Centre for Mental Health
Melbourne School of Population and Global Health

Reducing stigma and discrimination towards people with mental illness

Phase 3: Consultations with people with lived experience

3 February 2021

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Executive summary

Background and aims

Reducing stigma and discrimination is critical to improving the wellbeing of people with lived experience of mental illness. Priority Area 6 of Australia's Fifth National Mental Health and Suicide Prevention Plan outlines the need for a nationally coordinated approach to reduce stigma and discrimination towards people with mental illness that is poorly understood in the community. In the first phase, we reviewed the literature on anti-stigma programs in Australia. In the second phase, we conducted stakeholder consultations that aimed to inform options for an effective strategy for reducing stigma and discrimination in Australia. This report details the findings of the third phase of the project; consultations with people with lived experience, either their own or as a support person, or both.

A note on terminology: The language used to talk about mental illness can play a key role in reducing stigma and is constantly evolving. While we understand that views on the most appropriate terms differ, for the purposes of this project we have chosen to use the broad term 'mental illness' to reflect that used in the Fifth Plan. We also use the diagnostic terms schizophrenia, bipolar disorder and personality disorders as starting points to ensure that the focus is on low prevalence mental illness rather than on depression or anxiety. **We have also used the term 'people with lived experience' as a general term to refer to people who have experienced mental health conditions or emotional distress or have used mental health services and also to people who care for or support people with mental illness**. Alternative terms used in the report (particularly by participants) are 'consumers' or 'people with living experience' and 'carers'. Throughout this report we use stigma to refer to attitudes and discrimination to refer to behaviours towards a person with a diagnosis or experience of mental illness.

Methods

We conducted online video focus groups with 117 people with lived experience, either their own or as family members, friends and other support people. Participants were asked to provide feedback on the draft recommendations developed in Phase 2 of the project. All focus groups were recorded, transcribed and analysed to identify key themes.

Key findings

There was broad agreement that the recommendations were appropriate and comprehensive. In many cases, these discussions were wide-ranging, encompassing topics relating to broad health system and societal changes. However, we have focussed our changes to the recommendations on those more closely related to the project aims. A number of participants reiterated the urgent need for action, measurable goals with clear timelines and accountability. Limitations include relatively limited participation from people whose first language is not English, with low literacy levels, poor access to the internet or other factors that prevented them for participating in online focus groups.

Recommendations

Recommendation 1: Ensure that people with lived experience (either their own or as support people) have leadership roles in the strategy, by:

- Funding a national body, either an existing organisation such as the National Mental Health Commission or a new organisation, led by people with lived experience to develop and oversee implementation of the strategy;
- Involving, and adequately funding, national and state-based lived experience advocacy organisations, both large and small, in strategy development and implementation;
- Building collaborations between community, government and non-government organisations to create a cross-sector cooperative network with a shared purpose while also accounting for diversity in cultures, perspectives, skills and experiences;
- Ensuring that there is adequate and genuine lived experience representation on boards, advisory committees, or other decision-making entities by:
    - widely advertising lived experience roles, and detailing the supports that will be provided, to ensure representation from a broad range of people, including those with less common diagnoses, those from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities;
    - appropriately remunerating people with lived experience for their work;

    - creating career paths for people in these roles through provision of support, mentoring and educational opportunities;
    - ensuring that opportunities for participation are flexible enough to suit the individual circumstances of people with lived experience.

Recommendation 2: Ensure that anti-stigma programs and activities are led and co-designed by people with lived experience (either their own or as support people), by:

- Supporting people with lived experience to share narratives of mental health and recovery in ways that allow others to move beyond a view of them as being entirely defined by their illness;
- Focusing on narratives that:
    - move beyond raising awareness that mental illness and stigma are problems without offering solutions;
    - challenge, rather than avoid, stereotypes around dangerousness, unpredictability and unreliability;
    - challenge commonly held stereotypes that a person with a diagnosis of a mental illness is a burden to society, incapable of work, participation in education or family life or of achieving successes that are possible for people without these diagnoses;
    - are realistic, acknowledging that the experience of mental illness is different for everyone (e.g., single episode, episodic, long-term and recovered from clinical symptoms), and that it comes with challenges;
    - build empathy and understanding, including a focus on mental illness as a response to trauma and a failure of necessary supports (including those in the health and mental health system) rather than blaming the individual or their family;
    - acknowledge the benefits and strengths that lived experience of mental illness can bring, including greater empathy, interpersonal skills, assertiveness, creativity, adaptability and resilience
- Providing opportunities for face-to-face contact between community members with and without lived experience of mental illness, while also maximising opportunities to use video/online content;
- Ensuring sufficient financial support and training for people with lived experience who share their experiences through adequate resourcing of organisations that run programs involving people with lived experience;
- Evaluating the impact of involvement in the programs and activities on people with lived experience themselves.

Recommendation 3: Start now and take a long-term approach that:

- Builds on successes in changing attitudes to common mental health conditions;
- Is informed by successful strategies used by others advocating for social change, e.g. the LGBTIQA+ community;
- Has adequate funding and support for large scale campaigns that may take years, or even decades to have impact;
- Involves activities that build on successes and evolve over time, with new messages and strategies to sustain Interest and attention and that target sub-groups where attitude change is slow or stagnant;
- Incorporates actionable short, medium and long-term goals with clear timeframes and measurable outcomes.

Recommendation 4: Evaluate the impact of the strategy on the short, medium and long-term goals by:

- Using mixed methods approaches, including population surveys and qualitative research;
- Ensuring that people with lived experience co-design and conduct evaluations, including specification of the impact of any activities being undertaken;
- Ensuring that people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities co-design and evaluate activities carried out in their communities.

Recommendation 5: Align key messages or elements in the strategy, but tailor to local needs, by incorporating the following principles:

- Programs should be culturally appropriate, celebrate diversity and be led by local communities;

- Use of language, including diagnostic terms, should be tailored according to program and setting;
- Further research into the impact of key messages and interventions should be undertaken to assess effectiveness in different community groups and settings and avoid unintended negative consequences.

Recommendation 6: Address stigma and discrimination in health services by:

- Implementing reforms that support, at both structural and individual practitioner levels:
  - a fundamental shift away from treatment that only focuses on the symptoms of mental illness towards a focus on wellbeing, including social, spiritual and cultural aspects;
  - a shift in power dynamics between practitioners and people with lived experience, including both consumers and support persons;
  - moving away from approaches that offer people services and supports based on their diagnoses to those that focus on their needs and aspirations;
- Strengthening peer work as an emerging discipline:
  - through implementation of policies and processes that support their distinct role in multidisciplinary teams;
  - through comprehensive provision of career opportunities, supervision, mentoring, and training;
  - by providing fair and equitable working conditions, including parity of pay and reasonable adjustments to their roles;
  - by including peer support workers who are from a diverse range of language and cultural backgrounds;
- Incorporating strategies to address self-stigma in people diagnosed with mental illness, as well as stigma in support people, through better linkage between health services and local lived experience advocacy organisations and programs; while recognising that self-stigma is a product of the experience of stigma and discrimination in the community
- Encouraging, supporting and enabling psychiatrists, nurses and other allied health staff to take leadership roles in stigma reduction;
- Involving people with lived experience in systems-level changes in health services;
- Incorporating training in person-centred, trauma-informed care, led by people with lived experience into training for all health professionals;
- Incorporating aspects of reflective practice (including adequately funded supervision and mentoring), to allow health practitioners, senior managers and policymakers to understand their own attitudes and the impact of their work in mental health;
- Improving education for health professional students by including language guides, evidence about the harms of stigma and discrimination and positive narratives or contact with people with mental illness who have flourishing lives, to counter the impact of early encounters with people who are acutely unwell;
- Ensuring that training is ongoing to incorporate new evidence and address attitudes that may change over time;
- Implementing training and reflective practice initiatives that specifically focus on improving health professional attitudes, language and behaviours towards people with borderline personality disorder, including building skills to improve outcomes and reduce therapeutic pessimism;
- Evaluating anti-stigma initiatives in health services, including the impact on people with lived experience.

Recommendation 7: Address stigma and discrimination in workplaces by:

- Strengthening anti-discrimination policies and their enforcement;
- Promoting practices that support mentally healthy workplaces;
- Ensuring that people in senior leadership roles model positive attitudes and behaviours towards people with diagnoses of mental illness;
- Providing education including key messages that focus on the contribution that people with mental illness can make as well as on the importance of supporting people with mental illness in the workplace (including through reasonable adjustments);

- Implementation of interventions that address fears about competence, reliability, productivity and extra 'burden' related to employing someone living with a mental illness, by including people with lived experience telling stories of success;
- Adequately resourcing and supporting ongoing training for employers;
- Providing more access to programs for people with psychosocial disabilities to enter and be supported in the workplace, including flexible working arrangements, staying/returning to work plans, support around disclosure, mentoring, individual placement support and skills training;
- Using the momentum arising from changes in work practices caused by the COVID-19 pandemic to further strengthen access to flexible working environments, support greater openness about mental health issues and support for employees.

Recommendation 8: Address stigma and discrimination in the community by:

- Focusing on activities that demystify or normalise mental illness;
- Moving beyond a focus on the scale of the problem and what not to do, to incorporate suggestions for positive language and behaviours towards people with diagnosed with mental illness;
- Having a greater emphasis on symptoms or experiences (e.g. distress), rather than on diagnostic categories;
- Conducting media campaigns, including traditional media that reaches rural or culturally and linguistically diverse communities, digital and social media;
- Supporting grass roots events tailored to local community needs, including creative arts, food and sporting events (particularly in Aboriginal and Torres Strait Islander, LGBTIQA+ and culturally and linguistically diverse communities) that offer opportunities for positive interactions between community members with and without mental illness;
- Ensuring that Interventions intended for a mainstream audience also reflect the cultural diversity of the Australian population.

Recommendation 9: Address stigma and discrimination in the media by:

- Improving the quality of media reporting on mental illness, particularly that relating to violence and crime by:
  - encouraging the Australian Press Council to work with lived experience advocates and media organisations to improve practice for coverage of mental illness and crime;
  - encouraging media professionals to improve their mental health literacy (through accessing information resources or undertaking training);
  - implementing interventions for media professionals (including journalism, film, television, and communication students) that encourage them to:
    - regularly consider the impact of media reports and language on public attitudes and people living with mental illness;
    - report all relevant risk factors that contribute to violence and crime, including failings in the mental healthcare system and factors that are not related to mental illness;
    - use non-stigmatising language and images;
    - use social media responsibly when sharing or engaging with news content involving mental illness and crime;
  - strengthening monitoring of media reporting on mental illness and violence, e.g. through SANE Media Watch;
- Encouraging social media influencers and celebrities to improve their understanding of mental illness and how to use their platforms to support reductions in stigma and discrimination;
- Encouraging people with lived experience, advocacy bodies, and TV and film production companies to work together to improve portrayals of people with mental illness;
- Introducing segments on children's television programs that can start to appropriately introduce concepts of mental health and diversity of experiences from a young age

Recommendation 10: Address stigma and discrimination in educational institutions by:

- Providing ongoing mental health education in all schools and tertiary education institutions, that includes positive narratives of a diverse group of people with lived experience of low prevalence mental illness;

- Providing early intervention and support for students with mental health problems, particularly for international students and students at times of transition;
- Improving funding and standards for professional development and support for staff in schools and tertiary education institutions;
- Ensuring that staff who regularly provide mental health support in educational institutions are appropriately trained in person-centred, trauma-informed practice.

Recommendation 11: Address stigma and discrimination in police, social services, justice and welfare professionals, by:

- Implementing training led by people with lived experience that takes a trauma-informed approach, incorporating an understanding of the social determinants of health, and including narratives of hope and recovery;
- Adequately resourcing and supporting ongoing training;
- Incorporating peer-support workers or advocates into social and welfare services to assist clients in navigating these complex service systems.

1. Introduction

Discrimination against people with mental illness is prevalent in Australia.[1,2] Reducing this is critical to improving the wellbeing of people with mental illness and their families, friends and other supporters (hereafter referred to as support people). It is widely acknowledged that it will take a sustained and collective effort to dispel the myths associated with mental illness, change ingrained negative attitudes and behaviours, and ultimately support social inclusion and recovery.

