Royal Commission into
Victoria's Mental Health System

WITNESS STATEMENT OF ERIN DAVIES

I, Erin Davies[1], say as follows:

1 This statement is about the experiences of my family with the mental health system and trying to get care, treatment and support for my son Matthew. Matthew has a diagnosis of Autism Spectrum Disorder (**ASD**) and general and social anxiety disorder. He is currently eleven years old.

The start of our mental health journey

2 Matthew was a very sweet, 'easy' baby and toddler. He was affectionate, interested in the world and basically a delight. In kinder we started to notice he wasn't as settled, but put that down to the impending change of starting school. Also I had been on a number of unsuccessful IVF rounds, which despite my best efforts, no doubt created an atmosphere of stress. Then mid-year I became pregnant and for the first trimester I was very unwell. Then of course I had a growing bump with a baby brother for Matthew inside. I assumed all these changes were causing Matthew's changed behaviour. I spoke to my maternal child health nurse, but she assured me it was Matthew adjusting to change.

3 When Matthew started Prep at school, I gave birth to my second son, Henry. Matthew's behaviour went through the roof. He became very angry at home. Nothing pleased or placated him. He became very negative, rude, aggressive, angry. It was heartbreaking. I was speaking a lot to the school about it, but I felt like they dismissed me because Matthew had just started Prep, and I had a newborn. As the year progressed, it became clear that while Matthew was angry at home, he was quite anxious at school, afraid to try things, teary, having trouble making friends.

4 By the time Matthew was in Grade 1, both the school and we accepted that there was an issue beyond circumstances. We went to a psychologist, and she treated Matthew for generalised anxiety and social anxiety. She flagged the possibility of ASD, but she didn't push it. She didn't recommend an assessment, and we didn't pursue one as ASD, based on our understanding of it back then, seemed impossible. At this time, Matthew got his first mental health plan.

5 By the time Grade 2 rolled around for Matthew, things got worse. He was refusing to be in the learning area or classroom. He was climbing up on windowsills and trees. He was

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[1] The names and details of the witness and the people referred to in this statement have been changed to protect their identities.

quite aggressive. At this stage, we were really worried and frightened. We tried to navigate our way through what to do and who to see. We were trying to see a speech pathologist and a psychologist, but because Matthew was so anxious, he did not participate. It was made worse by being such a disruptive part of his day, as these services only operate during business hours. I would have to stop work, go and get him out of school, and get him to go to an appointment, which he did not want to be at. At appointments, he would be under the table, extremely upset. It just didn't work, it was very stressful for all of us.

6 Our experience with some of the allied health professionals we saw was, in itself, a pretty disappointing process. Like any bucket of apples, with practitioners you get good ones, and then others who you feel it was just about their business. They were booking in appointment after appointment, even though it clearly wasn't working for us. They weren't trying anything different, and it just felt like we were repeating ourselves. They kept charging, charging, charging, and then I started to feel angry that they were just making money from us without helping us.

7 Midway through year 2, Matthew got a diagnosis for ASD, but by that time, Matthew had missed the cut-off for the Early Intervention Funding because he was too old. The Australian Government was providing Early Intervention Funding to children with ASD who were six years old or less, to be spent on services and therapies from a panel of registered service providers, which included psychologists, speech pathologists, occupational therapists, music therapists, physiotherapists. It's expensive going to see psychologists, occupational therapists and speech pathologists.

8 When Matthew got his ASD diagnosis, we didn't talk to him about it right away. We waited until the end of Grade 2. The way we brought it up with him was we gave him a book to read, *Of Mice and Aliens* by Kathy Hoopmann, which is about a child with ASD.

9 Matthew is an avid reader, and he read *Of Mice and Aliens* over and over again. He kind of sidled up to me one night and said, “Mum, do you think I have Asperger's?” I asked, “What do you think?” He said, “I think I do.” I said, “I think you do too.” He had identified with the character.

10 It seemed like a massive breakthrough. Matthew had recognised aspects of himself in the character with Asperger's and seemed okay with it. But then, it all went downhill. He became very angry and upset about it, and his mental health took a turn for the worse. By that stage, Matthew was at the end of Grade 3.

11 By Grade 4, Matthew began medication for his anxiety—in particular, different sorts of Ritalin. What it did to Matthew meant he was not always in the classroom; instead, he was up a tree or on a window ledge.

