Royal Commission into Victoria's Mental Health System

WITNESS STATEMENT OF GRAHAM PANTHER

I, Graham Panther, co-founder of the Big Feels Club 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, my experience running the Big Feels Club, and my own first-hand experience of profound distress.

Background

3 I am the co-founder of the Big Feels Club, which I co-founded with Honor Eastly in July 2017. I describe the Big Feels Club below.

4 I am also:

(a) an independent consultant in the mental health sector, operating under the brand Redpanther, providing program evaluation, community consultation, and service design for the mental health sector. I have held this role since January 2011; and

(b) I consult to government and non-profits across Australia and New Zealand on the mental health system. In Victoria, examples of my past and present clients include Eastern Melbourne Primary Health Network, Mind Australia, Victoria Legal Aid, Banyule Community Health, and the Department of Health and Human Services (**DHHS**).

5 In all my work, I draw on my own personal experience of profound psychological distress, and my experiences using mental health services.

6 Prior to my current roles, I worked at Mind and Body Consultants in New Zealand. Between 2006 and 2010 I worked in a range of roles including as a peer support worker for two years, and as Senior Management Liaison focused primarily on the Like Minds, Like Mine initiative, New Zealand's national anti-discrimination campaign. Upon arrival in Australia I worked at Mind Australia between 2013 and 2015, as the Co-production Lead establishing Mind's Victoria-wide Recovery College.

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

7 Attached to this statement and marked 'GP-1' is a copy of my curriculum vitae.

The Big Feels Club

What the Big Feels Club is and why it was created

8 The Big Feels Club is a grassroots peer support initiative. It's somewhere you can go to hear from other people who, like you, are struggling with big, scary feelings. Real content about mental health, made by people who've been there.

9 Our podcasts and articles about life with 'big feelings' have been downloaded over a million times since 2018, and almost 6,000 people have signed up to our core online community. Most of these 6,000 people are located in Victoria. In addition to online content made by and for people with 'big feelings', we have also run real-life meet-ups – in Melbourne and in Sydney – and online discussion spaces. A single meet-up is typically attended by somewhere between 40 and 80 community members.

10 The Big Feels Club is partly funded by philanthropic investment from private donors, as well as through regular user donations.

11 My co-founder Honor Eastly and I created the Big Feels Club to offer support to people experiencing psychological distress – what we call 'big feelings'. Specifically, we wanted to create the thing we each wished already existed for ourselves when we were at our most desperate.

12 Both Honor and I have experienced profound periods of psychological distress and despair in our lives. Each of us spent years trying the typical forms of help – psychiatry, psychology, and psychiatric medications – but found they were often less helpful than we had hoped they would be.

13 Each of us also found it a very lonely experience – convinced we were the only ones who found life this hard for no particular reason. True positive change only began when we started to find other people like us, people who had gone through similar experiences. In short, peer support – or as we call it, 'finding your tribe'.

14 We also both worked in the mental health system – Honor as a peer support worker and advocate, and me as a consultant. We saw how lucky we were to have found 'our tribe' of other people going through similar things.

15 For so many Australians experiencing psychological distress, you can go for years 'asking for help' and only ever talk to mental health professionals who either do not have the same experiences as you, or – if they do – aren't allowed to tell you. It's a

recipe for feeling even more alone than when you started looking for help in the first place.

16 Honor and I thought *"Why isn't there a place you can go when you're having a hard time, to hear from other people who've gone through similar stuff? Somewhere you can feel like you belong on earth, even when you feel shit".* So we started the Big Feels Club to make something for ourselves, and it turned out that there are a lot people like us.

17 We explain the Big Feels Club in the following way:

> *If you've ever been struggling with your mental health, you've definitely heard these four words. "Just ask for help." But what if you've been asking for help for years, and the help hasn't helped?*

18 One in two cases of anxiety and depression will last for multiple years, even if you're doing all the right things. But the thing is, no one tells you that. So if that's you out there struggling, you start to think: *'I must just be really screwed up.'* Over time, this can leave you feeling really, really stuck.

19 The only way forward is to do the slow, tedious work of looking after yourself, but it's so hard to keep it up every, damn, day – especially when you're convinced you're the only one who finds life this hard. We made the Big Feels Club to show people they're not alone, to remind them they still belong on earth, even when life is really hard.

20 We also started the Big Feels Club to show the mental health system what is possible. I have helped set up and evaluate dozens of peer services across Australia and New Zealand, but here in Australia, they are almost always subsumed in clinical settings, where peers are generally not in charge of policy and budget decisions. There are very few examples of truly peer-led organisations, compared to New Zealand where we have had prominent peer-run not-for-profits for more than two decades, such as Mind and Body Consultants (who, when I worked there, held multiple sizeable service contracts across multiple cities, all managed, conceived and delivered by people with first-hand lived experience).

21 As a peer-run organisation, the Big Feels Club is notably different to even the peer services I have helped set up in Victoria, right down to the language we use to talk about the experience of 'big feelings', as well as our methods for engaging our user base. I think these differences are key to the astounding community impact we have seen with the Big Feels Club, which I describe below.

22 More broadly, I don't think peer-led organisations can be understood until you see them in action. Below, I outline why peer-led organisations are such a desperately needed addition to the larger service system if we are to truly offer people what they need when

they are struggling with their mental health. I outline what I think Victoria needs in this regard below.

Who the Big Feels Club supports and the impact we are seeing

23 The Big Feels Club is primarily for the many people who don't see significant improvements in their wellbeing in the first one or two years of seeking help. We call them 'sensitive cats' – people who, for whatever reason, are sad or scared much of the time, and have never found the usual labels (e.g. depression, anxiety) entirely comforting.

24 Our typical users are women aged mid-20s to early 40s, many of whom experience significant periods of distress and despair, but who nonetheless manage to continue working, often by pretending things are okay. This piece of feedback from one member sums it up*: 'My life looks good on paper, but I feel like a total fucking failure, all the time, and I have no idea why.'*

25 Our club members have typically been asking for help for years. Most of our members are in therapy or have tried it before, with mixed results. We don't ask about people's diagnosis or quantify their experiences in terms severity, but user feedback suggests a significant portion of our users have experiences of feeling so hopeless they are considering ending their life, as well as experiences of hospitalisation.

26 Our club members describe a range of experiences that mainstream services might call depression, anxiety, obsessive thinking, altered states, and grief. In our community, all these experiences fall under the broad rubric of 'big feelings'.

27 Users typically find us from Googling 'what to do when you've ruined your life' or similar, rather than specific mental health language.

28 Our work has broad appeal, but the core user-base seems to be those people who – like Honor and I – have been 'down the rabbit-hole' multiple times. People who have had multiple periods of months or years of experiencing profound psychological distress and being convinced that they are a lost cause. These are the people for whom the usual advice, 'just ask for help', rings hollow, because they've already done that multiple times. These are the people who, despite years of asking for and even receiving high quality help, still feel like shit much of the time, and – through lack of contact with people like them – have started to think the problem lies in them.

29 I present here examples of the many, many messages we receive about the value of our club – in the words of our club members. I present this feedback both as an indication of the impact of the Big Feels Club, and to help outline the gap in the service system that we are attempting to fill.

