

Ensuring people living with complex mental health issues can live a life free from stigma and discrimination

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About SANE Australia

SANE Australia is a national mental health charity making a real difference in the lives of people affected by complex mental health issues through support, research and advocacy.



About the Anne Deveson Research Centre

An initiative of SANE Australia, the Anne Deveson Research Centre conducts research that drives better social outcomes for people affected by complex mental health issues.



About the Melbourne School of Psychological Sciences

The Melbourne School of Psychological Sciences at the University of Melbourne is committed to transforming the world we live in through ground-breaking research, inspiring entrepreneurship, and by providing an outstanding education that reflects the needs of our domestic and global community.



About the Paul Ramsay Foundation

The Paul Ramsay Foundation seeks to identify and partner with individuals, communities and organisations working to create an Australia where people can overcome disadvantage and realise their potential.

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SANE Australia acknowledges the Aboriginal and Torres Strait Islander peoples as the traditional custodians of the land on which it operates, and pays respect to Elders past, present and emerging. SANE is committed to providing a safe, culturally appropriate, inclusive service for all people, regardless of their ethnicity, faith, disability, sexuality, or gender identity.

Foreword

More than thirty years on from deinstitutionalisation, Australians affected by complex mental health issues still experience unacceptably high levels of stigma and discrimination. Reducing this stigma and discrimination is not just about raising awareness; it requires us to do everything we can to ensure that people living with complex mental health issues, their families, friends and carers are treated with dignity and respect.

For almost 35 years, SANE Australia, which began as the Schizophrenia Australia Foundation, has endeavoured to reduce the stigma and discrimination experienced by people living with mental illness.

Anne Deveson AO, after whom our Research Centre is named, is remembered for her efforts in opening up the public conversation about mental health in Australia. Anne's SANE Australia co-founder Dr Marg Leggatt AM has fought for more than 40 years for better recognition and treatment of people affected by mental illness and their families.

While it may not always feel like it, their efforts have seen significant gains. Despite these gains, this research shows that there is still much to be done – we cannot take our foot off the pedal.

Participants who completed the **Our Turn to Speak** survey shared heartbreaking experiences of stigma and discrimination across a range of life domains including relationships, employment, physical and mental healthcare and in the media.

As Australia embarks on a path of rebuilding after a challenging 12 months of catastrophic bushfires and then the COVID-19 pandemic, it is critical we ensure that Australians affected by complex mental health issues are not left behind.

Thank you to the almost 2,000 Australians living with complex mental health issues who shared their stories with the **National Stigma Report Card** research team. Thank you to the team at SANE Australia, the Melbourne School of Psychological Sciences at the University of Melbourne and our sector partners who have worked on this project over the past two years. And finally, thank you to the Paul Ramsay Foundation which has generously supported the project, enabling change through the power of philanthropy.

Lucy Myer

Chair, SANE Australia

October 2020

Table of contents

roiewoiu	4
Table of contents	5
Acknowledgements	6
A note on content	7
What's needed?	8
Introduction	9
Summary of action required	12
Life domains	18
Relationships	19
Employment	20
Healthcare services	21
Social media	22
Mental healthcare services	23
Mass media	24
Welfare and social services	25
Education and training	26
Financial and insurance services	27
Housing and homelessness services	28
Cultural, faith or spiritual practices and communities	29
Sports, community groups and volunteering	30
Public and recreational spaces	31
Legal and justice services	32
Intersectionality	34
Take action	34
Glossany	35





A note on content

The National Stigma Report Card and Our Turn to Speak survey focus on understanding the impact of stigma and discrimination on people living with complex mental health issues, across a broad range of life domains. For many people, these experiences have a profound, sustained and negative impact. This document presents rich data on these themes, which some people may find confronting.

If you find the content of this document confronting, or if you or a loved one need support, the following services are available:

- To connect with a mental health professional Monday to Friday from 10am-10pm AEDT, you can call the SANE Helpline on 1800 187 263 or use the SANE Help Centre webchat. You can also email helpline@sane.org any time to receive a response from the SANE Help Centre team within 48 hours.
- For crisis support, call Lifeline on 13 11 14 at any time (24/7) or use the webchat at lifeline.org.au from 7pm to midnight AEDT every night.
- If you are in a situation that is harmful or life-threatening, call emergency services immediately on triple zero (000).

In the context of the **National Stigma Report Card**, people living with 'complex mental health issues' are defined as:

People aged 18 and over who identify as having:

- a complex mental illness
- an experience of complex trauma or
- very high levels of psychological distress

'Stigma' relates to the stigma associated with complex mental health issues unless otherwise specified. Further information on how stigma is defined is provided in the Introduction on page 9.

For more definitions see glossary on page 35.

We acknowledge that people's preferences about how they like their experiences to be described vary, and that not having these preferences respected can itself be stigmatising.

The intention of this document is to outline key areas for action in order to ensure that everyone is able to live a life free from stigma and discrimination.

What's needed?



Education is at the heart of reform.



Advocacy workshop participant

Australia's Long-Term National Health Plan acknowledges the impact stigma has on people accessing support for their mental health. Similarly, stigma and discrimination emerged as major themes impacting the experience of care during consultation work for the development of the 2030 Vision led by the National Mental Health Commission. Current reform opportunities such as the Productivity Commission's inquiry, the Royal Commission into Victoria's Mental Health System, and development of the 2030 Vision and National Preventive Health Strategy offer the policy imperative to invest in mental health and do things better.

The recommendations for action outlined in this report respond to the experiences of stigma and discrimination highlighted in the **Our Turn to Speak** survey findings. In particular, when participants were asked what change is most needed to reduce stigma and discrimination, three overarching themes emerged from their responses:

- Education, understanding and acceptance
- · Communication and visibility
- Accessible services, fair treatment and support

The only way to reduce stigma is exposure. If people can SEE that those with mental health conditions are just like them (and in fact were exactly them before experiencing mental health issues) they will learn it's not something to be afraid of or abusive about. Seeing people openly speak about mental health in general forums and not segregating the issue...

Our Turn to Speak participant

Queensland



To guide the elimination of stigma and discrimination within our community, our leaders need to act to:

- Develop and resource a comprehensive 10-year national program of work to reduce stigma and discrimination associated with complex mental health issues, drawing on the success of initiatives like 'Time to Change' in the United Kingdom.
- Provide coordinated interjurisdictional governance and oversight by the National Mental Health Commission for implementation of a comprehensive 10-year national program of work to reduce stigma and discrimination associated with complex mental health issues.
- Ensure people with lived experience of complex mental health issues play a central role in training, service planning and ongoing oversight for health and social services.

Introduction

People living with complex mental health issues are frequently, deeply and negatively impacted by stigma and discrimination.

