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

Witnesses

Ms Leonie Baker, chief speech pathologist, and
Ms Marisa Barbarioli, acting chief occupational therapist, Swan Hill District Health.

The CHAIR — Thank you all for coming this morning. Can I acknowledge that we have in the audience this morning Peter Walsh, the member for Murray Plains. Thank you for coming along, Peter, and thank you for allowing us into your electorate to conduct this very important inquiry.

This is the 10th public hearing to be held by the committee. In addition to hearings in Melbourne the committee has already travelled to Geelong, Bendigo, Shepparton and Morwell to meet with stakeholders and hold public hearings. The committee is delighted to be here in Swan Hill today. The committee is thankful for the ongoing support this inquiry is receiving from the public, particularly from people with ASD and their families who have participated in each of our public hearings to date.

These proceedings today are covered by parliamentary privilege and, as such, nothing that is said here today can be the subject of any action by any court or to any proceedings for defamation. If you have any special needs today, please see the committee staff, who will assist you.

I would like to call our first witnesses this morning: Ms Leonie Baker, chief speech pathologist, and Ms Marisa Barbarioli, acting chief occupational therapist, from the Swan Hill District Health service. Welcome to our public hearing this morning. 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 would like to invite you now, Leonie and Marisa, to make a presentation to the committee.

Ms BAKER — Good morning, and thank you for allowing us to present information today to assist in contributing to the committee's knowledge and insights into services for people with ASD in our region. My name is Leonie Baker and I am the chief speech pathologist at Swan Hill District Health. I have been in this role for nearly six years and have been working as a speech pathologist for over 25 years. My previous roles have been in acute, subacute and community health services in Melbourne, country Victoria, Queensland, the Northern Territory and the United Kingdom.

Ms BARBARIOLI — I am Marisa Barbarioli. I have been in this role for almost two years. I am the acting chief OT at Swan Hill District Health. My previous roles have included clinical and management roles in acute and subacute community and aged-care services in South Australia, Victoria, Queensland and the United Kingdom.

Swan Hill District Health acknowledges the traditional owners of country throughout Victoria. We pay our respects to them, their culture and their elders, both past and present.

Swan Hill District Health is a rural health service covering a 100-kilometre radius area. Swan Hill District Health is an integrated health service providing a range of services, including acute, subacute, residential, aged-care, community — that is, community health, HACC and — —

Ms BAKER — The Commonwealth Home Support Program.

Ms BARBARIOLI — That is it; sorry. And there are outreach services for an estimated population of around 30 000 people. Swan Hill District Health does not receive specific funding to provide services for those diagnosed with autism spectrum disorder. However, the health service provides clinical services to people with an ASD diagnosis across all settings, either as part of their general health care or for specific issues associated with ASD. This is essentially funded through the state community and women's health program, home and community care, HACC, for younger people under 65, the commonwealth home support program for those 65 years and over, and acute or subacute funding.

Swan Hill District Health provides allied health services, which include speech pathology, occupational therapy, physiotherapy, podiatry and dietetics. These are small departments ranging from three to six EFT and are required to provide services across acute, subacute, aged-care and community and outpatient services.

Ms BAKER — So there are a few key points that we would like to make in a summary statement, and these mainly relate to access to and availability of services, both assessment and diagnostic, and intervention services.

The first point relates to the assessment and diagnostic process. The diagnostic process for clients with suspected autism spectrum disorder is lengthy, costly and often confusing. Best practice indicates that an ASD diagnosis should be made by a multidisciplinary team, including a paediatrician, an occupational therapist, a speech pathologist and a psychologist. Currently in Swan Hill we do not have any multidisciplinary assessment services available, and we have no local paediatrician. A visiting private paediatrician attends once a month, and there is no child psychologist based in Swan Hill who can see children under school age.