While there have been some improvements in community understanding of common mental illnesses (particularly depression and anxiety), there is still widespread misunderstanding and ignorance. In particular, low prevalence mental illness, such as schizophrenia, bipolar disorder and personality disorders, tend to be poorly understood and attitudes towards people with these mental illness diagnoses are less positive than for more common mental health conditions.[3]

Recognising this, Priority Area 6 of Australia's Fifth National Mental Health and Suicide Prevention Plan outlines the need for a nationally coordinated approach to reduce stigma and discrimination towards people with mental illness that is poorly understood in the community. The first phase of this work involved a review of the evidence relating to the reduction of stigma and discrimination towards people with low prevalence mental illness.[4,5] The second phase involved consultations with a wide range of stakeholders, including anti-stigma program providers, health professionals (and students) and those working in the education, employment and social services sectors. Subsequent to these consultations, a set of draft recommendations for a nationally coordinated approach to stigma and discrimination reduction was developed. In this phase of the project we report on consultations with people with lived experience, either their own or as a support person. The principal aim of these consultations was to seek feedback on the draft recommendations.

2. Project aims and rationale

2.1. Aims

The aim of this phase of the project was to seek feedback from people with lived experience on the draft recommendations for an effective plan for reducing stigma and discrimination in Australia, particularly for people with mental illness which is poorly understood in the community.

2.2. Rationale

The project plan was informed by the need for national coverage and inclusion of key groups already at high risk of experiencing discrimination as well as those whose behaviours have a major influence on people living with a mental illness and their supporters. It also drew on key national surveys incorporating measures of stigma and discrimination[1-3,6-11] and the evidence for effective interventions.[4,12-14]

This project is based on the rationale that an effective national plan for reducing stigma and discrimination towards people with mental illness requires consultation with a broad range of stakeholders from the following key groups:

- Group 1: People who experience stigma and discrimination as a result of their own lived experience of mental illness or through experiences as family members, friends or supporters.
- Group 2: People whose attitudes and behaviours (negative and positive) towards people with mental illness have the potential to significantly influence the lives of people living with a mental illness.
- Group 3: People who implement Australian programs to reduce stigma and discrimination and can comment on the elements of a national plan that are likely to be both effective and feasible.

We note that, in the original project plan, it was our intention to undertake consultations with people with lived experience and their support people simultaneously with those in Groups 2 and 3. However, due to Covid-19, the project plan was revised and our interim report covered stakeholders in Groups 2 and 3, while this current report covers consultations with stakeholders in Group 1. We also note that people in peer worker and other lived experience-based roles in mental health services were involved in Phase 2 of the consultations. Therefore, there were lived experience perspectives on the development of the draft recommendations.

3. Methods

This part of the project, focus groups with people with lived experience, was approved by the University of Melbourne Medicine and Dentistry Human Ethics Sub-Committee (application number 1955980.4). The COREQ (COnsolidated criteria for REporting Qualitative research) Checklist was used to report our methods and results for this section of the report. [15]

3.1. Participants and recruitment

Participant recruitment occurred from September to October 2020. It was primarily conducted in the following two ways:

(1) A member of the research team directly contacted individuals and organisations recommended by the Department of Health RSDWG to request their assistance with recruitment.

(2) Snowball recruitment, involving asking participants from the previous phase for assistance with recruitment, encouraging them to pass on details of the project to their relevant networks.

We requested assistance with recruitment from 62 organisations. Individuals and organizations were asked to send out a recruitment email to their members advising them of the project and inviting them to participate. People with their own lived experience and support people who were interested in participating in a focus group were asked to contact one member of the research team directly or to fill in an online expression of interest survey, hosted on Qualtrics. Information collected in this survey was used to plan focus groups and allocate participants to either a group of people with their own lived experience or to one for support people.

Focus groups were organized to meet the preferences and availability of potential participants. Six people were initially sent an email invitation for each group. The email invitation included an attached plain language statement (PLS) describing the purpose of the study and further information about the focus group, including focus group type, date and time. Potential participants were given 48 hours to respond to the invitation. A follow up SMS reminder was sent for participants who did not check their email regularly. Additional people were invited to participate if a person did not respond to the email invitation in 48 hours or declined to participate, until six people confirmed their participation in a focus group. Individuals who contacted the researcher at a later date were either offered a place in another focus group (availability permitting) or were offered the alternative survey option to capture their feedback.

Those who agreed to participate were sent a follow-up email with further information about the focus group, including the consultation materials, small biographies of the facilitators, and details for joining the focus group via Zoom. Consent to participate was obtained through a socio-demographic questionnaire or via verbal consent at the start of the focus group. Participants were reimbursed with a $50 voucher for participating in a focus group; remuneration was not offered to individuals completing the alternative survey option.

For recruitment, data collection and reporting purposes, we classified participants as belonging to two groups: (1) people with their own lived experience, (2) support people. In the findings, verbatim quotations extracted from the focus group transcripts are used to illustrate key points. Each quotation is labelled with the participant's stakeholder group (e.g., person with their own lived experience) and focus group type (e.g., health services).

3.2. Data collection

3.2.1. Sociodemographic characteristics

The confirmation email to participants also contained a link to a short demographic survey, which was hosted on Qualtrics and included questions about participants' personal experiences with mental health conditions, age, gender and location.

3.2.2. Focus groups

Each group was facilitated by two facilitators from an 8-person research team (See Appendix A) and included no more than 6 participants. Focus groups were conducted via the Zoom online video-conferencing platform. Participants were also able to join focus groups using audio-only, although the large majority used video and audio. Most participants were in their home, some were in another location (for instance in their car), and efforts were made for people to be alone in the room. Focus group duration ranged from 60 to 90 minutes. The focus groups were semi-structured and were informed by the focus group guides and consultation materials given in Appendix B. They were designed to elicit opinions on a series of recommendations developed in the previous phase of the project. Each group had a particular theme (e.g., reducing stigma and discrimination in health services, in the general community or among LGBTIQA+ people). For participants in all focus groups, questions focussed on their views about the broad principle recommendations (e.g., Recommendations 1 to 5), their appropriateness, implementation enablers and barriers, and suggestions for improvements, including any missing recommendations. Recommendations related to key settings and communities were discussed in further detail depending on group theme. For participants in groups focused on specific communities, questions also focused on their views on tailoring to local contexts, inclusivity and delivery mechanisms. Facilitators ensured that each participant was offered opportunities to participate in the discussion.

Co-facilitators engaged in a debriefing discussion immediately following each focus group, based on their notes and experiences. Focus groups, including the debrief, were audio-recorded, and the audio files were transcribed by a professional transcribing service.

3.2.3. Additional data

Additional data were collected through the alternative survey options, and from participants via email after they had participated in focus groups. In addition, one person who, due to connectivity issues, was not able to participate in a focus group was interviewed over the phone. These data were also transcribed and included in data analysis.

3.3. Data analysis

All transcripts were de-identified and assigned codes. Identifying details such as the participant's name were removed during transcription. Data in transcripts were analysed using a mix of thematic and framework analysis. Framework analysis is a method of analysing qualitative data which combines *a priori* knowledge and assumptions, to gain information about specific questions, while also having the capacity to incorporate new themes from the data. [16,17] All analysis was conducted using the qualitative data management software NVivo. An initial coding framework was developed using the series of recommendations developed in Phase 2 of the project, with additional codes applied to themes emerging from the data. Four members of the research team (AR, CB, CM and JW) analysed the data. Two members of the research team (CM and JW) collaborated on initial coding of transcripts until a common approach was agreed upon.

One member of the research team, a researcher with lived experience of mental illness (JW) conducted the initial coding and analysis. Double-coding of transcripts was conducted by three additional members of the research team (CB, CM, and AR). Two researchers, one with lived experience of mental illness, double-coded transcripts across discussion groups (CB, CM), and a researcher with expertise in media reporting of mental illness double-coded the media focus group transcripts (AR). Interrater reliability was ascertained using NVivo, and instances where congruence of less than 90% was identified were discussed by the researchers.

Data on participant sociodemographic characteristics, professional or personal experiences with mental health conditions, age, gender and location were analysed using descriptive statistics.

4. Results

4.1. Recruitment

Of the 233 individuals who registered their interest, 222 individuals were invited to participate in one of 31 focus groups. Of the 222 individuals invited to participate, 41 did not respond to the invitation email, 27 were unable to proceed due to time constraints or late cancellation, 9 did not meet eligibility criteria and declined to participate, and 25 did not attend. In total, 117 people participated across 31 focus groups (Table 1). A further 13 people, two of whom contacted the researcher directly following close of registration, could not be offered a focus group due to lack of availability and were offered an alternative survey option to participate.

Table 1. Focus group topics and participation

Topic of focus group	Focus group IDs	Number of focus groups	Number of participants
Health services	HSLE01, HSLE02, HSLE03 HSSP01	3 x Own lived experience 1 x Support people	12 2
General community	GCLE01, GCLE02 GCSP01, GCSP02	2 x Own lived experience 2 x Support people	8 7
Workplaces	WKLE01, WKLE02, WKLE03 WKSP01	3 x Own lived experience 1 x Support people	12 6
Young people	YPLE01	1 x Own lived experience	5
Rural/regional	RRLE01 RRSP01	1 x Own lived experience 1 x Support people	4 3
Media	MELE01, MELE02 MESP01	2 x Own lived experience 1 x Support people	9 5
Social service and welfare	SWLE01, SWLE02, SWLE03 SWSP01	3 x Own lived experience 1 x Support people	8 5
Cultural and linguistically diverse	CALE01, CALE02 CASP01	2 x Own lived experience 2 x Support people	6 5
Criminal justice	CJLE01	1 x Own lived experience	4
Education	EDLE01 EDLE02	1 x Own lived experience 1 x Support people	4 4
LGBTIQA+	LGLE01, LGLE02	2 x Own lived experience	8
Total: 11		**31**	**117**

Abbreviations: LE = Lived experience of their own, SP = Support people, HS = Health services, etc.

4.2. Sociodemographic characteristics of participants

Sociodemographic characteristics of participants are given in Table 2, with 121 of 122 participants completing the questionnaire. The majority (73.8%) of participants were female, and the most commonly reported age categories were 45-49 (18%), 50-54 years (13.1%) and 40-44 years (12.3%). Participants were most likely to be from Victoria (31.1%) or New South Wales (29.5%) and from metropolitan areas (75.4%).

Table 2. Sociodemographic characteristics of participants

	n	%
Gender		
Female	90	73.8
Male	26	21.3
Gender diverse (e.g. trans, gender fluid)	5	4.1
Not reported	1	0.8
Lived experience*		
Person with their own lived experience	69	56.6
Support people	25	20.5
Person with their own lived experience and support person	27	22.1

Not reported	1	0.8
Mental health experience (their own) [a]		
Bipolar disorder	33	27.0
Personality disorders	31	25.4
Psychosis	22	18.0
Schizophrenia	7	5.7
Other [b]	50	41.0
Do not identify with a diagnosis	9	7.4
Mental health experience (as support person) [a]		
Bipolar disorder	28	23.0
Personality disorders	20	16.4
Psychosis	25	20.5
Schizophrenia	24	19.7
Other	20	16.4
Person does not identify with a diagnosis	3	2.5
State		
ACT	6	4.9
NSW	36	29.5
NT	1	0.8
QLD	15	12.3
SA	6	4.9
TAS	2	1.6
VIC	38	31.1
WA	17	13.9
Not reported	1	0.8
Region		
Metropolitan	92	75.4
Regional	21	17.2
Rural	8	6.6
Remote	0	0
Not reported	1	0.8

[a] Total percentages >100% due to possibility of multiple responses. [b] includes anxiety disorders, OCD, depressive disorders, complex PTSD and other trauma-related conditions, ADHD, psychotic experiences other than schizophrenia including psychotic depression and schizo-affective disorder, eating disorders, PMDD, autism, and suicidal ideation

4.3. Themes

4.3.1. General feedback on recommendations and consultations

(1) The need for accountability

People with lived experience were very keen to take part in the consultations. Participants were extremely passionate about the topic and openly and thoughtfully shared their experiences and gave feedback on the draft recommendations. The majority of participants agreed that the draft recommendations were appropriate, relevant, and covered many settings where stigma and discrimination towards people with mental illness take place. However, scepticism and frustration were expressed by people who have long been advocating for changes in policies, legislation, and services to decrease discrimination and stigma; with many noting that they have seen minimal changes. Therefore, many participants emphasised the need for accountability, including the development of actionable goals for each of the recommendations to allow for the measurement of progress over time.

