



WITNESS STATEMENT OF RACHEL BATEMAN

I, Rachel Bateman,1 say as follows:

- I make this statement on the basis of my own knowledge, save where otherwise stated.

 Where I make statements based on information provided by others, I believe such information to be true.
- I am giving evidence to the Royal Commission in my personal capacity, and not on behalf of my employer.

Personal experience

My experience of mental health challenges and with mental health crisis services

- I first encountered mental health services in 2004 at the age of 14. At the time, I was struggling with distress and shame and using self-harm as a way to express the pain I was feeling. I was struggling to navigate relationships and ways to seek support from my family, friends and school community.
- I felt high levels of shame and struggled to feel safe articulating my emotions, and experiences of abuse that I was living through. This led to intensified use of self-harm, and subsequently suicide attempts, to cope with my distress. I had a number of inpatient unit admissions at a Child and Adolescent Mental Health Service (CAMHS) throughout 2005 and early 2006. Many of my admissions were long stays, with me becoming highly distressed at the thought of leaving. During this time, I experienced disclosing sexual abuse and making police statements. I also experienced leaving home, living with strangers and in youth refuges.
- Although I had a CAMHS case manager and private psychologist, I didn't feel I had a great deal of mental health support outside of what I received from the student welfare coordinator at my high school, so I often felt at my most secure when I was in the inpatient unit. I made deep connections with some of the nurses there. Many of these connections overstepped "professional boundaries", but I valued them deeply as a part of me coming to understand myself and my place in the world.

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¹ The name and details of the witness referred to in this statement have been changed to protect their identity.

Please note that the information presented in this witness statement responds to matters requested by the Royal Commission.

- I had one particular nurse who (when I was not in hospital) would visit with me some weekends and let me come to her house. I admired her greatly, mostly because she was open and honest and made me feel valued as a person in her life.
- Other nurses exchanged email addresses with me, or simply had deep conversations with me when I was in hospital, sharing a lot about themselves. I built a relationship with a martial arts instructor who came to the ward frequently to run classes and we exchanged numbers and stayed in touch when I wasn't in hospital. Although they were all people who were paid to provide "care" to me, I didn't feel the strong "us" and "them" mentality that I do in mental health services today. It has left me craving a similar depth of connection that is beyond what I have been able to find as an adult.
- In 2006, I was living in a youth refuge and chose to move home with my parents, who had since moved from Melbourne to a country town in Victoria. This involved me ceasing a lot of relationships that I held very dearly but it provided an opportunity to re-connect with my family and start afresh.
- Por a number of reasons, I used minimal mental health supports between 2006 and 2014. Many of the supports and connections I received were through teachers and welfare coordinators at school, and from friends and mentors I found through a community youth group I was a part of. There were less formalised supports available, but I found greater opportunities for community engagement and significant connections, including meeting my now husband.
- In 2015, I had a major life change which involved my husband and I moving to another country town in Victoria and having significantly less income than I did previously. I went from having a full time job to becoming heavily reliant on Centrelink, unable to manage a car loan and debt, and did not have the large network of friends that I had established in previous years.
- I became quite distressed, turned online to seek support, and at times turned back to selfharm (which I had not used in the six years prior) as a way of managing my isolation and the distress this caused.
- I struggled to find adequate levels of work, so I decided to study. But I struggled to manage my mental health challenges in a university setting and subsequently dropped out. Although, a year later, I managed to work through a dual diploma in counselling and community service work. Studying eased a lot of my mental health challenges through my newfound sense of purpose, and the friendships I made with the people I was studying alongside.

- In 2017, three years after my previous relocation, my husband and I decided to move to Melbourne. I got a job as a peer support worker at an area mental health service. I talk about this experience below in paragraphs 74 to 77.
- The move to Melbourne contributed to an increase in my mental health challenges, due to my husband and I needing to re-establish ourselves in a place where we had no friends and no connection to our community.

My work in the consumer workforce

- Over the past three years, I have worked to build my skills in consumer peer support and consultancy. I am involved in the training, support and workforce development of the consumer workforce at a Mental Health Service. Alongside the training and support of our workforce, I also work to provide a consumer perspective at the executive level of my organisation and further the use of co-production in service development.
- Over the last three years of establishing myself within the consumer workforce, I have also been working to navigate the increase in mental health challenges I have been facing. This has been harder than usual to navigate given I am trying to navigate using the same services that I work for (as I live within the same catchment area for an Area Mental Health Service (AMHS) that is linked to my organisation).
- I also acknowledge the distress that can be present when working as a consumer worker within mental health services. For many of us, working in mental health services often replicates traumas that we have experienced. It is difficult working in an inpatient unit (or any part of the mental health system) where you are watching people being treated against their will, watching human rights sometimes not be upheld, and watching people who have been given similar labels to you be spoken about in demeaning ways.
- It is hard not to feel "less than" your colleagues, and it is hard not to wonder what they would think about you if they knew you had the same diagnoses as this group of people they often speak negatively about. Thankfully my relationship with work colleagues has felt safer over time. But there are significant challenges for consumers working within our public mental health system and these need to be addressed: see below at paragraphs 81 to 97.
- For the remainder of this statement, the majority of the experiences I describe draw upon my experiences within the consumer workforce, and my experiences using a variety of mental health services to seek support (mostly when in crisis). A large portion of this support came from the organisation that I work for, which comes with a level of complexity, and a heightened sense of shame. I have also received support from a private

clinical social worker and explored some alternate ways of seeking support, where I have found a sense of healing, and I speak about those supports below.

Mental health triage services

I have experienced so much shame and stigma calling mental health triage helplines and attending emergency rooms, that I now have a fear of using these services unless I have already harmed myself. In my experience, services are incredibly hard to gain access to, and fall short of meeting my needs when I am experiencing emotional distress.

I have had too many experiences of calling triage for support and being made to feel ashamed or like I was just seeking attention. I have only ever called triage when I was in genuine distress and this distress was often increased when I was made to feel ashamed by the person on the other end of the phone for reaching out for support. I now choose not to reach out to triage services to seek support myself, but have had occasions when other people have called them for me. This has mostly been my general practitioner (GP). I accept support from the triage line when they are called by my GP (or other support person), because I want to be respectful of their need to not carry too much risk (if I am thinking of harming myself). However, I am still often left feeling as though triage workers don't minimise my distress or risk because they do not feel safe to me.

In an ideal world, a phone call would be met with a connecting conversation that is free from shame, but that has rarely been my experience. There are usually really long wait times to get through to a triage worker, and conversations are either made up of a lot of risk assessment questions, where connection and empathy are missing completely, or the conversations are brief and I am told to have a cup of tea, or have a shower, or something else that I have already tried many times before. Five hours is the longest that I've waited on hold. There have also been times when someone has requested a call back for me, but I never got a call back.

In my experience, triage is not a service that is particularly responsive, especially when I'm in crisis. Also, the support that triage provide is very rarely the support that I need when I'm in crisis. Usually I need a really good conversation with someone who feels safe and approachable. I don't necessarily need a risk assessment, for example. That is a part of the triage service that I hate—getting on the phone with someone who just starts ticking the boxes. I wish calling this service came with a greater sense of empathy and connection. Usually I move through my distress more quickly when I have someone safe to speak with.

Emergency department presentations

- 24 From 2017 to 2019 I used the emergency department (**ED**) quite a lot. I went to the ED if I was having thoughts of hurting myself or had already harmed myself.
- 25 The level of safety I felt while accessing the ED really depended on that first person I saw at the ED triage. Most people are friendly, but there have been varying levels of how responsive the ED is. Some people just say, "Wait anywhere the waiting room. You'll be fine," and others say, "Can you wait at this chair in front of us?" Or some people actually bring you in from the waiting room to sit and wait on a couch until a cubicle is ready.
- When going to ED, prior to harming myself, I often experienced six to eight hour waits before being moved into a cubicle, then waiting for a number of additional hours before getting brief conversations with a mental health clinician.
- After having a conversation with a mental health clinician I am often turned away from services quite quickly. This makes me feel ashamed for having sought support in the first place. I have learned over time that the only way to decrease this shame and gain the level of time, connection and rest needed to decrease my distress, is by harming myself to a level that requires medical attention.
- Mental health clinicians have told me many times that it's easier for them to help me if I don't harm myself first, but my experience has been that when I haven't harmed myself it's just easier for them to send me home quickly without giving me genuine opportunity to express what I need. When my attempts at seeking empathy result in me feeling increased shame, it's no wonder that I turn to harming myself as a way of processing and communicating my pain.
- There have been times when I've been feeling really distressed and haven't hurt myself yet, and I've reached out to my GP who has suggested that I go to the ED. But even after having effectively reached out for help from someone else, as soon as I have to go the ED, I end up hurting myself before walking through the doors, because I get scared to go in there and tell them that I need help without having hurt myself first. If I hurt myself before going there, I usually hurt myself in such a way that they have to keep me there for 24 hours for the treatment that they give, and over that time it means that I actually get conversations with a mental health clinician or at least get enough of a break from my regular life to calm down to feel better to go home again.
- There have been times when I've had particularly bad experiences at the ED. One such occasion was when I went to the ED and was put in a cubicle space. I didn't actually get a conversation with any of the mental health clinicians in the ED. I did get a phone call from my interim key clinician who worked in the community team I was getting support

from. The interim key clinician told me that, because of their duty of care, they had to call my husband and my workplace to tell them I was a risk to myself. I was feeling really distressed because by that point I still hadn't had a conversation with the mental health clinician in the ED. Neither my interim key clinician nor the ED mental health clinicians had a conversation with me about how I was feeling or about what I would find beneficial in that moment. I was discharged from hospital. It was only after I was discharged that my interim key clinician called my husband to say that they were concerned about my safety, and also called my workplace to say they were concerned about my safety.

