

TRANSCRIPT

FAMILY AND COMMUNITY DEVELOPMENT COMMITTEE

Inquiry into services for people with autism spectrum disorder

Morwell — 5 December 2016

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Ms Angela Ellis, Executive Manager, Community Health Services and
Ms Lyn Nichol, Speech Pathologist, Gippsland Lakes Community Health.

The CHAIR — Ms Angela Ellis and Ms Lyn Nicol. Welcome to the public hearing today Ms Angela Ellis, Executive Manager, Community Health Services, and Ms Lyn Nicol, speech pathologist from Gippsland Lakes Community Health. Thank you both for attending 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.

We would like to invite you to make a presentation of around 15 minutes to the Committee.

Ms ELLIS — Thank you for the opportunity. We will be doing a bit of tagging across. I will introduce myself first. As you see, my name's Angela Ellis, Executive Manager of Community Health Services for Gippsland Lakes Community Health. Gippsland Lakes Community Health is based in far East Gippsland with head office in Lakes Entrance. We also have a service at Bairnsdale, Metung, Bruthen and Nowa Nowa. As your previous speakers have said, far East Gippsland is classified as rural and remote. We are a not for profit organisation and have the status as a stand alone community health centre with over 30 years now of service.

Our demographic is typical, I suppose, of rural Australia. We do have a higher percentage of Aboriginal population than the state average, low socio economic status. We can talk more about the prevalence of autism.

My role as executive manager is to manage the allied health services we deliver. I also manage a long daycare centre and a four year old kindergarten program and for the purposes of this, that's relevant. I suppose the uniqueness of the allied health service that we deliver is that we are now quite an established public/private service. So we have gone down the lines of combining all our varied funding sources. We are FaHCSIA registered. We provide services under Medicare, case management, private health insurance. We have the public funding of community health and HACC and CHSP. We also use client fees and successful submissions to be creative in how we deliver our services. Obviously we are fairly small in the big picture but that does allow us all that varied funding to basically recruit full time positions, one of our major challenges in rural and remote.

I will allow Lyn to introduce herself and then I'll come back to more about our service model.

Ms NICHOL — My name is Lyn Nicol. I am a speech pathologist at Gippsland Lakes Community Health. That follows on from about 30 years in the education department working mainly in rural primary schools. I also have a graduate diploma in special education and have worked in special school settings since moving across and doing a Master's in speech pathology. I have worked in a couple of different locations around the state. My main focus has been in paediatric speech pathology. So, basically, if I just go through some of the services as far as our paediatric team.

We actually have a frontline allied health paediatric team that consists of three speech pathologists, one part time of those, paediatric trained physiotherapists, paediatric trained OT and a clinical psychologist on board as well one day a week. Gippsland Lakes Community Health holds 17 ECIS places as well as we also provide services under the Latrobe Community Health places that were mentioned previously. In East Gippsland ECIS packages, as we know, in early childhood intervention services are provided by Noah's Ark and specialist children's services. We work fairly closely with specialist children's services. Care workers. Noah's Ark tend to have their own team although we communicate quite freely with them.

Currently we have 180 children on allied health, full allied health team list. That's excluding the clinical psychology, and of whom approximately 30 have or are awaiting diagnosis of Autism Spectrum Disorder. That comes out to about 20% of our client group.

Often we are the initial referrals. We work very, very closely with the maternal and child health nurses in both Bairnsdale and Lakes Entrance and often they see the first signs of something and difficulties with children and tend to do a co referral to the GP and to us to begin therapy services. So we tend to be working with the families for a very, very long time. Children within the Lakes Entrance catchment area tend to be fully supported at this

stage under our community health. So services are more available to them. Children within the Bairnsdale area unfortunately receive limited community health support at that initial stage, which makes it very challenging for us as clinicians working with the families because then we start having to look at other funding models to support their needs and obviously we know that early diagnosis and early support are very important for families. At this really early stage prior to diagnosis, the families require significant support. This is for all children with disabilities but at this stage families have not yet received a diagnosis of autism spectrum. It can be a fairly scary word for families and as a two and a half and three year old child, parents are very reluctant to start looking down that line. So there is a lot of support that's required for them. We often refer them to one of the first referrers into the early childhood intervention services. So the children refer from maternal child health, either a co referral to GP, to us and ECIS or then we have a look at it and refer on to ECIS. So that is one of the early stages with that.

