CURING THE SICKNESS OF THE SYSTEM

Y-CHANGE'S SUBMISSION TO THE ROYAL COMMISSION INTO VICTORIA'S MENTAL HEALTH SYSTEM

JULY 2019

BERRY STREET
We're for Childhood
SINCE 1877

ACKNOWLEDGEMENTS

Y-Change wishes to begin by acknowledging that we live on sacred land that belongs to the First Nations People. We pay our respects to Elders past, present and emerging and honour the self-determination and survival of Indigenous Australians. We acknowledge the continued impacts of colonisation on the communities of Aboriginal and Torres Strait Islander people. Always was, always will be Aboriginal land.

We also wish to acknowledge that as people who utilise personal experiences to influence social and systems change, we stand on the shoulders of giants. People who use mental health services have been part of an international human rights movement since the 1970s, with some activism recorded as far back as the 1800s.[1] To the global consumer movement, without your continued advocacy and fight for the influence of lived experience, we would not be here today. We continue to fight for and uphold your wisdom and vision for change in all we seek to do.

The insights throughout this submission are authorised and owned by the Y-Change team of Lived Experience Consultants. We wish to thank and formally acknowledge the team members whose perspectives have shaped this submission and its recommendations: Alyssa, Beanz, Emilie Cuinn, Janelle, Kaitlyne, K.C., Maddie, and Tash. Each of their names appear here and throughout this submission as they have requested, to either reveal or protect their identity.

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INTRODUCTION

About Berry Street

Berry Street is Victoria's largest child and family welfare organisation. We have supported children, young people and families for over 140 years to address the effects of violence, abuse and neglect. Through our services we: provide safe homes; heal childhood trauma; strengthen and empower families; advance children's learning and development; build and share knowledge; and advocate.

In 2017-18, we supported over 28,000 families, children and young people, including over 1,000 service users though our therapeutic services, over 12,000 through our family violence services, and over 1,850 through residential and foster care arrangements.

Berry Street continues to innovate and introduce evidence-informed and evidence-based practice in the work we do every day to improve the lives of families, children and young people. We believe children, young people and families should be safe, thriving and hopeful.

About Y-Change

Young people who have experienced disadvantage are the only people who can tell us what a policy looks and feels like when it comes to life. They are key knowledge holders in the search for 'what works' and the understanding of what doesn't, and they must be at discussion and decision-making tables, always. Berry Street aspires to make this a practical reality, not only in our organisation and our work, but in all contexts that are important in young people's lives.

Y-Change is a social and systemic change platform for young people aged 18-25 with lived experiences of socioeconomic disadvantage. Over six months, the team of young people receive training that enables them to understand, build on and adapt the skills and knowledge they have gained as a result of their experiences. They are then offered 12-months of employment with Berry Street as Lived Experience Consultants to use their skills, knowledge and experiences as a form of expertise to drive social, organisational and systemic change.

The team work on:

1. Internal projects and opportunities to develop youth partnership practices and inform and influence policy;
2. External projects contracted via our social enterprise consultancy – Momentum; and
3. Self-driven projects that emerge out of the team's areas of interest and for which we seek specific funding.

About Momentum

Momentum is the emerging social enterprise arm of Y-Change, offering a range of services to support organisations and government improve their youth engagement practices.
Momentum Lived Experience Consultants draw their expertise from lived experience of disadvantage, and use their skills, knowledge and insights to support the development of better programs, policies and systems to support children and young people.

The consulting team add value to clients' youth engagement practices through offering:

- Advice on youth engagement strategies and approaches;
- Bespoke training and workshop facilitation;
- Public speaking and keynote presentations;
- Tailored consultancy packages; and
- Undertaking peer consults with service users.

About Berry Street's youth participation approach

Shifting from Engage to Exchange

In 2012 Berry Street drew up a set of aspirational commitment statements (see below) outlining the way in which we hoped to partner with young people. Today those statements reflect our active practice. To get to where we are now, we have needed to take risks, experiment and take the time to seek out better ways of working, in partnership with young people.

Commitment to Youth Engagement

We have made a commitment to engage young people in the work of Berry Street because we respect them as the experts of their own experience. It is their fundamental right to be heard and we have a lot to learn from young people about the experience of contemporary childhood. We are challenging ourselves to find the best ways to enable young people to share their knowledge. For young people in services such as out-of-home care and others who experience disadvantage, genuine opportunities for participation are very limited; we are keen to redress this balance.

Our work alongside young people is based on the following principles[2]: **1) Equality of expertise; 2) Young people are not just the subjects of our work, they are our partners in it; 3) Being challenged is how we grow; 4) One Young Person ≠ All Young People; 5) Accessibility; 6) The person fits the project; 7) Safety; 8) No False Expectations; and 9) Setting up for success.**

Further reading

To understand what led Berry Street to this point in its youth participation practice, see *Elevating Youth Engagement*[3] by Lauren Oliver, Senior Advisor Youth Engagement at Berry Street.

To understand the role of Y-Change in progressing Berry Street's practice, read the *Y-Change Pilot Project Evaluation*[4], conducted by The Youth Research Centre at The University of Melbourne.

Defining lived experience

"Authentic help means that all who are involved help each other mutually, growing together in the common effort to understand the reality which they seek to transform. Only through such praxis – in which those who help and those who are being helped help each other simultaneously – can the act of helping become free from the distortion in which the helper dominates the helped."[5] **– Paulo Freire**

For the purpose of this submission, it's important to briefly touch on how lived experience is defined in the context of social change and the work of Y-Change.

It is useful to note that there is no singular definition for lived experience; rather, attempts at describing it in different contexts.

The main description we draw from comes from Oxford Reference[6]:

> *"Personal knowledge about the world gained through direct, first hand involvement in everyday events rather than through representations constructed by other people. It may also refer to knowledge of people gained from direct face-to-face interaction rather than through a technological medium."*

Thinking about the use of lived experience in the context of social change, here are two additional descriptions that work to illustrate the influence of personal experience.

> *"A political act that re-frames the balance of power and is part of a movement towards greater equity, rights and justice."*[7]

> *"The experience of people on whom a social justice issue, or combination of issues, has had a direct personal impact."*[8]

These definitions work to illustrate how and why lived experience is influential within a social change context. When lived experience is spoken about as an act of 're-framing the balance of power', it is through focusing on centring the voices of those who experience the effects of policy on a day-to-day basis. Those with a lived experience are in a unique position to tell the story about both the individual and collective impact of policy decisions and social systems on their everyday lives.

Broader system context to this submission

"People go to their doctors who prescribe medication, which is an inadequate response. If instead governments took issues such as inequality, poverty and discrimination seriously, then you can expect improving mental health. We need to target relationships rather than brains."[9] **– United Nations Special Rapporteur on Health, 2019**

In 2016, just under one in four young Australians aged 15-19 years who responded to the nation's largest annual online 'temperature check' of teenagers, *Mission Australia's Youth Survey*, met the criteria for having a probable serious mental illness. Concerningly, there has been a significant increase in the proportion of young people meeting this criteria over the past five years (rising from 18.7 per cent in 2012 to 22.8 per cent in 2016)[10].

Victoria spends the least per person on mental health in the country. As a state, our access to mental health services is nearly 40 per cent below the national average.[11] Young Victorians who experience socioeconomic disadvantage are increasingly at risk of mental ill-health[12] due to factors such as family violence[13], homelessness[14] and poverty[15] and experience significantly poorer mental health than the broader community. Recent findings show that experiencing poverty makes it significantly harder for people to deal with mental illness.[16]

It is important to contextualise this submission in the overarching systems and cultural norms that affect young people's everyday lives – mainly, that we live in a Western society that emphasizes productivity as a key factor in defining a person's worth. For those who are unable to work, for example, this measure of value impacts people's experiences of mental health and wellness, access to recovery supports and sense of belonging. Increasingly, the overarching message to those doing it tough in Australia is that if they are unable to 'pull themselves up by their bootstraps', then something must be inherently 'wrong' with them and they will be punished for it.[17] [18]

As you will read in the Y-Change team's narratives further into this submission, this mentality is pervasive and one that has profoundly influenced how these young people with mental ill-health have been viewed and therefore treated when needing to access help in a variety of settings. Through this submission, Y-Change wishes to highlight the harmful effects of punitive approaches to public policy setting, and the importance of pivoting towards and strengthening therapeutic responses in Victoria's mental health service system.

About this submission

At the heart of this submission are the voices of eight Lived Experience Consultants from the Y-Change team. These are young people with a lived experience of mental ill-health and other intersecting issues such as alcohol and drug abuse, homelessness, family violence and experiences of the out-of-home care system. Their insights have been privileged in the context of this submission as we believe that those with a lived experience are more often consulted than partnered with when it comes to recommendations for systems change.

Part of our work at Y-Change is to pass the microphone to those whose voices are traditionally unheard and support our consultants to envision and work towards the changes they wish to see in their communities. Their collective insights in this submission aim to tell the story about what is not working in Victoria's mental health service system, from the perspectives of young people who have used it.

Morgan Lee Cataldo, the appointed project worker who conducted interviews with the Y-Change team and collated this submission, is also a young woman with a lived experience of mental ill-health and has accessed the Victorian mental health service system.

This submission aims to capture the on-the-ground realities, from young people's perspectives, of what gets in the way of experiencing mental wellness. Even during times of upheaval and instability in their own lives, the Y-Change Lived Experience Consultants gave their time to feedback incredibly raw and visceral stories to us in the hope that they will influence systemic transformation.

The full transcripts of the Y-Change team's interviews, shared as part of this submission with their consent, can be found at the end of this report (see Appendix A).

Content warning

The Y-Change team wishes to share that for all those reading beyond this point, this submission includes detailed accounts of: self-harm and suicide, addiction and substance abuse, intrusive thoughts and negative self-talk, and hospitalisation and medications. It makes mention of: emotional and physical abuse, manipulation and sexual assault. There are implications of malpractice and negligence from medical professionals.

Language

The use of 'mental illness' and 'mental ill-health' are used interchangeably throughout this submission, as well as 'consumers', 'help-seekers' and 'service users.'

Methodology

At the heart of this submission are the insights of Y-Change's Lived Experience Consultants with personal experiences of Victoria's mental health service system and mental ill-health.

Long-form interviews

A total of eight members of the Y-Change team offered their expertise for the purposes of this submission response. Their perspectives were shared through one-on-one discussion sessions with the Project Officer Youth Engagement at Berry Street.

A series of two-hour sessions were scheduled in partnership with each of the team members, with significant pre- and post-session coaching and support. This included sending consultation questions in advance, check-ins to see what the team members might need to support the safe sharing of their stories during the process, and post-session follow-up.

The Lived Experience Consultants are paid as casual employees of Berry Street. These sessions are considered a core part of the team's advisory work.

Formal submission questions

The Y-Change team were asked to reflect on a series of open-ended questions in relation to Victoria's mental health service system. This set of questions was re-designed from the original set of recommended questions listed on the Royal Commission into Victoria's Mental Health System (RCVMHS) website[19] by the Project Officer Youth Engagement and Senior Advisor Youth Engagement at Berry Street. This was to ensure the questions being asked were more accessible.

These open-ended questions were as follows:

- How should mental illness be treated/supported and by whom?
- What makes experiencing mental illness hard systemically/socially/financially?
- What can be done to prevent mental ill-health?
- What do you think is being done well to support young people experiencing mental health?
- Who needs support and how do they need supporting?
- Who is being left out of the conversation about mental health & what barriers are they experiencing?
- How does lived experience consultancy work interact with your mental health?
- As a young person employed by an organisation, what do you need your employer to know/do to better support your mental health?
- Is there stuff we do in Y-Change that supports or makes more difficult your experience of mental health?
- Anything else you want to share?

The Y-Change team's responses to these questions can be found on pages 13-37 under *'Qualitative themes in response to the Commission's questions.'*

Consent process

The process of obtaining informed consent is a centrepiece of how Y-Change operates, values its team members and upholds the dignity and respect of young people and their stories.

All one-on-one sessions were organised in collaboration with the Y-Change team members. The process of a Royal Commission was explained in accessible terms and in a way that highlighted the importance of listening to the voices of young people at the centre of this process and having their insights formulate recommendations for change.

Each of the Lived Experience Consultants was notified of their rights during the interviewing process and was made aware that their information would end up in this report and may be used for other reporting purposes through Berry Street, but only with their explicit consent.

Confidentiality

The Y-Change team members' names appear throughout this submission as they have requested, to either reveal or protect their identity. It was also explained that the information they have shared would be available and accessible to the general public if the submission was uploaded to the Royal Commission into Victoria's Mental Health System website.

Specific mental health organisations and commercial companies named by young people have been de-identified, with the exception of good practice examples that the inquiry should examine.

Summary of Recommendations

- **Recommendation 1:**
  Nothing about us without us – developing the Commission's final recommendations in partnership with people with lived experience

  The Commission must to be mindful of the fact that, unless they are proportionally represented by people with a lived experience, they will be analysing the material from a position of privilege. If the Commission wishes to begin this reform process in the way they mean to continue it, partnering with people with a lived experience from this point on makes a powerful statement.

- **Recommendation 2:**
  A shift towards holistic and therapeutic care

  Fundamentally shifting towards a system that prioritises holistic care is about moving from the mindset of 'what's wrong with you' to an approach that asks 'what happened to you' – shifting the pathology away from the help-seeker and to the social systems affecting and surrounding them.

- **Recommendation 3:**
  Mental health literacy as part of Victorian Curriculum and schools' culture

  If teachers and schools don't have the capacity for wrap-around services for students doing it tough, it is crucial that significant training and understanding of and processes for appropriate referral pathways and follow-up are built-into school structures to ensure no young person falls through the cracks or gets left behind.

- **Recommendation 4:**
  Growing the lived experience workforce as a specialised, integrated and legitimate field of practice as part of service sector reform

  The methodologies of co-design and co-production are gaining momentum. When thinking about re-educating and re-designing the mental health service system, those with a lived experience of mental ill-health must be partnered with, and at the forefront, of sector reform.

- **Recommendation 5:**
  Strengthening the mental health and wider community service sector workforce through specialised training and workplaces that centre wellbeing

  Part of supporting the mental health service sector workforce to strengthen practice is through a commitment to ongoing professional development opportunities for specialised training and ensuring workplaces centre the importance of wellbeing for all staff.

- **Recommendation 6:**
  Lifting the most marginalised young people and their communities out of crisis and breaking the cycle of intergenerational trauma

  We cannot look at mental ill-health in isolation of intersecting oppression and traumas, such as child abuse, homophobia, poverty and racism. Without addressing the underlying, systemic inequalities profoundly impact young people's mental health, any movement we make towards reform will have us stuck at what we refuse to acknowledge. We need bold, progressive action towards a future for all children and young people in Victoria that is full of opportunity and centres dignity.

- **Recommendation 7:**
  Equalising the balance between awareness-raising and capacity building initiatives

  As part of reform in the mental health service system, it will be crucial to balance the investment made in awareness-raising campaigns *and* in building capacity of the sector to be able to handle the volume of people seeking help as a result of wide-spread culture change.

Each of these recommendations is detailed in full on pages 38-48 of this submission.

QUALITATIVE THEMES IN RESPONSE TO THE COMMISSION'S QUESTIONS

What young people who navigate the service system shared about their experiences

Due to the volume of data from the one-on-one sessions with the Y-Change Lived Experience Consultants and the depth and length of responses to each question, their quotes have been arranged in relation to emergent themes from their narratives, rather than ordered in a question/response style to each submission question.

The following are insights into what works well and not so well for young people who have used and continue to use the Victorian mental health service system. The themes are in relation to the types of personal/individual-level circumstances and system/structural-level circumstances. The number next to each young person's name signifies their age.

1. Addressing stigma and supporting inclusion

"We need a whole cultural shift, and this includes schools. If a kid chucks a tantrum, the typical response is that you get punished. No-one asks why they are acting out. There needs to be education about how to express emotion in a safe and healthy way, how to communicate about what you're going through. We're not dealing with the deep emotions in people." **– Emilie, 19**

Here we explore the ongoing experiences of stigma young people with mental ill-health continue to face in their schools, workplaces and communities. It also touches on the importance of informal supports and mental health literacy for young people to be able to support others doing it tough and knowing how and where to seek help if they need it.

The Y-Change Lived Experience Consultants interviewed for this submission reflected on the fact that, in our society, experiences of mental ill-health are pathologised and considered 'something to fix' rather than integrated as a normal and ongoing aspect of people's lives. They see themselves and their peers left stranded by a community-wide lack of informed education about mental health, mental illness, how to spot early warning signs and how to support others when they need help.

"We need real education about mental ill-health. We need to stop hiding it. My brother needs to be able to talk to someone to be able to understand and seek help with what he's going through as he watches me go through what I'm going through at home. For years and years, my mum didn't want to believe I had a mental illness. When I was first diagnosed at 14 then again at 15, she didn't believe it. I don't think she understood what was going on. She still talks about what happens like I don't have a mental illness. If she looked at people with symptoms of borderline personality disorder, she would be able to immediately identify every symptom with me, but when it comes to me – it's like she can't accept it." – Alyssa, 19

"We need to teach people strategies about how to cope in everyday life with their emotions and not label them as 'bad' – they are emotions, and everyone experiences them. Why are we still treating mental ill-health as taboo when one in five people[20] experience it?" – Emilie, 19

"Preventing mental ill-health isn't about trying to stop it – this isn't a goal we will ever reach. We need to understand that it's something that will always influence us and is something that is influenced by the world around us, just like everything else in life. It changes and moves with us as the world changes and moves. There's no such thing as fixing it. It's like spiders, most of us don't like them but we can't get rid of them because they are fundamental to the ecosystem." – Maddie, 21

When friends and fellow students aren't equipped to support their peers doing it tough, it can cause significant distress and a breakdown of relationships, which has a compounding effect on existing mental health issues.

"I remember speaking with a friend about my sleeping patterns, about how no matter how much or little I slept, I always felt tired and my friend said that this might be a sign of depression. There was silence after that and then there was nothing ever said about it beyond that. I also had a random classmate come up to me and ask if I was experiencing depression, so clearly people were seeing something. They didn't know what to do or that there was anything they could do to help me. So, I kept denying it because I didn't realise and eventually stopped talking about it altogether." – K.C., 25

An issue that is linked, but often seen as separate, is the lack of drug education and harm minimisation approaches for young people. This means that they are often left in the dark regarding the ways in which drug use can impact their mental health and unable to make informed decisions.

"The lack of drug education makes things way more difficult, too. I think the only reason I'm not psychotic right now is because my parents gave me proper drug education. One of the things I'm most grateful for is that I always had a safe place to take drugs." – Beanz, 22

Significant opportunity is missed by school systems that are unprepared and ill-equipped to support young people experiencing mental ill-health, especially high schools. The Y-Change team recognised an urgent need for mental health specialists, wellbeing staff and mental health literacy to be firmly embedded in Victorian schools.

"In terms of education, my school didn't support my mental health at all. My school told my friends not to hang around me and told people that I was dangerous." – Emilie, 19

"Because of how the teachers had approached my self-harm at school, when I did need to go to headspace I ended up delaying it for over a year because I felt like I would be disregarded and not treated seriously, the same as how I was treated by the teachers in high school. Teachers need training on how to sensitively approach young people's mental health. I felt like I was passed around like a piece of meat." – Janelle, 20

"Interestingly enough, my old high school now has an onsite youth worker. When I was there, we had a wellbeing coordinator and a chaplain. We also had a psychiatrist, but this was only on offer once a week. We had over 1000 students at my school, so the waiting lists were huge. We need more counsellors and wellbeing staff at schools, not just psychiatrists and clinicians. We need people who are human and who are holistic in their approaches." – Kaitlyne, 22

In young people's workplaces, a lack of mental health support and literacy can result in underemployment, unemployment and exclusion.

"Having to work whilst dealing with mental ill-health is extremely difficult. Like, when I worked at a fast food restaurant, I would drop something and then I'd obsess over it and start crying. I would then go to my supervisor and let them know, but they'd force me to stay. This makes it really hard because what I need is a bit more flexibility and more understanding staff. So, after my last hospitalisation, I had to leave that job because they weren't understanding and didn't support me… We need workplaces to be actively supportive for young people with mental ill-health, not just one poster in the staff room saying you can call an external provider to get help. We need mental health workplans to be brought into workplaces that you can give to your boss and get support. It should not affect you either getting or keeping your job, but it's there for your boss to know what's going on – to be able to access a self-care day or understand there may be times we have to leave if we're really overwhelmed." – Alyssa, 19

Young people who have been unsupported or unseen by the school system and excluded and judged in the workplace then turn to the government sector for support, often finding an insufficient understanding of mental ill-health and inadequate responses and support from job seeker agencies. This creates further exclusion for young people already doing it tough.

