Royal Commission into
Victoria's Mental Health System

WITNESS STATEMENT OF ERICA WILLIAMS

I, Erica Williams, say as follows:

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

Background and nature of condition

2 About five years ago, when I was 17, I started my first year of university. At the time, I was living with my partner, who was 19, and who was also a student. I had moved out of home when I was 15, in difficult circumstances. I completed year 12 in Mildura and got into university.

3 I felt quite unwell in my first year of university. I was very depressed and anxious, but I had other symptoms too, which were difficult to explain. I was experiencing rapid changes to my mood, suicidal thoughts, dissociation, an unstable sense of self, and impaired concentration. I started behaving impulsively and recklessly (eg walking on rooves, lying down on roads) and frequently self-harming.

4 My main diagnosis is borderline personality disorder or BPD. While my main diagnosis is BPD I also have anorexia nervosa and depression.

5 As it has been conveyed to me, BPD can be related to a history of neglect and abandonment. I believe my BPD is connected to the trauma I experienced as a child.

6 My BPD is a relational disorder in the sense that it can emerge in relationships with other people and with services. The trauma I experienced as a child was often compounded by the neglect I felt from the practitioners I sought help from. I felt that I was in a vicious cycle.

My experience with the mental health system

7 During my first year of university, I went and saw a number of different GPs. Each time I saw a GP I was told the same thing – they did not know what to do, there was no standard course of treatment for the emotions I was experiencing. I was not placed on any medication in my first year of university. I was referred to Headspace twice. I was

told similar things at Headspace; they were not sure what to do. In short they did not seem to know how to help me, so I did not go back.

8 In my second year of University, I saw a psychiatrist once. I was diagnosed with bipolar disorder and placed on lithium. I did not feel that this diagnosis was helpful or correct and I continued to have symptoms.

9 Although I had tried to get help from a number of professionals, I didn't feel that they were helping me and I still had symptoms. So I did not seek any treatment for about six months. Following this, I sought help through a DBT (Dialectical Behavioural Therapy) centre privately. It was somewhat helpful, but ultimately did not alleviate my symptoms. It was very expensive and I could not afford to complete the entire course.

10 The following year was a very difficult year for me, and I felt as though things were getting worse. I did not really have any strategies to manage my illness. I just struggled along. I had support from my partner, who has been incredible to me, but he was really all the support I had. I did not have family in Melbourne, or any other supports. I was really struggling and needed to submit documentation to uni to get special consideration. But I did not have a stable relationship with any GP so it was hard to get GPs to provide documentation to support my position. I failed a bunch of subjects because I could not get the documentation I needed.

11 As things were getting worse, I went to see a number of different GPs. I was diagnosed with depression and anxiety. It felt to me as though these GPs were not listening to me and were dismissive of me, I felt neglected and it made me feel worse. I was not diagnosed with BPD at this point, and felt that doctors were very hesitant to make the diagnosis. I knew I had some of the symptoms because of my own research and because of my trauma history, but doctors did not take me seriously when I mentioned BPD or trauma. This meant that I was afraid to let doctors know about my BPD symptoms – given they did not seem sure how to manage it or did not seem to take it seriously as an illness. I minimised my symptoms to avoid feeling neglected and dismissed. I often felt suicidal and unsafe, and I feared that expressing my feelings would lead to further rejection.

12 At that time, I was really scared. I knew I had certain symptoms and I knew they were related to my trauma history. I did not know if there was any accessible treatment for those symptoms. The symptoms of BPD can manifest as depression and anxiety, and I had those symptoms. But my BPD also meant that I exhibited disassociation: I lost my track of time, my own memories, my sense of being inside my body, and at times my capacity to speak. I experienced moments in which I could not recall how I came to be in a certain location. I had poor self-image – I did not know who I was supposed to be.

13 My self-injury became quite severe. I felt suicidal, and I could not stand being alone. My relationships with others were very strained. I didn't connect emotionally with those around me. I put on a social veneer in order to avoid the possibility of people leaving me when they noticed my symptoms. My relationship with my partner, Brendan, was turbulent – my BPD meant that I struggled to feel like my attachment with him was secure. I felt that I needed to be with him all the time in order to feel safe.

14 I once experienced anxiety that made me feel like I was having a heart attack. I presented to the ED, but was sent home without follow-up care.

