



National Mental Health Commission Draft National Stigma and Discrimination Reduction Strategy

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Table of Contents

Table of Contents	2
Introduction.....	3
Feedback on the Strategy.....	3
1. Foundational actions to reduce stigma and discrimination	4
2. Reducing structural stigma and discrimination.....	6
3. Reducing public stigma.....	8
4. Reducing self-stigma.....	12
Contact	13

Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, formed in 2002 with a focus on the private sector. All members of our Board and staff have mental health lived experience as either a consumer, family carer or both.

Our core business is to advocate for systemic change to improve mental health care across the whole Australian health system. This includes advocating for empowerment of consumers in the broad range of issues that impact their mental and physical health, empowering consumers in their own care and contact with health and social services, promoting engagement and inclusion of consumers and carers within system design, planning and evaluation and most importantly, advocating for consumer choice and family and carer inclusion and wellbeing. Our submission comes from the perspectives and experiences of people with lived experience of mental health challenges, their families, and carers.

We welcome the opportunity to provide our submission on the National Stigma and Discrimination Reduction Strategy.

Feedback on the Strategy

The four priority areas of the Draft National Stigma and Discrimination Reduction Strategy. These are:

- **Foundational actions to reduce stigma and discrimination**
- **Reducing structural stigma and discrimination**
- **Reducing public stigma**
- **Reducing self-stigma**

For each section of the Draft Strategy, we have considered the following questions:

- **Feasibility:** Are the actions achievable in the recommended timeframe and allocated to the correct responsible party/parties? Is there a readiness for change?
- **Enablers:** What might support the actions and/or assist the work needed to implement the change?
- **Barriers:** What might slow down or prevent the gaining of support for the actions, or their implementation?
- **Effectiveness:** Will the actions lead to the changes we want to see? Are there any potential unintended consequences?
- **Anything missing:** Are there any critical issues or actions to address stigma and discrimination that are not referenced or sufficiently prioritised in the Draft Strategy?

1. Foundational actions to reduce stigma and discrimination

We welcome this work from the National Mental Health Commission. Many studies have highlighted that stigma and discrimination thrives most within inpatient services in hospitals where we and others with lived experience of mental health challenges seek help for our mental and physical health and we note that far is a driving factor for stigma and discrimination. We need to inform policy makers, clinicians, and the public that much is changing. The cheerleaders for the 'medical model' are telling policy and politicians that nothing is getting better, and all we need to do is train and employ more clinical staff. We need to talk about the 'Peer Workforce' much more to embed this change within the many types of services that have contact with people with lived experience of mental health challenges.

As Lived Experience Australia Friends have argued:

"Fear of 'the system' is well entrenched, and still true. When I visit nearly all of the services, the culture is almost always unbelievably bad. Still. They have gotten better, but people should still fear most services as inpatients."

"We also have a long way to go in educating people on what 'recovery' is for us."

"We as a movement need to do better in helping people know how bad our experiences are, that are too often invisible, in general."

"A total move away from 'hospitalisation' in the medical model, to 'respite' beds in the community also long-term if needed under the NDIS is needed."

We also acknowledge the particular focus of the lived experience advocates on language and its reclamation as a result of the discriminatory ways it has been used as tools of shame and exclusion. As such Lived Experience Australia Friends have offered the following feedback in relation to the draft Strategy: "We need to embrace our current words for the public in general to get their heads around terms like: Psychosocial disability; Peer Workers; Mental health and wellbeing; Mad pride."

"LE voices being visible and out and proud is important. We can do this through aligning ourselves to 'I have a psychosocial disability' and I'm proud to say that and with others in the disability sector. We need to include family and community in that too."

"We need to listen to the intent behind the words when addressing stigma and discrimination. As an example, I have seen consumers and carers stomp all over people for saying 'stigma' (when discrimination is Right) or 'mental illness' when the intent of their message is with us. This is why we need to do much better at training LE advocates."

Another Lived Experience Australia Friend has argued that,

"We need to move away from the term 'trauma-informed care' to a description of what this actually means for people - and that is safety, familiarity, trust, collaboration etc - we have to move away from jargonism into reality. Service providers need to know that many of the people they support will have complex trauma backgrounds, as will many of the volunteers and peers within services. Understanding people's history and experiences is critical to being able to provide support and also ensuring that environments are 'safe and inclusive' in accordance with a person's background and needs."

