

THE SCOTTISH MENTAL ILLNESS STIGMA STUDY

Final report • September 2022

Produced through a partnership involving:





See Me is Scotland's national programme to end mental health stigma and discrimination. Our vision is for a fair and inclusive Scotland, free from mental health stigma and discrimination. We work to change negative attitudes, behaviours and cultures towards mental health. The programme is funded by Scottish Government, guided by people with lived experience and managed by Scottish Association for Mental Health (SAMH) and the Mental Health Foundation.



The Mental Health Foundation is the UK's leading charity for everyone's mental health. Its vision is for a world with good mental health for all. With prevention at the heart of what we do, we drive change towards a mentally healthy society for all, and support communities, families and individuals to live mentally healthier lives, with a particular focus on those at greatest risk.



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The Lines Between is a social research agency with expertise in accessible and engaging research and evaluation activity. We believe robust research and evaluation can achieve powerful positive change, particularly for communities and marginalised groups.

Acknowledgements

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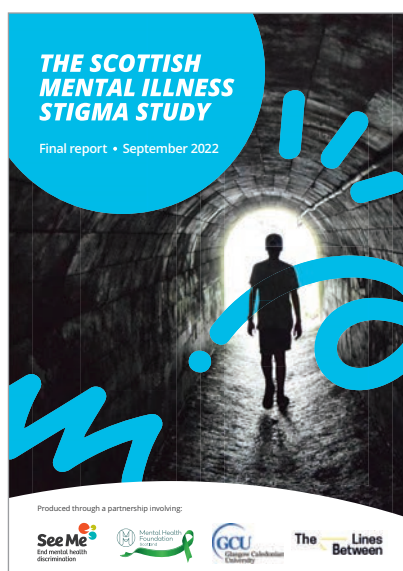
We owe a huge amount of gratitude to the members of the **Lived Experience Working Group** that included VOX members and See Me volunteers for consistently feeding into the research process, including development and testing of the survey, support with participant recruitment and openly sharing their own stories of stigma and discrimination, ensuring that the study has involved voices of lived experience. Without their input, this research would not have been as meaningful as it is. Individual members of the Lived Experience Working Group can be found in Appendix 5.

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Foreword

When preparing our strategy [With Fairness In Mind \(2021-2026\)](#) much of the data available for review described improvements in attitudes and behaviours towards people living with common mental health problems. Whilst this marks good progress for the challenge to end stigma in Scotland, our review also showed that this positive trend is not universal. Data and personal testimony describes that people living with complex mental conditions continue to experience stigma and discrimination. To understand more about the stigma affecting people living with mental illness and to gather views about what actions would make a difference, we commissioned this study. As a first of its kind to take place in Scotland it draws on pioneering research carried out in Australia. Almost 350 people completed the survey and 70 participated in interviews and focus groups, providing us with the clearest picture we have ever had of the types of stigma and discrimination people with severe, complex and enduring mental illness experience.

We found that people who experience mental illness face some of the most pervasive forms of stigma and discrimination in nearly all areas of their lives, and the impact of this can be devastating. The study shows the impact of self stigma, where people describe how they withdraw from the things most of us take for granted and need to feel happy. It highlights the negative impact of public stigma, and describes how stigma within relationships can adversely impact on intimate and family relationships and friendships. It brings into stark focus the impact of structural stigma and discrimination in work, mental health, health care and other life areas.

Although the study reinforces some long standing exclusion and social justice issues, I believe it gives us all an opportunity to take stock of what has been achieved, share learning from what works (or doesn't), share what is in place to address some of the issues raised and agree what steps we need to take now to make a lasting difference. It is time for concerted, collaborative action; with lived experience at the centre. We need to raise awareness of the ways that the stigma experienced creates a social, economic and health divide for many people who live with mental illness; and drive forward change to address this inequity.

Through combining our efforts, we can directly challenge the negative attitudes and prejudice that many people in Scotland continue to hold. We can raise awareness, understanding, and empathy surrounding mental illness and work to create environments, services and sources of support that are welcoming, compassionate, inclusive and fair.

Special thanks go to everyone who took part in this study; it can be challenging to talk about personal experiences of stigma and discrimination. We all have a duty to act on what people have told us. This is our time to come together, to act and make a difference towards ending stigma surrounding mental illness.

Wendy Halliday
Director, See Me

Executive summary

Overview

There is a growing appreciation that mental health exists on a spectrum, that mental health fluctuates and anyone can experience mental health problems. Despite this, the findings from this research indicate that stigma toward those living with mental illness endures across many areas of life.

The Scottish Mental Illness Stigma Study (SMISS) aimed to identify the experiences of stigma and discrimination faced by people who reported living with severe, complex and/or enduring mental illness in Scotland. It was inspired by the Australian National Stigma Report Card.

SMISS was commissioned by and carried out on behalf of See Me, Scotland's national anti-stigma programme, in partnership with the Mental Health Foundation (MHF) Scotland, Glasgow Caledonian University (School of Health and Life Sciences) and The Lines Between.

This first-of-its-kind research in Scotland aimed to answer the following questions:

- In what areas of life do people living with severe, complex and/or enduring mental illness experience stigma and discrimination and to what extent?
- What is the nature of the stigma and discrimination they experience?
- Which groups experience the most mental health stigma and discrimination, and in what life areas?
- How does the awareness, experience and anticipation of stigma and discrimination affect the lives of people living with severe, complex and/or enduring mental illness?
- What needs to change to improve people's experiences of living with severe, complex and/or enduring mental illness, and to reduce stigma and discrimination?

Adults in Scotland who identified as living with severe, complex and/or enduring mental illness were encouraged to participate in the survey to describe the ways in which they experienced stigma and discrimination in the last 12 months. The survey ran between 26th November 2021 and 7th March 2022 and received 346 eligible responses. Most responses were submitted online; and there were ten supported telephone/video call survey completions.

This study draws from the Our Turn to Speak survey developed by SANE Australia's Anne Deveson Research Centre, the Melbourne School of Psychological Sciences (University of Melbourne) and the Paul Ramsay Foundation. Ethical approval for the study was obtained from Glasgow Caledonian University's School of Health and Life Sciences Research Ethics Committee.

Core survey questions covered participants' sociodemographic characteristics, attitudes towards mental health and experiences of stigma and discrimination across 14 life areas (detailed in full in

Appendix 1), including employment, relationships and mental healthcare services. Respondents were asked to select the three life areas in which they had experienced the most significant impact of stigma and discrimination and asked detailed questions on:

- Perceived experiences of past stigma and discrimination.
- Anticipated future experiences of stigma and discrimination.
- Withdrawal from opportunities relevant to that life area because of stigma about mental illness.
- Experiences of positive treatment relating to living with complex mental illness.
- Intersectional experiences of stigma and discrimination.

Qualitative research was undertaken to add depth to the survey findings. This involved engaging with a sample of people who responded to the survey to gather additional insights into key aspects of the survey findings and with groups that were under-represented in the survey to explore their experiences of stigma and discrimination and understand the extent to which they aligned with the overall survey findings.

Themes explored through the qualitative research included gaining additional insight into key survey findings and further understanding of the experiences of groups under-represented in the survey including people aged over 65, people from Black, Asian and minority ethnic communities and men. People were offered the opportunity to take part in focus groups or individual discussions, either in-person or online.

Key findings

Research question 1: In what areas of life do people living with severe, complex and/or enduring mental illness experience stigma and discrimination and to what extent?

Experiences of stigma and discrimination span every life area explored in the survey, including personal, public and professional spheres. While each person's experience is unique, and the frequency and impact of stigma and discrimination related to mental illness vary by individual, the findings demonstrate that stigma and discrimination are found across many aspects of a person's life. The life areas where stigma and discrimination were reported to be experienced most frequently were relationships with family and friends, physical healthcare services, social media, mental healthcare services and mass media.

The five life areas where stigma and discrimination were reported to have the greatest impact differed slightly from the life areas where they were experienced most frequently. The life areas where stigma and discrimination were reported to have the most impact were relationships with family and friends, employment, mental healthcare services, healthcare services and social media.

Examples of stigma and discrimination respondents shared included rejection by family members and romantic partners, being made to take early retirement or redundancy, being made to take medication against their will, feeling ignored and/or having views and opinions dismissed in GP and mental health settings, and facing barriers to accessing welfare and housing support.

While the research paints a stark picture of stigma and discrimination being experienced across every life area explored in the survey, respondents also reported having positive experiences of living with mental illnesses in each of the life areas explored in the survey, to varying degrees. Life areas with the highest proportions of positive experiences included: seeing, reading or hearing

social media that portrayed people living with mental illnesses in a positive way, having positive experiences in their relationships, seeing, reading or hearing entertainment or creative mass media that portrayed people living with mental illnesses in a positive way and positive experiences in culture, faith, religious or spiritual practices and communities.

Research question 2: What is the nature of the stigma and discrimination people experience?

Aspects of stigma and discrimination were more prominent in some life areas than others but cut across every life area explored in the survey. Stigma and discrimination spanned interactions with individuals, bias within systems and processes, and broader systemic issues. The nature of the stigma and discrimination described by respondents across life areas was often severe and included:

- Being treated unfairly.
- Denial of access or opportunity.
- Being made to end or exit participation.
- Feeling pressured into unwanted decisions or actions.
- Exposure to hurtful, offensive and/or upsetting attitudes, views and portrayals of people living with mental illness.
- Dismissal of their thoughts, views and opinions.
- Being excluded from decision making.
- Having needs ignored, or preferences disregarded.
- Receiving inappropriate or inadequate service, care and/or support.

Research question 3: Which groups experience the most mental health stigma and discrimination, and in what life areas?

We urge caution in drawing conclusions about which groups experience the most stigma and discrimination about their mental illness based on the research findings. The data is not to be interpreted as statistically representative of all people with mental illnesses in Scotland.

Stigma and discrimination may also extend to life areas not covered in the survey and is also likely to be experienced by, or affect, individuals and groups impacted by severe, complex and enduring mental illness, including partners, children, carers and friends.

Evidence of intersectional elements of stigmatisation and discrimination related to other aspects of identity was also gathered. This may compound adverse experience and impacts for people with lived experience of severe, complex and/or enduring mental illness. Often, experiences of stigma and discrimination about other aspects individual identity were intertwined with stigma and discrimination about their mental illness.

There may be people in Scotland who have severe, complex and/or enduring mental illness who have not encountered stigma in the last 12 months; but have experienced it previously, with lasting impacts. The findings from the supplementary qualitative research suggests that there are also those with historical experiences of stigma and discrimination in a particular life area, which has led to them withdrawing from participating in those life areas, as well as others, to protect themselves.

Research question 4: How does the awareness, experience and anticipation of stigma and discrimination affect people living with severe, complex and/or enduring mental health problems?

On awareness of stigma, there are stark differences in how respondents viewed themselves because of their mental illness, how they perceived those in positions of power, and how the public viewed people living with mental illness; and their views of others living with mental illness. Most respondents seemed to expect that people in positions of power and members of the public have negative views with feedback from the qualitative research indicating that this is influenced by past experiences of stigma and discrimination.

Respondents seemed to hold more sympathetic beliefs about others with mental illness than they hold of themselves. The qualitative research highlighted that experiences of stigma and discrimination can have significant influence on a person's view of self, but also that other factors contribute to this. In terms of viewing others more sympathetically, the qualitative research found that instead of holding negative views about others, respondents empathised, identified with, and understood their experiences. For some, supporting or being kind to others seemed important to their own sense of self or was felt to benefit them too.

The data gathered through this study suggests that experiences of stigma and discrimination can lead to heightened anticipation of future stigma and discrimination. The combination of experiences and anticipation of potential stigma and discrimination can contribute to withdrawal from opportunities as a pre-emptive, protective response.

The research suggests that withdrawal from opportunities and participation in different aspects of everyday life as a result of experiences of stigma and discrimination can have a significant negative impact on people. It can impact on social connectedness, access to support and services, housing, employment and education. A small number of the wide and varied examples evidenced through the study include:

- People choosing not to start a family, withdrawing from relationships with friends or stopping themselves from getting close to others to avoid rejection:

"It has actually made me not have friends. Because I'm scared of explaining myself... I'm the one with the weird character. So it's easier, to try and not explain myself."

- People stopping themselves from applying for jobs or promotion opportunities, or leaving employment before they were ready or wanted to:

"I've had to leave jobs because of stress – managers have told me they would push me til they broke me – they would make up presumed diagnosis – mental health was used against me – this has impacted my confidence and makes it hard to go back."

- People stopping themselves from calling 999 for an ambulance or going to hospital for urgent medical care (mental and physical health):

"I try to keep away from mental health services in recent years because I find them to be damaging – the constant invalidation and poor responses – in terms of timeliness and effectiveness."

- People withdrawing from education or training courses when they didn't want to:

"I dropped out of my MSc because it felt impossible to access support I needed and it was nearly impossible to access flexible learning."

Research question 5: What needs to change to improve people's experiences of living with severe, complex and/or enduring mental health problems, and to reduce mental health stigma and discrimination?

This study gave people with lived experience a direct opportunity to identify what changes are needed in Scotland to reduce mental illness stigma and discrimination. An extensive range of changes were suggested and these fell into four overarching, inter-related areas that include social values; understanding and inclusion; work and education settings; identity and representation; and provision of services and support.

Cutting across each of these areas will require change in culture, policies, systems and practices and a move towards greater education, collaboration, accountability, inclusion, respect and empowerment.

Social values and understanding

The need for greater knowledge of, and understanding about, mental health issues in society was a recurring theme. This was seen to be fundamental to achieving increased inclusion and acceptance, with the importance of being treated with kindness, empathy and compassion being highlighted.

Socio-economic inclusion

The need to reduce social inequality and address exclusion in employment, education, welfare, financial support and relationships was seen as a critical enabler of reducing stigma and discrimination. This included reflections and suggestions relating to social policy and areas of systemic change that are needed to reduce discrimination, improve legal rights and representation, increase access to finance and resources and shift social values and expectations.

Identity and representation

The need to erase negative representations of people living with mental illness, particularly personality disorder diagnoses, was raised. Many urged an end to the dehumanised and stereotyped identities they felt ascribed to them, and greater use of more thoughtful and inclusive language. The media was discussed as both problem and solution to better representation, with a call for less stigmatised, more accurate or more celebratory representations of mental illness experiences by media platforms and outlets, while also recognising that all parts of society had a role in this.

Services and support

Improved services were identified as another important step. While NHS and mental healthcare supports were most repeatedly mentioned, physical healthcare, crisis support lines, welfare support, job centres, housing supports, policing and legal aid services were also discussed. Suggestions for improvement included broad comments relating to organisational and cultural change and service reform, through to specific changes related to accessibility and availability, resourcing and investment, staff training and greater coordination across services.

Conclusions and recommendations

The research indicates that many people in Scotland living with complex, severe and/or enduring mental illness experience stigma and discrimination across every life area explored in the survey. It has gathered a significant body of evidence and revealed hard-hitting findings about the extent, impact and nature of stigma and discrimination experienced by people with lived experience of complex, severe and/or enduring mental illnesses.

This is the first large scale piece of research undertaken into these issues in Scotland. Some of the examples of stigma and discrimination identified in this research are likely to have profound and enduring impacts for those who experienced them. Many of the examples in the full report are distressing and bring into sharp focus the need for ongoing improvement in systems and services that aim to engage and support people who live with mental illness.

The findings make a clear case for the continued investment into and focus on tackling stigma and discrimination in Scotland, with particular emphasis on how they impact on experiences and outcomes of people living with mental illness. The findings also illustrate the scale of the challenge, and the change that needs to take place if stigma and discrimination are to be genuinely tackled and reduced.

Those seeking to tackle stigma and discrimination will need to acknowledge these calls for change, identify any gaps through reflecting on the findings, and prioritise which steps to take. Achieving change will involve extensive engagement, buy in and commitment from a wide range of stakeholders and partners. This work should agree timescales, identify leadership and implementation roles, guide implementation and monitor desired changes, and generate resources. This must be a collective and collaborative effort across partners and stakeholders if the change required is to be achieved.

There is a need to consider where efforts to tackle these may have the greatest effect. For example, whether to prioritise reducing incidences of stigma and discrimination, or to focus on addressing aspects of stigma and discrimination which are reported to have the greatest impact.

Strategic recommendations identified in response to the findings from this study include:

1

Sharing the research in tailored ways with key stakeholders and generating engagement with, and acknowledgement of, the findings amongst people with lived experience, policy makers, funders, researchers, the wider mental health sector and others with an interest and responsibility for reducing stigma and discrimination.

2

Allocating and rallying resources which reflect the scale, scope and long-term nature of the work required to tackle stigma and discrimination. This may include reallocation of existing funding, redirecting or expanding services and drawing on the skills, experience, expertise, influence, connections and resources of stakeholders and partners.

3

Developing an action plan to address the issues set out in the report, demonstrating and covering ownership and accountability, resourcing, timescales, monitoring of progress and impact.

4

Repeating the survey on a larger scale to generate data which is representative at population level. This will require support from NHS Health Boards to reach people supported by mental health services.

5

Generating evidence to answer some of the questions raised during this research, such as:

- Does mental illness stigma and discrimination extend to life areas not covered in the survey?
- In what ways is stigma and discrimination experienced by, other groups impacted by complex, severe and/or enduring mental illness, including partners and children?
- Are there people with complex, severe and/or enduring mental illness who have not encountered stigma in last 12 months; but have experienced it previously, with lasting impacts? If so, what are those impacts and what effect do they have on the person's life?

1. Introduction

The Scottish Mental Illness Stigma Survey

- 1.1. There is a growing appreciation that mental health exists on a spectrum, that everyone's mental health fluctuates and anyone can experience mental health issues. Despite this, stigma towards those living with mental illness occurs globally and endures across many areas of life¹⁻⁴.
- 1.2. Inspired by the Australian [National Stigma Report Card](#)^a, and drawing from their Our Turn to Speak survey^b, this research in Scotland is the first-of-its-kind. The Scottish Mental Illness Stigma Study explores the real-life experiences of stigma and discrimination faced by people living with severe, complex and/or enduring mental illness in Scotland.
- 1.3. The research has been carried out on behalf of See Me, Scotland's national anti-stigma programme, in partnership with:
 - **Mental Health Foundation (MHF) Scotland** – Overall management and direction of the study, and played a key role in communicating and raising awareness of the study^c.
 - **Glasgow Caledonian University, School of Health and Life Sciences** – Principal Investigator for the research with a lead role in survey design and considering and articulating the ethical considerations of the study, and the ethics application and approval process.^d
 - **The Lines Between** – Independent social research organisation commissioned to undertake the study^e.
- 1.4. This study is one of the first activities to come from See Me's recently launched See Us social movement which seeks to end mental health stigma and discrimination^f. The survey is critical in beginning to understand what changes are needed, but also to identify the areas where more knowledge is required. See Me will use the evidence gathered to engage people with lived experience and to advocate for policy, practice and systems change.

Research aims

- 1.5. The Scottish Mental Illness Stigma Study aims to answer the following questions:
 1. In what areas of life do people living with severe, complex and/or enduring mental illness experience stigma and discrimination and to what extent?

a. Groot, C., Rehm, I., Andrews, C., Hobern, B., Morgan, R., Green, H., Sweeny, L. & Blanchard, M. (2020). 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. Accessed on 16/3/2022 from https://nationalstigmareportcard.com.au/sites/default/files/2021-06/NSRC_Full_Report.pdf

b. The Our Turn to Speak Survey was developed by SANE Australia's Anne Deveson Research Centre, Melbourne School of Psychological Sciences (University of Melbourne) and the Paul Ramsay Foundation. Accessed on 16/3/2022 from https://nationalstigmareportcard.com.au/sites/default/files/2021-06/NSRC_Full_Report.pdf

c. Mental Health Foundation (2022). Scotland. Accessed on 25/3/2022 from: <https://www.mentalhealth.org.uk/scotland>

d. Glasgow Caledonian University (2022). *School of Health and Life Sciences*. Accessed on 25/3/2022 from: <https://www.gcu.ac.uk/hls/research/>

e. The Lines Between (2022). Accessed on 25/2022 from: <https://www.thelinesbetween.co.uk/>

f. Glasgow Caledonian University (2021). GCU at forefront of mental health stigma research. Accessed on 25/3/2022 from: www.gcu.ac.uk/theuniversity/universitynews/2021-mentalhealthstigasurvey/.

2. What is the nature of stigma and discrimination they experience?
 3. Which groups experience most mental health stigma and discrimination and in what life areas?
 4. How does the awareness, experience and anticipation of stigma and discrimination affect the lives of people living with severe, complex and/or enduring mental illness?
 5. What needs to change to improve people's experiences of living with severe, complex and/or enduring mental illness, and to reduce stigma and discrimination?
- 1.6. To address these questions, a Scotland-wide survey was designed and distributed by the research partners. It ran for three months^g and received eligible responses from 346 people. Any adult (18+) living in Scotland with experience of stigma and discrimination within the previous 12 months because of severe, complex and/or enduring mental illness was eligible to take part.
- 1.7. The survey draws on the Australian Our Turn To Speak study in exploring experiences of stigma and discrimination across 14 life areas:
- Housing.
 - Employment.
 - Education and training.
 - Relationships with friends and family.
 - Healthcare services (excluding mental health services).
 - Mental healthcare services.
 - Sports, community groups and volunteering.
 - Public and recreational spaces.
 - Banking and insurance services.
 - Welfare benefits and financial support.
 - Legal and justice services.
 - Cultural, faith, religious or spiritual practices and communities.
 - Mass media.
 - Social media.

Stigma and discrimination in Scotland: some context

- 1.8. Successive government programmes, policies, and initiatives in Scotland in recent decades have attempted to address mental illness stigma and discrimination⁵. The Scottish Government Mental Health Strategy 2017–2027⁶ explicitly states an overarching vision of: *'A Scotland where people can get the right help at the right time, expect recovery, and fully enjoy their rights, free from discrimination and stigma.'* A new mental health strategy for Scotland is currently being developed, with the findings from this study intended to influence its development.
- 1.9. Despite this, the consequences of mental health stigma and discrimination remain severe and continue to threaten lives, and quality of life, in Scotland. These issues are discussed in more detail in the context review (Chapter 2), which summarises evidence and policy on severe and enduring mental health problems and inequalities in Scotland. A brief outline of context review findings is provided on page 9.

g. The survey ran between 26th November 2021 and 7th March 2022.

Summary

- Mental health problems are experienced by a significant number of people in Scotland, but specific data on the prevalence of severe and enduring mental health issues is harder to find. Numbers relating to psychiatric medication prescriptions and hospital discharges provide some (limited) indication about this.
- The COVID-19 pandemic has seen a deterioration in mental health among the Scottish population. Mental health inequalities also seem to have increased during this time⁷.
- There is a clear link between social inequalities and mental health distress. This is a bi-directional relationship, with social inequalities impacting mental health and vice versa⁸.
- “Inequality linked to disabilities, age, sex, gender, sexual orientation, ethnicity and background can all affect mental wellbeing and incidence of mental illness”⁹.
- Scotland evidences a social gradient for mental health, where living in the areas of highest deprivation increases the risk of experiencing a mental illness¹⁰. This gradient also appears evident for severe and enduring mental illnesses.
- The unequal distribution of stressful experiences, coupled with reduced protective factors, are thought to underpin inequalities in mental health¹¹.
- Gender and age-related inequalities have also been evidenced in Scotland¹². However, it may be that gender differences lie in the patterning of distress, rather than overall incidence¹³. Gender specific risk-factors for the diagnosis of mental illness in both women and men have been identified.
- Mental illness is associated with increased risk of physical health problems, lower life expectancy, socio-economic disadvantage and lack of parity in access to services¹⁴.
- The Mental Welfare Commission for Scotland¹⁵ highlights particular barriers to accessing services for ethnic minority groups and refugees.
- Equality of access, health and citizenship will not be achieved in Scotland without addressing stigma and discrimination¹⁶.
- The consequences of stigma and discrimination are, therefore, severe and impact the psychological and physical health, and life expectancy, of those living with mental health issues^{17–20}.
- Self-stigma may also play a role; a process where people internalise stigmatised societal attitudes, which impact negatively on sense of self and wellbeing, and act as a barrier to accessing support^{21,22}.
- Evidence suggests a gradient of public stigma severity with higher levels of stigma attached to severe and enduring mental health problems, such as psychosis and harmful substance use, than to more common diagnoses such as depression^{23,24}.
- The impact of stigma and discrimination on people living with longer-term, complex mental illnesses is multi-layered. It results not only in direct experiences of stigma and discrimination, but in fear and expectation of future experiences of these and withdrawal from life-opportunities as a protective response²⁵.

Addressing the evidence gaps

- 1.10.** The literature on stigma has been criticised for focusing on public attitudes towards people experiencing severe mental health distress, while the views of those with lived experience have been neglected²⁶. There is also a concern that studies which include the views of people with lived experience have prioritised *perceived* stigma and discrimination rather than actual experiences²⁷. Among more recent studies which do spotlight the voices of those with lived experience, stigma and discrimination have been found to be widespread, harmful and encountered in most aspects of life^{28,29}.
- 1.11.** In Scotland, no large national surveys have investigated experiences of mental health stigma from the perspective of those with lived experience of severe, complex, and/or enduring mental health issues. The Scottish Mental Illness Stigma Survey aims to address this gap. Following the Australian Our Turn To Speak study³⁰, it seeks greater representation of people living with such conditions, including those other than psychosis.

Content warning

- 1.12.** This report presents findings which readers may find triggering, upsetting and/or difficult to read. Throughout the report, quotes from respondents are used to illustrate findings and in many instances these recount distressing experiences of stigma and discrimination and the impact that they have had on respondents.
- 1.13.** Readers should give this careful consideration before continuing, and give thought to steps they could take to minimise any potential distress they could experience. We would urge readers to ensure they have access to any emotional or other support they may need should reading this report cause any unintended distress.

2. Context review

- 2.1. This review describes the context for The Scottish Mental Illness Stigma Survey. It summarises evidence and policy relating to severe and enduring mental illness and inequalities in Scotland.
- 2.2. We begin with an overview of key learning and then explain the approach taken to conduct the context review. The review is structured around the following themes: overview of mental health in Scotland; mental health in Scotland and the COVID-19 pandemic; the relationship between mental health and inequalities; how mental illness relate to inequalities in health, education, and employment; and the impact of stigma and discrimination.

Approach to the context review

- 2.3. Given the breadth of the topic and the wealth of information available, this review is not exhaustive. Relevant information has been gathered from key policy, implementation and campaign bodies, including: the Mental Health Foundation, Scottish Association for Mental Health, Samaritans, Public Health Scotland and The Scottish Government.
- 2.4. Documents from these bodies were reviewed using specific search terms, including:
 - 'Mental health', 'mental illness'.
 - 'Inequalities', 'inequality'.
 - 'Deprivation', 'deprived'.
 - 'Stigma', 'stigmatising'.
 - 'Discrimination', 'discriminate'.

An overview of mental health in Scotland

- 2.5. Mental illness is experienced by a significant number of people in Scotland. Around a quarter of Scotland's population experience mental illness in any one year³¹. Findings from the Scottish Health Survey 2019 Edition³² suggest a pattern of increasing occurrence of common mental illness with 14% and 12% of respondents reporting two or more symptoms of anxiety and depression respectively. The findings also indicate an increase in suicide attempt prevalence (7%). In 2020, 792 people died by suicide in Scotland³³. Between July and September 2021, 40,528 people were referred for psychological therapies, a referral rate which approximates pre-COVID-19 levels³⁴.
- 2.6. Specific data on the prevalence of severe and enduring mental health issues^h in Scotland is harder to find. Numbers relating to psychiatric medication prescriptions and hospital discharges provide some (limited) indication about this, although, in the West of Scotland the

h. For the purposes of this survey, the term 'severe and enduring mental health problems' is used to describe those that are experienced longer term and have a significant impact on people's lives. It refers to a range of experiences including very high levels of psychological distress, experiences of complex trauma and/or diagnoses including: psychosis, bipolar disorder, obsessive compulsive disorder, stress-related disorders (such as post-traumatic stress disorder), dissociative disorder, eating disorder, personality disorder, severe depression and severe anxiety.

unmet treatment needs of people living in the community with severe mental distress may be as high as 35–50%³⁵. In the Scottish context, it is estimated that only one third of those who may benefit from mental health treatment currently access this³⁶. One proposed reason for this is the stigma associated with mental distress and the fear of being labelled as having a mental illness and being discriminated against³⁷.

- 2.7. There has been increased use of dispensed medications for psychosis and related diagnoses in the last decade in Scotland³⁸. In the year 2019/2020 approximately 107,000 patients received at least one dispensed item of antipsychotics – (41.5% more than in 2010/2011)³⁹. Diagnoses associated with psychoactive substance use were the most common among people discharged from psychiatric hospitals⁴⁰. In the year 2020/2021, 49,610 people were discharged in total, 6% less than the previous year (thought to be linked to COVID-19 pandemic measures)⁴¹.

Mental health in Scotland and the COVID-19 pandemic

- 2.8. The COVID-19 pandemic has seen a deterioration in mental health among the population especially for certain groups. A rapid evidence review⁴² from the early stages of the pandemic concluded: ‘it seems likely that there is an increase in poor mental health in Scotland, particularly among those with pre-existing mental illnesses, healthcare workers, people who have had exposure to COVID-19 and females’. Recent surveys indicate the pandemic has increased risk factors for distress, such as feelings of loneliness and hopelessness⁴³. The Scottish COVID-19 (SCOVID) Mental Health Tracker Study⁴⁴ found an increase in mental health distress among respondents over time. For instance, rates of depressive symptoms, suicidal thoughts and levels of loneliness increased between May 2020 and May 2021, although average levels of mental wellbeing also increased⁴⁵.
- 2.9. Mental health inequalities in Scotland appear to have increased during the pandemic. Those suffering from the lowest levels of mental health before the pandemic also had the greatest decline in their wellbeing during lockdown⁴⁶. Young adults, women, people with pre-existing mental and/or physical health issues and people from more deprived socio-economic groups were found to be at greater risk of symptoms of depression, anxiety, and suicidal thoughts⁴⁷.
- 2.10. *“Differences in people’s response to the pandemic are not randomly distributed across Scotland – they arise from people’s social and economic position in society. Groups affected by socioeconomic inequalities have been more likely to experience anxiety, panic, hopelessness, loneliness, and to report not coping well with the stress of the pandemic”* (Mental Health Foundation, 2020, p.4⁴⁸).

The relationship between mental health and inequalities

- 2.11. The link between social inequalities and mental illnesses is well established^{49–51}. Internationally, there is awareness that wellbeing is intimately tied to structural factors – such as resources, education, employment and community solidarity⁵². In recent decades, Scottish mental health policy has focused on addressing the comparatively high level of inequalities in Scotland, compared with the rest of the UK⁵³.
- 2.12. There is a bi-directional relationship between mental health and inequalities, with social inequalities impacting mental health and vice versa. As NHS Health Scotlandⁱ (2016, p.13⁵⁴) explains: *‘Social inequalities have a significant impact on mental health, with adverse life circumstances increasing the risk of lower levels of mental wellbeing and developing mental health problems... In addition, people with mental health problems are more likely to experience physical health inequalities, as well as other social inequalities such as increased risk of unemployment, low income, stigma and social exclusion’*.

i. Now Public Health Scotland.

'Inequality related to disabilities, age, sex, gender, sexual orientation, ethnicity and background can all affect mental wellbeing and incidence of mental illness. Some groups are more likely than others in our society to experience mental ill-health and poorer mental wellbeing – for example, people who have experienced trauma or adverse childhood events, people who have substance use problems, people who are experiencing homelessness, people who are experiencing loneliness or social isolation, veterans, refugees and asylum seekers. There may also be specific issues around access to services and support for those living in remote and rural communities.' (Scottish Government, 2017, p. 11⁵⁵).

How social inequalities contribute to mental health inequalities

- 2.13. Scotland evidences a social gradient for mental health, where living in the areas of highest deprivation increases the risk of experiencing a mental health problem⁵⁶. For instance, the likelihood of experiencing common mental illness such as anxiety is doubled in the most socially disadvantaged areas⁵⁷. GP consultations in affluent areas are two times less likely to include reference to mental illness than those in areas of high socio-economic deprivation⁵⁸. This pattern is mirrored in recent findings from the Scottish Health Survey (2019⁵⁹) in relation to self-harm and suicide attempts. Moreover, as the degree of deprivation rises, so too do suicide rates, with these being significantly higher in the most deprived 30% of areas, compared with Scotland generally⁶⁰. Between 2011 and 2019, the suicide rate was three times more likely among those in the most deprived compared to the least deprived areas⁶¹.
- 2.14. This unequal distribution of mental health outcomes also appears to be evident for severe and enduring mental illnesses. In 2020/2021, experiences of inpatient mental health care in Scotland were roughly three times more likely among those from the most deprived, compared to the least deprived, areas⁶². There is evidence that this association between socio-economic deprivation and hospital detentions is more pronounced for Black people than for White people⁶³. Those living in the most deprived areas are also more likely to be dispensed antipsychotic medication⁶⁴. Evidence from England similarly suggests that occurrence of severe and enduring mental illnesses is greater among people living in more disadvantaged areas⁶⁵. As an NHS Clinical Psychologist explains *'...with respect to poverty in the UK, it is impossible to work in mental health with people who are experiencing complex psycho-social difficulties... and not regularly come across issues related to the impact of social deprivation'* (Afuape, 2011, p.24⁶⁶).
- 2.15. Higher rates of stressful experiences, coupled with reduced protective factors, are thought to underpin inequalities in mental health. As NHS Health Scotland (2017, p.4⁶⁷) outlines: *'the link between social status and mental health problems is the level, frequency and duration of stressful experiences and the extent to which these are buffered by social and individual resources and sources of support. These stressful experiences (including poverty, family conflict, poor parenting, childhood adversity, unemployment, chronic health problems and poor housing) occur across the life course and contribute to a greater risk of mental health problems if they are multiple in nature and if there are no protective factors to mitigate against their negative impact'*.
- 2.16. Gender and age-related inequalities have also been evidenced in Scotland⁶⁸. Globally, depression and anxiety occur more frequently among women than men⁶⁹. Recent surveys also indicate that young women aged between 16–24 years are more likely to experience common mental health problems and engage in self-harm⁷⁰. Furthermore, the first time a woman experiences mental ill health can be during pregnancy, and pre-existing mental health conditions can get worse in the perinatal period. Up to 20% of women are affected by perinatal mental health problems⁷¹.

- 2.17.** The most recent edition of the Scottish Health Survey found that reports of attempted suicide were more common among women than men (9% and 6% respectively), with this difference just short of reaching significance⁷².
- 2.18.** It may be that gender differences lie in the patterning of distress, rather than overall incidence⁷³. The World Health Organisation⁷⁴ highlights that, worldwide, rates of psychiatric diagnosis – including less common diagnoses such as psychosis and bipolar disorder – are roughly equivalent between the genders. However, men are more likely to receive a diagnosis of alcohol dependence and to die from suicide⁷⁵. In Scotland, there was equivalence between men and women in the proportion reporting two or more symptoms of both depression and anxiety in 2018/2019⁷⁶. Moreover, the majority of those experiencing inpatient care in 2020/2021 were male (54%) – although 65% of the under 18 age group were female⁷⁷. And, in line with previous years, the majority of those (55%) who received at least one dispensed item of antipsychotics were male⁷⁸.
- 2.19.** Gender specific risk-factors for the diagnosis of mental illness in both women and men have been identified. For women these include socio-economic disadvantage and increased exposure to discrimination and gender-based violence⁷⁹, alongside higher levels of carer responsibilities and insecure work⁸⁰. For men, gender stereotypes which deny them access to vocabularies of distress have been highlighted⁸¹. This may be linked to the finding that women are more likely than men to seek help and access Primary Care support⁸².

How mental health difficulties relate to inequalities in physical health, educational, and employment outcomes

- 2.20.** Mental illnesses are associated with increased risk of physical health problems, lower life expectancy, socio-economic disadvantage and lack of parity in access to services⁸³. As NHS Health Scotland⁸⁴ explains, people with mental health needs:
- Are at greater risk of alcohol and substance misuse. The mortality rate linked to alcohol use in Scotland is the highest in the UK; in 2020, 1,190 people died due to this⁸⁵. Since 2000, alcohol-related liver disease and mental health issues due to alcohol use have been the main causes of alcohol-related deaths⁸⁶. Harmful drinking is associated with increased risk of mental health problems⁸⁷. Since 1996/1997, the rate of drug-related admissions to both acute and psychiatric hospitals has increased. In 2017/2018 this represented 9,270 people⁸⁸. Again, a 'social gradient' is evident with those from the most deprived areas being more likely than those from the least deprived areas to be admitted for alcohol and drug related reasons⁸⁹.
 - Are more likely to experience poorer social, educational, health and employment outcomes.

Employment

- 2.21.** People with mental illnesses experience much lower employment rates than those without⁹⁰. This is despite many wanting to work and this being important to recovery⁹¹. Being without work has stark impacts in terms of income, daily routines, connection to others and inclusion⁹². Unemployment, as well as low income, job insecurity and debt have been identified as risk factors for both mental health problems and suicide^{93–95}. As someone with lived experience of mental illness shares: *'Everyone wants a job or to be valued in some way. To be part of society again because you were so excluded all the time. I don't care what anyone says... we're still excluded, excluded from the job market you know'*⁹⁶.

2.22. Stigma and prejudice have been identified as contributory factors for exclusion⁹⁷. For example, there is evidence that employers can be hesitant to take on people with mental health problems⁹⁸. People living with severe and longer-term mental illnesses are likely to be more greatly disadvantaged in this regard. An English survey found a 40% employment rate for those with severe mental health problems, in comparison to a 64% employment rate for those with common mental health problems and a 74% rate for those with no mental health problems⁹⁹. In addition, a German study, found strong negative reactions in response to people with psychosis returning to work¹⁰⁰.

Health

2.23. There is a clear link between physical and mental health inequalities. Scotland has one of the lowest life expectancies in Western Europe and the lowest of the UK Nations¹⁰¹. Despite recent improvements in the general health of the Scottish population, health inequalities¹⁰² have been increasing¹⁰³. This translates as thousands of avoidable premature deaths each year and, for those living in the most disadvantaged areas, 25 and 22 fewer years living in good health, for men and women respectively¹⁰⁴. NHS Health Scotland (2016¹⁰⁵) provide examples of the link between physical and mental health and associated inequalities:

- Living in deprived areas puts you at greater risk of both long-term physical health conditions and mental illness.
- There is a bi-directional relationship between physical and mental health. For instance, experiencing depression puts you at greater risk of cardiovascular disease and diabetes, and vice versa.
- Living with severe and enduring mental illness shortens your life expectancy by 15–20 years on average, compared with the general population.

2.24. In Scotland, around one fifth of premature deaths among people with severe and enduring mental illnesses are caused by suicide and accidental death, while a large proportion are linked to physical health conditions¹⁰⁶. Possible contributory factors include: smoking, *'poorer access to physical healthcare and diagnostic overshadowing (where physical problems are under-treated or wrongly attributed to mental health issues), inadequate diet, lack of exercise, the effects of long-term use of psychiatric medication, higher rates of suicide (compared to the general population), and accidental and violent deaths. Public health is failing this population'* (Scottish Government, 2017, p.31¹⁰⁷).

2.25. People living with severe and enduring mental illnesses are more likely to have physical co-morbidities and multi-morbidities than those without¹⁰⁸. Poor physical health also occurs earlier in life for this population¹⁰⁹. A recent English study found that compared to patients generally, there was a higher occurrence of conditions such as obesity, asthma, diabetes, COPD and stroke among those with severe mental illness¹¹⁰. Public Health England suggests that two out of three deaths from physical illness for this population are preventable; major causes of death include cardiovascular disease, respiratory disease, diabetes and hypertension¹¹¹.

2.26. The unequal distribution of population-based physical and mental health problems are understood to be underpinned by the same inequalities¹¹². Income, power and wealth are unevenly distributed¹¹³. This results in individuals and groups experiencing poverty and marginalisation and unequal access to good quality housing, green space, jobs, education, learning, and cultural opportunities¹¹⁴. These factors influence lived experiences of discrimination and access to services; these then combine to increase risk of ill health and death¹¹⁵.

Access to services

- 2.27.** Patients with severe and enduring mental health distress and comorbid physical conditions often receive lower levels of assessment and treatment than those without¹¹⁶. *'(T)he current healthcare system is not designed to support an integrated approach to meeting the mental and physical health needs of the population. In addition, the continued stigma associated with mental health and diagnostic overshadowing means that those with mental health problems, particularly long-term mental health problems, do not always receive the same quality of care for physical health problems. For example, despite higher rates of cardiovascular disease and related health issues among people with a diagnosis of schizophrenia, there is evidence of under-recognition and treatment of these conditions'* (NHS Health Scotland, 2017, p.7/8¹¹⁷).
- 2.28.** There are also inequalities in access to mental health services in Scotland. For instance, the maximum Emergency Department wait (of four hours) is more likely to be transgressed for those experiencing mental distress than those with physical health needs, representing an inequity in healthcare between physical and mental health¹¹⁸. Specialist mental health services – such as clinical psychology – are also less likely to be available in disadvantaged areas¹¹⁹, which, as outlined above, have a higher proportion of people experiencing mental distress. In the UK, people who are socio-economically disadvantaged are less likely to seek help for mental health related issues¹²⁰. Furthermore, GPs in more deprived areas are less likely to make a referral to specialist mental health services in relation to self-harm¹²¹.
- 2.29.** The Mental Welfare Commission for Scotland¹²² highlights particular barriers for ethnic minority groups and refugees in accessing services. These include: stigma around mental health, issues related to language and use of interpreters, not being offered services such as clinical psychology and a lack of understanding among mental health staff about the traumatic nature of racist micro-aggressions and the asylum process.

Stigma and discrimination^{j,k}

- 2.30.** Stigmatisation of people with mental health problems occurs globally and is centuries old – with some suggesting that women who were burned as witches may have been experiencing mental distress¹²³. Stigma and discrimination endure^{124–126} and continue to threaten both lives and quality of life. Stigma can: exacerbate the distress associated with experiences of mental illness¹²⁷, lower self-esteem, underpin human rights abuses, damage social relationships, limit access to housing and employment, and act as a barrier to help seeking and mental health care provision¹²⁸. Stigma has been shown to perpetuate health inequalities and to be linked to increased self-harm and risk of suicide^{129,130}. Self-stigma – 'acceptance of other's derogatory, mistaken ideas about oneself' – is thought to play a role¹³¹. Similarly, social processes, such as loneliness, stigma (social and self), trauma and social exclusion are believed to be implicated in the premature deaths of people with severe and enduring mental illnesses, through influencing their health and health behaviours¹³².
- 2.31.** In Scotland, 'Stigma and discrimination are major barriers to full participation in society and can contribute to mental problems themselves... Direct and indirect discrimination act as a major barrier to living well' (NHS Health Scotland, 2016, p.23¹³³). The Scottish Social Attitudes Survey 2013¹³⁴ found that 37% of people who identified as having a mental health problem had experienced some form of negative social consequence such as being verbally or

j. For the purposes of this survey, 'Stigma' is defined as 'the negative attitudes or beliefs based on a preconception, misunderstanding or fear of mental health and/or mental health problems.'

k. For the purposes of this survey, 'discrimination' is understood to occur 'when a person performs an action, whether intentional or unintentional, that creates barriers and inequality for people with lived experience of mental health problems.'

physically abused or turned down for a job. This represented an increase from 2008 where the figure was 23%. One in eight (13%) said they had been discouraged from attending an event due to their mental illness and 22% said they decided not to attend due to anticipatory fear as to how they would be treated. This fear is understandable. *'Consistently evidence points towards strongly negative attitudes towards people with mental health problems: in particular, there is an inaccurate view that they represent a danger to the community, a view strongly reinforced in the media. Negative attitudes are not only found among the general public, but even among mental health professionals. This and other elements of stigma increases social distance: it for instance reduces the likelihood of an individual becoming employed or accessing health care services'* (McDaid, 2008, p.2¹³⁵).

- 2.32.** There is widespread international evidence of a gradient of public stigma severity with higher levels of stigma attached to severe and enduring mental illnesses, such as psychosis and harmful substance use, than to more common mental health problems^{136–139}. Findings suggest that people with a diagnosis of psychosis are more likely to be stereotyped as dangerous and avoided by members of the public, than those with a diagnosis of mild-to-moderate depression¹⁴⁰. This is evident within the Scottish context. 43% of respondents in the Scottish Attitudes Survey 2013¹⁴¹, for instance, endorsed the view that someone with a diagnosis of psychosis was likely to be violent to others; this was compared to only 10% of respondents endorsing the statement when related to someone with a diagnosis of depression. Furthermore, 22% of respondents said they would not be willing to interact with someone with a diagnosis of psychosis in any situation compared to 15% for someone with a diagnosis of depression.
- 2.33.** The impact of stigma on people living with complex mental health illnesses is multi-layered. It results not only in direct experiences of stigma and discrimination, but in fear and expectation of potential future experiences of these and withdrawal from life opportunities as a protective response¹⁴². For example, in a study of the experiences of 75 people with a diagnosis of psychosis, across 15 different countries, withdrawal from interpersonal relationships was found to be common. Participants *'...described not wanting to be involved in romantic relationships, drifting apart from their friendships, avoiding other people, not going outside and avoiding social situations'* (Rose and colleagues, 2011, p199¹⁴³).
- 2.34.** Successive government programmes, policies and initiatives in recent decades in Scotland have attempted to address this stigma and discrimination¹⁴⁴. These include: the National Programme for Health and Wellbeing 2001–2008, which had ending discrimination as one of its aims; the national 'See Me' campaign (2002–ongoing) – which aims to challenge the stigma, discrimination and exclusion of people experiencing mental health problems; and the 'Choose Life' (2002) suicide prevention strategy focused on removing stigma. More recently, the Mental Health Strategy 2017–2027 advocates achieving parity between mental and physical health prevention and treatment and expresses *'...a commitment to tackle mental health inequalities and embed a human-rights based approach across services'* (Christie & Wilson, 2019, p.47¹⁴⁵).
- 2.35.** Despite this, as this review indicates, the stigma, inequalities and discrimination faced by people with mental illness in Scotland endures¹⁴⁶. There are signs of some progress in changing public attitudes, with Scottish survey respondents being more open to the idea of others knowing should they suffer from mental illness in 2006 than in 2004¹⁴⁷. However, the task of shifting long-standing public attitudes is challenging¹⁴⁸. By the 2013 edition of the same survey, attitudes had again shifted, with less people endorsing the idea of being open about mental illness¹⁴⁹. Moreover, although See Me (2020)¹⁵⁰ identify a positive societal shift over the last decade, with 50% of people in Scotland reporting improved perceptions of people living with mental illnesses, more than two thirds of those with lived experience still report having experienced stigma and been treated unfairly¹⁵¹.

3. Methodology

- 3.1. This chapter describes the methodological approach to conducting the research, with details on ethics approval, questionnaire design, recruitment of participants, data preparation and data limitations.
- 3.2. Sections 3.3 through to 3.34 set out the methodological approach for the survey element of the research study with sections 3.35 through to 3.46 detailing the approach.

QUANTITATIVE RESEARCH METHODOLOGY

Research ethics

- 3.3. All aspects of this study were conducted with prior ethical approval from the Glasgow Caledonian University School of Health and Life Sciences Research Ethics Committee. The study was given ethical approval on 9th November 2021 under the following approval code: HLS/PSWAHS/21/009.

Research advisory group

- 3.4. The research was guided by an Advisory Group, established to offer expertise, support and advice. This group met monthly via Zoom with representation from:
 - Mental Health Foundation.
 - See Me.
 - The Lines Between.
 - Glasgow Caledonian University.
 - VOX Scotland and people with lived experience.
 - Scottish Government.
 - Melbourne School of Psychological Sciences (University of Melbourne).
- 3.5. A panel of eight volunteers from VOX and See Me with lived experience of mental illness also contributed to the development, refinement and testing of the survey. Members of the Lived Experience Working Group were also invited to respond to an emerging findings presentation, delivered at the mid-point of the study.

Survey design process

- 3.6. The research survey was based on the Our Turn to Speak survey developed by SANE Australia's Anne Deveson Research Centre, Melbourne School of Psychological Sciences (University of Melbourne) and the Paul Ramsay Foundation. The Australian research team gave permission for the survey to be recreated for use in Scotland and shared copies of the survey in various formats with MHF and The Lines Between.

- 3.7.** Using the Our Turn to Speak survey as a template, the Scottish Mental Illness Stigma Survey was created using Snap Surveys, questionnaire design and analysis software. Some edits were made to the language throughout the questionnaire to tailor it to Scottish audiences, however the structure largely remained the same as the Australian survey.
- 3.8.** Once the survey was entered into Snap, a rigorous testing phase began to ensure the questionnaire was functioning as intended and all routing was applied correctly. The first step involved the research team testing various pathways to check for routing errors and ensure all relevant questions were asked. After the internal checks were complete, the survey was tested by the Lived Experience Working Group.

Content of survey

- 3.9.** The survey contained five separate sections:
1. An information sheet and consent form.
 2. An eligibility screening section.
 3. A section collecting information about respondent demographics.
 4. A set of questions about perceptions of attitudes toward mental health.
 5. Questions about stigma and discrimination related to specific life areas

Information sheet and consent form

- 3.10.** The first section of the survey presented participants with an information sheet with details about:
- Background and rationale for the study.
 - What participation would involve.
 - Possible risks/benefits of taking part.
 - What would happen to participant responses.
 - Contact details for the research team.
- 3.11.** Respondents were then asked to complete an 8-item consent form checklist confirming they had read and understood the information set out and agreed to different conditions of their participation. If respondents did not consent to each condition, they were unable to advance to the next section of the survey.

Eligibility screening section

- 3.12.** Respondents were then asked a series of questions to determine whether they were eligible to take part in the survey. Individuals were deemed eligible to participate if they met the following criteria at the time of completing the survey:
- Aged 18 or over.
 - Living in Scotland.
 - Had one of the following mental illnesses^{l,m}:
 - Schizophrenia or other primary psychotic disorder.
 - Bipolar or related disorder.

^l. A formal diagnosis was not required to participate in the survey.

^m. The following is a hybrid of items included in ICD-10 and ICD 11, and developed in consultation with a person with lived experience and two clinical psychologists.

- Obsessive-compulsive or related disorder.
- Disorder specifically associated with stress.
- Dissociative disorder.
- Feeding or eating disorder.
- Personality disorder.
- Severe and/or treatment-resistant depressive disorder.
- Severe and/or treatment-resistant anxiety or fear-related disorder.

- Had experience of stigma and discrimination within the last 12 months because of severe, complex, and/or enduring mental illnesses.

3.13. Respondents whose answers indicated they were ineligible (e.g., said they did not live in Scotland) to take part in the study were directed to a page thanking them for their interest in the survey and presenting a debrief statement with signposting information and contact details for the research team. This page also confirmed they were not eligible to take part and asked them to close the window.

Demographics section

3.14. This section collected data about respondents' sociodemographic characteristics, aligned to the Scottish 2022 census questions. Each question in this section had a 'prefer not to say' option. Respondents were asked their:

- Postcode (or nearest postcode to their residence).
- Gender, with a follow-up question about whether they were transgender.
- Ethnicity.
- Relationship status.
- Level of education.ⁿ
- Employment status.
- Type of residence (e.g. privately owned home, rented property etc).
- Disabilities/health conditions.
- Main language.
- Religion.

Attitudes to mental health section

3.15. This section contained a series of statements about self-stigma in terms of^o:

- Awareness of public and structural stigma.
- Agreement with that stigma.
- Application of that stigma to the self.
- Resultant harm to the self in terms of self-esteem.

3.16. Respondents were asked the extent to which they agreed with each statement by selecting one of six options on a scale of 'Strongly disagree' to 'Strongly agree'.

n. A list of qualifications was provided and respondents were asked to select each qualification they had.

o. A modified version of the Self-Stigma of Mental Illness Scale Short Form (SSMIS-SF) (Corrigan et al., 2012) was used. Modifications to the scale were made by the team leading the Our Turn To Speak study and replicated in this survey.

Experiences of stigma and discrimination in different areas of life

- 3.17.** Respondents were asked to select up to three of the following life areas^p which they felt had been most impacted by experiences of stigma and discrimination as a result of their mental illness in the last 12 months:
- Housing.
 - Employment.
 - Education and training.
 - Relationships with friends and family.
 - Healthcare services (excluding mental health services).
 - Mental healthcare services.
 - Sports, community groups and volunteering.
 - Public and recreational spaces.
 - Banking and insurance services.
 - Welfare benefits and financial support.
 - Legal and justice services.
 - Cultural, faith, religious or spiritual practices and communities.
 - Mass media.
 - Social media.
- 3.18.** A link to an information sheet providing further contextual information about each life area was included to aid respondents' understanding.
- 3.19.** Respondents were presented with a series of statements related to their chosen life areas and asked to indicate the extent to which they agreed with each statement by selecting one of six options on a scale of 'Strongly disagree' to 'Strongly agree'. There were also opportunities to provide open-ended comments.
- 3.20.** For up to three life areas, respondents were asked about over the preceding 12 months:
- Perceived experiences of past stigma and discrimination.
 - Anticipated future experiences of stigma and discrimination.
 - Withdrawal from opportunities relevant to that life area because of stigma about mental illness:
 - At the end of this section participants were invited to provide an open-ended response to the question *'Is there anything else you would like to share with us about your experience of mental health stigma and/or discrimination in [life area]? If yes, please tell us about this below'*.
 - Experiences of positive treatment relating to living with complex mental illness:
 - At the end of this section participants were invited to provide an open-ended response to the question *'Is there anything else you would like to share with us about any positive experiences you have had because of your mental health issues in [life area]? If yes, please tell us about this below'*.

p. Life areas, and their definitions, were replicate from the Australian Our Turn To Speak study with minor tweaks to language

- Intersectional experiences of stigma and discrimination (that is, stigma because of personal characteristics such as physical health or ability, racial or cultural background) and other protected characteristics):
 - At the end of this section participants were invited to provide an open-ended response to the question *'Is there anything else you would like to share with us about your experience of mental health stigma and/or discrimination in [life area], and the aspects of your identity you have identified above? If yes, please tell us about this below'.*

3.21. Respondents were then invited to share what they felt most needs to change to reduce stigma and discrimination for people living with severe and enduring mental illnesses in Scotland. This was also an open text response that enabled participants to respond in depth and detail.

3.22. Upon reaching the end of this section, respondents were directed to a debriefing statement which thanked them for taking part and asked them to submit their response. The debriefing statement contained a reminder of the aims and purposes of the study, contact details for the research team and details of support services to contact if their participation in the survey had caused them any distress.

Table 3.1: How did you hear about the survey? (n=346)^q

Medium			n	%
Social media			199	57%
Platform	n	%		
Facebook	105	53%		
YouTube	48	24%		
Twitter	23	12%		
Instagram	11	6%		
LinkedIn	3	2%		
Other	3	2%		
Did not specify	6	3%		
Email			72	21%
Press Coverage – Newspaper/Radio/TV/Online article			46	13%
Word of mouth			26	8%
Newsletter			15	4%
Other			11	3%
Did not specify			5	1%

Recruitment

- 3.23.** The survey was promoted through several different channels including social media (including paid targeted advertising), online, TV and radio press coverage and third sector organisations.
- 3.24.** Partner organisations and networks also supported the promotion of the survey through various channels, and directly to their service users and other people they work with. This activity helped to extend the reach of the survey.
- 3.25.** Most respondents (199, 57%) heard about the survey through social media.

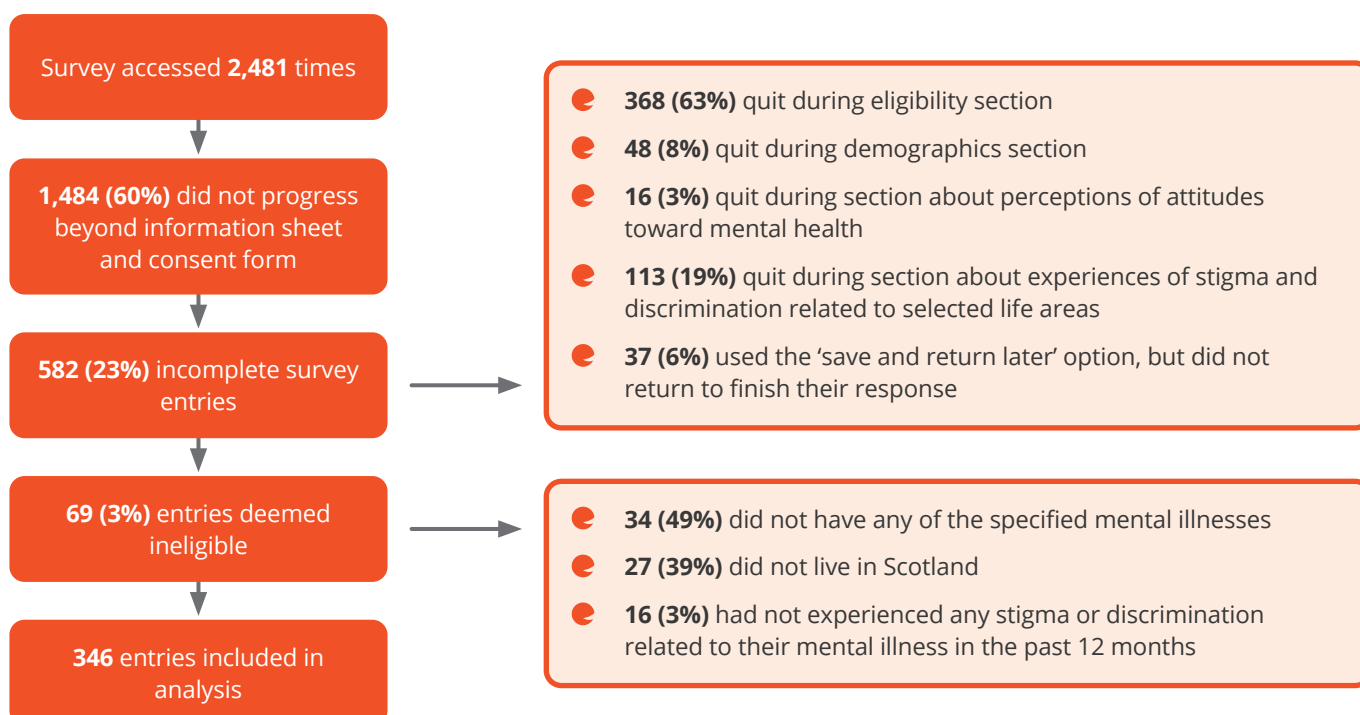
Participation methods

- 3.26.** All survey responses were received between 26th November 2021 and 7th March 2022.
- 3.27.** The majority of respondents (206, 60%) completed the survey on a PC or Laptop. Approximately a third (105, 30%) completed the survey on a mobile phone; the remainder (35, 10%) used a tablet. On average, respondents took 62 minutes to complete the survey.
- 3.28.** Respondents were given the option to contact the research team and request support to complete the survey; this involved completing the survey supported by a researcher via a telephone call or online video call. Few participants requested this – a total of 10 supported survey completions took place.

Data preparation

- 3.29.** Data from a total of 346 respondents were included in the analysis. While the survey was accessed 2,481 times, the majority of these entries did not result in a valid survey completion, as demonstrated in Figure 3.2.

Figure 3.2 Flowchart summarising data preparation



q. Respondents could select more than one option.

Quantitative data analysis

- 3.30.** Following the data preparation stage, analysis of quantitative data collected through the survey was carried out using Snap Surveys software. This involved running frequency tables for all closed-ended questions as well as cross-tabulations to identify any themes or patterns in the data. Tables and/or charts were then created for each question and included in this report along with commentary to highlight the key findings.
- 3.31.** In some cases, the sum of all responses to an individual question may not add up to exactly 100% due to rounding. Similarly, where we have combined two or more response options (e.g. the percentage of respondents who slightly agreed, agreed or strongly agreed with a statement) there may be a very small discrepancy and totals may not add up to the sum of the percentages given for each individual answer category. Furthermore, not every respondent answered every question in the life areas they selected and therefore the respondent base size is presented as a range (e.g. n=113-116).
- 3.32.** Qualitative data was exported to Excel for thematic analysis. This involved reviewing the data, identifying key themes and coding all the data according to those themes. This ensured a full, robust and systematic qualitative analysis process for all responses. The report summarises the main themes arising from each question and includes the range of views across all responses, further illustrated with quotes.
- 3.33.** In some cases, respondents gave answers that we felt were more relevant to another question or life area. For instance:
- In response to questions about positive experiences related to each of the life areas, some people described negative experiences here (and vice versa).
 - Comments related to intersectionality were sometimes found among responses to non-intersectionality questions.
 - Responses relating to one life area (e.g. mental health services), were sometimes given under questions about a different life area (e.g. health services).
- 3.34.** In these cases, we coded responses under the question or life area we deemed these to be most relevant to.

QUALITATIVE RESEARCH METHODOLOGY

Qualitative data collection

- 3.35.** After the online survey closed on 7th March 2022, the research team reviewed the profile of the 346 respondents. Initial analysis revealed that people from certain demographics were under-represented:
- Only 3% of respondents were aged 65 years old or over.
 - Men were under-represented; only 28% identified as male.
 - There was lack of diversity among the ethnicity of survey respondents; 97% reported being from White ethnic backgrounds.
 - No respondents were from West Lothian or West Dunbartonshire.
- 3.36.** Further, very little data was collected on the experiences of mental illness stigma and discrimination in some 'life areas', including banking and insurance services, legal and justice services and cultural, faith, religious or spiritual practices and communities.

r. The thematic analysis approach to qualitative data analysis is set out in detail in Braun, V and Clarke, V (2022), 'Thematic Analysis: A Practical Guide', Sage: London.

- 3.37.** In a bid to address these gaps, a follow-up qualitative study was carried out. The study also aimed to gain additional understanding and insight into specific areas of the survey findings.

Ethical approval

- 3.38.** Ethical approval for the study was obtained from Glasgow Caledonian University's School of Health and Life Sciences Research Ethics Committee.

Recruitment

- 3.39.** There were two channels of recruitment for the follow-up qualitative study:
1. Survey participants that had opted in to being notified of future research participation opportunities were contacted by the research team.
 2. Recruitment of under-represented groups followed a similar process to survey recruitment whereby SMISS partners were contacted to help raise awareness of the opportunity. Some partners used their social media and other channels to raise awareness of the research, and others volunteered to host a research visit to their premises to engage with their service users.
- 3.40.** Each individual recruited to take part in the follow-up qualitative study was provided with an information sheet and consent form about the research to help them decide whether or not they wanted to take part.

Fieldwork

- 3.41.** A combination of group and one-to-one discussion was used to engage with research participants, both in-person and remotely, through video and telephone calls. Face-to-face engagement only took place where a partner organisation agreed to host the discussion(s) on their premises in order to meet safeguarding requirements.
- 3.42.** The themes explored during discussions with those who had previously participated in the survey included:
- Participant views of others living with mental illness and views of themselves – how and why these differed, and the role of stigma and discrimination in this.
 - The influence of praise and positive feedback on views of self.
 - The relationship between experiences of stigma and discrimination; anticipated future stigma and discrimination; and withdrawal from participation and opportunities.
 - Experiences of stigma and discrimination in life areas with the fewest responses from the survey.
- 3.43.** The themes explored during discussions with those from under-represented groups that had not participated in the survey included:
- Perceived experiences of past stigma and discrimination (exploring frequency and impact).
 - Anticipated future experiences of stigma and discrimination.
 - Withdrawal from opportunities relevant to that life area because of stigma about mental illness.
 - What needs to change to reduce stigma and discrimination about mental illness.
- 3.44.** A total of 70 eligible participants took part in the qualitative research. This included 32 survey respondents and 38 people from under-represented groups, with some of those meeting

more than one of the under-representation criteria (e.g., 65+ males). The 38 participants from under-represented groups were made up of:

- 25 males.
- 6 participants residing in West Lothian.
- 18 participants from ethnic minority communities.
- 9 participants aged 65+.

3.45. All participants received a £15 gift voucher as a thank you for taking part in the qualitative research.

Analysis and reporting

3.46. With consent from participants, interviews and focus groups were recorded and transcribed. Qualitative data was then thematically analysed by the research team using a coding framework. Supplemental findings from the qualitative study are included throughout this report.

A note on language

3.47. We have used the term 'mental illness' and 'mental illnesses' in our writing of this report. However it is worth noting that there are also references to 'mental health', 'mental health condition', 'mental health problems' and 'mental health issue' in the wording of certain questions that were drawn directly from the Australia study and in the definitions used for stigma and discrimination. These terms will also be seen in open comment responses received from survey respondents and this reflects that people use different terms to describe their conditions, and that different people have different preferences about the terminology used.

3.48. For the purposes of the survey and this report, See Me's definitions of stigma and discrimination were used. These definitions are:

- **Stigma:** 'the negative attitudes or beliefs based on a preconception, misunderstanding or fear of mental health and/or mental health problems'.
- **Discrimination:** 'when a person performs an action, whether intentional or unintentional, that creates barriers and inequality for people with lived experience of mental health problems'.

Data limitations

3.49. The findings presented in this report are not to be interpreted as statistically significant, nor representative of the population of people living with complex, severe and/or enduring mental illnesses in Scotland. The lack of data about the total population means it is not possible to calculate confidence levels or levels of significance. However, this study does provide a baseline insight about this population that has never been previously available, and a foundation that can be built on as the evidence base is further developed.

Data limitations (continued)

- 3.50.** Aligned to the above, the eligibility criteria for participation in this study means that only those over the age of 18 living with a complex, severe and/or enduring mental illness who had experienced stigma and discrimination in the previous 12 months could take part. This is a further reason why the findings of this study should not be taken as reflective or representative of the whole population of people in Scotland living with complex, severe and/or enduring mental illnesses.
- 3.51.** Other data limitations which should be considered include:
- **Timescales** – the data collection period was relatively short: the survey was live for 14 weeks (which included the Christmas and New Year period, during which response rates dropped significantly). In comparison, the Australian Our Turn to Speak survey was open for seven months.
 - **Accessibility** – the survey was only available in an online format. No paper copies were produced due to the complex routing rules within the survey. There is therefore a risk that those without adequate digital skills and access to devices and/or internet have been excluded from participating in the survey.
 - **Language** – referring to ‘mental illness’ in the title of the survey may have been a barrier to participation for those who do not identify with that specific terminology (e.g. who may prefer to use other terms such as ‘mental health condition’, ‘mental health issues’ or ‘mental health problems’). However, this issue would likely be prevalent regardless of any single term selected for this study.
 - **Recruitment channels** – while a public-facing campaign and professional networks were used to promote the survey, it was not possible to advertise the study to NHS services or patients due to the conditions of ethical approval. As a result, many individuals eligible for the study may not have been aware of it, and the study team was not permitted to promote the survey to NHS partners.
 - **Profile of respondents** – the profile of respondents does not align completely with socio-demographic make-up of Scotland (e.g. women are over-represented, and there is lack of diversity among the ethnicity of respondents). Time, budget and capacity constraints meant that study materials could not be translated to accommodate other languages. However, the supplementary qualitative research that has been conducted with under-represented groups has helped to minimise this limitation.
 - **Small amount of data for some life areas** – as noted in the ‘survey content’ section above, participants were asked to select up to three life areas out of a list of 14 where they had experienced most stigma and discrimination as a result of their mental illness within the past 12 months. Subsequently, a number of life areas were selected by a small number of respondents. Eight out of 14 life areas were selected by fewer than 50 respondents. The supplementary qualitative research explored those life areas further and has helped to develop the evidence base and provide additional insights.
- 3.52.** While we urge some caution in data interpretation, it is worth noting that this survey explored experiences of stigma and discrimination in depth; the average response time was 62 minutes. The 346 responses were from individuals with lived experience who were able to share their experiences and views with confidence and in detail. All contributions are worthy of careful consideration regardless of sample size and type.
- 3.53.** We suggest that readers consider the results to be indicative rather than statistically valid. For context, we provide percentages and the number that percentages are based on.

4. Respondent profile

- 4.1.** This chapter presents a summary of the demographic profile of the overall survey respondent population. Appendix 1 provides the full demographic data tables.
- 4.2.** The average age across respondents was 40 years, with 25% aged between 25–34, and 20% aged 45–54. 18–24 year olds made up 16% of survey respondents, with 35–44 and 55–64 age brackets having 15% of respondents. Finally, 3% of respondents were 65 years old or over and 5% of respondents selected 'prefer not to say'.
- 4.3.** Almost all (97%) of survey respondents reported being from White ethnic backgrounds, with most reporting to be White Scottish (73%) or White English (11%). Only 1% reported being from mixed or multiple ethnic groups, and a further 1% reported as Asian, Scottish Asian or British Asian.
- 4.4.** Two thirds (67%) described their sex at birth as female, with 30% reporting male. In terms of gender, 58% of respondents identified as female, 28% male, 7% non-binary and 2% identify in another way. The majority of respondents reported to be heterosexual (54%), followed by bisexual (20%), homosexual (8%), and a further 4% selecting each of 'other' or 'don't know' option responses.
- 4.5.** Less than half of all respondents reported being in a relationship or married (21% and 23% respectively), while 40% reported being single. A small proportion of respondents reported being separated (3%), divorced (6%) or widowed (<0.5%).
- 4.6.** Just over half (51%) of respondents were in employment, with 28% employed full-time, 18% part-time and 5% self-employed. Over a quarter (28%) of respondents reported that they had no job. Almost one fifth (17%) of respondents were full-time or part-time students, while 11% held volunteer roles, 5% were retired and 2% reported being carers.
- 4.7.** Just over a third of respondents (36%) reported owning their own home, while a quarter lived in private rental property. A slightly smaller proportion (22%) were housed in local authority or housing association accommodation and 11% were living temporarily with friends and family. Very small proportions reported residing in sheltered accommodation (2%) or reported sleeping rough or staying in a hostel (<0.5%).
- 4.8.** Christianity was the most commonly reported spiritual belief or religion among respondents (21%), while Pagan was selected by 4%. However, the majority of respondents reported having no religion or spiritual beliefs (62%).

