Royal Commission into
Victoria's Mental Health System

WITNESS STATEMENT OF HONOR EASTLY

I, Honor Eastly, say as follows:

1 I make this statement on the basis of my own knowledge, except where otherwise stated. Where I make statements based on information provided by others, I believe that information to be true.

2 I am giving evidence in my personal capacity, drawing on my experience as a consultant and worker in the mental health system, my experience running the Big Feels Club - a consumer-led mental health initiative - and my own first-hand experience of profound distress.

3 I am a member of the Expert Advisory Committee and a senior consumer advisor to the Royal Commission into Victoria's Mental Health System.

4 In this witness statement I outline:

(a) my personal and professional experience of the mental health system and how it has shaped my views (paragraphs 5 - 38);

(b) an overview of reform advice (paragraphs 39 - 42);

(c) the need for consumer-led spaces to encourage self-determination, innovation and healing (paragraph 43 - 66);

(d) why we should include strategic partnerships with the media as a long-term strategy towards mental health reform (paragraphs 67 - 167);

(e) the challenges and opportunities of peer support in the mental health system (paragraphs 168 - 181).

A summary of my background using services and working in the mental health system

5 Since I was a teenager I have experienced periods of profound psychological distress, including significant and repeated periods of severe hopelessness and despair, often described as chronic suicidality. This has historically included profound suicidality of six months or more every couple of years.

6 I have sought to manage these experiences by using various mental health services and psychological treatments. I have used services on and off for over 15 years, including an

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

acute inpatient admission in 2014, and close to two years of hospital based group and individual group psychological programs, amongst many years seeing psychiatrists, psychologists and other mental health professionals. I continue to see a trusted psychologist when I feel it's useful.

7 My experiences of mental health services have been mixed. I am lucky to have been supported by and to work alongside some insightful, reflective, passionate, humble and hardworking clinicians. But I have also experienced many mental health professionals whose approach and regard has been not only unhelpful, but actively harmful to my mental health in ways I will explain further below.

8 I have worked as a peer worker across several headspace sites in the Melbourne metropolitan region. In this role I was in a multidisciplinary team in the headspace Youth Early Psychosis Program (**hYEPP**) which supported young people who had experienced psychosis or were deemed at high-risk of experiencing psychosis with wraparound services including peer support, psychological support, vocational support, and exercise physiotherapy.

9 I have also worked as a lead trainer and supervisor for the Department of Health and Human Services Expanding Post Discharge Support program. This program placed peer workers in acute in-patient settings across Victoria to provide peer support in the four weeks post-discharge from a mental health service. I trained and supervised new and experienced peer workers across Victoria, as well as training managers, clinicians, and directors of mental health services in a support model called Intentional Peer Support. This was a firsthand experience of some of the very real challenges that need to be grappled with when trying to include peer support as more of a feature in the mental health system.

10 Based on my own experiences of the mental health system, and what I felt was a significant gap in offerings from the mental health system, I created the Big Feels Club along with my co-founder Graham Panther. The Big Feels Club is designed to take the elements and principles of peer support, and create consumer-led content about mental health that spoke to some of the experiences of psychological distress, and of using the mental health system that are often untouched by mainstream media, population health programs, or anti-stigma campaigns. Since beginning in 2018 the Big Feels Club has had over 1 million downloads of our content, and over 6,000 people who identify as having 'big feelings' or having a loved one with 'big feelings' sign-up to our online community.

11 In 2018 my co-founder Graham Panther and I co-wrote the *No Feeling Is Final* podcast, a podcast series commissioned by the ABC that documented my own experiences of suicidality, and my efforts over many years to get assistance from the mental health system. The series was released in late 2018 and received critical acclaim, winning a

coveted Third Coast Award from the premiere podcasting festival in the US (considered the 'Oscars of podcasting'), and being named in numerous international 'top podcasts of the year' lists.

12 The series received positive feedback from across the spectrum, including from service users both in Australia and internationally, parents and friends of service users, as well as clinicians and academics.

Why I advocate for consumer-led spaces and genuine alternatives

13 I have been advocating for better mental health services since I started talking about my experiences publicly in the early 2010s. Back then I used to think that the problem with the mental health system was simply a lack of funding. My focus was on campaigning for better access to services, having been turned away from so many myself, or needing significant assistance from my family to be able to afford them. Indeed much of my adult life has been plagued by the impending fear of another period of significant psychological distress, and the extensive costs of accessing mental health services involved with these periods.

14 Back then I used to think that the problem with the mental health system was simply a lack of funding, and my story was simple – that I had an illness that the government refused to properly treat. My main ask was also simple - better access to care.

15 In the mid-2010s however, my opinion on what 'the problem' was, and thus what 'the answer' is began to shift. This happened over a period of several years, in particular as I experienced more of the acute end of the mental health system, but also as I started working in mental health services, taking part in advocacy programs, and being exposed to consumer spaces, thought, and peers. I consider this shift to be a period of 'consciousness raising' about how the mental health system had both helped and harmed me.

16 A key moment towards this shift in my thinking was when I was admitted as an inpatient to a Melbourne psychiatric hospital in 2014. My experience of mental health services up until this point had often been of not being eligible for treatment or programs. My underlying sense at the time (gained over years of being turned away or reaching service caps) was that mental health professionals thought I was not to be taken seriously and given access to treatment for this reason. So when I was admitted to a psychiatric hospital in 2014, I thought my psychological pain and distress was finally being believed, and that I would finally get the care I needed in that moment of crisis. As I said in the *No Feeling Is Final* podcast series:

> *"I thought something magic would happen here. This whole time I'd been thinking that someone was holding out on me. That once I was here people would take me seriously. That people would care. That I'd be enveloped by the warm hug of humanity that I felt like I needed."*

17 What I found was very different. In my initial assessment I was:

(a) told it "won't be worth it" for me to see the psychologist because I'm really just here "to calm down";

(b) told that my self-harm is "not that bad", but that if I do self-harm whilst an inpatient I will be kicked out;

(c) advised by the intake nurse not to reveal my diagnosis to other staff because I will be treated poorly if I do; and

(d) asked if I "give it up easily", as in, if I am likely to have sex with other patients (apropos of nothing).

18 Despite being in the middle of one of the worst moments of my life, and being surrounded by people who were being paid to help me out, it took three days for someone to ask me how I was and seem like they actually wanted to know the answer. By several of the staff I was, particularly initially, treated not as a person in the midst of a terrifying personal crisis, but as a problem to be managed, someone to be placated with medications and mandalas to colour in, rather than a person in the midst of an existential struggle for my life.

19 This was not what my idea of hospital was. This was nothing like the healing space I was expecting. As I noted in the *No Feeling Is Final* series, this admission was when I realised, *"hospital isn't the place you go to get well, it's the place you go to not die."*

20 This was an important part of my journey, because it was the moment when it started to dawn on me that it wasn't just that treatment was hard to access, it was that the mental health system didn't have 'the answer' in the way that I expected it did, in the way that the ads telling me to "just ask for help" portrayed it. And it was the moment that I made a promise to try to avoid an inpatient admission to hospital at all costs next time. Understandably, this created a constant hum of fear that next time I was in that dark place again, I would have nowhere to go.

21 After this inpatient admission I stayed on at the same hospital for over a year to access group and individual therapy programs. I'm grateful for the skills I gained from these programs, and I continue to use and build on those skills each day. My partner at the time described what I was learning skills-wise as "gaining superpowers", and in my heart of hearts I hope that more people will gain access to these types of skills.

22 But whilst the skills were widely applicable and often useful, the way I was treated as part of these programs and by the wider treating team continued to be paternalistic, and again, often as if I was a problem to be fixed or managed.

23 The problem was, even in this hospital program - held in high regard both nationally and internationally - I didn't just learn skills. Over that almost two-year period, I also received a number of far less useful messages from mental health professionals and the system I was engaged in. A shortlist of the messages most obviously harmful to my sense of self and hope for my future were:

(a) That the sexual and emotional abuse I experienced as a teenager was a symptom of my disorder. In this span of two years of using intensive psychological services at this hospital, I received no assistance for dealing with trauma from these experiences, and when I did bring it up was told there "wasn't enough time to get into it", and that I should consider doing a further six-month program if I wanted to deal with it;

(b) That my desire to not be on medications that had significant side effects was paranoia, a symptom of my illness, and that my complaints about the drugs were evidence of my non-compliance;

(c) That I was never to be trusted to be in a room alone without a clinician present, even with my peers, for reasons never explained;

(d) That I needed to be controlled, and deserved uncompromising treatment - a 12-month program I completed required a strict 80% attendance to all classes without compromise. One participant was kicked out because she had a stroke and missed too many classes;

(e) That I had a medical condition that meant I had emotional experiences at four times the intensity of a normal person;

(f) That if the 12-month program didn't work, it was because I didn't take on the information properly and would need to do the program again;

(g) That self-harm is something that warranted punishment;

(h) That I should comply with my family's, friends' and partner's wishes, and that I should feel lucky anyone will put up with me at all;

(i) That I am not allowed to get assistance from staff if I have already engaged in my "problem behaviour"; and

(j) That I had a 1 in 10 chance of dying by suicide.

