

# Mind: The Lived Experience of Mental Health, Executive Summary

On behalf of Mind from YouGov

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## Executive summary

### *Introduction*

This report summarises findings from research conducted by YouGov on behalf of Mind, with the purpose of gathering lived experience insights to inform the upcoming government 10-Year Mental Health Plan. The research aimed to ensure the voices and perspectives of people with lived experience of mental health problems are featured prominently in decision making. The research explored areas including: experiences of mental health support and service provision; the needs, preferences and priorities of people with lived experience of a mental health problem; and how experiences differ among different groups within the population.

The research consisted of four elements:

- A quantitative survey of adults with a diagnosed mental health problem;
- A quantitative survey of young people (aged 14-15);
- An online qualitative community with adults with lived experience of a mental health problem and;
- Depth interviews with young adults with learning disabilities as well as lived experience of a mental health problem.

Throughout the research, there was a focus on the experiences of groups who are at higher risk of experiencing mental health problems. Mind identified six priority groups who were of particular interest and relevance to the research. These were:

1. Black (African or Caribbean) people
2. LGBTQI+ people
3. People with severe mental illness
4. Young people with a learning disability
5. Young women who have experienced trauma
6. People living in poverty

### *Promoting positive wellbeing and preventing the onset of mental health problems*

Many factors can affect mental health, both positively and negatively, and promoting good wellbeing in general is likely to have a positive impact on mental health.

Most commonly, people cite relationships, traumatic experiences, and loneliness and isolation as factors which have had a *negative* impact on their mental health, while many also mention physical health, body image and employment issues. Fewer respondents cite stigma and discrimination (e.g. racism, homophobia, sexism), as a factor, but the proportion doing so rises among relevant groups such as Black adults and LGBTQI+ respondents.

Highlighting the role relationships can also play in maintaining positive mental health, three in five say that having supportive relationships has had a *positive* impact on their mental health. This is followed by hobbies and interests, having a good understanding of someone's own mental health, and feeling comfortable talking about mental health. This strongly highlights the importance of open and destigmatised discussions around mental health.

Many of those we spoke to in the qualitative community comment that their poor quality of life when it comes to relationships, housing and employment has a significant impact on their mental health. Most are facing multiple issues and marginalisation simultaneously, which exacerbate existing mental health problems. Whilst understanding of individual triggers and how they can help themselves is high, often their conditions impede them from putting steps in place to improve their own wellbeing.

### *Earlier intervention*

Over half of adults with lived experience selected 'providing early support for mental health problems' as a top priority area for the Government to address within the field of mental health, demonstrating the importance of early intervention.

Across the priority groups in the qualitative research, preventative measures (i.e. early support and quick diagnostic processes) were preferred over reactive solutions and treatment that tended to come once that their mental health had worsened. Many had only been able to access support once they had reached crisis point, which often meant their needs were complex and acute. Participants felt that care should be preventative, holistic, compassionate and consistent.

### *Quality and effectiveness of treatment*

When considering issues to address within the sphere of mental health, adults with lived experience are most likely to suggest 'improving access to services' as a focus area, with two-thirds of respondents selecting this.

Among adults with lived experience of a mental health problem, most sources of treatment, advice and support are seen as helpful by those who have accessed them. Private healthcare providers or counsellors are considered more helpful than NHS mental health services or counsellors. Whilst the majority say that NHS mental health services or counsellors are helpful, a fifth found these unhelpful, which could act as a barrier to people seeking treatment again. Notably, young women with experience of trauma were less likely than other respondents to feel that many sources of support were helpful, including GPs and NHS mental health services/counsellors.

When accessing mental health treatment, advice and support, the most common issues are: long waiting times; being embarrassed or ashamed to reach out for treatment and support; a lack of treatment and support options available, and support available not being relevant or suitable.

A key issue emerging from the research for this group is not feeling supported during the process of accessing treatment – an issue which is more common among: those with severe and enduring conditions; young people with a learning disability; young women with experiences of trauma; LGBTQI+ people, and those living in poverty.

