Royal Commission into
Victoria's Mental Health System

WITNESS STATEMENT OF
AARON ROBINSON AND KRISTY ROBINSON

I, Aaron Robinson, make this statement with my wife, Kristy Robinson and I, Kristy Robinson, make this statement with my husband, Aaron Robinson.[1] We make this statement together as carers for our daughter, Thea, on the basis of our own knowledge, save where otherwise stated. Where we make statements based on information provided to us by others, we believe that information to be true.

The background and nature of Thea's illness

1 Our daughter, Thea, is 22 years old. Thea was originally diagnosed with Autism when she was 6 years old. She began to show motor skill difficulties and, in her early teens, she began self-harm activities such as cutting. At the age of 12, Thea also developed a serious eating disorder. Her other diagnoses have included Obsessive Compulsive Disorder (**OCD**) and Generalised Anxiety Disorder.

2 When Thea was 14 years old, she was hospitalised for her eating disorder, and for depression. They were unable to manage Thea's anorexia properly at the hospital, and they had to put her into a psychiatric unit. Over the next three years, Thea was force-fed at the hospital. This was an intensely traumatic experience as Thea was restrained by six to eight men (security guards and nurses) and had a nasogastric tube forced up her nose six times a day to feed her. We think this caused a lot of trauma, and may well have led to a traumatic disorder for Thea.

3 In 2016, when Thea was 18 years old, she was diagnosed with Borderline Personality Disorder.

4 Thea has deteriorated so much over the last three to four years; she was in a much better place three years ago. Now, she struggles to access treatment and regularly runs away (at least once per week on average and more often recently) from home and treatment centres and attempts suicide.

5 This generally involves breaking windows and climbing the fence when escaping from home. Police and ambulance are called as a result. Between replacing broken windows and having to put in fence extensions, we have spent about $4,000 in the last month. We don't have endless pockets of money and the National Disability Insurance Scheme

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[1] The name and details of the witnesses (and others) referred to in this statement have been changed to protect their identities.

(**NDIS**) seems reluctant to reimburse us for these costs. Further to this, we have to keep all doors and windows locked, cupboards containing medicines locked, keys hidden and dangerous objects such as knives locked away.

6 Over the past four years, Thea has been hospitalised more than 50 times for suicide attempts. Thea's suicide attempts have included many different methods and means. For example, we have to keep all of the cupboards in our house locked up because of Thea's attempts to take overdoses of various medicines.

7 The last 12 months have been especially bad. Thea is highly suicidal. She has attempted suicide basically a few times every week in the past year. We are in a situation where, when our daughter disappears, we are afraid that will be the last time we see her alive. It is a nightmare. We have tried everything we can humanly think of to try and help Thea.

Some of Thea's recent hospital admissions

8 In mid-2019, Thea managed to open the combination of our keysafe at home and unlocked the cupboard where we keep her medication. She overdosed on some medication and we took her to the emergency department. I (Kristy) was with Thea from 3pm on the day the overdose happened to late the following day, when she was admitted into the ward for observation and heart monitoring. Thea was treated overnight as she had serotonin syndrome she was quite ill.

9 I (Kristy) spoke to Thea the next morning and she was improving and was waiting to see a psychiatric liaison before I picked her up on discharge. After getting in a disagreement with hospital staff, Thea got dressed and walked out of the ward even though she was on crutches with a recent broken ankle (broken from a jump off a bridge three weeks prior). The nurses watched Thea walk out without stopping her, even though she was in hospital after multiple suicide attempts. Thea hobbled half a kilometre and threw herself off a very high bridge. She survived, miraculously, breaking the L4 and L5 vertebrae in her back as well as her other ankle. Thea has required surgeries for her injuries, spent six weeks in a medical ward and still has ongoing physiotherapy due to these self-inflicted injuries.

10 This is just not acceptable – we left Thea in the hospital's care and they failed her and us. What now?!

11 In 2020, Thea has had two intensive care unit admissions as a result of suicide attempts. During one of the admissions, she was in an induced coma for 10 days.

Early intervention

12 We think that early intervention is extremely important. Thea's problems really started when she was around 12 years old, which is when she started cutting, and she also

developed full blown anorexia. As we mentioned above, Thea was hospitalised in her teens and we think that her experiences at the hospital, particularly being held down and force-fed, caused her a lot of trauma at a very young age.