Clients need to travel to specialist assessment clinics, and there is a long wait for publicly funded clinics. Private assessment clinics are available; however, again clients need to travel and the cost is often prohibitive for many families. An ASD assessment clinic can involve several assessment appointments in different locations and can be a lengthy and overwhelming process for families. It can often go for several days. There are also accommodation costs and travel costs associated with that.

Ms BARBARIOLI — The next key point relates to access to appropriate specialist intervention services. Swan Hill District Health allied health departments offer limited services to children with ASD. Evidence-based practice supports multidisciplinary management of these children under specialist early intervention services, and clients with an ASD diagnosis will typically be referred to that kind of service. There are limited options for early intervention services in our area. We have two early intervention providers — Noah's Ark and specialist children's services — and children can access these services until they commence school. These services have a central intake system based in Bendigo. There can be a wait time of several months for confirmation of eligibility for the service and the commencement of the service.

Children with an ASD diagnosis are also eligible for Helping Children with Autism funding coordinated through Amaze in Victoria. Amaze is the peak body for people with ASD and their supporters in Victoria and is the autism adviser service. The HCWA early intervention services program is administered by the commonwealth government's Department of Social Services and will transition to the national disability insurance scheme. The program is for children up until their seventh birthday, and eligible clients can access up to $12 000 with a maximum of $6000 per year. Once families receive their HCWA funding they are able to arrange additional private therapy related to their child's goals. Families report that this is a confusing and overwhelming process as they attempt to navigate the system. There are limited options for private allied health input in Swan Hill. This means that funded clients have often been unable to use their allocated funding or have limited choice. The limited private providers can also mean significant wait times for services or that families have to travel to access services. In addition, in a rural setting not all required allied health services are available in the private sphere.

Swan Hill is a border town and providing services to New South Wales clients is problematic — that is, New South Wales clients are unable to access early intervention services based in Swan Hill. The early intervention service in New South Wales is substantially different to Victorian early intervention services. Specifically Intereach do not generally provide allied health input. Local allied health services across the border within range of Swan Hill are either extremely limited or non-existent.

Ms BAKER — The next point we would like to make relates to the limited services for older children and adults with ASD. School-age children have access to speech pathology services through the Department of Education and Training; however, there are no occupational therapy of physiotherapy services available. Children with ASD often require a high level of support and intervention during transition to school, and there is a high demand for speech pathology services across schools in the region.

After their seventh birthday the children can no longer utilise the early intervention HCWA funding. There is the MBS Helping Children with Autism program for children from seven to 13 years of age; however, this only enables clients to access four assessment sessions and 20 treatment sessions in total before they reach the age of 15, and that can be across any of the allied health disciplines.

Once over 18 years of age adults with an ASD diagnosis can access allied health services at Swan Hill District Health through our community programs; however, these are time-limited services for clients with identifiable goals. Again there is no specific funding stream set up for clients with ASD, so they just have to access our services through our usual intake and priority systems.

Ms BARBARIOLI — The final point relates to recruitment and retention in a rural setting. There are workforce issues in maintaining an appropriately skilled and multidisciplinary workforce in a rural setting. The cost and availability of professional development, access to professional mentors in specialist areas and retaining skilled staff are significant issues in a rural setting.

With an increasing rate of diagnosis of ASD in Australia it is anticipated that the demand for services for individuals with ASD will continue to increase. In response to consumer feedback Swan Hill District Health will soon commence limited services for children with funding through Helping Children with Autism and HCWA. This will enable increased consumer choice and give further options for families to access additional therapy services for children to meet specific goals.

Ms BAKER — In addition to the above issues that we have raised, challenges for the future include exploring ways to reduce consumer confusion around choosing services and assisting consumers to navigate the system, ensuring service providers are adequately skilled to provide services and have access to ongoing supervision and mentoring, and ensuring consumers have access to a service model that brings specialists together to provide a coordinated service.

The CHAIR — Thank you very much to both of you. I think, summing up, what you have just presented to us is something that we have heard repeatedly across Victoria, particularly in our regional areas — that there is indeed a lack of services for young people and indeed all people with ASD. You have pretty much answered most of the questions that I had, but there were a couple I thought of as you were presenting. One of those was in relation to the cross-border services, so the NDS comes to this region in 2019; is that correct?

