

LEGISLATIVE ASSEMBLY FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON EDUCATION, EMPLOYMENT AND YOUTH AFFAIRS

(Reference: Inquiry into youth mental health in the ACT)

Members:

MR M PETTERSSON (Chair) MRS E KIKKERT (Deputy Chair) MS E LEE

TRANSCRIPT OF EVIDENCE CANBERRA

WEDNESDAY, 1 JULY 2020

The Hearing of 1 July 2020, conducted by the Standing Committee on Education, Employment and Youth Affairs for its *Inquiry into Youth Mental Health in the ACT*, was held *in camera* and so the transcript was originally a private document of the Committee.

In private meetings of 14 July 2020 and 4 August 2020, the Committee resolved that transparency, and its effort to prepare and table the report, were best served by the Committee authorising the transcript's publication. Witnesses were given an opportunity to identify any areas of potential sensitivity for redaction and these redactions were agreed by the Committee at its 4 August 2020 meeting. Aside from these redactions, the transcript has not been altered in any way other than to change its status from a private to a public document of the Committee.

Secretary to the committee: Ms S McFadden (Ph: 620 70524)

By authority of the Legislative Assembly for the Australian Capital Territory

Submissions, answers to questions on notice and other documents, including requests for clarification of the transcript of evidence, relevant to this inquiry that have been authorised for publication by the committee may be obtained from the Legislative Assembly website.

WITNESSES

Privilege statement

The Assembly has authorised the recording, broadcasting and re-broadcasting of these proceedings.

All witnesses making submissions or giving evidence to committees of the Legislative Assembly for the ACT are protected by parliamentary privilege.

"Parliamentary privilege" means the special rights and immunities which belong to the Assembly, its committees and its members. These rights and immunities enable committees to operate effectively, and enable those involved in committee processes to do so without obstruction, or fear of prosecution.

Witnesses must tell the truth: giving false or misleading evidence will be treated as a serious matter, and may be considered a contempt of the Assembly.

While the committee prefers to hear all evidence in public, it may take evidence incamera if requested. Confidential evidence will be recorded and kept securely. It is within the power of the committee at a later date to publish or present all or part of that evidence to the Assembly; but any decision to publish or present in-camera evidence will not be taken without consulting with the person who gave the evidence.

Amended 20 May 2013

The committee met at 2.32 pm.

, Carer

THE CHAIR: Good afternoon, and welcome to this in-camera hearing of the Standing Committee on Education, Employment and Youth Affairs. The proceedings today are in relation to the committee's inquiry into youth mental health in the ACT.

On behalf of the committee, **Theorem**, I thank you for attending today. Before we start, there are a few important matters that I wish to draw to your attention. Due to the hearing being held in camera, witnesses are not permitted to discuss proceedings with any person or organisation not present at the hearing.

Please be aware that the proceedings today are being transcribed by Hansard. The transcript will be confidential to the committee and not published. However, I must also advise that the committee reserves the right to publish the transcript in full or in part and to use the evidence taken in camera in its report, where the use may be by way of reference to evidence rather than quoting from it. Should the committee decide it wants to use the evidence taken at this hearing in that way, the committee will advise you and seek your comments and your advice on whether you have any objection to the use of evidence in that way. Is that clear?

: Yes, thank you. It is.

THE CHAIR: Can you confirm that you have read the privilege statement and you understand its implications?

: Yes, thank you.

THE CHAIR: Before we proceed to questions, would you like to make an opening statement?

: Yes, thank you, I would. I thank the committee for allowing me to address you and give you some further insight into my story. As a teacher I have a unique view of things in a different way and as a foster carer, again, I have some experience around what happens with our most vulnerable young people in the ACT.

As you are aware, my daughter was a foster child and I have adopted her. I have had her since the age of seven. So I have engaged with quite a range of different services through that time, starting, obviously, with child protection and moving through various education systems and various different service supports around that whole time.

Unfortunately, all of that was a little bit too much for her to bear, given her previous childhood trauma. That is why we have landed in the mental health space.

I want to let you know my thoughts about what I think might need to happen, for what

they are worth. I believe there needs to be a cultural change around how we handle our young people in the mental health space and a recognition that all of our children who are in care are already carrying trauma. Because they are carrying trauma, that leads very much into a mental health space before they have even started, and that is really unfortunate.

As a teacher I have seen trauma exist in kids as young as around six or seven. I have taught from year 2 all the way up to year 12. It is really, really distressing to see children that young carrying that kind of trauma, and I do not believe we really have support for them, as people perhaps believe. That is something we need to look at. I strongly recommend that we do.

I also think it is very, very important to involve carers all the way through. In my experience, the caring situation got complex when my daughter turned 16. There are some constraints around the Health Act that allow people of 16 and older to have a bit more of a say in their health and the way that they are treated by the system. Unfortunately, when people have mental health issues they are not necessarily thinking rationally.

I have been in a situation more than once where I have been locked out of a mental health unit at Canberra Hospital because my daughter decided that she did not want to speak to me that day. She had just got it in her brain: "No, that's it. Not talking to Mum at the moment." Therefore, I was locked out, and when you are locked out you cannot actually do anything about that. Then there is a situation where she will also say, "I don't want you involved in my care." She does at one level, but there is also that belligerent teenager thing going on and, therefore, she just wants to grab a little bit of control around what is happening for her. My experience has been one of quite a lot of frustration when it comes to that.

She is now in Hyson Green, and at Calvary private over the last couple of weeks the experience has been quite refreshing. They said to me their policy is to involve the family and carers of the people they are dealing with, and that is a general policy of that hospital. I know it is not a policy of the public system, but it certainly appears to be for at least Calvary. That made a tremendous difference in the way we were able to move forward for her, and we ended up being able to access Hyson Green for her. Along the way, I am involved in the discussion.

If I could hark back for a moment to the child protection side of it, every child has a care team around them and the care team involves maybe the treating psychiatrist—it might be a psychologist. It will certainly be social workers. It might be a Barnardos worker as well. It could be, if the child is under 18, someone from CAMHS, and, if they are over 18, someone from adult mental health. So there are a whole range of people around them. I think that that model, whilst I am not saying it has always been successful, is a good model to look at when you are looking at young people who need supports around them.

