



Centre for Mental Health
Melbourne School of Population and Global Health

Reducing stigma and discrimination towards people with mental illness

Targeted consultations: Interim report

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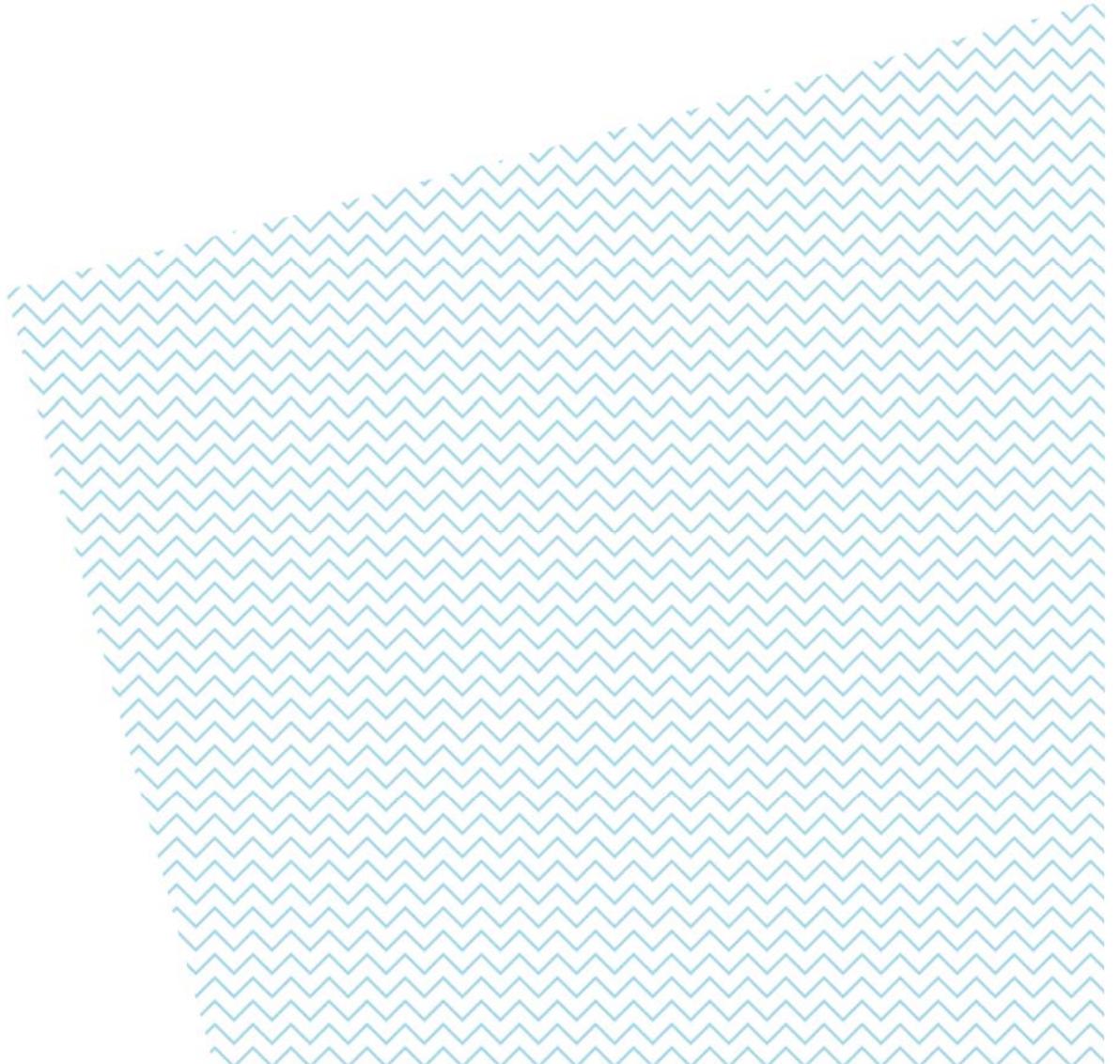


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Executive summary

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. We conducted stakeholder consultations that aimed to inform options for an effective strategy for reducing stigma and discrimination in Australia.

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 terminology 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' and 'carers'. Throughout this report we use stigma to refer to attitudes and discrimination to refer to behaviours towards a person with a diagnosis of mental illness.

Methods

We conducted online video interviews with 234 stakeholders from the following groups: advocates (who were often people with lived experience as consumers or carers), 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) and those working to support people with mental illness in employment, education and social services settings. All interviews were recorded, transcribed and analysed to identify key themes.

Key findings

Participants agreed that stigma and discrimination towards people with lived experience of mental illness are widespread. They reported that attitudes vary according to the type of mental illness, with people with diagnosed bipolar disorder typically seen as less stigmatised than people with schizophrenia, and people with borderline personality disorder being perceived as more likely to experience discrimination in health services than in other settings. There was strong support for a national strategy to address stigma and discrimination towards people diagnosed with schizophrenia, bipolar disorder and personality disorders. Participants also noted the need for a long-term approach as well as for ongoing evaluation of effectiveness.

The most common theme related to ensuring that people with lived experience are central to any strategy, including in leadership, co-design, delivery and evaluation roles. Many participants noted the need to provide opportunities and support for people with lived experience to share narratives of their experiences of living with mental illness in a range of settings. They noted that these stories need to be told in ways that create empathy and challenge stigmatising attitudes, notably those relating to people being seen as entirely defined by their diagnosis, as dangerous or unpredictable, or as unable to recover and live full and meaningful lives.

While there was a consensus that language around mental illness is important, there was no consensus on the use of diagnostic terms in approaches to addressing stigma and discrimination, with many participants noting both advantages and disadvantages of various approaches.

Key settings and populations

Interviews explored views on key settings for interventions and programs to reduce stigma and discrimination, and the most frequently nominated were health services, workplaces and the media. Many participants noted the need to target the general community; family and friends of people experiencing a mental illness; police and the justice system; policymakers and the education system (both schools and tertiary education institutions).

Participants noted the need to tailor activities for Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities. Interventions involving these communities should incorporate culturally appropriate

understandings of mental health, be delivered in a range of community languages, be community-led and engage community leaders in design, delivery and evaluation.

Health services

Many participants noted the need to address stigma and discrimination in health services. They talked about the need for structural reform, considering the biomedical paradigm on which the mental health system is based to be fundamentally discriminatory, because of the lack of agency afforded to people with lived experience of mental illness. Lack of services, particularly in rural and remote areas were also seen as contributing to discrimination due to inadequate treatment, escalation of symptoms and people with mental illness being seen as a 'burden'. Other participants talked about the need to address attitudes and behaviours of health professionals through education. Mental health peer support workers were seen as having a key role in reducing stigma and discrimination in the mental health system.

Workplaces

Workplaces were seen as a key setting for interventions, due to the importance of paid work for social and economic wellbeing and the role of discrimination in reducing participation in the workplace. As in other settings, recommendations for reducing stigma and discrimination in workplaces included strong organisational leadership and the involvement of people with lived experience in sharing positive accounts that challenge prevalent beliefs that people with mental illness are a burden in the workplace. Some participants noted the need for narratives to go beyond education about managing and supporting people with mental illness to those that emphasise the value that people living with a mental illness can bring to a workplace.

General population

Many participants talked about the need to educate the broad Australian community, with a focus on 'demystifying' and 'normalising' mental illness. Media campaigns, including those in traditional media (which was seen as particularly useful in reaching rural or culturally and linguistically diverse communities), digital and social media were often nominated as important in challenging stigmatising attitudes.

The media

The media itself was also seen as influential in shaping attitudes to mental illness. Negative and stigmatising portrayals of people with mental illness were perceived as common and as undercutting efforts to promote positive attitudes, particularly by stoking community concerns around crime. Improving the quality of media reporting on mental illness, in the context of violence and crime was viewed as essential for stigma reduction.

Educational institutions

Efforts to reduce stigma in educational institutions was viewed as necessary to create generational change in attitudes. Mental health education in schools, provision of support for young people with mental health difficulties and their families, as well as education and support for staff were seen as important in improving mental health in young people, with flow-on benefits to stigma reduction, through offering positive narratives of hope and recovery.

Recommendations

Recommendation 1: Ensure that people with lived experience 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, created specifically for the purpose;
- Involving national and state-based consumer and carer advocacy organisations;
- Focusing on mechanisms to create a cooperative community with a shared purpose while also accounting for diversity in cultures, perspectives, skills and experiences;
- Building collaborations between community, government and non-government organisations;
- Providing adequate funding for participation by consumer and carer advocacy organisations.

Recommendation 2: Ensure that people with lived experience are involved in co-designing and delivering anti-stigma programs and activities, 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 and unpredictability;
 - challenge stereotypes that a person with a diagnosis of a mental illness is 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 mental illness can follow a varying course (e.g., single episode, episodic and recovered), and that also acknowledging the challenges of living with a mental illness;
 - 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 system);
 - incorporate perspectives of families, friends and other supporters;
- 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 support for people with lived experience who share their experiences through adequate resourcing of organisations that run programs involving people with lived experience.

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 take years, or even decades to have impact;
- Implementing strategies 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.

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 the evaluation, including specification of the impact of any activities being undertaken.

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, it may be preferable to focus 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 unintended consequences.
- People with lived experience, including those from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities, should be involved in evaluation of initiatives.

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

- Implementation of 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.
 - a shift in power dynamics between practitioners and consumers;
 - moving away from approaches that offer people services and supports based on their diagnoses to those that focus on their needs and aspirations.

- Strengthening the peer workforce through a more comprehensive provision of training, fair and equitable working conditions, and access to supervision from more experienced mental health peer support workers;
- Incorporating strategies to address self-stigma in people diagnosed with mental illness;
- Encouraging, supporting and enabling psychiatrists and other senior professionals to take leadership roles in stigma reduction;
- Involving people with lived experience in systems-level changes in health services;
- Incorporation of opportunities for more intensive training in mental health, including that led by people with lived experience;
- Incorporating aspects of reflective practice that allow health practitioners, senior managers and policymakers to understand their own attitudes and the impact of these on decisions about services for people living with a mental illness;
- Improving education for health professional students by including 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 address attitudes that may change over time;
- Implementation of training and reflective practice initiatives that focuses on improving health professional attitudes to people with borderline personality disorder, including building skills to improve outcomes and reduce therapeutic pessimism.

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 model positive attitudes towards people with mental health problems;
- 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;
- Implementation of interventions that address fears about competence 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.

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 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 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:
 - 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 portrayals of people with mental illness.

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 transition;
- Improving professional development and support for staff in schools and tertiary education institutions.

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

- Implementing training led by people with lived experience that takes a trauma-informed approach and incorporates narratives of hope and recovery;
- Adequately resourcing and supporting ongoing training.

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 supporters. 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 who have a diagnosis of severe mental illness 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} Here we report on the second phase, comprising stakeholder consultations that will inform a nationally coordinated approach to stigma and discrimination reduction.

2. Project aims and rationale

2.1. Aims

The aims of the project were to:

- Develop a consultation paper and other documentation to inform discussions with agreed stakeholders, with documentation tailored for each stakeholder group.
- Undertake targeted consultations with agreed stakeholders, including people with lived experience, community groups and other key organisations, on options for a nationally coordinated approach to stigma and discrimination reduction with a focus on that experienced by people with mental illness that is poorly understood in the community.
- Prepare a report outlining the consultation findings and recommendations for government action.

2.2. Key questions

The project aims to answer the following key questions:

- What do people with lived experience, service providers and those from community groups and other key organisations see as the key enablers of stigma and discrimination reduction in Australia?
- What do people in these groups see as barriers for reducing effective stigma and discrimination?
- What is an effective plan for reducing stigma and discrimination in Australia, particularly for people with mental illness which is poorly understood in the community?

2.3. 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. Groups identified as already being at high risk of stigma and discrimination, include Aboriginal and Torres Strait Islander people, LGBTIQ people, and people from culturally and linguistically diverse backgrounds, since experiences of discrimination due to mental illness may be compounding other experiences of discrimination.¹¹⁻¹³ Moreover, ways of understanding concepts of mental health and illness, poor mental health literacy and different family or social structures may mean that the impact of social exclusion and inclusion operate in ways that are unique to these populations. It is also important to consult with

people living in regional/rural sites where social norms, demographic factors and characteristics of service systems are important contexts for experiencing and responding to stigma and discrimination. An effective national stigma reduction plan must take these factors into account.

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. Based on the evidence reviews and surveys cited above, we targeted key groups on the basis that either contact between people in these groups and people living with a mental illness is common, or that their actions (negative and positive) can have a major influence on a person living with a mental illness even if contact is not common. We also included adolescent peers and school staff as this is the age at which mental illness often has first onset. The years of compulsory schooling are also one of the few opportunities for universal intervention of any intensity. Moreover, attitudes may also be more malleable earlier in life. This also applies to the inclusion of health professional students. These key groups included:

- Family and friends
- Employment service professionals (including managers and supervisors)
- Mental health peer support workers
- Health and mental health professionals (including students training to be health professionals)
- Social service and welfare professionals
- Education professionals
- Young people working in advocacy roles
- Media professionals

We also include mental health peer workers in this group as they may both experience and observe stigma and discrimination through their roles in working with both professionals and consumers of health and other services.

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. Identification of participants in this group was based on the stakeholder list provided at Attachment A, the review of existing initiatives and evidence undertaken as the first stage of the project, the list of members of Mental Health Australia (the peak NGO representing the mental health sector in Australia), and snowballing by interview participants.

NOTE: In the original project plan, it was our intention to undertake consultations with people with lived experience and their carers simultaneously with those in Groups 2 and 3. However, due to Covid-19, the project plan was revised and this report only covers stakeholders in Groups 2 and 3. Consultations with those in Group 1 will be conducted at a later date.

3. Methods

3.1. Development of consultation materials

We developed a set of consultation materials for use as discussion prompts during stakeholder interviews. These consultation materials drew on an international survey of experiences of discrimination in people diagnosed with schizophrenia,¹⁵ Australian surveys outlining changes in attitudes towards people with depression or schizophrenia,³ the evidence for effective interventions,⁴ the review of existing initiatives and evidence undertaken as the first stage of the project¹⁶ and examples of large-scale stigma reduction initiatives undertaken in other countries (principally the UK's Time to Change¹⁷ and Canada's Opening Minds¹⁸). The aims, consultation materials, level of consultation and key questions for discussion were tailored to each stakeholder group, e.g. materials for health professionals included data on attitudes of health professionals. See Appendix B for consultation materials.

3.2. Consultations

3.2.1. Participants and recruitment

Recruitment and interviews were conducted by 11 researchers from March to June 2020. We requested assistance with recruitment from 67 organisations and approached 414 potential participants. Of the individuals invited to participate, 134 people did not respond to the invitation email or immediately declined, and 270 people initially agreed to participate, although 36 people did not proceed to interview due to time constraints or late cancellation. In total, we conducted 234 interviews.

Recruitment was primarily conducted in the following three ways:

- (1) Researchers directly contacted individuals with relevant expertise who were known to the research team, whose contact details were publicly available or whose names were provided by the Department of Health RSDWG.
- (2) Individuals from organisations listed provided by the Department of Health. Where contact details for individuals with appropriate responsibilities were publicly available, we used these. Where they were not, we contacted the organisations requesting their assistance with recruitment.
- (3) Snowball recruitment, involving asking participants for recommendations for additional people to interview, either by encouraging them to pass on details of the project to other relevant individuals or by recommending individuals for the research team to contact.

Potential participants were sent an invitation email with an attached plain language statement (PLS) describing the purpose of the study and an explanation for why they were approached (see Appendix C). Those who agreed to participate were sent a follow-up email with further information about the interview, including the consultation materials and a link to a short demographic survey, which was hosted on Qualtrics. Participants in lived experience roles (particularly those working part-time) were reimbursed with a \$50 voucher for completing the interview outside their professional working hours. This reimbursement was outlined in a specific PLS for this group.

Consent to participate was obtained through the Qualtrics survey or via verbal consent at the start of the interview.

For recruitment, data collection and reporting purposes, we classified participants as belonging to the groups outlined in Table 1. Many participants had a breadth of experience from a long career in mental health and also frequently held multiple concurrent roles relevant to the interview topic. To better account for participants' roles, in addition to those participants belonging to sub-groups of Groups 2 and 3 (described in section 2.3), we also included the groups 'advocacy' and 'broad expertise' (see Table 1). In the findings, verbatim quotations extracted from the interview transcripts are used to illustrate key points. Each quotation is labelled with the participant's identification number, which shows the participant group to which they were allocated (e.g., BE23). In the case of health professionals and health professional students, we have identified their profession.

Table 1. Participant groups

Participant group	Definition	N (%)
Advocacy (Adv)	Participants who predominantly work in roles advocating for the rights of people with lived experience, such as independent patient rights advocates, disability advocates and similar. These participants frequently had their own lived experience.	12 (5.1)
Broad expertise (BE)	Participants classified as having 'broad expertise' frequently held multiple positions relevant to the project and frequently had a long history of experience in the mental health sector, which allowed them to bring multiple perspectives to the interview.	27 (11.5)
Education (Edu)	Participants work to support people, primarily young people, with mental health difficulties to engage in education. Education participants include those working in support positions in universities and TAFE, or for mental health organisations with an education engagement program.	15 (6.4)
Employment (Emp)	Participants working to support people with lived experience to engage in work. Includes employment placement services and those providing individualised supports.	17 (7.3)
Health professionals (HP)	Health professionals are from a range of professions, such as psychiatry, psychology, pharmacy, social work and occupational therapy.	56 (23.9)
Health professional students (HPS)	Those training to become qualified in one of the above professions.	17 (7.3)
Mental health peer support workers (PW)	Mental health peer support workers draw upon their own personal lived experience of mental illness and recovery to provide support for people accessing mental health care. Support includes individual education with recovery, goal setting, referrals to community-based supports and individual and systemic advocacy.	26 (11.1)
Program providers (PP)	Participants involved in mental health education for groups other than health professionals (e.g. in schools or for police), stigma reduction strategies, recovery programs for people with lived experience and similar.	42 (17.9)
Social and welfare services (SSW)	Participants working in organisations providing psychosocial supports or wraparound services, such as housing and social support. Frequently includes non-government organisations.	22 (9.4)

3.2.2. Data collection

(1) Sociodemographic characteristics

In addition to presenting the PLS and consent form, the Qualtrics survey included questions about participants' professional or personal experiences with mental health conditions, age, gender and location.

(2) Interviews

Interviews were primarily conducted via the Zoom online video-conferencing platform. In cases where participants did not have access to Zoom or preferred not to use it, interviews were conducted by phone. Interview duration ranged from 30 to 60 minutes. The interviews were semi-structured and were informed by the interview guides and consultation materials given in Appendix B, which were tailored according to target group. These were designed to elicit opinions to some common questions across the groups and some questions specific to individual groups.

At the beginning of the interview, all participants were briefly asked to provide information about their relevant professional expertise.

For participants in Group 2, questions focussed on their views about experiences of discrimination from people in their setting, the role that people in their setting might play in a nationally coordinated stigma-reduction strategy; barriers to, and enablers of, stigma and discrimination reduction in their setting; terminology (use the term 'mental illness' or specific diagnostic terms); and the appropriateness for Australia of approaches outlined in the consultation materials.