30 By far the most common piece of feedback we receive is summed up in this user quote:

> *"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*

31 This theme of having 'given up' is a common one. It seems people find our offerings when they least expect to find something that will finally help, as this quote further outlines:

> *"It's so unexpected to hear that not only may my big feelings be OK, but that I may be OK too." – Big Feels Club member*

32 Countless messages from users suggest our offering is something new, something they'd been looking for but couldn't find despite asking for help through the usual channels:

> *"No mental health services are offering spaces like this." – Big Feels Club member*
>
> *"This is friggin' great! I've been looking at all the services lately and thinking, if only there was a place to talk to others that have lived this." – Big Feels Club member*
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> *"Big Feels Club is empowering people to discuss mental illness without stigma. It's a conversation, without having to have a 'result' or 'diagnosis' at the end of it. The point is discussion, expression, new ideas. There isn't a program like this anywhere else." – Big Feels Club member*
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> *"It's people with lived experience nurturing and really helping people with lived experience. No outsiders. Just us drawing on one another's strengths." – Big Feels Club member*
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> *"100% this is so needed. At the height of my illness I was in desperate need of connection to real people who were in the same shoes." – Big Feels Club member*
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> *"The Big Feels Club is the only forum where I have truly felt part of a community of people willing to share their experiences and support each other." – Big Feels Club member*
>
> *"Thank you for doing the work that you do and being real people. I find connecting with you has gone a long way in making my life feel less complicated and that while the big budget MH services fail on so many levels to listen to us normal folk, you listen and you feel for us." – Big Feels Club member*

33 I find it remarkable that something as simple as peer support – the deeply human need to feel less alone in life's struggles – is still so hard to find in the mental health space. As New Zealand comedian and mental health advocate Mike King says, scary thoughts and feelings won't kill you, but thinking you're the only one who has those scary thoughts and feelings? That's the killer.[1]

34 Feedback from our users underlines just how profoundly important it is to feel seen and understood through this experience:

> *"The Big Feels Club was a profound part of my own experience of clawing for life. And it continues to sustain me through current struggles. You guys are like vulnerability super heroes." – Big Feels Club member*
>
> *"You know when you don't realise that something beautiful and strange and important is missing from your life until you fall right on into it? The Big Feels Club is a unique little community where scary feelings aren't so scary and where loneliness isn't so lonely." – Big Feels Club member*

35 Some Big Feels Club members also report significant life changes which they attribute to their engagement with our content. This story of one Big Feels Club member in her mid-30s exemplifies this:

36 She'd always struggled with depression, from as far back as she could remember, but she had never told anyone close to her. She'd seen a GP and tried medications, but that was it. It was a private pain, hers to bear, not share.

37 In the 12 months after first engaging with the Big Feels Club's content, she'd opened up to her mum about it, and got a great response. She'd told her sister, and found out they both struggled with similar things. And she'd started seeing a therapist weekly, through a free program she was lucky enough to access through work.

38 We asked her what had prompted this incredible change in such a short period of time. She said it was something incredibly simple: signing up to our email newsletter. She'd read a piece about "the Long, Slow-Twisting Shame Spiral" and it had sparked something.

39 For her, the word "depression" had always been too heavy. "Who am I to be depressed?" she thought. There was no way she could imagine ever saying to her family, "I'm depressed." But she could tell them about her "Long, Slow-Twisting Shame

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[1] Mike King, 'My comedy has been a mask my whole life' <https://www.bbc.com/news/av/health-44256560/comedian-mike-king-my-comedy-has-been-a-mask-my-whole-life>.

Spiral". That was different. She said we gave her a new language for her experiences, which in turn meant she could communicate what had previously felt unspeakable.

40 We regularly hear people say 'this newsletter came at just the right time', or 'how are you in my head??' This is the power of peer support in action. We know, because we've been there.

> *"Thankyou. Just thankyou. Without even knowing what I needed, I needed this email today. Right now. This second. And because of it, I feel understood, I feel less alone. I feel less desperate. I can get through this day, when I really didn't think I would. Thankyou." – Big Feels Club member*

41 Other times, people will stumble on an old newsletter in their inbox, just when they need it. One man told us he doesn't read them all, but knowing they are there feels like a 'safety net' when he needs to.

Why it works: the power of peer support

42 'It's like you're in my head'. I think this is a key aspect of the value people get from our offering. We know because we've been there too.

43 There are many, well-funded programs and campaigns that aim to 'raise awareness' or 'reduce the stigma' of psychological distress. But so often, these campaigns and programs are not run by people like us, and it shows. They often use the language of the system – a language of deficits and disorder that, to many of us, feels like a laundry list of our worst traits, rather than a description of our rich internal experience.

44 Crucially, whatever language they may use, mainstream campaigns like this almost always pretend there's a simple answer – 'just reach out', 'go see your GP'. They trumpet the simple story of mental health: 'ask for help, get help, feel better'.

45 The simple story of mental health is everywhere. 'It's just like a broken leg in your brain'; 'just reach out, just ask for help'. To be clear, this is a vast improvement on where we once were – sweeping big feelings under the rug, seeing them as a sign of moral failure. But all those messages I get in the Big Feels inbox ('I'd given up ever feeling understood') suggest it might be time for another strategy.

46 If you are one of the many Australians who has experienced the not-so-simple story of mental health, who knows what it feels like to be right in the middle of that years-long slog for wellbeing, it can often feel like these well-meaning mental health campaigns are a kind of personal indictment. 'Are you okay?' begins to sound a lot like, 'why aren't you okay yet?'

47 If you're lucky, like I was, you stumble upon other people living the not-so-simple story of mental health. You compare notes, and you start to slowly realise, maybe this isn't just a 'you' problem. You can shrug off these well-meaning oversimplified campaigns.

48 But if you haven't had such luck – like so many of our users before they found the Big Feels Club – then the simple story of mental health is a *dangerous* story. If you've asked for help and you still don't feel better, what you take from the 'just ask for help' story is this: 'well, I must just be really screwed up.' This is a recipe for getting stuck, for years. Sometimes it's a recipe for giving up altogether.

49 Feedback from our users suggests there's a further benefit that comes from the fact the Big Feels Club is peer-led (that is, run by people who've been there too). We become a trusted source. People trust us because we 'get it', but it's more than that. They also trust us because we don't pretend to have the answer. As we say in the Big Feels Club, sometimes 'the answer' is finding other people asking the same big questions.

50 This is one of the great strengths of peer support. For most mental health professionals, there's a great deal of pressure to be the expert, to have the answer, even if you know you're only one tiny part of the solution. In the early days of seeking help, this can be a great comfort – *'finally, someone who'll tell me what to do!'* As the months and years go on however, this can become a source of further alienation. If the usual answers haven't helped all that much – cognitive behaviour therapy (**CBT**), medications – then it can be exhausting to have to explain to friends, family, or well-meaning clinicians why their answer might not be *your* answer.

51 At the Big Feels Club, we position ourselves as fellow travellers, not experts. For some users, the self-help techniques and strategies we suggest are new. For others, they may well have tried them all already and given up, but the fact they are coming from a trusted source means they try them again, and sometimes get different results.

52 A key aspect of this appears to be that we're never adopting the position of an expert, we're never suggesting we have 'the answer'. Instead, we're showing people our own messy process, which they can take inspiration from as they wish.

> *"I never feel like you are preaching anything (I find a lot of mental health things preachy), instead I feel like I am in an open dialogue with another person that feels genuine and insightful." – Big Feels Club member*

53 Here a reader describes finding one of our articles in which I shared a technique from Acceptance and Commitment Therapy (**ACT**) known as 'defusing':

> *"I just wanted to say a much belated thank you for this article. I'm 35 days sober & have been struggling badly with suicidal ideation all day. Have called multiple*

services for help to no avail. Decided to finally read your article on a whim & found your explanation of defusing extremely helpful. Did my own defusing on my panic thoughts & found it very helpful.

Definitely feeling calmer & less lost in the fog of my illness & the negative ruminations I often find myself trapped in. Thank you for your wise words & giving me the help I have been seeking all day. Much appreciated, more than words can say really."

54 Finally, the fact that all our content is produced by people who've been there too can help promote understanding among people who *haven't* been there. We hear from family members of people with big feelings, as well as health professionals, who tell us our work has given them new insights into the people they support. Consider this feedback from someone who had just listened to the podcast we made with the ABC, *No Feeling Is Final*:

"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."