It is really hard being an adolescent to begin with and then to have mental concerns on top of that, it is a wonder some of our young people make it to school. Some of them do not, but for some of them school is actually the most important and safest place for them to be. That leads me on to my next point, which is really about looking at an integrated approach. In other forums I have also advocated for this. I think it is important that education, child protection, CAMHS, adult mental health and the general health system all work together. We often get an approach that is very siloed. When that happens, the right hand does not know what the left hand is doing and so there is conflicting advice and conflicting information.

When my daughter has been in hospital, a psychiatrist will give her one set of information and put her on one set of medication. She goes back out into the community and all of that changes again. The medication mucks around with your brain quite a lot anyway, so to keep changing it all the time is not good. She does not know who the authority is, so it makes it quite problematic. I really think we need to look much more at integrating what we do for the young people and maybe even having a case manager who deals with all of those areas.

I have found myself, as a carer, that I am the one who has to try and do the integration. I am the one who has to ring people and try and make sure everyone's on the same page. That is really hard. It is not a great role to have when you are also trying to be the parent, looking out for your child's best interests, to also then have to do five or 10 phone calls—it can sometimes be that many—just to make sure everyone is on the same page. And then, as I said, sometimes people will not talk to me because they believe that is something they are not supposed to be doing because of the Health Act. So it becomes quite frustrating as well.

My final point I would like to talk about is the need for having a residential adolescent unit in Canberra. My daughter has been interstate three times. She has also been put, rather inappropriately, into the adult mental health unit. Her first stint in there, she was just 15, I think. Maybe she was 14, almost 15. Not an appropriate place. I would have an educated guess that even now, at the age of 19, given her emotional instability and immaturity, it is still not a good place for her to be. It has been a really bad experience. She has been in there twice.

The only way she ended up exiting that was to go to an adolescent mental health unit interstate. The waiting list for that is huge. The fourth time we tried to get her in and we were not successful, we were told by New South Wales that the ACT did not have an agreement. I had to go into bat and say, "Well, actually, I know they do. We've got an agreement with NSW Health about this and these are the reasons why I know it."

I ended up having to access the minister here—I cannot remember which minister it was at the time but certainly whoever was the Minister for Health—and say, "Listen, I really need some help here because these guys are not listening to what I know is the case." So that was also frustrating. For me as a carer to have to go in to bat like that is a bit silly, too. It ought to be that the system actually supports people. I think it is very important that that happens.

Obviously, it is going to take some time to get an adolescent mental health unit here. I believe it is essential and I also believe that it ought to go up to the age of 25, 26. The reason for that is neurological—your brain is still developing. The science tells us that we are still developing. We still have a chance to change neurological pathways right

up until about the mid-20s. To have this kind of arbitrary cut-off thing at 18 is a bit ridiculous.

My daughter got kicked out of the care system not because she did not have a further need or was not responding positively to it but because she turned 18. If we have an adolescent unit in Canberra, the last thing you want is for the young person to be kicked out as they turn 18, just because they have turned 18. Then we have actually abrogated our responsibility for them and it causes further issues down the track and we have people going into a cycle, like my daughter is now.

The only thing that is probably stopping her from being in a really bad situation is me, because I advocate a lot for her and I try and make sure that we always find the best services. Not every parent can do that or knows how to do that. And, really, it is unfair that a parent has to go to those lengths, instead of the system saying, "Here are the services that we can provide. This is what we can do for her. If we can't access something here, here's what is available interstate and let's help you to get there and work out a plan on what happens when you come back." That seems a fairly sensible approach to me, but I can tell you it is not really happening. I will leave my statement there. I just wanted to fill you in on what my thoughts were around that.

THE CHAIR: Can you tell us more about accessing adolescent mental health units interstate. What effect did it have on you having to travel interstate and what was the process like to get into these units interstate?

: The process that we went through varied. With Shellharbour it was easier than going to Orange. The Shellharbour one, I do not know whether we had a better link between Canberra Hospital and the people down there than we did with the Orange people. The one with Shellharbour was a discussion between psychiatrists in both places and an eventual agreement that that would be an appropriate placement for her.

Because she was under 18 and also working quite closely with people in the community, I think the support from the community in those circumstances was greater, even to the point where one of the workers from Canberra Hospital who works with adolescent mental health in Canberra Hospital drove her to Shellharbour. For me that meant, though, that I went down every weekend to see her. The first time, I think she was in there for three weeks, so there were four weekends but three weeks. The next time around, it was just under three weeks, only 2½ weeks.

With Orange, they required the family to be there. We had an extensive interview process via video link and it was not until I was able to guarantee that I could be there that she was allowed to go. Fortunately, it happened to be over January, so my holidays were spent in Orange—nice country town—and I was there for about four weeks.

They ended her placement because I could not be there for the rest of the time. There was some discussion that they might keep her a further couple of weeks if I could come down on weekends and maybe take a day or two off work every so often. I said, "Look, it's beginning the of the school year. It's really, really difficult for me to get to a school and then go, 'Excuse me, I know it's the beginning, but I need to take these days off." It does not balance terribly well.

I ended up actually going part time at school so that I had a little bit of a chance for my mental health as well but a chance also to support my daughter a little bit better. That has meant a bit of a financial constraint for me too, and that means that when we are talking about going interstate that can be sometimes problematic.

We have looked at going to Sydney, even as recently as a few weeks ago. But when she was under 18 going to Sydney also required people to go and stay. They want parents to be there daily, and if you have a placement in the middle of the year that just cuts out a whole stack of people because you cannot just leave your job and your life and your family and everything else and go down to Sydney and wait around until they ring you every day and say, "Come in for a family meeting." It does not really work. So it is problematic.

THE CHAIR: Did you receive any support from ACT Health during these times interstate?