24 These were all things that I was told explicitly by, and learned implicitly from well-intentioned mental health professionals, and these kinds of messages fundamentally

shaped how I saw myself and what I was going through. I wasn't a person going through an existential struggle, but a person with an illness that was both an unfortunate chance of fate and something I should be punished for.

25 And whilst at the time I believed a lot of these things (particularly scary to me was the likelihood that I'd die by suicide - a factoid that when I was again suicidal, was extremely difficult to erase from my mind), I also had a lot of questions that started to form in the back of my mind:

(a) Why had it taken 10 years of using mental health services and seeing psychiatrists to find the 'right' diagnosis? And why did it only take one psychiatrist 50 minutes to diagnose me with a 'serious mental illness', and other psychiatrists didn't want to diagnose me? Did I have the right diagnosis? If not, would it mean the treatment program I'd been pinning all my hopes on and pouring all my time and energy into wouldn't work?

(b) Why didn't any of the drugs I'd taken in 10 years appear to work? I'd never heard of that happening for anyone else - was I a particularly bad case? Was I 'treatment resistant'? (I was told during my inpatient admission from a staff member that the drugs I was taking worked for 85% of the population, and I was in the unlucky minority for whom the drugs didn't work. Years later I found out that there's still significant debate about the baseline effectiveness of many of the drugs I took).[1]

(c) How can self-harm or other "problem behaviours" be both a symptom of an illness, and something worthy of being punished for by the mental health system? Are people with cancer being treated like this?

(d) Why is it that in the mental health system my experiences of abuse are seen as a symptom of an illness, when in another realm I would be seen as a 'survivor' of abuse? Would I be treated differently?

(e) If this was an illness, why were we being treated like children? Again, are people with cancer being treated like this?

26 Over the subsequent three years, I found I was anything but alone in asking these questions, I just hadn't found the place where you're allowed to ask them.

Finding other people asking the same questions: peer support and the 'consumer movement'

27 In 2016 as part of my training as a peer worker at headspace I attended a training in Intentional Peer Support run by Flick Grey. Intentional Peer Support (IPS) is a model for

---

[1] Kirsch Irving, 'Placebo Effect in the Treatment of Depression and Anxiety' *Frontiers in Pyschiatry* 2019(10), 407.
Tim Newman, Medical News Today, 'Do antidepressants work better than placebo?' <https://www.medicalnewstoday.com/articles/325767> [Accessed 10 September 2020].

peer support from the United States that was created by Shery Mead. Shery has her own experience of using mental health services, and after finding the way she was treated in them less than helpful developed a model of peer support that is about "thinking about and inviting transformative relationships."[2] In IPS "practitioners learn to use relationships to see things from new angles, develop greater awareness of personal and relational patterns, and support and challenge each other in trying new things."[3]

28 It is in this training that I was exposed to the "consumer movement" and some of the different ways of making sense of psychological distress that is outside of the medical model that I had up until that point, swallowed whole.

29 Flick was the first person I'd ever heard talk about their experiences, of self-harm, of "madness" as she called it, not in terms of illness, but in terms of trauma and shame. And it cracked me wide open.

30 One of the things I learned from the Intentional Peer Support training is that it's easy to get stuck in the role of "the patient", where everyone, including you, sees you as a problem to be solved.

31 This was a major light bulb moment for me. It made me realise how my whole life had become centred around the idea that I was sick. In my fervour to do all the right things, and follow the doctors' orders, being "a sick person" had become my identity.

32 As I wrote in an early draft of *No Feeling Is Final*:

"I fear that I've been accidentally institutionalised, if that's even a thing? Not in an asylum-y way. More subtle than that. The kind of way that slowly erodes your self-worth. I think about the psychiatrist who told me that my feedback on how our sessions could work better, expressed only after I'd built up the courage to offer it, was actually just paranoia. I think about that same psychiatrist, telling me that the sexual abuse I experienced was a symptom of my disorder. Not a cause. A symptom.

But I also sweat the small stuff. The subtle ways my family and friends treat me differently now. The ways I encourage them to. The weekly diary cards, checking off my "problem behaviours". The patronising exercises and how idiotic they made me feel.

---

[2] Intentional Peer Support, 'What is IPS?' <https://www.intentionalpeersupport.org/what-is-ips/?v=6cc98ba2045f> [accessed 24 August 2020].

[3] Intentional Peer Support, 'What is IPS?' <https://www.intentionalpeersupport.org/what-is-ips/?v=6cc98ba2045f> [accessed 24 August 2020].

I find out that two different psychiatrists, given the same patient, only arrive at the same diagnosis 32-42 per cent of the time.[4] *This diagnosis that I pinned so much of myself to, that I spent the last two years of my life desperately trying to fix, suddenly looks so fragile."*

33 The Intentional Peer Support training was my introduction to the consumer movement and ideas that loosely come under the banner 'critical psychiatry'. To me at the time these were new ways of making sense of, and living well with, psychological distress than I'd come across so far, and it offered a world outside the hospital and mental health system that I had lost so much of my faith in. It offered hope, and it was the place where I could ask the questions that had been coalescing in the back of my mind over all those years.

34 Being exposed to the consumer movement, critical psychiatry, and more information to make sense of both my distress and the way I had been treated by the mental health system was a challenging but ultimately healing process for me. As the famous Gloria Steinem quote goes, "the truth will set you free, but first it will piss you off".[5] This was that kind of process.

35 It is these expanded ideas, and ways of seeing my experiences, as well as building up connections with people who understand these ideas and ways of being beside me (including at times trusted mental health professionals) that have formed the bedrock of how I have sustained myself in the years since. It has enabled me to shift my relationships away from that of a "sick" person, which has had a great impact on my life for the better.

36 Now, when I am experiencing a significant period of distress, I have both trusted mental health professionals I can draw on if I choose to, as well as a small network of peers I can go to for support. I no longer feel like I am beholden in the same way to whatever the mental health system will make of me. Now I am, for the most part, in the driver's seat, and I have found the "warm hug of humanity" I was looking for all those years ago when I went to hospital.

37 But even though I consider myself lucky to have found this, it has not and is not, by any stretch of the imagination, easy.

38 As I will discuss further below, what I have now found works for me leaves much of the mental health system (particularly the more acute end of services) antithetical to my needs, and it is difficult or impossible to find the services I think would be helpful in moments of crisis like peer support, mutual self-help (like Alternatives to Suicide groups), warm lines or peer-respite. So I am, for the most part, on my own, which is still a reasonably terrifying prospect.

---

[4] Sarah Wilson, 'First, We Make the Beast Beautiful: A New Story about Anxiety' (Pan Macmillan Australia, 2017), p 21.

[5] Gloria Steinem, 'The Truth Will Set You Free, But First It Will Piss You Off!' (Murdoch Books, 2019).

What needs to happen

39 Having summarised some of how my personal and professional experiences have informed my current thinking, the rest of this statement will focus on specific barriers and opportunities I see in the mental health system that I think would have assisted me in my experience, and the experience of others.

40 In particular I draw learnings in these recommendations from my professional experience in services, training mental health workers, and hearing from and working closely with people engaged with the Big Feels Club, which currently stands at over 6,000 members, a significant portion of whom are Victorian citizens and current or previous users of the Victorian mental health system.

41 Based on my professional and personal experience, I recommend the following:

(a) Outside of the current system:

  (1) invest in consumer spaces, thinking and services so that over time there develops a genuine alternative to the current mainstream offerings in the mental health system; and

  (2) invest in consumer-led media so that consumers' concerns are given voice in the public consciousness, with the aim to achieve:

    I. reporting that is sensitive to and reflects the diversity of consumers' experiences and is therefore less stigmatising;

    II. reporters that are able to hold the mental health system to account; and

    III. reporting that brings about a wider mobilisation of the public to keep mental health on the public and government agenda.

