australia's health system, including mental health.

A key outcome was to release the national report on Unmet Need, related to psychosocial disability - who is receiving NDIS support and who is missing out.

This latter group includes many people who may only be linked with public clinical services (which lost much of their psychosocial remit when NDIS was introduced), and psychosocial support services (struggling to provide holistic psychosocial supports with limited resources).

But it also includes many people whose only formal mental health support may be their GP, a psychologist, and private psychiatrist (when they can access these!), and people receiving no services and no support except from families, carers and informal supports, if they have them in their lives.

This report provides crucial information to inform so many aspects of reform and we are grateful to government and the Health Ministers for its long-awaited release to the community. South Australia was the first jurisdiction to have Unmet Needs figures released, thanks to the strong advocacy by the South Australian Mental Health Coalition and the lived experience sector there.

Figure 3: Steps in estimating unmet need for psychosocial support services and results by level of mental illness severity, 2022–23

		Level of severity:	
		Severe	Moderate
Step 1	Estimated need for psychosocial support (aged 12-64 years)	335,800	311,500
Step 2	Estimated psychosocial supports consumers – <i>within</i> NDIS (aged 12-64 years)	- 61,600	28,000
	Subtract step 2 from step 1 Estimated psychosocial supports consumers – <i>outside</i> NDIS (aged 12-64 years)	- 43,700	20,400
Step 3	Estimated unmet need for psychosocial supports (aged 12-64 years)	230,500	263,100

Numbers are rounded to the nearest 100.

These figures confirm what we have all been voicing so strongly in our lived experience advocacy for so long. It's now time to fix this appalling gap in community support to rebalance our increasingly crisis-driven mental health sector back to more basic support in the community. As LEA's Executive Director Sharon said at the Parliamentary Friends of Mental Health event at Parliament House in Canberra, facilitated by the Mental Illness Fellowship of Australia (MIFA) in March this year:

“So much of the unmet need is left to the person and their families....providing the glue between systems that don't talk to each other, get the story wrong, fail because it's 1am in the morning and the police are the only people who come, or just aren't there to see the needs beyond clinical care. There is so much effort in trying to gain and maintain some semblance of basic needs; to carve out a contributing life that is left to the person and their family...I'm left thinking about the many opportunities for prevention and early intervention that didn't happen for my family member's mental health and physical health, and the consequences that began decades ago.”

[Access the Report](#)

How Pharmacists view their contributions to the future of mental healthcare



PHARMACISTS IN 2030



The Pharmacy Society of Australia (PSA) has released its latest report 'Pharmacists in 2030' about its vision for the role of pharmacists within healthcare, including supporting mental healthcare, focused on medication safety and access to healthcare. Pharmacists sit across both the public sector (for example, supporting inpatient services) and the private healthcare sector (in private hospitals and as community pharmacists) in Australia.

PSA's CEO, A/Prof Steve Morris recently met with LEA and other organisations that contributed Lived Experience insights to this report. Leanne Wells, who is an independent consultant and known to many in her former role with Consumer Health Forum, facilitated the discussions with the Lived Experience sector, including our LEA Representative Panel members who joined the consultation for this report. Leanne said this about LEA's contributions:

“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.”

Some of the Key Messages of note in the report and in our discussion with Steve Morris:

- Pharmacists are underutilised in our health system, and with effective system reform and support, can do much, much more to support the health needs of the population.
- Pharmacists can play a role in supporting more equitable health care, to help address systemic health disparities experienced by priority population groups (including mental health).
- Prioritising medicine safety focused on areas of known challenges such as overuse of antipsychotic and sedative medicines, polypharmacy, antimicrobial resistance, transitions of care and opioid use.
- Ensuring all pharmacists and pharmacies create culturally safe/non-discriminatory environments for the people who access them.

PSA are planning to dedicate a further report to Lived Experience perspectives given the strength of what they heard from LEA and others. Stay tuned.

The Pharmacists in 2023 Report can be accessed here:

[View the Pharmacists in 2023 Report](#)

FACTORS Survey closing soon



Australia has one of the highest rates of forced community treatment for diagnosed mental illness in the world but there is considerable variation across the country and between mental health services.

We are seeking people to participate in an online survey that will investigate the experiences and perceptions of people who have been placed on a community treatment order (CTOs) for their mental health.