Mental illnesses

- 4.9.** Survey respondents were presented with a list of mental illnesses and asked to select all that they had experienced in the previous 12 months. Appendix 2 provides full data tables of the mental illnesses that respondents reported living with.
- 4.10.** The most commonly selected were: disorder specifically associated with stress (43%); severe and/or treatment-resistant anxiety or fear-related disorder (40%); severe and/or treatment-resistant depressive disorder (39%); and personality disorder (31%). Feeding or eating disorders were reported by a fifth of respondents with a similar proportion reporting obsessive-compulsive or related disorder (22%). Bipolar or related disorders and dissociative disorder were reported by similar proportions of respondents (15% and 12% respectively), with schizophrenia or other primary psychotic disorder was least commonly experienced among respondents (7%).
- 4.11.** This survey was open to those who had received a diagnosis of their mental illness from a healthcare professional, as well as for those who had self-diagnosed. A clear majority (87%) of survey respondents reported having had a diagnosis from a health professional, with the highest reported levels among respondents experiencing bipolar or related disorders (94%), while the lowest levels of health professional diagnosis were reported by those living with dissociative disorder (74%).
- 4.12.** Those who selected more than one mental illness were also asked which had affected them most over the past 12 months. The three most commonly selected were: disorder specifically associated with stress (22%), severe and/or treatment-resistant depressive disorder (18%) and severe and/or treatment-resistant anxiety or fear-related disorder (16%). One in ten (10%) reported that bipolar or a related disorder had affected them the most, with all other mental illness options being reported by less than 10% of respondents.
- 4.13.** Respondents were also asked to rate the distress and negative impact caused by the mental illnesses they live with (on a scale of minimal, mild, moderate, moderate severe, severe, very severe). Across all survey respondents 81% reported the impact caused as moderate severe through to severe, with 46% reporting severe or very severe.
- 4.14.** The highest proportion reporting a very severe impact was among those living with personality disorder (31%). Similar proportions of those living with obsessive compulsive disorder (29%), severe and/or treatment-resistant depressive disorder (28%), severe and/or treatment-resistant anxiety or fear-related disorder (27%) or dissociative disorder (26%) also reported their mental illness had a severe impact.
- 4.15.** Respondents were also asked whether they had received any other diagnoses that had not been asked about in the survey. The most commonly reported were: mild-moderate depressive disorder or episode (44%), mild-moderate anxiety disorder (45%), and autism spectrum disorder (18%).

5. Stigma overview

- 5.1. This chapter explores respondent perceptions of public attitudes and structural stigma, respondents' self-stigma, and how these impact on an individual's self-esteem.
- 5.2. We then present the survey findings about how frequently people living with severe and complex mental illnesses experience stigma and discrimination across the 14 different life areas. Following this we compare the frequency and impact of stigma and discrimination across the life areas.
- 5.3. The final section provides a summary of the positive experiences that people have had because of their mental illness in each life area.

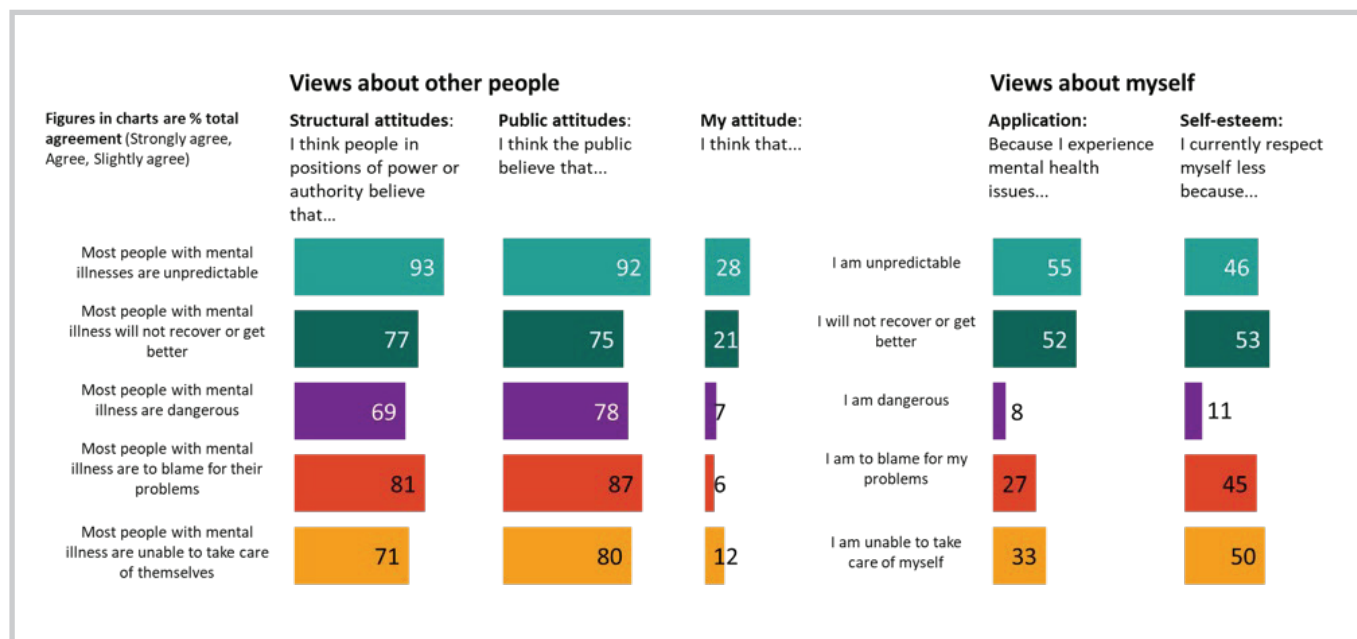
Mental health attitudes

- 5.4. Survey respondents were presented with a modified version of the Self-Stigma Mental Illness Scale^s which explores perceptions of how people with mental illness are viewed. Participants are presented with a range of statements and asked to rate the extent to which they agree that different segments of the population hold the views being communicated in those statements. This explored how respondents perceived the views of:
 - People in positions of power.
 - The general public.
 - Respondents' own views about people with mental illness.
- 5.5. Respondents then rated how each statement applied to them and how those views impacted on their self-esteem. The findings are presented in figure 5.1.

Structural and public attitudes

- 5.6. There is very little difference in perceptions of how those in positions of power and the general public view people with mental illness. The statements with the most notable differences relate to people with mental illness being dangerous (69% agreeing that people in positions of power have this view, and 78% agreeing that the public hold this view), and that people with mental illness are unable to take care of themselves (71% agreeing that people in positions of power have this view, and 80% agreeing that the public hold this view).
- 5.7. There is however, a very high level of agreement across all statements. The statement with the highest level of agreement related to people with mental illnesses being seen as unpredictable, with 93% of respondents agreeing this was the perception among people in power and 92% among the general public. The perception that the general public and people in positions of power believe that most people with mental illnesses are to blame for their problems (87% and 81% respectively) also received high levels of agreement.

s. Modifications to the scale were carried out by the Australia Our Turn To Speak study team and replicated in this study.

Figure 5.1. Perceptions of mental health attitudes (%) (n=331–336)

Respondents' perceptions of people with mental illnesses

- 5.8.** A stark difference is evident in how respondents perceive people in positions of power and the public view those living with mental illnesses, and how they themselves view people with mental illnesses. This is demonstrated through far lower levels of agreement across all statements. For example, 28% agreed that people with mental illnesses are unpredictable, compared to thinking 92% of the public and 93% of people in power perceive others in this way.
- 5.9.** The two areas of least agreement relate to people with mental illnesses being perceived as dangerous (7%) and people with mental illnesses perceived as being to blame for their problems (6%).

Respondents' views about themselves

- 5.10.** It appears that respondents' views of others with mental illnesses are more sympathetic than the views they hold of themselves. For all but one statement, respondents were at least twice as likely to view themselves negatively, compared to how they viewed others with mental illnesses. For example, 55% agreed that they were unpredictable, but only 21% felt this way about others with mental illnesses. The one area where agreement aligned was the 8% of respondents agreeing they were dangerous compared to 7% feeling the same way about others with mental illnesses.
- 5.11.** Regarding self-esteem, over half of respondents (53%) said they respected themselves less because they would not recover or get better, with a similar proportion (50%) reporting they respect themselves less because they are unable to take care of themselves. It is interesting that a higher proportion reported respecting themselves less because they are unable to take care of themselves than actually reported viewing themselves in that way.
- 5.12.** Just under half of respondents reported that they respected themselves less because they are unpredictable (46%) and because they are to blame for their problems (45%). Again, those reporting that they respect themselves less because they are to blame for their problems make up a higher proportion of those who reported having that view of themselves (45% vs. 27%).

- 5.13.** Only 11% of respondents reported that they respected themselves less because they are dangerous, which is a similar proportion to those who reported having that view of themselves.

Self-perceptions and internalised stigma: qualitative research findings

- 5.14.** The supplementary qualitative research explored the differences in how people living with mental illness viewed others, how they viewed themselves, and the relationship between experiences of stigma and discrimination and how this influences self-stigma. The findings are discussed in the following sections.
- 5.15.** When asked whether they related to the finding that survey respondents held more sympathetic views towards others living with mental illness than they did towards themselves, the vast majority of interviewees agreed. Some shared examples of negative self-perceptions, such as feeling incapable, a failure, a burden, or not being good enough. Others said that instead of holding negative views about others, they empathised, identified with, and understood their experiences. For some interviewees, supporting or being kind to others was important to their sense of self and was felt to benefit them too. One person reflected that their sympathy varied depending on the severity of the person's condition.

"I'm a little bit less sympathetic with more mild problems... when there's people who are a little bit more dramatic about things than they need to be... I've got a little bit less sympathy for that... Then there's quite a few people I know, who've got mental illness problems, and I think really highly of them as people. And I want to support and care about them. And I really understand how they feel... I really... enjoy being able to give them that support... It's a privilege. So that makes me view them with a lot of kindness. And I can relate to the feeling... so I suppose I've seen them as a whole person."

Researcher: ***"So those kinds of experiences have influenced how you feel about yourself. Why do you think that it's not influenced how you feel about other people?"***

Interviewee: ***"I think I've got more compassion – I know what it's like to be on the other end."***

Reasons for self-criticism

Stigma

- 5.16.** The most common explanation for why interviewees and survey participants were more sympathetic towards others living with mental illness than themselves, was the impact of stigma on self-perception. Some discussed absorbing or internalising negative societal or media representations of mental illness. A few felt that negative self-perceptions are fuelled by 'mental illness' or 'disability' labels that are stigmatising; or by disempowering, reductive and dehumanising healthcare systems, assessments, and treatment pathways. Others highlighted that stigmatising treatment from others, such as being unheard, dismissed, disbelieved, misunderstood, blamed, judged, and deemed incapable, caused them to doubt themselves and were a barrier to self-compassion, maintaining their distress.

"I didn't see myself as being a discriminat(ing) type of person. Like most people, I like to think that I'm understanding of other people and that I wouldn't treat someone differently...(but) somewhere in the back of my mind I must have had these views because once I was diagnosed myself, I immediately thought all these things about myself. I guess it was because you grew up around all these things and you're just taking them on board and you don't even realise... it was just, well, of course, now you're disabled. Now you're broken. You're incapable."

- 5.17. While some saw stigma as the cause of self-criticism, others felt that it interacted with, reinforced, and exacerbated pre-existing negative beliefs they held about themselves.

"It's probably something that was already there and made worse by stigma."

Mental health

- 5.18. The links between mental illness and self-criticism was the second most common theme. Some explained how their self-perception was impacted by their mental illness and associated cognitive, somatic, and mood-related issues, such as: rumination and over thinking, negative core beliefs and thinking styles, sleep difficulties, hearing critical voices, motivation difficulties, and isolation – leading to a lack of activity or distraction. Low self-worth, low self-esteem, and self-hatred were also mentioned. Mental illness was also described as a very 'personal battle', where people were more tuned into, and therefore more critical of, their own experiences than those of others. A few commented that their self-criticism, and the impact of stigma on this fluctuates – becoming stronger at times they are feeling low or struggling more with their mental health.

"It's a product, sometimes of depression... that you have this rumination... So you just think... I've made a mistake there... and then you can't stop thinking about it. And so it ends up being magnified and getting kind of worse and worse and dragging you down a bit... yeah, rumination and automatic negative thinking... and sometimes with a bit of a negative voice as well saying, well, why did you do that, that was stupid, or that kind of thing can kind of build-up. I think especially also, if you're in a depressive episode, where you don't really want to interact with people, and you're maybe a bit isolated – that can build because you haven't really got other things to distract you very much."

Expectations and comparisons

- 5.19. Interviewees linked self-criticism to falling short of their expectations, or having higher expectations of themselves than others. While a few described being perfectionistic or over-achieving, others explained that stigma and assumptions about mental illness played a role in the expectations they had of themselves – causing them to push themselves harder, or to invalidate their own distress.

"And so I think some of that self-criticism probably comes from, you're trying to overachieve. You're trying to not show that you're a bit down or that you're lacking. And so you're constantly pushing that bit further, you push yourself a bit further."

"I think... people look at my situation and think, 'well, what's she got to be ill about?'... I had a CPN... And I just got a promotion. But I was also off work with mania. And she was like, "oh, you've got promotion... oh, you get paid more than me, I don't know why you need my help". I was like, because money can't buy mental stability... it's easy for me to be very critical of myself, because I can look at myself on paper and say, well, actually, all of these things are really good. So what have you got to be ill about or worry about?"

- 5.20. Some found it easier to be dispassionate or objective when considering others or were more able to be compassionate towards, or 'give grace to' others than themselves.

"I do think we're much kinder to other people, then we are to ourselves, and we're much more likely to say, oh, yeah, they're having a hard time and make allowances. And we never make allowances for ourselves, even when we're having a hard time."

- 5.21. Negative self-comparison with others was also seen by some to be related to their self-criticism. While a couple of interviewees said they recognised others to also be struggling with mental illness or experiencing more severe difficulties than them, some believed they were coping relatively less well and felt they should be coping better. Social media and positive campaigns by mental health organisations were identified as fuelling negative self-comparisons with others.

"Your expectations are too high. I have expected myself to bounce back from this. And I've not. So then I started going 'well what's wrong with you? Why can't you bounce back?'... It's the expectation of you should be you know, I'm in my 30s I should be able to cope. People my age have kids. They have full time jobs. They've got adult kids in fact. You know, so they've coped in their lives with whatever has been thrown at them, they've coped. And you know... people only plaster the good stuff on Facebook they don't plaster all the rubbish they have in their personal lives."

Life experiences

- 5.22. The influence of stressful life experiences, such as trauma, abuse, difficult upbringings, and bullying, was highlighted by some interviewees as factors which influenced their self-perceptions. A couple of people also mentioned the cultural context in which they grew up.

"I grew up in a family where both my parents are alcoholics... I was abused and neglected, there was domestic violence... I didn't really have parents who were able to care for me, so I guess I just learned how they see me. And as a child, I learned that I'm worthless and that's what I brought here into my adulthood with me."

"I think quite a lot of people in Britain are like that anyway where you are quite self-critical."

Lack of acknowledgement and support

- 5.23. Not talking about their mental illness with others, a lack of acknowledgement of their experiences and insufficient support, was felt to have contributed to the negative self-perceptions held by some interviewees.

“You’ve got your internal feelings that you’ve probably felt for years. And a lot of those went unchallenged... I sat there thinking that I was a burden, for probably about 20 years... And realistically, it turned out that I’m probably not a burden at all. I just needed to get some help... CAMHS refused me... and then at 18 I got put on antidepressants, which at the time didn’t help... and because it took so long to (get help), I think my brain is unlikely to be able to rewire itself... there were how many years where we could have prevented this? But it doesn’t seem like prevention is important.”

Protective factors against self-criticism

- 5.24.** Interviewees identified a number of protective factors that either prevented them from being more critical of themselves than others living with mental illness, as was the case for 16% of interviewees, or helped to mitigate their self-criticism, encourage greater self-acceptance or support wellbeing. Most commonly, positive experiences with others were discussed, such as caring and kindness from others, having open discussions with others, and receiving praise or positive feedback.

“One lot of praise is worth 10 lots of nastiness... sometimes when you’re really, really struggling, just a small bit of kindness or a small bit of hope gets you through. And that doesn’t necessarily save your life, but it gets you through the next few hours and then you can do more and then you can do more...”

- 5.25.** However, some participants explained that they found it hard to accept praise, didn’t think they deserved it, or found it easier to believe the stigma or ingrained critical thoughts about themselves. A few mentioned the potential for praise to be patronising, be insincere or superficial. Others suggested that the impact of praise depends on context, an individual’s disposition, or their mental health at the time. A couple highlighted that the positive effects of praise are not long lasting or that the process of internalising this takes time.

“Because I think it’s a lot of the stigma... is against parents who have got mental health problems, or who have got poverty or employment issues... I really, really feel that so yeah, whenever somebody tell me I’m doing good, I’m holding on to it. But... it feels like a drop of water and there’s big waves of all this failure going over me all the time.”

- 5.26.** Another prevalent theme was the protective function of age and life experience against self-criticism. Interviewees spoke of being more open about their struggles, kinder to and more comfortable with themselves, better at coping with and understanding their distress, and more rejecting of stigmatised identities with increased age, time since diagnosis, stage of the recovery journey or personal growth.

“Four or five years down the line since my diagnosis I tried to consciously be... just a bit kinder to myself. Just to give myself a break, sometimes to stop feeling that everything has to be judged... to get off my own back.”

- 5.27.** Learning and developing coping techniques, boundaries, self-compassion or self-validation were also seen by some interviewees as important buffers against self-criticism. Recognising their own strength, not comparing themselves negatively to others, having an optimistic outlook and resilience were also highlighted.

"I think I've learned techniques. I think I mean, basically I've been dealing with depression since I was in my 20s... And I've learned ways of coping."

- 5.28. The importance of talking therapies or longer-term therapeutic relationships in challenging self-criticism or nurturing more positive self-perceptions were discussed by some.

"I went to therapy for almost six years now. And my therapist kept repeating to me... in an empathetic way that I'm a good person, I am acceptable. And she kept repeating this for three years. And I think after three years, I started to internalise it, because I didn't have that caring and acceptive voice inside, because no one really was able to give it to me when I was a child. So, I think there was the starting point... And then I was able to take it in from my partner, from my friends... And I think it's still in process, but it's becoming stronger. And the poor inner critic is getting quieter."

- 5.29. Rejecting or protecting themselves from stigma, by seeing it as other people's fault, 'pushing it aside', building a thick skin, or challenging it, was further identified by some as protective against self-blame and self-criticism. A couple of interviewees suggested that viewing stigma as part of life and without malicious intent was helpful.

"I think it's other people's weakness. To be honest. I think I've seen enough of life and I've seen enough of people mouthing off about other people and then looked at them and thought, well, actually, you're the one with the problem. So I don't think other people being rude or offhand, about mental illness doesn't make me feel bad about myself. It makes me wary of them and they are the one with the problem."

"If someone calls me unpredictable... I say... 'What do you mean by that?'. 'Give me an example'. I know, I'm predictable... mental tools to sort of say, you use logic, you can dismantle any argument."

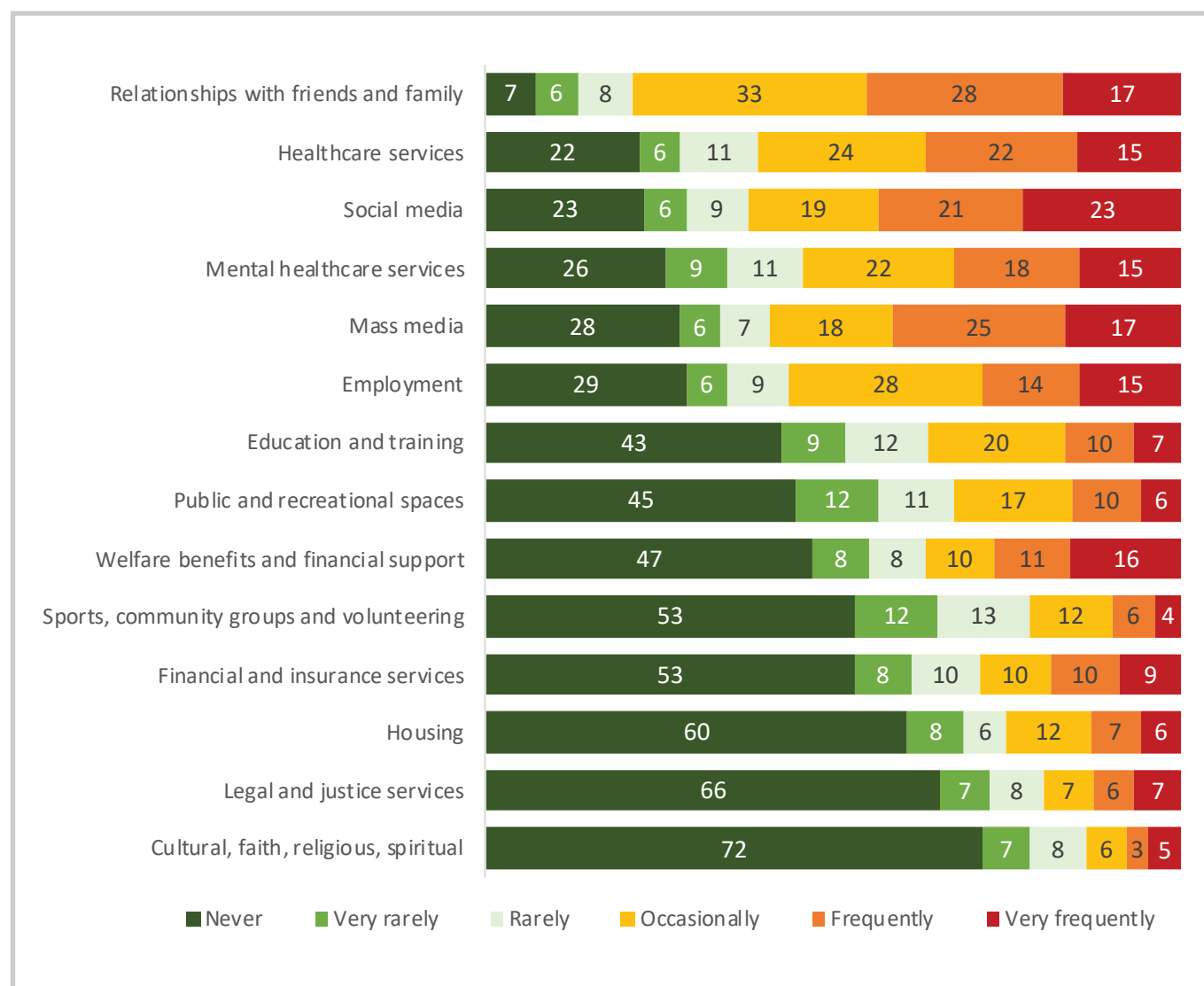
- 5.30. A few participants described the benefits of having access to resources, power, or meaningful activity, such as work, education, helping others, and fighting for justice, to support valued identities or defend against self-criticism.

"Coming back into work... That was also a new identity for me as well."

Frequency of stigma and discrimination

- 5.31. Survey respondents were asked to report on the frequency of which they had experienced stigma and discrimination in each life area over the previous 12 months. Respondents rated each life area ranging from 'never' through to 'very frequently'. Figure 5.2 provides an overview of the responses, broken down by life area and frequency rating.
- 5.32. Overall, the data demonstrates that respondents commonly experience significant stigma and discrimination across different areas of their lives.
- 5.33. Of the 14 life areas explored in the survey, relationships had the highest proportion of respondents reporting some level of stigma and discrimination (92%), followed by physical healthcare services and social media (each 78%), mental healthcare services (75%) and mass media (73%).

Figure 5.2. Perceived experiences of stigma and discrimination because of mental illness(es) in each life area in last 12 months (%) (n=346)



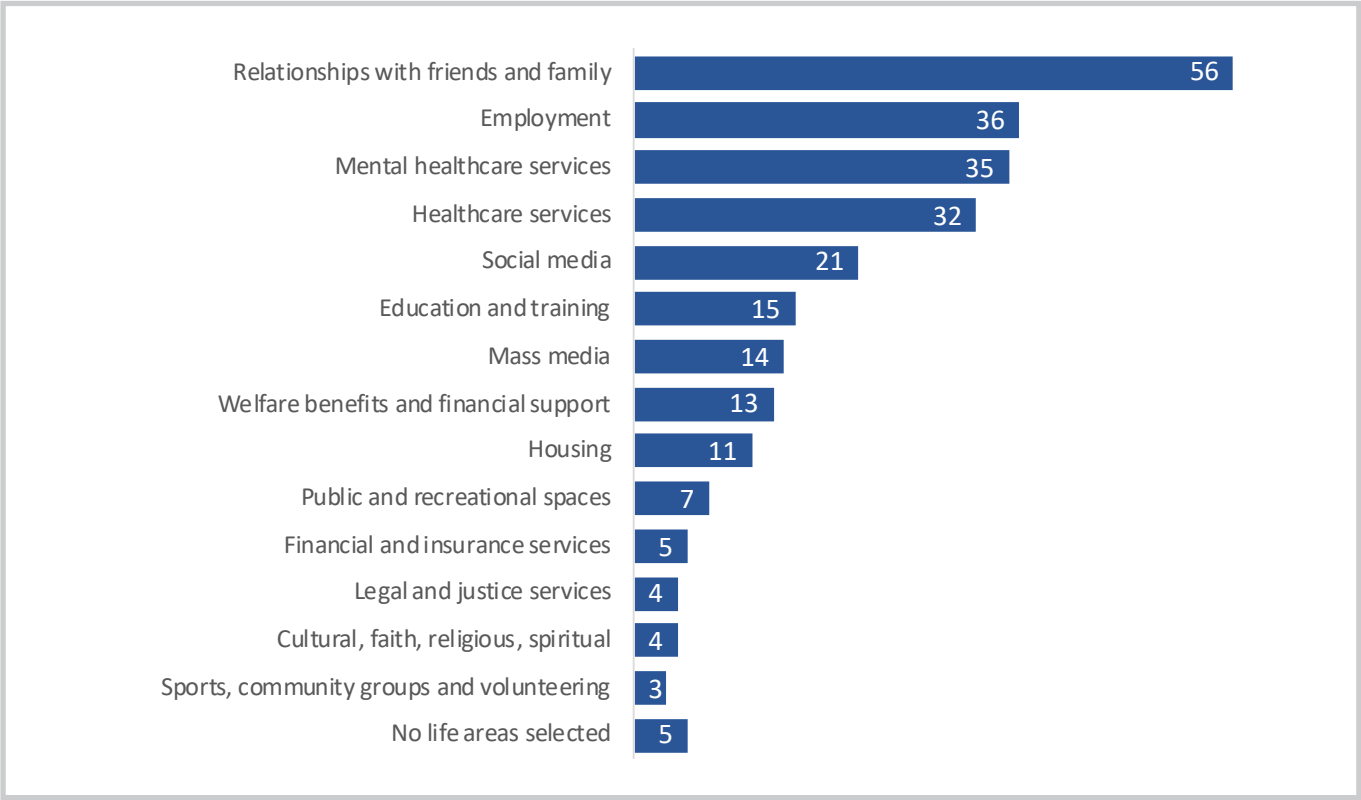
5.34. Only five of the 14 life areas recorded at least some level of stigma and discrimination from less than 50% of survey respondents. However, even those have substantial proportions of respondents reporting some level of stigma and discrimination in those life areas (ranging from 29% up to 47%).

5.35. High levels of frequency of stigma and discrimination (i.e. those selecting frequently or very frequently) broadly align with the pattern of experiencing any level of stigma and discrimination across life areas. Relationships remain the life area with the highest proportion reporting frequent or very frequent experiences of stigma and discrimination (45%). This was followed by social media (44%), mass media (42%), physical healthcare services (37%) and mental healthcare services (33%).

Frequency and impact

- 5.36. Respondents were also asked to identify the three life areas where stigma and discrimination had the greatest impact on them in the last 12 months, as shown in figure 5.3.
- 5.37. Relationships with friends and family was the life area that most respondents (56%) reported as being where stigma and discrimination had the greatest impact on them. This was followed by employment (36%), mental healthcare (35%), and physical healthcare services (32%). Social media was the fifth most commonly selected life area, chosen by 21% of respondents. All other life areas were selected by 15% or less of the survey population.

Figure 5.3. Life areas most impacted by experiences of stigma and discrimination because of mental illness(es) in last 12 months (%) (n=346) (Respondents could select a maximum of three)



- 5.38. Table 5.1 compares the five life areas of stigma and discrimination in relation to highest frequency of experience vs. greatest impact.
- 5.39. As the table above demonstrates, a higher frequency of stigma and discrimination does not necessarily translate into an equivalent level of impact. The relationships life area was reported as having the greatest frequency of stigma and discrimination and was the most commonly selected in terms of the impact of stigma and discrimination. However, this is not replicated in other life areas. Mass media, for example, features in the top five life areas where stigma and discrimination are experienced most frequently, but was not one of the five life areas in terms of the impact. Mental healthcare was recorded as the area with the third highest level of impact, but does not feature in the five areas where stigma and discrimination were reported most frequently.

Table 5.1 Comparison of most frequent and most impactful stigma and discrimination by life area

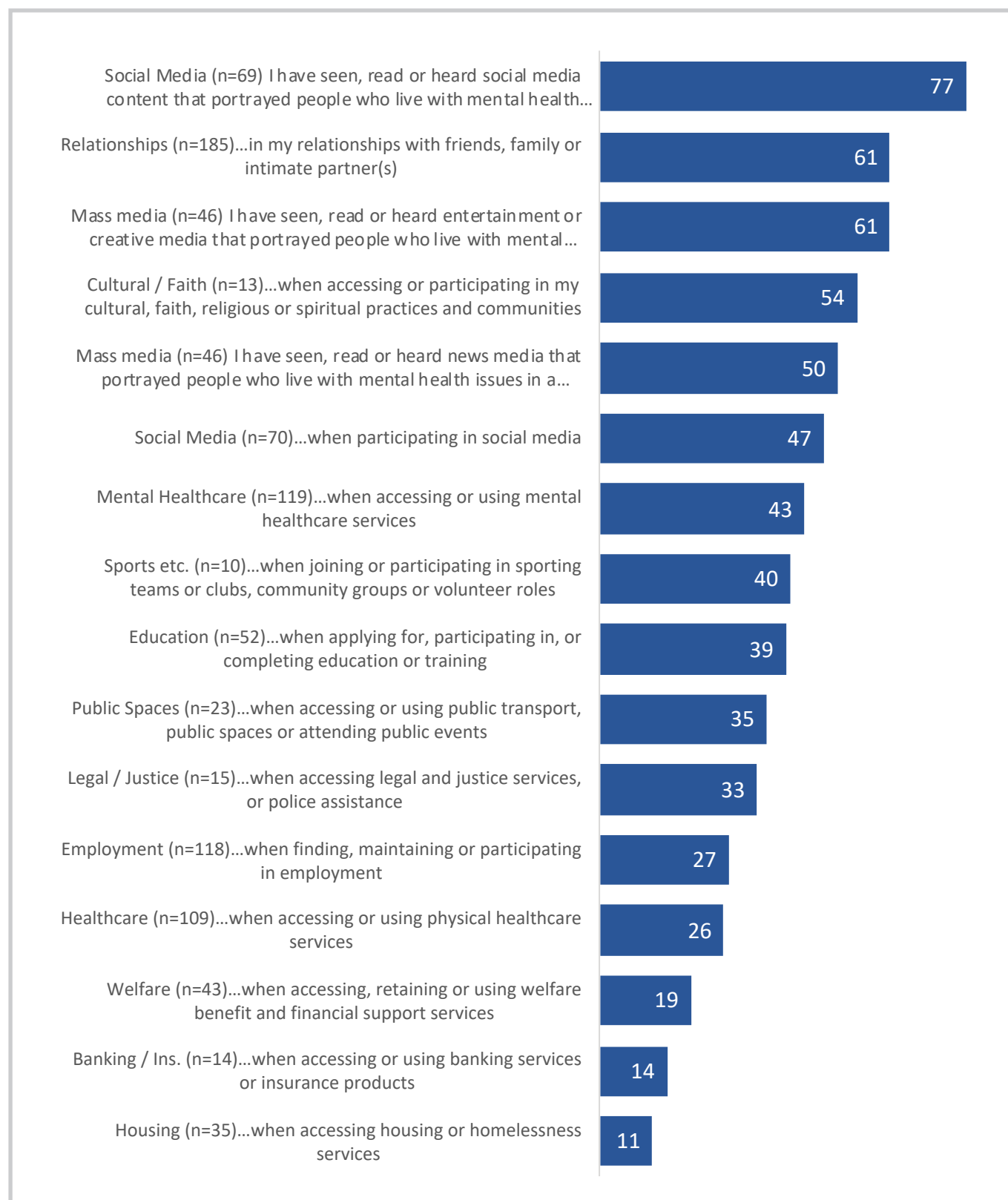
Position	Frequency (based on proportion of respondents reporting occasional, frequent or very frequent stigma and discrimination)	Impact (based on proportion of respondents selecting in their three most impactful)
1st	Relationships	Relationships
2nd	Social media	Employment
3rd	Healthcare (excluding mental healthcare)	Mental healthcare
4th	Mass media	Healthcare (excluding mental healthcare)
5th	Employment	Social media

5.40. We highlight that respondents who identified a life area as one of the most impactful tended to record a disproportionately higher frequency of stigma and discrimination in that area compared to the total survey sample. This ranged from 41% of respondents in the public and recreational spaces life area, through to 86% of respondents in the legal and justice life area. While the other respondents in each life area reported experiencing stigma and discrimination less frequently, it was still prevalent enough for them to select that life area as one of their most impactful.

Positive experiences across the 14 life areas

- 5.41.** Respondents reported having positive experiences because they live with mental illnesses in each life area, to varying degrees. Life areas with the highest proportions of positive experiences were: seeing, reading or hearing social media that portrayed people living with mental illnesses in a positive way (77%), having positive experiences in their relationships (61%), seeing, reading or hearing entertainment or creative mass media that portrayed people living with mental illnesses in a positive way (61%) and positive experiences in culture, faith, religious or spiritual practices and communities (54%)
- 5.42.** Just under half (47%) of respondents reported positive experiences when participating in social media, and 50% reported positive experiences when seeing, hearing or reading news media. Given that social media, mass media and relationships were among the life areas with the highest frequency of stigma and discrimination reported, it is interesting that they were also the life areas with the highest levels of positive experiences.
- 5.43.** The lowest levels of positive experiences were found in housing (11%), banking and insurance (14%), welfare benefits and financial support (19%), healthcare services (excluding mental healthcare 26%) and employment (27%).

Figure 5.4. Positive experiences in each life area because of participants' complex mental illness



6. Introduction to the life areas

- 6.1.** Chapters seven to 20 present the findings for the 14 life areas explored in the survey. Each respondent could select up to three life areas where stigma and discrimination about their mental illnesses has had the greatest impact.
- 6.2.** Life area chapters of the report are presented in order, based on the proportion of respondents that selected each life area as one of their three most impactful, from most to least.
- 6.3.** The structure of findings for each life area is set out as follows:
 - Overview of life area including the definition used and what is covered by each life area, the frequency of stigma and discrimination experienced, and the proportion of respondents that selected it as one of their three most impactful.
 - The profile of respondents who selected the life area.
 - Perceived experiences of stigma and discrimination.
 - Anticipation of experiencing stigma and discrimination.
 - Withdrawal from opportunities due to stigma and discrimination.
 - Intersectional stigma and discrimination based on protected characteristics.
 - View on the requirement for special considerations.
 - Thematic findings from open-ended responses about experiences and views.
 - Positive experiences in the life area due to respondents' mental illnesses.
- 6.4.** In each life area, we compare the profile of respondents who selected that life area against the overall survey population and draw out any differences. Full demographic data tables are included in Appendix 1 for reference.
- 6.5.** To measure perceived experiences, anticipated stigma and withdrawal from opportunity, respondents were asked the extent to which they agreed with a series of statements. The response scale was: strongly disagree, disagree, slightly disagree, slightly agree, agree and strongly agree. References to total agreement include all those who selected slightly agree through to strongly agree^s. In instances where we refer to one point in the scale – for example strongly agreed – this is explicitly stated.
- 6.6.** The same scale was used when respondents were asked about any positive experiences linked to their mental illnesses, and experiences of intersectional stigma and discrimination.
- 6.7.** Eight life areas included subcategories of experiences of stigma and discrimination. In these instances, results fluctuate based on the numbers that selected each subcategory. For example, in the relationships life area, respondents were asked whether they had

^s. Combined figures may not add to the total of the component figures due to rounding.

experienced stigma and discrimination in intimate relationships, friendships, parent or caregiver relationships and family relationships.

- 6.8.** Regardless of any subcategories selected, all respondents were presented with the same statements about (i) anticipated stigma and discrimination and (ii) withdrawal from opportunity.
- 6.9.** The life areas that included subcategory options are:
- Relationships.
 - Housing.
 - Banking and insurance services.
 - Public and recreational spaces.
 - Mental healthcare services.
 - Sports, community groups and volunteering.
 - Legal and justice services.
 - Cultural, faith, religious or spiritual practices and communities.
- 6.10.** Respondents did not have to answer every question, so in many cases the sample size for a question is slightly lower than the total number of respondents who selected that life area.

7. Relationships with friends and family

“Stigma is rife with family and friends.”

Overview

- 7.1. This chapter explores experiences of stigma and discrimination in developing, participating in, and maintaining relationships.
- 7.2. The survey question about relationships spanned:
 - People considered friends.
 - Biological, adopted, fostered and chosen family, relatives and children.
 - Intimate partners (e.g. dating, married, civil partner, co-habiting and casual).
- 7.3. In total, 321 respondents (93%) reported experiences of stigma and discrimination in the relationships life area within the past 12 months, with 28% reporting frequent or 17% very frequent experiences. Of all life areas, relationships was the most commonly selected area in terms of the frequency of stigma and discrimination experienced.
- 7.4. This area was selected by 192 respondents (55%) as one of up to three in which the stigma and discrimination they experienced had the greatest impact on them. Those who selected this life area as one of the three most impactful recorded slightly higher levels of perceived stigma and discrimination. Over half (56%) said they had experienced stigma related to this either frequently or very frequently, compared to 45% of all respondents.
- 7.5. Those who selected the relationships life area were asked to state in which types of relationships they had experienced stigma and discrimination. The choices were:
 - Familial relationships – selected by 178 respondents.
 - Friendships – selected by 173 respondents.
 - Intimate relationships – selected by 137 respondents.
 - Parent or caregiver – selected by 51 respondents.
- 7.6. Respondents were presented with a range of statements for each relationship category selected.
- 7.7. This chapter presents the profile and experiences of respondents who selected relationships as one of their three life areas where the greatest impact of stigma and discrimination is felt.

Respondent profile

- 7.8. The profile of those who selected the relationships life area in their top three is largely reflective of the overall respondent population.
- 7.9. In terms of mental illnesses, the sample that selected the relationships life area in their top three also aligns closely to the overall survey respondent population (see Appendix 2).

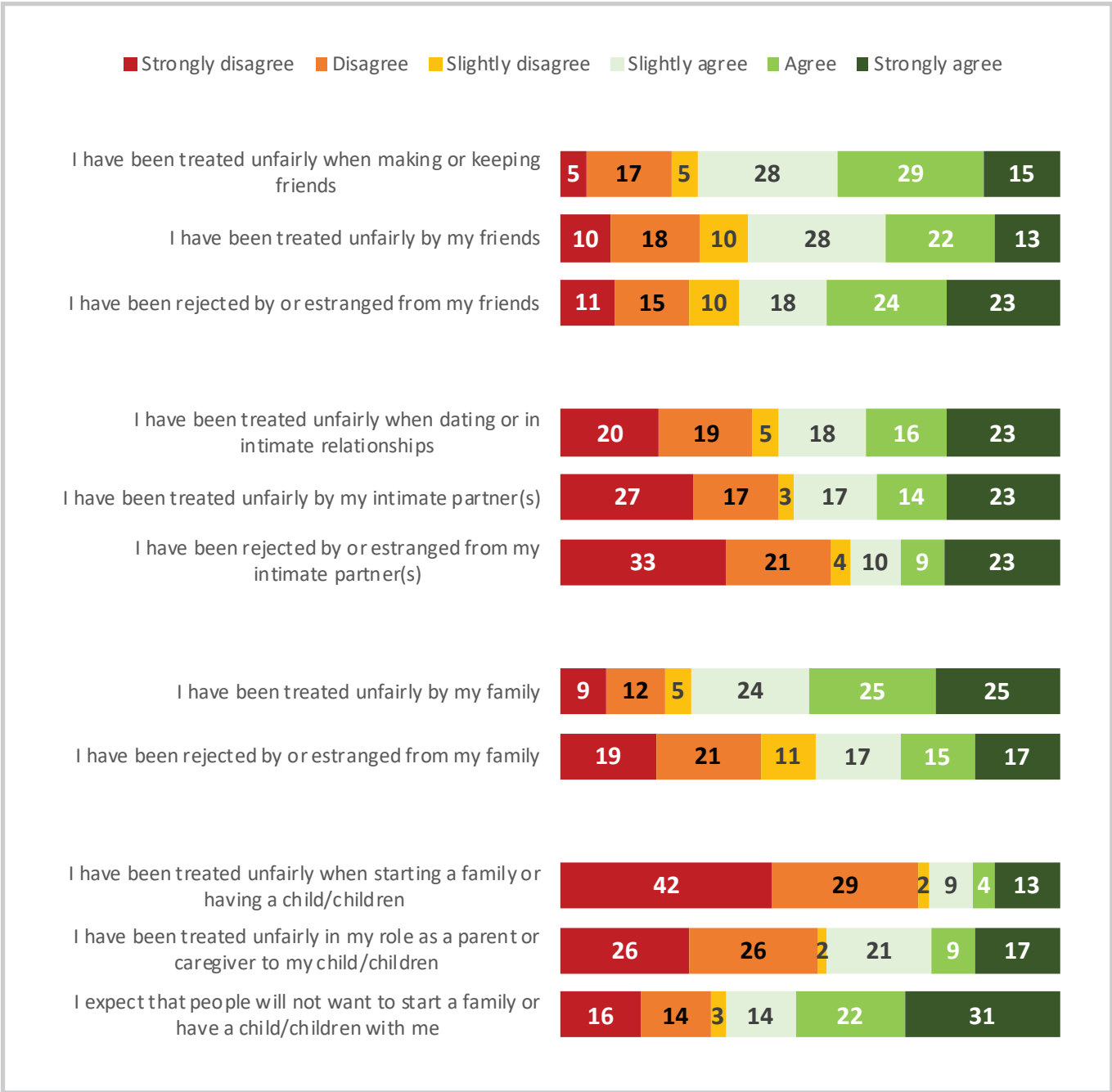
Perceived experiences of stigma and discrimination in relationships

“I had a friend who didn’t want me around her children any more as I was ‘probably dangerous’ because I have a mental illness diagnosis.”

7.10. Figure 7.1 presents the extent to which respondents agreed or disagreed with statements about stigma and discrimination in relation to their mental illness and relationships. Responses for each relationship category are shown.

Figure 7.1. Perceived experiences of stigma and discrimination in relationships: percentage agreement and disagreement

Because of stigma about my mental illness(es)...



- 7.11.** Experiences of stigma within family relationships was most common. Three quarters of respondents (75%) agreed they had been treated unfairly by family members. This statement received the highest level of endorsement of all the statements about experiences of stigma and discrimination within relationships. Close to half (49%) of respondents also reported experiences of being rejected by, or estranged from, family.

"In the past family members have said things like 'I was having a good day until you phoned'. It is very hurtful...Another situation when I spoke to family and they said 'why can't you not just be normal'. I think they try to help but don't understand what they are saying is so hurtful."

- 7.12.** In relationships with friends, the majority of respondents agreed that, due to stigma about their mental health, they had been treated unfairly (62%), rejected by or estranged from friends (65%) and treated unfairly when making or keeping friends (72%). This latter experience of stigma and discrimination was the second most commonly reported in the relationships life area.
- 7.13.** There were slightly lower levels of agreement with statements about unfair treatment or rejection in intimate relationships. Still, over half of respondents agreed they had been treated unfairly when dating (56%) and by their intimate partner(s) (53%). Four in ten (42%) respondents also agreed they had been rejected by, or estranged from, their intimate partner(s) due to stigma.
- 7.14.** Almost one third (27%) of respondents agreed with the statement that they had been treated unfairly when starting a family or having children due to mental health stigma. Close to a half (47%) of these respondents agreed that they had been treated unfairly in their role as a parent/caregiver.

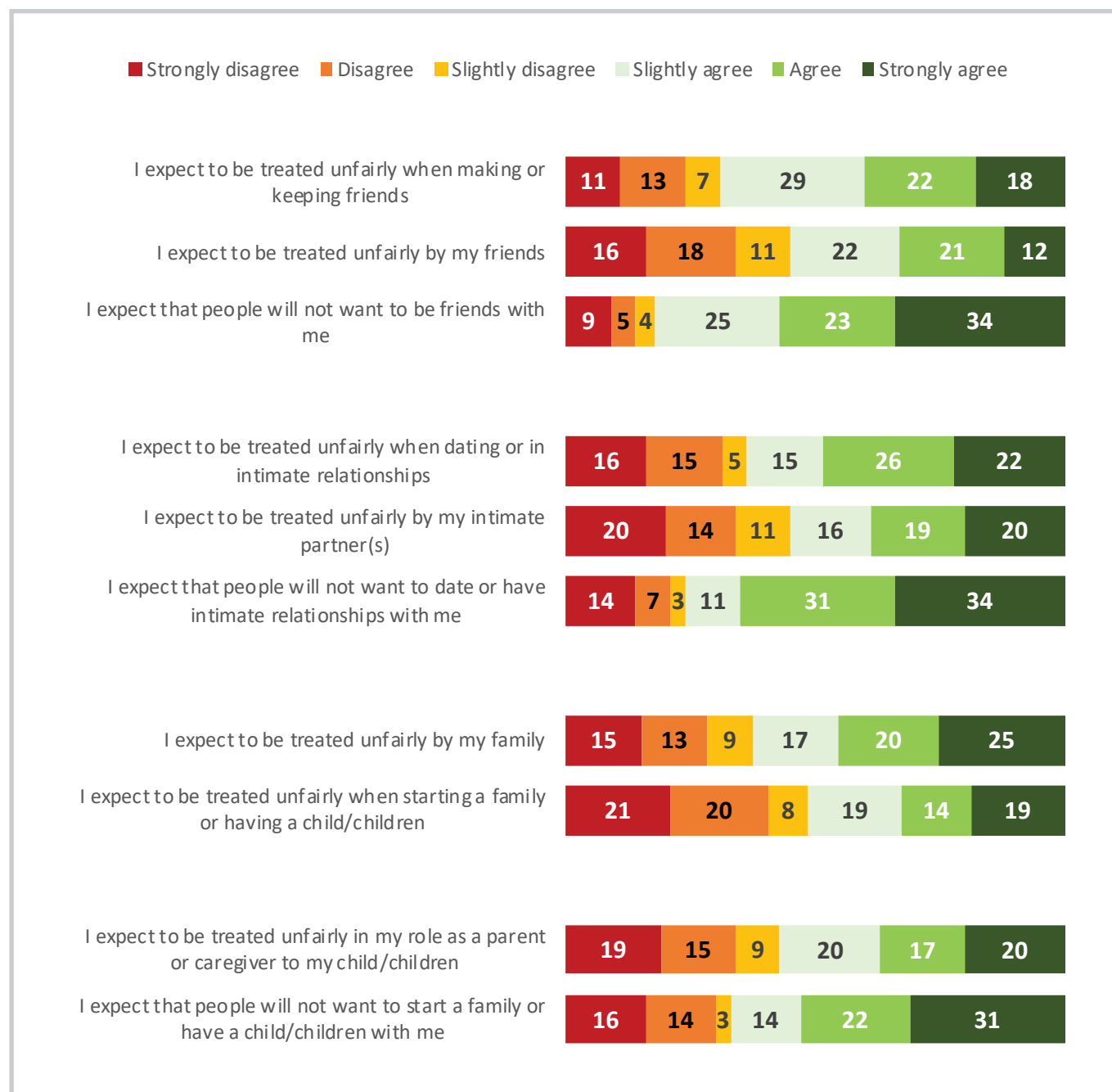
Anticipated stigma and discrimination in relationships

"Levels of discrimination and stigma can be dependent on how much you share with people. If they aren't aware of your situation, or the severity of it, then there is no stigma. But you're not being your whole self with them."

- 7.15.** Figure 7.2 presents the extent to which respondents agreed or disagreed with statements about anticipated stigma and discrimination about their mental illnesses in their relationships. Responses to statements are shown for friendships, intimate relationships, familial relationships, and parenting or caregiving for children.
- 7.16.** Each statement about anticipated stigma and discrimination in relationships was endorsed by more than half of respondents who answered the question.
- 7.17.** Responses to statements about anticipated stigma and discrimination in friendships broadly aligned to responses about experiences. Over half of respondents (55%) anticipated being treated unfairly by friends, and over two thirds (68%) anticipated being treated unfairly when making or keeping friends. Strikingly, 82% (the highest percentage agreement in this section) expected others would not want to be their friend due to their mental illness. Interestingly, slightly less agreed they had experienced rejection from friends (72%).
- 7.18.** As with perceived experiences, over half agreed they expected to be treated unfairly when dating (63%) and by their intimate partner (55%). Three quarters (76%) expected people would not want to date or have intimate relationships with them. It is worth noting that this statement received the second highest level of agreement in this section, despite only 42% of respondents reporting experiences of rejection in their intimate relationships due to mental health stigma.

Figure 7.2. Anticipated stigma and discrimination in relationships: percentage agreement and disagreement (n=183-187)

Because of stigma about my mental illness(es)...



- 7.19.** Six out of ten (62%) respondents agreed that they expected to be treated unfairly by their family due to mental health stigma; this is slightly less than those who reported actual experiences of being treated unfairly by family (75%). Over half of respondents (52%) also agreed they expected to be treated unfairly because of their mental illness when starting a family or having a child.
- 7.20.** Over half of respondents (58%) agreed they expected to be treated unfairly in their role as a parent/caregiver because of stigma about their mental illness. This is slightly higher than the 47% of respondents who reported experiences of being treated unfairly within this role. A still larger percentage of respondents (68%) endorsed the statement that they anticipated people would not want to start a family or have a child with them.

Withdrawal from opportunity in relationships

“I tend to push people away.”

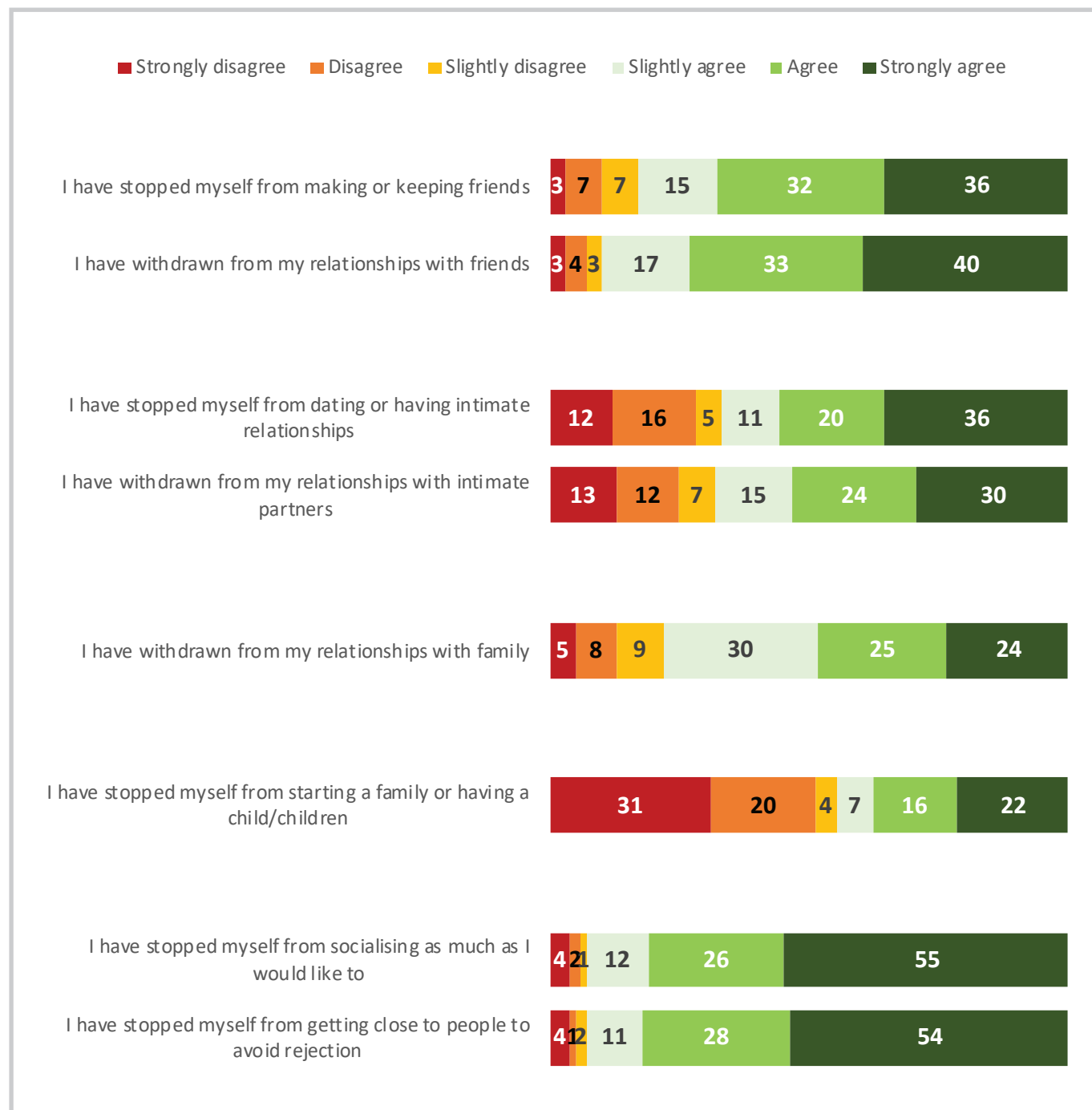
- 7.21.** Figure 7.3 presents the extent to which respondents agreed or disagreed with statements about withdrawing from relationships.
- 7.22.** Respondents linked stigma about their mental illnesses to very high levels of withdrawal from socialising as much as they would like to (93%) and getting close to others to avoid rejection (94%). Withdrawal from opportunities received the highest level of endorsement of all relationship statements.
- 7.23.** Similarly high levels of agreement were evident in withdrawal from relationships with friends (90%) and making and keeping friends (83%) due to mental health stigma.
- 7.24.** More than three quarters of respondents (79%) agreed that due to stigma and discrimination they had withdrawn from relationships with family.
- 7.25.** Over two thirds of those surveyed endorsed statements that they had stopped themselves from dating or having intimate relationships (68%) and had withdrawn from relationships with intimate partners (69%).

“I feel my conditions are a significant barrier to me being open and honest with partners or in pursuing potential partners as I believe there is significant stigma attached to BPD.”

- 7.26.** Although receiving the lowest level of agreement in this section, it is striking that four in ten (45%) participants agreed that they had stopped themselves from starting a family or having children due to mental health stigma.
- 7.27.** The high levels of agreement with these statements demonstrate that mental health stigma has a profound effect on how people with lived experience of mental illnesses interact with others and their opportunities to maintain or form relationships.

Figure 7.3. Withdrawal from opportunities in relationships: percentage agreement and disagreement (n=182-186)

Because of stigma about my mental illness(es)...



Intersectional stigma and discrimination within relationships

7.28. Intersectional experiences of stigma and discrimination within relationships is also evident from survey responses. Respondents were asked about experiences of stigma and discrimination associated with other aspects of their identity. Sexual orientation (22%), age (21%), sex (21%) and disability (21%) were the most commonly reported intersecting factors for this life area.

Views on the requirement for special considerations

7.29. Finally, respondents were presented with a statement about whether they should receive additional consideration within relationships because of their mental illness. Nearly two thirds (65%) of respondents agreed that they should receive additional consideration.

Other feedback about stigma and discrimination in relationships

7.30. Respondents were invited to share further details about their experiences of stigma and discrimination within their relationships. An analysis of comments identified four overarching, inter-related themes, discussed below:

- Trauma and power imbalances within relationships.
- Stigmatised perceptions and identities.
- Struggling for acceptance and connection.
- Impacts and protective strategies.

Trauma and power imbalances within relationships

7.31. Experiences of trauma, abuse and bullying in relationships were recounted by several respondents.

7.32. For some, these experiences had occurred earlier in their lives and were understood to be a contributing cause of their distress. For others, these experiences were more recent and were viewed as a consequence of their mental illnesses and the associated stigma they had experienced.

"I recently fled my last social and intimate relationship due to domestic violence which I believe was centred around my mental and neurological health difficulties, and I still seem to be viewed with pity and disbelief."

7.33. A few participants said that their traumatic experiences were met by disbelief or minimisation from others. One person explained the impact this had on their subsequent relationships:

"Part of my mental health issues relate to being in an abusive relationship a few years ago. A lot of people brush it off as being not too bad and don't think that my mental health issues that are caused by it are serious. This has prevented me from making/keeping friends, and from talking to family about my mental health."

7.34. Other power imbalances within relationships were described by respondents, which they linked to their mental illnesses and/or associated stigma. These included being disinherited, having their opinions or experiences minimised or dismissed and being disempowered around discussion of their mental health. One respondent described being silenced from

talking about their mental health with family; another's mental health difficulties were disclosed to others without their consent.

"I feel family think they have to make decisions regarding me – dismissing my opinion now and then as if I'm not as capable anymore."

"It is often used by my step-children as a weapon against me in any kind of confrontation."

Stigmatised perceptions and identities

- 7.35.** Respondents suggested they were viewed differently, looked down on or negatively evaluated within their relationships due to their mental illness.
- 7.36.** Some referenced degrading or stereotyped identities when considering others' perceptions of them. For example, they spoke of others viewing them as dangerous, incapable, or not 'normal', due to their mental illness.

"I suffered through several bad work situations and a divorce. After that I returned home and used a lot of my savings to attempt to stave off my depression, which became increasingly worse due to being considered 'a loser'. Most of my friends and family stopped speaking to me."

- 7.37.** A few respondents described comparing themselves negatively in relation to others and described how stigmatised identities fuelled a sense of inferiority or difficulties with self-acceptance.

"I always feel inadequate to others without mental health issues and I feel stigma has impacted this belief in me."

Struggling for acceptance and connection

- 7.38.** Mental illness and stigma were linked to struggles in gaining acceptance from, and connecting with, others. Some suggested this stemmed from a lack of understanding about mental illnesses, or fluctuations in mental health, among their social networks. A few shared their sense that others did not even attempt to understand, while some described unsupportive and invalidating responses from others.

"Most stigma/social issues I've faced around OCD have been because I've either not disclosed, and my behaviour have obviously then seemed aberrant, or an individual has simply not understood what the condition is. Most people are open to learning if given the chance."

"I think a lot of people, some of which were friends, have this idea that you can change depression for example by just 'thinking positively' or 'getting a grip of yourself'."

"My parents do not believe I have any mental health issues and constantly insult me and tell me to 'grow up' whenever I'm having a difficult time."

- 7.39. There were several comments about feeling blamed or judged for living with mental illnesses; the participant below suggested this was a barrier to receiving support.

"I have lost lifelong friends and partners due to them not understanding Bipolar. I often use the comparison that if you had a disease people want to help and support you but with bipolar people don't want to be around you and blame you for your actions/symptoms."

Impacts and protective strategies

- 7.40. Respondents highlighted the impacts of their mental illnesses and associated stigma on their relationships and opportunities to have social and family networks. Some spoke of communication difficulties or being treated differently; for instance, people 'walking on eggshells' around them. Others recounted experiences of relationship breakdown and loss, rejection and exclusion, and/or isolation and loneliness. Some reflected that this further exacerbated their distress.

"(I) get rejected by men I try to date in my city either because they get warned to stay away from me, or because they find me socially embarrassing. This makes me very depressed as I want nothing more than to find and be with a partner."

"I have never really had friends but these days I just don't feel inclined to work at making relationships. My main relationship is with the TV which is destroying my ability to think about anything or engage with any activities. I don't think getting older is an excuse. There is just less opportunity. If social opportunities arise, I feel inadequate because I have never had children or care dependents. I feel like a useless member of society with nothing to contribute. Being diagnosed with a mental health condition 30 years ago and living in cramped housing means having a family was never an option."

"I refrain from conversation with members of my family who have rejected me for reasons I do not understand. My daughter has cut me off completely for the last two years and that means I do not get to see three of my grandchildren. The 4th is at Uni so we keep in contact. This has caused me major distress."

- 7.41. Non-disclosure of their mental illness was discussed by several respondents. Most explained they did this to protect themselves from a stigmatised identity or the negative judgement of others. One person indicated they also did this to protect others.

"I haven't told my family. I pretend I don't have mental health difficulties. I don't want to be seen differently or for them to worry."

"This and previous page answers presume I have told people I have a mental health diagnosis. They don't know, I told people I was physically unwell when detained. My health is private not for discussion. People gossip and they tell others."

- 7.42. A few participants reflected that not sharing with others negatively impacted their wellbeing or was a barrier to authenticity and closeness within their relationships.

"I hide it and it is exhausting."

"I feel that I don't know how to cope with my condition very well and I don't really know how to explain it to other people. I think that other people wouldn't necessarily understand my situation or want to have to deal with it. I don't even want to have to deal with it myself, so that's understandable. Because of this it is hard to talk about these subjects with people, but it is something that affects me on pretty much a daily basis, so by not talking about that, it means I can't really talk about much in my life. And that leaves me feeling distant from people or just finding it easier not to try to deal with people. I withdraw and I feel sad or disappointed about that, but I don't know how to talk about it or what would happen if I did try."

- 7.43.** Wariness in, and avoidance of, relationships was commonly described by participants as a means of coping. Some explained their mental illnesses were a barrier to socialising. Others linked this to difficulties in trusting others – as a result of trauma and/or anticipated mental health stigma.

"I am working and then spending a lot of my spare time recovering from that (I absolutely LOVE my job and wouldn't want to do anything else, but it still takes energy to do it – getting out of bed, preparing and doing my best etc.) when others might be able to socialise and maintain friendships. I feel like if I spent time outside of work maintaining friendships, I would also have to take extra time off to recover and build up my energy levels."

"I cannot withstand further betrayals of my trust, so I am very cautious about having friendships."

Positive experiences

- 7.44.** Respondents were presented with a statement about positive experiences when entering, participating in and maintaining relationships. More than half (61%) of respondents agreed that they have had positive experiences in this life area because of their mental illness. Out of all the life areas, positive experiences within relationships ranked second equal.

"I wouldn't be here without my family; I'm incredibly lucky and my heart goes out to those struggling without that support."

- 7.45.** When invited to comment on any positive experiences in their relationships due to living with a mental illness, several respondents described negative experiences; these aligned with the themes detailed above. Two inter-related themes about positive experiences emerged:

- Appreciating relationships and connection.
- The value of lived experience.

- 7.46.** Experiences of love, connection, support, and empathy in relationships were shared by respondents. A few described an impression that the general public have become more accepting of mental illness. Some discussed how important their relationships were to them. Others spoke of the benefits of talking about their mental health with others or their surprise at the supportive responses they received.

"Having recently opened up to close friends amidst the pandemic I have found a significant amount of support that I previously would not have sought or expected."

- 7.47.** A few respondents shared, however, that while they greatly appreciated their loved ones' support, understanding and 'sanctuary', they felt undeserving of this, or guilty about the impact their difficulties had on others.
- 7.48.** The importance of choosing relationships carefully was talked about by a few respondents. A couple of people linked this to their past traumatic experiences or lifestyle choices among their friendship groups.

"I know now to keep away from making friends with people from school or college/ university or work because they are not willing to be friends without drinking alcohol or smoking cigarettes or doing drugs."

"My strongest and closest friends are the ones I can be very open and frank with. Those that care matter and those who don't care don't matter. As I've got older I've appreciated the importance of quality over quantity."

- 7.49.** The value of shared experience and peer support was raised by some participants. They described acceptance and understanding from others who lived with mental illnesses themselves. Some explained how their lived experience helped them to forge close friendships.

"I've been able to foster deep connections with friends because of it. My Complex Trauma is rooted in relational abuse so relationships can be difficult, but when I have made a connection and trusted a friend, they are with me for life. It doesn't happen often as my guard is naturally always up and being vulnerable is traumatic in itself- but when those vulnerabilities are met with empathy and compassion, that friendship is cemented. And, of course, it goes both ways. My CPTSD has made me a good listener with compassionate ears."

"I have friends who have similar experiences or empathy for my experiences. I have met people I wouldn't otherwise know due to my experiences that mean the world to me."

- 7.50.** Some highlighted how they hoped to be treated within their relationships and expressed a wish for increased understanding, acceptance and consideration, practical support and more realistic expectations in relation to their mental illness. The participant below explained that they still anticipated being held to the same behavioural standards as anyone else.

"Additional consideration means not taking it personally if a friend with CPTSD struggles with trust issues, and understanding that your bipolar / ADHD friend is an overly chatty today because they are a bit manic / hyper, not because they don't care about what you have to say. I have ended friendships with people who have the same disorders as I because they did not take responsibility for unacceptable behaviour, and I expect others to require the same emotional competency from me that they would anybody else."

Summary

- Relationships was the most commonly selected life area in terms of frequency of stigma and discrimination experienced by respondents in the past 12 months. The majority (321 or 93%) of all those surveyed reported experiences of this, with 28% reporting it was experienced frequently and 17% very frequently.
- This area was selected by 192 (55%) of respondents as one of up to three in which the stigma and discrimination they experienced had the greatest impact on them.
- Strongest levels of agreement were for statements about experiences of stigma and discrimination within family relationships, with three quarters (75%) of respondents agreeing they had experienced this and 62% anticipating experiencing this in the future.
- Stigma and discrimination within friendships was also frequently reported, with over six in ten respondents endorsing all relevant statements. Broadly similar proportions anticipated encountering mental health stigma within friendships in the future, with one difference of note being that 82% expected others would not want to be their friend, due to their lived experience of severe and enduring mental illnesses.
- Over half of respondents agreed they had been treated unfairly when dating (56%) and by their intimate partner(s) (53%). Again, broadly similar numbers expected to experience mental health stigma within intimate relationships in the future. A striking difference is that while 42% of respondents reported experiences of rejection in their intimate relationships due to mental health stigma, 76% anticipated this could happen to them in the future.
- The lowest level of agreement was for statements about experiences of stigma and discrimination linked to being a parent or carer. However, this is still a key issue for many; almost half (47%) of respondents agreed that they had been treated unfairly in these roles and levels of anticipation of experiencing this in the future were again higher (58%).
- Respondents linked stigma to striking levels of withdrawal from all types of relationships. Nine in ten said that, within their relationships generally, they avoided socialising as much as they would like to (93%) and getting close to others to avoid rejection (94%).
- In their free text responses about stigma and discrimination in relationships, four overarching, inter-related themes emerged. Respondents recounted experiences of trauma, abuse, and bullying. Stigmatised perceptions and identities were described, where respondents felt they were viewed differently, looked down on or negatively evaluated within their relationships due to their mental health difficulties. Stigma was also seen to link to struggles for acceptance and connection with others. Respondents highlighted the impacts of their mental illness and stigma on their relationships, and the range of protective strategies they put in place to minimise these impacts.

8. Employment

"I feel hyper-vigilant, like someone is going to attack me with their words or criticise me at any moment. It is really difficult to be in an environment where you are not believed and where you are dismissed – the employer, management and colleagues are all essentially gaslighting you when this happens and they dismiss your experiences and what is going on for you. It is traumatising to be told over and over that 'you've just got to think positively' or 'just do some meditation' or when your ideas are not taken seriously because of people's perception of you. It is physically painful to not be able to show your potential at work because of the perceptions of others and the roadblocks others put in place when they discriminate against you."

Overview

- 8.1.** This chapter explores experiences of stigma and discrimination in accessing and participating in employment for respondents living with complex, severe and/or enduring mental illnesses.
- 8.2.** Our definition of paid employment included casual or zero hours contracts, part-time, full-time, and fixed-term temporary and permanent employment contracts.
- 8.3.** Employment was the sixth most commonly selected life area in terms of the frequency of stigma and discrimination experienced. In total 247 (71%) of all respondents reported experiences of stigma and discrimination in this life area within the past 12 months, with 14% reporting it was experienced frequently and 15% very frequently.
- 8.4.** The employment life area was selected by 125 (36%) of respondents as one of up to three in which the stigma and discrimination they experienced had the greatest impact on them. Those selecting this life area as one of the most impactful also tended to experience higher levels of perceived stigma and discrimination in the employment life area.
- 8.5.** This chapter presents the profile and experiences of respondents who selected employment as one of their three areas where the greatest impact is felt.

Respondent profile

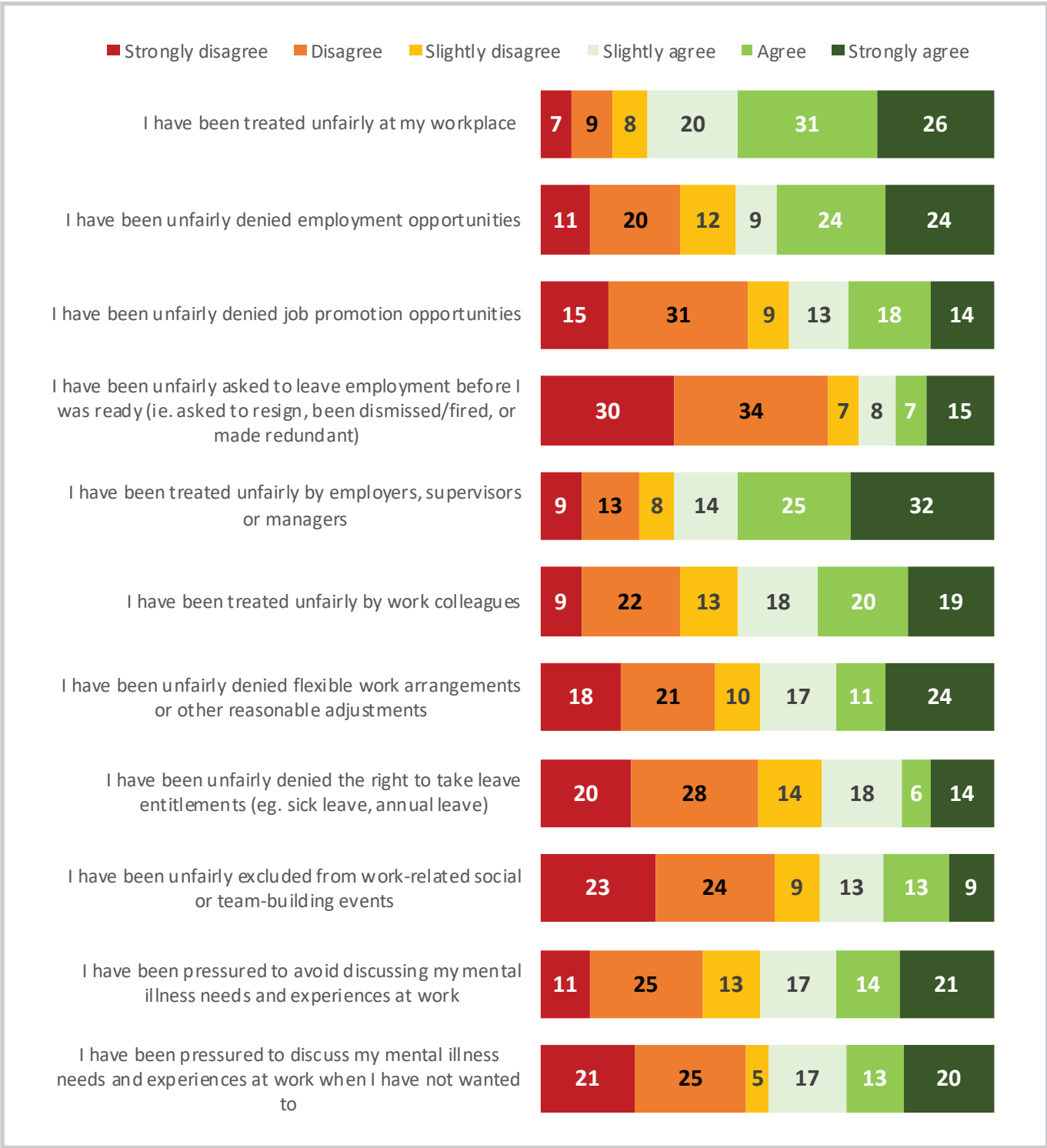
- 8.6.** The profile of participants who selected the employment life area in their top three is largely reflective of the overall respondent population. Notably, a higher proportion of respondents who selected this life area reported being in paid employment (70%) compared to the overall population of respondents (51%). A slightly higher proportion of private homeowners (44%) selected the employment life area compared to the overall respondent population (36%).
- 8.7.** In terms of the profile of mental illnesses among respondents, the overall survey respondent population is broadly comparable to the sample that selected the employment life area in their top three. The overall survey respondent population had a higher proportion of those living with personality disorders (31% in the overall sample vs. 24% in the employment life area sample) and feeding or eating disorders (20% in the overall sample vs. 14% in the employment life area sample).