- Another experience I had of being in the ED was in late 2018, when I was really struggling with a few different things. My key clinician and I were talking about whether I needed a hospital admission. I went to the ED and I stayed there for the night, before they offered to give me a hospital admission. But we agreed that I would go home for 24 hours, see how I went, and that I could come back to the hospital at any point if I needed it. I did end up coming back to the hospital. I had struggled to cope at home and harmed myself.
- But when I returned, the mental health clinician in the ED was annoyed at me, and said that she thought I was lying to her. She called my husband and basically said she thought I was lying. My husband got annoyed at her and backed up my need for support in that moment. I ended up being admitted into an inpatient unit, but the experience of reaching out for support and being told I was lying about my need for this was certainly not a pleasant experience. I subsequently went on to have an eight-day inpatient unit admission
- I don't go to the ED as much as I used to. Throughout 2019 and 2020 I have mostly stopped using self-harm as a way of managing my distress. This is due to a number of reasons including having a job that gives me an increased sense of belonging and connection. My job has also allowed me greater financial ability to seek support from a private social worker who is able to provide me with a greater level of support and connection than I've found through public mental health services.
- There are a number of other forms of support I have accessed, or would like to access to continue to navigate my experiences of emotional distress.

Peer respite

One such support that I'd like access to, that we don't currently have in Victoria, is a peer respite service. Peer respites are a voluntary service, staffed by consumer peer support workers, where people can come and stay for approximately seven days. During that time they can also have full access to their life as well. For example, people can go home and see their pets, or they're allowed to go to work during the day if work is really supportive of them and then come back and stay the night there. Or they can stay there all week and

not leave the place at all. It is just a place to be able to go to stay if you're feeling overwhelmed, and need that additional connection and opportunity to rest and feel supported, but you do not have to disconnect from life in order to do that.

I have obviously never stayed at a peer respite service, but the idea of them sounds really nice for me. Maintaining connection with my life and my work is highly important to me, especially in times of distress, and I would like to see increased opportunities for seeking crisis support without needing to disconnect from things that feel important to me.

Safe Haven Café

In Victoria, as far as I'm aware, the only thing that is somewhat close to peer respite is the Safe Haven Café at St Vincent's Hospital. But you can't stay overnight there and it is not necessarily a place I go to when I'm really deeply in distress.

The Safe Have Café is located on the hospital grounds but you don't have to actually walk into the hospital building to get into it. You can enter straight from outside and into the Café. It is usually set up in a gallery space, so it has plenty of art on the walls. When the Café is set up, they bring out things like books, board games and blankets. They have tea and coffee available and they sometimes also have biscuits, muesli bars or other snacks. It is staffed by peer support workers and a clinician who works under similar principles to the peer support workers.

I think the Safe Haven Café is the only service that I have ever gone to that, as I was leaving, they asked if they'd see me again tomorrow. Being asked that question made me feel like it's okay to need to come back again and again, that it's okay to want that connection, and I didn't need to feel ashamed. It didn't make me feel like I was a burden on their service. It is not like the ED, for example, where I feel like in order to come back I have to have hurt myself and I have to prove my need for a service in order to get a response.

I have been to the Safe Haven Café at times when I have been really upset and needed to talk with someone, but I've also been there at times that I just wanted to sit down and play a game of Scrabble with someone. It is a space where you can go if you're bored, or if you're in distress. They don't screen people who come through the door to make sure that they're 'eligible' for a service. Some people just walk in to the Café and sit on a couch and do not talk to anyone. Others come and read a book or play games or speak to one of the workers.

The majority of the people using this service were potentially homeless, or people who were utilising soup kitchens. There were often people who would go and get their lunch provided for them somewhere, and then come and sit at the Café for a few hours and

then go off and get dinner provided somewhere else. I think some people just needed a space in between other services they were accessing. Although many of the people using the service felt very different to me, I always felt safe and appreciated the opportunity to connect with a variety of people.

Places and people that have made my journey more positive

- There are a number of people and experiences that have helped with my healing, including:
 - (a) Having a GP who is willing to see me weekly and bulk bill me. She is consistent and judgment free in her support and listens more deeply than my key clinician ever has. It is great to know that I can see her every week no matter whether I 'need' it or not, and she has been careful to make sure my physical health needs never get lost in amongst my mental health concerns.
 - (b) I see a private social worker who has consistently worked hard to build a relationship with me over the past few years. This relationship has often been limited due to the financial cost involved in seeing someone privately. I haven't always had the financial means to pay for this support, even though it feels like the most useful support to me. However, with a change in jobs 12 months ago, an increase in income, and the willingness to forego other wants and needs, I've recently been able to access weekly support from her. If I'm able to access this support on an ongoing basis, I feel this will be one of the most significant opportunities I have to heal and hopefully not struggle with significant mental health issues over the long term.
 - (c) I have also worked hard to be able to connect regularly with a peer support worker who I see privately. For me, seeing a peer support worker doesn't take the place of support from the social worker I see but it has been such an integral part of me starting to view myself as someone who isn't "sick" or "broken". Connecting regularly with my peer support worker has helped me to feel more normal and reminded me that there are other people experiencing similar things to me.
 - (d) Having access to places like the Safe Haven Café. Places with peer support, no medical records, and no conversations about me when I'm not present. There is no pathologising, no pressure to be anyone that I'm not, and no sense of being any less than the people that work there. I value supportive relationships that feel equal and where I'm not treated like a broken person who needs a service to fix them.

Capabilities and skills organisations need to value lived experience

- In addition to my own lived experience, I come with knowledge of the consumer workforce and potential capabilities and skills mental health services need in order to better listen to and include lived experience perspectives and leadership.
- Some organisations lack the ability to genuinely listen to the voices and perspectives of the lived experience workforce, meaning that key expertise is lost.

Non-clinical nature of peer work

- Organisations need to understand the non-clinical nature of peer work. They need to understand peer work frameworks, how they are uniquely separate from clinical work, and how they are valuable.
- While peer support workers are a part of the non-clinical consumer workforce, they can at times start offering support in a way that is a lot more clinical rather than based on the values of consumer perspective. When that starts happening, you lose the value of what peer support is meant to be. Especially in our current landscape in Victoria, peer support workers are put into clinical organisations and often managed by people with little understanding of their discipline and the perspectives they work from.
- Organisations need to set up structures that allow peer support workers to work alongside clinical teams, but not work in clinical ways themselves. Peer support workers cannot follow peer values such as "nothing about us without us" while also attending handovers or clinical reviews without the consumer being present or consenting to the peer support worker being present.
- Similarly, peer workers cannot operate within peer values while also suggesting consumers take their medication or follow treatment plans outlined by services with little input from the consumer themselves.
- It is imperative that consumer peer workers work alongside consumers to understand and support them in their recovery journey, no matter how that may look from the consumers' perspective. Of course peer workers can help consumers explore multiple options, and appropriately share their own lived experience to promote connection and further thinking, but peer work should always remain transparent, voluntary, and in line with what consumers want and need from their own perspective.

Understanding the difference between peer worker and consultant roles

Organisations need to understand the difference between peer support workers and consultants.

I worked as a peer support worker and I really believe in peer support. Peer support workers do direct service work; they use their lived experience to support current consumers of the service. They are the people on the ground actually using their lived experience to support other individuals, whether that be one-on-one or in a group support setting. Peer support workers can also support consultants to do systemic work, but it's important to recognise how peer support differs from consultancy.

While consumer peer support workers do direct service work in supporting people currently using services, consumer consultants utilise their lived experience and the broader consumer perspective in order to support service improvement and systemic change. In other words, consumer consultants do systemic work. For example, consumer consultants sit on the executive meetings of an AMHS so that the voice and perspective of consumers and the consumer workforce is taken into account when decisions are made. Consumer consultants also regularly chair a consumer advisory group, which includes current consumers of the service. Those groups are used to make sure that the organisation is doing things in line with what the consumers actually want. That could be in the development of brochures or trainings, or their responses to the themes that come out of complaints and things like that. They help support consumer participation and codesign to be used throughout the organisation.

Consumer consultants also pick up projects in their individual services, which are focused on improving the practice of clinicians within the service. Usually the project is based on the perspectives of the consultant and the advisory group they facilitate, and additional needs identified through consumer feedback and surveys. For example, one of the consultants at my organisation is currently developing, alongside their advisory group, therapeutic engagement training for staff. The training is based around what consumers would like the organisation to do to engage better with them in their care.

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Although peer support workers don't often engage in service improvement activities, there are still ways for them to feed their expertise back to the organisation. The way that peer support workers feed their knowledge back to consumer consultants or advisors depends on the organisation and its structure. For example, some services have whole-team meetings. In these meetings, all the consumer workers gather together—whether they are peer support workers or consultants. In that space, peer support workers might be able to raise issues about, for example, the language that clinicians are using to discuss consumers. Having received that information, the consultants can then push forward with

different projects to address the issue. It is important for peer support workers to share suggestions for service improvement needs without breaking the confidentiality of the people they are working with. It is important for consultants to meet regularly with peer support workers and support them to identify service improvement opportunities – this helps peer support workers to know their perspectives are being heard and they can then focus their day-to-day attention on providing peer support to consumers.