In 2019, Lived Experience Australia conducted an international literature review on Stigma and Borderline Personality Disorder (BPD)¹, prompted by the findings of our lived experience research from 2 earlier national surveys^{2,3,4} that found structural stigma was pervasive for this population within mental health services. Stigma and discrimination experiences for this population act as a ‘canary in the coalmine’ for alerting to many fundamental drivers of stigma for people with mental health challenges, more broadly. Findings from 12 studies of the perspectives of people with a diagnosis of BPD and 18 studies of the perspective of mental health professionals (MHPs) who provide treatment and care to them led to six dynamic and distinct themes being identified. The first five themes (see Figure 1 below) describe issues contributing to the development and maintenance of stigma towards people with a BPD diagnosis, and the last theme is central to the solution to overcoming stigma towards people who are shaped by this diagnosis. Through the thematic synthesis, a conceptual framework was constructed to help show how these themes interact and relate to each other. The development and perpetuation of stigma towards people with BPD at the interface of care appears to arise from a number of fundamental processes which reinforce problems with health literacy by both patients and MHPs and which stall effective treatment and engagement, disempower all concerned and defer responsibility to others.

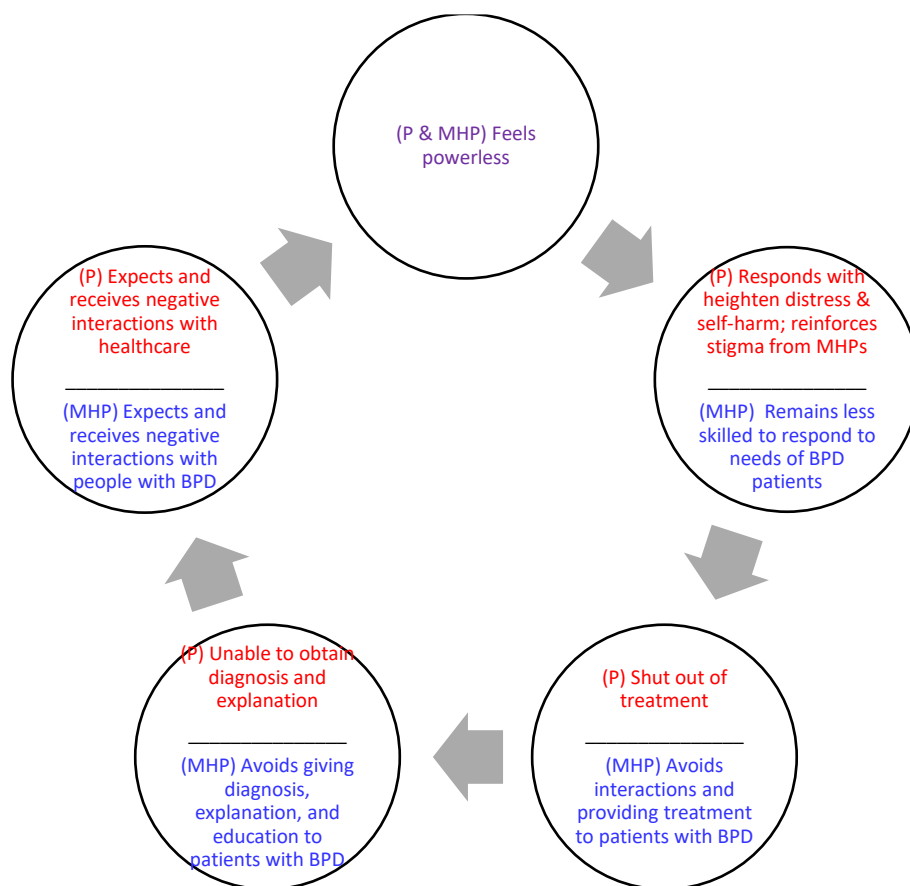


Figure 12. Patient (P) and mental health professional (MHP) perspectives on how stigma towards BPD is perpetuated – conceptual framework

¹ Ring D, Lawn S. (2019) Stigma perpetuation at the interface of mental health care: a review to compare patient and clinician perspectives of stigma and Borderline Personality Disorder. *Journal of Mental Health*. 12:1-21. <https://doi.org/10.1080/09638237.2019.1581337>

² Lawn S, McMahon J. (2015) Experiences of care by Australians with a diagnosis of Borderline Personality Disorder. *Journal of Psychiatric and Mental Health Nursing*, 22(7), 510-521. <http://onlinelibrary.wiley.com/doi/10.1111/jpm.12226/pdf>

³ Lawn S, McMahon J. (2015) Experiences of family carers of people diagnosed with Borderline Personality Disorder. *Journal of Psychiatric and Mental Health Nursing*, 22(4), 234-243. <http://onlinelibrary.wiley.com/doi/10.1111/jpm.12193/pdf>