55 We have achieved this impact on a shoestring. The Big Feels Club is two people working part-time on what has, essentially, been a labour of love, supported by occasional small grants as well as crowd-funding from our user-base. For a high-impact digital mental health initiative we are especially frugal. Our overall tech spend since our inception in 2017 is less than $5,000.

Acceptance and change: the gap in the system

56 Here I wish to unpack why, I think, we are seeing such profound impacts from such seemingly simple tools – an email newsletter, a podcast, and occasional meet-ups. I also wish to outline how I think the Big Feels Club is filling a substantial gap in the service system for our users.

57 This gap in the system can best be explained by zooming out.

58 In the past half-century, we've seen an explosion in the range of options our society has to respond to unexplained psychological distress. Very broadly speaking, we can map each of these on a spectrum between two poles: what I'll call the 'change-focused' treatments, and what I'll call the 'acceptance-focused' treatments.

59 Change-focused treatments prioritise changing your behaviour, changing your thought patterns. The underlying claim of change-focused interventions is 'we can fix you, we can make it better.' The clearest example can be seen in the rise of psych drugs as the main tool in a psychiatrist's toolkit. For decades, but particularly since the Prozac generation of the 1990s, the promise of psych drugs is 'we can change your brain chemistry, hopefully for the better.'

60 Acceptance-focused treatments on the other hand say that before you can successfully change, you first need to focus on accepting where you're at. The purest examples of this aren't really 'treatments' at all - they're things like mindfulness practices, which teach you to 'accept and allow' whatever is happening, even when it's desperately uncomfortable. If the goal of antidepressants is usually to alleviate difficult emotions, the goal of mindfulness is to allow more 'space' for those emotions to unfold, uncomfortable as they may be. The explicit goal is not to feel better, rather to get a little more okay with however it is you happen to be feeling. The underlying claim of acceptance-first approaches is something more like 'it's okay to not be okay.'

61 Talking therapies lie somewhere in the middle of this acceptance and change continuum. I'd argue that humanistic psychology lies closer to the acceptance end – the idea that before I can help you with your pain, I first need to witness it, to be present to you and your distress.

62 Then there are what psychiatrist Pat Bracken calls 'the technical therapies' - CBT and dialectical behaviour therapy (**DBT**) in particular – that have risen to prominence in recent decades. Increasingly, we even see the tenets of these therapies built into digital interventions, including a range of 'CBT bots' you can chat with online. A chat-bot may seem an unlikely source of emotional comfort, but the reason it's conceivable is that these therapies are heavily process-driven. Bracken calls them 'technical therapies' because, in theory at least, what matters most in these therapeutic traditions are the techniques they offer you, rather than the practitioner. In other words, as long as the practitioner knows what they're doing, and as long as you follow the correct steps, the therapy is meant to help.

63 In their content, the technical therapies include a mix of both acceptance and change. (This is what the 'D' in DBT refers to, the 'dialectical' relationship between self-acceptance and change.) In practice however, I would argue that the way we deploy these technical therapies in our mental health system places the emphasis very much

on change at the expense of acceptance. In the way these interventions are funded, evaluated, and advertised to users, the focus is very much on the supposed outcomes: less anxiety, less intrusive thoughts, and so on. (We can see a similar dynamic in the way mindfulness is sometimes presented in mental health and wellbeing circles. In these settings it is sometimes seen as primarily a stress-reduction tool, rather than as a way of becoming more intimately acquainted with the specific uncomfortable contours of your busy mind.)

64 Right up at the acceptance-focused end of the spectrum is where I would place peer support. The Big Feels Club is a particular innovative example of peer support – done at scale – but I am also referring here to formal one-to-one or group-based peer work, currently scattered through various parts of our system, as well as informal peer support that occurs between friends who discover a shared experience of distress. As I will unpack later, peer support is not about trying to 'fix' you. This is the subtext of all those messages the Big Feels Club receives: finally, somewhere I can feel like I belong on earth, even when I feel awful.

65 So, why does all this matter? I want to argue that in recent decades we have seen a heavy bias toward the change-focused end of the service continuum, with unintended consequences for people seeking help. I also want to argue that peer support is one large missing piece in balancing our service offerings by offering significantly more acceptance-focused supports to people in distress.

66 From a system perspective, investing in the evidence-based, change-focused end of the continuum surely makes perfect sense. If there's a growing mental health crisis in our midst, let's focus on interventions that claim to fix the problem, and fast, right? It makes sense to prioritise interventions that are outcome-focused, that have a clear goal in mind and easy-to-follow steps to get you there. Take the pills. Learn the techniques.

67 But there's a problem with this solution.

68 Imagine you are the one seeking help. Imagine you have already tried all the change-focused options - the pills, the evidence-based therapy interventions. Imagine that they have sort of helped, and sort of haven't. This is the experience of most of our Big Feels Club community. This was my experience.

69 Again, one in two cases of anxiety and depression will last for multiple years, even if you're doing all the things we tell you to do. So imagine that's you out there, doing all the right things, and still feeling absolutely desperate most days. After a while, how might you begin to feel about yourself?

70 If everyone and everything in your life is focused on 'fixing' you, and you still don't feel any better, you can start to feel like you are the problem. That's an incredibly lonely place to be, and it can leave you feeling really, really stuck. You've reached out, you've asked for help, you've done all the things those bus ads and TV spots tell you to, and you still don't feel any better. What does this say about you?

The hidden cost of asking for help

71 This is the hidden cost of asking for help. The cost to your sense of self.

72 There are the well-known costs of asking for help. There's all that money you can spend just trying to find something, anything that will make you feel better. And then there's the time-cost, the hours and hours it takes to get help in this labyrinthine mental health system - ringing around services to find available supports you are actually eligible for, wrangling insurance and GP referrals.

73 But no one ever talks about addressing the hidden cost. The cost to your sense of self. A devastating, sometimes life-long cost that most mental health practitioners and policy-makers don't even seem to notice.

74 Getting anywhere in this health system means taking on the language of that system. A language of deficits and disorders. After a while it can be hard to hear yourself think, or to think of yourself as more than just a set of symptoms. I had a particularly extreme example of this, when at age 23 my psychiatrist told me I had 'brain damage, probably irreversible', based on nothing more than the model he was taught: that unexplained psychological distress are best understood as signs of damage and disorder.

75 But it can be more subtle than that, like the Big Feels Club member described in paragraph 35 who never sought help beyond her GP, because the label 'depression' seemed too 'heavy' for her. I feel the same way every year, when I go to get my mental health plan, and have to do the dreaded Depression Anxiety Stress Scale (**DASS**) questionnaire. Almost without fail, I score as 'severely depressed' – even when things are going relatively okay for me. Every year I leave the GP's office with the term 'severely depressed' rattling around my head for days after. This has an impact.

76 If you've ever tried to get help in this mental health system, you've had to do a DASS – probably many of them, in fact. There's no room on that DASS questionnaire for all the work you've been doing, all the hard yards looking after yourself and pushing yourself even when life is really tough. Like so many things in this system, it's all about what's wrong with you – even when you're right there, in that doctor's office, doing the very thing you need to do to look after yourself.

77 This would be a reasonable trade off, if the GP actually had an easy fix to offer you, but for many of us, they don't. If the pills don't help, and if the therapy is at-best a slow-burn, then that yearly mental health plan is just your yearly reminder that your way of being in the world is considered sick and disordered.

78 Again, this has an impact. If you are already prone to self-judgement and doubt, if you are already feeling cut-off from the rest of the world for being the way you are, these micro-moments add up. They reinforce that idea, again and again: you shouldn't feel the way you do. You shouldn't be like this.

79 This is why the acceptance-focused approaches are so important. They balance out all that well-meaning, change-focused advice. They offer a space in which to keep working on yourself without falling down that rabbit-hole of judging yourself for not feeling better yet.