Moreover, there was an acknowledgement that, while federal anti-discrimination legislation exists in Australia, as well as anti-discrimination policies in many parts of society; employers, media outlets, education providers, insurance companies, welfare agencies and healthcare providers are rarely held accountable for discrimination through acts of exclusion, inappropriate use of language, and barriers to services and opportunities. The legislation was seen as "toothless". There was a general consensus that our community, government, workplaces, educational settings, and healthcare services should be made more accountable for inclusion of people with mental illness, and that the responsibility to educate the community or call out discrimination should not lie solely with the people who experience mental ill health, notwithstanding the considerable contribution towards advocating for change made by people with lived experience.

> *"that leaders within the system, within community, within government are committed to and responsible for ensuring the safety and wellbeing of people when they access services." (HSLE02)*
>
> *"I suspect that having kind of punitive action or things isn't necessarily the most conducive thing to changing attitudes and behaviours but there just does come a point where it's like how long does this have to keep going unchecked for, we're the ones having to wear this every day" (LGLE02)*

Some participants noted the need to move beyond awareness raising campaigns and raised issues relating to the root causes of stigma and discrimination toward people with mental illness.

> *"I'm so sick of awareness raising campaigns, they, raising awareness is one thing, having support around you, having a society that works for you, being able to have your own citizenship is very different and doesn't necessarily come from there being awareness. Awareness doesn't equal health services being in place or supports being in place" (HSLE02)*

(2) The need for broader mental health service system reform and improvement in access to services

Participants often spoke about the "medical model" of mental illness as contributing to stigma, and many argued that community understanding of the biopsychosocial model of mental health should be more actively promoted.

> *"it's pretty clearly established that the biological reductionist understandings of distress in this space contribute to stigma. And so I'm keen to see a strategy that attacks and addresses that, both within services and within the sort of community discourse around this." (EDSP01)*

The main themes that arose here included the urgent need for:

- More accessible and equitable, person-centred healthcare services for the prevention and treatment of mental illness; including more funding to support the (mental) health workforce who were widely recognised as being overworked and under resourced. A lack of services was reported in certain communities, e.g. rural and remote; for certain groups e.g. people with a culturally and linguistically diverse backgrounds; and for certain conditions, e.g. borderline personality disorder. In particular, people at the intersection, identifying with several of these groups, often reported a lack of services or support available to meet their individual needs. There was a view that this perpetuated stigma and discrimination in their communities.
- More accessible welfare services, including those provided through the National Disability Insurance Scheme (NDIS). Many participants commented on the difficulty of accessing services and particularly on the high threshold

for people with episodic (but severe and long-term) conditions. Those who had been successful in accessing NDIS services spoke of the benefits but noted that the long process and amount of time and effort to obtain access caused undue stress.

- Equitable access to employment and education opportunities which make reasonable accommodations for people with psychosocial disability, as these are important determinants of health and equity.

Participants from rural and remote areas spoke a lot about lack of services, the difficulties of addressing stigma in small towns where everyone knows each other, thus having minimal anonymity or privacy, and there are limited employment opportunities or second chances. In many of these communities, these issues have been compounded by ongoing financial insecurity and natural disasters (e.g. drought or bushfires) and lack of continuity in services due to short funding cycles.

> *"So yeah we had the floods, then we had the drought, then we had the fires, then we had still more drought so issues with agriculture, then we had COVID which then brought on issues with staffing, of actually getting, being able to pick fruit, that was just going to waste. So in amongst all of that we've had however many service providers in mental health come and go… Each organisation that comes in has, I think it's even an 18 month or 12-month contract, and by the time they've done their marketing to see where are the needs, the funding's gone, that was what the funding paid for... So on paper we have services. In reality we have services that have only got one, possibly 2 staff, only working, only funded for 2 days a week" (RRSP01)*

(3) The need for inclusivity

Many participants emphasised the need to better understand mental illness stigma and discrimination in groups who may already be at risk of discrimination because of their LGBTIQ+ status or ethnicity.

Some participants noted the need to ensure that it be made clear that support people are specifically included under the definition of lived experience in the strategy.

> *"when I see terms like lived experience or lived expertise, I'm also interested to unpack who are we speaking of. Because the consumer movement may perceive that that's exclusively them, and families will also identify that they are a part of that story, but we have to be invited in because we're excluded in many of these systems described in recommendation 6 to 11. So if we aren't explicitly named we may not self-identify as being participants in that discourse" (EDSP01)*

(4) Working with local organisations

Many participants emphasised the need to work with existing organisations so as not to duplicate efforts, in particular the grassroots and community initiatives, which have worked hard to advocate for change over many years, and even decades.

4.3.2. Feedback on draft recommendations

(1) Recommendation 1: Leadership of the strategy

Participants were largely in agreement with recommendation 1, which focused on leadership by people with lived experience of a nationally coordinated strategy. However, many suggested we should more strongly emphasize lived experience collaboration and co-design from early stages of developing strategies and actions. There was concern that these would be tokenistic roles and several participants noted the need for more than one role in each board or organisation, but rather multiple roles, for people with their own lived experience, as well as support people. Recommendations were made about adequately remunerating people with lived experience for their work, providing career paths, as well as supporting and upskilling people in these roles who may not yet have experience.

> *"I felt, and another person who's in the same situation as myself as a carer, they [other committee members] were just ticking boxes, they weren't genuinely interested in what we had to say and all the talk that they spoke was way above our heads, and even if we tried to understand it or question it we were dismissed… So yeah we stopped going" (EDSP01)*

> *"the confidence that comes not by being the only person in the room, so I love the idea of mentoring and I love the idea of having someone as a support" (WKLE01)*

> *"It needs to be quite solid in you know, that people with lived experience not only have important leadership roles in the strategy, but they're paid for their expert opinion" (HSLE03)*

Further, there was some concern that these roles are often not publicly advertised, but instead offered to a small pool of people who are already working with other organisations. It was suggested that people who have completed a clinical recovery from symptoms, or who are less severely impacted by mental illness, are often sought out for these roles. To ensure diversity, there should be adequate flexibility, time, and support for people in these roles.

> *"I guess there's a risk in terms of lived experience leadership that there are a lot of people that have worked in that sort of advocacy space for many years, some of them with decades of experience of trying to change and help influence change in the system and it's common to see a lot of those sort of same faces involved in many different projects which has an unfortunate sort of unintended side effect of silencing people who might not have had an opportunity to have a say" (SWLE03)*

> *"Even when we have lived experience voices you know who gets to pick the lived experience voices, so how do you find out about how to contribute" (SWLE02)*

Some participants expressed the opinion that relying on larger organisations is not sufficient to capture the diversity of the community or adequately support the needs of people with the less prevalent conditions. They noted the need to support smaller and grass-roots organisations help address this. Some participants mentioned that the lived experience advocacy environment can be challenging and that they like to be better supported to participate. These recommendations are in line with the themes that emerged from Phase 2 of the project in which those in the peer workforce talked about their difficulties in finding adequate support. Others mentioned inequitable conditions compared to the non-lived experience workforce (e.g. fractional appointments, "lone wolf" position, no parity of pay, lack of career advancement opportunities and insufficient support from managers and organisations) which has contributed to tensions within the lived experience workforce. Greater support for the workforce and increased opportunities for leadership roles and senior appointments was seen as essential to addressing these issues. The impact of this is described below:

> *"I'm going to go right back to the challenge that we have we are in a sector that is wanting the lived experience to have the voice and yet we can often be our worst enemies and our worst critics and I find that the lived experience movement is very toxic, very intimidating and there are times when I don't feel validated by my own movement, that there have been times that I've felt like well I am on this alone because I don't want to sit with this person as a potential mentor because they bully, there's that lateral violence and there is this invalidation and it's if there's a competition that my pain is worse than your pain, that my depression couldn't be any worse than yours my doctor told me that I've had the worst that sort of stuff and it does not help our stigma within us, it makes us look like an non-unified movement" (WKLE01)*

Finally, it was acknowledged by many that there are few advocacy organisations across Australia for support people of those with more severe mental illnesses, and that those that do exist are often not well funded or supported. The gaps in services and organisational representation was particularly significant for specific groups, such as people who don't speak English as a first language or who are in rural or remote areas.

These recommendations have been edited to reflect feedback on the need to strengthen guidance on the role of people with lived experience in leadership of the strategy, as well as the need for adequate funding.

Recommendation 1: Ensure that people with lived experience (either their own or as support people) have leadership roles in the strategy, by:

- Funding a national body, either an existing organisation such as the National Mental Health Commission or a new organisation, led by people with lived experience to develop and oversee implementation of the strategy;
- Involving, and adequately funding, national and state-based lived experience advocacy organisations, both large and small, in strategy development and implementation;

- Building collaborations between community, government and non-government organisations to create a cross-sector cooperative network with a shared purpose while also accounting for diversity in cultures, perspectives, skills and experiences;
- Ensuring that there is adequate and genuine lived experience representation on boards, advisory committees, or other decision-making entities by;
    - Widely advertising lived experience roles, and detailing the supports that will be provided, to ensure representation from a broad range of people, including those with less common diagnoses, those from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities;
    - Appropriately remunerating people with lived experience for their work;
    - Creating career paths for people in these roles through provision of support, mentoring and educational opportunities;
    - Ensuring that opportunities for participation are flexible enough to suit the individual circumstances of people with lived experience.

(2) Recommendation 2: Involvement of people with lived experience in anti-stigma programs and activities, including sharing narratives of their experiences

Participants agreed with recommendation 2, which focused in the involvement of people with lived experience, but recommended it more strongly emphasize that any strategies and activities should be co-designed with people with lived experience, to ensure they are central to the strategy and their roles are not tokenistic.

> *“I guess I’m a little bit curious at the language that you’re using, because you're using the word involve, and people like to use words like collaboration, consultation, co-production, co-design. Yeah and co-design by the way comes from the design industry and that’s where I got my Bachelor’s degree, and it means at every step and with equality. So that’s, and that’s not what is happening.” (GCLE02)*

Participants noted that often the people with lived experience were the focus of the work, whereas many wanted the responsibility to be with the system to commit to change, to bring down barriers and be more inclusive, rather than the person with lived experience.

Some participants raised concerns regarding people with lived experience sharing narratives, including: 1) that people sharing their story would need to be supported properly because in the current climate where stigma and discrimination is still rife, this could have negative consequences for e.g. their employment prospects; and 2) that sharing a narrative on its own may not bring about change; and 3) narratives need to be carefully selected, to avoid unintended consequences.

> *“I also have some concerns with there seems to be a lot of attention put on and responsibility put on people with a lived experience to be sharing their stories but sharing your story in and of itself, particularly if you’re not doing it in a safe environment or, there’s still a lot of stigma and discrimination around, opens up a lot of challenges there. And also sharing of story in and of itself I don’t think actually changes the system at the end of the day. Mental health professionals hear people’s stories day in and day out, and yet it doesn’t seem to break through that barrier sometimes.” (HSLE01)*

> *“we have to understand what the storytelling actually does, who tells the stories, how are they told and what’s the public perception because the public can perceive things wrongly and we can have unintended consequences” (MELE01)*

Participants mentioned it would be helpful to have a narrative of health that was not binary, e.g. physical versus mental, or healthy versus unwell, but rather a continuum, and that people can move along the continuum at different times of their lives. Some participants also commented that they did not identify with a narrative of recovery, instead we should recognize that full recovery is not always the end goal, and instead we should accept people for who they are.