"I mostly feel too overwhelmed to sit in Centrelink. It's really overwhelming being around other people at extreme levels of crisis. Three months after my brother took his life, I was told by a Centrelink worker that I "should be over it by now" so I could get back to doing job searching through Newstart. This is while I was grieving his death and asked if I could have an exemption from looking for jobs during this period. My mother gets medical certificates saying she can't work because of mental and physical health and is told by Centrelink that this is no longer plausible evidence, so has to give regular blood tests to prove she's unwell. In terms of Centrelink, you so rarely get the help you need. You are forced to work even if you're in crisis, traumatised or completely unable to work." – Tash, 23

Stigma is often layered and permeates through every level of systems, even when they are designed with the intention to elevate, encourage and support people. Our beliefs about what constitutes 'success' and 'worth' are informed by a broader system that discriminates and disregards when people don't or can't conform. At best, many young people doing it tough receive pity and sympathy and at worst, rejection and denial. Neither option is adequate for nurturing resilience and self-determination in relation to young people's mental health.

"The World Health Organisation's definition of mental health is 'a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.' [21] *This statement is so damaging. Who says that the person who is unable to work is unproductive or invaluable? People have different measurements of what worth and value looks like and this is often cultural and based on your values. Health is a spectrum, not something that is either complete or incomplete."* – Maddie, 21

Supporting genuine, systemic inclusion will require a culture shift, perhaps several. There will need to be seismic shifts across institutions regarding perceptions of 'success' and worth that incorporate a deep understanding of the pervasive and enduring nature of mental ill-health in modern society. Communities, schools and workplaces will need the tools and mechanisms to be able to open themselves up to the value and opportunities that become available when *everyone* is invited to participate, to whatever extent they are able. This requires approaches that are grounded in awareness, compassion, flexibility, understanding, and acceptance.

2. Getting the support you need when you need it

***"There's no such thing as a one size-fits-all approach because there's no such thing as a one-size-fits all solution for people's mental health."* – Kaitlyne, 22**

This section shines a spotlight on the current limitations to sufficient care for young people navigating Victoria's mental health service system. Each member of the Y-Change team had significant stories to share about seeking help as a young person in crisis, with the most common barriers and challenges captured here. This section illustrates what's getting in the way for young people in receiving the care they need, and what needs to shift in the system to improve quality of care and outcomes.

2a. Listening to and seeing the whole person, and consumers working in partnership

It appears clear to the Y-Change team members that the mental health service system has a mentality of 'fixing', versus meeting people where they're at and encouraging self-determination. Coupled with the fact that, in their experience, few mental health professionals truly listen or trust help-seekers' own knowing and understanding of themselves, this cocktail of disempowerment impacts young people's sense of agency and has ongoing affects. Particularly affected are those young people who are exposed to the service system from an early age.

"The progression of my own mental health and feeling better in terms of being able to manage my own mental health has very rarely relied on other services helping me. Most of the reasons why my mental health is better today is because I've done the work myself. The mental health sector comes from the point of view that they have to 'help' you and there's no real emphasis on what kind of work you have to do on yourself and how you have to help yourself. I've met people who rely on other people to fix them and I think a lot of mental health professionals have put that expectation on young people – that they can somehow 'fix' them." – Emilie, 19

"Whatever I said, she was very dismissive. She didn't know me but acted like she already knew what was best for me. It took me so long to find a medication that had worked for me in the first place, so I needed the doctor to listen to me and she refused." – Kaitlyne, 22

"When I'm asked for examples and give the 'wrong example' – I'm then written off. There's no room for nuance or exploration. It's so much about what you have and then having to prove you have it – such a lack of trust for a person's internal world and feelings. Anytime I've gone to a mental health professional with prior knowledge that I might have researched myself, I feel like they automatically dismiss it. There's a real stigma around self-diagnosis but ultimately, who knows me better than I know myself? I'm not self-diagnosing and never have, I've always gone in with the attitude of 'I've done some research, this is what is resonating with me so can we explore this?' and I've always been shut-down. How can you tell these things about a person in a single session when you don't know them and have no grasp of their past experiences?" – K.C., 25

A sense of territorialism amongst the workforce has communicated a lack of understanding that young people may need access to more than one mental health professional to feel fully supported.

"I've had mental health professionals be mad at me for saying I want to see other people, not solely them – when I know I need multiple forms of support, not just singular. I feel like we need multiple points of access, not just one who is meant to cover all bases. For years, I've known I need a counsellor for talk therapy and a clinical psychologist or psychiatrist for diagnoses and managing medications if necessary and I've struggled to find one that I'm happy with, let alone two or more." – K.C., 25

In turn, these factors feed into power differentials in the client-therapist relationship that impact young people seeking help, something which few mental health professionals seem to comprehend.

"You can't go into this work flippantly and seeing it just as work when you're going to have such a profound, direct impact on other people. In the mental health sector, there seems to be a huge culture of arrogance. Everyone is so sure of what they know because of what they've studied – that they're 100 per cent an expert. So much so that they refuse to be questioned and that's dangerous. The absolute assuredness, even when they are wrong. Being so sure to do things like prescribe medication – even when it's not the right one – to put the safety of clients at risk because they need to be right. That they have no concept of the fact that they might be wrong is frightening. This then gets even more complex when you have such self-assured professionals contradicting each other in their advice and diagnoses." – K.C., 25

Once young people access support, the overreliance on compliance, structure and clinical approaches to mental health and mental illness often don't benefit or resonate with them, especially those with trauma histories. Worse, experiences of hostile attitudes from mental health specialists, especially when young people are considered to have 'complex' care needs, add to and compound those experiences of trauma.

"This hospital treated me like a nuisance and like I needed protection from myself. As time went on, I think that attitude of protection went to an attitude of hostility. 'Why are you still here? Why aren't you getting better? Why are you still running away from home?' Towards the end of me being in hospital a lot, the mental health sector had almost lost all hope for me. It became increasingly hostile. I had staff in the mental health wards threating not to let me back into the 'normal' ward and put me straight into a High Dependency Unit (HDU). It's like a stroke – you've got something blocking an artery. You wouldn't ask someone having a stroke, "Why can't you move your arm? Why can't you move your face?" You get straight to figuring out what's causing the blockage. You don't get angry at the person for getting worse." – Emilie, 19

"There's an over-reliance on structure in the mental health system and this isn't matching people's experiences or needs. People are more likely to slip through the cracks because they are too focused on these checklists, which are ultimately another person's criteria. It should be the other way around. Young people should be supported in setting their own criteria and services should be able to meet their needs, not the other way around. The sector is so dependent on funding, and so services are built for outcomes, not the complexity of people."– Kaitlyne, 22

"A lot of the things I've experienced when trying to seek mental health support were the same emotional abuse and manipulation and knee-jerk reactions I experienced from people who had abused me and why I was going to seek help in the first place." – K.C., 25

"We need better ways to address mental health that aren't so clinical. There is such massive stigma and a history of people needing help with mental health as being 'crazy.' We're expecting people to engage with a system that is historically abusive and that we're still hearing is not capable of helping those at the highest need." – Tash, 23

A widespread disregard for the insight of lived experience in the clinical relationship has given rise to a system that routinely disregards, denies and in some cases re-traumatises young people. The ability to see individuals as whole people has been stripped away, leaving many too burnt by prior experiences or by the stories of others' experiences to approach the service system, even if they need help. There isn't time to build relationships, allow a young person's story to unfold at their pace, the resources to build sectoral capacity around the impact of trauma, or the space to allow for creative approaches to emerge in partnership.

"The cruelty in my time in the mental health sector was unbelievable. No one will get better when they're being screamed at." – Emilie, 19

"Those who are suffering need to stop being persecuted by systems that don't ask enough questions about what's really happening." – Kaitlyne, 22

"I have a lot of mistrust from my past abuse and trauma and experiences of mental health services. I don't feel like I can trust what they are telling me or that they have my best interests at heart. I am often not given the time or space to get to that level of trust." – K.C., 25

2b. Service gaps and limitations: affordability, difficulties navigating the service system and the need to be acute to get the help you need in the public system

***"The whole healthcare system operates on the basis that you can only access help once you've hit crisis point, which is ridiculous because you should be able to access help way before you get to that point."* – K.C., 25**

Y-Change describe a system that is very hit-or-miss in terms of quality, consistency, clarity and accessibility. They are acutely aware that the system operates *"on the basis that you can only access help once you've hit crisis point"* and that even then, the mental health service system still struggles to accommodate the needs of young people seeking help.

At a purely supply and demand level, there is a lack of integrated services and outreach services. This fact leaves young people experiencing mental health crises and those who are unable to access mainstream services unsupported when they need help most.

"Young people need support getting to and from appointments. We need help being able to afford medication. We need help accessing stuff like kick-boxing and things that support our wellbeing. Young people need their families to get help – my mum and brother really need help. My little brother doesn't understand what's going on with me, why I'm in and out of hospital. All he knows is what mum tells him about me trying to hurt myself." – Alyssa, 19

"We need more integrated services for young people where they can have every issue they are dealing with seen to at once, so they don't have to travel around to multiple different services. It's like when you're in high school and every teacher gives you half an hour of homework each night. If you have the standard six classes at high school, that's three hours of homework a night. It's the same with service delivery. Each service wants you to do something and by the time you add that up, it's a lot of time for a young person, especially if they are in crisis." – Janelle, 20

"There's not enough outreach services for people, you always have to go and see them. It would be good to have mental health professionals come out to people's homes, like the Home Doctors Service." – Janelle, 20

The current quota of ten sessions per calendar year through the Mental Health Care Plan[22] is chronically insufficient for supporting young people's mental health and adequately sustaining recovery. It is also somewhat of a lottery, because good quality care is largely unaffordable, an issue which has serious implications for young people who are then left to deal with the fallout of receiving inadequate treatment.

"If you want more than ten sessions, you probably have to change your psychologist, even if you like them. Like, I really like the psychologist I have now and I'm already feeling upset that I can't get attached to the one I have now because I'll have to see someone different once my sessions are up." – Beanz, 22

"There's no middle ground between having ten sessions within a calendar year through the mental health care plan and being involuntarily admitted if you're in crisis. It's too much of an extreme – either too much or not enough… There's also an expensive gap to pay with some doctors who don't bulk-bill and this is a huge barrier for people who don't have the money to access better quality care. The doctor I love and who listens to me is not local and is more expensive for me to access. It's really depressing knowing that if you have the money, you often have better access to the services you deserve and need." – Kaitlyne, 22

"At one point, I was accessing something called Schema Therapy and had to pay a $30 gap for the sessions. I was told during my first session that it worked best through having multiple sessions in very quick succession, but I couldn't afford to do that. My psychologist told me that this was fine and to come whenever I could afford to, which would be irregularly and every few months. It was so hard to find that extra money, at the time I was pretty much living day-to-day." – K.C., 25

"Comparing my experience to that of my friends in private hospital and the level of support they got, the barriers for them were nowhere near as much as mine were and as far as I knew, they were allowed to stay there as long as they wanted, provided they could pay to be there. They had access to specialists and then had continued, ongoing support post-hospitalisation from the same specialists. They also had access to programs and group therapy that they could continue to access. Although I'm glad that they got the support they needed, and it was beneficial for them, it's also infuriating to me because I could not afford the support I needed. I just couldn't get it." – K.C., 25

"I know young people with severe anxiety, depression and other things who just can't get on top of things because they're too busy trying to look after themselves. The fortnightly Centrelink benefit amount is way below the poverty line and we're expecting people to look after themselves when they can't even get their basic needs met." – Tash, 23

The Y-Change team sense a fundamental lack of understanding about what recovery looks like for people suffering mental ill-health, with services often not designed to support or sustain recovery efforts. They noted that recovery is not a linear process and that there may not be a point at which a person might be considered 'recovered' from their mental illness. They want systems and services to reflect the fact that, for some of them, recovery will be a life-long process.

"With your physical health, sometimes you can be someone who can be unwell but also maintain a sense of healthfulness. You fluctuate on a spectrum. With mental health, there's also a spectrum. Anyone can get bad and some people will not recover, or their recovery looks different to what 'experts' deem recovery looks and feels like." – Maddie, 21

In some specific instances, the team members noted a lack of understanding about and adequate support/responses for young people who are dealing with suicide ideation or the aftermath of losing someone close to them to suicide.

"Wanting to die every day is difficult. What makes mental illness hard, first and foremost, is the fucking mental illness itself. Constantly living with these thoughts that tell me that I am completely hopeless and useless and should die. Having feelings of fatigue and being so tired but having all the

doctors tell me that there's no reason for me to be feeling tired. Being told to get blood tests and having everything come back in the healthy range. So, then I end up not being believed because of this and they don't do anything more about it. I'm being told I'm fine, but I know I'm not!" – K.C., 25

"We need more integrated support for young people who are dealing with grief and losing people around them to suicide. This is a huge issue. There is nowhere to go for young people who are dealing with the complexity of things such as suicide and severe mental ill-health. There's so much stuff I haven't processed for example, because I'm still dealing with the repercussions of where I've come from in the present. How can I deal with everything I've been through when I'm still not at a stable enough point to be able to process things like my brother suiciding? There was nothing about what he really died from on the coroner's report, which was the trauma he had experienced. There was no history on there about what had led up to how he got there. If we had a better understanding of people's history, maybe we'd be better equipped to deal with the complexity of these issues." – Tash, 23

The team noted a distinct contrast in how physical injury and mental illness are perceived and treated. In some ways they see this as beginning to improve, but still feel as though the health system takes physical ailments more seriously. This has a knock-on effect in relation to challenges and limitations when it comes to assessment, diagnosis, classification and medication of mental health and mental illness. There were experiences of contradictory advice given by mental health professionals and being left uninformed about the effects of prescribed medications.

"Mental illness should be taken more seriously than it is now, especially when you're a young person. For me, my mental illnesses weren't treated seriously. I was thought to have depression at 12 years old and was told that it was linked to my hormones – the start of puberty – and that I would 'grow out of it.' After two years of seeing a counsellor and numerous psychologists, I was then diagnosed with depression and put on anti-depressants." – Alyssa, 19

"When I was prescribed Seroquel, I was told nothing about side effects or what might happen to me. I was told it was not addictive at all. I think the positives of the drug still outweigh the side effects, but it's really important for young people to know what might happen if they do take it rather than finding out the hard way." – Alyssa, 19

"I took Valium, and at that point in my life it did help. It was either taking a bunch of Valium's or having panic attacks. I chose the Valium, obviously. They gave me dissociation and it took me years to come out of that. One of the biggest issues I had was feelings of confusion." – Beanz, 22

"Whereas, one mental health professional told me I have perfectly described a manic episode, another mental health professional told me I wasn't experiencing manic episodes because of the length of time of the feeling. This was at the same clinic. How the fuck am I meant to figure out what's going on if the professionals can't?" – K.C., 25

"We need to approach it as a health issue in the same way we treat physical health and I think in society we're starting to do that. The GP I see, for example, is purely for my mental health and I can go to her to talk about my anxiety in the same way I would if I had a broken foot. I feel like we have

gotten closer to having mental health be integrated into our general experience in contrast to other generations, but we still have a long way to go." – Maddie, 21

The Royal Commission process was commended by one interviewee as being an important way for young people and others with lived experience to provide honest feedback on the system, but they want to see feedback loops for help-seekers integrated across the sector and feedback being held in higher regard.

"The feedback loop within so many organisations is appalling. The feedback needs to be held and regarded at the very top and in a serious way. Organisations need to be listening to feedback." – Emilie, 19

Bipartisan support for the adequate funding of mental health services is critical to the quality and consistency of care for consumers. When there are internal tugs of war, decimation of funding to community services, and the expansion of new services at the cost of historical ones, help-seekers are the people who feel the effects first.

"By its nature, addressing mental health takes time. For example, trying new medications take months to see whether they're right for you or not. Seeing a counsellor means you have to see them over a long period of time. Dealing with mental health is a time-consuming thing. Governments, policy and funding cycles refresh every 3-4 years, so what's accessible to me now might not be in future. There's always changes happening, current services being thrown out, new programs and services taking their place like the National Disability Insurance Scheme (NDIS)[23]. It's so hard to keep up as someone who is needing to navigate these systems." – Maddie, 21

2c. Trauma informed approaches, peer support models and seeing the whole family as an interconnected system

"For me, nobody was looking at my past. They weren't connecting the dots. You had a girl who was 13 years old with no scars on her body, to 15 years old with every limb scarred from self-harm. Why all of a sudden, in this two-year period, did things get so much worse for me? Those questions were never asked." **– Emilie, 19**

The point above has been touched on previously in this submission and will come up again in later sections; however it warrants specific exploration in order to drive home the profound importance of situating a young person in the context of the full spectrum of their experiences. In particular, when professionals are working to explore the causal factors and treatment pathways for mental ill-health. Specifically, the importance of acknowledging and understanding a person's trauma history in relation to their mental health is a foundational step for people to receive the care they need.

"A lot of reasons for my anxiety and depression are childhood trauma. That will always have happened to me. It can't be treated like it's been washed away. So, what's important is that I'm well supported to work through what I've experienced. I see things differently now that I'm older. I work with what happened to me differently to how I saw and treated that same trauma years ago – this is part of my growth." – Emilie, 19

There was discussion from Y-Change about their frustrations of not having links made to their histories of abuse, neglect and trauma – key components that needed addressing but were consistently overlooked. Leading trauma expert Bessel van der Kolk captures this issue from a clinical perspective: *"We still don't have an accurate way of diagnosing the majority of patients who were traumatized in the context of their early attachment relationships."* [24]

"People need to understand how trauma affects people, it literally interrupts healthy development. Being mentally unwell is not something I or anyone else can just turn off." – Kaitlyne, 22

Recognising intergenerational patterns of mental illness and associated trauma was raised, drawing our attention to the fact that even an understanding of an individual's specific experience of trauma may be inadequate. We should instead be seeking to understand people in the full context of their family, their history and the histories of those who have both cared for and hurt them.

"My mum had a mental illness and was a single parent and she didn't get any help. If it's not helped in one generation, it gets passed on. I do not mean that in a blaming way at all towards my mum, but it's a fact that if your parent is experiencing mental ill-health and addiction, you might too. They need help and support with their issues, as well as young people. Mental illness runs in my family – it runs so far back in our family tree, but it just keeps getting passed on and it's not stopping anywhere." – Alyssa, 19

For the purposes of this section, we are presenting a larger section of the interviews with two Y-Change team members. These individuals specifically touched on intergenerational trauma and the impact of trauma histories going 'unseen' in the treatment of their mental health.

"In 2015, I spent 26 weeks of that year in mental health wards. At one point, I was in there for five weeks consecutively without a break. I've seen a lot, mainly that the mainstream mental health system doesn't progress you, it only contains you for a while. When I was in the mental health ward for five weeks, I saw a psychologist maybe three times, which isn't even once every week. Any time I saw them, I was asked about how I was feeling in the present. But my mental ill-health wasn't caused by the present, it was about what happened to me in my past and that wasn't being delved into." – Emilie, 19

"For me, nobody was looking at my past. They weren't connecting the dots. My self-harm went from emergency, to rehabilitation and then to the Intensive Care Unit (ICU) in its severity. It went from me being out within a day, to being in the ICU for up to a week. I think the biggest issue is the hospitalisation and mental health wards process – there wasn't an understanding of how I was getting worse nor any questioning about what they might have been missing. You had a girl who was 13 years old with no scars on her body, to 15 years old with every limb scarred from self-harm. Why all of a sudden, in this two-year period, did things get so much worse for me? Those questions were never asked." – Emilie, 19

"One of the major hospitals I went to – they knew me so well and had an incredibly detailed history of what I was going through. I've only really been able to reflect now, at 19 years old, that nobody at school, nor my friends, nor anyone in the hospital system really delved into what I was. From 14 to 17 years of age, within a three-year period, I went from emergency to ICU, from mental health ward to HDU. It went from protection to hostility. Through all of that time, nobody asked me "What happened to you?" – Emilie, 19

"It's only now, I've come to realise my childhood and teenage years affected and affect me a lot. Not once was this explored. Not once did somebody think, 'Maybe we should ask her about what's happened because there's something that needs to be supported, delved into and recognised here.' The really unfortunate thing about this is that that time for me in hospital could have been spent sifting through what had happened to me and teaching me strategies of how to cope with it. Being supported to support myself." – Emilie, 19

"We need to seriously address intergenerational trauma and how it impacts on a near inability to form healthy relationships. It's also about having conversations with people that the situations they have come from are fucked but that this isn't the future they have to have. Nobody ever acknowledges that what you've been through is fucked. I had to work that out for myself. When you're in such a traumatised headspace, you can't expect someone in that situation to know what kind of future they want for themselves. They are too busy fighting the past and the present to think about what a better future might look like." – Tash

"I'm the only one in my family who has enough awareness about how to manage conflict and support the rest of my family. It's a lot to carry. The trauma and mental health issues my family and I have are so severe. What makes me really angry is that we have to deal with the repercussions of past trauma we've all experienced because none of us got the help we needed when we were in the system. Now, we're left to battle the aftermath on our own." – Tash, 23

2d. Experience of young people in psychiatric facilities and transitioning out

***"When you come out of hospital, I don't feel like you get enough help. The last two times I came out of hospital, when I was around 18 years old and just recently, I didn't get much help and support."* – Alyssa, 19**

There was significant commentary about the experiences of psychiatric and mental health wards, namely, the lack of one-on-one support from intake to discharge, and how insufficient funding is felt by those with the highest need for critical and immediate care.