Ms BARBARIOLI — That is right.

The CHAIR — And across the border, is that a similar rollout, or is that different?

Ms BAKER — I am actually not sure. I have a feeling that the Deniliquin region is going to be earlier than us, but I am not exactly sure about that.

The CHAIR — So there is no ability to access services in New South Wales and vice versa at the moment?

Ms BAKER — At the moment if the child's residential address is in New South Wales, they cannot access early intervention services through Noah's Ark or the Specialist Children's Services which are our local services.

The CHAIR — What is the estimated wait time for those diagnostic and early intervention services?

Ms BAKER — For a publicly funded assessment service it is about 12 months. That is the latest information I have heard — if someone was going to go through the public system to Bendigo. Through a private clinic it could be three or four months.

The CHAIR — How many private clinics are there?

Ms BAKER — The main one that I know of is the BEARS Clinic based in Bendigo.

The CHAIR — The nearest services available are in Bendigo?

Ms BAKER — Yes.

The CHAIR — The other question I had was in terms of workforce retention. Clearly your service provides a great service for people with ASD, but what is the turnover like at your service in terms of working with people with ASD?

Ms BAKER — We would employ lots of new graduate staff as a health service, so we are a really young allied health service in general. We are probably not very representative of the age of our service.

The CHAIR — You look pretty young to me.

Ms BAKER — So in that sense there are a lot of young allied health staff who need a lot of professional supervision and mentoring. Depending on the mix of these and the more senior staff we have, that can happen locally, but often we have to access specialist mentoring and that requires a lot of travel and cost for our staff.

Ms BARBARIOLI — And it is just hard to access, to be honest, in a timely fashion. We put a new OT on, and it took six months to get access to some appropriate early training for her, so it has delayed being able to start up some of the services that we wanted to. As Leonie said, often the staff are very junior in terms of experience, so the amount of training to get them up to speed is greater than, say, if a grade 2 — a more experienced therapist with a broad clinical background — was starting, where it is a kind of top-up bit of training. It is a different level of training really.

The CHAIR — Does your facility, your hospital, have a particular separate area for people with ASD, like a quiet room? Has there been any adaptation within the facility for people with ASD?

Ms BAKER — Our health facility is a very old building. We have one new building, the community rehabilitation centre, that was opened about two years ago, and that has a paediatric room with an outdoor access area that would be probably our most appropriate space for ASD clients. So we have the capacity to use that space, but that would be —

Ms BARBARIOLI — The only one.

Ms BAKER — the only space.

Ms BARBARIOLI — So OT, physio and speech all need to access that, and we are all very friendly about it and have sort of allocated times, but it is likely to come under some pressure.

Ms BAKER — If we see children with ASD in our allied health general area, we have a larger room, but for the safety issues in terms of children that might run off or children that have got language issues and are not responding to commands really well around safety, we do not have easy access to keep them safe and secure in the waiting room either.

Ms BARBARIOLI — And it is noisy and unregulated potentially, so from a sensory perspective it is a bit harder to manage.

The CHAIR — How many clients with ASD would you see in a year, and what would be the breakdown of children and adults?

Ms BAKER — I definitely see more children with ASD, in the speech pathology department, than adults. It would probably be, 80 per cent paediatrics and 20 per cent adults. I would say, in the six years I have been working in this position, definitely the referrals for children with potential diagnosis of ASD have been increasing. I would say we have maybe two or three a month now.

The CHAIR — And so it is definitely increasing.

Ms BAKER — Definitely increasing.

Ms BARBARIOLI — And the need for treatment service as well. The OT service has historically worked more around the diagnostic range, but it has become really, really clear that, you know, once there is a diagnosis, you still need the intervention. So that is why we put this time into trying to develop a way to fund and look at ways to provide treatment services, particularly with a multidisciplinary angle. There are private practitioners there, but sometimes it is more effective, when there are speech and physio and OT issues, for allied health to work in a team and coordinate around shared goals and that kind of thing. That is what we thought we could potentially bring.