: No. When you go to both Shellharbour and Orange, that is the treating team. Orange had a different approach to Shellharbour. Orange actually did look at helping the carer as well, so they recognised the fact that you actually have a certain amount of trauma yourself because you are dealing with someone with so much anxiety and a lot of mental health issues.

They actually helped and worked with me a bit in Orange, while I was there too, about, firstly, how to look after myself and make sure my mental health was stable and, secondly, being able to talk to my daughter in a particular way so that it would not end up being triggering for her. So there was that extra support. But when you are in the unit, you are working with the people in the unit. When you come back to Canberra then they get a report and they take it from there, with varying degrees of success.

MRS KIKKERT: I want to compare the different services that you experienced in Orange and Shellharbour to Canberra. Did, at any point, your daughter say that she did not want you to be there, as she did when she was at Canberra Hospital?

: Did not want me to be where?

MRS KIKKERT: Did not want you to be at Orange or Shellharbour.

: No.

MRS KIKKERT: Okay. So it was just at Canberra Hospital that she stated that?

: Yes.

MRS KIKKERT: I just wanted to know what their reaction would be, had she said that.

: Okay. It was Canberra Hospital and, apart from one time in the adult mental health unit, the other situation where it flared up a lot was when she was in the short-stay unit. There was a nurse there who was not actually very helpful or supportive towards me. Because he did not see when I visited, he actually accused me of not coming in and supporting her and put in a report to the Public Advocate, which then resulted in me having to go to a Public Advocate hearing.

it was quite unnecessary that that should have happened. But, because of that, too, I think that she is hearing conflicting things. She is hearing nurses saying certain things to her and, at other times, social workers saying things to her.

Since she has turned 18 it has been about, "You're 18. You can make your own decisions. You should be independent." So there has actually been a situation that undermines our relationship at times, and yet what she really needs is a whole lot of support, and that family connection is super important in all of that.

MRS KIKKERT: Yes, I agree. I want to touch base with your experience with CYPS when your daughter came into your home at the tender age of seven years. What sort of mental health support did you receive from CYPS at that time?

: None.

MRS KIKKERT: None whatsoever?

: That was prior to A step up for our kids and before anyone was talking about therapeutic interventions of any sort.

MRS KIKKERT: Did they share information about her background and the trauma that she had gone through?

: No. I subsequently, over the years, found out more information about that. What information I received initially was very, very scant. Having said that, when she came to me initially it was on a respite placement, and then she came to me in the capacity of just needing a foster placement. They explored the option with me as to whether I would take her on on a more permanent basis, and then the orders were made to 18 for me. Then, I think after two years, we applied for an EPR—enduring parental responsibility. That subsequently, after a year, flips over into the Federal Court and becomes an adoption order. That is the process that you go through with that. During most of that time it was pre A step up for our kids, so that kind of changed things a little bit, I suppose.

MRS KIKKERT: At what point before A step for our kids did you ask CYPS for any assistance?

: Quite often, yes.

MRS KIKKERT: What was their response?

: By and large, they were fairly helpful where they could be. At that stage we were carers with Marymead. We are now with Barnardos because of the changeover

of everything. But Marymead worked fairly closely with CYPS. My daughter was already known to CYPS as a fairly problematic child who had quite a lot of anxiety and anger issues and attachment issues as well. I cannot recall at what stage this was—possibly when she was maybe nine; it was fairly early on—CYPS offered a training session for carers, which I took up, which was around trauma. It was like a weekend thing that we went to.

MRS KIKKERT: A training for carers?

: Yes, training for carers around trauma. So that was really, really helpful. It built on some other earlier training I had, but this was like that really specific training that kind of bordered on, probably, psychology 1 or something. It was actually quite intensive. The Australian Childhood Foundation I think was running it. That was really helpful. In my view, it possibly should be something all carers should just do, rather than it being something you could opt into. That was actually very helpful.

So, variously, over the years they have been helpful. They certainly are there to support. They do not necessarily know the whole story, particularly when you are looking at an outsourced model where a lot of stuff is going through Barnardos. So it then becomes confusing for carers as to who you approach around some of that.

If you had a model where you have a case manager who deals with all the different agencies and the little subsets of people who are around, that would make it so much easier. If you are putting the carer in the centre, with the child, that also makes a difference. Rather than having an idea that carers might be one of many people surrounding the child, it is the carer and the child together who need to be surrounded by a whole range of people.

MS LEE: I want to take you to the final page of your submission and also to what you said in your opening statement about there not being enough training for teachers to recognise trauma, especially in children as young as six and seven. There is some concern from teachers that there may be quite a lot on their plate already. How do we find the balance of ensuring that our teachers are equipped with the training they may need without overburdening and overwhelming them?

: The six-million-dollar question. I have had a lot of experience as a teacher and I think it is probably about reframing what we do in schools, maybe thinking about the curriculum and the pedagogy differently. A lot of the time I have found that, although schools are variously quite supportive of children and young people in those situations, it is often a team that is set off to the side, the student services team.

The classroom teachers do not really get involved too much, and we often end up having situations blow up in a classroom because we do not have the information about the child or the young person. If we had had that information, that might have changed a whole lot of things for that person.

The emphasis on content over wellbeing probably needs to be flipped around. Again, there is good neurological evidence for that. If a child is flipping out or in some way traumatised or anxious, they actually physically cannot learn anything. They cannot participate in a class. If you do not have teachers that understand that then you are going

to have teachers saying, "Well, what's wrong with you? Sit down and do your work." That is not okay, because those children physically cannot.

You need to look after their wellbeing first. When they feel comfortable and when they feel okay with the world a little bit more and can trust and a relationship is built between the teacher and the child then you will find that they will be able to participate more fully in their own learning.

So it is not an easy answer to your question. I would never advocate for a second that we just pile on top of everybody else more and more stuff. I think it is about a reframing of the way we approach what we are doing.

MS LEE: You also spoke about school psychologists. Can you provide some insight for the committee into what you see as their role and how it can be improved?

: I know school psychologists are pretty overworked with what they are trying to do. A lot of the time they are spending diagnosing kids so that the kids can receive whatever points they need in order to get the learner assistants in the classroom for the kids. The time they spend doing that is time away from supporting kids who have high emotional needs.