"Before you even get into hospital, you have to be admitted. If it isn't a planned admission, which none of mine were, you have to go to the emergency department. If there aren't any beds available, which happens a lot, you have the choice of sleeping in the waiting room overnight and hoping something becomes available the next day or going back home and being unsafe." – Alyssa, 19

"I ended up going to the hospital by myself and having to tell the staff I was someone with 'high suicide risk.' I was left alone in the waiting room for hours and I kept thinking that I could just walk out on the road and get hit by traffic. So, whilst I was fighting to access support I was also fighting the urge to kill myself." – K.C., 25

For some, this commentary included a sense that a mental health ward is less a place of pro-active recovery or planning for future safety and more a space for 'decompression' from the outside world. Their comments imply that emerging from hospitalisation in an improved state or with strategies to support your mental health depends largely on whether you are an individual with the ability to pursue those things in some way.

"I eventually got checked into a psychiatric ward and was there for three days. During that stay, I saw a psychologist once and did not have an option to participate in any group or individual therapy. I was mostly in a room managing myself. It was helpful in the sense that I was in a place that was safe and that it was difficult to hurt myself, but there was no extra support or care given… When I was in the psychiatric ward, it was better in the sense that I didn't have to be so vigilant – that I could relax enough to start processing what I needed to process through writing and self-reflecting. I needed to be able to do that in safe place because the stuff I was processing was too heavy to me to be able to do on my own." – K.C., 25

For others, hospitalisation – while representing 'a break from the world' – is an intense period of time. The problem is that this doesn't translate to the outside world on departure, which leaves people feeling lost and unable to cope. Regardless of the intensity or lack of support while in hospital, the transition back to 'normal' life is seen as challenging by all who spoke about it.

"In hospital, everything stops. Hospital works because of this. You are just there and don't have anything to worry about, except in an adult psych ward. You have so much intensive help from doctors and workers, but once you get out, life is hard again and it goes back to the same as before… When I was discharged, I asked for a prescription because I found it hard to get back to normal life after being in hospital. I get a lot of anxiety and had a lot of trouble going back to my TAFE course. I wasn't able to get that prescription because I was told Valium is addictive. I wasn't offered any other medication to help me." – Alyssa, 19

"They discharged me as soon as they were legally allowed to. Because I was considered compliant and quiet, I wasn't branded as a 'risk' and so was considered 'good' enough to be discharged. That was it – there was no follow-up or investigation into whether the medication I was on was the right medication. Spoiler alert – it was not." – K.C., 25

In one instance, a peer mentoring model was mentioned, but the Y-Change team member commented that they only received one period of contact from their peer mentor.

"It felt like she just had to do this and tick a box. I didn't get to talk through what I was experiencing or anything like that, it was a really quick phone call." – Alyssa, 19

2e. Unique challenges faced by marginalised groups of young people

***"Thinking about how bleak the world is really affects my mental health. This world needs to change."* – Beanz, 22**

Young people have greater access to information about what is happening across the globe today than they have ever had. They are aware of increasing inequality caused by environmental destruction, racism, sexism, and the effects of the criminal justice system. They see it in their own lives and in the lives of their peers in other countries and cultures. It would be unwise to argue that this has no impact on their mental health and sense of hope. One team member in particular spoke about the impact on them and some of the solutions that they envisage.

"Less police presence in communities and less control over people in society is important. I feel like people feel so powerless because there's so much control over them. We need less environmental destruction. You want to help me with my mental health? Stop destroying my and my kids' future." – Beanz, 22

"We need to destroy beauty standards, particularly those aimed at women. I think those have made me pretty mentally ill throughout my life. Stop talking over women. One of the biggest things that has affected me mentally is that I've been taught that my existence is to serve men. Women's voices are valuable, and people perceive them as irrational." – Beanz, 22

"We need more funding into community projects and initiatives, especially art projects, land conversation and indigenous rights. The highest suicide rates are amongst indigenous people[25]. We need youth justice reform[26] and youth prison abolition[27]. We need less racist and sexist mainstream news – it puts fear into people and creates disconnection in community and between communities. It creates shame in people." – Beanz, 22

Whether young people are affected by the global context or not, experiencing intersecting disadvantages in combination with mental health issues can be chronically socially isolating, not to mention chipping away at an individual's sense of hope and worth.

"A huge social barrier I have experienced is sugar-coating my experiences for other people, so they don't feel overwhelmed by what I'm going through. This is a really isolating thing to have to do. This makes me feel like I'm destined to be with someone who is as fucked up as me, because those who haven't gone through what I have can't understand me. It's like traditional holidays such as Mother's Day. It makes me so angry because there's an ideal pushed onto me that doesn't fit my experience and people just automatically assume that everyone is having the same experience. It's so weird. You feel like an alien at times." – Kaitlyne, 22

"I kept trying to talk about my experiences, but I didn't know what was appropriate or helpful to be talking about because that's just how I had existed forever. So, trying to pick out behaviours and feelings that were considered 'abnormal' were impossible for me because it was all normal to me. I had no frame of reference for what was considered normal or abnormal. It's like family violence –

how do you know until you know? Some things I thought about a lot in this vein were 1) Why did nobody ask why I was experiencing depression from 13 years old? 2) Why did nobody pick up that I was going through family violence? The feeling of abandonment that comes with these questions. At that time, I felt like I was in my own world and nobody could see what was happening inside of me, but lots of people knew and could see but didn't do anything about it. It's worse than being alone – it's knowing you've been neglected." – K.C., 25

The Y-Change team between them share a breadth of experiential expertise spanning disability, LGBTQIA+, out-of-home care, homelessness, family violence, disrupted education, and rural and regional living. The following are some specific reflections on how those intersecting experiences have affected their experiences of the mental health system.

Young people who identify as LGBTQIA+ are being let down by systems of support that lack understanding of acceptance, diversity and inclusion in their practice.

"A child who has both experienced and witnessed extreme amounts of violence in their household and is coming out as trans – who wouldn't be affected by that? Who wouldn't have anxiety and depression from these experiences? Before I had ever experienced or had started exhibiting signs of mental ill-health, child protection was involved. They were aware that I had experienced abuse and just started to transition – there should have been a connection made right there and then that I would need additional support." – Emilie, 19

"Being asked about how hormones are affecting me, when what is really affecting me are experiences from my childhood. I don't believe there is any mandatory training for staff on how to work with LGBTI+ young people. A strip-search or being restrained, for example, is incredibly traumatising for someone who is trans or gender-diverse because they're having a body held down that has significant trauma attached to it and that doesn't feel like theirs. There is accumulated trauma and that is made so much worse through physical restraint." – Emilie, 19

"When I started accessing services for help, no-one was educated enough to support me as a trans person. Barely anyone could even call me by my correct pronouns or the correct name. It made me feel so unsafe. I can't unpack trauma when I don't even feel safe in the room. I don't think it's too big of an ask that the mental health professional I'm seeing calls me by my correct name – I don't feel like I've ever been asking for a lot." – K.C., 25

"If you are someone who identifies as LGBTQIA+ in a rural or regional community, it is close to impossible to get support. Where I am, you can go to Shepparton and access Goulburn Valley Pride Inc.[28], which is an independent organisation and they do amazing work, but still – it's not professional support. The closest clinic is in Melbourne and the waiting lists are forever. In city Shepparton, it's mostly accepting but if you go further out – there is a lot of stigma about LGBTQIA+ communities." – Janelle, 20

There are significant barriers and challenges being experienced by young people, their families and friends from rural and regional communities in Victoria.

"The lack of access, for one is a huge barrier. If you live outside of Shepparton, to get a one-hour appointment it would take someone at least three hours all up by the time they travel, have the session and then get home so there's a feeling of 'what's the point?' when you could be spending your time working. Especially for farmers at the moment, who are in a complete state of crisis." – Janelle, 20

"In rural and regional communities, you don't talk about mental health. I can't recall one situation where a person has said they're even sad. I remember at a funeral for a stillborn child in my family, nobody even cried. For me, it's normal – you just don't show emotion. It's just the way things are. When I moved out of home, it was only then that I understood that other people had a different normal. I remember hearing about an old friend who had killed themselves and I laughed from the shock. This sounds awful, but I had no idea how to process it." – Janelle, 20

"There's such a stigma here, especially for farmers – so many stereotypes for how they should be and how they should act. In the last couple of weeks, there's been some suicides and people are starting to talk but it's too late for a lot of people because they're already gone and when they do need support, there is none. My parents don't even have proper internet or phone connection and they live 15 minutes from the nearest town and 45 minutes from Shepparton." – Janelle, 20

"There is no support here. There's support in cities, towns and in extremely rural communities – everything in between is left out. For example, for young people over 25 in Shepparton, you have to pay in full for psychology sessions. To access affordable care, we're often told to go to Melbourne. Waiting lists are at around the one-month mark, even if you need urgent care." – Janelle, 20

There is a significant lack of adequate support and representation for kids in out-of-home care and who are victims of family violence. It is widely recognised that "*children and young people in Out-of-Home Care (OoHC) experience significantly poorer outcomes across multiple developmental, psychosocial, emotional and behavioural domains, compared to other children and young people in the community."*[29]

"Young people in out-of-home care are in desperate need of support... Some kids can't stay with their families. Some kids don't have happy families. We need more people to understand this." – Kaitlyne, 22

"Children are also rarely seen as true victims and so their pain and suffering isn't taken seriously. This builds up and the trauma impacts young people later on. There is also the issue of sexual assault of children and young people in care, which is something we are absolutely not acknowledging or addressing. There is a massive amount of victim-blaming that happens with high-risk young people." – Tash, 23

"Young people with experiences of extreme trauma, homelessness and out-of-home care are not in the picture. Children and young people are still being overlooked. We're not looking at mental ill-health through the lens of family violence or recognising the sense of entitlement parents often have over their children and what that does to and how that affects them." – Tash, 23

"Out-of-home care is one of the biggest barriers for young people. Once you're in the system, there is limited access to mental health support. You need a child protection or Department of Health and Human Services (DHHS)[30] referral to access other services and they've always got limited capacity and waiting lists. Generally, when you're in care the people who are taking care of you won't get around to getting you what you need. You could scream at the top of your lungs about being suicidal, but it often takes a crisis for carers to act, regardless of whether that's foster or residential care. I didn't realise how severely unwell I was when I was in care, but I would get a knife and put it against my wrist to get the attention I needed because there's such a lack of listening. My sister asked for support for years and years, and she never got what she needed. There's neglect at so many levels when you're in care."[31] – Tash, 23

"You can't expect someone who is living in unstable conditions to support themselves and deal with the severe mental health and trauma that comes with being a young person in care." – Tash, 23

"I lost my brother to suicide and I often wonder, why did it get to that point? My brother ran away from care, constantly. He kept running back to my mum's place, but they'd bring him back anyway. Eventually, they gave up on him and he was put back in a violent situation with my father and this led to him killing himself. Where's the accountability? I understand that the system is broken and that there's things they can't do, but from my perspective, they let him die." – Tash, 23

"Child death inquiries[32] end at the age of 18 years old. If it's any time before this, they have to investigate but after 18 years old an inquiry doesn't have to happen. So, kids are being released from care with severe mental health issues, and where are they going? Many are going straight into homelessness[33] or back into abusive homes. We don't have accurate data to show exactly what's going on with suicide rates and mental health for this cohort of young people." – Tash, 23

"The systemic response to children who are experiencing any sort of neglect or trauma is nothing. It's often left up to the mother to have a trauma-informed response to her child, who is often already traumatised herself. There are few services available and they are already over capacity. They tend to address younger kids and not adolescents, so there's a whole group of young people completely invisible to the system." – Tash, 23

"Take Two[34] is a great service for young people in out-of-home care but it still doesn't address the most severely traumatised young people. We need more services like Take Two that are even more specialised services for young people in care who have experienced severe abuse." – Tash, 23

There is a significant lack of understanding about those with disability who have experienced trauma and their barriers to accessing the mental health care they need.

"My oldest brother has autism and he is often misunderstood by his workers because they are unable to see past his disability to the trauma he has.[35] So, rather than getting the multitude of support he needs, his responses to trauma are often blamed on and linked to his autism instead." – Tash, 23

Young people who are struggling with mental illness and homelessness are being unjustly criminalised instead of receiving access to the supports they need.

"After two years of seeing a counsellor and numerous psychologists, I was then diagnosed with depression and put on anti-depressants. This was the period of time I started getting in trouble with the police, the first time I was arrested I was 14 years old. I felt like the anti-depressants reacted really badly with me. I also wasn't able to take my medication regularly as I was experiencing homelessness at the time." – Alyssa, 19

There is a lack of consistent support for victim survivors of family and sexual violence accessing the mental health support system including; the responses of police, the gendered nature of care within adult psychiatric units and the lack of mental health support for those navigating the court system.

"When I was younger and after experiencing sexual assault, the police came to my house and asked me if I would talk about what happened, whether I wanted to press charges. There was no follow-up after that afterwards, no opportunities for referrals for me or my family to help us through and understand what had happened." – Alyssa, 19

"The third time I was admitted was to inpatient unit two, which is an adult psychiatric unit. This was the worst experience I've had, mainly because I'm a young woman and there are grown men in there who tried to get my phone number and made inappropriate comments. There is a gender specific area in there, which I got put into after I talked to the nurse about the men's behaviour. Although you sleep in the gender sensitive area, you still have to be around them in the common areas like the kitchen, the TV room and the basketball area with chairs and outdoor area." – Alyssa, 19

"Women are also often misrepresented in the mental health system because it hasn't been created by them for them." – Beanz, 22

"We put a lot of emphasis on sexual assault, but less on physical, mental and emotional abuse. For example, you can have historical charges placed against a preparator of sexual assault but not for physical assault." – Tash, 23

"Another big issue is the court system and how people are treated by it when they have been traumatised and victimised. There should be mental health support workers in courts for people to access. What happens if you're in court and you have a panic attack? There's no-one there to support you." – Tash, 23

3. A workforce that is diverse, well-trained and well-supported

***"So many people are told that they are never going to amount to anything because of what they've been through. We need support workers who believe in our future and in our capabilities. We need more people with lived experience working in the sector, to make up a certain quota of the sector workforce."* – Tash, 23**

This section looks at workforce diversity: its responsiveness to cultural diversity, being trauma informed, holistic and therapeutic in its practice, and the growing importance of a strong lived experience workforce across policy development through to service delivery.

Y-Change is a team founded on the belief that experiences of trauma and disadvantage can be spaces of profound learning and personal development. The team's experiences are centred as a source of expertise we cannot access anywhere else. As such, young people with this expertise are engaged as employees and we ask them to use their skills and knowledge to advocate for and drive organisational, social and systemic change.

The expertise of consumers as system navigators is, at best, considered as part of consultative efforts across the service sector. Valuing lived experience beyond its role in providing feedback about services, or being the source of inspiring and heart-warming stories, is, in our opinion, fundamental to any systemic change process.

The methodologies of co-design and co-production are gaining momentum. When thinking about re-educating and re-designing the mental health service system, those with a lived experience of mental ill-health must be partnered with as integral part of sector reform.

There is also growing importance to valuing the insights of lived experience as a form of expertise and ensuring more service users are being employed in professional roles, whose insights are critical for service innovation and workforce evolution.

"The importance of comfort in psychiatric hospitals is so underrated. They have shitty colouring pages, the pencils are all blunt and you can't have a sharpener, and most of the textas don't work so you couldn't use them even if you really wanted to. Hospital food is another thing altogether. You get hospital blankets that aren't warm, the walls are all white and if feels like you're in prison. I go to hospital to make sure I'm safe and because I'm in danger, I shouldn't be punished for wanting to be safe. If young people with lived experience of mental ill-health designed the psychiatric wards and the activities, programs, and what the spaces looked like, it would actually become a place where people can start to recover." – Alyssa, 19

"Those with a lived experience know it better than anybody and we know how to fix it better than anybody else because we know emotionally and figuratively what needs to change. I really think lived experience consultants need to be very actively involved with mental health organisations. There needs to be a bank of lived experience consultants that organisations can call on to support the work of mental health professionals." – Emilie, 19

"We need to stop listening to professors telling organisations what's what and ask the people who are directly affected." – Emilie, 19

"Lived experience is the highest qualification you can have because you've experience something on so many levels – physically, emotionally, mentally, spiritually – and in many ways, there's a high price to pay. For people who go through the university system, they have a higher education loan. For someone who has lived experience, it's a debt you can never get paid back. It's with you forever. I think that also shows the value of this wisdom, too." – Emilie, 19

"Mental health professionals are so wrapped up in textbooks and the clinical information, without understanding the nuances of the experience of mental illness. Textbook definitions are very limited, and many of the professionals I've seen have been patronising and dismissive because what I'm explaining about what I'm experiencing and the way I'm behaving doesn't fit their diagnostic boxes." – K.C., 25

"The people who receive support are left out of the conversation and people who are not accessing services at all are being left out even more." – Janelle, 20

There is a need to understand the value add of lived experience as a legitimate practice and as integral to people's experiences of recovery. There was a strong theme about the importance of advocacy work for young people, knowing that what they have experienced can be used in the hope of transforming the mental health sector for the benefit of those who walk behind them.

"I'm able to use my experiences to advocate for change. I can use the shit things that have happened to me to help services understand what happens from a young person's perspective and do better. It makes me feel like what I've gone through, it's been for a reason. That there's something I can do with these experiences. I feel more of a passion for the work I do." – Alyssa, 19

"I think Y-Change specifically supports young people into getting work. It gives you an environment where it's okay to make mistakes but also to push yourself and feel responsibility. It gives you almost what a good work life could be like. Working with people inside and outside of the organisation and have balance. I feel proud to say I work with the Y-Change team at Berry Street. It makes me feel like I'm important and a I've found a career that I'm passionate about and want to work hard to achieve. When I turned 18, I thought "What the fuck do I do now?" I didn't even think I'd make it to that age. All I was focused on was surviving. I didn't really think of the future and it all kind of hit me when I was 18. What was I going to do for a job? For a career? With Y-Change, it helped me choose my career." – Alyssa, 19

"This is not easy work. A lot of people think getting us up on stage to tell stories and giving us a gift voucher is adequate. This work is difficult because for a lot of people with lived experience, you don't necessarily want to go back into exploring what you've been through, but you have to repeatedly delve back into these experiences to help educate others. In no other profession are you tasked with repeatedly revisiting your pain and trauma. We're tasked with running back into the fires we've escaped. Lived experience needs to be absolutely valued as a practice." – Emilie, 19

"I feel like this work has definitely been the catalyst for me to find my own potential and strengths. That my story isn't who I am. It's definitely shown me that I am more and that I can use my story and what's happened to me for good. Being a lived experience consultant can also be really stressful, especially when you have so many other commitments, like university." – Kaitlyne, 22

"I am someone who has a strong sense of advocacy and doing advocacy work is something I'm passionate about. I like to feel like I'm making a positive change and I get that a lot through the work that I'm doing. This has a hugely positive impact on my mental health, especially because I am using some of the terrible things that have happened to me to help make those same terrible things not happen to other people. Although it doesn't make the terrible things that happened to me okay, it does help to heal some of the hurt left behind. This is very important to me." – K.C., 25

"Doing this work doesn't make what happened okay or that I am able to completely heal, but it makes me feel better knowing that what I'm doing is helping to prevent those same things happening to others as much as I can." – K.C., 25

"Getting positive feedback from people after workshops I've done and how they have directly impacted them and thanking me for my work – hearing from people that they've put strategies into their work almost immediately after my education is fucking amazing. It gives me a sense of purpose, which is something I've really struggled with. My mental illness tells me I'm useless, so having this combatted directly through having evidence against that is awesome. It helps me remember that I am awesome." – K.C., 25

"Personally, advocacy for me has been more helpful in some respects than mental health services have because the things I'm working through and advocating for help other people and future policy changes. You're in a room with people with similar experiences, who understand what you've been through and who are supportive of listening to what you have to say." – Tash, 23

"Y-Change is really good in the sense that it doesn't treat young people like we're fragile. We are taught that our lived experience can be used to propel us forwards, rather than something that only holds us back or prevents us from finding fulfilling work." – Tash, 23

When it comes to the workforce behind the services, the team were clear that seeing themselves reflected, both as people from marginalised communities and as people with mental illness, makes a huge difference. Being supported by others who have 'been there' is critical to people's experiences of services, trust and recovery.

