ROYAL COMMISSION INTO VICTORIA'S MENTAL HEALTH SYSTEM

Melbourne Town Hall, Yarra Room, 90-130 Swanston Street, Melbourne, Victoria

On Wednesday, 3 July 2019 at 10.00am

(Day 2)

- Before: Ms Penny Armytage (Chair) Professor Allan Fels AO Dr Alex Cockram Professor Bernadette McSherry
- Counsel Assisting: Ms Lisa Nichols SC Ms Fiona Batten Ms Georgina Coghlan

1 MS NICHOLS: Good morning, Commissioners. Yesterday we 2 heard some very powerful and eloquent evidence from four 3 witnesses who spoke, among other things, about the impact 4 of stigma on their lives and, although they came from very 5 different walks of life, it was remarkable how they spoke 6 with one voice about the persistence of stigma and on its 7 lasting impact.

9 Today, we will hear from two more consumers, one of 10 whom is Janet Meagher, who will share her experience living 11 with schizophrenia and talk about how she became an 12 international advocate for consumers and has done some very 13 important work in the development of mental health literacy 14 and advocacy.

We will also hear from another consumer, Teresa, who will share the challenges she has faced getting the help she needed and describing her experiences of stigma.

As you know, Commissioners, the question of stigma in relation to mental health and discrimination in relation to mental illness is the subject of academic study in Australia.

We will ask some experts in the field questions about 25 how stigma is understood structurally in society, what the 26 significant studies have been about stigma in Australian 27 society, what are the trends, what are the differences 28 between stigmatising attitudes in relation to depression on 29 the one hand and schizophrenia on the other; whether there 30 are signs that these things can be improved, and what are 31 the likely measures that are likely to be effective to 32 improve the position in relation to stigma. 33

We'll hear from Associate Professor Nicola Reavley, who is head of the Population Mental Health Unit and deputy director of the Centre For Mental Health at the University of Melbourne.

40 We'll also hear from Dr Chris Groot who is a 41 psychologist who lectures at the Melbourne School of 42 Psychological Sciences, and directs the Mental Illness 43 Stigma Research Lab at that school.

Finally, we'll hear from Dr Michelle Blanchard who is
the deputy CEO at SANE Australia. Dr Blanchard will give
evidence in relation to stigma and structural

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discrimination for people affected by severe and complex 1 2 mental illnesses. Dr Blanchard will explain what structural discrimination is, how it manifests, the 3 4 attitudes of employers towards people with mental illness, the consequences of structural discrimination, and what is 5 known so far about what can be done to overcome structural 6 7 discrimination. 8 9 The first witness this morning is Janet Meagher, and I 10 call her to give evidence now. 11 12 <JANET MEAGHER, sworn: [10.03am] 13 14 MS NICHOLS: Ms Meagher, have you, with the Q. 15 assistance of the Royal Commission, prepared a statement 16 about your lived experience and your work as an advocate? 17 Α. Yes, I have. 18 I tender the statement. [WIT.0001.0015.0001] 19 Ο. 20 Ms Meagher, are you currently a member of the Independent Advisory Council of the National Disability Insurance 21 Agency? 22 23 Α. Yes. 24 Have you been a Mental Health Commissioner on the 25 Q. National Mental Health Commission? 26 Yes. 27 Α. 28 Have you been, and are you, a member of numerous 29 Q. ministerial and advisory bodies in relation to mental 30 health? 31 Α. 32 Yes 33 Have you been instrumental in developing numerous 34 0. bodies that both nationally and internationally work for 35 advocacy in mental health? 36 37 Α. Yes. 38 With that short introduction to your auspicious 39 Ο. career, can I take you back to your earlier life. Did you 40 grow up in Newcastle and then move to Sydney, where you 41 studied at Teachers College? 42 43 Α. Yes. 44 45 Ο. Did you work for a while as a teacher? Α. Yes, I did. 46 47

After that, did you become a nun? 1 Q. 2 Α. Yes. I know who I am. 3 4 Ο. But these people don't yet know who you are, 5 Ms Meagher, I'm sure that they will very shortly. There are many things we could ask you about in your life, but 6 7 I'm going to go directly to your first experience with 8 mental illness; can you describe that, please? 9 I had what was in those days called - I don't think we Α. 10 have them any more - nervous breakdown; in fact, I had several, multiple, and many - many, many - nervous 11 12 breakdowns. So, I suspect I'm not nervous any more. 13 14 The result of that was multiple hospitalisations, multiple cures tried on me, and multiple everything else 15 16 tried on me as well. And, after utilising most of the private hospital systems to the last point of possibility, 17 I was then moved in to become a guest of Her Majesty at one 18 19 of the large institutions in Sydney. 20 Over what period of time did you remain a quest of Her 21 Ο. Majesty at that institution? 22 Well, my initial breakdown was around about 1969, and 23 Α. 24 I was officially discharged, with question marks over it, in 1979; so pretty well, a decade of my life. 25 26 27 Did you receive a diagnosis? Ο. Multiple. The most persistent one was paranoid 28 Α. schizophrenia, which I suspect is probably what I still 29 have, yeah. 30 31 Did you stay mostly in a single institution while you 32 0. were involuntarily cared for? 33 Yes, yeah, I was institution - became 34 Α. institutionalised. 35 36 37 Yes, institutionalised. Can you describe the Ο. hallmarks of your experience at that place? 38 Α. Well, I'll preface it by saying that, there were 39 wonderful, committed and marvellous, humane staff there. 40 41 There were, parallel to that, monsters who were in the guise of nursing professionals and care professionals. 42 After I left I did a quick survey of people I knew who'd 43 44 been through, and I only ever met one who said they hadn't been sexually abused, and that pretty well confirms to 45 anyone else I speak to on a person-to-person basis who were 46 in these care situations. 47

1 2 I think you could sum up the experience - apart from the wonderful staff who were horrendously marvellous in the 3 4 circumstances that they were placed - there were staff who, you just had to know they were on duty to know that one of 5 you was going that night; so that was one aspect of it. 6 7 8 The other aspect is, the amount of emotional abuse, 9 the amount of physical abuse that went on, and I became 10 pretty good at that myself; I was a very excellent responder to violence. In other words, I was extremely 11 12 violent myself. And, I understand that now to be a reaction to the anger at the brazenness of people to claim 13 they were health professionals and at the same time turn 14 15 round and create the most inhumane system of "care" that 16 you could possibly imagine. And, because we were not competent before the law, no-one would listen to what was 17 happening, and those staff who did tell would say to them, 18 "We can't do anything, we are helpless to help you." 19 20 Ms Meagher, was there anyone to advocate for you then? 21 Ο. No, no. The staff were as much bullied and 22 Α. intimidated as we were - the good staff. 23 24 You spoke about anger a moment ago; did that drive you 25 Q. to become an advocate? 26 Yes, I'm still angry. 27 Α. 28 Towards the end of your time at that institution, did 29 Q. you find yourself working at the library of the Sydney 30 TAFE? 31 32 Α. Yes. 33 How did that come about? 34 Ο. Oh, it's a bit of a hilarious story, if you laugh at 35 Α. these things - I do. One of the long-term patients used to 36 37 have an idea in his head that he was in charge of all of us, and he ran - you'd have to know institutions to 38 understand this - but he ran what was called the watch 39 making service. Anyone who had a faulty watch or clock, 40 41 anybody, staff, community, patients, you know, if your watch gave up you'd take it along and he would fix it for 42 He had all this equipment in this little garagey 43 you. 44 thing in the grounds of the hospital. 45 Anyway, he decided that it was time I got out of there 46 to see what the other world was like, and so, he saw a job 47

in the Sydney Morning Herald and he applied for it in my
name. I got the job. No interviews, no nothing, just,
this one will do. My address was of course Gladesville
Hospital; Victoria Avenue, Gladesville, you know, obvious.
And, I got this job and I had to go to work every day and
that was extraordinary for me.

8 To control my behaviour, which as I said was not very 9 good, I was given heaps of tranquillisers, you know, to 10 moderate me, and of course, I'd get to work, which was a 11 major achievement just to turn up, for me to get the bus 12 and to know where to get off, and to actually walk to the 13 workplace, and I was exhausted; so I used to curl up on the 14 staff locker room floor and go to sleep for the day.

16 Three months later - and I quite liked getting paid, like, it was amazing, and I had money and it was pretty 17 I wasn't causing trouble in the hospital any more, 18 qood. so it was even better. The time for the interview 19 20 regarding your retention of job and increase in pay came up, and I was looking forward to it. I had to wake myself 21 up to make sure I got to Mrs Crisp's office. Mrs Crisp was 22 the head librarian, and Mrs Crisp is exactly what that 23 24 tells you in the name, and she says, "Sit down please Janet", and Janet sat down. "I'm afraid we can't give you 25 your increment." I was shocked and dismayed, shattered 26 actually, because I'd been to work every single day I was 27 supposed to come, you know. How dare they. Here's another 28 person who was knocking me around, you know. 29 It never occurred to me that I should have actually been physically 30 working. 31

Q. So, after that, Ms Meagher, I gather you --A. Physically worked.

Q. -- went to work, and is that a significant thing, that
you had a job and you were getting independence?
A. Yes.

40Q. Did you form part of what was then called an41experimental rehabilitation program in about 1980?42A. Yes.

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44 Q. Where you were moved out into small group
45 accommodation?
46 A. That started around the time my job was applied for.
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1 Q. Yes. 2 Α. And it continued on. 3 4 Ο. Yes. And we were - I was chosen basically to come from the 5 Α. back wards to prove that the program wouldn't work; you 6 7 know, these new fangled ideas in mental health were always 8 coming up and it was never going to work. 9 10 So they had us training to use the new - bank cards had just been introduced, we weren't used to using money, 11 we weren't used to washing our own clothes or looking after 12 13 ourselves, we didn't know about changing beds or all of that stuff; we really had to learn. It was called domestic 14 retraining, and it was life retraining really to 15 16 deinstitutionalise us and to get us used to not sleeping in a ward at night. We were allowed to sleep in the domestic 17 retraining unit eventually, and I was the one that was 18 19 supposed to fail. 20 21 Ο. And you didn't? I didn't. 22 Α. 23 24 Q. No. And I was the one who stayed in the community. 25 Α. 26 We spoke about you being angry before, but did you 27 Ο. find within you something of a vision to start to become an 28 advocate so things could change for other people? 29 Yes. Around the time I had to come off the major 30 Α. tranquillisers to work at work, my psychiatrist had decided 31 that, if I could stay off the major tranquillisers and 32 behave myself, be less violent, and if I could do that at 33 work, why couldn't I do it at the hospital, and we talked 34 about it. 35 36 37 And, when we talked about the causes of my anger, I could still articulate for you every single instance when I 38 got violent, and I can tell you why; I could tell you today 39 why and it's the same things that set me on fire now. 40 Because my doctor said to me, "I can't do anything to 41 change this system, I'm part of the system that's let you 42 43 down, but you can do something. You've got a brain you 44 should use and you've got the intelligence and you've got 45 the capacity, and you need a reason to keep going, and the reason you need to keep going is because things need to 46 change", and she said, "Tell me next week what your vision 47

is and I said, "I can tell you now, my vision is that 1 2 services will never ever again, in the name of treatment and care, cause harm." And that's my motto. 3 4 And, did you do a few things starting with picking up 5 Q. a copy of the then Mental Health Act, New South Wales. 6 7 Α. Yes. 8 9 And read it and become familiar with it? Ο. 10 Well, she put a challenge out to me and, anyone Δ Yes. who knows me, knows I hate challenges because I'll try and 11 meet them, and I got a copy of the Mental Health Act, you 12 13 know, as mad as I was supposedly at the time, and I read through it and read through it and read through it, and 14 15 then started talking to other people who were advocating 16 for change and I realised, here was a weapon, this was a 17 weapon. 18 And then I looked at other weapons, like Codes of 19 20 Practice and expectations of health services, et cetera, and so, my anger became targeted into, if you like, at 21 first an intellectual exercise in creating the weaponry 22 that I would need in the future to change mental health 23 24 services, and here I am, what, 40 years later. 25 Did you try and make your way into different groups 26 Ο. that were doing advocacy? 27 I did, and some didn't want a thing to do with a mad 28 Α. person, because they already had mad people at home and 29 they didn't need reminding of them, especially when they 30 went to meetings and things. 31 32 So, some pretty well just said, get out of our lives, 33 we don't need another one in our life, and others opened 34 their arms and mentored me and gave me the skills and the 35 balance I needed in my advocacy and promoted me beyond just 36 being an advocate, to being a board member, to being a 37 representative, through to wider and wider realms, yeah. 38 39 In 1993 the Human Rights and Equal Opportunity 40 Ο. Commission released the report, Human Rights and Mental 41 Was that a turning point for you in your work? 42 Illness. Well, the announcement of it was definitely, because 43 Α. we'd been working on advocacy around human rights for a 44 number of years. Around that time - you know, leading up 45 to the final report there were a number of sessions of 46 interviews from the Royal Commission - not Royal 47

Commission, the Human Rights Commission, and Brian Burdekin 1 2 was very interested in speaking to people with lived experience particularly, and this was the first time people 3 4 who'd been through a service, through an experience, actually got to articulate it and have it heard. 5 You know, many had articulated, but nobody had had it heard 6 7 previously, that things were happening that were not right. 8 9 So, it helped empower the consumer and was the start 10 of the consumer movement in Australia; to have that report produced and mental health service reform commenced on the 11 back of that. We now have the National Mental Health 12 13 Strategy, for instance, which came out of that process, and our lived experience voices started to be, not only valued 14 15 and heard, but there was a demand that we could now have 16 that there couldn't be nothing about us without us. 17 18 Did the National Mental Health Commission ask you to Ο. become involved in developing a framework for integrating 19 20 care and support into a person's whole-life trajectory? Well, all of us on the National Mental Health 21 Α. Commission had a workshop sort of thing to figure, what 22 frame were we going to place around the report cards that 23 24 we had to make and were committed to making to the Australian people about mental health in this country. 25 26 On that day that we were discussing it, I recalled 27 something I'd heard in some of the literature - who knows 28 where - I think in disability literature, that were stating 29 that all people ever wanted was a contributing life, and 30 that concept did appeal to all of us around that table. 31 32 And I'd done a lot of thinking about a contributing 33 life and what it meant to people and, if I may, I'll copy 34 something that the Commission wrote at the time? 35 36 37 Ο. Yes. And I'll explain the concept because I think it's 38 Α. really important, because I think it is a great frame 39 around which we can place a lot of reforms in our mental 40 health sector and it means it focuses on the individual as 41 well as the type of service is: 42 43 "A contributing life means a fulfilling 44 45 life enriched with close connections to family and friends and experiencing good 46 health and wellbeing to allow those 47

connections to be enjoyed. 1 It means having 2 something to do each day that provides meaning and purpose, whether this is a job, 3 4 supporting others, or volunteering. It means having a home and being free from 5 financial stress and uncertainty. It means 6 7 opportunity for education and good 8 healthcare, all without experiencing 9 discrimination due to having a mental 10 health difficulty." 11 12 That's what I wanted for Australia. That's what we agreed to, and that, I think, is the nexus of all mental 13 health service delivery and the point of all service 14 delivery should be around that. If you're not helping me 15 16 have a contributing life, you're not helping me. 17 In that framework, what's the difference between 18 Ο. thriving and just surviving? 19 20 Α. Currently, we are just surviving. We are having sustenance for our bodies and no sustenance for our spirit 21 and soul and humanity. We are often depersonalised and 22 humiliated and denigrated by the very fact we have a mental 23 24 illness and, secondly, by the nature of the services that are offered to us. And I think we really need now to turn 25 that. 26 27 We need health professionals who encourage and support 28 29 and enable, not just people who make us conform to medication regimes. 30 31 32 You've used the expression in your statement with the 0. Commission, that "a person is not just a mental illness 33 walking about." Can you say more about that? 34 Um, there's so much to say I don't know where to 35 Α. start. The trouble in mental health services is that you 36 37 are the mood disordered person in room 8, you are the bipolar one, you're the schizophrenic one, you're the 38 depressed one, and "what's your name?" And so, it becomes, 39 "Oh, you're the one on clozapine, or we have to make sure 40 41 we check your clozapine. Not, "Hi Janet, how are you, and are things going alright for you, do you think you need a 42 blood test in the next few weeks?" No, it's "oh, the 43 44 clozapine, we have to check your clozapine level. It's, you know, you're on lithium, we have to make sure. 45 You must conform, you must conform, and so, it becomes a 46 depersonalisation, and I could rant on about that for a 47

long, long time, and I'll try and control myself. 1 2 Depersonalisation is such a common mechanism to just 3 4 get things done according to policy, and we saw the Nazis do it, we see us doing it now with immigration and things 5 like that: we call something a name and then we don't have 6 7 to face the humanity of it. And I'm begging mental health 8 services to come back to person-to-person, to help people 9 who can't sit up here and talk to you. Help them to find a 10 way to re-contribute in society. 11 12 Human beings are givers and sharers. If you've got a 13 mental illness, you're probably not giving a great deal you're giving someone a job. You're probably sitting on 14 what I call Days of Our Life therapy and taking pills; 15 you're not contributing. You're dehumanising and the 16 17 services don't stereotypes at the present time. 18 19 Look, I say this as a sweeping statement, there probably are a handful, and I mean one handful, of services 20 in Australia that humanising and thoughtful and 21 person-centred. We hear all this language in mental 22 If I ask everyone in the audience, they could all 23 health. 24 rattle off a number of service modes: you know, person-centred, community based X or Y or Z, and this first 25 or that second. We can rattle them off: the trouble is, it 26 doesn't get to the core. 27 28 29 Q. What's at the core? Well, the heart is protected from us. You know, the 30 Α. heart of services is protected from us. Chances are, we 31 might actually cause change if we got to the heart of 32 We can't seem to get there, I'm sorry. 33 services. 34 Do you have views about why it's hard to get there? 35 Ο. Α. Oh, yeah. 36 37 38 What are they? Ο. Oh, the paperwork, the policy doesn't allow this, or 39 Α. we're building walls in services to protect either the 40 people in it or the fear of us, or the - I mean, there are 41 better people than me to talk about what causes problems. 42 43 44 But, we were chatting earlier, some of us, about a report that was written in the late 90s as part of the 45 national mental health strategies which was called, the 46 Attitudes of Health Professionals Project, a very scathing 47

and damning report which was shelved due to industrial 1 2 issues very early in its life. That's where we have to 3 start. 4 If we can't start where the face-to-face services are 5 happening - yes, we need a framework and a policy around 6 7 it, but if you're putting another framework, another 8 policy, another something out there - I once listed for a 9 speech I gave over 700 reports and reviews and so on that 10 had been written in Australia since the day colonisation began, and what we end up with is another report, and I'm 11 12 begging you not for another report. 13 14 I beg you for a change that's going to move people 15 from a place of behaviour modification to having a 16 contributing life, and that has to start with the professionals who deal with this; whether it be in the 17 non-government sector, the health sector or the community 18 19 sector, but along the way change has to happen within. 20 Ms Meagher, you said this in your statement, that: 21 Ο. 22 "A new service framework and strategy must 23 24 overtly move beyond focusing on beds, acute care and clinical services and move on to 25 include non-government community services 26 27 across all sectors, including peer and family workers." 28 29 Now, there are a number of concepts tied up in that 30 and I'd like to ask you, on the basis of your experience, 31 the importance of linking clinical and non-clinical 32 services. 33 34 Well, the importancy is that, none of us spend our Α. entire life under clinical governance. Most of us are 35 living a life, albeit not always a contributing life, we 36 are living a life in a community of our choice - and 37 sometimes without our choice - and that is where life 38 39 It doesn't happen in a hospital. Life happens in happens. our friends, in our family, in our community and if we're 40 41 solely tied up in purely clinical interventions, then you 42 have a very limited and very puerile life and, from my point of view, we need a contributing life, every single 43 44 one of us, every one of you sitting up there, everyone in this room needs a contributing life; whatever way we want 45 46 it. 47