> *“the word recovery, I mean I know it’s got good connotations but – do you understand what I mean and what I mean is that for people with mental illness, everyone’s at the – it’s not linear and everyone’s at their different stage and I just find that – actually even to get into services like I’ve been told ‘oh well you haven’t recovered so you can't get in this programme’..” (HSLE02)*

> *"I think there's also that aspect of like if you're not recovered then you're on that burden to society side of the line right. Like it's not just back with the herd it's also that you're legitimate, it's also that you're productive whatever that means and that you're trustworthy in some respect." (LGLE02)*

> *"it's not talked about enough I think what recovery really looks like and sometimes celebrating, because you know we're not broken people that need to be fixed, we don't necessarily have things that can be cured and all that and so it's like well what does it look like to live well you know with your condition. We don't see that depicted much, we don't see that celebrated." (LGLE02)*

Several participants mentioned they would like themselves and others with mental illness to feel proud of who they are and what they achieve despite challenges. The 'competitive advantage of disability'; the benefits of the experiences of mental illness on interpersonal skills, empathy, creativity, assertiveness, and managing experiences and emotions (e.g. resilience, self-regulation) in consumers was brought up several times as deserving more attention in narratives about mental illness. Also support people felt their resilience and knowledge and often unpaid work as a support people should be better acknowledged.

> *"it's okay for us to be like proud of ourselves for having a mental illness and if we start to help other people see that someone with a mental illness brings such depth of life and character and experience and that I think needs to be like a key message within the recommendation of how we reframe the entire narrative around what our life experience means" (MELE01)*

> *"But actually you know what if we reframe those conversations and say well actually BPD is kind of my super power because I have access to all of this kind of empathy and compassion, you know, yeah I have really intense emotions but those intense emotions can be really nice ones as well, and also I've been through more therapy than most people so I'm really good at dealing with those intense emotions." (MELE02)*

The concept that disability arises from an interaction between people and their environment should be better highlighted, so that the blame people and their families often feel is shifted to the environment and what is valued in people beyond their productivity.

> *"a true appreciation that it is the environment that disables us, not the illness." (WKLE03)*

> *"And can we look at positive outcomes from people's experiences, and promoting positive outcomes and having your own diverse approach in that all people have got a contribution to make to society and that perhaps our society needs to look at its value and who is valued for what roles in society and yet and looking beyond what is valued by – financially valued as to how we value each individual with their complexity and their individuality, so yeah I'd be looking at positive ways to perceive experiences." (HSLE02)*

Participants also debated the language that should be used in campaigns, and while some participants didn't like the use of terminology such as crazy or mad, others highlighted the Mad Pride movement's success in reclaiming and celebrating 'mad' identity. Mental illness was a term many participants didn't like using, and some preferred emotional distress; and some participants with personality disorders felt excluded if the term mental illness was used.

> *"the mad pride movement has been around now for nearly 30 years reclaiming the word mad so mad pride was really following on from gay pride and all those movements of the seventies it was really about reframing language and re-claiming language and mad was a word that they reclaimed and celebrated." (MELE01)*

These recommendations have been edited to reflect feedback on the need to strengthen the co-design and co-creation role of people with lived experience.

Recommendation 2: Ensure that anti-stigma programs and activities are led and co-designed by people with lived experience (either their own or as support people), by:

- Supporting people with lived experience to share narratives of mental health and recovery in ways that allow others to move beyond a view of them as being entirely defined by their illness;
- Focusing on narratives that:
  - move beyond raising awareness that mental illness and stigma are problems without offering solutions;

  - challenge, rather than avoid, stereotypes around dangerousness, unpredictability and unreliability;
  - challenge commonly held stereotypes that a person with a diagnosis of a mental illness is a burden to society, incapable of work, participation in education or family life or of achieving successes that are possible for people without these diagnoses;
  - are realistic, acknowledging that the experience of mental illness is different for everyone (e.g., single episode, episodic, long-term and recovered from clinical symptoms), and that it comes with challenges;
  - build empathy and understanding, including a focus on mental illness as a response to trauma and a failure of necessary supports (including those in the health and mental health system) rather than blaming the individual or their family;
  - acknowledge the benefits and strengths that lived experience of mental illness can bring, including greater empathy, interpersonal skills, assertiveness, creativity, adaptability and resilience
- Providing opportunities for face-to-face contact between community members with and without lived experience of mental illness, while also maximising opportunities to use video/online content;
- Ensuring sufficient financial support and training for people with lived experience who share their experiences through adequate resourcing of organisations that run programs involving people with lived experience.
- Evaluating the impact of involvement in the programs and activities on people with lived experience themselves.

(3) Recommendation 3: The need for a long-term approach

Participants agreed that the strategy needs to take a long-term approach, but many felt strongly that it should start as soon as possible as the lives of many are severely impacted by stigma and discrimination.

> *"Absolutely a long-term approach but long term needs to start now. It can't just start in 10 years and it would be a real shame to see this just become another publication that doesn't really do anything and I'm finding that there's a lot of those." (WKLE01)*

Participants across most of the focus groups strongly emphasised the need to develop actionable goals, to ensure that success can be actively measured over the short, medium and long term and there is accountability across different sectors and the community. Participants also emphasised the need to have adequate funding that would allow for upscaling of pilot projects, to ensure momentum would not be lost.

> *"it would be good to like have a look at what the immediate priorities are because I feel like although this is going to be a long term journey there are things that can be done like sooner rather than later and you know things like training if you look at question 11 you know I think training others within those social services and police are probably a high priority because as soon as we get to be able to do that it's going to have a flow on effect in other areas of the community and society in general." (SWLE03)*

> *"I've found in my dealings with the mental health system, is that you know, announcements are made from projects like that etc, and they're pilots. And that's cheap, anyone can run a pilot, it's really easy to run it in one population. But then the issue is when it's successful, the rolling it out, that's where the big money comes in and they don't have the money behind that so anyone can run a pilot in a location in Melbourne or Sydney or whatever. But for it to be a national strategy, there needs to be a plan where you're piloting it and you've funded the full rollout. So that's always missing" (CASP01)*

Participants often spoke about learning from and translating progressive strategies fostering self-acceptance and celebrating diversity used within the LGBTIQA+ community. Other public health campaigns were mentioned, such as "slip-slop-slap" and campaigns from the TAC, the Quitline and others. Also, more recently, the COVID-19 pandemic has taught us lessons in how to spread public health messages and change the behaviours of the entire community in a short time frame.

> *"learning from the queer community and about self-acceptance, having pride in who you are, reaching out to community, reaching out to others who are like you to not feel alone and moving together towards that kind of like looking at the bright side of things and not always focusing on the negative" (LGLE02)*

However, there was some concern that building on previous successes to change stigma towards people with more common mental health issues may not work for the more poorly understood mental illnesses. Depression and anxiety are relatable concepts for most people in the community whereas psychosis or mania are not.

> *"In terms of building on successes and changing attitudes to common mental health conditions yes we've been quite successful in doing that, but I think that's because they're common and they're easier to identify with… I think the more complex the illness, the more complex it will be to change the attitudes." (WKLE01)*
>
> *"people can relate to sadness and anxiety because we've all had it in some way, shape or form in our lives […] if they have never heard a voice in their head or been caught by a delusion or whatever, it's hard for them to be empathetic towards people that have those experiences because they don't have the vague experience of themselves to draw upon." (MELE01)*

These recommendations have been edited to reflect participants' comments about not delaying action and the need for short, medium and long-term measurable goals as well as those around building on changes to societal attitudes in other areas, notably those to the LGBTIQ+ community.

Recommendation 3: Start now and take a long-term approach that:

- builds on successes in changing attitudes to common mental health conditions;
- is informed by successful strategies used by others advocating for social change, e.g. the LGBTIQA+ community;
- has adequate funding and support for large scale campaigns that may take years, or even decades to have impact;
- involves activities that build on successes and evolve over time, with new messages and strategies to sustain interest and attention and that target sub-groups where attitude change is slow or stagnant.
- incorporates actionable short, medium and long-term goals with clear timeframes and measurable outcomes.

(4) Recommendation 4: The importance of evaluation

In line with Recommendation 3, participants thought it was important for the strategy to include measurable short, medium, and long-term goals that would be evaluated against prespecified indicators using a mix of methods including qualitative and quantitative measures.

> *"And so adding in key performance indicators going; what are the goals of this strategy, what are the timelines and how do we adjust to evaluate, are these formative assessments or summative assessments, and how do they adjust our curriculum going forward" (EDLE01)*
>
> *"I think something statistically valid from the ground up like a survey, co-designed, co-produced by the communities that you're looking at would really, really help this project." (CASP01)*
>
> *"I do think though that like some qualitative research does lend itself better at times to these, so I think it's important that like if we're recommending research that there's a diverse way, like methods, like form of methods that the research is being undertaken." (EDLE01)*

Participants agreed that evaluations should be co-designed by people with lived experience, as well as the communities it is intending to promote change in.

> *"I'd say that if this work is being done about stigma for people with lived experience of complex mental health they need to be at the forefront and they need to be included every single step of the way so if there's going to be evaluation or you know if there's videos being created, if people are being surveyed the people with lived experience should be the ones doing that. You know there may need to be, there probably should be some professionals, professionals with lived experience because there's plenty out there like consumer advocates and academics, people with the skills and the ability to be able to do this sort of work but making sure that there is inclusion of that lived experience voice so something like a 50/50 split is really good because you know that it's equitable." (LGLE01)*

Some participants voiced concern over how population surveys would include traditionally underrepresented communities, and how concepts such as attitudes and stigma would be measured. Some suggested that indicators such as employment among people who disclose their diagnosis could be included.

> *"I think recommendation 4 might be the most difficult in terms of evaluating the impact of any strategy I think it's difficult to, other than sort of random sampling, it's difficult to benchmark what people's you know opinions are, what people's attitudes are." (MELE01)*

These recommendations have been edited to reflect participants' comments on the need for specific measurable goals, both quantitative and qualitative evaluation methods and the need for the involvement of people from diverse communities in any evaluations.

Recommendation 4: Evaluate the impact of the strategy on the short, medium and long-term goals by:

- Using mixed methods approaches, including population surveys and qualitative research;
- Ensuring that people with lived experience co-design and conduct evaluations, including specification of the impact of any activities being undertaken.
- Ensuring that people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities co-design and evaluate activities carried out in their communities.

(5) Recommendation 5: The need to align key messages but tailor to local needs

Participants commented on the importance of recommendation 5, noting that diversity in the community should be recognised and celebrated. The idea of champions was raised by several participants, in particular when it came to reaching people from different communities and creating a safe space to share experiences.

> *"they certainly have to be driven by ambassadors we could call them of those cultures that reflect the communities that they're in. I think they, I don't think it's good enough for the government or any organisation to say we are culturally friendly and we do these things and yet there's no representation within that organisation for the people that want to access it." (CASP01)*
>
> *"Yes it's also, you also have to have a safe space to be able to say what, because I've got a lot of Aboriginal friends and they won't step up because they're not given a safe platform to share what they know and a lot of the time you can have solutions to situations from grass roots level rather than up the top" (RRLE01)*
>
> *"just by talking about it and getting community leaders, people who are known in those communities whoever would be targeted to stand up and talk openly and normalise seeking mental health help, what's mental health or about these particularly serious health issues people will open up to it because they will see these role models talking about mental health and be like wow okay and then I think that would make people or encourage people to shift their thinking." (CASP02)*

On the one hand many participants raised the point that diversity exists within the CALD community and the LGBTIQA+ community, and that these diverse communities may need a range of different messages. However, there was some concern that having separate messages for separate groups may further create division, so ideally messages would aim to unite and find commonality in experiences, while recognising and celebrating diversity.

> *"the needs of refugees are different to needs of migrants and international students and how you reach them. And how you target them in terms of stigma and discrimination so from my perspective this recommendation needs to be broken down to target the specific aspects of the CALD community. And likewise I'm in Western Sydney but the needs of Western Sydney will be different to the needs of Melbourne as well. And so therefore I think it needs to be a bit more targeted in terms of what you're talking about in terms of targeting stigma." (CASP01)*
>
> *"I don't think that messages should be separate for separate communities, in my opinion that creates a disconnect between already marginalized individuals. Vulnerable groups all experience discrimination and*

> *stigma in different forms, but we share the same struggle. Showing a diversity of experiences and identities in messaging is important to represent the wider community." (LGLE01)*

With respect to CALD communities, participants highlighted that simply translating resources would not achieve the aim of reaching these communities. Some participants indicated that bilingual educators may play an important role. In relation to cultures different to the Western culture, a deeper understanding of interpretations of symptoms and experiences is needed before messages are developed.