Orygen Youth Health

15 In late 2017, I was very unwell. I was not getting out of bed. I self-referred to Orygen Youth Health. I found Orygen Youth Health on the Internet and self-referred to them. I rang and asked for an assessment. My partner took me because at that point I could not go anywhere by myself. By way of example, I was too anxious to leave my house alone.

16 Things did not immediately improve, and I presented to emergency departments on numerous occasions in times of crisis of suicidality or self-harm. When I sought help, I felt my suicidality was not taken seriously by emergency staff.

17 Early in my admission with Orygen, I was very unwell. I was admitted to hospital on multiple occasions. I was an inpatient at both Orygen Youth Health's Inpatient Unit, and at other psychiatric hospitals in Melbourne. When I was admitted to hospital outside of Orygen's care, I felt ignored, neglected, and abandoned. I felt belittled and bullied by staff when asking for medication. The sense of rejection and alienation I felt when trying to reach out and place my trust in services led to my condition spiralling downward. My feelings of suicidality became worse. I have attempted suicide following discharge from hospital a number of times.

18 At Orygen, at the beginning of 2018, I saw a psychologist and the psychologist referred me to Orygen's HYPE (Helping Young People Early) program. I was diagnosed with BPD after I was admitted to the HYPE program.

19 Orygen has a model of care for BPD which includes Cognitive Analytic Therapy (CAT). CAT is a therapy model that involves weekly meetings with a psychologist and group programs, which I found very helpful. I also saw a psychiatrist at Orygen who organised my medications.

20 After Orygen got to know me, they were very responsive to my needs. I was able to access therapy more or less frequently as I needed it, I was regularly reviewed by a psychiatrist who considered my medications, and my suicide risk was monitored. I accessed Orygen's Youth Access Team on an out-of-hours basis, and was visited in my

home for a crisis assessment when I was too ill to leave my house. I also had access to Orygen's inpatient unit and the treating team in hospital had good contact with my outpatient team.

Eating disorder related hospitalisation

21 During my first few months with Orygen, things were quite turbulent. I had many short stays in hospital. With time, therapy, and medication, things improved – but then I unfortunately developed anorexia. My mood and suicidality also started to worsen again, and I had a longer period of hospitalisation.

22 I presented to a crisis appointment at Orygen with suicidal thinking and a very low food intake, but there were no beds available at Orygen. Orygen do not provide specific treatment for eating disorders, so I went to a public mental health facility.

23 I was then transferred from that facility to a public/private bed in the middle of 2018. As I understand it, a public/private bed is a bed in a private hospital that is paid for by the public health system (I did not have private health insurance at the time). However, the public funding did not cover the eating disorder unit, so I ended up in the general psych ward at the private hospital. The treatment and support provided in the eating disorder ward was not available in the general psych ward.

24 I was in the private general pysch ward for a couple of weeks, before I was discharged straight to a public emergency department. I was told that I was too "high risk" for the private general psych ward. I was told to get in an ambulance and I was taken to a public emergency department. My partner was not contacted. I was just shipped out to a public hospital emergency department. I stayed in the emergency department at the public hospital for about 14 hours. I was monitored to see if I was physically well.

25 I was then transferred to Orygen's inpatient unit. A bed had become available. Gradually, my mood improved and I was able to start eating again. I didn't receive specific eating disorder treatment, but I knew that my body was starving. I was encouraged by my case manager to tackle my anorexia and get well. She went above and beyond her role with me – and once stayed on the inpatient unit until 6:30pm playing Scrabble with me and giving me support while I ate dinner. I was discharged in the middle of 2018, and I had follow-up care with Orygen.

Re-admission to Orygen

26 However, I eventually started to get unwell again with my eating disorder, depression, suicidality, and BPD. I was re-admitted to Orygen in late 2018 after presenting to the emergency department. During that period, my mental health was the worst it has ever been. I was placed on a Compulsory Treatment Order by Orygen in November 2018

after attending a tribunal hearing. While I was a compulsory patient, I absconded from the hospital a few times with the intent to end my life by suicide. I had to be detained and handcuffed by police. I was placed in Orygen's Intensive Care Unit after being returned to the hospital.

27 I decided to have Electroconvulsive Therapy (ECT) while I was in hospital. The ECT was directed towards my depression. My understanding is that it becomes hard to treat BPD if depression is being experienced as well. I had the ECT but found it very difficult to tolerate. It has been explained to me that ECT can be difficult for patients who have experienced trauma given it involves being placed under anaesthetic and a loss of bodily control. I was experiencing severe panic attacks which I believe was due to my trauma, so I was not able to complete the treatment.