In the context of the **National Stigma Report Card**, stigma describes negative and damaging stereotyped ideas and emotional responses relating to the experience of complex mental health issues, with the central perceptions being that someone is flawed, undesirable or threatening because of this experience. Discrimination occurs when stigma is expressed through negative action towards those with complex mental health issues.

Stigmatising attitudes, prejudicial emotions and discriminatory behaviour may be held and expressed by:

- · members of the general public
- those in positions of power
- employers and colleagues
- teachers
- · the media
- healthcare and mental healthcare providers
- · friends and family
- intimate partners
- · and others.

Those affected are impacted in numerous ways, including but not limited to: direct experiences of stigma and discrimination, anxious anticipation of future instances of such experiences, and withdrawal from life opportunities for fear of being subjected to stigma and discrimination.

The National Stigma Report Card draws on evidence primarily from a national survey of experiences of stigma and discrimination completed by people living with complex mental health issues. The survey was named Our Turn to Speak by members of the project's steering committee who live with complex mental health issues and believe the name reflects the intent of the survey.

Critical to each stage of development was the collaborative stakeholder engagement framework embedded into the **National Stigma Report Card**, from its conceptualisation right through to implementation and ongoing dissemination of the findings. This includes people with lived experience of complex mental health issues.

This inaugural **Our Turn to Speak** survey explored experiences of stigma and discrimination related to complex mental health issues across 14 life domains:



RELATIONSHIPS



EMPLOYMENT



HEALTHCARE SERVICES



SOCIAL MEDIA



MENTAL HEALTHCARE SERVICES



MASS MEDIA



WELFARE AND SOCIAL SERVICES



EDUCATION AND TRAINING



CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES



FINANCIAL AND INSURANCE SERVICES



HOUSING AND HOMELESSNESS SERVICES



SPORTS, COMMUNITY GROUPS AND VOLUNTEERING



PUBLIC AND RECREATIONAL SPACES



LEGAL AND JUSTICE SERVICES

The study was not intended to elicit an epidemiological understanding of the prevalence of stigma and discrimination, but rather an exploration of people's experiences and opportunities for future advocacy. The data that emerged from the survey includes experiences of:

- Perceived/experienced past stigma and discrimination
- Anticipated future stigma and discrimination
- Withdrawal from opportunities
- Intersectional stigma and discrimination relating to experiences other than living with complex mental health issues
- Positive treatment in connection with participants' experience of complex mental health issues.

The results of the **Our Turn to Speak** survey suggest that people living with complex mental health issues experience stigma and discrimination across many areas of their life.

Between 25% and 70% of all 1,912 participants of the **Our Turn to Speak** survey said their experiences of stigma and discrimination in the previous 12 months had affected them most in terms of relationships, employment, healthcare services and social media.

For 12 of the 14 life domains, more people held concerns about future experiences of stigma and discrimination than about negative treatment they had experience in the previous 12 months. This is understandable, given the profound experiences of stigma and discrimination that many participants chose to write about in their survey answers or share with the interviewers.

The stories shared by participants also showed that for 10 life domains, rates of withdrawal from opportunities were also greater than experiences of stigma and discrimination in the previous 12 months. For example, participants reported that they had avoided:

- socialising with others
- applying for employment opportunities
- getting help for their physical and mental health issues when they needed it
- applying for flexible study arrangements that would help them participate in education and training.

It is highly concerning that stigma and discrimination has caused many people living with complex mental health issues to miss out on the important life opportunities, activities and social connections that are known to contribute towards personal and psychosocial recovery.

Three broad themes emerged from participants' responses to the final optional question about what most needs to change to reduce stigma and improve the experience of living with complex mental health issues:

- Education, understanding and acceptance:
 Participants wanted people around them to be informed about complex mental health issues, to understand and be understanding of their experiences, and to ultimately accept them.
- Communication and visibility: Participants
 wanted people to speak to them and about
 them with respectful and inclusive language.
 They wanted themselves and their peers living
 with complex mental health issues to be visible
 in their workplaces, in the media and in the
 community.
- Accessible services, fair treatment and support: Participants wanted to be able to access necessary services readily and without judgement, to be treated fairly by service providers, and to be supported in ways that were inclusive and accepting.

The purpose of this work is to firstly understand the experiences of stigma and discrimination impacting people living with complex mental health issues, and secondly to create meaningful change. SANE Australia, together with its Coalition of Advocates, looks forward to progressing the recommendations for action outlined in this document.



For more information about the project, including access to the full **National Stigma Report Card** findings and online data explorer, visit

www.nationalstigmareportcard.com.au



Summary of action required

Eliminating stigma and discrimination towards people living with complex mental health issues requires all tiers of government, and a multisectoral, whole-of-community effort. Actions that have been found to be effective in reducing stigma in other jurisdictions include:

- initiatives that promote empathy through increasing social contact and exposure to people living with complex mental health issues
- comprehensive campaigns that include concrete actions beyond awareness raising
- calling out and rectifying systemic barriers that permit discrimination.



More open and honest conversations need to take place. The 'people in control/with more power' i.e. media, politicians etc. should actually speak with people that have/are going through mental health issues and get an understanding of what it is like and what the processes are to get help.

Our Turn to Speak participant Victoria

Key to who is responsible



Federal Government



State and Territory Government



Local Government



NDIA



Primary Health Networks



Education providers



Employers



Healthcare organisations



Community organisations



Everybody

Summary of recommendations for action

KEY PRIORITIES			
1.	Develop and resource a comprehensive 10-year national program of work to reduce stigma and discrimination associated with complex mental health issues, drawing on the success of initiatives like 'Time to Change' in the United Kingdom.		
2.	Provide coordinated interjurisdictional governance and oversight by the National Mental Health Commission for implementation of a comprehensive 10-year national program of work to reduce stigma and discrimination associated with complex mental health issues.		
3.	Ensure people with lived experience of complex mental health issues play a central role in training, service planning and ongoing oversight for health and social services.		
RE	LATIONSHIPS		
4.	Expand access to evidence-based psychosocial programs, discussion groups and events that build meaningful connections, positive relationships and communication skills to reduce self-stigma and isolation.	III NDIA	
5.	Fund and implement evidence-based psychoeducation programs and respite options for carers, including young carers, to build their capacity to support their loved ones.		
6.	Improve identification of those supporting people living with complex mental health issues and increase their access to family therapy, open dialogues and models of care that include an individual's support network.	m moia	