We've certainly — Lakes Entrance in the last little while, the last lots of figures that came out on the AEDC data taken at prep level, Lakes Entrance has made significant improvements in the various first school entry. There were not quite the similar gains unfortunately in the Bairnsdale area. There are three paediatricians located at Central Gippsland Health Services in Sale and there is another private paediatrician who is located in Sale. They provide monthly visits. The three paediatricians from Central Gippsland provide monthly visits to Bairnsdale. The private paediatrician also has a monthly visit to Lakes Entrance as well. There is one more visiting paediatrician who works specifically with us on the Pathways to Good Health program and can also help us with some of the early diagnosis. We have termly meetings, so once a term. We have Telehealth meetings with all the paediatricians to support them and for us.

So with the diagnosis there are two areas of difficulty that we've noticed. Children can be diagnosed by the paediatrician with ASD and often we get children coming in that we have no evidence of a multi disciplinary team diagnosis, which is not a problem from our perspective until we start to help make families make submissions for school funding and the Education Department requires written evidence of a multi disciplinary team. So if that's not there in the early stages, trying to recall back to a diagnosis that is maybe two and a half to three is very difficult for us.

The other thing is that paediatricians refer for more intensive multi disciplinary assessment and that would be a referral to Traralgon, to GCAPs in Traralgon, or on down to Monash for an ADOS team assessment. There is a waiting list, as was mentioned earlier there is a long day in the car. In fact, Monash is an overnight trip from our area, complicated by having a child who has autism and potentially doesn't like being in the car and all the rest of it.

East Gippsland area is definitely aware of the needs locally. There is currently a Children with Additional Needs working group who are looking at providing effective referral pathways and access to information for families. So that is ongoing project that is happening in East Gippsland at the moment. We actually had noted that the ADOS, as in the Autism Diagnostic Observation Service, is not available further east than Traralgon and actually applied to the Primary Health Care Network to allow us to begin that service. So we now have staff who are trained to deliver that. We are still completing the training, which will happen by the end of December. We already have a wait list. We have informed the paediatricians locally that this is going to be available and all of the paediatricians have already started to say, "Well, here's my list. Let's go." It hasn't even started yet and we have a wait list. So there is definitely a need for that.

What happens with diagnosis at the moment is that a child's referred to the paediatrician. That can be a couple of months' wait to get in to see them. If we know the child and the family, sometimes we will send reports down with them but sometimes if the child isn't known to us then the paediatrician sends them back to speech pathology therapy, occupational therapy for reports. They go back to the paediatrician, then they're set down for another referral and then they are sent back to the paediatrician and each one of those steps has a several month wait. So an official diagnosis for the family drags out.

I noted a while ago, I think it was around 2007, Monash University completed a survey on families, the pressure of the families on the stage of diagnosis. They actually implemented a support program, I think it was about a six week support program, for families because they found that that was a really crucial time for families and to come to terms with diagnosis and support at that time and support for the families.

So that is starting with our younger children. At the other end we support families in schools to apply for support through the Education Department. We note, as was mentioned by several other people earlier, that

there are variable levels of support for children entering primary school. One of the difficulties with the diagnosis of Autism Spectrum Disorder is that the education department requires either IQs below 70 for access to special schools. They also require language skills to be below 70 for support in the mainstream school as well or an argument that the pragmatic language skills of the child actually bring those scores below 70. So that is the really, really time consuming. Just to write up a report is three or four hours, which is being taken out of the time that can be allocated for therapies and other things and transition programs. So that is a really big difficulty for families and for schools. So that's just one of the really big concerns that families have and therefore children don't seem to be supported as they best could be within the classroom, placing a strain on the schools. From my own experience, I know of one classroom where there were four diagnosed children within one classroom on the autism spectrum. I know of two children, who in their first two years of school, were unable to attend a full day of school and another two children with social difficulties that the school are struggling to address. Their academic progress is really good but one of the children's, for instance, mother reported that he was really only able to identify one peer that he would like to be with, which is, at the end of a full year at school, is really heartbreaking for parents. As families mentioned earlier, the not being invited to play dates, birthday parties, that sort of thing. Another child who had been subjected to comments and things in the playground and it was probably at least one school term before the child actually reported that back. So these kids have got real social skills issues there.