13 For around the last seven years, Thea has been under the care of a specialist mental health service for children and youth. When Thea was around 19 years old, a neuropsychologist based at that service did a test on Thea and concluded that she was borderline intellectually disabled. We have always felt that their thoughts about Thea's intellectual capacity were wrong – it is higher than what they thought. We think they felt that Thea couldn't be treated. They appeared to be unable to find solutions to Thea's suicidal behaviour and we feel she was put in the too hard basket. Once a fortnight, therapy sessions were conducted which in our view were clearly inadequate to treat Thea's Borderline Personality Disorder. We were pushing for Thea to receive formal Dialectical Behaviour Therapy (**DBT**), but the service felt their treatment was good enough.

14 Other treatment and support for Thea, and for us as her carers, is difficult to access, inconsistent, and obviously over-stretched in terms of staffing, funding and training. On many occasions, Thea has been told that she will not receive treatment until she stops her suicidal behaviour. This is putting the cart before the horse. They seem to be saying that Thea won't be treated until she gets better!

15 We have only just recently been referred to Spectrum and Thea is under their care at the moment, having treatment for her Borderline Personality Disorder. Through Spectrum, Thea is now receiving DBT. We feel that Thea should have been sent straight to Spectrum around three or four years ago (when she was 18-19 years old). We believe that if Thea had been receiving her current treatment three years ago or earlier, Thea may have not followed through with so many suicide attempts and she'd be a lot healthier than she is now.

16 In addition, transcranial magnetic stimulation (**TMS**) should be available through public mental health hospitals or as an outpatient. The early evidence shows that TMS has been helpful with depression and for Thea she sees TMS as a treatment that provides some hope for improving her life. We have not yet been able to access TMS.

Carer recognition and respite

17 We have had no carer respite whatsoever throughout the time we have been Thea's carers. The stress we have been under for the past 10 years has been horrific. We are suffering from carer fatigue, have stress on our marriage and financial stress. This in turn has affected our mental health and therefore physical health. I (Kristy) have stopped work

to care for Thea and I (Aaron) now work part time and nearby so I can be called upon when there is a crisis at home.

18 As carers we are unable to go out as a couple to dinner, the movies or to see friends, because at least one of us always has to be with Thea. Even if two support workers are at home, a parent always has to be there as well. The burden we are under is immense and we can see it leading to the death of one of us.

19 There needs to be recognition that carers are taking the main burden of looking after and assisting patients within the mental health system. Carers need to be supported by properly trained staff providing better treatment for complex, suicidal patients and respite for the carer.

20 One of the main problems for carers of mental health patients is the lack of secure housing facilities. We need regular respite, but at the same time Thea has to be in a place where she's secure and safe. We think that, for Thea to be safe and secure, there need to be at least two carers looking after her because she does things very quickly without people noticing. For example, we were eating dinner the other night as a family and Thea started swallowing chicken bones, on purpose.

21 It would be great to have proper, safe respite as carers desperately need this. We think there should be two types of respite available for carers:

(a) *First,* there should be some sort of short term respite available in an emergency scenario. People tell us we have respite when Thea goes into a psychiatric unit. But we don't really have any respite when Thea is in hospital because we don't trust the staff in the hospitals to give her the right care. So, we are often at the hospital with Thea for most of the time she is there, and that is not respite.

(b) *Second,* there should be some sort of regular respite available for carers over the long term. This respite could either be from other highly trained compassionate support workers coming into the family home to be with Thea, or from Thea going somewhere outside of the home where she is looked after, in a caring safe way.

22 Being a long term carer for someone with really complex needs places a soul destroying burden on families, and affects the ability of these families to keep working. Who needs financial pressures as well as extreme stress in their lives, just because they are doing the right thing and trying to care for someone who is struggling so much? To relieve some of that financial pressure, carers of people with really complex and long term cases need to be given increased financial payments from the government.

Psychiatric inpatient units

Our family's experience

23 Often, after arriving in the emergency department with Thea after a suicide attempt, we have to wait for many hours and there are no psychiatric beds and so Thea has to be discharged home, with inadequate follow up.

24 Thea has had a number of admissions to Acute Mental Health Units (**AMHUs**) within hospitals. AMHUs are not fully secure, and so patients at AMHUs are at risk of self-harm and death. Thea actually walked out the front door of one AMHU, and at another AMHU she swallowed batteries twice from a remote control. Thea is rarely admitted to an AMHU for longer than 48 hours – our sense is that there is so much pressure on getting a bed that early discharges are made, plus patients with Borderline Personality Disorder are not given the opportunity for a longer stay (as our experience is that the system believes it doesn't improve outcomes).