12 We adjusted the levels of Ritalin under supervision. Matthew was less disruptive. But he was quiet, and he'd gone inside himself. He hid behind books and teachers reported to me on a number of occasions he was cowering in a corner of the classroom crying.

Our first encounter with emergency health services

13 At the end of Grade 4, we had an incident during after school care. We had said to the staff, "If Matthew is going to be part of this service, he needs one person that he can build a relationship with and trust."

14 One night, there were staff at after school care who Matthew didn't know, and they didn't know him. We had given them some advice about Matthew, and told them not to chase him if he ran off, but to let him calm down and come back. However, the staff ignored the advice, and made the situation worse. It took an hour and a half for us and the staff to get Matthew so that I was able to drive him home.

15 Then the Principal said to me, "You need to call triple zero, because he's uncontainable." We didn't want to do that. We got Matthew home and in the house, but he had just lost it; he was at his worst. Normally, if Matthew lost it, we give him space, and he would calm down. But he just wasn't clicking out of this. So we called triple zero.

16 On the call to triple zero we got asked a lot of questions, and, naively, I answered them. They asked me, "Is he being violent?" And I said, "Well, yes, you know, this Grade 4 kid is being violent." Because of that, when they arrived, the ambulance paramedics would not enter the house without the police. The police took ages to arrive. When they did, they came into the house and restrained Matthew, and it got worse and worse. They said, "Okay, he needs to go to the emergency department." But the ambulance wouldn't take him without the police restraining him. So, there was a Grade 4 kid in the back of an ambulance being restrained.

17 My husband Nick went to the emergency department, and Matthew wasn't admitted. He was in a room with security staff constantly trying to restrain him for hours, and then trying to force medication into him. I had to stay home with my little one, and Nick stayed there with Matthew in the emergency department. By about midnight, Nick rang me and said, "I can't do this anymore. We need to swap." I put Henry (my little son) in the car and drove to the emergency department, and Nick and I did a swap. When I saw Matthew, I saw a kid in a room with these big adults still in there, and this had been going on since five in the afternoon.

18 The doctors finally used a nasal spray, which knocked Matthew out. Then they took him into the emergency department. I stayed the night with him. He woke up in the morning, and we were sent home with some medication. We were told, "If this happens again, do

what it takes to get this medication in him. If you need to hold him down, you hold him down."

19 I think we all had some sort of post-traumatic stress after the incident. Matthew was very unwell after that, and a week or two later, he lost it at home. He grabbed a knife. He threatened to kill himself. He'd often beg me to kill him, because he just couldn't handle life. I didn't for one minute think he would try to hurt anyone or himself, but he was in an agitated state and I was worried that there could be an accident. Nick, my partner, grabbed Matthew and held him down. I got the knife off him. Then we did what we had been told: we held him down, restrained him, and forced the medication into him.

Child and Adolescent Mental Health Service (CAMHS)

20 After our experience in the emergency department, I decided to ring CAMHS. I thought it would be a positive escalation, as we had struggled to find the right private provider. I had to ring up repeatedly and beg for Matthew to be accepted by the CAMHS. I said, "You need to take us on," and they said no. I rang up again and begged, and they agreed to a review. That's how we eventually got taken on by CAMHS.

21 But CAMHS didn't work for Matthew. I had to try to get him to go to appointments, but he wouldn't participate. Then I had to try to get him back to school, so that I could go to work. Matthew would refuse. It was terrible.

22 We were already all pretty traumatised by this stage. The psychiatrist at CAMHS put Matthew on Risperidone. Matthew did not react to that well.

23 The end goal was to try and get Matthew on a Selective Serotonin Reuptake Inhibitor (**SSRI**), being a form of antidepressant. But Matthew was put on Risperidone first, because we were told it was quicker acting. The idea was to taper off one drug and bring in the other. When we tried to bring in the SSRI, things went really bad—really, really bad.

24 So, then the psychiatrist said, "Okay, we'll get him off the SSRI and we'll switch the Risperidone to Abilify." When Matthew was on Abilify, he started rapidly putting on weight. He looked like he was medicated, and I know he felt terrible.

The hospital inpatient unit

25 CAMHS recommended an inpatient stay in the child unit at a hospital, and Matthew went there at the start of Grade 5. The inpatient unit felt like a horrible place, and its look made me feel terrible. As soon as I walked in there, I had a feeling of fear. It's scary—the hairs on my body stuck up. I said, "My God, does this place need to look like a bunker?" And they said something like, "Well, it needs to be pretty bomb-proof." The hospital didn't have a family unit, so we were in two bedrooms.