You know, if I want to be a dog trainer or if I want 1 2 to be a guard at the door of this Town Hall, it doesn't matter, I want to have a place in life where I feel I'm 3 4 contributing something, and if I'm a health professional, if the only thing I ever do with a person living with 5 mental illness is dish out pills, what am I contributing to 6 7 that person's life? Is that what you're trained for, for 8 God knows how many years? To dish out a pill? 9 10 Ms Meagher, you said in your statement that: Ο. 11 "The effort, control, guts and sheer 12 willpower it takes for a person with mental 13 health issues to participate fully in 14 15 society, it's extraordinary." 16 17 Α. Yes. 18 Can you tell the Commission about what you've seen 19 Ο. 20 about that guts, determination and sheer willpower along 21 your journey? I don't think anyone has any idea how hard it is to 22 Α. play at being normal. There are people in this audience 23 24 that know, they know it very deeply. 25 A lot of us live a job and a life and have families 26 and friends and whatever, and for me, and for them I'm 27 sure, just the drive and energy it takes to plan for each 28 day: if this happens, what am I going to do? If that 29 happens, what am I going to do? I still do it. You know, 30 40 years since I left services, I have to do it to support 31 the fact that I have to keep going, I have to maintain this 32 level of participation because, if I don't, I've failed. 33 And, if any of you here could say the same: they get up 34 each morning and have a plan for that day, and they cannot 35 fail. Failure means you're going backwards. 36 37 Sometimes we have episodes and you go backwards 38 without wanting to, but we do our best to come back quickly 39 and to get help early, and most of us have techniques 40 whereby we can get ourselves back on track fairly quickly, 41 but it is like a Ten Tonne Tessie hanging over your head 42 all the time that, if you just lose track or if you just 43 let go too much, things may not look too good. 44 45 It's a struggle and it's a struggle that takes a lot 46 of energy, a lot of ethical decisions based behind the way 47

you want to behave today or tomorrow or the next day, and in the impact that in my instance I want to have, it's critical that I maintain a very balanced way forward, so it's not a simple decision to get up and to go to the hearing and to tell you how wonderful everything is; it's a very critical, moral and ethical process I have to go through every time some of these things happen.

9 I might get up at home - if you were ringing me to 10 talk to me about X or Y, I might have to get up an hour earlier just to go in my head through, oh, what does this 11 person want? What am I likely to think about that? 12 Ι 13 don't think average people do that. I do and I think it's part of my professionalism that I do that, and I'm pretty 14 15 sure anyone with a mental health issue out there who wants 16 to contribute is doing the same sorts of things.

- Q. In your journey with mental health services, have you met people along the way who have, by their kindness and their service, given you cause for optimism about the service?
- Oh, yeah, there's amazing people, there are amazing 22 Α. people in this sector: my peers, other people with mental 23 24 health issues, some family members of other people - not And some of the bureaucrats along the way and health 25 me. providers, they've all given us a leg up, and I think any 26 of us who have moved in advisory circles or advocacy 27 circles will tell you that the issues get better hearing 28 when there's friends on the other side; when there's 29 support coming from higher places. 30
- We can't advocate if no-one's prepared to listen; that's the state we were in in the late 70s, early 80s: no-one was prepared to listen. We're not in that situation now. There are people who do listen, who do think there's a wisdom in knowledge and who do believe that there is an expertise that's borne of experience, and I think now's the time.
- 40 MS NICHOLS: Thank you very much, Ms Meagher. Chair, do 41 the Commissioners have any questions?
- 43 COMMISSIONER FELS: Yes, thank you for your excellent 44 evidence, I have a couple of questions. Would you be able 45 to say something about your views on the role of people 46 with lived experience and families and carers in helping or 47 participating in policy making, in also service delivery

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operations: what is their role? For example, are they just 1 2 passive recipients of whatever services are given to them? We are not passive. We will no longer receive. 3 We Α. 4 participate, and you can't take us back 40 years to when we There is no passivity any more or into the 5 were passive. future, and I think this is where the problem with mental 6 7 health services lies at the present, that they expect us to 8 be passive, they expect us to have a docile view when 9 offered service that might not suit. They do not expect us 10 to be intelligent participants in their own service or planning for service, and I think that has to change and it 11 12 has to change from the first instance when we arrive for 13 service. 14

We are frequently, if not more often than not, rejected for service, because you're not yet sick enough for a service. How dare they.

19 If you turned up with chest pains - let's hope we 20 don't - to a hospital today, they will at least do some exploratory tests and some investigations. 21 I can bet your socks that if all of us went and turned up at the nearest 22 emergency department saying, "My thought processes are not 23 24 able to be contained right now and I know, if I leave this much longer, I'm going to go into a full psychotic 25 episode", I know what's going to happen to me. 26 "Go home and have a cup of tea, you'll be alright." Well, quess 27 what? We're not, and that's what happens. 28 Then you have to go into fully-fledged psychotic episode before anyone 29 will even try to do anything to help you. 30

The trouble is we've been trained now, and those of us who are now activists and active as lived experience people, we've been trained to recognise our symptoms and to know how our mental health is at the present time. I can pick up, and most of my colleagues, can pick up when things are going a little bit off track and we like to do things then to prevent a further escalation.

There is no service, no early intervention for us you'll hear early intervention all the way through this hearing or these hearings, but there's no early intervention for us. There's no process, there's no place you can go, there's no intervention you can seek that will help you in that early onset stage: prevention, ha, ha, ha, what a farce.

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And then, we've now developed ways of service provision that includes people whose lived experience is an important and integral part of their role, and I've been very proud to be part of the blooming of that type of service provision, and I say that peer work is probably the most revolutionary thing that's happening in mental health at the present time.

And I add the proviso that, the type of peer work I'm talking about is well trained and well experienced peers, not just a consumer you know or someone really nice that lives up the street that needs a job; it's about someone who's got the skill and experience and the qualifications to be able to support someone alongside other allied health professionals.

17 Trouble is, in mental health we've been cutting back 18 on services and the use of ancillary health professionals. 19 If you're treating the whole person you really to treat the 20 entire person and their circumstances if we're having a 21 contributing life. So, I say, hey, hey, bring back the 22 broad service delivery we used to have once upon a time and 23 treat the contributing life potential of people.

25 Q. Would you be able to say something about the role of 26 families and carers?

A. Yeah. Well, alongside the person with lived
experience, the families and carers have a significant role
not to allow imperfect systems to damage the person they
love. And they have a role in helping alongside us to
advise and support services around what is best for the
person they love and care about.

Too often the systems and the reaction to systems burns out families and carers, and their attitudes to us get soured by their constant rejection and disrespect given by services. So, I think, if we're seeking respect and humanity from service delivery, we also need to expect that families are consulted and given the respect that's due to them.

There's still a pervasive thread that's not publically spoken about, about toxic parents. Now, that thread of toxic parenting still is pervasive when you rub the gloss off the top of mental health. Parents are still treated as if, "Well, we understand why Janet's like that, look at mum. Look at dad, is there any wonder", and we do this and

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that's again the disrespect I referred to earlier.

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I'm sort of angry about, I suppose, the amount of disrespect in the system, and that goes particularly to families who often feel helpless and hopeless.

7 Ms Meagher, you talked earlier about the fact CHAIR: 0. 8 that there are a handful of services that you've come 9 across, you've obviously travelled widely around Australia 10 and internationally and now have this wealth of experience that you bring to bear. Is there anything, other than the 11 12 peer workforce that you've talked about, that's common to 13 those models that you think are really important? Well, that's fairly easy to answer. Yes, it's the 14 Α. open door policies, it's the welcoming that you receive in 15 16 these sorts of service. You can tell - it's like a nursing home: you know, they say, if you go into a nursing home and 17 18 you can smell something nasty, that's not a great nursing 19 home.

Well, in a Mental Health Unit, you go in - if you can get in - and, if you're not welcomed and given what you would get if you went into any other type of service, you can pretty well guarantee it's going to be a stinker. The things that go with that are assertive, supportive: this is the language, we could write a whole dictionary.

Service providers who are there. I remember one I 28 visited way back in the dark ages, and they told me that 29 the staff in that service were employed by a lived 30 experience committee, a board. And so, if you were the 31 service provider and I'd missed an appointment, if you 32 hadn't followed up within X number of hours and documented 33 that, you run the risk of losing your job. If you didn't 34 make efforts to connect to lower the medication regimes, a 35 whole heap of other things, to create social advantage for 36 that person, you could be eliminated from that service. 37 Now, that might seem extreme to you, but I've never been in 38 a more friendly service environment. 39

In fact, I was there when I saw a police car pull up the front, and the police car brought in a person who was clearly living on the streets, but - I'll call him Joe -Joe had missed his appointment. The police knew Joe had an appointment, so they brought him up there, police taxi service. There was no animosity. It was just like, if we help Joe, Joe stays well, we have no work to do, so they

1 help him. So, that's an extreme, it's my ideal service. 2 But the real mental health services that I've seen 3 4 that really help not only look at my state of mind, but my state of body, my social environment, the things around me 5 that are causing issues; they look at me as a whole person: 6 what is preventing my contributing life moving forward? 7 8 Those places have very, very good physical health checks. 9 10 And the reverse of that of course is, any number of us could tell you experiences of going to a doctor with a 11 health issue. You know, I might go to the GP with a 12 13 migraine headache. You can bet yourself a million dollars it will be something to do with my mental health issue. 14 15 Guaranteed: you're too stressed, so how about we up the 16 minor tranquilliser for you. So, yeah, those - you get so sick of having to say, "No, I'm sick, this is the flu, this 17 is", so it just becomes too hard sometimes, you just give 18 up, and we don't want people giving up, we want people to 19 20 have healthy bodies, healthy minds and a healthy life, and I don't think we can have that under the present 21 circumstances 22 23 24 CHAIR: Thank you. 25 26 MS NICHOLS: Thank you very much, Ms Meagher. 27 Thank you very much for your time today. 28 CHAIR: 29 THE WITNESS: Can I add a thing because I've been stewing 30 on something overnight? 31 32 Yes. 33 MS NICHOLS: Since this is about stigma - I know I'm sick of 34 Α. hearing my own voice but anyway you're going to have to 35 listen for a few minutes. Today's about stigma and I got 36 churned up overnight, so here you go. 37 38 The word "stigma" I hate with a vengeance, I hate it, 39 and I hate it because it's soft and deflective. 40 It allows I've reached the stage, I don't allow for forgiveness. 41 forgiveness. It's a weasel word. I use "discrimination", 42 and unapologetically, whether it's legal or illegal, I 43 don't care; if you don't like me and you've done something 44 nasty, or you're thinking of doing something nasty, or you 45 have nasty thoughts about me because of my mental health 46 issue or because of my sexual orientation, or because of 47

whatever, religion or whatever, you're discriminating in mind or in act. So, to me, there is no way I will countenance the word "stigma".

And, I think it's intolerable to permit or excuse verbal or social exclusion or vilification for those of us who experience mental health issues, but we do. Twenty years ago we frequently heard people described as "spaz", "spastic" was a term in frequent use - we all remember.

And, that was not used to describe people with cerebral palsy. It was used as a common expression to talk about excitement or incompetence. Because of cultural and humane pressures within our community, that is now understood as being a denigrating term and was eliminated in a very short time. Not so in our field.

19 "Have you been to the crazy mad party?" I can go to 20 "a mad March sale", or "get crazy prices" and even "go 21 psycho" if my team doesn't do what I want it to do. 22 Melbourne can be described by pundits as being 23 "schizophrenic city" if they are two aspects in contrast in 24 its demography.

This stuff is possibly funny and it's probably clever to an advertising exec or publisher, but it's awful and humiliating and above all disrespectful for those who have to wear the terms, "crazy", "mad", "psycho".

And, if you think of it as disrespectful, think about the depths of isolation, despair and hopelessness that's represented in the real meaning of those words.

"Mad" is a condemnation, a summation, of all that has 35 happened to you. "Crazy" is about loss. The loss of 36 rationality, credibility and a normal life. Nothing is 37 "Psycho" is psychotic, loss of control. 38 harder. Loss of control of your thoughts, memories, reality. Not to be 39 laughed at. 40

"Skitzo", schizophrenic. Nothing to do with two
contrasts or aspects. A completely - a fallacy, and
everything to do with further vilifying and trivialising
those whose lives are shattered by experiencing what a
persistent mental health issue can do to your life
potential and purpose.

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One other aspect of stigma, if I can discriminate further: health services. No other part of health deals with patients as health does, and mental health. Ask any mental health consumer who's been treated for coronary oncology services; they will tell you the contrast is shocking, shameful and confronting.

9 In mental health services, generally speaking with few 10 exceptions, the tone is one of containment, is punitive in 11 nature, and is requiring compliance. It is even likely 12 that we could describe that modality and compare it to 13 gentle service, caring, support, anticipatory and in-home 14 interventions that happen with the other types of health 15 service.

In mental health, we talk of behaviour, not personal 17 guidance; compliance. Why don't we talk about adding help 18 to create positive self-help activities? 19 We talk of words 20 like "absconding", "non-compliance", "tribunal", "audits", All are related military terms and 21 et cetera, et cetera. legal in their context. Not humane and effective 22 23 terminology.

Now, I'm not here to change terminology in mental health, I'm just here to explain what underpins all these negativities that constantly arise in relation to mental health treatment and care.

I think we have to look at terminology to explain why we want humane, effective and supportive services that help us live a contributing life.

34 So, I think I'll shut up now and hope that some 35 message of your understanding of what it's like to live 36 through advocacy in this area and to find constantly that 37 we need to reform, not just ourselves, but attitudes as 38 well. Thank you.

40 MS NICHOLS: Thank you very much.

42 **THE WITNESS WITHDREW**

MS NICHOLS: Commissioners, the next witness is Associate
Professor Nicola Reavley. We'll call her before we have a
break, if that's alright. I call Associate Professor
Nicola Reavley.