28 Ultimately, I was not getting better – but I had been in hospital for a long time and it was decided that there weren't many options. The team caring for me agreed that I could give things a go at home, and my Compulsory Treatment Order was revoked. I was eventually discharged from Orygen, but I did not feel safe to be at home.

29 I was discharged and readmitted to Orygen twice. On the second readmission, I went to another public psychiatric ward because there were no Orygen beds. I was subsequently readmitted to Orygen.

30 On the two occasions I was readmitted to Orygen, I was discharged into the care of two friends and my partner, Brendan, but I was still very unwell. My friends and Brendan were with me all the time. Somebody slept in my bed every night. I was still not safe to be alone. After a couple of weeks, we decided I needed to be back in hospital, as I was getting worse, and it was impossible for my friends and Brendan to be with me every moment. An interim place between hospital and home was very needed for myself and my friends and partner.

31 It was hard to know how to live independently after being so mentally ill. I had lost a good deal of my general life management skills: I did not know when to have a shower or when to eat food. It has taken a lot of work to recover these skills.

Admission to a high dependency unit

32 On my second readmission to hospital after being discharged for about a week, I was readmitted to an inpatient ward at a public hospital. I went to a crisis appointment with Orygen and it was decided I needed to go back to hospital, but there were no beds at Orygen.

33 My psychiatrists put me on a Temporary Treatment Order. I was told the reason for this was that they did not feel that I was safe. I was put in the high dependency unit in a different public hospital.

34 The experience was terrifying. I have never been aggressive towards anybody and have never tried to hurt anyone, however a number of hospital security guards (if felt like eight) swooped around me and ushered me into the high dependency unit. I looked around and realised my partner was gone – they did not tell me where he was.

35 The Temporary Treatment Order was revoked on the day I was admitted to the hospital without consulting myself or my partner. My partner and I felt that I was too unwell to keep myself safe.

36 I was one of two women in the unit. The rest of the patients were older men. I was 22. There was no segregation of men's and women's bathrooms. Men would come in to the bathrooms unannounced. (There were no locks on the bathrooms, which I understand, however there was also no attempt to stop men going in the bathroom while I was in there.)

37 While the hospital was aware of my trauma background, no attempts were made to avoid my triggers. I was very ashamed of being unwell, and I was experiencing a lot of emotions related to my trauma. I had my period at the time, but I was not allowed to have more than one sanitary product at a time. My trauma history means that I did not want to talk to male nurses about these issues, but I was forced to do so each time I needed a sanitary product. I did not have private phone access and I did not have enough blankets to keep warm. There was little communication about when meals would occur, if legal aid would be provided, or when I would be able to see my family.

38 It was a scary place, and it felt like an invisible part of the hospital. By way of example, I did not feel like there was any access to the outside world. When I asked for medications or support in this hospital, I was brought into a small room where I was asked lots of questions that I found belittling about why I wanted my medication. I was already experiencing severe anxiety because of my trauma, BPD, and experiences in the High Dependency Unit. I was asking for my medication because my anxiety was becoming too much, but I wasn't allowed to take it until I gave extensive justification for why it was required. The nurses also lost my medication chart on one occasion, so I wasn't able to have any medications until it was located. I felt that my BPD diagnosis meant I was at times seen as oversensitive or irrational. This made it very hard for me to speak up for myself in times of crisis.

39 I feel very ashamed about my negative experiences in this hospital, and I did not feel like I could speak about them for a long time for fear of not being believed.

Re-admission to Orygen

40 I stayed in the public hospital for about two days and was then transferred to Orygen.

41 From Orygen, I was transferred to a private clinic because my treating team and I decided I would try Transcranial Magentic Stimulation (TMS). I had private health insurance at this point, and my team from Orygen sent a referral to the private clinic.

42 As I understand it, TMS is a relatively new treatment to help depression. I was told that TMS is painless and did not require anaesthetic, so I felt that it might be easier to tolerate than ECT. At the private clinic, I had six sessions of TMS. I felt that my mental health was staying the same. I didn't have a lot of contact with the treating team at the private clinic, and didn't feel like they wanted to listen to what I had to say.

43 After six sessions, the private clinic decided I was too "high risk" to stay. Nobody came to talk to me about my risk. I didn't feel too risky to be at the clinic and I was very disappointed and let down by their decision to discharge me, as I was hopeful TMS would work. TMS isn't available in the public system and, after the private clinic decided I was too risky to stay, the private clinic discharged me straight to an emergency department. From there, I waited overnight before being transferred back to Orygen.

