

National Mental Health Commission

Curiosity, Compassion and Care

A report on people's lived experience of distress and
mental ill-health in Australia.

October 2023



Australian Government
National Mental Health Commission

Acknowledgements

This report was written by Everymind, drawing on the research conducted in October 2022 by the University of New England. The views expressed in this report are those of the participants surveyed. Responses are selective and not representative of the population. The authors would like to acknowledge those people who shared their lived experience of distress and mental ill-health summarised in this report. Their open and honest contributions will contribute to our future work in Australia.

We would like to thank Professor Myfanwy Maple, Dr Jaelea Skehan OAM, and Sarah Wayland for their leadership on this report.

Acknowledgement of Country

The Commission acknowledges the traditional custodians of the lands throughout Australia. We pay our respects to their clans, and to the elders, past present and emerging, and acknowledge their continuing connection to land, sea and community.

Acknowledgement of Lived Experience

We acknowledge the individual and collective contributions of those with a lived and living experience of mental ill-health and suicide, and those who love, have loved and care for them. Each person's journey is unique and a valued contribution to Australia's commitment to mental health suicide prevention systems reform.

A note about language

We acknowledge in developing this report that individuals make sense of their experiences in different ways and will have their own preferences about language. Although every effort has been made to use inclusive and respectful language, the terms used may not describe the experience of all people.

The term 'lived experience' is used in this report to refer to anyone who identifies as having a personal experience of mental ill-health, distress, trauma and/or suicidal thoughts and attempts, regardless of whether or not they were diagnosed with a mental illness or accessed health care or other services.

This report generally uses the term 'mental ill-health' to describe a range of acute experiences of distress and changes in thoughts and feelings that may or may not include a formal diagnosis of mental illness.



About this report

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Foreword

Acknowledgement of Country

The Commission acknowledges the Traditional Custodians of the lands throughout Australia. We pay our respects to their clans, and to the Elders, past and present, and to emerging leadership. We acknowledge the continuing connection of Aboriginal and Torres Strait Islander peoples to land, sea, and community.

The Constitution of the World Health Organisation describes “...the highest attainable standard of health as a fundamental right of every human being.” Further, the UN defines the ‘right to health’ as the ‘right to the enjoyment of the highest attainable standard of physical and mental health.’

Irrespective of geography, culture, identity, or socioeconomic status, experiences of distress, trauma and mental ill-health can affect every aspect of a person’s life, including their relationships with others, their opportunities at school and work, and the way people are connected and included as part of a community.

In Australia, we often cite statistics to highlight the scale and impact of emotional and psychological distress and ill-health, and most often hear from researchers, clinicians and policy makers about the design and delivery of the mental health system. But to truly design services and supports that are relevant and impactful we must listen deeply, *hear*, and understand the experiences of those who are, or who have, lived the issues. These experiences, and the amalgamation of thousands of other experiences, constitute evidence, and provide an important opportunity to reform our approach based on what people need to live hopeful, connected and contributing lives.

This report is a plain language translation of five research studies conducted by the University of New England. It helps us to better understand how people in Australia experience distress and emotional and psychological ill-health and what services and supports they have found to be positive and supportive, or conversely, unhelpful.

People who participated in this research made it clear that we need to move away from a medical model reliance on diagnostic labelling and personal deficits, and transition to a person-centred approach focused on curiosity, compassion, and care. The research highlights the importance of service models that span all ages, acknowledging that challenges may commence early in life and then be exacerbated by stressors across the life course unless identified and remediated in a timely manner. It also provides unique insights into the physical and emotional experience of distress and the multiple missed opportunities within and between services and systems to provide supports early and often enough.

A public health framework can assist to prevent the onset and ongoing impacts of mental ill-health by identifying risks and intervening much earlier, not just early in life, but also early in the emergence of distress. This means ensuring there are supports available across communities that can be accessed where people live, work, learn and connect with a range of services. We must also rethink our service system, which people have described as crisis-driven, dismissive of people’s unique contexts, experiences, choices, and aspirations, which can contribute to further vulnerability and trauma. Conversely, system and service responses that emphasise individual and collective strengths can enhance the journey to wellbeing and healing.

To deliver better services and supports we must learn from, design with, and deliver alongside people with lived experience and the communities we serve. This report provides insights to support that work.

Professor Ngiare Brown
Chair, National Mental Health Commission

Snapshot

Every journey is personal, but collectively the knowledge of people who have lived experience of distress and mental ill-health provides unique insights that must shape future action.

- »» This report translates five research studies undertaken in October 2022 to better understand how Australians experience distress and mental ill-health, and their experiences of seeking help and support. It draws on the first-hand experience of over 3,400 people in Australia.
- »» While distress has been used to describe non-specific symptoms of stress and mental ill-health in research and policy reports, the first-person accounts of distress in this research detail intense physical and emotional experiences that often emerged in response to persistent stress or coincided with key life transitions.
- »» Despite the intensity of experience, distress was often seen as 'less serious' in the eyes of the service system, with people describing scenarios where they tried to access support but were met with a 'lack of urgency'.
- »» People described a range of social, interpersonal and community factors that were experienced before the onset of mental ill-health. These were most likely to emerge in later childhood, early working life and middle life, with variances across groups.
- »» Interpersonal concerns were the most significant concerns reported, including relationship stress, psychological and physical abuse, isolation or loneliness, and lack of support for grief.
- »» First Nations peoples were more likely to report social factors such as poor living conditions, poverty and underemployment, while people from a culturally and linguistically diverse background reported a range of community factors such as discrimination, economic insecurity, emergency situations, as well as inadequate water, sanitation and housing.
- »» Social isolation was identified as a significant theme across all the participant narratives. Over time, if people were unsupported and isolated when in distress it could contribute to more complex and acute periods of mental ill-health, which could further contribute to social isolation.
- »» First-person accounts of receiving a diagnosis of mental illness noted that it was rarely a time-limited event. For some, receiving a diagnosis of mental illness was a disempowering time, with a major focus on 'what was wrong with them' rather than identifying the supports they needed.
- »» Despite public messaging that encourages people to 'reach out' for help when in distress, people reported that when they reached out for support services, they were either not available or not able to assist unless they were in immediate crisis.
- »» Participants emphasised the importance of more preventative approaches that connected people to the right support at the right time. Instead, there were countless stories about the disconnected nature of services, which often put the responsibility on the individual in distress to navigate services, often on their own.

