TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Swan Hill — 14 February 2017

Members

Ms Maree Edwards — Chair
Ms Cindy McLeish — Deputy Chair
Ms Chris Couzens
Mr Paul Edbrooke
Mr Bernie Finn

Witnesses

Mrs Leah Williams, Occupational Therapist, Echuca Regional Health; and

Ms Denise Liddell, manager, Campaspe Early Childhood Intervention Service, Kyabram District Health Services.

The CHAIR — Good afternoon, Leah Williams, Occupational Therapist, Echuca Regional Health; and Denise Liddell, manager of Campaspe Early Childhood Intervention Service. Thank you so much for coming along today. All evidence at this hearing taken by the committee is protected by parliamentary privilege as provided by the Constitution Act 1975 and is subject to the provisions of the Parliamentary Committees Act 2003 and other relevant legislation. Any comments you make outside the hearing will not be afforded such privilege. It is a contempt of Parliament to provide false evidence. Recording of the proceedings will commence today, and you will be sent a proof copy of the transcript and be able to make factual or grammatical corrections if necessary. I will hand over to you to present to us today, and can I thank you for your submission. From memory it was one of the early ones we received, so thank you very much for that.

Mrs WILLIAMS — That is okay. Thank you for having us. I am Leah, and I am an Occupational Therapist from Echuca Regional Health. I will just talk about what services we provide currently, and then Denise will chat about what they do over at Kyabram Health with the Campaspe Early Childhood Intervention Service.

Currently at Echuca Regional Health we provide services across the acute, subacute, emergency, primary care, aged care and community health to a population of about 44 000, and that is in the Campaspe shire and also across the border to New South Wales, even though the funding is separate, but we still do it. Within my hat as an occupational therapist, I work predominantly with paediatrics, and I have a passion for ASD and working with children with ASD. I work with community health as a general OT. We service a very, very small amount of paediatric clients — not necessarily just ASD; any diagnosis.

The CHAIR — And they are referred to you from where?

Mrs WILLIAMS — Generally they are referred from kinders, schools, parents self-referring, GPs, other allied health professions. We also have a children's allied health team that has myself, a Physiotherapist and a Speech Therapist, and those referrals are only accepted internally, so from other health professions within Echuca Regional Health.

The CHAIR — What is the youngest age that you would have referred?

Mrs WILLIAMS — For ASD specifically?

The CHAIR — Yes.

Mrs WILLIAMS — We get lots and lots of young ones coming in around 12 to 18 months with no diagnosis — with something funny, not quite right going on. I was saying to Denise in the car on the way over that we had a little fellow with a tremor referred to us from a chiropractor. He was stimming with his hands, and they thought that was a tremor, so he was referred to the OT for that. It has been probably 12 or 18 months and we are only just coming to a diagnosis now for that little fellow, so it is hard.

We provide services across that sort of sector, and then I also am contracted as part of an allied health team to provide services to the local specialist school at Echuca as well. I think that is our service in a nutshell.

Ms LIDDELL — I am from Campaspe Early Childhood Intervention Services, well known as the ECIS agency. We are funded from the department of education. We are funded for 54 places across the whole Campaspe shire, and we see anyone with a developmental delay or disability. At the time of submission we noted that 14 per cent of our children had an official diagnosis of ASD, and another 21 were undergoing diagnosis, so quite a high percentage of our children do have ASD.

The CHAIR — Do you have a waiting list?

Ms LIDDELL — At times, yes. We are a service from zero to six, or now we call it zero to school age. About this time of the year a lot of our children go off to school. There are normally quite a few on the waiting list, so we pick them up. From now until the next couple of months we are probably not at full capacity, but the second half of the year we are normally at full capacity. It does fluctuate a little bit there.

We are a multidisciplinary team. We work under the key worker model in that we try and have that one key worker who understands the family and they have that one person to go to. In our team we have occupational therapists, speech therapists, a physio, an early years education adviser and an allied health assistant. We try and aim to provide our service in their natural environment. Of course it is the family's choice, so some of them choose to come into the centre. We also offer, if the family wish, that we can do visits to their kinder or child care to see how they are functioning there. If safety is an issue or the home environment is not suitable, then we will look at doing perhaps park visits or visits to the library for them.