I discuss the importance of supervision and support for consumer consultants further at paragraphs 92 and 92 below.

Co-production

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In order to strengthen service improvement and ensure that services are designed in a way that genuinely meets the needs of consumers and their families and carers, organisations need to engage in co-production. Co-production includes consumers being a central part of the co-planning, co-design, co-delivery and co-evaluation of service improvement activities. Co-production processes should include genuine opportunities for consumers to feel heard as equals, and opportunities for organisations to reflect upon the power held by them and by clinical professions.

Although I have not accessed training in co-production skills, I know that there has been such training on offer. Over a year ago, the Department of Health and Human Services (DHHS) and the Centre for Psychiatric Nursing helped develop some resources for co-production training with The Australian Centre for Social Innovation (TACSI) in South Australia.

Co-production training gives the lived experience and clinical workforce tools and resources for understanding relationships, ways of setting up co-production spaces, and the need for people to work together in addressing power imbalances and ensuring consumer perspectives are being heard. Alongside its training, TACSI provides a large number of resources that anyone can access online. Attending the training first would support an understanding of how best to utilise these resources, but in the absence of training the online resources are still helpful.

It is important for lived experience staff to access co-production training, but it is possibly even more important for clinical staff to have access to it. Clinical staff sometimes believe co-production is about inviting one or two consumers into a clinical meeting to hear their opinions. These meetings do not always give lived experience staff and clinical staff equal opportunity, or power, to address the issues in front of them. For example, in a training that I helped co-design, we made an effort to ensure all participants, consumers, carers and clinicians felt as though power was equally shared. However, after the training, we

conducted an evaluation. We asked participants to give us a rating out of 10 on how well we had navigated the issue of power in the group. On average, the clinicians rated us at 8.1 out of 10. But the consumers rated us at 2.8 out of 10.

That evaluation gave us a very different perspective of how well we had actually managed the issue of power. Among the people who had helped put that training together, only one had undertaken co-production training. I would be interested to see whether the results would improve if more of us undertook co-production training and better understood ways to help minimise power imbalances throughout the service improvement process.

Ensuring access to co-production training is an important part of increasing the use of coproduction. However, some staff, particularly clinical staff, might not be inclined to
undertake the training even when it is made available to them because they may not
understand the need for this training. Often people do not recognise the power that they
hold, and it is hard to encourage them to proactively choose to view things differently.
This is not true of all clinical staff: there are some who work alongside the lived experience
workforce and who actively try to collaborate, but further work on co-production is always
needed.

Deepening clinical staff's understanding of consumer perspectives

Organisations need to encourage reflective opportunities for clinical staff to partner with consumers and the consumer workforce, to deepen their understanding of consumer perspectives.

Co-reflection is a term that is used in the Intentional Peer Support (IPS) training model. It is an opportunity to have reflective practice with each other. In a co-reflection, a group of lived experience workers will come together and reflect upon how they are using IPS principles in their work. The co-reflection is an opportunity for them to talk about how they see values underpinning their work, and to reflect on working in alignment with those values.

I think it would be useful for peer support workers to have a co-reflective space with clinical staff. Sometimes peer support workers and clinicians each make assumptions about the intentions of the other. We need spaces to reflect upon why people might feel a certain way and to question how we can do things differently. Some of the best relationships that I have formed with clinical staff have been characterised by having opportunities to reflect and to ask questions of each other, in a space that is free of shame. But in a clinical setting it is hard to find the time to have those conversations and to deepen understanding.

- I sit on more than 15 different committees at work, which is a lot, but I am the only consumer in my area. If I have an agenda item, I am usually given 5 to 10 minutes to discuss that item. In that kind of setting, there is no way I can get my views across, genuinely be heard, and have the opportunity to engage in discussion and explore multiple worldviews.
- We need to be creating more spaces where change can happen. This could be done by changing meeting structures to allow more time for each agenda item, or by opening up reflective spaces.
- I discuss the role of co-reflection spaces further at paragraphs 105 to 107 below in the context of strengthening the skills, training and development of consumer lived experience workforces.

The need to listen to a diverse range of consumer perspectives

- Organisations need to acknowledge that listening to the perspectives of the consumer lived experience workers should not continuously take the place of seeking the thoughts and experiences of consumers who do not work for clinical mental health services. Organisations should seek a diversity of consumer experiences, from consumer workers and non-employees—from consumers with a variety of backgrounds and a variety of experiences—to inform how they provide treatment and support.
- In my experience, the consumers who become employees of organisations are at times more articulate, or educated, or fit nicely into clinical teams. That means that the lived experience workforce is not always representative of the full diversity of consumer perspectives. There are many consumers with whom organisations might feel less comfortable working, for example those who are actively opposed to clinical treatment. I elaborate on this issue at paragraph 85 below.
- Another issue is that, even though a member of the lived experience workforce can bring their own lived experience perspective to an organisation, they also have an internal view of the organisation and are aware of challenges that the organisation or their colleagues may face. Members of the lived experience workforce are in the difficult position of having to navigate having difficult conversations alongside colleagues. In that context, consumers can feel the need to censor themselves to some extent.
- In our organisation, there are many consumer advisory groups. Some people in those groups are not employed by the organisation. They still get paid for their time to be in these groups, but they are not employees. Advisory groups' views could be drawn upon for uncensored perspectives.

- Another source of diverse consumer perspectives could be from The Victorian Mental Illness Awareness Council (VMIAC) consumer register, where any consumer can put their name down, and can be called upon if, for example, DHHS or a service wants particular viewpoints.
- In addition to drawing upon the perspectives of a wide range of people, consumer consultants should be given the opportunity to learn and ground themselves in "consumer perspective". Consumer workers, who are connected with the wider consumer movement, and with a variety of consumer voices, bring individual and collective knowledge. While consumer consultants may be individuals, it is important for our perspectives to be understood as being representative of many consumers, especially when extensive work is being put into understanding the needs of a diverse group of consumers.

An example of a post-discharge peer support initiative

- For two years from 2017, I worked as a peer support worker as part of Victoria's postdischarge peer support initiative. This initiative has been around for about three years. It involves putting peer support workers into inpatient units, and getting those peer support workers to see people for at least 28 days after they have been discharged.
- The type of contact that the peer support workers have with consumers varies. For the majority of people with whom I was paired, we met in cafés as they felt comfortable meeting there and having a conversation in that space. As much as possible, I tried to meet people in places where they didn't feel like they were coming into a clinical meeting room. I very rarely met people at the location of the actual service.
- Where we met, and what we did as part of the program, depended on what the person needed. Some people just needed some connection and conversation, so a café worked well. Other people wanted to create better linkages with their community, so the peer support worker could do an activity to improve their confidence to go into community spaces, like attending a free art class together.
- One of the initial goals of the initiative was to reduce the readmission rate. Early on, this was recognised as a potentially unrealistic goal, because people may be readmitted into hospital for any number of reasons. Putting aside the question of readmission, the time post discharge from an inpatient unit is often a time of increased distress, so additional connection and support was often welcomed by consumers.

The need for ongoing peer support

It is a worthwhile idea to offer people support after they leave hospital. However, one of the major limitations of peer support programs is that some services keep the support strictly limited to 28 days. For the service I worked in, support was offered for up to three months post-discharge. However by the third month the support was mostly supposed to be in the form of phone calls, rather than face-to-face catch-ups.

Even with this longer timeframe, it was at times hard to establish a trusting relationship with someone, have contact with them for two or three months, and then to have to say goodbye to them. I often valued when people were readmitted, because I then had the opportunity to have longer relationships with them. Every time they were readmitted, we could resume that contact after discharge. I had relationships with some people for the full two years that I was working at that service, because they were continually being readmitted. In a way, that was better. It defeated the purpose of the short-term post-discharge support program, but it meant that we actually had the chance to form a relationship. We could have deeper conversations and I could provide a deeper level of peer support.

ldeally, people should be offered ongoing support from a peer support worker. For example, when a person comes into an inpatient unit for the very first time, without any prior experience of mental health services, they're often assigned a key clinician who they get to see for the length of their stay at the service. I don't see why they couldn't also be assigned a peer support worker (if the consumer wants one).

Difficulties faced by the peer workforce in the public mental health system

- I have mentioned a number of the difficulties that people in the peer workforce face in the public mental health system (see above at paragraphs 50–73).
- A further difficulty is peer support for lived experience workers. Even though there are peer support workers at my AMHS, I'm also an employee of the organisation and so all of the peer support workers are my colleagues and people who I look to for professional support. So, even though I access support from a key clinician and have had hospital admissions myself, I have chosen not to accept personal support from the peer support workers at my AMHS. As mentioned above, I have gone to the Safe Haven Café to access peer support, and have paid to see a peer worker privately, but I would have loved to also have access to peer support as part of my experiences in the AMHS I've received support from.

Discrimination based on lived experience in the workplace

When I first started as a consumer peer support worker, I didn't have a permanent contract in my job. My role was a part of the post-discharge peer support initiative and the funding wasn't yet recurrent.

When the funding did become recurrent funding, my employer wanted me and my colleague to reapply for our positions. When we reapplied for our positions, they re-hired my colleague, and instead of also re-hiring me, they hired an external applicant instead of me, which is fine—it is all part of the process. I would have understood if the successful applicant simply had a higher level of skill than I had. However, my then supervisor said afterwards that they thought my diagnosis may not be a good fit for working in that area. When I brought this up as something that wasn't okay for them to say, they did not understand why it was not okay. Peer support workers and people who are working from a consumer perspective are hired because of having a lived experience, however, their individual diagnoses and experiences should not be used as a means of discrimination. Other than the fact it's discrimination to name a person's diagnosis as a reason for losing (or not getting) their role, it's also not a very clear or productive way of describing what the issue is and what might need to change.