All focus groups had some discussion around the use of diagnostic terms, language around mental health and illness, and while it was difficult to establish consensus, there was broad agreement about the importance of using inclusive, person-first, and strength-based terminology. Participants also discussed that a better understanding of the consequences of trauma, stigma and discrimination on a person's mental health may contribute to more empathy and understanding.

> *"And I think that there kind of needs to be like a trauma connection thing where parents can come and heal with their kids a bit, try and understand that they've both had trauma, and try and understand what trauma can lead to, and how to like help that person that's now got transgenerational trauma that's now got a mental illness." (CALE01)*

Recommendation 5: Align key messages or elements in the strategy, but tailor to local needs, by incorporating the following principles:

- Programs should be culturally appropriate, celebrate diversity and be led by local communities;
- Use of language, including diagnostic terms, should be tailored according to program and setting;
- Further research into the impact of key messages and interventions should be undertaken to assess effectiveness in different community groups and settings and avoid unintended negative consequences.

(6) Recommendation 6: Addressing stigma and discrimination in health services

Health services were a key topic of discussion in most of the focus groups. There was broad consensus on the need for fundamental changes in healthcare services, and how health professionals are trained, and supported by their employers to care for people with mental illness. Some participants expressed the view that, while the healthcare system currently doesn't meet the needs of many people with mental illness, the blame is often put on the individual for not fitting into a service, or not recovering.

> *"educating health care professionals instead of saying the individual, you know putting the blame on the individual for not having any services that meet their needs and blame the system instead. And you know kind of say we're really sorry that there's actually no service that meets this person's need, rather than saying the person's trying to play the system." (EDSP01)*
>
> *"just the variations in care that people get makes such a huge difference to the outcome. And I know people that have gone through the public system and barely survived it and are not functional at the end of that. And the way I see that that's not because their illness is too severe to be managed, it's because they just didn't get the right care." (MELE02)*
>
> *"I thought that I would be seeing something that helps to understand disempowerment, to make sense of structural inequality, to make sense of resource poor inpatient settings, and the distress of workers in managing people's distress, and all of that was missed. There's a huge education piece missing in the system itself." (EDSP01)*

There was a consensus about the need for reform to ensure more equitable and timely access to high-quality care that was more clearly focused on meeting individual needs and incorporated a focus on social, spiritual and cultural aspects of a person's life as well as on their medical needs.

> *"Yes, actually we do know that these resources like Lifeline or Beyond Blue, we know all these numbers, but we never call them because we think that they don't understand what our problem is… I think they can't*

> *understand what I want to talk and because many of our concern, our anxieties, they are based on our cultural background, they can't be understood by people from other backgrounds." (CASP01)*
>
> *"Can I say something the PHNs are given a lot of money by the government – but they're focussing on anxiety and depression and that is because GPs don't want to address mental illness, they don't have the time, it's not time efficient, so until we change the PHNs and get them to focus on the serious and persistently mentally ill that is going to go – be persistent, and you know GPs are the first responders, they need to be trained in mental illness and most of them aren't" (GCSP01)*
>
> *"So I think what we need to do is rather than separate it between like medical and spirituality, we need to find a way where you can tie both in together. So maybe start with the medical approach and be like this, and then tie that in to how you can get spirituality to improve your condition, and that then you'll get like a better response from communities with like heavy religious beliefs – because at the end of the day they want to be able to include that in their process" (CALE01)*

Including ongoing training, supervision and reflective practice as part of the job for healthcare staff were seen as essential. Concerns were raised that in certain professions attitudes may not be conducive to supervision and reflexivity, and that healthcare workers' workloads are often already unmanageable.

> *"an acceptance that staff do have problematic attitudes, that staff do hold stigma and discrimination and that we actually persistently need to build in strategies and support that enables that to either be broken down or not developed" (HSLE01)*
>
> *"I've heard it repeatedly from psychiatrists that they're expected to work in trauma informed ways but they're never educated about it." (EDSP01)*
>
> *"nurses don't actually get supervision as standard practice, it's not set up that they will do that and there's not enough nurses to provide that. They often see supervision as being a, oh well you're in trouble, if you mention you're going off to supervision, oh you're going through some sort of, you're getting in trouble off the manager. So it's even changing the perception of what reflective practice and supervision is within certain workforces because you don't tend to see that come up as much in the allied health professions for example." (HSLE01)*

Some participants mentioned that there is very little opportunity for people with lived experience to provide feedback to services or healthcare providers, which participants thought would have the potential to improve their experiences. Several participants discussed their experiences of stigma and discrimination in health settings, and that it was difficult to have their experiences validated, and people or services held accountable and changes made to these practices. There may be exceptions, including the Queensland Consumer & Carer Association funded by Queensland Health, which renumerates consumers and support people for providing feedback on new initiatives and policies. More opportunities for consumers of services to provide feedback and input into how services could achieve better outcomes, as well as enforcing existing policies more could improve the standard of care.

> *"And what I would like to see is some really robust advocacy in place to support people making complaints if they've been discriminated and stigmatised" (HSLE03)*
>
> *"Medical facilities have a long way to go to remove internal stigma towards people with mental ill-health. And this stigma is present in staff in both mental health and non-mental health facilities. I know there are policies in place to ensure stigma does not exist. Unfortunately, these policies are not transferred into practice." (RRSP01)*

Some participants commented that the use of clinical guidelines is not promoted or enforced in Australia, unlike in other countries, but that this is likely to improve the level of care received.

> *"we have really great clinical guidelines for treating certain mental health issues in this country, but no one has to use them. And that's a problem. You know so we basically stole all of the UK's clinical guidelines, you know and just kind of tweaked them a little bit, we took art therapy out by the way which is offensive. But one*

> *of the things that we didn't do was that we didn't then legislate that like they did in the UK. So if you look at the mental health industry, psychiatrists, psychologist, least likely to be sued for malpractice to face any consequences of their actions." (GCLE02)*

Support people commented that their role and expertise was often not acknowledged or supported in health services, while they are a valuable source of information and experience.

> *"Our experience is of being dismissed. And the information is actually detrimental, not just missing, it's actually harmful, they're giving us wrong information most of the time, and they're so unaware of the good things that we're trying to engage and enable in our family member's life in spite of the system" (EDSP01)*

The peer workforce

Other participants talked about the importance of the peer workforce. Some peer support workers commented that mental health services were often the places where they were most stigmatised and that their expertise was often not recognised by mental health professionals. A more formal recognition of the value of the peer support workforce could empower them to bring about more systemic change. Many voiced concerns about peer support workers going into work environments that would not be conducive to good mental health, and that there was little understanding of flexibility for their needs in the workplace.

> *"it's really important before they chuck people into these piranha infested waters called clinical services that they actually – that the clinicians have some accountability because my experience was that I was consistently stigmatised and I don't experience that in the rest of my life." (HSLE02)*
>
> *"they come in with so much more experience and knowledge, the ability to connect, the ability to understand, the ability to normalise people's experiences almost in that first meet. You know, to be able to get more rich kind of disclosure and all of those things that can come from that peer workforce. And I feel like that it's not getting the recognition across all of the other allied health professionals that it should get I think." (HSLE01)*

Some participants noted the importance of having bilingual peer support workers from diverse cultural backgrounds to assist in bridging current gaps in services for culturally and linguistically diverse communities.

> *"I think we should encourage the government to set up more peer support workers that are from the diversity communities so they can provide other language speakers to the mental health system." (CASP01)*

Addressing self-stigma for people with a diagnosis of mental illness was seen as important, but difficult to do if there was no adequate support and services available. Participants also wanted it recognised that self-stigma originates from external stigma and discrimination. Addressing stigma for families and support people was also seen as an important part of this strategy. Suggestions were made that health services could more often refer both consumers and support people to peer support workers and local advocacy organisations and educational resources or programs to increase their knowledge, advocacy skills and equip them better to navigate the healthcare system. However, *"the cruelty of directing families to services that are non-existent or have massive waiting lists"* was also noted, indicating the urgent need to adequately resource these services first, before further increasing the already unmet need.

> *"Getting help is kind of hard at the moment because all the advocacy agencies have got waiting lists and some of them are even not taking waiting lists anymore and it's hard to get any kind of support if you don't have certain funding" (LGLE01)*

The recommendations have been edited and strengthened with additional detail, particularly to recommendations relevant to the peer workforce.

Recommendation 6: Address stigma and discrimination in health services by:

- Implementing reforms that support, at both structural and individual practitioner levels:
    - a fundamental shift away from treatment that only focuses on the symptoms of mental illness towards a focus on wellbeing, including social, spiritual and cultural aspects;

    - a shift in power dynamics between practitioners and people with lived experience, including both consumers and support persons;
    - moving away from approaches that offer people services and supports based on their diagnoses to those that focus on their needs and aspirations;
- Strengthening peer work as an emerging discipline:
    - through implementation of policies and processes that support their distinct role in multidisciplinary teams;
    - through comprehensive provision of career opportunities, supervision, mentoring, and training;
    - by providing fair and equitable working conditions, including parity of pay and reasonable adjustments (when required) to their role;
    - by including peer support workers who are from a diverse range of language and cultural backgrounds;
- Incorporating strategies to address self-stigma in people diagnosed with mental illness, as well as stigma in support people, through better linkage between health services and local (accredited?) consumer and advocacy organisations and programs; while recognising that self-stigma is a product of the experience of stigma and discrimination in the community
- Encouraging, supporting and enabling psychiatrists, nurses and other allied health staff to take leadership roles in stigma reduction;
- Involving people with lived experience in systems-level changes in health services;
- Incorporating training in person-centred, trauma-informed care, led by people with lived experience into training for all health professionals;
- Incorporating aspects of reflective practice (including adequately funded supervision and mentoring), to allow health practitioners, senior managers and policymakers to understand their own attitudes and the impact of their work in mental health;
- Improving education for health professional students by including language guides, evidence about the harms of stigma and discrimination and positive narratives or contact with people with mental illness who have flourishing lives, to counter the impact of early encounters with people who are acutely unwell;
- Ensuring that training is ongoing to incorporate new evidence and address attitudes that may change over time;
- Implementing training and reflective practice initiatives that specifically focus on improving health professional attitudes, language and behaviours towards people with borderline personality disorder, including building skills to improve outcomes and reduce therapeutic pessimism.
- Evaluating anti-stigma initiatives in health services, including the impact on people with lived experience.

(7) Recommendation 7: Addressing stigma and discrimination in workplaces

Participants overall recognised workplaces as a really important setting to change community attitudes to mental illness. However, many were sceptical and explained that while policies and anti-discrimination laws are in place, more needs to be done to enforce these as it hasn’t translated into practice change. Making discrimination a part of occupational health and safety legislation was suggested several times.

> *“it’s just tiring that you read all this stuff and you read policy and you read recommendations but it doesn’t translate to the workplace.” (LGLE01)*
>
> *“I think what it comes down to in workplaces is bottom dollar rather than ethical care or whatnot. So I think addressing point 7 is I don't know near to impossible.” (YPLE01)*
>
> *“I feel quite strongly that there should be some sort of watch dog looking after the corporations and making sure that maybe somebody checking the mental health of an organisation overall to make sure that they understand their responsibility.” (WKLE02)*
>
> *“I think some of the government rhetoric around getting people back to work, “if you have a go you will get a go”, can be quite stigmatising for people who are actually impacted by serious mental illness. This can translate into a community perception of people being “lazy”. Solutions could include education of politicians, relevant government media, policy and decision makers.” (MESP01)*

Before going down a formal complaint route, some participants wanted more informal support with workplace issues, such as an external organisation which would be able to provide advice and training, before having to go down a conflict resolution or legal pathway. Participants also wondered whether primary health networks, Safe Work, Fair Work, or unions needed to play a bigger role in training employers and advocating for healthy workplaces. One participant suggested an accreditation for organisations that meet certain standards of providing a safe workplace for people with mental illness and providing organisations who don't meet the standards a plan of action or recommendations on how they could achieve this.