Ms ELLIS — Thanks, Lyn. I shouldn't have given it away so early, should I? I suppose, the only additional thing that Lyn hasn't mentioned is we currently have a submission in with the Primary Health Network also to have some finance to basically recruit a project manager to develop a stepped model of care incorporating all our paediatric mental health programs into one particular model, because at the minute we are finding we have a particular program for a kid with autism and then this program for this. We really want a stepped model of care to open up that bottleneck we have got with the psychologist at the top of ATAPS et cetera. We're hopeful that that might give us an opportunity to streamline the programs that we've currently have got.

We've also gone down the line, and probably have for quite a few years now, of having a large team of support workers. We call it the Allied Health Assistance. Very much developed under the supervision and delegation framework and qualified AHPs developed competency packages to support the speech pathologists, occupational therapists and physiotherapists. So we do a lot of one to one intervention using the health professionals and we do a lot of group activities with the AHAs, particularly around language and we incorporate the families and educators. Our programs are delivered within the service but also out at the Lake Tyers Aboriginal Trust, Bung Yarrnda, GEGAC, Dala Yooro, into the kindergartens and now the long daycare centre.

The CHAIR — Thank you. You are doing an awful lot of work. Congratulations on the work that you're doing in this field. It is really important. It is really important for us to hear about that work because many of the things that you do may be, or could be, replicated elsewhere. How many children do you think come to your service that don't have an ASD diagnosis, so that they are in that transition of not being diagnosed? So they have behavioural needs and behaviours of concern or other symptoms but haven't actually been formally diagnosed?

Ms NICHOL — Off the top of my head now I can name four or five at this particular point in time, and that's from a speech pathology point of view. There are probably another four or five at any particular time seeing occupational therapy. There are probably quite a number because, as I mentioned earlier, we tend to be one of the first directions, so once maternal child health have been alerted there are some areas of difficulty. Interestingly enough, when I first started at GLCH about six years ago, the average age of our referrals was around about 4, so starting kinder. Now our average age of children being referred in is around about the two and a half.

The CHAIR — And that's because of the maternal and child health trained nurses who are able to refer children?

Ms ELLIS — We are onsite with them.

The CHAIR — Is that a really good system?

Ms ELLIS — Absolutely. Absolutely.

The CHAIR — Have you seen an increase in the number of children being referred with potential ASD?

Ms NICHOL — Probably, yes. Overall our number of referrals has increased.

The CHAIR — Is that because of better awareness, do you think, or is it because we have the maternal and child health nurses trained to understand and know what to look for?

Ms ELLIS — I think there's probably many reasons but one of the other reasons other than they are onsite, I think we have worked really, really hard to develop a fairly easily accessible model. We have got...

The CHAIR — They are in the one place.

Ms ELLIS — It is just there is a service access. It doesn't matter what they thought or what the referral says or what the service is that they request, eventually they will end up at the right spot.

The CHAIR — You are actually operating a little bit as a hub, aren't you?

Ms ELLIS — We are.

The CHAIR — Which is what we have heard about today and that model would actually be really beneficial in other communities, particularly isolated or rural communities. So you have a system in place so you get the referral, you do the assessment, diagnosis happens at your centre as well, yes?

Ms ELLIS — We have just received this funding so we actually don't report back on our initial pilot project until November. November's been so December, but we hope to transition. The challenge is still there about how we will fund it.

The CHAIR — Who are you reporting back to?

Ms ELLIS — The Primary Health Network gave us a seeding grant.

The CHAIR — Who does the report go back to?

Ms ELLIS — Primary health.

The CHAIR — Is that federal funding?

Ms ELLIS — Yes.

The CHAIR — Now I understand. So paediatric services, you said you had three paediatricians who visit monthly; is that correct?

Ms NICHOL — Yes.

The CHAIR — What is the cost to a family to do that?

Ms NICHOL — Not sure off the top of my head. I have heard a figure of around about \$170.

The CHAIR — Is that Medicare?

Ms ELLIS — It is Medicare subsidised. I don't know what the gap is. They are private. They are not employed by GLCH. I'm not sure what their model is.

The CHAIR — Paul?

Mr EDBROOKE — Welcome. I just wanted to focus on, again, the NDIS and just ask you a very simple question and that is are your clients nervous about it and how do you see it rolling out in your area?