For participants in Group 3, questions focused on their views about previous program approaches that have or have not worked, terminology, and the best approaches to be taken to delivery mechanisms, scalability, and tailoring to local contexts.

Interviews were audio-recorded, and the audio files were transcribed by a professional transcribing service. Some interviewers also took notes during some interviews.

3.2.3. 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 iterative thematic analysis.¹⁹ All analysis was conducted using the qualitative data management software NVivo. An initial coding framework was developing using the interview questions, with additional codes applied to themes emerging from the data. Three members of the research team (AN, AR and JW) analysed the data. They collaborated on initial coding of transcripts until a common approach was agreed upon. Data from the various participant sub-groups were analysed separately in the first instance and later integrated, where possible, by one member of the research team (AN). A researcher with lived experience of mental illness also double-coded three peer worker interview transcripts (CM), and discrepancies in coding were resolved through discussion. Where specific issues were raised by particular cohorts or groups, these were reported.

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. Sociodemographic characteristics of participants

Sociodemographic characteristics of participants are given in Table 2, with 214 of 234 participants completing the questionnaire. The majority (66.8%) of participants were female, and the most commonly reported age categories were 45-49 (15.4%), 55-59 years (14.5%) and 40-44 years (13.1%). Participants were most likely to be from Victoria (31.3%) or NSW (27.1%) and from metropolitan areas (64.5%). The majority (86%) of participants reported either having lived experience of, or working with, people with a mental health condition of relevance to the current project, with almost half (49.1%) of participants reporting having either lived experience of, or working with, people with all four diagnoses. The remainder reported experience with other mental health conditions, or did not support the use of diagnostic labels. Among those with professional expertise, health professionals were the most common category (47.7%).

Table 2. Demographic characteristics of interviewees

	n	%
Gender		
Female	143	66.8
Male	70	32.7
Gender diverse (e.g. trans, gender fluid)	1	0.5
Professional or personal expertise*		
Person with lived experience	83	38.8
Family, friend or supporter of a person with lived experience	60	28.0
Health professional	102	47.7
Health professional student or trainee	24	11.2
Employment services professional	34	15.9
Education professional	60	28.0
Social and welfare services professional	21	9.8
Anti-stigma program provider	33	15.4
Other	40	18.7
State		
ACT	3	1.4
NSW	58	27.1
NT	7	3.3
QLD	29	13.6
SA	10	4.7
TAS	1	0.5
VIC	67	31.3
WA	13	6.1
Not reported	25	11.7
Region		
Metropolitan	138	64.5
Regional	38	17.8
Rural	9	4.2
Remote	5	2.3
Not reported	24	11.2

* Total percentages >100% due to possibility of multiple responses.

4.2. Key themes

Guided by the semi-structured interview guides, findings are reported here according to key themes and settings for action.

4.2.1. Understanding that stigma and discrimination toward people with mental illness is common

Across all groups, participants stated that stigma and discrimination towards people with mental illness was widespread among the general community, and within their institutional contexts. Participants noted that attitudes varied according to the type of mental illness.

(1) Bipolar disorder

Bipolar disorder was seen as having become better understood and therefore less stigmatised over recent decades. This reduced stigma had occurred partly because of the visibility of some high-profile individuals (e.g., the actor, writer and comedian Stephen Fry) who have talked publicly about their experiences of living with bipolar disorder. This candour has demonstrated that bipolar disorder is experienced by 'successful' and high-functioning people and can be effectively managed.

'See I think bipolar is a bit... more accepted than the others as well because... there's a lot of celebrities that have bipolar so it's not as traumatic a diagnosis for many people because they're like oh yeah... all these different celebrities that have had bipolar but schizophrenia and borderline personality disorder especially take... the brunt of... stigma... especially within health and outside of health.' (HP23, Occupational therapist)

(2) Schizophrenia and psychosis

In contrast, participants often stated that schizophrenia was the most stigmatised mental illness within the general community. They speculated that this was partly due to day-to-day encounters with people acting in unusual ways (e.g. talking to themselves) that provoked alarm or fear and that they attributed (rightly or wrongly) to the person having schizophrenia. They may also absorb views from the media and popular culture that people living with schizophrenia are dangerous and unpredictable. There was a view that the community could not distinguish between schizophrenia and other psychoses, and that 'psychosis' or 'psychotic disorders' would not be commonly understood. Furthermore, participants frequently noted that, while contact with people experiencing anxiety and depression was common, contact with people living with mental illnesses such as schizophrenia was generally less frequent, and this led to 'fear of the unknown' and misunderstanding. Some participants noted that, while everyone experiences some degree of anxiety and sadness in their lives, making anxiety disorders and depression more relatable, experiences such as auditory hallucinations, are perceived as strange and frightening:

'[People need] the sense that people do recover; people live contributing lives, that it's not as portrayed in Hollywood movies... a diagnosis of schizophrenia [has] such stigma attached to that, but it's not the end of a person's life... you can lead a fabulous life, as you can if you have diabetes or epilepsy, it's just a matter of managing that... too often [people think] schizophrenia means a split mind... and split personality. So, there's just a lack of education there' (BE28)

(3) Borderline personality disorder

For people with a diagnosis of borderline personality disorder, discrimination from health and mental health professionals was seen as particularly problematic. Participants speculated that this discrimination was due to health and mental health professionals' views of people with borderline personality as being difficult to engage, impossible to 'treat', and aggressive. Recurrent presentations to services, especially emergency departments, due to suicide risk was also mentioned as contributing factor.

'...when people have a diagnosis of things like borderline personality disorder they're automatically discriminated against... they will be not allowed in services or put to a corner or decisions made about their behaviour or anything before they even have a chance to interact with people.' (BE10)

4.2.2. Support for a national strategy to address stigma and discrimination

Participants voiced widespread support for a national stigma and discrimination reduction strategy targeting these mental illnesses. Participants frequently pointed to the success of Australian organisations, such as Beyond Blue, in promoting mental health literacy and reducing stigma towards people with anxiety and depression. This progress provides a foundation for extending the national 'conversation' to promote better understanding of severe mental illness:

'the management of depression, and the stigma around that sort of thing, that's been an amazing change I think... everyone's not afraid of talking about that anymore so if we can somehow... manage schizophrenia, bipolar, in the same way, without the fear that goes along with it... certainly if we can make a campaign as well as the [campaigns focusing on] depression [then] it would be just amazing'. (HP27, Mental health nursing and paramedicine)

4.2.3. Ensure that people with lived experience have a central role

The most common theme emerging from the interviews was that people with lived experience of mental illness must have central roles in a stigma and discrimination reduction strategy. Participants believed that, practically and morally, those most affected by stigma and discrimination need to be involved in designing and delivering solutions. People with lived experience are described as holding unique and deep knowledge of experiences of being stigmatised and discriminated against and that this should be harnessed to formulate solutions.

Participants spoke of a range of ways that people with lived experience could be involved in a national strategy. These included ensuring that people with lived experience have leadership roles both in developing the strategy and in carrying out the activities prescribed by the strategy, which should include opportunities for community members to meet and talk with people with lived experience as well as supporting people with lived experience to share stories of hope and recovery. Mental health peer support workers (those who draw upon their own personal lived experience of mental illness and recovery to provide support for people accessing mental health care) were also seen as having a central role.

'The communities affected need to lead it, that's the case'. (PP26)

'... best practice is that there is a lived experience participation framework which maintains that those with lived experience should be involved... right from the inception of an initiative... to the evaluation phase... So best practice brings people in as early as possible and creates an equal inclusive and accessible space at the table for them... often what happens is they're brought in to consult later on and it's... lip service to co-design... it's about to what extent will that consultation filter through to impact... do they actually have a real capacity to create change and will their voices really be heard?' (AD12)

'Maybe I'm biased here, but I think the biggest change has been incorporating that lived experience. One of my big concerns... is what my colleague used to call *benevolent othering* – so for a service, or a clinician to determine what a group of people needs, and they're doing it with the best of intention and compassion, but they're not actually asking the person or people what's going to be helpful. And I think this is where you know so much service development, so many strategic plans, even you know stigma research, unless it's actually incorporating that lived experience, it's still missing the mark somewhat... I'd like to put that I actually think that it's important for people... with lived experience to be included from the very beginning, and not just included as an extra' (PP02, female)

Participants across all groups often referenced beliefs that people with lived experience are not expected to have successes or capabilities beyond management of their mental illness. They therefore emphasised that making people with lived experience 'visible' in programs and activities provides opportunities for challenging both public and self-stigma, and particularly attitudes relating to what people living with mental illness are able to achieve.

4.2.4. Having people with lived experience share narratives of hope and recovery

Participants across all groups talked frequently about the importance of having people with lived experience share their stories as the best, or only, way to reduce stigma and discrimination. Participants believed that community members' stigmatising views of people with mental illness most often revolve around seeing people with mental illness not as *living with* mental illness, but rather *as* their mental illness. Therefore, promoting opportunities for people with lived experience to share stories of hope and recovery can assist community members to see those with lived experience as 'whole' people:

'... they [an advertising campaign] did expose people to people with these diagnoses but they actually developed a relationship prior to the telling that they had a diagnosis so it was things like there was a series of ads it was you know "hi I'm [name], I'm a PhD candidate, I've got two kids" and the next one would be... "I went on a holiday last year with my husband to Central Australia"... and... around the eight- to ten-month mark... they then said oh and by the way I have a diagnosis of bipolar or...schizophrenia. So people had actually developed a relationship with them and knew them as human beings.' (PW18)

'they bring people along with a lived experience that tell their story and it's a way of sort of humanising these people who are otherwise portrayed as being monstrous...'. (BE 19)

Some participants also spoke of the importance of demonstrating to community members that people managing their mental illness can lead 'successful' and fulfilling lives. This was seen to help in overcoming what has been termed 'the soft bigotry of low expectations'²⁰, where (in this context) people with mental illness are viewed as incapable of attaining successes possible for other people:

'...my first diagnosis as a twenty-three-year-old... was a paranoid schizophrenia, change of diagnosis a year later to bipolar to manic depression at the time... So my career has been twenty years as a school teacher, a parent with two children who are successful at uni and that and married for twenty-nine years; so there's a different narrative and mine's not the only one that's out there... That people... living with a mental health issue... are just leading ordinary lives because they've had the opportunity to say, reengage at a critical time with employment.' (BE03)

'Well I'd like to see for a start advertising campaigns using people with mental illness, talking about what they do in life, and at the end of it sort of say oh yeah I've got bipolar. Or you know... [I have schizophrenia] . But as a sort of 'so what'... I've got a really good job as a nurse, as a radiologist, as a fireman. That's number one.' (PW20)

Mental health peer support workers often noted that mental health professionals frequently have low expectations about recovery and potential achievements of people with lived experience. (See below: Employment of mental health peer support workers in health system settings).

Some participants explained *how* enabling people with lived experience to tell their stories works to reduce stigma, emphasising the need to provide alternative narratives to those created by negative media portrayals of mental illness or by negative experiences of encountering people with assumed mental illness acting unusually:

'...it kind of goes back... [to] some of the stuff we know about other marginalised groups. It's getting to know people who have had that experience, actually seeing the person... rather than the stories in the media, or the stories that you've been told by other people and you made up in your head – actually connecting with people, getting to know people.' (PP12)

'...to a large extent I think you need people that potentially hold onto this stigma around mental health coming into contact with people who have mental health issues, and having light bulb moments going, "wow this person has schizophrenia but they're an effective operator, I get along well with them, they can hold their shit together when there's adversity, they're clearly managing their condition". So, I think it's about passing on some knowledge, following up that education with a bit of reinforcement, I think that's always important.' (PP13)

(1) Telling the 'real' story of living with a mental illness: challenges and recovery

In addition to promoting portrayals of people with lived experience as having whole lives, participants spoke of needing to discuss mental illness in a way that illustrates that it can follow a varying course (e.g., single episode, episodic and recovered), rather than purely being enduring and disabling. They also noted the need to take a 'recovery' focus.

'Most people do recover from mental illness, yet most people in the community wouldn't know that. They think there's an enduring illness where people cannot recover and it's kind of a scary thing and people think that... people with major mental illnesses either consciously or unconsciously should continue to be isolated, that that sort of distancing should continue. So, yes definitely positive stories would be the positive counterbalance.' (BE19)

Notwithstanding, participants often also mentioned that this portrayal should be realistic in showing the difficulties experienced when people are managing their mental illness:

'I know there's... very different perceptions of what it's like to live with episodic conditions and mental health, long term... we get very different messages from media and films and things, but maybe there's scope for more educational material about... how diverse these experiences [are]... they could all have a diagnosis of schizophrenia but their... life could just be like really completely different from the next... just because

they have that same label doesn't mean they have much in common with each other as a group of people necessarily'. (PW25)

'...without being histrionic, if you can have enough lived experience voices who can show what it looks like to be well, but also, can talk openly about what it was like not to be well, there aren't that many people who aren't receptive to that.' (BE27)

Participants frequently alluded to stigma related to perceptions of people with mental illness, particularly schizophrenia, or psychosis more broadly, as being dangerous and unpredictable. They also noted that some behaviours from people who are experiencing acute or initial episodes of mental illness can indeed be challenging for others. They recognised that to break down stigma and discrimination, these perceptions and experiences need to be addressed, rather than avoided.

'My observation [is that] a lot of... large scale anti-stigma campaigns [have] what I'd call an allergic reaction to some of the less glamorous... sides of mental illness and I know that this is borne out of wanting to avoid stereotypes and wanting to avoid people... picking up on things like impulsivity as being erratic and that sort of stuff but I actually don't think that that does us any favours... an anti-stigma campaign needs to be realistic. It needs to actually admit that whilst we don't want to portray people with schizophrenia or... bipolar as dangerous and erratic and people to be avoided... the very nature of these conditions means that at times we are erratic, we are a danger to ourselves and we may be a danger to others and I don't think it's actually useful to try and downplay that stuff... in doing so... you're actually creating a space where when people do have very short periods where these things occur then that allows the media to sensationalise it and it allows it to become, "but you said these people [weren't like this]". (PP23)

The need for inclusion of family members in order to provide other perspectives was also noted:

'Storytelling... but from both perspectives. So here's my brother, he has bipolar, or he has schizophrenia, this is what my family and I thought at the beginning, this is how hard it was for us, cut to the brother, he tells it then what it was like for him and those difficulties. And then model that journey of how they then got to their good point. It might not be the end point, it might be that there's a lot more to go, but I think... two-way communication always, you know it's about modelling what it's like on both sides... never shying away that it's challenging, and that it's hard and it's upsetting and it's distressing and all those negatives, but really showcasing the positives.' (PP08)

(2) Building empathy: Symptoms of mental illness as responses to difficulties

Building empathy for the challenges of living with a mental illness was frequently cited as being an effective way of reducing discrimination arising from negative portrayals and experiences:

'...the more you understand the more empathy you practice, the closer you get... to understanding and not judging and sort of helping them.' (AD01)

'... you don't want to focus too much on that aspect of it, but I think [communicating that] this is a person who is in pain, or who is suffering to some extent, and the need for that... compassion and not a fear-based approach... I think that is really powerful coming from carers.' (PP32)

'...and there's a lot of people who come along... perhaps even having been affected by a situation where someone with a psychotic illness... has committed an act of violence... in their community... in their family... rather than saying, "this is not aggression"... we say if [you really believed] somebody was following you around all day and you were sure that they were going to attack you, I mean what would you do... And it does sort of start to change the conversation.' (PP05)

Some participants also noted the importance of highlighting that mental illness can be a response to trauma:

'...if someone has a personality disorder they can function incredibly well 90% of the time and 10% of the time they might get re-traumatised back into some childhood trauma which brings on an episode akin to a personality disorder episode and that's when they would need extra support and understanding... a campaign that showed people how a young child develops that kind of disorder would go a long way to helping people to... understand it so as to not be so fearful of it.' (HP34, Psychologist)

Others noted that when people experiencing mental illness do act in unusual or dangerous ways, it is often the result of multiple risk factors (e.g. poverty, homelessness) or through the failure of the health system to provide adequate

support, rather than being the 'fault' of the person themselves. These participants stated that increasing community understanding of this could assist in creating empathy and understanding:

'to counterbalance some of the misconceptions... if people become dangerous, often it's because of a failure of not the person, but... of services. I've seen... where people have entered the forensic system because they haven't been able to get proper services... we know that most people who hear voices have experienced some sort of trauma, childhood or adverse events in their lives, it could be a number of things, that set up that natural human response to start an internal dialogue that can sometimes get out.' (BE03)

'...we need to understand that... a lot of mental health issues come from responses to... depression, racism, homophobia, homelessness, poverty - that really needs to be communicated too... people have a pathway into mental illness sometimes... and in the UK... there's a lot of research going on there with... black and ethnic minority communities recognising that racism is such an integral part of their mental health experience. I think that for me is a destigmatising sort of message - it's difficult to convey but a lot of people have past experiences that contribute to this...' (SSW14)

Conversely, some participants issued warnings about these two approaches, stating that they needed to be combined with more positive aspects, including talking about the person's recovery and successes, as described above. Some participants noted that it was important not to always imply that people living with a mental illness are 'suffering', as this can provoke pitying or paternalistic responses.

