NATIONAL STIGMA REPORT CARD

REPORT ON FINDINGS FROM THE OUR TURN TO SPEAK SURVEY:

Understanding the impact of stigma and discrimination on people living with complex mental health issues

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SANE AUSTRALIA

Anne Deveson Research Centre
A SANE Australia initiative

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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.

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Foreword from SANE Australia Chair, Lucy Myer

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, while her 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 health care 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, the Melbourne School of Psychological Sciences at the University of Melbourne and our sector partners who have worked on the project over the past two years. And finally, thank you to the Paul Ramsay Foundation who generously supported the project enabling change through the power of philanthropy.

Lucy Myer
Chair, SANE Australia

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We respect and acknowledge each and every one of your contributions to our shared mission, which aims to make a real difference in the lives of people affected by complex mental health issues.

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OUR TURN TO SPEAK CHAMPIONS

- Stefanie Caminiti
- Bede Carmody
- Matt Dale
- Eleanor Danks
- Hannah Hyatt
- Phoebe Kingston

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Dr Michelle Blanchard and Dr Christopher Groot

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- Dr Brian Graetz, Program Associate, Paul Ramsay Foundation (to December 2019)
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- Mark Orr AM, CEO, Flourish Australia
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COALITION OF ADVOCATES

We acknowledge the support of the following organisations who joined our Coalition of Advocates:

- Australian BPD Foundation
- batyr
- Beyond Blue
- Butterfly Foundation
- Everymind
- Flourish Australia
- Grow
- headspace
- Health Justice Australia
- HelpingMinds
- Homelessness Australia
- Lifeline Australia
- Mental Health Association of Central Australia
- Mental Health Australia
- Mental Health Carers Australia
- Mental Health Council of Tasmania
- Mental Illness Fellowship of Australia
- Mind Australia
- Mission Australia
- National Aboriginal Community Controlled Health Organisation
- National LGBTI Health Alliance
- National Rural Health Alliance
- Neami National
- New Horizons
- Orygen, the National Centre of Excellence in Youth Mental Health

- ReachOut Australia
- Rural and Remote Mental Health
- Wellways

In addition to these Coalition members, we are very grateful to a large number of other peer support, mental health and community service organisations who shared the call for participation in the **Our Turn to Speak** survey.

A note on language and 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 and sustained impact. This report presents rich data on these themes, which some people may find confronting or distressing.

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

- For information, referral and counselling support about complex mental health issues, call SANE Australia on 1800 187 263 between 10am and 10pm AEST/AEDT Monday to Friday.
- For crisis support, call Lifeline on 13 11 14 any time.
- If you are in a situation that is harmful or life-threatening, please call emergency services immediately on triple zero (000).

Throughout this report:

- 'living with complex mental health issues' is used to describe 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.

- 'stigma' relates to the stigma associated with mental ill-health unless otherwise specified. Further information on how stigma is defined is provided in the report.

We acknowledge that individuals have different preferences for how they would like their experiences described and that not having these preferences respected can itself be stigmatising.

We hope that the work of the **National Stigma Report Card** creates a space to explore these, and other issues, in order to ensure that everyone is able to live a life free from stigma and discrimination.

Executive summary

BACKGROUND

Much has been achieved in the last two decades by focusing efforts on de-stigmatising common mental health conditions such as depression and anxiety. However, people affected by complex mental health issues continue to report being profoundly impacted by stigma and discrimination. This experience of stigma and discrimination was a central theme in consultations held to inform the development of the:

- *Vision 2030; Blueprint for Mental Health and Suicide Prevention* by the National Mental Health Commission (National Mental Health Commission, 2020)
- *Interim Report from the Royal Commission into Victoria's Mental Health System* (Royal Commission into Victoria's Mental Health System: Interim Report, 2019)
- *Draft Report from the Productivity Commission Inquiry into Mental Health* (Productivity Commission, 2019).

It is well established in empirical literature that experiences of stigma and discrimination in relation to complex mental health issues, such as schizophrenia, are different to experiences of higher-prevalence disorders, such as depression. However, little is known about precisely how stigma and discrimination are experienced by Australians living with complex mental health issues across a range of life domains.

The aim of the **National Stigma Report Card** is to gather Australian-first evidence on the experiences of stigma and discrimination for people living with complex mental health issues and to use this to drive positive change across a range of domains such as interpersonal relationships, employment, physical and mental healthcare services and the media.

The **National Stigma Report Card** is the flagship project of SANE Australia's Anne Deveson Research Centre and is conducted in partnership with the Melbourne School of Psychological Sciences at the University of Melbourne, with the support of the Paul Ramsay Foundation.

This report presents the findings from the first **Our Turn to Speak** survey which was conducted as part of the project. A total of 1,912 participants aged between 18 and 86 (M = 39.21, SD = 12.81) who lived with complex mental health issues completed the survey. Participants came from every Australian state and territory and completed the survey either online, in person, or by telephone between October 2019 and April 2020.

METHODOLOGY

The **Our Turn to Speak** survey collected in-depth data on participants' experiences of stigma and discrimination related to their complex mental health issues across 14 domains of life, such as employment, relationships, and healthcare services. Within each of these life domains, the survey asked about participants':

- perceived experiences of stigma and discrimination;
- anticipation of stigma and discrimination;
- withdrawal from life opportunities because of stigma and discrimination.

Participants were also asked about positive experiences in each life domain, and whether they had additionally experienced stigma in relation to other personal characteristics such as physical health or ability, racial or cultural background, or gender identity. Participants' experience of complex mental health issues and their personal impact were also assessed in order to explore relationships between specific mental health experiences and stigma and discrimination.

Opportunities to elaborate on scaled survey responses were provided throughout the survey in order to capture participants' rich and detailed experiences. The survey ended on an empowering note and invited participants to share what they felt most needed to change in order to reduce stigma about complex mental health issues.

FINDINGS

The findings of the **Our Turn to Speak** survey are compelling. They demonstrate that Australians with complex mental health issues are commonly subject to pervasive, unrelenting, and impactful stigma and discrimination. The findings therefore also speak to their strength and resilience, as they not only navigate their lives affected by the various challenges associated with complex mental health issues, but also by stigma about those issues.

The findings presented in this report strongly suggest that people living with complex mental health issues experience stigma and discrimination across life. Across the 14 life domains investigated, experiences of stigma and were often noted to be frequent and impactful. These experiences were systematically observed alongside fearful anticipation of future experiences of stigma and discrimination, and resultant withdrawal from important life opportunities. In the sections that follow, highlight findings from participants' top three areas of concern are described.

Of the 14 life domains investigated, interpersonal relationships were of greatest concern. In total, 95.6% of participants indicated that they had experienced stigma and discrimination in in relationships in the past 12 months. Relationships were also identified by participants to be the life domain in which they had most frequently experienced stigma and discrimination, and wherein most participants had been significantly affected by that stigma and discrimination. More than half of participants who answered questions about their relationships said their experience of stigma and discrimination had been 'frequent' or 'very frequent' in the previous 12 months. On average, 72% of participants said that, because of stigma, they had avoided important things like socialising as much as they would have liked to, making new friendships and maintaining connections with existing friends, or dating or having intimate relationships.

Employment was of next-greatest concern, with 43% of all participants said they had been most affected by stigma about mental health issues in this domain. More than half of participants who answered questions about this life domain said their experience of stigma and discrimination in employment had been 'frequent' or 'very frequent' in the preceding 12 months. On average, 70% of participants said that, because of stigma about their complex mental health issues, they had avoided important things like applying for employment opportunities or asking for flexible work arrangements.

Healthcare services were the third-most common area of concern. Sixty percent of participants who answered questions about this life domain said their experience of stigma and discrimination in healthcare services had been 'frequent' or 'very frequent' in the previous 12 months. On average, 63% of participants said they expected to experience future stigma and discriminationin this area of their lives like being treated unfairly when trying to get help for physical health problems or being unfairly denied help for physical health problems. Many participants reported in turn forgoing accessing help for physical healthcare problems because of stigma.

Similar patterns of negative perceived and anticipated experiences, and withdrawal from important opportunities were observed across the findings from the remaining 11 life domains investigated here.

The current findings highlight that complex mental health issues were not the only subject of stigma experienced across life for participants. Across the 14 domains of life, participants indicated that they had experienced a range of areas of *intersectional* stigma and discrimination. Here, participants also described problems they had experienced that were associated with personal characteristics other than complex mental health issues yet interplayed, compounded or were experienced in addition to stigma about those mental health issues.

In addition to the pervasive experiences of stigma and discrimination reported across 14 life domains, many participants indicated that they had experienced positive treatment because of their complex mental health issues. While rates of average agreement with negative experiences exceeded those for positive experiences most commonly, it was encouraging to observe that positive experience regarding participants' complex mental health issues were reported across all of the life domains investigated. Indeed, many of the positive experiences described by participants highlight possible strategies to combat stigma and discrimination.

Participants concluded the **Our Turn to Speak** survey by telling us what they thought most needed to change to reduce stigma and improve the lives of Australians with complex mental health issues. Three overarching themes were identified in this feedback, including:

1. education, understanding, and acceptance
2. communication and visibility
3. accessible services, fair treatment, and support.

The feedback provided as regards potential solutions to stigma and discrimination was rich and demonstrated that valuable insights are often possible only through understanding the lived experience of complex mental health issues and related stigma and discrimination.

CONCLUSIONS

The **Our Turn to Speak** survey and the findings presented here represent an important step in understanding how stigma and discrimination affect Australians who live with complex mental health issues. The significance of these findings cannot be understated. Indeed, the undeniably authentic and moving stories that participants have contributed do more than inform us, they compel us to act.

The companion document to this report, *Recommendations for Action from the* ***Our Turn to Speak*** *Survey: Ensuring people living with complex mental health issues can live a life free from stigma and discrimination*, outlines the actions required by individuals, governments and other institutions to eliminate stigma and discrimination, and improve the lives of Australians living with complex mental health issues.

INTRODUCTION

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Chapter 1. Introduction

Stigma and discrimination are often nominated as central concerns for people with mental health issues (Corrigan et al., 2003; McNair, Highet, Hickie, & Davenport, 2002) and are significant barriers to help-seeking and inclusion. Stigma and discrimination can adversely affect wellbeing in a number of ways, including worsening psychological distress, inhibiting help-seeking and treatment adherence, limiting personal relationships, and reduced ability to achieve educational and vocational goals (Corrigan, 2004; Link, Struening, Rahav, Phelan, & Nuttbrock, 1997; Wells, Robins, Bushnell, Jarosz, & Oakley-Browne, 1994).

In the past three decades since de-institutionalisation, there has been increased public attention on personal narratives of living with mental health issues, and the need for better mental health care and support in Australia. Yet, there remains a real risk of complacency if we believe that the task of stigma reduction is complete.

While much has been achieved in the last two decades by focusing efforts on de-stigmatising high prevalence mental health conditions such as depression and anxiety, through the success of initiatives such as Beyond Blue, there is still much more to be done.

In 2018, SANE Australia partnered with with the Melbourne School of Psychological Sciences at the University of Melbourne and the Paul Ramsay Foundation to develop the **National Stigma Report Card**. The aim of the **National Stigma Report Card** is to understand how Australians living with complex mental health issues experience stigma and discrimination, in order to catalyse positive change across a range of domains such as as interpersonal relationships, employment, physical and mental healthcare services and in traditional and social media. The project includes two large-scale national surveys conducted two years apart which are designed to explore how stigma and discrimination affect people living with complex mental health issues.

The data collected through these surveys provide the basis for SANE Australia and other key stakeholders, to advocate for the establishment of stigma-reduction and mental health reform initiatives, at national, state, territory and local levels, and to facilitate better outcomes for people living with complex mental health issues.

This report summarises the findings from the inaugural **Our Turn to Speak** survey. The survey, conducted online, in person and via telephone, investigates experiences of stigma and discrimination across 14 life domains and directly engages with people with lived experience of complex mental health issues.

LIVING WITH COMPLEX MENTAL HEALTH ISSUES IN AUSTRALIA

It is estimated that almost 700,000 Australians live with complex mental health issues (National Mental Health Commission, 2014). For the purposes of this report, these issues are defined as those experienced as schizophrenia spectrum disorders, bipolar and related disorders, personality disorders, post-traumatic stress and dissociative disorders, eating disorders, obsessive-compulsive and related disorders, and severe and treatment-resistant anxiety and depression. These experiences often carry severe and debilitating symptoms, which have a profound impact on the lives of those affected.

Decades of mental health reform have failed to meet the needs of people affected by complex mental health issues. The Interim Report of the *Royal Commission into Victoria's*

Mental Health System has concluded that the current crisis-driven mental health system is a result of continual poor investment decisions, driven ultimately by stigma and discrimination (Royal Commission into Victoria's Mental Health System: Interim Report, 2019). This has led to enormous inequity, which in turn has created new, and deepened existing, barriers to access, with treatment quality often dependent upon socioeconomic status and geography.

STIGMA AND DISCRIMINATION

People living with complex mental health issues are frequently and deeply impacted by stigma and discrimination. Here, stigma describes negative and damaging stereotyped ideas and emotional responses relating to the experience of complex mental health issues, with the central theme being that one 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 (Fox et al., 2017).

Stigmatising attitudes, prejudicial emotions and discriminatory behaviour may be held and expressed by members of the public, those in positions of power, employers and colleagues, teachers, the media, healthcare and mental healthcare providers, friends and family members, intimate partners and others. Those affected are impacted in numerous ways, such as:

- direct experiences of stigma and discrimination
- anxious anticipation of future instances of such experiences
- withdrawal from life-opportunities for fear of being subject to stigma and discrimination.

Sometimes, that stigma can become internalised in a process known as self-stigma. Self-stigma can be described as including awareness and agreement with stigmatised public stereotyped attitudes, application of this stigma to the self, and resultant damage to the self – for example, in terms of reduced self-esteem (Corrigan et al., 2013; Corrigan & Rao, 2012). Self-stigma is also likely to have broader consequences for individuals living with complex mental health issues and may deter help-seeking, participation in treatment and activities that promote recovery, and compound signs and symptoms of mental illness.

It has long been established in international literature (Star, 1955) that stigma about complex mental health issues is meaningfully different to stigma relating to less severe and higher prevalence disorders (P. Corrigan et al., 2002). For example, members of the public are likely to stereotype people living with schizophrenia as being dangerous and, in turn, can become fearful and avoidant of people living with schizophrenia – a pattern of stigmatised responding that is not as strongly associated with mild-to-moderate depression (Jorm et al., 2012). This stereotype is often reinforced in the mass media. Therefore, understanding the specific experiences of stigma and discrimination for Australians living with complex mental health issues is critical to providing an evidence base for targeted action to address these issues.

The **National Stigma Report Card** aims to build on the good work already undertaken to investigate stigma about mental health problems from the perspectives of those with lived experience both internationally and within Australia. Noteworthy examples internationally include the ongoing evaluation of the *Time to Change* campaign in England, which has to this point, focused on understanding and combatting stigma about the full spectrum of mental health conditions, from mild experiences through to complex ones (e.g. Evans-Lacko et al., 2013). Within Australia, both the *Survey of High Impact Psychosis* (SHIP) study

(Morgan et al., 2012) and the 2014 study of discrimination and positive treatment (Reavley & Jorm, 2015) have made valuable contributions. While stigma and discrimination was not the sole focus of the comprehensive SHIP study, this investigation found evidence suggesting that discrimination experiences, fearful anticipation of stigma and discrimination, and withdrawal from opportunity are important issues for Australians living with psychosis. The 2014 study of discrimination and positive treatment surveyed Australians living with the full spectrum of mental health issues, finding evidence of both impactful discrimination and also positive treatment related to experiencing mental health issues (Reavley & Jorm, 2015). Despite these valuable studies, experiences of stigma and discrimination for people living with complex mental health problems remain poorly understood and addressed in Australia.

To date, few Australian research or practice initiatives have specifically targeted stigma and discrimination for people with complex mental health issues.

THE NATIONAL STIGMA REPORT CARD

The aim of the **National Stigma Report Card** is to fill this critical gap in knowledge and action to improve the lives of Australians living with complex mental health issues.

The project is designed to achieve this goal by:

1. gathering Australian-first evidence on the experiences of stigma and discrimination in many domains of life for Australians across the country living with complex mental health issues
2. sharing this evidence with decision-makers, other key stakeholders who are well placed to effect positive systematic change, and the Australian public
3. working closely with government, policymakers, thought leaders and the Australian public on an ongoing basis to drive positive change
4. monitoring outcomes in a diverse range of life domains over time for Australians living with complex mental health issues.

OUR TURN TO SPEAK

The **National Stigma Report Card** project draws on evidence from national surveys of experiences of stigma and discrimination for people living with complex mental health issues. These surveys have been named **Our Turn to Speak.** This name was chosen by members of the project's steering committee who live with complex mental health issues who believe the name reflects the intent of the surveys.

This report details findings from the inaugural **Our Turn to Speak** survey. The survey investigated experiences of stigma and discrimination related to complex mental health issues across 14 life domains:

Figure 1.1. Life domains explored in the Our Turn to Speak survey.

THIS REPORT

The structure of this report is informed in part by the current survey findings.

Two introductory chapters are provided. Firstly, the background and context to the **Our Turn to Speak** survey and **National Stigma Report Card** are described. Next, details of the survey development and general research methodology are provided, and a description of the sociodemographic and clinical makeup of those surveyed is specified. The report then provides the results of the **Our Turn to Speak** survey. Following a brief overview chapter, 14 chapters present the survey findings regarding each life domain investigated in turn. These chapters are organised in an order that corresponds to the percentage of participants who reported being personally impacted by stigma and discrimination in each life domain, in descending order. The penultimate chapter provides a qualitative analysis of what participants said most needed to change to reduce stigma and discrimination about complex mental health issues in Australia. The final chapter provides a summary and conclusion, and links to an accompanying **National Stigma Report Card** document that provides recommendations for action based on the current findings.

The authors hope that the rich data reported here will provide critical insights into how stigma and discrimination affect people living with complex mental health issues, and can be used to both inform and drive comprehensive and evidence-based approaches to ensuring that all Australians affected by complex mental health issues live long and fulfilling lives, free from stigma and discrimination.

METHODOLOGY AND PARTICIPANTS

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Chapter 2. Methodology and participants

HUMAN RESEARCH ETHICS

All aspects of the survey and research process were conducted with prior approval obtained from the Human Research Ethics Advisory Group of the Melbourne School of Psychological Sciences, and the Health and Applied Sciences Human Research Ethics Sub-Committee at the University of Melbourne (HREC Project no.1955446.2).

SURVEY DEVELOPMENT

The development of the first **Our Turn to Speak** survey involved five stages:

1. A scoping review of the empirical and grey literature to identify and short-list a range of candidate measures of stigma and discrimination in connection with mental health issues, for adaptation or direct inclusion to the survey.
2. Drafting a candidate battery of survey items to measure participants' multi-faceted experiences of stigma and discrimination across 14 life domains.
3. Submitting the drafted battery of survey items for independent quality assurance review and rating by a panel of experts with lived or learnt expertise using a structured feedback process called the Delphi Method.
4. Pilot testing the further revised draft of the survey, including survey logic and eligibility screening, with a sample of participants with lived experience of mental health issues to evaluate its acceptability and accessibility.
5. Refining the survey on the basis of pilot participants' feedback and conducting a final round of 'troubleshooting' before launching the survey nationally for recruitment.

Critical to each stage of development was the collaborative stakeholder engagement processes embedded into the **National Stigma Report Card** from its conceptualisation, through to implementation and ongoing dissemination of the findings:

- A **Steering Committee** was convened to regularly provide advice and support regarding research and advocacy strategies, and other high-level matters.
- An **Expert Reference Group,** which was comprised of people with lived experience of complex mental health issues, academics who conduct research about stigma and discrimination in connection with mental health issues, leaders and service providers from across the mental health, disability, homelessness, youth, health and medical, employment, justice, regional and rural, Aboriginal and Torres Strait Islander, LGBTQIA+, and culturally and linguistically diverse sectors and communities. These Expert Reference Group members participated in a Delphi Consensus Study to inform the measures used in the Survey.
- The **Our Turn to Speak Champions,** who promoted survey participation among their peer networks, as SANE Peer Ambassadors with lived experience of complex mental health issues.
- A **Coalition of Advocates** facilitated dissemination of survey advertisements and project materials; this was a coalition of mental health and related sector organisations that agreed to support participant recruitment and interviewing and well as to carry forward the recommendations from the study through advocacy.

LITERATURE REVIEW AND DRAFT SURVEY DEVELOPMENT

A scoping literature review was performed to identify and short-list a range of candidate measures for adaptation or inclusion to the **Our Turn to Speak** survey. The literature review was focused on identifying self-report measures of stigma and discrimination in relation to mental health issues. The literature review aimed to answer the following questions:

- Which measures of mental illness stigma and discrimination have adequate psychometric properties ie internal consistency, construct validity, criterion validity, test-retest reliability as outlined by COSMIN guidelines (Mokkink et al., 2010)?
- Do any of the measures with adequate psychometric properties relate to stigma and discrimination in the 14 life domains of relevance to the **National Stigma Report Card** (for example, housing, employment, relationships, justice and legal services, welfare and social services, etc.)?
- Can any of the relevant and psychometrically sound measures be readily used, or adapted for use, for administration in both online survey and interview formats?
- Are any of the relevant and psychometrically sound measures likely to be acceptable and accessible to Australians living with complex mental health issues (for example, easy to understand, use of non-stigmatising and inclusive language, culturally appropriate, relatively brief, etc.)?

PsychINFO, MEDLINE and numerous grey literature databases were searched for articles published between 2004 and 2019. Titles were scanned for relevance based on the title and abstract. Articles were only reviewed in full if they related to the measurement of stigma and discrimination from the perspective of people who live with mental health issues; not from the perspective of the general public, health professionals, or carers and family. Particular weight was placed on the findings and recommendations of previously published literature reviews that evaluated the psychometric properties of stigma measures (Brohan et al., 2010; Fox et al., 2018; Link et al., 2004).

Ultimately, 18 candidate measures were short-listed and evaluated for their psychometric properties, relevance to the **National Stigma Report Card**, and feasibility and flexibility of administration. No single measure was deemed sufficient to use as a standalone measure to meet the complex research aims of the project. As such, the **Our Turn to Speak** survey includes scales and individual items were adopted, adapted or extended from items drawn from six of the most appropriate short-listed measures:

- *Consumers' Experience of Stigma Questionnaire* (CESQ)(Wahl, 1999).
- *Costs of Discrimination Assessment* (CODA) (Wright et al., 2015).
- *Discrimination and Stigma Scales-12th edition* (DISC-12) (Brohan et al., 2013).
- *Internalised Stigma of Mental Illness Scale* (ISMI-24) (Ritsher et al., 2003).
- *Questionnaire on Anticipated Discrimination* (QUAD) (Gabbidon et al., 2013).
- *Self-Stigma or Mental Illness Scale-Short Form* (SSMIS-SF) (Corrigan et al., 2012).

Numerous bespoke items were also developed to ensure adequate data would be gathered about all 14 life domains of relevance to the **National Stigma Report Card.** In total, the research team developed a battery of 377 survey items to measure the multi-faceted experiences of stigma and discrimination in the 14 life domains of relevance to the **National Stigma Report Card**.

DELPHI CONSENSUS SURVEY QUALITY ASSURANCE STUDY

A Delphi consensus study was undertaken to ensure the quality of the drafted candidate measure. To support this process, a panel of experts was recruited to provide feedback through two rounds of consultation on the drafted measure and its constituent items. The panel of experts comprised a total of 26 people in the first round and 27 people in the second round, with expertise in a range of sectors and diverse stakeholder groups, including:

- people with lived experience of complex mental health issues
- stigma researchers from Australia and overseas
- other mental health sector stakeholders, and
- stakeholders and service providers from homelessness, youth, health and medical, employment, legal and justice sectors and those serving people from rural, regional and remote areas, Aboriginal and Torres Strait Islander backgrounds, people living with a disability, LGBTIQA+ individiduals and people from culturally and linguistically diverse backgrounds.

In each round of consultation, which was conducted via online survey, panel members reviewed and rated each proposed item for inclusion to the candidate measure, using a six-point Likert scale indexing degree of importance for inclusion in **Our Turn to Speak** as follows: (1) 'essential', (2) 'important', (3) 'slightly important', (4) 'slightly unimportant', (5) 'unimportant', and (6) 'should not be included'. Panel members also provided additional open-ended feedback on:

- ease of understanding
- cultural appropriateness
- feasibility, validity, and reliability
- opportunities to explain why ratings were given
- other measures that could be considered for inclusion and suggestions for improving the candidate measure items or overall survey design.

Consensus was defined in each round whenever an item or measure was (1) rated as 'important' or 'essential' by ≥80% of panellists; and (2) achieved a median rating of 1 ('essential') or 2 ('important') with an interquartile range (IQR) of <1.75. If these criteria were met following Round 1, an item (or complete measure) was accepted for inclusion in **Our Turn to Speak**. Any item that was rated as 'essential' or 'important' by 70-79% of the panel during the first round was rephrased as necessary based on feedback and re-rated by the panel in the second round. If an item received this same rating again in the second round, it was endorsed/accepted for inclusion in the survey. In both rounds, if <70% of panel members rated an item as 'essential' or 'important' and the median rating was ≥3 with an IQR of ≥3, then it was rejected. Of the 377 drafted items presented for review, excluding those from intact validated measures, 245 items were endorsed in their original form, 130 were rephrased to researcher's discretion based on panellists' feedback, and 2 items were rejected.

SURVEY PILOT STUDY

The drafted **Our Turn to Speak** survey, forthcoming from the Delphi consensus quality assurance process, was next subject to a pilot testing study. The three core aims of this pilot study were to: (1) identify survey phrasing, logic and navigation problems, (2) examine the fundamental user experience factors, such as time taken to complete the measure, and

(3) investigate the acceptability and accessibility of the survey for people living with complex mental health issues.

The draft survey was piloted for online delivery in an Amazon Mechanical Turk sample of participants aged 18+ who reported living with complex mental health issues. The *DSM-5 Self-rated Level 1 Cross-cutting Symptom Measure – Adult Version* (American Psychiatric Association, 2013c) was used to assess the severity of participants' self-reported mental health diagnoses. Pilot study participants completed the draft survey, and provided qualitative feedback about their experience of completing the survey and how it might be improved. The final version of the survey was developed on the basis of this data. The research team were particularly encouraged that the draft survey was positively reviewed by participants overall.

> ***I just wanted to say that I really liked how this survey approached everything. It was very clear that there was no judgement in the questions asked. But more importantly, they did not approach potentially sensitive topics in an aggressive way. It wasn't triggering at all. You did a great job!***
>
> **Pilot Study participant**

ASSESSMENT OF COMPLEX MENTAL HEALTH ISSUES

In addition to developing a survey that would comprehensively measure stigma and discrimination in connection with mental health issues across 14 life domains, it was important to gain a strong understanding of participants' mental health symptoms and their functional impact. Two additional components of the survey were therefore developed, the first component of which will be described herein:

- A comprehensive self-assessment of symptoms commonly associated with a range of complex mental health issues.
- A questionnaire designed to gauge the duration, severity, and functional impact of participants' complex mental health issues, including mental health services and treatments accessed.

A range of validated mental health assessment and screening tools were considered. To be clear, the purpose of such a tool in the context of the **Our Turn to Speak** survey was not to confirm or produce a clinical diagnosis, but to describe the nature and severity of the diverse mental health issues represented in the sample. When evaluating the utility of any assessment tools for inclusion to the survey, the following criteria were prioritised:

- The tool should assess all seven types of complex mental health issues prioritised for sampling in the **Our Turn to Speak** survey, according to contemporary diagnostic nosology (American Psychiatric Association, 2013a; World Health Organisation, 2018).
- The tool should have strong psychometric properties (for example, adequate inter-rater reliability, and good sensitivity and specificity for detecting likely instances of the presence of diagnosable complex mental health issues).

- The tool should be acceptable and accessible to participants, and feasible to implement in both online and interview formats.

No tools known to the research team were deemed appropriate to use as a standalone assessment of symptoms commonly associated with the diverse range of complex mental health issues relevant to the **Our Turn to Speak** survey. The self-report screening tool associated with the *Diagnostic Interview for Anxiety, Mood, OCD and Related Neuropsychiatric Disorders* (Tolin et al., 2018) came close to satisfying the abovementioned requirements but still required adaptation and extension. It featured numerous categorical (yes/no) items that determined the presence of at least one cardinal feature of all but two complex mental health issues relevant to the survey. Items to assess the presence of cardinal features of personality disorders and dissociative disorders were sourced from the *DSM-5 Self-rated Level 1 Cross-cutting Symptom Measure - Adult Version* (American Psychiatric Association, 2013). Similar to other validated clinician-administered and online assessments of mental health issues (Brodey et al., 2018; Nguyen et al., 2015; Shankman et al., 2018), if cardinal features were endorsed, a series of additional items were then presented so participants could rate the frequency and/or severity of a wider range of related symptoms. These additional items were drawn from the following validated assessment and screening tools:

- *Dissociative Experiences Scale-Brief (Modified for DSM-5)* (DES-B; selected items only) (American Psychiatric Association, 2013b).
- *Generalised Anxiety Disorder Screen-2* (GAD-2) (Kroenke et al., 2007).
- *McClean Screening Instrument for Borderline Personality Disorder* (MSI-BPD; selected items only) (Zanarini et al., 2003).
- *Patient Health Questionnaire-2* (PHQ-2) (Kroenke et al., 2003).
- *Positive and Negative Syndrome Scale* (PANSS; selected items only) (Kay et al., 1987).
- *PTSD Checklist Civilian version 2* (PCL-2) (Lang & Stein, 2005).
- *SCOFF Questionnaire* (Morgan, Reid, & Lacey, 1999).
- *Self-evaluation of Negative Symptoms* (SNS; selected items only) (Dollfus et al., 2016).
- *Standardised Assessment of Personality-Abbreviated Scale* (SAPAS; selected items only) (Moran et al., 2003).

We acknowledge that using medicalised language to describe people's experiences of their mental health can, for some people, feel stigmatising in and of itself. In deciding to include an assessment of participants' mental health symptoms, experiences and impact, we weighed up the need to validate that those responding to the survey represented the individuals whose experiences of stigma and discrimination we sought to understand. We hope that the **National Stigma Report Card** project might facilitate opportunities to examine other methods of collecting valid and reliable data, while ensuring that individual preferences for making sense of, and communicating about, their mental health issues is respected.

THE OUR TURN TO SPEAK SURVEY

The theoretical approach to the measurement of stigma in the **Our Turn to Speak** survey drew upon the *Mental Illness Stigma Framework*, which is a unifying theoretical taxonomy of stigma and discrimination about mental health issues (Fox et al., 2017). Resultantly, participants were asked about the following experiences within each of the 14 life domains investigated by the survey:

- Perceived experiences of past stigma and discrimination.
- Anticipated future experiences of stigma and discrimination.
- Withdrawal from opportunities relevant to that life domain because of stigma about mental health issues.
- Experiences of positive treatment relating to living with complex mental health issues.
- Intersectional experiences of stigma and discrimination (that is, stigma because of other personal characteristics like physical health or ability, racial or cultural background, and more).

Data from other components of the survey are not presented in this report. Instead, these data will be presented in upcoming academic publications and presentations. These other aspects of the survey included measurement of the following:

- **Self-stigma** in terms of:

    1) awareness of public and structural stigma
    2) agreement with that stigma
    3) application of that stigma to the self
    4) resultant harm to the self in terms of self-esteem.

- **Self-compassion**. This aspect of the survey was deemed important to include given observations that self-compassion can have a buffering effect against stigma (Wong et al., 2019; Yang & Mak, 2017).

The **Our Turn to Speak** survey flow is outlined in **Figure 2.1**. While there were a total 485 survey items (inclusive of items to screen for eligibility, sociodemographic, and mental health characteristics), a sophisticated survey logic ensured that participants were only presented with questions of greatest relevance to them based on their responses to earlier items. Some sections were counterbalanced in their order of presentation to mitigate against biased response patterns. A mix of multiple-choice, open-text, and scaling questions were included. The survey was hosted on Qualtrics (https://www.qualtrics.com).

After consenting to participate, participants were first asked to complete an eligibility screening questionnaire. This questionnaire included six core items to establish that participants:

- were aged at 18 years and above
- lived in Australia
- experienced a complex mental health issue during the last 12 months
- experienced stigma and discrimination associated with their experience of complex mental health issues during the last 12 months in at least one of 14 life domains.

Additional items in the eligibility screening questionnaire asked whether participants' complex mental health issues had ever been diagnosed by a health professional, and about which specific diagnoses their health professional had determined.

Eligible participants proceeded to the next stage of the survey, which included a comprehensive self-assessment of symptoms commonly associated with a range of complex mental health issues. This mental health symptom screen included 71 items in total, however, participants only answered questions that were relevant to them.

Participants next answered 12 questions about their socio-demographic characteristics, including gender, sexual orientation, relationship status, education, employment, living situation, health status, ancestry, language, and religious or spiritual affiliation.

Some participants were randomised to next complete the *Self-compassion Scale (Short Form)* (Raes et al., 2011) and the extended version of the *Self Stigma in Mental Illness Scale-Short Form* (Corrigan et al., 2012); or were asked to identify which 14 life domains had been most affected by their experience of stigma and discrimination because of mental health issues during the past 12 months. After selecting at least one, but no more than three, most affected life domains, participants were presented with several items enquiring about their specific experiences of stigma and discrimination within those domains. Items were organised to enquire about:

- perceived experiences of past stigma and discrimination relevant to the life domain
- anticipated future experiences of stigma and discrimination relevant to the life domain
- withdrawal from opportunities, situations, or services relevant to the life domain
- experiences of positive treatment in the life domain, as related to living with complex mental health issues
- intersectional experiences of stigma and discrimination relevant to the life domain (specifically, perceived stigma and discrimination associated with one's racial or cultural background, gender identify, sexual orientation, faith or spiritual beliefs, and physical health or ability).

There were typically between two and seven items in each of these sub-sections of the survey.

Following theses scaled items, participants were asked if they would like to share or expand upon anything else in relation to their experiences of stigma and discrimination, positive experiences because of mental health issues, and experiences of stigma and discrimination concerning other intersecting factors, in each domain selected.

Participants next completed nine questions designed to gauge the duration, severity, and functional impact of their complex mental health issues, including mental health services and treatments accessed, and the perceived effectiveness of those supports.

The survey ended by asking participants for their thoughts on what most needed to change in order to reduce stigma about complex mental health issues for all Australians.

Participants were provided with a debriefing statement upon completion of the survey and additionally provided with the contact details of mental health support services.

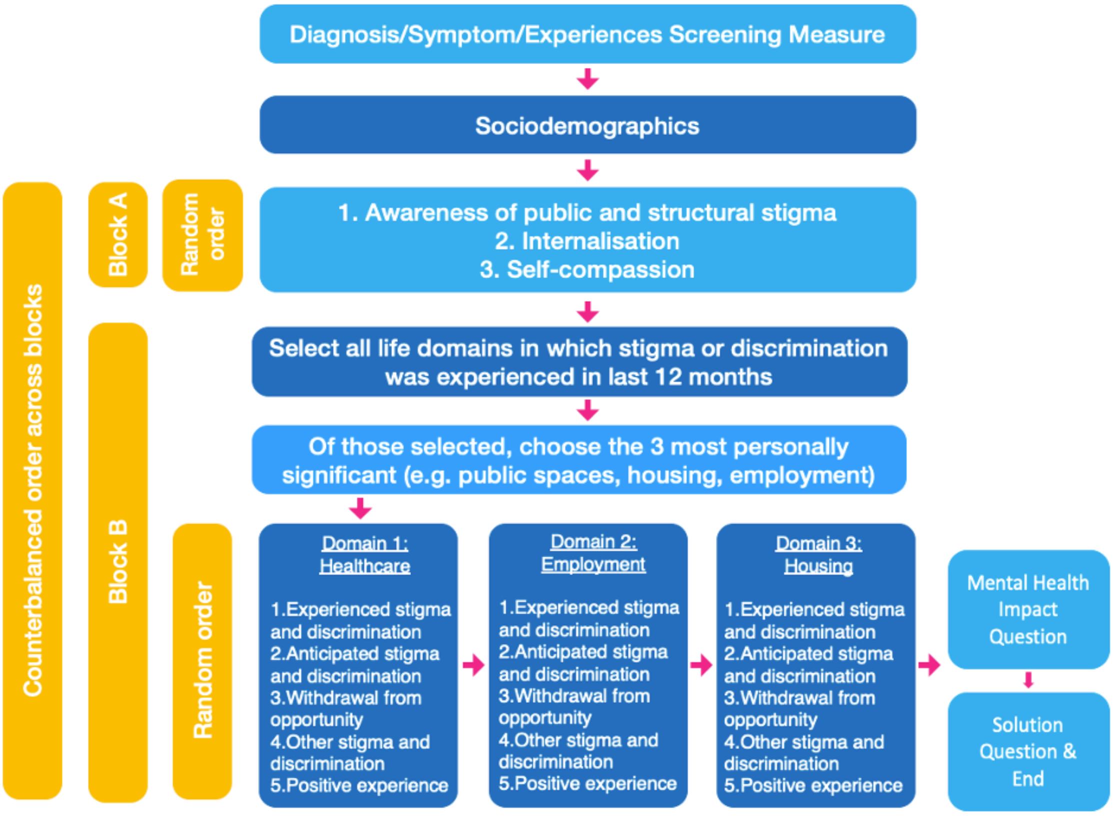

Figure 2.1. Our Turn to Speak survey flow with examples.

ADVERTISING AND PARTICIPANT RECRUITMENT

Epidemiological sampling methods were beyond the scope of the **Our Turn to Speak** survey despite its national focus. Exclusive systematic sampling based on recent service contacts within the Australian mental health system was also precluded because of one of the fundamental assumptions of this study – that stigma is a significant barrier to help seeking for people living with complex mental health issues. The **Our Turn to Speak** survey necessarily aimed to recruit participants who had, and had not, sought help for their experience of mental health issues in the previous 12 months. For these reasons, a non-probability approach to sampling was adopted, with sampling quotas originally established regarding specific complex mental health issues and demographic characteristics, including age, gender identity, and geographic location of participants.

Ultimately, originally planned quotas were not implemented given numerous barriers during the participant recruitment period, including but not limited to sector research and lived experience consultation saturation, the 2019/20 Australian bushfire crisis, and the COVID-19 pandemic.

Participants were recruited through advertisements placed on social media and the SANE Australia website, shared through the communications networks of a broad range of mental health and community organisations, on community noticeboards, and on electronic billboards. The survey was also promoted through numerous news stories and media interviews during the participant recruitment period. Based on the responses of 527 participants who were asked how they learned about the opportunity to complete the survey, it was evident that social media advertising and dissemination of adverts by support organisations played a significant role in recruitment.

As shown in **Table 2.1**, close to 40% of participants learned about the **Our Turn to Speak** survey through a support organisation or support worker. Many support organisations advertised the study through their online communications (for example, their social media platforms, website, or listserv), but hardcopy flyers and posters placed in waiting areas or handed out to service users were also encouraged. Thirty-four percent of participants learned about the survey through social media posts. Facebook was most commonly cited and accounted for 75% of all survey referrals that came via social media.

Table 2.1. Survey referral pathways as reported by 527 participants.

Survey Referral Pathway	% Participants
Word of mouth	**12.0%**
University or workplace	**3.2%**
Traditional media and advertising	**3.6%**
Support organisation or worker	**38.7%**
SANE Australia	48.5%
Flourish	8.3%
Beyond Blue	5.9%
Mind Australia	3.9%
GROW	3.9%
Lived Experience Australia	2.5%
Other support organisations	19.2%
Unspecified support organisation	7.8%
Social media	**34.0%**
Facebook	74.9%
Instagram	9.5%
Twitter	7.8%
LinkedIn	4.5%
Unspecified platform	3.4%
Other online source	**8.3%**
Unsure or other source	**0.2%**

PARTICIPATION METHODS

The **Our Turn to Speak** survey was open to participants from 25 October 2019 and closed on 6 April 2020. Participants could choose to complete the survey online (via the project website, https://ourturntospeak.com.au), or in a telephone or face-to-face interview. Face-to-face interviews were hosted at the sites of participating support organisations across Australia. The median survey completion time was 44.5 minutes and participants were reimbursed with a $25 gift voucher for their contribution.

Participants who opted to complete the survey online could do so independently, or with the assistance of a carer or support worker. Telephone and face-to-face interviews were facilitated by research assistants undergoing postgraduate psychology training at the University of Melbourne. Research assistants were required to complete a 90-minute online module about conducting research with people experiencing complex mental health issues like psychosis[1]; a face-to-face workshop with the research team, which included didactic interviewing and risk assessment practice; and at least one interview with a research participant that was observed by a member of the research team. Research assistants received ongoing supervision for the duration of their involvement. Face-to-face interviewing

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[1] RET Program: https://retprogram.org/portfolio-item/research-with-people-who-experience-mental-health-illnesses/

occurred under direct supervision of research team members who also had clinical experience.

A breakdown of participants' sociodemographic characteristics across survey completion methods is shown in **Table 2.2**. Compared to participants who opted to complete the survey online, interview participants were on average six years older; characterised by a higher rate of males (41.3% compared with 17.2% of online participants); reported lower rates of post-secondary education; and reported higher rates of unemployment and receipt of income support. The interview cohort was also characterised by a greater proportion of people not in a relationship (80.6% compared with 51.4% of online participants) and living with a schizophrenia spectrum disorder (28.6% compared with 6.7% of online participants). Reflecting the sites at which interviews were held, a much larger proportion of interview participants resided in New South Wales (44% compared with 23.1% of online participants), and no participants were interviewed in the Northern Territory or Australian Capital Territory.

Table 2.2. Participants' sociodemographic characteristics based on survey completion method.

Characteristics	Survey Completion Method Online (*n* = 1849)	 Interview (*n* = 63)
Average age	39.01 (*SD* = 12.77)	45.03 (*SD* = 12.79)
Gender identity		
Female	79.7%	55.6%
Male	17.2%	41.3%
Trans, gender diverse and/or non-binary	4.9%	3.2%
Unsure or questioning	0.9%	1.6%
Prefer not to say	0.4%	0.0%
Relationship status		
Not in a relationship	51.4%	80.6%
In a relationship	48.4%	19.4%
Prefer to self-describe	0.2%	0.0%
Sexual orientation		
Heterosexual	61.7%	71.4%
Lesbian, gay, bisexual, pansexual, queer, and/or asexual	36.1%	20.6%
Unsure or questioning	5.0%	1.6%
Prefer to self-describe	1.5%	1.0%
Prefer not to say	1.6%	4.8%
Employment		
Engaged in paid work	52.6%	25.4%
Engaged in unpaid work or studying	29.3%	11.1%
Unemployed or unable to work	21.8%	50.8%
Receiving a pension or benefits	24.0%	42.9%
Other	0.2%	0.0%
Education (highest level attained)		
Primary school	1.4%	7.9%
Secondary college (high school)	20.6%	30.2%
Educated post-secondary college	77.9%	61.9%
Other	0.2%	0.0%
Physical health		
Co-occurring brain injury, chronic health issue or disability	53.7%	55.6%
State of territory		
Australian Capital Territory	2.5%	0.0%
New South Wales	23.1%	46.0%
Northern Territory	0.6%	0.0%
Queensland	16.2%	6.3%
South Australia	9.7%	3.2%
Tasmania	3.7%	4.8%
Victoria	33.1%	33.3%
Western Australia	11.0%	6.3%
Region*		
Major city	74.4%	70.5%
Regional or remote	24.5%	29.5%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.

*Missing region data for 21 participants.

Figure 2.2 shows the breakdown of mental health characteristics of participants across survey completion methods. A greater proportion of participants living with a personality disorder completed the survey online (14.9%) rather than by interview (3.2%), and all participants living with an eating disorder completed the survey online. Mental health characteristics were otherwise largely comparable for the different survey completion methods.

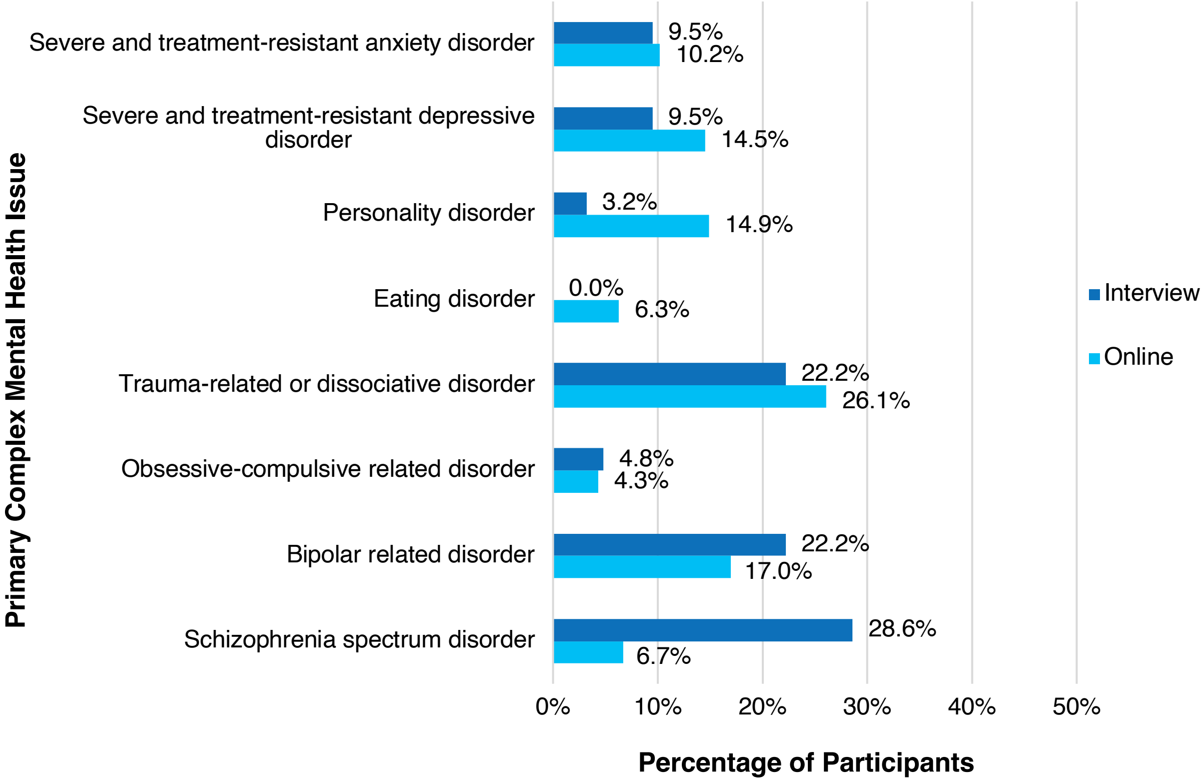


Figure 2.2. Mental health characteristics based on survey completion method (online *n* = 1849; interview *n* = 63).

DATA PREPARATION AND QUALITY ASSURANCE

A de-duplication and data validation protocol was adopted to screen for and exclude all non-valid survey entries. Non-valid survey entries were defined as non-human respondents (such as bots or spam) and duplicate entries. After removing ineligible and incomplete survey entries, a hybrid manual-automated protocol was implemented to identify non-valid cases; this protocol was adapted from, and informed by, best practices in data validation for online surveys in health and social sciences (Dewitt et al., 2018; Grey et al., 2015; Kennedy et al., 2020; Kennedy et al., 2020; Teitcher et al., 2015).

The data preparation protocol comprised three stages. In Stage 1, 17 of the strongest indicators of non-valid survey entries, including duplicates, were used to determine exclusion from the dataset. Seven indicators were detected automatically using statistical processing software, five indicators were identified with a combination of statistical programs and manual inspection of the data, and a further five indicators were identified using only manual inspection. At this level, the presence of only one of the 17 indicators was required to deem a case non-valid and exclude it from the dataset. For duplicates, only the first survey entry of each valid case was retained. In Stage 2, six additional indicators of non-valid survey entries were used to determine exclusion. Half of these indicators were identified with a combination of statistical programs and manual inspection of the data, and the other half were identified using only manual inspection. At this level, the presence of at least three indicators of suspect survey entries were required before the case was deemed non-valid and excluded from the dataset. Stage 3 comprised manual spot-checks of 5% of all completed survey entries to interrogate the reliability of decisions to exclude or retain cases in the dataset. Spot-checks were conducted independently by two researchers. Non-agreement was resolved upon review of a third researcher.

Data from a total of 1,912 participants who completed the **Our Turn to Speak** survey was retained for analysis. A participant flowchart is depicted in **Figure 2.3**. While a large number (*n* = 7892) initially accessed the survey, almost one-quarter of entries stopped at the consenting procedures; a small proportion (3.1%) were deemed ineligible to participate; 18% did not complete the survey in its entirety; and 30.2% of remaining survey entries were ultimately deemed non-valid.

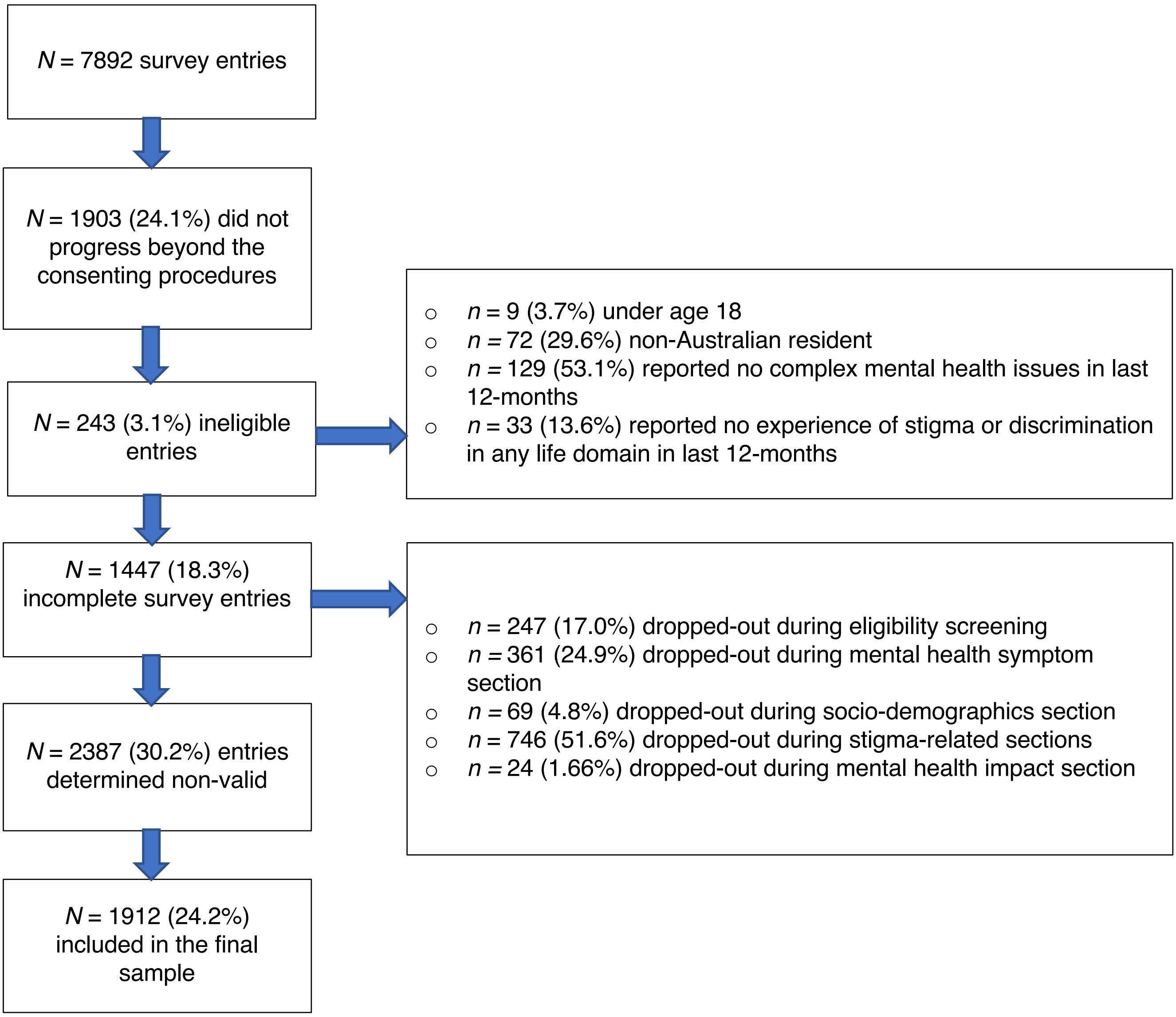


Figure 2.3. Flowchart summarising data preparation for the final Our Turn to Speak sample.

SOCIODEMOGRAPHIC CHARACTERISTICS

This section provides a summary of the sociodemographic characteristics of the **Our Turn to Speak** sample, such as participants' ages, gender identities, geographic locations and more.

While the purpose of the survey was not to establish the prevalence of stigma and discrimination in an epidemiological sense, the sociodemographic characteristics of the **Our Turn to Speak** participants are described with reference to the characteristics of participants from a range of population-based mental health studies, as appropriate, for context.

Overview

Table 2.3 provides an overview of participants' sociodemographic characteristics, which are examined in further detail in this chapter.

The average **Our Turn to Speak** participant was female (78.9%), aged 39.21 years (*SD* = 12.81, range = 18 – 86), living in a major city in Victoria, New South Wales or Queensland (55.4%), of Australian ancestry (84.2%), and whose main language was English (98.7%). Most participants identified as heterosexual (62.0%), educated post-secondary college (77.4%), and identified as having secular beliefs or other spiritual beliefs with no religious affiliation (66.4%). Just over half of participants were not in a relationship (52.1%), engaged in paid work (51.7%), living in a form of long-term housing (for example, private rental property) (59.2%), and were living with co-occurring physical health issues such as a head or brain injury, chronic health condition, or disability (53.8%).

Table 2.3. Sociodemographic characteristics of the total sample (N = 1912).

Characteristics		% Participants
Gender identity		
	Female	78.9%
	Male	18.0%
	Trans, gender diverse and/or non-binary	4.9%
	Unsure or questioning	0.9%
	Prefer not to say	0.4%
Relationship status*		
	Not in a relationship	52.1%
	In a relationship	47.3%
	Prefer to self-describe	0.2%
Sexual orientation		
	Heterosexual	62.0%
	Gay, lesbian, bisexual, pansexual, queer, and/or asexual	35.6%
	Unsure or questioning	4.9%
	Prefer to self-describe	1.5%
	Prefer not to say	1.7%
Education (highest level attained)		
	Primary school	1.6%
	Secondary college (high school)	20.9%
	Educated post-secondary college	77.4%
	Other	0.2%
Employment		
	Engaged in paid work	51.7%
	Engaged in unpaid work or studying	28.7%
	Unemployed or unable to work	22.8%
	Receiving a pension or benefits	24.6%
	Other	0.2%
Living situation*		
	Privately owned home (homeowner)	32.5%
	Long-term housing	59.2%
	Insecurely housed or homeless	8.2%
Cultural group or ancestry		
	Australian	84.2%
	Aboriginal and/or Torres Strait Islander	3.5%
	Asia-Pacific	6.6%
	African or Middle Eastern	1.5%
	European	27.7%
	American	1.0%
	Unsure, non-identifying or other	0.6%
Religious or spiritual affiliation*		
	Secular beliefs, and other spiritual beliefs and no religious affiliation	66.4%
	Christianity	24.7%
	Buddhism	2.7%
	Other religions	5.2%
	Unsure or questioning	0.6%

Note. Percentages for gender identity, sexual orientation, employment, and cultural group or ancestry do not add to 100 as participants could select more than one response option.

*Missing relationship data for six participants; missing living situation data for three participants; missing religious or spiritual affiliation for seven participants.

Age, gender and sex characteristics

Presented in this section is a further breakdown of participants' age, gender identity, and sex characteristics.

As shown in **Figure 2.4**, 29.3% of all participants were aged 35-44 years, followed by similar proportions of participants aged 45-54 years and 55-54 years. This age distribution is relatively comparable with national population prevalence studies of high-prevalence mental health issues (Australian Bureau of Statistics, 2008) and schizophrenia spectrum disorders (Morgan et al., 2012).

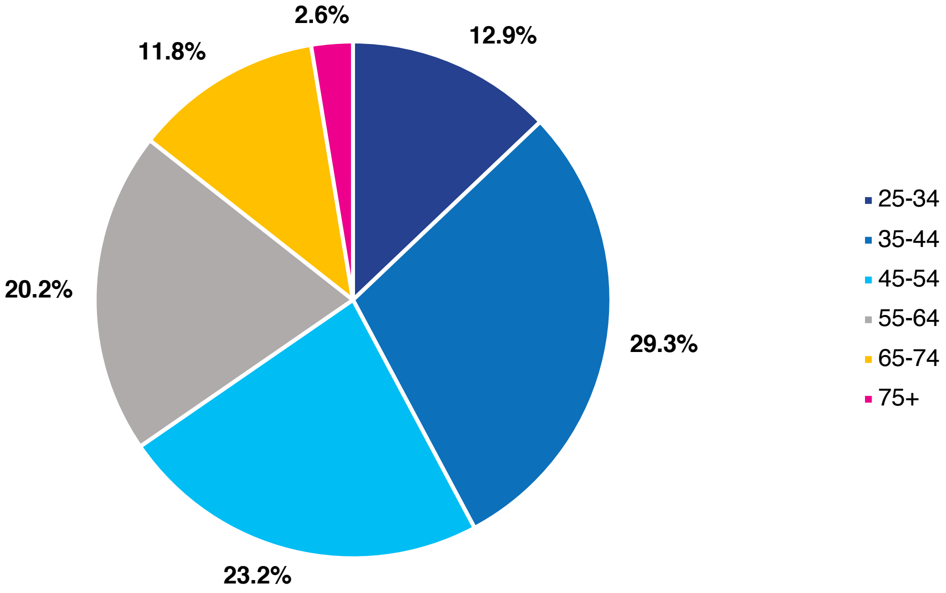


Figure 2.4. Age group (*N* = 1912).

Shown in **Figure 2.5**, the **Our Turn to Speak** participants identified with a diverse range of genders. Most identified as female, followed by male, non-binary and transgender. Population prevalence studies show that more females than males are affected by high-prevalence mental health issues (Australian Bureau of Statistics, 2008) while equal rates of males and females live with psychological disability (Australian Bureau of Statistics, 2012), however, there was a clear over-representation of females in the current data. This may be a reflection of the vast majority (over 95%) of participants being engaged in mental health treatment, and the known higher rates of mental health service use by females compared with males (Australian Bureau of Statistics, 2008; Pirkis et al., 2011).

In terms of sex characteristics, 98.5% of participants reported that they were not born with a variation of sex characteristics, 0.4% reported that they were, and 1.1% reported that they were unsure.

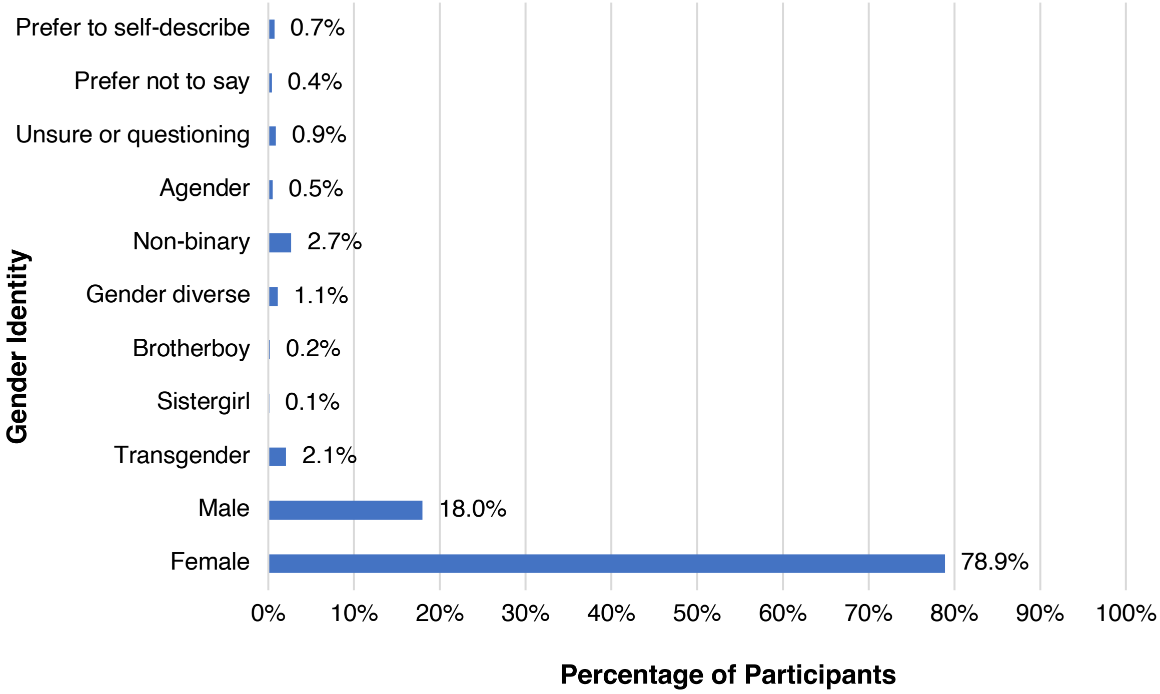


Figure 2.5. Gender identity (*N* = 1912).
Note. Percentages do not add to 100 as participants could select more than one response option.

Geographic and regional location

Presented in this section is a further breakdown of participants' geographic and regional locations of residence.

As shown in **Figure 2.6**, most participants resided in Victoria, New South Wales, and Queensland.

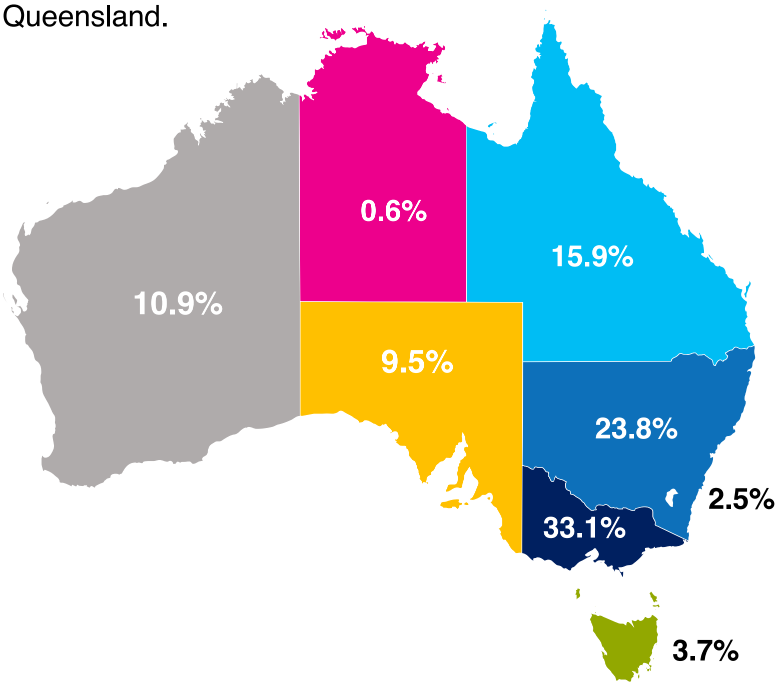


Figure 2.6. State or territory location of residence (*N* = 1912).

Table 2.4 depicts the regions in which participants were located across the states and territories. The majority of participants (74.2%) were located in major cities, while very few participants (0.7%) living in remote or very remote areas took part. The distribution of participants' geographic location is reflective of the **Our Turn to Speak** recruitment strategy, and of the national distribution and uptake of mental healthcare services (King et al., 2010; Pirkis et al., 2011). As stated earlier, the vast majority (over 95%) of participants were engaged in mental health treatment.

Table 2.4. Regional location of residence (*N* = 1912).

Location		% Participants
Australian Capital Territory		
	Major city	2.5%
New South Wales		
	Major city	17.2%
	Inner or outer regional	6.3%
	Remote or very remote	0.1%
Northern Territory		
	Inner or outer regional	0.5%
	Remote or very remote	0.1%
Queensland		
	Major city	11.2%
	Inner or outer regional	4.7%
South Australia		
	Major city	7.2%
	Inner or outer regional	2.1%
	Remote or very remote	0.1%
Tasmania		
	Inner or outer regional	3.6%
	Remote or very remote	0.1%
Victoria		
	Major city	27.0%
	Inner or outer regional	6.1%
Western Australia		
	Major city	9.1%
	Inner or outer regional	0.8%
	Remote or very remote	0.3%

Note. Missing region data for 21 participants.

Relationship status and sexual orientation

Presented in this section is a further breakdown of participants' relationship status and sexual orientations.

As shown in **Figures 2.7** and **2.8**, **Our Turn to Speak** participants represented a diverse range of relationship compositions and sexual orientations. Many participants were single, as is commonly reported among people living with specific types of complex mental health issues (Morgan, Mitchell, & Jablensky, 2005; Quirk et al., 2017). One in five participants were married, which is much lower compared with the proportion of the general Australian population who are married (48.1%) (Australian Bureau of Statistics, 2020). Among **Our Turn to Speak** participants who completed the survey via a telephone or face-to-face interview (*n* = 63), the proportion who were married was lower still, at 11.1%.

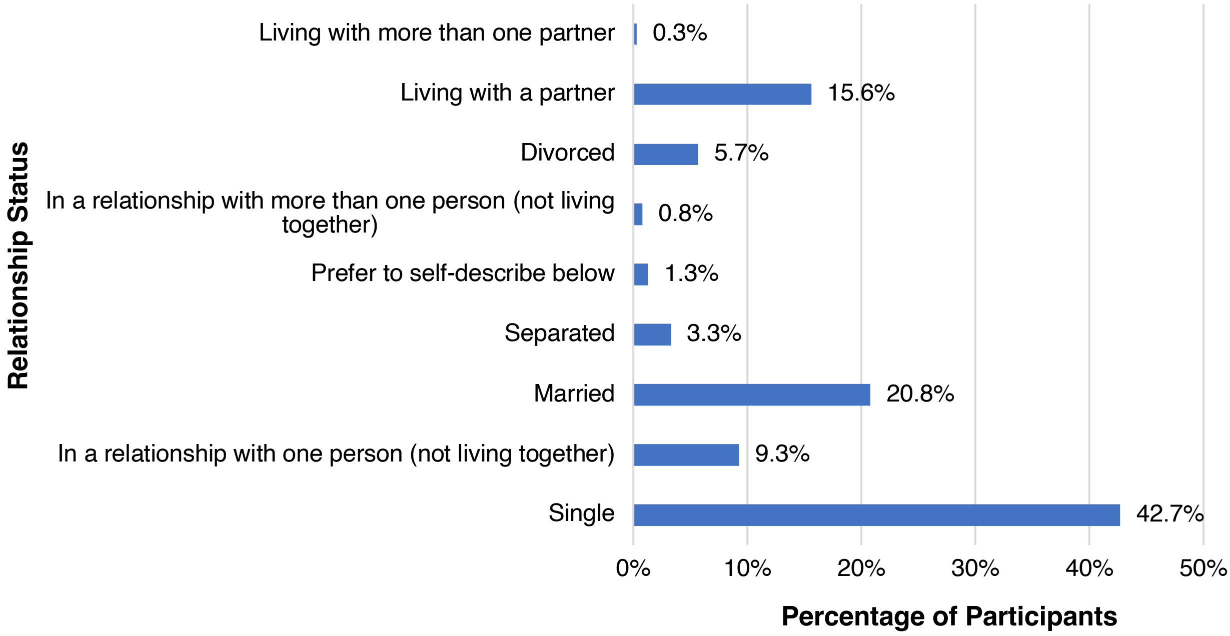


Figure 2.7. Relationship status (*N* = 1912).
Note. Relationship status was missing for six participants.

Most participants identified their sexual orientation as heterosexual, followed by bisexual and queer. Over 35% of participants identified as gay, lesbian, bisexual, pansexual, queer and/or asexual, which compares with 3% of the general Australian population who identified as gay, lesbian or as having an "other" sexual orientation (Australian Bureau of Statistics, 2015). While the representation of sexual orientations in the **Our Turn to Speak** sample is diverse, the proportion of participants identifying as gay, lesbian or bisexual (25.9%) was much lower than reported in a national study investigating the prevalence of more common mental health issues (41.4%) (Australian Bureau of Statistics, 2008).

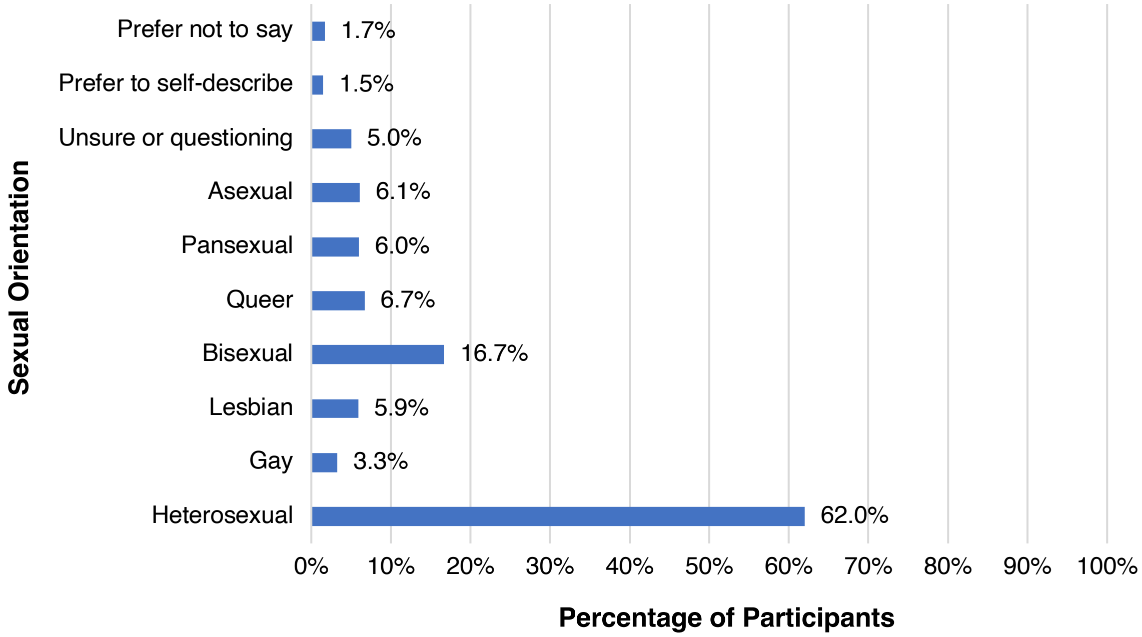


Figure 2.8. Sexual orientation (*N* = 1912).
Note. Percentages do not add to 100 as participants could select more than one response option.

Education, employment, living situation and physical health

Presented in this section is a further breakdown of participants' socio-economic characteristics and physical health.

As shown in **Figure 2.9**, most participants reported their highest level of education attained was a trade certificate or diploma, a high school (secondary college) education, or undergraduate degree. The proportion of participants whose highest level of education was an undergraduate degree or higher (45.4%) was much higher compared with people living with high-prevalence mental health issues (16.9%) (Australian Bureau of Statistics, 2008) and substantially higher than for people living with a 'severe or profound' psychological disability (5.4%) (Australian Bureau of Statistics, 2012). In the general population, the latest census indicated that 22% of Australians' highest educational attainment was an undergraduate degree or higher (Australian Bureau of Statistics, 2015).

Among participants who completed the survey via a telephone or face-to-face interview (*n* = 63), 34.9% reported their highest educational attainment to be an undergraduate degree or higher, compared with 45.7% of participants who completed the survey online. Overall, however, the **Our Turn to Speak** cohort was highly educated.

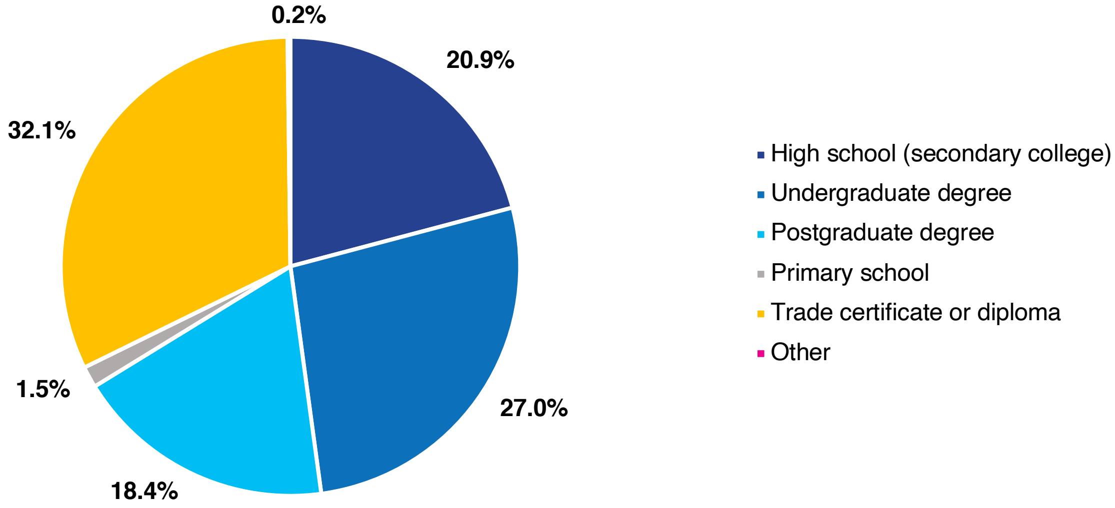


Figure 2.9. Highest level of education attained (*N* = 1912).

As shown in **Figure 2.10**, most participants were employed full-time, or part-time or casually. Approximately one in five participants were unemployed, and close to one-quarter were receiving a pension or benefits. Compared with the proportion of the general Australian population who are engaged in full-time or part-time (88.1%) (Australian Bureau of Statistics, 2020), the proportion of **Our Turn to Speak** participants in any paid employment (51.7%) was much lower.

However, more participants in the current cohort were in paid employment than has been reported in population prevalence studies of psychological disability (23.2%) (Australian Bureau of Statistics, 2012), specific complex mental health issues like schizophrenia spectrum disorders (32.7%) (Morgan et al., 2011), and high-prevalence mental health issues (20.3%) (Australian Bureau of Statistics, 2008). Among **Our Turn to Speak** participants who completed the survey via a telephone or face-to-face interview (*n* = 63), 25.4% were engaged in any paid employment, which is closer to the rates reported in the aforementioned studies.

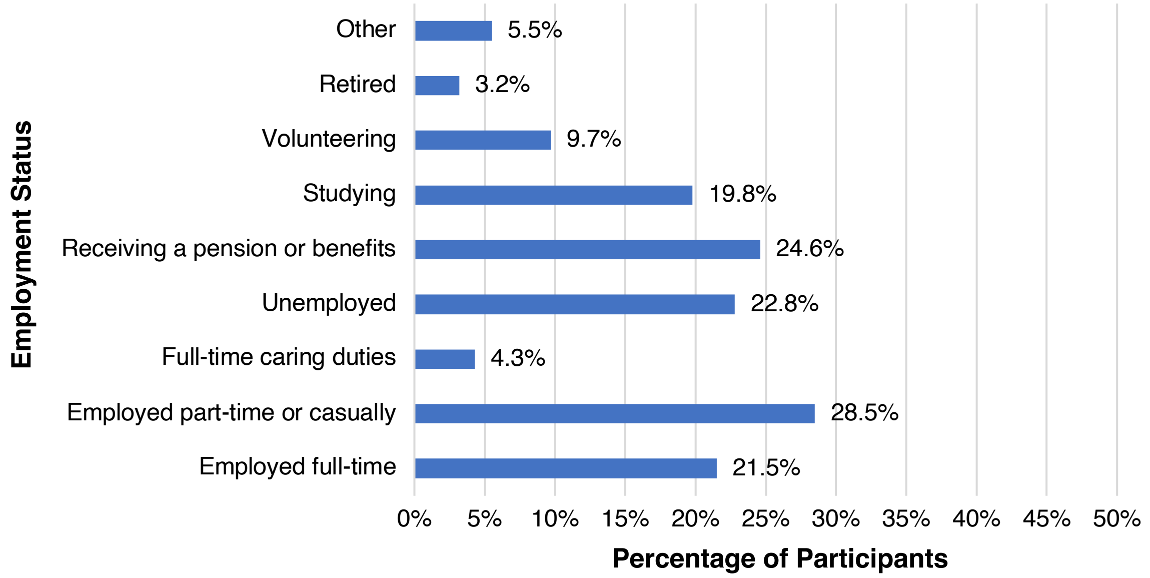


Figure 2.10. Employment status (*N* = 1912).
Note. Percentages do not add to 100 as participants could select more than one response option.

In terms of living situation, **Figure 2.11** shows that most participants were living in a private rental property or identified as homeowners. The proportion of participants living in private rental accommodation (41.7%) was not too dissimilar to the proportion reported in an Australian epidemiological study investigating the prevalence of schizophrenia spectrum disorders (48.6%) (Morgan et al., 2011). In the general Australian population, 30.9% of people live in rented accommodation and 65.5% are homeowners (Australian Bureau of Statistics, 2020).

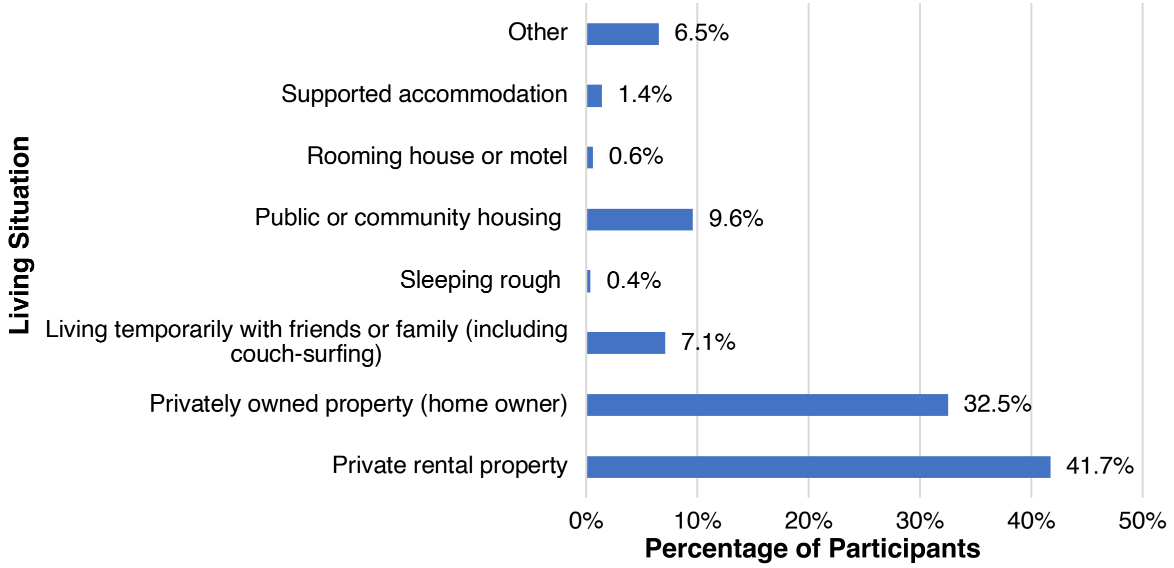


Figure 2.11. Living situation (*N* = 1912).
Note. Living situation data were missing for three participants.

Finally, just over half of all **Our Turn to Speak** participants (53.8%) reported living with a co-occurring physical health issue, such as head or brain injury, physical disability or chronic illness. **Figure 2.12** shows that, of those with a co-occurring physical health issue, a chronic illness (for example, diabetes, asthma, heart disease or cancer) was most often reported. Internationally, research has established that, more often than not, people living with complex mental health issues also live with physical health issues (Firth et al., 2019).

The proportion of participants in the current cohort who experienced physical health issues was more than double that reported in epidemiological research into high-prevalence mental health issues (23.4%) (Australian Bureau of Statistics, 2008).

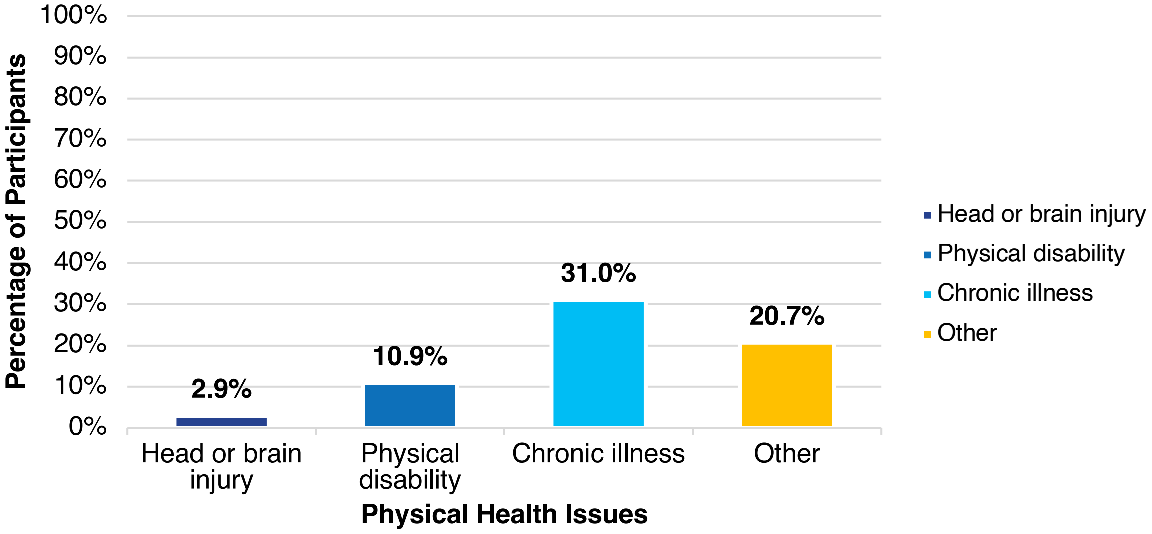


Figure 2.12. Physical health (*N* = 1912).
Note. Participants could select more than one response option.

Cultural characteristics

Presented in this section is a further breakdown of participants' cultural characteristics.

Shown in **Figure 2.13,** other religions reported by participants included Australian Aboriginal traditional religions, Judaism, Islam and Hindu.

As stated earlier, 98.7% of participants reported that their main language was English. Data were missing for four participants, but the remaining 1.1% of participants reported a highly diverse range of other main languages spoken. Seventeen other main languages were reported, including but not limited to: Cantonese, Mandarin, Afrikaans, Hebrew, Tamil, Italian, German, Punjabi, and Auslan (Australian sign language).

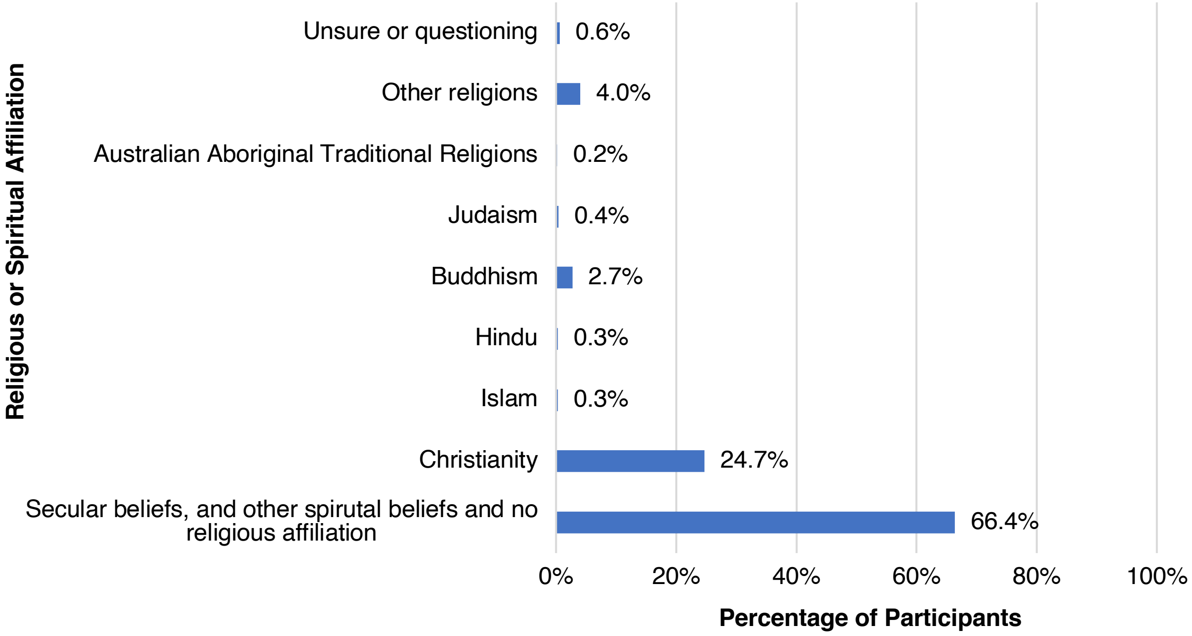


Figure 2.13. Religious or spiritual affiliations (*N* = 1912).
Note. Religious or spiritual affiliation data were missing for seven participants.

EXPERIENCES OF COMPLEX MENTAL HEALTH ISSUES

As part of eligibility screening, participants were asked if they identified with an experience of at least one of the eight types of complex mental health issues shown in **Table 2.6.**

Table 2.6. Complex mental health issues experienced by participants (*N* = 1912).

Complex Mental Health Issues	Primary	Any
Schizophrenia spectrum disorder	7.4%	10.5%
Bipolar related disorder	**17.2%**	27.8%
Obsessive-compulsive related disorder	4.3%	22.3%
Trauma-related or dissociative disorder	**25.9%**	**51.0%**
Eating disorder	6.1%	23.3%
Personality disorder	**14.5%**	27.7%
Severe and treatment-resistant depressive disorder	14.3%	**37.0%**
Severe and treatment-resistant anxiety disorder	10.2%	**34.7%**

Note. The top three, most reported types of complex mental health issues are emboldened.
Percentages for ‘any’ complex mental health issue do not add to 100 as participants could select more than one response option.
A ‘primary’ condition was defined as the only complex mental health issue identified by the participant; or, for those who reported multiple conditions, the condition that they identified as having most affected them during the last 12 months.

Sixty-seven percent of participants (*n* = 1287) endorsed experiencing two or more of these complex mental health issues during the last 12 months, while the remaining 32.7% identified as living with a single type of issue. As shown, over 50% of participants reported that they had experienced a trauma-related or dissociative disorder during the last 12 months. Severe and treatment-resistant depressive and anxiety disorders were also prevalent in this sample.

The majority of participants (97.1%) reported that their complex mental health issue(s) had been diagnosed by a health professional such as a general practitioner, psychologist or psychiatrist. Among the 1,857 participants who reported a diagnosed condition, major depressive disorder was the most common diagnosis (30.4%), closely followed by generalised anxiety disorder (27.8%), complex post-traumatic stress disorder (27.4%) and borderline personality disorder (25.5%).

The three most frequently reported diagnoses for each type of complex mental health issue screened in the **Our Turn to Speak** survey are listed in **Table 2.7**.

Table 2.7. Three most frequently reported diagnoses by type of complex mental health issue (*n* = 1857).

Complex Mental Health Issues	% Diagnosed
Schizophrenia spectrum disorder (*n* = 201)	
Schizophrenia	53.2%
Schizoaffective disorder	44.3%
Schizophreniform disorder	4.0%
Bipolar related disorder (*n* = 531)	
Bipolar II	51.4%
Bipolar I	32.0%
Cyclothymic disorder	4.7%
Obsessive-compulsive related disorder (*n* = 426)	
Obsessive-compulsive disorder	58.9%
Excoriation (skin-picking) disorder	29.1%
Body dysmorphic disorder	16.4%
Trauma-related or dissociative disorder (*n* = 976)	
Complex post-traumatic stress disorder	52.2%
Post-traumatic stress disorder	46.5%
Dissociative identity disorder	9.3%
Eating disorder (*n* = 464)	
Anorexia nervosa	32.1%
Binge eating disorder	13.3%
Bulimia nervosa	17.5%
Personality disorder (*n* = 529)	
Borderline personality disorder	89.4%
Avoidant personality disorder	5.5%
Obsessive-compulsive personality disorder	5.3%
Severe and treatment-resistant depressive disorder (*n* = 707)	
Major depressive disorder	80.1%
Persistent depressive disorder (dysthymia)	14.6%
Premenstrual dysphoric disorder	5.7%
Severe and treatment-resistant anxiety disorder (*n* = 663)	
Generalised anxiety disorder	78.4%
Social anxiety disorder (social phobia)	38.5%
Panic disorder	29.1%

Note. Participants could select more than one response option.

Of note (not shown), 63.6% of participants with a professional diagnosis reported co-occurring mental health issues that were considered outside the scope of the **Our Turn to**

Speak survey such as mild-to-moderate depression and anxiety, substance or alcohol use issues, and more.

Further highlighting the challenges of living with complex mental health issues were participants' responses to several items designed to gauge their duration, severity, and functional impact.

On average, participants' mental health issues developed during mid-adolescence (*M* = 15.8 years, *SD* = 9.6). The majority (74.4%) estimated that, since the onset of their mental health issue(s), they had lived fewer than 12 months of their lives without experiencing any negative impact of those issues.

In the 12 months before completing the **Our Turn to Speak** survey, 72.0% of participants rated the distress and negative impact caused by their mental health issues as 'moderate-severe' or worse. For the same time period, 40.5% of participants reported that they were totally unable to work, study, or manage their day-to-day activities because of their mental health for at least three months or more, and 53.0% reported a need to cut down on those activities for the same amount of time (refer to **Figure 2.14**).

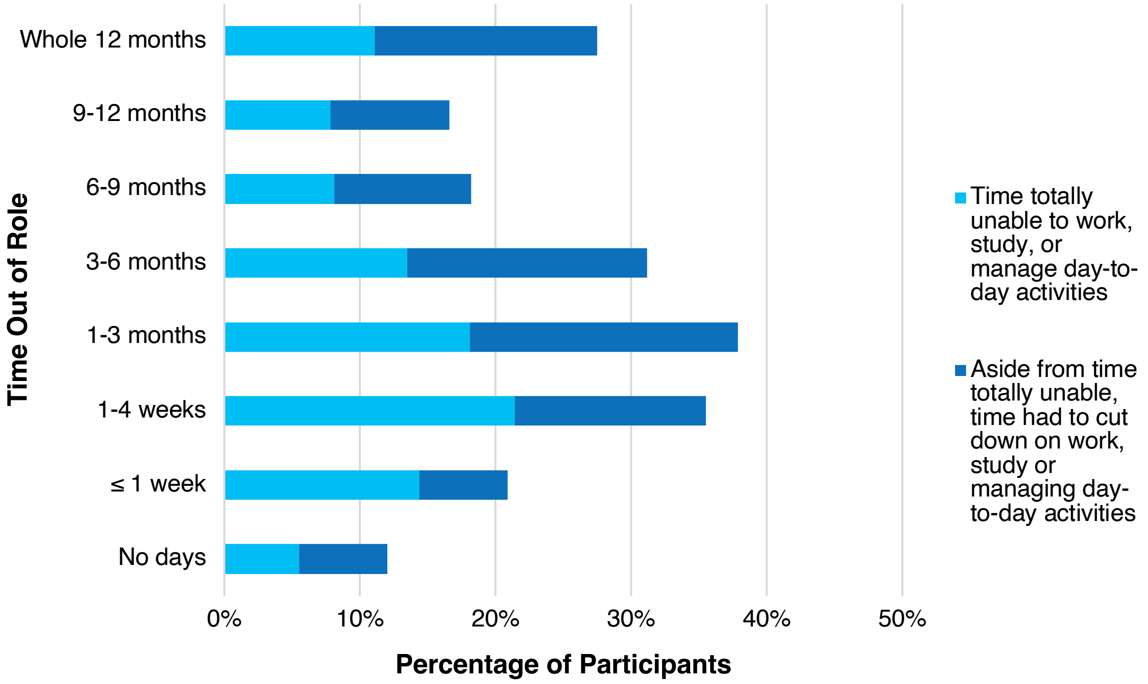


Figure 2.14. Participants' ratings of functional impact (time out of role) caused by their experience of complex mental health issues during the last 12 months (*N* = 1912).

Participants had accessed numerous types of mental healthcare and support services in the 12 months before completing the survey (**Table 2.8** contains a complete list). The vast majority (95.9%) had engaged in some form of mental health treatment; typically, evidence-based medications (84.0%) and psychotherapy or counselling (81.3%). This rate of treatment-engagement is substantially higher than was reported in a population prevalence survey of high-prevalence mental health issues (Australian Bureau of Statistics, 2008), which may be attributable to the majority of those individuals perceiving no need for mental healthcare.

Table 2.8. Mental healthcare services accessed by participants in the last 12 months (N = 1912).

Mental Healthcare Services	% Accessed
None	2.5%
General practitioner	87.6%
Psychiatrist	62.0%
Psychologist	70.0%
Other allied health professional (eg. social worker, occupational therapist, mental health nurse, nutritionist, exercise physiologist)	42.5%
Hospital inpatient service	24.8%
Community-based care (eg. day program, hospital outpatient service, outreach program)	23.4%
Residential care (eg. prevention and recovery centre, rehabilitation service)	4.8%
Specialist homelessness service	2.5%
Peer-worker or peer-support group	18.7%
Online peer-support group or forum	25.4%
Telephone or online counselling service	30.5%
Other type of service	10.9%
Unsure	0.1%

Note. Percentages do not add to 100 as participants could select more than one response option.

Figure 2.15 shows participants' ratings for the effectiveness of treatments. Among the 13.4% of participants (n = 247) who rated their treatments as having 'very much improved' their mental health and wellbeing over the last 12 months, the majority (83.8%) reported that this level of improvement had endured for at least four weeks.

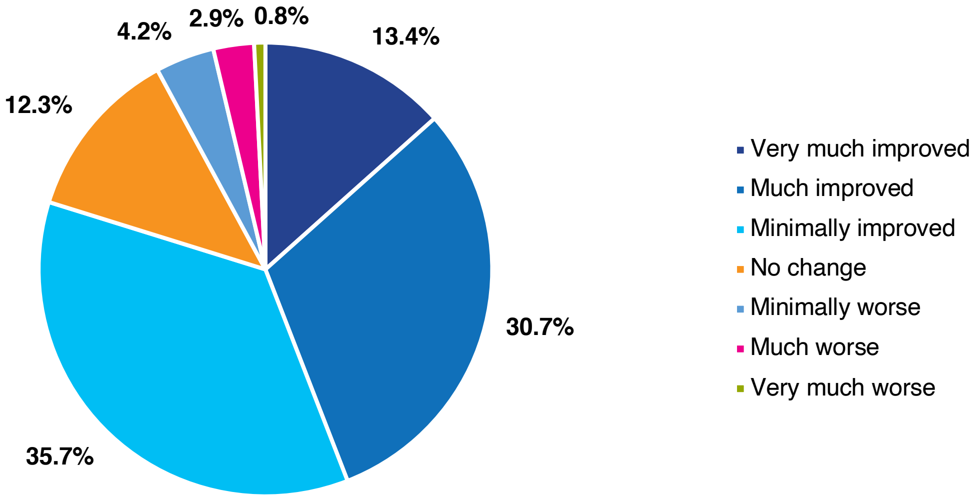


Figure 2.15. Participants' ratings of how much they perceived their most helpful treatment over the last 12 months had improved or worsened their mental health and wellbeing (n = 1831).

Overall, the mental health characteristics associated with the 1,912 **Our Turn to Speak** participants highlights the complex and severe nature of their experience of mental health issues; symptoms were enduring, co-occurring mental health and physical health issues were highly prevalent, functional impact on daily activities was significant, multi-agency service use was high, and treatment effectiveness was moderate.

GENERAL FINDINGS

03

Chapter 3. General findings

Each participant kindly took the time to contribute rich and detailed data to **Our Turn to Speak.** They told us about how they have been stigmatised and treated differently because of their complex mental health issues. They spoke about their worry and expectations of further negative experiences. They described the many instances in which stigma had induced them to forego a range of opportunities in life.

Now, with each story added to the other, the **Our Turn to Speak** findings provide undeniable evidence that no Australian who lives with complex mental health issues is alone in facing stigma about complex mental health issues. The problem is clearly both pervasive and destructive. Yet, there is hope to be found. The findings also speak to the strength and resiliency of people living with complex mental health issues in facing stigma in their everyday lives and additionally, highlight how people have also received positive treatment across their lives because of their mental health issues.

Collectively, these data inform us about where the key problems lie and where the possible solutions may be found. Indeed, participants embraced their turn to speak to those solutions and finished the survey by telling us, in their own words, what they thought most needed to change to reduce stigma and discrimination and improve the lives of Australians living with complex mental health issues.

This brief chapter outlines some of the high level trends observed in the survey data across the 14 life domains investigated. The trends highlighted here are subsequently discussed in greater detail in each of the remaining 15 findings chapters.

STIGMA AND DISCRIMINATION ACROSS LIFE

The **Our Turn to Speak** survey asked participants about stigma and discrimination across 14 areas of life and in terms of both frequency and impact of perceived experiences. **Table 3.1** summarises these data. It can be seen that overall, the rate of reported experiences of stigma and discrimination in the preceding 12 months across life domains was significant.

Of the 14 life domains investigated, **Table 3.1** shows that relationships were the primary concern, with 95.6% of participants indicating that they had experienced *some level* of stigma and discrimination. Particular concern was also shared regarding physical healthcare services and social media. **Table 3.1** also shows that half of those surveyed or more indicated that they had been subject to some level of stigma and discrimination in each life domain. The life domain receiving fewest reports of concern was justice and legal services. It is important to note, however, that still a remarkable proportion of the sample – some 37.3% – reported some level of problem in this domain.

Perceived experiences of stigma and discrimination were not only widespread. They were also frequent for many participants. **Table 3.1** shows that again, interpersonal relationships were again identified as the primary life domain in which *frequent* or *very frequent* stigma and discrimination occurred, with 46.4% of participants reporting such experiences. Next, mass media and social media were identified as areas of life in which participants had experienced frequent or very frequent negative experiences. Rates of frequent experience were otherwise largely variable otherwise across life domains.

Table 3.1. Stigma and discrimination experienced across the 14 life domains in the previous 12 months (*N* = 1912).