⁴ Lawn S, McMahon J, Zabeen S. (2017) Foundations for change: part 1 - consumers: experiences of consumers with the Diagnosis of Borderline Personality Disorder (BPD) Private Mental Health Consumer Carer Network (Australia) Inc: Marden, South Australia, Australia. <https://www.livedexperienceaustralia.com.au/research-bpd>

To describe the conceptual framework: “Patients are shut out of treatment by virtue of having a BPD diagnosis. This means that they are unable to obtain the education, diagnosis and consequent treatment they need to alleviate their conditions. This incomplete understanding leads them to expect a poor reception from health care services and MHPs, which leads them to lose trust even further and to feel powerless. In their interactions with MHPs, they experience loss of control and independence, which heighten their distress. They then react in ways that reinforce the stigmatising views they perceive and then ultimately receive from MHPs. MHPs operate within a system that historically has either avoided giving patients a BPD diagnosis or concealing that diagnosis from them. Coupled with this MHPs have expected negative interactions with these patients and perceived them to be untreatable. This has reinforced MHPs sense of powerlessness to affect any improvement, with many reacting by blaming the patient, seeing treatment for them as “too hard”, deflecting responsibility to others as a consequence of their own perceived powerlessness and consequently not investing in the development of more specific skills to successfully engage and treat the needs of people with BPD. These cycles of beliefs, attitudes and processes continue to feed each other, and stigma is not addressed. Both patients and MHPs are trapped in a stigmatised cycle in which the only place where the two parties meet is in their perceived powerlessness to change.”

Our conceptual framework proposes that perceived powerlessness to affect change is likely to be an important underpinning concept, making stigma a ‘self-fulfilling prophecy’ which also acts as a consequence of the interaction of the other processes that currently shape care for many people with this diagnosis. We concluded that addressing this stigma requires multiple strategies that include more targeted education (e.g., empathy training), advocacy and leadership. We note that a number of actions within the Strategy have reflected this need in a general sense. More could be said about the rationale for these actions, with evidence like this review’s findings helping to inform this detail.

2. Reducing structural stigma and discrimination

We welcome the inclusion of structural stigma and discrimination as a focus of the Strategy. In addition to the definitions provided in the document, we note further components of ‘intention’ suggested in the following suggestion. ‘Structural stigma occurs when institutions intentionally or unintentionally create policies, procedures, or practices that disadvantage those with a mental illness, leading to social inequities’⁵ This serves as an important reminder that structural stigma can sometimes be so pervasive in the fabric of how services operate that they hardly acknowledge it is there. It is like a culture that isn’t aware that other ways of doing things exist beyond their view. The ‘Risk culture’ that pervades many policies and procedures within clinical mental health services, in particular, is a good example of this, especially as its entrenched nature in the fabric or structure of how services operate then stifles attempts to fully embrace lived experience workforce, for example. It is the structures that stall progress. They remain unchanged unless there are solid efforts by services and their leaders to openly talk about them, reflect on them routinely in supervision and professional development, challenge their presence and take action to change them in everyday practice.

Structures that perpetuate stigma and discrimination are also in the physical geography of service settings, yet these are usually ‘unseen’ influencers, despite consumers and families receiving very clearly the subliminal messages from examples within services (e.g., of unwelcome spaces, signage that doesn’t account for diversity, closed doors and barriers to asking for help from health professionals that demarcate power, expertise, authority, access, privacy, worthiness, value).

We also wish to make reference to the potential stigma experienced by the peer workforce within mental health service systems. The exponential growth of the lived experience (peer) workforce over the past two

⁵ Stuart H. (2016) Reducing the stigma of mental illness. *Global Mental Health (Camb)*, 10;3: e17. doi: 10.1017/gmh.2016.11

and a half decades is now the focus of targeted national development and yet there continues to be stigma and discrimination of peer workers within many mental health workplaces, particularly within clinical settings where the culture and models of care continue to struggle to understand and integrate lived experience perspectives into practice within teams where illness-based models centred on deficit and dysfunction are pervasive.