There is also a separate survey for Family/Carers. The survey questions will ask about your experiences with the mental health service, your level of involvement, and your understanding of whether, when and why a CTO was made. This survey is part of a larger study funded by the Australian Research Council which aims to understand why and how this treatment varies, and to reduce coercive actions by mental health services.

Click the links below to complete the survey most relevant for you.

[Individuals Survey](#)

[Families/Friends/Supporters Survey](#)

NOCC Report Published in International Journal of Mental Health Nursing



Our research project from last year "Talking About Things Important to Me: Mental Health Consumers' Experiences of Consumer-Rated Measures" has been published in the International Journal of Mental Health Nursing.

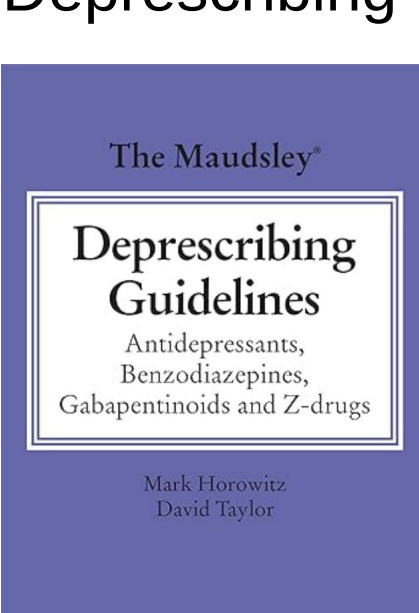
Your content goes here...

The aims of the research were:

- to seek the views and experiences of mental health consumers of using consumer-rated measures in their encounters with clinicians;
- to understand better whether there were benefits (and if so what) of consumer-rated measures being used in routine mental health practice;
- to understand how feedback on the use of consumer-rated measures can inform training for mental health staff;
- and to promote their wider use within mental health services.

[See the Published Report](#)

Deprescribing Psychotropic Medications



Psychotropic medications are a complex topic, and views can vary widely. A new book, the "Maudsley Deprescribing Guidelines" adds to this discussion.

These Deprescribing Guidelines are receiving major attention from many groups in Australia, including medical organisations including the college representing general practitioners (RACGP), the college representing psychiatrists (RANZCP), consumer advocacy groups, mental health organisations, the media and government.

Raising awareness among medical professionals and the Lived Experience community about this issue is essential to receiving safe and effective treatment.

It's about the importance of up-to-date information about de-prescribing psychiatric medications, side-effects and withdrawal effects. It's also therefore crucial to self-care, inclusion and improving collaboration between those who deliver mental health services and those who receive them.

We thank one of our Lived Experience friends from WA (Sharon Taylor) who has been advocating strongly for greater awareness of these guidelines:

"New consumers can be keen to start psychiatric meds, but after having medication changes and expensive poly-pharmacy, sometimes with disappointing results and unwanted side-effects like weight gain, emotional numbing, sexual dysfunction and brain-fog etc - many consumers are disillusioned with psychiatric medications and are questioning the research and efficacy and want evidence-based, supported deprescribing that monitor and minimise withdrawal symptoms when they are stable and wanting to withdraw from psychiatric medications." Sharon Taylor.

Thank you also to Liz Asser who has shared her experiences of tapering off medication and the importance of being informed and supported.

"For more than 25 years I have been taking prescription medication to assist with management of my emotional wellbeing. This is a collection of my experiences during that time when the amount of medication was changed with a goal of trying to stop taking pharmaceutical supports."

From my earliest experience, the prescribed medication was described to me by GPs or Mental Health Professionals as a short-term support to alleviate emotional dysregulation and allow talk therapy to establish and sustain change in my behaviour. Particularly during the first 15 years, I was not looking to change the medication regime as I continued to struggle with bouts of prolonged low mood and abuse of alcohol.

The first time I consciously attempted to decrease my dosage, I experienced a cycle of exaggerated wellbeing, mania some might call it, with some delusional and altered states of reality. As many will be aware, this is often followed by a crash - for me an episode of suicidal crisis and a return to my regime of antidepressants with addition of a mood stabiliser in Lithium, which for me eventually brought some peace to my turbo charged mind.

About 4 years ago, COVID provided increased online opportunity for me to meet and share experiences with others who imagined a life without their prescription medications. I read widely, chatted and learned, eventually deciding to attempt tapering of my SSRI medication. Following the tried and tested formula shared by my peers, once again I slowly and intentionally decreased my dosage, with support from my doctor to monitor, and a chance for me to be reflective about the experience.