Life Domain	Most Affected by Stigma and Discrimination[1]	Most Frequent Stigma and Discrimination[2]	Any Stigma and Discrimination[3]
Relationships	69.1%	46.4%	95.6%
Employment	43.0%	31.2%	78.1%
Healthcare services	26.3%	31.7%	83.9%
Social media	25.3%	40.0%	84.6%
Mental healthcare services	23.6%	22.1%	71.8%
Mass media	22.1%	40.8%	76.8%
Welfare and social services	12.5%	19.4%	58.9%
Education and training	10.5%	14.1%	60.0%
Financial and insurance services	7.3%	16.4%	50.9%
Housing and homelessness services	6.1%	9.7%	39.4%
Cultural, faith or spiritual practices and communities	5.3%	10.1%	39.4%
Sports, community groups and volunteering	5.2%	8.6%	50.7%
Public spaces and recreation	5.1%	10.1%	55.0%
Legal and justice services	4.8%	10.3%	37.3%

[1] Percentages do not add to 100 as participants could select up to three domains.

[2] Frequency of stigma and discrimination in each domain was calculated by summing the percentage of 'frequently' and 'very frequently' responses.

[3] Frequency of any stigma and discrimination in each domain was calculated by summing the percentage of responses: 'very rarely', 'rarely', 'occasionally', 'frequently' and 'very frequently'.

The survey also investigated the *impact* of stigma and discrimination across participants' lives. Relationships were again observed to be the primary concern. A total of 69.1% of participants indicated that relationships were one of the three areas of life in which they had been *most affected* by stigma and discrimination in the preceding 12 months. Employment was also reported by many to be an area of particular personal impact, with 43% of participants indicating such experience. Lower but comparable rates of agreed personal impact were observed for healthcare services, social media, mental healthcare services, and mass media. Impactful experiences of stigma and discrimination were reported by fewer participants in the remaining life domains.

GENDER IDENTITY AND THE IMPACT OF STIGMA AND DISCRIMINATION ABOUT COMPLEX MENTAL HEALTH ISSUES

The data describing the three life domains in which participants were most affected by stigma were explored according to reported gender identity. These data are presented in **Table 3.2**. It can be seen that overall, the broad pattern of reported personal impact across life domains is comparable for the overall sample and each gender identity group presented. For example, relationships and employment were the top two areas of concern reported by the overall sample and by each gender group. Moreover, the pattern of reported personal impact for the group of participants identifying as female was the same as that of the overall sample. While this is to be expected given that the majority of participants were female, there are some remarkable exceptions to this general trend of equivalence.

Male participants were approximately half as likely or less when compared to all other groups to report impactful experiences of stigma and discrimination in the physical healthcare system. Indeed, this was the only participant group for whom physical healthcare was not observed to be one of the top five areas of concern regarding the personal impact of stigma and discrimination. Participants identifying as male were also approximately twice as likely as any other participant group to report being impacted by stigma in sports, community groups and volunteering. **Table 3.2** additionally shows yet other life domains with relatively elevated rates of personal impact for male-identifying participants, including legal and justice services, public spaces, and more.

Participants who identified as trans, gender diverse and/or non-binary showed elevated rates of impactful experiences of stigma and discrimination in numerous life domains. For example, **Table 3.2** illustrates that while healthcare service use was a key area of concern for the overall sample and all gender identity groups, the rate of impactful experience observed for trans, gender diverse and/or non-binary was remarkably elevated. Also of note, the rates of impactful experiences in welfare and social services, and public and recreational spaces, were approximately doubled for the trans, gender diverse or non-binary group when compared to the overall sample and all other groups. Conversely, notably lower rates of impact were reported by this group for the legal and justice, and finance and insurance domains. Further exploration of stigma and discrimination and gender identity are provided in each findings chapter throughout this report.

Table 3.2. Life domains in which participants were most affected by stigma in the previous 12 months for the overall sample (*N* = 1912), female participants (*n* = 1508), male participants (*n* = 344) and trans, gender diverse and/or non-binary participants (*n* = 93).

Life Domain	Total Sample (*N* = 1912)	Female Participants (*n* = 1508)	Male Participants (*n* = 344)	Trans, Gender Diverse and/or Non-Binary Participants (*n* = 93)
Relationships	**69.1%**	**70.6%**	**64.2%**	**62.4%**
Employment	**43.0%**	**42.3%**	**46.2%**	**39.8%**
Healthcare services	**26.3%**	**28.7%**	13.7%	**35.5%**
Social media	**25.3%**	**26.5%**	**21.2%**	21.5%
Mental healthcare services	**23.6%**	**24.9%**	**17.2%**	**28.0%**
Mass media	22.1%	21.6%	**22.1%**	**25.8%**
Welfare and social services	12.5%	11.9%	12.8%	22.6%
Education and training	10.5%	10.7%	8.1%	15.1%
Financial and insurance services	7.3%	7.0%	9.3%	2.2%
Housing and homelessness services	6.1%	5.8%	7.6%	6.5%
Cultural, faith or spiritual practices and communities	5.3%	4.9%	7.3%	5.4%
Sports, community groups and volunteering	5.2%	4.0%	9.9%	5.4%
Public spaces and recreation	5.1%	4.7%	6.1%	11.8%
Legal and justice services	4.8%	4.3%	7.3%	2.2%

Note. For the overall sample and each gender group, the top 5 most commonly reported life domains in which participants reported being impacted by stigma and discrimination are emboldened.
Percentages do not add to 100 as participants could select up to three life domains in which they were most personally affected by stigma and discrimination.
Gender group sizes do not add to equal the sample size given that: 1) participants could choose more than one option; 2) the data for those participants who reported being unsure about or preferring not to report their gender is not presented here.

SEXUAL ORIENTATION AND THE IMPACT OF STIGMA AND DISCRIMINATION ABOUT COMPLEX MENTAL HEALTH ISSUES

The data describing the top three life domains in which participants were personally affected by stigma were also investigated according to reported sexual orientation. These data for the total sample, participants identifying as heterosexual, and participants identifiying as LGBQA+, are presented in **Table 3.3**. The overall trends of reported impact of stigma and discrimination across life domains were largely comparable across participant groups.

Indeed, the top five life domains of concern regarding the personal impact of stigma are consistent for each group. There are some noteworthy acceptions to this general trend of equivalency, however. Remarkably elevated rates of impact were reported by LGBQA+ participants in numerous areas, including physical and mental healthcare services, mass media, and others. Inversely, roughly half the rate of impact was reported by LGBQA+ participants in cultural, faith or spiritual practices and communities and sports, community groups and volunteering when compared to heterosexual participants and the overall sample. Additional examination of sexual orientation and stigma and discrimination is provided in each findings chapter throughout this report.

Table 3.3. Life domains in which participants were most affected by stigma in the previous 12 months for the overall sample (*N* = 1912), and participants identifying as LGBQA+ (*n* = 680).

Life Domain	Total Sample (*N* = 1912)	Heterosexual Participants (*n* = 1185)	LGBQA+ Participants (*n* = 680)
Relationships	**69.1%**	**72.1%**	**63.7%**
Employment	**43.0%**	**46.2%**	**39.6%**
Healthcare services	**26.3%**	**23%**	**31.9%**
Social media	**25.3%**	**24.0%**	**27.2%**
Mental healthcare services	**23.6%**	**19.7%**	**29%**
Mass media	22.1%	19.6%	25.3%
Welfare and social services	12.5%	11.1%	15.4%
Education and training	10.5%	9.1%	13.2%
Financial and insurance services	7.3%	7.3%	7.4%
Housing and homelessness services	6.1%	6.1%	6%
Cultural, faith or spiritual practices and communities	5.3%	6.2%	3.4%
Sports, community groups and volunteering	5.2%	6.2%	3.7%
Public spaces and recreation	5.1%	5.0%	5.3%
Legal and justice services	4.8%	5.2%	4.0%

Note: For the overall sample and each sexual orientation group, the top 5 most commonly reported life domains in which participants reported being impacted by stigma and discrimination are emboldened.

Percentages do not add to 100 as participants could select up to three life domains in which they were most personally affected by stigma and discrimination.

Sexual orientation group sizes do not add to equal the sample size given that: 1) participants could choose more than one option; 2) the data for those participants who reported being unsure about or preferring not to report their sexual orientation is not presented.

LGBQA+ = Lesbian, gay, bisexual, queer, pansexual and/or asexual.

THE IMPACT OF STIGMA AND DISCRIMINATION ABOUT COMPLEX MENTAL HEALTH ISSUES ON ABORIGINAL AND/OR TORRES STRAIT ISLANDER PARTICIPANTS

The data describing the top three life domains in which participants were personally affected by stigma were also examined for participants identifying as Aboriginal and/or Torres Strait Islander in comparison to the overall sample. Table 3.4 shows that that four of the top five life domains of concern for the overall sample were also chief issues for participants identifying as Aboriginal and/or Torres Strait Islander. There were, however, many notable differences in rates of reported impact across life areas for the overall sample and this participant group. For example, stigma and discrimination in mass media and social media were reported as particularly personally impactful for Aboriginal and/or Torres Strait Islander participants at a rate less than half of that observed in the overall sample. In contrast to this, rates of impactful experiences of stigma and discrimination were conspicuously elevated for the Aboriginal and/or Torres Strait Islander participant group in areas including welfare and social services, education and training, housing and homelessness services, sports, community groups and volunteering, and legal and justice services. Specific issues for Aboriginal and/or Torres Strait Islander participants are further reported thoughout the findings chapters of this report.

Table 3.4. Life domains in which participants were most affected by stigma in the previous 12 months for the overall sample (*N* = 1912), and Aboriginal and/or Torres Strait Islander participants (*n* = 67).

Life Domain	Total Sample (*N* = 1912)	Aboriginal and Torres Strait Islander Participants (*n* = 67)
Relationships	**69.1%**	**67.2%**
Employment	**43.0%**	**38.8%**
Healthcare services	**26.3%**	**25.4%**
Social media	**25.3%**	10.0%
Mental healthcare services	**23.6%**	**20.9%**
Mass media	22.1%	9.0%
Welfare and social services	12.5%	**17.9%**
Education and training	10.5%	**17.9%**
Financial and insurance services	7.3%	10.4%
Housing and homelessness services	6.1%	13.4%
Cultural, faith or spiritual practices and communities	5.3%	1.5%
Sports, community groups and volunteering	5.2%	10.4%
Public spaces and recreation	5.1%	7.5%
Legal and justice services	4.8%	9.0%

*Note***.** For the overall sample and each sexual orientation group, the top 5 most commonly reported life domains in which participants reported being impacted by stigma and discrimination are emboldened.
Percentages do not add to 100 as participants could select up to three life domains in which they were most personally affected by stigma and discrimination.

PERCEIVED STIGMA AND DISCRIMINATION, ANTICIPATION, AND WITHDRAWAL FROM LIFE OPPORTUNITIES

In each life domain, experiences of stigma and discrimination reported by participants were consistently observed alongside anxious anticipation of future negative experiences and withdrawal from important opportunities. **Figure 3.1** summarises these data.

Rates of reported negative experiences, anticipation of stigma, and withdrawal from opportunities varied dynamically across life domains. Of note, **Figure 3.1** shows that rates of agreement for survey items describing the anticipation of stigma surpassed those for actual perceived experiences in 12 of the 14 life domains investigated. Moreover, in 10 life domains, the highest rates of agreement with survey statements were actually seen in response to items describing withdrawal from opportunities. Collectively, then, these findings speak not only to a pervasive pattern of perceived stigma and discrimination experiences, but also to widespread anticipation of negative experiences, and withdrawal from important opportunities across life. The data describing participants experiences of stigma and discrimination, anticipation of stigma, and withdrawal from opportunities, is discussed in greater detail in each of the life domain findings chapters that follow.

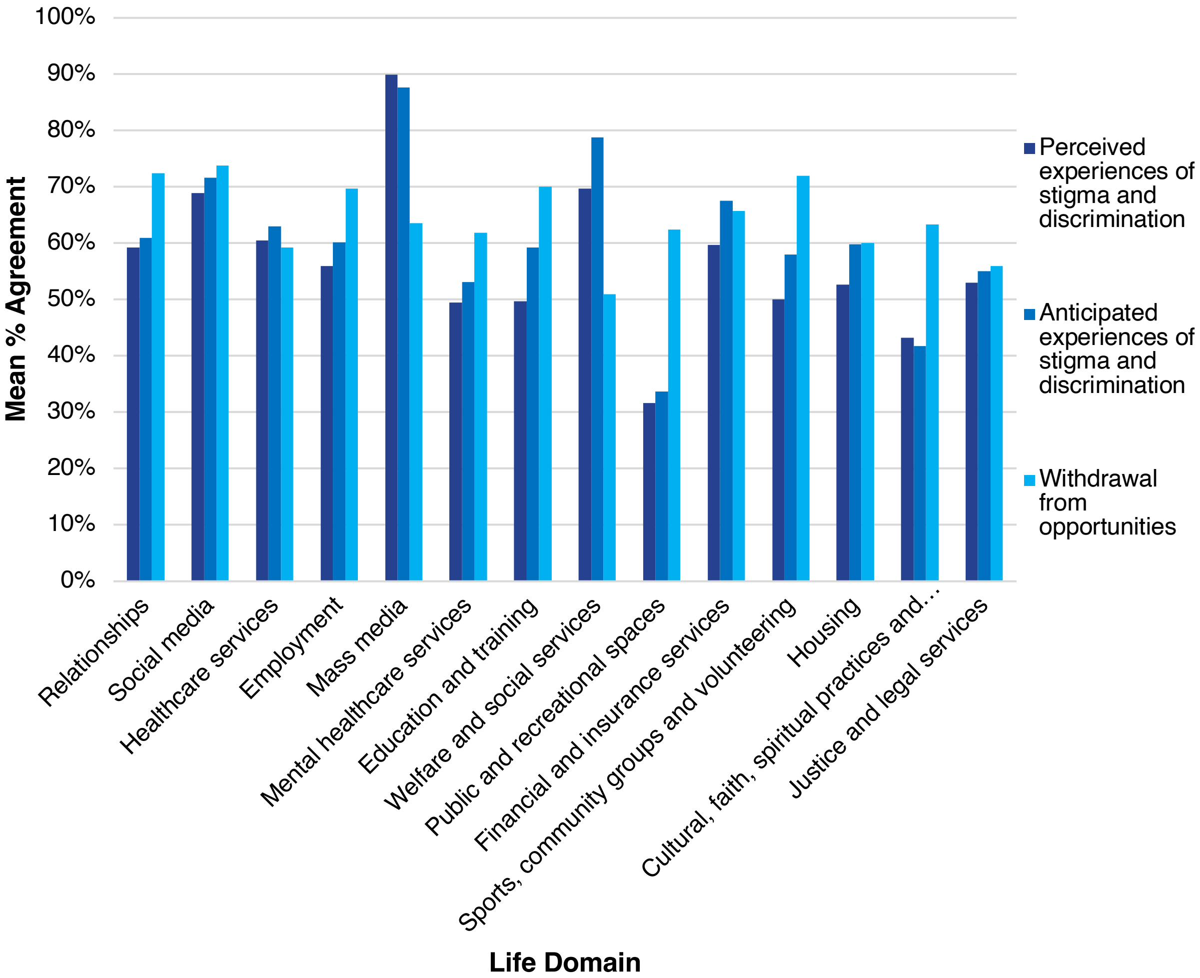


Figure 3.1. Average percentage agreement with statements describing perceived experiences of stigma and discrimination, anticipation of stigma and discrimination, and withdrawal from opportunities across life domains (*N* = 1912).

POSITIVE EXPERIENCES ACROSS LIFE DOMAINS

Participants were also asked about positive treatment they may have received in each life domain because of their complex mental health issues. **Figure 3.2** compares average rates of agreement for survey statements describing negative experiences and positive experiences.

In nine of the 14 life domains investigated, negative experiences were reported more commonly on average than positive experiences. Yet, positive experiences were not uncommon. The greatest level of agreement with statements describing positive experiences was observed in the domain of social media (77.7%). Such experiences were reported less frequently in other domains, yet even the lowest average rate of agreement (19.2%) observed, in the financial and insurance services, is noteworthy. The findings regarding positive treatment related to participants' complex mental health issues are presented and discussed in greater detail in each life domain findings chapter to come.

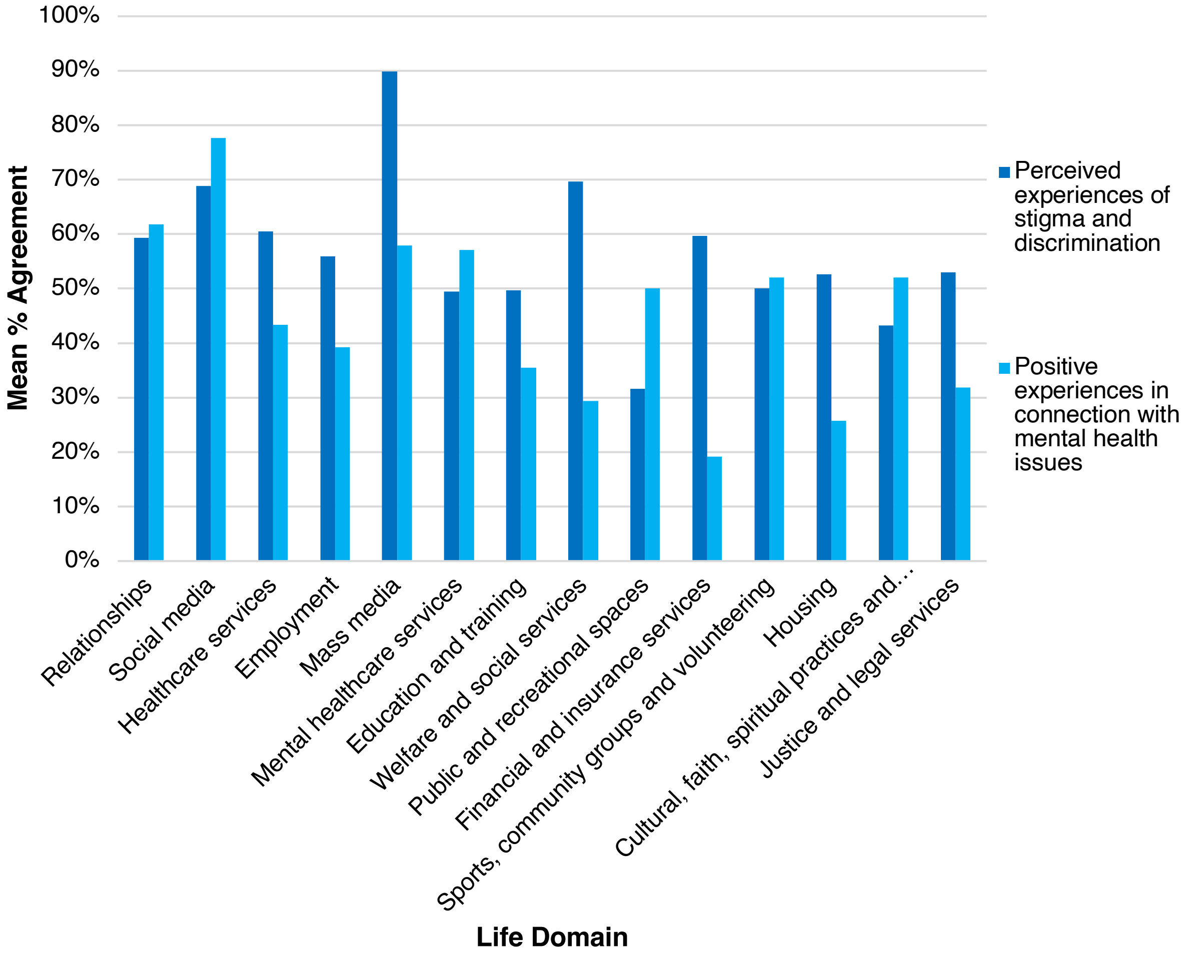


Figure 3.2. Average percentage agreement with statements describing experiences of stigma and discrimination, and positive experiences because of participants' mental health issues across life domains (*N* = 1912).

SUMMARY AND CONCLUSION

This chapter presented a snapshot of basic trends observed in the **Our Turn to Speak** survey findings. These trends spoke to perceived experiences of stigma and discrimination, anticipation of stigma and discrimination, and withdrawal from life opportunities being a common experience for participants across 14 areas of life. The findings were not exclusively concerning, however, with positive experiences related to mental health issues also being observed across life domains. In contrast to general trends, specific group differences in the findings were observed in relation to participants' personal characteristics such as gender identity, sexual orientiation, and Aboriginal and/or Torres Strait Islander background.

This report now moves on to present detailed findings from each life domain investigated by the **Our Turn to Speak** survey. Each of the 14 life domains investigated has a dedicated chapter, and chapters are organised according to the percentage of participants who reported personally impactful experiences in each life domain. Therefore, the following chapter is dedicated to describing the findings regarding stigma and discrimination, and positive experiences, in participants' relationships.

RELATIONSHIPS

04

Chapter 4. Relationships

Relationships play an important role in all our lives. Connection and social support can optimise wellbeing and buffer against challenging times. For people living with complex mental health issues, the impact of that support can be strengthened by having family, friends, and intimate partners who understand their unique experiences and the types of support that they personally find beneficial.

This chapter considers how people living with complex mental health issues experience stigma and discrimination in their relationships with friends, family, intimate partners and in their role as parents or caregivers to children.

OVERVIEW

Stigma and discrimination in the relationships domain was the most commonly endorsed concern among participants of the **Our Turn to Speak** survey; over 95% (*n* = 1828) of participants reported experiencing some level of stigma and discrimination in their relationships during the past 12 months.

As shown in **Figure 4.1**, 46.4% (*n* = 888) of all participants reported 'frequent' or 'very frequent' stigma and discrimination in their relationships, and 69.1% (*n* = 1320) identified this life domain as one of three in which they had been most affected by such experiences. **Figure 4.1** also shows that 54.3% of participants who selected the relationships domain reported 'frequent' or 'very frequent' rates of stigma and discrimination in this aspect of their lives; somewhat higher than was reported by the total sample.

This chapter focuses on the characteristics and experiences of those 1,320 participants who selected relationships as one of their top three, most affected life domains.

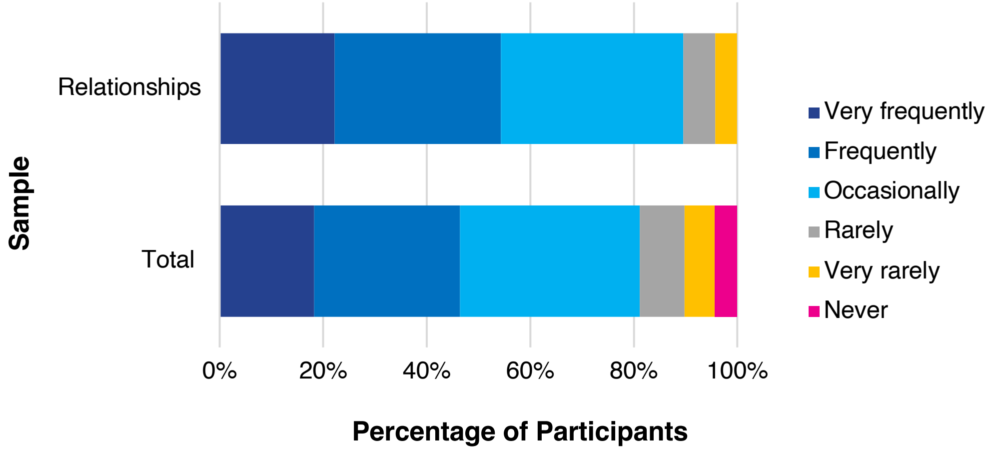


Figure 4.1. Frequency of stigma and discrimination in relationships among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 1320) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

The sociodemographic characteristics of participants who identified as being affected by stigma and discrimination in their relationships were closely comparable to those characteristics of the total sample. These data are summarised in **Table 4.1**.

The observed pattern of closely comparable characteristics is to be expected, given that the group of participants who responded to the relationships section of the survey made up 69.1% of the total participant sample.

Table 4.1. Sociodemographic characteristics: *relationships* sample compared with the total sample.

Characteristics		Relationships (*n* = 1320)	Total (*N* = 1912)
Mean age		39.56 (*SD* = 12.98)	39.21 (*SD* = 12.81)
Gender identity			
	Female	80.6%	78.9%
	Male	16.7%	18.0%
	Trans, gender diverse and/or non-binary	4.4%	4.9%
	Unsure or questioning	1.1%	0.9%
	Prefer not to say	0.3%	0.4%
Relationship status			
	Not in a relationship	52%	52.1%
	In a relationship	47.8%	47.3%
	Prefer to self-describe	0.2%	0.2%
Sexual orientation			
	Heterosexual	64.7%	62.0%
	Gay, lesbian, bisexual, pansexual, queer, and/or asexual	35.3%	35.6%
	Unsure or questioning	5.5%	4.9%
	Prefer to self-describe	1.4%	1.5%
	Prefer not to say	1.3%	1.7%
Education (highest level attained)			
	Primary school	1.0%	1.6%
	Secondary college (high school)	21.0%	20.9%
	Educated post-secondary college	77.8%	77.4%
	Other	0.2%	0.2%
Employment			
	Engaged in paid work	52.3%	51.7%
	Engaged in unpaid work or studying	27.7%	28.7%
	Unemployed or unable to work	22.7%	22.8%
	Receiving a pension or benefits	24.2%	24.6%
	Other	0.3%	0.2%
State			
	Australian Capital Territory	2.4%	2.5%
	New South Wales	23.2%	23.6%
	Northern Territory	0.2%	0.6%
	Queensland	16.8%	15.9%
	South Australia	9.1%	9.5%
	Tasmania	4.0%	3.7%
	Victoria	34.0%	33.1%
	Western Australia	10.2%	10.9%
Region*			
	Major city	73.9%	74.2%
	Regional or remote	26.1%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

Figure 4.2 presents a further breakdown of the nature of participants' relationships. As shown, the relationship status of participants who identified as being affected by stigma and discrimination in their relationships was closely comparable to those characteristics of the total sample.

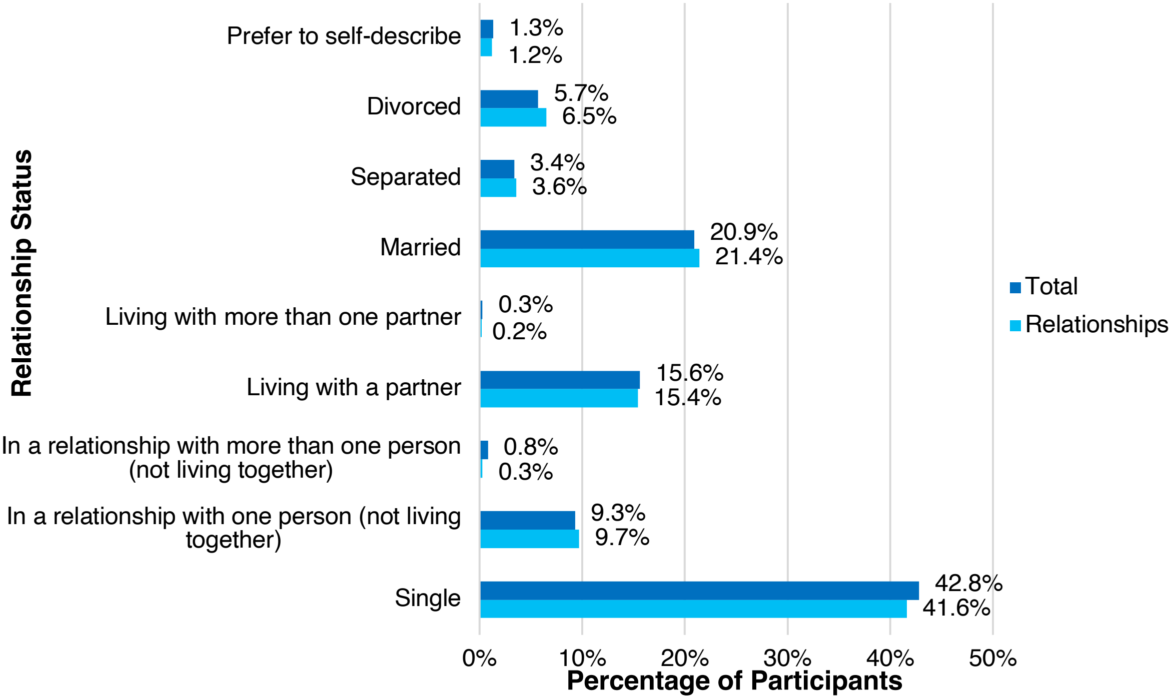


Figure 4.2. Relationship status among participants who selected *relationships* as one of three domains in which they had been most affected by stigma during the past 12 months (n = 1320) compared with the total sample (N = 1912).
Note. Percentages do not add to 100 as participants could select more than one response option.

As with the socidemographic data, the mental and physical health characteristics of participants who identified the relationships domain as having been most affected by stigma and discrimination were again similar to those of the total sample. These data are presented in **Table 4.2**.

Table 4.2. Mental and physical health characteristics: *relationships* sample compared with the total sample.

Characteristics	Relationships (n = 1320)	Total (N = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	6.1%	7.4%
Bipolar related disorder	16.3%	17.2%
Obsessive-compulsive related disorder	4.7%	4.3%
Trauma-related or dissociative disorder	25.5%	25.9%
Eating disorder	6.4%	6.1%
Personality disorder	15.2%	14.5%
Severe and treatment-resistant depressive disorder	14.8%	14.3%
Severe and treatment-resistant anxiety disorder	11.1%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	51.6%	53.8%

METHODS SNAPSHOT

Participants who identified relationships as one of three life domains in which they have been most affected by stigma-related experiences completed the relationships section of the survey. At the beginning of this section of the survey, participants were asked to indicate what types of relationships they had participated in during the previous 12 months. Relationships were described as those with:

- people the participant considered to be their friends
- biological and chosen family, relative or children
- intimate partners (for example, dating, married, de-facto and/or casual).

Participants were not asked about carer roles they may have engaged in, other than parenting or caring for children.

Ninety-one percent (*n* = 1207) reported they had participated in friendships; 69.7% (*n* = 920) had participated in intimate relationships; 91.1% (*n* = 1203) had participated in relationships with family members; and 37.4% (*n* = 494) reported acting in a parenting or caregiving role with children. Each relationship type endorsed by participants triggered a corresponding set of survey items to be presented, in turn.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in their relationships; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of relationships. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further elaborate on and describe their experiences of stigma and discrimination because of: (a) complex mental health issues, (b) in relation to other personal characteristics, and (c) experiences of positive treatment in their relationships. Additional comments in relation to these experiences were given by 303, 143 and 283 participants, respectively.

STIGMA AND DISCRIMINATION IN RELATIONSHIPS

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in relationships, which will be further examined in sections that follow.

As shown in **Figure 4.3**, approximately 60% of participants who completed the relationships section of the survey endorsed statements describing perceived experiences of stigma and discrimination in the past 12 months. A comparable proportion of this group endorsed statements indexing the anticipation of future stigma and discrimination in relationships because of their complex mental health issues. The frequency of agreement was greater still for statements that described withdrawal from opportunities in relationships, with over 70% of participants endorsing such statements, on average.

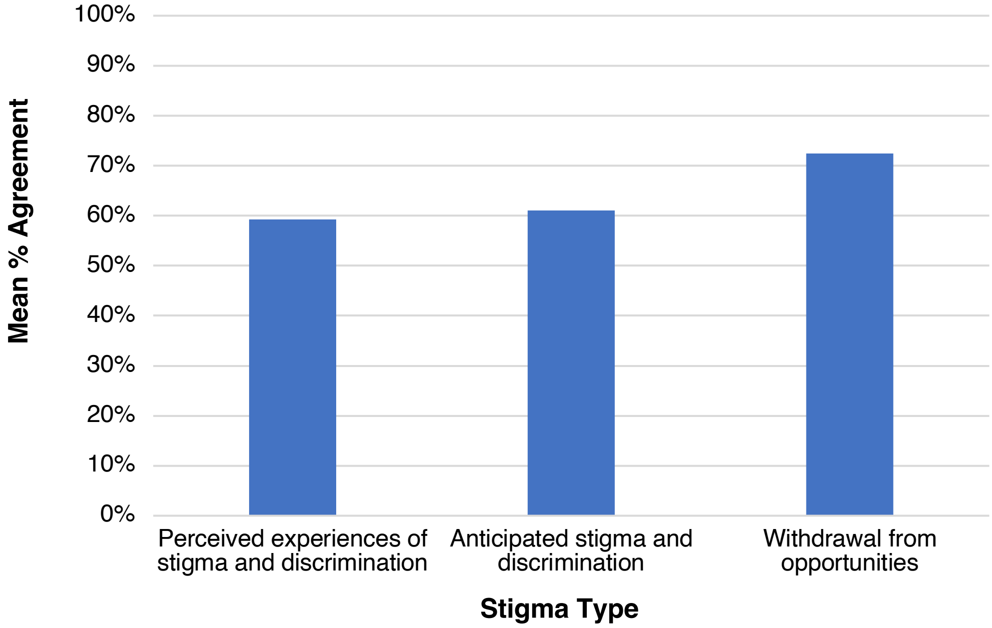


Figure 4.3. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *relationships* (*n* = 1320).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN RELATIONSHIPS

> ***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**

The findings regarding participants’ perceived experiences of stigma and discrimination in relationships because of their experience of complex mental health issues are presented.

Figure 4.4 illustrates the aggregated findings regarding perceived experiences of unfair treatment in establishing and maintaining relationships, and rejection and estrangement across the sub-domains of friendships, intimate relationships, familial relationships, and parenting or caregiving for children. It can be seen that, for the most part, negative experiences in relationships were endorsed by more than half of participants.

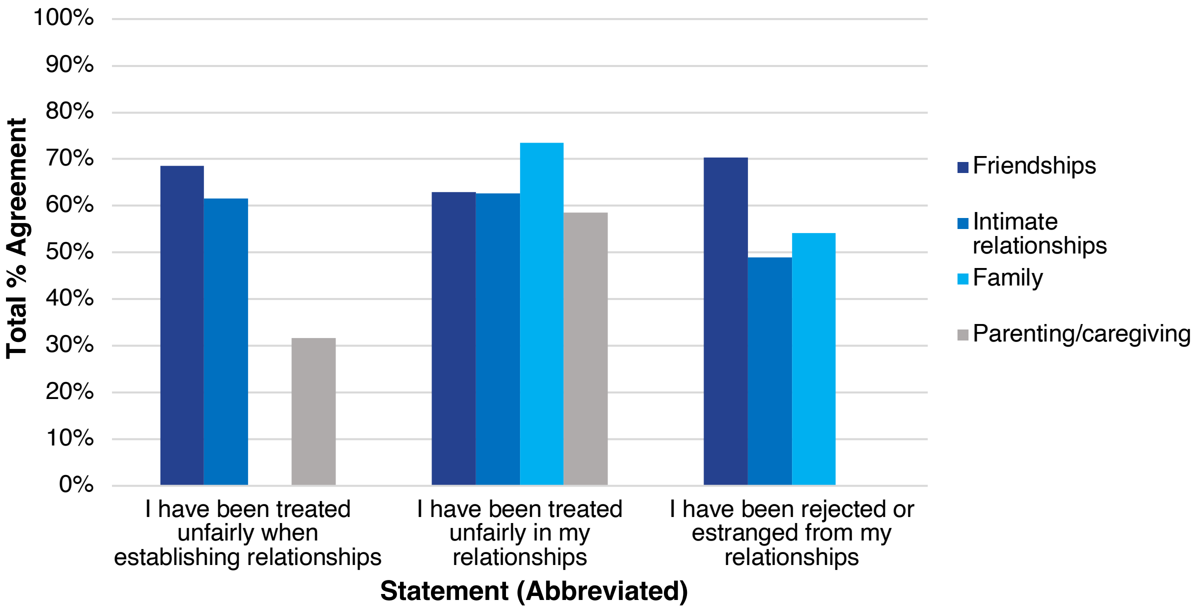


Figure 4.4. Highlight findings: total percentage agreement with perceived experiences of stigma and discrimination in *friendships* (*n* = 1207), *intimate relationships* (*n* = 920), *family relationships* (*n* = 1203) and *parenting or caregiving* (*n* = 494).

Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

The data presented examine the findings regarding participants' perceived experiences of stigma and discrimination in further detail. **Figure 4.5** highlights the two most frequently endorsed issues from the set of ten statements describing perceived experiences of stigma and discrimination. Unfair treatment by family members, and rejection or estrangement, received the highest levels of agreement, with over 70% of respondents indicating that they had experienced such treatment in the past 12 months.

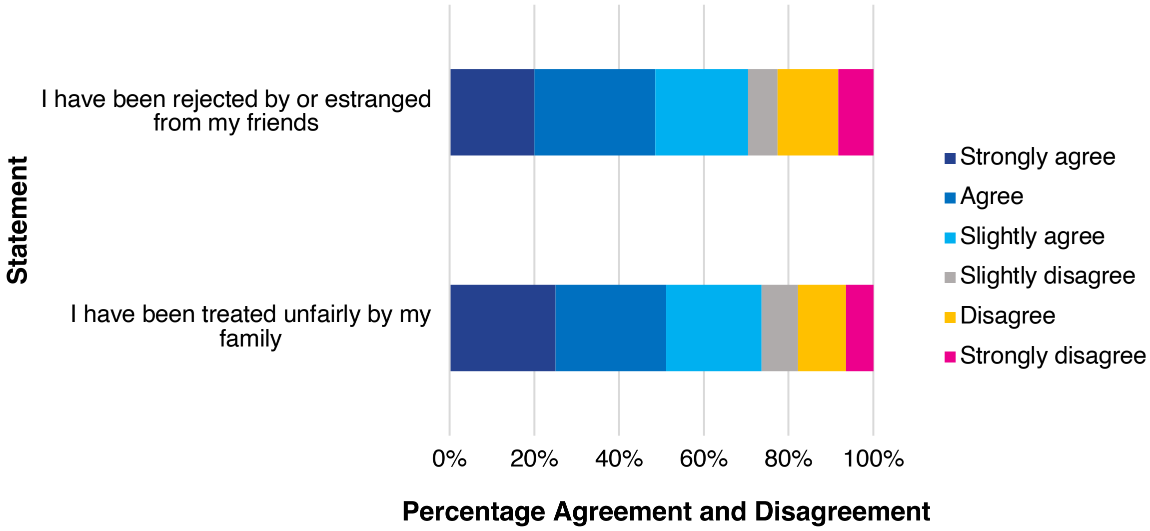


Figure 4.5. Highlight findings: the two most frequently endorsed statements describing perceived experiences of stigma and discrimination in *relationships* (*n* = 1207; *n* = 1203).

Most participants indicated agreement with statements describing perceived experiences of stigma and discrimination because of complex mental health issues across stages of friendships, including friendship formation, maintenance, and cessation. **Table 4.3** shows that over 60% of responding participants indicated having such experiences in the past 12 months.

Table 4.3. Perceived experiences of stigma and discrimination in *friendships*: percentage agreement and disagreement (*n* = 1207).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when making or keeping friends	6.4%	13.8%	11.3%	28.9%	27.4%	12.2%	**68.5%**
I have been treated unfairly by my friends	8.0%	19.1%	10.0%	30.2%	21.5%	11.2%	**62.9%**
I have been rejected by or estranged from my friends	8.3%	14.3%	7.0%	21.8%	28.6%	20.0%	**70.4%**

Perceived experiences of stigma and discrimination in the domain of intimate relationships were also commonly reported. As seen in **Table 4.4**, unfair treatment when dating was more commonly reported than rejection by, or estrangement from, an intimate partner. It is important to note, however, that despite the relatively lower rate of agreement observed, nearly half of responding participants perceived that they had been rejected by, or estranged from, their intimate partner(s) in the past 12 months because of stigma and discrimination about their complex mental health issues.

Table 4.4. Perceived experiences of stigma and discrimination in *intimate relationships*: percentage agreement and disagreement (*n* = 920).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when dating or in intimate relationships	12.7%	18.5%	7.3%	20.9%	23.0%	17.6%	**61.5%**
I have been treated unfairly by my intimate partner(s)	15.7%	15.2%	6.5%	22.4%	22.5%	17.7%	**62.6%**
I have been rejected by or estranged from my intimate partner(s)	22.7%	21.3%	7.1%	13.3%	17.7%	17.9%	**48.9%**

As shown in **Table 4.5**, variable rates of agreement were observed for individual statements inquiring about perceived experiences of stigma and discrimination in familial relationships. Perceptions of unfair treatment within familial relationships because of stigma about mental health issues were endorsed by nearly three quarters of responding participants.

In contrast, closer to half of the participant sample agreed that they had been rejected by, or estranged from, one or more members of their family because of stigma in the past 12 months. This does not mean that these individuals did not have any supportive family relationships, but that some of their family relationships had featured rejection or estrangement.

Table 4.5. Perceived experiences of stigma and discrimination in *family relationships*: percentage agreement and disagreement (*n* = 1203).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly by my family	6.5%	11.2%	8.7%	22.5%	26.0%	25.0%	**73.5%**
I have been rejected by or estranged from my family	16.5%	20.5%	8.8%	16.0%	17.4%	20.8%	**54.2%**

Table 4.6 shows that participants displayed lower levels of agreement on average in response to statements describing perceived experiences of stigma and discrimination in parenting.

Negative experiences surrounding having children or starting a family were least reported. Participants were nearly twice as likely to report unfair treatment in their ongoing experience as a parent of caregiver.

Table 4.6. Perceived experiences of stigma and discrimination in *parenting or caregiving*: percentage agreement and disagreement (*n* = 494).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when starting a family or having a child/children	32.4%	28.5%	7.5%	12.8%	10.5%	8.3%	**31.6%**
I have been treated unfairly in my role as a parent or caregiver for my child/children	15.6%	18.2%	7.7%	21.5%	21.5%	15.6%	**58.6%**

ANTICIPATED STIGMA AND DISCRIMINATION IN RELATIONSHIPS

> ***Because of the stigma around mental health, I hide my CPTSD & MDD from everyone as much as I can. Only my husband knows about it and even then I still hide some things from him.***
>
> **Our Turn to Speak participant**
> **Western Australia**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in Relationships, as related to their experience of complex mental health issues.

Figure 4.6 shows the aggregated findings regarding anticipation of unfair treatment when establishing and maintaining relationships, and expectations regarding others' willingness to engage in relationships with them. Overall, anticipation of others' unwillingness or disinterest in forming friendships and intimate relationships because of stigma about participants' complex mental health issues was the most endorsed concern. Anticipation of stigma and discrimination in maintenance of familial relationships was also reported as an area of concern.

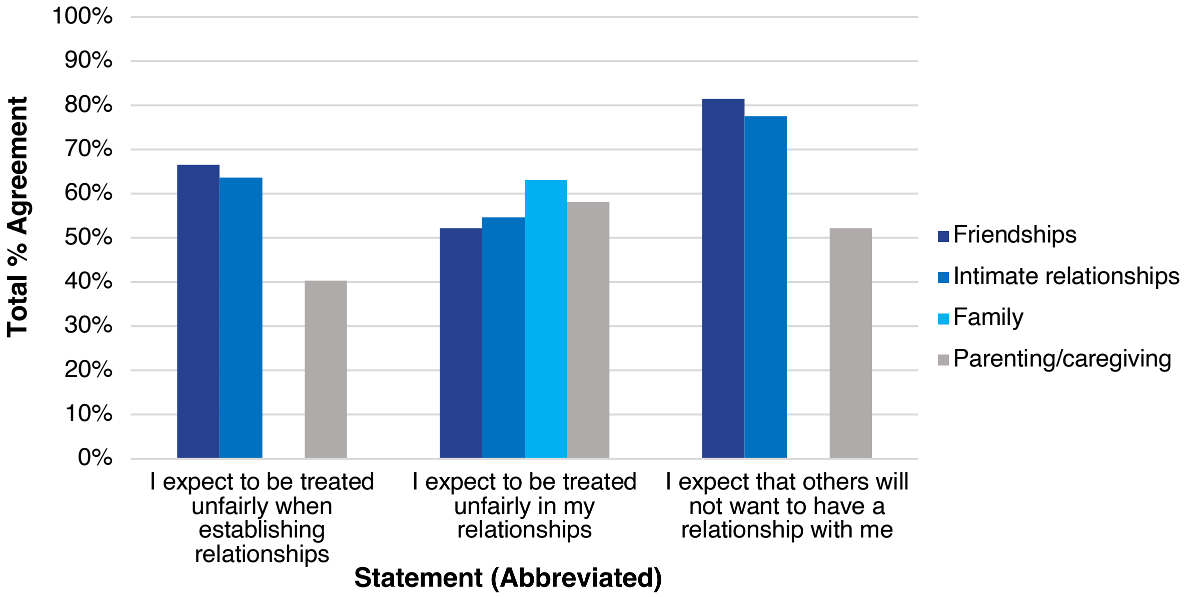


Figure 4.6. Highlight findings: total percentage agreement with anticipated stigma and discrimination in *friendships* (*n* = 1207), *intimate relationships* (*n* = 920), *family relationships* (*n* = 1203) and *parenting or caregiving* (*n* = 494).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

The data presented examine the findings regarding anticipation of stigma and discrimination in further detail. **Figure 4.7** shows the two most frequently endorsed statements in this section of the survey and highlights that anticipation that others will not want to form friendships or intimate relationships because of stigma about complex mental health issues was a core concern for participants.

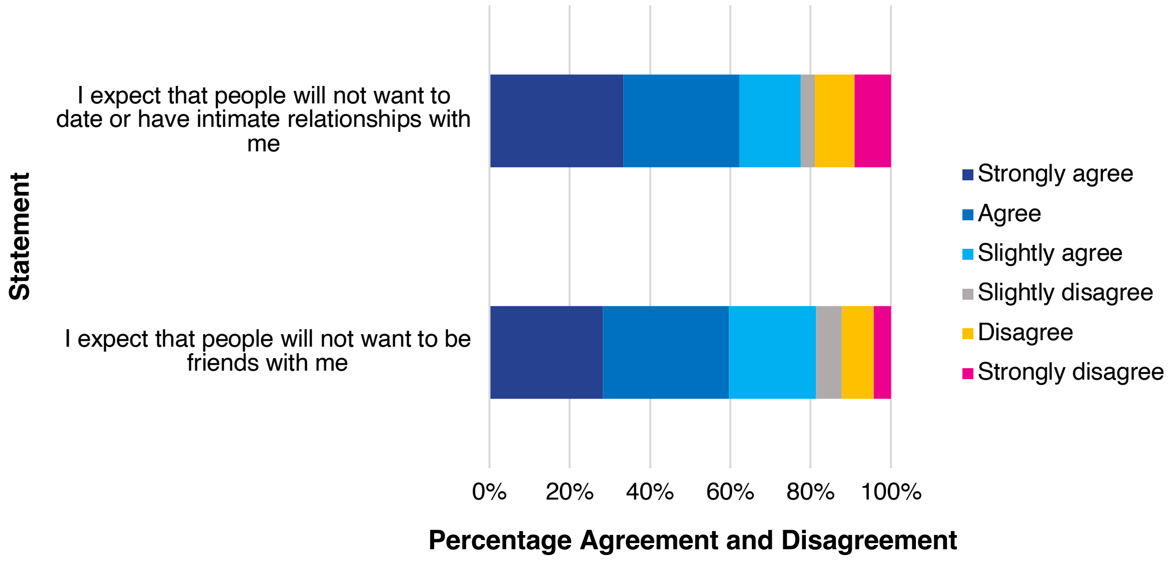


Figure 4.7. Highlight findings: the two most frequently endorsed statements describing anticipated stigma and discrimination in *relationships* (*n* = 920; *n* = 1207).

Table 4.7 shows that anticipation of unfair treatment in existing friendships in the past 12 months was reported with lower frequency than other issues, such as the expectation that people would not want to form friendships because of stigma about participants' complex mental health issues. Despite this relatively lower rate of agreement, it is again noteworthy than more than half of responding participants agreed that they had expected to be treated unfairly by friends because of stigma.

Table 4.7. Anticipated stigma and discrimination in *friendships*: percentage agreement and disagreement (*n* = 1207).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when making or keeping friends	9.2%	14.7%	9.5%	27.7%	26.3%	12.6%	**66.6%**
I expect to be treated unfairly by my friends	12.7%	22.0%	13.0%	24.9%	18.7%	8.6%	**52.2%**
I expect that people will not want to be friends with me	4.3%	7.9%	6.5%	21.6%	31.5%	28.3%	**81.4%**

A similar pattern of responses was observed for statements describing the anticipation of stigma and discrimination in intimate relationships.

Table 4.8 shows that the most commonly supported statement touched on the expectation that others would not want to date or engage in intimate relationships with participants because of stigma about mental health issues. Anticipation of unfair treatment by intimate partners received the least agreement. However, it is striking that over half of those surveyed endorsed these concerning expectations because of stigma and discrimination about their complex mental health issues.

Table 4.8. Anticipated stigma and discrimination in intimate *relationships*: percentage agreement and disagreement (*n* = 920).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when dating or in intimate relationships	12.3%	16.0%	8.2%	22.9%	24.9%	15.8%	**63.6%**
I expect to be treated unfairly by my intimate partner(s)	16.5%	19.6%	9.2%	19.8%	21.5%	13.4%	**54.7%**
I expect that people will not want to date or have intimate relationships with me	9.0%	9.9%	3.5%	15.4%	28.9%	33.3%	**77.6%**

Table 4.9 presents the data obtained on participants' anticipation of negative experiences in familial relationships. These summary data show that nearly two-thirds of responding participants indicated that they had expected to experience unfair treatment in familial relationships because of their complex mental health issues.

Table 4.9. Anticipated stigma and discrimination in *family relationships*: percentage agreement and disagreement (*n* = 1203).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly by my family	11.2%	15.6%	10.1%	21.1%	21.3%	20.7%	**63.1%**

Lastly, **Table 4.10** provides summary data describing respondents' agreements with statements describing anticipation of stigma and discrimination in parenting or caregiving relationships.

Participants most frequently agreed that they expected to experience unfair treatment in a parenting or caregiving role. Anticipation that people would not want to have children or start a family with participants, because of stigma about their mental health issues, received slightly less agreement. Fewer participants indicated that they expected to be treated unfairly in terms of starting a family. However, it is important that this was still an issue for 40.3% of participants.

Table 4.10. Anticipated stigma and discrimination in *parenting or caregiving*: percentage agreement and disagreement (*n* = 494).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when starting a family or having a child/children	25.1%	26.3%	8.3%	15.4%	14.8%	10.1%	**40.3%**
I expect to be treated unfairly in my role as a parent or caregiver for my child/children	16.2%	17.2%	8.5%	21.2%	20.6%	16.4%	**58.2%**
I expect that people will not want to start a family or have a child/children with me	22.3%	17.8%	7.7%	13.6%	19.0%	19.6%	**52.2%**

WITHDRAWAL FROM OPPORTUNITY IN RELATIONSHIPS

> ***People don't or can't understand, and it's very difficult to explain. When you can tell people are thinking you are weird in some way it makes you want to withdraw more and more because it feels shameful.***
>
> **Our Turn to Speak participant**
> **South Australia**

Presented in this section are the findings regarding participants' withdrawal from opportunities related to relationships, in connection with their experience of complex mental health issues.

Figure 4.8 illustrates the aggregated findings regarding withdrawal from opportunities in friendships, intimate relationships, familial relationships, and parenting or caregiving. The greatest level of variability is apparent in the area of withdrawal from establishing relationships. For example, the majority of responding participants agreed that they had withdrawn from opportunities to commence friendships in the past 12 months because of stigma and discrimination about complex mental health issues.

Approximately 20% fewer participants reported withdrawal from commencing intimate relationships and approximately 50% fewer indicated withdrawal from opportunities in terms of having children or starting a family. In contrast, aggregated responses appear more consistent in terms of withdrawal from relationships, with similar overall rates of withdrawal reported across friendships, intimate relationships and familial relationships.

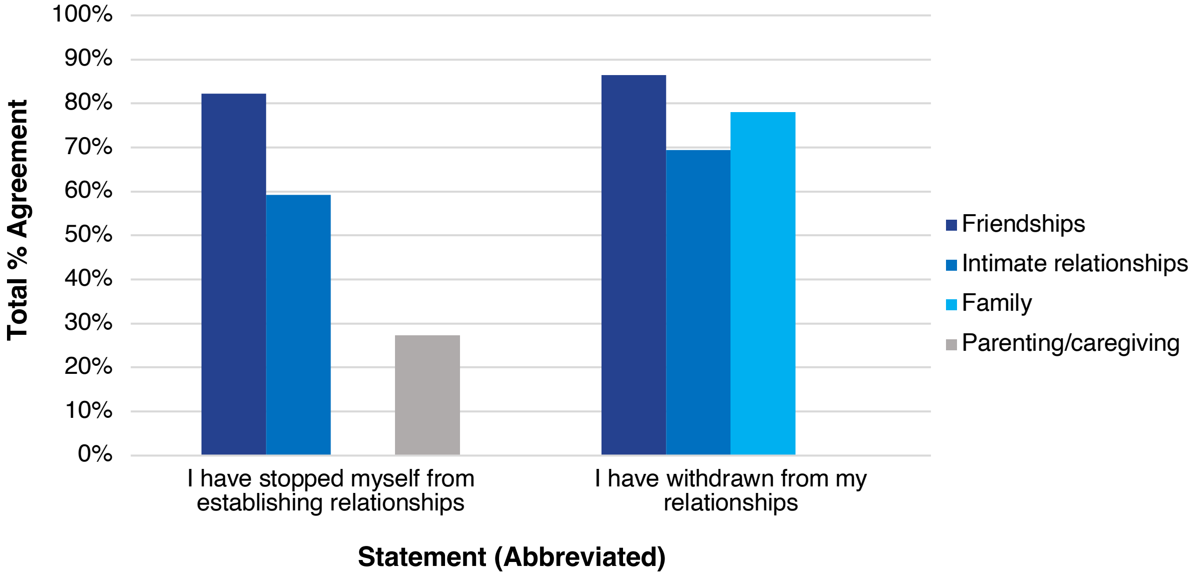


Figure 4.8. Highlight findings: total percentage agreement with withdrawal from opportunities in *friendships* (*n* = 1207), *intimate relationships* (*n* = 920), *family relationships* (*n* = 1203) and *parenting or caregiving* (*n* = 494).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

The data presented examine the findings regarding withdrawal from opportunities in relationships because of stigma and discrimination in further detail.

Figure 4.9 shows the two most frequently endorsed statements in this section of the survey. High levels of agreement were observed for statements describing withdrawal to avoid rejection and withdrawal from socialising because of stigma about complex mental health issues.

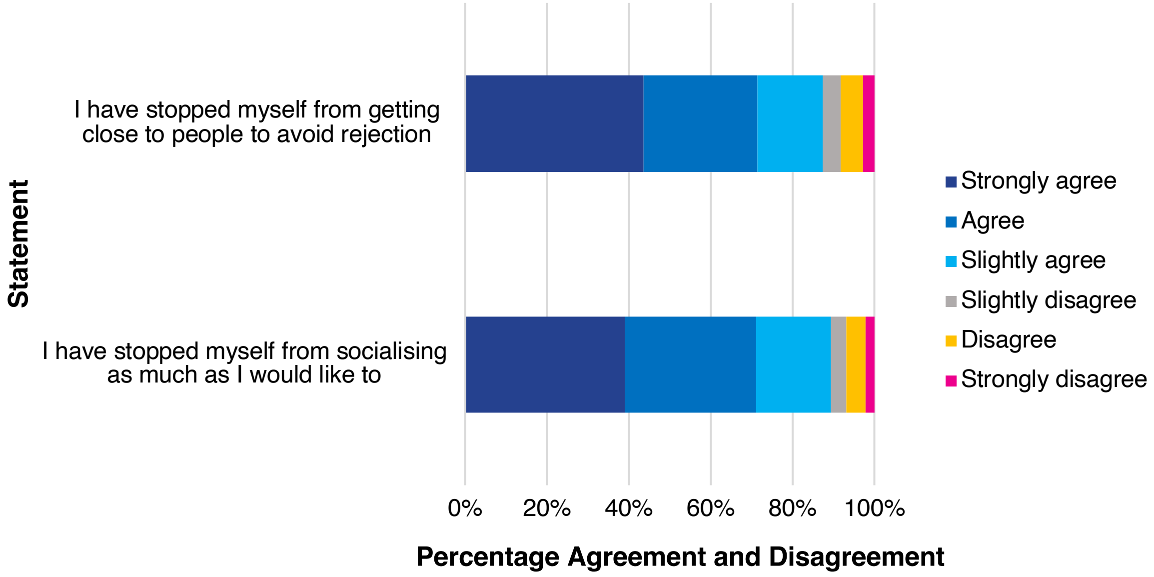


Figure 4.9. Highlight findings: the two most frequently endorsed statements describing withdrawal from opportunities in *relationships* (*n* = 1320).

Table 4.11 provides the details of agreement with survey statements describing withdrawal from opportunities in friendships. High levels of participant agreement can be seen in response to each aspect of withdrawal from friendships investigated.

Table 4.11. Withdrawal from opportunities in *friendships*: Percentage agreement and disagreement (*n* = 1207).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from making or keeping friends	4.7%	8.4%	4.7%	23.9%	30.6%	27.7%	**82.2%**
I have withdrawn from my relationships with friends	3.6%	6.1%	3.9%	22.5%	33.1%	30.8%	**86.4%**

Somewhat lower rates of withdrawal were observed regarding intimate relationships. Nonetheless, as seen in **Table 4.12**, withdrawal from intimate relationships was also found to be a common experience, affecting up to 69.4% of respondents.

Table 4.12. Withdrawal from opportunities in *intimate relationships*: percentage agreement and disagreement (*n* = 920).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from dating or having intimate relationships	16.3%	18.3%	6.2%	15.1%	17.3%	26.8%	**59.2%**
I have withdrawn from my relationships with intimate partners	12.2%	12.4%	6.1%	21.6%	23.2%	24.6%	**69.4%**

Table 4.13 presents the findings for withdrawal from familial relationships. A high level of participant agreement was seen regarding with withdrawal from family relationships in the past 12 months because of stigma and discrimination about complex mental health issues.

Table 4.13. Withdrawal from opportunities in *family relationships*: percentage agreement and disagreement (*n* = 1203).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have withdrawn from my relationships with family	5.9%	9.4%	6.7%	26.4%	27.0%	24.6%	**78.0%**

The results regarding withdrawal from parenting opportunities are presented in **Table 4.14**. Less agreement was seen in response to this item. It is nonetheless important to note that these indicate that 27.3% of the respondents had stopped themselves having children or starting a family in the previous 12 months because of concerns about stigma and discrimination regarding their complex mental health issues.

Table 4.14. Withdrawal from opportunities in *parenting or caregiving*: percentage agreement and disagreement (*n* = 494).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from starting a family or having a child/children	38.1%	29.1%	5.5%	6.7%	9.1%	11.5%	**27.3%**

Lastly, **Table 4.15** presents the findings regarding withdrawal from opportunities generally related to relationships. High levels of agreement were observed regarding statements describing withdrawal from socialisation and maintenance of social distance to avoid rejection in the past 12 months.

Table 4.15. Withdrawal from opportunities in general *relationships*: percentage agreement and disagreement (*n* = 1312).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from socialising as much as I would like to	2.2%	4.6%	3.7%	18.4%	31.9%	39.0%	**89.3%**
I have stopped myself from getting close to people to avoid rejection	2.8%	5.5%	4.3%	15.9%	27.9%	43.6%	**87.4%**

Note. Responded to by all participants except for eight who selected *parenting or caregiving* roles as the only relationships they had engaged in during the previous 12 months.

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN RELATIONSHIPS

> ***I'm not out, specifically because I don't have the energy or emotional capacity to deal with homophobia on top of the stuff I already have.***
>
> **Our Turn to Speak participant**
> **Queensland**

The findings from survey statements in relation to other experiences of stigma and discrimination in relationships, besides that about complex mental health issues, are presented in this section. Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 4.10**.

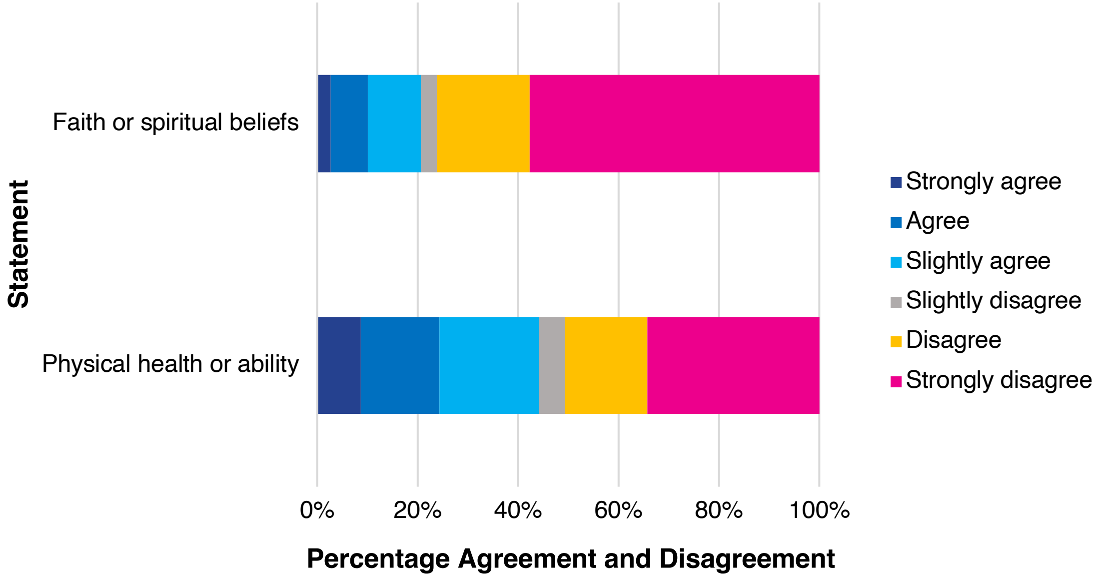


Figure 4.10. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *relationships* (*n* = 1320).

Table 4.16 shows the specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting participants' relationships in the previous 12 months.

Physical health or ability was the greatest area of additional by participants to be an additional area of stigma and discrimination in relationships other than complex mental health issues. Faith or spiritual beliefs were next most common areas in which participants perceived that they had experienced stigma and discrimination. Racial or cultural background and gender identity received the least amount of agreement; however, this does not detract from the profoundness of these experiences for participants reporting them.

Table 4.16. Experiences of intersectional stigma and discrimination in *relationships*: percentage agreement and disagreement (*n* = 1320).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in relationships because of my…							
Racial or cultural background	68.9%	19.8%	1.9%	3.9%	3.2%	2.3%	**9.4%**
Faith or spiritual beliefs	57.7%	18.5%	3.1%	10.6%	7.4%	2.7%	**20.7%**
Sexual orientation	59.2%	18.4%	3.0%	9.5%	6.2%	3.6%	**19.3%**
Gender identity	69.5%	20.2%	2.0%	3.3%	2.7%	2.2%	**8.2%**
Physical health or ability	34.2%	16.5%	5.1%	19.8%	15.7%	8.7%	**44.2%**

POSITIVE EXPERIENCES IN RELATIONSHIPS

> *Being in a relationship allows me to talk more than I ever have about how I feel. On my own, I never spoke to anyone about the things which consumed me.*
>
> **Our Turn to Speak participant**
> **Tasmania**

The survey also asked about positive treatment in relationships related to participants' complex mental health issues. Two core statements comprised this section of the survey: (1) the expectation of special consideration because of one's experience of complex mental health issues, and (2) manifest positive experiences in relationships because of one's experience of complex mental health issues.

As shown in **Figure 4.11**, 51.5% of participants agreed that they should receive special consideration in relationships because of their complex mental health issues. More participants (61.8%) agreed that they had positive experiences in relationships in the past 12 months because of their mental health issues.

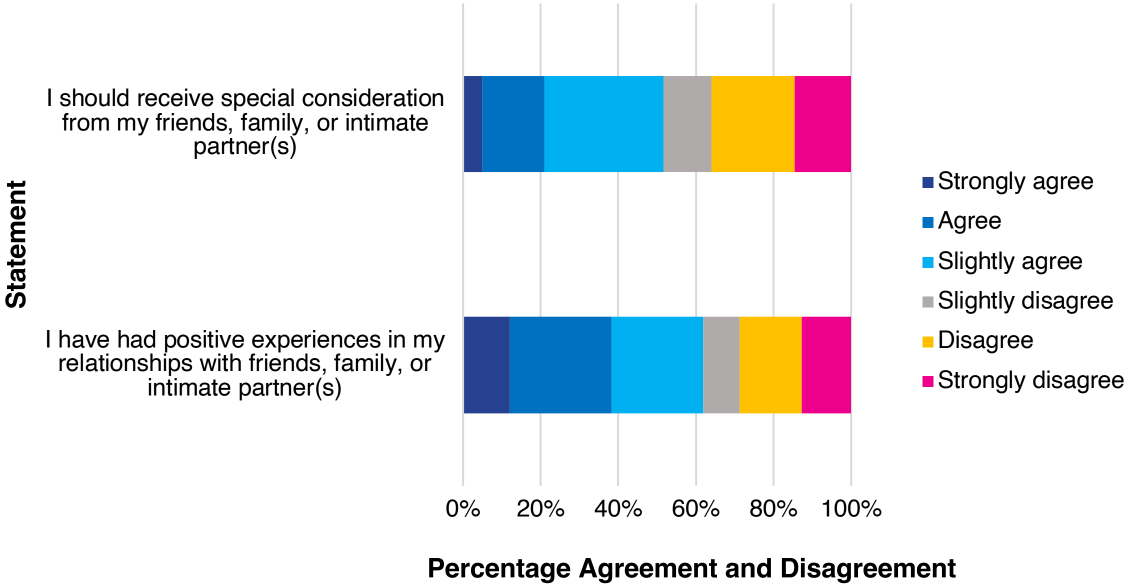


Figure 4.11. Highlight findings: responses to the statements regarding positive experiences in *relationships* because of participants' complex mental health issues (*n* = 1320).

SUMMARY OF QUALITATIVE FINDINGS IN RELATIONSHIPS

Several participants described experiences of violence and abuse. For some, these occurred during childhood, which impacted on adult relationships; for instance: *"I have huge abandonment issues from my childhood trauma and sexual assaults when I was an adolescent"* (**Our Turn to Speak** participant, South Australia). For many, however, these occurred during adulthood in relationships with an intimate partner and involved gaslighting – an example being: *"My previous partner used my mental health as a means to create* *confusion during arguments. Often using to make me second guess my actions or words and feelings about certain situations"* (**Our Turn to Speak** participant, Victoria) – or other abuses of power, such as "*During my marriage (now separated), my partner would frequently use my diagnosis as a basis for manipulation and control"* (**Our Turn to Speak** participant, Victoria). One participant described feeling gaslit by a psychiatrist.

Several participants explained how their mental health issues and associated stigma had contributed to a breakdown in relationships with family, friends, and partners, resulting in rejection and estrangement for some. *"My wife left a couple months ago as she can no longer deal with my moodswings and brain injury"* (**Our Turn to Speak** participant, Queensland) one participant shared; *"My children have rejected me completely and are saying it is because I am mentally unwell"* (**Our Turn to Speak** participant, South Australia), said another.

Some recounted experiences of friends and other acquaintances excluding and withdrawing from them; this could take the form of not being invited to social events, such as: *"I had a group of friends at uni, but they did not invite me when they went out together…"* (**Our Turn to Speak** participant, Western Australia); or not being responded to, for example: *"I have tried to rekindle old friendships but recieved little response in return…"* (**Our Turn to Speak** participant, New South Wales).

Many spoke of feeling judged, invalidated, and misunderstood, and felt that their experiences of having mental health issues were often not taken seriously; as one participant remarked: *"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). Being perceived as 'stupid' and 'lazy' by family members and partners was mentioned by a number of participants.

A commonly described impact of mental health stigma was a sense of shame, fear of disclosing, and a need to conceal the severity or aspects of their experience, including from intimate partners, friends, and family. *"There have been quite a few times where I've had to put on a mask to hide how I'm feeling so friends and family don't judge me"* (**Our Turn to Speak** participant, New South Wales), said one participant.

While some participants shared their sense of isolation, isolation could also be a deliberate behaviour to protect oneself – an example being: *"I isolate myself due to the discrimination and stigma I receive daily"* (**Our Turn to Speak** participant, New South Wales).

The difficulty of establishing and maintaining friendships and relationships with intimate partners for some was linked to a sense of feeling like a burden and unworthy – for instance, *"I'm currently single and feel I am not worthy of a healthy intimate relationship, it would be difficult to find, and feel I will be judged by people who don't know me well enough, or want to know me well enough, because of my mental health challenges"* (**Our Turn to Speak** participant, New South Wales). A couple of participants commented that some side effects of their medication had a negative impact on their libido, and thus their ability to be intimate with their partners.

When participants were asked about positive experiences in this life domain, many identified increased empathy and ability to connect with and help other people:

> *I find mutual support in relationships with friends who have some level of lived experience themselves. I don't expect 'special treatment' from my friends, but it is*

> *lovely to have someone understand what 'a bad day' feels like. These relationships are good for both of us because that sense of empathy and understanding exists on both sides and supports us both at different times* (**Our Turn to Speak** participant, Tasmania).

That said, one participant responded: *"I just don't see any positives in having high empathy"* (**Our Turn to Speak** participant, Queensland).

Another positive experience commonly identified by participants was that of being accepted and supported by family, friends, and partners, some of whom were carers; an example being as follows:

> *My children are all young adults now and from an early age have seen me at my most vulnerable. They have seen grown up mature 'Mum', a frightened little girl 'Mum', and a rebellious, angry teenager 'Mum'. They have learned to adapt to the 'switching' and interactions with a very young 'Mum' who looks and sounds like a little girl, and to accept her when she's frightened and crying with distress and fear, and then respecting her for being their grown up 'Mum' who guides them, nurtures them, and looks out for them. They even give my alters gifts and cards and letters. Whoever I am at any given time, they treat her like an important part of the family. Still, it is hard for them to see me so vulnerable at times. My husband interacts with my 'alters' also and they know he protects them and loves each one in a safe way. Whichever one is present, he relates to them on their age level* (**Our Turn to Speak** participant).

A couple of participants also mentioned that they had made new friends while receiving treatment.

Others commented that they had no positive experiences, or explained that their experiences varied – depending on the individual family member or friend, for example; and one participant reflected that *"many of my friends have been tolerant but very few from my own ethnicity"* (**Our Turn to Speak** participant, Victoria). Some participants commented further on negative experiences or challenges in response to this question, and several mentioned that they were selective in who they disclosed their mental health issues to.

Many participants explained, furthermore, that they did not want 'special' treatment in this domain (and some found the suggestion inappropriate), but to be treated as others were, and for there to be greater understanding and acceptance. A few commented that they felt special consideration was warranted.

When participants were asked about other factors that may have compounded their experiences of mental health stigma in relationships, the most frequently discussed were sexual orientation/homophobia, weight/fatphobia (with weight gain sometimes linked to medications), and having other physical health issues or chronic illness. Others that were mentioned included: age, appearance, disability, gender, location, being a parent, race, faith, substance use, and employment status.

SUMMARY

Of 1,912 participants who took part in the **Our Turn to Speak** survey, 95.6% indicated they had experienced some level of stigma and discrimination in their relationships during the past 12 months, and 69.1% reported that the impact of such stigma on their relationships had affected them the most during the same time period. This made the relationships domain the most frequently endorsed and impactful concern among survey participants. Such negative and impactful experiences in participants' relationships were experienced in terms of their friendships, intimate, familial, and parenting or caregiving relationships. Overall, friendships, intimate relationships – and to a slightly lesser degree, familial relationships – were the most consistent areas of concern across the survey domains of experienced stigma, anticipated stigma, and withdrawal from opportunity.

When presented with a series of statements describing specific and general perceived experiences of stigma and discrimination in the previous 12 months, rejection, estrangement, and unfair treatment came through as core concerns in both the quantitative and qualitative data. High levels of agreement with statements describing perceived experiences of stigma and discrimination in relationships were observed for the most part. The first of the two items most frequently endorsed in the scale indexing experiences of stigma and discrimination related to unfair treatment by family members. The high level of support observed for these statements was echoed in the qualitative data, with core themes including negative judgement and diminished agency or power in such relationships. The second of these highlight findings described perceived experiences of rejection or estrangement from friends. This finding again aligned with qualitative responses from participants, with many speaking to perceived experiences of social exclusion and of others withdrawing socially. Indeed, the establishment and maintenance of friendships in the face of withdrawal from others was a common concern. In contrast, the statement regarding perceived experiences of stigma in relationships receiving the least support from participants described unfair treatment when starting a family. It is apparent that more concern was expressed in relation to unfair treatment in one's ongoing role as a parent or caregiver rather than when commencing such a journey. It is nevertheless important to note that such perceived experiences of stigma and discrimination in the preceding 12-month period were reported by 31.6% of responding participants.

On average, 61.0% of participants agreed with statements describing the anticipation of future stigma and discrimination in their relationships. Of particular concern was the expectation that others would not be willing to engage in intimate relationships of friendships because of stigma. This concern also less frequently extended to starting a family. The initiation of relationships was again a concern as regards anticipation of stigma, with expectation of unfair treatment when establishing friendships or intimate relationships being the most commonly observed concerns. Anticipation of unfair treatment in established and ongoing relationships was reported as an issue across all types of relationships investigated. The qualitative data closely corroborated these quantitative data, with core themes touching on participants' expectations of judgment and of rejection in friendships, intimate relationships, and families because of stigma.

The most frequently identified issue in this section of the survey was participants withdrawal from relationship opportunities because of stigma. On average, 72.4% of participants supported statements describing such withdrawal. The pattern of agreement varied across domains of relationships. General experiences such as general withdrawal from socialising or saw particularly high rates of agreement from participants. Withdrawal from friends or from forming friendships was also a commonly reported issue. Withdrawal from intimate relationships was reported less frequently; however, individual survey items were still agreed with by approximately 60% or more of responding participants. The concern reported least frequently was withdrawal from starting a family; however, it remains remarkable that 27.3% of participants agreed that they had experienced such withdrawal in the previous 12 months. Themes present in the qualitative data again supported these trends, with withdrawal from commencing or continuing relationships arising as a common topic. Participants commonly discussed such withdrawal in terms of overt avoidance of relationships altogether, or of a more covert nature in terms of not bringing one's whole self to ongoing relationships – of hiding one's mental health issues to avoid stigma, judgment and abandonment.

When asked about other personal characteristics that may have contributed to the experience of stigma and discrimination in the past 12 months, participants' physical health or ability was the most frequently reported concern. Sexual orientation and faith or spiritual beliefs were agreed to be an area of concern to a moderate degree. Racial or cultural background and gender identity were personal characteristics that the least number of participants rated as other areas of worry regarding stigma and discrimination in relationships. The qualitative data again corresponded closely with survey responses, with participants commonly speaking of relationships being affected by weight stigma, by negative responses to other physical health issues, and regarding their sexual orientation.

Lastly, when asked about positive experiences, 51.5% of the participants agreed that they should receive special consideration in relationships because of their mental health issues. More participants (61.8%) indicated that they actually had positive experiences in relationships in the past 12 months because of their mental health issues. Taken together, these levels of agreement indicate that the experience of positive treatment in relationships was a very mixed one for participants. Such mixed experiences were also described in the qualitative data. Some participants discussed a desire to receive special consideration in relationships, while others rejected this notion and instead wrote about a fundamental need for equality, understanding and acceptance. Indeed, many participants spoke of finding refuge in relationships that were founded on empathy and understanding. Some participants discussed that the found such support specifically in relationships with others who have lived experience of complex mental health issues. In contrast, other participants wrote about their abject lack of positive experience in relationships regarding their mental health issues.

The findings of the **Our Turn to Speak** survey indicate that the experience of stigma and discrimination in relationships is a key issue of concern for many Australians living with complex mental health issues. The findings suggest that many such people have frequent and impactful negative experiences in relationships because of stigma; go on to hold expectations of similar future negative experiences; and commonly withdraw from participation in relationships and the opportunity to obtain much needed psychosocial support. It is well established that engagement in supportive relationships is a key factor in recovery and relapse-prevention for people living with complex mental health issues (Tew et al., 2012). These results are therefore of critical importance and highlight that interpersonal relationships are an important target for any comprehensive stigma-reduction initiative for people living with complex mental health issues.

EMPLOYMENT

05

Chapter 5. Employment

Having something meaningful to do is vital for mental health. Participation in employment can contribute to sense of purpose, accomplishment and more.

Sadly, the employment rate for individuals with severe and complex mental health issues, such as schizophrenia and bipolar related disorders, is unacceptably low (Modini et al., 2016). Australia has one of the lowest employment participation rates for people with disability or chronic conditions like mental health issues, anywhere in the developed world (Organisation for Economic Cooperation and Development, 2010). Those with mental health issues experience high levels of unemployment and underemployment.

For those with a schizophrenia spectrum disorder, the unemployment rate is more than five times that of the general population, at 27.4% (Modini et al., 2016). A major driver of low employment participation rates among people with a mental illness is disorder severity. A report by the Organisation for Economic Cooperation and Development (OECD) showed that 49% of people with a severe psychological disorder were employed, compared to 72% with a moderately severe disorder, and 81% with a mild or no psychological disorder (Hoedeman, 2012).

However, '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 enabling people to bring their whole selves to work. Such workplaces are likely to support wellbeing and recovery for people living with complex mental health issues.

This chapter considers how people living with complex mental health issues experience stigma and discrimination in accessing and participating in employment.

OVERVIEW

Stigma and discrimination in the domain of employment was identified as the second most common concern among participants of the **Our Turn to Speak** survey. A total 78.1% (*n* = 1493) of all participants reported experiencing some level of stigma and discrimination in employment during the past 12 months.

As shown in **Figure 5.1**, 31.2% of all participants reported 'frequent' or 'very frequent' stigma and discrimination in employment, and 43.0% (*n* = 822) identified this life domain as one of three in which they had been most affected by such experiences. **Figure 5.1** also shows that 51.5% of participants who selected the employment domain reported 'frequent' or 'very frequent' rates of stigma and discrimination in this aspect of their lives; somewhat higher than was reported by the overall sample.

This chapter focuses on the characteristics and experiences of those 822 participants who selected employment as one of their top three, most affected life domains.

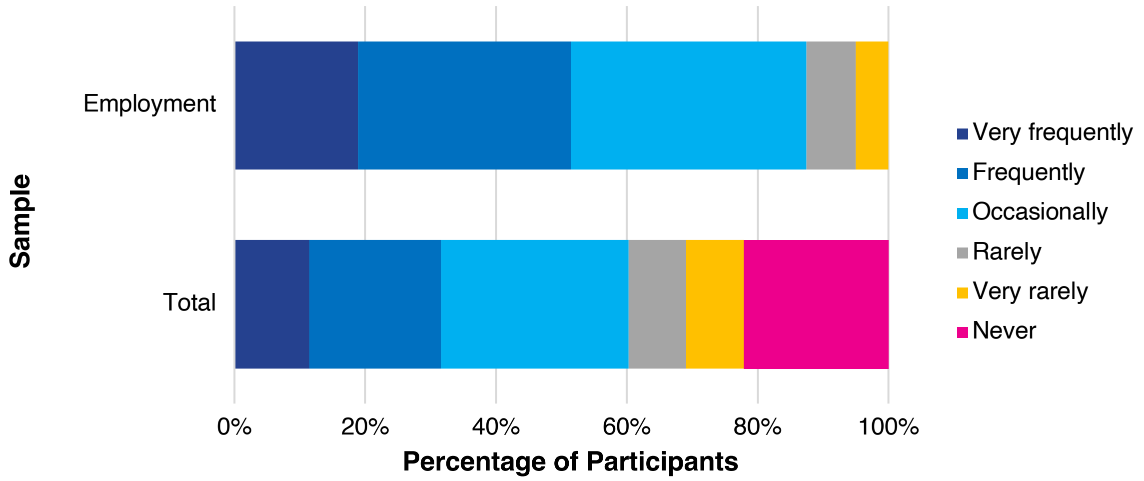


Figure 5.1. Frequency of stigma and discrimination in *employment* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (n = 822) compared with the total sample (N = 1912).

PROFILE OF PARTICIPANTS

Shown in **Table 5.1**, the sociodemographic characteristics of participants who identified as being affected by stigma and discrimination in employment were generally closely comparable to the broader **Our Turn to Speak** sample. Compared with the total sample, a greater proportion of the participant group responding to the employment domain were engaged in paid work and fewer were receiving a pension or other benefits.

Table 5.1. Sociodemographic characteristics: *employment* sample compared with the total sample.

Characteristics		Employment (*n* = 822)	Total (*N* = 1912)
Mean age		38.67 (*SD* = 11.79)	39.21 (*SD* = 12.81)
Gender identity			
	Female	77.6%	78.9%
	Male	19.4%	18.0%
	Trans, gender diverse and/or non-binary	4.5%	4.9%
	Unsure or questioning	0.7%	0.9%
	Prefer not to say	0.2%	0.4%
Relationship status			
	Not in a relationship	48.8%	52.1%
	In a relationship	51.1%	47.3%
	Prefer to self-describe	0.1%	0.2%
Sexual orientation			
	Heterosexual	66.5%	62.0%
	Gay, lesbian, bisexual, pansexual, queer, and/or asexual	32.7%	35.6%
	Unsure or questioning	4.3%	4.9%
	Prefer to self-describe	1.1%	1.5%
	Prefer not to say	0.9%	1.7%
Education (highest level attained)			
	Primary school	0.6%	1.6%
	Secondary college (high school)	17.8%	20.9%
	Educated post-secondary college	81.6%	77.4%
	Other	0.0%	0.2%
Employment			
	Engaged in paid work	61.1%	51.7%
	Engaged in unpaid work or studying	24.8%	28.7%
	Unemployed or unable to work	25.4%	22.8%
	Receiving a pension or benefits	14.4%	24.6%
	Other	0.1%	0.2%
State			
	Australian Capital Territory	2.3%	2.5%
	New South Wales	23.2%	23.6%
	Northern Territory	0.9%	0.6%
	Queensland	15.2%	15.9%
	South Australia	10.0%	9.5%
	Tasmania	3.8%	3.7%
	Victoria	32.2%	33.1%
	Western Australia	12.4%	10.9%
Region*			
	Major city	76.7%	74.2%
	Regional or remote	23.3%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

Figure 5.2 presents a further breakdown of the nature of participants' employment status. A greater proportion of participants who completed the employment section of the durvey were employed full-time, part-time or casually compared to the total sample. Fewer participants were receiving a pension or benefits in this group compared to the overall sample. Participants' employment characteristics were otherwise largely comparable with those of the total sample.

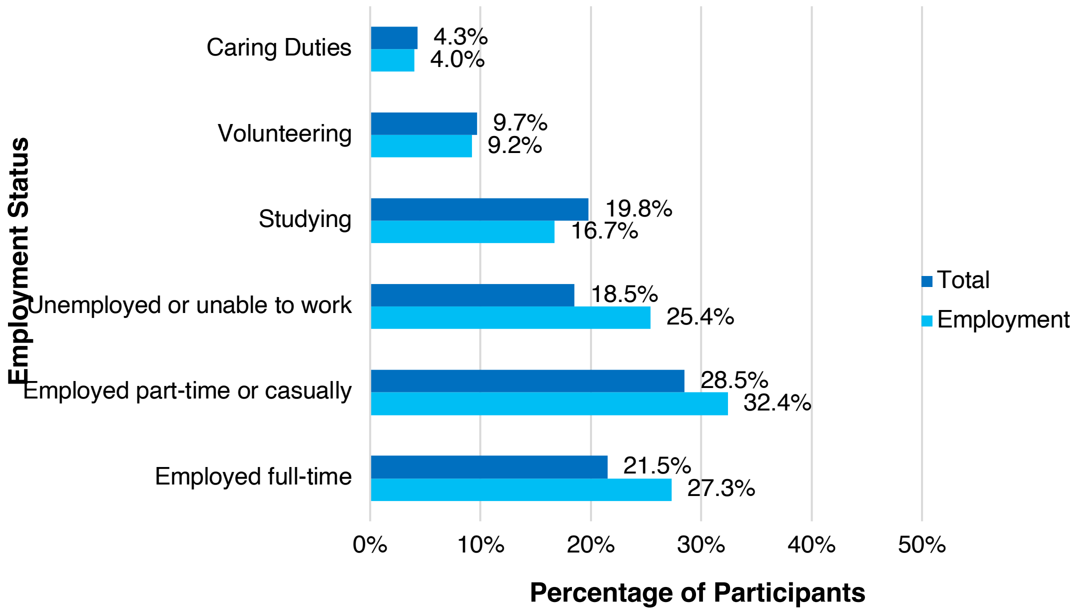


Figure 5.2. Employment status among participants who selected *employment* as one of three domains in which they had been most affected by stigma during the past 12 months ($n = 822$) compared with the total sample ($N = 1912$).
Note. Percentages do not add to 100 as participants could select more than one response option.

As with the socidemographic data, the mental and physical health characteristics of participants who identified the employment domain as having been most affected by stigma and discrimination were similar to those of the total sample. These data are presented in **Table 5.2.**

Table 5.2. Mental and physical health characteristics: *employment* sample compared with the total sample.

Characteristics	Employment ($n = 822$)	Total ($N = 1912$)
Primary complex mental health issue		
Schizophrenia spectrum disorder	6.6%	7.4%
Bipolar related disorder	21.2%	17.2%
Obsessive-compulsive related disorder	3.8%	4.3%
Trauma-related or dissociative disorder	24.7%	25.9%
Eating disorder	4.9%	6.1%
Personality disorder	12.0%	14.5%
Severe and treatment-resistant depressive disorder	15.9%	14.3%
Severe and treatment-resistant anxiety disorder	10.9%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	50.5%	53.8%

METHODS SNAPSHOT

Participants who identified employment as one of three life domains in which they have been most affected by stigma-related experiences completed the employment section of the survey. Employment was defined to include paid employment, be it casual, part-time, full-time or working to fixed-term contracts.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in employment; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of employment. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further elaborate on and describe their experiences of stigma and discrimination because of: (a) complex mental health issues, (b) in relation to other personal characteristics, and (c) their experiences of positive treatment in employment. Additional comments in relation to these experiences were given by 219, 74 and 177 participants, respectively.

STIGMA AND DISCRIMINATION IN EMPLOYMENT

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in employment, which will be further examined in sections that follow.

As shown in **Figure 5.3**, 55.9% of participants who completed the employment section of the survey agreed with all statements describing perceived experiences of stigma and discrimination in the past 12 months. A slightly greater proportion of this group (60.1%) agreed with statements indexing the anticipation of future stigma and discrimination in employment because of their complex mental health issues. The frequency of agreement was greater still for statements that described withdrawal from opportunities relevant to employment, with close to 70% of responding participants agreeing with such statements on average.

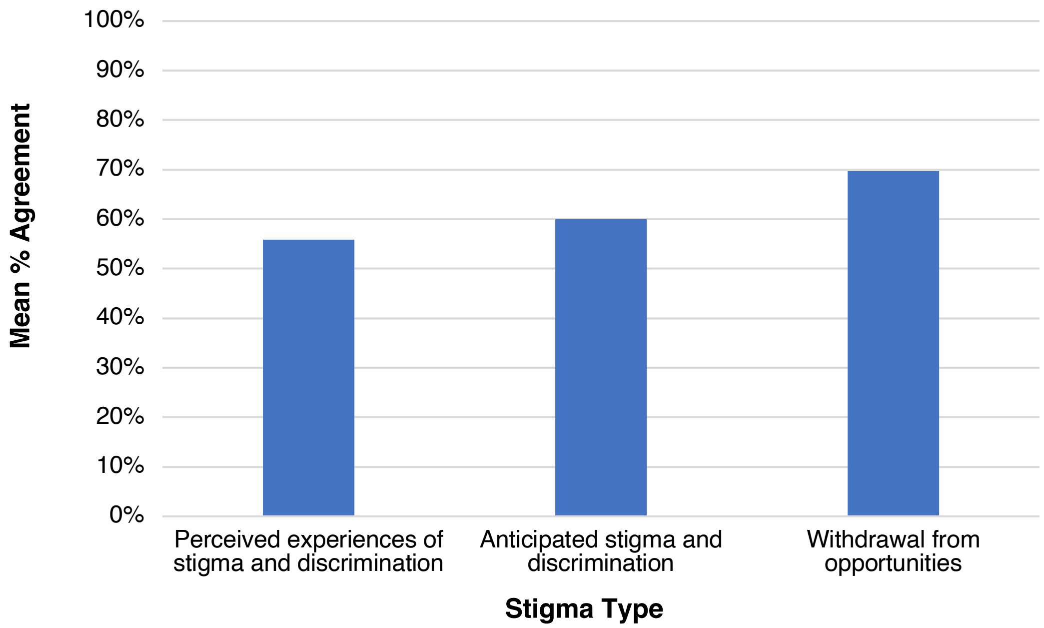


Figure 5.3. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *employment* (*n* = 822).

Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN EMPLOYMENT

> *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**

The findings regarding participants’ perceived experiences of stigma and discrimination in employment because of their experience of complex mental health issues are presented.

Figure 5.5 highlights the two most frequently endorsed issues from the set of ten statements describing perceived experiences of stigma and discrimination. Statements describing unfair treatment in the workplace and unfair treatment by employers, supervisors or managers were the two with which participants most frequently agreed, with nearly 80% of respondents indicating that they had experienced such instances of discrimination related to their complex mental health issues in the past 12 months.

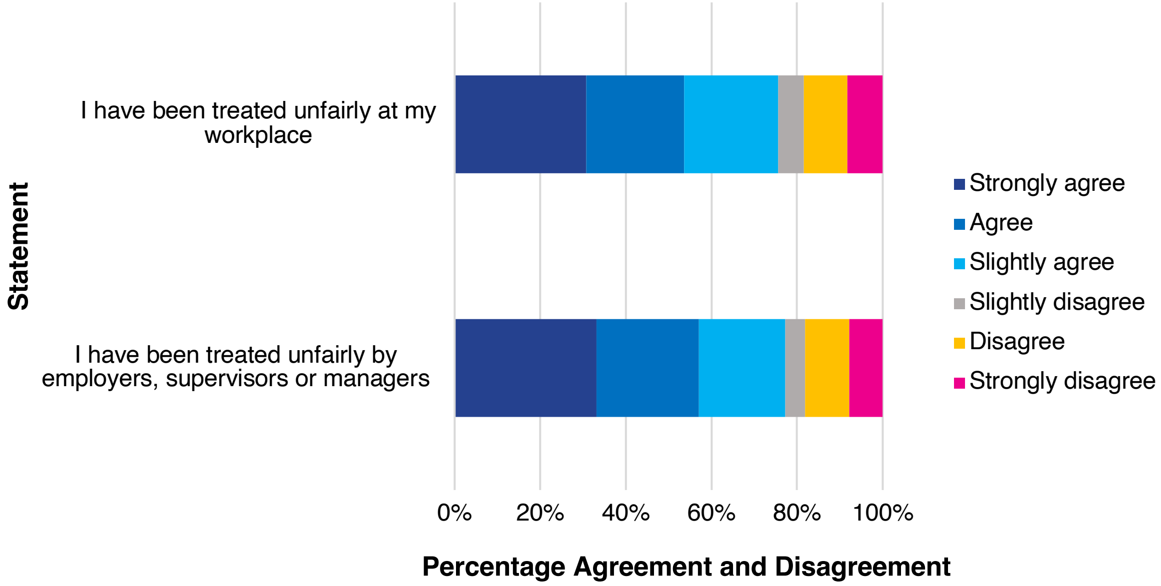


Figure 5.4. Highlight findings: the two most frequently endorsed statements describing perceived experiences of stigma and discrimination in *employment* (*n* = 822).

In addition to the findings regarding unfair treatment highlighted in **Figure, 5.4**, it can be seen in **Table 5.3** that unfair treatment by colleagues was also endorsed by over 60% of respondents. The statements next most frequently agreed with described discriminatory denial of employment and promotional opportunities. Concerns regarding denial of flexible working arrangements because of stigma about mental health issues were reported by roughly half of participants, with slightly fewer agreeing that they had been denied leave entitlements, such as sick leave. Over 40% of respondents indicated that they had been asked to leave employment before they wished to because of stigma about mental health issues. While social exclusion in the workplace received the least frequent agreement from participants, it is nonetheless notweworthy that 36.2% of responding participants indicated having these perceived experiences in the previous 12-month period.

Table 5.3. Perceived experiences of stigma and discrimination in *employment*: percentage agreement and disagreement ($n = 822$).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly at my workplace	8.3%	10.1%	6.0%	22.0%	23.0%	30.7%	**75.7%**
I have been unfairly denied employment opportunities	8.4%	16.2%	8.6%	15.6%	23.6%	27.6%	**66.8%**
I have been unfairly denied job promotion opportunities	11.9%	20.6%	10.3%	15.8%	20.2%	21.2%	**57.2%**
I have been unfairly asked to leave employment before I was ready (i.e. asked to resign, been fired or made redundant)	27.4%	22.5%	7.1%	8.3%	13.6%	21.2%	**43.1%**
I have been treated unfairly by employers, supervisors or managers	7.8%	10.3%	4.6%	20.2%	24.0%	33.1%	**77.3%**
I have been treated unfairly by work colleagues	10.3%	15.6%	10.7%	19.3%	21.4%	22.6%	**63.3%**
I have been unfairly denied flexible work arrangements	17.5%	20.4%	10.7%	13.1%	16.8%	21.4%	**51.3%**
I have been unfairly denied the right to take leave entitlements (e.g. sick leave)	22.5%	29.3%	10.1%	11.9%	11.9%	14.2%	**38.0%**
I have been unfairly excluded from work-related social and team-building activities	20.8%	32.2%	10.7%	11.7%	12.5%	12.0%	**36.2%**
I have been pressured to avoid discussing my mental health needs and experiences at work	12.8%	16.7%	10.1%	15.7%	20.7%	24.1%	**60.5%**
I have been pressured to discuss my mental health needs and experiences at work when I have not wanted to	19.0%	27.5%	8.5%	15.0%	14.8%	15.2%	**45.0%**

ANTICIPATED STIGMA AND DISCRIMINATION IN EMPLOYMENT

> *I've taken the 'don't ask, don't tell' approach - I was sacked ten years ago after disclosing my mental illness.*
>
> **Our Turn to Speak participant**
> **South Australia**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in employment, as related to their experience of complex mental health issues.

Figure 5.5 shows the two statements with which participants most frequently agreed, and highlights that expectations of unfair denial of employment opportunities and of general unfair treatment in the workplace were key issues for the majority participants responding to this section of the survey.

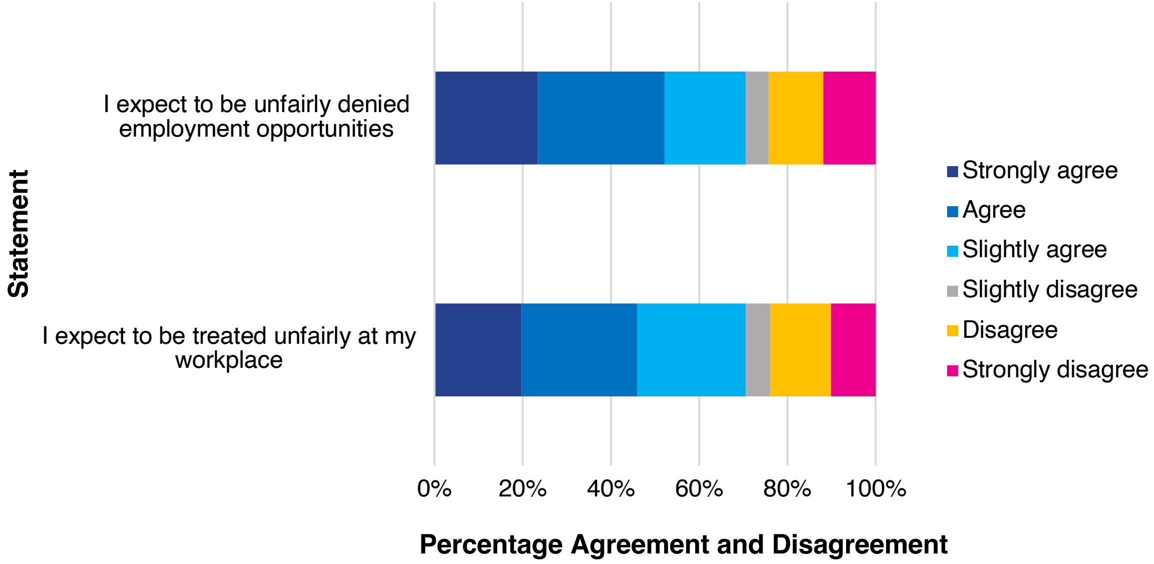


Figure 5.5. Highlight findings: the two most frequently endorsed statements describing anticipated stigma and discrimination in *employment* (*n* = 822).

The data presented examine the findings regarding participants' anticipation of stigma and discrimination in employment in further detail.

Table 5.4 shows that anticipation of unfair treatment by employers, supervisors or managers, and unfair denial of promotion opportunities were reported by participants with comparable frequency to the findings highlighted above regarding expectations of general unfair treatment and denial of employment opportunities. Relatively moderate rates of agreement in this dataset were observed regarding the expectation of being denied flexible working arrangements, being treated unfairly by colleagues, and feeling pressured to not discuss one's mental health in the workplace because of stigma. Expectations that one would be pressured into disclosing mental health status, unfairly asked to leave employment prematurely, unfairly denied leave, or socially excluded in the workplace were the least commonly reported experiences. However, it is noteworthy that still nearly half of responding participants agreed that they personally expected these things to occur.

Table 5.4. Anticipated stigma and discrimination in *employment*: percentage agreement and disagreement (*n* = 822).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly at my workplace	10.1%	13.9%	5.4%	24.7%	26.3%	19.7%	**70.7%**
I expect to be unfairly denied employment opportunities	11.9%	12.3%	5.2%	18.4%	28.7%	23.5%	**70.6%**
I expect to be unfairly denied job promotion opportunities	11.4%	13.3%	6.0%	20.1%	26.8%	22.5%	**69.4%**
I expect to be unfairly asked to leave employment before I am ready (i.e. asked to resign, been fired or made redundant)	18.1%	20.3%	9.4%	18.1%	18.2%	15.8%	**52.1%**
I expect to be treated unfairly by employers, supervisors or managers	11.4%	13.4%	6.3%	22.5%	25.7%	20.7%	**68.9%**
I expect to be treated unfairly by work colleagues	13.0%	15.6%	8.3%	23.1%	23.2%	16.8%	**63.1%**
I expect to be unfairly denied flexible work arrangements	14.8%	18.6%	8.6%	16.5%	22.5%	18.9%	**57.9%**
I expect to be unfairly denied the right to take leave entitlements (e.g. sick leave)	18.5%	23.6%	8.9%	14.4%	19.0%	15.7%	**49.1%**
I expect to be unfairly excluded from work-related social and team-building activities	19.0%	23.8%	10.1%	17.6%	17.5%	11.9%	**47.0%**
I expect to be pressured to avoid discussing my mental health needs and experiences at work	13.7%	14.5%	8.4%	18.6%	24.7%	20.1%	**63.4%**
I expect to be pressured to discuss my mental health needs and experiences at work when I do not want to	17.2%	23.1%	11.2%	17.2%	18.4%	13.0%	**48.6%**

WITHDRAWAL FROM OPPORTUNITY IN EMPLOYMENT

> *It is not so much that I have experienced stigma or discrimination at work, it's that I expect I would if I was honest about my mental health problems, so I keep them a secret. This has led to me having to leave my job.*
>
> **Our Turn to Speak participant**
> **Tasmania**

Presented in this section are the findings regarding participants' withdrawal from opportunities related to employment, in connection with their experience of complex mental health issues.