Also of concern, as highlighted by one LEA community member, “Recent public revelations in the context of the Royal Commission into Victoria’s Mental Health System, for example, revealed that in the first seven years since its establishment, the Victorian Mental Health Complaints Commissioner received 12,470 mental health discrimination complaints with compliance notices issued.”⁶ Another recent article reported that “the over-whelming majority of consumers reported a failure of services to uphold their rights, with a common theme of ‘power and control’ by mental health services emerging from their stories”⁷ Ore further explained that “Others reported that the complaints process reinforced their experiences of powerlessness.”^{6, 8} This indicates that while there has been significant investment in rhetoric which seeks to champion desired shifts towards the establishment of a human rights framework, it has done little to protect those in the community who identify as having lived experience of mental health challenges from sanist attitudes that limit full engagement with society.

We note that restorative justice practices increasingly developing within the justice system hold great potential for implementation in relation to improving governance in health and human service systems to address stigma and discrimination. As a recent article explains, “restorative justice, which broadly reflects an approach that attempts to heal the harm caused by a crime, is relatively new in being applied to health and human services.”⁸ Further, the article on Restorative Justice reiterates: “Restorative justice and responsive regulation provide combined frameworks and practices that may inform the better use of complaints processes. Responsive regulation, reflecting an approach built on progressive enforcement by regulators towards regulatees, has been well-established within healthcare and service delivery settings.”⁸ If the Strategy was able to reflect a Restorative Justice approach within the tone of the document, it is hoped that those most negatively affected in the experience of treatment and care will not only be able to regain trust in compassionate delivery of mental health services but also have their faith restored in their value as humans who do truly possess equal rights along with the rest of society.⁹

We welcome the many actions currently named, particularly **2.1f and 2.1g** that focus on the Lived Experience Workforce. However, as currently stated, these actions rely on supporting that workforce and increasing their physical presence in settings to evoke the cultural change that is needed. More could be said about the rest of the system and actions there to interface with the peer workforce.

Also, we note that the Public Trustee and Guardianship system is not mentioned in this priority. Like clinical mental health services, there are many structures in that system that keep people in a position of disadvantage, underpinned by stigmatised and discriminatory practices that fail to include supported decision-making and use capacity as a blunt and broad-based instrument, seeing people as either having capacity or not having it. There is no room for growth and acknowledgement of any strengths or capacities that the person may build, within such systems; deficits labels and assessment practices predominate.

⁶ Ore A, Davey M. (2022) “No action taken against Victorian mental health services despite more than 12,000 complaints,” *The Guardian*, May 26, 2022. [Online]. Available: <https://www.theguardian.com/society/2022/may/26/no-action-taken-against-victorian-mental-health-services-despite-more-than-12000-complaints>

⁷ Katterl S. (2021) Regulatory oversight, mental health and human rights. *Alternative Law Journal*, 46(2):149–156. doi: 10.1177/1037969X211013123.

⁸ Katterl S. (2022) Preventing and responding to harm: Restorative and responsive mental health regulation in Victoria. *Australian Journal of Social Issues*, 00, 1– 15. Available from: <https://doi.org/10.1002/ajs4.242>

⁹ Daya I, Hamilton B, & Roper C. (2019) Authentic engagement: A conceptual model for welcoming diverse and challenging consumer and survivor views in mental health research, policy, and practice. *International Journal of Mental Health Nursing*, 29. 10.1111/inm.12653.

Re action 2.2c, it would be useful to also include harmful gambling, given it is a highly stigmatised and hidden addiction.

Re actions 2.2b and 2.2f, these could appear next to each other. Their inclusion is valuable given the insidious structural issues that create silos and gaps in coordination and communication across physical health and mental health care systems. We also wonder how concerns about diagnostic overshadowing might be addressed in the Strategy, given much of its presence in the system comes from inherent stigma and discrimination, driven by negative assumptions about people with mental health challenges, seeing comorbidity as ‘the norm’, and failures to have hope for change in their lifestyle risk factors.

Re action 2.2h - could be clearer.

We note that, whilst there is mention of Medicare and GPs **2.2i**, there is virtually no reference to private mental health care service systems, policies within that system, and private health cover.

They are inherently discriminatory at a structural level because they expect people, many who are least able at the time, to navigate complex bureaucratic processes with little or no support, then blame, coerce and punish them when they do not comply with administrative processes. As one Friend of Lived Experience Australia recently stated in relation to accessing supports following a GP mental health plan:

“Even if you can find a service that is helpful there is no availability, highlighting the danger of statements such as ‘We don't have capacity’. ‘You're too complex’. ‘It's COVID’.”

Another Friend stated in relation to the distress this lack of understanding creates:

“If you're going to tell people to go to their GP, then those GPs need to know what to do, and how to actually get people support and follow the F*** up.”

These assumptions of health literacy and emotional capability from primary health providers in response to mental health distress presents an unnecessary barrier to accessing mental health support at the point of service delivery and constitutes a human rights issue.