Ms ELLIS — We don't roll out until 1 January '19. So the clients and the practitioners and the managers don't fully understand it to be honest. We have just started going to our meetings and information session and starting to develop funding models but from a manager's perspective it is a big transition to go from block funding onto NDIS. I'm nervous, I'll be honest. I'm really nervous that we haven't got the systems in place and the bulk number of people to guarantee that income that will keep people like Lyn fully employed. Clients, I can't comment. I don't think I've heard a client talk.

Ms NICHOL — There are a few of the parents. I guess one of the things with the NDIS that I have great hopes for it is that at the moment most of our funding occurs through ECIS, which finishes at the start of school for helping children with autism, which does allow us to support, within the school system, up to the age of seven. We have a fairly close relationship with a number of local schools where we continue to support the children. However, what we find is that at age seven funding for assistance stops and it seems to be a little bit unequal at the moment. We have some parents who seem to be able to organise lots of different funding for lots of different services, sources, and other parents who struggle with it a little bit. So a number of parents have already asked, you know, how is the NDIS going to impact, to which I can't answer generally. My answer is to make sure that they have whatever they can in place so that their child is noted as the NDIS roll out comes in. My hope is that those children from the age of seven onwards will be getting a little bit more support because that is very difficult.

Mr EDBROOKE — Just in relation to Maree's question about the cost to families, obviously the allied health services you provide in your area are all under the PHN. Are there many families that take a private route for different interventions or therapies?

Ms ELLIS — We don't actually receive our funding from the PHN, that was just a one off project to develop the ADOS. Our funding comes through the community health and HACC. It has a geographical eligibility to it, which is incredibly frustrating to a client that lives the other side of the Tambo. We support referrals going to Medicare and we support any other sort of external funding that we can. What was the next part of the question? Oh, and the private? We are in a bit of a unique position in that there aren't a large number of private practitioners around. So there are no other private practitioners living within the Lakes Entrance area. There are a bit more in Bairnsdale. It is a larger population and in Orbost.

Ms NICHOL — There are some providers that come from Sale to the Bairnsdale area as well.

The CHAIR — Christine?

Ms COUZENS — Thanks for presenting today. You talked about skilled professionals and the lack of, to some degree. Do you think that plays a significant role in the services that you are able to provide at a regional level?

Ms ELLIS — I don't know that I did say "the lack of". I think what I might have meant to say was the lack of funding to recruit full time positions. What we find particularly frustrating is that we are given small amounts of money for a small amount of speech pathology and occupational therapy and to attract rurally, no one is going to move from metro to a two day a week position. You can be lucky and get someone who moves into the area and go, "Yay. How lucky are we?"

Ms COUZENS — So that confirms that there is a lack of those professionals in your community though. So if you had the funding?

Ms ELLIS — If we had the funding I think we could recruit.

Ms COUZENS — From within your own community?

Ms ELLIS — I think people will move to a good position. If you have a decent reputation and offer a great workplace people will move. I mean Lakes Entrance is a good place to live. You've got to have the money to recruit.

Ms NICHOL — I think another thing is that before people were mentioning the telehealth model and I think it is interesting actually because having looked at the things and the training and other trainers there seems to be a number of trainers out there that are geared towards school based or parents, they don't seem to have any online or telehealth training that is geared towards allied health services and our provision. We certainly access anything we can, some through Speech Pathology Australia, and a number of therapists that have done specific training. Actually, that was one too that I'd like to mention. For example, one of our therapists is trained in Hanen. More than Just Words, which is an evidence based program for families. So it's actually training the parents to be the child's major, I guess, therapist at home, 24 hours a day, just incidentally through daily routines, conversations, that sort of thing. But, again, it's interesting that the ECIS and flexible funding that was

mentioned earlier can't be used to support that and yet it is an evidence based program for children with Autism Spectrum Disorder.

Ms COUZENS — Just going back to the NDIS, and Paul asked the question about that, I suppose I'm interested in whether you're actually looking at what's happening in trial areas, say, in Barwon, which is my electorate of Geelong, and the impact that that is having there on the changes that are happening there. Are you actually following that to get an indication of where things might go or not go?

Ms ELLIS — Yes, definitely we are. We are actually running a project with project lead from an old department head to tell us what we should be thinking about, what is happening out there, what is the future prediction. Yes, right about to launch into it. Yes, we are definitely.

Ms COUZENS — There are clearly some issues for people on what they are or aren't getting that they believe they should be getting?