80 So how do you actually do that? Peer support is a perfect example of a practical, acceptance-focused offering.

81 Your peer support worker may be the one person in your life who is not trying to 'fix' you. This is so important. If you've spent years on the change-focused treadmill, feeling more and more like a problem, consider the value of finding others like you, people who aren't 'fixed', and yet are getting on and living their lives.

82 Peer support may not offer an easy 'fix', but that's the whole point. Instead, your peers offer a nourishing space in which you can start to unpack a very important question: 'what if my big, scary feelings aren't a problem? What if they are just part of the human experience?'

83 When my psychiatrist told me he thought my experiences of distress were a sign of life-long brain damage, I came very close to feeling like life was not worth living anymore. Thank god I eventually found a second opinion. But it didn't come from within the health system – well, not exactly.

84 At 23, during one of my deepest and longest-lasting periods of distress, I made an abrupt career change, taking a job as a peer support worker in one of New Zealand's first professional peer services. This organisation, Mind and Body, was a peer-led organisation. I was part of one of the first professional peer services in the country.

85 So when I applied for this peer support role, the main qualification they were looking for was that I'd had my own messy life experiences to draw on. I couldn't believe my luck. I had that in spades. At Mind and Body, everyone who worked there had their own experience of using mental health services. The admin staff, the HR team, the managers, the cleaners. Everyone.

86 On day one of our training, Co-Founder and CEO Jim Burdett told us some of his own story. A philosophy-major-turned-successful-businessman, he'd had a breakdown that led to a rude awakening about the way our society responds to crisis and distress. He found himself caught up in a system that had no interest in the intelligence and resources he was bringing to the task of getting well again. To them he was just another broken burnout who wasn't very good at taking direction.

87 I was floored. I'd spent the past year dissecting the minutiae of my bewildering brain with psychiatrists, psychologists, and neurologists, feeling more and more like some kind of exotic bug in a glass jar. I'd spent years before that hiding my differences from friends, from colleagues, thinking I was the only one who struggled like I did. Suddenly here was a hive of people who not only knew what it was like to feel completely blown apart all the time, but who were smart and fun. People who were literally paid to be sensitive souls.

88 I'd finally found my tribe.

89 This radical little mental health agency turned out to be the single most nourishing place to have an ongoing nervous breakdown. I was still struggling day-to-day with my own mental health, that didn't magically change. But each day at work I was surrounded by others who simply 'got it', people who hadn't found 'the answer' yet either, but were getting on with their lives just fine, wobbles and all.

90 I remember one of the managers hitting a rough patch and taking extended leave. We'd visit her in the psych ward, when we were there seeing clients. The personal and the professional, intertwined.

91 In our work with clients, we never claimed to be any kind of experts, we never claimed to have 'the answer'. We were simply fellow travellers, people who knew what it was like to lose yourself completely, and could share what we'd learned along the way.

92 Again, sometimes 'the answer' is finding other people asking the same big questions.

93 It all had a profound effect on me. Through both my clients and my colleagues, I got to meet all sorts of people who'd been to hell and back and lived to tell the tale. I got to see how what I'd learned from my own hard times could be shared to the benefit of others. I got to try out a different 'life role' to the one I'd been stuck in for some time. Instead of the 'screw up' or the 'brain damaged one', I was becoming something else. A work-in-progress, for sure, but someone with some hard-won wisdom, at a young age.

94 It didn't hurt that this work also offered me a chance to make use of what I'd learned from my tough life experiences - to give people the help I wished I'd found sooner, to

help them find their tribe too. I was good at this work, partly because of the hard times I had experienced.

95 Maybe I didn't get the encouragement I was looking for from my psychiatrist, but I'd finally found people who did get it. As one colleague put it when I told her about my experience with my psychiatrist: 'if that's brain damage, give me some!' The strongest words of encouragement I'd ever heard.

96 This is why we made the Big Feels Club. Peer support is available in our system, but in Australia it remains extremely hard to find, and it's usually the last thing you are offered, once you have tried all the 'change-focused' options. In other words, you only get offered peer support once you've already paid that hidden cost of asking for help, once you've become very well acquainted with the idea that there is something wrong with you for feeling the way you do.

97 This is also why I think peer support needs a much larger role in our service system. Peer support is the acceptance-focused form of support we are missing.

98 The point is not that we need an acceptance-focused approach instead of a change-focused approach. The point is we need both. If you only focus on the 'fix', you feel more and more like a problem. Your view of yourself becomes more and more limited, your world becomes smaller, and you start to believe that's just how it is for people like you. On the other hand, if you only focus on acceptance, you may never identify the things you could conceivably change for the better. We need both approaches, working together.

The state of peer support in Australia

99 In the past two decades, peer support services (where the staff are people who are employed partly because they have used services themselves) have steadily grown in Australia, New Zealand, and around the world. They're now an established part of the workforce, with an emerging evidence base showing they're cheaper and at least as effective as more mainstream mental health supports.

100 I've helped set up and evaluate dozens of peer support services across Australia and New Zealand - staffed by people who've been to the scarier, more exotic parts of their own minds. Sometimes these people have worked in mental health before, but often it's their first job in this space.

101 When it's done right, the story of these services is always the same. Service users report off-the-charts life-changing outcomes. They say things like, 'I spent years getting nowhere in the mental health system, and then I found peer support.'

102 I remember one woman in particular trying to describe the complete transformation she'd experienced after just a few weeks with a peer support worker. This woman went from never leaving her house, having every window and curtain shut, to being 'never home anymore', always out working, volunteering, connecting with her community, doors and windows open to the world. This woman described her life before peer support as 'like having a dragon at the front door', stopping her from ever leaving. 'I don't know what she did, or how she did it', she told me in incredulous tones, when I asked why the peer support worker was so effective. 'It was almost like she'd waved a wand and just made it happen.'

103 In many instances, that magic wand appears to be a combination of two pretty simple things. First, there's the fact that this person has been through something similar to you - they 'get it'. Let's say you've spent years asking for help, having to open the 'Pandora's box' and tell your story time and again to each new professional you meet. Peer support offers a short-cut of sorts. There's a shared language, and a high level of trust that often develops very quickly - even for service users who've been given plenty of reasons to mistrust mental health workers in the past.

104 The second part of the 'magic' of peer support is this: unlike most other disciplines, peer support doesn't have an agenda. A peer worker doesn't claim to be able to explain what you're going through - the way a psychiatrist might, for instance, through a theory about what's happening in your brain.

105 If you're deep in the system, at that 'really stuck' point, you might be surrounded by all kinds of professional helpers. A psychiatrist, a psychologist, a nurse, not to mention family members who may - understandably - be just as desperate as you are for some kind of once-and-for-all answer.

106 Instead of an explanation, or an answer, a peer worker primarily offers understanding, which is subtly different. They know what it's like to *not* have an answer, to sit with the discomfort of not knowing what you are supposed to do next. Simply being around this kind of energy can be surprisingly encouraging.

107 Just like I experienced in my time working at Mind and Body, peer support offers you the chance to try out a different role. Instead of 'the screw up' or 'the one who needs fixing', with your peers you are simply a fellow traveller, perhaps even someone who has learned a thing or two from all that pain and suffering.

108 Like the woman with the dragon at her front door, trying out that new role can open up new possibilities you thought someone like you would never have, like going out into the world again. There's the curious paradox. Real acceptance of how you are right now can lead to real change.

109 And the benefits of peer support go beyond service users. For the peer workers themselves, the work can be a profound part of their own recovery - just as it was for me. They have a chance to see their messiest, most shameful life experiences in a new light - as a resource that can help others.

110 Yet this life-changing resource remains largely hidden, gate-kept. In most instances, you can access peer support only once you've first tried all the more expensive offerings – the psychiatrist, the nurse.

111 Beyond the mental health system, most people have still never even heard of peer support, the thing that not only saved my life, but helped make it worth living again.