Perceived experiences of stigma and discrimination in employment

8.8. This section explores respondents’ experiences of mental illness stigma and discrimination in relation to employment. Figure 8.1 presents the extent to which respondents agreed or disagreed with statements about workplace stigma and discrimination.

Figure 8.1. Perceived experiences of stigma and discrimination in employment: percentage agreement and disagreement (n=116–119)

Because of stigma about my mental illness(es)...



- 8.9.** The most frequently agreed with statement relates to experiences of unfair treatment in the workplace (77%). The next two statements with the highest proportion of respondents agreeing with statements relate to who they have been treated unfairly by; almost three quarters (71%) reported being treated unfairly by employers, supervisors or managers, while just over half (57%) agreed with the statement about being unfairly treated by work colleagues.
- 8.10.** Other areas of note include respondent experiences of being unfairly denied employment opportunities (57%) and pressure to avoid discussing their mental health needs at work (52%). Interestingly, a similar proportion of respondents agreed with the statement about being pressured to discuss their mental illnesses and experiences at work when they did not want to.
- 8.11.** While not receiving a high proportion of agreement, we highlight that 20% of respondents agreed to some extent that they had been unfairly asked to leave employment. Put simply, one fifth of employed respondents were asked to leave due to stigma about their mental illnesses.

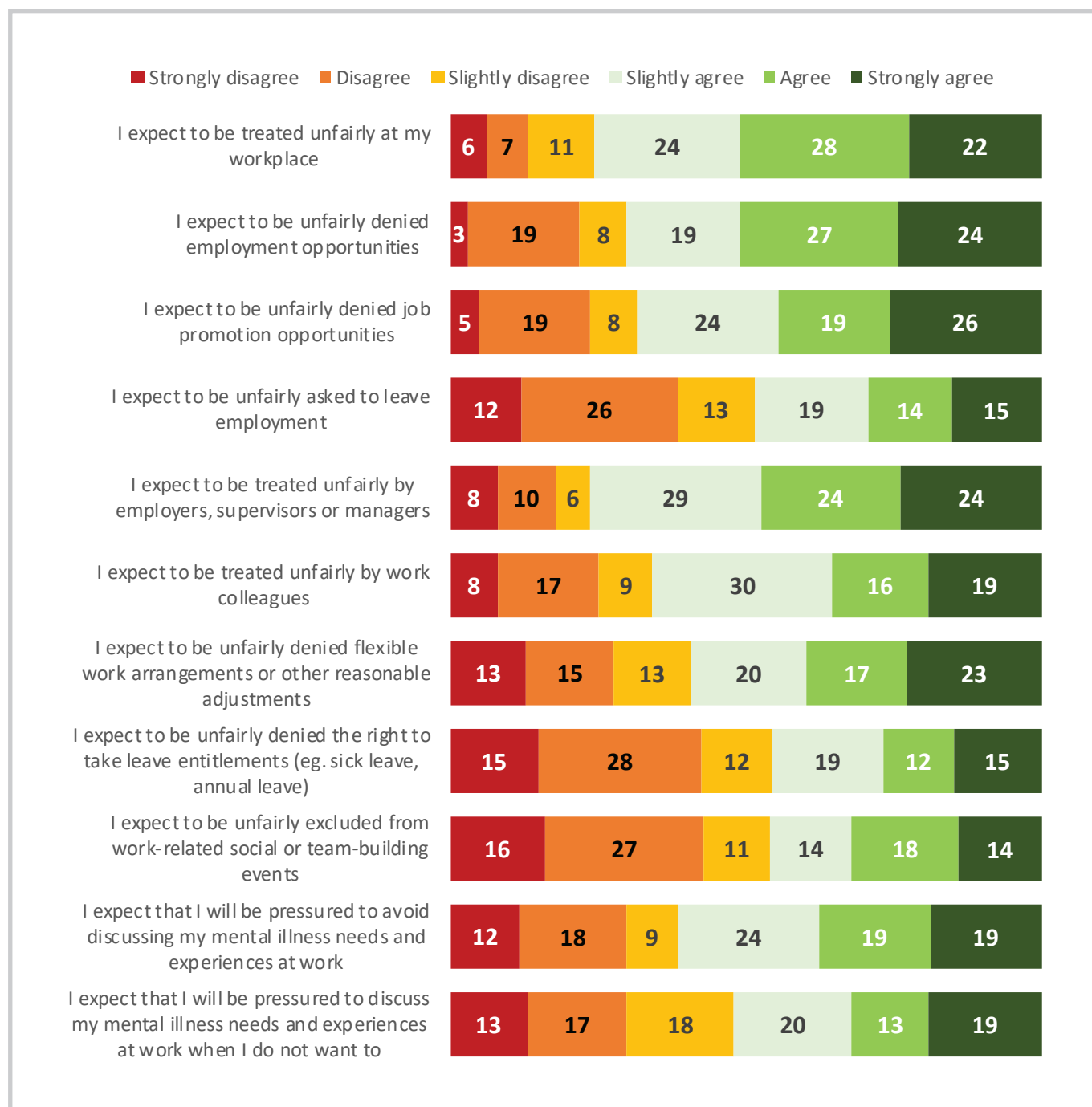
Anticipated stigma and discrimination in employment

- 8.12.** This section explores anticipation of experiencing stigma and discrimination because of mental illness. Figure 8.2 presents the extent to which respondents agreed or disagreed with statements about aspects of anticipated workplace stigma and discrimination.
- 8.13.** More than half of respondents agreed with at least eight of the 11 statements exploring anticipated stigma and discrimination. As with perceived experiences of stigma, statements about being treated unfairly in their workplace (74%), being treated unfairly by employers, managers and supervisors (77%), and being unfairly treated by work colleagues (66%) received the highest levels of agreement from respondents.
- 8.14.** There were also high levels of agreement from respondents for statements about their expectations of being unfairly denied employment opportunities and being unfairly denied promotion opportunities.
- 8.15.** We highlighted at 8.11 that 20% of respondents had agreed that they perceived stigma and discrimination about their mental illnesses had led to them being unfairly asked to leave employment. Almost 50% of respondents agreed with the statement that they expected to be asked to leave their employment before they are ready due to stigma about their mental illnesses.

"I put extra pressure on myself and work much longer hours than anyone else to prove that I am worthy/able to be employed. I fully expect to go in most days to be fired or pulled up for issues with what I'm doing in my job."

Figure 8.2. Anticipated experiences of stigma and discrimination in employment: percentage agreement and disagreement (n=118–119)

Because of stigma about my mental illness(es)...

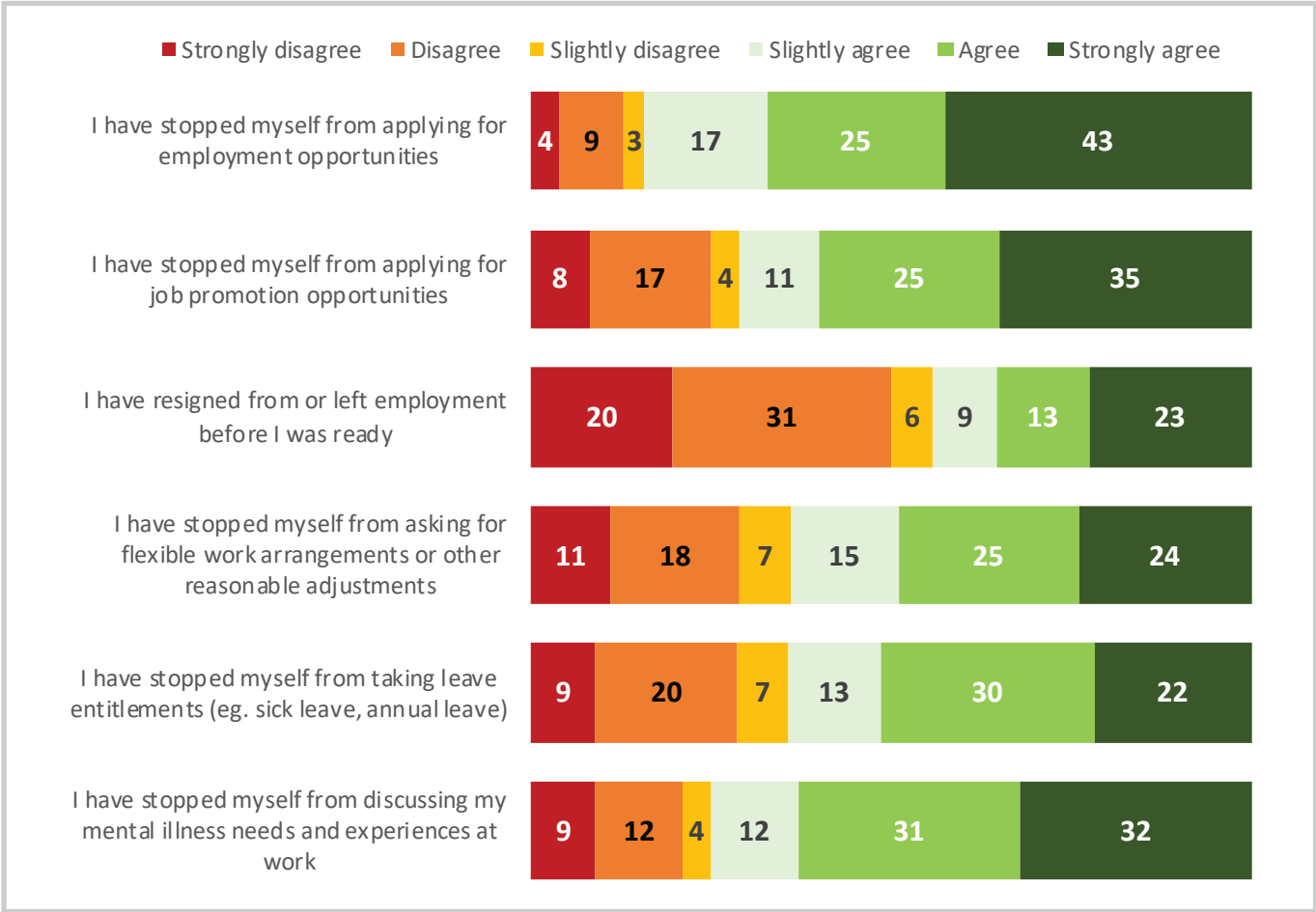


Withdrawal from opportunity in employment

8.16. This section explores the influence of stigma and discrimination on a respondent’s withdrawal from decisions and choices about employment. Figure 8.3 presents the extent to which respondents agreed or disagreed with statements on withdrawing from employment and employment opportunities.

Figure 8.3. Withdrawal from opportunities in employment: percentage agreement and disagreement (n=116–119)

Because of stigma about my mental illness(es)...



8.17. High levels of participant agreement were observed for most statements. Stigma was linked to a particularly high level of withdrawal from opportunities such as applying for employment or a job promotion, and discussion of mental health needs and experiences in the workplace.

“Application forms at work include questions about mental health problems even if they happened decades ago – it feels as if you will never escape the label.”

8.18. Just under half (44%) of respondents agreed with the statement on resignation from or leaving employment before being ready.

“I was forced to retire before I was ready to go. I felt my employer did not fully take account of my mental health issues.”

Intersectional stigma and discrimination

- 8.19.** Intersectional experiences of stigma and discrimination in the employment sphere is also evident from survey responses. Respondents were asked about experiences of stigma and discrimination associated with aspects of their identity. In relation to employment, age (37%), sex (21%) and physical disability (21%) were the three most commonly reported.

Views on the requirement for special considerations

- 8.20.** Finally, respondents were presented with a statement about whether they should receive additional consideration when finding, maintaining, or participating in employment. Almost three quarters (72%) of respondents agreed that they should receive additional consideration in employment because of their mental illness.

Other feedback about stigma and discrimination in employment

- 8.21.** Respondents were invited to share further details about their experiences of stigma and discrimination about their mental illness in the employment life area. The responses fell into four overarching thematic areas which often interlinked, and are each discussed below:

- Denied or lost opportunities.
- Workplace practices.
- Workplace culture and relationships.
- Impacts on wellbeing.

Denied or lost opportunities

- 8.22.** Losing or being denied opportunities was experienced by respondents while in employment and also when they tried to access employment.
- 8.23.** Experiences in the workplace included being marginalised at work and seeing responsibilities reduced. More commonly, respondents described stigma and discrimination in relation to feeling pressured or being forced out of their employment.

"The end result was that I lost my job, confidence and self-respect – went into a downwards spiral. Affected not only my income, but many other things in my life in a negative way."

- 8.24.** A few respondents reported that these instances of stigma and discrimination followed periods of sickness absence, or disclosure of their condition.

"I've suffered with mental health issues for 25 years and until 2019, had been with my employer for 19 years and had no reason to tell them of these issues until I had to take a period of time off (the only time) due to my mental health. Following return to work, I was marginalised and given less and less work to undertake until I was then made redundant one year following my period of time off."

- 8.25.** Experiences of stigma and discrimination while finding and accessing employment centred on application processes. Examples include being asked to disclose mental illnesses on application forms, which was perceived by respondents as a barrier to employment, which could lead to assumptions and judgements by employers about their abilities.

One respondent described having to undertake a medical assessment as a requirement to convince an employer that they were safe to carry out the role.

“Due to my bipolar disorder diagnosis, I failed a workplace medical for a teaching role, despite never having an issue related to my mental health throughout my teaching career.... They subsequently quoted the Glasgow bin lorry tragedy as their rationale, implying that my condition made me dangerous. I was certain that they felt I was unfit for work, so withdrew. I was without pay for four months as a result of this experience”

“I have been attempting to get into paid work for the last two years, before I even have an opportunity to properly discuss my needs employers have assumed that my disability is too much of a liability and they can’t accommodate me as they don’t have the set-up or its not cost-effective.”

Workplace practices

- 8.26.** The theme of workplace practice provided insights into experiences of processes, policies and rights, and issues with requesting or receiving reasonable adjustments to working arrangements.
- 8.27.** Much of the feedback about process and policies related to respondents’ experiences of sickness absence. These included examples of people feeling pressured to return from sick leave before feeling ready, and conversely, feeling isolated and wondering if anybody cared whether they returned or not.

“I have been on long term sick leave for 11 months; I have had little to no contact with work colleagues and supervisors. I have had no risk assessment done for my return, and they don’t seem to know/care what to do with me.”

“I was working full-time, and had a mental breakdown in August 2020. My employers did not take it seriously and continued to call me, to ask when I was going to get better, and when I was going to return to work.”

- 8.28.** One respondent described being made to feel like they were being dishonest about their ability to return to work from sick leave; another was continuously contacted about work by their employer, to the detriment of their mental health.

“They did not give me the time and space I needed and in the end I was unable to fully complete the programme because this experience made my mental health a lot worse. I feel like if they hadn’t contacted me during my time off I would possibly have felt well enough to return to the role, but instead I got more and more overwhelmed as I felt under a lot of pressure from them.”

- 8.29.** Although their employers claimed to be inclusive or had national accreditation that suggested they had everything in place to adequately support staff, a couple of respondents described this as a box-ticking exercise.

“Disability Confident Leader – DWP award. Means bugger all. Employed by a national company on a Scottish Government contract. All tick box exercises- peel it back and empty.”

- 8.30.** There were several comments about experiences of requesting or receiving reasonable adjustments for mental illnesses. Respondents shared examples of requests being denied; some described not knowing how to approach a conversation about adjustments or what would be reasonable to request, while another did not feel secure enough in their role.

"I recently left my employment after 9.5 years due to my flexible working request being denied"

"I don't really even know how to have a conversation about whether there are any adjustments that could help, because I don't know how to talk about the situation in the first place."

"I fear that I will crumble before I even reach the end of my six-month probation period and I don't feel secure enough to ask for changing to part-time hours to allow me to maybe cope with work better."

- 8.31.** One respondent observed that they did not think employers see mental illness as a disability which influences reasonable adjustments provided to support people to stay in work. Another felt that receiving adjustments led to colleagues asking unwarranted questions.

"Most employers do not recognise mental illness as a 'real' disability and this results in us being denied accommodations that would allow us to remain in work/work more hours."

"Managers and colleagues ask questions when they see you doing things differently, struggling or receiving adjustments for your difficulties. They feel entitled to mining for personal information, absolutely lacking in ability to discern what questions are none their business."

Workplace culture and relationships

- 8.32.** Themes in relation to workplace culture and relationships spanned harmful attitudes and stereotypes in the workplace, through to a lack of understanding from colleagues and employers.
- 8.33.** The influence of harmful attitudes and a lack of understanding was highlighted by a few respondents who reflected on experiences of disclosing details about their mental illnesses. Two described situations where they did not feel comfortable disclosing information about their mental health, and in one instance a respondent reported having been asked not to disclose any details so that they did not make others feel uncomfortable.

"Being told repeatedly I don't have to share details about my mental health because it might make others uncomfortable means I, by existing, make others uncomfortable, which is an incredibly depressing thought."

"I am a supervisor in retail. My manager has been very judgemental of one of our sales assistant's mental health struggles, and as a result I haven't told anyone about my specific diagnosis/symptoms."

- 8.34.** One respondent described difficult choices about whether to disclose information about their mental illness.

“From the moment you are hired you are in a vulnerable and impossible situation, choosing between explaining yourself to people who will resent you, or alienating yourself with a polite attempt at privacy.”

- 8.35. Others shared examples and insights about the impacts of harmful language and attitudes from managers and colleagues.

“I had a previous boss who kept referring to himself as ‘being a bit OCD’ – this is the kind of comment which perpetuates stigma and is completely untrue. He was not OCD at all and by making a claim like that, he was belittling real sufferers of OCD.”

“I have had people talk about the condition that I have in front of me without them realising that I have that condition and what they say is not meant to be cruel but it is not sympathetic either and it doesn’t make it feel like there is a place to talk about it at my workplace.”

“I was going through an extremely difficult time at home and because of my issues with mental health I went to them for support and was told that I was letting the company down and was becoming unreliable.”

- 8.36. Some respondents reflected on a lack of understanding among employers about how different conditions can affect people, and that the severity of conditions can fluctuate.

“There is very little understanding of some conditions. Often employers have no idea that these conditions are chronic and can vary in their severity over time. I have lost two jobs, one of which I loved, due to a flare up of mental illness and a lack of understanding from my employer.”

Impacts on wellbeing

- 8.37. Several respondents reflected on the impact of their experiences of stigma and discrimination in employment on their overall wellbeing. Some described these as traumatic events; others highlighted the additional stress and pressure this had led to. A few respondents suggested that stigma and discrimination had worsened the severity of their mental illnesses.

Positive Experiences

- 8.38. Respondents were presented with a statement about positive experiences when finding, maintaining or participating in employment. Only 27% of respondents agreed that they have had positive experiences. Out of all the life areas, positive experiences with employment ranked the fifth lowest out of 14.
- 8.39. In comments about any positive experiences due to living with mental illnesses, in relation to employment, some people reflected on the rarity of positive experiences or gave examples of negative experiences, which were included in our analysis of responses to the previous question. The remaining responses were categorised into two inter-related themes:
- What helps at work.
 - The strengths of lived experience.

What helps at work

- 8.40.** Some participants identified things they had found helpful, or would find helpful, in the work context. These included: legal rights and equality supports such as advocacy services and guaranteed interviews; being met with empathy, understanding and consideration of their mental health needs; and the straightforward implementation of reasonable adjustments or flexibility, if needed.

"I don't want to use my mental health as an excuse, I want to get a job etc. on my own merits. I also don't want a big fuss about it, but I'd like to feel I can have help/consideration when I need it e.g. being able to go a 5min break outside when things feel too overwhelming in the office."

"My team leader was very good about working my shift patterns around my weekly group therapy. I was nervous to approach him and he made it feel like no big deal at all."

The strengths of lived experience

- 8.41.** There was reflection in a few participants' accounts about what lived experience of mental illness brings to the workplace. They talked of their expertise in, and understanding, of mental health and described how this enabled them to be better at their job, and/or help others.

"Because I understand mental health issues, I understand how to talk to and treat my customers who seem to be suffering. It gives me comfort to be able to impart some measure of reassurance or compassion to my customers and colleagues who are having a hard time. This is the single most rewarding part of my job."

"I now work in mental health, as I feel I understand the condition."

Summary

- Nearly two thirds (246 or 71%) respondents reported that they had experienced stigma and discrimination in the employment life area within the past 12 months. 29% reported it was experienced frequently or very frequently.
- This life area was selected by 125 (36%) of respondents as one of up to three in which the stigma and discrimination they experienced had the greatest impact on them.
- Over two thirds (77%) of respondents agreeing that they had been treated unfairly in the workplace, with 71% reporting being treated unfairly by employers, supervisors or managers, and 57% agreed with the statement about being unfairly treated by work colleagues. Similar proportions of respondents expected to be treated unfairly in the workplace.
- One fifth (20%) agreed to some extent that they had been unfairly asked to leave employment. 49% agreed they expected to be unfairly asked to leave employment, while 44% agreed that they had left employment before they were ready.
- High levels of agreement were found in relation to expectations of being unfairly denied employment opportunities (70%) and being unfairly denied promotion opportunities (69%).
- A high proportion of respondents also agreed that they had withdrawn from opportunities to apply for employment (85%) or job promotion (71%) due to stigma and discrimination about their mental illness
- Only one quarter (27%) of respondents who selected this life area agreed they have had positive experiences due to their mental illnesses. Stigma and discrimination had also been experienced because of respondents' age (37%), sex (21%) and physical disability (21%).
- Nearly three quarters (72%) of respondents agreed that they should receive additional consideration in the workplace because of their mental illness.
- In their open comments about employment, respondents in this life area raised four core themes. Respondents described losing or being denied opportunities, both in work and when trying to access employment. This included experiences of being marginalised at work and seeing their responsibilities reduced, as well as stigma and discrimination following periods of absence or after disclosing their conditions. Another common theme was workplace practices. Much of the feedback related to experiences of sickness absence, but also to responses to requests for reasonable adjustments. Workplace culture and attitudes towards mental illnesses were also mentioned. Respondents described harmful attitudes and stereotypes in the workplace and a lack of understanding from colleagues and employers. Several respondents reflected on the impact of their experiences of stigma and discrimination in employment on their overall wellbeing.

9. Mental healthcare services

“I am genuinely traumatised due to stigma, discrimination and abuse that I have faced in mental health services and am reluctant to continue to reach out.”

Overview

- 9.1. This chapter explores experiences of stigma and discrimination in relation to accessing and using mental healthcare services, across public, private and third sector providers.
- 9.2. Mental healthcare services included but are not limited to:
 - Crisis helplines, community healthcare teams and other community-based services.
 - Hospital-based services (inpatient and outpatient).
 - Residential and rehabilitation services.
- 9.3. In total 256 (74%) respondents reported experiences of stigma and discrimination in this life area within the past 12 months, with 18% reporting it was experienced frequently and 15% very frequently. Mental healthcare is the fourth most commonly selected life area in the frequency of stigma and discrimination experienced.
- 9.4. The mental healthcare life area was selected by 121 (35%) of respondents as one of up to three in which the stigma and discrimination they experienced had the greatest impact on them. Those selecting this life area as one of the most impactful also tended to experience higher levels of perceived stigma and discrimination. Over half (57%) of those selecting this life area had experienced stigma and discrimination either frequently or very frequently, compared to 33% of all respondents.
- 9.5. Those who selected the mental healthcare life area were asked to indicate which services they had used, tried to use or wanted to use in the last 12 months. The options were:
 - Community-based healthcare services and crisis helplines – selected by 112 respondents.
 - Residential, rehabilitation or hospital-based services – selected by 40 respondents.
- 9.6. This chapter presents the profile and experiences of respondents who selected mental healthcare services as one of their three life areas where the greatest impact is felt.

Respondent profile

- 9.7. The profile of participants who selected the mental healthcare services life area in their top three largely aligns with the overall respondent population. However, this group were slightly less likely to privately own their home (27% vs. 36% of total sample).
- 9.8. Considering the profile of mental illnesses among this cohort of respondents, the overall survey respondent population is again broadly comparable. However, the sample that selected the mental healthcare life area in their top three had a slightly higher proportion of respondents with personality disorders (38% vs. 31% of the overall respondent population).

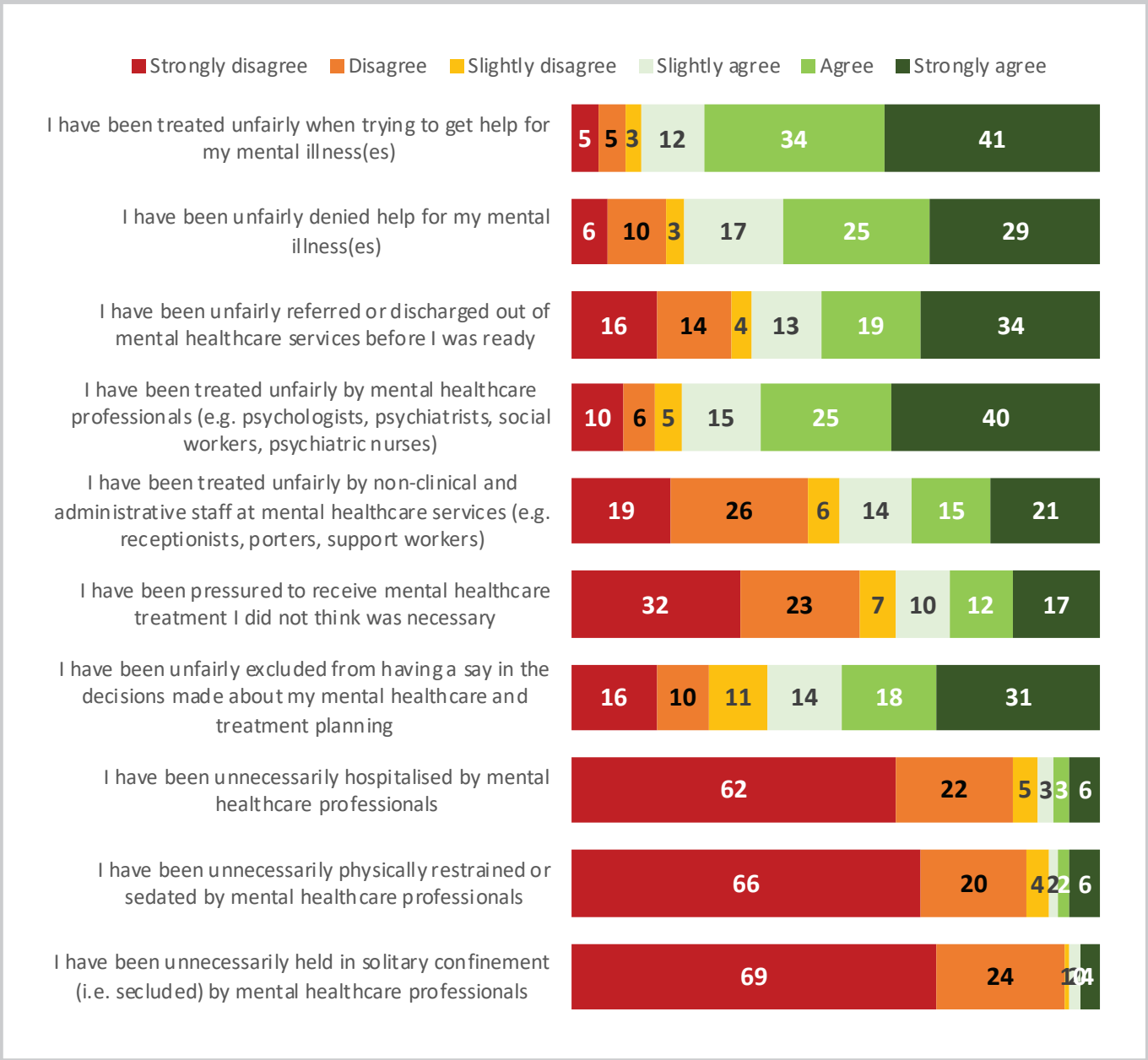
Perceived experiences of stigma and discrimination in mental healthcare

“Because of my BPD diagnosis, I have had crisis team staff hang up on me even when I’m feeling as though I couldn’t keep myself safe. I was discharged from my CMHT by a psychiatrist who never spoke to me once but decided to discharge me anyway. I have been called ‘attention seeking’, ‘manipulative’ by services. I feel as though mental health services don’t take me seriously because of stigma around my diagnosis.”

9.9. Figure 9.1 presents the extent to which respondents agreed or disagreed with statements about stigma and discrimination in mental healthcare services.

Figure 9.1. Perceived experiences of stigma and discrimination in mental healthcare services: percentage agreement and disagreement (n=114-116)

Because of stigma about my mental illness(es)...



- 9.10.** The three most frequently agreed with statements cover experiences of unfair treatment when trying to get help for mental health problems (87%), being unfairly denied help for their mental illnesses (81%) and unfair treatment by mental healthcare professionals (79%). Close to half (49%) of respondents also agreed they had been treated unfairly by non-clinical and administrative staff (e.g. receptionists, porters, and support workers).

"I think people with emotionally unstable personality disorder are all treated the same and put in a box labelled EUPD and are not treatable."

- 9.11.** Two thirds (66%) of respondents said they had been unfairly referred or discharged from mental healthcare services before being ready. Six out of ten (63%) respondents also agreed that they had been unfairly excluded from having a say in decisions about their mental healthcare and treatment planning.
- 9.12.** Over a third of respondents (38%) agreed they had been pressurised to receive mental healthcare treatment they did not think was necessary. Statements about being unnecessarily hospitalised (13%), unnecessarily physically restrained or sedated (10%) or unnecessarily held in solitary confinement (6%) by mental healthcare professionals received lower levels of agreement.

"Because I have always been forced to take medication by my circumstances, I find mental health services threatening. Medication seems like a punishment. Health treatments shouldn't seem like a punishment."

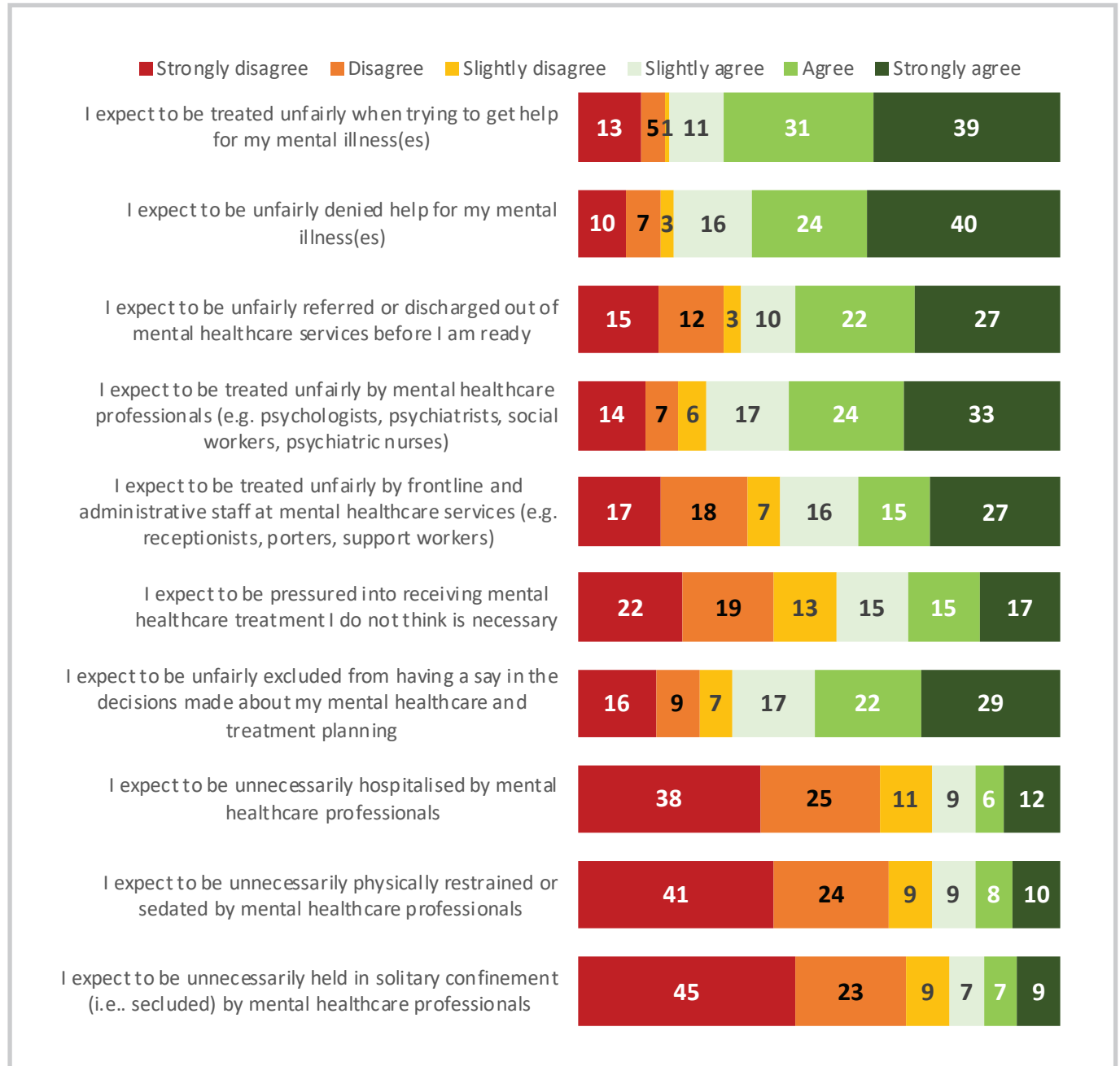
Anticipated stigma and discrimination in mental healthcare

"I sometimes worry about getting support from my community mental health team as my psychiatrist has put me on strong medication multiple times which didn't help. (I am no longer on these strong medications), but it is worrying."

- 9.13.** Figure 9.2 presents the extent to which respondents agreed or disagreed with statements about aspects of anticipated stigma and discrimination in relation to their contact with mental healthcare services.
- 9.14.** Responses to statements about anticipated stigma and discrimination in this life area generally aligned to the findings in this life area about experiences of stigma. Statements about anticipating being treated unfairly when getting help for mental health problems (81%), being unfairly denied help with mental health problems (80%) and being treated unfairly by mental healthcare professionals (74%) again received the highest levels of agreement.
- 9.15.** As with perceived experiences, over two thirds of respondents (69%) agreed that they expected to be unfairly referred or discharged from mental healthcare services before being ready. Similarly, 68% of respondents endorsed the statement that they expected to be unfairly excluded from decisions about their mental healthcare.
- 9.16.** Some statements about expectations for contact with mental healthcare services received higher levels of endorsement than their equivalents relating to perceived experiences. Despite only 6% agreeing they had been unnecessarily held in solitary confinement, 23% anticipated this could happen to them in the future.

Figure 9.2. Anticipated experiences of stigma and discrimination in mental healthcare services: percentage agreement and disagreement (n=117)

Because of stigma about my mental illness(es)...



9.17. Likewise, while 10% of respondents agreed they had experienced being unnecessarily physically restrained or sedated, 27% expected this could happen. Similarly, while 13% reported being unnecessarily hospitalised by mental healthcare professionals, more than a quarter (27%) anticipated experiencing this. Finally, while over half of respondents (58%) anticipated being treated unfairly by non-clinical and administrative staff, slightly less agreed they had experienced this (49%).

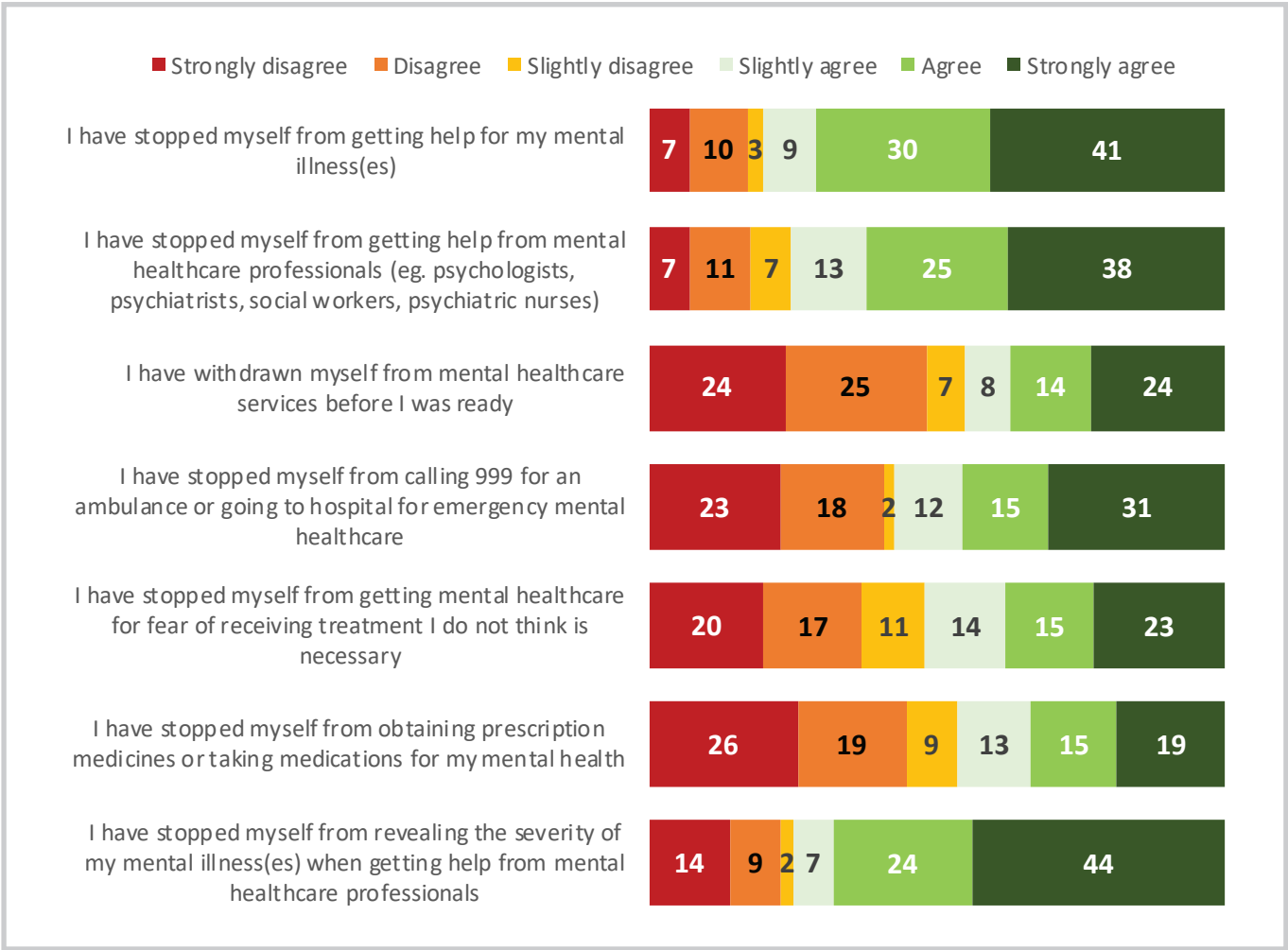
Withdrawal from opportunities in relation to mental healthcare services

9.18. Figure 9.3 presents the extent to which respondents agreed or disagreed with statements on withdrawing from accessing and using mental healthcare services.

"I try to keep away from mental health services in recent years because I find them to be damaging – the constant invalidation and poor responses – in terms of timeliness and effectiveness."

Figure 9.3. Withdrawal from opportunities in mental healthcare services: percentage agreement and disagreement (n=117–118)

Because of stigma about my mental illness(es)...



9.19. Respondents linked stigma to high levels of withdrawal from: getting help for their mental illnesses (80%), getting help from mental healthcare professionals (75%) and from revealing the severity of their mental illnesses to them (75%).

9.20. Of note, more than half of respondents endorsed statements that they had avoided calling an ambulance or attending A&E for emergency mental healthcare (58%) and had stopped themselves from getting mental healthcare for fear of receiving unnecessary treatment (52%). Just under half also agreed that they had stopped themselves from obtaining or taking medications for their mental health (47%) or had withdrawn from health care services before they were ready (45%).

- 9.21.** The high levels of agreement with these statements demonstrate that stigma around mental illness has a profound effect on whether and how people with mental illnesses experience and engage with mental healthcare services.

Intersectional stigma and discrimination

- 9.22.** Intersectional experiences of stigma and discrimination in relation to mental healthcare services is also evident from survey responses. Age (41%), sex (24%) and sexuality (20%) were the three most commonly reported intersecting factors where experiences of stigma and discrimination were linked to other aspects of a respondent's identity.

Views on the requirement for special considerations

- 9.23.** Finally, respondents were presented with a statement about whether they should receive additional consideration when accessing and using mental healthcare services. Eight in ten (82%) of respondents agreed that they should receive additional consideration because of their mental illness.

Other feedback about stigma and discrimination in mental healthcare

- 9.24.** Respondents were invited to comment on their experiences of stigma and discrimination in mental healthcare services. Four overarching, inter-related themes emerged in the analysis of these responses.
- Access barriers.
 - Problems with the medical model.
 - Ineffective, uncompassionate and unfair treatment.
 - Erosion of trust.

Access barriers

- 9.25.** A common theme identified in responses was the discussion of difficulties in accessing mental healthcare services. Various socio-economic, service design and provision issues were highlighted, including: lack of staff and funding, untimely responses and long waitlists, unavailability of appropriate assessment and treatment in the local area, being discharged too soon, reduction in support due to the pandemic, age-related service cut-offs, financial barriers to accessing private treatment and inflexibility of appointment arrangements.

"I have stopped myself from pursuing a LOT of drastically needed mental health care but it's in large part because they aren't provided or I've been precluded from them... Eating disorders and insomnia 'aren't treated' by my local health authority, and they do not refer out of our area. Consequently, I've had a reported but undiagnosed eating disorder for the past 10 years (it's actually older than that), because 'we don't treat that' (direct quote from the head of our only local mental health facility)."

"I was referred for therapy by GP but the therapy services discharged me as they didn't think what they offered was suitable for autistic people. They said as I am involved with an autism charity that they should help with my mental health but they don't have a mental health service. There is no way to access autism specific mental health support but autistic people are much more likely to have mental illness."

- 9.26.** Some respondents described experiences of being turned away from services, or a sense that these were being withheld from them. One person linked this to not presenting as 'ill enough', another to a lack of preventative intervention, while a few described stigma associated with their diagnoses or the enduring nature of their illnesses.

"I have only received discrimination since I received my diagnosis of personality disorder. I have been treated unfairly, dismissed and told to go away when seeking help from Crisis teams at the hospital."

"When I received treatment (counselling) I found it really helpful and had good relationship with the psychologist. However, I wasn't given access to their services several times in the years before because I presented as 'not ill enough.' My treatment was short-term, I don't have any help now. Although I was told my condition will likely always affect me, I feel on my own."

"It's very hard to get mental health care in the UK until it's an absolute emergency. It's like there's not a recognition that there's a spectrum between completely stability and imminent suicide, and that mental health care for people in the middle (and, frankly, even maintenance care for stable people) would prevent a lot of the imminent suicide care needs and ensure a good quality of life for persons with mental illness."

Problems with the medical model

- 9.27.** Problems with the medical model were talked about by some respondents. Concerns were expressed about ineffective psychiatric medication, health impacts and the imbalance of power between clinician and patient.

"The psychiatrist has an unfair amount of control about what goes into my body. They are using drugs without the knowledge of the long-term damage these medications can have on the brain. They are unwilling to explore more progressive forms of treatment because the system is out-dated and governed by large pharmaceutical companies' lobbying power. There is insufficient psychology and excessive use of damaging neuroleptic chemically-lobotomising drugs."

"The psychiatrist is constantly pushing me to go onto antipsychotics, which I do not wish to go on due to the real possibility that my car could be taken away."

"The medical model of mental health care does not work for me and, I would argue, other patients. Taking medications is enforced even when the medications probably make no difference. Worse, mental health services are incapable of admitting any errors in their philosophy or practice so that it becomes very difficult to hold a conversation on the efficacy of treatments."

- 9.28.** Issues with mental illness diagnosis were also raised. Some described experiences of misdiagnosis or of disagreeing with a clinician about their diagnosis, and the lack of collaborative approach to diagnosis. Others reflected on the stigmatised and stereotyped identities associated with their diagnosis. A small number of respondents suggested that a medical diagnosis neglects the causes of distress, such as trauma and life experiences.

"(I) was told I had Borderline Personality Disorder (which I think is a terrible diagnosis for me, the symptoms do not fit at all, and the whole range of personality disorders completely ignore the role of trauma in maladaptive behaviour, essentially blaming people for their reactions to their own lives)."

"I lost the relationship I had with the person I loved because of my illness, yet when discussing this as at least partly a cause of my problems, I was told that I had a genetic condition and that my life had nothing to do with why I was in their care."

Ineffective, uncompassionate and unfair treatment

- 9.29.** Many respondents described needs not being met when accessing mental healthcare services. Reasons included: clinicians' lack of knowledge of specific mental illnesses, a lack of psychological support, inappropriate treatment, a lack of diversity among clinicians and family members being excluded from appointments.

"It is diabolical the lack of understanding and knowledge trained professionals have – I am talking about Applied Psychologists, Clinical Psychologists and Psychiatrists... I do not believe that the way healthcare professionals are trained is nearly broad or in depth enough. The pathways are also extremely elitist which mean that the diversity in psychological practitioners is not nearly representative or good enough. All of these issues lead to a breeding ground of stigma and discrimination."

"I need one-on-one help – not group sessions. These group sessions are useless – I don't need to be told how anxiety works. I know. I am educated. It doesn't help."

"I feel alone, and hopeless. I get occasional calls from the mental health team. Even though they sound very sympathetic over the phone, and they insist that they will help me, by contacting additional services, nothing ever happens. I feel like I don't matter... I get medication, and reassurances that something is going to be done, but nothing ever happens."

- 9.30.** Concern about interactions with mental healthcare clinicians were commonly shared. Examples included poor communication, judgemental attitudes, stereotypical assumptions or uncompassionate, patronising, invalidating or abusive responses from staff. Power imbalances within relationships with mental healthcare practitioners were also highlighted by a few respondents, who spoke of a lack of autonomy, control, collaboration, or respect for their rights.

"The stigma that prevails around personality disorders is horrible. I have had mental health professionals tell me 'I can kill myself if I want to, I can hurt myself and they won't help me or stop me because that's just how people with personality disorders are.' It's so bad."

"(I) feel like treatment is done to me rather than with me and I am not involved in any decisions around / about my care – been sectioned, sedated, restrained many, many times but even in the community having 'therapy', I have no autonomy or control or power in my own care."

“As a patient, I have routinely been denied my right under the Mental Health Act to be given reasons for detention over the course of 14 years, despite arguing that it could help me find insight into my condition..... I guess, if you are already deemed ‘crazy and irrational’ then you don’t have the faculties to be told why you are incarcerated?”

Erosion of trust

- 9.31. Some respondents described the negative or traumatising impact of their experiences with mental healthcare services and/or characterised their trust in services as diminishing. Being wary about disclosing information to clinicians was mentioned; some avoided engaging with services altogether, as a result of their experiences.

“In my experience, a lot of mental health professionals see the disorder/illness only and not the person. Everyone presents differently and struggles more with different aspects of their disorder, which requires different and customised treatment plans. I’ve never met anyone who’s received this consideration and I’ve never met anyone who has been through the mental healthcare system and has not lost trust in it.”

“I do not reveal how much I am struggling at times as I have had previous experience of forever hospitalisation.”

Positive experiences

- 9.32. Respondents were presented with a statement about positive experiences when accessing or using mental healthcare services. More than two fifths (43%) of respondents agreed that they have had positive experiences in this life area. Out of all the life areas, positive experiences with mental healthcare services ranked the fifth highest out of 14.

“Most mental health professionals I have worked with are kind, understanding and do their best to help.”

- 9.33. In comments about any positive experiences with mental healthcare services, some respondents described a lack of positive experiences or mixed/negative experiences, which were included in the analysis presented above. An analysis of comments about positive experiences in this life area identified three inter-related themes:

- Supportive relationships.
- Helpful services.
- Improvements.

Supportive relationships

- 9.34. Supportive relationships with mental healthcare practitioners were discussed by some respondents, who described being treated with kindness, compassion, or understanding. Small numbers praised practitioners’ approaches, such as being collaborative, trauma-informed, informative and hard-working. One respondent said they felt their life had been saved by being treated in such a way.

"I had a psychiatrist who listened to me, included me in decisions about my care – such as asking if I wanted to take medication... who trusted me to make decisions, reassured me that it was okay to contact her if I was struggling and didn't make me feel ashamed for being in crisis. She validated the traumatic experiences I had both within services, as well as the trauma leading up to me developing my mental illness."

Helpful services

- 9.35.** Some respondents highlighted services they found helpful such as: specific NHS mental health teams (both community and inpatient), a learning disability service, a crisis service, a lived experience charity, voluntary services, hospital caterers or private healthcare.
- 9.36.** Reflections on ways to treat people, or improve mental healthcare were offered by respondents. These included: greater understanding and acknowledgement of distress, fairer access to services, early intervention and support for young people, trauma informed practice and education to challenge stigma.

"As someone with trauma related conditions, 'additional consideration' is expected in that I expect people to take a trauma informed approach in all engagement with me (just as someone who is blind would expect the impact of their disability to be taken into account in all engagement.)"

Summary

- Mental healthcare was the fourth most commonly selected life area against frequency of stigma and discrimination experienced. Almost three quarters (256 or 74%) of all respondents reported experiences of stigma and discrimination in this life area within the past 12 months, with 18% reporting it was experienced frequently and 15% very frequently.
- The mental healthcare life area was selected by 121 (35%) of respondents as one of up to three in which the stigma and discrimination they experienced had the greatest impact on them.
- Over three quarters of respondents agreed that, due to stigma and discrimination they had experienced unfair treatment when trying to get help for mental health problems (87%), been unfairly denied help for mental health problems (81%) and received unfair treatment by mental healthcare professionals (79%). A high percentage of respondents also agreed that they had been unfairly referred or discharged from mental healthcare services before being ready (66%) and unfairly excluded from having a say in the decisions made about their mental healthcare and treatment planning 63%. Broadly similar proportions of respondents agreed they expected to be treated unfairly in their contact with mental healthcare services.
- Despite only 6% agreeing they had been unnecessarily held in solitary confinement because of their mental illnesses, 23% anticipated this could happen to them in the future. Likewise, while 10% agreed they had been unnecessarily physically restrained or sedated, 27% expected this could happen. While 13% reported being unnecessarily hospitalised by mental healthcare professionals, more than a quarter (27%) anticipated experiencing this.
- Over three quarters of respondents agreed they had avoided: getting help for their mental illnesses (80%); getting help from mental healthcare professionals (75%) and revealing the severity of their mental illnesses (75%).
- More than half of respondents also agreed that due to stigma, they had avoided calling an ambulance or attending A&E for emergency mental healthcare (58%) and had stopped themselves from getting mental healthcare for fear of receiving unnecessary treatment (52%). Just under half also agreed that they had stopped themselves from obtaining or taking medications for their mental health (47%) and had withdrawn from mental healthcare services before they were ready (45%).
- Over two fifths (43%) of respondents agreed that they have had positive experiences in this life area.
- Stigma and discrimination had also been experienced due to respondents' age (41%), sex (24%) and sexuality (20%).
- Eight in ten (82%) respondents agreed that they should receive additional consideration when accessing and using mental healthcare services.
- Respondents shared further details about their experiences of stigma and discrimination in relation to mental healthcare services. Four key themes were evident. A common theme was barriers to accessing mental healthcare services, which included lack of resources, service design and being turned away from services. Some raised concerns about the medical model for mental healthcare, questioning aspects of diagnosis, ineffective psychiatric medication, health impacts and power imbalances. Many respondents described their needs not being met when accessing mental healthcare services, detailing ineffective, uncompassionate and unfair treatment. Some explained that their trust in mental healthcare services had been eroded.

10. Healthcare services

“My cardiac arrhythmia took three years to diagnose as they kept telling me it was my mental health and didn’t investigate... They were very wrong... I was at risk of stroke just because they refused to believe me. It’s very difficult to get people to believe you when you have a mental health diagnosis as they presume you aren’t truthful/attention/medication seeking. Mental health stigma is real; I could have died.”

Overview

- 10.1.** This chapter explores experiences of stigma and discrimination in relation to accessing and using physical healthcare services across public and private sectors. Healthcare services include but are not limited to:
 - GP surgeries, dental services, pharmacies, community healthcare teams, and other primary/community care services.
 - Hospital services (including, A&E, inpatient and out-patient services).
- 10.2.** In total 269 (78%) of respondents reported experiences of stigma and discrimination in this life area within the past 12 months, with 22% reporting these were experienced frequently, and 15% very frequently. Healthcare is the second most commonly selected life area in terms of the frequency of stigma and discrimination experienced.
- 10.3.** The healthcare life area was selected by 111 (32%) respondents as one of up to three in which the stigma and discrimination they experienced had the greatest impact on them. Those selecting this life area as one of the most impactful also tended to experience higher levels of perceived stigma and discrimination (65% of those selecting this life area said they had experienced stigma related to this either frequently or very frequently, vs. 37% of all respondents).
- 10.4.** This chapter presents the profile and experiences of respondents who selected healthcare as one of their three life areas where the greatest impact is felt.

Respondent profile

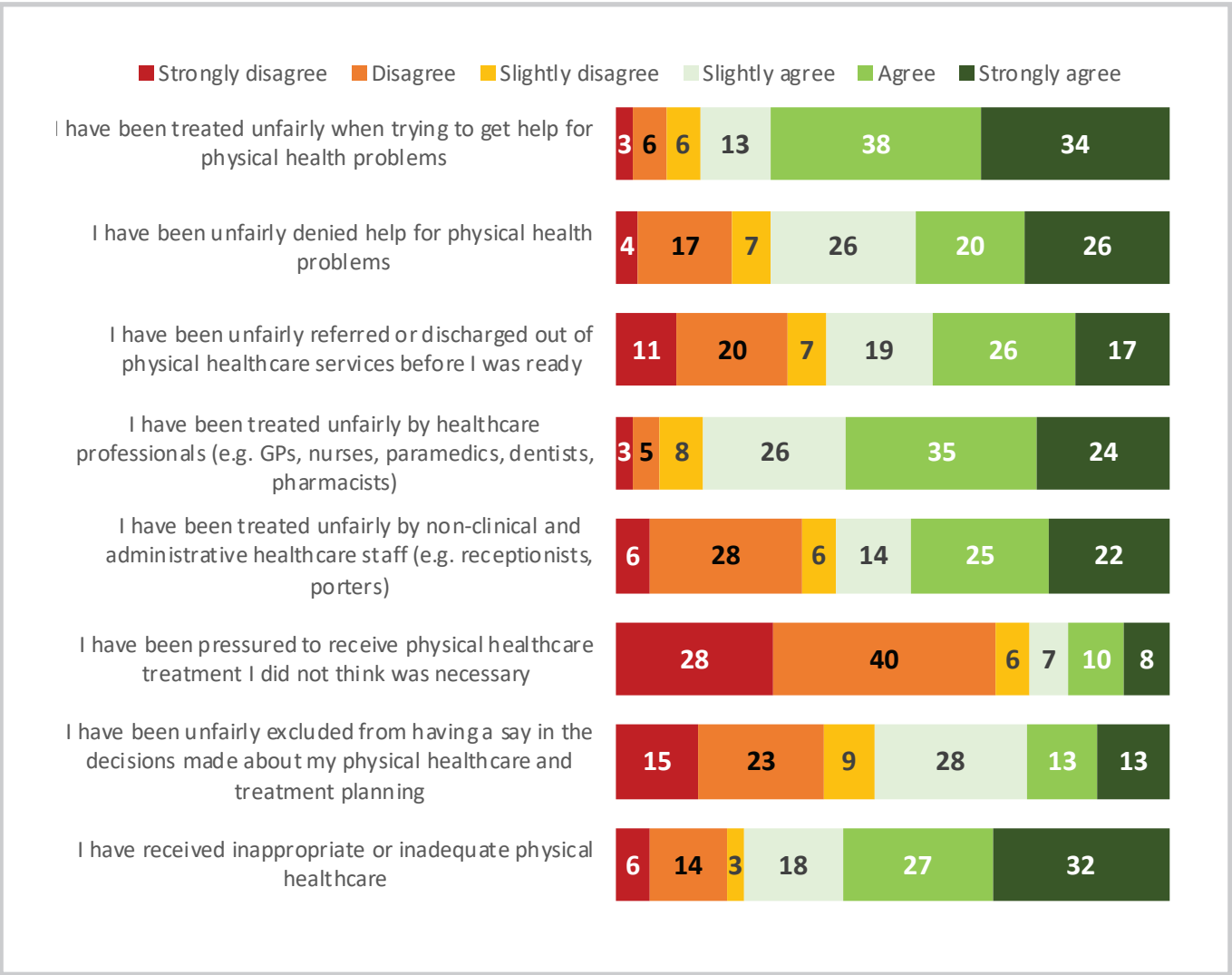
- 10.5.** The profile of participants who selected the healthcare life area in their top three has some differences from the overall respondent population.
- 10.6.** A greater proportion of this cohort identified their sex at birth (80%), or their gender (63%), as female compared to the overall population of respondents (67% and 58% respectively). Slightly more of those who selected this life area identified as non-binary (12%), compared to the overall respondent population (7%).
- 10.7.** A lower proportion of respondents (38%) identified as heterosexual among those who selected the healthcare life area, than the overall population of respondents (54%). A higher proportion identified as bisexual (25%) or asexual (12%) compared to the total population

of respondents (20% and 5% respectively). Lastly, a lower proportion of respondents who selected this life area (53%) reported having no religion, compared with the overall respondent population (62%).

10.8. In terms of the profile of mental illnesses, the overall survey respondent population is broadly comparable to the sample that selected the health life area in their top three. The healthcare life area sample had a slightly higher proportion of respondents with disorders specifically associated with stress (43% in the overall sample vs. 50% in the healthcare life area sample). This cohort also had a slightly lower proportion of respondents experiencing severe and/or treatment-resistant depressive disorder (32%) compared with in the overall sample (39%).

Figure 10.1. Perceived experiences of stigma and discrimination in healthcare services: percentage agreement and disagreement (n=109–110)

Because of stigma about my mental illness(es)...



Perceived experiences of stigma and discrimination in relation to healthcare services

"My concerns are dismissed, and I have even been laughed at. It doesn't matter if I turn up with a swollen wrist or abdominal pain, it feels as though they see my conditions on my notes and immediately label me as hysterical or delusional. I can feel quite infantilised sometimes as though they see mental illness as lack of intelligence. So much gets written off as 'just anxiety'."

10.9. Figure 10.1 presents the extent to which respondents agreed or disagreed with statements about healthcare stigma and discrimination.

10.10. The two most frequently agreed with statements relate to experiences of unfair treatment when trying to get help for physical health problems and unfair treatment by healthcare professionals (both 85%). Over half of the respondents in this cohort (60%) reported feeling unfairly treated by non-clinical and administrative staff.

"We are talked to as if we are lazy, greedy, ignorant, incapable of basic self-care, deliberately chaotic and non-compliant."

10.11. More than three quarters (77%) of respondents endorsed the statement that they had received inappropriate or inadequate healthcare. Perceived experiences of being unfairly denied help for physical health problems (72%) and of being unfairly referred or discharged out of physical healthcare services before being ready (62%) were reported.

"I feel shutdown by healthcare professionals a lot and they always tie my issues to my depressive disorder. I feel made out to be a hypochondriac at times (each time I have eventually proven them incorrect, and they found the physical issue). Even when the physical issue has been identified, I don't receive much further treatment they just 'monitor it'."

10.12. While not receiving the highest level of endorsement, over half of respondents (53%) agreed that they had been unfairly excluded from decisions about their physical healthcare due to stigma about their mental illness. Furthermore, over a quarter (26%) agreed they had been pressurised to receive physical healthcare treatment they did not think was necessary.

Anticipated stigma and discrimination in healthcare services life area

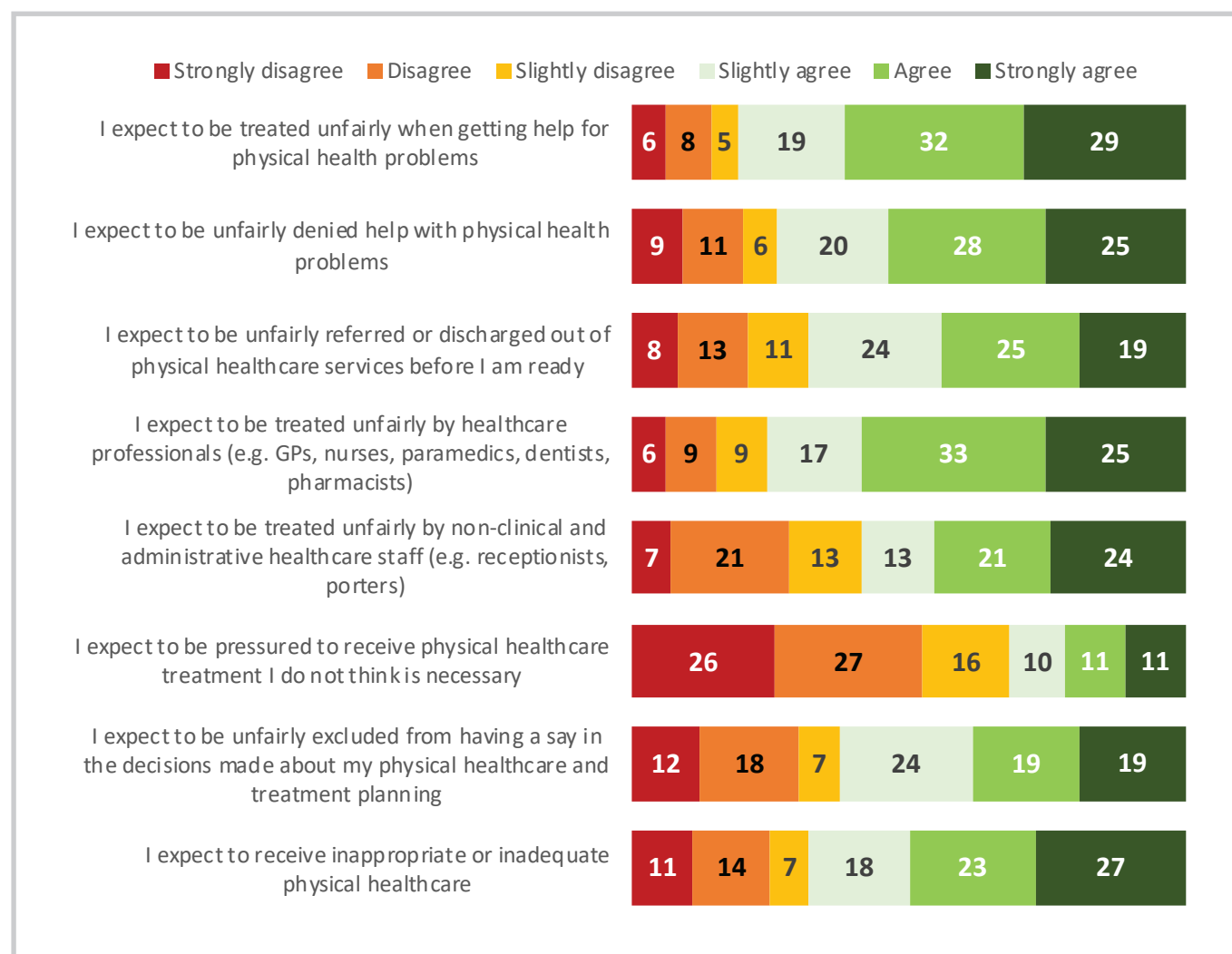
"I dread going to my GP about a physical health issue because often I am not taken seriously."

10.13. Figure 10.2 presents the extent to which respondents agreed or disagreed with statements about aspects of anticipated stigma and discrimination in their contact with healthcare services.

10.14. Agreement with statements about anticipated stigma and discrimination in this life area generally aligned to perceived experiences of stigma. Expectations of being treated unfairly when getting help for physical health problems (81%) and being treated unfairly by healthcare professionals (75%) again received the highest levels of agreement from respondents. However, there was slightly less agreement about anticipated unfair treatment by healthcare professionals (75%) than perceived experiences of this (85%).

Figure 10.2. Anticipated experiences of stigma and discrimination in healthcare services: percentage agreement and disagreement (n=107-109)

Because of stigma about my mental illness(es)...



10.15. Almost three quarters of respondents (73%) agreed that they expected to be unfairly denied help with physical health problems, which aligns with perceived experiences. Over two thirds of respondents (68%) agreed with statements on expecting to be unfairly referred or discharged from physical healthcare services before being ready and of receiving inappropriate or inadequate physical health care. Again, respondents were slightly less likely to anticipate receiving inadequate healthcare in the future (68%) than to have reported experiencing this (77%).

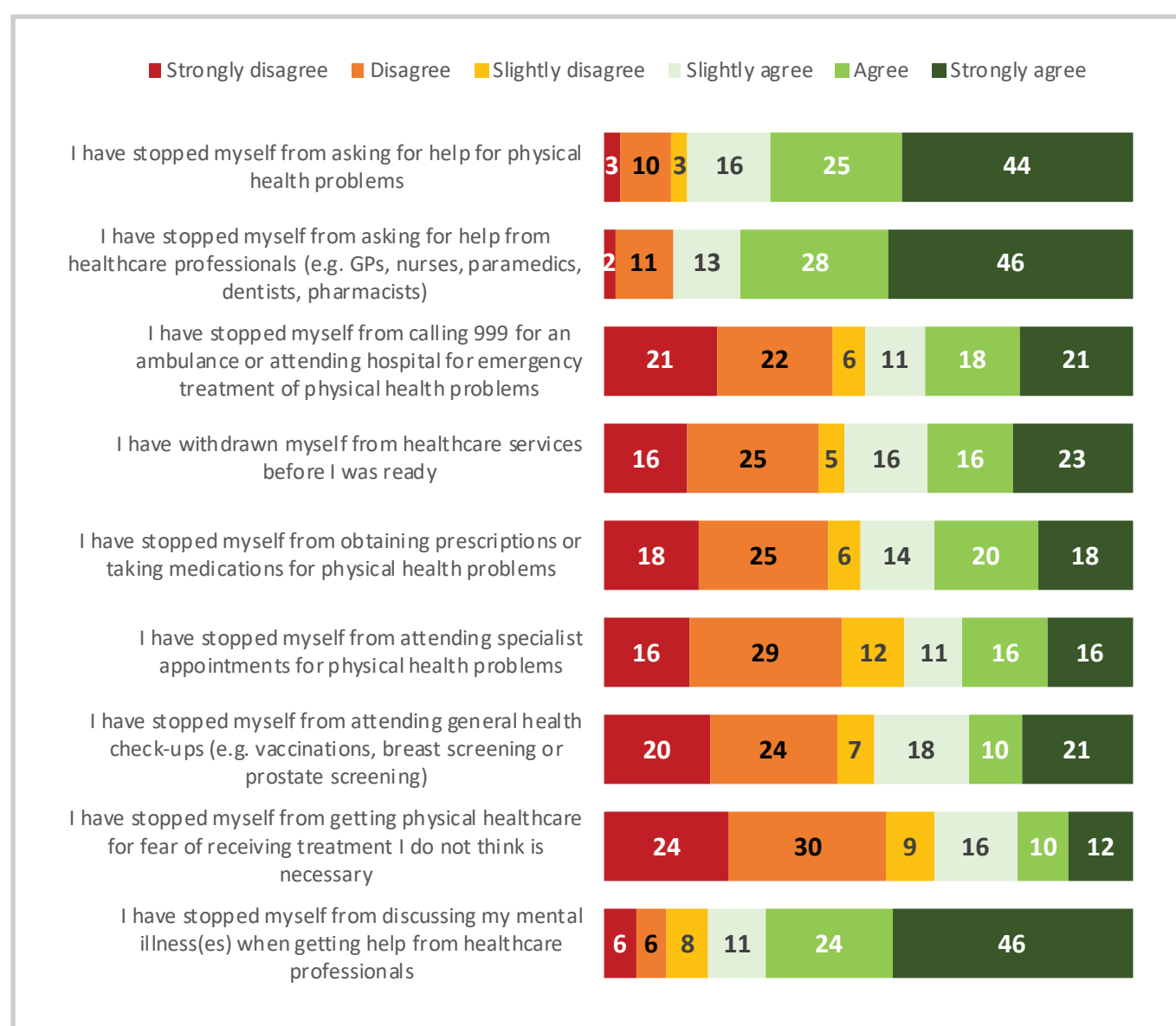
10.16. As with perceived experiences of stigma, over half of respondents (62%) agreed with the statement that they expected to be unfairly excluded from decisions about their physical healthcare treatment. However, the level of agreement was slightly greater than actual experiences of this (53%). Over a third (32%) anticipated being pressured into receiving physical healthcare treatment they did not think was necessary; again slightly less respondents (26%) had experienced this.

Withdrawal from opportunity in relation to healthcare services

10.17. Figure 10.3 presents the extent to which respondents agreed or disagreed with statements on withdrawing from accessing and using healthcare services.

Figure 10.3. Withdrawal from opportunities in healthcare services: percentage agreement and disagreement (n=109–110)

Because of stigma about my mental illness(es)...



10.18. Stigma was linked to particularly high levels of withdrawal from asking for help from healthcare professionals (87%) and asking for help for physical health problems (85%). Eight in ten (81%) agreed that they had avoided discussion of their mental health needs and experiences when accessing help from healthcare professionals for a physical health problem.