(b) Inside the current mental health system:

  (1) embed and support peer support to establish itself as a legitimate discipline;

  (2) invest in consumer leadership in an effort to rebalance power, to ensure that the system is reformed by the people who use it; and

  (3) include consumer-led training in all clinical training programs to shift stigmatising and discriminatory attitudes and behaviours of mental health workers.

42 I pay particular attention to investing in consumer-led media (paragraph 41(a)(2)) given my unique experience with the Big Feels Club and producing the *No Feeling Is Final* series, as I see particular opportunities for reform in this area. I do not go into detail about

embedding and supporting peer support (paragraph 41(b)(2)) and investing in consumer leadership (paragraph 41(b)(3)) as there are others who have already made significant contributions via witness statements on these subjects.

Need to invest in consumer spaces, thinking and services

43 My experience of treatment in the mental health system is not unique. In some regards it is on the more mild or better end of experiences in the system.

44 In terms of finding more useful ways of understanding my experiences, I also consider myself lucky, as some people using the system never find or know there's an opportunity outside of the expectations or attitudes often put upon them by the mental health system, and if they want such an opportunity, they have to struggle for it largely alone.

45 In Robert Whitaker's seminal book, *Anatomy of an Epidemic*, he investigates why the number of Americans who receive government disability for mental illness has approximately doubled since 1987. In it he interviews Kate[6], a woman with a diagnosis of schizophrenia, who *"for a person with schizophrenia… was doing extremely well. Yet she wasn't happy."* Whitaker reflected:

"[Kate] chafed too over how everybody in the system treated her. "Recovery on the med model requires you to be obedient, like a child," she explains. "You are obedient to your doctors, you are compliant with your therapist, and you take your meds. There's no striving toward great intellectual concerns."[7]

46 She describes her experience of trying to get off psychiatric medications and escape her identity as a "mentally impaired person" as a decision that "put her at odds with most everyone in her life". She had to disengage from the mental health system that had supported her, and keep her family at arm's length in the hope that there was something better beyond what the mental health system described as doing well. This was a blind act of faith. She describes her thinking:

"I had this hope, this faith, and so I said to myself, 'I am going to walk this tightrope across this horrible canyon, and hopefully when I get to the other side, there will be a mountain ridge I can stand on.' I had to focus on going forward regardless of where it took me, because if I fell off the tightrope, I was back in the hospital."[8]

47 She made it through to that mountain ridge, is now married, and doing well in her career, even if she still sometimes finds it "very difficult to deal with emotions." Her mother

---

[6] 'Kate' is not the real name of this person.

[7] Robert Whitaker, 'Anatomy of an Epidemic' (Crown Publishing Group, 2010) 123.

[8] Robert Whitaker, 'Anatomy of an Epidemic' (Crown Publishing Group, 2010) 124.

commented that she "is more comfortable in her own skin and more at peace with herself than ever. She is physically healthy. I didn't know that this kind of recovery was possible."[9]

48 This story mirrors my own experience of how isolating and difficult it can become when you want something more for your life than what the medical model or mental health system has ascribed for you. There is no real system of support outside of the dominant frame. This is where peer support found its origins. It was born of people like me, people like Kate, who wanted more than what the system saw them as, and so developed ways to support each other, like Intentional Peer Support. This is a phenomenon that has emerged amongst many marginalised or discriminated groups, for example, gay men during the HIV / AIDS crisis or 'consciousness raising' groups run by women in the 1960s.

49 There are small organisations out there supporting this in mental health - creating spaces where people can find others asking the same questions I was. As an example, the 'about' section describing a monthly reading group in Sydney run by consumer-led organisation, Off The Wall:

What is madness? Am I 'sick' or is the world 'crazy'? Do the dominant approaches to mental distress (psychiatry and pharmacology) aid or extend people's distress? What is the relationship between madness and power? Why does the society fear and discriminate against those with psychiatric diagnoses? Are there alternative discourses and ways of conceiving of what we call 'mental illness'?[10]

50 At the Big Feels Club we often say that sometimes 'the answer' is finding other people asking the same questions, as finding this has been a big part of our own (and many of our members') experiences of recovery. Spaces where you can ask these types of questions (as my co-founder Graham Panther outlines further in his witness statement) can be part of a healing process, it's just very hard to find and broadly speaking, not accessible in the system itself.

51 It makes sense to ask these questions, and to want more than how the system sees you. Research conducted in 2013 led by the University of Melbourne investigated the 'side effects' of the medicalisation of mental illness.[11] They found a biomedical view of mental illness "shapes contemporary thinking about psychological problems" and through a quantitative meta-analytic review found that "biogenetic explanations reduce blame, but induce pessimism about recovery" and that "medicalization is no cure for stigma and may create barriers to recovery."[12]

---

[9] Robert Whitaker, 'Anatomy of an Epidemic' (Crown Publishing Group, 2010) 124.

[10] Off The Wall, 'Reading Groups' <http://www.offthewall.net.au/reading-groups/> [Accessed 24 August 2020].

[11] Kvaale EP, Haslam N, Gottdiener WH. The 'side effects' of medicalization: a meta-analytic review of how biogenetic explanations affect stigma. *Clin Psychol Rev*. 2013;33(6):782-794.

[12] Kvaale EP, Haslam N, Gottdiener WH. The 'side effects' of medicalization: a meta-analytic review of how biogenetic explanations affect stigma. *Clin Psychol Rev*. 2013;33(6):782-794.

52 My subsequent experiences working in clinical services, in particular of observing clinical reviews and working alongside clinicians also reinforced the stigmatising attitudes that a significant portion of mental health professionals, even in settings regarded as the most progressive, still harbour.

53 This is backed up by Australian research that found that "the majority of consumers (61.1%) reported a lack of understanding about the lived experience of mental illness from their service providers, while over half (50.8%) worried that professionals have an unfavourable perception of them due to their mental illness." [13]

54 Whilst according to the above report by Mental Health Council of Australia there is little research into this area, recent analysis from Canada found that "people with lived experience of a mental illness commonly report feeling devalued, dismissed, and dehumanized by many of the health professionals with whom they come into contact" and that the "the pervasiveness with which negative interactions are reported suggests the problem is not isolated to a few insensitive providers but is more systemic in nature—that it is a problem with how healthcare culture prioritizes and perceives persons with mental illnesses." [14]

55 Obviously these findings and experiences have far-reaching implications for how we train mental health workers, deliver services, as well as how we frame the conversation around mental health, as I will explore further later.

56 I was lucky enough to stumble upon the consumer movement, which showed me that I could exist outside of the messaging the mental health system and the media gave me. As part of finding that movement I learned how to better advocate for my needs, how to better walk alongside someone in distress (and be walked alongside of) and find mental health professionals who see me as a human first, rather than an illness.

57 But this came at a price. It rendered much of the mainstream mental health system, particularly the acute end of the spectrum, antithetical to my needs. After finding these ideas I was determined that next time I 'fell back in the hole' that I would not come out the other side thinking of myself again as a broken, ill, dumb, nuisance of a person. This meant a lot of mental health services and professionals' approaches were counterproductive.

58 In my first attempt to deal with these experiences with this new perspective, out of desperation I went back to the psychologist from the long-term hospital program, and a

---

[13] Mental Health Council of Australia, 'Consumer and carer experiences of stigma from mental health and other health professionals' (2011) <https://mhaustralia.org/sites/default/files/imported/component/rsfiles/stigma/Consumer_and_Carer_Experiences_of_Stigma_from_Mental_Health_and_Other_Health_Professionals.pdf> [Accessed 10 September 2020].

[14] Knaak S, Mantler E, Szeto A. Mental illness-related stigma in healthcare: Barriers to access and care and evidence-based solutions. *Healthc Manage Forum*. 2017;30(2):111-116.

psychiatrist I'd previously seen long-term. Both are and were accomplished clinicians that I at the time respected in their own right. The psychiatrist could offer little beyond something to help me sleep (which was useful don't get me wrong) and telling me that she'd seen other people get through similar experiences of repeated suicidality (also helpful!), but my old psychologist's approach was so detrimental to my mental state at this vulnerable moment that after a number of sessions, even though I was actively suicidal I chose to stop seeing her. At the time both myself and my partner were worried that my sessions with her were making my distress significantly worse, not better, as she couldn't help but come to our sessions with a patronising approach towards me and my situation, and to consistently treat me as though she knew better than me - a therapeutic dynamic I not only had grown out of, but found actively unhelpful.