26 Matthew was in there for three weeks, but it all fell apart in there for him. In one episode at the start of our last week in the inpatient unit which lasted for hours, Matthew was having an episode that had been going on for hours. The doctors held him down and put a needle in him.

27 Matthew became more violent than he'd ever been in the unit. He went straight off his medication and he became incredibly violent, and the violence was focused at me. There were code greys all the time, with big people sitting on him. Matthew was restrained constantly. My little one, Henry, watched this (he wet his bed every night in there), and I was covered in bruises on my arms and legs from the kicking.

28 I said to the hospital during our stay, "Things have never been worse. What's happening?" They replied, "You wouldn't be here if he didn't have problems." I said, "Yes, but our problems are much worse now. What's this doing for us?" That's when we started having the sessions with the social worker. We also had family therapy.

29 On our family admission, I had decided to share with the hospital that I was worried I was using wine as a medication. Almost every night I would come home and have two to three glasses of wine. I knew I was using it as a medication. I shared that with the hospital, and they put me on delirium tremens (**DT**) observations. I thought I was being brave by opening up about something that I was concerned about, although it was really the least of our problems, and they put me on DT watch. They would come in and take my vital signs because of my "alcohol abuse" during the family admission.

30 Matthew told the mental health nurses that we had held him down and forced medicine into him. So then the hospital notified child protection, and they told us we couldn't proceed with family therapy because family therapy needs to be safe. They said, "It's not safe, because we've had to make a family protection notice against you." I was frustrated that when we had forced medication into Matthew, as the emergency department had told us to do, it resulted a child protection notification being made against us. I felt that it didn't make sense.

31 The hospital would send us home for the weekend all together. After the weekend, we would have to get him back to the hospital. We did this for three weeks. By the start of the third week, I was thinking, "Why are we here? You've made a child protection notice against us. We've now got family services involved. You've called that many code greys on us. What is the therapy?" All they seemed to be thinking about was attachment theory. They made Nick and me talk about all our parents' relationships, our childhoods and our relationship. Then they told us that Nick and I had attachment issues. It felt like they were saying it was our fault.

32 I had bruises on me, and our family had never been in a worse state than since we'd come to the hospital. Then came a Friday, when our time was up, the hospital said, "You've got to go home now." They sent us home with a safety plan told us to use lavender oil and, if that didn't work, to call triple zero. So, we went home together. Matthew was literally grabbing my head and punching me in the car. I said to the hospital, "How do we take him home?" They said, "Use your safety plan." We had rung triple zero before and we were not doing that again—ever. I wondered, what sits between lavender oil and triple zero?

33 I said to them, articulating myself as clearly as I could, "You can't do this to us. You have done this to us, and now you are sending us back home without any support, to continue on with our lives." In response, they said something like, "You wouldn't be here if there wasn't a problem. We had to lance the ulcer." I couldn't believe it. I thought, "Who mops up the mess? And who heals it?"

34 We were left with Matthew off medication, and we were all totally traumatised.

35 We were constantly being told how lucky we were to be in there, because there were only two such facilities in the entire state. I could not believe that this was the best of our system—it was like a really bad joke. We felt like there was a big black box that we were shoved in, to be processed without any consideration about the individuals involved. Nothing was tailored about our treatment.

Involvement of Family Services

36 A week after we left the inpatient unit, a social worker from the unit came to visit us. I suspect the visit was about whether we had Family Services engaged to support us because of the child protection notice that the hospital had made.

37 After our stay at the inpatient unit, it took two weeks for Family Services to get involved, even though we'd just been through a crisis. When they did finally get involved, and we got a visit from a man, I said to him, "We're really clear now about what we need, which is family therapy, in-home support, and some respite." But the man from Family Services did not help us with getting this support.

38 He came week after week and did absolutely nothing. To be honest, he came across as a highly unaccountable 'cowboy' - showing us photos of holiday houses that we could apply for through the service, which we had no interest in, and talking a lot about this own personal life. I kept asking him, "What is the point of this, we need family support, family therapy – are you able to connect us with a family therapist or not?" We ended up making a complaint about him, which just meant that service withdrew. It was pretty bad, and yet another waste of time and layer of stress, adding to our problems, not alleviating anything.