Figure 5.6 shows the two most frequently endorsed statements in this section of the survey. High levels of participant agreement were observed for statements describing withdrawal from discussion of mental health needs or experiences in the workplace and withdrawal from the pursuit of employment opportunities because of stigma about complex mental health issues.

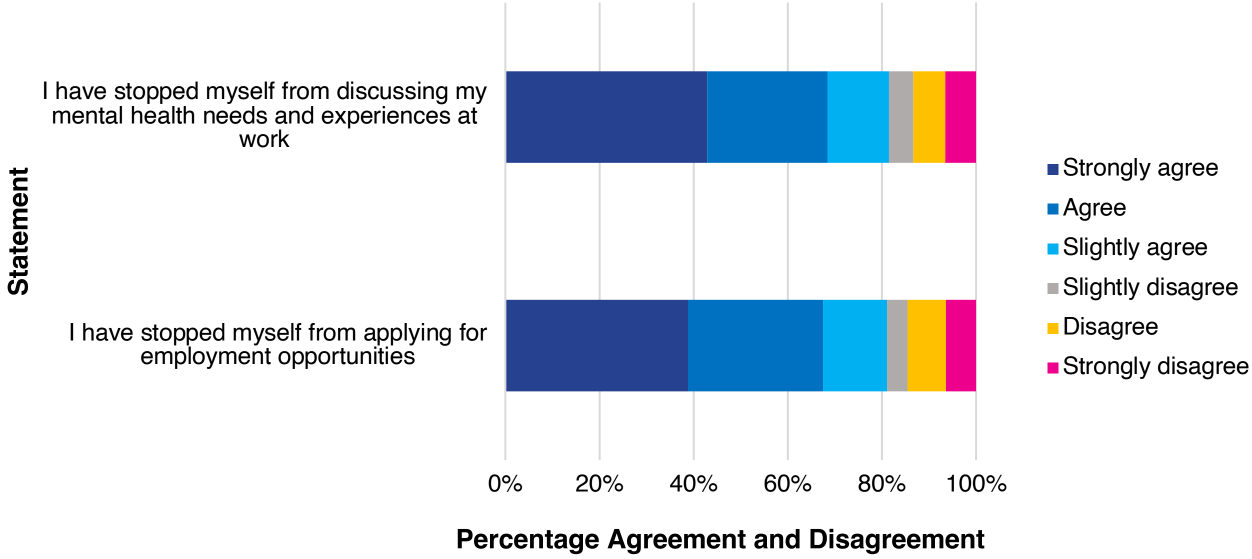


Figure 5.6. Highlight findings: the two most frequently endorsed statements describing withdrawal from opportunities in *employment* (*n* = 822).

The details of participants' agreement or disagreement with statements describing instances of withdrawal from opportunities in employment because of mental health stigma are presented in **Table 5.5**.

Withdrawal from discussing mental health needs and experiences in the workplace, and from applying for jobs or employment opportunities in the past 12 months, were the most commonly reported concerns. Comparatively, fewer participants agreed with statements describing withdrawal from opportunities such as applying for promotion or asking for flexible working arrangements. Withdrawal from leave opportunities or from employment itself through resignation, for example, were the least frequently supported concerns for participants. However, it is again important to note that these issues were reportedly experienced by approximately 60% of participants in the previous 12 months.

Table 5.5. Withdrawal from opportunities in *employment*: percentage agreement and disagreement (*n* = 654).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from applying for employment opportunities	6.4%	8.1%	4.4%	13.6%	28.7%	38.7%	**81.0%**
I have stopped myself from applying for job promotion opportunities	10.9%	12.4%	6.6%	14.1%	24.6%	31.5%	**70.2%**
I have resigned from or left employment before I was ready	18.5%	19.7%	4.1%	7.0%	18.8%	31.8%	**57.6%**
I have stopped myself from asking for flexible work arrangements	13.3%	13.1%	6.9%	14.5%	25.2%	26.9%	**66.6%**
I have stopped myself from taking leave entitlements (e.g. sick leave)	15.4%	18.0%	5.5%	11.5%	25.1%	24.5%	**61.1%**
I have stopped myself from discussing my mental health needs and experiences at work	6.5%	6.8%	5.2%	13.1%	25.5%	42.9%	**81.5%**

Note. Of the 822 participants who completed the *employment* section of the survey, 654 responded to the statements describing withdrawal from opportunity presented in **Table 5.5** due to an embedded survey logic issue.

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN EMPLOYMENT

> ***I'm over 50 and there is an obvious ageism as well as they constantly hire people 30 years younger than me.***
>
> **Our Turn to Speak participant**
> **Victoria**

The findings from survey statements in relation to other experiences of stigma and discrimination in employment, besides that about complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues relating to other experiences of stigma and discrimination are shown in **Figure 5.7.** It can be seen that 38.3% of participants indicated that physical health or ability was the primary area of additional stigma and discrimination in affecting employment besides stigma about mental health issues.

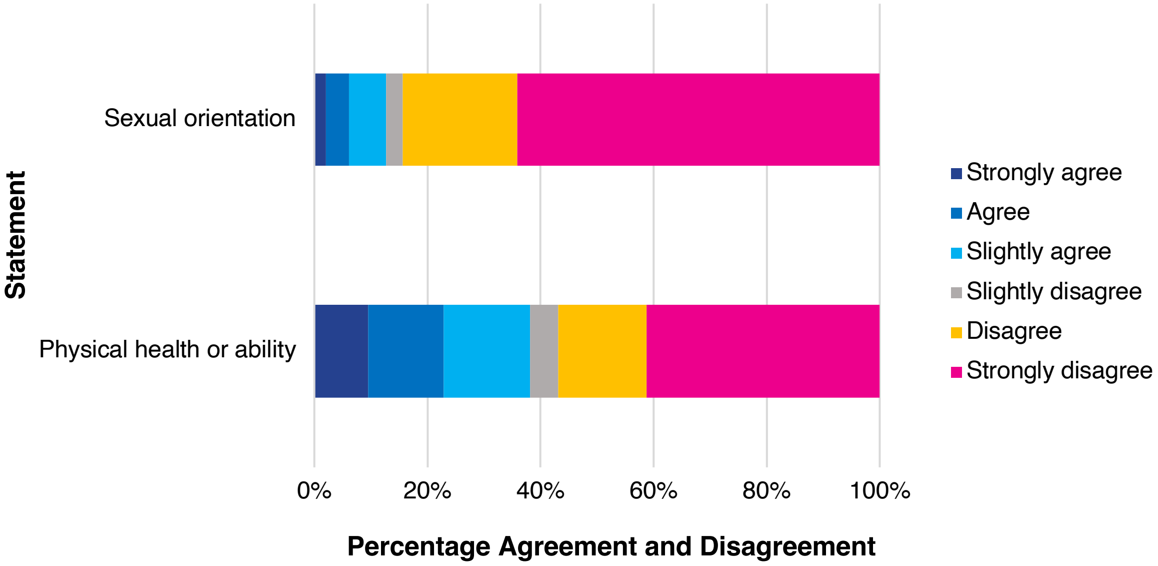


Figure 5.7. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *employment* (*n* = 822).

Table 5.7 shows the specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting employment for responding participants in the previous 12 months. It can be seen that statements describing additional discrimination in employment because of faith or spiritual beliefs, racial or cultural background, gender identity and sexual orientation received comparable levels of agreement from participants.

Table 5.7 Experiences of intersectional stigma and discrimination in *employment*: percentage agreement and disagreement (*n* = 822).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in employment because of my…							
Racial or cultural background	70.0%	18.7%	2.2%	3.5%	3.6%	1.9%	**9.0%**
Faith or spiritual beliefs	67.3%	19.0%	3.4%	5.1%	3.6%	1.6%	**10.3%**
Sexual orientation	64.1%	20.3%	2.9%	6.6%	4.0%	2.1%	**12.7%**
Gender identity	66.7%	19.3%	2.7%	3.2%	5.6%	2.6%	**11.4%**
Physical health or ability	41.4%	15.6%	5.0%	15.3%	13.4%	9.6%	**38.3%**

POSITIVE EXPERIENCES IN EMPLOYMENT

> *I don't think I should receive special treatment when seeking/maintaining employment, but I believe I should receive equal, unbiased, and compassionate treatment.*

Our Turn to Speak participant
South Australia

The survey also asked about positive treatment in employment related to participants' complex mental health issues. Two core statements comprised this section of the survey: (1) the expectation of special consideration because of one's experience of complex mental health issues, and (2) manifest positive experiences in employment because of one's experience of complex mental health issues.

As shown in **Figure 5.8**, many more participants (56.1%) agreed that they should receive special consideration in employment because of their complex mental health issues than agreed that they had positive experiences in employment in the past 12 months because of their mental health issues. Notwithstanding, it remains noteworthy that 39.2% of participants indicated receiving positive treatment in employment because of their experience of mental health issues.

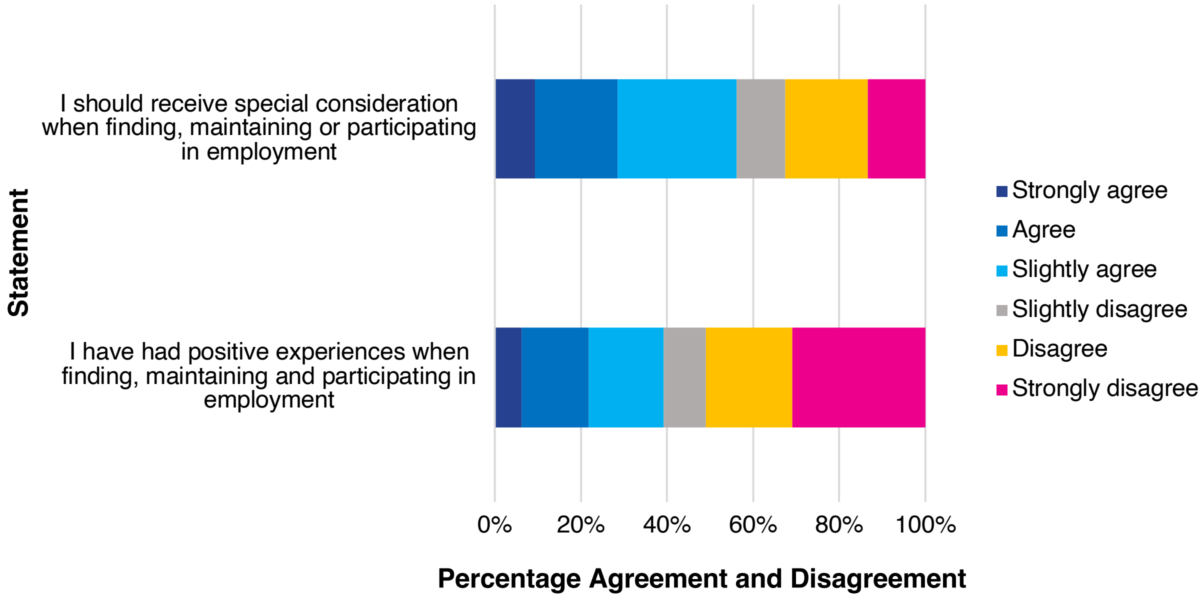


Figure 5.8. Highlight findings: responses to the statements regarding positive experiences in *employment* because of participants' complex mental health issues (n = 822).

SUMMARY OF QUALITATIVE FINDINGS IN EMPLOYMENT

Various barriers to gaining and maintaining employment were mentioned by participants. This could occur during the interview stage, for example:

> *When applying for a job, I have been denied an interview based on my mental illnesses and the specific requirements I need to keep them in line (eg. employers claim they don't have the necessary structures or resources to cater to me, such as a room where I can go if I feel a panic attack coming on, or time for me to take leave entitlements)* (**Our Turn to Speak** participant, Western Australia).

A couple also described unhelpful or negative experiences with disability employment services, such as the following:

> *I have physical and mental health disabilities so I have been told by many disability employment places that I'm a liability, no company would hire me, I need more money for proper medical treatment but have no way of feasibly earning money. There is a grey area for a lot of us, who are not "correctly" disabled, and it's scary and infuriating* (**Our Turn to Speak** participant, Victoria).

Other barriers included experiences of having been rejected by potential clients or employers;

> *Twice I'd got a job, then been asked to get a medical, and I was honest about things, and I didn't end up getting the job because they informed the boss about my mental health without my consent* (**Our Turn to Speak** participant, Victoria).

Also described were fears of having to disclose their experience of mental health issues, which prevented some participants from seeking new or further employment opportunities, for instance:

> *...I understand that yes if it effects the work it's within their rights to not hire you but most places just see you've said yes I have mental illness/s and find a reason to get rid of you ASAP. It discourages me greatly from even applying for jobs in the first place* (**Our Turn to Speak** participant, Western Australia).

A commonly discussed experience among participants in this domain was loss of employment after disclosing mental health issues, mental health issues affecting the ability to work, and/or because of the need for flexibility, which could include additional leave, reduced hours, and other arrangements and supports. Examples here include:

> *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).
>
> *I've been asked to immediately leave the premises when I told my employer that I was diagnosed with Bipolar disorder* (**Our Turn to Speak** participant, New South Wales).

A couple of participants gave examples of being forced to reduce their hours, and feeling pressured to resign.

Some participants would not pursue work opportunities due to previous trauma. Several gave examples of having been denied opportunities, such as: *"I was told that my manager was reluctant to give me a promotion as the increased workload may cause further issues for me"* (**Our Turn to Speak** participant, Victoria).

Instances of confidentiality breaches in the workplace were shared, and many participants expressed a fear of disclosing their mental health issues with their workplace; *"I've taken the 'don't ask, don't tell' approach - I was sacked ten years ago after disclosing my mental illness"*, being one example (**Our Turn to Speak** participant, South Australia). In some cases, participants had been advised not to disclose their mental health issues by a manager or health provider.

Some who were employed commented that they were afraid to look for other work, due to challenges of the interview process, and concerns that they would not be able to secure work somewhere else or that they would not receive as much support as in their current workplace. A couple described themselves as *"unemployable"*.

Different ways that mental health issues had impacted on work were discussed. The most common was that they had to resign or could not return; some reasons being because of extended leave, the situation was too hard to explain, periods of hospitalisation, feeling unable to perform tasks or that their ability was compromised, concerns that they might pose a risk to others, and memory loss. Another impact that a participant described was that they felt unable to 'speak up':

> *It's taken me 2 and a half years to finally approach her about being paid the proper minimum wage, because my issues with anxiety have prevented me from ever speaking up for myself until very recently* (**Our Turn to Speak** participant, Victoria).

Many ways that workplaces impacted on mental health were also raised. Unfortunately, bullying was often mentioned, for example:

> *work for myself because i was bullied so badly at work that I got major depression and wanted to commit suicide. I am still in treatment for this after 2 1/2 years, and have been unable to reapply for other work due to the trauma of it* (**Our Turn to Speak** participant, New South Wales).

Other ways included having one's mental health issues framed as a behavioural issue; unrealistic work demands and conditions; pressure to participate and wear *"a positive mask"*; fear of losing a job; and the inability to take leave (or have other supports and flexible arrangements in place), fear of asking for it, or having to take leave without pay, when needed;

> *I was told that I couldn't have flexible working arrangements as it wasn't fair to the other people I worked with. I ended up leaving that job, but now feel unsure about sharing the need for support with my mental health with my new boss in case the same things happens. I don't take leave for mental health issues even when I really need to because I have limited leave and I get sick often* (**Our Turn to Speak** participant, Victoria).

Participants commented that sometimes workplaces showed their support of significant mental health events, or appeared to have inclusive policies and to be open to discussing support options when approached by participants, but there was still a lack of understanding, and examples of words not backed up with appropriate action when needed.

Experiences of stigma, discrimination, and lack of understanding in employment were shared by a number of participants who worked in health and mental health care sectors, including peer support workers. However, several participants described positive experiences in this sector, too.

Examples of positive experiences in the domain of employment included increased empathy, connection with, and understanding of others (including clients/patients for those who work in mental health and other health and welfare services, for instance), securing employment, being self-employed, feeling supported by an employer, colleagues, and/or management (including the ability to be open about their experiences and so able to support others, flexibility, and understanding), and specific opportunities (particularly in the mental health sector, advocacy, and lived experience roles);

> *I am a better team player because my level of empathy and compassion is much higher. I can tell when my coworkers, colleagues, and even superiors are in need of support* (**Our Turn to Speak** participant, Western Australia).
>
> *I have since found a job where my mental health issues are seen as a pre-requisite to the position, as I am working in a kind of peer-mental health position, and it benefits the consumers I work with. My manager is very supportive and we have a great working relationship* (**Our Turn to Speak** participant, Western Australia).

When asked about positive experiences relating to employment, some participants described negative experiences or barriers, commented on the lack of understanding and support, or discussed mixed positive and negative experiences (including, for example, a fear that support may not be genuine or may not last), and several commented that they had no positive experiences. One participant reflected, furthermore, that: *“My current position makes allowances for my condition, but other employees can resent this”* (**Our Turn to Speak** participant, Victoria). Others noted that they had positive experiences because they did not disclose their mental health issues, or were selective in who they disclosed to.

A few participants commented that even if they did not agree with the idea of ‘special’ treatment in the workplace, they felt that compassion was important and appropriate flexibility and adjustments should be accommodated. For example:

> *I don’t think I should receive special treatment when seeking/maintaining employment, but I believe I should receive equal, unbiased, and compassionate treatment* (**Our Turn to Speak** participant, South Australia).

With regards to other factors that may have compounded participants’ experiences of mental health stigma in employment, the most frequently discussed were age and physical health (including chronic illness and workplace injury). Others included disability, education, faith, gender, immigration status, geographic location, neurodiversity, parenting, physical appearance, race, sexual orientation, socioeconomic status, transport, and weight. The stigma associated with being unemployed was also noted.

SUMMARY

The findings of the **Our Turn to Speak** survey highlight that stigma and discrimination in the domain of employment is a significant concern for Australians living with complex mental health issues. In total, 78.1% of all 1,912 survey participants indicated that they had experienced some level of stigma and discrimination in employment during the preceding 12 months.

Forty-three percent of participants indicated that employment was one of three life domains in which they had been most affected by stigma about mental health issues in the past 12 months. For participants who selected the employment domain as one of their most affected, 51.5% reported experuencing 'frequent' or 'very frequent' stigma and discrimination in this aspect of their lives. These participants were also more likely to be engaged in paid work and less likely to be receiving a pension of other benefits compared with the total sample of participants. Participants' qualitative commentary highlighted that negative experiences in this domain spanned a breadth of workplaces and sectors, including employment within the mental health system.

On average, 55.9% of participants agreed with a series of statements describing specific and general experiences of stigma and discrimination in relation to their employment during the previous 12 months. The greatest level of agreement was observed in response to statements describing unfair treatment in the workplace because of stigma. These concerns extended to general treatment in the workplace; unfair treatment by employers, supervisors or managers specifically; and to a slightly lesser degree, unfair treatment by colleagues. Also commonly endorsed were statements describing pressure to refrain from discussing mental health in the workplace, or conversely, pressure to discuss mental health status against one's will. Concerns also extended to unfair denial of flexible work arrangements, employment, and promotion opportunities, and to social exclusion. Overall, a pervasive pattern of stigmatised experience was indicated by participants with approximately half or more of participants agreeing with every statement presented.

The pattern of negative experiences was corroborated by participants' own words. Indeed, participants wrote about negative experiences more commonly than any other area of inquiry in the employment section of the survey. Many wrote of barriers to obtaining and sustaining employment. Participants spoke of difficulties commencing at the application and interview stages, or in 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.

An average of 60.1% of participants agreed that they expected to experience stigma and discrimination when seeking or participating in employment. Statements describing discriminatory denial of employment opportunities and general unfair treatment in the workplace were most commonly supported, with approximately 70% of participants indicating that they expeirenced such worries. Overall, a widespread pattern of agreement with general and specific statements describing the anticipation of stigma and discrimination in employment was observed, and again, approximately half or more of responding participants agreed to each presented item. The qualitative data again provided corroboration and context to these findings, with participants speaking of their fearful anticipation of stigma and discrimination; and how this might manifest in terms of interviewing, denial of employment, and withholding of support during employment.

The greatest level of participant agreement in the employment section of the survey was observed for statements describing withdrawal from opportunities. On average, 69.7% of participants indicated that they had withdrawn from employment opportunities in the preceding 12 months, with each statement being supported by more than half of responding participants. Withdrawal from the pursuit of employment opportunities and from discussing mental health needs and experiences at work were most reported, with 81.0% and 81.5% of participants agreeing to these experiences, respectively. In the qualitative data, considerable variability in participants' stories of withdrawal from employment opportunities came through. Many participants wrote about withdrawal from opportunities to seek support in the workplace regarding mental health, and that they had instead attempted to hide their problems for fear of negative outcomes. In contrast, other participants spoke of workplace environments that were sensitive and supportive to their mental health needs; however, they also expressed reluctance to leave these workplaces to further their careers or to pursue other employment goals, due to stigma. Others spoke of withdrawal from the pursuit of employment opportunities altogether based on previous negative experiences and the expectation that they would reoccur.

When asked about other personal characteristics that may have contributed to the experience of stigma and discrimination in the past 12 months, participants' physical health or ability was the most frequently reported concern. Major themes in the qualitative data corresponded closely with these survey responses, with participants commonly speaking of stigma about their age and physical health. Intersectional stigma associated with being unemployed was additionally noted by numerous participants.

Finally, when asked about positive experiences in employment, 56.1% of participants agreed that they should receive special consideration because of their mental health issues. In comparison, only 39.2% of participants indicated that they actually had positive experiences because of their mental health issues in the preceding 12 months in employment. These data succinctly speak to a disconnect between what many participants want and experience in employment. This dissonance resonated in participants' qualitative data, with many participants writing of lament regarding the lack of positive experience, while others wrote of remarkably positive experiences and safe workplaces, wherein, they felt able to be their full selves. Other participants yet spoke of a nuanced mix of positive and negative experiences regarding their mental health in the workplace.

It is well established that meaningful and well-supported employment plays a critical role in psychosocial recovery and a key determinant of health and wellbeing (Modini et al., 2016). However, the data presented in this chapter demonstrate that stigma and discrimination in employment is a pervasive, frequent, and impactful issue for many Australians living with complex mental health issues. The findings of the **Our Turn to Speak** survey highlight the critical need for organisations and workplaces to create mentally healthy environments that reasonably accommodate the full spectrum of mental health experiences. In doing so, organisations can best ensure that their workers can bring their authentic and whole selves to work.

HEALTHCARE SERVICES

06

Chapter 6. Healthcare services

Access to healthcare is critical to supporting physical and mental health and wellbeing. Mental health issues often occur in the context of physical problems. Likewise, physical issues are not uncommonly experienced in relation to a background of mental health issues. Nearly 80% of people with serious mental illnesses who die before the average life expectancy of 79.5 years for men, and 84 years for women, do so because of physical health conditions, losing between 10 and 36 years of expected life (Royal Australian and New Zealand College of Psychiatrists, 2016). The Royal Australian and New Zealand College of Psychiatrists (2016) has reported that, for people with psychological disorders, physical health comorbidities and their risk factors are the rule rather than the exception.

A health system that is supportive of, 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.

This chapter considers how Australians living with complex mental health issues experience stigma and discrimination in accessing and receiving care from physical healthcare services.

OVERVIEW

Stigma and discrimination in the domain of healthcare services was identified as the third most common concern among participants of the **Our Turn to Speak** survey. A total 83.9% (*n* = 1605) of all participants reported experiencing some level of stigma and discrimination in healthcare services during the past 12 months.

As shown in **Figure 6.1**, 31.7% of all participants reported 'frequent' of 'very frequent' stigma and discrimination in healthcare services, and 26.2% (*n* = 501) identified this life domain as one of three in which they had been most affected by such experiences. **Figure 6.1** also shows that 60.0% of participants who selected the healthcare services domain reported 'frequent' or 'very frequent' rates of stigma and discrimination in this aspect of their lives; much higher than was reported by the overall sample.

This chapter focuses on the characteristics and experiences of those 501 participants who selected healthcare services as one of their top three, most affected life domains.

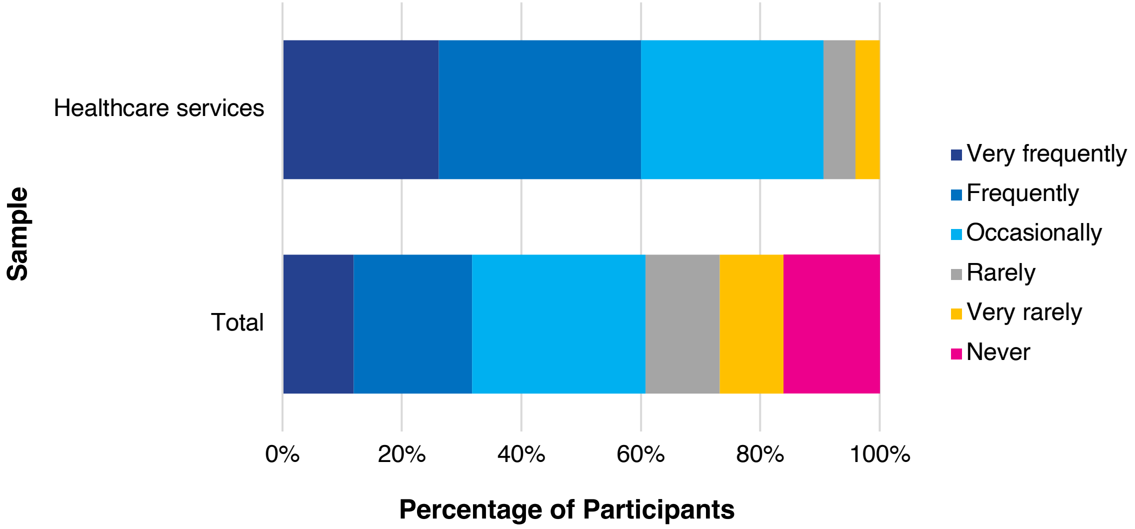


Figure 6.1. Frequency of stigma and discrimination in *healthcare services* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (n = 501) compared with the total sample (N = 1912).

PROFILE OF PARTICIPANTS

The sociodemographic characteristics of participants who identified as being significantly affected by stigma and discrimination in the healthcare services domain were generally comparable to those characteristics of the total sample.

Compared with the total sample, fewer respondents to this survey domain identified as male and a greater proportion identified as female. There were also fewer participants who identified as heterosexual and a greater number who identified as gay, lesbian, bisexual, pansexual, queer, and/or asexual. A greater number of participants in this group were receiving a pension or benefits, and fewer were engaged in paid employment, compared with the total sample. These data are summarised in **Table 6.1**.

Table 6.1. Sociodemographic characteristics: *healthcare services* sample compared with the total sample.

Characteristics	Healthcare Services ($n = 501$)	Total ($N = 1912$)
Mean age	38.67 (*SD* = 12.38)	39.21 (*SD* = 12.81)
Gender identity		
Female	86.4%	78.9%
Male	9.4%	18.0%
Trans, gender diverse and/or non-binary	6.6%	4.9%
Unsure or questioning	1.0%	0.9%
Prefer not to say	1.0%	0.4%
Relationship status*		
Not in a relationship	56.8%	52.1%
In a relationship	43.0%	47.3%
Prefer to self-describe	0.2%	0.2%
Sexual orientation		
Heterosexual	54.3%	62.0%
Gay, lesbian, bisexual, pansexual, queer, and/or asexual	43.3%	35.6%
Unsure or questioning	4.4%	4.9%
Prefer to self-describe	1.4%	1.5%
Prefer not to say	2.6%	1.7%
Education (highest level attained)		
Primary school	1.2%	1.6%
Secondary college (high school)	21.8%	20.9%
Educated post-secondary college	76.8%	77.4%
Other	0.2%	0.2%
Employment		
Engaged in paid work	44.5%	51.7%
Engaged in unpaid work or studying	31.5%	28.7%
Unemployed or unable to work	21.0%	22.8%
Receiving a pension or benefits	32.7%	24.6%
Other	0.2%	0.2%
State		
Australian Capital Territory	1.4%	2.5%
New South Wales	23.8%	23.6%
Northern Territory	1.2%	0.6%
Queensland	17.4%	15.9%
South Australia	10.2%	9.5%
Tasmania	5.2%	3.7%
Victoria	31.7%	33.1%
Western Australia	9.2%	10.9%
Region**		
Major city	71.8%	74.2%
Regional or remote	28.2%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing relationship data for one participant.
**Missing region data for 21 participants.
SD = standard deviation.

As with the majority of the sociodemographic data, the mental and physical health characteristics of participants who identified the healthcare services domain as having been most affected by stigma and discrimination were again similar to those of the total sample (see **Table 6.2**).

However, slightly fewer participants in this group were living with a bipolar related disorder and slightly more were living with a trauma-related or dissociative disorder compared with the total sample. A greater proportion (67.1%) also experienced a physical health issue such as a brain injury, chronic health issue or disability compared with the total sample (53.8%).

Table 6.2. Mental and physical health characteristics: *healthcare services* sample compared with the total sample.

Characteristics	Healthcare Services (*n* = 501)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	5.8%	7.4%
Bipolar related disorder	13.2%	17.2%
Obsessive-compulsive related disorder	3.2%	4.3%
Trauma-related or dissociative disorder	31.5%	25.9%
Eating disorder	9.4%	6.1%
Personality disorder	16.6%	14.5%
Severe and treatment-resistant depressive disorder	12.2%	14.3%
Severe and treatment-resistant anxiety disorder	8.2%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	67.1%	53.8%

METHODS SNAPSHOT

Participants who identified healthcare services as one of three life domains in which they have been most affected by stigma-related experiences completed the healthcare services section of the survey. Healthcare services were described as providing a range of physical healthcare services, across the public and private sectors, including but not limited to:

- community-based services
- clinical services
- residential or rehabilitation services
- hospital-based services.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in healthcare services; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of healthcare. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further describe their experiences of stigma and discrimination because of: (a) complex mental health issues, (b) in relation to other personal characteristics, and (c) their experiences of positive treatment in healthcare services. Additional comments in relation to these experiences were given by 173, 74, and 95 participants, respectively.

STIGMA AND DISCRIMINATION IN HEALTHCARE

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in the healthcare services domain, which will be further examined in sections that follow.

As shown in **Figure 6.2**, approximately 60% of participants, on average, agreed with all statements describing perceived experiences of stigma and discrimination; anticipation of future stigma and discrimination; withdrawal from opportunities relevant to healthcare services, during the previous 12 months.

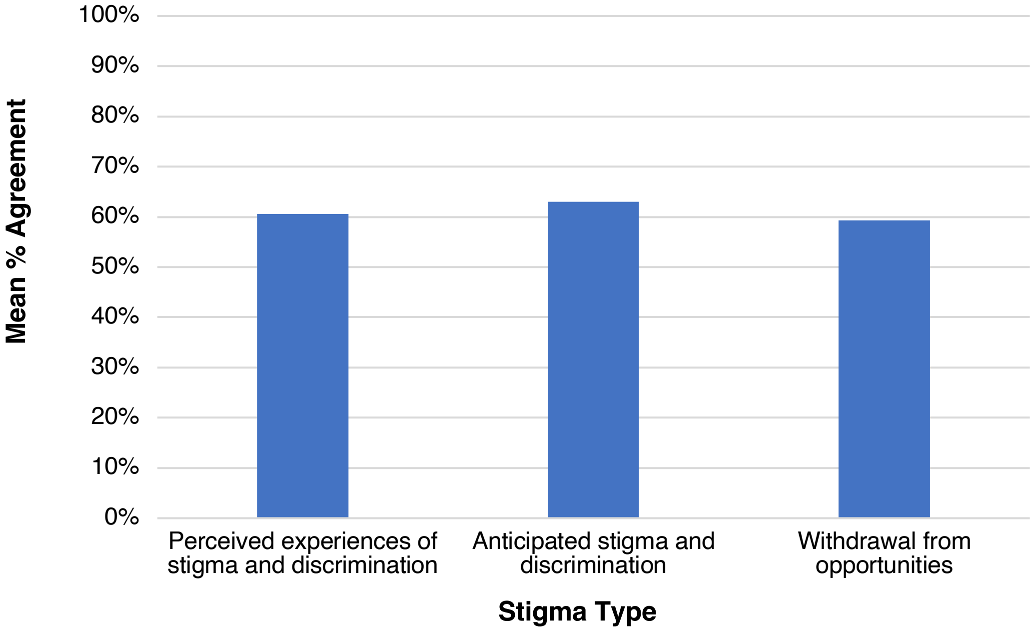


Figure 6.2. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *healthcare services* (*n* = 501).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN HEALTHCARE

> *Because of my mental health diagnosis, I almost died from sepsis due to a bowel perforation and I couldn't get anyone to take my symptoms seriously.*
>
> **Our Turn to Speak participant**
> **Victoria**

Presented in this section are the findings regarding participants' perceived experiences of stigma and discrimination in healthcare services, as related to their experience of complex mental health issues.

Figure 6.3 highlights the two most frequently endorsed issues from the set of eight statements describing perceived experiences of stigma and discrimination. Statements describing general unfair treatment in the accessing help for physical problems, and unfair treatment by physical healthcare professionals, were most commonly endorsed. Over 80% of participants indicated that they had experienced such instances of discrimination related to their complex mental health issues during the past 12 months.

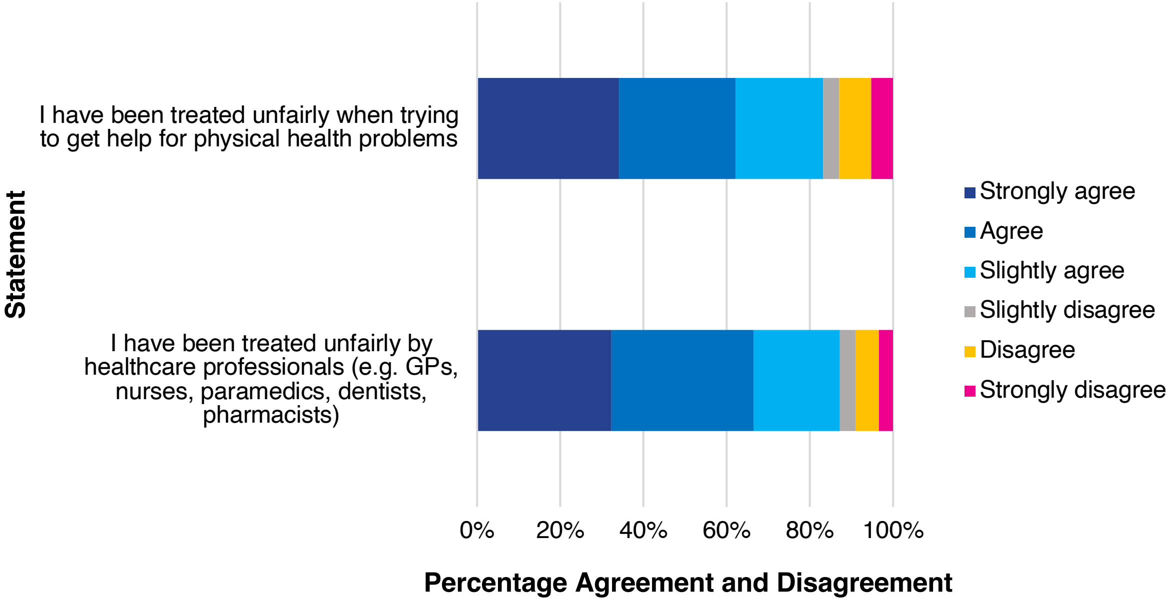


Figure 6.3. Highlight findings: the two most frequently endorsed statements describing perceived experiences of stigma and discrimination in *healthcare services* (*n* = 501).

Table 6.3 provides further details of participants' agreement and disagreement with statements describing perceived experiences of stigma and discrimination when accessing healthcare services during the past 12 months.

In addition to the findings regarding unfair treatment highlighted above, it can be seen that the majority of participants also agreed that they had been unfairly denied help for their physical health problems, or had received inadequate or inappropriate healthcare, because of stigma about their mental health issues. Next in order of percentage agreement, unfair premature discharge from healthcare services was a concern for 51.6% of participants.

Unfair treatment by frontline and administrative healthcare staff, and exclusion from input into treatment planning, were of next greatest concern, with 47.0% and 45.4% of participants respectively endorsing these experiences. Being pressured to receive perceivably unnecessary physical healthcare because of stigma was of relatively lesser concern. Notwithstanding, one-third of the participant group agreed that they had indeed had this experience in the preceding 12-month period.

Table 6.3 Perceived experiences of stigma and discrimination in *healthcare services*: percentage agreement and disagreement (*n* = 501).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when trying to get help for physical health problems	5.2%	7.8%	3.8%	21.0%	28.1%	34.1%	**83.2%**
I have been unfairly denied help for physical health problems	9.6%	17.8%	8.2%	19.4%	22.0%	23.2%	**64.6%**
I have been unfairly referred or discharged out of physical healthcare services	15.2%	24.8%	8.6%	12.8%	17.8%	21.0%	**51.6%**
I have been treated unfairly by healthcare professionals (e.g. GPs, nurses, paramedics, dentists, pharmacists)	3.4%	5.6%	3.8%	20.8%	34.1%	32.3%	**87.2%**
I have been treated unfairly by healthcare frontline and administrative staff (e.g. receptionists, personal care workers)	15.2%	25.9%	12.0%	16.2%	16.0%	14.8%	**47.0%**
I have been pressured to receive physical healthcare treatment I did not think was necessary	25.3%	33.9%	7.6%	12.8%	9.6%	10.8%	**33.2%**
I have been unfairly excluded from having a say in decisions made about my physical healthcare and treatment planning	19.0%	27.5%	8.2%	14.2%	15.4%	15.8%	**45.4%**
I have received inappropriate or inadequate physical healthcare	9.6%	13.6%	4.8%	22.4%	22.2%	27.5%	**72.1%**

ANTICIPATED STIGMA AND DISCRIMINATION IN HEALTHCARE

> ***I am scared of being forced to have treatment for mh when I seek physical health treatment.***
>
> **Our Turn to Speak participant**
> **Queensland**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in healthcare services, as related to their experience of complex mental health issues.

Figure 6.4 highlights the two statements with which participants most frequently agreed. Expectations of general unfair treatment when seeking help for physical health problems, and of unfair treatment by healthcare professionals, were two worries that resonated most with the majority participants.

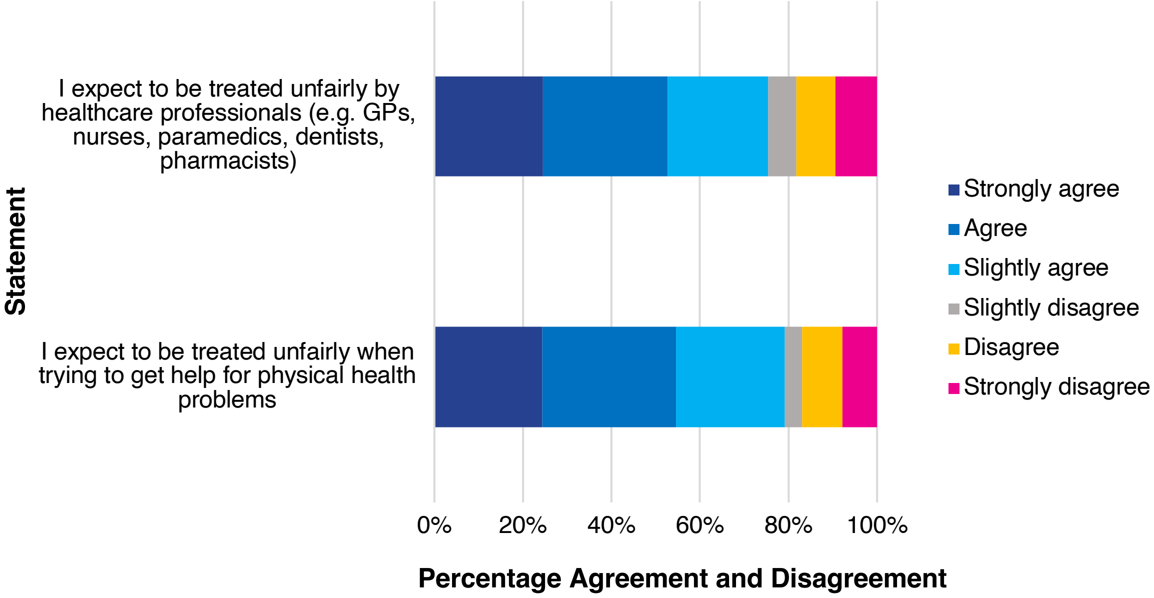


Figure 6.4. Highlight findings: the two most frequently endorsed statements describing anticipated stigma and discrimination in *healthcare services* (*n* = 501).

The data presented in **Table 6.4** further examine the findings regarding participants' anticipation of stigma and discrimination when thinking about accessing physical healthcare. In addition to the findings highlighted above, it can be seen that the anticipation of inadequate or inappropriate treatment, unfair denial of help, and unfair discharge or referral out of healthcare services because of stigma, were endorsed by the majority of participants. Slightly more than half of participants agreed that they expected to be treated unfairly by frontline or administrative staff, and to be unfairly excluded from input into treatment planning, because of stigma about their mental health issues.

Finally, while pressure to receive unnecessary physical healthcare was least anticipated by this group, just under half of responding participants agreed that they have had this concern.

Table 6.4. Anticipated stigma and discrimination in *healthcare services*: percentage agreement and disagreement (*n* = 501).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when trying to get help for physical health problems	7.8%	9.2%	3.8%	24.6%	30.3%	24.4%	**79.3%**
I expect to be unfairly denied help for physical health problems	10.8%	13.8%	8.8%	23.2%	24.6%	19.0%	**66.8%**
I expect to be unfairly referred or discharged out of physical healthcare services	11.8%	18.4%	8.2%	21.2%	24.6%	16.0%	**61.8%**
I expect to be treated unfairly by healthcare professionals (e.g. GPs, nurses, paramedics, dentists, pharmacists)	9.4%	8.8%	6.4%	22.8%	28.1%	24.6%	**75.5%**
I expect to be treated unfairly by healthcare frontline and administrative staff (e.g. receptionists, personal care workers)	12.8%	21.4%	12.0%	21.2%	18.0%	14.8%	**54.0%**
I expect to be pressured to receive physical healthcare treatment I did not think was necessary	20.0%	26.1%	11.8%	19.2%	14.8%	8.2%	**42.4%**
I expect to be unfairly excluded from having a say in decisions made about my physical healthcare and treatment planning	14.8%	21.6%	10.2%	20.2%	18.6%	14.8%	**53.6%**
I expect to receive inappropriate or inadequate physical healthcare	11.4%	11.4%	7.2%	22.8%	24.4%	23.0%	**70.2%**

WITHDRAWAL FROM OPPORTUNITY IN HEALTHCARE

> *I NEVER bring up my mental health unless I absolutely have to because I instantly get treated differently…*
>
> **Our Turn to Speak participant**
> **Queensland**

Presented in this section are the findings regarding participants' withdrawal from opportunities related to healthcare services, in connection with their experience of complex mental health issues.

Figure 6.5 shows the two most frequently endorsed statements in this section of the survey. High levels of participant agreement were observed for statements describing stigma-related withdrawal from help seeking for physical health problems, and from discussing mental health when accessing physical health services, in the previous 12 months.

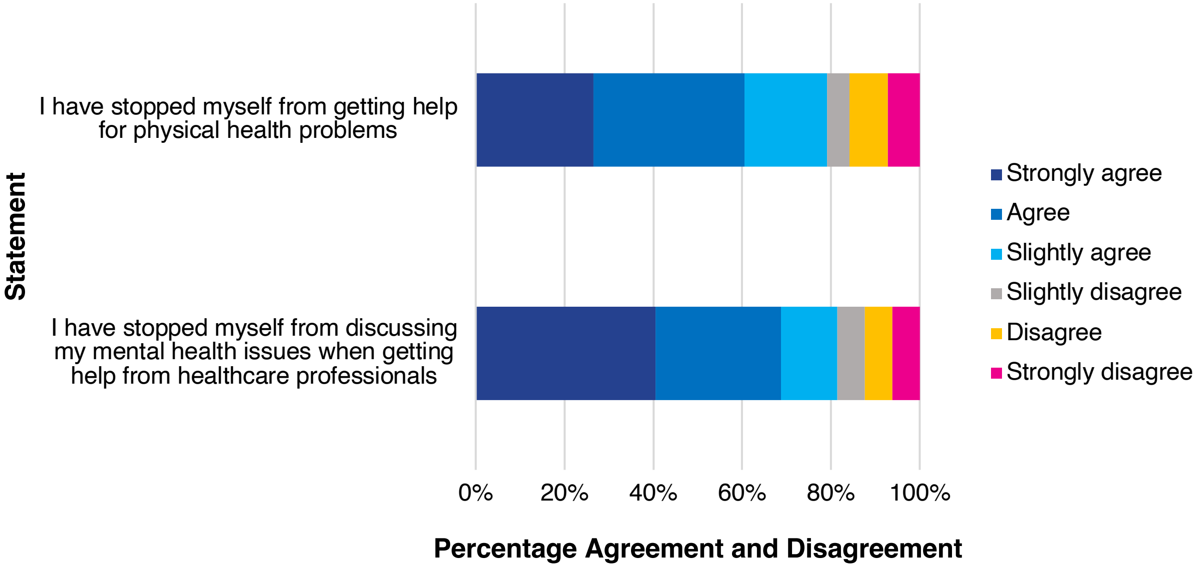


Figure 6.5. Highlight findings: the two most frequently endorsed statements describing withdrawal from opportunities in *healthcare services* (*n* = 501).

The details of participants' level of agreement or disagreement with statements describing instances of withdrawal from physical healthcare opportunities because of stigma about mental health issues are presented in **Table 6.5**.

In addition to the withdrawal experiences highlighted above, a large percentage of participants reported withdrawal from seeking help from physical healthcare professionals (77.8%). Approximately half of participants agreed that they had: (a) withdrawn themselves from healthcare services prematurely, (b) stopped themselves from attending physical healthcare check-ups or specialist appointments, (c) stopped filling prescriptions for physical health problems, or (d) had withdrawn from accessing emergency physical healthcare when it was needed. Fewer participants agreed that they had withdrawn from healthcare services for fear of receiving treatment they did not think was necessary. However, 37.8% of participants still reported such stigma-related withdrawal.

Table 6.5. Withdrawal from opportunities in *healthcare services:* percentage agreement and disagreement ($n = 501$).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from getting help for physical health problems	7.2%	8.6%	5.0%	18.6%	34.1%	26.5%	**79.2%**
I have stopped myself from getting help from healthcare professionals (e.g. GPs, nurses, paramedics, dentists, pharmacists)	7.6%	10.0%	4.6%	18.4%	31.5%	27.9%	**77.8%**
I have stopped myself from calling 000 for an ambulance or attending hospital for emergency treatment of physical health problems	22.8%	21.4%	6.6%	10.8%	15.2%	23.4%	**49.4%**
I have withdrawn myself from healthcare services before I was ready	15.2%	21.8%	6.6%	15.4%	22.8%	18.4%	**56.6%**
I have stopped myself from obtaining scripts or taking medications for physical health problems	19.8%	24.6%	8.6%	14.0%	19.2%	14.0%	**47.2%**
I have stopped myself from attending specialist appointments for physical health problems	17.4%	22.0%	7.2%	16.6%	21.6%	15.4%	**53.6%**
I have stopped myself from attending general health check-ups (e.g. vaccinations, breast screening or prostate screening)	18.2%	24.0%	7.4%	10.8%	20.6%	19.2%	**50.6%**
I have stopped myself from getting physical healthcare for fear of receiving treatment I do not think is necessary	21.8%	29.7%	10.8%	12.6%	13.6%	11.6%	**37.8%**
I have stopped myself from discussing my mental health issues when getting help from healthcare professionals	6.2%	6.2%	6.2%	12.6%	28.3%	40.5%	**81.4%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN HEALTHCARE

> ***I'm Transgender (nonbinary) and Pansexual. I always keep this to myself in fear of stigma and discrimination...***
>
> **Our Turn to Speak participant**
> **New South Wales**

The findings from survey statements in relation to other experiences of stigma and discrimination in relation to physical healthcare, besides those about complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 6.6.**

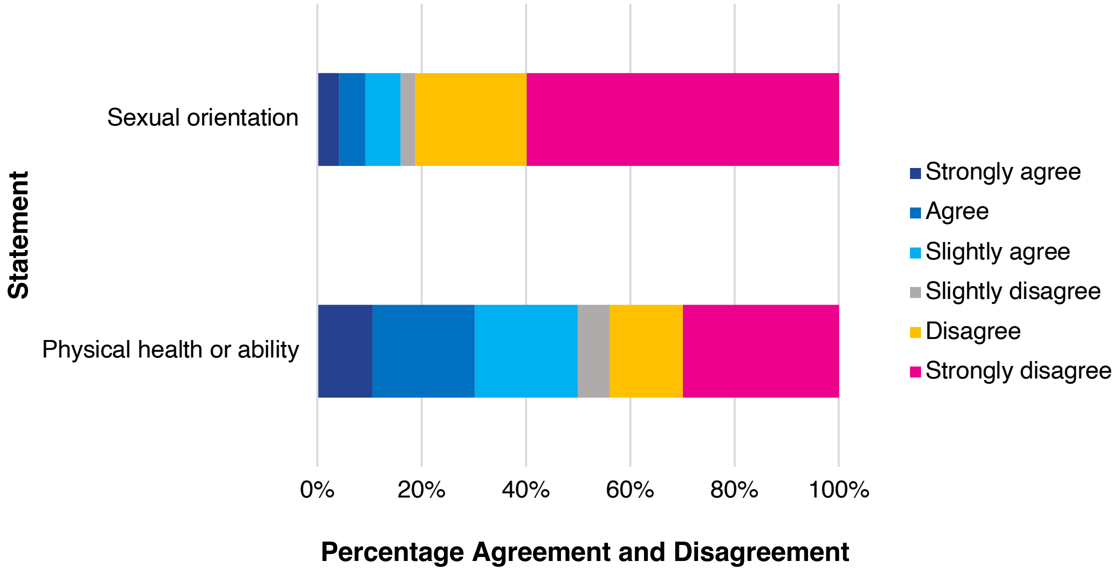


Figure 6.6. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *healthcare services* (*n* = 501).

Table 6.6 shows the specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting participants' healthcare access and engagement. It can be seen that 50.0% of participants indicated that physical health or ability was the primary additional area of stigma and discrimination affecting their access and use of healthcare services, other than complex mental health issues. Sexual orientation and gender identity were reported to be other areas of stigma and discrimination in this life domain for 16% and 13.8% of participants, respectively. Stigma related to faith or spiritual beliefs or racial or cultural background were reported to be concerns for fewer participants.

Table 6.6. Intersectional experiences of stigma and discrimination in *healthcare services*: percentage agreement and disagreement (*n* = 501).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in healthcare services because of my…							
Racial or cultural background	68.9%	22.6%	2.2%	2.8%	2.0%	1.6%	**6.4%**
Faith or spiritual beliefs	65.5%	23.4%	2.6%	4.6%	3.0%	1.0%	**8.6%**
Sexual orientation	59.9%	21.4%	2.8%	6.8%	5.0%	4.2%	**16.0%**
Gender identity	62.1%	22.6%	1.6%	3.4%	4.2%	6.2%	**13.8%**
Physical health or ability	29.9%	14.0%	6.2%	19.8%	19.6%	10.6%	**50.0%**

POSITIVE EXPERIENCES IN HEALTHCARE

> *I believe extra care and attention should be given to the mental health of a patient who has disclosed they have a mental illness or it is noted in their medical reports. The presence of physical illness can have significant impact on mental health.*
>
> **Our Turn to Speak participant**
> **Western Australia**

The survey also asked about positive treatment related to participants' complex mental health issues when accessing physical healthcare services. Two core statements comprised this section of the survey: (1) the expectation of special consideration in healthcare because of one's experience of complex mental health issues, and (2) manifest positive experiences in healthcare because of one's experience of complex mental health issues.

As shown in **Figure 6.7**, just over 40% of participants agreed to these each of these statements. The spread of agreement and disagreement for these statements was also closely comparable.

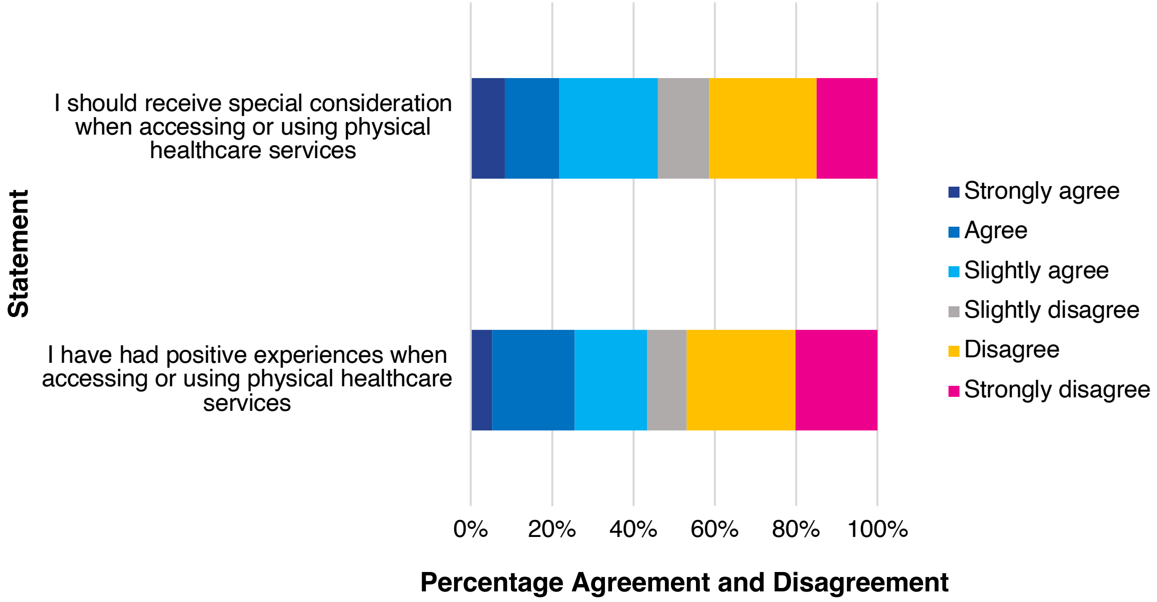


Figure 6.7. Highlight findings: responses to the statements regarding positive experiences in *healthcare services* because of participants' complex mental health issues (*n* = 501).

SUMMARY OF QUALITATIVE FINDINGS IN HEALTHCARE

A key theme in participants' responses in this domain was that of needs not being taken seriously when seeking treatment for physical health-related issues. Many participants explained, furthermore, that they felt their needs were (or expected that they would be) not taken seriously because their mental health issues inappropriately became a focus. For example: *"i paid $300 to see a neurosurgeon for 8 minutes about a spine issue and he spent half of that questioning my diagnosis and treatment of adhd"* (**Our Turn to Speak** participant, Queensland). This was potentially life-threatening for some, as a participant explained: *"Because of my mental health diagnosis I almost died from sepsis due to a bowel perforation and I couldn't get anyone to take my symptoms seriously"* (**Our Turn to Speak** participant, Victoria). Not surprisingly, a few participants suggested that they would not disclose their mental health issues to practitioners when seeking help for physical health-related issues.

A lack of understanding and support, as well as more (re)traumatising experiences, from healthcare professionals and in hospital or rehab settings were raised by many participants. *"I've had so many bad experiences over my lifetime that dealing with the healthcare system is an anxiety trigger now regardless of how they treat me"* (**Our Turn to Speak** participant, Australian Capital Territory), a participant reflected.

When commenting on positive experiences in relation to healthcare, participants most often described interactions with their GPs, psychologists and psychiatrists. Other positive experiences included peer work and advocacy, connecting with other people who had lived experience of mental health issues, particular services, and interactions with other health workers and police, as the following examples illustrate:

> *When I finally found a good GP recently I felt more validated and not having physical issues dismissed because of mental health as I had previously (***Our Turn to Speak** participant, New South Wales).

> *Because of my ptsd I have been unable to get myself to have pap smears or any gyno tests but recently a g.p told me of options with trauma informed gyno specialists and this has been a chance for me to do a necessary test with less distress* (**Our Turn to Speak** participant, Tasmania).

As in other domains, some participants described negative or mixed experiences – for example, *"I've had positive experiences when accessing help privately and as an outpatient but not as an inpatient (most of the time)"* (**Our Turn to Speak** participant, Victoria). One participant associated their positive experiences with not disclosing their mental health issues as follows: *"Generally I have great experiences with health care professionals when I choose not to disclose my mental health challenges"* (**Our Turn to Speak** participant, Victoria).

Some participants commented that more trauma-informed care was needed among healthcare professionals, and some felt that special consideration was needed for people with mental health issues accessing the healthcare system, as the following quotes suggest:

> *As I suffer with severe and chronic panic every day, waiting for an appointment in a waiting room causes me to panic and I need to flee. Due to this I avoid getting help. If I could wait somewhere quiet away from other people, which I think is reasonable, I could try to access help* (**Our Turn to Speak** participant, Queensland).

> *When I say that I agree with special care, I mean that both my mental and physical health should be considered holistically. For instance, I find getting a pap smear performed particularly anxiety provoking due to my past experiences of child sexual abuse. Special consideration to this anxiety should be made if the professional is aware of my history. Special consideration could look like the opportunity to self-collect, or offering a longer appointment so that time is given to manage potential anxiety. By special consideration I do not mean that I should receive services before others, or that I should be treated with more respect than others* (**Our Turn to Speak** participant, Victoria).

Others conveyed that special treatment as they understood it was not necessary; rather, what they wanted was to be treated "normally", "as an individual and with respect, like everyone", and to receive "fair treatment without judgement".

When asked about intersecting factors with mental health stigma in this domain, the two most frequently mentioned characteristics were weight and physical health (including chronic illness). Others included gender, geographic location, disability and access, sexual orientation, cultural background, spiritual beliefs, employment, physical appearance, and substance use. To quote one participant: *"Being in a wheelchair and then on crutches has meant people think my brain doesn't work…"* (**Our Turn to Speak** participant, Victoria). Another participant explained that:

> *I'm Transgender (nonbinary) and Pansexual. I always keep this to myself in fear of stigma and discrimination. But even when I am silent I hear staff talking badly of people like me and it's upsetting. In the past I have also had stigma and discrimination because of my weight, where I wouldn't be treated and would be told to "lose weight first." I lost all my weight to illness, which no one would treat until I became too thin, and now I am terrified of gaining that weight back. I often starve myself to avoid weight gain again* (**Our Turn to Speak** participant, New South Wales).

SUMMARY

Stigma and discrimination in the domain of Healthcare Services was a key concern for the participants. Almost 84% of all 1,912 **survey participants** indicated that they had experienced some level of stigma and discrimination in this aspect of their lives during the past 12 months.

A total of 26.2% of participants indicated that physical healthcare was one of three life domains in which they had been most affected by stigma in the past 12 months; for these participants, the regularity of stigma and discrimination was striking, with 90.6% of this group reporting 'frequent' or 'very frequent' such experiences in this life domain. Compared with the total sample, a greater proportion of participants who responded to the healthcare services section of the survey were also living with a brain injury, chronic health issue, or other disability.

On average, 60.5% of participants agreed with a series of statements describing specific and general perceived experiences of stigma and discrimination when accessing help for physical health problems in the previous 12 months. Broadly speaking, however, participants' rates of agreement with statements describing perceived experiences of stigma and discrimination varied considerably across different aspects of healthcare service provision. Statements describing unfair treatment when seeking help generally for physical health problems, or specifically from healthcare professionals (for example, GPs, nurses, paramedics, dentists and pharmacists), received the greatest level of agreement from participants. Moderate rates of support were observed regarding experiences such as unfair treatment by frontline administrative staff, inadequate healthcare treatment, denial of treatment, or premature discharge from physical healthcare because of stigma about participants' complex mental health issues. While perceived experiences of being pressured to receive unnecessary treatment were least reported, this was still observed to affect approximately one-third of the responding participant group.

In the qualitative data, participants spoke of a lack of understanding and support, and traumatising experiences when accessing healthcare. Numerous participants wrote of instances of inappropriate physical healthcare treatment, and of a perception that their l help-seekingfor physical problems was not being treated seriously, because of stigma about their mental health issues.

A similar pattern of responses was observed regarding the anticipation of stigma when accessing physical healthcare services, with about 63% of participants, on average, holding such expectations. The greatest concerns related to anticipated unfair treatment from specific types of healthcare professionals (for example, GPs, nurses, paramedics, dentists and pharmacists), and anticipated unfair treatment when generally seeking help for physical health problems. All other specific and general statements describing the expectation of negative treatment because of stigma while accessing healthcare services were supported by more than half of the participants, with one exception; a total of 42.4% of responding participants indicated that they expected to be pressured into receiving perceivably unnecessary physical healthcare treatment. Numerous participants also wrote about the expectation that they would not be taken seriously if they were to disclose their mental health status when help-seeking for physical issues.

On average, 59.3% of participants indicated that they had withdrawn from opportunities to obtain help and support for their physical health in the preceding 12 months. The greatest levels of agreement related to (a) refraining from discussing mental health issues when seeking physical healthcare and (b) generally avoiding help-seeking for physical health problems. Variable rates of support were once again seen for withdrawal across different aspects of physical healthcare access; however, all statements were endorsed by about 40% or more of responding participants. In the qualitative data, participants wrote of refraining from discussing their mental health issues for fear that this would negatively impact the physical healthcare that they received.

When asked about other personal characteristics that may have contributed to the experience of stigma and discrimination when accessing healthcare services in the past 12 months, physical health or ability was the most frequently reported concern, with 50.0% of participants agreeing that they had such experiences. Physical health issues, including weight specifically, were the most discussed intersectional concerns in participants' additional qualitative comments. Several other observations were made in terms of how intersectional stigma affects help seeking for physical healthcare, with sexual orientation and substance use issues being two such qualitative themes of concern.

Finally, when asked about positive experiences in physical health services, just over 40% of participants indicated that they had positive experiences because of their mental health issues when accessing mental healthcare services in the preceding 12 months. A comparable proportion of participants reported feeling that they should indeed receive special consideration because of their complex mental health issues when seeking physical healthcare. In the qualitative data, some participants wrote of positive treatment by specific health professionals. Numerous participants also contrasted positive treatment within the healthcare system with negative treatment in the public inpatient healthcare system. Other participants wrote of the need for greater training and education for physical healthcare providers regarding complex mental health issues and trauma-informed care.

It is well established that physical and mental health are inextricably interlinked. Many complex mental health issues carry with them unique health and medical needs in terms of assessment, treatment, and support required. Indeed, evidence suggests that, while people with complex mental health issues are often at elevated risk of experience poor physical health, they experience significant inequity in terms of access to standard healthcare (De Hert et al., 2011). These findings build on these previous observations and demonstrate that issues of stigma and discrimination are common for many Australians living with complex mental health issues when accessing physical healthcare services. Ultimately, it appears that, for many, these negative experiences contribute to their withdrawal from seeking necessary physical healthcare.

Altogether, the findings presented here highlight that healthcare services must respond to the physical health of people affected by complex mental health issues in a way that is compassionate, trauma-informed, holistic and health-promoting. Mental health issues should not dominate nor be dismissed in the course of seeking healthcare sercices, and should, at all costs, promote ongoing help-seeking to ensure best outcomes.

SOCIAL MEDIA

07

Chapter 7. Social media

Over the past decade, social media has become an almost ubiquitous part of our lives, helping us to connect with others and the world around us. For some people living with complex mental health issues, social media has provided an unprecedented opportunity to share their experiences with their peers and the public at large, and to advocate for themselves and others with similar lives experience. For others though, social media can perpetuate the stigma, discrimination and social exclusions they face in other aspects of their lives.

This chapter considers how people living with complex mental health issues experience stigma and discrimination in their engagement with social media platforms.

OVERVIEW

Almost 85% (*n* = 1618) of all **survey participants** reported experiencing some level of stigma or discrimination in social media during the past 12 months.

As shown in **Figure 7.1**, 40.0% of all participants reported 'frequent' or 'very frequent' stigma and discrimination in social media, and 25.3% (*n* = 483) identified this life domain as one of three in which they had been most affected by such experiences. **Figure 7.1** also shows that 58.5% of participants who selected the social media domain reported 'frequent' or 'very frequent' rates of stigma and discrimination in this aspect of their lives; somewhat higher than was reported by the total sample.

This chapter focuses on the characteristics and experiences of those 483 participants who selected social media as one of their top three, most affected life domains.

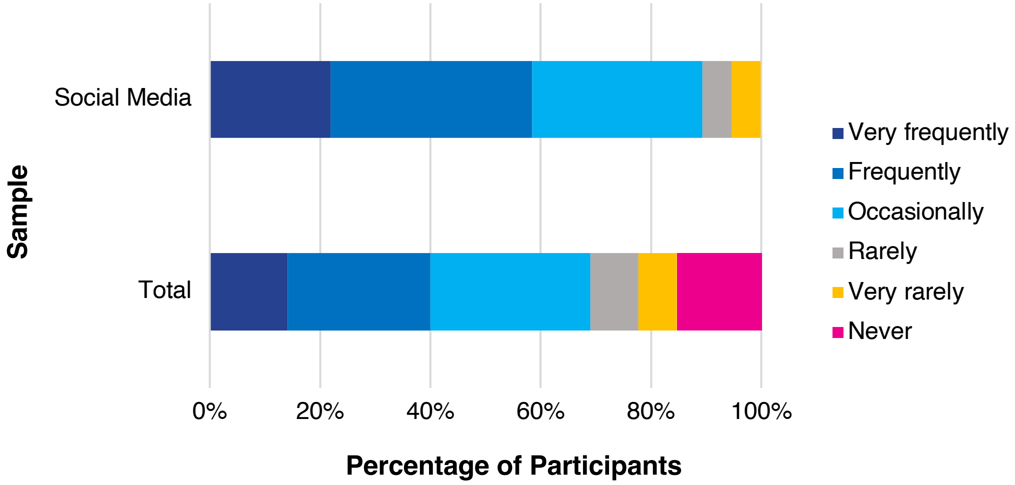


Figure 7.1. Frequency of stigma and discrimination in *social media* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 483) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

Overall, the sociodemographic characteristics of participants who identified as being personally affected by stigma and discrimination in social media were not dissimilar from the total sample (see **Table 7.1**). Compared with the total sample, a slightly greater proportion of participants who selected the social media domain identified as female; as gay, lesbian, bisexual, pansexual, queer or asexual; were in a relationship; and were engaged in paid work and/or unpaid work, including study.

Table 7.1. Sociodemographic characteristics: *social media* sample compared with the total sample.

Characteristics	Social Media (*n* = 483)	Total (*N* = 1912)
Mean age	35.89 (*SD* = 11.76)	39.21 (*SD* = 12.81)
Gender identity		
Female	82.6%	78.9%
Male	15.1%	18.0%
Trans, gender diverse and/or non-binary	4.1%	4.9%
Unsure or questioning	0.8%	0.9%
Prefer not to say	0.2%	0.4%
Relationship status		
Not in a relationship	47.0%	52.1%
In a relationship	52.6%	47.3%
Prefer to self-describe	0.2%	0.2%
Sexual orientation		
Heterosexual	58.8%	62.0%
Gay, lesbian, bisexual, pansexual, queer, and/or asexual	38.3%	35.6%
Unsure or questioning	6.4%	4.9%
Prefer to self-describe	1.9%	1.5%
Prefer not to say	1.0%	1.7%
Education (highest level attained)		
Primary school	1.7%	1.6%
Secondary college (high school)	23.2%	20.9%
Educated post-secondary college	75.2%	77.4%
Other	0.0%	0.2%
Employment status		
Engaged in paid work	55.9%	51.7%
Engaged in unpaid work or studying	34.2%	28.7%
Unemployed or unable to work	17.4%	22.8%
Receiving a pension or benefits	22.2%	24.6%
Other	0.2%	0.2%
State		
Australian Capital Territory	3.9%	2.5%
New South Wales	23.4%	23.6%
Northern Territory	0.8%	0.6%
Queensland	16.4%	15.9%
South Australia	7.2%	9.5%
Tasmania	2.7%	3.7%
Victoria	35.8%	33.1%
Western Australia	9.7%	10.9%
Region*		
Major city	75.6%	74.2%
Regional or remote	23.0%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation

As with the sociodemographic data, the mental and physical health characteristics of participants who identified the social media domain as having been most affected by stigma and discrimination were again similar to those of the total sample.

Shown in **Table 7.2**, slightly fewer participants who responded to the social media domain reported a primary diagnosis of an eating disorder, and slightly fewer were living with co-occurring physical health issues compared with the total sample.

Table 7.2. Mental and physical health characteristics: *social media* sample compared with the total sample.

Characteristics	Social Media (*n* = 483)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	5.8%	7.4%
Bipolar related disorder	18.6%	17.2%
Obsessive compulsive related disorder	5.6%	4.3%
Trauma-related or dissociative disorder	25.5%	25.9%
Eating disorder	9.5%	6.1%
Personality disorder	14.1%	14.5%
Severe and treatment-resistant depressive disorder	12.0%	14.3%
Severe and treatment-resistant anxiety disorder	8.9%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	51.3%	53.8%

METHODS SNAPSHOT

Participants who identified social media as one of three life domains in which they have been most affected by stigma-related experiences completed the social media section of the survey. Social media was described as including websites, apps and forums including platforms such as:

- Facebook
- Instagram
- Twitter
- Reddit
- YouTube.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in social media; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of social media. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further describe their experiences of stigma and discrimination in relation to: (a) complex mental health issues, (b) their other personal characteristics, and (c) any positive treatment in social media. Sixty-one, 18 and 59 participants provided additional comments in relation to these experiences respectively.

STIGMA AND DISCRIMINATION IN SOCIAL MEDIA

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in social media, which will be further examined in sections that follow.

As shown in **Figure 7.2**, the average level of agreement with all statements describing perceived experiences and anticipation of stigma and discrimination when accessing social media content was close to 90%. By contrast, the average total level of agreement with all statements describing perceived experiences and anticipation of stigma and discrimination during social media *interactions* were much lower, at 29.5% and 41.9%, respectively.

While agreement with experienced and anticipated stigma and discrimination related to social media content was high, agreement was somewhat lower (63.8%) for statements describing withdrawal from social media content. However, agreement with statements about withdrawing from social media interactions was much higher, at 78.8%. In other words, participants typically agreed that, more often than not, they stopped themselves from interacting with social media (like commenting on posts or joining forums and groups), even though perceived experiences and anticipation of stigma and discrimination during such interactions, were somewhat lower.

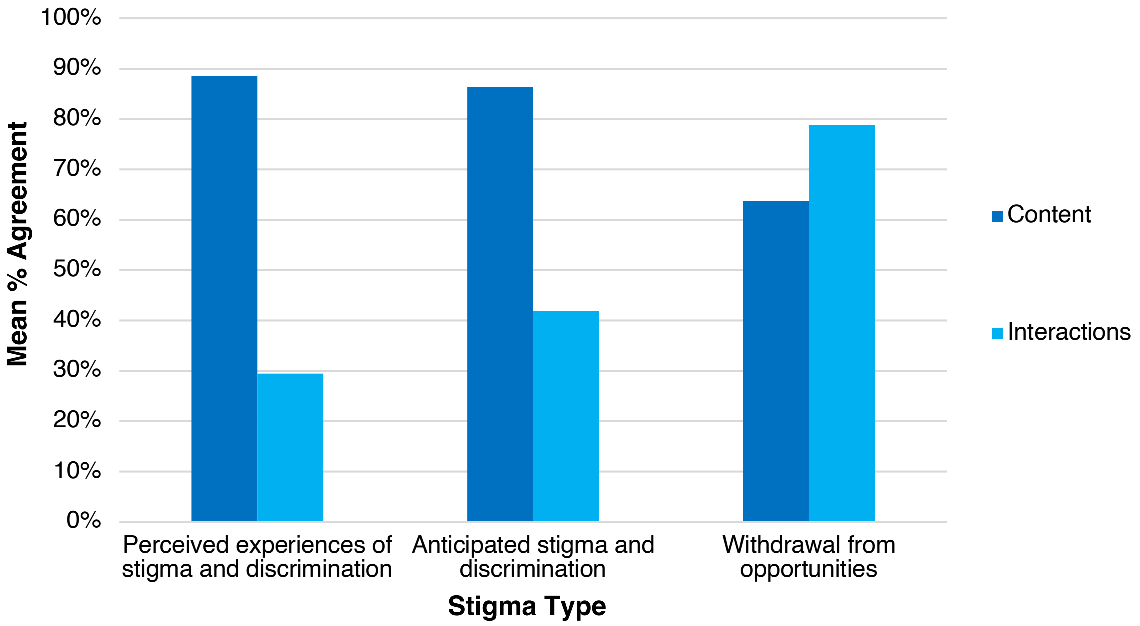


Figure 7.2. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *social media* (*n* = 483).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN SOCIAL MEDIA

> ***The most common kind of stigma online I have experienced is comments from peple telling me that all people with borderline personality disorder are abusive terrible people. Sometimes they will also say people with BPD can never get better, that they are a lost cause.***
>
> **Our Turn to Speak participant**
> **Queensland**

Presented in this section are the findings regarding participants' perceived experiences of stigma and discrimination in social media, as related to their experience of complex mental health issues.

Figure 7.3 highlights the findings from the two most frequently endorsed issues from the set of six statements that participants answered in this section of the survey. As shown, 94.2% of participants agreed that they had seen, read or heard social media content that they found hurtful or offensive during the last 12 months because of the way mental health issues were portrayed. Similarly, 90.3% of participants agreed that they had seen, read or heard social media content that portrayed people with mental health issues as being to blame for their issues during the same time period.

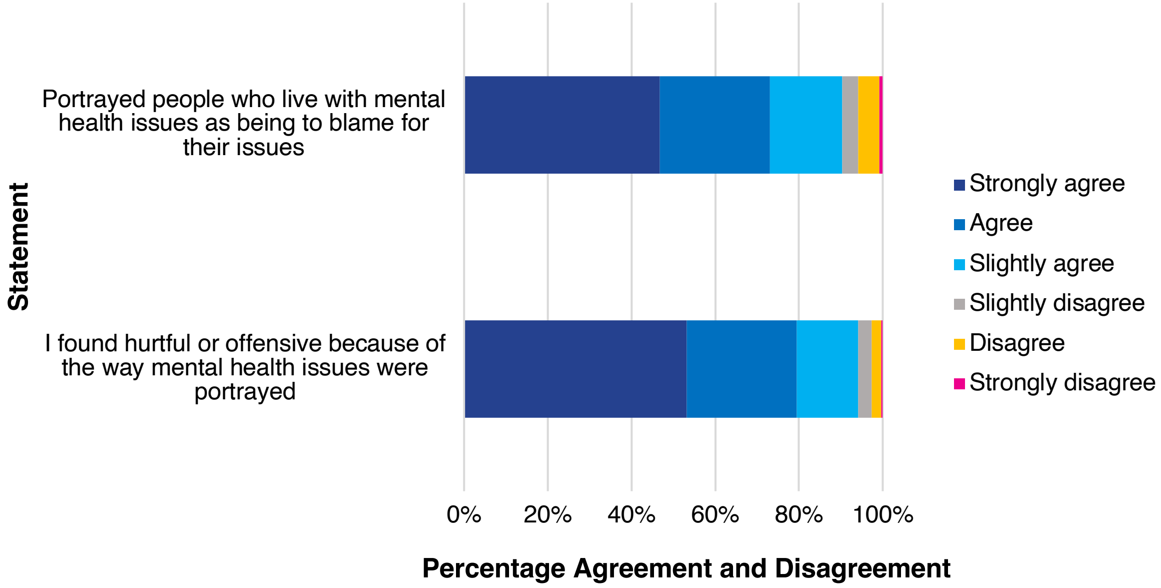


Figure 7.3. Highlight findings: the two most frequently endorsed statements describing perceived experiences of stigma and discrimination in *social media*.

Tables 7.3 and **7.4** provide the specific levels of agreement and disagreement for all statements relevant to perceived experiences of stigma and discrimination in social media.

Close to 90% of participants agreed that they had seen, read or heard social media content that portrayed people living with mental health issues as dangerous, unsafe or unpredictable during the last 12 months, while 79.9% had been exposed to social media content that suggested recovery from complex mental health issues is impossible.

Table 7.3. Perceived experiences of stigma and discrimination in *social media content*: percentage agreement and disagreement (*n* = 483).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have seen, read or heard social media content that…							
I found hurtful or offensive because of the way mental health issues were portrayed	0.4%	2.3%	3.1%	14.7%	26.3%	53.2%	**94.2%**
Portrayed people who live with mental health issues as dangerous, unsafe or unpredictable	1.4%	4.3%	4.6%	15.5%	27.7%	46.4%	**89.6%**
Portrayed people who live with mental health issues as being to blame for their issues	0.8%	5.0%	3.9%	17.2%	26.3%	46.8%	**90.3%**
Suggested that people who live with mental health issues cannot recover or get better	2.1%	8.5%	9.5%	17.6%	27.7%	34.6%	**79.9%**

Perceived experiences of stigma and discrimination in the context of social media interactions were somewhat lower, but nonetheless meaningful. About 42% of participants agreed that they had experienced online bullying because of mental health issues, while 17.0% perceived to have been unfairly denied access to social media forums or groups.

Table 7.4. Perceived experiences of stigma and discrimination in *social media interactions*: percentage agreement and disagreement (*n* = 483).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been unfairly denied access to social media (eg. blocked or deleted from forums, groups)	42.2%	35.4%	5.4%	8.3%	4.8%	3.9%	**17.0%**
I have been bullied on social media	25.9%	26.1%	6.0%	13.5%	14.1%	14.5%	**42.1%**

ANTICIPATED STIGMA AND DISCRIMINATION IN SOCIAL MEDIA

> *No one knows about my mental health issues online - only close friends and family - because I am so afraid of the stigmas and discriminations, and being bullied and being thought less of.*
>
> **Our Turn to Speak participant**
> **Victoria**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in social media, as related to their experience of complex mental health issues.

Figure 7.4 highlights the findings from the two most frequently endorsed issues from the set of six statements that participants rated in this section of the survey. As shown, almost 90% of participants agreed that they expected to see, read or hear social media content that they would find hurtful or offensive because of the way mental health issues were portrayed. Just over 88% of participants expected to be exposed to social media content that portrayed people who live with mental health issues as dangerous, unsafe or unpredictable.

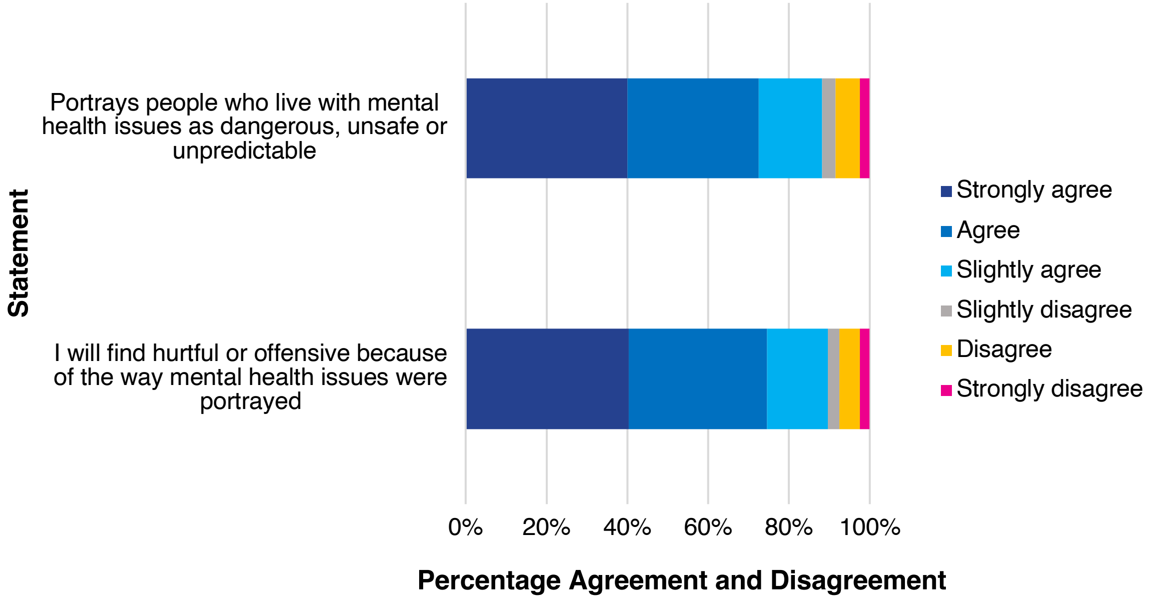


Figure 7.4. Highlight findings: the two most frequently endorsed statements describing anticipated stigma and discrimination in *social media* (*n* = 483).

Tables 7.5 and **7.6** provides the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in social media.

As shown, rates of agreement for the remaining statements were not much lower than the rates highlighted in **Figure 7.4**. Interestingly, the level of agreement for anticipated stigma and discrimination in social media was not dissimilar to the level of agreement reported for equivalent statements describing perceived experiences of stigma and discrimination.

Participants rated their agreement with statements describing anticipated stigma and discrimination in social media interactions, like bullying and blocking from groups/forums, as much lower than anticipated exposure to stigmatising social media content.

Table 7.5. Anticipated stigma and discrimination in *social media content*: percentage agreement and disagreement (*n* = 483).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I expect to see, read or hear social media content that…							
I will find hurtful or offensive because of the way mental health issues were portrayed	2.5%	5.0%	2.9%	15.1%	34.2%	40.4%	**89.7%**
Portrays people who live with mental health issues as dangerous, unsafe or unpredictable	2.5%	6.0%	3.3%	15.7%	32.5%	40.0%	**88.2%**
Portrays people who live with mental health issues as being to blame for their issues	2.5%	5.0%	4.6%	15.9%	31.9%	40.2%	**88.0%**
Suggests that people who live with mental health issues cannot recover or get better	2.9%	8.1%	9.3%	16.8%	32.7%	30.2%	**79.7%**

Table 7.6. Anticipated experiences of stigma and discrimination in *social media interactions*: percentage agreement and disagreement (*n* = 483).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be unfairly denied access to social media (eg. blocked or deleted from forums, groups)	27.5%	33.5%	12.0%	13.3%	8.7%	5.0%	**27.0%**
I expect to be bullied on social media	14.9%	19.9%	8.5%	22.2%	22.2%	12.4%	**56.8%**

WITHDRAWAL FROM OPPORTUNITY IN SOCIAL MEDIA

> ***I guess I find myself increasingly reluctant to use social meida, especially if I'm gpoing through a rough time. There's such intense pressure to be happy and successful, and if you're unemployed and kinda sad/anxious there's just no comfortable way to have a voice there? Without feeling life you're whining, I mean. Like if my life doesn't look glamorous, I don't post, which means withdrawing from a lot of opportunities to connect digitally.***
>
> **Our Turn to Speak participant**
> **Victoria**

Presented in this section are the findings regarding participants' withdrawal from opportunities related to social media, in connection with their experience of complex mental health issues.

Figure 7.5 highlights the two most frequently endorsed issues; 87% of participants agreed that, during the last 12 months, they had stopped themselves from commenting on posts, or sharing their opinions on social media platforms because of stigma about mental health issues. Just over 70% agreed that they had stopped themselves from joining social media groups or forums for the same reason.

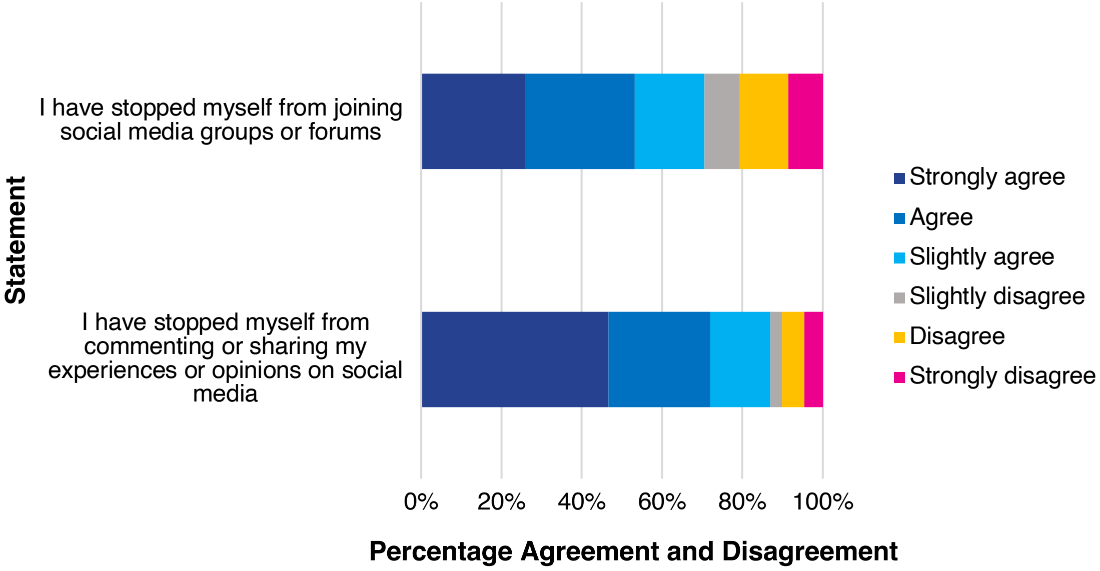


Figure 7.5. Highlight findings: the two most frequently endorsed statements describing withdrawal from opportunities in *social media*.

The specific levels of agreement and disagreement for each of the three statements participants rated in this section of the survey are shown in **Table 7.7**. In addition to the statements highlighted above, it is also of note, 63.8% of participants had stopped themselves from accessing social media altogether.

Table 7.7. Withdrawal from opportunities in *social media content* and *social media interactions*: percentage agreement and disagreement (n = 483).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from viewing, reading or accessing social media[1]	10.6%	16.8%	8.9%	24.0%	22.4%	17.4%	**63.8%**
I have stopped myself from commenting or sharing my experiences or opinions on social media[2]	4.6%	5.6%	2.9%	14.9%	25.5%	46.6%	**87.0%**
I have stopped myself from joining social media groups or forums[2]	8.5%	12.2%	8.7%	17.4%	27.3%	25.9%	**70.6%**

[1] Relates to content.

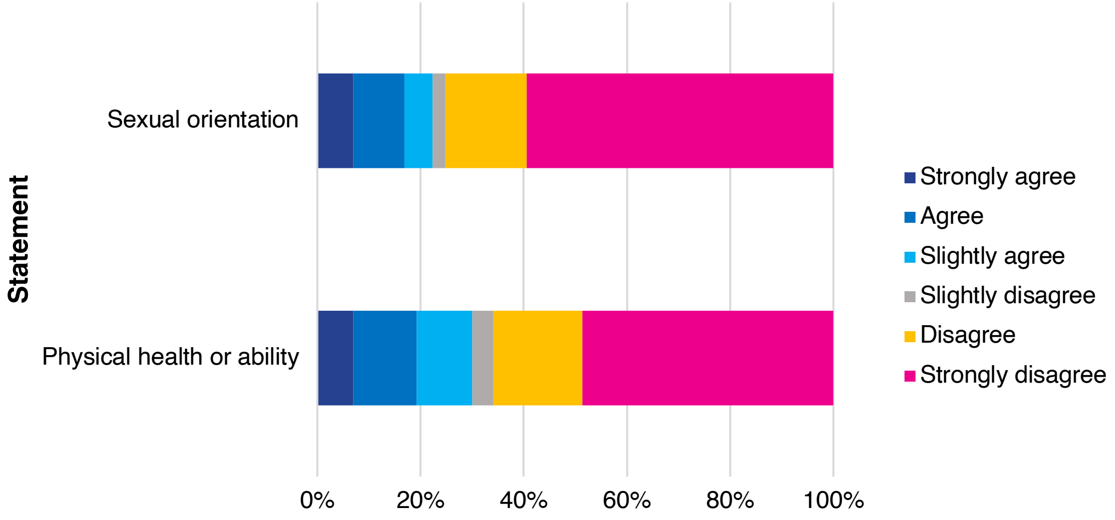
[2] Relates to interactions.

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN SOCIAL MEDIA

> ***I experience stigma and discrimination due to being a sex worker. I often refrain from commenting on articles that stigmatise sex work due to knowing the comments/replies I receive will deeply hurt my mental health.***
>
> **Our Turn to Speak participant**
> **Western Australia**

The findings from survey statements in relation to other experiences of stigma and discrimination in social media, besides that about complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 7.6**. As shown, 30.0% of participants agreed that they had experienced stigma and discrimination in social media because of their physical health or ability, while 22.3% agreed that they had experienced stigma and discrimination in social media because of their sexual orientation.



Percentage Agreement and Disagreement

Figure 7.6. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *social media* (*n* = 483).

The specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting social media are summarised in **Table 7.8.** Overall, a relatively low rate of agreement was found for statements describing experiences of stigma and discrimination in social media due to personal characteristics other than complex mental health issues.

Table 7.8. Experiences of intersectional stigma and discrimination in *social media*: percentage agreement and disagreement (*n* = 483).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in social media because of my…							
Racial or cultural background	71.6%	17.2%	1.7%	3.7%	3.5%	2.3%	**9.5%**
Faith or spiritual beliefs	65.0%	15.7%	2.3%	8.3%	6.4%	2.3%	**17.0%**
Sexual orientation	59.4%	15.7%	2.5%	5.4%	9.9%	7.0%	**22.3%**
Gender identity	66.7%	15.1%	2.3%	5.2%	5.6%	5.2%	**16.0%**
Physical health or ability	48.7%	17.2%	4.1%	10.8%	12.2%	7.0%	**30.0%**

POSITIVE EXPERIENCES IN SOCIAL MEDIA

> ***The mental health community on Twitter helps me feel connected to the world and like I have purpose.***
>
> **Our Turn to Speak participant**
> **South Australia**

The **Our Turn to Speak** survey also asked participants to rate their level of agreement with three statements about positive treatment and experiences in the social media domain.

As shown in **Figure 7.7**, only 17.5% of participants agreed that, in the last 12 months, they had seen, read or heard social media content that portrayed people who live with mental health issues in a positive way. By contrast, 74.9% of participants perceived to have had positive experiences in connection with their mental health issues when interacting with others on social media. Just over 80% agreed that their participation in social media should be supported with special consideration by others.

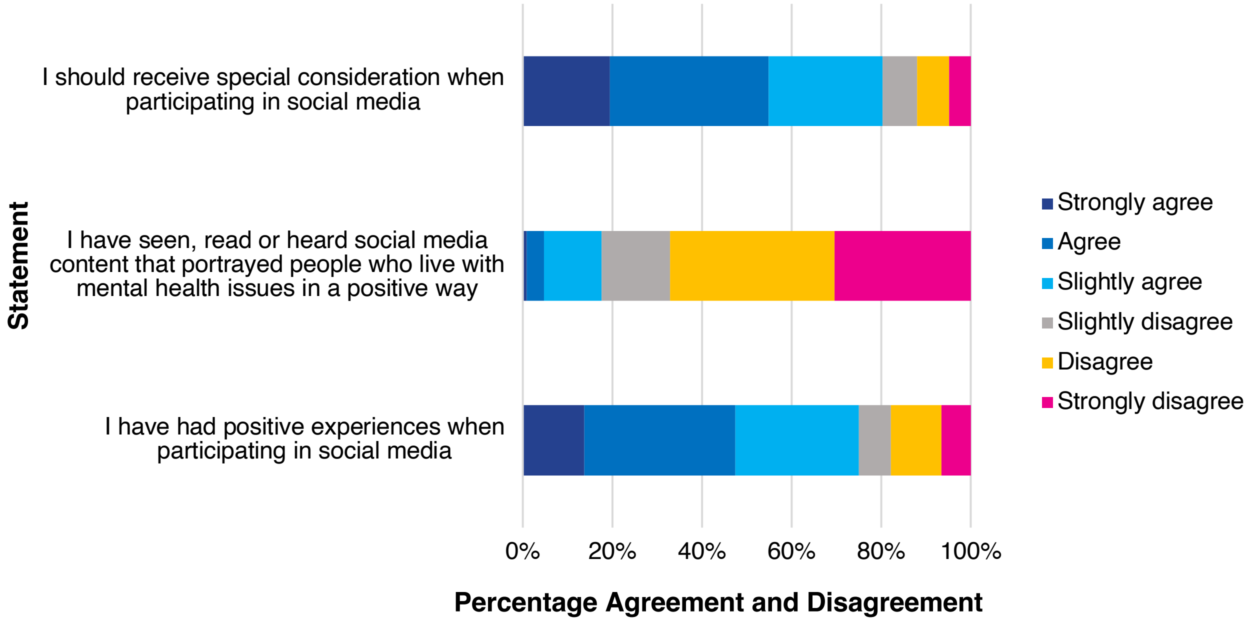


Figure 7.7. Highlight findings: responses to the statements regarding positive experiences in *social media* because of participants' complex mental health issues (*n* = 483).

SUMMARY OF QUALITATIVE FINDINGS IN SOCIAL MEDIA

The most frequently discussed areas in this domain concerned withdrawal and avoidance of social media, careful selection or filtering of information, and other measures to protect privacy. This included things like avoiding discussions about mental health on social media; limiting time spent on social media or avoiding it altogether during an episode, crisis, or when feeling vulnerable; following groups that are closed and/or carefully moderated; filtering out particular groups; not reading comments; keeping accounts private; creating an account under a different name; deleting accounts; only using particular platforms; deleting or blocking connections; limiting connections; taking breaks; browsing and not posting comments; and posting anonymously. Some examples of comments here included:

> *…Sometimes when you know you're going to be more vulnerable to people's comments or misinterpret them because one of your alters is active, it is better to stay away from it until you feel strong enough to cope with it. Sometimes I won't go on social media for days because I don't trust my responses and I know I'm going to be hurt by comments and posts* (**Our Turn to Speak** participant, Queensland).
>
> *Again, I am very careful about which groups, discussions, forums and content I allow on my social media accounts, and I choose carefully when and how I respond.*

> *However, I have seen and defended others who were less careful/more vulnerable, and had to withdraw from groups, pages, forums, discussions and block people who are discriminatory and offensive in their attitudes, language and discourse around the many different forms of mental health illnesses. I haven't been bullied, or kicked out of groups because of any mental health illness disclosures or discussions I have had personally, but I am aware of others who have experienced these problems regularly* (**Our Turn to Speak** participant, New South Wales).
>
> *I follow a lot of closed facebook groups for the reason that others will not discriminate. I've seen a lot of hate on open facebook pages about certain illnesses, and I do not comment on most things. Online arguments stress me out* (**Our Turn to Speak** participant, Australian Capital Territory).

Several participants explained that they do not disclose their mental health issues and experiences.

Another theme in this domain concerned negative representations and a lack of understanding and compassion for people with mental health issues, with several participants commenting specifically in relation to Borderline Personality Disorder and, to a lesser extent, eating disorders. For example:

> *People with BPD are badly discriminated against on YouTube. There are countless videos saying we are abusive, manipulative, attention-seeking, hard to treat, etc. I saw a comment that said all people with BPD should be in gaol* (**Our Turn to Speak** participant, New South Wales).
>
> *The most common kind of stigma online I have experienced is comments from people telling me that all people with borderline personality disorder are abusive terrible people. Sometimes they will also say people with BPD can never get better, that they are a lost cause* (**Our Turn to Speak** participant, Queensland).
>
> *I find extreme views difficult and diet culture really toxic. People can be very angry due to internal fat phobia and as a recovering anorexic, I have to be careful and just bow of many conversations* (**Our Turn to Speak** participant, Victoria).

Several participants conveyed negative impacts of bullying and trolling on social media, the feeling of it not being safe, and the lack of effective moderation or regulation. For example:

> *Trolling is common in mental health related facebook groups, particularly those about NDIS matters such as confusion about what is reasonable and necessary for people with 'psychosocial' disability* (**Our Turn to Speak** participant, New South Wales).
>
> *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).

A couple commented on feelings of being judged and bullied by other members of support groups, too. As one participant shared:

> *It is always a risk to share when you expect to be rejected or judged. Sometimes it is just too high a risk. I have been on a forum for survivors of abuse and then been told*

> *I could not make any reference to Dissociative behaviour without providing the paperwork for a professional diagnosis. Any posts I'd made with reference to dissociation were removed from the forum. They weren't graphic posts; just comments about what it was like to live with Dissociation. Because it had taken so much courage to reach out in the first place, I went back and deleted the four posts remaining because I wanted it to be like I was never there. I didn't feel safe…* (**Our Turn to Speak** participant, Queensland).

The issue of feeling judged when not appearing to be happy and positive was also raised by a few participants. This was conveyed responses such as:

> *I guess I find myself increasingly reluctant to use social media, especially if I'm going through a rough time. There's such intense pressure to be happy and successful, and if you're unemployed and kinda sad/anxious there's just no comfortable way to have a voice there? Without feeling like you're whining, I mean. Like if my life doesn't look glamorous, I don't post, which means withdrawing from a lot of opportunities to connect digitally* (**Our Turn to Speak** participant, Victoria).

> *I like the term "toxic positivity"... social media is full of it. The idea that you can just "choose" to suddenly be happy is so misguided and dangerous for people with serious mental health disorders. It makes you feel like a failure every day* (**Our Turn to Speak** participant, Victoria).

When discussing positive experiences in relation to social media, participants most often mentioned connections with peers, support groups, and mental health organisations. In particular, this entailed feeling supported and less isolated or alone, gaining access to information, seeing positive representations, raising awareness, opportunities to help others, a sense of hope and purpose, being able to speak more freely, and positive responses to disclosing mental health issues. A selection of comments here were as follows:

> *I have had many positive responses to my posts about living with bipolar* (**Our Turn to Speak** participant, New South Wales).