112 I don't think this is just a marketing problem. Peer support is an intuitive concept for most people to grasp. We see examples of it all around us in other settings - coffee groups for new mums, meet-ups for people battling cancer, Alcoholics Anonymous. Even within mental health, individual workers recognise the value of peer support for themselves in a professional sense, through mentoring and supervision relationships with other workers with the same role as them.

113 Peer support remains buried, patchily funded, and often considered a 'nice add-on' to the system, rather than a core offering.

114 Moving to Australia in 2013, I soon realised how much of anomaly my experience at Mind and Body was. New Zealand has had multiple peer-run mental health agencies, and prominent leaders with disclosed lived experience, like Mary O'Hagan, Mental Health Commissioner in the early 2000s. By contrast, in Australia then and now, peer workers are still often working in clinical settings, where their manager and most of their colleagues are clinicians, and even their position descriptions and training is often based on what's worked for clinical roles.

115 In a number of evaluations, I've heard from peer workers who say they feel they are expected to be 'mini-clinicians'. This includes peer support workers being asked to do decidedly non-peer things like monitor people's adherence to medications. (That 'change-focus', again. It's bedded in deep.)

116 There are a number of fantastic peer workers doing their best in Australia's mental health sector, but it's a tough gig, and at every step there are pressures to move away from the no-agenda, acceptance-first mode that makes peer support so valuable. If the KPIs for your role are designed for clinicians, your manager is a clinician, and most if not all of your colleagues are clinicians, it's very hard to resist the pull toward the 'change-focused' approach the rest of the system prizes so highly.

117 I've met many peer support workers in my evaluations. What I typically see is this: most peer workers resist the pressures to become 'mini-clinicians', as long as they can. They offer their clients the closest thing to true, acceptance-focused peer support as is possible in a clinical setting. Then, often, they get burnt out on the pressure of it all. Some leave altogether, so the role never really gets a chance to bed itself in.

118 There are definitely success stories too, places where it goes the other way and the presence of peer workers helps shift the culture of the organisation to a healthier balance of 'change' and 'acceptance'. These places almost always follow the 'rule of three'. When creating new peer positions, best practice is to create at least three peer roles at the same time, to work alongside each other.

119 The analogy I use for this is that of women entering historically male-dominated professions. If there's only one woman in a workplace, she may be likely to feel quite isolated. If there's two, there's the potential that colleagues will inadvertently play them off against each other. There's the one that 'gets it' and doesn't mind the culture as it is, and there's the one that complains or tries to make waves. Three or more women in a male-dominated workplace can potentially start to shift the culture if needed.

120 It's similar with peer positions. One peer worker alone is isolated. Two is better, but again, the dynamic can easily fall into 'the one that gets it', and 'the one that complains' or tries to avoid becoming a 'mini-clinician'. When there's three, a shift can start to happen. It becomes clearer to all team members that there's no single 'peer' view – that people with lived experience bring a diversity of views and talents to the work – so peers become harder to pigeonhole. And the peers begin to have something like the kind of collegial support that other disciplines often take for granted, which often helps them stay true to their role.

The importance of lived experience leadership

121 The problem is, things at the top haven't changed much, in terms of valuing lived experience in tangible ways. Even as the Australian peer workforce grows in terms of direct support roles, we have not seen the same uptick in executive positions. In other words, those setting the agenda are still mostly clinicians or people without lived experience.

122 There is no Victorian equivalent of Mind and Body we can point to – a large, thriving peer-led organisation operating a range of service contracts that were, until Mind and Body, delivered by mainstream agencies. There is no equivalent of Mary O'Hagan – a Mental Health Commissioner who openly talks about her experience of being in psych hospitals and how those experiences have shaped her views.

123 We have seen a small growth in senior consumer advisory roles in the past decade or so, people with lived experience sitting on leadership boards, but often their influence is largely informal. They don't make the big decisions. Their advice doesn't have to be taken.

124 In New Zealand the lesson of the past twenty years appears clear to me. Real change only happens when you start to see people with first-hand lived experience in positions to make policy and budget decisions. People like Mary O'Hagan, who as Mental Health Commissioner was instrumental in putting both recovery-oriented practice and peer support on the policy map twenty years ago. Jim Burdett, CEO of Mind and Body, and the rest of the Mind and Body executive team, who got to design and deliver a significant, multi-city alternative to more traditional clinical supports, from the ground up.

125 We see this same lack of lived experience leadership in the set up of this Royal Commission. The Commission has, to its credit, sought extensive feedback from people with lived experience throughout each stage of the process. The people making the decisions on what to do with that feedback, however, are not people with disclosed lived experience. To my knowledge, there are no Commissioners with disclosed first-hand lived experience of mental health issues, nor are there any prominent appointments of people with first-hand lived experience in the senior staffing of the Commission.

126 When we systematically exclude user experience in the design and delivery of any system, we invite major blind spots in our decision-making, so it's worth considering how this could have happened.

127 It's not a question of a lack of quality candidates. I can (but won't) name a handful of Victorians with storied CVs and significant relevant experience at the highest levels of system reform, who also happen to have first-hand lived experience of mental health issues. At least one of these people, or others like them, could have been added to the line-up of Commissioners to add an important additional perspective as they collectively undertake the enormous task of making sense of all the data at hand.

128 Indeed, if one in two Australians will experience mental health issues in their lifetime, then there are most certainly any number of well-qualified, talented Victorians in senior positions across the public sector who happen to have lived experience - even accounting for the fact that a small portion of this 'one in two' will have had major set backs in their working career, and are therefore unlikely to have the level of work experience we tend to look for in those leading formal enquiries.

129 Through this lens, there likely are a number of people staffing the Commission who have personal first-hand lived experience. Perhaps they are sharing their personal

insights alongside their professional insights in their work, but if this is not actively invited by employers it's a big ask, so often that simply does not happen.

130 From this perspective, it is difficult to understand the omission of someone with disclosed first-hand lived experience at the decision-making end of this Commission. But in another sense, it's completely understandable. It's a symptom of our current situation.

131 I think the problem is this. We still haven't reached a point where first-hand lived experience of psychological distress is considered an asset in senior professional roles – even within mental health.

132 As part of the Big Feels Club, we currently run a program designed for mental health professionals of all disciplines who happen to have lived experience. These include psychiatrists, psychologists, nurses, and senior managers, many of whom are not 'out' about their lived experience to most of their colleagues; many of whom struggle day-to-day to reconcile their personal experience with the limited, deficit-focused mindset of the system they work in.

133 There is hope here, nonetheless. The Big Feels Club and Mind and Body are two examples of just how much value we can add to the wider service system when people with lived experience lead the development and delivery of offerings for people in distress. Initiatives such as these provide much-needed balance to a mental health system that for years has only offered people half the solution – the change-focused approaches, that for so many of us simply leave us feeling even more lonely and despairing.

134 Beyond this, our engagement with mental health professionals through the Big Feels Club suggests there is a whole pool of talented, hard-working people working in all manner of roles across mental health, with their own lived experience, albeit often undisclosed and untapped.

135 But the wider story is one of service delivery, system design, and reform processes all led by people who either don't have lived experience (or don't disclose that they do). Real change means we need to expand our notion of what it means to be an expert in the field of mental health.

136 The question becomes, what needs to happen to promote lived experience leadership at the highest levels in Victoria's mental health sector? Or put another way, what changes do we need to see in the next decade so that the next time there is a high profile enquiry into mental health in Victoria, it is unthinkable that such an enquiry doesn't include prominent lived experience leadership?

137 As a leader in this space, Victorian government can expedite the growth of lived experience leadership in two main ways. Firstly, they can do what New Zealand did: take a calculated punt on hiring people with first-hand lived experience into prominent positions of real influence. That means positions where they can make decisions on policy and budget.