Intensive Mobile Youth Outreach Service

39 When we left the unit, CAMHS had said they wouldn't take us back. They referred us to the Intensive Mobile Youth Outreach Service (**IMYOS**). IMYOS is like an outreach version of CAMHS, and involved a mental health worker spending time with Matthew once a week.

40 I have no idea what Matthew and the mental health worker talked about. They didn't involve me at all. The worker came to the house or she met him at school. They would go for a walk to the ice cream parlour and have an ice cream together. Then she would take him back to school.

41 I don't know what her objectives were or what the plan was. I don't know whether it was supposed to calm him down temporarily. IMYOS was unable to answer my questions on the purpose and goals of their intervention.

School integration aide and funding

42 Following our release from the unit, I continued having meetings at the school with the Principal and Matthew's teacher. We agitated for the school to apply for funding through the Victorian Government's Program for Students with Disabilities (**PSD**) on the grounds that Matthew had a severe behaviour disorder. I thought this would help the school fund an integration aide, who would work with a number of kids in the classroom including Matthew. Based on this, the school was successful in securing an aide and funding for Matthew.

43 We made a huge effort trying to connect the school and the various services - IMYOS mental health service, the family service, the school, Travencore, YarraME special school. We were trying to understand what the integration aide was doing, and what that $13,000 worth of severe behaviour funding we got was going towards. We were trying to connect all these dots together.

44 We used to call the group of people who were supposedly supporting my son "Team Matthew." Then I became cynical and started calling it "Matthew Inc", because everyone who was there to help Matthew was getting a wage from his situation. Meanwhile nothing was changing for Matthew. The process felt like a sausage factory that had nothing to do with Matthew.

45 We felt hopeless and angry. We could not believe that this was the best that could be done. We couldn't believe how peripheral *Matthew* seemed to the process. The services just continued doing their thing, regardless of whether it was helping him.

Navigating the NDIS

46 At the same time as Matthew was seeing the mental health worker from IMYOS, and as we were trying to understand how the various services worked together, we had to navigate the National Disability Insurance Scheme (**NDIS**). Through the NDIS, we had access to some funding. We told the NDIS that we needed in-home support, family support, respite, and someone to work with Matthew in a recreation-based way so he could have some good experiences. What we received instead were a number of pre-determined appointments with occupational therapists and speech pathologists. But we had funded those sorts of therapies ourselves for years, and we knew they wouldn't work.

47 We felt pressure to spend the funding, because if you don't spend your NDIS money, then you lose it.

Engaging an NDIS provider

48 Matthew is currently on his second NDIS plan, which is a self-managed plan (this is where we manage the funding and arrange who we see). We decided to self-manage because we just couldn't handle the stress of plan-managed funding.

49 We've recently received $2,000 of support coordination funding. But very few providers exist for the support coordinator to coordinate. The support coordinator did find a Sydney-based company that is an NDIS provider, and we've since engaged them. They provide a behaviour management plan, because there have been safety issues in relation to Matthew's behaviour and we are required to create a plan before we can move on to setting up therapies for Matthew. The psychologist from NDIS provider says that to provide a plan, she needs to perform a school observation of Matthew. We have already had so many psychologists, occupational therapists and speech pathologists go into that school and perform an observation. I told her the psychologist from the NDIS provider that we would sign over all the money in our plan to her if she could find us someone to support Matthew who would become almost part of our family; who would be there for the long term. We wanted someone who we could all trust and build a relationship with, who would know us and who would respond accordingly.

50 We have been provided with two psychologists but they have not remained committed. Someone needs to case manage this, and it should be a clinical psychologist.

51 The alternative to having the Sydney-based company coordinate Matthew's care is for Nick and me to reduce our working hours and spend time managing his care. If we did that, then we would employ a couple of therapy assistants, and Nick and I would provide non-clinical supervision. But Nick and I wouldn't get paid for that work. There's money in the care plan for a clinical psychologist to do the coordination work, but not for parents to

do it. If we reduce our working hours and take on that role of a clinical psychologist, then we will be losing income, and we won't be paid for it.

52 Our current situation is that we have engaged this Sydney-based company, and the money is there for them to take. But they need to provide the service, and so far they have stalled. I am hopeful that we will get through this, and get a couple of therapy assistants who I hope we will get to know, and who I hope will stay with us in the long term.