About the research

Lived experience knowledge is essential in designing and implementing mental health services and community-based supports.

The case for a new approach

Australian dataⁱ indicates that over 40% of Australians will experience mental ill-health across their lifetime and the prevalence of mental ill-health and psychological distress is increasing. In 2020-2021:

- »» **21.4%** of people experienced mental ill-health (17.5% in 2014-15; 20.1% in 2017-18)
- »» **15.4%** of people experienced high or very high psychological distress (13% in 2017-18)
- »» **64.2%** of people with high or very high psychological distress experienced mental ill-health.

Over 3,000 Australians die by suicide each year and many more attempt suicide, live with suicidal thoughts or are impacted as family and friends. Recent national dataⁱⁱ, shows that across their lifetime:

- »» **16.7%** of people have had serious thoughts about suicide
- »» **7.7%** of people have made a suicide plan
- »» **4.8%** of people have attempted suicide.

The effects of mental ill-health and suicidal distress on a person's life is significant and can include:

- »» Reduced life expectancy
- »» Increased risk of problems with physical health and alcohol and other drugs
- »» Lifetime social and economic disadvantage.

Australian data, together with research, provides some evidence about the scale and impact of mental ill-health across our communities. But to truly design services, supports and prevention approaches that are effective, we must understand the experiences of people who have first-hand experience. Understanding how people in Australia experience emerging mental ill-health, how it progresses over time and the relevance of the social determinants of mental health are critical in mental health reform.



[I wanted] less diagnosis, more curiosity, compassion and care about what environmental and social problems were causing presentation of symptoms.

(Female, 18-24 years)

Gathering evidence to inform our approach

To expand on existing research and practice knowledge, the National Mental Health Commission funded the University of New England to conduct and synthesise research to:

- » Better understand how Australians experience mental ill-health and distress
- » Learn about people's experiences of seeking help and the services they received
- » Identify current evidence for effective community-based interventions and supports

This report is a plain language translation of the researchⁱⁱⁱ to inform policy makers, services and the broader community in Australia.

Findings presented in this report are drawn from:

First-hand accounts



- 1,498** Open-ended survey responses to better understand people's lived experience of distress, mental ill-health and suicide (survey 1).
- 20** Focus group participants from priority populations sharing their experiences (focus groups).
- 1,895** Survey responses to understand common experiences and the factors associated with mental ill-health (survey 2).

Literature reviews



- 84** Research studies to better understand effective community-based interventions (systematic review).
- 18** Reports about mental health service delivery in Australia that included community-based interventions (grey literature review).

Research ethics was obtained through the University of New England for survey 1 (Approval No. HE19-242) and survey 2 (Approval No. HE22-017) and through Hunter New England Local Health District for focus groups (Approval No. ETH00487).

Sections of this report

- »» Part 1: First-hand experiences of distress and mental ill-health
- »» Part 2: A focus on services and supports
- »» Part 3: Pulling it all together

Part 1:

First-hand experiences of distress and mental ill-health



I think there needs to be less outward comparison and more acknowledgement that we all have different experiences. We can all have different experiences, but still be in the same boat.

Focus group participant



Understanding distress

Distress has been used to describe non-specific symptoms of stress and mental ill-health, however first-person accounts detail intense physical and emotional experiences, resulting in shame and isolation.

The body and the mind connected

People described the way that ‘everything becomes louder and harsh’ (*non-binary, 25-34 years*) when distress is present. People spoke in detail about the physical experiences of distress, including chest pains, digestive upsets, uncontrollable crying, sweating, sleep problems and difficulty breathing. These physical symptoms could at times mask the underlying psychological pain being experienced.

For example, participants who identified as female described how their distress was often met with an initial diagnosis related to hormonal cycles or symptoms of puberty, with limited opportunities to explore more deeply what was contributing to their distress. Many noted simplistic responses to their requests for help when attempting to describe them to services, resulting in delays getting appropriate treatment and support.



...I was taken to a GP [general practitioner] who told me it was only hormonal and to wait a year to see if my mental illness was real. After 12 months of being on the pill and suffering many migraines and panic attacks, the GP finally prescribed me medication for my anxiety and depression. A few years later (at university) I was forced to move out of home and was living out of a suitcase for 3 months. I suffered a psychotic episode and experienced extreme paranoia, hallucinations, delusions and relapsed into self-harm. After 2 months of therapy and an appointment with a psychiatrist I was formally diagnosed with Bipolar II, and anxiety.
(Non-binary, 18-24 years)

Shame, humiliation and isolation

The rich descriptions of the physical nature of distress also provide deep insight into the emotions behind these physical manifestations. Some people, particularly, but not exclusively men, spoke about ‘self-medicating’ with alcohol and other drugs to cope. Others spoke about harming themselves physically to cope with the emotional pain.