"We need more diverse workers to suit diverse young people. We need lots of different workers walking into rooms. Unfortunately, lots of people who are privileged have better opportunities to study, especially in fields like psychology. Those who experience mental illness are usually less privileged. We need to provide opportunities for those with less privilege to get into and work in these fields." – Beanz, 22

"I don't think many mental health staff have experienced mental health issues. In my time, I saw one staff member with self-harm scars. The staff need support to understand what it is to be a young person in different situations to them." – Emilie, 19

"I feel like there needs to be more emphasis on people with a lived experience of mental illness supporting other people with a mental illness. There's a certain level of understanding you can't reach through only reading textbooks and having a purely analytical and theoretical approach. It's useful, definitely – but there's much more to it than that. The most helpful people in my life who have supported me with my experience of mental illness have been people who have experienced it themselves. Some of them have been professionals, but the large majority haven't." – K.C., 25

"Seeing a therapist who identifies as non-binary and who has shared similar experiences to me, I don't have to expend all this emotional energy educating my current counsellor or help them understand why it's important to use my correct pronouns. We don't even talk about trans stuff, but the foundation of my experience is already shared and understood. This is why lived experience is so important in mental health professionals or at minimum, being mandated to learn from people with a lived experience." – K.C., 25

This desire for diversity in the workforce also crossed into the conversation about who should be 'part of the conversation' about mental health. It's one thing to talk about diversity, it's another to ensure accessibility.

"Queer folk, specifically trans folk are left out of the conversation about mental health. I'm hesitant to speak on experiences that are not my own. Thinking about systemic barriers for people of colour, people with disabilities, people experiencing homelessness – basically, the further away you get from being a cis, straight, white, rich man means the more you're being left out of the conversation within mental health or anything else in society. It's important to point out that a lot of the time, the people who are being left out of conversations about mental health are the people who are most at-risk – this is bullshit and a huge problem." – K.C., 25

The Y-Change team recognises a significant need for capability building and further education and training for mental health practitioners and providers across the sector. They want to see a shift towards and investment in holistic care and therapeutic practice across the Victorian mental health service system. Fundamentally, they want to see more creative and innovative ways of making mental health support *more human*.

"I think mental health should be supported holistically. It seems to be treated like it's a disease, when things like anxiety and depression are working to protect us from things and can be reactions to life experiences." – Beanz, 22

"It was in 2016 when a major shift happened – I moved into foster care and then into a therapeutic care and housing organisation. My psychologists shifted from being obsessed with the Diagnostic and Statistical Manual of Mental Disorders (DSM)[36] system to therapeutic care and this is when change started to happen for me. My history was starting to be explored and released. I went from self-harming every single day and needing to be hospitalised at least three times a week, to being in hospital only once in 2018. I didn't self-harm or attempt suicide once. Therapeutic care was the difference. Since then, it's given me the power to support myself. Mental health workers aren't going to be there every day at your side, asking you how you're feeling from as scale of 1-10 while you're at work. You've got to learn how support yourself." – Emilie, 19

"We need formal opportunities to support young people to be able to reflect. We need support people who ask, "What happened to you?" and "What do you need?" rather than assuming and projecting prejudice." – Kaitlyne, 22

Alongside the development of skills and better practice, there was a call on the system to understand the importance of space and time to develop trust in a therapeutic relationship, especially for young people with trauma histories. Honouring a person's consent and boundaries should be at the forefront of our practice.

"I think it's also important to acknowledge that you both [Lauren and Morgan], in your own ways, have taken the time to allow me to build trust. That's so valuable and it has taken me a while to get there. The way that I've had my boundaries respected and not felt obligated to disclose anything, unless I wanted has been crucial. Authenticity, consistency and genuineness is important. That I could go through that process of building trust in my own way and at my own pace. This has been a huge barrier for me in mental health services." – K.C., 25

"The counsellor I'm currently seeing has been great with [trust] too. There was that initial shared experience that was a helpful tool, but that was only one step in the overall process in feeling like I could trust them. It's important that I'm able to experiment and explore different things and then have time to process responses and make sure that they aren't aggressive or manipulative and that I am going to be safe and comfortable to disclose information to them if I felt like I needed to and that wasn't going to be thrown back in my face or handled inappropriately. Being able to maintain an open and honest dialogue is crucial." – K.C., 25

The Y-Change team showed deep recognition of the emotional labour that the mental health workforce does. They expressed significant concern that system reform includes an emphasis on ensuring the wellbeing of staff, especially those whose work it is to directly support young people. This was about ensuring their sustainability in the workforce as much as it was about ensuring they are able to advocate for sector development themselves.

"Making sure the people I work with provide a safe space for everyone to work within. Organisations also need to understand that people need equity. Different people have different capacities, strengths and weaknesses. As a community, we work well together when we draw on each other's strengths and support each other with the rest." – Beanz, 22

"Organisations need to have mental health and wellbeing leave for staff. We have so many other forms of leave, but none of it covers mental health." – Emilie, 19

"In Y-Change, upholding mental health is an experience that is normalised, it's part of our culture. This should not be exclusive to Y-Change, but part of every organisation's culture." – Emilie, 19

"I feel like those who are in positions such as carers or role models in young people's lives could have a greater impact if they were given the platform to express how they can help change the system. So, we're not just focusing on young people, we're also supporting those who support young people." – Kaitlyne, 22

"The core of this approach is flexibility, understanding and being open to negotiation, having the same things be offered to you if you had a physical illness. We need the same understanding and support for mental illness that we do for physical illness." – K.C., 25

"We need to put some power in the hands of the people who are supporting these young people, too. Some people cannot acknowledge that there is something wrong and there's no way to convince them. But, there are ways you can support those who are supporting them to help them address these issues in ways that aren't too direct." – Tash, 23

"We also need to acknowledge the level of burnout for people working in the sector and the immense stress and traumatisation that can come with this work. We need to better support the people who are supporting others." – Tash, 23

Having advocated throughout this submission for an increased lived experience workforce, we feel compelled to be clear that lived experience work holds unique challenges that should be scaffolded and supported at all times. The emotional weight of revisiting and utilising traumatic experience to do one's work cannot be underestimated, nor should it be avoided.

Those who are drawing from their lived experience and are using it to influence systems change need access to tailored and ongoing support to ensure their sustainability in the sector. Supporting lived experience includes being flexible, non-judgemental, open to different ways of working and able to provide emotional support and understanding.

"Having a copy of my mental health care plan or creating one specific to the workplace would make this experience even better, then you guys know what do if anything happens. Flexibility is really important. If you have mental health appointments, or need to go into hospital, you don't want to feel like you can't because you're not allowed to miss out on work. It's really important if you're struggling with mental health to be able to take a step back. Making employment processes and working within organisations more accessible for people who experience mental ill-health, as an example, different ways to apply for jobs. Making the interview process more personable, meeting up with people for coffee in the first place and then having a second interview and knowing at least one of the people who will be there." – Alyssa, 19

"This work can be triggering at times and it can be healing at times as well." – Beanz, 22

"Part of my infinite debt is mental ill-health and what it takes to constantly and consistently be dedicated to managing this as part of my work." – Emilie, 19

"If you've got people who work for you with lived experience, you can't just ask that person to turn the lived experience on-and-off. People need to be able to take time off and take care of themselves because of this lived experience." – Emilie, 19

"Having someone who is my Team Leader say, "I feel you" in response to me telling them that I'm late to a meeting because I experience seasonal affective disorder (SAD)[37] matters. It matters because they experience the same thing and know how it feels. Having people around who understand what I'm going through and share the experience on a certain level is so important.

Compare this to somewhere like the hospitality industry, they would probably get angry if I showed up late if I was in a car accident. Mental illness impacts me physically as well as mentally, like right now with SAD – I'm fatigued all the time and it's so physically difficult for me to get up and out of bed, which makes me late for or miss things altogether. Having someone who understands how this works means that they don't interpret things like lateness as a sign of laziness, but rather, a warning sign to know I might need extra support." – K.C., 25

"Having people who can acknowledge my mental illness and have an open conversation about how I need to be supported is great, rather than jumping straight into risk management. Knowing that the team know who I am, compared to how I get when I'm genuinely struggling is enough to make me safe, supported and appreciated. That then becomes a positive cycle, as it becomes a part of how I manage my mental health better. In the past, I have been so obsessed with getting my mental health to a good place because there's been no-one else there to help me, that it's actually made my mental health even worse. So, being able to have what I'm dealing with understood and have people be able to act and advocate on my behalf if I need them to means I can breathe easier." – K.C., 25

"The other part to lived experience work is that I'm having to constantly dip back into traumatic experiences in my life and this often means I am reliving these experiences and that stays pretty fresh on the surface. That can be kind of dangerous when that's happening for a prolonged period. It's something I have to keep aware of and can be something that makes me head in a negative direction if I don't have a handle on it. I feel like Y-Change is well equipped to deal with that." – K.C., 25

"The fact that there's an underlying acknowledgement, always, about being aware and considerate about mental health is important – not in your face, where every second question is "How is your mental health?" It's woven into Y-Change as a fundamental way of operating. It's not about having a dedicated conversation all the time, but a genuine respect for mental health in general. Also, having formal channels we can use, such as check-ins and supervision. It's a good balance of it not being my sole responsibility, the team also check-in and ask how I'm going if they notice something's changed." – Maddie, 21

"Family Safety Victoria[38] & the Victim Survivor's Advisory Council (VSAC)[39] offers specialised counselling services through ShantiWorks.[40] We need more of this kind of support for young people who are attached to initiatives such as Y-Change and other youth advocacy jobs in general. Although this work has an aspect of healing and has helped my recovery on some level, it is still stressful, and it can be re-traumatising. We need the right support systems in place to be able to continue doing what we're doing." – Tash, 23

"The flexibility of advocacy work gives me the time and space to deal with my mental health when I need to. We need more full and part-time paid positions for advocates who are ready to step into the next stages of their advocacy careers – those who are looking for consistent and stable working hours." – Tash, 23

Y-CHANGE'S RECOMMENDATIONS

"To dedicate our time, energy and resources to eliminating mental health is missing the point, because we can't. We've got to make the experience of mental ill-health more integrated as a normal human experience. There's not always an 'other side.' Sometimes, things are just shit and you live with it and move on the best you can. We talk about getting over the mountain, but not everyone can and that's okay – the actual problem is the approach and belief that everyone should get over the mountain. It's okay not to be okay, and that's okay." **– Maddie, 21**

It is important to note that the following list of recommendations is not exhaustive and that we expect further exploration of the campaigns, policies, resources and services that have been mentioned to gain a broader understanding of the recommendation asks.

It is also important to note that although specific to the mental health sector, in some cases these recommendations have implications for agencies outside the specific remit of the mental health system.

As part of the one-on-one sessions, the Y-Change team drew our attention to one of the greatest fault-lines in the mental health system: that mental health is viewed and treated as somehow separate or distinct from other health-related disciplines, and society as a whole.

An overarching recommendation we would like to make is the importance of moving away from the discussion of mental health and mental ill-health as something only specific individuals experience. We *all* experience mental health on a spectrum and therefore, it is our collective responsibility as a community to look after one another, especially outside our immediate circles and networks.

The Y-Change recommendations begin on the next page, onwards.

Recommendation 1:
Nothing about us without us – developing the Commission's final recommendations in partnership with people with lived experience

"Lived experience is the highest qualification you can have because you've experienced something on so many levels – physically, emotionally, mentally, spiritually – and in many ways, there's a high price to pay. For people who go through the university system, they have a higher education loan. For someone who has lived experience, it's a debt you can never get paid back. It's with you forever. I think that also shows the value of this wisdom, too." **– Emilie, 19**

Although it may be considered unusual, Y-Change wish to begin their recommendations by explicitly commenting on the process of the Royal Commission into Victoria's Mental Health System itself. The team wishes to convey that people with a lived experience of mental ill-health and of navigating the service system are key to the analysis of the Commission's materials and should play a key role in developing the recommendations going forward.

The Commission must to be mindful of the fact, that unless they are proportionally represented by people with a lived experience, they will be analysing the material from a position of privilege. If the Commission wishes to begin this reform process in the way they mean to continue it, partnering with people with a lived experience from this point on makes a powerful statement.

Whilst we applaud the State Government of Victoria's commitment to accepting all recommendations made, if those recommendations are drafted by an exclusive and select few people without direct experience of mental-ill-health or the broader service system, we hold concerns about the impact of the Commission reform process as a whole.

In regard to developing the Royal Commission's recommendations and envisioning strategies for implementation, our key recommendation is that:

- People with a lived experience are partnered with in the **executive decision-making processes of the Royal Commission into Victoria's Mental Health System and are ensured a seat at the table** throughout the remainder of the process and beyond. This is to ensure accountability, and that the expertise of consumers is regarded at the highest level.

Recommendation 2:
A shift towards holistic and therapeutic care

"Holistic and therapeutic responses to mental ill-health are such a niche practice in the mental health sector but should be the mainstream approach. We need a much more empathetic approach. The times when it really did work, was when someone sat down with me and worked to figure out how I was feeling and why." **– Emilie, 19**

The Y-Change team members spoke at length about the difference between care and outcomes when receiving therapeutic responses, versus those that were overly clinical and detached. This included mental health professionals having a deeper understanding of trauma and knowing when to 'join the dots' of a person's history with what they are experiencing in the present.

Fundamentally shifting towards a system that prioritises holistic care is about moving from the mindset of 'what's wrong with you' to an approach that asks 'what happened to you' – shifting the pathology away from the help-seeker and to the social systems affecting and surrounding them.

Re-orienting widespread models of care is a large-scale culture-change process that would include multiple government-funded systems. Specifically, we recommend that:

- A plan to revisit and refresh the **Framework for Recovery-oriented Practice**[41] in partnership with mental health consumers, paying particular attention to more equitable holistic and therapeutic care approaches.

    - We support the Victorian Mental Illness Awareness Council's (VMIAC) recommendation that **addressing the underlying social determinants of mental ill-health**[42] [43] become a central consideration in shifting practice towards a holistic system of care, versus the historical focus of biomedical approaches.

- The mental health service system integrates practices that shift a historical culture of 'what's wrong with you' to 'what happened to you', through models such as the **Power Threat Meaning Framework**[44] from the United Kingdom.

- **Trauma-informed care**[45] becomes a fundamental requirement for all mental health practitioners and providers across Victoria, with cultural responsiveness and inclusion of diversity as a central pillar. This includes models of professional supervision that support a shift towards critical self-reflection, systems analysis and a trauma-informed mindset.

Recommendation 3:
Mental health literacy as part of Victorian Curriculum and schools' culture

"There needs to be an expansion of continued community education about mental health, especially in schools. For young people in particular, there's so much responsibility placed on our shoulders to 'conform' and 'fit.' When I was at school, me and my siblings clearly stuck out as the 'povo' kids. I've had to dig deep to get where I am." **– Kaitlyne, 22**

A common thread throughout Y-Change's narratives was that a significant point of system breakdown was during high school, with educator and staff responses either helping or severely hindering their experiences of education during times of crisis. For young people experiencing socioeconomic disadvantage, moving through the school system can be a traumatic experience in and of itself, especially when responses to and understandings of trauma are insufficient.

It is important to acknowledge that being an educator in today's times is a difficult task. Teachers are often under an enormous amount of pressure to not only support young people in their education but are also increasingly becoming accidental social workers in many ways when young people who enter their classrooms are dealing with intersecting disadvantages.

However, if teachers and schools don't have the capacity for wrap-around services for students doing it tough, it is crucial that significant training and understanding of and processes for appropriate referral pathways and follow-up are built-into school structures to ensure no young person falls through the cracks or gets left behind.

In supporting schools to shift towards trauma-informed and trauma-responsive approaches, we recommend that the following be rolled out through a staged approach across all Victorian primary and secondary schools:

- A further expansion of State Government of Victoria's rollout of **mental health professionals in Victorian schools**, including remote and regional communities, TAFEs and independent schools, ensuring appropriate teacher-student ratios are taken into consideration.

- Trialling a student led **peer education approach**[46] that specifically targets growing the mental health literacy of young people, to develop a more informal approach to co-designing information that is accessible, relevant and embedded in schools.

- **Youth Mental Health First Aid** or an equivalent curriculum be introduced to all primary and secondary school educators, staff and students.

Recommendation 4:
Growing the lived experience workforce as a specialised, integrated and legitimate field of practice as part of service sector reform

"Personally, advocacy for me has been more helpful in some respects than mental health services have because the things I'm working through and advocating for help other people and future policy changes. You're in a room with people with similar experiences, who understand what you've been through and who are supportive of listening to what you have to say." **– Tash, 23**

There is a growing need to understand and embrace the value add of lived experience as a legitimate practice and as integral to people's experiences of recovery. The Y-Change team members spoke strongly about the need for the wider sector to value the insights of lived experience as equivalent to 'formal' expertise. We know that the insights of consumers as system navigators are critical for service innovation and workforce evolution, however, there needs to be a greater investment from organisations to ensure lived experience as a practice is lifted.

The methodologies of co-design[47] and co-production[48] are gaining momentum. When thinking about re-educating and re-designing the mental health service system, those with a lived experience of mental ill-health must be partnered with, and at the forefront, of sector reform.

In supporting the mental health service system and wider community sector to embark on and invest in the journey towards partnership, we recommend:

- Dedicated **funding sources** be made exclusively available to support the evolution of programs, services and initiatives that focus on growing consumer participation practice and developing the leadership capability of those with a lived experience.

- Developing **a leadership and development scholarship program** targeted specifically for consumers, peer workers and other workers utilising their lived experience in a professional context. To be co-produced with consumers with relevant sector experience.

- Establishing **dedicated peer support teams** across all adult and youth mental health services in Victoria, including outreach support, and ensuring significant scaffolding support mechanisms are budgeted for, inclusive and sustainable.

- Greater access be granted for people to attain the **Certificate IV in Mental Health Peer Work**[49], with further study pathways to be developed in partnership with consumers.

- Setting up a formal **state-wide 'bank' of lived experience consultants**, who are offered professional development and skilling up opportunities. This bank must have a dedicated organisation and team behind them for administration, coaching and coordination support.

Recommendation 5:
Strengthening the mental health and wider community service sector workforce through specialised training and workplaces that centre wellbeing

"We also need to acknowledge the level of burnout for people working in the sector and the immense stress and traumatisation that can come with this work. We need to better support the people who are supporting others." **– Tash, 23**

Through the Y-Change narratives, we have heard a clear call for a more adaptive and flexible mental health service system that is able to cater to complexity. Looking at ways to begin transforming our practice, professionals and providers of mental health services must work to acknowledge power differentials, detrimental work cultures, and the serious impacts these have on help-seekers.

Part of supporting the mental health service sector workforce to strengthen practice is through a commitment to ongoing professional development opportunities for specialised training and ensuring workplaces centre the importance of wellbeing for all staff.

Looking at ways to 'support the people who are supporting others', the following recommendations are to be considered in relation to reform:

- Committing to organisational **mental health and wellbeing strategies** and strong internal cultures, ensuring they are modelled in practice. In an effort to approach mental illness as we would physical injury, we must consider mental health professionals as first responders to emotional and mental health crises, building internal capabilities accordingly.

- Considering the implementation of **mental health and wellbeing leave** across the mental health service sector and the wider community sector in Victoria.

- Ensuring that **first responders**, especially Victoria Police, are skilled up in trauma-aware and mental health first aid practice, and that a specialised mental health unit is considered.

- Implementation of mental health literacy frameworks and trauma-informed practice for **Employment Service Providers** throughout Victoria.

- Formalising learnings about **power differentials** and how they affect the client-worker relationship. This might look like an online training package, co-produced with mental health consumers and rolled out across the service system as part of mandatory professional development.

- Offering consistent **specialised training opportunities** for mental health and child protection workers, particularly when there are updates to best practice. This includes seeking consumer led training such as Youth Exchange, run by Y-Change at Berry Street.[50]

Recommendation 6:
Lifting the most marginalised young people and their communities out of crisis and breaking the cycle of intergenerational trauma

***"We need a nod to show that what we're going through actually exists. Some kids can't stay with their families. Some kids don't have happy families. We need more people to understand this."* – Kaitlyne, 22**

A significant theme that runs through this submission is how the effects of trauma and poverty influence young people's mental health. We know that some of the most marginalised groups in our communities are being profoundly let down, such as Indigenous young people, those who identify as LGBTQIA+, kids in out-of-home care and who are exposed to child protection and the criminal justice system, and young people living in regional and rural communities.

Often, these groups of young people are left to navigate service systems on their own, which is a lot for any young person to carry but especially for those who are in crisis.

We cannot look at mental ill-health in isolation of intersecting oppression and traumas, such as child abuse, homophobia, poverty and racism. Without addressing the underlying, systemic inequalities that profoundly impact young people's mental health, any movement we make towards reform will have us stuck at what we refuse to acknowledge. We need bold, progressive action towards a future for all children and young people in Victoria that is full of opportunity and centres dignity.

In regard to deep and entrenched social inequalities, the following recommendations point the way to long overdue reforms throughout interrelated systems that have long prevented marginalised groups of people from experiencing the quality of mental health they should:

- As the State Government of Victoria, advocate to the Government of Australia for **raising the rate of Newstart and Youth Allowance**[51] through championing **Raise the Rate**[52] and rejecting the punishing **Demerit Point System**[53] [54] for out-of-work Victorians and Australians.