(3) Need for provision of support for people with lived experience to tell their stories

In addition to noting the importance of having people with lived experience tell their stories, participants frequently talked about the importance of providing appropriate selection processes, support and training to do so. This training and support predominantly related to training people with lived experience to shape stories into a purposeful narrative that is told safely, providing guidance on setting boundaries around sharing personal experiences, encouraging use of self-care when carrying out advocacy or educative work, and organisations providing additional support when needed:

'you know, [we] really work with the speakers to craft their stories... You need to actually have a crafted story, because it needs to have information in it for the audience... it needs to talk about what people have experienced... to improve mental health literacy... to have that resilience and... recovery... elements to it... you have a lot of people who have great intention, but unless they've got some guidance around what to be doing and what to be saying, it cannot be helpful.' (PP26)

'...we would talk about what impact this is going to have on your life if you suddenly start sharing [your story] externally, and what impact is that going to have on your community, so your family, your friends, your work colleagues... So then from there we then look at... media training... things that are triggering... words that really are very stigmatising... things that are not safe to say... we would cover all of that.' (PP36)

Several program providers who employ people with lived experience talked about how their organisations support people to share their stories, encourage self-care and provide support around attendance at events:

'And then also from a self-care point of view, we would always have these check in points... [if] you're going to give a presentation, we would check in how you're doing a couple of days before... [if] the day of the event if you turn around and go "I can't do it", absolutely no problem, we would step in... we would be there straight after to check in and see how it went for you... then we would check in again a couple of days later just to see and make sure that you're putting things in place... [like] down time afterwards, or... self-care.' (PP36)

(4) The need for face-to-face interactions with people with lived experience

Program providers and those with broad expertise were supportive of presenting stories of lived experience digitally, such as through online video. However, it was very common for them to state that stigma reduction best occurs when community members can meet in person with someone living with a mental illness:

'for me I think it would be more powerful to get someone with a lived experience actually in the room... so that everyone across all mental health disciplines can actually do a Q&A with that person and even have the family there... I don't think that's actually quite common in the kind of communities that I work with. So, it's all very well to have it down written on paper... [but] when we have someone with lived experience actually reaching, from their heart, what they went through and getting that emotion out as to what the hinderances

have been in accessing services, that's when I think we get real engagement and awareness happening amongst the health professionals'. (BE21)

'...it's just trying to break down that what do you think a person with a mental illness looks like. And they go, "oh not somebody that's got a manager's role, not somebody that works full time"... they'll name all these things, and I'll go well hang on, "that's me!" [person running a program] So, the more I can get out in the community... and have that conversation, the more it helps.' (PP21)

(5) Mobilising champions

When asked about elements that would be integral to the strategy, numerous participants talked about the importance of mobilising 'champions': people who are passionate about changing stigma and discrimination toward people with mental illness, and who are willing to take on a high profile in talking about mental illness. Most frequently, the examples given were people with lived experience themselves or supporters of people living with a mental illness who hold positions that enable them to influence others within a particular group, organisation or community. In a similar vein, participants sometimes used terms such as creating a 'social movement', where people with lived experience were empowered to undertake advocacy for change. Less commonly, participants spoke about people without lived experience of mental illness acting as champions. A number of participants provided specific examples within their settings:

'[Name of university] does have mental health first aid champions... [they] ask for volunteers... to become mental health first aiders sort of thing in the teams. And they publicise the names and they give people ongoing training and they get refreshers and you know – which is fabulous, that was really fantastic initiative there.' (ED13)

Some examples outlined less structured emergence of champions:

'... I saw on one of the websites a thing about... worksite champions... that's a really good way of doing it. And thinking back to that young person I was supporting, because of that positive experience [with the boss] he... became a bit of a champion on the worksite... he... said to me... "it's been weird how... since I've become more confident talking about what's going on for me, everyone else is talking about what's going on for them and we're really open and honest and we support each other on the bad days, and it's kind of nice".' (ED01)

Others highlighted the value of people in leadership roles acting as champions, noting that their visibility, in itself, can change attitudes about the types of people who can be affected by mental illness:

'They could champion the actual issue, like you've got several CEOs who've come out recently around the world who say look I have a mental health issue and I'm willing to talk about it. And I think that's just so much courage and it normalises it. We look at someone like the former premier of NSW John Brogden who had a very public suicide attempt, and survived it, and now he's the chairman of Lifeline. His wife as a carer and is now the Chair of the national mental health commission [Lucy Brogden]. It's those sorts of examples. And it comes from all of society... we need to help to change that whole stereotype type of thinking that mental illness touches only certain groups... it touches all of us.' (EMP01)

4.2.5. The need for a long-term approach and evaluation of impact

Numerous participants, including program providers delivering stigma reduction programs in other countries (for example, *Minds Like Mine* in New Zealand and *Time to Change* in England), emphasised the importance of commitment to a long-term stigma and discrimination reduction strategy that spanned years or even decades. This need for a long-term commitment is based on the understanding that attitudinal and behavioural changes that are visible and measurable at the population level take a long time. This also requires that messages are reiterated and communicated in different ways to avoid fatigue and that allow for attitudes evolving over time. Many comments in this vein also mentioned the need for long-term research and evaluation approaches to measure the outcomes of the stigma and discrimination reduction strategy; to identify strategies that do and do not work; and population segments who might need additional targeting and alternative strategies:

'this is the work of a generation... if you're looking at major social change around something that's been so stigmatised for generations, these things don't turn into long-lasting irreversible change on the flip of a one-year campaign, or two-year campaign. You're embedding norms and behaviours for future generations... [you need] at least 15 years if you want to talk about somebody growing up with those attitudes and behaviours, or somebody moving on to adulthood.' (PP42)

'... it takes that multi-level, multi-systemic approach to be able to achieve the change that we need - not 12 months, not 2 years but 5 to 10 years, if not longer, to continue to educate the community, raise awareness but then also to measure and look at what specific things are needed to be able to change behaviour... where you need to have additional strategies... that's what we don't have in this country a long-term approach...'. (BE23)

4.2.6. The need for inclusion of strategies to address self-stigma

A number of participants stated that a stigma and discrimination reduction strategy must include strategies to address self-stigma (internalised stigma in people with lived experience). Self-stigma was seen as a barrier to help-seeking and was also related to poor self-esteem and a lack of aspiration.

'...there's obviously a huge issue with... societal structure stigma but... a lot less emphasis is placed on self-stigma with people with complex mental health issues... when they have a diagnosis [they can] struggle to own their own narrative and their own diagnosis because... the stigma, [has] been internalised and that prevents people from sharing... from help-seeking and that's even when you have very strong relationships in place... So you can imagine how that feels on a larger scale in a workplace setting or in a relationship... self-stigma is something that we really need to address... encouraging people to own what they're living with and managing to then be able to share it others.' (AD12)

'the content really focusses on... rebuilding people's sense of identity and self, and restoring their belief in themselves... then at the very end then we get them to say... what are your aspirations and let's do some goal setting... And it's really hard when a person's perception has just been mashed... how do I set goals for myself when I don't think I'm worthy of having goals... we've just got to allow people to put... the pieces of their identity back together, and then now they've reimagined themselves, then allow them to set some goals.' (PP15)

4.2.7. Language

Interview questions covered the use of specific diagnostic terms, such as schizophrenia, bipolar disorder and personality disorders, or if some alternatives should be used. Participants, including those with lived experience, were divided on whether these diagnostic terms should be used, and a clear consensus did not emerge.

Most providers of anti-stigma programs and health professionals thought that current diagnostic labels should be used, with the focus being on changing the stigma around those terms, often stating that energy should be spent on reducing the stigma, rather than on finding an alternative label. Mental health peer support workers were divided on whether the strategy should use diagnostic terms. In most cases, participants could argue both sides, listing both the advantages and disadvantages of using diagnostic labels. The fraught nature of deciding on a universally accepted terminology was discussed frequently:

'Yeah, this is the \$64,000 question, because language is really important. If there's one area, at least in my field, that's so, socio-politically hot, it's around language. It's hard to form a consensus...'. (HP10, Psychiatrist)

Participants also frequently noted that some diagnostic terms, particularly borderline personality disorder and schizophrenia, are far more stigmatised than others, such as bipolar disorder. Participants noted the lack of current consensus around acceptable terminology. There was also discussion about the use of broader terms such as 'mental illness' and whether these, or alternative terms, should be used. Many participants highlighted the need for people with lived experience to be at the centre of decision-making about terminology. In this section, we outline some of the arguments given for using and not using the current terminology, the positive and negative consequences of using diagnostic terminology, and suggestions regarding broader terms.

(1) Diagnostic terms should be used in the strategy

Some participants thought that using specific diagnostic terms in the strategy would help to maintain focus on low prevalence mental illness, reorienting focus away from the less stigmatised common mental illnesses (primarily depression and anxiety); increase visibility of people with these mental illnesses; and help create a shared understanding as long as the use of diagnostic terms was accompanied by accurate information:

'... from a communications point of view, it's better to be able to name and describe in understandable terms what you're referring to, so don't dodge it.' (BE01)

Some participants stated that avoiding the use of diagnostic terminology is in itself stigmatising, while naming specific mental illnesses helps to break down stigma by normalising them and making them part of the national conversation in the way that anxiety and depression have become:

'if we want to break stigma then avoiding talking about it or avoiding labelling it is stigmatising... it makes it scary; it makes it unknown. Whereas if we talk about it, it becomes a common language, then... people are less likely to stigmatise it... if we talk about mental illness... or mental challenges, they might even think stress, rather than an actual illness. So, I think it actually probably serves to stigmatise things more you know.' (PP01)

Some participants believe that the focus should be on changing stigma related to diagnostic terminology and on creating greater understanding of people living with these disorders, rather than on changing terminology. They stated that trying to change terminology sometimes distracted from other important discussions and often led to the use of overly complicated language that reduces the effectiveness of communications:

'Well the [organisation's] aim at this stage... is to rather change the narrative around what BPD is and help people to see the distressed person behind that term.' (PP02)

'... you can be so politically correct that you lose the meaning out of what you're trying to say... if you get too precious sometimes, you can lose your chance to communicate...' (BE27)

Many participants who supported the use of diagnostic terms noted that they should be used to label a person's experience and not the person:

'...someone who deals with bipolar is one that I also like.... I think it's accurate for me. I certainly don't think there's a better way of describing it than to say that I'm someone who deals with bipolar, as opposed to a bipolar person, which is not something that I would use.' (ED05)

The noted advantages for people with lived experience of using diagnostic terms were giving legitimacy, validation and understanding of the difficulties experienced by the person with the mental illness and their family and friends; being able to seek out treatment, information and other people who had similar experiences by using the diagnosis as a starting point; and for provision of targeted services:

'... so even though borderline personality disorder is such a stigmatising term, particularly in... mental health professionals... young people with BPD say when they got that diagnosis it really helped them connect with a whole bunch of other people... who were experiencing the same thing... That was huge.' (SSW14)

Health and mental health professionals noted that diagnostic terms are useful to them as a kind of communicative shorthand that can quickly orient them to common difficulties and treatments that the person might be experiencing, and other clinical considerations. These professionals sometimes noted that while they used these diagnoses in conversations with colleagues, they did not always do so in conversations with patients/clients, if that was not deemed useful:

'... it is still a useful label in terms of identifying that a person... is likely to have a chronic problem that is going to need chronic treatment... [as] a health professional... when you see a label you immediately have a sort of schema in your mind about what are the ten things I need to think about when I see somebody who has that label... How stable is this person, what medications are they on, what impacts do that medication have on their general health, are they engaged in services you know what's their social functioning, what supports do they have... how are they managing with their illness and so on. So, they do serve a purpose but it's making sure that the human being is visible beyond the labels'. (HP54, Psychiatrist)

(2) Diagnostic terms should not be used in the strategy

The main reasons that participants objected to diagnostic terms being used in the strategy were twofold: using a diagnostic category allows people to 'other' those who have been given that label, and the diagnostic terms themselves should be changed as the stigma built up around certain terms, especially schizophrenia and borderline personality disorder, can never be undone:

'... there is some evidence that... if you start to use medical terminology and medical frameworks for talking about these things, that can actually help to create more stigma and discrimination because people are 'othered'... through being called 'mentally ill' they're othered. And that might create a desire for social distance.' (PP33)

'...in Japan and Korea they've changed the name of schizophrenia... And the one I like is the Korean... it's "attunement disorder", which I think is really lovely because it's that idea of you're musical, that there's something you can do to get back in tune... I do think there's so much baggage with schizophrenia that that does make it hard...' (HP19)

Participants commonly noted the disadvantages of applying diagnostic labels, including the tendency to see people as their diagnosis and to make assumptions about the person's treatment and needs, rather than focusing on individual experiences and circumstances and recognising that people with a common diagnosis will have varying needs. Some participants commented that this was a particular issue for people with a diagnosis of borderline personality disorder, which, as noted above, often led to a person being considered 'difficult', with consequent negative effects on their care:

'... particularly... personality disorder; people are treated a particular way, and they feel like that label's just informed so much of what the health service then does with them, and informs the reactions from health workers to their very real stress... instead of the health workers being self-aware of their own impacts, it's then projected onto the other person, to the consumer... and yeah so for them it hasn't been an empowering experience.' (PP12)

(3) Alternatives to diagnostic terms

When participants objected to the use of diagnostic labels in the strategy, they were asked about possible alternatives, noting the need to keep the focus on low prevalence mental illness rather than on depression and anxiety.

Individualised use of language

Many participants talked about using those terms that individuals experiencing mental illness were most comfortable with, and therefore that the most 'appropriate' language was person- and situation-specific:

'It depends on who I'm talking to. With employers we try not to use [the diagnosis]... If it's brought up in conversation we will, or if the job seeker feels that it's an issue and that they need to know about it, we will. Some job seekers... don't acknowledge it themselves; therefore, we can't do it when it comes to employers... Obviously when we're communicating to [people in the] the mental health ward... Our language changes to them and... we acknowledge their mental illness and that they are unwell at the moment, and that's why they're here seeking a treatment.' (EMP08)

While participants understood that this individualised adaptation of language was not feasible for population- or community-level communications, they did encourage promotion of this approach in mental health education and in all direct interactions with people with lived experience.

Terms related to symptoms or experiences rather than diagnoses

Commonly, participants spoke of their preference for referring to symptoms or experiences, rather than diagnostic 'categories':

'... [use] language that describes the experience... I'm not having auditory hallucinations I'm hearing a voice; I'm seeing a vision... learning to understand the language that the person uses to describe their experience because everybody's experience will be different is very important to helping break down stigma and discrimination but also to be able to relate and work with a person'. (AD02)

Participants also frequently expressed a preference for referring to those experiences as occurring on a spectrum or continuum, as this implies that each person exists on that continuum and can be at different points, depending on external influences. This allows anyone, including a person who has not had an experience of a mental illness, to see themselves on that spectrum, thereby reducing 'othering':

'... the US College of Psychiatry... is now talking about a spectrum of psychosis... from mild through to severe; it's a little bit like being on the autism spectrum... it's more about the spectrum and the level of severity rather than a particular label... if we can say that we are experiencing a level of psychosis as a result of a whole range of things happening in our life... if we start talking more about a spectrum of psychosis then... it doesn't exclude me from being on that spectrum... we push people to the boundaries because they're different, they're dangerous... if you have a spectrum then... in some way we would all be on that spectrum.' (BE23)

Some participants expressed a preference for not delineating diagnoses at all, but rather talking about various mental illnesses as reactions to trauma in order to create greater understanding and empathy:

‘I think it's dangerous to use clinical... or diagnostic terms [because] there's not enough knowledge in the community... I've got... empathy towards trauma or calling it trauma-related conditions... because most of the community... have gone through traumatic events, and they understand how that affects them physically, emotionally... that it's a person that's been hurt in the past and there's a reason or a causation for those behaviours today... It's a somewhat more relatable terminology. [With] bipolar and schizophrenia... they jump to conclusions which may effectively disadvantage the person with the mental illness’ (PP24)

A number of mental health peer support workers, and, to a lesser degree, participants from other groups, stated their preference for using the broader term ‘distress’ when talking about the full range of mental health difficulties. This preference arose because, again, distress is something to which all people can relate and is experienced on a spectrum. Talking about distress also makes that distress experienced by the person the focus, rather than specific symptoms, which may be more or less distressing to different people with the same symptom. It is notable that the New Zealand program *Like Minds Like Mine* uses the term ‘distress’, and several participants referred to this program directly.

‘...we purposefully use ‘distress’ [which] can apply to anyone on any day of the week... we do that... to stop that sense of this is a group of people who are other... the best thing you can do about... the word[s] schizophrenia [and personality disorders] is just to get rid of [them]... no amount of massaging of these terms and... making nice little pictures of people with schizophrenia on family picnics or... in workplaces, is going to take the... yuck out of those terms to the general public. So, I'm very critical of a lot of the ways people approach this issue.’ (PP33)

In addition to discussion of individual mental illness diagnoses, participants also frequently gave opinions regarding the use of broader terms such as ‘mental illness’, though there was no consensus on the best alternative terms to use. Many participants talked about this lack of consensus among organisations and people with lived experience as a barrier to adopting an acceptable alternative. ‘Mental health issues’ or ‘complex mental health issues’ has been commonly adopted as an alternative to ‘mental illness’, though some participants expressed that they use these terms because they are the currently accepted vernacular, rather than because they prefer that terminology:

‘But I think within our sector and within... broader mental health... we've got to go with what consumers are telling us... what people are finding offensive or they're finding challenging, but the other side of the coin being that people have differing opinions, so what's the generally accepted term for one person might not be for the other... it's really complex.... we tend to just be guided by what we're hearing nationally and then kind of go okay at the moment we're going to say mental ill health, or complex mental illness...’ (PP20)

4.2.8. Target settings and groups

While the need to target a range of settings and groups was implicit in the design of the project, we also asked participants whether there were any specific settings or groups that they believed to be particularly important to target in the activities of the strategy. The most commonly nominated settings were the general community, workplaces, health services and the news media. Employers, and health and mental health professionals were noted as needing particular attention.

Other participants noted the need to tailor elements of the strategy to Aboriginal and Torres Strait islander and culturally and linguistically diverse communities; family and friends of people experiencing a mental illness; police and people working in the justice system; people working in the education system (in both schools and tertiary education institutions); people working in social and welfare services; and policymakers.

(1) Members of the general community

Family and friends

Participants often noted that family and friends of a person living with a mental illness could behave in discriminatory ways, though this was frequently unintentional and sometimes subtle. Few participants could articulate how stigma and discrimination from family and friends could be reduced, though some participants suggested that providing family and friends with direct information about how to support the person living with a mental illness and recognising the needs of family and friends themselves could be helpful.

The following quotation illustrates a number of these points:

'...it's about modelling the real behaviour... of how you want the help givers and the friends and family to respond... people respond really well to here's what you should [and] shouldn't say, here's what you should [and] shouldn't do. And of course there are people that... need more information... [but] simplifying it and having a format like 'You Can't Ask' [referring to the ABC television show]... then you go more into... here's how you can get some help and coping strategies. And quite often people do just want to vent, you know they do just want to say this is bloody tough... and my friends don't understand what it's like, because I'm fearful that they judge him or her, or they're going to judge me. And I just want someone to understand.'

(PP08)

Many participants talked about the need to educate the broad Australian community, with a focus on 'demystifying' and 'normalising' mental illness:

'I truly believe in order to break down stigma people need to have a good knowledge around mental health, mental ill health, suicide, complex mental health conditions... getting their head around exactly what it is, goes a long way to smashing the stigma...knowledge and understanding heals and defeats stigma almost every time.' (PP13)

A population-level media campaign

There was an assumption among many participants that a national strategy to reduce stigma and discrimination would include a population-level media campaign. Participants frequently discussed the types of delivery mechanisms that could be used to promote the key messages of such a campaign. There was general agreement that this would require a multi-platform or multifaceted approach. Three commonly mentioned mechanisms for delivering population-level education were through celebrity endorsement, a mass media campaign and through digital platforms and social media.

Some participants also noted that 'awareness raising' or provision of information about the problem of stigma, without interventions that involved contact with people living with a mental illness or hearing stories of lived experience, or opportunities to learn positive behaviours, would be unlikely to reduce stigma and discrimination:

'I think where there is an overreliance on awareness raising in itself, I doubt that's... effective, and when I say awareness raising [I mean] simply saying... people in the community have mental ill health... it [referring to specific awareness raising campaign] left people saying, "my goodness I didn't realise there were that many people that I need to watch out for"... it didn't create a positive approach... simply thinking that if we raise people's awareness then of course they'll know what to do about it or how to think about it.' (BE01)

'So I do think campaigns work, it's just that when it's not done right or done to the right degree it may just be kind of tokenistic because... if you want to change stigma and discrimination you need to change culture and attitudes, and culture and attitudes are not 'read this flyer' and *voila*. It needs to be a broad in-depth embedded way of doing it.' (PW29)

Celebrity endorsement

Many participants described the positive impacts that can be achieved by having a celebrity (such as an actor) or a high-profile public figure (such as a politician or athlete) talk about their experiences of mental illness in a national campaign. There was an understanding of the complexities of having a high-profile person disclose a mental illness such as bipolar disorder or schizophrenia.