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1 2 <NICOLA REAVLEY, affirmed and examined: [10.56am] 3 4 MS NICHOLS: Q. Professor Reavley, have you prepared a statement about your work in the area of stigma and 5 discrimination concerning mental health? 6 7 Yes, I have. Α. 8 9 You have. I tender the statement.[WIT.0001.0022.0001] Ο. 10 Can I ask you a little bit about your background and your research interests first. Are you the head of the 11 12 Population Mental Health Unit and deputy director of the 13 Centre For Mental Health at the University of Melbourne? Yes, that's right. 14 Α. 15 16 Have you undertaken considerable research on mental 0. 17 health literacy and stigma? 18 Α. Yes. 19 20 Have you authored and co-authored a number of research Ο. 21 papers in this area? 22 Α. Yes. 23 24 Ο. I'll ask you firstly, how does the World Health Organisation define "stigma"? 25 So, there's a number of different definitions of 26 Α. "stigma", but the WHO, the World Health Organisation, 27 defines it as a mark of disgrace or shame that results in 28 someone being rejected, discriminated against or excluded 29 from participation in social and economic activities. 30 31 In this field of learning, do studies look separately 32 0. at attitudes and behaviour ? 33 So, people do use these terms a bit differently, but 34 Α. for the purposes of what I'm going to talk about today, we 35 do make a distinction between stigmatising attitudes and 36 37 discrimination which is more about the actual behaviours or perceived behaviours, yeah. 38 39 Why is it necessary, for the purposes of this academic 40 Ο. study, to distinguish between those two things? 41 So, obviously attitudes lead to behaviours or dictate 42 Α. behaviours to a degree but not perfectly, and a lot of the 43 44 earlier research in this area asked people about their 45 attitudes towards people with mental illness because it's relatively easy to do it; it's much harder to get to people 46 and ask about their experiences, but that is more 47

cutting-edge research and that's only really been done more 1 2 recently. 3 4 Ο. Why is it much harder to actually ask about behaviours as opposed to attitudes? 5 So, because you have to actually find those people, 6 Α. 7 and the nature of the research we do is population health 8 research, and so, we're interested in doing research as 9 rigorously as possible to quantify the proportion of the 10 population that have these experiences, so you need to sample people in a - you know, get people into your study 11 12 in a rigorous way to be able to make reasonable statements 13 about the number of people that have these experiences. So, you need to effectively kind of screen them and only 14 15 get to the people who have mental health problems if you 16 want to ask about that - ask about those things. 17 18 Essentially, is it more onerous to enquire about Ο. behaviours? 19 20 Α. Definitely more onerous and therefore more expensive, 21 ves. 22 In this context, what's the distinction between public 23 Ο. 24 stigma, perceived stigma and self stigma? So, in our research we use the term personal stigma, 25 Α. and we mean the attitudes that people themselves hold: 26 sometimes you see that described as public stigma. 27 28 29 Perceived stigma is about what you as a person think about what other people's attitudes are. And, you know, 30 that can - I think, has been quite eloquently described by 31 people, that can deter help seeking for example because 32 they think that other people are going to view them 33 34 negatively. 35 Self stigma is the attitudes. Effectively, you're 36 37 kind of internalising the attitudes of others and holding them about yourself, which again can be inhibiting people's 38 participation in many activities in society or seeking help 39 when they need to. 40 41 42 Thank you. Just by way of background, have you Q. investigated at least the following kinds of stigma: 43 44 beliefs that people living with mental illness are 45 dangerous and unpredictable? Α. Yes. 46 47

1 Ο. And beliefs that a mental illness is a sign of 2 personal weakness? 3 Α. Yep. 4 That mental illness is not a real medical illness or 5 Ο. that the person could snap out of the problem? 6 7 So that's really the idea - yes, that's really the Α. 8 idea, that it's not a real illness and they just need to 9 get out more or something, yes. 10 And unwillingness to interact socially or 11 0. 12 professionally with people with mental illness or 13 willingness to avoid people with mental illness? Yeah, so that's sometimes referred to as the desire 14 Α. for social distance. 15 16 Could I ask you just to speak a little bit closer to 17 Ο. the microphone so that I can at least hear you better. 18 Can I ask you next about the National Survey of Mental Health 19 20 Literacy and Stigma. Is that a survey that was and is Australia-wide and was conducted amongst adults in 1995, 21 2003 to 2004 and 2011? 22 Yes, that's right. Α. So, the first one was done in 23 24 1995, and that was a household survey. The subsequent ones, 2003-04 and 2011 were telephone surveys. 25 So, they're computer-assisted telephone interviews, they're random 26 digit dialling of, in the most recent one anyway, landlines 27 and mobile phones, and that's important because, if you 28 only use landlines you tend to under-sample younger people 29 who only have mobiles, so you're more able to say that 30 you're getting a sample that's more representative of the 31 general population. 32 33 Were there two surveys of young people in 2006 and 34 Ο. 2011? 35 There were, yes, done in a similar way, yeah. 36 Α. 37 What does "young people" mean for the purposes of 38 Ο. 39 those surveys? Aged 12-25 for the most recent survey. 40 Α. 41 Is that work being updated, in effect, by 42 Thank you. Q. the National Stigma Report Card? 43 44 That, I'm not - I'm not directly doing that work. Α. 45 I believe that will be using somewhat a different methodology, but you should ask them about that. 46 47

Yes, we will ask your colleague, Chris Groot, about 1 Q. 2 that later today. 3 Α. Yes. 4 But as far as you're concerned, the national survey is 5 Ο. as - it's dated back to 2011? 6 The most recent one was 2011, yeah. 7 Α. 8 9 I think you've covered how it was that it was Ο. 10 conducted. What sorts of questions were people asked? So, in terms of stigma, we - as you've just described, 11 Α. 12 we asked them about their beliefs about whether it's - and 13 we looked at a range of mental health problems in that: so, depression, psychosis, chronic schizophrenia, PTSD and 14 15 social phobia in the most recent one. 16 And we asked them about their beliefs about whether a 17 person could snap out of it, whether it's not a real 18 We ask about whether they believe a person with 19 illness. 20 the problem is dangerous or unpredictable, whether they would avoid the person or whether they would tell someone 21 if they had the problem. Also some things about how 22 willing they would be to vote for a politician or have a 23 24 person with the problem marry into their family. And the desire for social distance questions which are around maybe 25 having someone living in the neighbourhood, socialising 26 with the person, having the person marry into your family. 27 28 29 Q. Can I ask you about what the survey reveals about trends in relation to depression in the period between 1995 30 and 2011? 31 Yeah, so overall between those years there was a small 32 Α. decrease in desire for social distance. 33 34 35 Ο. Yes. Α. Probably for depression, kind of a decrease in beliefs 36 37 about depression being a personal weakness. 38 39 0. Yes. Also, the thing we also found was that, between 40 Α. 41 those years there were increases in beliefs about 42 dangerousness of the person, even for depression. 43 44 Even for depression? Ο. 45 Α. M'mm. 46 Alright. And, what did you find about the willingness 47 Q.

1 of people to disclose their mental health status in 2 relation to depression? Α. So, that has increased quite a bit. 3 4 Sorry, does that mean people are more willing to 5 Ο. disclose? 6 7 They're more willing to disclose. Α. So, up from around, 8 I think about 20 per cent in 2003, to about 30 per cent in 9 2011. They are also more likely to know someone with the 10 problem, so really up from 45 per cent to 71 per cent. 11 12 Are those figures confined to depression? Ο. 13 Α. Yes, largely, yes. 14 15 What did the survey tell you about the state of mental Ο. 16 health literacy? Sorry, before - I've asked the question badly. Can I ask you firstly to tell us what is mental 17 health literacy? 18 So mental health literacy I believe is attitudes about 19 Α. mental health problems that aid in their recognition 20 management and prevention; that's how it's been defined. 21 22 What does that lead to? 23 Ο. 24 Α. The stigma questions weren't included in the 1995 They weren't included in the 1995 survey. 25 survey. The questions in that survey were mostly around whether you 26 could recognise and label the mental health problem. 27 So, people were given a little vignette written to satisfy the 28 DSM criteria for a disorder, the Diagnostic and Statistical 29 Manual criteria, and then you ask those people what, if 30 anything, is wrong with the person and see what they say in 31 response to that. And then a range of questions about what 32 they believe about treatments. 33 34 So, between 1995 and 2011, which is a reasonably 35 long - well, reasonably lengthy time period, we can see 36 37 that people are much better at recognising depression, so around 39 per cent in 1995, up to about 74 per cent in 38 2011, and also beliefs about treatments move closer to 39 health professionals, so they're much more likely to 40 41 believe that, for example, antidepressants are helpful or 42 cognitive behavioural therapy is helpful. So, we've seen attitudinal change in that time. 43 44 45 What are the major predictors of poor mental health Ο. literacy? 46 So, in general, if you're female you tend to have 47 Α.

better mental health literacy. Younger people, so people 1 2 aged younger than 60, tend to have better mental health Having a higher level of education tends to be 3 literacy. 4 associated with higher mental health literacy. 5 Can I ask you now, what does the 2011 survey reveal 6 Ο. 7 about differences in stigmatising attitudes about 8 depression on the one hand and schizophrenia on the other? 9 So, probably not surprisingly, stigmatising attitudes Α. 10 tend to be higher for people with chronic schizophrenia than depression. 11 12 13 Q. When you say tend to be higher, what did the survey actually reveal? 14 So they do reveal that they're higher. 15 So, it varies Α. 16 according to the type of attitude that you're talking 17 about. So, certainly views about dangerousness are higher for people with schizophrenia than depression. But if 18 you're talking about, for example, believing that 19 20 something's not a real illness, then those beliefs tend to be higher for a social anxiety disorder for example than 21 schizophrenia. I think that's an important point to make, 22 people tend to talk about stigma as if it's this 23 24 uni-dimensional thing but actually it's not, it encompasses different types of attitudes. 25 26 Did the survey find the following: that 27 Ο. Yes, I see. beliefs in dangerousness and unpredictability are notably 28 higher for schizophrenia than other illnesses; in fact, 29 37 per cent of respondents believe that a person with 30 chronic schizophrenia is dangerous, whereas 22 per cent of 31 respondents held the same believe with respect to a person 32 33 with depression? Yes. 34 Α. 35 Has the survey been able to detect gradations of 36 Ο. belief within certain parts of the Australian community? 37 So, these are general population surveys. 38 Α. So, if you want to, for example, look at beliefs in part - you know, 39 people in Australia who relatively make up a very small 40 41 proportion of the percentage of the population, so that might be people from culturally and linguistically diverse 42 backgrounds or Aboriginal and Torres Strait Islander 43 44 people. There are very small numbers in the survey, so really this is not kind of the best way to fully explore 45 beliefs in those people, those groups of people. 46 47

Is it correct to say that it's an Australia-wide 1 Q. 2 survey that's generalised across the population? 3 Α. Yes. 4 5 Is it generalisable to Victoria? Ο. Yes, there's no reason to think that it would be any 6 Α. 7 different; it's reasonable to assume that, yeah. 8 9 In summary, what have been the hardest attitudes to Ο. 10 shift? So, I think the interesting thing - one of the 11 Α. 12 interesting things we've seen is the increase in beliefs 13 about dangerousness over time. And, you know, thinking about this, one possibility is that in order to, you know, 14 15 destigmatise and encourage people to seek help for common 16 mental disorders like depression, the idea that it's a disease like any other, that it's a chemical imbalance, has 17 been promoted and this has probably reduced blame of 18 people, so reduced that idea that, you know, they can snap 19 20 out of it. 21 But it's absolutely possible that what that's done is, 22 if you've given the message that it's really not that 23 24 person's fault, it's not in their control, possibly the corollary of that has been that people might be seen as out 25 of control and therefore more dangerous. 26 27 And I think for us this highlights the need to be 28 29 really careful about the messages that these types of campaigns and interventions send so you're not unwittingly 30 doing harm and increasing the negative attitudes in some 31 32 ways. 33 Can you expand on that a little bit? What do you mean 34 0. by campaigns' capacity to unwittingly cause harm? 35 Α. Well, I think, you know, obviously a lot of effort has 36 37 been put in to improving mental health literacy and stigma and it's done - you know, it's really changed attitudes in, 38 we would say, positive ways: people are more willing to 39 disclose, people are more willing to seek help, and that 40 41 has definitely been positive. 42 But, if you're then, you know - I think possibly 43 44 another thing that may well have happened, and we can see that from evidence from some other campaigns, is that, when 45 people hear the term "mental illness" we've got evidence 46 that they tend to think about more severe illness. 47 And

possibly what some of the campaigns are doing is broadening 1 2 the idea of mental illness out to include depression as well and, therefore, that's possibly why we can see that 3 4 some of the attitudes about dangerousness even for people with depression, for which really there is no evidence that 5 this is the case, is possibly you know has that unintended 6 7 consequence. 8 9 So, I think we just need to be really careful about 10 the messages that we send. 11 12 Am I right in thinking that there is not a lot known Ο. 13 as to the basis on which the attitudes about dangerousness and more severe mental illness have increased? 14 Α. Not a lot is known? 15 16 17 Ο. About why? About why. So, because we haven't directly asked 18 Α. people if that is what they're thinking. 19 Looking at the 20 data in other countries as well, so other people for example in Germany have looked at this, and there it's a 21 hypothesis that it's a reasonable conclusion to draw. Can 22 we be definitive about it? Not definitely, but rarely in 23 24 this type of research are there definitive conclusions. 25 Can I ask you about your work with the National Survey 26 Ο. of Discrimination and Positive Treatment. Was that work 27 that you and your colleagues conducted in 2014? 28 29 Α. Yes. 30 Was it the first of its kind in the world? 31 Ο. 32 Α. Yes. 33 34 Can you tell the Commissioners about what that survey Q. was? 35 Α. Yes, I can. So, because I said before, you know, it 36 is relatively easy to do work just asking people about 37 their attitudes, it is more difficult to capture their 38 experiences, but we thought this was an important direction 39 that research should take to kind of inform interventions 40 41 to reduce the problem. 42 So, in 2014 we did a similar survey; it was, again, a 43 44 computer-assisted telephone interview with a random sampling of the population, and in that survey we screened 45 people on a symptom questionnaire and we also asked them if 46 they'd had a diagnosis, and the people that met a certain 47

cut off for symptoms or said they had a diagnosis, we then 1 2 asked them a range of questions about the experiences This was, as you mentioned, a world-first 3 they'd had. 4 survey, in that we asked about their experiences of 5 discrimination and also positive treatment in a really broad range of domains: so it was friends and family, 6 7 workplace and education, health services, other aspects 8 like in the neighbourhood, insurance, legal situations, 9 things like that. 10

Can I just ask you to run through the contexts that 11 0. 12 you address? So, you started with friends? 13 Α. So, we did spouse, family, friends, in the workplace, looking for work, education, health services, and then we 14 15 talked about other people, so that might be landlords or 16 neighbours and then some other situations like insurance and legal, Centrelink for example. 17

We'll get to those in a moment. Can I just ask you 19 Ο. 20 about the key findings of the survey, and is it correct that the survey reported that in most domains the 21 respondents said there were more positive treatment 22 experiences than avoidance or discrimination? 23 24 Α. Yes. So, people were more likely to say yes or no with the answers we asked them at first, were more likely 25 to say that they had been treated positively than avoided 26 or discriminated against. 27

29 So, in friends I think it was around 50 per cent of 30 people said they had been treated more positively. I think 31 maybe around 14 or 15 discrimination and about 20 per cent 32 been avoided, as an example.

Q. And so, that question asked people to compare the extent to which they were treated positively to the extent to which they were treated negatively?

A. Yes. So, it really - the percentages I've just given
you there are the percentages of people who said, yes, to
the question. And we then asked them to flesh that out a
little bit and give us a bit of detail, but yes, that's
right.

Q. Was there any significant exception to that trend?
A. So, the exception to that was when we asked people how
they'd been treated looking for work, so the negative
experiences for people looking for work tended to outweigh
the positive.

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1 2 Ο. Do you know by how much? I think it was around 15 per cent, as opposed to 3 Α. 4 10 per cent. 5 Can we just focus for a moment on the circumstance of 6 Ο. 7 looking for work. What was the most common type of 8 discrimination in that context? 9 So, about half of the people - among those who said Α. 10 they'd been discriminated against looking for work, about half of them said they'd been denied job opportunities. 11 12 They also reported not disclosing their problem and being 13 quite concerned about that and keen not to tell; so, it's a kind of anticipated discrimination. 14 15 16 Ο. Did people report that they had not been hired because of their mental health problems? 17 They did, about 15 per cent of people. 18 Α. 19 20 Can you say on what basis that conclusion was reached? Ο. Well, it is difficult because of course you are going 21 Α. by what people themselves perceived, and of course it is 22 possible that they may perceive things differently to how 23 24 the person intends; it's very difficult to kind of tease that out. 25 26 27 But one of the things we did do in that survey with another group of people who actually did not report having 28 a problem or symptoms, we asked them whether they'd 29 observed - what they'd observed in others they knew with 30 mental health problems and the patterns were quite similar. 31 32 33 Ο. What did the survey report about people's treatment within the health system? 34 We again did - you know, people were more likely to 35 Α. report positive experiences but certainly some of the 36 things they talked about were, being treated dismissively, 37 not being listened to, and I think - and you know, what 38 39 Janet talked about this morning very eloquently highlights it, and I think one of the things we think about 40 41 discrimination in health services, people being seen just in the context of their mental illness and having the other 42 aspects of their health and life more broadly, like their 43 44 physical health, just being completely ignored. 45 Did the survey also reveal that people had positive 46 Q. experiences in the health system? 47

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A. Yes, certainly, yes.

Was the survey able to provide a proper basis on which 3 Ο. 4 to draw any conclusions about the behaviour of insurers offering or refusing to offer health coverage? 5 So, the numbers of people who had - because of course, 6 Α. 7 you know, a lot of people in the population, that situation 8 simply doesn't arise for them, so this is not probably the 9 best method to really draw conclusions about that, so the 10 numbers of people that reported were very small, so I wouldn't say that this is the best way to get at that, 11 12 yeah.

14Q. Can I ask you about your research on what it is that15drives stigma?

16 Α. So, we have looked at this. As part of that survey also, we asked people about their views about the 17 dangerousness of somebody with a mental health problem and 18 we asked also about their exposure to media reports, 19 20 whether they knew someone with a mental health problem or whether they'd had experiences of being afraid of or being 21 harmed by someone with a mental health problem. 22

24 Other literature - and this really did confirm that that people are much less likely to have stigmatising 25 attitudes if they know someone with a mental health 26 And that's because people are obviously - you 27 problem. know again what Janet was talking about today, talking 28 about the depersonalisation. If you know someone with a 29 problem, which of course is more likely to be depression 30 because it's a more common problem, you're more likely to 31 think about that in terms of the whole person in a more 32 Whereas if you don't know someone you might 33 complex way. be more likely to go just by stereotypes. 34

36 So that was one finding, that if you know someone it 37 confirmed that, you're less likely to have stigmatising 38 attitudes.

40 For the influence of media it seemed not particularly 41 strong for depression and I think that's because of what I 42 just said before, people don't just think about the 43 stereotypes.

But for schizophrenia, the media does probably play a greater role, because if you're only thinking about someone in a stereotypical way, the media is definitely one of the 1 influences on that.