Re action 2.3i Re child protection responses, more could be said about support for earlier help-seeking and the role of stigma and discrimination in contributing to failures here, and avoidance of services that may represent longstanding experiences of structural discrimination for some groups in the community.

One Friend of Lived Experience Australia who is a parent of young children recently reported being silenced whilst seeking help for post-natal distress by the GP who cautioned, “You should think carefully about what you say to me because I’m a mandatory reporter.”

Re actions for legal systems (**2.5a and 2.5b**), there are many parts and parties within these systems (e.g., community service and hospital legal teams, insurance companies, and in family violence or custody situations that can call on the person’s psychiatric history and use their case notes/health records to discredit them. The concern as stated needs to be more than to ‘encourage people to seek help’; it concerns the whole pathway of contact points within these systems.

3. Reducing public stigma

We welcome the Commission’s focus on reducing public stigma as this is crucial not only to how the community perceives and responds to people in their workplaces, community settings, cultural and social settings and homes, but this attitudinal shift is able to be truly activated. These public shifts also have flow on effects to both structural reform as well individual acceptance of oneself as a valuable member within their own interpersonal settings. Stuart, in their 2016 review of evidence of strategies for reducing stigma in mental health⁵ stated, “Link and Phelan suggest that interventions targeted at only one mechanism (such as employment equity), will be doomed because their effectiveness will be undermined by the broader social factors that are left untouched. They suggest that interventions must either produce fundamental

changes in the negative attitudes and beliefs of members of powerful groups, or change the power relations that underlie their ability to act on these attitudes and beliefs.”¹⁰

Stuart⁵ provides further useful analysis on various stigma reduction strategies and the evidence (or not) for their impact. They state, as one example, that, “New Zealand's *Like Minds Like Mine* anti-stigma program has developed strong partnerships with policy makers at the Ministry of Health, an external social marketing firm, as well as researchers from the Institute of Psychiatry in the UK. They assessed the personal experiences of discrimination among mental health service users and their opinions as to whether discrimination had improved over the previous 5 years. Using a modified version of the Discrimination and Stigma Scale developed by the UK-based researchers for *Time to Change*; they surveyed a representative sample of service users selected by officials at the Ministry of Health. Most common discrimination experiences came from family members (30%) and making or keeping friends (28%). A total of 16% of participants identified mental healthcare staff as ‘moderately’ or ‘a lot’ discriminatory, and this was higher (26%) among those who had more than 25 mental health contacts in the previous year. Just over half (54%) had reported that there had been some improvement in stigma and discrimination over the previous 5 years, and 48% considered that the *Like Minds Like Mine* program had assisted in reducing discrimination.”¹¹

Stuart’s review of evidence for various strategies is potentially helpful here.⁵ In summary, they found the following:

- **Awareness raising programs** - Stigma reduction is a hoped-for side effect; however, few have been fully evaluated. The *Like Minds Like Mine* offers some useful evaluation, as per above.
- **Literacy programs** (e.g., *Beyond Blue*, *Mental Health First Aid*) – as with awareness raising, the underlying assumption is that improved knowledge and awareness about stigma and discrimination will lead individuals to take action. Stuart’s analysis concluded that, “while literacy programs are important from the point of view of mental health prevention, it is unlikely that they can be used as a formal stigma reduction strategy.” More research was deemed as needed.
- **Protest** (e.g., *StigmaWatch/SANE*) – These programs/strategies work through stigma objection or denouncement, and work at the structural level, attempting to change organisational behaviours and practices. “In 2008, the proportion of *StigmaWatch* reports about the media portrayal of depression was 33%. By 2010, this had dropped to 10%, and has since remained at about 5%, suggesting that the program has been successful in improving media reporting.”
- **Advocacy** – The outcomes are largely unknown because these activities are diffuse and they are difficult to measure, particularly their impact on the institutional structures and potential vested interests that perpetuate the status quo,
- **Social contact** – This is based on the idea that, “greater social contact with members of a stigmatized group could replace faulty perceptions and generalizations, and reduce prejudice and discrimination.” So far, the evidence for this approach is mixed.

Stuart, in their review of evidence, concluded that, “Being cast as a ‘disease like any other’ has not led to reductions in stigmatising views”. Stuart further argued that existing stigma campaigns, “have had little or no effect on social intolerance” and that, “Many community-based advocacy programs in high-income countries address stigma with good intentions, but with no sound evidence to support their activities “.⁵

¹⁰ Link BG, Phelan JC (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363–385.