- 10.19.** Of note, over half of respondents endorsed statements that they had withdrawn early from health care services (55%), had stopped themselves obtaining prescriptions or taking medication for physical health problems (52%) and had avoided calling an ambulance or attending A&E for their physical health (51%). Close to half (49%) also agreed with the statement that they had stopped themselves attending general health check-ups (e.g. vaccinations, breast screening or prostate screening).
- 10.20.** The high levels of agreement with these statements demonstrate that stigma around mental illness has a profound effect on how people with lived experience of mental illness engage with healthcare services.

"I self-harmed during an episode and punctured my brachial artery... the doctor stuck the wound, which was very deep obviously, with steri-strips. He told me to stick it together with tape when I got home. Pretty much as soon as I reached home the strips had come unstuck and my arm was pouring with blood again. The last time I self-harmed I refused to go to A&E for fear of the same useless treatment... I was afraid of leaving the hospital with inadequate treatment again and starting to bleed over everything on my journey home... Totally traumatic and I risked getting an infection in the wound."

Intersectional stigma and discrimination

- 10.21.** Intersectionality in experiences of stigma and discrimination in relation to physical healthcare services is also evident from survey responses. Respondents were asked about experiences of stigma and discrimination associated with other aspects of their identity. Age (46%), sex (45%) and physical disability (30%) were the three most commonly reported intersecting factors for this life area.

Views on the requirement for special considerations

- 10.22.** Finally, respondents were presented with a statement about whether they should receive additional consideration when accessing and using healthcare services. Three quarters (75%) of respondents agreed that they should receive additional consideration.

Other feedback about stigma and discrimination in relation to healthcare services

- 10.23.** Respondents were invited to share further details about their experiences of stigma and discrimination in relation to healthcare services. Different services were mentioned in responses including: GP practices, physiotherapy, gynaecology, pharmacology, Accident and Emergency, dentistry and reproductive health. Three overarching, inter-related themes were identified in responses:

- Stigmatised and stereotyped identities.
- Unmet needs.
- Relationship dynamics.

Stigmatised and stereotyped identities

- 10.24.** As with other life areas, some respondents referenced degrading, dehumanising or stereotyped identities when considering healthcare workers' perceptions of them. They spoke of being seen as dangerous, attention-seeking, antagonistic, hysterical, lazy, illogical or incapable because of their lived experience.

"We're not viewed as human."

"I am not heard. I am simply mentally ill, incapable, deranged."

"It seems to come up over and over again that GPs and physios and anyone with any access to my NHS records can look at a diagnosis I received about eight years ago (that I consider to be completely inappropriate to my history and symptomology, and also inappropriate to apply to human beings in general – that'd be Borderline Personality Disorder) as a reason to treat me as hostile or hysterical or dangerous."

- 10.25.** When discussing experiences of healthcare, several participants raised further aspects of their identities that they believed interacted with the with the mental health stigma they faced – such as their gender, sexuality or disability.

"I believe that ALL healthcare professionals, including admin staff, need to be also taught about the social aspects of mental health and of the intersectional issues faced by people with mental health difficulties. I think that it would be especially important to address the stigma around females with mental health problems and address the stereotype of the 'hysterical woman' as I have seen how this impacts care."

Unmet needs

- 10.26.** Unmet physical health needs were a common theme across responses in this life area. Two key reasons were given; diagnostic over-shadowing – the attribution of physical symptoms to mental illness without proper assessment; or physical health needs being neglected due to mental health.
- 10.27.** Participants described their physical concerns not being taken seriously and/or of being denied treatment – such as pain / UTI medication, IVF procedures or appropriate care following self-harm. A few highlighted the life-threatening consequences of this, either through missed diagnoses or the suicidal feelings their physical health issues engendered in them.

"My doctor's ignored my repeated calls about various debilitating symptoms for 9+ years, repeatedly blaming my severe anxiety and/or inconsequential things, it turned out I was very close to dying due to severely low iron."

"I know that I am entitled to an annual health check, but I don't think it is administered very well. I don't think anyone has the time or money to care whether the side effects of the drugs I am on are monitored. Mostly I worry about getting older and not being able to afford the support I will need if I develop another mental health condition like... Dementia... I just feel that I am injected with medication and left to get on with it."

"After I disclosed my mental illnesses, I was told I 'wasn't sick enough' to be admitted to the gastro ward... I was so upset by these comments and genuinely felt it was due to being discriminated against, as the Dr was fine with me until I told them about my personality disorder. I was later admitted to the gastro ward despite being told this, and had to undergo a procedure of which I was told I would be sedated for. I was... denied a sedative at the last minute for unknown reasons. I cried throughout the full procedure."

- 10.28.** A lack of understanding and consideration of mental health needs, within physical health care, was also described by some respondents. Some said their physical healthcare clinicians did not understand their mental health conditions and/or their associated needs, such as trauma-informed care, communication support, or adaptation requirements for appointments. A few raised inadequacies with professional healthcare training on these aspects of support.
- 10.29.** Others spoke of their mental health needs not being recognised, dismissed or neglected, within their physical healthcare provision. Some explained that these factors represented a barrier to them accessing physical health care services.

"I have asked for help and had none...It's like a blind spot – they shrug, or laugh or brush it off. I presume they don't understand it. They will listen and try to help for physical conditions, but mental conditions seem to bring down a curtain."

"I come from a trauma background and find it very distressing... when medical professionals ask questions like 'Do family support you?'. Often I leave medical appointments feeling triggered and distressed because I have had to explain for what feels like the millionth time that I don't speak to my family because I was abused by them as a child and teenager. It could all be avoided if they simply asked: 'who supports you?'."

"They often don't consider the impact that routine things like cervical smears would have on someone with a history of trauma, and don't take the time to check if you are ok before, during or after."

"Due to being unable to attend appts as a result of overwhelming mental health symptoms, I find I'm then not offered appts for physical health care needed."

Relationship dynamics

- 10.30.** Some reflected on relationships with healthcare staff and spoke of being treated without care, compassion, respect, belief, or validation. Others highlighted issues with transparency, confidentiality, and communication. Examples of feeling blamed by staff or experiences of discriminatory treatment or abuse were also shared.

"I was verbally and emotional abused by health professionals solely based on the fact that I was a psychiatric patient."

"I have been told by three different health professionals (GP, physio and gynae) that I am not in as much pain as I think I am. That people with a history of depression often exaggerate their symptoms so there is nothing they can do for me (this while I was in tears of pain getting an internal scan at gynae)."

"I cannot seem to communicate adequately with healthcare professionals, I think I'm talking sense, they either fail to understand, or they misconstrue what I am trying to get across... My learned distrust obviously does not aid a good relationship with health professionals."

- 10.31.** A few respondents spoke of engaging in protective behaviours based on negative experiences, for example: being wary about how much information they shared with healthcare workers about their distress or avoiding services altogether. One highlighted the serious potential consequence for their self-harm wound to become infected due to not accessing treatment.

"On several occasions over the last year while receiving treatment for physical-health conditions, I was asked about old scars on my stomach. If I replied that these were self-harm scars from 25 years ago then the attitude to me often changed immediately. As a result, I changed my answer to say it they were knife wounds from an attack."

Positive Experiences

- 10.32.** Respondents were presented with a statement about positive experiences when accessing or using physical healthcare services. Only 26% of respondents agreed that they have had positive experiences in this life area. Out of all the life areas, positive experiences with physical healthcare services ranked the fourth lowest out of 14.

"I have found some GPs at my practice to be very attentive and understanding. It has never felt as though they treat me any differently from anyone else."

- 10.33.** In comments on any positive experiences due to living with mental illness in relation to healthcare services, some highlighted the lack of positive experiences, or described mixed or negative experiences which are included in the analysis above. Two inter-related themes about positive experiences with physical health services emerged:

- Supportive relationships.
- Recognition of needs.

Supportive relationships

- 10.34.** Supportive relationships with health practitioners were discussed by some. Examples included being listened to, validated, collaborated with, and treated with kindness, compassion, understanding and respect. Some mentioned positive experiences of communication with healthcare staff or spoke of being seen as an individual, rather than having assumptions made about them. One highlighted the life-saving effects of being treated in this way. A couple of respondents reflected on the positive impact of their own approach (such as being open about their mental health, or advocating for themselves), on their relationships with healthcare staff.

"I felt that they saw my needs rather than judging me for them or making me feel as though having such needs was 'different or difficult'. They did not speak down to me or make assumptions and saw me rather than the 'mentally ill' person."

Recognition of needs

- 10.35.** Some respondents recounted experiences of having either their physical and/or mental health needs recognised by their healthcare practitioners. Trauma informed care, physical health concerns being taken seriously, and mental health needs being considered, were all mentioned here.

“My previous GP was very good. Example: I had some chest pain, we both thought it might be stress, but to be sure, he sent me for an ECG and a chest x-ray, because he said it’s too easy to write these things off as stress in women, and he didn’t want to take that risk. Fortunately, the results came back saying all was well. Even the fact that I could tell him I thought it might be stress was a sign of a good relationship.”

“When struggling with an appointment, I mentioned my sensory needs to 2/3 healthcare professionals in the past 12 months and they took a moment to ask me what might help to assure me and agree upon a signal to stop or take a break. They also altered the environment for me and acted in a manner that was considerate rather than condescending.”

- 10.36.** Hopes for their contact with healthcare services were expressed by a few respondents. While one person emphasised equality of treatment, others spoke of the importance their needs being taken into account.

“Just an awareness of the fact that I might find some things difficult or more stressful than other people do, would be a great help. Handling phone calls, phone appointments and waiting room for example. People who need wheelchairs and other physical aids for disabilities should have that bit more consideration and so should people with psychiatric disabilities.”

Summary

- Healthcare is the second most commonly selected life area in terms of the frequency of stigma and discrimination experienced. Over three quarters (269 or 78%) of respondents reported experiences of stigma and discrimination when accessing and using physical healthcare services within the past 12 months. More than one third (37%) reported it was experienced frequently or very frequently.
- The healthcare life area was selected by 111 respondents (32%) as one of up to three in which experiences of stigma and discrimination had the greatest impact on them.
- Over three quarters of respondents (85%) agreed they had been treated unfairly by healthcare professionals and when trying to get help for physical health problems. Broadly similar proportions of respondents agreed they expected to be treated unfairly in their contact with healthcare services.
- Over three quarters (77%) of respondents agreed they had received inappropriate or inadequate healthcare, due stigma about their mental health. 72% of respondents agreed they had been unfairly denied help for physical health problems and 62% agreed they had been unfairly referred or discharged out of physical healthcare services before being ready. Similarly, there were relatively high levels of agreement around expectations of receiving inadequate healthcare.
- A high proportion of respondents also agreed that they had avoided asking for help from healthcare professionals (87%) and asking for help for physical health problems (85%) due to stigma and discrimination about their mental illness.
- Over half (55%) of respondents agreed they had withdrawn early from health care services; 52% had stopped themselves obtaining prescriptions or taking medication for physical health problems, while 51% had avoided calling an ambulance or attending A&E for their physical health. Close to half (49%) also agreed they avoided attending general health check-ups (e.g. vaccinations, breast screening or prostate screening), due to stigma and discrimination about their mental health.
- High levels of agreement (81%) were also found in withdrawal from discussion of mental health needs and experiences when accessing help from healthcare professionals.
- Only one quarter (26%) of respondents to this life area agreed they have had positive experiences due to their mental illness. Stigma and discrimination had also been experienced due to respondents age (46%), sex (45%) and physical disability (30%).
- Three quarters (75%) of respondents agreed that they should receive additional consideration when accessing and using physical healthcare services.
- Open comments about healthcare services covered a variety of services including GP practices, physiotherapy, gynaecology, pharmacology, Accident and Emergency, dentistry and reproductive health. Some raised the stigmatised and stereotyped identities which influenced healthcare workers' perceptions of them, describing these identities as degrading or dehumanising. Another common theme was unmet physical health needs (as a result of the attribution of physical symptoms to mental illness without proper assessment, or physical health needs being neglected due to mental health). Some reflected on their relationships with healthcare staff and spoke of being treated without care, compassion, respect, belief, or validation within these. Others commented on issues with transparency, confidentiality, and communication.

11. Social media

“People are even less empathetic online than in the real world.”

Overview

- 11.1.** This chapter explores the stigma and discrimination experienced by respondents when engaging with social media. This includes websites, applications and forums including Facebook, Instagram, Twitter, WhatsApp, Reddit, Pinterest, Snapchat, Tik Tok and YouTube.
- 11.2.** Over three quarters of all respondents (266, 77%) reported experiencing stigma or discrimination on social media because of their mental illness in the past 12 months, with 21% reporting it was experienced frequently, and 22% very frequently.
- 11.3.** Social media was selected by 74 respondents (21%) as one of up to three life areas where mental health stigma and discrimination have had the greatest impact in the past 12 months. This was the fifth most commonly selected life area. Of those selecting this life area in their top three, almost two thirds (62%) said they experienced stigma related to social media either frequently or very frequently, compared to 43% of all respondents.
- 11.4.** This chapter presents the profile and experiences of respondents who selected social media as one of their three life areas where the greatest impact of stigma and discrimination about their mental health is felt.

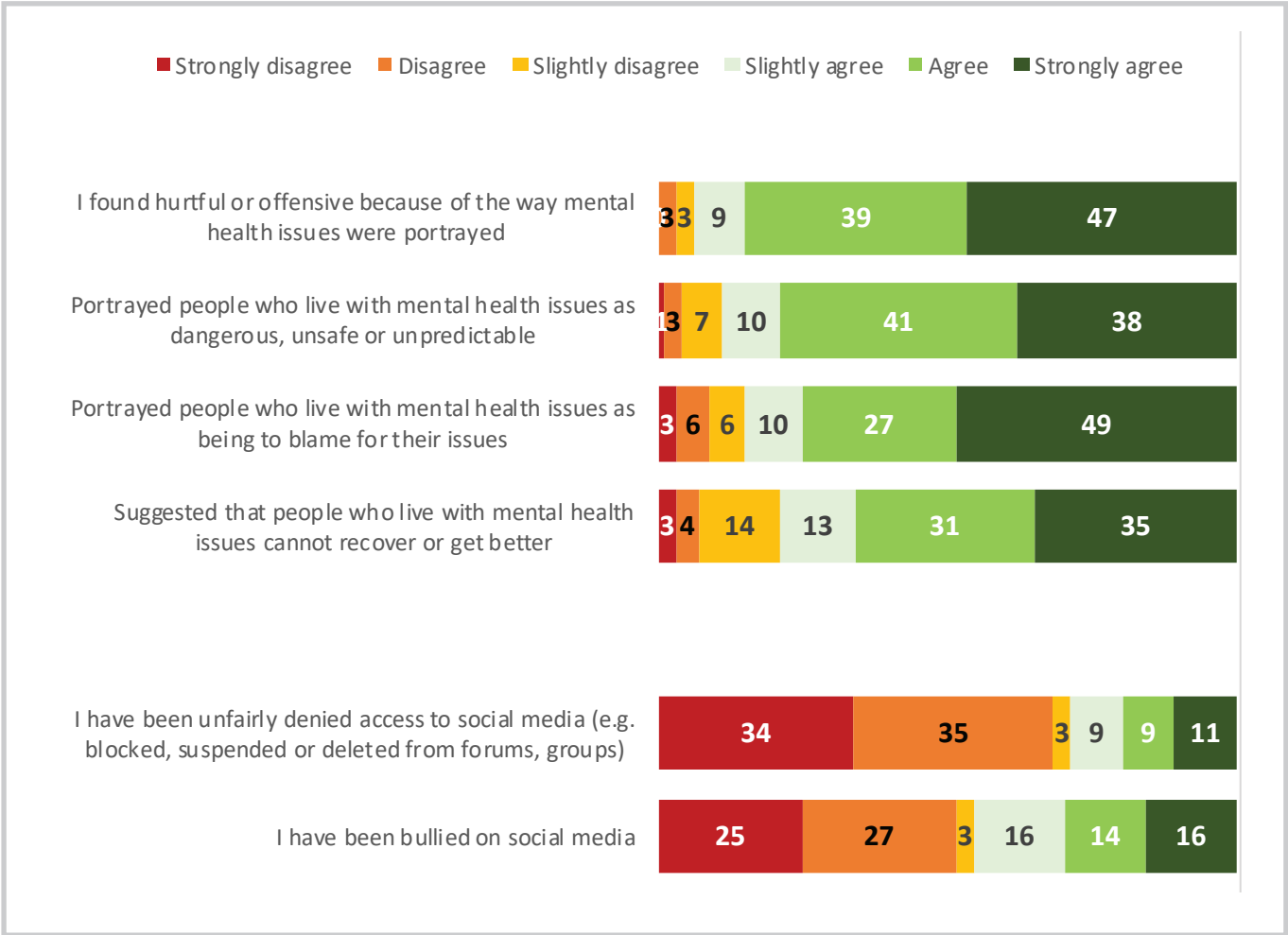
Respondent profile

- 11.5.** The profile of participants who selected social media in their top three life areas is largely reflective of the overall respondent population. Those who selected social media as a life area were more likely to have a university degree than the general survey population (55% vs. 46%).
- 11.6.** Mental illnesses among respondents who selected social media in their top three life areas is broadly comparable to the overall survey respondent population. A slightly higher proportion of respondents had a feeding or eating disorder when compared with the overall sample (28% vs. 20%).

Perceived experiences of stigma and discrimination on social media

- 11.7.** Figure 11.1 shows the extent to which respondents agreed or disagreed with statements about their experiences of mental illness stigma and discrimination when using social media.
- 11.8.** All statements about experiences of mental health stigma and discrimination in relation to social media content were met with high levels of agreement. Nearly all respondents (94%) agreed they had experience of interacting with social media content that was hurtful or offensive due to the way mental illness was portrayed.

Figure 11.1. Perceived experiences of stigma and discrimination on social media: percentage agreement and disagreement (n=71)



- 11.9.** Almost 90% had seen, read or heard social media content that portrayed people with mental illness as dangerous, unsafe or unpredictable. A similar proportion (86%) had been exposed to content that portrayed people with mental illness as being to blame for their issues, while 79% reported content that suggested people with mental illness cannot recover or get better.
- 11.10.** Nearly half (45%) had experience of being bullied on social media because of stigma about their mental illness, while 28% reported being unfairly denied access to social media due to stigma about their mental illness.

“In the past, people who pretended to be my friends would screenshot things I posted and say awful things behind my back about me.”

Anticipated stigma and discrimination on social media

- 11.11.** Figure 11.2 presents data on the extent to which respondents agreed or disagreed with statements about anticipated stigma and discrimination about their mental illness when accessing social media.
- 11.12.** Responses to statements about anticipated stigma and discrimination on social media closely aligned with perceived experiences of stigma and discrimination. There were high levels of agreement with statements about expectations of seeing content that is: hurtful or offensive

due to the way mental illnesses are portrayed (90%), portrays people with mental illness as being to blame for their problems (87%); or portrays people with mental illness as dangerous, unsafe or unpredictable (86%).

11.13. Just under a third (31%) agreed that they expect to be unfairly denied access to social media platforms due to stigma around their mental illness, and over half (56%) said that they expect to be bullied on social media because of their mental illness.

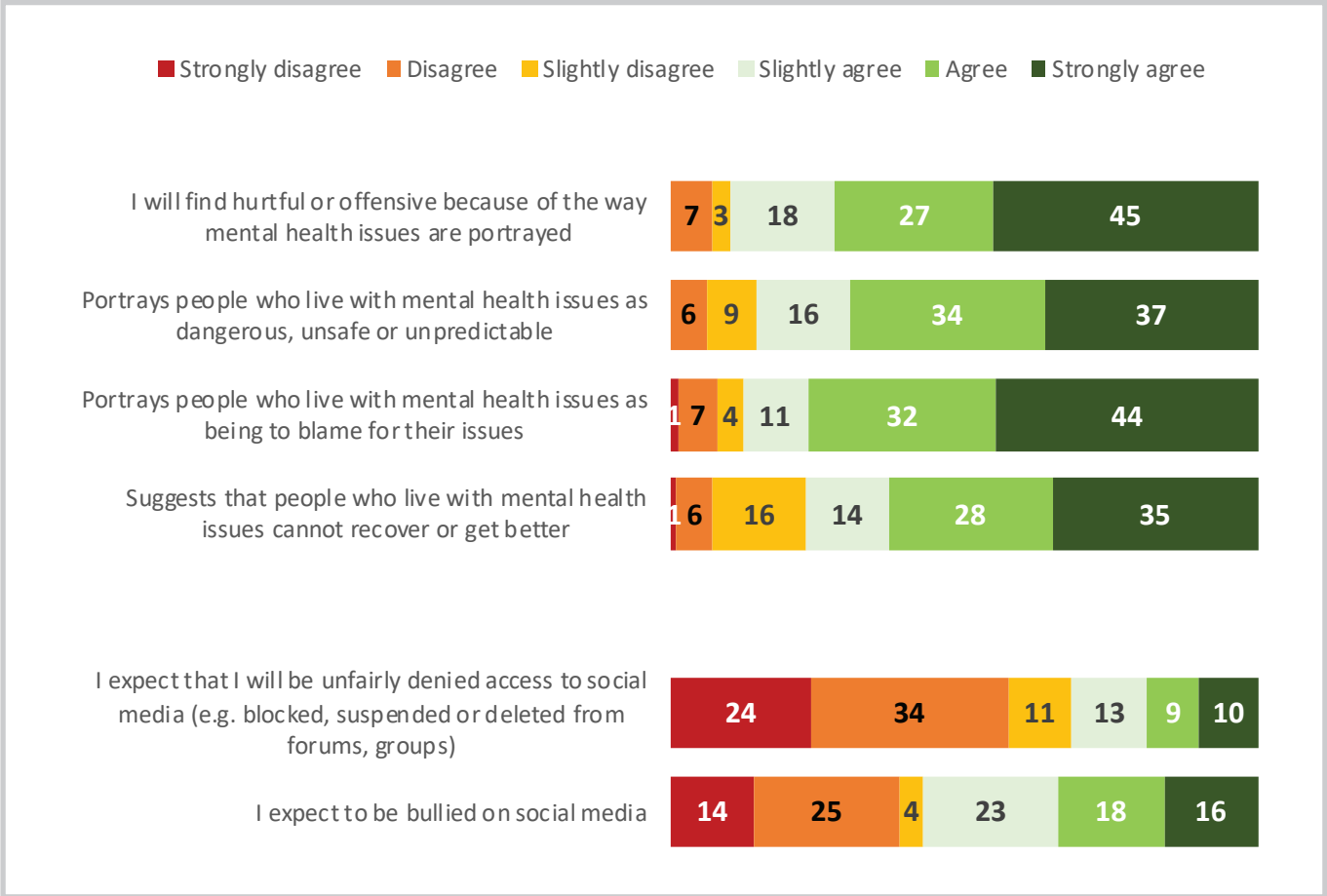
“It’s part and parcel of going online that you’re expected to encounter trolls. You can take it on the chin but it’s very difficult when you’re holding a device in your hand and there are strangers saying the most horrific things about you.”

Withdrawal from opportunity on social media

11.14. This section explores the influence of stigma and discrimination on respondents’ decisions and choices about accessing and using social media. Figure 11.3 presents the extent to which respondents agreed or disagreed with statements about withdrawal from opportunities.

11.15. Statements about stopping myself from sharing opinions and experiences online had the highest level of agreement, at 90%. In addition, over three quarters (78%) had stopped themselves from joining social media groups or forums. More than half of the respondents (58%) agreed that they had deleted at least one of their social media profiles due to stigma about their mental illness.

Figure 11.2. Anticipated experiences of stigma and discrimination in social media: percentage agreement and disagreement (n=71)

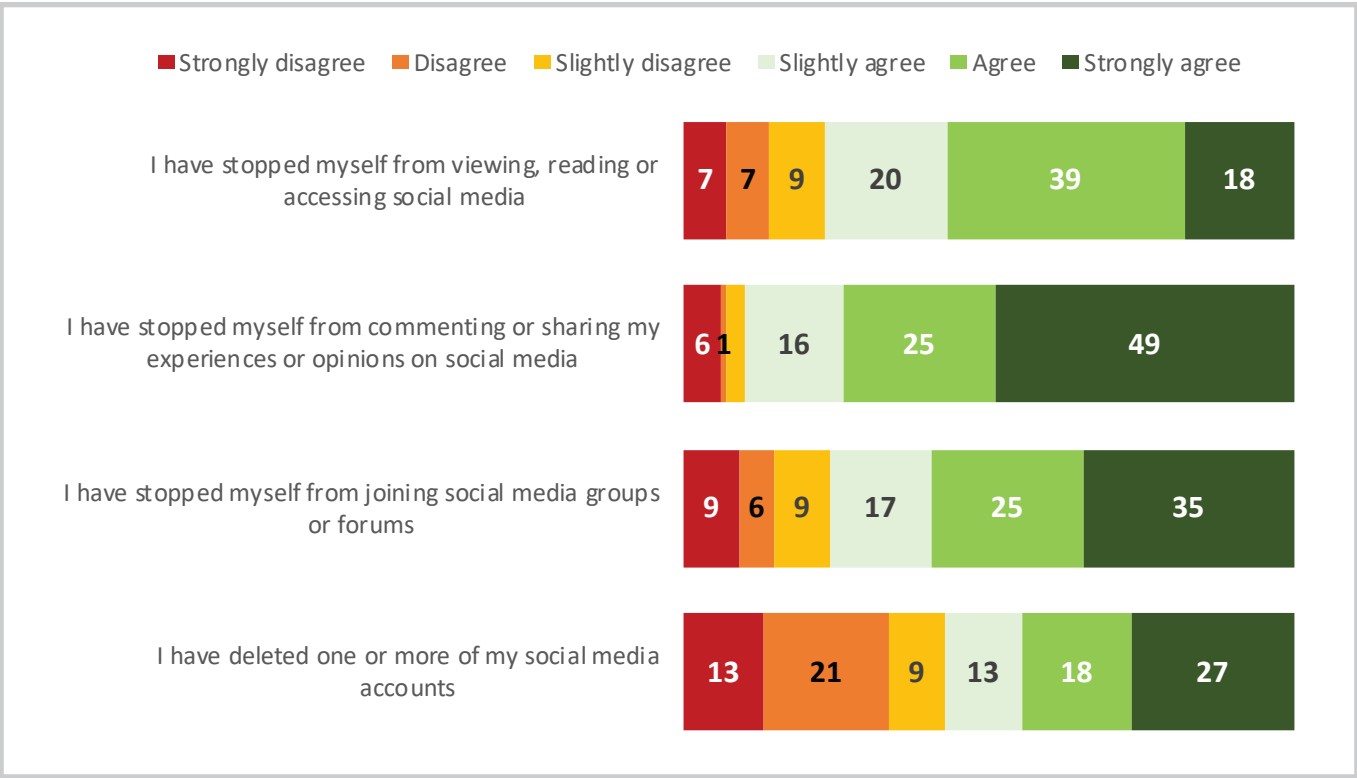


11.16. High levels of agreement with each statement demonstrates that stigma around mental illness has a profound effect on how respondents engage with social media.

| *“I avoid posting content regarding my own issues due to professional concerns.”*

Figure 11.3. Withdrawal from opportunities in social media: percentage agreement and disagreement (n=71)

Because of stigma about my mental illness(es)...



Intersectional stigma and discrimination with social media

11.17. Respondents were asked about experiences of stigma and discrimination in social media related to other aspects of their identity. The most commonly reported stigma and discrimination in this life area linked to sex (47%), age (42%) and sexual orientation (40%).

| *“Social media for trans people right now is hellish and incredibly damaging to the mental health of a group who already disproportionately have mental illnesses or disabilities.”*

Views on the requirement for special considerations

11.18. Nearly half (47%) of respondents agreed they should receive additional consideration when using social media because of their mental illness.

Other feedback about stigma and discrimination in social media

11.19. Some additional themes emerged in open-text comments about mental illness stigma and discrimination when engaging with social media. Comments fell into two broad themes:

- Measures taken to protect from harmful content.
- Toxic positivity.

Measures taken to avoid harmful content online

11.20. Several respondents discussed the measures they take to mitigate the negative effects of social media and protect themselves online. For example, some use options to filter or mute words or phrases from their timelines, to protect them from harmful or offensive content. Some discussed sticking to 'safe spaces' or creating 'bubbles' where only close friends or family were able to interact with them. One welcomed the growing use of 'trigger warnings' which help them navigate the type of content they want to avoid.

"I have ended up deleting my Facebook account last year, and after six months off Facebook, I made a new account with a fake name, cartoon profile picture and only my close friends and the family members I get on with."

"You can have certain words omitted in your feed on Twitter... you can set filters to stop certain words coming through on your account."

11.21. Some called for social media companies to better regulate online comments and messages and vet social media profiles to enable action against those who make harmful and offensive posts.

Toxic positivity online

11.22. The perpetuation of unhelpful positivity online was discussed, with reference to its impact for people with mental illness. Examples of misrepresenting mental illness through 'toxic positivity' on social media included:

- Mental health content which focuses on 'recovery'; this can be distressing and harmful for people living with enduring and treatment resistant conditions which have no cure.
- 'Pill-shaming'; the notion that taking medication for mental ill health is a harmful approach and that there are other 'natural' cures for mental illness, e.g. exercise, diet and positive thinking.
- In some cases, 'self-care' for people with mental illness has been commercialised and unhelpfully conflated with 'pampering' instead of its true meaning, which can be as simple as rest and 'saying no'.

"I think the suggestion that people can recover from mental health issues creates unrealistic, and potentially harmful, expectations; the implication being that taking pills is bad and if you don't feel better being in nature, or living a particular lifestyle, or being mindful, or meditating, then that's about you not trying hard enough, so it's your own fault you're ill. For me, as someone dealing with chronic mental illnesses that have to be managed on a day to day basis over several decades, the suggestion and/or belief that everyone can recover from mental health issues, with or without pills, is hurtful, damaging, toxic and unhelpful."

Positive experiences with social media

- 11.23.** Respondents were asked to what extent they agreed with the statement 'I have had positive experiences when participating in social media'. Nearly two thirds of respondents (63%) agreed with the statement, and shared examples such as connecting and socialising with others online and hearing about others' lived experience of mental health. Social media is the life area with the highest level of agreement with the statement about positive experiences.
- 11.24.** In open-text comments, one respondent observed that social media helps people who struggle with face-to-face contact to socialise and make friends. Others celebrated social media for its role in opening up conversations about mental illness and helping to drive out stigma regarding mental health.

"There is a lot of great work being done to normalise mental illnesses out there on social media... there are so many people now connecting or getting help/treatment who might not have done so in the past."

"I read a story on LinkedIn about the positive impact of having a neurodiverse workforce and was delighted to share it."

- 11.25.** Other positive experiences included supportive interactions on posts about personal experiences of mental illness.

"Whenever I have shared my experience of living with a mental illness people from extended family/friends have reached out to show support or share their own stories letting me know I'm definitely not alone."

Summary

- Over three quarters of respondents (266, 77%) said they had experienced stigma or discrimination on social media because of their mental illness in the past 12 months, with 21% reporting it was experienced frequently, and 23% very frequently.
- Social media was selected by 74 (21%) respondents as one of up to three life areas in which the stigma and discrimination they experienced had the greatest impact on them.
- All statements about experiences of mental health stigma and discrimination in relation to social media content were met with high levels of agreement. Nearly all (94%) had experience of interacting with social media content that was hurtful or offensive due to the way mental illnesses were portrayed.
- Nearly half (45%) had experience of being bullied on social media because of stigma about their mental illness.
- There were high levels of agreement with statements about expectations of seeing content on social media that is hurtful or offensive due to the way mental illnesses are portrayed (90%), seeing content that portrays people with mental illness as being to blame for their problems (87%) and seeing content that portrays people with mental illness as dangerous (86%).
- Nearly two thirds of respondents (63%) had positive experiences when engaging with social media. Positive experiences included hearing stories from other people with lived experience of mental illness, socialising online and receiving supportive messages from online connections/followers.
- The main themes in open comments related to measures that respondents take to avoid harmful and upsetting content online, and concerns about toxic positivity online.

12. Education and training

“They would tell me I was short tempered, unpredictable and loud. Rather than a short temper, I felt I was instead very anxious and had so much going on in my head, sometimes when someone asked me to do something (like homework etc.) I would feel anxious about it and subsequently react by appearing stressed/under pressure. I felt I was made out to be some type of monster at times, when in fact, I was scared and just needed some extra support to achieve everything I wanted to. After starting university to study my degree, my personal tutor has been great, and I have been open and up front about my mental health from the beginning in order to get the support if I require it. I have however been told that it may be useful if I ‘took a year out’ on one occasion, whilst in my first year, but quickly informed the individual that this wasn’t an option for me, and I am fit and well to be on my course.”

Overview

- 12.1.** This chapter explores respondents experiences of stigma and discrimination about their mental illnesses in relation to education and training. The survey definition of this life area included secondary education, college and university education, vocational qualifications and modern apprenticeships, short courses, continuing professional development and work-related training/qualifications.
- 12.2.** Education and training was the seventh most commonly selected life area in terms of the frequency of stigma and discrimination experienced. In total 198 respondents (57%) reported experiences of stigma and discrimination in this life area within the past 12 months, with 16% reporting it either frequently or very frequently.
- 12.3.** Fifty-two respondents (15%) selected education and training as one of the three life areas in which stigma and discrimination about their mental illness had the greatest impact, making it the sixth most selected by level of impact. Those selecting this life area also reported experiencing stigma in this area more frequently – 42% either frequently or very frequently compared to 16% of all survey respondents.
- 12.4.** This chapter presents the profile and experiences of respondents who selected education and training as one of the three life areas where they experience most stigma and discrimination.

Respondent profile

- 12.5.** In general, the demographic profile of respondents who selected this life area broadly aligns with the total sample. However, this audience was more likely to: describe their gender as female (67% vs. 58% overall); identify as bisexual (31% vs. 20% overall); and be single (50% vs. 40% overall). While half are students (50% vs. 17% of the total sample), 38% also reported being employed either full-time or part-time (compared to 46% overall).

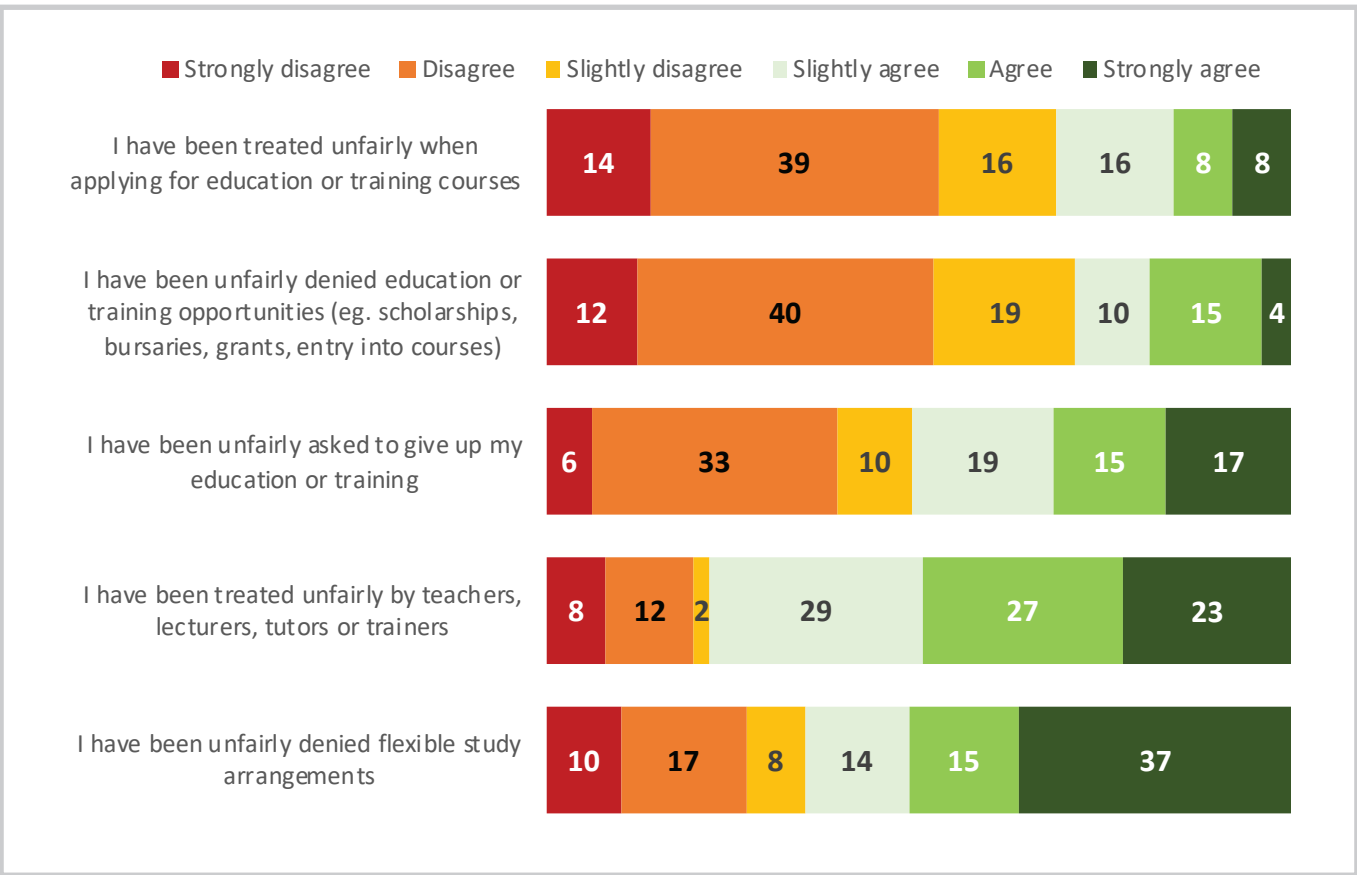
12.6. Mental illnesses among those who selected the education and training life area broadly align with the profile of the overall survey sample. In this cohort, the most frequently reported were severe and/or treatment-resistant depressive disorder (46%), anxiety/fear-related disorder (42%) and disorders associated with stress (40%).

Perceived experiences of stigma and discrimination in education and training

12.7. Figure 12.1 presents the extent to which respondents agreed or disagreed with each statement about this life area.

Figure 12.1. Perceived experiences of stigma and discrimination in education and training: percentage agreement and disagreement (n=51-52)

Because of stigma about my mental illness(es)...



12.8. Respondents were most likely to report experiences of unfair treatment within an education setting, rather than during the application and entry process. Four fifths (79%) agreed they had been unfairly treated by teachers, lecturers, tutors or trainers, with one quarter (23%) agreeing strongly that this had been their experience. A slightly smaller proportion (65%) felt they had been denied flexible study arrangements, strong agreement with this experience was the highest of all five statements (37%).

| *“There is a difference in educational stigma at each level of education.”*

12.9. Half (52%) agreed that they had been unfairly asked to give up their education or training. However, in relation to accessing education and training, there appears to be fewer experiences of stigma and discrimination linked to mental illness. Three in ten agreed that they had been treated unfairly when applying (31%) or had been unfairly denied education or training opportunities (29%).

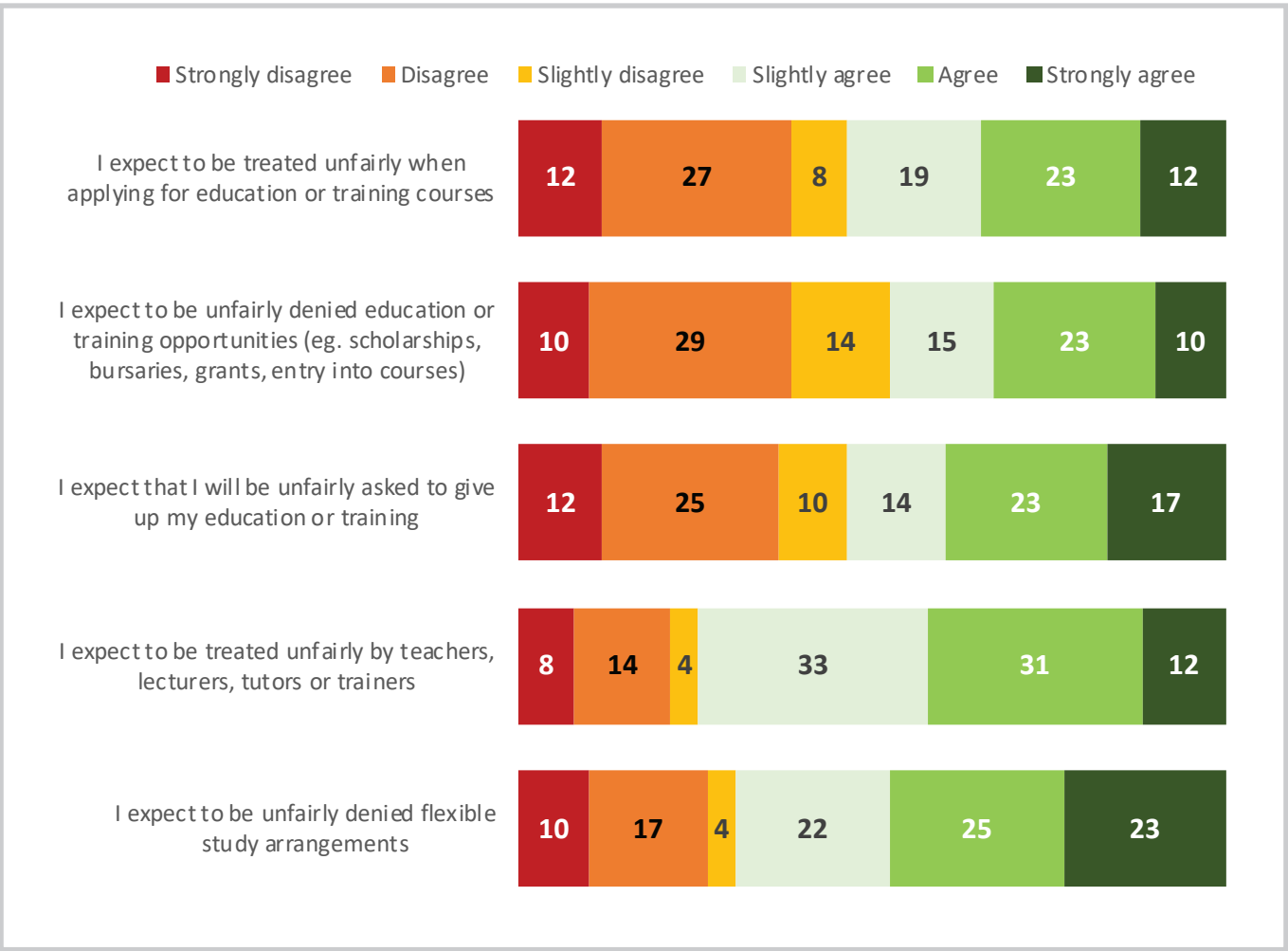
“Tutors say education is for all potential learners only until they have the course fees in December. After that they don’t want anyone there who has health problems. No equal rights to learning.”

Anticipated stigma and discrimination in education and training

12.10. Figure 12.2 presents the extent to which respondents agreed or disagreed with each statement.

Figure 12.2. Anticipated experiences of stigma and discrimination in education and training: percentage agreement and disagreement (n=52)

Because of stigma about my mental illness(es)...



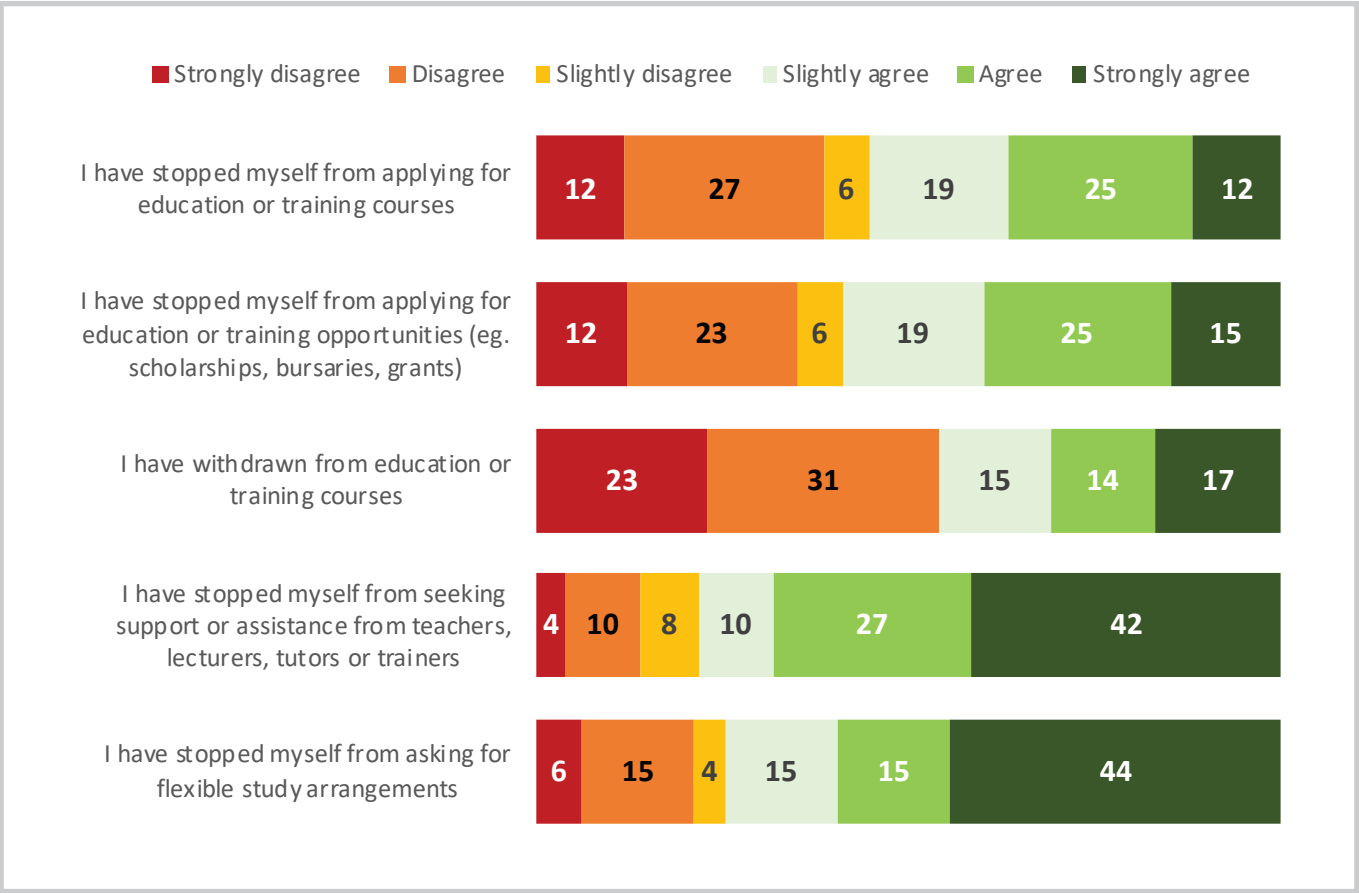
- 12.11.** Respondents were presented with statements about expectations concerning five different aspects of training and education. Expectations around being treated unfairly when applying for courses, or being unfairly denied opportunities, are higher than those recorded for perceived experiences. Over half (54%) expect to be treated unfairly when applying (compared to 31% who indicated they had experienced this), and 48% expect to be denied opportunities (compared to 29% who felt they had experienced this).
- 12.12.** Other expectations broadly aligned with perceived experiences. Just over half (54%) expect to be asked to give up their courses (compared to 52% who experienced this). Seven in ten (70%) expect to be unfairly denied flexible study arrangements; this statement again records the highest level of strong agreement (23%). Three quarters (75%) anticipate being treated unfairly by teaching staff.

Withdrawal from opportunities in education and training

12.13. Figure 12.3 shows the extent to which respondents agreed or disagreed with statements related to this.

Figure 12.3. Withdrawal from opportunities in education and training: percentage agreement and disagreement (n=52)

Because of stigma about my mental illness(es)...



- 12.14.** Four of the five statements about withdrawing from opportunities in education and training because of stigma about mental illness were agreed with to some extent by over half of respondent. The highest level of agreement concerned stopping from seeking support or assistance from teachers, lecturers, tutors or trainers received (79% agreed, 42% agreed strongly), closely followed by stopping from asking for flexible study arrangements (75% agreed, 44% agreed strongly).
- 12.15.** Three fifths (60%) agreed they had stopped applying for education or training opportunities, and 56% agreed they had stopped applying for courses. Although fewer than half agreed, 46% still indicated they had withdrawn completely from education or training courses.

"I am a skills network and open university student. I have struggled to hand in assignments cos I've had a bad week or time. Meaning I've had to give up the course, then being banned for I think its 6-12 months from applying for another course"

Intersectional experiences of stigma and discrimination in education and training

- 12.16.** Intersectionality in experiences of stigma and discrimination in relation to education and training is also evident from survey responses. Respondents most commonly reported stigma and discrimination in relation to their sex (44%), age (38%), sexual orientation (29%) and disability (29%).

"I have experienced a lot of sexism, ableism and antisemitism in my work."

"An international society at the university openly called me racist comments on social media and then termed me as someone who needs mental health support."

Views on the requirement for special considerations

- 12.17.** When asked whether they should receive additional consideration when applying for, participating in, or completing education or training, four fifths (79%) agreed they should, with 19% agreeing strongly. This represents the fourth highest level of total agreement across all 14 life areas.

"I feel individuals with a mental illness should have the opportunity for extra support when applying for a job or education etc, and most importantly made to feel safe and accepted as this unfortunately isn't always the case. I feel it's important for individual's to be able to discuss their mental health without the fear of stigma or discrimination, both of which I have experienced on multiple occasions."

Other feedback about stigma and discrimination in education and training

- 12.18.** Respondents were invited to share further details about their experiences of stigma and discrimination in relation to their education and training. The responses fell into four overlapping and interlinked thematic areas, each discussed below:

- Lack of institutional support or accommodation.
- Unhelpful staff.
- Avoiding and ignoring mental health.
- Challenging post graduate work environments.

Lack of institutional support or accommodation

- 12.19.** Respondents highlighted a lack of support for or accommodation of their mental health needs at an institutional level. Examples included a lack of pathways to support and assistance, challenging access to distance learning, and an inflexible approach to academic conventions and expectations.

“Because of the way my brain functions and my life experiences (Trauma), I think and therefore write in a certain way – this has been called many things – including an idiosyncratic prose style. The institutions are insistent that I write the way they dictate, and so far are inflexible in considering that my form of writing might be OK? Despite many requests they insist on changing things at the very last minute – three days’ notice and less – The problem is that they refuse to see the effect that this has on me, and the depth of despair I go to (complex post-traumatic stress disorder).”

- 12.20.** Often respondents mentioned this was despite the institutions being made aware of their illnesses.

“[There was a] lack of support during learning despite being identified as a disadvantaged student due to my mental health.”

- 12.21.** Respondents highlighted that the lack of support directly impacted their ability to continue in their programs.

“I dropped out of my MSc because it felt impossible to access support I needed and it was nearly impossible to access flexible learning access.”

Unhelpful staff

- 12.22.** Unhelpful actions or inaction by individual staff members were described. While some respondents left general remarks, others provided examples of staff who were perceived to be untrained and unsympathetic in their approach to students with mental illness, in one case even recommending a termination of study.

“Staff were totally uneducated on my illness, and instead of approaching me and checking in with me, would ignore my concerns until I was on the verge of a panic attack/emotional breakdown. This stopped me and made me very hesitant to seek advice or help from my lecturers.”

“I have been encouraged by the head of postgraduate student support, in the name of my mental health, to give up my PhD.”

“Lecturers couldn’t care less about the struggles you’re going through.”

Avoiding and ignoring mental health

- 12.23.** Examples of having needs ignored also appeared in multiple responses. These included practices of avoidance, such as instructing respondents not to speak of their mental illness, or a lack of acknowledgment of mental illness.

“The course I was on was fairly open about mental health discussion between students and lecturers during the academic section of the degree (it was a PGDE for Secondary Teaching). But as soon as placements began, any talk about mental illness was strongly recommended to stop (both in person and over social media). This was due to the potential impact of employers or parents of pupils finding out about this regarding their prospective teacher and the resulting fallout. This situation and having schizophrenia made me feel extremely anxious as I felt that I was going to be discovered any minute of the day. This was a major factor into why I left the course and why I do not want to go back to university.”

“When I was a child at a top private school, they refused to acknowledge that I was ill and did not give me help instead ignored it.”

Challenging post graduate education work environments

- 12.24.** In comments from respondents with experience of postgraduate education, negative and discriminatory experiences in their work environments were described. This included fears about the dependence of personal success on colleagues and managers.

“At the PhD level, certain accommodations are easier but you have to go through so many hoops and waiting periods to get there. Also, the judgement you get from your supervisors could lead to your losing your support.”

- 12.25.** One respondent highlighted institutional stigmas against those who are seen as different or challenging to the status quo.

“People feel entitled to and justified in ladder-pulling, that is, limiting or obstructing the advancement of those with difficulties and disorders, feeling they are undeserving. Their grandiose fantasy is punctured when they see people who they consider inferior succeed, and they feel they are balancing the ledger with their own sense of victimisation by denying access to others. Case in point, almost twenty years later I have still not found closure with how badly I was bullied and traumatised by the head of student disability during my post graduate studies, and how little anybody cared.”

Positive experiences in education and training

- 12.26.** Respondents were asked about positive experiences when applying for, participating in, or completing education or training, and two fifths (39%) agreed they have had positive experiences, meaning this ranked seventh out of the 14 life areas.
- 12.27.** In comments on any positive experiences linked to mental illness in relation to education and training a few respondents reiterated a lack of support from staff and institutions, particularly at post-secondary level. Some respondents also mentioned positive experiences with education and training. Two overarching themes emerged during the analysis of comments:
- Good support services.
 - Inclusive classroom experiences.

Good support services

12.28. A few respondents mentioned that they found the support services at universities to be considerate and accommodating.

"I find that education services are really good at accommodating people's needs with a disability/mental health condition and ensure the right support is in place when this is declared."

"I recently got my DSA needs assessment. The person who conducted this was very – VERY – considerate and a good listener. This restored my faith to some degree. The only problem with this is that I cannot take her in to the university course with me!"

12.29. One respondent described the support at both individual staff and institutional level as 'very refreshing'.

Inclusive classroom experiences

12.30. Two respondents described the positive integration of their lived experience of mental illness into classroom discussions and assessments. One respondent wrote, it is positive 'being able to incorporate lived experiences into assessments'.

"Doing a mental health first aid course for work, my own experience of mental health issues was valued."

Summary

- Overall, 198 respondents (57%) reported experiences of stigma and discrimination in education and training within the past 12 months, with 16% reporting it either frequently or very frequently.
- Around one in six respondents (52, or 15%) selected education and training as one of the three life areas in which they had experienced the greatest impact because of stigma and discrimination about their mental illness.
- Respondents most commonly reported stigma and discrimination in relation to their sex (44%), age (38%), sexual orientation (29%) and disability (29%).
- Among those who selected this life area, four fifths (79%) agreed they should receive additional consideration when applying for, participating in, or completing education or training.
- In open comments about education and training, four overarching themes were evident. Firstly, an absence of institutional support was highlighted which, alongside a lack of pathways to assistance, also included inconsistent access to distance learning and an inflexible approach to teaching and assessments. Secondly, were descriptions of unhelpful staff whose actions, or inactions, were seen as unsympathetic and untrained in their approach to mental health. Respondents also discussed feelings that their mental health was avoided or ignored. Finally, experiences of intimidation and harassment at in post graduate education work settings were shared.
- Two fifths (39%) of respondents to this life area agreed that they have had positive experiences due to their mental illness. In comments, examples included good support services and inclusive classroom experiences.

13. Mass media

"I think I have just accepted that mental health is not well represented in the media."

Overview

- 13.1.** Respondents' experiences of stigma and discrimination about their mental illness in relation to mass media are presented in this chapter. Mass media is defined as news media (including televised news programmes, radio, newspapers, magazines and online news sources) and entertainment or creative media (such as films, music, books, televised entertainment programmes).
- 13.2.** Just under three quarters of respondents (249, 72%) said they had experienced stigma or discrimination through mass media because of their mental illness in the past 12 months, with 25% reporting it was experienced frequently, and 17% very frequently.
- 13.3.** Mass media was selected by 48 respondents (13%) as one of up to three life areas in which mental health stigma and discrimination has had the greatest impact on their life in the past 12 months. This was the seventh most commonly selected life area. More than half (54%) of those who selected this life area claimed to have experienced stigma related to this either frequently or very frequently, compared to 42% of all respondents.
- 13.4.** This chapter presents the profile and experiences of respondents who selected mass media as one of their three life areas where the greatest impact of stigma and discrimination about their mental health is felt.

Respondent profile

- 13.5.** The profile of participants who selected mass media as one of their top three life areas is broadly reflective of the overall respondent population. However, a greater portion of respondents who selected the mass media life area were single than the general survey population (52% vs. 40%).
- 13.6.** Mental illnesses among the overall survey respondent population is also largely comparable to the sample that selected mass media in their top three life areas.

Perceived experiences of stigma and discrimination in mass media

- 13.7.** Figure 13.1 shows the extent to which respondents agreed or disagreed with statements about their perceived experiences of mental illness stigma and discrimination in mass media.
- 13.8.** All statements about experiences of mental illness stigma and discrimination in relation to mass media content were met with high levels of agreement. Nearly all respondents (96%) had been exposed to news media in the past 12 months that they found hurtful or offensive

because of the way mental illnesses were portrayed; a similar percentage (91%) agreed this was also the case with entertainment or creative media.

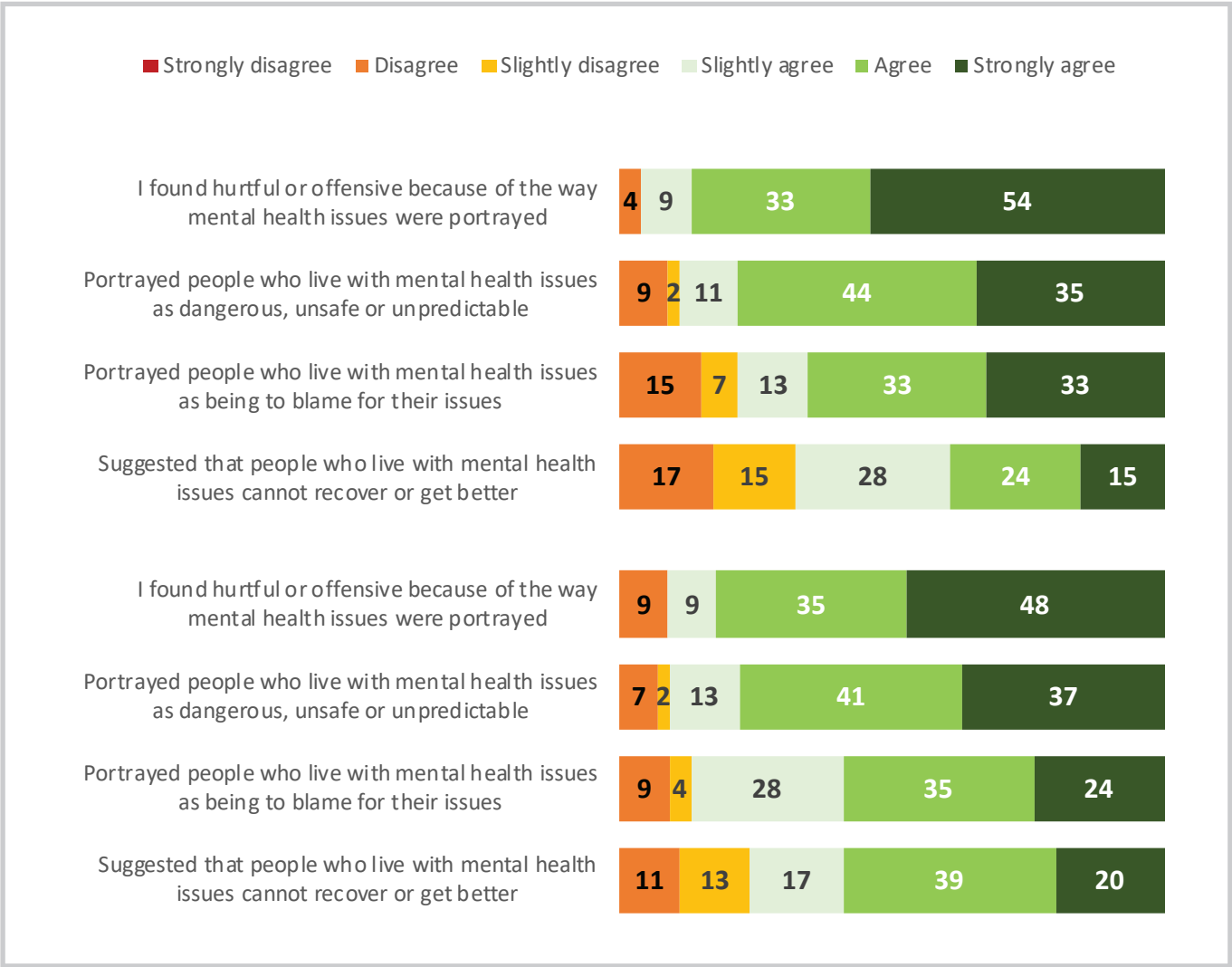
13.9. Almost 90% had seen, read or heard news media content that portrayed people with mental health issues as dangerous, unsafe or unpredictable; this was slightly higher for entertainment and creative media (91%). More than three quarters (76%) had consumed entertainment media that suggested that people who live with mental health issues cannot recover or get better.

“I think the newspapers still have a long way to go, very discriminative and stigmatising.”

“Portrayed as dangerous and capable of doing wrong things and self-inflicted choices.”

13.10. In open text comments, respondents described seeing particularly harmful depictions of Borderline Personality Disorder and Dissociative Identity Disorder in creative media in recent years, which have created a misconception that people living with mental illness are dangerous and violent.

Figure 13.1. Perceived experiences of stigma and discrimination in mass media: percentage agreement and disagreement (n=46)



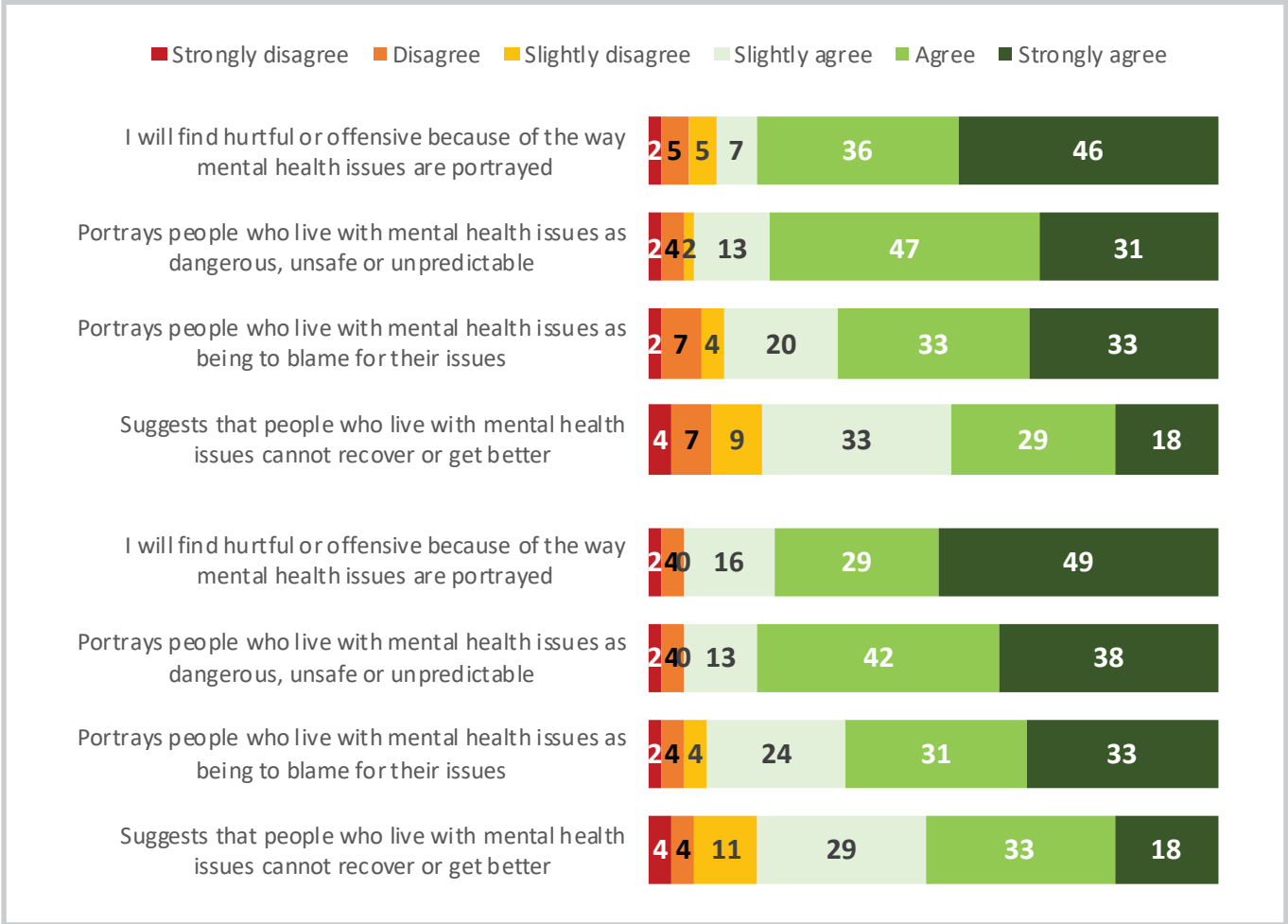
“DID is a huge one – people just cannot get it into their heads that it doesn’t mean you have a million people in your head and one of them is The Beast, who is violent and dangerous. That is almost solely down to the movie Split, which was absolutely disgusting and wasn’t condemned publicly by any health authority I’m aware of.”

“The portrayal of people with Borderline Personality Disorder continues to be horrendous in most cases.”

Anticipated stigma and discrimination in mass media

- 13.11. Figure 13.2 presents data on the extent to which respondents agreed or disagreed with statements about anticipated stigma and discrimination about their mental illness when engaging with mass media.
- 13.12. Responses to statements about anticipated stigma and discrimination in mass media were closely aligned to perceived experiences of stigma and discrimination. There were high levels of agreement with statements about expectations of seeing news stories that: portrays people with mental health issues as dangerous, unsafe or unpredictable (91%); are hurtful or offensive due to the way mental health issues are portrayed (87%), or portrays people with mental health issues as being to blame for their problems (87%).

Figure 13.2. Anticipated experiences of stigma and discrimination in mass media: percentage agreement and disagreement (n=44-45)



13.13. Similarly, there were high levels of agreement with statements about expectations of seeing stigmatizing and discriminatory depictions of mental illness in creative and entertainment media. Nearly all respondents who selected mass media in their top three life areas expected to see, read or hear entertainment or creative media that was hurtful or offensive because of the way mental health issues are portrayed (93%). Similar proportions also expected to engage with creative and education media that suggested people with mental illness are dangerous, that they are to blame for their problems and that they will not recover or get better.

Withdrawal from opportunity in mass media

13.14. Figure 13.3 shows the extent to which respondents agreed or disagreed with statements on withdrawing from interacting with news, entertainment and creative media due to stigma and discrimination about their mental illness.

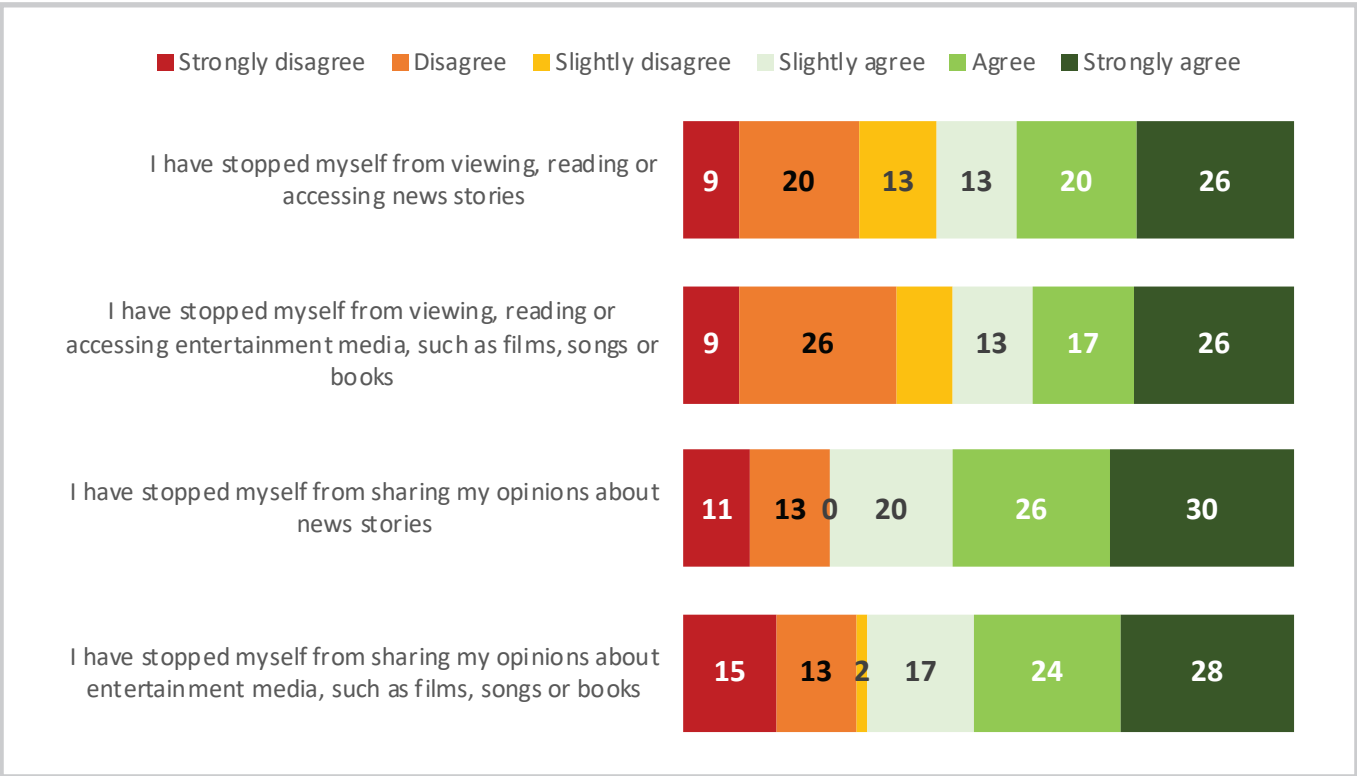
13.15. More than half of the respondents had stopped themselves from viewing, reading or accessing media content due to mental health stigma and discrimination, with 59% agreeing they limited their interaction with news media and 57% agreeing they limited their interaction with entertainment media.

| *“I find it is easier to avoid certain shows and programmes to protect myself.”*

13.16. More than three quarters (76%) had stopped themselves from sharing their opinions about news stories and a similar proportion (70%) from sharing their opinions about entertainment media due to stigma about their mental illness.

Figure 13.3. Withdrawal from opportunities in mass media: percentage agreement and disagreement (n=46)

Because of stigma about my mental illness(es)...