EM	IPLOYMENT	
7.	Ensure that the National Workplace Initiative and other approaches to improving mental health in the workplace are inclusive of complex mental health issues by promoting reasonable adjustments, flexibility, safe disclosure, unconscious bias training and mental health first aid.	@ @
8.	Increase visibility, representation and valuing of lived experience perspectives in the workplace through inclusion in training, decision-making and establishment of peer support roles.	©
9.	Increase funding for programs that support people affected by complex mental health issues to identify their strengths and employment goals with the option to access support during their employment.	III NDIA
HE	ALTHCARE SERVICES	
10.	Deliver education opportunities (informed by individuals with lived experience) and trauma-informed care training for the health workforce to build mental health literacy among health workers – including doctors, nurses and paramedics – to a level that corresponds with physical health literacy among that cohort.	
11.	Provide physical health screening within mental health services to better meet the physical health needs of people affected by complex mental health issues.	
12.	Increase availability of the lived experience workforce across key parts of the health system, such as emergency departments.	
SO	CIAL MEDIA	
13.	Develop a social media campaign to share positive stories of hope and recovery from people with lived experience of complex mental health issues.	
14.	Develop a resource to educate social media users about the impact of stigmatising language.	
15.	Encourage social media platforms to consider safety-by-design principles and include a reporting function that enables people affected by complex mental health issues to report stigmatising behaviour.	
ME	NTAL HEALTHCARE SERVICES	
16.	Facilitate shared decision-making in clinical settings by:	
a.	embedding it in professional development programs for clinicians; and	
b.	increasing uptake of advance care directives.	
17.	Increase funding for holistic clinical and psychosocial mental health services, support coordination and system navigation specific to the needs of people affected by complex mental health issues.	m mia
18.	Increase training and professional development for mental health professionals inclusive of the outcomes of complaint processes, the legislative context and overarching human rights framework.	

MA	SS MEDIA	
19.	Increase complex mental health literacy among journalists and media outlets through education and training.	
20.	Ensure journalists and media outlets report stories involving people with complex mental health issues responsibly and respectfully, and increase inclusion of the perspective of people with lived experience.	
21.	Encourage media outlets, political leaders and key community spokespeople to adopt the relevant Mindframe guidelines and include help-seeking information that is specific for people affected by complex mental health issues in their stories.	
WE	LFARE AND SOCIAL SERVICES	
22.	Provide training for client-facing staff and decision makers working for welfare and social services (such as Centrelink, Child Services and the National Disability Insurance Agency) to increase awareness and capability in responding to the needs of people living with complex mental health issues.	m mdia
23.	Ensure advisory and governance groups overseeing the delivery of welfare and social services include people affected by complex mental health issues, embodying co-design principles.	m mda
24.	Reduce barriers to income support and social services support by:	
a.	increasing flexibility for the Disability Support Pension to allow for increased engagement in the workforce without the threat of losing access to the pension;	
b.	raising the rate of unemployment benefits to permanently align with the current standard of living and other welfare payments;	
C.	increasing access to the National Disability Insurance Scheme (NDIS) for eligible participants living with complex mental health issues who meet the criteria; and	NDIA
d.	improving access to information about available support services.	























Community organisations Everybody



Local Government



NDIA

Primary Health Networks

Education providers

Employers

EDUCATION AND TRAINING 25. Increase promotion of and support available for people affected by complex mental health issues in educational settings, inclusive of students, and all academic and professional staff. 26. Provide capacity-building training for educational staff to better recognise and support the needs of people affected by complex mental health issues. 27. Revise special consideration criteria to ensure that the supports/modifications provided are tailored to the unique needs of students living with complex mental health issues. FINANCIAL AND INSURANCE SERVICES 28. Support the work of organisations such as the Insurance Discrimination Working Group in seeking to address stigma and discrimination faced by people affected by complex mental health issues when accessing (or trying to access) insurance products. 29. Remove existing standard exclusions impacting people affected by complex mental health issues when accessing (or trying to access) insurance and banking products. 30. Establish financial services programs that cater to the needs of people affected by complex mental health issues including financial planning, financial literacy and support to manage finances during any period of acute distress. HOUSING AND HOMELESSNESS SERVICES Increase funding to provide long-term, ongoing support for people affected by complex mental health issues to access and maintain safe and affordable housing. 32. Establish education programs coupled with incentives designed to help real estate agents and landlords better understand complex mental health issues and their role in supporting tenants, to reduce experiences of stigma and discrimination. 33. Facilitate greater integration between homelessness, public/social housing and mental health services for people accessing both systems who require ongoing support to access and maintain safe and affordable housing. **CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES** Work with cultural and faith leaders to increase their understanding of how complex mental health issues impact people and to develop appropriate mental health literacy resources for their communities.