The CHAIR — The last question: obviously you are a very important regional health service here. What do you think needs to be done to improve access to better services for people with ASD?

Ms BARBARIOLI — Probably timeliness would be one of the things that could be improved, because there are just delays all along the line. The evidence shows clearly that timely intervention is actually important, so timeliness is a big issue. There are waits for the assessment and approval for funding. There are waits for access to treatment. So by the time you add them all up, it can be quite a considerable delay. Would you agree with that?

Ms BAKER — Yes, and I think just with the ease of access, clients can initially be seen by our services within the health service, but then if they require referring on, the process that has to happen for people to access the specialist services and then gather the information that they need, it is just very difficult to navigate the system, and that is for people who work in health care. So for families and for disadvantaged families or people who have English as a second language, I would say it is a very difficult system to work your way around at the moment in order to receive the services.

Ms BARBARIOLI — Just the other thing is that there are probably issues that we notice with probably the older school-aged children, the teenagers, because the services are focused around early intervention, and there is evidence around that. But there do continue to be issues for the kids as they get older and also as they transition into adult life. There is really just a complete lack of services to support that transition, from a school life to working and sort of community life. We are hoping that the NDIS will pick up that, but that is a big gap, and we do not really know what the demand is because people get lost to the system basically.

Ms McLEISH — Thank you for coming in, and thank you, everybody, for coming in; it is a great crowd here today. You may have just answered this when you talked about timeliness and ease of access, but what are the main complaints that you hear from families?

Ms BAKER — Definitely, from my point of view, difficulty obtaining a diagnosis. So because we do not have easy access to paediatricians or a specialist assessment team, sometimes families will come in and say, 'Can you just do a speech pathology assessment so I can take that to a paediatrician so I can get a diagnosis for my child?', I will do that, but unfortunately, just the paediatrician and the speech pathologist saying that they think the child has ASD is not enough to get children all the funding that they are eligible for. So they have to go through the gold standard assessment process, which is — —

Ms McLEISH — The gold standard?

Ms BAKER — It is the gold standard assessment process that will definitely get them funding within the education department, and that requires four disciplines, at least a speech pathologist, psychologist and a paediatrician, and hopefully an OT. That is best practice assessment for ASD. So sometimes different funding areas will allow just a paediatrician and a speech pathologist to have completed reports, but to access funding throughout their school life, that is not enough.

Ms McLEISH — When you talked about timeliness in getting a diagnosis, are there many people who are looking for a diagnosis that actually do not end up getting that diagnosis?

Ms BAKER — Yes.

Ms McLEISH — And is that because their child does not have ASD or because it is just the system?

Ms BAKER — No. It is the system. They cannot get through the system to obtain the diagnosis and they do not have the money to go privately. Sometimes, by the time the assessment occurs and they get the HCWA funding, they have run out of time to actually utilise their funding. So that actually means that early intervention has not occurred in the way that that funding stream was set up.

Ms McLEISH — And are there any obvious process delays that could be improved?

Ms BAKER — I think, like Marisa said, it seems to be delays at every point of entry really. But definitely not having a publicly funded assessment service that comes to our area is a problem, because there are lots of families that actually do not have the ability to travel, do not have the ability to pay for accommodation while the assessment happens and actually, before a diagnosis, do not have any sort of caseworker or anybody necessarily assisting them with the process of how to get that diagnosis.

Ms McLEISH — Can you just confirm: the paediatrician that comes once a month is a private paediatrician coming from Bendigo?

Ms BAKER — Yes.

Ms McLEISH — And is that the only availability that they have to come?

Ms BAKER — Yes.

Ms McLEISH — Do they cover other areas?

Ms BAKER — Yes.

Ms McLEISH — Where else?