¹¹ Thornicroft C, Wyllie A, Thornicroft G, Mehta H (2014). Impact of the “*Like Minds, Like Mind*” anti-stigma and discrimination campaign in New Zealand on Anticipated and Experienced Discrimination. *Australian and New Zealand Journal of Psychiatry*, 48, 360–370.

We strongly support incorporating observations from this study by Stuart in tandem with highlighting evidence-based effective anti-stigma approaches into the tone of the Strategy itself to clearly guide ongoing implementation work. Observations are as follows:

- Improving mental health literacy and stereotypic attitudes will not necessarily lead to greater social tolerance or improved social equity.
- Large social marketing approaches to improve public attitudes are expensive, and have yielded mixed results in high-income countries,
- We have seen the importance of targeting anti-stigma programs to particular population groups (such as youth or healthcare providers), but it is not clear to what extent anti-stigma programs also should be targeted to specific mental health diagnosis categories.

It is evident that this is an area for further targeted research and yet, if it is not flagged as such in the Strategy. Its omission means that the current set of actions within the Strategy might inadvertently continue to perpetuate the mental health literacy culture, the validity of which is questioned by Stuart's analysis.

Re action 3.1a (tailored and culturally-safe training within primary, secondary and tertiary education settings): It is undoubtedly feasible to design and implement the proposed education initiatives in the short term. However, the need to change must be assessed carefully before doing this. A critical aspect of these initiatives is to start with training the teachers on how to recognise signs of mental ill health in students. Another aspect is to begin these initiatives at a young age and cover topics that train students on common mental health conditions, where to seek help and why it is essential to target public stigma.

Co-production, represented in co-selection, co-design, co-delivery and co-evaluation, is a key implementation method that will enable the relevant stakeholder to be empowered to make decisions about the project. It is critical to communicate that stigma needs to be reduced in order to be eliminated rather than aiming for elimination immediately, which will create another set of problems.

Barriers exist on multiple levels, including funding, stakeholder resistance, limited access to relevant experience, social behaviours and attitudes towards the initiatives, inability to measure the impact of these initiatives in a tangible way, implementation approach and the selection of appropriate project management methodology that focus on people rather than processes.

The stigma reduction education system is essential to make a positive impact in this space. However, some of the unintended consequences of this system might include privacy issues, over generalisation of mental health conditions, and the inability to respond to specific cultural requirements. It is essential that this system is able to identify clearly what is considered a mental health issue versus normal emotions. This could be confusing for young kids.

Re action 3.1b (training with a Rights-based framework for all workers in contact with people with personal lived experience): An extremely important action in order to reduce stigma and other discrimination factors in the workplace or other places where people are in direct contact with lived experience.

Co-production and funding are extremely important to support these initiatives. Management support from each of the entities is critical. For example, SA Police have been engaging in cultural awareness training over the last two years to reduce stigma in mental health among CALD communities. This had considerable support from senior management.

Funding, time conflict and availability of the people attending this training.

In some contexts, this will lead to improving the workplace culture and environment, quality of care, professionalism and improve resource efficiency (people don't have to be hiding from these matters); these programs will also improve integration, integrity, empathy and compassion which are very much needed

qualities at any workplace. The promotion of lived experience leadership roles will contribute to a culture of fairness and allow lived experience staff to utilise a set of unique skills and pursue career dreams.

Re action 3.1c (pilot initiatives in collaboration with key communities): In CALD communities, reducing stigma is a sensitive project which requires careful consideration of the targeted cohort and their background. There is definitely a readiness to change and improve access to mental health services, and one of the factors that could contribute to this is reducing stigma in these communities.

Co-production and involvement of community leaders and their representatives. Consideration that CALD communities belong to different categories and backgrounds, and it is not effective to generalise or adopt a single approach and assume it applies to everyone. Consideration of the unique challenges facing CALD communities is also important to develop a clear understanding of the stigma involved and spread in these communities.

Generalisation within the same community is a major barrier to success. Although CALD communities have specific characteristics, some members are completely unique and different. For example, members of the LGBTQ+ in CALD communities and refugees face completely different challenges and stigma than other communities. Any designed solution or initiative should take into account the uniqueness of these communities while leaving space for those outsiders to use these services.

I am certain that these initiatives will produce a massive impact in CALD communities. However, some of the unintended consequences include cultural sensitivity, lack of trust, inability to overcome language barriers, ineffective resources and unintentional confusion.