138 These do not have to be specific 'lived experience' roles, instead lived experience becomes an explicitly named desirable trait of all senior roles – backed up by accountability measures to ensure this isn't just lip service. Mary O'Hagan as a Mental Health Commissioner in New Zealand is an example of how this might look. She wasn't the 'lived experience Commissioner', she was simply one of the Commissioners, but brought both her personal and professional experience to the work, and would speak to both of these aspects of her decision-making.

139 The second immediate way forward I see is for government to invest in developing more and better-resourced peer-led organisations in Victoria. This has to be a proactive undertaking, as it was in New Zealand. It can be an explicit strategy for creating alternative offerings for people seeking support, while at the same time also increasing lived experience leadership in a structural sense. By this I mean, we can't just expect lived experience leadership to flourish in work settings designed and run almost exclusively by people without lived experience. If lived experience expertise is to truly have a voice in shaping the future service system, we need peer-led organisations that advocate for and further develop that expertise, alongside mainstream bodies and agencies.

140 By investing in peer-led organisations, we offer both workers and service users a genuine alternative to the mainstream offerings. We offer a balancing force to the current system, overly focused on change-focused approaches, which comes with a hidden cost for many who seek help. We foster spaces like Mind and Body or the Big Feels Club, in which lived experience leaders can explore new ways of making sense of psychological distress, and pioneer new and innovative ways of supporting people doing it tough.

141 At Mind and Body, we got to re-think what it means to try to help people in crisis. We got to start from scratch – to dig into the policies and procedures and constantly iterate based on what our clients told us they found most useful. Most mainstream services don't get to do this no matter how much co-design and consultation they do, because they are fitting peer support into a pre-existing clinical framework – the 'change-focused' school. Peer workers in Victoria are working in the system. At Mind and Body we were making an alternative to that system, for the benefit of service users.

142 To explain the significance of peer-led organisations, I often use a model developed by a colleague of mine, Nan Wehipeihana. She developed this model to describe stages of Indigenous self-determination.[2] In the New Zealand context, she describes five levels of self-determination, as follows:

(a) Things done to Māori;

(b) Things done for Māori;

(c) Things done with Māori;

(d) Things done by Māori; and

(e) Things done as Māori.

143 At the lowest level of self-determination, policies were done 'to' Māori, with little regard for their impact. At the next level, services were provided 'for' Māori – that is, help was often well-intentioned, but provided in a way that could be paternalistic or have unintended bad consequences. The next level is 'with Māori', referring to policies and services developed through consultation. The fourth level is services provided 'by' Māori, referring to the many Māori-led services in Aotearoa / New Zealand that may be funded by the government but are run by Māori for Māori.

144 Adapting this model to lived experience leadership in mental health, we can see that most mainstream mental health services operate at the third level – things done 'with' people with lived experience, usually via consultation. Virtually no services are run 'by' people with lived experience, and some service provision – such as compulsory treatment – occurs at the second-lowest level of self-determination ('for') or arguably the lowest level ('to') in some instances.

145 Peer-led services offer the chance to see organisations run 'by' people with lived experience. In New Zealand, Mind and Body is an example of this second-highest level of self-determination.

146 The fifth and final level of Wehipeihana's model is that services and supports be run not just 'by Māori ' but 'as Māori'. In the New Zealand setting, examples of this include iwi that have the land and independent resources to develop and spend as they see fit, for the good of their community. It is a greater level of self-determination compared to, say, a Māori-led not-for-profit, because iwi can be self-sufficient, not beholden to government funding and the pakeha-determined rules and KPIs it can come with.

147 In the mental health context, I think the Big Feels Club is an example of a mental health initiative run 'as' people with lived experience, because we do not take on government

[2] N. Wehipeihana. (2013). A Vision for Indigenous Evaluation.

money unless it is very clearly earmarked for innovation, and encourages us to develop our own metrics of success in partnership with our service users.

148 Perhaps this last level of self-determination is difficult to achieve within the system, but I would argue that we can still load the dice for more organisations like the Big Feels Club to appear, in two ways.

149 Firstly, we can recognise the unique value that initiatives like the Big Feels Club bring to the community, and prioritise more ways of funding them with flexible grants (e.g. innovation grants) that explicitly seek out peer-run ventures. This includes more flexible ways of funding initiatives that don't neatly fit into a pre-determined box. We are neither a service in a traditional sense, nor are we just doing health promotion – we're a hybrid, which has been a barrier in the past, for example PHNs interested in funding what we do.

150 It may be useful here to include a tangible example of how an initiative like the Big Feels Club departs from business as usual. Unlike many mental health initiatives, at the Big Feels Club we have no interest in asking or ascertaining our users' level of 'severity' of distress, or their diagnoses, despite regularly surveying our user base to better understand their needs and experience. We avoid asking about severity or diagnosis not only because such questions can be painful to be asked again and again when you are seeking help and connection, but because we fundamentally do not think in these terms. Indeed, we understand that for many of our users, the language of mental health has itself been a barrier to them accepting their experiences. I present this simply as an example of how an initiative run 'as' people with lived experience can look quite different to a mainstream service, sometimes in subtle ways that nonetheless massively impact the user experience.

151 There is a second way that we can load the dice for more initiatives like the Big Feels Club, run 'as' people with lived experience. I would argue that having more peer-led organisations – services run 'by' us – can help support the development of services run 'as' us, over time. As a practical example, the Big Feels Club is auspiced by Self Help Addiction Resource Centre (**SHARC**), an organisation with significant peer leadership at the top ranks (see paragraph 156.)

152 To have a lasting impact on the overall service system mix, any investment in peer-led organisations needs to move beyond the environment of funding scarcity and precarity that defines mental health right now, but has especially defined the peer-led space since it first gained any kind of recognition from the mainstream.

153 Victorian Mental Illness Awareness Council (**VMIAC**) is the peak organisation for people with a lived experience of mental health problems or emotional distress. Within the

system, VMIAC is structurally positioned as the single peer-led organisation in the state (a difficult position from the outset) but its annual funding is a fraction of any of the mainstream mental health organisations that continue to define the space. VMIAC do what they can with this funding, as grassroots community organisations do so well, but it is not a recipe for growing the prominence of lived experience leadership. Nor is it a pathway to showing the sector genuine, large-scale alternatives to the existing change-focused approaches that leave so many people feeling under-supported and unseen.

154 In a recent piece of work undertaken by my consultancy, Redpanther, prominent lived experience consultant Gareth Edwards argues that to be truly set up for success, a peer-led organisation in Victoria would ideally have the following attributes:

(a) Funded for an initial period of 10 years;

(b) A peer organisation with lived experience board and staff, contracting other roles as required, e.g. GP, psychiatry, psychology, social work etc;

(c) Decision-making and resource allocation autonomy with flexibility to develop services with other funders and as fee-for-service revenue;

(d) Mandate to promote and advance lived experience and peer work;

(e) Providing peer respite and acute alternative for people who don't want to go to hospital;

(f) Providing tailored self-help resources, programs and digital content delivery;

(g) Self-referred access to unlimited help (in-person, online, phone/text, 1-2-1 and groups) including peer support, service navigation, advocacy and coaching;

(h) A community of engagement and participation for input into mental health, alcohol and drug, suicide prevention and stigma discrimination services;

(i) Partnership with academia to develop the evidence base and best practice; and

(j) Professional development (internal and external) including education, training and supervision and conference, symposium, forum etc., to further develop the knowledge base and visibility of lived experience expertise.

155 To be truly trusted by mainstream organisations, peer-led organisations also need to be supported from the outset to develop their leadership capacity. This includes the capacity to do the complex but vital work of translating acceptance-first, peer-led approaches into a system that is clinical and change-focused.