Distress is like the world is ending. It’s fear filled and anxiety driven. Distress is being unable to think, and panic attacks setting in. Distress means wanting to harm myself, and the feeling like my brain just wants to escape. Distress is searching for the nearest exit and not being able to run.
(Male, 18-24 years)

[Distress is] emotions that are too intense to bear. For me the emotions are humiliation and shame, a sense of someone taking my power off me, and an emotional pain that I feel in my arms and chest and front of my head.
(Female, 35-44 years)

Commonly, feelings of shame associated with distress led to a withdrawal from others. People described 'a chasm' between being wanting to tell others and being unable to find the words to express what they were feeling. There was also a deep fear about how their experiences may be understood by others.



I had a panic attack at work after the pressure of being a manager of a government customer service centre drove me to go hide in a dark cupboard till, I could stop crying and breathe normally...The added stress of having to face that environment every day and the shame I felt only compounded my deteriorating mental health.

(Female, 55-64 years)

...I struggle to find words and express what I'm feeling when highly distressed whereas normally I have excellent emotional language.

(Female, 35-44 years)

The role of life events and key transitions

People with personal and lived experience noted that distress often emerged in response to acute and persistent stress or coincided with key life transitions. Distress was often described in connection to a single stressor or traumatic event that then led to ongoing challenges that built up over time. At other times people described co-occurring or repeated stressors at key periods in their life. This included descriptions of situational crises at school or at work, the loss of a job, the loss of a significant relationship or a bereavement.



Working full-time, sometimes 12-hour days. Relationship breakdown/empty nester and loss of a loved family pet. I started not being able to sleep. Next my eating patterns changed then my emotional coping mechanisms started to fail (family, friends, hobbies) me. I began wanting to hurt myself and fantasised about [ways to hurt myself].

(Female, 55-64 years)

Distress as 'less serious' in the eyes of the service system

People described scenarios where they tried to access support when experiencing more generalised distress but were met with a 'lack of urgency' from a range of services and supports. They described feeling as though they needed to be in suicidal crisis or have a specific mental illness diagnosis to be able to access supports.



I saw the school counsellor on and off. 2 teachers supported me however they had to involve local (regional) mental health services. This was a negative experience. They called my parents without consent and then left me to deal with everything alone. ...No follow up support provided. At 19 I had a crisis and went to ED [emergency department].

(Female, 18-24 years)

I was scared that I wouldn't be able to be 'fixed' because I thought I was 'broken', I wish the nurses at the psych ward tried a little harder to understand my experience and not tell me I'm 'making it up'.

(Non-binary, 18-24 years)

Factors contributing to mental ill-health

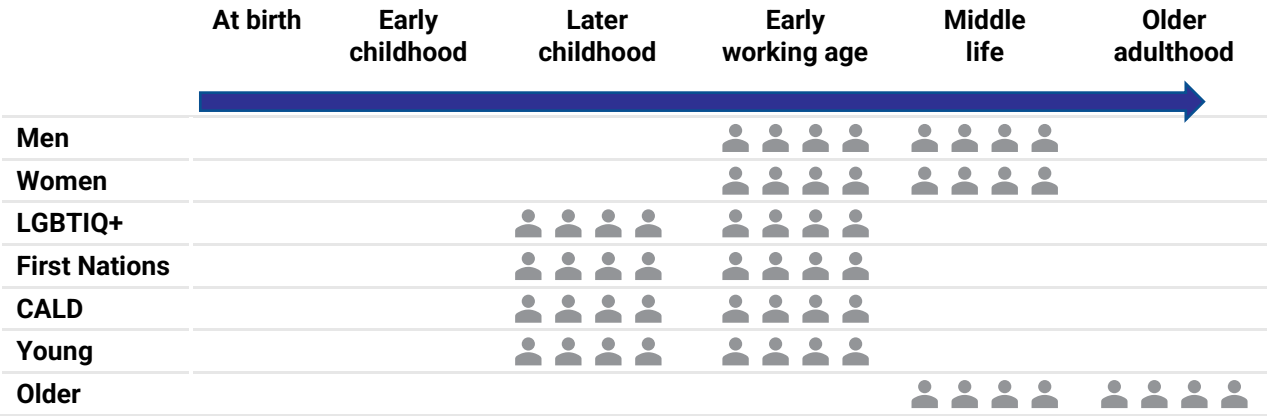
For many people, the lead up to mental ill-health was lengthy with a range of adverse experiences in childhood, adolescence and adulthood reported and many attempts to ‘seek help’.

Experiences of poor social, interpersonal, personal and community factors

In the thousands of experiences shared through surveys and focus groups, people described a range of social, interpersonal, personal and community factors that were experienced before the onset of mental ill-health as well as a range of factors that exacerbated the severity and impacts of the experience. While many people shared adverse experiences in early and later childhood, for both men and women they were more likely to report experiencing significant impacts in early working age and middle life (see Figure 1 below). Young people as well as people identifying as LGBTIQ+, First Nations, or from a culturally and linguistically diverse background were more likely to report significant concerns in later childhood and early adult life, with older adults reporting them in adulthood and later life.

For men and women, young people, older people and LGBTIQ+ people, interpersonal concerns were the most significant concerns reported, including relationship stress, psychological and physical abuse, isolation or loneliness, lack of support or grief. First Nations peoples more likely to report social factors such as poor living conditions, poverty, under employment or poor-quality employment, while people from a culturally and linguistically diverse background were more likely to report community factors such as discrimination, violence, economic insecurity, inadequate access to health care, disaster or emergency situations, as well as inadequate water, sanitation, and housing.