NDIA





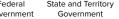












Local

NDIA

Primary Health

Education

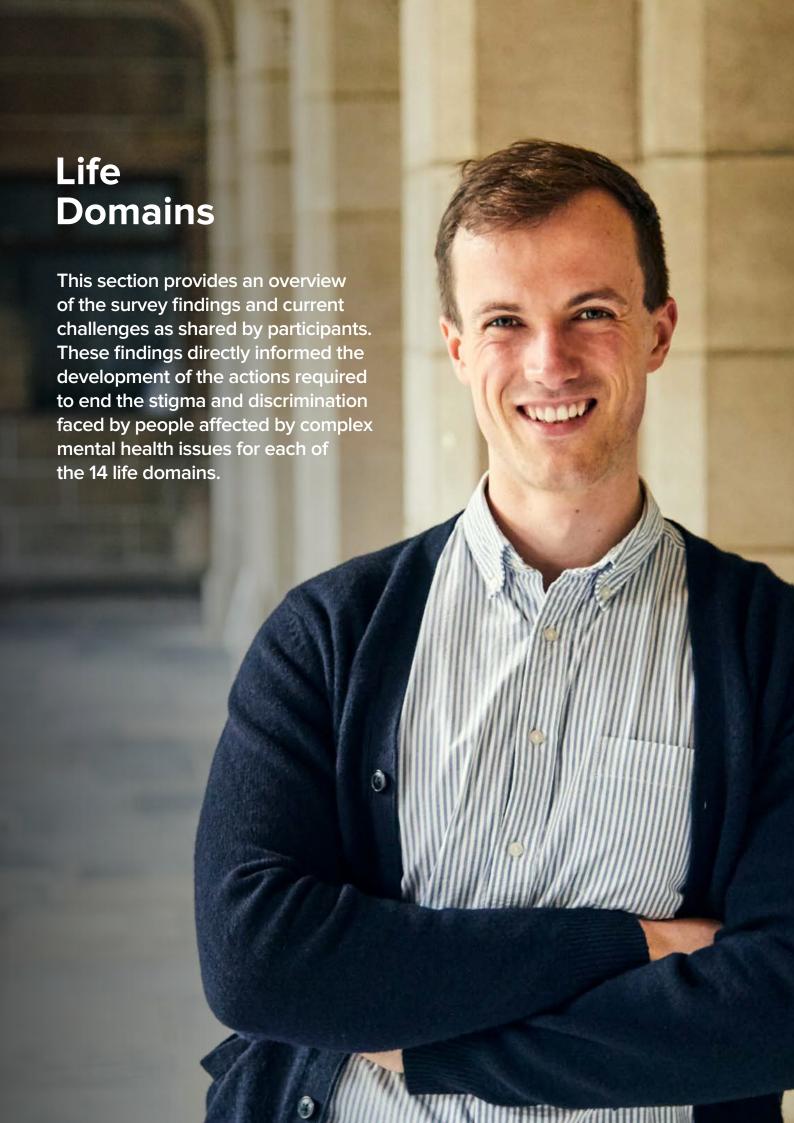
Employers

Healthcare

Community organisations

Everybody

SPO	ORTS, COMMUNITY GROUPS AND VOLUNTEERING	
35.	Encourage influential and elite sporting codes to improve their complex mental health literacy by raising awareness about the full range of mental health experiences to their players, supporters, networks and the general public.	
36.	Increase inclusion of lived experience storytelling in communications and events to improve community group members' understanding and inclusion of people living with complex mental health issues.	
37.	Promote participation of people with complex mental health issues in sport by raising awareness about these experiences and celebrating sporting leaders living with complex mental health issues.	
PU	BLIC AND RECREATIONAL SPACES	
38.	Increase training about the needs of people affected by complex mental health issues for public transport leaders and staff.	
39.	Increase accessibility of public spaces and recreational activities for people affected by complex mental health issues by providing funding opportunities through psychosocial services and allowing a support person (or animal) to attend.	
LEG	GAL AND JUSTICE SERVICES	
40.	Promote zero tolerance approach to violence and harassment by law enforcement officials and ensure all uniformed police officers have received trauma-informed and mental health training that includes a focus on appropriate responses to people affected by complex mental health issues.	
41.	Increase the availability of programs that support dual attendance by police and a trained mental health professional or peer worker at police callouts responding to distress involving people affected by complex mental health issues.	
42.	Increase availability of peer support programs for people affected by complex mental health issues to support people accessing the courts in both state and federal jurisdictions, and increase provision of pro bono legal support, including for those who wish to self-represent.	
INT	ERSECTIONALITY	
43.	Provide improved physical health screening and care which focusses on indicators of health other than weight, with a focus on providing size inclusive, weight neutral 'Health At Every Size'-informed care across both physical healthcare and mental healthcare settings.	*
44.	Ensure mental health information, resources and campaigns include diverse imagery that is inclusive of the LGBTIQA+ community, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, people with disability, and any age, size, gender, sex, sexuality, culture and religion.	
45.	Increase education and understanding among mental health professionals of the unique needs of people from diverse cultural backgrounds, communities, and intersectional experiences; including people who identify as Aboriginal or Torres Strait Islander, people of colour, people of diverse faiths and spiritual beliefs, people with physical and chronic health issues and disabilities, and people who identify as LGBTIQA+.	NDIA &



RELATIONSHIPS

Relationships are central to the human experience. Connection with others has the ability to optimise wellbeing and provide support during challenging times. For people affected by complex mental health issues, the impact of that support can be strengthened by having families and friends who understand their unique experiences and provide the types of support that are beneficial for their loved one.



Having my illness dismissed, ignored, unaccommodated and being avoided by potential friends is a constant reality for me.

Our Turn to Speak participant Western Australia

Not all relationships are positive all of the time. While the reasons for this are complex and multi-dimensional, it tells us that more support is needed to equip people affected by complex mental health issues, as well as their families, friends and communities, and others in their support networks, to increase understanding and to help nurture and maintain their personal relationships.

Many carers, families and friends offer significant and sustained support to loved ones directly affected by complex mental health issues. The impact of their caring role can be hard to quantify and many carers report feeling unsupported by the services and systems in place to assist them and their loved one. Providing adequate carer support is integral to ensuring that people affected by complex mental health issues enjoy healthy and positive relationships with their loved ones.





Without social connections life gets very difficult. I think we need campaigns for carers, friends and family, so they can get the information they need, in order to understand and support us better.



- Expand access to evidence-based psychosocial programs, discussion groups and events that build meaningful connections, positive relationships and communication skills to reduce self-stigma and isolation.
- Fund and implement evidence-based psychoeducation programs and respite options for carers, including young carers, to build their capacity to support their loved ones.
- Improve identification of those supporting people living with complex mental health issues and increase their access to family therapy, open dialogues and models of care that include an individual's support network.

EMPLOYMENT

Having something meaningful to do is vital for mental health. Being employed can contribute to our sense of purpose and accomplishment. 'Mentally healthy' workplaces – those that are sensitive and equipped to respond to the needs of people with complex mental health issues – can offer a nurturing environment in which people can bring their 'whole selves' to work. It is these types of workplaces that are likely to support wellbeing and recovery for people living with complex mental health issues.



I found returning to work really hard after periods of acute illness. I've had to change jobs and downsize my career but with more legitimate support I could achieve more.

Our Turn to Speak participant

Victoria

Respondents to questions about this life domain reported unfair treatment in the workplace as a result of stigma associated with their complex mental health issues. Concerns also extended to unfair denial of flexible work arrangements, employment and promotion opportunities, and social exclusion. Others highlighted barriers to obtaining or sustaining employment, ranging from difficulties at the application and interview stages, or the process of engaging with employment support services. These difficulties continued throughout the lifecycle of employment for many, with discussion of unfair treatment, pressure to disclose or to conceal mental health status, and termination following disclosure being common themes.





I got asked why I needed to take sick leave; I told them that I was unwell, the manager kept pushing me to talk, so I told him I had to see a psychiatrist, and the next day I was fired from my job as it was "unsafe to have an unstable employee working with the team.

Our Turn to Speak participant

Western Australia

Some people affected by complex mental health issues may require more support to enter or maintain employment – from carers, families and others supporting people impacted by these issues. Many employers need guidance to understand the support needs of people affected by complex mental health issues and how they can create a more inclusive work environment. These goals tie in neatly with the work currently underway to develop the National Workplace Initiative, led by the National Mental Health Commission and Mentally Healthy Workplace Alliance.

- Ensure that the National Workplace Initiative and other approaches to improving mental health in the workplace are inclusive of complex mental health issues by promoting reasonable adjustments, flexibility, safe disclosure, unconscious bias training and mental health first aid.
- Increase visibility, representation and valuing of lived experience perspectives in the workplace through inclusion in training, decision-making and establishment of peer support roles.
- Increase funding for programs that support people affected by complex mental health issues to identify their strengths and employment goals with the option to access support during their employment.