We have psychologists who are still split across a number of different schools, as I am sure you are probably aware. So for a child who is having an issue at a particular point and might need psychological support, they may not be able to access anybody because it is not that psychologist's day at that school. That is not okay.

The people who pick up the slack on that would be, first of all, the student services team, who are teachers. We all have to have some psychological training in our degree, so we have some understanding of that. But they may not have taken further training in that area. They are just teachers who are trying to do a really good job and support the kids the best that they can.

I guess the other thing that has happened in schools recently is around removing chaplains from the schools. I understand why that happened, but the chaplain often worked hand in hand with the psychologist. If we changed that role, that position, that is an extra person in the school who could be of assistance to children and young people, and it has been. I understand taking out the religious component; in a secular society, and particularly in our state schools, that is quite appropriate. But to have an extra person in there was really important for kids. So taking that away has actually diminished the service to our children in our schools and made it very much more difficult.

THE CHAIR: **Matrix**, thank you so much for being here today. I have found your story very moving and I thank you for your contribution. You will be forwarded a copy of the transcript from today. Please review that to make sure what you said is what is written down. I remind you that today was confidential, so do not discuss today's proceedings with anybody else.

ideas. I hope it makes some difference, and I wish you every success with the inquiry.

THE CHAIR: Good afternoon, and welcome to this in-camera hearing of the Standing Committee on Education, Employment and Youth Affairs. The proceedings today are in relation to the committee's inquiry into youth mental health in the ACT.

On behalf of the committee, I thank you for being here today. Before we start, there are a few important matters that I wish to draw to your attention. Due to the hearing being held in camera, witnesses are not permitted to discuss proceedings with any person or organisation not present at the hearing.

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: Yes, absolutely.

THE CHAIR: Can you confirm for the record that you have read the privilege statement?

: Yes, I have read it.

THE CHAIR: Before we proceed to questions, would you like to make a short opening statement?

: I have not prepared anything, so I might just start with the fact that I am a foster mum to a five-year-old Aboriginal girl who has a mental health diagnosis and is an amazing little child.

THE CHAIR: Could you tell us about your experience in accessing youth mental health services in the ACT?

: Our journey in accessing services began when my daughter was three. We involved her in the early access Koori program at **Services**. We knew from when she joined our family that she was an active toddler, but I also come from a family that literally has seven adopted siblings, and my mum has fostered nearly 50 children, so I am quite accustomed to being around active children with lots of needs.

It really was not until preschool that they started to look at referrals. In Koori preschool she was referred to CDS—child development services—and that was basically where we started our journey. She received a speech pathology assessment and an occupational therapist assessment, both of which picked up minor things that then fed into her later diagnosis of unspecified stress and trauma-related disorder, which is developmental trauma disorder. So that was where we began.

It has now been $2\frac{1}{2}$ years that we have been going through this process. Initially, the focus was on her speech and her fine motor skills. Then, when she moved to the next preschool, which was the mainstream program at **managing**, she struggled a little bit, managing within a group setting. Her needs increased. We noticed her behaviour at home became a lot less manageable, a lot more disruptive and a lot more aggressive, so we requested from our GP to be referred to the community paediatrician.

We were given that referral, I think in August 2018, and we got our first appointment in August 2019, so it took 12 months to see the paediatrician. That area of CDS is used to dealing with children from out of home care, and because of the complicated nature of trauma and particularly with my daughter's case, trauma in utero, we thought it worth waiting for people who were very knowledgeable. We saw the paediatrician in August and then had a review appointment in September and that is when she received her diagnosis.

We noticed around December that the difficult behaviours, opposition and a lot of violence had increased both at school and at home. That is when we went back to the paediatrician, requesting an urgent appointment. They were busy. It took us until March to get back in and by that point the wheels had almost completely fallen off in kindy and we were just grasping at everything to get help.

It was probably the first and only time I have ever thought, "We're in crisis. Are we going to be able to keep doing this?" which is brutal. We were her forever family; that has always been the case. It has never been a question about her going anywhere, but it just came to sheer capacity and being able to keep our biological son safe and all of those factors.

One of our biggest challenges was navigating the system with a child who is so young who should not have a mental health issue. The fact that she had had such severe exposure in utero to a variety of substances, we assumed—we definitely know heroin was the predominant factor—was really what made people have to listen to us because we had a documented history of this trauma. I do not know how families do it without that because, as I said, it was almost impossible to get support at the beginning.

The school side of things has been really challenging. Literally up until today, I am still going through it. Initially, in December, when we realised her behaviours were increasing and that the challenges were becoming more obvious, we were feeling pretty happy with the idea that the school had identified our girl as being in a small group supported learning program that was going to commence in kindy. Then in December the preschool teacher mentioned to me in casual passing conversation that that was not happening anymore. I immediately got in touch with the deputy and the principal and asked what was going on and they said, "No, we're not doing that."

Reading between the lines, I assume there was a miscommunication in the background because the school psychologist who had told both me and the preschool teacher this was happening was no longer there. I had a number of meetings with them. I raised that this was not going to work, that that kind of environment was not going to suit our daughter's needs and that she required more support. But because she does not fit the categories within the ACT Education Directorate's policy she was going mainstream.

So we did that and it went sideways very quickly.

It was probably week four that she got suspended as a kindergartener, which was horrible on so many levels. In the meeting with the deputy and the principal, I had said, "What happens if she starts to become violent? What happens if she tries to run from rooms and things? Is she going to get suspended?" Of course, at that point that seemed like a ridiculous notion, but then three months later that is exactly where we were.

COVID then hit, which for us was actually really helpful. We had the follow-up with the paediatrician in March of this year, and that was the appointment when the paediatrician said, "Yes, she needs to start medication. We need to look at potentially an additional diagnosis but, as she is five, we will start off on Risperdal," which is an antipsychotic.