Having lived experience is often used to discriminate against consumer peer support workers in ways that the organisation does not even see is discrimination. As I mentioned in paragraphs 68 and 69 above, I think organisations need more support to listen to a variety of consumer voices, especially the consumer voices that aren't easy to listen to. In my experience, if a consumer speaks up with a really big issue, or if they speak up in a way that is full of a lot of emotion or passion, or in a way that sometimes isn't easy to hear, then organisations end up saying that person is unwell and that they need to wait until they are better before they can keep seeking to resolve the systemic issues they are seeing (see further paragraph 175 below).

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Organisations are effectively shutting the down the voices of people because they think that they might be unwell, which is really another way of saying "the organisation finds them difficult to deal with". I think organisations need support in how they can listen to voices that they're not used to listening to. This is especially necessary at the executive level of organisations where people are used to listening to each other's voices, being the voices of those who are people who have worked in the sector for 20, 30 or 40 years, who have really high levels of education, who are really privileged people and who have learnt how to speak in those spaces. For consumers to be heard, especially at the higher levels, or at any level of an organisation, organisations need to go out of their way to listen to them. Rather than encouraging consumers to speak in ways that are easier to listen to, sometimes organisations need to improve their ability to hear.

Lack of supervision and support

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I have had two different roles in the consumer workforce, and my experience has been different in each space. When I was working as a peer support worker, I was at an inpatient unit. I at times felt distressed working in this environment, however, my distress never came from supporting consumers; my distress came from my colleagues. I would often hear nurses in the nurses' station speaking about consumers who perhaps had a similar diagnosis to me and saying really negative things about them. They weren't talking about me, but it felt like they were talking about me. Their negative comments meant that I found it really hard to connect and feel safe in the workplace alongside my colleagues and feel integrated into a team. For me, in my work at an inpatient unit, one of the things that became really important was consumer perspective supervision. I know a lot of workers don't have access to consumer perspective supervision. Services don't necessarily have access to enough supervisors to provide it to everyone, but that has always been really integral for me.

I was lucky enough to have a couple of clinical colleagues in allied health roles in the workplace who were trained in IPS, which is the framework that most of our peer support workers are using, especially in AMHSs. This training meant that they understood the work that I was doing, and because of that, it was easier to connect with them as individuals. Then it became easier to go to them when I at times found the work challenging.

It is important to build a network of people who support peer workers, even if they are not peer workers themselves. I hope that in growing the workforce, peer workers will naturally become more supported by those in the same workforce as them, but in the meantime a diverse amount of support is needed. At the inpatient unit where I was working, I was one of two peer workers, and we were the only consumer employees in the whole organisation. So we didn't have any other consumer employees to go to, to talk about some of these challenges and to feel like we were connected and understood at work. It was really isolating.

In my current role, which is more focused on service improvement and systemic change, it can be equally isolating without people to back up the work that I do. I have been in meetings recently where some really important things are being discussed. In one of these meetings, I was feeling anxious and did not say anything. Then after the meeting, I had three colleagues come into my office and say, "I feel like the consumer voice is being missed. I don't want to step on your toes, but maybe you need to speak up a bit more." And I was like, "Actually, I'm the only consumer, and if you're also noticing that the consumer voice is being missed, then as a clinical colleague you're allowed to speak up

as well and say, 'Let's do something about this'." But it's hard when it falls back on one person (see further paragraph 167 below).

Our peer workforce is going to grow very quickly, but I'm concerned about our consumer consultant workforce, because peer support workers are kind of this fancy new thing that everyone thinks we need everywhere—which we do, and that's fantastic—but our consultants are often holding the load of advocating for changes in the organisation. Consumer consultants are often the sole voice when it comes to advocacy in meetings, and it can be a challenging position to be in where you need to continually speak up and challenge the perspectives of your colleagues.

The more peer support workers we have, the more they are going to notice changes that need to happen, and they are going to be filtering them through to consultants. Consultants are often the ones who hold the capacity to lead this change and to encourage organisations to co-design the solutions. Consultants shouldn't be expected to hold this responsibility alone as one individual, who often only works part time in this role. Having adequate levels of consumer perspective supervision is an essential part of helping consultants to be able to feel supported in the work they do.

There will always be a portion of the workforce that feels like it doesn't need supervision and support—there's always a portion of every workforce that questions why that supervision and support is needed. But I know that members of the consumer workforce are wanting to feel supported in their roles and it's important that there be a variety of opportunities for that to happen. I discuss the importance of supervision for the consumer workforce further at paragraphs 101 to 104 below.

The role of digital technology in providing supervision and support

I am not sure whether there is a way for digital technology to help provide supervision and support for the consumer workforce. I know at one point, probably about a year or so ago, as part of the uptake of IPS, a number of online co-reflections were running. As discussed above at paragraph 63, co-reflection provides an opportunity for peer support workers to come together and reflect upon their work within the IPS framework. But there was a really low uptake of online co-reflections. I'm not sure why there was such a low uptake. Possible factors are: a lack of advertising; a lack of access to technology; a lack of safe and private colleagues at work for peer support workers to even have these conversations; organisations not freeing workers up to attend them; people not feeling comfortable to ask their organisation if they can attend; and/or people perhaps preferring opportunities to reflect in person rather than online.

Part-time work and lower pay

Most people in the lived experience workforce are employed part-time, and are often paid less than what their clinical colleagues are being paid to do their roles in similar environments. The pay differences between clinical and lived experience workforces implies that clinical expertise is seen as more valuable than lived experience expertise; however, it is my hope that this changes. Lived experience workers have high levels of value to add to organisations and the consumers and carers who use them. Further inequalities are seen in that some organisations choose to only employ lived experience workers part-time. I know some services only offer consumer/peer support jobs for two days a week. I think it is fine if that is what an employee chooses, but it should not be assumed that a consumer/peer worker does not want, or cannot cope with full time hours. Where possible, roles should be offered at full time with the ability for employees to negotiate part-time hours if they wish.

Due to the part-time nature of many lived experience roles (I am contracted for three days per week), lived experience workers often do not have a liveable wage. There are a number of lived experience workers who are working multiple jobs in order to gain a liveable wage. The need to work multiple jobs can increase workplace stress and decrease adequate work-life balance. I believe wherever possible lived experience workers should be able to gain their liveable wage through working one position for one employer (if this is their preference). Having a good wage improves people's lives so much, because you can actually afford to live and to make decisions and to save and not to worry about how you're going to put food on the table.

Stepping from a peer support worker into a more senior consumer role, my pay increased. Being moved into a more "senior" position has allowed me the opportunity to filter that additional money into accessing private mental health supports, or going to things like yoga, or out for breakfast with my husband, or to be more engaged in things I enjoy doing in life. This supports me to meet some of the needs that are not met from our public system, or from workplace support. The additional pay also put me into a position of being able to not live week to week. For example, if I want to buy a new outfit, I can go and buy a new outfit.

Capabilities and skills that consumer lived experience workers need in order to play greater roles in mental health services

I think that consumer lived experience workers need different sector skills, depending on what a person's individual desire is, whether it's through systemic work or direct contact work.

- 99 A brief list of the things (which are not necessarily skills) that consumer lived experience workers need includes:
 - (a) understanding the history of the consumer movement throughout the world and where it came from:
 - (b) knowing what the values are that really underpin the consumer movement;
 - (c) understanding what the difference is between a peer support worker and a clinical staff member:
 - (d) understanding how the support that the consumer workforce offers is very different and unique and essential; and
 - (e) understanding differing roles within the consumer workforce and the unique functions they play, ie. peer support, consultants, advisors, educators, researchers etc.

Strengthening the skills, training and development of consumer lived experience workforces

There are several things we can do to strengthen the skills of the lived experience workforce, including greater levels of internal and external supervision for lived experience workers and co-reflection spaces.

Supervision for consumer workers

- First (as I outlined above at paragraphs 87 to 94), it is important that consumer workers have access to supervision from consumer workers who have more experience in the workforce. Consumer peer support workers need guidance so their work is in line with peer support values, and consumer consultants need guidance to ensure their work is in line with consumer perspectives and advocacy. Supervision is one way to provide this guidance (another is co-reflection, which I discuss below).
- Consumer workers sometimes take on large emotional loads that may feel burdensome and in some cases might be triggering for that worker. The availability of debriefing support for these workers varies between organisations. Most peer support programs have co-ordinators who supervise peer support workers, and hopefully they are people who are really understanding of the work. But it varies as to whether a co-ordinator has lived experience or not, and so it might vary as to how safe and comfortable a peer support worker feels debriefing openly to that co-ordinator.

The role of external supervision

Where possible, consumer peer support workers and consumer consultants should have access to external supervision. For example, it can be difficult for a consumer worker to navigate their own mental health challenges inside an organisation, or to navigate what it's like to work within an organisation that may hold different values to them, and they may not feel able to speak openly about those challenges. That is one reason why it is important to have someone external who consumer workers can just speak very openly with. However, at the moment there is not a huge pool of consumer supervisors available. Even if there were, I doubt all organisations would be willing to pay for consumer workers to access that support.