HEALTHCARE SERVICES

Access to healthcare is critical to supporting physical and mental health and wellbeing. Mental health issues often occur alongside physical problems. Likewise, physical issues are commonly experienced in relation to a background of mental health issues. A health system that is supportive and sensitive to complex mental health issues is one that is likely to contribute to whole-of-self health and wellbeing for people with lived experience, and for those around them.



I am scared of being forced to have treatment for mental health when I seek physical health treatment.



Our Turn to Speak participant
Queensland

66

We need to stop treating mental health as something separate to physical health. There's just health. I should be treated the same having bipolar disorder as if I had a chronic 'physical' illness. There isn't a difference: the brain is just another one of the body's organs.



Our Turn to Speak participant Victoria

These findings indicate a need for building capacity across the health workforce to ensure clinicians understand the needs of people affected by complex mental health issues, particularly across key parts of the health system. This includes ensuring that healthcare settings are welcoming and supportive for people with diverse needs. Improving the interface between physical and mental health services to ensure that people affected by complex mental health issues are supported within both settings and treated holistically is crucial to improving health outcomes.

For many people affected by complex mental health issues, accessing healthcare services can be problematic. Many survey participants reported instances of their mental health diagnosis dominating their interactions with health services, resulting in neglect of their physical healthcare needs. Some responses indicated that physical health needs were ignored or dismissed due to the presence of complex mental health issues. This deterred people from disclosing their mental health needs or seeking treatment for their physical health conditions. Other people reported that health services did not adequately take into consideration their mental health needs, particularly in relation to the provision of traumainformed care.

- Deliver education opportunities (informed by individuals with lived experience) and traumainformed care training for the health workforce to build mental health literacy among health workers – including doctors, nurses and paramedics – to a level that corresponds with physical health literacy among that cohort.
- Provide physical health screening within mental health services to better meet the physical health needs of people affected by complex mental health issues.
- Increase availability of the lived experience workforce across key parts of the health system, such as emergency departments.

SOCIAL MEDIA





People are awful. I wrote about how I'd tried to take my life, and was absolutely attacked by trolls who commented sarcastically and extremely hurtfully. It's not safe to express yourself on social media. Not at all.

Our Turn to Speak participant Victoria

Social media can be a powerful tool for people to connect, learn and have fun. However, it also presents significant challenges: many survey participants reported seeing or reading content that was hurtful or offensive in terms of how mental health issues were portrayed. There is an enormous opportunity to ensure online communities are safe, inclusive and respectful of all experiences, including complex mental health issues. To do this, users need to be educated about the impact of the language and imagery they use when referring to complex mental health issues. Mechanisms to report content that is offensive are also critical to improving the online experience for people with complex mental health issues.

Many survey participants reported they had withdrawn from or avoided social media, filtered the information they share, not read or contributed to comments about mental health, and taken other measures to protect privacy. Some shared stories of seeing stigmatising content about specific mental health diagnoses, examples of trolling, bullying and inappropriate language. Where participants did share positive experiences, these related to the use of social media within advocacy projects or the ability to foster community through closed or private online groups.

In order to create a social media environment that is inclusive and safe for people affected by complex mental health issues, users need to have a better understanding of such issues and how to speak about them positively. Conversely, where content about mental health is not positive, users need a mechanism where they can easily report this behaviour, with social media platforms taking responsibility for harmful content that perpetuates stigma and discrimination.

- Develop a social media campaign to share positive stories of hope and recovery from people with lived experience of complex mental health issues.
- Develop a resource to educate social media users about the impact of stigmatising language.
- Encourage social media platforms to consider safety-by-design principles and include a reporting function that enables people affected by complex mental health issues to report stigmatising behaviour.

MENTAL HEALTHCARE SERVICES



Access to supportive mental healthcare is essential. This is particularly relevant for people living with complex mental health issues, whose needs often benefit from ongoing and frequent access to multiple mental healthcare services. The experiential quality of mental healthcare service access is an important part of the treatment and recovery process. It can promote positive treatment outcomes if supportive, welcoming and encouraging; or if negative, can lead to poor outcomes by discouraging treatment participation and help seeking.



The gap between the standard of care in the public mental health system - especially the hospital system and the private system needs to close. The public mental health system needs a big injection of funds and attention.



I have been denied services at the ER because of my borderline personality disorder - I have been told that I will 'always feel suicidal... it's chronic and I should learn how to live with it' and was denied admission to the ER despite saying I was extremely suicidal, was unsafe to go home and would hurt myself if I went home.

Our Turn to Speak participant

Queensland

Our Turn to Speak participant

Victoria

Stigma and discrimination negatively impact people affected by complex mental health issues and those accessing the mental health system. Urgent investment and reform are required to address the fundamental structural issues which perpetuate much of the stigma and discrimination experienced by service users.

Participants shared experiences of perceived and anticipated stigma in accessing residential, rehabilitation or hospital-based mental health services. There were many accounts of people being denied care, discharged prematurely, excluded from treatment planning, as well as the use of restrictive practices. For some, these experiences resulted in them withdrawing from seeking support and treatment opportunities in mental healthcare services. A number of participants drew comparisons with the private mental health system, which they reported as offering more therapeutic and accessible service

offering more therapeutic and accessible services.

Many of the experiences reported in this domain echo the findings of previous inquiries into the public mental health systems across Australia. Consistently, access, support coordination, navigation and workforce capacity have been cited as areas requiring reform.

- Facilitate shared decision-making in clinical settings by:
 - a. embedding it in professional development programs for clinicians; and
 - b. increasing uptake of advance care directives.
- Increase funding for holistic clinical and psychosocial mental health services, support coordination and system navigation specific to the needs of people affected by complex mental health issues.
- Increase training and professional development for mental health professionals inclusive of the outcomes of complaint processes, the legislative context and overarching human rights framework.

MASS MEDIA

Many people who have not had exposure to people living with complex mental health learn about such experiences through mass media reporting. Unfortunately, portrayals are often inaccurate, perpetuating misinformation as well as harmful stereotypes – including that people living with complex mental health issues are dangerous or unpredictable. While there are existing guidelines used to promote safe and responsible reporting of mental illness, there is varying uptake of these across media outlets. The media can be a powerful tool in educating people about experiences of mental health and can also be used to profile lived experience stories of hope and recovery.



Often concerns about stigma are unfortunately dismissed as overreactions or being too sensitive. Depiction of mental illness in the media is one of the biggest contributors to my reluctance to share my personal experiences.

Our Turn to Speak participant Western Australia



More true stories need to be told to the public.



Our Turn to Speak participant New South Wales

Participants reported that they had seen, read or heard media stories that perpetuate stigma about mental health issues. Almost all participants who responded to the mass media-specific section of the survey reported being exposed to news media outputs that portrayed people who live with mental health issues as dangerous, unsafe or unpredictable. Participants explained that nuanced messaging around the multi-faceted relationships between mental health issues and violence is typically lacking. Many participants reported that they had withdrawn from or opted out of watching, reading or listening to mass media content.