Ms ELLIS — Some of the initial immediate thinking is that we probably are a very traditional allied health service and we need to be thinking a little bit less traditionally. The classic example was one of the presentations I went to was about one of the ladies that was working for the AIDS Council and one of the most sought services for her clients was personal trainers. So I was thinking, okay, personal trainers. So for the children we are doing animal assisted therapy and aqua therapy and that sort of thing and it is making us think we need to be really looking at the services we are providing and we can be less tied because we are not reporting statistically to the Department for that one hour of physio or that one hour of speech. It will give us much more flexibility for sure. We just need to get the funding model right.

Ms NICHOL — I think also as a general regional thing as well, Children With Additional Needs Working Group is very conscious of mapping exactly what is available in the area across all the services, respite, those sorts of things, finding out what exactly it is that parents need, what's the level of frustration with parents and, I guess, the information either overload or undersupply is one that the families mentioned, but they're certainly looking at the NDIS and how the mapping of that rolls over into an NDIS.

Ms COUZENS — I know we are pushed for time but in terms of overall support in the community, what are the key things that you think we need to change and, you know, the message to Government, "Well these are the things that we want to see happening in our community" in terms of ASD?

Ms ELLIS — One of our biggest frustrations is that the navigation of the service system for parents is actually, you know, it is really complex too. The financial model that we have developed is really complex and if you live just outside our geographical area it is such a challenge. If you live within our geographical area we can certainly provide a pretty good, schmick system. I suppose if we could, and we have tried and tried to get increased community health for allied health paediatrics in Bairnsdale and have been given five hours a week, which really creates more frustration and more wait so therefore we have had to develop a model of where you get five funded services and then, "How else can we fund you?" So then we get supported through Medicare and then blah, blah, blah, it just gets too complex. So, you know, one of our frustrations is get rid of geographical eligibility and increase access to community health services just while those kids are in the process of getting a diagnosis.

Ms COUZENS — That will change on NDIS anyway, won't it?

Ms ELLIS — Well, HACC will change. We are not really sure what's going to happen with community health. HACC will change.

Ms NICHOL — I think the other thing too is maybe taking into account that the East Gippsland area, we are really kind of on the Melbourne edge of East Gippsland. It goes a lot further out than that. And that it needs to be acknowledged that it is different because it is rural and remote. I imagine the only other area in the state would be up around Mildura, which would be as distinct from services and even things like the funded ADOS clinics are all within a two hour radius of each other but we are kind of on the outer edge of it and then there is people further away. So actually acknowledging that East Gippsland does have its own unique needs and really services located in Melbourne are really inaccessible for a lot of our families, particularly given the socio economic background to the area.

The CHAIR — Thank you. I just have one last question. In your experience, how do you think families are managing, particularly if they have a child or an adult with ASD? What is the general feeling?

Ms ELLIS — I'll probably respond immediately from what I see and then Lyn will have real experience. It's tough. It's tough. They walk into our waiting room and they share it with, you know, it might be veterans' gym on and there is big meltdowns happening in the corner and they are all just staring thinking, "Just give that kid a whack." It is really hard. It is really hard. I think just the access of services is a challenge for them as well. We are traditional. We are 8:30 to 5 o'clock so they have to bring all the siblings with them or it has to happen within the school hours. We are not as flexible as what we should be. That would be my immediate response.

Ms NICHOL — It is tough. I guess the other thing that I find is that, and this is from another area, but I remember one of my fellow clinicians getting a phone call from a mother who she actually hadn't worked with the child for about six months because the child was getting support at school and what have you, and she just rang up to say, "Look, I really had to share this story with you because such and such happened" and the steps of progress that some of the children make, it is very difficult for the families to actually have somebody they can share that with. For mainstream kids, that is something they did when they were three and a half years old. You know, I had a child come in the other day who is eight and mum was excited because he now uses the toilet. How do you tell another parent that your 8 year old is now using the toilet and this is such an amazing breakthrough? It is really having somebody to share that with is very difficult. That's a big step.

The CHAIR — Thank you so much. It is much appreciated. You are obviously doing some very good work so thank you very much. I look forward to perhaps having some comments from you in our report when it's tabled next year. Thanks a lot.

That draws to a conclusion today's public hearing. Thanks to Hansard and thank you secretariat and thank you Christine and thank you Paul.

Committee adjourned.