STANDING COMMITTEE ON ENVIRONMENT AND PUBLIC AFFAIRS

PETITION NO 23 — MENTAL HEALTH BEDS FOR ADOLESCENTS

TRANSCRIPT OF EVIDENCE
TAKEN AT PERTH
WEDNESDAY, 2 JULY 2014

SESSION TWO

Members

Hon Simon O'Brien (Chairman)
Hon Stephen Dawson (Deputy Chairman)
Hon Brian Ellis
Hon Paul Brown
Hon Samantha Rowe

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Hearing commenced at 10.29 am

Mrs CHRISTINE BROWN
Director, More Mental Health Placements for Perth Children's Hospital, examined:

Mrs LINDA STILLITANO
Director, More Mental Health Placements for Perth Children's Hospital, examined:

The CHAIRMAN: On behalf of the committee, I would like to welcome you to our meeting. You both will have signed a document entitled "Information for Witnesses". Did you both read and understand that form?

The Witnesses: Yes.

The CHAIRMAN: These proceedings are being recorded by Hansard and a transcript of your evidence will be provided to you. To assist the committee and Hansard, could you please quote the full title of any document you might refer to during the course of the hearing just for the record. I remind you that your transcript will become a matter for the public record. If for some reason you wish to make a confidential statement during today's proceedings, you should request that the evidence be taken in closed session. You can do that at any time if you feel the need. If the committee grants your request, any public and media in attendance will be excluded from the hearing. Please note also that until such time as the transcript of your public evidence is finalised, it should not be made public.

Mrs Stillitano, did you wish to make an opening statement?

Mrs Stillitano: I would prefer Christine to go first.

The CHAIRMAN: Okay; we will go to Mrs Brown first.

Mrs Brown: Thank you for giving us the opportunity to speak today. What I am saying is my personal story. It is the story of the experience that my family has had with the public mental health system and specifically my 16-year-old daughter, Caitlyn. I have got the tissues handy but I am going to do my best not to need them. Three years ago, I could not have imagined that I would be sitting here talking about this today, because I had had no experience with mental health. No-one in my family identified as having a mental illness, and certainly my colleagues and friends were not acknowledging any problems. Then one Friday night, my daughter came to me and she told me that she was suicidal, and our world turned upside down at that time. So we attended Princess Margaret Hospital and we sat in the emergency department until four o'clock in the morning when we were able to be seen by a psychiatrist. At that time there were no beds available in the Princess Margaret Hospital mental health section. He spoke to me and he spoke to my daughter and he spoke to us both together, and after a short amount of time we were sent home. At that time we were given some phone numbers and a promise of a visit from the acute community intervention team. We had our first visit and then five days later my daughter took her first overdose. Since that time she has been diagnosed with post-traumatic stress disorder caused from trauma in her childhood. What that means to us is there are just times when she is not able to function. She is very unwell; she cannot function effectively and cope with the activities that are a normal part of daily living.

What we have done for Caitlyn is over the past few years we have been taking her for therapy up to four times a week, used hundreds of days of leave from work to stay at home and care for her, maintained her medications and we have loved and supported her as best we could. But what has happened is we have cared for Caitlyn, we have done the best we can, but there has still been the

series of overdoses, suicide attempts and the need for hospital admissions. About a year ago, Caitlyn seemed to improve and she seemed to be recovering, and things did go well for a long time—about eight months. Then, unfortunately, Cait started experiencing those negative effects from the trauma and she took another overdose, and we took her to the Armadale emergency department; this was about three months ago. In the emergency department, she was treated for the physical effects of the overdose and then when her physical needs were met, ideally she would have been transferred to Princess Margaret Hospital's adolescent psychiatric ward, which is called ward 4H. Unfortunately, there are only eight mental health beds in 4H, and those beds were all full—not for the first time that we have needed access to them, but on this particular occasion they were all full. She was medically cleared and Caitlyn remained in the emergency department. I stayed in this brightly lit, chaotic environment with my unwell daughter for three days. She was then transferred to 4H for a short stay. The benefit of a dedicated psychiatric ward is that the staff there are experienced with mental illness and patients are seen regularly by a psychologist.