2 In terms of the positive factors that can ameliorate 3 Ο. 4 against or prevent stigma, has the research indicated that 5 the most powerful factor is having knowledge of or a personal relationship with someone with a mental health 6 7 condition? 8 Α. Yes, that certainly seems to predict lower 9 stigmatising attitudes. So, interventions to reduce stigma 10 tend to obviously have that as a component, so they're known as contact interventions, so they usually involve 11 12 someone with a lived experience talking about their 13 experience, so that could be in person; it could be on a video, sometimes it's also imagined contact. The other 14 15 probable main --16 17 Q. Can I just stop you there. What do you mean by 18 imagined contact? Well, there are some studies that ask people to 19 Α. 20 imagine having contact with a person with a mental illness and then trying to create a more kind of empathetic 21 response to that person, some studies do do that, not so 22 It's more common to have an actual, hear an actual 23 many. 24 story from a person. Video is - using video testimonies is quite common because it's relatively easy to do. 25 26 You say this is common, but if we can put things in 27 Ο. the context of public health campaigns or interventions 28 29 from a policy perspective --Yep. 30 Α. 31 -- when you speak about contact interventions having 32 Ο. efficacy, what sorts of contact interventions, according to 33 the evidence, actually work? 34 Α. So it might be useful to maybe make a distinction 35 between a campaign which could be more like a media 36 37 campaign aimed at the general population or an intervention which might be, for example, people going into a classroom 38 at a school and talking about their experience. So, maybe 39 I'll make that distinction for the purposes of this. 40 41 Yes, so if you were to construct a hierarchy of 42 Q. things, leaving to one side close personal relationships 43 44 which are hard to regulate from a policy perspective --45 Α. Yes. 46 -- if you were to identify the kinds of things from a 47 Q.

1 policy perspective that work as contact interventions, what 2 are they? So, there have been a number of campaigns which 3 Α. 4 involve people talking about their experiences, education around myths and how to combat stereotypes. 5 Those are probably the kind of whole-of-population campaigns. 6 7 8 There are, in terms of more small-scale interventions, 9 so going into schools as I just described, or with health 10 and medical students, sometimes with employers, so they operate both on a kind of broad scale and on a smaller 11 12 scale. 13 So, is the common thread in those sorts of programs, 14 Ο. 15 having a person with lived experience speak about their own 16 lived experience? That's a common thread in what we call contact 17 Α. interventions. There's also what's called 18 psycho-education, which might not - which is more around 19 20 dispelling myths and giving correct information, and a lot of interventions combine those two components. 21 22 Is psycho-education effective without contact 23 Ο. 24 intervention? Yes, sometimes. Yes, they both - they both seem to 25 Α. have small-to-medium effects so far as we can tell. We've 26 done a systematic review and meta-analysis looking at the 27 effects of these interventions for severe mental illness. 28 29 Just on that analysis, focusing on severe to mental 30 Ο. illness, you've said that the research shows 31 small-to-medium effects. What do you mean by 32 small-to-medium in that context? 33 You can get - so we talk about effect sizes, and when 34 Α. they're small-to-medium it's a kind of - yeah, we can get 35 small changes in attitudes. In the short term what we 36 don't really know is the extent to which things are 37 sustained; often because we don't measure it and, sometimes 38 when you do measure it slightly longer term, the changes 39 seem to drop off. So, one of the things we need to know 40 41 more about is how to sustain those attitudinal changes in 42 the longer term, what might be needed for that. 43 44 When you say "drop off", do you mean that the changes Ο. 45 don't remain after the interventional program (indistinct)? For a long-term, we're not - so, one of those things, 46 Α. it's like it's not often measured, so can I say that it 47

definitely doesn't sustain? No, I can't, but we've got 1 2 some reason to suspect that it might not. So, you might need ongoing or top up type of interventions. 3 4 Alright. Can I now turn to asking you some questions 5 Q. about other jurisdictions. Was there a significant 6 7 campaign in the UK called Time to Change? 8 Α. Yes. 9 10 Can you tell the Commissioners what that campaign was? Ο. So that's probably been the best funded and best 11 Α. evaluated anti stigma campaign anywhere. It's mainly 12 13 involving - so there was a media campaign, social media, TV, various things, and also kind of mass contact 14 15 interventions which are often sporting events, so 16 encouraging contact between people with mental illness and members of the community. 17 18 Can I just ask you to slow down for a minute. 19 I would Ο. 20 like to get from you the elements of that campaign. So, can we start with television? 21 So, they would involve people with lived experience 22 Α. talking about that, talking about obviously again you know 23 24 the idea about dispelling myths and giving accurate information about mental illness. 25 26 So, television, social media? 27 Ο. Alright. Yes, also, similar, similar elements in the campaigns. 28 Α. Just, I guess, delivered in a different way. 29 So, similar elements and messages but delivered in a different way. 30 31 You mentioned sporting events, I think? 32 Ο. Yes, they had mass sporting events in local 33 Α. communities. 34 35 Do you mean sporting events with sponsorship related 36 Ο. 37 to mental illness, or something different? Α. Sponsorship: so, well, I guess the campaign was in a 38 sense the sponsor, but it was in order to promote contact 39 between people with mental health problems and the local 40 41 communities in a - you know, as a mechanism for doing that 42 really. 43 44 So, did the sporting events involve people with mental Ο. 45 health issues playing games? Participating. 46 Α. 47

1 Q. Participating? 2 Α. Yes. 3 4 Q. With people who did not? 5 Α. Yes. 6 7 Was there any other significant element of Ο. I see. 8 that campaign? 9 Those were the main elements. They also did some more Α. 10 tailored interventions, for example with medical students. 11 12 Ο. Yes. 13 Α. And some work with employer - employers as well, 14 businesses. 15 16 Ο. Were these different aspects of the campaign 17 coordinated? Yes, to some degree, yes. 18 Α. 19 20 Over what length of time did they run? Ο. So that's been going since about 2008, a bit more 21 Α. intensive in the earlier years, and they evaluated it with 22 an annual viewpoint survey. 23 24 Do you know whether it was run by a coordinating 25 Q. 26 agency? So, it's - yes, there was a campaign set up and it's -27 Α. it was funded by the UK National Lottery, so yes, there is 28 29 a coordinating agency, Rethink Mental Illness, yes. 30 Is one of the significant things about this campaign, 31 Ο. that it has involved evaluation of the results? 32 Probably been the best evaluated, so because they did 33 Α. an annual survey, and it's hard to evaluate these kind of 34 campaigns because you can never be sure. You know, they're 35 usually done with surveys at one time point and then later, 36 37 and of course you're never really sure if you haven't got a comparison community that hasn't had the intervention, it's 38 difficult to be sure, but within those you know restraint -39 constraints, yes, it's had a - it's quite well evaluated. 40 41 And what did the evaluation show? 42 Q. Α. So the most recent evaluation has shown that there 43 44 have been changes in attitudes which - so, I think that's most recently published in 2017, and that, given the 45 difficulties, that is a positive finding and most of those 46 changes were in the target group, which I think was people 47

1 aged about 24-44, so that's a positive finding for them. 2 What were the attitudes that had changed? 3 Ο. 4 Α. They have questions about beliefs about people and also they do look at the desire for social distance there. 5 So, more willing to have interaction, yeah. 6 7 8 Ο. Did the attitudes concern people living with more 9 severe mental illnesses? 10 So, I think that this is probably one of the sort of Α. caveats of this: their questionnaires that they use in that 11 12 campaign just ask about mental illness. And, as I sort of mentioned before, possibly what some of these campaigns do 13 is broaden the definition of mental illness to include 14 depression and, therefore, are you really capturing changes 15 16 in attitudes to people with severe illness, or are you broadening the definition of mental illness and people view 17 people with depression in a less stigmatising way anyway? 18 19 Everything has its limitations in that regard. 20 Yes, but can anything be learned from the evaluation 21 Ο. of that survey and the way the questions were asked about 22 whether the attitudes towards schizophrenia for example 23 24 were able to be shifted? I think we can say that it's possible that the 25 Α. attitudes have been shifted a bit with those kind of 26 caveats around it, yes. 27 28 29 Q. And, why is that, on the basis of that survey? On the basis of - yes, yeah, so --30 Α. 31 What did that survey reveal that allowed researchers 32 0. to conclude that there may have been a shift in attitudes 33 towards schizophrenia? 34 Well, because they do use the term "mental illness" in 35 Α. their questionnaires, and when most people hear that term 36 37 they think of more severe mental illness. Much less likely to think of depression, although that's possibly shifting a 38 bit. 39 40 41 Insofar as that survey showed a positive shifting in Q. attitudes, did it descend to working out what elements of 42 the campaign were particularly important in that? 43 44 That is more difficult. Α. 45 46 Q. Yes. Because it is hard to tell. Because, even if you ask 47 Α.

people - people don't always recall what they heard or saw.
So, you can make some assumptions, but it's very difficult
to be definitive about that.

I see. Can I ask you about the World Psychiatric 5 Ο. Association's campaign called Open the Doors and the 6 7 rolling out and evaluation of that in Austria and Germany? 8 Α. So, most campaigns either specifically have targeted 9 depression or they have targeted mental illness broadly, 10 but the WPA's Open the Doors campaign specifically targeted schizophrenia. And again, these were sort of more contact 11 interventions, people with lived experience talking about 12 their experience, and they had public events and some media 13 as well. And in both those places, they did, like, a 14 15 before and after survey.

17 So, in Germany, the campaign reach was very small. So, when they asked people in those surveys - you know, 18 less than 10 per cent of people in both those surveys had 19 20 even heard of the campaigns, so already the reach is small, so you've got to kind of think about it with that 21 limitation. In Germany it seemed that there were some 22 small changes in positive attitudes, but in Austria it 23 24 looked like actually some of the negative attitudes, including about dangerousness, actually increased. 25

And, the researchers working on that evaluation thought that possibly that was because not long before the follow-up survey there was a case that had quite a lot of high profile in the media, someone with schizophrenia shot someone, and they think that this impacted on the attitudes.

And I think this highlights a really difficult point in this area that, with all the work that people do in campaigns, one very high profile media event involving someone with schizophrenia is a very difficult thing to kind of mitigate against.

Has your research showed that one of the things that 40 Ο. is likely to be needed is to have more positive messages? 41 I think there is an argument for that. So, when we 42 Α. did our discrimination survey, what you often find is that 43 friends and family in particular are more likely to avoid 44 the person, and I think we know from this and other pieces 45 of work that we've done that most people I think want to 46 help, want to, but they often are stopped doing that 47

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because they don't want to do the wrong thing and make the 1 2 situation worse and say the wrong thing. 3 4 And I think a lot of stigma campaigns are about what not to do, and helping people know a bit more about what to 5 do and have confidence about what to do is something that 6 7 we should try and do and test and evaluate. So, certainly 8 an intervention like mental health first aid, which is 9 analogous to physical first aid but how to help someone 10 developing a mental health problem in a crisis, that's been really well evaluated and that's what that does; it gives 11 you guidance on how to help someone and that has 12 13 anti-stigma effects, that's pretty well-established. 14 15 Can you say a little bit more about that concept, Ο. 16 mental health first aid? So, I think most people are familiar with the 17 Α. Yep. concept of physical first aid which is about that really 18 short-term help to get someone into professional help; it's 19 20 a similar idea. And, it's a training course, usually two days, and it's designed for members of the public and it is 21 that: it's how to give someone that early help until they 22 get professional help. 23 24 Do you know where that's being trialled? 25 Q. Yes. So, that is run by an organisation, Mental 26 Α. Health First Aid, and that's guite widespread into 27 Australia. Actually I think it's now up to about 28 29 3 per cent of the population's been trained in that and it's spread to about 25 mainly high income countries. 30 31 Is it the case that that program's been evaluated for 32 0. anti-stigma effects? 33 Yes, in high quality studies, in randomised control 34 Α. trials, yes, several now. Not just in Australia, in other 35 countries too. 36 37 What did those studies show? 38 Ο. They do show reductions in stigmatising attitudes: 39 Α. beliefs about dangerousness, beliefs about not being a real 40 illness, and desire for social distance. 41 42 43 Is it relevant that participants in that had very Ο. 44 personal high contact experience with that educational 45 event? Well, it's a two-day course so, you know, certainly if 46 Α. you think about exposure, you know, some media campaign, 47

someone might just see one TV ad or two TV ads or a clip on 1 2 YouTube. I mean, that's obviously really different to doing a two-day course specifically about mental health. 3 4 Finally, in your statement with the 5 Q. Thank you. Commission, you say that: 6 7 8 "Reducing stigma is a process of bringing 9 about long-term cultural change." 10 If you were asked to recommend one thing, what would 11 12 that be? 13 Α. I think we should do those interventions at, I think it needs to be whole-of-system. So, of course the media 14 campaigns are very important, I think we need to know a 15 16 little bit more about the active ingredients in that. Tailoring to different groups. So, there's of course the 17 general population but you know, as has been again amply 18 described this morning, people in health services, people 19 20 in other services, to know a bit more about the active ingredients in those. How not to do harm, how not to 21 increase attitudes, because there is some evidence with 22 contact interventions that, if you can't relate to the 23 24 person or if their story's not positive, you're actually doing harm and increasing stigma. 25 26 And we need to know a bit more about how to use social 27 media. It's obviously in our world really important, can 28 be very polarising and negative, but it's also definitely 29 opportunities for intervention. 30 31 32 We need to probably know a bit more about the effects on social and economic participation, health service use, 33 and we should evaluate it and we should evaluate what we do 34 so we don't waste money. And, the survey we did, the 35 national survey, kind of offers the opportunity of that for 36 37 a baseline, that we could then repeat that survey in future years to see if there's been changes. 38 39 Sorry, one more question on social media: am I right 40 Ο. 41 that there has not been much, if any, research on the power of social media to prevent and mitigate against stigma? 42 Certainly we need more. I've done a small project 43 Α. 44 where we looked at the stigmatising language that people used on social media, and also the extent to which it was 45 being used to promote more positive attitudes, but we 46 definitely need to know much more about how that impacts on 47

1 people. 2 Thank you very much. 3 MS NICHOLS: Chair, do the 4 Commissioners have any questions? 5 Thank you very much. 6 CHAIR: No. 7 8 MS NICHOLS: May Professor Reavley be excused, please? 9 10 Yes, thank you. CHAIR: 11 12 **<THE WITNESS WITHDREW** 13 MS NICHOLS: Commissioners, would it be convenient to take 14 a 15 minute break now? 15 16 17 CHAIR: Yes, adjourn. 18 SHORT ADJOURNMENT 19 20 MS BATTEN: Chair, I understand there's a restricted 21 publication order in relation to the next witness. 22 23 24 CHAIR: Thank you. The Royal Commission has made an order pursuant to the Inquiries Act 2014 prohibiting the 25 publication of the surname of the next witness who is about 26 to give oral evidence to the Commission. 27 28 29 I'd like to remind all persons present or watching the live stream, including the media, that any material which 30 would enable the identification of the surname of this 31 witness cannot be published. 32 33 It is a criminal offence under the Inquiries Act for 34 any person to breach this order. A copy of the order has 35 been placed on the door of the hearing room. Counsel, you 36 37 may call the next witness 38 Thank you, Chair. The next witness is Teresa. 39 MS BATTEN: 40 I call Teresa. 41 <TERESA, affirmed and examined: [11.59am] 42 43 44 If you can just sit so MS BATTEN: Thank you, Teresa. 45 that you can speak into the microphone, just adjust it to make yourself comfortable. 46 Is that okay? 47 Α. Sure.

1 2 Thank you. Have you, with the assistance of the Royal Q. Commission team, prepared a statement that outlines your 3 4 experience with the mental health system? 5 Α. Yes. 6 7 I tender that statement. [WIT.0001.0009.0001] Teresa, Ο. 8 you grew up in a country town with your family, and you 9 went to the local school, and you had a normal family 10 upbringing with your mum, your dad, your younger brother and your older sister? 11 12 Α. Yes. 13 And your parents provided a safe environment for you 14 Ο. 15 where you could explore your interests which were primarily 16 reading and music; is that right? Yes, that's correct. 17 Α. 18 From when you were about 12, can you tell the 19 Ο. 20 Commissioners a bit about how you started to feel? I think, when I reflect back on my childhood, my 21 Α. earliest memories are memories of feeling uncomfortable and 22 feeling uncertain; they're not positive memories, despite 23 24 my family's upbringing. 25 And, I'd been living with these memories as a child 26 for a very long time, and I had this - I had a distrust of 27 my peers, I didn't know how to connect in. And, by the 28 time I got to about the age of 12, I think, I explored 29 these thoughts and reached the conclusion that my life just 30 The thoughts that I just kept having wasn't worth living. 31 were just so scary and I didn't know what to do with them, 32 that I just, I felt like I'd reached a point where there 33 was no other choice, that this would be the best option, to 34 end my life. 35 36 At that time, I didn't have means to do anything like 37 that, and it was one of the things that was always really 38 important to me, was thinking about the impact that that 39 decision would have on my family. So, obviously, I didn't 40 enact that plan and I just kind of kept on going and living 41 with that, but I had no idea what was going on or how to 42 talk to anyone about that. 43 44 45 When you say "about that", was it easy to tell other Ο. people what you were experiencing? Was it easy to 46 describe? 47

It was incredibly difficult to describe. 1 Α. Like, I 2 didn't understand, I didn't have any language to share it with people, and I felt so much shame that I had this 3 4 wonderful family and all of these opportunities, that this I just didn't feel like is what was going on in my brain. 5 I could talk to anyone, and there was no-one to talk to 6 7 about it.

9 When you were about 15, did you try and talk to a Ο. 10 school friend about it? Yeah. When I was 15, I happened to be in the school 11 Α. bathroom, doing something I probably shouldn't have been 12 13 doing, and this friend explained that she had recently reached out to the school counsellor about how she'd been 14 feeling and that that had been a positive experience for 15 16 her, and I thought, okay, well maybe that's something that would be worthwhile to do. 17

So, I got in contact with the school counsellor and 19 20 she arranged for my mother to take me to the local GP. The GP prescribed me a packet of antidepressants and, in short, 21 two days later I took the whole packet of antidepressants 22 because I didn't see that anyone was going to be able to 23 24 help me with what I was going through and I thought, well, I've got this available to me, I've gotta just give it a 25 26 qo.