44 I stayed in the inpatient unit at Orygen for a few weeks, and continued with therapy and medication adjustments. Then I was discharged. With intensive case management and a team that really understands me, I was able to slowly overcome my mental health crisis. That was about four months ago.

45 Orygen has been my primary support since late 2017. I have a GP, a psychologist, a psychiatrist, and a case manager – all in the one place. I still have the same case manager from when I first started at Orygen. She has worked very hard to understand my trauma history and my BPD, and together we have developed ways of understanding my illness that make sense to me. Without my case manager and doctors at Orygen persisting with me even when things were very severe, I would not be alive.

Need for reform of the mental health system

46 Based on my experience with the mental health system, I have four main areas of concern.

Treatment of BPD

47 My first concern is the treatment of BPD. BPD is a complex illness. However, there is little unity in the way it is treated; there is no systemically recognised model for understanding and treating BPD. I feel that the treatment of BPD is affected by stigma.

48 My experience of BPD is it is sometimes assumed I am seeking attention or faking symptoms, and my illness is often not understood in terms of early childhood trauma. My illness seems to be often thought of as less serious or less life threatening than other illnesses. And it seems to be notoriously difficult to treat, in spite of recognised treatment options that exist in literature I have read about BPD. In my experience, medical professionals seem to have been fearful of diagnosing me with BPD. When I sought treatment, I was at risk of suicide or self-harm, and I felt that I was not taken seriously.

49 All of this has led me to believe that the association between BPD and attention seeking behaviour focuses on blaming, and frames BPD as a fault in character rather than an illness. The invisibility of childhood trauma in medical understandings of BPD meant that clinicians failed to act towards me with adequate empathy and sensitivity regarding the development of the illness. Stigma regarding BPD seemed to influence treating professionals' behaviour towards me at many levels of care – GPs were afraid of BPD, ED staff did not take it seriously, and mental health professionals did not seem to want to work with me when I was struggling with the illness. I believe that if stigma were replaced with the research that exists on how to treat BPD, our system would be much better equipped to manage the illness.

50 My experience of the treatment of BPD within the mental health system has at times been "all or nothing". I have been admitted as an inpatient in a crisis but then have received little or no follow up support. While Orygen has provided extensive follow up support to me, the structure of the system itself meant that there just was not enough resources to provide a true middle ground for me. There was little in the way of living arrangements between hospital and home, and a lack of funding for supporting people who provided care to me. It was also conveyed to me that there has been a significant loss of funding for group programs I participated in – which meant that publicly funded services like Orygen struggled to bridge the gap between high care and low care.

51 I believe that I only recovered from BPD because I found care with Orygen. Orygen has a systemic understanding of BPD – and a means of treating it through a relational model of care. My impression is that there is a high degree of cohesion amongst staff regarding how BPD operates and how it should be treated. I am listened to, valued, and understood by my case manager and treatment team. A combination of psychological treatment, psychiatric treatment, and hospital care has led to my recovery. Through the

relational model of care, I have been able to learn better patterns of help-seeking. Cognitive Analytic Therapy has been imperative to my recovery.

Inpatient and emergency care

52 There needs to be closer scrutiny and accountability of the level of care provided in inpatient facilities and emergency departments. A person in a high dependency unit should not have to advocate for a blanket, sanitary products and to use the public phone. I was in the high dependency unit because I was vulnerable and very unwell. The severity of my illness meant I was not able to speak up for myself. It is unreasonable for someone in that situation to have to advocate for basic care.

Lack of middle ground services

53 I have found myself not quite sick and not quite well multiple times. On these occasions I tried to keep myself afloat alone, and I ended up in an emergency department. For me, mental illness extends as a permanent condition. It fluctuates, but it doesn't ever disappear. It would have assisted me if there was a system which accounts for that fluctuation – so I could have moved from sickness to health and in between, with services to meet me at each point.

What is meant by "community" in a community care model

54 The community care model has asked my untrained partner to manage my very acute stages of mental illness. I have been discharged to "care in the community" multiple times, without actually feeling like I had a community to begin with. The mental health system needs to support carers, families and friends. They should be involved in care early. They need to be provided with information on the illness and what they can do to support their loved one, and should be supported to provide that care.

sign here ►

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