My peers had told me that some symptoms may return during this process and to be aware that this was not necessarily an indication of becoming unwell, rather a withdrawal indicator. We, my doctor and I, maintained a 25% reduction for 6 months. Maybe it was timing - hello, epidemic may cause anxiety - maybe it was seasonal - winter is challenging for me, maybe my system has become dependent, maybe I will take these medications for the rest of my life. Maybe the truth is a combination of all of these things.

My experience was not just about the amount of medication I was, and continued to consume. It was much more about my agency. My capacity to understand and manage me. I may attempt to reduce my medication again, with support, when I am ready. In the meantime, I am so very grateful for the life that I have, the work that I do, and the meaning my experiences provide for me.

Change is about intentional choice. I choose to take my medication so that I have the capacity to do what I want to do. If that capacity changes, then choices will need to be made. I am satisfied with my choices and the lessons learned thus far." Liz Asser

You can view the official media release by the RACGP promoting the important role GPs can have in deprescribing psychiatric medications:
<https://www.racgp.org.au/gp-news/media-releases/2024-media-releases/july-2024/australians-urged-to-see-their-gp-for-help-stoppin#>

There is also a webinar recording by the NSW Mental Health Commission including Dr Mark Horowitz, one of the well-respected authors of the Maudsley Deprescribing Guidelines, who talked about his own experience of withdrawal side-effects. You can access the recording below:

[View the Deprescribing Webinar](#)

Wen's story about the experience of losing a Twin



Hearing from Lived Experience advocates is a regular and core part of our Executive Director's working week.

Wen Gibson shared their passion for advocacy and shining a light on this particular experience.

As Wen said, "When one twin dies, the remaining twin can be profoundly affected. We term this person a lone or twinless twin. They are still a twin and will always be a twin. The depth of this grief is often not well understood."

Wen has helped coordinate an Australian and New Zealand group for those who have lost their twin – at or pre-birth, in early life or as an adult. Wen also links in with similar organisations in the UK and USA.

There is also an interesting article about this: [Twinless Twins: The Unique, Heartbreaking Grief of Losing a Twin Sibling \(vice.com\)](#)

You can reach out to Wen here: wendygibsoncounselling@outlook.com or find out more information about the Australian and New Zealand organisations here:

[View Twinless Twins Resources](#)

Cost of living pressures having 'concerning' impact on healthcare decisions



LEA's Executive Director Sharon had the pleasure of catching up with a close partner organisation, Australian Patients Association (APA) CEO David Clarke, recently about some shared concerns with healthcare access.

The APA and Healthengine have just delivered the annual Australian healthcare Index nationwide survey on what 9000+ people across the country are saying about Australian healthcare. It covers how people are rating overall healthcare in Australia

along with their experiences on costs of prescription medicines, GP visits, Dental care, Private Healthcare Insurance along with access to Mental Health Support, Elective Surgery and Emergency Departments (EDs).

- Of note for people who answered the survey:
- 75% said cost of living increases had impacted their healthcare decisions
 - 60% are delaying GP/doctor visits
 - 53% are delaying dental treatment
 - 32% are postponing a diagnostic test or scan
 - 28% are skipping buying needed medicine
 - 26% are delaying mental health support
 - Almost 50% of people who went to the ED believed their care could have been provided by a GP or Urgent Care Clinic instead
 - Many are questioning if their private health insurance is money well spent (with lack of affordability (67%) and poor value for money (65%) as reasons given).

You can request a copy of the full report here:

[View the Full Report](#)

Our Online Learning site is getting an upgrade!

Lived Experience Australia Online Learning



Consumers, Families & Carers

Learning designed to support consumers, families, and carers in representation and advocacy roles.



Peer Workers

Learning designed to support peer and lived experience workers. You may also like to explore learning for consumers and carers.



Clinicians, Leaders & Organisations

Learning designed to support clinicians and leaders with lived experience, consumer and carer engagement.

Our online learning site is getting a fresh new look! At the end of this week (13 September 2024), our online learning site will be off-line for a few days while we transfer to a new upgraded site. The link to access online learning will be the same, but it will have a fresh new look and lots of new features. Existing users will be sent further information prior to the upgrade.

You can still access learning in the meantime via <https://learn.livedexperienceaustralia.com.au>

AN INTRODUCTION TO

LIVED EXPERIENCE ENGAGEMENT

New online module launching next week!