- A commitment to building **no new prisons for children in Victoria** and seriously considering the policy options laid out in the Federation of Community Legal Centres (FCLC) "Free Our Sisters, Free Our Kids" campaign.[55]

- A commitment to **ending poverty**[56] in Victoria, together with a plan for how this will happen and setting an ambitious target for when it will happen by.

- Building on state government's commitment to social and community housing, a further investment to deliver **3,000 social housing properties a year in Victoria**[57] is required to effectively curb the growing tide of homelessness across the state. We also need a bold commitment to ending youth homelessness.[58]

- Ensuring **culturally diverse young Victorians**, including newly arrived, are supported through self-determining, community led approaches to mental health and recovery.

- Ensuring **Indigenous communities** are supported through self-determining, First Nations led approaches to healing and recovery, such as the Koori Mental Health Program run by the Victorian Aboriginal Community Controlled Health Organisation Inc. (VACCHO)[59]

- Further investigation into and greater investment for specialised supports for **people with disability** who have histories of abuse, neglect and trauma.

- Greater investment in **outreach support initiatives** for young people and their families living in regional and rural communities and looking closely at the recommendations made by the Victorian Council of Social Service (VCOSS) for mental health services in rural Victoria[60].

- Greater investment needed for specialised, trauma-informed support services, both direct and indirect, to improve the mental health of **young people in out-of-home care**.

- Implement organisation-wide models of care and referral pathways[61] specific to **trans and gender diverse young people** accessing the mental health system and interconnected service support services, such as homelessness.[62]

- Increase support for **victims of family violence and sexual assault** through an expansion of recovery programs like iHeal at Drummond Street[63] and the Centre Against Sexual Assault (CASA)[64].

- Invest in a campaign promoting pathways for **diverse young Victorians** to enter the mental health service system workforce, especially those with lived experience.

- Invest in specialised, therapeutic and accessible mental health services for **children and young people who are or have been victims of abuse, family violence and neglect** – including outreach.

- Make **suicide prevention programs** such as Applied Suicide Intervention Skills Training (ASIST)[65] readily available and accessible for communities, secondary schools and workplaces. We must shift towards a whole of community response to suicide, versus pathologising those who experience suicidality.

Recommendation 7:
Equalising the balance between awareness-raising and capacity building initiatives

"We put a lot of effort into normalising mental ill-health and making it part of everyday conversation and that's important, but you know what – not everyone is a licensed counsellor and we can't all be responsible for the burdens of others. Not everyone is equipped to be having these conversations. It can be helpful to get advice and understanding from others, of course – but ultimately you need expert and professional advice in the same way you would with physical health." **– Maddie, 21**

As mentioned in the introduction section of this submission, Victoria spends the least per person on mental health in the country. Although awareness-raising campaigns are an important mechanism for normalising seeking help for mental health, without the abundance of mental health services required to meet demand, we are leaving people stranded with nowhere to go. This is where we see people 'fall through the cracks' of a system that is unable to catch them during times of crisis.

As part of reform in the mental health service system, it will be crucial to balance the investment made in awareness-raising campaigns *and* in building capacity of the sector to be able to handle the volume of people seeking-help as a result of wide-spread culture-change.

To balance the scales of awareness-raising and capacity building efforts, we recommend the following:

- Ensure that the **investment of funds** dedicated to the final recommendations of this Royal Commission are weighted evenly between awareness-raising initiatives and direct service support or tipped in favour of frontline services to offset the historical under-investment in mental health services across the state.

- Further investment in the expansion of the **Support Prehospital Response of Mental Health and Paramedic Team (PROMPT)**[66] with consideration to a trial peer-led stream.

CONCLUSION

Young people are often excluded from decision-making tables, as it is assumed their experiences and knowledge are somehow incomplete. This submission and its findings prove otherwise. Each of the Y-Change team members who offered up their experiences, insights and recommendations has powerfully articulated not only what went wrong during times of crisis in their lives, but also clear visions for the future of what a system of care for those with mental ill-health could look like.

If this submission reveals one fundamental aspect of what is broken within Victoria's mental health service system, it is that young people somehow aren't seen to be already whole as they are and that their experiences of disadvantage enable a whole service system to feel entitled in its approach – with a misplaced mentality of thinking it knows what's best *for* young people, rather than partnering *with* them in their journey towards recovery and belonging.

It is clear that co-design and co-production approaches must be placed centrally to system reform. To do otherwise would be to replicate the same mistakes we have made in the past, and regretfully, continue to make. This work begins and is made possible through a deep commitment to understanding and re-imagining power differentials between consumers and workers and pivoting towards supporting more human and holistic responses to trauma and adversity.

As made clear by the Y-Change team, it is in the space between intention and response that our whole system falls down. Without clear and informed analysis about the 'why' behind how people present, we will continue to demonise, pathologise and other those whose experiences are different to our own, rather than placing the pathology where it belongs – in the intertwining, surrounding systems that we are all responsible for transforming.

To echo the wisdom and insight of one of the Y-Change team members, *"We cannot begin to help people with their sickness unless we cure the sickness within the mental health care system first."* Reform begins with us – our approaches, mindsets and intentions. Let's begin there.

APPENDICES

Appendix A – Long-form interview transcripts

Below are the full transcripts of the Y-Change team's one-on-one sessions. These have been shared as part of this submission with each of their consent. Names marked with an asterisk (*) have been abbreviated or changed for privacy at the young person's request.

Alyssa*, 19 years old

1. How should mental illness be treated/supported and by whom?

Mental illness should be taken more seriously than it is now, especially when you're a young person. For me, my mental illnesses weren't treated seriously. I was thought to have depression at 12 years old and was told that it was linked to my hormones – the start of puberty – and that I would 'grow out of it.' After two years of seeing a counsellor and numerous psychologists, I was then diagnosed with depression and put on anti-depressants. This was the period of time I started getting in trouble with the police, the first time I was arrested I was 14 years old. I felt like the anti-depressants reacted really badly with me. I also wasn't able to take my medication regularly as I was experiencing homelessness at the time.

At 14, I tried to take my own life and was admitted into the Adolescent Psychiatric Unit. When I was 15, I was given another diagnosis of borderline personality disorder. At the time, I was seeing a child psychologist, and this was also around the time when I was discharged from hospital.

When you come out of hospital, I don't feel like you get enough help. The last two times I came out of hospital, when I was around 18 years old and just recently, I didn't get much help and support. When I first went to the emergency department a couple of months ago, they gave me Valium to calm me down – then when I went into the hospital, they gave me more Valium. When I was discharged, I asked for a prescription because I found it hard to get back to normal life after being in hospital. I get a lot of anxiety and had a lot of trouble going back to my TAFE course. I wasn't able to get that prescription because I was told Valium is addictive. I wasn't offered any other medication to help me.

I was offered a Peer Mentor, who called me once and I never heard from then again. The Peer Mentor called me around two weeks after I left hospital and asked how I was going. It felt like she just had to do this and tick a box. I didn't get to talk through what I was experiencing or anything like that, it was a really quick phone call.

In hospital, everything stops. Hospital works because of this. You are just there and don't have anything to worry about, except in an adult psych ward. You have so much intensive help from doctors and workers, but once you get out, life is hard again and it goes back to the same as before.

I've been in three psychiatric wards so far: one was an adolescent psychiatric unit, the second was a Psychiatric Assessment and Planning Unit (PAPU) – you can only stay there up to three nights and that's for people who need to stay in hospital but only need a shorter stay with less-intensive care. It's only four beds and isn't as scary as the adult unit. PAPU is always full, you're lucky to get a bed there but the nurses were lovely, supportive, and always up for a chat.

The third time I was admitted was to inpatient unit two, which is an adult psychiatric unit. This was the worst experience I've had, mainly because I'm a young woman and there are grown men in there who tried to get my phone number and made inappropriate comments. There is a gender specific area in there, which I got put into after I talked to the nurse about the men's behaviour. Although you sleep in the gender sensitive area, you still have to be around them in the common areas like the kitchen, the TV room and the basketball area with chairs and outdoor area.

You're usually not allowed to have shoe-laces, knives – anything considered dangerous, but they gave me a knife and let me cut up my dragon fruit in my room. Before you even get into hospital, you have to be admitted. If it isn't a planned admission, which none of mine were, you have to go to the emergency department. If there aren't any beds available, which happens a lot, you have the choice of sleeping in the waiting room overnight and hoping something becomes available the next day or going back home and being unsafe.

2. What makes experiencing mental illness hard systemically/socially/financially?

Having to work whilst dealing with mental ill-health is extremely difficult. Like, when I worked at a fast food restaurant, I would drop something and obsess over it and start crying. I would then go to my supervisor and let them know, but they'd force me to stay. This makes it really hard because what I need is a bit more flexibility and more understanding staff. So, after my last hospitalisation, I had to leave my that job because they weren't understanding and didn't support me.

We need workplaces to be actively supportive for young people with mental ill-health, not just one poster in the staff room saying you can call an external provider to get help. We need mental health workplans to be brought into workplaces that you can give to your boss and get support. It should not affect you either getting or keeping your job, but it's there for your boss to know what's going on – to be able to access a self-care day or understand there may be times we have to leave if we're really overwhelmed.

People's health should matter more than profit. You can get another worker in, make sure you have casual and on-call staff. Where I worked, there were around 50 people on staff. Even just having a time-out room or space. There was a time where I burnt my hands and needed to run my hands under cold water, and I was being yelled at to get back out on the floor.

I had a friend who worked with me at the fast food place who lost their sister. They then had to come into work the next day, because they needed the money and didn't know where to go to get help.

3. What can be done to prevent mental ill-health?

When I was younger and after experiencing sexual assault, the police came to my house and asked me if I would talk about what happened, whether I wanted to press charges. There was no follow-up after that afterwards, no opportunities for referrals for me or my family to help us through and understand what had happened.

My mum had a mental illness and was a single parent and she didn't get any help. If it's not helped in one generation, it gets passed on. I do not mean that in a blaming way at all towards my mum, but it's a fact that if your parent is experiencing mental ill-health and addiction, you might too. They need help and support with their issues, as well as young people. Mental illness runs in my family – it runs so far back in our family tree, but it just keeps getting passed on and it's not stopping anywhere.

4. What do you think is being done well to support young people experiencing mental health? What do we need more of?

I used to struggle with only getting ten sessions through the mental health plan. Until I was hospitalised and accessed support through Child & Youth Mental Health Service. Now, I get free psychologist and psychiatrist appointments once a week. Sometimes, there are psychologists that are really busy, so you might only get an appointment once every two weeks, especially if what you're experiencing isn't classified as 'severe.' This helps me a lot and is something I wouldn't be able to get if it wasn't free.

5. Who needs support and how do they need supporting?

Young people need support getting to and from appointments. We need help being able to afford medication. We need help accessing stuff like kick-boxing and things that support our wellbeing. Young people need their families to get help – my mum and brother really need help. My little brother doesn't understand what's going on with me, why I'm in and out of hospital. All he knows is what mum tells him about me trying to hurt myself.

We need real education about mental ill-health. We need to stop hiding it. My brother needs to be able to talk to someone to be able to understand and seek help with what he's going through as he watches me go through what I'm going through at home. For years and years, my mum didn't want to believe I had a mental illness. When I was first diagnosed at 14 then again at 15, she didn't believe it. I don't think she understood what was going on. She still talks about what happens like I don't have a mental illness. If she looked at people with symptoms of borderline personality disorder, she would be able to immediately identify every symptom with me, but when it comes to me – it's like she can't accept it.

The importance of comfort in psychiatric hospitals is so underrated. They have shitty colouring pages, the pencils are all blunt and you can't have a sharpener, and most of the textas don't work so you couldn't use them even if you really wanted to. Hospital food is another thing altogether. You get hospital blankets that aren't warm, the walls are all white and if feels like you're in prison. I go to hospital to make sure I'm safe and because I'm in danger, I shouldn't be punished for wanting to be safe. If young people with lived experience of mental ill-health designed the psychiatric wards and

the activities, programs, and what the spaces looked like, it would actually become a place where people can start to recover.

6. Who is being left out of the conversation about mental health & what barriers are they experiencing?

A lot of the time in appointments, I start crying and can't keep talking to my psychologist, so I have to leave. Even though I have to leave, there's nowhere to go. Most of the times I've been left in the waiting room crying and not coping. You'd think for a mental health service, they'd have somewhere private for you to go when this happens.

I want Seroquel to be investigated. Professionals say that it's not addictive, but we know it can be. I first got put on it when I was 17 years old – it's a sedative and anti-psychotic mainly used for bipolar and schizophrenia but can be used for borderline personality disorder. I've been using it for two years, between the ages of 17-19, and there's been two nights I didn't take it in that time. What happened was, the first night – I did not sleep, was vomiting and felt very sick and dizzy. I started getting very paranoid and the voices in my head came back. The second time I didn't take it, the same thing happened. One of my friends also takes the same dose as I do: 100mg a day and she has to have it. If she doesn't have it, the same thing happens to her, she gets the same symptoms and really suffers. When I was prescribed Seroquel, I was told nothing about side effects or what might happen to me. I was told it was not addictive at all.

I think the positives of the drug still outweigh the side effects, but it's really important for young people to know what might happen if they do take it rather than finding out the hard way.

For people diagnosed with borderline personality disorder, you can get dialectical behavioural therapy. As far as I know, headspace is the only service that offers this for free and so there's a lot of people wanting to access it. There needs to be more places you can go to get it.

7. As a young person employed by an organisation, what do you need your employer to know/do to support your mental health better?

Having a copy of my mental health care plan or creating one specific to the workplace would make this experience even better, then you guys know what do if anything happens. Flexibility is really important. If you have mental health appointments, or need to go into hospital, you don't want to feel like you can't because you're not allowed to miss out on work. It's really important if you're struggling with mental health to be able to take a step back. Making employment processes and working within organisations more accessible for people who experience mental ill-health, as an example, different ways to apply for jobs. Making the interview process more personable, meeting up with people for coffee in the first place and then having a second interview and knowing at least one of the people who will be there.

8. How does lived experience consultancy work interact with your mental health?

I'm able to use my experiences to advocate for change. I can use the shit things that have happened to me to help services understand what happens from a young person's perspective and do better.

It makes me feel like what I've gone through, it's been for a reason. That there's something I can do with these experiences. I feel more of a passion for the work I do.

9. Is there stuff we do in Y-Change that supports or makes more difficult your experience of mental health?

I think Y-Change specifically supports young people into getting work. It gives you an environment where it's okay to make mistakes but also to push yourself and feel responsibility. It gives you almost what a good work life could be like. Working with people inside and outside of the organisation and have balance. I feel proud to say I work with the Y-Change team at Berry Street. It makes me feel like I'm important and a I've found a career that I'm passionate about and want to work hard to achieve. When I turned 18, I thought "What the fuck do I do now?" I didn't even think I'd make it to that age. All I was focused on was surviving. I didn't really think of the future and it all kind of hit me when I was 18. What was I going to do for a job? For a career? With Y-Change, it helped me choose my career.

Beanz*, 22 years old

1. How should mental illness be treated/supported and by whom?

I think mental health should be supported holistically. It seems to be treated like it's a disease, when things like anxiety and depression are working to protect us from things and can be reactions to life experiences. I feel like mental illness should be treated with acceptance and that we should be learning from a young age about mental health rather than when we hit teenage years, when we're all fucked up and have to do something about it when it's too late.

Learning self-care practices in school would be amazing, from kindergarten onwards. Getting to know about yourself, it's the one thing you need to spend the rest of your life with, anyway. I also think parents needs to focus on their own and their kids' self-care. Less focus on technology and more focus on connection.

2. What makes experiencing mental illness hard systemically/socially/ financially?

When I had psychosis, the hardest thing for me wasn't the psychosis, it was the stigma attached to it. I didn't feel comfortable talking to anyone about what was happening in my brain. That made everything really difficult and it made it scarier too. I remember being at work and feeling really scared. My mum made me go to work. I took Valium, and at that point in my life it did help. It was either taking a bunch of Valium's or having panic attacks. I chose the Valium, obviously. They gave me dissociation and it took me years to come out of that. One of the biggest issues I had was feelings of confusion.

As far as money goes, ten sessions a year is not enough. If you want more than ten sessions, you probably have to change your psychologist, even if you like them. Like, I really like the psychologist I have now and I'm already feeling upset that I can't get attached to the one I have now because I'll have to see someone different once my sessions are up. With mental illness, I feel like there comes a point where you get even more punished by the mental health system. Like, by the time you've passed headspace and Orygen as a young person, you end up in psych wards – locked away and treated like a monster by society for being mentally ill. To me that is absolutely fucked.

The lack of drug education makes things way more difficult, too. I think the only reason I'm not psychotic right now is because my parents gave me proper drug education. One of the things I'm most grateful for is that I always had a safe place to take drugs. Like, my parents knew if I didn't get to take drugs at home I'd go out and take them anyway, so they would take drugs with me. They wouldn't encourage me to, but they would take drugs with me and take care of me through that experience to make sure I was safe.

3. What can be done to prevent mental ill-health?

Meditation was really helpful for me. It taught me to be aware of my thoughts and when you've got psychosis, you get thoughts that arise like, 'these people are watching me' – paranoid thoughts, and you get a choice whether to believe them or not. When you've got psychosis, more often than not you lean towards believing them. Meditation helps you stop for a second, breathe and focus on your

breath and that's really needed when you have psychosis. You need to be able to get out of your thoughts for a second, to catch yourself.

Taking care of your physical health is important, too. People need to stop advertising shit fucking food. People need to try and eat healthier. At least, this helps me. When I eat healthier, I feel less mentally ill. Exercise and stuff helps too, when you can do it. I know that when I do exercise, I feel better. Less police presence in communities and less control over people in society is important. I feel like people feel so powerless because there's so much control over them.

We need less environmental destruction. You want to help me with my mental health? Stop destroying my and my kids' future. We need to destroy beauty standards, particularly those aimed at women. I think those have made me pretty mentally ill throughout my life. Stop talking over women. One of the biggest things that has affected me mentally is that I've been taught that my existence is to serve men. Women's voices are valuable, and people perceive them as irrational.

Thinking about how bleak the world is really affects my mental health. This world needs to change.

4. What do you think is being done well to support young people experiencing mental health? What do we need more of?

We need more public art. We need to advertise people's art. Art makes people happy. Seeing something that is pleasing to your eye is awesome. We need more diverse workers in the youth mental health space. We need more workers who reflect the young people coming into the system. We need more workers with lived experience in the sector. For example, we need people who are trans working with young people who are trans.

We need more funding into community projects and initiatives, especially art projects, land conversation and indigenous rights. The highest suicide rates are amongst indigenous people. We need youth justice reform and youth prison abolition. We need less racist and sexist mainstream news – it puts fear into people and creates disconnection in community and between communities. It creates shame in people.

We need more education about cultural awareness and sensitivity. Having an understanding of people's history and experiences can create a stronger connection with them and it's really important for us to connect with each other.

5. Who needs support and how do they need supporting?

I think it's a bit weird that they are offering trials to young people for different therapies and it seems to be targeting more vulnerable young people in the community. So, for those who need more than the ten sessions a year, they can be offered to get into these trials where they get free therapy, payments for attending the trials and medication. That makes a young person's life easier, especially those who are doing it tough, but it might not be what they need or what's good for them.

We need more diverse workers to suit diverse young people. We need lots of different workers walking into rooms. Unfortunately, lots of people who are privileged have better opportunities to study, especially in fields like psychology. Those who experience mental illness are usually less

privileged. We need to provide opportunities for those with less privilege to get into and work in these fields.

We need to work to decolonise the land and support Aboriginal and Torres Strait Islander young people on their land, to live in ways that support them. They are the traditional custodians of this land. We need more diverse representation in the Government, so that young people can feel represented by people who have had similar experiences to them.

6. Who is being left out of the conversation about mental health & what barriers are they experiencing?

Children are being left out of the conversation about mental health. The barrier that then manifests is that people don't respect the voices of young people. Women are also often misrepresented in the mental health system because it hasn't been created by them for them.

7. As a young person employed by an organisation, what do you need your employer to know/do to support your mental health better?

Making sure the people I work with provide a safe space for everyone to work within. Organisations also need to understand that people need equity. Different people have different capacities, strengths and weaknesses. We need to work as a community to understand what people are good at. As a community, we work well together when we draw on each other's strengths and support each other with the rest.

Having supervision is a positive. I feel like we should have this once a month.

8. How does lived experience consultancy work interact with your mental health?

This work can be triggering at times and it can be healing at times as well.

9. Is there stuff we do in Y-Change that supports or makes more difficult your experience of mental health?

For most of the time I worked with Y-Change, I didn't feel like I had a place here and that's because my skills are not conventional to this work. I feel like I've had to work to make my skills fit Y-Change and for a long time, that's made me feel left out. Up until the family violence project I'm working on now, I didn't feel like there was much I could do. I felt like everyone else was working on their own thing that they really connect with, but I didn't have that.

I feel like it's really important to bring new skills to this platform. Young people don't speak in one language, nobody does. Everyone speaks in a different way. It's really important for anyone walking into this space that they can express themselves and say what they want to say, as long as it respects other people's rights and safety.