Intersectional stigma and discrimination with mass media

13.17. Respondents were asked about whether any stigma and discrimination in this mass media life area related to other aspects of their identity. The most commonly reported characteristics were sex (47%), age (42%) and sexual orientation (33%). This is very similar to intersectionality related to social media.

“There are often horror films and shows i.e. Greta, Fatal Attraction, Friend Request etc. that centre around a single woman with BPD traits who gets obsessed and is the dangerous protagonist.”

“As a person of colour I believe there is a significant degree of disproportionate and discriminatory representation of ethnic minorities in mainstream media (such as the news).”

Other feedback about stigma and discrimination in mass media

13.18. Open-text comments about stigma and discrimination broadly focused on inaccurate portrayals of mental illness in mass media. Respondents criticised films, books and TV series which use mental illness as a plot device or for dramatic effect, without recognising or accurately depicting the reality of living with mental illness. In a similar vein, others expressed dissatisfaction with creative and entertainment media content which depicts characters quickly recovering from mental illness; this can be distressing and harmful for people living with enduring and treatment resistant conditions which have no cure.

“Portrayals are often inaccurate – for me with OCD and eating disorders, the stereotypes are just horrendous and so damaging... they often glamourise eating disorders, or minimise what living with them is really like – it is a snapshot of someone becoming ill very fast then recovering very fast when the reality is bleak, tortured monotony.”

Positive experiences with mass media

13.19. Respondents were asked to what extent they agreed with the statement ‘I have seen, read or heard news media/entertainment or creative media that portrayed people who live with mental health issues in a positive way’. More respondents agreed with the statement about positive portrayals of mental health in creative or entertainment media than news media (61% compared with 50%).

13.20. Few respondents shared examples of positive experiences in their open text comments. Some felt that representation of mental illness in news and entertainment media has increased in recent years, which was welcomed. A small number described specific TV shows which have handled plots about mental illness with sensitivity.

“This Way Up by Aisling Bea was a positive. It didn’t make me feel good about my depression and anxiety but it was honest, and honest representation is kind of the best we can get now. The fact that she won a BAFTA for it was also encouraging, like making a show about mental illness that’s also funny and engaging was worth that award. That was good.”

13.21. Some said that they had noticed celebrities and public figures being more open about their mental health in the news, which they welcomed as a step towards normalising and reducing stigma around mental illness.

“I think more well-known people coming forwards to share experiences is a good thing as it humanises experiences – mental illness is so isolating it is nice to see people talking openly.”

Summary

- Just under three quarters of respondents (249, 72%) said they had experienced stigma or discrimination because of their mental illness through mass media in the past 12 months, with 25% reporting it was experienced frequently, and 17% very frequently.
- Mass media was selected by 48 respondents (13%) as one of up to three life areas in which mental health stigma and discrimination has had the greatest impact on their life in the past 12 months.
- All of the statements about experiences of mental health stigma and discrimination in relation to mass media content were met with high levels of agreement. Nearly all respondents (96%) had been exposed to news media in the past 12 months that they found hurtful or offensive because of the way mental health issues were portrayed; a similar percentage (91%) agreed this was also the case with entertainment or creative media.
- More than three quarters (76%) had stopped themselves from sharing their opinions about news stories due to stigma about their mental illness.
- There were high levels of agreement with statements about expectations of seeing stigmatising and discriminatory depictions of mental illness in both news and creative and entertainment media.
- More respondents had seen positive portrayals of mental health in creative or entertainment media than news media (61% compared with 50%).
- Open-text comments about stigma and discrimination broadly focused on inaccurate portrayals of mental illness in mass media.

14. Welfare benefits and financial support

"I feel that, just like with disability, the DWP don't have any clue of dealing with people with mental health conditions."

Overview

- 14.1. Experiences of stigma and discrimination because of mental illnesses when accessing, using and retaining welfare benefits and state financial support are explored in this chapter. Our definition when asking about this life area included, Universal Credit, Jobseekers Allowance, Employment and Support Allowance, Personal Independence Payments, and Child Benefit.
- 14.2. This life area was the ninth most commonly selected in terms of the frequency of stigma and discrimination experienced. In total 183 respondents (53%) reported experiences of stigma and discrimination related to welfare benefits and financial support in the past 12 months. One in ten (11%) reported experiencing this frequently and 16% very frequently. This was the fourth highest level of experiencing stigma very frequently of the 14 life areas.
- 14.3. Forty five respondents (13%) selected the welfare life area as one of up to three life areas in which the stigma and discrimination they experienced had the greatest impact on them. It was the eighth life area most commonly selected as one of the three in which stigma and discrimination has the greatest impact. Over two thirds (69%) who selected this area as one of the three most impactful reported to have experienced stigma in this life area either frequently or very frequently, compared to 27% of all survey respondents.
- 14.4. This chapter presents the profile and experiences of respondents who selected welfare benefits and financial support as one of the three life areas where they experience most stigma and discrimination. **Given the small sample size, findings in this chapter should be treated as indicative.**

Respondent profile

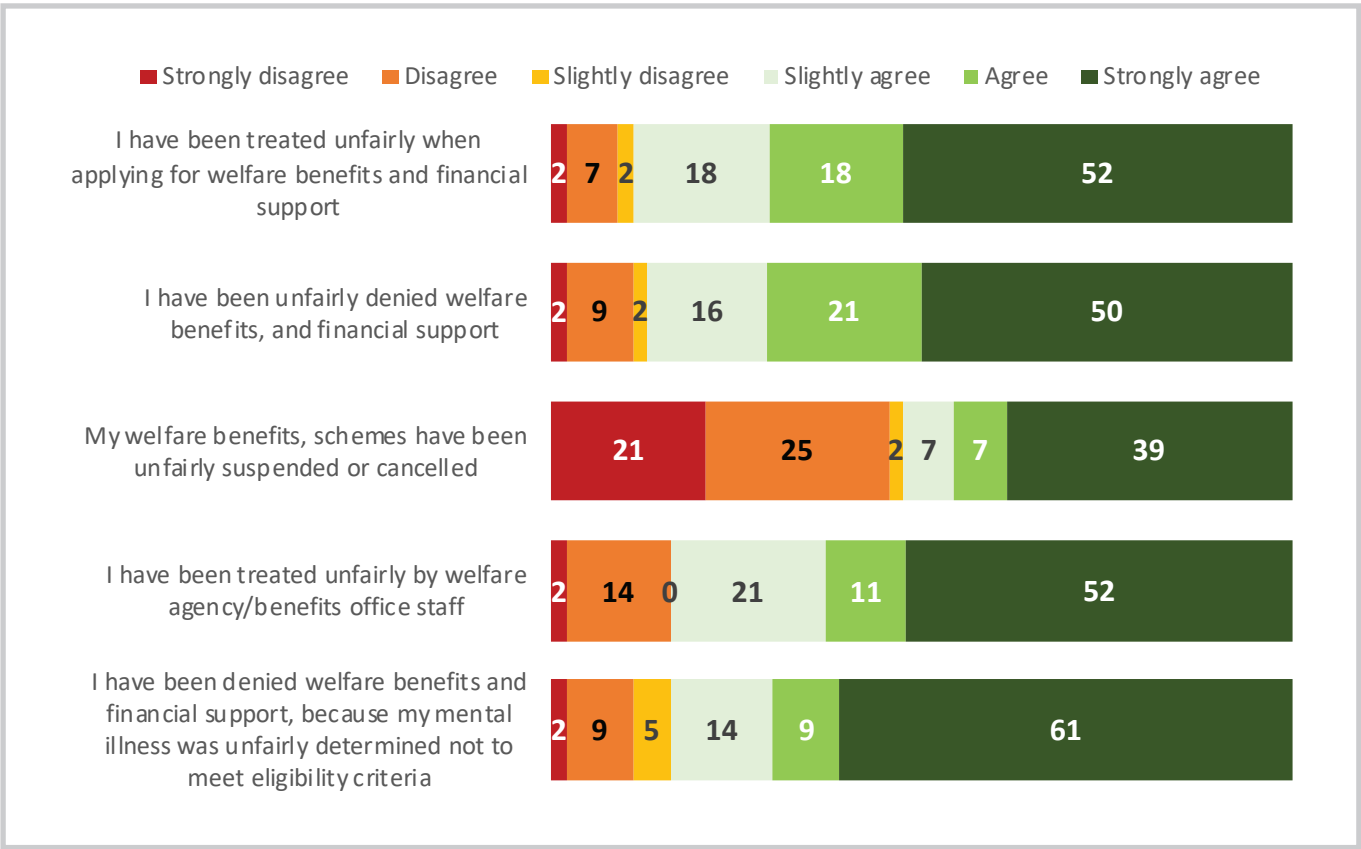
- 14.5. The profile of the cohort who selected this life area in their top three is largely reflective of the overall respondent population. Notable differences include this group of respondents being less likely to be employed (27% vs. 50% overall) and more likely to report that they currently have no job (58% vs. 28% overall). They were also more likely to be in local authority or social housing (33% vs. 22% overall), to identify as heterosexual (62% vs. 54% overall), and/or to be divorced (11% vs. 6% overall).
- 14.6. Mental illnesses among those who selected the welfare benefits and financial support life area broadly aligns with the profile of overall survey sample. Most commonly reported among this respondent group were severe and/or treatment-resistant depressive disorder (49% vs. 39% overall), anxiety/fear-related disorder (42%, in line with 40% among the total sample) and disorders associated with stress (42% vs. 43% in the total sample). Respondents in this life area recorded the second highest level of dissociative disorder of the 14 areas (20% vs. 12% overall).

Perceived experiences of stigma and discrimination in welfare benefits and financial support

14.7. Figure 14.1 presents the extent to which respondents agreed or disagreed with statements about welfare benefits and financial support.

Figure 14.1. Perceived experiences of stigma and discrimination in welfare benefits and financial support: percentage agreement and disagreement (n=44)

Because of stigma about my mental illness(es)...



14.8. Respondents were presented with five statements on unfair treatment with welfare and benefits system. Very high levels of agreement were evident, with strong agreement. the most common response. Nine out of ten (89%) agreed they had been treated unfairly when applying for benefits or support, 86% that they had been unfairly denied support and 84% that they have been treated unfairly by staff in welfare/benefits offices. At least half of respondents agreed strongly with four of the statements on unfair treatment with welfare and benefits.

14.9. Over four fifths (84%) agreed they had been denied support because their mental illness did not meet the eligibility criteria, with three fifths (61%) expressing strong agreement, the highest level of strong agreement across the five statements.

“I have been told that it is unlikely that I will ever work again in any effective capacity so why am I not entitled to something similar to Personal Independence Payments.”

14.10. Just over half (52%) agreed they had seen their welfare benefits unfairly suspended or cancelled. Two fifths (39%) agreed strongly with this experience.

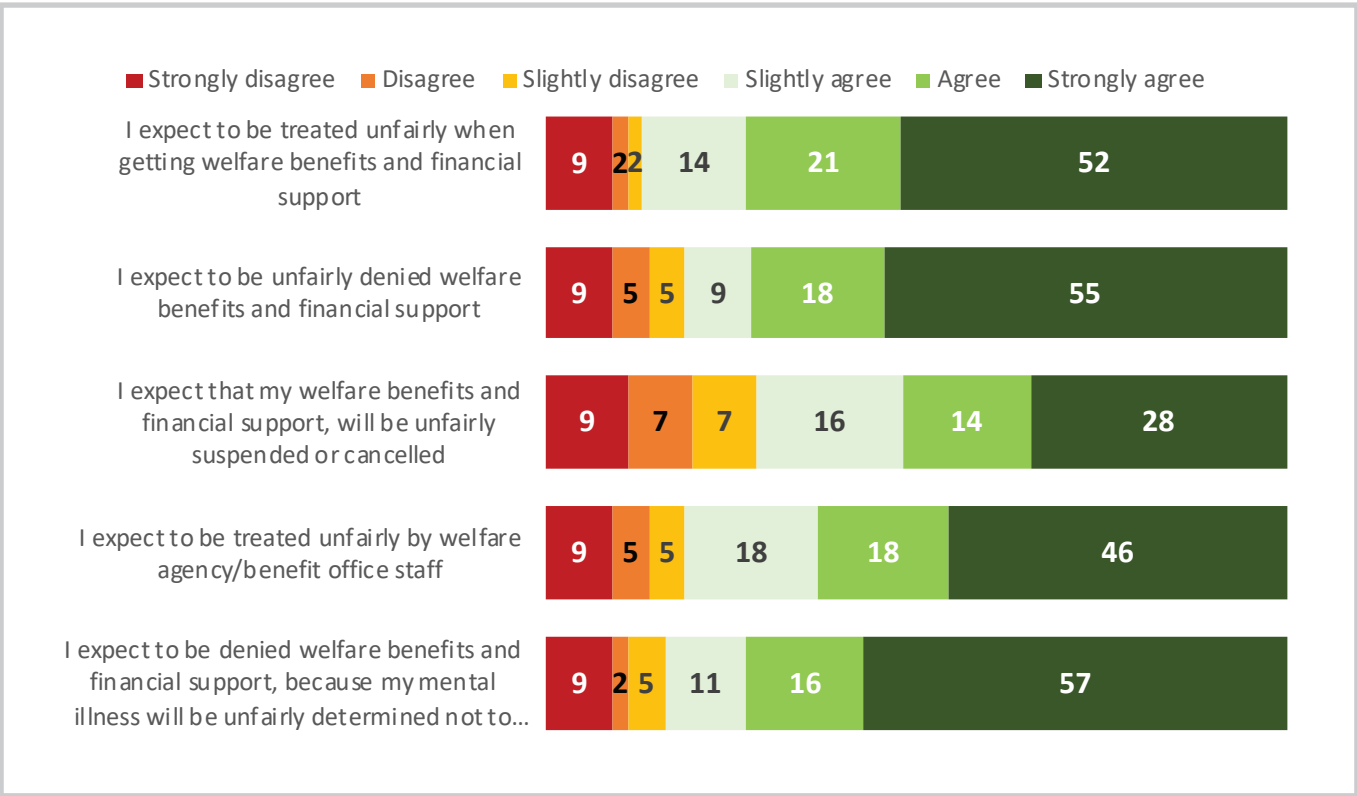
“My experience was in relation to applying for PIP after my lifetime award of DLA was stopped. Having to prove the impact of my mental ill health was challenging esp. as I am now in a place when I can hold down a full-time job despite the daily impact this has on me. I felt unbelievable.”

Anticipated stigma and discrimination in welfare benefits and financial support

14.11. Figure 14.2 presents the extent to which respondents agreed or disagreed with statements about aspects of anticipated stigma and discrimination around welfare benefits and financial support.

Figure 14.2. Anticipated experiences of stigma and discrimination in welfare benefits and financial support: percentage agreement and disagreement (n=44)

Because of stigma about my mental illness(es)...

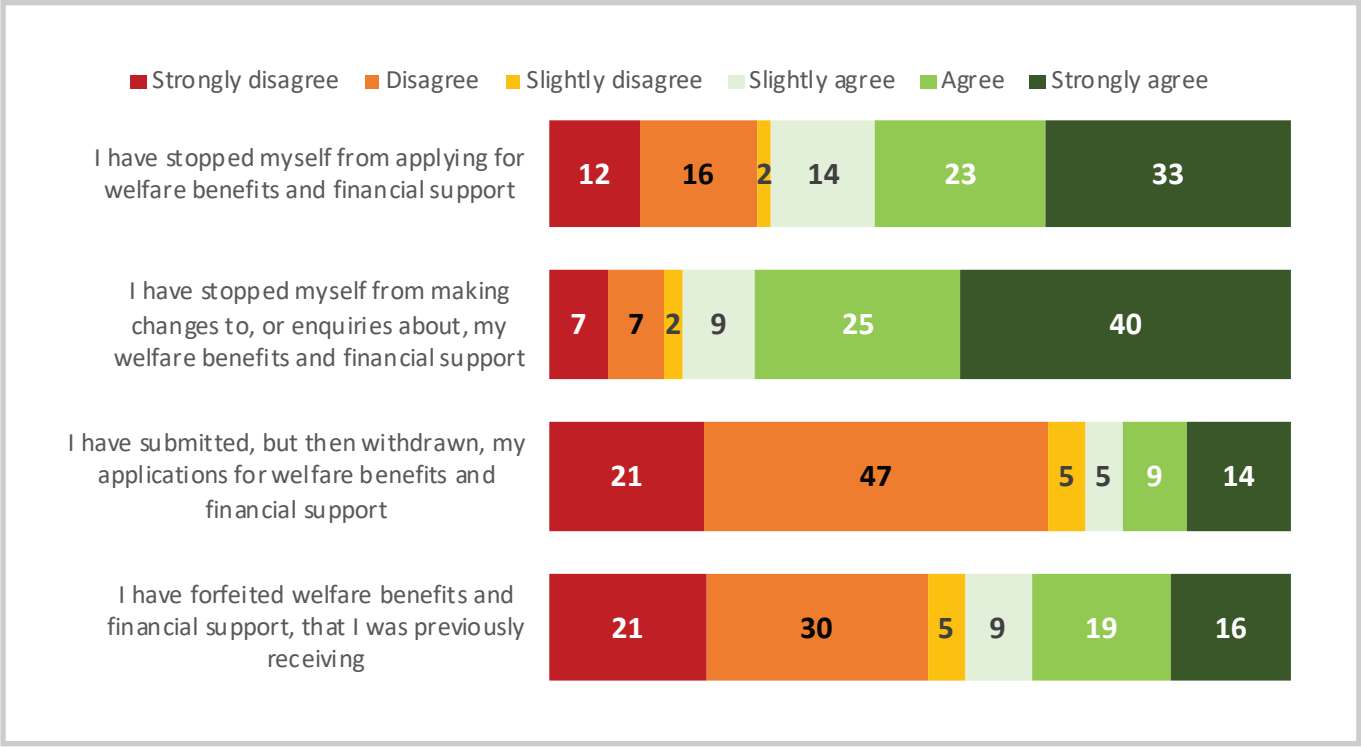


14.12. High levels of agreement were evident for anticipated stigma and discrimination in welfare benefits and financial support. Over three quarters agreed with all five statements, indicating high levels of expectation of unfair treatment in the future.

14.13. While just over half (52%) reported having experience of their support being unfairly suspended or cancelled, three quarters (77%) expect that this might happen in the future due to stigma and discrimination about their mental illness. More than a quarter (28%) agreed strongly that they anticipated this happening to them.

Figure 14.3. Withdrawal from opportunities in welfare benefits and financial support: percentage agreement and disagreement (n=43)

Because of stigma about my mental illness(es)...



“I expect to be discriminated against by the benefits agencies because the format they use for communication is largely where I struggle. It is almost impossible to face to face meet and there are very few local offices. I was advised to use the CAB but our local office has closed. I get flustered talking on the phone and I always seem to mess up the forms that are used.”

Withdrawal from opportunity in welfare benefits and financial support

- 14.14.** Figure 14.3 presents the extent to which respondents agreed or disagreed with statements about withdrawal from decisions and choices about welfare benefits and financial support.
- 14.15.** Varied experiences of withdrawing from opportunities around welfare and financial support by respondents in this life area were evident. The highest level of agreement was 84% who agreed that they had stopped making changes to, or enquiries about, their support. Seven in ten (70%) agreed that they had stopped applying for support.
- 14.16.** Over two fifths (44%) agreed they had forfeited financial support they had previously been receiving. In addition, one quarter (28%) reported that they had submitted but then withdrawn applications for support.

Intersectional experiences of stigma and discrimination with welfare and financial benefits

- 14.17.** Experiences of stigma and discrimination around welfare and financial benefits tended to show less evidence of intersectionality than many of the other life areas. There was however a

much higher perceived experience of stigma and discrimination related to physical disabilities (45% vs. 21% in the total sample). Age was the second most commonly mentioned reason for discrimination (26%).

Views on the requirement for special considerations

14.18. The vast majority of respondents in this life area (91%) agreed they should receive additional consideration when accessing, retaining, or using welfare benefit and financial support services. This is the second highest level of total agreement after the legal and justice life area. Two fifths (42%) agreed strongly that this should be the case, the second highest level of strong agreement after housing (46%).

“Realistically, people should be told by their GPs to apply. And should not have to deal with the relentless stress that the application process brings. I had to complain after the healthcare worker said I was completely fine. It really messed with my confidence and self-worth leading me to start self-harming again.”

Other feedback about stigma and discrimination in accessing, using, and retaining welfare benefits and financial support

14.19. Respondents were invited to share further details about their experiences of stigma and discrimination relating to welfare benefits and financial support. In an analysis of responses, four interlinked themes emerged:

- Difficult application processes.
- Problematic assessors.
- Systemic disregard for mental health.
- Ineligible for benefits, yet still struggling.

Difficult application processes

14.20. Many respondents described the difficulties they faced when applying for certain benefits, often highlighting long and burdensome administrative processes. Some questioned the inclusivity of application processes that involve extensive paperwork. Many highlighted the time it took to receive benefits or even status updates, ranging from a few months to years.

“The PIP application process is an utter disgrace. The forms are ridiculously time consuming to fill out. Of course, they need as much detail as possible, but I don’t understand why a letter of support from medical professionals involved in treating someone can’t just be enough. There has to be a more humane and dignified way of treating people. The sheer amount of information they require is overwhelming and I put off applying for several years before I finally was persuaded by a friend who supported me through the process. They also are terrible at providing you with updates – I waited five months before getting an assessment and I know that my wait time isn’t too long compared to some people, but you don’t hear from them in between. It would greatly reduce peoples’ anxiety if they could even just send a quick odd test to say your claim is still being processed as otherwise people just end up feeling like they’ve been abandoned and forgotten about.”

"I am on PIP now, but I had to fight for three years to get it."

- 14.21.** Respondents described applications that were repeatedly rejected, and experiences of facing multiple tribunals which eventually led to an award. Due to the cyclical nature of the application and appeals process, one respondent found themselves constantly applying and reapplying.

"Initially I did not apply. But after some time, I was told to by my mental health nurse. I have a background in finance and law, and I have used every resource (family that cares) that I can leverage in order not to die on the street. Because it seems that's where they want me. It has been extremely difficult to deal with the current system. I have been rejected repeatedly and had to submit mandatory reconsideration at every stage. Half the time it has gone to Tribunal which we have won. It is the most denigrating system I have ever been exposed to, at the worst point in my life. Giving care earlier would have saved us all a lot of time and money."

"My benefits get reviewed every two years, I'm found fit for work and my benefits are stopped. I always win the appeal but that can take up to two years, which means as soon as I've won an appeal, the whole process starts again. It's a never-ending cycle."

- 14.22.** The costs of seeking help from administrators or appealing decisions was highlighted by respondents as discouraging. One described the cost of making mistakes in the application process, resulting in the need to pay back certain benefits.

"Even the cost of phone calls and postage in applying for benefits and appeals is a discouragement. An hour on the phone at 5p a minute is £3. Sometimes I don't have phone credit left. Posting a bundle of evidence to appeal is £5. Photocopying is expensive. Trying to get appointments with any support organisation, GP etc is time-consuming and difficult, and without those appointments there is no medical evidence. Bus fare to an assessment is £9, £18 with a companion – it can be claimed back, but it has to be paid out first."

"I have received benefits in the past however on several occasions (and currently ongoing) I have made a mistake and had to repay. I have a bill of £495 I apparently owe from December 2019 which they just told me about but they can't deduct because I'm not eligible for, or currently receiving benefits so they threatened court action instead. They made it out as though I had intentionally defrauded them."

Insensitive assessors

- 14.23.** Poor treatment by assessors also emerged as a theme in open comments. Respondents explained that when applying for benefits, assessors were poorly trained in how to speak about mental illness, had a poor understanding, were rude or inconsiderate with their attitude, approach, or line of questioning, and belittled or disbelieved respondents.

"I took the appointment. During the interview all I felt was shame. I was told that they would not judge, only to make me feel small when I told her I struggle to clean, especially my bathroom. She responded with disbelief. I didn't receive PIP as I downplayed my condition."

"I recently had a PIP telephone assessment and felt extremely judged by the woman conducting the assessment. I'm a very articulate person and I feel like this so often leads people to assume that because I can express myself clearly that I can't really be that ill. I felt like she was very judgemental and my friend who was supporting me had to speak on my behalf on some occasions to fully get across to the assessor the extent of my difficulties."

"The healthcare assessors at Capita / ATOS LIE. They lie repeatedly. They use healthcare 'professionals' with no mental health training or qualification. A surgeon was reprimanded by GMC for doing mental health assessments he wasn't qualified for. I have multiple 'assessments' which have been overturned at mandatory reconsideration or tribunal. The last assessment the assessor said I was laughing during the (phone) assessment. I wasn't. I was crying and suicidal."

Systemic disregard of mental health

14.24. While poor understanding of mental health issues by the assessors and the application processes was discussed above, respondents also spoke about a general disregard for mental illness as a disability by the government, DWP and benefits systems.

"Mental health is not seen as an illness to DWP."

"I think the translation of our scientific practice of judging what constitutes mental illness into our welfare system is woeful and discriminatory. Psychiatrists routinely discuss difficulties ignored by the welfare system. The consequences are far reaching and have had a hugely negative impact on my life. I am uncertain whether I can live on benefits (and by live I mean survive as they are so little) or whether I have to work to survive. Working to survive with a mental health condition if it deteriorates is a pitfall. I actually cannot do the job and I burn bridges with colleagues and managers as a result making it ever more difficult to move on and find new work. I have had to leave two jobs because of this and was asked to leave one job."

14.25. Other respondents identified systemic problems with the DWP assessments. They highlighted examples where their DWP assessments disagreed with their medical diagnoses or where benefits were removed due a lack of knowledge about mental illnesses.

"I am being 'told' by benefit assessors that my mental health condition does not meet the criteria needed to receive the benefit even though I am diagnosed as 'clinical'. My condition is at the worst case possible, I live with this condition daily, yet they proceed to 'tell' me what I'm experiencing and what I'm not. No compassion whatsoever."

"They don't seem to understand that we are people too and we have good days and bad days. They expect us to be having bad days all the time and when we start to feel a little better, our benefits get taken away when it was the safety net of welfare that was actually supporting our recovery and when it is taken away, it triggers episodes of illness."

Ineligible for benefits, yet still struggling

14.26. Ineligibility for welfare benefits was highlighted by a few respondents. While some made general statements about not qualifying for benefits without expanding on their situation, others noted that their benefits changed once their mental illness started to improve. Some respondents described their mental illness as impacting their ability to earn enough to live, but being unable to access welfare assistance.

"I can't afford to live without working full-time. I am autistic with depression and anxiety. I work as much as I can but then burnout/ dissociate and go on sick. If I could work two days less I would probably avoid burnout but I can't afford this. I know I wouldn't be eligible for PIP because I get by but if I could get support to work slightly less it would save me so much stress, trauma and embarrassment. I would probably live longer and be healthier too."

"I know people who pretend to have stuff wrong with them and get all the help but when there is someone like me, I and others get zero help."

Positive Experiences

14.27. Respondents were presented with a statement about positive experiences when accessing, retaining or using welfare benefit and financial support service. Only one fifth (19%) agreed they have had positive experiences, the third lowest level of agreement across the 14 life areas after housing (11%) and banking and insurance (14%).

"The creation of Social Security Scotland is gradually changing the landscape here."

14.28. Respondents were invited to comment on any positive experiences because of their mental illness in relation to welfare benefits and financial support. Some reiterated their examples of poor application processes or the difficulty they had talking about their mental health as described above. In discussion of positive experiences, two overarching themes emerged:

- Wider support.
- Functional appeals processes.

Wider support

14.29. In describing the welfare benefits system, respondents highlighted positive experiences with individuals, services and organisations who provided support during the benefits application processes.

"It's the welfare support charities that gave me the positive experiences, not the DWP."

"I feel like a lot of people assume that people with mental illnesses and disabilities 'pick and choose' what work they can and can't do. I've had people in my own life say that. And I feel like the benefits system perpetuates that attitude because it is designed to just push people back into work with little thought for whether the person can cope with the role or not. So, if you say 'I can't do that job' there's always a fear that you will be judged or, worse, have benefits reduced. I'm lucky that all my work coaches to date have been very kind and understanding about mental health but the fear never really goes away that one day I will be pushed into a job that's not right for me. The reality is that while I can thrive in some working environments others I simply can't."

“When I was first hospitalised, the Social Workers who interviewed me were kind enough to complete an assessment pack for benefits on my behalf because I could not complete it myself. This has been my only positive experience of having to use the welfare system in this country to date, other than receiving the little money it has allowed me.”

Functional appeals process

14.30. Two respondents discussed positive experiences with the appeals process, reflecting on individual DWP employee intervention and the tribunal system.

“The experience with the DWP decision maker restored some faith in the system because the benefits were stopped suddenly in the summer of 2021 and I was told on the phone by that individual and in writing in her ‘decision’ that I didn’t ‘sound anxious’. However, the decision maker understood when he spoke to me on the phone months later after I had incurred a huge bank overdraft to live on. Had it not been for his decision, his understanding of the conditions that I suffer and his willingness to overturn the original decision, I not only would have been financially in a terrible position, but I was also made to feel like a fake claimant.”

Summary

- Just over half of respondents (183 or 53%) reported experiences of stigma and discrimination related to welfare and financial support in the past 12 months. One in ten (11%) reported experiencing this frequently and 16% very frequently.
- Welfare benefits and financial support was the eighth most commonly selected life area in the survey. It was selected by 45 respondents (13%) as one of the three in which the stigma and discrimination they experienced had the greatest impact.
- Stigma and discrimination had also been experienced due to respondents’ physical disabilities (45%).
- The vast majority of respondents in this life area (91%) agreed they should receive additional consideration when accessing, retaining, or using welfare benefit and financial support services. This is the second highest level of total agreement of the 14 life areas.
- Four themes emerged in open responses about experiences with welfare benefits and financial support. Comments on difficult application experiences were common, which highlighted long, costly and complicated processes. Problematic assessors were also described, who lack sympathy and training to speak to people about their mental health. Respondents also spoke about a systemic disregard of mental health, which was mentioned in relation to institutional procedure and policy. Finally, respondents discussed being ineligible for benefits yet still having financial difficulties.
- Only one fifth (19%) agreed they have had positive experiences when accessing, retaining, or using welfare benefit and financial support services; the third lowest level of agreement across the 14 life areas. Examples included good experiences with support workers peripheral to the welfare benefits applications processes as well as successful appeals.

15. Housing

"It appears that a mental illness is disregarded at times when asking for social housing services, or is used against you."

Overview

- 15.1.** This chapter discusses respondents' experiences of stigma and discrimination related to housing services. Our definition of housing included private rental, local authority, housing association and social housing as well as homelessness services such as emergency and temporary accommodation and other homelessness support provision.
- 15.2.** Compared with all the life areas explored in the survey, housing was the third least commonly selected area in terms of the frequency of stigma and discrimination experienced. Stigma and discrimination related to housing had been experienced by two fifths (138, 40%) of all respondents within the past 12 months, with 7% indicating it was experienced frequently and 6% very frequently.
- 15.3.** Thirty-eight respondents (11%) selected housing as one of up to three life areas in which the stigma and discrimination they experienced had the greatest impact on them. This is the ninth life area most commonly selected as one of the three most impactful. Over two thirds (70%) of those who selected this life area claimed to have experienced stigma related to this either frequently or very frequently, compared to 13% of all respondents.
- 15.4.** Those who selected the housing life area were asked to indicate which types of housing and homelessness services they had used, attempted to use or wanted to use and experienced stigma and discrimination. The option choices were:
 - Private rental housing – selected by 13 of the total 37 that selected the life area.
 - Local authority, housing association or social housing – selected by 28 of the total 37 that selected the life area.
 - Homelessness services – selected by seven of the total 37 that selected the housing life area.
- 15.5.** For each housing category selected, respondents were presented with a range of specific statements.
- 15.6.** This chapter presents the profile and experiences of respondents who selected the housing as one of the three life areas where the stigma and discrimination they experience has the greatest impact on them. **Given the small sample size, findings in this chapter should be treated as indicative.**

Respondent profile

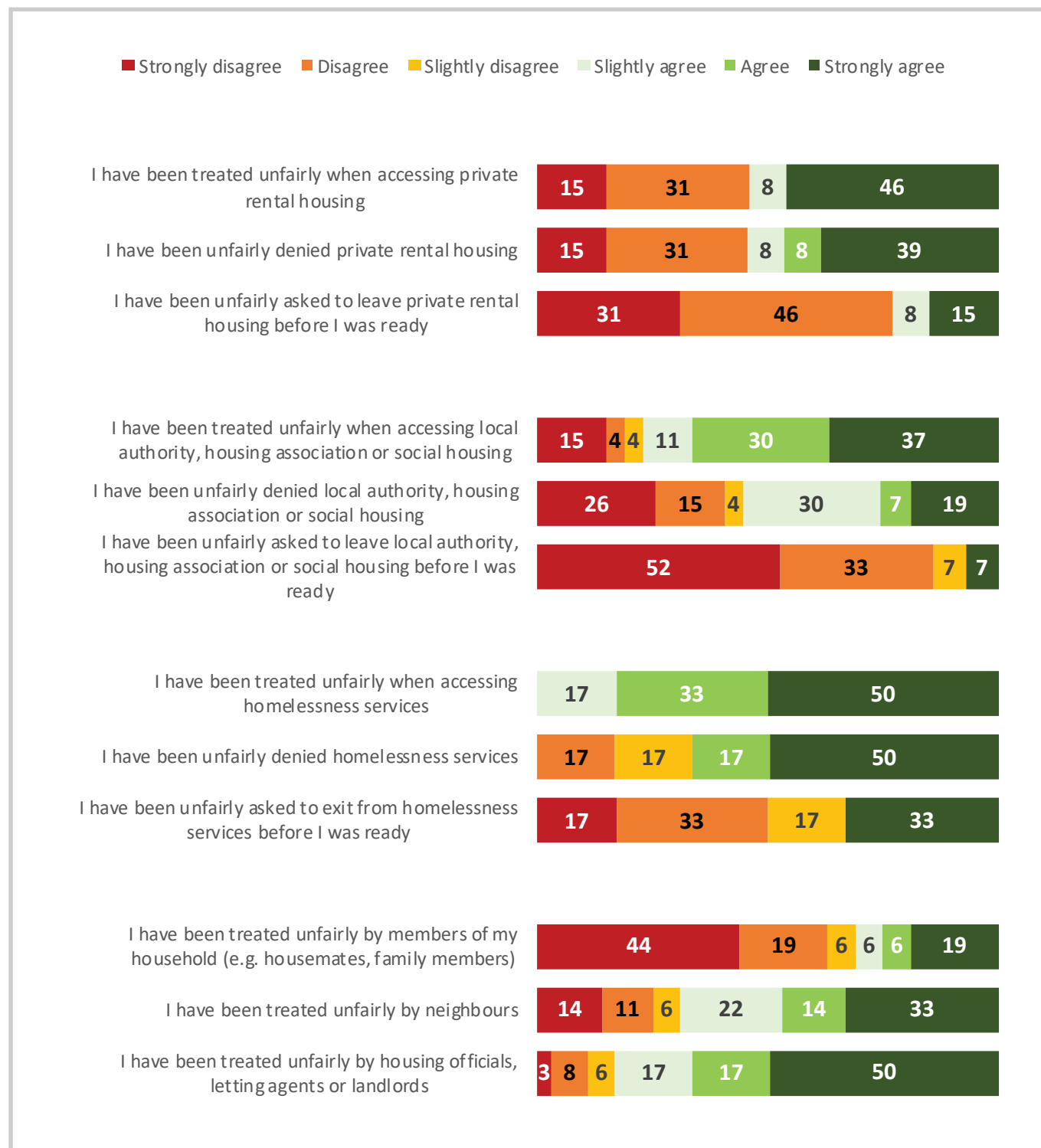
- 15.7.** The profile of participants who selected the housing life area as one of the three areas where they felt the biggest impact is broadly consistent with the overall respondent population. However, a greater proportion of respondents had no job (51%) in this life area compared to all respondents (28%). A higher proportion of individuals who selected this life area live in local authority or social housing (41%) than the overall sample (22%). In terms of gender, a larger proportion of those who selected this life area described themselves as male (41%) than in the total sample (28%).
- 15.8.** The profile of mental illnesses among respondents overall and those who selected housing as one of their top three impactful life areas is largely comparable. However, the overall survey respondent population had a lower proportion of those living with obsessive-compulsive disorder or related disorder (22% vs. 30% in the housing life area sample), a disorder specifically associated with stress (43% vs. 60%) and severe and/or treatment resistant anxiety or anxiety-related disorder (40% vs. 65%).

Perceived experiences of stigma and discrimination in housing

- 15.9.** Respondents' perceived experiences of stigma and discrimination when accessing housing is explored in this section. Figure 15.1 presents the extent to which respondents agreed or disagreed with statements about stigma and discrimination about their mental illness in housing.
- 15.10.** More than four fifths (83%) of respondents in this life area perceived themselves to have been treated unfairly by housing officials, letting agents or landlords in the past 12 months, 69% reported unfair treatment by neighbours, and 31% said they have been treated unfairly by other members of their household.
- 15.11.** Over half (54%) said they have been treated unfairly when accessing private rental housing. Notably, the same proportion (54%) felt they have been unfairly denied private rental housing due to stigma or discrimination related to their mental health, and almost a quarter (23%) reported being unfairly asked to leave private rental housing before they were ready.
- 15.12.** There are some differences between experiences with local authority, housing association or social housing and private rental housing. A higher proportion – 78% – agreed that they have been treated unfairly when accessing local authority, housing association or social housing compared with private rental housing (54%). Similar proportions said they have been unfairly denied local authority, housing association or social housing (56%) and private rental housing (54%). However, a lower proportion (7%) felt they have been unfairly asked to leave local authority, housing association or social housing before they were ready, than 23% who reported it about private rental housing.
- “Housing providers don’t understand the disproportionate effect antisocial behaviour, poor housing quality, lack of maintenance and poor environment have on people with mental health problems.”**
- 15.13.** Although a small number (6) answered questions about homelessness services, all agreed they have been treated unfairly when accessing these services. Four (67%) said they have been unfairly denied homelessness services, while two reported being unfairly asked to leave homelessness services before they were ready due to stigma about their mental illness.

Figure 15.1. Perceived experiences of stigma and discrimination in housing: percentage agreement and disagreement

Because of stigma about my mental illness(es)...

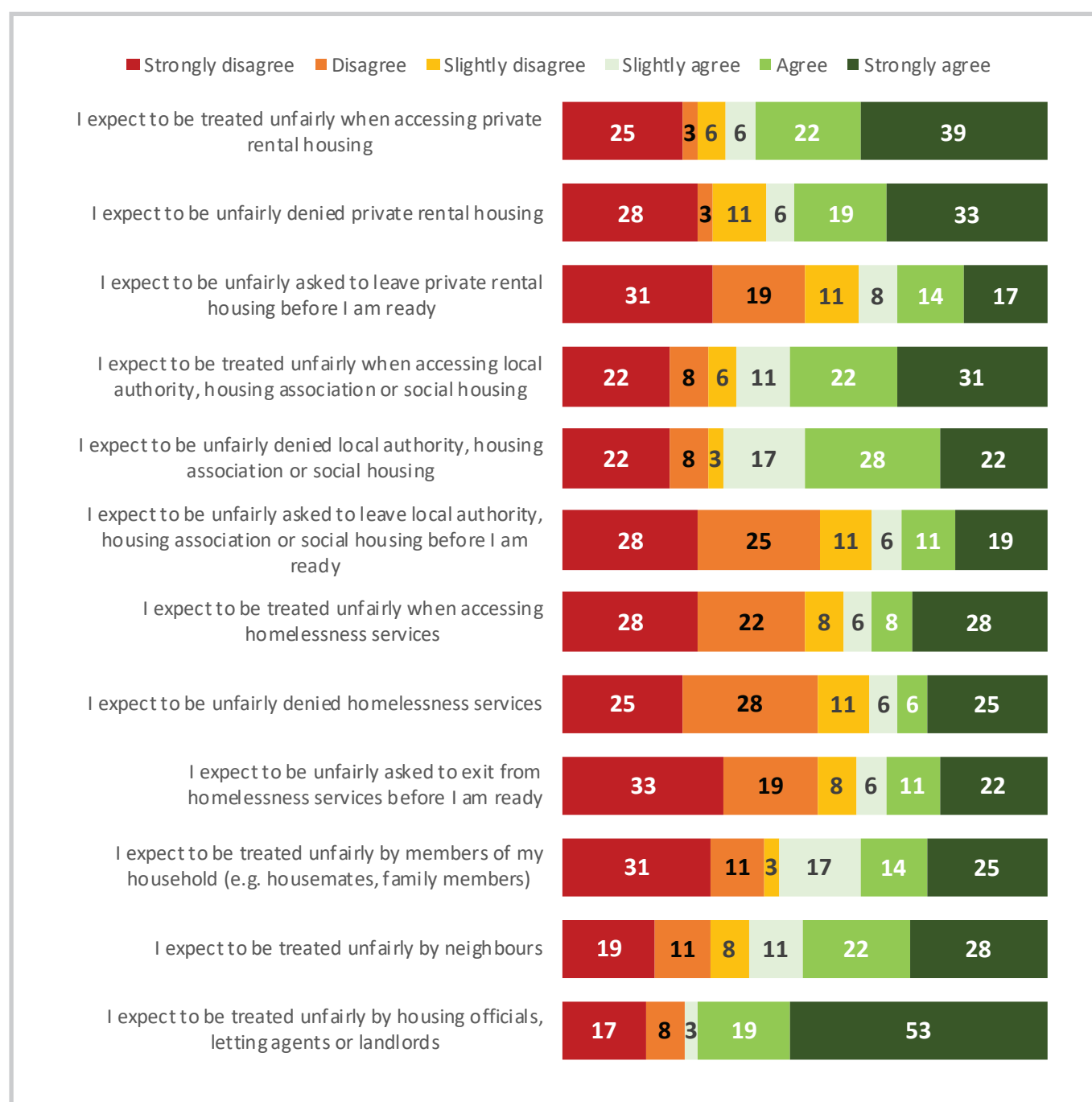


Anticipated stigma and discrimination in housing

15.14. Figure 15.2 displays how much respondents agreed or disagreed with statements related to housing and the anticipated stigma and discrimination about respondents' mental illness.

Figure 15.2. Anticipated experiences of stigma and discrimination in housing: percentage agreement and disagreement (n=36)

Because of stigma about my mental illness(es)...



15.15. There were agreement rates of over 50% in seven of the 12 statements about anticipated stigma and discrimination. Consistent with perceived experiences of stigma, large proportions of respondents expected unfair treatment from housing officials, letting agents or landlords (75%) or when accessing private rental housing (67%). Many expected to be unfairly denied (67%) or treated unfairly (64%) when accessing local authority, housing association or social housing, while unfair treatment by neighbours was anticipated by 61%.

“My Housing Association is not listening to me and as a result I can’t do anything in my place.”

15.16. While 7% of respondents reported being unfairly asked to leave local authority, housing association or social housing before they were ready, a notably larger proportion (36%) expected to be unfairly asked to leave this type of housing before they are ready.

15.17. All six respondents who answered questions about homelessness services felt unfairly treated, but a lower proportion (42%) expected to be treated unfairly when accessing these services.

Withdrawal from opportunity in housing

15.18. Figure 15.3 displays how far respondents agreed or disagreed with a series of statements about their decisions to withdraw from opportunities related to housing.

15.19. The data indicates that stigma and discrimination have had a significant impact on respondents’ behaviour. Most notably, 86% have stopped themselves from reporting maintenance issues or making complaints to housing officials, letting agents or landlords. This reflects the high proportion (83%) who said they had experienced unfair treatment by these officials.

15.20. Mental health stigma and discrimination have affected respondents’ relationships with neighbours and other members of their households. More than four fifths (83%) agreed they have withdrawn from relationships with their neighbours as a result of mental health stigma and discrimination. This is higher than the proportion (69%) of those who had accessed private sector housing who said they have experienced being treated unfairly by neighbours. Similarly, three fifths (60%) said they have withdrawn from relationships with members of their household.

15.21. It is also notable that over half (54%) agreed that they have stopped themselves from applying for private rental housing as a result of stigma and discrimination about their mental illness. In addition, while the proportions are quite small, it is striking that some respondents have chosen to leave their home (14% in private rental housing and 17% in local authority, housing association and social housing) or homelessness services (14%) before they were ready because of stigma and discrimination about their mental illness.

Intersectional experiences of stigma and discrimination with housing

15.22. The survey also explored intersectionality in experiences of stigma and discrimination related to housing. Respondents were asked about experiences of stigma and discrimination associated with aspects of their identity. In terms of housing, physical disability (51%), age (29%) and sex (24%) were the three most commonly reported.

Views on the requirement for special considerations

15.23. Finally, almost three quarters (71%) of respondents agreed when asked if they should receive additional consideration when accessing housing or homelessness support services as a result of their mental illness. This is the life area with the seventh highest level of agreement regarding additional consideration.

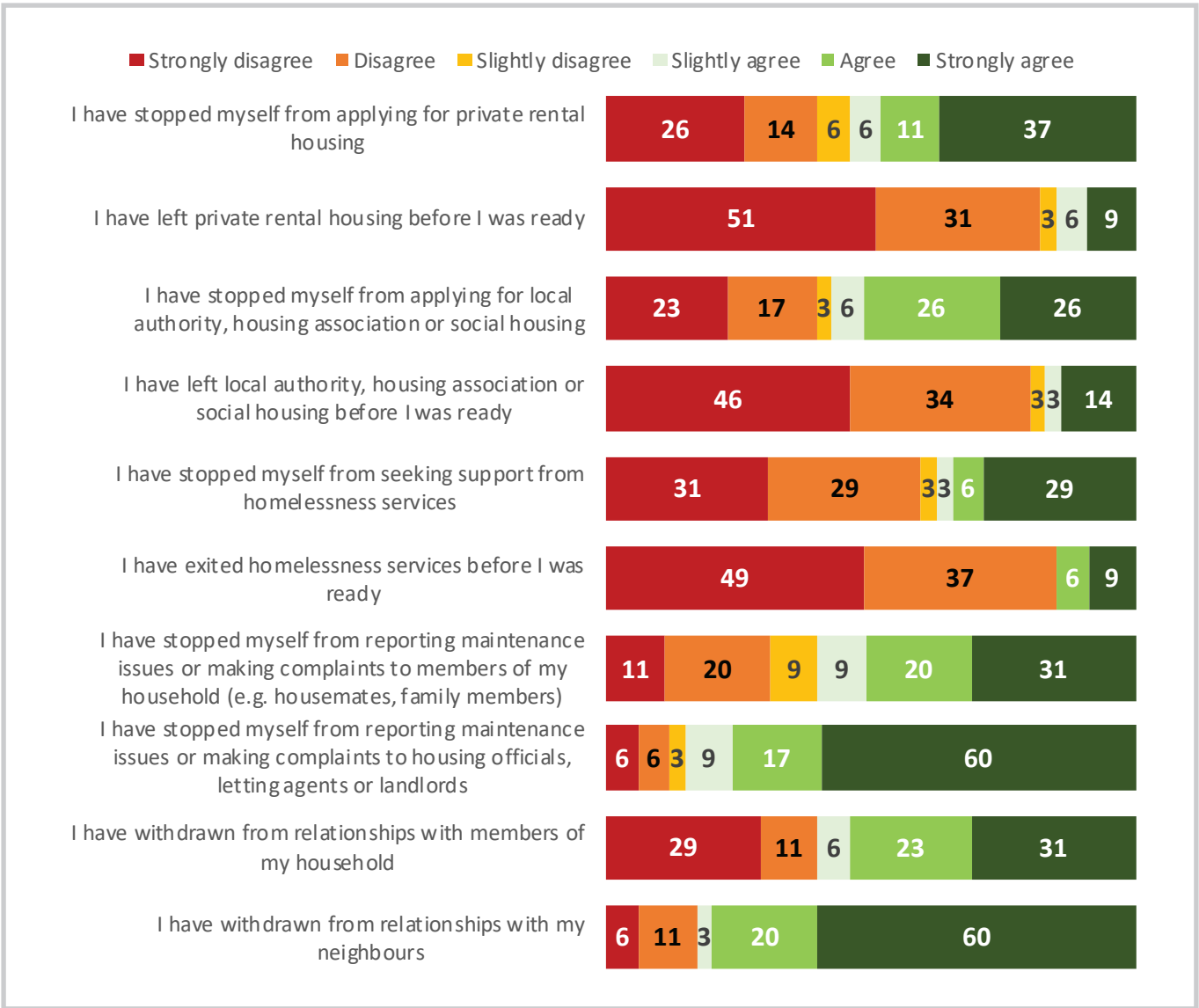
Other feedback about stigma and discrimination in housing

15.24. Some respondents shared comments to explain their experience of stigma and discrimination in relation to housing. The main themes raised were:

- Limited choice of housing.

Figure 15.3. Withdrawal from opportunities in housing: percentage agreement and disagreement (n=35)

Because of stigma about my mental illness(es)...



- Unfair treatment by housing providers.
- Unfair treatment by neighbours and/or other household members.

Limited choice of housing

15.25. Over half (54%) of respondents who had accessed or tried to access private rental housing reported being unfairly denied housing in this sector due to stigma and discrimination about their mental illness. One respondent reflected that, in their experience, some private sector landlords appear to be reluctant to provide housing to people with mental illnesses.

“The private [rental] sector is very quick to exclude/deny housing if they know about your poor mental health.”

15.26. A small number of other respondents noted that housing options are further reduced by low income. Fifty-one per cent of respondents who selected housing as one of the most impactful life areas have no job, and a few respondents commented that low income can reduce the options available to people with mental illness. Another reported difficulties in finding private rental housing due to their benefits status.

“Ideally it would be beneficial for my mental health if I lived alone, but I cannot find a landlord or letting agency that accepts housing benefits.”

15.27. Challenges in finding landlords willing to rent their property can limit the choice of housing available to people with mental illnesses. There was also a feeling that the available stock is often poor quality, not adequately maintained and/or does not meet the needs of people with mental illness.

“Myself and many others with long term mental health conditions are often forced to live in substandard housing conditions because it’s all we can afford. Our mental illnesses limit our income due to most workplaces not being understanding of the barriers we face and we are stuck renting very poor quality housing from the private rental sector.”

“Living with low income often forces you into very poor quality private rentals. The landlords and letting agents that own these flats seldom do any maintenance and repairs are often shoddy. This compounds the situation.”

Unfair treatment by housing providers

15.28. A few respondents expressed a view that the needs of people with mental illness are not recognised by housing providers, or taken into account when allocating or prioritising housing. This is consistent with the quantitative findings that indicated experiences of unfair treatment by housing providers among people with mental illness.

“When trying to apply for more affordable social housing we do not receive any ‘points’ that would make us higher priority due to many mental health conditions being less visible and not seen as ‘real’ disabilities by local councils.”

15.29. Examples were shared of local authorities or housing associations allocating housing to respondents that did not suit their needs and could make their mental health worse.

"My local authority placed my family and myself in a drug ridden area despite telling them about my CPTSD and anxiety... [the local authority] simply does not care about mental health and the effects, I have sent letters from my CPN and psychiatrist which documented how bad this affects me and my social anxiety and the area we're in has a dramatic impact on me and my recovery. My CPN has also stated in a letter that my current housing situation is having a major impact on my recovery plan and holding me back [but I] was still ignored."

"In a recent housing application on assessment of medical conditions... the officers simply did not understand or appreciate the need for peaceful and quiet own space or the urgency to get out of being put up temporarily by my sister, who had regular grandchild care which was far from peaceful/restful."

Unfair treatment by neighbours/other members of household

15.30. Echoing the quantitative survey responses, another theme among respondents' open comments related to unfair treatment by neighbours and/or other members of the respondent's household. In two examples, respondents commented on problems with their neighbours which were compounded by a lack of support from their social housing providers.

"I live alone, and have experienced non-stop harassment from the neighbours who live above me. I have sought help from the local council, as I am renting from them, but my mental illness has been completely ignored, and the neighbours have even been defended... Local authority housing have no interest in my mental health issues, and say that they don't class it as a disability. Therefore, I have zero priority to be relocated, and continue to suffer... I have explained to the local authority how this all affects me, but they have not taken my mental illness into consideration at all. This has been going on since I moved in about five years or so ago. I have asked the mental health services to help me, with the local housing authority, but nothing has been done at all."

"For months I've lived with intimidating close neighbours... to date, two social housing providers and their managers have failed in stopping it! I've been stuck in the house for days on end and nobody cares or gets the detrimental impact on my health."

15.31. A couple of others described examples of unfair or discriminatory treatment by neighbours and housemates.

"One of the housemates bullies me, frequently shouting at me and making ableist and sexist comments towards me."

"A couple of issues that I've had to raise with neighbours – after a period of discussion, [I] mentioned that I have basic mental health issues – I never wanted it to be a focus, but it hasn't been taken into consideration and I think it's actually had a negative response."

Positive experiences in housing

- 15.32.** Only 11% of respondents agreed that they have had positive experiences when accessing housing or homelessness services because they live with a mental illness. Of all the life areas, housing ranked the lowest of all 14 for positive experiences.
- 15.33.** However, two respondents gave examples of positive experiences of favourable treatment as a result of their mental illness. One said they obtained priority status on a waiting list, while the other received support from a third sector organisation.

“Despite waiting years on a housing list, I was put in a disability grouping, giving me priority over some applicants meaning I did get a flat eventually. I would have otherwise had to stay with family, as most private lets don’t accept people on benefits (which I was, at the time I moved in).”

“I was put in touch with Houseability a few months ago to help with my housing situation. They have been very supportive and helpful.”

Summary

- Nearly two fifths of respondents (138 or 40%) reported that they have experienced stigma and discrimination related to housing within the past 12 months. Thirteen per cent said they experienced it either frequently or very frequently.
- Thirty-eight respondents (11%) selected housing as one of up to three life areas in which the stigma and discrimination they experienced had the greatest impact on them.
- Many respondents felt they have been treated unfairly in relation to housing. Eighty-three per cent of respondents in this life area perceived themselves to have been treated unfairly by housing officials, letting agents or landlords in the past 12 months, 69% reported unfair treatment by neighbours, and 31% said they have been treated unfairly by other members of their household.
- There are some differences between local authority, housing association or social housing and private rental housing. A higher proportion – 78% – agreed that they have been treated unfairly when accessing local authority, housing association or social housing compared with private rental housing (54%). Similar proportions said they have been unfairly denied local authority, housing association or social housing (56%) and private rental housing (54%). However, a lower proportion (7%) felt they have been unfairly asked to leave local authority, housing association or social housing before they were ready than 23% who reported it about private rental housing.
- Only a small number (6) answered questions about homelessness services, but all felt they have been treated unfairly when accessing these services and 67% stated they have been unfairly denied these services.

Summary (continued)

- In terms of expectations, high proportions of respondents agreed they expected to be treated unfairly by housing officials, letting agents or landlords (75%), when accessing private rental housing (67%) or local authority, housing association or social housing (64%).
- Sixty-seven per cent expected to be unfairly denied local authority, housing association or social housing, and 36% anticipated being asked to leave this type of housing before they are ready. The equivalent figures related to private rental housing were 58% and 39% respectively.
- Stigma and discrimination seems to have had a significant impact on respondents' relationships with neighbours and other members of their households. Large proportions said they had withdrawn from relationships with neighbours (83%) or members of their household (60%).
- Other notable impacts of stigma and discrimination on respondents' behaviour include stopping themselves from reporting maintenance issues or making complaints to housing officials, letting agents or landlords (86%), stopping reporting maintenance issues or making complaints to other people in their household (60%), or deciding not to apply for private rental housing (54%) as a result of stigma about their mental illness.
- While the proportions are quite small, it is striking that some respondents have chosen to leave their home (14% in private rental housing and 17% in local authority, housing association and social housing) or homelessness services (14%) before they were ready because of stigma and discrimination about their mental illness.
- Only one in nine respondents to this life area (11%) agreed that they have had positive experiences due to their mental illness. In terms of intersectional stigma and discrimination, experiences were reported in relation to respondents' physical disability (51%), age (29%) and sex (24%).
- When asked if they should receive additional consideration when accessing housing or homelessness support services as a result of their mental illness, almost three quarters (71%) of respondents agreed.
- Key themes in qualitative comments from respondents related to experiences of unfair treatment by neighbours, other members of their household, and housing providers. Another common issue discussed in open-ended responses focused on the limited options of housing available to some people with mental illnesses, because of a low income and/or because of a perceived reluctance among some private landlords to accept tenants who receive benefits and/or who have mental illness.

16. Public and recreational spaces

“While it’s an awful thing to experience, I understand why some people treat me the way they do. They don’t understand because they haven’t been educated, or have never encountered a paranoid/hypomaniac/hyperactive person before. I don’t blame them, though it does affect me pretty badly sometimes.”

Overview

- 16.1.** This chapter explores respondents’ experiences of stigma and discrimination in accessing or using public and recreational spaces including public transport and public spaces such as parks, retail, hospitality and events open to the public.
- 16.2.** In total, 190 respondents (55%) reported experiences of stigma and discrimination in this life area within the past 12 months, with 10% reporting it was experienced frequently and 6% very frequently. This makes it the eighth most commonly selected life area in terms of frequency of stigma and discrimination experienced.
- 16.3.** The public and recreational spaces life area was selected by 24 (7%) of respondents as one of three in which the stigma and discrimination they experienced had the greatest impact on them. This makes it the tenth life area most commonly selected as one of up to three in which stigma and discrimination had the greatest impact on respondents. Four in ten (42%) of those selecting this life area claimed to have experienced stigma related to this either frequently or very frequently, compared to 15% of all respondents.
- 16.4.** Those who selected the public and recreational spaces life area were asked to choose which types of public and recreational spaces they had used, attempted to use or wanted to use and experienced stigma and discrimination. The option choices were:
 - Public transport – selected by 15 of the total 24 who selected the life area.
 - Public spaces or events – selected by 23 of the total 24 who selected the relationships life area.
- 16.5.** For each public and recreational spaces category selected, respondents were presented with a range of specific statements.
- 16.6.** This chapter presents the profile and experiences of respondents who selected public and recreational spaces as one of their three areas where the greatest impact is felt.

Respondent profile

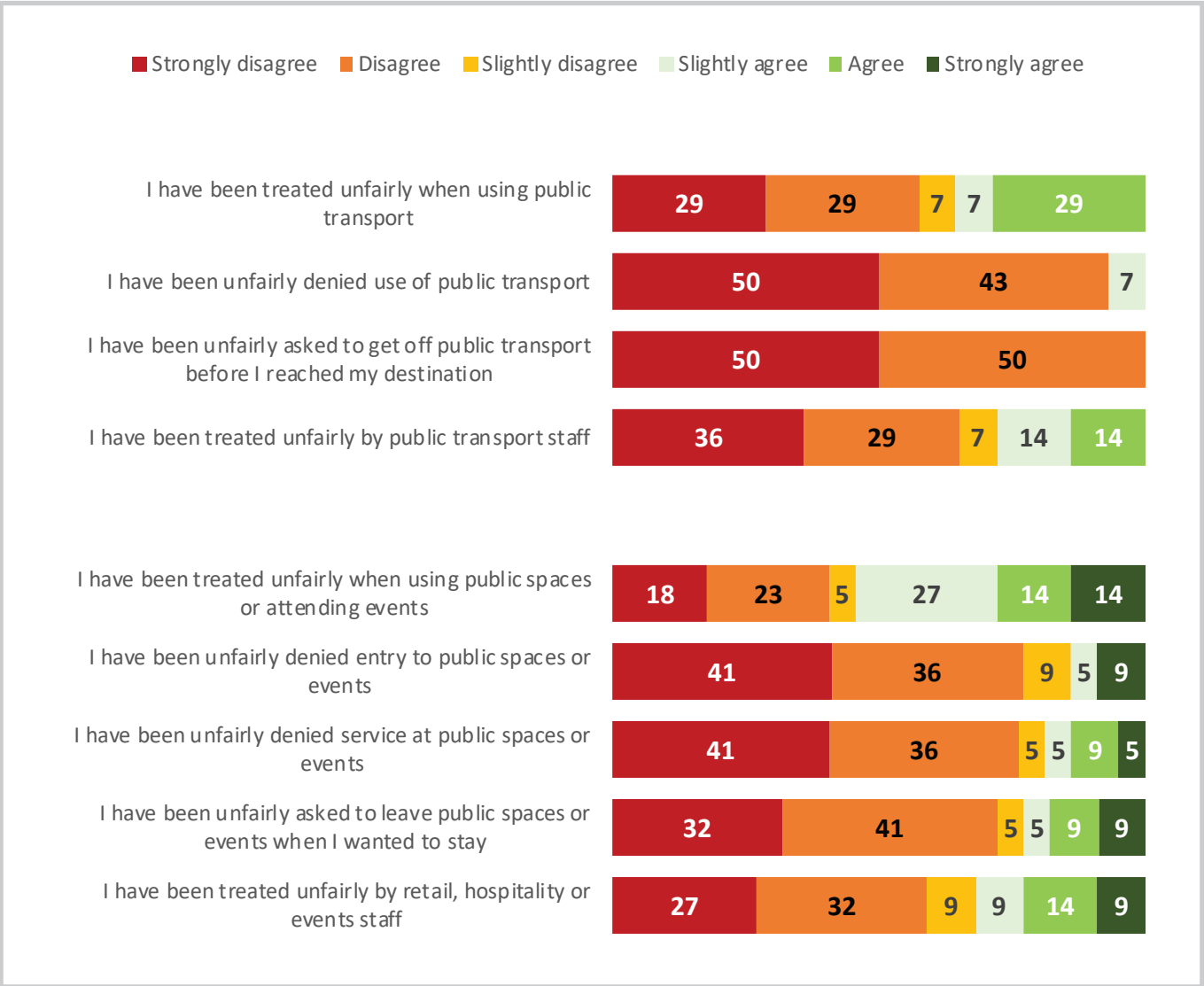
- 16.7.** There were a small number of differences in the profile of respondents who selected this life area compared to the overall respondent population. However, a higher proportion of respondents who selected this life area described their gender as non-binary (13%) or other (13%) compared to the overall population of respondents (7% and 2% respectively).

Respondents who selected this life area were also more likely to be bisexual (50%) than respondents in general (20%). Ninety-six per cent described their ethnicity as White, similar to the overall survey population (97%), but a greater proportion said they were White English (35% of White respondents) than in general (11%). A slightly higher proportion (54%) reported they were single compared with the survey population (40%).

16.8. The profile of mental illnesses is also broadly comparable to the overall survey population among those who selected the public and recreational spaces life area in their top three areas of impact. However, the overall survey respondent population had a higher proportion of respondents with disorders specifically associated with stress (43% compared with 29%). Conversely, respondents who selected this area as one of their three most impactful were more likely than the general survey population to have severe or treatment-resistant anxiety or fear-related disorder (54% compared with 40%), a feeding or eating disorder (33% compared with 20%), or schizophrenia or another primary psychotic disorder (21% compared with 7%).

Figure 16.1. Perceived experiences of stigma and discrimination in public and recreational spaces: percentage agreement and disagreement

Because of stigma about my mental illness(es)...

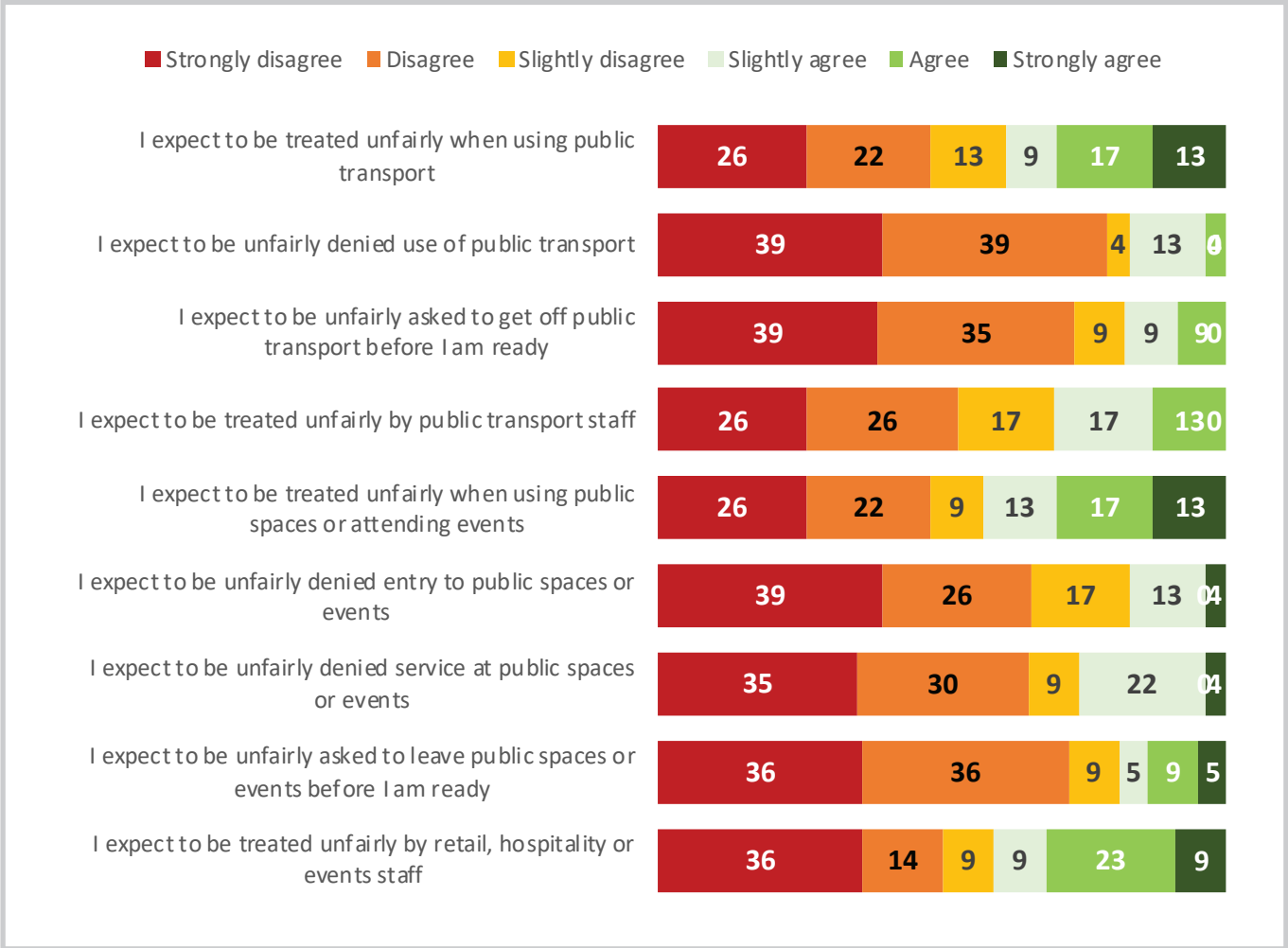


Perceived experiences of stigma and discrimination in public and recreational spaces

- 16.9. Figure 16.1 shows how much respondents agreed or disagreed with statements about this life area.
- 16.10. In responses about experiences of stigma and discrimination while using public transport, just over a third (36%) felt they have been treated unfairly while using public transport and 29% stated they have received unfair treatment from public transport staff. A minority (7%) agreed they have been unfairly denied use of public transport, and none reported being asked to get off public transport before they reached their destination.
- 16.11. Over half (55%) of the respondents who responded to statements about public spaces and events reported being treated unfairly when using public spaces or attending events. One third (32%) have received unfair treatment from retail, hospitality or events staff, and 23% have experienced being unfairly asked to leave public spaces or events when they wanted to stay. Lower proportions said they have been unfairly denied service (18%) or entry (14%) at public spaces or events.

Figure 16.2. Anticipated experiences of stigma and discrimination in public and recreational spaces: percentage agreement and disagreement (n=22-23)

Because of stigma about my mental illness(es)...



Anticipated stigma and discrimination in public and recreational spaces

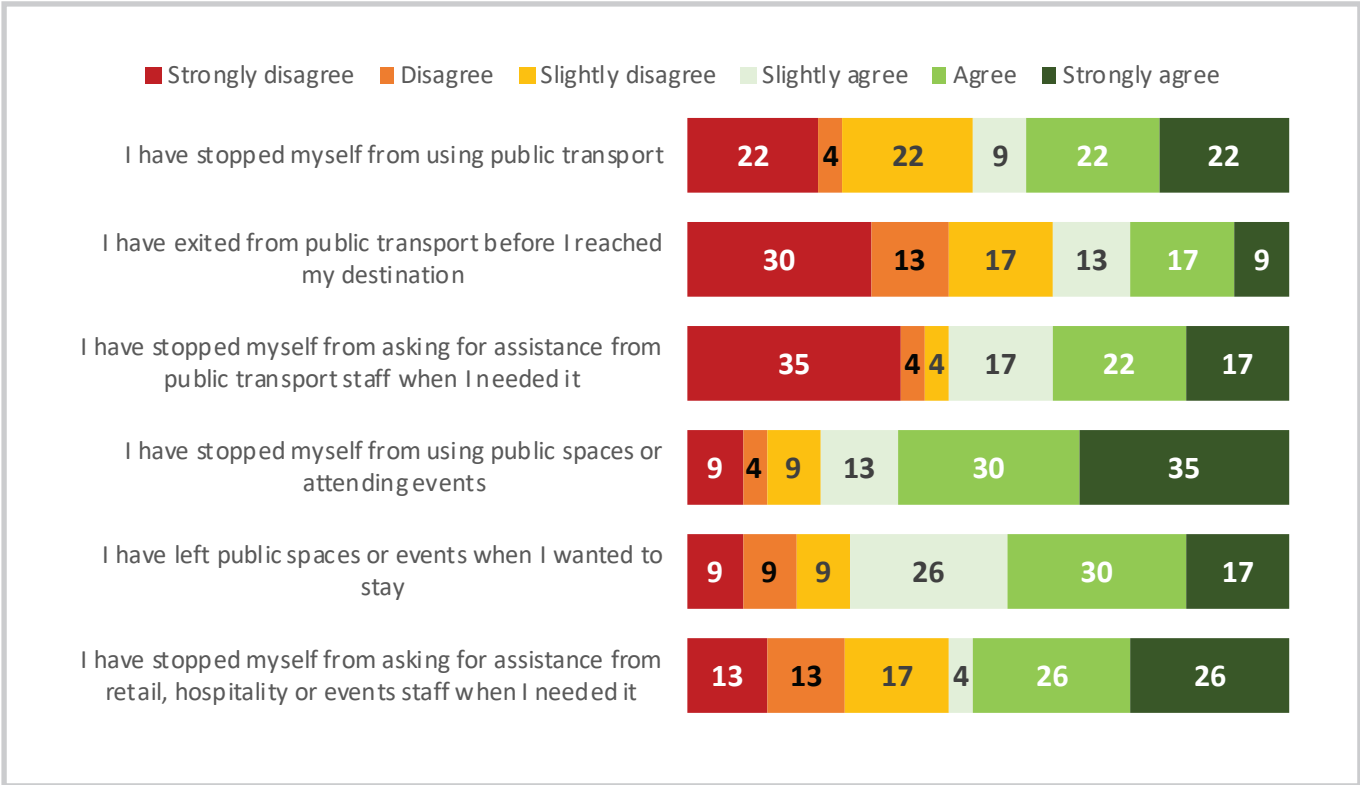
- 16.12. Figure 16.2 displays respondents' levels of agreement with a series of statements about stigma and discrimination in this life area.
- 16.13. Levels of agreement with statements about anticipated stigma and discrimination were generally consistent with levels of perceived experience. However, while no respondents reported being asked to get off public transport before they reached their destination, 17% anticipated that this would happen to them. In addition, over two fifths (44%) of respondents expected to be treated unfairly when using public spaces or attending events, 41% expected to be treated unfairly by retail, hospitality or events staff, and 39% expected unfair treatment when using public transport.