156 In Victoria there is already an organisation in AOD that would serve both as a shining example of just how this can be done with great success, and could also potentially offer support to budding peer-led organisations in mental health. SHARC in Melbourne

is not explicitly a peer-led organisation, but it features prominent peer leadership throughout its ranks, including CEO Heather Pickard, who was once a client of the service. SHARC auspices the Big Feels Club, providing us with the support on governance we would struggle to find elsewhere.

157 The Big Feels Club had been offered partnerships with prominent mainstream organisations before working with SHARC, but we found our vision and approach to mental health was difficult to reconcile with mainstream clinical frameworks. SHARC helped provide us with the translation piece, to maintain the integrity of our own model while also speaking the language of the system when needed. SHARC excel at this themselves, and because of this are a trusted part of the service network in AOD in Melbourne, partnering with a range of mainstream organisations, while also holding onto their core peer values.

158 Well-funded, well-run peer-run agencies may also stand a better chance of enticing talented people with lived experience who would otherwise never work in the mental health system, further growing lived experience leadership. In Auckland, Mind and Body Consultants became a feeder organisation of sorts, the starting point for many talented people who would otherwise never have worked in mental health, and have since gone on to lead organisations of their own such as Changing Minds, a high-profile, innovative peer-led organisation run by ex-Mind and Body staffer Taimi Allan.

159 Simply put, the Big Feels Club wouldn't exist if Mind and Body Consultants didn't exist, because there is no way I would have ever gone into the field of mental health if not to work at a peer-led organisation. I wouldn't have even considered it, had I not stumbled across this organisation where my big feelings were simply the norm.

160 In Victoria, when we try and attract lived experience workers to the system we tend to do it on the system's terms. We use the system's words such as "consumer roles", "lived experience" and "mental illness". Some people will go through the system, get help and get better, and they will happily identify with those words. But then there are all the other people who go through the system, and who don't get better, grow more and more despairing, and go elsewhere to find an answer.

161 These people may find something like the Big Feels Club and then think of themselves as having big feelings, or join a mindfulness insight mediation and think of themselves as someone on an ongoing journey of self-discovery. There are many frames as there are many ways of making sense of your experience. By and large, these people leave the system and so do not identify as "consumers" or even necessarily as having a "mental illness". When the system tries to capture this talent in those terms, many of these people either never even see the job ad, or they ask themselves, "*Why would I want to go back into a system that doesn't understand my experience?*"

162 I would add to this that I don't think peer-run organisations need to be confined to just service delivery, but can also add value in other parts of the wider system, such as public health. The Big Feels Club is more health promotion than service delivery. Mind and Body Consultants provided not only dozens of direct support workers to New Zealand's health system, it also held contracts as part of New Zealand's nationwide anti-discrimination campaign, *Like Minds, Like Mine*.

163 Likewise, user feedback suggests the Big Feels Club offers something that large mainstream advocacy and awareness-raising organisations do not – something they had found sorely missing. Looking at the impact the Big Feels Club has achieved on the smell of an oily rag, consider the potential impact of peer-led campaigns with even a tenth of the funding of mainstream awareness-raising campaigns.

Requirements to enable initiatives such as the Big Feels Club to be created and thrive

164 There's a simple reason the Big Feels Club is so immensely valuable to our users. It's because we made something we wished already existed for ourselves. That's a rare thing in this system, where so many initiatives are conceived 'for' us, not 'by' us (and certainly not 'as' us).

165 In some ways the Big Feels Club is a perfect storm. My co-founder Honor Eastly and I each bring a very specific mix of professional skills and personal experience that it would be hard to replicate all in one place without a much higher operating budget. Top-flight marketing and content creation skills, knowledge of the mental health system both as professionals and as service users, experience and training in peer roles, and first-hand lived experience and a willingness to talk about it.

166 I will say though, before we started the Big Feels Club, both Honor and I had years of trying to offer these same skills within mainstream mental health organisations, with limited results. In my experience, the mainstream mental health organisations I have worked for have desperately wanted to make use of my skills at engaging people in distress, but haven't necessarily been able to follow through in a meaningful way. Some of the ideas we have successfully implemented through the Big Feels Club, were ideas that I tried to introduce in projects I've worked on in mainstream settings, to no avail.

167 For instance, the notion of moving away from deficit-based language and the medical model is something I had tried to implement on projects with various mainstream organisations. Even the peer models I have worked on – staffed in part by people who don't personally identify with terms such as 'mental illness', and offering people a decidedly non-clinical form of support – have mostly needed to operate using clinical terms such as 'mental illness' or 'mental ill-health'. In one case, the particular program I

was helping establish had a level of funding autonomy (philanthropic) that would have technically allowed us to use non-medical language at every step, but the inertia of the organisation being a mainstream clinically-led organisation meant in practice we did not always have that freedom at the level of service culture.

168 To be fair, I think I personally have learned a lot since leaving mainstream mental health settings and striking out on my own with the Big Feels Club. Nevertheless, I wonder how many talented, hard-working people with lived experience there are working in mainstream settings, who could be working in more innovative and effective ways if they were given the freedom to do so.

169 As is, for much of its existence, the Big Feels Club has largely been a labour of love – sometimes paying the bills, but often done in between our day jobs.

170 The money we've accepted has been money that came with few strings attached – philanthropic donations from private donors who've been personally burned by the limitations of the existing mental health system, along with crowd-funding from our users. This has allowed us to experiment in a way that we could not have if we were funded via health funding.

171 The government funding we have received has been exclusively via innovation funding – specifically in the workforce development space. We received a small consumer workforce innovation grant from DHHS Victoria, followed by an extension on that funding when the COVID-19 crisis hit. In both cases, we were encouraged to develop our own metrics for success in partnership with not only the funder but our users. This flexibility from the funder has been invaluable, especially since – to truly build your offering with your users, you *have* to go into it not knowing what your solution will be. In practical terms, this means keeping deliverables flexible for the early stages of delivery, then reviewing with the funder as the project unfolds.

172 I have found it a very rare thing indeed to find this same level of flexibility with any government funder (for the Big Feels Club, or in my work as a consultant) when it comes to funding initiatives for the community, rather than initiatives for the workforce. Where we currently stand, if the system doesn't change, I can't see many situations where we could realistically accept government funding for the hours and hours of work we do supporting people in distress. This is frustrating to say the least, given the amount of Big Feels Club users telling us how it was our initiative that made all the difference, after years of trying more mainstream offerings.

173 Nonetheless, as a labour of love, the Big Feels Club is always in danger of disappearing. We've been running it for two and a half years, through personal crisis

and multiple levels of burnout. The impact we're seeing is what keeps us going, but in the medium- to long-term, it simply won't survive without more significant investment.

174 Outside of SHARC and DHHS, by far the biggest supports for the Big Feels Club have come from outside the health system altogether, which I think is telling.

175 Firstly, when it comes to funding our community impact, we have found arts funding a more fruitful avenue than health funding. We were chosen to partake in the select-entry Foundry658 Start-Up Accelerator, run by Australian Centre for the Moving Image (**ACMI**) and State Library Victoria, and designed to give art-based businesses a leg up. This program came with a small amount of funding, an office space, and a whole lot of professional development. Specifically, we significantly upped our business skills and product development capacity.

176 The 4-month accelerator is also the period in which we got to spend the most time simply talking to Big Feels Club members and finding out how best we could help them. We spent over 100 hours on the phone in conversation to people from around Australia and the world, hearing about their big feelings, hearing about what they find particularly hard, and what helps.

177 I've helped set up plenty of services, often on co-design principles, yet in a mainstream mental health setting I've never had such a profound opportunity to simply sit and listen to so many people without a clear agenda. I credit this period as the most important part of my career when it comes to really deeply understanding the problems we are trying to solve when it comes to mental health.