59 That a client's sense of self-agency could narrow so acutely the services that are helpful to them is absurd, and is one reason why we need genuine alternatives. It is not enough to educate mental health workers to treat service users with more dignity. Self-agency should be central to the mental health system, not at odds with it. Or as a clinician said in an Intentional Peer Support training I was facilitating, "I get worried when people just vacantly nod at me. If someone's disagreeing with me, it means they've still got some fight in them. It means they're still alive."

60 No one should have to go through it alone, and that requires significant investment in alternatives, so that there aren't pockets of something different, but genuine offers to choose what works best for you. This is about resourcing other alternatives that we know many consumers want - for example, making peer respite available to all, 'care' farms, warm lines, and crisis alternatives like the Safe Haven cafe.

61 I support The Wellbeing Manifesto's call to see peer workforces gain an equitable balance alongside "traditional workforces (such as medical professionals, allied professionals and support workers)".[15]

62 As discussed later in this statement at paragraph 168 onwards, there are significant challenges to embedding peer support services inside clinical settings, which is why it is important to make sure that peer support, and consumer thinking and services also have a strong foundation outside of clinical services in order to create a backbone for what is a significant shift in the makeup of mental health service offerings and approach to mental health support.

---

[15] Wel being Manifesto. 'A submission to the Government Inquiry into Mental Health and Addiction' <https://static1.squarespace.com/static/5acd7513620b857f1f567e85/t/5b551ef4562fa7375406fb00/1532305150225/Wellbeing+Manifesto+Full+Submission+Digital.pdf> [Accessed 10 September 2020].

Conditions for a genuine alternative

63 What is needed to establish and develop consumer-led services is significant long-term investment in the foundations that would make this genuine alternative a reality:

(a) long-term (10 years+) investment in skilling up of consumer-led organisations, including professional development to become sustainable, healthy businesses that provide competitive services to the public, including;

(b) long term investment in data capture and development, including research and evaluation for consumer-led organisations to build their ability to provide qualitative and quantitative evaluation on services they provide. Often peer alternatives are trapped in a Catch-22 where the argument against commissioning alternative models of care is based on them having a less established evidence-base compared to other models, and yet it is often difficult to get substantial funding to research consumer-led alternatives to build that evidence base. It is disingenuous to rule out alternatives, which consumers are calling for based on lack of research if we aren't willing to invest in research into it;

(c) mechanisms to continually provide increased and sustainable funding for consumer-led initiatives in the long term (minimum 10 years), including ways to ring-fence funding for consumer-led initiatives;

(d) establishment of a centre for consumer-led research, community development and thought leadership with funding benchmarked to professional colleges for other sectors in mental health;

(e) support for strategic partnerships between lived experience-led organisations who are more matured, if sometimes from adjacent areas. As Graham Panther outlined in his witness statement, through the Big Feels Club we've been able to receive funding through partnership with the Self Help Addiction Resource Centre (**SHARC**), who have auspiced us and guided us to fulfil necessary contract criteria such as risk management processes. This has opened up opportunities that we otherwise would not have been able to take on without this support. Another example is Soteria Vermont, a peer-led crisis alternative whose contract is held by a housing organisation, as they found this organisation better aligned with the intentions of the service than local mental health services.

64 Developing consumer-led initiatives as genuine alternatives to traditional service offerings will offer Victorians a genuine choice, and will raise the bar for the standard of care offered by mental health services. It will also mean that many people who are not satisfied with the approach or treatment from traditional services won't have to go it alone.

65 But to do this we need a critical mass, and to achieve this we need long-term commitment to developing the capabilities of this emergent space. If we are to invest in peer-led services, please let us not recreate some of the same barriers that always plague consumer-led initiatives - lack of resources, lack of evaluation funding built into funding, lack of professional development, and inappropriate governance.

66 Now is an opportunity for Victoria to join with the global progress in mental health and be a leader in the world in this arena, and to truly value and elevate the wisdom of lived experience.

Invest in consumer-led media so that consumers concerns are given voice in the public consciousness

67 It wasn't until I started working in advocacy in the mid 2010s that I started to understand that a big part of what I was dealing and struggling with was a broken and traumatic system. I had, up until that point, thought that what was happening was because I was a broken and ill person.

68 This is in part because nowhere did I see my experiences reflected in media portrayals of mental health, and mental health care.

69 For the past 15 years the media has been singing from the same "just ask for help" song sheet, and it appears to be working. A 2019 survey of Australian GPs found "psychological issues (such as depression, mood disorders, and anxiety) again appear as the most common health issue managed by GPs."[16]

70 Partly due to the time and the personal context I grew up in (for example, supportive and understanding parents), as well as the success of these public campaigns, I've never had major issues asking for help. I was reasonably open about my experiences, and I was also a reasonably good advocate for asking for care.

71 But after ten years of asking for help, and still not being 'fixed', I was convinced that there was something uniquely wrong with me.

72 This was backed up by the stories I heard in the media, that always seemed to fit two narratives. There was the "just ask for help" story, where someone sees a psychologist and then is better. And then there were the stories usually told about people in third person, where their life shatters into fragments, to the horror of their friends and family.

---

[16] Royal Australian College of General Practitioners, 'General Practice Health of the Nation 2019', <https://www.racgp.org.au/FSDEDEV/media/documents/Special%20events/Health-of-the-Nation-2019-Report.pdf> [Accessed 24 August 2020].

73 I remember realising this when I was an inpatient in 2014. I was admitted during mental health week, which meant there was extensive mental health programming on TV. Without a lot to do at night or on weekends I watched a lot of it, and realised that everything I saw fit into one of those two categories.

74 And lying in my bed in hospital, I realised that I had been putting my hand up for help for ten years. Hearing only these two stories over and over again, I became frightened that my fate was sure to be sealed, and that my life would also become that second story where I get talked about in third person.

75 I didn't see myself, or my experience, anywhere in the media.

76 It wasn't until years later that I learned that one in two cases of depression will last multiple episodes (and those who have more than two episodes have approximately 80% chance of another recurrence).[17] And yet, in all my experiences of the system, no one had ever told me that! I had been thinking that I must have some uniquely persistent and awful version of this illness, but actually my experiences were not just common, but extremely common.

77 A recent study from New Zealand found that 86% of those in the study '"met the criteria for at least 1 disorder" by age 45.[18] They went on to say that "this seemingly high lifetime prevalence is not unique to this cohort; it matches prevalence reports from multiple psychiatric-epidemiology studies around the world".

78 Again, as Dr Russ Harris, author of the famous book The Happiness Trap, which I would go on to read says "almost one in two people will go through a stage in life when they seriously consider suicide and will struggle with it for a period of two weeks or more".[19]

79 What I was going through might be on the more extreme side, but in my first ten years in the system, and consuming media about mental health, I never heard that these persistent experiences were *this* common.

80 This is essentially why Graham Panther and I created the Big Feels Club. In our experience, and that of many others, psychological distress was compounded by the fact that media portrayals made us feel that the level or persistence of our distress was extremely unusual, leaving us feeling isolated, and even more hopeless. That's why the Big Feels Club is about normalising, and humanising psychological experiences that are by the numbers, pretty normal.

---

[17] Burcusa SL, Iacono WG. Risk for recurrence in depression. *Clin Psychol Rev*. 2007;27(8):959-985, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2169519/> [Accessed 24 August 2020].

[18] Caspi A, Houts RM, Ambler A, et al. Longitudinal Assessment of Mental Health Disorders and Comorbidities Across 4 Decades Among Participants in the Dunedin Birth Cohort Study. *JAMA Netw Open*. 2020;3(4) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7175086/> [Accessed 24 August 2020].

[19] Dr Russ Harris, 'The Happiness Trap' (Robinson, 2007).

81 And this is further reflected by treatment from the system. My difficult experiences of the system, of discrimination, dismissal and punishment were reinforced by media coverage that failed to reflect that experience.

82 In the words of Dr Gabor Maté, a renowned trauma and addiction expert, “trauma is not what happens to us, but what we hold inside in the absence of an empathetic witness.”[20]

83 Not seeing what I was going through, both emotionally and systemically, reflected in the media was traumatising.

84 And it made me a disempowered advocate for myself and others when I was accessing mental health care, because I saw what was happening to me as a personal failing rather than a systemic issue.

85 If we want to truly empower consumers to lead in their own lives, and in the system, we need a media ecosystem that reflects the realities, concerns and issues for people using the system.