'[Mass media campaigns] work but it's got to be high profile celebrities... sports people... [and] politicians that identify. So, if you're prepared to get them to come out of the closet then go for it, but if you don't get a good bunch or if you don't get people that resonate well within the focus groups, what's the point of going through the exercise?' (BE08)

'... it's all about normalising it and getting... respectable and influential people speaking up about it is always ... weighs well with certain populations. Particularly young males and Aboriginal and Torres Strait Islanders and people like that, if it's someone that they identify [with]... I think that's really meaningful impact on them. You know AFL stars or music stars or whatever... I've seen quite a bit of that, and I think that's really impactful.' (PP27)

Frequently, participants recognised that while it was no longer uncommon for celebrities to discuss their experiences of anxiety and depression, disclosure of other diagnoses was rare and could also lead to stigmatising media commentary. Participants also frequently recognised that disclosure of mental health difficulties was sometimes undertaken in the context of trying to 'explain' poor or even criminal behaviour and could in fact increase stigma.

'Although a celebrity thing can help as it sort of has with Osher [Gunsberg – a TV presenter] in terms of talking about psychosis, because we don't get many people speaking on that' (PP14)

'And that's where having people coming out who are known to others... celebrities etc... there's been some great work done in people coming out with depression and anxiety now, but there's not been a huge queue of people coming out to say I've had the diagnosis of schizophrenia. Bipolar is a little bit more trendy and there's some groovy people coming out as bipolar, because that's associated with creativity and being artistic, and so that seems to kind of be a little bit more acceptable for somebody at their victory speech at the Academy Awards to talk about that, or their brother's or sister's or father's bipolar. But schizophrenia is particularly probably the hardest one.' (EMP05)

Digital and social media

Participants often spoke of the importance of harnessing digital platforms and social media to deliver information and messaging to a broad audience and particularly to a younger audience in a cost-efficient way. It was also common for participants to talk about the need to combine digital media with mass media and interventions that involve contact between people with lived experience of mental illness and other members of the community without lived experience. Video was also mentioned as an important component of digital interventions.

'I mean I see that question as being around marketing, and digital marketing which is... part of it could be peer-to-peer connections and community connections, but part of it is just advertising and getting those stories out there on different tools, on different media, so social media, or elsewhere. But you know being able to distil a story into a very short clip that can go out to young people at school or to people in whatever way they're consuming their media... that's probably one of the key ways that we should be getting out there. Because I think creating... a personal connection is always going to be most powerful if you actually sit down and have dinner with someone, but that's also the hardest thing to actually do.' (PP28)

Mass media

There was some support from participants for the use of a mass media campaign using 'traditional' media platforms such as television, radio and print media, in order to reach those who might not actively engage in seeking information about mental illness.

'I would think that having a mass media campaign would in fact be really useful. I think there was a campaign many years ago, that sort of compared mental illness with having asthma or something like that, but we haven't really seen those sorts of mass media campaigns for a long time and then I think tailored versions of those, that targeted into multicultural communities would be quite helpful. Because I think that if you're, people aren't going to seek information through a website, like you really need to bring the information to people to make them engaged and then maybe they'll go to a website'. (PP39)

Other participants cautioned against seeing mass media campaigns as the only solution.

'I think the problem that certainly has been identified in the UK is that... having national media campaigns... works to some extent but it doesn't budge perceptions of very severe mental illness and... it can actually contribute to solidifying sections which is... obviously the unintended consequence... It might be better to do like grassroots educational campaigns... because there is so much fear of mental illness... and particularly in relation to people who might be perceived as acting irrationally or have behaviour disturbance when they're distressed, that it's very hard to budge that prejudgement of who that person is, so I'm not sure that a national campaign like that can really budge what is just part of human nature... I'd be wary of putting all your eggs in one basket and think that that's going to do the work.' (BE28)

A positive example: You Can't Ask That

Participants frequently cited The ABC television show 'You Can't Ask That' (<https://iview.abc.net.au/show/you-can-t-ask-that/series/2/video/LE1617H004S00>) as a good example of how stigma and discrimination toward marginalised groups can be tackled. The show allows viewers to send in 'awkward or uncomfortable questions' that are then answered by the people appearing in that episode representing a particular marginalised group (recent examples include people who use the drug Ice, children with same sex parents, and people who have survived a suicide attempt). There have been episodes of the show that included people with mental illness. Participants talked about the effectiveness of community members being able to ask any question without judgement or reprimand, and the humorous and positive approach taken in this show. They saw that the openness of participants in the show promoted greater understanding of, and therefore reduced stigma toward, people from these marginalised groups. Several participants emphasised the need for this non-judgemental approach to educating the community regarding mental illness.

Grassroots development: Engaging the community and adapting to their needs

Participants across groups talked about the importance of mobilising and engaging a range of community groups to roll out community education around mental illness, noting that provision of resources and approaches that could be taken up by local groups would be essential. Adapting these strategies for engaging people living in rural and remote communities was seen as particularly important, although it was acknowledged that this is not straightforward due to variations across communities. Consideration of residents' interest in community engagement initiatives was seen as useful in developing activities.

More generally, participants argued that to reduce stigma, people need to see information and positive portrayals of people with mental illness repeatedly within the course of their daily lives, rather than actively having to seek out such information, which they are not likely to be motivated to do. Participants believed this approach to be an essential adjunct to, or even a better strategy than a national mass media campaign:

'I think we need to get better as a sector in not assuming, not trying to shift people too far from their current behaviours... with regards to the [stigma reduction] project... we had this new website over here, and if you go over there you're going to get all this information. Whereas that's completely different to how people are working and living. So, trying to get people to go over there to something new is hard. If you can embed it into what their daily thing is then it's going to be easier... you know rather than creating a separate event for example, where you need people to go to that event, you get the speak into the events that are already happening.' (PP26)

'I think it's a multi-faceted approach... targeted at different workplaces and different contexts but also in the broader community and you've got to have similar messaging at the broader level and stuff that you're doing locally in the community or in different contexts all really aligning to the same message that you're trying to put out there publicly on billboards, on TV ads, what sportsmen say etc. You've got to drive that at the community level as well, not just because some sportsman said this is what you should do and everybody will listen. (BE23)

'That's definitely where we see what works really well with teachers [and] workplaces, give them assets and they will work it in to however best fits for them. And they'll tell you if they need something else... Always make it very adaptable and flexible, for people's own content'. (PP08)

(2) Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities

Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities were often identified as an important target for stigma and discrimination reduction activities for two primary reasons. There was an understanding that some cultural groups have different cultural understandings of mental illness, higher levels of stigmatising attitudes and lower mental health literacy, which may lead to discrimination toward people with mental illness from within their own families and communities:

'And we see extraordinary stigmatised attitudes amongst our families who arrive – they hold very fixed views around the origins of their mental health...' (HP41, Nurse working in culturally and linguistically diverse communities)

There was also a recognition that community education or campaigns aimed at the general Australian community are unlikely to reach some Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities because of differing ways of accessing information, different cultural understandings of mental illness, and language and other cultural differences. Therefore, community leaders and other key community members in individual Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities need to have need to have a central role in activities to ensure they are culturally appropriate and designed with particular community needs in mind:

'I think that you are going to have to investigate around the Aboriginal community and culture; we're significantly diverse.... within our Aboriginal communities we really just focus on articulating social and emotional wellbeing you know the whole concepts around mental health is viewed in a completely different way and therefore that kind of messaging really wouldn't be appropriate and so you look at that cultural appropriateness and also the way that you know CALD communities respond to diagnosis as well so I think you need to not forget that aspect of it as well.' (AD03)

(3) Health services

Addressing structural stigma

Many participants, including mental health peer support workers and health and mental health professionals, stated that in order to achieve a reduction in stigma and discrimination toward people with mental illness, there needs to be a fundamental shift in the overarching philosophy that governs how mental health policy is written and enacted, and therefore how services are structured and delivered. Participants used a range of different terms to describe the approach that is needed, including 'recovery-oriented practice', 'person-centred care', 'consideration of psychosocial environments', encouraging 'flourishing not languishing', 'renegotiating identity' and 'recovering citizenship'. Terminology aside, the essence of this change is that health and mental health systems must move away from a focus on treatment of mental illness symptoms to promotion of the person's complete wellbeing. This necessarily includes recognition of each person with lived experience as having their own strengths, difficulties, needs, preferences and aspirations. This shift requires an optimistic outlook, particularly from mental health professionals, that with proactive and tailored support, the person with lived experience can flourish to not only 'manage' their symptoms, but to succeed in their life, as all people have the fundamental right to do. Put another way, people with mental illness should not be offered services and supports based purely on the commonality of their illness, but rather based on their diverse needs, interests and aspirations:

'for a long time we've got it wrong... it's professional or institutional stigma that starts that sense of 'otherness' and how we've shaped services to reinforce a sense of 'you're different'. And then we internalise it ourselves, and our family and friends, we start to relate to ourselves and get a sense of our own identity as being different... The system... teaches us how to do that. And then we go out into the community and... expect to be treated differently... But the actual start of it is actually way back.... this is why... community anti-discrimination programs... have failed, because we're tackling the wrong end... right from being given a diagnosis, right from being given different programs to participate in, we're told that we're different and then we internalise our difference and we become our difference, and then we start to forget I'm Helen, I'm Bill... my... identity... starts to shape into... I'm an illness that is different and... I can't engage and communicate and participate in the same things that other people do... when you relate to me through my difference, I become my difference. And... when my difference is not valued, such as the mental illness... I become invalid. So, when we try to think about how do we change those systems that are built on difference to address... how it thinks about stigma, I don't think it can. Because it's actually framed around the illness.' (BE05)

'I think health practice in Australia in general and most of the western world... is so deficit focussed, and that real hard deficit focus has driven fear... and people not realising that that fear is a systematic product, people are influenced by what they learn or what they hear and then they react based on that and... most of the health information that comes out is cold, hard, deficit discourse... and the majority of health professions... learn that, so I am not surprised by some of the attitudes that come... when you're only ever taught deficit discourse it's hard to escape forming stereotypical views.' (HP13, Psychologist)

In light of this, numerous participants spoke of the need to target policymakers and senior management in health and mental health services, in order to bring about policy and legislation changes to tackle systemic or structural stigma and discrimination. Generally, this discussion focused on having greater involvement of people with lived experience

in informing and making high-level policy decisions, then making sure these policies are translated into service changes that are acceptable to people with lived experience.

‘so I’m just... looking at... how do we train up champions [with lived experience] to try and do some systems change influence... and then deploy them so that they sit around all the right tables, so that they’re able to... influence from their personal perspective how services are built, how they are maintained... what are the barriers that means people aren’t accessing them... how can we do that sort of change at that kind of system level.’ (PP42)

Other participants recommended that policymakers seek to better understand their own stigmatising attitudes and the effects of these on policies or management decisions.

‘I’d say that generally speaking if you wanted to change the perception, you’re wanting to change the service delivery model, which is the public service, to have a greater understanding federally and state about what stigma is and how it can actually impact on your decision making, prioritisation and classifications of people’s needs – I think that that would be a fairly broad area to start with.’ (PP24)

Lack of services, particularly in rural and remote areas were also seen as contributing to discrimination due to inadequate treatment, escalation of symptoms, and people with mental illness being seen as a ‘burden’.

Health and mental health professionals

Health and mental health professionals were frequently identified as a key target group in a national strategy. Most commonly, these included general practitioners; emergency department staff; and mental health professionals, including psychiatrists and those working in acute care settings. Stigma and discrimination in health professionals was also readily recognised by health professional participants themselves. Mental health peer worker participants often spoke of their own direct experiences of stigma and discrimination from health professionals when accessing mental health services, highlighting their feelings of powerlessness and the health professionals’ lack of positive expectations about their recovery and general potential for a ‘successful’ life:

‘...my first psychiatrist that I saw that diagnosed me... said... you’ve been diagnosed with a personality disorder with... post-traumatic stress disorder and some other thing, you’re never going to be able to live a normal life, you’re not going to be able to study, you’re not going to be able to work so just be comfortable in receiving your disability support pension and live off that for the rest of your life. So pretty much he just said to me you’ve... got no future so don’t bother. So that really deflated me... for a couple of years... [Then] I was like “no, this doctor is not right”... and I’ve proved him wrong.’ (PW08)

Health professionals working in emergency departments (EDs) were identified as an important target. Diagnostic overshadowing (situations in which physical health complaints are neglected once a mental illness diagnosis is identified) was cited as particularly problematic in the ED:

‘I’ve heard lots of stories of clients who turn up to ED for physical health and their physical health is disregarded because everyone assumes they’ve got a psych history so that must be what they’re there for.’ (HP04, Mental health nurse)

Approaches to people with borderline personality disorder were also noted as especially problematic in the ED (see below: Health professionals and borderline personality disorder).

Leadership from psychiatrists

Many participants highlighted negative experiences that they ascribed to stigmatising attitudes in psychiatrists. Participants also frequently recognised that psychiatrists are at the top of the hierarchy within the mental health system, and therefore have power to promote positive cultural changes among other mental health and health professionals:

‘So psychiatry is still the top of the hierarchy... and so to some degree you can try and change public perceptions and help people become empowered and help create the conditions in which they can recover but if the profession at the top of the pile is still speaking... as though these diagnoses are gospel and as though the medications can fix everything... then that’s the unspoken message that continues to get perpetuated... so I think there is this politics and culture that is very difficult to address.’ (HP26, GP)

In proposing solutions to reducing discrimination from professionals, participants who were not health professionals themselves most frequently spoke of two connected ideas: changing power dynamics between professionals and 'patients', and treating people with mental illness as people, rather than as their diagnosis. These themes echo those described in the section on addressing structural stigma in health services.

'...when I think of health professionals... I just also think it's reflective of the power structures that [have] been allowed to build up in the clinical treatments... they'll have the staff at the hospital or the case managers in the outpatient ward and then they've got their junior psychiatrist and then senior psychiatrist, and it's like if the senior psychiatrist says it, it just rolls down. And there's this really locked in positions of power. And right at the bottom of that power chain is the patient... they've got this really rigid power structure and then on one hand they're saying we want patients to be more involved in their decision making, but on the other hand they're like locked at the bottom of the power structure. And I think that stigma is part of that, and... the medical model is probably really more the source of that... I have spent a lot of time working with patients or clients... [and] they tell me... they're talked down to, they feel like they're treated as idiots. And that might be through the procedural response set up in the workplace, but it's often due to the stigma or the attitudes of the staff.' (PP15)

'... they were giving a presentation and... [a] consumer had said to her, I wish when I see the health professionals, so whether it's a psychiatrist, a psych registrar, nurses, whoever – I wish they would not ask me about my symptoms but ask me about my life... my capabilities, my loves, my interests, my family or the lack thereof, rather than seeing me as schizophrenia, bipolar, borderline personality disorder etc. I think that's the key to everything... if we're targeting health professionals, they're the ones that say... "how are your delusions, are you hearing anything, what are the voices doing"... Rather than saying... "what have you been doing this week",... "[are there] times that have been really good for you"... people would feel as though they are a person rather than a diagnosis.' (PP06)

Employment of mental health peer support workers in health system settings

Participants often saw mental health peer support workers as having a key role in a stigma and discrimination reduction strategy. Peer work was seen as essential to challenging power imbalances; reducing self-stigma and improving attitudes in health professionals by providing examples of people with mental illness in recovery and having valuable roles in the workplace. Others noted that mental health peer support workers often have effective coping and management strategies that they can share with others:

'And I think having them [mental health peer support workers] there [in the mental health service] starts to equalise the power imbalance.' (PP15)

'... it's about them starting to employ peer workers being educated in the role of peer work.... peer work is... a real key to changing it, I often use the idea that... we've got systems that have been broken and constantly we're being told that the mental health system's broken... so why do we reinvest in a broken system... I use the analogy of peer work and climate change... the system's broken and it's overloading with carbon dioxide and yet we keep investing in fossil fuel workforces. Whereas peer work is like a renewable resource ... and [in] every place that I've condemned there are good people.' (BE03)

'I think that's one of the things... that peer workers can offer. If you've got the right person with the right skills, they can offer to others to help destigmatise that human experience of going through life.' (PW17)

'... we put a lot of focus on developing our peer workforce over the years because we can see what a peer worker brings to the team... in working with an individual its very unique compared to well trained staff who don't have a lived experience. So a level of connection they can build with the person and a level of... confidence... [they] understand that they're working with a person who has been on a similar journey or had a similar experience... as a community [we should] look at the strengths that they bring to the workforce and... if anyone is working with a sector they could benefit from having someone with a lived experience work within their workplace, it does make a big difference.' (EMP19)

Provision of structure, training and support for mental health peer support workers

Many mental health peer support workers and others with roles in mental illness advocacy noted the importance of building capacity within the peer workforce through appropriate structures (including access to supervision by experienced mental health peer support workers), education and training. The implementation of the Certificate IV in

Mental Health Peer Work was generally viewed as a very positive step in building this capacity for the lived experience workforce, though participants also spoke of the need for additional training and ongoing support:

'... a lot of my time at the moment is in training and providing co-reflection for peer workers, trying to get the peer workforce properly educated because it's new and emerging. I've been delivering the Cert IV in Mental Health Peer Work but we need more... professional development for our peer workforce and we need to build capacity... Peer workers across Australia have a range of different supports. Sadly some of them don't get any, some of them will have clinical, some will have line management but what I advocate for is lived experience supervision... I'm an external supervisor that provides that co-reflective space for peer workers which is... very new but proving to be really helpful because it's a certain skillset in being a peer worker and how you work... and it's very hard in a clinical model... those that are working in health in a health department... sometimes... don't stay true to the values of peer work and are almost corrupted into becoming little mini clinicians and... they don't have enough support from lived experience practitioners.' (AD02)

'... professionalization of the peer workforce would be amazing, because the moment we do that we give a precedence to it that it has its own skillset... And it has its own theoretical underpinnings... it gives it credibility and... a voice... the national frameworks around the peer workforce will help give it some credibility and some understanding as well, to reduce stigma in that sense... And I think that will have a flow-on effect with the whole community – if we get it right' (PW22)

Addressing health professional knowledge and attitudes toward mental health peer support workers

Most mental health peer support workers reported direct experiences of discrimination from other health professionals in their workplace, some of which were ascribed to a lack of understanding of their roles:

'...people discriminate, a lot of the time just based on lack of education or knowledge about what the peer role is, so we've had peer workers who [have] explained what their role is... "I provide peer support to people on the wards" and they've had people say oh congratulations that you're being paid to do that... things that are discriminatory but really just around people having a lack of education and not realising that it's an actual workforce you know and a profession...' (PW27)

Many mental health peer support workers also reported feeling that they were treated differently to other staff members, with exclusion from staff activities most commonly mentioned. This exclusion included not receiving referrals from other staff members and being excluded from decision-making and meetings:

'I have heard definitely stories from other peer workers who, they walk into the room and everyone stops talking, or they're just not included in the day-to-day or decisions that are made.' (PW12)

'I think that... peer workers can be discriminated against on the team... psychiatrists will tell people not to refer to peer workers, because they make things more difficult, because they basically advocate for family and carers or consumers. So any sort of pushback from family and carers or consumers is brought to the attention of the multidisciplinary team, whereas when previously peer positions didn't exist there was less advocacy and less ways for consumers and family and carers to express their opinions.' (PW27)

It was also common for mental health peer support workers to report indirect experiences of discrimination, particularly those relating to incorrect presumptions that they would take more sick leave; and health professionals using stigmatising or derogatory language, or expressing disparaging views, about the people with mental illness in their services in the presence of the peer worker. While not directly aimed at them, mental health peer support workers talked about the negative effects of this stigma and discrimination on them personally:

'...it doesn't have to come from a[n] intentional place, but... in peer supervision... we spoke about how frustrating and tiring and emotionally exhausting it [is]... when you hear language that is really inappropriate, or... someone talking about a client... that they're working with in a way that's disrespectful... in your career to protect yourself... you kind of pick your battles and you don't speak up every time, because if you do you're going to be seen as a problem, or you're going to be just completely burnt out... it's a big responsibility to be a peer in organisations and places, workplaces that aren't used to it... if you hear stigmatising language or you hear things that really aren't in line with what you believe and what your values are, then it can feel like a bit of a personal attack...' (PW25)

Highlighting positive experiences of peer work

Despite mental health peer support workers frequently discussing negative experiences with health professionals in their workplace, a substantial number also highlighted positive experiences relating to being respected and valued as having important expertise different to that of other health professionals. These experiences illustrate that the integration of mental health peer support workers into the mental health workforce can benefit not only those using services, but also health professionals without lived experience:

'...we don't come across... the sort of negative attitude towards peer workers... not having a Bachelor degree or not as educated with a piece of paper *per se* but we are really valued as an individual that's got life experiences in the sector that we're working in especially having still hearing voices myself day to day but being able to work and get paid for what I love doing...'. (PW13)

Need for improved education and training about mental illness

Health professional participants, and others, noted the need to improve training in the area of mental illness across all health professions, either in student training or as part of continuing professional development. They also highlighted the importance of the inclusion of people with lived experience in such education programs. Participants noted that poor training was particularly problematic as people with mental illness frequently have complex and enduring health difficulties, and therefore, routinely present as patients to non-mental health professionals. Participants hypothesised that inadequate knowledge, understanding and contact with people with mental illness during health professional training raised fears, leading to stigma and discrimination:

'...health professionals are a pretty broad church themselves and somebody who works in an ENT [Ear, nose and throat] outpatients wouldn't necessarily have the same level of exposure or have the same kind of training [as]... somebody who has chosen to work in a mental health service... [but] people with mental illness just like people who are pregnant turn up in all sorts of different levels of the health service... you're always going to also come across people... who have mental illness..... health professionals feel a bit unsure of themselves, or like they haven't had enough training, particularly in some of the less common mental health conditions... and without that training then people's imaginations... run riot, or they're more likely to be influenced by... public perceptions, or the media, rather than actually knowing anything...'. (HP46, Nurse)

Echoing the key theme in this report, of making lived experience central to anti-stigma interventions, many health professional participants emphasised the importance of having direct contact with people with lived experience as part of health professional education, in order to shape better attitudes of health professionals towards people with mental illness:

'In terms of the patient voice and hearing patient stories and reflecting back to medical staff their own experience of being in the service, and I'm sure most doctors don't think they're being stigmatising in their attitudes and probably don't get to hear most of the time about when they are and feeding back those stories... is very powerful in education and changing attitudes and similar to racism I suspect that a lot of racism is not recognised... So storytelling I think can be a very powerful tool in changing behaviour.' (HP54, Psychiatrist)

'...in my experience the most powerful thing is the opportunity to meet people who have had it and humanise that experience.' (HPS18)

Targeting health professional students

The importance of targeting health professional students as a means of making long-term changes in the culture of health services was recognised among health professionals and other participant groups. However, it was also noted that students can struggle to maintain positive attitudes once they are employed in workplaces where negative attitudes toward people with mental illness are pervasive. Some participants pointed to the need for students to have contact not only with people in acute episodes of mental ill health, as is common, but also with people in recovery, as a way of challenging low expectations of people experiencing mental illness.

'the bit that the students enjoy most with us is going out with the crisis team and seeing people right at that very, very pointy end, and learning how staff deal with people very sympathetically and also having to sort of manage potentially scheduling and things like that... and what our students' value again and again is seeing patients, it's the one thing they want to do all the time... So if you can create ways of spending time with well patients, or people who have recovered, or what recovery looks like, then you stand a chance of

challenging things... putting those things together really challenges them. And we know that creating cognitive dissonance challenges people' (HP01, Psychiatrist)

An example of education incorporating lived experience as central: Recovery Camp

Recovery Camp, where health students and people with lived experience of mental illness spend up to a week together at an outdoor recreation camp, was highlighted by a number of health professionals as a good example of a unique and positive training model for reducing stigma and discrimination among health professionals. However, it was also recognised that while the model is good, implementation of this model on a large scale would not be feasible for standard education of health students. Some participants stated that while maintaining the underlying philosophy, there may be ways to adapt the model to make it more accessible in health professionals' training.

'I think a recovery camp, whether it's five days or even if it's one day, you just have people come into uni and just be their normal self is really valuable. But definitely over a period of time I think you have time to bond with people and make connections and really have the opportunity to understand them and... have the opportunity to get their perspective on health care or how society feels about mental health, how they feel about mental health... the impact of stigma on them... Which then could be reflected upon by the students and then utilised in practice. So I just thought it was a really great initiative. And I think it would just be really really really effective for people to have the opportunity – we get case studies, but we don't actually get to meet real people... especially it says everyone at camp is of equal status.' (HPS17, Final year occupational therapy student)

Reflective practice

Some health professional and students also discussed the importance of reflective practice in addressing stigma, as this offers the opportunity for students and health professionals to reflect on their own biases and attitudes.

'if we did something that was a bit more in-depth and got us to self-reflect a little bit more as well... I can think of one class where we... reflect[ed] on our own gender... our sexuality, our different ways that we have come into the world... and what that could mean for our understandings but it would be good if that was like extended a little bit more like maybe a few more classes or a bit more of a program on that or something...'
(HPS18, final year occupational therapy student)

Health professionals and borderline personality disorder

People with borderline personality disorder were commonly singled out as being at particular risk of experiencing stigma and discrimination from health professionals. This was noted by several participant groups, including health professionals themselves. Participants noted that health and mental health professionals are often reluctant to work with people with borderline personality disorder because they perceive them as being difficult to work with and 'untreatable'. Repeat presentations to EDs due to self-harm and suicide risk were also nominated as common drivers of negative attitudes among health professionals, leading to a culture of blaming people with borderline personality disorder for their own difficulties. Some participants ascribed this to a lack of adequate training for health professionals.

'When people self-harm and present to emergency departments you know that they're often treated extremely badly, there's very little compassion or even at times... there's hostility... they might be kept waiting... for very long periods of time and not triaged appropriately... Emergency services... struggle a lot because they... have this idea that the person can make a choice not to do what they're doing and... there are other people who should have higher priority... We're not asking them to do therapy with them ... just to be reasonable really and treat them... with some kindness but... I don't think that emergency services really understand this group particularly well and even when they do... when they come into the emergency department they can be angry or hostile and you know that's a lot to bear.'
(HP05, Mental Health Nurse)

Some participants noted that this poor treatment increased self-stigma in people with borderline personality disorder and reduced the likelihood of receiving appropriate care and support, which could result in worsening ill health, and worsening discrimination. Diagnostic overshadowing was reported as particularly problematic for people with borderline personality disorder who present to the ED.

'And my hunch is that if people with BPD get the support that they actually require early in the onset of mental illness, also early within any periods of increasing distress, that the actual levels of distress and the challenges that that poses to other people's beliefs, will actually decrease substantially. I think a lot of the behaviours that we see are because people aren't getting the support that they need when they need it... And feelings of shame and worthlessness... A number of people with BPD find it really difficult to ask for help. And without that sort of understanding, you'll ask the person if they need help and they might cut you off – and that tends to trigger you know a response in yourself. So having an understanding that they just... might feel so shamed about themselves for feeling this way when everything's okay, that they just can't ask for help.' (PP02)

While solutions for reducing health professionals' stigma and discrimination toward people with borderline personality disorder align with broader recommendations, participants did note the need for specific education and skills training to better enable health and mental health professionals to work with people with borderline personality disorder, which would improve support and treatment outcomes, which would then reduce treatment pessimism and negative attitudes. Mental health professionals with expertise in the treatment of people with borderline personality disorder highlighted the need for other health and mental health professionals to understand that, in recent years, significant progress has been made in treatment for people with borderline personality disorder, and that training needs to include these treatment approaches:

'I would say the reason that people with personality disorders get a bad rap is because of whatever those acting out tendencies are that are hard to manage... [but] they're hard to manage... because the clinician doesn't have the training or the expertise to deal with it... often these disorders get stigmatised because people in positions like mine feel incompetent to treat it so because of that it goes into the too hard basket leave it alone. They can be treated...' (HP34, Psychologist)

A role for health professionals in reducing stigma and discrimination in the general community

Some health professional participants noted that health professionals can also be harnessed to promote positive change in attitudes toward people with mental illness in the general community. In particular, health professionals in senior positions were perceived as having social standing that enabled them to lead by example, by identifying discriminatory behaviour and taking direct action to intervene.

'I think health professionals are in a key spot to provide education, because as soon as anyone finds out I work in mental health, members of the public... always have a lot of questions... you can help dispel the myths... a nurse [is] in a prime spot to promote the recovery model and person-centred care. And people follow nurses' example, so if nurses are talking disparagingly about people with mental health, the community's going to follow suit. If nurses are speaking positively about them, that's going to help reduce the stigma... we can educate on a one-to-one basis on a ward, or we can be educating out in the community... But we need to all be saying the same, sending the same message.' (HP04, Mental health nurse)

(4) Workplaces

Workplaces were one of the most frequently named settings to be targeted in a national strategy based on two main factors: recognition of the importance of participation in work for many people living with a mental illness and the relatively high frequency of experiences of discrimination in the workplace. These include being excluded from entry into the workforce, being prevented from progressing in their roles, suffering negative consequences if mental health difficulties affect the ability to work, and interpersonal difficulties with supervisors or other colleagues.

'...we know that... having steady and stable employment has such a profound effect on people's mental health, giving them that sense of purpose, that routine, stable income, and it's really a key indicator in longer term recovery.' (EMP02)

Participants frequently spoke of the lack of knowledge and understanding of mental illness in the workplace. Commonly noted stigmatising attitudes related to fears about dangerousness or unpredictability (as noted in other settings); fear of not knowing how to talk to the person about their difficulties or how to assist them to continue their work while managing their mental illness; and fear that employing someone living with a mental illness will create extra work.

'From the stuff we did around the country and the broad people that we've engaged with in different senses, for us it's still fear. They are quite fearful of the person going postal in their workplace; they're fearful of having someone that they don't fully understand and can't have a control frame around. And we think it's really a base as fear and so... we need actually strategies to overcome that fear...' (EMP10)

'I just think also people are really busy, they're under a lot of pressure, but there's money to have. You have a lot more people doing a lot more roles, and they just don't want hassles and they just go, "There's going to be this extra hassle with this person if I hire them," and it's stupid because you could have just as much hassle with someone else needing other things. But it's just the way that they think around mental health.' (EMP07)

Unwillingness to disclose a mental illness in the workplace was also noted as a barrier to individuals receiving appropriate adjustments or supports, where needed, to facilitate continued participation in work:

'And I think this is all part of it, people don't have a language that they can use in workplaces so that makes it really hard to even then ask questions about accommodations and things like that because they can't even name what they're starting with. So, I think that's a real challenge.' (EMPO2)

Rural-based participants believed that workplaces, including mines, abattoirs and agricultural industries, were important sites for delivering mental health education and outreach programs. Strategies ranged from 'light touch' programs such as having posters in tearooms to an initiative that involved visiting remote mines on a particular day over a series of weeks:

'I spent all day out there with the boys... I do a presentation in the morning to about 30 staff because they had all these different shifts coming in and then they would actually take me out on site and drop me up on one of the sites where the boys went for lunch and then they would come and sit with me [during their lunch break.]' (BE29)

A mental health outreach worker explained that they often 'piggybacked' on other kinds of information-sharing get-togethers:

'Say a local land service might have a vet out having a morning tea for farmers out in the little community and you get quite a good roll up, maybe 30 to 40 farmers. We might get invited along to have a little bit of a chat about mental health stuff, so we've got a captive audience... some of them are very, very interested in what you're saying and they'll come up and have a chat afterwards' (BE32).

'Organisations such as the Country Women's Association can be helpful for engaging women on mental health issues (BE11)'.

Ongoing commitment and investment at all levels of the organisation

Participants proposed several solutions to reducing stigma in the workplace. Broadly, these centred around changing workplace culture related to mental illness and education strategies to increase knowledge and understanding of mental illness. As one participant put it:

'I'd say in the last ten years... the responsibilities that now sit on employers and boards of directors has really come to the forefront where they're knowing that [they've] got to be doing more.' (BE29)

A number of participants, particularly those involved in supporting people with mental illness in the workplace, emphasised the importance of embedding a commitment to workplace mental health in the culture of the organisation. Discussion often included references to a 'top-down' commitment to mental health, in which the attitudes of high-level management pervade the broader workplace culture:

'...how do we actually make it part of the DNA and I personally am not a fan of companies that want to show me their flex policy, their diversity policy... that sit on the intranet. I'd rather... it was actually this is the way we do business and it comes from an ethos or a philosophy for the organisation than a compliance, we've got to have this policy, so we've got it... So we need to really integrate it into the DNA, the everyday operations of the organisation and I think if we can learn anything, it is from some of these gender things, that we actually need the role models in roles and not just gender diversity but even ethnicity and other things.' (EMP10)

'... training alone is only as good as the culture so... it constantly needs to be reinforced and talked about... a one off [is not] enough... it needs to be embedded throughout the culture whether that's in the communications that go out internally, ongoing professional development... it's just about providing a safe space where people feel like they can talk about it and that comes from the culture and the exec team and throughout... our organisations that have partnered with us are... investing not only their money but their team members' time and we have mentors from all levels so we have exec who are sitting in the training along with maybe someone who has only been there for a year and is at sort of entry level and I feel like that says so much about the fact that they believe in [it]. (EMP03)

Workplace education

Workplace education was viewed as a means of improving knowledge about mental health and attitudes towards people with mental illness, thereby bringing about cultural change. Participants suggested that such education programs should cover information about mental illness and how to support people with lived experience; education of managers about legal responsibilities, including making reasonable adjustments for a person with a psychosocial disability; and taking action to raise awareness of the advantages of including people with lived experience in the workplace, including increasing diversity and compassion for those with different life experiences.

One participant mentioned a workplace training program in which staff were encouraged to openly ask questions, with nothing being 'off-limits' (as previously mentioned in the section

A positive example: You Can't Ask That

Participants frequently cited The ABC television show 'You Can't Ask That' (<https://iview.abc.net.au/show/you-can-t-ask-that/series/2/video/LE1617H004S00>) as a good example of how stigma and discrimination toward marginalised groups can be tackled. The show allows viewers to send in 'awkward or uncomfortable questions' that are then answered by the people appearing in that episode representing a particular marginalised group (recent examples include people who use the drug Ice, children with same sex parents, and people who have survived a suicide attempt). There have been episodes of the show that included people with mental illness. Participants talked about the effectiveness of community members being able to ask any question without judgement or reprimand, and the humorous and positive approach taken in this show. They saw that the openness of participants in the show promoted greater understanding of, and therefore reduced stigma toward, people from these marginalised groups. Several participants emphasised the need for this non-judgemental approach to educating the community regarding mental illness.

), and also pointed to the positive effects that workplace education, particularly that going beyond pure information provision, can have on the broader community:

'...there's so much more that EAPs [Employee Assistance Programs] can do... I think that having someone who's really approachable, like as a psychologist come into your team and say to you let's have a bit of a "You Can't Ask That" [referring to the ABC TV show] session, "Who knows what schizophrenia is? "...How might they behave? What do you think they might say? What do you think you could do in that situation? And I think that you know what I always find when we have workplace events and sessions... invariably you have a queue of people at the end who want to tell you about their friend... workplaces are such a connector for community, regardless of what job we're in. It's always that ripple effect, which I think is important.' (PP08)

'So we developed a workplace program... And what that looks at is again the conversation, it's not looking at how do you recognise symptoms, it's not looking at wellbeing tools... It's about how do we understand the topic of mental health... and what we think and feel about it... looking at stigma, where that came from specifically, why it's in society, how it's around and how it shows up, how it feels and then what we can do and what the barriers are... particularly in the workplace. And what we can do, what actions we can take to reduce stigma ourselves and as a community and as a workplace.' (PP36)

Some participants pointed to the value of programs such as Mental Health First Aid training, that improve the ability to identify when someone might be having mental health difficulties and to offer appropriate support. Participants viewed this participation as a way to reduce stigma from fear of 'doing the wrong thing' when talking to someone with mental health difficulties and therefore to reduce avoidance and promote engagement:

'...the feedback from our mentors after doing the mental health first aid is... they're not so afraid anymore of... talking about [mental illness]... they feel more confident in approaching it and talking about it with the right terminology. I think a lot of them felt unsure and they didn't want to offend so they're not sure how to reference suicide or you know other mental health conditions as well... the feedback that we get from our mentors is that this should be mandatory in the workplace and in schools in the community but in terms of the workforce I hear shocking things from some young people in terms of what some employers have said to them and I think something like this can just help shed some light on it and also educate people in this space...' (EMPO3)

'So it's really about building employers' capacity with the appropriate information, with education, and build that confidence in them to approach in the right way, to understand first of all... unless you are a psychiatrist or psychologist... all other professionals really need to be aware of and have basic information about those conditions that you just listed, you know the most common ones, but at the same time again you know by having effective communication with those who experience a mental health condition...' (EMP11)

Some participants noted the need for changes to legislation that they viewed as inherently discriminatory, including insurance policies.

'In terms of increasing participation in the workforce we do have issues of structural stigma that we need to really be mindful of and I know that the insurance sector is working on this... People in some sectors, [like] professional services, will not get a mental health plan because that's notifiable on their insurance... to me that's sort of a structural discrimination point that for a lot of issues, the insurance sector has kind of been too global and too risk averse... we've done a lot of work with the workers comp[ensation] sector to try and get them to only request specific information from doctors when they're doing their returns not the whole file on someone and working with the College of GP's and the College of Psychiatrists to try and come up with some new protocols that will stop this... Because they're actually picking on things that may not be relevant and appropriate and that then just becomes a legal battle not a helpful return to work kind of process.' (EMP10)

Showcasing stories of success

Numerous participants noted that for workplaces to be more open to employing people with mental illness, they need to see examples of people with mental illness as successful in the workplace. However, they also noted the understandable reluctance of people with mental illness who are successful in their workplace to disclose their mental illness, potentially putting themselves at risk of discrimination. Interventions (face to face or online) that involve interactions with people with lived experience from other workplaces, who could speak of their successes, were proposed as an alternative strategy to personal disclosure from individuals within a workplace.

(5) Educational institutions

Schools, TAFE and universities were often cited as key settings to target. We interviewed a number of participants working with people with mental health difficulties in education settings, and several other participant groups (e.g., program providers, those working in employment for people with mental illness) also stated the importance of targeting educational institutions. Activities recommended for educational institutions commonly centred around using schools as a place to deliver early education about mental illness in order to reduce stigma. Other participants mentioned the need to improve identification and support for students with mental health difficulties as well as supporting students with mental health difficulties at transition points, such as the move from high school to TAFE or university and from university or TAFE to the workforce.