After returning home, Cait was still having a very difficult time and, shortly after, she asked to return back to hospital for her safety. Throughout our personal experience with kids, what we know is when they say they need to go to hospital, they need to go, so we took her back. We listened to her, responded to her needs but, unfortunately, at this time, again, there were no beds at ward 4H. This time she was admitted to a general ward in Princess Margaret Hospital. Caitlyn was in the general ward for three days. During this time she was placed in the room right next to the nurses' station, which has a glass window so they can keep an eye on her and have a bit of awareness for her safety, but basically it was just monitoring her and keeping an eye on her. I stayed with Cait most of the time. I just went home when I needed to shower, get changed and have some sleep, not that there was much happening, but that is what I did. At one stage I returned back to the hospital after going home for a shower and to change and Caitlyn was missing. It was terrifying. I panicked. The staff at the hospital are always wonderful and I appreciate what they do, but what that said to me was that the staff did not seem to be aware of the need for the constant attention that those young people that are in crisis need. She needed to have that constant surveillance there. She actually was safe; she had gone to another part of the hospital where she had been sent for some recreation activities. But that would not have happened if she was in 4H at that time.

After a short stay, she was sent home on a Monday. She still was not feeling 100 per cent, but we do understand that a hospital stay is not indefinite, so she came home. Within a couple of weeks of discharge, she made her CAMHS therapist aware that she was feeling unsafe and that she needed support again. They deemed that she required hospital admission at this stage; that was their professional opinion. So they contacted PMH and they insisted that she be admitted into ward 4H; however, there were no beds available again. So she was sent to the Bentley adolescent unit. This measure was taken to keep her physically safe. However, we are in agreement, as the carers of Caitlyn, that it is not the best option for her. Bentley adolescent unit offers a different, more intense and much less therapeutic environment, but it was the step that needed to be taken at that time for her physical safety.

These are recent events for us. We hold great hope that Cait will recover and that she will live a happy and fulfilling life, but in the meantime our hope for her and other young people in her situation is that they have access to the medical services that they require to survive and to recover; and, if this includes a hospital admission, I feel that it is a basic human right to have the need for appropriate medical care met. Since our experience, since this has been part of our life, something that we have learned very quickly is that we are not alone. There are many, many people in the same situation as us; in fact, last year, we were contacted by a young girl via our Facebook page and she was very concerned that her friend had not been able to have hospital admission and she felt, for her safety, that was a requirement. They could not get her into hospital and a short time later she committed suicide.

When I first spoke, I mentioned that up until a few years ago we knew very little about mental health and the mental health system. What I have come to understand is that until you have that firsthand experience, you really cannot fully understand what it is truly like. We would not wish anyone to have to have these experiences, but what we would like is for the people who are making the decisions about the number of adolescent mental health beds that will be available to consider what it is like to need this assistance and not have it available to you. What we would say is if it was their child, they would just want to know that they were safe. It would be our hope that in the future, when our young people need admission to hospital to keep them alive, a bed is available to them. I personally and we passionately believe that the number of adolescent mental health beds available in the future needs to be vastly increased. Twenty beds at the Perth Children's Hospital will be inadequate to save lives.

[10.40 am]

The CHAIRMAN: Mrs Brown, thank you very much. I know it was not easy to tell that story. I am sure you have the good wishes of my colleagues and I, and all of the community that we represent. Thank you for bringing this matter to our attention through your petition. It is our response to try to quantify the problem to see if something can be done about it.

Mrs Brown: We appreciate it.

The CHAIRMAN: Hopefully, we are giving back a bit as well. I am sure that other families in a like situation appreciate your coming forward. On a point of clarification, and I am sorry to take you back to that Friday night when Caitlyn first came and said she was contemplating suicide. How long ago was that?