That was a complete game changer for us and our home life went from "Can we survive any longer like this?" to "We are utterly in love with our girl." We were at home with a child with trauma surrounded only by family. We had to go into isolation completely because we needed the support of my parents and they are vulnerable. They have a foster bub who has complex medical needs and is very vulnerable so we kind of, in conjunction, went into isolation and it was fantastic. All the aggressive behaviour stopped. All the violence stopped. She was loving and needed so much support emotionally, holding hands all the time, physical contact, but it was not anywhere near what we had been experiencing.

Then we started school again. Even though she was on this medication and we had three solid months knowing it was effective for her, it was probably two weeks in that we got the first call to come and collect her because she had hurt one of the teachers. That continued to escalate, as I said it would. Just this week, three of the support staff quit and the school had to make the ruling that she can only be supported specifically by teachers because those support staff noted the difficulty and challenges of working with her as the reason for them leaving.

So it has been a long journey to get anywhere with the ACT Education Directorate, unfortunately. And it is as of yesterday that they have agreed to make a policy exception and move her to an LSU. It has taken 2½ years and six months of total distress for her, for us, for the teachers. Every single step of the way I have been approaching the right people, speaking to the family support section at the ACT directorate, at the weekly meetings at the school for over an hour every week while I am trying to work full time. We do not know if this is going to be successful, but it is just the next step for her.

THE CHAIR: Your journey has been very intense for such a seemingly short period.

: Yes, it feels like it should have been spread over a longer period.

THE CHAIR: Can you comment on the connectivity of health services you have received. Going from one treating professional to another, did you find the connectivity between services appropriate or suitable?

: We have had so much difficulty accessing services that connectivity has not even really been a factor at this point. The initial delay for the paediatrician was a big thing because, in order to get her NDIS package organised, in order to do anything, we needed a diagnosis. So that 12-month delay was hard.

Since receiving that, we were then successful with our application for an NDIS package. I have now been on four or five wait lists with occupational therapists since December, so seven months now. I had a two-month wait with a psychologist; however, I found somebody in the interim that was recommended by CYPS who was not taking on children but because our case was so intense she agreed to take on a new patient. We then managed to slot in with another therapist within the same practice and that is the only way that we have managed to access services.

As I said, I am still waiting for an OT service to be able to come to the table. So for us it has been more about access to the support services. We have got this funding and we have not been able to use it. It has been frustrating.

MRS KIKKERT: Do you have full custody of your daughter?

: No, we have enduring parental responsibility. She is Aboriginal and in the ACT adoption of Aboriginal children is not really on the table at this stage, so we have gone through the EPR process. We did that with her very early on. Because she came into my mother's care at three days old, we developed a connection with her from the get-go, and when the decision came that she had to move to a family we put our hands up. Then we argued and then we wrote letters and then we were successful in our training, and it took about two years from that to get EPR. So she was about three, just before all this started.

MRS KIKKERT: Has CYPS offered support in any pathways that you find a hurdle to overcome?

: I contacted them—I am trying to remember; so many things have happened this year. It was before the hailstorm, so it would have been around December that I contacted them and spoke to a really lovely lady that my mum had recommended. I think she was head of therapeutic services, somewhere around that area. I explained our problem and said, "Who can I talk to? What do I do?" She put me in touch with a really good child psychologist in Canberra, the one whose books were closed, so she made the exception for us, but essentially that was their suggestion.

MRS KIKKERT: To see a psychologist?

: Yes. We have done all of the options we can through ACT Together and CYPS in terms of parent and relational training, circle of security, and caring through therapeutic trauma. All of the parenting options we could do we have done, and that is kind of where ACT Together and CYPS were more aligned, rather than the actual therapeutic service on the other end. That is where we seemed to have to go find our own things and do things ourselves.

MRS KIKKERT: What would you like CYPS or ACT Together to have done from the very beginning to support you, and throughout your journey, to make it a little easier for you?

With CYPS and ACT Together I never had an issue with the way they supported us. Their responsiveness to training and to providing opportunities for carers I found quite good. But we have the added bonus of not really having to deal with them much. Because of EPR we are no longer case managed by ACT Together. So we—being my husband and I—have the parental authority to make decisions and to do things we feel are in our daughter's best interests. We went to them for advice but, so far as their support goes, we are not supported by them. Part of EPR is knowing that we can manage without their support.

MRS KIKKERT: But they can also offer support as well if you wish.

: Yes, absolutely. One thing I did not mention—it has been a busy year—was that it was about September last year that the service withdraw for after school care. That was the first time I approached ACT Together and said, "Look, we're stuck. My work's having to give me flexible working arrangements to be able to manage this." We were then given the information for the in-home care program, which is run by Marymead. The program coordinator at Marymead was fabulous. She supported us so well. The difficulty is, again, getting the actual service.

The system is set up so that, essentially, educators are self-employed. They have to have their own ABN, pay their own tax and do all their registrations themselves. We could not get anyone. We were on their list until June, when we were given additional funding through NDIS to get a support worker simply because we could not get anyone in that role. We were approved for their services last September and we gave up in June. As far as I am aware, there were at least eight or nine families on the waiting list.

You have to find your own person. Being able to find someone who is trauma-informed, is disability aware, can do 3 pm till 5.30 pm five days a week and is happy to run their own business is not easy. And, as I said, the service withdrew. I had a lot of meetings with Communities@Work saying, "What can I do? How can we make this work?" As I said, my husband and I work full time. Initially, their response was that she needs one to one, which we knew. They said, "Can you talk to NDIS, get a support worker?" We did that. We had approval in less than 24 hours for additional funding. Our coordinator said, "I've never seen this happen before."

I went back to Communities@Work and they said, "That's great, but we don't have the ability to have external people come into our service." That is what they told me to do and I have done it, but now she still cannot access it because of their bureaucratic process.

MRS KIKKERT: You mentioned that your daughter was diagnosed in September. Was she given medication afterwards?

: No.

MRS KIKKERT: Do you know why?

Risperdal—I can never remember the technical drug name—is one of the very few, if any, drugs that they will give children under six to manage behavioural problems, and

it is brutal. She has gained eight kilos since February; she is chronically tired. It is a horrible medication, and we really hope that we can get her away from that and that, as she gets older, they can look at any other appropriate options. But when you have no other choices, you do what you do.