Education about mental illness in schools

Numerous participants stated that there should be greater education about mental health and mental illness as standard within the school system, starting as young as possible. This recommendation is grounded in the idea that reducing stigma and discrimination toward people with mental illness requires generational change and that normalising discussion and consideration of mental health at a young age prevents development of stigmatising attitudes later in life:

'I really was serious when I said that it should start in schools as well... what better time to mould people's thinking than when they're young and I would see that as people with lived experience... attending schools... talking about their experience, humanising them and giving a positive portrayal of themselves at an early time.' (BE19)

'...the education should happen the earlier the better.' (SSW28)

Early intervention and support for students with mental health difficulties

Participants noted the need for students with mental health difficulties to be supported in their educational institutions in the early stages:

'We want to put the support networks in place first and make sure students know that they're well supported, so then it doesn't get to kind of worst case scenario where they're not attending and we've lost... that connection with the students, and it's a lot harder to do it that way. So from the get go we have lots of different programs that we run within the school so all kids... know mental health is relative to everybody...

we make sure that all kids feel very well supported by the school and have strategies in place, and they know what to do if they're feeling overwhelmed at school, they know who they can come to and get that extra support...' (ED04)

In order for students to access greater support when experiencing mental health difficulties, and therefore feel less discriminated against, participants pointed to the need for professional development and support for teachers, parents and supporters, and others linked into the school system to better identify mental health difficulties and encourage others to access appropriate support. Participants working in education settings, in particular, highlighted the need for educators to understand the supports available to them and to the student experiencing difficulties, and to be aware that they need not manage those difficulties alone.

'... sometimes you've got those younger graduate teachers that are... very connected with the young people and want to do everything they can, but then the boundaries get crossed and then suddenly they're kind of like outside of teacher brain and... attempting to be youth workers without training kind of brain, and the whole thing falls apart... they don't feel that they can put their hand up and go "help me", and they don't know who to... reach out to.... they want to know who can they safely entrust this person they care about... that's hard when you feel like you're doing it alone'. (ED01)

'... the most common one that I see within TAFE is having an actual disability coach, so whether they're attending classes with them or they are somebody that they can check in with on a regular basis, particularly if it's a mental health consideration... if you're feeling like you're needing some extra support come and see me... and they can take... agreed action if needed. They will often provide... education for the educators as well, so they'll have that conversation with the lecturers or the teachers or the tutors to say this particular person needs you to do this or may need to take these actions and... if you've got questions come and talk to me. So, it's that mediator type role.' (ED18)

A small number of participants pointed to the need for mental health education in primary schools to be improved.

'I feel very strongly that we need to be doing more work in the primary schools... we're quite good at providing professional development in the secondary school system to both students [and] teachers, but we... know that these issues are emerging in primary school for many young people [like] ... externalising behaviours... [if] left may then develop... and teachers really struggle in terms of ... the responses... they give... I think we do need to support teachers and parents in schools more in that area.' (ED11)

Support for students at times of transition: high school and university

Several of the participants were involved in support roles within educational settings, and they emphasised the need for additional support for students with mental health difficulties to transition from high school to university or TAFE or from educational institutions into the workforce:

'I think it's really important that those transition points that the student is well supported, whether it's leaving high school, going to TAFE or going to university, or even going to employment, and that's a really crucial transition point, and we need to learn how to do that well. And your other transition point is... completing TAFE or... your university course and... seeking employment... unless you've got somebody who's good at what they do, and they can support their student well, the student can fall through the cracks. They've gone through the school system, and then they've got to leave that system and step into a totally new environment, and that can be very scary for them. And if they're not well supported they may not take those steps...' (EMP17)

(6) The media

News media, and to a lesser extent, dramatic or fictional media, was frequently highlighted as an important setting to take action to reduce stigma and discrimination toward people living with a mental illness. Stigmatising media reports (particularly 'tabloid' media) were commonly seen as a particularly destructive force in being able to quickly undo positive stigma reduction work done elsewhere in the community. The perpetuation of views of people with mental illness as unpredictable and dangerous was most frequently noted. Media monitoring (e.g., SANE's StigmaWatch), training of journalism students and working with journalists to write more balanced, and less stigmatising, media reports related to mental illness were highlighted as important strategies for reducing the adverse impact of news media. Working with screenwriters and other writers of dramatic fiction to present alternative portrayals of people living with mental illness was also suggested.

'...in a lot of mainstream media you see representations of people with mental health issues particularly psychosis or schizophrenia... and it's always when there's violence ... It is always when there's crime it's like oh you know this person committed this crime but of course they had mental health issues... but... 98% of people who have those problems don't do that... [I] get pretty angry when I continuously see this coming up in news stories... it's a really core issue because people do get their reference points from the media and even if they don't watch it on TV they might see it shared in their social media feeds... So I think that's really problematic and it doesn't really present a realistic view at all of what it's like.' (PP35)

'I think a lot of stigma programs completely miss a trick of a really cost-effective way of securing change... working with journalists and producers and script writers... We ran training events for the media, delivered by other journalists and journalists with lived experience, we absolutely can evidence a very statistically significant improvement... in print reporting across England over 10 years, and broadcast media, documentaries and dramas... you really need face-to-face and online training from one journalist that does the same job saying look this is how I avoid those pitfalls, and this is the language I use... peer-to-peer work with journalists... we know, from some research that still schizophrenia remains the only diagnosis likely to be presented in a stigmatising... way in newspapers.' (PP42)

(7) Social service and welfare professionals

Social service and welfare professionals include those working in services such as homelessness, housing, and disability services; aged care; human services; and Centrelink and the NDIS. Some participants stated the need for education and training aimed at social service and welfare professionals to reduce stigma and improve skills to create more positive interactions between them and people with lived experience. As in other areas, the importance of trauma-informed approaches and the need for positive narratives of hope and recovery were noted.

'... it needs to go beyond mental health clinicians. It really needs to be a grassroots health and welfare training and education approach that includes a bit like... what's happened in the past decades around issues with equal opportunity for women and people with disabilities, and we need to have that approach with training and educating people working in the health and welfare sectors. (HP10, Psychiatrist)

'... bureaucrats, clerics, administrators, people over the desk at Centrelink, just highlights the importance of understanding how trauma affects individuals, that applies also to whether it's psychosis or whether it's borderline [personality disorder]... various administrators, clerical people, even rehab, the NDIS people, they're not really quite understanding how they can trigger a reaction which can produce unnecessary decompensation or aggravate the condition. The fact is there needs to be a lot more done in terms of stigma around all those areas...' (BE15)

(8) Police and the justice system

Participants were often aware that police are frequently called upon to intervene in cases where people with mental illness are behaving erratically or endangering others, potentially leading to involvement in the criminal justice system, with all the attendant negative consequences. Some participants, including police involved in mental health training, viewed such events as inherently problematic and as significant contributors to stigma and discrimination. They often referred to the need to 'decriminalise' mental illness, treating it as a health challenge, rather than a justice issue. In addition, participants frequently noted the need for greater mental health training for police, including training in communicating and interacting with people experiencing acute mental ill health as well as more explicitly anti-stigma approaches.

'I had a lived experience recently... and I... made a comment that this is a mental health matter, not a criminal matter, and the policeman was very quick to say no this is a criminal matter, but it was a young person who was presenting with obviously mental health challenges and the police were called out to the property, but... it was so quick and so reflexive for this mature policeman to say no it's a criminal matter, when I was adamant... it was a mental health matter and... as far as stigma goes and changing the system, I think the training for the police could be better in that regard.' (PW16)

'part of the discrimination is... due to the way it's treated. If I'm picked up by police and put in the back of my van off to hospital, then everybody in the street knows it... on the one hand you're trying to say these people are not dangerous, and yet... here is police coming to take somebody away.' (PP41)

'... we need to... decriminalise the idea or concept of mental illness... NSW Police got called to 55,000 mental health incidents last year... because when [the community] see behaviours that are erratic or aggressive or

defiant, they automatically link that to a law enforcement approach, not a health issue. So as a result police with less training, less capability and the worst equipment get called to more incidents where people are behaving in a way that would generate a belief that this is a mentally ill person, rather than approaching it from a health perspective.’ (PP24)

‘... most people aren’t trained, let’s be frank, I’ve got 33 years in the police force and I only did the mental health training course 2 years ago when I took over as the manager. So I actually did the course and then went on to manage the area... it’s not mandatory...’ (PP24)

5. Discussion and recommendations

In order to inform 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 interviewed 234 key stakeholders, including people from advocacy organisations, program providers, mental health peer support workers, health professionals, health professional students, and those working in education, employment and social service settings.

Across these diverse participant groups, several common themes emerged, along with issues unique to particular groups or settings. Perhaps 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.

Participants also noted that stigma and discrimination varied according to diagnoses, with people living with bipolar disorder being viewed more positively than people living with schizophrenia. This less stigmatising view is possibly due to celebrities and high-profile people living with bipolar disorder publicly discussing their experiences in a way that is rarely seen in people living with schizophrenia, which is also subject to much more negative media reporting and associations with crime.²¹ For people with a diagnosis of borderline personality disorder, discrimination from health and mental health professionals was highlighted as a key issue. People with this diagnosis may be viewed as difficult to engage, impossible to ‘treat’, aggressive, and causing problems by presenting recurrently to services, especially EDs, due to self-harm and suicide risk.

5.1. Leadership and involvement of people with lived experience

The most common theme, which was mentioned by almost all participants, related to ensuring that people with lived experience are central to any strategy, including in leadership, co-design, delivery and evaluation roles. This finding is not surprising given the types of participants in the study, many of whom were recruited from national and state-based lived experience-run organisations who engage in advocacy and representation. However, it is also in line with over-arching rights-based frameworks for mental health and wellbeing,²² the evidence for stigma-reduction interventions, and the views of those who emphasise the need for protest and advocacy in addressing stigma and discrimination.²³

Drawing on the strengths of the well-developed consumer advocacy movement in Australia is likely to be central to driving change in community attitudes, not least because people with lived experience are holders of unique knowledge and experience that can be harnessed to formulate solutions.²⁴ Central involvement of people with lived experience is also likely to be particularly effective in challenging beliefs that people with lived experience are not expected to have successes or capabilities beyond living with their mental illness. However, while the principle of lived experience involvement is often included in policy recommendations and frameworks, implementation in practice remains challenging, resulting in tokenistic approaches and disagreement between groups as to the best way to tackle key issues. A successful strategy must overcome these limitations, with lived experience workforce development likely to play a critical role.

Recommendation 1: Ensure that people with lived experience 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 created specifically for the purpose;**
- **Involving national and state-based consumer and carer advocacy organisations;**
- **Focusing on mechanisms to create a cooperative community with a shared purpose while also accounting for diversity in perspectives, skills and experiences;**
- **Building collaborations between community, government and non-government organisations;**
- **Provision of adequate funding for participation by consumer and carer advocacy organisations.**

As noted in a previous literature review⁴ and in the report undertaken during the first part of this project,¹⁶ the most commonly used stigma-reduction strategies involve the provision of educational materials or the inclusion of people with lived experience recounting experiences (often referred to in the academic literature as ‘contact interventions’). The findings of the current project are in line with this and offer guidance for the sustainable implementation of programs that involve people with lived experience in key roles. Contact interventions are likely to be particularly important in the case of low prevalence mental illness as, by definition, people are less likely to know someone living with schizophrenia than depression or anxiety and are therefore more likely to rely on stereotypes, including those informed by media reports or films.²⁵ However, a number of participants also spoke of the need to be realistic about the challenges of living with a mental illness, as well as illustrating that it can follow a varying course (e.g., single episode, episodic and recovered), rather than purely being enduring and disabling. They also noted the need to take a ‘recovery’ focus, which recognises the ability of people living with a mental illness to live flourishing and meaningful lives.²⁶ The need for trauma-informed approaches, which are founded on an understanding that people with diagnoses of mental illness are more likely to have experienced trauma, was also noted by some participants.²⁷

A number of participants also noted the value of having high-profile, successful people tell their stories, whether at a national level or a local level (e.g., in a particular workplace). Such people can also act as ‘champions’, playing key roles in bringing about structural or organisational changes.²⁸ However, the quality of evidence on the elements of contact interventions that are most effective is low and further research is needed to improve it.²⁹

A number of program providers, particularly those involved in running programs that supported people with lived experience to tell their stories, noted the need for provision of support and had organisational policies in place to do this; for example, SANE’s peer support program or Batyr’s school and workplace programs (<https://www.batyr.com.au/>). Supports included assisting people with crafting their stories, providing guidance on setting boundaries around sharing personal experiences, encouraging use of self-care when carrying out advocacy or educative work, and additional support when needed. It should be noted that this is resource-intensive for organisations, and adequate funding for these support services would be essential for wider implementation of programs that are currently successful and sustainable on a small scale.

Recommendation 2: Ensure that people with lived experience are involved in co-designing and delivering anti-stigma programs and activities, 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 and unpredictability;
 - challenge stereotypes that a person living with a mental illness is incapable of work, participation in education or family life or successes that are possible for people without these diagnoses;
 - are realistic, acknowledging that mental illness can follow a varying course (e.g., single episode, episodic and recovered), and also acknowledging the challenges of living with a mental illness;
 - 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 system);
 - incorporate perspectives of families, friends and other supporters;
- Providing opportunities for face-to-face contact between community members with and without lived experience, while also maximising opportunities to use video/online content;
- Ensuring sufficient support for people with lived experience who share narratives through adequate resourcing of organisations that run programs involving people with lived experience.

5.2. The need for a long-term approach and evaluation of effectiveness

Several participants emphasised the need to take a long-term approach to stigma reduction, with one noting that this is the “work of a generation” and emphasising the need to embed new norms and behaviours, drawing parallels with changes in attitudes to smoking, seatbelts, drink driving or same-sex marriage.

Many participants pointed to shifts in attitudes towards people with depression and anxiety over the last two decades,³⁰ noting the key role of organisations such as Beyond Blue, which has been well-funded by government. There was a view that these attitudinal changes lay the foundation for efforts to address attitudes to people with low prevalence mental illness. Some participants noted that a strategy would need to be adequately resourced for a long period of time. This also aligns with views of those working on anti-stigma programs in other countries, including Time to Change in the UK, who are now considering a focus on those ‘left behind’, including people of lower socioeconomic status, some ethnic minority groups and those with low prevalence mental illness.³¹

A number of participants also noted the need for evaluation of the strategy to assess its effectiveness, to help avoid unintended consequences and to drive change and adaptation where necessary. Such evaluation, which has typically been done both through population surveys and through evaluation of local initiatives, has been valuable in assessing the impact of Australian mental health literacy initiatives³⁰ and also has a key role in the UK’s Time to Change program, enabling them to gauge the impact of activities over a 10-year period and to guide future action to target population groups that require more attention.³¹ Time to Change has also undertaken evaluation of programs in key settings and groups, such as in medical students.³² The nationally representative Survey of Discrimination and Positive Treatment in People with Mental Health Problems conducted in 2014 has baseline data that could be used to assess change over time, although the majority of participants reported having common mental health conditions.²

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 take years, or even decades to have impact;

- **Implementing strategies that build on successes and evolve over time, with new messages and strategies to sustain interest and attention.**

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 the evaluation, including specification of the impact of any activities being undertaken.**

5.3. Multifaceted approaches with tailoring to key settings

When asked about the key settings to target, those most commonly nominated included health services, workplaces and the media, although many participants noted the need to target the general community, family and friends of people experiencing a mental illness; police and the justice system; those working in social and welfare services; policymakers; and the education system (both schools and tertiary education institutions).

Other participants also noted the need for tailoring to Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities, noting that any interventions conducted by these communities should incorporate culturally appropriate understanding of mental health, be community-led and engage community leaders in design and delivery. Very few participants raised the issue of stigma and discrimination in LGBTIQ people, other than noting that stigma related to mental illness diagnoses often compound experiences of discrimination related to sexuality.

5.4. Language and use of diagnostic terms

Classification of mental illness is an area of intense debate among mental health professionals and people with lived experience, many of whom reject the use of any diagnostic terms and the 'medical model' that ascribes symptoms and experiences to a mental illness.³³ Unsurprisingly, participants in the current project also had diverse views on the appropriateness of the use of terminology as part of a strategy to reduce stigma and discrimination, with many participants outlining the advantages and disadvantages of either approach. For example, the majority of program providers and health professionals thought that current diagnostic labels should be used, with the focus being on changing the stigma around those terms, as this would assist in ensuring that the focus remains on low prevalence mental illness rather than depression or anxiety, would assist with clear communication (avoiding overly complex terminology or excessive 'political correctness') and avoid having discussions about terminology distract from other, more important, issues.

However, others considered that diagnostic labels themselves should be changed as the stigma built up around certain terms, particularly schizophrenia and borderline personality disorder, could never be undone. Some participants felt that applying labels to people with mental illness creates 'othering' or distancing, whereas using generic terms such as 'distress' or 'trauma' makes people with mental illness more relatable as everyone can relate to experiences of distress and trauma. This aligns with the continuum model of mental illness, which considers that experiences and behaviours are distributed across the population in a continuum from 'normal' to 'severely ill'.³⁴ There is some evidence that continuum beliefs are associated with lower levels of stigmatising attitudes.³⁵ However, a drawback of this approach is that it is not clear how use of terms such as distress would ensure that the focus is on low prevalence mental illness rather than on depression and anxiety.

While some participants had strong views about the use of terminology, for most, the guiding principle in any interactions with people with lived experience was to be guided by the wishes of that person. However, it was acknowledged that this would be difficult in certain circumstances, such as media campaigns targeted to the general community. It is also likely that one of the aspects of tailoring to settings may involve the use of diagnostic terms in some situations and not in others, e.g. in an intervention involving a person with lived experience telling their story, language and terminology will depend on the preferences of that person, while for interventions aiming to impact on attitudes to people with particular diagnoses (e.g. interventions aiming to change health professional attitudes to people with borderline personality disorder), they may be useful. Decisions about the use of diagnostic terms and the explanation of the associated complexity are likely to be usefully informed by further research, including that involving people with lived experience as well as experimental approaches. Such research should also aim to explore potential adverse consequences of particular approaches, particularly in the context of emerging evidence that the use of

concepts such as ‘chemical imbalance’ may have increased attitudes about dangerousness of people with mental illness.³⁶

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, it may be preferable to focus 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 unintended consequences;**
- **People with lived experience, including those from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities, should be involved in evaluation of initiatives.**

5.5. Addressing stigma and discrimination in health services

Many participants talked about the need to address stigma and discrimination in health services including the need for structural reform, considering the biomedical paradigm on which the mental health system is based to be fundamentally discriminatory.²² Other participants talked about the need to address issues in specific parts of the health system, e.g. attitudes towards people with borderline personality disorder in emergency departments.