The impact on all the family

53 When a parent has a child with ASD, they also become the child's case manager. But it's too much; it's overwhelming. For example, the stress has taken a massive toll on my relationship with my husband, Nick. All our energy goes into Matthew's care, and there's nothing left for anything else. We have been in couples counselling, trying to hold our relationship together. If he and I split up, what would that do for Matthew's mental health? What does that do for all our mental health? I am medicated, and Nick is medicated.

54 Henry, our youngest, is growing up in a very stressful household. He still wets the bed every night; although, funnily enough, since starting school Henry has been having more dry nights. We send our kids to two separate schools, because I don't think it would help Matthew to have his little brother with him at school.

55 Because of everything Henry has witnessed, I took him to see a developmental paediatrician. I wanted to know whether he was traumatised from the experience in the hospital inpatient unit. I wanted to know whether he could also potentially have ASD.

56 The developmental paediatrician gave us a referral for Henry to have an assessment. But I've sat on that referral, because it's not my top concern at the moment. With Henry attending school now, I will see how he gets on, and we'll ask Henry's teachers for their views as well.

Looking to the future

57 Matthew is now staring down the barrel of high school. I'm worried about how he is going to go once he leaves the loving arms of primary school. How is he going to cope in secondary school? How is he going to cope with puberty and adolescence?

58 Nick and I will help Matthew with his mental health issues. At the moment, the ASD is the least of our worries. Our top concern is his anxiety. At the moment, we have to travel with toilet paper in our car, because Matthew gets so anxious that he gets diarrhoea and we have to pull over to the side of the road. That kind of experience is traumatising. If Matthew

goes out with his grandparents, they know they have to have hand sanitizer and toilet paper in the car.

59 Once we have calmed down Matthew's anxiety, we can then start addressing the ASD. If we can't manage to calm Matthew down, then we won't be able to address the ASD. Both the ASD and the mental health issues will probably be with Matthew for life, but for us the goal is to get them to a manageable level.

60 Every summer we spend as much time outside in nature as we can. We do lots of camping. What works for me and my family is time in nature—being in our bodies, being in the physical world.

61 Matthew has started the school year brilliantly. He is doing a little bit of work. Recently I cried my heart out, because Matthew said, "Mum, can you help me with homework?" He never said that to me before.

62 Matthew is really trying, and there has been a change. He is still not all the way there, but he is massively improved. I'm crediting Matthew with the change I've seen in him, and also attributing it to him getting a bit older. He's developing and maturing, in spite of the mental health system. In my view the system has done nothing to help him; it has traumatised him and our family. In spite of that, he's able to get up and go to school. He knows we love him.

63 Nick and I have been reflecting recently about what we have been through. Around this time last year, in March 2019, we were at the hospital inpatient unit with Matthew. We feel traumatised by it, and are still reliving it. But we also look at how far we've come since then.

Problems with the current mental health system

64 Drawing on my experience as Matthew's parent, I wish to raise the following problems with the current mental health system: (a) rigidity of the system; (b) silos in the system; (c) failure to create trusting and respectful relationships; (d) financial opportunism; and (e) missed opportunities for prevention and early intervention.

(a) Rigidity of the system

65 I feel that we have been put through a system that is rigid. It didn't matter what shape we were or what our circumstances were; there was a very rigid set of rules that needed to be applied. It was more about rule fidelity than getting to know us and understanding our individual circumstances, strengths and challenges. It was a one-size-fits-all system, and because Matthew is on the spectrum, as well as having mental health challenges, he did not fit into what they had to offer.

66 Instead of recognising that and problem-solving *with* us, we were escalated within the system that didn't fit Matthew. For example, because the system didn't fit us at the CAMHS level, we were escalated into the even more rigid level of the hospital's child mental health unit. And because that didn't fit, halfway through the third week, and with a lot of violence, a lot of code greys, and a lot of restraints, the hospital said, "We want you to go home."

67 They sent us home with all of us mentally unwell and feeling like we had no way of coping. If the hospital couldn't hold us and help us—with all their psychiatrists, rotating 24/7 staff, and back-up security for code greys—then what were we supposed to do at home?

68 Then we were put into another system—the Family Services system. I felt like we just kept getting moved through the system, to the detriment of all of us.

69 For a kid on the spectrum, and for parents of a kid on the spectrum, what do we need to do to prevent mental health issues from being such a big part of the landscape? How do we avoid a situation where we're dialling triple zero, in the emergency department, and in mental health units? How do we avoid a situation where a child is having countless experiences of adults in uniforms restraining him? I still cannot believe that we got to that point.