> *My support group has a Hidden social media page which helps me a lot. When unwell we can say or do things we normally wouldn't. If we do that on social media it can be socially devastating* (**Our Turn to Speak** participant, Victoria).

> *There are some beautiful community-building things happening on social media to support mental health. Mother's groups, bipolar support groups, carers groups.So great to have these connections if you're not well enough to leave the house* (**Our Turn to Speak** participant, Victoria).

> *Seeing posts on social media about mental illness and ways to offer practical help for anxiety has been encouraging and has helped the sense of isolation* (**Our Turn to Speak** participant, Queensland).

Other positive experiences that participants discussed involved using social media for advocacy work, to change attitudes, and reduce stigma.

As in other domains, in response to this question some participants also described negative or mixed experiences, such as the following:

> *There are a lot of supportive posts and memes on social media and I'm grateful for that. But there's also a lot of what I call positive shaming... by telling people with mental ill-health they just need to be positive etc it actually shames and further stigmatizes* (**Our Turn to Speak** participant).
>
> *Social media is a good place to talk to others in groups I've found when your very isolated. Unfortunately the only positively portrayed mental health issues I see on social media are just mild anxiety and depression and "r u ok" day which nobody knows how to even respond when you actually say no I'm actually not ok. There's never campaigns or videos showing more severe/ complex mental health in a positive light or at least they are very outweighed by the negatives unfortunately if they are out there* (**Our Turn to Speak** participant, Queensland).
>
> *In social media I find mental health advocates portray mental health in a postive way. But the memes and posts by people in general can be negative. I like a good laugh at myself, however, sometimes the content is hurtful and spreads misinformation about the "cra-cra's"* (**Our Turn to Speak** participant, New South Wales).

With regards to other factors that may have compounded experiences of mental health stigma in relation to social media, participants' responses included age, disability, faith and spiritual beliefs, gender, political beliefs, race, being a sex worker, sexual orientation, and weight. One participant shared that:

> *I experience stigma and discrimination due to being a sex worker. I often refrain from commenting on articles that stigmatise sex work due to knowing the comments/replies I receive will deeply hurt my mental health* (**Our Turn to Speak** participant, Western Australia).

Another reflected: *"Again homophobia is the most dominant form of stigma for me, and some misogyny. I have also experienced racism because my skin colour is "ambiguous""* (**Our Turn to Speak** participant, Victoria).

SUMMARY

Of 1,912 participants who took part in the **Our Turn to Speak** survey, 25.3% identified social media as one of up to three life domains that had been most affected by stigma and discrimination in connection with complex mental health issues. Close to 60% of participants who social media as one of their most affected life domains during the last 12 months indicated 'frequent' or 'very frequent' experiences of stigma and discrimination in this aspect of their lives.

When presented with a range of statements describing general and specific examples of stigma and discrimination in social media, it became clear that exposure to hurtful or offensive content about mental health issues was driving perceptions of stigma and discrimination in this domain, as opposed to personal interactions with others on social media platforms. For example, approximately 90% of participants, or more, agreed that they had been exposed to social media content that depicted people living with mental health issues as dangerous, unsafe or unpredictable; or as being to blame for their issues. By contrast, 42.1% had perceived that they were bullied on social media and 17.0% agreed that they had been unfairly denied access to social media (for example, blocked or deleted from forums and groups).

Overall, it was highly concerning that almost all 483 participants who responded to this domain (94.2%) had seen, read or heard social media content that they found offensive or hurtful because of the way mental health issues were portrayed. These findings appear to reinforce other research that indicated endorsement of stereotypes about mental health issues are on the increase among the Australian general public (Reavley & Jorm, 2012). Given the global reach of social media, it is likely that participants were also being exposed to stigmatising content from across the world (Robinson et al., 2019) despite the efforts of anti-stigma campaigns that use traditional and online media platforms (Betton et al., 2015; Livingston et al., 2014; Sampogna et al., 2017).

Rates of agreement with statements describing various kinds of anticipated exposure to stigma and discrimination in social media were roughly equivalent to the rates of agreement in relation to perceived experiences. Again, exposure to hurtful or offensive content about mental health issues were rated as much more problematic than expectations for personal interactions with others. Just under 90% of participants agreed that they expected to see, read or hear social media content that depicted people living with mental health issues as dangerous, unsafe or unpredictable; or as being to blame for their issues. By contrast, 56.8% expected to be bullied on social media and 27% agreed that they expected to be unfairly denied access to social media forums and groups. The high rates of anticipated stigma and disclination on social media are understandable given the nature of experiences participants described in their qualitative commentary. It was particularly disappointing to read about participants with Borderline Personality Disorder being presumed to be “abusive, manipulating, attention-seeking” and “hard to treat”; and of participants who were “attacked by trolls” after disclosing their suicidality.

Just over 63% of participants agreed that they had stopped themselves from joining social media groups or forums altogether. While the average rate of agreement with statements describing withdrawal from opportunities in social media was somewhat lower than the average rates of agreement for experienced and anticipated stigma and discrimination, participants’ qualitative comments highlighted a wide range of self-protective strategies for maintaining their social media participation. For example, participants described strategies such as limiting time spent on social media, avoidance of reading others’ or posting their own comments, and filtering out or blocking specific social media groups and users. The numerous self-protective strategies participants mentioned are a form of withdrawing from opportunities for online peer-support, maintaining connection with friends and family, and using social media platforms to share one’s experiences, opinions, and creativity with a wide-reaching audience. The stigma and discrimination experienced by participants on social media has arguably had a silencing effect on the voices of those with complex mental health issues. This is likely to disproportionately affect people living with complex mental health issues, given research that has found a greater prevalence of stigmatising and trivialising Twitter posts in relation to mental health issues, like schizophrenia and obsessive compulsive disorder, compared with physical health issues (Joseph et al., 2015; Robinson et al., 2019).

For 30.0% of **Our Turn to Speak** participants who selected the social media domain, their experience of stigma relating to mental health issues had been compounded by stigma about their physical health or ability. One in five participants agreed that they had experienced stigma and discrimination in social media in relation to their sexual orientation.

Finally, positive experiences on social media in connection with one’s experience of mental health issues was related by 74.9% of participants. Contrasting with other life domains examined in the **Our Turn to Speak** survey, this endorsement of positive experiences is very high. Indeed, participants' qualitative comments reflected on the ways in which social media could be used for mental health advocacy work, as a tool for combatting stigma, and for giving and receiving peer-support. Other research has similarly indicated that social media peer-support groups for people experiencing low-prevalence and poorly understood mental health issues can be beneficial (Naslund et al., 2020). Despite these positive experiences, only 17.5% of participants agreed that they had seen, read or heard social media content that portrayed people who live with mental health issues in a positive way.

As with mass media, like news and entertainment media, the findings of the **Our Turn to Speak** survey suggest there is still much work to be done to educate the public, and to reduce the spread of misinformation and damaging stereotypes of complex mental health issues that are circulating online.

MENTAL HEALTHCARE SERVICES

08

Chapter 8. Mental healthcare services

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

Sadly, more than half of Australians with a mental illness do not get the help they need from our mental health system (National Mental Health Commission, 2014). Of those who do, many receive help far too late, or their experience of care leaves much to be desired. The system fails consistently in the provision of prevention and early intervention services, and in providing appropriate services sensitive to the needs of carers, families and friends who are supporting a loved one with a mental illness.

This chapter examines how people living with a range of complex mental health issues experience stigma and discrimination in accessing mental health services across Australia.

OVERVIEW

Close to 72% (*n* = 1,372) of all **Our Turn to Speak** participants reported experiencing some level of stigma and discrimination in mental healthcare services during the past 12 months.

As shown in **Figure 8.1**, 22.1% of all participants reported ‘frequent’ or ‘very frequent’ stigma and discrimination in mental healthcare services, and 23.6% (*n* = 452) identified this life domain as one of three in which they had been most affected by such experiences. **Figure 8.1** also shows that 58.6% of participants who selected the mental healthcare services domain reported ‘frequent’ or ‘very frequent’ rates of stigma and discrimination in this aspect of their lives; much higher than was reported by the overall sample.

This chapter focuses on the characteristics and experiences of those 452 participants who selected mental healthcare services as one of their top three, most affected life domains.

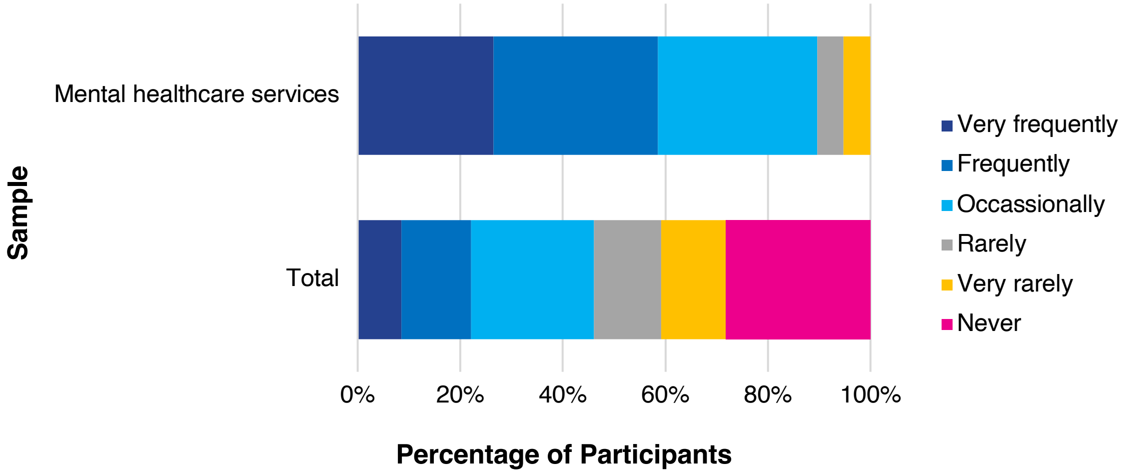


Figure 8.1. Frequency of stigma and discrimination in *mental healthcare services* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 452) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

The sociodemographic characteristics of participants who identified as being significantly affected by stigma and discrimination when accessing mental healthcare services were, for the most part, closely comparable to the characteristic of the total sample. These data are summarised in **Table 8.1**. One exception to this trend was observed regarding sexual orientation, with fewer respondents in this group who identified as heterosexual compared with the total sample.

Table 8.1. Sociodemographic characteristics: *mental healthcare services* sample compared with the total sample.

Characteristics		Mental Healthcare Services (*n* = 452)	Total (*N* = 1912)
Mean age		37.64 (*SD* = 12.77)	39.21 (*SD* = 12.81)
Gender identity			
	Female	83.0%	78.9%
	Male	13.1%	18.0%
	Trans, gender diverse and/or non-binary	5.8%	4.9%
	Unsure or questioning	0.7%	0.9%
	Prefer not to say	0.2%	0.4%
Relationship status			
	Not in a relationship	57.7%	52.1%
	In a relationship	42.0%	47.3%
	Prefer to self-describe	0.2%	0.2%
Sexual orientation			
	Heterosexual	51.8%	62.0%
	Gay, lesbian, bisexual, pansexual, queer, and/or asexual	43.6%	35.6%
	Unsure or questioning	5.8%	4.9%
	Prefer to self-describe	1.8%	1.5%
	Prefer not to say	2.0%	1.7%
Education (highest level attained)			
	Primary school	1.5%	1.6%
	Secondary college (high school)	23.7%	20.9%
	Educated post-secondary college	74.3%	77.4%
	Other	0.4%	0.2%
Employment			
	Engaged in paid work	45.6%	51.7%
	Engaged in unpaid work or studying	27.4%	28.7%
	Unemployed or unable to work	21.9%	22.8%
	Receiving a pension or benefits	28.8%	24.6%
	Other	0.4%	0.2%
State			
	Australian Capital Territory	3.8%	2.5%
	New South Wales	22.8%	23.6%
	Northern Territory	1.1%	0.6%
	Queensland	14.6%	15.9%
	South Australia	10.8%	9.5%
	Tasmania	3.8%	3.7%
	Victoria	32.1%	33.1%
	Western Australia	11.1%	10.9%
Region*			
	Major city	75.1%	74.2%
	Regional or remote	24.9%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

As with the socidemographic data, the mental and physical health characteristics of the group of participants who identified the mental healthcare services domain as having been most affected by stigma and discrimination were again similar to those of the total sample. These data are presented in **Table 8.2**.

The singular exception to this trend was observed for participants who reported living with personality disorder; 24.6% of participants who responded to this section of the survey were living with a primary personality disorder, compared with 14.5% of the total sample.

Table 8.2. Mental and physical health characteristics: *mental healthcare services* sample compared with the total sample.

Characteristics	Mental Healthcare Services (*n* = 452)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	6.6%	7.4%
Bipolar related disorder	14.2%	17.2%
Obsessive-compulsive related disorder	3.1%	4.3%
Trauma-related or dissociative disorder	23.0%	25.9%
Eating disorder	6.9%	6.1%
Personality disorder	24.6%	14.5%
Severe and treatment-resistant depressive disorder	12.6%	14.3%
Severe and treatment-resistant anxiety disorder	9.1%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	56.0%	53.8%

Figure 8.2 presents a further breakdown of the mental health characteristics of participants who responded to the mental healthcare services section of the survey. This figure compares the proportion of people living with each type of complex mental health issue who reported ‘frequent’ or ‘very frequent’ stigma and discrimination in mental health care services during the past 12 months, and those who selected this life domain as having been most affected by such experiences.

It can be seen that participants living with personality disorders reported the most frequent and most impactful stigma and discrimination in mental healthcare services.

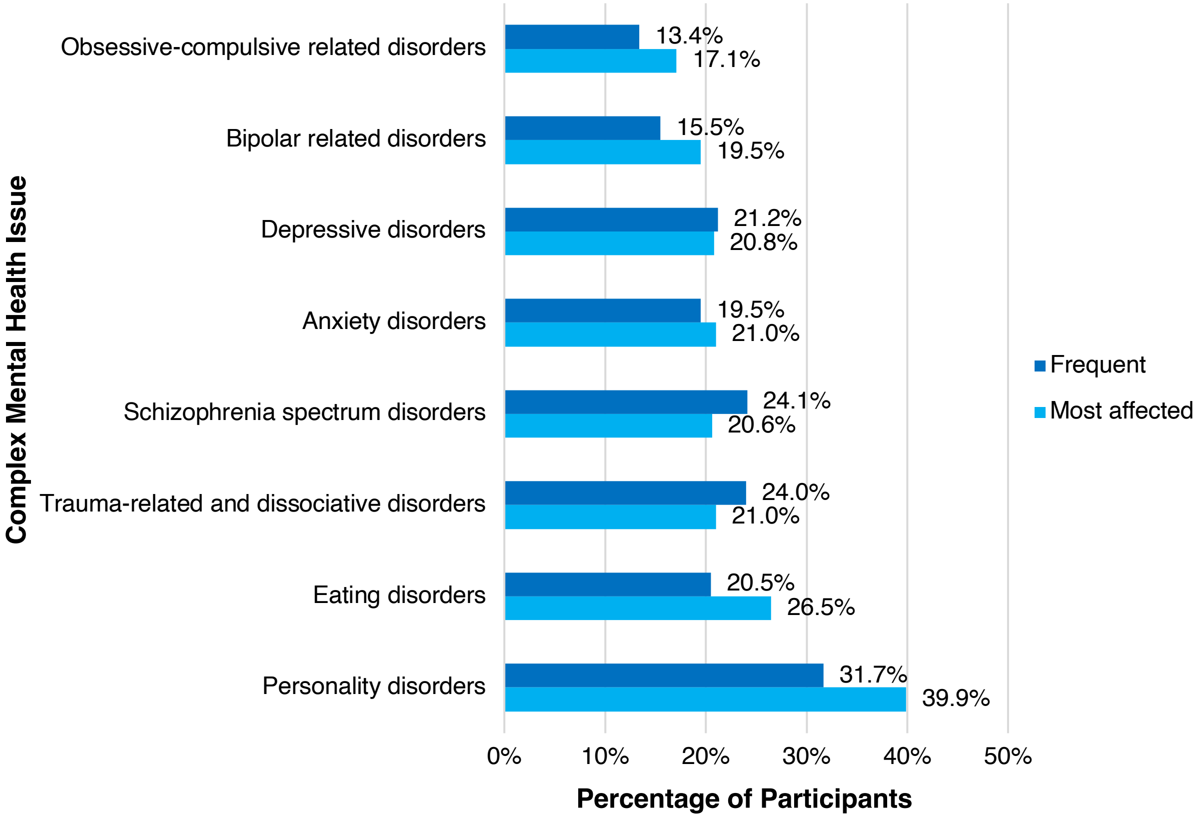


Figure 8.2. Mental health characteristics among participants who selected *mental healthcare services* as one of three domains in which they had been most affected by stigma during the past 12 months (*n* = 452): frequency compared with impact of stigma and discrimination.
Note. Frequency refers to the aggregate of responses: 'very frequent' and 'frequent'.

METHODS SNAPSHOT

Participants who identified relationships as one of three life domains in which they have been most affected by stigma-related experiences completed the mental healthcare services section of the survey. At the beginning of this section of the survey, participants were asked to indicate what types of services they had participated in during the previous 12 months. Mental healthcare services were described as providing a range of services, across the public and private sectors, including but not limited to:

- community-based and outreach services
- residential or rehabilitation services
- hospital-based services.

Just over 87% (*n* = 394) had accessed community-based and/or outreach services, while 62.4% (*n* = 282) had accessed residential, rehabilitation and/or hospital-based services. Participants were then presented with only the questions that matched their reported mental healthcare experiences. For example, participants who reported only accessing residential, rehabilitation and/or hospital-based services during the past 12 months received questions corresponding to those services.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in mental healthcare services; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of mental healthcare. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further describe their experiences of stigma and discrimination because of: (a) complex mental health issues, (b) in relation to other personal characteristics, and (c) their experiences of positive treatment in mental healthcare services domain. Additional comments in relation to these experiences were given by 103, 42 and 82 participants, respectively.

STIGMA AND DISCRIMINATION IN MENTAL HEALTHCARE SERVICES

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in mental healthcare services, which will be further examined in sections that follow.

As shown in **Figure 8.3**, an average 49.5% of participants who responded to the mental healthcare services section of the survey survey agreed with all statements describing perceived experiences of stigma and discrimination in this domain during the past 12 months. A slightly greater proportion of this group (*M* = 53.1%) endorsed statements indexing the anticipation of future stigma and discrimination when accessing mental healthcare services. The frequency of agreement was greater still for statements that described withdrawal from mental healthcare opportunities, with an average 61.9% of responding participants agreeing with such statements.

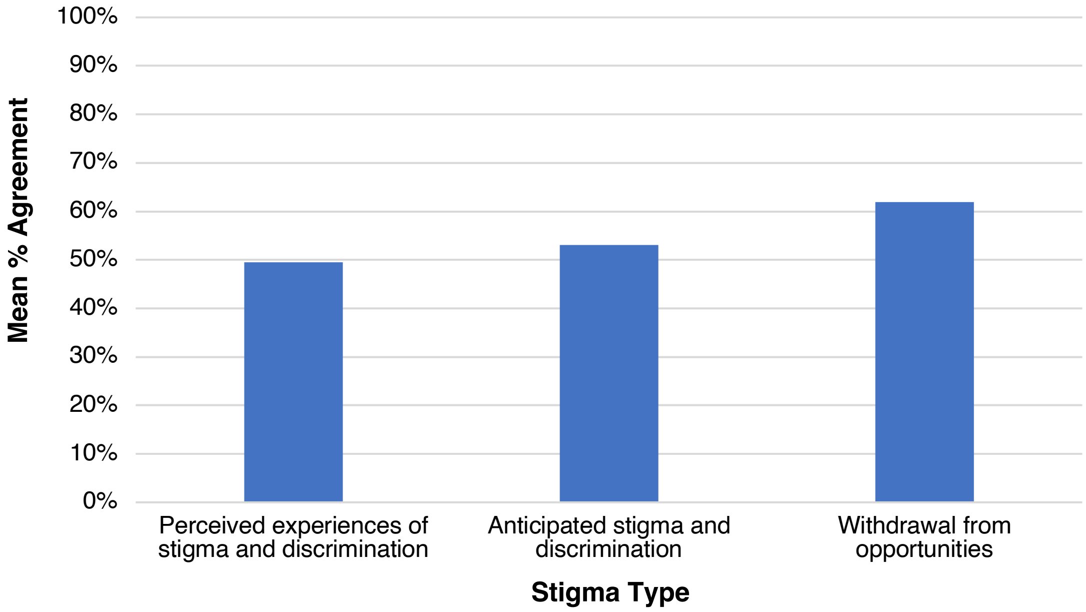


Figure 8.3. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in mental healthcare services (n = 452).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN MENTAL HEALTHCARE SERVICES

> *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**
> **Victoria**

Presented in this section are the findings regarding participants’ perceived experiences of stigma and discrimination in mental healthcare services, as related to their experience of complex mental health issues.

Figure 8.4 highlights the two most frequently endorsed issues from the whole set of statements describing perceived experiences of stigma and discrimination. As shown, 81.6% of participants agreed that they had been treated unfairly by specific mental health care professions because of stigma during the past 12 months, while 76.6% agreed with the general experience of having been trated unfairly when trying to seek help for their mental health issues.

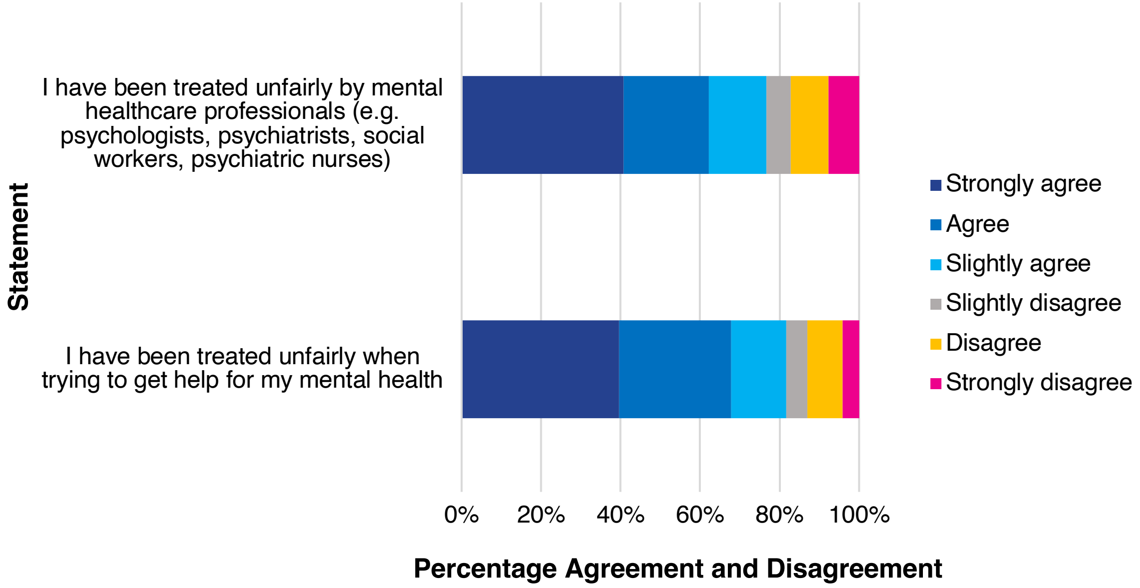


Figure 8.4. Highlight findings: the two most frequently endorsed statements describing perceived experiences of stigma and discrimination in *mental healthcare services* (*n* = 452).

Table 8.3 provides the details of participants' agreement with statements describing perceived experiences of stigma and discrimination in accessing community-based, outreach or other similar mental healthcare services. In addition to the findings regarding general unfair treatment and unfair treatment by mental healthcare professionals highlighted above, it can be seen that 69.2% of responding participants perceived that they had been unfairly denied help for their mental health. Unfair early discharge or referral out was of next greatest concern, with 60.6% of participants agreeing to this experience. The statements next most frequently agreed with described exclusion from input into treatment planning, unfair treatment from frontline administration staff, and being pressured to receive perceivably unnecessary treatment.

Table 8.3. Perceived experiences of stigma and discrimination in *mental healthcare services*: percentage agreement and disagreement (*n* = 452).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when trying to get help for my mental health	4.2%	8.8%	5.3%	13.9%	28.1%	39.6%	**81.6%**
I have been unfairly denied help for my mental health	6.2%	16.8%	7.7%	13.9%	20.6%	34.7%	**69.2%**
I have been unfairly referred or discharged out of mental healthcare services before I was ready	12.6%	19.0%	7.7%	8.0%	17.9%	34.7%	**60.6%**
I have been treated unfairly by mental healthcare professionals (e.g. psychologists, psychiatrists, social workers, psychiatric nurses)	7.7%	9.5%	6.2%	14.4%	21.5%	40.7%	**76.6%**
I have been treated unfairly by frontline and administrative staff at mental healthcare services (e.g. receptionists, intake workers, residential support workers)	13.9%	23.9%	11.3%	12.4%	15.5%	23.0%	**50.9%**
I have been pressured to receive mental healthcare treatment I did not think was necessary	21.2%	27.4%	7.3%	12.8%	10.6%	20.6%	**44.0%**
I have been unfairly excluded from having a say in decisions made about my mental healthcare and treatment planning	15.7%	21.2%	9.1%	14.2%	15.3%	24.6%	**54.1%**

Note. All participants received these items, regardless of whether they had accessed community based and/or hospital-based services.

Table 8.4 provides the details of participants' agreement with statements describing perceived experiences of stigma and discrimination in accessing residential, rehabilitation or hospital-based mental health services.

Overall, the statements presented received lower rates of agreement from responding participants. Unfair hospitalisation was reported by 21.4% of participants. Fewer participants (20.2%) perceived that they had been unnecessarily physically restrained or sedated in this setting in the past 12 months. Just under 15% (*n* = 38) of participants agreed that they had been unnecessarily secluded or isolated while in hospital-based care.

Table 8.4. Perceived experiences of stigma and discrimination in *residential, rehabilitation and/or hospital-based mental healthcare services*: percentage agreement and disagreement (n = 282).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been unfairly hospitalised by mental healthcare professionals	34.0%	34.4%	7.4%	4.6%	6.7%	12.8%	**24.1%**
I have been unnecessarily physically restrained or sedated by mental healthcare professionals	45.4%	30.9%	3.5%	4.3%	4.6%	11.3%	**20.2%**
I have been unnecessarily held in solitary confinement (i.e. secluded) by mental healthcare professionals	55.0%	30.1%	1.4%	1.8%	2.1%	9.6%	**13.5%**

ANTICIPATED STIGMA AND DISCRIMINATION IN MENTAL HEALTHCARE SERVICES

> ***…I am now so afraid of psychiatric care that I have panic attacks when I pass a hospital. I believe I have to lie to doctors and mental health professionals to avoid being harmed…***
>
> **Our Turn to Speak participant**
> **New South Wales**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in mental healthcare services, as related to their experience of complex mental health issues.

Figure 8.5 shows that the two core areas of concern among participants were expectations of unfair treatment when trying to get help for their mental health issues in general, and unfair treatment by specific mental healthcare professionals.

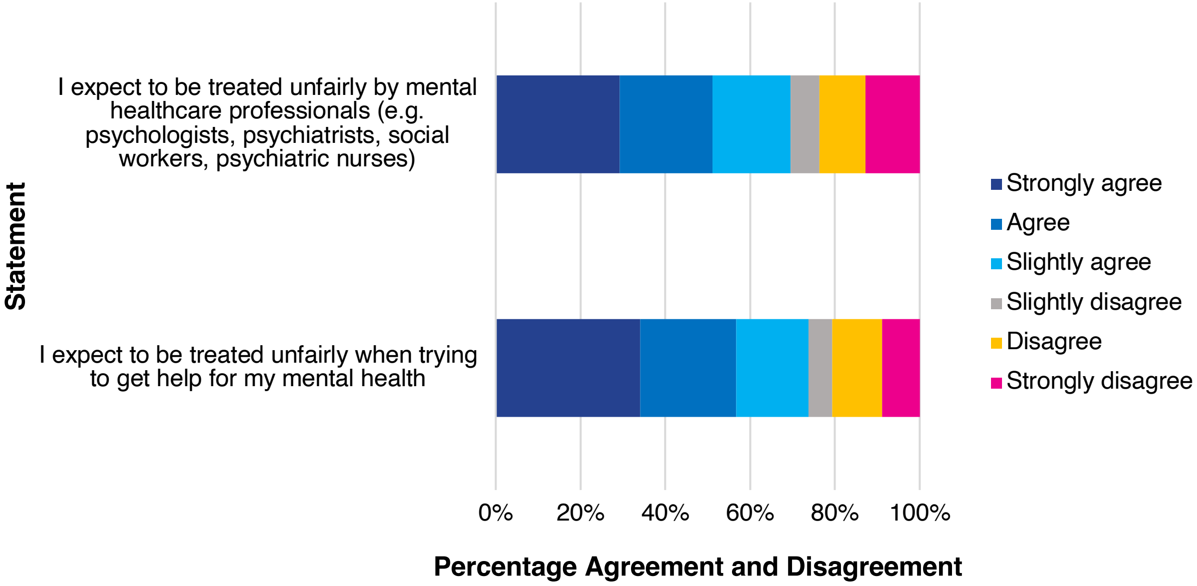


Figure 8.5. Highlight findings: the two most frequently endorsed statements describing anticipated stigma and discrimination in *mental healthcare services* (*n* = 452).

The data presented in **Table 8.5** examines the findings regarding participants' anticipation of stigma and discrimination in accessing community-based, outreach or other similar mental healthcare services in further detail.

In addition to the data highlighted above, **Table 8.5** shows that anticipation of unfair denial of help for mental health and of premature discharge from mental healthcare were also common experiences, with just under 70% of participants agreeing with these statements. Expectations that one would be unfairly excluded from providing input into treatment planning, treated unfairly by frontline and administrative staff, or pressured to receive perceivably unnecessary treatment, were also common concerns, with more than 50% of participants indicating that they held these concerns.

Table 8.5. Anticipated stigma and discrimination in *mental healthcare services*: percentage agreement and disagreement (*n* = 452).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when trying to get help for my mental health	8.8%	11.9%	5.5%	17.0%	22.6%	34.1%	**73.7%**
I expect to be unfairly denied help for my mental health	10.2%	14.6%	7.3%	17.5%	20.1%	30.3%	**67.9%**
I expect to be unfairly referred or discharged out of mental healthcare services before I am ready	13.3%	13.5%	7.1%	13.1%	19.7%	33.4%	**66.2%**
I expect to be treated unfairly by mental healthcare professionals (e.g. psychologists, psychiatrists, social workers, psychiatric nurses)	12.8%	10.8%	6.9%	18.4%	21.9%	29.2%	**69.5%**
I expect to be treated unfairly by frontline and administrative staff at mental healthcare services (e.g. receptionists, intake workers, residential support workers)	16.6%	18.1%	9.5%	17.7%	15.5%	22.6%	**55.8%**
I expect to be pressured to receive mental healthcare treatment I do not think was necessary	20.6%	18.4%	7.7%	18.8%	15.3%	19.2%	**53.3%**
I expect to be unfairly excluded from having a say in decisions made about my mental healthcare and treatment planning	17.9%	14.8%	8.2%	19.7%	16.2%	23.2%	**59.1%**

Note. All participants received these items, regardless of whether they had accessed community based and/or. hospital-based services.

Table 8.6 provides the details of participants' agreement with statements describing anticipation of stigma and discrimination in accessing residential, rehabilitation and/or hospital-based mental health services.

Overall, the statements presented again received relatively lower rates of agreement from responding participants. Anticipation of unfair hospitalisation was reported by 33.3% of participants. Slightly fewer participants (29.4%) agreed that they expected to be restrained or sedated when accessing mental healthcare. Relatively fewer participants also agreed that they had experienced unnecessary seclusion or isolation while in hospital-based care, with 22.8% of responding participants indicated this expectation.

Table 8.6. Anticipated stigma and discrimination in *residential, rehabilitation and/or hospital-based mental healthcare services*: percentage agreement and disagreement (n = 282).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be unfairly hospitalised by mental healthcare professionals	27.7%	30.1%	8.9%	10.3%	7.8%	15.2%	**33.3%**
I expect to be unnecessarily physically restrained or sedated by mental healthcare professionals	35.5%	28.7%	6.4%	8.9%	6.7%	13.8%	**29.4%**
I expect to be unnecessarily held in solitary confinement (i.e. secluded) by mental healthcare professionals	42.2%	28.4%	7.1%	5.3%	5.0%	12.1%	**22.4%**

WITHDRAWAL FROM OPPORTUNITY IN MENTAL HEALTHCARE SERVICES

> ***I have stopped reaching out to crisis and suicide prevention services because I don't want to be treated like a criminal or be undermined.***
>
> **Our Turn to Speak participant**
> **Queensland**

The findings regarding withdrawal from support and treatment opportunities in mental healthcare services because of stigma and discrimination are presented.

Figure 8.6 shows the two most frequently endorsed statements in this section of the survey. High levels of participant agreement were observed for statements describing withdrawal from help seeking both generally and in emergency settings.

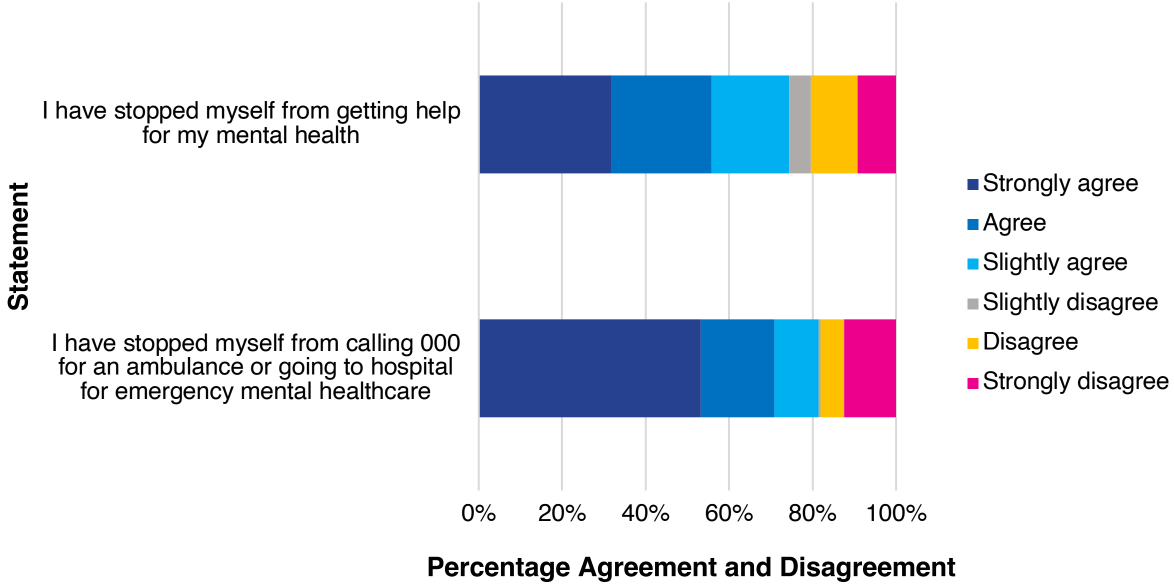


Figure 8.6. Highlight findings: the two most frequently endorsed statements describing withdrawal from opportunities in *mental healthcare services* (*n* = 452; *n* = 282).

The details of participants' level of agreement or disagreement with statements describing instances of withdrawal from accessing mental healthcare services in the past 12 months because of stigma and discrimination about mental health issues are presented in **Tables 8.7** and **8.8**.

In addition to the findings highlighted in **Figure 8.6**, it can be seen that more than 70% of this participant group agreed that they had withdrawn from obtaining help from mental health professionals or from revealing the severity of their problems to mental health professionals. More than half of participants reported withdrawing from treatment prematurely and for fear of receiving treatment that they did not think was necessary.

Comparatively, fewer participants agreed that they had abstained from filling prescriptions, and fewer still agreed that they had withdrawn from applying from Medicare rebates because of stigma and discrimination about their complex mental health issues. However, it remains remarkable that these comparatively uncommon issues were reportedly still experienced by approximately one-third or more of participants in the previous 12-month period.

Table 8.7. Withdrawal from opportunities in *mental healthcare services*: percentage agreement and disagreement (*n* = 452).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from getting help for my mental health	9.3%	11.1%	5.3%	18.6%	23.9%	31.9%	**74.4%**
I have stopped myself from getting help from mental healthcare professionals (e.g. psychologists, psychiatrists, social workers, psychiatric nurses)	10.4%	12.6%	5.5%	18.4%	25.9%	27.2%	**71.5%**
I have withdrawn myself from mental healthcare services before I was ready	14.2%	16.8%	6.9%	15.0%	22.3%	24.8%	**62.1%**
I have stopped myself from getting mental healthcare for fear of receiving treatment I do not think is necessary	17.5%	21.9%	5.5%	13.1%	18.1%	23.9%	**55.1%**
I have stopped myself from filling scripts or taking medications for my mental health	28.5%	21.9%	4.9%	11.7%	16.4%	16.6%	**44.7%**
I have stopped myself from applying for Medicare rebates for mental healthcare services (i.e. going on a Mental Health Treatment Plan)	31.9%	28.1%	7.5%	7.3%	9.3%	15.9%	**32.5%**
I have stopped myself from revealing the severity of my mental health issues when getting help from mental healthcare professionals	10.8%	10.2%	5.5%	15.5%	20.6%	37.4%	**73.5%**

Note. All participants received these items, regardless of whether they had accessed community based and/or hospital-based services.

Table 8.8 shows the breakdown of agreement and disagreement for the statement describing withdrawal from accessing emergency mental healthcare.

The pattern of responses show that not only did this statement receive broad general agreement, but that over half of responding participants ‘strongly agreed’ that they had withdrawn from accessing emergency mental healthcare in the past 12 months because of stigma.

Table 8.8. Withdrawal from opportunities in *residential, rehabilitation and/or hospital-based mental healthcare services*: percentage agreement and disagreement (*n* = 282).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from calling 000 for an ambulance or going to hospital for emergency mental healthcare	12.4%	5.7%	0.4%	10.6%	17.7%	53.2%	**81.5%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN MENTAL HEALTHCARE SERVICES

> *Doctor called me very overweight and fat and so did my psychiatrist.*
>
> **Our Turn to Speak articipant**
> **Victoria**

The findings from survey statements in relation to other experiences of stigma and discrimination in mental healthcare services, besides that about complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 8.7**. As shown, 38.7% of participants indicated that physical health or ability was the primary additional area of stigma and discrimination they experienced in mental healthcare services, other than stigma because of their complex mental health issues.

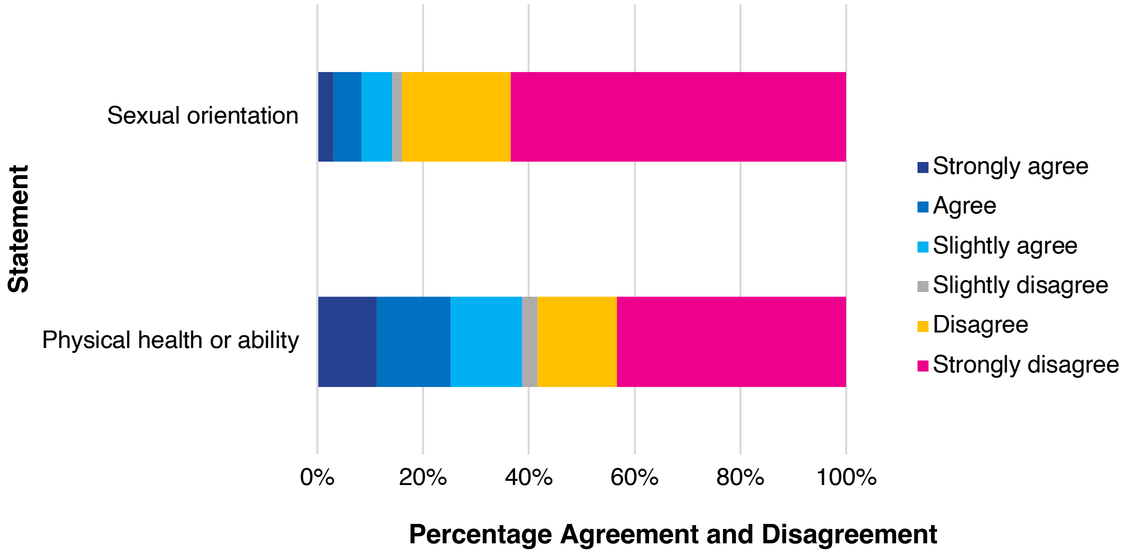


Figure 8.7. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *mental healthcare services* (*n* = 452).

Table 8.9 shows the specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting employment for responding participants in the previous 12 months. Statements describing additional discrimination in mental healthcare services because of one's faith or spiritual beliefs, racial or cultural background, gender identity, or sexual orientation received comparable degrees of endorsement.

Table 8.9. Experiences of intersectional stigma and discrimination in *mental healthcare services*: Percentage agreement and disagreement (*n* = 452).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in mental healthcare services because of my…							
Racial or cultural background	72.3%	18.4%	2.2%	2.4%	3.5%	1.1%	**7.0%**
Faith or spiritual beliefs	69.9%	17.0%	3.1%	4.6%	4.2%	1.1%	**9.9%**
Sexual orientation	63.5%	20.6%	1.8%	5.8%	5.3%	3.1%	**14.2%**
Gender identity	68.8%	18.4%	1.3%	3.1%	5.1%	3.3%	**11.5%**
Physical health or ability	43.4%	15.0%	2.9%	13.5%	13.9%	11.3%	**38.7%**

POSITIVE EXPERIENCES IN MENTAL HEALTHCARE SERVICES

> ***I've been blessed with remarkable clinicians, who are highly skilled and dedicated. This is because I have money, live in Melbourne, and was able to advocate for myself.***
>
> **Our Turn to Speak articipant**
> **Victoria**

The survey also asked about positive treatment experiences in mental healthcare related to participants' complex mental health issues. Two core statements comprised this section of the survey: (1) the expectation of special consideration because of one's experience of complex mental health issues, and (2) manifest positive experiences in accessing mental healthcare because of one's experience of complex mental health issues.

As shown in **Figure 8.8**, more than half of participants (55.0%) agreed that they should receive special consideration in accessing or using mental healthcare services because of their complex mental health issues. Again, over half of the responding participants (57.1%) indicated that they had positive experiences when accessing mental healthcare services in the past 12 months.

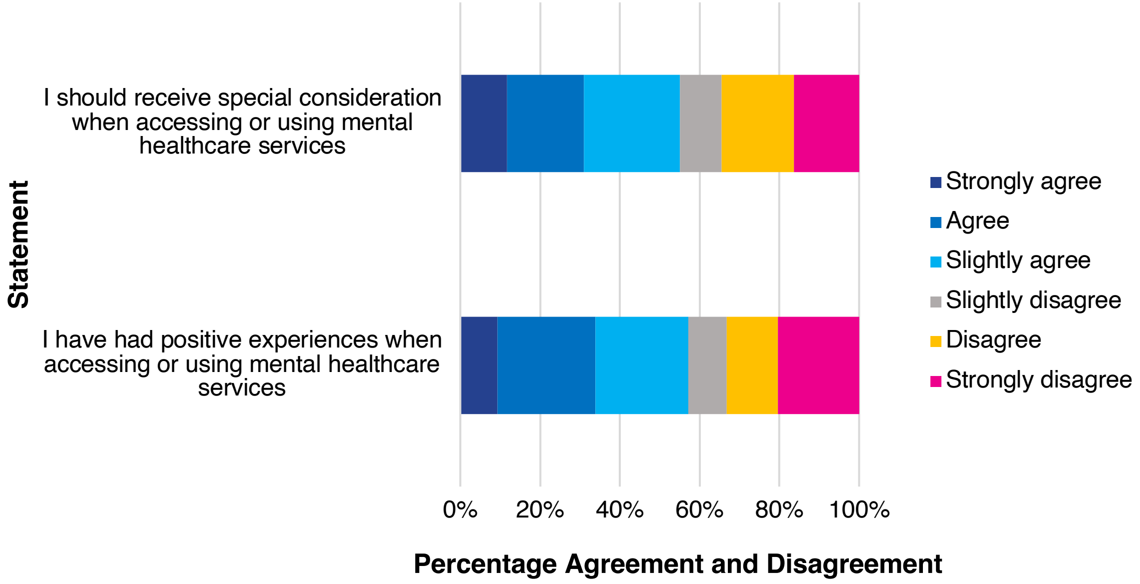


Figure 8.8. Highlight findings: responses to the statements regarding positive experiences in *mental healthcare services* because of participants' complex mental health issues (*n* = 452).

SUMMARY OF QUALITATIVE FINDINGS IN MENTAL HEALTHCARE SERVICES

A key theme arising from participant responses concerned the accessibility of the mental health system and experiences of having been denied care, including when there was a risk of self-harm. This was especially discussed among participants with Borderline Personality Disorder. As one participant shared:

> *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, Victoria).

Participants associated their experiences of having difficulty accessing mental health services or being denied care with a range of reasons. One reason included prohibitive costs of treatment (with several participants commenting on the disparity between public and private systems);

> *…A lot of my disorders have no publically funded assisted. I have had to go private to get any assistance* (**Our Turn to Speak** participant, Victoria).
>
> *There is no help out there if you don't have private health insurance. You are discriminated against if you are poor. I used over $100000 of my own money on private hospitals now have no super and my daughter can't get any treatment for her own mental health issues* (**Our Turn to Speak** participant, Queensland).

Other examples of reasons included lack of specific services and support (or lack of services generally in rural areas); intake systems; the physical environment (such as waiting room areas); and being deemed too hard or complex or, alternatively, not in a critical enough condition to justify support, as the following comments suggest:

> *My GPs are good but there is nothing available for me re my MH on MHCP. I don't need mainstream therapy such as CBT, been there done that* (**Our Turn to Speak** participant, Victoria).
>
> *Several times I have either presented myself or have had people I know present to the emergency room because they know they are likely to hurt themselves. Unfortunately, because they are not "in crisis" at that exact moment (usually because they have come to the hospital to get help) they are turned away. It is not until they are physically at risk that they can be admitted to hospital. So I don't think it's the individual practitioner's fault that we face stigma, but the stigma placed on mental health through funding and bed allocation* (**Our Turn to Speak** participant, Western Australia).
>
> *The BPD diagnosis basically makes it impossible to get help. Then a lot of professionals either don't believe in dissociation or just want nothing to do with complex trauma. Especially in the public system. I get told that there is nothing they can offer me… They say i have to find a long term therapist who specializes in trauma etc. Yet i can't afford that on a pension…* (**Our Turn to Speak** participant, South Australia).

Two participants linked their difficulties accessing mental health services, including their experiences of stigma and discrimination, to their employment in the mental health sector. One participant was excluded from a psychiatric hospital as a relationship developed with one of the staff members.

Many participants described experiences of treatment that was lacking in empathy and understanding; judgemental, dismissive, and/or patronising; or in several cases involved bullying and other abusive behaviour, including that which resulted in being discharged early and often deciding to avoid seeking help in future:

> *…There is very much a mentality of 'be quiet or get kicked out' on the inpatient ward, and this results in staff being able to get away with unfair treatment, inappropriate and unprofessional conduct, without any consequence. Subsequently, patients are too scared to speak up and endure this rather than feeling like their voices will be heard. I did speak up, and I was immediately discharged despite not being ready* (**Our Turn to Speak** participant, Victoria).
>
> *In hospital, the stigma and discrimination can be more subtle. For instance, having appointments changed without telling you, staff not taking concerns about treatment/challenges on the ward seriously, or being spoken for or told to accept certain things. The main challenge has been being really assertive when I feel that something is unjust/breaching on my rights, and trying to get staff to take me seriously. The expectation is for people to always be compliant and not question their treatment/arrangments in the hospital and that is hard* (**Our Turn to Speak** participant, Victoria).
>
> *I have stopped reaching out to crisis and suicide prevention services because I don't want to be treated like a criminal or be undermined* (**Our Turn to Speak** participant, Queensland).

> *I was discharged after presenting to the emergency department when acutely suicidal. I will never go there for mental health treatment ever again no matter how sick I get* (**Our Turn to Speak** participant, Tasmania).

A couple of participants commented that they deliberately downplayed the severity of their symptoms when seeking help to avoid being hospitalised. As one participant explained:

> *After four hospitalisations, I am now so afraid of psychiatric care that I have panic attacks when I pass a hospital. I believe I have to lie to doctors and mental health professionals to avoid being harmed, for example, I avoid admitting how severe my suicidal thoughts can be in case I am hospitalised. Was once left in seclusion 10+ hours overnight in ED, did not see a doctor or nurse once, I was not dangerous or inebriated (there because I had attempted suicide). I'm still afraid of small spaces, and have frequent nightmares about seclusion and hospital in general* (**Our Turn to Speak** participant, New South Wales).

When asked about positive experiences in the mental health domain, many participants discussed positive interactions with professionals (such as psychologists, psychiatrists, and GPs), as well as particular services and programs. *"Some mental health professionals are incredible clinicians that are able to support me in progressing through life in a more helpful way with insight into my experience,"* (**Our Turn to Speak** participant, New South Wales) said one participant. Another commented on connecting with peers. A few linked their positive experiences to their particular circumstances and ability to self-advocate, such as:

> *My ability to articulate myself sometimes leads to preferential treatment among patient cohorts. That ability while I'm in distress is a symptom of my OCPD* (**Our Turn to Speak** participant, Western Australia).
>
> *I've been blessed with remarkable clinicians, who are highly skilled and dedicated. This is because I have money, live in Melbourne, and was able to advocate for myself* (**Our Turn to Speak** participant, Victoria).

Many others provided negative or mixed experiences in response to this question, or specified that their positive experiences related to treatment in the private (rather than public) system, for instance:

> *Since having access to private cover my treatment has been caring, kind, professional* (**Our Turn to Speak** participant, Western Australia).
>
> *These experiences have only applied to private hospital facilities where you get treated well. The public system is an entirely negative experience* (**Our Turn to Speak** participant, Queensland).
>
> *My private psychiatrist/ psychotherapist is a great support, but barely affordable and no equivalent is available locally* (**Our Turn to Speak** participant, Victoria).

Many participants also commented on the issue of special consideration in this domain, with some suggesting this was needed (associating this with the provision of trauma-informed care), and others suggesting it was more about being treated fairly and respectfully.

When participants were asked about other factors that may have compounded their experiences of mental health stigma in this domain, responses discussed age, socioeconomic status, disability, faith, childhood abuse, being adopted, financial situation, gender, location, physical appearance, physical health, race, sexual orientation, substance use, and weight. Some examples of comments provided here are as follows:

> *I am mixed race and have had Drs see me as white and I don't identify as that* (**Our Turn to Speak** participant, New South Wales).
>
> *I had one psychologist tell me I was not transgender or pansexual and that I was just mentally ill. They treated me terribly the whole time and spoke down to me like I was something disgusting. Others too have been dismissive and not even allowed me to talk about it. Now I keep it to myself in fear of a negative response* (**Our Turn to Speak** participant, New South Wales).
>
> *Doctor called me very overweight and fat and so did my psychiatrist* (**Our Turn to Speak** participant, Victoria).
>
> *The discrimination for faith and spiritual beliefs was because of my absence of faith or spiritual beliefs. In a mental health inpatient ward a nurse persistently told me that I cannot heal without God and would ask to pray for me daily and tell me which churches I need to attend* (**Our Turn to Speak** participant, Victoria).

SUMMARY

Mental healthcare services have long operated on the fundamental premise that sanctuary from negative experiences is in itself therapeutic. Yet, the findings of the **Our Turn to Speak** survey highlight that stigma and discrimination affects many Australians when seeking treatment or support for their complex mental health issues. A total of 71.8% of all 1,912 participants indicated that they had experienced some level of stigma and discrimination in the preceding 12 months when seeking mental healthcare.

A total of 23.6% of participants indicated that mental healthcare was one of the three life domains in which they had been most affected by stigma in the past 12 months. For people reporting such impactful experiences, the regularity of stigma and discrimination was much higher than that of the total sample, with 58.6% of this group reporting ‘frequent’ or ‘very frequent’ problems. Those participants living with a personality disorder were most likely to have reported both frequent and impactful experiences of stigma and discrimination in the mental health system.

On average, 49.5% of participants agreed with a series of statements describing specific and general perceived experiences of stigma and discrimination in the previous 12 months. Statements describing unfair treatment when seeking help generally for their mental health, or specifically from psychologists, psychiatrists, social workers or psychiatric nurses, received the greatest levels of agreement from participants. These concerns extended to unfair treatment from mental healthcare workers to frontline administration staff; general unfair treatment in the course of seeking or engaging with mental healthcare services; exclusion from making decisions about their own mental healthcare; and other disempowering and discriminatory treatment practices. Issues of unfair hospitalisation, unnecessary physical restraint or sedation, or seclusion were the least commonly reported experiences. Taken altogether, a widespread range of stigmatising and discriminatory experiences in the mental health system were reported by participants.

Participants' qualitative comments further corroborated the quantitative survey responses. Service accessibility and denial of care when help-seeking for self-harm issues was one such commonly discussed concern. This concern was especially raised by participants who lived with Borderline Personality Disorder. Other key themes included service provision that was characterised by a lack of empathy and understanding; power differentials that manifest in overt and covert ways; financial barriers to accessing necessary services; an outright lack of appropriate services; and unfair treatment or denial of supports due to being perceivably either 'too complex' or alternatively, 'not complex enough', to obtain support. Numerous participants living with Borderline Personality Disorder noted that their diagnosis appeared to be a significant barrier in accessing support.

An average of 53.1% of participants agreed that they expected to experience stigma and discrimination when seeking help for their mental health. Statements describing general unfair treatment, and unfair treatment from specific mental health professionals, were most endorsed by participants at approximately 70%. As with perceived experiences, a widespread pattern of agreement with general and specific statements describing the anticipation of stigma and discrimination in the mental health system was observed; again, approximately half or more of responding participants agreed to most statements describing anticipated future negative experiences in this life domain. The additional statements presented to participants who had accessed residential, rehabilitation and/or hospital-based services described aniticipation of unfair hospitalisation, physical restraint or sedation, and seclusion; these statements received less frequent support from participants. Nonetheless, each these statements received agreement from over 20% of the responding participant group.

Many participants further discussed the anticipation of stigma in the mental health system, and in doing so, drew clear links between negative previous experiences and withdrawal from seeking help for mental health problems.

The highest level of participant agreement in the mental healthcare services section of the survey was observed for statements describing withdrawal from opportunities. On average, 61.9% of participants indicated that they had withdrawn from opportunities to obtain help and support for their mental health in the preceding 12 months. In those who responded to the additional statements rated by participants who had accessed residential, rehabilitation and/or hospital-based services in the past 12 months, 81.5% of participants indicated that they had withdrawn from accessing emergency mental healthcare because of stigma. In addition, 74.4% of participants indicated that they had withdrawn from accessing support for their mental health in the past 12 months because of stigma. The high rates of participant agreement with withdrawal from opportunity were mirrored in the qualitative data, where themes identified commonly related to forgoing receipt of care or support for one's mental health issues. Participants spoke of downplaying the severity of their experience to avoid being hospitalised against their will. Concerningly, many others wrote of withdrawal from seeking help when at risk of suicide or self-harm.

When asked about other personal characteristics that may have contributed to their experience of stigma and discrimination when accessing mental healthcare services in the past 12 months, participants' physical health or ability was the most frequently reported concern. Physical health and weight in particular were raised in the qualitative data as an area of intersection concern, too. Sexual orientation and gender identity also came through in both the quantitative and qualitative data as areas of stigma for participants when seeking help for mental health problems.

Finally, when asked about positive experiences in mental healthcare services, 55.0% of participants agreed that they should receive special consideration because of their mental health issues. Comparably, 57.1% of participants indicated that they actually had positive experiences because of their mental health issues when accessing mental healthcare in the preceding 12 months. In the qualitative data, participants spoke of general positive treatment when accessing care, particularly from private services; public services were often provided as a point of contrast to this positive experience. Other participants wrote more specifically of positive treatment when accessing support from particular mental health professionals, such as psychologists or psychiatrists. Some participants also lamented about their manifest lack of positive experiences, and that certain diagnoses, such as Borderline Personality Disorder, seemed to preclude positive help-seeking experiences.

It is incumbent upon mental healthcare services to provide assessment, treatment and support that is free from stigma and discrimination, and in a way that is sensitive to the needs and preferences of all whom they serve. The data presented in this chapter, however, suggests that many Australians who live with complex mental health issues do not have such an experience when accessing mental healthcare services. Indeed, the results of the **Our Turn to Speak** survey corroborate the negative experiences of service users who made recent contributions to the *Royal Commission into the Victorian Mental Health System* (Royal Commission into Victoria's Mental Health System: Interim Report, 2019), wherein it was observed that stigma embedded within the organisation, policies and resourcing of the Victorian mental health system, and its workforce, contribute to poor outcomes for those experiencing complex mental health issues. Such negative outcomes included referral or discharge out of services before the individual feels ready; exclusion from decision-making and treatment planning; unnecessary use of restrictive interventions; or avoidance of help-seeking altogether. The current findings additionally highlight on the impact, frequency, and breadth of stigma and discrimination in the mental health system for people living with complex mental health issues on a national scale.

Taken together, there is critical need for swift and targeted action to reduce stigma and discrimination in the Australian mental health system and to improve its capacity to support people living with complex mental health issues. Based on the findings of the **Our Turn to Speak** survey, such action will require systematic targeting of stigma at multiple levels of the system, from service funding to training, education, supervision, and support of mental health workers; and throughout service delivery itself. Crucially, significant investment in the development and implementation of evaluative and compliance mechanisms is essential to monitor progress and drive ongoing improvement.

MASS MEDIA

09

Chapter 9. Mass media

Media portrayals are well known to influence the public's beliefs about mental health issues (Ross et al., 2019). The way in which the media covers issues relating to mental health, and portrays people living with mental health issues, can either promote understanding and empathy or contribute to negative stereotypes driving stigma and discrimination.

For this reason, many anti-stigma programs, including SANE Australia's own *StigmaWatch* program, work with the media to promote more responsible reporting regarding these issues and to present diverse and holistic representations of people's experiences.

This chapter considers how people living with complex mental health issues experience stigma and discrimination in their engagement with mass media.

OVERVIEW

Close to 77% (*n* = 1469) of all **Our Turn to Speak** participants reported experiencing some level of stigma and discrimination in mass media during the past 12 months.

As shown in **Figure 9.1**, 41% of all participants reported 'frequent' or 'very frequent' stigma and discrimination in mass media, and 22.1% (*n* = 422) identified this life domain as one of three in which they have been most affected by such experiences. **Figure 9.1** also shows that 69.9% of participants who selected the mass media domain reported 'frequent' or 'very frequent' rates of stigma and discrimination in this aspect of their lives; much higher than was reported by the total sample.

This chapter focuses on the characteristics and experiences of those 422 participants who selected mass media as one of their top three, most affected life domains.

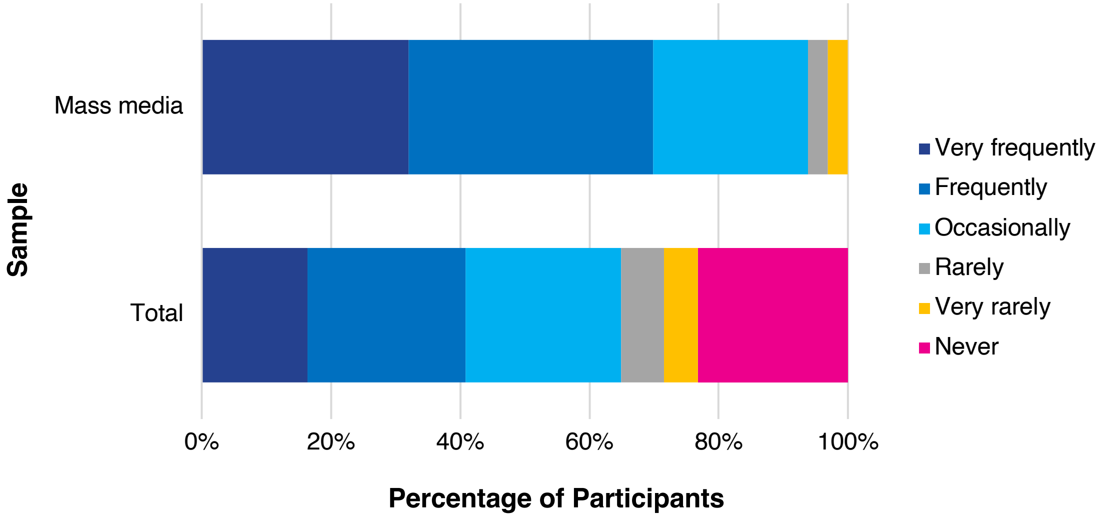


Figure 9.1. Frequency of stigma and discrimination in *mass media* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 422) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

Overall, the sociodemographic characteristics of participants who identified as being personally affected by stigma and discrimination in mass media were not dissimilar from the wider cohort (see **Table 9.1**).

Compared with the total sample, a slightly greater proportion of participants who selected mass media identified as being gay, lesbian, bisexual, pansexual, queer or asexual; educated post-secondary college; living in a major city; and 10% more were engaged in paid work.

Table 9.1. Sociodemographic characteristics: *mass media* sample compared with the total sample.

Characteristics		Mass Media (*n* = 422)	Total (*N* = 1912)
Mean age		37.54 (*SD* = 12.08)	39.21 (*SD* = 12.81)
Gender identity			
	Female	77.3%	78.9%
	Male	18.0%	18.0%
	Trans, gender diverse and/or non-binary	5.7%	4.9%
	Unsure or questioning	1.2%	0.9%
	Prefer not to say	0.5%	0.4%
Relationship status			
	Not in a relationship	47.9%	52.1%
	In a relationship	51.4%	47.3%
	Prefer to self-describe	0.2%	0.2%
Sexual orientation			
	Heterosexual	55.0%	62.0%
	Gay, lesbian, bisexual, pansexual, queer, and/or asexual	40.8%	35.6%
	Unsure or questioning	5.2%	4.9%
	Prefer to self-describe	1.4%	1.5%
	Prefer not to say	1.9%	1.7%
Education (highest level attained)			
	Primary school	1.2%	1.6%
	Secondary college (high school)	18.5%	20.9%
	Educated post-secondary college	80.3%	77.4%
	Other	0.0%	0.2%
Employment status			
	Engaged in paid work	61.6%	51.7%
	Engaged in unpaid work or studying	30.3%	28.7%
	Unemployed or unable to work	15.4%	22.8%
	Receiving a pension or benefits	23.7%	24.6%
	Other	0.0%	0.2%
State			
	Australian Capital Territory	3.8%	2.5%
	New South Wales	21.3%	23.6%
	Northern Territory	0.7%	0.6%
	Queensland	14.0%	15.9%
	South Australia	9.0%	9.5%
	Tasmania	2.8%	3.7%
	Victoria	36.7%	33.1%
	Western Australia	11.6%	10.9%
Region*			
	Major city	78.0%	74.2%
	Regional or remote	21.1%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

As with the sociodemographic data, the mental and physical health characteristics of participants who responded to the mass media section of the survey were again similar to those characteristics represented in the total **Our Turn to Speak** sample. These data are shown in **Table 9.2**.

Table 9.2. Mental and physical health characteristics: *mass media* sample compared with the total sample.

Characteristics	Mass Media (*n* = 422)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	8.5%	7.4%
Bipolar related disorder	20.6%	17.2%
Obsessive-compulsive related disorder	4.5%	4.3%
Trauma-related or dissociative disorder	21.1%	25.9%
Eating disorder	6.6%	6.1%
Personality disorder	15.6%	14.5%
Severe and treatment-resistant depressive disorder	14.5%	14.3%
Severe and treatment-resistant anxiety disorder	8.5%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	50.5%	53.8%

METHODS SNAPSHOT

Participants who identified mass media as one of three life domains in which they had been most affected by stigma-related experiences completed the mass media section of the survey. Mass media was described as including:

- news media (for example, televised news programmes, radio, newspapers, magazines, and online news sources)
- entertainment or creative media (for example, movies, music, books, and televised entertainment programmes)

Participants rated their agreement with statements relating to previous exposure to stigmatising or discriminatory mass media content; anticipated future exposure to stigma and discrimination; and withdrawal from opportunities in terms of mass media content. Participants were asked if they had experienced stigma and discrimination in this life domain related to their other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about their exposure to positive mass media portrayals of mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) 'strongly disagree', (2) 'disagree', (3) 'slightly disagree', (4) 'slightly agree', (5) 'agree', and (6) 'strongly agree'. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further describe their exposure to of stigma and discrimination in mass media content relevant to: (a) complex mental health issues, (b) in relation to other personal characteristics, and (c) their exposure to positive mass media portrayals of mental health issues. Additional comments in relation to these experiences were given by 81, 42 and 78 participants, respectively.

STIGMA AND DISCRIMINATION IN MASS MEDIA

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in relation to mass media, which will be further examined in sections that follow.

As shown in **Figure 9.2**, the average total level of agreement with all statements describing perceived and anticipated experiences of stigma and discrimination were both close to 90%. In other words, participants agreed that, far more often than not, they both experienced and expected to experience stigma and discrimination when viewing, reading or listening to mass media content. Similarly, they typically agreed that, more often than not, they had stopped themselves from viewing, reading or listening to the mass media.

At 63.3%, the average total level of agreement with all statements describing withdrawal from opportunities in mass media was lower than for experienced and anticipated stigma and discrimination, was nonetheless substantial.

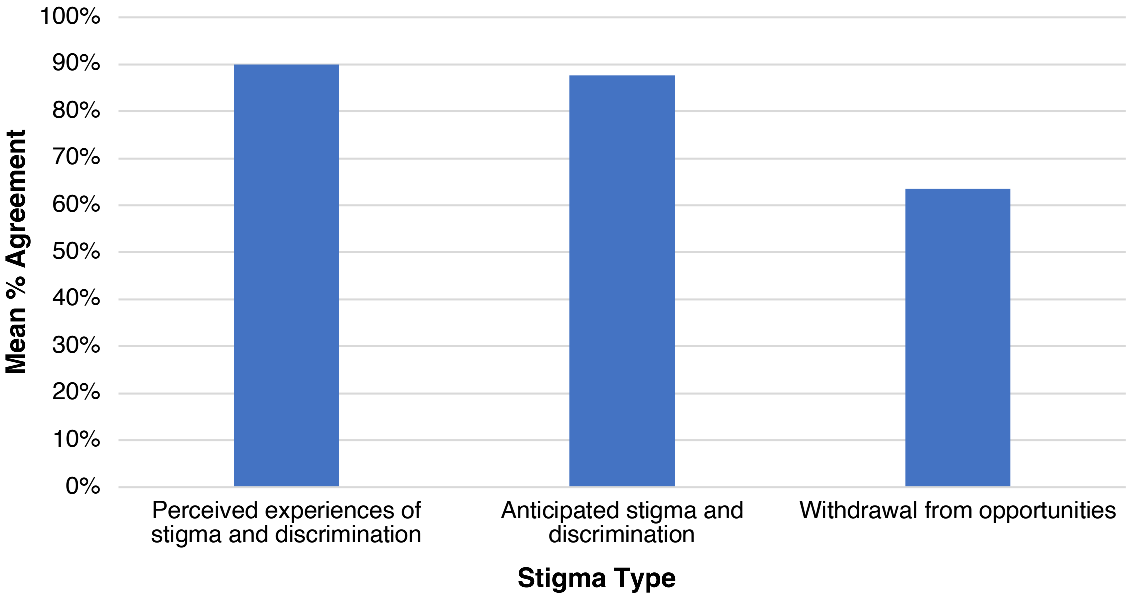


Figure 9.2. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *mass media* (*n* = 422).

Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN MASS MEDIA

> *It is good that there is more 'talk' of mental illness in the media, but unfortunately it seems to be coming out predominantly in relation to suicides and prevention awareness, as well as the usual explanation for the perpetration of particularly news worthy crimes. Both these situations link mental health with tragedy and so the publicity is futile.*
>
> **Our Turn to Speak participant**
> **New South Wales**

Presented in this section are the findings on participants' perceived experience of stigma and discrimination in relation to mass media depictions of complex mental health issues in the past 12 months.

Figure 9.3 compares perceived stigma and discrimination in news media depictions of mental health issues compared with depictions made in entertainment or creative media. As shown, levels of agreement were exceptionally high and not too dissimilar between the two types of mass media content; the average percentage agreement for the eight statement participants rated in this section was 89.9%.

Perceived stigma and discrimination were rated as slightly higher in terms of news media than for entertainment or creative media for statements describing: (a) hurtful or offensive portrayals of mental health issues, (b) portraying people who live with mental health issues as being dangerous, unsafe or unpredictable, and (c) portraying people who live with mental health issues as being to blame for their issues.

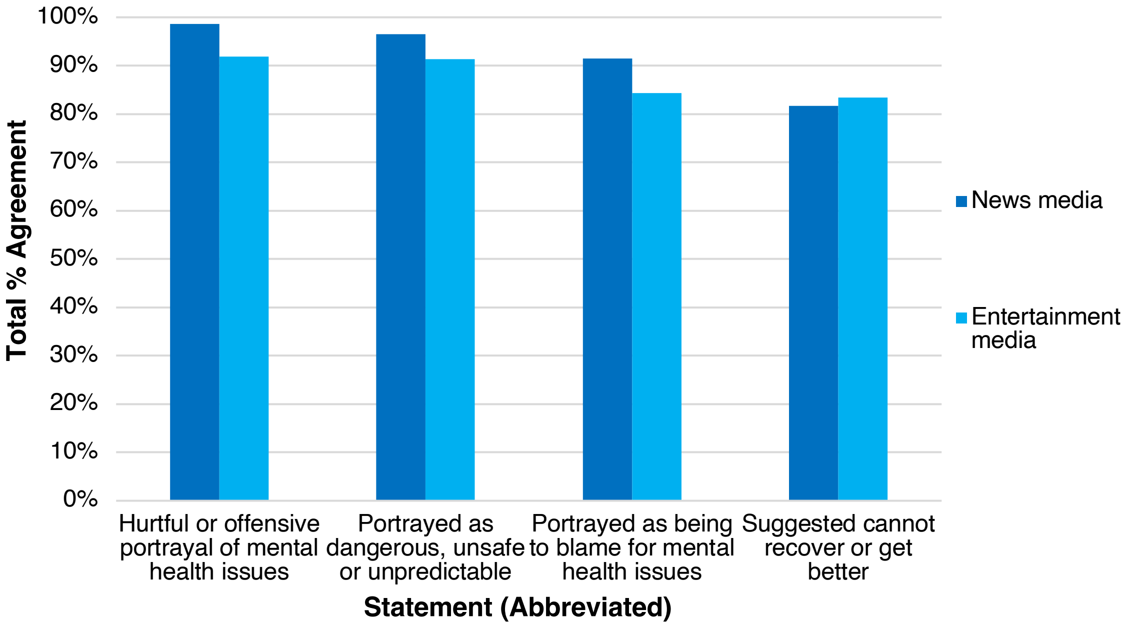


Figure 9.3. Highlight findings: total percentage agreement with perceived experiences of stigma and discrimination in *news media* and *entertainment or creative media* (*n* = 422).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

Tables 9.3 and **9.4** provide the specific levels of agreement and disagreement for all statements relevant to perceived experiences of stigma and discrimination in news media, and entertainment or creative media. The tables are also summarised in **Figure 9.3**.

Table 9.3. Perceived experiences of stigma and discrimination in *news media*: percentage agreement and disagreement (*n* = 422).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have seen, read or heard news media that…							
I found hurtful or offensive because of the way mental health issues were portrayed	0.2%	0.5%	0.7%	10.4%	34.4%	53.8%	**98.6%**
Portrayed people who live with mental health issues as dangerous, unsafe or unpredictable	0.7%	1.7%	1.2%	8.8%	30.1%	57.6%	**96.5%**
Portrayed people who live with mental health issues as being to blame for their issues	1.4%	3.1%	4.0%	17.8%	28.4%	45.3%	**91.5%**
Suggested that people who live with mental health issues cannot recover or get better	1.7%	5.2%	11.4%	18.2%	31.0%	32.5%	**81.7%**

Table 9.4. Perceived experiences of stigma and discrimination in *entertainment or creative media*: percentage agreement and disagreement (*n* = 422).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have seen, read or heard entertainment or creative media that…							
I found hurtful or offensive because of the way mental health issues were portrayed	1.4%	3.1%	3.6%	14.9%	31.0%	46.0%	**91.9%**
Portrayed people who live with mental health issues as dangerous, unsafe or unpredictable	1.7%	2.4%	4.7%	13.3%	30.6%	47.4%	**91.3%**
Portrayed people who live with mental health issues as being to blame for their issues	1.4%	4.7%	9.5%	17.5%	31.5%	35.3%	**84.3%**
Suggested that people who live with mental health issues cannot recover or get better	2.8%	5.0%	8.8%	19.4%	30.8%	33.2%	**83.4%**

ANTICIPATED STIGMA AND DISCRIMINATION IN MASS MEDIA

> *I prefer not to watch, read, or talk about any media (news or creative) that mentions mental illness because I except* [sic] *it to be portrayed in a way that is hurtful and/or triggering.*
>
> **Our Turn to Speak participant**
> **New South Wales**

Presented in this section are the findings on participants' anticipated stigma and discrimination in relation to mass media depictions of complex mental health issues in the past 12 months.

As shown in **Figure 9.4**, across all statements, anticipated stigma and discrimination was slightly higher in relation to the way news media might depict mental health issues in comparison with entertainment or creative media. As with perceived experiences of stigma and discrimination, anticipated stigma and discrimination in mass media was, again, exceptionally high. The average percentage agreement for all statements rated in this section of the survey was 87.7%.

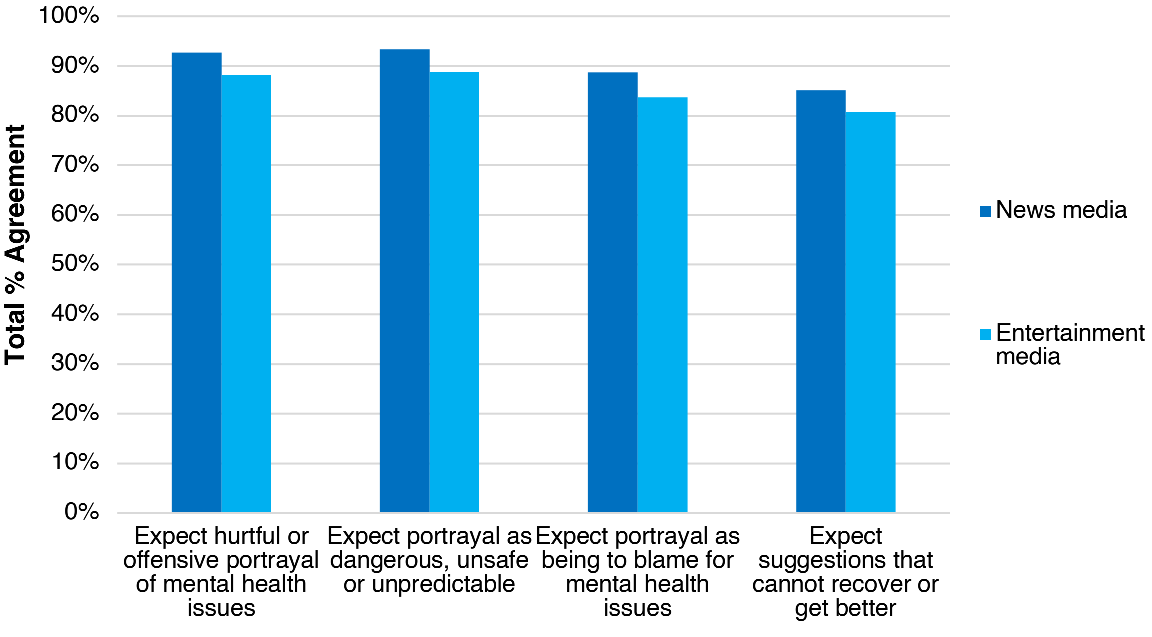


Figure 9.4. Highlight findings: total percentage agreement with anticipated stigma and discrimination in *news media* and *entertainment or creative media* (*n* = 422).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

Tables 9.5 and **9.6** provide the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in news media, and entertainment or creative media. The findings in these tables were summarised in relation to **Figure 9.4**.

Table 9.5. Anticipated stigma and discrimination in *news media:* percentage agreement and disagreement (*n* = 422).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I expect to see, read or hear news media that…							
I will find hurtful or offensive because of the way mental health issues are portrayed	2.1%	1.9%	3.3%	12.6%	32.0%	48.1%	**92.7%**
Portrays people who live with mental health issues as dangerous, unsafe or unpredictable	1.7%	1.9%	3.1%	13.7%	31.5%	48.1%	**93.3%**
Portrays people who live with mental health issues as being to blame for their issues	2.1%	4.0%	5.2%	15.9%	32.5%	40.3%	**88.7%**
Suggests that people who live with mental health issues cannot recover or get better	3.1%	4.3%	7.6%	19.7%	31.8%	33.6%	**85.1%**

Table 9.6. Anticipated stigma and discrimination in entertainment or *creative media*: percentage agreement and disagreement (*n* = 422).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I expect to see, read or hear entertainment or creative media that…							
I will find hurtful or offensive because of the way mental health issues are portrayed	2.6%	2.8%	6.4%	14.9%	32.5%	40.8%	**88.2%**
Portrays people who live with mental health issues as dangerous, unsafe or unpredictable	3.3%	2.1%	5.7%	15.9%	32.5%	40.5%	**88.9%**
Portrays people who live with mental health issues as being to blame for their issues	2.6%	3.6%	10.2%	20.9%	32.5%	30.3%	**83.7%**
Suggests that people who live with mental health issues cannot recover or get better	2.6%	5.5%	11.1%	20.1%	31.0%	29.6%	**80.7%**

WITHDRAWAL FROM OPPORTUNITY IN MASS MEDIA

> *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**

Presented in this section are the findings regarding participants' withdrawal from opportunities related to mass media, in connection with their experience of complex mental health issues.

Figure 9.5 compares withdrawal from opportunities in relation to news media compared with entertainment or creative media. As shown, across all statements, withdrawal from opportunity was somewhat higher in relation to news media. Specifically, 67.7% of participants agreed that they had stopped themselves from viewing, reading or otherwise accessing news media in the opast 12 months because of stigma about mental health issues. By contrast, 56.9% of participants had stopped themselves from accessing entertainment or creative media due to the same concerns. Almost 70% of participants agreed that they had stopped themselves from sharing their opinions about news media in the past 12 months because of stigma about complex mental health issues, compared with 60.6% of participants who did the same in relation to entertainment or creative media.

Overall, a slightly greater proportion of participants agreed that they withdrew from sharing their opinions about mass media compared with withdrawing from viewing or otherwise accessing mass media content itself.

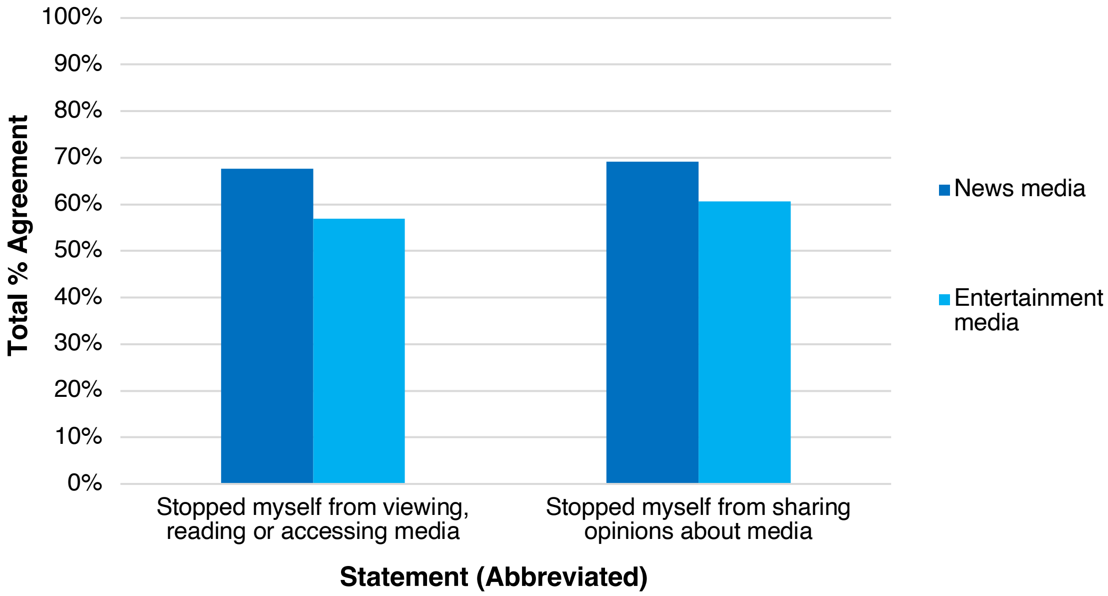


Figure 9.5. Highlight findings: total percentage agreement with withdrawal from opportunities in *news media* and *entertainment or creative media* (*n* = 422).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

Tables 9.7 and **9.8** provide the specific levels of agreement and disagreement for all statements relevant to withdrawal from opportunities in news media, and entertainment and creative media. The findings in these tables have been summarised in relation to **Figure 9.5**.

Table 9.7. Withdrawal from opportunities in *news media*: percentage agreement and disagreement (*n* = 422).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from viewing, reading or accessing news stories	8.8%	17.1%	6.4%	20.6%	27.7%	19.4%	**67.7%**
I have stopped myself from sharing my opinions about news stories	11.6%	11.8%	7.3%	16.8%	24.9%	27.5%	**69.2%**

Table 9.8. Withdrawal from opportunities in *entertainment and creative media*: percentage agreement and disagreement (*n* = 422).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from viewing, reading or accessing entertainment media such as films, songs or books	12.3%	19.4%	11.4%	23.9%	19.0%	14.0%	**56.9%**
I have stopped myself from sharing my opinions about entertainment media such as films, songs or books	14.5%	14.0%	10.9%	17.5%	23.9%	19.2%	**60.6%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN MASS MEDIA

> ***The constant referral to the "obesity epidemic" being due to moral failings, and not attributed correctly in my view to what I view as a mental health epidemic.***
>
> **Our Turn to Speak participant**
> **Western Australia**

The findings from survey statements in relation to other experiences of stigmatising mass media depictions, besides those about complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 9.6**. As shown, just over 44% of participants agreed that they had been exposed to stigma and discrimination by the mass media in connection with their physical health or ability, while 34.9% agreed that they had experienced stigmatising mass media depictions in relation to their sexual orientation.

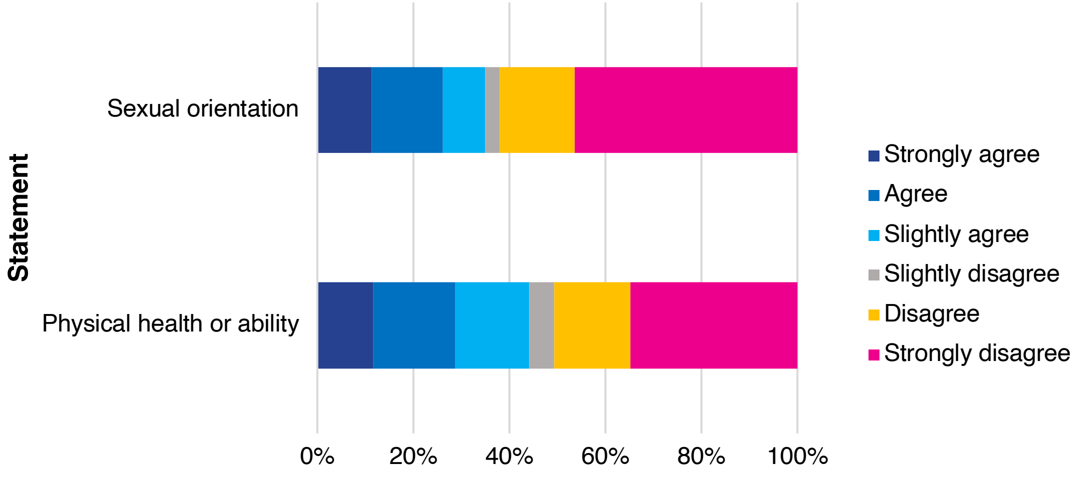


Figure 9.6. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *mass media* (*n* = 422).

The specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting housing are summarised, in **Table 9.9**. Overall, a lower rate of agreement was observed for statements describing experiences of stigma and discrimination in relation to mass media depictions about characteristics other than lived experience of mental health issues.

Table 9.9. Experiences of intersectional stigma and discrimination in *mass media*: percentage agreement and disagreement (*n* = 422).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in relation to mass media content because of my…							
Racial or cultural background	65.4%	20.9%	2.6%	3.6%	3.6%	4.0%	**11.2%**
Faith or spiritual beliefs	54.3%	20.6%	4.0%	7.3%	9.5%	4.3%	**21.1%**
Sexual orientation	46.4%	15.6%	3.1%	8.8%	14.7%	11.4%	**34.9%**
Gender identity	54.3%	18.7%	3.8%	5.7%	9.5%	8.1%	**23.3%**
Physical health or ability	34.8%	15.9%	5.2%	15.4%	17.1%	11.6%	**44.1%**

POSITIVE EXPERIENCES IN MASS MEDIA

> [Stationary brand] *marketed 2020 diaries by mentioning OCD in their marketing. I complained on social media and they got in contact and took down their entire marketing that mentioned OCD globally.*
>
> **Our Turn to Speak participant**
> **South Australia**

The **Our Turn to Speak** survey also asked about experience of positive depictions of complex mental health issues by the mass media.

As shown in **Figure 9.7**, 58.8% of participants agreed that, in the past 12 months, they had seen, read or heard entertainment or creative media that portrayed people who live with mental health issues in a positive way, while 56.9% agreed they had seen similarly positive depictions about living with mental health issues in news media.

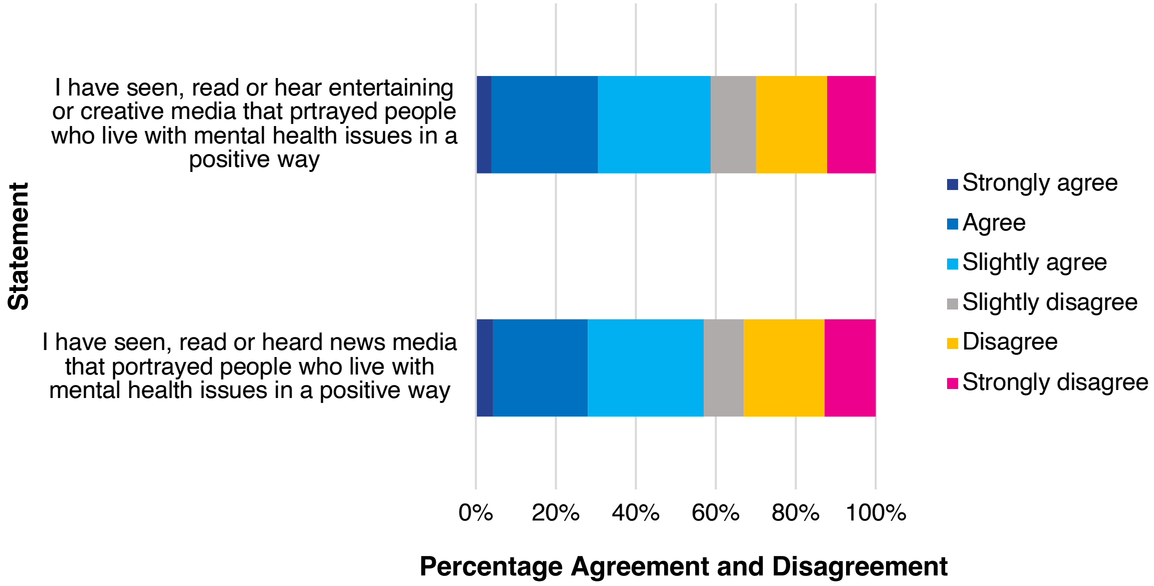


Figure 9.7. Highlight findings: responses to the statements regarding positive experiences in *mass media* because of participants' complex mental health issues (*n* = 422).

SUMMARY OF QUALITATIVE FINDINGS IN MASS MEDIA

A variety of media sources were discussed by participants in relation to this domain, such as news media, film and television, marketing and advertising campaigns, print media (including books), radio and podcasts, theatre, video games, social media (including YouTube) and other online media. The most frequently mentioned was film and television.

A major theme arising from participant responses in the mass media domain concerned sensationalisation and stereotypes. This included stereotyping people with mental health issues as dangerous or criminal, stereotypes around treatment and recovery, misrepresentation and selective representation of mental health issues, and portrayal as victims or as sources of ‘inspiration’.

The portrayal of people with mental health issues as dangerous or criminal was the most frequently discussed stereotype. A key element of which, according to some participants, was a failure to make important distinctions where the existence (or lack thereof) of support and treatment were concerned, as the following example comments convey:

> *One of the most frustrating aspects of mass media reporting on crimes that may have been caused by an underlying mental illness, is that there is no depth to the journalism. Often if the mental illness is mentioned, the journalist fails to do the research or mention that the mental illness that person was living with was undiagnosed/untreated/mistreated because our public mental health system is broken. It's not that you can't recover successfully from episodes of severe mental illness. You can with the right care. Right now access to that care is means dependent. If you can't afford private health insurance, your chances of recovery and a functional life are much lower and it is a much harder road back to wellness* (**Our Turn to Speak** participant, Queensland).
>
> *I find that the news often reports mental health issues along with bad news, such as someone out of control. Then the public assumes that everyone with mental health issues is crazy or out of control or dangerous, whereas the fact is you can live a stable and functioning life with medication and therapy. I think the mass media doesn't understand the distinction between mental health issues that are controlled by medication, and those where the mentally ill person is not taking their medication* (**Our Turn to Speak** participant, Victoria).

Although nuanced discussion around treatment and support for people with mental health issues were felt to be missing from media reporting on crime, some participants highlighted that problematic stereotypes around treatment and recovery exist elsewhere in the mass media. This included simplistic narratives of being *“cured”*, for instance:

> *In alot of films or television programs they suggest that you can recover from mental illness but that it is a quick and simple straightforward thing to do such as just take medication or get some therapy for a few weeks or months then you'll be right that there are never any hiccups along the way or that it might take quite a long time to get the right medication or to get the right combination of treatments* (**Our Turn to Speak** participant, Tasmania).
>
> *Honestly, I find the narrative in creative media to be more like...recovery is always possible and 100% complete, which I find worse than the idea of it being impossible to recover from mental illness. I don't think I'm ever going to be 'healthy' like someone who has never been mentally ill, I've been in and out of recovery for bulimia for years and like...it's work? Every day. It doesn't magically go away one day, it's all the little bits of work that have to be done day in, day out in order to keep everything together. And I find the lack of that kind of narrative really damaging, because all I'm seeing is not my reality. And people expect that to become my reality, and it's...bleh* (**Our Turn to Speak** participant, Victoria).
>
> *Not all mental health issues need to be cured or fixed, it is okay to live with an accept people with conditions without trying to cure everything. Including people with lived experience in mass media, allowing them to tell their own stories and share their own*

> *experiences is better than telling them for us* (**Our Turn to Speak** participant, Queensland).

One participant noted that such stereotypes could also include refusal to take medication:

> *I have also read a lot of novels where the central character may have post-natal depression, say, or post-natal psychosis, or just plain depression, and refuses to consider taking medication and going to therapy...and disaster happens in the novel…* (**Our Turn to Speak** participant, Victoria).

Misrepresentation and selective representation (neglecting those which are complex and more stigmatised) of mental health issues was also raised by a few participants, for example:

> *OCD is portrayed pretty poorly, it is minimised, lots of misinformation - classic stereotype of "cleanliness"* (**Our Turn to Speak** participant, Western Australia).
>
> *At times media will present mental illness in a positive light for example news articles about new treatments - however this positivity is always limited to media about mild to moderate anxiety and depression. I have never seen positive media about severe mental illness such as bpd* (**Our Turn to Speak** participant, New South Wales).
>
> *They only show people who have mild mental health issues, not those of us with complex and difficult mental health issues* (**Our Turn to Speak** participant, New South Wales).

A further stereotype involved the portrayal of people with mental health issues in the mass media as victims or, alternatively, as sources of 'inspiration':

> *Mass media often portrays people who are experiencing mental health problems in a victim role, repeatedly making bad decisions, only makes things worse, sensationalisation on the news* (**Our Turn to Speak** participant, Queensland).
>
> *People like me, with depression, autism and body dysmorphia are portrayed through narrow and often pathetic images for people to feel sorry for. I am not Melvin from As Good As It Gets or a gym junky. I am not The Good Doctor or the people on Love on The Spectrum I look like you. The difference is on the inside* (**Our Turn to Speak** participant, Queensland).
>
> *I just don't want coverage to veer towards inspiration porn or super crip narratives. I want more media that doesn't other people like me but I don't need to be celebrated or anything* (**Our Turn to Speak** participant, Australian Capital Territory).

Several participants mentioned that they endeavour to avoid mass media generally, and some specified that they would avoid media if it mentioned mental health issues, or that they avoided speaking about their experiences in the media. A couple explained that, as they worked in the media (for instance, in journalism), they could not avoid it.

A couple of participants commented on problematic and outdated language around mental health issues used in the mass media, and also used more broadly by the general public;

> *There is a lot of casual language around mental health issues, people are referred to as crazy or nutters, or OCD…* (**Our Turn to Speak** participant, Victoria)
>
> *…It's when words like bipolar or schizophrenic become shorthand for unstable or irrational or dangerous that it's problematic* (**Our Turn to Speak** participant, Victoria).

A few participants also commented on the need for stronger media regulation and reporting guidelines.

When asked about positive experiences in the mass media domain, many participants shared examples of positive portrayals in film and television, books, articles, podcasts, and video games. Some discussed positive benefits of connecting with peers through social media, and of campaigns such as R U OK day. Others noted positive impacts of celebrities speaking out about their experiences with mental health issues, and a couple mentioned comedians. Several participants discussed examples of negative treatment in the media, but many gave examples that were mixed or conveyed that they felt it was improving, such as:

> *I think the number of high profile entertainment, sporting etc. stars coming out of the mental health closet has been good. Their portrayal by the media has not necessarily been up to par in my view* (**Our Turn to Speak** participant, Western Australia).
>
> *The only problem with the above is they only (generally) talk about the rich and/or famous which is only a minor fraction of the lived experience community* (**Our Turn to Speak** participant, Queensland).
>
> *I think that there is a greater understanding about mental illness now in the community and that media outlets are changing for the better, promoting mental illness in a better light and portraying the truth about it instead of creating myths and hysteria* (**Our Turn to Speak** participant, Victoria).
>
> *It is easier to find entertainment now with positive messages or representations but you have to seek it out specifically* (**Our Turn to Speak** participant, Australian Capital Territory).

When participants were asked about other factors that may have compounded their experiences of mental health stigma in this domain, comments most frequently related to weight. Others included gender, race, sexual orientation, faith and spirituality, substance use, relationship type, employment (for instance, sex work), socioeconomic status, and age. One participant also shared that, in addition to their Complex Post Traumatic Stress Disorder: *"I am an adoptee and no one wants to hear about the impact that adoption has had on those of us who have grown up not knowing anything about their true identity"* (**Our Turn to Speak** participant, New South Wales).

SUMMARY

Of 1,912 participants who took part in the **Our Turn to Speak** survey, 22.1% identified mass media as one of up to three life domains that had been most affected by stigma and discrimination in connection with complex mental health issues. Almost 70% of participants who selected the mass media domain as one of their most affected life domains in the past 12 months indicated 'frequent' or 'very frequent' experiences of stigma and discrimination in this aspect of their lives.

When presented with a range of statements describing general and specific examples of stigma and discrimination in mass media, it was evident that news media was rated as slightly more problematic than entertainment or creative media. Regardless of the type of mass media participants were reporting about, however, the vast majority (> 80%) agreed that they had seen, read or heard media that promoted stigma about mental health issues. In other words, the majority of participants agreed that they had been exposed to news and entertainment/creative media that portrayed mental health issues in an offensive or hurtful way; and depicted people living with mental health issues as dangerous, to blame for their issues, and suggested that recovery is impossible. It was highly concerning that almost all 422 participants who responded to this domain (96.5%) had been exposed to news media that portrayed people who live with mental health issues as dangerous, unsafe or unpredictable. This was also the most frequent stereotype mentioned in participants' qualitative comments. Participants explained that nuanced messaging around the multi-faceted relationships between mental health issues and violence is typically lacking. Unfortunately, the high rates of exposure to dangerous stereotypes reported by **Our Turn to Speak** participants are reflective of past research, which found that beliefs about dangerousness and unpredictability associated with complex mental health issues, like schizophrenia, were on the increase among the Australian general public (Reavley & Jorm, 2012).

Rates of agreement with statements describing various kinds of anticipated exposure to stigma and discrimination in mass media were equivalent to the rates of agreement in relation to perceived experiences (≥ 80%). Again, news media was rated as slightly more problematic than entertainment or creative media for all statements. Almost all participants (96.5%) agreed that they expected to see news media that portrayed people who live with mental health issues as dangerous, unsafe or unpredictable (although it must be noted that expectations for exposure to stigmatising content in entertainment or creative media really did not fare much better). Somewhat fewer participants reported that they had withdrawn from or opted out of watching, reading or listening to mass media. Specifically, just under 70% of participants agreed that they had stopped themselves from accessing or sharing their opinions about news stories because of stigma about mental health issues, while around 60% of participants agreed that they had done the same in relation to entertainment media like films, songs or books. Given the ubiquitousness of media (including social and online media) and how important it is for keeping updated with current affairs and for recreation, it makes sense that engagement remains high despite around 90% of participants expecting that they would be exposed to hurtful or offensive content that is stigmatising about mental health issues. Besides mental health issues, 44.1% and 34.9% of participants agreed that they had been exposed to stigmatising media content in relation to their physical health or ability, or sexual orientation, respectively.

Finally, positive portrayals of mental health issues were reported by close to 60% of in relation to both entertainment or creative media and news media. In their additional commentary, participants highlighted their appreciation for celebrities or sportspeople sharing their lived experience of mental health issues in the media. However, there was a sense from some participants that the experiences of these ambassadors were quite distinct from their own experiences of living with complex mental health issues. Others mentioned sanitised or overly optimistic portrayals of mental health issues and recovery. Overall, media depictions of mental health issues that were accurate, sensitive, taken seriously and promoted hope were described in a positive light.