> *"So at the moment like your options are to go down a more, you know like disability discrimination route, and often to me that's a very adversarial kind of option, and if you are wanting to hang onto your job, if you're wanting to kind of not enter into a territory of conflict or you know you're kind of working with friends, there's lots of reasons why the disability discrimination commissioner isn't the appropriate kind of thing to go down. But what it means is there's all these, it's an insidious thing that's spoken about that really does, it impacts so greatly on your mental health, and to be able to go to say a national organisation like Beyond Blue or somebody who would be like a workplace watch, who you could go and actually say this is what is being said to me, and you could get like a bit of reassurance, a bit of skill development about here's how you can deal with that kind of thing." (WKLE03)*

Participants suggested that government had a big role to play in bringing more people with mental illness into workplaces, and providing a safe and healthy workplace for all people to thrive in. Some participants commented that large tertiary education settings have successful policies and procedures which adequately accommodate the needs of students with mental illness, and are in an ideal position to advocate these policies to employers where students might go for placements. However, it was noted that particularly in first-responder services and health service providers, it was perceived as very detrimental to disclose or seek help for any type of mental health issues as this may result in a loss of work, duties or career prospects. These workplaces may need particular focus on policies and procedures to facilitate help-seeking and reduce stigma and discrimination.

> *"if you speak up in the services, be it the army or the police or any of those first responder services.. you're immediately taken off front line duties, and so you are discriminated against and you're just put into a corner on desk duty" (RRSP01)*

> *"there has to be dedication from the top down to prove that people with lived experience do have a vital role and they are important and that they should be incorporated into workplaces. So honestly it has to be something from the top down, I'm talking like government level down there should be dedication to embracing people with lived experience and bringing them into workplaces and it's going to have to be put their money where their mouth is" (WKLE02)*

> *"what makes a mental illness is not the symptoms or the structures or the behaviours, but it's how they relate to capitalist functionality" (EDLE01)*

Hiring practices were frequently discussed as being prohibitive due to e.g. extensive psychometric testing or large interview panels, which bear no resemblance to what is required for the position, or lack of flexibility in work hours. Performance reviews, extremely high workloads and other workplace practices were also mentioned as needing improvement to meet the needs of people with mental illness. In particular for people with episodic conditions, it was thought helpful to have a plan for supporting people through difficult periods according to their needs and preferences, just like when people have epilepsy or a death in the family.

> *"these general merit selection processes aren't working for all people generally, you know like maybe it's more about being able to customise employment generally for your workforce" (WKLE03)*

Participants commented on existing resources and programs in other areas which may reduce stigma and discrimination. They suggested that these could be expanded including guides from the disability discrimination commission, mental health first aid, and programs that teach non-adversarial ways of challenging stigma and discrimination.

> *“There was an excellent project done on this in the context of reducing the bystander effect in racism by Western Sydney University. It would be great if something similar could be done in the MH context - workplaces, MH settings”(WKLE03)*

These recommendations have been edited to reflect recommendations around the need for strengthening of enforcement of anti-discrimination policies as well as on the provision of workplace supports.

Recommendation 7: Address stigma and discrimination in workplaces by:

- Strengthening anti-discrimination policies and their enforcement;
- Promoting practices that support mentally healthy workplaces;
- Ensuring that people in senior leadership roles model positive attitudes and behaviours towards people with diagnoses of mental illness;
- Providing education including key messages that focus on the contribution that people with mental illness can make as well as on the importance of supporting people with mental illness in the workplace (including through reasonable adjustments);
- Implementation of interventions that address fears about competence, reliability, productivity and extra ‘burden’ related to employing someone living with a mental illness, by including people with lived experience telling stories of success.
- Adequately resourcing and supporting ongoing training for employers;
- Providing more access to programs for people with psychosocial disabilities to enter and be supported in the workplace, including flexible working arrangements, staying/returning to work plans, support around disclosure, mentoring, individual placement support and skills training;
- Using the momentum arising from changes in work practices caused by the COVID-19 pandemic to further strengthen access to flexible working environments, support greater openness about mental health issues and support for employees.

(8) Recommendation 8: Addressing stigma and discrimination in the general community

Participants largely agreed with recommendation 8, and particularly liked supporting grass roots events run by people with lived experience. They provided many examples of positive experiences with small local community groups and community houses. An additional recommendation suggested by several participants was that the use of arts, sports, food, creativity as well as humour could reach people from diverse communities, including young people and people from CALD communities. Examples were also taken from the queer community, especially around pride.

> *“people need to get together and work together in a caring way. And a lot of these cultural communities work on those bases. You know for example the Greek community, their food just gets us together, you know, their elderly support groups that they have around the country helps us get together, their youth groups. Other cultural linguistically diverse communities use sport, the power of sport to get people together. So these are the key messages, you’ve got to look at what they do to get people together, and work on those benefits if you like and try to teach other CALD communities that lack them” (CALE01)*
>
> *“it is definitely be seen and be heard don’t let it stop you know make it loud make it proud and make it colourful and make it fun.” (LGLE02)*
>
> *“And using art is a good way of getting messages across to a variety of people right, because art in itself is interpreted differently by different people, but the main messages are coming across to all of them. So art is an acceptable medium of communication, and I feel that using creativity and trying to get messages across, particularly with the cultural communities” (CALE01)*
>
> *“The art scene seems to be one of those environments that enjoy the fruits of “crazy”. Exposing the wider community to art shows where pieces can be sold, awarded, publicly appreciated with the artist will go a long way in teaching that individual that they have worth and the wider community, that they should be valued - both in skill and in dollars” (RRSP01)*

In terms of media campaigns, participants recognised the value of having celebrities and social media influencers as champions, but they also wanted to see stories of the average person with a normal job and family and income who they could identify with. Participants emphasised the importance of having adequate representation from diverse communities. Bilingual and multicultural people with lived experience should be involved in creating messages, and simply translating resources, without taking into account cultural context, should be avoided. Participants suggested having education campaigns including scenarios of what symptoms may look and feel like, and how the community can respond in a positive and supportive way.

> *"A campaign with like a sportsperson that has a mental illness but also include somebody that's just your Average Joe your normal person, so that people don't just hold that person on a pedestal and say it's ok because he's a whatever, they can humanise with somebody else" (GCLE01)*
>
> *"I feel like there needs to be more kind of public education campaigns on what does a manic episode look like, what does a psychotic episode look like, what can you do if you see someone at the shop behaving erratically or if you see a neighbour walking down the street dressed funny and you know they're perhaps not doing okay. Try and expand the awareness and the acceptance you know beyond depression and anxiety" (HSSP01)*
>
> *"each community needs its own resources, things need to be translated into each language and so on so I would say in the case of your project I would really welcome resources targeted at you know the trans community in particular or the lesbian community or the gay male community not just the umbrella" (LGLE02)*

Recommendation 8: Address stigma and discrimination in the community by:

- Focusing on activities that demystify or normalise mental illness;
- Moving beyond a focus on the scale of the problem and what not to do, to incorporate suggestions for positive language and behaviours towards people with diagnosed with mental illness ;
- Having a greater emphasis on symptoms or experiences (e.g. distress), rather than on diagnostic categories;
- Conducting media campaigns, including traditional media that reaches rural or culturally and linguistically diverse communities, digital and social media;
- Supporting grass roots events tailored to local community needs, including creative arts, food and sporting events (particularly in Aboriginal and Torres Strait Islander, LGBTIQA+ and culturally and linguistically diverse communities) that offer opportunities for positive interactions between community members with and without mental illness;
- Ensuring that Interventions intended for a mainstream audience also reflect the cultural diversity of the Australian population.

(9) Recommendation 9: Addressing stigma and discrimination in the media

Participants agreed that media reporting of mental illness had a significant impact on current community attitudes, in particular reporting about people with severe mental illness being dangerous, unpredictable, and highlighting extreme and rare cases of violence. Many pointed out that the media should take responsibility in also sharing facts about how people with mental illness are far more likely to be victims of crime and violence than perpetrators, and that people who display symptoms of mental illness are far more likely to be scared and confused rather than dangerous and violent. However, many also pointed out that TV shows and films have made positive contributions to the acceptance of people from the LGBTIQA+ community, and therefore, had a lot of potential to counter stigma and discrimination for people with mental illness. There was recognition that some media outlets were generally trying to do the right thing, but that other outlets were sensationalising stories aiming for more "clicks" through to their news sites. While the recommendations generally resonated with participants, there was an overall feeling that unless there was an agreed set of standards, coupled with an independent body which could raise and address concerns with media organisations and their staff, change was unlikely to come fast enough.

> *"there needs to be sort of standards that yes they're agreed upon by maybe the Press Council or each media organisation and then if they're in breach of those standards there needs to be some arm that knocks on their door and like did you know that you crossed this line. So that they're not just constantly getting away with it" (MELE01)*

> *"The real crucial point of it though is how long it takes to have things raised or get addressed and do they get addressed by an independent body that has the power to make binding recommendations." (CASP01)*

Participants commented on recent TV programs which featured the stories of people with mental illness, which intended to shine a light on stigma and discrimination but had unintended consequences. Participants felt that the involvement of lived experience advocates could have improved the quality of the programs and avoided unintended consequences. Conversely, several participants preferred to not include health professionals as they were concerned their voices would dominate and might emphasise the medical model more.

> *"what tends to happen, and what I guess I'm concerned with that dot point [addressing stigma and discrimination in the media], is that the professionals tend to dominate and the medical model can be given can be inserted into things in a way that it might not if you were just allowing the person with lived experience to work directly with the TV and film people." (MELE01)*

Several participants wondered whether introducing concepts of mental health to children through segments in existing programs would be beneficial. Further, one participant mentioned that while it was very important to have representation of people with different types of mental illness in TV shows and movies, it would also be beneficial sometimes not to point out their difference and have it as a separate issue, but as a normal integration of a diverse group of people.

Participants commented that social media is the 'wild west' and difficult to control. Some suggested providing free training for celebrities and social media influencers to change the conversation about mental illness, and use their platforms to educate their communities about the harms of stigma and discrimination. Hashtag campaigns were also mentioned

> *"approaching influencers or people who have a platform, people have a voice and training them and getting them to engage with this kind of stuff if they're willing to sort of get them to use their platform to change the conversation." (MELE01)*
>
> *"If you were to have something along the lines of like 'crazy and proud' or something, and I know that not everyone's comfortable with re-claiming that word so that's probably a conversation for another time but the hashtag campaigns and things like that can also be very effective on social media if done by the right people."(MELE01)*
>
> *"I don't know I'm not up on the laws that govern social media, but I imagine that if you put something really, I don't know racially offensive, or really really awful up, it may well be pulled down by the moderators of their social media account. So if you could get to the point where these things could be picked up and pulled down, by a bigger body, not just individuals" (MELE01)*

Recommendation 9: Address stigma and discrimination in the media by:

- Improving the quality of media reporting on mental illness, particularly that relating to violence and crime by:
  - Encouraging the Australian Press Council to work with lived experience advocates and media organisations to improve practice for coverage of mental illness and crime;
  - Encouraging media professionals to improve their mental health literacy (through accessing information resources or undertaking training);
  - Implementing interventions for media professionals (including journalism, film, television, and communication students) that encourage them to:
    - Regularly consider the impact of media reports and language on public attitudes and people living with mental illness;
    - report all relevant risk factors that contribute to violence and crime, including failings in the mental healthcare system and factors that are not related to mental illness;
    - use non-stigmatising language and images;
    - use social media responsibly when sharing or engaging with news content involving mental illness and crime;

  - Strengthening monitoring of media reporting on mental illness and violence, e.g. through SANE Media Watch;
- Encouraging social media influencers and celebrities to improve their understanding of mental illness and how to use their platforms to support reductions in stigma and discrimination;
- Encouraging people with lived experience, advocacy bodies, and TV and film production companies to work together to improve portrayals of people with mental illness;
- Introducing segments on children's television programs that can start to appropriately introduce concepts of mental health and diversity of experiences from a young age.