70 I choose to believe that people are intelligent and well-meaning, but that they are constrained in what they can do when they're operating in a system with rule fidelity and a cookie-cutter model; when it is all about adhering to the guidelines. In my view that model does not work—it causes damage.

(b) Silos in the system

71 We found the "siloed" nature of the mental health system to be unhelpful. It was like a full-time job trying to link up the school, after school care, and the psychologist. It was hard trying to get everyone in a room and having to pay for people to be in that room to have that meeting. I have had meetings where there's been a person from IMYOS, a special school worker, a hospital worker, a special education teacher for Matthew (funded by Matthew's severe behaviour funding), an after school care safety officer, the Principal, and Matthew's teacher. I have to organise these meetings and coordinate everyone's diaries. I work full-time, and I'm also trying to coordinate meetings with professionals.

72 Matthew does have NDIS funding, but NDIS funding stops at the school gate, because what happens after the school gate is the responsibility of the Department of Education. We wanted to use some of the NDIS funding for an integration aide at school, but we were told that was not possible. I said to the school, "We will pay for an integration aide out of our own money." I was told that we were not allowed. With the school we applied for severe behaviour funding support, which was around $13,000 per year. This money

goes to the school and contributes to their employment of a shared education aide. When I asked the school what difference to Matthew would this funding make, they couldn't really answer. I guess because with one aide in one very large, open classroom, they can only do so much.

73 Requiring people to fit themselves into a rigid, fractured system that does not function across the domains of people's lives is damaging and not helpful or healing. For us, the requirement that we fit into the system just added unnecessary stress to all the stress we were already experiencing. It would be great to, instead, have a child-centric approach that can move seamlessly across school grounds, the family home, public health systems and private providers. The child and family should feel that it's about them, not about them fitting into the fractured system.

74 My family really values education, but I have a child who is not receiving an education. Our priority is getting Matthew engaged in school. It is frustrating that I cannot use the NDIS money for his education.

(c) Failure to create trusting and respectful relationships

75 Everything about our experience in the hospital inpatient unit made us feel like we were in trouble. Matthew certainly felt he was being punished. The mental health model at the hospital was about attachment theory; and so, in the middle of all our chaos, when things had never been worse for us, Nick and I felt that we were being told it was our fault. We were told that we had "ambivalent attachment". That is how we were assessed by someone who had only ever met us in the circumstances of a hospital inpatient unit.

(d) Financial opportunism

76 Private psychologists are running small businesses. We have come across some private psychologists who we felt did not get to know us, and who seemed more concerned about billable hours. We felt that they were making money from us without helping us at all. They would do things like make an appointment with us, during which they would watch a video with us that we had already seen through Amaze (Victoria's peak body for people with autism and their carers). And that appointment would cost $220 or $180.

77 That made me sick. For us, this was life-and-death stuff. We experienced a lot of disappointment in the private sector.

78 There are certainly businesses that have sprung up in response to the NDIS which advertise themselves as one-stop shops. They're saying, "We employ our allied health workers. They're not on contracts, they're employed by us and are here for the long term." Absolutely some of these businesses have integrity and put the needs of their clients first. However, in our experience, not all of these businesses work towards the greater good

of the client. It can be easier to keep an existing client than finding a new client or referring a client on to another maybe more appropriate service. It seems they hang on to people who they know can and will keep paying, even if it is not in that person's best interests. Mental health care should not be in the hands of people who just want to make money. How do you get the balance right to run a successful private clinic? Some are definitely better than others, so it's patient beware.

79 On the other end of the spectrum, mental health care plans do not provide sufficient care for people who cannot afford ongoing private services. A mental health care plan will provide someone with six to ten visits per year with a psychologist or other practitioner. However, six to ten visits is not enough, especially for a person suffering trauma-informed mental health issues. To provide effective treatment, there needs to be trust, rapport, a decent relationship established between the clinician and the person with mental illness. The mental health care plan does not provide enough sessions to build those relationships much less address mental health illness that is in any way complex or ongoing.

(e) Missed opportunities for prevention and early intervention

80 The system does not prioritise prevention or early intervention at a population level. Matthew has ASD, which is not preventable. However, the mental ill-health that has come from his ASD, and exacerbates his experience of it, could have been reduced if there had been earlier intervention.

81 As I have described in my story, there were so many opportunities along the way for our family to be connected with services and supported. I feel that these opportunities were missed and turned into disasters. If we had been supported earlier on, it would have been better for both Matthew and our family.