Withdrawal from opportunity in public and recreational spaces

- 16.14. Figure 16.3 presents data about how much respondents agreed or disagreed with statements about withdrawing from opportunities related to public and recreational spaces.
- 16.15. Stigma and discrimination appear to have had a significant impact on using public spaces or attending events. More than three quarters (78%) reported stopping themselves from using public spaces or attending events and 74% said they have left public spaces or events when they wanted to stay, as a result of stigma and discrimination. Furthermore, 52% had stopped themselves from asking for assistance from staff because of stigma about their mental illness.

Figure 16.3. Withdrawal from opportunities in public and recreational spaces: percentage agreement and disagreement (n=23)

Because of stigma about my mental illness(es)...



- 16.16.** With public transport, over half (57%) have stopped themselves from asking for assistance from public transport staff when they needed it, 52% reported stopping themselves using public transport, and 39% had exited public transport before they reached their destination because of stigma and discrimination.

Findings from supplementary qualitative research

- 16.17.** This section presents the findings from the supplementary qualitative research conducted, which explored and gathered further examples and insights into experiences of stigma and discrimination in the public and recreational spaces life area.
- 16.18.** Only three participants reported experiences of stigma and discrimination in the public and recreational spaces life area, and all of these were prior to the previous 12 months. Much of the discussion centred on difficulties with or avoidance of this life area. This tended to be due to problems linked to their mental illness rather than fear of stigma and discrimination.

Experiences of stigma and discrimination

- 16.19.** Participants who provided examples in the public and recreational spaces life area described having episodes where the symptoms of their mental illness had led to them behaving in a way that attracted unkind comments or resulted in members of the public stopping and staring at them.
- 16.20.** During discussions with participants, some were able to share their thoughts on the steps they took to ensure that they minimised the likelihood of experiencing stigma and discrimination.
- 16.21.** The first of these was about understanding their own mental illness in terms of recognising when they weren't managing as well or when they felt they were experiencing symptoms that could lead to unpredictable or unexpected behaviour.

"You have to actually say if you are in a public space 99% of people don't know you have a mental health problem. And it's down to you to manage that if you know what I mean."

- 16.22.** The second protective step was ensuring that they were with people they knew and trusted so that in the event of anything happening, they were with somebody who could help and look after them.

"I feel quite nervous getting on a bus on my own. So I usually go with someone. I'm just worried that maybe I have some sort of panic attack and the driver wouldn't understand because they're just there to sort of drive the bus."

- 16.23** A small number of interviewees also spoke about having a mental illness that was not noticeable or obvious to members of the public, or having symptoms that could be passed off as a physical ailment, such as chronic fatigue.

"I suppose I'm lucky in a lot of ways because a lot of other people have mental health problems that's more visible. Whereas mine if I'm 'up', then you genuinely wouldn't see it."

Anticipation and withdrawal

- 16.24.** There was an expectation among interviewees that if their mental illness did cause them to act or behave in a way that is not generally expected by society in public, then the likelihood is that they would face some form of stigma or discrimination.

16.25. This generally meant that interviewees considered when they would and would not participate in this life area, and what that participation would involve. Participants spoke about the need to feel confident that they were managing well, comfortable about what they were going to be doing, and that their mental illness would not be apparent or known to those around them.

Intersectional experiences of stigma and discrimination within public and recreational spaces

16.26. Survey responses also provided evidence of intersectionality in experiences of stigma and discrimination in public and recreational spaces. Respondents were asked about experiences of stigma and discrimination associated with aspects of their identity. In relation to employment, sex (35%), sexual orientation (30%) and physical disability (27%) were the three most commonly reported.

Views on the requirement for special considerations

16.27. Finally, nearly two thirds (65%) agreed that should receive additional consideration when accessing or using public transport, public spaces or attending public events.

Other feedback about stigma and discrimination in public and recreational spaces

16.28. A small number of respondents shared comments about experiences of stigma and discrimination in public and recreational spaces. The main themes included a lack of public awareness and understanding, and issues around the visibility of mental illnesses.

Lack of public awareness and understanding

16.29. Four respondents described a lack of awareness and understanding of mental illnesses among the general public, highlighting that members of the public can sometimes display discriminatory attitudes towards people with mental illnesses because they do not understand the conditions.

“Although the public is getting better aware of people with mental health illnesses I do still believe there is still a long way to go... I believe people with EUPD [emotionally unstable personality disorder] are more stigmatised as attention seekers etc than any of the other mental health illnesses. I put this down to lack of understanding and awareness of the condition.”

16.30. Another respondent reported a row with a fellow bus passenger who complained over their use of a seat reserved for disabled people, and also described being ‘given dagger eyes’ by members of the public when using disabled toilets. These examples also indicate a lack of understanding of mental health conditions among the general public.

Visibility of mental illnesses

16.31. Three respondents commented on the visibility of their condition and how their ability or inability to conceal their mental illness can have an effect on experiences of stigma and discrimination in public. One noted that they try to keep their mental illness hidden to avoid stigma and discrimination.

"I avoid at all costs anyone knowing I have a mental health issue. I keep it hidden as people treat you as less."

- 16.32.** This individual commented that they avoid some public spaces such as public transport because these settings can heighten their social anxiety, and this can make it more difficult to hide their mental illness.

"I also avoid public transport, spaces, or asking for help because of my social anxiety – it's heightened in these spaces and I often can't cover it up. Because of stigma, I never want to reveal it so I just avoid."

- 16.33.** Another noted that they are able to behave 'normally' in public spaces and this helps to reduce experiences of discrimination.

"A lot of discrimination is avoided because my mental health condition allows me to outwardly behave 'normally' in public spaces, so for example my anxious condition is not visible."

- 16.34.** A third respondent expressed feelings of self-consciousness related to travelling on public transport with visible self-harm scars.

"Having short sleeves with exposed self-harm scars on my arm, means the whole train carriage will be looking at me and whispering to who they're with."

Positive experiences

- 16.35.** Just over one third (35%) said they have had positive experiences when accessing or using public transport, public spaces or attending public events. Out of all 14 life areas covered in the survey, public spaces and events ranked eighth in terms of positive experiences.

"There are things that I can access being someone who is living with mental health problems."

- 16.36.** Two respondents recounted examples of empathetic and understanding behaviour displayed by members of the general public towards them. One described an example of a person showing concern and providing a listening ear.

"I've had someone ask me if I was okay, and they let me cry on their shoulder and listened to me. I'll never forget that moment."

- 16.37.** Another reported that members of the public have treated them respectfully when they are wearing a sunflower lanyard, which is a sign that the wearer has hidden disabilities.

"I use the sunflower mental health lanyard when I'm in situations where I might feel anxious. I've never had any problems and other people have treated me with patience and allowed me to take my time, and seem to care that I have mental health issues, e.g. in the supermarket and at the dentist."

- 16.38.** Two respondents referred to opportunities for people with mental health conditions to use public transport, leisure facilities and other public amenities for free or at a reduced rate. One also mentioned receiving a radar key which allows access to disabled toilets.

"The use of a travel card has provided essential for accommodation, very helpful in public transport."

Summary

- Stigma and discrimination in relation to public and recreational spaces had been experienced by more than half of respondents (190 or 55%) in the past 12 months. Sixteen per cent reported that they had experienced it frequently or very frequently.
- Twenty-four respondents (7%) selected this life area as one of up to three in which the stigma and discrimination they experienced had the greatest impact on them.
- Fifty-five per cent reported unfair treatment when using public spaces or attending events, and 44% expected unfair treatment in public spaces or at events. Thirty-two per cent said they have received unfair treatment from retail, hospitality or events staff, and 23% felt they have been unfairly asked to leave public spaces or events when they wanted to stay.
- Over a third (36%) felt they have been treated unfairly when using public transport, and 39% expected unfair treatment on public transport because of stigma and discrimination. Twenty-nine per cent reported experiences of unfair treatment by public transport staff and 7% said they have been unfairly denied use of public transport, but none have been asked to get off public transport before they reached their destination.
- Stigma and discrimination have prompted many respondents to withdraw from opportunities related to public and recreational spaces. Seventy-eight per cent reported stopping themselves from using public spaces or attending events and 74% said they have left public spaces or events when they wanted to stay.
- Fifty-seven per cent said they have stopped themselves from asking for assistance from public transport staff when they needed it, 52% reported stopping themselves using public transport, and 39% have exited public transport before they reached their destination because of stigma and discrimination.
- Stigma and discrimination had also been experienced due to respondents' sex (35%), sexual orientation (30%) and physical disability (27%).
- Nearly two thirds (65%) of respondents agreed that they should receive additional consideration when accessing or using public transport, public spaces or attending public events.
- A small number of respondents highlighted that stigma and discrimination stem from a lack of awareness and understanding of mental health conditions among the general public. A few others observed that stigma and discrimination were less likely if they were able to conceal their mental illnesses in public.
- Just over a third (35%) of respondents to this life area agreed that they have had positive experiences due to their mental illness. Examples of positive experiences include respectful and empathetic treatment from members of the public and access to public transport and other amenities for free or at a reduced rate.

17. Banking and insurance services

“Banks and insurance companies see me as too high risk.”

Overview

- 17.1. Experiences of stigma and discrimination for respondents living with complex, severe and/or enduring mental illnesses when accessing and participating in banking and insurance services are explored in this chapter.
- 17.2. The question about this life area defined banking and insurance services as accessing, using and maintaining services such as:
 - Bank accounts (e.g. savings or everyday current accounts).
 - Credit cards, loans (e.g. personal loans, business loans, mortgages).
 - Insurance cover (e.g. health, life, home or car insurance).
- 17.3. Overall, just under half of all survey respondents (164 or 47%) reported experiences of stigma and discrimination in this life area in the past 12 months. One in ten (10%) reported it was experienced frequently and 9% very frequently.
- 17.4. Banking and insurance services was the 11th most commonly selected life area, being selected by 16 respondents (5%) as one of the three in which the stigma and discrimination they experienced had the greatest impact. Of these, 15 had used insurance products in the last 12 months, and 11 banking services. Half (50%) of those selecting this life area claimed to have experienced stigma related to this either frequently or very frequently, compared to 19% of all respondents.

“My economic status is intrinsically linked to my health status.”

- 17.5. This chapter presents the profile and experiences of respondents who selected banking and insurance services as one of the three life areas where the greatest impact is felt. **Given the small sample size, findings in this chapter should be treated as indicative.**

Respondent profile

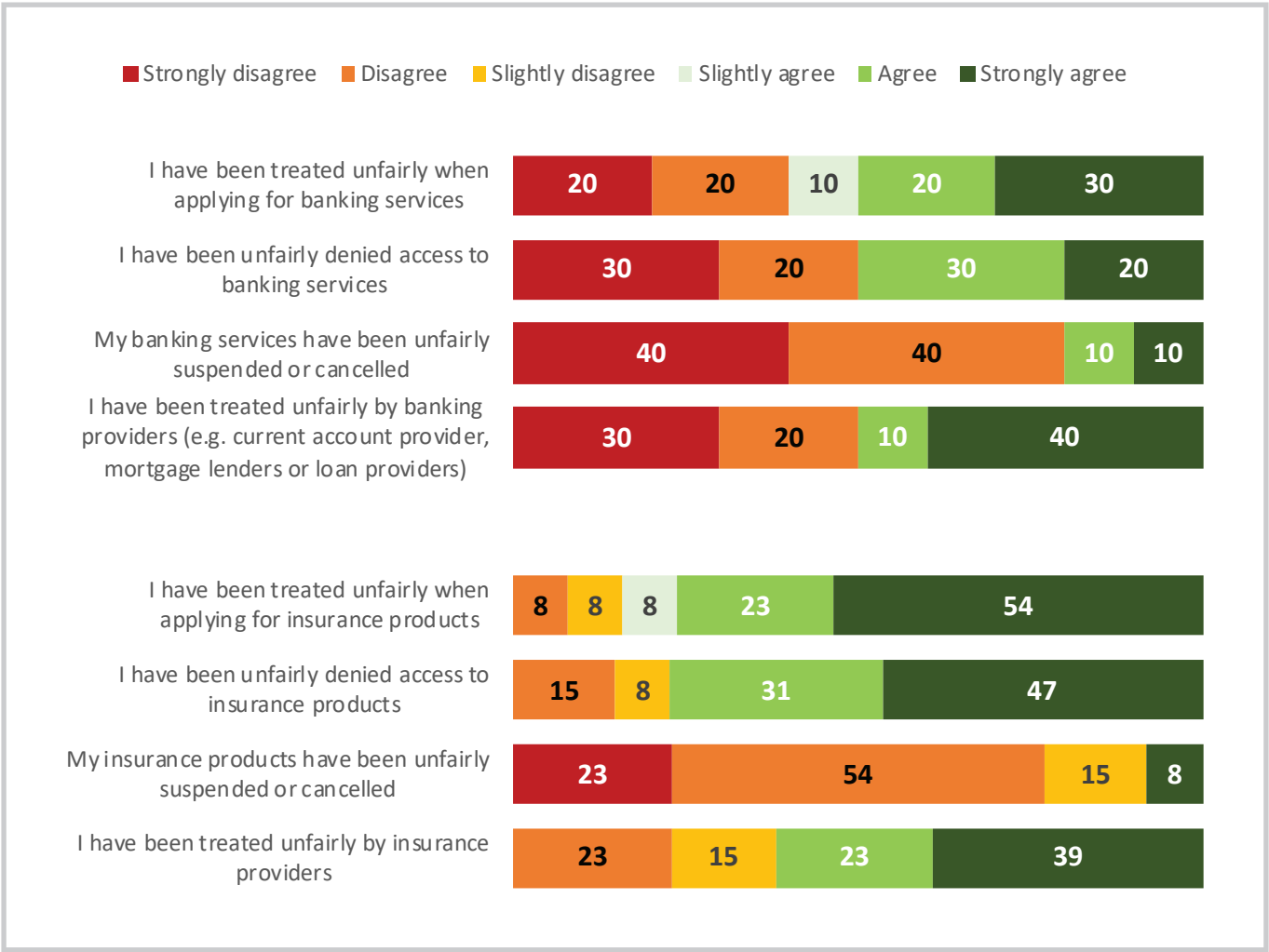
- 17.6. The profile of participants who selected the banking and insurance life area in their top three largely reflects the overall respondent population. There were some small differences; this group were more likely to be married (44% compared to 23% of total sample) and to be employed full-time (50% vs. 28% of total sample).
- 17.7. Those who selected the banking and insurance life area typically reported lower incidence of most illnesses in the last 12 months than the total sample. In particular, 13% reported severe and/or treatment-resistant depressive disorder vs. 39% of the total sample, and 13% reported experiencing personality disorder vs. 31% overall. However, they were more likely to report experiencing bipolar or related disorder (31% vs. 15% of the total sample).

Perceived experiences of stigma and discrimination in banking and insurance services

17.8. Figure 17.1 presents the extent to which respondents agreed or disagreed with statements about stigma and discrimination in relation to banking and insurance services.

Figure 17.1. Perceived experiences of stigma and discrimination in banking and insurance services: percentage agreement and disagreement (n=10-13)

Because of stigma about my mental illness(es)...



17.9. Perceived experiences of stigma and discrimination are more pronounced for insurance products than banking services. The three highest levels of agreement are recorded for insurance services: the vast majority (85%) agree they have been treated unfairly when applying for insurance, with over half (54%) agreeing strongly; three quarters (77%) agree they have been denied access to insurance products; and three fifths (62%) feel they have been treated unfairly by insurance providers.

“Prior diagnosis of depression means I can’t get insurance to get cover if I lose my job due to any mental health condition.”

“On trying to apply for life insurance, I found only one provider who would insure me because of past instances of mental illness. The premiums were very high. There is a six year history question with respect to being admitted to hospital. I have to wait another year before this event is deemed irrelevant, and I can possibly afford to buy life insurance.”

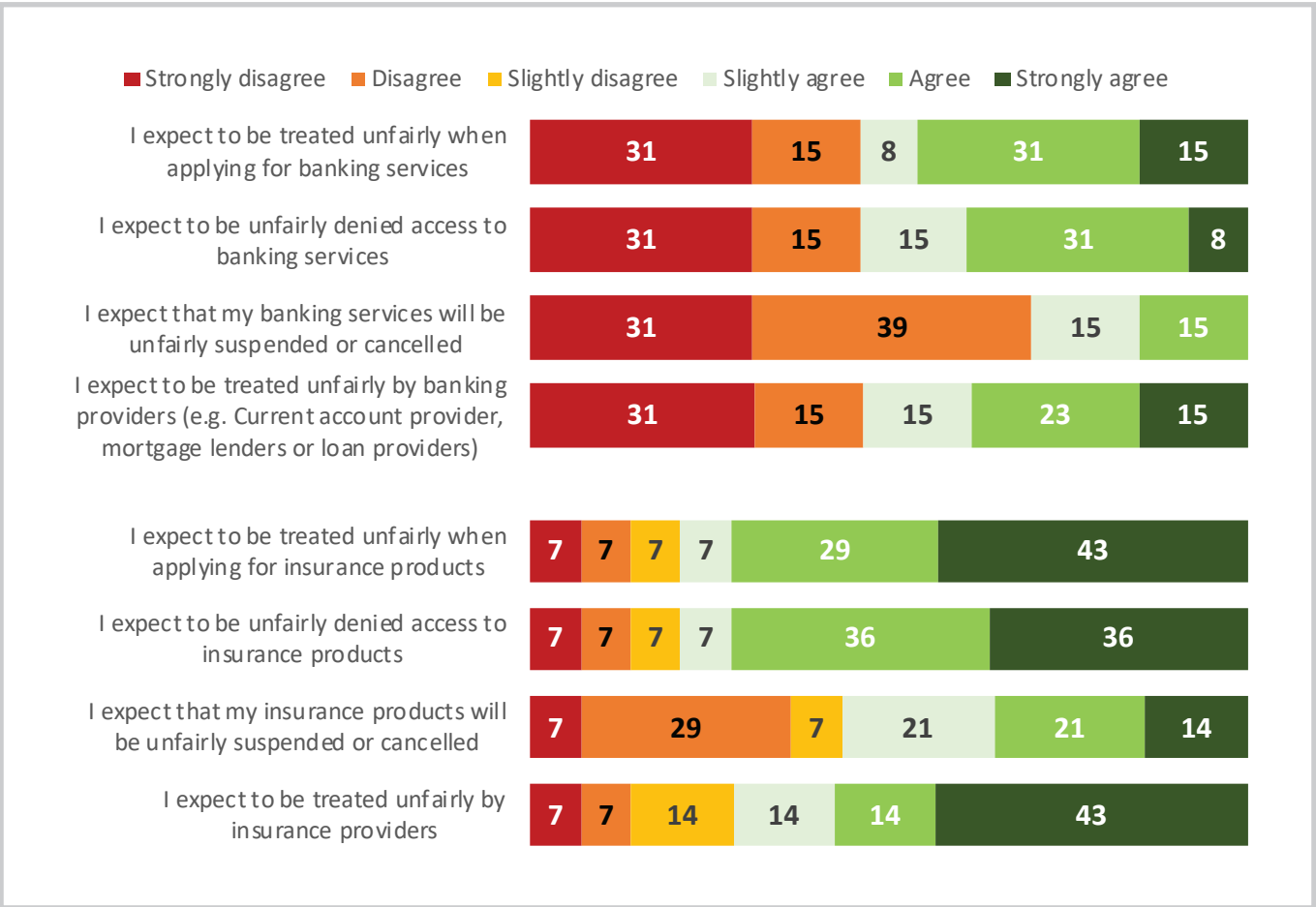
- 17.10.** A minority (8%) agree that their insurance products have been unfairly cancelled or suspended. One quarter (23%) disagreed strongly that this is the case. This suggests the challenge is around obtaining insurance policies, rather than once they are in place.
- 17.11.** A similar pattern of responses was recorded for perceived experiences with banking services; between half and three fifths agree they have been treated unfairly when applying for or accessing banking services. One fifth (20%) felt their banking services had been unfairly suspended or cancelled.

Anticipated stigma and discrimination in banking and insurance services

17.12. This section explores anticipation of experiencing stigma and discrimination. Figure 17.2 presents the extent to which respondents agreed or disagreed with statements about aspects of anticipated stigma and discrimination in relation to banking and insurance.

Figure 17.2. Anticipated experiences of stigma and discrimination in banking and insurance services: percentage agreement and disagreement (n=13-14)

Because of stigma about my mental illness(es)...



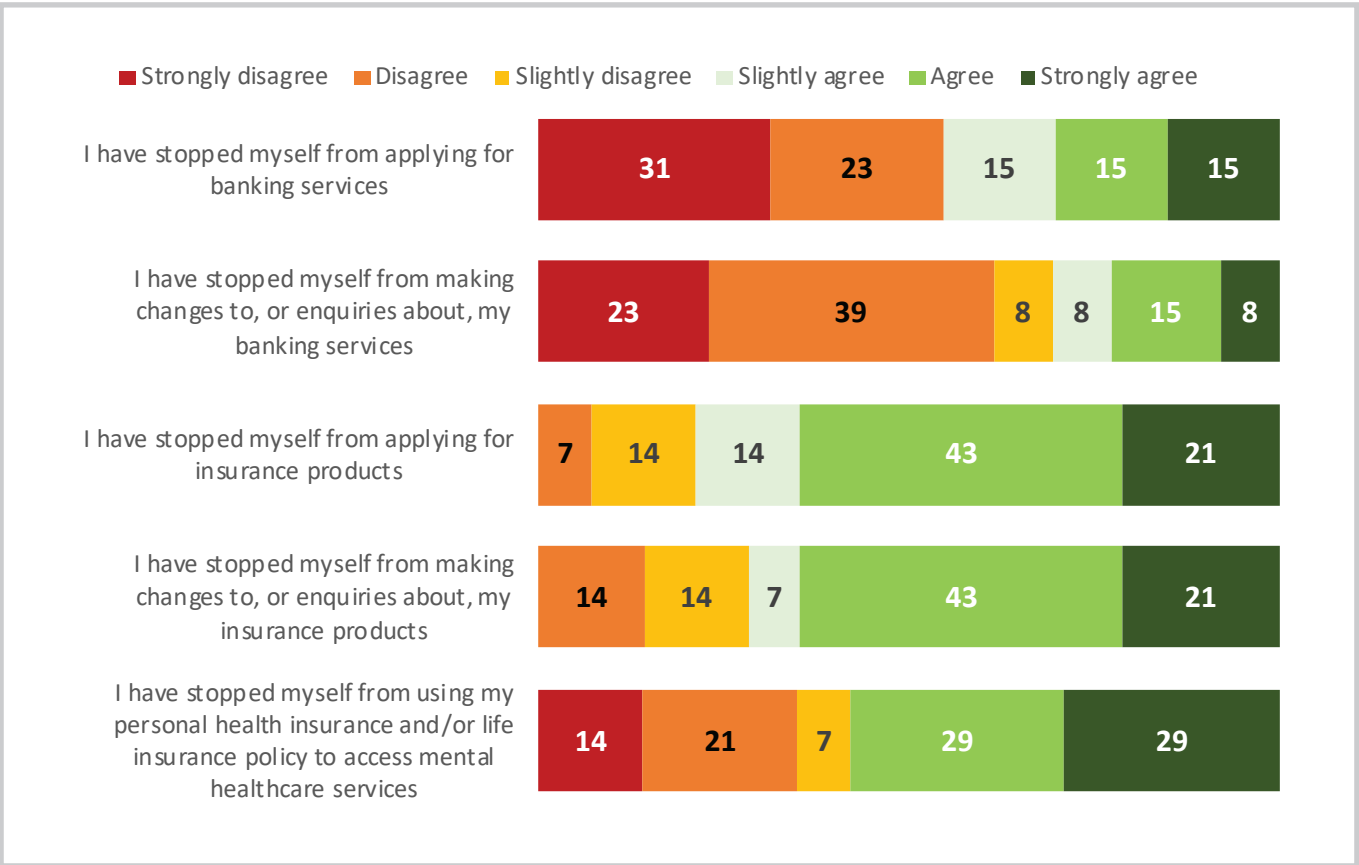
- 17.13.** More than half of respondents agreed with seven of the eight statements exploring anticipated stigma and discrimination. As with perceived experiences, respondents held stronger views on the statements related to insurance products, with four fifths anticipating they will be unfairly treated when applying for, or denied access to, insurance products (79% for both statements). Despite only 8% experiencing their insurance products being unfairly suspended or cancelled, over half (57%) anticipate this will happen to them in the future.
- 17.14.** We note the more pronounced difference between experience of and anticipation about cancellation in relation to insurance compared to banking. While only 8% have experienced cancellation of insurance products, 50% expect this to happen in the future. However, 20% have experienced cancellation of banking products, with just 30% anticipating this in the future.
- 17.15.** While agreement is lower, over half (54%) agree with three of the four statements about anticipated stigma and discrimination in banking services. However, opinion is relatively polarised, with three in ten (31%) disagreeing strongly with all four statements.

Withdrawal from opportunity in banking and insurance services

17.16. This section explores the influence of stigma and discrimination on respondents' withdrawal from decisions and choices about banking and insurance. Figure 17.3 presents the extent to which respondents agreed or disagreed with statements about withdrawal.

Figure 17.3. Withdrawal from opportunities in banking and insurance services: percentage agreement and disagreement (n=13-14)

Because of stigma about my mental illness(es)...



- 17.17.** In line with experiences and expectations, respondents were more likely to agree they had withdrawn from opportunities around insurance than banking: 79% agreed they had stopped themselves applying for insurance products and 71% had stopped making changes or enquiries.
- 17.18.** Specifically on health insurance, over half (57%) agreed that they had stopped themselves from using personal health or life insurance policies to access mental healthcare services. Three in ten (29%) agreed strongly.
- 17.19.** Withdrawal from banking services appears less pronounced. Just under half (46%) reported that they had stopped applying for banking services, and 31% agreed that they had stopped making changes or enquiries to banking services.

"I don't feel that people should be stopped from having bank accounts or have their insurance cancelled because of mental health."

Findings from supplementary qualitative research

- 17.20.** This section presents the findings from the supplementary qualitative research conducted, which explored and gathered further examples and insights into experiences of stigma and discrimination in the banking and insurance services life area.
- 17.21.** Experiences of stigma and discrimination in the banking and insurance life area were shared by ten interviewees, though several of the incidents had taken place more than 12 months ago. Discussing these experiences provided additional insights into future expectations and participation in this life area.
- 17.22.** Furthermore, a small number of interviewees reported that they had not directly experienced stigma and discrimination but through hearing about others' experiences, anticipate stigma and discrimination if they do try to access services in this life area in the future.

Experiences of stigma and discrimination

- 17.23.** Participants who had experienced stigma and discrimination in the banking and insurance services life area most commonly reported this when trying to access travel or life insurance.
- 17.24.** Three interviewees explained that previous attempts to access travel insurance resulted in prohibitively expensive premiums.

"You can be quoted thousands. And it isn't fair really."

- 17.25.** Interviewees shared similar experiences when trying to access life insurance. For two, the quotes were simply too expensive for them to take out a policy; the other two were refused cover altogether as they were deemed to be at increased risk of suicide.

"I attempted to get life insurance and it was just after I had been diagnosed with complex PTSD and I was refused life insurance, no one would insure me."

- 17.26.** One interviewee who reported no experiences of stigma or discrimination when accessing insurance products explained that they did not disclose details about their mental illness. Another questioned whether refusal or prohibitively expensive insurance or other financial products was stigma or discrimination. Their view was that the industry makes assessments based on risk. They made the comparison of being charged more previously when they had cancer and ended up paying higher premiums than if they had a clean bill of health. They did not see that should be any different for mental illness.

“So I think, you know, judging it on that sort of thing, I don’t really see that as stigmatisation, I think it’s just a case of, you’ve got an illness that potentially might need treated when you’re abroad.”

- 17.27.** Only one interviewee reported experiencing stigma and discrimination related to banking services. They had encountered difficulties in navigating complicated systems and processes, with little support from staff to accommodate their needs.

Anticipation and withdrawal

- 17.28.** Interviewees who had experienced refusal or prohibitively expensive quotes for insurance products strongly anticipated that this would be the case if they tried again in the future. A few participants reported that they had given up trying.

“So I’ve been refused life insurance twice. And I’ve given up now, I can’t get it.”

- 17.29.** Even though travel insurance was expensive, two interviewees suggested that if they can afford to they will buy on the basis it is better to have the cover than risk something happening and not being covered.

“The thing would then be to not disclose I have a mental health problem, because it’ll cost more, but the danger is, say you were at the pool and you fell over and broke your leg. The insurer may then not pay out your claim because you have OCD.”

- 17.30.** The broader impacts of not being able to access insurance services due to stigma and discrimination were discussed by two interviewees. In one example, a participant who was quoted a prohibitively expensive amount for a life insurance policy spoke about the frustration of not being able to ensure her children were financially secure if anything happened to her.

“I could, but it’s about £250 a month, because of having bipolar. So I would rather just save that £250 a month and try not to die. It’s all you can do. It’s frustrating because I have young children that I am a single parent to.”

- 17.31.** Another participant had plans to travel but has now given up hope of being able to due to expensive quotes for travel insurance. It had been a dream of theirs which currently does not feel possible.

“And, you know, most insurers wouldn’t insure me. So I had to go through a specialist firm for mental health. And do you know how much it would cost? £1,400. Yeah, I can’t afford that.”

- 17.32.** Stigma and discrimination in the banking and insurance services life area are anticipated and expected even among those who have not tried to access insurance products in the past.

“I mean, I hear that once you tell them it’s mental health, as far as insurance goes it usually goes whoosh.”

- 17.33.** One interviewee who reported difficulties with their bank moved to another company and acknowledged that it would be challenging not to use a bank at all; complete withdrawal from that life area did not seem feasible. Their current bank has been very supportive, and they reported having fewer difficulties. Another participant who had not experienced stigma and discrimination in this life area did say that they tried to do all of their banking online to avoid person-to-person contact and any potential for stigma and discrimination.

Intersectional stigma and discrimination with banking and insurance

17.34. Intersectional experiences of stigma and discrimination in relation to banking and insurance services is also evident from survey responses. Respondents most commonly reported stigma and discrimination in relation to their age and physical disabilities (both 39% compared to 21% among the total sample). Almost one fifth (17%) reported discrimination in this area due to their marriage/civil partnership; this is higher than the 9% among the total sample. Stigma resulting from all other aspects of identity was lower among this group than the total sample.

Views on the requirement for special considerations

17.35. Finally, respondents were presented with a statement about whether they should receive additional consideration when accessing or using banking services or insurance products. Over two fifths (43%) agreed that they should receive additional consideration. This was the lowest level of agreement across all 14 life areas.

"If people suffer from an episode of very poor mental health, they should be offered financial support and loans etc., should be aware that payments might not be kept up to date with because the person is just 'getting by' and making direct debits is a hard thing to keep up with and an easy way for banks to make money."

Other feedback on stigma and discrimination in banking and insurance

17.36. Respondents were invited to share further information about their experience of stigma and discrimination while using banking and insurance services. During analysis of their responses two main themes emerged:

- A lack of access to services.
- Confusing systems.

A lack of access to services

17.37. Respondents described being unable to access banking and insurance services. This was either directly linked to their mental health status; or indirectly through their mental health impacting their employment status.

"I have tried recently to apply for life insurance and was honest in all my responses, including my diagnosis, and was told that because of my bi-polar diagnosis no-one would offer me a policy. The broker was very apologetic, but he could not find a single company that would."

"I cannot get a mortgage that would cover me to buy a place close to family as the properties are too expensive for areas nearby. My disability benefit isn't included as income by the bank, because despite having chronic mental illness from childhood, as the DWP only give an award out for a few years at a time. I have been in full-time employment less than one year since I was off-sick, so I can't apply yet based on salary, which along with my deposit would be enough. I am in limbo. The same situation for interest rates – higher because of my health and benefit situation."

- 17.38.** Banking and insurance policies impact respondents' employment experiences. One respondent mentioned feeling compelled to return to work prematurely; another spoke about being unable to receive insurance to meet their job requirements, such as driving a car.

Confusing systems

- 17.39.** The services provided by insurers and banks were described by respondents as difficult and confusing to use. A few respondents mentioned feeling that these companies intentionally took advantage of those with poor mental health.

"I get so confused when dealing with them I become practically incoherent, at least, they don't seem to understand that I don't understand. Like the general population seem to be, they are ignorant of mental illness and do not recognise it, so that while perhaps it is not deliberate on their part, they treat me as if I am a fraudster."

Positive experiences

- 17.40.** Respondents were presented with a statement about positive experiences when accessing or participating in banking and insurance. Only 14% of respondents in this life area agreed they have had positive experiences; the second lowest of all 14 life areas. Moreover, this 14% represented respondents who selected slightly agree; no respondents selected agree or strongly agree. Half (50%) strongly disagreed – the second highest level after the housing life area (57% strongly disagreed).
- 17.41.** Some reiterated examples of difficult experiences, which were included in the analysis presented above; no positive examples were shared in response to this open-comments question.

Summary

- Overall, just under half of all survey respondents (164 or 47%) reported experiences of stigma and discrimination in this life area in the past 12 months. One fifth (19%) reported it was experienced frequently or very frequently.
- Banking and insurance services was selected by 16 respondents (5%) as one of the three in which the stigma and discrimination they experienced had the greatest impact. It was the 11th most commonly selected life area.
- Perceptions of stigma and discrimination appear to be more pronounced in relation to insurance products than banking services. Over seven in ten feel they have been unfairly treated when applying for, or denied access to, insurance products, with the same proportion expecting this to happen in the future and having withdrawn from insurance products as a result.
- Despite only 8% experiencing their insurance products being unfairly suspended or cancelled, over half (57%) anticipate this could happen to them in the future. The same proportion (57%) agreed that they had stopped themselves from using personal health or life insurance policies to access mental healthcare services.
- Views on stigma and discrimination related to banking services are more polarised. While just over half agree they have been treated unfairly in the past, and expect to be in the future, withdrawal from using banking services is more limited.
- Only 14% of respondents in this life area agreed they have had positive experiences due to their mental illness; the second lowest of all 14 life areas. Respondents most commonly reported stigma and discrimination in relation to their age and physical disabilities (both 39%).
- Over two fifths (43%) agreed that they should receive additional consideration when accessing banking and insurance services. This was the lowest level of agreement across all 14 life areas.
- Respondents cited two main themes of stigma and discrimination in their open responses: a lack of access to services and confusing systems.

18. Legal and justice services

“The faceless legal and justice services leave a lot to be desired. I suppose that is how they are meant to be, but I feel that allowances need to be made in some instances, e.g. mental conditions.”

Overview

- 18.1.** This chapter explores experiences of stigma and discrimination in accessing and participating in legal and justice services for respondents living with complex, severe and/or enduring mental illnesses.
- 18.2.** The questions about this life area covered aspects of policing, including the use of 101 and 999 calls; civil and criminal courts of law, including accessing legal representation and advice; and family courts including child protection.
- 18.3.** Just over one third (119 or 34%) of all survey respondents reported that experiences of stigma and discrimination in legal and justice services in the past 12 months. Around one sixth (13%) reported they had experienced it frequently or very frequently.
- 18.4.** Legal and justice services was the 12th most commonly selected life area. It was selected by 15 respondents (4%) as one of the three in which the stigma and discrimination they experienced had the greatest impact. Of those who selected this life area, 12 had experience with the police, 10 with courts and two with family courts in the last 12 months.
- 18.5.** The vast majority (87%) of those who selected this life area reported experiencing stigma or discrimination either frequently (20%) or very frequently (67%); this compares to only 13% of all survey respondents.
- 18.6.** This chapter presents the profile and experiences of respondents who selected legal and justice services as one of the three life areas where they experience most stigma and discrimination. **Given the small sample size, findings in this chapter should be treated as indicative.**

Respondent profile

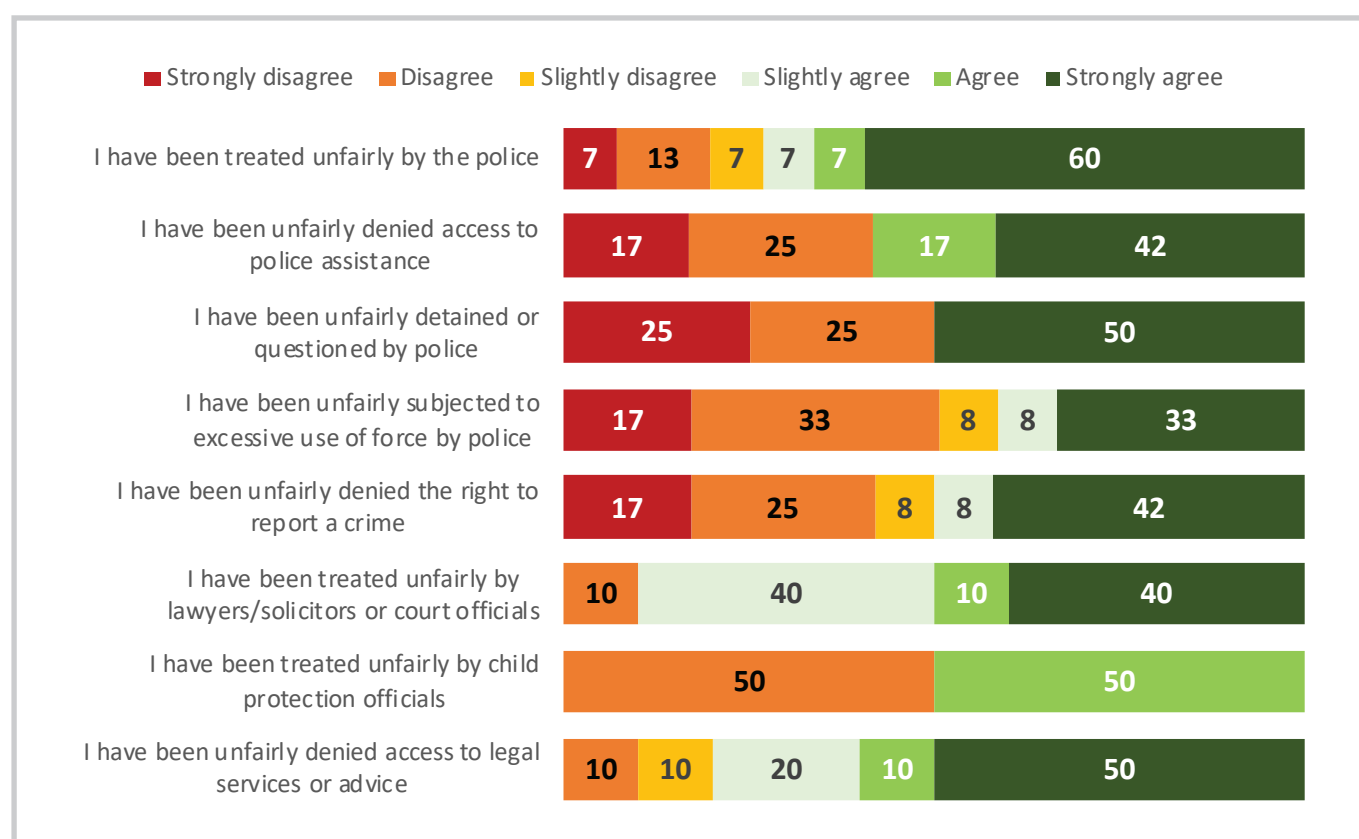
- 18.7.** The profile of participants who selected legal and justice services as one of their top three life areas is largely reflective of the overall respondent population. Some small differences are evident, however; this group was more likely to be female (73% vs. 58% of total sample), not to have a job (40% vs. 28% overall) and to be Christian (47% vs. 21% overall).
- 18.8.** An analysis of mental illnesses among those who selected the legal and justice services life area demonstrates the higher prevalence of disorders associated with stress (67% vs. 43% among all survey respondents) and of dissociative disorder (27% vs. 12% overall). This cohort reported a lower prevalence of most other illnesses compared to the total sample. This group was also less likely to report that their complex mental health issues had been diagnosed – 67% compared to 87% among the total sample.

Perceived experiences of stigma and discrimination in legal and justice services

- 18.9.** Respondents' experiences of stigma and discrimination in relation to legal and justice services are explored in this section. Figure 18.1 presents the extent to which respondents agreed or disagreed with statements about this topic.
- 18.10.** Respondents were most likely to agree that they had been treated unfairly by lawyers, solicitors or court officials (90% agree) or by the police (73%). However, those with negative police experiences were more likely to agree strongly that they had been treated unfairly – 60% compared to 40% of those who agreed strongly in relation to being treated unfairly by the legal system.
- 18.11.** Four fifths (80%) agreed they had been unfairly denied access to legal services because of their mental illness, with half agreeing strongly. Almost three fifths (58%) agreed they had been unfairly denied access to police assistance.
- 18.12.** Half of respondents (50%) agreed with most of the remaining statements about experiences – that they had been unfairly detained or questioned by police or denied the right to report a crime. Opinion on these was more polarised, with respondents more likely to strongly agree/disagree than slightly agree/disagree.
- 18.13.** While only a minority of respondents agreed they had been subjected to excessive use of force by police, this still accounted for over two fifths of respondents that selected this life area as one where stigma and discrimination had the greatest impact.

Figure 18.1. Perceived experiences of stigma and discrimination in legal and justice services: percentage agreement and disagreement (n=10-15; n=2 for child protection statement)

Because of stigma about my mental illness(es)...



Anticipated stigma and discrimination in legal and justice services

- 18.14. This section explores anticipation of experiencing stigma and discrimination. Figure 18.2 presents the extent to which respondents agreed or disagreed with statements about aspects of anticipated stigma and discrimination in legal and justice services.
- 18.15. Levels of agreement were lower for all statements about expected stigma and discrimination compared to the proportion who reported experiencing challenges in this life area in the last 12 months. However, the key concerns correlated with past experiences of stigma: anticipation that respondents will be treated unfairly by lawyers or court officials (73% agree) or police (60%), or denied access to legal services or advice (67%).
- 18.16. In line with past experiences, 47% anticipate being unfairly detained or questioned by the police, with two fifths (40%) expecting to be subjected to excessive use of force or denied the right to report a crime.

Withdrawal from opportunity in legal and justice services

- 18.17. This section explores the influence of stigma and discrimination on a respondent’s withdrawal from decisions and choices about legal and justice services. Figure 18.3 presents the extent to which respondents agreed or disagreed with statements on this.

Figure 18.2. Anticipated experiences of stigma and discrimination in legal and justice services: percentage agreement and disagreement (n=15)

Because of stigma about my mental illness(es)...

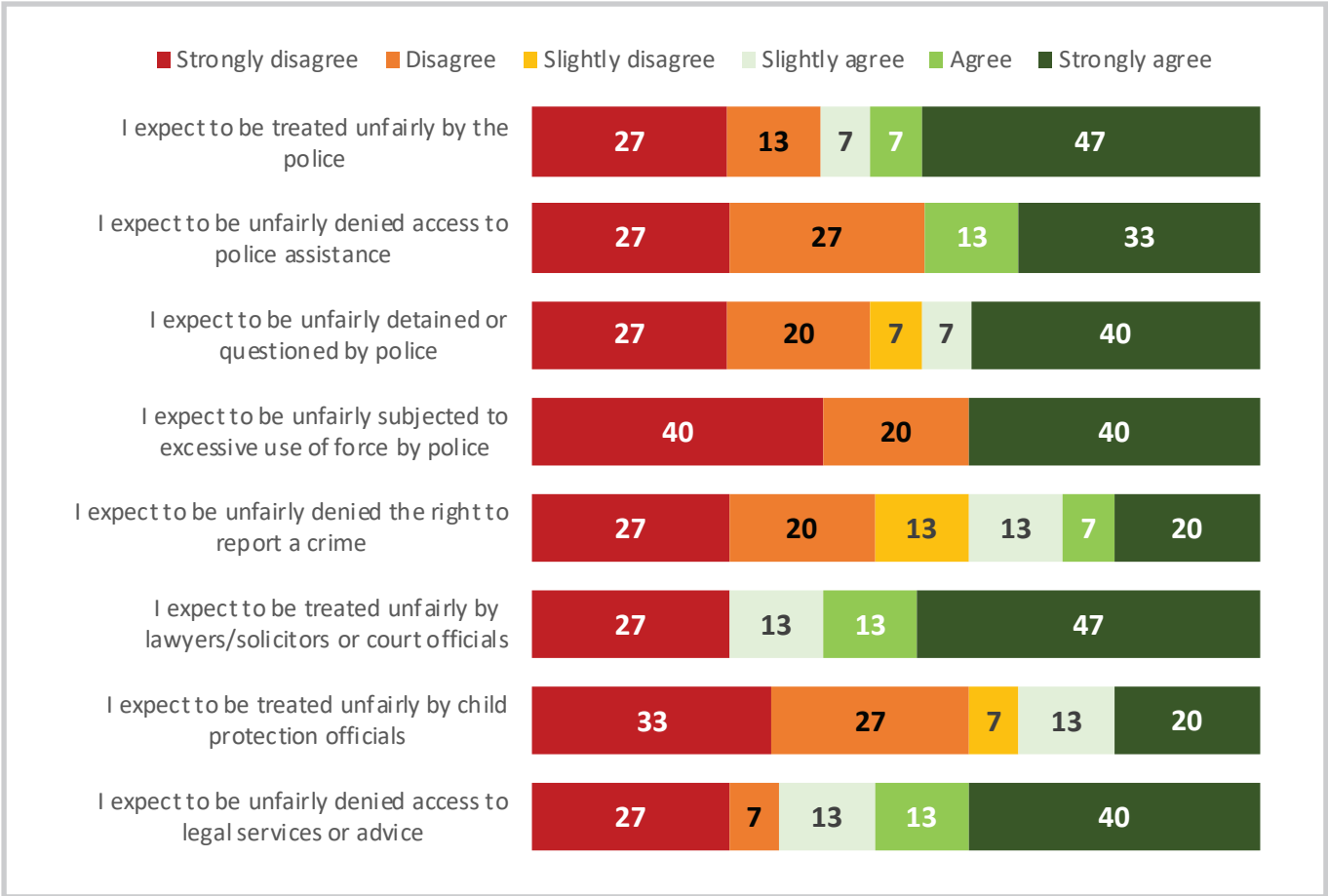
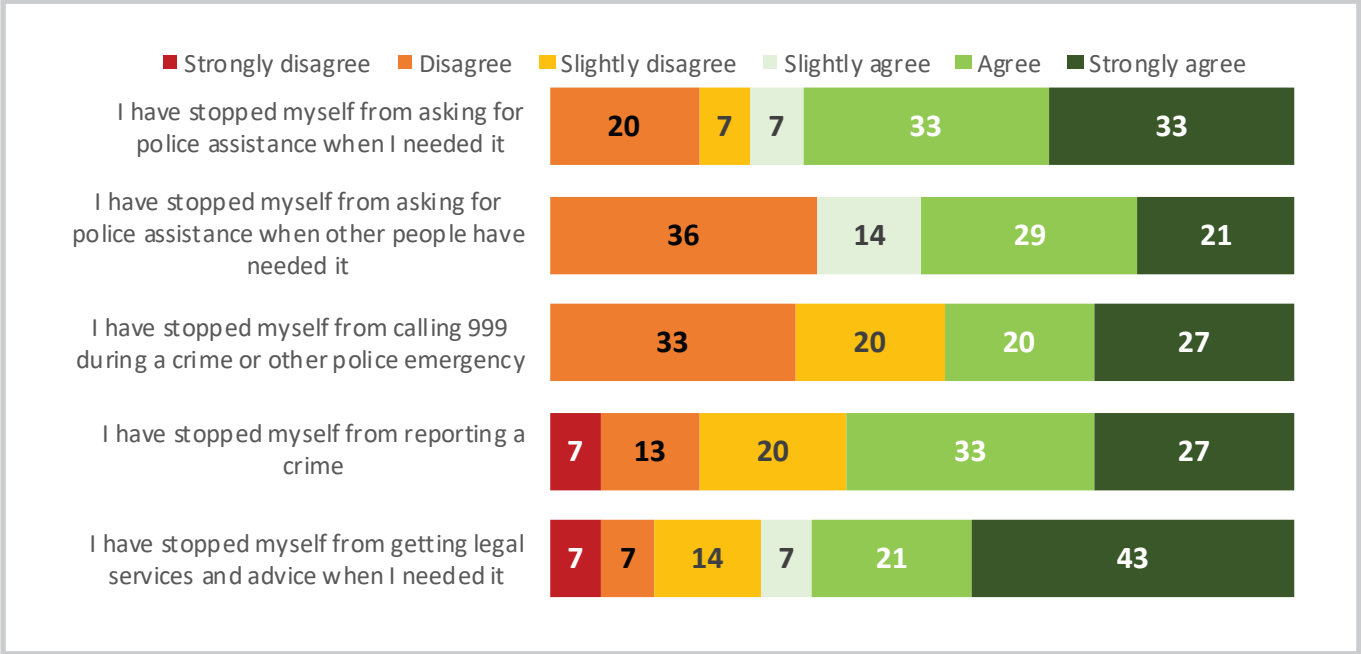


Figure 18.3. Withdrawal from opportunities in legal and justice services: percentage agreement and disagreement (n=14-15)

Because of stigma about my mental illness(es)...



18.18. Almost three quarters (73%) of respondents who selected legal and justice services as one of the three areas in which stigma and discrimination they experienced had the greatest impact agreed that, they had stopped asking the police for assistance when they needed it. Proportions were similar (71%) for those who agreed that they had stopped getting legal services and advice for themselves, however with legal services, respondents were more likely to agree strongly (43%).

18.19. The highest level of withdrawal related to getting help for themselves when needed, and respondents also reported reluctance to get help for others due to stigma and discrimination about their mental illness. Two thirds (64%) agreed they had stopped themselves from asking for police assistance for someone else, and 60% agreed they had stopped themselves from reporting a crime. In spite of the seriousness of the situation, just under half (47%) agreed they had stopped themselves from calling 999 during a crime or emergency.

Findings from supplementary qualitative research

18.20. This section presents the findings from supplementary qualitative research, which explored and gathered further examples and insights into experiences of stigma and discrimination in the legal and justice services life area.

18.21. Experiences of stigma and discrimination in the legal and justice services life area were shared by thirteen interviewees. Most of these examples centred on interactions with the police, with a smaller number related to attending court. Some of these experiences took place more than 12 months ago. However, this opened discussions about how those experiences influenced expectations of future stigma and discrimination and their participation in this life area.

Experiences of stigma and discrimination

18.22. Most interviewees said their interactions with courts and the justice system were infrequent. This limited their experiences of engaging with this life area in the research and, therefore, the extent to which they had experienced stigma and discrimination.

18.23. The most commonly reported experience of stigma and discrimination with the police involved being handcuffed/restrained or being threatened with arrest. Interviewees said that these instances took place during a time of mental health crisis for them and that the police approach was heavy-handed and unnecessary.

"So when they've been called, I have been put in handcuffs and put in the back of a police van. Not because I was violent, but because I was upset."

"I mean, so I try to end my life, and the police threatened to arrest me. Because the nurse who assessed me in the mental health assessment, said I had capacity. So the police were like if you do it again, because you have capacity we are going to arrest you."

18.24. In addition to sharing personal experiences, two interviewees also described the stigma and discrimination they had witnessed. This included a young person with mental illness being treated unfairly and another instance of someone being mistreated by police while having a mental health crisis.

18.25. One interviewee said the police had misrepresented the events leading up to their arrest in a report. They only became aware of this misrepresentation when the information was shared with their social worker; this severely diminished their trust in the police.

"And the police have just like made up a lie... And blind lies about me because they can get away with it. It's really, I still get angry about that. The police behave like that, they don't realise that, you know, I could be sitting on a jury one day hearing police evidence."

18.26. A final example involved reporting a suspected crime when the police became dismissive after the person disclosed details of their mental illness. Related to this, one interviewee also noted that a young woman she was working with had been told she was not a reliable witness after reporting a crime and disclosing her mental illness.

"And yes, I had mental health problems, they were like we can't help you. And I was just like, what does that have to do with the fact that I think that I might have been Rohypnoled? Like, surely you should be going in investigating?"

18.27. Three interviewees described experiences of stigma and discrimination when attending court. In two instances, this related to a lack of additional considerations or adjustments for their mental illness, and another whereby the person did not feel supported when being questioned by a lawyer.

"Okay, there was absolutely zero understanding, and the slightest word used in the wrong context or in me taking something they said the wrong way was heightened and turned on its head and was just a complete disaster."

"I mean, it's turn up or you don't get any benefits. I mean, did I feel accommodated? Not really, basically turn up and that's it."

Anticipation and withdrawal

18.28. Interviewees who had experienced stigma and discrimination during contact with police expected to experience similar stigma and discrimination again. The extent to which this influenced potential future interaction with police services varied, from those who would avoid contacting the police unless it was an emergency, and those who would not seek help from the police at all.

"I wouldn't seek out help. Because I don't trust them, because in the past, I've had discrimination. So I wouldn't, I wouldn't trust them. So I'll never seek it out."

"Yeah, I wouldn't contact them unless I was in immediate physical danger. I'll probably try to avoid the police."

18.29. Experiences of stigma and discrimination by police had other consequences beyond the influence on likelihood of interacting with police services in the future. One interviewee constantly worried about how it may affect future job prospects, while another described the ongoing emotional impact.

"Because putting you in handcuffs and putting them back to a police van, only heightens the situation. It makes you feel like a criminal. It makes you feel like a bad person in society, when you already feel like a bad person in society."

"And actually, to get the experience you need a PVG. I've got a PVG it's clear it's fine. There's nothing on it. But I'm always, every time I get the PVG, I'm terrified. Because I'm like, what if I don't know what they said, I shouldn't because I never got charged or anything, but I'm immediately terrified that something crops up."

18.30. Anticipation of future stigma and discrimination was also heightened for those who had experienced this in court. One participant explained that even though they expected they would face stigma and discrimination again in a court setting, they would engage with justice systems again if required. However, another said that they would not report being a victim of crime, to avoid a repeat of their previous experience in court.

"If I'm ever the victim of any sort of crime, I would just deal with that because that is bad enough. It's only adding another 10 layers of difficulty to involve courts and lawyers and such. Absolutely never again."

18.31. One interviewee had not experienced stigma and discrimination in this life area previously but said they expected to because of the stigma they had experienced in other parts of their life. They described avoiding accessing legal support when they needed expert advice due to fear of their mental health being used against them.

Intersectional stigma and discrimination with legal and justice services

18.32. Experiences of stigma and discrimination with legal and justice services because of other aspects of respondents' identities broadly aligned with the total sample. However, those who selected this area were more likely to record stigma and discrimination because of their physical disabilities (53% vs. 21% overall).

"I cannot call 999 or NHS24 due to being deaf. I wouldn't dare visit a police station because they don't understand dyspraxia."

Views on the requirement for special considerations

18.33. When asked if they should receive additional consideration when accessing or participating in legal and justice services, or police assistance, almost all (93%) agreed they should, with 40% agreeing strongly. This represents the highest level of agreement across all 14 life areas, and the third highest level of strong agreement.

Other feedback on legal and justice services

18.34. Respondents were invited to discuss their experiences of stigma and/or discrimination with legal and justice services. Many of the comments criticised aspects of the legal and justice system, particularly the police force. Four main themes were evident across the responses:

- Unmet needs.
- Mistrust of services.
- Better awareness and training for legal and justice service providers.

Unmet needs

18.35. A few respondents described interactions with legal and justice services in which they were ignored, or left unfulfilled. Respondents highlighted instances where they sought help and received little support:

"I have made complaints (and had them upheld) on several occasions, regarding police and courts/tribunals service only to have to make them again because no change has happened as a result of these being upheld."

Mistrust of services

18.36. A few respondents described specific incidents of poor experiences with justice services that convinced them not to use those services again. In one case, this was due to threats and the misuse of force by police during an attempted suicide.

18.37. Another respondent mentioned an inherent fear of seeking help due to the expected response of others:

"To be honest I'm not sure whether it is just my perception of other people's responses which intimidates me, when needing to deal with police it seems that my duty overcomes my reluctance. When the need is purely in my own interests I fail miserably."

"When I was 19 I went to a bridge twice in one day. This was when I lived in Edinburgh. The first time I went to MHAS they refused to see me because I had been assessed that morning for an overdose and was assessed as having capacity. Then I went back to jump off and the police were there waiting and once we went back to MHAS the nurse threatened to get me arrested for breach of the peace and the police said that should I do this again I would end up in the cells with a criminal record. I want to go into youth work, and this would have ruined my life if they had arrested me. Since then, I have been scared of the police. Also Police Scotland in Edinburgh use excessive force instead of talking and calming down. I now live in Dumfriesshire and the police have been amazing and when I'm upset they talk to me not handcuff me."

Better awareness and training for legal and justice service providers

18.38. Respondents spoke about a lack of awareness or training around mental health and physical disabilities. These factors impacted the respondents' willingness to use legal and justice services.

18.39. Two respondents suggested the services need to be improved or changed:

"There needs to be more actual training in impartiality for police officers and it's actually awful the lack of interagency communication especially in reference to people with mental or neurological health issues. And regardless of age the police should never be able to question or direct a person's behaviour especially when that person has learning and communication difficulties."

"Having recently been the victim of domestic violence and then been a victim of malicious reporting I am of the very strong opinion that these services need to be examined and adjusted."

18.40. When presented with a statement about positive experiences when accessing or participating in legal and justice services, one third (33%) agreed they have had positive experiences. Out of all the life areas, positive experiences with legal and justice services ranked ninth out of 14.

"Police training in diplomacy in dealing with the public is certainly evident when dealing with 'the dotty old lady'. I have nothing but praise for them."

"The procurator fiscal refused to put me to trial after I sent a personal letter. Information that included all the NHS/ police/etc. discrimination."

Summary

- Just over one third (119 or 34%) of all survey respondents reported experiences of stigma and discrimination in legal and justice services in the past 12 months. Around one sixth (13%) reported they had experienced it frequently or very frequently.
- Legal and justice services selected by 15 respondents (4%) as one of the three in which the stigma and discrimination they experienced had the greatest impact.
- Respondents recorded high levels of agreement with statements about being unfairly treated by police, solicitors and court officials, and being unfairly denied legal advice and services. Given past experiences, the expectation is for similar unfair treatment in the future.
- Specifically in relation to experience of the police service, half (50%) agreed they had been unfairly detained or questioned by police. While a minority agreed, over two fifths (42%) agreed they had been subjected to excessive use of force by police.
- Because of their mental illness, 73% agreed they had stopped asking the police for assistance when they needed it, and 71% agreed that they had stopped getting legal services and advice for themselves. Respondents also reported reluctance to get help for others. Of note, just under half (47%) agreed they had stopped themselves from calling 999 during a crime or emergency, because of their mental illness.
- One third (33%) of respondents to this life area agreed they had positive experiences due to their mental illness. Respondents selecting this area were more likely to record stigma and discrimination because of their physical disabilities (53%).
- When asked whether they should receive additional consideration when accessing or participating in legal and justice services, or police assistance, almost all (93%) agreed they should, with 40% agreeing strongly. This represents the highest level of agreement across all 14 life areas.
- Respondents provided open responses clarifying their experiences of stigma and discrimination by the legal and justice services. These can be broken in four main themes: unmet needs, intimidation or mistrust of services, better awareness and training for legal and justice service providers.

19. Cultural, faith, religious or spiritual practices and communities

"In the past I have experienced very negative reactions from my spiritual community and had to leave."

Overview

- 19.1.** Experiences of stigma and discrimination because of mental illnesses when accessing or participating in cultural, faith, religious or spiritual practices and communities are explored in this chapter.
- 19.2.** Questions about this life area covered a range of practices. These included: customs and traditions; prayer and meditation; regular services; celebrations; and other important rituals, practices or spaces of significance to respondents.
- 19.3.** Overall, more than a quarter of all survey respondents (97 or 28%) reported stigma and discrimination in this life area in the last 12 months – the lowest of all 14 life areas. Among this group, regular stigma or discrimination was uncommon; it was experienced frequently by 3% and very frequently by 5%.
- 19.4.** Cultural, faith, religious or spiritual practices and communities was the second least commonly selected life area, being selected by 13 respondents (4%) as one of the three in which the stigma and discrimination they experienced had the greatest impact. However, over half (54%) of those who selected this life area as one of the most impactful reported to have experienced stigma related to it either frequently or very frequently, compared to 8% of all survey respondents.
- 19.5.** This chapter presents the profile and experiences of respondents who selected cultural, faith, religious or spiritual practices and communities as one of the three life areas where the greatest impact is felt. Of the 13 respondents selecting this life area, all had experience of faith communities in the last 12 months and seven of cultural communities. Given the small sample size, findings in this chapter should be treated as indicative.

Respondent profile

- 19.6.** While the profile of the small number of respondents who selected the culture and faith life area in their top three is largely reflective of the overall respondent population, there were a few differences of note. This group were more likely to not provide their sex registered at birth (15% vs. 3% of the total sample) and were more likely not to have a job (62% vs. 28% overall). While they were more likely to be married (54% vs. 23% of total sample), they were also more likely to be separated or divorced (16% vs. 9% of total sample). Specifically in relation to faith, they were more likely to be Christian (46% vs. 21% overall), Muslim (8% vs. 1%) or Pagan (8% vs. 1%).

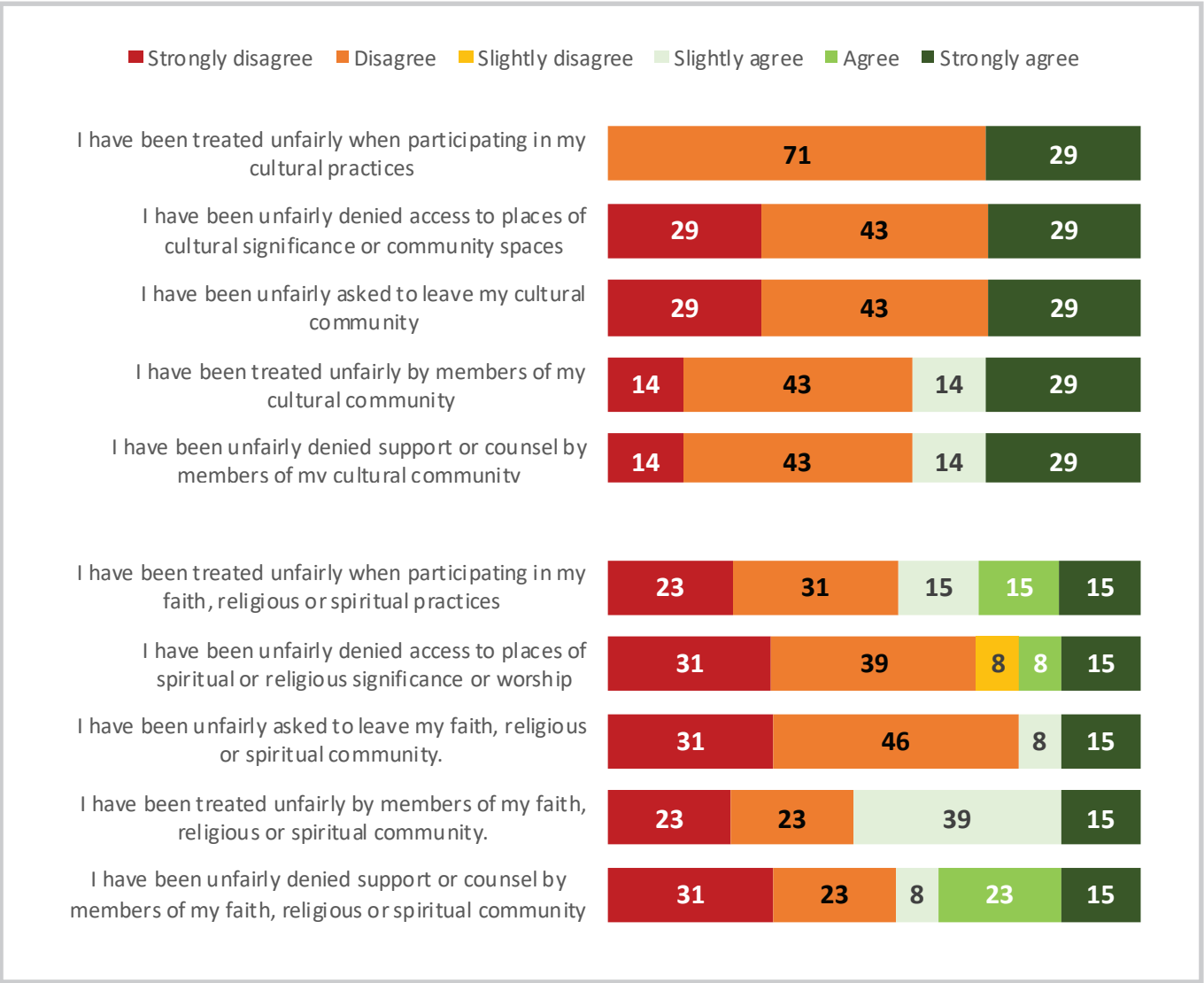
19.7. Among those selecting the cultural and faith life area, over half (54%) reported they had experienced schizophrenia or a psychotic disorder in the last 12 months, compared to 7% in the total survey sample. This group were less likely to report feeding/eating disorder (8% vs. 20% in the total sample) and anxiety/fear-related disorder (15% vs. 40% in the total sample).

Perceived experiences of stigma and discrimination in cultural, faith, religious or spiritual practices and communities

19.8. This section explores respondents’ experiences of stigma and discrimination in relation to cultural, faith, religious or spiritual practices and communities. Figure 19.1 presents the extent to which respondents agreed or disagreed with statements about stigma and discrimination related to these practices.

Figure 19.1. Perceived experiences of stigma and discrimination in cultural, faith, religious or spiritual practices and communities: percentage agreement and disagreement (n=7 for cultural practices, n=13 for faith practices)

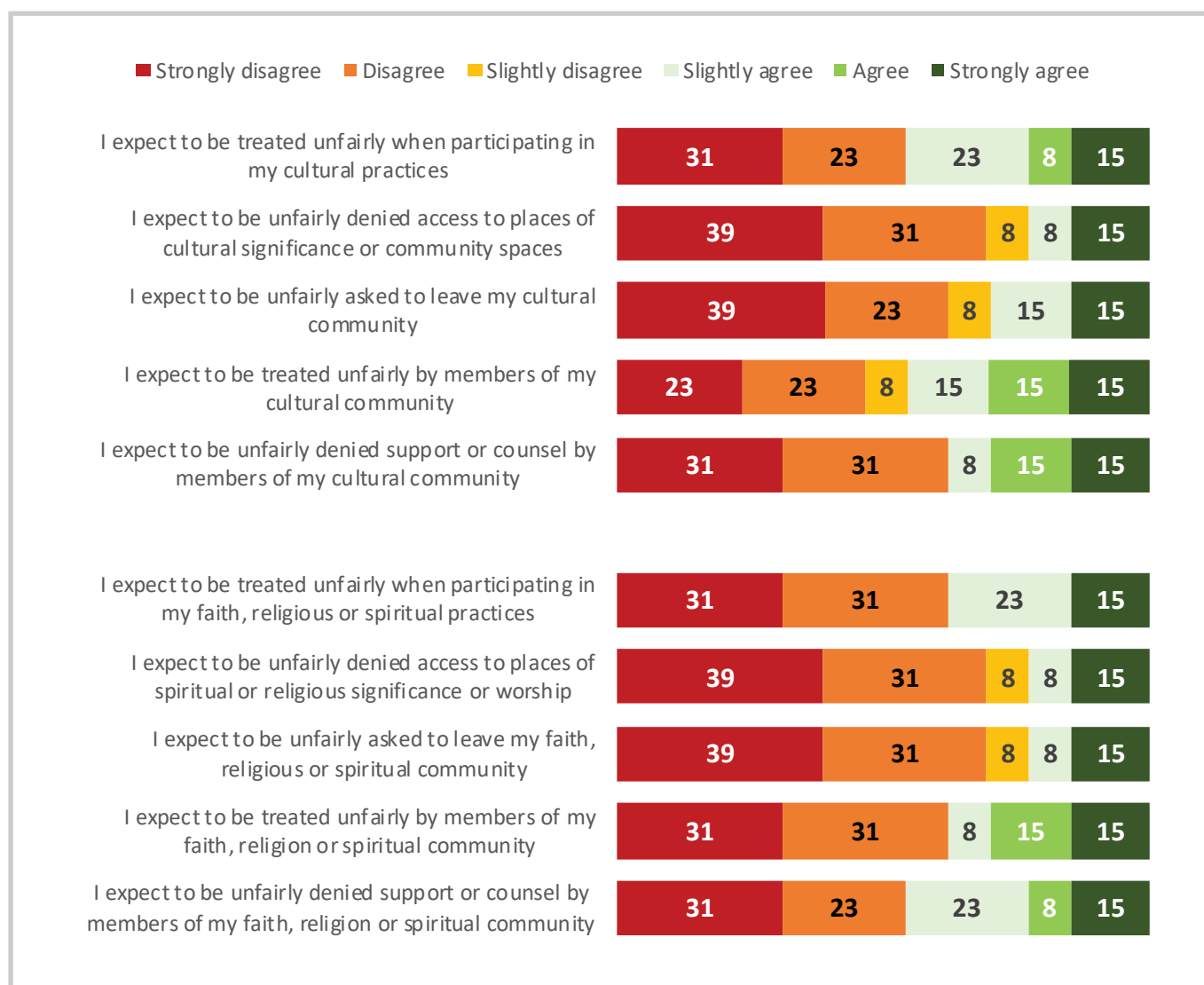
Because of stigma about my mental illness(es)...



- 19.9.** Experiences of stigma and discrimination in relation to cultural practices and communities were mixed. Of the small number who answered these questions, 43% agreed they had been treated unfairly, or denied support or counsel, by members of their cultural community. A smaller proportion (29%) agreed that they had been treated unfairly while participating, had been denied access to spaces or asked to leave.
- 19.10.** In relation to faith, religion and spiritual practices and communities, experiences were similarly mixed. Over half (54%) agreed that they had been treated unfairly by members of their community, though only 15% agreed strongly with this statement. Just under half (46%) agreed they had been unfairly treated when participating, or unfairly denied support or counsel by their community. One quarter (23%) agreed they had been unfairly denied access or asked to leave.
- 19.11.** However, levels of strong disagreement were typically higher for statements relating to faith communities than for cultural communities.