I ended up in hospital. My parents found me the next day and I was conscious enough to describe what I had done, so they took me into the local hospital. I remember just feeling such deep shame about what I had done. I remember hospital staff making me feel like - telling me that I'd done something silly, and I just - I felt so, so alone and so stuck that I just honestly had no idea what to do.

It was offered that I could go and spend some time in an inpatient facility down in Melbourne, it was an inpatient facility designed for young people, and I knew I couldn't go home and face my family, I couldn't go to school and face friends at school, so I went down and spent two weeks down at that inpatient facility.

43 Q. Can you tell the Commissioners what the inpatient 44 facility was like?

A. I think the first thing is, it's incredibly
disempowering. Anything - everything that you have is
searched and even the most basic things are taken away from

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you. It was - I learnt, in some ways it was like a school for teaching you how to do things that are harmful for yourself, because it had never occurred to me that spray-on deodorant could be used in a harmful way until they took my spray-on deodorant away from me, and I was like, okay, that's something new.

8 And, you know, the staff were kind, but I don't recall 9 anyone being able to help me understand why my brain was 10 like the way it was. I could see that I didn't feel connected to the other people who were in there. I felt, 11 12 again, that shame of having a very supportive family and 13 home and I came away with the sense that I really need to pick this up myself and keep pretending that everything's 14 15 okay.

Just before we move on to that, can you describe how 17 Ο. you feel you were treated while you were an inpatient? 18 I think at that time, being an inpatient - like, 19 Α. 20 you're - you're not treated as a human, as a person, you're treated as a, kind of someone whose behaviour needs to be 21 managed and controlled, and everything that you do has to 22 be - you have to seek someone else's permission to do it, 23 and yeah, there was no kind of - I think my voice just 24 wasn't heard. 25

I remember being in a group therapy session and being challenged because I wasn't doing enough to explain what was going on for me, and it was assumed that I wasn't being compliant and that was the conversation; there was no understanding that it was incredibly difficult for me to talk about.

Q. You've said that you didn't feel that the inpatient
facility could help you at that time; is that right?
A. Yeah, there wasn't - I didn't get any kind of insight
into why I was like I was, and I didn't really get any
insight into what I would need to do to improve my health.

Like, I didn't come out of it with an understanding of a condition, or a story that was presented as a, well, here's a respite from your life; great, you've had your respite, now move on.

Q. Were you offered any follow-up treatment after you'd
been in the facility?
A. I must have been, because I remember when I returned

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to my hometown I remember going to see a psychologist in a 1 2 neighbouring town; there wasn't any services in the town that I was living in. 3 4 Q. So, how far away was that? 5 It was about an hour's drive, or maybe just under an 6 Δ 7 So, in order for me to get there my parents, hour's drive. 8 one of my parents, had to drive me there, and that was just 9 an incredibly difficult experience, because I'd spend more 10 time sitting in a car with a parent who I felt so quilty for feeling the way that I did, more time with that 11 experience than perhaps getting the help that I needed from 12 13 the psychologist. I don't - yeah, I don't really remember how that psychologist was able to help. 14 15 16 Ο. So, did you continue seeing the psychologist, or did 17 you stop seeing them? I don't remember entirely, but it didn't - I don't 18 Α. remember seeing them that often. I think I must have been 19 20 able - I was - the incentive to see the psychologist just wasn't there because it was too challenging to get to it 21 and, yeah, I just - I wanted to move on with my life and do 22 things to try and see if there was a different way I could 23 24 get better. 25 So, how did you manage your mental health from that 26 Ο. point? 27 I think, I mean, over a long period of time I 28 Α. developed a whole lot of different strategies. 29 I'd set goals for myself so that, you know, we'll just focus on 30 this thing that's going to happen and then, you know, don't 31 think about what's going on in your brain; you can make 32 that decision after you've done that. 33 34 Self-harming was always a big way for me to cope. 35 T'd started self-harming at probably about 12 or at the age of 36 12 or 13 when I first was trying to think through options 37 to end my life. The self-harming was always about testing 38 out how far I could go, but also was a really effective 39 mechanism for helping me feel calmer and in control. 40 And, yeah, I managed it that way and I managed to complete 41 Year 12. I did really well in Year 12. 42 43 44 You did really well and got into medicine at a Ο. 45 university? Yep. 46 Α. 47

1 Q. You tried to use the mental health system again at 2 that point? Yeah. 3 Α. 4 Can you tell us about that? 5 Ο. Yeah, I mean, I was really conscious that the thoughts 6 Α. 7 and the feelings that were going on in my brain hadn't gone 8 away, and I knew that studying medicine was going to be an 9 incredibly stressful thing. 10 And I also had this need that, if I was going to be a 11 12 good doctor and be able to help patients, I needed to be as 13 well as I possibly could be, so I reached out for support through the - there was a GP associated with the medical 14 15 school that I was in and she was really kind and really 16 supportive and referred me to a psychiatrist, and I saw 17 that psychiatrist a few times. 18 But it was - it was just so hard to explain what was 19 20 going on in my head, and I was so fearful that, if I started exploring that, I'd lose everything that I'd worked 21 so hard to achieve. So, I just - I didn't know how, and 22 there wasn't anyone who could help me kind of find that 23 24 safe space to actually talk about what was going on. 25 And I think that kind of, from that point on I kind of 26 entered into this cycle of reaching out for help. 27 Generally you go to a GP and you get referred, and it just 28 became my life as an adult, became this cycle of things 29 getting bad, or something happening that meant that I'd go, 30 okay, I've got to be a bit more proactive about this. 31 I'd reach out for help, get referred, and yeah, none of those 32 really helped me get to the bottom of what was going on. 33 34 35 0. You went to the emergency department a few times in this period. 36 37 Α. Yeah. 38 Can you tell the Commissioners about what it was like 39 Ο. going to the emergency department and trying to get help 40 that way? 41 So, there was a couple of times where things 42 Α. Yep. would become so distressing that I would use whatever I had 43 available to try and end my life, and I ended up in the 44 45 emergency department, probably about four or five times. 46 The emergency departments are not designed to support 47

and understand what's going on for someone who's incredibly vulnerable and distressed. I think they're incredibly public environments, everyone's got too much - there's too many things going on, no-one's got time to really explore.

6 And generally what would happen is, I'd get into the 7 emergency ward, eventually I'd see a psych registrar, and 8 the message that I heard consistently was that, you don't 9 want to enter the public mental health system, it's not a 10 system for people like you, go to your GP, go get a 11 referral, that's your best option of getting the treatment 12 that's going to help you.

- Q. You mentioned that in the emergency ward there's no opportunity for privacy and you have to speak to someone in front of everyone else. Can you tell the Commissioners a bit about what that feels like?
- So, you're in a bed and they'll come into your bed and 18 Α. they'll draw a curtain, a very flimsy curtain to separate 19 20 you from the person next door, and most of the time you can hear what's going on for the person next door, and they'll 21 say, "Oh, so tell me what brought you in today." 22 And you'll explain that you tried to overdose, or you - however 23 24 the mechanism you use. And they'll say, "So, why did you And you hear between you and this flimsy curtain do it?" 25 the person next door, and there's just no - no place. 26 You don't know the person that you're talking to, you don't 27 know the answer as to why you've ended up here; it's just, 28 29 this impossible situation.
- And it's the same experience: like, I remember at one 31 point I got moved up to a ward and it was the same 32 The doctor comes in, draws the curtain, you've 33 experience. got the person next door to you and you're expected to open 34 up about something that's so painful, and so scary to you, 35 that it's forced you into thinking that the best option is 36 37 to end your life. Yeah, I don't know how else to, it's just --38 39
- Q. I think you've done really well. Teresa, can we talk
 about diagnosis. In the early 2000s, did you get a
 diagnosis?
 A. Yeah. So, I don't really remember how the diagnoses
- A. Yeah. So, I don't really remember how the diagnoses
 came up, but I think I recall that it was within the someone at the emergency department said to me, oh, I think
 that you've probably got this, and that diagnosis that I
 was given was borderline personality disorder, and that was

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amazing on one level because now I had something that I could research, that I could look into and try to understand what - how I could get better and how I could recover.

And, I was very proactive about it. I flew up - I recruited my friend and we flew up and went to maybe - I think it might have been the first Australian conference on borderline personality disorder. I, you know, purchased textbooks, I did all of the research that I could do to try and find something that would be a suitable program.

13 At that time, in the early 2000s, there wasn't many programs available. I think even in the private health 14 system there wasn't that many programs available, and when 15 16 I'd ring up or when someone would ring up on my behalf, because it's really hard to - when you're feeling really 17 vulnerable it's really hard to ring up and talk to people 18 about what you're experiencing, I would just get told, oh, 19 20 I didn't fit the categories, yeah.

22 Q. What were some of the categories, what were some of 23 the reasons why you didn't fit?

24 Α. Some of it was about location, some of it was about earning capacity, and some of it was about the severity of 25 the symptoms. Yeah, I've always been fortunate that I've 26 been able to keep myself going and stay well enough so that 27 I can be educated. I have a masters degree and I have a 28 relatively successful career - not as a doctor - but still, 29 a relatively successful career. So, I've just - I've never 30 been - it's that thing of, I've never been bad enough to 31 meet the criteria. Another time I was too old, just missed 32 the cut-off for Headspace at that particular time. 33

35 Q. Can we move to 2015. You became pregnant at that 36 time.

37 A. Yep. 38

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And you said, you knew becoming a parent would be 39 Ο. challenging for you to maintain your mental health, and at 40 41 that point you reached out for support. Can you tell the Commission a little bit about what you did to try and get 42 support at that point? 43 44 So, I'd fallen pregnant and, as you said, I Α. Yeah. 45 realised that that was likely to be quite a stressful

46 environment. So, I was receiving some amazing care through
 47 my pregnancy at one of our public hospitals. I also have

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1 type 1 diabetes, so I was considered a high risk pregnancy 2 for that reason, and I was able to access just phenomenal 3 care to support me with my diabetes through my pregnancy.

And, it occurred to me as I was going through that 5 process, that possibly it would be worthwhile linking in to 6 7 the services available at that hospital, so I spoke to 8 someone and reached out, but by the time I got the call to 9 organise an appointment, it just felt like the risk of 10 going back into the system was too high and I had created all of this - I had created this fear that, because of the 11 12 condition that I had and the diagnosis that I had, that I 13 might be considered by the medical community as someone who wouldn't be fit to be a mother and I hadn't had an 14 15 experience of being able to get help; the thing that had 16 helped me the most was whatever strategies I could put in 17 place to manage it. So, when that support was offered, I declined it. 18

20 What about once your baby was born with the maternal Ο. child health nurse; did you feel you could talk about how 21 you were feeling in your condition with that nurse? 22 I think, again, I think because of the 23 Α. No. 24 associations around something like a diagnosis of borderline personality disorder, I was so fearful that my 25 child could be taken away, or that they would say that I 26 was a bad mother, that I didn't feel like I could share it 27 with the nurses. 28

The nurses have a very kind of standard approach. I think my perception - and some of the nurses that - I've had experience with a range of different nurses, and some of them have been quite supportive, but some of the nurses are very, this is how you do it; if you don't do this then you're not doing what's right for your child.

Some of the conversations that I had with nurses 37 really cemented for me this idea I had in my head that 38 maybe I wasn't going to be a good mother for my son, 39 because I wasn't making - they made me feel like I wasn't 40 41 capable of making good decisions for my son, so I would just - yeah, I'd - despite the fact that being a mother was 42 incredibly stressful and my brain was flying out with all 43 44 sorts of terrifying and scary thoughts, I didn't talk to 45 anyone about it.

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Q. Last year, Teresa, things became really challenging

1 for you; can you describe what happened when things became 2 challenging? Yeah, so I think - I mean, I'd had this incredibly -3 Α. 4 becoming a mother is one of the most challenging experiences, and I think it is for everyone, but I think 5 for me it brought up all sorts of thoughts about whether or 6 7 not what I could do to protect my son from ending up like 8 me, and whether or not I was doing enough, and it was just 9 an incredibly stressful time. 10 And, for whatever reason, I became just incredibly 11 12 distressed by it and consumed by thoughts of harming myself 13 and harming my child. It was one of the most scary things for me, and I knew at that point that I had to act to 14 15 ensure the safety of my son. 16 So I again reached out to a GP and he took me 17 seriously enough that he - I didn't share a whole lot with 18 him, but he took me seriously enough that he gave me - told 19 20 me to come back in a day or so and gave me the number of the local CAT Team and just said, look, if things get 21 worse, this is what you do, you call this number. 22 23 24 So, things did get pretty bad later that night, so I called the Cat Team, and again, the person I spoke to on 25 the Cat Team took me seriously and said, "Look, I think you 26 should come in so we can talk to each other face-to-face", 27 so he organised for an ambulance to come and pick me up and 28 29 he met me at the emergency department, or at least that's how I recall it. 30 31 And, this emergency department was different. 32 It's like, if you were suffering from mental health, you got 33 separated into a different space. I'm not sure if it was 34 actually the case, but I recall it being like I had my own 35 room, so when people would come and talk to me and ask me 36 what was going on, I had that sense of privacy. 37 38 So, it was a different experience to what had happened 39 in the past, and it was quiet. There was another patient 40 in, but it was quiet and there was somewhere where I 41 could - there was a couch where you could play a game, or 42 there was something to do, you weren't just confined to a 43 44 bed. 45 After they assessed me, they suggested that I get 46 admitted, and knowing - like, at that stage my ability to 47

1 make any decision was completely gone, so I said, yes, and 2 agreed, so I was admitted as a voluntary patient.

Entering a psych ward as an adult is an incredibly confronting experience. When a bed was made available for me, I was put in a wheelchair - and I'm used to being put in a wheelchair in hospitals, I've been there, done that, that's fine - but when you're getting admitted to a psych ward you're followed by two security guards who walk behind you, I assume to make sure you're not going to do anything dangerous - I don't know. I've never been in an environment where I've been followed by security guards before; it was incredibly confronting.

And then, when you enter the psych ward, they take everything, they search everything. You're warned about other patients and having any kind of belongings with you that you wouldn't want to lose. You're encouraged to lock everything up for safety, which means that you don't have access to anything without getting permission.

And, yeah, it couldn't be a different environment to 22 the world that I had been the week before, where I was a 23 24 senior leader and manager in a large government organisation, to now being - having to go and ask 25 permission to access things that I needed to keep me 26 healthy, so things like things for my diabetes. They took 27 away my insulin pump, which is what I use, because they 28 were concerned about my safety, of having that much insulin 29 available, which meant that I had to compromise the care 30 that I have for my diabetes. 31

I don't - I've always used an insulin pump, to go back 33 on needles is incredibly different and, you know, in 34 order to test my blood sugar and to get insulin I'd have to 35 talk to the nurses. So, I remember the first night having 36 an incredibly high sugar level and just not being able to 37 do anything about it because, in order to get access to 38 insulin I'd have to get a doctor to come and sign off that 39 it was okay for me to take my insulin, so it was incredibly 40 41 scary. 42

Q. Ultimately, you've said that the hospital experience
overall was very positive?
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Q. What was positive about it, what was the outcome of

being in hospital at that time that was positive?
A. So, after I got over the first shock and, I guess,
proved myself to be somewhat able to maintain my own
safety, I was able to access doctors, and in particular a
psychologist who seemed to really understand where I was
coming from.

8 I felt really heard and understood, and it was a 9 process of being able to - yeah, for the first time I felt 10 like they were interested in me and they could see my value 11 as a human being and were interested in supporting me.

And so when, like at one point they talked to me about discharging me, and I didn't feel like I was ready for that because I was really worried about what I was going back to, and they listened to me and they let me stay for longer and connected me in with a service that would help me transition out of hospital.

And that service that I was able to access post the well, during my hospital stay and post hospital stay was absolutely incredible and has - I credit it with being able to get me to the point where I am able to sit here, I'm back at work full-time, and able to share my story.

What did the service offer that enabled you to get to 26 0. this point? 27 So, the first thing the service did was that they 28 Α. 29 would - when I was in hospital they said that, we're going to turn up at this time, and they turned up at that time. 30 And that just - it sounds like such a little thing, but 31 that was the first thing that they - I guess, the first 32 time I was able to have some control over my time and where 33 I was at any other point. 34

And the service that I was offered was a - I don't know how they describe it themselves and how they describe it to get funding, but for me the service was having people who would check that I was okay and help me navigate through the process of getting access to support that would help me in the long term.

One of the things that I learnt through my hospital stay, is that, this condition that I've got is not gonna go away, and I will get better and I've got lots of strengths that have helped me be here today, but that I do need to invest in quality therapy with someone who I can connect in

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with. So this service in the hospital helped me find a private psychologist where I'm able to do that therapeutic work that I need to do.

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The service did these incredibly basic things: like, 5 they drove me to the appointments and helped me introduce 6 7 myself when I didn't know how to do that for myself. When 8 I got out of hospital, I felt so much shame for where I had 9 been and felt like I had lost so much because I had gone 10 from, you know, doing this great job of pretending I was this successful working mother, to having to face up to all 11 12 of the struggles that I've had over my life, and I was 13 terrified of seeing people that I knew, that I worked with, because I just didn't know how - and I was, my brain was so 14 15 confused at that time, I had no idea how to explain it.

Q. And so, what's brought you to this point? Why have
you decided to be open about your mental health after that
hospital admission?

A. So I think it's been an overall kind of - like, it's been an iterative process from me and I'm slowly testing it out. This is one of the biggest things, this is the most open that I have been.

I think when I recognised that - when I was in hospital I recognised that it was my fear and shame about what I had been going through that had really prevented me from being able to access support, and I didn't - it just didn't make sense and I didn't want someone else to feel that way.