178 Finally, the other major support we've had is from the Australian Broadcast Corporation. After being chosen from about 1300 applicants, we partnered with the ABC to create the memoir podcast series, *No Feeling Is Final*, about my partner Honor's experience of crisis and despair. It has been perhaps the single most far-traveling thing we've made. We've received messages from around the world, not to mention a coveted Third Coast Award from the premiere podcast festival in the US (the 'Sundance Festival of podcasts'), and countless 'top five podcasts of the year' accolades from international publications.

179 I remember something Honor said near the end of the production process back in 2018. She said something to the effect of, 'I've worked in mental health for years, and I've never felt this supported to tell my real story'. I found this particularly striking, since Honor's professional experience in mental health was often in explicitly lived experience roles, where 'telling your story' is a key part of the work. Yet it was here at the ABC she felt most supported to do that, in what you would think would be a far more terrifying setting – telling your story to the world.

180 I felt the same way. To me, the difference was that, with the ABC, we were equal partners. They helped us develop the show, and they provided the platform, but they were there to support us to tell the story *we* wanted to tell. They made it their job to understand our worldview, something they took very seriously as they helped steward our story.

181 Likewise, with the start-up accelerator, they made it clear they were here to support our vision for what our business could achieve, and the social impact we wanted to have, on our terms.

182 In my roles in mental health (outside of Mind and Body and the Big Feels Club) it's never felt like that. It's always felt like me – and my lived experience colleagues – doing our best to fit ourselves into a system that doesn't understand us. A system that, often, doesn't even understand that it doesn't understand us.

183 Yet I can't quit mental health. Every time I try to leave, I sense the unfinished business. I read the messages in my inbox telling me that the Big Feels Club is the only reason they're still trying, and I think, surely we can do better than this as a system?

184 In our daily work, I am acutely aware that we are a small fish in a big pond. We have a larger reach than many mental health initiatives with significantly more funding than us. We have an impact that makes the CEO of one of Australia's most prominent awareness-raising organisations tell me, 'you do what we can't do'. But we're just two people.

185 If there are more peer-led organisations in the sector, or organisations like SHARC that clearly embrace the 'acceptance-first' end of the service continuum, we will have more 'natural allies' in the sector – more places we could go for funding or other forms of support, without having to worry about losing the magic of what we do.

186 As is, high profile mainstream mental health organisations tell us they love what we do, and we have turned down at least one offer of formal partnerships with a large mainstream mental health agency precisely because we couldn't see how their clinical approach could work with our peer-led approach in a sustainable way.

187 Larger peer-led organisations provide a kind of translator role here. In New Zealand, peer-led organisations and other organisations with prominent lived experience leadership (like Connect Supporting Recovery) have reached a size where they can partner with clinical organisations and not get swept up in the change-first way of doing things.

188 As just one example of this dynamic in action, I helped evaluate a program in Auckland, where the local funder tendered for an acute alternative respite. No single bid met the

criteria, so they asked two leading bidders to join bids. One was a well-known, relatively conservative clinical service, and the other was an organisation with significant peer leadership at the highest levels. It seemed an unlikely pairing to all involved at the outset, but the partnership was a fruitful one, bringing the best of both worlds.

189 Consider how different this dynamic would have been if instead the funder had done the simple thing, and simply contracted a mainstream organisation on the proviso that they hire some peer workers. The leadership would still have been clinicians, the approach likely the same old thing we've done before. Instead, the peer expertise in that partnership had its own home, its own organisation with its own equal standing. That's what we're missing here in Victoria. That's one thing I think we could get started on right away that would make real and lasting change.

sign here ►

print name Graham Panther

date 6 July 2020

Royal Commission into
Victoria's Mental Health System

ATTACHMENT GP-1

This is the attachment marked 'GP-1' referred to in the witness statement of Graham Panther dated 6 July 2020.

Graham Panther – Curriculum Vitae

Overview

I'm a Melbourne-based consultant with 14 years experience in Australia's and New Zealand's mental health sectors. I started Redpanther in 2011 to combine the best of lived experience consulting and evidence-based service improvement. We use evaluation and design thinking to help government and mental health agencies better understand the communities they serve.

My big thing is peer support. I helped set up **Australia's first Recovery College** and was involved in **New Zealand's first Peer Support Services**. I've evaluated multiple peer services across Australia, and published with the leading international commentators on mental health service design. I believe that when it comes to mental wellbeing, no one has all the answers, so it helps to share what we've learned – whether it's from professional experience, life experience, or both.

I'm also a writer, podcaster, and mental health advocate. I've written a number of articles and podcasts about mental health for **the ABC**. In 2017, along with Honor Eastly, 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.

Recent projects (select examples)

Consulting projects

- Value for Money Evaluation of RaSP AOD Program – Banyule Community Health (2019-2020)
- Evaluation of Mental Health and AOD Peer Support – Banyule Community Health (2018-2019)
- Development of Co-designed Training for Clinicians with Lived Experience: 'Big Feels @ Work' – DHHS (VIC)(2019-2020)
- Evaluation of Gambling Peer Support – Banyule Community Health (2018)
- Evaluation of Peer Support for Beneficiaries Pilot, Ministry of Social Development (NZ)(2018)
- Roadmap for Child and Youth Wellbeing – Central and Eastern Sydney Primary Health Network, with Synergia (2017)
- Design of Primary-led Mental Health System – Eastern Melbourne PHN, with Synergia (2017)
- Model Design: Severe and Enduring Mental Health – Central Eastern Sydney PHN, with Synergia (2017)
- Development of Outcome Measurement Tool for Lower Murray Partners in Recovery (2016-2017)
- Evaluation of Lower Murray Partners in Recovery (2016)
- Evaluation of Eastern Melbourne Partners in Recovery (2016)
- Evaluation of Northern Melbourne Partners in Recovery: Phase II (2016)
- Development of Capital PHN Regional Plan, with Synergia (2016)

- Developmental Evaluation of Peer Work Traineeship Pilot – Geelong (2015-2016)
- Evaluation of Northern Melbourne Partners in Recovery (2015)

The Big Feels Club (2017 – 2020)

- Role: Co-founder
- The Big Feels Club aims to change the way Australians talk about emotional distress and crisis. Real content about mental health, made by people who've been there too.
- This ground-breaking initiative is a working example of how to do great peer support, at scale, on the smell of an oily rag. We've had **over 1 million downloads of our content** since 2018, and **close to 6,000 people** sign up to our online community. Our users tell us we're they're "safety net", and the reason they're finally taking action on their mental health.
- Find out more at https://bigfeels.club

Professional positions held

- 2011 – Present: Director, Redpanther
- 2017 – Present: Co-founder, The Big Feels Club Pty Ltd
- 2016 – 2018: Associate, Synergia Consulting Ltd
- 2013 – 2015: Co-Production Lead, Recovery College, Mind Australia
- 2012 – 2014: Honorary Lecturer, Centre for Mental Health Research, University of Auckland
- 2010 – 2011: Managing Director, Positive Thinking Ltd
- 2006 – 2010: Mind & Body Consultants – Various strategic and operational roles

Select publications

Panther, G., King, J. (2015). Peer Support Themes. *AOD Provider Symposium,* Auckland.

Thom, K., Black., S., and Panther, G. (2015). The Decision-making of the Mental Health Review Tribunal in New Zealand. *Journal of Law and Medicine*. 2015 22 JLM 667.

Slade, C., Amering, M., Farkas, M., Hamilton, B., O'Hagan, M., Panther, G., Perkins, R., Shepherd, G., Tse, S., and Whitley, R. (2014). Uses And Abuses Of Recovery: Implementing recovery-oriented practices in mental health systems. *World Psychiatry* 2014 Feb;13(1):12-20.

Bell., T., Panther, G., and Pollock, S. (2014). Establishing An Effective Peer Workforce. Mind Australia.

Panther, G., and Hardy, D. (2014). 'The Magic of Co-production: Lessons from the establishment of the Mind Recovery College'. *TheMHS Conference Book of Proceedings*.