Emilie, 19 years old

1. How should mental illness be treated/supported and by whom?

Mental health never ends – it needs to be supported, not 'treated.' A lot of reasons for my anxiety and depression are childhood trauma. That will always have happened to me. It can't be treated like it's been washed away. So, what's important is that I'm well supported to work through what I've experienced. I see things differently now that I'm older. I work with what happened to me differently to how I saw and treated that same trauma years ago – this is part of my growth.

My progression of my own mental health and feeling better in terms of being able to manage my own mental health has very rarely relied on other services helping me. Most of the reasons why my mental health is better today is because I've done the work myself. The mental health sector comes from the point of view that they have to 'help' you and there's no real emphasis on what kind of work you have to do on yourself and how you have to help yourself. I've met people who rely on other people to fix them and I think a lot of mental health professionals have put that expectation on young people – that they can somehow 'fix' them.

In my experience, holistic care is really important. I've had over 10 psychologists and multiple psychiatrists through the mental health system – I've been in over four mental health wards and four High Dependency Unit's (HUD) in Victoria. I've had a lot of experience in the public mental health system.

In 2015, I spent 26 weeks of that year in mental health wards. At one point, I was in there for five weeks consecutively without a break. I've seen a lot, mainly that the mainstream mental health system doesn't progress you, it only contains you for a while. When I was in the mental health ward for five weeks, I saw a psychologist maybe three times, which isn't even once every week. Any time I saw them, I was asked about how I was feeling in the present. But my mental ill-health wasn't caused by the present, it was about what happened to me in my past and that wasn't being delved into.

Five weeks for anybody is a long time. When you're in a mental health ward, time is incredibly elongated. In the 'real world', we wake up, have a shower, have breakfast and go to work. We talk to people, go out for dinner – maybe see a movie. Time goes much quicker. In a mental health ward, you have arts programs, music lessons, time at the gym – but time goes incredibly slowly. Five weeks in a mental health ward is not really five weeks. When you don't have anything to do, and you don't have any responsibilities – it's the perfect time to reflect on your mental health but you don't get the opportunity to do that.

For me, nobody was looking at my past. They weren't connecting the dots. My self-harm went from emergency, to rehabilitation and then to the Intensive Care Unit (ICU) in its severity. It went from me being out within a day, to being in the ICU for up to a week. I think the biggest issue is the hospitalisation and mental health wards process – there wasn't an understanding of how I was getting worse nor any questioning about what they might have been missing. You had a girl who was 13 years old with no scars on her body, to 15 years old with every limb scarred from self-harm.

Why all of a sudden, in this two-year period, did things get so much worse for me? Those questions were never asked.

One of the major hospitals I went to – they knew me so well and had an incredibly detailed history of what I was going through. I've only really been able to reflect now, at 19 years old, that nobody at school, nor my friends, nor anyone in the hospital system really delved into what I was. This hospital treated me like a nuisance and like I needed protection from myself. As time went on, I think that attitude of protection went to an attitude of hostility. 'Why are you still here? Why aren't you getting better? Why are you still running away from home?' Towards the end of me being in hospital a lot, the mental health sector had almost lost all hope about me. It became increasingly hostile. I had staff in the mental health wards threating not to let me back into the 'normal' ward and put me straight into a HDU.

From 14 to 17 years of age, within a three-year period, I went from emergency to ICU, from mental health ward to HDU. It went from protection to hostility. Through all of that time, nobody asked me "What happened to you?" It's only now, I've come to realise my childhood and teenage years affected and affect me a lot. Not once was this explored. Not once did somebody think, 'Maybe we should ask her about what's happened because there's something that needs to be supported, delved into and recognised here.' It's like a stroke – you've got a thing blocking an artery. You wouldn't ask someone having stroke, "Why can't you move your arm? Why can't you move your face?" You get straight to figuring out what's causing the blockage. You don't get angry at the person for getting worse. This kind of treatment doesn't happen at the same level with physical health, it happens purely with how mental health is treated. The really unfortunate thing about this is that that time in for me in hospital could have been spent sifting through what had happened to me and teaching me strategies of how to cope with it. Being supported to support myself.

It was in 2016 when a major shift happened – I moved into foster care and then into a therapeutic care and housing organisation. My psychologists shifted from being obsessed with the Diagnostic and Statistical Manual of Mental Disorders (DSM) system to therapeutic care and this is when change started to happen for me. My history was starting to be explored and released. I went from self-harming every single day and needing to be hospitalised at least three times a week, to being in hospital only once in 2018. I didn't self-harm or attempt suicide once. Therapeutic care was the difference. Since then, it's given me the power to support myself. Mental health workers aren't going to be there every day at your side, asking you how you're feeling from as scale of 1-10 while you're at work. You've got to learn how support yourself.

2. What makes experiencing mental illness hard systemically/socially/financially?

In terms of education, my school didn't support my mental health at all. My school told my friends not to hang around me and told people that I was dangerous. When you're at school and you're young, you need to have people help you understand what mental health is. My friends relied on the school to educate them, and the way they received that information from my school really affected my friendships with them. It goes back into what I was saying before – my school became increasingly hostile towards me and that affected me and my friends a lot. They were getting a lot of

misinformation. The school wasn't saying, "Emilie is dealing with a lot right now and there are going to be times that are really tricky, and we'll work through them together", instead their response was to say, "Emilie is a dangerous person, stay away from her."

3. What can be done to prevent mental ill-health?

Childhood experiences – knowing the strong indicators in a child's life that dictate whether they are at a higher change to experience mental ill-health. Knowing that children who experience abuse and bullying from their family, in addition to transitioning from being male to a female, are signals that they're a child that needs extra support. A child who has both experienced and witnessed extreme amounts of violence in their household and is coming out as trans – who wouldn't be affected by that? Who wouldn't have anxiety and depression from these experiences? Although this doesn't mean they definitely will, they have a significantly higher chance of experiencing mental health issues.

I think a lot of people see mental health as 'bad' – but it's neither good nor bad, it's just something we need support with. In terms of preventing it, looking at what someone has experienced from a holistic point-of-view. Before I had ever experienced or had started exhibiting signs of mental ill-health, child protection was involved. They were aware that I had experienced abuse and just started to transition – there should have been a connection made right there and then that I would need additional support. Holistic ways of working are not embedded into these systems, in the meantime – we're building more hospitals because we can't hold the amount of people who need support in crisis. We need to watch the signs and stop seeing each issue separately and like they are somehow not linked. It's really just common sense to me.

We need a whole cultural shift, and this includes schools. If a kid chucks a tantrum, the typical response is that you get punished. No-one asks why they are acting out. There needs to be education about how to express emotion in a safe and healthy way, how to communicate about what you're going through. We're not dealing with the deep emotions in people. Going back to my first point, we need to teach people strategies about how to cope in everyday life with their emotions and not label them as 'bad' – they are emotions, and everyone experiences them. Why are we still treating mental-ill-health as taboo when one in five people experience it?

4. What do you think is being done well to support young people experiencing mental health? What do we need more of?

Holistic and therapeutic responses to mental-ill-health are such a niche practice in the mental health sector but should be the mainstream approach. We need a much more empathetic approach. The cruelty in my time in the mental health sector was unbelievable. The times when it really did work, was when someone sat down with me and worked to figure out how I was feeling and why. No one will get better when they're being screamed at.

We also need to get feedback much more from young people. This process of seeking feedback at a large scale through the Royal Commission should be consistently happening at a micro scale within mental health wards. The feedback loop within so many organisations is appalling. The feedback

needs to be held and regarded at the very top and in a serious way. Organisations need to be listening to feedback. We need to stop listening to professors telling organisations what's what and ask the people who are directly affected.

5. Who needs support and how do they need supporting?

Mental health staff need support about how to do their jobs effectively. I don't think many mental health staff have experienced mental health issues. In my time, I saw one staff member with self-harm scars. The staff need support to understand what it is to be a young person in different situations to them. Those with a lived experience know it better than anybody and we know how to fix it better than anybody else because we know emotionally and figurately what needs to change. I really think lived experience consultants need to be very actively involved with mental health organisations. There needs to be a bank of lived experience consultants that organisations can call on to support the work of mental health professionals.

6. Who is being left out of the conversation about mental health & what barriers are they experiencing?

LGBT+ young people are left out of conversations about mental health, majorly. The major barriers are specifically for trans and gender diverse people. How would you feel if your name was Emilie, but you kept being called Barry and you were called that ten times a day? How do you think that's going to affect you? So many times, they can't put our preferred names on their information systems and so we are continually called by names that are no longer ours. Being asked about how hormones are affecting me, when what is really affecting me are experiences from my childhood. I don't believe there is any mandatory training for staff on how to work with LGBTI+ young people. A strip-search or being restrained, for example, is incredibly traumatising for someone who is trans or gender-diverse because they're having a body held down that has significant trauma attached to it and that doesn't feel like theirs. There is accumulated trauma and that is made so much worse through physical restraint.

7. As a young person employed by an organisation, what do you need your employer to know/do to support your mental health better?

If you've got people who work for you with lived experience, you can't just ask that person to turn the lived experience on-and-off. People need to be able to take time off and take care of themselves because of this lived experience. Lived experience is the highest qualification you can have because you've experienced something on so many levels – physically, emotionally, mentally, spiritually – and in many ways, there's a high price to pay. For people who go through the university system, they have a higher education loan. For someone who has lived experience, it's a debt you can never get paid back. It's with you forever. I think that also shows the value of this wisdom, too.

Organisations need to have mental health and wellbeing leave for staff. We have so many other forms of leave, but none of it covers mental health.

8. How does lived experience consultancy work interact with your mental health?

This is not easy work. A lot of people think getting us up on stage to tell stories and giving us a gift voucher is adequate. This work is difficult because for a lot of people with lived experience, you don't necessarily want to go back into exploring what you've been through, but you have to repeatedly delve back into these experiences to help educate others. In no other profession are you tasked with repeatedly revisiting your pain and trauma. We're tasked with running back into the fires we've escaped. Lived Experience needs to be absolutely valued as a practice. Part of my infinite debt is mental ill-health and what it takes to constantly and consistently be dedicated to managing this as part of my work.

9. Is there stuff we do in Y-Change that supports or makes more difficult your experience of mental health?

I think there's universal understanding by our whole team that this work is tricky sometimes. Mental health is at the forefront of our minds all the time. We acknowledge how this work affects us. We have an understanding that each person has their own unique way of looking after themselves best they can. In Y-Change, upholding mental health is an experience that is normalised, it's part of our culture. This should not be exclusive to Y-Change, but part of every organisation's culture.

Janelle, 20 years old

1. How should mental illness be treated/supported and by whom?

It should be acceptable to have challenges to our mental health in the first place. There also needs to be mental health and wellbeing leave for workers.

In terms of individual people, you need support from family and friends of course but sometimes their advice is not okay. This is where it's important to seek professional support. It's like being in a family violence situation, being told to either stay or leave isn't helpful because they don't completely understand the situation. You could be putting yourself or your friend in danger.

In rural and regional communities, you don't talk about mental health. I can't recall one situation where a person has said they're even sad. I remember at a funeral for a stillborn child in my family, nobody even cried. For me, it's normal – you just don't show emotion. It's just the way things are. When I moved out of home, it was only then that I understood that other people had a different normal. I remember hearing about an old friend who had killed themselves and I laughed from the shock. This sounds awful, but I had no idea how to process it.

There's such a stigma here, especially for farmers – so many stereotypes for how they should be and how they should act. In the last couple of weeks, there's been some suicides and people are starting to talk but it's too late for a lot of people because they're already gone and when they do need support, there is none. My parents don't even have proper internet or phone connection and they live 15 minutes from the nearest town and 45 minutes from Shepparton.

A lot of discussion can be like, "my cows are doing worse than yours, so what are you complaining about?" and this shuts down any opportunity for connection.

2. What makes experiencing mental illness hard systemically/socially/financially?

The lack of access, for one is a huge barrier. If you live outside of Shepparton, to get a one-hour appointment it would take someone at least three hours all up by the time they travel, have the session and then get home so there's a feeling of 'what's the point?' when you could be spending your time working. Especially for farmers at the moment, who are in a complete state of crisis. There's so much work to do and so much attention needed to do it. They don't have the capacity to think about their own mental health.

There is no support here. There's support in cities, towns and in extremely rural communities – everything in between is left out. For example, for young people over 25 in Shepparton, you have to pay in full for psychology sessions. To access affordable care, we're often told to go to Melbourne. Waiting lists are at around the one-month mark, even if you need urgent care.

Having people compare experiences makes things hard, like people can be in competition to see whose pain is worse. Also, when people say things like, "You'll be okay" or try to tell you that your pain isn't as serious as other people's, it makes you feel so much worse and it invalidates other people's feelings completely.

R U OK? teaches people to ask others about how they're going but gives them little to no support or understanding of how to respond or even have that conversation if the answer is, "No, I'm not okay." I remember at school, we ran around the school screaming it to people because it was funny. It's become a joke and an opportunity for publicity stunts for organisations.

If you are someone who identifies as LGBTQIA+ in a rural or regional community, it is close to impossible to get support. Where I am, you can go to Shepparton and access Goulburn Valley Pride Inc., which is an independent organisation and they do amazing work, but still – it's not professional support. The closest clinic is in Melbourne and the waiting lists are forever. In city Shepparton, it's mostly accepting but if you go further out – there is a lot of stigma about LGBTQIA+ people.

3. What can be done to prevent mental ill-health?

I've been running some workshops on wellbeing, relationships and sex in Shepparton because there's no education for young people for wellbeing or healthy relationships in schools at all. The young people don't know about it or know anyone else who does. We need education in schools about mental health, self-care and what to do when life gets shit. We need education on what to do when our friends are not okay. We need something like Youth Mental Health First Aid in all schools. I've recently gone through this course myself and it helps you understand what to do when your friends are not okay and why you use the strategies they tell you to use.

I also remember doing something called Peer Skills in year 8 or 9 in high school and it touched on how to have hard conversations with your friends. After doing this course, you'd sign-up to be a Peer Leader at the school. This was good, but nobody wanted to see you because of school gossip. There was a belief that if you go to a professional within the school, you know it stays private, but if you have to tell fellow students, it feels like a risk and your information will be shared with people you don't want it to be shared with. I think this was a good idea, but it would have been better if we were used as people who were the bridge between young people and services, so that we could have that initial chat with them and then support them with referrals.

4. What do you think is being done well to support young people experiencing mental health? What do we need more of?

Awareness raising campaigns like R U OK? are good but need more follow-up. It's good for them to start the conversation, but not lead it. I really like headspace. For me, having a bright and colourful service is really important. The Shepparton headspace I go to has a really great receptionist who is so friendly, and it makes such a big difference. She really calms you down and makes the whole experience less scary.

We also need more integrated services for young people where they can have every issue they are dealing with dealt with at once, so they don't have to travel around to multiple different services. It's like when you're in high school and every teacher gives you half an hour of homework each night. If you have the standard six classes at high school, that's three hours of homework a night. It's the same with service delivery. Each service wants you to do something and by the time you add that up, it's a lot of time for a young person to commit to.

5. Who needs support and how do they need supporting?

Literally everyone needs education and support at some point in their lives. It's important to get the prevention work happening so people can get the help they need before they reach crisis point.

I remember being in high school and there was no wellbeing team, so I went to the school nurse. He was great, but only worked every other day, so it was never consistent days. He also had the duties of a school nurse and was seeing kids one-on-one and so never had enough time.

One day, a teacher saw scars on my arm. She told me to see her outside, grabbed my arm and asked why I was doing what I was doing. Then another teacher walked past, and she showed that other teacher my scars. I was then sent to the staff room and my parents were called, all while I had teachers walking in and out seeing what was happening. I ended up saying I would tell my parents myself, which was really intense and didn't go well at all. The principal ended up calling my parents after-hours and talking to them about what was going on. I did appreciate him taking time out of his day to do this, but the whole experience was really full-on.

I was then referred to see a psychologist, which was a service offered in-school. The first issue was that I had to go home and get the permission slipped signed by my parents, even though I was self-harming and wanted to keep that private. The second issue was that the psychologist never showed up, so I never got the support I needed. Nothing happened after that, the support was forgotten about from the school's perspective because in their mind, they had hand-balled me to the psychologist. There was no follow-up and I was shitting myself, so I didn't say anything. This was the worst day of my life. My interpretation of being told I had to see a psychologist at the time was that I must have been crazy and would be locked away. There was no-one there to support me through this process or talk to me about how I was feeling.

Because of how the teachers had approached my self-harm at school, when I did need to go to headspace I ended up delaying it for over a year because I felt like I would be disregarded and not treated seriously, the same as how I was treated by the teachers in high school. Teachers need training on how to sensitively approach conversations about young people's mental health. I felt like I was passed around like a piece of meat.

6. Who is being left out of the conversation about mental health & what barriers are they experiencing?

The people who receive support are left out of the conversation and people who are not accessing services at all are being left out even more. My own dad asked me if I could help get a service out where they live and I'm just one young person. This is a huge thing for my family to acknowledge in the first place, so it shows how much they need it.

There's not enough outreach services for people, you always have to go and see them. It would be good to have mental health professionals come out to people's homes, like the Home Doctors Service. It would be good to have someone come out and walk around the farm with farmers, take them out for coffee and ask how they're going. Having support that's no so in your face. Some people just want a conversation, an opportunity to have a chat with someone who isn't their family.

7. As a young person employed by an organisation, what do you need your employer to know/do to support your mental health better?

I remember when I was in training, I found out about an important family thing and had to leave. Lauren was really flexible and totally okay that I had to leave early. Flexibility is important.

8. How does lived experience consultancy work interact with your mental health?

I'm very good at being able to switch into a professional mode. I am lucky in that I am able to remove myself from the story and the situation and focus on what needs to be done to support others.

9. Is there stuff we do in Y-Change that supports or makes more difficult your experience of mental health?

Overall, it's pretty good. The flexibility is very important.

Kaitlyne, 22 years old

1. How should mental illness be treated/supported and by whom?

There's no middle ground between having ten sessions within a calendar year through the mental health care plan and being involuntarily admitted if you're in crisis. It's too much of an extreme – either too much or not enough. There's this huge gap in the middle where a lot of people fit, but there's not enough ongoing or funded support when you're there. There's no happy middle with the services that are provided.

When people are admitted, they can have their medications used against them to conform or do what they're told. There needs be more up-to-date training for frontline mental health workers and those who work in mental health wards about how to support each person on a case-by-case basis and the importance of consent. Also, so they understand that people have setbacks and how to deal with these, rather than punish people for them. They need to understand that the journey to recovery is not a straight line.

2. What makes experiencing mental illness hard systemically/socially/financially?

People need to understand how trauma affects people, it literally interrupts healthy development. Being mentally unwell is not something I or anyone else can just turn off. A monumental time for me with my own mental health was in high school. This was both when things went to shit but also when I began to understand my own mental health. There's nothing more powerful than being able to understand what you're going through because you can then verbalise what's happening and be better able to ask for what you need. There's no such thing as a one size-fits-all approach because there's no such thing as a one-size-fits all solution for people's mental health.

There's an over-reliance on structure in the mental health system and this isn't matching people's experiences or needs. People are more likely to slip through the cracks because they are too focused on these checklists, which are ultimately another person's criteria. It should be the other way around. Young people should be supported in setting their own criteria and services should be able to meet their needs, not the other way around. The sector is so dependent on funding, and so services are built for outcomes, not the complexity of people. Last time I checked, this was mental health not the retail industry.

There's was a time recently where I visited a new GP because it was cheaper to see this person – already there's a cost over quality issue. She didn't know any of my health history or what works for me, and this is where is becomes so important to know yourself and what you need. My condition has meant I've had to try many different medications to see what works for me, which is difficult. With this new doctor, I had brought with me the script for a particular medication that I know works and that I needed more of because my old batch had expired. She was insistent on me using another medication, which was very expensive and not something I could afford. I stressed to her that I am a student and don't have a lot of money. Whatever I said, she was very dismissive. She didn't know me

but acted like she already knew what was best for me. Again, it's a one-size-fits all approach rather than dealing with each person as an individual.

So, I then left with the new script, found out the medication cost $80.00 with no option of finding it cheaper elsewhere. I then had to go back to the clinic and get her to sign-off on my original medication. If she has just listened to me in the first place, I could have saved time and the money I spent travelling around everywhere. It took me so long to find a medication that had worked for me in the first place, so I needed the doctor to listen to me and she refused.

There's also an expensive gap to pay with some doctors who don't bulk-bill and this is a huge barrier for people who don't have the money to access better quality care. The doctor I love and who listens to me is not local and is more expensive for me to access. It's really depressing knowing that if you have the money, you often have better access to the services you deserve and need.

A huge social barrier I have experienced is sugar-coating my experiences for other people, so they don't feel overwhelmed by what I'm going through. This is a really isolating thing to have to do. This makes me feel like I'm destined to be with someone who is as fucked up as me, because those who haven't gone through it can't understand you. It's like traditional holidays such as Mother's Day. It makes me so angry because there's an ideal pushed onto me that doesn't fit my experience and people just automatically assume that everyone is having the same experience. It's so weird. You feel like an alien at times.