Media is not reflective of consumer experiences or concerns

86 One of the issues is that the current media narrative around mental health is highly controlled by mental health organisations, which means it is not always reflective of consumers’ experiences or concerns. This is a problem because it means as a service user it reinforces the idea that any issues are a “you” problem, rather than a system problem.

87 As an example of how this works on the ground, when I was working with a respected Australian mental health organisation that fielded a lot of media requests, a journalist got in touch wanting to speak to consumers who had found psychiatric medications not useful for them. The person fielding this request refused to find the journalist consumers with such stories because it didn’t align with the organisation’s agenda on psychiatric medications.

88 It’s common for there to be understandable fear around reporting on people who haven’t had positive experiences with medications. People are afraid talking about people having neutral or negative experiences of psychiatric medications might encourage people to stop taking their drugs, and suffer significant side effects.

89 But there is also another risk that people get a misguided sense of what mental health treatment may offer. I know because this was my experience. As I’ve mentioned, I spent over a decade on and off psychiatric medications, to no perceived benefit and at times

---

[20] Dr Gabor Maté in the forward to Peter Levine, ‘In an Unspoken Voice: How the Body Releases Trauma and Restores Goodness’ (North Atlantic Books, 2010)

with significant side effects that impacted my ability to work and function. And yet, because of what I was told, and the stories I saw about psychiatric drugs, I thought I must be 'treatment resistant', or something of a lost cause.

90 What I learned much later through meeting peers was that my experiences with psychiatric medications was actually very common (and of course there are others who find psychiatric medications very useful and swear by them), but I didn't see my own experience anywhere. The story I was told about mental health (or the lack of the full spectrum of experiences with mental health treatment) led me to feel more hopeless and afraid than if there had just been more honest reporting on the topic.

91 This speaks to the paternalistic way in which mental health is often reported on - we outweigh the risk of speaking honestly about the realities of mental health care over the risk that people will feel that because something isn't working it is a problem with them.

92 I certainly found that learning more about the system, and how illogical some of its structures were, was actually a cause for relief. It meant the system didn't make sense, not my inability to "get better".

93 For example, the 10 session cap under the Better Access GP Mental Health Care plan I thought would be based on some kind of strong logic. It must mean that it worked for the majority of people and was probably backed by evidence. The fact that in my experience those 10 sessions often barely scratched the surface felt like a searing indictment on my prognosis. Over time, particularly when it was difficult to get treatment more substantial than these 10 sessions, I felt extremely pessimistic about my future.

94 And yet, in the National Mental Health Commissions' review of mental health services in Australia, increasing access to these sessions was one of the top complaints from service users and was "by far the biggest complaint" from mental health professionals.[21] When the government did a review of the Medicare Benefits Schedule and asked for public submissions, Australian psychologist Dr Ben Mullings compiled a list of evidence supporting why the 10 session cap wasn't supported by service users, mental health professionals, policy or scientific evidence.[22]

95 And yet, as a long-term user of the system, prior to working in the mental health system, I never saw this information anywhere. All I saw were the same two stories: the person who asks for help and gets better, and the person whose life falls apart. Having clearly

---

[21] Australian Government, National Mental Health Commission, 'Report of the National Review of Mental Health Programmes and Services – Volume 3' (30 November 2014) p 11, 14. <https://www.mentalhealthcommission.gov.au/getmedia/03c74344-ddb6-431f-8b92-53f233774741/Monitoring/Vol-3.pdf> [Accessed 24 August 2020].

[22] 'Increase visits of psychological care' (2015) <http://drben.com.au/d/DrBen_summary_2015.pdf> [Accessed 24 August 2020].

not "gotten better" I felt increasingly sure that my life would be one of the ones that completely fell apart.

96 If you are someone who feels like they have been in something of a battle with the system (which many consumers and carers do), seeing mental health coverage that asks you to "just ask for help" can end up feeling like it's rubbing salt into the wound.

97 And to my earlier point around the benefit of finding the 'consumer movement', media portrayals of psychological distress and the mental health system not only made me feel more broken and unusual than I actually was, but there was no awareness of or indication in the media that would've pointed me towards one thing that was really genuinely helpful: consumer spaces and different ideas for making sense of what was happening for me. I stumbled into it, and had I not, could very easily still be on the mental health merry-go-round, still considering myself to be a person deserving of dismissive, paternalistic, and stigmatising treatment from mental health professionals.

Mental health narratives are dictated by mental health organisations

98 There is an often overlooked way in which reporting on mental health is shaped by the mental health system itself: speakers bureaus.

99 Speakers bureaus are set up by many mental health organisations as a group of chosen consumers to tell their story at events, or to the media.

100 This is one of the very common ways that journalists access the consumer voice. This means journalists are largely getting information about people's experience of the mental health system that is filtered by the system itself, like in the example above around reporting on psychiatric medications.

101 And of course, organisations will selectively choose consumers whose personal stories align with the organisation - which makes perfect sense for the organisation.

102 But having been one of these consumers, and been through training for 'how to tell my story' I know first-hand how organisations can shape consumers' stories for their own agenda.

103 This can have significant consequences on consumers, as it means the mental health system defines the scope of what we're allowed to talk about in mental health, and therefore shapes the general public's expectations and understanding of the mental health system and what it offers, again, as in the psychiatric medication example above. It's part of why I never came across reporting that pointed me to the 'consumer movement'.

104 This is also evidenced in the recently updated Mindframe guidelines on reporting suicide and mental ill-health, which encourage journalists to sensitively interview people with lived experience to reduce stigma, increase awareness and promote hope - which is good advice.[23] What is interesting to note however is that they recommend accessing lived experience through people already associated with mental health organisations (so they are being supported through the process),[24] and whilst their guidelines recommend visiting their website for story sources,[25] their 'find an expert' page on their website points to Sane's media centre and the media units of various health departments across Australia.[26] Whilst the logic of this advice makes sense, the result is that none of these avenues offer access to consumer voice that isn't filtered through non consumer-led organisations.

105 We notice the differences when people are able to access content that is consumer-led through Big Feels Club, where we do cover issues like people's varied experiences of psychiatric medications. An article and podcast on this topic had overwhelmingly positive responses, including ones like the following:

"It's real and honest and what people need to hear. We can't understand what others are going through unless we hear it in their own words as well as hearing from professionals." – Big Feels Club member.

"Prior to the Big Feels Club featuring in my life I was sure I was a uniquely fucked up wierdo. I can't accurately express via email just how much it's helped. Thank you to both yourself and Honor for being vulnerable and courageous in creating a space where the less talked about can be talked about." – Big Feels Club member.

106 We got similar comments through an episode about medications for Big Feels @ Work, a Big Feels Club project designed for mental health professionals with their own lived experience (in all roles including clinical roles):

"It sparked a confidence in me to seek a psychiatrist and get diagnosed. Prior to The Big Feels Club, a diagnoses would have been crushing; a sure confirmation that I am royally fucked up and a dysfunctional member of society, a fraud as a professional in the MH system. All the big feels at work episodes have contributed to a new found confidence to seek the diagnosis and prove just the opposite. That it does not make me a fuck up and that because of my own journey I'm actually really good at my job." – Big Feels Club member.

---

[23] Everymind, 'Reporting suicide and mental ill-health: A Mindframe resource for media professionals (2020), 28 <https://mindframemedia.imgix.net/assets/src/uploads/MF-Media-Professionals-DP-LR.pdf>, [accessed 10 September 2020].

[24] Everymind, 'Reporting suicide and mental ill-health: A Mindframe resource for media professionals (2020), 28.

[25] Everymind, 'Reporting suicide and mental ill-health: A Mindframe resource for media professionals (2020), 16.

[26] Mindframe, 'Find a topic expert' <https://mindframe.org.au/find-a-topic-expert> [Acessed 10 September 2020].

Utilising media as a tool to reflect consumers experiences and advocate for change

107 The first way I would advocate for is to move to what I call a "dual-expertise model", that is a model of mental health reporting which sees consumer leaders *as well as* clinicians as experts, meaning reporting should ideally include the voices of both.

108 We draw on and elevate those with lived experience - a significant shift in the past few decades - in reporting on many other social and cultural issues affecting vulnerable, oppressed, discriminated and / or minority groups; for examples, issues affecting LGBTQI+ and First Nations people. We are asking for the same expectations and treatment for consumers. This shift would move away from consumers being seen and included in reporting only as human interest or case study examples.