Alignment with initiatives currently underway in Australia, including the Victorian Royal Commission into the Mental Health System and the Productivity Commission Inquiry into Mental Health, may offer opportunities to address structural stigma as the recommendations arising from these initiatives are likely to include the need for person-centred care and for the ability for people with lived experience to actively participate in community, education and workplaces.³⁷

Health and mental health professionals were frequently identified as a key target group in a national strategy, both by people with lived experience and by health professionals themselves. Participant often noted the need for training. Several people pointed to the limited understanding of mental illness among non-mental health professionals as problematic, given the likelihood of people with mental illness having other health problems and therefore presenting to other health services. In line with a key theme, the importance of including people with lived experience in the training was mentioned by many participants. This was seen as being particularly important in addressing the ‘treatment pessimism’ that can result from contact with people when they are acutely unwell rather than functioning well. Several participants pointed to the importance of ongoing training (e.g. as part of continuing professional development), particularly for health professional students who, while they may receive training as students, often struggle to maintain positive attitudes once they are employed in workplaces where negative attitudes toward people with mental illness are pervasive. As the new generation of health professionals, students were seen as having a critical role in bringing about long-term cultural change.³² As senior leaders in the mental health system, psychiatrists were also seen as central to bringing about cultural change, and some participants also mentioned the role that health professionals can play in educating the broader community around mental health issues.

5.5.1. The peer workforce

Mental health peer support workers were seen as having a key role in reducing stigma and discrimination in the mental health system. There is increasing evidence that employing mental health peer support workers has a positive impact on the quality of services and client outcomes, with the potential to impact positively on stigma and discrimination in health services and in the broader community.³⁸ Peer work was seen as essential to challenging existing power structures that assign roles to ‘patients and professionals’; repairing a ‘broken’ mental health system; reducing self-stigma by enabling people with lived experience to see people with similar diagnoses or symptoms making a contribution through peer worker roles; reducing stigma in health professionals by enabling them to see a person managing their mental illness while working as a peer worker; and promoting self-management through the peer worker sharing their own coping and management strategies. Many peer worker participants noted that mental

health peer support workers themselves were often targets of discriminatory behaviours and noted the need for further professionalisation of the workforce and for opportunities to highlight positive aspects of their roles.

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

- **Implementation of reforms that support, at both structural and individual practitioner levels:**
 - a fundamental shift away from the treatment of mental illness symptoms towards a focus on wellbeing.
 - a shift in power dynamics between practitioners and patients;
 - moving away from approaches that offer people services and supports based on their diagnoses to those that focus on their needs and aspirations.
- **Strengthening the peer workforce, through a more comprehensive provision of training, fair and equitable working conditions, and access to supervision from more experienced mental health peer support workers;**
- **Incorporating strategies to address self-stigma in people with mental illness;**
- **Encouraging, supporting and enabling psychiatrists and other senior professionals to take leadership roles in stigma reduction;**
- **Involving people with lived experience in systems-level changes in health services;**
- **Incorporation of opportunities for more intensive training in mental health, including that led by people with lived experience;**
- **Incorporate aspects of reflective practice that allow health practitioners, senior managers and policymakers to understand their own attitudes and the impact of these on decisions about services for people living with a mental illness;**
- **Improving education for students by including positive narratives or contact with people who are in recovery to counter the impact of early encounters with people who are acutely unwell;**
- **Ensure that training is ongoing to address attitudes that may change over time;**
- **Implementation of training that focuses on improving health professional attitudes to people with borderline personality disorder, including building skills to improve outcomes and reduce therapeutic pessimism.**

5.6. Addressing stigma and discrimination in workplaces

Workplaces were one of the most frequently named settings to be targeted in a national strategy, due to a recognition of the importance of participation in work for many people living with a mental illness and the relatively high frequency of experiences of discrimination. These include being excluded from entry into the workforce, being prevented from progressing in their roles, suffering negative consequences if mental health difficulties affect the ability to work, and interpersonal difficulties with supervisors or other colleagues.¹⁰ Some participants noted the potential for the aftermath of Covid-19 to worsen employment opportunities for people with mental illness, due to greater competition for jobs.

As with other settings, recommendations for reducing stigma and discrimination in workplaces included the involvement of people with lived experience telling positive stories of success and strong organisational leadership. Participants noted the need for workplace programs to address attitudes relating to fear that employing someone living with a mental illness will create a lot of extra work related to their management; fear of not knowing how to talk to the person about their difficulties; skills to assist them to continue their work while managing their mental illness; and education to address fears about dangerousness.

Recommendation 7: Address stigma and discrimination in workplaces by:

- **Focusing on policies and practices that support mentally healthy workplaces;**
- **Supporting senior leaders to model positive attitudes towards people with mental health problems;**
- **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;**
- **Implementation of interventions that address fears about competence and the 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.**

5.7. Addressing stigma and discrimination in the general population

Many participants talked about the need to educate the broad Australian community, with a focus on ‘demystifying’ and ‘normalising’ mental illness. Media campaigns were often seen as important ways of challenging negative attitudes in the general population, and some participants mentioned being able to build on and draw on the expertise of organisation such as Beyond Blue to do this. Involvement of celebrities or high-profile, successful figures was frequently mentioned, although it was often noted that people with lived experience of low prevalence mental illness were less likely to disclose such experiences than people with common mental health conditions. Disclosure of diagnoses to explain poor or criminal behaviour was seen as particularly damaging.

The need to harness the power of digital and social media was frequently raised as a key element in a national campaign. However, some participants, including those in regional and rural areas, also noted the importance of traditional media in reaching community members who have limited engagement with digital media. This was also mentioned as being important in reaching culturally and linguistically diverse communities (e.g. through the use of radio in languages other than English). Some participants noted the need to move beyond mental illness education and offer positive behaviour change strategies.

Some participants pointed to the importance of grass roots community-driven approaches incorporating opportunities for community members to be exposed to positive portrayals of, or have positive encounters with, people with mental illness in the course of their daily lives, rather than at separate events. These events, which may include sporting events, film or music festivals, have been a feature of anti-stigma programs in Australia and in other countries.^{16,39} This is likely to be particularly important in Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities and rural and regional areas.

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

- **Focusing on activities that demystify or normalise mental illness;**
- **Move beyond a focus on the scale of the problem and what not to do, to incorporate suggestions for 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 community members with and without mental illness.**
- **Ensuring that interventions intended for a mainstream audience also reflect the cultural diversity of the Australian population.**

5.8. Addressing stigma and discrimination in the media

Media reports were frequently highlighted as a cause of stigmatising attitudes, able to quickly undo positive stigma reduction work done elsewhere in the community, particularly in the case of media reporting about mental illness and violent crime. An analysis of Australian print and online news reports found violence to feature in 47% of news stories that mentioned schizophrenia.⁴⁰ This is a particular concern for people with low prevalence mental illness, as attitudes are often influenced by media-driven stereotypes about dangerousness and unpredictability.²⁵ ‘Tabloid’ media coverage was noted as particularly problematic. Initiatives such as SANE’s Stigma Watch and Mindframe’s media reporting guidelines attempt to address unsafe and poor-quality media reporting, although further work on aspects of reporting on mental illness and violence is needed (and is currently being undertaken by members of the project team).⁴¹ Working with the Australian Press Council to improve standards of practice for coverage of mental illness and crime as has been done in the area of suicide may also assist in improving the quality of media reporting.

There is some evidence that interventions with media professionals can improve the quality of reporting on mental illness, and, as with health professionals, interventions with journalism and media students are likely to be particularly important.⁵ Some participants mentioned the opportunities for improving portrayals of people with mental illness in popular series (e.g. Home and Away) and recommended that people with lived experience and health professionals could work with TV and film production companies to do this.

Recommendation 9: Address stigma and discrimination in the media 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;
- Improving the quality of media reporting on mental illness, particularly that relating to violence and crime by:
 - Implementing interventions with media professionals (including journalism students) that encourage them to:
 - consider the impact of media reports on public attitudes and on 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 portrayals of people with mental illness.

5.9. Addressing stigma and discrimination in educational institutions

We interviewed a number of participants who were involved in provision of mental health literacy or anti-stigma programs in educational institutions. None of these programs had a specific focus on low prevalence mental illness, although some did involve people with lived experience of these types of mental illness as part of their activities. Increasing participation of people with low prevalence mental illness could assist in reducing stigma in young people. Common themes arising from the interviews were the need for early education about mental illness and the need for early intervention and support for students, particularly at times of transition. While this is primarily aimed at improving outcomes for those students, it was also noted that this would also have an anti-stigma effect, by providing examples of people successfully overcoming challenges. They also noted the need for professional development and support for schoolteachers or staff in higher education institutions to enable them to better support students.

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

- Providing mental health education in schools and tertiary education institutions, including stories 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 transition;
- Improving professional development and support for staff in schools and tertiary education institutions.

5.10. Addressing stigma and discrimination in police, and social service and welfare professionals

A number of participants talked about the need to address issues relating to the involvement of people living with mental illness in the criminal justice system. While the great majority of people living with mental illness (including those with low prevalence mental illness) do not commit crimes, they are over-represented in police encounters.⁴² Recommendations included improved training, including that led by people with lived experience and that incorporated positive stories of recovery to counter the experience of police who often encounter people with low prevalence mental illness when they are acutely unwell. One participant with a high level of expertise in the area noted the need for fundamental reform in the area of mental health emergency care.⁴³

Similar recommendations for training for social service and welfare professionals were also made, with participants highlighting the need for trauma-informed approaches and the need for positive narratives.

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

- Implementing training led by people with lived experience that takes a trauma-informed approach and incorporates narratives of hope and recovery;
- Adequately resourcing and supporting ongoing training.

6. Strengths and limitations

Key strengths of this stakeholder consultation project include the large number of interviews conducted and the diversity of participants, in terms of both personal and professional expertise. We were therefore able to capture data on areas of consensus across participants as well as identify unique perspectives.

Limitations include greater numbers of participants from NSW and Victoria and from metropolitan areas, perhaps reflecting the relatively high proportion of program providers and health professionals who tend to live in these areas. The other key limitation was a lower than expected participation from people from Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities as well as in people from the LGBTIQ population. This partly relates to there being relatively few people in Australia who specialise in activities that seek to reduce stigma and discrimination to people with low prevalence mental illness in these communities. It is anticipated that future consultations with people with lived experience will help to address these gaps.

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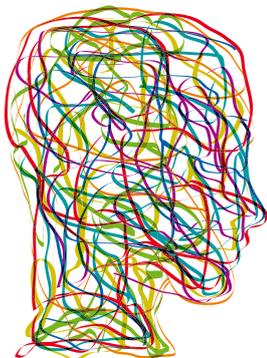
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- Prof Deborah Warr



Stigma and discrimination



What we know about stigma and discrimination

Stigma and discrimination towards people **with mental illness** are common. They contribute to the **poor health outcomes** and the **social and economic hardship** that some people with mental illness experience.

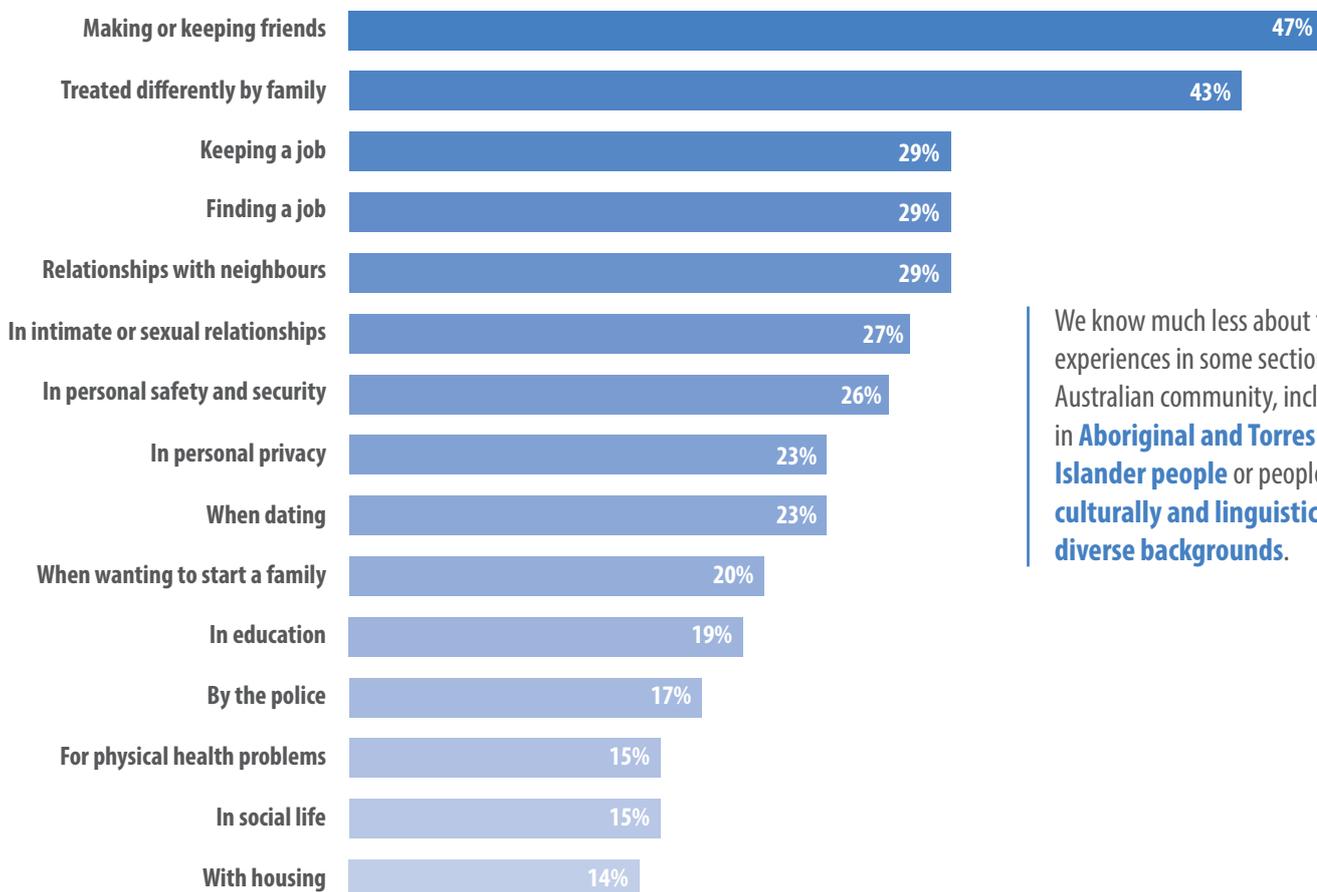
We have made progress in reducing stigma related to the idea that **depression and anxiety** are not real mental illnesses.

We have been **less successful** in reducing stigma towards people with mental illnesses such as **schizophrenia, bipolar disorder, psychosis, and personality disorders**, particularly as this relates to dangerousness and unpredictability.

While we acknowledge that not everyone uses these diagnostic terms, we are using them as a starting point for these discussions and to ensure that the focus is on these conditions rather than depression or anxiety.

Stigma and discrimination towards people with schizophrenia

A survey in 27 countries showed the % of people with schizophrenia reporting negative experiences in the following life domains:



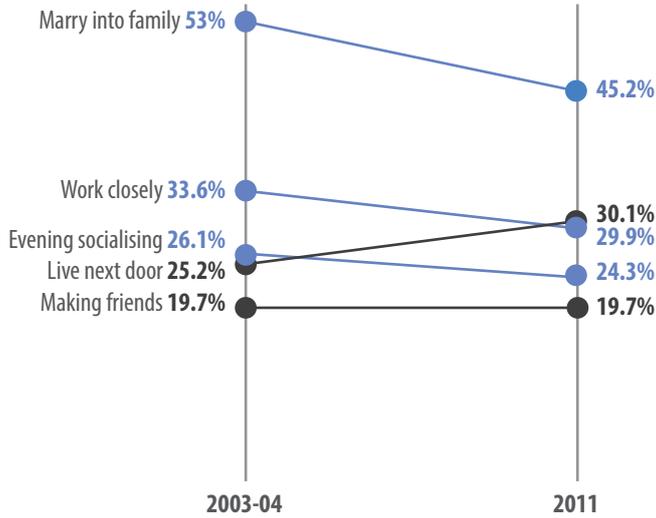
We know much less about these experiences in some sections of the Australian community, including in **Aboriginal and Torres Strait Islander people** or people from **culturally and linguistically diverse backgrounds**.

Attitudes in Australia: recent changes

Long-term schizophrenia

Changes in desire for social distance

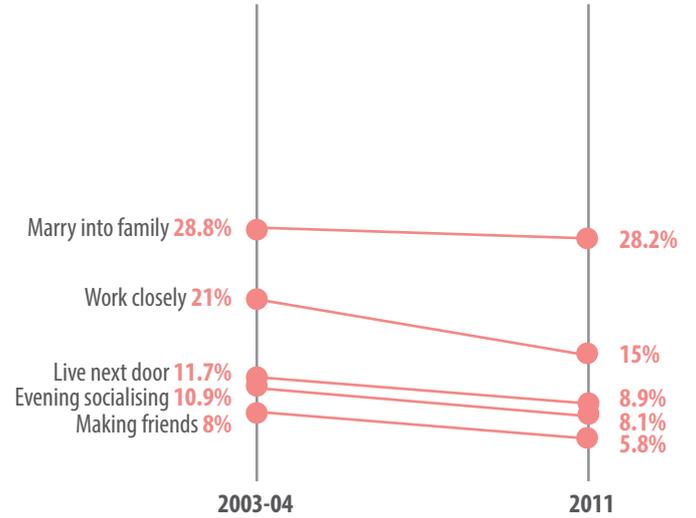
Unwilling to...



Depression

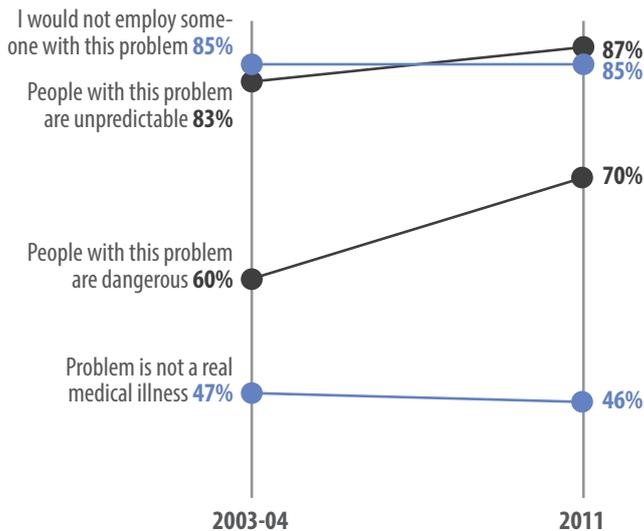
Changes in desire for social distance

Unwilling to...



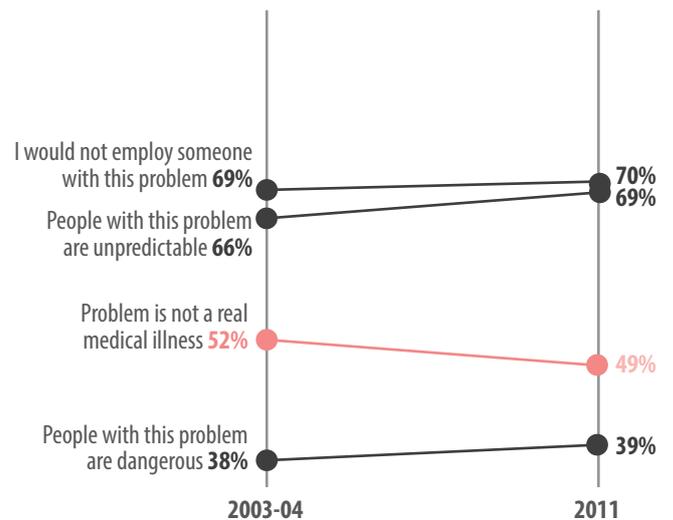
Long-term schizophrenia

Changes in some key attitudes



Depression

Changes in some key attitudes



References

- Thornicroft, G., et al. (2009). "Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey." *Lancet* 373(9661): 408-415.
- Reavley, N. J. and A. F. Jorm (2012). "Stigmatizing attitudes towards people with mental disorders: changes in Australia over 8 years." *Psychiatry Research* 197(3): 302-306.