82 There also needs to be a better understanding about the intersection of mental health and ASD - it can't all be explained by Attachment Theory. This would allow for better support and services to be provided to individuals and their families.

Our future mental health system

83 A system that is centred around the person would display the following seven features: (a) involvement of family; (b) co-ordination of supports; (c) prevention; (d) outreach; (e) therapeutic relationships of trust and respect; (f) a pleasant working and treatment environment; and (g) lived experience.

(a) Involvement of family

84 What we need is not just person-centric care. We need *human*-centric care. We need to bite the bullet around accepting what humans are. Human-centric care would involve the family as well. There's been an obstinate, blinkered approach in the development of systems, and that approach has ignored what we know about humans.

85 We have said what we need. What we still need, to this day, is family support for us as a unit. We need support that is not just focused on Matthew, but that is focused on *us*. We also need someone who can supervise Matthew's care. We need one person, such as a case manager, who will make sure that we are getting the whole-family support that we need. We need someone to provide clinical supervision for two people who will hang out with Matthew and do fun activities with him. That would give him the chance to have a laugh, to forget the stress in his life, and to forget the fact that he still does not always participate in school.

(b) Co-ordination of supports

86 Since engaging the Sydney-based company with the NDIS funding, we constantly have to chase them for support and do the work. I still have to connect the psychologist with the school. It is a job trying to find services and bond with the support co-ordinator.

87 When our house is in chaos, and Matthew is having a turn, it is difficult for me to sit down and coordinate meetings and appointments. That is when I think of the other people who do not have the capacity to manage their child's care at all.

88 The support coordinator's job is to link us into various support services. But I have found that there are very few services for a highly anxious child who is not well—who is not able to get in the car and go to an office. We need specialised services who can come to us.

(c) Prevention

89 There needs to be more attention paid to, and more resources invested in, prevention. It is time to be honest about what makes healthy humans. We have a mental health crisis like never before. We know that in the community people feel socially isolated. We know that people are being forced to socially isolate. I wonder what is going to come out of this? I think now is an opportunity for us to be honest and say, "We're not robots. We're humans and we have vulnerabilities and we have needs." We need:

(a) safe and trusting relationships;

(b) not too much pressure and stress, but enough to feel challenged;

(c) a healthy environment; and

(d) contact with nature.

90 When humans do not get those needs met, we do not operate well. We do not function well as patients, as parents, or as workers.

91 If we humans continue lives of stress, pressure, consumerism and screen time, then things are only going to get worse and there'll be more people needing mental health services. To cope with that increase in demand, the system is not suddenly going to say, "Okay, we'll slow down and tailor our response." It is just going to create more cookie-cutter models.

92 Investment in relationship-based support and responses might require a bit more money up front, but ultimately we will save money by avoiding the crises, the ambulances, the police and the acute beds.

93 I have a small charity, which has a health trust, among other things. The health trust is concerned with all sorts of diseases, including mental illness. Because of this, I'm fairly familiar with the research about what factors make for healthy humans. The more we live our lives and those of us with special needs are living our lives the way we are, the system is going to continue to be flooded.

94 We need to accept what it takes for humans to be well and healthy (both mentally and physically). We need to do what we can to ensure everyone has access to a healthy environment and way of life. If we do that, then when the wheels do fall off (because of course they will), we will have a tailored response around where that person is at, where their family or support system is at, and what can we do in situ to help them deal with it and build their capacity. I say "in situ", because we should not have to take people out of their environments. We should not be requiring appointments in offices and stays in places that look like bomb shelters.

95 For my family, prevention means greater support around parenting a child on the spectrum. It would be about getting us greater support in our home. It is not just about how we can help Matthew with his anxiety; we also need to manage our own stress. Both Nick and I have had multiple mental health plans throughout this, and we remain medicated.

(d) Outreach

96 After our stay in the inpatient unit, we were all struggling. We were also exacerbating each other. As a parent, when you know you're becoming part of the problem, your confidence unravels.

97 I described above what happened the one time that we rang triple zero. After the hospital, things were terrible at home and unsafe for all of us. The safety plan we were given went from "Try some lavender oil," to "Call triple zero." There was no way were going to call triple zero again, and so I would ring around to hospitals saying, "I just need someone to come around and help defuse this. You don't need to send a big expensive ambulance around accompanied by police. Just send us someone who will help us talk him down, in his own home. And then we can calm him down."