109 For an example of why this is relevant, I point to a recent article by the ABC which followed a Crisis Assessment and Treatment (**CAT**) team, called 'On the frontline with a mental health emergency team as they respond to the dark reality of the coronavirus crisis'.[27]

110 It appears to be a well-resourced and produced article, that follows two clinicians on a shift as part of a CAT team. The article deals heavily with compulsory treatment, and opens with:

> *The man in the ambulance in front of us doesn't want to go to hospital.*
>
> *But tonight, he doesn't get a choice.*
>
> *A mental health crisis team from Melbourne's Alfred Hospital has assessed him and determined he's too much of a risk to himself.*

111 The article goes on to touch on several cases involving involuntary treatment or cases that are "a bit 50/50 or 60/40, where they really don't want to go to hospital and the idea of going to hospital can be very, very distressing for them — they're the horrible cases."

112 Yet throughout the article at no point do we hear from someone who's experienced involuntary treatment, or hear why people might find the idea of going to hospital very distressing. There is also no critical eye on police involvement, the article simply saying "the bottle of capsicum spray clasped in the police officer's hand seems unnecessary. But anything can happen on these call-outs and the CAT team have decided it's best the police are in attendance."

---

[27] Jessica Longbottom, ABC News 'On the frontline with a mental health emergency team as they respond to the dark reality of the coronavirus crisis' (7 July 2020) <https://www.abc.net.au/news/2020-07-05/coronavirus-mental-health-crisis-response-team-during-covid-19/12402370> [Accessed 24 August 2020].

113 There’s nothing in the article that speaks to why people might reasonably resist hospitalisation, and no attempt to connect the question of how often we’re getting these ‘50/50 calls’ right to the state of compulsory mental health care in Victoria: double the Australian rates of physical restraint in mental health settings, double the average time spent in seclusion in mental health settings, above national average rates for involuntary admissions to hospital, as well as the highest rate of community treatment orders nationally, and as one study suggests, perhaps even the highest rates of community treatment orders in the world.[28]

114 In other words, this article deals with compulsory treatment quite significantly, whilst omitting much important context. There is one patient interviewed but he does not provide any kind of critical lens on the issues discussed and he’s not a consumer leader, he’s a patient, as per the ‘case study’ template of involving consumers in reporting.

115 Had the journalists interviewed any consumer leaders in Victoria they would have gotten the critical perspective I’m naming as absent.

116 I chose to highlight this article from ABC, not to single them out, but because they regularly cover mental health issues and have some of the best reporting in the country on mental health. They initiate projects across their programming, like Mental As and Your Mental Health week (of which the above article was a part of) to genuinely bring awareness to these issues. They have put significant resources into covering this topic over many years and I believe they have good intentions with their coverage.

117 And yet, for a well-resourced article from Australia’s most trusted news source to cover CAT teams and not question anything about the treatment of people whose rights are being taken away is also an example of where reporting on mental health is currently at. It is evidence of the lack of support that ABC journalists can have to report on what is a complex and sometimes fraught system in a way that understands the realities and diversities of consumer experiences and seeks to hold power to account. Support for reporters includes training and education, and internal support for example editors and management to produce media that rebalances power towards consumer perspectives.

118 I want to also make note that when ABC has included critical consumer voices it has been able to shine a light on issues facing consumers - as with their recent coverage of VMIAC’s seclusion report.[29] Journalists need more support to produce stories like this

---

[28] Dr Peirs Gooding and Dr Yvette Maker, ‘Why are the rates of restrictice practice in Victoria’s mentalh health services so high’ <https://pursuit.unime b.edu.au/articles/why-are-the-rates-of-restrictive-practices-in-victoria-s-mental-health-services-so-high> [Accessed 10 September 2020].

[29] Zalika Rizmal, ‘Victoria's mental health wards are putting more patients in seclusion and the impacts may be long-lasting’ <https://www.abc.net.au/news/2020-07-29/victorian-mental-health-wards-increasingly-using-seclusion/12500352> [Accessed 10 September 2020].

that put consumer voices at the forefront and are willing to challenge the treatment available in Victoria's mental health system.

119 Similarly, in the *No Feeling Is Final* series that we made with the ABC we explored some of the ways that hospitalisation is not always useful. In this context it's notable that *No Feeling Is Final* was written by two consumer leaders in Victoria, myself and Graham Panther. But in my experience this is not business-as-usual for most Australian media outlets.

120 Moving to this dual-expertise model would move us towards the aims I listed above at paragraph 41(a)(2):

(a) Reporting that is sensitive to and reflects the diversity of consumers experiences and is therefore less stigmatising;

(b) Reporters that are able to hold the mental health system to account (I will discuss this further below); and

(c) Reporting that brings about a wider mobilisation of the public to keep mental health on the public and government agenda (again discussed further below).

121 We would need several foundational things to achieve this:

(a) consumer-led centre, organisation and high-profile designated consumer role for media to access consumer expert opinion. As mentioned above, journalists access expert voices through known channels that currently are usually mental health organisations. To achieve a dual-expertise model in reporting there would need to be a known, reliable, skilled channel to access consumer expert opinion. This could be a function of the consumer-led centre or 'think tank'; and

(b) training to build capacity for journalists and media organisations to understand a dual-expertise model of reporting on mental health issues. I explore this further below.

Co-produce media with consumers

122 Another way to ensure better representation of consumers is what we did with the *No Feeling Is Final* podcast series with ABC: co-produce media with consumers. This is something that we are increasingly doing in other areas of media and reporting involving discriminated or minority groups. What we're asking is for the same standards for representation in media to apply to mental health consumers, including a diversity of experiences and perspectives.

123 This is how we ensure that people see themselves represented in the stories we tell about mental health.

124 As I mentioned above, to have these traumatic experiences, both of psychological distress, and then of the system meant to help you, and to not see that story accurately reflected anywhere in ‘the conversation’ is traumatic. And it sends the message that your experiences are yours alone, which in reality is so very far from the truth. We just need that truth to be told so that consumers have more agency in their lives, feel less alone, and are better equipped to stand up for themselves when they face discrimination, dismissal and disrespectful attitudes both from mental health professionals and society at large.

125 We know this kind of media is possible. It’s what Graham and I have aimed to do with the Big Feels Club for the past three years, it’s what we did with *No Feeling Is Final*, and it is why we often get messages like this from our Big Feels Club members and *No Feeling is Final* listeners:

> *“I listened to your podcast last night. I couldn’t stop crying. I have never felt so understood in all my life. I had given up hoping I might ever hear it spoken from another person, who isn’t just trying to imagine, but who knows. Truly, thank you. It means so much.” – Big Feels Club member.*

> *“I started listening to your podcast, not for me but for my son. You have awakened me. See, I have been a self-reliant, self-taught, self-healing person my whole life. ‘Grow some balls’ I told my wife was what our son needed to do. I understand now, thanks to you. I feel frightened by what comes next, by the possibility he won’t get better. But for now I will feel grateful I stumbled on your voice. Know that you have done something for me, him, and my wife.” – No Feeling is Final listener*

126 Many more messages like this are outlined in Graham Panther’s witness statement.

127 My sincere hope is that in the future, people do not have to wait so long, or search so hard, to find themselves reflected in Australian media and culture, and we can do that, by letting people with lived experience lead the conversation.

128 There are several avenues that could be explored to achieve this:

(a) investing in consumer-led organisations and giving them the remit and resources to partner with media organisations to skill up journalists, as well as arts and cultural funding bodies like Film Victoria and Creative Victoria in reporting sensitively and making media about mental health and the mental health system that reflects the experiences and concerns of consumers;

(b) make available flexible funding to consumer-led organisations aiming to reflect the diversity of consumer experiences and achieve representation of the complexity of consumer experiences and concerns. Currently, it is difficult to access funding for an initiative like the Big Feels Club through mental health channels because they rarely fit into funding criteria - as an initiative we're not a population health program or a service in the traditional sense. The small amount of funding support we've received has consisted of donations from users, philanthropic donations, workforce innovation grants, and funding we received to take part in the Foundry658 accelerator program. Foundry658 is an arts accelerator program we applied for because we felt we'd have more success looking for funding through arts grants given the creative nature of our work.

Skilling up journalists to reflect the diversity of consumer experiences

129 One way, as I mentioned above, to ensure that consumers' needs, experiences and concerns are at the forefront of reporting on mental health is to skill up journalists.

130 The Executive Producer of the *No Feeling Is Final* series, Joel Werner, is a world-leading radio journalist and science reporter, with a background in research psychology.