What is happening in Australia

We searched the academic literature and the 'grey' literature (via Google) for Australian anti-stigma programs run by lived experience groups and other key non-government organisations. We also looked for any available evidence of effectiveness.

We also did an online survey of these organisations, inviting them to provide details of their programs and associated evaluation or evidence of effectiveness.

We found **60 programs** currently operating in Australia.

29 face-to-face programs

7 awareness campaigns

5 advocacy programs

19 publicly available online resources



Face-to-face programs

55% focused on stigma towards people with a **non-specific mental illness**

21% targeted a range of disorders including **psychosis, schizophrenia, bipolar disorder or personality disorder**

10% specifically focused on **psychosis or schizophrenia**

7% focused on 'severe' mental illness, and **7%** on **Borderline Personality Disorder**.

MOST COMMON SETTINGS



1. Community settings 45%

2. Community health centres **38%**
3. Workplaces **38%**
4. University or tertiary education **34%**
5. Primary healthcare **17%**
6. High school **14%**

Only 2 programs were run in Primary Schools **7%**

THEY TARGETED



1. Adults 59%

2. All ages **14%**
3. Adolescents **14%**
4. Young adults **7%**
5. Children 8-18 years old **3%**

AND REACHED

1. Up to 1,000 people **43%**
2. 1,000 – 10,000 **24%**
3. 10,000 – 100,000 **19%**
4. Over 100,000 people **14%**

IT INVOLVED



Most programs involved people with lived experience in their design **59%** or delivery **76%**

Programs often included multiple types of components, but the most common were:

1. Education **62%**
2. Face-to-face contact **62%**
3. Online/video contact **24%**
4. Protest or advocacy **24%**
5. Hallucination simulation component **4%**



Online resources

The search identified **19 online resources** with a focus on reducing stigma. These were available through organisational **websites, Facebook** and **YouTube**.

Most online resources focused on reducing stigma towards **non-specific mental illness (26%)** and **psychosis or schizophrenia (26%)**, with the remainder focused on 'complex' mental illness (**16%**), **bipolar disorder (16%)** and **personality disorders, primarily borderline personality disorder (16%)**. Most online resources (84%) involved contact with a person with lived experience, usually via online videos.



Awareness campaigns

We identified **seven community campaigns** in Australia with a focus on reducing stigma towards mental illness.

These are mainly campaigns held annually that last for 1 day, 1 week, or 1 month. Apart from Borderline Personality Disorder Awareness Week and Schizophrenia Awareness Week, all campaigns focus on non-specific mental illness. All but two are conducted Australia-wide.

Action under the 5th Plan

Priority Area 6 of the 5th National Mental Health and Suicide Prevention Plan is as follows:

Governments will take action to **reduce the stigma and discrimination** experienced by people with mental illness that is poorly understood in the community. This will:



involve **consumers** and **carers, community groups** and other key organisations



build on **existing initiatives**, including the **evidence base** of what works in relation to reducing stigma and discrimination



account for the specific experience of groups already **at high risk of stigma** including Aboriginal and Torres Strait Islander peoples and people who identify as LGBTI.

Stigma-reduction initiatives (national & international)

The following types of interventions are supported by evidence:

- all types of **contact interventions**, as intervention effects did not appear to differ according to intervention length or whether interventions used in-person, video or online contact.
- all types of **education interventions**, as effects did not differ according to program length
- **psychoeducational interventions** for family members of people with severe mental illness
- mass **media and social marketing campaigns** that run over a number of years and involve multiple activities targeted to the general public as well as key groups likely to have contact with people with severe mental illness.

Examples from other countries



Time to Change (UK)

www.time-to-change.org.uk/



Time to Change is delivered by the charities Mind and Rethink Mental Illness. It involves:

- social marketing campaigns (e.g. digital media, posters and flyers)
- work with target groups, including employers, school students and medical students.
- local community events and campaigns

Time to Change is a well-evaluated program. The findings indicate that the mental health stigma related outcomes of knowledge, attitudes and desire for social distance have improved between 2009 and 2019. There is also some evidence for a reduction in experiences of discrimination.

Opening Minds (Canada)

<https://www.mentalhealth-commission.ca/English/opening-minds>



Opening Minds focuses on addressing stigma within four main target groups: health care providers, youth, the workforce and the media.

However, Time to Change and Opening Minds focus on 'mental illness' in general and it is possible that some of the changes reflect changes in attitudes to depression.

Very few campaigns focus on schizophrenia or the other disorders that are poorly understood in the community. Those that do have not been shown to be effective or have not been evaluated.

Stigma and discrimination from health professionals



Research in Australia shows that:

In general, **health professionals are less likely** than members of the general public to believe that **schizophrenia is not a real illness** or that people with schizophrenia are dangerous.

Their desire for social distance from people with mental illness is **not significantly different** to the general public.

GPs are more likely to hold **personally stigmatising attitudes** and to desire social distance than psychologists and psychiatrists.

The types of negative experiences that people with mental illness report from health professionals, include:

34.1%

advised to **lower their expectations** for accomplishments in life

29%

shunned or avoided by the professional treating their mental illness

44.7%

changed their behaviour toward them once finding out about their mental illness

28.7%

reported that professionals were **not comfortable** talking to them

61.1%

reported a **lack of understanding** about the lived experience of mental illness from their service providers.

References

Mental Health Council of Australia (2011). Consumer and carer experiences of stigma from mental health and other health professionals. Canberra, Australia, Mental Health Council of Australia.

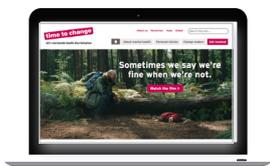
Henderson, C., et al. (2014). "Mental health-related stigma in health care and mental health-care settings." *Lancet Psychiatry* 1(6): 467-482.

Reavley, N. J., et al. (2014). "Stigmatising attitudes towards people with mental disorders: a comparison of Australian health professionals with the general community." *Australian and New Zealand Journal of Psychiatry* 48(5): 433-441.

Examples of programs from other countries:

Time to Change (UK)

www.time-to-change.org.uk/

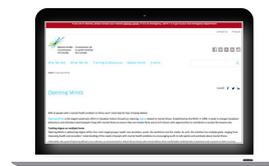


Time to Change has had a focus on health professionals as part of its efforts.

<https://www.time-to-change.org.uk/about-us/about-our-campaign/professionals>

Open Minds (Canada)

<https://www.mentalhealthcommission.ca/English/opening-minds>



Various interventions, some targeting students and different types of mental health professionals. Most target mental illness in general.

Best practice case examples: health professional students

Recovery Camp



What is it?

A non-traditional placement for nursing students. Health students and people with a lived experience of mental illness attend a recreation camp, participating in an adventure activities program in the Australian bush.



Where is it available?

Metropolitan NSW since 2013. It has been attended by **800 students** and **690 people** with lived experience.



What does the program cover?

The Camp is for **5 days and 4 nights**. Camps comprise **40-130 people**, including 40 students, 40 people with lived experience, 5 nurse facilitators, several other staff.

Lived experience attendees are encouraged to share their stories related to mental health and recovery with students. Everyone at camp is of equal status and contact is outside an acute setting (recovery focused).



How is the program funded?

Recovery Camp is a not-for-profit organisation and is funded by earned income from universities, who pay for their students to attend.



What does the research say?

Two controlled trials found reduced anxiety about mental illness, negative stereotyping, and social distance after the placement compared with traditional nursing placements. In particular, there was decreased endorsement of statements that describe people with mental illness as unpredictable, incapable and dangerous.



References

Patterson C, Perlman D, Taylor EK, Moxham L, Brighton R, Rath J. Mental health nursing placement: A comparative study of non-traditional and traditional placement. *Nurse Education in Practice*. 2018;33:4-9.

Moxham L, Taylor E, Patterson C, Perlman D, Brighton R, Sumskis S, et al. Can a clinical placement influence stigma? An analysis of measures of social distance. *Nurse Education Today*. 2016; 44: 170-4.

Best practice case examples: health professional students

Remind Training and Education Program



What is it?

Pharmacy students attend a tutorial with trained mental health consumer educators, receive a series of mental health lectures and undertake supervised weekly placements in the community pharmacy setting.



Where is it available?

Faculty of Pharmacy, the University of Sydney, NSW. Since 2010 approx. **2,500 students** have taken part.



What does the program cover?

During the 2-hour contact tutorial, consumer educators discuss their history with mental illness, the medications they take, ways of coping with their illness, the important role that pharmacists need to play in supporting people with mental illnesses, and how they were real people who led normal lives despite their illness. Students are given opportunity to interview the educators during the tutorial. Consumer educators are trained by the Schizophrenia Fellowship of NSW.



How is the program funded?

The program is provided to students within the Pharmacy course; no specific funding source is described.



What does the research say?

Evaluations in a controlled trial and an uncontrolled trial found reductions in stigma after the program and up to 12 months later. Consumer educators felt empowered by their participation, reported improved confidence and public speaking skills, and enjoyed the social contact with other consumers.



References

O'Reilly CL, Bell JS, Chen TF. Consumer-led mental health education for pharmacy students. *American Journal of Pharmaceutical Education*. 2010;74(9):167.

Nguyen E, Chen TF, O'Reilly CL. Evaluating the impact of direct and indirect contact on the mental health stigma of pharmacy students. *Social Psychiatry and Psychiatric Epidemiology*. 2012;47(7):1087-98.

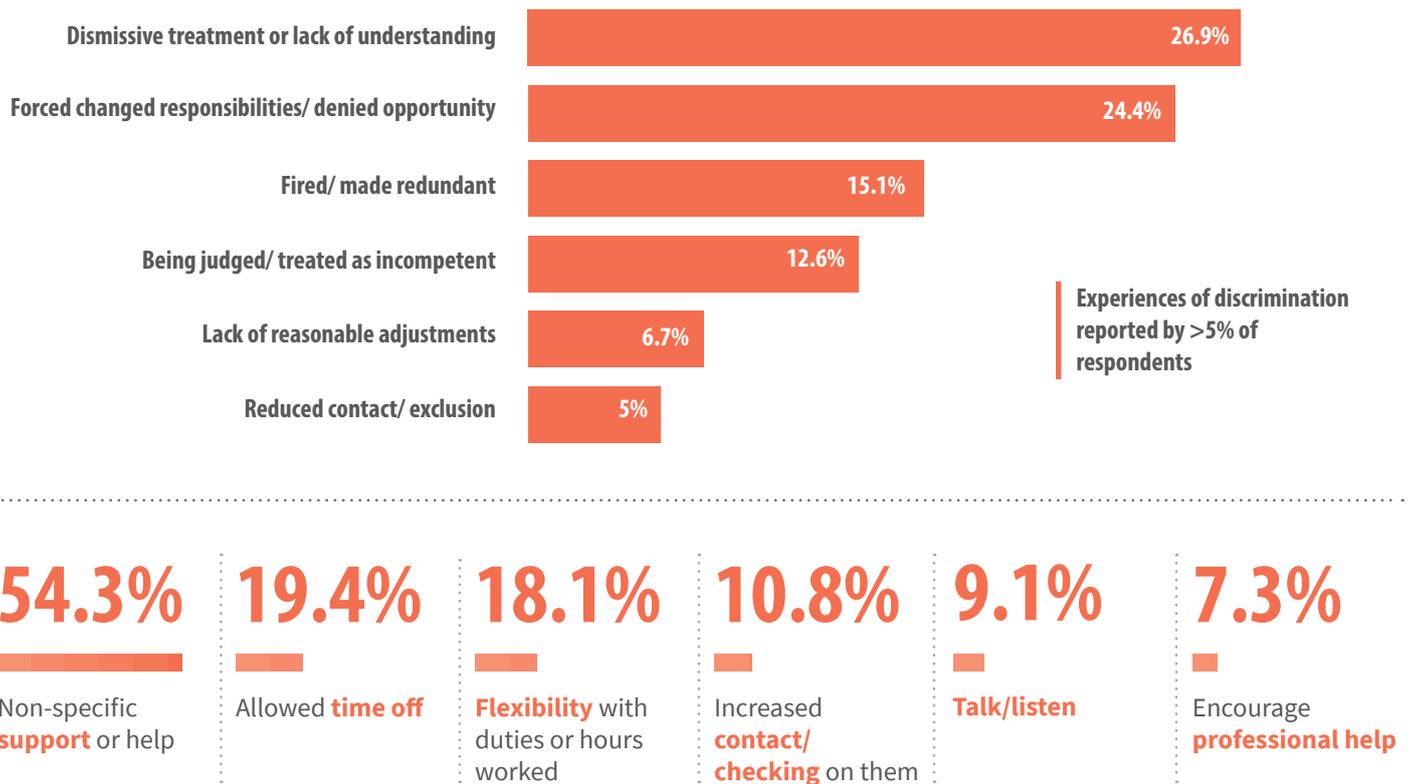
O'Reilly CL, Bell JS, Chen TF. Mental health consumers and caregivers as instructors for health professional students: a qualitative study. *Social Psychiatry and Psychiatric Epidemiology*. 2012;47(4):607-13.

Stigma and discrimination from employers and workplaces



Research in Australia shows that:

the types of **negative and positive experiences** that people with mental illness report from employers include (%):



References

Reavley, N. J., et al. (2017). "Discrimination and positive treatment towards people with mental health problems in workplace and education settings: Findings from an Australian national survey." *Stigma and Health* 2(4): 254-265.

Examples of programs from other countries

Time to Change (UK)

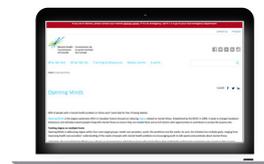
www.time-to-change.org.uk/



Time to Change has had a focus on workplaces as part of its efforts <https://www.time-to-change.org.uk/get-involved/get-your-workplace-involved>

Open Minds (Canada)

<https://www.mentalhealthcommission.ca/English/opening-minds>



Same focus on workplaces https://www.mentalhealthcommission.ca/sites/default/files/2019-01/aspiring_workforce_toolkit_2019_eng.pdf

Stigma and discrimination from educators



Research in Australia shows that:

People with mental health problems experience **discrimination in education** settings.
Common experiences are:



Lack of **understanding** of their illness



No **leniency** or special consideration



Teasing/mocking

The also experience **positive treatment**:



Non-specific **support**



Special **consideration**



Encouragement to seek/receipt of **professional help** at the institution

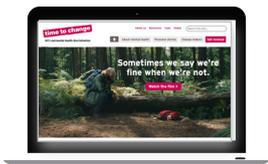
References

Reavley, N. J., et al. (2017). "Discrimination and positive treatment towards people with mental health problems in workplace and education settings: Findings from an Australian national survey." *Stigma and Health* 2(4): 254-265.

Examples of programs from other countries

Time to Change (UK)

www.time-to-change.org.uk/



Time to Change has had a focus on schools as part of its efforts.
<https://www.time-to-change.org.uk/get-involved/schools>

Open Minds (Canada)

<https://www.mentalhealthcommission.ca/English/opening-minds>



Same focus on schools
<https://www.mentalhealthcommission.ca/English/resources/training/headstrong>

Informing a national strategy to reduce stigma and discrimination towards people with mental illness that is poorly understood in the community

Project aim

The aim of the project is to undertake consultations to inform a national stigma and discrimination reduction strategy, with a focus on mental illness that is poorly understood in the community. While we understand that not everyone uses these diagnostic terms, for the purposes of this project, 'mental illness that is poorly understood in the community' refers to schizophrenia, bipolar disorder, psychosis, and personality disorders. We are using these terms because we wish to emphasise that the focus should not be on anxiety and depression. The project is funded by the Commonwealth Department of Health.

Who we are

The project team includes researchers from the University of Melbourne, LaTrobe University and Charles Sturt University. The team is led by Associate Professor Nicola Reavley from the Centre for Mental Health, Melbourne School of Population and Global Health, University of Melbourne. Other team members from the University of Melbourne include Dr Angela Nicholas, Dr Amy Morgan, Associate Professor Eva Alisic, Professor Anthony Jorm, Professor Jane Pirkis, Dr Ashley McAllister, Dr Karen Block, Dr Georgina Sutherland, Ms Judith Wright, Dr Claudia Marck and Ms Anna Ross. Professor Deb Warr is from Charles Sturt University and Professor Lisa Brophy and Catherine Minshall are from LaTrobe University. Kate Kelleher and Justin Noel are external consultants.

Why we're doing it

Stigma and discrimination towards people with mental illness are common in Australia. While there have been some improvements in community understanding of common mental health conditions (such as depression and anxiety), there is often still misunderstanding and ignorance. This is especially true for less common mental health disorders, such as schizophrenia and bipolar disorder. These are often poorly understood and attitudes towards people who have these diagnoses are less positive than for anxiety and depression.

Recognising this, the Commonwealth Government's Fifth National Mental Health and Suicide Prevention Plan outlines the need for a national strategy to address stigma and discrimination. This project aims to inform that strategy.

How we're doing it

We will use focus groups and interviews to explore opinions on the content and barriers to and enablers of, a nationally coordinated stigma reduction strategy.

What will I be asked to do?

You will be asked to participate in a one-on-one interview that will take about 30 minutes. This interview will be conducted online using Zoom video-conferencing.

The interviews will be audio-recorded. These audio recordings are for internal reporting purposes only and will not be shared with any outside parties.

Are there any risks?

Some people may find discussing stigma towards people with mental illness distressing and some participants may be concerned about their privacy and the confidentiality of their contributions.

We have in place a participant safety protocol so that we can help anyone who becomes upset by the discussion in the interviews. We will make sure that any participant who becomes upset will be supported, and we will support anyone who wants to stop their participation in the research and recommend appropriate counselling services, if needed.

Additionally, if you would like to talk to someone about feeling upset, please call one of the following support services (available 24hrs): Lifeline: 13 11 14 (toll-free) or Beyond Blue: 1300 22 4636

If you change your mind

Participation in this project is voluntary. If you change your mind about participating, you are free to withdraw from the project at any time and you may also withdraw your data if you wish, simply by contacting the project coordinator Judith Wright (contact details provided below).

Your privacy

Any data we collect from you will be held under password protection and not given to others. We will protect the confidentiality of your data, subject to any legal requirements. Due to research code requirements, we will be storing the information collected for 5 years after the study, but none of your information will be able to be traced back to you.

If you are interested in participating or require further information

If you are interested in participating, please contact Ms Judith Wright at wright.j@unimelb.edu.au or phone: 03 9035 7543.

If you have concerns about the project

If you have concerns about way the project is being conducted, please contact the project leader, A/Prof Nicola Reavley on nreavley@unimelb.edu.au or 03 9035 7628.

This research project has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Office for Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 2073 or Fax: +61 3 9347 6739 or Email: HumanEthics-complaints@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team or the name or ethics ID number (HREC#: 1955980.2) of the research project.



A/Prof Nicola Reavley. Email: nreavley@unimelb.edu.au, Ph: 03 9035 7628