Figure 1. Life stage when factors associated with mental ill-health were most commonly reported.



Organic onset

For some people, mental ill-health emerged early in life without any identifiable psychosocial risk factors. People noted that sometimes there were early indicators of feeling different or being told they were different, but there were no identifiable events or concerns that contributed to the experience.



...commented on by family that I was 'highly strung' and overly emotional - rollercoaster was a common phrase.
(Female, 45-54 years)

Often mental ill-health presented as something other than a mental health concern. As a result, people reported going undiagnosed or unsupported until later in life, at which point the illness had progressed and the symptoms were much worse.



Started having suicidal thoughts at age 16/17 and self-harming. Felt rejected and outcast. All of my emotions were felt in extremes and any small inconvenience felt debilitating. It wasn't until I was at my worst and had ruined relationship after relationship, none of my antidepressants were helping, I felt lost, I made the effort to get a referral for a psychiatrist and was diagnosed with unmanaged mental health conditions at 27 years old. Changing medications has helped. And psychology, though I did feel in my youth that they didn't take the time to listen to my symptoms or try to understand or [seek to] suggest other underlying issues.
(Female, 25-34 years)

Impact of adverse childhood experiences

People with lived experience reflected on the role of adverse childhood experiences in contributing to mental ill-health as an adolescent or adult. People described witnessing and or being the victim of family violence, being sexually abused (mostly by family members or close non-kin connections), living in unsafe homes where emotional neglect was common, and the experience of bullying at school.



I was sexually abused by a family member as a child I did not disclose. By the time I was 12 I had been to the GP on my own and she diagnosed me with depression, anxiety, social phobia, panic disorder, dyslexia, attention deficit disorder (ADD), and a few other things. My parents didn't allow me to see a psychologist. I first saw one when I was 17 and had moved out of home.
(Non-binary, 35-44 years)

These experiences were rarely described as a 'one off' event, rather they were repetitive and cumulative in their impact. There were also intergenerational experiences described, with some referring to mental illness and drug and alcohol problems within the family, grief and bereavement as a child, as well as the impact of adoption and negative family responses to the emergence of a child's sexuality.



...when I was 11 (I was) exposed to death and grief which contributed to a lot of my anxiety struggles. I didn't understand that the struggles I was having during my adolescence were due to anxiety and was only diagnosed when I was 20 and sought help from my GP. Taking medication and talking to a psychologist has really helped my recovery and management.
(Female, 25-34 years)

Missed opportunities for children and young people

While the onset of distress and mental ill-health was commonly identified as emerging during adolescence, people also reported that it was often minimised by schools, health professionals and family. Participants reported feelings of being 'unheard' and 'lost, sad and alone' at this stage in their lives, with many reporting that distress often escalated to more complex experiences of mental ill-health and suicidal thoughts.



First self-harmed at 13 after knowing an older friend who did it. Struggled with confidence issues all through high school and adopted 'emo' style after having a lot of friends abandon me.... Saw therapist for anxiety in primary school because severe fear of dark and then returned at age 17 after suicide attempt. Incorrectly diagnosed with bipolar, took [medication] then decided the medications and treatment of psychiatrist was poorly done. Left therapy for years until 2021 as a result of finally doing the work on my own and ready to accept someone to talk to.

(Female, 18-24 years)

Participants in the focus groups shared concerns about the number of young children experiencing mental health concerns and the added impacts of societal changes, including the pandemic.



A lot of young individuals on the autism spectrum, humongous. Oh my goodness. We've got kids six years old that don't want to be here anymore. Who are [self-harming], who are six years old. And COVID has just exasperated that because those kids have been taken out of school and a lot of them don't like that change....

(Young individuals focus group)

Those who identified as neurodiverse reported additional challenges, including being labelled as 'problematic' by education and health professionals. During primary school and early adulthood their social and emotional needs were often viewed through a behavioural lens, providing limited scope for their distress to be noticed. Often their diagnoses of attention deficit hyperactivity disorder (ADHD), Tourette's Syndrome, and autism spectrum disorders, were seen as the primary concern rather than exploring co-occurring distress and mental ill-health.

Life transitions and increased vulnerability

Many people described experiences where one event, or several events that occurred in close time proximity, contributed to the initial onset of mental ill-health. These were often events that occurred during life transitions – birth of a child, breakdown of an important relationship, change in economic status, transition from military service. Often these events exacerbated prior issues that the individual 'had under control' until the stress resulted in a quick, and often severe, decline in mental health. Men often disclosed workplace issues or relationship losses in their personal accounts.



Bullying at work led to a breakdown from which I have never fully recovered. I lost my career, my family broke up, I couldn't work so ended up on a disability pension, accumulated a huge debt, used alcohol to try to cope with the anxiety which then led to me staying depressed longer.

(Male, 55-64 years)

Women also reported the loss of a relationships, exposure to domestic and family violence and the death of loved ones, as key periods of vulnerability. In addition, they often shared experiences of a sudden change that occurred during the perinatal period or the loss or termination of a pregnancy.



I have struggled with anxiety since adolescence, but my major issue happened with postnatal depression (PND) after the birth of my son. I hid the true extent, but still desperately sought help from many agencies because I could not cope and it took many weeks until I finally got help...I am still in recovery several years later, but I'm alive and have a good relationship with my son.

(Female, 35-44 years)

Exiting the workforce through retirement, injury or disability was identified as key point of vulnerability for adults and older adults. Concerns about economic resources, changes in social relationships and declining health all contributed to increased stress, especially where it was a forced change.