Mrs Brown: That was about three and a half years ago now.

The CHAIRMAN: Thank you, I just wanted to clarify that. We will come back for some more questions soon.

Mrs Stillitano, did you have an opening statement that you want to make?

Mrs Stillitano: I did, thank you.

The CHAIRMAN: Please do.

Mrs Stillitano: Good morning and thank you for this opportunity to talk to you. My family has not experienced the mental health unit at Princess Margaret Hospital for Children. My daughter Amanda was 17 when she was first diagnosed and we were referred to a private psychologist. She is now 20 and has had many self-harm episodes, suicide attempts and hospitalisations. She has had therapy as an inpatient and outpatient at Perth Clinic. Twice Amanda has been admitted to the Armadale mental health unit. She was so scared to be in this unit with older people in their 30s and 40s, when she was only 18. She felt like she was in a prison and being punished. The difference between public and private mental health units is astonishing. Everyone talks about early intervention and, yes, we need to get our young people treated at an early age. When they feel they need hospitalisation is when they are at their most desperate and they want to kill themselves and, at this time, they need a bed immediately. They need to be able to feel safe and cared for. They need staff who have been trained in mental health. If they are told, "We have no beds", it is a feeling of being unloved and unwanted. Some then go on to suicide if they cannot get a bed. For a family to deal with 24-hour suicide watch at home is enormously exhausting, and it should not be this way. For people to understand young people with mental health issues, they need to experience it firsthand. It is not a normal way of life. Other people look at this young person and say, "There's nothing wrong with them; they should get over it." They just do not comprehend the pain the person is going through with their mental health. My daughter expresses it like having third degree burns, the pain is that bad for her. We lose so many young people to suicide in WA. Twenty beds at Perth Children's Hospital will not be sufficient for a whole state in the future, especially with our ever-increasing population growth. We need to help our young people now. They are our future, and if

they need a hospital bed today, they should be able to get one. They need to feel safe when they are at their lowest point. Thank you.

The CHAIRMAN: Thank you in turn for that as well. You have covered in your opening statement a lot of the things that the committee wanted to explore, so thank you for at that. Could I just ask: dispassionately, we often hear professionals talking about the need for provision of primary care for other forms of early intervention to avoid the need for inpatient services to be provided. What is your response to that based on your circumstances?

Mrs Stillitano: I agree that if they got early intervention and therapy as an outpatient maybe that would certainly go a long way to help them in their suicidal feelings and it may prevent hospitalisation. They certainly need early intervention, and I would look at something like outpatient therapy for them, where they feel they can go to a safe place and feel comfortable in a surrounding. The most important thing is that they have to feel comfortable with the professional person as well. My daughter has had several psychologists and counsellors, and if she does not feel like she is comfortable with that person, she will not open up. They need to be able to feel comfortable with that person in this early intervention.

The CHAIRMAN: Thank you for that balanced response. I know this is an emotional matter.

Mrs Brown, when Caitlyn first came to you it was a shot out of the blue, was it not?

Mrs Brown: When she told us she was suicidal, yes.

The CHAIRMAN: And you attended at PMH?

Mrs Brown: Yes.

The CHAIRMAN: If I remember correctly from your opening remarks, the primary assessment was that she should be admitted or needed to be admitted but there was not room; is that right?

Mrs Brown: That is right. There was a suggestion of admitting her. The psychiatrist at the time said he was concerned, because it was her first expression of feeling suicidal, but he was not 100 per cent certain about admitting her. But there were no beds so he made the decision to send her home.

The CHAIRMAN: I see. Because it was the first presentation, it was the reaction of that professional to say, "We need to pour some resources on this case."

Mrs Brown: There was a possibility at that time he would have been leaning to not admitting her anyway. My point is that at that time, if I had been pushing for that, it would not have been a possibility.

The CHAIRMAN: Because of the availability of beds at the time?

Mrs Brown: That is right.

The CHAIRMAN: You explained that subsequently there were a number of occasions when, in your experience, admission was indicated but not possible because of the lack of beds.