There should be formal pathways for consumer workers to find and access consumer perspective supervision. For example, my organisation has put aside a pool of money so that the consumer workers within the post-discharge program can access external supervision, but there is no formal way to find a supervisor. Most people know someone in the consumer space who is a bit more experienced who they can approach and ask if they would be willing to see them as a supervisor. But then it's up to the person who has been approached to set up an ABN and to issue invoices. And the person who has agreed to provide supervision has not necessarily received any supervision-related training. There is a "consumer perspective supervision framework" that has been created, but as yet there is no training to go alongside that. Hopefully this will be available in the near future.

Co-reflection spaces

Another thing we can do to strengthen the skills of peer support workers is to ensure they have access to co-reflection spaces. I discussed the concept of co-reflection above (see paragraphs 62 to 66).

Peer support workers must have adequate opportunities to reflect with each other. They very often end up working in ways that are potentially more aligned to what their clinical co-workers are doing, rather than what peer support workers should be doing. That is especially the case when a solo peer support worker is put into a clinical team. Having time and space for co-reflection can help to rectify some misaligned values.

107 Co-reflection can be seen as very similar to supervision. As I see it, consumer perspective supervision is underpinned by the values of consumer perspective work, and while co-reflection is also underpinned by these values, co-reflection is also aligned specifically to the IPS framework and provides a space for people to reflect upon what it is like working specifically from this framework. Both supervision and co-reflection can happen in one-

on-one or group settings, and although more senior workers often facilitate these conversations it is important for power imbalances to be acknowledged and mutuality upheld wherever possible.

Organisational meetings - specific to lived experience work

In addition to having access to supervision and co-reflection as a way of feeling supported to work in line with the values that underpin consumer perspective work, consumer workers also need to be supported with organisational structures that will enable them to explore what foundations need to be set in order for this workforce to flourish. Within my organisation we have a Consumer and Carer Advisory group, which is made up of the consultants from each of the connected AMHS programs. While this group functions as a way of ensuring my organisation's executive has access to consumer and carer perspectives, it is also a group where we hold the workforce development needs of the consumer and carer consultant workforces. We similarly have a peer support working group where we can consider the workforce development needs of the peer support workforce.

These spaces provide opportunities to look at a variety of needs of the consumer workforce, including areas such as supervision and support, training and workforce development and research and evaluation. For example, at our service we are currently creating a peer support orientation handbook. It will cover a variety of topics and is allowing us the opportunity to look at the specific training needs of our workforce, for example, in areas such as documentation. But other services that have smaller workforces might not be able to justify putting resources into developing these sorts of resources. That is where on-the-job support through co-reflection or mentoring from more experienced members of the workforce can be especially helpful.

There may also be a role for some kind of centralised repository of digitised training resources to help peer support workers at services that have less resources, or are less aware of what the needs of this workforce might be.

Consumer workforce structures

In addition to having meetings to discuss the needs of the lived experience workforce, it is also essential that workforce structures are reviewed to ensure that there are enough lived experience workers sitting at all levels of the organisation. There need to be adequate support structures created in order to effectively grow the lived experience workforce. While I think it is essential for consumer workers to work across a variety of teams, I also think it is essential to have clear support structures to ensure members of

this workforce are given the support they need to continue to work in line with their training.

- 112 Currently, many organisations, including my own, have inconsistent workforce structures.

 This can mean that consumer workers are left working isolated and without senior consumer workers overseeing their training, supervision and support.
- 113 By way of example, at one organisation I'm aware of, there are consumer and carer peer workers working within an inpatient unit with one coordinator overseeing the work of both workforces. While this coordinator does this role to the best of their ability I believe it's not ideal to have the one person overseeing the work of both consumer and carer workforces. Ideally they would each have a coordinator who works from the same perspective as them. In addition, there are consumer peer workers working in a community site that is linked to this same AMHS - they are working solo within their teams and are supervised by managers who have not received IPS training or organisational readiness training specific to managing consumer workers. This same organisation also has consumer and carer peer workers located in their Prevention and Recovery Care (PARC) service, and consumer and carer consultants who focus on systemic work. While there are many workers who have high levels of experience, and the team members supports each other where possible, there is little structure in place where lived experience workers have access to managers and support from people working from their same perspective. The lack of structures in place at this service has caused issues were lived experience employees feel under supported and unclear about where best to turn to support for their issues.
- In contrast, another organisation I'm aware of has consumer workers who work both in their community and the inpatient unit. They are looking to extend peer support out to their ED, and they also have consumer consultants. This organisation has appointed a consumer manager who oversees the work and support of the consumer workforce, regardless of what team and site they work within. This is a more ideal structure, from my perspective. No matter what team peer workers within this organisation work within, they'll always have access to a peer support manager to provide them with workforce specific support and professional development as needed. I imagine that, as this workforce grows, this structure would allow for senior peer workers to be employed in the inpatient unit, community and ED. These senior workers would provide support to individuals working within these separate spaces and would then report back to and seek support from the consumer manager.
- I used to be hesitant to suggest that consumer workforces re-create the same hierarchies that are seen within clinical disciplines, because I didn't want us to re-create some of the same power imbalances that exist within organisations. However, I am now growing to

believe that it is essential for consumer workforces within AMHSs to operate within similar structures as other disciplines if they are to continue to grow in a way that is sustainable. It is imperative that consumer workers are supported and managed by those with a consumer lived experience wherever possible. If we do not create these structures for the lived experience workforce, they will continue to be managed by people without a lived experience, or without a solid understanding of the values, frameworks and perspectives that underpin the work that they do.

Carer workforce structures

It is also important to acknowledge that the needs of consumer and carer workers differ and at times the values of these two workforces can be at odds with each other. I believe that structures that are created to support the consumer workforce similarly need to be created to support the carer workforce, with consumers managing consumers and carers managing carers wherever possible (see also paragraph 180 below).

Community model

Specific ways for a future community-based mental health system to support people who are experiencing a crisis or following a suicide attempt

Person-centred care

- The phrase "person-centred care" is thrown around a lot, but I personally don't feel like I've ever received it from an AMHS. I don't feel like person-centred care is offered broadly throughout organisations.
- A huge barrier to person-centred care is the *Mental Health Act 2014* (Vic) (the **Act**) in general, and compulsory treatment, restrictive practices and risk assessments in particular. In my view, you can't really provide person-centred care if someone is being treated against their will –I think you can provide elements of it, but overall it's not really taking them, their beliefs and their needs fully into account.
- Even for someone like me, who has never been treated under the Act, I still feel like services have fallen short of delivering person-centred care. I have often felt ashamed for reaching out for support too much, or not enough, or in ways that don't suit the organisation and the people who work there. If organisations were truly person-centred, they'd be set up in a way that delivers the support that people need at various parts of their recovery journey.
- Personally, my most beneficial therapeutic relationship has been with the social worker who I currently pay to see privately. It is a relationship where I've been able to communicate in person, over the phone, through text and email. The ability to

communicate in writing has been very important to me, as this is how I've always been able to best express myself and has allowed people insights into my life which they would never have received if I was made to solely communicate in person.

- The AMHS that I access does not allow any communication through text or email. They do allow me to bring written things into session with me, but this feels like a less safe option that is outside of what works well for me.
- Additionally, my relationship with my private social worker is one where I can receive therapy. I get to have genuine conversations about how I'm feeling, about current day stressors and about past trauma. We very rarely talk about risk or about thoughts of self-harm and suicide. I know I'm allowed to talk about these things if I choose, but I often don't feel the need, because I know our other conversations are far more beneficial. I know I'll genuinely be able to talk about what I'm thinking and how I'm feeling and experience a deeper sense of connection. This has been the most significant thing in being able to reduce the risk I pose to myself.
- When meeting with my key clinician at my AMHS, we never have a conversation where risk and self-harm doesn't come up. I don't feel like we've ever acknowledged or addressed past trauma that I've experienced, or had adequate space to genuinely talk about the day-to-day struggles that I face. I think sometimes the risk-averseness of our organisations can get in the way of their capacity to actually provide person-centred care.
- I acknowledge that my key clinician and private social worker play vastly different roles in my life. I will choose the support of my social worker long term because I acknowledge that she better meets my needs and will support me to receive a deeper level of healing and recovery. However, I also acknowledge that I have not always, and may not always, have the financial means to pay for her support. I believe that all people should have equal access to mental health support regardless of their financial means. Ideally, key clinicians at AMHSs would be equipped to provide similar levels of therapy and support that people can receive by paying to see someone privately. AMHSs should not be so focused on minimising risk that they end up missing out on opportunities to genuinely support people to work through the challenges that caused them to be a risk to themselves or others in the first place.

Greater access to a greater variety of support

There needs to be a variety of support options available to people, whether it be: phone support; drop-in clinics; care or food packages; follow-up appointments at home (where people feel comfortable); and access to groups, including groups in the community (eg art classes, visits to the zoo, cafés). Connection to community is one of the things I've

struggled the most to establish without support from people around me. I acknowledge how integral connection is in decreasing my own distress.

- People need to be able to access support and appointments outside of business hours. It is hard to be in crisis, or to have recently had a suicide attempt, and be trying to remain connected with life and important structures, and then have to miss half a day of work in order to make it to an appointment. Follow-up appointments can be important, but are often tricky to facilitate.
- There is a lack of access to support. For example, for myself, in my own care that I receive, I would love things like:
 - (a) being able to access care outside of business hours;
 - (b) being able to access therapy from well-trained key clinicians; and
 - (c) knowing that if I call up triage, for example, they're going to ask me how I am and what I need, rather than potentially being left waiting hours for them to answer, or the triage worker jumping into risk assessment questions straight away.
- In my view, some of these access issues (particularly the lack of after-hours services) contribute to non-attendance at scheduled clinic appointments, which I discuss at paragraphs 156 to 159 below.