I also felt like, I think we need to hear stories of people who have had a positive interaction with the mental health service, I think it's really important, because I think you need to know that things can be - that you can help and I'm so grateful for all of the people who have been part of my life and who have helped me.

And I think, because in my work I'm in a leadership position, and I think that puts a responsibility on me to stand up and say, this is what my experience has been and I'm still a worthwhile person, I've still been able to achieve so much despite struggling with something that no-one wants to talk about.

46 Q. So, what did you say when you went back to work? What 47 did you tell your colleagues? A. So, when I went back to work - I think the other thing that, just a little kind of contextual thing I think, because I was able to connect my hospital stay with having a child, I was able to kind of grab on to one of the least, stigma-free mental health illnesses, so I was able to tell people I had postnatal depression which is one of the ones that kind of is a bit more acceptable.

I didn't necessarily use those words with my colleagues, because I still feel a bit like a fraud saying I had postnatal depression. But when I went back I deliberately explained that, yep, I've been in a psych ward and it was really hard, and that I had, you know, through that process been able to see all of the things that had contributed to me getting to that level of distress and that I knew that I needed to take responsibility for my own health and that's what I was doing, and I continue to have those conversations at work where I feel safe to do so.

20 What are some of the problems that you see with the 0. 21 mental health system? I think it's got a bad reputation, hasn't it? 22 Α. I think that there's a bit of a thing of not - it comes from a 23 24 place of treating people as, like they're lacking, and it forgets that we're talking about humans, and humans are 25 complicated, and there's so many things that can 26 contribute. 27

I think it's hard, it's based on a medical model that 29 says that you can be fixed within a certain time period. 30 Ι mean, I've accessed the Medicare ten sessions numerous 31 times and then stopped after ten sessions because I've 32 gone, well, I must have failed, I didn't get myself fixed 33 in those ten sessions and no-one's gonna offer me more ten 34 sessions, so I must be fixed if I've done what those ten 35 sessions, that they're allocated to. 36

I'm lucky that I can have the financial resources now 38 that I can fund and that I understand that the brain that 39 I've got needs lots of care and attention, and so, I'm able 40 to put my resources into weekly therapy sessions. But it's 41 been hard for me to kind of think that through and go, ah, 42 43 is that where my money should be going? Should I be - am I doing enough? Am I getting enough out of those sessions? 44 And that's been something that I've had to kind of work 45 through and go, okay, that's just where your money's going 46 to go at this point and that's the best thing that you can 47

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1 do for you and your family.

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Yeah, I think there are good things in the system, 3 4 there's some people who really deeply care, but you've always got to remember that you've got, the people who you 5 are treating are incredibly vulnerable and the problem is 6 7 generally with their thinking and their brain, so you've 8 just got to be so sensitive to what might be going on for 9 them, and I think it's really hard to advocate for yourself 10 when your brain - when you can't even trust what's going on in your brain. 11

13 Q. Just finally, Teresa, you said at the end of your written statement why you've made a public statement. 14 15 Would you like to either read that or paraphrase why you've made the decision to make a public statement? 16 17 Α. Yeah. I mean, the thing for me is, I reflect back on my life as a teenager and I think about my son and the 18 world that he's growing up in, and I think about all the 19 20 stories that we hear of people who are struggling, and I wanted to make this statement to say that, you are actually 21 worthwhile and you are okay, and you deserve to get help, 22 and you deserve a system that actually works for you. 23

And, every time it's hard, you've just got to keep on going and reach out because you matter and your voice matters and, for us to hear your voice, it needs to be here.

30 MS BATTEN: Thank you very much, Teresa. Chair, are there 31 any questions from the Commissioners?

I've got one I'd like to ask. 33 CHAIR: 0. I think you talked, Teresa, about the impact of you when you sought 34 help and were told you were either too old to access that 35 service, not sick enough to access that service, I can't 36 37 remember exactly the other words you used. But can you just help us to appreciate what that meant for you at that 38 time? 39

It meant that I was alone, that there wasn't anything 40 Α. there, and I had to work out my way by myself. 41 And it also meant that, I guess, it made me feel like I was so 42 difficult, that there was something wrong with me; or on 43 other the side it was, well, maybe I'm not difficult enough 44 because I'm not worth helping, and it made me feel like my 45 life didn't really matter and my experience didn't really 46 47 matter.

1 2 CHAIR: I think you've shown us very much about how it does matter, so thank you. 3 4 MS BATTEN: Thank you, Chair. May this witness please be 5 excused? 6 7 8 CHAIR: Yes. 9 10 <THE WITNESS WITHDREW 11 12 MS BATTEN: If this is a convenient time, I think we might 13 break for lunch. 14 15 CHAIR: Thank you. 16 17 LUNCHEON ADJOURNMENT 18 19 UPON RESUMING: 20 Thank you, Chair. 21 MS BATTEN: The next witness is Dr Chris Groot. I call Dr Groot. 22 23 24 <CHRISTOPHER JOHN GROOT, affirmed and examined: [2.01pm] 25 26 MS BATTEN: Ο. Thank you, Dr Groot, would you please make yourself comfortable and make sure the microphone is 27 in the right place. 28 29 Α. Yes, can you hear me okay there? 30 31 I can, thank you. Can you please tell the Ο. Commissioners what your current roles are? 32 Certainly. I am a lecturer in the Melbourne School of 33 Α. Psychological Sciences at the University of Melbourne, 34 where I co-ordinate the undergraduate clinical psychology 35 teaching, direct the Mental Illness Stigma Research Lab, 36 37 and I'm also the research lead on the National Stigma Report Card Project, which is a project led by SANE 38 Australia in collaboration with the School of Psychological 39 Sciences and with the support of the Paul Ramsay 40 41 Foundation. 42 43 I will ask you some questions about the National Ο. 44 Stigma Report Card Project, but I wanted to ask you some questions first about some of the other research projects 45 you're working on. Could you tell the Commissioners 46 briefly about the work you're doing in the Hearing Voices 47

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A. The Hearing Voices Project is a very exciting teaching, curriculum development and research initiative that is, again, being delivered in partnership with SANE Australia, Dr Michelle Blanchard, and the Dax Centre, which is a centre comprising a gallery that has a repository of art produced by people with lived experience of mental illness.

10 In a recent review of the undergraduate clinical 11 psychology curriculum at the University of Melbourne, I 12 observed that there was nowhere in the curriculum where the 13 voice of people with lived experience was valued or present 14 in that curriculum.

So, the Hearing Voices Project aims to address this. Last year, we trialled taking our first year students, of whom we have roughly 2,000 each semester, to the Dax Centre where they received a guided tour of the art produced by people of lived experience and where they got to hear from a SANE Australia lived experience ambassador directly about that experience and have a question and answer session.

24 This all came together very quickly and we did a quick evaluation which was very positive in terms of the outcomes 25 both pedagogically, in terms of students enriched 26 understanding of mental illnesses and mental health issues, 27 but also in terms of stigma and stigma reduction; we had 28 29 students reporting across the board that they were less fearful of people with psychotic illness, for example, now 30 that they had actually met somebody with that experience 31 and heard from them directly. 32

We heard that students were more willing to seek help in theory in the future should they experience mental health issues themselves. So, building on this pilot and our evaluation, we were lucky to secure grant funding from the Melbourne Engagement Grant Scheme and we are now, this year, semester 2, coming up very shortly, rolling out the program for the entire 2,000 first year students.

So, the aim here, again, is to enrich and contextualise the information that I provide in lectures and to give people of lived experience an opportunity to tell their stories, and to let students know what they think they should know about what their experience is like, and indeed, that has been our process throughout.

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2 As we have filmed videos - so we're doing this via videos and live streams rather than having someone do many, 3 4 many talks. I have worked with SANE lived experience ambassadors at their direction essentially and posed them 5 the question, what would you like students to know? 6 So 7 it's really about valuing lived experience, destigmatising 8 experiences of mental health issues and mental illness 9 through an education program which, we hope in turn, 10 translates into an emerging workforce that is more compassionate, has better insight into the reality of lived 11 12 experience, and a more socially responsible and 13 compassionate graduate cohort, essentially. 14

Q. I'll come back to some of your other research projects in a minute, but can you tell the Commissioners about your background in large-scale mental health service delivery, specifically what telephone and online services have you been involved with?

A. Sure. So, I've been involved in the telephone and
online mental health service sector at numerous levels.
Originally at the very start as the person on the phones
working on services like the Suicide Call Back Service and
the Beyond Blue Info Line back in the day.

Subsequently, I directed the Clinical Services and 26 Research Department for a range of these services, 27 including the Suicide Call Back Service, Suicide 28 Line Victoria, the Defence Force Mental Health Services, 29 the Vietnam Veterans Counselling Service after hours line, 30 There was quite a few of them, yes. Beyond Blue. 31 Generally all very high risk services and very relevant to 32 what we're talking about today. Certainly in our 33 evaluation and research data a very consistent theme was 34 that people who were affected by stigma and reluctant to 35 seek help face-to-face would commonly go to a telephone or 36 37 an online counselling service as a first step because of this. 38

Just briefly, and at a higher level, what did the 40 Ο. research involve for those telephone and online services? 41 These services were either state-based or national in 42 Α. terms of their scope and their reach, and the research and 43 44 evaluation fulfilled a number of roles including regular analysis of service data, detection of emerging themes, 45 particularly around risk and at risk groups. The majority 46 of the services were high risk services. 47

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In addition, we developed a range of new service paradigms, trialed new service paradigms and disseminated those findings to government, to the scientific and clinical sector both in Australia and internationally.

7 Can I turn to the issue of mental illness stigma. Ο. 8 Associate Professor Reavley gave some definitions of how 9 she defines the term for her research, but for the purposes 10 of your evidence it would be helpful to understand your definition. So, could you tell us how you would define 11 12 mental illness stigma for the purposes of your research? 13 Α. So, that's a really interesting question. There are a range of descriptions and taxonomies of stigma that have 14 15 been provided over the last 70 years essentially. They are 16 generally variations on a theme, and certainly my take is very similar to Professor Reavley's take, in that I 17 consider mental illness stigma to be a multi-dimensional, 18 very complex construct, but for the purposes of today's 19 20 evidence, I think it's useful to draw on a taxonomy provided by Pryor and Reeder, which breaks the construct 21 into four elements, which are: structural stigma; public 22 stigma; self stigma; and stigma by association. 23

Can we just take each of those in turn and can we 25 Q. start with public stigma. Can you explain to us what you 26 mean when you say public stigma? 27 So, public stigma, according to Pryor and Reeder, 28 Α. involves the - and we heard this this morning as well -29 public attitudes and behaviours, but also, I do a lot of 30 work including emotions as well. So, public stereotyped 31 attitudes, prejudicial emotions and discriminatory 32 behaviours towards people with lived experience of mental 33 illness; that's what we talk about when we talk about 34 public stigma. 35

Q. Can you give an example of public stigma?
A. Yeah, so in this morning's discussion the stereotype
of violence and dangerousness about schizophrenia came up,
and that is because this is one of the core and enduring
and arguably worsening attributions about schizophrenia and
severe mental illness.

44 So, if I was a member of the public and I held the 45 stereotyped attitude that people with schizophrenia are 46 dangerous and unpredictable and potentially violent, then 47 my emotional response will be one of fear, and my

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behavioural response would be one of avoidance. And again, this might be in terms of social distancing, limiting the amount to which somebody with schizophrenia could be in my life as a colleague or a friend or an intimate partner and so forth.

Q. I think it's important to clarify: you said that
that's a stereotype. Is that stereotype accurate, of the
dangerousness?

10 The dangerousness, no. Well, let me say no with a Α. So, no, the majority of the research that we have 11 caveat. 12 highlights that people with schizophrenia are far more 13 likely to be victims of violence than perpetrators of violence, and indeed there's literature indexing that 14 15 people with schizophrenia report being victims 14 times 16 more often than there is an instance of perpetration.

And I think anybody is capable of violence given the correct circumstances, and I think today we heard a lot about how lacking system resources could maybe set the scene for isolated instances of violence.

But the link between schizophrenia and violence is 23 24 really yet to be fleshed out well in the literature. There is a lot of literature addressing this, and in fact in the 25 empirical literature itself there is a systematic bias in 26 terms of the proportion of the literature that's looked at 27 schizophrenia and violence; the majority of it looks at 28 people with lived experience of schizophrenia as 29 perpetrators rather than examining the issue of being a 30 victim. 31

So, we were going through the four elements of stigma, 33 Ο. and you discussed public stigma for us. Can you explain 34 what you mean when you say structural stigma? 35 So, structural stigma is stigma that's manifested at 36 Α. an institutional or a societal level and powerful bodies 37 within society, and it's often manifested via 38 discriminatory laws and practices and ideologies that 39 restrict opportunities for people with lived experience of 40 41 mental illness. 42

Q. Are there two aspects to that: is there unintentional
and intentional structural stigma?
A. Yeah, that's right. So, Pat Corrigan, one of the
world's leading stigma researchers, would say that there's
unintentional stigma - sorry, unintentional structural

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stigma which comes about, as the name would suggest,
 without the intention to discriminate.

We've heard today a lot of discourse around mental health system resourcing; arguably, this could be said to be an example of unintentional structural discrimination, where there is a pot of funds, if we even zoom out to the health system generally, there is a pot of funds to be distributed across medical and mental health, and maybe mental health does not get the resources that it actually requires as a system to adequately serve the need.

13 And within that system itself, Pat McGorry talks, for example, about the missing middle and this idea that - so 14 15 many of the system resources are targeting high prevalence 16 disorders such as mild to moderate anxiety and depression, however there is a vast proportion of people who experience 17 other disorders more complex and severe, and persistent and 18 severe and episodic conditions that require more resources 19 20 that are not currently on the radar really in terms of the amount of funds they receive. 21

Just to clarify there, why is that unintentional 23 Ο. 24 structural stigma, why is that? That's a really good question. So, it's 25 Α. unintentional, Patrick Corrigan would say, because those 26 who would be, in plain terms, sitting around the table and 27 carving up that pot of money, did not have the intention to 28 29 explicitly discriminate against people with schizophrenia; it's an inadvertent outcome of limited system resources. 30

32 Q. I have some more questions about that, but we'll move 33 on. Does structural stigma exist in relation to agents of 34 the mental health system?

Agents of the mental health system, yeah, that's 35 Α. absolutely right. So, this can manifest in various ways. 36 The classic example is for people who live with borderline 37 personality disorder. This is historically a very 38 stigmatised disorder within the mental health system and 39 people who work in the mental health system, and I'm 40 41 obviously speaking in very broad brush strokes right now, and this is well-established in the face-to-face 42 literature, so face-to-face mental health service delivery 43 44 in an emergency department, mental health service delivery 45 and so forth for example. We know that the label of borderline personality disorder elicits stigmatised, again 46 cognitive, emotional and behavioural responses from a range 47

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of mental health workers, from nurses through to 1 2 psychiatrists, and there's a range of moderating and mediating factors here. 3 4 And this is actually a perfect example of how 5 structural discrimination at the level of an agent, who is 6 7 really responsible for delivering clinical support and 8 care, can disintegrate that care, in that, one of the 9 common hallmarks of borderline personality disorder can be 10 a fear of abandonment. 11 12 Now, if I am a clinician who holds stigmatised 13 attitudes towards people with borderline personality disorder and my attitude when I meet a new client is that 14 15 this person is going to be difficult to work with, I'm 16 going to distance myself in that therapeutic alliance, and my client will have insight into this, and no doubt that 17 will trigger that fear of abandonment and from that 18 point the process disintegrates. 19 20 Still moving through the elements of stigma, you've 21 Ο. said that self-stigma has multiple components. Can you 22 briefly explain what the elements of self-stigma are? 23 24 Α. Yes, so within Pryor and Reeder's taxonomy, self-stigma would refer to the direct negative outcomes and 25 experiences of discrimination, whether it's as a result of 26 public or structural discrimination, so the direct negative 27 experience of being denied employment, for example, as a 28 result of one's experience of mental health issues. 29 30 They would go on to say that self-stigma also involves 31 anxious anticipation of future instances of such 32 discrimination, and also, you could extend that to the 33 phenomenon of withdrawal from opportunity. If I've had 34 this negative experience and tried to access employment, 35 for example, before then I'm going to anticipate that this 36 37 will happen again and I would be less likely to try if my expectation was negative. 38 39 The last, but very important aspect, is 40 41 internalisation of, for example, public stigma. So we've all grown up in a society and a culture that does 42 stigmatise mental illness, and if one starts to develop 43 44 signs of mental illness or mental health issues, then that's very difficult to grapple with. 45 46 If one is aware of public attitudes, agrees with those 47

attitudes, and applies those attitudes to the self, then we 1 2 see damage to self-esteem, exacerbation of depressive symptomatology and so forth. 3 4 Finally, just very briefly, what is stigma by 5 Ο. association? 6 7 Stigma by association is very similar in Pryor and Α. 8 Reeder's taxonomy of self-stigma, but it's experienced by 9 family, carers, people who are supporting people with lived 10 experience, experiencing stigma vicariously because of that association. 11 12 13 Ο. I think you started to elaborate on this, but why is public stigma considered the driver of the three other 14 15 forms of stigma? 16 Α. Yeah, so public stigma is certainly considered to be the driving force, it's the touchstone, I suppose the 17 reference point, for self-stigma. It is the attitudes and 18 emotions that policymakers inevitably bring to the table in 19 20 some way, even implicitly, when they draft or contribute to the drafting of policy, for example, that might 21 discriminate against people with a lived experience. 22 23 24 And actually, that's a really interesting point that I sort of skipped over before: there's another layer of 25 stigma that we do think about beyond attitude and that's 26 actually the subconscious, we think about implicit biases 27 as well, although the link between that in particular and 28 29 behaviour is particularly tenuous and complicated. 30 31 Can we move on to the current knowledge on stigma and Ο. discrimination. You've stated: 32 33 "A fundamental tenet of modern 34 psychological practice is the notion that 35 thoughts often drives emotion and 36 behaviour." 37 38 Can you explain how this concept applies to public 39 40 stiqma? 41 Α. So, I think with public stigma again, when we Yeah. think about behaviour as the observable component of public 42 stigma, we think about discrimination, and that 43 44 discrimination around public stigma is very often something like avoidance or social distancing, but it can be much 45 more subtle than that. 46 47

There's literature that's examined, for example, public stigma and discrimination manifested in terms of reduced eye contact during interaction with somebody with lived experience. And it is very important to examine behaviour and discrimination, but always I think it's equally important to examine the problem as holistically as you can and consider how cognition and emotion also feed that behaviour.