131 After making the *No Feeling Is Final* series, he reflected that spending six months working on the series was a big learning curve. He said that being immersed in the experiences of consumers like myself and Graham Panther, who co-wrote the series, helped him to develop a more nuanced understanding of consumers' experiences, as well as the complexity of reporting on mental health issues.

132 Joel is now overseeing the production of ABC's *All In The Mind* podcast, one of Australia's most popular mental health and psychology podcasts. He brings the learnings from working intensely with people with lived experience to all the reporting he oversees on mental health.

133 Co-producing with people with lived experience, he reflected, was the best way to understand the complexity of the consumer experience.

134 From my viewpoint, making the *No Feeling Is Final* series is also one of the most satisfying professional experiences I've had. Nowhere in my work in the mental health system have I so authentically been 'given the keys' to my own story, and the support to truly realise it. This is despite working roles that were explicitly about sharing my story. I've reflected that we are lucky to have a national broadcaster like ABC that will take on shows like *No Feelng Is Final* that deal with difficult topics in creative ways, and lend the mic to those with lived experience. There are few media outlets that would fully support this kind of storytelling on this issue to this extent.

135 The problem is, this type of experience, on both sides, is extremely rare. Most journalists learn about topics they're reporting on off the back of their own initiative, and with increasingly limited time and budget. This means journalists largely have the same

understanding of mental health as the general public, and their sources, as I've mentioned above, are often filtered by the mental health system itself.

136 This is why I propose proactive partnerships between consumer organisations and the media, to grow the capacity of journalists and media outlets in Australia to respectfully report on mental health issues, and to engage with the diversity and complexity of consumer views and concerns. It is vital this work is consumer-led.

137 My recommendation is for a consumer-led organisation to have the remit to develop and roll out a fellowship program for journalists and consumers wishing to cover mental health in the media. This would look like:

(a) a fellowship program for journalists interested in mental health to support them to have a stronger sense of consumer experiences and enable them to report on elements critical to mental health system function with regard to consumer experiences; and

(b) a fellowship program for consumers interested in writing about mental health and the mental health system, with professional development and networking opportunities to enable them to produce content for mainstream publications that covers issues critical to the function of the mental health system from the consumer perspective.

138 I see these as being akin to leadership programs rolled out to educate, and empower consumer leaders, or leaders in other sectors. We need to develop allies in the media space to build on and make space for consumer voice and concerns.

Media as a lever for change

139 If we get this right, the media can act as a lever to keep the system accountable, and drive reform.

140 Journalists are some of a few bodies that have remit to reflect the issues of the people. This means reflecting the reality of mental health care and consumers' experiences, including exposing mistreatment and human rights abuses. This is a lever for long-term system reform that is at current underutilised. Not only this, but the media also have the ear of the wider public, and so can leverage this into wider community engagement and drive for engagement with issues at the heart of care in the mental health system

141 In talking about this issue with a Victorian consumer leader, she reflected on her experience trying to get media coverage on a report that shone a light on gendered violence in mental health care settings. She was told by a journalist from a reputable

mainstream media outlet that no one wanted to hear about women getting sexually assaulted or raped in psych hospitals.

142 There are very real and ongoing problems in mental health care, one of the ways to drive reform is to shine a light on the reality of what is happening in the system. This requires both public reporting of data, as well as a media ecosystem that will report on that data. Without it these reports are lost to the ether and fail to galvanise public support for change.

143 There is no better example I can think of for the power of journalism than the work of Robert Whitaker.

144 Whitaker is an American journalist and author who writes primarily about medicine, science, and history. He has won numerous awards for his writing, including being shortlisted for a Pulitzer Prize for Public Service for reporting on ethics in psychiatric research. He is the author of several books looking at the base scientific literature and history of psychiatric medications, including *Anatomy of an Epidemic*, which won the IRE 2010 Book Award for best investigative journalism and which I discussed at paragraphs 45 - 47.

145 The book investigates the history of psychiatric medications as well as the scientific literature, and asks an important but controversial question: over the long term, are psychiatric medications making people more disabled?

146 Steven Morgan, a consumer advocate in Vermont, in the United States, used Robert Whitaker's *Anatomy of an Epidemic* as a way of advocating for what consumers (and many clinicians) had been advocating for, for years; an alternative to the run-down state hospital. They gave each of the legislators a copy of the book, seeing it as a necessary step to educate those in power. My colleague remarked that the *"legislators would've never read anything like that on their own. They'd been hearing from us psych survivors for a long time, but all that was taken as anecdotal testimony, and Whitaker's book makes the case based on dispassionate scientific evidence… so it won a lot of folks over"*.

147 As a result, in 2012 the legislative body chose to change the law, requiring that the state must provide "alternative treatment options for individuals seeking to avoid or reduce reliance on medications".[30]

148 This resulted in funding being allocated for Soteria House in Vermont, a residential peer-led service, that still exists today.

149 *Anatomy of an Epidemic* has also been used by other consumers advocating for change like Jim Gottstein, an Alaskan lawyer who is also a consumer. After reading Robert

---

[30] 79 V.S.A. § 7255(3) (2012).

Whitaker's book he founded PsychRights and used Whitaker's book as a roadmap for advocating for consumers' rights. He has and continues to be extremely influential (Robert Whitaker names him as the person doing the most in the US to change mental health in a recent edition of the book[31]), having successfully advocated for a Soteria home in Alaska, won a landmark case to protect consumers' rights and funding for mental health services in Alaska, and being integral to the release of papers showing that a pharmaceutical company had concealed that "its top-selling drug caused diabetes and other life-shortening metabolic problems"[32]. He continues to advocate for consumers, with Robert Whitaker's book being the catalyst for his advocacy.

150 It is the work of those outside the system, who have the remit to credibly shine a light inside, that can help shape our system for the better in the long term. Unfortunately, as it stands, consumers are often not taken seriously when they advocate for serious change, but when they ally with other aspects of the system (journalists, values-aligned clinicians, carers), they have a much stronger voice to advocate for change. To hold the system to account now and in the long-term we need these kinds of strong alliances that can hold the system to account and ensure its continual progression towards better care and treatment of the people who use the system.

Where's the revolution?

151 The other benefit of an approach like this is that it has the ability to mobilise the general public around mental health reform.

152 In 2018, VICE media conducted a survey of over 3,700 young Australians.[33] It found that whilst young Australians think mental health is one of the most important issues, overall they're *"not overly interested in the topics they find extremely important"*.

153 The findings were perhaps most stark for mental health. Of the 17 topics listed in the survey - ranging from immigration to drug policy - mental health was voted the second most important (behind saving the environment), but the second least interesting.

154 A friend who's been having a rough time lately said, in a moment of black humour, that most mental health messaging *"assumes that you're so ill that you have zero personality and no sense of humour."*

155 Makes sense then why people might not be fully engaged on this topic.

---

[31] Robert Whitaker, *Anatomy of an Epidemic* (Crown Publishing Group, 2010) p355.

[32] Jim Gottstein, 'The Zyprexa Papers' (Jim Gottstein Anchorage, 2020).

[33] VICE, The Big Shrink 2018 Youth Survey <https://www.scribd.com/document/463057514/The-Big-Shrink-2018-Youth-Study> [Accessed 10 September 2020].

156 My experiences creating the *No Feeling Is Final* series and the Big Feels Club shows that there are other ways of having “the conversation” that are much more engaging.

157 And we’re not the only ones.

158 Some of the same experiences, frustrations and concerns I’ve talked about here, have now been laid out in detail in recent New York Times’ bestselling books.

159 In 2018 Australian Sarah Wilson released her opus on anxiety, *First, We Make The Beast Beautiful: A new story about anxiety*.[34] It is an intimate examination of her life with anxiety where she:

> *“...pulls at the thread of accepted definitions of anxiety, and unravels the notion that it is a difficult, dangerous disease that must be medicated into submission. Ultimately, she re-frames anxiety as a spiritual quest rather than a burdensome affliction, a state of yearning that will lead us closer to what really matters.”*[35]

160 The book has been hugely successful, a New York Times’ bestseller, and despite it dealing head-on with the controversial science behind diagnosis (the statistic I mentioned earlier at paragraph 32 about the fallibility of diagnosis is in the opening pages of her book), it is endorsed by some of Australia’s most well-known and respected psychiatrists, Dr Mark Cross and Professor Patrick McGorry.

161 If presented in the right form, we can discuss mental health in ways that are not only engaging to the wider public, but also supported by Australia’s top clinicians. This leaves us with so much more potential to engage people in new ways on this topic, and bring about citizen-led mobilisation on this issue.