Psychological, physical abuse and neglect in childhood, abandonment during teen years by parents, physical abuse up to age 21 by father... abuse in workplace at age 26, no support from workplace and ended up with my first diagnosis in 2004 and a workers compensation claim. Systemic abuse via workers compensation claim, no return-to-work support... pensioned out through my superannuation...

(Female, 35-44 years)

Social isolation

Social isolation was identified as a significant theme across all the participant narratives. Over time, if people were unsupported and isolated when in distress it could contribute to more complex and acute periods of mental ill-health, which could further contribute to social isolation.

People also spoke of social connections as being protective and a way to reduce distress. This was important across the lifespan, but people spoke of how important it was to ensure children and young people were socially connected, with many impacted through the COVID-19 pandemic.



It's connections, like connection is so important for young individuals. So, if they're struggling with those connections and getting through, that's really, really big thing.

(Young individuals focus group)

Being physically isolated from friends and support networks (such as at school) made me withdraw completely from social life and I spent a lot of my time trying to sleep so I wouldn't have to deal with any of it.

(Female, 18-24 years)

The period transitioning from the family home to independent living was identified as a time when loneliness and isolation could occur. Physical illness as well as mental illness could isolate people from the range of support they need. People who live alone and have unique needs require additional social supports but are often left isolated.



People who live alone, especially, need immediate access to professional support when they become unwell. The difficulty is that when one is really unwell they are less likely to reach out for support from family or friends because they don't want to burden others, because of stigma, feelings of worthlessness, etc. Telephone counselling is not particularly helpful when one is in serious crises (assuming one is capable of even making a call) because what one often needs in such circumstances is practical support (food, an outing, someone to sit with, etc) ...

(Female, 65-74 years)

Stigma and shame

Stigma remains an important issue across the community, with experiences of stigma and shame shared across first-person accounts. Stigma acted as a barrier to support and impacted significantly on the person, but could also impact on family and friends, particularly for those who identified as coming from a culturally and linguistically diverse background.



So the community is putting pressure on them and in terms of stigma, parents must have done something wrong that their kids end up like this. Or you are not a good person because you are addicted or all of that, their own community puts as a pressure on them.

(Culturally and linguistically diverse focus group participant)

Shame, stigma and the need to educate individuals early about mental ill-health, and diversity of gender and sexual orientation were also strong themes emerging through the LGBTIQ+ focus groups. Participants spoke about multiple and intersecting stigmas that could be experienced by people and the way that tokenistic approaches do not address the causes of distress.



Something I feel kind of compelled to raise is, as a neurodiverse, disabled and chronically ill person, is that a lot of the stigma that's around things like mental illness, suicidality and drug and alcohol usage is rooted in ableism...And a lot of that is to do with the oppression of individuals with disabilities and chronic health issues. So if we talk about that, get that normalised, it can kind of explain some of the reasons why individuals engage with, what are called now, maladaptive coping mechanisms, or maybe they're actually protective coping mechanisms...

(LGBTIQ+ focus group participant)

Diagnosis alone was not a panacea for distress

First-person accounts of receiving a diagnosis of mental illness noted that it was not a time-limited event and was often unhelpful unless it 'unlocked' services and supports.

The most common age of diagnosis was 18-29 years, however those who identified as LGBTIQ+ also commonly reported diagnosis occurring before the age of 18 years. People with lived experience described diagnosis as a continual process, often changing across a person's life. Participants noted that much of the public education about mental illness did not communicate this effectively. Instead, diagnosis is often presented as an endpoint or the gateway to effective treatment, support and recovery.



...they always paint the picture of it can be fixed easily when that is false, the resources are limited and the demand exceeds supply. Everything is also practitioner dependent, individuals can't currently get into see psychologists, especially children... Realistic resources that are available immediately would have to be a help.

(Female 65-74 years)

For some, receiving a diagnosis of mental illness was a disempowering time, with a major focus on 'what was wrong with them' rather than identifying the supports they need. The involvement of multiple health professionals was described as confusing and 'othering', with diagnosis only being helpful if it enabled them to be linked in with effective community-based interventions.



I started experiencing mood swings around 20 years of age... Diagnosed with depression and PTS. Saw umpteen counsellors with little effect. Kept pushing myself but my work suffered. Lost my confidence, had panic attacks. Lots of sick leave as so tired and would be convinced that if I left my house something bad would happen. Despite antidepressants ended up losing my husband as he didn't understand. Had to stop working as so anxious and depressed, suicidal and had a couple of manic episodes. Ended up bankrupt and living in a shed. Finally found a wonderful psychiatrist who diagnosed bipolar type 2. Referred for [a specific treatment] which saved my life along with eventually finding an antidepressant that worked and a mood stabiliser.

(Female, 45-54 years)

Others reflected that diagnosis did not change community perceptions or make life easier for people to live with mental ill-health. In some cases, it could increase distress experienced through stigma. There was a desire to ensure that community attitudes shifted to make living with a diagnosis easier for people.



...So individuals are willing to talk. 'Oh yeah, go to your GP. Talk about this, do that.' But for example, if they get a diagnosis, you find that most of the friends disappeared. And so there is still a level of stigma that isn't really, it's not budging from the CALD communities. And that can be quite hard.

(CALD focus group participant)

Part 2:

A focus on services and supports



...our country's mental health system feels like a dodgy show ride...while trying to get help you end up going around in circles until you end up sick and then you give up and get off and you're just left on your own dizzy and feeling worse than when it started.