Participants in the qualitative research also mentioned dismissive health care professionals, inconsistent care and incorrect diagnoses. Those with additional needs or vulnerabilities (e.g. learning disabilities or severe and enduring mental health problems) are more likely to have a negative experience due to a lack of tailored options and strained services which mean that healthcare professionals do not have the extra time needed to dedicate to understanding their situation and helping them to feel heard.

Among adults with lived experience of a mental health problem, a quarter say they have personally experienced substance misuse issues. This is almost twice as likely among those with experience of trauma than those without such experience, and also more common among those living in poverty.

Among those with lived experience of substance misuse issues, over half say that they experienced barriers as a result of this when accessing treatment, support or advice for their mental health. The issues most commonly experienced are: being blamed for health issues due to substance misuse; healthcare professionals attributing wider mental health issues to substance misuse; and stigma related to substance misuse.

## *Support beyond mental health*

There is a complex interaction between mental and physical health, with both of these able to negatively or positively affect the other.

Half of those with lived experience of a mental health problem state that greater continuity of care for people with mental health problems (for example being able to see the same GP regularly) would have a positive impact on physical health, and over two-fifths say that improving the ability to discuss physical health alongside mental health would have a positive impact. Continuity of care is a particular priority for those living in poverty. Taken together, the results suggest that the distinction between mental and physical health can be experienced as restrictive or unhelpful by patients.

## *Crisis support*

Over half of adults with lived experience selected 'supporting people in need of immediate care or experiencing a mental health crisis' as a top priority area for the Government to address within the field of mental health, demonstrating the importance of this area.

A mental health crisis is defined as when someone feels at breaking point and needs urgent help. This could include feeling extremely anxious and having panic attacks or flashbacks, feeling suicidal or self-harming, having an episode of hypomania or mania, and psychosis. When asked, around two-fifths of adults with lived experience of a mental health problem say they have experienced a mental health crisis. This is more common among those in lower income groups and those with a background of trauma.

In the view of those with lived experience, the three most helpful ways to support those in need of crisis care are shorter waiting times; better treatment and support before reaching a crisis point, and increased treatment or support options available, including follow-up support.

## *Key conclusions and recommendations*

Mental health can be affected by many factors, which interact in complex ways, and these should be viewed holistically rather than considering mental health as an issue in isolation. Actions to improve other aspects of people's lives, such as promoting healthy relationships, promoting good physical health, and combating stigma and discrimination, are also likely to have a beneficial impact on mental health.

When accessing mental health treatment, common issues include long waiting times, being embarrassed or ashamed, a lack of treatment and support options available, and support available not perceived as relevant or suitable. There could be value in producing communications that inform people about mental health treatment and support, who it is suitable for, and how it could be relevant to them.

Given the varied experiences of those with lived experience of a mental health problem, there is a necessity for a tailored approach for individuals, as opposed to 'one-size-fits-all'. This is particularly key for people with co-occurring conditions, those who have experienced trauma, and marginalised groups. Additionally, for those in marginalised groups, support needs to be culturally sensitive with an understanding of how they may have been impacted in other facets of their lives due to their identities.

Those with additional needs or vulnerabilities, such as learning disabilities or severe and enduring mental health problems, are more likely to have a negative experience of mental health treatment due to lack of tailored options, and time-pressured services. This highlights a need to ensure sufficient time is allocated to those living with disabilities, in order to better explain medication and ensure understanding.

Support for those in poverty with mental health problems needs to take account of the multiple stressors that may exacerbate their mental health problems, such as housing and employment pressures. A multi-disciplinary approach, with signposting to other support organisations, will help to ensure that such individuals can fully benefit from treatment.

The findings suggest that the distinction between mental and physical health can be experienced as restrictive or unhelpful, with many saying that the ability to discuss physical health alongside mental health would have a positive impact on their physical wellbeing. As highlighted earlier, improving physical wellbeing is also likely to improve mental health, and it would be beneficial to consider different aspects of health more holistically.

The recommendations outlined above can also be expected to contribute to the improvement of crisis care: a more tailored, personal and holistic approach in primary care, and delivering care with a more long-term focus and with more follow-up, may act preventatively, making it less likely that a crisis point will be reached.