Ms BAKER — So Dr Tennakoon, I think, is definitely based in Bendigo and here, and I am not sure actually where his other visiting sites are. There is a paediatrician that visits Kerang. Some families go and see the paediatrician there, but he has a waiting list of many months.

Ms McLEISH — So the one that comes here, how many people would he see a day?

Ms BAKER — I do not know actually. I have not asked for the figures for that. The autism assessment clinic that is publicly funded in Bendigo would see three clients a day. Every fortnight they run that clinic and they can see three clients a day.

Ms BARBARIOLI — The other area of difficulty, which relates really to OT, is around school interventions, because the OTs are not employed through the education department. They rely on accessing our services and there can be delays in that. So clearly when kids are presenting with issues in terms of being able to engage with the educational process, the longer they have to wait for us to come out and help develop school-based strategies — you get this compounding disability thing where you have got kids not learning on top of everything else. So if we could respond in a more timely way, that would be useful as well.

Ms McLEISH — And what is the relationship between the speech pathologists and OTs with the schools? Are you able to actually go into the schools to see the children in there?

Ms BARBARIOLI — Yes, we can.

Ms BAKER — The education department, though, employs their own speech pathologists. So as a health service we are not visiting schools; the education department has their own speech pathologists, which is different to Occupational Therapy.

Ms McLEISH — And where do they come from?

Ms BAKER — They are here. They are based in Swan Hill.

Ms McLEISH — And there are how many of them?

Ms BAKER — There are 2.5 EFT.

Ms McLEISH — I just have one more question regarding the staff. You mentioned a lot of junior staff. Is that because they have come for experience up here because it is easier to get jobs? Why is it that there are so many junior staff that need mentoring?

Ms BAKER — Partly it is availability of jobs. In speech pathology at the moment, jobs are hard to come by, so we are in a position where we have got a lot of choice with our ability to recruit. That has not always been the case. I think a lot of younger clinicians are really attracted by starting in a generalist position and having the option to work across different service areas without specialising immediately.

Ms BARBARIOLI — Yes, I think that is right. That applies to OT as well. I think it is probably just some of the pragmatic realities of relocating. The younger staff are often single and it is just a question of moving themselves. Some of our young staff are actually returning to an area where they were brought up.

Ms BAKER — That is true too. So with the training available now in Bendigo we are able to keep a lot more locally grown health clinicians in the area too.

Ms McLEISH — So what was happening previously? People would have to go to Melbourne and then maybe stay?

Ms BAKER — Melbourne, yes.

Ms COUZENS — Thanks for coming along today. Just on the workforce issues, I am wondering if you have a view on how in an ideal world you would have those professional staff located here to deal with the issues that the community needs? Is there a particular view that you have that would actually solve that problem, putting aside funding issues and things — if you had the funding?

Ms BAKER — Do you mean in terms of upskilling our own staff or in terms of accessing the specialist services we need?

Ms COUZENS — Accessing the specialist services and having them here as you need them.

Ms BAKER — I think there are lots of options going forward in using telehealth that we have not been able to really explore fully yet. I know that more and more we are trying to do some consulting with specialists in Melbourne using telehealth. I just think that often the diagnostic requirements for ASD are quite difficult using telehealth, so that is a limitation. But we are certainly continuing to look at ways that we can do that.

As much as we can, we are trying to have consistency in approaches across allied health within Swan Hill so that we are all giving the same messages to the families. So we try to have meetings. I know from a speech pathology point of view, we have meetings with speech pathologists across all the different service areas and we try to make sure that we are working together to identify the gaps and work out ways that we can give that consistent message, because I think that has been one of the problems in the past. We have all got slightly different bits of information, and it has been hard for us to work out how everything should coordinate and work too.