Relative to the other life domains examined in the **Our Turn to Speak** survey, the rates of agreement with statements describing stigma and discrimination were very high in relation to mass media. On average, about 80% of participants agreed with all 20 statements describing stigma and discrimination in this domain (that is, perceived experiences, anticipated experiences, and withdrawal from opportunity). 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 (Hazell et al., 2006; Skehan et al., 2006), misinformation and outright damaging stereotypes are still being circulated.

WELFARE AND SOCIAL SERVICES

10

Chapter 10. Welfare and social services

The Universal Declaration on Human Rights says that countries must, within the resources it has available, ensure access to a social security scheme that provides a minimum level of benefits to all individuals and families to enable them to acquire at least essential health care, basic shelter and housing, water and sanitation, food, and basic education.

While welfare and disability services are intended to provide such support to people when they need it the most, recent research has found that Australian Disability Support Pension (DSP) recipients actually experienced a deterioration to their mental health over and above of the effect of living with a disability (Milner, Kavanagh, McAllister, & Aitken, 2020). The harms associated with receiving the DSP were attributed to stigma and the psychosocial stressors involved in applying for, and maintaining, that support

This chapter considers how people living with complex mental health issues experience stigma and discrimination in accessing welfare and social services.

OVERVIEW

Almost 60% (*n* = 1126) of all **Our Turn to Speak** participants reported experiencing some level of stigma and discrimination in welfare and social services during the past 12 months.

As shown in **Figure 10.1**, 19.8% of all participants reported 'frequent' or 'very frequent' stigma and discrimination in welfare and social services, and 12.4% (*n* = 238) identified this life domain as one of three in which they had been most affected by such experiences. **Figure 10.1** also shows that 63% of participants who selected the welfare and social services domain reported 'frequent' or 'very frequent' rates of stigma and discrimination in this aspect of their lives; much higher than was reported by the overall sample.

This chapter focuses on the characteristics and experiences of those 238 participants who selected welfare and social services as one of their top three, most affected life domains.

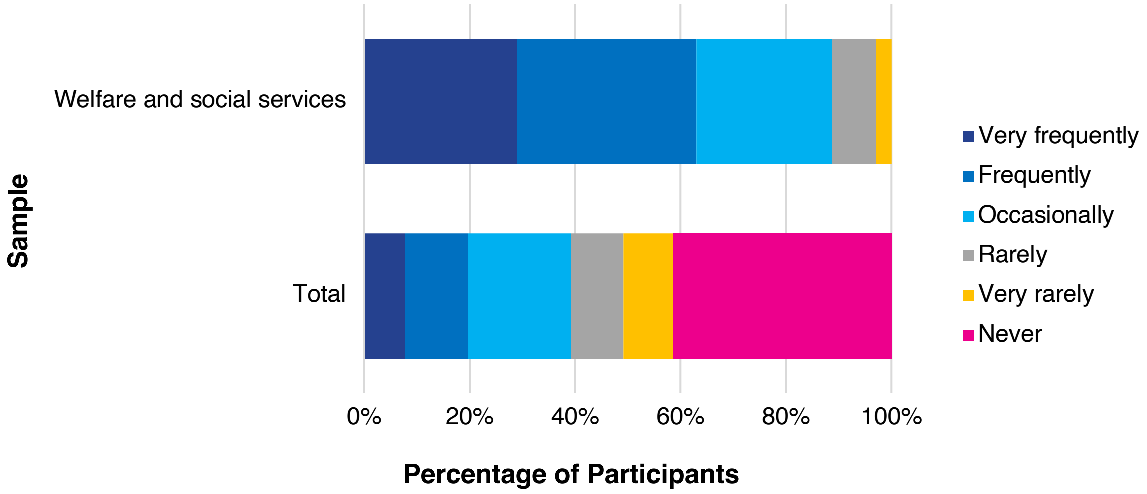


Figure 10.1. Frequency of stigma and discrimination in *welfare and social services* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 238) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

Table 10.1 presents the sociodemographic and clinical characteristics of participants who identified as being personally affected by stigma and discrimination when accessing welfare and social services.

With the exception of employment status, the sociodemographic and clinical characteristics of participants who selected this life domain were not too dissimilar from those of the total sample. Compared with the total sample, 8.5% more participants who selected the welfare and social services domain identified as gay, lesbian, bisexual, pansexual, queer and/or asexual.

Table 10.1. Sociodemographic characteristics: *welfare and social services* sample compared with the total sample.

Characteristics		Welfare and Social Services (*n* = 238)	Total (*N* = 1912)
Mean age		39.03 (*SD* = 12.62)	39.21 (*SD* = 12.81)
Gender identity			
	Female	75.2%	78.9%
	Male	18.5%	18.0%
	Trans, gender diverse and/or non-binary	8.8%	4.9%
	Unsure or questioning	1.3%	0.9%
	Prefer not to say	1.3%	0.4%
Relationship status			
	Not in a relationship	54.6%	52.1%
	In a relationship	45.0%	47.3%
	Prefer to self-describe	0.0%	0.2%
Sexual orientation			
	Heterosexual	55.0%	62.0%
	Gay, lesbian, bisexual, pansexual, queer, and/or asexual	44.1%	35.6%
	Unsure or questioning	3.8%	4.9%
	Prefer to self-describe	1.7%	1.5%
	Prefer not to say	0.8%	1.7%
Education (highest level attained)			
	Primary school	1.7%	1.6%
	Secondary college (high school)	22.7%	20.9%
	Educated post-secondary college	75.6%	77.4%
	Other	0.0%	0.2%
Employment			
	Engaged in paid work	29.4%	51.7%
	Engaged in unpaid work or studying	37.8%	28.7%
	Unemployed or unable to work	36.6%	22.8%
	Receiving a pension or benefits	30.7%	24.6%
	Other	0.4%	0.2%
State			
	Australian Capital Territory	1.7%	2.5%
	New South Wales	24.8%	23.6%
	Northern Territory	0.4%	0.6%
	Queensland	16.0%	15.9%
	South Australia	12.6%	9.5%
	Tasmania	3.4%	3.7%
	Victoria	29.4%	33.1%
	Western Australia	11.1%	10.9%
Region*			
	Major city	71.0%	74.2%
	Regional or remote	29.0%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

Table 10.1 also shows that, compared with the total sample, 22% fewer participants who selected the welfare and social services domain were engaged in paid work compared with the total sample, and a much greater proportion reported that they were engaged in unpaid work (for example, caring duties, studying and volunteering); unemployed or unable to work; and receiving a pension or other benefits.

Figure 10.2,, shows in greater detail the employment status of participants who selected the welfare and social services domain compared with the total sample. While rates of part-time or casual employment were relatively similar, only 2.1% of participants who selected the welfare and social services domain were engaged in full-time work compared with 21.5% of the total sample.

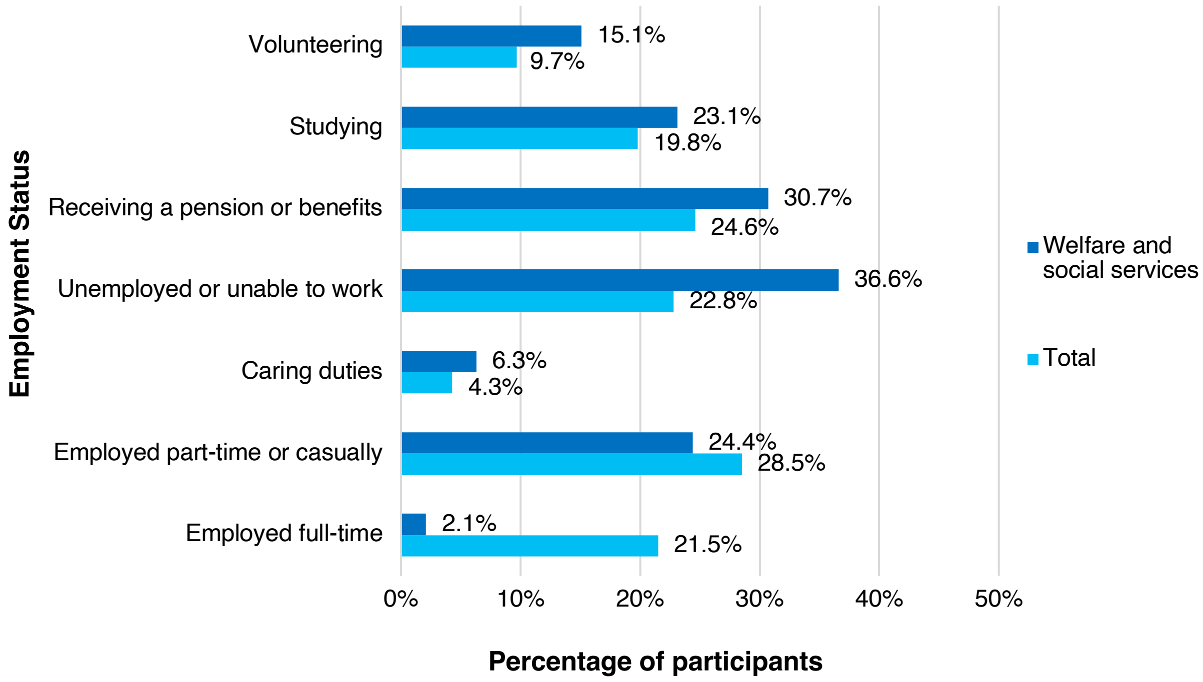


Figure 10.2. Employment status among participants who selected *welfare and social services* as one of three domains in which they had been most affected by stigma during the past 12 months (*n* = 238) compared with the total sample (*N* = 1912).
Note. Percentages do not add to 100 as participants could select more than one response option.

As with the sociodemographic data, the mental and physical health characteristics of participants who identified the welfare and social services domain as having been most affected by stigma and discrimination were similar to those of the total sample (see **Table 10.2**).

The exception was that approximately 10% more participants in this group reported a primary diagnosis of a trauma-related or dissociative disorder compared with the total sample.

Table 10.2. Mental and physical health characteristics: *welfare and social services* sample compared with the total sample.

Characteristics	Welfare and Social Services (*n* = 238)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	4.2%	7.4%
Bipolar related disorder	14.7%	17.2%
Obsessive-compulsive related disorder	3.8%	4.3%
Trauma-related or dissociative disorder	35.7%	25.9%
Eating disorder	2.9%	6.1%
Personality disorder	12.2%	14.5%
Severe and treatment-resistant depressive disorder	16.0%	14.3%
Severe and treatment-resistant anxiety disorder	10.5%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	62.2%	53.8%

METHODS SNAPSHOT

Participants who identified relationships as one of three life domains in which they have been most affected by stigma-related experiences completed the Welfare and social services section of the survey. Welfare and social services were described as receiving benefits, disability pensions or income support including, but not limited to:

- Centrelink benefits (for example, Newstart Allowance, Disability Support Pension)
- Disability funding such as that from the National Disability Insurance Scheme (NDIS).

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in welfare and social services; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in relation to welfare and social services. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further describe their experiences of stigma and discrimination because of: (a) complex mental health issues, (b) in relation to other personal characteristics, and (c) their experiences of positive treatment in welfare and social services domain. Additional comments in relation to these experiences were given by 58, 35 and 43 participants, respectively.

STIGMA AND DISCRIMINATION IN WELFARE AND SOCIAL SERVICES

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in welfare and social services, which will be further examined in sections that follow.

As shown in **Figure 10.3**, the average total level of agreement with all statements describing perceived experiences of stigma and discrimination in welfare and social services was almost 70%, and close to 80% for anticipated stigma and discrimination. In other words, participants typically agreed that, more often than not, they experienced and expected to experience stigma and discrimination when accessing welfare and social services.

At 50.9%, the average total agreement for all statements describing withdrawal from opportunities in welfare and social services was lower, but nonetheless substantial.

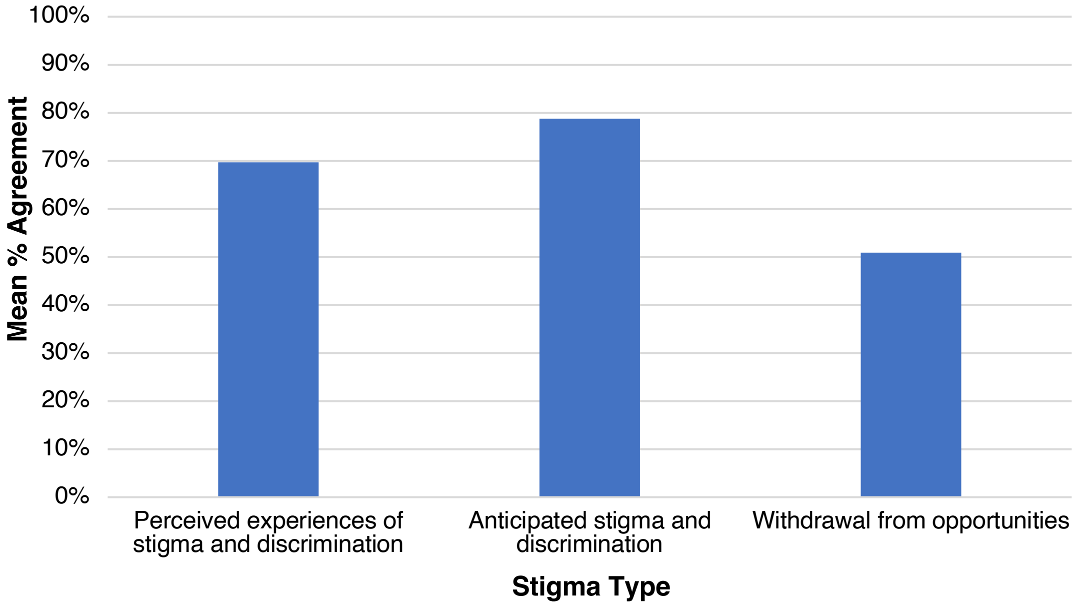


Figure 10.3. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *welfare and social services* (*n* = 238).

Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN WELFARE AND SOCIAL SERVICES

> ***Getting on the DSP is so very difficult and I am still in the process after 4 months living with extreme anxiety. Just going into appointments crushes me. After going to a psychologist to get evidence I was faced with my situation in life and was so suicidal I had to go to the ED for some hours to calm down. Back in the 90s the system was much more kind and I would go on and off the DSP when I was too unwell to work. Now the process may well end me.***
>
> **Our Turn to Speak participant**
> **Tasmania**

Presented in this section are the findings regarding participants' perceived experiences of stigma and discrimination in welfare and social services, as related to their experience of complex mental health issues.

Figure 10.4 highlights the findings from the two most frequently endorsed issues from the set of five statements that participants answered in this section of the survey. As shown, close to 80% of participants agreed that they had been treated unfairly: (a) when applying for welfare benefits, disability pensions or disability schemes, and (b) by welfare agency or social services staff in the past 12 months because of stigma about complex mental health issues.

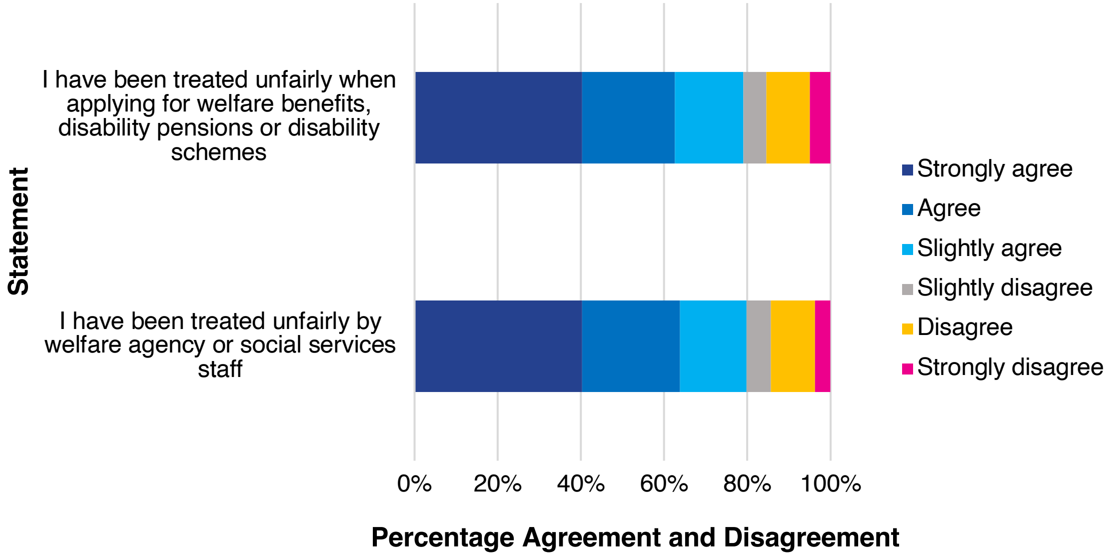


Figure 10.4. Highlight findings: the two most frequently endorsed statements describing perceived experiences of stigma and discrimination in *welfare and social services* (*n* = 238).

Table 10.3 provide the specific levels of agreement and disagreement for all statements relevant to perceived experiences of stigma and discrimination in welfare and social services. Rates of agreement in relation to different forms of stigma and discrimination, not highlighted in **Figure 10.4**, were similarly high.

Of note, approximately 70% of participants agreed that they had been unfairly denied welfare benefits, disability pensions or disability schemes, and about the same proportion agreed that those supports had been denied specifically because their mental health issues were unfairly determined not to meet the required eligibility criteria. Close to 50% agreed that their welfare benefits, disability pensions or disability schemes had been unfairly suspended or cancelled because of stigma about complex mental health issues.

Table 10.3. Perceived experiences of stigma and discrimination in *welfare and social services*: percentage agreement and disagreement (*n* = 238).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when applying for welfare benefits, disability pensions or disability schemes	5.0%	10.5%	5.5%	16.4%	22.3%	40.3%	**79.0%**
I have been unfairly denied welfare benefits, disability pensions or disability schemes	6.3%	15.5%	6.3%	14.3%	19.3%	38.2%	**71.8%**
My welfare benefits, disability pensions or disability schemes have been unfairly suspended or cancelled	18.9%	28.2%	5.9%	8.8%	13.0%	25.3%	**47.1%**
I have been treated unfairly by welfare agency or social services staff	3.8%	10.5%	5.9%	16.0%	23.5%	40.3%	**79.8%**
I have been denied welfare benefits, disability pensions or disability schemes because my mental health issues were unfairly determined not to meet eligibility criteria	10.5%	16.4%	2.5%	9.7%	17.2%	43.7%	**70.6%**

ANTICIPATED STIGMA AND DISCRIMINATION IN WELFARE AND SOCIAL SERVICES

> ***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**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in welfare and social services, as related to their experience of complex mental health issues.

Figure 10.5 highlights the findings from the two most frequently endorsed issues from the set of five statements that participants rated in this section of the survey. As shown, almost 80% of participants agreed that they expected to be: (1) treated unfairly when applying for welfare benefits, disability pensions or disability schemes, and (2) unfairly denied welfare benefits, disability pensions or disability schemes because of stigma about complex mental health issues.

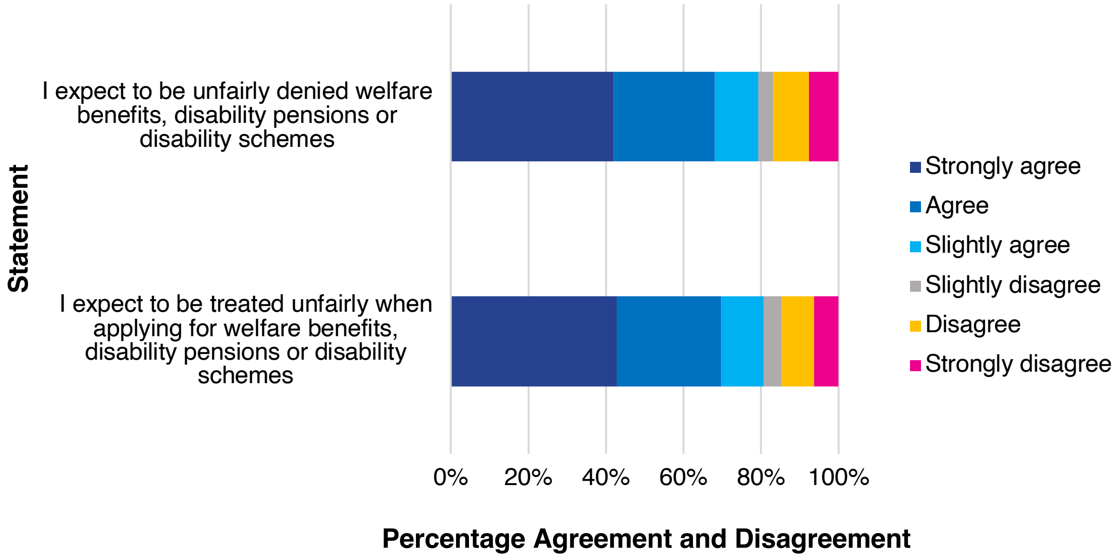


Figure 10.5. Highlight findings: the two most frequently endorsed statements describing anticipated stigma and discrimination in *welfare and social services* (*n* = 238).

Table 10.4 provides the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in welfare and social services.

As shown, over 70% of participants agreed to the remaining statements not highlighted in **Figure 10.5**. The level of agreement for anticipated stigma and discrimination in welfare and social services was higher in comparison with ratings of equivalent statements describing perceived experiences of stigma and discrimination. Concerningly, 72.3% of participants expected that their welfare benefits, disability pensions or support from other disability schemes would be unfairly suspended or cancelled.

Table 10.4. Anticipated stigma and discrimination in *welfare and social services*: percentage agreement and disagreement (*n* = 238).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when applying for welfare benefits, disability pensions or disability schemes	6.3%	8.4%	4.6%	10.9%	26.9%	42.9%	**80.7%**
I expect to be unfairly denied welfare benefits, disability pensions or disability schemes	7.6%	9.2%	3.8%	11.3%	26.1%	42.0%	**79.4%**
I expect that my welfare benefits, disability pensions or disability schemes will be unfairly suspended or cancelled	9.7%	10.9%	7.1%	14.7%	26.5%	31.1%	**72.3%**
I expect to be treated unfairly by welfare agency or social services staff	6.7%	8.4%	5.9%	16.0%	25.2%	37.8%	**79.0%**
I expect to be denied welfare benefits, disability pensions or disability schemes because my mental health issues will be unfairly determined not to meet eligibility criteria	8.4%	10.1%	2.5%	9.2%	22.7%	47.1%	**79.0%**

WITHDRAWAL FROM OPPORTUNITY IN WELFARE AND SOCIAL SERVICES

> *I don’t ask for support from community welfare services because I feel like they will ignore my PTSD and mental health and only look at my financial assets.*
>
> **Our Turn to Speak participant**
> **New South Wales**

Presented in this section are the findings regarding participants’ withdrawal from opportunities related to welfare and social services, in connection with their experience of complex mental health issues.

Figure 10.6 highlights the two most frequently endorsed issues from the set of four statements that participants rated in this section of the survey. Almost 80% of participants agreed that, in the past 12 months, they had stopped themselves from making changes to, or enquiries about, their welfare benefits, disability pensions or other disability schemes because of stigma about mental health issues. Close to 64% agreed that they had stopped themselves from even applying for such supports.

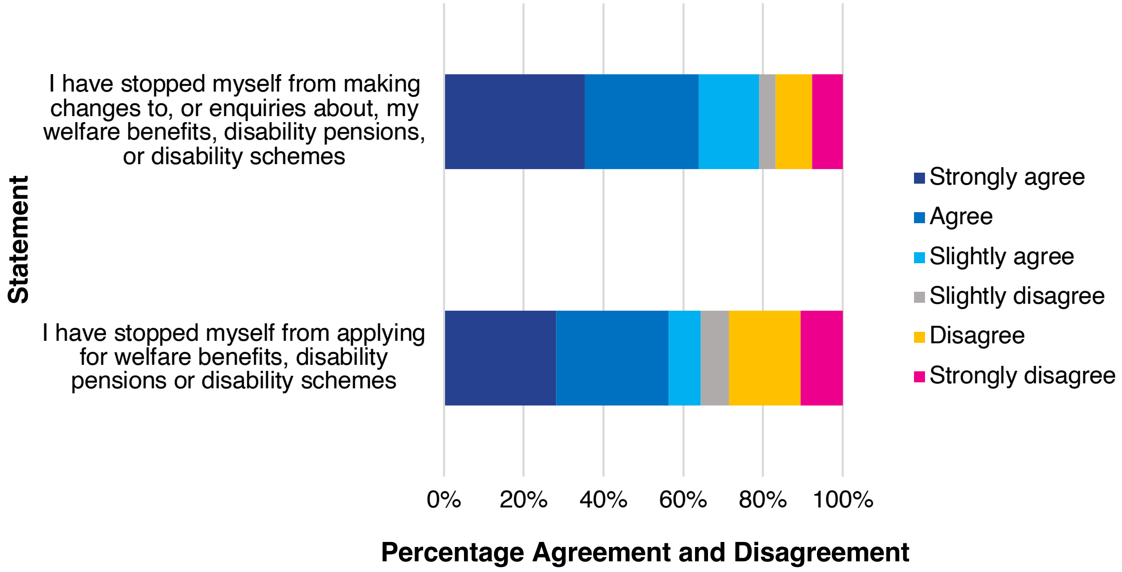


Figure 10.6. Highlight findings: the two most frequently endorsed statements describing withdrawal from opportunities in *welfare and social services* (*n* = 238).

Table 10.5 provides the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in welfare and social services.

As shown, over 34% of participants agreed that they had submitted, but then withdrawn, applications for welfare benefits, disability pensions or other schemes because of stigma about mental health issues in the past 12 months. Over a quarter of participants agreed that they had forfeited benefits, disability pensions or other disability support schemes during the same time period. While the level of agreement with statements describing withdrawal from opportunities was lower than for perceived experiences and anticipated stigma and discrimination in welfare and social services, the rates reported here are nonetheless meaningful.

Table 10.5. Withdrawal from opportunities in *welfare and social services*: percentage agreement and disagreement (*n* = 238).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from applying for welfare benefits, disability pensions or disability schemes	10.5%	18.1%	7.1%	8.0%	28.2%	28.2%	**64.4%**
I have stopped myself from making changes to, or enquiries about, my welfare benefits, disability benefits, disability pensions, or disability schemes	7.6%	9.2%	4.2%	15.1%	28.6%	35.3%	**79.0%**
I have submitted, but then withdrawn, my applications for welfare benefits, disability pensions or disability schemes	27.3%	28.2%	10.5%	8.0%	11.3%	14.7%	**34.0%**
I have forfeited welfare benefits, disability pensions or disability schemes that I was previously receiving	31.1%	36.1%	6.7%	5.9%	9.7%	10.5%	**26.1%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN WELFARE AND SOCIAL SERVICES

> *I have also faced issues with my welfare regarding being in a polyamorous relationship.*
>
> **Our Turn to Speak participant**
> **Western Australia**

The findings from survey statements in relation to other experiences of stigma and discrimination in welfare and social services, besides complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 10.7**. It can be seen that 49.5% of participants agreed that they had experienced stigma and discrimination in welfare and social services because of their physical health or ability, while 13.1% agreed that they had experienced stigma and discrimination in this domain because of their gender identity. Stigma and discrimination in connection with one's sexual orientation was not far off, at 12.6% of participants indicating agreement.

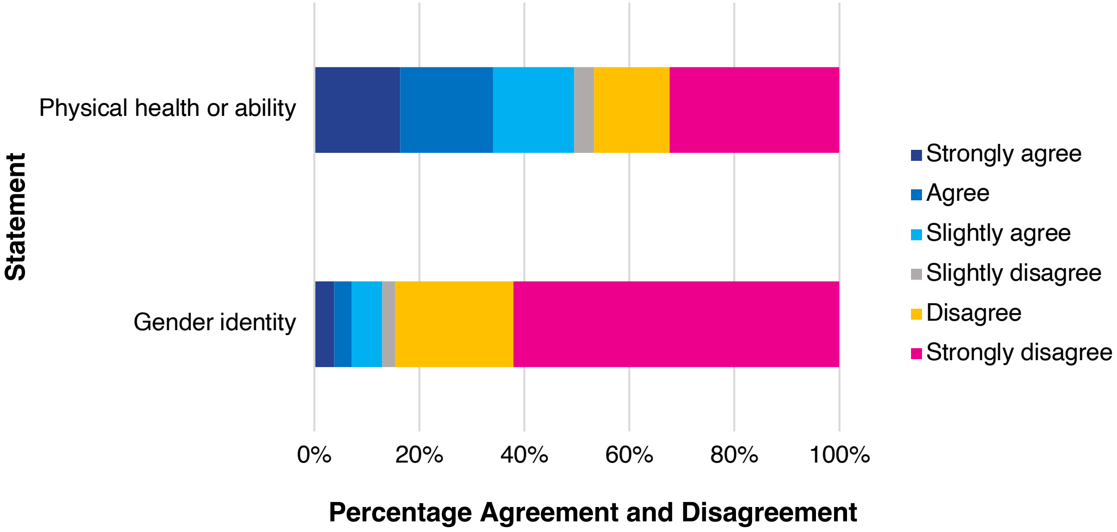


Figure 10.7. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *welfare and social services* (*n* = 238).

The specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting welfare and social services are summarised in **Table 10.6**. Overall, a relatively low rate of agreement was observed for statements describing experiences of stigma and discrimination when accessing welfare and social services due to personal characteristics other than complex mental health issues.

Table 10.6. Experiences of intersectional stigma and discrimination in *welfare and social services:* Percentage agreement and disagreement (*n* = 238).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in housing because of my…							
Racial or cultural background	65.5%	21.4%	3.4%	2.9%	4.6%	2.1%	**9.6%**
Faith or spiritual beliefs	67.2%	23.5%	2.9%	2.9%	2.5%	0.8%	**6.2%**
Sexual orientation	61.8%	22.3%	3.4%	6.3%	3.4%	2.9%	**12.6%**
Gender identity	61.8%	22.7%	2.5%	5.9%	3.4%	3.8%	**13.1%**
Physical health or ability	32.4%	14.3%	3.8%	15.5%	17.6%	16.4%	**49.5%**

POSITIVE EXPERIENCES IN WELFARE AND SOCIAL SERVICES

> *I was able to join an LGBT disability support job agency who were great with my needs.*
> **Our Turn to Speak participant**
> **Victoria**

The survey also asked about positive treatment in the welfare and social services domain. Two core statements comprised this section of the survey: (1) the expectation of special consideration because of one's experience of complex mental health issues, and (2) manifest positive experiences in education and training because of one's experience of complex mental health issues.

As shown in **Figure 10.8**, 73.1% of participants agreed that they should receive special consideration when accessing, retaining or using welfare and social services. By contrast, 29.4% agreed that they had experienced anything positive in connection to their complex mental health issues when accessing or using welfare and social services in the past 12 months.

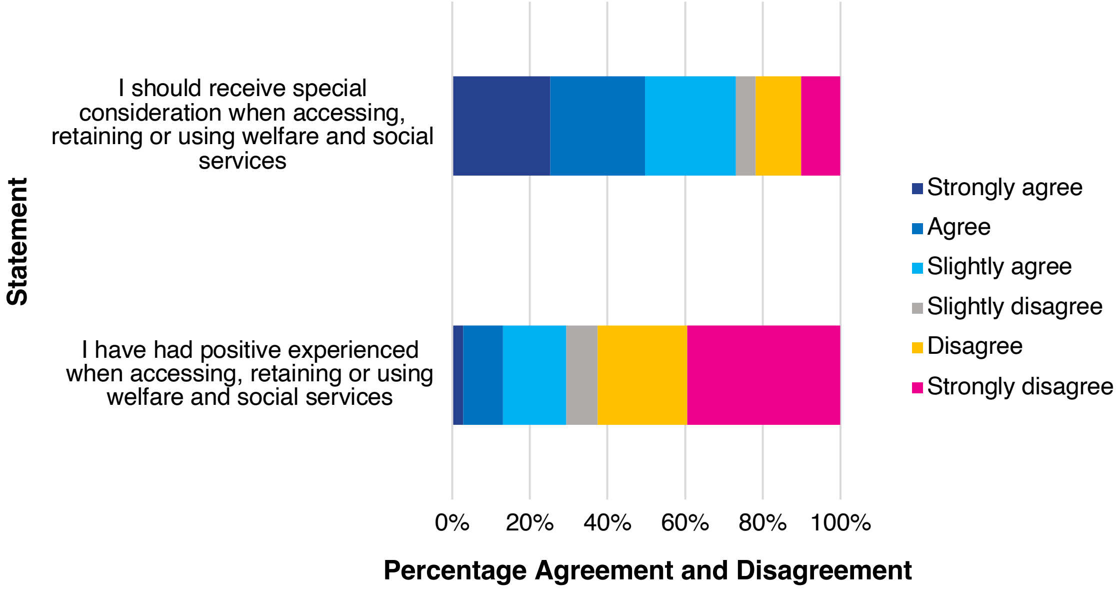


Figure 10.8. Highlight findings: responses to the statements regarding positive experiences in *welfare and social services* because of participants' complex mental health issues (*n* = 238).

SUMMARY OF QUALITATIVE FINDINGS IN WELFARE AND SOCIAL SERVICES

A key theme in this domain concerned barriers for people attempting to access welfare services. Several participants explained that they had been deemed ineligible due to various reasons, including, for example, because the DSP *"threshold is too high"*; they were *"not sick enough"* (or, alternatively, their particular situation was *"too complex"*); not meeting financial requirements; other requirements that were difficult to meet in an *"inflexible"* system; or due to administrative errors, as the following example comments illustrate:

> *I tried to apply for the DSP mainly due to my chronic illness but also my mental health issues - PTSD, anxiety and major depressive disorder but did not meet requirements when my GP assured me I would be able to get it easily. I was devastated and forced to apply for part time work which I am now participating in. Although I am having difficulties in coming to work even for my part time hours* (**Our Turn to Speak** participant, Queensland).
>
> *I am unable to work to support myself because of my mental health, but I am not "sick enough" to be receiving centerlink benefits which then makes me feel very hopeless* (**Our Turn to Speak** participant, Victoria).
>
> *…My plan is minimal because I do not have my needs met, including essential equipment for my mobility impairment. I cannot get that through statewide programs, because I am an NDIS participant. Equally service providers refuse to work with me saying I am too complex. I now have no supports, no way of getting supports. I have not left my home in over 4 months, have not used the telephone or sent an email or text message. I am literally waiting to die, as I am deemed too complex. NDIA told me to sort it out myself* (**Our Turn to Speak** participant, Victoria).
>
> *I have an adequate NDIS plan that includes funding for personal care as I have physical limitations due to my chronic neurological illnesses, in addition to my mental illnesses. However, I have had the plan for six months but am yet to receive any personal care because all the agencies we have sent referrals to have rejected it on the basis that my mental health problems make me 'too complex' a client* (**Our Turn to Speak** participant, Victoria).

A few participants commented that they did not know why they were rejected after seemingly meeting requirements and providing all the necessary documentation.

Another barrier mentioned by many participants was that welfare services were particularly difficult to navigate. One participant described the NDIS as: *"Extremely ableist and hard to navigate. Almost impossible to navigate. It is designed for people with diasbilities but is poorly designed. It is poorly designed for people with mental illness…"* (**Our Turn to Speak** participant, Victoria). Another reflected that: *"The NDIS application & approval process is still woefully unsuitable for psychosocial disability, & the process of applying is traumatic, invalidating, & damn near impossible with limited support…"* (**Our Turn to Speak** participant, Queensland). Specific challenges in navigating welfare services included unhelpful staff, long waiting periods, and gaining and completing the required documentation, especially without adequate support during this process. Another participant expressed their frustration as follows:

> *The process of applying for social welfare is extremely infuriating for anyone, but when run down and already wishing I'm not alive, it feels beyond unjust that there are so many hoops to jump - basically, only the people who ARE fit are capable of accessing welfare. I am constantly enraged when this realisation hits me, and it has a negative effect on my mental and physical health. I wish something could be done to right this fundamentally flawed element of our society and welfare system* (**Our Turn to Speak** participant, Western Australia).

Many participants shared experiences of poor treatment in the welfare system, whether through the actions of staff or automated processes. Some used words such as *"threatening"* and *"punitive"* to describe the system or aspects of it. Several commented, furthermore, on the impact (including but not limited to things like Robodebt or the prospect of an audit or reassessment of need) in feelings of worthlessness, hopelessness, being judged and told they *"should be able to cope"*, increased stress, and triggering or exacerbating their mental health issues. One participant described a situation whereby: *"In trying to set up my partner as my primary carer at centrelink I was handed a child's A-Z book of animals and told to "...read that while the adults speak" by a centrelink staff member" (***Our Turn to Speak** participant, Victoria). Another explained that the anticipated impact on their mental health resulted in their decision not to seek assistance: *"I am planning to return to study next year, but won't be applying for financial assistance. I couldn't handle the stress of an audit when I always do the right thing"* (**Our Turn to Speak** participant, Western Australia).

Several participants noted an apparent lack of mental health training and need for more training among staff at welfare services – most commonly the NDIS, Centrelink, and disability employment services. One participant suggested that: *"Centrelink should definitely have a set of staff who are trained to deal with Mental Health clients. I'd be surprised if there haven't been 'crashes' or even suicides after talking to some of their staff and getting trapped in their red tape"* (**Our Turn to Speak** participant, Victoria).

When asked about positive experiences in the welfare services domain, several shared negative experiences, and a few shared experiences that were mixed. For example:

> *There are some positive experiences from the local centrelink office, there's been understanding and flexible in helping me understand the paperwork. it is hit and miss depending on who you get. But systems overall aren't very hopeful and tend to exacerbate mental health issues from most people. i've experienced it and a lot of people try and avoid having to deal with these systems in the first place because of it. I put off applying with centrelink for a few years because of the stigma and discrimination - the system is not designed to be flexible. mainly avoided because my mental health just crashed at having to walk into their office and deal with them* (**Our Turn to Speak** participant, New South Wales).

Nonetheless, many participants had positive experiences to share. These included, for instance, positive interactions with a worker, carer, or organisation; being connected to other supports; being given priority, and receiving a transport allowance;

> *Re my robodebt, the last person I spoke to at Centrelink was very helpful and understanding. She understood my stress levels associated with the situation and determined that she would make the decision that day to save me further stress and angst. This was very much appreciated* (**Our Turn to Speak** participant, South Australia).
>
> *Not all the support services have been negative. Some have been fantastic. The RSL could not help me with many of my problems, but they were wonderful supplying a kind listening ear and company at times and after an initial run in with a local Policeman, he listened to my story and my family and he thought I had been very much overlooked by the system and he organised help with some great social support networks which have been a great help, particularly getting my family to understand my problems much better* (**Our Turn to Speak** participant, New South Wales).

A number of participants commented that they were not expecting special treatment or consideration from welfare services, but rather treatment that was trauma-informed, conveyed greater consideration and understanding of their experiences, and that was fair and accessible, for example.

When participants were asked about other factors that may have compounded their experiences of mental health stigma in this domain, responses most often included physical health. Others included physical appearance, weight, disability, race, age, relationship type, sexual orientation, and educational status.

SUMMARY

Of 1,912 participants who took part in the **Our Turn to Speak** survey, 12.4% (*n* = 238) identified welfare and social services as one of up to three life domains that had been most affected by stigma and discrimination in connection with complex mental health issues. Sixty-three percent of participants who selected the welfare and social services domain as one of their most affected life domains in the past 12 months indicated ‘frequent’ or ‘very frequent’ experiences of stigma and discrimination in this aspect of their lives.

When presented with a range of statements describing general and specific examples of stigma and discrimination in welfare and social services, it was apparent that interactions with staff/providers and inflexibility within the system itself, were driving perceptions of stigma and discrimination in this domain. Between 70.6% and 79.8% of participants agreed that they had been treated unfairly: (a) when applying for welfare benefits, disability pensions or disability schemes, (b) by welfare agency or social services staff specifically, and (c) were denied welfare benefits, disability pensions or disability schemes because their mental health issues were unfairly determined not to meet eligibility criteria. The latter experience was prominent in participants’ qualitative comments. 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’.

As described by **Our Turn to Speak** participants, and reported elsewhere (Malbon, Carey, & Meltzer, 2019; Milner, Kavanagh, McAllister, & Aitken, 2020; Saffer, Nolte, & Duffy, 2018), support systems such as the DSP and NDIS are incredibly challenging for people to access, navigate, use, and maintain due to a host of systemic barriers like changes to eligibility criteria; even with advocacy and assistance from family, carers, and/or health professionals. For 49.5% of participants, stigma and discrimination in relation to their physical health and (dis)ability unfortunately compounded the challenges to accessing and making use of welfare and social services.

Rates of agreement with statements describing various kinds of anticipated discrimination relevant to welfare and social services were somewhat higher than for perceived experiences of stigma and discrimination. A majority of participants (> 70%) agreed with all five statements describing expectations of unfair treatment in the process of applying for and maintaining welfare benefits, disability pensions or disability schemes. Concerningly, 72.3% of participants endorsed concerns that their welfare benefits, disability pensions or disability schemes might be unfairly suspended or cancelled in the future. Participants’ qualitative comments elaborated on these concerns. Several participants were clearly worried about the outcomes of audits or re-assessment procedures that might decide against their continued access to supports. Some participants mentioned that they feared receiving a ‘Robodebt’; an automated income compliance debt calculated on the basis of averaged income taxation data irrespective of the recipient's actual income. Since 2015, an estimated 600,000 Robodebts have been issued and is now the subject of a class action (Gordon Legal, 2020). In the context of this high-profile example of structural discrimination, and the numerous examples of other instances of systemic and interpersonal forms of discrimination experienced by participants, it is understandable that so many live in anticipation of future stigma and discrimination in this aspect of their lives.

Some participants explained that their expectations for future stigma and discrimination influenced their decision not to apply for welfare and social services at all. Indeed, 64.4% of participants agreed that they had stopped themselves from applying for welfare benefits, disability pensions or disability schemes because of stigma about mental health issues. Seventy-nine percent had stopped themselves from making changes, or even simple enquiries, about the supports they were receiving. Again, participants stated fears for possible adverse consequences – like being re-assessed as no longer eligible for supports or negatively judged by welfare and social services staff – are relevant here. In contrast with most other life domains examined in the **Our Turn to Speak** survey, the average rate of agreement with statements describing withdrawal from opportunities relevant to welfare and social services was much lower compared with the average rate of agreement for experienced and anticipated stigma and discrimination. This is because comparatively fewer participants (< 35%) had forfeited welfare benefits or supports they were already receiving, or had submitted but then withdrawn applications for such supports, because of stigma.

The lower rates of agreement in relation to these potential outcomes of stigma make sense given how challenging it can be for welfare and disability support to be approved in the first instance (National Social Security Rights Network, 2018); and in the context of the socioeconomic disadvantages already faced by people living with complex mental health issues (Allen et al., 2014; Isaacs et al., 2018). In other words, what – often inadequate (Li et al., 2019; Malbon et al., 2019) – supports one can access is perceived as hard fought for, greatly needed, and therefore unlikely to be relinquished.

Relatively few participants (29.4%) agreed that they had experienced any positive treatment in welfare and social services because of their experience of mental health issues. When participants did describe positive experiences, it was apparent that understanding about the nature and impact of mental health issues and compassionate care by welfare and social services staff, was critical. Indeed, participants similarly conveyed a desire, not necessarily for 'special consideration' in their dealings with these services and supports, but for a system that demonstrated an understanding of the unique and intersecting needs of people living with complex mental health issues. The majority (73.1%) were in support of receiving special consideration to help them overcome barriers to accessing, retaining or making use of welfare and social services.

While welfare and disability services are intended to provide support to people when they need it the most, recent research has found that Australian DSP recipients actually experienced a deterioration to their mental health over and above of the effect of living with a disability (Milner Kavanagh, McAllister, & Aitken, 2020). The harms associated with receiving the DSP were attributed to stigma and the psychosocial stressors involved in applying for and maintaining that support. These findings appear to support this interpretation and points to a need for system-wide reform to welfare and social services to meet the needs of those living with complex and mental health issues.

EDUCATION AND TRAINING

11

Chapter 11. Education and training

The opportunity to participate in education and training is essential to enabling an individual's future economic, social, and cultural capital and participation.

Approximately 63% of people with mental health conditions are reported to have no post-school qualifications (Australian Bureau of Statistics, 2003). This compares to 50% for people living with a physical disability. The onset of mental illness can impact primary, secondary and tertiary educational attainment, and engagement with vocational training. This can in turn disrupt career development. For psychotic disorders, this may occur because the typical age of onset is between 10 and 30 years, which coincides with the critical career stages of completing formal education and establishing a career pathway (Waghorn & Lloyd, 2005).

This chapter examines how people living with a range of complex mental health issues experience stigma and discrimination in terms of accessing and completing education and training opportunities in Australia.

OVERVIEW

Almost 60% (*n* = 1147) of all **Our Turn to Speak** participants reported experiencing some level of stigma or discrimination in education and training during the past 12 months.

As shown in **Figure 11.1**, 14% of all participants reported 'frequent' or 'very frequent' stigma and discrimination in education and training, and 10.5% (*n* = 200) identified this life domain as one of three in which they had been most affected by such experiences. **Figure 11.1** also shows that that 46.5% of participants who selected the education and training domain reported 'frequent' or 'very frequent' rates of stigma and discrimination in this aspect of their lives; much higher than was reported by the total sample.

This chapter focuses on the characteristics and experiences of those 200 participants who selected education and training as one of their top three, most affected life domains.

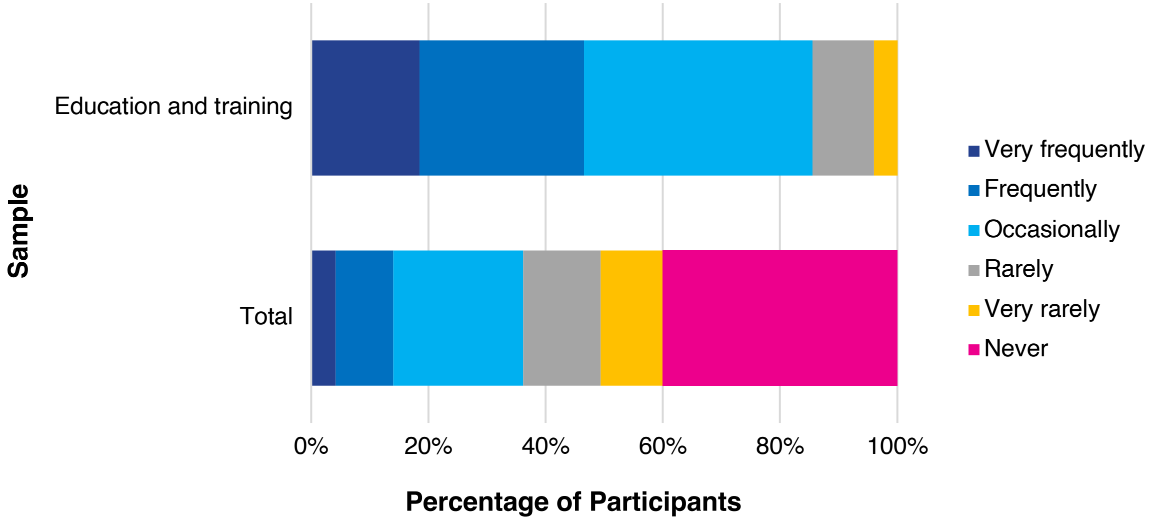


Figure 11.1. Frequency of stigma and discrimination in *education and training* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 200) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

Overall, the sociodemographic characteristics of participants who identified as being significantly affected by stigma and discrimination in education and training were not dissimilar from the wider cohort (see **Table 11.1**).

Participants who selected this life domain were slightly younger compared with the average age of the total sample. A greater proportion reported secondary college as their highest level of education compared with the total sample, which was characterised by a greater proportion of participants who completed post-secondary college education (that is, higher education). Compared with the total sample, slightly more participants who selected the education and training domain were gay, lesbian, bisexual, pansexual, queer or asexual; experienced a co-occurring physical health condition; and lived in a major city, compared with the total sample.

Table 11.1. Sociodemographic characteristics: *education and training* sample compared with the total sample.

Characteristics		Education and Training (*n* = 200)	Total (*N* = 1912)
Mean age		34.31 (*SD* = 12.92)	39.21 (*SD* = 12.81)
Gender identity			
	Female	81.0%	78.9%
	Male	14.0%	18.0%
	Trans, gender diverse and/or non-binary	7.0%	4.9%
	Unsure or questioning	1.0%	0.9%
	Prefer not to say	0.5%	0.4%
Relationship status			
	Not in a relationship	55.0%	52.1%
	In a relationship	45.0%	47.3%
	Prefer to self-describe	0.0%	0.2%
Sexual orientation			
	Heterosexual	54.0%	62.0%
	Gay, lesbian, bisexual, pansexual, queer, and/or asexual	45.0%	35.6%
	Unsure or questioning	6.5%	4.9%
	Prefer to self-describe	1.0%	1.5%
	Prefer not to say	1.0%	1.7%
Education (highest level attained)			
	Primary school	3.0%	1.6%
	Secondary college (high school)	27.5%	20.9%
	Educated post-secondary college	69.5%	77.4%
	Other	0.0%	0.2%
Employment			
	Engaged in paid work	46.5%	51.7%
	Engaged in unpaid work or studying	53.0%	28.7%
	Unemployed or unable to work	23.5%	22.8%
	Receiving a pension or benefits	25.0%	24.6%
	Other	0.0%	0.2%
State			
	Australian Capital Territory	3.5%	2.5%
	New South Wales	22.0%	23.6%
	Northern Territory	0.0%	0.6%
	Queensland	17.5%	15.9%
	South Australia	11.0%	9.5%
	Tasmania	4.5%	3.7%
	Victoria	30.5%	33.1%
	Western Australia	11.0%	10.9%
Region*			
	Major city	80.4%	74.2%
	Regional or remote	19.6%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

Table 11.1 also shows that, compared with the total sample, approximately 5% fewer participants who selected the education and training domain were engaged in paid work (full-time, part-time or casual) and 24% more of these participants were instead engaged in studies or unpaid work (like caring duties or volunteering).

Figure 11.2 shows in greater detail the employment status of participants who selected the Education and Training domain compared with the total sample. A much greater proportion of participants who selected the education and training domain were volunteering, much fewer were employed full-time, and almost 50% (*n* = 93) were studying.

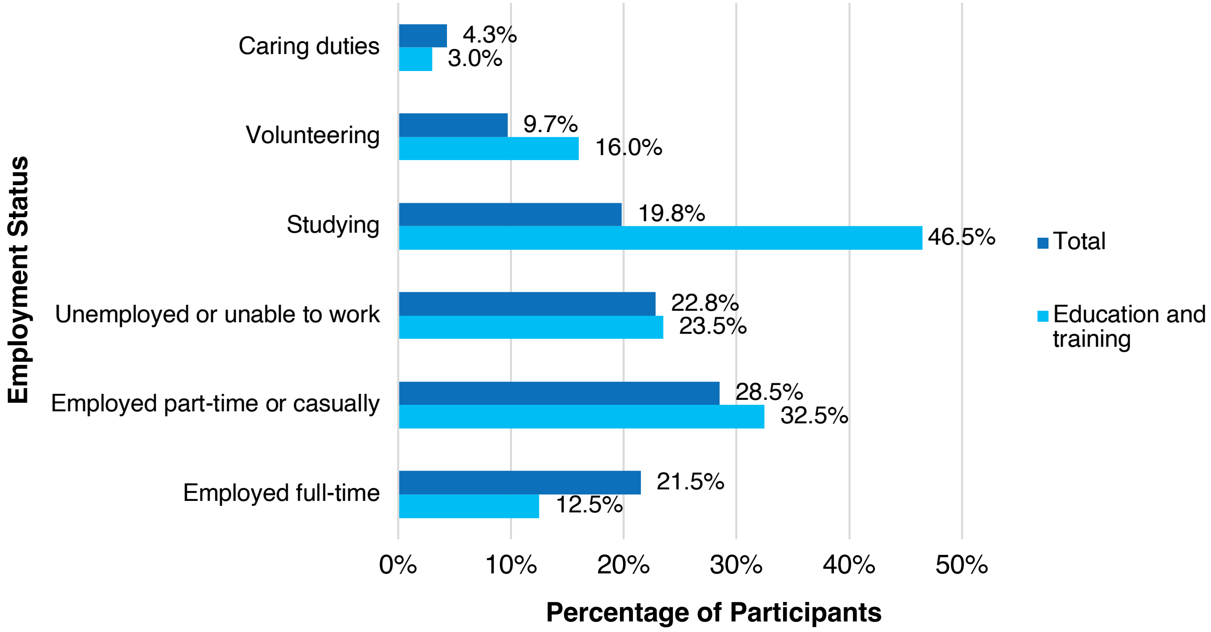


Figure 11.2. Employment status among participants who selected *education and training* as one of three domains in which they had been most affected by stigma during the past 12 months (*n* = 200) compared with the total sample (*N* = 1912).
Note. Percentages do not add to 100 as participants could select more than one response option.

As with the sociodemographic data, the mental and physical health characteristics of participants who identified the education and training domain as having been most affected by stigma and discrimination were similar to those of the total sample.

Shown in **Table 11.2**, slightly fewer participants who selected the education and training domain reported a primary diagnosis of a bipolar related disorder compared with the total sample.

Table 11.2. Mental and physical health characteristics: *education and training* sample compared with the total sample.

Characteristics	Education and Training (*n* = 200)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	7.5%	7.4%
Bipolar related disorder	13.0%	17.2%
Obsessive-compulsive related disorder	4.0%	4.3%
Trauma-related or dissociative disorder	24.5%	25.9%
Eating disorder	10.0%	6.1%
Personality disorder	13.5%	14.5%
Severe and treatment-resistant depressive disorder	14.0%	14.3%
Severe and treatment-resistant anxiety disorder	13.5%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	57.0%	53.8%

METHODS SNAPSHOT

Participants who identified relationships as one of three life domains in which they have been most affected by stigma-related experiences completed the education and training section of the survey. Education and training included that which was undertaken on a part-time or full-time basis, at private or public institutions, across:

- secondary (high school) education
- short courses
- vocational training or trade courses
- undergraduate and postgraducate degrees

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in their education and training; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of education and training. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further elaborate on and describe their experiences of stigma and discrimination because of: (a) complex mental health issues, (b) in relation to other personal characteristics, and (c) their experiences of positive treatment. Additional comments in relation to these experiences were given by 65, 19 and 46 participants, respectively.

STIGMA AND DISCRIMINATION IN EDUCATION AND TRAINING

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in education and training, which will be further examined in sections that follow.

As shown in **Figure 11.3**, the average total level of agreement with all statements describing perceived experiences of stigma and discrimination in education and training was about 50%. At close to 60% and 70%, the average level of agreement was greater still for anticipated stigma and discrimination, and withdrawal from opportunities, respectively. In other words, participants typically agreed that, more often than not, they expected to be discriminated against when applying for, or engaging in, education and training.

Similarly, participants typically agreed that, more often than not, they had stopped themselves from accessing opportunities relevant to education and training (like applying for scholarships, bursaries, and entry to courses or seeking flexible study arrangements).

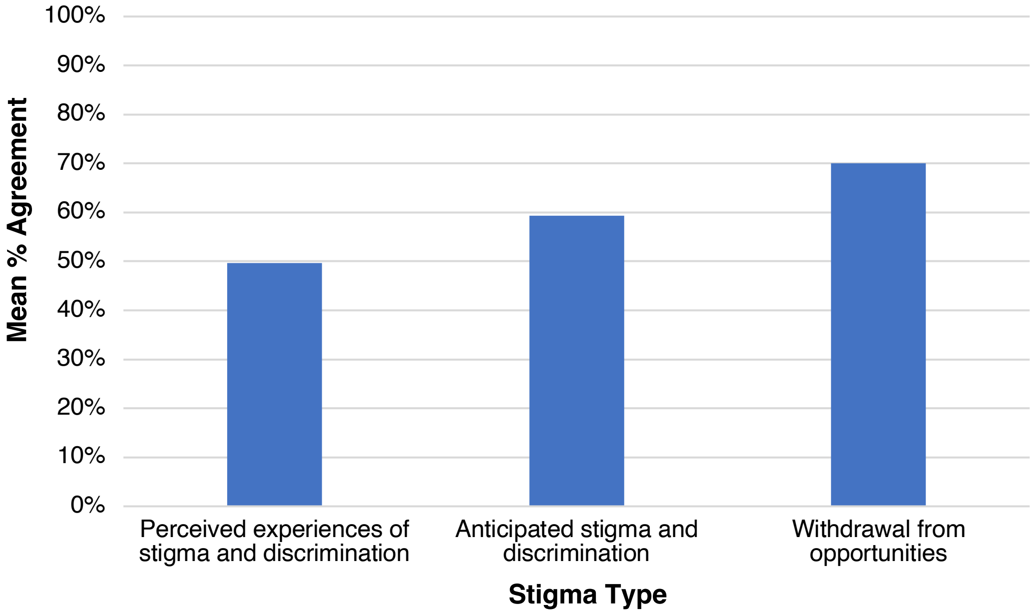


Figure 11.3. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in education and training (n = 200).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN EDUCATION AND TRAINING

> ***When I was in secondary school I was given very little support […] as the teacher did not know how to manage my difficulties and most of the teachers just did not get me. I was just left to play games on my computer up the back of the class. I felt as though I was worthless and that I would not amount to anything as no one would ever give me a job. Since I commenced at TAFE things have improved.***
>
> **Our Turn to Speak participant**
> **Queensland**

Presented in this section are the findings regarding participants' perceived experiences of stigma and discrimination in education and training, as related to their experience of complex mental health issues.

Figure 11.4 highlights the findings from the two most frequently endorsed issues from the set of five statements that participants answered in this section of the survey. As shown, 66.5% of participants agreed that they had been treated unfairly by teachers, lecturers, tutors or trainers in the past 12 months because of stigma about complex mental health issues. Close to 60% perceived that they had been unfairly denied flexible study arrangements.

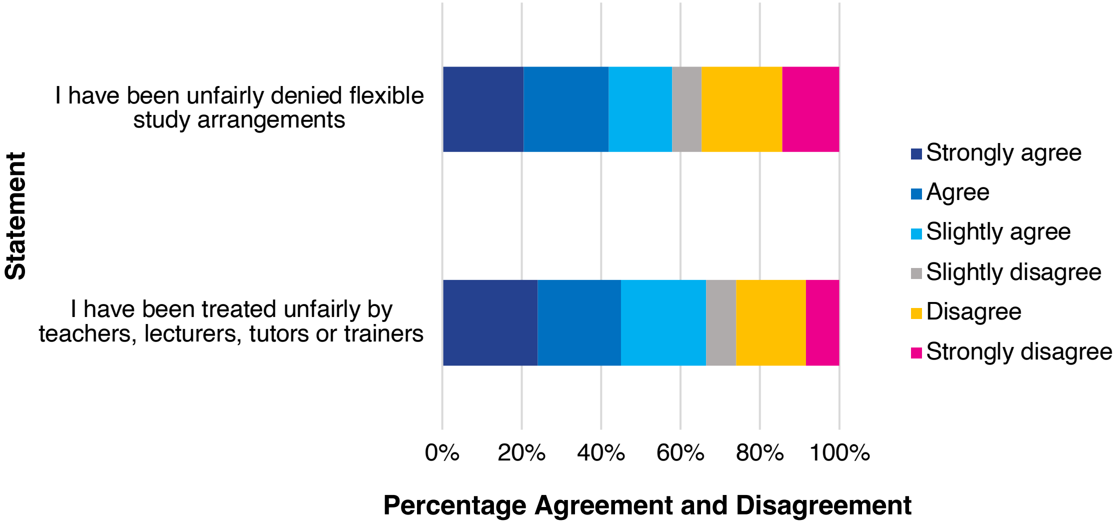


Figure 11.4. Highlight findings: the two most frequently endorsed statements describing perceived experiences of stigma and discrimination in *education and training* (*n* = 200).

Table 11.3 provides the specific levels of agreement and disagreement for all statements relevant to perceived experiences of stigma and discrimination in education and training.

While rates of agreement in relation to different forms of stigma and discrimination were not as high as those highlighted in **Figure 11.4**, they were still meaningful.

Of note, 42% of participants agreed that they had been unfairly asked to give up their education or training because of stigma about mental health issues in the past 12 months, and 39.5% agreed that they had been unfairly denied opportunities in education or training such as access to scholarships, bursaries, or entry into courses.

Table 11.3. Experiences of stigma and discrimination in *education and training*: Percentage agreement and disagreement (n = 200).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when applying for education or training courses	17.0%	27.5%	13.0%	18.0%	13.5%	11.0%	**42.5%**
I have been unfairly denied education or training opportunities (eg. scholarships, bursaries, entry into courses)	22.0%	29.0%	9.5%	13.5%	14.0%	12.0%	**39.5%**
I have been unfairly asked to give up my education or training	20.5%	30.0%	7.5%	15.0%	15.0%	12.0%	**42.0%**
I have been treated unfairly by teachers, lecturers, tutors or trainers	8.5%	17.5%	7.5%	21.5%	21.0%	24.0%	**66.5%**
I have been unfairly denied flexible study arrangements	14.5%	20.0%	7.5%	16.0%	21.5%	20.5%	**58.0%**

ANTICIPATED STIGMA AND DISCRIMINATION IN EDUCATION AND TRAINING

> *I know there is a high chance I will experience at least some misunderstanding or judgement, and I have enough to deal with, so as a result, I experience less stigma because I don't put myself in the position to experience it.*
> **Our Turn to Speak participant**
> **Queensland**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in education and training, as related to their experience of complex mental health issues.

Figure 11.5 highlights the findings from the two most frequently endorsed issues from the set of five statements that participants rated in this section of the survey. As shown, almost 70% of participants agreed that they expected to be treated unfairly by their teachers, lecturers, tutors, or trainers because of stigmatising beliefs about mental health issues. Just over 60% of participants expected to be unfairly denied flexible study arrangements. These figures are reflective of the high rates of perceived experiences of stigma and discrimination in the same areas, as described earlier (see **Figure 11.4**).

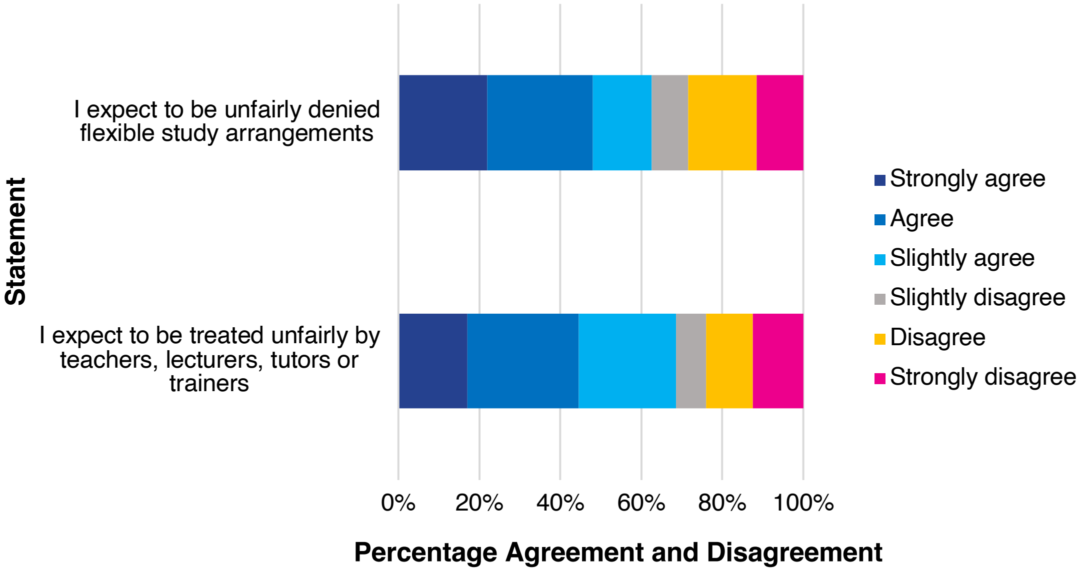


Figure 11.5. Highlight findings: the two most frequently endorsed statements describing anticipated stigma and discrimination in *education and training* (*n* = 200).

Table 11.4 provides the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in education and training.

As shown, over 50% of participants agreed to the remaining statements not highlighted in the **Figure 11.5**, and the level of agreement for anticipated stigma and discrimination in education and training was higher in comparison with ratings of equivalent statements describing perceived experiences of stigma and discrimination. Of note, close to 60% of participants expected that they would be treated unfairly when applying for education or training courses.

Table 11.4. Anticipated stigma and discrimination in *education and training*: percentage agreement and disagreement (*n* = 200).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when applying for education or training courses	16.0%	16.0%	9.5%	21.0%	26.0%	11.5%	**58.5%**
I expect to be unfairly denied education or training opportunities (eg. scholarships, bursaries, entry into courses)	17.0%	17.5%	9.0%	15.5%	26.0%	15.0%	**56.5%**
I expect to be unfairly asked to give up my education or training	15.0%	20.5%	11.0%	19.0%	23.0%	11.5%	**53.5%**
I expect to be treated unfairly by teachers, lecturers, tutors or trainers	12.5%	11.5%	7.5%	24.0%	27.5%	17.0%	**68.5%**
I expect to be unfairly denied flexible study arrangements	11.5%	17.0%	9.0%	14.5%	26.0%	22.0%	**62.5%**

WITHDRAWAL FROM OPPORTUNITY IN 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**

Presented in this section are the findings regarding participants' withdrawal from opportunities related to education and training, in connection with their experience of complex mental health issues.

Figure 11.6 highlights the two most frequently endorsed issues from the set of four statements that participants rated in this section of the survey. Just over 80% of participants agreed that, jn the past 12 months, they had stopped themselves from seeking support or assistance from teachers, lecturers, tutors, or trainers because of stigma about mental health issues. Seventy-two percent agreed that they had stopped themselves from asking for flexible study arrangements for the same reason.

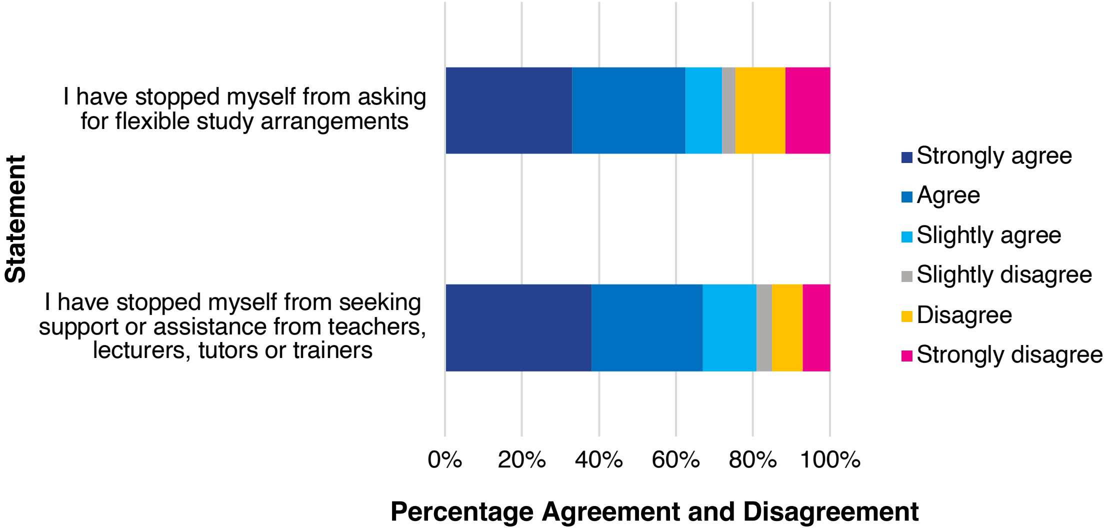


Figure 11.6. Highlight findings: the two most frequently endorsed statements describing withdrawal from opportunities in *education and training* (*n* = 200).

Table 11.5 provides the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in education and training.

As shown, over 60% of participants agreed to the remaining statements not highlighted in the **Figure 11.6**, and the level of agreement for statements describing withdrawal from opportunities in education and training was greater than was reported for both perceived experiences and anticipation of stigma and discrimination. Concerningly, 64.0% of participants agreed that they had stopped themselves from applying for education or training, 65.0% agreed that they had withdrawn from their education or training, and 68.0% had stopped themselves from applying for opportunities like scholarships, bursaries or entry to courses.

Table 11.5. Withdrawal from opportunities in *education and training:* percentage agreement and disagreement (*n* = 200).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from applying for education or training courses	15.0%	16.5%	4.5%	15.5%	21.0%	27.5%	**64.0%**
I have stopped myself from applying for education or training opportunities (eg. scholarships, bursaries, entry into courses)	12.0%	14.5%	5.5%	16.5%	24.0%	27.5%	**68.0%**
I have withdrawn from my education or training courses	15.5%	15.0%	4.5%	7.5%	24.5%	33.0%	**65.0%**
I have stopped myself from seeking support or assistance from teachers, lecturers, tutors or trainers	7.0%	8.0%	4.0%	14.0%	29.0%	38.0%	**81.0%**
I have stopped myself from asking for flexible study arrangements	11.5%	13.0%	3.5%	9.5%	29.5%	33.0%	**72.0%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN EDUCATION AND TRAINING

> ***Once being identified as part of the queer community, my placement supervisor treated me different and coupled with my mental illness subsequently failed me on my placement.***
>
> **Our Turn to Speak participant**
> **Victoria**

The findings from survey statements in relation to other experiences of stigma and discrimination in education and training, besides complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 11.7.** It can be seen that 44.5% of participants agreed that they had experienced stigma and discrimination in education and training because of their physical health or ability, while 18.0% agreed that they had experienced stigma and discrimination in education and training associated with their sexual orientation.

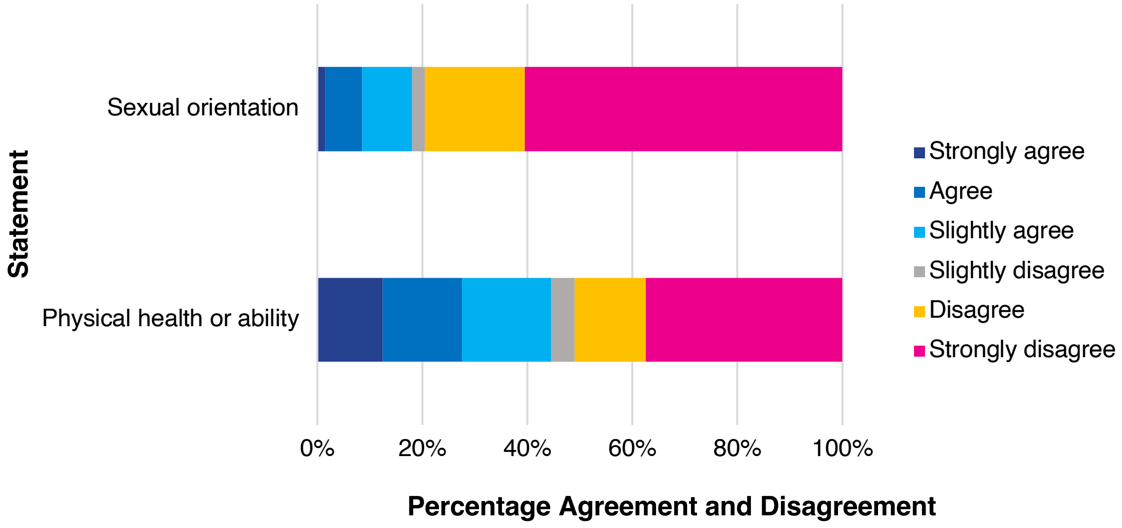


Figure 11.7. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *education and training* (*n* = 200).

The specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting education and training are summarised in **Table 11.6**. Overall, a relatively low rate of agreement was observed for statements describing experiences of stigma and discrimination in education and training due to personal characteristics other than complex mental health issues.

Table 11.6. Experiences of intersectional stigma and discrimination in *education and training*: percentage agreement and disagreement (*n* = 200).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in education and training because of my…							
Racial or cultural background	69.0%	18.0%	3.0%	4.0%	4.5%	1.5%	**10.0%**
Faith or spiritual beliefs	68.5%	20.5%	3.5%	2.0%	3.5%	2.0%	**7.5%**
Sexual orientation	60.5%	19.0%	2.5%	9.5%	7.0%	1.5%	**18.0%**
Gender identity	63.0%	20.0%	4.5%	4.0%	4.0%	4.5%	**12.5%**
Physical health or ability	37.5%	13.5%	4.5%	17.0%	15.0%	12.5%	**44.5%**

POSITIVE EXPERIENCES IN EDUCATION AND TRAINING

> ***Despite my relationship issues, I have made a lot of friends at university and do enjoy spending time with my fellow students. We have all been supportive of one and other* [sic] *with our activities at law school and have assisted each other in maintaining a positive outlook.***
>
> **Our Turn to Speak participant**
> **South Australia**

The survey also asked about positive treatment in the education and training domain. Two core statements comprised this section of the survey: (1) the expectation of special consideration in relation to complex mental health issues, and (2) manifest positive experiences in education and training because of one's experience of complex mental health issues.

As shown in **Figure 11.8**, 67.0% of participants agreed that they should receive special consideration when applying for or completing education and training. Fewer participants (35.5%) agreed that they had experienced anything positive in connection to their complex mental health issues when applying for, or in the course of completing, their education and training in the past 12 months.

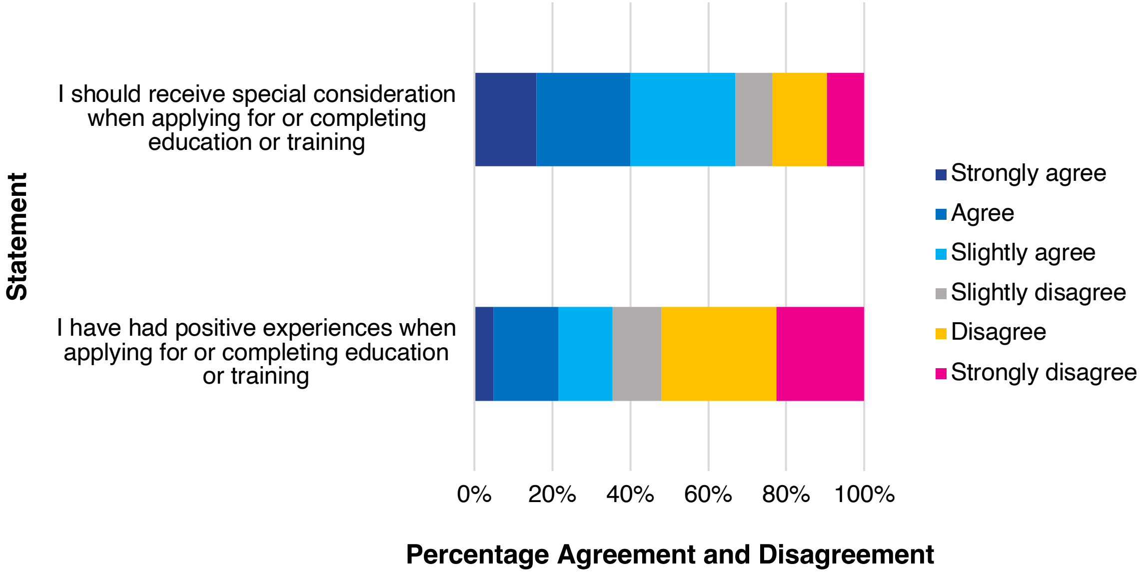


Figure 11.8. Highlight findings: responses to the statements regarding positive experiences in *education and training* because of participants' complex mental health issues (*n* = 200).

SUMMARY OF QUALITATIVE FINDINGS IN EDUCATION AND TRAINING

Several responses that participants provided about their experiences of stigma and discrimination in education related to accessibility. Examples included difficulty finding and navigating support services and enrolment (or re-entering the system after a period of hospitalisation, needing to defer, or other reasons for extended absence and difficulty meeting census dates); using a service dog; using technology; location; and asking for, and receiving, special consideration and flexible arrangements. As one participant explained:

> *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 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).

Another participant's experience of anticipated stigma prevented them from attending events such as university open days; *"My mental health issues have stopped me from reaching out in my university and attending open days, university events and student guild events because of the fear of discrimination and stigma of being judged for who I am and how I interact with students"* (**Our Turn to Speak** participant, Western Australia).

Others suggested challenges due to the impacts of trauma, memory loss, inability to concentrate, and lack of consistency in lecturers and tutors.

Numerous participants commented on the lack of support from education institutions (including schools, TAFEs, and universities) while experiencing mental health issues. Sometimes this manifested in interactions with a supervisor, but more often in difficulty organising flexible arrangements that would be accommodating of their complex mental health issues;

> *I am studying a PhD and my supervisor always makes inappropriate remarks about my illness and its impact upon my work. For example, she will say in a sarcastic tone that I must have written something while mentally unwell* (**Our Turn to Speak** participant, South Australia).

> *When being offered flexible study options I have been told that individualised arrangements are impossible to provide to students and I have to make do with the standard suit of adjustments offered to all students with mental health/disability support plans. If I don't think they are adequate I should reconsider study at higher education levels* (**Our Turn to Speak** participant, Queensland).

A further theme touched on by a number of participants was that of barriers to completion, including the need to defer or withdraw, or in some cases being withdrawn by the educational institution.

Several participants commented that they felt judged and misunderstood (by peers and staff), and a few commented that education provider staff suggested they should 'reconsider' their career pathways in healthcare settings.

> *I have been judged for having self-harm scars and treated differently because I opened up about my anxiety. One lecturer told me I wasn't fit to work in mental health because I suffer with it myself (when I was enquiring about studying Certificate IV in Mental Health at Tafe)* (**Our Turn to Speak** participant, Western Australia).

Some participants also shared their experiences of being bullied, and of feeling 'lost', 'alone', 'inadequate', 'hard work', 'dumb', or 'too hard to deal with', and 'a burden'.

As in other domains, when asked about positive experiences, some participants responded that they had none, or shared negative experiences, and some stated that they did not disclose their mental health issues; whereas some described a mix of positive and negative experiences, for example:

> *The positive I have had is I guess perspective, and being able to help and bond with other people because of shared experiences, really trying to counter the lack of mental health education people receive at school. It wasn't AS bad in high school, but the way my school treated me in primary was unacceptable* (**Our Turn to Speak** participant, Victoria).

A number of participants associated their lived experience of mental health issues with heightened empathy and understanding, and increased capacity as an advocate. Others discussed the positive impacts of receiving special consideration, flexible arrangements, and other resources and supports; as well as supportive staff, peers, and educational institutions.

Echoing comments in other domains, one participant explained that they wanted more understanding:

> *I am not asking to be put on a pedestal up high for special consideration, I simply want people to understand and have consideration for times when the black dog sits at my side and all motivation is gone or when my voices are so loud I just cannot think, or when my head is so muddled with drugs that a simple sentence is a near impossible task* (**Our Turn to Speak** participant, Queensland).

Some commented that they felt special consideration was not appropriate or depended on the situation; and one participant pointed out that the term *"implied that I am unable to participate without first being excluded on some basis and then offered a helping hand based on disablist mentality"* (**Our Turn to Speak** participant, Queensland).

With regards to other factors that may have compounded participants' experiences of mental health stigma in education, participants responses included physical disability, physical appearance, weight, physical health, sexual orientation, gender, geographic location, race, and faith.

SUMMARY

Of 1,912 participants who took part in the **Our Turn to Speak** survey, 10.5% (*n* = 200) identified education and training as one of up to three life domains that had been most affected by stigma and discrimination in connection with complex mental health issues. Just over 45% of participants who selected the education and training domain as one of their most affected life domains in the plast 12 months indicated 'frequent' or 'very frequent' experiences of stigma and discrimination in this aspect of their lives.

When presented with a range of statements describing general and specific examples of stigma and discrimination in education and training, it became clear that interactions with educational or training staff and inflexibility around study arrangements were driving perceptions of stigma and discrimination in this domain. Over 66% of participants agreed that they had been treated unfairly by teachers, lecturers, tutors or trainers, and 58% perceived that they had been unfairly denied flexible study arrangements because of stigma about mental health issues. While not as high, 42% of participants perceived that they had been unfairly asked to give up their education or training because of stigmatising beliefs about complex mental health issues. Being asked to withdraw from one's education or training may be a consequence of inadequate supports, special consideration or flexibility provided to students or trainees experiencing mental health issues, which otherwise make it difficult to engage in, and successfully complete, their course requirements. This was evident in participants' qualitative comments; for instance, many participants explained how the cognitive, emotional and social impacts of experiencing complex mental health issues acted as barriers to both attending classes and training placements, and to completing associated coursework and assignments to the required standard and timeframe. Without adequate institutional supports, participants often explained that they were failed, had to defer or withdraw from their education entirely, and some were even advised to reconsider their educational and career goals. The latter experience suggests that some educational providers – who are often gatekeepers into specific career pathways and professional roles – hold mistaken beliefs about the capacity for effective and meaningful workforce participation among people with a lived experience of complex mental health issues.

Stigma and discrimination in relation to other personal characteristics, such as physical health and (dis)ability in particular, only compounded the challenges of pursuing and successfully completing education and training. Almost 45% of participants agreed that they had experienced stigma and discrimination in their education and training because of their physical health issues.

Rates of agreement with statements describing various kinds of anticipated discrimination, and withdrawal from opportunities relevant to education and training, were somewhat higher than for perceived experiences of stigma and discrimination. In terms of anticipated stigma and discrimination, rates of agreement were highest again for interactions with educational or training staff and inflexibility around study arrangements. Close to 70% of participants expected that they would be treated unfairly by teachers, lecturers, tutors or trainers, and 62.5% expected to be unfairly denied flexible study arrangements because of stigma about complex mental health issues. As one participant stated, “Asking for consideration is embarrassing and humiliating”. In the context of participants’ past experiences of stigma and discrimination, it is understandable that so many participants expressed reticence to seek reasonable accommodations and supports to help them engage in, and complete, their education or training. Such comments also indicate there may be a need for education and training providers to proactively reach out to students in need of supports.

Participants’ expectations for future stigma and discrimination were followed up with even higher rates of withdrawal from opportunity, as 81% of participants agreed that, in the past 12 months, they had stopped themselves from seeking support or assistance from teachers, lecturers, tutors or trainers. Seventy two percent agreed that they had stopped themselves from asking for flexible study arrangements. This can be interpreted as suggesting that participants do not feel emotionally safe to seek appropriate supports when needed. Participants’ qualitative comments indicated that, even when assistance is directly pursued, it is not always granted, and if granted, it is not necessarily tailored to one’s specific needs. Relatively few participants (35.5%) agreed that they had experienced any positive treatment in connection with their experience of mental health issues, and the majority (67%) were in support of receiving special consideration to help them overcome barriers to applying for, engaging in, and completing their education or training.

As others have reported, stigma about mental health issues often dissuades young people in higher education from seeking support for their concerns, and limited understanding about mental health issues on the behalf of university staff and administrators can lead to ineffectual interventions when students do seek help (Orygen The National Centre of Excellence in Youth Mental Health, 2017). These findings suggest that these experiences are not limited to young people attending university but are relevant to students and trainees of all ages and across the tertiary education sector.

FINANCIAL AND INSURANCE SERVICES

12

Chapter 12. Financial and insurance services

Access to banking products are an important part of almost all of our lives. Insurance allows us to protect our income and to continue providing for those who rely on us, should we become unwell, injured, or pass away.

A number of recent enquiries have found that structural discrimination exists within the banking and financial services sector, which impacts on individuals who experience mental health issues. This has been particularly highlighted in the insurance industry where people who have experienced or sought treatment for a mental health issue, regardless of severity, have found themselves denied coverage or forced to pay exorbitant premiums to secure coverage. In a number of well documented cases, those who have managed to secure coverage have found themselves unable to receive the benefit when they make a claim, with the reasons given being their experience of a mental health issue.

This chapter considers how people living with complex mental health issues experience stigma and discrimination in accessing financial and insurance services.

OVERVIEW

Just over 50% (*n* = 973) of all **Our Turn to Speak** participants reported experiencing some level of stigma or discrimination in financial and insurance services during the past 12 months.

As shown in **Figure 12.1**, 16.4% of all participants reported ‘frequent’ or ‘fery frequent’ stigma and discrimination in financial and insurance services, and 7.3% (*n* = 140) identified this life domain as one of three in which they have been most affected by such experiences. **Figure 12.1** also shows that 57.9% of participants who selected the financial and insurance services domain reported ‘frequent’ or ‘very frequent’ rates of stigma and discrimination in this aspect of their lives; substantially higher than was reported by the total sample.

This chapter focuses on the characteristics and experiences of those 140 participants who selected financial and insurance services as one of their top three, most affected life domains.

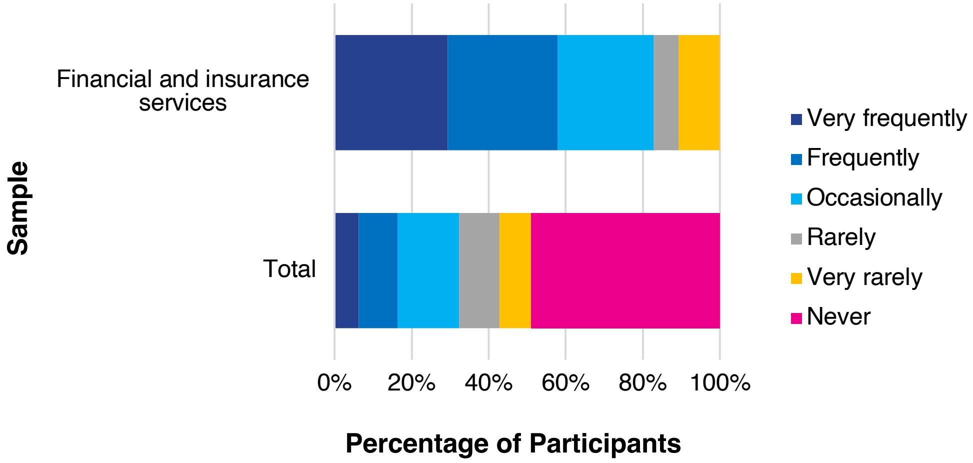


Figure 12.1. Frequency of stigma and discrimination in *financial and insurance services* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 140) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

Table 12.1 presents the sociodemographic characteristics of participants who identified as being personally affected by stigma and discrimination in financial and insurance services.

Participants who selected this life domain were slightly older compared with the average age of the total sample. A greater proportion were educated post-secondary college and engaged in paid work, whereas fewer participants who selected the financial and insurance services domain were engaged in unpaid work or studying compared with the total sample (14.2% compared with 28.7%).

Table 12.1. Sociodemographic characteristics: *financial and insurance services* sample compared with the total sample.

Characteristics		Financial and Insurance Services (*n* = 140)	Total (*N* = 1912)
Mean age		42.53 (*SD* = 11.03)	39.21 (*SD* = 12.81)
Gender identity			
	Female	75.7%	78.9%
	Male	22.9%	18.0%
	Trans, gender diverse and/or non-binary	1.4%	4.9%
	Unsure or questioning	1.4%	0.9%
	Prefer not to say	0.7%	0.4%
Relationship status			
	Not in a relationship	53.6%	52.1%
	In a relationship	46.4%	47.3%
	Prefer to self-describe	0.0%	0.2%
Sexual orientation			
	Heterosexual	62.1%	62.0%
	Gay, lesbian, bisexual, pansexual, queer, and/or asexual	35.7%	35.6%
	Unsure or questioning	2.9%	4.9%
	Prefer to self-describe	0.7%	1.5%
	Prefer not to say	2.1%	1.7%
Education (highest level attained)			
	Primary school	2.1%	1.6%
	Secondary college (high school)	15.7%	20.9%
	Educated post-secondary college	82.1%	77.4%
	Other	0.0%	0.2%
Employment status			
	Engaged in paid work	66.4%	51.7%
	Engaged in unpaid work or studying	14.3%	28.7%
	Unemployed or unable to work	17.9%	22.8%
	Receiving a pension or benefits	25.0%	24.6%
	Other	0.0%	0.2%
State			
	Australian Capital Territory	0.0%	2.5%
	New South Wales	24.3%	23.6%
	Northern Territory	0.7%	0.6%
	Queensland	17.9%	15.9%
	South Australia	7.9%	9.5%
	Tasmania	3.6%	3.7%
	Victoria	30.7%	33.1%
	Western Australia	15.0%	10.9%
Region*			
	Major city	76.4%	74.2%
	Regional or remote	22.1%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

As with the socidemographic data, the mental and physical health characteristics of participants who identified the financial and insurance services domain as having been most affected by stigma and discrimination were generally similar to those of the total sample (see **Table 11.2**).

Compared with the total sample, 9.2% more participants who selected this domain reported a primary diagnosis of a bipolar related disorder and 7.7% more were living with a trauma-related or dissociative disorder.

Table 12.2. Mental and physical health characteristics: *financial and insurance services* sample compared with the total sample.

Characteristics	Financial and Insurance Services (*n* = 140)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	8.6%	7.4%
Bipolar related disorder	26.4%	17.2%
Obsessive-compulsive related disorder	2.1%	4.3%
Trauma-related or dissociative disorder	33.6%	25.9%
Eating disorder	3.6%	6.1%
Personality disorder	7.1%	14.5%
Severe and treatment-resistant depressive disorder	15.0%	14.3%
Severe and treatment-resistant anxiety disorder	3.6%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	55.7%	53.8%

METHODS SNAPSHOT

Participants who identified financial and insurance services as one of three life domains in which they have been most affected by stigma-related experiences completed the financial and insurance services section of the survey. At the beginning of this section of the survey, participants were asked to indicate what types of services they had used, tried to use or wanted to use during the previous 12 months. Banking and insurance products described, included ut were not limited to:

- bank accounts (for example, savings or everyday spending accounts) and credit cards
- loans (for example, home loans, business loans and car loans)
- insurance coverage (for example, health insurance, life insurance, total and permanent disability insurance, indemnity insurance and income protection)

Close to 68% (*n* = 95) had accessed banking services and 73.6% (*n* = 103) had accessed insurance services. Participants were subsequently presented with only the questions that matched their reported financial and insurance services experiences. For example, participants who reported accessing banking services only during the last 12 months received questions corresponding to those services. Those who indicated they had accessed more than one type of financial and insurance service received questions corresponding to each of those areas.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in fincancial and insurance services; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of financial and insurance services. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further describe their experiences of stigma and discrimination in relation to: (a) complex mental health issues, (b) their other personal characteristics, and (c) any positive treatment in financial and insurance services. Forty-seven, 11 and 30 participants provided additional comments in relation to these experiences respectively.

STIGMA AND DISCRIMINATION IN FINANCIAL AND INSURANCE SERVICES

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in financial and insurance services, which will be further examined in sections that follow.

As shown in **Figure 12.2**, the average total level of agreement with all statements describing perceived experiences of stigma and discrimination in financial and insurance services was 59.7%. In other words, participants typically agreed that, more often than not, they had experienced stigma and discrimination because of complex mental health issues when trying to access or use banking and insurance products.

Similarly, the average total level of agreement with all statements describing anticipated stigma and discrimination, and withdrawal from opportunities in justice and legal services, was around 65%. In other words, participants typically agreed that they expected stigma and discrimination when accessing financial and insurance services and, more often than not, had stopped themselves from accessing such services (for example, claiming insurance rebates for mental healthcare services) because of stigma about complex mental health issues.

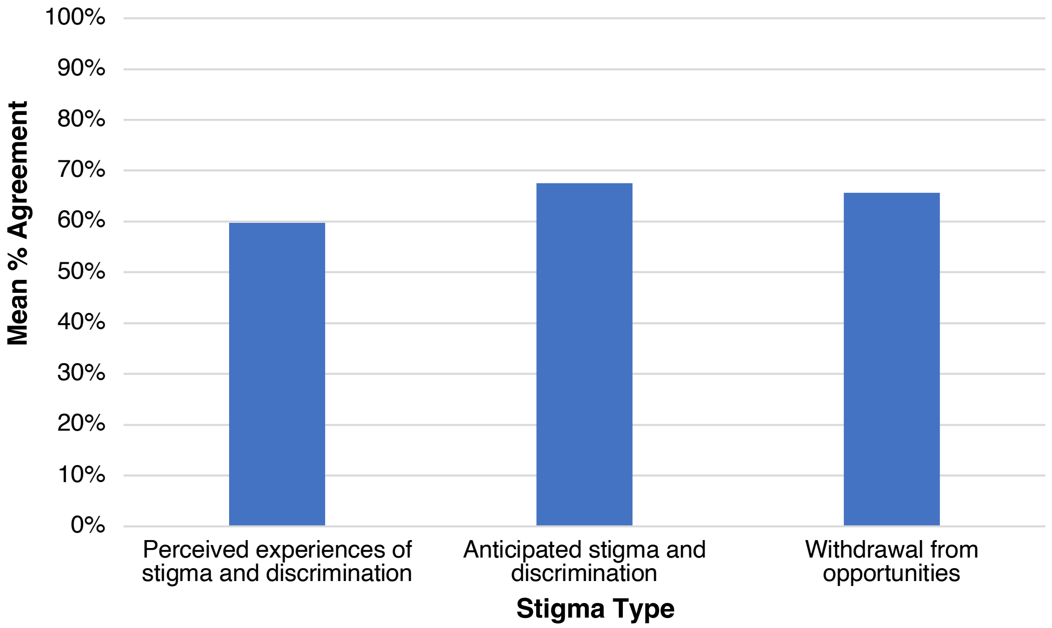


Figure 12.2. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *financial and insurance services* (*n* = 140).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN FINANCIAL AND INSURANCE SERVICES

> *I had car accident which all my mental and physical injuries are covered for lifetime and yet I was declined income protection because I admitted to diagnosis of PTSD.*
>
> **Our Turn to Speak participant**
> **Victoria**

Presented in this section are the findings regarding participants’ perceived experiences of stigma and discrimination in financial and insurance services, as related to their experience of complex mental health issues.

As shown, in **Figure 12.3**, across three of the four statements, perceived experiences of stigma and discrimination were much higher in relation to insurance services when compared to banking services. For instance, 89.4% of participants who had accessed insurance products during the last 12 months perceived that they had been treated unfairly when trying to apply for such products compared with 62.1% of participants who had tried to access banking products during the same time period.

Roughly the same proportion of participants who had accessed banking (26.3%) and/or insurance (24.3%) during the last 12 months agreed that these services had unfairly suspended or cancelled their financial products because of stigma about complex mental health issues.

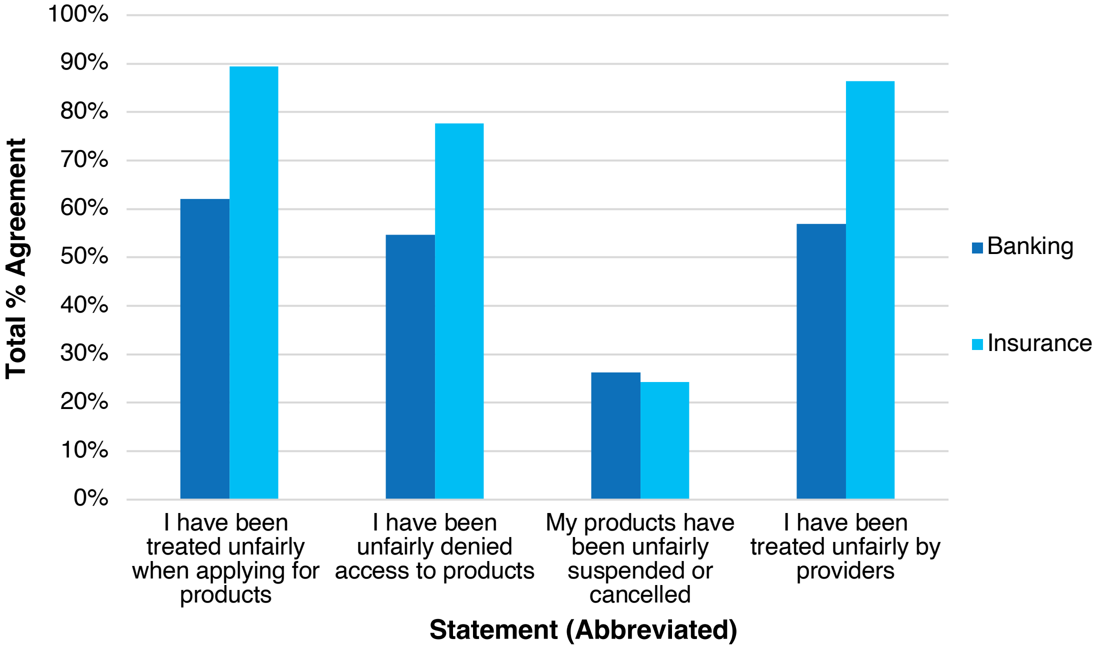


Figure 12.3. Highlight findings: total percentage agreement with perceived experiences of stigma and discrimination in *banking services* (*n* = 95) and *insurance services* (*n* = 103).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

Tables 12.3 and **12.4** provide the specific levels of agreement and disagreement for all statements relevant to perceived experiences of stigma and discrimination in banking and insurance services. The findings in these tables were summarised in relation to **Figure 12.3**.

Table 12.3. Perceived experiences of stigma and discrimination in *banking services*: percentage agreement and disagreement (*n* = 95).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when applying for banking products	9.5%	21.1%	7.4%	25.3%	18.9%	17.9%	**62.1%**
I have been unfairly denied access to banking products	11.6%	23.2%	10.5%	17.9%	18.9%	17.9%	**54.7%**
My banking products have been unfairly suspended or cancelled	27.4%	41.1%	5.3%	9.5%	6.3%	10.5%	**26.3%**
I have been treated unfairly by banking providers (e.g. mortgage lenders or loan providers)	14.7%	21.1%	7.4%	12.6%	23.2%	21.1%	**56.9%**

Table 12.4. Perceived experiences of stigma and discrimination in *insurance services*: percentage agreement and disagreement (*n* = 103).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total AgreeA
Because of stigma about mental health issues…							
I have been treated unfairly when applying for insurance products	3.9%	2.9%	3.9%	14.6%	28.2%	46.6%	**89.4%**
I have been unfairly denied access to insurance products	5.8%	11.7%	4.9%	9.7%	27.2%	40.8%	**77.7%**
My insurance products have been unfairly suspended or cancelled	31.1%	36.9%	7.8%	3.9%	5.8%	14.6%	**24.3%**
I have been treated unfairly by insurance providers	3.9%	6.8%	2.9%	16.5%	30.1%	39.8%	**86.4%**

ANTICIPATED STIGMA AND DISCRIMINATION IN FINANCIAL AND INSURANCE SERVICES

> *I worry about losing my current insurances and not being able to get cover again.*
>
> **Our Turn to Speak articipant**
> **Queensland**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in financial and insurance services, as related to their experience of complex mental health issues.