Mrs Brown: That is right. This is the most recent. This was another time when my daughter was in hospital and was sent home when she was still feeling unsafe but there were no beds, and we feel she was encouraged to leave before she was ready and that resulted in another overdose.

The CHAIRMAN: I will pass to my colleagues.

Hon STEPHEN DAWSON: I thank you Chris and Linda for sharing your stories this morning. We are told that we need a variety of services across the spectrum of the mental health system. One of the things that has been raised with us this morning was the issue of Hospital in the Home. I guess we will ask the Mental Health Commissioner later on, but I presume that professionals would go to your house to give your loved one the services they need. But I guess that is not always

going to work if you have children and teenagers who need constant care. It will probably not be feasible if you have a job. What do you think?

Mrs Brown: I agree 100 per cent. I would sleep with my daughter; I would be with her 24 hours a day if she would let me. Having someone there is not the answer. I can be there with her, but in my particular instance her trauma means that she does not want anyone physically close to her. So, when she is in her room at night time, that is when the problem is when the thoughts are going through her head over and over again. Having someone come and visit our home is not going to work. When she gets to that crisis she needs to be in a place where it is a completely contained and safe environment. We do our best, but I do not know having someone come into the home at those times would be of any benefit. I cannot understand how it would be of any benefit.

Hon STEPHEN DAWSON: One other quick question relates to waiting lists for access to acute inpatient care. It is probably unfair of me to ask you how many beds you think we need in the system. Is it always your experience that there is a waiting list and a lack of beds?

[10.50 am]

Mrs Brown: I would say definitely more than 50 per cent of the time, yes.

Hon SAMANTHA ROWE: From your experience?

Mrs Brown: Yes, personally.

The CHAIRMAN: That is an important point. In your experience—there have been a number of occasions when you have referred Caitlyn in a situation that ideally required admission—that has not been possible. Have there also been occasions when it has been possible?

Mrs Brown: Yes, there have.

Hon STEPHEN DAWSON: Anecdotally, 50 per cent is about right?

Mrs Brown: Yes. I do not have that statistic, but it could be slightly more 60; you know, 60–40.

Hon STEPHEN DAWSON: In terms of other families involved with the group with a Facebook page, do you hear the same story?

Mrs Brown: Yes.

Mrs Stillitano: Unfortunately, we do.

Hon BRIAN ELLIS: Linda, you mentioned the comparison with the private hospitals. Was it just the access to the beds that you were happy with or was it the treatment?

Mrs Stillitano: It is everything. If my daughter is feeling unwell, she can get a bed normally within 12 hours. The last time she was admitted we had a bed within an hour. But also at the private hospitals they do inpatient therapy groups for them. They get up; they have breakfast, they go to a group; they have morning tea; they go back to another group, so there is always a therapy group going on. They have therapy groups in the evening and the afternoon for them as well. I felt that when she was in the Armadale hospital, there were no therapy groups as such. There was art therapy for them but not like CBT—cognitive behaviour therapy—or DBT, which they need to help in their recovery. She was using that as an inpatient and then when she left hospital she was able to access them as an outpatient as well. I feel that is what we definitely need. We need them to have their therapy, not just to feel safe and be in their ward; they need to have help in order to help their recovery.

Hon BRIAN ELLIS: The whole package.

Mrs Stillitano: The whole package. I also felt the atmosphere in the Armadale was like a prison. They had the big steel doors with the little opening you open up so you can see inside. Everything was cold and it was a very unfriendly environment compared to the private ones.

Hon BRIAN ELLIS: When your daughter did get to ward 448, did she get that sort of treatment or that sort of package?