25 Prevention and Recovery Care centres (**PARCs**) and Community Care Units (**CCUs**) are unsuitable for Thea because they are not locked. The only secure place in Melbourne that has been offered to Thea as a possibility is a Secure Extended Care Unit (**SECU**). Thea has never been to the SECU, but we went there to check it out and talk with the staff there about 12 months ago (in 2019).

26 While it is great that the SECU is secure, the problem is that some of the other inhabitants are violent and some have just come out of jail. In addition, the SECU has a low staff-to-patient ratio, with around half the staff of acute care units. The SECU patients are mainly people with Schizophrenia and Psychosis, and the staff therefore have little to no experience or understanding of looking after people with Borderline Personality Disorder, like Thea. They were quite daunted when we mentioned how suicidal Thea is.

27 Thea is still contemplating an admission at the SECU, but we are not sure whether they would necessarily accept Thea as a patient. The specialist mental health service for children and youth recently suggested that a SECU would not be an appropriate environment for Thea – they have stated that our current situation is "untenable", but they don't offer any solution!

28 We are now at the stage with Thea where the Department of Health and Human Services (**DHHS**), NDIS and the mental health service are all saying that Thea needs to be living in a secure place. However, the kind of secure, therapeutic place that would be suitable for Thea does not exist in Melbourne. The DHHS and NDIS are therefore trying to sort out whether they can access a house and convert it into something that would be suitable for Thea.

29 We have got to the point where we don’t want Thea going into psychiatric units. During her last experience (as a result of an admission for a suicide attempt), Thea was transferred straight from the intensive care unit to the high dependency unit of an adult mental health inpatient service, without first going to the hospital medical ward. When Thea got to the inpatient psychiatric unit, she could not walk; when she asked for a pan, she was denied this so she crawled to the toilet while being yelled at by the mental health nurse.

Recommended reforms to psychiatric units

30 There need to be secure psychiatric units where patients can spend time and be assessed and helped in a caring and organised environment. All psychiatric units should be safe. There should be no danger of suicide or rape and patients should be unable to escape from secure units. There need to be facilities that are well-staffed, where treatment is much more holistic and healing. We don't believe a place like this exists in Victoria.

31 For the safety of everyone, all psychiatric units should be fitted with CCTV in all rooms except bathrooms. The video surveillance footage should be monitored 24 hours per day. Without video surveillance, safety of patients and staff at AMHUs is patchy. Nurses are supposed to check on patients at 15 minute intervals, but for various reasons this often does not happen. Video surveillance would make the units safer and would take the strain off staff.

32 Bed capacity in acute psychiatric units should be doubled. Four more secure psychiatric units should be opened up in Victoria, including one that specialises in treatment of Borderline Personality Disorder.

33 In addition, emergency departments should have secure areas, which are sectioned off for mentally ill patients or have completely separate emergency departments for mental health patients like there are in the Australian Capital Territory. Those areas should be quiet and healing, with staff who understand mental illness. So many times we have had nursing staff clearly not trained in mental health saying inappropriate things to Thea and exacerbating situations. The cubicles also need to soundproof so others patients don't stir up emotions in other mentally ill patients, when having episodes.

34 Further to this, it would be great to have a holistic residential centre like the Olivia Newton-John Cancer Wellness & Research Centre that offers holistic plus mainstream therapies.

35 No one should be turned away from a hospital when they have attempted suicide – they must be admitted, and admitted for an appropriate period of time, to allow medications to

be assessed and some treatment given in the hospital. They also need to be given proper support once they leave hospital.

More flexible age brackets for psychiatric units

36 You can't always judge a person by their age. A lot of people are very immature at 18 years old, so you can't just say that when a person turns 18, they're an adult and so they now have to go to the adult area of the psychiatric unit. For example, while Thea is 22 years old, in terms of emotional maturity she is more like a 14 or 15 year old. It therefore doesn't make any sense to put her in an adult psychiatric unit, because she's so much still like a child or adolescent.

37 When Thea has been admitted into an adult psychiatric unit, she tends to hide in her room. She won't often go out into the common areas. She's physically scared of some of the other patients. There are often people in these units who are yelling and screaming out, and Thea doesn't do that sort of thing so it frightens her. Staff are often impatient with Thea and she has been treated quite badly in recent admissions when she is difficult.