The CHAIR — How many staff do you have?

Ms LIDDELL — There are probably seven, but we are all part time.

The CHAIR — For the whole Campaspe region?

Ms LIDDELL — Yes. I think our EFT is perhaps four EFT. With ASD, I guess I want to touch on that our biggest challenge that we probably face is the time frame for our children to get assessed. We refer to CAMHS in Bendigo, but the average they can be sitting on the waiting list can easily be 12 months, and then there is a lot of anxiety that the families face at the moment about this magical age of six — you know, we have to get them diagnosed before then. Unfortunately not many of our families can afford to get their diagnosis funded privately. We have had some who have had to take out loans and gone to family members and things like that to try and get it done, but as a service we really do try and facilitate that diagnosis as much as we can. Sometimes we also have a challenge that they might have got a diagnosis from a paediatrician, but then when they are heading off to school that diagnosis — —

Mrs WILLIAMS — Does not necessarily hold.

Ms LIDDELL — Then we get a couple of months out before school and we realise we need to get that multidisciplinary diagnosis. Even if they can pay, perhaps to get into a psychologist or something, it might be a four, five or six-month waiting list, even if they are going to pay privately. So those are the issues we do have.

With our service another real challenge we have is that once they are hitting a major transition milestone — heading off to school — unfortunately that is where our funding stops. We might have worked with these families for three or four years.

The CHAIR — So up till six years of age?

Ms LIDDELL — At school age now, yes. It used to be zero to six, but now it is — —

The CHAIR — Seven.

Ms LIDDELL — Yes. That December they are heading off to school is when we are meant to close. A lot of families are really anxious about that. We will often do social stories and do lots of transition with them in November–December, but they are making a really big transition to school, and unfortunately that is where our funding ceases at the moment.

I guess also we have lots of issues about families attending appointments. We have a lot of 'failed to attend's. It is probably just our clientele, our families, and things like that.

The CHAIR — Is that a cost and travel thing?

Ms LIDDELL — No, because we often go to them.

Mrs WILLIAMS — It is a minimal cost at their public hospital, but it is still quite a problem. We will offer home visits as well to help with that, so it is not always the case.

Ms McLEISH — What do you put it down to?

Ms LIDDELL — Lots of other issues perhaps going on — low socio-economic. There are drugs and domestic violence within these families as well. That is not just our ASD diagnosis kids, but across the whole developmental delay, across the broader — —

Ms McLEISH — What about with your ASD kids?

Ms LIDDELL — Probably 50-50.

Ms McLEISH — Fifty fail to attend?

Ms LIDDELL — Yes. I guess the big thing that I just want to touch on for our ECIS agencies and ECIS agencies across the state is that we will lose our entire DET funding once the NDIS comes, which is May this year for us. We are on a rollout scheme transitioning over to NDIS, so that will be from August to October for our families.

The CHAIR — Do you think you will see a greater demand for your services once that is rolled out, despite the fact that you are going to lose your funding?

Ms LIDDELL — Yes, I think so.

The CHAIR — So you are going to find a real slump because, A, you have got more demand and, B, you are losing your funding?

Ms LIDDELL — Yes, possibly. We will definitely lose our funding. Well, not lose our funding. We have traditionally been block funded, and we will go to fee-for-service funding, so it is really a whole change of going into the private sector.

The CHAIR — Yes, in that sense.

Ms LIDDELL — Yes, that is right. But it will offer an advantage that we are going to increase our model of care into school age to try and help them with that transition into school age. That will be a real plus, and they will get that transition, and not just ASD kids — other kids as well.

The CHAIR — Is there more demand from across the border? Is there a breakdown?

Ms LIDDELL — At the moment we are just Campaspe. We cannot go across the border.

Mrs WILLIAMS — But the hospital can.

Ms LIDDELL — No, our team does not at all.

Mrs WILLIAMS — They cannot, but we can. There is a little bit of funding that we can access within community health, which is through the SACS funding. It has to be short-lived, goal-oriented therapy, so very short stints. We find it really hard, because the goals of kids with ASD are forever changing, so it is really hard to do those short-lived, goal-oriented — —

The CHAIR — What is the breakdown of demand from across the border and Victoria?

Ms LIDDELL — For ASD?