Trauma-informed care

- I think organisations think they're offering trauma-informed care, but I would argue that they are not. People need to think more about how they can understand what trauma-informed care actually is, including how to not just understand the principle of it, but how to genuinely support people who have experienced trauma. I've heard that something like 85% of people using mental health services identify as having experienced some kind of trauma. That is a huge percentage of people, so why aren't we offering them support for the trauma that they've experienced?
- I think trauma-informed care needs to be looked at on a few different levels. For example, trauma-informed care between an individual consumer and their support person needs to be very individual to what a person needs, whether that it is therapy or increased community connection, or whatever the person identifies that they might need.
- But I think we can also look at it more broadly by organisations thinking about how they can turn themselves into a trauma-informed organisation. For example, in our current waiting rooms, when consumers walk in, there are huge pieces of glass up in front of reception desks. Receptionists feel the need to protect themselves, but consumers are

like, "Do you think that we're dangerous?" It's not trauma-informed if that's the way that it's set up.

- Even things like having locked doors or in-patient units being locked and people not being able to come and go freely, or being limited in the number of visitors that they get, is not trauma-informed. Another example is people being strip-searched. When I was in an inpatient unit as a teenager (16 years ago) I was often strip-searched. I hope that's something that doesn't happen as much now. I imagine it is something that is still happening, and that is not trauma-informed in any way.
- There are a lot of really practical things that organisations need to change in order to move in the direction of being trauma-informed. For example, with compulsory treatment, you can't treat a person against their will and say you're offering them trauma-informed care. That doesn't work. I think that treating a person against their will is a huge barrier to being able to support people in a trauma-informed way.
- The fear of being put under a compulsory treatment order is not trauma-informed. As mentioned above, I have never been subject to a compulsory treatment order under the Act; I have always sought treatment on a voluntary basis. But I'm scared to call someone and say that I'm feeling suicidal, I'm scared to reach out for support, because of a fear of being subjected to compulsory treatment under the Act. That fear of whether you're going to be treated compulsorily or not is not trauma-informed. There will always be that fear of accessing services, and always feeling as though you have to censor yourself and limit what you say in order to let people know that you need support, but not make them so concerned that they think you need to be treated under the Act. It is a constant juggle from the perspective of a consumer trying to figure out, "How do I say everything I need to say, but not so much that I'll no longer be in control of this?"

Training clinicians in providing therapy

- I would like to see more key clinicians within AMHSs trained in therapy and actively using it in their work. By therapy, I mean therapy when you genuinely sit and listen and explore what is going on for a person. I don't mean the ability to list the things a person "should" do when in distress, or ways they could alter their behaviour. From my perspective, therapy needs to be led by the consumer with the support of a skilled clinician who can safely hold space for their experiences.
- In my experience, clinicians within AMHSs do not view their role as providing therapy. For example, I've seen a key clinician at the same service for about two years now. That's the longest consistent support that I've ever received from any individual at any service in my life, but the key clinician wouldn't be able to tell you what my trauma history was,

or why I respond the way that I respond. They know elements of my history, but they don't know my full story and they've never asked for it. They just keep saying, "That's not what we're here for. Go and get therapy elsewhere."

But it is a huge financial stretch to get therapy elsewhere. As mentioned above, I have a private social worker who I'm currently seeing. I saw her on 19 March, when I used my last mental health care plan session for 2020. I can't access a mental health care plan again until 1 January next year. I will continue to see her, because I need therapy, but I can't afford to see her as much as I need her. My social worker and I have had discussions about how it would be great if I could see someone at least once a week, if not twice a week, for an extended period of time, to actually work through some of the things that I'm struggling with.

AMHSs are funded to offer that level of support, but their clinicians are not *trained* to offer that level of support. I think that currently the system is under so much pressure that they're just ticking boxes. Hopefully over time, the pressure is taken off the system so that AMHSs can see a wider variety of people and offer a wider variety of support for them. I hope that when that pressure is taken off, the key clinicians are also offered support to upskill in various therapies and understand trauma-informed care in a way that allows them to offer support that is tailored to individual needs.

I know I can't speak on behalf of what any other consumer wants, but for me, I'm someone who has met criteria to access an AMHS, but I'm also someone who doesn't need any medication from an AMHS. I do have medication that I take as needed, but that's only a handful of times each year. I avoid taking medication as much as possible; medication isn't part of what I want. The AMHS actually respects that, but if I don't need them for medication, and they are not really offering anything else, then what are they doing?

They do offer me check-ins and conversations, and I can catch up with them once a week. I've got an interim case manager at the moment because mine is away. But in the conversation that I recently had with him, he was just like, "Have you thought about hurting yourself this week?" And "How are you managing these thoughts?" I answered the questions, but I wasn't actually thinking about hurting myself at all, he just asked the questions because he thought it was what he was meant to ask. He kept saying, "What will you do to manage your distress?" But I wasn't actually distressed in the first place. It felt like he had just opened up a first-year textbook and was asking a list of questions that's in it, rather than actually engaging with where I was at in that moment. Having genuine engagement with people is really important to me. I dread experiences where I walk away feeling as though I wasn't seen or heard, but that's how I feel about most of experiences with my AMHS.

Communication

- One of the biggest complaints that comes from consumers either direct to the organisation or to the Mental Health Complaints Commissioner is about communication. I don't know what other consumers need specifically when they talk about a lack of communication, but it's just something that I am constantly mindful of. I know that a big piece of work needs to go into figuring out how to better communicate with consumers, and also to better hear what they want and need.
- If we flag communication as a thing that needs focussing on, I think we run the risk that organisations will say, "Okay, let's hand out more brochures," or "Let's communicate more with the consumers to tell them what we think they need". Instead, organisations should be opening up that line of communication back the other way to humanely consider, "Well, what do consumers want?", whether that be by asking, "What do individual consumers want?" or "What do collective groups want for the whole organisation?".
- 143 Communication is a tricky issue. As much as possible, the consumer needs to communicate what they want to the organisation and to their key clinician, and the organisation needs to be responsive to what is being communicated. But often it ends up being an organisation making sure that they are handing out paperwork and bits and pieces, just so people are informed about the stuff that's going to happen to them.
- I would like to see an increase in ways that consumers can communicate with key support people. I have always felt so much more comfortable communicating in writing, and often I reach out for support from people and places that allow this as a means of communication. Community AMHSs do not communicate in writing. The only point of contact is over the phone or in person, and I often find it difficult to communicate verbally because my shame and fear increases when I am distressed. I talk further about the different types of communication I have with my private social worker, compared with my key clinician at paragraphs 120 to 124 above.

The importance of involving consumers in conversations or decisions about them

- When thinking about the topic of communication I also can't help but think about the number of conversations that are had about consumers when they're not present. This takes place in handovers, clinical reviews, or general conversations between clinicians behind closed doors. Consumers are never a central part of the conversations that are had about them, and often aren't even aware that these conversations are taking place.
- I can understand from an organisation's perspective why they might think conversations need to take place without consumers present, but I also can only think of very few situations where that would actually be in the best interest of the consumer.

- In my role as part of the consumer workforce, I've had so many people approach me and talk to me about a consumer they're supporting and ask me what I think that consumer might need. My response will always be, "Have you asked them what they think they need?". Too often people turn to asking their colleague what a consumer might need, rather than asking the consumer themselves.
- I haven't always been in a position where I've made the best choices to keep myself safe, or to seek support in ways that work for other people, but being in control of my choices and the support I receive has always been highly important to me. My distress is increased greatly when I know that I'm being 'supported' by a service that discusses me when I'm not present.
- 149 I've read hundreds of pages of notes that were documented in my medical record throughout the hospital admissions I had as a teenager. This was a highly confronting experience for me because I realised that clinical staff held vastly different perspectives of me than I held of myself. I don't see how it is helpful for the perspectives of consumers to not be genuinely understood by the people who are meant to be supporting them, and vice versa.
- I believe that all consumers should have access to sitting in on clinical reviews and handovers, if this is what they choose. I additionally believe that all mental health staff should co-write notes with consumers wherever possible, allowing opportunities for mutual discussion about what should be documented and providing a greater level of transparency and opportunities to recognise when differing perspectives are held over the same conversation.
- At the moment, the perspectives of clinicians are privileged because they are the ones who write in the medical records, and who lead conversations about consumers when they're not present. There needs to be a shift in ensuring that consumer perspectives are held central in the individual care that they receive.

Supporting people who would prefer not to attend a clinic or centre-based mental health service

There are some people who prefer not to attend clinics or centre-based mental health services. To support these people, we need to look more carefully at the bigger picture of people's lives. For myself, a lot of the time I view some of my challenges as stemming from a lack of connection and social support. I have to assume that if I built better connections and a sense of community, then I would struggle less with some of the things that I'm struggling with. I know it's not as simple as that, but I think that we sometimes fail to consider what a person needs to rediscover value in their life.