Female, 25-34 years





People’s experiences of services

The energy required to access support and navigate between services was described as exhausting and discouraging. People wanted early and proactive community supports that were trusted and accessible.

Helpful services are not always available and accessible

Participants in community Survey 2 were asked to rate their experience with a range of services and supports. In general, the services rated by participants as most helpful (e.g. psychologists, Aboriginal health workers and psychiatrists) were less likely to be rated as available and accessible. Conversely, the most available and accessible services (e.g. telephone or online supports) were rated as less helpful.

	Rated as helpful		Rated as available and accessible
	69% Psychologist		72% Crisis telephone support
	67% Aboriginal health worker		71% Online support
	60% General practitioner		63% General practitioner
	56% Psychiatrist		55% Clergy/religious
	44% Counsellor		40% Counsellor
	42% Social worker		39% Mental health nurse
	42% Mental health nurse		39% Psychologist
	37% Online support		38% Social worker
	34% Crisis telephone support		35% Psychiatrist
	30% Clergy/religious		16% Aboriginal health worker

A crisis-driven system that responds too late

Many of the stories shared by people with lived experience were shaped by the interactions they had with the system. Many people with lived experience of distress and mental ill-health identified the need for more community-based mental health supports long before a crisis emerges. Despite public messaging that encourages people to ‘reach out’ for help when in distress, people reported that when they reached out for support services, they were either not available or not able to assist unless they were in immediate crisis. Sometimes this meant that people indicated that they had plans to attempt suicide, just to access support.



Well, I suppose for me, it's individuals getting the appropriate care for their condition... I've given this advice and I've done it to somebody when they were deeply distressed... I said 'look, the only way that they will admit you is you have to say to them, 'I have a plan to kill myself'... I knew it wasn't true, it was the only way... that's the red flag that the clinician that's doing the admission has that if a person says that, then I will do it.

(Male focus group participant)

Being asked to wait for crisis meant that distress became more severe, and the impacts were more significant. People spoke about their lives 'being on hold', sometimes for more than 10 years, trying to get support.



I notice when my distress starts to rise and I usually reach out early - but get turned away from mental health services because I am not in 'crisis', even though I know I am heading for one. My self-harm increases, the voices in my head get louder and I lose perspective - blaming people around me for things that may not have occurred. Before I know it, I am in crisis either planning or making a suicide attempt, but at that stage it is too late for early intervention. I get admitted to hospital and know that I will be there for more than a month - disrupting my life and my family's life.

(Female, 35-44 years)

While for some, their general practitioner was the first health professional that they discussed their mental health concerns with, others went to the emergency department. People reported feeling judged and shamed for taking up precious health resources, especially if seeking help in a suicidal crisis.



Emergency departments are also a harmful experience. If I end up in an ED I am usually told something like 'we don't have enough beds for you, we only take the sickest of the sickest, it's your choice if you want to kill yourself' I'm not kidding, I have been told those exact words, 'it's your choice if you want to kill yourself' before being sent home.

(Non-binary, 25-34 years)

The way health professionals responded to people was a barrier for people wanting to continue with care or to access care again in the future. People reported that responses were cold, harsh and unwelcoming. The opposite of what someone needs when in distress.



I cannot emphasise enough that frontline workers and healthcare workers need to be more adequately trained in responding to mental health and suicide presentations. Across both public and private facilities and healthcare professionals I have encountered shaming, belligerence, lack of understanding, negative attitudes, inadequate care responses, uninformed care responses, and a total lack of interest or respect in really listening to the patient's story.

(Female, 45-54 years)

Disconnected services requiring the person to be their own navigator

Connections between services and within communities are a vital part of an effective mental health system so that support is provided regardless of the person's location, age, economic circumstances or cultural group^{iv}. However, in this research, there were countless stories about the disconnected nature of services and supports, which often put the responsibility on the individual in distress to navigate services. The onus was on the person to 'seek help again and again', often repeating information multiple times.



How about emergency staff take a person seriously. They feel it's OK to tell someone who is distressed that they can't help and to go somewhere else. I have always gone on my own to the hospital and leave with an address to go to. There is no way I can gather the strength to present somewhere else. I think it would be helpful if when you present at emergency or call access line that they can bring up your details and see your story and psych history so you don't have to repeat it again and again.

(Female, 45-54 years)

There was a sense that there were two ends of the service spectrum with very little in between that people could easily access. People specifically mentioned that only having the option of crisis responses or GP care is insufficient. Other options for those who are experiencing distress or mental ill-health that are available when needed and accessible were suggested as an improvement to the service offering.



...it's two weeks to get into the GP cause that's the first point of call as these sort of thing... There's help lines, you can tell the help lines and all those sorts of things, but it just seems there's that for individuals that are moving from ...mild to the moderate to the not suicidal...it is GPs...

(Male focus group participant)

A two-tiered system, where support is better when you can afford it

The difference between experiences of public and private health service experiences was evident. Those who had access to financial resources were provided with more choice about the professionals and services they accessed. For those able to access private services, ease of access, reduced wait times and what was perceived as better levels of care were reported.



The process is: ring a psychiatrist and ask if they are taking new patients. If no, scrub off your list. If yes, get a referral from your GP, submit the referral and wait a good couple of weeks to be told no. Ring the next psychiatrist on your list. Ask same question and if yes, go back to your GP and get a referral. And so on and so on...I opted for private over public as the waiting list for public is horrendous and I wanted a say in whom I had treatment from...

(Female, 45-54 years)

Cost was also reported as a barrier to private health care, particularly when considering that people living with mental illness will often have a reduced income and have out of pocket costs associated with accessing a psychologist and paying for medication. This makes it impossible for some people to access the right care, while those with the financial means were aware of this privilege.