We note that there is limited mention of actions focused on rural and remote communities e.g., **3.1c**

Re action 3.1d (professional mental health education and training curricula): The impact of stigma on people with lived experience is unimaginable, and the inclusion of any training program/initiative targeting this matter is highly valuable. A lot of individuals are working alone to accomplish this without any support or funding. Many individuals with lived experience are changing public opinion about mental health, and one of the things this initiative can do is support them.

Involvement of lived experienced professionals in the design and implementation of this initiative. Co-production with lived experience, especially those who are active in the role of stigma reduction.

Funding and access to experience. This initiative will also share the challenges that already exist in higher education and by the accreditation bodies. Involvement of lived experience who are already in this field is extremely important.

Yes, some educators are already creating content in their curriculum to address stigma in mental health. I have participated in similar content creation that targeted students in the field of social science and psychology. The aim was to transfer a message to those students that their actions matter and the decisions that they make in the future (in relation to patients) could have significant impact.

Re action 3.1e (ensuring future public stigma reduction campaigns incorporate human rights, strengths-based, codesign, and acknowledge multiple forms of discrimination): Many ideas can respond to this initiative, such as a citizen of the year recognition or any other sort of public recognition event that highlights the achievement of lived experience and promotes hope and recovery. Support from local communities and champions.

An effective communication plan that aims to reach people with lived experience to step forward. Education in institutions such as city councils and local communities about recognising the achievements of lived experience. Co-production.

Lived experience recognition might create a feeling of unfair treatment and evaluation. Achievement from some members of the lived experience community might create certain expectations among the community members. Some members of the lived experience community won't be able to meet those expectations.

4. Reducing self-stigma

We thank the National Mental Health Commission for the inclusion of Priority 4: Reduce self-stigma. We believe it is as important as the other priorities and is not mutually exclusive in its development or impacts; the many facets of stigma and discrimination are often inter-related. This is captured somewhat in the statement on p.37 of the Strategy with the statement ‘Self-stigma cannot be addressed without overarching actions to reduce public and structural stigma and discrimination.’ We suggest that it also cannot be understood without more fully understanding the reasons for, development and ongoing perpetuation of public and structural stigma.

At present, there is a general recommendation to conduct prevalence research into self-stigma **(4a)**. We suggest that more research on how self-stigma relates to stigma and structural stigma and discrimination is needed. As important, more research is needed on how it relates to other concepts like hope, shame, racism, loneliness and isolation, and human rights is needed.

If we take the concept of shame, which arguably shares space with self-stigma, even some of our most current prominent thinkers, may fail to grasp this concept within a mental health context. In a recent Radio National episode of The Mindfield focused on shame¹², for example, Dr Walid Ali, Professor Scott Stephens and their guest Professor Owen Flanagan from the US, discussed that shame “is regarded, certainly in the West, as uniquely destructive to a healthy sense of self, as psychologically damaging and socially abusive, and to be avoided at all costs.” They argued that shame has positive benefits within a number of cultures, as moral education; as “a powerful socialising emotion”. Professor Stephens described it as, “something about how people are seen and regarded by other people; an external judgment that makes its way inwards” and that this was not necessarily a bad thing. However, at no point in the podcast was the act of shaming another person regarded as other than a single event. We know from our lived experience and of meeting many others with lived experience of mental health challenges that a deep sense of shame has developed for some individuals, often because they have been made to feel shame cumulatively and relentlessly over time within abusive relationships or grinding circumstances of poverty, unemployment, homelessness, and so forth. How has mental illness become contemptuous in the eyes of some in the community, a spoilt identity, as Goffman said almost 60 years ago.¹³ The problem we have with current expert views like those expressed on The Mindfield, is that what they propose relies on a fair and equitable community, informed and aware, respectful and tolerant of diversity. Whether it is the ongoing adverse experiences of colonisation for Aboriginal and Torres Strait Islander Peoples, migrant communities, or people with mental health challenges, is that there is much to do for the community to be fair and equitable. The ideas expressed about shame on The Mindfield also don’t consider the accountability of the people doing the ‘shaming’. We propose that there is a two-way responsibility as a community, with reciprocal obligations to each other to not ‘harm’ others in the act of ‘shaming’. Shame, stigma and discrimination cause harm and we suggest, perpetuate self-stigma.

Re action 4b, on the peer workforce and self-stigma, it would be useful for the strategy to provide some context for the inclusion of this action.