Ms BARBARIOLI — I guess there are two answers to that really. There is the clinical service delivery aspect. A locally located multidisciplinary assessment team is the way to go really. Even if it happened not as frequently as we liked, just having a locally based one would be great. Telehealth is definitely useful in terms of mentoring and upskilling staff. There are always some technical issues, but you know, that is just technology; people work their way around that. But the principal issue is actually finding senior staff who have the capacity to engage at the level that we need, because all the services seem stretched and without having dedicated time allocated for building relationships with the more rural services and building time for education and problem-solving on a case-by-case basis, it is just really not available. It is not that there is a lack of goodwill. People have goodwill and they have an intent to support, but it is just that in the pragmatic reality of them juggling priorities at their end, it tends to fall through the cracks a bit. Would you say that too?

Ms BAKER — Yes.

Ms COUZENS — So what would it take to have a dedicated team here?

Ms BAKER — I think the first issue is addressing the lack of paediatricians that are publicly available, because then if you have the lead paediatrician, I think the rest would follow.

Ms COUZENS — Do you have support groups here for families with autistic children?

Ms BAKER — Noah's Ark and Specialist Children Service are probably better placed to answer that. Amaze has visited the library, and there is a network through the library that I know of, and there are some playgroups that are autism specific that are available, but I am not exactly sure about the frequency.

Ms COUZENS — So your service does not provide a sort of support service in any way?

Ms BAKER — No.

The CHAIR — I just have a couple more questions. The referrals that come to you, are they mostly from GPs, from schools or do you get referrals from maternal and child health centres?

Ms BAKER — We receive a lot of referrals from maternal and child health. We have lots of referrals just from the families themselves — they just self-refer or come to the desk — and referrals from the paediatricians as well. The school referrals go to the education department speech pathologist, through their systems.

Ms BARBARIOLI — Ours is different because we target different groups. So we target school-aged kids because there are the early intervention services who can see the younger kids. So our referrals are mostly from the paediatrician and from GPs, and actually I get quite a lot of referrals from the schools themselves.

The CHAIR — With the referrals from the maternal and child health centres, we have heard of certain maternal and child health centres across regional Victoria who actually are doing this in a very coordinated fashion so that children who are identified as potentially having ASD are set up very quickly for diagnosis. So do you think that is a really good selling point for early intervention in having that assessment done at a very early age?

Ms BAKER — Yes. I think that the paediatrician and the early assessment is really important. That is probably where it falls down for us, in that the maternal and child health nurse will see the child, maybe refer to us at the hospital and do an early referral to early intervention at the same time. So we start the process until the child is picked up through the early intervention system when a space becomes available, but then in the meantime sometimes the diagnosis is not confirmed, so that slows it all down.

The CHAIR — Do you have any clients who have inquired about applied behavioural analysis?

Ms BAKER — No, not personally.

The CHAIR — And one last question: how many of your clients would be Indigenous?

Ms BAKER — With ASD?

The CHAIR — With ASD.

Ms BAKER — We have a clinic at Mallee District Aboriginal Services once a week on a Wednesday morning, and probably over 50 per cent of the clients I see there would have ASD or a possible ASD diagnosis. I am only probably seeing about four clients a week there, though.

Ms McLEISH — What do you see as the role of the GP in this?

Ms BAKER — From my point of view as a speech pathologist, the role of the GP is vital. If they make the referral to us, I will send the report back to the GP and ask them to organise the referral to an assessment clinic or a paediatrician. Or, if the child comes to me not having seen a GP, then again I will do the assessment report and ask the GP to make the referral. The GP should be central to the whole process, because — —

Ms McLEISH — And are you finding they are?

Ms BAKER — I think most of the time the GPs are really good at making the specialist referrals. Some GPs may be reluctant to refer on to specialists and would like to do a wait and see approach, but that is personality dependent, I think. In general, if they are requested to organise a paediatrician's referral, they will. I know some families — —

Ms McLEISH — Are the paediatricians fairly actively engaging with local GPs?

Ms BAKER — I am not sure.

The CHAIR — Thank you so much, Leonie and Marisa, for coming along this morning. That has been a really informative presentation, so thank you again. We really do appreciate it.

Witnesses withdrew.