10 And so, all of the research that we've done to date in 11 the Mental Illness Stigma Lab at the School of 12 Psychological Sciences includes, in any given study, 13 measures of cognition, emotion and behaviour so that we can 14 really understand these causal pathways that ultimately 15 result in what we're interested in, the discrimination, the 16 manifestation of stigma.

Can I ask you about your research into diagnostic 18 Ο. The lab has undertaken work examining the role of 19 labels. 20 psychiatric labels and how they elicit stigma. Can you explain to the Commission what that work's involved? 21 Absolutely. This is actually what first caught my eye 22 Α. in the world of stigma. Stigma was not my background, my 23 24 background was in the cognitive neuropsychiatry of hallucinations with Henry Jackson and Susan Russell. 25

There was a wonderful review of the literature on 27 re-labelling schizophrenia by Antonio Lasalvia a few years 28 ago and this weighed in on all the literature surrounding 29 this idea that re-labelling schizophrenia would reduce 30 stigma about the disorder, and there are a range of labels 31 32 that have been produced, essentially either eponymous labels, which are labels named after somebody that are 33 thought to be effectively neutral and carry no stigmatising 34 connotations, and there's also informative labels that are 35 thought to be destignatising through the provision of some 36 psychoeducation such as attention deficit hyperactivity 37 disorder that tells you about what's going on with that 38 experience and is a little bit demystifying, which is 39 thought to help with stigma reduction. 40

42 So, we embarked on a program of experimental research 43 looking to see if alternative labels would reduce stigma in 44 terms of cognition, emotion and behaviour about 45 schizophrenia, and the answer was, no, we did not observe 46 any meaningful reductions in stereotyped attitudes, 47 prejudicial emotions or discriminatory behaviours.

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1 2 But we did also attempt to operationalise the heterogeneity of schizophrenia which of course presents in 3 4 many different ways for many different people. Some people might experience hallucinations for example, and others may 5 not, and so, we have looked at replacing the label of 6 7 schizophrenia with another label as a function of illness 8 phase, looking at active and remitted illness phases; we've 9 looked at positive and negative symptoms, and we've since 10 embarked on a program of research that's drilled down to responses - again across attitudes, emotion and behaviour -11 12 to individual symptoms and symptom subtypes, and we've 13 found wildly different responses to different elements of schizophrenia and of psychosis more broadly, but the label 14 15 itself, changing the label had no meaningful effect. 16 17 Q. Can you give us an example of your findings in terms of the positive findings and the stigma, and then the 18 19 negative symptoms on the stigma? 20 Α. Yeah, and I think this is so important to understand because we've been talking - we do, for the sake of time -21 talk about stigma and mental illness in quite parsimonious 22 and simple ways, but these are actually really complicated 23 24 processes, complicated on the part of the experience of mental health issues and what comprises it and its many 25 facets and how they each elicit stigma differentially. 26 27 For example, we've found that positive symptoms such 28 as hallucinations and delusions elicit perceptions of 29 fearfulness - perceptions of dangerousness and those 30 prejudicial emotions of fear and again leading to social 31 distance. 32 33 In contrast, we've found that negative symptoms such 34 as anhedonia and alogia and so forth --35 36 37 Sorry, what are those things? Ο. We're talking about impairments in speech for example, 38 Α. or the ability to experience pleasure, or maybe being 39 avolitional, having difficulties with motivation and 40 41 volition for example. These elicit different types of attitudes that are stigmatised, such as the perception that 42 one is lazy, they're seen through the lens of not mental 43 44 illness but of behaviour that's more relatable to many So, if somebody's having problems with motivation, 45 people. they're just lazy, they just need to - as Nicky said this 46 morning - snap out of it. And, in turn, we see emotional 47

responses of anger and frustration, and again, social 1 2 distancing. 3 4 Ο. Can I turn to the National Stigma Report Card. This 5 project hasn't started as yet, it's going to start in, well --6 7 The data collection phase hasn't started yet, but Α. 8 we're certainly well into the development phase. 9 10 First of all, can you tell us what the National Stigma Ο. Report Card Project is? 11 12 So, the National Stigma Report Card Project, again, is Α. 13 delivered by SANE Australia in partnership with the Melbourne School of Psychological Sciences, and of course, 14 the SANE Australia and Deveson Research Centre of which 15 16 Dr Michelle Blanchard is the director and also has the support of the Paul Ramsay Foundation. 17 It is both a research and an advocacy project. 18 19 20 Our ultimate aim is to effect positive systems change for people living with severe and complex mental illnesses, 21 and specifically I'm talking about severe and persistent, 22 severe and episodic, and severe mental illnesses that have 23 24 complex multi-agency need such as schizophrenia spectrum disorders, bipolar and related disorders, personality 25 disorders, hoarding disorders, eating disorders and so 26 forth. 27 28 So, we have I suppose a few key elements to the 29 project. First, we are gathering the evidence - well, 30 preparing to gather the evidence. We're developing a 31 survey of the experience of discrimination and stigma in 14 32 life domains, and we are building on previous work such as 33 the Time to Change program that we heard about this 34 35 morning. 36 37 We are looking to really drill down a little bit more than has been done before in this area and gather some 38 really rich data. Our, I should say, point of difference 39 to Time to Change for example would be our focus in terms 40 41 of severe and persistent mental illness, and also in terms of our aim to not evaluate an awareness raising campaign, 42 but to gather evidence to support an advocacy campaign and 43 44 a policy development campaign. 45 How many people are you hoping to survey? 46 Q. That's a really good question. So, we have an 47 Α.

ambitious but, I believe pragmatically, feasible target 1 2 sample of 7,000 people. We're looking to recruit 7,000 Australians with experience of severe mental illness across 3 4 Victoria, across every state in Australia because we are 5 acknowledging, as a central assumption, that people - some people do not access treatment and support because of 6 7 stigma, we are needing to be creative with our sampling 8 strategy to reach people who do not access treatment or 9 support. 10

So, this means that some types of standard 11 12 epidemiological sampling strategies aren't necessarily 13 useful in this instance and we're having to be a little bit creative but nonetheless build in a range of quotas to 14 15 ensure that our sample is representative of our accessible 16 population, in that, we've got good, valid, reliable data that will support a very targeted and meaningful advocacy 17 piece to agitate system change. 18

Q. Just one final question on the report card. You mentioned that, I think, it was across 14 domains? A. Yes.

Q. Could you tell us about at least some of the domains?
A. Yes, sure. So, these domains are areas like
education, employment, housing, justice, finances, public
spaces, relationships, the mental health system, health
systems and so forth.

Q. I did say one final question, sorry, but one more
question on that. When are you hoping to have the results
from that investigation?

The results from the first round of the National 33 Α. Stigma Report Card will be released in - where are we? 34 2019 - 2020, and we will actually have a second round of 35 the survey which will drill down into intersectional stigma 36 for particular groups, including LGBTI, Aboriginal and 37 Torres Strait Islanders and so forth to understand 38 intersectional stigma between, for example, the experience 39 of mental illness and living as a gay person in Melbourne, 40 41 for example.

Q. You touched on this briefly before, but can you tell
the Commissioners about the trends in mental health stigma?
A. The trends on mental health stigma, we did touch on
this a little bit before, didn't we? So, I suppose, some
of the - if we really zoomed out and went all the way back

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to the 1950s, there was a very famous study done back then with what were called the Starving Yets(?), which essentially indexed the public's responses in the United States to descriptions of people living with schizophrenia, or depression, or alcohol dependency and so forth, and again, was indexing those responses to that in the general public.

9 Another noteworthy stigma researcher, Bruce Link, 10 followed up in 1996 and then again in 2006 on this, and some of the most important trends I would say were that, in 11 the period from the 1950s through to 1996 there was 12 13 evidence that suggested the stereotype of schizophrenia as being a violent condition actually got worse over this time 14 15 - far worse, which is a really interesting phenomenon, and 16 so, there's a range of theory around this tapping into pop culture and into mass media, and news reporting of violent 17 crime and schizophrenia and pairing of that in news 18 And we do know there is, through content 19 reporting. 20 analyses and so forth, certainly a systematic bias towards pairing schizophrenia and violent crime in a very 21 decontextualised and sensationalist way in news reports. 22

24 But in terms of actually demonstrating that causal link, there's not a lot of literature out there; in fact, 25 there's a smattering of recent studies, and in fact one of 26 my PhD students, Kelton Hardingham, is currently doing a 27 randomised experimental design, which is the type of design 28 you really need to draw out those legitimate inferences of 29 cause and effect to demonstrate if, and how, TV news and 30 internet news reporting elicits those attitudes of 31 dangerousness; this idea of violence and fear responses and 32 social distance and so forth. 33

And so, does that feed into the issue of why 35 Ο. stigmatising attitudes remain? 36 Yes, arguably so. So, arguably yes, we would look at 37 Α. media and, not only news reporting, but also creative works 38 Back in the 1950s, we hadn't then had Alfred 39 as well. Hitchcock's Psycho. We had an associated psycho, 40 psychotic, that stem, with a butcher knife behind the 41 shower curtain, and there has been a plethora of creative 42 works that have demonised and dehumanised and stigmatised 43 schizophrenia since. 44

A perfect example is, Me, Myself and Irene, which was a movie that portrayed a person living with psychosis in a

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very demonising way and actually highlights the importance 1 2 of initiatives like SANE Australia's StigmaWatch initiative which was able to respond to that and modify the way in 3 4 which that film was promoted in Australia. 5 In terms of the news reporting linking violence and 6 Ο. 7 mental illnesses, what's the impact of that kind of 8 reporting? 9 The impact is that it precipitates and it perpetuates Α. 10 stigma about schizophrenia, and you can counteract that to a point with positive messages and with stigma reduction 11 12 intervention. However, once that link is conditioned initially, and then you address it with some sort of 13 intervention, because of just fundamental conditioning 14 paradigms like reacquisition, it's much easily - it's much 15 16 easier to reacquire that link the second time; you maintain that link very easily with every problematic news report or 17 media piece of pop culture work that you would encounter. 18 19 20 You've also referred to the fact that another Ο. challenge for combatting stigma is getting support for the 21 cause when the cause itself is stigmatised. 22 23 Α. Yes, okay. 24 Can you explain what you mean by that? 25 Ο. So, that's a bit circular, isn't it, this idea of 26 Α. getting support to destigmatise mental illness is 27 problematic when that cause, in terms of servicing 28 clinically and therapeutically the need for - people's need 29 for help around mental illness is lacking. 30 31 We know, we just know fundamentally that the 32 proportion of the health budget that's dedicated to mental 33 illness has not shifted nationally significantly in a very, 34 very long time, and therefore is it feasible to be able to 35 leverage additional funds to reduce stigma about that 36 mental illness when you can't even get the services, the 37 resources to fuel services to service that? I'm not 38 sure that that's - it's a very difficult thing to do. 39 40 41 I think there's a connection here, I think that - and I think all too often we sort of think about stigma 42 reduction and mental health service delivery in a 43 44 duplicitous way, but actually it goes hand-in-hand: you 45 need to reduce that stigma to open up the doors and promote help seeking and then, if people are going to seek help, 46 then you really need to have those resources there to 47

.03/07/2019 (2) 143 C J GROOT (Ms Batten) Transcript produced by Epiq 1 provide that help when it's needed

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MS BATTEN: Thank you very much, Dr Groot. Chair, are there any questions from the Commissioners?

COMMISSIONER McSHERRY: Yes, I just have one question 6 Q. 7 and I think you touched on it when you talked about looking 8 at perhaps intersectional stigma. I think we are 9 understanding that this is very complex, that there are 10 lots of layers to how stigma is defined in the literature. But I was just wondering whether you've done any work on, I 11 12 think it's a concept of double-stigma, in that, I believe 13 there's some literature about ageist attitudes as well as what some people have called saneist attitudes and 14 15 combining the two.

I'm thinking in particular about aged care mental health services. Is there a double-stigma for those who use those services and for staff working in those services as well?

I'm not up on this literature, to be honest. 21 Α. My supposition is that there certainly would be. Generally, 22 we stigmatise anything that lends itself to a dichotomous 23 24 conceptualisation; anywhere where we can draw a perceivable distinction between myself and them - this is the problem, 25 and I think this is the problem with - and you can relate 26 this to aged care and could be a discrimination based on 27 some type of categorical perception of age. 28 And we know that people tend to vary in their propensity to think 29 either dichotomously or dimensionally about things. 30

And I think this is a problem for mental illness 32 stigma, that we historically have conceptualised mental 33 illness in a very categorical way, and it ties into the 34 utility of the diagnostic system itself, in that a 35 diagnosis really embodies a decision to treat it and you 36 know what's going to help, but it does carry a double-edged 37 sword in that it creates this categorical perception of, 38 you are ill or you are not, which we know is not the case. 39

Of course, people are generally not mentally ill or not. We know, and even the DSM 5 has moved in a dimensional way in terms of chapter organisation and severity rating of symptoms and so forth, but we know that we are all more or less mentally healthy or unwell over time and that vacillates, just like our physical health vacillates more or less, not all or none.

1 2 COMMISSIONER McSHERRY: Thank you. 3 4 CHAIR: I'd just like to ask one other point. We've heard a lot today about the importance of a contributing life and 5 the importance of pathways to employment and people being 6 7 able to access employment opportunities without 8 discrimination. 9 10 I note in your survey that you're planning to undertake, you are going to ask people with lived 11 12 experience of their experiences of stigma and 13 discrimination. Α. Yes. 14 15 16 Ο. It was put earlier I think about perception, that it 17 might be a perception that they were discriminated against, for example in securing a job. Is there evidence that 18 supports also the evidence from the, let's say, an 19 20 employer's perspective, where we can look to see that there is discrimination occurring, for example? 21 From the employer's perspective? 22 Α. That's a really So, in terms of evidence around this interesting question. 23 24 problem of employment discrimination for people with mental illness, certainly the Time to Change program, and Graham 25 Thornicroft and colleagues who work there have identified 26 I believe, however, that this is going to be this problem. 27 the central topic of what Michelle is testifying on next, 28 29 and Dr Blanchard might have some specialist insights into this. I probably don't want to step on your toes too much, 30 Michelle, at this point. 31 32 33 CHAIR: Thank you. 34 35 MS BATTEN: Thank you, Chair. May this witness please be excused. 36 37 38 Yes, thank you. CHAIR: 39 <THE WITNESS WITHDREW 40 41 May we have a short break before the next 42 MS BATTEN: 43 witness, please? 44 45 CHAIR: Thank you. 46 SHORT ADJOURNMENT 47

1 2 MS BATTEN: Thank you, Chair, thank you for the indulgence, I think the microphone's back on. 3 The final 4 witness for today is Dr Michelle Blanchard. I call Dr Blanchard. 5 6 <MICHELLE ELIZABETH BLANCHARD, affirmed and examined:</pre> 7 8 [2.59pm] 9 Q. 10 MS BATTEN: Thank you, Dr Blanchard. Have you made a statement to this Royal Commission? 11 12 Α. I have. 13 Are the contents of that statement true and correct? 14 Q. 15 Α. They are. 16 I tender that statement, Chair. [WIT.0001.0007.0001] 17 Ο. Dr Blanchard, could you please briefly describe your 18 background and experience for the Commission? 19 20 Α. So, I've been involved in the Australian mental health sector for about the last 19 years. I am currently the 21 Deputy CEO at SANE Australia, which is a national charity 22 that aims to make a real difference in the lives of people 23 24 affected by severe and complex mental illness. 25 Previously, I've worked at a number of other national 26 mental health organisations, including ReachOUT Australia, 27 the Young and Well CRC, and also the Butterfly Foundation 28 for eating disorders. Also the Non-Executive Director of a 29 youth mental health charity called batyr. 30 31 You've told the Commission what SANE Australia is. 32 0. Can you explain the work that SANE does in the area of 33 stigma reduction? 34 So, stigma reduction has been part of the DNA of SANE 35 Α. Australia for over 30 years. So, our organisation really 36 came from the lived experience of families and friends of 37 people affected by schizophrenia. It started as the 38 Schizophrenia Australia Foundation back in 1986, and our 39 co-founder, and Anne Deveson, was a broadcaster and 40 41 journalist, and was one of the first Australians of a high profile nature to tell her family's story of caring for a 42 loved one affected by schizophrenia. 43 44 45 So SANE was responsible, or the Schizophrenia Australia Foundation was responsible for some of the first 46 stigma reduction campaigns around schizophrenia towards the 47

end of the 1980s, and in 1998 we commenced the StigmaWatch initiative, which is about working really closely with the media to respond to community concerns about the way in which mental illness and suicide are represented in the media.

7 We also do a lot of work to take the stories of those 8 of us who have lived experience of mental health 9 difficulties out into the community to educate, to inform, 10 and really to break down some of the stigma and discrimination that people affected by severe and complex 11 mental illness might face. 12 13 Ο. In relation to the work you do with StigmaWatch, is it possible to give an example without rebroadcasting the 14 15 material that you're concerned about? If it's not 16 possible, we'll leave it?