Mrs Brown: I am glad you asked that question. I had had limited experience and I did not know a lot about the private system so we went through the hospital because that is what I thought you did. Since meeting Linda I have seen the difference between the public and the private system, and it is not even comparable. My feeling is that 4H is full of lovely, caring, beautiful, kind people who keep the kids safe and they do have access to a psychologist every day, so it is helpful, but all the therapies that are available in the private system are not there. We have made a decision with Caitlyn turning 17 that we will go into the private system because what is available for those 17 and 18-year-olds at the moment is scary for me. I do not want to go there. I think about the time when I was a single mum and people who do not have the money to access private health, and it is a big disparity at the moment of what is available.

Hon SAMANTHA ROWE: With the group you have got going on Facebook and everything, is it the same age group of children you are finding—that 16 to 18-year-olds—or is it across all age groups of children?

Mrs Brown: It is across all age groups, yes.

Hon SAMANTHA ROWE: Even the younger children are also not getting the beds they require, across the board?

Mrs Brown: Yes. I was speaking to a mum recently whose daughter was self-harming and she was really concerned that she was suicidal. She had been trying to access CAMHS and they did not consider at that stage that her needs were great enough for her to access. I know; I found it shocking as well. Anecdotally, I have been told there is up to a three-month waiting list to see CAMHS.

Hon STEPHEN DAWSON: Christine, I think you mentioned earlier the pressure on you or Caitlyn to leave hospital early. Has that happened a few times?

Mrs Brown: Very much so, yes.

Hon STEPHEN DAWSON: It is simply a case of "We need beds for someone else and we deem this person to be more at risk and, therefore, Caitlyn has to go home."?

Mrs Brown: Yes, I believe there have been times when that was the case, for sure. It is true I have been told.

Hon STEPHEN DAWSON: We have been told this morning that Western Australia has only 50 per cent of the number of psychiatrists it needs. Have you had experience when have you not been able to access a child psychiatrist?

Mrs Brown: For Caitlyn, part of her CAMHS therapy is a regular meeting with a psychiatrist because they are in charge of her medication, but that is the only access.

Hon STEPHEN DAWSON: How regularly would that happen?

Mrs Brown: I am not sure. With a regular review, I think it is every two months.

The CHAIRMAN: We have received your petition, of which you are the principal petitioner. Who else have you raised this with in, for example, the health hierarchy—people in authority?

Mrs Brown: We have written to the Minister for Mental Health. It is a long time ago when we were writing letters furiously to everyone we could think of.

The CHAIRMAN: What sort of response did you receive from those in authority?

Mrs Stillitano: We actually did get an email reply back from them and I think it said something along the lines that with the new mental 10-year plan that is coming out they are hoping to address some of the concerns because they are more looking at out-of-hospital care and not really increasing

the number of beds, when it is necessary. I mean, WA is a big state. It is only going to be the one hospital that will care for the whole state of WA with 20.

The CHAIRMAN: Was that that correspondence raised on behalf of your group?

Mrs Stillitano: Yes.

The CHAIRMAN: You received what sounds to me like a global response?

Mrs Stillitano: Yes.

The CHAIRMAN: Has either of you had the opportunity to raise your individual cases with someone in authority, and say "Look here's where my child is not receiving the attention with a problem that her case requires."?

Mrs Brown: Through emails. You are the first people to ever hear that specific an account of what is going on but I do refer back to specific instances when Caitlyn has not been able to access the help that she needs.

The CHAIRMAN: Has that been acknowledged?

Mrs Brown: Yes they say, "I'm sorry to hear about your circumstances, blah, blah, blah."

The CHAIRMAN: On behalf of the committee, we certainly appreciate you coming in today and giving us the benefit of your experience. A transcript of the hearing will be forwarded to you for correction of any minor errors. Any such corrections must be made and the transcript returned within 10 days from the date of the letter accompanying the transcript or it will be deemed to be correct. New material cannot be provided via corrections and the sense of your evidence cannot be altered. However, if you want to provide any further information or elaborate on any points we have covered, we would be more than happy to receive a further submission, although we have already received submissions from you in writing, and we appreciate that as well. Thank you once again for coming in today. Best wishes to your families and your loved ones too on behalf of us all.

Hearing concluded at 10.59 am

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