98 In the case of primary-school-aged children, there needs to be more person-centric, de-escalating responses. We needed someone to come into our home on a regular basis and get to know us, and whom we could get to know—someone that we could establish trust with, who would help us be what Matthew needed us to be, help us understand what was going on for him, and help him to feel that there was adequate support.

99 Therefore, I think that for families at risk, there should be an investment in providing one or two professionals who are very child-focused, but who are working with both the child and the parents. Each family would have two people they could form a relationship with. The two workers would alternate, in case one of them is not available. Every week, one of them could do something with the child. For us, it might be doing GoClimb with Matthew, or sitting there gaming with him, because that is what Matthew loves to do. In those activities, Matthew feels like he gets a chance to be successful. Once the workers have established that connection with Matthew, then it might inch towards, "Let's have a look at your homework."

100 And when there is a crisis, one of those two people ideally could be available either to get on the phone or to come around. As a family, you would not have to re-tell the story. These people would know you. Between you and them there would be rapport and trust. This would provide a tailored response that would take the child and the parents into consideration. Even though that kind of model might seem resource intensive, I think that, by the time you have called an ambulance or triple zero twice, it actually works out cheaper. It is going to be much more effective and it will cost less.

101 I see that as a more child-friendly response. Not someone in uniform; not someone who is going to go straight to using restraints. Someone who is skilled — like a hostage negotiator — who can talk the child down from the roof and then stick around and help with the repair.

102 These services would need to be place-based. There has to be regional centres where people can have a hub. The workers could be based in a hub, from which they can travel to a catchment area. It might not matter so much where the hub is from the workers' perspective, because we've all learnt to work remotely now, but that professional needs to be able to get to the child's home in 20 minutes.

103 There need to be long-term, ongoing relationships that remain in place. Then when crises do happen (as they will), those relationships can remain in place, but there can be more resources brought into the home. I am not saying that there is no need for acute care mental health beds. I am just talking about the vast majority of people who don't require that.

(e) Therapeutic relationships of trust and respect

104 Let's go back to the very basic fact that we are not widgets. We are humans. What do we know about humans? What brings out the best in humans, what brings out the worst in humans, whether you're a patient or a worker? What is going to bring out the best for the patient, and what is going to bring out best for the worker?

105 For mental health and wellbeing, the answer is relationships. It is about rapport, trust and getting the right fit for the person. You do not necessarily have to like the people who are working to help you, but there needs to be a trust and a respect.

106 An example of a missed opportunity to create a therapeutic relationship is our experience with IMYOS. When Matthew was seeing the IMYOS mental health worker, her attitude was one of "I'm here for Matthew." I thought, "That's great, but we need to be here for Matthew too. You're going to move on, so how do we extend what you're doing with him?" There are all these things happening in silos. It comes back to relationships: humans need healthy, trusting relationships.

(f) Providing and receiving care in a safe and pleasant environment

107 As I said above, our family felt horrible in the hospital inpatient unit. If we felt that bad in there, if the environment not conducive to mental health, then how do the staff feel? What is their mental health like?

108 I felt for the staff, first because it felt like such a horrible environment, and secondly because the staff had such a limited range of responses available to them. It must have felt bad for them, because we were clearly distressed and asking for help, and all they could say was, "This is what I'm allowed to do."

109 If our mental health workers are working in unhealthy, unhelpful physical environments, in an unhealthy, unhelpful system, dealing with crisis after crisis, then we are not giving them the chance to be the best mental health workers they can be. If their mental health is poor, then how can they provide effective mental health care?

110 It is a compounding negative. The workers are negatively affected, and the patients are negatively affected. What is the point of it?

(g) Lived experience

111 It is very important to hire people with lived experience of mental health issues and/or ASD. A big part of the problem with the system - and society - is the ongoing stigma that attaches to mental health issues. People are afraid of it. The stigmatism of mental illness is perpetuated when people are not used to studying, living, working with and for people with mental illness, and there are no accessible models of how to do this.

112 The way that we overcome stigma is for people to be regularly exposed to and experience working with people with mental illness. For example, society previously thought that it was impossible for women to hold any position of responsibility. However, when women eventually did work alongside men, it showed society that it was possible for women to succeed in positions of responsibility - despite menstruating, having babies or reaching menopause - and it has gradually become the new normal in many places. It is vital to show difference and diversity out in the open, at the heart and at the top of things, not just on the fringes of society.

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