- Often, when we are presented with people who are struggling, our response is to give them therapy (sometimes not good therapy) or medication. But we don't really look at the bigger picture of what else they might need in their life to sustain their wellbeing and find value in life. It might be that they need help to find a hobby, to join a group somewhere, or to volunteer for something. Community supports need to look more carefully at the bigger picture of people's lives.
- I don't know what organisations should do to help individuals work out what they need, but I know that for myself, there have been times when it would have been beneficial for me to have more of this type of support. We shouldn't assume that people have the skills or confidence to help themselves in this way. It's really scary to go from having identified what activities or hobbies you would like to do, to locating a place to do that activity and going alone for the first time. That is especially true for someone who has experienced anxiety. I think it would be beneficial to have a peer support worker who can go with you and trial these things with you—to walk alongside you in the journey of recreating a life.
- Some people experience mental health challenges for the first time later in life, but other people experience them for the first time when they are young. In my own case, I was 14 when I had my first hospital admission. It created disconnections in friendship groups, which didn't help me in the task of exploring what I liked and wanted to do. It is hard for a young person to start figuring out how to recreate a life for themselves when they feel that they have missed out on some opportunities that their peers had at that point in time to explore life.

Reducing rates of non-attendance at scheduled clinic appointments

- I know I don't hold all the answers for how to reduce non-attendance of scheduled clinic appointments. If you want to reduce rates of non-attendance at scheduled clinic appointments, then ask people why they don't feel able to attend and listen to them!
- 157 From my own experience, waiting rooms suck. Reception staff and big glass barriers make me feel "less than". As mentioned at paragraph 131 above, these reception areas are not trauma-informed. I feel ashamed sitting in the waiting room with clinicians watching me through the glass.
- Appointments between 9am and 5pm are often inconvenient for people who have other commitments—sometimes when I want appointments, they're simply not available at a time that suits. When I choose to connect over the phone instead, often these appointment times are missed or delayed, and it limits my ability to stay in a safe and private space to have this conversation.

I want to acknowledge that non-attendance at scheduled appointments is not something that I've ever faced. My desire for connection is always so strong, that I'll even prioritise connection with people and organisations who fall short of meeting my needs. I think it's important to think about a variety of reasons why people might not attend clinic appointments, and rather than trying to improve their attendance, perhaps ask them what alternate supports they might want and need.

Role of telephone helplines

Strengths and limitations of current telephone helpline services

- I don't call helplines anymore because, in my experience, helpline staff just list off a bunch of coping techniques rather than genuinely sitting and listening. It is too hit and miss when you call them. It is hard not knowing how skilled or empathetic the person you're calling might be. When I'm already distressed, I can't afford to walk away from a phone call that will potentially increase my feelings of isolation and being unheard.
- At times I will use online chat or text services, however I'll only do this if I need a distraction and I never enter into these conversations expecting a high level of support.
- When I communicate with a helpline, I am never completely honest about the distress that I am feeling because helplines are not transparent about how they might encourage you to seek additional support, or when the choice for receiving this support will be taken out of your hands. I hold a fear that if I call a helpline and ask for empathy and connection, instead of getting the support I need, they will call the police if I even hint at thoughts of harming myself. I will only ask people for help when I am confident that I will remain in full control of the help that is given (again, often this "help" falls short of needs).
- However, I used to LOVE the Kids Helpline when I was a teenager, because they had the option of connecting to the same counsellor every time you called. If I sent an email, I knew it would go to the same person every time, and she would share her shifts with me so I knew the times during the week when I could try and get a hold of her. It wasn't always possible for me to speak with that same person, but I could also speak to others there if needed. We would often only have brief conversations though until I was able to connect back in with my regular counsellor there.
- I think a barrier to me using helpline services as an adult is that I can't make an ongoing connection with the person I speak to. It is scary to start a relationship from scratch every conversation.

Lived experience in governance

The contribution of people with lived experience to making services more reflective of consumers' needs

- If people with lived experience are involved in the development of policy, practice and research, then the services that result from that work will become more reflective of what consumers think and need.
- But it is not as simple as employing one person with lived experience in a service and saying, "great, we've done it—we've got a lived experience worker on the team, therefore that perspective will be captured." Organisations need to put a lot of work into thinking about how they can heal people with lived experience and what mechanisms they have in place.
- For example, my role sits at the executive level of the organisation I work at. As mentioned above, I sit on more than 15 different committees, and I chair the Consumer and Carer Advisory group. The organisation ticks the boxes for having a consumer in that space and having an advisory group to inform the executive. It sometimes feels like I'm working very much on my own. Even when I can identify changes that need to happen from consumer perspectives, it can still be hard get the rest of the executive to think about and understand those viewpoints (see also paragraphs 65 and 90 above).
- When the COVID-19 pandemic first started to hit Australia, many of my organisation's regular meetings stopped happening. New meetings have since been set up, but for me to be included in some of them, I have had to advocate my way into them. It is hard to be a solo consumer worker trying to convince people that they should listen to my voice. To be the one consumer amongst 10 to 15 clinicians in an executive meeting is sometimes a scary experience. Even if you hear things that you don't agree with, that doesn't mean you're always going to speak up about them.
- There are not always other mechanisms for consumer workers at senior levels to make their perspectives heard. I personally am getting better at forming relationships with executive colleagues and trying to raise things outside meetings. But it takes a lot of effort and energy for a solo consumer worker to figure out how to ensure they are heard if there aren't mechanisms in place encouraging executives to listen to them.
- 170 It would be good if services genuinely wanted to hear the consumer voice and sought it out. The only way that is going to happen is if there are more and more consumer positions at senior parts of organisations, and if services increase their understanding of the importance of co-design.

Ensuring that people with consumer lived experience have a meaningful and enduring voice in decision-making at all levels of system design and service delivery

- There needs to be additional focus, resources and support given to consumer consultant roles. The peer support workforce is growing quickly, but consultant roles remain isolated and with limited full-time equivalent (**EFT**) positions. Services are moving in the direction of doing more co-design (and hopefully eventually co-production) but there is not an adequately supported and trained consultant workforce to drive this work forward.
- We need budget lines created to support consumer "participation". Not all consumer advisory groups in the State pay for consumers to attend, let alone have additional money set aside to support consumers on additional committees and in co-design groups. This means that additional pressure is put on the peer support workforce to be involved in systemic meetings and often this pulls them away from their already limited EFT roles in direct service work with consumers.
- We need a culture shift for people to understand the value of lived experience, and to understand the importance of including people with lived experience early in all decision-making processes. Having one consumer on an executive committee does not count as giving them a "meaningful and enduring voice". These meetings often still operate in a "majority rules" fashion and there's little space to slow down decisions and explore alternatives.
- 174 I have been involved in situations where I have been brought in at the last minute to consult on something that is already decided. I have also been involved in the early stages of planning for things, only to have future meetings held without my involvement and have decisions changed without consumer input.
- That people with lived experience may possibly show a lot of emotion in the workplace needs to be accepted, listened to, openly invited and not pathologised and viewed as though their emotions are a symptom of mental illness. I feel like when I have really strong emotions about a particular situation, I can end up being silenced, even if unintentionally. Past experiences of being pathologised for speaking up at work has made me fearful to keep speaking up about very important issues in the workplace.

Facilitating more service provider organisations that are governed and delivered by people with lived experience

176 I would like to see the development of an organisation that is run by people with a consumer lived experience and is given adequate funding to set up services such as peer

- respites, peer support groups and other services that meet the needs of consumers in their community.
- For this to happen, the organisation would need to be well-funded, remain separate from the current mental health services, and be given the opportunity to learn from similar models throughout the world.
- There are many examples, but I often look at the Western Mass Recovery Learning Community that I discuss below at paragraphs 194 to 196.
- I believe this organisation would need to be co-designed, with scope to operate in a way that might be different to other government funded organisations. Such an organisation should have KPIs which match the priorities set out by the co-design group and should not be swayed by governmental pressure to potentially operate in a way that is outside of peer values.
- I also believe that such organisations should be governed by either consumers (supporting other consumers) or carers (supporting other carers), not both at the same time. These two workforces (carers and consumers) are often placed under the one banner of "lived experience", however the values that underpin their respective work can be quite different. I am not sure how well carer and consumer values would come together to establish an organisation with clear values that upholds the rights of consumers.
- I think highly of the carer workforce that I work alongside, but feel strongly about the need for a consumer-led service that has strong enough values and consumer leadership to run peer respites and to hold groups such as Hearing Voices and Alternatives to Suicide (see paragraph 194 below).

Suicide prevention

The effectiveness of existing mental health services in responding to people at risk of suicide and their families and carers

- Suicide prevention is a sensitive topic for services. Services are risk averse and often feel that they are doing a good job at supporting people who are having thoughts of suicide. But suicide rates are high, so obviously something is not right.
- There are definitely things we can do differently. I don't think I have all the answers for how to reduce suicide rates, but I know that, at the very least, services should meet people with empathy and a genuine desire to understand what's going on for them. In my personal experience, when I seek support from EDs, I am not always met with empathy.

Sometimes I am just met with general questions based on a risk assessment checklist (see further paragraphs 24 to 33, 122, 123 and 140 above).

It is not always clear, even to the person themselves, why they are experiencing suicidal thoughts. If you were to ask a person what's wrong in that moment, they cannot always give a black and white answer. It is not always a situation where someone has had something bad happen to them, and then suddenly they're suicidal and end up in hospital. People can't always articulate what is happening to them. It is often a mix of experiences and emotions and things that aren't easily resolved.

In thinking about how services respond to people experiencing thoughts of suicide, we should also be thinking about families and carers. From my own experience of suicidal thoughts and self-harm, the ED usually only gets my husband involved if they want to gather collateral information. I really respect my husband, because he knows that he does not hold any responsibility for protecting me. All he can do is love me as my husband.