(10) Recommendation 10: Addressing stigma and discrimination in educational institutions

Participants broadly agreed with recommendation 10 and noted that many large tertiary educational institutions already provide high quality and up-to-date education as well as mental health services for students. However, more educational opportunities were needed in rural and remote areas, where participants reported a lack of mental health education courses. One person with lived experience who was a TAFE teacher spoke about the benefit of openly speaking about mental illness with his students. However, other participants pointed out there would be risks of disclosing a diagnosis to students and colleagues to career prospects and schools worrying about their reputation or complaints from parents.

> *" I found out through the rest of my 15 years the number of people in my courses who had bipolar, BPD, schizophrenia, depression, anxiety, post-traumatic stress – you name it, and I found that that was a wonderful place – a great leveller because you probably had about 10% of each class who had some form of mental illness and by the time the course were ended the rest of the class were all completely comfortable with that – I found that TAFE is a wonderful place where if you've got the right pitches and the right environment you can actually learn a lot from both sides." (GCLE01)*

However, participants noted that sometimes the transition from university to placements or workplaces was not smooth, and they would benefit from more support during that transition.

> *"I found that when it came to like going for placements and actually having my needs recognised in the workplace so that I could actually get through my placement, I actually met discrimination… So that sort of discrimination of like in the workforce supported by the university, because the university did actually support me and everything and they actually said 'no that's not good enough, you can't treat her like that' and they got me a better placement." (EDLE01)*

> *"I found the tertiary market is where, the tertiary education is where there's the most acceptance… I studied to be a high school teacher and I qualified, and I went out to the workforce, and my placements so deeply scarred me, with specifically mental health stigma, that I decided I couldn't work in that industry." (EDLE01)*

Participants commented that primary and high schools are often under-resourced and staff overworked, which are barriers to providing high quality education on mental illness, as well as providing extra support to students with mental health concerns. Several participants mentioned that the quality of training for staff who provide mental health support in schools is low, and that there should be a higher standards and minimum training requirement for someone to qualify as a school counsellor or chaplain, given the important role they hold. Several young people mentioned they would also find peer support workers in schools helpful to navigate through finding the right services and supports.

> *"it's very easy to become a school therapist through chaplaincy and there is a lot of, well a big lack of school education there, and there's funding given by the government, but less so for an actual counsellor who's done you know their master's at minimum, or something like that. The same as a teacher has to have their master's you know. It's kind of expected that you would want the same from your therapist, where instead you can do a 6-month course and become a chaplain and then you're responsible for an entire school's mental health." (YPLE01)*

One participant also commented that the way schools are funded prohibits them from making accommodations for, or providing support to, students with special needs, and that this funding system would need to change to provide a supportive environment for all. Some participants also mentioned the need for more accessible remedial education for young people with long-term illness who miss long periods of school.

> *"I think one of the biggest challenges will be uptake from schools or education providers when they don't have the funding to actually use these services, and a lot of the areas that we service in my organisation is through funded programs because they can't actually afford to access them themselves, and without the funding they just wouldn't have education around mental health or even their wellbeing support lacks in structured ways because they can't afford it." (EDSP01)*

> *"I think private schools and also low-income schools, and I've worked at 2 schools where … – even if students did badly it was fine, as long as they didn't take up too many work hours. Because they needed to have a certain number of enrolled students using a certain number of enrolments in a certain number of subject areas to receive the funding they needed. And they needed certain subject areas to have certain numbers of students, didn't matter if they all failed. And so long as students were able to continue enrolling in the full number of courses in these high schools that was all that mattered, and if a student required like, less courses or differentiated courses, they needed to go somewhere else because the school couldn't afford that." (EDLE01)*

> *"And we have the ever falling education standards of the entrance requirements to go into secondary teaching dropping every year because they're such an under paid and under-appreciated profession, there's this deep systemic pressure towards people with the least dedication and the most prejudiced, being the ones most likely to succeed in the industry." (EDLE01)*

Ongoing and high-quality education for students of all ages about the biopsychosocial model of mental health, social determinants of health, the prevention and management of mental illness, coping strategies, emotional regulation, and the harms of stigma and discrimination was seen as absolutely essential to start changing community perceptions over time. Participants wanted positive narratives of people with mental illness to represent a diverse group of people, including young and old. Particularly for long-term mental illness, participants thought it would be beneficial to show students how people have managed to live well for decades with their mental illness. Participants wanted teachers and other school staff to be better trained in trauma-informed practices, and to be more aware of adverse childhood experiences and have more understanding for struggling families. A reframing of disability, and the interaction with the environment might lead to change in practice as suggested by one participant:

> *"in their school if a kid is disabled that's the teacher's fault, because they define disability as meaning I'm unable to do something, which I should be able to do, which means you haven't put in the correct accommodations, and the student only has disability in the moment they're unable to do something, otherwise they have whatever their personal state of being is. And framing it like that confronted a lot of teachers but led to a sizable change in practice which I found very exciting." (EDLE01)*

Recommendation 10: Address stigma and discrimination in educational institutions by:

- Providing ongoing mental health education in all schools and tertiary education institutions, that includes positive narratives of a diverse group of people with lived experience of low prevalence mental illness;
- Providing early intervention and support for students with mental health problems, particularly for international students and students at times of transition;
- Improving funding and standards for professional development and support for staff in schools and tertiary education institutions;
- Ensuring that staff who regularly provide mental health support in educational institutions are appropriately trained in person-centred, trauma-informed practice.

(11) Recommendation 11: Addressing stigma and discrimination in police, social services, justice and welfare professionals

Participants discussed at length the difficulties they experienced with accessing social services and often negative experiences with first responders, including violence and discrimination. Some participants had far better experiences with first responders who had mental health training, such as through the Police Ambulance Clinicians Emergency Response (PACER), or special mental health police, however, the resources and reach of these initiatives were often limited. Some participants mentioned that voluntary disclosure forms or emergency alerts which detailed information about the person with mental illness, registered with their local police station assisted police responding better when they were called out to that person, but many other focus group participants were unaware if this was available in their local area. Participants wanted training for all police and first responders to recognise a person with potentially severe mental illness and use a stepped approach, rather than escalating their approach immediately. It was agreed that in particular the police needed mandatory mental health and de-escalation training.

> *"I think having the police under that same heading is really problematic because the police are the only ones that can actually engage with you and shoot you. So in terms of impact on them having either a bias or not understanding mental illness there's a huge problem in that area. (SWLE01)*
>
> *"in Geelong last year, mid last year they trialled, because of the stigma with police they trialled a service where there's always a clinician with the police, and that's been very successful, and so they're continuing it. It should be all around Australia, where there's either a clinician or a peer worker or both alongside the police. Because the police really are going way too far with their violence" (HSLE03)*
>
> *"So the education I think for frontline workers like police is going to be where the importance is, how can they identify mental health straight up because if they don't even – a lot of police don't even know that that's what they're dealing with" (GCSP01)*
>
> *"The thing that all the police say to me "look we don't want to harm anyone but what do we do?" they don't know – they're really not taught the de-escalation skills" (GCSP01)*

Participants described their experiences with first responders in light of the lack of empathy and understanding for people with severe mental illness, as well as the confusion between mental illness and drug use. There was a recognition that people working in these professions are themselves at higher risk for mental illness due to the high stress and workload, but are often discouraged from seeking help. The self-stigma that is created in employees of social services and welfare services was seen as exacerbating their stigma and discrimination towards people with mental illness they come into contact with on the job. The mining and building industries were mentioned as places where the mental health training and support has improved in recent years, and could serve as an example. Participants mentioned that the benefits of including person-centred trauma-informed, reflective, and de-escalation practices in these settings for people with mental illness, the community and employees' own experiences at work should be front and centre in education programs for police, first-responders, and welfare services.

> *"NDIS has complicated the situation as well. I've found a lot of NDIS support coordinators have their own stigma and biases and lack of knowledge and training in the area of complex mental health, which then impacts on the participant's ability to access the right kind of supports. So a lot of education is required there too" (SWSP01)*
>
> *"I think if we can demonstrate the positive benefits of you know it's not just about competence in your practice it's about having better outcomes for people including our own workforce you know it's not just about how we deal with others it's how we deal with each other in our own workplace context." (SWLE03)*
>
> *"I'm sort of picking on the police a bit but I think that even you know crisis teams attached to hospitals are overwhelmed and often burnt out sort of limiting their ability to demonstrate compassion because they're so overworked and under-resourced. " (SWLE01)*
>
> *"in some like you know institutions I guess like police or welfare or social service I actually think that the training needs to be mandatory that everybody does some form of mental health training not only because of perhaps the clients or the people that they're dealing with but with each other there's a huge increase of*

> *mental health in the workplace but you know I would be reluctant to in a workplace to come forward and say I have bipolar only because you know in the workplace that's a huge risk, well I feel, to disclose" (SWLE01)*

Several participants thought that people working in the justice system, in particular judges, magistrates and lawyers, as well as politicians should be included in this recommendation, and that they can play a role in changing the language and addressing stigmatising and discriminating behaviours towards people with severe mental illness.

> *"The other area of the criminal justice system that fails is magistrates and judges. They know what the police have and haven't done, whether it was correct or not, and they never bring it up and address them if they've done the wrong thing to the person." (CJLE01)*

Recommendation 11: Address stigma and discrimination in police, social services, justice and welfare professionals, by:

- Implementing training led by people with lived experience that takes a trauma-informed approach, incorporating an understanding of the social determinants of health, and including narratives of hope and recovery;
- Adequately resourcing and supporting ongoing training
- Incorporating peer-support workers or advocates into social and welfare services to assist clients in navigating these complex service systems.

5. Discussion

In order to further refine options for a nationally coordinated approach to reduction of stigma and discrimination towards people with mental illness that is poorly understood in the community, we conducted 31 focus groups with 117 people with lived experience of mental illness, either their own or as a support person. Each focus group involved asking participants to provide feedback on the broad recommendations as well as those targeted to particular settings, such as health services or workplaces. There was broad agreement that the recommendations were appropriate and comprehensive. In many cases, these discussions were wide-ranging, encompassing topics relating to broad health system and societal changes, as exemplified in the following quote.

> *"we need to actually fundamentally change the root cause of most of this, or we're never ever going to get anywhere with these other superficial recommendations. It's a fundamental reorganisation of responses that probably even moves away from mental health services and starts to talk about the resources, including an integrated health and services response to mental health that's currently absent. I think until we actually resource families appropriately, recolonise mental health services away from the medical model, we're probably never going to break this one" (EDSP01)*

While we have reported on these discussions (and acknowledge the importance of such changes for the reduction of stigma and discrimination), we have focussed our changes to the recommendations on those more closely related to the project aims.

Unsurprisingly, given the communication of the aims of the study in the recruitment materials, interviewees agreed on the need for a national strategy to address stigma and discrimination towards people with low prevalence mental illness. However, a number of participants reiterated the urgent need for action, and the fear that it may not be feasible to achieve real change in the stigma and discrimination that is experienced by many on a regular basis. Many participants stated the need for measurable goals with clear timelines and accountability arising from projects like this. This would ensure that progress and success of strategies resulting from the project is measured and reported, and future projects can take into account previous successes and failures.

5.1. Limitations

Participants were from all parts of Australia, including rural and regional areas. However, given the sampling methodology, they may not be representative of all Australians with poorly understood mental illness and support people. In particular, people whose first language is not English, with low literacy levels, poor access to the internet or other factors that prevented them for participating in online focus groups, were less likely to be included. Further, it was noted that the factors associated with stigma and discrimination due to mental illness in culturally and linguistically diverse groups are less well known, and that it's potentially premature to suggest recommendations before the problems in each of these groups is better investigated and documented. This may also be the case for other groups at risk of marginalisation or discrimination.