As shown in **Figure 12.4**, across all four statements, anticipated stigma and discrimination was much higher in relation to insurance services compared with banking services. For instance, 87.4% of participants who had accessed insurance services during the last 12 months expected to be treated unfairly when applying for insurance products compared with 61% of participants who had accessed, or tried to access, banking products during the same time period. Almost 90% of participants who had accessed (or tried to access) insurance services expected to be unfairly denied such products compared with 60% of participants who had accessed banking services during the last 12 months.

Over 80% of participants expected to be unfairly treated by insurance providers, while 68.4% expected the same in terms of banking providers. While fewer participants expected either type of service to unfairly suspended or cancel their products, the proportion of participants in agreement was still meaningful.

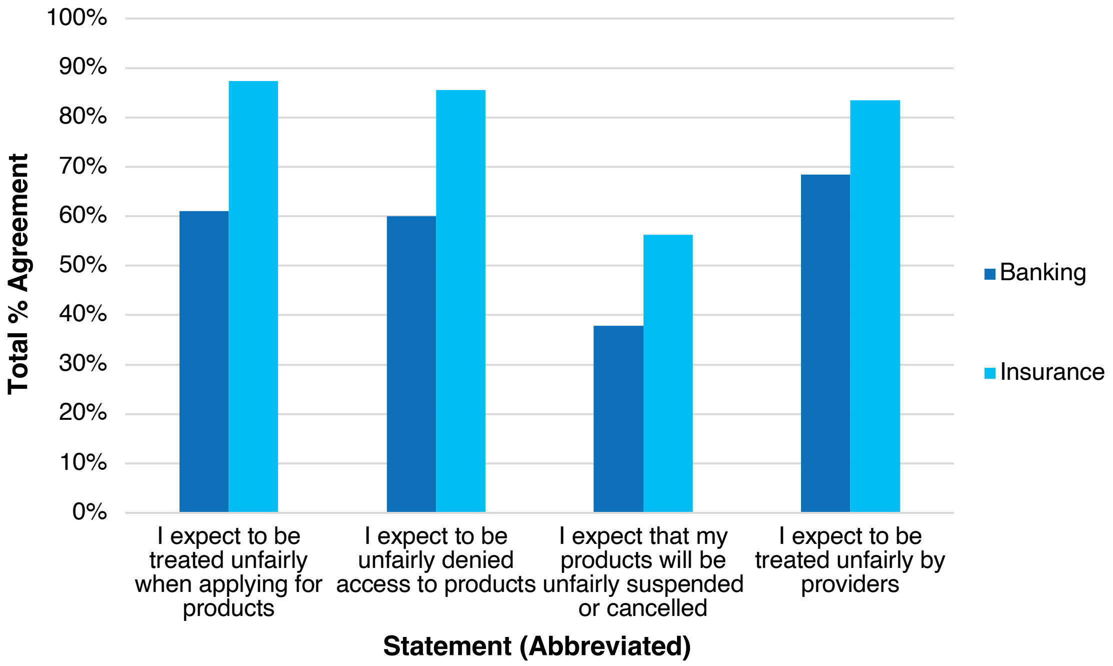


Figure 12.4. Highlight findings: total percentage agreement with anticipated stigma and discrimination in *banking services* (*n* = 95) and *insurance services* (*n* = 103).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

Tables 12.5 and **12.6** provide the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in banking and insurance services. The findings in these tables were summarised in relation to the **Figure 12.4**.

Table 12.5. Anticipated stigma and discrimination in *banking services*: percentage agreement and disagreement (*n* = 95).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when applying for banking products	18.9%	14.7%	5.3%	14.7%	22.1%	24.2%	**61.0%**
I expect to be unfairly denied access to banking products	20.0%	14.7%	5.3%	15.8%	20.0%	24.2%	**60.0%**
I expect that my banking products will be unfairly suspended or cancelled	22.1%	31.6%	8.4%	13.7%	12.6%	11.6%	**37.9%**
I expect to be treated unfairly by banking providers (e.g. mortgage lenders or loan providers)	15.8%	12.6%	3.2%	11.6%	28.4%	28.4%	**68.4%**

Table 12.6. Anticipated stigma and discrimination in *insurance services*: percentage agreement and disagreement (*n* = 103).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when applying for insurance products	3.9%	6.8%	1.9%	11.7%	33.0%	42.7%	**87.4%**
I expect to be unfairly denied access to insurance products	4.9%	5.8%	3.9%	9.7%	28.2%	47.6%	**85.5%**
I expect that my insurance products will be unfairly suspended or cancelled	9.7%	24.3%	9.7%	11.7%	15.5%	29.1%	**56.3%**
I expect to be treated unfairly by insurance providers	4.9%	7.8%	3.9%	11.7%	25.2%	46.6%	**83.5%**

WITHDRAWAL FROM OPPORTUNITY IN FINANCIAL AND INSURANCE SERVICES

> ***The way things are now insurance companies make things so hard that a lot of people with mental health issues can't cope and give up, especially when they really need the support access appropriate services.***
>
> **Our Turn to Speak participant**
> **Victoria**

Presented in this section are the findings regarding participants' withdrawal from opportunities associated with financial and insurance services, as related to their experience of complex mental health issues.

As shown in **Figure 12.5**, withdrawal from opportunity was higher in relation insurance services compared with banking. Close to 80% of participants agreed that they had stopped themselves from applying for insurance products, or making changes or enquiries about these products, compared with approximately 64% of participants who rated their agreement on equivalent statements in relation to banking.

In addition, those participants who had accessed (or tried to access) insurance services during the last 12 months were asked to rate their agreement with a statement about accessing rebates from their insurance provider for mental healthcare services. While lower than for other statements describing withdrawal from opportunities in this domain, it is of concern that 41.7% of participants agreed they had stopped themselves from accessing mental healthcare rebates offered by their insurance provider.

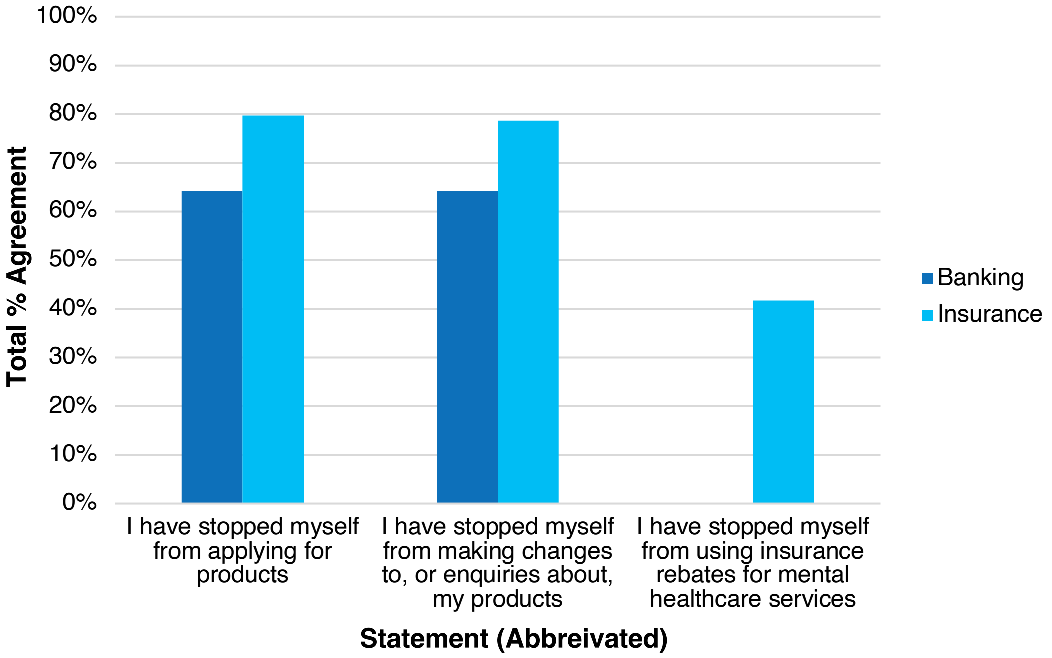


Figure 12.5. Highlight findings: total percentage agreement with withdrawal from opportunities in *banking services* (*n* = 95) and *insurance services* (*n* = 103).

Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

Finally, **Tables 12.7** and **12.8** provide the specific levels of agreement and disagreement for all statements relevant to withdrawal from opportunities in banking and insurance services. The findings in these tables were summarised in relation to the **Figure 12.5**.

Table 12.7. Withdrawal from opportunities in *banking services*: percentage agreement and disagreement (*n* = 95).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from applying for banking products	12.6%	13.7%	9.5%	11.6%	26.3%	26.3%	**64.2%**
I have stopped myself from making changes to, or enquiries about, my banking products	12.6%	13.7%	9.5%	8.4%	21.1%	34.7%	**64.2%**

Table 12.8. Withdrawal from opportunities in *insurance services*: percentage agreement and disagreement (*n* = 103).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from applying for insurance products	7.8%	7.8%	4.9%	10.7%	31.1%	37.9%	**79.7%**
I have stopped myself from making changes to, or enquiries about, my insurance products	6.8%	8.7%	5.8%	14.6%	22.3%	41.7%	**78.6%**
I have stopped myself from using insurance rebates for mental healthcare services	26.2%	28.2%	3.9%	8.7%	18.4%	14.6%	**41.7%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN FINANCIAL AND INSURANCE SERVICES

> ***Ive* [sic] *been refused life insurance due to a congenital heart condition that was completely rectified at age 2 (now 55).***
>
> **Our Turn to Speak participant**
> **New South Wales**

The findings from survey statements in relation to other experiences of stigma and discrimination in financial and insurance services, besides complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 12.6**. It can be seen that 34.4% of participants agreed that they had experienced stigma and discrimination in financial and insurance services because of their physical health or ability, while 8.5% agreed that they had experienced stigma and discrimination in connection with their sexual orientation.

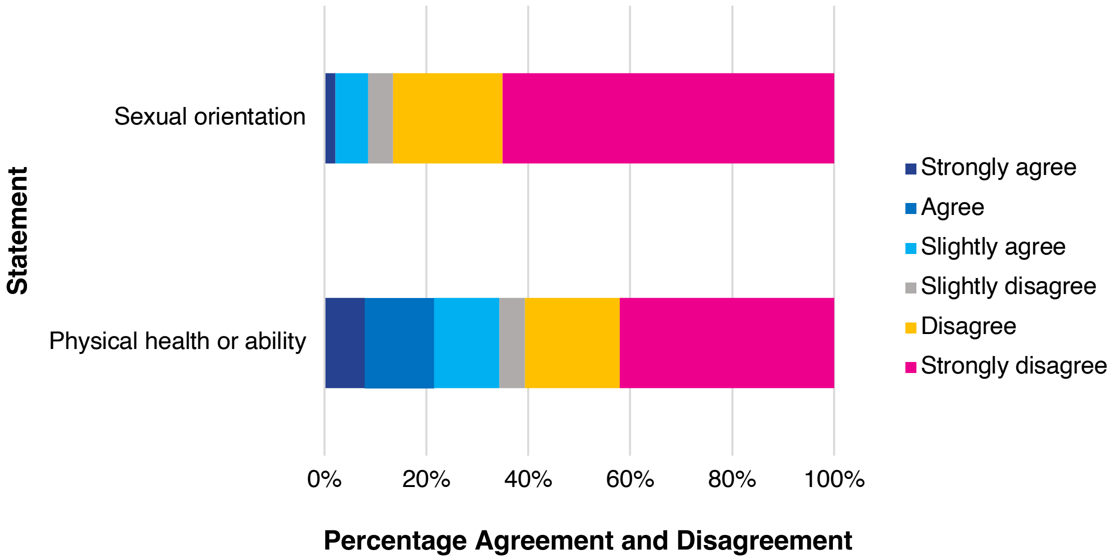


Figure 12.6. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *financial and insurance services* (*n* = 140).

The specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting this domain are summarised in **Table 12.9**.

Overall, a relatively low rate of agreement was found for statements describing experiences of stigma and discrimination in financial and insurance services due to personal characteristics other than complex mental health issues.

Table 12.9. Experiences of intersectional stigma and discrimination in *financial and insurance services*: percentage agreement and disagreement (n = 140).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in financial and insurance services because of my…							
Racial or cultural background	70.7%	19.3%	2.9%	2.9%	1.4%	2.9%	**7.2%**
Faith or spiritual beliefs	71.4%	17.1%	5.0%	3.6%	1.4%	1.4%	**6.4%**
Sexual orientation	65.0%	21.4%	5.0%	6.4%	0.0%	2.1%	**8.5%**
Gender identity	67.9%	22.1%	2.9%	3.6%	1.4%	2.1%	**7.1%**
Physical health or ability	42.1%	18.6%	5.0%	12.9%	13.6%	7.9%	**34.4%**

POSITIVE EXPERIENCES IN FINANCIAL AND INSURANCE SERVICES

> ***The ombudsman helped make the banks communicate with me in writing when I couldn't talk on the phone to sort bills.***
>
> **Our Turn to Speak participant**
> **Victoria**

The survey also asked about positive treatment in financial and insurance services. Two core statements comprised this section of the survey: (1) the expectation of special consideration because of one's experience of complex mental health issues, and (2) manifest positive experiences in housing because of one's experience of complex mental health issues.

As shown in **Figure 12.7**, 52.1% of participants agreed that they should receive special consideration when accessing financial and insurance services. Unfortunately, fewer participants (19.2%) agreed that they had had positive experiences when accessing financial and insurance services as a result of their complex mental health issues.

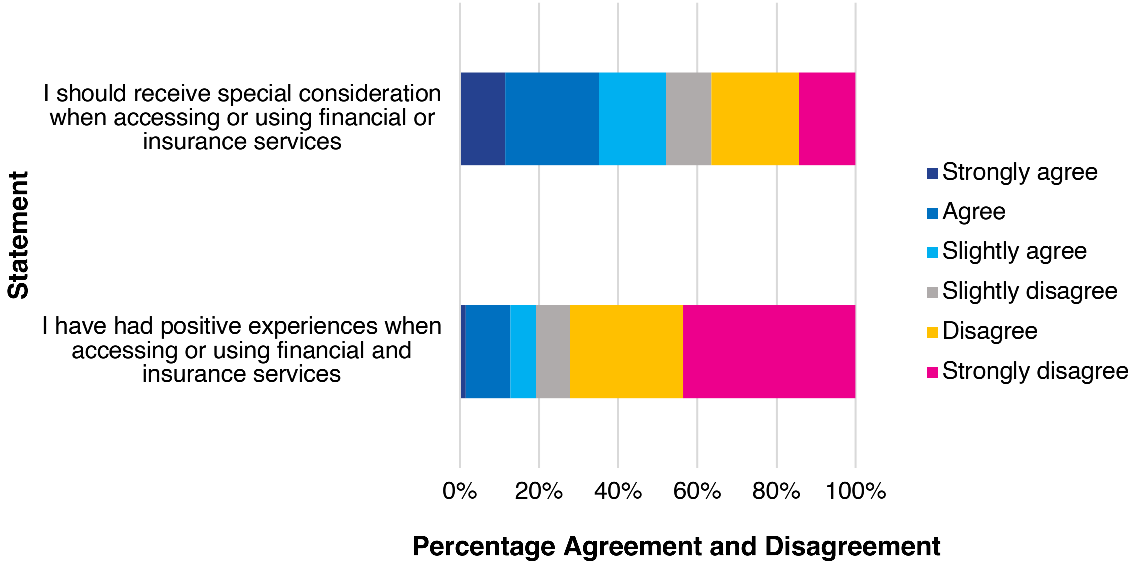


Figure 12.7. Highlight findings: responses to the statements regarding positive experiences in *financial and insurance services* because of participants' complex mental health issues (*n* = 140).

SUMMARY OF QUALITATIVE FINDINGS IN FINANCIAL AND INSURANCE SERVICES

Participants discussed a variety of areas relating to finance and insurance, such as income protection, life insurance, total and permanent disability insurance, travel insurance, health insurance, credit cards, car loans, home loans, work cover, debt collection, and experience of bankruptcy.

A key theme was that of being denied insurance (particularly income protection, life insurance, and travel insurance) and loans due to mental health issues and/or being on the disability support pension, as the following comments convey:

> *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).
>
> *I don't believe I was assessed fairly and on my own merits when applying for life insurance. Misunderstandings/ignorance about my condition and about past drug use and previous suicide ideation were cited as a reason to not give me insurance. The cited reasons were 15 years ago for me yet apparently once the suicide ideation box is ticked it's never in ticked again for insurance companies* (**Our Turn to Speak** participant, Victoria).

Conversely, one participant explained that they had to declare bankruptcy while experiencing mental health issues, and that their bank *"did not take mental illness into consideration despite medical evidence"* (**Our Turn to Speak** participant, South Australia).

A few participants commented on the issue of disclosure, and were not comfortable with the level of detail that they were expected to share, for example:

> *I don't like the amount of information i need to disclose about my mental health and experiences in order to get life insurance* (**Our Turn to Speak** participant, Victoria).
>
> *I believe they should not ask you why are you receiving a DSP* (**Our Turn to Speak** participant, Queensland).
>
> *It's embarrassing having to share diagnoses with health, travel, life and income insurance providers in order to find out if I am eligible to purchase their products* (**Our Turn to Speak** participant, Western Australia).

One participant felt they had *"been taken advantage of by banking providers. Paying off credit card that went up to $10,000, no duty of care from the providers"* (**Our Turn to Speak** participant, Victoria).

Several participants mentioned that empathy and understanding of people with mental health issues was lacking in this domain, and that more support was needed. For example:

> *I have been unable to deal with my financial issues due to mental illness and there is no avenue for effective help. Financial counseling focuses on things I can do when well. I need some sort of suspension or recognition of what happens with my illness* (**Our Turn to Speak** participant, South Australia).

When asked about positive experiences in relation to finance and insurance, several participants commented that they had not had any, or described negative experiences. One participant said that they did not disclose their mental health issues due to fear. Some examples of positive experiences that were described by participants included accessing income protection, and positive interactions with banks, other lenders, insurance companies, state trustees, and ombudsman.

As in other domains, several participants remarked that they did not want or expect special treatment, just treatment that was 'equal'. One participant said that: *"It would just be nice if they insured us, full stop"* (**Our Turn to Speak** participant, New South Wales). Some participants suggested particular measures or approaches that might be helpful, such as being able to take out bigger loans for those on the DSP, and other resources:

> *I experience extreme anxiety when accessing and trying to use financial services. I don't believe that I should receive special consideration per se, but if there was a really simplified explanation of particular processes at financial services, and a way to feel less judged when I panic a little, that would be really helpful and I'd feel more comfortable seeking those services* (**Our Turn to Speak** participant, Western Australia).

When asked about intersectional experiences of stigma and discrimination, the most frequently mentioned characteristic was physical health. Others included age, disability, physical appearance, weight, and financial situation.

SUMMARY

Of the 1,912 survey participants, 7.3% (*n* = 140) identified financial and insurance services as one of up to three life domains that had been most affected by stigma and discrimination in connection with complex mental health issues. Fifty-eight percent of participants who selected financial and insurance services as one of their most affected life domains during the last 12 months indicated ‘frequent’ or ‘very frequent’ experiences of stigma and discrimination in this aspect of their lives.

When presented with a range of statements describing general and specific examples of stigma and discrimination in financial and insurance services, it was evident that 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 during the last 12 months.

Almost 90% of participants agreed they had been treated unfairly by insurance providers when applying for insurance products. Approximately 60% of participants endorsed receiving similar treatment from banking providers (for example, mortgage lenders and loan providers) and when applying for related products.

It is of particular concern that 77.7% of participants who had used (or tried to use) insurance services agreed that they had been unfairly denied access to insurance products because of stigma about mental health issues. In contrast, 54.7% of participants who had used (or tried to use) banking services agreed that they had been denied access to banking products for the same reason, although we note this is still a significant proportion of participants.

Participants’ qualitative comments shed light on the types of insurance products they were unfairly denied access to. This included income protection, life insurance, total and permanent disability insurance, travel insurance, and health insurance. Participants explained that they were more likely to be approved for such insurance products if they did not disclose their experiences of complex mental health issues. Unfortunately, the experiences reported by participants of the **Our Turn to Speak** survey are not new and reflect relatively recent legal contests and investigations describing very similar situations (Beyondblue, 2015; The Victorian Equal Opportunity and Human Rights Commission, 2019). For instance, participants were charged higher insurance premiums, and were subjected to more, or even blanket exclusions, to insurance coverage because of their mental health issues.

Rates of agreement with statements describing various kinds of anticipated discrimination and withdrawal from opportunities relating to financial and insurance services were somewhat greater than for perceived experiences of stigma and discrimination. Again, participants who had used (or tried to use) insurance services were more likely to expect future unfair treatment and denial of products than those responding to questons about banking services and products. For instance, 87.4% of participants agreed that they expected to be treated unfairly when applying for insurance products compared with 61% of participants in relation to banking products (a difference of over 26%).

Interestingly, the difference in agreement between the two services decreased in relation to expected unfair treatment by providers specifically. Just over 83% of participants expected to be treated unfairly by insurance providers, and close to 70% of participants expected to be treated unfairly by banking providers (for example, mortgage lenders or loan providers). In the context of participants’ past experiences of stigma and discrimination, it is understandable that so many expressed high rates of anticipated stigma and discrimination in the future and, further, that between 64.2% and 79.7% of participants had actually stopped themselves from applying for banking and insurance products, respectively.

Again, it is concerning that 41.7% of participants who had insurance cover agreed that they had stopped themselves from claiming insurance rebates for mental healthcare services to which they were entitled. This suggests that people who live with mental health issues – who are already more likely to be experiencing or at risk of experiencing socioeconomic disadvantage (Allen et al., 2014; Isaacs et al., 2018) – are unnecessarily shouldering the full costs of mental healthcare because of related stigma and discrimination. Further, 34.4% of participants agreed that their negative experiences in relation to financial and insurance services had been compounded by their experience of stigma and discrimination in relation to their physical health or (dis)ability.

Unfortunately, few participants (19.2%) agreed they had experienced any positive treatment in connection with their mental health issues when accessing or using financial and insurance services. The low level of agreement on this survey item was corroborated by limited examples of positive treatment and experiences in participants' written commentary. Of 30 participants who provided further commentary specifically about their experiences of positive treatment in the sector, only five actually described anything of a positive or favourable nature. One participants' positive experience related to having sought assistance from an ombudsman to resolve communication difficulties with their banking provider: "The ombudsman helped make the banks communicate with me in writing when I couldn't talk on the phone to sort". Comments like this highlight the numerous barriers to basic services that people living with complex mental health issues can face, and further demonstrate why 51.2% of participants agreed that they should receive special consideration when accessing or using financial and insurance services.

In March 2018, a Parliamentary Joint Committee on Corporations and Financial Services (2018) made a series of recommendations, including implementing a mandatory Code of Practice, to ensure that discrimination on the basis of disclosed mental health issues or a treatment history does not occur. These findings suggest that, almost two years later, discriminatory practices – including structural barriers to accessing services and products – continue to pose challenges in the sector.

HOUSING AND HOMELESSNESS SERVICES

13

Chapter 13. Housing and homelessness services

Having a safe place to call home is a fundamental human right and critical to recovery for those living with complex mental health issues.

Sadly, many people who live with complex mental health issues do not have access to safe, secure and stable accomodation. Depending on the study, anywhere between 30% and 85% of people experiencing homelessness live with a mental health issue (Gilbert, 2011). A recent study, which focused on people accessing care for their mental health while experiencing homelessness, found that 59% of participants had been homeless for more than a year. The most common diagnoses experienced by these participants were substance use disorder (66%) and psychosis (51%). Forty-two percent had experienced trauma and 21% had recently been discharged from a psychiatric hospital (Nielssen et al., 2018). These figures speak to the challenges of maintaining safe and secure housing while also coping with the impacts of complex mental health issues.

This chapter considers how people living with complex mental health issues experience stigma and discrimination in their access to housing and homelessness services.

OVERVIEW

Almost 40% (*n* = 755) of all **Our Turn to Speak** participants reported experiencing some level of stigma or discrimination in housing during the past 12 months.

As shown in **Figure 13.1**, 9.7% of all participants reported ‘frequent’ or ‘very frequent’ stigma and discrimination in housing and homelessness services, and 6.1% (*n* = 117) identified this life domain as one of three in which they have been most affected by such experiences. **Figure 13.1** also shows that 61.5% of participants who selected the housing domain reported ‘frequent’ or ‘very frequent’ rates of stigma and discrimination in this aspect of their lives; substantially higher than was reported by the overall sample.

This chapter focuses on the characteristics and experiences of those 117 participants who selected housing and homelessness services as one of their top three, most affected life domains.

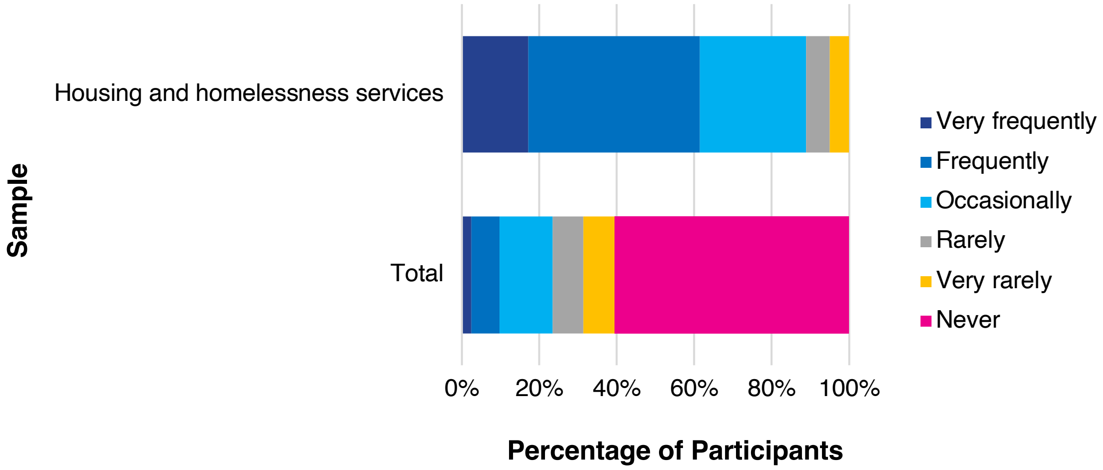


Figure 13.1. Frequency of stigma and discrimination in *housing and homelessness services* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 117) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

Table 13.1 presents the sociodemographic characteristics of participants who identified as being significantly affected by stigma and discrimination in housing.

Participants who selected this life domain were slightly older compared with the average age of the total sample. A greater proportion were not in a relationship compared with the total sample; the latter being characterised by approximately equal numbers of partnered and non-partnered participants. Compared with the total sample, slightly more participants who selected the housing domain were male; 10% fewer were educated post-secondary college; 26% fewer were engaged in paid work (full-time, part-time or casual); and 28% more were receiving a pension or other benefits.

Table 13.1. Sociodemographic characteristics: *housing and homelessness services* sample compared with the total sample.

Characteristics		Housing and Homelessness Services (*n* = 117)	Total (*N* = 1912)
Mean age		42.81 (*SD* = 12.77)	39.21 (*SD* = 12.81)
Gender identity			
	Female	75.2%	78.9%
	Male	22.2%	18.0%
	Trans, gender diverse and/or non-binary	5.1%	4.9%
	Unsure or questioning	1.7%	0.9%
	Prefer not to say	1.7%	0.4%
Relationship status			
	Not in a relationship	70.9%	52.1%
	In a relationship	28.2%	47.3%
	Prefer to self-describe	0.9%	0.2%
Sexual orientation			
	Heterosexual	61.5%	62.0%
	Gay, lesbian, bisexual, pansexual, queer, and/or asexual	35.0%	35.6%
	Unsure or questioning	4.3%	4.9%
	Prefer to self-describe	1.7%	1.5%
	Prefer not to say	2.6%	1.7%
Education (highest level attained)			
	Primary school	6.0%	1.6%
	Secondary college (high school)	27.4%	20.9%
	Educated post-secondary college	65.8%	77.4%
	Other	0.9%	0.2%
Employment			
	Engaged in paid work	25.6%	51.7%
	Engaged in unpaid work or studying	24.8%	28.7%
	Unemployed or unable to work	24.8%	22.8%
	Receiving a pension or benefits	53.0%	24.6%
	Other	0.0%	0.2%
State			
	Australian Capital Territory	0.9%	2.5%
	New South Wales	25.6%	23.6%
	Northern Territory	0.0%	0.6%
	Queensland	17.1%	15.9%
	South Australia	7.7%	9.5%
	Tasmania	5.1%	3.7%
	Victoria	29.9%	33.1%
	Western Australia	13.7%	10.9%
Region*			
	Major city	78.6%	74.2%
	Regional or remote	15.4%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

Of note, the living situations of participants who selected the housing domain differed substantially compared with the total sample, as shown in **Figure 13.2**.

Overall, participants who selected the housing domain were disproportionately living in public and community housing or supported accommodation facilities (such as hospitals and residential care facilities); or were insecurely housed (for example, living in motels or rooming houses) or homeless (for example, sleeping rough or couch-surfing). Far fewer participants who selected the housing domain were living in a privately-owned home (6.0%) compared with the total sample (32.5%).

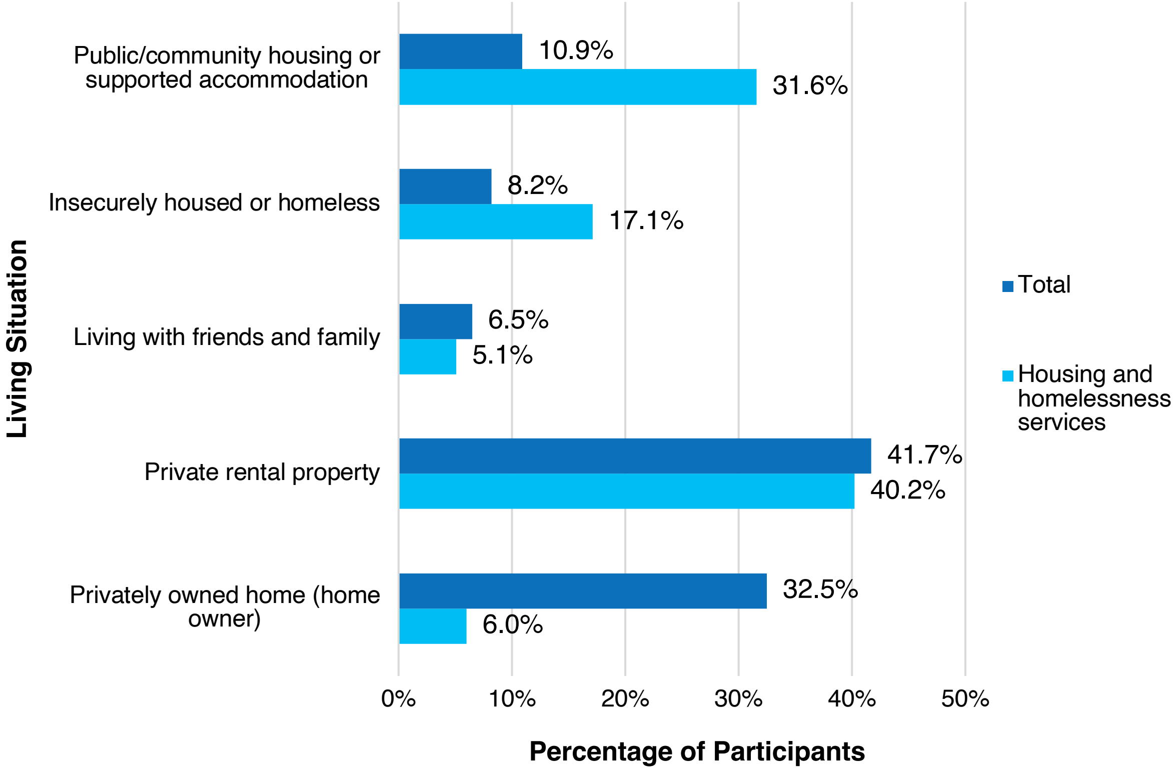


Figure 13.2. Living situation among participants who selected *housing and homelessness services* as one of three domains in which they had been most affected by stigma during the past 12 months (*n* = 117) compared with the total sample (*N* = 1912).
Note. Percentages do not add to 100 as participants could select more than one response option.

As with the socidemographic data, the mental and physical health characteristics of participants who responded to the housing and homelessness services section of the survey were generally similar to those characteristics represented in the total sample.

As shown in **Table 13.2**, a slightly greater proportion of participants who selected the housing and homelessness services domain reported a primary diagnosis of a schizophrenia spectrum disorder, or trauma-related or dissociative disorder, compared with the total sample.

Table 13.2. Mental and physical health characteristics: *housing and homelessness services* sample compared with the total sample.

Characteristics	Housing and Homelessness Services (*n* = 117)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	10.3%	7.4%
Bipolar related disorder	12.0%	17.2%
Obsessive compulsive related disorder	5.1%	4.3%
Trauma-related or dissociative disorder	35.0%	25.9%
Eating disorder	5.1%	6.1%
Personality disorder	12.0%	14.5%
Severe and treatment-resistant depressive disorder	12.0%	14.3%
Severe and treatment-resistant anxiety disorder	8.5%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	53.8%	53.8%

METHODS SNAPSHOT

Participants who identified housing as one of three life domains in which they have been most affected by stigma-related experiences completed the housing and homelessness services section of the survey. At the beginning of this section of the survey, participants were asked to indicate what types of housing or homelessness services they had lived in or tried to access during the previous 12 months. Housing was described as including:

- private rental, and public and public and community (non-profit) housing
- homelessness services, including crisis accommodation and other homelessness support programs.

Sixty-two percent (*n* = 73) had accessed private rental housing, 64.1% (*n* = 75) accessed public or community housing, and 26.5% (*n* = 31) had accessed homelessness services in the past 12 months. Participants were then presented with only the questions that matched their reported housing experiences. For example, participants who reported accessing private rental housing received only questions corresponding to private rental housing. Those who indicated that they had accessed more than one type of housing received questions corresponding to each of those areas.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in housing; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of housing and homelessness services. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further describe their experiences of stigma and discrimination in relation to: (a) complex mental health issues, (b) their other personal characteristics, and (c) any positive treatment in terms of housing and homelessness services. Forty-four, 19 and 26 participants provided additional comments in relation to these experiences respectively.

STIGMA AND DISCRIMINATION IN HOUSING

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in housing, which will be further examined in the sections that follow.

As shown in **Figure 13.3**, the average total level of agreement with all statements describing anticipated stigma and discrimination, and withdrawal from opportunities in housing and homelessness services, was about 60%. In other words, participants typically agreed that, more often than not, they expected to be discriminated against when accessing private rental housing, public or community housing, and/or homelessness services. Similarly, they typically agreed that, more often than not, they had stopped themselves from accessing opportunities relevant to housing (like putting in applications to secure housing or reporting maintenance issues).

At 52.6%, the average total level of agreement with all statements describing perceived experiences of stigma and discrimination in housing was lower than for anticipated stigma and discrimination, and withdrawal from opportunities, but was still high.

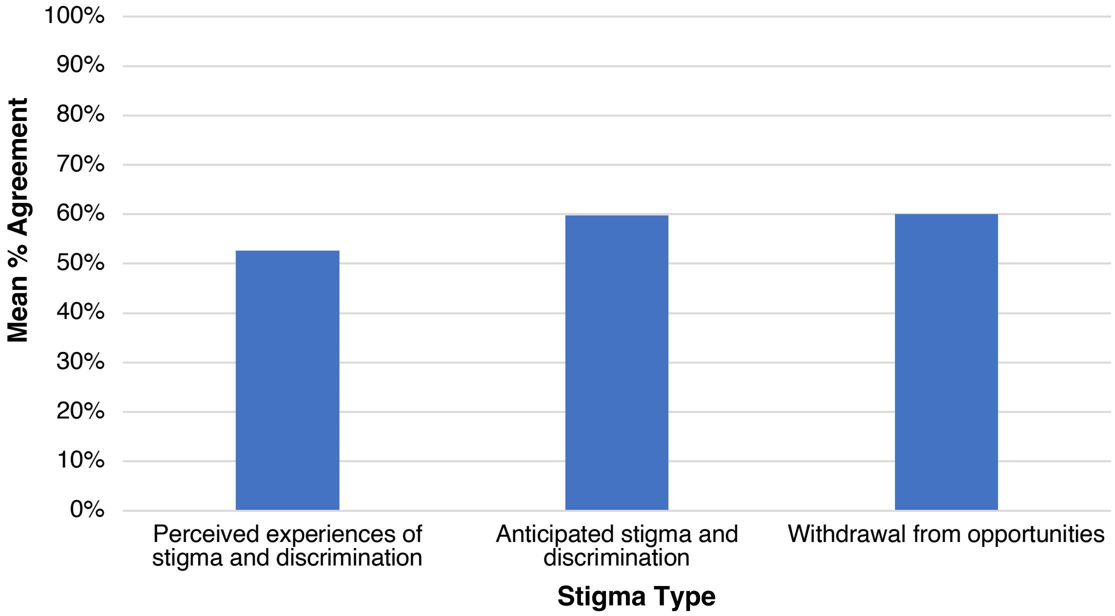


Figure 13.3. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *housing and homelessness services* (*n* = 117).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN HOUSING

> ***I was told to leave my uni's residential college halfway through semester because of my mental health problems, and because I may have a negative impact on other residents, and the college thought I couldn't look after myself.***
>
> **Our Turn to Speak participant**
> **Western Australia**

Presented in this section are the findings regarding participants' perceived experiences of stigma and discrimination in housing, as related to their experience of complex mental health issues.

Figure 13.4 highlights the findings in relation to the three statements to which all 117 participants who selected the housing domain responded, regardless of whether they had specifically accessed private rental housing, public or community housing, and/or homelessness services during the last 12 months. These three items were thought to be relevant to all participants who selected the housing domain, regardless of the nature of housing or services they had accessed.

As shown, unfair treatment by housing officials or landlords was perceived by close to 60% of participants. Perceptions of unfair treatment by household members and neighbours were also unfortunately high, as agreed to by 54.7% and 49.5% of participants, respectively.

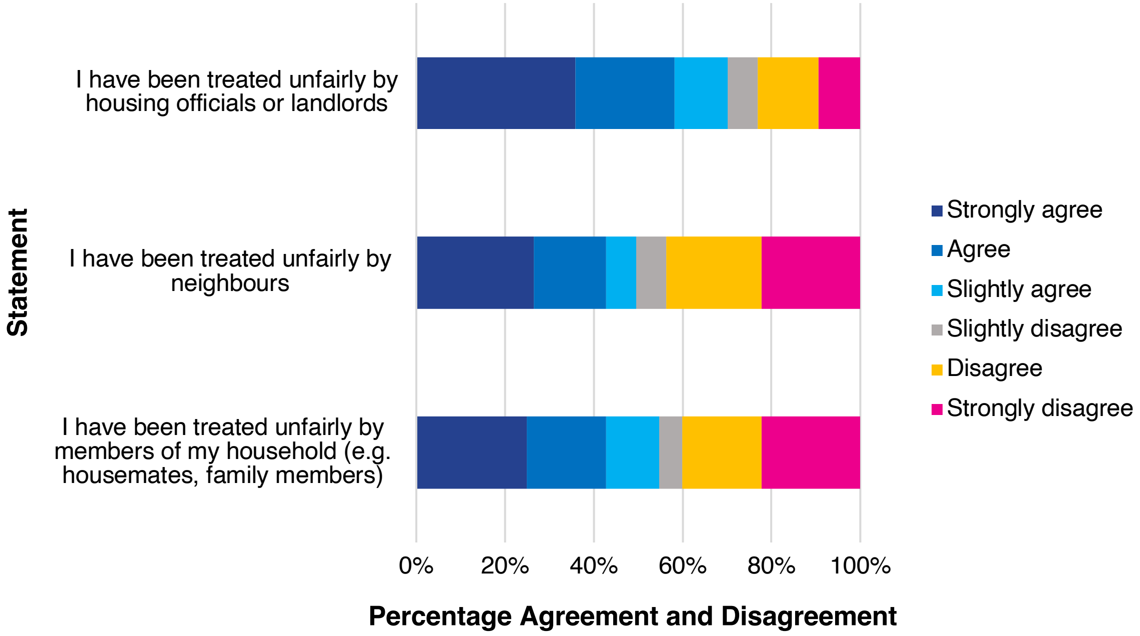


Figure 13.4. Highlight findings: the two most frequently endorsed statements describing perceived experiences of stigma and discrimination in *housing and homelessness services* (*n* = 117).

Further, **Figure 13.5** compares perceived experiences of stigma and discrimination in connection with private rental housing, public or community housing, and homelessness services. As shown, across all three statements, perceived experiences of stigma and discrimination were much higher in relation to private rental housing compared with public or community housing and homelessness services. For instance, 78% of participants who had accessed private rental housing during the last 12 months agreed that they had been unfairly treated when trying to access this type of housing, compared with 54.9% of participants who had accessed homelessness services during the same time period.

Roughly the same proportion of participants who had accessed private rental housing (38.3%) and/or homelessness services (38.8%) perceived being unfairly asked to leave their housing, compared with 20.0% of participants who had been living in public or community housing during the last 12 months.

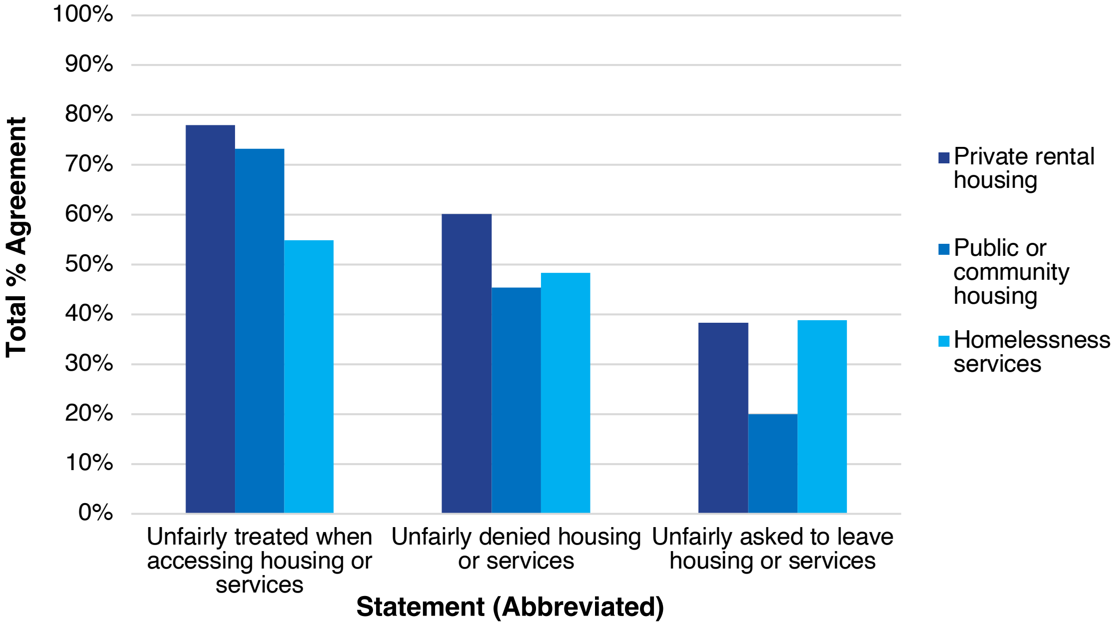


Figure 13.5. Highlight findings: total percentage agreement with perceived experiences of stigma and discrimination in *private rental housing* (*n* = 73), *public and community housing* (*n* = 75) and *homelessness services* (*n* = 31).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

Finally, **Tables 13.3, 13.4** and **13.5** provide the specific levels of agreement and disagreement for all statements relevant to perceived experiences of stigma and discrimination in private rental housing, public or community housing, and homelessness services. The findings in these tables were summarised in relation to the aforementioned figures.

Table 13.3. Perceived experiences of stigma and discrimination in *private rental housing*: percentage agreement and disagreement (*n* = 73).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when accessing private rental housing	8.2%	9.6%	4.1%	20.5%	27.4%	30.1%	**78.0%**
I have been unfairly denied private rental housing	15.1%	17.8%	6.8%	12.3%	31.5%	16.4%	**60.2%**
I have been unfairly asked to leave private rental housing before I was ready	31.5%	24.7%	5.5%	2.7%	13.7%	21.9%	**38.3%**

Table 13.4. Perceived experiences of stigma and discrimination in *public or community housing*: percentage agreement and disagreement (*n* = 75).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when accessing public or community housing	6.7%	14.7%	5.3%	24.0%	20.0%	29.3%	**73.3%**
I have been unfairly denied public or community housing	21.3%	30.7%	2.7%	10.7%	20.0%	14.7%	**45.4%**
I have been unfairly asked to leave public or community housing before I was ready	44.0%	30.7%	5.3%	1.3%	8.0%	10.7%	**20.0%**

Table 13.5. Perceived experiences of stigma and discrimination in *homelessness services*: percentage agreement and disagreement (*n* = 31).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when accessing homelessness services	22.6%	22.6%	0.0%	9.7%	12.9%	32.3%	**54.9%**
I have been unfairly denied homelessness services	19.4%	32.3%	0.0%	3.2%	9.7%	35.5%	**48.4%**
I have been unfairly asked to leave public or homelessness services before I was ready	29.0%	32.3%	0.0%	6.5%	9.7%	22.6%	**38.8%**

ANTICIPATED STIGMA AND DISCRIMINATION IN 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**

Presented in this section are the findings on participants' anticipation of stigma and discrimination in housing, as related to their experience of complex mental health issues.

Figure 13.6 highlights the findings in relation to the three statements to which all 117 participants who selected the housing domain responded, regardless of whether they had specifically accessed private rental housing, public or community housing, and/or homelessness services during the last 12 months. These three items were thought to be relevant to all participants who selected the housing domain, regardless of the nature of housing or services they had accessed.

As shown, 70% of participants expected to be treated unfairly by housing officials or landlords. Anticipated unfair treatment by household members and neighbours was also relatively high, as agreed to by 52.1% and 50.4% of participants, respectively.

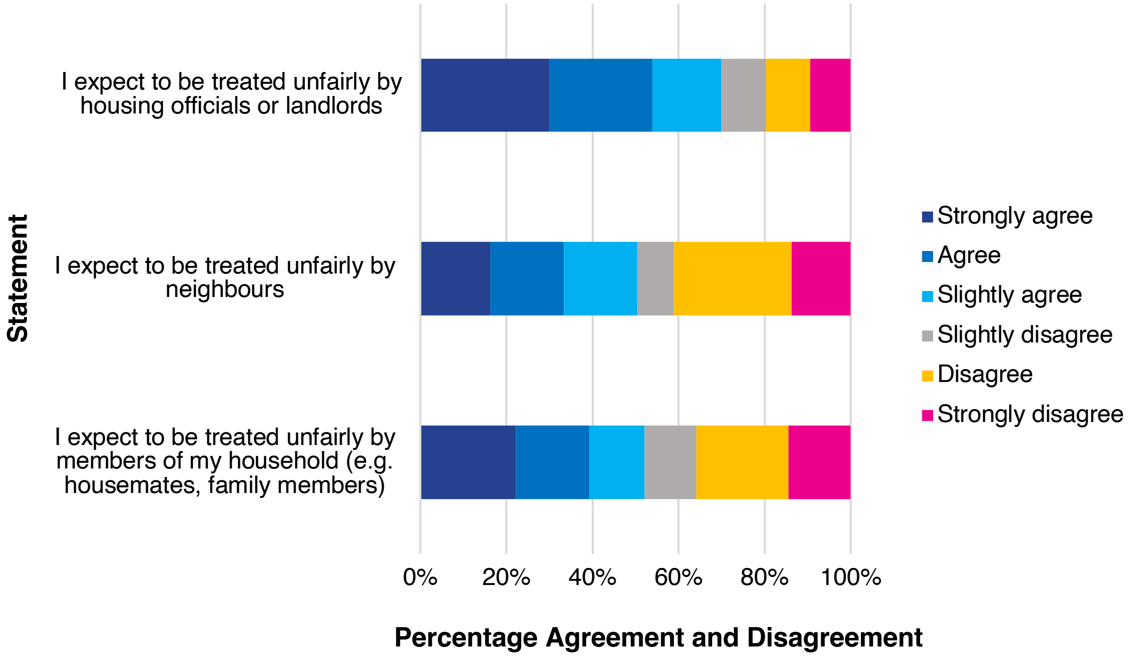


Figure 13.6. Highlight findings: the two most frequently endorsed statements describing anticipated stigma and discrimination in *housing and homelessness services* (*n* = 117).

Further, **Figure 13.7** compares anticipated stigma and discrimination in connection with private rental housing, public or community housing, and homelessness services.

As shown, across all three statements, anticipated stigma and discrimination was much higher in relation to private rental housing compared with public or community housing and homelessness services. For instance, 84.8% of participants who had accessed private rental housing during the last 12 months expected that they would be treated unfairly when trying to access this type of housing, compared with 62.7% of participants who had accessed public or community housing during the same time period.

About 75% of participants who had accessed (or tried to access) rental housing expected to be unfairly denied private rental housing, compared with 50.7% of participants who had accessed (or tried to access) public or community housing during the last 12 months.

A similar proportion of participants with experience of private rental housing (57.5%) and homelessness services (54.9%) during the last 12 months expected that they would be unfairly asked to leave their accommodation, compared with 33.4% of participants who had accessed public or community housing.

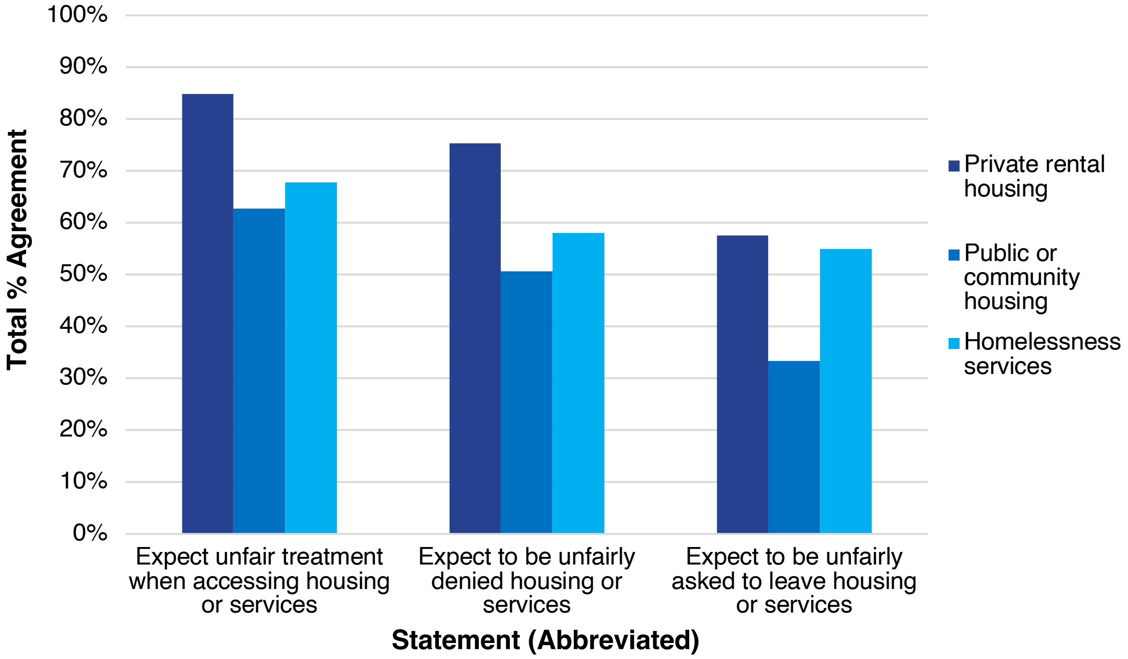


Figure 13.7. Highlight findings: total percentage agreement with anticipated stigma and discrimination in *private rental housing* (*n* = 73), *public and community housing* (*n* = 75) and *homelessness services* (*n* = 31).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

Finally, **Tables 13.6, 13.7** and **13.8** provide the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in private rental housing, public or community housing, and homelessness services. The findings in these tables were summarised in relation to the aforementioned figures.

Table 13.6. Anticipated stigma and discrimination in *private rental housing*: percentage agreement and disagreement (*n* = 73).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when accessing private rental housing	1.4%	6.8%	6.8%	20.5%	34.2%	30.1%	**84.8%**
I expect to be unfairly denied private rental housing	2.7%	9.6%	12.3%	20.5%	23.3%	31.5%	**75.3%**
I expect to be unfairly asked to leave private rental housing before I was ready	13.7%	17.8%	11.0%	24.7%	13.7%	19.2%	**57.5%**

Table 13.7. Anticipated stigma and discrimination in *public or community housing*: Percentage agreement and disagreement (*n* = 75).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when accessing public or community housing	9.3%	21.3%	6.7%	22.7%	21.3%	18.7%	**62.7%**
I expect to be unfairly denied public or community housing	12.0%	28.0%	9.3%	12.0%	20.0%	18.7%	**50.7%**
I expect to be unfairly asked to leave public or community housing before I was ready	18.7%	33.3%	14.7%	12.0%	10.7%	10.7%	**33.4%**

Table 13.8. Anticipated stigma and discrimination in *homelessness services*: percentage agreement and disagreement (*n* = 31).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when accessing homelessness services	6.5%	22.6%	3.2%	16.1%	19.4%	32.3%	**67.8%**
I expect to be unfairly denied homelessness services	9.7%	29.0%	3.2%	16.1%	9.7%	32.3%	**58.1%**
I expect to be asked to leave public or homelessness services before I was ready	16.1%	29.0%	0.0%	12.9%	19.4%	22.6%	**54.9%**

WITHDRAWAL FROM OPPORTUNITY IN HOUSING

> ***1 week notice for inspections*** **[for]** ***people with severe mental health issues causes serious distress, especially if not in a positive to clean an entire house in one week. My landlord drove past my house and took photos of my front yard to show the real estate agent how awful of a tenant I am for not weeding – the house was advertised as low maintenance yards. Naturally instead of kicking up a fuss about the invasion of privacy, I had to get an outside family member to help fix it. I'm lucky I could get this help, but others are not so lucky.***
>
> **Our Turn to Speak participant**
> **South Australia**

Presented in this section are the findings regarding participants' withdrawal from opportunities in housing, as related to their experience of complex mental health issues.

Figure 13.8 highlights the findings in relation to four statements to which all 117 participants who selected the housing domain responded, regardless of whether they had specifically accessed private rental housing, public or community housing, and/or homelessness services during the last 12 months. These three items were thought to be relevant to all participants who selected the housing domain, regardless of the nature of housing or services they had accessed.

As shown, 68.4% of participants had stopped themselves from reporting maintenance issues or making complaints to housing officials or landlords. Almost 61% had stopped themselves from reporting similar issues to household members. Withdrawal from relationships with neighbours and household members was also high, as agreed to by 67.5% and 62.4% of participants, respectively.

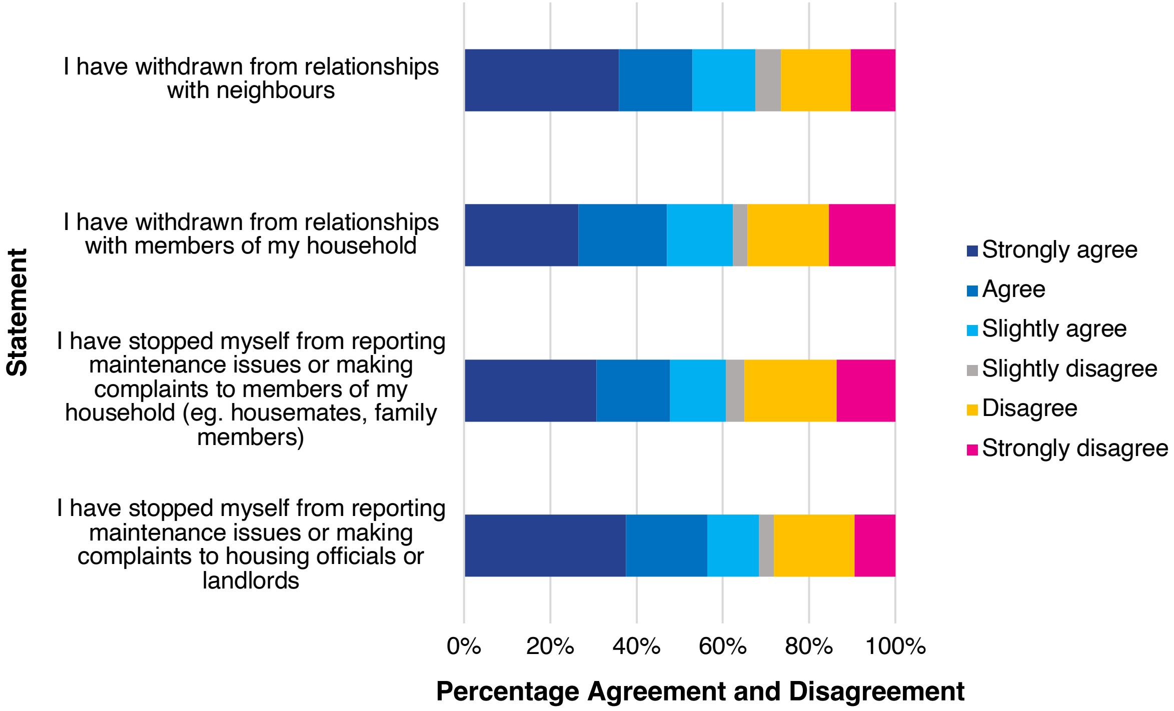


Figure 13.8. Highlight findings: the two most frequently endorsed statements describing withdrawal from opportunities in *housing and homelessness services*.

Further, **Figure 13.9** compares withdrawal from opportunities in relation to private rental housing, public or community housing, and homelessness services.

As shown, across both statements, withdrawal from opportunity was generally higher in relation to private rental housing and homelessness services, compared with public or community housing. Of particular concern, 64.5% of participants who had accessed (or tried to access) homelessness services agreed that they stopped themselves from applying for such support during the last 12 months because of stigma about mental health issues. Approximately 60% of participants who had accessed (or tried to access) private rental housing endorsed the same.

Close to 55% of participants who had been living in private rental housing during the last 12 months agreed that they had left their private rental before they were ready because of stigma about mental health issues. Similarly, 45.2% of participants who had accessed homelessness services reported the same.

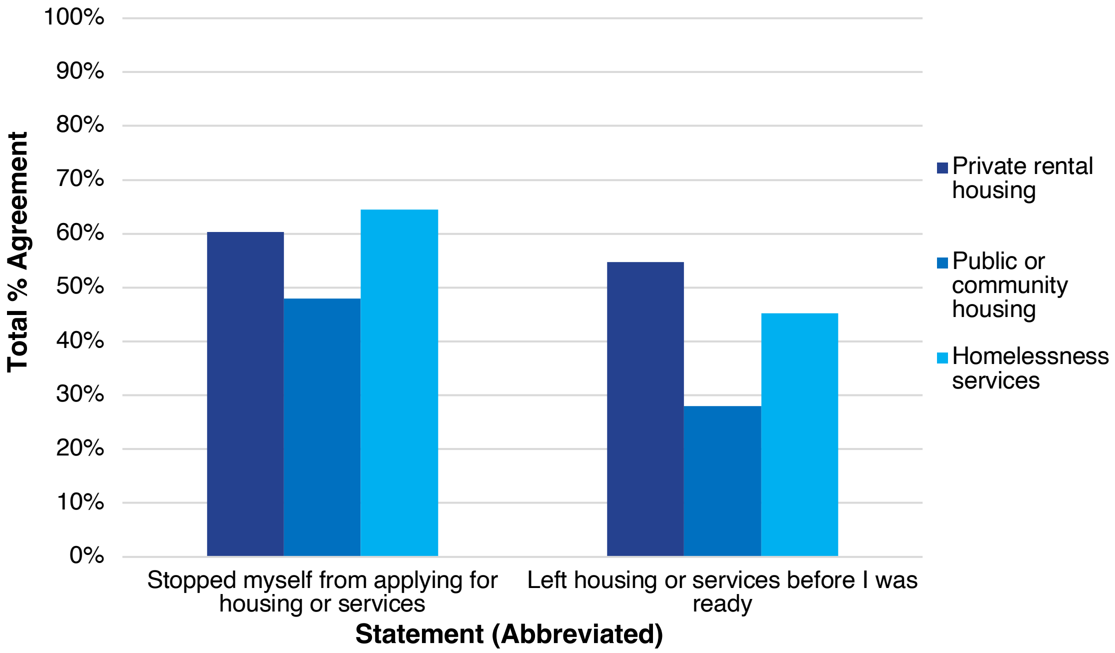


Figure 13.9. Highlight findings: total percentage agreement with withdrawal from opportunities in *private rental housing* (*n* = 73), *public and community housing* (*n* = 75) and *homelessness services* (*n* = 31).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

Finally, **Tables 13.9, 13.10** and **13.11** provide the specific levels of agreement and disagreement for all statements relevant to withdrawal from opportunities in private rental housing, public or community housing, and homelessness services. The findings in these tables were summarised in relation to the aforementioned figures.

Table 13.9. Withdrawal from opportunities in *private rental housing*: percentage agreement and disagreement (*n* = 73).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from applying for private rental housing	12.3%	15.1%	12.3%	5.5%	24.7%	30.1%	**60.3%**
I have left private rental housing before I was ready	23.3%	17.8%	4.1%	8.2%	20.5%	26.0%	**54.7%**

Table 13.10. Withdrawal from opportunities in *public or community housing:* percentage agreement and disagreement (*n* = 75).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from applying for public or community housing	16.0%	30.7%	5.3%	9.3%	16.0%	22.7%	**48.0%**
I have left public or community housing before I was ready	30.7%	38.7%	2.7%	5.3%	6.7%	16.0%	**28.0%**

Table 13.11. Withdrawal from opportunities in *homelessness services*: percentage agreement and disagreement (*n* = 31).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from seeking support from homelessness services	12.9%	19.4%	3.2%	12.9%	25.8%	25.8%	**64.5%**
I have exited homelessness services before I was ready	25.8%	29.0%	0.0%	9.7%	12.9%	22.6%	**45.2%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN HOUSING

> ***I believe when I was kicked out of one particular household it was not only because of one of my mental health issues but because one member of the household didn't find me 'appealing'.***
>
> **Our Turn to Speak participant**
> **Victoria**

Findings in relation to other experiences of stigma and discrimination in housing, besides complex mental health issues, are presented in this section.

Results for the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 13.10**. As shown, 47.8% of participants agreed that they had experienced stigma and discrimination in housing because of their physical health or ability, while 17.1% agreed that they had experienced stigma and discrimination in housing in connection with their faith or spiritual beliefs.

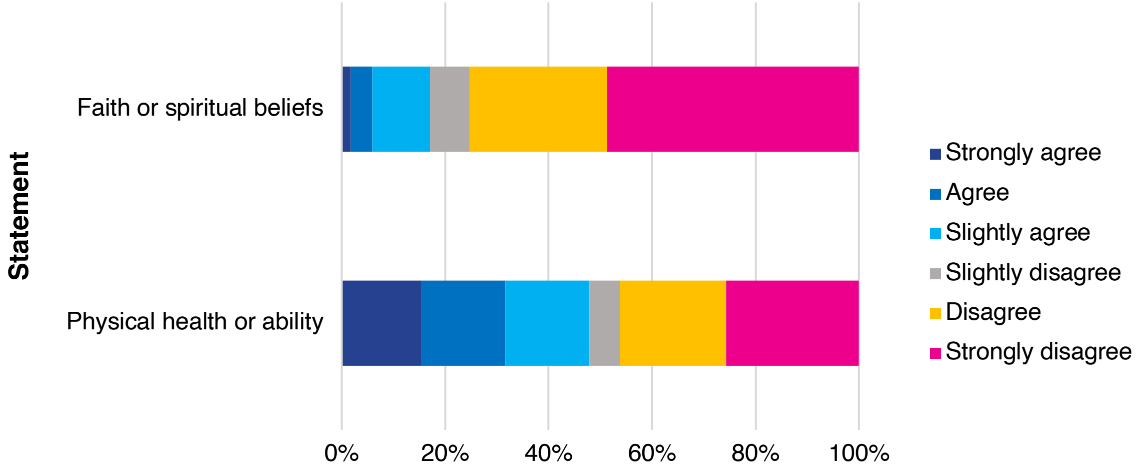


Figure 13.10. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *housing and homelessness services* (*n* = 117).

The specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting housing are summarised in **Table 13.12**. Overall, a relatively low rate of agreement was observed for statements describing experiences of stigma and discrimination in housing due to personal characteristics other than complex mental health issues.

Table 13.12. Other experiences of intersectional stigma and discrimination in *housing and homelessness services*: percentage agreement and disagreement (*n* = 117).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in housing because of my…							
Racial or cultural background	50.4%	29.1%	5.1%	6.0%	6.0%	3.4%	**15.4%**
Faith or spiritual beliefs	48.7%	26.5%	7.7%	11.1%	4.3%	1.7%	**17.1%**
Sexual orientation	49.6%	28.2%	6.8%	6.0%	5.1%	4.3%	**15.4%**
Gender identity	48.7%	27.4%	7.7%	6.8%	6.0%	3.4%	**16.2%**
Physical health or ability	25.6%	20.5%	6.0%	16.2%	16.2%	15.4%	**47.8%**

POSITIVE EXPERIENCES IN HOUSING

> ***Received compassionate treatment when seeking temporary (crisis) homelessness accommodation and support due to evacuation from bushfires.***
>
> **Our Turn to Speak participant**
> **New South Wales**

The survey also asked about positive treatment in the housing domain. Two core statements comprised this section of the survey: (1) the expectation of special consideration in relation to complex mental health issues, and (2) manifest positive experiences in housing because of one's experience of complex mental health issues.

As shown in **Figure 13.11**, 68.4% of participants agreed that they should receive special consideration when accessing housing or homelessness services. Unfortunately, fewer participants (25.7%) agreed that they had has positive experiences in connection to their complex mental health issues when accessing housing or homelessness services.

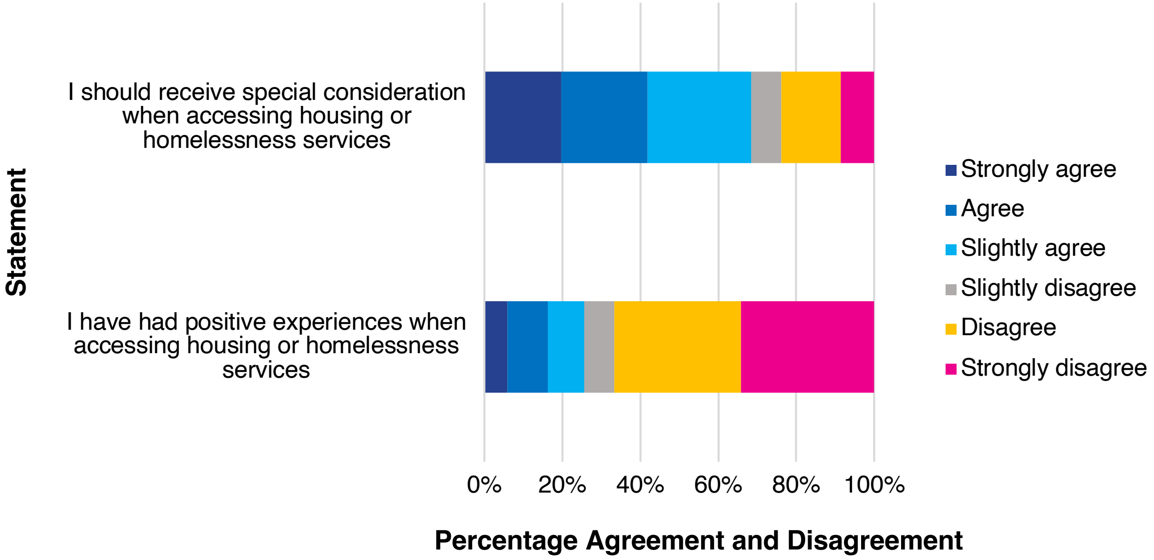


Figure 13.11. Highlight findings: responses to the statements regarding positive experiences in *housing and homelessness services* because of participants' complex mental health issues (*n* = 117).

SUMMARY OF QUALITATIVE FINDINGS IN HOUSING

The additional commentary participants provided about their experiences of stigma and discrimination in housing referred to numerous barriers to accessing and maintaining housing, relevant support services, or transfers to other accommodation. Examples included having to complete *"large complex documents"* (as well as having to provide supporting documentation), precarious financial and employment situations, living on the disability pension, location of residence, living with a service assistance dog, and participants' complex mental health issues not being understood or taken seriously;

> *I was evicted from a women's refuge early and rejected from crisis accommodation constantly as no one could seem to understand exactly how bad my BPD had flared up and how bad my mental health was from the trauma and violence I had gone through or the serious safety issues I had because I "seemed" like a high or "normal" functioning person. Because of this stigma and discrimination, I ended up homeless for 8 months this year. I went through thousands* [of dollars] *of my savings paying for accommodation – camp sites, motels, cabins etc and ended up living in my ute for the last 3 months. I was actually told by a court victim support officer that "crisis accommodation isn't for people like me, it's for people that genuinely need it" ... just because I had savings. My mental health, safety and PTSD were completely overlooked when I needed the support the most* (**Our Turn to Speak** participant, New South Wales).

Anticipated stigma and discrimination in housing was also reflected in participants' qualitative comments and appeared to demonstrate how past negative experiences influenced expectations of similar treatment in future. Two participants conveyed that they avoided disclosing their mental health issues (to housemates, for instance). Feeling afraid of violence and harassment from neighbours or other public housing residents were mentioned by a number of participants. Some examples included being assaulted, damage to property, theft, and other *"disruptive"* behaviour;

> *Due to my PTSD I cannot cope with people yelling. I commented to my neighbour that I wasn't able to cope with him yelling at his 5 year old child and he has refused to speak to me, and has requested me to text him if I want to communicate with him* (**Our Turn to Speak** participant, Queensland).

Another participant explained that they felt afraid when looking to purchase a property; *"I did not feel welcomed in fact I felt physically scared when viewing areas to potentially build a home"* (**Our Turn to Speak** participant, Victoria). Negative experiences with housing officers, real estate agents, and landlords were also shared by a few participants; for instance, *"Having a housing officer walk through your house taking photos for their records without asking and thinking it is alright just because I had a mental health support worker with me"* (**Our Turn to Speak** participant, Western Australia). One participant described a situation where their confidentiality had been breached by a housing provider regarding their mental health issues. Others linked their negative experiences in housing to encounters with the justice system (that is, tribunals such as VCAT and equivalents in other jurisdictions).

Participants linked their reluctance to apply for housing and related services, and withdrawal from household members and neighbours, to past negative experiences and expectations;

> *I had a neighbour who was very drunk* [and] *stood outside my unit and yelled my name saying "you have mental illness..." other neighbours who did not know heard and changed their behaviour towards us. There were also people walking along the footpath who we see at the local shops. I was very angry with this neighbour as this is our story to tell to people when we choose tell.* [W]*e were close with this woman but have stepped back from her over the past few months* (**Our Turn to Speak** participant, New South Wales).

While many participants explained in the comments section that they had mixed or no positive experiences to report in connection with their experience of complex mental health issues and housing, a number of participants did describe instances of positive treatment or special consideration. These included positive experiences with landlords and neighbours, success in finding a home, being prioritised for public housing, access to social and community housing schemes, supportive homelessness and housing services, and supportive real estate agents;

> *When upset during phone call re rental, owner of* [Real Estate] *agency unexpectedly came to check on my welfare* (**Our Turn to Speak** participant, South Australia).

It was evident that, when housing services were accommodating of participants' unique needs in relation to their complex mental health and intersecting issues, participants described their experiences and outcomes in positive terms. In the absence of positive experiences in housing, some participants explicitly recommended or otherwise implied various strategies that could have improved their treatment in this domain;

> *I definitely don't believe that I deserve "special" consideration for housing support just because I have a mental health diagnosis but I do believe that more services need to assess each situation on an individual basis and take the whole situation into account. I did receive support from a homelessness service for people living in their vehicles called Our Backyard who were absolutely amazing and the end of my homelessness journey this year* (**Our Turn to Speak** participant, New South Wales).

> [B]*ecause of my extra vulnerbilities I believe my family & I should have much greater consideration & empathy when needing help to find appropriate housing. Our needs are considerable & not having barely any choice of the type of housing or even have it available in area's nearer to our support network is very upsetting & debilitating* (**Our Turn to Speak** participant, Queensland).

Participants mentioned numerous other personal characteristics that had been the subject of stigma and discrimination beyond those specifically asked about in the survey. These additional characteristics included age, experience of family violence, physical appearance, and aspects of socioeconomic status (such as education, employment, and financial situation);

> *There should be more secured community Housing for women escaping domestic violence and family violence. Landlords shouldn't discriminate or at least give tenancy a three month trial basis if unsure about signing a lease. Agencies discrimate based on appearance, clothing, lack of employment and social status* (**Our Turn to Speak** participant, Victoria).

Participants' commentary also referred to the ways in which stigma and discrimination about other personal characteristics, such as physical health issues and disability, affected their housing security, physical and emotional safety, anticipation of future stigma and discrimination, and reluctance to disclose their housing needs to others (another form of withdrawal from opportunities).

SUMMARY

Of the 1,912 survey participants, 6.1% (*n* = 117) identified housing as one of up to three life domains that had been most affected by stigma and discrimination in connection with complex mental health issues. Just over 60% of participants who selected the Housing and Homelessness Services domain as one of their most affected life domains during the last 12 months indicated 'frequent' or 'very frequent' experiences of stigma and discrimination in this aspect of their lives.

When presented with a range of statements describing general and specific examples of stigma and discrimination in housing, it was evident that participants living in private rental housing reported greater perceived experiences of unfair treatment and denial of accommodation compared with participants living in public or community housing or those accessing homelessness services. It is particularly concerning that 60.2% of participants relying on the private rental market perceived that they had been denied housing on application because of stigma about mental health issues. Compared with participants living in private rental housing or accessing homelessness services (~38%), fewer participants living in public or community housing (20.0%) agreed that they had been unfairly asked to leave their accommodation before they were ready to.

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. Indeed, participants' qualitative comments highlighted numerous instances whereby others' limited understanding about complex mental health issues had acted as a barrier to finding and maintaining safe, comfortable, and appropriate accommodation that would meet their multifaceted needs.

Stigma and discrimination in relation to other personal characteristics, such as physical health and (dis)ability in particular, only compounded the challenges to securing and maintaining appropriate housing as described by some participants. Close to 50% of participants agreed that they had experienced stigma and discrimination in housing because of their physical health issues. It is well known that, more often than not, people living with complex mental health issues also experience co-occurring physical health issues. This combination drastically affects psychosocial functioning, quality of life, and even reduces life expectancy (Firth et al., 2019). Insufficient access to, and inadequate housing, only exacerbates and prolongs the numerous health, wellbeing, social, and economic disadvantages those living with complex mental health issues face and, as such, must be addressed to improve both physical and mental health outcomes (Singh et al., 2019).

Rates of agreement with statements describing various kinds of anticipated discrimination and withdrawal from opportunities relating to housing were somewhat greater than for perceived experiences of stigma and discrimination. Again, participants living in private rental housing reported greater expectations of future unfair treatment and denial of housing than did participants living in public or community housing or accessing homelessness services.

Regardless of the type of housing participants had accessed (or tried to access) during the last 12 months, 70% of participants expected that they would be treated unfairly by housing officials or landlords because of stigma about mental health issues. In this context, it is understandable that a similar proportion of participants reported that they had stopped themselves from reporting maintenance issues or making complaints to these people in positions of power. As evidenced in participants' qualitative comments, it may be "easier" not to ask for reasonable repairs, changes, or accommodations to be made, in order to avoid the risk of being unfairly denied, undermined, ignored or otherwise disrespected. Depending on the nature of housing accessed, between 28% and 55% of participants reported that they had actually left their accommodation earlier than they wanted to, because of stigma and discrimination in connection with their experience of mental health issues.

Finally, approximately one quarter of participants agreed that, because they live with mental health issues, they have had positive experiences when accessing housing or homelessness services. Participants' qualitative responses similarly indicated few positive experiences, and detailed explanations of individual circumstances clearly indicated a need for housing providers and other stakeholders to accommodate and take the intersectional needs of people living with complex mental health issues seriously.

Similarly, almost 70% of participants who completed the housing section of the survey agreed that they should receive special consideration for their mental health issues when accessing housing or homelessness services. Safe, quality and affordable housing is essential to general mental health and facilitating psychosocial recovery among people living with complex mental health issues (Brackertz et al., 2019). These findings indicate a need to ensure that stigma and discrimination, in all its forms, does not continue to prevent people with mental health issues from accessing and maintaining housing that meets their specific and intersecting needs.

CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES

14

Chapter 14. Cultural, faith or spiritual practices and communities

For many people, participating in cultural, faith or spiritual practices, either alone or within a community, is an important part of their daily lives and identity.

Cultural, faith or spiritual communities can be important places for people to access social support, to experience a sense of belonging. The structures and rituals they provide can provide comfort and meaning for many. Regardless of an individual's personal beliefs, it is important that people who live with complex mental health issues can participate in the cultural, faith or spiritual practices and communities that are important to them.

This chapter considers how people living with complex mental health issues experience stigma and discrimination in participating in cultural, faith or spiritual practices and communities.

OVERVIEW

Almost 40% (*n* = 754) of all **Our Turn to Speak** participants reported experiencing some level of stigma or discrimination in cultural, faith or spiritual practices and communities during the past 12 months.

As shown in **Figure 14.1**, 10.1% of all participants reported 'frequent' or 'very frequent' stigma and discrimination in their cultural, faith or spiritual practices and communities, and 5.3% (*n* = 102) identified this life domain as one of three in which they have been most affected by such experiences. **Figure 14.1** also shows that 44.1% of participants who selected the cultural, faith or spiritual practices and communities domain reported 'frequent' or 'very frequent' rates of stigma and discrimination in this aspect of their lives; much higher than was reported by the overall sample.

This chapter focuses on the characteristics and experiences of those 102 participants who selected cultural, faith or spiritual practices and communities as one of their top three, most affected life domains

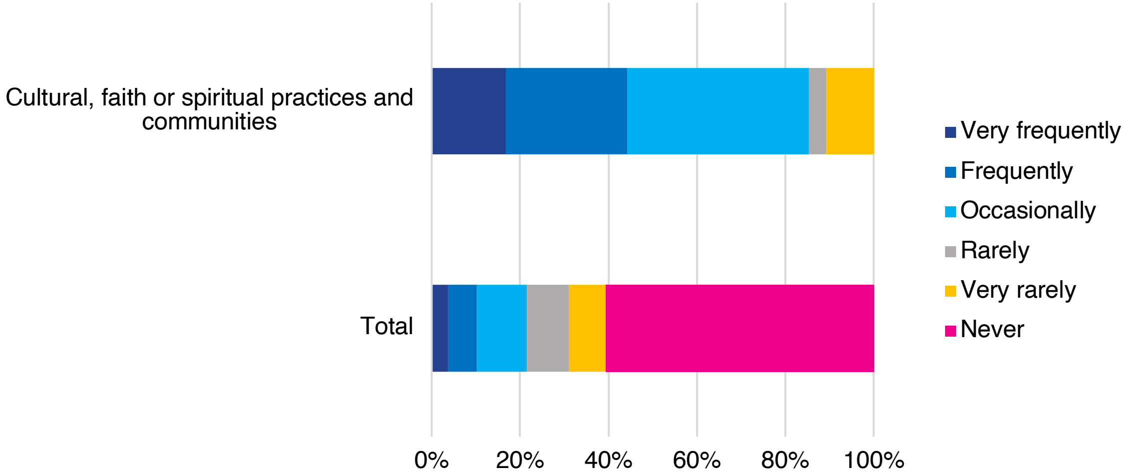


Figure 14.1. Frequency of stigma and discrimination in *cultural, faith or spiritual practices and communities* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 117) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

Overall, the sociodemographic characteristics of participants who identified as being personally affected by stigma and discrimination in cultural, faith or spiritual practices and communities were not dissimilar from the total sample (see **Table 14.1**).

Compared with the total sample, there was a slightly higher proportion of males represented in the cultural, faith or spirital practices and communities domain, and 13.1% fewer participants who identified as gay, lesbian, bisexual, pansexual, queer and/or asexual. A greater proportion of participants reported a post-secondary college education. Eight percent more participants who responded to this life domain were living in New South Wales and 8.6% more were located in regional or remote areas.

Table 14.1. Sociodemographic characteristics: *cultural, faith or spiritual practices and communities* sample compared with the total sample.

Characteristics	Cultural, Faith or Spiritual Practices and Communities (*n* = 102)	Total (*N* = 1912)
Mean age	41.27 (*SD* = 13.46)	39.21 (*SD* = 12.81)
Gender identity		
Female	72.5%	78.9%
Male	24.5%	18.0%
Trans, gender diverse and/or non-binary	4.9%	4.9%
Unsure or questioning	2.0%	0.9%
Prefer not to say	1.0%	0.4%
Relationship status		
Not in a relationship	54.5%	52.1%
In a relationship	45.5%	47.3%
Prefer to self-describe	1.0%	0.2%
Sexual orientation		
Heterosexual	72.5%	62.0%
Gay, lesbian, bisexual, pansexual, queer, and/or asexual	22.5%	35.6%
Unsure or questioning	2.9%	4.9%
Prefer to self-describe	2.0%	1.5%
Prefer not to say	3.9%	1.7%
Education (highest level attained)		
Primary school	1.0%	1.6%
Secondary college (high school)	13.7%	20.9%
Educated post-secondary college	85.3%	77.4%
Other	0.0%	0.2%
Employment status		
Engaged in paid work	52.0%	51.7%
Engaged in unpaid work or studying	32.4%	28.7%
Unemployed or unable to work	25.5%	22.8%
Receiving a pension or benefits	23.5%	24.6%
Other	1.0%	0.2%
State		
Australian Capital Territory	2.0%	2.5%
New South Wales	31.4%	23.6%
Northern Territory	1.0%	0.6%
Queensland	11.8%	15.9%
South Australia	5.9%	9.5%
Tasmania	2.0%	3.7%
Victoria	33.3%	33.1%
Western Australia	12.7%	10.9%
Region*		
Major city	66.7%	74.2%
Regional or remote	33.3%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.

Of note, the religious or spiritual affiliation of participants who selected the cultural, faith or spiritual practices and communities domain differed in important ways compared with the total sample (see **Figure 14.2**).

Far fewer participants who selected the current domain (23.5%) reported secular beliefs and other spiritual beliefs with no religious affiliation compared with the total sample (66.4%), while there was a much higher representation of participants of Christian faith (64.7%) compared with the total sample (24.7%).

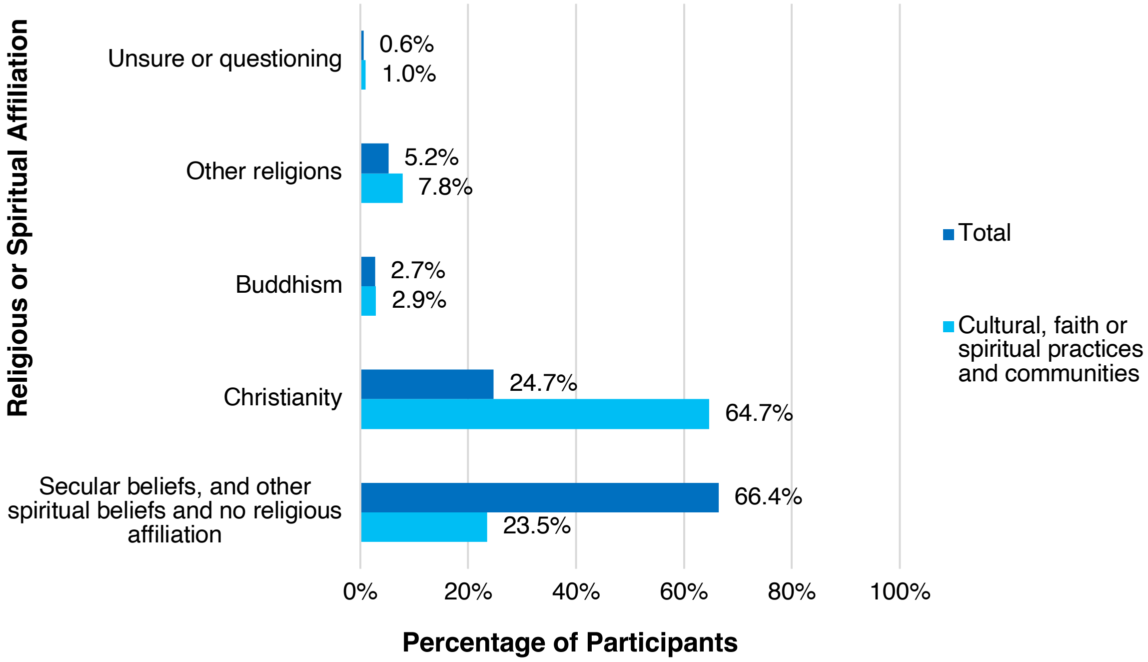


Figure 14.2. Religious or spiritual affiliation among participants who selected *cultural, faith and spiritual practices and communities* as one of three domains in which they had been most affected by stigma during the past 12 months (*n* = 102) compared with the total sample (*N* = 1912).
Note. Religious and spiritual affiliation was missing for seven participants in the total sample.

Shown in **Figure 14.3,** there was also a greater proportion of participants whose ancestry or cultural background was from the Asia-Pacific region (14.7%) compared with the total sample (6.6%).

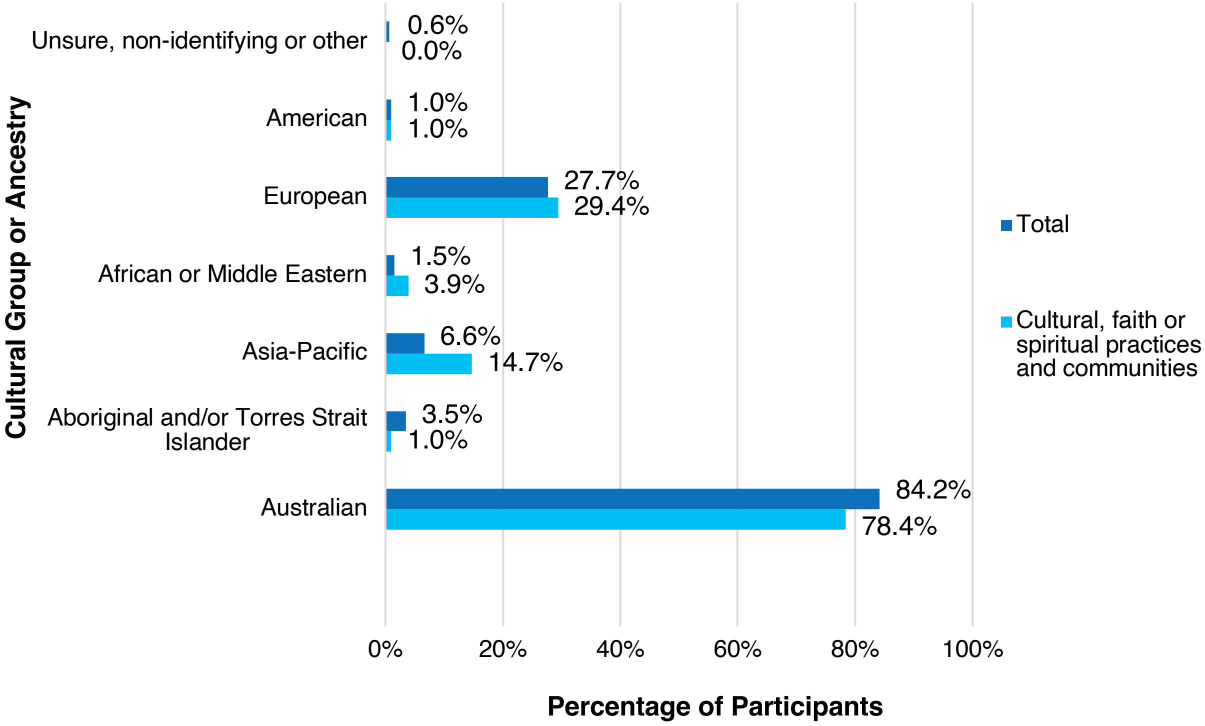


Figure 14.3. Cultural group or ancestry among participants who selected *cultural, faith and spiritual practices and communities* as one of three domains in which they had been most affected by stigma during the past 12 months (*n* = 102) compared with the total sample (*N* = 1912).
Note. Percentages do not add to 100 as participants could select more than one response option

As with the sociodemographic data, the mental and physical health characteristics of participants who responded to the cultural, faith or spiritual practices and communities section of the survey were mostly similar to those of the total sample.

Shown in **Table 14.2**, fewer participants living with a primary bipolar related disorder were represented in this life domain compared with the total sample, while there was a greater representation of participants with a primary diagnosis of trauma-related or dissociative disorders, and obsessive-compulsive related disorders.

Table 14.2. Mental and physical health characteristics: *cultural, faith or spiritual practices and communities* sample compared with the total sample.

Characteristics	Cultural, Faith or Spiritual Practices and Communities (*n* = 102)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	10.8%	7.4%
Bipolar related disorder	10.8%	17.2%
Obsessive-compulsive related disorder	8.8%	4.3%
Trauma-related or dissociative disorder	32.4%	25.9%
Eating disorder	2.9%	6.1%
Personality disorder	12.7%	14.5%
Severe and treatment-resistant depressive disorder	13.7%	14.3%
Severe and treatment-resistant anxiety disorder	7.8%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	52.9%	53.8%

METHODS SNAPSHOT

Participants who identified cultural, faith or spiritual practices and communities as one of three life domains in which they have been most affected by stigma-related experiences completed the cultural, faith or spiritual practices and communities section of the survey. At the beginning of this section of the survey, participants were asked to indicate what types of practices and communities they had participated in during the previous 12 months. These were described as including, for example:

- customs and traditions
- prayer and meditation
- regular services and celebrations
- any other important rituals, practices or spaces of cultural, faith or spiritual significance.

Thirty-one percent (*n* = 32) had participated in, or wanted to participate in, cultural communities or practices and 83.3% (*n* = 85) had had participated in, or wanted to participate in, faith or spiritual communities or practices. Participants were subsequently presented with only the questions that matched their reported experience of such practices and communities. For example, participants who reported participating in cultural practices and communities during the last 12 months only received questions corresponding to cultural practices and communities. Those who indicated they had accessed more than one type of cultural, faith or spiritual practices and communities received questions corresponding to each of those areas.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in their relationships; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of relationships. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further elaborate on and describe their experiences of stigma and discrimination in relation to: (a) complex mental health issues, (b) their other personal characteristics, and (c) any positive treatment in relation to their cultural, faith or spiritual practices and communities. Twenty-two, 5 and 14 participants provided additional comments in relation to these experiences, respectively.

STIGMA AND DISCRIMINATION IN CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in cultural, faith or spiritual practices and communities, which will be further examined in sections that follow.

As shown in **Figure 14.4**, the average total level of agreement with all statements describing withdrawal from opportunities in this domain was about 63.3%. In other words, participants typically agreed that, more often than not, they stopped themselves from accessing opportunities relevant to this domain (for example, attending places of cultural, spiritual or religious significance; participating in cultural, spiritual or religious practices; or seeking support or counsel from community members).

At around 42%, the average total level of agreement with all statements describing perceived experiences and anticipation of stigma and discrimination in cultural, faith or spiritual practices and communities was lower than for withdrawal from opportunities, but still substantial.

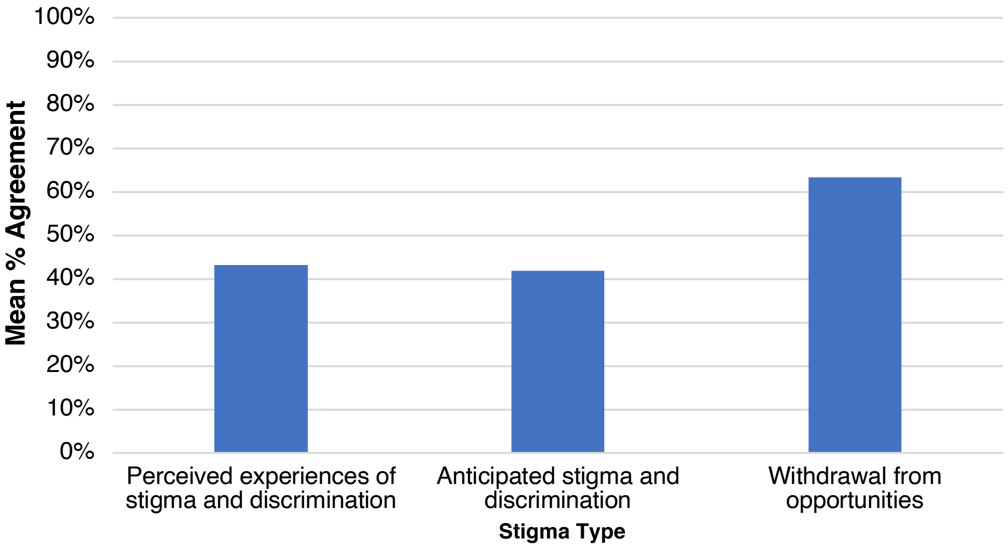


Figure 14.4. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *cultural, faith and spiritual practices and communities* (*n* = 102).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES

> *I am always left feeling like I am not accepted for my mental illness. ‘God will fix my mental illness’ is the subtle message I keep feeling when connecting with people in this community, but I believe I have been given my illness for a reason; to help others. By having this belief I am going against what they believe and thus don’t feel accepted.*
>
> **Our Turn to Speak participant**
> **Western Australia**

Presented in this section are the findings regarding participants’ perceived experiences of stigma and discrimination in cultural, faith or spirutal practices and communities, as related to their experience of complex mental health issues.

Figure 14.5 compares perceived experiences of stigma and discrimination associated with *cultural* practices and communities with *faith and spiritual* practices and communities. As shown, across most statements, perceived experiences of stigma and discrimination during the last 12 months were higher among those participants who identified with faith and spiritual practices and communities, in comparison to cultural practices and communities. For instance, 80.0% of participants agreed that members of their faith and spiritual practices and communities had treated them unfairly, compared to 59.4% who had participated in cultural practices and communities.

The opposite pattern was found in relation to having been unfairly asked to leave one’s community because of stigma about mental health issues, with a higher proportion of participants who identified with cultural practices and communities (28.2%) reporting this experience than among participants who identified with faith or spiritual practices and communities (18.8%).

Rates of agreement in relation to having been unfairly denied access to places of significance (for example, temples, mosques and churches) were similar for both groups – about 25% of all participants agreed with this statement.

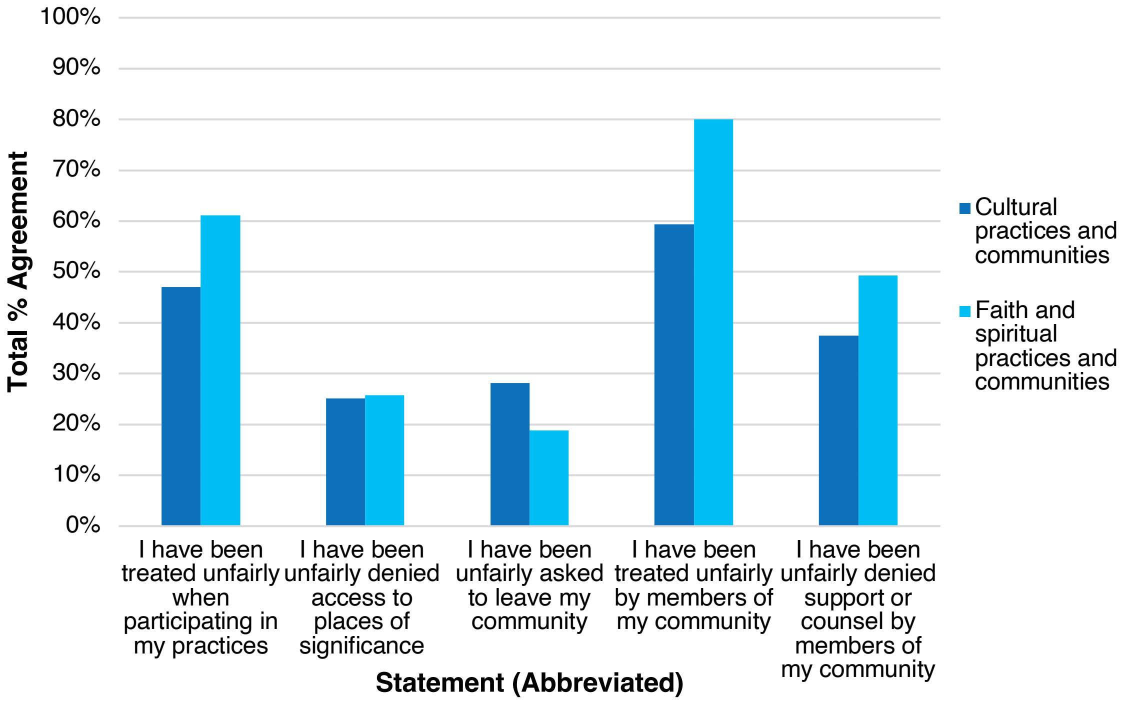


Figure 14.5. Highlight findings: total percentage agreement with perceived experiences of stigma and discrimination in *cultural practices and communities* (*n* = 32) and *faith and spiritual practices and communities* (*n* = 85).

Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

Tables 14.3 and **14.4** provide the specific levels of agreement and disagreement for all statements relating to perceived experiences of stigma and discrimination in faith or spiritual practices and communities, and cultural practices and communities. The findings in these tables were summarised in relation to the figure.

Table 14.3. Perceived experiences of stigma and discrimination in *cultural practices and communities*: percentage agreement and disagreement (*n* = 32).

Statement	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree	Total agree
Because of stigma about mental health issues …							
I have been treated unfairly when participating in my cultural practices	12.5%	21.9%	18.8%	18.8%	18.8%	9.4%	**47.0%**
I have been unfairly denied access to places of cultural significance or community spaces	34.4%	31.3%	9.4%	6.3%	12.5%	6.3%	**25.1%**
I have been unfairly asked to leave my cultural community	34.4%	31.3%	6.3%	9.4%	9.4%	9.4%	**28.2%**
I have been treated unfairly by members of my cultural community	15.6%	21.9%	3.1%	25.0%	25.0%	9.4%	**59.4%**
I have been unfairly denied support or counsel by members of my cultural community	18.8%	28.1%	15.6%	15.6%	9.4%	12.5%	**37.5%**

Table 14.4. Perceived experiences of stigma and discrimination in *faith or spiritual practices and communities*: percentage agreement and disagreement (n = 85).