Figure 19.2. Anticipated experiences of stigma and discrimination in cultural, faith, religious or spiritual practices and communities: percentage agreement and disagreement (n=13)

Because of stigma about my mental illness(es)...

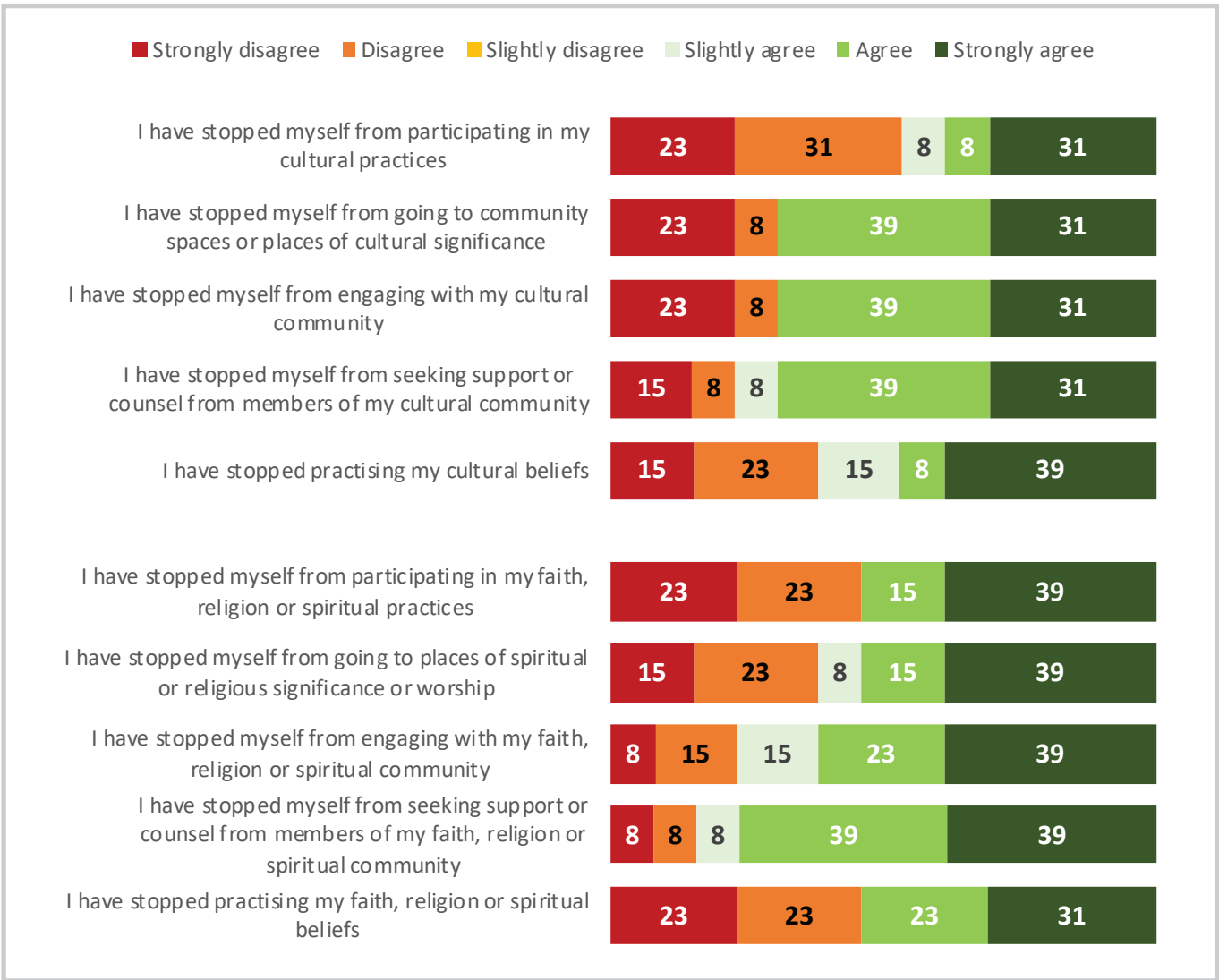


Anticipated stigma and discrimination in cultural, faith, religious or spiritual practices and communities

- 19.12. This section explores anticipation of experiencing stigma and discrimination. Figure 19.2 presents the extent to which respondents agreed or disagreed with statements about aspects of anticipated stigma and discrimination related to cultural, faith, religious or spiritual practices and communities.
- 19.13. On balance, expectations of future stigma and discrimination in this life area are lower than many other areas. For each statement, over half of respondents disagreed to some extent while strong agreement was recorded by two respondents (15%).
- 19.14. Respondents were most likely to anticipate being treated unfairly when participating in cultural practices (46% agree), treated unfairly by members of their cultural community (46%), and denied support or counsel by members of their faith community (46%). While 54% agreed that they had experienced unfair treatment by members of their religious communities in the past, only 38% anticipate it happening in the future.

Figure 19.3. Withdrawal from opportunities in cultural, faith, religious or spiritual practices and communities: percentage agreement and disagreement (n=13)

Because of stigma about my mental illness(es)...



19.15. The lowest levels of agreement were recorded for anticipated exclusion from cultural or community spaces (23% agree), or from places of spiritual significance or worship (23%), or to be asked to leave a faith community (23%).

Withdrawal from opportunity in cultural, faith, religious or spiritual practices and communities

19.16. This section explores the influence of stigma and discrimination on a respondent's withdrawal from decisions and choices about cultural, faith, religious or spiritual practices and communities. Figure 19.3 presents the extent to which respondents agreed or disagreed with statements about this.

19.17. While experiences and anticipation of stigma and discrimination because of mental illness were typically lower than in other life areas, respondents who selected the culture and faith life area still reported their withdrawal from these activities.

19.18. Around half reported they had stopped participating (46% in their cultural practices and 54% in their faith practices), with a slightly higher proportion agreeing they had stopped practicing altogether (54% stopped their faith practice and 62% their cultural beliefs).

19.19. More concerningly, over three in ten reported stopping going to places of cultural or spiritual significance (69% and 62% respectively) and from engaging with their cultural or spiritual community (69% and 77% respectively). The highest levels of withdrawal were recorded for seeking support or counsel – 77% stopped making such approaches within their cultural community and 85% for their spiritual community, perhaps reflecting the higher level of anticipation that this would be denied.

Findings from supplementary qualitative research

19.20. This section presents the findings from supplementary qualitative research which explored and gathered further examples and insights into experiences of stigma and discrimination in the cultural, faith, religious or spiritual practices and communities life area.

19.21. Only three interviewees reported experiencing stigma and discrimination in this life area. However, for two of these three people, their experiences were not as a direct result of participating in that life area. In these instances, they had experienced stigma and discrimination from people in religious communities and perceived that the stigma and discrimination they experienced resulted from the religious views held.

Experiences of stigma and discrimination

19.22. One interviewee had grown up in a religious family and said that the stigma and discrimination they experienced from family members stemmed, in part, from their religious beliefs. They felt that religious beliefs conflicted with aspects of modern attitudes and understanding of mental illness.

“And yeah, I just think it’s a very outdated, very old-fashioned perspective. And I don’t think they have a great deal of understanding around modern-day issues.”

19.23. Another interviewee reflected that the stigma and discrimination they experienced about their mental illness was cultural, explaining that areas of her country of origin did not have a good understanding of mental illness. They also expressed the view that religious people held

beliefs that those with mental illness are possessed by the devil, or that the mental illness a person is living with is a punishment from god for wrongdoing.

“And also in like, really religious communities. It’s like the devil has possessed you! You’re just you did something wrong. So this is why God is punishing you kind of thing.”

- 19.24.** One interviewee actively participated in the religion life area. They reported that while there were many supportive people in their church, they had also experienced stigma and discrimination from others. Again, the nature of this stigma and discrimination stemmed from the religious beliefs held by those people.

“But, you know, I have been told that, you know, I’m sinful, and that really impacts me.”

“I have been told that I might be possessed by the devil and things. And they’re ungodly thoughts... she was like, can I pray for you, and she started praying and saying, I pray that these ungodly thoughts will go away.”

Anticipation and withdrawal

- 19.25.** The interviewee who actively participated in religion as a life area expected they would continue to experience similar stigma and discrimination in the future. However it had not made them withdraw from participating entirely. Instead they were looking for a new church to join, but would be more cautious about what they disclosed and to who. This person also explained that they recently realised that they were gay and expected that this would also make it more difficult to find a church community that would accept them for who they are.
- 19.26.** While the other two people did not actively participate in this life area, their experiences and views still influenced the choices they would make or had made. One explained that they would not see a religious community as a place to seek out support, even though they were from a religious family. The other had stopped themselves from disclosing their mental illness to their partner’s parents. Their partner had recommended that they did not tell their parents about their mental illness as they held strong religious beliefs and did not think they would accept it.

Intersectional stigma and discrimination within culture and faith

- 19.27.** Intersectional experiences of stigma and discrimination in relation to the culture and faith life area is also evident from survey responses. Respondents most commonly reported stigma and discrimination in relation to their age (33%), sex (33%), race (25%) and religion or belief (25%), with each of these levels being higher than recorded among the total sample.

Views on the requirement for special considerations

- 19.28.** Just under half (46%) agreed that they should receive additional consideration when accessing or participating in their cultural, faith, religious or spiritual practices and communities. Three in ten (31%) strongly agreed that this should be the case.

Other feedback about stigma and discrimination in cultural, faith, religious or spiritual communities

- 19.29.** Respondents were invited to share further details on any stigma and discrimination they experienced in relation to cultural, faith, religious or spiritual communities. A small number of responses were provided in this life area and most concerned the satisfaction of the respondents in relation to religious communities. Most comments mentioned feeling unsupported, but a few spoke about positive experiences.
- 19.30.** Of those who felt unsupported, they spoke about their mental health issues causing 'negative reactions'. These negative reactions were extreme in one case, according to the respondent, who was told they 'don't belong here' and 'should be killed and tortured'.

"My faith community demonises mental health issue."

"I was in a fundamentalist protestant church. Escape was the best option."

Positive experiences

- 19.31.** When presented with a statement about positive experiences when accessing or participating in cultural, faith, religious or spiritual practices and communities, over half (54%) agreed they have had positive experiences; the fourth highest level of agreement of all 14 life areas. Moreover, almost one quarter (23%) agreed strongly, the equal highest level of strong agreement alongside positive experiences with social media.
- 19.32.** In describing positive experiences, some mentioned changing religious affiliations to communities that were more tolerant. One respondent mentioned non-religious cultural organisations that have also provided a positive experience.

"Overall, I have very positive experiences in the LGBTQI community, though I expect to be unfairly treated. In my spiritual community I am well treated as it is an inclusive church where all are welcomed and affirmed."

- 19.33.** The virtual religious services offered during the COVID-19 pandemic had a positive effect on one respondent, as it allowed them to attend without 'becoming very awkward due to [their] mental health'.
- 19.34.** Finally, two respondents discussed their feelings about religious and spiritual communities, mentioning a respect for the 'belief and behavioural norms' of these groups, while reflecting on their own relationship to them.

"It cannot be just assumed that it is ok to take part in a faith activity whoever you are especially if your behaviour does not conform to that of the faith community concerned."

"Cultural events are about celebrating community and family life it is not about being friends with strangers. There is a time and space for practising faith and it is just not right for me just now."

Summary

- Overall, slightly more than one quarter of all survey respondents (97 or 28%) reported experiencing stigma and discrimination in this life area in the last 12 months – the lowest of all 14 life areas. It was, however, experienced frequently or very frequently by 8%.
- Cultural, faith, religious or spiritual practices and communities was the second least commonly selected life area, being selected by 13 respondents (4%) as one of the three in which the stigma and discrimination they experienced had the greatest impact.
- Over half (54%) agreed that because of their mental illness they have had positive experiences of cultural, faith, religious or spiritual practices and communities. Respondents most commonly reported stigma and discrimination in relation to their age (33%), sex (33%), race (25%) and religion or belief (25%)
- Just under half (46%) agreed that they should receive additional consideration when accessing or participating in their cultural, faith, religious or spiritual practices and communities.
- Given the small number of responses and the variation in subject of those responses, the only major theme to emerge from the open questions were statements about feeling unsupported by religious and spiritual communities. There were also a few comments about positive experiences and two responses that highlighted a sympathetic approach to religious guidance and teachings.

20. Sports, community groups and volunteering

“Joining a support group in which many people were struggling with psychological aftereffects of damaging experiences (whether these had been formally diagnosed as a specific kind of mental illness or not) made me feel less alone. Talking to other people with broadly similar past experiences and present struggles made it feel like I didn’t have to know how to explain everything and that they would understand what I was meaning even if I couldn’t fully articulate it. That has been really positive and I hope that it will gradually make it more possible to talk to people outside the support group as well. The facilitators’ committee of the support group has been a bit discouraging or re-alienating, but the support group has been positive.”

Overview

- 20.1.** This chapter explores respondent experiences of stigma and discrimination about their mental illnesses in accessing and participating in sports, community groups and volunteering.
- 20.2.** The question about this life area covered several activities. These included: local sporting teams and clubs; arts, crafts, music groups, book clubs, or other social/community groups; and volunteer (unpaid) work or committee positions.
- 20.3.** Just under half of all respondents (163 or 47%) reported experiencing stigma and discrimination in this area. However, only 10% reported experiencing it either frequently or very frequently, the second lowest frequency after cultural and faith practices.
- 20.4.** Sports, community groups and volunteering was the least selected life area in the survey. It was selected by 10 respondents (3%) as one of the three in which the stigma and discrimination they experienced had the greatest impact. Those who selected this life area were asked to state which types of experiences they had had in the last 12 months. Nine had volunteered, three participated in community and social groups and two in social teams or clubs.
- 20.5.** Those who selected this life area also reported experiencing stigma in this area more frequently – 50% frequently or very frequently compared to 10% of all respondents.
- 20.6.** This chapter presents the profile and experiences of respondents who selected sports, community groups and volunteering as one of the three life areas where they experience most stigma and discrimination. **Given the small sample size, findings in this chapter should be treated as indicative.**

Respondent profile

- 20.7.** The profile of the small number of respondents who selected the sports, community groups and volunteering life area in their top three is largely reflective of the overall respondent population.
- 20.8.** The profile of mental illnesses among those who selected this area is broadly comparable to the overall survey sample, with the most common being disorders associated with stress (40% vs. 34% in the total sample) and anxiety/fear-related disorder (40% vs. 40% in the total sample).

Perceived experiences of stigma and discrimination in sports, community groups and volunteering

20.9. Respondents' experiences of stigma and discrimination in relation to sports, community groups and volunteering are explored in this section. Figure 20.1 presents the extent to which respondents agreed or disagreed with statements about this topic.

Figure 20.1. Perceived experiences of stigma and discrimination in sports, community groups and volunteering: percentage agreement and disagreement (n=2-8)

Because of stigma about my mental illness(es)...

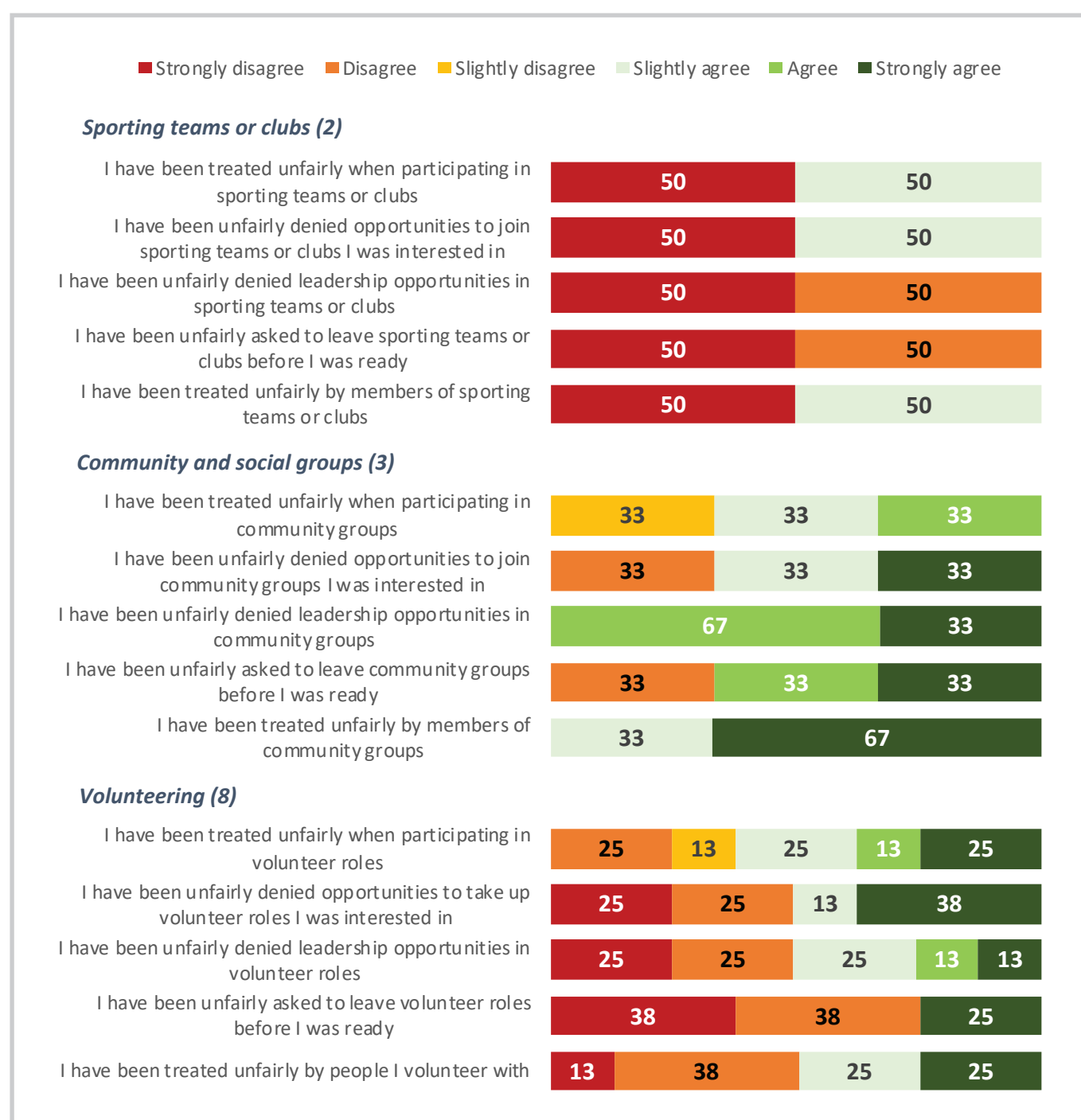
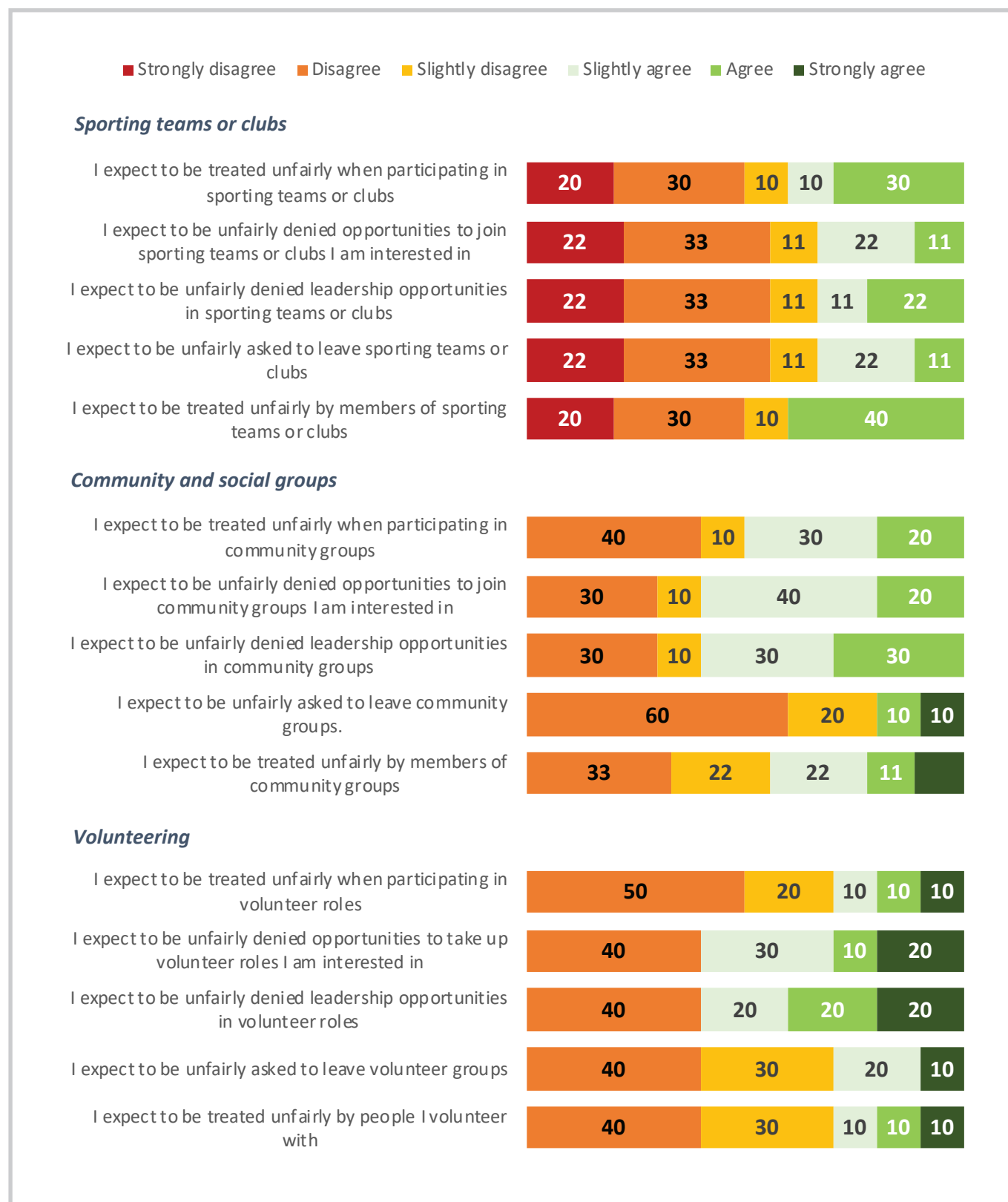


Figure 20.2. Anticipated experiences of stigma and discrimination in sports, community groups and volunteering: percentage agreement and disagreement (n=9-10)

Because of stigma about my mental illness(es)...



- 20.10.** The highest levels of agreement with perceived experiences of stigma and discrimination are recorded in relation to community groups. While the sample size is very small, all respondents who selected this area as one of their top three areas of impact felt they had been treated unfairly by members of community groups and had been denied leadership opportunities. Two thirds (67%) indicated they had been treated unfairly in groups, denied opportunities to join, or been asked to leave.
- 20.11.** Around half reported challenges in volunteering, notably 63% who agreed they had been treated unfairly when participating in volunteering, and one quarter felt they were asked to leave their volunteering role before they were ready.
- 20.12.** Only two respondents recorded their experience with sports groups, but they appeared to be more positive than for other aspects of this life area with one respondent agreeing slightly to three of the five statements.

Anticipated stigma and discrimination in sports, community groups and volunteering

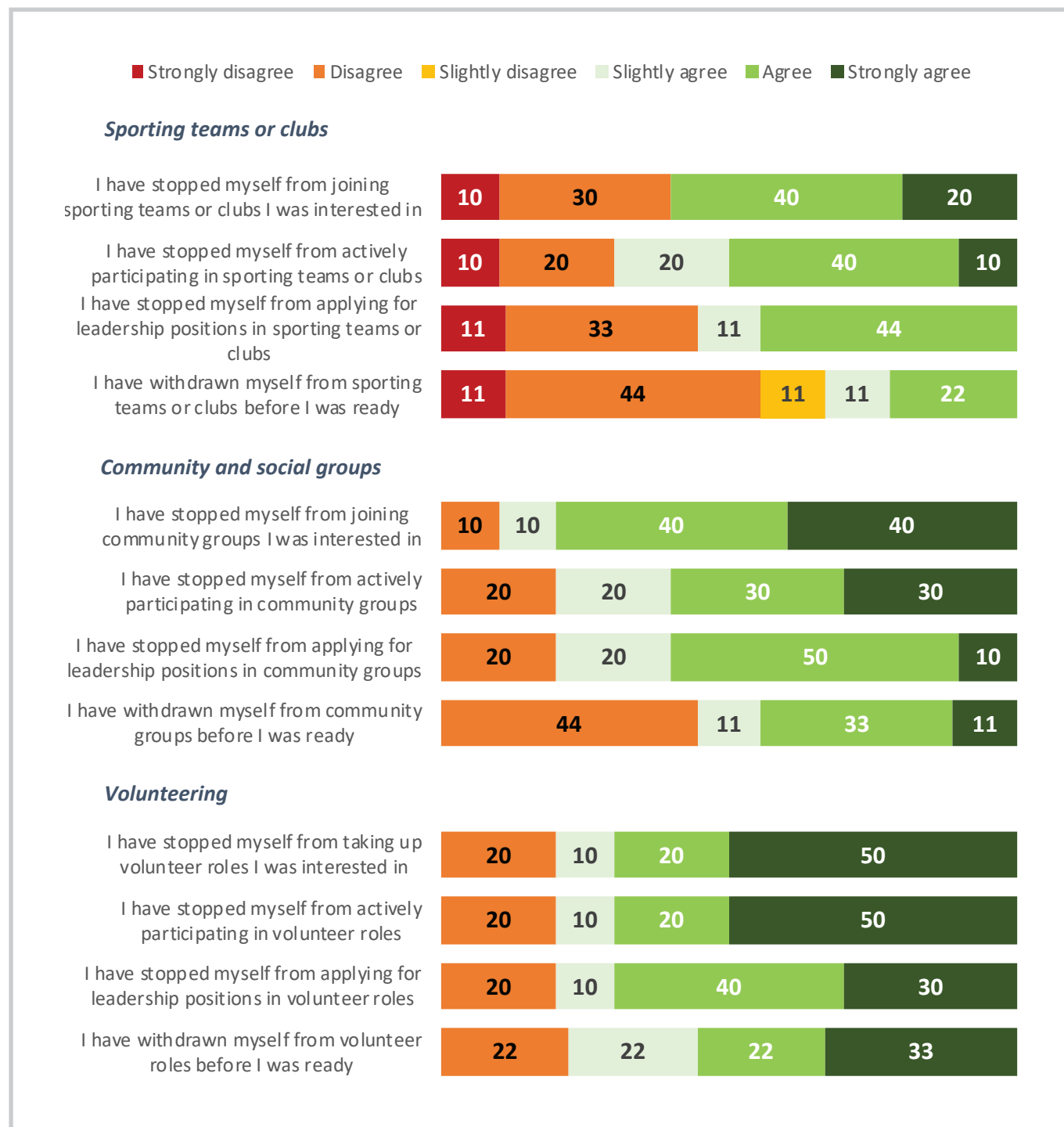
- 20.13.** This section explores anticipation of experiencing stigma and discrimination. Figure 20.2 presents the extent to which respondents agreed or disagreed with statements about aspects of anticipated stigma and discrimination around to sports, community groups and volunteering.
- 20.14.** Anticipated stigma and discrimination from sports groups appears to be relatively low. At most, two fifths (40%) feel they may be treated unfairly when participating or by other members of their club. No respondents agreed strongly with any of the statements related to sports clubs.
- 20.15.** Though there was also little strong agreement with statements relating to community groups, respondents were more likely to anticipate future challenges. Three fifths (60%) expect to be denied opportunities to join or opportunities to lead their groups, and half (50%) expect to be treated unfairly when participating. However, only 20% anticipate being asked to leave their group.
- 20.16.** Similarly, three fifths (60%) expect to be denied opportunities to take up or lead volunteering opportunities, and 30% agree that they expect to be treated unfairly, by others in their group, or asked to leave groups they are part of.

Withdrawal from opportunity in sports, community groups and volunteering

- 20.17.** This section explores the influence of stigma and discrimination on a respondent's withdrawal from decisions and choices about sports, community groups and volunteering. Figure 20.3 presents the extent to which respondents agreed or disagreed with statements about this.
- 20.18.** A majority of respondents in this life area reported they had withdrawn from opportunities related to community groups or volunteering. Most (90%) claimed they had stopped joining community groups of interest, and 80% had not taken up volunteer roles they were interested in. While levels of agreement were lower, over three quarters (78%) had left volunteer roles before they were ready and over half (56%) had removed themselves from community groups.
- 20.19.** Agreement with statements about sports groups was lower. Nevertheless, over half have avoided joining, participating or leading groups, with one third (33%) leaving their group before they felt ready.

Figure 20.3. Withdrawal from opportunities in sports, community groups and volunteering: percentage agreement and disagreement (n=9-10)

Because of stigma about my mental illness(es)...



Findings from supplementary qualitative research

- 20.20.** This section presents the findings from supplementary qualitative research which explored and gathered further examples and insights into experiences of stigma and discrimination in the sports, community groups and volunteering life area.
- 20.21.** Experiences of stigma and discrimination in the sports, community groups and volunteering life area were shared by nine interviewees. Across these experiences, five related to volunteering, one to sports clubs and two to community groups. Two interviewees spoke more broadly about their own self-stigma and how it affected their ability to participate in this life area.

Experiences of stigma and discrimination

- 20.22.** Two people described how their own self-stigma presented barriers to their participation in this life area, and both felt that anxiety also played a role in it.

“Again, it’s the sort of, well, why would they want to have me along and so, you know, all that sort of negative chatter.”

“I’ve been like, terrified of what they all thought of me and it’s just how twisted it gets in your head. But that’s, that’s the perception of you think people are going to judge you badly. And even if it’s not true, it begins to be true in your head.”

- 20.23.** One interviewee experienced stigma and discrimination in a volunteering role, when not being selected to take part in an event due to previous behaviour, even though they perceived themselves to be in a better place and that previous behaviour would not be repeated.

“There’s been times where events have come up. And I’ve been on before all these people and they’ve got picked and I’ve not. And I’m like why not? Because we know you’ll go off the handle. But then I would have went off the handle before but now I’m calmed down and I wouldn’t.”

- 20.24.** Another interviewee who carried out a number of different volunteer roles for an organisation was asked to apply for a job. Their application was unsuccessful, and it was explained to them that they did not hold the necessary qualifications. However, the person who made the suggestion knew that they did not have the qualification and the interviewee felt that discrimination about their mental illness played a role.

“But instead of just saying we can’t give you the job. We would like you to apply so that we can see what your skills are like. Okay. But yeah, I think just a wee bit of discrimination was there.”

- 20.25.** One interviewee who was part of a community group had disclosed information about their mental illness to other members. One member of the group made negative remarks and expressed stereotyped views about the particular mental illness.

“And I was like, okay, but we’re not all like that, you know, a little bit different. And she went, I hope you don’t feel offended, but I don’t trust you.”

- 20.26.** Another interviewee shared experiences of their volunteering activity, where they needed additional support to be able to carry out aspects of their role. They reported that while the organisation was willing to fund extra support that would overcome challenges presented by her physical disability, they refused to fund support that would help them overcome challenges associated with their mental illness.

“But can I have a companion with me? So that if I do get distressed, I can just talk to them for a minute, calm myself down, do all the things that you do to get yourself calm? And they said, no, we won’t fund that. We will fund somebody literally to push a wheelchair round but we won’t fund somebody to give you emotional support.”

- 20.27** An example shared by one interviewee provides insight to the risks of not disclosing details of mental illness. By not disclosing it, the organisation could not put in place additional measures to support the person and ensure that they were not being allocated more work than they were able to manage.

“I kept my issues to myself. It’s not something I revealed. But then that can have a negative effect. Maybe if you are able to say right well, I’ve got these issues. This doesn’t really work for me, this does. And actually the place would have been fine, because the place I volunteered was brilliant, really accommodating but you don’t want to appear demanding or show your kind of weakness and things like that.”

- 20.28.** One interviewee shared an experience with their book club. Sometimes characters in the book live with mental illness and during discussions the language used about those characters by other members of the group could be stigmatising.

“But I think sometimes it’s just surprising that people you assume be either empathetic, or at least, I guess educated enough to understand that people go through different things, you realise they’re really not in the language that is used to discuss mental health issues in the, in the way they talk about it.”

- 20.29.** Another spoke about the scars from her previous self-harming. They are visible when she participates in sports and also if she wears short sleeves while carrying out her volunteer role in a charity shop, and often led to others around her staring at her scars

“Actually it’s sports club wise, you know, when I wear shorts or wear t-shirt, my scars are out and people immediately sort of look at you and are like, Oh my God, what’s happened to her? And people don’t know how to react.”

Anticipation and withdrawal

- 20.30.** All interviewees expected to experience similar stigma and discrimination in this life area in the future; however the impact on their ongoing participation was mixed.

- 20.31.** At one end of the spectrum, the stigma and discrimination experienced did not influence participation in this life area. For example, the person that spoke about the stigma they experienced at their book club continued to participate but was very careful about disclosing any information about their mental illness. Likewise, the interviewee who described the stigma linked to their scars explained that they had become more comfortable with their scars and could more easily dismiss the negative attention they attract.

“Yeah, I mean, I’ve over the years become a lot more comfortable with my scars. And I think that I have got to a point where people stare well, that’s rude, you know, they shouldn’t stare. I know for other people that they feel the need to hide them all the time, because they’re worried about the judgement.”

- 20.32.** There were also those who continued their participation in the life area but had made changes. In these instances, they had either changed the group or organisation they were part of, or remained where they were but did not participate as fully as they would have

otherwise. The reason for their continued participation was that the benefits and enjoyment from participating in these activities outweighed the negative impact of the stigma and discrimination. For example, the interviewee who was not selected to volunteer at an event continued in their role at the same organisation but would not put themselves forward for things anymore through fear of rejection and how rejection makes them feel, but can still take pleasure from what they could continue to do.

“It doesn’t change what I do because I still do what I do. But I don’t ask because I hate rejection.”

- 20.33.** In terms of the most significant impact on participation, two interviewees reported that their experiences of stigma and discrimination in this life area resulted in them withdrawing from this life area. This included the interviewee who had been asked to apply for a job which they were not successful in securing and the interviewee who had been told that they were not trusted because of their mental illness by another member of their group.

Intersectional stigma and discrimination with sports, community groups and volunteering

- 20.34.** Intersectional experiences of stigma and discrimination within sports and community groups was broadly in line with the total sample. However, the relationship with physical disabilities was more prevalent – 60% reported this in relation to the sports and community groups compared to 21% overall.

“My difficulty is I have mobility and pain issues at the moment which preclude me from joining in physical activity groups.”

Views on the requirement for special considerations

- 20.35.** Half (50%) agreed that they should receive additional consideration when joining or participating in sporting teams or clubs, community groups or volunteer roles.

Other feedback about stigma and discrimination in sports, community groups and volunteering

- 20.36.** Some additional themes appeared in the open-text responses regarding stigma and discrimination in sports, community groups and volunteering. The two most common themes were:

- A sense of exclusion.
- Effects of the COVID-19 pandemic.

- 20.37.** Most respondents wrote about inclusivity. Some respondents mentioned the positive experiences of partaking in group activities and one mentioned the negative impacts of the COVID-19 pandemic on volunteering prospects.

A sense of exclusion

- 20.38.** A lack of inclusivity was a main theme in responses. Respondents highlighted specific moments where they felt excluded from group activities, particularly community groups and volunteering experiences, leaving them with a sense of isolation.

“There appear to be ‘acceptable’ disabilities that are accommodated within the community and volunteer sectors. Disabilities that fit with the social expectation of what disability looks like or behaves like. Outside of these parameters, you are subject to a great deal of stigma and discrimination because you don’t fit the profile. Not disabled enough but not quite normal enough to be given an opportunity or to be involved.”

“It felt discriminative when I realised that even this support group which deals with a lot of crappy circumstances feels that certain types of abuse shouldn’t be talked about and that even hearing about these experiences is damaging to other people. The support group has really helped me feel less alone, but the facilitators’ committee makes me feel that no matter where you go everyone would just prefer that no one speak about childhood sexual abuse and the mental health consequences of it.”

- 20.39.** Respondents mentioned other reasons for feeling excluded. One mentioned the expense of participating in sports activities, particularly gym memberships. Another referenced mobility and pain issues that stop them from joining in.

Effects of the COVID-19 pandemic

- 20.40.** Finally, one respondent noted that the COVID-19 pandemic abruptly stopped their volunteering experiences and thereby ending ‘the only social contact’ they had. This was made more difficult to the respondent due poor communication on behalf of the organisation, making them feel undervalued.

Positive experiences

- 20.41.** Respondents were presented with a statement about positive experiences with sports, community groups and volunteering. Two fifths (40%) agreed they have had positive experiences, meaning this ranked sixth out of the 14 life areas.

“Most if not all of the volunteering I’m involved in are understanding about my sensory and mental health conditions.”

This included an experience of accommodation and assistance in a moment of need.

“I decided to try a new gym class, and the instructors took the time to understand my needs when I approached them and took time in the class to check in with me and make adaptations to how they taught. On one occasion I had a health flare-up and they helped me by making a phone call and getting me to a suitable resting place.”

In contrast to those who felt excluded from groups and activities, some respondents mentioned the positive sense of inclusion gained from participation.

“When I was volunteering it was good, it was nice, I met nice women, we did gardening and stuff, it was really good and really positive.”

Summary

- Just under half of all survey respondents (163 or 47%) reported experiencing stigma and discrimination in this life area. However, only 10% reported experiencing it either frequently or very frequently, the second lowest level of frequency.
- Sports, community groups and volunteering was the least selected life area in the survey. It was selected by 10 respondents (3%) as one of the three in which the stigma and discrimination they experienced had the greatest impact.
- The highest levels of agreement with statements about stigma and discrimination are recorded in relation to community groups. All respondents felt they had been treated unfairly by other members of community groups and had been denied leadership opportunities. Two thirds (67%) indicated they had been treated unfairly in groups, denied opportunities to join, or been asked to leave. Respondents were more likely to anticipate future challenges with community groups and the vast majority had stopped joining or leading groups they were interested in.
- While around half reported challenges in volunteering, notably 63% who agreed they had been treated unfairly when participating, only one quarter felt they had been asked to leave their volunteering role before they were ready. Three fifths (60%) expect to be denied opportunities to take up or lead volunteering opportunities.
- Anticipated stigma and discrimination from sports groups appears to be relatively low. At most, two fifths (40%) feel they may be treated unfairly when participating or by other members of their club. While withdrawal from opportunities at sports clubs was lower, over half have avoided joining, participating or leading groups, with one third (33%) leaving their group before they felt ready.
- Two fifths (40%) of respondents for this life area agreed that they have had positive experiences due to their mental illness. Stigma and discrimination had also been experienced due to respondents' physical disabilities (60%)
- Among those who selected this life area, half (50%) agreed that they should receive additional consideration when joining or participating in sporting teams or clubs, community groups or volunteer roles.
- The open responses highlighted three main themes in relation to stigma and discrimination when joining or participating in sporting teams or clubs, community groups or volunteer roles. They were: a sense of exclusion, positive feelings of inclusion and effects of the COVID-19 pandemic.

21. The impact of experienced stigma and discrimination on anticipation and withdrawal: qualitative research findings

- 21.1.** This chapter presents findings from the supplementary qualitative research conducted to explore and enhance the quantitative research. It discusses the influence of experienced stigma and discrimination on future expectations of stigma and discrimination. It also discusses the impact of stigma and discrimination on future participation in life areas including withdrawal.

The important bit... is that (stigma) can affect people a lot more... from one incident than you might otherwise think".

Anticipating stigma in the same life area

- 21.2.** Experiences of stigma in a life area commonly led interviewees to anticipate future stigma in that life area. Interviewees shared examples of this in employment, including: fear of applying for a new job after facing discrimination in a previous role; witnessing colleagues being stigmatised and anticipating the same treatment on disclosing their mental illness; having job offers retracted once employers learned about their mental illness and expecting to encounter further rejection; envisaging repeatedly being overlooked for training and other opportunities; and feeling apprehensive in a new job after being bullied by a former manager.

"I think I was discriminated at one of my previous jobs... And I was fired from that job... And I was just full of fear to apply anywhere, because I just was scared... I won't be accepted, it's gonna be horrible again... Looking for a job was really difficult. I felt that I'm not worthy of anything, and no one is going to hire me."

- 21.3.** When discussing relationships with friends, family, and community some interviewees spoke about: anticipating rejection if others learned about their mental ill health; feeling anxious about being out in public, interacting with neighbours or making new friends in case they re-encountered negative judgement; hearing family talking about relatives living with mental illness and envisaging being talked about in a similar way, and watching out for 'warning signs' of stigmatising attitudes.

"So you kind of are already sort of looking for signs, like warning signs with people. So it's not necessarily that you've experienced that with that person, but you're kind of already sort of aware and sensing about people."

- 21.4.** Examples of anticipated stigma in healthcare included being wary of disclosing mental illness conditions due to expecting to be talked down to, or have their experiences minimised again; worrying that their GP would again attribute their physical health issues to anxiety; or being

guarded, cautious or pre-emptive in medical settings after receiving treatment that was not trauma-informed.

“Going for physical health issues to a hospital, I will take a sheet of paper with me that says, I live with trauma, please take a trauma informed approach. Because otherwise, the chances are that... somebody in the department will tread on my emotional toes and I’ll have a panic attack and have to leave... so I have to, in some ways, anticipate the potential in relation to attending clinics.”

- 21.5. Within mental health services some interviewees anticipated they would once again receive discriminatory, inappropriate or inadequate support; experience the same stigmatising treatment from mental health services when they moved to a new region; or would end up feeling worse after contacting their Community Psychiatric Nurse by once again having their distress minimised. A few said they had very low expectations of future contact with mental health services based on their past experiences of receiving reductive, dehumanising or violent treatment.

“I expect a very low level of service because I’ve been an inpatient in the past, and the conditions were appalling. And there was violence and stuff from the nurses and yeah, that kind of put me off a lot.”

- 21.6. A small number of interviewees also shared examples of anticipating stigma within community groups or support groups. For instance, one described worrying that others would have a negative view of them after a group member said they did not trust them because of their mental health diagnosis. Another explained they were scared of the police after receiving stigmatising treatment from them, while another said they ‘dreaded’ having to fill out another Personal Independence Payment form after their previous assessment which they felt was discriminatory.

“I mean, logically, I know that now that the support worker that’s actually taking that group... will probably nip (judgmental comments) it in the bud really quickly and make sure that everybody was okay...but it still affects you. It just makes you feel shameful for having an illness that you didn’t choose. And then you end up sitting there thinking everybody thinks that I’m horrible.”

- 21.7. There were mixed views on sources of stigma and discrimination. Some said they did not necessarily anticipate re-encountering stigma every time they engaged in a particular life area, but rather saw stigma as person, organisation, or situation-specific. One interviewee explained they tried to give others the ‘benefit of the doubt’ initially. Another shared that their recent positive experiences made them more hopeful about how they might be treated in the future.

“From my experience, generally, it was the workplace. But... also I wouldn’t say that (stigma) effects all workplaces.”

“I feel a lot more comfortable with the way that I’ve been treated more recently, I would say in the last 10 years, it’s really improved. There are still instances where I’ve not been happy with the way I’ve been treated, and that does tend to be a bit triggering... But no, I think in general, looking to the future, I’d be more thinking about it in a more positive way than I had done in the past”.

Anticipating stigma in different life areas

- 21.8.** Many interviewees suggested that anticipation of future stigma was not constrained to experiences within a specific life area but spilled out into other spheres of their lives. However this was less commonly anticipated than a recurrence of stigma in the same life area.

“Interviewer: “Does that experience impact how you expect to be treated in other areas of life, out with health services?”

Participant: “Aye, I’m negative about everything...because (of) experiences like this I’m pure negative about trying new things, trying to access things... I’m scared of everything...when I go outside is when I had panic attacks... That’s down to prior experiences trying to get help out there in a big wide world.”

- 21.9.** Fears of re-encountering stigma were pervasive for some interviewees, who shared that they had ‘lost faith in humans’, struggled to trust others, or felt unsafe, generally.

“I just don’t trust people... I don’t know where I’m safe. I just constantly don’t feel safe... And I don’t know how to get rid of this feeling... I guess, I worry that they’ll think I’m weird, or I’ll say something wrong... And sometimes I feel like I have to over justify myself if I if I don’t want to do something. And... I don’t know that people will be accepting of that... I want to give them a chance. But... it’s really difficult for me to... trust that everything will be okay. Because there’s been so many times in the past when it hasn’t.”

- 21.10.** Some participants felt others could ‘just tell’ that they lived with mental illness, which left them anticipating judgement or differential treatment, feeling on edge, and questioning themselves or their behaviour.

“No, I very much stay in the house. I struggle to go to Tesco. So I don’t go out and socialise – I would never be able to feel confident doing that because I would always feel like someone’s gonna guess,... and actually, you’re then like, well is that because I’m unwell. So then that can feed into you thinking that you’re unwell.”

- 21.11.** Concerns about re-encountering stigma, and the impact this had on participants’ lives varied depending on the source of stigma. Some felt that anticipated stigma from family or those they were close to had the most significant impact. Others felt there were stronger legacies of experiencing stigma from those in an official role, who they sought help from, relied on and expected to be able to trust, such as GPs, mental health workers, or Jobcentre staff.

“With for instance, a neighbour... because I don’t have to interact with them and I don’t care what they think. But you really do care when you’re going to see GP or seek some help from the mental health team or... local council because you’re asking for help... and you’re interacting with them in a different way.”

- 21.12.** Indirect or general forms of stigma, such as stigmatising language or TV depictions were felt by some to have less of a negative effect than ‘face-to-face’ or targeted stigma. While a small number felt that attributing stigma to a lack of understanding, rather than cruelty, helped them ‘rationalise it a wee bit more’, one felt lack of understanding could be worse.

“I suppose it’s more is around the people that have that one-to-one connection with you or that responsibility for helping you to navigate through things. Whereas if it was the media, I’m not overly bothered, because they can’t speak for everyone... that kind of personal relationship... that’s the one that impacts on me the most.”

- 21.13.** Experiences of stigma in one life area did not lead some interviewees to anticipate stigma in another area of their life. A small number attributed this confidence to their relatively privileged position in society, while another linked it to openness in their relationships.

"I do count myself quite lucky. In that I work full time... I'm paid quite well, I don't have some of the issues that people have around money or lack of employment and the opportunities that being employed brings. So I am quite lucky in that regard. So I don't think that I would then have all of the other issues across all the factors in my life. So when it comes to like housing or any of the others, like, I'm not going to face any of that discrimination."

"Yeah, I would say it was work... Friends I'm very open with and I find when you are maybe an empath or are more open to those kinds of emotional conversations, because you've experienced mental health issues, you sort of attract friends who are similar, or who are open to those discussions, too... So yeah, it doesn't extend to friends. It doesn't extend to family."

Reasons for anticipating future stigma

- 21.14.** Reasons for anticipated stigma included a lack of trust in others, pessimism that things would change or a sense that stigma was the 'norm' or chronic within language and society. A few felt others' lack of understanding of the lived experience of mental illness – or tokenistic attempts at this, underpinned their expectations.

"You're not Superman, you're not going to be able to change the whole language thing. I mean, if you look at the Scottish language words like 'crazy', 'mental'... I live with schizophrenia. And when you hear those kind of words... it starts a thinking process in your head. Was that person like talking about me specifically?... but the thing is it's all engrained into the Scottish language."

- 21.15.** Doubts about whether they would encounter future stigma was expressed by some interviewees. In these conversations they reflected that they perhaps overestimated the likelihood of this, or wondered if they were 'misjudging' others. Self-stigma, thinking styles linked to their mental health and anxiety were identified by some as possible contributors to concerns about future stigma.

"I mean, for me personally, it's part of my mental health- the depression, anxiety stuff is tied in with that. So that in some ways, you overreact and you're overreacting. But that's part of the illness, right? So I do things like I totally over analyse what people say and that might not have been meant that way... you start to feel stigmatised by people that don't mean it."

- 21.16.** However, despite being aware they may overestimate the risk of re-encountering stigma, the sense of risk and fear attached to doing so remained high for some; a few described feeling 'confused' or 'conflicted' as a result.

"It's just that you think... if that happens once, in your head, it's telling you, it's going to happen again... no matter where you go people it's like, I've got a lightbulb above my head saying, this person is not quite right. But in your heart, you know it probably wouldn't happen again. So it's like a conflict that causes you want to go and enjoy things with people and do things, but at the same time, you think if I go out, and I do that, they're gonna say, oh we don't want her involved she's got mental health issues."

Avoidance, withdrawal, and protective strategies

- 21.17.** Many, but not all, interviewees reported avoiding certain life areas, supports, services, relationships, activities, or opportunities, as a protective response to anticipating stigma. Common themes in discussions about protective strategies included self-isolation or limiting social interactions. Interviewees shared examples of breaking up from partners or remaining single, deleting people from Facebook, avoiding asking advice from neighbours, keeping social circles small and 'keeping myself to myself'.

"I'm very socially isolated, because I find it hard to trust people and don't think I can talk to people about issues I'm having or my state of mind. So basically, I live a very insular lifestyle... I don't socialise and I don't talk. I don't go on social media. Basically, I'm pretty shut down as a person."

- 21.18.** Within the employment sphere, some discussed leaving jobs, not applying for jobs, training, or promotions, and not realising their potential or 'exploring my dreams', due to concerns about re-encountering stigma. Others said they did not disclose their illness, or access supports, or their rights, at work for fear of stigma-related repercussions – which then had a negative impact on their wellbeing.

"Applying for jobs certainly has had a big impact on me. And I know that a lot of stuff I do apply for but it always pulls me back and again, it's that question about your mental health and the Equalities Act and are you on any medication, almost always makes me think, well, what's the point me doing this because when they see that I'm on medication or that I have ongoing mental health that kind of holds me back."

"It feels like the safest option is to just try to continue to appear to be doing well, and try to continue to not be visible as having any issues or problems or anything. And to do that I have to work in a way that... means that my anxiety levels do get set off, and... I have to push through periods of struggle as opposed to going, oh, I need to pause for a sec."

- 21.19.** On healthcare, some explained that they avoided accessing healthcare services, such as their GP or A&E, or spoke of the additional effort it took to overcome their fears of re-encountering stigma to ask for the care they need and are entitled to.

"I've had that to talk to my dad recently about, should I actually go to the doctor about X amount of things that is going on?... and my dad had to go yeah, because that's their job. But I'm sitting there thinking they've already, like, if you look at my medical records, are they gonna think I'm dramatic? And they're gonna think that I'm a hypochondriac, I'm trying to get attention....like battling yourself to actually come to a logical decision about something."

- 21.20.** One interviewee described the lasting impact their fear of re-encountering non-trauma informed sexual health services, and subsequent avoidance of these, had on their life choices.

"Because of the impact that some of the interactions in sexual health, I made the decision in my 20s, that I probably wouldn't have children, because of the interactions in GP practices with nurses, sexual health clinic... cause the physical idea of having children just terrified me beyond belief, and now, I just, I can't, I am on medication, that means that I just can't. So like that decision was made and that decision is going

to have to stick... And so I think there's part of me that knows... that stigma's, you know, kind of lifelong. And so that there are decisions that I've made that I kind of do regret a little bit."

- 21.21.** Avoidance of mental health services was also mentioned by some interviewees. One person, who chose to access private healthcare rather than go back to NHS mental health services, highlighted the inequalities linked to being able to afford a different type of care.
- 21.22.** Other, less frequent areas that interviewees spoke of avoiding, or limiting their participation in due to fear of re-encountering stigma included voting and political activity; support groups, shops, and social media.

"I'm not putting myself forward for political election, again, because... I got a lot of abuse, through social media, and through print media, because I'm just very open about being having physical and mental health issues... a couple of members of the public... were saying things like, how can you be a politician with such severe mental deficiencies?"

- 21.23.** A few reflected that withdrawal from participating in certain life areas also stemmed from their mental ill health, highlighting confidence and self-esteem issues, worries that they might not cope, or it "feel(ing) impossible to handle small things never mind going and participating in stuff".

Protective strategies

- 21.24.** Overt avoidance of life areas was not the only strategy that interviewees used to protect themselves from anticipated stigma. Some described more subtle approaches, such as staying 'hypervigilant' for signs of stigma and remaining guarded or cautious when interacting with others; oversharing about their experiences – to minimise the chance of being misunderstood; keeping quiet; 'people pleasing'; taking their dog as a 'security blanket' and preparing or planning in advance to try and control situations and increase their sense of safety. One person, who had been told they shouldn't have children due to their mental illness, talked of 'pushing' themselves 'hard' as a parent to protect against re-encountering such views and the self-stigma linked to them.

"Well, I live with trauma. And so I'm hyper vigilant anyway... if I experience prejudice, discrimination, exclusion, then my hyper vigilance means I'm there spotting it in advance."

- 21.25.** A couple of participants also talked about analysing their behaviours after interacting with people, or taking preventative steps to try and stop others viewing them negatively because of their mental health.

"I'm anxious just about everything. Like yesterday, I spoke over a friend and then I messaged her straight afterwards. And I hope you're okay. And I didn't annoy you. Because my, my reaction to that is partly to do with in brain trauma and in brain behaviour but it's also to do with, I panic about everything, because please don't view me as horrible person. It's not that I want everyone to like me. I don't mind if people don't like me, as long as it's not to do with my illness."

- 21.26.** Many interviewees spoke of deciding not to disclose to others that they lived with mental illness, or of being cautious or selective about who they would share with.

"I had a bit of a difficult time personally, last year... and I had really bad anxiety. And I had two weeks off work with anxiety. And I remember speaking to my boss, probably a year later... I said, I don't feel like you're treating me fairly, because you're not giving me the same opportunities as everyone else. And he said, yeah, but... you had really bad anxiety last year, and I don't want to give you any more pressure. And I thought so if that was me with two weeks anxiety that was very directly related to my (personal situation)... what's your opinion of bipolar going to be? So, I think it's justified to not say anything to them, I think it wouldn't have helped my career."

- 21.27.** Barriers to discussing their specific mental illness or related behaviours were described by some interviewees. One explained they do not talk about their substance-use due to mental health workers' lack of openness about this, while another shared they did not tell their parents about their suicide attempt as they felt this was something 'nobody would really want to discuss'. One person living with PTSD said they found it easier not to disclose this to avoid questions about what had happened to them. A couple of participants said they chose not to disclose their mania to others due to embarrassment about associated behaviours.

"I was involved with a walking group, locally, which was people that mild to moderate mental health issues... But generally, I wouldn't say anything, because I don't know whether I think I got to a stage where I was actually embarrassed by my mental health. And because of the actions I had taken, because of my mental health, it's you know... it wasn't nice... It wasn't nice for my family, it wasn't nice for... people close by to me."

- 21.28.** Some described "masking", 'sticking the face on', trying to 'appear normal', or focusing the discussion on others rather than themselves to avoid having to talk about their experiences. Reasons given for this included ensuring that others did not know the extent to which they were struggling; to avoid being 'a burden' to others; not wanting others to feel responsible for them; or because they felt they, or others, did not know how to talk about it, especially in person. A few people referenced the cultural context of 'putting an outward face on and getting stuff done' as informing their behaviour.

"I really feel like I'm a burden. And I don't want to be I don't want (my daughter) to remember me as oh gosh I had to go up and look after my mum today or... instead of spending time with the kids, I had to go look after my mother. So that's why I sort of try and keep myself in my wee box and do what I can for myself... I do get up in the morning and stick the smile on. I know I do that."

- 21.29.** The detrimental impact of not discussing their mental illness with others was reflected on by some interviewees. They spoke of not getting the support they needed, and this affecting their wellbeing; distance within their relationships; not being able to 'integrate' their mental illness into their day-to-day lives expending energy trying to 'keep the face on'; and struggling to explain their behaviours to others.

"And socially, I think it just makes me feel like, I am often trying to perform the idea of what a functional person looks like, because I can't, I don't know how to get into or how to broach the other stuff. And it's exhausting. And you feel like I'm keeping myself at a distance from other people. Like I'm creating barriers."

- 21.30.** A few people described struggling to be authentic within their relationships, due to not discussing their mental health. A couple of participants compared themselves to those who were more open and wished to have the confidence to be so, or felt 'cowardly' and 'not as good' in comparison.

"It is incredibly painful for me. Like, even at home, there's certain things that I don't discuss. And it's like, not being able to be completely myself is excruciating, because I shouldn't have to pop things away in boxes and push into the back of my head, or feel like everything I do is inappropriate with one group of friends, but with another group of friends, it's fine, and then you never know what you're supposed to be doing."

- 21.31.** However, some also talked about the benefits to their wellbeing or sense of self of being more open about their experiences with time, or of finding spaces where they felt safe to discuss these. Examples were also given by participants of sharing experiences in their day-to-day lives, at work, within healthcare training, on TV, and within the political arena to help normalise mental illness, increase understanding and challenge stigma. Some felt a positive cultural shift within Scotland in recent decades towards a more open culture around mental illness, had helped.

"But if I see they are someone I can be safe with, then I tend to practice this openness about my mental health, because I find it very healing."

"I've had some good feedback for being open and honest... And that does make me feel good. It makes me feel like I'm maybe empowering other people who aren't willing to speak out... it makes me feel like validated I suppose as, as a person... it's like, would you fix your brain?... I would fix the distress I have, but I don't think I'd want to change completely, you know, and it makes me more accepting, I suppose on myself a little bit."

"I had one (episode) when I was in my 20s, and I'm 47 now... and that was a lot harder because people wouldn't talk about it or the information was much less and it wasn't discussed and there wasn't even TV characters that had their issues. Simple stuff like that... I do appreciate that. Even though there may be stuff on social media, there's a lot more discussion around this. For me, I think it's a bit of a positive that people do discuss it."

22. Intersectional stigma and discrimination

- 22.1.** In this chapter we explore respondents' experiences of intersectional stigma and discrimination. Participants stated the extent to which they had experienced stigma and discrimination in relation to protected characteristics.

Race

- 22.2.** Stigma and discrimination around race was reported in all life areas except banking and insurance services. It was reported by the highest proportions of respondents in the areas of culture, faith, religion and spiritual practices and communities, social media, mass media, housing and sports, community groups and volunteering.
- 22.3.** Six respondents commented on their experiences of racial stigma and discrimination. Four of these did not provide any specific details but confirmed that they had experiences racial stigma and discrimination.

"I have also experienced mental health stigma and discrimination because of my nationality and citizenship and ethnicity and skin tone colour and speaking skillset."

"I am originally from the US. I do not consider this a race, yet the abuse indicates that other people certainly do and, also, the term xenophobia does not quite accurately reflect hatred targeted at a specific country. While the severity does not compare to that of other targets of racism, my experiences are not recognised at all – despite the blatant, open antipathy expressed toward Americans."

- 22.4.** One respondent commented on how mental illness is portrayed differently for different ethnicities by the media, and particularly when it related to crime. Another reported that they experienced stigma and discrimination due to being English.

"I'm an old English woman living in Scotland, it does sometimes feel that my accent counts against me in many regards due to the antipathy of the Scots towards the English. Everything works fine when communication is confined to writing, as soon as it comes to the spoken word things seem to go downhill."

Religion or belief

- 22.5.** Stigma and discrimination relating to respondents' religion or belief was reported across all but one life area (banking and insurance services). Most commonly it was reported to be experienced in the life areas of social media, culture, faith, religion or spiritual practices and communities, relationships, mass media and education.
- 22.6.** Only one respondent provided an open comment response. In this, they recounted having experienced antisemitism in their workplace.

Sex

21.7. Almost 50% of respondents in four life areas reported experiences of stigma and discrimination about their sex. These were: social media, mass media, healthcare (excluding mental health) and education. Stigma and discrimination were reported by the lowest number of respondents in the sports, community groups and volunteering life area.

22.8. Open text responses were left by 22 respondents, and several described combined stigma about sex and age. These tended to involve stereotypes of females being better able to manage pain, and being too young to be ill.

"Along with IBS, I am currently living with chronic back pain, including a slipped/bulging disc. I have been told I'm 'too young' to be in this amount of pain etc. on multiple occasions. As a female, I feel I am also expected to put up with pain more than males, and have sometimes struggled getting the pain relief medication needed."

"I was scolded to stop crying and reacting to the invasive, painful procedure or they wouldn't proceed – that was with a topical anaesthetic ready and available to the nurses, they just didn't offer it or think using it was worth their time."

22.9. A few recounted dismissiveness, particularly in healthcare (physical and mental health), and not being taken seriously.

"Being a young woman it is difficult to be taken seriously. Had to seek private healthcare to obtain accurate diagnoses and compassionate care."

"It sometimes feels like any women's health issues I've had aren't taken seriously. Debilitatingly bad period cramps get written off as 'not that bad'. Female doctors tend to be more understanding but male doctors are very hit or miss."

"I feel I've been treated as a 'hysterical woman' in the past and denied appropriate investigations until I have put up a fight."

22.10. Three respondents shared examples of stigma and discrimination about their sex in the workplace, including dismissal linked to misogyny.

"I don't think I have suffered discrimination in relation to getting my job, but in general conversation/work allocation I think there is discrimination based on gender and age."

"Was constructively dismissed from my job working in TV due to misogyny, threats, abusive language, and subtle bullying. The people in charge of those responsible privately apologised and admitted those people were problems, but unfortunately, nothing changed."

"My previous employer created working conditions that made it physically impossible for me to work whilst I was menstruating. When I brought it to their attention the issues were deflected back on to me and it was implied I was overreacting because I have BPD. I was the only female full-time centre attendant / lifeguard / swimming instructor."

22.11. In the remaining comments, participants shared experiences of stigma and discrimination including harassment, abusive language and misogynistic attitudes in the workplace, in public

spaces and in their personal relationships. One person highlighted decreasing visibility as women age, and another reported experiencing stigma and discrimination for women who don't conform with societal expectations.

"I often feel the stigma and discrimination of being a woman in her thirties who is single with no children. People ask questions of your life, and are judgemental when your life isn't what everyone expects."

Sexual orientation

22.12. In all life areas there were reports of stigma and discrimination linked to sexual orientation. This was seen most predominantly by those who identified social media as one of the life areas in which stigma and discrimination had the greatest impact on them. This was followed by mass media, public and recreational spaces, education and relationships.

22.13. Seven respondents provided further detail in open text responses. One confirmed they had experienced stigma and discrimination by mental health services but did not provide details, and another was not sure if they had experienced stigma and discrimination in their workplace because of their sexual orientation or whether it was because of something else.

"I haven't told anyone that I am bi, but they probably suspect it. The only person that I told about being trans was my old manager, and he told at least one other staff member. I don't know if he told anyone else, but my new manager probably knows. Because of all of this, I don't know for sure if I am experiencing stigma/discrimination based on my sexuality and/or sex/gender."

22.14. One person reported that mental health services made judgements about them based on their sexual orientation, with three respondents sharing experiences of stigma and discrimination from friends and/or family.

"I have also had it recorded in my notes that being LGBT is proof of 'unstable sense of self', as well as dressing androgynously."

"Since the death of my parents in 2013 and 2019, I have lost touch with most of my family. Although I came out as gay in 2015 my dad had already passed and mum had dementia till passing in 2019, so it was only known to my four siblings. Due to their strict religious beliefs I felt outcast by much of my own family."

"I have been told by some family that my sexual orientation is a 'phase' or because of my mental illness, and that I should be straight."

22.15. The final comment related to the portrayal of pansexual women in the media.

"There are basically no portrayals of pansexual women in mass media, unless they are used as a plot device to make a female character even more sexualised or to emphasise their mental illness (see? she can't even decide who she's attracted to, she's crazy in every way possible!) I can think of one male pansexual character in a relatively popular recent show – David in Schitt's Creek. But he only has one short sexual relationship with a woman and then is exclusively involved with men, or one man, for the rest of the show. The actor who plays the character is gay as well, so it's like they just reverted to type after getting their 'representation' in."

Gender reassignment

- 22.16.** Stigma and discrimination about gender reassignment was reported in all but two life areas, though the overall proportion of participants reporting this was among the lowest.
- 22.17.** The life areas where reports of stigma and discrimination about this characteristic was highest were public and recreational spaces, social media, education, housing and healthcare services (excluding mental health).
- 22.18.** Only two respondents provided examples of the stigma and discrimination they experienced due to gender reassignment, in the areas of mass media and social media.

“Social media for trans people right now is hellish and incredibly damaging to the mental health of a group who already disproportionately have mental illnesses or disabilities.”

“I hopefully don’t have to explain the muck that is the media portrayal of trans people in the UK right now, including here in Scotland.”

Physical disability

- 22.19.** Stigma and discrimination about physical disability was most commonly reported by respondents. In three life areas more than 50% of respondents reported experiences of stigma and discrimination about their physical disability. These were: sport, community clubs and volunteering, legal and justice services and housing.
- 22.20.** All life areas had at least 20% of respondents reporting experiences of stigma and discrimination about their physical disability with the exception of culture, faith, religious or spiritual practices and communities.
- 22.21.** Open text responses from 11 participants provide further insight into the experiences of stigma. Several alluded to being treated unfairly or differently due to a physical disability. Examples ranged from interactions with DWP, in the workplace/applying for work, applying for insurance and membership of community groups.

“I have also been unfairly discriminated against when seeking insurance due being HIV+.”

“When I don’t disclose my disability my application progresses, if I do I never progress.”

“Again, just to say that DWP don’t want to learn about disability and make their own decisions about what is wrong with a person.”

“Currently I cannot walk great distances because of poor recovery from a hip injury in May 2020. I do think that sometimes in one of my groups I am treated differently because of this as I cannot help with the physical stuff such as leafleting.”

- 22.22.** Two respondents explained how stigma and discrimination about their physical disability has excluded them from participation in, or access to support and services.

“Because I have a physical disability during lockdowns when my community support worker was taking patients for a walk, she explained she couldn’t see me at all or do anything with me ‘because I’m physically disabled’, therefore I was left without that support and it was then unfairly taken from me because the service is not person centred and is not accessible to all.”

"I discovered that for very rich people, private psychiatrists will see deaf people but NHS people will not."

- 22.23.** Examples of unfair treatment by members of the public, due to their physical disability were shared by two respondents, and another that suggested the stigma and discrimination was a result of a lack of understanding.

"My neighbour screamed at me and called me names when I was washing the windows because a little water dropped on her. I'm clumsy because I have ataxia. I apologised and she continued to scream at me."

"It doesn't help that due to the physical disability, my comprehension and retention of any conversation is compromised. No allowance is made for either the physical or mental difficulties, no attempt is made to understand."

"Co-morbid disabilities are rarely understood and stigma/discrimination appears to become a default through refusal to understand."

Age

- 22.24.** Age was another aspect of identity where experiences of stigma and discrimination were commonly identified. In five life areas, more than 40% of respondents reported experiences of stigma and discrimination about their age. These were: banking and insurance services, mass media, social media, mental healthcare and healthcare (excluding mental health).

- 22.25.** All life areas had over 20% of respondents reporting experiences of stigma and discrimination about age.

- 22.26.** Further insight into the experiences of age-related stigma and discrimination were provided by comments from 18 respondents. Several described how their age influenced their treatment when trying to access services and support, with younger people encountering perceptions that they will 'grow out of it' or are too young to have the extent of issues they describe, older people facing barriers to accessing support and services, and middle-aged people encountering expectations that they can cope, based on their age.

"I believe I am expected to manage better as I am in my thirties. Someone older or younger might receive more help."

"Older women with mental health issues, then get a second dose of stigma – you are older so it is dementia rather than a long term mental health issue. As an older woman it's almost impossible to access talking therapies."

"Along with IBS, I am currently living with chronic back pain, including a slipped/bulging disc. I have been told I'm 'too young' to be in this amount of pain etc. on multiple occasions."

"Being 18, going on 19, I am now an adult. But I still repeatedly get treated as if I'm a 'teenager that will grow out of it' this has made it very difficult to get the help I actually need."

"Being a woman of 30, I have been denied services based off of 'dealing with it this long'."

22.27. A few respondents provided examples of age-related stigma and discrimination in the workplace or when applying for vacancies.

"Have found access to employment difficult due to my age and when in employment not enough understanding of age-related issues."

"I believe any qualifications are immediately discounted because of my age especially."

"My employer kept me on for 10 years but when younger employees appeared it turned out my experience was not valued."

22.28. One respondent reported that mental illness and young people is misrepresented in the media, while another explained they are discriminated against for being older. Aligned to this, one respondent felt older people were aggressively marketed with adverts for anti-ageing products.

"I feel media representation of mental health among young people is wildly out of touch with reality and often framed in a context that is of political advantage to a given media outlet."

"One of these that's a surprise, thinking about it, is age. As an 'elder millennial', I wish I still didn't get discriminated against for my age, but it is pretty common."

Marriage or civil partnership

22.29. Respondents reported experiences of stigma and discrimination about marriage or civil partnerships in every life area apart from sports, community groups and volunteering, though the proportion in each life area was relatively low.

22.30. The highest proportion of stigma and discrimination linked to marriage or civil partnerships was found in mass media, banking and insurance services, culture, faith, religion or spiritual practices and communities, and legal and justice services.

22.31. Only three open text responses provided further details about the stigma and discrimination faced. One focused more on the stigma of divorce while another was related to difficulties in being a common law partner.

"I was what is called a 'common law' wife, on a state pension and supporting my partner both financially and with physical nursing (he had dementia). His pension went straight into his bank account, I was paying for everything. I believe that had I been his wife on paper, as well as in practice that I would have been treated differently, had COVID and my mental condition not prevented me from taking action sooner I might well have recovered monies I had spent on his behalf, including his debts and funeral costs."

"I put my answer for marriage as is, as I'm divorced and that is still quite stigmatised regardless of how emotionally damaging a relationship may have been."

22.32. A final comment about marriage focused less on stigma and more on their disempowerment, with authority for decisions on treatment being granted to their partner through marriage status.

“Just because you have been married 30+ years doesn’t mean your partner is supportive. While detained he had rights to decide aspects of my treatment. He appears concerned but really doesn’t care. Sometimes married doesn’t mean happy. Sometimes we are just stuck in a marriage that we can’t escape from. People presume they know what goes on behind closed doors, discharged home without any options being offered. Offer a choice for discharge, I’d have gone to respite/supported living etc”

Pregnancy or maternity

- 22.33.** Pregnancy or maternity received the lowest proportion of respondents reporting intersectional stigma and discrimination across all life areas. In 13 of the 14 life areas the proportion of respondents reporting experiences of stigma and discrimination about pregnancy or maternity was less than 10%; mass media was the only exception.
- 22.34.** No respondents provided open text responses to share their experiences about pregnancy or maternity stigma and discrimination.

Stigma and discrimination about other aspects of identity

- 22.35.** 32 respondents shared examples of stigma and discrimination they had experienced about other aspects of their identity. These spanned stigma and discrimination concerning:
- Economic status.
 - Size/physical appearance.
 - Lack of social connections.
 - Being care experienced.
 - Having a mental disability.
 - Being a parent.
 - Physical difficulties (not classed as physical disabilities).
 - Sexually transmitted infections.