... if you don't have the finances to be able to afford something and if you are depressed and that and it's not on the PBS and it's private, then how are you able to afford that? And then you become more depressed and then it's just a cycle that you become into. I'm fortunate to be able to afford private health, but then some individuals aren't able to, and then it's just, how are you to be able to access that certain treatment that you might need to?

(LGBTIQ+ focus group participant)

A need for safe and appropriate services for all people

First-person perspectives highlighted the shortcomings of the current service system that was more accessible if you were not from a rural area, not male, not young, not from LGBTIQ+ community, not Indigenous and not from a culturally and linguistically diverse background. People reported a number of instances where services were not safe spaces for people.



Anxiety from an early age meant I coped and managed relatively well with my mental health issues. High school was the most difficult time with little help...From my mid-twenties onwards, it has been challenging finding the right help. What has hindered recovery most of all is the inability to access appropriate help at the right time, as well as additional stressors and lack of support.

(Non-binary, 35-44 years)

People from culturally and linguistically diverse backgrounds described the need for services to adopt principles of cultural humility and cultural curiosity. It is important to consider the way people are engaged in difficult conversations, especially where there were cultural barriers to talking about suicide.



But we still have a lot to go, especially in things that it's difficult to train individuals, they have to actually experience it. You can train individuals how to use an interpreter, but they need experience to learn actually that the whole conversation is run completely differently with somebody from CALD background when you, for example, do a suicide risk assessment. So those two ends are very, very hard for individuals.

(Culturally and linguistically diverse focus group participant)

Participants highlighted the need for community designed and community-led initiatives that allow individuals to share their experiences in ways that are safe and appropriate for the community. The socially stigmatising experience of 'othering' was diminished when individuals could see others who are identifiable, 'individuals who reflect me', accessing as well as providing the services.



I really would love to see it more as a community responsibility and talking about how we support individuals in our community, how we support our friends...

(LGBTIQ+ focus group participant)

An opportunity to address social determinants across the lifespan

Participants emphasised the importance of more preventative approaches, where lasting positive change could target the needs of specific populations, including men and boys. This remit is well beyond the health system and includes exploring social factors such as housing and education to make a difference.



The answer to fixing the health system will never be found in the health system...It's housing, it's education, it's all those sorts of things. So it's the social determinants of health, and I think a lot of this extra mental health funding that goes in for governments, it's easier to do that and say, 'Look, we are doing a load of this,' when you're saying really the solution to a lot of the mental health issues and stuff are right back at the education level, the housing.

(Male focus group participant)

People also spoke about the opportunity to support people earlier, through ensuring improved emergency services, courts and other systems that interact with people who have experienced abuse. Many people shared the range of overlapping harms and challenges they experienced, which often distanced them from others and contributed to stigma. The opportunity to support people early in life and early in distress often sits outside of the formal mental health system.



Being too frightened to tell anyone of my childhood abuse eliminated any means of help for me, although having support for bullying may have given me more confidence at an earlier age, which may have helped me find work. After my first marriage failed, a mentor or social worker, maybe connected with Centrelink or the police, would have helped with general problem solving, financial and legal advice and given me more mental strength and confidence. Having a psychologist remain in my area would have saved me having to re-live my experiences and given me a sense of stability and longer-term support, potentially stopping me from having to take medication. In an ideal world, having someone I know and trust, immediately contactable to help relieve panic attacks while they are actually occurring would really have made a difference in my quality of life...

(Female, 45-54 years)

Evidence-based approaches

While a range of supports are needed, people with lived experience identified the need for more proactive approaches that respond early and can prevent the onset and impact of mental ill-health.

To complement the lived experience knowledge gathered through this research, a systematic review of the literature was conducted to identify studies reporting on preventative and community-based interventions. This was enhanced by a review of recent policies and reports. In Australia, the importance of community-based and preventative interventions, is emphasised. There is, however, a lack of clarity about what interventions, when, for whom and how they are best designed and evaluated.



Tailoring supports to the severity of experience

Interventions are most effective where they consider the severity of experience and the ways in which people prefer services to be delivered. Individuals with mild to moderate symptoms were more likely to benefit from a range of digital and light touch interventions that are highly interactive and build a sense of connection. Individuals with more complex mental ill-health were less likely to benefit from these interventions, requiring more targeted and tailored supports.



Earlier responses to distress

Prevention and early intervention programs can change the trajectory of an individual's journey of distress and mental ill-health. Programs have primarily been targeted at 'early in life', but early intervention may also be considered as 'early in distress'. There is also an opportunity to extend the environments where interventions are delivered, considering any setting where distress can emerge.



Responding to trauma is key

Early community-based intervention needs to be targeted to those who are more vulnerable to mental ill-health. Targeted interventions for those who have experiences of trauma can help to prevent further harm experienced by individuals reaching out for help. Enhanced awareness of the cumulative impact of trauma is needed so that interventions can reach people when they need it.



Community based interventions following service contact

The importance of community-based interventions following contact with health, justice and other social care services has been highlighted through policies and the perspectives of people with lived experience. The models of community outreach and support, and their effectiveness, have been less well described. There is an opportunity to co-develop and evaluate these services with community.



Strengthening the evidence

Further efforts are needed to strengthen the evidence base. Interventions need to improve their recruitment strategies, offer hybrid delivery options, commit to standardised outcome measures, have a targeted approach, and embed co-creation in development and delivery of interventions.