MRS KIKKERT: Did they give you tools on how to deal with her after she was diagnosed in August, because she was not able to partake of the medications?

: Not really. We self-sought. I work at **an example and I** am fairly across how to look up research papers and things. I am not an academic by any means, but I just sought out as much information as I could about developmental trauma disorder, about neonatal abstinence syndrome and the effect and the long-term outcomes for children who are born drug dependent. It led me down a number of different pathways, one of which was to come across a neurosequential method of therapeutics, which is basically for children with developmental trauma disorder, where you try and essentially repair by building the brain from the bottom up.

The concept is they were not able to develop the lower regulation—the way we manage in everyday life to even control our heartbeat enough to be calm. The idea is to kind of work from the bottom up. But to find that was by reading the A to Z of therapeutic parenting, *The Body Keeps the Score* by Bessel van der Kolk. It was contacting different services in Sydney to say, "I've read about this. What do I do?"

In the end, we were offered a scholarship placement by the Dalwood Spilstead Service in Sydney. There are amazing people there, and if we lived in Sydney we would almost be guaranteed to be going to their little school there because it is specifically around trauma and children with trauma. That was just the best step we did. It gave us a complete map to our little girl and we could focus on and where she struggles, where she is at cognitively. But everything we did we found ourselves.

MS LEE: You mentioned the school side of things and that, despite the diagnosis, despite the acceptance for NDIS, the school deemed that your daughter was not eligible to enter an LSU. Can you tell us a little more about that and the reasons that were provided? You mentioned that maybe there was a miscommunication, but what was the circumstance around that?

: We went to the local school.

MS LEE: Is that a government school?

: Yes. They do not have an LSU at that location. So when we were looking at the transition from preschool to primary school that is when the school psychologist said, "Yeah, we've identified her. If she needs some additional support, this is what we are doing." When I asked for the meeting with the deputies, after being told that that was not happening, their explanation was basically, "We don't have that program. We had not intended on that program and we're not quite sure where this came from." So it was only because the preschool teacher had also been informed of the same thing that I think they understood there had been an error somewhere.

They applied for ISP for us initially, at literally the last week of school before it ended

last year, and we got approval over the holidays. I had no idea what that meant or what that meant for her at school. We just got a letter saying, "You've been approved for ISP and the school will do whatever they need to do." We did a SCAN meeting, I think in week one or two. I genuinely do not even know if they got the answer back or anything from that, because it escalated much faster than the SCAN results came back.

In that SCAN meeting I remember the executive teacher saying to me, "Oh, you know, we might get a bit of funding for maybe half an hour or an hour for an LSA each day." It was by week three that they had to have an LSA assigned to her from beginning to end, through breaks without fail. And that is when the LSAs started to get hurt.

The arguments against or the push-back has come more from the directorate level and not from the school. I think that was because, like us, the school were dealing with the day to day and they could see that, no matter what the policy says, she needs support. I did a bit of a dive into the Education Directorate policy, which was riveting, but it also showed me that when you look up the ACT disability criteria under the policy she ticks it. Under the mental illness section of the criteria she literally hits every point. Once she started medication she hit every point. She is still not eligible because the policy only covers intellectual disability or autism. That is it.

It has been this week that they have made that exception. Because her behaviour has become so extreme, they had to stop traffic last week when she was sitting out the front and would not walk back in the school. I said to them at the beginning, "My daughter will force this on you because she is not subtle and this is what she needs," and that is exactly what has happened.

MS LEE: But that is only because of an exception?

: Yes, absolutely. I am now dealing with the directorate and school operations. The directorate operations, the occupational violence team and the Tuggeranong district director, I think it was, had a meeting with the school principal and care team and everything on Monday. I had to collect my little one early and take the day off because there were no teachers left to take care of her. The call was made there that the exception would be made. We have been told this morning that **meeting** has been identified, so I will be going tomorrow to have a look at the school and meet the principal.

But a number of times it was mentioned on the phone that, "Even though she's not eligible, we feel this might be a better fit. Because she's not eligible the end goal is that we are working towards her reintegrating into the mainstream." We have said from the get-go that that is what we want. We do not want her to be in a position where she is not able to develop social skills, because that is one of the areas in which she suffers.

MS LEE: So if it is under an exception that your daughter has been allowed to go to this LSU, does that mean that there is no certainty about what her future looks like in school?

Absolutely. There has been no certainty for this entire year. When I ask the question of what do we do if this does not work, I do not get answers. As parents, we are managing the monumental task of trying to repair as much as we can of the damage that this little warrior has sustained. Added to that, I literally do not know day to day if

I am picking her up from school and whether I can complete my job. We have no out of school care services. We have no support.

I cannot imagine how this could be managed by a family where they have their own challenges. We have access to some of the most knowledgeable people and we have an amazing support network that drop everything to be there for us and we have barely managed to get through this six months. I am pretty sure a part of the reason we have is because of the shutdown, because that gave us a chance to breathe. If we had had to keep going, I do not know where this term would have ended.

MS LEE: In terms of a school psychologist, have you had a chance to access that service as yet?

: Almost immediately we came under the care of the senior psychologist in the NSET team. I have met the school psychologist twice, one of which times was when I was asked to collect my daughter early because of violence. I met the school psychologist who was going to observe her at the time, which I informed her would not happen because I was collecting her. So that was the one of two times. The other time was in a meeting. It was not me and her; she was part of this weekly meeting with me, the school, NSET and the school psychologist.

THE CHAIR: MALE, on behalf of the committee, I thank you for appearing today. I also remind you of the need to keep your evidence presented today confidential and that a transcript will not be published without additional advice from the committee.

: Thank you for this opportunity.

THE CHAIR: Good afternoon, and welcome to this in-camera hearing of the Standing Committee on Education, Employment and Youth Affairs. The proceedings today are in relation to the committee's inquiry into youth mental health in the ACT.

On behalf of the committee, I thank you, **Example**, for being here today. Before we start, there are a few important matters I wish to draw to your attention. Due to the hearing being held in camera, witnesses are not permitted to discuss proceedings with any person or organisation not present at the hearing.