38 It is always interesting to us that when Thea gets home after a few days in an adult psychiatric unit, she is always so happy to be home. We think that's because the adult psychiatric units are not very nice environments – they are really quite frightening environments for her.

39 Rather than having hard and fast age brackets for particular psychiatric units and for other mental health services there should be more variable age ranges. It should be up to a person's treating psychiatrist as to whether they think it's appropriate for the person to go into an adult unit once they turn 18. The age limit for adolescent units should be extended to 25 or even 30 years old.

Separating men and women in psychiatric units

40 A lot of female patients in the psychiatric units feel threatened by having men in the same area as them. Thea hasn't experienced any sexual violence, but a lot of women in these units have experienced that trauma.

41 Providing women in psychiatric care with a safe space is a matter of human rights. To achieve this, men and women in psychiatric units should be separated. They should still be able to mix together in the main areas, but there should be a separate section where only women can go.

42 Even though you're in a same sex area, you are still not safe in those units. Our daughter has been threatened by other female patients and cruelly treated by some staff.

Workforce improvements

43 There needs to be a much bigger mental health workforce, with more access for all patients. There need to be enough staff per patient in every area. From our observations and experience, both specialist mental health services for children and youth and psychiatric units are under resourced in terms of staffing.

44 There also needs to be better training for mental health care workers at all levels, particularly when it comes to treating people who suffer complex conditions such as a dual diagnosis of Borderline Personality Disorder and Autism.

45 There needs to be much less paperwork to be completed in hospitals, and more time spent with patients. There also needs to be more empathy.

46 Staff should be rewarded for their compassion and abilities to improve patient outcomes. Hope for a better future is so important. This means that mental health staff should talk in a positive, hopeful way. Unfortunately, we have had very little experience of this from the mental health staff we have encountered during Thea's interactions with the mental health system.

47 We have become quite cynical about psychiatric units because we see a lot of the workers sitting behind the glass windows, typing notes endlessly, with not a lot of interaction with the patients in the units.

Skills training and guidance for people with mental illness

48 The most important thing about caring for people with mental illness is that mental health support workers and services are highly skilled and able to really assist people to get back out into the community. Everyone needs to feel useful and have a purpose.

49 To achieve this, there needs to be more effective and appropriate skills training and career guidance for people with mental illness. There need to be safe places where there is an emphasis on real life preparedness through practical training, life skills and working with patients to improve their physical health and wellbeing.

50 This training and guidance needs to be delivered by specialised staff who are trained in mental health, training and employment. These workers should be innovative and able to teach skills. They need to understand mental illness and have the talent to get the best out of their students or patients and build their confidence.

51 Vocational work for people with mental illness should be a priority. People with mental illness and/or a disability should be assessed by highly trained staff to see if they are capable of working and where their strengths lie – are they able to be trained in an area

they would be able to get work in? The government should provide more employment opportunities where there are managers who are trained to assist people with mental health issues.

Specialised support for people with Borderline Personality Disorders

52 People with Borderline Personality Disorder need a lot more help than they are currently getting. These patients need to be managed better with much more funding and alternatives than are offered now. They are treated like lepers and discharged promptly and prematurely with little support.

53 Staff need to be highly trained to work with people with Borderline Personality Disorder. There needs to be better training around Borderline Personality Disorder for doctors and psychiatrists. In addition, all nurses (in emergency, general wards and psychiatric units) need training about how patients with Borderline Personality Disorder behave and how to assist people with this diagnosis in a non-judgmental way.

54 There should maybe also be some form of financial reward for staff who work successfully with patients with Borderline Personality Disorder.

55 In the UK and the USA, they have intensive residential facilities that are specifically for people with Borderline Personality Disorder. For example, in the USA, McLean Hospital and Windmoor Healthcare of Clearwater both have intensive, long term treatment programs. We have had different sources recommend their programs as being cutting edge and successful. If not for the prohibitive cost, we would seriously consider attending them. Our sense from our research plus contacts of Thea is that the facilities in the UK also offer longer term programs in secure facilities. Nothing like that exists in Australia.

Extra support for dual diagnoses and other complex cases

56 Complex cases should be referred to a state wide complex care team. The complex care team should present fresh ideas and opinions about innovative treatment options. This extra support is particularly needed for patients with Borderline Personality Disorder and chronic suicidality.