The CHAIR — Yes.

Mrs WILLIAMS — At the minute, if I look at our case load for ASD kids, we would probably have 50-50.

Ms LIDDELL — It is quite difficult, because we are through a central intake, so we do not see any of those referrals — —

Mrs WILLIAMS — That are rejected. If they are not suitable.

The CHAIR — So you do not even know how many are falling through the gaps?

Ms LIDDELL — That is right. Yes, we are a central intake, which will disappear as well too.

Mrs WILLIAMS — Sometimes it can differ for us. They sometimes come to us from across the border because of lack of services. Periodically there is a lack of OTs or physios or speechies and it fluctuates, so they will come across to us because they know we have those therapists. Sometimes we will accept them because we are nice, but we should not really be doing that. It makes it hard, because then they cannot recruit staff because we are servicing them and it is a bit of a tricky one. Sorry.

The CHAIR — You got sidetracked again.

McLEISH — With the kids on the spectrum that you are seeing, what ages are you mostly seeing them at? Where do they first come to your attention?

Ms LIDDELL — Ours probably come in at around two years old, but some are straight, clear query ASD. But a lot of them might have come from a maternal child health nurse or community health with perhaps some developmental delays or some concerns, and then when we have worked through with them for a while we have looked at getting a diagnosis.

Ms McLEISH — Where do you get most referrals from?

Ms LIDDELL — We get quite a few, very similar to Leah, from maternal child health nurses, other community health, GPs, a few self-referrals and kindergarten teachers.

Ms McLEISH — Are you finding that the awareness is greater at that early age now or not?

Mrs WILLIAMS — It is getting better, but it is still not great. I have got young children, so I have followed them through child care, kinders and schools, and because of my background I can sort of pick these kids out sometimes. I wonder whether they are actually getting picked up as much as they could be. I do not feel like our early childhood educators and carers necessarily have that skill and knowledge to be able to pick up on those traits earlier, especially child carers who have some kids from babies. I do not think they are picking up on those traits as often as they should.

Ms McLEISH — So you are just talking about general child care that, when people go back to work, they enrol their kids in and might not realise?

Mrs WILLIAMS — Yes, and those transitions become more difficult than your general typically developing child. That separation anxiety is a little bit more than others. The need for routine and ritualistic behaviours and all of that sort of stuff, they are not picking up on. They are kind of putting it down to normal childhood development, but I think there are certainly some triggers there that you can see that would be different. I do not think they are picking up on that.

Ms LIDDELL — I think a lot of ours pick up on perhaps speech difficulties and will often refer to community health speech if speech is not quite right, or that is something mum will really pick up on. Once they go to community health speech they perhaps see — —

Ms McLEISH — In your catchment are there a lot of speech therapists, not enough or just right?

Ms LIDDELL — There could always be more. I think in our community health, speech would probably only have about a month or so waiting list, which I think is pretty reasonable. Where I have worked at other places it has been a lot longer.

Ms McLEISH — And what about OT and psychology?

Mrs WILLIAMS — Psychology is almost non-existent.

Ms LIDDELL — Unless you go private, and even then private is several months.

Mrs WILLIAMS — And way too expensive for lots of our families. There are not many private OTs and speechies around, so it means that there is a big wait list generally in our public system.

Ms LIDDELL — With that, speech and OT probably only go to before school as well. Once they hit school, the service is really limited.

Mrs WILLIAMS — There is no funding.

Ms McLEISH — So it is only private beyond that time?

Mrs WILLIAMS — Yes.

Ms McLEISH — Just finally I want to explore the transition process. Are you finding that the better that transition process is, the less need there is for services for kids at school? Or regardless of how good the transition is, do these kids still have the same amount of needs?

Ms LIDDELL — We do find it really difficult to comment because we are no longer involved with them when they are at school. I do think the more transition we can do, the better, definitely, but it does differ from school to school.

Mrs WILLIAMS — Yes, I agree.

Ms McLEISH — So some schools are much more open to the transition process?

Ms LIDDELL — Yes, just more aware and have more systems in place.

Mrs WILLIAMS — And they might have had more ASD students come through in the past, so they have got a little bit more knowledge and skill from previous students.