The media has a strong influence over the public's understanding of mental health issues. Unfortunately, the findings reported here suggest that, despite decades of mental health reporting guidelines, journalist training initiatives and public-facing campaigns, misinformation and damaging stereotypes are still being circulated. Continuing work through the StigmaWatch program is required to promote responsible reporting and ongoing education about complex mental health issues.

- Increase complex mental health literacy among journalists and media outlets through education and training.
- Ensure journalists and media outlets report stories involving people with complex mental health issues responsibly and respectfully, and increase inclusion of the perspective of people with lived experience.
- Encourage media outlets, political leaders and key community spokespeople to adopt the relevant Mindframe guidelines and include helpseeking information that is specific for people affected by complex mental health issues in their stories.

WELFARE AND SOCIAL SERVICES



Welfare and social services exist to help improve the wellbeing of people who need financial support or have multi-system needs. For people who manage complex presentations, such as those living with complex mental health issues, welfare and other social services can play a critical role in coordinating their care. Too often, these services are more geared towards physical illness and lack appropriate models to adequately assess and support mental health experiences. This creates inequity, unnecessary barriers, and can result in withdrawal from support altogether.

Survey participants indicated that interactions with staff/providers, and inflexibility within the system itself, were driving perceptions of stigma and discrimination in this life domain. Some participants explained that their applications for welfare and social services had been denied because of mental health issues that were deemed to be 'too complex' or they were told they were 'not sick enough'. The Disability Support Pension (DSP) and National Disability Insurance Scheme (NDIS) were identified as incredibly challenging for people with complex mental health issues to access, navigate, use, and maintain due to a host of systemic barriers like changes to eligibility criteria. Concerningly, a significant proportion of participants endorsed concerns that their welfare benefits, disability pensions or disability schemes might be unfairly suspended or cancelled in the future.

Creating systems that are compassionate, inclusive and responsive to the needs of people affected by complex mental health issues will help ensure that people can access the support they need. Further work is required to reform welfare and social services so that eligibility and assessment processes are inclusive of complex mental health issues and that they provide sustainable support for those who need it.



It's impossible to get a DSP and it is hard to gain evidence. I've felt that NDIS was never likely and have started and stopped applications. [...] I manage [my] way through the system being polite and not asking for support I might be eligible for as I'm fearful it will come back to bite me down the track. It's a punitive system and does little to understand individual need and is more and exercise of box ticking.

Our Turn to Speak participant

Victoria

- Provide training for client-facing staff and decision makers working for welfare and social services (such as Centrelink, Child Services and the National Disability Insurance Agency) to increase awareness and capability in responding to the needs of people living with complex mental health issues.
- Ensure advisory and governance groups overseeing the delivery of welfare and social services include people affected by complex mental health issues, embodying co-design principles.
- Reduce barriers to income support and social services support by:
- a. increasing flexibility for the Disability Support Pension to allow for increased engagement in the workforce without the threat of losing access to the pension;
- raising the rate of unemployment benefits to permanently align with the current standard of living and other welfare payments;
- c. increasing access to the National Disability Insurance Scheme (NDIS) for eligible participants living with complex mental health issues who meet the criteria; and
- d. improving access to information about available support services.

EDUCATION AND TRAINING





I was due to start university in early 2019 however I had to go into hospital for my mental health. I met with the student services/guidance councillor [sic] and I was not given any options for my study, simply just told I could not start and that there was no alternate pathway for me so I HAD to defer.

Our Turn to Speak participant
New South Wales

Benefits of access to education and training include: enabling people to pursue their chosen profession, upskilling and enhanced economic and social participation. In general, people affected by complex mental health issues have lower educational attainment than the general population. Ensuring educational institutions are responsive to the needs of people affected by complex mental health issues and can support them to complete their educational goals is crucial to increasing educational attainment among this cohort.

Survey participants reported that interactions with educational or training staff and inflexibility around study arrangements drove their perceptions of stigma and discrimination in this area. Rigid arrangements within many educational institutions and anticipation of stigma and discrimination have left many respondents reluctant to ask for flexible study arrangements. Some described having withdrawn from study altogether as a result. Many respondents also shared that the cognitive, emotional and social experiences associated with complex mental health issues were barriers to attending classes and placements, and completing coursework.

Increased awareness of complex mental health issues within educational settings is required to ensure students and staff are informed about available support to better recognise and support people's needs.

- Increase promotion of and support available for people affected by complex mental health issues in educational settings, inclusive of students, and all academic and professional staff.
- Provide capacity-building training for educational staff to better recognise and support the needs of people affected by complex mental health issues.
- Revise special consideration criteria to ensure that the supports/modifications provided are tailored to the unique needs of students living with complex mental health issues.

FINANCIAL AND INSURANCE SERVICES



Financial and insurance services are tools that enable people to manage their finances in a range of different circumstances. The exclusion of people affected by complex mental health issues from these services can have a devastating impact on their wealth and living conditions throughout their lives. It is essential that access to financial support and insurance is improved, to ensure people affected by complex mental health issues are aware of their rights and can enjoy equal access to these services.

Participants who had accessed insurance services reported greater perceived experiences of unfair treatment and denial of products compared with participants who had accessed banking services. Almost all participants who responded to the financial and insurance-specific section of the survey said they had been treated unfairly by insurance providers when applying for insurance products. More than half of participants reported receiving similar treatment from banking providers (for example, mortgage lenders and loan providers) when applying for related products.

In March 2018, a Parliamentary Joint Committee on Corporations and Financial Services made a series of recommendations, including implementing a mandatory Code of Practice to avoid discrimination on the basis of disclosed mental health issues or treatment history. The **Our Turn to Speak** survey findings suggest that, almost two years later, discriminatory practices – including structural barriers to accessing services and products – unfortunately continue to pose challenges to people living with complex mental health issues.



I am not able to receive travel insurance unless I exclude my mental health condition. I am not able to receive, Income Protection, or Life insurance due to my mental health condition.

Our Turn to Speak participant
South Australia

- Support the work of organisations such as the Insurance Discrimination Working Group in seeking to address stigma and discrimination faced by people affected by complex mental health issues when accessing (or trying to access) insurance products.
- Remove existing standard exclusions impacting people affected by complex mental health issues when accessing (or trying to access) insurance and banking products.
- Establish financial services programs that cater to the needs of people affected by complex mental health issues including financial planning, financial literacy and support to manage finances during any period of acute distress.