3. What can be done to prevent mental ill-health?

There needs to be an expansion of continued community education about mental health, especially in schools. Those who are suffering need to stop being persecuted by systems that don't ask enough questions about what's really happening. For young people in particular, there's so much responsibility placed on our shoulders to 'conform' and 'fit.' When I was at school, me and my siblings clearly stuck out as the 'povo' kids. I've had to dig deep to get where I am. I used to compare myself to people in high school but now I look at those people and think, 'I've had to really suffer for what I've got now. It hasn't just been handed to me.'

We need formal opportunities to support young people to be able to reflect. We need support people who ask, "What happened to you?" and "What do you need?" rather than assuming and projecting prejudice. I was told at school that I wasn't putting in the effort and that I was giving up, rather than being supported for what I was going through. This is where history is important. There's such a focus on the present and the future, and no acknowledgement of how my past has shaped and impacted me. I couldn't tell if anyone genuinely cared. I do know there are teachers out there who do care but at the end of the day, there's only so much they can do within this system.

When I made the decision to leave high school and go to TAFE, I was treated like I didn't know what I was doing. I was shamed for taking control of my life. I should have been praised and supported but ultimately, the best I could do for me wasn't considered good enough for them. Funnily enough, the careers councillor at my high school was the only one who was supportive of me.

She was an advocate for TAFE and it made such a difference, even though she was the last person I expected to have on my side.

4. What do you think is being done well to support young people experiencing mental health? What do we need more of?

Despite what I've said previously about how slow change is within schools around issues such as mental health, I went to the Youth Health Conference in 2018 and there was discussion about research supporting mental health professionals in schools. Even if I didn't get to experience this, I'm really happy they're doing that now.

Interestingly enough, my old high school now has an onsite youth worker. When I was there, we had a wellbeing coordinator and a chaplain. We also had a psychiatrist, but this was only on offer once a week. We had over 1000 students at my school, so the waiting lists were huge. We need more counsellors and wellbeing staff at schools, not just psychiatrists and clinicians. We need people who are human and who are holistic in their approaches.

5. Who needs support and how do they need supporting?

Young people in out-of-home care are in desperate need of support, as well as young parents. There needs to be more money they can access, and money that can go towards helping them raise their kids and afford the stuff they need for them. It shouldn't be easier to have a kid and get a regular income from Centrelink than it is to find a job. Kids in out-of-home care need more mainstream acknowledgement and representation, like how Sesame Street has recently brought in a kid in foster care. I wish I had seen this when I was younger. We need a nod to show that what we're going through actually exists. Some kids can't stay with their families. Some kids don't have happy families. We need more people to understand this.

6. Who is being left out of the conversation about mental health & what barriers are they experiencing?

Young people are being left out of the conversation in a big way. As I've already said, services have this weird way of making young people fit their services rather than the other way around. I feel like those who are in positions such as carers or role models in young people's lives could have a greater impact if they were given the platform to express how they can help change the system. So, we're not just focusing on young people, we're also supporting those who support young people.

We need more ongoing support for young people, not 'once off' opportunities. We need services that are structured to have follow-ups or options to jump in and out as we need them.

7. As a young person employed by an organisation, what do you need your employer to know/do to support your mental health better?

Y-Change does a good job of giving us reality checks around self-care and sustainability. We feel like you genuinely care how we are. Consistent supervision, check-ins and giving us time and space to ask questions is important.

8. How does lived experience consultancy work interact with your mental health?

I feel like this work has definitely been the catalyst for me to find my own potential and strengths. That my story isn't who I am. It's definitely shown me that I am more and that I can use my story and what's happened to me for good.

9. Is there stuff we do in Y-Change that supports or makes more difficult your experience of mental health?

Y-Change supports the importance of self-care, when it used to be something I scoffed at and still often struggle with. I realise there's things in my life I still struggle with, but I'm working on them. Being a lived experience consultant can also be really stressful, especially when you have so many other commitments, like university.

K.C., 25 years old

1. How should mental illness be treated/supported and by whom?

I feel like there needs to be more emphasis on people with a lived experience of mental illness supporting other people with a mental illness. There's a certain level of understanding you can't reach through only reading textbooks and having a purely analytical and theoretical approach. It's useful, definitely – but there's much more to it than that. The most helpful people in my life who have supported me with my experience of mental illness have been people who have experienced it themselves. Some of them have been professionals, but the large majority haven't.

With a lot of mental illnesses, because they are so multifaceted you often need a group of support people rather than only one specific person. Now, I have a great counsellor who helps me so much with talk therapy, but they can't help me with everything. It's been rare that I have been able to find a psychiatrist or psychologist who has been willing to work with me at my own speed. My counsellor is unable to prescribe me medication or give me a formal diagnosis, so can't help me in this area.

I've had mental health professionals be mad at me for saying I want to see other people, not solely them – when I know I need multiple forms of support, not just singular. I feel like we need multiple points of access, not just one who is meant to cover all bases. For years, I've known I need a counsellor for talk therapy and a clinical psychologist or psychiatrist for diagnoses and managing medications if necessary and I've struggled to find one that I'm happy with, let alone two or more.

There needs to be broader and more general education about mental illness, what it looks like and how to seek support because there's not enough information out there. For me, it took so long to figure out what was going on because nobody around me would talk about it – I had no frame of reference. It took years before I thought about trying to see someone, I didn't know what I was going through was mental illness. There's not a lot out there that teaches you about how to recognise symptoms of mental illness in yourself or others and what to do if you do see them. I feel like a lot of people around me knew I was suffering from depression, but nobody knew what to do about it.

I remember speaking with a friend about my sleeping patterns, about how no matter how much or little I slept, I always felt tired and my friend said that this might be a sign of depression. There was silence after that and then there was nothing ever said about it beyond that. I also had a random classmate come up to me and ask if I was experiencing depression, so clearly people were seeing something. People were seeing signs of depression in me and didn't do anything about it. They didn't know what to do or that there was anything they could do to help me. So, I kept denying it because I didn't realise and eventually stopped talking about it altogether.

Information about a broader range of mental illnesses is also important beyond anxiety and depression. These seem to be the two that are talked about the most, but there are other illnesses beyond these and they and their symptoms need to be talked about as well. If people don't know any different, then they can't pinpoint what's going on and I struggled with this for a long time.

I kept trying to talk about my experiences, but I didn't know what was appropriate or helpful to be talking about because that's just how I had existed forever. So, trying to pick out behaviours and feelings that were considered 'abnormal' were impossible for me because it was all normal to me. I had no frame of reference for what was considered normal or abnormal. It's like family violence – how do you know until you know? Some things I thought about a lot in this vein were 1) Why did nobody ask why I was experiencing depression from 13 years old? 2) Why did nobody pick up that I was going through family violence? The feeling of abandonment that comes with these questions. At that time, I felt like I was in my own world and nobody could see what was happening inside of me – but lots of people knew and could see but didn't do anything about it. It's worse than being alone – it's knowing you've been neglected.

2. What makes experiencing mental illness hard systemically/socially/financially?

Wanting to die every day is difficult. What makes mental illness hard, first and foremost, is the fucking mental illness itself. Constantly living with these thoughts that tell me that I am completely hopeless and useless and should die. Having feelings of fatigue and being so tired but having all the doctors tell me that there's no reason for me to be feeling tired. Being told to get blood tests and having everything come back in the healthy range. So, then I end up not being believed because of this and they don't do anything more about it. I'm being told I'm fine, but I know I'm not!

Mental health professionals are so wrapped up in textbooks and the clinical information, without understanding the nuances of the experience of mental illness. Textbook definitions are very limited, and many of the professionals I've seen have been patronising and dismissive because what I'm explaining about what I'm experiencing and the way I'm behaving doesn't fit their diagnostic boxes. A lot of the ways mental illnesses are assessed are based on behaviours, but everything I experience is internally. It comes out in behaviour sometimes and that's quite mild, but what's going on in my head is much bigger and how that affects me and my emotions. This has never really been understood by professionals. I talk a lot about how I feel manic because I experience things to extremes including joy, but then be told that because I don't impulsively buy things when I'm in this state that I don't fit the box for particular illnesses. Whereas, one mental health professional told me I have perfectly described a manic episode, another mental health professional told me I wasn't experiencing manic episodes because of the length of time of the feeling. This was at the same clinic. How the fuck am I meant to figure out what's going on if the professionals can't?

Not being able to afford mental health care really fucking sucks. When I needed to be hospitalised, the difference between my experience in a public hospital and when my friends were hospitalised through the private healthcare system was fucking disgusting. Nobody wanted me to be there. It took so much of me begging and pleading, whilst being suicidal, to get the help I needed. I went to a GP and told them that I desperately needed help and to be hospitalised because I was scared of what I was going to do. I kept being told that hospital was only for people with 'extreme cases' – what part of wanting to die is not an extreme case? I was told that I really needed to avoid hospital because of the risk of being traumatised. I kept saying that I wanted to kill myself and that I didn't

feel safe, I had no family around me and nobody around me who could give me the 24 hour support I needed.

At every step of the way, people were trying to stop me from going. I ended up going to the hospital by myself and having to tell the staff I was someone with 'high suicide risk'. I was left alone in the waiting room for hours and I kept thinking that I could just walk out on the road and get hit by traffic. So, whilst I was fighting to access support I was also fighting the urge to kill myself. I eventually got checked into a psychiatric ward and was there for three days. During that stay, I saw a psychologist once and did not have an option to participate in any group or individual therapy. I was mostly in a room managing myself. It was helpful in the sense that I was in a place that was safe and that it was difficult to hurt myself, but there was no extra support or care given. They discharged me as soon as they were legally allowed to. Because I was considered compliant and quiet, I wasn't branded as a 'risk' and so was considered 'good' enough to be discharged. That was it – there was no follow-up or investigation into whether the medication I was on was the right medication. Spoiler alert – it was not.

It ended up being that the medication I was on caused me to have extreme mood swings. I was on anti-depressants at the time and they were pretty much making everything worse. I was told a long time before I was taking anti-depressants that if I had a mood disorder, in particular – bipolar, that the medication I was on would make it worse. When I saw the GP, I expressed concerns that this might be what I had but didn't have the words to explain why. The GP was not convinced that I experienced any sort of "manic" tendencies, and therefore I could not have Bipolar Disorder. She did however recognise the symptoms of depression, and so concluded that that's what the problem was, despite me stating several times that I believed there was more to it than that. She prescribed sertraline, and because I was desperate with no other options, I took the prescription. It was only after I had taken the script from her and was heading out of the appointment that she casually mentioned that if I *did* have Bipolar Disorder, Sertraline would worsen my symptoms.

Out of fear, I didn't take the prescription then, but years later was prescribed the same antidepressants by another GP and found they did exactly what the original doctor was convinced they wouldn't do – they worsened my symptoms. The consensus at the psychiatric ward was that the anti-depressants hadn't been given enough time to take affect and that after a while, I would calm down.

When I was in the psychiatric ward, it was better in the sense that I didn't have to be so vigilant – that I could relax enough to start processing what I needed to process through writing and self-reflecting. I needed to be able to do that in safe place because the stuff I was processing was too heavy to me to be able to do on my own. It was at the time I was understanding I was in a family violence situation – the core had been ripped out of me and I had to re-assess everything. It was so overwhelming and so hard to come to understanding this myself. Part of why I processed experiences internally was due to family violence. From an early age, I learnt that if I spoke up or even acted weirdly, I wouldn't be safe. So, I then had to do everything internally. If I externalised

anything, it would put me in danger. Going through the mental health system, that exact process ended up being used against me because my process was internal and not external, nobody believed me or would do anything to help me.

Comparing this experience to that of my friends in private hospital and the level of support they got, the barriers for them were nowhere near as much as mine were and as far as I knew, they were allowed to stay there as long as they wanted, provided they could pay to be there. They had access to specialists and then had continued, ongoing support post-hospitalisation from the same specialists. They also had access to programs and group therapy that they could continue to access. Although I'm glad that they got the support they needed, and it was beneficial for them, it's also infuriating to me because I could not afford the support I needed. I just couldn't get it.

In regard to the mental health care plan, the ten sessions per calendar year is fucking ridiculous. I can't even explain how this is not enough for most people. For someone going through what they're going through, you need to be able to access support for an extended period. You can't fix anything within ten confined sessions. At one point, I was accessing something called Schema Therapy and had to pay a $30 gap for the sessions. I was told during my first session that it worked best through having multiple sessions in very quick succession, but I couldn't afford to do that. My psychologist told me that this was fine and to come whenever I could afford to, which would be irregularly and every few months. It was so hard to find that extra money, at the time I was pretty much living day-to-day.

Even though I was promised it would be fine based on my availability, it clearly wasn't working based on how much was coming up in between sessions and how much I was holding onto in between those sessions. There was too much to talk about in one session and the therapist could pretty much not remember what I talked about in past sessions because of the length of time in-between. I would get the same spiels each session from him, which I politely pointed out to him and then he would get defensive and tell me that he was just 'refreshing my memory.' So, this made me feel super unsafe and having therapists yell and get aggressive at me has happened heaps of times. This is not helpful for someone who is trauma-affected and has a hard time finding safe spaces. These are the people who are meant to be supporting you work through your mental illness but end up making everything more unsafe for you.

A lot of the things I've experienced when trying to seek mental health support were the same emotional abuse and manipulation and knee-jerk reactions I experienced from people who had abused me and why I was going to seek help in the first place. The fact that some professionals take things so personally when it's not about them at all is something mental health professionals should know. It's not about them. They are there for the client. They are human beings and human beings make mistakes. If a client points out that there is something they've just said and it's not entirely accurate, they don't need to get defensive about that. They need to be aware of the impact of their emotional responses on their clients who, for the majority, are there to unpack trauma and who have been subject to abuse. You need to be very aware of your own reactions and how they might affect the client.

You can't go into this work flippantly and seeing it just as work when you're going to have such a profound, direct impact on other people. In the mental health sector, there seems to be a huge culture of arrogance. Everyone is so sure of what they know because of what they've studied – that they're 100 per cent an expert. So much so that they refuse to be questioned and that's dangerous. The absolute assuredness, even when they are wrong. Being so sure to do things like prescribe medication – even when it's not the right one – to put the safety of clients at risk because they need to be right. That they have no concept of the fact that they might be wrong is frightening. This then gets even more complex when you have such self-assured professionals contradicting each other in their advice and diagnoses.

I'm at a point where I'm desperate for an accurate diagnosis, but don't feel safe enough to continue accessing help from the mental health sector. I don't even feel safe to go to a mental health professional and ask for medication in fear of being labelled 'drug-seeking.' I honestly think there is a mistrust towards clients from mental health professionals. I feel like when I've tried to describe my experiences most times, I haven't been believed and I've had to work at proving myself. I get that they want to give the right diagnoses and that's something that I want, but there needs to be more of an exploration process where I can go and see someone and unpack my experiences in ways I understand them best and in a way that makes sense to me.

When I'm asked for examples and give the 'wrong example' – I'm then written off. There's no room for nuance or exploration. It's so much about what you have and then having to prove you have it – such a lack of trust for a person's internal world and feelings. Anytime I've gone to a mental health professional with prior knowledge that I might have researched myself, I feel like they automatically dismiss it. There's a real stigma around self-diagnosis but ultimately, who knows me better than I know myself? I'm not self-diagnosing and never have, I've always gone in with the attitude of 'I've done some research, this is what is resonating with me so can we explore this?' and I've always been shut-down. How can you tell these things about a person in a single session when you don't know them and have no grasp of their past experiences?

3. What can be done to prevent mental ill-health?

Families shouldn't abuse each other, number one. Don't abuse people, that's a start. I think education is so important – what mental illness looks like and how it presents. That won't necessarily prevent mental illness, but it should help prevent people getting to crisis point. If people can recognise what they're experiencing and see the warning signs earlier, they can access support earlier.

What happened to me didn't need to happen, so many things could have been prevented. I didn't need to get to that crisis point. I know so many other people who this has happened to. They didn't need to go that far down, and this is how we lose a lot of people. So many people don't survive that experience and their deaths could have been prevented. The whole healthcare system operates on the basis that you can only access help once you've hit crisis point, which is ridiculous because you should be able to access help way before you get to that point.

4. What do you think is being done well to support young people experiencing mental ill-health? What do we need more of?

When I started accessing services for help, no-one was educated enough to support me as a trans person. Barely anyone could even call me by my correct pronouns or the correct name. It made me feel so unsafe. I can't unpack trauma when I don't even feel safe in the room. I don't think it's too big of an ask that the mental health professional I'm seeing calls me by my correct name – I don't feel like I've ever been asking for a lot.

As someone who identifies as non-binary and who has shared similar experiences to me, I don't have to expend all this emotional energy educating my current counsellor or help them understand why it's important to use my correct pronouns. We don't even talk about trans stuff, but the foundation of my experience is already shared and understood. This is why lived experience is so important in mental health professionals or at minimum, being mandated to learn from people with a lived experience.

5. Who needs support and how do they need supporting?

The people who most need support are the ones who are the currently least supported and they need to be supported by people who understand their experiences. There needs to be more mental health professionals who are people of colour, LGTBQIA+ and more professionals who have disabilities, are neurodiverse and who experience mental ill-health themselves. The mental health workforce must be educated by people who have lived it too.

6. Who is being left out of the conversation about mental health & what barriers are they experiencing?

Queer folk, specifically trans folk. I'm hesitant to speak on experiences that are not my own. Thinking about systemic barriers for people of colour, people with disabilities, people experiencing homelessness – basically, the further away you get from being a cis, straight, white, rich man means the more you're being left out of the conversation within mental health or anything else in society.

It's important to point out that a lot of the time, the people who are being left out of conversations about mental health are the people who are most at-risk – this is bullshit and a huge problem.

7. As a young person employed by an organisation, what do you need your employer to know/do to support your mental health better?

Having someone who is my Team Leader say, "I feel you" in response to me telling them that I'm late to a meeting because I experience Seasonal Affective Disorder (SAD) matters. It matters because they experience the same thing and know how it feels. Having people around who understand what I'm going through and share the experience on a certain level is so important. Compare this to somewhere like the hospitality industry, they would probably get angry if I showed up late if I was in a car accident. Mental illness impacts me physically as well as mentally, like right now with SAD – I'm fatigued all the time and it's so physically difficult for me to get up and out of bed, which makes me late for or miss things altogether. Having someone who understands how this works means that they

don't interpret things like lateness as a sign of laziness, but rather, a warning sign to know I might need extra support.

Having people who can acknowledge my mental illness and have an open conversation about how I need to be supported is great, rather than jumping straight into risk management. Knowing that the team know who I am, compared to how I get when I'm genuinely struggling is enough to make me safe, supported and appreciated. That then becomes a positive cycle, as it becomes a part of how I manage my mental health better. It helps me feel less isolated and like I'm not struggling with this alone. It helps remind me that there's people there for me. In the past, I have been so obsessed with getting my mental health to a good place because there's been no-one else there to help me, that it's actually made my mental health even worse. So being able to have what I'm dealing with understood and be able to act and advocate on my behalf if I need them to means that I can breathe easier.

The core of this approach is flexibility, understanding and being open to negotiation, having the same things be offered to you if you had a physical illness. We need the same understanding and support for mental illness that we do for physical illness.

8. How does lived experience consultancy work interact with your mental health?

I feel like it has a two-pronged affect that I must be careful navigating with the work I do. I am someone who has a strong sense of advocacy and doing advocacy work is something I'm passionate about. I like to feel like I'm making a positive change and I get that a lot through the work that I'm doing. This has a hugely positive impact on my mental health, especially because I am using some of the terrible things that have happened to me to help make those same terrible things not happen to other people. Although it doesn't make the terrible things that happened to me okay, it does help to heal some of the hurt left behind. This is something that's very important to me.

I want to be clear – it doesn't make what happened okay or that I am able to completely heal, but it makes me feel better knowing that what I'm doing is helping to prevent those same things happening to others as much as I can. Getting positive feedback from people after workshops I've done and how they have directly impacted them and thanking me for my work – hearing from people that they've put strategies into their work almost immediately after my education is fucking amazing. It gives me a sense of purpose, which is something I've really struggled with. My mental illness tells me I'm useless, so having this combatted directly through having evidence against that is awesome. It helps me remember that I am awesome.

The other prong is that I'm constantly dipping back into traumatic experiences in my life and this often means I am reliving these experiences and that stays pretty fresh on the surface. That can be kind of dangerous when that's happening for a prolonged period. It's something I have to keep aware of and can be something that makes me head in a negative direction if I don't have a handle on it. I feel like Y-Change is well equipped to deal with that.

9. Is there stuff we do in Y-Change that supports or makes more difficult your experience of mental health?

Berry Street give me things to cuddle and fidget with and I appreciate that. Knowing you have that understanding there, especially with the management team, there is an honesty and transparency that makes me feel able to talk about what's going on if I'm struggling with mental health and having that active or proactive listening from the team. I can talk about what's going on with me, but I can also talk about what I need and that you will listen, not try to manage me.