Ms McLEISH — How many schools would you have that kids transition into? Lots?

Ms LIDDELL — A dozen.

Ms WILLIAMS — We are not funded to go into schools at all at the hospital. I will do some work with kinders if I have to. Once we get to school age, if it is a school issue, we cannot service that child, but if it is a home issue, then we can service that child through the community health funding.

Ms McLEISH — Do you know how it is going to operate with the NDIS —

The CHAIR — A whole different ballgame.

Ms McLEISH — if they need your skill and they are school aged and the parents want — —

Mrs WILLIAMS — I am not exactly sure how that will work, because I think some of it will still fall under the department of education funding body.

The CHAIR — I think it is still being worked through.

Mrs WILLIAMS — Yes.

The CHAIR — It has been identified as quite a significant issue down in Geelong, where it is already rolling out.

Mrs WILLIAMS — Yes. I might just say, though, that in our local region there is definitely funding there within the department of education for allied health, but it is managed by the schools, and they can use that wherever they like. So a lot of our local schools, for instance, have used that for a welfare office or a social worker and things like that. Therefore there is no more funding left for speech and OT to then come through as an extra service.

Ms COUZENS — You mentioned the assessment time frame being a big issue. What do you see the answer to that being?

Ms LIDDELL — I personally think that there have been more and more children trying to get a diagnosis in the last even, say, five or 10 years without more and more diagnostic centres or clinics.

Ms WILLIAMS — The public diagnostic clinics, I think, is the other thing, and the cost and having more within our region, because they are still having to travel quite some distance. Bendigo is our closest one, and that is still an hour travel at minimum.

Ms LIDDELL — An hour and a half to 2 hours.

Ms COUZENS — So there is nothing this end of the state?

Mrs WILLIAMS — I am not sure about this direction. I think Bendigo. We are Echuca. I am not sure, but I think Bendigo is still the one — —

Ms LIDDELL — For public.

Mrs WILLIAMS — Yes, and then Melbourne is the other one.

Ms COUZENS — You mentioned earlier that you have a lot of no-show families. Do follow them up?

Ms LIDDELL — Yes, of course we do. Definitely. If they are perhaps at high risk of failing to attend, we will do a phone call the day before or a text message that morning, which is what they like. Then we would ring them that afternoon. If we cannot get hold of them, we would ring them the next week. At the moment we would certainly offer them another appointment without doubt.

Ms COUZENS — Are there situations where they do not take up additional appointments?

Ms LIDDELL — They normally agree to it initially on the phone. It is just on that day whether there is something else that arises that makes it difficult for them to attend, I suppose.

Mrs WILLIAMS — At the hospital we have a policy of three fail to attends in a row and then you are discharged from the service. We clinicians are a little bit more kind, and we will tend to give them a few more goes and follow them up in different ways. Sometimes it might be that, for instance, our fortnightly clinic only operates on a Monday. That is not always suitable for some families, so we certainly will try and work around that as best we can doing home visits if need be, or kinder visits, and trying to work out what the barrier is before we say, ‘See you later’.

Ms COUZENS — Thanks.

The CHAIR — We are out of time. I have tried so hard to stay on time today. I just wanted to ask about any parents inquiring about the applied behavioural analysis and if you have actually referred any to applied behavioural therapists in Melbourne. Are you aware of any?

Ms LIDDELL — Last year we put quite a few of our own therapists through ABA training. I think we ended up putting five or six therapists through. So a lot of them will use the same principles from ABA.

The CHAIR — So you have them available in Echuca or across the whole Campaspe — —

Ms LIDDELL — We will just do it with each family individually as we need.

The CHAIR — Are they parents who have trained?

Ms LIDDELL — No, sorry, they are our staff.

Ms McLEISH — What sort of staff?

Ms LIDDELL — We had OT, speech and early years education advisers.

Ms McLEISH — Which is a bit of everything.

Ms LIDDELL — Yes.

Mrs WILLIAMS — I have also done the training myself, so on an individual basis I will use that with clients.

The CHAIR — I have more questions, so are you okay if the secretary puts them in writing to you?

Ms LIDDELL — Sure.

Mrs WILLIAMS — No worries.

The CHAIR — Thank you very much for your time today. It is much appreciated.

Witnesses withdrew.