HOUSING AND HOMELESSNESS SERVICES



Access to safe and affordable housing is a fundamental ingredient to mental health and wellbeing. This relationship is bi-directional in that experiencing an exacerbation in mental health issues can create housing insecurity if people are not adequately supported, and tenuous housing arrangements can in turn create psychological distress. Trajectories, led by Mind Australia in partnership with the Australian Housing and Urban Research Institute (AHURI), found that housing is the foundation for mental health recovery.

The survey data showed that participants living in private rental housing reported greater perceived experiences of unfair treatment and denial of accommodation than participants living in public or community housing, or those accessing homelessness services. Regardless of the type of housing or services participants had accessed, there was strong agreement that unfair treatment by housing officials, landlords and household members was influenced by stigma about mental health issues. Participants reported that housing officials' perceived limited understanding about complex mental health issues had acted as a barrier to them finding and maintaining safe, comfortable, and appropriate accommodation that would meet their diverse needs.

Improving access to housing for people affected by complex mental health issues requires a multifaceted approach targeting the whole housing continuum. There are existing efforts to advocate for increased funding to establish more affordable housing and support programs to maintain housing as articulated by the work of Trajectories and the Everybody's Home campaigns. Adoption of the recommendations outlined in these campaigns is vital to improving access to long-term sustainable supported housing.



I now will avoid telling housemates about my mental health issues unless they have gained my absolute trust after many months.

Our Turn to Speak participant Victoria

In addition to improving the availability of affordable housing, improved support to maintain housing is required. This can range from enhanced integration between housing and mental health services, to programs that support those who wish to upskill in maintaining their homes and finances.

- Increase funding to provide long-term, ongoing support for people affected by complex mental health issues to access and maintain safe and affordable housing.
- Establish education programs coupled with incentives designed to help real estate agents and landlords better understand complex mental health issues and their role in supporting tenants, to reduce experiences of stigma and discrimination.
- Facilitate greater integration between homelessness, public/social housing and mental health services for people accessing both systems who require ongoing support to access and maintain safe and affordable housing.

CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES



Cultural, faith or spiritual practices provide a source of community and connection for many people. Unfortunately, some people affected by complex mental health issues have experienced stigma and discrimination in such groups or communities, due to a lack of awareness or erroneous beliefs about their mental health needs. Educating all communities to be empathetic and inclusive will ensure people affected by complex mental health issues can enjoy full participation.

Survey participants who responded to the section of the survey specific to this life domain reported that they had been unfairly treated by members of their cultural, faith or spiritual communities and 'othered'. They shared experiences of being denied support by community members, including people in positions of power such as priests and pastors, only to be met with criticism about their 'lack of faith', 'weak character', or being coerced to undergo interventions like exorcism.

Cultural practices, spiritual beliefs, and religion can facilitate social support and belonging, structure and ritual, existential meaning, guidance on ethics and morality, reflective practice, identity development and more. They can also be important contributors to mental health generally, and personal recovery in the context of living with complex mental health issues. It is critical that people affected by complex mental health issues can participate in the cultural, faith or spiritual practices and communities that are important to them, without fear of stigma and discrimination. This requires building capacity among members of these communities to improve their understanding of complex mental health issues.

Mental illness is seen as a symptom of lack of faith and/or demonic possession. Tired of people trying

to cast demons out of me and also seeing my sexual orientation as a symptom of mental illness.

Our Turn to Speak participant
Australian Capital Territory

Action required:

 Work with cultural and faith leaders to increase their understanding of how complex mental health issues impact people and to develop appropriate mental health literacy resources for their communities.

SPORTS, COMMUNITY GROUPS AND VOLUNTEERING



Sport, interest groups and volunteering are all great ways to create a sense of connectedness and participation in our community. Organisations or groups that host these activities should be kind, inclusive and open to the diverse needs of anyone who wishes to take part. Unfortunately, people affected by complex mental health issues often report exclusion from these groups and say many such groups lack understanding about their experiences.

Survey participants indicated that unfair treatment and exclusion may have been driven by other group members' lack of understanding about ways in which complex mental health issues can affect a person's capacity to participate. Some respondents reported that their concerns around disclosure and associated stigma and discrimination had stopped them from joining such groups. These experiences were amplified in rural and remote communities. Conversely, stories about positive experiences as a result of participation in sports, community groups and volunteering were reported when compassion, understanding and connection underpinned other members' responses to participants' experiences of complex mental health issues.

Inclusion of people affected by complex mental health issues across the fabric of our society not only strengthens diversity and inclusion, but is also a powerful anti-stigma strategy in itself. While some sporting codes have supported the disclosure of high prevalence mental health conditions such as anxiety and depression, further work is required to ensure awareness raising across sport and community groups is inclusive of the full continuum of mental health experiences.

The more I am open and talk about my illness, it lets others in the community know that I have an understanding of mental illness, and it creates positive discussions with them. Conversations which may save lives, break down stigma, and the change we want to see in this space. Others around me then become aware of what my specific needs are and are circumstances that may be triggering for me.

Our Turn to Speak participant Western Australia

- Encourage influential and elite sporting codes to improve their complex mental health literacy by raising awareness about the full range of mental health experiences to their players, supporters, networks and the general public.
- Increase inclusion of lived experience storytelling in in communications and events to improve community group members' understanding and inclusion of people living with complex mental health issues.
- Promote participation of people with complex mental health issues in sport by raising awareness about these experiences and celebrating sporting leaders living with complex mental health issues.

PUBLIC AND RECREATIONAL SPACES



Everyone should be able to enjoy public spaces and participate in recreational activities. These are key ingredients to people feeling connected and part of their community. Sadly, many respondents reported perceived or anticipated stigma in relation to this area of their life, indicating that there is much work to be done to ensure the places where people come together are inclusive for all.

Survey participants reported a range of experiences, including being unfairly treated by hospitality and public transport staff, denied service at public spaces or events, and in some instances, denied entry. Participants' free text and interview responses comments highlighted numerous instances of unfair treatment (particularly unwanted attention or negative reactions) in relation to aspects of complex mental health issues that are visible to others (for example, the use of a service dog or self-harm scars).

While reducing stigma and discrimination was introduced in 2017 as a priority target area for the Fifth National Mental Health and Suicide Prevention Plan, these findings suggest that many people living with complex mental health issues continue to experience discrimination in public spaces. Participants' experiences included avoidance or unwanted attention from members of the general public, and retail, hospitality, events and public transport staff refusing to assist them. Such instances of stigma and discrimination are known to compound the isolation of people affected by complex mental health issues, and ultimately compromises their psychosocial recovery – a key facilitator of which is social connectedness and participation.

Improved education and evidence-based, antistigma interventions designed to improve the public's understanding of, and compassion towards, those who experience complex mental health issues is required. This is particularly relevant to sectors where high levels of stigma and discrimination are reported, such as hospitality and public transport. More broadly, mechanisms that can increase participation across public spaces and events are needed.