Stigma and discrimination across multiple aspects of identity

- 22.36.** This chapter has discussed the experiences of stigma and discrimination related to each individual aspect of personal identity. However it was not uncommon for respondents to report instances where this stigma and discrimination was intertwined with, or in addition to, stigma and discrimination experienced about more than one of these aspects of identity and/or their mental illness.

23. Stigma and discrimination experienced by under-represented groups: qualitative research findings

- 23.1.** Qualitative research with groups that were under-represented among survey respondents was undertaken to understand if their experiences of stigma and discrimination aligned with the survey findings. The findings from this research are presented in the following sections
- 23.2.** Consistent with the survey findings, interviewees experienced stigma and discrimination across several life areas, to varying extents. While frequency levels were not rated or ranked for each life area, interviewees identified the life areas where they felt they experienced stigma and discrimination most frequently; these aligned with the survey findings. Relationships with family or friends was commonly cited as the most frequent experiences of stigma and discrimination, with other commonly cited life areas being employment, healthcare (mental and physical health), social media and mass media. Other life areas were also cited by a smaller number of participants (e.g. housing and homelessness services, education and training, sports clubs, community groups and volunteering).
- 23.3.** The most significant impact tended to mirror the areas of life where stigma and discrimination have the highest frequency. In a small number of instances, the ordering changed slightly, or a different life area was included.
- 23.4.** Future expectations were reported to be heightened by previous experiences of stigma and discrimination, though to different extents among interviewees. A range of factors contributed to this, and people were affected in different ways. Contributory factors included the sources, nature and impact of stigma and discrimination, and interviewees' vulnerabilities at the time they experienced them.
- 23.5.** These different factors also influenced the extent to which expectations of future stigma and discrimination were contained to the life area in which they were experienced, or permeated into other areas of their lives. Stigma and discrimination from friends and family, and during interactions with health care professionals were most commonly cited as increasing expectations of stigma and discrimination in other life areas.

"They are supposed to understand it most. Be the most educated, so if they say these things, and have those views, why wouldn't everyone else."

"If the people closest to you cannot treat you with kindness, what are you supposed to think?"

- 23.6.** The extent to which experiences of stigma and discrimination influenced interviewees' participation in life areas also varied. Common themes in terms of variations of withdrawal included:
- Refusing to let stigma and discrimination influence participation at all.
 - Delaying or putting off activity in a particular life area.

- Making changes to how, or with who, they participate in a life area.
- Completely withdrawing from participating in a life area.

"I naturally learned on my own how to ignore bullies. So I grew up with that mindset that no one can bully me."

"I would say it's my overall life. In almost every aspect of my life I would say. It affects almost all my choices in life. It makes me timid."

"So that's also kind of had a knock on effect about when I'm going to the doctor's and when I need to ask for help for other things. Like at the minute I need my pain meds increased and I really need that badly but I've put off phoning and try to make an appointment and just because I don't know what kind of reaction I'm gonna get."

- 23.7. While the findings from the qualitative research broadly reflect and align with the survey findings, discussions with interviewees also identified aspects specific to particular demographic group. We discuss this below.

Participants from Black, Asian and minority ethnic groups

- 23.8. A few interviewees from Black, Asian and minority ethnic communities reported challenges in terms of cultural views and community beliefs relating to how mental illness is perceived. Experiences differed even among those from the same cultures and communities were perceived as rooted in ignorance and a lack of awareness and education.

- 23.9. At one end of the spectrum, interviewees described community members who perceived people with mental illness as 'faking it', 'lazy', 'making it up' or 'weak' people.

"I'm black. So I feel like most, if you notice, I don't want to sound racist or something. But if you notice, only white people are more involved in mental health, and understand mental illnesses, other cultures feel like it's a sign of weakness."

"And if you know one thing about black people, we don't believe in mental illness. Like if you say you're mentally ill, they'll just write it off as you just trying to be lazy or trying to give excuses for your bad attitude."

- 23.10. At the other end of the spectrum, interviewees described extreme views, whereby those with mental illness were viewed as mad, dangerous and incapable.

"Once I was back home, and my cousins here heard about my mental illness, and they assumed that I was mad. Yeah, the stereotype they had for thinking I was something from like, I was crazy, something from the ward for mental illness."

- 23.11. Interviewees reported that these attitudes could feel isolating and make it difficult for those living with mental illness to seek support from people in their communities.

- 23.12. Another common theme was intersectional stigma and discrimination relating to ethnicity. As with stigma about mental illness, many interviewees reported experiences of this in different areas of their lives. Some perceive stigma and discrimination about race, rather than mental illness, to be most prevalent. A few interviewees suggested this was because of being a visible minority; you can see skin colour and hear accents, whereas the mental illness they live with is not apparent.

23.13. However, several interviewees perceived that racial stigma and discrimination have reduced over time. They attributed this to changes in law which has made racism a crime. Interviewees reflected that similar laws could also contribute to a reduction of stigma and discrimination for mental illness.

Participants aged over 65

23.14. Participants aged over 65 described experiences of stigma and discrimination in ways that suggest that frequency of experience is lower than it is for other groups. Interviewees reflected that as a person ages, they become more invisible in society.

"It's the way society see's older people, or don't see us. You feel hidden, more ignored."

23.15. Interviewees described changes to their participation in life areas as they have aged, and the significance of having more of a set routine. They also mentioned having small groups of trusted people around them and support to carry out day-to-day tasks. Further, the community groups, volunteering roles, and services they accessed were geared towards people with similar life experiences and provided safe, non-judgemental spaces. This was seen to reduce the potential exposure to stigma and discrimination.

"I come here most days, my friends are here, we've all got wee jobs to do and everyone is supportive of each other."

"I don't do as much as I used to. I've got my friends here, I'll go for my shopping at the start of the week. I've got my own wee routine and it works for me, keep myself to myself."

23.16. A few interviewees shared stories about growing up in a different era, with much less understanding and acceptance of mental illness. Interviewees described being told by their parents never to tell anyone about their mental illness because of how they would be treated. Interviewees also suggested that this was because of the stigma surrounding mental illness and the shame and embarrassment that was likely felt by family members during those times.

23.17. Interviewees explained this shame had guided them for a long time, and described doing everything they could to keep their mental illness hidden from others. Interviewees felt that times had changed, and levels of understanding and acceptance were increasing.

23.18. Intersectional stigma and discrimination linked to age was also raised by interviewees. This tended to relate to overheard comments by neighbours or members of the public, or changes to the services that can be accessed for mental health support.

"When the voices are there, and I do speak to them, I can hear them making fun of the loopy old guy."

"Aye, one of the personal things, you know, is being thrown off the cliff when I was 65. When you reach a certain age, you no longer qualify for mental health for psychiatric services."

24. What needs to change?

“Socially people could use more awareness and education about conditions. It shouldn’t be hidden. I shouldn’t be ashamed or afraid of being found out. The stigma and shame are equally as bad as the condition itself. I can’t really explain how much this has shaped and affected my life.”

24.1. The final survey question asked respondents what they thought most needed to change to improve their, and others’ experiences of living with mental health issues, and/or to reduce stigma and discrimination about mental health issues. In total, 267 people answered this question. An analysis of comments identified four overarching, inter-related themes, each with several sub-themes:

- Societal values and understanding.
- Socio-economic inclusion.
- Identity and representation.
- Services and support.

Societal values and understanding

24.2. The need for greater knowledge of, and understanding about, mental health issues in society was a recurring theme. Some respondents felt this was fundamental to achieving increased inclusion and acceptance within society. Across comments, the importance of being treated with kindness, empathy, and compassion by the public, family and friends, mental health/health care staff, public sector workers, higher education staff and religious organisations was highlighted.

“Mental ill health makes us vulnerable and instead of the normal human reaction of offering kindness triggered by that display of vulnerability, we blame, shame, dismiss and ignore. That’s a societal issue. Education is key, openness is key, acceptance and tolerance, is key. I’ve known so many mentally ill people, each one intelligent and sensitive and completely wasted by society because of dismissal. We could learn so much from them.”

“People seem to be scared by the idea of a mental illness which makes us scary and difficult. I am not, and I am not looking for special treatment. Just be kind.”

“If the people around me had been able to accept that mental health is an ‘ok’ thing to live with, nothing to be frightened of, and also understood that its ok to be sad or cry, then maybe I would have been able to get help a long time ago. I nearly took my own life last year, just as a way to escape from myself. A sad thought now. When all I needed was love and understanding.”

- 24.3.** While some respondents proposed mental health education as part of the school curriculum, others suggested improved student or workplace education, more open dialogue at home, or public campaigns. As one respondent explained: 'MH education in every level of society; throughout education at age-appropriate levels.'
- 24.4.** Increased education/awareness was also described by respondents as being central to:
- Enabling the realities of their day-to-day struggles to be seen and heard by others.
 - Increasing awareness of the 'variety and fluctuations in mental health'.
 - Dispelling misinformation about mental health distress ("someone can be suffering but be high achieving as well").
 - "Blowing away myths" about recovery – for example that people never recover from mental illness. Or, conversely, promoting the understanding that, for some, mental illness may be a life-long experience rather than one that is easily and quickly recovered from.
 - Encouraging people to seek support.
 - Helping others to know how to offer support.

"I've experienced cruel comments that 'I just need to count my blessings' or 'try herbal remedies'.... To change these experiences would mean society really opens their eyes to how others can be affected in their lives, we need more compassion, no one is immune."

"My sister says I'm milking it, my mum says pull yourself together! They don't understand as they have no knowledge – and this is down to them having no information as there is none available."

"Education that many mental illnesses can be temporary. Support and appropriate treatment can help."

- 24.5.** Several respondents identified a need for education about complex mental health diagnoses. They advocated for: increased awareness about how complex mental health may present or be experienced to encourage people to seek help; and more awareness of how complex mental health might differ from more common mental health problems.

"A lot seems to have been done in the field of raising awareness about general mental wellbeing, and the sorts of mental health issues that may be more temporary in nature, or which are a bit milder, with a lot less emphasis on the really challenging end of the mental illness spectrum, which in some ways may even create more stigma for those illnesses perceived by the public to be more complex. There's been lots of talk over recent years about Depression (mild to moderate really, not the severe end of things), Anxiety, Bipolar, even Obsessive Compulsive Disorder (although people still seem to have completely the wrong idea about what it is), but I don't think we should be afraid to talk directly about illnesses like Schizophrenia, Borderline Personality Disorder, Dissociative Identity Disorder, Psychosis."

- 24.6.** A need for greater awareness of the determinants and maintaining factors of mental health distress, including trauma, abuse, genetic/physiological factors and systemic inequalities, including poverty, racism, homophobia, transphobia and misogyny was highlighted by a number of respondents. Some argued this was important to reduce the blame directed towards people with living with mental illness.

“Understand the causes of mental illness better and move away from many dominant narratives of depression and anxiety based on personal lifestyle choices and ‘wellness’. These are obviously important, but people must also understand the political and economic dimensions of it – and also adverse child experiences and chemical imbalances in the brain.”

Socio-economic inclusion

“There needs to be a change in government legislation which incentivises the hiring of people with mental illness. As it stands with competition in industry there is no real reason an employer would take a risk and hire someone with mental illness rather than looking at ‘the next C.V’. Not having a job is the key factor in most/ any mental illness from depression to bipolar in our poor public perception. We are perceived as incapable but never given the chance to change that.”

24.7. Increased socio-economic inclusion involves compassionate treatment of people living with severe and enduring mental health problems. Many respondents focused on the need to reduce social inequality and address exclusion in employment, education, and relationships.

24.8. Some reflected that social policy and systemic change was needed to reduce discrimination, improve legal rights and representation, increase access to resources and shift social values and expectations. These comments included general observations, for example ‘political reform’, and specific suggestions. Examples included: a four-day working week to promote a healthier work/life balance; a reversal of Brexit policy ‘to rebuild the workforce on a foundation that values diversity in every form’ and an official regulator to handle discrimination complaints.

“The (UK) government must stop denigrating unemployed, disabled, poor, vulnerable, benefits-claiming people. We are labelled as second-class citizens and treated as such. It’s not our fault and we don’t choose to be like this. Government values and policies are discriminatory, divisive, and oppressive.”

“Disabled people are limited by financial systems that cause them to have limited freedoms or choice. This needs to change. We need to start planning our public spaces based on the social model of disability...our infrastructure and built-spaces still predominantly base their design on the ‘able’ mind and body.”

24.9. Changes to aspects of the capitalist model including a work-orientated, profit driven, individualistic, and competitive value-system were advocated by some respondents.

“The society in which we live is far too individualistic and the role of society and the underlying stresses (poverty, job insecurity, lack of opportunities, etc.) have a much bigger impact on mental illness than is currently accepted.”

“Society (and politicians) needs to realise that mental health sufferers may need additional help – for some this may mean additional income, as many of us don’t thrive in today’s target driven workplaces.”

24.10. A few respondents emphasised leading from the top, with both government officials and policy modelling how to treat people with severe and enduring mental problems.

“Society as a whole needs to...move blame from the individual and look at it from a cultural-social perspective with each individual recognising...the impact we all have on one another as a collective. That starts at the top (government policy), with compassion being shown and support given to those who need it, schemes and education provided to build a more inclusive society where lack of stigma and discrimination is rewarded.”

- 24.11.** Greater inclusion within employment and a removal of barriers to gaining and maintaining employment for people with lived experience of mental illness and their carers was another theme in responses. Improved employment opportunities with properly implemented and more transparent policies, procedures, rights and supports, including guaranteed interviews were called for.

“Companies and further education establishments need to have real working policies that are adhered to by all staff. I feel I am merely a statistic to prove they follow good practice. They need to be inclusive too and not treat those with mental health issues as useless or stupid.”

- 24.12.** To enable those with lived experience to thrive at work, some conveyed the need for a workplace ethos supportive of reasonable adjustments, such as part-time and flexible working, working from home, more regular breaks, and mental health leave. A few respondents also called for employers to ensure adjustments were accessible, offered and easily implemented.

“There also needs to be initial meetings with new employees about adjustments or mental health details the manager needs to know; not for negative reasons but instead to be more accommodating, understanding and flexible for employees – maybe they need a break more often for anxiety reasons, maybe they need days workings more spread out instead of a block of days back-to-back etc.”

- 24.13.** Some respondents identified a need for better workplace cultures. Examples included tackling any bullying, judgement, or stigmatising attitudes that exclude them, impair their ability to work, or exacerbate their distress. Others felt this would enable them to be more open about their mental health and access appropriate supports. The theme of increased understanding and education, was also evident in some comments on workplace culture. Understanding was described as being important to enable employers to better appreciate mental health experiences (and their fluctuations), and to know how to support their staff or implement equality law.

“Employers to treat mental health like physical health (my PTSD was triggered by overwork), employers addressing abuse, bullying and harassment.”

“If we want to talk, for goodness sake let us talk. If I want to share details about my mental illness with the team of 25 people I work with, that’s my decision, and I’m ok with making it public as long as you don’t act like I’ve revealed I have syphilis or leprosy. That’s not bravery, it’s practicality – you can’t watch out for it if you don’t know it’s there.”

- 24.14.** The importance of opportunities for social connection, and/or greater inclusion within relationships and communities for those with lived experience of mental health difficulties, was raised in some comments. Experiences of isolation, relationship break down, negative or abusive treatment, or disconnection from others were described. To counter these, improved mental health education, understanding, consideration and compassion were called for, as well as improved support for those isolated in the community.

“More provision of services specifically for adults with Asperger’s Syndrome living independently and isolated in the community.”

“If for example you cancel a night out because you are suffering, a lot of friends may stop asking you. They don’t ask if you’d like to have a coffee daytime or a phone chat for example. When you withdraw due to illnesses, it shouldn’t then mean that your value as a friend or person decreases.”

- 24.15.** Greater inclusion within higher education for people living with mental illness was advocated by a small number of respondents. They called for more lived experience involvement in teaching; better inclusion and diversity; less stigmatising attitudes among higher education staff and ‘more education opportunities including remote attendance.’

Other suggestions included education about mental health being a standard part of college courses, more up-to-date medical training at universities; and increased support and adjustments to accommodate the needs of people with complex mental illnesses.

Identity and representations

- 24.16.** Central to social inclusion was a desire, articulated by numerous respondents, to erase negative representations of people living with mental illness, particularly personality disorder diagnoses. Many urged an end to the dehumanised and stereotyped identities they felt ascribed to them, including that they are: villainous, stupid, incapable, abusive, lazy, weak, a burden, or faking it.

“I have never felt so stigmatised as I do with the diagnosis of EUPD. This diagnosis is about mad and dangerous people.”

“People with illnesses should be humanised rather than simply being seen as the illness alone.”

- 24.17.** A few respondents felt that the positioning of severe and enduring mental health issues as less socially acceptable than other forms of mental health struggles was problematic.

“There seems to be one type of mental health for professional people like nurses, social workers and policemen who are fit and healthy and can run marathons and eat broccoli. They get to do mindfulness and use online Apps. The rest of us are medicated and policed like criminals.”

“There is an atrocious stigma attached to alcohol and other drug harms. So-called anti-stigma organisations add to this by excluding it entirely as a serious mental disorder, as if its ‘unrespectable’, dirty, a case of immorality perhaps.”

“It might be more socially acceptable to say you’re feeling depressed, but it is not more socially acceptable to say you have bipolar disorder.”

- 24.18.** The use of less stigmatising and abusive, or more thoughtful and inclusive language was advocated for by a few respondents.

“Having a mental illness doesn’t mean you’re ‘psycho’ ‘crazy’ or any other derogatory terms towards mental health.”

"I would say that we still live in an era where it is OK and common to talk about mental health issues as a laugh and a joke like people talked about people of colour using the N word years ago. I still hear 'I've been manic' every day from others."

"People need to stop defining autism as a disorder (as it was in this survey). Autism is a developmental difference and, in most cases, the disorders it leads to are a direct result of discrimination and lack of understanding."

- 24.19.** Some highlighted the need for support to address the shame and self-stigmatisation that can occur when negative identities are ascribed to you.

"The survey doesn't seem to fully acknowledge self-stigmatisation which can be severe and enduring. This can occur even when 'rationally' being fully aware of the many sociocultural factors which contribute to stigma."

"(What) isn't mentioned is the impact of how I think about myself – self stigma – and how it impacts my life and the challenges getting any support with that."

- 24.20.** Greater openness about mental health was discussed by some as key to promoting more positive representations of mental illness, and to enable people to feel 'less alone'. Some requested contexts that allowed them to feel safer to share their complex mental health experiences. A few advocated for the normalisation or celebration of mental illnesses, to encourage recognition of mental illness as normal and/or an important part of human experience.

"I can present as being really well, and that means I experience hearing conversations about things I struggle with, without the others knowing that I do. This is the biggest reason I am not more honest about my experiences. It isn't safe."

"This is one of the reasons I speak openly in real life and on many other platforms about my struggles with my mental illness – to humanise those of us struggling but to also educate. There are not enough people talking about these things in a way that is productive."

"Mental illness is not caused by the individual, they are not to blame, it can happen to anyone. It doesn't discriminate on age, race, religion, economic status or job."

"Celebrating neurodiversity needs to be a priority from primary school on through adulthood so that we can see our superpowers early on."

- 24.21.** Sharing lived experience in day-to-day life and professional settings and roles, including academia, mental healthcare, healthcare, media, training, education, the music industry, and leadership was urged by some.

"We need to see more academics with lived experience, writing research and papers in language and formats that is accessible to people with lived experience and not just other academics. People at the top of the Psychiatry, Psychology and research fields need to start basing their work on lived experience and not theory from 100 years ago."

"I would like to see more people suffering from these conditions to be the ones voicing these complaints and leading bodies that support projects and campaigns designed to enact change."

"The NHS needs to employ more people with lived experience, allow them peer supervision, parity of pay and freedom to use their lived experience in their professional role."

- 24.22.** The media was discussed as both problem and solution to better representation of those with lived experience of complex mental health conditions. While some made broad comments about the role of the media, others specifically mentioned social media, print, television, adverts, and film. Numerous respondents called for less stigmatised, more accurate or more celebratory representations of mental illness experiences by media platforms and outlets.

"I would really like to see media and cultural recognition of chronic or recurring mental illnesses as normalised – they're aspects of my life. Pretty big ones, disabling ones, but they don't make up it entirely. I would like to see mental illness as background information about characters or about real people, not their only story."

"For each news article about a person with mental illness who commits a crime, there should be proportionate coverage of the day-to-day realities of living with a S&E mental illness. If one in 100 people commit a crime, there needs to be 99 stories of people being denied benefits, assaulted by nursing staff, coping with side-effects from meds and rarely leaving their homes."

"Factual representation of mental illness in mass media and social media. Cessation in romanticisation of mental illness. Most representations of OCD show only contamination OCD, resulting in many people thinking OCD is washing your hands over and over....It took me years to figure out what was going on because I thought 'I can't have OCD, my room's a mess.'"

- 24.23.** Within media representations of mental health, greater inclusion of experiences of severe and enduring mental health issues, as distinct from milder mental health difficulties or forms of distress, were called for by a few respondents.

"Campaigns from See Me and SAMH (are) making a difference, at least around the idea that people have mental health problems (and that we all do) and that people can be kind in responding to them... But... there is a lack of representation of people who, for instance, hear voices in the media. A lack of representation of them as otherwise normal people. And a lack of representation of what difficulties we face."

"More is required to be done regarding social media and the stigma which it portrays to younger people. People with minor mental health issues or perceived mental health issues appear to have more of a voice than people with severe and enduring mental health problems."

- 24.24.** Celebrities or role models were identified by some as being helpful to promote more honest and constructive representations, while others advocated for improved mental health campaigns. A few called for better online safety and moderation to clamp down on inaccurate and abusive content/activity.

"Change in society and societal values needs to be led by the opinion makers by the 'models' whom 'everyone' looks up to and this needs to be a very visible and GENUINE presentation... there also needs to be a positive representation of people who are different and the way they make up and contribute to the wonderful diversity of human culture/life."

“Public campaign attention on mental illness is actually doing more harm than good. Focus should just be on the overall message of All Differences are not only good but essential for the with entire human species.”

“Social media needs better policing. Too many people using these platforms do so as a way to bully and abuse people. As someone who has no friends and can’t even talk to neighbour it is the only way I can connect with people other than who lives with me. It makes it more difficult to interact online.”

Services and supports

24.25. Improved public and third sector services were identified as another important step towards the increased social inclusion of people with lived experience of mental illness. While NHS and mental healthcare supports were most repeatedly mentioned, physical healthcare, crisis support lines, welfare supports, Jobcentres, housing supports, policing and legal aid services were also discussed.

24.26. Numerous respondents highlighted the need for more accessible services and the removal of barriers to accessing and seeking support. These included: waiting lists; age-related cut-offs; service gatekeeping; COVID-19 restrictions; costs of private therapy; communication issues; stigma around accessing therapy and, as one respondent explains ‘find(ing) it hard to ask for help when we really need support’.

“People living with long-term mental health issues need to access... the right support to live a decent life (e.g. benefits, housing and healthcare) (and) suffer significantly from a lack of consideration toward those who find communication difficult....While it may seem insignificant, the simple addition of being able to book appointments or communicate with GPs/Job centre advisors, etc. via email or some other online system means the world to me and reduces a massive barrier from my access to the help I need.”

24.27. Various other suggestions were made for how to improve access to mental health support including same day appointments, self-referral to services, ‘a crisis hotline for when things get bad’, ‘easy access to understanding mental health support for autistic people’, increased provision of counselling and psychology and ‘setting aside a few flats separate for people with mental illness for emergencies’. The need for more timely mental health support with reduced waiting times, increased crisis supports and earlier intervention, as well as more preventative/longer term support and planning was repeatedly highlighted.

“I have had moments of thinking ‘How bad do I need to be before they will support/treat me?’ Occasionally, I have had thoughts about going off missing or taking an overdose etc because it can sometimes genuinely feel like they require you to do something that drastic before adequately supporting you.”

“Services to not give up on people who have been ill a long time, or when people seem to be coping better, not assuming that they are completely well and cured and are no longer needing help.”

24.28. Numerous ideas for improved or alternative treatment/support approaches were also offered. These included: greater variety in therapy approaches offered to reflect ‘the diversity in the needs of all the patients accessing mental health care’; more peer support; an inpatient service for young adults to meet their unique needs; increased involvement of those with

lived experience of complex mental health issues in service delivery (including creative arts projects) and better support for carers.

"I do think there needs to be more services to help support friends and family of those who are struggling with mental illness as my mum has found it incredibly hard and distressing to see me deteriorate and no one has really helped her to come to terms with it or to help her to cope with my problems."

"Somewhere you can go, for a cup of tea, no agenda, no questions asked, just come along and talk to other people struggling with mental health."

- 24.29.** Some respondents focused on the limitations of current NHS systems and treatment approaches, particularly medication but also including medicalised/diagnostic frameworks, therapy, cognitive behavioural therapy, and group therapy. Acknowledgement of these limitations was described as important to ensure such treatments are not overly relied upon, or that service users are not left holding the blame if these are ineffective.

"I think all health services need to think more about what their core purpose is. I get that resources are incredibly overstretched and that staff are really struggling. But treating people as units to be fitted into the system and blaming them when they don't/can't is not healthcare. The overall message I have got in the past few years is 'just bugger off and stop annoying us!'."

"Instead of being aware... that it lacks the tools to tackle mental health problems beyond medication, which does not cure any mental illness, psychiatry acts as if they do have solutions and it is up to the patient to enact them."

"I completely disagree with the whole gamut of personality disorders, most especially with that classification. How humiliating and degrading, 'personality disorder'.... Doesn't it feel wrong that they bothered to include all of those nasty subcategories in the DSM-IV and not C-PTSD? ...they (doctors) refer to it (DSM-IV) constantly and it clearly prioritises being able to categorise negative behaviours rather than acknowledging the trauma at the heart of almost every single mental healthcare diagnosis, which is the first step to actually addressing root causes and improving quality of life."

- 24.30.** Greater parity in allocation of resources, and access to support, for both physical and mental health was suggested in some comments. There were calls for better links between physical and mental health services, removing treatment distinctions between types of health issues, such as alcohol or substance use and mental illness, or for taking mental health problems as seriously as physical health problems. Some also highlighted the need to ensure equality of access to physical health treatment for those living with mental illness.

"Having a better link between mental health services and physical health services in that both problems can be interlinked not separate issues."

"The majority of disability benefits (and even insurance) is written almost entirely with physical disability in mind. I barely received any points toward the mental health part of (Personal Independence Payments) despite being so mentally unwell that my friend was practically acting as my carer lest I not feed myself or ever go outside.... Benefits like this especially need to realise that mental health problems can be just as debilitating as physical ones."

“GP(s) don’t take you seriously. They blame mental health illness (for) every pain and other illness in my body and won’t give you any treatment at all. That is another reason why people with mental health died earlier than others.”

- 24.31.** A need for greater awareness of and understanding about mental health issues, was echoed in comments about improved services and supports. There were calls to increase trauma-informed care by offering reasonable adjustments or longer appointments for those with trauma experiences, remove barriers to seeking help, improve communication, promote awareness of disability rights, and increase accuracy of mental health diagnosis.

“Services... greatly let down those of us from trauma backgrounds... Over the years I’ve had several professionals, and while they’ve all undoubtedly helped me, I find it retraumatising because I feel like I have to start from scratch again. The lack of consistency in... who you see and for how long is a huge problem, especially if you’re from a background where you’ve never had much.”

“Anyone working in the NHS or DWP should have some basic knowledge and understanding of mental illness and extreme anxiety... and (of) how daunting it can be – almost to the point of not calling to speak to a Dr in case you’re interrogated beforehand and having to tell a complete stranger (receptionist) why you need to speak to your GP. Or when just the thought of applying for or having to constantly renew your application to keep your benefits can be enough to stop you from doing so.”

“Much more needs to be done to understand Neurodivergent disorders. So many of us has spent a lifetime suffering, on meds we should never have been on because Psychiatrists don’t know how to spot and diagnose adult ADHD and Autism or make the link between undiagnosed Dyslexia and long-term anxiety and depression.”

- 24.32.** Respondents highlighted the need for culture change, to erase stigmatising attitudes, and promote more empathic and validating treatment of those living with enduring mental health problems. Specific to services and supports was the call for a range of staff, but especially mental health staff, to disempower less, work more collaboratively, stop minimising distress, communicate more respectfully, and offer more individualised and person-centred care. A couple of respondents also called for less ‘heavy handed’ treatment by police or during physical restraint in hospital.

“Mental health services are actually the worst for stripping autonomy from people and dehumanising patients – they don’t do it consciously, but the way services are designed and delivered, patients are not at the centre of their own care. This might not be so problematic for other areas of the NHS but for mental health care, a person’s very humanity is at the core of their treatment and must be a priority. They cannot be treated as an illness or a problem; they are a person first.”

“(There) should be a clear pathway on discharge from any mental health service and planning should be done collaboratively with the patient – too often we are left not knowing the plan and this can be very distressing.”

“More police intervention to assist in abuse from neighbours shouting ‘weirdo’ etc. The police tell people to just ignore it. They are dismissive – if the police can’t understand the problem, how are they are to police it?”

- 24.33.** Some respondents argued for more or better staff training in stigma, mental health, trauma, and neurodiversity awareness, or increased investment in the public and third sectors to achieve the above improvements to supports and services.

“Targeted training needs to be made available to frontline NHS staff (receptionists etc.)... the effects it can have on a person who builds up courage to actually come to an appointment to then be treated shabbily or dismissively or even cautiously!... Benefits staff also require further training – not just lip service and a pamphlet – about people suffering from all ranges of mental illness. One unkind word or look from someone in that kind of authority can make the difference of feeling helped or reaching for a knife to harm oneself.”

“Public services have been cut and cut again. They need to be funded... From the police who are left to pick up the pieces because there is no mental health service at 2am when I’m lonely and only have a sharp knife for company... haven’t seen a GP in about four years. Been waiting three months for ‘first available’ nurse appointment. Even things like street cleaning, why would I want to go out for a walk when I have to step over litter, dog mess, it’s just so dispiriting.”

- 24.34.** Finally, more significant organisational changes or service reforms were also suggested. Respondents mentioned more effective complaints procedures, greater accountability and/or a ‘zero tolerance approach’ to staff who discriminate; better partnership working and joined up services so that ‘you’re not running from place to place’, and an overhaul of the benefits assessment process, to ensure fair access and make applications less stressful and demeaning. A few suggested removing the need for being ‘constantly reviewed when you have a long-term diagnosis.’ Another proposed GP involvement in the assessment process to ensure more accurate assessment of need.

“The NHS has massive understaffing issues compounded by people being seconded and not backfilled... I think it will take reform to overcome this crisis... The NHS (also) needs to be able to learn to work in partnership to commission and deliver sustainable services that are out with its remit, capabilities or interest.”

“Employment and Support Allowance and Personal Independence Payment reviews are a disgrace. I have been consistently crushed by them and upheld on Tribunals. The current system causes far more damage (in health and monetary cost), than it solves, it’s a failed system. It doesn’t take an Economist like me to say, preventative is better than dealing with the fallout like me.”

25. Conclusions and recommendations

- 25.1.** This report presents a significant body of evidence and stark findings about the extent, impact and nature of stigma and discrimination experienced by people with lived experience of complex, severe and/or enduring mental illnesses. It is the first large scale piece of research undertaken on this issue in Scotland. The examples in this report are distressing and do not reflect well on some of the systems and services that support Scotland's most vulnerable people. Some messages may be challenging for readers to digest; for many stakeholders this evidence will validate their perceptions, and be a key reference point and call to action.
- 25.2.** The evidence, generated from 346 survey responses from people with lived experience of complex, severe and/or enduring mental illness is powerful. Their experiences and perspectives span a broad spectrum of mental illness, ages and locations. This is a rich, detailed and new source of data for campaigners, advocacy groups, policy makers, funders, service providers, people with lived experience and researchers, and the findings cannot be ignored.

Our conclusions are structured around the five key research questions, plus final thoughts on the research and its findings. The intention is not to repeat findings but to reflect across the data and distil the knowledge gained. We close the chapter with a series of strategic recommendations for See Me and Mental Health Foundation (Scotland) to consider in future efforts and activity to tackle stigma and discrimination.

Research question 1: In what areas of life do people living with severe, complex and/or enduring mental illness experience stigma and discrimination and to what extent?

- 25.3.** The research strongly suggests that stigma and discrimination are experienced in Scotland across every life area explored in the survey. Experiences of stigma and discrimination span personal, public and professional spheres such as relationships, employment and accessing vital services. While each person's story is unique, and the frequency and impact varies by individual, stigma and discrimination are found everywhere.
- 25.4.** This means the scope of the task to tackle mental health stigma and discrimination is significant. Each life area will require a unique strategy, with considerable thought about what to prioritise, how to resource efforts, which partners to involve, and identification of levers that will have the greatest impact. While each life area may need a unique strategy, careful consideration will also need to be given to the interlinked nature of stigma and discrimination, with identification of actions and activities that contribute across different areas.
- 25.5.** The five most commonly reported life areas where stigma and discrimination had the greatest impact on respondents' lives are: relationships, employment, mental healthcare services, healthcare services and social media. These are diverse spheres and three of these areas – employment, mental healthcare services, and healthcare services – are heavily regulated environments. It is of particular concern that mental healthcare settings, staffed by

professionals with the greatest levels of knowledge of and contact with people with mental illnesses, rank third highest for where stigma and discrimination has the greatest impact.

- 25.6.** Some of the examples of stigma and discrimination identified in this research are likely to have profound and enduring impacts for those who experienced them. They include rejection by family and intimate partners, forced early retirement, redundancy, being forced to take medication, feeling ignored in GP and mental health settings, and facing barriers to accessing welfare and housing support. The findings in this survey provide insight into how experiences of stigma and discrimination influence and impact on the extent to which people choose to, or feel able to embrace participation and opportunities in different areas of their lives.
- 25.7.** The links between frequency and impact of stigma and discrimination are inconsistent, and there is a need to consider where efforts to tackle these may have the greatest effect. For example, there are decisions that need to be taken about whether to prioritise reducing the incidences of stigma and discrimination, or to focus on addressing aspects of stigma and discrimination which are reported to have the greatest impact.
- 25.8.** In some cases, higher frequencies of stigma and discrimination align with the highest levels of impact; stigma and discrimination in relationships was reported as having the greatest frequency and also the highest proportion of respondents identifying it as the life area where stigma and discrimination has the biggest impact. Conversely, mental healthcare ranked third in terms of the proportion of respondents identifying stigma and discrimination in this area having the biggest impact, but did not feature in the five areas where stigma and discrimination were reported most frequently.

Research question 2: What is the nature of the stigma and discrimination people experience?

- 25.9.** The findings make a clear case for the continued need to tackle stigma and discrimination in Scotland; they also point to the scale of the challenge. Respondents' experiences provide insights into the multifaceted nature of stigma and discrimination, which can be insidious or blatant and take many forms. The examples span interactions with individuals, to perceptions of bias within systems and processes, and wider systemic issues.
- 25.10.** We could not detail every example in this report, but the nature of the stigma and discrimination described by respondents was often severe. The nature of stigma and discrimination that respondents reported experiencing, fits into the following themes:
- Unfair treatment.
 - Denial of access or opportunity.
 - Being made to end or exit participation.
 - Feeling pressured to into unwanted decisions or actions.
 - Being exposed to hurtful, offensive and/or upsetting attitudes, views and portrayals of people living with mental illness.
 - Having their thoughts, views, opinions dismissed or not taken seriously.
 - Being excluded from decision making.
 - Having needs ignored or wishes disregarded.
 - Receiving inappropriate or inadequate service, care and/or support.

25.11. Different life areas had aspects of stigma and discrimination that were more prominent than other life areas, but the themes listed above, to varying extents, cut across every life area explored in this survey.

Research question 3: Which groups experience the most mental health stigma and discrimination, and in what life areas?

- 25.12.** Knowledge of who experiences the most stigma and discrimination, and in which areas of life, is an important research question. This data is a key tool for identifying and engaging with affected communities and an important resource when designing and monitoring effective strategies to tackle stigma and discrimination. It is also worth considering whether it is more important to understand 'most' in terms of frequency, or in terms of impact.
- 25.13.** However, we urge some caution in drawing conclusions about which groups experience the most stigma and discrimination about their mental illness based on the survey findings. The data is not to be interpreted as statistically representative of all people with mental illnesses in Scotland. This is because there are gaps within the survey sample, the true incidence of mental illness is unknown, and for some life areas the sample is very small. In a related vein, the inclusion criteria required participants to identify as having experienced stigma or discrimination in the preceding 12 months and so cannot be used to gauge absolute prevalence (e.g. it is not possible to estimate the overall percentage of people living with a severe and/or enduring mental illness experience stigma or discrimination in any given life area). Furthermore, the inclusion criteria allowed respondents to self-report their mental illness if they had not received a formal diagnosis from a healthcare professional.
- 25.14.** Given the above, this study provides a baseline and starting point in terms of evidencing the experiences of stigma and discrimination amongst people living with complex, severe and/or enduring mental illnesses and bolsters the case for a) a larger scale survey in Scotland and b) establishing which groups are of specific interest; for example, whether the requirement is to know impacts by types of mental illnesses, age, sex and gender, location or sexuality.
- 25.15.** With the caveats described above in place, any divergence in the profile of respondents that selected each of the five most commonly reported life areas where stigma and discrimination has the greatest impact, from who of the overall survey population is drawn out below.
- 25.16.** Respondents who selected the employment life area were more likely to be in paid employment, and a private homeowner compared with the overall respondent population. They were less likely to be living with personality disorders and less likely to have a feeding or eating disorder.
- 25.17.** Those who selected mental health services were slightly less likely to privately own their home and more likely to be people living with personality disorders. In the healthcare life area, a greater proportion of this cohort identified their sex at birth or gender as female compared to the overall population of respondents and slightly more identified as non-binary. A lower proportion identified as heterosexual, and a higher proportion identified as bisexual or asexual. Lastly, a lower proportion reported having no religion, compared with the overall respondent population.
- 25.18.** People who selected the social media life area were more likely to have a university degree than the general survey population and a slightly higher proportion had a feeding or eating disorder when compared with the overall sample.
- 25.19.** Evidence of intersectional elements of stigmatisation and discrimination related to other aspects of a person's identity was also gathered. This may compound adverse experiences and impacts for people with lived experiences of complex, severe and/or enduring mental

illness. Often, experiences of stigma and discrimination about other aspects of an individual's identity were intertwined with stigma and discrimination about their mental illness. Building on this evidence, there may be scope for the Mental Health Foundation and See Me Scotland to share the findings in this report more widely and work in partnership with, or learn from, stakeholders from other sectors with an interest in tackling facets of stigma and discrimination linked to different characteristics.

- 25.20.** Given that this research has established such a clear picture of prevalence and reach among participants, we suggest stigma and discrimination may extend to life areas not covered in the survey. It is also likely to be experienced by, or affect, other groups impacted by severe and enduring mental illness, including partners, children and friends. There may be people in Scotland who have complex, severe and/or enduring mental illness who have not encountered stigma in last 12 months; but have experienced it previously, with lasting impacts. Their experiences are not captured in this research. There are also likely to be those who have historical experiences of stigma and discrimination in a particular life area, which has led to them withdrawing from participating in those life areas to protect themselves. Again, the views and experiences of these people may not be fully represented in this research. These areas may be useful future lines of inquiry for other research into stigma and discrimination in Scotland or elsewhere.

Research question 4: How does the awareness, experience and anticipation of stigma and discrimination affect people living with severe, complex and/or enduring mental health problems?

- 25.21.** Experiences and anticipation of stigma and discrimination are evident across every life area. Given the sample size, we have not sought to establish a causal link between these different aspects (experiences and future expectations) and suggest that further analysis be undertaken if an expanded data set becomes available in future.
- 25.22.** On awareness of stigma, there are stark differences in how themselves because of their mental illnesses, how they perceive those in positions of power and the public view people living with mental illness, and their own views of others with mental illness. The majority of respondents expect that people in positions of power and members of the public have negative views; and respondents also hold far more sympathetic views about others with mental illness than they hold of themselves. However, what cannot be established through the findings of this study is the extent to which experiences of stigma and discrimination influences these views.
- 25.23.** Beyond the extensive evidence about experiences of mental health stigma and discrimination presented in this report, anticipated stigma has clearly had a significant impact on the lives of survey respondents. There appears to be a vicious cycle of experiences of stigma and discrimination leading to anticipated stigma, which in turn leads to people with complex, severe and/or enduring mental illness withdrawing from opportunities as a pre-emptive, protective response. Withdrawal can have a detrimental impact on mental health, due to isolation, not getting needs met or not accessing services. Crucially, it means that people are not living the life they want to be and would be if not for the stigma and discrimination they had experienced.
- 25.24.** Stark examples of the powerful corrosive impact of stigma and discrimination include the data on people choosing not to start a family, have friendships or enter relationships due to anticipated experiences of stigma and discrimination. Similarly, the numbers who would not call an ambulance or the police in an emergency shows the significant impact of anticipated experiences of stigma and discrimination at points of crisis, when people are most vulnerable.

25.25. The context review highlighted links between societal attitudes and self-stigmatisation, and our survey results add weight to those findings. This suggests that the battle to tackle stigma and discrimination about mental illness in Scotland will include efforts to address self-stigmatisation among people with lived experience of complex, severe and/or enduring mental illness.

Research question 5: What needs to change to improve people's experiences of living with severe, complex and/or enduring mental health problems, and to reduce mental health stigma and discrimination?

- 25.26.** This research gave people with lived experience a direct opportunity to identify what changes are needed in Scotland. They suggested an extensive range of changes to address stigma and discrimination, in different spheres. These steps emerged in answers to the question on what needs to change, and through the experiences shared elsewhere in participants' responses.
- 25.27.** A need for change in four overarching, inter-related areas was highlighted, spanning social values, understanding and inclusion; work and education settings; identity and representation; and provision of services and support. Cutting across each of these areas will require change in culture, policies, systems and practices and a move towards greater education, collaboration, accountability, inclusion, respect and empowerment.
- 25.28.** Improved resourcing, prioritisation, knowledge, awareness and understanding lie at the heart of respondents' views on how to achieve change. On a broad level this requires funding and strategy by policy makers and organisations that advocate for people with severe and enduring mental illness. It also means embedding awareness-building activity at every touchpoint in Scotland's education system, and providing dedicated training in specific settings such as mental health services, welfare and benefit systems, education, and workplaces.
- 25.29.** Change involves creating opportunities for people with lived experiences to be heard, and for their contributions to be valued and responded to. This will require establishing processes and environments which people with complex, severe and/or enduring mental illnesses trust. There must be no adverse impacts from disclosing their illness, expressing their needs, or sharing their experiences. It also means investing in further research into the lived experience of complex mental illness.
- 25.30.** Many different components of change are set out across the report and the types of changes required vary depending on the life area. Examples include specific investment in mental health services, greater accessibility, more inclusive approaches, removal of barriers, offering flexibility and reasonable adjustments, empowerment of people with lived experience, accountability for individuals or organisations that perpetuate stigma and discrimination, changes in attitude and culture, positive representation of people with severe and enduring mental illnesses, and service reforms.
- 25.31.** Those seeking to tackle stigma and discrimination will need to acknowledge these calls for change, identify any gaps through reflecting on the findings, and prioritise which steps to take. Achieving change will involve extensive engagement from a wide range of stakeholders and partners. This work should agree timescales, identify leadership and implementation roles, determine how to implement and monitor the changes sought, and generate resources. This must be a collective and collaborative effort across partners and stakeholders if the change required is to be achieved.

Final thoughts on the research

- 25.32.** Mental illness stigma and discrimination is a traumatic experience which may compound other traumas. Given the prevalence identified in this research, we suggest it needs to be acknowledged and addressed in mental healthcare settings. This could include incorporating an assessment of experiences of stigma and discrimination in mental health assessments, and exploring these experiences during treatment when helping someone develop an understanding of their distress and coping responses. Such a step would add to the evidence base and recognise the profound role of stigma in the lives of people with complex, severe and/or enduring mental illnesses.
- 25.33.** The frequency and impact of stigma and discrimination experienced by respondents in their relationships with friends and family is the highest of all life areas. It is often family and friends that can provide, and are looked to, for social relational emotional support. It is this support which could act as a preventative factor for decline in someone's mental health and reduce the need to access clinical or non-clinical support, and therefore greater investment in this area should be considered.
- 25.34.** Much of the narrative in this report has focused on the negative experiences and impact of stigma and discrimination. However, positive experiences were identified by respondents across every life area, albeit by a smaller proportion of survey participants and to varying degrees across the different life areas. In their comments, respondents described examples of good practice, kindness, knowledge, understanding, inclusivity, flexibility, and compassion. Significantly, these experiences demonstrate that many of the changes called for in response to the question 'what needs to change?' are achievable at an individual and structural level.

Recommendations

- 25.35.** Our five strategic recommendations build on the conclusions set out above.

1. To share the research in tailored ways with key stakeholders and generate engagement with, and acknowledgement of, the findings amongst:

- People with lived experience of complex, severe and enduring mental illness and the friends and family surrounding them.
- Policy makers, reflecting the strategic policy commitment required and also the cross policy nature of the challenge.
- Potential funders.
- Researchers, including the international teams involved in related projects.
- Those leading and delivering public services.
- The wider mental health sector.
- Organisations with a remit to tackle stigma and discrimination.
- Representative organisations and/or key players aligned to each of the life areas explored in the survey.

2. Allocate and rally resources which reflect the scale, scope and long term nature of the work required to tackle stigma and discrimination. This might include:

- Allocation of existing funding.
- Redirecting or expanding the scope of existing services.
- Seeking external funding from stakeholders such as the Scottish Government and Trusts.
- Drawing on the skills, experience, expertise, influence, connections and resources of stakeholders and partners.

3. Develop an action plan to address the issues set out in the report, covering:

- Ongoing participatory research and projects to address and/or build on the findings and recommendations set out in this report.
- Specific aspects of stigma and discrimination to focus on, identifying whether specific life areas are to be prioritised.
- The ambitions for change and what success looks like.
- Levers of change that will have the greatest impact.
- Which partners to involve.
- Ownership and accountability.
- Timescales for change (aligned to short-, medium- and long-term actions and goals).
- How change will be implemented.
- How to monitor progress and impact.

4. Repeat the survey on a larger scale to generate data which is representative at a population level. This will require support from NHS Health Boards to reach people supported by mental health services. An expanded sample will enable See Me and Mental Health Foundation (Scotland) to:

- Increase the robustness of data collection and evidence demonstrating the true scale of stigma and discrimination in Scotland.
- Provide the opportunity to engage with seldom heard communities – (and those who did not have the opportunity to contribute to this study).
- Undertake further analysis of key issues including establishing whether a causal relationship between experiences and anticipated stigma, and withdrawal effects exists.
- Further exploration around self-stigma and its impact.
- Looking in depth at the interpersonal stigma within close relationships – what can be done to understand more about and address this issue?

5. Generate evidence to answer some of the questions raised by this research.**These include:**

- Does mental illness stigma and discrimination extend to life areas not covered in the survey?
- In what ways is stigma and discrimination experienced by, or affecting, other groups impacted by complex, severe and/or enduring mental illness, including partners and children?
- Are there people with complex, severe and/or enduring mental illness who have not encountered stigma in last 12 months; but have experienced it previously, with lasting impacts? If so, what are those impacts and what effect do they have on the person's life?
- Why do people living with a complex, severe and/or enduring mental illness have a more sympathetic or positive view of others living with mental illness than they do of themselves?

Appendices



26. Appendix 1: Demographics data tables

Table A. Demographic breakdown

	Total Sample (n=346)	Housing (n=37)	Employment (n=123)	Education (n=52)	Relationships (n=192)	Healthcare (n=111)	Mental Health (n=121)	Sports etc. (n=10)	Public Spaces (n=24)	Banking / Ins. (n=16)	Welfare (n=45)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Mass media (n=48)	Social Media (n=74)
SEX (what is your sex?) Please select your sex registered at birth															
N=	346	37	123	52	192	111	121	10	24	16	45	15	13	48	74
Female	67	57	69	73	70	80	67	60	67	63	56	60	46	69	68
Male	30	41	29	25	27	16	29	40	29	38	42	33	39	29	30
Prefer not to say / Not answered	3	3	2	2	3	4	4	-	4	-	2	7	15	2	3

Table A. Demographic breakdown (continued)

	Total Sample (n=346)	Housing (n=37)	Employment (n=123)	Education (n=52)	Relationships (n=192)	Healthcare (n=111)	Mental Health (n=121)	Sports etc. (n=10)	Public Spaces (n=24)	Banking / Ins. (n=16)	Welfare (n=45)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Mass media (n=48)	Social Media (n=74)
GENDER How would you describe your gender?															
N=	346	37	123	52	192	111	121	10	24	16	45	15	13	48	74
Female	58	49	59	67	62	63	56	60	38	56	51	73	54	60	57
Male	28	41	29	21	23	18	28	40	25	25	38	27	31	25	27
Non-binary	7	5	7	8	7	12	8	-	13	6	4	-	8	6	10
In another way	2	-	-	4	2	2	2	-	13	-	4	-	-	-	3
Don't know	1	-	1	-	1	2	2	-	4	-	-	-	-	-	-
Prefer not to say / Not answered	5	5	5	-	6	4	4	-	8	13	2	-	8	8	4

Table A. Demographic breakdown (continued)

	Total Sample (n=346)	Housing (n=37)	Employment (n=123)	Education (n=52)	Relationships (n=192)	Healthcare (n=111)	Mental Health (n=121)	Sports etc. (n=10)	Public Spaces (n=24)	Banking / Ins. (n=16)	Welfare (n=45)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Mass media (n=48)	Social Media (n=74)
SEXUALITY Do you consider yourself to be															
N=	346	37	123	52	192	111	121	10	24	16	45	15	13	48	74
Heterosexual (straight)	54	60	61	48	56	38	48	50	25	63	62	53	69	50	50
Homosexual (Lesbian or Gay)	8	11	8	12	5	7	7	10	4	-	11	13	15	2	7
Bisexual	20	5	16	31	21	25	22	20	50	6	9	7	-	19	26
Asexual	5	3	4	6	3	12	5	10	4	-	9	20	-	6	7
Other	4	3	2	4	5	7	7	-	4	13	-	7	8	8	5
Don't know	4	5	4	-	4	5	4	10	8	6	2	-	-	4	1
Prefer not to say / Not answered	6	14	5	-	7	6	7	-	4	13	7	-	8	10	4

Table A. Demographic breakdown (continued)

	Total Sample (n=346)	Housing (n=37)	Employment (n=123)	Education (n=52)	Relationships (n=192)	Healthcare (n=111)	Mental Health (n=121)	Sports etc. (n=10)	Public Spaces (n=24)	Banking / Ins. (n=16)	Welfare (n=45)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Mass media (n=48)	Social Media (n=74)
ETHNICITY What is your ethnic group?															
N=	346	37	123	52	192	111	121	10	24	16	45	15	13	48	74
White	97	95	97	94	97	96	97	90	96	100	98	100	92	94	93
Mixed or multiple ethnic groups	1		1	2	1	2	1	-	4	-	-	-	-	2	4
Asian, Scottish Asian or British Asian	1	5	1	2	-	-	1	10	-	-	2	-	-	-	3
Prefer not to say / Not answered	2	-	2	2	2	3	2	-	-	-	-	-	8	4	-

Table A. Demographic breakdown (continued)

	Total Sample (n=346)	Housing (n=37)	Employment (n=123)	Education (n=52)	Relationships (n=192)	Healthcare (n=111)	Mental Health (n=121)	Sports etc. (n=10)	Public Spaces (n=24)	Banking / Ins. (n=16)	Welfare (n=45)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Mass media (n=48)	Social Media (n=74)
ETHNICITY (AMONG WHITE PARTICIPANTS) And which one of these options best describes your ethnic group or background?															
N=	334	35	119	49	186	16	117	9	23	16	44	15	12	45	69
Scottish	73	74	77	69	77	71	71	67	52	75	75	73	67	71	75
English	11	9	9	8	9	12	9	22	35	13	16	20	17	7	10
Welsh	1	-	2	2	1	1	-	-	-	6	-	-	-	-	-
Northern Irish	1	-	1	6	1	1	2	-	4	-	-	-	-	4	-
Irish	1	-	2	-	1	1	2	-	-	-	-	-	8	2	1
Polish	2	-	2	-	2	2	-	-	4	-	2	-	-	2	1
Other white ethnic group	11	17	8	14	10	11	15	11	4	6	5	7	8	13	12
Prefer not to say / Not answered	1	-	-	-	-	1	2	-	-	-	2	-	-	-	-

Table A. Demographic breakdown (continued)

	Total Sample (n=346)	Housing (n=37)	Employment (n=123)	Education (n=52)	Relationships (n=192)	Healthcare (n=111)	Mental Health (n=121)	Sports etc. (n=10)	Public Spaces (n=24)	Banking / Ins. (n=16)	Welfare (n=45)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Mass media (n=48)	Social Media (n=74)
RELATIONSHIP STATUS Are you:															
N=	346	37	123	52	192	111	121	10	24	16	45	15	13	48	74
Single	40	47	36	50	41	42	45	20	54	19	38	47	15	52	41
In a relationship	21	19	20	19	21	23	17	30	21	13	13	20	8	17	26
Married	23	3	28	23	21	19	23	30	13	44	24	20	54	21	22
Separated	3	5	4	-	2	2	1	-	-	-	7	-	8	2	3
Divorced	6	22	3	-	6	5	6	10	4	-	11	7	8	-	3
Widowed	<0.5	-	1	2	1	-	-	-	-	-	-	-	-	-	-
Other	1	-	2	2	2	4	-	10	-	6	-	7	-	2	1
Prefer not to say / Not answered	6	3	7	4	7	5	8	-	8	19	7	-	8	6	6

Table A. Demographic breakdown (continued)

	Total Sample (n=346)	Housing (n=37)	Employment (n=123)	Education (n=52)	Relationships (n=192)	Healthcare (n=111)	Mental Health (n=121)	Sports etc. (n=10)	Public Spaces (n=24)	Banking / Ins. (n=16)	Welfare (n=45)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Mass media (n=48)	Social Media (n=74)
EMPLOYMENT STATUS (Multi-choice) Do you have a job? Please select all that apply															
N=	346	37	123	52	192	111	121	10	24	16	45	15	13	48	74
Employed full-time	28	3	44	21	30	23	24	10	21	50	16	7	8	27	32
Employed part-time	18	16	21	17	17	18	17	10	25	13	9	7	23	17	22
Self-employed	5	3	5	8	6	5	3	-	4	6	2	7	-	6	3
Volunteer	11	16	12	19	12	8	7	30	25	6	7	20	15	13	15
Student (part or full-time)	17	3	11	50	15	22	23	10	33	-	7	20	8	19	23
Carer	2	3	2	4	2	2	3	-	13	6	2	-	-	4	3
Retired	5	8	2	-	4	5	7	20	-	6	2	13	-	2	3
Other	4	3	3	4	4	5	3	-	-	6	4	-	8	2	4
No job	28	51	20	19	27	27	31	30	33	13	58	40	62	25	23
Prefer not to say / Not answered	2	-	1	-	3	2	1	-	-	4	4	8	8	4	3

Table A. Demographic breakdown (continued)

	Total Sample (n=346)	Housing (n=37)	Employment (n=123)	Education (n=52)	Relationships (n=192)	Healthcare (n=111)	Mental Health (n=121)	Sports etc. (n=10)	Public Spaces (n=24)	Banking / Ins. (n=16)	Welfare (n=45)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Mass media (n=48)	Social Media (n=74)
HOUSING STATUS Which option best describes your current place of residence?															
N=	346	37	123	52	192	111	121	10	24	16	45	15	13	48	74
Private rental property	25	35	29	33	23	32	22	20	29	6	9	20	15	29	26
Privately owned home	36	3	44	37	38	31	27	70	17	69	33	40	39	40	32
Living temporarily with friends/family	11	5	10	12	12	7	16	-	17	13	13	7	8	13	11
Sleeping rough	<0.5	-	-	2	1	-	-	-	-	-	-	7	-	-	-
Local authority or social housing	22	41	15	10	19	23	26	10	29	13	33	7	23	15	24
Hostel	<0.5	3	-	-	1	-	1	-	-	-	-	-	-	-	-
Supported or sheltered accommodation	2	11	-	-	3	3	3	-	-	-	4	7	-	2	1
Other	3	3	2	8	2	2	3	-	4	-	4	13	8	-	4
Prefer not to say / Not answered	2	-	1	-	2	3	2	-	4	-	2	-	8	2	1

Table A. Demographic breakdown (continued)

	Total Sample (n=346)	Housing (n=37)	Employment (n=123)	Education (n=52)	Relationships (n=192)	Healthcare (n=111)	Mental Health (n=121)	Sports etc. (n=10)	Public Spaces (n=24)	Banking / Ins. (n=16)	Welfare (n=45)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Mass media (n=48)	Social Media (n=74)
RELIGION/FAITH What is your religion or spiritual belief?															
N=	346	37	123	52	192	111	121	10	24	16	45	15	13	48	74
None	62	62	70	65	67	53	58	80	50	56	64	40	23	71	74
Christian	21	30	18	19	18	19	23	10	29	13	27	47	46	8	10
Muslim	1	-	1	-	1	-	-	-	-	-	-	-	8	2	-
Buddhist	1	3	2	-	2	5	1	10	-	-	-	-	-	-	1
Jewish	1	-	-	4	-	1	-	-	-	-	-	-	-	-	1
Pagan	4	-	3	2	4	8	4	-	4	13	4	-	8	4	4
Other	7	3	4	8	7	10	9	-	13	13	2	7	-	10	5
Prefer not to say / Not answered	4	3	2	2	2	5	5	-	4	6	2	7	15	4	4

27. Appendix 2: Mental and physical health characteristics data tables

Table B. Complex mental health issues experienced by participants in the last 12 months (%)

% Experiencing	Total Sample (n=346)	Relationships (n=192)	Employment (n=123)	Mental Healthcare (n=121)	Healthcare (n=111)	Social Media (n=74)	Education (n=52)	Mass media (n=48)	Welfare (n=45)	Housing (n=37)	Public Spaces (n=24)	Banking / Ins. (n=16)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Sports etc. (n=10)
Schizophrenia or other primary psychotic disorder	7	6	7	7	4	4	4	6	7	-	21	-	-	54	-
Bipolar or related disorder	15	13	15	20	17	14	10	15	11	14	17	31	7	15	10
Obsessive-compulsive or related disorder	22	25	19	22	27	26	17	23	20	30	29	13	13	23	10
Disorder specifically associated with stress	43	42	40	46	50	43	40	46	42	60	29	38	67	39	40
Dissociative disorder	12	11	15	14	14	10	12	10	20	11	13	6	27	8	10
Feeding or eating disorder	20	21	14	21	23	28	21	21	11	16	33	13	20	8	10
Personality disorder	31	28	24	38	32	28	31	25	33	35	46	13	33	39	20
Severe and/or treatment-resistant depressive disorder	39	41	43	37	32	42	46	42	49	43	46	13	27	31	30
Severe and/or treatment-resistant anxiety or fear-related disorder	40	39	40	31	38	41	42	35	42	65	54	38	33	15	40

NOTE: Participants were shown examples within each response option. Percentages do not add up to 100 as participants could select more than one response.

Table C. Whether complex mental health issue has been diagnosed (%)

	Total Sample (n=346)	Relationships (n=192)	Employment (n=123)	Mental Healthcare (n=121)	Healthcare (n=111)	Social Media (n=74)	Education (n=52)	Mass media (n=48)	Welfare (n=45)	Housing (n=37)	Public Spaces (n=24)	Banking / Ins. (n=16)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Sports etc. (n=10)
% diagnosed	87	89	89	84	84	89	85	90	96	87	83	75	67	92	90

Table D. Level of distress and negative impact caused by mental health issue(s) (%)

%	Minimal	Mild	Moderate	Moderate – severe	Severe	Very severe	TOTAL Severe
Total Sample (n=346)	2	5	12	34	28	18	81
Schizophrenia or other primary psychotic disorder (n=24)	-	29	17	21	17	17	54
Bipolar or related disorder (n=52)	4	10	12	27	33	15	75
Obsessive-compulsive or related disorder (n=77)	1	3	8	26	34	29	88
Disorder specifically associated with stress (n=149)	1	2	12	36	30	20	85
Dissociative disorder (n=42)	-	-	12	21	41	26	88
Feeding or eating disorder (n=70)	1	1	13	29	34	21	84
Personality disorder (n=102)	2	1	14	26	27	31	83
Severe and/or treatment-resistant depressive disorder (n=136)	-	2	9	33	29	28	90
Severe and/or treatment-resistant anxiety or fear-related disorder (n=139)	1	1	12	27	32	27	86

28. Appendix 3: Positive statements data tables

Table E. Positive experiences in each life area because of participants' complex mental health issues

ff	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree	Total agree
Because I live with mental illness(es) I have had positive experiences...							
Relationships (n=185) ...in my relationships with friends, family or intimate partner(s)	15	15	10	23	24	14	61
Employment (n=118) ...when finding, maintaining or participating in employment	30	36	8	14	12	2	27
Mental Healthcare (n=119) ...when accessing or using mental healthcare services	33	16	8	22	13	8	43
Healthcare (n=109) when accessing or using physical healthcare services	28	28	17	12	10	4	26
Social Media (n=70) ...when participating in social media	20	14	19	27	13	7	47
Social Media (n=69) I have seen, read or heard social media content that portrayed people who live with mental health issues in a positive way	12	7	4	28	26	23	77
Education (n=52) ...when applying for, participating in, or completing education or training	14	31	17	21	10	8	39

Table E. Positive experiences in each life area because of participants' complex mental health issues (continued)

ff	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree	Total agree
Because I live with mental illness(es) I have had positive experiences... (continued)							
Mass media (n=46) I have seen, read or heard news media that portrayed people who live with mental health issues in a positive way	22	17	11	22	22	7	50
Welfare (n=43) ...when accessing, retaining or using welfare benefit and financial support services	42	26	14	9	7	2	19
Housing (n=35) ...when accessing housing or homelessness services	57	17	14	3	6	3	11
Public Spaces (n=23) ...when accessing or using public transport, public spaces or attending public events	35	26	4	22	13	-	35
Banking / Ins. (n=14) ...when accessing or using banking services or insurance products	50	29	7	14	-	-	14
Legal / Justice (n=15) ...when accessing legal and justice services, or police assistance	33	27	7	20	7	7	33
Cultural / Faith (n=13) ...when accessing or participating in my cultural, faith, religious or spiritual practices and communities	15	-	31	8	23	23	54
Sports etc. (n=10) ...when joining or participating in sporting teams or clubs, community groups or volunteer roles	20	30	10	20	10	10	40

Table F. Desire for additional consideration in each life area because of participants' complex mental health issues

%	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree	Total agree
Because I live with mental illness(es) I should receive additional consideration...							
Relationships (n=185) ...in my relationships with friends, family or intimate partner(s)	10	14	11	34	21	10	65
Employment (n=118) ...when finding, maintaining or participating in employment	6	11	11	25	27	20	72
Mental Healthcare (n=119) ...when accessing or using mental healthcare services	4	7	7	24	27	31	82
Healthcare (n=109) when accessing or using physical healthcare services	6	8	12	27	34	14	75
Social Media (n=70) ...when participating in social media	20	14	19	27	13	7	47
Education (n=52) ...when applying for, participating in, or completing education or training	4	10	8	31	29	19	79
Welfare (n=43) ...when accessing, retaining or using welfare benefit and financial support services	5	5	-	19	30	42	91

Table F. Desire for additional consideration in each life area because of participants' complex mental health issues (continued)

%	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree	Total agree
Because I live with mental illness(es) I should receive additional consideration... (continued)							
Housing (n=35) ...when accessing housing or homelessness services	14	6	9	11	14	46	71
Public Spaces (n=23) ...when accessing or using public transport, public spaces or attending public events	13	13	9	30	30	4	65
Banking / Ins. (n=14) ...when accessing or using banking services or insurance products	21	29	7	-	14	29	43
Legal / Justice (n=15) ...when accessing legal and justice services, or police assistance	7	-	-	13	40	40	93
Cultural / Faith (n=13) ...when accessing or participating in my cultural, faith, religious or spiritual practices and communities	8	23	23	15	-	31	46
Sports etc. (n=10) ...when joining or participating in sporting teams or clubs, community groups or volunteer roles	10	20	20	10	30	10	50

29. Appendix 4: Intersectionality data tables

Table G. Experiences of intersectional stigma and discrimination in each life area: percentage TOTAL Agreement

% TOTAL Agreement	Relationships (n=192)	Employment (n=123)	Mental Healthcare (n=121)	Healthcare (n=111)	Social Media (n=74)	Education (n=52)	Mass media (n=48)	Welfare (n=45)	Housing (n=37)	Public Spaces (n=24)	Banking / Ins. (n=16)	Legal / Justice (n=15)	Cultural / Faith (n=13)	Sports etc. (n=10)
I have also experienced stigma and discrimination in relation to employment because of my...														
Race	8	10	5	4	21	12	16	7	15	9	0	7	25	11
Religion or belief	17	9	7	6	27	18	18	7	6	13	0	7	25	11
Sex	21	21	24	45	47	44	47	12	24	35	17	14	33	11
Sexual orientation	22	7	20	15	40	29	33	7	15	30	17	14	17	22
Gender reassignment	6	7	7	11	17	13	10	8	12	18	0	7	8	0
Disability (physical)	21	21	19	30	21	29	23	45	51	27	39	53	8	60
Age	21	37	41	46	42	38	42	26	29	25	39	21	33	22
Marriage or Civil Partnership	9	10	9	6	9	2	17	13	15	14	17	14	17	0
Pregnancy and/or Maternity	3	6	3	2	5	2	10	3	3	5	0	0	8	0

30. Appendix 5: Members of Working Groups

Members of the Lived Experience Working Group:

Gordon Johnston	<i>Board of Directors (VOX) and Peer Researcher</i>
Joanna Higgs	<i>Board of Directors (VOX)</i>
Matt Hu	<i>Board of Directors (VOX)</i>
Nigel G Honey	<i>Volunteer (See Me), Lead Trainer (Ability Post Production Academy)</i>
Susan Falconer	<i>Volunteer (See Me)</i>

Members of the Research Advisory Group:

Lee Knifton	<i>Director, Mental Health Foundation (Scotland and Northern Ireland)</i>
Dr Simon Hunter	<i>Professor of Applied Psychology, Glasgow Caledonian University</i>
Karen Lally	<i>See Me volunteer, former Chair of See Me Advisory Group, Lived Experience Representative</i>
Wendy McAuslan	<i>Manager, VOX</i>
Wendy Halliday	<i>Director, See Me</i>
Jo Finlay	<i>(Chair), Senior Research Manager, Mental Health Foundation (Scotland)</i>
Dr Pamela Jenkins	<i>Senior Research Officer, Mental Health Foundation (Scotland)</i>
Carol Brown	<i>Principal Researcher, The Scottish Government</i>
Dr Chris Groot	<i>Lecturer and Director (Mental Illness Stigma Lab), Melbourne School of Psychological Sciences</i>
Dr Imogen Rehm	<i>Senior Lecturer in Clinical Psychology, Victoria University</i>
Benjamin McElwee	<i>Lived Experience Representative</i>
Derek Ewens	<i>Senior Researcher, The Lines Between</i>
Lorraine Simpson	<i>Director, The Lines Between</i>
Abi Sharp	<i>Researcher, The Lines Between</i>

Members of the Project Management Group:

Lee Knifton	<i>Director, Mental Health Foundation (Scotland and Northern Ireland)</i>
Dr Simon Hunter	<i>Professor of Applied Psychology, Glasgow Caledonian University</i>
Karen Lally	<i>See Me volunteer, former Chair of See Me Advisory Group, Lived Experience Representative</i>
Julie Cameron	<i>Associate Director, Mental Health Foundation (Scotland and Northern Ireland)</i>
Jo Finlay (Chair)	<i>Senior Research Manager, Mental Health Foundation (Scotland)</i>
Dr Pamela Jenkins	<i>Senior Research Officer, Mental Health Foundation (Scotland)</i>
Karen Lally	<i>See Me volunteer, former Chair of See Me Advisory Group, Lived Experience Representative</i>
Derek Ewens	<i>Senior Researcher, The Lines Between</i>
Lorraine Simpson	<i>Director, The Lines Between</i>

31. Appendix 6: Glossary

A&E

Accident and Emergency; hospital department for emergency care.

ADHD

Attention Deficit Hyperactivity Disorder; “a condition that affects people’s behaviour. People with ADHD can seem restless, may have trouble concentrating and may act on impulse.” (NHS)

Anticipated stigma

The extent to which an individual expects to be the target of stereotypes, prejudice, or discrimination in the future.

BPD

Borderline Personality Disorder; “a disorder of mood and how a person interacts with others.” (NHS)

CAB

Citizen’s Advice Bureau; local organisations offering information and advice to assist people with legal, debt, consumer and housing issues.

Carer

A family member or friend who helps a person living with a complex mental health issue.

CMHT

Community Mental Health Team.

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.

CPN

Community Psychiatric Nurse

CPTSD

Complex Post-Traumatic Stress Disorder (See PTSD).

DID

Dissociative Identity Disorder; “someone diagnosed with DID may feel uncertain about their identity and who they are. They may feel the presence of other identities, each with their own names, voices, personal histories and mannerisms.” (NHS)

Discrimination

Unfair or unjust behaviours directed at people experiencing complex mental health issues (Allport, 1954; Brewer, 2007).

DLA

Disability Living Allowance; a tax-free benefit for people with illnesses or disabilities who need help with mobility or care costs.

DSM-IV

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition.

DWP

The Department for Work and Pensions; the UK Government department responsible for welfare, pensions and child maintenance policy.

ESA

Employment and Support Allowance; state benefit for those who cannot work due to illness or disability.

EUPD

Emotionally Unstable Personality Disorder.

GMC

General Medical Council.

GP

General Practitioner.

Institutional Stigma

Also known as structural stigma. See below.

Intersectionality

“The interconnected nature of social categorizations such as race, class, and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage.” (Oxford Dictionary)

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)

MHAS

Mental Health Assessment Service.

MHF

Mental Health Foundation.

NHS

National Health Service; the UK’s publicly funded healthcare system.

OCD

Obsessive Compulsive Disorder; “a mental health condition where a person has obsessive thoughts and compulsive behaviours.” (NHS)

Perceived stigma

How the individual thinks most people or the society view them personally as a member of the stigmatised group.

PIP

Personal Independence Payment; a tax-free benefit for people with illnesses or disabilities who need help with mobility or care costs. PIP was introduced to replace DLA.

Prejudice

Emotional reaction or feelings that people have toward a group or member of a group (Stangor, 2009).

PTSD

Post-Traumatic Stress Disorder; “an anxiety disorder caused by very stressful, frightening or distressing events.” (NHS)

SAMH

Scottish Association for Mental Health.

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.

Zero hours contract

A type of employment contract between an employer and an employee whereby the employer is not obliged to provide any minimum number of working hours to the employee.

32. Appendix 7: Endnotes

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See Me

End mental health
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