When our site comes online next week, we are excited to announce the launch of a new online learning module "**Introduction to Lived Experience Engagement**". We work with many organisations, research and project teams to support trauma-informed, inclusive and appropriate engagement of individuals with living and lived experiences from consultation to collaboration and co-design. This online module provides an overview of key considerations for lived experience engagement, a range of practice models and a checklist to support authentic, planned lived experience engagement.

Organisations can request customising of the module to suit your specific needs and branding. You can even host the SCORM course on your own online learning platform. [Contact us](#) for more information and a quote.

Mental Health Sector News

Aboriginal and Torres Strait Islander Lived Experience-Led Peer Workforce Guide launched

The Aboriginal and Torres Strait Islander Lived Experience Led Peer Workforce Guide (Guide) launched in August.

The Guide, which we developed in partnership with the Black Dog Institute's Aboriginal and Torres Strait Islander Lived Experience Centre, was created to support the implementation of the Western Australian Lived Experience (Peer) Workforces Framework.

The first of its kind in Australia, the Guide is a learning tool for all lived experience workforces and organisations, supporting with the establishment, sustainability, and continuous improvement of the Aboriginal Lived Experience workforce space.

It will also help workforces better understand their roles and responsibilities.

The development of this Guide aligns with our broader strategy of integrating culturally appropriate practices and promoting the inclusion of lived experience in all aspects of care within the mental health, alcohol and other drugs, and suicide prevention systems.

[View the Guide](#)

NDIS Amendment 2024 Passed

The National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 has been passed by the Parliament.

The passage of the Bill allows the NDIS to continue working with you to make the NDIS stronger and improve the experience for participants. There will be changes in the coming weeks once the laws come into effect.

Until then:

- all access and planning processes, decisions and supports will continue in line with current operational guidance
- participants should continue spending in accordance with their plans and existing operational guidance
- providers should continue to claim for supports in line with current operational guidance.

The Bill will receive Royal Assent in the coming days. The new laws will come into effect 28 days after Royal Assent.

Rules will be developed with the disability community, continuing to put people with disability at the heart of NDIS reforms. The NDIS will provide more information over the next few weeks to explain what the changes mean, when they will impact you and how you can get ready.

For an overview of the changes, including when they come into effect, and more information visit the NDIS website.

The NDIS is focused on making sure participants have a better experience and the Scheme is there for the future.

[View the NDIS Website](#)

Human Rights Commission call to legislate on housing

The Human Rights Commission has supported a private member's bill that would recognise the human right to adequate housing and support improved housing outcomes for all Australians. Insecure housing or lack of a secure place to live are well known socio-environmental contributors to mental health distress and have been exacerbated as a result of the current cost of living crisis. In welcoming the National Housing and Homelessness Plan Bill, Commission President Hugh de Kretser signalled that progressing economic and social rights, including the right to adequate housing, would be a priority of his term.

"Everyone needs a home. We should all be able to live somewhere in security, safety and dignity. Yet for many people in Australia, this is currently out of reach," he said. "This Bill, if passed, would help to address this. It would promote a human rights-based approach to housing policy by requiring the federal government to develop a long-term plan to prevent and end homelessness and improve housing supply and affordability."

"We need to treat housing as a human right, not a commodity."

[Read More](#)

Equity, accessibility and appropriate delivery of outpatient and community mental health care in New South Wales – Government response

The NSW Government have provided a response to the Inquiry into Equity, Accessibility and Appropriate Delivery of Outpatient and Community Mental Health Care in New South Wales. This report provides recommendations for systems to be more responsive to mental health in NSW.

[Read the Government Response](#)

Lived Experience Australia provided a submission to the Inquiry with evidence regarding experiences of people located in NSW from our [Missing Middle Research](#) and our research conducted in partnership with Equally Well on [Mental Health and Physical Health](#) which highlighted issues in workforce education and siloed systems.

[View LEA's submission into the Inquiry](#)

Find Us On



Lived
Experience
AUSTRALIA



Lived Experience Australia acknowledges the Traditional Owners of all the lands on which we undertake our advocacy. We pay our respects to their Elders past, present, and emerging.

We also recognise those with lived experience of mental ill-health. 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.

\$(HF:ORGADDRESS)\$

You are receiving this email as you signed up to receive updates and information about lived experience advocacy.
Want to change how you receive these emails?
You can [Unsubscribe](#) or [Update your preferences](#)