Re action 4c, alongside programs designed to build stigma-resistance, resilience and self-compassion, we think that building hope should be included. Also, the current focus places responsibility for fixing self-stigma within the person, by teaching them strategies and educating them on how they can resist or change their attitude to their circumstances. This may inadvertently reinforce the very thing that it seeks to solve. When people live in a world where they are surrounded by intractable structural stigma, where they experience repeated exclusion, lack of access, diagnostic overshadowing, powerless and shame, self-stigma

¹² The Ethics of Shame. The Mindfield, Radio National, 11 Aug 2022. <https://podcasts.apple.com/us/podcast/the-ethics-of-shame/id985462397?i=1000575744859>

¹³ Goffman E. (1968) Stigma: Notes on the Management of Spoiled Identity, Harmondsworth: Pelican Books.

may well be a powerful response and impact. Whilst the Strategy has other actions in other sections and priorities about public awareness raising, workforce education, and so on, more must be actioned to make the links between all these forms of stigma and discrimination.

Re action 4d, the aspiration of a human rights-based approach to underpin best practice cannot be achieved without frank and fearless conversations about shame, racism, discrimination and so forth. The coming referendum on A First Nations Voice to Parliament is one example.

Contact

We thank the National Mental Health Commission for the work it is doing on this important national and community issue. We wish you every success with the next steps. We would be keen to discuss further, any clarification or issues raised here with you.

Your sincerely

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Email: jkhateeb@livedexperienceaustralia.com.au

Darren Jiggins
Lived Experience Australia Ltd
Deputy Board Chair
Email: djiggins@livedexperienceaustralia.com.au

Privacy statement and Questions

Do you consent to the National Mental Health Commission's collection, use and disclosure of your personal and sensitive information that you contribute to this survey, in accordance with our [Privacy Statement](#)?

X Yes

No - In selecting 'No' you are advising the Commission you do not consent to this privacy agreement. This will mean that you cannot complete the survey and your feedback cannot be considered. See [here](#) for other opportunities to contribute to the Strategy's development.

Q1: I am uploading a submission (required): (Choose any one option)

- on behalf of myself (please continue and complete questions 2-8)
- on behalf of an organisation (please complete question 2, then skip to question 9)

Q2: What part(s) of the Strategy does your submission relate to? (select all that apply)

- Foundational actions
- Mental health system
- Health system
- Social services
- Financial services and insurance
- Legal systems
- Getting a job and staying in the workforce
- Education and training
- Public Stigma
- Other (please specify):

For submissions from organisations (Q9-13)

Q9: What are the primary areas of focus for the work of your organisation? (Select all that apply)

- Mental health system (including alcohol and other drug services and services to support people who experience gambling harm) Health system
- Social services (including aged care, disability, housing/homelessness, children and family services and employment services) Legal system (including courts, police and legal practice)
- Financial services (including banking, insurance, superannuation, financial counselling, complaints and/or advocacy)
- Education and training (including early childhood, primary and secondary education, university, vocational education and training (VET), and adult, community and other education)
- The media

Q10: What is the key function of your organisation? (Choose all that apply)

- Provider of goods/services
- Peak/representative body
- Policy and advocacy
- Research

Other (please specify) : __LE research, LE capacity building/training_____

Q11: Does your organisation have a specific focus? (Choose all that apply)

- People with lived experience of mental ill-health, trauma, distress and/or suicidality
- Families, carers and support people
- Aboriginal and Torres Strait Islander people and communities
- Culturally and linguistically diverse people and communities
- LGBTIQ+
- Older Australians
- Children and/or young people
- People with disability
- Other population group (please specify): _____

Q12: What location(s) does your organisation work in? (Choose all that apply)

- NSW
- Victoria
- Queensland
- Western Australia
- South Australia
- Tasmania
- ACT
- Northern Territory
- Nationally
- Online only
- Regional, rural and/or remote areas
- Other (please specify): _____

Q13: What is the name of your organisation? __Lived Experience Australia Ltd_____

Q14: Please provide a contact in your organisation regarding your submission

Name and position title: Sharon Lawn, Chair and Executive Director_____

Email: _slawn@livedexperienceaustralia.com.au_____

Consent to be contacted

As we review your submission, we might identify a potential quote that illustrates a key point, idea or experience that supports the objectives of the Strategy.

We will not publish or otherwise use any of your contributions without first contacting you to seek your consent.

Do you consent to the National Mental Health Commission contacting you to seek further information about your response and/or to seek your consent to use parts of your response as a deidentified quote in the Final Strategy or project materials?

Yes

If yes, please provide your preferred contact details (complete at least one of the following):

Email me at: ___slawn@livedexperienceaustralia.com.au_____

Call me on: ___0459 098 772_____

Send me a text to: ___0459 098 772_____

No