17 Α. Of course. So, we heard earlier today about some of the stereotypes of people affected by mental illness and 18 19 schizophrenia in particular. So, some of the types of 20 media reporting that we're concerned about are articles that incorrectly attribute a person's behaviour to their 21 experience of mental illness. So, stereotypes of people 22 who - drawing on kind of senses of violence, for example, 23 24 would be one of the pieces that we would respond to.

When you say "respond to", what do you do exactly? 26 Ο. So, we receive complaints from the community about 27 Α. articles or pieces of media that might breach what are 28 29 called the Mindframe guidelines. We then investigate whether or not that piece of journalism constitutes a 30 breach, and then our team will actually write to the media 31 outlet to educate them about the way in which that piece 32 might be perceived and the impact that it might have on 33 people with a lived experience of mental illness or 34 suicide. 35

37 Sometimes that results in that article or that piece 38 of content being altered to discuss the issues in a more 39 respectful and inclusive way, or sometimes it may be 40 withdrawn from publication altogether.

Q. Okay, thank you. You've made a statement to the
Commission as you've said. Can you briefly outline the
evidence base for the views contained in your statement?
A. So, the evidence that I'm presenting today is based on
my own professional experience in the mental health sector,
but particularly SANE Australia's experience of working

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with our Peer Ambassadors. We have 91 people with
experience of complex mental illness or of caring for
someone who form part of our Peer Ambassador cohort and
work with us to tell their stories of living with mental
illness.

It's also based on our experience of taking calls, emails and web chats through our help centre. We receive about 12 to 15,000 contacts each year, and also from conversations that come from the SANE online community forum, which is an online peer to peer support community for both people with a lived experience of mental illness and their families, friends and supporters.

15 We've heard a lot today about stigma and the different Ο. 16 elements of stigma. Can I ask you about structural discrimination. So, what's structural discrimination? 17 So, the definition that I use around structural stigma 18 Α. or structural discrimination is very similar to the ones 19 20 that you've heard today, but in particular, it's about the societal level conditions, cultural norms and institutional 21 practices that constrain the opportunities, the resources 22 and the wellbeing for the community that may be 23 24 stigmatised. So, in this situation, it's particularly for people who have a lived experience of mental illness. 25

Q. There are different elements of structural
discrimination as I understand it. Can you explain to us
what environmental barriers are?

So, for me that's really around the kind of cultural 30 Α. norms that might exist in relation to a person's experience 31 of mental illness. So, it might be the way that a 32 workforce views mental illness and the kinds of practices 33 So, if you work in a profession where that are in place. 34 it's considered important to have a stiff upper lip and to 35 just get things done, those environmental factors certainly 36 shape how people view mental illness. 37

Q. Are there institutional barriers as well, are they
separate from environmental barriers?
A. So, institutional barriers might be more around the
systems and processes that may make it difficult for
someone with a lived experience of mental illness to really
flourish or thrive in those kinds of environments.

46 We see these kinds of practices in a whole range of 47 domains, whether it's in employment or education, in

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housing, access to financial services, things like 1 2 insurance. 3 4 Ο. Can you give us a brief example of attitudinal barriers? 5 So, attitudinal barriers might be the kinds of 6 Δ 7 attitudes that people hold towards people with mental 8 illness, so assumptions, but it may also be the attitudes 9 that the person themselves experiences. So, we've heard a 10 little bit today about self-stigma, and certainly self-stigma has a role to play in these kinds of issues as 11 12 well. 13 I want to ask you some questions about the workplace 14 Ο. 15 in particular. For people affected by severe and complex 16 mental illness, how does structural discrimination manifest 17 in the workplace? So, it manifests in a couple of different ways. 18 Α. We know that people who are affected by severe and complex 19 20 mental illness can be less likely to have completed post secondary education. It may be that their education has 21 been interrupted and they've been unable to continue, so 22 that certainly has an impact on whether or not people may 23 24 hold the qualifications required to be able to take up employment positions in the community. 25 26 27 It may also manifest in the attitudes that employers hold towards employing someone who discloses that they have 28 a lived experience of a mental illness, and it also 29 manifests in the kinds of adjustments that employers might 30 be willing or unwilling to make so that someone with a 31 lived experience of mental illness can really thrive in any 32 workplace. 33 34 Sometimes those barriers can prevent someone from 35 disclosing their experience of mental ill-health 36 37 altogether, but other times when someone has made that disclosure they can find that some of those barriers play 38 out in a very overt way. 39 40 41 You referred to assumptions that employers hold. Q. In your experience, do employers hold assumptions and what's 42 your kind of evidence base for making that assertion? 43 44 They do. It's certainly something that a number of Α. 45 our Peer Ambassadors have spoken directly to us about, but is also seen in the research evidence, and there's a report 46 by the Collaborative For Work Participation that I 47

1 referenced in my statement, where they surveyed Australian 2 employers about their attitudes towards people with mental 3 illness.

There was a sense that employers were more likely to employ someone with a physical disability rather than a mental illness, and some of the attitudes that they held were around people being unreliable, unpredictable, perhaps difficult to work with; so really, quite stigmatising and negative attitudes towards people with mental illness.

12 What are some of the consequences of structural Ο. discrimination in the workplace for individuals? 13 So, I think there's lots of implications of this 14 Α. structural stigma and discrimination for people in the 15 16 workplace. I think there are challenges for people in actually entering the workforce and finding suitable 17 employment, but I think once people are there, if the 18 structural stigma and discrimination is playing out in a 19 20 way where people feel that they can't disclose their experience of mental ill-health, it can make people feel 21 very isolated and alone in the workplace. 22

24 It can mean that sometimes some of the additional supports that they might require to really be able to make 25 a contribution and feel valued aren't available. 26 So. perhaps, if someone requires a little bit of flexibility to 27 be able to attend medical appointments, or requires the 28 ability to take additional unpaid leave to take care of 29 their wellbeing: if they feel that they're not able to be 30 open about those experiences, sometimes those supports 31 simply aren't available for them. 32

Sometimes it plays out in much more overt ways, and 34 certainly, in doing this work, I've spoken to a number of 35 individuals with lived experience who have said that they 36 feel like they haven't had opportunities for promotion or 37 opportunities to take on additional responsibility because 38 they've been quite open about their mental illness, and 39 they've felt like their employer has doubted whether they 40 41 would have the capacity to be able to take on something more ambitious. 42 43

Q. So, that's obviously their perception of the
situation. Is it a bit of a difficult area to establish
what exactly the causes were and whether it was the mental
illness and the perception and whether that is in fact the

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1 reason? Is there research to support that, basically, is 2 my question? So, the report of the Collaboration For Work 3 Yeah. Α. 4 Participation certainly asked employers about the views 5 that they hold, and that research reinforced that some of those attitudes around, you know, unpredictability or 6 7 unreliability were certainly attitudes that were held by 8 employers. 9 10 You're right that we don't necessarily have the data to correlate the two, and one of the challenges of doing 11 research in this space is that, you know, if we go and we 12 13 ask people openly in the community, "Would you discriminate against someone on the basis of them having a mental 14 15 illness?" More often than not people are gonna say, "No, 16 of course not, I wouldn't do that." 17 But stigma and discrimination in this space play out 18 in a much more insidious way, and there are lots of 19 20 different factors that contribute, but it certainly seems to be something that comes through, not only in the 21 literature, but in people's lived experience of engaging in 22 the workplace. 23 24 Just taking you back to the Collaborative Partnership 25 Q. report, was that across all mental illnesses, or which 26 mental illnesses was that focused on? 27 So, my understanding is, it looked at mental illness 28 Α. in general, and one of the real challenges of work in this 29 space is that we often do use mental illness as an umbrella 30 term to describe a range of experiences people might have 31 around mental ill-health. 32 33 My sense is that, there is a very real difference 34 between the way in which people respond to experiences like 35 depression and anxiety, particularly if it's mild to 36 moderate, compared to some of the more severe and complex 37 experiences people might have, whether it's around 38 schizophrenia or other psychotic disorders, personality 39 disorder, eating disorders and bipolar disorder, and so, we 40 41 certainly hear very strongly from the community that we serve that they feel that those with severe and complex 42 experiences are often marginalised. 43 44 45 And certainly, when we sort of see large-scale public surveys that look at these issues, some of those types of 46 illnesses are often not included in the data at all. 47

2 Ο. You've talked about what some of the consequences of structural discrimination in the workplace are for the 3 4 individual who's experiencing the mental illness. What 5 about for the family and friends of that person? Can you talk about some of the implications for them? 6 7 I think family and friends experience these issues Α. 8 really acutely as well. So, there is a phenomenon around 9 stigma by association, and that can mean that people who 10 are family, friends or supporters of people with mental illness can find that they experience some of the same 11 12 forms of stigma and discrimination that other people with a 13 lived experience might face and that can make it difficult for them to engage in the workforce as well. 14

16 You know, certainly people describe experiences of coming back to work after caring for someone who's had an 17 episode of mental ill-health, and describing that as being 18 very different from the experience of caring for someone 19 20 who's had an accident or a physical health problem. That, you know, often the sort of workforce will band together to 21 support that individual and their family, and people often 22 report it being very difficult to have that same level of 23 24 support in the workforce.

The episodic nature of severe and complex mental illness can also mean it's quite difficult for people who are carers to access the reasonable adjustments that they might need to be able to continue to flourish and thrive in the workplace. So, access to things like unpaid leave or more flexible working conditions can be difficult.

There's also been research that has looked at economic 33 security for family, friends and supporters of people with 34 mental illness, and that, people who have taken on caring 35 responsibilities might find themselves in precarious 36 37 financial situations and tend to even have a lower superannuation balance, for example, compared to other 38 people in the community. They're issues that are very 39 acutely felt by the person with a lived experience of 40 41 mental illness, but they're equally felt by family, friends 42 and other supporters. 43

Q. Do we know to what extent structural discrimination
exists in the workplace in Victoria?
A. So, we don't have any good data that quantifies the
scale of the problem. Certainly, we would think that some

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of the things that have been found in reports, like the one 1 2 that I spoke to before, would certainly be representative of the experience of people here in Victoria, that those 3 4 attitudes certainly seem to be quite persistent, and people's lived experience here in Victoria would suggest 5 that they certainly do experience a variety of different 6 7 forms of stigma and discrimination in the workplace. 8 9 If we don't have that data, I assume we don't have Ο. 10 data across different workplaces in terms of how stigma manifests in different environments? 11 Not necessarily, but we do have a bit of a sense that 12 Α. 13 there are particular types of workplaces where stigma might be more prevalent, and they tend to be in industries where 14 they're very high-pressured environments, they tend to be 15 16 in environments where people are expected to just tough it up and sort of deal with various issues. 17 18 19 Can you give us an example, which type of environments 0. 20 are you talking about? So, the experience of people who are first 21 Α. Yeah. responders, for example. So, in environments where people 22 are often exposed to quite challenging information but sort 23 24 of expected to just kind of get on with it and face the Certainly, those attitudes are changing and next job. 25 there are some really good initiatives to really highlight 26 the need for better support for people in industries like 27 first responders. 28 29 But I think one interesting observation that I've made 30 in engaging with the workplace in promoting mental health 31 and wellbeing has been that there can be an assumption that 32 people with severe and complex mental illness don't exist 33 in particular types of workplaces. So, people are much 34 more open about acknowledging issues like depression and 35 anxiety, and even to a certain extent post-traumatic stress 36 37 disorder if there's sort of a clear sense that perhaps that was a direct response to the workplace. 38 39 So, you know, we hear public narratives of people who 40 have taken time out from the police force, for example, 41 having been exposed to quite traumatic content. When we're 42 in environments like professional services or financial 43

services and talking to people about schizophrenia or
personality disorder, we do still hear from employers an
assumption that people with those experiences aren't in
those environments.

1 2 But we certainly know that there are people with experiences of severe and complex mental illness in all 3 4 walks of life, at all levels of organisations, in public life, people who hold roles in a whole range of different 5 areas, but we don't have this open narrative about what it 6 7 looks like to live a contributing life with a severe and 8 complex mental illness. 9 10 And, why do you think that is? Ο. So, I think a really key barrier has been the stigma 11 Α. 12 that is associated with a severe and complex mental illness, and the lack of public role models of people that 13 have taken on various roles in the community who have the 14 15 more severe and complex experiences around mental illness. 16 And we see this across a whole range of sectors: 17 whether it's in the health sector, people who might be 18 working as medical professionals or working as helping 19 professionals, and people in financial services. 20 It seems to be much more acceptable to be able to share those 21 stories around mild to moderate experiences and it just 22 perpetuates the same cycle of, we hear those same stories 23 24 and it doesn't necessarily open up the space for people with experiences that are more severe and complex to be 25 able to be part of that conversation as well. 26 27 It's also a lot to ask, though, of someone with a 28 Ο. severe and complex mental illness, isn't it, in this 29 current environment? 30 Α. It is, yeah. 31 32 33 Ο. To put their hand up to basically say that they have those conditions --34 It is. Α. 35 36 37 -- in the current stigmatised framework. Ο. How do you see that changing, or do you see it changing? 38 So, I see it changing incrementally at the moment, and 39 Α. I see it changing through leaders in organisations and 40 41 people in the community who are starting to become more 42 open about their own experience of mental ill-health. 43 44 It's certainly something that I've experienced as a 45 leader in an organisation needing to get more comfortable talking about my own lived experiences and the experiences 46 that I bring alongside my professional training. 47

2 And, you know, I think for me it was always the sense that you couldn't have an identity both as someone who had 3 4 their own lived experience as well as be someone who was an expert or a professional. But, the more I see people 5 around me who are role models for both: people who are 6 7 leaders in their organisation, or are doing really, really 8 amazing things, but also are quite open and honest and 9 authentic, I think that certainly has helped a lot. 10 And I think it's important that, when we do encourage 11

And I think it's important that, when we do encourage people to speak and to share their experiences, we do that in a way where they feel absolutely supported. I guess I'm incredibly lucky to work in an environment where that's okay, but I acknowledge that for a large number of people that's not necessarily the case.

Returning to the issue of structural discrimination in 18 Ο. the workplace, if no action is taken, what are the likely 19 20 future impacts of structural discrimination and stigma in the workplace in relation to mental illness? 21 So, if we don't do anything, how do you see the future? 22 Yeah, so I think there are impacts in a whole variety 23 Α. 24 of different ways. I think a really important one is around the economic security of people who live with a 25 mental illness. 26

So, you know, people then find it difficult to be able to support themselves and their families and to access the kind of care and support that they need if they're unable to generate income to be able to do that. So, there are certainly those economic impacts.

We know also that there are impacts - economic impacts on businesses themselves if they don't seek to support the mental health and wellbeing of their workforces.

But I actually think, on a more human level, we lose the opportunity to learn from people with experiences of mental illness; that people with mental illness have so much to bring to the table and to bring to our workforces.

I have been incredibly lucky to work alongside a number of people who have their own lived experience of mental ill-health or of trauma, and what they bring to the workplace in terms of their sense of empathy, their commitment to supporting others, is incredibly beneficial

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for us as an organisation, and I think, if we don't act to create workplaces and environments where people feel valued and respected and that they can bring their whole selves to work, we as a workforce and as a community really lose out.

Q. Finally, Dr Blanchard, can you tell the Commission some positive steps that you think can be taken to counter structural discrimination and stigma in the workplace, specifically in relation to mental illness?

A. So, I think one of the really important things we can do is create work environments where people feel like they can be open about their mental ill-health so that they can access appropriate help and support to be able to thrive in the workplace.

16 A really great way to do that is through encouraging 17 people to share their stories of living with mental illness 18 and to do that in a really safe and a really supported way.

I think though, it's also really important for there to be training in workplaces for managers, for HR leads and others, to be able to create these environments where people do feel supported and where there are also supports available if someone's mental health and wellbeing is not tracking well.

There's work that we can do in terms of designing people's roles so that they are able to contribute in a meaningful way, but also to reduce stressors or other factors that might negatively impact their mental health and wellbeing.

So, SANE is part of a group called the Mentally 33 Healthy Workplace Alliance, with a number of other mental 34 health organisations including the National Mental Health 35 Commission who are leading around that, and there is I 36 think a really important opportunity to create a framework 37 that can then be taken up and adopted by workplaces to 38 really create these environments where everyone's mental 39 health and wellbeing is important, so we're preventing the 40 41 onset of mental health problems for people who might develop those while in the workforce, but really critically 42 that we're also supporting those who do have a mental 43 44 illness to enter, to remain in and feel supported as valued members of our workforce. 45

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MS BATTEN: Thank you, Dr Blanchard. Chair, are there any

1 questions for Dr Blanchard?

2 Q. Yes, I just have one. I noted in your written 3 CHAIR: 4 submission you said that people living with mental health conditions are three times as likely to be unemployed as 5 the general population and that this was amongst the 6 7 highest ratio in the OECD. Are there any other countries 8 you would point us to where you think they are doing better 9 and have a lower ratio than we experience here in 10 Australia? Yeah, that's a really good question, and I'm part of a 11 Α. 12 group called the Global Anti-Stigma Alliance, where we get 13 together once a year with our colleagues from organisations and campaigns, like Time to Change in the UK that you heard 14 15 about earlier today. 16 In some of the Scandinavian countries there are good 17 initiatives to support people to engage in the workforce, 18 19 but it really does seem to be a challenge that people 20 across jurisdictions are grappling with. 21 Thank you, Chair, no further questions? 22 MS BATTEN: 23 24 CHAIR: Yes. 25 May this witness please be excused? 26 MS BATTEN: 27 28 CHAIR: Yes. 29 <THE WITNESS WITHDREW 30 31 MS BATTEN: Thank you, Chair, that concludes our evidence 32 for today. 33 34 AT 3.30PM THE COMMISSION WAS ADJOURNED TO 35 THURSDAY, 4 JULY 2019 AT 10.00AM 36 37 38 39 40 41 42 43 44 45 46 47

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