Part 3: Pulling it all together

...I think there are just so many individuals out there in the universe with a wide variety of untold stories of all different kinds... and I wonder what kind of institution we could dream, where individuals could go, or access somehow, and feel safe to tell those stories that maybe they can't tell anybody else...

Focus group participant



Mapping common experiences

Mapping common experiences is not an attempt to simplify the complexity of individual experiences. Rather it allows for a broader understanding that can assist with the design of services and supports.

While each person's journey is unique, there were some common experiences identified through the first-person research. By mapping common experiences, we are better able to highlight the interaction between social determinants of mental health, life experiences and transitions, and people's experiences of distress and mental ill-health. The common pathways identified have been mapped to assist with identifying opportunities to intervene and provide support earlier in a person's journey. They should not, however, be used to simplify the complexity of experiences, which are different for each person.

Journey 1

Where a situational crisis occurs, and early tailored support is received, the person can move through the challenge and reflect on what occurred.



Opportunities

- Prevention action, together with early responses to distress can shift the trajectory away from more complex and lengthy experiences of mental ill-health.
- Action occurs in the environments where people live, work, learn and connect with a range of services (health, social, legal and other).
- Health messaging that focuses on the broader social determinants of mental health, including the impact of significant life transitions and where to access early, appropriate support.

Journey 2

Where a significant stressor or life transition occurs, an individual can experience distress. When the right support is not received early enough, distress increases and mental ill-health may follow.



Opportunities

- Distress is identified as a serious concern that can impact current and future health and wellbeing, with early supports provided. This includes proactive responses to distress that meet people 'where they are' rather than requiring them to seek help only in a crisis.
- Targeted outreach and support at critical points of disconnection and transitions, for example, adolescence to adulthood, becoming a parent, relationship breakdown, exposure to disaster, retirement, generally with multiple challenges occurring simultaneously.

Journey 3

Where an individual experiences multiple adverse experiences, this can result in ongoing vulnerability, further abuse and more complex experiences of mental ill-health.



Opportunities

- Understanding the interwoven experience of mental ill-health as an outcome of a trauma and abuse history is needed across health services, social services and other key settings.
- All services must be trauma-informed, with a supported workforce as prior experiences may resurface at times when individuals are under increasing stress and strain.
- Tailored and effective services and supports are required, with a focus on more proactive community-based supports and care-coordination that links people with the range of services they may need.

Journey 4

Where an individual experiences mental ill-health they can experience associated trauma if the treatment and support is withheld or what is provided is not person-centred.



Opportunities

- The diagnosis and treatment of mental ill-health can contribute to and exacerbate trauma, especially where people have poor experiences of care.
- Trauma-informed and person-centred care is needed, with considerations for improved community and peer-led supports.
- A reduction in societal, service and setting-based stigma and discrimination would improve opportunities for people to contribute at home, school, work and in the community.

Conclusions

Each person's experience is unique but personal accounts from over 3,400 people provide an opportunity to better understand distress and mental ill-health, and deliver supports that have people at the centre.



Shifting the responsibility for 'good mental health' from the individual to a whole of community, whole of service system approach

Interpersonal, community or societal challenges contribute to the onset, severity and impact of mental ill-health; yet responsibility for maintaining and improving mental health and wellbeing is still often focused on the individual. Service improvement should consider ways to design interventions that acknowledge the social determinants of mental health and the ways in which broader experiences shape the experience for individuals.



Prioritising services that increase connectedness and support people to connect with the right care at the right time

These types of care-coordination approaches are best provided by allied health and primary care providers with options for peer-to-peer connection. This allows for partnerships between the person providing care and the person receiving care to track and reflect on the emergence of mental ill-health, explore the suitability of a diagnosis and treatment options, and investigate the role of social determinants. More connected services and supports would ensure people do not need to seek help repeatedly or tell their story over and over again.



Focusing on early responses to distress across settings

Estimating the impact of distress in peoples' lives and responding early to mitigate impacts is critical to offering compassionate and person-centred service delivery. A significant proportion of people with lived experience highlighted the ways in which distress emerged, sometimes months or years prior to a significant crisis. Example strategies to respond early to distress include introducing questions about the emergence of distress and increasing health promotion messaging about the importance of responding to distress.



Monitoring points of disconnection and transition

Providing proactive supports at points of disconnection and transition can reduce severity and prevent the onset of distress and mental ill-health. Key moments such as relationship breakdowns, becoming a parent, moving between primary school and high school, leaving home and becoming unemployed are significant life transitions where people benefit from support. There is a role for services outside of health to provide support, and approaches should be co-designed to build on existing evidence.



Moving away from describing mental ill-health as a single event or point in time

There can be a misconception among communities and people working in mental health and suicide prevention that distress and mental ill-health are time-limited events that require people to 'seek help'. This includes messaging that suggests diagnosis as the gateway to services and supports. The reality for many people is quite different, with often a lifetime of events, childhood and adult traumas, and socioeconomic, environmental and situational factors that can all change how distress is experienced over time. Enhancing public health messaging to demystify diagnosis may assist in helping people to understand that diagnosis can be an ongoing, inexact response to both mental illness, trauma and distress. There is a role for people with lived experience to be an active partner in the design and delivery of this messaging.



Using language that takes a holistic view and incorporates the role of social determinants to describe distress

People engaging with services or accessing supports need an approach that seeks to understand what happened to them rather than what is 'wrong' with them. This approach considers how a person's life circumstances may be impacting their distress. Many people noted that their engagement with health services, particularly during crisis periods, focused only on the acute presentation rather than considering their broader situation. This contributed to inappropriate care and longer periods in acute distress.

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