57 When a person has a disability on top of Borderline Personality Disorder, it further complicates things. As we mentioned above, our daughter has attempted suicide more than 50 times over the past three-and-a-half to four years and the specialist mental health service for children and youth was seeing her every 12 weeks at home. Is that adequate treatment? We don’t think so. Things need to change.

58 Treatment for people with a dual diagnosis of a disability and Borderline Personality Disorder must be sent right up the chain to the top of the DHHS and the mental health

system. All the expert opinions need to be collated and prompt, intensive treatment (medication, different therapies etc) like what occurs in the private intensive residential facilities in the USA needs to be given to that person, because the way things are now has totally ruined our lives.

Analysis of data to help provide better support for patients

59 Statistics need to be properly analysed for mental health patients, and outcomes need to be looked at to see who is getting adequate help. For example:

(a) Police and ambulance services statistics would show what happened to patients that were taken to the emergency department. Patients are often taken to hospitals and after a quick examination they are discharged because they are "not sick enough".

(b) Data on emergency department presentations could be used to identify, and help, people who have had repeated attempts at suicide. This data should be red flagged and sent to an alternative health service or expert committee for input and fresh ideas about how to help these patients.

60 In addition, hospitals need to be analysed really closely for the way they treat mental health patients. How much money is spent at each hospital on mental health and what are the bed numbers per population of the area? From our perspective, hospitals seem to be using money on things that are not important, whereas other areas are sorely lacking resources.

Central hubs and outreach services

61 Every municipality should have a drop-in Mental Health Hub where people can receive help 24 hours per day. These centres should be places where patients can get complete support for diagnosis, treatment and housing, with longer term follow-up treatment. They should include suitable accommodation and have on-site doctors who can help with health issues and prescriptions for medications

62 There also needs to be provision of outreach services, at the patient's home, for patients who cannot safely access treatment.

63 In addition, ongoing phone assistance needs to be available for people who are not coping, and it needs to be provided by highly trained personnel, not just crisis helpline volunteers. Some people may need this kind of assistance every day.

The NDIS

64 Thea has an NDIS package. On the whole, we have found the NDIS to be another roadblock. It is a slow and complex system and the support workers seem to be under-trained.

65 Everything is always changing with the NDIS, which is really upsetting for people who are struggling already to cope with their life. For example, when the NDIS came in, the Partners In Recovery and Personal Helpers and Mentors programs were closed down when Thea went on to an NDIS plan, and she could no longer access those programs. This has caused undue stress and contributed to Thea's deterioration. We feel that we are constantly passed from one bureaucracy to another.

66 We're finding that we are now getting a lot more help from the DHHS Behaviour Intervention Specialists and other areas, including support workers through Extended Families support coordination service, a private Neurologist and Occupational Therapist. Much of the extra help is available due to the NDIS.

67 In contrast, when we turn to the mental health area, we are getting very little help – very few consultations, no reflection or lateral thinking to improve Thea's situation and no follow up on action items from our Complex Care team meetings. We both have a sense that the public health service is "tired" of Thea's case.

68 The NDIS has the potential to be very beneficial for people with psychosocial disability, but it is in its infancy and we are the guinea pigs who are suffering. They need to stop putting in so many changes, and make the NDIS funding appropriate and more flexible.

More money and resources

69 There is something wrong with the Victorian mental health system. Currently, there are not many areas of suicide prevention that we think are working well. Many things can and should be done to lower the rate of suicide. The system is so overrun and services and staff just can't cope with the amount of work they've got. They are therefore very limited in what they can do.

70 The biggest issue in implementing changes to the mental health system is going to be money and resources. There needs to be a massive investment of money into mental health beds and services, which are currently woefully underfunded. If half the money

that was spent on other medical conditions, such as cancer, was spent on mental health, there would be major changes for the better.

71 Our fear at the moment is that, after Coronavirus, there is not going to be any, or enough, money left to spend on making the changes that are needed to the mental health system. But we just need to keep on trying, keep pushing for change.

The importance of compassion and respect for human rights

72 Compassion and respect for a person's human rights need to be the fundamental principles in treating mental distress. Too often, especially in psychiatric units, we have observed that compassion and respect seem to be missing.

73 There needs to be a recognition of the value and autonomy of the person as an individual, rather than just seeing the "pathology."

Dated: 12 June 2020