Statement	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree	Total agree
Because of stigma about mental health issues …							
I have been treated unfairly when participating in my faith or spiritual practices	9.4%	20.0%	9.4%	16.5%	28.2%	16.5%	**61.2%**
I have been unfairly denied access to places of spiritual significance or worship	31.8%	36.5%	5.9%	4.7%	8.2%	12.9%	**25.8%**
I have been unfairly asked to leave my faith or spiritual community	37.6%	35.3%	8.2%	5.9%	3.5%	9.4%	**18.8%**
I have been treated unfairly by members of my faith or spiritual community	5.9%	12.9%	1.2%	29.4%	23.5%	27.1%	**80.0%**
I have been unfairly denied support or counsel by members of my faith or spiritual community	17.6%	27.1%	5.9%	12.9%	17.6%	18.8%	**49.3%**

ANTICIPATED STIGMA AND DISCRIMINATION IN CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES

> ***I recently changed churches because of it, but I'm expecting the same to happen. People give up on me after a while.***
>
> **Our Turn to Speak participant**
> **Victoria**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in faith, spiritual and cultural practices and communities, as related to their experience of complex mental health issues.

Of note, the pattern of agreement with all five statements about anticipated stigma and discrimination in this domain was not dissimilar from the pattern observed in relation to perceived experiences of stigma and discrimination.

As shown in **Figure 14.6**, anticipated stigma and discrimination during the last 12 months was generally higher among participants who identified with *faith and spiritual* practices and communities compared with those who identified with *cultural* practices and communities. Close to 65% and 47% of participants who engaged in faith and spiritual practices and communities agreed that they expected to be: (a) treated unfairly, and (b) denied support or counsel by members of their community, respectively. This compared with 56.3% and 37.5% of participants engaged in cultural practices and communities.

A similar proportion (approximately 25%) of participants engaged in cultural practices and communities, and/or spiritual and faith practices and communities, agreed that they expected to be unfairly denied access to places of cultural or spiritual significance because of stigma about complex mental health issues.

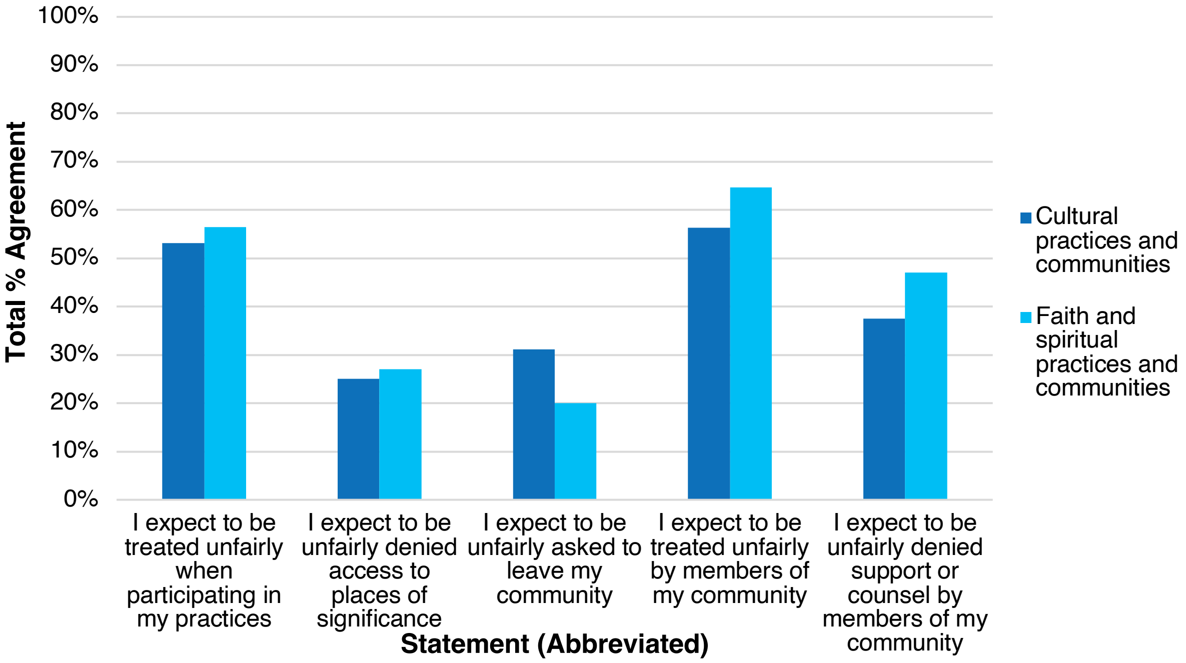


Figure 14.6. Highlight findings: total percentage agreement with anticipated stigma and discrimination in *cultural practices and communities* (*n* = 32) and *faith or spiritual practices and communities* (*n* = 85).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

Tables 14.5 and **14.6** provide the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in faith and spiritual practices and communities, and cultural practices and communities. The findings in these tables were summarised in relation to to **Figure 14.6**.

Table 14.5. Anticipated experiences of stigma and discrimination in *cultural practices and communities*: percentage agreement and disagreement (*n* = 32).

Statement	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree	Total agree
Because of stigma about mental health issues …							
I expect to be treated unfairly when participating in my cultural practices	28.1%	15.6%	3.1%	28.1%	21.9%	3.1%	**53.1%**
I expect to be unfairly denied access to places of cultural significance or community spaces	34.4%	28.1%	12.5%	6.3%	15.6%	3.1%	**25.0%**
I expect to be unfairly asked to leave my cultural community	37.5%	25.0%	6.3%	15.6%	12.5%	3.1%	**31.2%**
I expect to be treated unfairly by members of my cultural community	18.8%	18.8%	6.3%	34.4%	21.9%	0.0%	**56.3%**
I expect to be unfairly denied support or counsel by members of my cultural community	31.3%	21.9%	9.4%	15.6%	18.8%	3.1%	**37.5%**

Table 14.6. Anticipated experiences of stigma and discrimination in *faith or spiritual practices and communities*: percentage agreement and disagreement (*n* = 85).

Statement	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree	Total agree
Because of stigma about mental health issues …							
I expect to be treated unfairly when participating in my faith or spiritual practices	18.8%	20.0%	4.7%	28.2%	21.2%	7.1%	**56.5%**
I expect to be unfairly denied access to places of spiritual significance or worship	36.5%	27.1%	9.4%	8.2%	8.2%	10.6%	**27.0%**
I expect to be unfairly asked to leave my faith or spiritual community	40.0%	30.6%	9.4%	3.5%	7.1%	9.4%	**20.0%**
I expect to be treated unfairly by members of my faith or spiritual community	20.0%	10.6%	4.7%	22.4%	28.2%	14.1%	**64.7%**
I expect to be unfairly denied support or counsel by members of my faith or spiritual community	24.7%	18.8%	9.4%	17.6%	20.0%	9.4%	**47.0%**

WITHDRAWAL FROM OPPORTUNITY IN CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES

> ***I left my spiritual community because of mental health issues, and was not allowed back in because these issues are ongoing.***
>
> **Our Turn to Speak participant**
> **Victoria**

Presented in this section are the findings regarding participants' withdrawal from opportunities in cultural, faith or spiritual practices and communities, as related to their experience of complex mental health issues.

Compared to that observed for perceived experiences and anticipated stigma and discrimination, there was much less variation in rates of agreement for statements describing withdrawal from opportunity in *cultural* practices and communities versus *faith and spiritual* practices and communities.

As shown in **Figure 14.7**, approximately 70% of participants agreed that they had stopped themselves from: (a) participating in cultural, faith or spiritual practices and communities, (b) going to places of significance, and (c) engaging with their community. Participants who identified with faith and spiritual practices and communities agreed that they had stopped themselves from seeking support or counsel from members of their community at a much higher rate (72.9%) in comparison with those who identified with cultural practices or communities (53.2%).

In both groups, fewer than 50% agreed that they had stopped practicing their cultural, faith or spiritual beliefs during the last 12 months because of stigma about mental health issues.

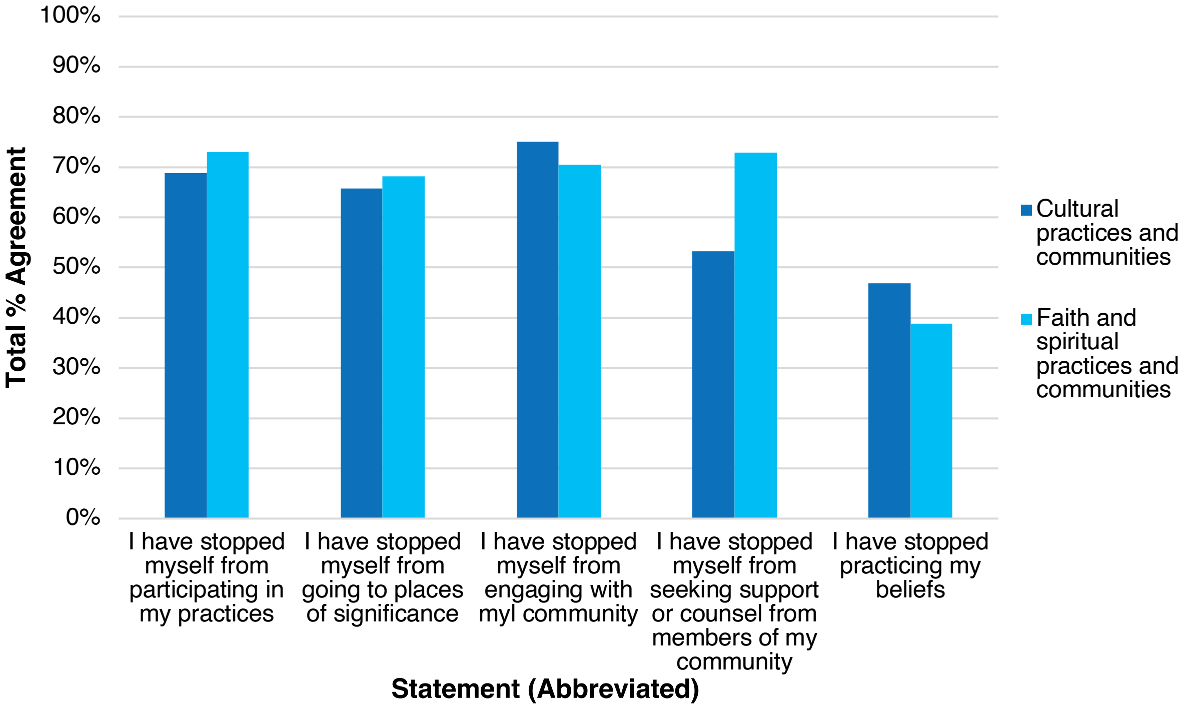


Figure 14.7. Highlight findings: total percentage agreement with withdrawal from opportunities in *cultural practices and communities* (*n* = 32) and *faith and spiritual practices and communities* (*n* = 85).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

Finally, **Tables 14.7** and **14.8** provide the specific levels of agreement and disagreement for all statements relevant to withdrawal from opportunities in cultural, faith and spiritual practices and communities. The findings in these tables were summarised in relation to **Figure 14.7**.

Table 14.7. Withdrawal from opportunities in *cultural practices and communities*: percentage agreement and disagreement ($n = 32$).

Statement	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree	Total agree
Because of stigma about mental health issues …							
I have stopped myself from participating in my cultural practices	18.8%	3.1%	9.4%	25.0%	34.4%	9.4%	**68.8%**
I have stopped myself from going to places of cultural significance or community spaces	18.8%	6.3%	9.4%	9.4%	37.5%	18.8%	**65.7%**
I have stopped myself from engaging with my cultural community	12.5%	3.1%	9.4%	25.0%	31.3%	18.8%	**75.1%**
I have stopped myself from seeking support or counsel by members of my cultural community	15.6%	18.8%	12.5%	15.6%	18.8%	18.8%	**53.2%**
I have stopped practicing my cultural beliefs	21.9%	21.9%	9.4%	25.0%	15.6%	6.3%	**46.9%**

Table 14.8. Withdrawal from opportunities in *faith or spiritual practices and communities*: percentage agreement and disagreement (*n* = 85).

Statement	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree	Total agree
Because of stigma about mental health issues …							
I have stopped myself from participating in my faith or spiritual practices	9.4%	8.2%	9.4%	24.7%	22.4%	25.9%	**73.0%**
I have stopped myself from going to places of spiritual significance or worship	11.8%	12.9%	7.1%	18.8%	25.9%	23.5%	**68.2%**
I have stopped myself from engaging with my faith or spiritual community	8.2%	12.9%	8.2%	17.6%	28.2%	24.7%	**70.5%**
I have stopped myself from seeking support or counsel from members of my faith or spiritual community	8.2%	11.8%	7.1%	11.8%	28.2%	32.9%	**72.9%**
I have stopped practicing my faith or spiritual beliefs	27.1%	20.0%	14.1%	12.9%	5.9%	20.0%	**38.8%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES

> ***Churches are notoriously inaccessible. In addition, attitudes are very closed. People with disability are either objects of pity requiring charity, or are considered broken and in need of divine healing.***
>
> **Our Turn to Speak participant**
> **New South Wales**

The findings from survey statements in relation to other experiences of stigma and discrimination in cultural, faith or spiritual practices and communities, besides complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 14.8.** As shown, 38.1% of participants agreed that they had experienced stigma and discrimination in this domain because of their physical health or ability. Interestingly, 28.4% of participants agreed that they had experienced stigma and discrimination in their cultural, faith or spiritual practices and communities because of the beliefs they hold in connection with those practices and communities.

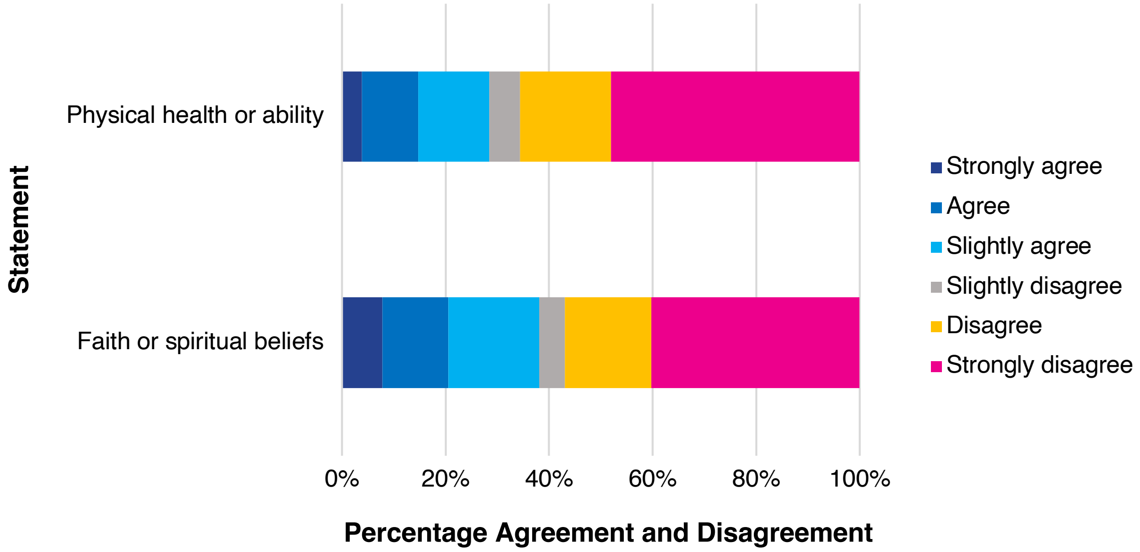


Figure 14.8. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *cultural practices and communities* (*n* = 102).

The specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting this domain are summarised in **Table 14.9**. Overall, a relatively low rate of agreement was observed for statements describing experiences of stigma and discrimination in cultural, faith or spiritual communities due to personal characteristics other than complex mental health issues.

Table 14.9. Experiences of intersectional stigma and discrimination in *cultural, faith or spiritual practices and communities*: percentage agreement and disagreement (*n* = 102).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in cultural, faith or spiritual practices and communities because of my …							
Racial or cultural background	69.6%	14.7%	3.9%	4.9%	4.9%	2.0%	**11.8%**
Faith or spiritual beliefs	40.2%	16.7%	4.9%	17.6%	12.7%	7.8%	**38.1%**
Sexual orientation	60.8%	18.6%	0.0%	2.0%	5.9%	12.7%	**20.6%**
Gender identity	72.5%	13.7%	1.0%	2.0%	6.9%	3.9%	**12.8%**
Physical health or ability	48.0%	17.6%	5.9%	13.7%	10.8%	3.9%	**28.4%**

POSITIVE EXPERIENCES IN CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES

> *I have met a few people who have a sincere heart to help others and express kindness and compassion. I have come to cherish the kindness of others - recognising they could bever understand but seeing the heart behind our contact. Kindness and compassion are true gifts and even on the darkest day, if someone is willing to listen and smile, it goes a long way. To feel validated in the middle of pain and grief and confusion, is a treasure.*
>
> **Our Turn to Speak participant**
> **Queensland**

The survey also asked about positive treatment in cultural, faith or spiritual practices and communities. Two core statements comprised this section of the survey: (1) the expectation of special consideration because of one's experience of complex mental health issues, and (2) manifest positive experiences in this domain because of one's experience of complex mental health issues.

As shown in **Figure 14.9**, 45.1% of participants agreed that they should receive special consideration when participating in their practices and communities. Fifty-two percent of participants agreed that they have had positive experiences when participating in their cultural, faith or spiritual practices and communities in connection with their experience of complex mental health issues.

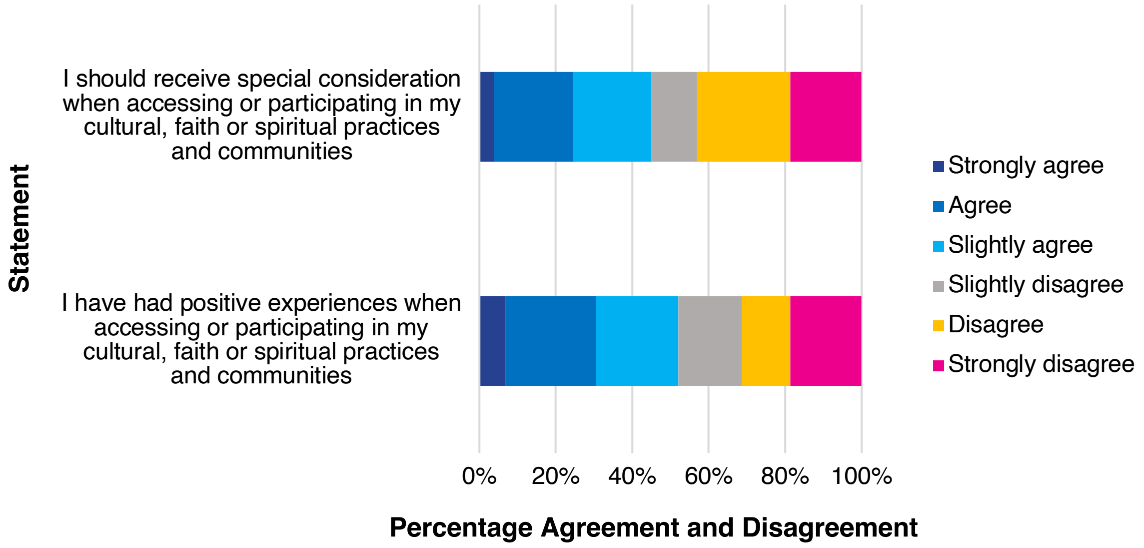


Figure 14.9. Highlight findings: responses to the statements regarding positive experiences in *cultural practices and communities* because of participants' complex mental health issues (*n* = 102).

SUMMARY OF QUALITATIVE FINDINGS IN CULTURAL, FAITH OR SPIRITUAL PRACTICES AND COMMUNITIES

Due to the small number of responses in this domain, it was difficult to draw out major themes. That said, a few participants shared feelings of not being accepted, or concerns about feeling ‘othered’. For example:

> *I am always left feeling like I am not accepted for my mental illness. 'God will fix my mental illness' is the subtle message I keep feeling when connecting with people in this community, but I believe I have been given my illness for a reason; to help others. By having this belief I am going against what they believe and thus don't feel accepted* (**Our Turn to Speak** participant, Western Australia).
>
> *I feel different to the other members of my congregation. They all seem to have come from perfect families, have perfect children and lead perfect lives. They haven't been exposed to the things I have been exposed to. They may travel to Africa to help orphans or send care packages to refuges, but they don't see what is happening right under their nose. They pray outwardly for those who are sick, they make meals for new Mums and those with breast cance, but the mentally ill just suffer in silence* (**Our Turn to Speak** participant, New South Wales).
>
> *Discrimination is subtle. It is very rarely overt. It comes in language and it comes in attitudes; sometimes even those that are ostensibly loving and supportive. As long as the end result is an individual is treated as an “other” then it should be closely examined* (**Our Turn to Speak** participant, Victoria).

A couple of participants shared that they had left their church or spiritual community; for example: *“I left my spiritual community because of mental health issues, and was not allowed back in because these issues are ongoing”* (**Our Turn to Speak** participant, Victoria).

Several participants commented on a lack of understanding for people with mental health issues. Some said that mental health issues had been interpreted in their community as lacking faith or being possessed by demons (with a few participants describing experiences of having exorcisms performed on them):

> *A priest performed an excorsism on me when he found out I had Psychosis and was hearing voices* (**Our Turn to Speak** participant, Queensland).
>
> *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).
>
> *There are a number of people in our church, unfortunately, who think that Depression and Mental Illness stem from a lack of faith in God. So they just tell me over and over again to have more faith in God, and that I need to stop sinning, and then everything will be okay. I've tried to explain to them that it doesn't work that way, that I hear voices all the time, etc., and that it's not a lack of faith, however they are stubborn, and I just cannot attend a Bible study meeting with people who think I'm crazy and have no faith. It's sad that this is the case* (**Our Turn to Speak** participant, Western Australia).

One participant felt that they had seen increased awareness among churches over the years, as they reflected:

> *…I believe - compared to many years ago - when I started on my healing journey, churches have become more aware of the need mentally ill people have. They now seem to have more resources and are able to refer people to those more qualified. Thirty years ago, there was not much available to support those on the front line, and there was more stigma for the mentally ill. Although so much is spoken about it now, I still carry the scars from trying to find my way without help and risking trust in people I should not have trusted* (**Our Turn to Speak** participant, Queensland).

When asked about positive experiences in relation to this domain, some participants gave examples such as feeling cared for and supported; connecting with other people and experiencing their kindness; and the opportunity to raise awareness about complex mental health issues;

> *I have also experienced great support and genuine caring & understanding within my faith* (**Our Turn to Speak** participant, New South Wales).

> *My pastor has kept in touch with me via text while I haven't been able to go to church for most of the last twelve months. And a couple other people from my service have also text messaged me regularly throughout the year. I've only had a handful of pastoral visits though* (**Our Turn to Speak** participant, New South Wales).

> *I was confined to a mental health clinic because of I attempted to take my life. While there, the pastoral carers who visited me were very kind and supportive* (**Our Turn to Speak** participant, Western Australia).

Some other participants described negative or mixed experiences when asked if they could share positive experiences in their cultural practices, faith or spiritual practices and communities. *"I have a great relationship with my Pastor and his wife, and they are very supportive to me. However, I have issues with other people within the congregation that I really struggle with"* (**Our Turn to Speak** participant, Western Australia), one participant explained. Another commented that:

> *There are some people even now - almost unbelievably - who think that mental illness is basically the fault of not praying enough. I do not know about Islam, Judaism, Hinduism, and Buddhism in this respect. But certainly this attitude occurs at times within Christianity, although it is probably less widespread in Australia than it is in the USA* (**Our Turn to Speak** participant, Victoria).

When participants were asked about other factors that may have compounded their experiences of mental health stigma in this domain, responses included disability and accessibility, physical health, weight, and being involved in other interests. For example:

> *Churches are notoriously inaccessible. In addition, attitudes are very closed. People with disability are either objects of pity requiring charity, or are considered broken and in need of divine healing* (**Our Turn to Speak** participant, New South Wales).

> *I am heavily involved in my sporting community, and one thing that I am always left feeling guilty about is not supporting the church enough. It seems that they just don't understand I can't be at the church 24/7, on top of dealing with complex mental*

> *illness. I feel judged about this by members in the community* (**Our Turn to Speak** participant, Western Australia).
>
> *Being fat hasn't helped me in any aspect of my life* (**Our Turn to Speak** participant, Victoria).

SUMMARY

Of 1,912 participants who took part in the **Our Turn to Speak** survey, 5.3% (*n* = 102) identified cultural, faith or spiritual practices and communities as one of up to three life domains that had been most affected by stigma and discrimination in connection with complex mental health issues. Just over 44% of participants who selected cultural, faith or spiritual practices and communities as one of their most-affected life domains during the last 12 months indicated 'frequent' or 'very frequent' experiences of stigma and discrimination in this aspect of their lives.

When presented with a range of statements describing general and specific examples of stigma and discrimination in cultural, faith or spiritual practices and communities, it became clear that interactions with members of one's cultural, faith or spiritual community were driving perceptions of stigma and discrimination in this domain – particularly for those who identified with faith and spiritual practices. For example, 80% of participants who had participated in faith and spiritual practices and communities agreed that they had been unfairly treated by members of that community during the last 12 months, compared with 59.4% of participants who had participated in cultural practices and communities. Just under 50% of participants who had participated in faith and spiritual practices and communities perceived having been unfairly denied support or counsel by members of their community, compared with 37.5% of participants who had participated in cultural practices and communities.

Indeed, participants' qualitative comments reflected instances of covert exclusion that led to some participants feeling "othered". This may have been driven by limited understanding about the development and nature of complex mental health issues among community members.

Other participants described instances of seeking support from community members – including people in positions of power (for example, priests and pastors) – only to be met with criticism about their "lack of faith", "weak character", or being coerced to undergo interventions such as exorcism.

For 38.1% and 28.4% of participants respectively, their experience of mental health stigma in this domain had been compounded by stigma and discrimination relating to their faith or spiritual beliefs, and physical health or ability. Unfortunately, no participants provided qualitative commentary about the ways in which they have been discriminated against on the basis of their beliefs in the context of participating in cultural, faith or spiritual practices and communities.

Rates of agreement with statements describing various kinds of anticipated stigma and discrimination in one's cultural, faith or spiritual practices and communities were roughly equivalent to the rates of agreement in relation to perceived experiences. Again, participants who identified with faith and spiritual practices and communities reported somewhat higher expectations for stigma and discrimination in comparison with those who identified with cultural practices and communities – particularly in relation to unfair treatment by, or denial of support and counsel from, their community members.

It was also concerning that 30% of participants who identified with cultural practices expected to be unfairly asked to leave their communities because of stigma about mental health. One in five participants who identified with faith and spiritual practices expected the same exclusion by members of their communities. Given the examples of both overt and covert forms of discrimination portrayed in participants' qualitative comments, it is understandable that anticipated stigma and discrimination was, on average, just as high as reports of experienced stigma and discrimination in this domain.

Participants' expectations for future stigma and discrimination were followed with even higher rates of withdrawal from opportunity. This time, however, rates of agreement in relation to withdrawal from opportunity were generally equal, regardless of whether participants identified with cultural practices, or faith and spiritual practices. For instance, over 65% of all participants agreed that, during the last 12 months, they had stopped themselves from: (a) participating in cultural, faith or spiritual practices and communities, (b) going to places of cultural, religious or spiritual significance, or (c) engaging with their community. One exception related to seeking support or counsel: 72.9% of those who had participated in faith or spiritual practices agreed that they had stopped themselves from seeking support or counsel from members of their community, compared with 52.2% of participants who had participated in cultural practices. Almost 50% of participants who identified with cultural practices agreed that they had even stopped practicing their cultural beliefs because of stigma about mental health issues. This compared with 38.8% of participants who identified with faith or spirutal practices.

Positive experiences in cultural, faith or spiritual practices and communities were endorsed by 52% of participants. In their additional commentary, participants described a mix of both positive and negative experiences. In particular, participants highlighted instances of support and understanding offered by members of their faith communities, and impressions of increased awareness of mental health issues. For others, experiences of support and understanding had been dependent on location or context.

At 45.1%, in contrast to the other life domains examined in the **Our Turn to Speak** survey, endorsement for special consideration when accessing or participating in cultural, faith or spiritual practices and communities was relatively low. Participants did not offer insights into this aspect of positive treatment in their qualitative commentary.

It should be noted that most participants who selected this domain identified as having a Christian religious affiliation (64.7%), followed by other spiritual or secular beliefs (23.5%) or religions (7.8%). It is difficult to identify the nature of cultural practices and communities that participants were referring to when they completed this section. Almost 80% of participants who selected this domain described their cultural group or ancestry as Australian, followed by 29.4% European. A total of 14.7% described their background as being from the Asia-Pacific region.

Regardless of the specific type of cultural, faith or spiritual practices participants were referencing as the completed the survey, these communities are important to many peoples' identity and sense of self. As facilitators of social support and belonging, structure and ritual, existential meaning, guidance on ethic and morality, reflective practice, identity development, culture, spirituality, and religion can be important contributors to mental health generally (Eckersley, 2007), and to personal recovery (van Weeghel et al., 2019). It is critical that people who live with complex mental health issues can participate in the cultural, faith or spiritual practices and communities that are important to them, free from stigma and discrimination.

SPORTS, COMMUNITY GROUPS AND VOLUNTEERING

15

Chapter 15. Sports, community groups and volunteering

For many Australians, participating in sports, community groups or volunteering are a way of life. Participating in these activities can have a range of benefits including physical activity, social inclusion and connectedness, and contributing to a sense of purpose or meaning (Bradshaw et al., 2007; Leamy et al., 2011; van Weeghel et al., 2019). Such experiences are all critical to psychosocial recovery for those living with complex mental health issues.

Unfortunately, sporting clubs, community groups and volunteer roles are not always open to everyone who would like to participate.

This chapter considers how people living with complex mental health issues experience stigma and discrimination in participating in sports, community groups and volunteering.

OVERVIEW

Just over 50% (*n* = 970) of all **Our Turn to Speak** participants reported experiencing some level of stigma or discrimination in their sporting teams, community groups or volunteer roles during the past 12 months.

As shown in **Figure 15.1**, 8.6% of all participants reported 'frequent' or 'very frequent' stigma and discrimination in sports, community groups and volunteering, and 5.2% (*n* = 99) identified this life domain as one of three in which they have been most affected by such experiences. **Figure 15.1** also shows that 35.4% of participants who selected the sports, community groups and Volunteering domain reported 'frequent' or 'very frequent' rates of stigma and discrimination in this aspect of their lives; much higher than was reported by the overall sample.

This chapter focuses on the characteristics and experiences of those 99 participants who selected sports, community groups and volunteering as one of their top three, most affected life domains.

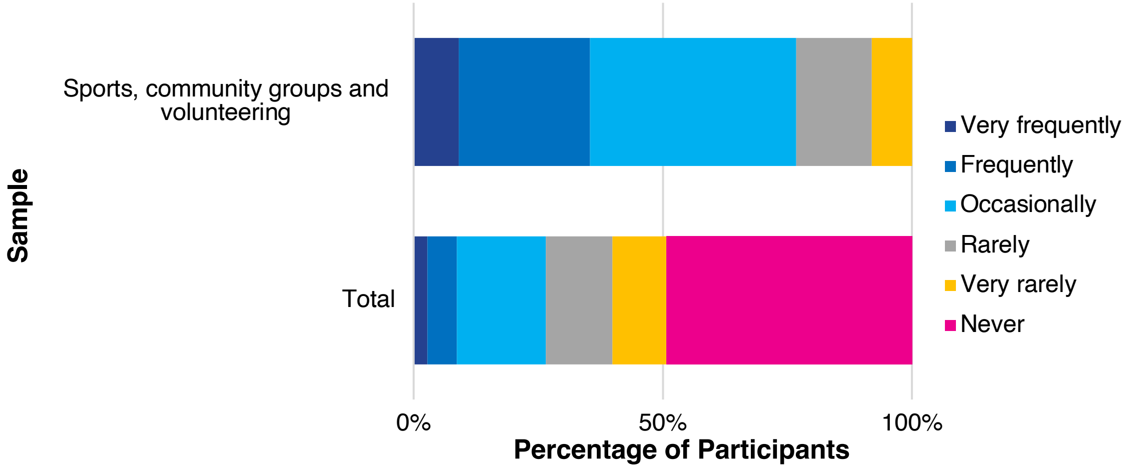


Figure 15.1. Frequency of stigma and discrimination in *sports, community groups and volunteering* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 99) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

Table 15.1 presents the sociodemographic characteristics of participants who identified as being personally affected by stigma and discrimination in sports, community groups and volunteering.

Participants who selected this life domain were slightly older compared with the average age of the total sample. A much greater proportion (>16%) were male compared with the total sample. Compared with the total sample, there was also a greater representation of participants who identified as heterosexual and a greater representation of participants who were unemployed or unable to work.

Table 15.1. Sociodemographic characteristics: *sports, community groups and volunteering* sample compared with the total sample.

Characteristics	Sports, Community Groups and Volunteering (*n* = 422)	Total (*N* = 1912)
Mean age	42.59 (*SD* = 14.53)	39.21 (*SD* = 12.81)
Gender identity		
Female	61.6%	78.9%
Male	34.3%	18.0%
Trans, gender diverse and/or non-binary	5.1%	4.9%
Unsure or questioning	1.0%	0.9%
Prefer not to say	0.0%	0.4%
Relationship status		
Not in a relationship	51.5%	52.1%
In a relationship	46.5%	47.3%
Prefer to self-describe	2.0%	0.2%
Sexual orientation		
Heterosexual	73.7%	62.0%
Gay, lesbian, bisexual, pansexual, queer, and/or asexual	25.3%	35.6%
Unsure or questioning	5.1%	4.9%
Prefer to self-describe	2.0%	1.5%
Prefer not to say	2.0%	1.7%
Education (highest level attained)		
Primary school	3.0%	1.6%
Secondary college (high school)	18.2%	20.9%
Educated post-secondary college	78.8%	77.4%
Other	0.0%	0.2%
Employment status		
Engaged in paid work	41.4%	51.7%
Engaged in unpaid work or studying	28.3%	28.7%
Unemployed or unable to work	32.3%	22.8%
Receiving a pension or benefits	25.3%	24.6%
Other	0.0%	0.2%
State		
Australian Capital Territory	3.0%	2.5%
New South Wales	19.2%	23.6%
Northern Territory	0.0%	0.6%
Queensland	16.2%	15.9%
South Australia	7.1%	9.5%
Tasmania	2.0%	3.7%
Victoria	38.4%	33.1%
Western Australia	14.1%	10.9%
Region*		
Major city	77.3%	74.2%
Regional or remote	22.8%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

As with the sociodemographic data, the mental and physical health characteristics of participants who responded to the sports, community groups and volunteering section of the survey were largely similar to those characteristics represented in the total sample.

Shown in **Table 15.2**, a slightly greater proportion (4% to 5%) of participants who responded to this section of the survey reported a primary diagnosis of a schizophrenia spectrum disorder or treatment-resistant depressive disorder compared with the total sample, while slightly fewer participants living with a personality disorder were represented.

Table 15.2. Mental and physical health characteristics: *sports, community groups and volunteering* sample compared with the total sample.

Characteristics	Sports, Community Groups and Volunteering (*n* = 422)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	12.1%	7.4%
Bipolar related disorder	17.2%	17.2%
Obsessive-compulsive related disorder	5.1%	4.3%
Trauma-related or dissociative disorder	26.3%	25.9%
Eating disorder	5.1%	6.1%
Personality disorder	8.1%	14.5%
Severe and treatment-resistant depressive disorder	18.2%	14.3%
Severe and treatment-resistant anxiety disorder	8.1%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	50.5%	53.8%

METHODS SNAPSHOT

Participants who identified sports, community groups and volunteering as one of three life domains in which they have been most affected by stigma-related experiences completed the sports, community groups and volunteering section of the survey. At the beginning of this section of the survey, participants were asked to indicate what types of community groups they had participated in, or wanted to participate in, during the previous 12 months. Such groups were defined as:

- local sporting teams and clubs
- arts, crafts, music groups, book clubs, and other social or community groups
- volunteer (unpaid) work or committee positions.

Forty-four percent (*n* = 44) had participated in sporting teams or clubs, 66.7% (*n* = 66) had participated in volunteer roles, and 59.6% (*n* = 59) had participated in other community groups. Participants were subsequently presented with only the questions that matched their reported area of community participation. For example, participants who reported only participating in sports teams during the last 12 months received questions corresponding to sports teams. Those who indicated they had been involved in more than one type of community participation received questions corresponding to each of those areas.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in their relationships; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of relationships. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further describe their experiences of stigma and discrimination in relation to: (a) complex mental health issues, (b) their other personal characteristics, and (c) any positive treatment in the sports, community groups and volunteering domain. Twenty-five, 9 and 16 participants provided additional comments in relation to these experiences respectively.

STIGMA AND DISCRIMINATION IN SPORTS, COMMUNITY GROUPS AND VOLUNTEERING

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in sports, community groups and volunteering, which will be further examined in sections that follow.

As shown in **Figure 15.2**, the average total level of agreement with all statements describing perceived experiences and anticipated experiences of stigma and discrimination were 50.0% and 58.0%, respectively.

At 72.0%, the average level of agreement with statements describing withdrawal from opportunities in sports, community groups and volunteering, was even higher. That is, more often than not, participants agreed that they had stopped themselves from accessing opportunities relevant to this life domain – for example, joining various groups, or applying for leadership opportunities within them.

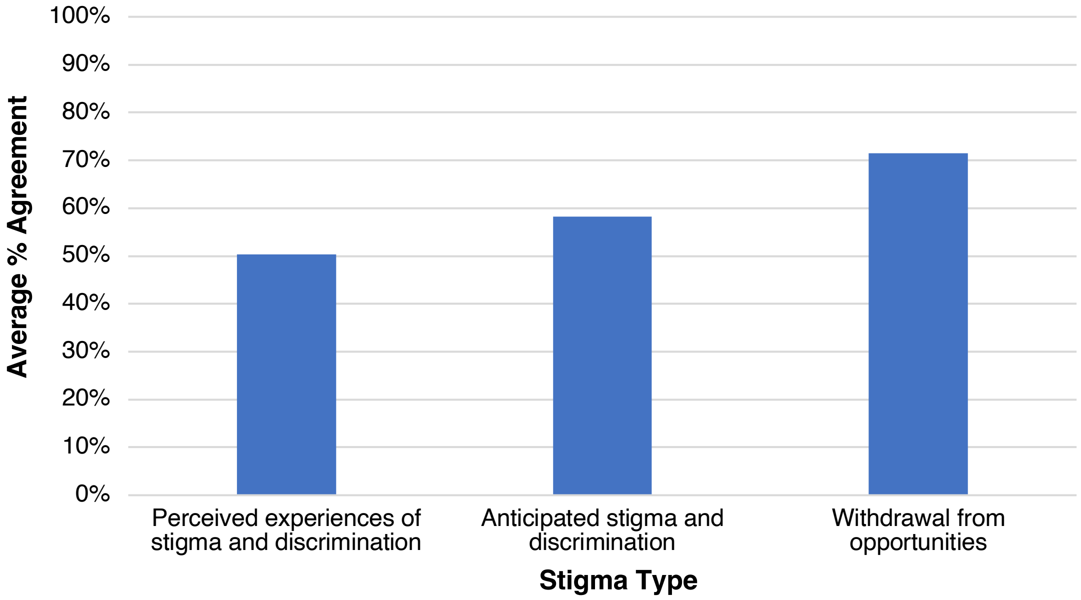


Figure 15.2. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *sports, community groups and volunteering* (*n* = 99).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN SPORTS, COMMUNITY GROUPS AND VOLUNTEERING

> *At my cricket a lot of the coaches, players and other parents did not get me and did not understand when I did not want to do certain things,* [sic] *They thought I did not want to play and that my parents were forcing me to play ; I just want to be able to play when I felt I was able to participate.*
>
> **Our Turn to Speak participant**
> **Queensland**

Presented in this section are the findings regarding participants’ perceived experiences of stigma and discrimination in sports, community groups, and volunteering, as related to their experience of complex mental health issues.

Figure 15.3 compares perceived experiences of stigma and discrimination in connection with the three different types of community participation during the last 12 months. Across the three different types of community groups and roles, there was similarly high agreement among participants that they had been treated unfairly when participating in sports teams, community groups or volunteering because of stigma about mental health issues. The average percentage agreement for this specific statement across the three types of community participation was 65.8%.

There was also relatively high agreement among participants that they had been unfairly denied opportunities to join sports teams (50%) and community groups (49.1%) in particular, but the rate was somewhat higher for volunteer roles; 57.7% of participants agreed that they had been unfairly denied opportunities to volunteer during the last 12 months because of stigma about mental health issues. Slightly fewer participants agreed that they had been unfairly denied leadership opportunities in sports teams, community groups and volunteer roles, and rates of agreement lower still for perceptions of being unfairly asked to leave such groups because of stigma about complex mental health issues. Nevertheless, it is meaningful that 34.1% of participants agreed that they had been asked to leave sports teams, in particular, because of such stigma.

Finally, the greatest variation in rates of agreement were apparent for the statement describing unfair treatment by members of sports teams, community groups and volunteer roles. Agreement was lowest among participants who had engaged in community groups (49.2%), compared with 65.1% and 63.6% of participants who had perceived unfair treatment by their fellow members of volunteering and sports teams, respectively.

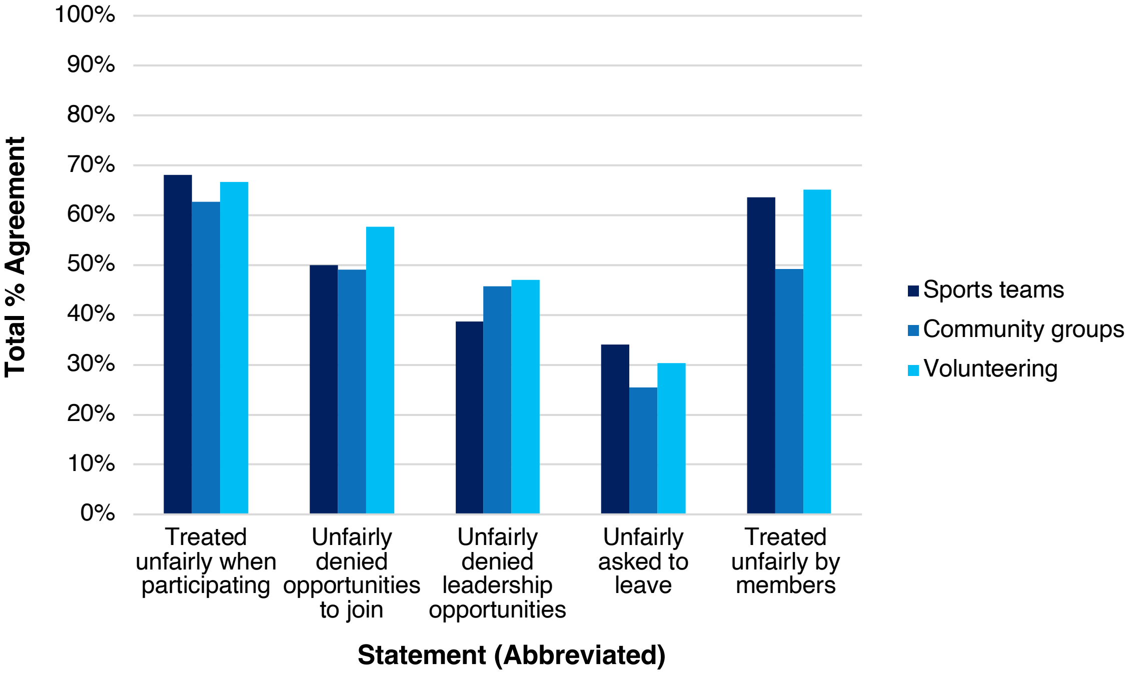


Figure 15.3. Highlight findings: total percentage agreement with perceived experiences of stigma and discrimination in *sports* (*n* = 44), *community groups* (*n* = 59) and *volunteering* (*n* = 66).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

Finally, **Tables 15.3, 15.4** and **15.5** provide the specific levels of agreement and disagreement for all statements relevant to perceived experiences of stigma and discrimination in sports teams, community groups, and volunteering. The findings in these tables were summarised in relation to **Figure 15.3**.

Table 15.3. Perceived experiences of stigma and discrimination in *sporting teams*: percentage agreement and disagreement (*n* = 44).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when participating in sporting teams or clubs	13.6%	6.8%	11.4%	29.5%	25.0%	13.6%	**68.1%**
I have been unfairly denied opportunities to join sporting teams or clubs I was interested in	25.0%	20.5%	4.5%	11.4%	25.0%	13.6%	**50.0%**
I have been unfairly denied leadership opportunities in sporting teams or clubs	31.8%	18.2%	11.4%	18.2%	9.1%	11.4%	**38.7%**
I have been unfairly asked to leave sporting teams or clubs before I was ready	29.5%	22.7%	13.6%	15.9%	6.8%	11.4%	**34.1%**
I have been treated unfairly by members of sporting teams or clubs	22.7%	11.4%	2.3%	15.9%	31.8%	15.9%	**63.6%**

Table 15.4. Perceived experiences of stigma and discrimination in *community groups*: percentage agreement and disagreement (*n* = 59).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when participating in community groups	8.5%	18.6%	10.2%	18.6%	37.3%	6.8%	**62.7%**
I have been unfairly denied opportunities to join community groups I was interested in	18.6%	22.0%	10.2%	20.3%	16.9%	11.9%	**49.1%**
I have been unfairly denied leadership opportunities in community groups	16.9%	23.7%	13.6%	13.6%	22.0%	10.2%	**45.8%**
I have been unfairly asked to leave community groups before I was ready	27.1%	30.5%	16.9%	3.4%	11.9%	10.2%	**25.5%**
I have been treated unfairly by members of community groups	8.5%	18.6%	6.8%	23.7%	27.1%	15.3%	**49.2%**

Table 15.5. Perceived experiences of stigma and discrimination in v*olunteering*: percentage agreement and disagreement (*n* = 66).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when participating in volunteer roles	12.1%	12.1%	9.1%	27.3%	19.7%	19.7%	**66.7%**
I have been unfairly denied opportunities to join volunteer roles I was interested in	18.2%	13.6%	10.6%	15.2%	25.8%	16.7%	**57.7%**
I have been unfairly denied leadership opportunities in volunteer roles	25.8%	15.2%	12.1%	15.2%	19.7%	12.1%	**47.0%**
I have been unfairly asked to leave volunteer roles before I was ready	34.8%	25.8%	9.1%	9.1%	15.2%	6.1%	**30.4%**
I have been treated unfairly by people I volunteer with	13.6%	16.7%	4.5%	24.2%	27.3%	13.6%	**65.1%**

ANTICIPATED STIGMA AND DISCRIMINATION IN SPORTS, COMMUNITY GROUPS AND VOLUNTEERING

> *The only way to survive out here is to never admit to any mental health issyes. The community view* [mental health] *as a weakness to exploit and outcase you.*
>
> **Our Turn to Speak participant**
> **South Australia**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in sports, community groups, and volunteering, as related to their experience of complex mental health issues. **Figure 15.4** compares anticipated stigma and discrimination in connection with the three different types of community participation during the last 12 months.

As shown, across all five statements, anticipated stigma and discrimination was slightly higher in relation to community groups compared with sports teams and volunteering. There was little variation in rates of agreement between the different types of community participation across all statements though. Regardless of whether participants were reporting on their expectations for treatment in sports teams, community groups or volunteer roles, between 64% and 70% of participants expected that they would be: (a) treated unfairly when participating in these groups and roles, (b) unfairly denied leadership opportunities in these groups and roles, and (c) treated unfairly by their fellow group members.

Approximately 55% of participants who had engaged in (or tried to engage in) sports or volunteering during the last 12 months expected that they would be unfairly denied opportunities to join these groups because of stigma about mental health issues. Sixty-one percent of participants expected to be unfairly denied opportunities to join other community groups.

A somewhat lower proportion of participants expected to be unfairly asked to leave their various forms of community participation compared with the other statements describing anticipated stigma and discrimination in this domain. Close to 40% of participants engaged in community groups and/or volunteering during the last 12 months expected that they would be unfairly asked to leave these groups compared with 29.6% of participants who had participated in sports teams.

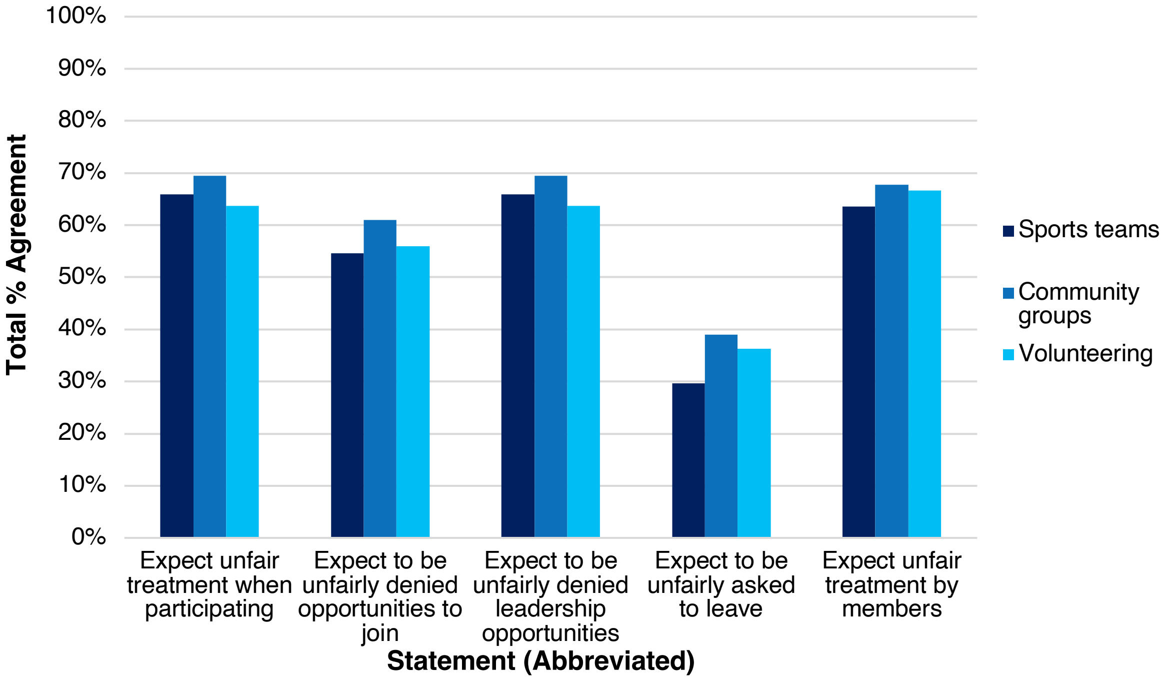


Figure 15.4. Highlight findings: total percentage agreement with anticipated stigma and discrimination in *sports* (*n* = 44), *community groups* (*n* = 59) and *volunteering* (*n* = 66).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

Finally, **Tables 15.6, 15.7** and **15.8** provide the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in sports, community groups, and volunteering. The findings in these tables were summarised in relation to **Figure 15.4**.

Table 15.6. Anticipated stigma and discrimination in *sporting teams*: percentage agreement and disagreement (*n* = 44).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when participating in sporting teams or clubs	15.9%	11.4%	6.8%	25.0%	31.8%	9.1%	**65.9%**
I expect to be unfairly denied opportunities to join sporting teams or clubs I was interested in	13.6%	25.0%	6.8%	20.5%	20.5%	13.6%	**54.6%**
I expect to be unfairly denied leadership opportunities in sporting teams or clubs	11.4%	13.6%	9.1%	25.0%	27.3%	13.6%	**65.9%**
I expect to be unfairly asked to leave sporting teams or clubs before I was ready	27.3%	22.7%	20.5%	9.1%	11.4%	9.1%	**29.6%**
I expect to be treated unfairly by members of sporting teams or clubs	11.4%	18.2%	6.8%	22.7%	25.0%	15.9%	**63.6%**

Table 15.7. Anticipated stigma and discrimination in *community groups*: percentage agreement and disagreement (*n* = 59).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when participating in community groups	5.1%	16.9%	8.5%	37.3%	22.0%	10.2%	**69.5%**
I expect to be unfairly denied opportunities to join community groups I was interested in	8.5%	20.3%	10.2%	28.8%	20.3%	11.9%	**61.0%**
I expect to be unfairly denied leadership opportunities in community groups	6.8%	16.9%	6.8%	25.4%	30.5%	13.6%	**69.5%**
I expect to be unfairly asked to leave community groups before I was ready	15.3%	32.2%	13.6%	16.9%	13.6%	8.5%	**39.0%**
I expect to be treated unfairly by members of community groups	8.5%	18.6%	5.1%	27.1%	27.1%	13.6%	**67.8%**

Table 15.8. Anticipated stigma and discrimination in *volunteering*: percentage agreement and disagreement (*n* = 66).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when participating in volunteer roles	9.1%	18.2%	9.1%	28.8%	16.7%	18.2%	**63.7%**
I expect to be unfairly denied opportunities to join volunteer roles I was interested in	12.1%	25.8%	6.1%	21.2%	24.2%	10.6%	**56.0%**
I expect to be unfairly denied leadership opportunities in volunteer roles	10.6%	16.7%	9.1%	27.3%	19.7%	16.7%	**63.7%**
I expect to be unfairly asked to leave volunteer roles before I was ready	18.2%	36.4%	9.1%	13.6%	10.6%	12.1%	**36.3%**
I expect to be treated unfairly by people I volunteer with	9.1%	19.7%	4.5%	28.8%	27.3%	10.6%	**66.7%**

WITHDRAWAL FROM OPPORTUNITY IN SPORTS, COMMUNITY GROUPS AND VOLUNTEERING

> ***Experiencing severe anxiety, depression & shame over questions of sexuality led me to mostly avoid my sporting club.***
>
> **Our Turn to Speak participant**
> **Western Australia**

Presented in this section are the findings regarding participants' withdrawal from opportunities in sports, community groups and volunteering, as related to their experience of complex mental health issues**.**

Figure 15.5 compares withdrawal from opportunities during the last 12 months in relation to the three different types of community participation. As shown, across most statements, withdrawal from opportunity was higher in relation to community groups, as compared with sports teams or volunteer roles. By contrast, withdrawal from opportunity was lowest among participants engaged in sports teams across most statements. For instance, 81.3% of participants who had (or tried) to participate in community groups had stopped themselves from joining such groups because of stigma about complex mental health issues, compared with 72.8% and 65.9% of participants who had (or tried) to participate in volunteer roles or sports teams, respectively.

Similarly, almost 85% of participants engaged in community groups agreed that they had stopped themselves from actively participating in these groups compared with 75.7% and 72.8% of participants engaged in volunteering or sports teams, respectively. An approximately equal proportion of participants had stopped themselves from applying for leadership positions in community groups and volunteer roles (73-74%), while fewer (54.6%) – bit a nonetheless substantial proportion – agreed that they stopped themselves from applying for leadership opportunities in sports teams.

Rates of agreement in terms of withdrawing from sports teams, community groups or volunteer roles before they were ready to leave, were also unfortunately substantial, ranging between 61.4% and 77.9%.

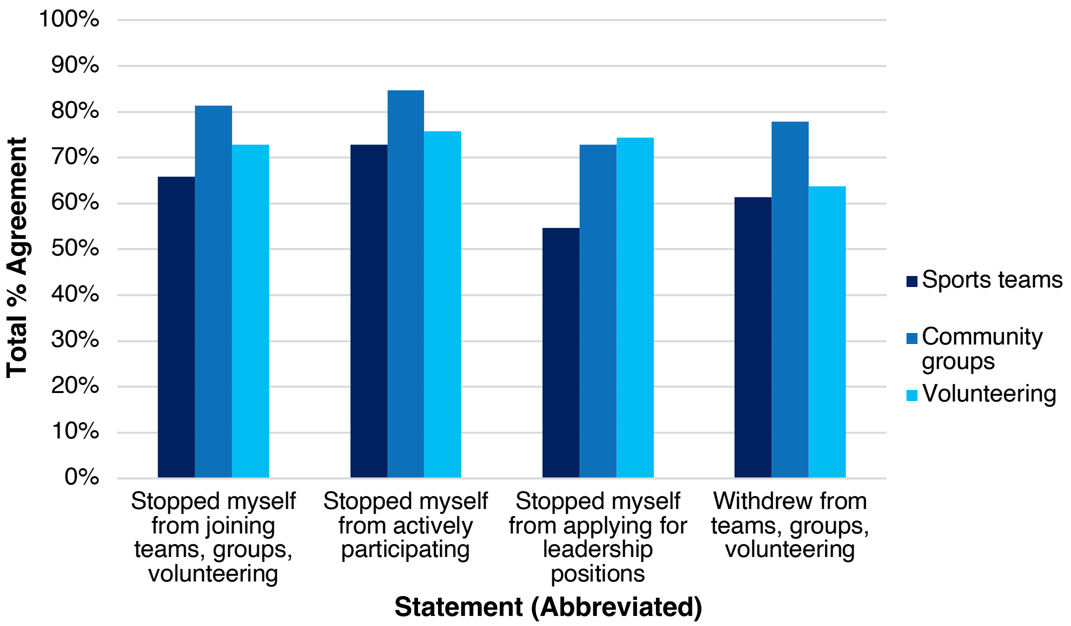


Figure 15.5. Highlight findings: total percentage agreement with withdrawal from opportunities in *sporting teams* (*n* = 44), *community groups* (*n* = 59) and *volunteering* (*n* = 66).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'

Tables 15.9, 15.10 and **15.11** provide the specific levels of agreement and disagreement for all statements relevant to perceived experiences of stigma and discrimination in sports teams, community groups, and volunteer roles. The findings in these tables were summarised in relation to the aforementioned figures.

Table 15.9. Withdrawal from opportunities in *sporting teams*: percentage agreement and disagreement (*n* = 44).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from joining sporting teams or clubs I was interested in	15.9%	11.4%	6.8%	15.9%	20.5%	29.5%	**65.9%**
I have stopped myself from actively participating in sporting teams or clubs	9.1%	15.9%	2.3%	20.5%	25.0%	27.3%	**72.8%**
I have stopped myself from applying for leadership positions in sporting teams or clubs	22.7%	15.9%	6.8%	11.4%	25.0%	18.2%	**54.6%**
I have withdrawn myself from sporting teams or clubs before I was ready	15.9%	20.5%	2.3%	18.2%	22.7%	20.5%	**61.4%**

Table 15.10. Withdrawal from opportunities in *community groups*: percentage agreement and disagreement ($n = 59$).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from joining community groups I was interested in	3.4%	13.6%	1.7%	18.6%	39.0%	23.7%	**81.3%**
I have stopped myself from actively participating in community groups	1.7%	11.9%	1.7%	23.7%	37.3%	23.7%	**84.7%**
I have stopped myself from applying for leadership positions in community groups	10.2%	10.2%	6.8%	23.7%	18.6%	30.5%	**72.8%**
I have withdrawn myself from community groups before I was ready	5.1%	13.6%	3.4%	22.0%	33.9%	22.0%	**77.9%**

Table 15.11. Withdrawal from opportunities in *volunteering*: percentage agreement and disagreement ($n = 66$).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from joining volunteer roles I was interested in	7.6%	12.1%	7.6%	18.2%	28.8%	25.8%	**72.8%**
I have stopped myself from actively participating in volunteer roles	10.6%	7.6%	6.1%	21.2%	24.2%	30.3%	**75.7%**
I have stopped myself from applying for leadership positions in volunteer roles	7.6%	13.6%	4.5%	19.7%	25.8%	28.8%	**74.3%**
I have withdrawn myself from volunteer roles before I was ready	12.1%	16.7%	7.6%	19.7%	15.2%	28.8%	**63.7%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN SPORTS, COMMUNITY GROUPS AND VOLUNTEERING

> ***Uncomfortable attitudes due to my sexual orientation as well as mental health issues.***
> **Our Turn to Speak participant**
> **New South Wales**

The findings from survey statements in relation to other experiences of stigma and discrimination in sports, community groups and volunteering, besides complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 15.6**. As shown, 39.1% of participants agreed that they had experienced stigma and discrimination in such groups because of their physical health or ability, while 17% agreed that they had experienced stigma and discrimination in housing in connection with their faith or spiritual beliefs.

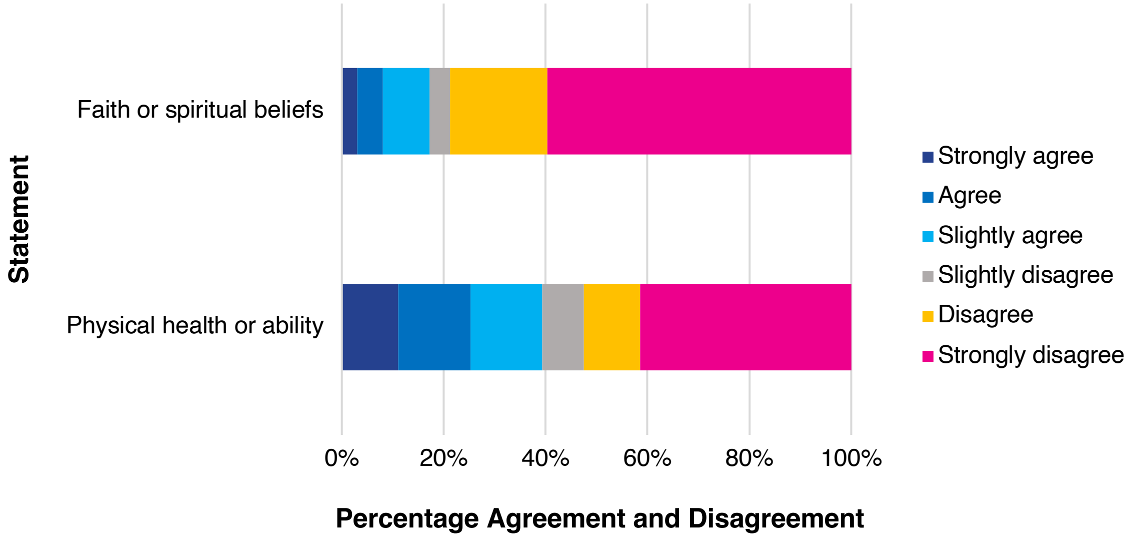


Figure 15.6. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *sports, community groups and volunteering* (*n* = 99).

The specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting community participation are summarised in **Table 15.12**. Overall, a relatively low rate of agreement was observed for statements describing experiences of stigma and discrimination in sports, community groups and volunteering due to personal characteristics other than complex mental health issues.

Table 15.12. Experiences of intersectional stigma and discrimination in *sports, community groups and volunteering*: percentage agreement and disagreement (*n* = 99).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in sports, community groups and volunteering because of my…							
Racial or cultural background	60.6%	18.2%	4.0%	4.0%	10.1%	3.0%	**17.1%**
Faith or spiritual beliefs	59.6%	19.2%	4.0%	9.1%	5.1%	3.0%	**17.2%**
Sexual orientation	66.7%	16.2%	5.1%	4.0%	6.1%	2.0%	**12.1%**
Gender identity	67.7%	20.2%	3.0%	4.0%	4.0%	1.0%	**9.0%**
Physical health or ability	41.4%	11.1%	8.1%	14.1%	14.1%	11.1%	**39.3%**

POSITIVE EXPERIENCES IN SPORTS, COMMUNITY GROUPS AND VOLUNTEERING

> *My positive experience in sport has been fantastic.The sense of inclusion is immense.The respect & friendship given & received is lovely. It provides for me self respect, self worth & a positive experience of learning & succeeding.*
>
> **Participant**
> **Female, 51, New South Wales**

The survey also asked about positive treatment in sports, community groups, and volunteering. Two core statements comprised this section of the survey: (1) the expectation of special consideration because of one's experience of complex mental health issues, and (2) manifest positive experiences in housing because of one's experience of complex mental health issues.

As shown in **Figure 15.7**, 43.0% of participants agreed that they should receive special consideration when joining or participating in sports, community groups or volunteer roles. Just over 50% reported positive experiences in connection to their complex mental health issues when joining or participating in sports, community groups or volunteer roles during the last 12 months.

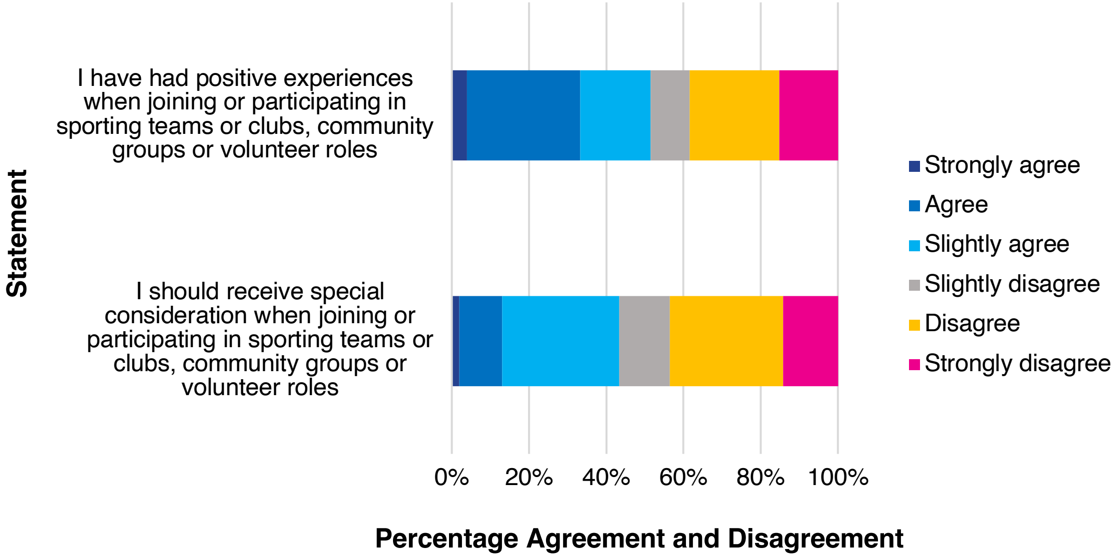


Figure 15.7. Highlight findings: responses to the statements regarding positive experiences in *sports, community groups and volunteering* because of participants' complex mental health issues (*n* = 99).

SUMMARY OF QUALITATIVE FINDINGS IN SPORTS, COMMUNITY GROUPS AND VOLUNTEERING

Due to the small number of responses in this domain, it was difficult to draw out major themes.

A few participants discussed different impacts of their mental health issues on their ability to participate in sports and volunteering, such as fatigue, dizziness, medical appointments, a need to avoid triggers of distress, and *"trust issues"* associated with past experiences of abuse.

A lack of understanding from others in relation to the ways in which complex mental health issues can affect a person's capacity to participate in sports, community groups and volunteering was apparent:

> *At my cricket a lot of the coaches, players and other parents did not get me and did not understand when I did not want to do certain things, They thought I did not want to play and that my parents were forcing me to play ; I just wanted to be able to play when I felt i was able to participate* (**Our Turn to Speak** participant, Queensland).
>
> *I have felt like my best isn't good enough, because my unpredictable mental health means I am occasionally unable to make trainings, so my level of commitment is perceived as lower* (**Our Turn to Speak** participant, South Australia).
>
> *I was told to stop training many times and thye would say its because of my lack of committment but they were the one's telling me not to come back and they would say im too unwell to train and they would make that decision rather than me or a doctor* (**Our Turn to Speak** participant, Victoria).
>
> *My experiences are more subtle, than direct stigma or discrimination. I find that my coaches have very 'outdated' views of mental health, and others I train with have little*

> *understanding of mental illness. Mental health in sport for me as young male can be seen as a weakness* (**Our Turn to Speak** participant, Western Australia).

Several participants discussed instances where they felt judged, undermined, and were excluded, rejected, or otherwise negatively impacted:

> *I was going to organise something for a community group, I felt like they thought I had crazy ideas and they didn't support me even though it was a good idea* (**Our Turn to Speak** participant, New South Wales).
>
> *…I also find at that choir I am definitely treated differently and people laugh at me when I'm in distress; with my assistance dog people have said "what is wrong with you?" and when I say she helps with my disabilities (I do not feel safe to disclose further) the reply "you don't look disabled"...and a myriad of other very negative and discriminatory things have happened...I feel as though I am excluded and can never belong because of my issues which stem from trauma so it feels like more is being robbed of me because of my life situation* (**Our Turn to Speak** participant, Queensland).
>
> *My experiences have built up over many years so the stigma and discrimination have concretely occurred, just not in the last 12months as it has happened so often and continually that I know, no matter how well I perform, that as soon as they find out about my diagnosis they kick me out. I've been told I'm not of good character by five different volunteer groups, despite the worst thing i've done is get a parking ticket 23years ago, as soon as they find out about my diagnosis. It just hasn't happened in the last year cause I've given up* (**Our Turn to Speak** participant, Queensland).

A few participants discussed additional barriers to participation in more isolated communities, such as other group members – sometimes with limited training in mental health – holding multiple roles in relation to the participant, and *"narrow-minded cliques".*

When asked about positive experiences in connection with their mental health and community participation, benefits included: connecting with others and feeling supported, friendship, enjoyment, a sense of inclusion, opportunities for learning and leading, increasing awareness, increased self-worth and self-respect, and positive impacts on mental health. Some examples of comments here included:

> *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).
>
> *Lot of support from sport club, didn't expect this* (**Our Turn to Speak** participant, Victoria).
>
> *My positive experience in sport has been fantastic.The sense of inclusion is immense.The respect & friendship given & received is lovely. It provides for me self respect, self worth & a positive experience of learning & succeeding* (**Our Turn to Speak** participant, New South Wales).

Other participants had no positive experiences to share, or provided examples of negative or mixed experiences; *“Some gym's have been very nice to be a part of some are just plain dangerous. Some communities are also hazardous”* (**Our Turn to Speak** participant, Victoria), said one participant; *“The only way to survive out here is to never admit to any mental health issues. The community view MH as a weakness to exploit and outcast you”* (**Our Turn to Speak** participant, South Australia) said another.

When participants were asked about other factors that may have compounded their experiences of mental health stigma in this domain, few participants gave responses. Those that that did discussed sexual orientation, physical health, weight, appearance, and having a criminal history. For example:

> *Experiencing severe anxiety, depression & shame over questions of sexuality led me to mostly avoid my sporting club* (**Our Turn to Speak** participant, Western Australia).
>
> *They like to criticise my weight but they're not willing to support me or help me to get in shape* (**Our Turn to Speak** participant, Victoria).

SUMMARY

Of the 1,912 survey participants, 5.2% (*n* = 99) identified sports, community groups and volunteering as one of up to three life domains that had been most affected by stigma and discrimination in connection with complex mental health issues. Just over 35% of participants who selected sports, community groups and volunteering as one of their most affected life domains during the last 12 months indicated ‘frequent’ or ‘very frequent’ experiences of stigma and discrimination in this aspect of their lives.

When presented with a range of statements describing general and specific examples of stigma and discrimination related to sports, community groups and volunteering, it was evident that some forms of discrimination were more prevalent in specific types of community participation than in others. For example, around 65% of participants who had been involved in sports teams and volunteer roles during the last 12 months agreed that they had been treated unfairly by members of these groups because of stigma about mental health issues, compared with 49.2% of participants involved in other types of community groups. Among participants who had participated in (or wanted to participate in) volunteering, 57.7% agreed that they had been unfairly denied opportunities to join volunteer roles in the first place. This compared with approximately 50% of participants in relation to joining sports teams and other community groups. In terms of being unfairly denied leadership opportunities, this affected a greater proportion of participants involved in community groups and volunteering (approximately 46%) than for participants involved in sports teams (38.7%).

Participants’ qualitative comments indicated that unfair treatment and exclusion may have been driven by other group members’ lack of understanding about the ways in which complex mental health issues can affect a person’s capacity to participate (for example, being misinterpreted as a lack of commitment or interest). Another issue mentioned by participants related to challenges of participating in sports, volunteering and other groups in specific communities – for example, rural and remote communities – where stigmatising attitudes and limited mental health literacy can be acutely felt by those living with complex mental health issues and a range of intersecting identities (Bryant & Garnham, 2015; Griffiths et al., 2009; Lyons et al., 2015). Besides the compounding effects of stigma and discrimination associated with living in small communities, 39.1% of participants agreed that they had experienced stigma and discrimination in sports, community groups and volunteering because of their physical health or (dis)ability; and 17% because of their faith or spiritual beliefs.

Rates of agreement with statements describing various kinds of anticipated discrimination, and withdrawal from opportunities relevant to sports, community groups and volunteering, were even higher than for perceived experiences of stigma and discrimination. Anticipated stigma and discrimination was slightly greater in relation to community groups compared with sports teams and volunteering, and there was little variation in rates of agreement between the three different types of community participation. Between 55% and 70% of participants expected to be treated unfairly in the course of applying for and participating in sports teams, community groups and volunteer roles, including in relation to leadership opportunities. Many fewer participants expected that they would be unfairly asked to leave such groups and roles because of stigma about mental health issues, and the rate of agreement on this statement was particularly low among those participating in sports teams (26.9%). It was particularly concerning that so many participants (> 70%) agreed that they had stopped themselves from joining or participating in community groups, including applying to leadership opportunities. Close to 80% of participants agreed that they had withdrawn themselves from community groups before they were ready to leave because of stigma. Rates of withdrawal from opportunities in relation to sports teams were lower than for volunteering and other community groups, but were high nonetheless. For example, 72.8% agreed that they had stopped themselves from actively participating in sporting teams or clubs because of stigma about mental health issues.

The high rates of withdrawal from sports, community groups and volunteering is particularly concerning given how important social inclusion and connectedness is to recovery (Bradshaw et al., 2007; Leamy et al., 2011). As participants explained in their qualitative comments, positive experiences associated with community participation and in connection with their experience of mental health issues included: friendship and social support, opportunities for learning and leading, mastery and enjoyment, and increased self-worth and self-respect. Such positive experiences were facilitated when group members responded to participants' experiences of mental health issues with compassion, understanding and connection. Overall, 50% of participants agreed that they had had positive experiences when joining or participating in sports, community groups or volunteer roles as a result of their complex mental health issues during the last 12 months.

Further, 43.0% agreed that they should receive special consideration when joining or participating in these groups. Participants' additional commentary unfortunately did not elaborate on the nature of special consideration or accommodations they desired. We would echo the sentiment of one participant in particular: *"I am an intelligent capable person and should be treated accordingly"*.

PUBLIC AND RECREATIONAL SPACES

16

Chapter 16. Public and recreational spaces

Being able to spend time in and move freely through public and recreational spaces is important to social and civic participation. This in turn facilitates social connectedness and a sense of belonging, which are key to personal and psychosocial recovery.

Unfortunately, for some people living with complex mental health issues, being in and moving through public and recreational spaces does not always feel safe.

This chapter considers how people living with complex mental health issues experience stigma and discrimination in their use of public and recreational spaces.

OVERVIEW

Fifty-five percent (*n* = 1052) of all **Our Turn to Speak** participants reported experiencing some level of stigma or discrimination in public and recreational spaces during the last 12 months.

As shown in **Figure 16.1**, 10.1% of all participants reported ‘frequent’ or ‘very frequent’ stigma and discrimination in public and recreational spaces, and 5.1% (*n* = 98) identified this life domain as one of three in which they havd been most affected by such experiences. **Figure 16.1** also shows that 35.7% of participants who selected the public spaces domain reported ‘frequent’ or ‘very frequent’ rates of stigma and discrimination in this aspect of their lives; much higher than was reported by the total sample.

This chapter focuses on the characteristics and experiences of those 98 participants who selected public and recreational spaces as one of their top three, most affected life domains.

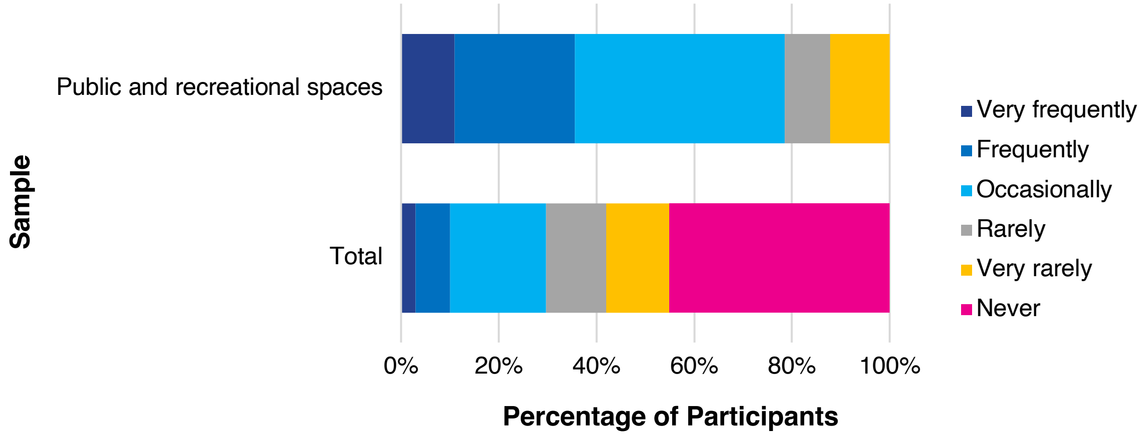


Figure 16.1. Frequency of stigma and discrimination in *public and recreational spaces* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 98) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

Table 16.1 presents the sociodemographic characteristics of participants who identified as being personally affected by stigma and discrimination in public and recreational spaces.

Compared with the total sample, there was a greater representation of participants who selected the public spaces domain who identified as trans, gender diverse and non-binary (6.3% more compared with the total sample). Fewer participants were educated post-secondary college, 10% fewer participants were currently engaged in paid work, and 9.1% more participants who selected the public spaces domain were receiving a pension or other benefit compared with the total sample. There was also a slightly greater representation of participants living in New South Wales and located in a metropolitan region.

Table 16.1. Sociodemographic characteristics: *public and recreational spaces* sample compared with the total sample.

Characteristics	Public and Recreational Spaces (*n* = 98)	Total (*N* = 1912)
Mean age	38.30 (*SD* = 12.71)	39.21 (*SD* = 12.81)
Gender identity		
Female	72.4%	78.9%
Male	21.4%	18.0%
Trans, gender diverse and/or non-binary	11.2%	4.9%
Unsure or questioning	2.0%	0.9%
Prefer not to say	1.0%	0.4%
Relationship status		
Not in a relationship	56.1%	52.1%
In a relationship	43.9%	47.3%
Prefer to self-describe	0.0%	0.2%
Sexual orientation		
Heterosexual	60.2%	62.0%
Gay, lesbian, bisexual, pansexual, queer, and/or asexual	36.7%	35.6%
Unsure or questioning	4.1%	4.9%
Prefer to self-describe	1.0%	1.5%
Prefer not to say	1.0%	1.7%
Education (highest level attained)		
Primary school	6.1%	1.6%
Secondary college (high school)	24.5%	20.9%
Educated post-secondary college	69.4%	77.4%
Other	0.0%	0.2%
Employment status		
Engaged in paid work	41.8%	51.7%
Engaged in unpaid work or studying	24.5%	28.7%
Unemployed or unable to work	26.5%	22.8%
Receiving a pension or benefits	33.7%	24.6%
Other	0.0%	0.2%
State		
Australian Capital Territory	4.1%	2.5%
New South Wales	29.6%	23.6%
Northern Territory	1.0%	0.6%
Queensland	15.3%	15.9%
South Australia	7.1%	9.5%
Tasmania	2.0%	3.7%
Victoria	29.6%	33.1%
Western Australia	11.2%	10.9%
Region*		
Major city	79.6%	74.2%
Regional or remote	18.4%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

As with the socidemographic data, the mental and physical health characteristics of participants who identified the public and recreational spaces domain as having been most affected by stigma and discrimination were generally similar to those of the total sample (see **Table 16.2**).

A greater proportion of participants who responded to this domain reported a primary diagnosis of a schizophrenia spectrum disorder or obsessive-compulsive related disorder compared with the total sample.

Table 16.2. Mental and physical health characteristics: *public and recreational spaces* sample compared with the total sample.

Characteristics	Public and Recreational Spaces (*n* = 98)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	14.3%	7.4%
Bipolar related disorder	11.2%	17.2%
Obsessive-compulsive related disorder	7.1%	4.3%
Trauma-related or dissociative disorder	23.5%	25.9%
Eating disorder	0.0%	6.1%
Personality disorder	15.3%	14.5%
Severe and treatment-resistant depressive disorder	13.3%	14.3%
Severe and treatment-resistant anxiety disorder	15.3%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	52.0%	53.8%

METHODS SNAPSHOT

Participants who identified public and recreational spaces as one of three life domains in which they have been most affected by stigma-related experiences completed the public and recreational cpaces section of the survey. At the beginning of this section of the survey, participants were asked to indicate what types of public spaces they had accessed or tried to access during the previous 12 months. Public and recreational spaces were described as including:

- public transport (for example, buses, trains, trams and taxis)
- public spaces for gathering, events, recreation and fitness (for example, parks, shopping centres, museums, pubs, cafes, restaurants, community festivals and sporting grounds).

About 68% (*n* = 67) had accessed public transport and 87.8% (*n* = 86) had accessed public spaces or event*s* (that is, for gathering, events, recreation and fitness)*.* Participants were subsequently presented with only the questions that matched their reported use of public and recreational spaces. For example, participants who only reported accessing public spaces or events during the last 12 months only received questions corresponding to public spaces for gathering, events, recreation and fitness. Those who indicated they had accessed more than one type of public space received questions corresponding to each of those areas.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in public and recreational spaces; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities relevant to public and recreational spaces. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further describe their experiences of stigma and discrimination in relation to: (a) complex mental health issues, (b) their other personal characteristics, and (c) any positive treatment in public and recreational spaces. Thirty-four, 12 and 22 participants provided additional comments in relation to these experiences respectively.

STIGMA AND DISCRIMINATION IN PUBLIC SPACES

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in public and recreational spaces, which will be further examined in sections that follow.

As shown in **Figure 16.2**, the average total level of agreement with all statements describing withdrawal from opportunities in public spaces was 62.4%. In other words, participants typically agreed that, more often than not, they had stopped themselves from accessing public spaces (for example, using public transport or attending public events) because of stigma and discrimination related to complex mental health issues.

At around 32%, the average total level of agreement with all statements describing both perceived experiences and anticipation of stigma and discrimination in public spaces was lower than for withdrawal from opportunities, but nevertheless significant.

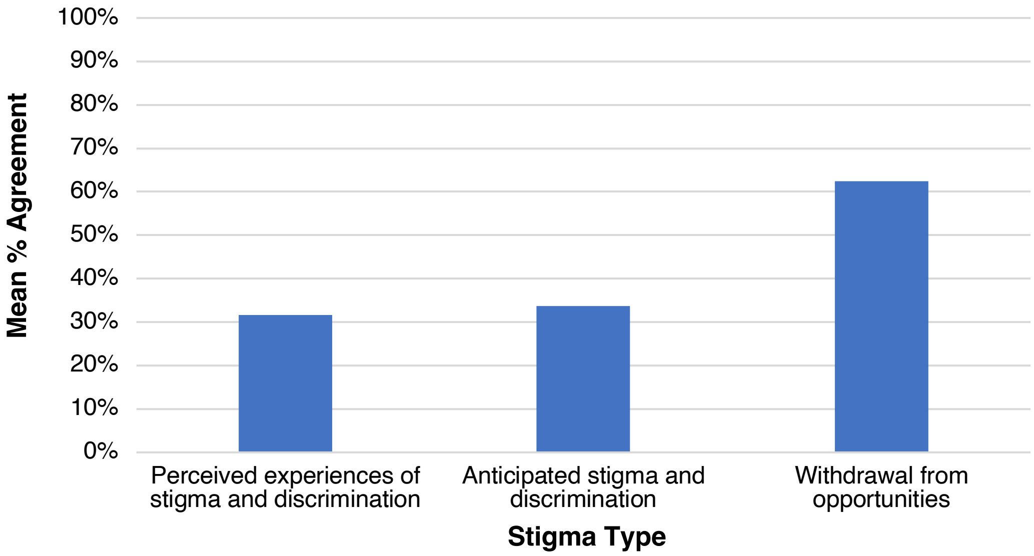


Figure 16.2. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *Public and recreational spaces* (*n* = 98).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN PUBLIC AND RECREATIONAL SPACES

> ***This is mainly due to lack of public awareness regarding the importance of service dogs. Inappopropriate questions, hostility, touching without asking, pointing and commenting and being asked to leave. No dogs allowed. Security guards and managers are the worst in public spacesm they run after you like criminal some times and ask "what does your dog do".***
> **Our Turn to Speak participant**
> **New South Wales**

The findings from survey statements in relation to other experiences of stigma and discrimination in public spaces, besides complex mental health issues, are presented in this section.

As shown in **Figure 16.3**, perceived experiences of stigma and discrimination, across all four statements, were higher in relation to public spaces and events compared with public transport. Close to 64% of participants who had accessed public spaces and events during the last 12 months perceived that they had been unfairly treated in these spaces and events because of stigma about mental health issues, compared with 56.8% of participants who had accessed public transport.

Just over 50% of participants who had accessed public spaces and events agreed that they had been treated unfairly by retail, hospitality or events staff, while 26.9% of participants who had accessed public transport agreed they had been treated unfairly by transport staff. Rates of agreement were much lower in response to statements about unfair denial of entry or use, and being asked to leave both kinds of public spaces.

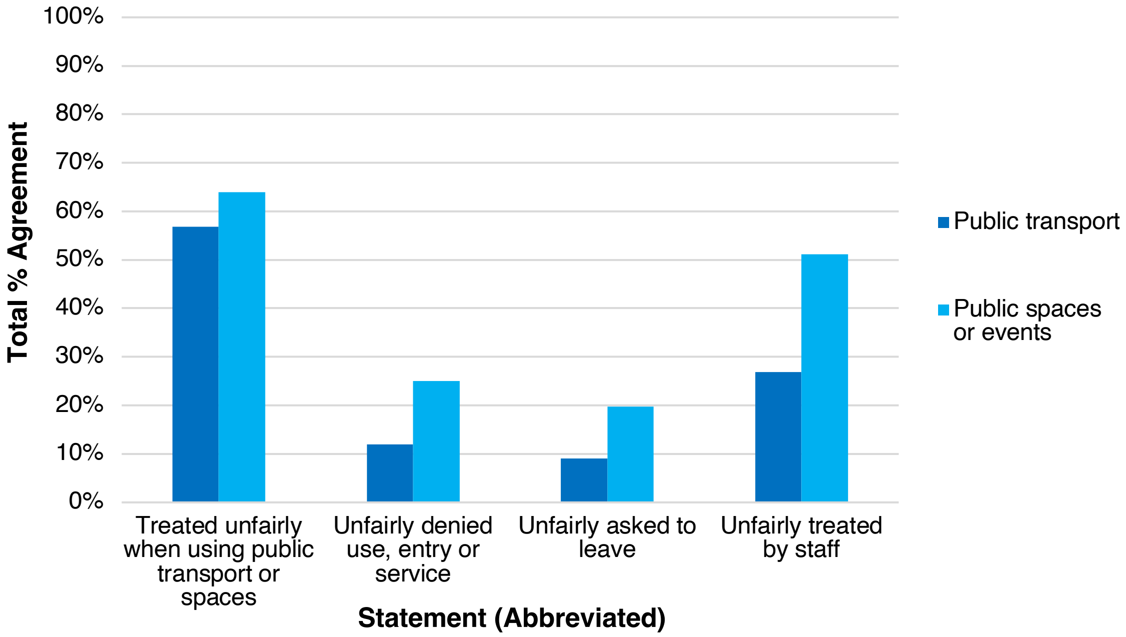


Figure 16.3. Highlight findings: total percentage agreement with perceived experiences of stigma and discrimination on *public transport* (*n* = 67) and *public spaces and events* (*n* = 86).
Note. Agreement refers to the aggregate of responses: 'slightly agree', 'agree' and 'strongly agree'.

Tables 16.3 and **16.4** provide the specific levels of agreement and disagreement for all statements relevant to perceived experiences of stigma and discrimination in public spaces and events, and public transport. The findings in these tables were summarised in relation to the figure.

Table 16.3. Perceived experiences of stigma and discrimination in *public transport*: percentage agreement and disagreement (*n* = 67).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when using public transport	14.9%	17.9%	10.4%	25.4%	28.4%	3.0%	**56.8%**
I have been unfairly denied use of public transport	46.3%	37.3%	4.5%	4.5%	6.0%	1.5%	**12.0%**
I have been unfairly asked to get off public transport before I reached my destination	56.7%	32.8%	1.5%	0.0%	4.5%	4.5%	**9.0%**

I have been treated unfairly by public transport staff	46.3%	22.4%	4.5%	11.9%	7.5%	7.5%	**26.9%**

Table 16.4. Perceived experiences of stigma and discrimination in *public spaces and events*: percentage agreement and disagreement (*n* = 86).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly when using public spaces or attending events	16.3%	12.8%	7.0%	29.1%	26.7%	8.1%	**63.9%**
I have been unfairly denied entry to public spaces or events	40.7%	29.1%	8.1%	7.0%	11.6%	3.5%	**22.1%**
I have been unfairly denied service at public spaces or events	37.2%	31.4%	3.5%	15.1%	9.3%	3.5%	**27.9%**
I have been unfairly asked to leave public spaces or events when I wanted to stay	41.9%	34.9%	3.5%	3.5%	11.6%	4.7%	**19.8%**
I have been treated unfairly by retail, hospitality or events staff	25.6%	14.0%	9.3%	24.4%	16.3%	10.5%	**51.2%**

ANTICIPATED STIGMA AND DISCRIMINATION IN PUBLIC AND RECREATIONAL SPACES

> ***I use an assistance dog, there are always access issues***
>
> **Our Turn to Speak participant**
> **New South Wales**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in public and recreational spaces, as related to their experience of complex mental health issues.

Figure 16.4 shows that anticipated stigma and discrimination, across all four statements, was much higher in relation to public spaces and events compared with public transport. Ratings for anticipated stigma and discrimination were slightly higher than for perceived experiences of stigma and discrimination, and the pattern of ratings across the statements were also similar. For instance, levels of agreement were high in relation to statements describing anticipated unfair treatment generally (and by staff specifically), but much lower in terms of unfair denial of entry/use, and being asked to leave public spaces/events and public transport.

Almost 63% of participants who had accessed public spaces and events during the last 12 months anticipated unfair treatment in these spaces and events because of stigma about mental health issues, compared with 55.2% of participants who had accessed public transport.

Of note, 53.5% of participants who had accessed public spaces and events agreed that they expected to be treated unfairly by retail, hospitality or events staff, while 31.3% of participants who had accessed public transport expected that they would be treated unfairly by transport staff.

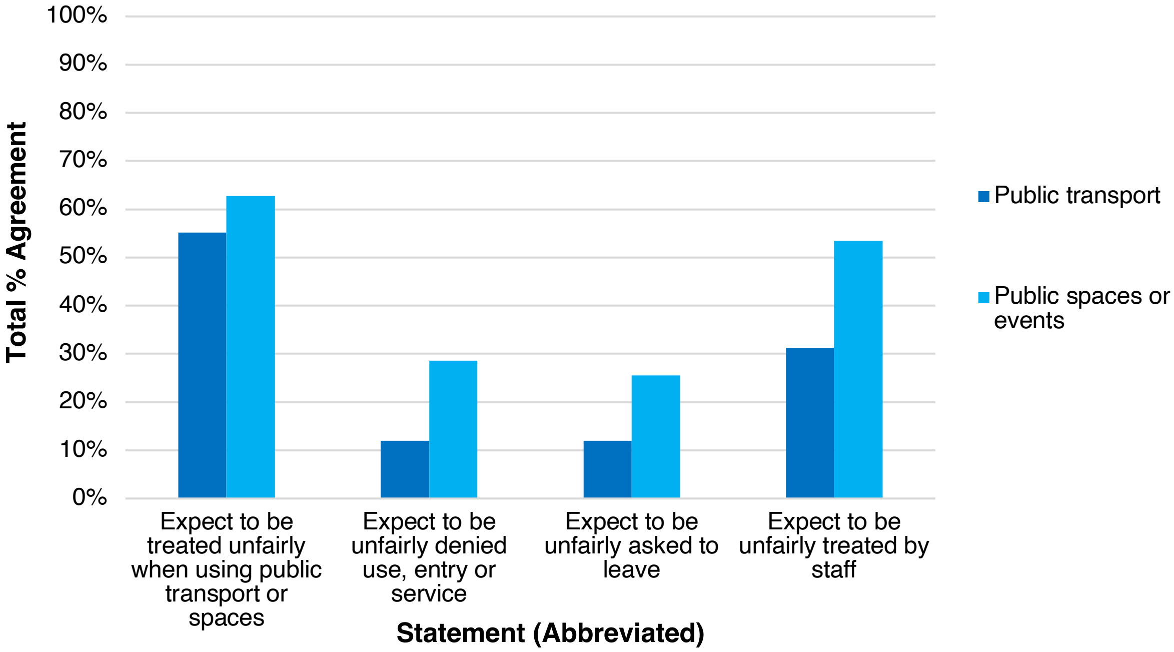


Figure 16.4. Highlight findings: total percentage agreement with anticipated stigma and discrimination on *public transport* (*n* = 67) and *public spaces and events* (*n* = 86).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

Tables 16.5 and **16.6** provide the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination in public spaces and events, and public transport. The findings in these tables have been summarised in relation to **Figure 16.4**.

Table 16.5. Anticipated stigma and discrimination in *public transport*: percentage agreement and disagreement (*n* = 67).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when using public transport	19.4%	19.4%	6.0%	34.3%	13.4%	7.5%	**55.2%**
I expect to be unfairly denied use of public transport	37.3%	41.8%	9.0%	4.5%	6.0%	1.5%	**12.0%**
I expect to be unfairly asked to get off public transport before I reached my destination	35.8%	41.8%	10.4%	4.5%	6.0%	1.5%	**12.0%**
I expect to be treated unfairly by public transport staff	29.9%	25.4%	13.4%	14.9%	13.4%	3.0%	**31.3%**

Table 16.6. Anticipated stigma and discrimination in *public spaces and events*: percentage agreement and disagreement (*n* = 86).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly when using public spaces or attending events	14.0%	15.1%	8.1%	24.4%	29.1%	9.3%	**62.8%**
I expect to be unfairly denied entry to public spaces or events	30.2%	31.4%	8.1%	14.0%	12.8%	3.5%	**30.3%**
I expect to be unfairly denied service at public spaces or events	30.2%	30.2%	12.8%	9.3%	14.0%	3.5%	**26.8%**
I expect to be unfairly asked to leave public spaces or events when I wanted to stay	32.6%	30.2%	11.6%	10.5%	11.6%	3.5%	**25.6%**
I expect to be treated unfairly by retail, hospitality or events staff	18.6%	23.3%	4.7%	19.8%	25.6%	8.1%	**53.5%**

WITHDRAWAL FROM OPPORTUNITY IN PUBLIC AND RECREATIONAL SPACES

> *I have a service dog for my mental illnesses and often encounter problems because of this which leaves me not wanting to go out.*
>
> **Our Turn to Speak participant**
> **Victoria**

Presented in this section are the findings regarding participants' withdrawal from opportunities in public and recreational spaces, as related to their experience of complex mental health issues.

Figure 16.5 compares withdrawal from opportunities in relation to public spaces and events compared with public transport. As shown across the three statements, withdrawal from opportunity was somewhat higher in relation to public spaces and events compared with public transport.

Between 69.8% and 80.2% of participants who had accessed public spaces and events during the last 12 months agreed that, because of stigma about mental health issues, they had: (a) stopped themselves from using public spaces or attending public events, (b) left such spaces and events even though they wanted to stay, and (c) stopped themselves from asking for assistance from retail, hospitality or events staff when they needed it.

Among participants who had accessed public transport during the last 12 months, between 40.3% and 50.7% of participants agreed they had withdrawn from similar opportunities in the context of using, or wanting to use, public transport.

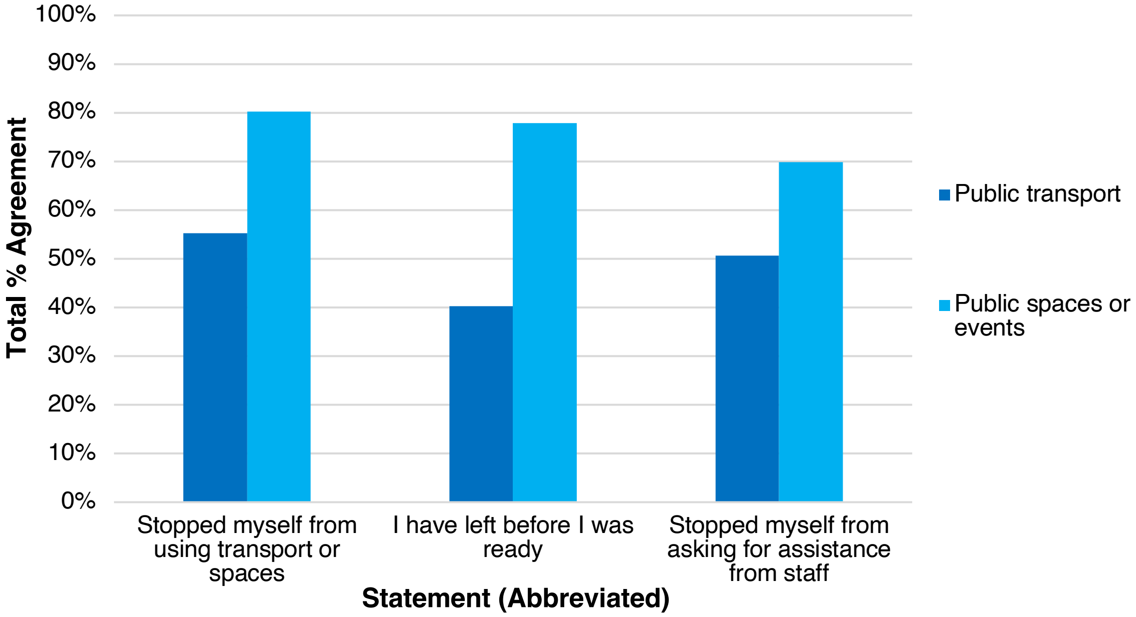


Figure 16.5. Highlight findings: total percentage agreement with withdrawal from opportunities on *public transport* (*n* = 67) and *public spaces and events* (*n* = 86).

Finally, **Tables 16.6** and **16.7** provide the specific levels of agreement and disagreement for all statements relevant to withdrawal from opportunities in public spaces and events, and public transport. The findings in these tables were summarised in relation to **Figure 16.5**.