If you're recognised in public as someone with a mental illness they might point and laugh at you, which is an experience of stigma and discrimination that I've had. If you're not recognised, then you can be another normal person in the crowd and go about your business.

Our Turn to Speak participant New South Wales

This includes working with local councils, mental health psychosocial services and event organisers to improve access for people affected by complex mental health issues. The high rates of withdrawal from opportunity endorsed by participants unfortunately suggests this aspect of their psychosocial recovery is at risk, and demands change.

- Increase training about the needs of people affected by complex mental health issues for public transport leaders and staff.
- Increase accessibility of public spaces and recreational activities for people affected by complex mental health issues by providing funding opportunities through psychosocial services and allowing a support person (or animal) to attend.

LEGAL AND JUSTICE SERVICES



Legal and justice services exist to provide support to people who are interacting with police, legal practitioners or the courts. People living with complex mental health issues should not feel that those services are poorly equipped to adapt to their diverse needs, or that justice has been denied them because of systemic stigma and discrimination. Disturbingly, however, for those participants who responded to the section of the survey specific to this life domain, that is often the case.

Difficulty accessing services was a common issue reported by participants. The belief that their issues were either trivialised or dismissed also emerged as a recurring theme. To compound matters, the anticipation of stigma and discrimination – often based on prior experiences of unfair treatment within the justice system – deterred people living with complex mental health issues from seeking legal redress.

Participants' free text and interview responses revealed that a lack of flexibility, empathy and support, at all levels within the justice system and across a range of legal disciplines, militated against the very principles of justice – namely liberty, autonomy, equality, and fairness. Several participants gave deeply troubling accounts of their interactions with police and the courts system, and considered that their mental health issues had been used against them in some way and had led to unjust outcomes.



Experience with family court, it definitely gets used against you. Felt like the magistrate couldn't be bothered, he cut me off after I'd get two words in. It's like they put dishonesty and mental illness in the same basket.

Our Turn to Speak participant Victoria

I was taken to hospital by force due to a police officer not understanding mental health. I was been taken to ED and they tried to put me in a paddy wagon.

Our Turn to Speak participant
Queensland

As with the majority of the life domains under examination, ignorance or inaccurate assumptions lie at the heart of these unacceptable experiences. Improved education and training are key factors in addressing stigma and discrimination within the justice system. Discriminatory beliefs and practices in this domain can have devastating impacts on people living with complex mental health issues, as our survey participants and all too often, the media, report.

- Promote zero tolerance approach to violence and harassment by law enforcement officials and ensure all uniformed police officers have received trauma-informed and mental health training that includes a focus on appropriate responses to people affected by complex mental health issues.
- Increase the availability of programs that support dual attendance by police and a trained mental health professional or peer worker at police callouts responding to distress involving people affected by complex mental health issues.
- Increase availability of peer support programs for people affected by complex mental health issues to support people accessing the courts in both state and federal jurisdictions, and increase provision of pro bono legal support, including for those who wish to self-represent.



Intersectionality

People may experience compounded stigma and discrimination as a result of their identity, physical characteristics or other health issues. The survey explored experiences of intersectional stigma and discrimination to better understand the impact that racial or cultural background, faith or spiritual beliefs, sexual orientation, gender identity and physical health or ability had on participants' experiences.

Action required:

- Provide improved physical health screening and care which focusses on indicators of health other than weight, with a focus on providing size inclusive, weight neutral 'Health At Every Size'informed care across both physical healthcare and mental healthcare settings.
- Ensure mental health information, resources and campaigns include diverse imagery that is inclusive of the LGBTIQA+ community, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, people with disability, and any age, size, gender, sex, sexuality, culture and religion.
- Increase education and understanding among mental health professionals of the unique needs of people from diverse cultural backgrounds, communities, and intersectional experiences; including people who identify as Aboriginal or Torres Strait Islander, people of colour, people of diverse faiths and spiritual beliefs, people with physical and chronic health issues and disabilities, and people who identify as LGBTIQA+.

Take action

Eliminating experiences of stigma and discrimination needs a community-wide and country-wide response. Every individual and organisation has a role to play and can help create a more equal and just society for people affected by complex mental health issues.

You can make change happen for people living with complex mental health issues by supporting SANE Australia and our vision for an Australia where people affected by complex mental health issues live long and fulfilling lives, free from stigma and discrimination by:

- Standing with people affected by complex mental health issues using the #StigmaAndMe hashtag
- Supporting us as we call on governments to develop and resource a comprehensive 10-year national program of work to reduce stigma associated with complex mental health issues
- Sharing these 'Recommendations for Action' and making a personal commitment to eradicate stigma and discrimination.

To learn more and support the project visit:

www.nationalstigmareportcard.com.au

Glossary

Anticipated stigma The extent to which an individual expects to be the target of stereotypes,

prejudice, or discrimination in the future.

Carer A family member or friend who supports a person living with a complex

mental health issue.

Complex mental health

issue

Describes a range of experiences including identifying as having a complex mental illness, having had an experience of complex trauma or experiencing

very high levels of psychological distress.

Complex trauma describes both exposure to multiple traumatic events –

often of an invasive, interpersonal nature – and the wide-ranging, long-term

effects of this exposure.

Discrimination When stigma is expressed through negative action towards people living

with complex mental health issues.

Lived experience Lived experience is defined as "personal knowledge about the world gained

through direct, first-hand involvement in everyday events rather than through representations constructed by other people." (Oxford English Dictionary)

People affected by complex mental health

issues

Individuals who themselves experience, or support someone experiencing, a

complex mental health issue.

Perceived stigma How someone thinks most people or the society view them personally, as a

member of a stigmatised group.

Prejudice Emotional reaction or feelings that people have toward a group or member

of a group.

Public stigma General public's reaction to people who have been diagnosed with a

mental illness, consisting of three components: stereotypes, prejudice and

discrimination.

Self-stigma The extent to which someone endorses the negative beliefs and feelings

associated with the stigmatised identity for themself. Sometimes known as

internalised stigma.

Stereotype Beliefs or 'cognitive schemas' about the characteristics and behaviours of

groups of individuals.

Stigma Describes negative and damaging stereotyped ideas and emotional

responses relating to the experience of complex mental health issues, with the central perceptions being that someone is flawed, undesirable or

threatening because of this experience.

Stigmatisation The social and cultural processes which result in negative stereotypes and

ideas.

Structural stigma Societal-level conditions, cultural norms, and institutional policies that

constrain the opportunities, resources, and wellbeing of the stigmatised.

Withdrawal from

opportunity

When an individual chooses not to participate in an activity for fear of being

stigmatised.



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