I think it's also important to acknowledge that you both (Lauren and Morgan), in your own ways, have taken the time to allow me to build trust. That's so valuable and it has taken me a while to get there. The way that I've had my boundaries respected and not felt obligated to disclose anything, unless I wanted has been crucial. Authenticity, consistently and genuineness is important. That I could go through that process of building trust in my own way and at my own pace. This has been a huge barrier for me in mental health services, I have a lot of mistrust from my past abuse and trauma and experiences of mental health services. I don't feel like I can trust what they are telling me or that they have my best interests at heart. I am often not given the time or space to get to that level of trust.

The counsellor I'm currently seeing has been great with that too. There was that initial shared experience that was a helpful tool, but that was only one step in the overall process in feeling like I could trust them. It's important that I'm able to experiment and explore different things and then have time to process responses and make sure that they aren't aggressive or manipulative and that I am going to be safe and comfortable to disclose information to them if I felt like I needed to and that wasn't going to be thrown back in my face or handled inappropriately. Being able to maintain an open and honest dialogue is crucial. Something I have experienced a lot in the past with mental health professionals is that they have acted aggressively and defensively when I have tried to discuss how something they have done or said has made me feel.

Maddie, 21 years old

1. How should mental illness be treated/supported and by whom?

When we talk about mental health, there's the more biological and formal way of looking at health like physical health for example. We need to approach it as a health issue in the same way we treat physical health and I think in society we're starting to do that. The GP I see, for example, is purely for my mental health and I can go to her to talk about my anxiety in the same way I would if I had a broken foot. I feel like we have gotten closer to having mental health be integrated into our general experience in contrast to other generations, but we still have a long way to go.

There are so many services out there, particularly for young people and that's important. But, the longevity of these services in our system are not sustainable. A lot of this is because of funding cycles and where money gets dedicated to going. If there's not services filling the gaps where mainstream services are lacking, there are going to be people falling through the gaps.

It's important to look critically at where money needs to be spent, not just throw lots of money in one place. There's things that are already working, and we need to support what's working and look at what's not and then invest in fixing what's broken – not starting all over again. Don't throw the baby out with the bathwater.

We put a lot of effort into normalising mental ill-health and making it part of everyday conversation and that's important, but you know what – not everyone is a licensed counsellor and we can't all be responsible for the burdens of others. That's the risk we run with events like R U OK? Not everyone is equipped to be having these conversations. It can be helpful to get advice and understanding from others, of course – but ultimately you need expert and professional advice in the same way you would with physical health.

2. What makes experiencing mental illness hard systemically/socially/financially?

By its nature, addressing mental health takes time. For example, trying new medications take months to see whether they're right for you or not. Seeing a counsellor means you have to see them over a long period of time. Dealing with mental health is a time-consuming thing. Governments, policy and funding cycles refresh every 3-4 years, so what's accessible to me now might not be in future. There's always changes happening, current services being thrown out, new programs and services taking their place like the National Disability Insurance Scheme (NDIS). It's so hard to keep up as someone who is needing to navigate these systems.

We are lucky in comparison to countries like the United States when it comes to healthcare, but there's still heaps of issues we're battling with here. Bulk-bulling and getting affordable scripts changes all the time, which can completely put you back your recovery or ability to just exist in the same way you would if you had a physical injury. One setback can completely throw you out of whack, back to square one. Dealing with mental health can be so precarious.

I have Bipolar II, so when I think I'm getting better – I don't see my GP and don't take my meds. This is actually an indication of me getting worse. I need the most support when I think I'm getting better. Just because we have all these services available, it doesn't mean they're accessible to people. Creating new services is not what's going to fix everything. It's like domestic and family violence with the narrative of, "why don't they just leave?" We know that it's not that simple, but we haven't yet come to the same understanding about the barriers that exist for people who are needing to access support for their mental health.

3. What can be done to prevent mental ill-health?

With your physical health, sometimes you can be someone who can be unwell but also maintain a sense of healthfulness. You fluctuate on a spectrum. With mental health, there's also a spectrum. Anyone can get bad and some people will not recover, or their recovery looks different to what 'experts' deem recovery looks and feels like. Preventing mental ill-health isn't about trying to stop it – this isn't a goal we will ever reach. We need to understand that it's something that will always influence us and is something that is influenced by the world around us, just like everything else in life. It changes and moves with us as the world changes and moves. There's no such thing as fixing it. It's like spiders, most of us don't like them but we can't get rid of them because they are fundamental to the ecosystem.

To dedicate our time, energy and resources to eliminating mental health is missing the point, because we can't. We've got to make the experience of mental ill-health more integrated as a normal human experience. This experience is part of us, not something we can eliminate – this approach is pushing a belief and understanding of something on people who are suffering. There's not always an 'other side.' Sometimes, things are just shit and you live with it and move on the best you can. That quote, "If it's not okay, it's not the end" is nice, but it's not realistic. We talk about getting over the mountain, but not everyone can and that's okay – the actual problem is the approach and belief that everyone should get over the mountain. It's okay not to be okay, and that's okay.

4. What do you think is being done well to support young people experiencing mental health? What do we need more of?

What I think is working is completely subjective to my experience. No matter how well services work or how great everything is, there's always a chance that things may not work because everyone's experience is completely unique. I think it's hard to measure how things are going, because I can talk about my own personal experience of how well things are working in terms of treatment, but I'm still unwell. I think it's hard to measure what's considered working or not working, successful or not successful.

I'm a recovering drug addict and my belief is that you are always in recovery, *"Sobriety is not owned, it's rented, and that rent is due every day."* Often, when you think you're 'good' or 'fixed', this can be the most dangerous place to be because you forget that you need to be vigilant and that you need to put in the work. It's the same for me with mental health – I'd rather be safe than sorry. Deep down, I know my illness doesn't get fixed or better – it will always be something I have to consider.

I am constantly assessing the risk and it sucks to do that, but some people have to do that and that's okay. There is no winning or ticking the box of 'being sober' or 'not being mentally ill.'

5. Who needs support and how do they need supporting?

It's important to ask people how they want to be supported, not assume how they need to be supported. It's a fine line between giving people a voice and not putting the onus and responsibility squarely on the person who needs support. There's giving someone agency versus sole responsibility, especially if you're not in the head space to be making decisions. Working with people, not for them or leaving them to figure things out completely on their own.

6. Who is being left out of the conversation about mental health & what barriers are they experiencing?

The World Health Organisation's definition of mental health is, *"a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community."* This statement is so damaging. Who says that the person who is unable to work is unproductive or invaluable? People have different measurements of what worth and value looks like and this is often cultural and based on your values. Health is a spectrum, not something that is either complete or incomplete.

7. As a young person employed by an organisation, what do you need your employer to know/do to support your mental health better?

I have never been asked this or had the opportunity to think about it or had the education and resources to be able to understand what I can ask for and what is acceptable to ask for. I feel like I don't know enough because I haven't yet sought or been given access to the tools I need to comment.

8. How does lived experience consultancy work interact with your mental health?

I don't think my mental health is at a point where I can make a clear statement about this. Absolutely this work would affect my mental health, but I don't have enough awareness or insight around my mental health at this point to answer.

9. Is there stuff we do in Y-Change that supports or makes more difficult your experience of mental health?

The fact that there's an underlying acknowledgement, always, about being aware and considerate about mental health is important – not in your face, where every second question is "How is your mental health?" It's woven into Y-Change as a fundamental way of operating. It's not about having a dedicated conversation all the time, but a genuine respect for mental health in general. Also, having formal channels where we can formally deal with it through check-ins and supervision. It's a good balance of it not being my sole responsibility – the team also check-in and ask how I'm going if they notice something's changed.

Tash, 23 years old

1. How should mental illness be treated/supported and by whom?

Young people with experiences of extreme trauma, homelessness and out-of-home care are not in the picture. Children and young people are still being overlooked. We're not looking at mental ill-health through the lens of family violence or recognising the sense of entitlement parents often have over their children and what that does to and how that affects them.

2. What makes experiencing mental illness hard systemically/socially/financially?

Out-of-home care is one of the biggest barriers for young people. Once you're in the system, there is limited access to mental health support. You need a child protection or Department of Health and Human Services (DHHS) referral to access other services and they've always got limited capacity and waiting lists. Generally, when you're in care the people who are taking care of you won't get around to getting you what you need. You could scream at the top of your lungs about being suicidal, but it often takes a crisis for carers to act, regardless of whether that's foster or residential care. I didn't realise how severely unwell I was when I was in care, but I would get a knife and put it against my wrist to get the attention I needed because there's such a lack of listening. My sister asked for support for years and years, and she never got what she needed. There's neglect at so many levels when you're in care.

If you're under 16 and not eligible for youth allowance, you're not going to be able to access much because you don't have the money, even if you do have a mental health care plan. You can't expect someone who is living in unstable conditions to support themselves and deal with the severe mental health and trauma that comes with being a young person in care.

I lost my brother to suicide and I often wonder, why did it get to that point? My brother ran away from care, constantly. He kept running back to my mum's place, but they'd bring him back anyway. Eventually, they gave up on him and he was put back in a violent situation with my father and this led to him killing himself. Where's the accountability? I understand that the system is broken and that there's things they can't do, but from my perspective, they let him die.

Child death inquiries end at the age of 18 years old. If it's any time before this, they have to investigate but after 18 years old an inquiry doesn't have to happen. So, kids are being released from care with severe mental health issues, and where are they going? Many are going straight into homelessness or back into abusive homes. We don't have accurate data to show exactly what's going on with suicide rates and mental health for this cohort of young people.

The systemic response to children who are experiencing any sort of neglect or trauma is nothing. It's often left up to the mother to have a trauma-informed response to her child, who is often already traumatised herself. There are few services available and they are already over capacity. They tend to address younger kids and not adolescents, so there's a whole group of young people completely invisible to the system.

Youth mental health service providers can often act as a barrier for those in extreme states of distress. My sister approached them for help and was told to wait three weeks and they would call her back. She ended up waiting six weeks, didn't hear anything so called them herself and was told she had to wait another six weeks. This was for a specialised trauma-informed service who were already at capacity. She told them she was desperate for help but again, nobody listened to her, so she gave up. I ended up finding a suicide note from her and was able to intervene, but if I hadn't found it, who knows what would have happened. I ended up calling the police but there was no follow-up because she wasn't she wasn't going to do it there and then. Once she got bad enough, I called the triage services and was told, "Unless she's about to suicide, we can't help her. You'll need to call the police." The only response we have as a society for people in this state is the police.

I'm the only one in my family who has enough awareness about how to manage conflict and support the rest of my family. It's a lot to carry. Earlier this year, I completely exploded and threatened suicide. The police and the Crisis Assessment and Treatment Team (CATT) were involved at this time, but I could have talked myself out of that situation so easily. When you've had so much exposure to these services, you know what they want to hear and even though that may be true, people like me are still not getting the help they actually need – we only get what's available.

The trauma and mental health issues my family and I have are so severe. What makes me really angry is that we have to deal with the repercussions of past trauma we've all experienced because none of us got the help we needed when we were in the system. Now, we're left to battle the aftermath on our own.

Children are also rarely seen as true victims and so their pain and suffering isn't taken seriously. This builds up and the trauma impacts young people later on. There is also the issue of sexual assault of children and young people in care, which is something we are absolutely not acknowledging or addressing. There is a massive amount of victim-blaming that happens with high-risk young people.

3. What can be done to prevent mental ill-health?

We need to seriously address intergenerational trauma and how it impacts on a near inability to form healthy relationships. It's also about having conversations with people that the situations they have come from are fucked but that this isn't the future they have to have. Nobody ever acknowledges that what you've been through is fucked. I had to work that out for myself. When you're in such a traumatised head space, you can't expect someone in that situation to know what kind of future they want for themselves. They are too busy fighting the past and the present to think about what a better future might look like.

I think Peer Support is a huge part of the solution. You need to be around other people who have gone through similar experiences and come out the other side. We need to put some power in the hands of the people who are supporting these young people, too. Some people cannot acknowledge that there is something wrong and there's no way to convince them. But, there are ways you can support those who are supporting them to help them address these issues in ways that aren't too direct.

We need better ways to address mental health that aren't so clinical. We need to focus on therapeutic care and making mental health support less scary for people to access. There is such massive stigma and a history of people needing help with mental health as being 'crazy.' We're expecting people to engage with a system that is historically abusive and that we're still hearing is not capable of helping those at the highest need.

We need more integrated support for young people who are dealing with grief and losing people around them to suicide. This is a huge issue. There is nowhere to go for young people who are dealing with the complexity of things such as suicide and severe mental ill-health. There's so much stuff I haven't processed for example, because I'm still dealing with the repercussions of where I've come from in the present. How can I deal with everything I've been through when I'm still not at a stable enough point to be able to process things like my brother suiciding? There was nothing about what he really died from on the coroner's report, which was the trauma he had experienced. There was no history on there about what had led up to how he got there. If we had a better understanding of people's history, maybe we'd be better equipped to deal with the complexity of these issues.

4. What do you think is being done well to support young people experiencing mental health? What do we need more of?

Centre Against Sexual Assault (CASA) is a free service for people who have experienced sexual assault, so we need them to have more capacity to support people. We also put a lot of emphasis on sexual assault, but less on physical, mental and emotional abuse. For example, you can have historical charges placed against a preparator of sexual assault but not for physical assault.

Take Two is a great service for young people in out-of-home care but it still doesn't address the most severely traumatised young people. We need more services like Take Two that are even more specialised services for young people in care who have experienced severe abuse.

The CATT are good in the sense that they're a crisis response and they will see you every couple of days to once a week for a little while, wherever you are. The issue is that once they think you're out of crisis, they drop-off. Once that person is de-escalated and isn't at the point of crisis anymore, the CATT need to then have the ability to be able to refer people to get ongoing support from other mental health services. There is way too much emphasis on the person suffering to seek support and navigate the system on their own.

I mostly feel too overwhelmed to sit in Centrelink. It's really overwhelming being around other people at extreme levels of crisis. Three months after my brother took his life, I was told by a Centrelink worker that I "should be over it by now" so I could get back to doing job searching through Newstart. This is while I was grieving his death and asked if I could have an exemption from looking for jobs during this period. My mother gets medical certificates saying she can't work because of mental and physical health and is told by Centrelink that this is no longer plausible evidence, so has to give regular blood tests to prove she's unwell. In terms of Centrelink, you so rarely get the help you need. You are forced to work even if you're in crisis, traumatised or completely unable to work.

5. Who needs support and how do they need supporting?

People experiencing disadvantage are the people who need support the most and they don't get what they need. We need to increase the amount of sessions people can access each year through the mental health care plan. I know young people with severe anxiety, depression and other things who just can't get on top of things because they're too busy trying to look after themselves. The fortnightly Centrelink benefit amount is way below the poverty line and we're expecting people to look after themselves when they can't even get their basic needs met.

It's impossible for people to get on top of their mental health when all their energy and effort is absorbed into living. I know a young person who has significant fines from the time she was in out-of-home care and she often says, "living is more important than having to deal with my mental health", so she focuses instead on working to pay off her fines and her living expenses at the cost of her mental health. She suffers from suicidal ideation, often.

Talk therapy doesn't help everyone. Some people are so traumatised that they aren't able to develop rapport with workers because what's going on internally is so severe. We need creative ways to engage with people if they're not able to engage in traditional ways. Pet therapy is a great example.

Another big issue is the court system and how people are treated by it when they have been traumatised and victimised. There should be mental health support workers in courts for people to access. What happens if you're in court and you have a panic attack? There's no-one there to support you.

People also need to know they can get medical certificates from their doctor for their mental health – not a lot of people know about this either.

6. Who is being left out of the conversation about mental health & what barriers are they experiencing?

Young people who are traumatised are left out of the conversation. My oldest brother has autism and he is often misunderstood by his workers because they are unable to see past his disability to the trauma he has. So, rather than getting the multitude of support he needs, his responses to trauma are often blamed on and linked to his autism instead.

So many people are told that they are never going to amount to anything because of what they've been through. We need support workers who believe in our future and in our capabilities. We need more people with lived experience working in the sector, to make up a certain quota of the sector workforce.

We also need to acknowledge the level of burnout for people working in the sector and the immense stress and traumatisation that can come with this work. We need to better support the people who are supporting others.

7. As a young person employed by an organisation, what do you need your employer to know/do to support your mental health better?

Family Safety Victoria & the Victim Survivor's Advisory Council (VSAC) offers specialised counselling services through ShantiWorks. We need more of this kind of support for young people who are attached to initiatives such as Y-Change and other youth advocacy jobs in general. Although this work has an aspect of healing and has helped my recovery on some level, it is still stressful, and it can be re-traumatising. We need the right support systems in place to be able to continue doing what we're doing.

8. How does lived experience consultancy work interact with your mental health?

Personally, advocacy for me has been more helpful in some respects than mental health services have because the things I'm working through and advocating for help other people and future policy changes. You're in a room with people with similar experiences, who understand what you've been through and who are supportive of listening to what you have to say.

9. Is there stuff we do in Y-Change that supports or makes more difficult your experience of mental health?

Y-Change is really good in the sense that it doesn't treat young people like we're fragile. We are taught that our lived experience can be used to propel us forwards, rather than something that only holds us back or prevents us from finding fulfilling work.

The flexibility of advocacy work gives me the time and space to deal with my mental health when I need to. We need more full and part-time paid positions for advocates who are ready to step into the next stages of their advocacy careers – those who are looking for consistent and stable working hours.

Appendix B – Alyssa's poem

One of the Y-Change team members wished to share a poem she wrote in reflection of her journey of mental ill-health and the mental health service system.

It will get better one day, it will.

It will get better one day, it will. The first time I heard that I was 12 years old and in the car with my mum. She got a call earlier that day from the school counsellor saying that her daughter wanted to kill herself and had cuts all up her arm. "Why didn't you tell me, how could you tell a stranger that?"

It will get better one day, it will. I was told by my first psychologist at age 13 after the school counsellor said that I needed more help than he could give. Mum had locked every single sharp knife, razor, pencil sharpener, deodorant can, scissors, and anything else that could be used to hurt myself in a red tool box.

It will get better one day, it will. 14 years old admitted to the adolescent psychiatric unit after trying to take my own life. Dropped out of school, prescribed anti-depressants but they don't stop the pain, the nightmares and the suicidal thoughts. Smoking everyday now, I wish it would kill me faster.

15 years old and addicted to smoking. Drinking every day of the week and taking any drug that will make me happy. I have gone through six psychologists, didn't like any of them. They don't understand. I have been diagnosed with borderline personality disorder. My mum got the discharge notice but, 'it will get better one day, it will.'

It will get better one day, it will. I overheard my older brother telling my mum. She was scared every time she rang me that I wouldn't pick up. Every night she would lay awake terrified. She feared getting the phone call that her daughter had killed herself. Every time she would knock on my bedroom door, her heart sank that I wouldn't answer, and she would find her 16-year-old daughter with a note in her hand.

It will get better one day, it will. 17 years old, another couple of psychologists and psychiatrists later. Again, being diagnosed with Borderline personality disorder, this time with bipolar style. Prescribed Seroquel: an anti-psychotic. I was barely eating and when I did eat, the shame, voices and my inner thoughts would make me vomit it up or promise not to eat again. I lost 20 kilograms in two months. I got so many compliments. Everyone said I looked amazing and that I'd lost so much weight. No-one knew how destroying these comments where, they gave me the fire to continue to not eat.

It will get better one day, it will. Grabbing the steering wheel of the car because I couldn't handle the voices anymore, no one wants me here, why bother? Back to the emergency department after a psychotic break. I was screaming, digging my nails in to my old scars until they reopened and bleed. Admitted to the psychiatric and planning unit. Everything's different now, I'm 18 – officially an adult. I get a text from my 14-year-old brother, "I heard what you did, promise me you won't do it again.

You're the only one that I can talk to, who understands." It's heartbreaking that my brother, my parents, and even I don't understand anything about mental illness, or my mental illness, altogether.

19 years old, on the floor uncontrollably kicking and screaming. Looking like a toddler having a tantrum. Fresh out of inpatient unit two, this is my first time in an adult psych ward. The scars haven't faded, the reality has set in that they will never go away. Just new ones added. The pain hasn't stopped, I'm still here. I'm addicted to Seroquel, vomiting, not sleeping, and they come back without it. My fondest memory as a child is a box stacked with suicide letters, but I promise Mumma it wasn't your fault. Each and every day I am fighting for my life. When's the day it gets better? When will it?

Appendix C – Tash's film

Y-Change alumni and member of Victoria's Victim Survivor's Advisory Council, Tash, has given her consent to submit her animated film – Tash – as part of this submission. Tash tells her story as a witness to, and survivor of, family violence. The film was supported by Family Safety Victoria and selected for the Sydney International Film Festival. A link to the trailer of the film can be found at Reference 25 of this submission. No public release date has yet been announced.[67]

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