162 Internationally, Swiss-Scottish journalist, Johann Hari has been making waves with his wildly successful books, Chasing the Scream,[36] about how our framing of addiction is incorrect, and Lost Connections.[37] In this second book he asks “what really causes depression and anxiety - and how can we truly solve them?”

163 The Lost Connections book traces Hari’s own long term experiences of depression and his journey to find answers. From the blurb:

> *He was told that his problems were caused by a chemical imbalance in his brain. As an adult, trained in social sciences, he began to investigate if this was true - and he learned that almost everything we have been told about depression and anxiety is wrong.*

---

[34] Sarah Wilson, ‘First, We Make The Beast Beautiful: A new story about anxiety’ (Pan Macmillan Australia, 2018).
[35] Sarah Wilson, ‘First, We Make The Beast Beautiful: A new story about anxiety’ (Pan Macmillan Australia, 2018).
[36] Johann Hari, ‘*Chasing the Scream’* (Bloomsbury Publishing, 2015).
[37] Johann Hari, ‘*Lost Connections’* (Bloomsbury Publishing, 2018).

164 The book has won glowing endorsements from people from Hillary Clinton and Elton John to Tucker Carlon of Fox News. Pulitzer Prize winning journalist Glenn Greenwald says of the book:

> *"Johann Hari follows his ground-breaking and revolutionary book on addiction with an equally vital, compelling and eye-opening examination of the myths we have been taught to believe about depression and anxiety. With this book that brilliantly interweaves science, philosophy and searing personal experience, and which methodically dissects the truth around mental health, Hari again proves that he is one of the world's most important and most enlightening thinkers and social critics."* [38]

165 Engagement with the public on these issues is already happening, we just need to bring people in.

166 In Australia I also look to examples like The Big Anxiety[39], a mental health arts festival that is a world-leading example of how we can make that space for people to ask these big questions. The Big Anxiety festival is a great coming together, bringing together "artists, scientists and communities to question and re-imagine the state of mental health in the 21st century and create the conditions for social change." Much of the programming is led by people with lived experience, but it also brings in clinicians and the general public, in an effort not towards treatment, but inquiry into what it all means. This is consciousness-raising in practice, and transforms mental health from its current stance as a dull or tragic topic, into something that reflects our humanity, history and culture.

167 My hope is that the Commission's work will mean that one day, perhaps decades from now, there will not be just a handful of examples at my fingertips, but too many to name. And that young Victorians like I was, when faced with psychological distress, will know of countless places they can go to meet people like them, work out who they are, and know for sure that what they need is to be treated with respect, love and humanity, and they won't settle for anything less.

Challenges with embedding peer support in the mental health system

168 One of the key difficulties in embedding peer support in mental health is that the dominant paradigm often does not understand the need or desire for an alternative.

169 Years ago I sat in on a planning meeting for a youth mental health service looking to add peer support to its suite of service offerings. It was a meeting almost exclusively of clinical workers. I was one of only two people who had done any type of peer work at the meeting, the other peer worker was relatively new to it.

---

[38] Johann Hari, '*Lost Connections*' (Bloomsbury Publishing, 2018).

[39] The Big Anxiety <https://www.thebiganxiety.org/>.

170 It was clear that the clinicians at the meeting thought that peer work was a good idea, but they had very little grasp of *why* it was a good idea. How they seemed to see peer work in their service was as a nice casual job for young people with mental illness to do while they were at university to build up their confidence. They in no way saw it as a discipline, or connected to a history and movement of people looking for social change.

171 This was reinforced also in the services I worked in, where other staff seemed very positive about bringing in peer workers (even though some requested that they be notified each time peer workers were onsite as they didn't want peer workers overhearing their conversations), yet they struggled to explain to service users or each other what peer workers did or what their value might bring.

172 Having worked in peer support, trained many peer workers, as well as their managers and directors of services, and been involved in helping services set up peer work programs, there is often a fundamental lack of understanding from clinical staff about the value of peer support.

173 In youth services, peer work is considered to be a nice job on the side while you're at university. In adult services it is considered a nice job to give someone who's down on their luck.

174 When I facilitate training in Intentional Peer Support with managers and clinicians, one of the common responses is that they realise they have totally underestimated the complexity of peer work as a profession. Many relay that it is much more sophisticated than they thought, containing ideas and approaches in some ways similar to aspects of their clinical training.

175 This lack of understanding of peer work is a fundamental challenge that stymies all efforts to build peer work as a discipline of its own, and to keep fidelity to the value of peer support when it is incorporated, often as an 'add-on', to clinical services.

176 When I was a peer worker one of the main challenges was that whilst my fellow clinically trained colleagues were on board with peer work, access to peer workers was gate-kept, with referrals to peer support having to come through clinicians. And whilst there was support from clinicians, they also found they struggled to know how to explain peer support to clients, and thus referrals initially were very slow.

177 It is very hard to build a genuine alternative inside of clinical services who do not understand the value or need of peer support, often with peer workers who may themselves not be connected to the value or rich history of peer support (like myself when I began).

178 This is even more the case when we consider that peer workers are often thought of or set up not to just provide support services, but to shift the culture of clinical services. Anyone who's been involved in any kind of workforce culture change programs will know how difficult moving the needle in this way is. And yet, we often expect this task to be done by some of the lowest paid, least supported, and least trained staff in the mental health system.

179 For peer support to become a significant feature in the new mental health system, including many consumers' hope that it be offered as a genuine alternative through peer-run organisations throughout the system, we need to resource it with the same structures of support that sit behind other disciplines.

180 This would look like a professional college like in other disciplines (for example the Australian Psychological Society, or Australian Medical Association) that is peer-run and supports:

(a) professional development, networking and training opportunities for peer workers, including developing and rolling-out new curricula and organisational readiness programs for services. The Commission can look to the Yale Program for Recovery and Community Health (Yale-PRCH) as an exemplar of this. They have developed in partnership the LET(s)LEAD program to skill up consumer leaders, and the programs and tools to support organisations to embed peer work and recovery-orientated practice; and

(b) advocates for peer work, including conducting or partnering on research that underpins the profession (again, like what is happening at Yale-PRCH).

181 One risk that is prevalent for peer work is the 'co-optation' of peer support. This can happen unintentionally, as in the situation I've described above when clinical services tried to set up a peer work program without understanding the discipline. This happens when services want to engage peer workers but don't have a comprehensive understanding of the role, value or history of peer support. This is why there needs to be a stable consumer-led 'home' for peer support in Victoria, or we risk setting up peer work to fail at scale. Given how emergent the field is, this would be dire for the discipline as a whole if it were set up without the foundations in place to ensure its success.

14 September 2020

Royal Commission into
Victoria's Mental Health System

ATTACHMENT HE-1

This is the attachment marked 'HE-1' referred to in the witness statement of Honor Eastly dated 14 September 2020.

Honor Eastly – Curriculum Vitae

I am a Melbourne based lived experience worker, and trainer.

I'm interested in how we can use the wisdom of people with lived experience to design better services, and tell better stories.

I work with Redpanther, a consultancy that uses the hard-won wisdom people gain from difficult life experience to design better services. Through Redpanther I have consulted with NGOs and governments, from aspects of the system ranging from the role of advocacy in mental health tribunal settings, to assisting PHNs to commission to the stepped-care model of reform.

I am also a national trainer in Intentional Peer Support, and in 2016-2017 I was a lead trainer and supervisor for the DHHS Expanding Post Discharge Support program, a program that saw peer workers placed in acute settings across Victoria.

Alongside this I was also a member of one of the first youth peer support teams through headspace, and on the inaugural Youth Advisory Committee for Orygen, the National Centre for Excellence in Youth Mental Health.

In 2017, along with Graham Panther I co-founded the Big Feels Club, a grassroots peer support initiative. We've had over 1 million downloads of our content since 2018, and close to 6,000 people sign up to our online community, from across Australia and beyond. It's real content about mental health, made by people who've been there too.

My background is also in arts and media, having created several critically-acclaimed podcasts. Most recently I was selected from over 1200 pitches to make the *No Feeling Is Final* podcast with the ABC, chronicling my experiences of suicidality. The series was launched to critical acclaim, debuting at #4 on iTunes, winning the coveted Third Coast / Richard H. Driehaus Foundation Competition, and being named one of the best podcasts of 2018 by multiple international publications including The Atlantic and TIME. It has been seen by many in mental health as an incisive example of how lived experience can be used ethically and authentically, to reflect necessary changes, and influence wider public discourse.