Please be aware that the proceedings today are being transcribed by Hansard. The transcript will be confidential to the committee and not published. However, I must also advise that the committee reserves the right to publish the transcript in full or in part and to use the evidence taken in camera in its report, although the use will be by way of reference to evidence rather than quoting from it. Should the committee decide it wants to use the evidence taken at this hearing in that way, the committee will advise you and seek your comments and your advice on whether you have any objection to the use of the evidence in that way. Is that clear?

: Yes, it is.

THE CHAIR: Can you confirm that you understand the privilege implications of the privilege statement?

: Yes, I do.

THE CHAIR: Before we go to any questions, would you like to make an opening statement?

: Yes, thank you very much, and thank you, committee, for giving me the opportunity to provide some follow-up information for you. I represent a family member who has been involved in both court proceedings and mental health issues.

I would like to make a couple of points and certainly would like to respond to your questions around justice, secure mental health and the messaging and support for under 25s.

The key points are that there are issues around appropriate justice for those under 25 suffering a mental illness. Those relate to legal access and the high cost of defence, should it go through the court system, which I believe is a significant power imbalance for those with mental illness.

I also raise issues around overcrowding and infrastructure for mental health and also the Alexander Maconochie Centre, which has significant issues for mental health provision. I raise issues around inadequate resourcing for both mental health and the corrections systems and generally inadequate support for under 25s in the community, in acute settings and in the justice systems. Thank you for the opportunity to provide an opening statement.

MS LEE: I have a question about how we educate our young people. You mentioned in your opening statement the messaging and the importance of that, particularly around illnesses such as psychosis, which may have a huge stigma attached to them. What is the best way we can get the messaging right and educate our young people?

: I know that there is a quite a bit of emphasis at the moment on anxiety and depression, and that is totally understandable because it is much more prevalent in society. However, about one in a hundred people suffer from schizophrenia and potentially psychosis, from a range of issues relating to depression, schizophrenia or schizoaffective disorder. You obviously have more expert witnesses than me.

I believe there needs to be broader messaging around, potentially: is this young person acting out of character from what you know as they grow up? Obviously, mood and affect are very important, but sometimes with psychosis people tend to get obsessed with one issue or they certainly can become more withdrawn or have other features associated with mental illness. In the schools and in the general community and online I believe the messaging needs to be broader, to talk around changes in behaviour and unusual behaviour.

Part of the challenge is that, for young people in later adolescence, sometimes they move away from their family groups and are seen more often by their friends. So some behaviour is not seen by parents. The online presence and the impact of social media is clearly quite important. I believe all the messaging needs to be broadened to include unusual behaviour. I also shared with the committee secretary a newsletter or fact sheet from SANE Australia which talks about psychosis. That provides some very good points to be shared in youth settings. It is a broader message, rather than just anxiety and depression.

MS LEE: Are you aware of any educational programs that are being targeted for our later-years students, talking about these issues?

interest in the University of Canberra and there was certainly some noticeboard messaging about that, but I do not know about online work. I think that is where you would have to speak with headspace or Beyond Blue or the Black Dog Institute or SANE Australia, as they would obviously have a closer handle on to that than me, as a carer.

THE CHAIR: Can you talk about some of the shortcomings your family member experienced in accessing mental health services whilst in detention? Can you particularly focus on the provision of services they received and any lack of focus on youth considerations?

: In my submission to the committee I outlined the process that my family member went through. Yes, it was a serious offence, but from the outset psychiatrists were involved and identified that psychosis was an issue. When the family member was referred, there was a limited time for the psychiatrist to make a decision and then, from that, there was not the opportunity for the family member to remain in a mental health facility and he was required to go to corrections system. Given his age—he was just 18—he was detained in the Alexander Maconochie Centre.

He was first moved to what was called a crisis support unit, which essentially I would describe as a seclusion unit. It was unclean and had cigarette butts all over the floor. As a former asthmatic, the health standards I do not think would meet any requirement. I certainly had to advocate for contact with other people and to get psychiatric service.

When he was first detained, his medication was not provided. When I visited I asked what was the situation and the response was, "We don't know what happened." Therefore, I had to pursue it with the health services there for him to gain medication, which is a very serious issue. This was then addressed. Then, following up, he received psychological and psychiatric support, but I suggest that justice health services are vastly overstretched, given the number of people in corrections who present with mental illness. At the time, a junior member was providing psychological support, but I do not believe that was sufficient.

These are clear signs of someone deteriorating in their mental health condition. Numerous times it was raised with justice health and we raised a complaint with them. They have tried to respond, but I also believe there are issues around jurisdiction with correctional services and who has the responsibility.

I note that a new forensic mental health model of care was developed in 2019. That could be tabled for the committee's reference. That includes reference to restructuring and reviewing justice health services; the integration of primary physical care and mental health care; increasing greater collaboration between the ACT courts, mental health and justice health services regarding the management of people with mental illness or disorder; the importance of identifying outcome measures tailored to forensic settings; and, in line with interstate examples, exploration of operations to include a mental health support unit at the AMC.

Given the overcrowding, they changed the administration of services for those with mental health issues. It is my understanding—which is probably two years ago; I do not know if that has changed; that would be a further inquiry for you—that those identified with mental illness were also included with those requiring protective services. As an example, my family member was remanded with other detainees who had been sentenced to more than 30 years imprisonment, and also he shared a cell with a sex offender.

. That is totally unsatisfactory.

Those are some comments. Justice health is certainly aware of some of these issues. There has been a recent review of corrections services by the Inspector of Correctional Services. However, mental health and the assisted care unit, in whatever format, were excluded from those review issues. In the most recent Healthy Prisons Review there are, I think, 72 recommendations. Only three of those refer to mental health service provision, and I believe that is because essentially the mental illness detainees were excluded from that. There are three recommendations.