References

1. Reavley NJ, Jorm AF. Stigmatizing attitudes towards people with mental disorders: Findings from an Australian National Survey of Mental Health Literacy and Stigma. *Aust N Z J Psychiatry* 2011; **48**(12): 1086-93.
2. Reavley NJ, Jorm AF. Experiences of discrimination and positive treatment in people with mental health problems: Findings from an Australian national survey. *Aust N Z J Psychiatry* 2015; **49**(10): 906-13.
3. Reavley NJ, Jorm AF. Stigmatizing attitudes towards people with mental disorders: changes in Australia over 8 years. *Psychiatry Res* 2012; **197**(3): 302-6.
4. Morgan AJ, Reavley NJ, Ross A, Too LS, Jorm AF. Interventions to reduce stigma towards people with severe mental illness: Systematic review and meta-analysis. *J Psychiatr Res* 2018; **103**: 120-33.
5. Ross AM, Morgan AJ, Jorm AF, Reavley NJ. A systematic review of the impact of media reports of severe mental illness on stigma and discrimination, and interventions that aim to mitigate any adverse impact. *Soc Psychiatry Psychiatr Epidemiol* 2019; **54**(1): 11-31.
6. Morgan AJ, Reavley NJ, Jorm AF, Beatson R. Experiences of discrimination and positive treatment from health professionals: A national survey of adults with mental health problems. *Aust N Z J Psychiatry* 2016; **50**(8): 754-62.
7. Morgan AJ, Reavley NJ, Jorm AF, Beatson R. Discrimination and support from friends and family members experienced by people with mental health problems: findings from an Australian national survey. *Soc Psychiatry Psychiatr Epidemiol* 2017; **52**(11): 1395-403.
8. Morgan VA, Waterreus A, Jablensky A, et al. People living with psychotic illness in 2010: the second Australian national survey of psychosis. *Aust N Z J Psychiatry* 2012; **46**(8): 735-52.
9. Reavley NJ, Jorm AF. Young people's stigmatizing attitudes towards people with mental disorders: findings from an Australian national survey. *Aust N Z J Psychiatry* 2011; **45**(12): 1033-39.
10. Reavley NJ, Morgan AJ, Jorm AF. Discrimination and positive treatment towards people with mental health problems in workplace and education settings: Findings from an Australian national survey. *Stigma and Health* 2017; **2**(4): 254-65.
11. Reavley NJ, Morgan AJ, Jorm AF. Predictors of experiences of discrimination and positive treatment in people with mental health problems: findings from an Australian national survey. *Soc Psychiatry Psychiatr Epidemiol* 2017; **52**(3): 269-77.
12. Reavley NJ, Jorm AF. Community and population-based interventions to reduce stigma associated with depression, anxiety and suicide: An evidence review to inform future research directions: Sax Institute and University of Melbourne, 2013.
13. Reavley NJ, Jorm AF. Strengthening Community Understanding of Mental Health: A Literature Review. Sydney, NSW: National Mental Health Commission, 2013.
14. Corrigan PW, River LP, Lundin RK, et al. Three strategies for changing attributions about severe mental illness. *Schizophr Bull* 2001; **27**(2): 187-95.
15. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; **19**(6): 349-57.
16. Parkinson S, Eatough V, Holmes J, Stapley E, Midgley N. Framework analysis: a worked example of a study exploring young people’s experiences of depression. *Qualitative Research in Psychology* 2016; **13**: 109-29.
17. Srivastava A, Thomson SB. Framework analysis: a qualitative methodology for applied policy research, 2009.

Appendix A: Research team

University of Melbourne

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- Ms Judith Wright, Centre for Mental Health
- Ms Anna Ross, Centre for Mental Health
- Dr Karen Block, Centre for Health Equity
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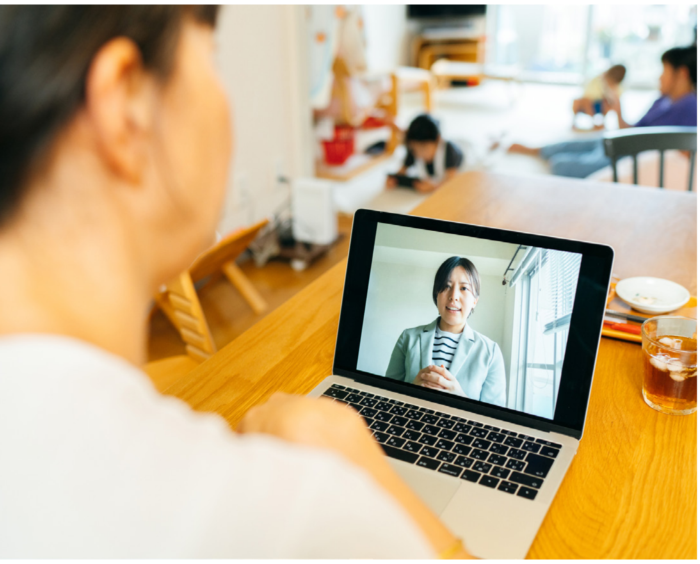
Appendix B

THE UNIVERSITY OF
MELBOURNE

Reducing stigma and discrimination towards people with mental illness that is poorly understood in the community



During the first part of the project, we conducted **online video interviews** with **234 stakeholders** from the following groups:

- advocates (who were often people with their own lived experience or support people)
- anti-stigma program providers
- mental health peer support workers
- health professionals
- health professional students
- people with 'broad expertise' (who held multiple roles relevant to the project)
- those working to support people with mental illness in:
    - employment settings
    - education settings
    - social service settings

All interviews were recorded and analysed to **identify important topics**, so we could make recommendations to the government for a **national strategy to lessen stigma and discrimination** towards people with mental illness.

Summary of recommendations

Recommendation 1:

Ensure that people with lived experience have important leadership roles in the strategy

Recommendation 2:

Ensure that people with lived experience are involved in decisions about how the anti-stigma activities will be developed and provided

Recommendation 3:

Take a long-term approach that builds on successes in changing attitudes to common mental health conditions

Recommendation 4:

Evaluate the impact of the strategy. This could be done through population surveys and evaluations of specific programs

Recommendation 5:

Align key messages or elements in the strategy, but tailor to specific settings and communities

Recommendation 6-11:

Address stigma and discrimination in the general community and also in health services, workplaces, educational institutions, the media, police, social services and welfare professionals

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This project is part of a larger project: The Fifth National Mental Health and Suicide Prevention Plan – Reducing Stigma and Discrimination. For more information, please contact the principal researcher: **Associate Professor Nicola Reavley**, nreavley@unimelb.edu.au

Detailed recommendations

Recommendation 1: Ensure that people with lived experience have leadership roles in the strategy, by:

- Funding either an **existing organisation** such as the National Mental Health Commission **or a new national organisation**, created specifically for the purpose
- Involving **national and state-based** consumer and carer advocacy organisations
- Creating a community with a shared purpose that also allows for differences in **cultures, perspectives, skills and experiences**
- Building links between community, government and non-government organisations
- Providing enough **funding for participation** by lived experience advocacy organisations

Recommendation 2: Ensure that people with lived experience are involved decisions about how the anti-stigma activities will be developed and provided, by:

- Supporting people with lived experience to **share narratives of mental health and recovery** so others can move beyond seeing them as being entirely defined by their illness
- Focusing on narratives that:
  - go beyond raising awareness that mental illness and stigma are problems **without offering solutions**
  - challenge, rather than avoid, stereotypes around dangerousness and unpredictability
  - **challenge stereotypes** that a person with a diagnosis of a mental illness is unable to have successes in work, study, or family life
  - **are realistic**, acknowledging that the experience of mental illness is different for everyone (e.g., single episode, episodic and recovered), and that it comes with challenges
  - build **empathy and understanding**, including a focus on mental illness as a response to trauma or a lack of necessary supports (including those in the health system)
  - include the **views of families**, friends and other supporters
- Providing opportunities for people with and without lived experience of mental illness to **meet face to face**, as well as online
- Ensuring that organisations that run programs involving people with lived experience have **enough funding and support**

Recommendation 3: Take a long-term approach that builds on successes in changing attitudes to common mental health conditions, by:

- Ensuring **adequate funding and support** for campaigns that may last for years, or even decades
- Implementing strategies that **build on successes and change over time**, to sustain interest and target sub-groups in whom attitude change is slow

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Recommendation 4: Evaluate the impact of the strategy through population surveys and evaluations of programs in key settings, by:

- Ensuring that people with **lived experience are involved in co-designing** evaluations

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Recommendation 5: Align key messages or elements in the strategy, but tailor to local needs, by incorporating the following principles:

- In Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities, programs should be **culturally appropriate and led by local communities**
- **Use of language**, including diagnostic terms, should be **tailored** according to program and setting
- For programs targeted to the general community, consider focussing on **symptoms or experiences** (e.g. distress), rather than diagnostic ‘categories’
- Further **research into the impact of key messages** and interventions should be undertaken to assess effectiveness and avoid negative outcomes
- People with lived experience, including those from **Aboriginal and Torres Strait Islander and culturally and linguistically diverse** communities, should be involved in evaluation of activities

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Addressing stigma and discrimination in health service settings

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Recommendation 6: Address stigma and discrimination in health services by:

- Make improvements that **support**, at both organisational and individual practitioner levels:
  - a shift away from treatment that only focuses on the symptoms of mental illness towards a **focus on wellbeing**
  - a **shift in power dynamics** between practitioners and people with lived experience
  - avoiding approaches that offer people services and supports based on their diagnoses to those that **focus on their needs**
- **Strengthening the peer workforce** through training, fair working conditions, and supervision from more experienced mental health peer support workers
- **Addressing self-stigma** in people diagnosed with mental illness;
- Supporting psychiatrists and other senior professionals to take **leadership roles in stigma reduction**
- Involving people with lived experience in **systems-level changes** in health services
- Offering **opportunities for training** led by people with lived experience
- Offering training in reflective practice to allow people working in health services to **understand their own attitudes** and how these affect people living with a mental illness
- **Improving education** for health professional students by including positive narratives from people with lived experience
- Ensuring that **training is ongoing** to address attitudes that may change over time
- Training that has a particular **focus on improving health professional attitudes** to people with borderline personality disorder

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Addressing stigma and discrimination in workplaces

Recommendation 7: Address stigma and discrimination in workplaces by:

- Focusing on **policies and practices** that support mentally healthy workplaces
- Ensuring that people in senior leadership roles **show positive attitudes** towards people with lived experience
- Providing education that focuses on the **contribution that people with mental illness can make** in the workplace, not just on the support they may need
- Providing education **addressing fears about competence** and extra ‘burden’ related to employing someone living with a mental illness
- Providing **education** that includes people with lived experience telling stories of success
- Adequately **funding and supporting** ongoing training

Addressing stigma and discrimination in the general community

Recommendation 8: Address stigma and discrimination in the community by:

- Focusing on activities that **challenge myths** about mental illness
- Moving beyond a focus on the scale of the problem and what not to do, and **focus on positive behaviours** towards people with mental illness diagnoses
- Conducting **media campaigns**, including traditional media (including in rural or culturally and linguistically diverse communities), digital and social media
- Supporting **grass roots events** tailored to local community needs (particularly in Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities) that offer opportunities for positive interactions between people with and without mental illness
- Ensuring that interventions intended for a mainstream audience also reflect the **cultural diversity** of the Australian population

Addressing stigma and discrimination in the media

Recommendation 9: Address stigma and discrimination in the media by:

- Improving the **quality of media reporting** on mental illness, particularly that relating to violence and crime by:
  - Working with the Australian Press Council to improve standards of practice for **coverage of mental illness and crime**
  - Improving the **mental health literacy** of media professionals;
  - Implementing interventions with media professionals (including journalism students) that encourage them to:
    - consider **the impact** of media reports on public attitudes and people living with mental illness
    - report all **relevant risk factors** that contribute to violence and crime, including those that are not related to mental illness
    - use **non-stigmatising language** and images
    - use **social media responsibly** when sharing or engaging with news content involving mental illness and crime
  - Strengthening **monitoring of media reporting** on mental illness and violence
- Encouraging people with lived experience, health professionals and TV and film production companies to **work together** to improve descriptions of people with mental illness

Addressing stigma and discrimination in educational institutions

Recommendation 10:

Address stigma and discrimination in educational institutions by:

- Providing mental health **education in schools** and tertiary education institutions, including positive narratives of young people with lived experience of low prevalence mental illness
- Providing **early intervention and support** for students with mental health difficulties, particularly at times of change
- Improving **professional development** and support for staff in schools and tertiary education institutions

Addressing stigma and discrimination in social services and welfare settings

Recommendation 11:

Address stigma and discrimination in police, social services and welfare professionals, by:

- Implementing training led by **people with lived experienc**e that takes a trauma-informed approach and incorporates narratives of hope and recovery
- Adequately **funding and supporting** ongoing training