The focus of conversations between services and families or carers should be focused on asking how *they* are and offering *them* support. Those conversations should not be about trying to elicit from them collateral information about the consumer. At times, I have asked the hospital *not* to call my husband, because I'm scared that they will seek collateral information from him that I don't always want to be shared. I wish that the focus of that conversation was on offering him support; then I'd probably be more open to them contacting him. I acknowledge that sometimes family members know information that could support the consumer to receive a higher level of support, but I believe if this information is shared it should always be done in an open conversation with the consumer, where they have the opportunity to make sure their viewpoint isn't lost.

187 While I am not in support of conversations about consumers happening with families and carers without the consumer's consent (see paragraphs 47 and 145 to 151 above), I do believe that families and carers need to receive a higher level of support than they currently receive from AMHSs. There are definitely ways for services to offer support to families and carers without breaking the confidentiality of the consumer.

Working with families and carers is important for another reason. Sometimes a service will try to "fix" the consumer, and then just put them back into the environment that they had previously come from. But that environment might be the source of some of the consumer's issues. If consumers don't have support to work out the relationships in their family, things might keep repeating themselves.

I acknowledge that I am in a safe and long term relationship so it is easy for me to have a clear idea around when my husband should or shouldn't be called by the service I am

receiving support from. I know not all consumers are in similarly safe relationships to me, and additional focus needs to be put on understanding the needs of consumers within relationships where family violence exists. I can't speak to this, but trust that others will.

My personal experience with suicide

- My experiences of individuals within services has greatly varied, but currently there is no mental health service I feel consistently safe going to when I'm feeling at risk of suicide.
- I had my first suicide attempt when I was 15, and I have had a few since then, or have hurt myself in ways that put me at risk of suicide. When I had my first suicide attempt, or even when I first started seriously self-harming, I feel like that was something that the mental health system taught me to do. I don't think I would be hurting myself right now if I had never had contact with an AMHS as a teenager and if I never learnt EDs needed me to physically hurt myself to access their services (see paragraphs 27 to 29 above).
- My very first suicide attempt was while I was in the middle of my first inpatient unit admission. It was at a time in my life when I was being actively sexually abused and I hadn't disclosed that. I was scared about going home. I felt that the only way that the service would listen to my fears was if I hurt myself. So that's why I attempted suicide. I feel like none of the times that I've attempted suicide has been me genuinely wanting to die. I feel like it's been, "I need someone to listen to me," and our systems are not listening. And so I've learnt to communicate my distress through hurting myself, because it's the only way that services are listening.
- Recently, I've been hurting myself less. Some of the biggest things that are actually helping me as an individual are not actually any of the public mental health supports I've been getting—it's the fact that I have, over the past year, been in a job that I love and that I feel secure in, and I am also receiving very beneficial support from my GP and the private sector (see paragraphs 33, 42, 97 and 120 to 124 above).

Peer-led group support: existing models

In Massachusetts, America, they have a peer-led organisation called the Western Mass Recovery Learning Community. Within that organisation, they run things such as peer respites and "Hearing Voices" groups. They also run a group called "Alternatives to Suicide", which is a weekly group-support program. The facilitators of Alternatives to Suicide are people who have experiences of suicide themselves – people who have either had thoughts of suicide or have attempted suicide and who can genuinely connect with the issues faced by people who have thoughts of suicide. The facilitators have to be counted as consumers. I did the Alternatives to Suicide training myself in 2018 (which I discuss below).

In our Australian landscape, Roses in the Ocean (as an example of an organisation that does suicide support) counts lived experience not just as people who have had thoughts of suicide, but also as people who have *lost* people to suicide or whose loved ones have had a suicide attempt. I acknowledge that is a 'carer' or 'supporter' lived experience. Putting these various groups collectively under "lived experience of suicide" feels as though they assume that we can speak for each other. I believe all perspectives are important when looking at suicide as a health issue, but in my experience, people who have lost people to suicide are more likely to advocate for restrictive practices or for high-level support that might not actually help those struggling with thoughts of suicide. But they're scared, and they're understandably scared, because they've had a huge loss. From my perspective, if anything, I want to advocate for less restriction, but more conversation.

These support groups are underpinned by the essential need to keep people in control of their own lives and to hopefully make them feel heard enough and connected enough to openly work through their experiences. If someone is saying that they're suicidal at that point in time, the facilitator's instant response isn't, "let's get you a hospital." Rather, it is, "let's have a conversation with you." And it's not just a conversation around, "do you have a plan to hurt yourself? or "do you have the means to follow through with that plan?". It is not that kind of a conversation. It is a conversation on what is genuinely affecting you, whether that be a social issue, or a political issue, or whatever the issue might be. These groups talk openly about what some of the things are that we struggle with in the world, and have a space that can actually hold those bigger conversations. This is in stark contrast to the recent experience I had with my interim key clinician, which I described at paragraph 140 above.

I, and many others, hold big emotions and don't always feel as though we fit neatly into our society. These groups are all about having space to talk about these big things, and to support people to know that they are not alone. Everyone in the group has had similar thoughts and experiences and have all found reasons to hold onto life. While some people may still be holding on day by day, others have learned to live with thoughts of suicide for most of their life and still built lives that have strength and purpose; there's a lot to be learned from that.

Changing the discussion around suicide

Talking about suicide scares people. For example, I have very few friends who I can speak openly about suicide with, because they're scared and they don't know how to respond. You need a space to be able to talk about thoughts of suicide where someone can hold some of that fear and distress without instantly sending the person to hospital. My understanding is that the rates of suicide increase after people are discharged from

inpatient units. So, the current hospital model isn't reducing suicide rates. If anything, I think it could be making it worse. We need to continue to explore other options for supporting people.

I think hospitals still have their place in supporting people with thoughts of suicide, but I don't think they are a long-term solution for people. Individual needs differ so greatly, but I don't think increased numbers in hospital beds will ever be the answer to decreasing suicide rates in Victoria. We need to continue to look at a variety of supports for people.

The lack of organisational support for peer-led groups in Victoria

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I've briefly shared about Alternative to Suicide groups, and I would love to see these groups established within Victoria. However, I also believe that these groups need to be held by an organisation with adequate structures to support the group facilitators. As mentioned, I have done the Alternatives to Suicide training myself. At the start of 2018 there was a group of 20 of us, who all have a personal lived experience of suicide, who did this training.

One of the reasons I haven't started a group here is because I acknowledge that it's hard to hold the group as individuals, as facilitators, without an organisation supporting you. Any group like this needs support and structure that could be provided by an organisation that works closely in line with the values that underpin the group. But there are no organisations that currently exist in Victoria that can support this. These groups purposefully aren't linked to public mental health systems, because they need to operate under different policies and procedures and responses to risk. But we don't have a consumer-led organisation here. We have VMIAC, but they are different: they're a peak body, and while they do offer some peer support, that is not their main focus.

202 I believe an additional consumer led service should be set up with the sole focus of providing peer support groups, operating peer respites and supporting the provision of one-to-one peer support.

I am not sure what a consumer lived-experience-led organisation would look like in Victoria. I think it is tricky, because organisations that are well established to offer good levels of support are funded by DHHS. DHHS also has certain procedures that they need people to follow, and certain KPIs they need people to meet.

I think if you're going to have a consumer-led organisation, then it would need different structures and KPIs, and would need to be allowed to operate in a way that's very different to current organisations. It would absolutely still operate in a way that supports consumers to stay safe, but I think this response would need to look very different to how our current system and services respond to risk.

- Consumers would also need to be given the opportunity to genuinely co-design these kinds of organisations—preferably with support from people that have set up similar things elsewhere (maybe even overseas) who can help inform what these organisations look like and how they are run.
- I don't pretend to be an expert on this topic, but I know we have some incredible consumer leaders in Victoria, and across Australia who would have strong ideas around how a consumer led organisation, for the provision of peer support, could be set up.
- 207 While I am suggesting potential avenues for addressing suicide rates, I also acknowledge that there are many factors that might be outside the scope of what this Royal Commission can have control over, like raising the Job Seeker payment, or reducing homelessness, or reducing unemployment rates. Suicide is a complex issue that isn't always underpinned by mental health challenges.

How mental health services can better respond to the needs of those at risk of suicide

208 It appears that mental health services think that preventing suicide is all about risk assessment and not at all about connection, time and conversation. This attitude prevents them from responding properly to the needs of people who are at risk of suicide.

How mental health crisis services could help prevent people who present in crisis from attempting suicide

- I am not sure we can ever "prevent" people from attempting suicide. I would make the assumption that if someone is "presenting" in crisis, they have at some point chosen to express their distress to someone. From my experience, it is imperative that these first moments of disclosure are shame-free and non-pathologising. Time and space need to be given for people to explore what they are feeling. Some people will have specific experiences and concerns, and we need to be responsive to that.
- We cannot prevent suicide if we're not looking at all aspects of a person's life! Risk assessments might help determine whether or not a person is put in hospital or sent home (and they rely so strongly on whether an individual feels safe being honest about their thoughts). But no matter what intervention is provided, if we're sending people back to homelessness, poverty-level wages, domestic violence, inadequate (or no) support from key clinicians, then suicide can't be prevented.
- Suicide is not always a "symptom" of a "mental illness"; often it is a "symptom" of extreme distress, frustration, hopelessness, fear or shame that can be caused by challenging life

circumstances. Often people aren't given the time to be understood or listened to, let alone given the support to move through moments of extreme distress and challenges.

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