Table 16.6. Withdrawal from opportunities in *public transport*: percentage agreement and disagreement (*n* = 67).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from using public transport	16.4%	22.4%	6.0%	20.9%	22.4%	11.9%	**55.2%**
I have exited from public transport before I reached my destination	22.4%	34.3%	3.0%	13.4%	22.4%	4.5%	**40.3%**
I have stopped myself from asking for assistance from public transport staff when I needed it	22.4%	19.4%	7.5%	11.9%	23.9%	14.9%	**50.7%**

Table 16.7. Anticipated stigma and discrimination in *public spaces and events*: percentage agreement and disagreement (*n* = 86).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from using public spaces or attending events	8.1%	5.8%	5.8%	20.9%	33.7%	25.6%	**80.2%**
I have left public spaces or events when I wanted to stay	7.0%	12.8%	2.3%	25.6%	33.7%	18.6%	**77.9%**
I have stopped myself from asking for assistance from retail, hospitality or events staff when I needed it	9.3%	14.0%	7.0%	12.8%	31.4%	25.6%	**69.8%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN PUBLIC AND RECREACTIONAL SPACES

> *The medication that I take has caused me to put on a lot of weight and I feel that people judge this as well.*
>
> **Our Turn to Speak participant**
> **New South Wales**

The findings from survey statements in relation to other experiences of stigma and discrimination in public spaces, besides complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 16.6**. As shown, 38.8% of participants agreed that they had experienced stigma and discrimination in public spaces because of their physical health or ability, and 28.5% agreed that they had experienced stigma and discrimination in public spaces because of their sexual orientation.

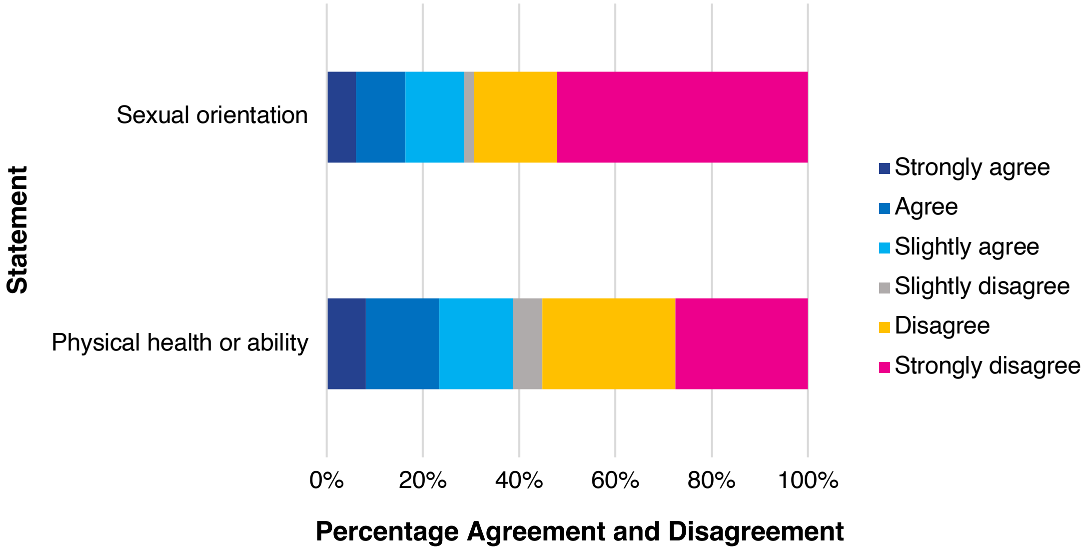


Figure 16.6. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *public and recreational spaces* (*n* = 98).

The specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting this domain are summarised in **Table 16.8**. Overall, a lower rate of agreement was found for statements describing experiences of stigma and discrimination in public and recreational spaces due to personal characteristics other than complex mental health issues.

Table 16.8. Other experiences of intersectional stigma and discrimination in *public and recreational spaces*: percentage agreement and disagreement (*n* = 98).

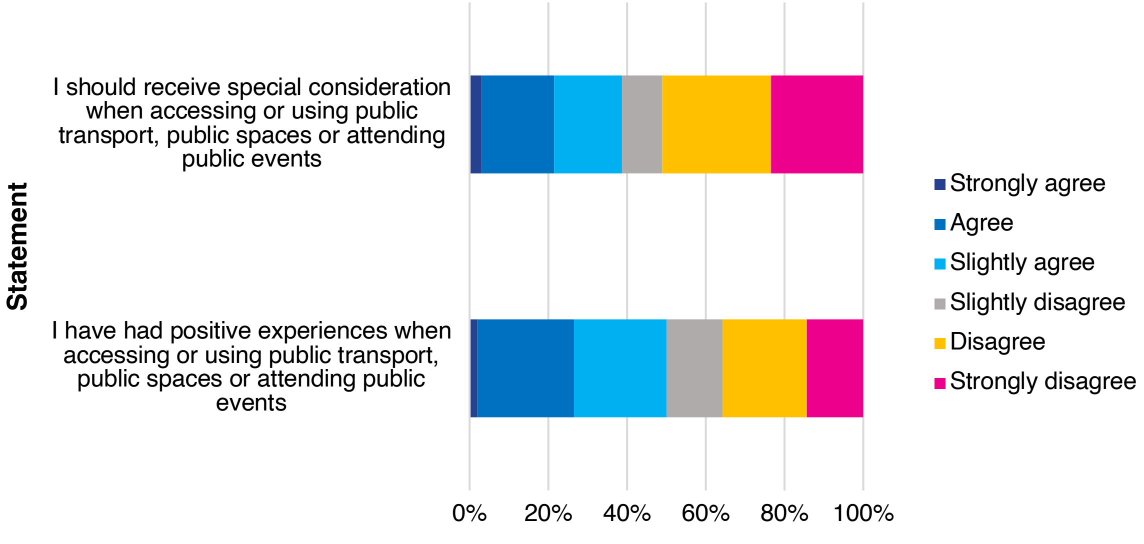
Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in public spaces because of my…							
Racial or cultural background	62.2%	14.3%	3.1%	8.2%	8.2%	4.1%	**20.5%**
Faith or spiritual beliefs	63.3%	17.3%	5.1%	7.1%	4.1%	3.1%	**14.3%**
Sexual orientation	52.0%	17.3%	2.0%	12.2%	10.2%	6.1%	**28.5%**
Gender identity	61.2%	19.4%	3.1%	2.0%	6.1%	8.2%	**16.3%**
Physical health or ability	27.6%	27.6%	6.1%	15.3%	15.3%	8.2%	**38.8%**

POSITIVE EXPERIENCES IN PUBLIC SPACES

> ***A lot of mentally and physically ill people travel on the bus, so I sometimes get to talk to them and I feel welcomes and less alone.***
>
> **Our Turn to Speak participant**
> **New South Wales**

The survey also asked about positive treatment in the public spaces domain. Two core statements comprised this section of the survey: (1) the expectation of special consideration because of one's experience of complex mental health issues, and (2) manifest positive experiences in public spaces because of one's experience of complex mental health issues.

As shown in **Figure 16.7**, 38.8% of participants agreed that they should receive special consideration when accessing public spaces. Half of all participants (50%) agreed that they had had positive experiences when accessing public spaces as a result of their complex mental health issues.



Percentage Agreement and Disagreement

Figure 16.7. Highlight findings: responses to the statements regarding positive experiences in *public and recreational spaces* because of participants' complex mental health issues (*n* = 98).

SUMMARY OF QUALITATIVE FINDINGS IN PUBLIC SPACES

Participants mentioned a variety of public spaces and situations in relation to their experiences of stigma and discrimination in this life domain. Examples included public transport, taxis, retail stores and shopping centres, hospitality, recreational spaces, in crowds, and public events.

In these public spaces, visibility emerged as a key theme. Specifically, participants feared negative consequences if their mental health issues were visible to members of the public. As a participant conveyed:

> *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).

One related factor concerning visibility was being accompanied by a service dog;

> *Again, most of the stigma and discrimination I experience is because of my Assistance Dog. I experienced much less discrimination before I had her. She helps my mental illness, but does make me more visible* (**Our Turn to Speak** participant, Victoria).
>
> *With my assistance dog, I become completely invisible, people then only see my dog, and then don't realise that that dog is there for my assistance* (**Our Turn to Speak** participant, New South Wales).

Other challenges associated with being accompanied by a service dog that participants raised included restrictions, inappropriate behaviour from other people, and accessibility issues.

Other participants also mentioned the theme of accessibility, particularly with regards to navigating roads and the public transport system, which was described as highly anxiety-provoking, distressing, or “triggering” of dissociative episodes for some.

A further theme arising from participant responses was that of feeling judged or “looked down” on, and receiving other unwanted attention in public spaces. A number of participants linked this to their self-regulatory behaviours, like skin picking and self-harm scars, for instance:

> *Most of the stigma is surrounded by other people on the bus staring or moving away from me due to self harm scars. Not the staff* (**Our Turn to Speak** participant, Victoria).
>
> *People look down on you if you're picking/self harming to cope or trying to use other means such as sensory toys* (**Our Turn to Speak** participant, Queensland).

In addition, a few participants commented on the lack of support from staff, security guards, and police in public spaces when help was needed.

When asked about positive experiences in the public spaces domain, several participants had examples to share. These included: positive treatment from public transport staff; connecting with other people who also experiences mental health issues on public transport; having a travel pass; positive experience with carers; positive experiences with other parents while taking children to school; and a couple of participants commented on positive experiences because of their assistance dog – an example being that: *“…People like the dog and are sometimes more friendly because of her presence”* (**Our Turn to Speak** participant, Victoria).

Other participants responded that they did not have any positive experiences to share, or conveyed negative experiences or mixed experiences such as:

> *In last two years I’ve been with my psychiatric service dog which makes some tings easier and others harder. Experience both greater awareness of my struggle, but also duscrimination from people in public spaces* (**Our Turn to Speak** participant, New South Wales).

Two participants commented that they did not want special treatment or consideration, but to be treated with *“equitable consideration”* and *“common courtesy”*.

When participants were asked about other factors that may have compounded their experiences of mental health stigma in this domain, responses included physical appearance, weight, socioeconomic status, gender, sexual orientation, disability, and physical health.

SUMMARY

Of the 1,912 survey participants, 5.1% (*n* = 98) identified public spaces as one of up to three life domains that had been most affected by stigma and discrimination in connection with complex mental health issues. Just over 35% of participants who selected public spaces as one of their most affected life domains during the last 12 months indicated ‘frequent’ or ‘very frequent’ experiences of stigma and discrimination in this area of their everyday lives.

When presented with a range of statements describing general and specific examples of stigma and discrimination in public spaces, it was evident that more participants agreed they had experienced stigma and discrimination in relation to general public spaces and events as compared with public transport. For example, 63.9% of participants agreed that they had been treated unfairly when using public spaces or attending events because of stigma about mental health issues, compared with 56.8% of participants who felt the same way in relation to using public transport.

Just over 50% of participants agreed that they had been treated unfairly by retail, hospitality or events staff because of stigma about mental health issues compared with 26.9% who agreed they had been treated unfairly by public transport staff specifically. Concerningly, 27.9% of participants agreed they had been unfairly denied service at public spaces or events and 22.1% agreed they had actually been denied entry. Rates of agreement were far lower for similar experiences when using public transport.

Participants' qualitative 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).

Almost 40% of participants agreed that their physical health and (dis)ability was also the subject of stigma and discrimination during the last 12 months. Unfortunately, the examples of social avoidance throughout participants' qualitative comments are a well-known consequence of stigmatising attitudes held by the public (Jorm & Oh, 2009; Reavley & Jorm, 2011). These attitudes have been a primary target in anti-stigma campaigns (Corrigan, 2011) designed for the general public.

Participants' qualitative comments also highlighted the impact of anticipated experiences of stigma and discrimination in public spaces. As one person commented, the worry that their experience of mental health issues might become visible or identifiable to members of the public was related to their fear of being treated negatively ("laughed at"). Rates of agreement with statements describing anticipated discrimination reflected such fears and were roughly equivalent as for rates of agreement about perceived experiences of stigma and discrimination. Again, expectations of unfair treatment were greater in relation to general public spaces and events than for use of public transport. For instance, 62.8% of participants agreed that they expected to be treated unfairly when using public spaces or attending events because of stigma about mental health issues, compared with 55.2% of participants who expected the same when using public transport. Interestingly, 53.5% of participants expected unfair treatment by retail, hospitality or events staff specifically, while far fewer (31.3%) expected unfair treatment by public transport staff. The difference between these two types of public spaces is unclear, but it may be that when using transport like trains and trams, interactions with staff are typically limited, and therefore less likely to factor into participants' fears for their experience in this domain.

The average rate of agreement with statements describing withdrawal from opportunity in relation to public spaces was double the average rates of agreement for experienced and anticipated stigma and discrimination in this domain. In other words, many more participants reported that they had stopped themselves from accessing public spaces and transport because of stigma about mental health issues in comparison with their reported experiences and anticipation of stigma and discrimination.

Again, agreement with statements describing withdrawal and avoidance were greater for general public spaces and events than for public transport. Between 69.8% and 80.2% of participants agreed that, because of stigma about complex mental health issues, they had stopped themselves from: (a) using public spaces or attending public events, (b) asking for assistance from retail, hospitality, or events staff when it was needed, and (c) they had actually left public spaces earlier than they wanted to. By contrast, between 40.3% and 55.2% of participants agreed with similar experiences of withdrawal from opportunity in relation to using public transport (although we note these rates still reflect a significant proportion of participants). Participants' commentary described – sometimes in great detail – the nature of discriminatory treatment they had endured in public spaces. These comments clearly demonstrate why so many participants had withdrawn from or avoided accessing what are daily activities for most Australians.

When asked specifically about positive experiences in public spaces, participants described mixed examples of their interactions with the public. Half of participants agreed they had had positive experiences when accessing or using public transport, public spaces or attending public events as a result of their mental health issues. Almost 40% of participants agreed they should receive special consideration for their experience of mental health issues when accessing public transport, spaces and events, although some participants' qualitative comments indicated a preference simply for fair treatment as opposed to specific accommodations.

These findings of the **Our Turn to Speak** survey suggest that many people living with complex mental health issues continue to experience discrimination in public spaces – such as avoidance or unwanted attention from members of the general public, and withholding of assistance by retail, hospitality, events and public transport staff. Such stigma and discrimination is known to compound the isolation of people who experience complex mental health issues (Hatzenbuehler et al., 2013) and ultimately compromises their psychosocial recovery (Corrigan, 2002) – a key facilitator of which is social connectedness and participation (Bradshaw et al., 2007; Leamy et al., 2011). The high rates of withdrawal from opportunity endorsed by participants unfortunately suggests this aspect of their psychosocial recovery is at risk, and supports a need for evidence-based, anti-stigma interventions to improve the public's understanding of, and compassion towards, those who experience complex mental health issues.

LEGAL AND JUSTICE SERVICES

17

Chapter 17. Legal and justice services

Everyone has a right to be protected from crime, as well as a right to justice when they are a victim of crime.

Unfortunately, people who experience complex mental health issues find themselves more likely to experience violent crimes and can face additional barriers when trying to access the support they need to protect themselves, their loved ones, and their possesions.

This chapter considers how people living with complex mental health issues experience stigma and discrimination in their experience of legal and justice services.

OVERVIEW

Approximately 37% (*n* = 714) of all **Our Turn to Speak** participants reported experiencing some level of stigma or discrimination in legal and justice services during the past 12 months.

Figure 17.1 shows that 10.3% percent of all participants reported 'frequent' or 'very frequent' stigma and discrimination in legal and justice services, and 4.8% (*n* = 91) identified this life domain as one of three in which they have been most affected by such experiences. **Figure 17.1** also shows that 63.7% of participants who selected the legal and justice services domain reported 'frequent' or 'very frequent' rates of stigma and discrimination in this aspect of their lives; substantially higher than was reported by the overall sample.

This chapter focuses on the characteristics and experiences of those 91 participants who selected legal and justice services as one of their top three, most affected life domains.

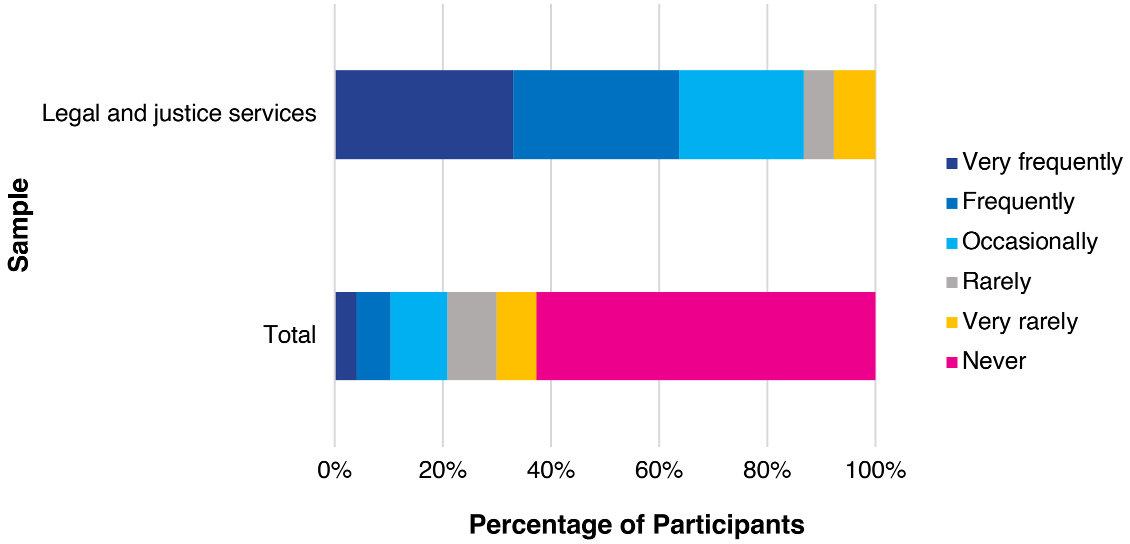


Figure 17.1. Frequency of stigma and discrimination in *legal and justice services* among participants who selected this domain as one of three in which they had been most affected by stigma during the past 12 months (*n* = 91) compared with the total sample (*N* = 1912).

PROFILE OF PARTICIPANTS

Table 17.1 presents the sociodemographic characteristics of participants who identified as being personally affected by stigma and discrimination in legal and justice services.

As shown, participants who selected this life domain were slightly older compared with the average age of the total sample. Compared with the total sample, almost 10% more participants who selected the justice and legal services domain were male and slightly fewer identified as trans, gender diverse and/or non-binary. There was also a greater representation of participants not currently in a relationship, and slightly fewer who identified as gay, lesbian, bisexual, pansexual, queer and/or asexual. Compared with the total sample, 17.6% fewer participants were engaged in paid work, 10.2% more were unemployed or unable to work, and 11.7% more participants were receiving a pension or other benefit. There was also a slightly higher representation of participants living in Queensland and located in a regional or remote area compared with the total sample.

Table 17.1. Sociodemographic characteristics: *legal and justice services* sample compared with the total sample.

Characteristics	Legal and Justice Services (*n* = 91)	Total (*N* = 1912)
Mean age	43.31 (*SD* = 12.74)	39.21 (*SD* = 12.81)
Gender identity		
Female	71.4%	78.9%
Male	27.5%	18.0%
Trans, gender diverse and/or non-binary	2.2%	4.9%
Unsure or questioning	1.1%	0.9%
Prefer not to say	0.5%	0.4%
Relationship status		
Not in a relationship	61.5%	52.1%
In a relationship	37.4%	47.3%
Prefer to self-describe	1.1%	0.2%
Sexual orientation		
Heterosexual	68.1%	62.0%
Gay, lesbian, bisexual, pansexual, queer, and/or asexual	29.7%	35.6%
Unsure or questioning	4.4%	4.9%
Prefer to self-describe	3.3%	1.5%
Prefer not to say	2.2%	1.7%
Education (highest level attained)		
Primary school	4.4%	1.6%
Secondary college (high school)	19.8%	20.9%
Educated post-secondary college	75.8%	77.4%
Other	0.0%	0.2%
Employment status		
Engaged in paid work	34.1%	51.7%
Engaged in unpaid work or studying	23.1%	28.7%
Unemployed or unable to work	33.0%	22.8%
Receiving a pension or benefits	36.3%	24.6%
Other	1.1%	0.2%
State		
Australian Capital Territory	1.1%	2.5%
New South Wales	26.4%	23.6%
Northern Territory	0.0%	0.6%
Queensland	19.8%	15.9%
South Australia	8.8%	9.5%
Tasmania	1.1%	3.7%
Victoria	33.0%	33.1%
Western Australia	9.0%	10.9%
Region*		
Major city	75.8%	74.2%
Regional or remote	19.8%	24.7%

Note. Percentages for gender identity, sexual orientation and employment status do not add to 100 as participants could select more than one response option.
*Missing region data for 21 participants.
SD = standard deviation.

The mental and physical health characteristics of participants who identified the legal and justice services domain as having been most affected by stigma and discrimination were generally similar to those of the total sample (see **Table 17.2**).

Of note, a greater proportion of participants who selected the justice and legal services domain were living with co-occurring physical health issues (11% more than the total sample) and a primary diagnosis of a trauma-related or dissociative disorder (12.6% more than the total sample).

Table 17.2. Mental and physical health characteristics: *legal and justice services* sample compared with the total sample.

Characteristics	Legal and Justice Services (*n* = 91)	Total (*N* = 1912)
Primary complex mental health issue		
Schizophrenia spectrum disorder	8.8%	7.4%
Bipolar related disorder	7.7%	17.2%
Obsessive-compulsive related disorder	4.4%	4.3%
Trauma-related or dissociative disorder	38.5%	25.9%
Eating disorder	3.3%	6.1%
Personality disorder	17.6%	14.5%
Severe and treatment-resistant depressive disorder	11.0%	14.3%
Severe and treatment-resistant anxiety disorder	8.8%	10.2%
Physical health		
Co-occurring brain injury, chronic health issue or disability	64.8%	53.8%

METHODS SNAPSHOT

Participants who identified legal and justice services as one of three life domains in which they have been most affected by stigma-related experiences completed the legal and justice services section of the survey. At the beginning of this section of the survey, participants were asked to indicate what types of legal and justice services they had accessed during the previous 12 months. Legal and justice services were described as including:

- federal and state police
- civil and criminal courts of law, including legal representation (for example, lawyers or Legal Aid)
- family courts and child protection services.

Sixty-eight percent (*n* = 62) had accessed police services, 65.9% (*n* = 60) had accessed courts of law, and 34.1% (*n* = 31) had accessed family courts. Participants were subsequently presented with only the questions that matched their reported legal and justice services experiences. For example, participants who reported accessing only police services during the last 12 months received only questions corresponding to police services. Those who indicated they had accessed more than one type of justice and legal received questions corresponding to each of those areas.

Participants rated their agreement with statements relating to previous experiences of stigma and discrimination in legal and justice services; anticipated future experiences of stigma and discrimination; and withdrawal from opportunities in terms of legal and justice services. Participants were asked if they had experienced stigma and discrimination in this life domain because of other personal characteristics, such as sexual orientation, or racial or cultural background. They were also asked about any positive treatment they may have experienced in relation to their complex mental health issues. Each of these sections were presented in a randomised order. Participants were asked to rate their agreement with each statement according to a six-point Likert scale: (1) ‘strongly disagree’, (2) ‘disagree’, (3) ‘slightly disagree’, (4) ‘slightly agree’, (5) ‘agree’, and (6) ‘strongly agree’. Participants were asked to reflect on their experiences during the past 12 months when rating their level of agreement for each statement presented.

Participants were also given opportunities throughout the survey to further describe their experiences of stigma and discrimination in relation to: (a) complex mental health issues, (b) their other personal characteristics, and (c) any positive treatment in relation to their use of legal and justice services. Twenty-four, 10 and 19 participants provided additional comments in relation to these experiences respectively.

STIGMA AND DISCRIMINATION IN LEGAL AND JUSTICE SERVICES

This section presents a summary of the average level of agreement with statements describing stigma and discrimination in justice and legal services, which will be further examined in sections that follow.

As shown in **Figure 17.2**, the average total level of agreement with all statements describing perceived experiences of stigma and discrimination in justice and legal services was 53%. Similarly, the average total level of agreement with all statements describing anticipated stigma and discrimination, and withdrawal from opportunities in justice and legal services, was about 55%.

In other words, participants tended to agree that they had experienced, and expected to experience, stigma and discrimination when accessing such services; and that they tended to stop themselves from accessing such services (through actions such as reporting a crime or seeking legal advice) because of stigma and discrimination about complex mental health issues.

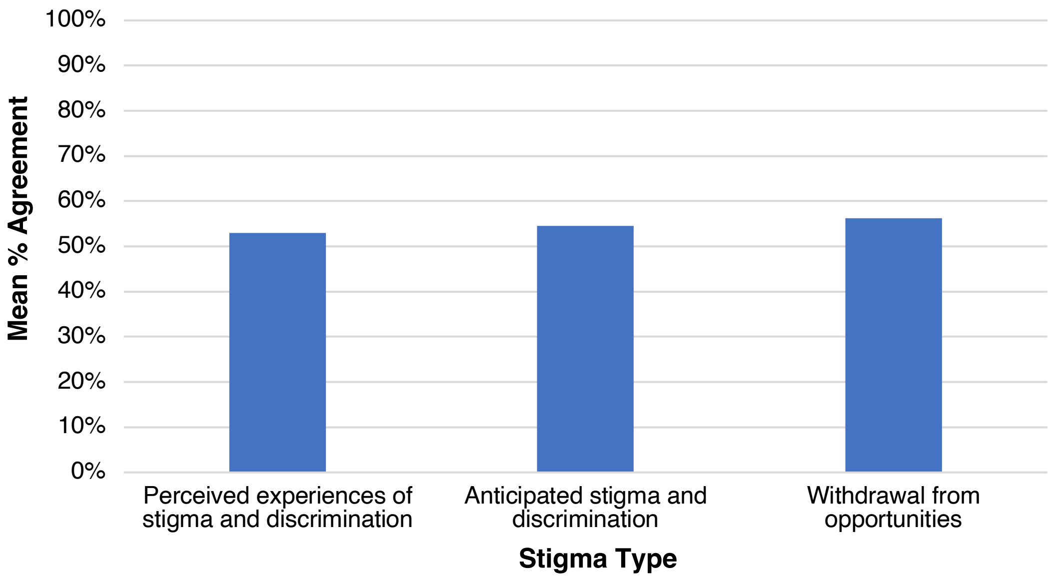


Figure 17.2. Average percentage agreement for all statements relating to perceived experiences of stigma and discrimination, anticipated stigma and discrimination, and withdrawal from opportunities in *legal and justice services* (*n* = 91).
Note. Agreement refers to the aggregate of responses: ‘slightly agree’, ‘agree’ and ‘strongly agree’.

PERCEIVED EXPERIENCES OF STIGMA AND DISCRIMINATION IN LEGAL AND JUSTICE SERVICES

> ***Unfairly singled out in a bar, strip searched, humiliated, held longer than necessary.***
>
> **Our Turn to Speak participant**
> **New South Wales**

Presented in this section are the findings regarding participants’ perceived experiences of stigma and discrimination in legal and justice services, as related to their experience of complex mental health issues.

Figure 17.3 highlights the findings relating to two statements presented to all 91 participants who selected the Legal and Justice Services domain, regardless of whether they had specifically accessed police services, courts of law and/or family courts during the last 12 months. These items were thought to be relevant to all participants who selected the Legal and Justice Services domain, regardless of the nature of services they had accessed.

As shown, 53.9% of participants agreed that they had been unfairly denied access to legal services or advice because of stigma about complex mental health issues, while 42.9% perceived they had been denied the right to report a crime because of such stigma.

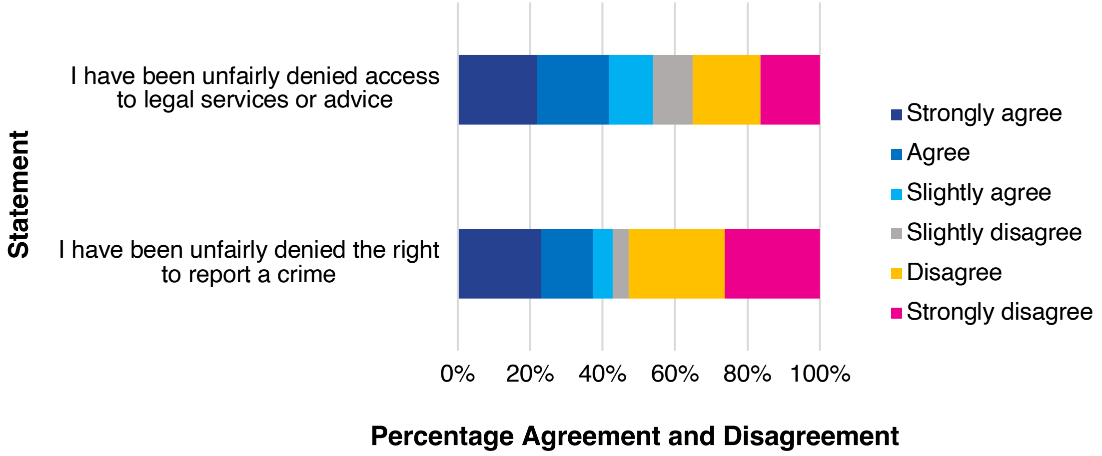


Figure 17.3. Highlight findings: perceived experiences of stigma and discrimination in *justice and legal services* (*n* = 91).

Tables 17.3 and **17.4** provide the specific levels of agreement and disagreement for all statements relevant to perceived experiences of stigma and discrimination in police services, courts of law, and family courts.

The highest rate of agreement was in relation to treatment by police; 77.5% of participants who responded to this statement perceived they had been treated unfairly by police because of stigma about mental health issues during the last 12 months. This compared with 65.7% of participants who perceived unfair treatment by lawyers or court officials and 45.2% who perceived unfair treatment by child protection officials during the same time period.

Close to 65% of participants who had accessed police services also agreed that they had been unfairly denied police assistance when needed; 43.6% believed they had been unfairly detained or questioned by police; and 30.6% of participants believed they had been subjected to excessive police force because of stigma about complex mental health issues.

Table 17.3. Perceived experiences of stigma and discrimination in police services: percentage agreement and disagreement (*n* = 62).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly by the police	4.8%	14.5%	3.2%	8.1%	24.2%	45.2%	**77.5%**
I have been unfairly denied access to police assistance	4.8%	29.0%	1.6%	11.3%	17.7%	35.5%	**64.5%**
I have been unfairly detained or questioned by the police	27.4%	24.2%	4.8%	6.5%	11.3%	25.8%	**43.6%**
I have been unfairly subjected to excessive use of force by the police	32.3%	30.6%	6.5%	3.2%	4.8%	22.6%	**30.6%**

Table 17.3. Perceived experiences of stigma and discrimination in *courts of law* and *family courts*: percentage agreement and disagreement.

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have been treated unfairly by lawyers or court officials[1]	13.7%	12.3%	8.2%	9.6%	21.9%	34.2%	**65.7%**
I have been treated unfairly by child protection officials[2]	35.5%	16.1%	3.2%	12.9%	6.5%	25.8%	**45.2%**

[1] Completed by participants who had accessed both courts of law and family courts during the last 12 months (*n* = 73).

[2] Completed by participants who had accessed family courts during the last 12 months (*n* = 31).

ANTICIPATED STIGMA AND DISCRIMINATION IN LEGAL AND JUSTICE SERVICES

> ***…Police training in relation to mental ill health & trauma are glaringly insufficient, & this is something which is causing harm on a large scale, for those of us with mental ill health.***
>
> **Our Turn to Speak participant**
> **Queensland**

Presented in this section are the findings regarding participants' anticipation of stigma and discrimination in justice and legal services, as related to their experience of complex mental health issues.

Figure 17.4 highlights the findings relating to two statements presented to all 91 participants who selected the justice and legal services domain, regardless of whether they had specifically accessed police services, courts of law and/or family courts during the last 12 months. These items were thought to be relevant to all participants who selected the justice and legal services domain, regardless of the nature of services they had accessed.

As shown, 55.0% of participants expected to be unfairly denied access to legal services or advice because of stigma about complex mental health issues, while 51.7% expected that they would be denied the right to report a crime.

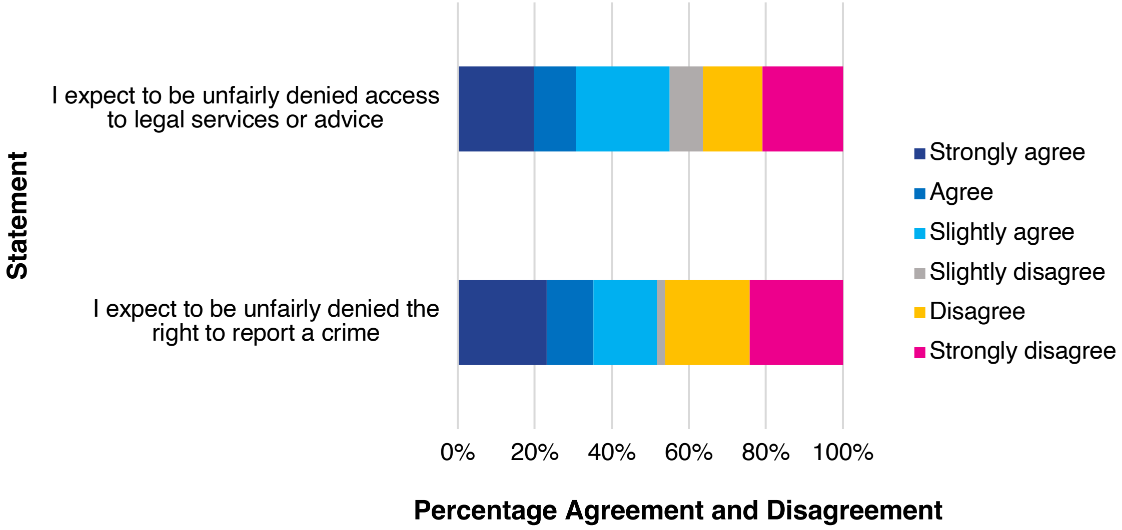


Figure 17.4. Highlight finding: anticipated stigma and discrimination in *legal and justice services* (*n* = 91).

Tables 17.4 and **17.5** provide the specific levels of agreement and disagreement for all statements relevant to anticipated stigma and discrimination by police services, courts of law, and family courts.

The highest rates of agreement were in relation to treatment by police, and lawyers or court officials: 69.3% of participants who had accessed police services expected to be treated unfairly by police, and 68.6% of participants who had accessed courts of law expected to be treated unfairly by lawyers or court officials because of stigma about mental health issues. In comparison, 45.1% of participants who had accessed family courts agreed that they expected to be treated unfairly by child protection officials. About 63% of participants who had accessed police services also agreed that they expected to be denied police assistance when it was needed; 46.8% expected to be unfairly detained or questioned by police; and 37.1% expected that police might use excessive force because of stigma about complex mental health issues.

Table 17.4. Anticipated stigma and discrimination in *police services*: percentage agreement and disagreement (*n* = 62).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly by the police	12.9%	14.5%	3.2%	8.1%	17.7%	43.5%	**69.3%**
I expect to be unfairly denied access to police assistance	14.5%	21.0%	1.6%	9.7%	16.1%	37.1%	**62.9%**
I expect to be unfairly detained or questioned by the police	25.8%	22.6%	4.8%	11.3%	11.3%	24.2%	**46.8%**
I expect to be unfairly subjected to excessive use of force by the police	29.0%	21.0%	12.9%	9.7%	4.8%	22.6%	**37.1%**

Table 17.5. Anticipated stigma and discrimination in *courts of law* and *family courts*: percentage agreement and disagreement.

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I expect to be treated unfairly by lawyers or court official	13.7%	13.7%	3.9%	15.7%	17.6%	35.3%	**68.6%**
I expect to be treated unfairly by child protection officials	41.9%	6.5%	6.5%	12.9%	3.2%	29.0%	**45.1%**

[1] Completed by participants who had accessed both courts of law and family courts during the last 12 months (*n* = 51; missing data for *n* = 22 participants due to a survey administration error).

[2] Completed by participants who had accessed family courts during the last 12 months (*n* = 31).

WITHDRAWAL FROM OPPORTUNITY IN LEGAL AND JUSTICE SERVICES

> ***Gave up purusing opponents through legal and OSH systems because* [mental health] *issues and experiences like psychological abuse are virtually impossible to prove, thus making winning my case extremely unlikely.***
>
> **Our Turn to Speak participant**
> **Western Australia**

Presented in this section are the findings regarding participants' withdrawal from opportunities in legal and justice services, as related to their experience of complex mental health issues.

Figure 17.5 highlights the findings relating to two statements presented to 91 participants who selected the justice and legal services domain responded, regardless of whether they had specifically accessed police services, courts or law or family court services during the last 12 months. These items were thought to be relevant to all participants who selected the justice and legal services domain, regardless of the nature of services they had accessed.

As shown, 47.3% agreed that they had stopped themselves from seeking legal services or advice when they needed it because of stigma about complex mental health issues, and 52.8% agreed that they had stopped themselves from reporting a crime during the last 12 months for the same reason.

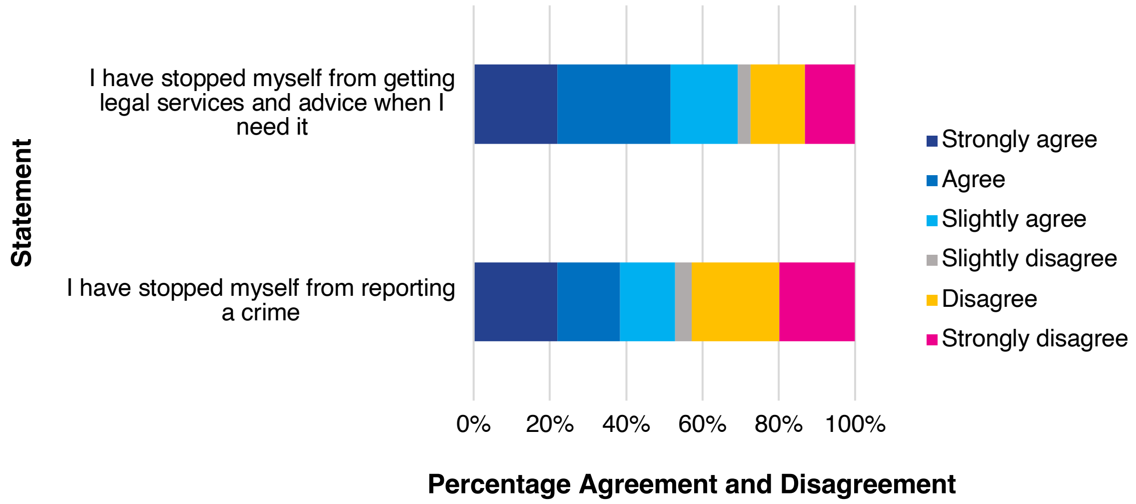


Figure 17.5. Highlight findings: withdrawal from opportunities in *legal and justice services* (*n* = 91).

Table 17.6 provides the specific levels of agreement and disagreement for all statements relevant to withdrawal from opportunities in relation to police services specifically.

Over 70% of participants had stopped themselves from asking for police assistance when they needed it, and about 48% had stopped themselves from asking for police assistance for someone else or calling 000 in an emergency.

Table 17.6. Withdrawal from opportunities in *police services*: percentage agreement and disagreement (*n* = 62).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
Because of stigma about mental health issues…							
I have stopped myself from asking for police assistance when I needed it	6.5%	17.7%	3.2%	4.8%	24.2%	43.5%	**72.5%**
I have stopped myself from asking for police assistance when other people have needed it	17.7%	25.8%	8.1%	8.1%	19.4%	21.0%	**48.5%**
I have stopped myself from calling 000 during a crime or other police emergency	19.4%	25.8%	6.5%	12.9%	19.4%	16.1%	**48.4%**

OTHER EXPERIENCES OF STIGMA AND DISCRIMINATION IN JUSTICE AND LEGAL SERVICES

> ***Because my health conditions both physically and mentally are not recognised by Centrelink they are not recognised by Legal Aid.***
>
> **Our Turn to Speak participant**
> **Victoria**

The findings from survey statements in relation to other experiences of stigma and discrimination in justice and legal services, besides complex mental health issues, are presented in this section.

Findings from the two most frequently endorsed issues regarding other experiences of stigma and discrimination are shown in **Figure 17.6**. As shown**,** 27.5% of participants agreed that they had experienced stigma and discrimination in justice and legal services because of their physical health or ability, and 15.4% agreed that they had experienced stigma and discrimination in connection with their racial or cultural background in the context of accessing justice and legal services.

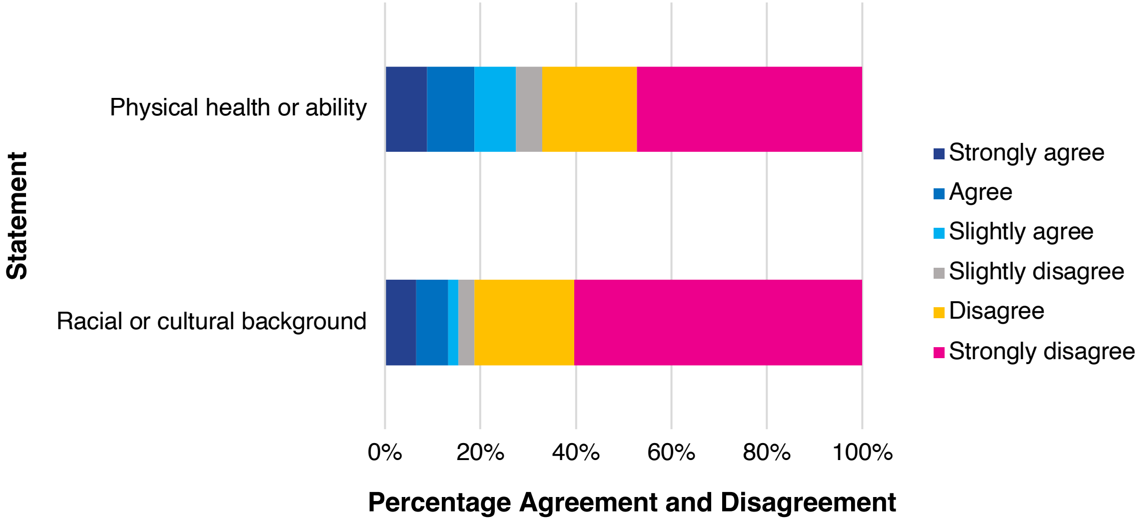


Figure 17.6. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *legal and justice services* (*n* = 91).

The specific levels of agreement and disagreement for all statements relevant to other sources of stigma and discrimination impacting justice and legal services are summarised in **Table 17.6**. Overall, a relatively low rate of agreement was observed for statements describing experiences of stigma and discrimination in justice and legal services due to personal characteristics other than complex mental health issues.

Table 17.6. Experiences of intersectional stigma and discrimination in *legal and justice services*: percentage agreement and disagreement (*n* = 91).

Statement	Strongly Disagree	Disagree	Slightly Disagree	Slightly Agree	Agree	Strongly Agree	Total Agree
I have also experienced stigma and discrimination in legal and justice services because of my…							
Racial or cultural background	60.4%	20.9%	3.3%	2.2%	6.6%	6.6%	**15.4%**
Faith or spiritual beliefs	63.7%	20.9%	4.4%	4.4%	3.3%	3.3%	**11.0%**
Sexual orientation	63.7%	23.1%	5.5%	3.3%	1.1%	3.3%	**7.7%**
Gender identity	63.7%	22.0%	2.2%	2.2%	4.4%	5.5%	**12.1%**
Physical health or ability	47.3%	19.8%	5.5%	8.8%	9.9%	8.8%	**27.5%**

POSITIVE EXPERIENCES IN LEGAL AND JUSTICE SERVICES

> ***The police were really understanding, came and visited in the home, made sure I was comfortable and there was another female present, took into account the little things. He tried ease the stress a bit.***
>
> **Our Turn to Speak participant**
> **Victoria**

The survey also asked about positive treatment in the justice and legal services domain. Two core statements comprised this section of the survey: (1) the expectation of special consideration because of one's experience of complex mental health issues, and (2) manifest positive experiences in justice and legal services because of one's experience of complex mental health issues.

As shown in **Figure 17.7**, 61.6% of participants agreed that they should receive special consideration when accessing justice and legal services (including police assistance). Fewer participants (31.9%) agreed that they had experienced anything positive in connection to their complex mental health issues when accessing these services.

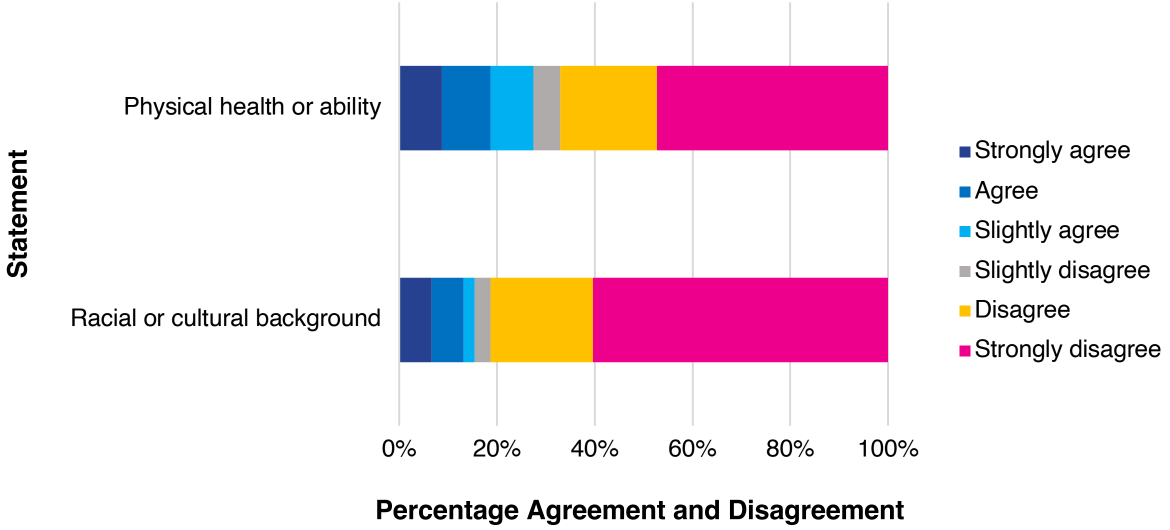


Figure 17.7. Highlight findings: the two most frequently endorsed statements describing experiences of intersectional stigma and discrimination in *legal and justice services* (*n* = 91).

SUMMARY OF QUALITATIVE FINDINGS IN LEGAL AND JUSTICE SERVICES

Owing to the small number of responses in this domain, it was difficult to draw out major themes. Some of the more frequently discussed areas included a lack of flexibility, understanding and support in the justice system, not being taken seriously, and mental health issues being used against them.

With regards to the lack of flexibility, understanding, and support in the justice system, some participants highlighted such aspects as a lack of reasonable adjustments, lack of training among police in responding to people with mental health issues, forceful police behaviour, and barriers to making complaints about such experiences;

> *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).
>
> *The mechanism for making a complaint about police, in regards to undue force, or other mistreatment, doesn't empower anyone to make a complaint or provide feedback or start a dialogue regarding issues, least of all those of us with mental ill health* (**Our Turn to Speak** participant, Queensland).

Several participants described situations where they had not been taken seriously, for example:

> *Explained to police that I was having a panic attack after being followed into my yard by police and they ignored my words and instead asked me to be breath tested* (**Our Turn to Speak** participant, Queensland).
>
> *Police treated me like I was an annoyance, like my fear was less important than perpetrators feelings. I was told my information was not enough to "get it over the line" but they'd see what their sergeant thought. Told me not to have high hopes. This was all to do with emotional and verbal abuse by ex husband, including threats*

> *to kill me. I was concerned for our children who were with him at the time. The police thought I was "acting a bit crazy"…* (**Our Turn to Speak** participant, Victoria).

Several participants described situations, including interactions with police and the court system, that had involved family violence and felt that their mental health had been used against them:

> *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).

> *Court system and child protection as soon as they find out you have mental health issues, it completely alters outcome. Based on involuntary admission, determined that I was a risk to my children. Advised by lawyers that because of mental health judge would look disapprovingly on application, advised to take lesser thing than I or my children needed or wanted. In different context been unable to access legal help for civil matter because of mental health* (**Our Turn to Speak** participant, Victoria).

Nonetheless, another participant pointed out that *"... not all cases are about violence, some are civil unjustice"* (**Our Turn to Speak** participant, Western Australia), and many people living with mental health issues are facing financial stress and poverty, as well as a variety of other barriers that impact upon their engagement with the justice system.

A couple of participants mentioned that, due to disappointing outcomes and difficulty proving abuse, they had 'given up' and would not use the legal system or report a crime in future. A few participants also commented on their fear and distrust of the police.

When asked about positive experiences in relation to this domain, a few participants gave examples of positive interactions with police;

> *The police were really understanding, came and visited in the home, made sure I was comfortable and there was another female present, took into account the little things. He tried ease the stress a bit* (**Our Turn to Speak** participant, Victoria).

> *The Legal Aid lawyer who I was finally granted funding to have assist me with my criminal court dealings has been lovely, although she's unable to help me with the mechanisms of complaining about police using undue force or ignoring my rights, too. I'm still not sure who'll be helping me with that, but I'm very glad I've got assistance with some of it, especially as it's from someone so kind & competent at her job* (**Our Turn to Speak** participant, Queensland).

Other participants shared negative or mixed experiences. Several also discussed the issue of special treatment and consideration;

> *I do not wish to receive special consideration but would like to be treated fairly without discrimination. In my viewpoint I perhaps would not have had to go down the journey I went through legally if there was not a doubt around my mental health diagnosis. I think my mental diagnosis impacted an accusation which went further legally than in my opinion would have without my mental health diagnosis being there. Also although my lawyer was fantastic and acted in my best interests. She informed that perhaps she would not be able to help me if my mental health became*

> *unstable. I viewed this as a lack of understanding in her part of mental ill health in general which may have resulted in a not so favorable outcome if I had a mental health setback at the time. Thankfully I did not experience a setback during this time* (Male, age 48, SA).
>
> *Again I don't think I should get special treatment, I should be treated with dignity and respect. I am so offended that this survey keeps using the word special* (**Our Turn to Speak** participant, New South Wales).

Two participants commented that ‘special consideration’ should include more patience.

When participants were asked about other factors that may have compounded their experiences of mental health stigma in this domain, responses included gender, sexual orientation, housing, race, not being believed, and the fact that *“Because my health conditions both physically and mentally are not recognised by Centrelink they are not recognised by Legal Aid”* (**Our Turn to Speak** participant, Victoria).

SUMMARY

Of the 1,912 survey participants, 4.8% (*n* = 91) identified legal and justice services as one of up to three life domains that had been most affected by stigma and discrimination in connection with complex mental health issues. Close to 64% of participants who selected legal and justice services as one of their most affected life domains during the last 12 months indicated ‘frequent’ or ‘very frequent’ experiences of stigma and discrimination in this aspect of their lives.

Participants were presented with a range of statements describing general and specific examples of stigma and discrimination in legal and justice services. Among participants who had accessed police services during the last 12 months, 77.5% agreed that they had been treated unfairly by police and 64.5% agreed they had been unfairly denied access to police assistance when they needed it. Agreement with statements describing unfair questioning, detainment or excessive police force were much lower, but nonetheless significant, with between 30.6% to 43.6% of participants endorsing those experiences.

Participants’ qualitative comments suggested that these types of experiences were driven by police members’ limited understanding of complex mental health issues or the influence of trauma upon a person’s response to stress in the moment. For instance, participants described police responses that were inflexible towards the needs of those with intersecting physical and mental health issues, and attitudes that were reflective of stereotypes about impaired decision-making or capacity for insight. As a consequence, participants’ needs and experiences appear to have been minimised or undermined.

Of participants who had engaged with other justice services, such as courts of law or family courts, during the last 12 months, 65.7% agreed they had been treated unfairly by lawyers or court officials, and 45.2% perceived unfair treatment by child protection officials. Among all participants who selected the justice and legal services domain, rates of agreement with statements describing unfair denial of access to legal services, advice or the right to report a crime were also relatively high (between 42.9% and 53.9%). Again, participants’ qualitative comments suggested stereotypes and misinformed attitudes about mental health issues may have influenced the actions taken by court officials.

Rates of agreement with statements describing various kinds of anticipated discrimination, and withdrawal from opportunities relevant to justice and legal services, were slightly higher than for perceived experiences of stigma and discrimination. The same patterns were observed in terms of which statements were agreed with by the majority of participants, and which statements were agreed with by fewer participants. On average, 55% of participants agreed with all statements describing anticipated stigma and discrimination in their future interactions with police and law officials. Given the types of stigma and discrimination participants reported and described, it is understandable that many expected to experience more of the same in future.

Unfortunately, participants' fears reflect that those who live with complex mental health issues and intersecting issues – such as alcohol and other drug use, physical health issues and disability, socioeconomic disadvantage, and being part of a minority ethnic background – are over-represented in, and at risk of, interacting with the justice system (Australian Institute of Health and Welfare, 2018; Dowse et al., 2014; Law Council of Australia, 2019). Among **Our Turn to Speak** participants, 27.5% and 15.4% agreed that their experiences of stigma in justice and legal services have been compounded by stigma and discrimination in relation to their physical health or (dis)ability, and their racial or cultural background, respectively.

On average, 56.0% of participants agreed with all statements describing withdrawal from, or avoidance of, accessing supports or assistance related to legal and justice services. Of particular concern, 72.5% of participants who had personally needed access to police services during the last 12 months agreed that they had stopped themselves from asking for it because of stigma about mental health issues. Almost 50% agreed that they had stopped themselves from calling 000 during an emergency that required police assistance because of stigma about mental health issues.

Similarly, 47.3% of all participants who selected the legal and justice services domain agreed they had stopped themselves from accessing legal services and advice when they needed it. Participants' qualitative comments highlighted that the impact of past negative experiences with police and other legal services influenced their decisions to *"NEVER report any crime again*". It is well established that people who live with complex mental health issues are at a higher risk of experiencing violence (Desmarais et al., 2014; Hiroeh et al., 2001). The findings reported here suggest that the consequences of stigma and discrimination relating to mental health in justice and legal services may be perpetuating this risk, as well as the risk of adverse consequences of experiencing violence.

Relatively few participants (31.9%) agreed that they had experienced any positive treatment in legal and justice services in connection with their experience of mental health issues. Positive experiences were associated with instances in which police, lawyers or other service providers demonstrated empathy, competence and compassion in their interactions with participants. Such interactions appeared to reflect an understanding of the challenges of living with complex mental health (and intersecting issues) and accommodating the needs of the participant as a person.

While participants' qualitative comments indicated discomfort with the term 'special consideration', the majority (61.6%) were in support of receiving special consideration to help them overcome barriers to accessing legal and justice services, or police assistance. Participants expressed a desire for fairness, dignity, and respect in their dealings with people working in the justice and legal services. They also indicated a need for improved mental health training for these personnel.

WHAT MOST NEEDS TO CHANGE

18

Chapter 18. What most needs to change.

Valuing the lived experience of people affected by complex mental health issues is central to the **National Stigma Report Card**. The **Our Turn to Speak** survey focused on listening to real people's stories in order to understand how stigma and discrimination affect Australians living with these issues across different areas of their lives. We did not want to simply ask participants about the problems they faced, their ideas for solutions was equally important. Participants were therefore asked what changes *they* believed were most needed to reduce stigma and improve the experience of living with complex mental health issues.

This chapter presents a summary of the qualitative data participants submitted in relation to what they thought most needs to change to effect positive outcomes for people living with complex mental health issues in Australia.

WHAT MOST NEEDS TO CHANGE

A total of 1,609 participants provided responses to the survey's final question, which asked:

> *Thinking about the life domains that you identified as having been most affected by stigma about mental health issues in the last 12 months, what do you think most needs to change to improve your own and other's experiences of living with mental health issues; or to reduce stigma and discrimination about mental health issues?*

Participants' responses to this question were coded and analysed thematically to discern emergent patterns and recurring ideas, divided into themes and sub-themes, where possible (Braun et al., 2019).

While some of these participants suggested that they were unsure or did not know, three overarching themes were identified among others' responses, including:

1. Education, understanding, and acceptance
2. Communication and visibility
3. Accessible services, fair treatment, and support.

Education, understanding, and acceptance

Many comments relating to this theme were concerned with improving education and understanding, as well as empathy and acceptance, within the general public. An example, here, included: *"More understanding of mental health worries - education for the public*" (**Our Turn to Speak** participant, Queensland). Other examples were as follows:

> *More education and awareness should be made available to the general public to give them an idea of what we deal with on a daily basis and how this impacts on us. Also that we are not dangerous but when they see us looking 'strange' we are often frightened by our thoughts and are trying to work out how to feel safe* (**Our Turn to Speak** participant, New South Wales).
>
> *Understanding and actually listening to those who are going through mental health issues. Having an open mind is key, don't assume anything..making assumptions can be deadly"* (**Our Turn to Speak** participant, Northern Territory).

> *There needs to be more information provided about mental health issues to everyone not just people living with these issues. I also believe that if more people understood the effects of mental health issues there would be less stigma and discrimination* (**Our Turn to Speak** participant, New South Wales).

Some responses were less specific, such as *"Better understanding from others"* (**Our Turn to Speak** participant, New South Wales). Some participants called for more understanding among government and policymakers.

However, many comments focused on the need for increased understanding (including through training, particularly that which is trauma-informed), and addressing negative attitudes among workers. This most often included those who work in health services (especially doctors, nurses, paramedics, mental health professionals such as psychiatrists, psychologists, and counsellors, and other frontline staff), but extended to those in welfare services (such staff at Centrelink, NDIA, and social workers), the justice system (legal services, police, lawyers, and the courts – especially relating to experiences of trauma and family violence), and workplaces generally. For example:

> *Knowledge and perception of Health Care Professionals when dealing with MH issues. I am TERRIFIED to bring something up because I always fear I will be misjudged, mistreated or not taken seriously* (**Our Turn to Speak** participant, Northern Territory).

> *…I think nurses and doctors in the emergency wards at hospital need to learn that just because I have a mental illness doesn't mean that I don't have a urgent physical issue* (**Our Turn to Speak** participant, New South Wales).

> *I think there's still work to be done with regards to implementing a trauma-informed/ trauma awareness approach to client care for mental health professionals, especially in situations such as psychiatric units, impatient units, and emergency departments* (**Our Turn to Speak** participant, Victoria).

> *..I was an emergency nurse for 13 years, and had to keep my bipolar silent as there is still lack of education. I would hear nurses during handover discuss patients who had bipolar, and say things like "they're off their meds so just be careful", or of patients with borderline personality disorder, "they're manipulative so be aware". Of suicidal patients "they're from ... so no one will care if they kill themselves", or "attention seeker"…* (**Our Turn to Speak** participant, South Australia).

> *Centrelink needs to have special trained staff to deal with Mental Health, and they also need to adjust their systems for DSP under that heading.*
> *If they had listened to the Drs, I would have been on DSP years ago. I would have received more funding and support and it is unlikely I would have descendent to quite the depths of depression and anxiety I have. I likely wouldn't have become homeless, which has added a whole mess of shrapnel to my already struggling mental health* (**Our Turn to Speak** participant, Victoria).

A few participants conveyed, furthermore, that increased education and understanding is needed with regards to working with people from diverse cultural backgrounds, communities, and intersectional experiences; including for instance, people who are Aboriginal and 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 are LGBTIQA+. As one participant explained, there is a need for:

> *Much more understanding of Aboriginal mental health - I can never get the point across that half of my illness is caused by disconnection from land & people* (**Our Turn to Speak** participant, Queensland).

Various participants discussed the need to increase understanding and reduce stigma for and among people in their support networks. Some suggestions included the following:

> *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* (**Our Turn to Speak** participant, New South Wales).
>
> *Simple, informative education for laypersons (family, friends etc) which give them an insight into the experiential difficulties of living life with trauma and mental illness. simplified definitions, examples and how to be with/help, practical ways they can help, what they can say/do* (**Our Turn to Speak** participant, Victoria).
>
> *Personally, my own family's lack of education in regards to my health issues and conditions have left me feeling very hurt, alone and abandoned. More needs to be done to help educate families who have members suffering and what to do in regards support and also offering regular information sessions and access to sites with up-to-date useful information on a multitude of mental health issues. Seeing as family will in most cases be a sufferer's main source of support and who they're around most, it makes sense to encourage more to be done in this area* (**Our Turn to Speak** participant, Victoria).

A few participants felt that more work is also needed to increase understanding within some religious communities:

> *People of faith need to come into the 21st century and understand that mental health isn't a "curse" because you "sinned", nor is it something you can just "get over"* (**Our Turn to Speak** participant, Queensland).

Many participants drew attention to the need for more awareness of different types and presentations of complex mental health issues – that is, beyond anxiety and depression. Examples of those that were specifically mentioned included BPD, OCD, DID, bipolar I and II, PTSD (including as it relates to the long-term impacts of family/intimate partner violence and childhood trauma and abuse), CPTSD, PMDD, schizophrenia, schizoaffective disorder, functional neurological disorder, and eating disorders. As two participants shared:

> *While the awareness surrounding depression is growing, which is fantastic, I still feel there is not enough for other illnesses. I was diagnosed with depression at age 12, but not with BPD until age 30. Although I had heard of BPD, I really had not idea what it was and had to go searching online for more information* (**Our Turn to Speak** participant, Tasmania).
>
> *I think understanding of anxiety and depression is improving because people are experiencing it more through greater life stressors. However, the more severe illnesses such as bipolar or schizophrenia are a long way off being understood*

> *because the stigma is so entrenched. These words, in my view, are associated with crazy and unpredictable. I don't know how this can be altered ... maybe if people just spend time with those who have been diagnosed?...* (**Our Turn to Speak** participant, Australian Capital Territory).

Some participants mentioned the need for more understanding with respect to treatment and recovery, for example:

> *People need to understand that for some people with mental illness their illness is treatment resistant, and it isn't their "fault"* (**Our Turn to Speak** participant, Western Australia).
>
> *My experience of bipolar was initially met by myself with denial. That lasted a long time largely because I had 'supporting' religious convictions. If there had been a general awareness that bipolar is a now treatable but longstanding part of human historical experience, and a greater understanding that treatment is not 'one drug fits all' or even 'one psychologist or psychiatrist is the same as the next', then I might have persisted early on in my search for help. If that awareness had been around in the past 12 months I probably would still have my marriage intact. It would also have protected me from some nefarious workplace behaviour…* (**Our Turn to Speak** participant, New South Wales).
>
> *…Some mental illnesses are chronic and will require years of treatment, if not lifelong treatment. If people are only informed of cases where people make a quick and full recovery, the people suffering from illness may have unrealistic expectations for their own recovery and may feel frustrated with themselves and think they are not trying hard enough to recover. Similarly for the people around them, they will hold people with illness to the standard of the recovery stories they have heard previously* (**Our Turn to Speak** participant, Queensland).

Lastly, some participants responded to the final survey question with what they felt needed to change within themselves to address self-stigma, and what might be conducive. Some identified a need to become more compassionate and accepting towards themselves; to improve self-perception and self-esteem; to be more trusting; to open up more with others; and for more support and education with regards to understanding mental health and building resilience:

> *…Education those with mental illness that it's not their fault or an inadequacy in them. I think there's a lot of self stigmatising, fear and shame perhaps thru lack of knowledge as well as symptoms of illness…* (**Our Turn to Speak** participant, Victoria).
>
> *Honestly - I think I need to change. I have so much compassion for ANYONE ELSE living with a mental health disorder, but I really struggle to apply that same compassion to myself* (**Our Turn to Speak** participant, New South Wales).

Communication and visibility

Communication and representation are key components in building understanding of complex mental health issues. Many participants commented on the importance of not perpetuating misinformation and stereotypes – such as that people with mental health issues are dangerous – and this includes representations in the media. For example:

> *A more realistic display in media of people with mental illness who are NOT hurting people, able to work and contribute to their community* (**Our Turn to Speak** participant, Victoria).
>
> *I find the media's portrayal of mental illness is very distressing. Every time there is a violent crime I brace myself for the inevitable assumptions about the perpetrator's mental health that will be made in the media. It almost never fails. There is no context provided. For example, if someone was high on the drug ice and experiencing a drug induced psychosis, the media will say something like, the perpetrator had a diagnosed mental illness. They should be providing detail such as, the perpetrator was in a drug induced psychosis. Failing to mention this is extremely detrimental to those of us with mental illness. It makes me retreat into my shell a little more every time, determined that no one will find out I have bipolar disorder for fear they will think I am dangerous… The media have an incredible amount of power to influence the perception the public have of people living with mental disorders. Society believes what the media tells them, particularly reputable news outlets. Without radical changes in this area, I don't have much hope that we will ever eradicate stigma and discrimination. That makes me incredibly sad and keeps me living with my mental illness in secret* (**Our Turn to Speak** participant, Victoria).
>
> *People need to remember we are human too. We are not monsters. The way we are portrayed in the media and on social media is disgusting. Especially for people with BPD, even within the mental health community, we are seen as less than human due to a diagnosis. Every person with BPD is an individual, we are not all the same* (**Our Turn to Speak** participant, New South Wales).
>
> *The Language used in the media is a major problem where headlines and text use mental health diagnosis in ways that reinforce myths, sterotypes, and stigma. Phrases like "Government schizophrenic on foreign policy" or similar are common, on the Parliament of Australia website there is an article titled "Constitutional Schizophrenia: Then and Now" Phrases and headlines like these only reinforce negative stereotypes and myths about people with mental health concerns same* (**Our Turn to Speak** participant, New South Wales).

As identified by participants, integral to dismantling stereotypes and promoting deeper understanding is increased visibility, representation, sharing of stories, and valuing the perspectives of people with lived experience; not just in the media (mass media, social media, and marketing/awareness-raising campaigns) but also in the workplace, training, health system, inclusive decision-making, co-design of services and programs, and through peer support roles in the workforce, to mention a few examples. To quote one participant: *"The voice of lived experience needs to be heard loud and clear in all the domains identified"* (**Our Turn to Speak** participant, South Australia). As others similarly shared:

> *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).

> *…If the general public saw how hard people who have a mental illness work to do everyday activities like studying or going to work, cleaning and keeping things tidy or keeping their medical program - I think there would be a lot of sympathy* (**Our Turn to Speak** participant, Northern Territory).
>
> *Being able to see all people of all walks of life... not just sporting stars but every day people. Teachers, doctors, accountants who are living through it every day. Helping people to understand the amount of work people with a mental illness do every week to get better and the cost both financially and personally it has. A greater understanding of the positive things that having a mental illness brings to the community- compassion, creativity, passion* (**Our Turn to Speak** participant, Victoria).
>
> *Instead of demonising those with it, devaluing them or seeing them as flawed, weak or incapable - respecting them, being equitable, not blaming them. Include us in the treatment, seek our involvement and wisdom. Listen to us. Consider that we know a lot, are intelligent and have the capacity to make decisions and manage our own lives* (**Our Turn to Speak** participant, Northern Territory).

Many participants drew attention to the importance of normalising mental health issues, so that it is understood as something that can affect anyone and does affect a great many people. Thus, many identified the need for more open conversation beginning from an early age and, in particular, taking place within schools and workplaces;

> *We need to keep talking about it and normalize it. We need to let everyone know that having a mental illness is not something to be ashamed of* (**Our Turn to Speak** participant, Victoria).
>
> *Clearer information about mental health issues to be taught throughout schools; I was told I had anger, attitude, substance or learning issues throughout my school experience which negatively impacted my journey in seeking solutions* (**Our Turn to Speak** participant, Victoria).
>
> *We all need to accept we all suffer from mental health issues. Some of us suffer lifetime symptoms* (**Our Turn to Speak** participant, Tasmania).
>
> *There needs to be more open discussion. There is still a lot of stigma related to mental illness and it's sad to think that a lot of people are silently suffering, afraid to speak out about their troubles or seek help because of it* (**Our Turn to Speak** participant, Western Australia).

Numerous participants also highlighted the importance of appropriate language and frameworks when it comes to discussing mental health issues. Some objected to the term ‘mental illness’ or ‘mentally ill’, for instance, while others did use those terms. Some participants also identified problematic terminology associated with particular disorders, or the medical model generally and pathologising language, emphasising approaches that are holistic, person-centred, and recognise social determinants and the social model of disability, for example:

> *Psychosocial disability should be re-framed within a social model of disability that recognises the key role played by social determinants in prevention, causation, and*

> *recovery. The biomedical approach to psychosocial disability has been and remains an abject failure* (**Our Turn to Speak** participant, New South Wales).

> *Ditch the separation between physical and mental health care, its all health care* (**Our Turn to Speak** participant, Victoria).

A related concern, here, was the need to approach mental health issues with the same regard as physical health issues, and to show the same respect. Some discussion involved specific contexts such as workplaces, clinics and hospitals, or reflected in government policy and funding, but many comments were of a more general nature; examples included:

> *Mental illness needs to be accepted as an illness, rather than something which is 'just inside your head'* (**Our Turn to Speak** participant, Tasmania).

> *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).

> *Mental health needs to be seen in the same light as physical health. It can affect anyone* (**Our Turn to Speak** participant, Western Australia).

> *I just want to be treated the same as i was before i was diagnosed with a mental illness,not spoken to as if i am all of a sudden not intelligent enough to know my needs* (**Our Turn to Speak** participant, New South Wales).

Another related issue concerned appropriate language regarding treatment and recovery, and not trivialising people's mental health journeys through casual jokes, comments, and supposed quick fixes; as conveyed :

> *For mental health to be considered like any physical illness. If I've broken my leg, you won't tell me to climb a flight of stairs. If I've got major treatment resistant depression, don't tell me to "snap out of it" or "get a good nights sleep"* (**Our Turn to Speak** participant, Victoria).

> *…People need to understand that having a mental health condition is not something we can just "get over". You wouldn't tell someone with a terminal or physical illness.. just get over it or just be happy…"* (**Our Turn to Speak** participant, Queensland).

> *People need to understand that going outside or going for a walk won't magically fix mental health. Saying these things to people is hurtful"* (**Our Turn to Speak** participant, Western Australia).

Lastly, numerous participants commented on the need for improved communication and leadership on mental health among government and policymakers to drive cultural change. Suggestions included things like more supportive language and attitudes; showing more empathy and less tokenism; engaging more with people who have mental health issues, and different types of mental health issues. Some examples of comments here were as follows:

> *The language and attitudes of Government and all of it's agencies and systems. Stop "doing to" and start "doing with"* (**Our Turn to Speak** participant, South Australia).

> *Less blame by politicians/media and more funding into mental health places so people can afford help* (**Our Turn to Speak** participant, Western Australia).
>
> *Actually prioritise mental health issues and see them as societal issues, not always following the medical model of the problem lying within the individual. Need to stop victim blaming. We need action and funding, not more useless talk from politicians who have no intention of actually addressing individuals' needs, wants and passions to re-engage in their lives in whatever way they choose! (***Our Turn to Speak** participant, Victoria*).*
>
> *Our government's language and stances against welfare recipients or "a fair go for those who have a go" are also damaging. We don't all start on a level playing field - especially not in the case of complex trauma…* (**Our Turn to Speak** participant, Queensland).
>
> *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).

Accessible services, fair treatment, and support

Many participants discussed the need for more accessible services, fair treatment, and to reduce barriers – not just in regards to mental health and welfare support, but also affordable housing, educational institutions, legal institutions, insurance, as well as employment. One participant captured this as follows:

> *…Removing stigma so that mentally ill people can seek treatment. I am discriminated against and at risk in the legal, insurance and other arenas if I admit to mental health issues. E.g. my mental health issues can be used against me in court. I have been denied insurance cover due to mental illness. It affects my employability. My record precedes me in referrals from my GP to other specialists…"* (**Our Turn to Speak** participant, New South Wales).

Another described the *"vicious cycle"* in attempting to access support as such:

> *…I am often told I am "not sick enough" or "too sick" for any help. So I live in a situation where I don't get the help I need until it's too late and I am passed the point of help. In which I then get attacked for not getting help sooner and that there are no services that will take someone as ill as me. It can be a vicious cycle filled with a lot of stigma that I am either not doing enough or I am demanding too much… It's like I am not good enough unless I somehow am cured and act "normal." I just wish I was treated like someone who is ill, rather then someone who isn't trying hard enough. I am doing the best I can, and yet it is never enough. I feel incredibly alone and isolated from the help I need* (**Our Turn to Speak** participant, New South Wales).

A critical aspect of increasing the accessibility of health and welfare services is providing more affordable care; many participants commented on financial barriers to receiving adequate care and the inadequate number of subsidised sessions through mental health care plans. For example:

> *Providing affordable access to programs for those who are in the "grey zones"- too well for hospital and too sick to be normal* (**Our Turn to Speak** participant, Victoria).
>
> *Better access to psychologist. I got a mental health care plan but the gap is still between$70-over $100. With my extensive mental health concerns I need to see someone weekly and I am unable to do so. I have had to put my name down to a completely bulk billing psychologist but they don't have any appointments until March next year. My concern is that I will get worse before then. I really want help I just can't afford it (***Our Turn to Speak** participant, Queensland*).*
>
> *It's a long journey...also I live in a rural area. So practitioners are very conservative and often ignorant.Access to adequate services is a about four hours away. Any support accessed means time off work, and travel. This makes it inaccessible, and especially costly. It is not adequate"* (**Our Turn to Speak** participant, Victoria).

Many participants commented, moreover, on the need to reduce barriers to accessing welfare support, including the need for improved access to information about the kinds of support available:

> *The NDIS needs to be more accessible for those that are needing support or something needs to be put in place to support those who do not meet the NDIS criteria. Linking people who do not meet the NDIS criteria with only emergency relief contacts is not helpful, more needs to be done to prevent people who need support from having to rely on emergency relief solutions. More support is needed to help people with mental health issues to apply for the services they need. Filling out forms can be problematic especially if this is triggering symptoms"* (**Our Turn to Speak** participant, Western Australia).
>
> *…I also think that Centrelink need to understand that you should be allowed to study and apply for DSP at the same time. It's impossible for me to study and work and I find studying very difficult, but I need to study at least 75% of full time to get Austudy, but it's impossible for me live off of Austudy, especially because I can't work. I want to be able to at least continue studying somewhat, but I wouldn't be able to get DSP. Mental health severely affects me, and DSP needs to be more accessible and empower people* (**Our Turn to Speak** participant, Western Australia).
>
> *Centrelink and the NDIS need to change. Treating people like criminals and bludgers isn't helpful for mentally ill people. Trying to cut support, rather than offer it (when the entire point of the organisation is to support people in need) isn't helpful* (**Our Turn to Speak** participant, Queensland).

Many called for increased funding to provide more services and appropriate responses – with reduced waiting periods – for people experiencing mental health issues (as well as other issues such as homelessness, substance use issues, unemployment, family violence, legal issues, and physical health or disability) and effectively to reduce the gap between public and private systems. A few also mentioned funding for mental health research. One participant captured the importance of increased funding as follows:

> *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. My answers in this survey don't reflect it because they only look at the last twelve months, which have been very*

> *stable for me, but over the course of my Bipolar 1 Disorder I have experienced episodes of severe psychosis, mania, and catatonic depression. I have spent months in hospital and in addition to needing a lot of medication have needed ECT courses at different times to get me better. I see my psychiatrist and psychologist regularly. I exercise and live a healthy life style. I have functional happy relationships with my husband and children. I have been as sick as you can get and I have gotten better every time. And the only thing that has saved me from the collateral damage (of relationship breakdown, loss of employment, loss of housing, possibly substance abuse as self medication), that symptoms such as mania and psychosis often drag with them, is my private health insurance and access to the best mental health care there is. My early rapid diagnosis and appropriate treatment has meant, I could just concentrate on getting better and managing the illness rather than having to haemorrhage energy on fighting stigma. The only way we will eliminate stigma surrounding mental illness is to allow everyone access to the level of care I have been fortunate to access, regardless of their income or socioeconomic status* (**Our Turn to Speak** participant, Queensland).

With regards to the need for more services and appropriate responses, participants' suggestions included:

- More hospital beds
- PARCs
- Early intervention services
- Post-crisis services
- Post-discharge and after-hours support
- Longer-term support and facilities
- Services and targeted awareness-raising programs in rural, regional, and remote areas
- Online options like telehealth programs and services
- Respite services and support programs for carers
- Programs to provide social support and to help navigate not just the mental health system, but other aspects of day-to-day life such as access to meals, groceries and transport.

Other suggestions included improved coordination and integration of multi-disciplinary and multi-agency services, and ending involuntary treatment orders under the *Mental Health Act (2014)*. Several participants also shared their concerns about an emphasis on medication-based treatments prescribed by health professionals, including over-medication. As one participant suggested;

> *People need to be assessed holistically and not given a label and medicated* (**Our Turn to Speak** participant, Tasmania).

As mentioned, the importance of reducing barriers to gaining and maintaining employment was raised by many participants. Numerous suggestions were made, including:

- Hiring more people with a lived experience of complex mental health issues
- Increasing peer-support worker roles
- Increasing accountability of employers when mental health issues are disclosed during job interviews
- Mental health training to increase understanding in workplaces
- Creating workplace cultures where people feel comfortable asking for leave and time off for mental health-related appointments
- Greater recognition and appreciation of individual strengths

- Establishing mental health days as a form of leave
- More flexible working arrangements and polices that are accommodating of people experiencing mental health issues (including leave, hours worked, and other entitlements)
- More assistance in planning for mental health impacts, recovery, and returning to work
- Providing more support for workplace injuries involving mental health
- Prioritising mental health in business planning
- Including impacts of the workplace on mental health in regular reporting and evaluations
- Approaching mental health issues with the same level of support as physical health issues.

The following comments capture some of these ideas and concerns:

> *…I take my annual leave when I am unwell because of the stigma and attitude of employer if I am taking sick leave when they can't "see" that I'm sick. The company forces us to take a week minimum leave at Christmas, so I struggle to have enough days available to manage my illness. My GP wants me to take more sick leave but because of the stigma, I can't. So I rarely take a holiday, not enough leave. Coworkers routinely discuss 'mental ', 'psycho', 'nutcases' and often any suggestion of a real illness is laughed away because mental illness is just bullshit, the people should just get off their backside. I am a professional with years of experience in the health industry and in the IT industry. The only way to survive is to not let people know…* (**Our Turn to Speak** participant, Victoria).
>
> *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).
>
> *…Rather than looking at me as a liability or my deficits my employer, supervisors and colleagues should recognise my ability to get better, do my job well and the unique understanding I bring to the workplace… (***Our Turn to Speak** participant, South Australia).
>
> *I am very lucky that my employer is extremely understanding. The idea of a back to work plan for a non-physical injury is not common place and it has been very helpful to get the most capacity from me* (**Our Turn to Speak** participant, Victoria).

A final area that will be mentioned, which a few participants commented on, was the issue of isolation and the need to increase opportunities for connection, including through more discussion, groups, and other gatherings:

> *I find it very difficult to make friends and keep friends due to feelings of worthlessness. I find it really hard to enjoy life and love myself. I think we need to be taught these things. a group. would be great . to support and encourage each other* (**Our Turn to Speak** participant, Victoria).
>
> *There needs to be more community gatherings for those who feel like me, or at least more advertisement for gatherings. It'd be nice to meet others who I know can relate to me (***Our Turn to Speak** participant, Australian Capital Territory).

Or, as one participant put it, *“Having people walk the journey with you”* (**Our Turn to Speak** participant, South Australia).

SUMMARY

This chapter has discussed some key themes arising from participant responses to the final survey question as to what most needs to change. Three overarching themes were identified, including education, understanding, and acceptance; communication and visibility; and accessible services, fair treatment, and support.

Within the theme of **education, understanding, and acceptance** many participants commented on the need to increase mental health and trauma-informed training and address negative attitudes among workers, especially in health services, but also in welfare services, the justice system, and workplaces generally. Some participants identified the need for increased awareness and acceptance among people in their support networks (such as family and friends) and faith groups. Some also highlighted the need for deeper understanding of working with people from diverse backgrounds and communities. Another sub-theme, here, concerned the need for greater awareness of different types and presentations of complex mental health issues. Finally, some participants focused on self-stigma, and what they felt needed to change to increase self-compassion.

Within the overarching theme of **communication and visibility**, the importance of not perpetuating problematic stereotypes and misinformation – especially through media portrayals – was discussed. Participants also emphasised greater visibility, representation, sharing of stories, and valuing the perspectives of people with lived experience of complex mental health issues across society. Improving communication and visibility included, moreover, normalising mental health issues (recognising as something that many people are affected by), and promoting more open conversation from an early age – starting in schools and continuing right through to workplaces, for instance. The use of appropriate language and frameworks for discussing complex mental health issues was a further focus and, in particular, the importance of approaching mental health issues holistically and with the same respect as physical health issues. Participants also called for improved communication and leadership on mental health among government and policymakers.

The third overarching theme included **accessible services, fair treatment, and support**. Discussion, here, included a strong focus on the currently inadequate number of subsidised sessions available to people with complex mental health issues, and need for increased funding to provide more affordable mental health care, as well as the need to reduce barriers to welfare support. Many participants identified that more services and appropriate responses are needed, and provided various suggestions as to what this should entail – more hospital beds; longer-term support; post-crisis, post-discharge, and after-hours support; social programs, and targeted awareness-raising in rural/regional/remote areas being a few examples. Another significant area that participants felt needed to change included reducing barriers to gaining and maintaining employment. Again, various suggestions were provided; a few examples were employing more people with lived experience; increasing peer support worker roles; more mental health training; creating more supportive workplace environments where people feel comfortable discussing mental health and asking for leave and, as previously mentioned, approaching mental health issues in the workplace with the same level of support as physical health issues. A final area discussed was the need for more support to reduce isolation and increase opportunities for connection.

People living with complex mental health issues have keen interest in informing solutions to reducing stigma and discrimination. Indeed, 84.2% of participants freely chose to contribute to this optional final question in the survey. Their unconstrained contributions, summarised here, present valuable insights into the numerous ways in which stigma affects people living with complex mental health issues, and where equally abundant solutions may lie. It is important to note that these insights are unique and come with a particular expertise that is gained only through lived experience. It is therefore vital that people living with complex mental health issues play a central role in the design, development, implementation and governance of stigma reduction initiatives if they are likely to be successful.

SUMMARY AND CONCLUSION

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Chapter 19. Summary and conclusion

SUMMARY OF FINDINGS

The findings presented in this report clearly demonstrate that stigma and discrimination are everpresent issues affecting the lives of Australians who live with complex mental health issues. This final chapter explores some of the primary themes that have emerged from the **Our Turn to Speak** data in terms of experiences and anticipation of stigma and discrimination, withdrawal from opportunity, impact and frequency of stigma of discrimination, intersectional stigma, positive experiences, and what participants thought most needed to change to reduce stigma and improve the lives of people living with complex mental health issues. The chapter then goes on to discuss the contributions and limitations of the current study and what is yet to come for the **National Stigma Report Card**.

Throughout the findings presented, experiences of stigma and discrimination were regularly observed alongside participants' anxious anticipation of similar, future experiences and withdrawal from opportunities across life. In fact, in 12 of the 14 life domains investigated, rates of agreement for survey items describing anticipation of stigma were higher than those for perceived experiences. Further, in 10 life domains investigated, the highest overall rates of agreement with survey statements were seen in response to items describing withdrawal from opportunities. At a high level, these findings therefore speak not only to a pervasive pattern of perceived experiences of stigma and discrimination. They also speak to a ubiquitous experience of worry about stigma and discrimination, and the avoidance of potentially negative circumstances through self-denial of important life opportunities.

Overall, the rate of perceived experiences of stigma and discrimination reported by participants was high. In the relationships domain, 95.6% of responding participants indicated that they had experienced some level of stigma and discrimination in the past 12 months. Physical healthcare services and social media were other life domains where some level of stigma and discrimination was particularly widespread. Most commonly, more than half of all participants indicated that they had been subject to some level of negative experience in each of the 14 life domains because of stigma about mental health issues. The life domain of least common concern was legal and justice services; however, it is noteworthy that 37.3% of the participants still reported some level of stigma and discrimination in this area. The results collectively demonstrate that stigma and discrimination are pervasive for people living with complex mental health issues. Indeed, based on the consistency of negative experiences observed here, it is likely that stigma and discrimination is an issue in other areas of life not investigated by the **Our Turn to Speak** survey for people living with complex mental health issues.

Perceived experiences of stigma and discrimination were not only ubiquitous, but also *frequent*. Again, relationships were identified as the primary life domain in which 'frequent' or 'very frequent' stigma and discrimination occurred, with 46.4% of participants reporting such experiences. Mass media – and again, social media – were also identified as areas of life in which participants experienced 'frequent' or 'very frequent' stigma and discrimination. Rates of frequent experience were otherwise largely variable across the other life domains investigated by the **Our Turn to Speak** survey; and while experienced to a relatively lesser average frequency in areas such as sports, community groups and volunteering, or housing and homelessness services, significant proportions of participants reported these issues, nonetheless.

Participants also informed our understanding of the *impact* of stigma and discrimination across their lives. Again, relationships were the primary concern for participants. In total, 69.1% of participants indicated that relationships were one of the three life domains in which they had been most affected by stigma and discrimination in the preceding 12 months. Next, employment was identified by 43.0% of the participants to be another such area of personal impact, followed by physical healthcare. Slightly lower but comparable rates of agreed personal impact were observed for social media, mental healthcare services, and mass media. Impactful experiences of stigma and discrimination were reported by fewer participants in the remaining life domains. Again, it should be noted that even for the relatively least often endorsed areas, namely, legal and justice services, the issues described therein were meaningful and of particular personal impact for those particiapnts reporting them.

When considering participants reports of perceived and anticipated experiences of stigma and discrimination across the 14 life domains investigated, two noteworthy latent themes emerge. The first such theme is interpersonal stigma and discrimination. Interpersonal stigma and discrimination regarding complex mental health issues was most obviously observed in regarding relationships settings such as family, friendships, intimate partners and parenting or caregiving. The importance of psychosocial support that can obtained from nurturing relationships for people with complex mental health issues cannot be understated. Supportive relationships are a key factor in preventing relapse and promoting recovery (Tew et al., 2012). Equally, critical or discriminatory relationship settings are well established to act as psychosocial stressors and are predictive of relapse for people living with conditions such as schizophrenia (Butzlaff & Hooley, 1998). The current results are therefore of critical importance and underline that interpersonal relationships should be an important target for any comprehensive stigma-reduction initiative for people living with complex mental health issues.

Evidence of problematic interpersonal dynamics can be further observed across most of the 14 life domains investigated. These data, present here in the accounts of people with lived experience, likely reflect footprints of widespread public stigma about complex mental health issues. Public stigma refers to negative stereotyped attitudes, and prejudicial emotional and discriminatory behavioural responses that the general public may display towards people living with complex mental health issues (Fox et al., 2017).

Negative stereotypes such as dangerousness and unpredictability have long been attached to complex mental health conditions such as schizophrenia (Star, 1955). International evidence suggests that while public attitudes and intended behaviour towards high prevalence and better understood conditions like depression have improved in recent decades, responses to complex mental health issues have not, and in fact, are likely to have become worse (Pescosolido et al., 2010). These phenomena extend not only to the general public, but also to mental health professionals (Stuber et al., 2014) and beyond. Public stigma is likely to permeate culture, and shape and maintain wide ranging responses to people living with complex mental health issues, including structural or institutional stigma (Link et al., 2011).

The second latent theme running through the current findings is that of *structural* or *institutional* stigma. Strutural stigma manifests in terms of discriminatory policies, laws, and institutional practices that serve to marginalise and block opportunities for people living with complex mental health issues (Fox et al., 2017). This aspect of stigma is said to manifest both intentionally and unintentionally (Corrigan et al., 2004). **Our Turn to Speak** found clear evidence that Australians living with complex mental health issues are affected by structural stigma at both of these levels.

Participants' responses to statements and qualitative data provided evidence of the effects of intentional structural stigma across numerous life domains. For example, some of the highest levels of agreement were observed for survey items describing having seen, read or heard mass media news stories that stigmatised people with complex mental health issues. Systematic, sensationalised and decontextualised news media representations of people with schizophrenia, for example, are often conceptualised as an example of intentional structural stigma (Corrigan et al., 2004).

The current findings, especially that describing experiences of stigma and discrimination from the mental healthcare services, physical healthcare services, and welfare and social services survey domains, show clear evidence of unintentional structural stigma as regards mental healthcare system funding and in particular, the National Disability Insurance Scheme (NDIS). Professor Pat McGorry (University of Melbourne) coined the term "missing middle" to describe the unintentionally discriminatory distribution of government funding across the Australian and Victorian mental health systems (McGorry, 2019). From this perspective, the current spread of funding and system of access can be conceptualised as being geared towards addressing mild to moderate high prevalence disorders such as anxiety and depression in particular, and in turn, unintentionally providing insufficient resources for Australians living with complex mental health issues.

The current findings highlight that complex mental health issues were not the only subject of stigma experienced across life for participants. Across the 14 domains of life, participants indicated that they had experienced a range of areas of *intersectional* stigma and discrimination. Here, participants described problems they had experienced that were associated with personal characteristics other than complex mental health issues yet interplayed, compounded or were experienced in addition to stigma about those mental health issues. The findings presented in this report demonstrated that intersectional issues also extended beyond experiences to anticipation of stigma and discrimination and withdrawal from opportunities across life.

Participants' physical health or ability was observed to the primary intersectional concern across the breadth of our quantitative investigation. The qualitative data provided by participants contextualised these findings further, with weight stigma being identified as a core theme. The pervasive and impactful experience of weight stigma observed here is of particular concern for two chief reasons. First, it is well established that weight management is a common problem for people who live with complex mental health issues, such as schizophrenia (Bradshaw & Mairs, 2014). These weight management issues are frequently linked both to mental health issues and treatment factors. Given the numerous metabolic conditions and reduced life expectancy associated with being overweight or obese, it is imperative that people affected who also live with complex mental health issues have good access to physical health services. Yet, the findings presented here highlight that physical healthcare services are a key area in which Australians living with complex mental health issues experience and anticipate stigma, and withdraw from helpseeking. Secondly, there is considerable evidence demonstrating strong links between weight stigma and poor mental health (Emmer et al., 2020). Problematically, while effective help can be found through professional supports, the current findings also speak to both weight stigma and stigma about complex mental health issues as being a barrier to accessing support from mental health services. Collectively, then, the findings presented here portray a concerning and vicious interplay of mental health, physical health, and stigma and discrimination, and underscore that futher investigation into this intersection is undertaken as a matter of priority for Australians living with complex mental health issues.

Participants also raised concerns regarding intersectional stigma and a range of other personal characteristics. Gender identity, sexual orientation, racial and cultural background, and faith or spiritual beliefs were areas of intersectional stigma for many participants. For example, some Aboriginal and/or Torres Strait Islander participants idenitied their racial and cultural background as an intersectional area of stigma and discrimination in numerous life domains. Of note, one important theme was that dominant clinical conceptualisations of complex mental health issues and mental health service frameworks themselves can be considered discriminatory. One participant astutely observed that Aboriginal understandings of mental health issues are not commonly known or applied in mental health services. It can be taken from their commentary that an inclusive Australian mental health system is one that, at a minimum, respectfully incorporates notions such as disconnection from land and from people as being central to the experience of complex mental health issues for Aboriginal and/or Torres Strait Islander people, into the provision of support, assessment and treatment.

While this first iteration of **Our Turn to Speak** was developed in consultation with representatives of various communities including Aboriginal and Torres Strait Islander communities, it is important to note that this represents a preliminary step in a process. Upcoming work is planned within the **National Stigma Report Card** program, which will hinge upon being further guided by Aboriginal and/or Torres Strait Islander people, and people of other communities including those identifying as CALD and LGBTI+, to further develop culturally competent methods of inquiry into stigma and discrimination about complex mental health problems and intersectional issues.

In addition to the ubiquitous experiences of stigma and discrimination reported across life domains, many participants indicated that they had also experienced positive treatment because of their complex mental health issues. While rates of average agreement with negative experiences exceeded those for positive experiences most commonly, it was encouraging to observe that positive experience regarding participants' complex mental health issues were reported across all of the life domains investigated. Indeed, in some instances such as social media and public and recreational spaces, the rates of positive experience were greater than those reported for negative experiences. Again, the qualitative data provided valuable context throughout as regards actual and desired positive experiences, and highlighted that participants' holistic experiences in each life domain incorporated a dynamic interplay of stressors and supportive factors. While we have reported descriptive statistics and thematic analyses in this report, upcoming scientific reports in the **National Stigma Report Card** program will further interrogate the **Our Turn to Speak** data with inferential statistical procedures. These further investigations will allow us to better understand the deleterious effects of stigma and discrimination, the buffering effects of positive experiences, and how these collectively influence participants' complex mental health issues and life experiences.

The findings of the **Our Turn to Speak** survey identified a broad range of critical issues that must be addressed to reduce stigma and discrimination and improve the life experiences of Australians living with complex mental health issues. In the final question of the survey, we asked participants to tell us what they thought most needed to change to achieve these goals. Three overarching themes were identified in this feedback, including:

1. education, understanding, and acceptance
2. communication and visibility
3. accessible services, fair treatment, and support.

The feedback provided as regards potential solutions to stigma and discrimination was rich and demonstrated that valuable insights are often possible only through lived experience of complex mental health issues and related stigma and discrimination.

LIMITATIONS

The reader of this report should be aware of the context and limitations of the current study, and in particular, as they relate to generalisability. The data presented in this report should not be taken to infer population prevalence regarding the issues investigated. An epidemiological approach to sampling was beyond the scope of the **Our Turn to Speak** survey. Moreover, such an approach did not neatly fit with the aims of the study.

Given these limitations, the reader should consider the sociodemographic and mental health sample descriptions provided throughout this report, and the comparisons with larger, more representative groups of the Australian population, as discussed in Chapter 2 (Methodology and Participants). Of particular note is the underrepresentation of males among the **Our Turn to Speak** participants. In terms of mental health characterstics, the primary limitation that should be noted is that, those participants who completed the survey online (rather than by telephone or face-to-face interview) may, on average, best represent the Australians living with complex mental health issues who experience higher functioning or greater psychosocial recovery. Moreover, the statistical approach taken in this report has been purely descriptive. In other words, our strategy here has exclusively been to describe the data submitted by participants.

While theoretical relationships have been posed throughout the survey, and the findings for issues such as experienced stigma and discrimination, anticipated stigma and discrimination, and withdrawal from life opportunities have been described, the relationships between these different facets of stigma and discrimination have not been tested here. Nor have we yet tested relationships between the particular sociodemographic or mental health characteristics of participants and experiences of stigma and discrimination. Statistical examination of these hypothetical relationships will be reported in upcoming peer-reviewed scientific publications. We hope that the information provided within this report will assist each reader in forming thoughts regarding the meaning of the current findings and the degree to which they are generalisable to the broader population of Australians living with complex mental health issues.

CONTRIBUTIONS OF OUR TURN TO SPEAK

The **Our Turn to Speak** survey and **National Stigma Report Card** have provided a range of valuable contributions. In terms of methodology, the project and survey are the first of their kind in Australia to focus on unpacking the experience of stigma and discrimination for people with complex mental health issues in such a holistic manner. In addition to the description of the survey development, implementation, and findings provided here, upcoming scientific papers will provide further details of the survey's development, and the central role that people with lived experience played throughout this process. These papers will also provide details of the survey's psychometric properties based on responses from the current sample. It is hoped that these tools will support replication and extension of the **Our Turn to Speak** survey, within Australia and internationally, and a research framework that is founded upon both best scientific practice *and* meaningful input from people living with complex mental health issues.

Our Turn to Speak has yielded comprehensive data on how Australians living with complex mental health issues have been affected by stigma and discrimination across their lives. While the data have been reported descriptively in this report, further iterations of reporting are planned during the next phases of the **National Stigma Report Card** project. In addition to the methodological papers described, numerous reports focusing on inferential quantitative analysis and further qualitative analysis of the data are already in development, and will be published through a scientific peer-review process. These resources will be made freely available on the **National Stigma Report Card** website in due course.

This research reported in this report represents just the first Australia-wide study of the **National Stigma Report Card** project. In addition to contributing data to this survey, 88.5% of participants consented to receive information about future similar studies and participation opportunities, such as further iterations of the **Our Turn to Speak** survey. It is our hope that many of our much-valued participants will once again contribute their expertise, experiences and stories in the future, as part of a longitudinal cohort study. This will enable us to assess evidence for changes in stigma and discrimination that may occur across life domains for Australians living with complex mental health issues, over time.

CONCLUSION

The **Our Turn to Speak** survey and the findings presented here represent an important step in understanding how stigma and discrimination affect Australians who live with complex mental health issues. The significance of these findings cannot be understated. Indeed, the undeniably authentic and moving stories that participants have contributed do more than inform us, they compel us to act.

The **National Stigma Report Card** team have produced an additional dedicated document: *Recommendations for Action from the **Our Turn to Speak** Survey: Ensuring people living with complex mental health issues can live a life free from stigma and discrimination*.

You can read more about these recommendations for action at www.nationalstigmareportcard.com.au.

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Glossary

Anticipated stigma	The extent to which an individual expects to be the target of stereotypes, prejudice, or discrimination in the future.
Bot	A software application that is programmed to take a particular course of action automatically.
Carer	A family member or friend who helps a person living with a complex mental health issue.
Complex mental health issue	Experiences which encompass: complex mental illness, complex trauma or high levels of psychological distress.
Complex mental illness	A mental disorder which has a significant and debilitating impact on an individual's wellbeing and functioning.
Complex trauma	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.
Delphi technique	A process used to arrive at a group opinion or decision by surveying a panel of people with lived or learnt expertise.
Discrimination	Unfair or unjust behaviours directed at people experiencing complex mental health issues (Allport, 1954; Brewer, 2007).
Institutional Stigma	Also known as structural stigma. See below.
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 Dictionary).
People affected by complex mental health issues	Individuals who themselves experience, or support someone experiencing, a complex mental health issue.
Perceived stigma	How the individual thinks most people or the society view them personally as a member of the stigmatised group.
Prejudice:	emotional reaction or feelings that people have toward a group or member of a group (Stangor, 2009).
Public stigma	General public's reaction to people who have been diagnosed with a mental illness and consists of three

	components: stereotypes, prejudice, and discrimination (Corrigan, Mueser, Bond, Drake, & Solomon, 2008).
Self-stigma	The extent to which people endorse the negative beliefs and feelings associated with the stigmatized identity for the self. This is sometimes known as internalised stigma.
Stereotype	Beliefs or 'cognitive schemas' about the characteristics and behaviours of groups of individuals.
Stigma	Stigma describes negative and damaging stereotyped ideas and emotional responses relating to the experience of complex mental health issues, with the central theme being that one 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.

NATIONAL STIGMA REPORT CARD

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