For young people, research recommends that all those suffering mental illness would be better served with services under a mental health model, rather than an incarceration model. I think young people under 25 are specifically and particularly vulnerable, given their young age and exposure to significant other trauma in terms of an environment that has violence and high levels of mental illness. It is heartbreaking to be a carer for a young person who says to you on a visit, "These people are so unwell they should not be incarcerated. There should be a better system."

For those people who are incarcerated, given the justice system, our experience is that the young person did not have access to appropriate legal representation when first asked, when they were remanded. No Legal Aid person was available. When our family was finally involved, we then provided solicitor/barrister support and additional psychiatric support. For us to run the case through the ACT courts it cost us \$200,000 to be able to provide additional psychiatric assessment reports and enable Sydney psychiatrists to come to Canberra, because there is insufficient independent psychiatric ability to review detainees.

There were more than eight Canberra Health Services psychiatric reports and yet the custodial situation and the Office of Public Prosecutions fought that. They certainly have a right to vigorously prosecute, but when Justice questions the good judgement of the prosecution's office then it suggests that perhaps an overreach has occurred or an overreach is possible for the prosecution. Certainly, the public good has to be defended, but I believe that people with a mental illness are often estranged from their family. They often fall by the wayside and do not have access to financial means and often they do not have the capacity to defend themselves in a justice situation.

I believe for people with mental illness there is a distinct power imbalance to enable those people to be appropriately represented in court. Unless they have some very supportive family, that is why we end up with the prisons having such high levels of people with mental illness when they would be better served and the community would be better supported by additional psychiatric and psychological support for those people to manage both their mental and physical health.

MRS KIKKERT: Was your family member diagnosed with schizophrenia?

: Yes, and the challenge is that we were not aware of how unwell the family member was until the psychotic incident.

For the corrections services, they are in a very difficult situation. Their staff are correctional officers; they are not mental health workers and they are being asked to supervise people with mental health issues and mental illness. One of the deputy managers raised the issue about the challenges of supporting people with mental illness. That is not their specialty. They certainly need additional training and support to manage in that way.



believe there should be more provisions in place to be contacting nominated persons under the Mental Health Act rather than only having a reactive response.

This seems to be an issue both in correctional services and also in secure mental health. It only seems to be once something happens that the mental health people raise issues. It should be a more collaborative approach. Part of the challenge is that if you have got over 18-year-olds and under 25-year-olds they certainly have a right to privacy. But when you have such a significant issues, sharing of information would lead to better outcomes.

THE CHAIR: Do you have any recommendations for how we can better improve the system such that, while we can respect the right to privacy for someone going through these situations, a parent or a carer can more involve themselves in the process?

: There is a big challenge with the current system with the requirements for the nominated person. Earlier on, when the young person is in a position that they can work with the family, general agreement should be given to be able to share this information. The restrictions on health professionals are very difficult, knowing that the best interests of the consumer or patient should be the priority rather than, necessarily, privacy.

I know there have been restrictions for justice health services where there were concerns of a suicidal nature. But, again, you should be speaking to justice health rather than me,

being a third person in this process. There certainly should be a slightly broader provision to be able to share information.

THE CHAIR: What were the instances where you do not think you got the information that you think would have been broadly beneficial to the entire situation if you had been informed?

But also with the secure mental health provisions, for us to participate in any individual care planning we essentially have to ask when these things are scheduled. There does not seem to be an accessible overarching plan for the person. It is very difficult because in some family situations the person is estranged from the family and it is their priority that they do not want the family involved. But, at the outset, if the family member involved is okay with it then there should be increased sharing of information.

: The challenge for the family member is that Dhulwa policies and the procedures are very restrictive and staffing is an issue. So there always has to be an accompanying staff member for any activity. For example, going to the gym, there has to be a staff member.

I think the environment is very restrictive.

There is currently some remedial work being done at the next site, the Extended Care Unit, which hopefully will be completed by October. That has more generous visiting provisions. But, given that there has been reduced access because of the refurbishment, the movement has not occurred. A bit more flexibility with Dhulwa's provision of services and scheduling would be beneficial.

MRS KIKKERT: Obviously having more time to see him will help him during his

rehabilitation or during his time in Dhulwa?

: Yes, I think the family connection and friend connection is incredibly important. I would suggest that it is somewhat restrictive. By the time you have been through this process, those connections with friends and family can be lost. It is a very challenging environment and the organisation required to keep those connections going is very challenging. Unless someone is very committed to it, it is quite difficult to persist.

MRS KIKKERT: Is he allowed to make phone calls at any time?

: There are a limited number of phone calls available to three family members. There has been a little bit of videoconferencing. There currently is not email at the site, even though other places, like AMC, have email.

It was meant to be in place by March, and the facility has been open since 2016. That is a definite delay for the family member to be able to contact other family members and friends.

MRS KIKKERT: Is he limited to how long his videoconference is?

: Yes.

MRS KIKKERT: And how long is it?

I think it was 45 minutes.

MRS KIKKERT: Forty-five minutes a week?

You have to schedule anything. It has to be an approved visit, an approved visitor. Again, you would have to have nursing staff, so it is quite difficult to arrange.

MRS KIKKERT: And the phone calls, you said three times. Is that per week?

: No, he is only able to call three different people, and it is to a maximum of 10 minutes.

MRS KIKKERT: Ten minutes a week? So he can only choose three people a week to call?

: He could ring more each night. That does not seem to have a limit. But the telephone call is 10 minutes.

MRS KIKKERT: What impact do you think that is having on him and his mental health?

. I believe the staff at Dhulwa are compassionate. They are trying to do a good job. They are challenged by the availability of experienced staff. Quite a few of the staff are agency staff and I do not believe they have sufficient training in mental health issues. They often have to do recruitment drives. I also believe the conditions for them and the remuneration are insufficient to retain people long term in the industry. I believe the management is trying to do the right thing, but I believe there are structural impediments to having well-trained staff to supervise.

THE CHAIR: MALE, on behalf of the committee I thank you for appearing today. I remind you of the need to keep the evidence presented today confidential and that a transcript will not be published without official advice from the committee.

: Thank you very much again for allowing me to share this information with you.

The committee adjourned at 4.02 pm.